American University *of* Armenia
Հայաստանի Ամերիկյան Համալսարան
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Center for Health Services Research and Development

Institutional consultancy on assessing livebirth and stillbirth registration and reporting in Armenia

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Study Team:
Anahit Demirchyan, MD, MPH
Dzovinar Melkom Melkomian, DVM, MPH, MBA
Gohar Abelyan, MS, MPH
Arusyak Harutyunyan, MD, MPH
Varduhi Petrosyan, MS, PhD

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ABBREVAITONS

ADHS	- Armenian Demographic and Health Survey
AMD	- Armenian Dram (currency)
AUA	- American University of Armenia
CHSC	- Child Health State Certificate
CHSR	- Center for Health Services Research and Development
CSAR	- Civil Status Acts Registration
CSARB	- Civil Status Acts Registration Body
ENAP	- Every Newborn Action Plan
ENM	- Early Neonatal Mortality
FGD	- Focus group discussion
ICD-10	- International Classification of Diseases 10th revision
IDI	- In-depth interview
IMR	- Infant Mortality Rate
M&CHPC	- Mother and Child Health Protection Center
MDG	- Millennium Development Goals
MOH	- Ministry of Health
MOJ	- Ministry of Justice
MOLSA	- Ministry of Labor and Social Affairs
NIH	- National Institute of Health
NSS	- National Statistical Service
Ob/gyn	- Obstetrician/gynaecologist
OCSC	- Obstetric Care State Certificate
PHC	- Primary health care
RA	- Republic of Armenia
RHPOGC	- Reproductive Health, Perinatology, Obstetrics and Gynecology Center
SHA	- State Health Agency
UNICEF	- United Nations Children's Fund
WC	- Women Consultation
WHO	- World Health Organization

EXECUTIVE SUMMARY

Stillbirth rate is a problem often left out from national and global agendas, despite causing a considerable burden worldwide – 2.6 million late (over 28 weeks of gestation) stillbirths in 2015, with 98% of these occurring in low- and middle-income countries. The perception that most stillbirths are inevitable has no scientific foundation; the majority of late intrauterine deaths are attributable to modifiable risk factors. World Health Organization (WHO) recommends tracking stillbirths starting from 22 weeks of gestation in compliance with WHO ICD 10th definitions. However, misclassifications of both stillbirths and neonatal deaths are more common for births occurring at 22-27 weeks of gestation.

The official data on stillbirth, neonatal and infant mortality in Armenia is available from vital statistics registry and health services reportings, and the rates reported by these two differ to some extent due to relative independence of the data sources. However, both sources indicate a similar pattern of data since the adoption of the WHO ICD 10th classification definitions for livebirth, stillbirth, and perinatal period in Armenia – considerable increase in stillbirth rates while the rates of neonatal and infant mortality for the same period demonstrated decreasing trend. This situation raised a question whether that there is over-registration of stillbirths and under-registration of early neonatal deaths in the country. Also, the sharper increase in stillbirth rates after including stillbirths at 22-27 weeks of gestation raised another concern that a portion of late abortion cases (happening before 22 weeks) could be registered as stillbirths.

The American University of Armenia (AUA) Center for Health Services Research and Development (CHSR) conducted this study with support from UNICEF and the Ministry of Health (MOH) to identify whether there are problems in classification of late abortions, stillbirths and live births as well as in registration and reporting of stillbirths and early neonatal deaths in Armenia. The research applied different methods including review of existing legislative and sub-legislative frameworks related to classification of newborns as livebirth or stillbirth, and registration of birth and death cases; analysis of the statistics on livebirths, stillbirths and neonatal deaths reported by health facilities and Civil Status Acts Registration Bodies (CSARB); assessment of the knowledge of health care providers on the WHO ICD 10th definitions of livebirth, stillbirth, and perinatal period; and qualitative study through focus group discussions (FGD) and in-depth interviews (IDI) among different groups of stakeholders to identify their perceptions and practices on the subject.

The qualitative study took place in Yerevan, Gyumri, and Vanadzor cities. Seven groups of participants were involved in the study: 1) maternity hospital neonatologists, 2) maternity hospital ob/gyns, 3) women consultation ob/gyns, 4) maternity hospital midwifes, 5) pathologists, 6) CSARB representatives, and 7) policymakers/experts. Overall, 121 study participants were recruited from Yerevan (65), Gyumri (24), and Vanadzor (32). Twenty-three IDIs and 13 FGDs with neonatologists, ob/gyns and midwifes were conducted. Also, 101 providers from FGDs/IDIs completed the knowledge questionnaire.

The legislative and sublegislative framework in Armenia concerning the registration and reporting of livebirths, stillbirths and neonatal/infant deaths was rather complete and comprehensive. The anaysis of the official statistics from civil registration system and health sector identified some moderate mismatches between the two and a number of inconsistencies,

including unusually high stillbirth to infant mortality and stillbirth to early neonatal mortality ratios, increase in stillbirth rates mainly due to increasing rates among <1000 gram births, no increase in the proportion of livebirths among extremely premature births after adoption of the WHO ICD 10th definitions, and huge differences in stillbirth and early neonatal mortality rates across hospitals with over 40% of all stillbirths in Armenia occurring in a singe institution.

The knowledge of providers on the new definitions of livebirth, stillbirth, and perinatal period was low than average. It decreased since the study conducted by the Ministry of Health in 2009, and a low ability to apply the theoretical knowledge when answering situational questions was evident among the respondents.

The qualitative study findings, in combination with the statistical data analysis and the knowledge assessment study, indicated that the shift to the WHO ICD 10th definitions of abortion and delivery, livebirth and stillbirth in the maternity hospitals of Armenia is still incomplete. The healthcare sector is perceived not ready to make that shift because of inadequate technological capacities in the majority of maternity hospitals and inadequate knowledge and attitude of their staff members to the shift.

A tendency of misreporting some portion of late abortions and early neonatal deaths as stillbirths was taking place to a different extent in different maternity hospitals. Therefore, the observed increase in stillbirth rates may have two components – real and artificial (due to misreporting). According to the study participants, the factors underlying the real component may include low affordability of tests to make preconception diagnosis of conditions that could lead to stillbirth, increasing prevalence of sexually transmitted infections (STI) among couples because of widespread seasonal migrant work among men, low affordability of tests/examinations for identifying and treating causes of stillbirths to prevent their reoccurrence, lack of appropriate equipment for early identification of birth defects, and unfavorable environmental factors, inadequate nutrition and poor socioeconomic conditions in the country.

The factors that contribute to misreporting of some portion of late abortions and neonatal deaths as stillbirths include providers' attitude of prioritizing some signs of livebirth over others, their efforts to avoid showing high neonatal mortality rates, their avoidance of different problems related to neonatal death cases, and, most importantly, the pressure from the maternity hospital heads on them and the hospital's financial motivation to get additional funding in the scope of Obstetric Care State Certificate Program through misreporting some portion of late abortions as stillbirths.

Based on the study findings and suggestions provided by the study participants, the research team developed a set of recommendations that include improving technological capacities of neonatal units and women consultations, introducing controlling mechanisms in maternity hospitals to address the issue of misreporting, finding ways to eliminate financial incentives leading to misreporting, paying equal attention to stillbirth and neonatal mortality rates, increasing the knowledge of providers on the new definitions and their practical implications, extending the package of diagnostic tests for pregnant women and for conducting more specific pathological tests under the State Order, strengthening pathological services and their connections with providers, and simplifying the procedure for receiving child birth allowance.

Further case-based investigation/audit is recommended to identify the exact reasons for the observed moderate discrepancies between the numbers of livebirth, stillbirth, and neonatal death available from the vital statistics registry and health services reportings.

1. INTRODUCTION

1.1 Global trends in neonatal mortality rates

Reduction of under-5 mortality rate by two-thirds during the period of 1990-2015 was one of the most important Millennium Development Goals known as MDG 4 target. Although this target remained globally underachieved, the worldwide progress made toward this goal was unprecedented. Under-five mortality rate has reduced by 53% from 90.6 (per 1000 live births) in 1990 to 42.5 (per 1000 live births) in 2015.[1] This reduction, however, was disproportionate and more attributable to decline in mortality among children aged 1-59 months, while the pace of reduction of neonatal mortality was slower.[2] During this 25-year period, the global rate of neonatal mortality (deaths during the first 28 days of life) has decreased from 33 to 21 deaths per 1000 live births, meaning that the reduction was only by 37%.[3] Currently, the estimated annual number of neonatal deaths in the world is 2.8 million.[4] According to different estimates, neonatal deaths account for 42-44% of under-five deaths compared to ~37% in 1990.[4,5] Among these deaths, the share of early neonatal deaths (occurring during the first 7 days of life) is 73%, and the share of deaths that occur during the first day of life is 36%, indicating that the first week and, in particular, the first day of life is the most vulnerable period for a child.[4]

Recognizing that the progress in reduction of overall child mortality cannot be maintained without focusing more on neonatal health, many governments and other stakeholders endorsed the Every Newborn Action Plan (ENAP, launched in 2014 by the World Health Assembly resolution), which aims to reduce neonatal mortality rates below 10 deaths per 1000 live births in all countries by 2035.[3] The measures to achieve this goal include, first of all, reduction of preventable neonatal deaths and stillbirths through cost-effective interventions during the time of birth and the first week of life (e.g., breastfeeding support and kangaroo mother care), as well as during antenatal period.

1.2 Global trends in stillbirth rates

Focusing on antenatal period is important to address another issue, the stillbirth rate, a problem often left out from national and global agendas, despite causing a considerable burden worldwide – 2.6 million late (28 weeks of gestation and later) stillbirths in 2015, with 98% of these occurring in low- and middle-income countries.[6] In the United States, the number of stillbirths

per year is equivalent to the number of deaths during infancy, with obstetric conditions (29.3%) and placental abnormalities (23.6%) causing more than half of all stillbirths, followed by fetal abnormalities (13.7%), maternal infections (12.9%), umbilical cord abnormalities (10.4%), hypertension (9.2%), and other maternal conditions (7.8%).[7]

During the period from 2000 to 2015, the global rate of stillbirths has decreased from 24.7 to 18.4 per 1000 total births, resulting in average annual rate of reduction of only 2.0%, much slower than that for neonatal mortality (3.1% for the same period) and post neonatal mortality (4.5% for the same period)[6]. In the meantime, the perception that most stillbirths are inevitable has no scientific foundation. Congenital abnormalities are estimated to be accountable for only 7.4% of late stillbirths while the majority of late intrauterine deaths are attributable to modifiable risk factors (e.g., maternal age, maternal infections and non-communicable diseases, nutrition and lifestyle factors, and prolonged pregnancy).[6] The vast majority of these deaths occur in deprived settings and largely reflect socioeconomic disparities.[8]

The ENAP target for stillbirth reduction is achieving 12 or fewer stillbirths per 1000 total births in all countries by 2030.[6] Currently, stillbirth rates vary widely between countries. According to the available estimates, country-specific late (≥28 weeks) stillbirth rates range from 2 per 1000 births in Finland to 46 per 1000 births in Pakistan.[9] Countries with the highest stillbirth rates are usually those less developed, experiencing armed conflicts and emergencies. Serious efforts should be made to achieve the ENAP target for stillbirth reduction, as it requires an average annual reduction rate of 4.2, over two times higher than the current rate of 2.0%.[6] Also, better registration and reporting of stillbirth rates are needed to track the progress toward achieving this goal.

1.3 Issues with registration and reporting of stillbirths for global statistics

Despite the existing correlation between stillbirth rates and both neonatal and maternal mortality indicators, until recently, stillbirth rates were left out from the global health monitoring systems like MDGs, United Nations tracking or Global Barden of Disease metrics.[9] While two-thirds of the live births in the world are covered with birth registration, birth is registered for less than 5% of stillbirths and death – for even fewer of them.[6] Although the number of countries with available rates for stillbirths has reduced during the last five years from 68 (in 2011) to 38 (in

2015), many countries have no nationally representative data and even more – have no trend data.[6] Moreover, the national estimates of stillbirth rates are often uncertain because of deficiencies in stillbirth reporting and registration. Because of these and the usage of different definitions for stillbirth in different countries, the current global estimates for stillbirth rates are heavily based on modeling methods.[6,9]

The International Classification of Diseases 10th revision (ICD-10) defines fetal death as death occurring during the last two trimesters of pregnancy in a fetus weighting at least 500 grams or, if the weight is not available, having gestational age of 22 weeks or more, or, if the age is also unknown, having crown-heel length of at least 25 cm. However, as in many countries stillborn babies are often not weighted or measured, especially when the birth occurs at home, the main criterion remains gestational age (mostly calculated starting from the last menstrual period), which usually leads to higher estimates (by ~15%) than the estimates based on weight.[9]

For international comparisons of stillbirth rates, WHO recommends reporting third trimester stillbirths (after 28 weeks of gestation weighting 1000 gram or more or having body length of 35 cm or more). The threshold of 28 weeks of gestation is based on epidemiological data showing that in low- and middle-income countries, where 98% of all stillbirths occur, births with shorter gestational age rarely survive.[9] Nevertheless, for better representation of the reality, countries are recommended to track stillbirths starting from earlier thresholds as well, and different thresholds are used in different countries, varying from 18 to 28 weeks, with more developed countries using lower thresholds because of achieving better survival at earlier gestational ages due to enhanced intensive care services.[6,10] Different early thresholds used to define stillbirths largely influence the reported rates impeding their comparability. For instance, a large-scale prospective study in the United States identified that almost one-third of stillbirths occurred between 20 and 24 weeks of gestation.[7] It is estimated that the change in gestational age threshold from 28 weeks to 22 weeks increases the number of stillbirths substantially (according to some estimates, by ~40%).[9,10] Another reason for artificial variability between countries could be that some countries do not report termination of pregnancies (constituting 3-28% of total fetal deaths in European countries) as stillbirths regardless of the term of pregnancy, while others do.[10] Also, the term of pregnancy when termination is conducted in case of lethal congenital anomalies depends from the term of routine screenings. If the term is earlier than the

registration limit for stillbirth, terminations lead to lower stillbirth rates and, vice-versa, later terminations lead to higher stillbirth rates if included in the stillbirth statistics.[10]

Misclassifications of both stillbirths and neonatal deaths are more common for births occurring at 22-27 weeks of gestation. In some countries, immediate neonatal deaths of extremely small (22-27 weeks) neonates are often not registered as live births.[10] The importance to improve the quantity and quality of data on stillbirths and neonatal deaths is widely recognized and different means are suggested to achieve this target including better civil registration procedures, introducing perinatal death certificates, applying advanced verbal autopsy methods for stillbirths, and improving ICD codes for stillbirths in ICD 11 revision that is currently underway.[9]

1.4 Indicators for tracking preventable stillbirths

Stillbirth rates largely reflect socioeconomic inequalities, especially those connected with access to timely and quality care.[6,8] According to the recent estimates, about half of all late stillbirths in the world (1.3 million of 2.6 total stillbirths) occur intrapartum – during the labor.[6] Intrapartum stillbirths are considered to be a sensitive marker of intrapartum care as they are usually preventable when timely and quality care is available. Not surprisingly, the proportion of intrapartum stillbirths is about 6-fold higher in developing countries as compared to the developed world (~60% in the former versus ~10% in the latter).[6] It is higher in rural areas than in urban, and in the countries where caesarean section rates are below 10% (although there is no detectable benefit for maternal and newborn health from further (>10-15%) increase in caesarean section rates).[6] Despite its importance, data for intrapartum stillbirths are scarce, which limits policy makers in developing potentially effective targeted interventions.[11] Therefore, it is important to routinely record and review on both local and national levels not only total stillbirths, but separately intrapartum stillbirths that occur during labor and could be prevented with early identification of pregnancies at-risk and provision of high quality obstetric care.[6] Globally, a considerable portion of stillbirths is attributable to maternal infections, particularly syphilis and malaria (each responsible for around 8% of all stillbirths worldwide) and these stillbirths are deemed to be completely preventable even in countries with the weakest health systems with appropriate screening of reproductive-age women for these infections.[6]

Other potentially modifiable factors associated with stillbirths include non-communicable diseases (especially, hypertension and obesity), lifestyle factors (e.g., smoking), nutritional factors (e.g., small-for-gestational age because of inadequate nutrition) and maternal age over 35.[12] Around 14% of the stillbirths globally is attributable to prolonged pregnancies.[6] Thus, targeted health education activities along with reduction of socioeconomic inequities could be effective in reducing these stillbirths.

To reduce preventable stillbirths in a given country effectively, the causal structure of stillbirths in that country should be identified. An ideal approach to this is conducting autopsy of all cases of stillbirths accompanied with placental histology and karyotype, as with these three types of evaluation, the cause of stillbirth could be identified for two-thirds of all cases.[7] In summary, the usefulness of data available from stillbirth registration can be increased, if the data are disaggregated by timing of stillbirth (ante- and intrapartum), gestational age, birth weight, cause of stillbirth, and the most vulnerable population groups.[6,11]

1.5 Infant and neonatal mortality and stillbirth: data sources and trends in Armenia

The official data on stillbirth, neonatal and infant mortality in Armenia is available from vital statistics registry. Civil Status Acts Registration (CSAR) Bodies annually report about the registered cases of live births, stillbirths and infant deaths to the National Statistical Service (NSS), where these data are summarized and included in Statistical Yearbooks and other relevant publications. Ministry of Health (MOH) is the second source of information on stillbirths, neonatal and infant mortality rates, as it uses health facilities' annual reports to generate data on stillbirths and infant mortality. Due to relative independence of the used data sources, the rates reported by NSS and MOH differ in some extent. This difference was even bigger during the decade of 1995-2005, as the two agencies officially used different definitions of live birth and stillbirth. Before 1995, both agencies based their calculations of stillbirth, neonatal and infant mortality rates on a stringent definition of live birth adopted during Soviet times and different from the World Health Organization's (WHO) 10th classification definition. According to the Soviet definition, only those neonates born after at least 28 weeks of gestation with a birth weight of 1000 grams or more and who had drawn at least one breath were considered as live born. Neonates born weighing less than 1000 grams were considered fetuses (neither stillbirths nor live births), unless surviving for at least 7 days, and were not registered in any mortality

statistics. In 1995, the MOH adopted WHO 10th classification definition of live birth, according to which all those neonates demonstrating at least one sign of life at birth (e.g., heartbeat, rippling of umbilical cord, or muscular movements) are considered live birth regardless of their weight or term of birth. Meanwhile, NSS continued to follow the old definition of stillbirth and live birth, hence leaving out from the official reporting all those neonates weighting less than 1000 grams at birth who were born dead or alive but died during the first 7 days of life.

The situation has changed since 2005, when NSS also adopted the WHO definition of live birth. However, for some discrepancies in the registration, the rates of stillbirth and infant mortality reported by these two agencies still differ in some extent. Another difference is detected when comparing the rates from these two sources with the corresponding rates found during different population-based surveys including Armenia Demographic and Health Surveys (ADHS), or calculated using country-specific international criteria. Consistently, infant mortality estimates provided by the latter two sources are notably higher than the MOH rates, which in their turn exceed the NSS rates. This diversity is considered a serious obstacle for the objective assessment of the situation with stillbirth, neonatal and infant mortality in the country and for developing strategies aimed to their reduction.

In 2009, a study was conducted by the MOH and UNICEF to explore the knowledge and practice of health care providers on the newly adopted definitions of live birth and stillbirth.[13] According to the study results, practitioners demonstrated sufficient theoretical knowledge on the definitions of stillbirth and live birth, but the ability to apply this knowledge in practice was very low. The study concluded that the deficiencies in classification and registration of births and deaths within health care system were the main reasons for inaccurate official reporting of births and deaths and recommended to closely supervise the process of birth and death registration and reporting at all levels through employees specially assigned for this task.

In addition to the issues described above, a considerable (~30-40%) increase in the official rates of stillbirth (defined as fetal deaths at 22 weeks gestation or later) was observed in Armenia during 2003-2006 compared to 2000-2002 (first wave) and during 2010-2012 compared to 2007-2009 (second wave), while the rates of infant mortality for the same periods remained relatively stable. Since 2010, the stillbirth rates exceeded infant mortality rates almost two times. This ratio is higher than one could expect, as in a large-scale study conducted in the USA, the ratio of

stillbirths (defined as fetal deaths at 18 weeks gestation or later) to deaths during infancy was 1:1.[7] Likewise, during this period, stillbirth rates in Armenia exceeded early neonatal mortality rates over three times, which is quite unusual, as the usual ratio of stillbirths to early neonatal deaths for WHO EURO B group countries (Armenia belongs to) is 1.2:1. This situation raised concerns that there is over-registration of stillbirths and under-registration of early neonatal deaths in the country.

Besides, stillbirth rates in Armenia that include stillbirths weighting 500-999 gram (or having gestational age of 22-27 weeks) exceed the rates that exclude this weight/gestational age category over 2-2.5 times. This huge increase in stillbirth rates when applying 22 weeks gestational age cutoff compared to 28 weeks is observed consistently since 2003 (interestingly, before that (during 2000-2002), this increase was only around 50%). This situation is rather unusual, as, according to the available estimates, the change in gestational age threshold from 28 weeks to 22 weeks increases the number of stillbirths by only approximately 40%.[9,10] A possible explanation for this mismatch with the estimates from other countries could be some over-registration of early stillbirths in Armenia, when a portion of late abortion cases (happening before 22 weeks) is registered as stillbirths. This was another concern needing exploration.

Therefore, the current study was designed to identify whether there are problems in classification of late abortions, stillbirths and live births, as well as in registration and reporting of stillbirths and early neonatal deaths in Armenia. The results of this study could serve as a basis for developing a set of interventions aimed at improving the data quality and data management system on infant mortality rates both within and out of the health care system.

1.6 Study objectives

The aim of the current study is to identify the existing problems with classification of live births and stillbirths as well as the main issues with registration and reporting of stillbirths and early/late neonatal deaths in Armenia.

The study objectives include:

- Conduct desk review of existing legislative and sub-legislative frameworks related to classification of newborns as live birth or stillbirth, and registration of infants' birth and death cases
- Check the correspondence of statistics on live births, stillbirths and neonatal deaths reported by health facilities and Civil Status Acts Registration Bodies (CSARB)
- Assess the knowledge of health care providers (neonatologists, gynecologists and midwives) on classification of live birth and stillbirth
- Assess the current practice of applying live birth and stillbirth classification standards as well as of registration of stillbirth and neonatal death cases in health facilities
- Identify the main causes and barriers leading to misclassification of newborns as live birth or stillbirth and misregistration and misreporting of neonatal death cases
- Develop recommendations to improve the current practice of classification of live- and stillbirths in health care facilities as well as the registration process of infant deaths in state civil status registration system.

2. METHODS

2.1 Study design

The study aimed to make an understanding of the overall situation with providers' knowledge, registration and reporting of livebirth, stillbirth, neonatal and perinatal mortality in the country through reviewing the existing legislation and officially reported data in this area, assessing the knowledge of providers and conducting a qualitative study with different stakeholders, through which the existing problems and barriers in the field could be identified and recommendation for improvement made. For this purpose, the study team designed and implemented a mixed study – a combination of desk review of the relevant literature and documentation, data extraction and analysis, providers' knowledge assessment through quantitative technique, and a qualitative study through in-depth interviews and focus group discussions with different groups of stakeholders. Rigorous assessment methodologies were applied to explore the perspectives of policy makers/experts in the field, health care providers (neonatologists, obstetricians/ gynecologists (ob/gyns) providing inpatient and outpatient care, as well as midwifes in maternity hospitals), pathologists, and CSAR body representatives.

2.2 Study setting

The study took place in Yerevan city and in two marzes – Shirak and Lori, to understand knowledge, attitudes and practices towards diagnosis, registration and reporting of livebirths, stillbirths and neonatal deaths on the national and regional levels. Within Shirak marz, the data collection took place in Gyumri city, and within Lori marz, in Vanadzor city.

2.3 Study participants

The research team identified the study participants using purposive sampling methods and applying sequential approach that includes representativeness and comparability.[14] The method aimed at obtaining pertinent information for the assessment, based on participants' experience and expertise in the area of diagnosis, registration and reporting of livebirths, stillbirths, and neonatal deaths in the country.

Seven groups of participants took part in the study: 1) maternity hospital neonatologists, 2) maternity hospital ob/gyns, 3) women consultation ob/gyns, 4) maternity hospital midwifes, 5)

pathologists, 6) CSAR body representatives, and 7) policymakers/experts involved in legislation or actual practice of registration/reporting of livebirths, stillbirths, and neonatal/infant mortality in Armenia.

2.4 Research instruments

The CHSR/AUA research team developed in-depth interview and focus group discussion guides that were reviewed and approved by UNICEF and MOH. The guides were designed to optimize the value of the data collected during the interviews/discussions through tailoring their content to the area of expertise of each particular informant/group. Hence, the questions in each guide were adapted to specific participants' roles, responsibilities and professional/individual experience in the areas related to registration and reporting of stillbirths, livebirths, and neonatal/infant mortality. The guides were continuously refined during the process of data collection. All the guides were developed in English and translated into Armenian. Appendices 1 and 2 provide English and Armenian versions of the focus group discussion and in-depth interview guides (respectively) used in this study.

The research team developed a short demographic information form to be completed by the study participants prior to each focus group discussion. With the MOH and UNICEF approval, the research team included in this form a 15-item knowledge assessment tool taken from a previous study conducted by MOH and UNICEF in 2009 on the same issues and with the same stakeholder groups.[13] The same set of knowledge-measuring items was used in this study to ensure the comparability of the results with the findings from the 2009 study. Appendix 3 provides the English and Armenian versions of the demographic/knowledge assessment form.

Finally, the study team developed a data extraction form to obtain the existing official data from the available sources on livebirths, stillbirths, neonatal and infant deaths at sufficient level of details, i.e. per marzes, per obstetric services and neonatal units in Yerevan, per birth weight groups (with 500 g intervals), per gestational age (preterm/term), per place of birth (maternity/home), and place of death (maternity/other hospital/home). Appendix 4 provides the English and Armenian versions of the data extraction form.

2.5 Data collection and analysis

The extraction of data on livebirths, stillbirths, neonatal and perinatal deaths from the available sources (NSS, National Institute of Health (NIH), relevant publications), data collection and analysis for the qualitative study took place during February-July 2016. The CHSR/AUA research team conducted all the in-depth interviews (IDI) and focus group discussions (FGD). Each focus group had a trained moderator and a note-taker. With few exceptions, the interviews and FGDs were audio recorded (with permission of all study participants). The research team took detailed notes in the few instances when the audio recording was not allowed. All FGDs and IDIs were transcribed. The qualitative study applied the research methods of heterogeneity and triangulation, and completed interviews/discussions with each type of participants when saturation was achieved.[14] In the stage of data analysis, the research team utilized conventional content analysis techniques to analyze IDI and FGD transcripts.[14,15] The themes identified during the analysis generally repeated the sequence of the main themes included in the field guides. The research team organized the results section based on the identified main themes.

Overall, 121 study participants (100 female and 21 male participants) were recruited from Yerevan (65 participants) and the cities of Vanadzor (32 participants) and Gyumri (24 participants). The study participants often demonstrated unwillingness to express their ideas openly on the discussed issues, but none of them refused to complete the discussion/interview once started. Some providers did not attend FGDs after giving preliminary consent to participate, mainly reasoning it with busyness (e.g., only two providers from Gyumri maternity hospital attended the FGD as the rest were busy in the operation room). Also, six persons (including two policy makers/hospital heads, two providers, two pathologists, and two CSAR body representatives) refused to participate in IDI after being informed about the discussion themes and five policy makers/hospital heads referred us to their employees better informed about/involved in registration and reporting of livebirths, stillbirths, and neonatal deaths.

Of the 23 IDIs with key informants, 14 were conducted in Yerevan, five in Gyumri city, and four in Vanadzor city (Table 1). The key informants were representatives/policy makers from MOH (2), Marz Health Departments (2), National Assembly of RA (1), Ministry of Labor and Social Affairs (1), CSAR body representatives from Yerevan (2) and Vanadzor (1), heads of maternity hospitals or obstetric/neonatal departments from Yerevan (4) and marzes (2), obstetric care

providers from Yerevan (3) and marzes (2), and pathologists involved in autopsies of stillbirths and neonates from Yerevan (1) and marzes (2). The interviews with the key informants lasted 42 minutes in average (range 10-85 minutes).

Table 1. Number of IDI and FGD participants by specialty/type and study site

	Yerevan	Vanadzor	Gyumri	Total
IDIs				
Policymakers	4	1	1	6
Maternity hospital/department heads	4	1	1	6
Providers (ob/gyn or midwife)	3	-	2	5
Pathologists	1	1	1	3
CSAR body representatives	2	1	-	3
FGDs				
Neonatologists	13	3	2	18
Ob/gyns from in-patient settings	16	7	-	23
Ob/gyns from out-patient settings	7	9	6	22
Midwifes	15	9	11	35
Total	**65**	**32**	**24**	**121**

Overall, 98 providers participated in 13 focus group discussions in Yerevan, Shirak and Lori marzes. Of the seven FGDs conducted in Yerevan, two involved neonatologists, two – ob/gyns, two – midwifes from maternity hospitals, and one – ob/gyns from women consultations in Yerevan. Ten of the 12 maternity hospitals of Yerevan were represented in FGDs and IDIs.

Three FGDs were conducted in each of the marzes of Lori and Shirak, with the following categories of participants: maternity hospital physicians, maternity hospital midwifes, and women consultation ob/gyns from the cities of Vanadzor and Gyumri, respectively. Numbers of participants to each FGD are provided in Table 1.

The mean duration of FGDs was 72 minutes. On average, the discussions took longer in Yerevan than in the marzes (84 minutes versus 59 minutes) and with hospital staff than with women consultation staff (76 minutes versus 58 minutes). Also, FGDs with neonatologists took longer than those with the other groups (103 minutes with neonatologists versus 74 minutes with midwifes and 84 minutes with ob/gyns from Yerevan maternity hospitals).

The mean age of providers who participated in FGDs was 48 years (52 years for ob/gyns from women consultations, 49 years for midwifes, 46 years for ob/gyns from maternity hospitals, and 44 years for neonatologists). The mean duration of professional experience of providers was 22 years (27 years for ob/gyns from women consultations, 24 years for midwifes, 20 years for ob/gyns from maternity hospitals, and 15 years for neonatologists). Fifty percent of the FGD participants mentioned that they have received some training on the new classification of live births, stillbirths and perinatal period after 2005. Of the specialty groups, 65% of neonatologists, 55% of ob/gyns from women consultations, 45% of midwifes and 41% of ob/gyns from maternity hospitals reported that they have received such training.

Both during IDIs and FGDs, there were few participants expressing their ideas openly, while the majority were brief and general in their answers and, sometimes, reluctant and critiquing the themes under discussion. During the FGDs, often participants warned each other to be careful in expressing their ideas on particular issues to avoid getting into trouble. The overall impression was that the majority of the participants were telling what they felt they need to tell rather than the truth. Sometimes they questioned the meaning of replying to the questions about the actual practice of diagnosing, registering, and reporting stillbirths, telling that their hospital heads and higher instances knew very well the situation in the hospitals on these matters.

2.6 Categorization of study participants

The direct quotes provided in the boxes in the Results section were abstracted from both in-depth interviews and focus group discussions. The FGD participants were categorized into four groups: 1) neonatologist, 2) ob/gyn, 3) midwife, 4) WC ob/gyn. The IDI participants were categorized into six groups: 1) ob/gyn, 2) neonatologist, 3) midwife, 4) pathologist, 5) CSARB, and 6) policymaker.

The first three categories of the FGD participants were, respectively, neonatologists, obstetrician/gynecologists, and midwifes employed in maternity hospitals, while the WC ob/gyns were obstetrician/gynecologists employed in women consultations (primarily). For IDI participants, the first four categories included providers involved in diagnosis, registration, reporting, or autopsies of stillbirths and neonatal deaths. The CSARB category involved employees of Civil Status Acts Registration Bodies involved in registration of livebirths,

stillbirths and neonatal deaths, and policymakers were administrative workers or professionals involved in development or implementation of health policies with regard to registration and reporting of livebirths, stillbirths and neonatal deaths.

The individual informant identifiers (e.g., Policymaker 3.4.1.1.) specify the category of participants who provided the quote (e.g., Policymaker), the subtitle of the report (e.g., 3.4.1.) and the sequential number of participant who provided the quote for the given subtitle of the report (e.g., 1.). If the same participant provided more than one quote for a given subtitle, these quotes are provided under the same identifier. A single informant who provided quotes for more than one subtitle has different identifiers under each subtitle. After each identifier, the type of qualitative study method applied (FGD or IDI) and the residency area of the participant (Yerevan or marz) are provided. Here is an example of a complete identifier for an ob/gyn, FGD participant from Yerevan, who provided the first quote under the Results section's subtitle 3.4.1: (Ob/gyn 3.4.1.1, FGD, Yerevan).

2.7 Ethical considerations

The AUA Institutional Review Board approved the study protocol to comply with locally and internationally accepted ethical standards. All participants were informed about their rights (voluntary participation, refusal to answer any question they chose or to continue interview/discussion at any time, anonymity and confidentiality of provided information) through a consent form. Audio-recording was conducted only with permission of all participants and only written notes were taken if a participant did not want to be audio-recorded. The final report does not contain any identifiable information such as respondents' names, positions, institutions, and even specialties for IDI participants.

3. RESULTS

3.1 Laws and regulations concerning livebirth and stillbirth reporting and registration in Armenia

The RA Law on Civil Status Acts,[16] supported by the RA Minister of Justice Decree N 97-N, on *"Endorsing the Instructions concerning Registration of Civil Status Acts"*,[17] is the main law regulating birth and death registration in the Republic of Armenia (RA). It states that CSAR bodies are obliged to perform registration of births and deaths in Armenia. Registration of birth is conducted based on a written declaration about birth submitted to a CSAR body by the parent(s) of a child or some other interested person. The declaration should contain information on child's name, father's name, and family name, place of birth, time of birth, gender, and other relevant information. The written declaration should be presented together with a document of a prescribed form certifying the birth of a child issued by the medical facility where the child was born (or, when the birth took place outside a medical facility, by the medical facility/person that provided assistance during the labor). Besides, the identity document of the person submitting the declaration (usually – parents) and a document serving as a basis for the necessary information on child's father should be presented. The declaration about birth should be presented to a CSAR body within one year after the child's birth. However, omission of this term cannot serve as a basis for rejection of birth registration and, legally, there is no any time limitation for birth registration.[16]

Birth registration is conducted by a CSAR body in the area where the child was born or where the child's parents live. In the case of child's death within 4 weeks after birth, the registration of birth can be conducted by the CSAR body in the area where the death took place. In addition, birth registration can be carried out by the RA Ministry of Justice (MOJ) Birth and Marriage Ceremonial Registration Chamber, and deaths (including neonatal deaths) in Yerevan are registered by the CSAR Agency's Yerevan specific service area body within the system of MOJ.[16,17]

Registration of birth of a stillborn child is performed by a CSAR body based on a document of a prescribed form on perinatal death issued by a medical facility or a doctor. Only the birth of a stillborn child is registered (death is not registered), and no birth certificate is issued. Instead, a

document certifying the registration of birth of a stillborn child is provided upon parents' request.[16]

If a child died during the first four weeks of life (within neonatal period), the registration of both birth and death is performed based on documents of the prescribed form on birth, perinatal death, and death issued by a medical facility or a doctor. In the case of neonatal death, based on registration of both birth and death, only death certificate is issued. Also, a document certifying the registration of birth of a newborn that died during the neonatal period is provided upon parents' request.[16]

Registration of birth of a stillborn or birth and death of a newborn that died during the first four weeks of life is the responsibility of the head of the medical facility where the birth and death, respectively, took place or the head of the medical facility/doctor who confirmed the birth of a stillborn or the death of a newborn within the first four weeks of life. The term for declaring about the birth of a stillborn or a neonatal death is seven days since the day of birth or death, respectively.[16]

The RA Government Decision N 949-N on *"Improving the situation with respect to problems of classification and registration of infant mortality and births"*[18] is the main legislative act based on which Armenia officially adopted the ICD-10 definitions for live birth and stillbirth, and the gestational age threshold between abortion and delivery. Some of the terms that were defined and adopted by this decision are provided below:

- *Livebirth* defined as a complete expulsion or extraction of a product of conception from its mother, irrespective of the duration of the pregnancy, after which the fetus breathes or shows any other evidence of life, such as heart beating, pulsation of the umbilical cord or definite movement of voluntary muscles irrespective of the umbilical cord being cut and/or the placenta separated. All the cases of live birth weighting 500 g or more are to be registered in CSAR bodies.
- *Stillbirth* defined as a complete expulsion or extraction of a product of conception from its mother, after which the fetus does not breathe or show any other evidence of life, such as heart beating, pulsation of the umbilical cord or definite movement of voluntary

muscles. All the cases of stillbirth weighting 500 g or more (or having gestational age of 22 weeks or more) are to be registered in CSAR bodies.

- *Birth* defined as a complete expulsion or extraction from its mother of a death fetus (in case of stillbirth) weighting 500 g or more (or having gestational age of 22 weeks or more) or an alive fetus (in case of livebirth) irrespective of the term of pregnancy.
- *Miscarriage (abortion)* defined as termination of pregnancy (spontaneous expulsion of the fetus or its extraction) before 22 weeks of gestation or before the weight of the fetus reaches 500 g.
- *Induced abortion* defined as intentional termination of pregnancy due to women's will before 22 weeks of gestation. After 12 weeks of gestation, induced abortion due to women's will is conducted only with medical or social indications.
- *Perinatal period* defined as the period that commences at 22 completed weeks (154 days) of gestation, when the fetal weight is normally 500 g and ends seven completed days (168 hours) after birth.
- *Perinatal mortality* defined as annual number of stillbirths and early neonatal deaths (occurring during first seven days of life) per 1000 total births (that includes stillbirths and livebirths).
- *Neonatal period* defined as the period that commences at birth and ends after 28 full days (4 weeks) after birth.
- *Neonatal mortality* defined as death of liveborns during the first 28 full days (4 weeks) of life. It is separated to early neonatal mortality – deaths occurring during first 7 complete days of life, and late neonatal mortality – deaths occurring after the 7th day but before the 28th complete day of life. The age of death that occurs during the first day of life is registered in minutes or hours. The age of death occurring during the second (day 1), third (day 2) and before the 27th complete day of life is registered in days.

RA Government Decision N 949-N[18] obliged healthcare facilities and organizations:

- to shift to these new definitions,

- to register in medical documentation all births with newborns weighting 500 grams or more (or, if the weight is unknown, with gestational age of at least 22 full weeks or with body length of at least 25 cm), irrespective of being born alive or dead,
- to register in CSAR bodies all newborns (being born alive or dead) weighting 500 grams or more (or, if the weight is unknown, with gestational age of at least 22 full weeks or with body length of at least 25 cm),
- to issue the following medical forms about the birth or death of a child (including stillborns and liveborns weighting 500-1000 grams) to be presented to CSAR bodies:
    - "Medical certification of birth" in the case of live birth,
    - "Medical certification of perinatal death" in the case of stillbirth and early neonatal death,
    - "Medical certification of death" in the case of death after early neonatal period,
- to include all these cases into both administrative (field) and state (national) statistics,
- to carry the responsibility for registration in CSAR bodies of all cases of stillbirths and neonatal deaths (occurring in the given medical facility or at home – in the latter case, the corresponding primary healthcare facility carries the responsibility),
- to register the cases of stillbirths and neonatal deaths in CSAR bodies within seven days following the death,
- to carry out autopsy of all cases of perinatal mortality (including those weighting 500-1000 g),
- for international comparability, in administrative (field) statistics to calculate indicators separately for those weighting 1000 grams or more as well.

A number of legislative acts were issued later on to support the implementation of the RA Government Decision N 949-N. *The Minister of Health Decree N 778-A*[19] obliged the heads of health departments and facilities in Armenia to ensure the implementation of the RA Government Decision N 949-N. It suggested the heads of the administrative subdivisions of Armenia (Yerevan and the marz governors) to establish Interagency Coordinating Bodies with inclusion of stakeholders at marz level to improve the situation with infant mortality and birth

registration and classification, as well as to develop Action Plan at marz level to achieve this goal. It also suggested making a list of specialists (pediatricians and ob/gyn-s) in each marz responsible for coordinating the process of implementation of the RA Government Decision N 949-N, and to present to regional CSAR bodies these lists and the lists of those health facilities that have a legal right to issue medical certification of birth and death. It obliged the heads of mother and child healthcare facilities to designate a person at the facility-level to carry the responsibility for coordinating the processes of registration of births and infant deaths.

The procedure for issuing and recording medical certifications of birth, perinatal death and death in healthcare facilities, as well as the prescribed forms for journals to report births, perinatal deaths and deaths were adopted in 2011 by the *RA Government Decision N 1156-N*.[20] The decision reinforced the provisions of the RA Law on Civil Status Acts.[16] In addition, it obliged authorized medical facilities to provide medical certification of birth to the confined woman within three days after she presents valid identity document or the husband of the woman after he presents valid identity document and the marriage certificate with the woman. If the child was discharged from the medical facility without issuing medical certification of his/her birth (because of the absence/invalidity of the listed documents), the medical certification of birth for the child is issued by the medical facility after the listed persons present the needed documents – irrespective of the time passed since the birth of the child.

As to issuing medical certification of perinatal and late neonatal death, in addition to the issues covered in the RA Law on Civil Status Acts,[16] the RA Government Decision N 1156-N states that the medical facility where the stillbirth or neonatal death has occurred is responsible for issuing the medical certification of perinatal/neonatal death, while in the cases when no medical assistance was provided to a women during delivery and the newborn was born dead or died, the district primary healthcare facility (PHC) facility organizes transfer of the child's body through ambulance service to a health facility licensed to provide autopsy services and the medical certification of perinatal death is issued by the pathologist who conducted the autopsy.[20] The RA Government Decision N 1156-N obliges those medical facilities that provide medical certification of birth, perinatal death or death, to carry out accounting of the certifications they issue through completing separate journals of prescribed forms for births, perinatal deaths and deaths. The pages of these journals must be enumerated and each completed page must be

signed and stamped by the person completing the journal. In the case of losing a medical certification, medical facility should provide a copy of it (marking it as a "copy") within three days of receiving corresponding written application from a person authorized to receive it.[20]

Another government document, *"Standards of Organization of Care of and Medical Assistance to Newborns within the Framework of the State-Guaranteed Free Medical Assistance and Service", adopted by the RA Minister of Health Decree N 3144-A*,[21] details the procedure of reporting and registration of births, perinatal and neonatal deaths in healthcare facilities. In addition to the procedures described above, it states that a Newborn Record Form is completed in maternity hospital for each live born child, while the information on a stillborn child is recorded in the Delivery History Form. In the case of stillbirth or neonatal death, parents should be informed about their right to get information on the possible causes of the death and the results of the autopsy, to see the body of the newborn, and to know which name is given to the child in the medical certification of death, as well as about their right to abandon the body of the fetus/newborn. The fact of provision of such information should be recorded in the medical record form and verified by the parent's signature. Also, all cases of perinatal death, including those weighting 500 grams or more at birth, should undergo postmortem examination (autopsy).[21]

The "Standards of Organization of Care of and Medical Assistance to Newborns within the Framework of the State-Guaranteed Free Medical Assistance and Service" states that maternity hospitals should discharge a neonate after his/her birth is registered in CSAR bodies and a corresponding note made in the Newborn Record Form containing the number of child's birth certificate and the time and place of the birth registration. In particular cases, when the birth registration in compliance with the existing procedures is impossible because of objective reasons, the neonate is discharged from the maternity hospital and the neonatologist makes a note (verified by the department head) about unregistered birth in the Newborn Record Form.[21]

According to this document, if the confined woman has no identity document, medical facility does not issue a medical certification of the child's birth. The "Standards…" oblige medical facilities to inform the district police and the subdivision on children's issues of the local governor's office about the fact of delivery of a woman without identity documents. If the identity of the woman remains unknown, a corresponding note (verified by the department head)

should be made in the "Neonates' Journal" at the time of the newborn's discharge. In such cases, the photo of the confined woman is attached to the woman's delivery history and verified by the woman's signature before the woman is discharged. The woman (or her legal representative) provides a declaration of a prescribed form about the reason for not having an identity document and the fact of being discharged without receiving a medical certification of the child's birth. This declaration is also attached to the delivery history and verified by a committee consisting of the women's ob/gyn or midwife, the head of obstetrical service, and the chief nurse. If the women (or her legal representative) presents a valid identity document to the medical facility after she was discharged, the facility must issue medical certification of her child's birth based on the information recorded in the medical documentation and the identification of the mother with the photo attached to the delivery history, irrespective of the time passed since the delivery.[21]

The RA Government Decision N 275-N on Child Birth Allowance[22] adopted in 2014 is another legal act that might indirectly influence the neonatal death registration. It establishes one-time child birth allowance, the amount of which depends on the sequential number of the newborn child in the family. The size of the allowance for the first and second children in the family is 50,000 AMD, for third and fourth children – 1,000,000 AMD, and for fifth and higher-order children – 1,500,000 AMD. According to this Decision, the sequential number of a child that died during the perinatal period is always 1st and the birth allowance for such child is paid in the amount defined for the first child in the family (50,000 AMD). In other timing of child's death (after the perinatal period), the birth allowance for that child is assigned and paid on general principles (as for alive newborns). Besides, according to this Decision, when determining the birth order of a newborn, the previous children of the newborn's parents that were born during the three-year period prior to the birth of the newborn child and died, are being considered unless they died during perinatal period.[22] Thus, if a died child's birth order is third or more, there is a substantial difference in the amount of birth allowance to be paid to the parents depending on the time of the child's death - early (first seven days of life) versus late (7-28 days of life) neonatal period. And this difference could be still in place when determining the amount of birth allowance for the next child in the family.

3.2 NIH and NSS data on livebirth, stillbirth, neonatal and infant mortality

As it was mentioned in Chapter 1.5, there are two relatively independent sources of data on live births, stillbirths, neonatal and infant mortality in Armenia that report surveillance-based data annually. These sources are NSS and MOH or, specifically, National Institute of Health (NIH) of Armenia. NSS data are based on annual reporting of all CSAR bodies countrywide, while NIH data are collected via annual reporting of all healthcare facilities. Hence, NSS data reflect the coverage and completeness of registration of births and deaths in the CSAR system, while NIH data reflect the coverage of births and deaths by the healthcare system, the coverage of healthcare facilities and private providers with annual reporting, as well as the accuracy of registration and reporting of births and deaths in healthcare facilities. However, these two sources are only relatively independent as, according to the existing legislation, both birth and death registration in CSAR bodies is conducted based on medical certification of births/deaths issued by authorized healthcare facilities or private providers.

The purpose of this chapter is to explore the existing trends in livebirth, stillbirth, neonatal and infant mortality indicators at different levels (countrywide, between Yerevan and marzes, and between healthcare facilities) and to compare indicators available from different sources to understand if and why there are differences between them.

3.2.1 Data on livebirth

Both sources of data on livebirth, NIH and NSS demonstrated a sharp decline in the number of livebirths in early 1990s, followed by milder decline during 1995-2000. As a result, the number of livebirths in the country reduced more than twice. The rate stabilized in early 2000s and during 2003-2010 demonstrated an increasing trend, which, however, disappeared since then (Table 2 and Figure 1).

Table 2. Absolute numbers of live births in Armenia, based on NSS and NIH data[23]

Year	1990	1995	2000	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014
NIH	80022	45430	35142	37681	37706	40055	41258	44306	44330	42882	42346	41668	43061
NSS	79882	48960	34276	37499	37639	40105	41185	44413	44825	43340	42480	41790	43031

Figure 1. Absolute numbers of live births in Armenia, based on NSS and NIH data[23]

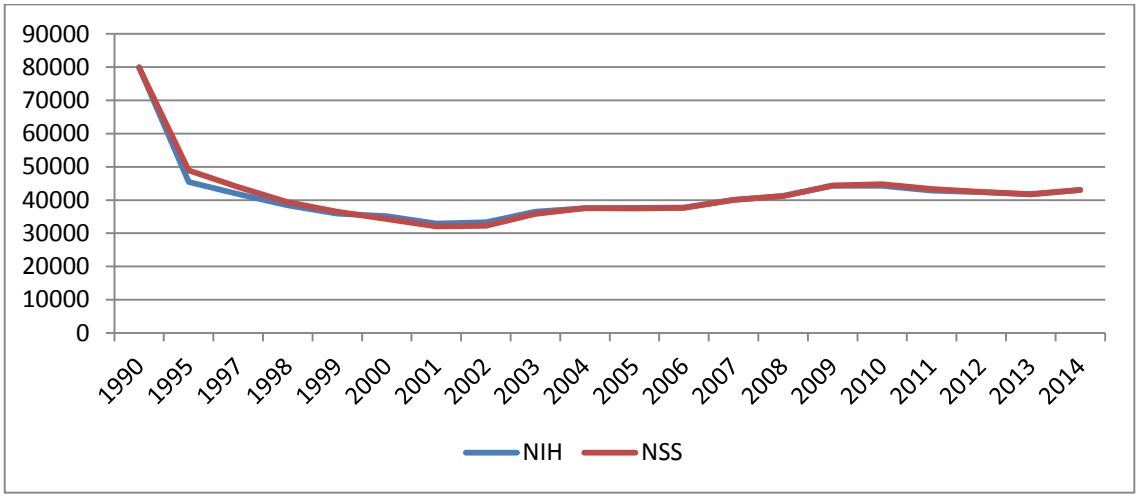
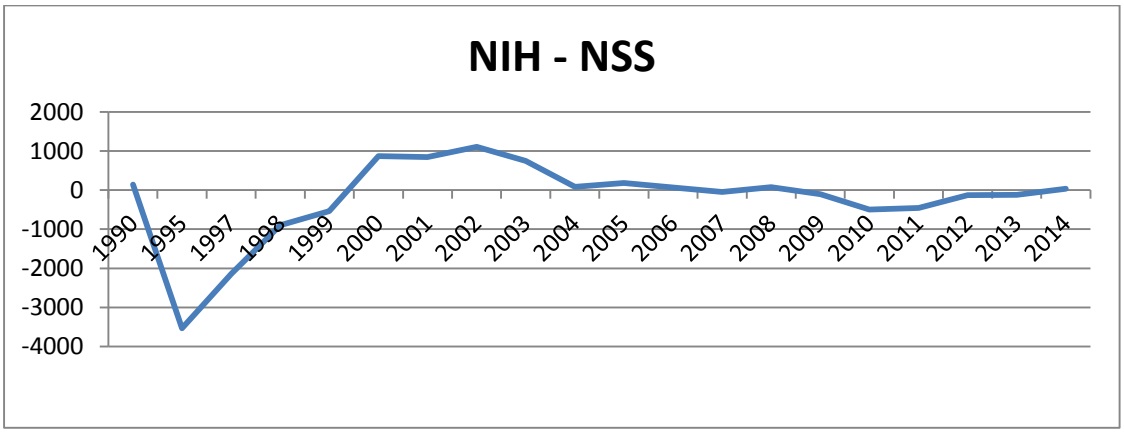


Figure 2. Differences in absolute numbers of livebirth between NIH and NSS data[23]



Comparison of data on livebirth from NSS and NIH revealed no consistent pattern. As demonstrated in Figure 2, NSS numbers exceeded NIH numbers during 1995-99, especially for the years 1996-97, although one could expect an opposite trend considering that in 1995 the healthcare system made a shift to WHO 10th classification definition of livebirth (which produces higher numbers of live births), while CSAR system continued using the old definition of livebirth till 2005. The expected pattern (higher NIH numbers of live births) was observed during 2000-2003, possibly indicating late actual introduction of the new classification in the healthcare system. During 2004-2009, the numbers of livebirth from the two sources were almost identical, while during 2009-2013, NSS numbers again exceeded NIH numbers. However, when comparing these numbers, one should keep in mind that the NIH numbers are

based solely on the annual reporting of those facilities that provide obstetric services. These facilities are obliged to include in their annual reporting all the births that took place in the facility, as well as all those cases when a woman gave birth outside but later was hospitalized (Annual Reporting Form N-32 available from http://nih.am/arm/reporting-forms/). Still, if the birth occurred outside an obstetric service, and the mother and child couple was not hospitalized later on, the case of birth will be left out from the NSS annual reporting, while, according to the existing law, it will be registered in CSAR bodies based on a birth certifying document issued by the medical authority (included non-obstetric) which assisted during the confinement or, if no medical assistance was provided during the confinement, a certificate on health issued by a medical authority which examined the child.[16] Meanwhile, the annual reporting form for outpatient pediatric services (Annual Reporting Form N-31available from http://nih.am/arm/reporting-forms/) includes only one summative number of all those children that were taken under the facility's control during the given year, making impossible to distinguish between those born during that year (in the hospital or at home) and those transferred from other areas/providers. However, according to NIH officials, the number of such births is very few, although there is no data to support this perception.

There are several other factors that might result in positive or negative differences between NIH and NSS data on live births. One is that births in the families of non-Armenian citizens taking place in Armenia are included in NIH data but could be omitted from NSS data resulting in higher NIH numbers. In contrary, some proportion of Armenian women could give birth outside Armenia and then move to Armenia and register their newborns in Armenia resulting in higher NSS numbers. Other, less probable factors underlying the negative difference between NIH and NSS numbers of livebirth might include incomplete coverage with annual reporting of all obstetric services/providers functioning in the country and/or incomplete reporting of registered births by them. Therefore, further case-based investigation is needed to explain the exact reasons for the differences between the NSS and NIH numbers of livebirth.

3.2.2 Data on stillbirth

According to the data available from NIH,[23] since the adoption of WHO 10th classification definition of stillbirth in the healthcare system in 1995, the rates of stillbirth in Armenia demonstrated increasing trend. During 1995-2005, this trend was evident solely in NIH

statistics, while after 2005, when the WHO 10th classification definition was adopted by vital registry system as well, the increasing trend in stillbirth rates was reflected in NSS data also.

As Table 3 and Figure 3 demonstrate, the pace of increase in stillbirth rates was not stable. The NIH data indicated three major bursts of stillbirth rates during the last 25 years. The first burst, as expected, was observed in 1995 and coincided with the adoption of the changed definition of stillbirth in the healthcare system. At its pick, this burst resulted in ~50% increase in stillbirth rates compared to the rates in early 1990s (from 10.0 to 15.0 per 1000 total births), which is consistent with the available estimates from the literature indicating that the change in gestational age threshold from 28 weeks to 22 weeks increases the number of stillbirths by ~40%.[9,10] However, a second burst occurred in 2003 resulting in almost doubled stillbirth rates (compared to early 1990s) without any visible reason. The third burst occurred in 2010 after some reduction in stillbirth rates during 2007-2009 and reached even higher values than in 2003, after which, again, some slight decrease was observed.

Table 3. Rates of stillbirth and perinatal mortality (per 1000 live and still births) in Armenia

	NSS[24,25]		**NIH**[23]	
Year	**Stillbirth rate**	**Perinatal mortality**	**Stillbirth rate**	**Perinatal mortality**
1990	10.6	17.6	10.1	17.6
1995	6.7	13.2	15.0	22.9
2000	8.4	16.8	13.4	23.7
2001	8.3	17.1	12.0	21.1
2002	7.3	15.3	12.2	20.5
2003	8.0	14.8	19.0	26.8
2004	7.7	14.2	18.0	24.8
2005	9.5	16.9	17.4	24.0
2006	17.3	26.0	18.4	25.6
2007	13.8	20.8	15.3	20.5
2008	14.4	20.7	15.3	20.0
2009	17.7	23.2	15.0	19.1
2010	18.5	24.1	18.9	23.1
2011	19.2	25.3	20.0	24.4
2012	18.7	24.1	18.8	22.5
2013	16.7	21.9	16.5	20.2
2014	17.0	21.8	17.2	22.2

As to the NSS rates, these were low and relatively stable before the adoption of the new definition of stillbirth in 2005 requiring to register 500-999 gram births in the vital registration system.[18]

Figure 3. Stillbirth rates: NSS vs. NIH

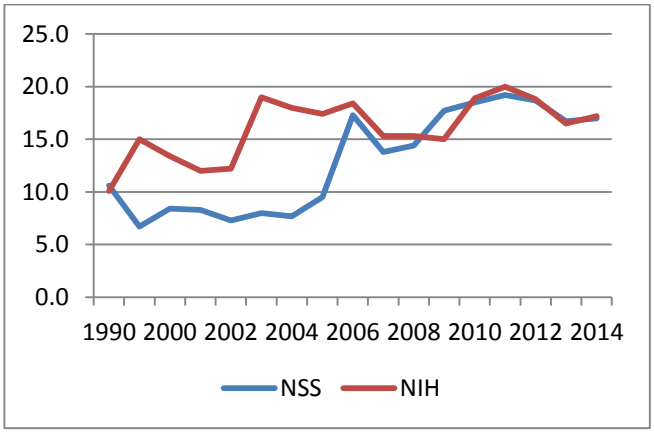
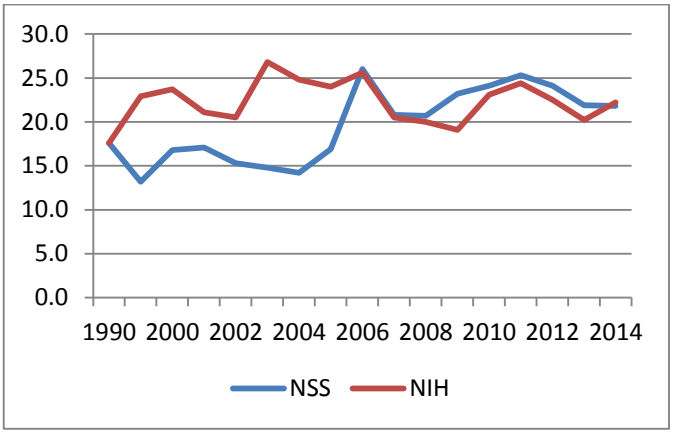


Figure 4. Perinatal mortality rates: NSS vs. NIH

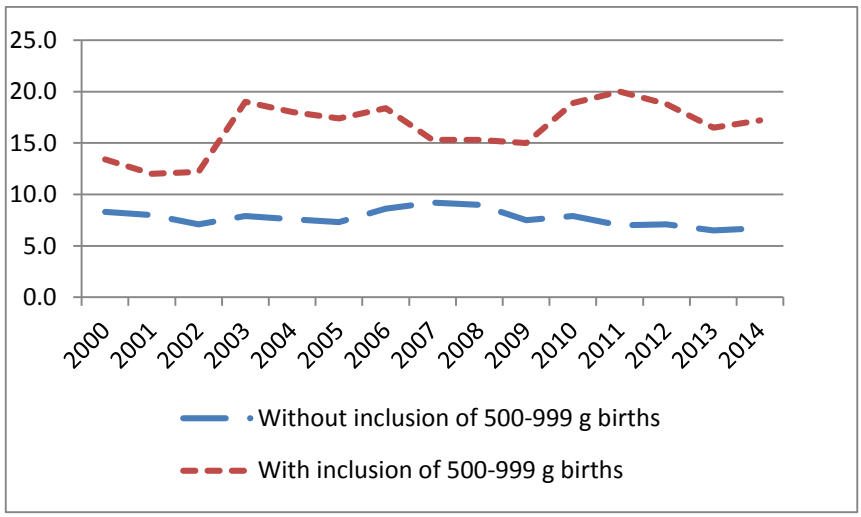


Hence, the difference in stillbirth rates between NIH and NSS was mainly attributable to including extremely low birthweight (<1000 gram) stillbirths in the statistics of the former while excluding these from the statistics of the latter. The first burst of the stillbirth rates in NSS data coincided with the adoption of the new classification in 2005, after which the NSS rates repeated the patterns of the NIH rates. However, some differences between the two data sources were observed after 2005 as well. The NIH rates of stillbirth were generally higher than the NSS rates, although there were few years (2009; 2013) when an opposite pattern was observed (Figure 3).

The trends in perinatal mortality (Figure 4) largely repeated the trends in stillbirth rates. However, during 2009-2013, perinatal mortality rates were consistently higher in NSS data compared to NIH data, even though NSS used higher denominators to calculate these rates, as the NSS numbers of livebirth during these years were consistently higher than the NIH numbers. The possible reason for this difference could be that the NIH rates include solely the cases of perinatal mortality that occurred in maternity hospitals, thus omitting those that took place in other places (for the same reason as described above with regard to livebirth numbers), while the NSS numbers include both.[23]

It is worthwhile mentioning that according to NIH data, the observed increase in stillbirth rates is mainly attributable to increasing rates among those neonates born with extremely low birth weight (<1000 grams), because, as Figure 5 depicts, no increasing trend is observed in stillbirth rates among those born 1000 g or more. The comparison of this pattern with corresponding data from NSS is impossible, as NSS does not analyze any data on distribution of stillbirths, livebirths, or neonatal deaths by weight, gestational age, diagnosis, or any other health- or medical service-related domain. Thus, the discussion on these factors provided here solely relays on NIH statistics.

Figure 5. Stillbirth rates by birth weight, NIH[23]



In 2014, the share of under-1000 gram births among stillbirths was 61.3%, while the share of 1000-2499 gram births 25.2% and over 2499 gram births 13.5%. It is noteworthy that the percentage of under-1000 gram births among stillbirths increased considerably since the evaluation conducted by the MOH in 2009.[13] This study evaluated the situation in three marzes (Gegharkunik, Syunik, and Vayots dzor) and five maternity hospitals in Yerevan ("Erebuni", "S.Gr.Lusavorich", "S.Astvatsamayr", "Qanaqer-Zeytun", and Family Planning Center). It found that the cumulative percentage of under-1000 gram stillbirths among all stillbirths in 2008 was 16.0% in the selected marzes and 37.5% in the selected maternity hospitals. In 2014, according to NIH data, these percentages were 32.0% and 58.6%, respectively, indicating notable increase in the share of extremely low birth weight stillbirths in the overall rate of stillbirth.

Meanwhile, the proportion of under-1000 gram births among live births was constantly negligible during the last two decades. Under-1000 gram births accounted for only 0.2% of live births. Interestingly, there was no tendency of increase in the numbers of under-1000 gram live births in Armenia after changing the threshold for delivery from 28 weeks to 22 weeks of gestation (Figure 6).

Figure 6. Percentages of under-1000 gram and 1000-2499 gram births among live births, NIH, 2014.

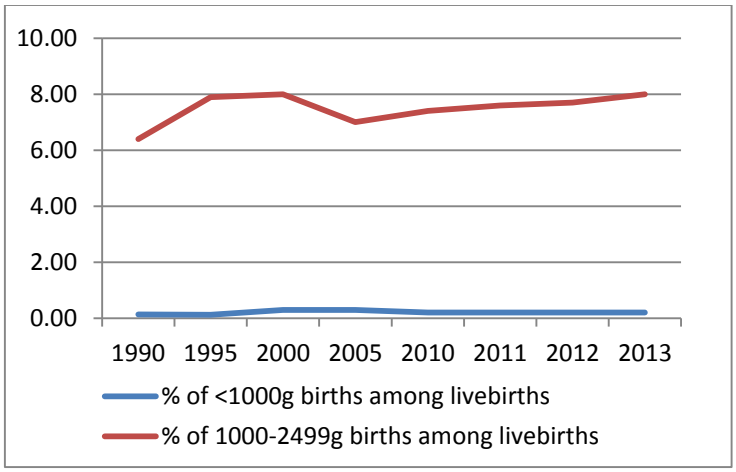
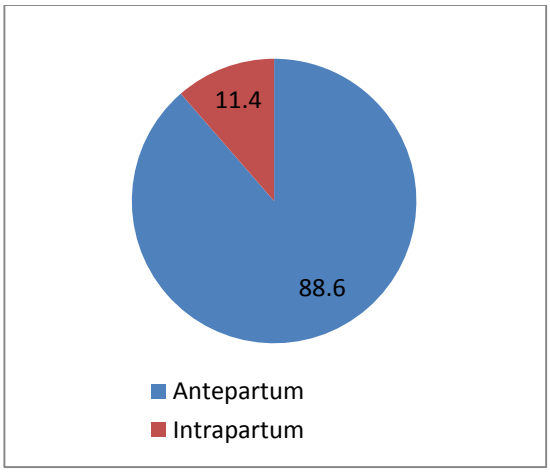


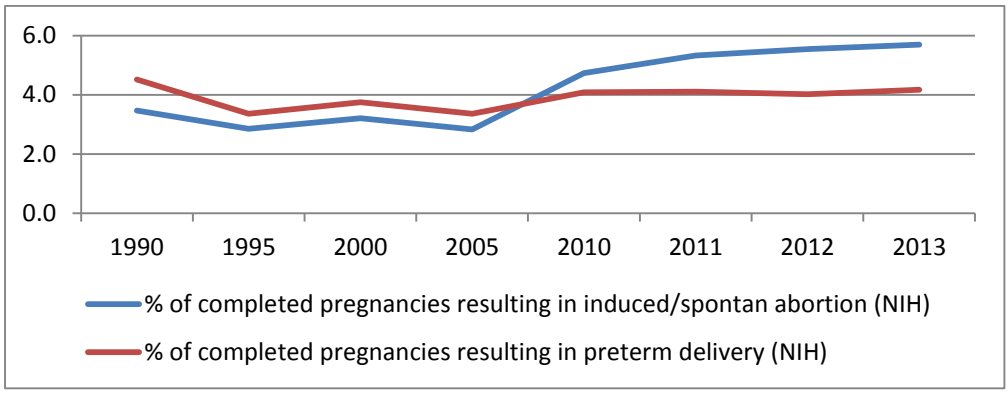
Figure 7. Intrapartum stillbirths, 2014, %



Despite relatively high stillbirth rates, stillbirths occurring during labor or *intrapartum* stillbirths constituted only 11.4% of all stillbirths in Armenia in 2014 (Figure 7, NIH data). It is known that the proportion of intrapartum stillbirths is a sensitive indicator of the quality of intrapartum care and, accordingly, varies in a wide range in the world from as low as 10% in developed countries with advanced healthcare services to up to 60% in developing countries.[6] The low rates of intrapartum stillbirths in Armenia indicate either high quality obstetric care throughout the country or a tendency of underreporting intrapartum and over-reporting antepartum stillbirths.

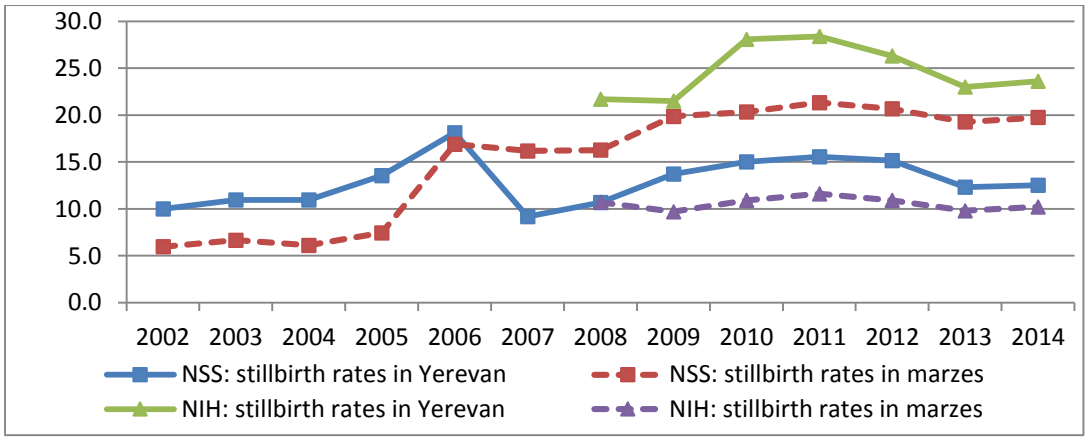
It is noteworthy also that according to the NIH data based on annual reports from the hospitals providing obstetric care, an increase have been observed since 2006 in the proportion of completed pregnancies ending up with induced or spontaneous abortion, while there was no such trend in the proportion of preterm births during the same period (Figure 8). Further investigation is needed to explain this tendency.

Figure 8. Completed pregnancies ending with induced/spontaneous abortion & preterm birth, NIH



Yerevan-marz distribution: Figure 9 demonstrates the dynamics in stillbirth rates in Yerevan city and the ten marzes of Armenia according to NSS and NIH data. It shows that after 2006, stillbirth rates according to NSS are constantly higher in the marzes than in Yerevan, while according to NIH, an opposite pattern is in place – much higher rates in Yerevan than in the marzes. This difference, however, is easy to explain as many maternity hospitals in Yerevan are referral centers for marz healthcare facilities and the stillbirths occurring in Yerevan hospitals, regardless of the residency of the patients, are included in Yerevan hospitals' annual reporting. Hence, NIH data treats these cases as occurring in Yerevan. Unlike this, since 2006, NSS considers the residency of parents of a stillbirth child when calculating the stillbirth rates in marzes and Yerevan, regardless of the location of the CSAR body where the case of stillbirth was registered. The big difference between the NIH and NSS data on stillbirth rates that took place in Yerevan versus marzes, thus, indicates the high numbers of women from marzes giving birth in Yerevan hospitals with an outcome of stillbirth.

Figure 9. Dynamics in stillbirth rates in Yerevan and marzes of Armenia, NSS and NIH



The patterns of NSS data in Figure 9 indicate that before 2006, the rates of stillbirths were lower in marzes than in Yerevan, but in 2006, after adoption of WHO 10th classification definition of livebirth and stillbirth in the Civil Registration System in 2005,[18] both Yerevan and marz rates sharply increased, after which Yerevan rates quickly went down, while marz rates remained high and since then, the rates in marzes continuously exceeded those in Yerevan. The increase in NSS rates both in Yerevan and marzes in 2006 was thus produced by including in the NSS statistics those stillbirths born from pregnancies of 22-27 weeks of gestation. However, the increase in these rates was disproportionate in Yerevan and marzes – marz rates increased more than Yerevan rates and thereafter continued to be higher than the rates in Yerevan. This pattern can be explained by the fact that, as described above, before 2006 NSS, like NIH, considered the place of registration of a stillbirth when producing the rates for Yerevan and marzes, while since 2006 this approach was changed and the parental residence was considered instead.

Another observation that could be made from NSS data is the clear increasing trend of stillbirth rates in the marzes since 2005, while Yerevan rates vary but with a milder increasing tendency. As the increase in stillbirth rates after 2005 could be mainly attributable to the inclusion of 22-27 week gestational age births in the statistics of stillbirths, one could conclude that the rate of extremely preterm deliveries increases in particular among women from the marzes.

Figures 10 and 11 show the distribution livebirths and stillbirths by marzes based on NIH and NSS data. According to it, considerable proportion of women from the closest marzes delivers in Yerevan. Specifically, over 50% of livebirths from Armavir, over 45% of livebirths from Aragatsotn, and about one-third of livebirths from Ararat and Kotayk marzes take place in Yerevan. With respect to stillbirths, about 80% of stillbirths among women from Armavir, Gegharkunik, Vayots Dzor, and Aragatsotn marzes, and about 60% of stillbirths among women from Syunik, Tavush, Kotayk, Lori, and Ararat marzes occur in Yerevan maternity hospitals. Shirak is the only marz that is relatively self-sufficient in this respect.

Figure 10. Between-marz distribution of live births, absolute numbers, 2014, NSS, NIH

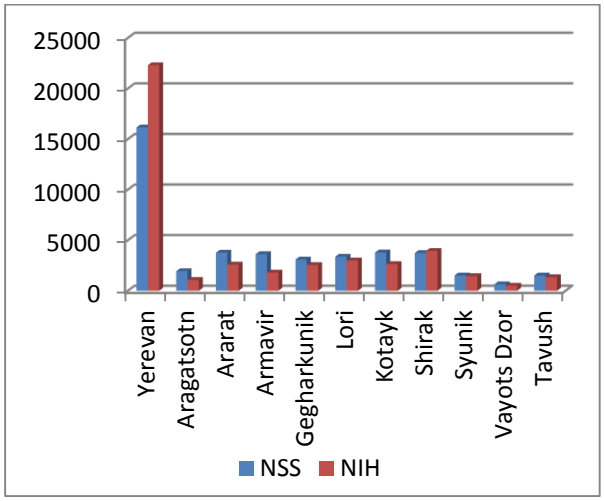
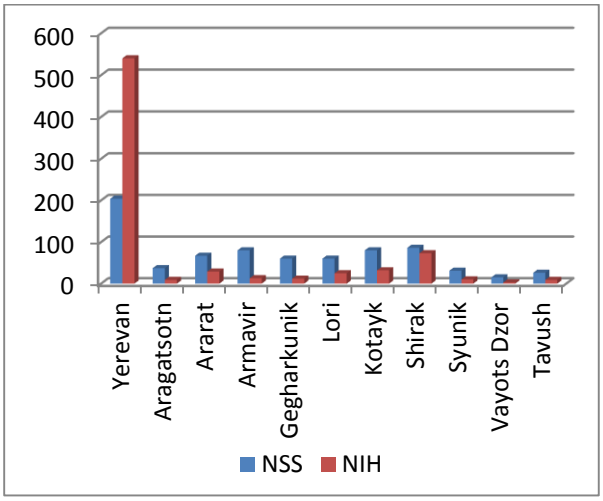


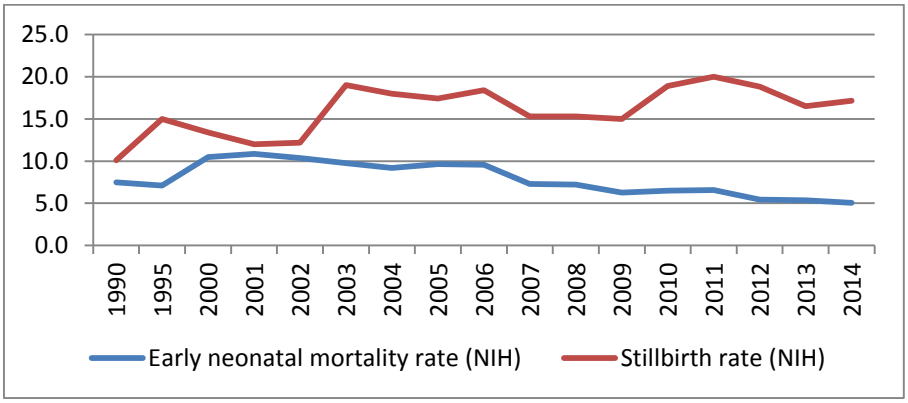
Figure 11. Between-marz distribution of stillbirths, absolute numbers, 2014, NSS, NIH



3.2.3 Data on neonatal and infant mortality

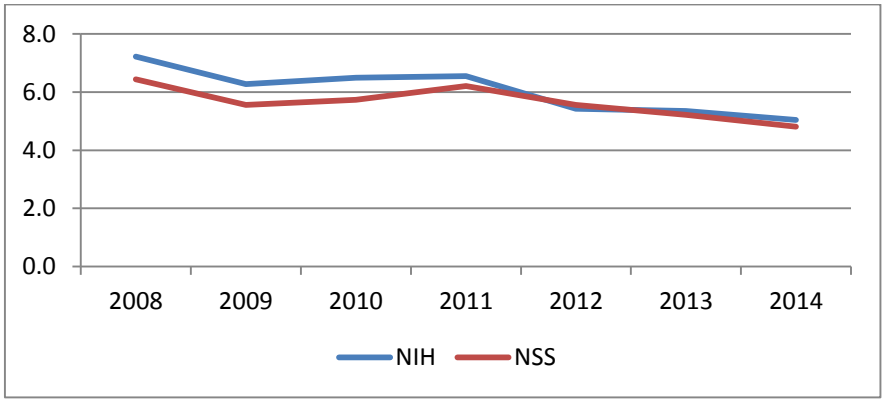
After a short period of increase following the adoption of WHO 10th classification definitions for abortion, stillbirth, and livebirth in the healthcare system, the rates of early neonatal (first 7 days) mortality in Armenia demonstrated consistent decreasing trend. This trend was the opposite of what one could expect considering the widened indications for diagnosing livebirth according to the newly adopted classification and, especially, bearing in mind the increasing rates of stillbirths during the same period (Figure 12). During the last several years, the early neonatal mortality to stillbirth ratio in Armenia was one to over three, while the usual ratio in WHO EURO B group countries Armenia belongs to is 1:1.2. This situation might indirectly indicate a possible tendency of overestimating stillbirth rates while underestimating early neonatal mortality rates.

Figure 12. Rates of early neonatal mortality and stillbirth in Armenia according to NIH[23]



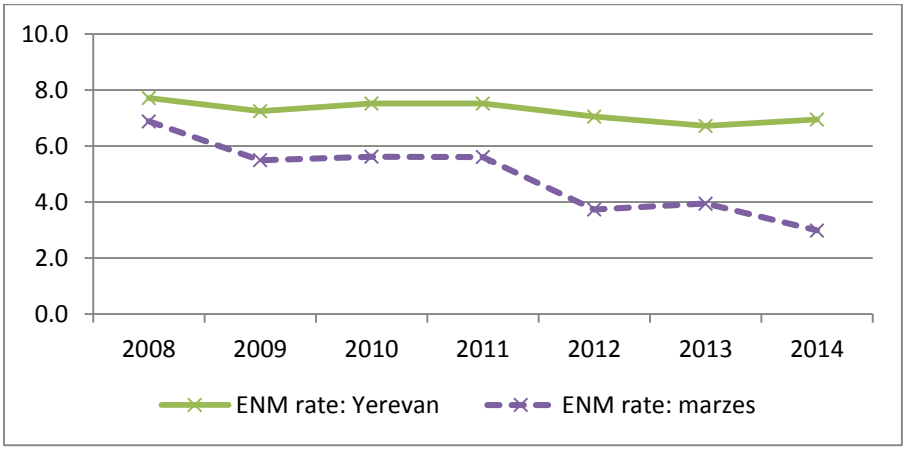
During recent years (except 2012), the rates of early neonatal mortality based on NIH data were consistently higher than those based on NSS data (Figure 13). The differences between the rates from the two sources were not very big. One of the possible reasons for these differences could be including neonatal deaths in the families of non-Armenian citizens in hospital reporting, hence, in NIH data while excluding these from the NSS data, as these deaths are not being registered in the CSAR system of Armenia. However, additional case-based investigation is necessary to accurately answer this question.

Figure 13. Early neonatal mortality rates, 2008-2014, NIH rates versus NSS rates



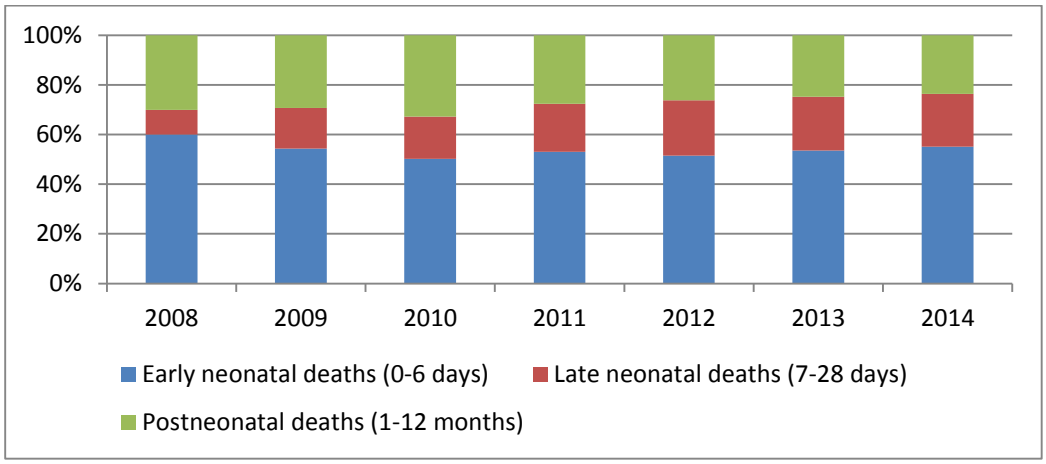
The Yerevan-marz distribution of early neonatal death rates available from NIH reports demonstrates steeper decrease of these rates in the marzes as compared to Yerevan (Figure 14). As many maternity hospitals in Yerevan are referral centers for the regions, increasing share of complicated births from marzes taking place in Yerevan hospitals could be responsible for this difference.

Figure 14. Dynamics of early neonatal mortality (ENM) rates in Yerevan and marz hospitals, NIH



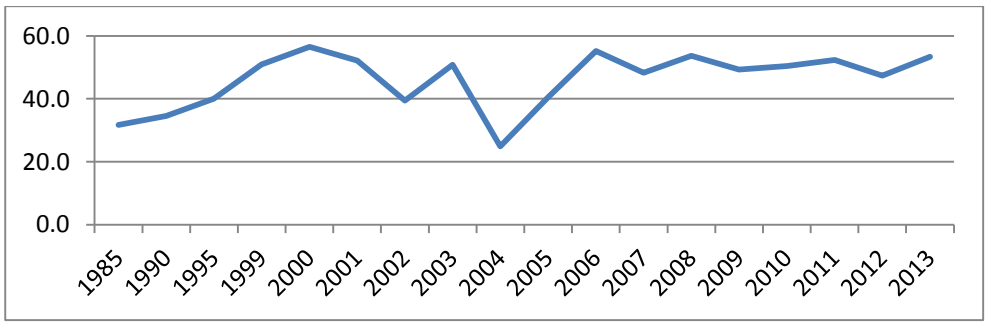
According to the NSS data, neonatal deaths (during the first four weeks of life) constitute over 70% of all infant deaths in Armenia. Most of these deaths (75% in average) occur during early neonatal period (first 7 days). The share of early neonatal deaths in the structure of infant deaths is thus over 50% (Figure 15). These numbers are consistent with the worldwide estimates indicating that early neonatal deaths account for 73% of deaths during neonatal period.[4]

Figure 15. Structure of infant mortality in Armenia by the timing of death, NSS, %



Data on late neonatal and post-neonatal mortality is not available from NIH, as these data is not included in the annual reporting forms of medical facilities. Thus, NSS is the only source for these rates. Unlike this, hospital reporting forms contain data on the first 24-hour deaths, hence, NIH data provide this indicator, while NSS data – do not. According to NIH data, approximately 50% of early neonatal deaths in Armenia occur within the first day of life, which is again consistent with the worldwide estimate of 49%[4] and underscores the importance of early intervention to prevent these deaths. It is noteworthy that no clear trend in the proportion of first 24-hour deaths was observed in Armenia during the last decades (Figure 16).

Figure 16. Percentage of first 24-hour deaths in the structure of early neonatal mortality



Infant mortality: Figure 17 depicts the dynamics of infant mortality in Armenia during the last decades according to NIH and NSS data.[23] It demonstrates consistent decreasing trend in infant mortality rate (IMR) from 18.3 per 1000 live births in 1990 to 8.7 per 1000 livebirths in 2014 (NSS data). In the meantime, stillbirth rates increased from 10.6 per 1000 total births in 1990 to 17.0 per 1000 total births in 2014 (NSS data). While the increase in stillbirth rates could be partially explained by the change in definition of livebirths and stillbirths during this period, the big difference between the current numbers of stillbirths and infant deaths is difficult to explain, as according to the literature, the annual number of stillbirths is usually equivalent to the annual number of deaths during infancy.[7] Apparently, this is not the case in Armenia, where, according to the NSS data, the number of stillbirths in 2014 (n=746) exceeded the number of infant deaths during the same year (n=376) almost two times. Thus, the existing ratio of stillbirths to infant deaths in Armenia needs further exploration to identify factors underlying it.

Figure 17. Dynamics of infant mortality rates (IMR) in Armenia, NIH and NSS, 1990-2014

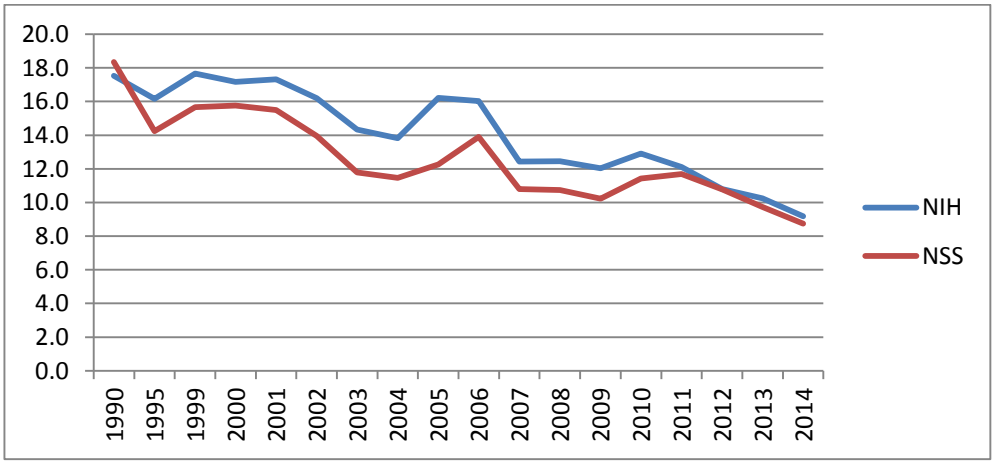


Table 4. Absolute numbers of infant deaths in Armenia, based on NSS and NIH* data

Year	1990	1995	2000	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014
NIH	1403	734	603	611	604	498	514	533	572	519	457	427	398
NSS	1465	697	540	460	523	433	442	454	512	507	458	407	376

* NIH data includes the sum of hospital and home deaths that are reported separately starting from 2005.

Figure 17 demonstrates that NIH rates of infant mortality were consistently higher than NSS IMRs for the period of 1995-2010. While this difference is expectable for the decade of 1995-2005 when different criteria of registration of livebirths and stillbirths was applied between the systems of healthcare and civil registration, the observed difference thereafter (till 2010) is

difficult to explain as since 2005, the WHO 10th classification definition was introduced in the civil registration system as well. Table 4 provides the absolute numbers of infant deaths according to the both sources and shows that during 2006-2010, NIH numbers still exceed NSS numbers by 12-17%, and only since 2011 they become really close to each other. This could possibly indicate later actual introduction of the government decision on adoption WHO 10th classification definition of livebirth and stillbirth in the civil registration system.[18] Other possible reasons for the observed difference in NIH and NSS numbers during 2006-2010 could include omission from registration of a portion of infant deaths because of lack of motivation among parents or low accessibility of CSAR bodies in some areas, or some other difficulties with infant death registration (e.g., lack of the needed documents). Thus, a case-based investigation is necessary to explain this difference.

3.2.4 Share of stillbirth and early neonatal death cases at the hospital level

Interesting patterns are observed when looking at the hospital-level distribution of livebirths, stillbirths, and early neonatal deaths according to NIH data. While slightly over half of all livebirths in the country take place in Yerevan (53.7% in 2015), about three-fourths of all stillbirths and early neonatal deaths (77.0% and 73.8%, respectively, in 2015) occur in Yerevan. There are 12 maternity hospitals in Yerevan, and the three major maternity hospitals, Reproductive Health, Perinatology, Obstetrics and Gynecology Center (RHPOGC), Mother and Child Health Protection Center (M&CHPC) and "Erebuni" hospital account for about half (48.3% in 2015) of all livebirths in Yerevan. However, over four-fifth (81.2% in 2015) of all stillbirths in Yerevan take place in these three facilities and about three-fourth (72.9% in 2015) of all early neonatal deaths in Yerevan maternity hospitals occur in these facilities.

Among these three maternities, RHPOGC has the biggest share of stillbirths and early neonatal deaths. As Figures 18, 19, and 20 depict, this center accounts for only about one-third of all livebirths, but for two-thirds of all stillbirths and early neonatal deaths that occur in these three hospitals. Moreover, while accounting for 9% of all livebirths in Armenia (Figure 18), this center reports 41% of all stillbirths happening in the country (Figure 19) and 18% of all early neonatal deaths (Figure 20).

Figure 18. Livebirths in Armenia by place of occurrence, 2015, %

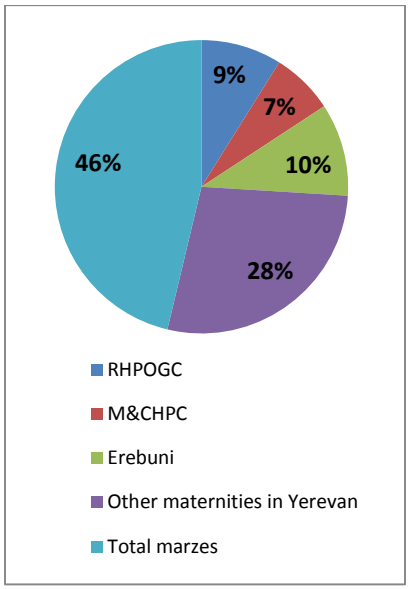


Figure 19. Stillbirths in Armenia by place of occurrence, 2015, %

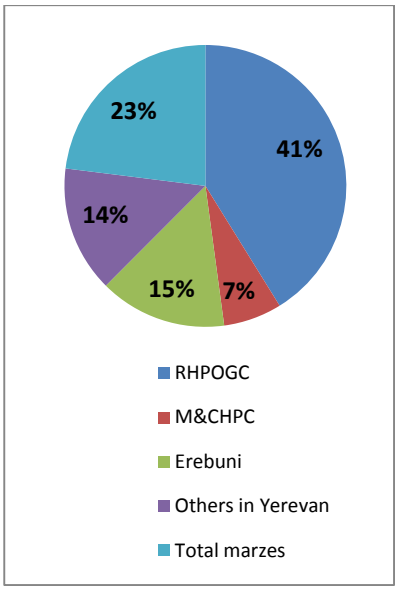
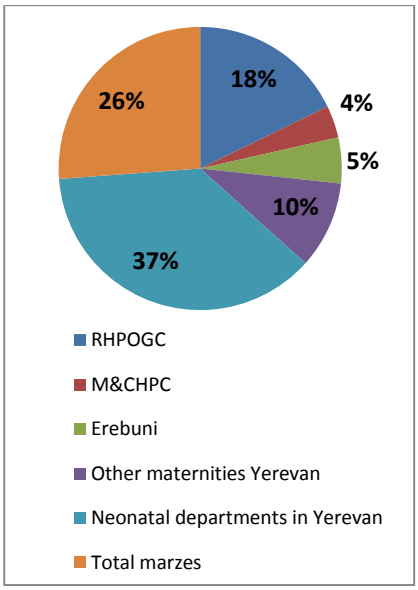
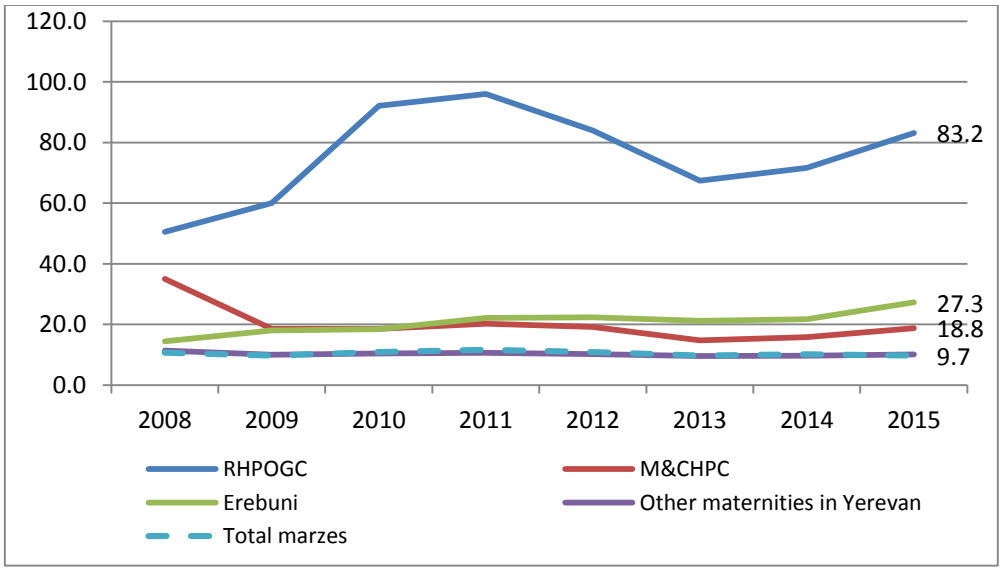


Figure 20. Early neonatal deaths in Armenia by place of occurrence, 2015, %



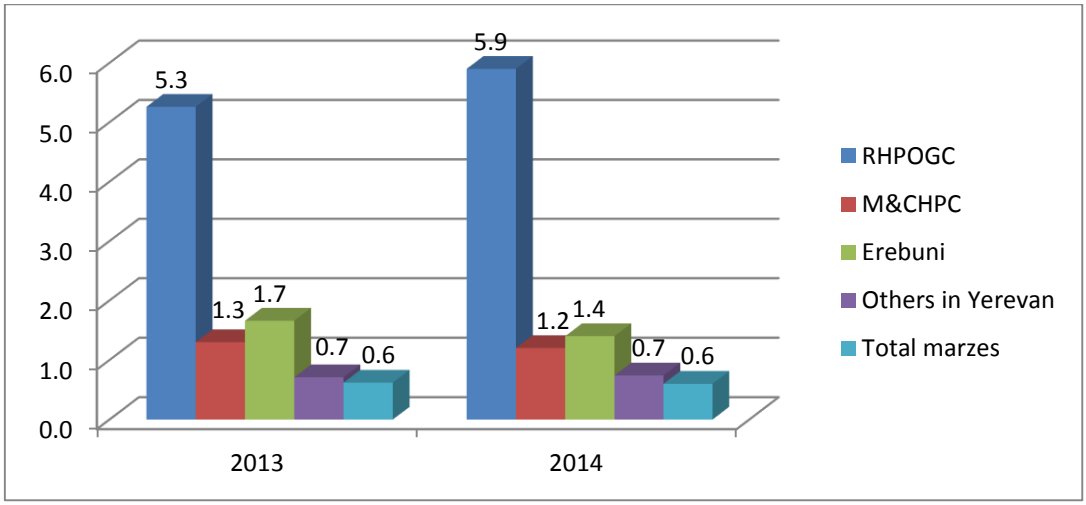
The rate of stillbirths in RHPOGC in 2015 was 83.2 per 1000 total births taking place in that center, which exceeded the similar rate in "Erebuni" hospital three times and in M&CHPC – 4.4 times (Figure 21). Meanwhile, as Figure 21 shows, the stillbirth rates demonstrate an increasing trend both in RHPOGC and in "Erebuni" hospital, while no such tendency is evident either in M&CHPC, the remaining maternity hospitals in Yerevan, or maternity services in marzes.

Figure 21. Per-facility/area rates of stillbirths (per 1000 total births in a given facility/area), NIH



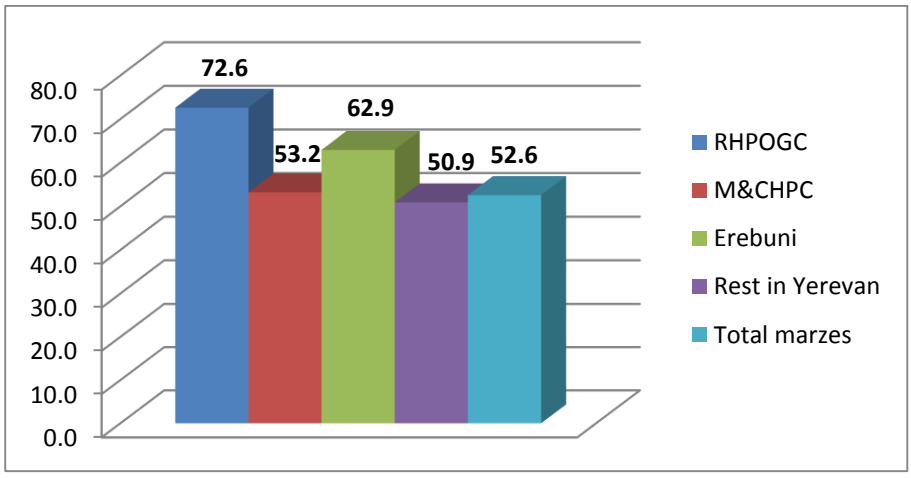
It is noteworthy that the proportion of under-1000 gram births among all births occurring in a given facility was also much higher in RHPOGC as compared to the other two major hospitals, as well as all the remaining maternities in Yerevan and in marzes (Figure 22). However, the possibility that some overestimation of this proportion could have place because of reporting some portion of late abortions as deliveries should be checked before using it for inferences.

Figure 22. Percentage of under-1000 gram births among all births in a given facility/area, NIH



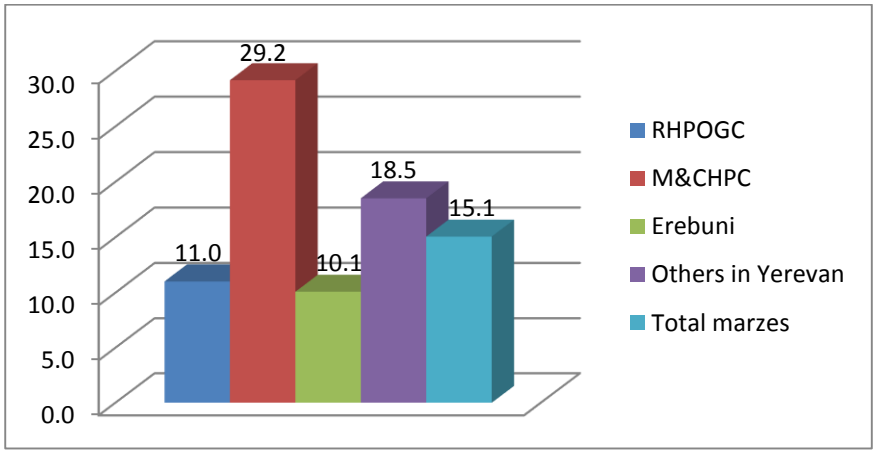
The percentage of under-1000 gram stillbirths among all stillbirths in a given facility/area was also higher in RHPOGC and "Erebuni" hospital compared to M&CHPC, the remaining maternity hospitals in Yerevan and the marz obstetric services (Figure 23).

Figure 23. Percentage of 500-999 gram stillbirths among all stillbirths in a given facility/area, NIH



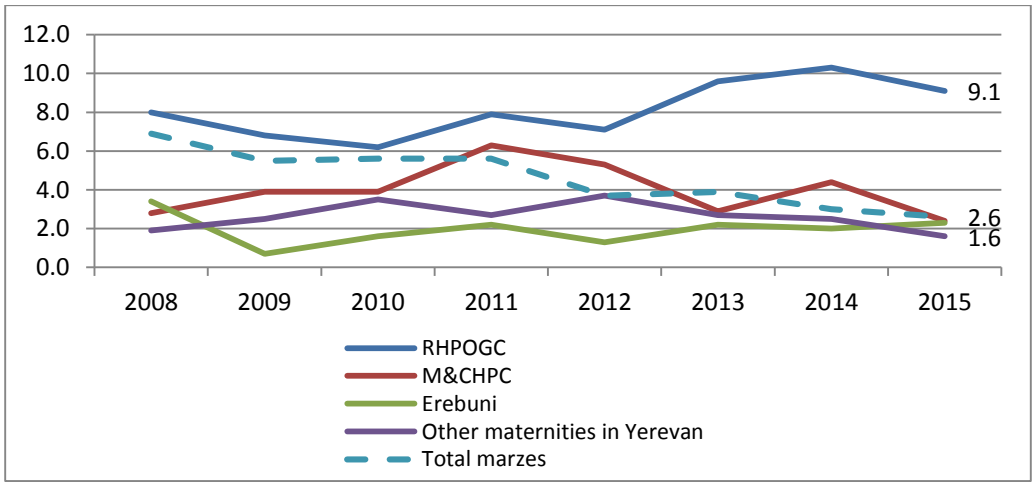
According to the cumulative numbers for the years of 2013 and 2014, the proportion of livebirths among those born with less than 1000 gram weight was 10.1% in "Erebuni" hospital, 11.0% in RHPOGC and almost three times more – 29.2% in M&CHPC (Figure 24). Moreover, the proportion of livebirths among those born with extremely low weight in these two major referral centers – RHPOGC and "Erebuni" hospital, was 85% lower than the average proportion in the remaining maternity hospitals in Yerevan (18.5%) and even 50% lower than the average proportion in marz hospitals (Figure 24). This fact also needs careful investigation to find out the reasons for these differences.

Figure 24. Proportion of livebirths among under-1000 g births that occurred in 2013- 2014, NIH



The rate of early neonatal mortality in RHPOGC in 2015 was 9.1 per 1000 livebirths, which again exceeded the corresponding rates in the remaining hospitals 3.5-5.7 times (Figure 25).

Figure 25. Per-facility/area early neonatal mortality rates in Armenia (per 1000 livebirths), NIH



Also, a slight increasing trend in this rate has been observed in RHPOGC during recent years, while no any trend was evident in the remaining Yerevan hospitals and a clear decline in the early neonatal mortality rate has occurred in marz hospitals (dashed lines).

Figures 25 and 26 depict the relative share of each maternity hospital/service in the overall quantity of stillbirths and early neonatal deaths, respectively, occurring in the country during the last years.

Figure 25. Relative share in the overall number of stillbirths in Armenia, NIH, %

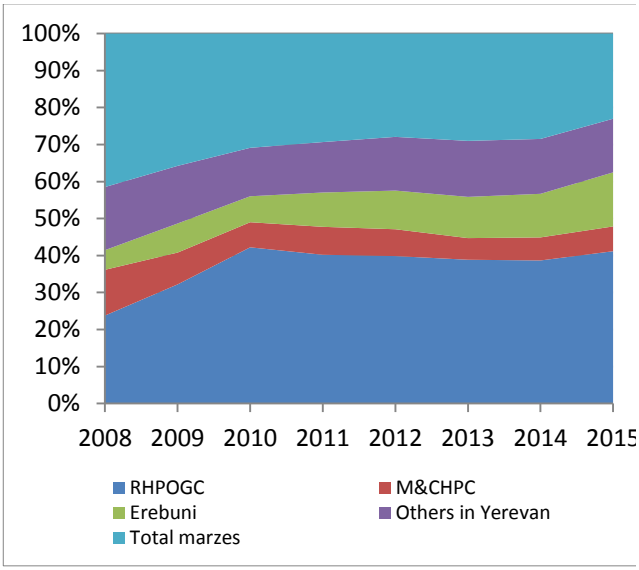
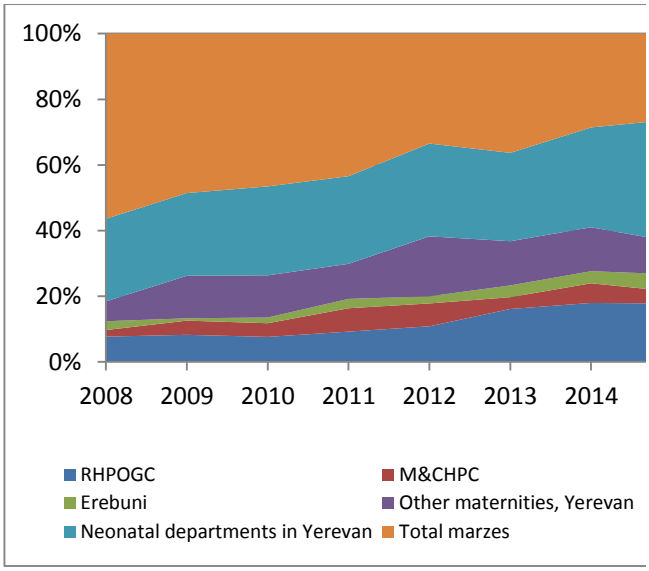


Figure 26. Relative share in the overall number of early neonatal deaths in Armenia, NIH, %



The figures clearly demonstrate an increasing role of the RHPOGC in these numbers. During the soviet period, RHPOGC was the main hospital serving women with complicated pregnancies referred from marzes, which explained the higher numbers of stillbirths and early neonatal deaths there. However, since the soviet times, the situation has changed. Currently, eight of the 12 maternity hospitals in Yerevan are considered tertiary hospitals and referral centers. Thus, the huge difference in stillbirth and early neonatal mortality rates between RHPOGC and the remaining maternity hospitals cannot be solely explained by being the only hospital on the "first line" for referrals of complicated cases from marzes. Neither this could explain the clear increasing trend in stillbirth rates in this center and "Erebuni" hospital, while in the remaining maternity hospitals there is no such trend, or, indeed, there is an opposite trend. Further investigation is needed to find answers to the questions that come out from these figures. It is

clear, however, that changing the situation even solely in RHPOGC may have great impact on the stillbirth rates in the country as this facility accounts for over 40% of all cases of stillbirths in Armenia.

3.3 Providers' knowledge on the new definitions of livebirth, stillbirth, and perinatal period

To make an understanding about the awareness of providers on the WHO ICD 10th definitions of livebirth and stillbirth, as well as the required practices of registration and reporting of livebirths, stillbirths, and neonatal deaths, the study included in its short demographic form a knowledge assessment tool, a 15-item questionnaire (Appendix 3) that was developed by the Ministry of Health of RA and first applied among providers (ob/gyns, neonatologists, and midwifes) in selected Yerevan and marz maternity hospitals in 2009 in the scope of an evaluation study.[13] This study used the same questionnaire, so that the results could be compared with the estimates obtained in 2009.

The questionnaire was administered to those FGD and in-depth interview participants who were practicing in the fields of neonatology, obstetrics/gynecology, or midwifery. These participants completed the questionnaire prior to the discussion/interview, after giving their consent for completion. Overall, 96 FGD and 5 in-depth interview participants completed the questionnaire (two FGD participants and four eligible in-depth interview participants refused completing it). Of those who completed the questionnaire, 19 were neonatologists, 45 ob/gyns (of whom 24 from in-patient settings, 15 from out-patient, and 6 employed in both), and 37 midwifes (all from in-patient settings). Around half of the respondents (51) were from Yerevan, others (50) from marzes (Vanadzor or Gyumri).

The proportions of correct answers to each item included in the questionnaire are presented in Table 5. The highest proportion (86.1%) of correct answers received the question on the term when perinatal period starts according to WHO 10th ICD that is applied in Armenia (22nd week of gestation). The next highest proportions (76.2% and 75.2%, respectively) received the items on the term of pregnancy corresponding to 500 gram birth weight (22nd week of gestation) and on the stillbirth definition according to WHO 10th ICD. Almost 70% of the respondents

correctly answered the item on the WHO 10th ICD definition of livebirth. However, to the situational question on classifying a newborn who demonstrated only voluntary muscle movements, only 16.8% of the respondents gave correct reply. The same response pattern to these questions was observed in the MOH study in 2009, when more than 90% of the participants correctly answered the questions about current definitions of livebirth and stillbirth, but much less – 27.6%, to the situational question.[13] While the pattern was the same – higher theoretical knowledge than the ability to apply it in a life situation, the percentages of correct answers we got to these three items were even lower than in 2009. Over 60% of the participants knew that newborns weighting 500-999 g are registered in CSAR bodies regardless of the duration of their life and more than half (56.4%) were aware about the minimal weight of a newborn (500 g) when it should be included in the state statistics.

Table 5. Study participants' knowledge on WHO 10th classification definitions for livebirth, stillbirth, and perinatal mortality, their registration and reporting

Question	Correct, % (n)	Incorrect, % (n)
1. Stillbirth definition according to WHO 10th classification	75.2 (76)	24.8 (25)
2. Livebirth signs according to WHO 10th classification of diseases	69.3 (70)	30.7 (31)
3. Voluntary muscle movements as the only sign of livebirth	16.8 (17)	83.2 (84)
4. Minimal birth weight (500g) for being included in the state statistics	56.4 (57)	43.6 (44)
5. Duration of life for 500-999g newborn to be registered in CSAR body	62.4 (63)	37.6 (38)
6. Term when perinatal period starts according to WHO 10th classification	86.1 (87)	13.9 (14)
7. Duration of perinatal period	49.5 (50)	50.5 (51)
8. Body length of a newborn corresponding to 500 g birth weight	47.5 (48)	52.5 (53)
9. Term of pregnancy corresponding to 500 g birth weight	76.2 (77)	23.8 (24)
10. Perinatal mortality indicator as stillbirth plus death during 0-6 days of life	35.6 (36)	64.4 (65)
11. Definition of "very low" birth weight (under 1500 g)	28.7 (29)	71.3 (72)
12. Definition of "low" birth weight (under 2500 g)	42.6 (43)	57.4 (58)
13. Definition of "extremely low" birth weight (under 1000 g)	33.7 (34)	66.3 (67)
14. Child's age of death for it to be registered in CSAR body by health facility	7.9 (8)	92.1 (93)
15. Period of registration of child's death in CSAR body by health facility	41.6 (42)	58.4 (59)

The remaining items received correct answers by less than half of the participants. Although almost half of them (49.5%) knew about the duration of perinatal period, only 35.6% could correctly define perinatal mortality (as stillbirth plus mortality during 0-6 days of life). Again, these questions received much higher proportions of correct answers during the MOH study in 2009 (71.6% and 75.6%, respectively). The question on newborn's body length corresponding to 500g birth weight (25 cm) received correct answers from 47.5% of respondents. Slightly over 40% of them answered correctly to the question on the period (7 days) within which health facility should register child's death in a CSAR body. Strikingly low proportion of respondents (42.6%) knew the range for low birth weight (as less than 2500 g). The proportions of those being aware about WHO ICD 10th definitions of very low (as less than 1500 g) and extremely low birth weight (as less than 1000 g) were very low (28.7% and 33.7%, respectively) and similar to those during the MOH study in 2009 (about 33% for both). And only 7.9% was aware that health facility is responsible for registering death cases of under-28 day old children in CSAR bodies. Interestingly, the proportion of correct answers to this question during the MOH study in 2009 was much higher – 44.5%. According to our study results, overall, providers' knowledge on livebirth, stillbirth and neonatal death diagnosis and registration has decreased since the MOH study in 2009, which is paradoxical given that fifty percent of the respondents to the knowledge questionnaire reported that they have received some training on these issues after the definition changes were introduced.

Table 6. Mean knowledge score of study participants by specialty group

Specialty group	Mean	SD	Range	n
Neonatologists	10.3	2.6	5-15	19
Obstetrician-gynecologists from maternity hospitals	8.4	2.4	4-13	30
Obstetrician-gynecologists from women consultations	6.1	2.1	1-9	15
Midwifes in maternity hospitals	5.3	2.2	0-11	37
Total sample	**7.3**	**3.0**	**0-15**	**101**

A summative knowledge score was calculated based on the correct answers to these 15 items with a range of 0-15 (Table 6). The mean score for the whole sample was 7.3 (SD 3.0) with the highest score among neonatologists (10.3, SD 2.6), followed by ob/gyns from in-patient settings (8.4, SD 2.4) and ob/gyns from out-patient settings (6.1, SD 2.1). Midwifes had the lowest mean knowledge score – 5.1 (SD 2.2). This was consistent with the 2009 MOH study findings, which

also identified the lowest level of knowledge among midwifes.[13] The participants from Yerevan had slightly higher mean knowledge score (7.9, SD 3.2) than those from Gyumri (6.8, SD 2.9) and Vanadzor (6.4, SD 2.4).

3.4 Qualitative study results

3.4.1 General atmosphere of discussions and interviews

The discussions and interviews during this study were generally accompanied with certain amount of unease and caution. The manner of responding to the study themes varied across the key informants with some of them presenting a very stable and effectively working environment in the maternity sector, while others revealing certain issues impeding the activities and creating an unhealthy atmosphere for the healthcare staff. Several participants reacted to certain "sensitive" questions expressing frustration, nervousness, or even anger. However, the majority responded calmly to the same questions and, sometimes, mentioned certain issues that needed to be addressed.

During the FGDs the participants were generally cautious and often exchanged glances and smiles when more sensitive questions were asked. This manner was more expressive during discussions with ob/gyns. In almost all groups, there were respondents who were more confident and spoke relatively more freely – in some cases stating that they were not afraid to tell the truth, and then there were those who were noticeably worried throughout the discussion, advising other team members to be discreet with their answers on occasion. Some questioned the meaning of asking them about the practices related to stillbirth diagnosis and reporting, as, according to them, higher instances (their hospital heads, officials at health departments and the MOH) were very well informed on these issues.

A group of gynecologists from Yerevan particularly stood out from the others with the negative attitude and aggressive behavior. One of the participants in this group was very skeptical of the study and when the moderator asked a sensitive question, this participant became aggressive, accused the research team in trying to defame them, required that the recorders be turned off and created panic among other group members. As a result, some others also began arguing,

displaying aggressive behavior, questioning the research team's motives. Some even went to the extent to forbid their group-members from speaking, "Don't tell them anything", "Do not respond to that", and expressing their doubt as to what their neonatologist colleagues – with whom the FGD had taken place on the previous day – had reported to us. At the end of the discussion two participants from different health facilities informed the moderator that, "we are going to warn our midwives to not say anything to you when they come for their FGD". As another repercussion of this highly-stressed FGD, one of the facility heads informed the research team that his physicians had been "very weary of the interview" and had reported "tricky and dubious questions" being asked to them and therefore he decided that their staff members would no longer participate in the study and refused to send any other staff member for the next pre-scheduled interview.

You ask questions, answering to which could get us fired. You want to know how we work at our hospital... It is better to be silent because anyway nothing will change, and it's better not to let the information get out. (Ob/gyn, 3.4.1.1, FGD, Yerevan)

There are certain issues that must not be publicized. The MOH is aware of those questions that are not to be publicized. If the MOH is aware of those questions, but has still invited us to this discussion to waste our time, then it is not good. This was an interesting but unpleasant discussion. (Ob/gyn, 3.4.1.2, FGD, Yerevan)

3.4.2 Changes in definitions (abortion and delivery, stillbirth and livebirth)

3.4.2.1 Abortion and delivery

The participants unanimously agreed on the current cut-point between abortion and delivery being 22 weeks of gestation. The vast majority of them were aware that the cut-point was 28 weeks before. However, some participants stated different transitional cut-points ranging from 20- 27 weeks before the 22 week cut-point was finally introduced. Also, the participants were not sure about the time when this change has been made. They reported different dates ranging from 2004 to 2009 with some inconsistencies both within and between the groups.

In all groups, participants stated that the birthweight of 500 grams corresponds to the gestational age of 22 weeks and could be used instead as a cut-point between abortion and delivery. They

stated also that before, the birthweight of 1000 grams corresponding to 28 weeks of gestation was considered as a cut-point between abortion and delivery.

However, there was some inconsistency in the understanding of term delivery. Opinions about the existence of a normative document defining term delivery were contradicting – some thought there is no such document and some others stated that there is. They mentioned different gestational age ranges for term delivery, such as 36-40 weeks, 37-41 weeks, 38-40 weeks, and none of the participants provided the correct range for it as 37-42 complete weeks. Interestingly, when a participant from one of the FGDs with midwifes provided the period of 36-40 weeks for term deliveries, nobody in the group argued with it. It was noted that the weight of the newborn also helps to determine whether the delivery is term or not, but for one participant that weight was 2.5 kg, while for another – 2.7 kg.

Of course the definitions have been changed…in the past, deliveries above 28 weeks of gestational age were considered as childbirths, but now the cut point is 22 weeks… and deliveries below 22 weeks of gestational age are considered as abortions. (WC ob/gyn, 3.4.2.1.1, FGD, marz)

[The cut-point between delivery and abortion] *Became 22 weeks… also the weight has been changed.* **(**Ob/gyn, 3.4.2.1.2, FGD, Yerevan)

Deliveries before 22 weeks of gestation period are considered as abortions, and deliveries after the 22 weeks of gestation period are considered as births. Before it was 20 weeks. **(**Midwife, 3.4.2.1.3, FGD, marz)

The cut-point was 24 weeks for a short period of time, later 23 weeks and then 22 weeks. (WC ob/gyn, 3.4.2.1.4, FGD, Yerevan)

Before 2008, when the new definitions of these terms hadn't been adopted, a fetus born before 27th weeks of pregnancy was considered as an abortion, more exactly, deliveries earlier than 26 weeks and 6 days were considered as such… There were some changes [before that], *but the law was introduced by the Ministry in 2008.* (Neonatologist, 3.4.2.1.5, FGD, Yerevan)

As far as I know, in the past, 28 weeks was considered to be a delivery. This has currently been reduced to 22 weeks... Starting form 2009 when I started my residency. (Neonatologist, 3.4.2.1.6, FGD, Yerevan)

Some relevant things [changes in definitions of abortion and delivery] *happened between 2004 and 2005.* (Ob/gyn, 3.4.2.1.7, FGD, Yerevan)

In the past, the weight [for the newborn to be considered stillbirth] *was 1 kg, and now it starts from 500 grams and 22 weeks.* (WC ob/gyn, 3.4.2.1.8, FGD, marz)

…Deliveries by 22 weeks of gestation are considered abortions and after 22 weeks of gestation as births...that's all... deliveries until 37 weeks are considered as preterm deliveries. (WC ob/gyn, 3.4.2.1.9, FGD, marz)

No, [deliveries] *from 38 weeks of gestation* [are considered term] *because we do not have an order* [referring to state order on the definition]... (WC ob/gyn, 3.4.2.1.10, FGD, Yerevan)

We do not state our opinions, the order states since 37 weeks [delivery is considered term] (WC ob/gyn, 3.4.2.1.11, FGD, Yerevan)

…deliveries between 22 and 36 weeks of gestation [are regarded] *as preterm deliveries.* (Midwife, 3.4.2.1.12, FGD, Yerevan)

When deliveries occur between 36 and 37 weeks of gestation, the weight of infants helps neonatologists to decide whether the delivery is a term or preterm. (WC ob/gyn, 3.4.2.1.13, FGD, Yerevan)

A weight of 2.5kg also suggests about term deliveries. (WC ob/gyn, 3.4.2.1.10, FGD, Yerevan)

A weight of more than 2.7 kg suggests about term deliveries. (WC ob/gyn, 3.4.2.1.14, FGD, Yerevan)

3.4.2.2 Stillbirth and livebirth

The majority of IDI participants both from Yerevan and marzes stated that the live birth and stillbirth definitions are the same and changes were not introduced here. A few participants indicated that the current definitions are according to WHO definitions and for stillbirth those include gestational age starting from 22 weeks and birth weight starting from 500 grams.

Concerning the sings of livebirth, there were some discrepancies both within the groups and between them. Firstly, while some participants reported that there had been no changes in

respect of livebirth definition and signs, others reported that a new definition was adopted, according to which even one sign of life is indicative for livebirth.

Secondly, while the majority of participants reported and agreed to four signs of live birth, several participants reported five, while a few mentioned only three. Signs of livebirth mentioned by various participants were heartbeat, breathing, umbilical cord pulsation, muscular movements, muscle tone, skin coloration and crying, reported in different combinations by different participants. In general, midwifes were the least informed category of the participants, sometimes being unable to mention even one sign of livebirth. When asked whether breathing alone was considered as a sign of livebirth previously, the participants from one of the groups (midwifes) responded that it was not and all the signs had always been considered when present altogether. However, they added that it could be possible that they were not aware of the changes being made, as they have had very few cases of stillbirth at their respective facilities, and/or because neonatologists were the ones recording these in the past.

It was noticed that on several occasions, even when participants would mention the correct signs, they would go on to express their opinion on how breathing and heartbeat were given a priority as a sign of life. A couple of participants even explained that they do not consider muscular movement alone as a sign of life, since muscles sometimes twitch in dead bodies. On the other hand, they found only breathing or heartbeat as a definite sign. Several neonatologists agreed that resuscitation could be successful if there is heartbeat as a sole sign of life and that it is usually unsuccessful in the case of other sole signs.

The [stillbirth] *definition is 22 weeks of gestation and having birth weight more than 500 grams. There were no changes in this. The sings of live births are the same too.* (Ob/gyn, 3.4.2.2.1, IDI, Yerevan)

They [definitions for stillbirth and livebirth] *are the same and correspond to WHO definitions.* (Neonatologist, 3.4.2.2.2, IDI, Yerevan)

There were no changes in the standards. (Ob/gyn, 3.4.2.2.3, IDI, marz)

Those five signs [of life] *did not exist in the past… but now even one movement of muscles suggests live birth… we were guided by other criteria in the past, we took into account the heartbeat, breathing, and the pulsation of the umbilical cord… those signs are substantially specified and*

toughened, and in this respect how accurately this [the protocol] *is preformed we could not tell you…* (WC ob/gyn, 3.4.2.2.4, FGD, Yerevan)

If the infant is born and there is at least one sign [of life] *present – be it a heartbeat or breathing – the infant is considered live born. One of five indicators must be present.* (Ob/gyn, 3.4.2.2.5, FGD, Yerevan)

After 2008, all fetuses born at and after 22 weeks of gestational age weighting at least 500 grams and having any sign of live birth (which are four) are considered as babies, and we must introduce all medical procedures intended for the birth and care of these infants… Live birth is characterized by one out of four signs of life that include breathing, pulsation of the umbilical cord, heartbeat, or muscular movement. (Ob/gyn, 3.4.2.2.6, FGD, Yerevan)

Sometimes there are random twitches [of muscles] *and it is incorrect to consider these as livebirth. I agree with the presence of breathing, heartbeat and umbilical cord pulsation alone as signs of livebirth, but not when there is only muscular movement.* (Neonatologist, 3.4.2.2.7, FGD, Yerevan)

Skin color, heartbeats, muscle tone and respiration: if those four signs are present, then it is a livebirth. (Midwife, 3.4.2.2.8, FGD, Yerevan)

If we have registered a heartbeat, which has then stopped then we try to revive them. In such cases we have had a positive outcome. However if we have heard a beat, which appears to have been an umbilical cord pulsation as it is evident from the newborn that they have not died recently, then we still try but it is usually unsuccessful. (Neonatologist, 3.4.2.2.9, FGD, Yerevan)

P8: Live-birth solely due to the fact that they are breathing? [responding to a question about this from the moderator concerning past times] *No. Muscle tone was also taken into account... muscle tone, respiration, skin coloration, pulse, all of it. I have been working as a midwife for 20 years already and as long as I have been working it has been this way. We have not noticed a change in live birth signs... We haven't had many cases, so we haven't noticed a big change. Moreover, in the past these signs were recorded by neonatologists, so that's probably why we have not paid particular attention* [to these]. (Midwife 3.4.2.2.10, FGD, Yerevan)

When infant is born, the crying... [is a sign of livebirth]. (Midwife 3.4.2.2.11, FGD, marz)

Heart beating, muscle movement, reflexes... are considered live birth [signs]. (Midwife 3.4.2.2.12, FGD, marz)

[Even if the infant is at 450 grams birthweight and displays signs of life health providers must] *to register as delivery, to report the outcome of the pregnancy as live birth, and perform all medical*

and registry procedures…Mothers may intentionally or accidentally confuse the term of the pregnancy. So, only the term of the pregnancy is not enough… More comprehensive observation is required, which will consider parameters such as the weight, the height, the term, etc. (Ob/gyn 3.4.2.2.13, FGD, Yerevan)

3.4.2.3 Rationale and ease of the shift to the new definitions

According to the majority of participants both from FGDs and IDIs, as the shift to the new definitions had been introduced as a ubiquitous law for all healthcare services and the staff in that services works according to the protocols approved by the MOH, the shift to the new definitions happened completely and easily as it refers to registration and reporting. However, the participants did not quite agree with this statement, when it referred to the actual practice. It was almost unanimously noted among all participants from IDIs and FGDs that one of the major issues in this area is that babies born with extreme prematurity – especially at 22 weeks of gestation and with 500 gram birthweight – require special conditions and equipment to survive and that in this sense, no sufficient preparations were made in the healthcare sector for the shift. As a result, providers, both in Yerevan and, at greater extent, in marzes face several challenges which are difficult to address given the available resources. A participant from a FGD with neonatologists noted that the improvement in neonatal services do not refer to all hospitals, but only the major three maternity hospitals, while the conditions in 35 of the remaining 65 hospitals are inadequate. When another argued, *"but there are some changes in the last 16 years",* this same participant agreed that there are some in comparison to ancient times and the entire group giggled and laughed sarcastically. Also, while a couple of participants spoke of the change in definitions as a global issue of trying to improve the care, others disagreed, stating that Armenia was just following the example of other countries.

The shift to these new definitions has been made and accepted entirely. It is currently being implemented as a law. (Midwife, 3.4.2.3.1, IDI, Yerevan)

Yes, it [the shift] *has been easy. This shift is based on an order of the ministry. It's not like each facility has its own norms and protocols; this is a general law for all of us and we comply with it.* (Neonatologist, 3.4.2.3.2, IDI, Yerevan)

We didn't have any difficulties [to make the shift], *because there are packages, which have protocols and we follow these protocols.* (Ob/gyn, 3.4.2.3.3, IDI, marz)

Seminars were conducted where we were provided with instructions which should guide us further... midwifes, obstetrician-gynecologists, and neonatologists all participated…. (Midwife, 3.4.2.3.4, FGD, marz)

Maybe the shift regarding the registration process was fluent, if we talk about the registration. But if considering medicinal-scientific aspects, the questions are still hanging in the air. (Ob/gyn, 3.4.2.3.5, FGD, Yerevan)

Before the adoption of the new law, it was necessary to see whether or not our country is ready for the change, I mean are there specialists with specific competencies that could provide the necessary treatment to preterm low birth weight infants who were born between 22-27 weeks of gestational age or are there a full range of intensive care equipment for an adequate treatment…we didn't have and we don't have them. (Ob/gyn, 3.4.2.3.6, FGD, Yerevan)

In my opinion we have not been that country and haven't been equipped sufficiently to nurse such children. Here in my opinion the medical-scientific issues and moral issues collapse with each other. (Ob/gyn, 3.4.2.3.5, FGD, Yerevan)

I cannot think of any 22-24 week old born at our facility that has survived. Mainly those born over 26 weeks are vital and survive. We don't have equipment. If abroad similar newborns are viable then we have problems here in Armenia. (Ob/gyn, 3.4.2.3.7, IDI, Yerevan)

Gyumri does not have appropriate conditions [to nurse extremely preterm neonates], *let's say the truth...* (WC ob/gyn, 3.4.2.3.8, FGD, marz)

Such 22-week-old babies are like a corpse. They need special conditions for care. They need to have parenteral feeding, which we cannot provide. (Neonatologist, 3.4.2.3.9, FGD, Yerevan)

The improvements in the quality of neonatology services among three maternity hospitals do not mean the improvements occurred among other 65 maternity hospitals, of which 35 are characterized by inadequate conditions. (Ob/gyn, 3.4.2.3.10, FGD, Yerevan)

There is some change…if we compare the current situation with the primitive communal systems of ancient times, then yes, we have great advancements. (Ob/gyn, 3.4.2.3.10, FGD, Yerevan)

Armenia is inclined to follow the principles of the American medicine and it seems to me that it is the main reason for the changes in definitions and not for making the quality of perinatal services adequate. (WC ob/gyn, 3.4.2.3.11, FGD, marz)

This definition was there throughout the world, it has just reached us (Armenia) a little bit late. (Ob/gyn, 3.4.2.3.12, FGD, Yerevan)

The whole Europe and the world now operate on those definitions and we are integrating. Whether we like it or not, we must try to reach a level at which we can work with newborns of low weight and low gestation age. (Ob/gyn, 3.4.2.3.13, IDI, marz)

The main reason behind making these changes, according to some participants, was technological advancement leading to improved quality of neonatal services and making possible the survival of extremely premature neonates. During IDIs, some key informants highlighted the positive sides of these changes, including ensuring better conditions in neonatal units for keeping extremely premature children alive and conducting detailed diagnosis to identify the possible health problems newborns may have. Some participants mentioned about the cases, when neonates born at below 28 weeks of gestational age have survived. Few FGD participants also reported that due to the change in the cut point between abortion and delivery, extremely premature neonates received more chance for survival due to having higher probability of being attended then before, when they were considered as fetuses.

If the child was born having 500 grams weight, and there are all the necessary conditions for that child to survive, then we have a human being, a child who has a right to live. And the government also should provide all the necessary conditions so that the less weighted newborns continue to live. The conditions are created. Year by year the technical capacity is provided to them [maternity hospitals]. (Policy maker, 3.4.2.3.14, IDI, Yerevan)

It [the shift] *was probably right because, specifically in our hospital, there have been instances where 27-28 weeks-old newborns have survived. There have been no problems and later they have developed normally and become healthy people. They could not have been classified as miscarriages as it would have caused problems for the parents later on. Admittedly, that change was necessary. With today's technology, considering a day below 28 weeks to be a miscarriage would be wrong.* (Ob/gyn, 3.4.2.3.15, IDI, marz)

Of course I see a positive side [of the shift]. *Years ago, we had no idea about the SPAP neonatal ventilator and now we know that it is a quite simple salvation for those newborns. If formerly such newborns survived only by God's will, well now we contribute to that and are able to achieve the discharge of 600-650 gram newborns.* (Ob/gyn, 3.4.2.3.16, IDI, marz)

Maternity hospitals are able to provide adequate neonatal services… we have seen many cases when infants born with 500 or 600 grams weight were growing rapidly and becoming such great newborns that they did not underperform in comparison to term infants. (Midwife, 3.4.2.3.17, FGD, Yerevan)

In some sense, it [the change] *was correct in terms of... in the past, when infants were born at 22 weeks of gestation and made a couple of voluntary muscle movements, nobody would pay attention, because such cases were reported as abortions. But now we try to resuscitate infants born at 22 weeks of gestation with 500 grams birth weight that demonstrated even one life sign. To what outcomes it leads is difficult to say and refers to another problem... subsequent problem. But we try to resuscitate anyway.* (Neonatologist, 3.4.2.3.18, FGD, marz)

Another positive aspect of the changes in the definitions discussed during one of the FGDs with neonatologists was the ability to have better statistics on the situation in the country, as the indicators became comparable with those from other countries and, therefore, may contribute to better understanding of the quality of our perinatal services as compared to other countries.

The participants generally agreed that the change in the definitions of abortion and delivery has increased the number of registered stillbirth, as many cases of stillbirth happen between the periods of 22 to 28 weeks of gestation. The explanation for this was that if in the past these cases would have been considered as abortions, now they are being registered as stillbirths. However, one of the policy makers and a few FGD participants stated that the stillbirth rates have not increased much, because extremely preterm births are rare.

We could compare the outcomes of our country across the countries of our planet. When our statistical indicators did not include cases less than 28 weeks of gestation, we would not be capable of finding whether our outcomes were better than [for example] the outcomes of Pakistan… do you get my point?...But now when the scheme with the same indicators are used both in our country and Pakistan, then outcomes can be compared and combined. (Ob/gyn, 3.4.2.3.6, FGD, Yerevan)

In Armenia the chance is low that infants with 500-600 grams weight will stay alive. As a result of this shift, the numbers of stillbirth and infant mortality have increased. (Neonatologist, 3.4.2.3.2, IDI, Yerevan)

In the past, when it was from 28 weeks of gestational age, we were not receiving such big numbers [of stillbirth cases]. *However, as now it* [stillbirth] *is* [registered starting from] *22 weeks, the numbers have increased.* (Midwife, 3.4.2.3.19, IDI, Yerevan)

Perhaps stillbirth is now registered a lot because in the past, we were considering them miscarriages and they were not registered. Now there are lots of stillbirth cases up to 28 weeks of gestation… (Ob/gyn, 3.4.2.3.15, IDI, marz)

We have not had any substantial changes in the statistics after the change in the cut-point. While in the past cases less than 28 weeks of gestation were reported as abortions, now hospitals report them as stillbirths. The growth [in stillbirth rates] *was not too much because infants with 500 grams birth weight are also not as many. But anyway, there is a subtle growth.* (Policy maker, 3.4.2.3.20, IDI, marz)

Nevertheless, all the participants stated that these changes have created much difficulty for them, as there is a very big difference between a newborn weighting 1 kg and one at 500 g. Some participants from marzes considered this shift meaningless for them as they don't have the technologies necessary for caring of extremely premature neonates, such as medical ventilators for artificial breathing, neither they could transfer such babies to third-level hospitals as these are often located too far, mostly in Yerevan, while severely premature infants cannot be moved long distances. Another issue raised was that even many "third-level" hospitals are not equipped enough to be able to take care of these babies and thus transfer them to other third-level hospitals, which is abnormal.

We have parenteral feeding at our maternity ward, however even in this case the 500 gram babies do not survive; the 700-800 gram babies do though. (Neonatologist, 3.4.2.3.21, FGD, Yerevan)

The cut point is set at 22 weeks of gestation, let it remain so... but with respect to the care I agree with my colleague, it's very challenging... of course it's clear that the care for infants with 500 grams and 1 kg is very different. (WC ob/gyn, 3.4.2.3.22, FGD, marz)

The 28 week term was more realistic… (Ob/gyn, 3.4.2.3.23, FGD, Yerevan)

The shift was meaningless for our marz… Such children [born at 22-27 weeks of gestation] *need specific equipment and intensive supervision that does not exist in our marz.* (Neonatologist/ob/gyn, 3.4.2.3.24, FGD, marz)

I would like to note that this change is more difficult to perform in the regional hospitals. It happens when conditions in the regional hospitals do not allow saving lives of such [extremely preterm] *infants. I mean existing opportunities are restricted, such as intensive care units. We*

also need the supply of specialists in the resuscitation departments. (Policy maker, 3.4.2.3.19, IDI, marz)

It is important to equip all maternity centers with the necessary equipment to take care of the newborn in order to ensure that the baby will not die in the first 10 hours and the hospital will be able to transfer the baby. That is the main problem. Because the hospital may not have the equipment, the capacities to give the newborn an oxygen before the transfer. I don't know who shall provide the equipment: the municipality or other organizations… But the equipment should be provided; the child should receive the oxygen and receive the care before the transfer. (Ob/gyn, 3.4.2.3.25, IDI, marz)

I believe that the number of the [third-level] *hospitals must be small, yet* [they should be] *located favorably to allow moving* [extremely preterm] *infants to a third-level hospital in a very short period of time. Also, some of these so-called third-level hospitals do not correspond with accepted requirements – sorry for being very honest – and need to be equipped so that infants are not transferred to other hospitals… due to the lack of equipment or some kind of medication.* (Ob/gyn, 3.4.2.3.6, FGD, Yerevan)

Some participants expressed doubt about the long-term effects of extreme prematurity on child's further development. One participant stressed that changes must be introduced according to the specifics of the country and not as a general rule for all. Moreover, analyzing the long-term outcomes of extreme prematurity was also seen as important by some participants to understand what exactly they were working towards and whether the results were worth the efforts made.

We have the matter of how viable that child is? How will it develop into an adult? Usually, when the child requires hospital tests and when certain defects develop during their adult life, the medical staff goes backwards to see at what gestational age they were born… I think that naturally all the deficiencies will be recorded in people who were born as preemies. (Midwife, 3.4.2.3.26, FGD, Yerevan)

You need to understand that the issue isn't only about heart-beat, but the brain activity also suffers in such cases [of extremely low birthweight]. *We end up growing potential "retards"... We keep comparing with other countries, but it's impossible to compare everything with them. I have never heard of a 22 week-old surviving and developing into a healthy individual.* (Neonatologist, 3.4.2.3.27, FGD, Yerevan)

…As a physician I do not believe resuscitated infants born at 22 weeks of gestation with 500 grams birth weight could be completely healthy... We have just not met such cases in our maternity hospital... (Neonatologist, 3.4.2.3.18, FGD, marz)

Research conducted in developed countries have arrived at a conclusion that if a 26 week newborn does not show signs of livebirth, resuscitation procedures are not performed. Taking care of 500g and above newborns, and studying them, the world came to a conclusion that in the future these children have mental health, nervous, motion and visual impairments. (Ob/gyn, 3.4.2.3.12, FGD, Yerevan)

Don't you think that at times we try to compare us with developed countries suggested by WHO? …The decision should not be brought from other places and just carried out in our country by stating that, "now we are thinking in this new way". Each country has its own peculiarities and those should be considered [when making decisions]. *That is it.* (Ob/gyn, 3.4.2.3.28, FGD, Yerevan)

It would be good if we could have data on the later development of premature babies [in Armenia]. (Ob/gyn, 3.4.2.3.29, FGD, Yerevan)

Yes, so that we can understand if the supreme efforts we put into saving those infants' lives were worth it. For example, as I said, I have seen one, and it was such that I thought to myself that it was not worth saving that child… (Ob/gyn, 3.4.2.3.30, FGD, Yerevan)

3.4.2.4 Financial aspects of the change in definitions

The participants generally agreed that the change in the cut-point between abortion and delivery had positive financial consequences for both the facility and medical staff: the facility receives bonuses based on the number of deliveries and, thus, the medical staff also receives more payment than in the past, because while before births at 22-27 weeks of gestation were considered as abortions, now they are counted as deliveries and paid in the scope of the Obstetrical Care State Certificate (OCSC) program as such. It must be noted that the financial implications of this change were the main positive aspects of it mentioned by FGD participants. Moreover, the participants stated that the maternity hospitals providing third and second-level care (where the majority of very preterm deliveries take place) receive even higher financial benefit from this change, as the amount transferred to them from the State Health Agency for each OCSC is considerably higher than that transferred to maternity services providing first-level care. One of the IDI participants also stated that the change in the definitions were beneficial for parents too, because women receive postpartum bulletin even if the child is born in 22 weeks of gestation and has 500 grams weight.

However, some participants mentioned that there has not been a noticeable positive shift in the finances for the providers as the numbers of cases born at 22-28 weeks of gestation are not that high. Interestingly, one of the midwives mentioned that this change did not have any positive financial influence on the salaries of the medical staff in her facility. Another participant mentioned that the hospital heads get the benefit from this shift, not the staff. Neonatologist participants stated that they were not aware of any financial implications of this change and that this question should be directed to the facility administrations and gynecologists.

When the live birth date was 28 weeks, delivery [before that term] *was not under state care and there was no bonus system. Everything came under the general financing of the maternity hospital. Now the hospital is paid according to the number of deliveries and if 22 weeks is also considered a delivery, it benefits the hospital from the financial point of view.* (Ob/gyn, 3.4.2.4.1, IDI, marz)

As far as now the delivery at 22 weeks is considered a preterm birth, the physician receives money based on the OCSC. In case of abortions which are covered by BBP, the physician's payment is lower. But the payment for birth is enough. That is why the issue of physicians' payment is somehow positively resolved. (Ob/gyn, 3.4.2.4.2, IDI, marz)

Since 22 weeks of gestation physicians receive financial advantage… When deliveries are reported, it definitely adds the amount [of salaries] *based on the bonuses.* (Midwife, 3.4.2.4.3, FGD, marz)

If it is considered birth, then we have a system of bonuses, based on which midwifes and doctors are paid - the personnel who delivered the baby. (Midwife, 3.4.2.4.4, FGD, marz)

It is wrong to consider 22 weeks and 500 grams as a delivery, although women who have such deliveries receive a postpartum bulletin which of course is beneficial to them. As to the consequences that moving the cut-point between abortion and delivery from 28 weeks to 22 weeks has had on the facility, well… there has been a positive effect of receiving more money for deliveries through provision of OCSC. (Neonatologist, 3.4.2.4.5, IDI, Yerevan)

If we are discussing third level hospitals, then financial resources allocated for intensive care and treatment units have been increased, as well as for the second level hospitals. (Ob/gyn, 3.4.2.4.6, FGD, Yerevan)

There can be no financial consequences on the institution due to this change. We receive the same sum which is not affected by the weeks of gestation in any case. (Midwife, 3.4.2.4.7, IDI, Yerevan)

I think there are financial incentives for the hospitals, but not for the staff members, the situation is getting worse, not better, isn't that right? (Midwife, 3.4.2.4.8, FGD, Yerevan)

The head of the facility and head of the department will know such things. (Neonatologist, 3.4.2.4.9, FGD, Yerevan)

The numbers that we are dealing with aren't that great to bring a significant income to the maternity hospitals… If we count the number of births at our facilities, then we can each see this. For example, if we have 2600 births and 24-25 stillbirths then this isn't exactly a great profit. (Midwife, 3.4.2.4.10, FGD, Yerevan)

Some participants noted that the high cost of taking care for the extremely low-birthweight neonates outweighs the financial benefit related to the increased number of deliveries. Some others added that they did not find efficient at all the high cost spent on numerous expensive medical equipments and procedures for keeping these babies alive, as these children have little chance to survive.

Although the changes in definitions have positive financial results for the facility, if we also think about the cost to the hospital of caring for a 550-700 or 800 grams newborn, even for one week, it turns out that one cancels the other out and there is no financial gain at all. (Ob/gyn, 3.4.2.4.1, IDI, marz)

The expenses on children weighting 600– 800 grams are very high: oxygen, light, heating, etc. They need special attention and they stay in the hospital for months. …The process needs more appropriate funding... (Ob/gyn, 3.4.2.4.11, IDI, marz)

We accepted [the cut-point of] *22 weeks with ease, but we spend a lot of money on these cases.* (Neonatologist, 3.4.2.4.12, FGD, Yerevan)

The game is not worth the candles [a Russian saying, which means that the outcome is not worth the efforts]*… Even during war, one chooses to save a slightly wounded, injured person rather than heavily injured. The odds are bigger in that case.* (Ob/gyn, 3.4.2.4.13, FGD, Yerevan)

The expenditures made [on keeping extremely low birth weight babies] *are not worth the outcome.* (Ob/gyn, 3.4.2.4.14, FGD, Yerevan)

One major issue raised during the FGDs with gynecologists from women's consultations was related to the fact that to increase the number of women giving birth in their hospitals, some hospital heads urge their specialists to recruit more pregnant women during the prenatal period, for which most hospitals have opened consultation services. This leads to actively recruiting pregnant women by in-patient services, while otherwise they would be served at the primary level by women's consultations. Some participants felt that this tendency has led to hospital gynecologists attending to highly increased numbers of pregnant women and not having enough time to provide sufficient consultation to them. Moreover, several participants from women's consultations believed that this overload may pose women at higher risk of maternal mortality at the in-patient service level. It was suggested that one possible solution to this issue would be to set a cap for the number of patients that could be enrolled per physician. The need to improve the connections between specialists in WCs and maternity hospitals was also stressed to end the feud and unfair competition between them. The participants stressed the significance of the matter and expressed a hope that the present study would help to raise this issue.

Our salaries are based on the number of pregnant women… they [maternity hospital specialists] *must take more* [pregnant women] *in order to earn higher salaries. But it's necessary to work with pregnant women correctly and spend more time… pregnant women call me each moment and ask questions, so it's impossible to provide consulting services to 200 pregnant women... It just means that physicians have to work all day and night.* (WC ob/gyn, 3.4.2.4.15, FGD, Yerevan)

Almost all of them [maternity hospitals] *have established such* [consultation] *services… I do not know how much this approach is justified, but it seems to me that the consulting services* [to pregnant women] *should be performed separately.* (WC ob/gyn, 3.4.2.4.16, FGD, Yerevan)

Hospitals are strongly interested in this [consulting large numbers of pregnant women]. *Especially distinguished physicians … provide consulting services to around 200 pregnant women, while working at the in-patient department. I have been a head of the obstetric department and I know that it's impossible to work in the maternity hospital and provide consulting services to 200 expectant women at the same time. It seems to me that the cause of maternal deaths in the obstetric departments is the result of carelessness, because physicians cannot manage* [the volume of the work]. (WC ob/gyn, 3.4.2.4.16, FGD, Yerevan)

That's why [referring to each provider attending to far too many women] *the consultation for each pregnant woman does not exceed one minute … It's practically impossible; there must be*

a definite limit that would not allow physicians to take more pregnant women. (WC ob/gyn, 3.4.2.4.17, FGD, Yerevan)

It's necessary to introduce a cut-point on how many pregnant women a physician should take and provide relevant services. (WC ob/gyn, 3.4.2.4.15, FGD, Yerevan)

Also, maternity hospitals tell that WCs aren't necessary and what kind of physicians are working there [referring to quality of specialist]. …*Why we* [specialists in WCs and maternity hospitals] *should not be considered as equal? …It would be good* [more favorable in terms of valuing/respecting each other] *if the connection between women's consultations and obstetric departments becomes stronger.* (WC ob/gyn, 3.4.2.4.16, FGD, Yerevan)

3.4.3 Circumstances under which a fetus/liveborn could be registered as stillbirth

During the IDIs and FGDs the research team discussed several issues/factors that could somehow be related to the increasing trend in stillbirth rates observed in the country since the adoption of WHO 10th classification definition of stillbirth in the healthcare system in 1995, a trend which might be artificial as it is inconsistent with the dynamics of early neonatal and infant mortality rates during the same period. It is important to note, that throughout FGDs with various stakeholders, the research team witnessed that on several occasions one or two participants from a group would provide certain information related to the circumstances/reasons when intentional misreporting of livebirths as stillbirths could occur. In most cases, the reaction of the rest of the group members would be to counter the information provided and deny the possibility of such things happening. On the other hand, in some cases other group members would also agree with their colleague and provide fragments of the truth with a nervous laugh, as if seeking assistance from other members and feeling scared/shy. Then they would suggest that the research team approach another group of stakeholders (e.g., maternity hospital heads) and direct that certain question to them.

3.4.3.1 Perceived causes of stillbirth

The participants were asked about the possible reasons of increasing rates of stillbirths in Armenia. Some of them mentioned that this question is difficult to answer as very often they are limited in doing the needed volume of tests and examinations to identify the cause of a given stillbirth. In the meantime, they agreed that the stillbirth rate increases. The participants noted

that there are many causes leading to stillbirth. Of these, infections were among the most frequently mentioned ones, followed by placental abnormalities and congenital defects. Some participants from various FGDs and IDIs noted that infections they speak of are not necessarily related to STIs – although this is a big issue as well – but rather infections in general. Some participants from marzes connected the issue of STIs specifically to husbands going abroad for migrant work, contracting the disease and transmitting to wife when returning home. Other causes of stillbirths which participants (pathologists and gynecologists) mentioned included intrauterine asphyxia, umbilical cord wrapping, genetic anomalies as well as unknown reasons. Besides these, women's consultation participants pointed out that the ecology, nutrition and overall social conditions play a major role in the stillbirth dynamics. A few participants pointed out the need to better study this issue. Some noted that often they do not understand what the cause of fetal death could be, especially when the fetus dies very close to the date of delivery.

Because we don't have capacities to do complex examination, it is very difficult to answer to your question [about the causes of stillbirth]. *Based on our experience, it is mostly... The stillbirths are occurring because of the placenta's transformations. Whether those transformations are due to the viruses or mother's diseases, it is difficult to say. Mostly these lead to intrauterine hypoxia and asphyxia.* (Pathologist 3.4.3.1.1, IDI, marz)

In our practice the three main things [causing stillbirth] *are... infection, something mechanical and any malformation. In that sequence. The most cases are infections.* (Pathologist 3.4.3.1.2, IDI, marz)

Infections. It is not the STIs that we have seen in the past. These are the infections that the ordinary people can acquire. And you can't explain the new couple where they have got the infection from. They just married, they are young, intelligent, and are knowledgeable on hygiene, sexual live; but eventually we see that their first fetus has got an infection. Also during outbreaks of air born infections there are no recommendations for prophylaxis for pregnant women. Now we have far more cases of stillbirths than ever before. Even if I compare with the previous year, the number is already increased for approximately 10 cases. (Pathologist 3.4.3.1.3, IDI, Yerevan)

Mostly infections. About 90 % are infections and also birth defects. (Midwife, 3.4.3.1.4, IDI, Yerevan)

… *The main reasons are related to viruses, congenital malformations... Also, toxoplasmosis, cytomegalovirus, influenza.* (Neonatologist/ob/gyn 3.4.3.1.5, FGD, marz)

[The main causes of stillbirth are] *Congenital developmental defects, fetal asphyxia, infections, accidents, bleeding, etc.* (Neonatologist/ob/gyn 3.4.3.1.6, FGD, Yerevan)

The causes [of stillbirth]*... Starting from unknown causes to the cases when women themselves take measures to induce delivery. ...They take medication on their own initiative, or jump from somewhere, etc... Medical causes of stillbirth can be severe pathologies, such as high blood pressure or intrauterine infections. ...Social causes, birth defects and sex-selective abortions usually apply to small gestational periods.* (Ob/gyn, 3.4.3.1.7, IDI, Yerevan)

All women living in villages across Gyumri send their husbands [abroad for migrant work] *when the food ends after New Year... but when they come back in October and November, we are faced with cases of STDs and must refer them to other hospitals... do these people go to work so that they can then distribute* [the earned money] *to laboratories?... 10,000...20,000... Medication is expensive...* (WC ob/gyn 3.4.3.1.8, FGD, marz)

It is social conditions, nutrition and lifestyle, but in my opinion 99% [of stillbirths] *is due to infections.* (Midwife 3.4.3.1.9, FGD, Yerevan)

I cannot say [what the causes are]. *Stillbirths are usually at 12-13 weeks. Often it occurs with firstborns. I cannot say anything. If anyone does say anything, it would be a lie... if I say the general reasons, they would be: ecology, nutrition, and social conditions. But to say that these are the main reasons, we cannot say that...* (Ob/gyn, 3.4.3.1.10, IDI, marz)

The participants mentioned the importance of detecting the cause of stillbirth when it occurs so that the woman could avoid its re-occurrence. They mentioned that when a woman has a stillbirth, she is sent for diagnostic testing and treatment for her condition before she conceives again. They underscored the importance for both parents to undergo the needed medical examinations before conceiving. Raising awareness of future parents is important here, but still not enough, because the tests and treatment are often too expensive for those living in poor socioeconomic conditions, and therefore a portion of the population would conceive without undergoing the necessary examinations/treatment, even in cases when they know that they must do so. Thus some specialists reported that they are facing the issue of growing numbers of varying infections (both STIs and others) and the difficulty to diagnose these cases. They suggested increasing financial allocations provided to pregnant women under state order to enable them undergoing the necessary tests for preconception diagnosis.

The ob/gyns from WCs stated that the scope of services they should cover according to the existing regulations does not include some important ones like dental examination or genetic testing. They are limited in doing ultrasound examination at 15-16 weeks of pregnancy when stillbirths most frequently occur, as they have no such equipment and, according to the existing regulations, they cannot refer women for ultrasound examination at this period. The women need to pay for these additional services, but many of them cannot afford it.

When there is a case of an abortion or stillbirth, mothers …are subjected to detailed examination after which they [think of] *giving birth again.* (Midwife, 3.4.3.1.11, FGD, marz)

The main reason is probably the lack of preconception diagnosis among women who plan to become pregnant. Without proper diagnosis... women may have complications that could be treated before becoming pregnant, however, once they conceive we cannot provide medical procedures anymore… (Midwife, 3.4.3.1.12, FGD, Yerevan)

If parents are well informed and they have a planned pregnancy, husbands are also subjected to diagnostic viral testing and are treated before conceiving... otherwise; they could face such problems [stillbirth]... (Midwife, 3.4.3.1.13, FGD, marz)

More awareness raising activities should be performed in [rural] *communities. Each woman should be aware of her responsibility that she is obliged to be subjected to certain types of examinations to assess the condition of the fetus.* (Policy maker, 3.4.3.1.14, IDI, marz)

They should be tested before the pregnancy, especially if they had abortions before... to find out the problems, and see whether they are healthy and then become pregnant. (Midwife 3.4.3.1.15, FGD, marz)

The better way is when the woman becomes pregnant after the examination. But it depends on the social status. (Midwife, 3.4.3.1.16, FGD, marz)

They [parents] *could be aware* [of the necessary pre-conception examinations] *but be unable to afford the services... One medical test is performed at 20,000 to 25,000 drams, and many cannot afford it even if they are aware.* (Midwife, 3.4.3.1.17, FGD, marz)

The most dominant reason of stillbirth are infections… local authorities need to initiate steps to increase the amount of allocations for pregnant women in order to make more feasible preconception diagnosis for them. Not all women can afford medical expenses for

preconception diagnosis… I only mentioned about infections, but the role of hormonal changes is also instrumental. Many of pregnant women need to pass relevant medical tests, but these are not included in the basic benefit package. (Midwife, 3.4.3.1.18, FGD, Yerevan)

Say a 16 week pregnant woman comes with normal uterine floor but I cannot hear a heartbeat. I cannot send her to ultrasound to identify the heartbeat. …According to our regulations, the first ultrasound is between 11-14 weeks… so then how am I supposed to find a heartbeat at 15 weeks? …there is a scan at 11 weeks and, then up to 18-19 weeks I can only decide whether the pregnancy is progressing normally or not by checking the uterine floor… Even if an old piece of equipment is set up in an ordinary examination room, so that we can at least hear the heartbeat during that period, then that would work. …in many cases the dead fetus is not discovered until it is miscarried. (Ob/gyn, 3.4.3.1.10, IDI, marz)

…there is no indication in the regulation on dental examination. …I think that it is a very wrong approach. All our endogenous problems may be related to the teeth... endogenous infections, septic risk factors after the birth... they do not pay attention to it... there is no such service… In the past... each WC had a dentist …and the work that was done was very important... There was a special position for that but now no attention is given [a group member agrees]...
In Yerevan, genetic testing is performed in the WCs after 20 weeks of gestation, which is not performed here... We work with "fingers crossed " to avoid such cases, because we know what should be performed but the Ministry sends regulations that guides us what to perform and what not. … We know what should be performed but patients cannot afford the services... (WC ob/gyn 3.4.3.1.19, FGD, marz)

3.4.3.2 Diagnosis of stillbirths and neonatal deaths

<u>*Specialists diagnosing stillbirth*</u>: There was some diversity in the responses of the participants concerning the specialists being responsible for the diagnosis of stillbirth. The majority of the study participants mentioned that stillbirth is diagnosed by both the ob/gyn who accouches the delivery and the neonatologist who is present during the delivery. However, in the cases of antenatal stillbirth, when the diagnosis is made antenatally by the ob/gyn and/or midwife and then confirmed by sonography or Doppler examination, a neonatologist is not involved in the diagnosis, while in the cases of intranatal stillbirth the neonatologist is responsible for the final diagnosis of stillbirth. Some IDI and FGD respondents mentioned that if intra-uterine death is confirmed, the presence of a neonatologist during the delivery becomes unnecessary. However, one group of midwives countered this by stating, "No delivery takes place without a

neonatologist being present, regardless of whether or not they are certain that the fetus is alive or dead". It is noteworthy that during one FGD with neonatologists, all the group members unanimously stated that the delivering ob/gyn is responsible for the diagnosis of stillbirth.

The gynecologist and the pediatrician [neonatologist] *are responsible for this* [stillbirth] *diagnosis at our facility. We have 24-hour duty here, thus the pediatricians* [neonatologist] *are always aware of births and they are present at all these cases. So the decision is made jointly by the two specialists.* (Neonatologist, 3.4.3.2.1, IDI, Yerevan)

The obstetrician gynecologist and the neonatologist are responsible for the final diagnosis of the stillbirths… Rarely, when we admit already known dead fetus confirmed by USE, there is no need for confirmation by the neonatologist. (Ob/gyn, 3.4.3.2.2, FGD, Yerevan)

[In the case of] *Antenatal death …if the ob/gyn with the midwife did not hear the heart beats, a sonography is done and the ultrasound specialist in its turn confirms the diagnosis of a dead fetus. During that delivery a pediatrician is not invited to the delivery room* [in this case]. *In case of intranatal death, sometimes it happens that we invite the pediatrician to the delivery room, but eventually during the last ditch the newborn appears to have no sign of livebirth. In that case the role of pediatrician is bigger as he/she was expecting a live newborn, and at that moment he/she is the one who evaluates the heart, respiratory functions, movements etc. Otherwise the sonography specialist and obstetrician gynecologists* [make the stillbirth diagnosis]. (Ob/gyn, 3.4.3.2.3, IDI, Yerevan)

[The diagnosis makes] *The one who delivers the baby. If the fetus has succumbed and is diagnosed by the USE or Doppler, then it is diagnosed in advance. Otherwise, the final diagnosis is set by the physician on duty who delivered the baby. The person in charge of the maternity unit at that particular moment is the one who sets the diagnosis.* (Policy maker, 3.4.3.2.4, IDI, Yerevan)

Neonatologists [are responsible for final diagnosis of stillbirth]… *When an infant is born, they examine life signs and in cases when these are absent - regardless of the weight and gestational age* [of the newborn] - *such newborns are reported as stillbirths.* (Neonatologist, 3.4.3.2.5, FGD, marz)

Immediately after birth neonatologists are responsible for the diagnosis and notification about it [case of stillbirth] *to the obstetrician-gynecologists.* (Midwife, 3.4.3.2.6, FGD, Yerevan)

The physician who delivered the baby gives the final diagnosis of stillbirth. (Neonatologist, 3.4.3.2.7, FGD, marz)

The delivery process is controlled by the midwife, but the stillbirth diagnosis is performed by the obstetrician-gynecologist. (Midwife, 3.4.3.2.8, FGD, marz)

Diagnostic criteria for stillbirth: According to the study participants, the cut points between abortion and stillbirth (in case of birth of a dead fetus) are a gestation age of 22 weeks and above, and a weight of 500 grams and above. With this gestational age and weight, the birth of a dead fetus is diagnosed as stillbirth while its birth from an earlier-term pregnancy and with lower weight is considered abortion. However, the participants differed in prioritizing gestational age or birthweight, if the two did not coincide. The majority of them noted that gestational age is more important for diagnosing stillbirth, as in the case of intrauterine growth failure a fetus at 22 weeks of gestation could weight less than 500 grams. Unlike this, a few participants mentioned that they prioritize weight over gestational age and if a dead fetus is born from a pregnancy of 22-weeks but weights less than 500 gram, they don't report it as stillbirth, justifying this approach with a possibility that the gestational age could have been calculated incorrectly.

The diagnosis depends from the time of baby's death in a way that after 22 weeks of gestation and with the weight above 500 g it is considered stillbirth, which is a birth, while under this cut-off it is considered an abortion. (Ob/gyn, 3.4.3.2.9, IDI, Yerevan)

Before 22 weeks of gestation, if the pregnancy is no longer continued and the fetus is dead we don't consider it as a stillbirth, instead we consider it as a non-developing pregnancy which is terminated. …Intrauterine death or death during delivery from a pregnancy exceeding 22 weeks of gestation will be called stillbirth. The weight on 22 weeks of gestation is 500 grams, which is the cut-off point in the definition. But maybe a woman has approached to 22 weeks of gestation while the fetus has not been growing since 18 weeks… Our main indicator is the gestational age. (Ob/gyn, 3.4.3.2.3, IDI, Yerevan)

We are mainly guided by gestation currently, rather than weight, as there is a possibility of intra-uterine slowed growth. (Neonatologist, 3.4.3.2.10, FGD, Yerevan)

The weight is also important. If it is born at 22 weeks, but with a weight of 450gr, we do not record it as a delivery…there may be deviations in calculations; it may not be exactly 22 weeks, but we are guided by the infant's weigh. (Ob/gyn, 3.4.3.2.11, FGD, Yerevan)

Misregistration of livebirth as stillbirth: When discussing the possibility of registering a newborn that demonstrated some signs of life before dying as a stillbirth, the majority rejected it.

Some participants, however, acknowledged such possibility. They explained that this could be done unintentionally because of being unaware about the signs of livebirth. Lack of knowledge as a reason for misregistration of livebirths as stillbirths became evident from the words of some FGD and IDI participants who either didn't know all the signs of live birth, or even though they knew them, they still concentrated on breathing and, sometimes, also on heartbeat as the most important ones, diminishing the importance of the other signs (see more citations on these in the section *3.4.2.2. Stillbirth and livebirth*). It is noteworthy also that some key informants did not reject the possibility of registering some portion of early neonatal deaths as stillbirths purposefully. One participant made a suggestion to introduce some controlling mechanism in the maternity hospitals to address this issue.

No, we do not do such things [reporting a live born as a stillbirth]. *Even when parents ask us to do such things we are saying that it's on the hands of God, we do not have a right to do so.* **(**WC ob/gyn, 3.4.3.2.12, FGD, marz**)**

I think that there can be two reasons for incorrect registrations [of livebirths as stillbirths] *…lack of knowledge and purposeful incorrect registrations. …We have had a situation like this in one of our maternity hospitals - of course it was a long time ago when these new definitions were being introduced - when only stillbirths were being registered and there weren't any early neonatal deaths and we were trying to understand the reason behind this. So when we asked the ob/gyn what the definition of livebirth was, they responded that the baby had to breathe to be considered a live birth. The neonatologist, on the other hand, knew all the signs, but the ob/gyn's lack of knowledge was an opportunity for not registering these cases.* (Poliy maker, 3.4.3.2.13, IDI, Yerevan)

There have been no changes in the definitions of stillbirth and livebirth. The deceased newborn that has taken at least one breath after birth is considered livebirth. This concept has probably come down from the Tsarist period. Stillbirth is when, even if there has been a heartbeat, not a single breath has been taken. So the heartbeat and breathing are central. (Ob/gyn, 3.4.3.2.14, IDI, marz)

Mostly the child has to breathe to say that it is a livebirth. (Neonatologist, 3.4.3.2.1, IDI, Yerevan)

Yes, the existence of muscular movements alone is not a sign of livebirth. (Neonatologist, 3.4.3.2.15, FGD, Yerevan)

If we believe that physicians do not strictly follow the definitions [of stillbirth], *it is not done for bad purposes, just because they either do not know* [the definitions], *or do not deem it wrong to register a newborn who has taken a breath as a stillbirth. If there are people controlling the correct registration of those cases* [in other countries], *here we don't have one to do that, thus we can register those livebirths as stillbirths.* (Ob/gyn, 3.4.3.2.3, IDI, Yerevan)

3.4.3.3 Inconsistencies in gestational age calculation

According to diverse participants, differences almost always happen between the gestational age calculated by the women's consultation and maternity hospital staff: most frequently the difference is about two weeks, which deems within the allowable norm and, even, unavoidable, especially when calculations are based on the date of the last menstruation, as the exact time in the menstrual cycle when the woman has conceived cannot be determined, also, the cycle could be irregular, the woman could misreport/forget the date of the last menstruation, etc. Even though a few participants from the WC FGDs stated that they manage to have more accurate data thanks to ultrasounds, in some instances their calculations don't match to that of the maternity hospital with a difference of approximately 2-3 weeks, and in that cases they record the average. Some ob/gyn FGD participants reported that mismatches between the calculations happen "very often". Sometimes, the difference can reach to one month. A majority of FGD participants reported that in case of inconsistencies they use the average of the two estimates, while some reported that the hospital ob/gyn is the final decision maker. One of the participants stated that even if a 450 gram fetus from a pregnancy of 21 weeks is registered as 500 gram from 22-week pregnancy, it could be done unintentionally and it is not really shameful as the difference in negligible and such cases happen very rare to make a notable change in the statistics. Neonatologist participants stated that they completely rely on the decision of ob/gyns when the debate is between a pregnancy term of 21 or 22 weeks, as there is no way for them to judge about the actual gestational age of a child born at such early term. Some participants rejected the possibility of intentional misreporting of the pregnancy term in their respective institutions.

For [pregnancy term] *calculation we consider last menstruation,* [woman's] *first consultation information, as the menstruation may be non- regular. The gestational age is calculated also based on comparative data of fetus movements and ultrasound results. We consider both*

women consultation and our estimated ages and give an average one but the exact gestational age can be estimated after the birth when seeing the sizes of the newborn. (Ob/gyn, 3.4.3.3.1, IDI, Yerevan)

…On the whole, the date provided by the in-patient services is considered as final, because we are dealing with the fetus, and we can see it… When ultrasound came into use, it eased the calculation of the gestation age considerably because sometimes women forget the date of their period or when they first felt the [fetal] *movements…* (Ob/gyn, 3.4.3.3.2, IDI, marz)

There are some subjective reasons [for differences in calculated pregnancy terms between the WC and hospital]*... first, pregnant women may be registered late, the intrauterine growth retardation may exist and they could be poorly diagnosed… but such cases happen…* (WC Ob/gyn, 3.4.3.3.3, FGD, Yerevan)

[We take] *The average. If they* [maternity hospital] *provide 24 weeks of gestation and I give 22 weeks of gestation, we average.* (WC ob/gyn, 3.4.3.3.4, FGD, marz)

Not often [referring to inconsistencies between gestational age calculated in WC and hospital]*... there are just permissible small deviations such between 10-15 days.* (WC ob/gyn, 3.4.3.3.5, FGD, marz)

It occurs frequently that the difference accounts for 2-3 weeks, but that's within the norm. (WC ob/gyn, 3.4.3.3.6, FGD, Yerevan)

No matter how much we desire, it is impossible to have an accurate gestation age, and we always have a 2-week error. (Neonatologist, 3.4.3.3.7, FGD, Yerevan)

…It [the deviation in calculated versus real pregnancy term] *depends on the length of the menstruation cycle, thus the 1-2 weeks difference is acceptable. But also we frequently have a difference in one month, as the woman has bloody secretions which they confuse with the menstruation, while in the reality the secretions were associated with the pregnancy.* (Ob/gyn, 3.4.3.3.8, IDI, Yerevan)

The physician might write it [22 weeks instead of 21] *by mistake, but not on purpose. However, even if the physician records 21 weeks of gestational age as 22 weeks, it's not as shameful, but not 16 weeks of gestational age as 22 weeks. The physician knows its complications and difficulties. If the fetus is 450 grams why can't you write 500 and consider it as delivery. It is for one day. Among 1000 births 1-2 such cases might happen. It cannot be more than that.* (WC ob/gyn, 3.4.3.3.9, FGD, marz)

We are guided by the decision of the ob/gyn, as 22 weeks is a very small period. It is not the period when we can judge about maturity/prematurity of the fetus. Therefore there are no criteria for us to argue the ob/gyn about the accuracy of the gestational age. We are not speaking of 35 weeks here [referring to the fact that the age can be determined from child's appearance]. (Neonatologist, 3.4.3.3.10, FGD, Yerevan)

Recently we had a case and a pregnant woman at 22 or 23 weeks (we had some doubts for accuracy) of gestation came from Goris, physicians clearly reported as live birth and then as neonatal death, but it also has happened a case when gestational age was a little smaller and they reported it as an abortion, late abortion, I have not noticed that they increased gestational age. (WC ob/gyn, 3.4.3.3.11, FGD, Yerevan)

3.4.3.4 Registration when terminating pregnancies at late terms

FGD participants unanimously agreed that termination of pregnancies between 20-37th weeks of gestation is only conducted based on medical indications and the will of the parents is not taken into consideration. Even though one participant reported that induced abortion is formally allowed until 12th week of pregnancy, some others stated that it is performed until 14th week with parents' request. Child's (male) gender preference and poor social conditions of the family or mother were mentioned as the most common reasons for parents to apply for abortion. The WC specialists stated that they never allow later abortions due to parental desires. Instead, they try to convince them that pregnancy termination at later stages is related to serious complications.

Parent's will is not considered, [late abortions are conducted] *only* [when there are] *medical indications.* (WC ob/gyn, 3.4.3.4.1, FGD, Yerevan)

Usually sex-selective abortions [are requested by parents at later term]. *But these* [terminations] *could be performed at most at 14 weeks of gestation and not later.* (WC ob/gyn, 3.4.3.4.1, FGD, Yerevan)

There is only one explanation for the termination due to parents' desire. It's related to social conditions of parents...the husband may be a prisoner, or it might be rape case or something like that... (WC ob/gyn, 3.4.3.4.2, FGD, marz)

It also happens that expectant women do not know that they are pregnant and face serious challenges at 20 weeks of gestation... there are cases when they want [to terminate], *but I think*

nobody [of physicians] *would terminate the pregnancy.* (WC ob/gyn, 3.4.3.4.3, FGD, Yerevan)

Who would perform such a thing [induced abortion post 20th week of gestation]*?... who would ascend against God?* (WC ob/gyn, 3.4.3.4.4, FGD, marz)

[If women want to have an abortion in later stages of pregnancy] *We must convince and present them with all* [potential] *challenges that could be fatal for them...* (WC ob/gyn, 3.4.3.4.3, FGD, Yerevan)

According to the participants, fetal defects are among the most common reasons for termination of pregnancy at later stages. Some of them reported a decrease in the frequency of birth defects among newborns and stated that the main factor underlying it is early detection of severe birth defects through advanced ultrasound examination techniques leading to timely termination of such pregnancies. The participants of FGDs stated that fetal defects may be diagnosed starting from 12 weeks of gestation, depending on the type of defect and the examination technique applied. However, some participants noticed that with older equipment the diagnosis of fetal defects is conducted only after 22nd week of gestation. They mentioned that in case of defects incompatible with life, they try to terminate the pregnancy as soon as possible, before the fetus reaches the 22nd week, so that perinatal death cases are avoided. In this respect, one of the issues specialists face is the lack of appropriate three-dimensional ultrasound equipment in all settings to allow timely diagnosis of fetal defects. This issue was especially emphasized in regions. As one participant joked, "*You wear 3-D glasses and sit down with the ultrasound examination scanner produced in 1980"*.

It [cases of birth defects] *has now decreased... They* [sonographers] *may not see them but if they do and it is confirmed (by Doppler, ultrasound), the women may have abortion. If it* [severe fetal defect] *is 99% confirmed they* [doctors] *naturally don't allow it to go to full term*. (Midwife, 3.4.3.4.5, FGD, Yerevan)

The diagnosis with the ultrasound scanner is much better than in the past; instead of two-dimensional ultrasound scanner, now hospitals use three-dimensional ultrasound scanners which provide greater options even for mid-level medical personnel; the reliability of diagnosis is also improved due to the application of new methods, but not all hospitals are adequately equipped. (Neonatologist, 3.4.3.4.6, FGD, Yerevan)

We have screening tests, up to the 12th, then 18-22 weeks. That has helped us a lot to diagnose cardiac defects in time. There [defects] *were more* [frequent among newborns] *previously.* (Ob/gyn, 3.4.3.4.7, FGD, Yerevan)

Fetal defects are diagnosed from 15 to 16 weeks, but [the time] *depends on the type of diagnosis.* (WC ob/gyn, 3.4.3.4.8, FGD, marz)

It's necessary not to postpone the detection of serious fetal defects until 22 weeks' gestation. For example, obstetric sonographer could detect spinal bifida at 18 weeks of gestation. (WC ob/gyn, 3.4.3.4.1, FGD, Yerevan)

We detect [birth defects] *generally between 20 and 22 weeks of gestation and we try to avoid perinatal deaths… Obstetric sonographers do not accept* [patients before 22 weeks of gestation] *and note that we refer them very early. It's the issue of technological capacity, when they do not have three-dimensional ultrasound scanner, they could not examine the defects of a very small heart, etc., which is why they avoid from early diagnosis and have to diagnose later, but late diagnosis leads to late detections and while here and there, perinatal deaths occur due to heart or other defects.* (WC ob/gyn, 3.4.3.4.9, FGD, Yerevan)

[Fetal defects are usually diagnosed] *above 22 weeks of gestation…It depends on whether the production year of the ultrasound equipment is 1980 or 2000...* (WC ob/gyn, 3.4.3.4.10, FGD, marz)

Yesterday we had a case of hydrocephalus. That was the second pregnancy, the second delivery. The examination was done, the defect was found by sonography at 23 weeks of the gestation. (Midwife, 3.4.3.4.11, FGD, marz)

Please also indicate that Gyumri is seen as a second level city… let it be recorded, I am not afraid of it… We are in the backplane. Even cities such as Kirovakan, Spitak are in better conditions than us. (WC ob/gyn, 3.4.3.4.4, FGD, marz)

The participants stated that depending on the gestational age at the pregnancy termination (before 22 weeks or after) the birth could be considered an abortion or delivery, with the latter resulting in stillbirth or livebirth. Interestingly, from the words of participants it was evident that they did not recognize the possibility of a livebirth if the pregnancy is terminated before 22nd weeks. According to the majority of FGD participants, when the pregnancy is terminated due to fetal defect after 22nd weeks and the fetus shows signs of life, the case is reported accurately as live born. However, a few argued with this stating that the cases with birth defects incompatible

with life are always reported as stillbirths, regardless of being born alive or not, or the duration of life.

The IDIs also revealed similar findings. One of the gynecologists stated that in case of "severe defects" (e.g., anencephaly) the births are registered as stillbirths, because no one is going to resuscitate these newborns. This participant was sure that there is no way that physicians would record in a medical card for the child with anencephaly that it was born alive and died 2 hours after the birth.

An interesting phenomenon was noticed by the interviewers during the interviews: there were participants who were giving two contradicting opinions when speaking about the same topic. For example, a head of department was saying that induced abortions might result into both livebirth and stillbirth and in the former case it will be registered accurately as live born. However, when the interviewer further prodded with questions, the participant confessed that "*If you have a baby with a birth defect that is inconsistent with life, who only takes one breath, then of course you won't write it as …* [live born]". Another example was the information reported by a midwife, according to whom if the child has a birth defect incompatible with life and after the birth it lives for several days, then it will be reported as neonatal death. At the same time this participant pointed out that when pregnancy is terminated because of a serious birth defect, the result is almost always stillbirth, and that in cases with birth defects incompatible with life they do not even check whether or not the newborn has a heartbeat. As a result, if they do not check the heartbeat, some part of such cases might be misreported as stillbirths.

When the pregnancy is terminated because of a birth defect, both stillbirth and live birth with birth defects are possible. (Neonatologist, 3.4.3.4.12, IDI, Yerevan)

Quite often you have a live birth [in case of termination of pregnancy because of fetal defect], *… if it is born alive and die in one hour, then of course it is a post-partum death and the pathologist will see… they check the heart and the lungs.* (Neonatologist, 3.4.3.4.13, IDI, Yerevan)

If before the death the child had muscular movement, 1-2 heartbeat or breathing, then it is considered as neonatal death. However, in different facilities the approach is different [the participant smiled]. *If you have a baby with a birth defect that is inconsistent with life who*

only takes one breath, then of course you won't write it as… [trails off]*… the defect is already inconsistent with life and it is not going to survive.* (Neonatologist, 3.4.3.4.13, IDI, Yerevan)

It [reporting] *depends on the gestational age. When the detection of fetal defect and pregnancy termination happened before 22 weeks of gestational age, we cannot talk about live births.* (WC ob/gyn, 3.4.3.4.14, FGD, marz)

…When the pregnancy is terminated due to the medical indications because the fetus has birth defects, it is called a stillbirth because the cases occur after 22 weeks of gestation... (WC ob/gyn, 3.4.3.4.10, FGD, marz)

If newborns [with birth defects] *breath after birth then they are considered live births.* (Midwife, 3.4.3.4.15, FGD, marz)

It is not permitted to terminate the pregnancy after that [22 weeks]. *If the date has passed, they usually leave it to be born… the cardiologist does not even look at the heart because even if there is a defect, it makes no difference, it will not be terminated…* (Ob/gyn, 3.4.3.4.16, FGD, Yerevan)

For example, cases with fetal defects [are reported as stillbirth when the newborn actually had some signs of life at birth]. (WC ob/gyn, 3.4.3.4.17, FGD, Yerevan)

It's possible [baby being born alive and reported as stillbirth] *when newborns have birth defects, but usually no.* (Midwife, 3.4.3.4.18, FGD, Yerevan)

In case of rude, evident birth defects [it is possible to report a newborn as a stillborn when indeed in demonstrated signs of life]. *For instance we have a fetus with anencephaly, which needs to be terminated with medical indications for having a condition incompatible with life. No one will guarantee that the fetus will be born dead. But assume if 1.5 kg fetus with anencephaly is born, only with heart bits, or breath; no one will try to resuscitate it, and eventually it will be registered as a stillbirth. …in these situations with rude birth defects, when the pregnancy is terminated due to medical indication, we almost always write it as a stillbirth.* (Ob/gyn, 3.4.3.4.19, IDI, Yerevan)

It would be correct to terminate such pregnancies [with birth defects incompatible with life] *and avoid having a live birth. However, if after the termination we have a live birth and it will die within one hour or may be one day or maybe even two days and the doctors cannot provide any medical therapy, from the logical point of view it is a stillbirth, …however, from the formal point of view it is considered as a live birth…There are lots of cases like this and*

definitely if the child has obvious congenital developmental defects, they will not register it as a live birth… (Neonatologist, 3.4.3.4.20, FGD, Yerevan)

…They [maternity hospital staff] *consider* [neonatal] *deaths due to fetal defects as stillbirth.* (WC ob/gyn, 3.4.3.4.17, FGD, Yerevan)

It is impossible to write a stillbirth when it lived for several days. When we identify the birth defect and do intervention, most of the time they are born as stillbirths. …First of all the weight is too small, plus their defect and medication... We do not even check whether or not there is a heartbeat or not, because by medical instructions it should be terminated... (Midwife, 3.4.3.4.21, IDI, Yerevan)

3.4.3.5 Registration in case of extremely premature births

Some participants rejected the possibility of registering livebirths as stillbirths even if they are extremely preterm and demonstrate only few signs of life for a short period of time. A participant insisted that even when such newborn has a single life sign the resuscitation procedures are done. In addition, a policy maker stated that there are clearly written laws and standards and the physicians do not have a right to decide that this/that livebirth should be registered as stillbirth.

Even if there is only one sign of life, we struggle. Even if the infant dies later, it is not considered stillborn. (Ob/gyn, 3.4.3.5.1, FGD, Yerevan)

I do not think that physicians would not fight to save the lives of infants who show one of life signs. I do not consider so and even do not want to think of it. (Neonatologist, 3.4.3.5.2, FGD, marz)

Our hospital is considered class II, the pediatrician is always present at delivery even in the case of a stillbirth, which has already been diagnosed as such. Even if there is one muscular movement the pediatrician is obliged to resuscitate…the gynecologist is happy that the infant has been born alive…. (Ob/gyn, 3.4.3.5.3, IDI, marz)

It happens that at the first moment after delivery only a <u>single</u> heart beat is detected and the newborn is considered dead, but if the neonatologist effectively performs the resuscitation procedures, the newborn will be registered as a live birth… I just had a similar case nearly 2 weeks ago, that is why I remember this. (Ob/gyn, 3.4.3.5.4, FGD, Yerevan)

The indicators and standards are written clearly. If the signs according to these standards exist, then the child cannot be registered as stillbirth. Those indicators are approved by the orders of the Minister, by the protocols, manuals... All medical specialists have to follow to those regulations. It can't be that the child is live birth but is registered as stillbirth. All that indicators are clearly defined, and it is not the doctor who sets those indicators of the stillbirths and live births. (Policy maker, 3.4.3.5.5, IDI, Yerevan)

No, if infants are born as stillbirths then they are registered as stillbirths and if live births then as live births. (Neonatologist, 3.4.3.5.6, FGD, Yerevan)

However, our interviews have revealed that the actual situation is quite different from what is described above. These findings triangulated between IDI participants from various groups and FGDs, who mentioned that registering preterm live born babies and even babies born at higher gestational ages as stillbirth is either done at their hospitals or in others (they have heard about such cases). The participants explained that the main reasons for such violations are: to ensure a small number of neonatal deaths (high neonatal death rates are considered a bad indicator for a maternity hospital) and for having fewer problems in case of stillbirth. As an IDI participant stated, when the ob/gyn is sure that the infant will not survive, in order to avoid conflicts with colleagues (neonatologists), it is preferable to record that case as a stillbirth. Thus, if the preterm infant demonstrates 1-2 life signs at birth and then dies, the case is registered as stillbirth. The participant spoke of this issue as the hospitals' "unwritten rules". A policy maker also noted that there is an issue of keeping a balance between the interests of ob/gyns and neonatologists when deciding whether the newborn who demonstrated few signs of life before dying should be registered as liveborn or stillborn. Moreover, a neonatologist from one FGD noted that psychologically the knowledge of a stillborn child is easier for a mother to take than to know that the baby died after birth. However, another participant mentioned that even though such cases could be widespread in the past, they have decreased now as women became very attentive and fix the real situation during the first post-delivery seconds.

According to a participant from a WC FGD, sometimes a baby is born with signs of life and reported as stillborn because the maternity hospital does not want to report a neonatal death, and such cases are attributed to WCs. The participants from this same group had various responses when asked whether a newborn with only muscular movement would be recorded as stillbirth or livebirth. The responses were: stillbirth, livebirth, "ask them [maternity hospital staff]", "it

depends who and how would register". Two participants explained (very nervously completing each-other's sentences and giggling in between) that the decision on how to report extremely premature babies or babies with birth defects is made on the spot immediately after birth.

The following paragraph provides a section of the discussion which took place during a FGD with ob/gyns and neonatologists. A group member addressed a colleague with a statement and question at the same time, *"But when have we registered the 500g as a livebirth? Anyone of us?"*. The colleague in question confirmed that they have done, by bringing an example of a recent death where the baby died 2 minutes post-delivery. Other participants also joined in to counter the first respondent, but she remained unconvinced and expressed surprise at her colleague's response, stating that nobody registers these cases as live birth. As a result the entire group reacted to this and she was told to stop speaking. Her colleague expressed frustration that the pathologist can easily find out that the infant was a live born, by simply checking the lungs during autopsy, and went on to mutter that it felt like the colleague was trying to get her sued.

…The newborn may have a small sign of life but no chance to revive. Such as 1-2 heartbeat and in order not to call it neonatal mortality, it can be formulated as a stillbirth, because the death of a newborn is a little bit difficult situation and in case of a stillbirth, well... it was born dead. (Midwife, 3.4.3.5.7, IDI, Yerevan)

[Agrees with the question asked by the moderator] *the newborn may have a heartbeat and end up being recorded as stillborn.* (WC ob/gyn, 3.4.3.5.8, FGD, marz)

It [the low level of neonatal mortality] *demonstrates the level of quality and safety of patient care held by physicians…obstetricians.* (Neonatologist, 3.4.3.5.9, FGD, Yerevan)

…for the hospital one of the most important indicators is the newborn deaths. The higher the number of newborn deaths is, the more the hospital's effectiveness suffers. (Ob/gyn, 3.4.3.5.10, FGD, Yerevan)

Of course. I imagine that it is possible [registering preterm cases as stillbirth]. *When the child has lived for a short time (for a few minutes), had a small birthweight (let's say 600 grams) and died after unsuccessful resuscitation attempt, I have heard that in most of the cases, especially people in regions* [marzes] *do not report it as neonatal death in order to avoid "bad" figures/numbers, "bad" statistics. …In the past there were lots of cases like that, but now... no. This misregistration can happen in case of higher birth weights too.* (Neonatologist, 3.4.3.5.11, IDI, Yerevan)

I cannot indicate where and how many cases, but if the newborn dies, then considering such cases as stillbirths will be preferable for the hospital. (Neonatologist, 3.4.3.5.12, FGD, Yerevan)

We could not do such kinds of things [babies with signs of life being reported as stillbirth]. *It is not the same as in the past... when mother gives birth and if she see at that moment that the baby is normal you cannot persuade her that you baby was not born alive. She fixes that moment perfectly, even if 50 physicians say...* (WC ob/gyn, 3.4.3.5.13, FGD, marz)

What refers to the matter of incorrect registrations, there is a dilemma - a conflict of interest - between the two specialists who are present at the delivery: the ob/gyn and the neonatologist. So in this case a stillbirth is more beneficial for the neonatologist, as this moves it out of their area since they can argue that it was born dead and they could not do anything. On the other hand, the ob/gyn can say the same thing when it is an early neonatal death. So it depends on the maternity hospital and on how these two settle the issue. (Policy maker, 3.4.3.5.14, IDI, Yerevan)

When parents knows that their baby was a stillborn, they handle the so-called perinatal period easier rather than if they are informed that their baby lived for a day or a short time [then died]... (Neonatologist, 3.4.3.5.12, FGD, Yerevan)

...If the weigh is too small, you see that it does not have any sign [of life] *or it is rare* [the sign], *you say "here it is. It is a stillbirth". ...If there is 1-2 heartbeat and they do not manage even to do intubation, how it should be counted? As a neonatal death?* [Smiles]. (Midwife, 3.4.3.5.7, IDI, Yerevan)

Not only cases with fetal defects [may be reported as stillbirth], *it may happen that the infant is born and cries, but physicians report it as stillbirth... I think maternity hospitals prefer to report such cases as stillbirths as they are attributed to the women's consultations... yes such cases happen.* (WC ob/gyn, 3.4.3.5.15, FGD, Yerevan)

I cannot exclude the possibility that someone in the country may register an infant that has been born alive but only lived for let's say ten minutes as stillborn. It would be exclusively in the case of severe prematurity. ...I don't think there are many cases like that. And whoever does it does not talk about it or say that they do it. (Neonatologist, 3.4.3.5.16, IDI, Yerevan)

If a newborn is delivered in small gestations, to say in 22 weeks, only with a muscular movement, and if I as a gynecologist open a newborn card for the baby [as a live born], *the neonatologist will kill me… These cases are more frequent when the baby is born alive and*

dies in 5 minutes, or when the baby is born and we feel that it is going to die while we can do nothing. …It is set that these cases should be reported this way… This is an unwritten law in the hospital. (Ob/gyn, 3.4.3.5.17, IDI, Yerevan)

Our neonatologists have recently conducted an assessment, according to which we currently have some maternity hospitals, where all the deaths are only due to stillbirths. It is possible that incorrect registration is done on purpose, because in any case the responsibility on healthcare providers isn't that great during stillbirth. (Policy maker, 3.4.3.5.14, IDI, Yerevan)

What do you mean we don't write [addressing their colleague who asked "Who reports 500 g babies as live born?"], *how old was the case with the placenta abruption? We delivered it and after two minutes the newborn died, thus it was registered at the CSARB. Don't you write that?* (Neonatologist/ ob/gyn, 3.4.3.5.18, FGD, marz)

Let anyone show a case in their medical records, where they have registered a 500g [baby] *as a livebirth.* (Neonatologist/ ob/gyn, 3.4.3.5.19, FGD, marz)

The pathologist puts the lungs into water which float on the water surface; then they [pathologist] *will create a situation because of this… stop talking. This woman is going to have me sued* [referring to the colleague who keeps insisting that they report 500 g babies as stillbirth in any case]. (Neonatologist/ ob/gyn, 3.4.3.5.20, FGD, marz)

3.4.3.6 Financial reimbursement for late abortions (at 13-21 weeks) vs. stillbirths (>22 weeks)

One of the potential incentives for the maternity hospitals to serve more cases of deliveries and fewer cases of late abortions/miscarriages could be the differential remuneration that hospitals receive from the State Health Agency (SHA) for these two types of services. Considering this, the participants were asked about the existing difference in the financial reimbursement of pregnancy termination at 13-21 weeks of gestation versus 22 weeks of gestation and above, and the possible consequences of this difference.

The participants stated that providers get bonuses for each delivery they serve, as in the scope of the Obstetric Care State Certificate (OCSC) program introduced since 2008, the SHA transfers to maternity hospitals a pre-defined amount of money for each delivery, if the woman presents OCSC. Unlike this, hospitals get no additional money and providers – no bonuses for conducting late abortions (at 13-21 weeks of gestation). Pregnancy termination at 13-21 weeks should be conducted only when medically indicated and is included in the Basic Benefits

Package (BBP), thus, no payment other than the amount transferred to the hospitals from the SHA for the state-guaranteed services is provided for this and providers get no additional bonuses.

The payment system is different in these cases [of pregnancy termination at 12-22 weeks vs. 22 weeks and above]. *In case of terminating the pregnancy on 22 weeks of gestation the payment is done through obstetric care state certificate, and the government pays the physician. In case if a pregnant woman has approached with bleeding, miscarriage on 12-22 weeks of gestation, it is covered by the BBP without any additional payment through obstetric care state certificate.* (Ob/gyn, 3.4.3.6.1, IDI,marz)

After 22 weeks of gestation [the termination of pregnancy] *is considered a birth, thus we are paid for birth, but* [termination within] *12-22 weeks* [of gestation] *is considered an abortion, and only the physician managing the delivery is paid.* (Neonatologist/ ob/gyn, 3.4.3.6.2, FGD, marz)

No, they are not remunerated in the same way… the doctor does not get a bonus from performing abortions. Over 22 weeks, it is considered a birth, and they get a bonus. In instances of miscarriages of up to 12 weeks in the gynecology department and up to 20-21 weeks in the pathology department, they are remunerated according to the number of patients. There is no bonus. (Ob/gyn, 3.4.3.6.3, IDI, marz)

We have bonus payment mechanism which works only in case of births and C-sections. It means, according to the bonus mechanism, based on the number [of births/C-sections], *a definite amount of money is added to the healthcare workers'* [basic] *salary. In the cases if the gestational age is lower than 22 weeks, there is no bonus for those cases* [only the basic salary]. (Ob/gyn, 3.4.3.6.4, IDI, Yerevan)

Obstetrical coverage in the state-guaranteed basic benefit package after 22 weeks of gestation is different from the coverage of an abortion within 12 to22 weeks of gestation… Coverage for childbirth is definitely higher... [The difference is] *around 120,000 drams.* (Neonatologist, 3.4.3.6.5, FGD, Yerevan)

[Early] *Abortion is performed up to the 12th week… It is a paid-for procedure. After that, an abortion is only performed on medical indications and it is state-paid… that is our country's policy.* (Ob/gyn, 3.4.3.6.6, FGD, Yerevan)

The participants stated that either WCs or maternity hospitals issue the OCSC for those pregnant women who reached the 22nd week of pregnancy. They specifically expressed much frustration

in relation to these certificates, as they explained that in some cases the dates are modified (sometimes they are pushed by the maternity hospitals to do so) so that the certificate will be issued to a pregnant woman who needs termination of pregnancy at earlier-than-22-weeks term, so that the hospital gets additional financial benefit from the procedure.

The obstetric care certificates were introduced in 2008. That's when they [births] *became important to medical institutions.* (Midwife, 3.4.3.6.7, FGD, Yerevan)

Yes, it's clear that based on [the quantity of] *certificates physicians receive financial advantages.* (Midwife, 3.4.3.6.8, FGD, marz)

After 22 weeks of gestation [parents] *receive obstetric care certificate that suggest about deliveries.* (Midwife, 3.4.3.6.9, FGD, marz)

If a woman has a certificate, then that is a delivery. (Ob/gyn, 3.4.3.6.9, FGD, Yerevan)

I am not ashamed and I am not afraid of telling that such cases happened when many maternity hospitals based on the introduction of the certificate report cases below 22 weeks of gestation as preterm deliveries in order to receive relevant financing. …none of us could argue about this… (WC ob/gyn, 3.4.3.6.10, FGD, Yerevan)

When the certificate is completed in the maternity hospital, who could know how the certificate is provided. … The gestation age could be 21 weeks... (WC ob/gyn, 3.4.3.6.10, FGD, Yerevan)

… It has happened so many times when they [maternity hospitals] *sent a request* [for a certificate to a woman with a pregnancy term below 22 weeks' gestation] *and imposed to give a certificate, but I did not provide, so I know something that I am telling now.* (WC ob/gyn, 3.4.3.6.11, FGD, Yerevan)

The majority of participants from FGDs, when asked about the repercussions of the difference in the payment for these two types of services, responded that there were none. The group members from a FGD with WC gynecologists unanimously agreed that despite the difference in remuneration, the maternity hospital staff would not take the risk of misreporting miscarriages/induced late abortions as deliveries – especially since the amount in question was very small.

However, a few participants mentioned that sometimes the hospital staff over-report the pregnancy term, if it is slightly less than 22 weeks, so that the case is considered a delivery and reimbursed accordingly. One participant even mentioned that most of the time they misreport less-than-22-week terms as 24 weeks, not 22, because 22 weeks may seem too doubtful (being too close to the border line). The paradoxical thinking, which the study team noticed pretty often during the interviews, was noticed here also: few participants pointed out that providers may report a slightly higher gestational age in order to register the case as delivery and receive more money. However, at the same time they mentioned that misreporting of abortions as deliveries is not performed, demonstrating that they did not perceive this behavior as misreporting. While a couple of participants saw this practice as not being shameful, and not having any negative consequences, some others stated that they are informing us about this practice as they want to help to eliminate it. Several participants thought that changing pregnancy term by up to 2 weeks cannot be considered as misreporting, since no technique could identify the pregnancy term with the accuracy of one week, therefore nobody can blame the ob/gyn in misreporting.

Please turn off the recorder, although I could say it loudly, financial allowances are so small that physicians cannot take such risks [misreporting the term of pregnancy to receive bonuses]*, which may lead to criminal cases... then how much money physicians should pay to manage the situation?* (WC ob/gyn, 3.4.3.6.12, FGD, marz)

I can't accuse the physician who writes the 20 weeks as 22 weeks, it is the same mechanism of delivery, the same efforts… But changes from 16 weeks to 24 weeks (as they don't write 22 weeks, because 22 weeks look suspicious) are full of other concerns, i.e. in those cases physicians don't send the fetuses for the histological examination; how can I send something of 200g instead of 500g fetus. But in case of changing the 20 weeks to 22 weeks, the physician can confidently write it in the diagnosis, weight the fetus and send to the pathology requesting them to know why the fetus is 400g, maybe it has a hypotrophy. (Ob/gyn, 3.4.3.6.4, IDI, Yerevan)

Let's suppose childbirth occurred at 21 weeks and 3 days of gestation that is so close to the cut-point of delivery, if it is necessary to add some 50 grams to change something… Of course it will be done. (Neonatologist, 3.4.3.6.13, FGD, Yerevan)

In case of 20 weeks it [deciding the gestational age] *is very confusing... but at 22 or 23 weeks there is a certificate that is provided. Thus, the hospital staff will say..."be clever and report*

bigger data" [in case of inconsistency, report the bigger gestational age]. (WC ob/gyn, 3.4.3.6.14, FGD, marz)

The physician might write it [22 weeks instead of 21] *by mistake, but not on purpose. However, even if the physician records 21 weeks of gestational age as 22 weeks, it's not as shameful, but not 16 weeks of gestational age as 22 weeks.* (WC ob/gyn, 3.4.3.6.14, FGD, marz)

We mean, if there is an option to register [the case of pregnancy termination/miscarriage] *under the category of delivery to receive additional financing, it will be done...* (Neonatologist/ ob/gyn, 3.4.3.6.5, FGD, Yerevan)

For statistics…It is reported correctly…There might be cases when it is 20-21 weeks of gestational age, and after one week it will be 22 weeks. So I might make a small change to make it a delivery, and if you want to hear that I can say that. However, there is no misreporting. If it is a birth it is reported as a birth. (Midwife, 3.4.3.6.15, IDI, Yerevan)

[For example]*…in case of 21 weeks, I can write "abortion" or I can change to 22 weeks and it is a "birth"... You cannot "catch gynecologist's hand"… Sometimes you are mistaken in gestational age for plus or minus 2 weeks... The ultrasound examination etc... they are mistaken for 1-2 weeks and if he/she writes 22 weeks, no one can say "you wrote wrong". It is a difficult question.* (Ob/gyn, 3.4.3.6.16, IDI, Yerevan)

The participants from a FGD with neonatologists explained that not only the financial reimbursement from SHA varies considerably between late abortions and deliveries, but it varies also for deliveries taking place in hospitals providing different-level care, with those providing third-level care receiving much more amount, and those providing second-level care – more amount of money for each delivery than those hospitals providing first-level care. They reported that the difference in the amount of transferred money is about 10% higher for each level of care and thus, hospitals providing higher-level care are more motivated to serve higher number of deliveries. Also, maternity hospitals are striving to be recognized as hospitals providing higher-level care so that their services are better reimbursed. The group suggested that the possible risks related to variations in financial payments should be evaluated and the gaps in the system removed, as they provided means for people to change facts.

It is important to note that during a FGD with WC gynecologists, one of the group-members reported that another issue related to payments is the fact that maternity hospital staff encourage

women to have C-sections instead of vaginal delivery, when the former is not really indicated. They considered the primary reason for this was the much higher financial reimbursement received from SHA for C-sections compared to vaginal deliveries. Even though this was not related to the present topic, the research group included this finding here, as this is another major issue related to financial remunerations for services leading to negative behavior among providers.

> …[The amount of money transferred to the hospital under OCSC is] *118 thousand…/ 154 thousand… Bonuses are calculated according to the class of the maternity hospital; remuneration differs according to the class: I, II, or III… But there is no remuneration for abortions.* (Midwife, 3.4.3.6.17, FGD, Yerevan)
>
> *I could say only one thing... It seems that maternity hospitals encourage* [pregnant women] *to use the method of cesarean section, I believe that the allocated amounts* [for vaginal delivery and C-section] *should be equal in order to prevent this encouragement.* (WC ob/gyn, 3.4.3.6.18, FGD, Yerevan)
>
> *The allocation for the vaginal birth accounts for 117,000 drams and for the Cesarean section 210,000 drams, almost twice* [higher]... (WC ob/gyn, 3.4.3.6.19, FGD, Yerevan)
>
> *I know that the coverage of 96,000 drams is intended for regions* [for deliveries]. (Neonatologist, 3.4.3.6.20, FGD, Yerevan)
>
> *…when there are gaps* [in the system of financial reimbursement], *our society is flexible and will definitely use these gaps…We want to eradicate these practices.* (Neonatologist, 3.4.3.6.21, FGD, Yerevan)

Many participants stated that the different approach applied for financing deliveries and late abortions is not fair, as late abortions are being conducted only when medically indicated and are usually complicated cases that demand serious/lengthy efforts from providers, while a healthy delivery could be very easy process both physically and psychologically. On the other hand, some participants found the system to be correct, as they found deliveries to be more time-consuming and difficult.

Interestingly, several participants mentioned that mainly the hospital, not the provider benefits from the additional financing for deliveries. Providers receive very small bonuses if any, thus

they are not personally interested in misreporting abortions as deliveries, while their employers (the hospitals) are. Participants from one FGD with ob/gyns reacted very strongly to this same question about the differences in remuneration between abortions and deliveries, and adopted an aggressive behavior. They were unwilling to discuss this matter and stated that it is personal information, which is not related to the topic.

We only receive bonuses for deliveries, that is, over 22 weeks, while abortions carried out before that time demand no less effort. (Neonatologist, 3.4.3.6.22, FGD, Yerevan)

Of course, each pregnancy greater than 12 weeks is like a "bomb". She may have terrible bleeding and you may not be able to do anything...it is the same as other deliveries...what is the difference? Now they say that you have to "clean" [terminate pregnancy] *pregnancies greater than 12 weeks of gestational age for free. For less than 12 weeks everyone pays* [the country and parents]. (WC ob/gyn, 3.4.3.6.14, FGD, marz)

Yes, we come across more complications during that time [miscarriages] *because, after all, it is an artificial intervention. It is a harder situation for us, while childbirth is a natural one… Fewer complications are met during full term deliveries* [compared to late miscarriages]. *…our remuneration is not fair at all.* (Ob/gyn, 3.4.3.6.23, FGD, Yerevan)

No [it is not fair], *we perform medical services for which we are not compensated.* (Midwife, 3.4.3.6.24, FGD, marz)

The same work activities are performed [for pregnancy termination/delivery at 12-22 weeks and 22 and above] *but we are not compensated.* (Midwife, 3.4.3.6.25, FGD, marz)

No. It is not fair. So up to 12 weeks, I agree, but after that, until 22 weeks there is a big gap. Weeks 17, 18, and 20 are dangerous periods... They [abortions] are easy at 10 weeks, but at 18-20 weeks it becomes a huge problem. Sometimes we even have to perform early C-section, and there is no remuneration for that… Actually the amount of work is the same as it is for delivery. (Ob/gyn, 3.4.3.6.26, IDI, marz)

…There might be miscarriages, when in 20 weeks a birth defect is diagnosed, while it is the first pregnancy. Termination of such pregnancy may last 3-4 shifts… Sometimes it can be very difficult as the body of woman is not yet ready to deliver the baby. That is why I think, the payment mechanism is unfair, because those cases may require more efforts than the ordinary delivery. (Ob/gyn, 3.4.3.6.4, IDI, Yerevan)

Why maternity hospitals should not receive allocations for abortions? Abortions are very difficult cases… Especially when termination occurs at 20 weeks of gestational age… Any kind of complication may occur such as bleeding, etc., demanding a lot of expenses. I think if allocations for abortions and deliveries became equal, you would witness that perinatal deaths do not happen so frequently. I am saying this and I take the responsibility. (WC ob/gyn, 3.4.3.6.10, FGD, Yerevan)

Yes, this payment system is fair and the physician is paid accordingly. (Ob/gyn, 3.4.3.6.27, IDI, marz)

We cannot state that deliveries in 12-22 weeks of gestation are not financed. They are financed but lower… In any case it [the work related to abortion] *is not comparable to the delivery to be financed equally.* (Neonatologist/ ob/gyn, 3.4.3.6.28, FGD, marz)

Of course [there is a difference between the volume of work], *the work connected with the delivery is much more* [then that for late abortion]... (Midwife, 3.4.3.6.29, FGD, marz)

A certain amount of money is given for each medical form [case] from the agency [SHA]. *Medical personal does not receive any money; the organization is paid for that. So the money goes to the fund of the organization and we do not receive anything* [referring to 12-22 weeks]. (Midwife, 3.4.3.6.30, FGD, marz)

It does not mean that the physician wants that, but we also need to look at the issue from a more human standpoint: you will receive 5000 drams from abortions and 15000 drams from delivery. Yes, you will "bring" [to the hospital] *more than hundred thousand drams of benefit, but it does not mean that you will put that money in your pocket.* (WC ob/gyn, 3.4.3.6.15, FGD, marz)

Let's leave the question of providers' payment aside. It is not related to the topic of our discussion at all. I think in some respect, it is personal information… You invited as today to present the accepted procedures regarding the stillbirths' registration. It is not related with the physician's salary. If you have questions, you may approach the Ministry of Health and get to know how the payment is done. (Ob/gyn, 3.4.3.6.31, FGD, Yerevan)

I don't want to answer this question [about the difference in the financial reimbursement of providers]. (Ob/gyn, 3.4.3.6.32, FGD, Yerevan)

In terms of making suggestions for improving the current financial reimbursing mechanism, the opinions were very different. While some stated that the bonus payment must be provided in case

of terminating pregnancies at 13-22 weeks of gestational ages too, others thought that although 21, 22, 24 weeks of gestation might require similar procedures as delivery, there is no need to go into details and make changes here. One of the gynecologists said that even if the threshold for bonus payment is changed in the future, the medical staff will always find a way to misreport the gestational ages and receive more money.

As a possible mean to address the issue of reporting abortions at 13-22 weeks as deliveries because of the financial motivation, participants from a FGD with ob/gyns suggested conducting assessments in this area and increasing physician's salary in case of abortions to counter this effect. Another suggestion made was to remove late abortions from being a state-paid service and include them under paid-for services.

My suggestion is that doctors be remunerated [via bonus system] *for* [pregnancy terminations at] *12-22 week periods as well.* (Ob/gyn, 3.4.3.6.26, IDI, marz)

Obviously, the pregnancies on 21, 22, 24 weeks of gestation might require similar procedures but the differentiation of definitions for organizing the payment will go in too much details. (Ob/gyn, 3.4.3.6.32, IDI, Yerevan)

We will argue on disadvantages of any introduced mechanism... If we set a payment [bonus for providers] *for the abortion at 16-22 weeks of gestation, tomorrow we will try to shift it to 14 weeks telling that it is fair... Implementation of whatever has been accepted should be strictly controlled, thus preventing making benefits from these situations... Maybe it is possible to introduce the degree of difficulty for payment for the delivery and similarly the abortions, for instance to count the hours spent in the hospital before delivery. …Anyhow, physicians will find another mechanism to bypass... they will deceive the hour of admission.* (Ob/gyn, 3.4.3.6.4, IDI, Yerevan)

Proportional financing of abortion and delivery may solve the problem of [correct] *registration.* (Neonatologist, 3.4.3.6.33, FGD, Yerevan)

I think every service - both abortion and delivery - should have a fee, which should be directed towards doctors' salaries…otherwise people should sort out their own problems… free services have only derogated the reputation of doctors. We are not protected in any way… (Ob/gyn, 3.4.3.6.9, FGD, Yerevan)

As the state is not rich, there could be paid-for services… (Ob/gyn, 3.4.3.6.23, FGD, Yerevan)

3.4.3.7 Recognition of the need for accurate reporting of stillbirths and neonatal deaths

Some participants from FGDs with neonatologists and ob/gyns recognized that there is widespread misreporting of data on stillbirths and neonatal deaths in the country, which is evident from simple comparison of the rates of stillbirths and neonatal mortality in Armenia with the rates in other similar countries. They stated that because of the tendency to artificially decrease neonatal mortality rates, Armenia is considered belonging to a group of countries with better health indicators than it truly belongs to. Ultimatively, this affects the country negatively, as potential donors that could otherwise help to improve the existing health services in Armenia are not considering it necessary given the "favorable" rates we present. The participants considered the lack of political will to improve the situation and the fear of employees to be fired if reporting the cases accurately as the main reasons for the existing situation. They warned the research team that misreporting is becoming a norm for health care professionals and that they start feeling comfortable with this situation and even to gain benefits from it. According to the participants, this means that if the efforts to fix the situation start now, at least two generations are required to achieve the understanding of the value of correct reporting and having accurate statistics. These efforts should include educating professionals and applying innovative solutions to address the issue of hiding true facts. Even though a single participant dominated during the entire interview with the information provided, the entire group unanimously agreed with the statements provided and solutions suggested.

Misreporting is the worst thing as in most cases it damages the country itself. …Our country belongs to another group of classification with respect to real neonatal mortality rates than it currently holds. ...My own analysis showed to me that the rates in the country are two times lower than they must be in reality. It is necessary to continue to emphasize that there is a problem with neonatal deaths and we need solutions…when we demonstrate that the situation is beyond the control, suitable potential donors may shift their activities to other countries that are behind catching up. I consider this as a bad point, because Armenia is not a country with rich resources and potential to afford the loss of these investments… (Neonatologist, 3.4.3.7.1, FGD, Yerevan)

This is a matter of political will and not only healthcare-related concern…when the political will does not exist, you will not succeed in your attempts to improve the situation as it may

result in clashes between performers and related spectators. (Neonatologist, 3.4.3.7.2, FGD, Yerevan)

Analysis of the existing situation suggests that staff members have threats of losing their jobs that serves as a basis for them to provide artificially better estimates and ensure the required performance. But when you have a friendly conversation with your colleagues, they confess that the situation is not so favorable. Moreover, in some cases it is too threatening, they are afraid to speak out due to the perception that they will be fired. This is the reason why health care professionals are reluctant to provide the real statistics to the public. (Neonatologist, 3.4.3.7.1, FGD, Yerevan)

It would be right to start from small number of hospitals, as you could not handle all of them at the same time… It may happen that one, two, or three hospitals improve the reporting, but you could not induce others to follow the same way because it is difficult to do. (Neonatologist, 3.4.3.7.3, FGD, Yerevan)

…It is too dangerous that it [misreporting] *is becoming a norm for health care professionals and they start feeling comfortable with the situation… and even gain benefits. So, if you want to improve something in this situation, I have to disappoint you…you just have to continue your efforts as long as required for developing an understanding of negative effects because of staff members' misreporting… Everything starts from the accurate assessment of the situation; the treatment could not be effective when the diagnosis is inaccurate.* (Neonatologist, 3.4.3.7.1, FGD, Yerevan)

I believe that there is no single optimal solution and it is impossible to make [quick] *improvements, because change requires better educated professionals with new ideas and solutions… By the way, it requires also at least two generations in order to develop an understanding that lying, deception and betrayal of trust are unacceptable and to provide real statistical records…If you try to intervene for improving the situation, you would not succeed; you would just induce physicians to find new information-hiding techniques, they would hire new skilled staff.* (Neonatologist, 3.4.3.7.1, FGD, Yerevan)

We would like to receive information as to what conclusion you arrived at [from the current study]… (Midwife, 3.4.3.7.4, FGD, Yerevan)

3.4.4 Procedures of registration and reporting of livebirths, stillbirths, and neonatal deaths

3.4.4.1 Ease of registration procedure

In general, all the IDI hospital staff and FGD participants stated that the formal registration process of livebirths, stillbirths and neonatal deaths is very easy and in this sphere there is no need to introduce any changes or improvements. They noted that they have got used to the current procedure and any new change in that may introduce some confusion. Indeed, some participant stressed that the registration procedure will soon become electronic, which will significantly decrease the workload with paperwork, make the process rapid and reduce the probability of doing mistakes. A CSARB representative also underscored the convenience of shifting to the electronic system of birth registration.

It is worthwhile to mention that in all FGDs only a few participants (and in some cases just one) were actively speaking when the topic of registration was discussed. And in some cases it was clarified by the group members that the active respondents were those in charge of registration procedures at their respective facilities, while those keeping silence were not involved in it and generally unaware of the procedure.

It [the registration procedure] *is very easy…* [There is] *No need for improvement. There are laws and protocols stating when we must register…* (Midwife, 3.4.4.1.1, IDI, Yerevan)

It [the registration procedure] *is normal and very easy. There is no any problem with the registration process. There is no need for improvement, because everything is on adequate level and there is no need to add or remove anything.* (Midwife, 3.4.4.1.2, IDI, Yerevan)

It's not necessary to change anything [in the birth registration procedure] *or to create a new bike. We are used to using the existing procedure. When a change occurs, new issues arise. There is no problem… The procedure is performed within one hour if everything is correct. If parents present all the required documents to the CSARB...* (Neonatologist/ob/gyn, 3.4.4.1.3, FGD, Yerevan)

I have heard that the registration is going to become electronic. Each doctor will have his/ her own name in the system, and we will not complete the document by hand. The physician will just complete the newborn data electronically to which CSARB would have access to, so we will be escaped from excessive documentation. … After the adoption of the electronic system, parents will be given a registration number from the maternity hospital, which they can

present to the CSARBs, where the staff will access and see the data of their child. (Midwife, 3.4.4.1.4, FGD, Yerevan)

By using the electronic system, the registration of births became incomparably easy. Earlier, when the father or the mother, the applicant came, the registration of birth could take a long time: 10-15 minutes, causing waiting lines, complains… Now, in our CSARB …if I receive the documents, the registration can take 2.5-3 minutes. Besides that, with the usage of electronic system the probability of doing mistakes decreased and the problem of handwriting solved. This is a big achievement. **(**CSARB, 3.4.4.1.5, IDI, Yerevan)

The participants unanimously stated that there are no differences in the registration process of babies born with less than 1000 grams weight compared to babies weighting more than 1000 grams. A few participants from various groups stated that such difference existed in the past, when only those babies weighting less than 1000 grams who survived for seven days were registered as livebirths in CSAR bodies. One group of midwifes reported that even though the same documents (medical certification of birth) are prepared for extremely premature and underweight newborns, they hold back with giving it to parents (to proceed with registration of the birth at the CSAR body). Instead, they wait for 6 days to see whether or not the baby will survive, because in case of child's death or transfer to another hospital this certification form is processed by the hospital (not parents).

During a FGD with neonatologists and ob/gyns, this topic turned into a lengthy discussion among the group members, as some of them had uncertainties concerning the length of life for a newborn to be registered as livebirth. While some thought that the registration of a livebirth child should be conducted regardless of the duration of the child's life, others were unsure whether this is/should be the case.

Interestingly, many participants were unsure about the definitions of perinatal, early and late neonatal mortalities. In fact, only a few participants clearly provided the definitions for each of these terms; in most cases these were heads of the maternity units during IDIs and neonatologists during FGDs. Among the IDI participants, there were specialists, such as midwifes, who tried to guess and answer this question, but felt that it is challenging for them (although they were responsible for registration of perinatal and neonatal mortality cases in their institutions).

The procedures are the same. …The live birth, even the child with lower than 1000g weight should be registered in the same way. (Ob/gyn, 3.4.4.1.6, IDI, marz)

It [being born under 1000 grams] *does not matter. The procedures are the same for everybody and in any case.* (Midwife, 3.4.4.1.2, IDI, Yerevan)

What does it matter if the baby is 1000 or 2000 grams? If we have recorded a live birth, then the registration process is the same. (Neonatologist, 3.4.4.1.7, FGD, Yerevan)

I know that before 2008, only infants who were born at least 28 weeks of gestational age and stayed alive during the perinatal periods were registered. (Neonatologist, 3.4.4.1.8, FGD, Yerevan)

[Previously] *only a child that lived 7 days with less than 1 kg body weight was considered a live birth.* (Ob/gyn, 3.4.4.1.9, FGD, Yerevan)

[The documentation is] *the same for babies with less than 1000 grams birth weight. Let me say, we complete, but do not provide to the relatives of newborns because infants with less than 1000 grams birth weight may not survive within six days. After six days we provide* [the medical certification of birth] *to the parents... Because such infants may not survive or be moved to Yerevan... when moved to Yerevan, the medical certification of birth is required... in case of infant death it* [the medical certification of birth and the death notification form] *is also required to present to CARBs based on which they record both childbirth and child death.* (Midwife, 3.4.4.1.10, FGD, marz)

Now a child that lived even 2 hours is also registered [as livebirth]. (Neonatologist/ob/gyn, 3.4.4.1.11, FGD, marz)

Yes, the medical card is opened but is that registered in the CSARB? [And, after receiving a confirmatory reply from other participants] *It is very wrong.* (Neonatologist/ob/gyn, 3.4.4.1.12, FGD, marz)

Some time ago we registered [as livebirth] *a newborn that lived 5 minutes.* (Neonatologist/ob/gyn, 3.4.4.1.13, FGD, marz)

Does not matter if it lived 5 minutes or 1 minute, if the newborn has shown one of livebirth signs, it is necessarily registered. (Neonatologist/ob/gyn, 3.4.4.1.14, FGD, marz)

When the fetus dies after the 22 weeks of intrauterine life, it is called perinatal mortality. It is registered as perinatal mortality. However, when the child is born and continues to live 5-10 minutes etc it counts as neonatal mortality. (Midwife, 3.4.4.1.2, IDI, Yerevan)

After the birth...Probably during the first hours it will be "neonatal mortality". The late one will be if the newborn lives longer...I cannot say any specific time… (Midwife, 3.4.4.1.1, IDI, Yerevan)

Within 6 days after birth it is considered perinatal death, within 28 days as early [neonatal death], *right?* (Midwife, 3.4.4.1.10, FGD, marz)

3.4.4.2 Registration and reporting procedures in maternity hospitals

Registration of livebirths: The medical certification of birth – based on which a birth certificate is prepared – is the main document provided by maternity hospitals to the CSARB. This document is prepared by the ob/gyn or senior nurse, signed by the head of the hospital and provided to the parents of the newborn, who are then responsible for taking it to the CSARB and returning with a birth certificate. A few participants mentioned that the medical certification of birth is completed in two copies, one of which is kept at the maternity hospital. Once the parents present the birth certificate to the maternity hospital, they receive a Child Health State Certificate (CHSC) and then the mother and newborn may be discharged. Some participants mentioned that they write the number of child's birth certificate in their journals and even require a copy of birth certificate to be kept in medical documentation before discharging the mother and child. A few participants noted that, given all of these, only in exceptional cases CSARB could be unaware of the child that was born in a maternity hospital and discharged. In the case if for some reason, such as lack of the needed documents, the mother cannot receive child's birth certificate on time, she is discharged after writing a commitment letter that the birth certificate will be presented to the hospital as soon as it is received. According to the participants, they usually bring the certificate later-on, as they need to receive the Child Health State Certificate from the maternity hospital. One thing was clarified that the CHSC, which ensures state order healthcare for children up to 7 years of age, is not provided without the birth certificate, unless due to certain issues the child needs to be moved to another facility. In that case the CHSC will be completed without child's name and surname and provided to parents.

We also provide a medical certification of birth, which is signed and stamped by the head doctor and provided to the parent: this document is used to register the child at the CSARB and receive a birth certificate. Without the birth certificated they are not discharged from the hospital. …Moreover, before discharging, we provide each mother with a free medical care certificate [CHSC] *for the baby.* (Neonatologist, 3.4.4.2.1, IDI, Yerevan)

Immediately next day after the delivery mother receives the birth reference [medical certification of birth] *which is later taken to the CSARB to take the birth certificate. …Later the child birth certificate is shown to us based on which the child development passport* [and the CHSC] *is provided by the neonatologist.* (Ob/gyn, 3.4.4.2.2, IDI, marz)

[Hospitals contribute to the registration of newborns at the CSARBs through] *Provision of a signed and stamped notification slip* [medical certification of birth]. *The attending doctor writes up the notification and the head of the facility sings and stamps it…The birth notification slip is written based on the* [mother's] *passport. Then they return with the* [child's] *birth certificate from the CSARB, based on which they are discharged.* (Midwife, 3.4.4.2.3, FGD, Yerevan)

…We provide the mother of the newborn a notice [medical certification of birth]. *This is taken to the CSARB by the father within 3 days, before the mother is discharged from the maternity hospital, and they are provided with a birth certificate.* (Midwife, 3.4.4.2.4, IDI, Yerevan)

The documents are filled in order to receive birth certificate. The referral [medical certification of birth] *is written by the senior nurse, based on the identification document and marriage certificate... The referral is given to parents, so that they could register their child either in regional CSARB, central CSARB on in local CSARB.* (Midwife, 3.4.4.2.5, IDI, Yerevan)

When the CSARB bodies return the birth certificate, we record that and write up the child health state certificate for 0-7 year-old children. (Neonatologist/ob/gyn, 3.4.4.2.6, FGD, marz)

The birth certificate number is always noted on the newborn's medical form; nowadays we also request a copy of the document, which we attach to the newborn's medical form. (Midwife, 3.4.4.2.7, FGD, Yerevan)

The department's head nurse is required to fill in the medical certification of birth, based on which patients can receive the birth certificate from the CSARB. …We force the pregnant women to bring the copy of the birth certificate. The procedures are easier done if the couples are registered in CSARB, discharge is much easier organized and even without birth certificate such patients are discharged. …Now as the child health state certificates are

provided by the maternity centers for which the birth certificate is needed, even if the mother leaves the hospital with child we know that tomorrow or later she will anyway bring the birth certificate to receive the other one [child health state certificate]. *I think the case should be exceptional for the CSARB to be unaware of the child that was born and discharged.* (Ob/gyn, 3.4.4.2.8, IDI, Yerevan)

There are two copies of the birth notification form [medical certification of birth]*; one stays in the hospital.* (Ob/gyn, 3.4.4.2.9, FGD, Yerevan)

Allow me to explain it to you... If the birth certificate is not presented (these are cases such as: not having a passport or proof of identity, not having a place of residence and so on), taking into account the reasons, we give them time depending on how many days they need to resolve those issues. They [the women] *are discharged from the maternity hospital with a commitment letter. So apart from these cases when there is a certain issue causing difficulty, they always bring it, because the child is provided with a child health state certificate. So the fact that healthcare is free for their child from the ages of 0-7 compels them….We explain it them and people bring it.* (Midwife, 3.4.4.2.10, FGD, Yerevan)

The information of the birth certificate is recorded on the free-of-charge child health state certificate, so this [provision of child health state certificate when the birth certificate is absent] *cannot be done. There have been cases where the infant was low weight, and was transferred, so they only partially completed the* [child health state] *certificate, with no name or surname – since there is no birth certificate. Of course that happens in very rare cases.* (Midwife, 3.4.4.2.3, FGD, Yerevan)

Registration of stillbirths: As some of the participants from different groups stated, the registration documents processed in the case of the birth of a dead newborn include: newborn card; autopsy referral form, stillbirth register; and perinatal death certification form consisting of two parts, which is delivered to the CSARB by the hospital, and then the second part of it is returned to the hospital. The newborn card and autopsy referral form are usually completed by the ob/gyn who accouched the delivery. As to the stillbirth register (journal) and the perinatal death certification form, there was some uncertainty among FGD participants as to who is responsible for filling in these documents. It differed in different places and, usually, either the head nurse was responsible for this task or the ob/gyn completed all the documents and then there was somebody at the hospital responsible for taking the completed forms to the CSARB. The midwifes from a marz FGD reported that in cases when delivery takes place at home in a village, the woman is usually transferred to maternity hospital, which undertakes the

responsibility for completing the needed documentation, thus, the village nurse is not involved in this. A policy maker noted that the forms are often completed inaccurately, and explained it with the lack of specific instructions on how to complete each form.

When we have even one stillbirth at night, I know that the documentation to be filled in is tremendous: …the same newborn card …an autopsy referral form - with the suspected cause of death ...a special big book for the CSARB, where we record the name, surname, etc. (Ob/gyn, 3.4.4.2.8, IDI, Yerevan)

If it is a stillbirth then the newborn card is filled in, where we [the ob/gyn] *write the diagnosis, the course of the pregnancy, record 0 points per Abgar scale and also mention that there were no signs of livebirth. Then we fill in the autopsy referral for the pathology department. In this form we include the name and surname, the symptoms, uterus pathology and mother's pathology. This paper must be filled during a 2-hour period post-delivery. The ambulance comes and takes the fetus to the pathology department. Later we open the perinatal death certification form which consists of 2 parts, which is sent to the CSARB; later one of this* [second] *part is returned. The healthcare facility is responsible for sending the documents to the CSARB.* (Ob/gyn, 3.4.4.2.11, IDI, Yerevan)

The ob/gyn completes the [perinatal death certification] form for stillbirths… based on this form stillbirths are written in the registry… The same procedure is valid for infants that die during the neonatal period. Again, we fill in death certification form, and based on this form they are also recorded in other types of registries. Both stillbirths and live births are registered at the CSARBs… (Neonatologist, 3.4.4.2.12, FGD, Yerevan)

It [stillbirth] *is immediately recorded, immediately….and also at the CSARB, just as live births are.* (Ob/gyn, 3.4.4.2.13, IDI, marz)

An autopsy referral is written, a death certification form is presented to CSARBs, and then to the Funeral Service Board: for example, our hospital has a staff specialist who presents these documents to the CSARB. (Midwife, 3.4.4.2.14, FGD, Yerevan)

The registration is not necessarily on me, although I have always performed it. But all physicians know that we cannot send them [perinatal death certification forms] *after 7 days... I gather all the necessary documents and provide them to the physician who completes the forms and then I send them to the CSARB.* (Midwife, 3.4.4.2.15, FGD, Yerevan)

Both the ob/gyn and the head nurse can report the birth of the stillborn infant. Different institutions place this duty on one or other of them. (Ob/gyn, 3.4.4.2.16, FGD, Yerevan)

If the delivery happened at home, the women are transferred to maternity hospital and the registration is done at maternity hospital. The nurse of the village is not allowed to give these documents. (Midwife, 3.4.4.2.17, FGD, marz)

… Every document must have specific instructions for completion, so that people know what they need to write on every given sentence. The procedures we have were passed on from the old Soviet era, and even though there have been some amendments, etc. we currently do not have a procedure confirmed by the ministry. So everybody fills in the documents the way that they know how. (Policy maker, 3.4.4.2.18, IDI, Yerevan)

Registration of neonatal deaths: Participants from different groups stated that maternity hospitals carry the responsibility of registering neonatal deaths if occurred in the maternity, therefore these are mainly early neonatal deaths, while registering late neonatal deaths is the responsibility of the healthcare facility where the newborn was transferred. Maternity hospitals only report the number of neonates who were transferred to other healthcare facilities. The participants also mentioned that if the newborn died at home, the primary healthcare facility takes the responsibility for registering that case. Several participants mentioned that they report neonatal deaths without separating those into early or late deaths. None of the participants mentioned that the medical certification form that is issued by the hospital to be presented to the CSAR body is different for perinatal death cases (intended for registration of stillbirths and early neonatal deaths and called "Medical Certification about Perinatal Death") and late neonatal death cases (called "Medical Certification about Death"). Indeed, many of them stated that the documents are the same for deaths occurring during the whole neonatal period (which is incorrect and probably is due to the lack of practice with late neonatal death cases in the maternity hospitals, as these children are usually transferred to pediatric departments at earlier ages). Some participants were not aware about the exact deadline for registration of neonatal death cases as well.

During a FGD with neonatologists, when discussing the issue with registration of neonatal death cases, one member reported that each facility should have somebody who is aware of the laws and procedures to handle the paperwork. Another member stated that the law requires that this person be a lawyer, while others did not agree with this, but stressed the necessity for that person to know the law. They went on to report that they do not want to complete these forms, because of both lack of the necessary knowledge and the psychological stress it causes to them. They also

suggested that the address of parents in the "Medical Certification about (Perinatal) Death" form are not written by physicians, but completed in CSARB to avoid possible mistakes.

They [babies that die in the late neonatal period] *would be already discharged from the hospital and they would be at their homes, so we are not responsible for that.* (Midwife, 3.4.4.2.19, FGD, Yerevan)

The responsibility of reporting deaths lies with the facility where the child has died. If it has happened at our maternity hospital then we are responsible for it, however if they are transferred to the ICU of another hospital then they have to take care of this. (Neonatologist, 3.4.4.2.20, FGD, Yerevan)

If there are seriously ill infants who stay for a long time in the maternity hospital – let's say, a month – in the case of their death, we enter it in our report… If the infant has been transferred to another institution and it dies there, then that does not go into our report; we only mention that this number of children have been transferred to other institutions. (Ob/gyn, 3.4.4.2.21, FGD, Yerevan)

Late neonatal death is recorded at the place where the baby has died, so the responsibility of reporting falls with that facility. In cases when the death occurs at home, the local primary healthcare facility is responsible for the reporting. (Policy maker, 3.4.4.2.22, IDI, Yerevan)

The documents are the same for those dying on the 1st minute or after 7 days. (Neonatologist/ob/gyn, 3.4.4.2.23, FGD, marz)

Perinatal and neonatal deaths are recorded separately from each other. The head of the delivery department deals with the former and the head of neonatal department together, of course, with the attending doctor – with the latter. (Neonatologist, 3.4.4.2.24, FGD, Yerevan)

We have a statistician who summarizes all the data at year end, and reports it. That is his/her job. (Midwife, 3.4.4.2.25, FGD, Yerevan)

…Each hospital should have one person responsible for this [reporting neonatal deaths], *and is aware of laws for correct registration… That person should not necessarily be a lawyer but should have complete understanding of the process. Our hospital has such a worker who is not a lawyer, but is competent.* (Neonatologist, 3.4.4.2.12, FGD, Yerevan)

According to law, that person [responsible for completion of forms] *must be a lawyer.* (Neonatologist, 3.4.4.2.26, FGD, Yerevan)

They [physicians] *are unwilling to complete* [the forms for neonatal death reporting], *because I suppose they are not aware enough.* (Neonatologist, 3.4.4.2.27, FGD, Yerevan)

We experience psychological side effects; nobody wants to complete these forms… It's challenging for me to complete the forms because you are dealing with death cases considering also the fact that you must not do any mistake. (Neonatologist, 3.4.4.2.28, FGD, Yerevan)

…All documents [for notification about neonatal death] *are completed and sent to the CSARB, but next day they bring them back and physicians are obliged to complete again. For example, the address that they indicate may not match to the real address that is shown in the computer program. …I have a suggestion related to the address completion* [in this forms], *which should not be performed by physicians.* (Neonatologist/ob/gyn, 3.4.4.2.29, FGD, marz)

In-hospital statistics for livebirths, stillbirths and neonatal deaths: As for the way of keeping data on livebirths, stillbirths, and neonatal deaths within hospitals for their own statistics, different people are responsible for this task. It was reported that mainly the head nurse bears the responsibility for it, although there is no unified protocol on who should do it and thus it differs across facilities. The way of keeping the data also differs in some extent. Usually, the hospitals have separate journals/registries for livebirths, stillbirths, and neonatal deaths, based on which they calculate the respective numbers. Some participants noted that just calculating the numbers of births and deaths and reporting those to higher instances cannot be called as having own statistics. Meanwhile, some others complained of having too much paperwork to do and suggested to decrease it through computerized recording. There were differences in the practice of keeping information of those newborns transferred from the maternity hospital to other settings. Participants also mentioned that the hospitals do not keep separate statistics for early and late neonatal mortality cases.

It [the information on births] *is written at the delivery room's journal: the number of C-sections, birth, stillbirth, preterm birth, birth defects, etc... For everything there is a report… birth defects, preterm birth, twin fetus... Nowadays, the writing work and reporting is too much...* (Midwife, 3.4.4.2.5, IDI, Yerevan)

After a month, the medical forms of mother and child are inserted into each other, the infant's history is inserted into the pregnancy history and they are sent to the archives. (Midwife, 3.4.4.2.30, FGD, Yerevan)

So how it [keeping data for own statistics] *is done in our organization:...the cesarean sections are* [kept] *separate from others arranged by months, the usual delivery is kept separately, the cases of reanimation department, I mean newborn reanimation, the disease histories of that newborns are arranged separately, the stillbirths in a separate folder, I register them separately, the neonatal death cases are kept separately... So everything is sorted and arranged, so that if anything is needed anytime I can give appropriate information.* (Midwife, 3.4.4.2.31, FGD, marz)

It [stillbirth] *is considered a delivery and registered with its sequential number in our birth registration certification form register.* (Midwife, 3.4.4.2.30, FGD, Yerevan)

I know that there are two hospitals that implement this procedure [keeping detailed internal statistical data]. *Furthermore, they keep it in electronic forms, which allows looking at any relevant information even after five years…The statistics that are assumed to be kept in other countries, Armenia does not have good statistics…I just want to say that we perfectly know the number of newborns in each hospital that we could compare, but let us not call this statistics.* (Neonatologist, 3.4.4.2.27, FGD, Yerevan)

What are the computers for? Otherwise, write, find, write, find… It is not considered even as work. (Neonatologist/ob/gyn, 3.4.4.2.32, FGD, marz)

It [late neonatal death] *is reported in the hospital where it was transferred. It is not reported in our hospital's annual report, because it* [the newborn] *did not die here. If it* [the death] *happened at home, it is difficult to say… I think it is forensic medicine's problem…* (Neonatologist, 3.4.4.2.33, IDI, Yerevan)

If babies are moved to another hospital then a transfer register [journal for transfers] *is also used…* (Ob/gyn, 3.4.4.2.34, FGD, Yerevan)

We don't have a register for transferred babies, we register them in our own way. (Neonatologist/ob/gyn, 3.4.4.2.35, FGD, marz)

No, [if the baby died after being transferred, then it is not registered at their facility] *it is registered as being transferred. There is a special registration journal, where the transferred cases are registered separately.* (Midwife, 3.4.4.2.31, FGD, marz)

The participants mentioned that they report the number of births to the MOH periodically. The providers from IDIs and FGDs stated that the report, which their maternity hospitals provide to

the MOH, contains the numbers of live births and stillbirths, separately for each sex. They mentioned providing it to the MOH and their respective regional administrative center yearly, monthly, weekly, and even - daily. The participants from women's consultation also stated periodically reporting to the higher instances the numbers of pregnant women served by their facilities. Participants also noted that the hospitals do not report early and late neonatal mortality cases separately to higher instances.

I already know that each morning at 9 am we report to the Ministry of Health. If you have been on duty, in the morning the head of the department comes and takes the registers and reports the number of births, live or dead fetuses and the number of girls and boys to the respective department at the MOH. (Ob/gyn, 3.4.4.2.36, IDI, Yerevan)

We report the weight either if it is less than 2500 gm, or if it is over four kilos. In the past, this was my daily job as a head midwife. The first thing I'd do after coming to work in the morning would be to call the municipality and communicate the number of boys and girls. This was done in the morning, for the previous day - the period between 0 to 24 hours. Then we inform the ministry about how many [births] *are from the regions, how many C-sections were performed, whether it was with the use of general or spinal anesthesia, the use of painkillers for deliveries, low weight* [births]*, twins, stillbirths, neonatal deaths and if a woman has had a fifth infant (or more). We report all of this on a daily basis. Then we provide weekly report, and monthly report.* (Midwife, 3.4.4.2.37, FGD, Yerevan)

We also provide an annual report to the ministry… [we report] *only to the ministry, how many deliveries occur, how many of them have complications, how many cases are with birth defects, the number of stillbirths* (Neonatologist/ob/gyn, 3.4.4.2.29, FGD, marz)

Each month [the following data is reported to the respective Regional Administrative Center]. *The number of women provided with consulting services, how many of women were pregnant, how many of pregnant women were at 12 weeks of gestation, how many of them were outside* [not provided with services]*, how many pathological cases occurred during the pregnancy, how many of them were hospitalized, how many abortions occurred, how many preterm births occurred.* (WC ob/gyn, 3.4.4.2.38, FGD, Yerevan)

We provide [the reports] to the other department and they send... we do not provide directly... (WC ob/gyn, 3.4.4.2.34, FGD, marz)

We report every day...we even have an order from the MOH. When the child is born and we have a stillbirth, in the morning we report about that to the head of the facility and there is a worker, who reports to the MOH the number of stillbirths for that day. …Every day in the

morning we report not only [about] *stillbirths but all birth cases too: we report the number of births, stillbirths, C-sections, spinal anesthesia, the numbers by marzes, by gender etc. …We give this information* [number of girls and boys] *to ''Armnews'' too. We also give information to the Municipality every Friday. That's it.* (Midwife, 3.4.4.2.4, IDI, Yerevan)

Each month all maternity hospitals under the MOH jurisdiction report the data. MOH can ask the names (names/surnames) and we will report the requested information to them. (Ob/gyn, 3.4.4.2.39, FGD, Yerevan)

Late neonatal death is not reported [to higher instances] *separately and the data is provided together with the rest of the cases.* (Policy maker, 3.4.4.2.40, IDI, marz)

The number of neonatal deaths is included in the reports, the number of stillbirths is included. Everything is included... and the weights are mentioned. But whether it is a late neonatal death or early, it is not mentioned. (Midwife, 3.4.4.2.31, FGD, marz)

3.4.4.3 Registration and reporting procedures in CSAR bodies

The interviewed CSARB representatives mentioned that the main legislative acts regulating birth and death registration in the country are the Family Code, the Civil Code, as well as orders and directives of the minister of justice. These legislative acts are the same for both live births and stillbirths. Nevertheless, one participant pointed out that in case of stillbirths the Law on Civil Status Acts is the primary one. According to a CSARB representative, the current legislation on civil status acts registration was introduced since 2005. It allows registering the birth and death of a newborn either in the CSARB where his/her father or mother is registered or in the territorial CSARB of the hospital where the child was born. This was also stated during FGDs.

We have family code, civil code…. Mainly we use the family code, civil code, some other regulations, orders of minister and directives. They are the same for both live births and stillbirths. (CSARB, 3.4.4.3.1, IDI, Yerevan)

First of all, it is the law on Civil Status Acts of the Republic of Armenia and we also have directives that are approved by the Minister of Justice on May 14, 2007. For stillbirth they are the same, but the Law on Civil Status Acts is in the first place. (CSARB, 3.4.4.3.2, IDI, marz)

In 2005 the new family code and CSARB law were adopted. With this code and law, the registration process of civil status acts in general was considerably improved. It [the change]

was quite targeted and greatly simplified the procedures with citizens. (CSARB, 3.4.4.3.3, IDI, Yerevan)

Livebirth registration: The required documentation for registering the birth in CSARB is slightly different depending on the place of birth. If the birth took place in the maternity hospital, a parent needs to present the medical certification of birth provided by the maternity hospital, parents' passports, as well as their marriage certificate if parents are legally married. However, if parents are not legally married, they should apply for fatherhood recognition. Several participants from FGDs and one from the IDIs stated that there are numerous cases, when parents are not married and the reason is the financial allowance that single mothers receive from the government. It is noteworthy that this is an issue specific to the marzes and none of the Yerevan participants reported it. In case if the birth took place at home, besides the parents' passports and their marriage certificate, a certificate on the infant's health provided by a healthcare facility/doctor and the statements of witnesses, who were present during the birth are also required for the birth registration.

The process of birth registration is as follows: …when the child is born, the father or mother visits the CSARB, where he/she is registered or the child can be registered in the CSARB of the region, where it was born: where the maternity is placed. The parents can be from marzes, and the child can be born in Yerevan, so for birth registration the parents can apply to the territorial CSARB near to the maternity. The process is not as difficult: they must present the medical certification of birth from the hospital and their passports, as well as the marriage certificate in the case if the parents are married. The person, who applies, in this case mother or father, brings with him/her the medical certification of birth. We never register birth without the medical certification of birth. (CSARB, 3.4.4.3.1, IDI, Yerevan)

It doesn't matter where they [parents] are from. Even if they are from the regions, they are still provided with a birth certificate at the city registry. A woman who delivers a child at a given maternity hospital is provided with a birth certificate at the local registry office. (Midwife, 3.4.4.3.4, FGD, Yerevan)

There are cases where they [parents] want to use the registry office at their marz. We explain that it's not a problem in reality, just a matter of wasting their time. For example, our local registry office is very close to the maternity hospital so it is easier to get to…. Perhaps it was strict at one time, and they could only take the document from their local registry office, but it is not like that now; they can take it from the Yerevan registry office. (Midwife, 3.4.4.3.5, FGD, Yerevan)

If parents are in legal marriage, then passports of the parents [are needed], *their marriage certificate and the most important is the medical certification of birth, which is given by maternity hospital. If they are not in legal marriage, then they present the same documents and also they need to apply for recognition of fatherhood. Besides the medical certification of birth* [and their passports] *they should also present the application for the recognition of fatherhood.* (CSARB, 3.4.4.3.2, IDI, marz)

The financial allowance (subsidies) is the main reason, why they [parents] *do not register their marriage. There are many cases, when parents do not register their marriage and after the child's birth they recognize the fatherhood. If they have a registered marriage, then anyone [any family member] comes and presents the passports of the parents and the medical certification of child's birth. And if they do not have a registered marriage, then the parents... the father comes and we give him the application form* [for fatherhood recognition***].*** (CSARB, 3.4.4.3.2, IDI, marz)

If the delivery happened at home, then a doctor should be present, so it should be done based on the certificate given by the doctor …or if the doctor was not present, then in the presence of the witnesses... the witnesses should come and bear their witness. So the procedure is a little bit different. It [the registration] *is possible by the* [witnesses'] *statements and a health certificate of the child a certain organization gives to certify that the child is healthy.* (CSARB, 3.4.4.3.2, IDI, marz)

A difference in documentation exists [when the birth occurs at home], *because in this case we need to have 2-3 witnesses* [of birth]. *Additional documents include the witnesses' statements, indicating that they were present at the birth. They fill in a specific form about their presence at the birth of the boy or girl* [the gender of the child]. *They confirm the fact of the child's birth. ...So this is already enough: the statements of the witnesses and the birth notification form about the child's birth.* (CSARB, 3.4.4.3.1, IDI, Yerevan)

In case if the child is of a single mother, the mother gives authorization to a person, so she signs the application, the chief of the maternity hospital confirms, the authorized person comes. The birth is registered... in the name of the mother as a single mother's child... (CSARB, 3.4.4.3.2, IDI, marz)

Stillbirth registration: According to CSARB members, in case of stillbirth only the birth is registered in the CSARB and the responsibility for notifying the CSARB about the stillbirth is placed on the healthcare facility where the birth took place. FGD participants explained that the designated person from each facility collects the needed documents for registration of stillbirths and takes them to the CSARB, since in the case of stillbirth the parents are not responsible for

registering the birth. In cases where the delivery happened at home, the person who is responsible for that stillbirth registration is the physician who was present during delivery. The deadline for registering stillbirth cases is 7 days after the birth. During IDIs two of the CSARB participants mentioned that the deadline for registration has been changed. According to several FGD participants this deadline has increased from 3 days to 7. This was seen as a positive change, as it allowed more time for them to process necessary documentation.

There is a specific form for the stillborn… we have two [types of forms]*: a birth certification form for the birth certificate and a special form* [perinatal death certification form] *for stillbirth.* (Midwife, 3.4.4.3.6, FGD, Yerevan)

[In the case of stillbirth] *The birth certification form that should have been written is not filled in, instead we write a death certification form for the CSARB.* (Neonatologist/ob/gyn, 3.4.4.3.7, FGD, marz)

In case of stillbirth only the birth registration is done. The registration of death is not done. No document is provided [to parents]. *If it is essential to the parents to have information, they can be provided with a notification concerning the registration. The healthcare facility provides the death certification form and they bring the relevant documents. There is an authorized person in* [hospital] *administration who deals with this process. We do the registration and we record the corresponding remark that such registration has taken place.* (CSARB, 3.4.4.3.3, IDI, Yerevan)

In case of stillbirth... only the birth is registered and the certificate is not given. If the parents demand [a certification], *then* [it is provided] *in a form of notification only. But if the child was born and then died, then both the birth and the death are registered. There is a form on perinatal death, which is given by the maternity. Usually, in practice, that is how it is done. They* [healthcare facilities] *have to apply to CSARB within seven days.* (CSARB, 3.4.4.3.2, IDI, marz)

If the stillbirth occurred at home, they call a doctor, ok? So the responsibility is on that doctor. He/she prepares the document. According to current legislation, within seven days after the death of the child [or stillbirth] *the medical institution should inform us. …They* [the medical institution] *apply precisely on time and the registration is done. In case of stillbirth we only register the birth and a birth certificate is not given. The stillbirths are registered based on the document provided by the medical institution: a document specifically issued for the registration of perinatal deaths.* (CSARB, 3.4.4.3.1, IDI, Yerevan)

The change is [in] *the 20th article in the law on CSAR. The change concerns the deadlines. The 8th point* [of the law] *states that the notification of the birth of an infant born alive who died within four weeks of the birth must be made no later than seven days from the day of the birth, or death. Perhaps I may not remember very well how it was previously. I think it was perhaps not seven days, it was less. Previously four weeks of life was not mentioned, I think it was two or.... And seven days is quite enough time for them* [the hospital] *to apply with the* [needed] *documents and register.* (CSARB, 3.4.4.3.3, IDI, Yerevan)

At the beginning, it [the registration deadline] *was three days and then they changed to 7 days, because it was more reasonable as we could not sometimes manage...* [For example], *when stillbirths were reported on Friday, we had a problem to manage with reporting until Monday... the registration of stillbirths is convenient now as we manage to register within 7 days.* (Midwife, 3.4.4.3.8, FGD, marz)

Neonatal death registration: All CSARB participants, as well as some FGD participants stated that in case of early and late neonatal deaths both the registration of birth and death is done. The necessary documents for registration include birth notification form (medical certification of birth), parents' passports, their marriage certificate and the death notification form (medical certification of death). A statement from the witnesses of death is also needed if the death took place at home. CSARB representatives noted that they do not provide parents with a birth certificate if the child has died, but they provide them with a death certificate (and a document confirming the registration of the child's birth upon parent's request – to receive financial allowance). In the case if parents obtained a birth certificate before the child's death, they must return it to CSARB in order to receive the death certificate. A respondent from CSARB mentioned that in some cases, double registration of the birth of a dead neonate is possible when the child's birth is registered in one CSARB shortly after the birth (based on medical certification of birth issued by the obstetric service), and then again in another CSARB – together with death registration (based on medical certification of both birth and death issued by the neonatal department of the hospital where the child died).

There was some confusion concerning the reporting period of early and late neonatal deaths. Some FGD participants mentioned that registration must be done within 7 days, however some others were not sure about the timeline, while another participant from one FGD – who was personally responsible for the registrations at the CSARB for their maternity hospital – reported

that the time had been reduced from 7 days to 3 days and now they were reporting everything within this 3-day limit. Again, the issue with holidays was brought forward.

During a FGD with neonatologists, one participant reported that in case of neonatal death, after registration of the child's birth at the CSARB by the hospital, parents have to go and register the child's death at the Funeral Service Board, as this is the only body that registers deaths in Yerevan. Another participant added that the latter must be done in case of both perinatal (early neonatal) and (late) neonatal deaths, to which the first one agreed.

Two registrations are done [for a neonatal death case]*: birth and death. So the medical institution gives a birth notification form* [medical certification of birth] *and a death notification form* [medical certification of death]. *The birth is registered in Yerevan city* [CSAR bodies] *and the death is registered in the department of a special service* [there is organization, which registers deaths of newborns]. *The birth certificate is not given to the child; only death certificate is given. We can give a document to a parent, which is needed for them to receive the financial allowance. Additional documents* [needed for registration] *are the same as in case of live births: passports of the parents, their marriage certificate and if the newborn died at home then we take statements of the witnesses and the doctor prepares the birth notification form.* (CSARB, 3.4.4.3.1, IDI, Yerevan)

For babies that have died during the first 4 weeks of life, registration is done in the CSARB at the place of death. For example, the baby has been born in Gyumri and transported to Margaryan hospital because of some condition, but unfortunately he/she has died there. In this case, other than the CSARB in Gyumri where the baby was registered, we also now have the CSARB at the place of death. So in this case the registration may be done in 2-3 places... If the child has died at another healthcare facility, then the head of the facility [where the child died] *is responsible for providing the relevant documentation* [based on which the registration is conducted]. (CSARB, 3.4.4.3.3, IDI, Yerevan)

The registration [of perinatal death] *should be accomplished within 7 days. Let's say it is a New Year's holyday, but there is no any indication in the protocol that the registration period matched with the holydays, while it requires to register.* (Neonatologist, 3.4.4.3.9, FGD, Yerevan)

There are no differences in the registration process of children who die within 7 days or 8-28 days after the birth. Both the birth and the death are registered. In case of death the death certificate is provided, but not the birth certificate … only a document about the registration of the birth. In case the birth certificate was provided and the

child died after, they [the parents] *should return it so that we give them the death certificate.* (CSARB, 3.4.4.3.2, IDI, marz)

…yes, the procedure [for registering early and late neonatal death at the CSARB] *is the same, but implemented by them* [hospitals]. (Neonatologist, 3.4.4.3.10, FGD, Yerevan)

The hospital is responsible for informing the CSARB about such [neonatal] *deaths.* (Neonatologist, 3.4.4.3.11, FGD, Yerevan)

In the past the timeframe [for reporting to CSARB] *was 3 days but the period is now prolonged to 7 days.* (Neonatologist/ob/gyn, 3.4.4.3.9, FGD, marz)

It [perinatal and neonatal deaths] *must be registered within 7-28 days…* (Midwife, 3.4.4.3.6, FGD, Yerevan)

Within three days [neonatal deaths should be registered at CSARB]. *Before it was seven days, now it must be done within three days… If there are no holidays or weekend... we do everything to keep that timeframe... so that we do not have problems.* (Midwife, 3.4.4.3.12, FGD, marz)

… *for a case of child death even when parents have obtained a birth certificate, we record the death and send with the birth certificate to the CSARB. They take back the birth certificate of a dead child…* (Midwife, 3.4.4.3.13, FGD, marz)

After registering in CSARBs, parents must go to Funeral Service Board and register… (Neonatologist, 3.4.4.3.14, FGD, Yerevan)

Both perinatal and neonatal deaths should be registered in the Funeral Service Board. (Neonatologist, 3.4.4.3.15, FGD, Yerevan)

<u>*Data kept in CSAR bodies:*</u> As to the data on the registered births kept in the SCAR bodies and data that they report elsewhere, the IDI participants from CSARB stated that in case of live birth they keep the following documentation and data: copies of parents' passports, information on father, mother, the person who applied, the serial number of the certificate and the date of issuing it, the medical certification of birth, the date on the medical certification of birth and the name of the facility which provided it, infant's name, surname, patronymic, the date of birth, gender, nationality, place of birth and place of residency.

According to IDI participants, the CSARBs report the numbers of registered births to NSS and MOH monthly. The reporting to NSS is done in the form of acts, where the birthweight of a child is not included. Thus, there is no differential reporting for children born with a birthweight less than 1000 grams and therefore NSS has no separate data on children in the extremely low birthweight category. The participants stressed also that the reporting acts to NSS contain a column on the child's permanent residency (parents' residency), which is reported instead of the actual place of child's birth (often, hospital). As to reporting to the MOH, only the numbers of registered births and deaths are reported.

CSARB participants stated that for stillbirths, they keep almost the same information in their records as in case of livebirths. The only difference is that they do not record a name for a stillbirth and a place of residence. The documents that they keep include perinatal death certification form received from the maternity hospital where the stillbirth took place and the copy of the passport of the person who applied for registration. The frequency of reporting to NSS about registered stillbirth is the same as for livebirths: it is done each month.

The medical certification of birth and the copies of the parents' passports, and of course, the application for the birth registration. All of these are kept … as an internal document of the CSARB, the copy of the act. (CSARB, 3.4.4.3.2, IDI, marz)

The main information which is interesting for us includes data on the child: name, surname and patronymic, date of birth, sex, nationality, birthplace, living place, data from medical certification of child's birth, when it is given, from which institution, and data about the parents: data on father, mother, data on the person who applied, the serial number of the certificate, and the date when the certificate is given. (CSARB, 3.4.4.3.1, IDI, Yerevan)

When we register a birth, we have the following data: infant's name, surname and patronymic, time and date of birth, and within the framework of the changes in this new project, we have a column where the infant's place of residence is noted. We note this place of residence according to the parent's application as to which address the infant should be registered at and that registration automatically goes to the passport office. (CSARB, 3.4.4.3.3, IDI, Yerevan)

We send a report to the NSS once a month. We present the birth acts which they used to investigate and process the data. We only sent acts to the NSS. ...All registered births are included in this report [the report which they send to NSS], *irrespective of whether it was*

stillborn or died within 4 weeks after the birth. Besides that we send only the numbers [number of births] *to the ministry.* (CSARB, 3.4.4.3.3, IDI, Yerevan)

Every month. Every month we send a report to the Ministry... how many birth we registered during a month, how many stillbirths we had. …We send only the acts [to the NSS]*... the copies of the acts are included in the NSS reporting form. It does not contain information about the child's weight. The weight is registered only in maternity hospital, in the medical certification of birth, based on which the birth is registered. The information on the place of birth in the act is not included: as a place of birth the residency place is mentioned. Even if the child is born at home, the city is indicated as the place of birth. The maternity home as a birth place is mentioned in the medical certification of birth, but as a place of birth the city is mentioned.* (CSARB, 3.4.4.3.2, IDI, marz)

Once a month we report to MOH and NSS. (CSARB, 3.4.4.3.1, IDI, Yerevan)

[In case of stillbirths] *We keep the same act as with live births, but as I mentioned before, a name is not recorded and naturally a place of residence is not recorded either. The rest of the columns are filled in completely just as they are done in case of live births. So the only difference is that there is no name, no residence address and no birth certificate is provided.* (CSARB, 3.4.4.3.3, IDI, Yerevan)

So the names are not registered [in case of stillbirths]. *Information about the mother is filled from the document given by the medical institution. Data about the father are taken from the marriage certificate, if the parents have registered their marriage. If they do not have registered marriage, data about the father are not registered. So only child's surname, the time of the birth, sex, birthplace and mother's data are registered based on this. And at the end data about the person, who applies.* (CSARB, 3.4.4.3.1, IDI, Yerevan)

The same [documents are kept for a stillbirth case]*: Perinatal death certification form and the copy of the passport of the applicant.* (CSARB, 3.4.4.3.2, IDI, marz)

[The reporting to NSS for stillbirths is conducted with] *The same frequency* [as for livebirths]*... at the end of the month, up until the 5th of the next month. So reporting for all cases is done at once. But we would note the number of stillbirths or newborn deaths on a separate line.* (CSARB, 3.4.4.3.3, IDI, Yerevan)

3.4.4.4 Possible reasons for under-registration of births and deaths in CSAR bodies

According to the CSARB representatives, the registration of birth is considered to be late, if parents apply for registration more than one year after the child's birth. However, such cases are

very rare, perhaps due to the efforts of maternity hospitals that demand birth certificate in order to discharge mothers from the hospital, although it is not required by the law. Nevertheless, even if parents apply after one year, the CSARB registers the birth.

Participants from different IDIs and FGDs indicated that the main reason for postponed registration of births is parents' inability to present the needed documents, the reasons for which could include lost documents, being in the process of obtaining a new passport, unregistered marriage, foreign nationality, under-age mother, etc. According to CSARB representatives, difficulties could arise with registration of orphans or foundlings because of the lack of necessary documents. Another reason for postponed birth registration could be parents' inability to determine a name for the child.

One of the main issues in the marzes – with some marzes being more inflicted – is the absence of marriage registration. This phenomenon is mainly due to poverty: people who are known to be husband and wife do not register their marriage officially so that the wife receives financial benefit from the Government as a single mother. Therefore, when the baby is born, the father has to accept paternity. Moreover, in some cases the maternity hospital which does not have a paternity establishment form from the CSARB may register the baby by their mother's name, which may cause further difficulties. Another issue raised during FGDs by various specialists was that the registration process is slowed down during lengthy holidays, such as New Year holydays when all the offices in the country are closed for up to 10 days. Among the factors that accelerate the registration of births in CSARBs, the participants mentioned providing Child State Health Certificate from maternities and birth allowance from the Ministry of Labor and Social Affairs.

According to Article 16 of the CSARB law, written notification on child birth shall be submitted to CSARB agency not later than within one year after the date of child's birth. After one year the registration of a birth is considered belated and supplementary documents are needed. This is a separate procedure and is called Post-deadline birth registration act. (CSARB, 3.4.4.4.1, IDI, Yerevan)

After one year it [birth registration] *can be considered to be late, but again, the registration is conducted. Such cases are very few... During the last 5 years, all* [parents] *are very punctual.*

Maybe it is connected with the strictness of maternity hospitals, which demand the birth certificates. (CSARB, 3.4.4.4.2, IDI, Yerevan)

…We try to discharge when parents present birth certificates. …We must indicate the number of birth certificate in the medical record… (Neonatologist, 3.4.4.4.3, FGD, Yerevan)

That [late registration] *could happen when the documentation is not presented properly or is incomplete, when there are specific debatable issues concerning the infant's name or nationality. …After the legislative change of 2005, the nationality of the infant must be written with the mutual agreement of the parents* [if they have different nationalities]. *If both parents are present and agree, the infant can have the nationality written, if they are not both present and there is no such written appeal, the nationality column may be left blank.* (CSARB, 3.4.4.4.1, IDI, Yerevan)

[The registration is postponed] *Only when the mother has problems with the passport. Maybe she applies for a new passport or there is a need to get the marriage registered at the CSARB in a week... There are people, who lost their passports and now they cannot get a new one...they have to bring the 9th form etc, until they receive a passport. …If there is no passport, we should inform the police. They cannot just take the child and go …because you don't know what will happen to that child.* (Midwife, 3.4.4.4.4, IDI, Yerevan)

...when birthing mother is a teenager… or when the documents are in another language and there is a need for translation… so these factors could suspend the registration process in the CSARBs… (Midwife, 3.4.4.4.5, FGD, Yerevan)

They [CSARBs] *require a form for paternity establishment in order to register newborns with father's name. But when we do not have a paternity establishment form or any other form provided by the CSARB, we register based on the mother's name and related problems arise...* (Neonatologist/ob/gyn, 3.4.4.4.6, FGD, marz)

We only have issues with documentations if the parents are foreign nationals. For examples in cases where the parents are citizens of Armenia, but they live in another country (for example in Georgia) and wish to take their baby's birth certificate from there, we do not discharge the woman even though it takes a long while [before they bring the certificate], *because we are scared that they might just disappear and never return to provide the documents. Imagine how big the responsibility is for the maternity hospital if that child dies.* (Neonatologist, 3.4.4.4.7, IDI, Yerevan)

Parents sometimes have a desire to register their newborns later. For example, it may happen when they have not decided the name of the child. (Neonatologist/ob/gyn, 3.4.4.4.8, FGD, Yerevan)

In my opinion, problems can happen with foundlings. ... Documentation problems can happen, because we do not have information on who are the [child's] *father and the mother, when the child was born.* (CSARB, 3.4.4.4.2, IDI, Yerevan)

I have observed that the discharge without a birth certificate happens more often, though in the past it was controlled stricter and the baby wasn't discharged without the certificate. But now as the reversed paper [PHC provider notification form, a piece of which is returned to maternity] *exists, we discharge them. But as you know the families also receive money, which is an incentive to take the birth certificate as soon as possible so that they can receive money by the birth certificate from the Ministry of Labor and Social Affairs, though it is a small amount but still they receive.* (Ob/gyn, 3.4.4.4.9, IDI, Yerevan)

Now as long as the newborns are given the Child Health State Certificate, the process of registration is accelerated. (Ob/gyn, 3.4.4.4.10, FGD, Yerevan)

This [late registration] *is extremely rare, as babies must be registered at the polyclinic to receive their vaccines, as well as other free healthcare services. This is enough reason for the family to be willing to do the paperwork on time.* (Policy maker, 3.4.4.4.11, IDI, marz)

… *if there is a reason for not presenting documents before discharging* [the mother] *from the hospital, we could take/require a photo from them in order to make sure that the same person is presented later on for obtaining the medical certification of birth.* (Midwife, 3.4.4.4.12, FGD, marz)

Concerning the deadline for registration of stillbirths and neonatal deaths, which should be done by the hospitals, the participants mentioned that it is much shorter than for birth registration – only 7 days (yet longer than the prior deadline of 3 days), and several factors such as lengthy holidays, the need to bring passport from far distances in case of unexpected delivery, or having invalid passport, all can cause late registration.

Some policy makers suggested extending the 7 day deadline for registration of stillbirths and neonatal deaths in CSAR bodies, reasoning it with the need to include in the medical certification of death form the final diagnosis confirmed by pathological examination, which is received much later. However, the majority of FGD participants did not considered this necessary as, according to them, the final autopsy diagnosis does not concern the CSARB. A couple of neonatologists suggested computerizing the system of registration of deaths in CSAR bodies or having a special person on-duty there during holidays to avoid the issues of exceeding the registration deadline during lengthy holydays.

As to the possibility of leaving out a stillborn from registration, according to one of the CSARB representatives, this could happen if the delivery took place at home. The participants from CSARB rejected the possibility of leaving out stillborns from registration, especially if the case occurred in a hospital. However, they admitted the possibility of late registration of a stillbirth case in some instances.

The maternity hospital is responsible for registering stillbirths or the death of babies during the first 28 days. But when a woman does not provide us with identification documents, then we are unable to provide a medical certification of birth, which automatically affects our ability to register the birth or stillbirth on time. …The reason why they don't have the document could be that they have arrived at the hospital unplanned because of a miscarriage that happened while they were visiting relatives in Yerevan - while they live in a far-away village. If they delay these documents, then we have to start apologizing and sending letters to the MOH requesting permission to register these belated cases. …I would also like to add that late registrations are never denied and are always conducted. (Neonatologist, 3.4.4.4.13, IDI, Yerevan)

The 7-day limit is not sufficient, and should be extended. Some procedures, such as histological examination of samples require a longer period of time and it is impossible to include those results in the CSARBs' reports. (Policy maker, 3.4.4.4.14, IDI, marz)

…In 99% of cases they [maternity staff] *provide* [in the medical certification of death form] *the clinical* [preliminary] *diagnosis. But then if the final cause of death is changed post autopsy, then the providers must issue a new death certification form with this new information and take it to the CSARB again. According to this the cause of death changes... but I believe this is something that is not being done at all to this date. Not only do they not conduct this, but they also report that there is no significant change in the preliminary and final diagnosis.* (Policy maker, 3.4.4.4.15, IDI, Yerevan)

We receive the answer [the results of autopsy] *and attach it to the medical card. The CSARB doesn't need it, we send them no result whatsoever… they merely need to be informed that the infant has died… within three days or sooner. Some send the information within 24 hours…* (Ob/gyn, 3.4.4.4.16, FGD, Yerevan)

I have a suggestion related to the birth registration. It happens that the infant needs to be registered during holydays and recess periods; it would be useful to have in place duty-on workers, who will register infants during those days. (Neonatologist/ob/gyn, 3.4.4.4.9, FGD, Yerevan)

I think this procedure should be conducted electronically [group member agrees] (Neonatologist, 3.4.4.4.17, FGD, Yerevan)

Maybe [leaving out a case of stillbirth from registration could happen] *in cases of birth at home. Otherwise if the child was born in the medical institution and died, I do not think that it will be left out from being registered. But in case of births at home, it is possible, that they do not apply for the birth registration. Sure... In my opinion: only in those cases.* (CSARB, 3.4.4.4.2, IDI, Yerevan)

I don't think such things can happen. They may be registered late, but not be completely left out... it shouldn't happen. I cannot be aware of this, because I only know about cases that approach us to notify us about it. So if anything is left out, I will not even know about them. (CSARB, 3.4.4.4.1, IDI, Yerevan)

3.4.5 Pathological examination in case of stillbirths and neonatal deaths

3.4.5.1 Existing procedures for autopsy of stillbirths and neonatal deaths

According to different participants, the procedures which follow the birth of a stillbirth or a newborn death include weighting the body, measuring and putting it in a special packet, after which it is send for autopsy (together with the placenta – in a separate packet). All participants agreed that both the body and the placenta are sent to the pathology unit. These are accompanied with mandatory documentation: newborns' card (where all the required information is included) and autopsy referral form. Later on the newborn's medical card and autopsy results are returned to the maternity unit and attached to the mother's medical history.

A majority of FGD participants reported that the body is transported to the pathology department – when this is not located at the facility - by a special ambulance, but one midwife from a FGD reported that at their facility nurses take the bodies to the pathology department, to which another participant agreed.

We weight the body, measure it and put inside the packet then into the refrigerator until the documents are filled. After that, in the morning it is sent to the pathologist, with its own documents, child card, autopsy referral... We send both the body and the placenta, especially for stillbirth... If it is an early delivery we put the placenta, write name and surname and if the child lives for 10-12 hours we keep the placenta so that later we [can] *send them together. However, if the newborn lives for a little bit longer* [than 10-12 hours] *and then dies, at that*

time only the newborn is sent [to the pathology department]. (Midwife, 3.4.5.1.1, IDI, Yerevan)

All bodies along with the placentas are sent for the autopsy. Immediately after the stillbirth delivery the placenta and corpse are separately weighted and are put in the refrigerator in separate packets. Next morning, the cleaner comes and along with the autopsy referral takes the bodies to the pathology department. (Ob/gyn, 3.4.5.1.2, IDI, Yerevan)

… we use a separate referral form [for autopsy], *with the* [newborn's] *medical form, where all the anamnesis is written: how the pregnancy passed, what complications and infections the mother had during the pregnancy, and how the delivery passed. So the pathologist reviews this information and writes the protocol of the autopsy. Then this document is sent to us …and is attached to the mother's medical form.* (Ob/gyn, 3.4.5.1.3, IDI, marz)

The body goes to the morgue together with the infant's history form, or in the case of a stillbirth, again with the neonatal history form in which it is stated that the newborn is a stillbirth. That card is returned to us with the autopsy results. (Neonatologist, 3.4.5.1.4, IDI, Yerevan)

…we call 103; they come and take the bodies [to the pathology department]. (Ob/gyn, 3.4.5.1.5, FGD, Yerevan)

A nurse takes the stillborn body, along with a newborn medical form to the morgue. (Midwife, 3.4.5.1.6, FGD, marz)

We always send the body for autopsy. We do not give it to the parents directly from the maternity hospital. (Ob/gyn, 3.4.5.1.7, FGD, Yerevan)

The pathologists highlighted the importance of receiving placenta for pathological examination, as it its pathology is often the reason of perinatal death and as it remains informative for a longer period than the body. However, one pathologist stressed that there are still some issues with sending placentas for autopsy, especially when a newborn lives for a few days and dies after being transferred to another hospital. In such cases most of the time the maternity hospital staff does not preserve the placenta. The pathologist underscored the importance of keeping a sample of placenta in refrigerator for all births and discarding those only after making sure that the newborn is discharged healthy.

According to all participants, rarely parents take the bodies of dead infants post-autopsy. As one pathologist mentioned, sometimes they take the body if the child was a big one, while if it was a small fetus they do not take. Another pathologist stated that they themselves do not support the idea of taking the newborn's body, because it is a huge stress for parents.

The autopsy of placenta is informative, because 90% of the [perinatal] *deaths are due to placenta's transformations. …The fetal nutrition is* [carried out] *through placenta...* (Pathologist, 3.4.5.1.8, IDI, marz)

…Sending the placenta is required by the law, and it is mandatory. There are many diseases that are connected with the condition of the placenta, such as dystrophic malformations, exfoliation etc... Moreover, the umbilical cord must also be examined and thus, these too are brought to us by the cleaning staff. (Pathologist, 3.4.5.1.9, IDI, marz)

We have a serious problem regarding the placenta. Several times we have suggested that regardless if the baby is a livebirth, a stillbirth, its weight and etc., before discharging the baby, a small sample of placenta should be taken and put into refrigerator, we can also provide formalin [to keep it]. *Many times the baby gets worse on 2-3rd days, the hospital transfers the baby to the IC unit and if the baby later dies, the procedures conducted on the child in the IC unit blur the picture for the pathologist to some extent. Here the most informative organ indicative of intrauterine life is the placenta. When the physicians are informed that the baby is fine and is discharged they can throw away the* [sample of] *placenta. But if they transfer the baby to the IC unit and they don't know the future faith of the child, they will keep the placenta. When the baby dies in Muratsan* [hospital] *or other center and is sent for an autopsy, we can know where the baby was born, and we can ask the* [sample of] *placenta from them. …The placenta keeps the information, it is very interesting organ. This is a very, very serious problem. We have even approached the head specialist with this issue. We made suggestions but the ice doesn't move from its place.* (Pathologist, 3.4.5.1.10, IDI, Yerevan)

…by the law, we keep the corpses for 3 days… If in 3 days the parent come and wish to take the body, we give them. But it constitutes very small percentage. Generally, they don't come; don't show interest, especially for stillbirths or miscarriages. (Pathologist, 3.4.5.1.10, IDI, Yerevan)

In 90% of the cases parents do not take them [bodies]. *If the fetus is small: 26-27 weeks, mostly they don't take, but if it is almost mature fetus, they may take...* (Pathologist, 3.4.5.1.8, IDI, marz)

There are some cases when parents take the body. If we were to speak by statistics, then in one case out of every 10 the parent may ask for the body to be returned to them. We ourselves do not approve this, because it creates additional misery for the parents. (Pathologist, 3.4.5.1.9, IDI, marz)

3.4.5.2 Coverage of stillbirths and neonatal deaths with autopsy

The majority of participants from all groups reported that autopsy is conducted in 100% of cases of stillbirths and neonatal deaths. Some participants were very precise in their response, pointing out that all stillbirths weighting 500 g and/or being greater than 22 weeks of gestation are sent for autopsy. However, some participants reported that even though the law requires conducting autopsy for all cases of stillbirths and neonatal deaths, in some cases it is not conducted. The reasons behind this were parents' refusal – reported mainly among minorities and some religious groups; weight of the fetus less than 500 grams; and lack of pathologist or pathological unit in the given area. The participants mentioned that these issues interfere with correct identification of the reasons of stillbirths and neonatal deaths. In order to avert this situation, some participants stressed the importance of working with parents, which they do, in order to explain them the importance of doing autopsy for revealing the reason of fetal/neonatal death.

According to the law, all perinatal deaths are subject to autopsy to ensure pathological diagnosis. This is mandatory. If the parents desire to take the body post-mortem, then they can take that from the pathological laboratory. (Ob/gyn, 3.4.5.2.1, IDI, Yerevan)

If it is under 22 weeks, it is a miscarriage and an autopsy is carried out at the parents' request. If there has been a delivery, an autopsy is OBLIGATORY…and we receive the result... and attach it to the medical card, so that we also know the reason… (Ob/gyn, 3.4.5.2.2, FGD, Yerevan)

Yes, when stillbirths are born above 22 weeks of gestation with 500 grams weight, then such cases are considered deliveries and not abortions. And when parents do not refuse, stillbirths are referred to the autopsy examination. (Neonatologist/ob/gyn, 3.4.5.2.3, FGD, marz)

All stillborns above 500 grams weight and 22 weeks of gestation are sent for autopsy. So it is 100%. I know that in certain maternity hospitals in the regions there are no pathologists, no laboratories. In other words there are some newborns and fetuses in the republic, which do not undergo an autopsy. (Neonatologist, 3.4.5.2.4, IDI, Yerevan)

According to current regulations, autopsy for stillbirths must be conducted in 100% of cases. In general, the only obstacle to autopsy is when the family members do not agree to having one done. There are no obstacles to following regulations otherwise, as everything is available. The center has a corpse transportation vehicle, so they actually come and pick up the corpses themselves; they serve all communities in the entire marz. (Policy maker, 3.4.5.2.5, IDI, marz)

One hundred percent of all dead or stillborn infants go to autopsy. We receive the report where the results of the examinations on both the infant and the placenta are noted….Rarely, but on occasion the parents refuse the autopsy. We try to persuade them that it is necessary but if a conflict seems to be arising, we concede. Such cases happen 2 or 3 times a year... (Ob/gyn, 3.4.5.2.6, IDI, marz)

We have a serious problem with remote marzes, also with near marzes… When looking at the numbers I guess that they do not send all the cases [of stillbirths/neonatal deaths to autopsy]. *It should be regulated by law. It is very serious problem. …But I can confidently tell that in Yerevan all cases are autopsied.* (Pathologist, 3.4.5.2.7, IDI, Yerevan)

We had an issue related to Molokans who have specific religion... But we refer all stillbirths for autopsy, it does not matter. Stillbirths are not referred to the autopsy only if the relatives express the desire to refer them to other place for autopsy if they do not trust us... but this happens very rarely like at most once in a year. (Midwife, 3.4.5.2.8, FGD, marz)

All... In few cases, when the parents refuse the autopsy, they sign a paper about their refusal. These cases are very rare… Last year we had 25 stillbirths, only one refused, others were sent to the pathological department, where the autopsy was done. (Midwife, 3.4.5.2.9, FGD, marz)

3.4.5.3 Reporting and registration of autopsy results

According to the pathologists' records, it takes around 1-2 weeks to send the autopsy results to the physicians and one of these participants stated that in case of histological examination it may take one month. One of the pathologists stated that sometimes the maternity unit may receive the results after a long period, because they are not actively seeking for the results and wait until the pathologist sends it at his/her convenience. All the participants from FGDs with neonatologists and ob/gyns, including WC ob/gyns, ascertained that they receive the results of the autopsy from the pathology department. However, WC ob/gyns expressed their concern that even when they receive the autopsy results, it does not help with treating the mother, as the women only attend WC to get the free examinations but do not follow up with the needed

additional tests and treatment. In almost all FGDs, it was reported that sometimes parents also inquire about the results of the autopsy.

It [preparing the autopsy results] *depends on the case.... maybe from 10 days to 2 weeks.* (Pathologist, 3.4.5.3.1, IDI, marz)

One week, 10 days... If it is delayed because of the histology, then it may take about a month. (Pathologist, 3.4.5.3.2, IDI, marz)

If the hospital is interested, then in 10-15 days it receives the results, otherwise the final results are kept here, till we send to them per our convenience or if occasionally one of the hospital staff appears in the vicinity and takes the results. I mean at times physician may know the cause of a miscarriage only at the end of the year. But we don't see a tendency from physicians of being concerned, coming on time to take the medical cards, discussing the results. (Pathologist, 3.4.5.3.3, IDI, Yerevan)

If relatives of the stillborn baby are interested [with the results of autopsy], *they go to the morgue and ask the pathologist who informs them when to return and receive the autopsy results.* (Midwife, 3.4.5.3.4, FGD, marz)

Definitely [we receive the autopsy results], *we are in close relations with maternity hospitals. However, it does not have any benefits* [in terms of patients going for checkups...] (WC ob/gyn, 3.4.5.3.5, FGD, marz)

[After the results of stillbirth autopsy have been provided] *women come only for the examination to receive the volume of services that we provide* [free of charge]. *That's all... and then when you urge women to pass certain medical tests* [they do not]... (WC ob/gyn, 3.4.5.3.6, FGD, marz)

The participants stated that they record the pathological diagnosis in the medical history of mother/newborn. They do not send the autopsy results to the CSARB, because these do not apply to the CSARB and because the 7-day timeframe for registration of stillbirths and neonatal deaths in CSARB is too short to receive the results of autopsy that sometimes arrive in a month. Also, CSARB is not interested in receiving these diagnoses. For these reasons, only the initial diagnosis is sent to the CSARBs when the death is being reported, while the final diagnoses confirmed by pathological examination are kept only in maternity hospitals.

We record pathological diagnosis in newborn medical forms which is a document and kept for a long time… When we present an annual report, all cases are included started from January 1. (Neonatologist/ob/gyn, 3.4.5.3.7, FGD, marz)

The autopsy diagnosis is not for CSARB. It is for medical documentation, to know the cause of stillbirth, and to advice the woman so she will prevent a similar situation in the future. We don't wait for autopsy diagnosis to report to the CSARB. It may take a month but the CSARB immediately registers the stillbirths. We report the suspected cause of death and the CSARB registers that one. The CSARB is not interested in knowing the true cause of death. The physician and the parents are the ones interested in knowing the true cause. (Ob/gyn, 3.4.5.3.8, IDI, marz)

No, it would be meaningless and additional work with documentation [to have the autopsy results registered at the CSARB]. (Neonatologist/ob/gyn, 3.4.5.3.7, FGD, marz)

The death is registered [in CSARB] *within the first 7 days after death. The official reply* [about the results of autopsy] *arrives much later. In other words, if I wait for the reply and only then register the death, I will exceed the 7 day timeframe. I record the results* [in the Medical Certification of Death form] *based on the initial pathological results, because the corresponding attending doctor is present at all autopsies. That is not compulsory; we have that procedure.* (Neonatologist, 3.4.5.3.9, IDI, Yerevan)

The women must know what caused the problem, so that they can receive the treatment which is necessary before becoming pregnant again. (Neonatologist/, 3.4.5.3.10, FGD, Yerevan)

3.4.5.4 Informativity and accuracy of pathological examination

The opinions of participants on the accuracy and informativity of the results received after pathological examination of stillborns and newborns were diverse. Although some of them stated that the autopsy results they received were satisfactory, many participants both from IDIs and FGDs mentioned that most of the time the results were poor, similar to each other, describing only visible defects and general changes (e.g., hypoxia of tissues) and that the diagnoses of physicians and pathologists are almost always the same. While the pathologists agreed that the clinical and pathological diagnoses are usually the same for neonatal deaths, they disagreed with that for stillborns, stating that in 20% of cases the autopsy diagnoses differ from the diagnoses on the referral forms. Moreover, they mentioned that ob/gyns frequently fill incomplete the autopsy referral forms and even omit the clinical diagnosis.

A few participants stated that in cases when they need a comprehensive examination (mainly, when parents are interested in knowing the exact reason of the child's death or when the case is considered criminal), they ask the pathologists to do the autopsy thoroughly. However, participants from a FGD with ob/gyns reported that no matter how much detailed autopsy they request, the results provided are very general and describe changes in the tissues and organs, rather than the concrete cause of the death. This finding triangulated between groups with several participants expressing a desire for more detailed analysis which would give them valuable insight on the cause of death. Some stressed the importance of knowing the type of infection leading to stillbirth to be able to prevent/treat it.

Another issue raised and discussed was that some of the tests to diagnose the particular condition are paid-for services, which the parents must order if they want further investigation. However, given the socio-economic conditions in the country, many parents cannot afford these costs and since the infant is already dead, they do not pursue this further. The participants suggested including these examinations in the list of state-ordered (free-of-charge) services to address this issue.

Yes, the results provide sufficient information. They provide us with good feedback, because they themselves are interested in knowing what the issue is. If 1, 2 or 3 days have passed since the child have died in the mother's body, then as a reason we write hematoma, maceration…In cases when we need the results as detailed as possible, we tell them [the pathologists] *so…* (Neonatologist, 3.4.5.4.1, IDI, Yerevan)

Specifically, there are no problems in our town because we have a very good pathology lab. Of course, in order to have a more precise diagnosis we probably need many more examination parameters which are not performed here, beginning with genetic tests… this of course is not conducted and during autopsy they discover bigger issues that are visible to the eye. (Ob/gyn, 3.4.5.4.2, IDI, marz)

I have had one or two cases when the pathological and histological examinations have given me an additional insight on the cause of death. …In all remaining cases, similar [to ours] *diagnoses are made and sent back to us. More deeply they describe the secondary changes that occur after the death, than the causes that have occurred before the death. Maybe it is a result of the shortage of resources.* (Ob/gyn, 3.4.5.4.3, IDI, Yerevan)

Look how many diagnoses you would see as cause of stillbirth. They are probably all written as hypoxia. There are no other diagnoses. … I have sat in many committees in healthcare

establishments around Armenia and intrauterine severe hypoxia is written as the main cause. If there are severe visible defects, they may also be written. (Neoatologist, 3.4.5.4.4, IDI, Yerevan)

In case if the majority of children that have been diagnosed and already have received a treatment, we usually don't have a mismatch [in diagnosis]. *Though there might be a random discovery of birth defects. I would say that now the pediatric services work very well. But their number is small. What concerns the maternity centers; we don't even receive a diagnosis. Their records are too non-informative; contain only the gestation age, and a somehow described delivery process. They write three rows. They don't even write the diagnosis…* (Pathologist, 3.4.5.4.5, IDI, Yerevan)

In about 20% of the cases [the clinical and autopsy diagnoses differ]. *… There are things that are clear, for example wrapping of the umbilical cord or exfoliation of the placenta. …There can be different malformations visible to the naked eye... The rest is done through autopsy.* (Pathologist, 3.4.5.4.6, IDI, marz)

I do not want to believe that the autopsy is not performed; it may happen that histological and cytological examinations are not performed at microscopic level, but the autopsy is performed. (Neonatologist, 3.4.5.4.7, FGD, Yerevan)

They mainly conduct macroscopic examination in the beginning, but then if the parents demand more detailed examinations then they look at infections. However, this requires additional payment which isn't covered by the hospital. (Neonatologist, 3.4.5.4.8, FGD, Yerevan)

I can tell that the autopsy is done more meticulously when criminal cases occur, that is when bigger children die, and the pediatricians go to the pathology department and participate in the autopsy. (Ob/gyn, 3.4.5.4.3, IDI, Yerevan)

Regardless how much we have asked [the pathologist], *we are not given concrete answers. They say that they only describe the results, what changes have taken place, but they do not mention the causes...* (Ob/gyn, 3.4.5.4.9, FGD, Yerevan)

It would be better if the autopsies were done in more detail …and the doctors would understand what they are dealing with. After some time this would allow us to see the rates of death due to certain infections. This will allow us to understand the bacterial trends in the country… whether or not the issue is due to hospital-acquired infections or individual causes. It will help us on a larger scale. (Neonatologist, 3.4.5.4.10, FGD, Yerevan)

As far as I know, tissue and microbiology tests are officially paid-for services. Now, this raises the issue that they should not pay for them, they should be tested for free, in order for us also to know what the reason was. Autopsy gives us the "rough" answer of what the reason was. In order for us to know it in more detail, specific tests must be conducted. They take more time, sometimes from one week to ten days... And the relatives have to pay for them. Many can't afford to pay. The infant is already dead, and as far as I know the tests are quite expensive…. There are some who do pay, are persistent and pick up the results… (Ob/gyn, 3.4.5.4.11, FGD, Yerevan)

The opinions of pathologists on whether or not the autopsies of extremely premature neonates (weighting below 1000 gram) are as informative as autopsies of bigger neonates were slightly divergent. While one of the pathologists stated that the autopsy is informative even in case of extremely preterm infants, others stated that it is less informative than for those neonates weighing more than 1000 grams, because the organs of extremely preterm babies are not still completely formed.

Of course, each autopsy, unless the corpse is not putrefied, is very informative. The difference is that when doing autopsy in babies with a weight above 1000 grams we look to all organs, while in those with the weight below 1000 grams we study 2-3 organs: lungs, liver, thymus, brain and the umbilical cord as well as the placenta. In this case the complex examination is not necessary. In case of newborns, in contrast to older children or adults, a macroscopic autopsy is done. Thus looking with the naked eye does not show anything and is not informative. (Pathologist, 3.4.5.4.5, IDI, Yerevan)

No it's not as informative, but in all cases the autopsy is informative. (Pathologist, 3.4.5.4.6, IDI, marz)

…in most cases when it [autopsy examination] *is not performed we cannot know the causes that led to the death of the infant.* (Neonatologist/ob/gyn, 3.4.5.4.12, FGD, marz)

No, it's not as informative as in case of newborns weighing more than 1000 grams. The bigger the weight, the more informative it is. Organs are still in modification process, and it is difficult to differentiate the normal tissues from the pathological. (Pathologist, 3.4.5.4.13, IDI, marz)

When asked if it is possible to identify via pathological examination whether the newborn died after being born alive or was born dead, the pathologists unanimously stated that it is possible.

However, in some situations it is much easier than in others. For instance, if the fetal death occurred antenatally, the skin of the fetus gets macerated, which is an obvious sign. It is also easy to identify whether there is air in the lung, by simply putting it into water and looking if it dives. But when artificial ventilation was conducted to resuscitate the baby, histological examination of the lung tissue is needed to identify whether the neonate breathed on its own or the air was artificially inserted into the lungs. When the death occurred intranatally (during the labor), it is difficult to differentiate it from the case when the newborn demonstrated one-two heart bits and then died without breathing. The pathologists stated that in these cases they need to communicate with doctors who attended the delivery to know the details.

…if the child died in the uterine and stayed there... that is called maceration ... that is 100% ... The skin can become wrinkled, and it is called maceration. (Pathologist, 3.4.5.4.6, IDI, marz)

…There is a mechanical experiment of the lungs... whether they stay in the surface of the water or not... but it does not give a 100 % correct result, as it is possible that they did reanimation with artificial respiration pads, and the lungs ... the answer to this gives the histological examination. If you do the histology of the lungs... it is visible under the microscope clearly... whether it is a breathed lung or it contains artificially inflated air... (Pathologist, 3.4.5.4.6, IDI, marz)

[The case with] *1-2 heartbeats are difficult to find out… It is a little bit difficult... It can happen that the child was born and had a heartbeat but did not breathe... the doctors put on a medical ventilator and the oxygen filled into the lungs. Then it will be difficult to understand whether the child breathed on his/her own or the oxygen was filled into its lungs artificially. We can say, that the child breathed, but we need to see in the medical form, to understand whether artificial equipment was used for breathing or not. However, it is possible to find out that the child had a heartbeat but did not breathe. It is possible.* (Pathologist, 3.4.5.4.13, IDI, marz)

It is impossible to identify during autopsy if the neonate was born dead or died within the first minutes after birth without breathing but demonstrating some other signs of life (heartbeat, umbilical cord pulsation or muscular movement). In this case we have to look at the neonatologists' records to see what they noticed in that moment, when they did the assessment with Abgar scale. (Pathologist, 3.4.5.4.6, IDI, marz)

Sometime physicians send the fetus saying that they have tried to make the newborn breathing. We see that, but here we have a secondary but very important sign which is the operation of veins. The main guide for us to orient if the newborn has been artificially given the medical

ventilation or it has performed a respiratory act, is the veins that are closed which haven't provided air to the tissues. Still, definitely physicians help us. (Pathologist, 3.4.5.4.5, IDI, Yerevan)

3.4.5.5 Challenges of pathological examination of stillbirths and newborns

One of the challenges the pathologists reported was lack of the opportunity to conduct genetic analysis as a part of pathological examination. The absence of virology laboratory was also listed as one of the major autopsy challenges, as this limitation does not allow detecting viral causes of fetal/neonatal death. Because of these shortcomings, which are mainly the results of financial restrictions, pathological examination fails to receive important information that may explain the precise reason of fetal/newborn death.

Around 80% of our work is to conduct histological and cytological examination, so autopsy isn't even 20-30 % of the entire work. ...There are technical problems... like inability to conduct genetic analysis. …there are no [such] *capacities in Yerevan either… and the reason is the financial limitation. … We need to improve our technical capacity.* (Pathologist, 3.4.5.5.1, IDI, marz)

We do not have a virology laboratory. So people say why you are going to do the autopsy if you don't have the required equipment to do [a complete] *examination. Pathologists... we have to do what we can do... If there is a need for more advanced analysis, they can be referred to Yerevan.* (Pathologist, 3.4.5.5.2, IDI, marz)

If we had a laboratory, those patients [with genetic disorders] *would be studied, but there is only one such laboratory in the Republic: the Genetic Center.* (Neonatologist/ob/gyn, 3.4.5.5.3, FGD, marz)

Another major obstacle for pathological examination of stillborns/neonatal deaths, which was raised by some of the participants, was the shortage of pathology specialists. The participants stated that both this specialization and the salary pathologists get are not attractive for people. Therefore, very few want to become pathologists. According to one of the pathologists, the "scarcity" of pathologists is a problem throughout the country. Some participants from FGDs with neonatologists also noted the poor capacity/quality of pathological services for stillborns and neonates.

One of the pathologists suggested equipping the pathology department as needed, hiring a qualified specialist and giving him/her an acceptable salary, as a way to solve the problem with the shortage of pathology departments/specialists, while another pathologist made an alternative suggestion – teaching maternity hospital staffs in the areas where there is no pathology service how to take samples from corpses of newborns and preserve those, so that they could be send to Yerevan and examined later-on.

In the marz we have a shortage of specialists: pathologists. People do not want to study and become a pathologist. Besides, the salary is not appropriate... During these years no new specialists came to work here. That is a problem in all of Armenia: even in Yerevan the issue of shortage of specialists exists. (Pathologist, 3.4.5.5.1, IDI, marz)

The number of morphologists, pathologists that would also have pediatric knowledge is small in our center. It is very difficult to get further trainings [for pathologist in pediatric specialization], *since the pediatric pathology and especially the perinatology is a deeper, more interesting and larger- scale specialization. We don't have specialist, and this work is not profitable and not interesting from the financial aspect.* (Pathologist, 3.4.5.5.4, IDI, Yerevan)

I think that there are improvements in the quality of neonatology services but not in pathology services. (Neonatologist, 3.4.5.5.5, FGD, Yerevan)

There should be a competent specialist, in a professional environment with sufficient capacities, who will receive at least the minimally needed salary allowing him/her to stay and work here. (Pathologist, 3.4.5.5.1, IDI, marz)

As there is a shortage of pathologists in the country and as now we have good communication means, we can work with hospital staffs online, and teach them what parts of the dead fetus to sample. Teach that they should work clean, that they should necessarily have paraclinical examinations that are cytology, bacteriology which are also of immense assistance. We can tell them which parts of the lungs, thymus to take, also sample different parts of umbilical cord, and also sample a part of placenta and keep these in a right solution with a correct concentration. Even after four months when by occasion they come to Yerevan [and bring the samples], *we will do the study in 10 days and inform* [them] *the results.* (Pathologist, 3.4.5.5.4, IDI, Yerevan)

The pathologists mentioned the low quality of completion of autopsy referral forms by maternity hospital staff members as an obstacle to have satisfactory information on each given case that would guide the pathological examination. According to them, most of the time the referral

forms they receive are poorly completed and the quality of the information included in these forms largely depends on qualification of the physician completing the form. One participant also added that sometimes physicians do not complete some points mentioned in the referral form in order to hide some case-related information. The participant stressed the importance of working with parents of a dead newborn for obtaining the needed information, as the latter is often missing from the referral form. Another pathologist mentioned that the referral form itself – which has recently undergone changes and is currently more detailed - is a good one and if completed as needed, it will contain all the necessary information. However, another pathologist stressed the importance of introducing new autopsy referral form, as the increasing number of premature births and stillbirths require new approach to the pathological examination than the one practiced before, an approach that should be developed together with neonatologists and be reflected in the referral form.

Whether it [autopsy referral form] *is informative or not depends on doctor's qualification, his/her ability to provide the information.* [While showing a completed form]: *Look, is there anything informative here? Scarce information is provided about the newborn. The main things are probably written in the mother's medical form. …death fetus... there is no information... They don't give us any information concerning mother's disease. If mother's data was also provided... maybe mother had some illnesses...which would affect the pregnancy, then, it would have more information and our work would be easier. …For example, the woman has diabetes... we do not have that data...For most of the cases we have no information on the course of the pregnancy and mother's diseases.* (Pathologist, 3.4.5.5.2, IDI, marz)

Indeed, it [autopsy referral form] *is incomplete. When the* [corps of the] *newborn is coming, it should be accompanied with a referral form where the mother's age, the number of pregnancies are written.* [While showing a completed form]: *This is more or less filled in, still, the most part of the information we seek immediately from the parents. There are some points in the referral form that physicians refuse to fill in to keep some case-related information confidential. But when the couple comes and if the child was very much wanted, we talk to them and make thorough notes… But clinicians are not interested in this.* (Pathologist, 3.4.5.5.4, IDI, Yerevan)

It [the volume of information a pathologist may gain from the autopsy referral form] *depends on how the neonatologist describes the case.* (Midwife, 3.4.5.5.6, FGD, marz)

Look, it is not bad [the autopsy referral form itself]... *Everything* [all the necessary points] *is included in the form. In case of correct completion, there will be enough information.* (Pathologist, 3.4.5.5.1, IDI, marz)

Maybe a new [autopsy referral] *form should be developed, as this form has come from the Soviet health care system. In the past, the form we use now had also been developed by pathologists but now, since the demand has increased because of increasing number of preterm births and stillbirths, the pathologists should present a new form, which should be developed jointly with neonatologists …to understand what investigations they want from us and to what extent we can help them.* (Pathologist, 3.4.5.5.4, IDI, Yerevan)

One pathologist expressed a concern with the fact that often maternity hospital staff seems uninterested in learning about or not trusting the results of pathological examination. The participant mentioned that this problem is very common in case of preterm newborns. Because of low interest/trust, sometimes physicians don't send the corpse of fetuses/ newborns to pathology department within the first 24 hours as required. The situation is completely different when parents demonstrate an interest in knowing the reason(s) of stillbirth/neonatal death – in such cases physicians are interested in pathological examination results, as they are scared that these cases may become forensic medicine cases. The pathologist was concerned with the lack of conferences, discussions, and case reviews that should be conducted periodically with participation of both clinicians and pathologists to analyze inconsistencies between clinical and pathological diagnoses, hence contributing to the professional development of physicians. She made a suggestion to consider the extent in which the maternity hospital staff collaborates with pathological services, when making a decision about assigning a higher class to the maternity. An IDI participant also expressed an interest in a true collaboration between doctors and pathologists, so that they both are not just filling useless papers and sending those back and front without even reading the content, but doing useful work to benefit both patients and physicians.

The maternity units now are concerned with only those cases [of stillbirth/neonatal death] *that might result in becoming an object of forensic medicine. Otherwise, if the parents do not complain, they* [physicians]*… do not come to know the autopsy diagnosis. They are not interested at all. Neither they are interested in receiving the results, regardless if there is inconsistency in the diagnosis, or not… I have heard a lot from gynecologists that "We don't believe in your diagnosis; we are not interested in them; we already knew" but this is about those cases when the newborn is small or premature. But what if the child was normal and*

was expected and they don't have the answer for those cases?! They don't even come to know about those latest cases. We mainly work with the parents. …Another important thing [also often violated] *is timeliness of sending the corps to the autopsy department* [within 24 hours after stillbirth/neonatal death to avoid post-mortem changes]. (Pathologist, 3.4.5.5.4, IDI, Yerevan)

Another important issue is that no conferences, discussions and feedbacks with maternity units take place whatsoever [concerning the results of pathological examination]... *I think this* [the extent of collaboration between the maternity unit and pathology services] *should be one of the indicators based on which the maternity unit is given a class…* (Pathologist, 3.4.5.5.4, IDI, Yerevan)

It would be better to know the reason of baby's death [from pathologists]*; to send the case, then receive the cause of death, and have the pathologist replied to our suspected diagnosis as "you are illiterate, why did you write this?!" Very frequently we bypass, violate this thinking that it is not important. When we fill in the papers, the time of death etc, that effort seems too big as there is no one who reads those. But if I were sure that …the information* [I write] *will be used by the pathologist in making the diagnosis, and my patient will benefit from it, believe me, I would give importance to my work. But after the death, writing up the papers that no one will read... We shall give an importance to our work, when our work seems unnecessary we try to bypass it by all means.* (Ob/gyn, 3.4.5.5.7, IDI, Yerevan)

3.4.6 Financial allowance of childbirth in case of stillbirth and neonatal death

Since according to the existing legislation, the amount of child birth allowance to be paid to the parents by the government differs depending on the time of neonatal death – within perinatal period or after it (see Chapter 3.1 of this report) – the participants of IDIs and FGDs were asked whether they are aware about this legislation and how much they think this could influence the registration of the time of a newborn's death.

The majority of the IDI and FCD participants stated that they are not aware about the differences in the child birth allowance received by parents (both for that child and for calculating sequential number of future children in that family) if the child was born dead or died during the first week or died during the 2-4th weeks of life. Of the remaining participants, some indicated that there is a difference in the amount of financial allowance depending on the time of the child's death, while others thought that there is not. In addition, some participant stated that parents do not receive financial allowance in case of stillbirth as they not receive birth certificate, which is

necessary to get the allowance. While discussing this issue, some FGD participants expressed surprise and confusion as to why people would receive any benefit for a dead baby, while others argued that everyone would receive the allowance which is intended for delivery, thus not depending on the outcome. Several participants from various FGDs reported that if the parents manage to register their baby before it dies, they would receive the allowance. An IDI participant described a case when a parent asked him to register the stillbirth child as a livebirth in order to receive birth allowance for that child.

In general, the level of awareness of the existing legislation on child birth allowance was very low among the participants. Considering this, the research team asked a representative of the Ministry of Labor and Social Affairs (MOLSA) to clarify the issue. The latter clearly stated that the parents of a child who died during the perinatal period receive 50.000 drams regardless of the sequential number of that child in the family and this child is not considered when deciding the next child's sequential number in that family. Unlike this, children who die after the perinatal period (after the 7th day of life) are being treated as living babies.

The live births receive a financial allowance; they are taken to the social department [MOLSA] *where they receive a single financial allowance. As far as I know the stillbirths do not receive that. I don't know about the difference between amounts depending on the* [sequential] *number of the child. It is beyond my work.* (Ob/gyn, 3.4.6.1, IDI, marz)

I know that for the 1st and 2nd children the amount is the same, the 3rd one is 1,000,000 AMD (I think they provide 500,000 of this to the parent and another 500,000 is kept in the form of a mortgage which is then used for educational purposes. In case of stillbirth you do not receive a one-time financial allowance, because there is no birth certificate. (Neonatologist, 3.4.6.2, IDI, Yerevan)

I think there is no significant difference [in the amount of allowance depending from the time of child's death]. *I don't know. We had a case that caused some troubles when registering it. One of twins was dead and the other one was alive and we could not find the law on how the similar cases should be reported. Eventually we wrote a financial allowance for two live births.* (Ob/gyn, 3.4.6.3, IDI, Yerevan)

I do not know whether parents are provided with financial allowances or with any benefits intended for dead babies. This question is dark for us. (Neonatologist/ob/gyn, 3.4.6.4, FGD, marz)

But if we are talking about stillbirths, what kind of financial allowance parents could receive? (Neonatologist, 3.4.6.5, FGD, Yerevan)

The money is given to a woman for the delivery, regardless of whether or not the baby dies. If the baby dies on the 7th day after birth then this isn't the woman's fault, so if the birth is registered at the CSARB then they will receive this payment. However if the baby is born dead and there is no birth certificate, or if the certificate has already been turned in to the funeral service once the baby has died after a few days, then the parents will not have a birth certificate on the basis of which the allowance is given. (Neonatologist, 3.4.6.6, FGD, Yerevan)

The stillbirth does not receive a financial allowance, the 7 days also will not receive… But newborns that died between 7-14 days may have time to receive [it] *from the MOLSA.* (Neonatologist/ob/gyn, 3.4.6.7, FGD, marz)

If parents obtain a birth certificate and present it to the Ministry of Social Affairs and Labor, then they can receive financial allowance. (Neonatologist, 3.4.6.8, FGD, Yerevan)

I don't have much experience regarding this [differences in financial allowance], but I have had a case, when I was asked to register a baby as a live birth, and I was told that if registering that way the parents will receive a financial allowance. But it was the sole case, and those parents were highly informed on that issue, as they mentioned that the main purpose to have the baby was to receive the money. These types of things exist but certainly we don't violate such rules. (Ob/gyn, 3.4.6.9, IDI, Yerevan)

In case of stillbirth parents receive 50.000 AMD. In general, in case of perinatal death the given financial allowance is 50.000 AMD. If the 3rd child died within 7 days of life, then the parents will receive 50.000 drams, and the child will not be counted when deciding the next newborn's number. However, if the 3rd child died during the 8, 9 or 10 days, in one word after 7 days, then the financial allowance will be 1.000000 AMD and this child will be taken into account when calculating the next newborn's number. (Policy maker, 3.4.6.10, IDI, Yerevan)

The study participants unanimously denied the possibility of late registration of a newborn's death for allowing parents to receive financial benefits, stating that every detail is constantly recorded and, as soon as the baby dies, all the information is provided to the authorities making it impossible to misreport. In one FGD with ob/gyns and neonatologists, one of the participants insisted that it was possible to postpone the registration of child's death in order to receive the benefits. This was met with glares and strict comments from the group members, such as "Have

you heard? Of course, not!" and "Why don't you provide your personal information, name and surname as well?!"

No, when a child dies, the morgue and the hospital become aware of it. So it [late registration of the death to receive benefits] *cannot happen.* (Midwife, 3.4.6.11, FGD, marz)

Late? We register hours and minutes immediately after the birth. How can misreporting occur? (Midwife, 3.4.6.12, FGD, Yerevan)

Even when parents express a desire to change the date [of the child's death] *for example, April 7 to April 8… it's even impossible to register the delivery time one hour later than the actual birth time.* (Midwife, 3.4.6.13, FGD, Yerevan)

This is not the sphere of our work, but if they [officials from the MOLSA] *want they may do anything. How many cases were disclosed on dead persons that have received the retirement pension? The same way could be done with the child birth allowances.* (Neonatologist/ob/gyn, 3.4.6.14, FGD, marz)

In addition, a few participants mentioned that even with healthy babies, the procedure of receiving child birth allowance is often very difficult and time consuming. Some participants believed that in many cases parents don't receive the allowance at all or receive it too late because of artificially created difficulties, even though the allowance could be the reason for having given birth to third or higher-order children in poor families. A policy maker noted that parents should be informed from the hospital staff that the case of stillbirth/neonatal death was registered in the CSARB and that they can receive a document certifying the fact of registration from there, but this point is not included in the existing regulations and in practice parents are often left uninformed about the registration and their right to receive child birth allowance.

Also, the amount of the allowance for the first and second child (50,000 AMD) is perceived as too small. One participant brought an example when parents of a newborn calculated the amount of money they needed to spend for buying basic things for the baby, which was about 80.000 drams per month. Besides, the participant stressed the role of the financial allowance in obtaining birth certificates as soon as possible, because often the financial allowance serves as a motivation for receiving birth certificates on time.

…I know that everyone says that it is difficult to receive that money. I think there is no difference depending on when the [child's] *death has occurred. …However, they* [parents] *always complain, especially for 3rd and 4th child, when they have to receive a little bit more. They say, "They* [MOLSA officials] *torture us telling that we have to bring this/that paper, document...and we have spent so much money"...* (Midwife, 3.4.6.15, IDI, Yerevan)

Even if there is a financial allowance by law that the parent must receive, today, none of our parents receives it. Not because of the documents we give... It does not have anything to do with any hospital. If there is such kind of law, probably the CSARB does not give referral or if it gives the referral then probably the MOLSA does not give [the money], which tries to postpone it by saying "come today, come tomorrow". Maybe they [the government] transfer that money but people at the lower level use that money, thinking that "now I am a head of the MOLSA, I can use that money and when I have money I will return that. It is Ok, let mothers wait... they don't understand." I think that is the problem... (Midwife, 3.4.6.16, IDI, Yerevan)

Sometimes it drags on. I know from my daughter's example, our personal experience… for example, she is registered at one place but resides elsewhere. You must transfer your registration from one place to the other... The infant's social card… that is not among the documents required by the maternity hospital, however it is required by the MOLSA. (Midwife, 3.4.6.17, FGD, Yerevan)

As far as I know there is a limit, after which they don't give the financial benefits. (Neonatologist/ob/gyn, 3.4.6.18, FGD, marz)

The financial allowance is transferred so late that even those who are eligible to receive it may not get it. (Neonatologist/ob/gyn, 3.4.6.14, FGD, marz)

Even a one month newborn will not receive it [birth allowance]. (Neonatologist/ob/gyn, 3.4.6.18, FGD, marz)

In most cases, the financial allowance is the reason for having giving birth to a child. For the people who are poor... after the second child... the third, the forth... they do not think that the money will end and they will still have to take care of the children. (Midwife, 3.4.6.19, FGD, marz)

It is necessary to initiate steps for improving the social conditions of pregnant women. Many of them live in extremely bad conditions. …There are even pregnant women that become pregnant to receive financial allowance and maternity allowance… (Midwife, 3.4.6.13, FGD, Yerevan)

I believe a special point should be added to the existing standards stating that parents should be informed about the registration of death, and that they can receive a notification form about it....
None of our procedures provide the point that the healthcare personnel must inform the parents about the registration. So they have to be informed that the case is being registered, and they can receive a notification about it if they would so desire; moreover this should then be noted in the medical forms. So even though they [healthcare personnel] *insist that the parents have been notified orally, in reality none of this is done.* (Policy maker, 3.4.6.20, IDI, Yerevan)

Sometimes they [parents] *complain ... for receiving the same 50,000 drams financial allowance for the first and for the second child. ...I have heard such kind of complains.* (Midwife, 3.4.6.21, FGD, marz)

Actually, I think that the MOLSA needs to increase the financial allowance. I mean, 50.000 is such a small amount. There was a case when parents of the newborn came to me and said that their minimal calculations show that only for infant formula and diapers they need minimum of 80.000 drams per month. So the financial allowance must be increased. The financial allowance for the first child is too small… [The participant was feeling pity]. *Currently, parents take the birth certificate as soon as possible in order to receive that financial allowance.* (CSARB, 3.4.6.22, IDI, Yerevan)

4. MAIN FINDINGS

Data from NIH and NSS on livebirths, stillbirths, and neonatal deaths

Livebirths

- According to the available data, the rate of livebirth in Armenia declined more than twice during the period of 1990-2000, after which it was stabilized.
- Comparison of data on livebirth from NSS and NIH revealed no consistent pattern with some periods when NSS numbers exceeded NIH numbers (1995-99, 2009-13) and some others when NIH numbers exceeded NSS numbers (2000-03).
- Possible reasons for the discrepancy between these two sources include omission of some home births from NIH data, omission of births taking place in families of non-Armenian citizens from NSS data, omission of births in Armenian families occurring outside Armenia from NIH data, and, less probably, incomplete coverage with annual reporting of all obstetric services in the country and/or incomplete reporting of registered births by them.
- Further case-based investigation is needed to explain the exact reasons for the differences between the NSS and NIH numbers of livebirth.

Stillbirths

- Stillbirth rates were generally higher according to NIH data compared to NSS data, although an opposite pattern was also sometimes observed.
- Stillbirth rate has increased from 10.6 per 1000 total births in 1990 to 17.0 per 1000 total births in 2014, while infant mortality rate has decreased from 18.3 to 8.7 per 1000 live births during the same period. The stillbirth to infant mortality ratio was 2:1 in 2014, while it should be 1:1 based on literature estimates.
- The observed uneven increase in stillbirth rates since early 1990s in Armenia cannot be explained solely with the adoption of WHO ICD 10th definition for stillbirth and livebirth during that period, as the latter change causes an estimated 40% increase, while in Armenia the increase was 70-100%.
- The increase in stillbirth rates was mainly attributable to increasing rates among those neonates born with extremely low birth weight (<1000 grams). The share of under-1000 gram births among all stillbirths increased considerably and was 61.3% in 2014.

- The proportion of under-1000 gram births among live births was constantly negligible (0.2%) and has not increased after changing the delivery threshold from 28 to 22 weeks of gestation.
- Despite relatively high stillbirth rates in the country, intrapartum stillbirths constituted only 11.4% of all stillbirths in 2014, possibly indicating a tendency of underreporting intrapartum stillbirths and overreporting antepartum ones.
- While one-third to half of all livebirths from the closest marzes occur in Yerevan, about 80% of stillbirths among women from the closest marzes and about 60% of those from the rest of the marzes (except Shirak) take place in Yerevan hospitals .
- There was clear increasing trend of stillbirth rates in the marzes since 2005 (NSS data), while Yerevan rates varied but with a milder increasing tendency, indirectly pointing out that the rate of extremely preterm deliveries increases especially among women from the marzes.

Neonatal deaths

- NSS does not provide data on distribution of stillbirths, livebirths, or neonatal deaths by weight, gestational age, diagnosis, or any other health- or medical service-related domain, therefore NIH is the only source for such statistics.
- Neonatal deaths constituted over 70% of all infant deaths in Armenia in 2014 and 75% of these deaths occurred during early neonatal period, including 50% of early neonatal deaths occurring within the first day of life, which is consistent with the worldwide estimates.
- The rate of early neonatal mortality in Armenia demonstrated consistent decreasing trend since early 2000s, while an opposite pattern was expected given the widened indications for diagnosing livebirth and the increasing rate of stillbirth during the same period.
- The stillbirth to early neonatal mortality ratio in Armenia is 3:1, while the usual ratio in WHO EURO B group countries (Armenia belongs to) is 1.2:1.
- This situation indirectly indicates a possible tendency of overestimating stillbirth rates while underestimating early neonatal mortality rates.

Hospital-level data

- About three-fourths of all stillbirths and early neonatal deaths in Armenia occur in Yerevan, of which over four-fifth of stillbirths and about three-fourth of early neonatal deaths take place in three major maternity hospitals – RHPOGC, M&CHPC and “Erebuni”.

- Among these three hospitals, RHPOGC has the biggest share of stillbirths and early neonatal deaths occurring in these facilities – two-thirds of both, while its share of livebirths is only one-third.
- RHPOGC accounts for 9% of all livebirths, 18% of all early neonatal deaths, and as much as 41% of all stillbirths occurring in Armenia.
- The rate of stillbirths in RHPOGC in 2015 was 83.2 per 1000 total births taking place in that center, which exceeded the similar rate in "Erebuni" hospital three times and in M&CHPC – 4.4 times.
- Stillbirth rates demonstrated an increasing trend in RHPOGC and "Erebuni" hospitals during the last 8 years, while no such tendency was observed in M&CHPC, the remaining maternity hospitals in Yerevan, or maternity services in marzes.
- In RHPOGC and "Erebuni" hospital, the proportion of livebirths among under-1000 gram births is three times lower than that in M&CHPC, 85% lower than the average proportion in the remaining maternity hospitals in Yerevan and 50% lower than the average proportion in marz hospitals.
- The rate of early neonatal mortality in RHPOGC in 2015 was 9.1 per 1000 livebirths, which again exceeded the corresponding rates in the remaining hospitals 3.5-5.7 times.
- As eight of the 12 maternity hospitals in Yerevan are considered tertiary hospitals and referral centers, the huge difference in stillbirth and early neonatal mortality rates between RHPOGC and the remaining maternity hospitals cannot be solely explained by RHPOGC being the only hospital on the "first line" for referrals of complicated cases from the marzes.
- The available data indicates that improving the situation even solely in RHPOGC may have great impact on the stillbirth rates in the country, as this facility accounts for over 40% of all cases of stillbirths in Armenia.

Providers' knowledge on the new definitions

- The mean knowledge score of providers on the WHO 10th classification definitions for livebirth, stillbirth, and perinatal mortality, their registration and reporting was 7.3 of 15 or 48.7%.

- The highest score was found among neonatologists (10.3 or 68.7%), followed by ob/gyns from in-patient settings (8.4 or 56.0%) and ob/gyns from out-patient settings (6.1 or 40.7%), while midwifes had the lowest mean knowledge score (5.1 or 34.0%).
- The highest proportion (86.1%) of correct answers received the question on the term when perinatal period starts (22nd week of gestation), while the lowest (7.9%) – the knowledge that health facilities carry the responsibility for registering death cases of under-28 day old children in CSAR bodies.
- Similar to the findings of MOH study in 2009, the demonstrated theoretical knowledge on current definitions of livebirth and stillbirth was much higher among providers, than their ability to apply it in a life situation.
- Overall, providers' knowledge on livebirth, stillbirth and neonatal death diagnosis and registration has decreased since the MOH study in 2009.
- Knowledge deficit among providers on current definitions of livebirth and stillbirth and their implication in practice could be among the reasons contributing to some misreporting of livebirths, stillbirths, and neonatal deaths in Armenia.

Qualitative study findings

Transition to the new definitions

- The discussions and interviews during this study were generally accompanied with certain amount of unease and caution making an impression that participants were not willing to give honest opinions on the discussed themes and were skeptical about the possibility of any positive changes in the result of this study.
- A number of participants thought that the live birth and stillbirth definitions are the same and no changes were introduced here. Signs of livebirth they mentioned included heartbeat, breathing, umbilical cord pulsation, muscular movements, muscle tone, skin coloration and crying, but they gave different priority to these signs valuing heartbeat and breathing over the others.
- Midwifes were the least informed category of the participants, sometimes being unable to mention even one sign of livebirth.

- While participants agreed that the shift to the new definitions has occurred completely, when it refers to formal registration and reporting, they disagreed that the shift has been completely introduced in the actual practice.
- The major issue with the shift was that while babies born with extreme prematurity require special conditions and equipment to survive, no sufficient preparations were made in the healthcare sector for that. As a result, the shift was considered meaningless for marzes and even for the majority of hospitals in Yerevan, because of the lack of necessary technology to enable taking care of extremely premature children.
- The shift to the new definitions was perceived by many participants as a result of mechanically following the example of other countries, while few participants viewed this change as an attempt to improve the care of neonates or to obtain internationally comparable indicators.
- The participants generally agreed that the change in the definitions of abortion and delivery has increased the number of registered stillbirth, as many cases of stillbirth happen between 22 to 28 weeks of gestation.
- Some participants expressed doubt about the long-term effects of extreme prematurity on child's further development. They expressed a desire to know the long-term outcomes of extreme prematurity in Armenia to understand what exactly they were working towards and whether the results were worth the efforts made.
- According to the participants, the change in the cut-point between abortion and delivery had positive financial consequences for both the facility and medical staff, as births at 22-27 weeks of gestation are covered by OCSC program and this was noted as the main positive aspect of the change.
- However, some participants noted that they receive no/very little financial benefit from this shift, and that the hospital heads get the main benefit from it, not the staff. Also, according to them, the high cost of taking care for extremely low-birthweight neonates outweighs the financial benefit related to the increased number of deliveries.
- WC ob/gyns reported that for financial reasons, maternity services are now interested in attending more pregnant women. Therefore, they recruit highly increased number of pregnant women via all means while being unable to provide them the needed antenatal care

because of being overloaded. Setting a cap for the number of patients that could be enrolled per physician was suggested as one possible solution for this problem.

Circumstances under which a fetus/live-born could be registered as stillborn

- Participants agreed that the stillbirth rates have increased in Armenia and, along the common causes of stillbirth (infections, including those brought by labor migrants, placental abnormalities, congenital defects, genetic anomalies, intrauterine asphyxia, umbilical cord wrapping, etc.), they stressed the importance of unfavorable ecology, nutrition and overall social conditions as factors underlying the negative dynamic in stillbirth rates.
- Limitations in testing and treatment of women (and their partners) to prevent stillbirth were brought to attention and viewed as a result of low awareness of couples about the importance of preconception diagnosis and low affordability of these tests and treatment for them.
- The existing package of diagnostic tests for pregnant women included in the state order was considered insufficient. In particular, the need for regular dental examinations, genetic testing, and more flexible schedule for ultrasound examinations were suggested.
- Although the majority of participants rejected the possibility of registering a newborn that demonstrated some signs of life before dying as stillbirth, some participants acknowledged such possibility and listed possible reasons, including unintentional misreporting due to poor knowledge of the signs of livebirth or prioritizing some signs (e.g., breathing and heartbeat) over others (muscular movements and cord pulsation).
- Some key informants did not reject the possibility of registering some portion of early neonatal deaths as stillbirths purposefully and made a suggestion to introduce some controlling mechanism in the maternity hospitals to address this issue.
- Mismatches between WC and hospital specialists in gestational age calculation happen "very often". Sometimes, the difference can reach to one month, and a two-week difference is perceived as normal. In case of inconsistencies either the average of the two estimates or the estimate of the hospital ob/gyn is taken as the final.
- Pregnancy terminations due to parental will are conducted before 12-14th weeks of gestation and are mainly attributable to poor socioeconomic conditions or selective gender preferences of parents (mainly, boys are preferred). Pregnancy terminations at later terms are conducted only with medical indications (e.g., severe fetal defect).

- With older equipment, diagnosis of fetal defects is conducted only after 22nd week of gestation. Therefore, to avoid perinatal death cases due to late termination of pregnancies because of lately diagnosed birth defects, appropriate three-dimensional ultrasound equipment is needed, especially in marzes.
- Although many participants stated that when the pregnancy is terminated due to fetal defect after 22nd week and the fetus shows signs of life, the case is reported accurately as live-born, a few disagreed stating that the cases with birth defects incompatible with life are always reported as stillbirths, regardless of being born alive or not, or the duration of life.
- A number of participants reported a practice of registering preterm live-born babies and even babies born at higher gestational ages with few signs of life as stillbirth. The main reasons for such violations were listed as ensuring a small number of neonatal deaths and having fewer problems (less paperwork, less issues with parents) in case of stillbirth.
- WC representatives reported that sometimes maternity hospitals push them to modify the dates so that a woman who needs termination of pregnancy at earlier-than-22-weeks term receives Obstetric Care State Certificate to allow the hospital reporting the case as delivery and getting financial benefit from the procedure.
- Although the majority of participants rejected the possibility of over-reporting the term of pregnancy in case of late termination of pregnancy (to allow the case to be reimbursed as a delivery), a few participants mentioned that sometimes, if the term is slightly less than 22 weeks, the hospital staff misreport it as 22-weeks or over, so that it is considered a delivery.
- Some participants did not perceive this behavior as misreporting. Others stated that changing pregnancy term by up to 2 weeks cannot be considered as misreporting, since no technique could identify the pregnancy term with the accuracy of one week, therefore nobody can blame the ob/gyn in misreporting.
- Hospitals providing higher-level care are more motivated to serve higher number of deliveries, as due to differentiated reimbursement they get more money from SHA for each delivery than hospitals providing first-level care. The same motivation presents for conducting more C-sections, as the cost of C-section is much more than that of vaginal delivery. Thus, the possible risks related to variations in financial reimbursement should be evaluated and the gaps in the system removed to prevent possible misreporting and malpractice.

- Many participants stated that the different approach applied for financing deliveries (under OCSC) and late abortions (none but regular salary) is not fair, as late abortions are being conducted only when medically indicated and are usually complicated cases that demand serious/lengthy efforts from providers.
- Several participants mentioned that mainly the hospital, not the provider benefits from the additional financing for deliveries (in the scope of OCSC). Providers receive very small bonuses if any, thus they are not personally interested in misreporting abortions as deliveries, while their employers (the hospitals) are.
- Providing bonus payment in case of late termination of pregnancies as well or including them under paid-for services were suggested for addressing the issue of reporting late pregnancy terminations as deliveries because of the financial motivation.
- Some participants from FGDs with neonatologists and ob/gyns recognized that there is widespread misreporting of data on stillbirths and neonatal deaths in the country, which is evident from simple comparison of the rates of stillbirths and neonatal mortality in Armenia with the rates in other similar countries.
- Lack of political will to improve the situation and fear of doctors to be fired if reporting the cases accurately were perceived as the main reasons for the existing misreporting, which will become a norm for health care professionals if ignored.

Registration and reporting procedures of livebirths, stillbirths, and neonatal deaths

- The few participants personally involved in the formal procedure of registration and reporting of livebirths, stillbirths, and neonatal deaths perceived the existing procedure as appropriate and saw no need to introduce any changes in it (other than the electronic reporting which is being introduced).
- Many participants were unaware about these procedures and unsure about the definitions of perinatal, early and late neonatal mortalities and the length of life (if any) for a newborn to be registered as livebirth.
- Child Health State Certificate, which ensures state order healthcare for children up to 7 years of age, is provided by maternity hospitals only after parents obtain birth certificate for the child, which, along with the birth allowance from the Ministry of Labor and Social Affairs, are the main incentives for parents to register their newborns in CSAR bodies.

- Although the majority of participants knew that the hospital is responsible for registering stillbirths and neonatal deaths in CSAR bodies, they were unfamiliar with the existing reporting forms and the exact deadline for registration of these cases in CSAR bodies. They were reluctant to complete these forms and considered that in each hospital a designated person (preferably – lawyer) should be responsible for handling the paperwork in these cases.
- Legally non-married status of parents was the main factor delaying the registration of livebirths in CSAR bodies, as in such cases parents needed to apply for fatherhood recognition. This was an issue specific to the marzes and was related to the intent of parents to receive financial allowance for single mothers.
- According to CSARB representatives, in some cases double registration of the birth of a dead neonate is possible when the child's birth is registered in one CSARB shortly after the birth, and then again in another CSARB – together with death registration.
- Although CSAR bodies keep the "Medical certification of death" forms for stillbirths and neonatal deaths in their archives, the forms they use for reporting to NSS do not include child's weight or any other medical information (including the diagnosis), thus NSS generates no any statistics on medical characteristics of stillbirths/neonatal deaths.
- The current deadline of seven days for registration of stillbirths and neonatal deaths in CSAR bodies was still considered rather short, as several factors such as lengthy holidays, the need to bring passport from far distances in case of unexpected delivery, or having invalid passport, all can cause late registration.
- According to CSARB representatives, a stillbirth might be left out from registration in CSAR bodies only in rare cases when it occurred at home and parents did not apply for registration or medical assistance.

Pathological examination in case of stillbirth and neonatal death

- Pathological examination of placenta is important for both stillbirth and neonatal death cases. While the placenta is always sent for autopsy with stillbirth, it is often not sent with a neonate's corps. Therefore, a suggestion was made of keeping a sample of placenta in refrigerator for all births and discarding those only after making sure that the newborn is discharged healthy.

- Coverage of stillbirths and neonatal deaths with autopsy is perceived as very high in the places where this service is available. However, lack of pathologist or pathological unit in the given area, parents' refusal from autopsy, and weight of the fetus less than 500 grams are the major factors interfering with complete coverage of stillbirth and neonatal deaths with pathological examination.
- Pathological diagnosis in received in 2-4 weeks and recorded in the medical history of the mother/newborn. It is not send to the CSARB, not only because the 7 day time limit for registration is usually passed when the diagnosis received but because CSARB is not interested in receiving these diagnoses.
- According to many providers, the results of autopsy are often non-informative, similar to each other, describing only visible defects and general changes and that the diagnoses of physicians and pathologists are almost always the same. Therefore, when a comprehensive examination is needed, providers ask the pathologists to do the autopsy thoroughly.
- According to pathologists, in 20% of stillbirth cases the autopsy diagnoses differ from the diagnoses on the referral forms. Moreover, ob/gyns frequently fill the autopsy referral forms unsatisfactory and even omit the clinical diagnosis. The need to improve both the autopsy referral form and the way it is completed was acknowledged.
- The depth of pathological examinations suffer because some specific tests are paid-for services, but parents often cannot afford those tests or perceive those as unnecessary given that the child is already dead. Therefore, including these examinations in the list of state-ordered services could be a solution for this issue.
- Poor capacities of pathology departments, lack of the opportunity to conduct genetic analysis as a part of pathological examination and absence of virology laboratory were listed as the major challenges for making the results of autopsy informative.
- Shortage of pathology specialists was another challenge the country faces. The perceived reasons included low attractiveness of both the specialization itself and the salary pathologists receive. Increasing pathologists' salaries was suggested as a solution and/or teaching maternity hospital staffs in the areas where there is no pathology service how to take samples from corpses of newborns and preserve those, so that they could be send to Yerevan and examined later-on.

- The interest of maternity hospital staff in learning about autopsy results was perceived as low, possibly because of low trust in those results. The contributing factor to this low interest/lack of trust was lack of collaboration between clinicians and pathologists via joint conferences, discussions, or case reviews to analyze inconsistencies between clinical and pathological diagnoses.
- Considering the extent in which a maternity hospital collaborates with pathological services when making a decision about assigning a higher class to the hospital was suggested.

Financial allowance of childbirth in case of stillbirth and neonatal death

- In general, the level of awareness of the existing legislation on child birth allowance was very low among the participants – many were unaware about the procedure of receiving birth allowance, its size for each particular case and the eligibility criteria for it.
- The study participants unanimously denied the possibility of misreporting/postponing the date of a child's death for allowing parents to receive financial benefit. An exception was an ob/gyn FGD participant telling that it is possible.
- The procedure of receiving child birth allowance was perceived as very difficult and time consuming, because of which parents often do not receive the allowance at all or receive it too late. Also, its amount for the first and second child was considered very low (50,000 AMD).
- Another reason for not receiving birth allowance in case of perinatal death was that parents often are unaware about their right to receive it as they are not informed from the hospital about it, as well as about registration of the case in the CSARB by the hospital and their right to receive a document from the CSARB through which they can receive the allowance.

5. CONCLUSIONS AND RECOMMENDATIONS

- The comparison of Armenia's stillbirth and neonatal mortality rates with the corresponding rates in other comparable countries identified a number of inconsistencies:
  - Higher increase in stillbirth rates than expected after adoption of WHO ICD 10th definitions (70-100% increase instead of an expected 40%)
  - An unusually high stillbirth to infant mortality ratio (2:1 versus an expected 1:1),
  - An unusually high stillbirth to early neonatal mortality ratio (3:1 versus an expected 1.2:1)
  - Opposite direction of change in stillbirth and early neonatal mortality rates (increase of the former and decrease of the latter when the same direction of change for both is expected)
  - Increase in stillbirth rates mainly due to increasing rates among <1000 gram births, that constitute over 60% of all stillbirths and are mainly from marzes
  - No increase in the proportion (0.2%) of under-1000 gram births among live births after changing the delivery threshold from 28 to 22 weeks of gestation.
- The hospital-level data indicated that:
  - RHPOGC accounts for 9% of all livebirths, but as much as 41% of all stillbirths in Armenia.
  - The rates of stillbirths and early neonatal deaths in RHPOGC are several times higher than in other comparable hospitals,
  - The proportions of livebirths among under-1000 gram births in RHPOGC and "Erebuni" hospital are three times lower than that in M&CHPC.
- The study of providers' knowledge on the new definitions of livebirth, stillbirth, and perinatal period identified:
  - Low-than-average mean knowledge of the new definitions among providers
  - Inability to apply theoretical knowledge in the daily practice by a majority
  - Decrease of providers' knowledge on the study subject compared to that in 2009.
- Based on the above-mentioned points and the qualitative study findings, the following conclusions can be made:

- The shift to the new definitions of abortion and delivery; livebirth and stillbirth was introduced incompletely into the actual practice.
- The healthcare sector of Armenia was not ready to make the shift to taking care of extremely premature neonates, mainly in terms of technological capacities.
- At the maternity hospital level, there is a tendency of misreporting some portion of late abortions and early neonatal deaths as stillbirths.
- There are both real and artificial components in the observed increase in stillbirth rates. The factors underlying the real component include:
  - Low affordability of tests to make preconception diagnosis of conditions that could lead to stillbirth
  - Low knowledge among population on the importance of preconception tests
  - Increasing prevalence of STDs among couples because of widespread migrant work among men
  - Lack of adequate technology to diagnose birth defects at earlier stages of pregnancy
  - Low affordability of tests/examinations to identify and treat the causes of stillbirths to prevent their reoccurrence
  - Unfavorable environmental factors, inadequate nutrition and poor socioeconomic conditions.
- The factors underlying the artificial component of the increase in stillbirth rates include:
  - Inadequate knowledge of providers on the signs of livebirth and their selective understanding of the importance of each sign
  - The perception that high neonatal mortality is worse indicator for a hospital than high stillbirth rate
  - The belief that stillbirth requires less paperwork and causes less problems with parents than neonatal death, especially in cases of extremely premature births or pregnancy terminations because of severe birth defects
  - The financial motivation among providers and, in higher extent, hospital heads to report some portion of late abortions as deliveries to get the benefit under the OCSC project.
  - The lack of political will to improve the situation and the fear of doctors to be fired if reporting the cases accurately.

Based on the main findings of the study, the following recommendations can be made for improving the practice of diagnosing, registration and reporting of livebirths, stillbirths and neonatal deaths in Armenia:

- Improve technological capacities of neonatal units both in Yerevan and marz hospitals to enable them caring of extremely low birth weight neonates.
- Introduce controlling mechanisms in maternity hospitals to address the issue of misreporting of some portion of late abortions and early neonatal deaths as stillbirth, paying particular attention to RHPOGC.
- Eliminate financial incentives leading to misreporting and malpractice, including differential payment between late pregnancy terminations and deliveries, vaginal deliveries and C-sections, and hospitals providing different-level care. Instead, introduce other mechanisms of adequate reimbursement of the provided care, which is not case-dependent.
- Eliminate the widespread belief that high neonatal mortality rate is worse indicator for a hospital than high stillbirth rate.
- Increase the knowledge of providers on the new definitions of livebirth, stillbirth, and neonatal death, and their practical implication.
- Improve the connection and collaboration between WCs and maternity hospitals. Set a cup of the number of pregnant women each specialist could recruit.
- Extend the package of diagnostic tests for pregnant women included in the state order and the awareness of population on the importance of preconception testing.
- Equip WCs (both in Yerevan and marzes) with appropriate three-dimensional ultrasound equipment to make possible early identification of severe fetal defects.
- Think of extending the deadline for registration of perinatal and late neonatal deaths in CSAR bodies and designate a position in hospital responsible for carrying out this task.
- Improve capacities of pathology departments and increase salaries of pathologists to fill the existing gap in pathological departments and specialists.
- Add to the Basic Benefits Package more specific tests (genetic, virology, etc.) that could help to identify and treat the specific conditions resulting in stillbirth or neonatal death.

- Encourage tighter collaboration between pathologists and providers through regular joint conferences and case reviews to analyze inconsistencies between clinical and pathological diagnoses of stillbirths and neonatal deaths.
- Simplify the procedure for receiving child birth allowance and inform parents about their right to receive the allowance in case of perinatal death.
- Conduct further case-based investigation to identify the exact reasons for the differences between the NSS and NIH numbers of livebirth, stillbirth, and neonatal death.

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7. APPENDICES

Appendix 1. FGD guides (in English and Armenian)

Focus Group Discussion with Healthcare Providers

Consent form

Hello. My name is …… . I am a researcher at the Center for Health Services Research and Development of the American University of Armenia. At the request of UNICEF Armenia and the Ministry of Health, our Center is conducting a Research on Live Birth and Stillbirth Registration and Reporting Practices in Armenia. The aim of this study is to improve the practices of classification, registration and reporting of stillbirths and neonatal deaths.

This discussion, which you have been invited to attend, is a part of this project. You have been selected to participate in this study, as you are a specialists working in an area related to the identification, registration and reporting of stillbirths and neonatal deaths. Your experience, views and suggestions will help us to understand the current situation with registration and reporting of stillbirths and neonatal deaths and find solutions for improvement.

The discussion will last about an hour and a half. After receiving your verbal consent for participation, we will ask each of you to complete a short questionnaire. Then we will provide you with some discussion themes and urge you to express your ideas concerning these matters. Your participation is voluntary. You can stop it at any time. Also, you may refuse to answer any question, if you so wish. There will be no any consequences for you if you decide to participate or decline to do so. You will not receive any direct benefits from participation either, but your active participation will assist us in developing suggestions to improve the existing practices.

During the discussion we will take notes and, if you allow, we will also audio-record the conversation to ensure that none of the ideas that you express escapes our attention. The discussion will be audio-recorded only if all participants agree to it. Participation carries no risks for you. The information you provide will be kept confidential. All the information received during the study will be summarized and presented as a report containing no any personal or institutional data or contact information.

If you have any questions regarding this study you can call the study coordinator Anahit Demirchyan (060 61 25 62). If you feel you have not been treated fairly during the study or think your participation in the study has damaged you in any way, you can contact the IRB Human Participants Administrator of the American University of Armenia, Kristina Hakobyan (060 61 25 61).

Do you agree to participate? If yes shall we start?
Do you agree to audio-recording? Please say yes or no.
If you are ready now we will start.

Focus Group Discussion Guide (Hospital Ob/gyns, Neonatologists and Midwives)

Date: _____ Time: _____

Place: _____

Moderator: _____

Recorder: _____

Good afternoon and thank you very much for coming. My name is _____. I represent the School of Public Health of the American University of Armenia. With UNICEF's support, we conduct a study to explore the main obstacles to ensure adequate registration and reporting of stillbirth and live birth, as well as early and late neonatal mortality in Armenia. We would like to ask you to share your expertise in this area, which is very valuable for us. I will suggest you the themes for the discussion and ask all of you to express your opinion on those themes. It would be better if the discussion will pass as a free conversation, and everybody will participate in it without waiting to his turn. As mentioned in the informed consent form, the information you will provide will be fully confidential, and your name will not appear with that information. So, please, express your ideas freely. We will ask you to complete a short questionnaire first, and then we will start the discussion. If you don't mind, we will tape-record our conversation so that no any important piece of it is lost. Is it Ok?
Please, let us begin now.

1. KNOWLEDGE ON DEFINITION CHANGES: ABORTION AND DELIVERY, STILLBIRTH AND LIVE BIRTH

Fetus and newborn, live birth and stillbirth

1.1 In your institution, who is responsible for the final diagnosis of stillbirths? Does the diagnosis depend from the term of delivery or baby's birth weight? If yes, how? For extremely low-weight babies (< 1000 g), how many hours after birth does the baby have to die to still be considered as stillbirth?

1.2 Are there any consequences of moving the cut-point between abortion and delivery from 28 weeks of gestation to 22 weeks of gestation (including financial consequences for you and your facility)?

2 REPORTING AND REGISTRATION OF LIVE BIRTHS, STILLBIRTHS, AND NEONATAL DEATHS

Live birth registration

2.1 Could you please describe the formal procedures following the birth of a newborn? What documents are filled in and by whom? How does the hospital contribute to the registration of the newborns in Civil Acts Registration Bodies (CARBs)? How the hospital keeps its own statistics of births?

2.2 Are there any differences in these procedures if the baby was born alive but with less than 1000 g weight? If yes, what are these differences?

2.3 In your opinion, in what cases live births are not registered in CARBs or are registered late? Is there anything that could be done to reduce late registration of births? How easy is the procedure for birth registration in Armenia? How this procedure can be improved?

Stillbirth registration

2.4 In your institution, who is responsible for the final diagnosis of stillbirths? Does the diagnosis depend from the term of delivery or baby's birth weight? If yes, how? For extremely low-weight babies (< 1000 g), how many hours after birth does the baby have to die to still be considered as stillbirth?

2.5 Could you please describe the procedures following the birth of a dead newborn? Who takes the baby and what do they do? Are the bodies returned to the parents? If not, where do they go?

2.6 Please describe the reporting procedure following the birth of a dead newborn: is there any additional documents filled? By whom? Which body does the hospital report to about the birth of a dead newborn? Is there any deadline for this reporting?

2.7 Is there any person in the hospital officially designated as responsible for registration and reporting of perinatal deaths? Does the hospital keep information on these cases? How?

2.8 Do you think there could be some circumstances when the birth is reported as stillbirth when in reality the newborn demonstrated some signs of life before dying? What could be these circumstances?

2.9 Could this be the case with extremely premature infants (22-26 weeks)? Have you ever heard of cases when the baby was born alive and was reported as a stillbirth? Would you like to share the story?

2.10 In your opinion what are the main causes of stillbirth and at what gestational age does this happen more frequently? Why?

2.11 Based on what is gestational age calculated (during pregnancy or after delivery/miscarriage)? How often does it happen that the gestational age is incorrectly calculated? Could you recall any case that it was incorrectly reported to you by women's consultation? Which one do you report?

2.12 Do you see many newborns with birth defects in your practice? At what gestational age are they usually diagnosed? What happens with these pregnancies? When the pregnancy is terminated because of a birth defect, is it usually resolves in a live birth or a stillbirth? How is it reported? Is there any difference in you payments in case of stillbirth versus live birth?

2.13 Is provider payment the same if a pregnancy is terminated at 12-22 weeks of gestation compared to higher term of pregnancy? If yes, is it fair? What can be done to address this issue? What could be the possible consequences if the issue of financing remains unsolved?

2.14 What are the indications for conducting autopsy in the case of stillbirth? Are there any restrictions for autopsy related to gestational age or birth weight of the newborn? If yes, what restrictions? Are there any obstacles/difficulties for conducting autopsy of stillbirths? What obstacles?

2.15 What is the average percentage of stillbirths that undergo autopsy in your institution? Do you receive the results of autopsy? Is the diagnosis made during the autopsy registered in hospital

documentation? In what documentation is it registered? Is the autopsy diagnosis reported to CSARB? If no, why? What can be done to have accurate causal structure of stillbirth in Armenia?

Registration of perinatal and neonatal deaths

2.16 Are there any differences in birth registration procedures if the baby was born alive but died during the first week? What documents are filled by the hospital in these cases? Does the hospital carry any responsibility for registration of these cases in CSARB? What responsibility? Is there any timeframe for registration of these cases? Does the hospital keep its own registration of these cases? How?

2.17 What are the definitions of perinatal mortality, early neonatal mortality and late neonatal mortality? What documents are filled by the healthcare facility in the case of late neonatal death? If a neonate dies during 7-28th days of life, is this case included in the maternity's annual reporting form as late neonatal death? If a child is transferred to other hospital and dies there within late neonatal period, is this case included in that hospital's annual reporting form as late neonatal death?

2.18 Does any healthcare facility carry a responsibility for registration of the cases of late neonatal mortality in CSARB? If yes, what facility and what responsibility? Is there any timeframe for registration of these cases?

2.19 Are there any differences in the amount of financial allowance received by parents (for that child and for calculating sequential number of future children) if the child was born dead or died during the first week or died during the 2-4th weeks of life? If yes, what differences?

2.20 Do you think there could be cases of misreporting (postponing) the day of child's death to allow parents receiving bigger allowance? How often this might happen?

Summarizing question

Do you have suggestions on what could be done better in Armenia to improve the registration of live births and stillbirths?

Thank you very much for your time and contribution, which we highly appreciate!

Focus Group Discussion Guide (Ob/gyns from Women's Consultations)

Date: _____ Time: _____

Place: _____

Moderator: _____

Recorder: _____

Good afternoon and thank you very much for coming. My name is _____. I represent the School of Public Health of the American University of Armenia. With UNICEF's support, we conduct a study to explore the main obstacles to ensure adequate registration and reporting of stillbirth and live birth, as well as early and late neonatal mortality in Armenia. We would like to ask you to share your expertise in this area, which is very valuable for us. I will suggest you the themes for the discussion and ask all of you to express your opinion on those themes. It would be better if the discussion will pass as a free conversation, and everybody will participate in it without waiting to his turn. As mentioned in the informed consent form, the information you will provide will be fully confidential, and your name will not appear with that information. So, please, express your ideas freely. We will ask you to complete a short questionnaire first, and then we will start the discussion. If you don't mind, we will tape-record our conversation so that no any important piece of it is lost. Is it Ok?
Please, let us begin now.

1 OPINION ON DEFINITION CHANGES: ABORTION AND DELIVERY

1.1 Please, express your opinion about the changes that were introduced in the definitions of abortion and delivery (or fetus and newborn). What is the current definition of delivery? What was changed in this definition, when and why? Do you think this change was necessary? For what reason?

1.2 In your opinion, how the changes in the definitions of abortion and delivery influenced the statistics of live births and stillbirths in Armenia? Do you think the shift to the new definitions happened completely or not? If not, why?

2 STILLBIRTHS AND LATE ABORTIONS: CAUSES AND REPORTING

2.1 In your opinion, what are the main causes of stillbirth and at what gestational age does this happen more frequently? Why?

2.2 At what gestational age fetal defects are usually diagnosed? What happens with these pregnancies? When the pregnancy is terminated because of a birth defect, is it usually resolves in a live birth or a stillbirth? How is it usually reported?

2.3 How often early termination of pregnancy (between ~ 20^{th} and 37^{th} weeks of gestation) is indicated medically and how often it is due to parents' will? Till what gestational age induced abortion can be conducted? What is the usual practice if parents don't want the baby at a later term of pregnancy? Is there a possibility that some portion of late abortions is registered as stillbirth?

2.4 Do you receive information from maternity hospitals about the results of delivery of women supervised in your institution during pregnancy? Are there any forms to be completed by the hospital and sent back to you? Who delivers these forms? What information these forms provide?

2.5 For what proportion of delivered women do you receive these forms? How and where these forms are kept? Do you use these forms for your statistics and reporting?

2.6 Based on what is gestational age calculated? How often does it happen that the gestational age you calculate does not coincide with that calculated in the maternity hospital (and recorded in the forms they send to you)? Could you recall any case of such inconsistency? Do you have any explanation for such difference?

2.7 Do you think there could be some circumstances when the birth is reported as stillbirth when in reality the newborn demonstrated some signs of life before dying? What could be these circumstances? Could this be the case with extremely premature infants (22-26 weeks)? Or with newborns having serious birth defects? Why this could happen?

2.8 Do you think the current way of reimbursing healthcare facilities for the cases of abortions versus deliveries could play a role in reporting a case of a late abortion as stillbirth? What could be done in this respect to assure correct statistics of stillbirths?

Summarizing question

Do you have something to add on what could be done better in Armenia to improve the statistics of stillbirths?

Thank you very much for your time and contribution, which we highly appreciate!

Բուժաշխատողների հետ խմբային քննարկման իրազեկ համաձայնագիր

Բարև Ձեզ, իմ անունը …… է: Ես Հայաստանի ամերիկյան համալսարանի Առողջապահական ծառայությունների հետազոտման և զարգացման կենտրոնի գիտաշխատող եմ: ՅՈՒՆԻՍԵՖ-ի և Առողջապահության նախարարության պատվերով մեր կենտրոնն իրականացնում է որակական հետազոտություն՝ Հայաստանում կենդանածնության և մեռելածնության գրանցման և հաշվետվության գործելակերպերի վերաբերյալ: Հետազոտության նպատակն է բարելավել մեռելածնության և նորածնային մահացության դասակարգման, գրանցման և հաշվետվության գործընթացները:

Նշված հետազոտության մաս է կազմում այս քննարկումը, որին Դուք հրավիրվել եք մասնակցելու, քանի որ Ձեր աշխատանքն առնչվում է մեռելածնության և նորածնային մահացության դեպքերի ախտորոշմանը, գրանցմանն ու հաշվետվությանը: Ձեր փորձը, տեսակետներն ու մոտեցումները կօգնեն մեզ պարզել այս ասպարեզում ներկայումս տիրող իրավիճակը և առաջարկել բարելավման ուղիներ:

Հարցազրույցը կտևի մոտ մեկ ու կես ժամ: Մասնակցելու Ձեր բանավոր համաձայնությունն ստանալուց հետո մենք կառաջարկենք Ձեզ լրացնել կարճ հարցաթերթիկ: Այնուհետև կսկսենք քննարկումը, որի ժամանակ Ձեզ կառաջարկենք թեմաներ և կխնդրենք արտահայտվել դրանց շուրջ: Ձեր մասնակցությունը կամավոր է: Դուք կարող եք ցանկացած պահի ընդհատել այն: Կարող եք նաև չպատասխանել որևէ հարցի, եթե չեք ցանկանում: Հարցազրույցին մասնակցելը կամ դրանից հրաժարվելը Ձեզ համար որևէ հետևանք չի ունենա: Դուք որևէ ուղղակի օգուտ ևս չեք ստանա մասնակցությունից, սակայն Ձեր մասնակցությունը կօգնի համակարգը բարելավելու առաջարկներ կատարել:

Քննարկման ընթացքում մենք գրի կառնենք և, եթե թույլ տաք, կձայնագրենք քննարկումը, որպեսզի այստեղ հնչած ոչ մի գաղափար չվրիպի մեր ուշադրությունից: Քննարկումը կձայնագրվի միայն բոլոր մասնակիցների համաձայնության դեպքում: Մասնակցությունը որևէ ռիսկ չի պարունակում Ձեզ համար: Ձեր տրամադրած տեղեկությունները կպահվեն գաղտնի: Հետազոտության ընթացքում ստացված բոլոր տեղեկությունները ի մի կբերվեն և կներկայացվեն միայն ընդհանրացված ձևով՝ չպարունակելով որևէ անուն, հաստատության անուն կամ անձնական տվյալ:

Այս հետազոտության վերաբերյալ հարցեր ունենալու դեպքում Դուք կարող եք զանգահարել հետազոտության համակարգող Անահիտ Դեմիրճյանին՝ 060 61 25 62 հեռախոսահամարով: Եթե մտածեք, որ այս հետազոտությանը մասնակցելու ընթացքում Ձեզ լավ չեն վերաբերվել կամ որ մասնակցությունը Ձեզ վնաս է պատճառել, կարող եք զանգահարել Հայաստանի ամերիկյան համալսարանի Էթիկայի հանձնաժողովի քարտուղար Քրիստինա Հակոբյանին՝ 060 61 25 61 հեռախոսահամարով:

Դուք համաձա՞յն եք մասնակցել: Եթե այո, կարո՞ղ ենք սկսել:

Դուք համաձա՞յ ն եք, որ ես միացնեմ ձայնագրիչը: Խնդրում եմ ասեք՝ ԱՅՈ կամ ՈՉ:

Եթե Դուք պատրաստ եք, կարող ենք սկսել:

Խմբային քննարկման ուղեցույց
(Հիվանդանոցի մանկաբարձ/գինեկոլոգներ, նեոնատոլոգներ և մանկաբարձներ)

Ամսաթիվ: _____ **Ժամ:** _____
Վայր: _____
Վարող: _____
Գրանցող: _____

Բարի օր և շնորհակալություն, որ համաձայնեցիք զրուցել մեզ հետ: Իմ անունը _____: Ես ներկայացնում եմ Հայաստանի ամերիկյան համալսարանի Հանրային առողջապահության ֆակուլտետը: ՅՈՒՆԻՍԵՖ-ի աջակցությամբ մենք իրականացնում ենք հետազոտություն՝ ուսումնասիրելու կենդանածնության և մեռելածնության, ինչպես նաև վաղ և ուշ նորածնային մահացության ճիշտ գրանցմանն ու հաշվետվությանը խոչընդոտող գործոնները: Մենք կցանկանայինք, որ Դուք ներկայացնեիք այդ հարցերի վերաբերյալ Ձեր կարծիքը, որը մեզ համար շատ գնահատելի է: Ես Ձեզ կառաջարկեմ քննարկման թեմաներ և հարցրեք, այնուհանդերձ կխնդրեմ բոլորիդ արտահայտել Ձեր կարծիքներն այդ թեմաների վերաբերյալ: Լավ կլինի, եթե քննարկումը անցնի որպես ազատ զրույց, և բոլորը մասնակցեն առանց իրենց հերթին սպասելու: Խնդրում եմ արտահայտվեք ազատորեն, նկատի ունենալով, որ Ձեր տրամադրած ողջ տեղեկատվությունը մնալու է գաղտնի և Ձեր անունը ոչ մի տեղ չի հրապարակվելու: Նախքան հարցազրույցը սկսելը, կցանկանայինք խնդրել Ձեզ լրացնել կարճ հարցաշար: Եթե չեք առարկում, ես կձայնագրեմ մեր զրույցը, որպեսզի Ձեր արտահայտած ոչ մի կարևոր միտք չվրիպի մեր ուշադրությունից: Դեմ չե՞ք: Խնդրում եմ, թույլ տվեք այժմ սկսել:

1. ՍԱՀՄԱՆՈՒՄՆԵՐԻ ՓՈՓՈԽՈՒԹՅՈՒՆ՝ ՎԻԺՈՒՄ ԵՎ ԾՆՆԴԱԲԵՐՈՒԹՅՈՒՆ, ՄԵՌԵԼԱԾՆՈՒԹՅՈՒՆ ԵՎ ԿԵՆԴԱՆԱԾՆՈՒԹՅՈՒՆ

<u>Պտուղ և նորածին, կենդանածին և մեռելածին</u>

1.1 Ձեր հաստատությունում ո՞վ է ախտորոշում մեռելածնությունը: Այդ ախտորոշումը կախվա՞ծ է ծննդաբերության ժամկետից կամ երեխայի ծննդյան քաշից: Եթե այո, ապա՝ ինչպե՞ս: Ծայրահեղ ցածր քաշով (<1000 գրամ) երեխան ծնվելուց հետո որքա՞ն ժամանակ անց պետք է մահանա, որ համարվի մեռելածին:

1.2 Ըստ Ձեզ, ի՞նչ հետևանքներ է ունեցել վիժման ու ծննդաբերության միջև սահմանը հղիության 28 շաբաթականից 22 շաբաթական ժամկետ տեղափոխելը (այդ թվում՝ ֆինանսական հետևանքները Ձեր և Ձեր հաստատության համար):

2. ԾՆՈՒՆԴՆԵՐԻ, ՄԵՌԵԼԱԾՆՈՒԹՅԱՆ ԵՎ ՆՈՐԱԾՆԱՅԻՆ ՄԱՀԵՐԻ ՀԱՇՎԵՏՎՈՒԹՅՈՒՆԸ ԵՎ ԳՐԱՆՑՈՒՄԸ

<u>Ծնունդների գրանցում</u>

2.1 Նկարագրեք, խնդրեմ, նորածնի ծննդյանը հաջորդող պաշտոնական ընթացակարգը: Ի՞նչ փաստաթղթեր են լրացվում և ու՞մ կողմից: Ինչպե՞ս է հիվանդանոցը նպաստում նորածինների գրանցմանը Քաղաքացիական կացության ակտերի գրանցման (ՔԿԱԳ) մարմիններում: Ինչպե՞ս է հիվանդանոցը պահում ծնունդների վերաբերյալ իր սեփական վիճակագրությունը:

2.2 Արդյո՞ք ծննդի գրանցման ընթացակարգում կան տարբերություններ, եթե երեխան ծնվել է կենդանի, բայց մինչև 1000 գ քաշով: Եթե այո, որո՞նք են դրանք:

2.3 Ըստ Ձեզ, ո՞ր դեպքերում ծնունդը կարող է չգրանցվել ՔԿԱԳ-ում կամ գրանցվել ուշացումով: Հնարավո՞ր է ինչ-որ բան անել՝ այդ դեպքերը նվազեցնելու համար: Որքա՞ն հեշտ է ծննդի գրանցման ներկա կարգը: Ինչպե՞ս կարելի է այն բարելավել:

<u>Մեռելածնության գրանցում</u>

2.4 Ձեր հաստատությունում ո՞վ է ախտորոշում մեռելածնությունը: Այդ ախտորոշումը կախվա՞ծ է ծննդաբերության ժամկետից կամ երեխայի ծննդյան քաշից: Եթե այո, ապա՝ ինչպե՞ս: Ծայրահեղ ցածր քաշով (<1000 գրամ) երեխան ծնվելուց հետո որքա՞ն ժամանակ անց պետք է մահանա, որ համարվի մեռելածին:

2.5 Կարո՞ղ եք նկարագրել մահացած երեխայի ծննդին հաջորդող գործելակերպը: Ո՞վ է վերցնում մարմինը և ինչ է անում: Մարմինը վերադարձվու՞մ է ծնողներին, թե ոչ: Եթե ոչ, ու՞ր է տարվում:

2.6 Նկարագրեք, խնդրեմ, մահացած երեխայի ծննդին մասին հաշվետվության ընթացակարգը: Կա՞ն, արդյոք, որոշակի փաստաթղթեր, որ պետք է լրացնել: Ո՞վ է լրացնում դրանք: Ծննդատունը ո՞ր մարմնին պետք է հաղորդի մահացած երեխայի ծննդի մասին: Ի՞նչ ժամկետում պետք է կատարվի այդ հաղորդումը:

2.7 Ծննդատանը որևէ մեկը պաշտոնապես պատասխանատու՞ է պերինատալ մահերի գրանցման և հաշվետվության համար: Հիվանդանոցը պահու՞մ է տվյալներ մեռելածնության դեպքերի վերաբերյալ: Ի՞նչ ձևով:

2.8 Ի՞նչ եք կարծում, կարո՞ղ է որոշ հանգամանքներում նորածինը գրանցվել որպես մեռելածին, երբ իրականում ցույց է տվել կյանքի որոշ նշաններ մինչև մահանալը: Ի՞նչ հանգամանքներ կարող են լինել դրանք:

2.9 Հնարավո՞ր է, որ դա լինի ծայրահեղ անհասության (22-26 շաբաթական) դեպքում: Երբևէ լսե՞լ եք այնպիսի դեպքերի մասին, երբ երեխան ցուցաբերել է կենդանության նշաններ, բայց գրանցվել է որպես մեռելածին: Չէի՞ք ցանկանա պատմել դրա մասին:

2.10 Ձեր կարծիքով, որո՞նք են մեռելածնության հիմնական պատճառները և ո՞ր գեստացիոն տարիքում է այն ավելի հաճախ լինում: Ինչու՞:

2.11 Ինչի՞ հիման վրա է հաշվարկվում գեստացիոն տարիքը (հղիության ընթացքում կամ ծննդաբերությունից / վիժումից հետո)։ Որքա՞ն հաճախ է գեստացիոն տարիքը սխալ հաշվարկվում։ Կարո՞ղ եք հիշել որևէ դեպք, երբ կանանց կոնսուլտացիայի կողմից Ձեզ հաղորդված գեստացիոն տարիքը եղել է սխալ։ Այդ դեպքում Դուք ո՞րն եք զեկուցում՝ նրանց հաղորդա՞ծը, թե՞ Ձեր հաշվարկածը։

2.12 Դուք հաճա՞խ եք տեսնում բնածին արատներով պտուղներ կամ նորածիններ։ Ո՞ր գեստացիոն տարիքում են նրանք սովորաբար ախտորոշվում։ Ի՞նչ է լինում այդ հղիությունների հետ։ Երբ հղիությունն ընդհատվում է բնածին արատի պատճառով, այն սովորաբար հանգեցնում է մեռելածնությա՞ն, թե՞ կենդանածնության։ Իսկ ինչպե՞ս է այն զեկուցվում։ Մեռելածնության դեպքում Ձեր ստացած փոխհատուցումը տարբերվու՞մ է կենդանածնության դեպքում ստացածից։

2.13 12-22 շաբաթական հղիության ընդհատման հետ կապված բուժօգնության համար բուժաշխատողները նույն կե՞րպ են վարձատրվում, ինչ որ՝ 22 շաբաթական կամ ավելի ժամկետով հղիության ընդհատման։ Եթե ոչ, կարծու՞մ եք, արդյոք, որ դա արդարացի է։ Ի՞նչ կարելի է անել այդ առումով։ Ի՞նչ հետևանքներ կարող են լինել, եթե այդ հարցը չլուծվի։

2.14 Որո՞նք են դիահերձում կատարելու ցուցումները մեռելածնության դեպքում։ Կա՞ն արդյոք դիահերձման սահմանափակումներ՝ մեռելածնի գեստացիոն տարիքի կամ ծննդյան քաշի հետ կապված։ Եթե այո, ապա ի՞նչ սահմանափակումներ։ Կա՞ն արդյոք ինչ-որ դժվարություններ կամ խոչընդոտներ՝ մեռելածինների դիահերձում կատարելու համար։ Ի՞նչ խոչընդոտներ։

2.15 Միջինում, մեռելածինների ո՞ր տոկոսն է դիահերձման ենթարկվում Ձեր հաստատությունում։ Դուք ստանու՞մ եք դիահերձման արդյունքները։ Դիահերձման ախտորոշումը գրանցվու՞մ է հիվանդանոցի փաստաթղթերում։ Որտե՞ղ է գրանցվում։ Դիահերձմամբ ճշտված ախտորոշումը զեկուցվու՞մ է ՔԿԱԳ մարմին։ Եթե ոչ՝ ինչու՞։ Ի՞նչ կարելի է անել Հայաստանում մեռելածնության ճիշտ պատճառական կառուցվածք ունենալու համար։

<u>Պերինատալ և նորածնային մահերի գրանցում</u>

2.16 Կա՞ն, արդյոք, տարբերություններ ծննդի գրանցման ընթացակարգերում, եթե երեխան ծնվել է կենդանի, բայց մահացել է կյանքի առաջին շաբաթվա ընթացքում։ Նման դեպքերում ի՞նչ փաստաթղթեր են լրացվում հիվանդանոցում։ Արդյո՞ք հիվանդանոցը պատասխանատու է ՔԿԱԳ մարմիններում այդ դեպքերի գրանցման համար։ Ինչպե՞ս։ Կա՞ այդ դեպքերի գրանցման որևէ ժամկետ։ Հիվանդանոցը պահու՞մ է այդ դեպքերի մասին իր սեփական տվյալները։ Ի՞նչ կերպ։

2.17 Ո՞րոնք են պերինտալ, վաղ նորածնային և ուշ նորածնային մահացությունների սահմանումները։ Ի՞նչ փաստաթղթեր են լրացվում բուժհաստատությունում՝ ուշ նորածնային մահացության դեպքում։ Կյանքի 7-28-րդ օրը մահացած երեխայի մահը ներառվու՞մ է ծննդատան տարեկան հաշվետվության ձևերում առանձին տողով՝ որպես ուշ նորածնային մահ։ Եթե երեխան ծննդատնից տեղափոխվում է այլ բուժհաստատություն և մահանում ուշ նորածնային

շրջանում, նրա մահը ներառվու՞մ է բուժհաստատության տարեկան հաշվետվության մեջ՝ որպես ուշ նորածնային մահ:

2.18 Արդյո՞ք որևէ բուժհաստատություն կրում է պատասխանատվություն՝ ՔԿԱԳ մարմնում ուշ նորածնային մահացության դեպքերի գրանցման համար: Եթե այո, ի՞նչ պատասխանատվություն և ո՞ր հաստատությունը: Կա՞ ՔԿԱԳ մարմնում այդ դեպքերի գրանցման որևէ ժամկետ:

2.19 Կա՞ն, արդյոք, տարբերություններ ծնողներին տրվող ծննդյան միանվագ նպաստի չափի մեջ (ինչպես տվյալ ծննդի համար, այնպես էլ՝ապագա երեխաների հերթական կարգաթվի հաշվարկման առումով), եթե երեխան ծնվել է մահացած, կամ մահացել է կյանքի առաջին շաբաթում, կամ մահացել է 2-րդից 4-րդ շաբաթներում: Եթե այո, ապա ի՞նչ տարբերություններ:

2.20 Ձեր կարծիքով՝ հնարավո՞ր է, որ երեխայի մահվան օրը գրանցվի իրականից ավելի ուշ, որպեսզի ծնողներն ավելի մեծ նպաստ ստանան: Որքա՞ն հաճախ կարող է դա պատահել:

<u>Ամփոփիչ հարց)</u> – Կցանկանայի՞ք ավելացնել որևէ բան, որ կարելի է անել՝ Հայաստանում մեռելածնության և նորածնային մահացության վիճակագրությունը բարելավելու համար:

Շնորհակալություն Ձեր ժամանակի և արդյունավետ քննարկման համար:

Խմբային քննարկման ուղեցույց
(Կանանց կոնսուլտացիաների մանկաբարձ-գինեկոլոգներ)

Ամսաթիվ: _____ **Ժամ:** _____

Վայր: _____

Վարող: _____

Գրանցող: _____

Բարի օր և շնորհակալություն, որ համաձայնեցիք զրուցել մեզ հետ: Իմ անունը _____: Ես ներկայացնում եմ Հայաստանի ամերիկյան համալսարանի Հանրային առողջապահության ֆակուլտետը: ՅՈՒՆԻՍԵՖ-ի աջակցությամբ մենք իրականացնում ենք հետազոտություն՝ ուսումնասիրելու կենդանածնության և մեռելածնության, ինչպես նաև վաղ և ուշ նորածնային մահացության ճիշտ գրանցմանն ու հաշվետվությանը խոչընդոտող գործոնները: Մենք կցանկանայինք, որ Դուք ներկայացնեիք այդ հարցերի վերաբերյալ Ձեր կարծիքը, որը մեզ համար շատ գնահատելի է: Ես Ձեզ կառաջարկեմ քննարկման թեմաներ և հարցրեք, այնուհանդերձ կխնդրեմ բոլորիդ արտահայտել Ձեր կարծիքներն այդ թեմաների վերաբերյալ: Լավ կլինի, եթե քննարկումը անցնի որպես ազատ զրույց, և բոլորը մասնակցեն առանց իրենց հերթին սպասելու: Խնդրում եմ արտահայտվեք ազատորեն, նկատի ունենալով, որ Ձեր տրամադրած ողջ տեղեկատվությունը մնալու է գաղտնի և Ձեր անունը ոչ մի տեղ չի հրապարակվելու: Նախքան հարցազրույցը սկսելը, կցանկանայինք խնդրել Ձեզ լրացնել կարճ հարցաշար: Եթե չեք առարկում, ես կձայնագրեմ մեր զրույցը, որպեսզի Ձեր արտահայտած ոչ մի կարևոր միտք չվրիպի մեր ուշադրությունից: Դեմ չե՞ք: Խնդրում եմ, թույլ տվեք այժմ սկսել:

1. ՍԱՀՄԱՆՈՒՄՆԵՐԻ ՓՈՓՈԽՈՒԹՅՈՒՆ՝ ՎԻԺՈՒՄ ԵՎ ԾՆՆԴԱԲԵՐՈՒԹՅՈՒՆ

1.1 Խնդրում ենք արտահայտել Ձեր կարծիքը վիժման և ծննդաբերության (կամ պտղի և նորածնի) սահմանումներում կատարված փոփոխությունների մասին: Ո՞րն է ծննդաբերության ներկայիս սահմանումը: Ի՞նչն է փոխվել այդ սահմանման մեջ, ե՞րբ և ինչու՞: Ի՞նչ եք կարծում, այդ փոփոխությունն անհրաժե՞շտ էր: Ինչի՞ համար:

1.2 Ձեր կարծիքով, ինչպե՞ս են վիժման և ծննդաբերության սահմանումների փոփոխություններն ազդել Հայաստանում կենդանածության ու մեռելածնության վիճակագրության վրա: Ի՞նչ եք կարծում, անցումը նոր սահմանումներին տեղի է ունեցել ամբողջությա՞մբ, թե ոչ: Եթե ոչ, ապա ինչու՞:

2. ՄԵՌԵԼԱԾՆՈՒԹՅՈՒՆ ԵՎ ՈՒՇ ՎԻԺՈՒՄ. ՊԱՏՃԱՌՆԵՐԸ ԵՎ ՁԵՎԱԿԵՐՊՈՒՄԸ

2.1 Ձեր կարծիքով, որո՞նք են մեռելածնության հիմնական պատճառները և ո՞ր գեստացիոն տարիքում է այն ավելի հաճախ պատահում: Ինչու՞:

2.2 Ո՞ր գեստացիոն տարիքում են պտղի արատները սովորաբար ախտորոշվում: Ի՞նչ է տեղի ունենում այդ հղիությունների հետ: Երբ հղիությունը դադարեցվում է բնածին արատի պատճառով, այն սովորաբար ավարտվում է կենդանածնությա՞մբ, թե՞ մեռելածնությամբ: Ինչպե՞ս է դա սովորաբար ձևակերպվում:

2.3 Որքա՞ն հաճախ է 20-ից 37 շաբաթական հղիությունն ընդհատվում բժշկական ցուցումներով և որքա՞ն հաճախ՝ ծնողների կամքով: Մինչև ո՞ր գեստացիոն տարիքը կարելի է կատարել հղիության արհեստական ընդհատում: Սովորաբար ի՞նչ է արվում, եթե ծնողները չեն ցանկանում երեխա ունենալ հղիության ավելի ուշ ժամկետում: Հնարավո՞ր է, որ ուշ աբորտների ինչ-որ մասը ձևակերպվի որպես մեռելածնություն:

2.4 Դուք ծննդատներից ստանու՞մ եք տեղեկություն Ձեր կողմից վարված հղի կանանց ծննդաբերության ելքի մասին: Կա՞ն արդյոք ձևեր, որոնք պետք է լրացվեն ծննդատանը և ետ ուղարկվեն կանանց կոնսուլտացիա: Ո՞վ է բերում այդ ձևերը: Ի՞նչ տեղեկություն են դրանք պարունակում:

2.5 Ձեր վարած հղի կանանց ո՞ր տոկոսի համար եք Դուք ստանում այդ ձևերը: Ինչպե՞ս և որտե՞ղ են դրանք պահվում: Դուք օգտագործու՞մ եք այդ ձևերում եղած տեղեկությունները Ձեր վիճակագրության և հաշվետվությունների համար:

2.6 Ինչի՞ հիման վրա է գեստացիոն տարիքը հաշվարկվում: Որքա՞ն հաճախ է լինում, երբ Ձեր կողմից հաշվարկված գեստացիոն տարիքը չի համընկնում ծննդատան կողմից հաշվարկվածի (և Ձեզ ուղարկված ձևում նշվածի) հետ: Կարո՞ղ եք հիշել այդպիսի անհամապատասխանության որևէ դեպք: Դուք ունե՞ք որևէ բացատրություն այդ անհամապատասխանության համար:

2.7 Ըստ Ձեզ, կարո՞ղ է որոշ հանգամանքներում ծնունդը գրանցվել որպես մեռելածնություն, երբ իրականում, մինչև մահանալը, նորածինը ցույց է տվել կյանքի որոշ նշաններ: Ի՞նչ հանգամանքներում դա կարող է տեղի ունենալ: Կարո՞ղ է դա լինել ծայրահեղ անհասության (22-26 շաբաթական) կամ կյանքի հետ անհամատեղելի ծանր արատով նորածնի ծննդյան դեպքում: Ի՞նչ պատճառով դա կարող է տեղի ունենալ:

2.8 Ձեր կարծիքով, ծննդատանը փոխանցվող գումարի տարբերությունը ծննդաբերության համար՝ համեմատած վիժման հետ, կարո՞ղ է ազդել այն բանի վրա, որ ուշ վիժումը ներկայացվի որպես ծննդաբերություն: Ի՞նչ կարելի է անել այս առումով՝ մեռելածնության ճիշտ վիճակագրություն ունենալու համար:

<u>(Ամփոփիչ հարց)</u> – Կցանկանայի՞ք ավելացնել որևէ բան, որ կարելի է անել՝ Հայաստանում մեռելածնության վիճակագրությունը բարելավելու համար:

Շնորհակալություն Ձեր ժամանակի և արդյունավետ քննարկման համար:

Appendix 2. IDI guides (in English and Armenian)

In-depth Interview participants

Consent form

Hellow. My name is …… . I am a researcher at the Center for Health Services Research and Development of the American University of Armenia. At the request of UNICEF Armenia and the Ministry of Health, our Center is conducting a Research on Live Birth and Stillbirth Registration and Reporting Practices in Armenia. The aim of this study is to improve the existing practices of classification, registration and reporting of stillbirths and neonatal deaths.

This interview, which you have been invited to participate in, is a part of this project. You have been selected to be interviewed, as you are involved in statistics, legislation, or actual practice of classification and reporting of stillbirths and neonatal deaths. Your experience, views and attitudes will help us to identify the current situation in this sphere and suggest ways for improvement.

The interview will last about an hour. After receiving your verbal consent for participation, we will ask you to complete a short questionnaire. Then we will start the interview asking some questions and urging you to express your ideas concerning these matters. Your participation in this interview is voluntary. You can stop the interview at any time. Also, you may refuse to answer any question, if you so wish. There will be no any consequences for you if you decide to participate or decline to do so. Your will not have any direct benefits from participation either, but your participation will assist us in developing effective measures for improving the existing practices in Armenia.

During the interview we will take notes and, if you allow, we would also like to audio-record the conversation to ensure that none of the ideas that you express escapes our attention. This interview carries no risks for you. The information you provide will be kept confidential. The information received during the study will be summarized and presented as a report containing no any personal or institutional data or contact information.
If you have any questions regarding this study you can call the study coordinator Anahit Demirchyan (060 61 25 62). If you feel you have not been treated fairly during the study or think your participation in the study has damaged you in any way, you can contact the IRB Human participants Administrator of the American University of Armenia, Kristina Hakobyan (060 61 25 61).

Do you agree to participate? If yes shall we start?
Do you agree to audio-recording? Please say yes or no.
If you are ready now we will start.

In-depth Interview Guide (Policy Makers)

Date: _____ Time: _____
Place: _____
Moderator: _____
Recorder: _____

Good afternoon and thank you very much for the opportunity to talk to you. My name is _____. I represent the School of Public Health of the American University of Armenia. As mentioned in the informed consent form you have read, with UNICEF's support, we conduct a study to explore the main obstacles to ensure adequate registration and reporting of stillbirth and live birth, as well as early and late neonatal mortality in Armenia. We would like to ask you to share your expertise in this area, which is very valuable for us. If you don't mind, we will tape-record our conversation so that no any important piece of it is lost. As mentioned in the informed consent form, the information you will provide will be fully confidential, and your name will not appear with that information. So, please, express your ideas freely. If you don't mind, let us begin now.

1. OPINION ON DEFINITION CHANGES: ABORTION AND DELIVERY, STILLBIRTH AND LIVE BIRTH

1.1 Please, express your opinion about the changes that were introduced in the definitions of abortion and delivery (or fetus and newborn). What was changed in these definitions, when and why? Do you think these changes were necessary? For what reason? Why these changes were not introduced earlier?
1.2 Please, describe the changes that were introduced in the definitions of live birth and stillbirth in Armenia. When these changes were introduced and for what purpose? Do you think these changes were necessary and why?
1.3 How the changes in the definitions of abortion, delivery and live birth influenced the statistics of live births and stillbirths in Armenia? In your opinion, have the shift to the new definitions happened completely or not? If not, why?
1.4 In your opinion, what could be done to improve correct identification and classification of stillbirths, live births and neonatal deaths in Armenia?

2 REPORTING AND REGISTRATION OF LIVE BIRTHS, STILLBIRTHS, AND NEONATAL DEATHS

Live birth registration

2.1 Could you please describe what changes (if any) took place in the regulations concerning health facilities' obligations for ensuring timely registration of live births in Civil Acts Registration Bodies (CARBs)?
2.2 In your opinion, in what cases live births are not registered in CARBs or are registered late? Is there anything that could be done to reduce these cases? How easy is the procedure for birth registration in Armenia? How this procedure can be improved?

Stillbirth registration

2.3 Could you please describe the procedures following the birth of a dead newborn? Who is responsible for reporting to CARB about the case of stillbirth? Is there any deadline for this reporting? Does the hospital keep its own statistics about stillbirths? How? Is there usually a person in hospitals responsible for supervising the process of registration and reporting of births and perinatal deaths?
2.4 Was something changed in the procedures following the birth of a dead newborn? If yes, what was changed and why? Do you think these changes contributed to better registration of

stillbirths? How and to what extent? Is there anything that could be done to further improve the registration of stillbirths?

2.5 In your opinion, what is the current situation with registration of stillbirths? Are the numbers over-reported or under-reported? Why do you think they are? Are there any differences in the numbers of stillbirths reported to the Ministry of Health and the National Statistical Service? What could be the reasons for these differences?

2.6 Do you think there could be some circumstances when the birth is reported as stillbirth when in reality the newborn demonstrated some signs of life before dying? What could be these circumstances?

2.7 Do you think the current way of reimbursing healthcare facilities for the cases of abortions and deliveries could play a role in classifying a case as stillbirth or live birth? If yes, how and why? What could be done in this respect to assure correct statistics of stillbirths?

2.8 What else could be done to improve the registration of stillbirths and live births in Armenia?

2.9 What is the current regulation for conducting autopsy in the case of stillbirth? Is the regulation followed sufficiently? If no, what are the obstacles to follow the regulation? What could be done to improve the situation?

2.10 What is the situation with registration of causes of stillbirths based on the diagnosis confirmed by autopsy? Is the timeframe (7 days) allocated to healthcare institutions for reporting about the case of stillbirth to CARBs is enough to register the final diagnosis? What could be done to improve the situation with registration of causes of stillbirth both within health services and in CARBs?

Registration of perinatal and neonatal deaths

2.11 Are there any differences in birth registration procedures if the baby was born alive but died during the first week? What documents are filled by the hospital in these cases? Does the hospital carry any responsibility for registration of these cases in CARB? What responsibility? Is there any timeframe for registration of these cases? Does the hospital keep its own registration of these cases? How?

2.12 What is the current definition of perinatal mortality? What underreporting or misreporting of perinatal mortality cases can happen? For what reason? How easy is the procedure of registration of perinatal mortality? Do you see any room for improvement in this procedure?

2.13 What documents are filled by the healthcare facility in the case of late neonatal mortality? If a neonate dies during 7-28th days of life, is this case included in the maternity's annual reporting form as late neonatal death? If a child is transferred to other hospital and dies there within late neonatal period, is this case included in that hospital's annual reporting form as late neonatal death?

2.14 Does any healthcare facility carry a responsibility for registration of the cases of late neonatal mortality in CARB? If yes, what facility and what responsibility? Is there any timeframe for registration of these cases? How easy is the procedure of registration of late neonatal mortality? Do you see any room for improvement of this procedure?

2.15 Are there any differences in the amount of financial allowance received by parents (for that child and for calculating sequential number of future children) if the child was born dead or died during the first week or died during the 2-4th weeks of life? If yes, what differences?

2.16 Do you think there could be cases of misreporting (postponing) the day of child's death to allow parents receiving bigger allowance? How often this might happen?

Summarizing question

Do you have something to add on what could be done better in Armenia to improve the registration of live births and stillbirths?

Thank you very much for your time and contribution, which we highly appreciate!

In-depth Interview Guide (Healthcare Providers and Hospital Administrators)

Date: _____ Time: _____
Place: _____
Moderator: _____
Recorder: _____

Good afternoon and thank you very much for the opportunity to talk to you. My name is _____. I represent the School of Public Health of the American University of Armenia. As mentioned in the informed consent form you have read, with UNICEF's support, we conduct a study to explore the main obstacles to ensure adequate registration and reporting of stillbirth and live birth, as well as early and late neonatal mortality in Armenia. We would like to ask you to share your expertise in this area, which is very valuable for us. If you don't mind, we will tape-record our conversation so that no any important piece of it is lost. As mentioned in the informed consent form, the information you will provide will be fully confidential, and your name will not appear with that information. So, please, express your ideas freely. We will ask you to complete a short questionnaire first, and then we will start the discussion. Please, let us begin now.

1. KNOWLEDGE ON DEFINITION CHANGES: ABORTION AND DELIVERY, STILLBIRTH AND LIVE BIRTH

Fetus and newborn

1.1 Let us discuss what changes were introduced in the definitions of abortion and delivery. When and why these changes were introduced?

1.2 How the changes in definitions of abortion and delivery (or fetus and newborn) influenced the actual practice? What is your opinion regarding this change? Was it easy to shift to the new classification of these conditions? Have the shift happened completely or not?

1.3 Are there any consequences of moving the cut-point between abortion and delivery from 28 weeks of gestation to 22 weeks of gestation (including financial consequences for you and your facility)?

Live birth and Stillbirth

1.4 What changes were introduced in the definitions of live birth and stillbirth in Armenia? When these changes were introduced and for what purpose? What are the current criteria for diagnosing stillbirth?

1.5 In what extent the changes in definitions of live birth and stillbirth influenced the actual practice? Was it easy to shift to the new classification of these conditions? Have the shift happened completely or not?

1.6 In your institution, who is responsible for the diagnosis of stillbirth? Does the diagnosis depend from the term of delivery or baby's birth weight? If yes, how? Does it depend from the time of baby's death? How many hours after birth have to die an extremely low-birth-weight baby to still be considered as stillbirth?

1.7 Do you think there is a need to make changes in the definitions of abortion and delivery (or fetus and newborn)? If yes, what changes? Do you think there is a need to make changes in the definition of stillbirth and live birth? If yes, what would you suggest?

2 REPORTING AND REGISTRATION OF LIVE BIRTHS, STILLBIRTHS, AND NEONATAL DEATHS

Live birth registration

2.1 Could you please describe the formal procedures following the birth of a newborn? What documents are filled in and by whom? How does the hospital contribute to the registration of the newborns in Civil Acts Registration Bodies (CARBs)? How the hospital keeps its own statistics of births?

2.2 Are there any differences in these procedures if the baby was born alive but with less than 1000 g weight? If yes, what are these differences?

2.3 In your opinion, in what cases live births are not registered in CARBs or are registered late? Is there anything that could be done to reduce these cases? How easy is the procedure for birth registration in Armenia? How this procedure can be improved?

Stillbirth registration

2.4 Could you please describe the procedures following the birth of a dead newborn? Who takes the baby and what do they do? Are the bodies returned to the parents? If not, where do they go?

2.5 Please describe the reporting procedure following the birth of a dead newborn: is there any additional documents filled? By whom? Which body does the hospital report to about the birth of a dead newborn? Is there any deadline for this reporting? Does the hospital keep information on these cases? How?

2.6 Is there any person in the hospital officially designated as responsible for correct/timely registration and reporting of perinatal deaths? Are there any documents received by parents in the case of stillbirth? Do the parents receive birth or death certificate or something else? If yes, who is responsible for issuing it?

2.7 Do you think there could be some circumstances when the birth is reported as stillbirth when in reality the newborn demonstrated some signs of life before dying? What could be these circumstances? Could this be the case with extremely premature infants (22-26 weeks)? Have you ever heard of cases when the baby was born alive and was reported as a stillbirth? Would you like to share the story?

2.8 In your opinion what are the main causes of stillbirth and at what gestational age does this happen more frequently? Why?

2.9 Based on what is gestational age calculated (during pregnancy or after delivery/miscarriage)? How often does it happen that the gestational age is incorrectly calculated? Could you recall any case that it was incorrectly reported to you by women's consultation? Which one do you report?

2.10 Do you see many fetuses/newborns with birth defects in your practice? At what gestational age are they usually diagnosed? What happens with these pregnancies? When the pregnancy is terminated because of a birth defect, is it usually resolves in a live birth or a stillbirth? How is it reported? Is there any difference in you payments in case of stillbirth versus live birth?

2.11 Is provider payment the same if a pregnancy is terminated at 12-22 weeks of gestation compared to higher term of pregnancy? If yes, is it fair? What can be done to address this issue? What could be the possible consequences if the issue of financing remains unsolved?

2.12 What are the indications for conducting autopsy in the case of stillbirth? Are there any restrictions for autopsy related to gestational age or birth weight of the newborn? If yes, what restrictions? Are there any obstacles/difficulties for conducting autopsy of stillbirths? What obstacles?

2.13 What is the average percentage of stillbirths that undergo autopsy in your institution? Do you receive the results of autopsy? Is the diagnosis made during the autopsy registered in hospital documentation? In what documentation is it registered? Is the autopsy diagnosis reported to CARB? If no, why? What can be done to have accurate causal structure of stillbirths in Armenia?

Registration of perinatal and neonatal deaths

2.14 Are there any differences in birth registration procedures if the baby was born alive but died during the first week? What documents are filled by the hospital in these cases? Does the hospital carry any responsibility for registration of these cases in CARB? What responsibility? Is there any timeframe for registration of these cases? Does the hospital keep its own registration of these cases? How?

2.15 What is the definition of perinatal mortality? What underreporting or misreporting of perinatal mortality cases can happen? For what reason? How easy is the procedure of registration of perinatal mortality? Do you see any room for improvement in this procedure?

2.16 What is the definition of neonatal mortality? What about early and late neonatal mortality? What documents are filled by the healthcare facility in the case of late neonatal mortality? If a neonate dies during 7-28th days of life, is this case included in the maternity's annual reporting form as late neonatal death? If a child is transferred to other hospital and dies there within late neonatal period, is this case included in that hospital's annual reporting form as late neonatal death?

2.17 Does any healthcare facility carry a responsibility for registration of the cases of late neonatal mortality in CARB? If yes, what facility and what responsibility? Is there any timeframe for registration of these cases? How easy is the procedure of registration of late neonatal mortality? Do you see any room for improvement of this procedure?

2.18 Are there any differences in the amount of financial allowance received by parents (for that child and for calculating sequential number of future children) if the child was born dead or died during the first week or died during the 2-4th weeks of life? If yes, what differences?

2.19 Do you think there could be cases of misreporting (postponing) the day of child's death to allow parents receiving bigger allowance? How often this might happen?

Summarizing question

Do you have something to add on what could be done better in Armenia to improve the statistics of live births and stillbirths?

Thank you very much for your time and contribution, which we highly appreciate!

In-depth Interview Guide (Ob/gyns from women's consultations)

Date: _____ Time: _____
Place: _____
Moderator: _____
Recorder: _____

Good afternoon and thank you very much for the opportunity to talk to you. My name is _____. I represent the School of Public Health of the American University of Armenia. As mentioned in the informed consent form you have read, with UNICEF's support, we conduct a study to explore the main obstacles to ensure adequate registration and reporting of stillbirth and live birth, as well as early and late neonatal mortality in Armenia. We would like to ask you to share your expertise in this area, which is very valuable for us. If you don't mind, we will tape-record our conversation so that no any important piece of it is lost. As mentioned in the informed consent form, the information you will provide will be fully confidential, and your name will not appear with that information. So, please, express your ideas freely. Please, let us begin now.

1 OPINION ON DEFINITION CHANGES: ABORTION AND DELIVERY

1.1 Please, express your opinion about the changes that were introduced in the definitions of abortion and delivery (or fetus and newborn). What is the current definition of delivery? What was changed in this definition, when and why? Do you think this change was necessary? For what reason?

1.2 In your opinion, how the changes in the definitions of abortion and delivery influenced the statistics of live births and stillbirths in Armenia? Do you think the shift to the new definitions happened completely or not? If not, why?

2 STILLBIRTHS AND LATE ABORTIONS: CAUSES AND REPORTING

2.1 In your opinion, what are the main causes of stillbirth and at what gestational age does this happen more frequently? Why?

2.2 At what gestational age fetal defects are usually diagnosed? What happens with these pregnancies? When the pregnancy is terminated because of a birth defect, is it usually resolves in a live birth or a stillbirth? How is it usually reported?

2.3 How often early termination of pregnancy (between ~ 20^{th} and 37^{th} weeks of gestation) is indicated medically and how often it is due to parents' will? Till what gestational age induced abortion can be conducted? What is the usual practice if parents don't want the baby at a later term of pregnancy? Is there a possibility that some portion of late abortions is registered as stillbirth?

2.4 Do you receive information from maternity hospitals about the results of delivery of women supervised in your institution during pregnancy? Are there any forms to be completed by the hospital and sent back to you? Who delivers these forms? What information these forms provide?

2.5 For what proportion of delivered women do you receive these forms? How and where these forms are kept? Do you use these forms for your statistics and reporting?

2.6 Based on what is gestational age calculated? How often does it happen that the gestational age you calculate does not coincide with that calculated in the maternity hospital (and recorded in the forms

they send to you)? Could you recall any case of such inconsistency? Do you have any explanation for such difference?

2.7 Do you think there could be some circumstances when the birth is reported as stillbirth when in reality the newborn demonstrated some signs of life before dying? What could be these circumstances? Could this be the case with extremely premature infants (22-26 weeks)? Or with newborns having serious birth defects? Why this could happen?

2.8 Do you think the current way of reimbursing healthcare facilities for the cases of abortions versus deliveries could play a role in reporting a case of a late abortion as stillbirth? What could be done in this respect to assure correct statistics of stillbirths?

Summarizing question

Do you have something to add on what could be done better in Armenia to improve the statistics of stillbirths?

Thank you very much for your time and contribution, which we highly appreciate!

In-depth Interview Guide (Pathologists)

Date: _____ Time: _____
Place: _____
Moderator: _____
Recorder: _____

Good afternoon and thank you very much for the opportunity to talk to you. My name is _____. I represent the School of Public Health of the American University of Armenia. As mentioned in the informed consent form you have read, with UNICEF's support, we conduct a study to explore the main obstacles to ensure adequate registration and reporting of stillbirth and early and late neonatal mortality in Armenia, including their causal structure confirmed by autopsies. We would like to ask you to share your expertise in this area, which is very valuable for us. If you don't mind, we will tape-record our conversation so that no any important piece of it is lost. As mentioned in the informed consent form, the information you will provide will be fully confidential, and your name will not appear with that information. So, please, express your ideas freely. If you don't mind, let us begin now.

1. KNOWLEDGE ON DEFINITION CHANGES: ABORTION AND DELIVERY, STILLBIRTH AND LIVE BIRTH

Fetus and newborn

1.1 Could you, please, describe the changes that were introduced in the definitions of abortion and delivery (or fetus and newborn)? When and why these changes were introduced?

1.2 How the changes in definitions of abortion and delivery (or fetus and newborn) influenced the actual practice? What is your opinion regarding this change? Have the shift to the new definitions happened completely or not?

1.3 In your opinion, what could be the consequences of moving the cut-point between abortion and delivery from 28 weeks of gestation to 22 weeks of gestation? How the mortality statistics will change, both the rates and the causal structure of deaths.

1.4 Do you think there is a need to make further changes in the definitions of abortion and delivery or fetus and newborn? If yes, what changes?

Live birth and Stillbirth

1.5 Please, describe what changes were introduced in the definitions of live birth and stillbirth in Armenia? When these changes were introduced and for what purpose? What are the current criteria for diagnosing stillbirth?

1.6 To your opinion, in what extent the changes in definitions of live birth and stillbirth influenced the actual practice? Have the shift happened completely or not? Why yes or why not?

1.7 Do you think there is a need to make further changes in the definition of stillbirth and live birth? If yes, what would you suggest?

2 AUTOPSIES IN THE CASE OF STILLBIRTH AND NEONATAL DEATH

2.1 Could you please describe the procedures following the birth of a dead newborn or a newborn died in the maternity hospital? Who takes the baby and what do they do? Are the bodies returned to the parents? If not, where do they go?

2.2 Please describe whether any changes were introduced in the regulations about autopsies of stillbirths and neonatal deaths? When these changes were introduced and why? Do you think these changes were necessary? Why?

2.3 In what cases of stillbirths or neonatal deaths autopsies are officially required? What is the actual coverage with autopsies of dead neonates born over 1000 gram of weight? What about those below 1000 gram of weight? Do you think autopsies of extremely premature neonates (weighting below 1000 gram) are as informative as autopsies of larger neonates? If no, why?

2.4 Could you, please, describe the process of referring a dead newborn to autopsy? What referral forms are filled, by whom? Is the information provided in these forms necessary/useful? How well these forms are usually completed? Do you think the forms or their completion can be somehow improved? How?

2.5 Where do you record the results of autopsy? Are the referral forms or other related documents kept in your department? If yes, what documents and for what purpose? Do you use the information there for some statistics or reporting? What statistics or reporting?

2.6 Usually, how many days after the referral to autopsy doctors receive its results? How often the diagnosis made in the result of autopsy differs from the diagnosis on the referral form? In the case of mismatch, which diagnosis is usually reported for official statistics (to Civil Status Acts Registration Bodies and to the Ministry of Health)? Do you think doctors pursue that the final autopsy diagnosis is reported for statistical purposes?

2.7 In your opinion what are the three most frequent causes of stillbirth in Armenia? How often placentas are sent to autopsy in the case of stillbirth? How important is it?

2.8 In your opinion what are the three most frequent causes of early neonatal deaths (within first 7 days of life) in Armenia? What are the three most frequent causes of late neonatal deaths (within 8-28 days of life) in Armenia?

2.9 Is it possible to identify during autopsy if the neonate was born dead or died within first minutes after birth without breathing but demonstrating some other signs of life (heartbeat, umbilical cord pulsation or muscular movement)? How?

2.10 Have you ever noticed that a neonate was sent to autopsy as stillbirth but was possibly alive at birth? How often (if ever) this could happen? Could this be the case with neonates having very severe birth defects or extremely low birth weight? If yes, do you have any explanation for this?

2.11 Do you weight stillborns before autopsy? If yes, how often the weight recorded in your department does not coincide with the birth weight mentioned in the referral form? How often this could be the case with extremely low weight babies (below 1000 gram)? Why this might happen?

2.12 Where there any instances in your experience when the gestational age of a stillborn was reported 22 weeks while you suspected a gestational age less than 22 weeks? If yes, what could be the possible reason for this difference?

Summarizing question

What can be done to increase the coverage of stillbirth and neonatal death cases with autopsy and to improve the knowledge on causal structure of stillbirths and neonatal deaths in Armenia?

Thank you very much for your time and contribution, which we highly appreciate!

In-depth Interview Guide (Civil Status Acts Registration Body staff)

Date: _____ Time: _____
Place: _____
Moderator: _____
Recorder: _____

Good afternoon and thank you very much for the opportunity to talk to you. My name is _____. I represent the School of Public Health of the American University of Armenia. As mentioned in the informed consent form you have read, with UNICEF's support, we conduct a study to explore the main obstacles to ensure adequate registration and reporting of stillbirth and live birth, as well as early and late neonatal mortality in Armenia. We would like to ask you to share your expertise in this area, which is very valuable for us. If you don't mind, we will tape-record our conversation so that no any important piece of it is lost. As mentioned in the informed consent form, the information you will provide will be fully confidential, and your name will not appear with that information. So, please, express your ideas freely. If you don't mind, let us begin now.

1. CHANGES IN REGISTRATION OF LIVE BIRTHS

1.1 Please, describe whether any changes were introduced during the last decade in the regulations concerning registration of live births? If yes, what changes? Starting from what weight (or what term of pregnancy) the cases of live birth are registered in Civil Status Acts Registration Bodies (CSARB) currently? What was the situation before?

1.2 What are the main legislative acts regulating birth registration? Could you, please, describe the process of birth registration: what CSARBs should register the birth, what documents are needed, who provide and present these documents in the cases of birth in maternity? At home?

1.3 In what circumstances problems can arise with birth registration? How these problems are usually solved? Is there any term for registration of babies weighting less than 1000 gram? What cases of birth registration are considered late? What is the average percentage of late birth registration in your CSARB?

1.4 What data on registered births do you keep in your records? How frequently do you report about the registered births to the National Statistical Service (NSS) or some other agency, if any (what agency)? What cases of registered births do you include in these reports (do you include those with extremely low birth weight: 500-1000 gram)? What data on registered births are included in the NSS reporting forms (or some other agency's reporting forms if any)? Are birth weight categories or the place of birth (hospital or home) included?

2. CHANGES IN REGISTRATION OF STILLBIRTHS AND NEONATAL DEATHS

Stillbirth registration

2.1 Please, describe whether any changes were introduced during the last decade in the regulations concerning registration of stillbirths? If yes, what changes? Starting from what weight (or what term of pregnancy) the cases of stillbirth are registered in CSARB currently? What was the situation before?

2.2 What are the main legislative acts regulating stillbirth registration? What registration is made for a stillbirth (registration of birth, of death, both)? What documents (if any) are provided to parents?

2.3 What documents are needed for registration of a stillbirth? Who is responsible for informing CSARB about a case of stillbirth (parents or healthcare providers)? How this process is organized if the birth of a dead child occurred in maternity hospital? How is it organized if the stillbirth occurred at home?

2.4 Is there any deadline for registering a case of stillbirth? Was this deadline changed? If yes, how and why? What is the average percentage of late registration of stillbirths in your CSARB? For what percentage of the registered stillbirths the final cause of death (diagnosis confirmed during autopsy) is recorded in your documentation?

2.5 In what circumstances stillbirths can be left out from registration? In your opinion, how frequently this takes place in the case of a child being more than 1000 gram? Less than 1000 gram?

2.6 What data on registered stillbirths do you keep in your records? How frequently do you report about the registered stillbirths to the NSS or some other agency (if any)?

2.7 What cases of registered stillbirths do you include in these reports (are 500-1000 gram stillbirths included)? What data on registered stillbirths are included in the NSS (or some other agency's, if any) reporting forms? Are birth weight categories (500-999 g, 1000-1499 g, 1500-1999 g. etc.) or the place of birth (hospital or home), or death cause categories included?

Early (within first 7 days) and late (within 8-28th days) neonatal death registration

2.8 What CSARBs should register the birth of a newborn that died during the first 7 days of life? During the 8-28th days of life? Was anything changed in this regard? If yes, when and why?

2.9 What registration(s) is made for a newborn that died during the first four weeks of life? What documents (if any) are provided to parents?

2.10 What documents are needed for registration of a newborn that died during the first four weeks of life? Who provides that documents if the newborn died in maternity, in other hospital, or at home? How well this procedure works? Do you see any room for improvement in this procedure?

2.11 Who is responsible for informing CSARB about a case of early neonatal death (first 7 days)? Who is responsible for informing CSARB about late neonatal death (8-28th days)? Was something changed in this respect?

2.12 Is there any timeframe for registering a case of neonatal death in CSARB? Was this deadline changed? If yes, how and why? What is the average percentage of late registration of neonatal deaths in your CSARB? For what percentage of the registered neonatal deaths the final cause of death (diagnosis confirmed during autopsy) is recorded in your documentation?

2.13 Are there any differences in the amount of financial allowance received by parents (for that child and for calculating sequential number of future children) if the child was born dead or died during the first week or died during the 2-4th weeks of life? If yes, what differences?

2.14 Do you think there could be cases of misreporting (postponing) the day of child's death to allow parents receiving bigger allowance? How often this might happen?

2.15 What data on registered neonatal deaths are included in the NSS (or some other agency if any) reporting forms? Are the categories of early (7 days) or late (8-28th days) neonatal death, birth weight categories, the place of birth (hospital or home), or death cause categories included?

Summarizing question

Do you have something to add on what could be done better in Armenia to improve the registration of live births, stillbirths and neonatal deaths?

Thank you very much for your time and contribution, which we highly appreciate!

Խորացված հարցազրույցի իրազեկ համաձայնագիր

Բարև Ձեզ, իմ անունը …… է: Ես Հայաստանի ամերիկյան համալսարանի Առողջապահական ծառայությունների հետազոտման և զարգացման կենտրոնի գիտաշխատող եմ: ՅՈՒՆԻՍԵՖ-ի և Առողջապահության նախարարության պատվերով մեր կենտրոնն իրականացնում է հետազոտություն՝ Հայաստանում կենդանածնության և մեռելածնության գրանցման և հաշվետվության գործելակերպերի վերաբերյալ: Հետազոտության նպատակն է բարելավել մեռելածնության և նորածնային մահացության դասակարգման, գրանցման և հաշվետվության գործընթացները:

Նշված հետազոտության մաս է կազմում այս հարցազրույցը, որին Դուք հրավիրվել եք մասնակցելու, քանի որ Ձեր աշխատանքն առնչվում է մեռելածնության և նորածնային մահացության վիճակագրությանը, գրանցմանն ու հաշվետվությանը, կամ դրանց վերաբերյալ օրենսդրության մշակմանը: Ձեր փորձը, տեսակետներն ու մոտեցումները կօգնեն մեզ պարզել այս ասպարեզում ներկայումս տիրող իրավիճակը և առաջարկել բարելավման ուղիներ:

Հարցազրույցը կտևի մոտ մեկ ժամ: Մասնակցելու Ձեր բանավոր համաձայնությունն ստանալուց հետո մենք կառաջարկենք Ձեզ լրացնել կարճ հարցաթերթիկ, այնուհետև կսկսենք հարցազրույցը, որի ժամանակ կխնդրենք արտահայտել Ձեր կարծիքը հետազոտության նյութին առնչվող մի շարք հարցերի վերաբերյալ: Ձեր մասնակցությունը կամավոր է: Դուք կարող եք ցանկացած պահի ընդհատել այն: Կարող եք նաև չպատասխանել որևէ հարցի, եթե չեք ցանկանում: Հարցազրույցին մասնակցելը կամ դրանից հրաժարվելը Ձեզ համար որևէ հետևանք չի ունենա: Դուք որևէ ուղղակի օգուտ ևս չեք ստանա մասնակցությունից, սակայն Ձեր մասնակցությունը կօգնի մշակել համակարգը բարելավելու առաջարկներ:

Հարցազրույցի ընթացքում մենք գրի կառնենք և, եթե թույլ տաք, կձայնագրենք մեր զրույցը, որպեսզի Ձեր արտահայտած ոչ մի գաղափար չվրիպի մեր ուշադրությունից: Այս հարցազրույցը որևէ ռիսկ չի պարունակում Ձեզ համար: Ձեր տրամադրած տեղեկությունները կպահվեն գաղտնի: Հետազոտության ընթացքում ստացված բոլոր տեղեկություններն ի մի կբերվեն և կներկայացվեն միայն ընդհանրացված ձևով՝ չպարունակելով որևէ անուն, անձնական տվյալ կամ տվյալ հաստատության վերաբերյալ, որտեղ Դուք աշխատում եք:

Այս հետազոտության վերաբերյալ հարցեր ունենալու դեպքում կարող եք զանգահարել հետազոտության համակարգող Անահիտ Դեմիրճյանին՝ 060 61 25 62 հեռախոսահամարով: Եթե մտածեք, որ այս հետազոտությանը մասնակցելու ընթացքում Ձեզ լավ չեն վերաբերվել կամ որ մասնակցությունը Ձեզ վնաս է պատճառել, կարող եք զանգահարել Հայաստանի ամերիկյան համալսարանի Էթիկայի հանձնաժողովի քարտուղար Քրիստինա Հակոբյանին՝ 060 61 25 61 հեռախոսահամարով:

Դուք համաձա՞յն եք մասնակցել: Եթե այո, կարո՞ղ ենք սկսել:

Դուք համաձա՞յ ն եք, որ ես միացնեմ ձայնագրիչը: Խնդրում եմ ասեք՝ ԱՅՈ կամ ՈՉ:

Եթե Դուք պատրաստ եք, կարող ենք սկսել:

Խորացված հարցազրույցի ուղեցույց
(Քաղաքականություն մշակողներ)

Ամսաթիվ: _____ **Ժամ:** _____

Վայր: _____

Վարող: _____

Գրանցող: _____

Բարի օր և շնորհակալություն, որ համաձայնեցիք զրուցել մեզ հետ: Իմ անունը _____: Ես ներկայացնում եմ Հայաստանի ամերիկյան համալսարանի Հանրային առողջապահության ֆակուլտետը: Ինչպես նշված է Ձեր կողմից ընթերցված համաձայնության ձևում, ՅՈՒՆԻՍԵՖ-ի աջակցությամբ մենք իրականացնում ենք հետազոտություն՝ ուսումնասիրելու կենդանածնության և մեռելածնության, ինչպես նաև վաղ և ուշ նորածնային մահացության ճիշտ գրանցմանն ու հաշվետվությանը խոչընդոտող գործոնները: Մենք կցանկանայինք, որ Դուք ներկայացնեիք այդ հարցերի վերաբերյալ Ձեր կարծիքը, որը մեզ համար շատ գնահատելի է: Եթե չեք առարկում, ես կձայնագրեմ մեր զրույցը, որպեսզի Ձեր արտահայտած ոչ մի կարևոր միտք չվրիպի մեր ուշադրությունից: Խնդրում եմ արտահայտվեք ազատորեն, նկատի ունենալով, որ Ձեր տրամադրած ողջ տեղեկատվությունը մնալու է գաղտնի և Ձեր անունը ոչ մի տեղ չի հրապարակվելու: Խնդրում եմ, թույլ տվեք այժմ սկսել:

1. ԿԱՐԾԻՔ ՍԱՀՄԱՆՈՒՄՆԵՐԻ ՓՈՓՈԽՈՒԹՅԱՆ ՎԵՐԱԲԵՐՅԱԼ. ՎԻԺՈՒՄ ԵՎ ԾՆՆԴԱԲԵՐՈՒԹՅՈՒՆ, ՄԵՌԵԼԱԾՆՈՒԹՅՈՒՆ ԵՎ ԿԵՆԴԱՆԱԾՆՈՒԹՅՈՒՆ

1.1 Արտահայտեք, խնդրեմ, Ձեր կարծիքը վիժման և ծննդաբերության (կամ պտղի և նորածնի) սահմանումներում կատարված փոփոխությունների մասին: Ի՞նչն է փոխվել այդ սահմանումներում, ե՞րբ և ինչու՞: Կարծու՞մ եք, արդյոք, որ այդ փոփոխություններն անհրաժեշտ էին: Ի՞նչ պատճառով: Ինչու՞ դրանք չեն մտցվել ավելի վաղ:

1.2 Խնդրում եմ, նկարագրեք, թե ի՞նչ փոփոխություններ են մտցվել Հայաստանում՝ կենդանածնության և մեռելածնության սահմանումներում: Ե՞րբ և ի՞նչ նպատակով են այդ փոփոխությունները մտցվել: Կարծու՞մ եք, արդյոք, որ այդ փոփոխություններն անհրաժեշտ էին և ինչու՞:

1.3 Ինչպե՞ս են վիժման, ծննդաբերության և կենդանածնության սահմանումների փոփոխություններն ազդել Հայաստանում կենդանածության ու մեռելածնության վիճակագրության վրա: Ի՞նչ եք կարծում, անցումը նոր սահմանումներին տեղի է ունեցել ամբողջությա՞մբ, թե՞ ոչ: Եթե ոչ, ապա ինչու՞:

1.4 Ըստ Ձեզ, ի՞նչ կարելի է անել Հայաստանում մեռելածնության, կենդանածնության և նորածնային մահացության ախտորոշումն ու դասակարգումը բարելավելու համար:

2. ԿԵՆԴԱՆԱԾՆՈՒԹՅԱՆ, ՄԵՌԵԼԱԾՆՈՒԹՅԱՆ ԵՎ ՆՈՐԱԾՆԱՅԻՆ ՄԱՀԱՑՈՒԹՅԱՆ ՀԱՇՎԵՏՎՈՒԹՅՈՒՆԸ ԵՎ ԳՐԱՆՑՈՒՄԸ

Կենդանածնության գրանցում

2.1 Կարո՞ղ եք նկարագրել, թե ինչ օրենսդրական փոփոխություններ են տեղի ունեցել (եթե այդպիսիք կան) բուժհաստատությունների պարտավորություններում՝ ուղղված Քաղաքացիական կացության ակտերի գրանցման (ՔԿԱԳ) մարմիններում կենդանածինների ժամանակին գրանցումը ապահովելուն:

2.2 Ըստ Ձեզ, ո՞ր դեպքերում է, որ ծնունդը չի գրանցվում ՔԿԱԳ-ում կամ գրանցվում է ուշացումով: Հնարավո՞ր է ինչ-որ բան ձեռնարկել՝ այդ դեպքերի քանակը նվազեցնելու համար: Որքա՞ն հեշտ է ծնունդների գրանցման կարգը Հայաստանում: Ինչպե՞ս կարելի է այս կարգը բարելավվել:

Մեռելածնության գրանցում

2.3 Կարո՞ղ եք նկարագրել այն ընթացակարգը, որ հաջորդում է մահացած նորածնի ծննդյանը: Ո՞վ է պատասխանատու ՔԿԱԳ-ին տեղեկացնելու մեռելածնության դեպքի մասին: Այդ տեղեկացման համար կա՞ որևէ ժամկետ: Ծննդատունը պահու՞մ է մեռելածնության մասին իր սեփական վիճակագրությունը: Ինչպե՞ս: Ծննդատանը կա՞ որևէ պատասխանատու, ով վերահսկում է ծնունդների և պերինատալ մահերի գրանցման ու հաշվետվության գործընթացը:

2.4 Ինչ-որ բան փոխվե՞լ է մահացած նորածնի ծննդյանը հաջորդող ընթացակարգում: Եթե այո, ապա ի՞նչն է փոխվել և ինչո՞ւ: Կարծու՞մ եք, որ այդ փոփոխությունները նպաստել են մեռելածնության գրանցման բարելավմանը: Ինչպե՞ս և ի՞նչ չափով: Կա՞ որևէ բան, որ կարելի է ձեռնարկել՝ մեռելածնության գրանցման հետագա բարելավման համար:

2.5 Ձեր կարծիքով, ինչպիսի՞ն է մեռելածնության գրանցման ներկայիս իրավիճակը: Արդյո՞ք թվերը ուռճացված են կամ նվազեցված: Ինչու՞ է այդպես: Տարբերություններ կա՞ն մեռելածնության թվերի միջև, որոնք ներկայացվում են Առողջապահության նախարարություն և Ազգային վիճակագրական ծառայություն: Որո՞նք կարող են լինել այդ տարբերությունների պատճառները:

2.6 Ի՞նչ եք կարծում, կարո՞ղ են լինել հանգամանքներ, երբ ծնունդը զեկուցվում է որպես մեռելածին, բայց իրականում նորածինը ցույց է տալիս կյանքի որոշ նշաններ մինչև մահանալը: Որո՞նք կարող են լինել այդ հանգամանքները:

2.7 Ի՞նչ եք կարծում, ծննդաբերության և վիժման դեպքի համար ծննդատանը փոխանցվող գումարի տարբերությունը կարո՞ղ է ազդել, որ դեպքը դասվի որպես կենդանածին կամ մեռելածին: Եթե

այո, ապա ինչպե՞ս և ինչո՞ւ: Այս առումով ի՞նչ կարելի է անել՝ մեռելածնության ճիշտ վիճակագրություն ունենալու համար:

2.8 Ուրիշ ի՞նչ քայլեր կարելի է ձեռնարկել՝ Հայաստանում մեռելածնության և կենդանածնության դեպքերի գրանցումը բարելավելու համար:

2.9 Ո՞րն է մեռելածիններին դիահերձման ենթարկելու ներկայիս կարգը: Արդյո՞ք այդ կարգին հետևում են բավարար չափով: Եթե ոչ՝ այդ կարգին հետևելու ի՞նչ խոչընդոտներ կան: Ի՞նչ կարելի է անել իրավիճակը բարելավելու համար:

2.10 Ինչպիսի՞ն է իրավիճակը մեռելածնության՝ դիահերձմամբ հաստատված վերջնական ախտորոշումների գրանցման առումով: Արդյո՞ք 7-օրյա ժամկետը, որի ընթացքում բուժհաստատությունը պետք է տեղեկացնի ՔԿԱԳ-ին մեռելածնության դեպքի մասին, բավարար է, որ գրանցվի վերջնական ախտորոշումը: Ի՞նչ կարելի է անել մեռելածնության պատճառների գրանցումը բարելավելու համար՝ ինչպես ՔԿԱԳ մարմիններում, այնպես էլ՝ բուժհաստատություններում:

<u>Պերինատալ և նորածնային մահերի գրանցում</u>

2.11 Ծննդի գրանցման ընթացակարգում կա՞ն տարբերություններ, եթե երեխան ծնվել է կենդանի, բայց մահացել է կյանքի առաջին շաբաթվա ընթացքում: Նման դեպքերում ի՞նչ փաստաթղթեր է լրացնում հիվանդանոցը: Հիվանդանոցը կրու՞մ է պատասխանատվություն՝ ՔԿԱԳ մարմիններում այդ դեպքերի գրանցման համար: Ի՞նչ պատասխանատվություն: Որևէ ժամկետ կա՞ այդ դեպքերի գրանցման համար: Ծննդատունը գրանցու՞մ է այդ դեպքերը իր հաշվետվությունների համար: Ինչպե՞ս:

2.12 Ո՞րն է պերինատալ մահացության ներկայից սահմանումը: Պերինատալ մահացության դեպքերի թերգրանցման և սխալ գրանցման ի՞նչ դեպքեր կարող են լինել: Ի՞նչ պատճառներով: Որքա՞ն հեշտ է պերինատալ մահացության դեպքերի գրանցման կարգը: Դուք տեսնու՞մ եք այս կարգի բարելավման որևէ անհրաժեշտություն:

2.13 Ի՞նչ փաստաթղթեր են լրացվում բուժհաստատությունում՝ ուշ նորածնային մահացության դեպքում: Արդյո՞ք որևէ առողջապահական հաստատություն կրում է պատասխանատվություն՝ ՔԿԱԳ-ում ուշ նորածնային մահացության դեպքերի գրանցման համար: Եթե այո, ո՞ր հաստատությունը և ի՞նչ պատասխանատվություն: Որևէ ժամկետ կա՞ այդ դեպքերի գրանցման համար: Որքա՞ն հեշտ է ուշ նորածնային մահացության դեպքերի գրանցման կարգը: Դուք տեսնու՞մ եք այս կարգի բարելավման որևէ անհրաժեշտություն:

2.14 Կա՞ն, արդյոք, տարբերություններ ծնողներին տրվող ծննդյան միանվագ նպաստի չափի մեջ (ինչպես տվյալ ծննդի համար, այնպես էլ՝ապագա երեխաների հերթական կարգաթվի

հաշվարկման առումով), եթե երեխան ծնվել է մահացած, կամ մահացել է կյանքի առաջին շաբաթում, կամ մահացել է 2-րդից 4-րդ շաբաթներում: Եթե այո, ապա ի՞նչ տարբերություններ:

2.15 Ձեր կարծիքով՝ հնարավո՞ր է, որ երեխայի մահվան օրը գրանցվի իրականից ավելի ուշ, որպեսզի ծնողներն ավելի մեծ նպաստ ստանան: Որքա՞ն հաճախ կարող է դա պատահել:

(Ամփոփիչ հարց) - Կցանկանայիք ավելացնել որևէ բան, որ կարելի է ձեռնարկել՝ Հայաստանում մեռելածնության և կենդանածնության գրանցումը բարելավելու համար:

Շնորհակալություն Ձեր ժամանակի և արդյունավետ զրույցի համար:

Խորացված հարցազրույցի ուղեցույց
(Ծնողատների / հիվանդանոցների բուժանձնակազմ և տնօրեններ)

Ամսաթիվ: _____ **Ժամ:** _____

Վայր: _____

Վարող: _____

Գրանցող: _____

Բարի օր և շնորհակալություն, որ համաձայնեցիք զրուցել մեզ հետ: Իմ անունը _____: Ես ներկայացնում եմ Հայաստանի ամերիկյան համալսարանի Հանրային առողջապահության ֆակուլտետը: Ինչպես նշված է Ձեր կողմից ընթերցված համաձայնության ձևում, ՅՈՒՆԻՍԵՖ-ի աջակցությամբ մենք իրականացնում ենք հետազոտություն՝ ուսումնասիրելու կենդանածնության և մեռելածնության, ինչպես նաև վաղ և ուշ նորածնային մահացության ճիշտ գրանցմանն ու հաշվետվությանը խոչընդոտող գործոնները: Մենք կցանկանայինք, որ Դուք ներկայացնեիք այդ հարցերի վերաբերյալ Ձեր կարծիքը, որը մեզ համար շատ գնահատելի է: Եթե չեք առարկում, ես կձայնագրեմ մեր զրույցը, որպեսզի Ձեր արտահայտած ոչ մի կարևոր միտք չվրիպի մեր ուշադրությունից: Խնդրում եմ արտահայտվեք ազատորեն, նկատի ունենալով, որ Ձեր տրամադրած ողջ տեղեկատվությունը մնալու է գաղտնի և Ձեր անունը ոչ մի տեղ չի հրապարակվելու: Խնդրում եմ, թույլ տվեք այժմ սկսել:

1. ՍԱՀՄԱՆՈՒՄՆԵՐԻ ՓՈՓՈԽՈՒԹՅՈՒՆ՝ ՎԻԺՈՒՄ ԵՎ ԾՆՆԴԱԲԵՐՈՒԹՅՈՒՆ, ՄԵՌԵԼԱԾՆՈՒԹՅՈՒՆ ԵՎ ԿԵՆԴԱՆԱԾՆՈՒԹՅՈՒՆ

<u>Պտուղ և նորածին</u>

1.1 Ի՞նչ կարծիքի եք վիժման և ծննդաբերության սահմանումներում կատարված փոփոխությունների մասին: Ե՞րբ և ինչու՞ են այդ փոփոխությունները մտցվել:

1.2 Ինչպե՞ս են վիժման և ծննդաբերության (կամ պտղի և նորածնի) սահմանումներում կատարված փոփոխություններն ազդել իրական գործելակերպի վրա: Ի՞նչ կարծիք ունեք այս փոփոխության վերաբերյալ: Արդյոք հե՞շտ էր անցումը նոր դասակարգմանը: Այդ անցումը տեղի է ունեցել ամբողջությա՞մբ, թե՞ոչ:

1.3 Ըստ Ձեզ, ի՞նչ հետևանքներ է ունեցել վիժման ու ծննդաբերության միջև սահմանը հղիության 28 շաբաթականից 22 շաբաթական ժամկետ տեղափոխելը (այդ թվում՝ ֆինանսական հետևանքները Ձեր և Ձեր հաստատության համար):

<u>Կենդանածին և մեռելածին</u>

1.4 Ի՞նչ փոփոխություններ են մտցվել Հայաստանում՝ կենդանածնություն և մեռելածնություն սահմանումների մեջ: Ե՞րբ և ի՞նչ նպատակով են այդ փոփոխությունները մտցվել: Որո՞նք են ներկայիս չափանիշները՝ մեռելածնության ախտորոշման համար:

1.5 Ի՞նչ չափով են կենդանածնության և մեռելածնության սահմանումների մեջ կատարված փոփոխություններն ազդել իրական գործելակերպի վրա: Արդյոք հե՞շտ էր անցումը նոր սահմանումներին: Այն տեղի է ունեցել ամբողջությա՞մբ, թե՞ոչ:

1.6 Ձեր հաստատությունում ո՞վ է ախտորոշում մեռելածնությունը: Այդ ախտորոշումը կախվա՞ծ է ծննդաբերության ժամկետից կամ երեխայի ծննդյան քաշից: Եթե այո, ապա՝ ինչպե՞ս: Մեռելածնության ախտորոշումը կախվա՞ծ է երեխայի մահվան ժամկետից: Ծնվելուց հետո որքա՞ն ժամանակ անց պետք է ծայրահեղ ցածր քաշով երեխան մահանա, որ համարվի մեռելածին:

1.7 Կարծու՞մ եք, որ անհրաժեշտ է նոր փոփոխություն մտցնել ծննդաբերության և վիժման (կամ նորածնի և պտղի) սահմանումներում: Եթե այո՝ ի՞նչ փոփոխություն: Կարծու՞մ եք, արդյոք, որ կարելի է փոփոխություններ մտցնել մեռելածնության և կենդանածնության սահմանումներում: Եթե այո, ապա ի՞նչ կառաջարկեիք:

2. ԾՆՈՒՆԴՆԵՐԻ, ՄԵՌԵԼԱԾՆՈՒԹՅԱՆ ԵՎ ՆՈՐԱԾՆԱՅԻՆ ՄԱՀԵՐԻ ՀԱՇՎԵՏՎՈՒԹՅՈՒՆԸ ԵՎ ԳՐԱՆՑՈՒՄԸ

<u>Ծնունդների գրանցում</u>

2.1 Նկարագրեք, խնդրեմ, նորածնի ծննդյանը հաջորդող պաշտոնական ընթացակարգը: Ի՞նչ փաստաթղթեր են լրացվում, ու՞մ կողմից: Ինչպե՞ս է հիվանդանոցը նպաստում նորածինների գրանցմանը Քաղաքացիական կացության ակտերի գրանցման (ՔԿԱԳ) մարմիններում: Ինչպե՞ս է հիվանդանոցը պահում ծնունդների վերաբերյալ իր սեփական վիճակագրությունը:

2.2 Արդյո՞ք ծննդի գրանցման ընթացակարգում կան տարբերություններ, եթե երեխան ծնվել է կենդանի, բայց մինչև 1000 գ քաշով: Եթե այո, որո՞նք են դրանք:

2.3 Ըստ Ձեզ, ո՞ր դեպքերում ծնունդը կարող է չգրանցվել ՔԿԱԳ-ում կամ գրանցվել ուշացումով: Հնարավո՞ր է ինչ-որ բան անել՝ այդ դեպքերը նվազեցնելու համար: Որքա՞ն հեշտ է ծննդի գրանցման ներկա կարգը: Ինչպե՞ս կարելի է այն բարելավել:

<u>Մեռելածնության գրանցում</u>

2.4 Կարո՞ղ եք նկարագրել մահացած երեխայի ծննդին հաջորդող գործելակերպը: Ո՞վ է վերցնում մարմինը և ինչ է անում: Մարմինը վերադարձվու՞մ է ծնողներին, թե ոչ: Եթե ոչ, ու՞ր է տարվում:

2.5 Նկարագրեք, խնդրեմ, մահացած երեխայի ծննդին մասին հաշվետվության ընթացակարգը: Կա՞ն, արդյոք, որոշակի փաստաթղթեր, որ պետք է լրացնել: Ո՞վ է լրացնում դրանք: Ծննդատունը ո՞ր մարմնին պետք է հաղորդի մահացած երեխայի ծննդի մասին: Ի՞նչ ժամկետում պետք է կատարվի այդ հաղորդումը: Հիվանդանոցը պահու՞մ է տվյալներ մեռելածնության դեպքերի վերաբերյալ: Ի՞նչ ձևով:

2.6 Ծննդատանը որևէ մեկը պաշտոնապես պատասխանատու՞ է պերինատալ մահերի ժամանակին և ճիշտ գրանցման համար: Ծնողները ստանու՞մ են որևէ փաստաթուղթ մեռելածնության դեպքում: Դա ծննդյա՞ն վկայական է, մահվա՞ն, թե՞ ինչ-որ այլ փաստաթուղթ: Ո՞վ է պատասխանատու այն տրամադրելու համար:

2.7 Ի՞նչ եք կարծում, կարո՞ղ է որոշ հանգամանքներում նորածինը գրանցվել որպես մեռելածին, երբ իրականում ցույց է տվել կյանքի որոշ նշաններ մինչև մահանալը: Ի՞նչ հանգամանքներ կարող են լինել դրանք: Հնարավո՞ր է, որ դա լինի ծայրահեղ անհասության (22-26 շաբաթական) դեպքում: Երբևէ լսե՞լ եք այնպիսի դեպքերի մասին, երբ երեխան ցուցաբերել է կենդանության նշաններ, բայց գրանցվել է որպես մեռելածին: Չէի՞ք ցանկանա պատմել դրա մասին:

2.8 Ձեր կարծիքով, որո՞նք են մեռելածնության հիմնական պատճառները և ո՞ր գեստացիոն տարիքում է այն ավելի հաճախ լինում: Ինչու՞:

2.9 Ինչի՞ հիման վրա է հաշվարկվում գեստացիոն տարիքը (հղիության ընթացքում կամ ծննդաբերությունից / վիժումից հետո): Որքա՞ն հաճախ է գեստացիոն տարիքը սխալ հաշվարկվում: Կարո՞ղ եք հիշել որևէ դեպք, երբ կանանց կոնսուլտացիայի կողմից Ձեզ հաղորդված գեստացիոն տարիքը եղել է սխալ: Այդ դեպքում Դուք ո՞րն եք զեկուցում՝ նրանց հաղորդա՞ծը, թե՞ Ձեր հաշվարկածը:

2.10 Դուք հաճա՞խ եք տեսնում բնածին արատներով պտուղներ կամ նորածիններ: Ո՞ր գեստացիոն տարիքում են նրանք սովորաբար ախտորոշվում: Ի՞նչ է լինում, այդ հղիությունների հետ: Երբ հղիությունն ընդհատվում է բնածին արատի պատճառով, այն սովորաբար հանգեցնում է մեռելածնությա՞ն, թե՞ կենդանածնության: Իսկ ինչպե՞ս է այն զեկուցվում:

2.11 12-22 շաբաթական հղիության ընդհատման հետ կապված բուժօգնության համար բուժաշխատողները նույն կե՞րպ են վարձատրվում, ինչ որ՝ 22 շաբաթական կամ ավելի ժամկետով հղիության ընդհատման: Եթե ոչ, կարծու՞մ եք, արդյոք, որ դա արդարացի է: Ի՞նչ կարելի է անել այդ առումով: Ի՞նչ հետևանքներ կարող են լինել, եթե այդ հարցը չլուծվի:

2.12 Որո՞նք են դիահերձում կատարելու ցուցումները մեռելածնության դեպքում: Կա՞ն արդյոք դիահերձման սահմանափակումներ՝ մեռելածնի գեստացիոն տարիքի կամ ծննդյան քաշի հետ

կապված: Եթե այո, ապա ի՞նչ սահմանափակումներ: Կա՞ն արդյոք ինչ-որ դժվարություններ կամ խոչընդոտներ՝ մեռելածինների դիահերձում կատարելու համար: Ի՞նչ խոչընդոտներ:

2.13 Միջինում, մեռելածինների ո՞ր տոկոսն է դիահերձման ենթարկվում Ձեր հաստատությունում: Դուք ստանու՞մ եք դիահերձման արդյունքները: Դիահերձման ախտորոշումը գրանցվու՞մ է հիվանդանոցի փաստաթղթերում: Որտե՞ղ է գրանցվում: Դիահերձմամբ ճշտված ախտորոշումը զեկուցվու՞մ է ՔԿԱԳ մարմին: Եթե ոչ՝ ինչու՞: Ի՞նչ կարելի է անել Հայաստանում մեռելածնության ճիշտ պատճառական կառուցվածք ունենալու համար:

<u>Պերինատալ և նորածնային մահերի գրանցում</u>

2.14 Կա՞ն, արդյոք, տարբերություններ ծննդի գրանցման ընթացակարգերում, եթե երեխան ծնվել է կենդանի, բայց մահացել է կյանքի առաջին շաբաթվա ընթացքում: Նման դեպքերում ի՞նչ փաստաթղթեր են լրացվում հիվանդանոցում: Արդյո՞ք հիվանդանոցը պատասխանատու է ՔԿԱԳ-ում այդ դեպքերի գրանցման համար: Ինչպե՞ս: Կա՞ այդ դեպքերի գրանցման որևէ ժամկետ: Հիվանդանոցը պահու՞մ է այդ դեպքերի մասին իր սեփական տվյալները: Ի՞նչ կերպ:

2.15 Ո՞րն է պերինատալ մահացության սահմանումը: Պերինատալ մահվան դեպքերի թերգրանցման կամ սխալ գրանցման ի՞նչ դեպքեր կարող են լինել: Ի՞նչ պատճառներով: Որքա՞ն հեշտ է պերինատալ մահերի գրանցման կարգը: Դուք տեսնու՞մ եք այդ կարգի բարելավման անհրաժեշտություն:

2.16 Ո՞րոնք են նորածնային, վաղ նորածնային և ուշ նորածնային մահացության սահմանումները: Ի՞նչ փաստաթղթեր են լրացվում բուժհաստատությունում՝ ուշ նորածնային մահացության դեպքում: Կյանքի 7-28-րդ օրը մահացած երեխայի մահը ներառվու՞մ է ծննդատան տարեկան հաշվետվության ձևերում առանձին տողով՝ որպես ուշ նորածնային մահ: Եթե երեխան ծննդատնից տեղափոխվում է այլ բուժհաստատություն և մահանում ուշ նորածնային շրջանում, նրա մահը ներառվու՞մ է բուժհաստատության տարեկան հաշվետվության մեջ՝ որպես ուշ նորածնային մահ:

2.17 Արդյո՞ք որևէ բուժհաստատություն կրում է պատասխանատվություն՝ ՔԿԱԳ մարմնում ուշ նորածնային մահացության դեպքերի գրանցման համար: Եթե այո, ի՞նչ պատասխանատվություն և ո՞ր հաստատությունը: Կա՞ ՔԿԱԳ մարմնում այդ դեպքերի գրանցման որևէ ժամկետ: Որքա՞ն լիարժեք է ուշ նորածնային մահերի գրանցման կարգը: Դուք տեսնու՞մ եք այդ կարգի բարելավման անհրաժեշտություն:

2.18 Կա՞ն, արդյոք, տարբերություններ ծնողներին տրվող ծննդյան միանվագ նպաստի չափի մեջ (ինչպես տվյալ ծննդի համար, այնպես էլ՝ապագա երեխաների հերթական կարգաթվի հաշվարկման առումով), եթե երեխան ծնվել է մահացած, կամ մահացել է կյանքի առաջին շաբաթում, կամ մահացել է 2-րդից 4-րդ շաբաթներում: Եթե այո, ապա ի՞նչ տարբերություններ:

2.19 Ձեր կարծիքով՝ հնարավո՞ր է, որ երեխայի մահվան օրը գրանցվի իրականից ավելի ուշ, որպեսզի ծնողներն ավելի մեծ նպաստ ստանան: Որքա՞ն հաճախ կարող է դա պատահել:

(Ամփոփիչ հարց) – Կցանկանայի՞ք ավելացնել որևէ բան, որ կարելի է անել՝ Հայաստանում մեռելածնության և նորածնային մահացության վիճակագրությունը բարելավելու համար:

Շնորհակալություն Ձեր ժամանակի և արդյունավետ զրույցի համար:

Խորացված հարցազրույցի ուղեցույց
(Կանանց կոնսուլտացիաների մանկաբարձ-գինեկոլոգներ)

Ամսաթիվ: _____ Ժամ: _____

Վայր: _____

Վարող: _____

Գրանցող: _____

Բարի օր և շնորհակալություն, որ համաձայնեցիք զրուցել մեզ հետ: Իմ անունը _____: Ես ներկայացնում եմ Հայաստանի ամերիկյան համալսարանի Հանրային առողջապահության ֆակուլտետը: Ինչպես նշված է Ձեր կողմից ընթերցված համաձայնության ձևում, ՅՈՒՆԻՍԵՖ-ի աջակցությամբ մենք իրականացնում ենք հետազոտություն՝ ուսումնասիրելու կենդանածնության և մեռելածնության, ինչպես նաև վաղ և ուշ նորածնային մահացության ճիշտ գրանցմանն ու հաշվետվությանը խոչընդոտող գործոնները: Մենք կցանկանայինք, որ Դուք ներկայացնեիք այդ հարցերի վերաբերյալ Ձեր կարծիքը, որը մեզ համար շատ գնահատելի է: Եթե չեք առարկում, ես կձայնագրեմ մեր զրույցը, որպեսզի Ձեր արտահայտած ոչ մի կարևոր միտք չվրիպի մեր ուշադրությունից: Խնդրում եմ արտահայտվեք ազատորեն, նկատի ունենալով, որ Ձեր տրամադրած ողջ տեղեկատվությունը մնալու է գաղտնի և Ձեր անունը ոչ մի տեղ չի հրապարակվելու: Խնդրում եմ, թույլ տվեք այժմ սկսել:

1. ՍԱՀՄԱՆՈՒՄՆԵՐԻ ՓՈՓՈԽՈՒԹՅՈՒՆ՝ ՎԻԺՈՒՄ ԵՎ ԾՆՆԴԱԲԵՐՈՒԹՅՈՒՆ

1.1 Խնդրում ենք արտահայտել Ձեր կարծիքը վիժման և ծննդաբերության (կամ պտղի և նորածնի) սահմանումներում կատարված փոփոխությունների մասին: Ո՞րն է ծննդաբերության ներկայիս սահմանումը: Ի՞նչն է փոխվել այդ սահմանման մեջ, ե՞րբ և ինչու՞: Ի՞նչ եք կարծում, այդ փոփոխությունն անհրաժե՞շտ էր: Ինչի՞ համար:

1.2 Ձեր կարծիքով, ինչպե՞ս են վիժման և ծննդաբերության սահմանումների փոփոխություններն ազդել Հայաստանում կենդանածության ու մեռելածնության վիճակագրության վրա: Ի՞նչ եք կարծում, անցումը նոր սահմանումներին տեղի է ունեցել ամբողջությա՞մբ, թե ոչ: Եթե ոչ, ապա ինչու՞:

2. ՄԵՌԵԼԱԾՆՈՒԹՅՈՒՆ ԵՎ ՈՒՇ ՎԻԺՈՒՄ. ՊԱՏՃԱՌՆԵՐԸ ԵՎ ՁԵՎԱԿԵՐՊՈՒՄԸ

2.1 Ձեր կարծիքով, որո՞նք են մեռելածնության հիմնական պատճառները և ո՞ր գեստացիոն տարիքում է այն ավելի հաճախ պատահում: Ինչու՞:

2.2 Ո՞ր գեստացիոն տարիքում են պտղի արատները սովորաբար ախտորոշվում: Ի՞նչ է տեղի ունենում այդ հղիությունների հետ: Երբ հղիությունը դադարեցվում է բնածին արատի

պատճառով, այն սովորաբար ավարտվում է կենդանածնությա՞մբ, թե՞ մեռելածնությամբ: Ինչպե՞ս է դա սովորաբար ձևակերպվում:

2.3 Որքա՞ն հաճախ է 20-ից 37 շաբաթական հղիությունն ընդհատվում բժշկական ցուցումներով և որքա՞ն հաճախ՝ ծնողների կամքով: Մինչև ո՞ր գեստացիոն տարիքը կարելի է կատարել հղիության արհեստական ընդհատում: Սովորաբար ի՞նչ է արվում, եթե ծնողները չեն ցանկանում երեխա ունենալ հղիության ավելի ուշ ժամկետում: Հնարավո՞ր է, որ ուշ աբորտների ինչ-որ մասը ձևակերպվի որպես մեռելածնություն:

2.4 Դուք ծննդատներից ստանու՞մ եք տեղեկություն Ձեր կողմից վարված հղի կանանց ծննդաբերության ելքի մասին: Կան՞ արդյոք ձևեր, որոնք պետք է լրացվեն ծննդատանը և ետ ուղարկվեն կանանց կոնսուլտացիա: Ո՞վ է բերում այդ ձևերը: Ի՞նչ տեղեկություն են դրանք պարունակում:

2.5 Ձեր վարած հղի կանանց ո՞ր տոկոսի համար եք Դուք ստանում այդ ձևերը: Ինչպե՞ս և որտե՞ղ են դրանք պահվում: Դուք օգտագործու՞մ եք այդ ձևերում եղած տեղեկությունները Ձեր վիճակագրության և հաշվետվությունների համար:

2.6 Ինչի՞ հիման վրա է գեստացիոն տարիքը հաշվարկվում: Որքա՞ն հաճախ է լինում, երբ Ձեր կողմից հաշվարկված գեստացիոն տարիքը չի համընկնում ծննդատան կողմից հաշվարկվածի (և Ձեզ ուղարկված ձևերում նշվածի) հետ: Կարո՞ղ եք հիշել այդպիսի անհամապատասխանության որևէ դեպք: Դուք ունե՞ք որևէ բացատրություն այդ անհամապատասխանության համար:

2.7 Ըստ Ձեզ, կարո՞ղ է որոշ հանգամանքներում ծնունդը գրանցվել որպես մեռելածնություն, երբ իրականում, մինչև մահանալը, նորածինը ցույց է տվել կյանքի որոշ նշաններ: Ի՞նչ հանգամանքներում դա կարող է տեղի ունենալ: Կարո՞ղ է դա լինել ծայրահեղ անհասության (22-26 շաբաթական) կամ կյանքի հետ անհամատեղելի ծանր արատով նորածնի ծննդյան դեպքում: Ի՞նչ պատճառով դա կարող է տեղի ունենալ:

2.8 Ձեր կարծիքով, ծննդատանը փոխանցվող գումարի տարբերությունը ծննդաբերության համար՝ համեմատած վիժման հետ, կարո՞ղ է ազդել այն բանի վրա, որ ուշ վիժումը ներկայացվի որպես ծննդաբերություն: Ի՞նչ կարելի է անել այս առումով ՝ մեռելածնության ճիշտ վիճակագրություն ունենալու համար:

<u>(Ամփոփիչ հարց)</u> – Կցանկանայի՞ք ավելացնել որևէ բան, որ կարելի է անել Հայաստանում մեռելածնության վիճակագրությունը բարելավելու համար:

Շնորհակալություն Ձեր ժամանակի և արդյունավետ զրույցի համար:

Խորացված հարցազրույցի ուղեցույց
(Ախտաբանաանատոմ)

Ամսաթիվ: _____ **Ժամ:** _____
Վայր: _____
Վարող: _____
Գրանցող: _____

Բարի օր և շնորհակալություն, որ համաձայնեցիք զրուցել մեզ հետ: Իմ անունը _____: Ես ներկայացնում եմ Հայաստանի ամերիկյան համալսարանի Հանրային առողջապահության ֆակուլտետը: Ինչպես նշված է Ձեր կողմից ընթերցված համաձայնության ձևում, ՅՈՒՆԻՍԵՖ-ի աջակցությամբ մենք իրականացնում ենք հետազոտություն՝ ուսումնասիրելու կենդանածնության և մեռելածնության, ինչպես նաև վաղ և ուշ նորածնային մահացության ճիշտ գրանցմանն ու հաշվետվությանը խոչընդոտող գործոնները: Մենք կցանկանայինք, որ Դուք ներկայացնեիք այդ հարցերի վերաբերյալ Ձեր կարծիքը, որը մեզ համար շատ գնահատելի է: Եթե չեք առարկում, ես կձայնագրեմ մեր զրույցը, որպեսզի Ձեր արտահայտած ոչ մի կարևոր միտք չվրիպի մեր ուշադրությունից: Խնդրում եմ արտահայտվեք ազատորեն, նկատի ունենալով, որ Ձեր տրամադրած ողջ տեղեկատվությունը մնալու է գաղտնի և Ձեր անունը ոչ մի տեղ չի հրապարակվելու: Խնդրում եմ, թույլ տվեք այժմ սկսել:

1. ՍԱՀՄԱՆՈՒՄՆԵՐԻ ՓՈՓՈԽՈՒԹՅՈՒՆՆԵՐ՝ ՎԻԺՈՒՄ ԵՎ ԾՆՆԴԱԲԵՐՈՒ-ԹՅՈՒՆ, ՄԵՌԵԼԱԾՆՈՒԹՅՈՒՆ ԵՎ ԿԵՆԴԱՆԱԾՆՈՒԹՅՈՒՆ

<u>Պտուղ և նորածին</u>

1.1 Չէի՞ք ներկայացնի այն փոփոխությունները, որ մտցվել են վիժման և ծննդաբերության (կամ պտղի և նորածնի) սահմանումներում: Ե՞րբ և ինչու՞ են այդ փոփոխությունները մտցվել:

1.2 Ինչպե՞ս են վիժման և ծննդաբերության (կամ պտղի և նորածնի) սահմանումների փոփոխություններն ազդել իրական գործելակերպի վրա: Ի՞նչ կարծիք ունեք այդ փոփոխությունների վերաբերյալ: Արդյո՞ք անցումը նոր սահմանումներին տեղի է ունեցել ամբողջությամբ, թե՞ ոչ:

1.3 Ձեր կարծիքով, ի՞նչ հետևանքներ կարող է ունենալ վիժման և ծննդաբերության միջև սահմանը հղիության 28 շաբաթական ժամկետից 22 շաբաթական ժամկետ տեղափոխելը: Ինչպե՞ս կփոխվի դրանից մահացության վիճակագրությունը՝ թե՛ ցուցանիշների, թե՛ պատճառական կառուցվածքի առումով:

1.4 Ի՞նչ եք կարծում, կարիք կա՞ հետագա փոփոխություններ մտցնել վիժման և ծննդաբերության կամ պտղի և նորածնի սահմանումներում: Եթե այո՝ ի՞նչ փոփոխություններ:

<u>Կենդանածին և մեռելածին</u>

1.5 Խնդրում ենք՝ նկարագրեք, թե Հայաստանում ի՞նչ փոփոխություններ են մտցվել կենդանածնության և մեռելածնության սահմանումներում: Ե՞րբ են այդ փոփոխությունները մտցվել և ի՞նչ նպատակով: Որո՞նք են մեռելածնության ախտորոշման ներկայիս չափանիշները:

1.6 Ձեր կարծիքով, ի՞նչ չափով են կենդանածնության և մեռելածնության սահմանումներում կատարված փոփոխություններն ազդել իրական գործելակերպի վրա: Արդյո՞ք անցումը նոր սահմանումներին տեղի է ունեցել ամբողջությամբ, թե՞ ոչ: Ինչու՞ այո կամ ինչու՞ ոչ:

1.7 Ըստ Ձեզ, կարիք կա՞ հետագա փոփոխություններ մտցնել մեռելածնության և կենդանածնության սահմանումներում: Եթե այո, ապա ի՞նչ կառաջարկեիք:

2. ԴԻԱՀԵՐՁՈՒՄԸ ՄԵՌԵԼԱԾՆՈՒԹՅԱՆ ԵՎ ՆՈՐԱԾՆԱՅԻՆ ՄԱՀՎԱՆ ԴԵՊՔՈՒՄ

2.1 Չէի՞ք նկարագրի, թե ինչ ընթացակարգ է հաջորդում մահացած նորածնի ծնվելուն կամ ծննդատանը նորածնի մահանալուն: Ո՞վ է վերցնում երեխայի մարմինը և ինչ են անում դրա հետ: Արդյո՞ք մարմինները վերադարձվում են ծնողներին: Եթե ոչ, որտե՞ղ են դրանք տարվում:

2.2 Խնդրում ենք նկարագրել, թե արդյո՞ք որևէ փոփոխություն մտցվել է մեռելածինների և նորածնային շրջանում մահացածների դիահերձման կարգում: Ե՞րբ և ինչու՞ են այդ փոփոխությունները մտցվել: Ի՞նչ եք կարծում, այդ փոփոխություններն անհրաժե՞շտ էին: Ի՞նչու:

2.3 Մեռելածնության և նորածնային մահերի ո՞ր դեպքերում է դիահերձումը պաշտոնապես պահանջվում: 1000 գրամից ավելի քաշով ծնված մեռելածինների ո՞ր տոկոսն է իրականում դիահերձվում: Իսկ 1000 գրամից պակաս քաշով ծնված մեռելածինների՞: Կարծու՞մ եք, արդյոք, որ ծայրահեղ ցածր քաշով (մինչև 1000 գրամ) ծնվածների դիահերձումը նույնքան ինֆորմատ է, որքան ավելի խոշոր նորածիններինը: Եթե ոչ, ապա ինչու՞:

2.4 Կարո՞ղ եք նկարագրել մահացած նորածնին դիահերձման ուղեգրելու գործընթացը: Ուղեգրման ի՞նչ ձևեր են լրացվում և ու՞մ կողմից: Արդյո՞ք այդ ձևերում ներառված տեղեկություններն անհրաժեշտ են և օգտակար: Որքա՞ն լիարժեք են այդ ձևերը սովորաբար լրացվում: Կարծու՞մ եք, որ այդ ձևերը կամ դրանց լրացումը կարող է ինչ-որ կերպ բարելավվել: Ի՞նչ կերպ:

2.5 Որտե՞ղ եք գրանցում դիահերձման արդյունքները: Ձեր բաժանմունքում պահվու՞մ են ուղեգրման ձևերը կամ այլ առնչվող փաստաթղթեր: Եթե այո, ի՞նչ փաստաթղթեր և ի՞նչ նպատակով: Օգտագործու՞մ եք արդյոք այնտեղ պարունակվող տեղեկությունները ինչ-ոչ վիճակագրության կամ հաշվետվության համար: Ի՞նչ վիճակագրության կամ հաշվետվության:

2.6 Սովորաբար, դիահերձման ուղեգրելուց քանի՞ օր անց են բժիշկները ստանում դիահերձման արդյունքները: Որքա՞ն հաճախ է դիահերձման ախտորոշումը տարբերվում ուղեգում նշվածից:

Անհամապատասխանության դեպքում ո՞ր ախտորոշումն է սովորաբար զեկուցվում պաշտոնական վիճակագրության համար (ՔԿԱԳ մարմիններ կամ առողջապահության նախարարություն): Ի՞նչ եք կարծում, բժիշկները հետամու՞տ են լինում, որ դիահերձմամբ հաստատված վերջնական ախտորոշումը հաղորդվի վիճակագրական նպատակների համար:

2.7 Ձեր կարծիքով, որո՞նք են մեռելածնության երեք առավել հաճախ հանդիպող պատճառները Հայաստանում: Մեռելածնության ժամանակ որքա՞ն հաճախ է ընկերքն ուղարկվում հերձման: Որքա՞ն կարևոր է դա:

2.8 Ըստ Ձեզ, որո՞նք են վաղ նորածնային մահացության (կյանքի առաջին 7 օրվա ընթացքում) երեք առավել հաճախ հանդիպվող պատճառները Հայաստանում: Որո՞նք են ուշ նորածնային մահացության (կյանքի 8-28 օրվա ընթացքում) երեք առավել հաճախ հանդիպվող պատճառները Հայաստանում:

2.9 Դիահերձման ընթացքում հնարավո՞ր է պարզել՝ նորածինը ծնվել է մահացա՞ծ, թե՞ մահացել է կյանքի առաջին րոպեների ընթացքում՝ առանց շնչելու, բայց դրսևորելով կյանքի այլ նշաններ (սրտի բաբախում, պորտալարի անոթազարկ կամ կամային մկանային շարժումներ): Ինչպե՞ս:

2.10 Երբևէ նկատե՞լ եք, որ նորածինն ուղարկվել է դիահերձման որպես մեռելածին, բայց հավանաբար ծնվելիս եղել է կենդանի: Որքա՞ն հաճախ (եթե երբևէ) դա կարող է պատահել: Հնարավո՞ր է, որ դա լինի շատ ծանր բնածին արատներով կամ ծայրահեղ ցածր ծննդյան քաշով նորածինների դեպքում: Եթե այո, ապա Դուք որևէ բացատրություն ունե՞ք դրա համար:

2.11 Նախքան հերձելը, Ձեր բաժանմունքում կշռու՞մ են մեռելածիններին: Եթե այո, ապա որքա՞ն հաճախ Ձեզ մոտ գրանցված քաշը չի համապատասխանում ուղեգրի մեջ նշվածին: Որքա՞ն հաճախ դա կարող է լինել ծայրահեղ ցածր քաշով (մինչև 1000 գրամ) նորածինների դեպքում: Ի՞նչ պատճառով կարող է դա պատահել:

2.12 Ձեր փորձում եղե՞լ են դեպքեր, երբ մեռելածնի գեստացիոն տարիքը նշված է եղել 22 շաբաթ, բայց Դուք կասկածել եք 22 շաբաթից փոքր գեստացիոն տարիք: Եթե այո, ապա ի՞նչը կարող է լինել այս տարբերության հնարավոր պատճառը:

<u>(Ամփոփիչ հարց)</u> – Հայաստանում ի՞նչ կարելի է անել բարելավելու համար մեռելածինների և նորածնային շրջանում մահացածների դիահերձման ցուցանիշները, ինչպես նաև՝ մեռելածնության ու նորածնային մահացության պատճառական կառուցվածքի վերաբերյալ գիտելիքները:

Շնորհակալություն Ձեր ժամանակի և արդյունավետ զրույցի համար:

Խորացված հարցազրույցի ուղեցույց

(Քաղաքացիական կացության ակտերի գրանցման մարմինների աշխատակիցներ)

Ամսաթիվ: _____ **Ժամ:** _____
Վայր: _____
Վարող: _____
Գրանցող: _____

Բարի օր և շնորհակալություն, որ համաձայնեցիք զրուցել մեզ հետ: Իմ անունը _____: Ես ներկայացնում եմ Հայաստանի ամերիկյան համալսարանի Հանրային առողջապահության ֆակուլտետը: Ինչպես նշված է Ձեր կողմից ընթերցված համաձայնության ձևում, ՅՈՒՆԻՍԵՖ-ի աջակցությամբ մենք իրականացնում ենք հետազոտություն՝ ուսումնասիրելու կենդանածնության և մեռելածնության, ինչպես նաև վաղ և ուշ նորածնային մահացության ճիշտ գրանցմանն ու հաշվետվությանը խոչընդոտող գործոնները: Մենք կցանկանայինք, որ Դուք ներկայացնեիք այդ հարցերի վերաբերյալ Ձեր կարծիքը, որը մեզ համար շատ գնահատելի է: Եթե չեք առարկում, ես կձայնագրեմ մեր զրույցը, որպեսզի Ձեր արտահայտած ոչ մի կարևոր միտք չվրիպի մեր ուշադրությունից: Խնդրում եմ արտահայտվեք ազատորեն, նկատի ունենալով, որ Ձեր տրամադրած ողջ տեղեկատվությունը մնալու է գաղտնի և Ձեր անունը ոչ մի տեղ չի հրապարակվելու: Խնդրում եմ, թույլ տվեք այժմ սկսել:

1. ՓՈՓՈԽՈՒԹՅՈՒՆՆԵՐ ԿԵՆԴԱՆԱԾԻՆՆԵՐԻ ԳՐԱՆՑՄԱՆ ՄԵՋ

1.1 Ասացեք, խնդրեմ, որևէ փոփոխություն տեղի ունեցե՞լ է ծնունդների գրանցման կարգում՝ վերջին տասնամյակի ընթացքում: Եթե այո, ի՞նչ փոփոխություն: Ներկայումս ո՞ր քաշից (կամ հղության ո՞ր ժամկետից) սկսած են ծնունդները գրանցվում Քաղաքացիական կացության ակտերի գրանցման (ՔԿԱԳ) մարմիններում: Ինչպիսի՞ն էր իրավիճակը նախկինում:

1.2 Որո՞նք են ծննդի գրանցումը կարգավորող հիմնական օրենսդրական ակտերը: Կարո՞ղ եք նկարագրել ծննդի գրանցման գործընթացը. ո՞ր (որտեղի՞) ՔԿԱԳ մարմինները պետք է գրանցեն տվյալ ծնունդը, ի՞նչ փաստաթղթերի առկայության դեպքում, ովքե՞ր են տրամադրում և ովքե՞ր են ՔԿԱԳ մարմին ներկայացնում այդ փաստաթղթերը, եթե ծնունդը տեղի է ունեցել ծննդատանը: Իսկ եթե՝ տանը՞:

1.3 Ո՞ր դեպքերում կարող են առաջանալ ծննդի գրանցման խնդիրներ: Ինչպե՞ս են այդ խնդիրները սովորաբար լուծվում: Գոյություն ունի՞ ինչ-որ ժամկետ՝1000 գրամից ցածր քաշով ծնված նորածինների ծնունդը գրանցելու համար: Ո՞ր դեպքերում է ծննդի գրանցումը համարվում ուշացած: Միջին հաշվով, ծնունդների ո՞ր տոկոսն է գրանցվում ուշացած Ձեր ՔԿԱԳ-ում:

1.4 Գրանցված ծնունդների վերաբերյալ ի՞նչ տվյալներ են պահվում ՔԿԱԳ մարմնի գրանցամատյաններում: Ի՞նչ հաճախախանությամբ եք Դուք գրանցված ծնունդների վերաբերյալ հաշվետվություն ներկայացնում Ազգային Վիճակագրական Ծառայություն (ԱՎԾ) կամ որևէ այլ գործակալություն (ի՞նչ գործակալություն): Գրանցված ծնունդների ո՞ր դեպքերն եք ներառում այդ հաշվետվության մեջ (ներառու՞մ եք ծայրահեղ ցածր՝ 500-1000 գրամ քաշով ծնված երեխաներին): Գրանցված ծնունդների վերաբերյալ ի՞նչ տվյալներ են ներառում ԱՎԾ (կամ այլ

գործակալության) հաշվետվության ձևերը: Արդյո՞ք դրանք ներառում են խմբավորումներ ըստ ծննդյան քաշի կամ ըստ ծննդյան վայրի (հիվանդանոց կամ տուն):

2. ՄԵՌԵԼԱԾՆՈՒԹՅԱՆ ԵՎ ՆՈՐԱԾՆԱՅԻՆ ՄԱՀԵՐԻ ԳՐԱՆՑՄԱՆ ՓՈՓՈԽՈՒԹՅՈՒՆՆԵՐ

<u>Մեռելածնության գրանցում</u>

2.1 Ասացեք, խնդրեմ, որևէ փոփոխություն տեղի ունեցե՞լ է մեռելածնության գրանցման կարգում՝ վերջին տասնամյակի ընթացքում: Եթե այո, ի՞նչ փոփոխություն: Ներկայումս ո՞ր քաշից (կամ հղության ո՞ր ժամկետից) սկսած են մեռելածինները գրանցվում ՔԿԱԳ մարմիններում: Ինչպիսի՞ն էր կարգը նախկինում:

2.2 Որո՞նք են մեռելածնության գրանցումը կարգավորող հիմնական օրենսդրական ակտերը: Ի՞նչ գրանցում է կատարվում մեռելածնի համար (ծննդի՞, մահվա՞ն, թե՞ երկուսի էլ): Որևէ փաստաթուղթ տրամադրվու՞մ է ծնողներին:

2.3 Ի՞նչ փաստաթղթերի հիման վրա է կատարվում մեռելածնի գրանցումը: Ո՞վ է պատասխանատու մեռելածնի մասին ՔԿԱԳ մարմնին տեղեկացնելու համար (ծնողնե՞րը, թե՞ բուժհաստատությունը): Ինչպե՞ս է գրանցման գործընթացը կազմակերպվում, եթե մահացած երեխան ծնվել է ծննդատանը: Իսկ եթե ծնվել է տանը՞:

2.4 Գոյություն ունի՞ որևէ ժամկետ, որի ընթացքում ՔԿԱԳ մարմինը պետք է տեղեկանա և կատարի մեռելածնի գրանցումը: Այդ ժամկետը փոխվե՞լ է: Եթե այո, ապա ինչպե՞ս և ինչու՞: Ձեր ՔԿԱԳ-ում մեռելածինների մոտավորապես ո՞ր տոկոսն է սահմանված ժամկետից ուշ գրանցվում: Մեռելածինների ո՞ր տոկոսի համար է ՔԿԱԳ մարմնի գրանցումներում նշվում մեռելածնության վերջնական՝ դիահերձմամբ հաստատված, պատճառը:

2.5 Ի՞նչ հանգամանքներում մեռելածինը կարող է դուրս մնալ գրանցումից: Ձեր կարծիքով, ինչքա՞ն հաճախ է դա տեղի ունենում 1000 գրամից ավելի քաշով ծնված մեռելածինների դեպքում: Իսկ 1000 գրամից պակաս քաշով ծնվածների դեպքու՞մ:

2.6 Գրանցված մեռելածինների վերաբերյալ ի՞նչ տվյալներ են պահվում ՔԿԱԳ մարմնի գրանցամատյաններում: Ի՞նչ հաճախականությամբ եք մեռելածինների վերաբերյալ հաշվետվություն ներկայացնում ԱՀԾ (կամ այլ գործակալություն):

2.7 Գրանցված մեռելածինների ո՞ր դեպքերն են ներառվում այդ հաշվետվության մեջ (ներառվու՞մ են 500-1000 գրամ քաշով մեռելածինները): Գրանցված մեռելածինների վերաբերյալ ի՞նչ տվյալներ են ներառում ԱՀԾ (կամ այլ գործակալության) հաշվետվության ձևերը: Արդյո՞ք դրանք ներառում են խմբավորումներ ըստ ծննդյան քաշի (500-999 գ, 1000-1499 գ,1500-1999 գ. և այլն), ծննդյան վայրի (հիվանդանոց կամ տուն) կամ մահվան պատճառի:

<u>Վաղ (7 օրյա) և ուշ (8-28 օրյա) նորածնային մահացության գրանցում</u>

2.8 Ո՞ր (որտեղի՞) ՔԿԱԳ մարմինը կարող է գրանցել կյանքի առաջին 7 օրվա ընթացքում մահացած նորածնի ծնունդը: Իսկ կյանքի 8-28-րդ օրվա ընթացքում մահացածինը՞: Այս առումով ինչ-որ բան փոխվե՞լ է: Եթե այո, ապա ե՞րբ և ինչու՞:

2.9 Ի՞նչ գրանցում է կատարվում (ծննդի՞, մահվա՞ն, թե՞ երկուսի էլ), եթե նորածինը մահացել է կյանքի առաջին 4 շաբաթվա ընթացքում: Որևէ փաստաթուղթ տրամադրվու՞մ է երեխայի ծնողներին:

2.10 Ի՞նչ փաստաթղթերի հիման վրա է կատարվում կյանքի առաջին 4 շաբաթվա ընթացքում մահացած նորածնի գրանցումը: Ո՞վ է ներկայացնում այդ փաստաթղթերը, եթե նորածինը մահացել է ծննդատանը, այլ հիվանդանոցում, կամ տանը: Այս կարգը լա՞վ է գործում: Դուք տեսնու՞մ եք այս կարգի բարելավման հնարավորություն:

2.11 Ըստ գործող կարգի, ո՞վ պետք է ՔԿԱԳ մարմնին տեղեկացնի վաղ նորածնային մահվան (մինչև 7 օրականը) դեպքի մասին: Ո՞վ պետք է ՔԿԱԳ մարմնին տեղեկացնի ուշ նորածնային մահվան (7-27 օրականը) դեպքի մասին: Այս կարգում ինչ-որ բան փոխվե՞լ է:

2.12 Գոյություն ունի՞ ՔԿԱԳ մարմնում նորածնային մահվան դեպքի գրանցման որևէ ժամկետ: Այդ ժամկետը փոխվե՞լ է: Եթե այո, ապա ինչպե՞ս և ինչու՞: Ձեր ՔԿԱԳ մարմնում նորածնային մահերի մոտավորապես ո՞ր տոկոսն է սահմանված ժամկետից ուշ գրանցվում: Գրանցված նորածնային մահերի ո՞ր տոկոսի համար է ՔԿԱԳ մարմնի գրանցումներում նշվում մահվան վերջնական՝ դիահերձմամբ հաստատված, պատճառը:

2.13 Կա՞ն, արդյոք, տարբերություններ ծնողներին տրվող ծննդյան միանվագ նպաստի չափի մեջ (ինչպես տվյալ ծննդի համար, այնպես էլ՝ապագա երեխաների հերթական կարգաթվի հաշվարկման առումով), եթե երեխան ծնվել է մահացած, կամ մահացել է կյանքի առաջին շաբաթում, կամ մահացել է 2-րդից 4-րդ շաբաթներում: Եթե այո, ապա ի՞նչ տարբերություններ:

2.14 Ձեր կարծիքով՝ հնարավո՞ր է, որ երեխայի մահվան օրը գրանցվի իրականից ավելի ուշ, որպեսզի ծնողներն ավելի մեծ նպաստ ստանան: Որքա՞ն հաճախ կարող է դա պատահել:

2.15 Գրանցված նորածնային մահերի վերաբերյալ ի՞նչ տվյալներ են ներառում ԱՎԾ (կամ այլ գործակալության) հաշվետվության ձևերը: Արդյո՞ք դրանք ներառում են խմբավորումներ ըստ մահվան ժամկետի (վաղ և ուշ նորածնային մահ), ծննդյան քաշի (500-999 գ, 1000-1499 գ,1500-1999 գ. և այլն), ծննդյան վայրի (հիվանդանոց կամ տուն) կամ մահվան պատճառի:

<u>(Ամփոփիչ հարց)</u> – Կցանկանայի՞ք ավելացնել որևէ բան, որ կարելի է անել Հայաստանում ծնունդների, մեռելածնության և նորածնային մահացության դեպքերի գրանցումը բարելավելու համար:

Շնորհակալություն Ձեր ժամանակի և արդյունավետ զրույցի համար:

Appendix 3. Demographic/knowledge questionnaire for the study participant

Please answer to the following questions:

1. Your age (completed years): _____

2. Your gender: □ Male
   □ Female

3. Your residency: □ Yerevan city
   □ Marz

4. Your specialization: □ Neonatologist
   □ Obstetrician/Gynecologist
   □ Midwife
   □ Regional pediatrician

5. In total, how many years have you worked with your specialization: _____ years

6. After 2005, have you received any training on the new classification of live births, stillbirths and perinatal period:
   □ Yes □ No

7. ***(Please answer to this question, if you work at women's consultation)***
   Do you also work or have duty on in a maternity hospital?
   □ Yes □ No

Questionnaire on definitions and registration of live births, stillbirths and perinatal period

Please, select one correct response to each question, marking (√) the square next to it:

1. According to the World Health Organisation's (WHO)10th International Classification of Diseases (ICD-10), the newborn is considered as stillbirth, if during the birth it has an absence of:
   □ 1. Breathing
   □ 2. Muscular movement
   □ 3. Umbilical cord pulsation
   □ 4. Heartbeat
   □ 5. All of the above

2. According to the WHO ICD-10, the sign(s) of live birth is/are considered:
   □ 1. Breathing
   □ 2. Muscular movement
   □ 3. Umbilical cord pulsation
   □ 4. Heartbeat
   □ 5. Any of the above mentioned

3. The newborn does not have any sign of life but muscular movement. This newborn is considered as:
   □ 1. Stillbirth
   □ 2. Live birth, if it was born after 22 complete weeks of pregnancy
   □ 3. Live birth, if it was born after 28 complete weeks of pregnancy
   □ 4. Live birth, despite the pregnancy duration

4. The newborns should be included in the state statistics through registration in Civil Status Acts Registration (CSAR / ЗАГС) bodies, if his/her birth weight is:
   - □ 1. At least 500 gr
   - □ 2. 500 gr and the child has lived for 7 days
   - □ 3. 1000 gr
   - □ 4. 1500 gr

5. Newborns with 500-1000 gr birthweight are registered in CSAR bodies, if they live:
   - □ 1. 24 hours and more
   - □ 2. 7 days and more
   - □ 3. Independent of the living duration
   - □ 4. 28 days and more

6. According to the ICD 10 adopted in Armenia, perinatal period starts from:
   - □ 1. 20th week of pregnancy
   - □ 2. 22th week of pregnancy
   - □ 3. 28th week of pregnancy
   - □ 4. 37th week of pregnancy

7. The duration of perinatal period is:
   - □ 1. From 22 complete weeks of fetus's intrauterine life to 7 days after birth
   - □ 2. From 28 complete weeks of fetus's intrauterine life to 7 days after birth
   - □ 3. From 37 complete weeks of fetus's intrauterine life to 7 days after birth
   - □ 4. From 22 complete weeks of fetus's intrauterine life to 28 days after birth

8. If the birthweight of a newborn is unknown, it is considered that 500 gr corresponds to the following body length:
   □ 1. 20 cm □ 2. 25 cm □ 3. 30 cm □ 4. 35 cm

9. If the birthweight of a newborn is unknown, it is considered that 500 gr corresponds to the following term of the pregnancy:
   □ 1. 20 weeks □ 2. 22 weeks □ 3. 28 weeks □ 4. 37 weeks

10. The indicator of perinatal mortality includes:
    - □ 1. Stillbirth
    - □ 2. Stillbirth + postnatal death in 0-3 days
    - □ 3. Stillbirth + postnatal death in 0-6 days
    - □ 4. Stillbirth + postnatal death in 0-27 days

11. Which weight of a newborn is classified as "very low birth weight"?
    - □ 1. Less than 2500 gr
    - □ 2. Less than 1500 gr
    - □ 3. Less than 1000 gr
    - □ 4. Less than 500 gr

12. Which weight of a newborn is classified as "low birth weight"?
    - □ 1. Less than 2500 gr
    - □ 2. Less than 1500 gr
    - □ 3. Less than 1000 gr
    - □ 4. Less than 500 gr

13. Which weight of a newborn is considered as “extremely low birth weight”?
    - □ 1. Less than 2500 gr
    - □ 2. Less than 1500 gr
    - □ 3. Less than 1000 gr
    - □ 4. Less than 500 gr

14. Healthcare facility must register the death of a child in CSAR bodies, if the child is:
    - □ 1. 0-1 years old
    - □ 2. 0-7 days old
    - □ 3. 0-28 days old
    - □ 4. 0-5 years old

15. The death of the child is registered in CSAR bodies by healthcare facility within:
    - □ 1. 3 days
    - □ 2. 7 days
    - □ 3. 28 days
    - □ 4. 24 hours

Thank you very much for completing the questionnaire!

Հարցաթերթիկ հետազոտության մասնակցի համար

Խնդրում ենք պատասխանել հետևյալ հարցերին՝

1. Ձեր տարիքը (լրացրած տարիների թիվը). _____

2. Ձեր սեռը. □ Արական
□ Իգական

3. Ձեր բնակավայրը. □ ք. Երևան
□ Մարզ

4. Ձեր մասնագիտությունը. □ Նեոնատոլոգ
□ Մանկաբաձ-գինեկոլոգ
□ Մանկաբարձուհի
□ Մանկաբույժ / շրջմանկաբույժ

5. Քանի՞ տարի եք աշխատել Ձեր մասնագիտությամբ: _____ *տարի*

6. 2005թ.-ից հետո անցե՞լ եք ուսուցում կենդանաձնության, մեռելաձնության և պերինատալ շրջանի նոր դասակարգման վերաբերյալ:
□ Այո □ Ոչ

7. ***(Պատասխանեք այս հարցին, եթե աշխատում եք կանանց կոնսուլտացիայում)***
Դուք համատեղության կարգով աշխատում կամ հերթապահու՞մ եք նաև ծննդատանը:
□ Այո □ Ոչ

Հարցաշար կենդանաձնության, մեռելաձնության, պերինատալ շրջանի հասկացությունների և գրանցման վերաբերյալ

Խնդրում ենք յուրաքանչյուր հարցի համար ընտրել մեկ ճիշտ պատասխան՝ նշելով համապատասխան վանդակը՝ ✓:

1. Ըստ Առողջապահության համաշխարհային կազմակերպության (ԱՀԿ) Հիվանդությունների 10-րդ միջազգային դասակարգման (ՀՄԴ-10), մեռելաձին է համարվում այն նորածինը, որի մոտ ծնվելիս բացակայում է.

□ 1. շնչառությունը
□ 2. կամային մկանների շարժումները
□ 3. պորտալարի անոթազարկը
□ 4. սրտխփոցը
□ 5. Նշված բոլորը

2. Ըստ ԱՀԿ ՀՄԴ-10-ի, կենդանածնության նշաններ են համարվում.

□ 1. շնչառությունը
□ 2. կամային մկաններ շարժումները
□ 3. պորտալարի անոթազարկը
□ 4. սրտխփոցը
□ 5. վերը նշված բոլորը

3. Նորածնի մոտ, բացի կամային մկանների շարժումներից, կենդանածնության այլ նշաններ չեն արձանագրվել: Այս նորածինը համարվում է.

□ 1. մեռելածին
□ 2. կենդանածին՝ եթե նա ծնվել է 22 լրացած շաբաթական և ավելի հղիությունից
□ 3. կենդանածին՝ եթե նա ծնվել է 28 լրացած շաբաթական և ավելի հղիությունից
□ 4. կենդանածին՝ անկախ հղիության տևողությունից

4. Պետական վիճակագրության մեջ (ՔԿԱԳ / ЗАГС) պետք է ընդգրկվեն այն կենդանածինները, որոնց քաշը ծնվելիս.

□ 1. առնվազն 500 գրամ է
□ 2. 500 գրամ է և երեխան ապրել է 7 լրիվ օր
□ 3. 1000 գրամ է
□ 4. 1500 գրամ է

5. 500-1000 գրամ ծնված նորածինները գրանցվում են ՔԿԱԳ մարմիններում, եթե ապրում են.

□ 1. 24 ժամ և ավելի
□ 2. 7 օր և ավելի
□ 3. անկախ ապրելու տևողությունից
□ 4. 28 օր և ավելի

6. Պերինատալ շրջանը, ըստ Հայաստանում գործող ՀՄԴ 10 դասակարգման, սկսվում է.

□ 1. հղիության 20-րդ շաբաթից
□ 2. հղիության 22-րդ շաբաթից
□ 3. հղիության 28-րդ շաբաթից
□ 4. հղիության 37-րդ շաբաթից

7. Պերինատալ շրջանի տևողությունն է.

□ 1. Պտղի ներարգանդային կյանքի 22 լրացած շաբաթից մինչև ծննդից 7 օր հետո
□ 2. Պտղի ներարգանդային կյանքի 28 լրացած շաբաթից մինչև ծննդից 7 օր հետո
□ 3. Պտղի ներարգանդային կյանքի 37 լրացած շաբաթից մինչև ծննդից 7 օր հետո
□ 4. Պտղի ներարգանդային կյանքի 22 լրացած շաբաթից մինչև ծննդից 28 օր հետո

8. Եթե պտղի ծննդյան քաշն անհայտ է, ապա համարվում է, որ 500 գրամ քաշին համապատասխանում է հետևյալ մարմնի երկարությունը.

□ 1. 20 սմ □ 2. 25 սմ □ 3. 30 սմ □ 4. 35 սմ

9. Եթե պտղի ծննդյան քաշն անհայտ է, ապա համարվում է, որ 500 գրամ քաշին համապատասխանում է հետևյալ հղիության ժամկետը.

□ 1. 20 շաբաթ □ 2. 22 շաբաթ □ 3. 28 շաբաթ □ 4. 37 շաբաթ

10. Պերնատալ մահացության ցուցանիշը ներառում է.

□ 1. մեռելածնություն
□ 2. մեռելածնություն + հետծննդյան մահ՝ 0-3 օրերին
□ 3. մեռելածնություն + հետծննդյան մահ՝ 0-6 օրերին
□ 4. մեռելածնություն + հետծննդյան մահ՝ 0-27 օրերին

11. Նորածնի ո՞ր քածն է դասակարգվում որպես ծննդյան «շատ ցածր» քաշ:

□ 1. 2500 գրամից ցածր
□ 2. 1500 գրամից ցածր
□ 3. 1000 գրամից ցածր
□ 4. 500 գրամից ցածր

12. Նորածնի ո՞ր քածն է դասակարգվում որպես ծննդյան «ցածր» քաշ:

□ 1. 2500 գրամից ցածր
□ 2. 1500 գրամից ցածր
□ 3. 1000 գրամից ցածր
□ 4. 500 գրամից ցածր

13. Նորածնի ո՞ր քածն է դասակարգվում որպես ծննդյան «ծայրահեղ ցածր» քաշ:

□ 1. 2500 գրամից ցածր
□ 2. 1500 գրամից ցածր
□ 3. 1000 գրամից ցածր
□ 4. 500 գրամից ցածր

14. Երեխայի մահվան դեպքը ՔԿԱԳ մարմիններում պարտադիր գրանցվում է բուժհաստատության կողմից, եթե երեխան.

□ 1. 0-1 տարեկան է
□ 2. 0-7 օրական է
□ 3. 0-28 օրական է
□ 4. 0-5 տարեկան է

15. Բուժհաստատության կողմից երեխայի մահվան դեպքը գրանցվում է ՔԿԱԳ մարմիններում.

□ 1. 3 օրվա ընթացքում
□ 2. 7 օրվա ընթացքում
□ 3. 28 օրվա ընթացքում
□ 4. 24 ժամվա ընթացքում

Շնորհակալություն հարցերին պատասխանելու համար:

Appendix 4. Data extraction form

Stillbirths, early and late neonatal and postneonatal deaths in Armenia

In 2014:	Live births	Stillbirths		Early (0-6 d.) neonatal deaths		Late (7-28 d.) neonatal deaths		Postneonatal (29 d.-12 m.) deaths	
	Absolute number, 1000s	Absolute number	Rate (per 1000 total births)	Absolute number	Rate (per 1000 live births)	Absolute number	Rate (per 1000 live births)	Absolute number	Rate (per 1000 live births)
By Marzes									
Aragatsotn									
Ararat									
Armavir									
Gegharkunik									
Kotayk									
Lori									
Shirak									
Syunik									
Tavush									
Vayots Dzor									
Yerevan									
ByYerevan healthcare institutions									
Mother & Child Health Protection Center									
Repr. Health, Perinat., Ob. & Gyn. Center									
“Elen-Nare” Maternity Center									
“Qanaqer-Zeytun Maternity Hospital”									
“Erebuni” Medical Center									
“S. Gr.Narekatsi” Medical Center									
“Malatia” Medical Center									
Family Planning (“Beglaryan”) Center									
“S. Gr.Lusavorich” Medical Center									
“S. Astvatsatsin” Maternity Hospital									
“Shengavit” Medical Center									

In 2014:	Live births	Stillbirths		Early (0-6 d.) neonatal deaths		Late (7-28 d.) neonatal deaths		Postneonatal (29 d.-12 m.) deaths	
	Absolute number, 1000s	Absolute number	Rate (per 1000 total births)	Absolute number	Rate (per 1000 live births)	Absolute number	Rate (per 1000 live births)	Absolute number	Rate (per 1000 live births)
"Slav Med" Medical Center									
"Muratsan" University Hospital									
"S. Asttvatsamayr" Medical Center									
"Nork Marash" Medical Center									
By birthweight									
500-999 g									
1000-1499 g									
1500-1999 g									
2000-2499 g									
2500-2999 g									
3000-3499 g									
3500-3999 g									
>=4000 g									
By gestational age									
Preterm (22-36 weeks)									
Term (>=37 weeks)									
By timing of death									
Ante-partum									
Intra-partum									
By place of birth									
Maternity hospital									
Home									
By place of death									
Maternity hospital									
Other hospital									
Home									

Stillbirths by birthweight and infant deaths

In 2014:	Early preterm stillbirths (500-999 g)		Preterm stillbirths (1000-2499 g.)		Term stillbirths (>=2500 g)		Infant (0-1 y.) deaths	
	Absolute number	Rate per 1000 total birth	Absolute number	Rate per 1000 total birth	Absolute number	Rate per 1000 total birth	Absolute number	Rate per 1000 livebirths
By marzes								
Aragatsotn								
Ararat								
Armavir								
Gegharkunik								
Kotayk								
Lori								
Shirak								
Syunik								
Tavush								
Vayots Dzor								
Yerevan								
By place of birth								
Maternity hospital								
Home								

Մեռելածինները, վաղ և ուշ նորածնային և հետնորածնային մահերը Հայաստանում

2014 թ.	Կենդանի ծնունդներ	Մեռելածիններ		Վաղ (0-6 օր) նորածնային մահեր		Ուշ (7-28 օր) նորածնային մահեր		Հետնորածնային (29 օր - 12 ամս.) մահեր	
	Թիվ (հազար)	Թիվ	Ցուցանիշ (1000 ծննդից)	Թիվ	Ցուց. (1000 կենդանա-ծնից)	Թիվ	Ցուց. (1000 կենդանա-ծնից)	Թիվ	Ցուց. (1000 կենդանա-ծնից)
Ըստ մարզերի									
Արագածոտն									
Արարատ									
Արմավիր									
Գեղարքունիք									
Կոտայք									
Լոռի									
Շիրակ									
Սյունիք									
Տավուշ									
Վայոց ձոր									
Երևան									
Ըստ Երևանի բուժհաստատությունների									
Մ և Մ առողջ. պահպ. գիտ. կենտրոն									
«Վերարտադրող. առողջ., ՊՄԳ կենտրոն»									
«Էլեն-Նարե» ծննդօգնության կենտրոն									
«Քանաքեռ Զեյթուն ծննդատուն»									
«Էրեբունի» ԲԿ									
Սբ. Գր. Նարեկացի ԲԿ									
Մալաթիա ԲԿ									
Ընտանիքի պլանավորման կենտրոն									
Սբ.Գր. Լուսավորիչ ԲԿ									
«Սբ.Աստվածածին» ծննդատուն									
Շենգավիթ ԲԿ									
«Սլավ Մեդ» ԲԿ									

2014 թ.	**Կենդանի ծնունդներ**	**Մեռելածիններ**		**Վաղ (0-6 օր) նորածնային մահեր**		**Ուշ (7-28 օր) նորածնային մահեր**		**Հետնորածնային (29 օր - 12 ամս.) մահեր**	
	Թիվ (հազար)	**Թիվ**	**Ցուցանիշ (1000 ծնվդից)**	**Թիվ**	**Ցուց. (1000 կենդանա-ծնից)**	**Թիվ**	**Ցուց. (1000 կենդանա-ծնից)**	**Թիվ**	**Ցուց. (1000 կենդանա-ծնից)**
«Մուրացանի» համալսար. հիվանդանոց									
«Սուրբ Աստվածամայր» ԲԿ									
Նորք Մարաշ ԲԿ									
Ըստ ծննդյան քաշի									
500-999 գ.									
1000-1499 գ.									
1500-1999 գ.									
2000-2499 գ.									
2500-2999 գ.									
3000-3499 գ.									
3500-3999 գ.									
>=4000 գ									
Ըստ գեստացիոն հասակի									
Անհաս (22-36 շաբաթ.)									
Հասուն (>=37 շաբաթ.)									
Ըստ մահվան պահի									
Մինչ-ծննդաբերական									
Ծննդաբերելիս									
Ըստ ծննդյան վայրի									
Ծննդատուն									
Տուն									
Ըստ մահվան վայրի									
Ծննդատուն									
Այլ հիվանդանոց									
Տուն									

Մեռելածիններն ըստ ծննդյան քաշի և մանկական մահերը

2014 թ.	500-999 գ. քաշով մեռելածիններ		1000-2499 գ. քաշով մեռելածիններ		2500գ. և ավելի քաշով մեռելածիններ		Մանկական (0-1տ.) մահեր	
	Թիվ	Յուցանիշ (1000 ծննդից)	Թիվ	Յուցանիշ (1000 ծննդից)	Թիվ	Յուցանիշ (1000 ծննդից)	Թիվ	Յուց. (1000 կենդանա-ծնից)
Ըստ մարզերի								
Արագածոտն								
Արարատ								
Արմավիր								
Գեղարքունիք								
Կոտայք								
Լոռի								
Շիրակ								
Սյունիք								
Տավուշ								
Վայոց ձոր								
Երևան								
Ըստ ծննդյան վայրի								
Ծննդատուն								
Տուն								