Developing and Populating a User Guidance Template for Multi-Country, Mortality Datasets

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1. Background

Low- and Middle-Income Countries (LMICs) are subject to disproportionately high rates of drowning mortality (e.g. Hyder et al., 2008; Peden & McGee, 2010). Amongst a range of key objectives recommended by the World Health Organisation (WHO) to effectively address this global health issue, is the development of National Water Safety Plans (WHO, 2014). In order to develop such a plan, 'accurate, timely, inclusive' drowning data are first needed, to assess and generate awareness of drowning rates and risk (WHO, 2014, p. 36). This should provide a foundation of robust evidence to inform subsequent drowning prevention policies and interventions, and later, provide a means of evaluating these, once implemented.

Currently, four multi-country mortality databases (with corresponding datasets) documenting global drowning-related data are accessible online for stakeholder use. These are the WHO Mortality Database[1], the Global Burden of Disease (GBD) study[2], the International Disaster Database (EM-DAT) [3], and INDEPTH Network[4]. There is a large body of documentation available online for each of these databases, outlining the caveats of their usage. This includes a range of literature detailing data collection and/or data estimation processes (if raw data are not available), for example, or the validation protocol for the mortality records underlying the dataset.

For the non-expert user, meaningfully interpreting such documentation may pose a substantial challenge. This may prevent their accessing the data, or lead to inappropriate selection and processing of data, with potential impacts for drowning response and prevention decision-making. In order to mitigate this, the current work seeks to identify the strengths and limitations of these four datasets, and present these evaluations as accessible, 'user guidance', to inform stakeholder decision-making regarding dataset adoption. It evaluates these datasets with broad reference to the 'Data Appraisal and Assessment Criteria' developed as Deliverable A1 of the current project.

2. Methodological Approach

In order to develop user guidance articulating the strengths and limitations of the four priority mortality datasets (WHO, GBD, EM-DAT, and INDEPTH Network), a four-stage process was adopted (see Figure 1 below).

[1] WHO Global Mortality Database: http://www.who.int/healthinfo/mortality_data/en/
[2] Global Burden of Disease Study: http://www.healthdata.org/gbd
[3] The International Disasters Database: http://www.emdat.be/
[4] INDEPTH Network: http://www.indepth-network.org/about-us

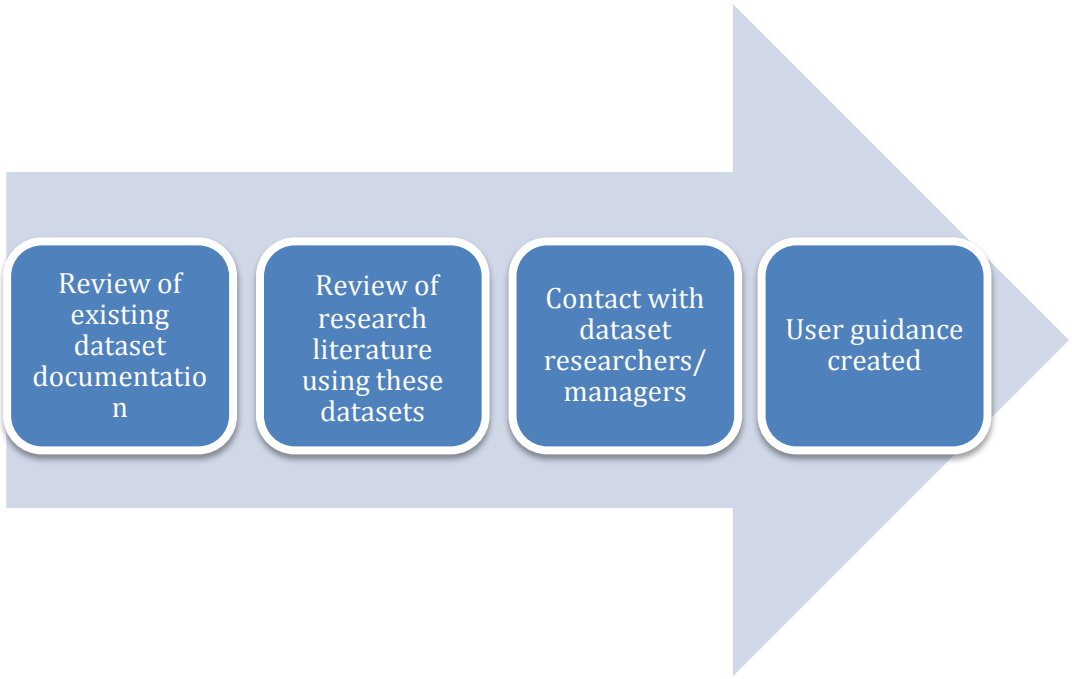

Figure 1. Approach to creating user guidance for four priority mortality datasets

Stage 1 - Review of existing dataset documentation

An extensive review of the documentation provided online for each of the four priority datasets was conducted. This involved a comprehensive search of each database's parent site (e.g. in the case of the EM-DAT, all documentation provided at 'http://www.emdat.be/', was accessed), and synthesis of all relevant material identified (e.g. EM-DAT's 'Explanatory Notes' section). Material was considered relevant if it related to the 'Data Appraisal and Assessment Criteria' developed as Deliverable A1 of the current project, and deemed suitable to potentially inform accessible strengths and limitations of the relevant dataset.

Stage 2 - Review of research literature using these datasets

Similarly, an extensive review of published research literature, drawing from these datasets, was conducted. Within these studies, authors may identify strengths and limitations of the datasets, and these reflections can inform the current work. The literature reviewed primarily consisted of epidemiology studies (e.g. De Roos, 2015; Sankoh & Byass, 2012). Again, material was considered relevant for incorporation in the synthesis if it related to the 'Data Appraisal and Assessment Criteria', and was deemed appropriate to inform stakeholder usage considerations.

Stage 3 - Contact with dataset researchers/managers

Last, those involved in the maintenance of each of the four priority datasets were contacted with requests for clarification/confirmation regarding any inconsistent/unclear findings documented during the review process (e.g. a request for their working definition of a 'drowning' fatality was emailed through INDEPTH's online query

function). Any clarifications deemed relevant to the strengths and limitations of the datasets reviewed were incorporated into the final synthesis.

Stage 4 - User guidance created

Based on the synthesised findings of the three stages, user guidance, with a focus on the strengths and limitations for each of the four priority data sources, was created. For each source considered, an overview and detailed description of its specific means of capturing drowning data (given the importance of this for the current report and project) was first outlined. The key (i.e. most important) strengths and weaknesses for the particular data source are then described. Last, a summary table, contrasting the strengths and weaknesses of all four data sources across the characteristics of drowning data captured, data coverage and completeness, quality, and accessibility is then provided.

1. World Health Organisation Mortality Database

Overview

The World Health Organisation (WHO) Mortality Database is the largest repository of international data on causes of death. It documents mortality data by sex, age and cause of death from 1950 to date, as reported annually by >100 WHO member states from their civil registration systems. Access to the user-friendly, online database, corresponding basic data extraction tool (the 'Cause of Death Query Online', or 'CoDQL'), and country-level, aggregate microdata underpinning these tools, is all provided on the WHO Mortality Database website.

The WHO Mortality Database aims to present detailed mortality data in a user-friendly, accessible way to international users. It does so to achieve the overall aim of the WHO, which is to combat disease and premature death through improving equity in health, reducing identified health risks, promoting healthy lifestyles and settings, and responding to the underlying determinants of health.

Drowning Data Characteristics

The data available in the WHO Mortality Database comprise deaths registered through national vital registration systems. The underlying cause of death is coded by the relevant national authority in accordance with the latest version of the International Classification of Disease (ICD) rules. Regarding drowning deaths, the latest ICD version, the ICD-10[5], distinguishes between drowning fatalities by the nature of the body of water (e.g. a bathtub versus a swimming pool), and the mechanism of drowning (e.g. while in water versus following a fall into water).

When using the online database, 'Accidental drowning and submersion' can be selected as a cause of death sub-group (under 'No. of deaths - External causes'). This

[5] Equivalent datasets with ICD-7, ICD-8, and ICD-9 coding are also available on the WHO Mortality Database webpage.

incorporates all accidental drowning codes from (ICD-10 codes W65-W74, see Table 1 below).

Table 1. *Accidental drowning and submersion codes specified by the WHO online database*

ICD-10 Code	Description
W65	Drowning and submersion while in bath-tub
W66	Drowning and submersion following fall into bath-tub
W67	Drowning and submersion while in swimming pool
W68	Drowning and submersion following fall into swimming-pool
W69	Drowning and submersion while in natural water (incl. lake, open sea, river, stream)
W70	Drowning and submersion following fall into natural water
W73	Other specified drowning and submersion (incl. quenching tank, reservoir)
W74	Unspecified drowning and submersion (incl. drowning NOS, fall into water NOS)

The CoDQL and WHO microdata allow the user to select any desired codes however, and as such, can also incorporate codes for drowning by suicide (e.g. X71 'Intentional self-harm by drowning and submersion'), assault (X92 'Assault by drowning and submersion'), transport accidents (V90 'Accident to watercraft causing drowning and submersion', and V92 'Water-transport-related drowning and submersion with accident to watercraft'), or undetermined drowning deaths (Y21 'Drowning and submersion, undetermined intent'). Codes for death due to extreme environmental incidents (e.g. X38 'Victim of flood'), which may potentially include drowning related deaths, can also be selected (although these do not relate to drowning alone).

Key Strengths and Weaknesses

Key strengths of the WHO Mortality Database include that it is the sole multi-country data source to use only medically-certified data, with detailed microdata freely available for immediate download. It is also the only multi-country mortality data source to capture drowning-specific data in relation to accidental, intentional, water transport and undetermined/unspecified incidents. Similarly, it is the only data source to capture information relating to the nature of the body of water the fatality occurred in, and the mechanism of drowning. This level of detail is very beneficial when designing targeted drowning prevention measures.

Not all countries provide data to the WHO however (the list of countries who do are available on the WHO database website), and these countries are not included in the dataset. Also, the microdata provided consists of large, complex datafiles, which require expertise in data processing, and software (e.g. SPSS, Stata) to manage and analyse, which may be beyond the average user.

2. Global Burden of Disease Study

Overview

The Global Burden of Disease Study (GBD) is the most comprehensive observational epidemiological study conducted worldwide to date, and is coordinated by the Institute for Health Metrics and Evaluation, in Seattle, Washington. Through their online Global Health Data Exchange platform (GHDx), it provides mortality and morbidity estimates compiled by over 1,800 collaborators, for over 300 diseases, injuries and risk factors in 188 countries, from 1990 to 2015.

It aims to promote an understanding of the differing health challenges, and their impacts, being experienced across the world in the 21st century. It strives to provide results that can be used by policymakers, health professionals, and funding agencies to identify priorities for improving the health of the world's populations.

Drowning Data Characteristics

Cause-specific mortality estimates from the GBD are generated based on researcher synthesis of extensive country/region-specific data, including vital registration statistics, census data, surveillance systems, to hospital data. This synthesis is then used to inform mathematical estimates of different mortality/morbidity-related variables, such as Disability-Adjusted Life Years (DALYS; the sum of years lost due to premature death, and years lived with disability), using various established statistical techniques. Cause of death data in the GBD is categorised under the following three main groupings, typically mapped from ICD codes provided by data sources:

Group 1) Communicable, maternal, neonatal, and nutritional diseases,
Group 2) Non-communicable causes,
Group 3) Injuries.

'Drowning' deaths are documented as such, under the sub-group 'Unintentional Injuries' within the broader category of Group 3, 'Injuries'.

Key Strengths and Weaknesses

Key strengths of the GBD data include that best practice mathematical modeling methods are used to provide detailed mortality estimates (including drowning deaths) for 188 countries worldwide, even those with little to no source data. Predominately established data sources inform GBD data and estimates, and undergo extensive screening and adjustment processes by experts prior to publication (described in detail in a GBD protocol available on the GBD website).

Estimated mortality data cannot be fully accurate however, nor can they be validated. The margins of error associated with GBD data are also not a default setting for the highly accessible visualisation tools provided on the GBD website, which could mislead potential users regarding the quality of the data. In terms of drowning data, the GBD solely captures accidental drowning deaths without any information regarding the nature

of the body of water the drowning death occurred in, or mechanism of drowning. Last, GBD microdata are not available in real-time, and GBD models and data are updated in regular intervals meaning that previous GBD publications and datasets cannot be compared.

3. EM-DAT

Overview

The International Disaster Database (EM-DAT) is maintained by the Centre for Research on the Epidemiology of Disasters (CRED), at the School of Public Health of the Université Catholique de Louvain, in Brussels, Belgium. It contains core data on the occurrence and impacts of >22,000 natural and technological disasters, from 1900 to date.

CRED's key objectives in maintaining this database are to:

- aid humanitarian action at national and international levels.
- inform evidence-based decision-making for disaster preparedness.
- provide an objective foundation for vulnerability assessment and priority setting.

Drowning Data Characteristics

Across an array of disaster categories, EM-DAT documents fatalities and injury data on water-related disasters, in which drowning data are captured. A disaster is categorised here as involving one or more of the following:

- 10 or more individuals deceased.
- 100 or more individuals affected.
- The declaration of a state of emergency.
- A call for international assistance.

EM-DAT's approach to categorising water-related disasters is outlined in table 4.

Table 2. *EM-DAT categorisation of water/drowning-related disasters*

Disaster Sub-group	Disaster Type	Disaster Sub-type
Hydrological disaster	Flood	Coastal flood
		Riverine flood
		Flash flood
		Ice jam flood
	Landslide	Avalanche (snow, debris, mudflow, rock fall)
	Wave Action	Rogue wave
		Seiche
Geophysical disaster	Earthquake	Tsunami
	Volcanic Activity	Lahar
	Glacial Lake Outburst	
Technological disaster	Traffic Accident	Water

Of note, drowning-specific deaths cannot be isolated from these data, as all deaths/injuries resulting from the specific disaster are aggregated.

Key Strengths and Weaknesses

EM-DAT is the sole database to capture detailed mortality data in relation to global, water-related disasters. Very limited evidence surrounding the epidemiology of drowning due to natural disasters is currently available. As such, this dataset is of unique importance to those seeking to design preventative/preparedness measures in LMICs prone to water-related disasters. It is regularly updated (every three months, once data has been cross-checked and validated) to ensure up-to-date coverage of disasters is provided.

The majority of drowning fatalities do not occur as a result of disasters however, and as such, this database is not useful if seeking to design national drowning prevention measures. Also, although deaths due to water-related disasters are captured by EM-DAT, it is not possible to isolate drowning-specific fatalities from the aggregate data provided. Similarly, key mortality and demographic variables (e.g. age and gender) are not reported. Access to the raw data provided to EM-DAT staff may be required for these data, which involves an online request process, with no time schedule provided. Last, it should be noted that EM-DAT data are collated from a series of sources, including media reports, which typically do not retain reliable information. Little detail regarding how these data are screened and processed prior to data entry is available on the database.

4. INDEPTH NETWORK

Overview

Established in 1998, the INDEPTH Network of Health and Demographic Surveillance Systems (HDSS) documents the lives of over 4 million people, across 47 research centres, in 20 countries in Africa, Asia and Oceania. Their INDEPTH Data Repository contains an online archive of (to date) 68, high-quality, longitudinal datasets from various compilations of member HDSS centres. Summary statistics from these are available through INDEPTHStats, a platform developed by the INDEPTH Network for visualising key demographic indicators.

The INDEPTH Network's goal is to enable member HDSSs and associated researchers, to contribute to and share high-quality HDSS datasets with the scientific community, and translate INDEPTH's research findings into policy and practice.

Drowning Data Characteristics

Deaths, including drowning deaths, are routinely registered at HDSS sites, and followed-up with standardised Verbal Autopsies (VA; see WHO, 2012, and 2016), involving a structured interview regarding the death, typically with a family member. The VA report is then computer-processed (with the validated program InterVA-4) to identify and code the cause of death, based on the information collected, and link this to the individual's

longitudinal data. Drowning incidents are coded per the WHO VA instrument (2012, 2016) as code 12.04 ‘Accidental drowning and submersion’.

Key Strengths and Weaknesses

INDEPTH data are uniquely collected in remote rural districts and informal urban settlements (consisting, on average, of 60,000 people) throughout Africa, Asia and Oceania, where morbidity and mortality trends are typically ignored/undocumented. Within the defined populations in which HDSS data are collected, INDEPTH Network data are considered to present the most reliable, complete mortality data for this population, particularly when considering that these data are consistently collected over a series of years. Established VA tools are used to collect these data.

The data collected are not nationally representative however, and as such, cannot be used to derive a national drowning burden. Also, in terms of drowning data, the INDEPTH Network solely captures accidental drowning deaths, without any information regarding the nature of the body of water the drowning death occurred in, or mechanism of drowning. Cause-of-death (e.g. drowning) data are also not available on the INDEPTHStats visualisation tool. Drowning-specific data are only available through INDEPTH Network microdata, which involves an online request process, without a time schedule.

Table 3. *Summarised strengths and limitations of the mortality data provided by the WHO Mortality Database, GBD Study, EM-DAT and INDEPTH Network*

	WHO Mortality Database	GBD	EM-DAT	INDEPTH Network
Drowning Data Characteristics	Drowning-specific deaths are documented under ICD-10 drowning codes, including V90, V92, W65-W74, X71, X92 and Y21. These codes capture deaths due to water transport, accidental, intentional and undetermined drowning incidents. Deaths due to water-related environmental incidents (e.g. X38 - Victim of flood) are also documented, but drowning-specific fatalities cannot be extracted from these data.	'Drowning' specific deaths are documented as such under the variable 'Unintentional Injuries', within the broader category of 'Injuries'. Drowning deaths due to water transport, intentional (i.e. by suicide, or assault), unspecified or environmental (e.g. due to floods) incidents cannot be extracted from GBD data.	Deaths due to water-related disasters (e.g. tsunamis) and that meet EM-DAT disaster criteria (e.g. 10 or more individuals deceased) are captured. Drowning-specific deaths cannot be isolated within these data however.	Drowning-specific deaths are documented under the variable 'Accidental drowning and submersion'. Drowning deaths due to water transport, intentional (i.e. by suicide, or assault), unspecified or environmental (e.g. due to floods) incidents cannot be extracted from INDEPTH Network data.
	The ICD-10 codes also capture the nature of the body of water (e.g. W65 - Drowning and submersion while in bath-tub) and the mechanism of drowning (e.g. W70 - Drowning and submersion following fall into natural water) of a fatal drowning incident.	The nature of the body of water relating to the fatal drowning incident, and mechanism of drowning are not captured.	The nature of the water-related disaster is recorded (e.g. flood, tsunami). The nature of the body of water relating to the fatal drowning incident, and mechanism of drowning are not captured (as drowning-specific data are not documented).	The nature of the body of water relating to the fatal drowning incident, and mechanism of drowning are not captured.

	WHO Mortality Database	GBD	EM-DAT	INDEPTH Network
Data Coverage and Completeness	A complete list of the countries (>100) for whom medically-certified mortality data are available since 1950, is provided on the WHO Mortality Database website.	The GBD provides estimated mortality data for 188 countries, listed on the GBD website, from 1990-2015.	EM-DAT provides mortality data for >22,000 global disasters (including water-related disasters) from 1900 to the time of writing. These are identified in the 'Disaster List' section of the database.	A complete list of the 47 sites for whom longitudinal data are available (predominately in LMICs), is provided on the INDEPTH website.
	Not all countries send data to the WHO, and some send it in a format rendering it unsuitable for use. Also, some do not report corresponding population data (for calculating prevalence, e.g. deaths per 100,000 population), so UN population data are used.	For countries with little to no observed mortality data (and/or population data) mathematical modes are used to generate estimates based on neighbouring countries. These estimates have margins of error associated with them however, which must be acknowledged.	It is not clear what proportion of global disasters (including water-related disasters) is actually captured by EM-DAT. Corresponding population data for the region impacted is not provided.	The INDEPTH Network only provides data for the sites it covers, which are not deemed to be nationally representative. Links to corresponding data sources (e.g. national census data) for comparison are provided on the INDEPTH website.
	Measures of WHO data coverage and completeness are provided on the WHO Mortality Database website.	Estimated measures of data completeness, and representativeness are listed on the GBD website.	It is not clear what proportion of global disasters (including water-related disasters) is actually captured by EM-DAT.	The INDEPTH Network only provides data for the sites it covers, which are not deemed to be nationally representative.
	The level of data coverage and completeness reported varies from country to country, and must be acknowledged when assessing data suitability.	The data completeness and representativeness reported varies from country to country, and must be acknowledged when assessing data suitability.	Non-disaster-related drowning fatalities are not captured by this database/dataset.	When using Verbal Autopsies a small portion of deaths in a site will always be impossible to follow-up on (e.g. due to lack of witnesses to interview).

	WHO Mortality Database	GBD	EM-DAT	INDEPTH Network
Data Quality	Only medically-certified, nationally registered deaths are included in the WHO Mortality Database.	Predominately established data sources (e.g. vital registration data, census data) listed on the GBD website and best practice modeling techniques create GBD data and estimates.	EM-DAT data are collated from UN agencies, NGOs, insurance companies, research institutes and media reports, and is cross-checked extensively by the EM-DAT team.	Standardised Verbal Autopsy (VA) instruments and the InterVa-4 program are used to provide consistent, validated cause of death coding across the fatalities documented.
	Accuracy in cause of death coding may still vary from country to country, due to biases in coders (e.g. not wanting to record a death as a suicide) or mis-coding. ICD coding schemes have also changed from ICD-1 to ICD-10 since 1948, becoming more detailed. As such, caution is needed when making historical trend comparisons.	Any estimated mortality data cannot be fully accurate, nor can they be validated. This also includes the estimated uncertainty levels (error margins). In addition, accuracy in cause of death coding may still vary from country to country, due to biases in coders (e.g. not wanting to record a death as a suicide) or mis-coding.	Given the varied nature of the data sources for this database (e.g. media reports, which frequently report errors) EM-DAT provide a disaster record reliability score, which must be acknowledged.	Biased or insufficient recall from family interviews when using a VA tool may influence coding accuracy and quality.
	Little detail regarding the WHO data screening/ entry protocol is provided online. The percentage of ill-defined (‘dump’ or ‘garbage’ codes) per member states is listed on the website.	Raw, GBD source data undergo screening and preparation processes by experts, including redistribution of codes to correct for errors and biases. A detailed GBD protocol is provided on the website.	Little detail regarding the EM-DAT data screening/ entry protocol is provided online.	A rigorous dataset screening/quality approval protocol is observed (and described on the INDEPTH website) for INDEPTH Network datasets before publication, including staged checks for data errors.

	WHO Mortality Database	GBD	EM-DAT	INDEPTH Network
Data Quality (contd.)	Key mortality and demographic variables (e.g. age and gender) are included in the WHO Mortality Database (and datasets), and a detailed data dictionary is provided for all variables listed.	Key mortality and demographic variables (e.g. age and gender) are included in GBD data, and a detailed data dictionary is provided for all variables listed. These are provided in line with the best practice Guidelines for Accurate and Transparent Health Estimates Reporting (GATHER).	Key variables (e.g. the type, name, timeline of the disaster, no. of deaths and injuries) are included, for which a detailed data dictionary is provided. Key mortality and demographic variables (e.g. age, gender, specific cause of death) are not provided however (access to microdata may be required for this).	Key mortality and demographic variables (e.g. age and gender) are included in the INDEPTH Network datasets, and a detailed data dictionary is provided for all variables listed.
	Age standardised death rates are calculated and included to facilitate mortality comparisons across countries, and time periods.	Age standardised death rates are calculated and included to facilitate mortality comparisons across countries, and time periods.	It is not clear what demographic information is captured by EM-DAT (access to microdata may be required for this).	The use of age-sex-year standardisation (using the INDEPTH standard population) facilitates comparison across sites and time periods.
	Countries typically submit data to the WHO within 12-18 months after the closure of their records for the calendar year, and there is a further delay for processing before the WHO publish the data online.	GBD models and data are updated in regular 'rounds' (e.g. GBD 2010, GBD 2015). This means that previous GDB publications and datasets cannot be compared however.	EM-DAT is updated internally on a daily basis, with publically accessible information being updated every 3 months, once all data has been cross-checked and validated using different sources.	It is unclear how often surveillance data are recorded/updated, and how long before this is published on the INDEPTH website. Different surveillance sites also cover different time periods.

	WHO Mortality Database	GBD	EM-DAT	INDEPTH Network
Data Accessibility	An online visualisation tool (providing tables and figures), and CoDQL (basic data extraction tool) provide aggregate mortality data including variables such as cause of death, age, gender and location in-real time. Detailed user guidance is provided for both.	A series of online visualisation tools (providing tables, figures and maps) and GBD Results tool (basic data extraction tool) provide aggregate mortality data including variables such as cause of death, age, gender and location in-real time. Detailed user guidance is provided for both. Default settings for these tools do not show margins of error.	The online database (providing tables, figures, maps, downloadable CSV files) provides aggregate mortality data including variables such as disaster type, location, total injuries and those made homeless through a series of interfaces. Brief user guidance is provided to use these.	INDEPTHStats is an online visualisation tool which provides aggregate mortality data including variables such as age, gender, site location and country in real-time. Data for cause-specific deaths cannot be selected using INDEPTHStats at present. Detailed user guidance is provided for this.
	Detailed microdata (including 2015 data) are available for immediate download online.	Access to certain GBD microdata is available through the GHDx platform. In addition, some GBD microdata require a registration/application process, and some require fees. No time schedule for accessing these is provided.	Access to more detailed microdata is solely available through an online request procedure, where applications are reviewed by the team on a case-by-case basis (with no time schedule provided).	Access to more detailed microdata is solely available through an online request procedure on the INDEPTH Data Repository, where applications are reviewed by the team on a case-by-case basis (with no time schedule provided).
	The microdata are very complex, large files, which require expertise in data processing and software to manage and analyse.	The microdata vary, but are relatively large files, which require some expertise in data processing and software to manage and analyse.	It is not clear how complex the microdata are, as access to them is restricted.	It is not clear how complex the microdata are, as access to them is restricted.

Closing Remarks

Each dataset has unique strengths and limitations, which, depending on the needs and standards of the user, can be used to determine the optimal dataset(s) for their work. The guidance presented in this report can be used to inform this decision.

Of note, during the course of the current project, requests for microdata were sent to the GBD, EM-DAT and INDEPTH Network in February, 2017. Responses to these requests have not yet been received. As such, for those seeking to use drowning microdata within a rapid timeframe, the WHO dataset may represent an optimally accessible option.

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