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Accuracy of Mortality Statistics in Palestine

December 2015

Contents

Acknowledgment

We would like to thank all those who assisted in the preparation of this evaluation report.

First we would like to thank Dr Lars Age, the principle investigator, for his technical support throughout the study and for writing the study report. We also extend our thanks to Dr. Mohammad Abu Ghali, the former General Director of the Public Administration of Hospitals; Dr Jawad Bitar, Director of the Palestinian Health Information Center in the West Bank; and Dr Usama Balawi, the former Director of the Palestinian Health Information Centre in the Gaza Strip, for their continuous help and support throughout the study. We are grateful to the directors of all the hospitals that participated in the study, and also thank the staff working in the focal points located in hospitals for retrieving patient files for the purposes of our research.

Special thanks are due to his Excellency Dr Asad Ramlawi, the deputy minister of the Ministry of Health, for his valued comments and feedback on the study findings. We are also grateful to Dr Mohamed Ali and Dr Iman Aly from EMRO for revising the study report and for their valuable input.

Accuracy of Mortality Statistics in Palestine

Abbreviations

CoDR: Cause of Death Registry
DNF: Death Notification Form
EDC: Evaluation Death Certificate
ICD: International Classification of Diseases, 10th revision (if not stated otherwise)
MoH: Ministry of Health
MoI: Ministry of Interior
PHC: Primary Health Care
PHIC: Palestinian Health Information Centre
UC: Underlying cause of death
WHO: World Health Organization

1. Executive summary

1.1 Background

Mortality statistics are widely used for medical research, monitoring trends in public health, and the planning and evaluation of health care. It is vital to ensure a high degree of accuracy due to the many important public health needs served by cause of death statistics. This requires an accurate diagnosis of the cause of death by the person certifying the event, in addition to the correct identification and coding of the underlying cause of death in line with international standards.

1.2 Method

We retrieved the medical records for a random sample of hospital deaths reported in 2012: 371 deaths in the West Bank and 199 deaths in the Gaza Strip. Specially trained reviewers completed medical extraction forms, termed evaluation death certificates (EDC), in order to evaluate the original Death Notification Forms (DNF) on the basis of the patient's hospital records.

For each death, we compared three underlying causes of death:

- the underlying cause according to the EDC;

- the underlying cause according to the original DNF, coded by international Iris coding software;
- the underlying cause according to the original DNF, coded by the Palestinian Health Information Centre (PHIC).

We conducted most comparisons at two levels of detail: (a) the most detailed level available in the International Classification of Diseases (ICD) to assess the accuracy of the coding at the PHIC; and (b) at ICD code block level. The ICD code block level is an aggregation of detailed ICD codes and is often used for public health overviews. Comparison at code block level enables an assessment of the usefulness of PHIC mortality data for public health purposes.

1.3 Results

Demographic data were far better specified in the Gaza sample than in the West Bank sample.

1. (Demographic data were complete for 3% of the West Bank DNFs compared with 54% of the Gaza DNFs. The certifier›s signature was complete for 50% of the West Bank DNFs and for 25% of the Gaza DNFs.)

2. Even at an aggregated level, less than half of the underlying causes in the PHIC register stated the correct cause of death. This indicates a low degree of accuracy.
   (Assessed by comparing the underlying cause of death coded by the PHIC with that determined in the EDC: 19% (West Bank) and 31% (Gaza Strip) agreement at a detailed level, both 44% at block level.)

3. The original DNFs stated the correct underlying cause more often than the PHIC Cause of Death Registry, but a substantial number of DNFs were still unsatisfactory.
   (Assessed by comparing the underlying cause of death stated on the original DNF with that in the EDC: 56% (West Bank) and 52% (Gaza Strip) of agreement at a detailed level and 68% and 62% agreement respectively at block level.)

4. Procedures for coding and classification at the PHIC deviate considerably from

the international norms defined in the ICD and account to a considerable extent for the discrepancies between the cause of death determined on the EDC and the cause of death coded by the PHIC.
(Assessed by comparing the underlying cause of death coded by the PHIC with the underlying cause stated on the DNF as coded by international Iris software: 23% (West Bank) and 39% (Gaza Strip) at a detailed level, 46% and 53% respectively at block level.)

5. In general, deaths due to malignant neoplasms were more accurately reported on DNFs than other causes of death, and metabolic diseases (including diabetes) were the most problematic. Issues with coding and classification at the PHIC were most apparent for perinatal conditions and congenital anomalies.

1.4 Conclusions and recommendations

The two major reasons for low accuracy in the causes of death recorded in the PHIC Registry are:

- Discrepancies between the coding and classification procedures set out in the ICD and the procedures actually applied by the PHIC.
- Incomplete or otherwise unsatisfactory reporting on a considerable number of DNFs.

To address these points, the following measures are proposed:

- The use of international coding software for coding and classification, such as Iris software.
- Iris software incorporates ICD coding instructions and an extensive dictionary of English medical terms is also available. This would make coding more consistent and improve international comparability.
- Improve the design of the Death Notification Form.
- The current DNF has very little space available to write the causes of death, resulting in compressed and often illegible entries. More space and a clear layout would make it easier for certifiers to report the causes of death correctly and unambiguously. It is particularly important to make a clear distinction between Part 1 (the chain of events leading to death) and Part 2 (conditions contributing to the death, but which are not part of the chain of events leading

to death).

- Feedback to certifiers.
  If the underlying cause reported on the DNF is unsatisfactory, the certifier should be asked to provide the missing information. This could be checked at the local hospital, for example by a review committee, by the directors of the district directorates in the West Bank, and by the PHIC.
- Review and improve data handling at hospitals with electronic patient records.
  Surprisingly, hospitals with electronic patient records had more difficulties in retrieving the requested data. There were also more errors in essential administrative data; in a few cases, as to whether the patient was dead or alive. There is clearly a need to review and improve data availability and accuracy at hospitals with electronic patient records.

2. Background

In Palestine, the Cause of Death Registry (CoDR) is part of the national vital statistics database that holds information on both births and deaths. The Cause of Death Registry holds information on deaths and the causes of deaths since 1994 in a database held in the Palestinian Health Information Centre (PHIC) at the Ministry of Health (MoH). Prior to that date, causes of death were registered with the Israeli Civil Administration.

The main source of data for the CoDR is the Death Notification Form (DNF), filled either by the attending physician in hospitals or by a licensed physician if the death occurred outside a hospital. The DNF (Appendix 1 West Bank form and Appendix 2 Gaza form) includes information about the main and underlying causes of death. (There are no DNFs for neonatal deaths and a monthly report of neonatal deaths is sent by each hospital to PHIC.) In both the West Bank and Gaza, a copy of the DNF is sent to PHIC, either from PHC directorates, government hospitals, or from both. This results in more work for the coder when DNFs are duplicated. Some PHC directorates in the West Bank use summary codes for the underlying cause of death before sending them to PHIC, while others do not code the underlying cause of death. In Gaza, only PHIC does the coding. One senior staff member in Gaza and the director of PHIC in the West Bank assign ICD-10 codes to the underlying cause of death. These codes are then entered into the

database for further analysis. Based on 2011 data, around 50-60% of deaths occur in hospitals.

The family of the deceased is responsible for notifying the death. In the West Bank, the family of the deceased are given three copies of the form: they keep one and the other two are handed over to the PHC directorate in each district. In the Gaza Strip, some hospitals keep a copy of the DNF, while others do not. One of the stamped copies is either sent by the PHC directorate to the Ministry of Interior (MoI), or the family of the deceased hand the form themselves to the MoI. The MoI requires both a stamped DNF and the ID of the deceased in order to issue a Death Certificate. At the end of each month the PHC Directorate compiles all DNFs and mails them to PHIC. The procedures are the same in the Gaza Strip, except that there is a separate District Death Notification Office (DDNO) based in the PHC directorate and also a Central Death Notification Office (CDNO). The DDNO sends the DNFs to the CDNO, which then mails all forms to the PHIC Gaza.

2.1 Rationale

Cause of death information can be used in many ways to evaluate the health of the population. Mortality data are commonly used to calculate the burden of major diseases within population groups or across geographical regions. As in many countries, in Palestine the leading causes of death are regularly included in official statistics. Leading causes of death are defined as the underlying cause of death categories or major ICD groupings that usually account for large numbers of deaths within a specified population group and time period. Determining and monitoring the leading causes of death is a vital activity as these are primary indicators of the overall health or quality of life of a population. [1]

Accuracy is crucial due to the many important public health needs served by cause of death statistics. This requires that an accurate diagnosis of the cause of death is determined by the person certifying the event, and that the underlying cause of death is correctly identified and coded in line with international standards. [2]In October 2012, the Palestinian National Institute of Public Health carried out an assessment of CoDR in both the West Bank and the Gaza Strip in close collaboration with the MoH. One of the main findings was the lack of standard

1 http://www.who.int/healthinfo/CRVS_ResourceKit_2012.pdf
2 ibid

operating procedures for the CoDR in Palestine. There are no guidelines to assist doctors in completing the form, minimal training of doctors and little supervision by senior doctors of junior doctors in hospitals. The assessment recommended that the DNF be revised, guidelines drawn up for filling in the form, and evaluation of the quality and completeness of DNFs and the accuracy of CoDR in terms of the code entered for the cause of death.[3] This study serves as a baseline to identify gaps, and to monitor and evaluate planned interventions to improve the CoDR.

3. Methods

3.1 Study design

This retrospective death registry-based study examines a stratified random sample of DNFs of patients who died in hospitals in the West Bank and Gaza Strip in 2012. We randomly selected 600 deceased from the Cause of Death Registry: 400 from the West Bank and 200 from the Gaza Strip.[4] We took a random sample of hospital deaths from the following three age groups: 0-19 years, 20-59 years and 60+ years. The audit study was carried out in close collaboration with the Ministries of Health (MoH) in the West Bank and Gaza Strip in 2014. The response rate was 100%: all selected hospitals in the West Bank and Gaza Strip agreed to participate in the study. To test the study protocol, we carried out a pilot study with 40 randomly selected DNFs, 20 from each region.

3.2 Material

For each death in the sample we collected the following data:

Death Notification Form (DNF):

- Scanned image of the DNF
- Formal assessment of the DNF, such as legibility of the handwriting and if the administrative data had been filled out correctly with the certifier's signature. (For a complete list, see Appendix 2 and 3.)
- The causes of death in free text and administrative information were extracted from the DNF.

3 http://www.pniph.org/wp-content/uploads/2013/11/WHo-Assessment-Final.pdf

4 The sample size was estimated using the SampleXS program and based on the following assumptions: The number of registered deaths in 2012 was 12,000; the completeness of death certificates was 60% based on the recent PCBS study of the completeness of the Cause of Death Registry; the margin of error was 5%; design effect 1.5.

Data from the Palestinian Health Information Centre (PHIC):

Date on which the death was registered by the PHIC in the Death Registry.

- ICD codes for underlying causes of death as recorded by the PHIC in the Death Registry.

Medical Extraction Forms (EDC) (Appendix 3):

- Medical Extraction Forms (EDC) based on medical data extracted from the deceased patient's hospital records were completed by specially trained physicians working in each hospital in the study using a standardized protocol (see Appendix 3).

Hospital case summaries:

- Scanned image of the hospital case summary.
- Case summary based on hospital records, completed by specially trained physicians in each hospital.

In the West Bank, hospital records could only be found for 371 cases from the 400 randomly selected DNFs; 265 cases (71%) were from governmental hospitals and 106 (29%) were from private and non-governmental hospitals. Of the 265 cases from governmental hospitals, 85 (23%) were from hospitals using electronic records. Of the 29 West Bank deaths without any hospital records, five cases were deaths within the first week of life, eight were children aged less than 18 years of age and 16 were adults. Twenty-five were deaths that took place in governmental hospitals and four were from hospitals with electronic patient records. In the Gaza Strip, we found hospital records for 199 of the 200 randomly selected DNFs. All cases were from governmental hospitals. The missing case was a 44-year-old woman.

The PHIC Registry gave an ICD code for the underlying cause of death in 358 of the 371 cases in the West Bank sample for which hospital records were available. In the Gaza Strip, 189 of the 199 cases in the sample had an ICD code for the underlying cause of death and 70 cases also included multiple causes of death registered by PHIC. No multiple causes were present in the West Bank sample.

The DNFs contained medical data on the cause of death in 348 cases in the West

Bank sample and in 198 deaths in the Gaza Strip sample. These data were extracted and entered into an Excel spreadsheet. Hard copies of DNFs were available for 320 deaths in the West Bank sample. Of the 51 cases where no hard copies of DNFs existed, 39 were from governmental hospitals and fourteen cases were from hospitals with an electronic patient data system. Eighteen cases were neonatal deaths, eight were children, 18 were adults below 65 years of age and seven were adults above 65 years of age. In the Gaza Strip sample, DNFs were available for all deaths.

EDC data on file were available for 365 West Bank deaths and for all Gaza Strip deaths. Of the missing cases in the West Bank sample, two were registered as still alive in hospitals using electronic records.

Case summaries in free text, compiled by the physician who extracted the data from the hospital records and describing the events leading to death, were available on file for 195 of the West Bank cases and in all Gaza Strip cases. The death report in the hospital medical records was available for 289 West Bank deaths and for 198 Gaza Strip deaths.

Graph 1: Data availability and attrition in WB

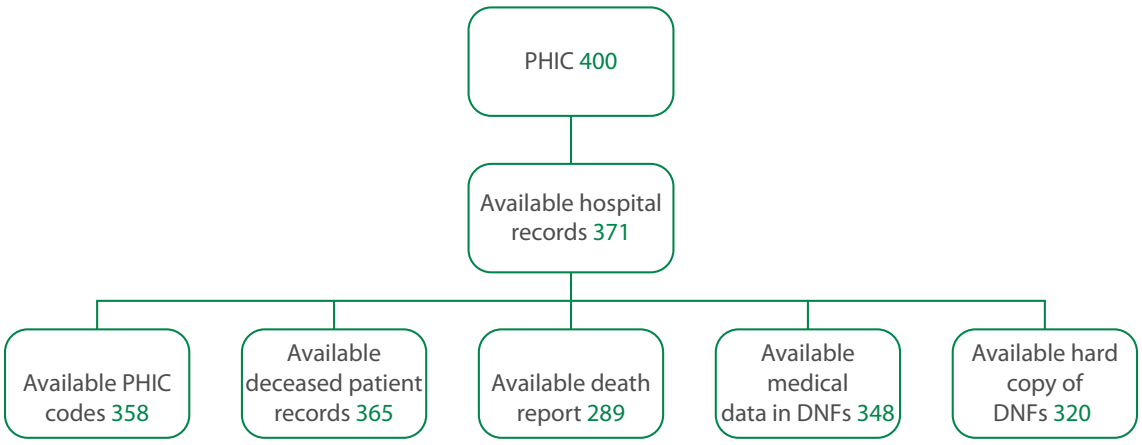


Table 1: Deaths in 2012 and study sample by age and sex, West Bank

	Male		Female		Total	
Age in years	Vital Registry	Study sample	Vital Registry	Study sample	Vital Registry	Study sample
<5	434	50	379	51	813	101
5-14	69	8	62	7	131	15
15-24	125	7	54	3	179	10
25-34	100	7	40	5	140	12
35-44	136	12	91	7	227	19
45-54	339	34	191	15	530	49
55-64	516	32	329	31	845	63
65+	2021	51	2130	51	4151	102
Grand Total	**3740**	**201**	**3276**	**170**	**7016**	**371**

Graph 2: Data availability and attrition in Gaza

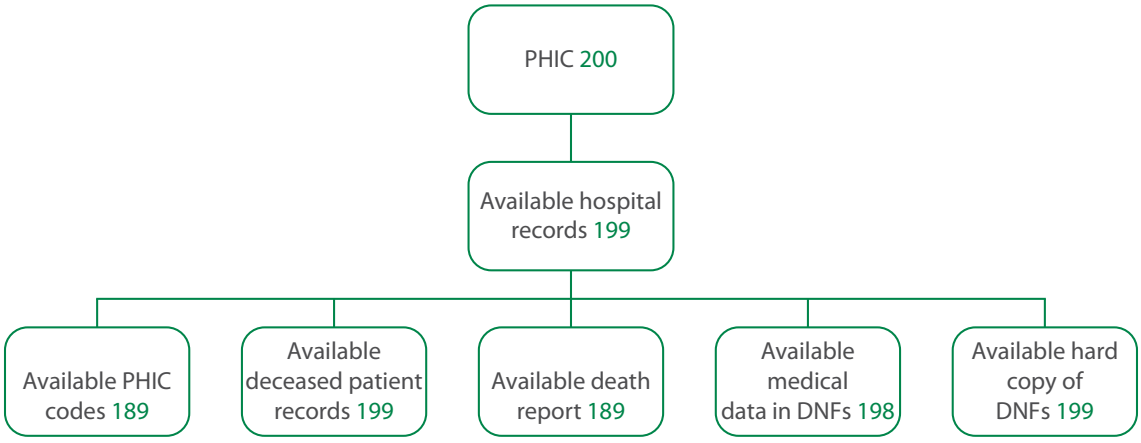


Table 2: Deaths in 2012 and study sample by age and sex, Gaza Strip

	Male		Female		Total	
Age group	Vital Registry	Study sample	Vital Registry	Study sample	Vital Registry	Study sample
<5	704	32	537	33	1241	65
5-14	110	2	62	5	172	7
15-24	225	5	54	3	279	8
25-34	158	4	63	3	221	7
35-44	116	6	81	8	197	14
45-54	222	10	127	14	349	24
55-64	312	13	256	7	568	20
65+	1116	27	1253	27	2369	54
Grand Total	**2963**	**99**	**2433**	**100**	**5396**	**199**

3.3 Data analysis

3.3.1 Completeness and timeliness

We examined the proportion of complete DNFs in terms of personal data, immediate and underlying causes of death, and the attending physician and notifying person's signature (Appendix 4).

We also examined the timeliness of registration, measured from the time of death to the time the deceased was registered in the Cause of Death Registry (Appendix 5).

3.3.2 Underlying cause of death based on the deceased patient›s hospital file and on the DNF

A team of specially trained physicians from each hospital in the study extracted data from the hospital record on the train of events leading to the death. The extraction followed a structured format (Appendix 3). The extraction file contained data on the reason for hospitalization, previous medical history (including at least approximate dates of the onset of the various conditions), and the course of events

during the hospitalization (complications that may have occurred, including the terminal complication, newly diagnosed conditions and surgery, or other major medical procedures).

Using the data extracted from the hospital file, we determined the underlying cause of death and coded it using ICD-10. We also examined if competing causes of death were present i.e. if the patient had two or more etiologically independent conditions, either of which would have been sufficient to constitute the underlying cause of death.

All coding, both of the original DNFs and of the EDC data, was done using Iris coding software. Iris software was developed by an international group of experts in coding and classification of the causes of death in close cooperation with several WHO Collaborating Centres for Classifications in Health Care. Further information on the Iris system can be found at the website of the Iris Institute [1]. The current Iris version, the one used for coding the two samples, is V4.4.1. This version of Iris corresponds to the 2013 edition of ICD-10.

For a more detailed description of how we arrived at the underlying cause codes, please see section 3.3.4 (Selecting the underlying cause of death).

After review and coding, we compared the three underlying causes – the one coded by PHIC; the one stated on the DNF form but coded and classified by Iris; and the one according to the EDC – pair by pair:

- Underlying cause on the DNF, coded by Iris <> Underlying cause in the PHIC Registry
  These two underlying causes are based on the information in the DNF. The Iris codes comply with international standards as described in the ICD. Therefore, this comparison measures PHIC compliance with international rules for selection of the underlying cause of death.
- Underlying cause on the DNF, coded by Iris <> Underlying cause according to the EDC
  Here, the underlying cause of death reported on the DNF is

compared with the underlying cause of death determined by the extracted medical records (EDC). This measures the accuracy of the original DNF.

- Underlying cause according to the EDC <>Underlying cause in the PHIC Registry

  This comparison of the underlying cause of death in the PHIC Cause of Death Registry with the underlying cause of death determined by an evaluation of the case, measures the overall accuracy of the underlying cause registered in the PHIC Registry.

Initially, we compared the underlying causes at four levels of detail:

- ICD detailed level (henceforth referred to as ICD 4-character level, although some ICD categories lack subdivisions at fourth character level): for example, I25.1 Atherosclerotic heart disease;
- ICD three character level: for example I25 Chronic ischaemic heart disease;
- ICD block level: for example I20-I25 Ischaemic heart diseases;
- ICD chapter level: for example Chapter IX, I00-I99, Diseases of the circulatory system.

As indicated by the term itself, ICD detailed level gives the maximum detail possible to capture ICD codes. There are about 14,000 detailed level codes in the ICD, and the level of detail may be more complex than that required for some public health purposes. For the monitoring of public health and evaluation of public health initiatives, aggregated data may be more suitable, partly because aggregated statistics have fewer groups and provide an easier overview, and partly because minor differences in terminology and coding are not visible at an aggregated level.

There are three standard aggregated levels: ICD three character, ICD block and ICD chapter. At three character level the finer details are removed. For example, at detailed level there are 50 codes for diabetes, but only four at three character level. There are around 2,100 three character codes, but for mortality statistics, the actual difference between detailed level and three character level is generally

small because causes of death reported on death certificates often lack finer clinical detail.

At ICD block level the grouping is broader still (for example, all diabetes currently form a single ICD block) and there are about 280 blocks. The blocks are arranged according to clinical and etiological relationship and often, if not always, give the information needed for routine public health monitoring.

The broadest grouping, based on the 21 ICD chapters (19 for underlying causes of death), is sometimes used for brief overviews. ICD chapter level is generally not detailed enough for epidemiological use, and comparisons at chapter level may not give a useful assessment either for the same reason.

Since differences between detailed level and three character level are generally small, and since chapter level is too crude for most epidemiological purposes, we limited cross tabulations against background variables to ICD detailed level and ICD block level. The principal use of measures at detailed level data is to estimate the precision of the coding and classification, while measures at ICD block level provide a broad assessment of the general trustworthiness for public health purposes.

For cross tabulation, we divided the underlying causes according to the EDC into eight main diagnostic groups:

- Neoplasms (ICD-10 Chapter II)
- Metabolic diseases (ICD-10 Chapter IV)
- Cardiac diseases (ICD-10 I00-I51)
- Cerebrovascular diseases (ICD-10 I60-I69)
- Perinatal conditions (ICD-10 Chapter XVI)
- Congenital anomalies (ICD-10 Chapter XVII)
- External causes (ICD-10 Chapter XX)
- Other causes of death (ICD-10 chapters and codes not included elsewhere) ("Other" includes infectious diseases, diseases of the blood, neurological diseases, diseases affecting vision and hearing, respiratory diseases, gastrointestinal diseases, skin diseases, musculoskeletal diseases, urogenital

diseases and symptoms with no clear connection to a single underlying disease.)

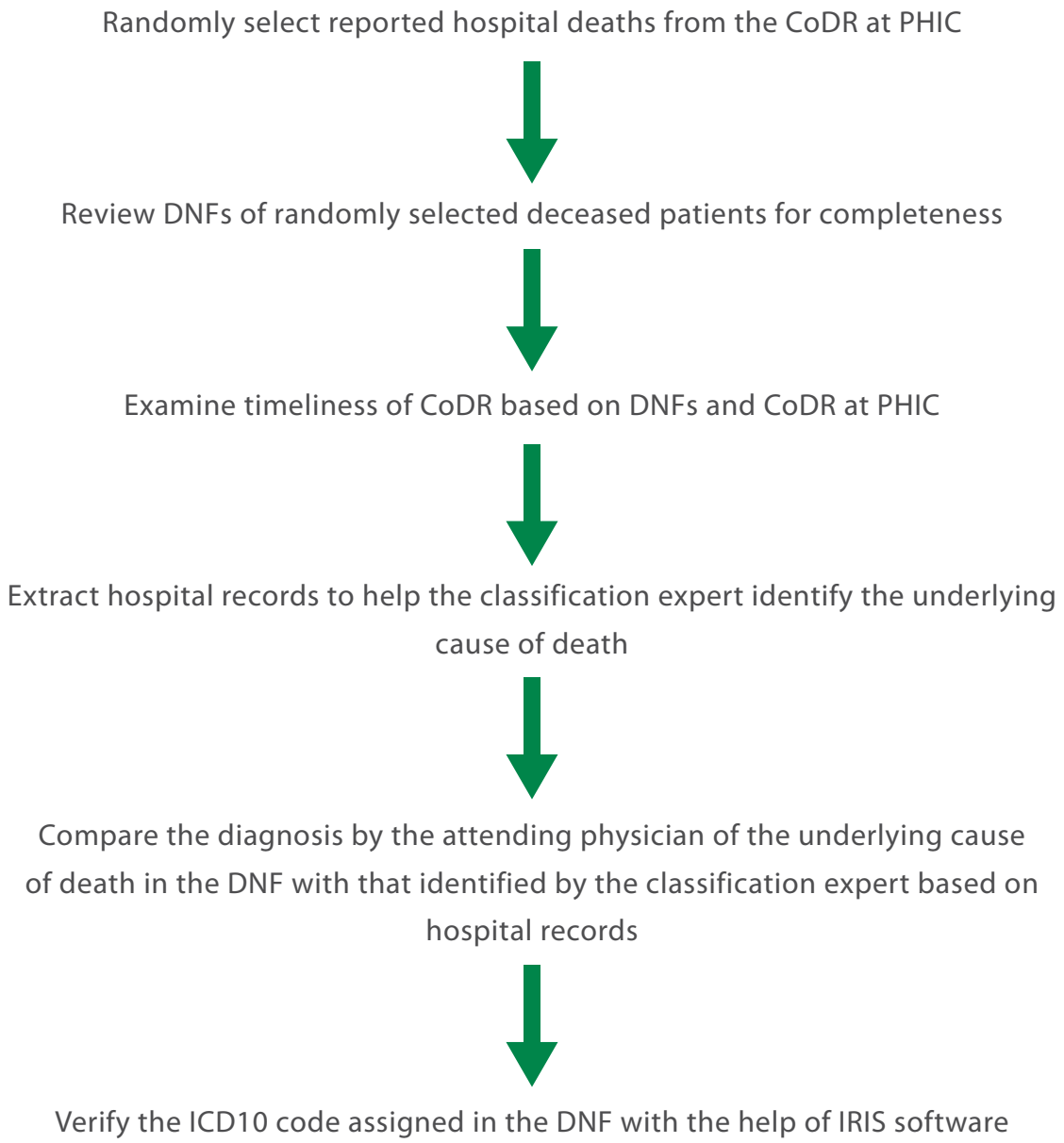
The number of diagnostic groups and their contents were determined by the frequency of the most common underlying causes according to the EDCs.

For cross tabulation by age, we used the following age groups:

- Less than 1 completed year of life
  Predominantly perinatal deaths and later deaths related to anomalies and perinatal complications.
- Between 1-17 completed years of life
  Childhood deaths other than perinatal
- Between 18-64 completed years of life
  Adults
- 65 or more completed years of life
  Elderly

The main sample groups, the West Bank and Gaza Strip, differed considerably in many respects. For that reason we kept them separate in the analysis and did not calculate measures combining the two samples.

3.3.3 Flow chart of the study



3.3.4 Selecting the underlying cause of death

During the coding process, the classification expert (Dr Lars Age) checked the free text causes of death registered in the DNF files against the scanned images of the DNFs, and corrected the registered text if it differed from the scanned image. Similarly, the classification expert checked the causes of death reported on the EDCs against the case summaries and against the scanned images of the hospital summaries. If an EDC was inconsistent with the case summary or the hospital

summary, the EDC was corrected according to the description of the case in the summaries.

Also, for each DNF, the following markers were used to record non-compliance with WHO instructions for completion of the death certificate:

- Abbreviations used in medical section

  Rationale: Abbreviations are often difficult to interpret, especially ambiguous ones such as «RF» («renal failure» or «respiratory failure»?). As a result, the incorrect diagnosis may be recorded as the underlying cause of death.
- Illegible writing in medical section

  Rationale: If a diagnostic statement cannot be read, potentially important diagnostic information is lost.
- Sequencing errors in Part 1

  Rationale: In Part 1 of the WHO death certificate form, the certifier is required to report the train of events leading to death. The causes should be reported in causal order, and each condition on an upper line should be a complication of the condition reported on the next lower line. The condition initiating the train of events should be stated on the lowest completed line in Part 1. If the conditions reported in Part 1 are not in causal order, it may not be possible to determine the underlying cause of death correctly.
- Symptomatic or secondary condition reported as underlying cause of death

  Rationale: A secondary or symptomatic condition (such as kidney failure or acute heart failure) should not be reported as the only cause of death. Mortality statistics aim to provide information on the diseases or injuries behind such secondary conditions. If only secondary conditions are reported, the certificate has no underlying cause of death as per the WHO definition i.e. the condition that initiated the train of events leading to death.
- Cause of death insufficiently specified

  Rationale: Imprecise terms can be meaningless from a public health perspective. For example, «blood disease» or «tumour» do not provide sufficient information for either health care planning or the evaluation of health care initiatives.

- Other reporting errors

  Other errors that compromise the accuracy of mortality statistics include reporting several causes on the lowest completed line in Part 1, or placing the underlying cause in Part 2 of the certificate, or using the wrong field on the DNF to report causes of death. Rationale: Such errors make it more difficult to identify the underlying cause of death and therefore reduce the reliability of mortality statistics.

Further, the following data were recorded:

- Competing causes of death

  Did the patient have more than one condition that on its own could explain the death? Rationale: The presence of «competing» causes of death makes the task of filling out the death certificate more difficult. While the presence of competing causes of death is not an error on the part of the certifier, it may explain why it was difficult to complete the certificate according to ICD instructions.
- Registry delay

  The time elapsed between the date of death and the date of entry in the PHIC Registry.
- Type of hospital

  Governmental or private
- Type of hospital records

  Electronic or paper-based.

4. Results

4.1 Completeness of DNF forms and other characteristics

Table 4.1 gives a summary of other characteristics of DNFs unrelated to the accuracy of the underlying cause of death (the characteristics not related to agreement in the underlying cause). For example, 23 of the DNFs in the West Bank sample contained no medical data. Interestingly, 15 of these cases with missing data were from a hospital with an electronic patient record system. In the Gaza sample, only one DNF had no medical data. Administrative data (Part I of the

DNF) were complete in only 3%: 2% from hospitals using paper records and 7% of DNFs from hospitals with electronic patient records respectively.

There were far more illegible entries on West Bank DNFs (30%) than on Gaza DNFs (6%). The West Bank DNFs also contained more text in the medical section that did not contribute to the selection of the underlying cause than in the Gaza DNFs (West Bank 33%, Gaza 11%). Delays in registration — the delay between the date of the death and the date the death was reported to the PHIC— were shorter in the Gaza sample (median of 57 days; range 0-405 days) than in the West Bank. Although most deaths had been reported within a year (median of 89 days; range excluding extreme values 0-365 days), some deaths from the 1980s and 1990s were only reported to the authorities in 2012.

Table 4.1 DNF completeness and other characteristics

	West Bank (N=320)		*Gaza Strip (N=199)*	
	Cases	*%*	*Cases*	*%*
Administrative data complete (Part I)	9	3	108	54
- Hospital using electronic records (DNF=71)	5	7	-	-
- Hospital using paper records (DNF=249)	4	2	-	-
Medical data available (Part II)	297	93	198	99
- Hospital using electronic records (DNF=71)	56	79	-	-
- Hospital using paper records (DNF=249)	241	97	-	-
Abbreviations used	132	41	76	38
Illegible writing	96	30	11	6
Sequence errors	64	20	38	19
Non-informative UC	74	23	51	26
UC lacking specificity	36	11	12	6
Irrelevant information	105	33	22	11
Other certification errors	92	29	40	20
Competing causes of death	36	11	23	12
Certifier's signature complete	159	50	50	25
Registry delay (days; median)	89		57	

4.2 Agreement between the three underlying causes

Agreement on the underlying cause (Table 4.2.1) was highest between the underlying cause derived from the original DNF and the medical extraction forms (DNF-EDC). This is a measure of the accuracy of the DNFs. At the most detailed level, ICD 4-character, the agreement was 56% for the West Bank sample and 52% for the Gaza Strip sample, and at ICD block level it was 68% and 62% respectively. The difference between the two sample groups was not statistically significant.

Agreement was lowest between the EDC and the underlying cause recorded in the PHIC Registry. This is an indicator of the extent of accuracy of the causes of death recorded in the PHIC Registry (assuming that the cause of death stated on the EDCs is the correct one). At ICD 4-character level (detailed level), EDC-PHIC agreement was 19% in the West Bank sample and 31% in the Gaza sample. At detailed and three-character level, the difference between the two samples was statistically significant. However, there was no difference at ICD block level, where both samples had agreement of 44%.

DNF-PHIC agreement between the DNF coded in line with international standards and the underlying cause as coded by the PHIC was 23% in the West Bank sample at ICD 4-character level, and 39% in the Gaza sample. This is an indicator of the extent of PHIC accuracy in the coding and classification of the cause of death stated on the DNF. The difference between the samples was statistically significant. At ICD block level the West Bank sample had a DNF-PHIC agreement of 46% and the Gaza sample 53%, a difference that was not statistically significant.

As anticipated, the differences between ICD 4-character level and ICD 3-character level were small.

Available records for comparisons of WB and GS

Data source	Number in WB	Number in GS
PHIC-DNF	348	189
PHIC-EDC	358	189
EDC-DNF	348	198

Table 4.2.1 Agreement on underlying cause by ICD level: point estimates, and for ICD-4 character level and ICD block level, 95% confidence intervals

		ICD 4-char		ICD 3-char		ICD block		ICD chapter	
	PE (%)	95% CI	PE (%)	95% CI	PE (%)	95% CI	PE (%)	95% CI	
DNF-EDC	*West Bank*	56	51-62	61	56-66	68	63-73	77	73-82
	Gaza Strip	52	44-59	54	47-61	62	55-68	74	68-80
DNF-PHIC	*West Bank*	23	19-28	29	25-34	46	41-51	67	62-72
	Gaza Strip	39	31-46	47	40-54	53	46-60	69	62-76
EDC-PHIC	*West Bank*	19	15-23	26	21-30	44	38-49	69	64-74
	Gaza Strip	31	24-38	36	29-43	44	37-51	64	57-71

There were considerable differences in agreement between diagnostic groups. At ICD 4-character level (Table 4.2.2), the accuracy of the DNFs (DNF-EDC agreement) was best for external causes (West Bank 78%, Gaza no cases) and neoplasms (West Bank 76%, Gaza 84%). The weakest agreement was for metabolic conditions (West Bank 32%, Gaza 29%). The differences between the two samples were not statistically significant.

Agreement in the West Bank sample between the original DNFs and PHIC Registry data (DNF-PHIC, measuring accuracy of PHIC coding) was best for cardiac diseases, but still weak at 42%. It was generally better in the Gaza sample, with the highest value for neoplasms (64%) and cerebrovascular conditions (63%), both significantly better than in the West Bank sample. The lowest DNF-PHIC agreement in the West Bank sample was for anomalies and external causes (3% and 9% respectively), significantly lower than in the Gaza sample. In the Gaza sample, the lowest DNF-PHIC agreement was for perinatal causes (5%). This difference between the samples was not statistically significant.

The accuracy of the underlying causes in the PHIC register, measured by EDC-PHIC agreement, was highest, but still moderate, for neoplasms and cardiac conditions in the West Bank sample (both 36%). In the Gaza sample the highest agreement was for neoplasms at 62%, significantly higher than in the West Bank sample. The lowest agreement was for metabolic conditions in the West Bank sample (4%, no significant difference from the Gaza sample), and for perinatal causes in the Gaza

sample (5%, significantly lower than in the West Bank sample).

Table 4.2.2 Agreement in underlying cause by diagnostic group: ICD 4-character level, point estimates and 95% confidence intervals

	DNF-EDC				*DNF-PHIC*			
	West Bank		*Gaza Strip*		*West Bank*		*Gaza Strip*	
	PE (%)	95% CI	PE (%)	95% CI	PE (%)	95% CI	PE (%)	95% CI
Neoplasm	76	65-87	84	73-95	39	26-51	64	49-79
Metabolic	32	12-52	29	8-50	16	1-31	19	1-37
Cardiac	49	38-61	37	13-61	42	30-54	29	5-54
Cerebrovascular	53	38-68	45	21-69	16	5-27	63	39-87
Perinatal	46	27-66	45	23-68	11	0-23	5	0-15
Anomaly	51	34-69	47	21-74	3	0-9	29	5-54
External	78	60-96	-		9	0-22	-	
Other	56	43-69	45	32-59	16	6-26	36	22-50

	EDC-PHIC			
	West Bank		*Gaza Strip*	
	PE (%)	95% CI	PE (%)	95% CI
Neoplasm	36	26-50	62	47-77
Metabolic	4	0-11	10	0-23
Cardiac	36	25-48	24	1-46
Cerebrovascular	7	0-15	26	5-48
Perinatal	11	0-21	5	0-15
Anomaly	3	0-9	24	1-46
External	9	0-22	-	
Other	10	2-18	31	18-45

At ICD block level, DNF-EDC agreement (Table 4.2.3) was best for neoplasms (West Bank 82%, Gaza 89%) and external causes (West Bank 78%, Gaza no cases). The lowest agreement was for metabolic conditions (West Bank 48%, Gaza 38%). The differences between the two samples were not statistically significant.

Agreement at block level between the DNFs and the underlying causes registered by the PHIC (DNF-PHIC) was best for cerebrovascular conditions in the West Bank sample (66%, Gaza 63%; not significantly different) and for neoplasms in the Gaza

sample (83%, West Bank 52%; significantly different). The lowest agreement was for anomalies in the West Bank sample (38%, Gaza 53%; not significantly different) and perinatal conditions in the Gaza sample (14%, West Bank 44%; significantly different).

Agreement between the EDC and the underlying cause registered by PHIC (EDC-PHIC) at block level was best for cerebrovascular conditions in the West Bank sample (69%, Gaza 32%; significantly different) and for neoplasms in the Gaza sample (83%, West Bank 54%; significantly different). The lowest EDC-PHIC agreement at block level was for external causes in the West Bank sample (9%, Gaza no cases) and for perinatal deaths in the Gaza sample (5%, West Bank 43%; significantly different).

Table 4.2.3 Agreement on underlying cause by diagnostic group: ICD block level, point estimates and 95% confidence intervals

	DNF-EDC				*DNF-PHIC*			
	West Bank		*Gaza Strip*		*West Bank*		*Gaza Strip*	
	PE (%)	95% CI	PE (%)	95% CI	PE (%)	95% CI	PE (%)	95% CI
Neoplasm	82	72-92	89	78-98	52	39-64	83	72-95
Metabolic	48	27-69	38	15-61	44	23-65	33	11-55
Cardiac	65	54-77	47	23-72	61	49-73	47	21-74
Cerebrovascular	75	62-88	65	42-88	66	51-80	63	39-87
Perinatal	70	52-89	55	32-77	44	24-64	14	0-31
Anomaly	63	46-80	71	46-95	38	21-55	53	26-79
External	78	60-96	-		9	0-22	-	
Other	59	46-72	53	39-66	29	16-41	51	37-65

	EDC-PHIC			
	West Bank		Gaza Strip	
	PE (%)	95% CI	PE (%)	95% CI
Neoplasm	54	41-67	83	72-95
Metabolic	19	3-34	19	1-37
Cardiac	49	37-61	35	10-61
Cerebrovascular	69	55-83	32	9-55
Perinatal	43	26-60	5	0-15
Anomaly	50	32-68	53	26-79
External	9	0-22	-	
Other	28	16-39	43	29-57

There were few statistically significant differences between males and females in underlying cause agreement (Table 4.2.4).

Table 4.2.4 Agreement on underlying cause by sex: ICD 4-character level and ICD block level, point estimates and 95% confidence intervals

		West Bank				Gaza Strip			
		ICD 4-char		ICD block		ICD 4-char		ICD block	
		PE (%)	95% CI	PE (%)	95% CI	PE (%)	95% CI	PE (%)	95% CI
DNF-PHIC	Male	25	19-31	45	38-52	33	23-43	51	41-61
	Female	21	15-27	47	39-55	44	34-54	55	45-66
DNF-EDC	Male	57	50-64	66	60-73	53	43-63	69	59-78
	Female	56	48-63	70	63-77	51	40-61	55	45-65
EDC-PHIC	Male	21	15-27	43	36-51	29	19-38	47	37-57
	Female	16	10-21	44	36-52	33	23-43	41	31-52

There were few significant differences between the four age groups, either at ICD 4-character or ICD block level. At a detailed level there was, however, significantly lower agreement for the youngest age groups in the two comparisons involving the codes in the PHIC Registry (DNF-PHIC and EDC-PHIC). At block level, only the DNF-PHIC comparison showed a significant difference, probably reflecting difficulties in the coding of congenital anomalies and perinatal causes (Tables 4.2.5 and 4.2.6).

Table 4.2.5 Agreement on underlying cause by age group: ICD 4-character level, point estimates and 95% confidence intervals

	DNF-EDC				DNF-PHIC				EDC-PHIC			
	West Bank		Gaza Strip		West Bank		Gaza Strip		West Bank		Gaza Strip	
	PE (%)	95% CI	PE (%)	95% CI	PE (%)	95% CI	PE (%)	95% CI	PE (%)	95% CI	PE (%)	95% CI
< 1 year	61	49-74	46	33-60	7	0-13	25	13-37	8	2-15	19	8-30
1-17 years	52	37-68	53	28-77	14	3-25	22	1-43	12	2-22	22	1-43
18-64 years	58	49-66	62	50-74	27	20-34	45	32-58	24	16-31	38	26-50
> 64 years	53	43-63	43	29-56	31	22-40	50	36-64	22	14-30	37	24-50

Table 4.2.6 Agreement on underlying cause by age group: ICD block level, point estimates and 95% confidence intervals

	DNF-EDC				DNF-PHIC				EDC-PHIC			
	West Bank		Gaza Strip		West Bank		Gaza Strip		West Bank		Gaza Strip	
	PE (%)	95% CI	PE (%)	95% CI	PE (%)	95% CI	PE (%)	95% CI	PE (%)	95% CI	PE (%)	95% CI
< 1 year	75	64-87	46	33-60	43	30-56	34	21-47	47	35-59	32	19-45
1-17 years	60	44-75	53	28-77	31	16-46	26	5-48	38	23-53	39	14-64
18-64 years	72	64-79	66	55-77	42	34-50	58	45-71	40	32-49	56	43-68
> 64 years	63	53-72	46	33-60	60	50-69	54	40-67	48	38-58	44	31-58

As shown in Table 4.2.7, the only statistically significant difference between governmental and non-governmental hospitals was in DNF-EDC agreement at ICD 4-character level, but this difference was not significant at ICD block level.

Table 4.2.7 Agreement on underlying cause by hospital type (governmental, non-governmental) and ICD level: point estimates and 95% confidence intervals

		Governmental		Non-governmental	
		PE (%)	95% CI	PE (%)	95% CI
DNF-PHIC	ICD 4-char	23	17-28	24	15-32
	ICD block	46	40-52	46	36-56
DNF-EDC	ICD 4-char	53	47-59	64	55-74
	ICD block	66	60-72	74	65-83
EDC-PHIC	ICD 4-char	18	14-23	19	11-27
	ICD block	43	37-49	45	35-55

Note: All Gaza hospitals in the sample were governmental

With the exception of EDC-PHIC comparison at a detailed level, the use of an electronic patient record system or traditional paper medical records by the hospital had no impact on agreement. The difference disappeared at block level.

Table 4.2.8 Agreement on underlying cause by patient record type (paper, electronic) and ICD level: point estimates and 95% confidence intervals

		Paper		Electronic	
		PE (%)	95% CI	PE (%)	95% CI
DNF-PHIC	ICD 4 char	25	20-30	16	7-25
	ICD block	47	41-53	43	31-55
DNF-EDC	ICD 4 char	58	52-64	51	39-63
	ICD block	70	64-75	63	51-74
EDC-PHIC	ICD 4 char	21	16-26	11	4-19
	ICD block	44	38-50	42	31-53

Note: All Gaza hospitals in the sample used paper records

5. Observations and comments

5.1 General accuracy

Agreement between the underlying cause according to the EDC and the underlying cause of death actually registered by the PHIC was low: 19% (West Bank) and 31% (Gaza) at the most detailed level and 44% (both samples) even at ICD block level. The EDC reflects the best information that could be obtained on each death, which implies that the PHIC Cause of Death Registry gives a poor picture of the causes of death in both the West Bank and Gaza Strip. Even at aggregated ICD block level, less than half of the underlying causes in the PHIC Registry were correct. This hampers the assessment of important aspects of public health, such as the burden of disease, maternal mortality, and the prevalence of congenital anomalies.

There are two main reasons for the discrepancy between the EDC and the PHIC. First, accuracy is poor on the original Death Notification Form (DNF). At the most detailed level, agreement between the DNFs, coded and classified by Iris, and the EDCs was 56% (West Bank) and 52% (Gaza); at ICD block level it was 68% and 62% respectively. This means that even at block level, certifiers recorded the incorrect underlying cause on about one third of the DNFs.

The other main reason for the discrepancy between the EDC cause of death and the PHIC cause of death is that coding and classification procedures at the PHIC differ considerably from international standards, represented in this study by Iris software. Although far from perfect, DNF-EDC agreement is considerably better than EDC-PHIC agreement. For the West Bank, the estimated agreement between the original DNF coded by Iris and the cause of death registered by the PHIC (DNF-PHIC) was 23% at detailed level and 46% at block level, which is almost as low as the agreement between the EDCs and the PHIC cause of death. For Gaza the agreement between DNF and PHIC causes of death was somewhat better at 39% (detailed level) and 53% (block level), but is still low. The conclusion is that PHIC mortality statistics are not comparable to statistics from other countries that adhere to the ICD instructions more closely, and also that the medical precision of the statistics (measured by EDC-PHIC agreement) would be improved if the international coding and classification rules were adhered to.

Departures from the international coding standards defined in the ICD include formal errors in the PHIC data. Some ICD codes that are invalid as underlying causes have still been used as such by PHIC. For example, codes from Chapter XIX (Injury, poisoning and other consequences of external causes) should not be used for an underlying cause. Instead, these cases should be coded according to Chapter XX (External causes of morbidity and mortality). Also, codes from Chapter XXI (Factors influencing health status and contact with health services) should not be used for an underlying cause, but should be coded by the condition that necessitated contact with the health services.

One example is code Z55 (Problems related to education and literacy). This probably refers to cases of developmental retardation and code Z55 would have been correct for a medical consultation while the patient was still alive. According to the ICD instructions, codes in the range Z00 to Z99 are invalid for an underlying cause of death and in cases of mortality, a code in the range F80-F89 (Disorders of psychological development) should be used instead. There are also cause-specific instructions in Volume 2 of ICD-10 which have not been followed. For example, code P07 (Disorders related to short gestation and low birth weight) should not be used for an underlying cause if any other cause of perinatal mortality is referred to on the certificate. Or it should not be used if a sequence of medical events has not been followed back to its starting point. An example of this particular coding error is where A41 (sepsis) is recorded as an underlying cause of death rather than the condition causing the sepsis. In several similar, but not identical, cases, diagnostic expressions appear to have been confused, suggesting that the coding was based on a short list rather than the complete ICD, or that much coding is done from memory rather than by consulting the ICD volumes.

EDC-PHIC agreement is lower than in other published studies on the accuracy of mortality statistics. For example, a validation of mortality statistics in Cape Town showed accuracy of 55% at WHO tabulation list 1 level11 (103 groups corresponding roughly to block level). Other studies vary widely in their assessment of the accuracy of mortality statistics,4 but since they generally refer to mortality statistics in high-resource countries and to specific causes of death, the results are difficult to compare to the present study. A Swedish study found that death certificates were correct in about 77% of hospital deaths at Basic Tabulation List

level (350 groups of ICD categories).2 In contrast, a Danish study of deaths on an internal medical ward found that reliability was so poor –ten doctors who issued death certificates for 40 patients arrived at different causes of death in 73 cases– that mortality statistics are of little use, at least for complex internal medicine cases.12

However, DNF-EDC agreement in our study is approaching the same range as many published studies, which indicates that the implementation of international standards for selection of the underlying cause of death would be a significant step forward.

5.2 Diagnostic groups

As in several other studies on the quality of mortality statistics, accuracy varies between diagnostic groups [2–4]. Accuracy in the causes of death in the PHIC register, indicated by EDC-PHIC agreement, was best, but still moderate, at 69% for cerebrovascular diseases in the West Bank sample. This is surprising since most studies show the highest agreement for neoplasms, which is also the case in the Gaza sample (83%) [3]. In the West Bank sample, neoplasms show 54% of agreement, which is low in comparison with other studies. Both samples show low agreement for metabolic conditions, which is consistent with findings from other studies.

Agreement between DNF-EDC at block level for neoplasms is high in both samples, which indicates reliability in cause of death certification for neoplasms. It is also reasonably high for cerebrovascular diseases in both samples, and for perinatal conditions in the West Bank sample. In both samples, the DNFs are least reliable for metabolic diseases, which is consistent with findings in other studies.

Classification issues, as reflected in the DNF-PHIC agreement, are most apparent in anomalies in the West Bank sample and perinatal conditions in the Gaza sample, whereas neoplasms fare quite well in the Gaza sample. Anomalies and perinatal conditions are notoriously difficult to code and classify in the ICD and similar results have been seen in other studies.

5.3 Sex, age and other background variables

In both samples, there was no noticeable relationship between the sex and age of the decedent and the accuracy of the cause of death. Also, the West Bank sample showed only minor differences between governmental and non-governmental hospitals, and no differences in accuracy between DNFs from hospitals using an electronic patient record system or those using paper-based documentation. But as section 3.1 above points out, 15 of the 20 DNFs missing from the West Bank sample were of deaths at the hospital with electronic records. Other problems with electronic records included several deaths that had been registered twice or more, and some of the deceased recorded in the hospital files were still alive. It is apparent that electronic record systems do not necessarily make it easier to retrieve data.

5.4 Filling in the DNF - quality of the certification

Several DNFs had been completed in a less than satisfactory manner. The most common problem was the widespread use of abbreviations, which occurred on more than one third of all DNFs in both samples. Abbreviations cause problems, partly because they can be ambiguous, such as «MI» («mitral insufficiency» or «myocardial infarction»), and partly because some abbreviations are specific to a certain medical speciality or clinic and are difficult to interpret. Needless to say, if the statistical office cannot interpret an abbreviation or interprets an abbreviation incorrectly, this may result in the recording of an incorrect underlying cause.

A similar difficulty results from illegible entries. Doctors› handwriting is notoriously difficult to read and the DNFs in the samples were no exception; 30% of the West Bank DNFs had entries that specially trained staff could not read when extracting the data. Just as with ambiguous or non-standard abbreviations, illegible entries increase the risk that the underlying cause will not be correct. Interestingly, the problem of illegible entries was much smaller in the Gaza sample at only 6%.

The ICD rules and guidelines on selection of the underlying cause are built on the concept of sequence, meaning the consecutive train of events from the underlying cause (the starting point), through subsequent complications to the terminal complication that eventually brought about the death. If the conditions are reported in an erroneous non-causal order, the underlying cause of death is

less reliable, despite the ICD defining strict procedures for such cases. Sequence errors with an impact on the underlying cause of death occurred in about 20% of both samples; this is a comparatively high figure in an international context.

There are related errors that also make it far more difficult to identify the sequence of events leading to death. These are included in Table 4.2 under the heading «Other certification errors». The most important are: (a) placing several conditions on the lowest completed line in Part 1; and (b) placing the underlying cause in Part 2.

The presence of several conditions on the lowest completed line in Part 1 indicates that the certifier did not devote serious thought to determining which of these conditions constituted the patient›s primary problem. The ICD specifies how the coder should select the underlying cause of death in these cases, but selection is inevitably far more arbitrary than if the certifiers themselves identify a single underlying cause. In the West Bank, 14% of the DNFs had several causes on the lowest completed line in Part 1, excluding cases where one or more of the conditions were clearly complications of another condition referred to on the same line (e.g. «myocardial infarction with pulmonary edema»). In the Gaza sample, 10% of the DNFs had several conditions on the lowest completed line.

By placing the underlying cause in Part 2, which is for conditions that are not part of the sequence leading to death, certifiers show that they have not understood the difference between Part 1 and Part 2 of the death certificate. The ICD specifies the procedures for dealing with such cases, but, once again, the accuracy of the selection may be compromised if the certificate is not completed properly. The underlying cause was placed in Part 2 in 7% of the West Bank sample, and in 11% of the Gaza sample. Combined with the errors referred to above (incorrect order or entries and several causes on the lowest completed line in Part 1), the result was that in both samples 30-40% of DNFs had sequence-related errors, and more than one on some DNFs. From an international perspective, this is a high figure [5].

Another indication that the existing forms are not fulfilling their purpose is the comparatively high frequency of DNFs in which the certifier has written items

in the medical section that are not relevant to the selection of the underlying cause of death (Table 4.2). A self-instructing DNF form with clear lead texts and in which Part 1 and Part 2 are clearly separate could greatly improve cause of death certification in this respect. Clear layout of the form could assist physicians considerably to report the causes of death in the appropriate section [6], and properly filled out certificates are far easier to code correctly. A good example to follow is the new international form for medical certification of death, currently under preparation. This new form should be part of the new ICD instructions for the coding and selection of causes of death and will be a part of the ICD-10 updates for 2016 [7].

A fairly high number of DNFs (24% West Bank, 26% Gaza) reported an underlying cause of death that presumably developed as a complication of some other condition, yet this underlying condition is not recorded. In several DNFs, kidney failure was reported as the underlying cause of death, but there was no mention of the reason why kidney failure developed, for example, due to diabetes, glomerulonephritis or urinary obstruction. The DNF should specify that the cause of secondary conditions should always be reported.

In a number of cases the underlying cause was stated in such vague terms as to make it more or less useless for public health analysis. For example, «blood disease» (anemia, which type? hematologic neoplasm?) or «tumour» (anatomical site? malignant?); the DNF should instruct certifiers to use established medical terminology.

The presence of competing causes of death – where the decedent had several serious diseases, any of which could alone explain the death – makes it more difficult for the certifier to fill out a death certificate. The ICD format presupposes that the death was caused by one condition, with or without complications, and not by the combined effect of several, etiologically unrelated conditions. 3 Judging from the case summaries, competing causes of death were present in 11% of the West Bank cases and 12% of the Gaza cases. This is lower than in two studies from England 8 and Sweden 9, which both found competing causes in about 20% of deaths. The lower figure in the Palestinian sample probably reflects the lower average age of the decedents; fewer individuals suffer from more than

one serious chronic condition at a younger age.

5.5 Challenges in retrieving patient files

There were several challenges in retrieving the data for the study. The most important were:

1. The PHIC Registry sometimes registered the patient file number instead of the deceased patient›s ID number.

2. The deceased patient›s ID number registered at PHIC sometimes differed from the ID number in the hospital records.

3. The first or last name of the deceased patient on the DNF sometimes differed from that in the hospital records.

4. For some infants, the DNF named the infant, but the hospital records were under the name of the mother and her ID number. The files stated that the deceased infant was the child of the woman under whose name the record was filed.

5. For out-of-hospital deaths or deaths that occur at private hospitals without morgue facilities, the hospital that receives the body for storage in the morgue fills in and stamps the DNF, although the patient records are filed elsewhere.

6. If physicians employed by a hospital attest a death that occurs at a private home, they often report the name and address of their hospital on the DNF. In such cases no patient files may be available.

7. If a deceased patient is referred for autopsy to another hospital, the hospital where the autopsy took place and where the DNF was issued does not have a copy of the patient file.

8. Sometimes birth certificates are not issued for infants with a slim chance of survival, for example children referred to intensive care immediately after birth. However, if no birth certificate has been issued, there is also no patient

record.

9. At hospitals with electronic patient record systems, it was very difficult for the physicians preparing the data extracts for our study to retrieve the patient files. The help of an IT person was required to find the records.

10. At hospitals with paper-based documentation, it was a challenge to find archived patient files because archiving practices varied or had not been followed.

6. Conclusions and recommendations

As noted in section 4, there are two major reasons for discrepancies between the EDC and the cause of death registered by the PHIC:

- Differences between the coding and classification procedures defined in the ICD and the procedures actually applied by the PHIC.
- Incomplete or otherwise unsatisfactory reporting on a considerable number of DNFs.

To address these points, the following measures are proposed:

- Improve the design of the Death Notification Form

  On the current DNF the space actually available for writing a diagnosis is very restricted, less than one-fourth of the width of the page. On most forms, the space available has proved insufficient and certifiers have tried to create more space for the diagnosis by using abbreviations, using two or more lines for a single diagnostic statement, squeezing several lines of text between two dotted lines on the form, or simply disregarding the dotted lines altogether and stating the causes of death in one long clause. All these «solutions» make it more difficult to follow the sequence of events leading to death, and consequently, to identify the underlying cause of death. The lack of sufficient space forces certifiers to use a small script that is difficult to read and further

increases the risk of misinterpretation.

Also, the current DNF does not make a clear distinction between Part 1 and Part 2 of the medical section. This distinction is crucial for identifying the underlying cause: Part 1 is for the underlying cause of death and its subsequent complications; Part 2 is for conditions that may have accelerated the process, but are not a part of the sequence from the underlying cause to the terminal complication. If the distinction is not evident from the form, the certifier may unintentionally place the underlying cause in Part 2. It then becomes more difficult for the coder to determine whether a condition written in the lower portion of the medical section actually belongs to Part 1 or Part 2. Both these circumstances jeopardize accurate selection of the underlying cause.

It is recommended that the Death Notification Form be redesigned according to the template now being prepared by the WHO. More space should be provided for the causes of death and there should be clear lead texts between the lines to emphasize that the conditions recorded on each line in Part 1 are a complication of the condition(s) referred to on the line below. There should be a clear distinction between Part 1 and Part 2, both by lead texts and by the layout itself, for example by placing Part 1 and Part 2 in separate boxes.

- Use of international coding software for coding and classification

The use of internationally recognized coding software would bring several benefits. The software automatically applies ICD instructions for the selection and classification of causes of death. It also covers less common cases that coders may be unfamiliar with and brings coding and classification in line with the ICD instructions. A dictionary of medical terms is included in the software, contributing further to consistent coding. Further, coding software speeds up the coding process since it reduces the burden on the sole individual at PHIC who is currently responsible for all the coding. At present there can be a delay of several months from the time the DNF is received by the PHIC

until it is coded and entered in the CoDR. Also, an automated coding system would facilitate the training of new coders.

A further advantage of automated coding is that the software gives a code to all causes of death mentioned on the certificate, both the underlying cause and the contributing causes. With automated coding, the PHIC Registry would contain multiple causes of death for all deaths, and the potential for detailed analysis and monitoring would be considerably enhanced.

For several decades the MMDS (Medical Mortality Data System, developed by the US National Center for Health Statistics) was the most widespread system for the coding and classification of causes of death. The international version of MMDS is no longer maintained and the current version of MMDS is now available only to US users. However, Iris software is available and is easier to adapt to different settings. Continuously updated, Iris reflects the most recent version of ICD-10.1

- At hospitals: supervision of cause of death certification

Studies of the quality of mortality statistics often suggest that training for certifiers on how to complete the death certificate would resolve issues related to quality. Unfortunately, it has been difficult to demonstrate any significant effect from such training [3, p.21-22]. Even so, a pamphlet with brief instructions on how to complete the medical section of the DNF could be helpful, especially in contacts between coders and physicians.

Another proposed approach is that each death certificate should be written and signed by two physicians, or that a senior physician should review all death certificates issued at the hospital. In some locations, a specialist committee has been set up to review all hospitalizations that end with the death of the patient, and also to verify the accuracy of the death certificate. Such measures are resource-demanding and require senior staff who are prepared to invest time and commitment

into death certification.

- Review and improve data handling at hospitals with electronic patient records. Electronic patient record systems are supposed to improve data availability and facilitate the administration of hospital care, but appeared to have the opposite result in our study. Legislation requires the DNF to be issued on paper; there is no digital DNF in the electronic system. Instead, paper DNFs are kept in a special file. As a result, several DNFs could not be retrieved from hospitals with electronic patient record systems. There were also other aberrations, for example deceased patients recorded as still being alive. Electronic systems must be adapted to meet the legal requirements for reporting causes of death, and updating by hospital staff of basic variables such as whether the patient is alive or not should be facilitated.

- Feedback from the statistical office

  Feedback from the statistical office to the individual hospital could be an option to highlight certificates with any of the problems listed in Table 3.2. It would be even more efficient if the hospital or certifier could be contacted in such cases and asked to amend the DNF .10 It would be worthwhile to revert to the certifier in cases of illegible entries or ambiguous abbreviations on the DNF; if the reported sequence is not medically plausible; or the underlying cause lacks specificity, especially if the reported underlying cause seems to be a complication of a fundamental condition that is not reported on the certificate.

This type of check could also be performed by specially trained staff or an evaluation committee at the local hospital.

7. Study limitations

Several factors may have hampered verification of the underlying causes of deaths:

1. There are no DNFs for deaths occurring during birth or within a few days after birth. Instead, a monthly report of neonatal deaths is filled out by each hospital and sent to the PHIC. Therefore, the cause of death for infants who died at birth could not be validated.
2. There are no patient files for emergency deaths or those who arrived dead and were put in the morgue. For these deaths we could not verify the underlying cause of death stated in the DNF.
3. We do not know the number of deaths that are not reported to the authorities at all. The Palestinian Central Bureau of Statistics estimates that about 40% of deaths may never be reported.15 The presence of deaths that occurred several decades ago in the sample indicates that some deaths are unreported. It is important to estimate the number of non-reported deaths and determine if the causes of death in such cases differ significantly from those actually reported to the authorities.
4. In the West Bank sample, case summaries were missing from the medical hospital records for 82 deceased patients (only one was missing in the Gaza Strip). This makes the EDC on the underlying cause of death less reliable.
5. Data on the duration of a condition were often missing in both DNFs and patient reports. In extracting patients' hospital records, it is crucial to capture all information on the date and time when a specific condition developed or was diagnosed, or a specific event that occurred during the treatment. This is important to establish the correct sequence of events.
6. Incomplete diagnostic information in case summaries. Sometimes the hospital case summaries lacked diagnostic information that may have changed the underlying cause, especially in cases of longstanding conditions.
7. Restricted sample size. Reporting difficulties vary with the cause of death. A larger sample may have offered the possibility to describe cause-specific problems in more detail, but would also have seriously delayed the study.
8. The study was limited to hospital deaths. A future study is needed to examine the accuracy of DNFs for deaths outside the hospital context.

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Appendix 1: Death Notification Form- West Bank

Palestinian National Authority
Ministry of Interior

Death Notification Form
Form is filled in 4 copies

MoH at District _____

Act No. 426 on ID and population registry 1972-5732, hereby I am informing on the details of the dead person mentioned below and I testify that all these details are accurate and correct.

1-ID Number of the Deceased | | | | | | | | | | 2-Forename 3-Father Name

4-Grandfather's Name 5-Family Name

5- Husband's /wife's name ID number | | | | | | | | | | 6- Sex

7-Social status 8-Religion/nationality 9-Permanent residency address city/village street house no.

10- Date of Death: Day.....Month.....Year.....hour.....

11- Place of Death: city/village..... If death occurred in a hospital indicate the name of the hospital.....

Date of Birth: Day Month Year If the deceased was a new born that lived less than 24 hours please indicate number of hours of life

Place of birth: city/Village..... .....Country/town of origin.....

Nationality on the date of death .....Occupation of the deceased.....

Name of the notifying person .....

Address of the notifying person city/village ..... street..... House no.....

Date ..... Signature of notifying person..... Relationship to deceased.....

	Period of Illness	
A. Direct cause of death 1).....	.....	
B. Caused from.....	.....	
C. Caused from (original disease) 2:	.....	

Other diseases…… ……

If the deceased was a women please indicate if she was pregnant or gave birth before dying
…… (P.M)

The body was/was not examined before death

Testimony: I certify that I have treated the above-mentioned deceased person since _____

I saw the deceased last time alive on date ……The death occurred on date: ……. I saw the body on: ……..

I certify according to my personal knowledge that the above mentioned details are correct and accurate

Date Signature

Name of the signatory (stamp or name)……Title……Address
……..

For Use of Department

Received on…….. Burial permit given…….. Place of burial
……..Referred to registration office …….. On the date of
……Stamp and signature of the Primary Health Directorate

Attached is ID No

Appendix 2: Death Notification Form-Gaza Strip

Death Notification form -Gaza

Palestinian National Authority

Ministry of Interior

Death Notification Form

This form has 4 copies

MoH at District _____ Original Copy

Act No. 426 on ID and population registry 1972-5732, hereby I am informing on the details of the dead person mentioned below and I testify that all these details are accurate and correct.

1-ID Number of the deceased | | | | | | | | | |

2-Forename _____

3-Father Name _____

4-Grandfather's Name _____

5-Family Name _____

6-Sex _____

7-Name of Deceased's mother _____

8-Social status _____

9-Religion/ nationality _____

10-Permanent residency address/city _____

Street and house No. _____

Date of Death: Day _____ Month _____ Year _____ Time _____

Place of Death: city/village _____

If death occurred in a hospital indicate the name of the hospital _____

Date of Birth: Day _____ Month _____ Year _____

If the deceased was a new born that lived less than 24 hours please indicate number of hours _____

Place of birth: city/Village _____

Country/town of origin _____

Nationality on the date of death _____

Occupation of the deceased _____

Name of the notifying person _____

Address _____

Relation of the notifying person _____

	Period of illness		
a) Direct cause of death _____ b) As a result of _____ c) Caused from (original disease/illness)_____ d) Other _____		□ Pneumonia □ Cerebral Hemorrhage □ Complete Hemiplegia □ Atherosclerosis	□ Pulmonary Embolism □ Thrombophlebitis □ St. P. Gastrectomy Duodenum Ulcer

		□ Duodenal Ulcer □ Cardiac Arrest □ Myocardial Infarction	□ Hypertension □ Heart Failure □ Diabetes
If the decreased was a women, please indicate if she was pregnant or had miscarriage, or gave birth prior to death			
The body was/was not examined before death		□Yes □No	

Testimony: I certify that I have treated the above-mentioned deceased person since _____

I saw the deceased last time alive on _____ The death occurred on date: _____ I saw the body on: _____

I certify according to my personal knowledge that the above mentioned details are correct

Date _____ Signature _____

Name of the signatory (stamp or name) _____ Tile _____

Address _____

For use of MoI office only

For official use only

Received on the day of _____ Burial permit given _____ Place of burial

Referred to registration office _____ On the date of _____

Stamp and signature of the health office

_____

Attached is ID No _____

Note: The items from 1-10 should be recorded according to deceased ID , date of birth certificate or a visiting permit

Any death case should be reported within a period of maximum of 7 days. A fine should be paid for any delay beyond that period according to the ministry of Interior laws.

From No. W09017

Appendix 3: Medical Extraction Forms (EDC)

Administrative Data			
Hospital ----------	Deceased Patient name ----------	Deceased Patient ID __ __ __ __ __ __ __ __ __	
Sex	☐ Female	☐ Male	☐ Unknown
Date of birth	/ /	Date of death	/ /
Date of notification	/ /		

Medical data: Part 1 and 2			
Disease or condition directly leading to death. Antecedent causes that gave rise to the cause above, stating the underlying cause on the lowest line	1	Cause of death	Date of onset
	A	*Terminal complication*	/ /
	B	*Complication of 1c*	/ /
	C	*Complication of 1d*	/ /
	D	*Diagnosis that started the chain of events*	/ /

Other significant conditions contributing to death but related to the illness or conditions causing it	2	*Unrelated but contributory conditions*

Was surgery performed within the last 4 weeks?	☐ Yes	☐ No	☐ Unknown
Date of surgery _____ /_____ /_____			
If yes please specify reason for surgery			

Was an autopsy requested?	☐ Yes	☐ No	☐ Unknown
Were the findings used in the certification?	☐ Yes	☐ No	☐ Unknown

Manner of death		
☐ Disease	☐ Accident	☐ Intentional self-harm
☐ Assault	☐ Pending investigation	☐ Legal intervention
☐ War	☐ Could not be determined	☐ Unknown

If external cause or poisoning / Road traffic accidents			Date of injury	D	D	M	M	Y	Y
Please describe how external cause occurred (If poisoning please specify poisoning agent)									
Place of occurrence of injury/poisoning									
☐ At home	☐ Residential institution	☐ School, other institution, public administrative area	☐ Sports and athletics area						
☐ Street and highway	☐ Trade and service area	☐ Industrial and construction area	☐ Farm						
☐ Other place:			☐ Unknown						

Infant Death					
Multiple pregnancy		☐ Yes No.	☐ No	☐ Unknown	
Number of completed weeks of	wks	Birth weight			grams

pregnancy				
Age of mother (years)	yrs			

For women of fertile age, was the deceased pregnant?			
☐ At time of death	☐ Within 42 days before the death		
☐ Between 43 days up to 1 year before death	☐ Unknown		
Did the pregnancy contribute to the death?	☐ Yes	☐ No	☐ Unknown

Death Notification Form			
Illness or condition directly leading to death. Antecedent causes that gave rise to the cause above, stating the underlying cause on the lowest line	1	Cause of death	Date of onset _____ /_____ /_____
	A	Terminal complication	
	B	Complication of 1c	
	C	Complication of 1d	
	D	Diagnosis that started the chain of events	

Minor errors			
Error in use of abbreviations	☐ Yes	☐ No	☐ Unknown
Error due illegible writing	☐ Yes	☐ No	☐ Unknown
Error in recording of inappropriate information	☐ Yes	☐ No	☐ Unknown
If Yes, specify:			
ICD10 code at DNF-PHIC			

Death Report: Note: Please provide a copy of the death report with the extraction files
Summary of events leading to death according to the death report _____ _____ _____ _____ _____ _____ _____ _____ _____

Appendix 4: Completeness of DNFs- Administrative Data

1. District
2. ID number
3. Forename
4. Father's name
5. Grandfather's name
6. Family name
7. Sex
8. Religion/nationality
9. Permanent residency address
10. Street/neighborhood
11. Date of death
12. Time
13. Place of death
14. Hospital
15. Date of birth
16. Place of birth
17. Nationality on date of death

Appendix 5: Timeliness of Cause of Death Registry Form

Case No.	Date of Death	Date of Notification	Death Registry Date
1.			
2.			
3.			
4.			
5.			
6.			
7.			
8.			
9.			
10.			
11.			
12.			
13.			
14.			
15.			
16.			
17.			
18.			
19.			
20.			

Notes:

1- Date of Death and Date of Notification will be obtained from the DNF.
2- Death Registry Date will be obtained from the Cause of Death Registry.