Are vital registration systems fit for purpose? Asian Regional assessment of Death and Cause of Death Statistics, 2015-19

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Outline

- Why good quality mortality statistics matter?
- What is the state of mortality statistics in the region (based on publicly available data)?
- What can countries do to rapidly improve the availability and quality of their mortality statistics?

Uses of mortality statistics from vital registration systems

1. Periodic assessment of the burden of disease (two-thirds from YLLs) by age, sex, cause, location and socioeconomic group
2. Tracking emerging health challenges/crises such as HIV, COVID 19, etc
3. Monitoring progress with national and global health goals such as SDG3
4. Assessing the impact of health policies and interventions (e.g. tobacco control measures; road safety regulations, etc).
5. Informing epidemiological research priorities (e.g. smoking and lung cancer trends in the UK in the 1950s)

*Good quality, timely and disaggregated cause of death data are an essential input for informing **all** health policy debates*

Why does mortality data quality matter?

- Remember availability of data does NOT guarantee quality
- Policy should be informed by ***accurate*** and ***timely*** data
- Poor quality data leads to poor decisions and often the wrong allocation of resources, with potentially significant consequences for improving population health
- The 14(out of17) SDG3 indicators that specifically require cause-specific mortality data for monitoring progress need to be based on reliable data to guide policy responses

- Policy requires accurate and timely cause of death data: just how bad are they?
  Some examples of problems with vital registration data and resulting uncertainty

VITAL REGISTRATION DIAGNOSES	MEDICAL RECORDS DIAGNOSES																
	HIV/AIDS (20)	Liver cancer (31)	Lung cancer (34)	Other cancers (46)	Diabetes (52)	Hypertensive diseases (66)	Ischaemic heart diseases (67)	Other heart diseases (68)	Cerebrovascular diseases (69)	Pneumonia (74)	COPD (76)	Liver diseases (80)	Other digestive diseases (81)	Genitourinary diseases (84)	Transport accidents (96)	All other causes	Total
Septicaemia (12)	44	2	3	3	53	6	8	3	55	38	16	27	19	47	2	144	**470**
Ill defined conditions (94)	16	6	7	5	27	16	75	36	25	14	39	10	14	13	9	135	**447**
Cerebrovascular diseases (69)			1		7	1	4	5	203					1	9	31	**262**
Ischaemic heart diseases (67)	1		2		26	5	138	9	3	2	3		3	6		16	**214**
Pneumonia (74)	40		3		9	1	4	2	25	44	21	7	1	10	3	37	**207**
All other external causes (103)					1	1	2	1	25	1					93	61	**185**
Genitourinary diseases (84)	1	1		1	37	24	2	3	3	1	1	5	2	58		17	**156**
Lung cancer (34)		1	85	6					1		4					5	**102**
Transport accidents (96)								1							91		**92**
Liver diseases (80)	2	2			1		2		2			63	2	1		11	**86**
HIV/AIDS (20)	79											1				3	**83**
Other cancers (46)	1	14	3	24						2				1		34	**79**
COPD (76)	1		2		2		3	3	2	3	54			2		5	**77**
Other digestive diseases (81)	3	1	2			2	1		2		1	16	17	1	1	27	**74**
Other respiratory diseases (77)	5		2	1	4	1	5		8	3	12	3		3	1	25	**73**
Other heart diseases (68)	1		1		1	4	15	14	4	1	4	1	1	5	1	18	**71**
Liver cancer (31)		58		2			1					3				4	**68**
Other infectious diseases (25)	18			1	3			1	5	1	1	1	1	3		17	**52**
Tuberculosis (5)	20				1						2					17	**40**
Other nervous system disorders (61)	10				2			1	4			1				10	**28**
Diabetes (52)				1	16		2		1	1				2	1	2	**26**
All other causes	14			8	9	8	5	3	18	1	1	9	4	6	2	336	**424**
Total	256	85	111	52	199	69	267	82	386	112	159	147	64	159	213	955	**3316**

Adjusted cause-specific mortality fractions compared with vital registration data, Thailand, 2005, MALES

Vital Registration (VR)			Adjusted VR estimates		
Cause of death	%	rank	rank	Cause of death	%
Ill-defined diseases	33.3	1	1	Stroke	9.6
Other infectious diseases	6.1	2	2	HIV/AIDS	8.3
Ill-defined injuries	5.0	3	3	Road traffic accidents	8.2
Other cancer	4.4	4	4	Ischaemic heart disease	7.3
Stroke	4.1	5	5	COPD	5.8
Liver cancer	3.9	6	6	Cirrhosis	5.1
Road traffic accidents	3.8	7	7	Liver cancer	4.6
Lower respiratory infections	3.2	8	8	Ill-defined diseases	3.8
Ischaemic heart disease	3.0	9	9	Lung cancer	3.7
Nephritis and nephrosis	2.5	10	10	Diabetes mellitus	3.3
Lung cancer	2.5	11	11	Lower respiratory infections	2.9
Other digestive diseases	2.4	12	12	Suicide	2.7
		13	13		
		17	15		
		20	18		
		22	22		
		23	67		

Policy implications of correcting Thai mortality statistics

% increase in TRUE versus REPORTED causes of death in Thailand:

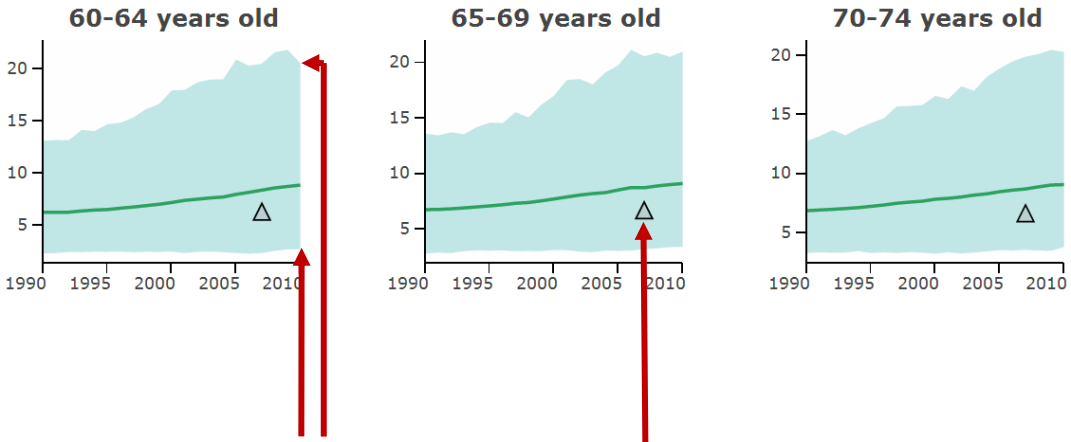
Stroke:	200% (3 times higher than reported in the VR system)
IHD:	250% (3.5 times)
HIV/AIDS:	400% (5 times)
COPD:	350% (4.5 times)
Road Acc:	100% (2 times)

Conclusion: vital registration system in Thailand performs too poorly to support policy, monitor epidemics, & guide health priorities

Misclassification matrix: Bohol Regional Hospital (BRH),Philippines, 2012

Misclassification matrix tables, BRH Bohol 2012															
	Gold standard diagnosies from BRH														
Hospital diagnosis	Stroke	AMI	Other CVD	Diab-etes	Cirrhosis	Renal Failure	Other NCD	Pneu-monia	TB	Other Infect	RTA	Hom-icide	Falls	All other	Total
Stroke	173	1	1	0	0	0	5	9	0	1	1	0	0	1	192
Acute myocardial infarction(AMI)	5	31	1	2	0	0	2	1	0	0	1	0	1	0	44
Other cardiovascular diseases(CVD)	13	6	33	2	0	1	4	4	0	0	0	0	2	0	65
Diabetes	8	3	2	33	0	0	7	5	1	2	0	0	0	0	61
Cirrhosis	0	0	0	0	16	0	5	0	1	0	0	0	0	0	22
Renal failure	0	1	0	4	2	10	5	2	0	6	0	0	0	1	31
Other NCD	12	2	5	3	2	29	121	17	2	15	2	0	1	16	227
Pneumonia	11	3	1	1	0	1	7	36	4	4	0	0	0	0	68
Tuberculosis(TB)	0	0	2	0	0	1	4	12	27	9	0	0	0	2	57
Other infectious diseases	3	0	1	0	2	2	17	6	0	27	0	0	0	2	60
Road traffic accidents(RTA)	0	0	0	0	0	0	0	0	0	0	75	0	0	0	75
Homicide	0	0	0	0	0	0	0	0	0	0	2	24	0	1	27
Falls	1	0	0	0	0	0	1	0	0	0	0	0	14	0	16
All other causes	6	1	0	1	0	0	10	11	5	2	7	2	3	62	110
Total	**232**	**48**	**46**	**46**	**22**	**44**	**188**	**103**	**40**	**66**	**88**	**26**	**21**	**85**	**1055**
Correctly identified by hospital (BRH	173	31	33	33	16	10	121	36	27	27	75	24	14	62	682
Percent correctly certified	74.6%	64.6%	71.7%	71.7%	72.7%	22.7%	64.4%	35.0%	67.5%	40.9%	85.2%	92.3%	66.7%	72.9%	64.6%

Myanmar: Uncertainty in IHD (Males 1990-2010)



*Uncertainty means deaths could be **2%**, or **20%(!)** in 2010*

Source:

Myint S, Lwin A, Lwin K. Community Based Verification of Cause of Death in Pyinmana Township. Myanmar Health Systems Research, 2007.

Comparison of leading causes of death according to ICD (with garbage) and GBD (garbage reallocated) Lists – Males, Egypt 2008

ICD Males

Rank	Percentage	ICD code	Name of category
1	16.7%	I50.-	Heart failure
2	6.4%	I46.-	Cardiac arrest
3	5.3%	R54	Senility
4	5.2%	K72.-	Hepatic failure, not elsewhere classified
5	4.9%	I61.-	Intracerebral haemorrhage
6	4.7%	K74.-	Fibrosis and cirrhosis of liver
7	3.5%	I10	Essential (primary) hypertension
8	2.6%	J96.-	Respiratory failure, not elsewhere classified
9	1.9%	I63.-	Cerebral infarction
10	1.8%	R99	Other ill-defined and unspecified causes of mortality
11	1.8%	I21.-	Acute myocardial infarction
12	1.7%	R09.-	Other symptoms and signs involving the circulatory and respiratory s...
13	1.7%	Y34	Unspecified event, undetermined intent
14	1.6%	I74.-	Arterial embolism and thrombosis
15	1.5%	I70.-	Atherosclerosis
16	1.5%	J18.-	Pneumonia, organism unspecified
17	1.5%	N17.-	Acute renal failure
18	1.4%	C22.-	Malignant neoplasm of liver and intrahepatic bile ducts
19	1.3%	R73.-	Elevated blood glucose level
20	1.2%	N18.-	Chronic kidney disease

GBD Males

Rank	Percentage	GBD code	Name of category
1	6.0%	B05	Cirrhosis of the liver
2	5.0%	B03.3.2	Hemorrhagic and other non-ischemic stroke
3	3.3%	B03.2	Ischemic heart disease
4	2.4%	A15.1.5	Other lower respiratory infections
5	2.1%	B02	Diabetes mellitus
6	1.9%	B03.3.1	Ischemic stroke
7	1.5%	B03.4.7	Other circulatory diseases
8	1.4%	B01.3	Liver cancer
9	1.0%	B09.2.2	Other endocrine, nutritional, blood and immune disorders
10	1.0%	C01.1.1.4	Motorized vehicle with three or more wheels
11	1.0%	B03.4.2	Cardiomyopathy and myocarditis
12	0.9%	B04.1	Chronic obstructive pulmonary disease
13	0.9%	B07.2	Congenital heart anomalies
14	0.9%	A04.1.10	Other diarrheal disease
15	0.7%	A17.1	Preterm birth complications
16	0.7%	B01.4.2	Trachea, bronchus and lung cancers
17	0.7%	B06.11	Other digestive diseases
18	0.6%	B01.19	Brain and nervous system cancers
19	0.6%	B01.24	Leukemia
20	0.5%	B01.18	Bladder cancer

IHME

Global , regional and national assessment of mortality statistics; methods and findings

Data sources used to assess quality and availability of mortality statistics

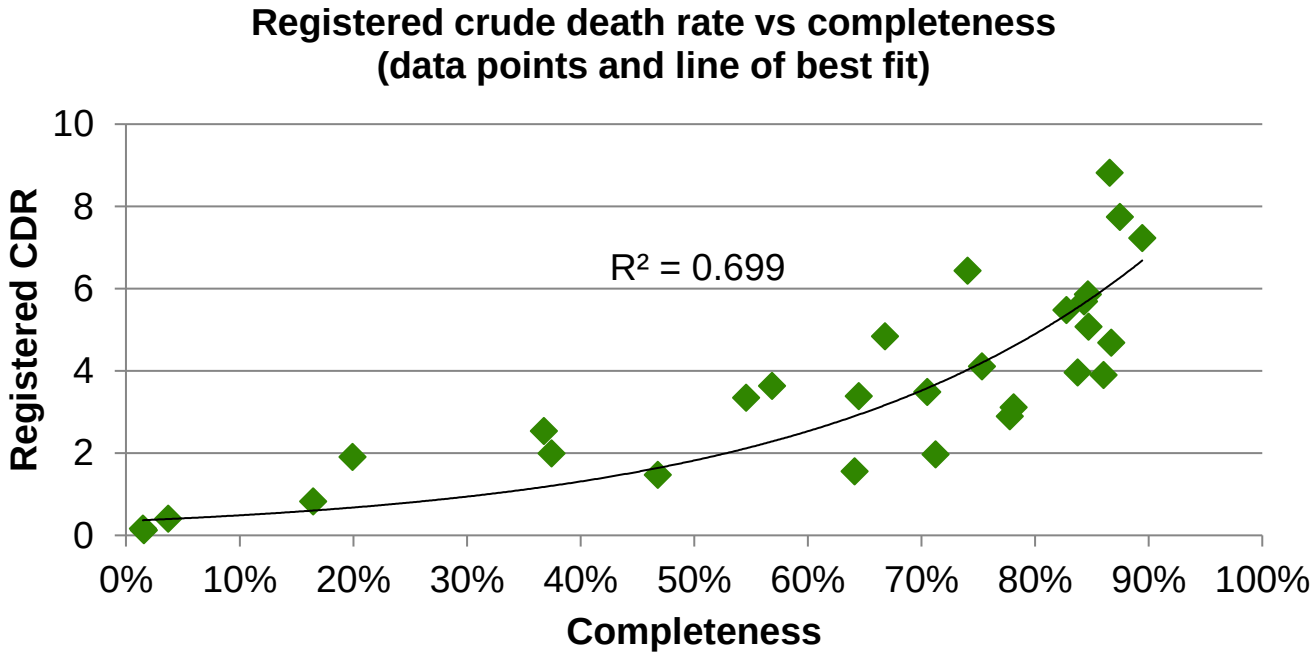
- We based this assessment on the availability and quality of death and cause of death statistics that are:
  - from a ***routine data registration or reporting system*** that aims to count all events within its jurisdiction (e.g. birth or death registration system or hospital death reporting system). This excludes sample registration systems, health and demographic surveillance system (HDSS) sites, surveys and censuses.
  - based on ***events registered with, or otherwise reported to, the government***, compiled by national authorities and which are publicly available either through national reports (e.g. vital statistics reports), international databases (e.g. UNSD database, WHO mortality database), CRVS assessments or made available to the authors by relevant government agencies.

Definitions and calculation: Death Statistics

- Completeness:
  - Registered or reported deaths, measured where possible by year of occurrence.
  - Completeness (calculated separately for males, females and both sexes combined) was estimated primarily using the *empirical completeness method* (Adair & Lopez 2018). In some countries, the GBD or UN World Population Prospects estimated deaths are used to calculate completeness (where, for example, there is high HIV mortality).

- Quality:
  - Availability of registered/reported death data by age of decedent.

Relationship between Registered CDR & completeness; 28 countries with incomplete death registration



Modelling the relationship between the registered CDR & completeness

- The “true” CDR in a population is primarily influenced by two measures:
  - The *overall level of mortality*: can be approximated by using 5q0; widely available and closely correlated to LE
  - The *population age distribution*: based on the demographic observation that death rates and numbers of deaths are much higher at older ages; we use the % of the population aged 65+ as a measure of population ageing

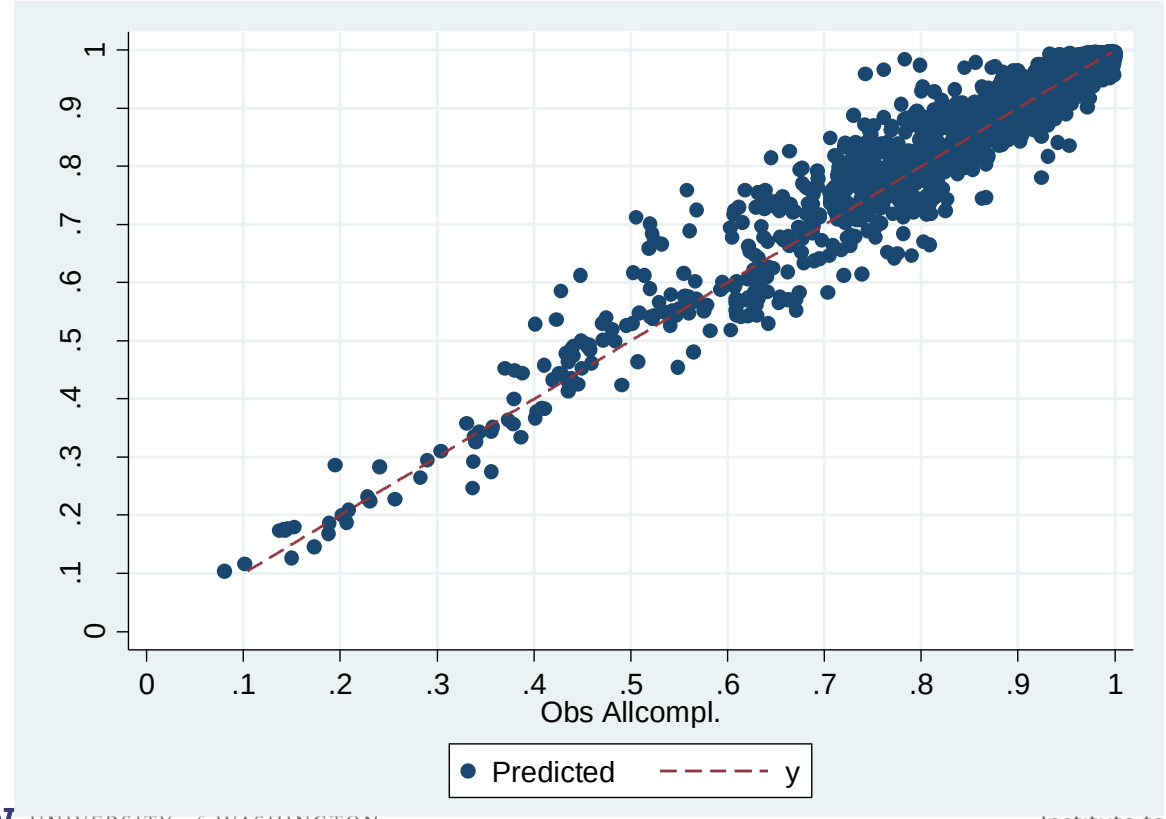
- We fit the following model to estimate completeness:

$$logit(Completeness) = (RegCDR^2 * -0.0187471) + (RegCDR * 0.6125569) + (65plus * -12.58245) + (ln_5q_0 * -1.134923) + (Compl\_{}_5q_0 * 2.319505) + (Year * -0.0184299) + 31.40303 + \gamma$$

Characteristics and inputs for the Adair-Lopez completeness prediction model

- R-squared of 0.85
- *logit (Completeness)* = $ln\left(\frac{Completeness}{1-Completeness}\right)$
- *RegCDR* is the CDR calculated from the registration data
- *65plus* is the fraction (%) of the population aged 65+
- ln_5q_0 is the natural log of the true under-five mortality rate (a measure of the overall mortality level in the population)
- $Compl\_{}_5q_0$ is the estimated proportion of under 5 deaths in the population that are registered.
- Year = cal. year of data; *γ* is country-level random effect.

How does the model perform? Predicted v observed completeness (observed compl. = Reg CDR/True CDR)



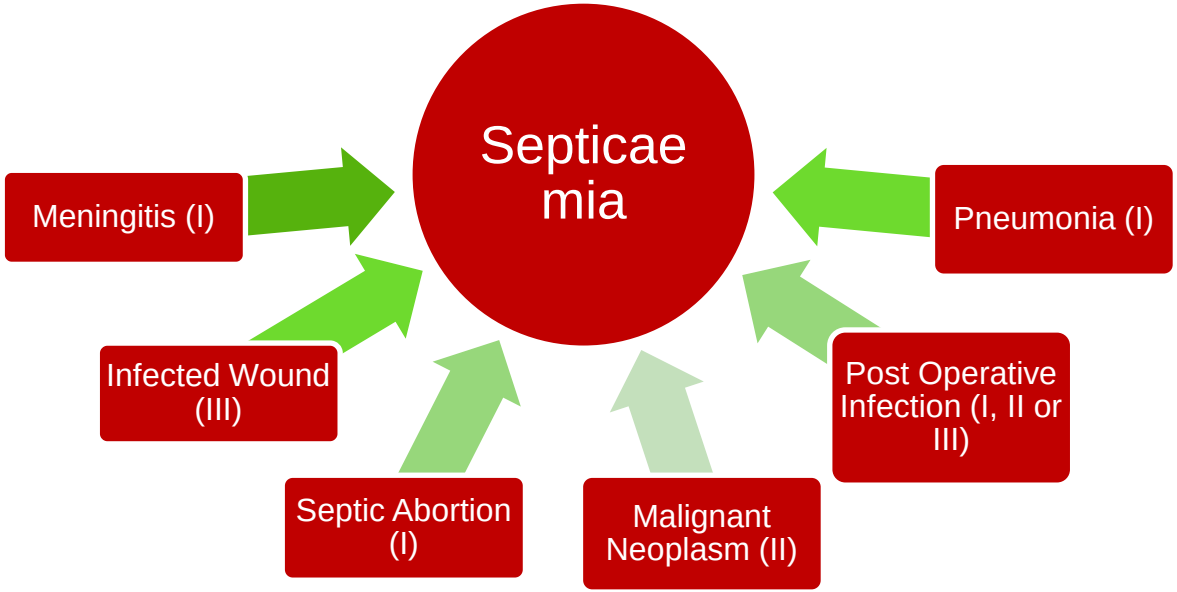
Definitions and methods: cause of death statistics

- Completeness:
  - Deaths where the cause is ascertained using the International Medical Certificate of Cause of Death (MCCOD), as a % of total estimated deaths.
- Quality:
  - % of MCCODs that are assigned ‘garbage codes’ which are classified as having either *very high*, *high* or *medium* severity implications for informing policy (i.e. causes which have have little or no public health value).
  - % of total deaths with a ***usable*** cause; i.e. the % of estimated total deaths that have a cause ascertained using the International MCCOD and where the assigned cause is ***not*** classified to one of *very high*, *high* or *medium* severity garbage.

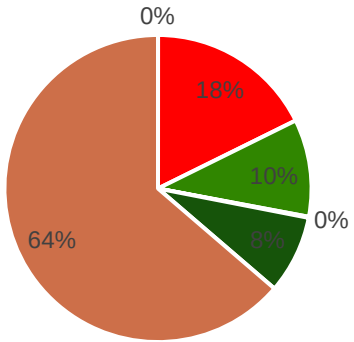
Classification of Garbage Codes based on severity of impact for guiding policy

- *Level 1(Very High):* codes where the misdiagnosis has ***serious*** implications for public health policies (true UCoD could be a Communicable disease, an NCD or an Injury)
- *Level 2 (High):* codes with ***substantial*** implications for guiding public health policy (true UCoD could be any specific cause within any one of these broad categories)
- *Level 3 (Medium):* codes with ***important*** implications for policymaking (true UCoD within a specific Chapter of ICD)
- Lev*el 4 (Low):* codes with ***limited*** implications for public health policies (true UCoD known but could be further specified; eg type of stroke)

Example of Septicaemia (Level 1 GC) as the UCoD : possible underlying causes from unrelated broad cause categories (I – Comm Dis.; II – NCDs; III – Inj.)

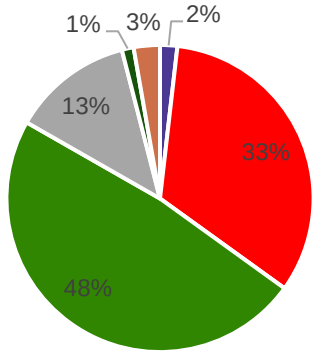


Summary: State of mortality statistics, WHO WPR



- Estimated deaths in countries without death statistics (0%)
- Estimated unregistered deaths in countries with death statistics (18%)
- Estimated registered deaths but no Estimated deaths with MCCOD (10%)
- Estimated deaths with MCCOD but insufficient detail to assess quality (0.1%)
- Estimated deaths with garbage cause (very high, high or medium severity) (8%)
- Estimated deaths with usable cause (64%)

Summary: State of mortality statistics in WHO SEAR



- Estimated deaths in countries without death statistics (2%)
- Estimated unregistered deaths in countries with death statistics (33%)
- Estimated registered deaths but no Estimated deaths with MCCOD (48%)
- Estimated deaths with MCCOD but insufficient detail to assess quality (13%)
- Estimated deaths with garbage cause (very high, high or medium severity) (1%)
- Estimated deaths with usable cause (3%)

Conclusions about mortality statistics worldwide

- Less than ***half of global deaths have a usable cause***, and <5% in Africa and South-East Asia. Both low completeness ***and*** poor MCCOD practices contribute to this problem.
- One in two deaths with an MCCOD in AFR and EMR are assigned an unusable cause of little or no policy value. In SEAR, this proportion rises to five in six, primarily due to lack of detail to assess quality.

- These results are based on publicly available data. While every effort was made to access data, completeness estimates would undoubtedly be higher if additional data compiled by national authorities could have been included.
- Future global and regional assessments would benefit from increased reporting of vital events data to WHO

What can we do to reduce uncertainty and improve the availability and quality of national mortality statistics for planning?

GBD & vital statistics: synergies and importance

- Unquestionable policy and developmental value of having detailed, annual estimates of disease burden in populations, what are the main causes, and how these are changing
- Very significant fraction of DALYs from YLLs (60-70%)
- Very poor CoD data in many parts of the world; thus to improve policy utility of DALYs/GBD, cannot ignore imperative to improve CoD data systems.

Focus on integrating research methods with IT advances (e.g. automated VA), and making CoD data systems more automated and effective (e.g. Myanmar).

Main challenges with civil registration/ vital statistics systems

- Incomplete ***registration*** of deaths (less so for births)
- Poor ***certification*** of the cause of death
- Little or no reliable information on ***causes of home deaths***
- Poor ***availability/timeliness*** of data
- Poor ***use*** of data
- Poor ***understanding*** of the true value of reliable birth, death and CoD data

Vast and unacceptable uncertainty in rankings of leading causes of death and how they are changing

So what can we do about it? How can we rapidly improve the availability and quality of mortality data for health policy making?

- For deaths that occur in hospitals, train doctors in correctly certifying the cause of death using the WHO international Certificate of cause of Death form, and applying ICD rules.
- Introduce training in correctly certifying deaths into medical school curricula
- For deaths that occur outside of hospitals, with limited health care contact, apply automated ‘verbal autopsy’ (VA) methods to diagnose causes of death. Recent research has shown that diagnostic algorithms are more accurate , cheaper, quicker and more cost-effective than doctors in diagnosing causes of death from VA.
- Enormous potential to improve CoD data quality when combined with IT advances.

What can we do to reduce ignorance about who dies of what, especially for home deaths?

Are there alternatives to physician review?

Advances in **VA research** and **IT** have led to the use of **computer algorithms** to analyse VA responses. These use the computational power of computers to recognise patterns in the data between symptoms and specific causes of death

Are computers reliable?

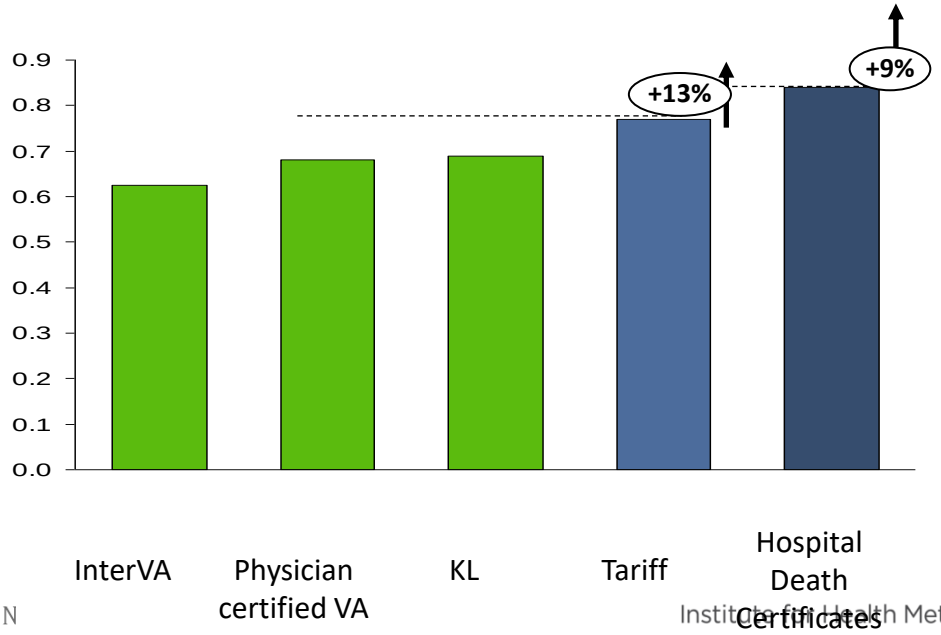
Because the computer methods are **based on data, not the opinion of doctors**, they will always give the same diagnosis for a particular VA questionnaire. Hence **inter-rater reliability is high**

Are computers more accurate than physicians in diagnosing causes of death from VA?

A **scientific test** of different computer methods compared with physician review, using the same VA questionnaires, revealed that almost all of the computer methods were ***more accurate*** than physicians, and that one method in particular, the **"Tariff" method**, performed best in accurately predicting the true cause of deaths in the study dataset

Can computers accurately diagnose the cause of death?

Accuracy of computer methods versus doctors in diagnosing causes of death, i.e. ensuring the cause of death distribution is correct at the ***population*** level



Summary: what do countries need to do to improve their vital registration systems?

- **Improve Medical certification of causes of death by doctors in hospitals**
- **Introduce coding software wherever possible: e.g.**Automated CoD coding software (IRIS) in the Phillipines
- **Trial innovative ways to increase notification of vital events in communities**
- **Increase use of verbal autopsy:** Incorporate automated verbal autopsies into routine CR systems to rapidly improve information on causes of death for home deaths
- **Bulid capacity for and routinely use available data quality assessment tools:** Build capacity and tools for critical appraisal of data quality (ANACONDA for hospital deaths; VIPER for deaths diagnosed by verbal autopsy)