

Improving the Completeness and Accuracy of the Primary Health Care Death Registry for Infant Deaths and Stillbirths

November 2020

Infant mortality rate is a key public health indicator, reflecting the overall health of the population as well as the social, economic, and environmental conditions under which children and their communities live.¹ Stillbirth rate is also an important indicator, however reporting is typically sparse and is rarely prioritized or appropriately financed in policies and programs.² In general, data on causes of neonatal death is less reliable than data on causes of mortality for other age groups due to challenges encountered in investigating the cause of death, and limited interest by health care systems in studying these issues.³ Based on a WHO study in 2016, around 30% of the documented underlying causes of infant deaths in the West Bank, and 16% in the Gaza Strip were considered unusable.⁴

In 2019, the reported infant mortality rate was, 11.1 per 1,000 live births in West Bank (870 cases), and the still birth rate was 3.6 per 1,000 total births (284 cases). In Gaza, the infant mortality rate was 10.7 per 1,000 live births. There was no reporting of still births.

However, there are discrepancies in reported infant mortality. In 2018, the MoH reported an infant mortality rate of 11.7 per 1,000 live births in the West Bank and 10.4 in the Gaza Strip. According to the UN Inter-Agency Group for Child Mortality Estimation (IGME), the estimated IMR in Palestine in 2018 was 17.3.

(Source: PHIC/UN IGME)

In 2020, PNIPH and the MoH conducted a study on the completeness and accuracy of the Primary Health Care (PHC) Community Health Department (CHD) Database in the West Bank and PHC Death Registry in the Gaza Strip for infant deaths and stillbirths. Data from the registries was compared with information at the Palestinian Health Information Center (PHIC) to examine the completeness of PHC registries, including administrative and clinical data, and the accuracy of reported underlying cause of death. The following policy brief provides an overview of study findings as well as policy recommendations to improve the completeness and accuracy of reporting for infant deaths and stillbirths at the PHC level.

¹ Reidpath DD, Allotey P (2003); Infant mortality rate as an indicator of population health Journal of Epidemiology & Community Health; 57:344-346.

² Lawn JE, Blencowe H, Waiswa P, et al. (2016) Ending Preventable Stillbirths 2. Stillbirths: rates, risk factors, and acceleration towards 2030. Lancet.

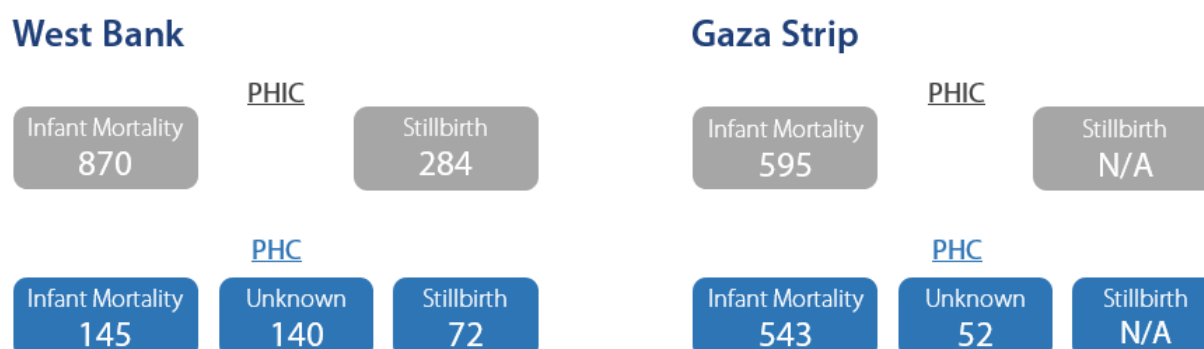
³ Alexander, M. et al. (2019); National, regional, and global levels and trends in neonatal mortality between 1990 and 2017, with scenario-based projections to 2030: a systematic analysis. The Lancet Global Health, Volume 7, Issue 9, Pages e1179

⁴ World Health Organization. Making Every Baby Count: Audit and review of stillbirths and neonatal deaths. January 2016.

Completeness of the PHC Database for Infant Mortality and Stillbirth in 2019

While all cases of infant mortality and stillbirth in the PHIC Death Registry were found in the PHC Death Registry in the Gaza Strip, less than one-third of infant mortality and stillbirth cases reported by PHIC were found in the CHD infant deaths and stillbirths database in the West Bank (Figure 1).

Figure 1: Completeness of PHC CHD/PHC Death Registry, by region in 2019



Completeness of Administrative Data in Investigation Forms/DNFs for Infant Deaths and Stillbirths

In the West Bank, the most critical missing data was related to case type (stillbirth vs. infant death) and attending physician. Case type was missing for almost 40% of cases in the West Bank and 9% in the Gaza Strip. In both the West Bank and Gaza, information that was missing most often pertained to the person reviewing the form (100% in Gaza, 93.5% in the West Bank). In the Gaza Strip, background information on parents was missing. Table 1 shows the main missing administrative data variables.

Variable	West Bank (N=357)	Gaza Strip (N=595)
	(N)%	
ID number	(311) 87.11	(595) 100%
Case type	(217) 60.78	(543) 91.3
Gender	(279) 83.19	(595) 100
District	(350) 98.04	(595) 100
Date of birth	(356) 99.71	(595) 100
Place of birth	(330) 92.44	(595) 100
Date of death	(356) 99.71	(595) 100
Place of death	(337) 94.39	(595) 100
Name of Hospital	(254) 82.73 (N=307)	(543) 100 (N=543)
Mother ID	(0) 0	(468) 78.7
Parent smoke	(276) 77.31	NA
Parent relatives	(305) 85.43	NA
Physician/supervisor	(94) 26.33	(471) 79.2
Person filling form	(157) 43.97	(0) 0
Person reviewing form	(21) 5.82	NA

Completeness of Clinical Data in Investigation Forms/DNFs for Infant Deaths and Stillbirths

Completeness was a serious issue in DNFs and investigation forms for infant deaths and still births in 2019, especially for information on maternal and infant complications, limiting the ability to use the data to examine underlying cause of death. In the West Bank, direct cause of death was missing for 57% of cases. There were no ICD-10 values for direct, intermediate, or underlying cause of death for any cases. In Gaza, there was no data in the DNF on antenatal or postnatal care, infant complications during delivery, maternal complications, or number of twins. Gestational age was missing for almost half of cases in Gaza.

Table 2: Completeness of Clinical Data in Investigation Forms and DNFs for Infant Deaths and Stillbirths, 2019

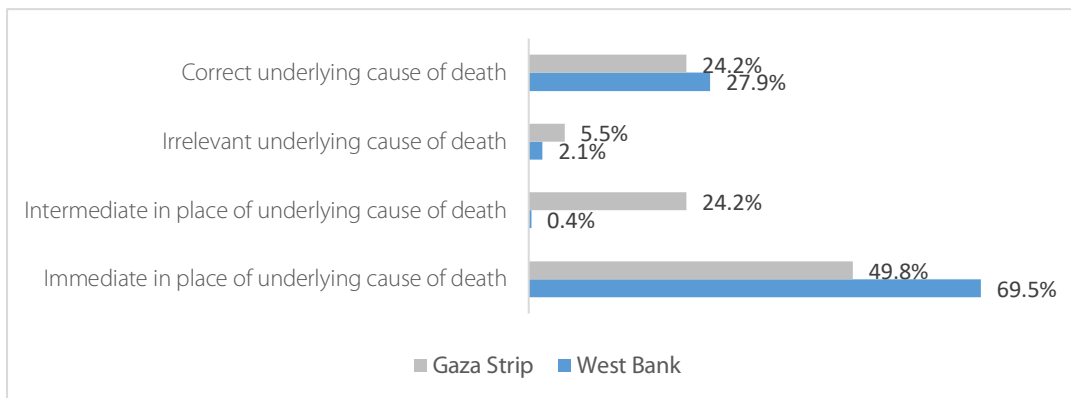
Variable	WB (N=357)	GS (N=595)
	(N)%	
Mother disability/NCDs	(300) 84.03	NA
Number of abortions	(253) 70.86	(288) 48.4
Number of stillbirths	(230) 64.42	NA
Date of last delivery	(337) 94.39	NA
Pregnancy-related diseases	(291) 81.51	NA
Pregnancy medication	(301) 84.31	NA
Eclampsia	(221) 61.9	NA
Preeclampsia	(220) 61.62	NA
Hemorrhage	(220) 61.62	(314) 52.7
Type of delivery	(316) 88.51	(314) 52.7
Birth weight	(328) 91.87	(487) 81.9
Birth order	(265) 74.22	(468) 78.7
Gestational age	(300) 84.03	(287) 48.2
Twins/single	(312) 87.39	(499) 83.9
Fetal organ test	(282) 78.99	(207) 34.7
Congenital diseases	(229) 64.14	(314) 52.7
Infant complications during delivery	(255) 71.42	NA
Direct cause of death	(154) 43.13	(582) 97.8
Underlying cause of death	(300) 84.03	(319) 53.6
Intermediate cause of death	(0) 0	(466) 78.5

Accuracy of Filling the Clinical Data in Investigation Forms/DNFs

Based on the available clinical data, only around 1 in 4 cases in both the West Bank and Gaza Strip had the accurate underlying cause of death listed. Irrelevant information was included in the underlying cause of death line for some cases, such as cyanosis, chest pain, and temperature fluctuations. The rate of sequence error was 77% in the West Bank and 43% in Gaza Strip (Figure 2).

70% of forms in the West Bank and 50% in the Gaza Strip had the immediate cause of death in place of the underlying cause of death.

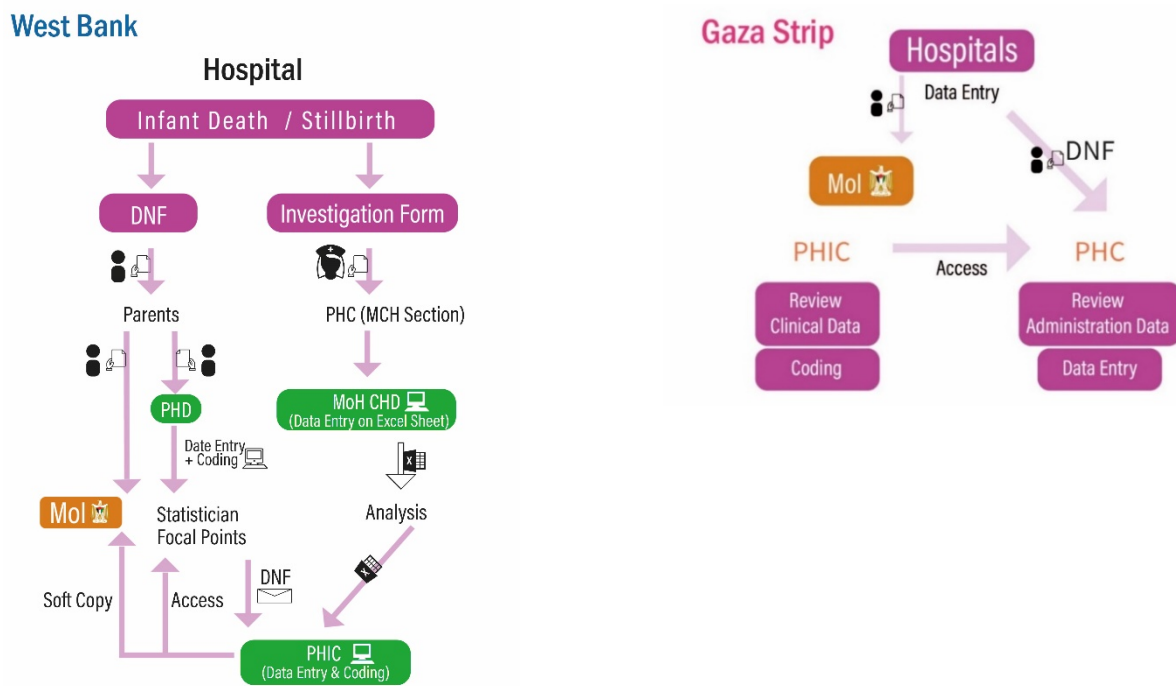
Figure 2: Accuracy of Reporting Underlying Cause of Death in Investigation Form/DNF, by Region (West Bank: N=233, Gaza Strip N=273)



Data Flow from Issuing DNF and Investigation Form at Hospital to PHC Death Registry

In the West Bank, there are two systems used for death registries—Oracle at PHIC and DHIS2 for the PHC Death Registry—resulting in duplications of data entry and coding (Figure 3).

Figure 3: Pathway of DNF and investigation from hospital/attending hospital to PHIC in West Bank and Gaza Strip

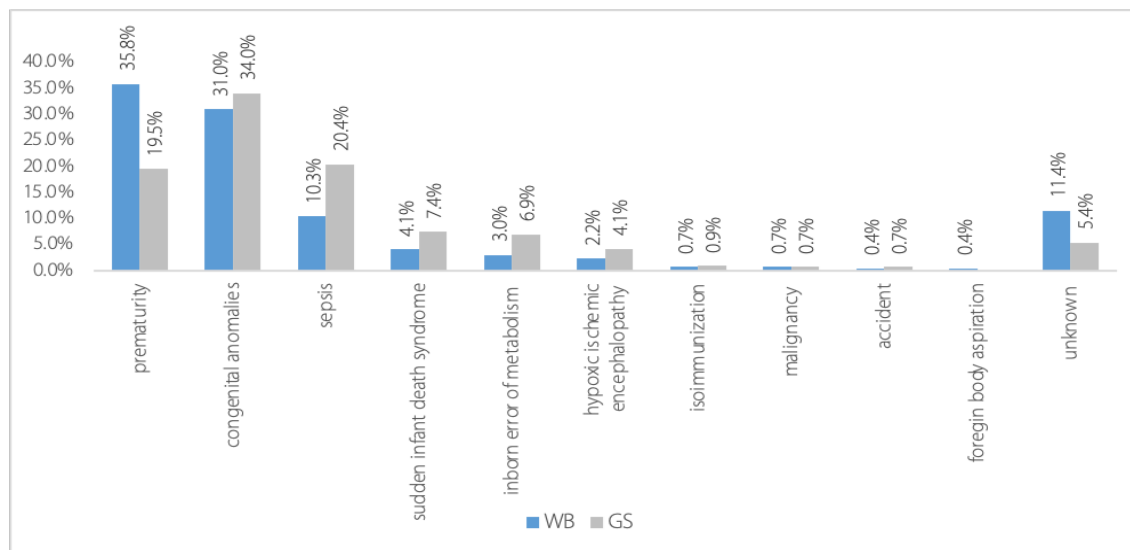


Underlying Cause of Death – Infant Mortality

As shown in Figure 4 below, based on the reported data (240 cases of infant deaths in the WB, 548 cases in the GS), the top five underlying causes of death in the West Bank and Gaza were the same: prematurity, congenital anomalies, sepsis, sudden infant death, and metabolic disorders. The leading cause of infant

death in the West Bank was prematurity, while in the Gaza Strip it was congenital anomalies. Most infant deaths in 2019 were preventable in both the West Bank and Gaza Strip (87.5% and 80%, respectively).

Figure 4: Underlying cause of death for infant mortality in 2019, by region

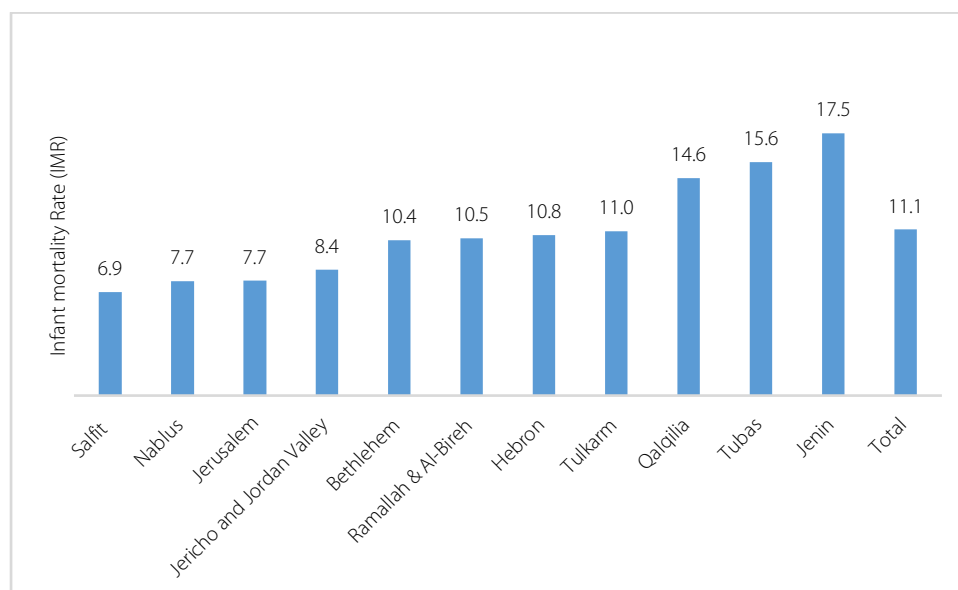


Rh isoimmunization: A condition that happens when a pregnant woman's blood protein is incompatible with the baby

Variability in Reported Infant Deaths and Stillbirth by District

Based on infant deaths reported to PHIC, the infant mortality rate was highest in Jenin (17.5 per 1,000 births) and lowest in Salfit (6.9 per 1,000 births) (Figure 5). The high infant mortality rate in Jenin could be due to having the best reporting among all districts, or the highest number of deaths in all districts.

Figure 5: Infant Mortality in 2019 Based on PHIC registry, by district

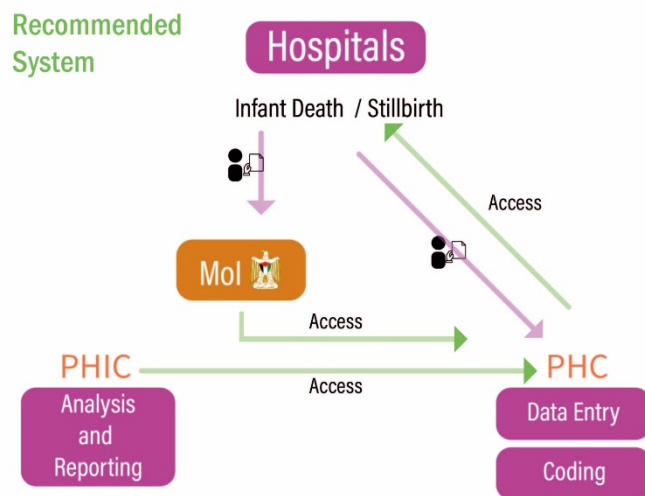


STUDY RECOMMENDATIONS

POLICY LEVEL

- Enforce reporting of all perinatal deaths by the obstetric/pediatric/neonatal departments in hospitals.
- Add the investigation form to the DNF so it will be one form with two pages; mandate the use of the investigation form to report all perinatal deaths.
- Mandate the review of stillbirths and neonatal deaths as a standard practice in all hospitals
- Develop a web-based DNF in the West Bank to be used by hospitals for hospital deaths and by PHC directorates to record deaths outside hospitals.
- Unify death registries at PHIC and the PHC Directorate so gathering data from DNFs and coding is done only once in the PHC Death Registry through the following mechanisms (Figure 11):
 - Provide PHC CHD with access to the PHC Death Registry for reporting and analysis
 - Provide PHIC with access to the PHC Death Registry to conduct analysis and reporting
 - Provide MoI with access to the PHC Death Registry
- Improve preconception care, antenatal care, delivery care, and postnatal care to end preventable deaths in infants.

Figure 6: Recommended System for Death Registry in the West Bank and Gaza



- In the Gaza Strip, assign a medical doctor in each directorate to review the clinical portion of the DNF. The existing focal points do not have medical backgrounds, and therefore only check the administrative section.
- Establish a committee to follow up on improving the accuracy of the Death Registry.

HOSPITAL LEVEL

- Establish a specialist committee/assign a senior physician to review all DNFs and death certificates issued at the hospital for completeness and accuracy. Increase reporting of all perinatal deaths.
- Enforce completion of essential data from patient files in the electronic hospital system through internal validation (i.e. mother and infant complication and case management).

PRIMARY HEALTH CARE LEVEL

- Review all DNFs and investigation forms for infant deaths and still births for completeness and accuracy. Feedback from the PHC focal point to the individual hospital could be an option to highlight certificates with any issues.
- Improve coding of underlying causes of death.

PALESTINIAN HEALTH INFORMATION CENTER LEVEL

- Improve analysis and reporting on infant deaths and stillbirths.