Identifying and understanding the problem

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Using epidemiological principles to assess impacts of emergencies and disasters

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2.1.1 Learning objectives

To understand how data can be gathered for epidemiological research in emergencies and disasters in order to assess the risk factors and health consequences, including:

1. Sources of vulnerability and exposure to hazards.
2. Impacts of disasters on mortality and morbidity.
3. Sources of data and databases that are available for epidemiology research.
4. Value of surveillance mechanisms for epidemiological studies of disasters.

2.1.2 Introduction

To adequately describe a disaster, or any other significant health event, requires some quantification of the scale of its impact on humans and society at large: we need to describe how people's health is affected by such events and analyse the causes of those effects. Without this understanding of the problem, we are not equipped to develop targeted measures – in health and other sectors – to reduce risks before, during and after emergencies.

Epidemiological studies can help us with this by investigating the distribution and determinants of health or disease. Epidemiological studies may also identify ways to prevent diseases and other health problems at source, to control them or to mitigate their effects. Ideally, studies should investigate the long-term impacts of disasters, but this is rare, with most studies focusing on the immediate effects (typically those during the first year).

Applying the principles of epidemiology to the study of the determinants and the effects of disasters on human populations is crucial. It provides some of the evidence base for effective health emergency and disaster risk management (Health EDRM), and it includes assessment of the adverse health effects of disasters, analysis of the risk factors that affect exposure and vulnerability to hazards, and of the capacities of individuals, communities and institutions to manage these risks. The aim of such analyses is to inform preparedness and response efforts, recovery strategies and – crucially – to help to explain, predict and mitigate the consequences of future disasters by allowing the development of targeted measures to prevent and reduce hazards as well as the exposures and vulnerabilities of populations at risk.

Epidemiology is a vital tool for situational awareness, which in disaster settings provides much needed information to allow the identification of population needs, plan a response and gather appropriate resources. The main objectives of disaster epidemiology are therefore:

- to prevent or reduce the number of deaths, illnesses, and injuries caused by disasters;
- to provide timely and accurate health information for decision-makers and practitioners to improve risk assessments, prevention, mitigation, preparedness, response and recovery strategies;
- to provide a fundamental body of evidence on the health impacts of disasters that can be used for research and evaluations *(1).*

WHO estimates that, in the last decade, more than 2.6 billion people have been affected by disasters such as earthquakes, tsunamis, landslides, cyclones, heat waves, floods, or severe cold weather *(2)*. This chapter outlines some of the methods that may be used to arrive at such a figure and to study the factors that contribute to this burden.

Disasters may lead to displacement of populations, disruption to health systems and damage to health infrastructure. Each of these has consequences for public health, including increased mortality, deteriorating mental health, outbreaks of infectious diseases and acute malnutrition. Such consequences are all more severe when people are living in high density, frequently temporary settlements with insufficient food, water, housing or sanitation *(3–5)*. Furthermore, displaced people are at increased risk of violence, including sexual and gender-based violence.

A range of expertise is needed to manage the risks of a variety of public health problems. These include specialists in vaccine-preventable and other infectious diseases, water, sanitation, and hygiene (WASH), nutrition, injury, sexual health, and mental health — as well as leaders, managers, emergency service personnel, risk communicators, logisticians, and evaluators in health and other sectors. Identifying the different health impacts of disasters and the causes of these impacts may require a similarly broad range of methods. Using epidemiological principles to underpin surveillance for research in disaster settings is largely contingent on recognizing opportunities when they occur to collect actionable information that can be used for developing or evaluating interventions to preserve health and save lives (for example, identifying the first cases of measles or diarrheal disease in a camp).

Epidemiological assessments might involve analysing risk factors and studying health outcomes, but the tasks required for this are rendered especially complex because of the involvement of many different agencies, using non-aligned data collection systems. Furthermore, data may be collected, collated or stored at some distance from the location of the initial disaster. These challenges need to be considered carefully when designing an epidemiological study — and are discussed in this chapter. Some of the key techniques for disaster epidemiologists include assessments of need (which may require rapid assessment), health surveillance, the use of registries of affected individuals and assessment of outbreaks and other cascading hazards that may follow the initial event.

2.1.3 Rapid needs assessments

One of the key pieces of epidemiological research to undertake — and one that is normally applied in a sudden-impact emergency and disaster situation — may be to assess the immediate impact on the health of the affected population and their consequent healthcare needs.

Rapid needs assessments employ survey and population sampling methods to determine the health status and basic needs of those in the area affected by a sudden-impact disaster. The use of appropriate sampling provides epidemiological rigour and a rationale on which to base planning, operational response and resourcing decisions. Care must be taken to ensure that the population sampled is truly representative of the wider population for whom the findings will be extrapolated. Furthermore, because limited comprehensive information is typically available on the consequences, scale and severity of the disaster at the time of impact, the use of reliable epidemiological methods may be important in preventing undue reliance on data gathered by responders who may be working independently or without coordination. Nonetheless, the purpose of the rapid needs assessment is to provide an opportunity to collate what data might be available, even if such informal data gathering may result in assessments that are incomplete, conflicting or unreliable.

One of the survey tools that might be used to gather data for epidemiological research is the Multi-Cluster/Sector Initial Rapid Assessment (MIRA). This was developed by the Inter-Agency Standing Committee (IASC)'s Needs Assessment Task Force (NATF) and is an example of a system to facilitate a rapid needs assessment. It seeks to address the problem of conflicting findings from needs assessments conducted by different crisis responders within and between sectors *(6)*.

A MIRA can be carried out jointly by key stakeholders in a short period of time (days or weeks) and aims to provide a foundation of commonly understood information about the affected population and their needs. It may also support the identification of information sources in the early stages of the process, which can be used to support prioritization of the humanitarian response and immediate development of a strategy through three components:

i) The systematic collation and analysis of secondary data, which may initially be the only information available and which were collected for other reasons — epidemiological methods can be used to analyse these data in order to describe the extent of the disaster, the number of affected people and places, and allow articulation of immediate priorities, bearing in mind the identified hazards and risk factors.

ii) Community level assessment, which is a standard approach for collecting and analysing new or primary data — this allows agencies to integrate the needs and priorities of affected communities into the broader assessment of strategic humanitarian priorities. Such community level assessments are limited to those communities that can be found or accessed and as such must be considered in the context of the secondary data analysis noted above.

iii) Collation and analysis of all data and information following an agreed structure, which analyses and describes the primary and secondary data obtained by all agencies or responders.

2.1.4 Health and health facility surveillance

Many countries have their own national or regional systems for health surveillance, which are vital during outbreaks, disasters from natural and technological hazards, and conflicts. In public health, this surveillance includes the systematic collection, analysis and interpretation of health-related data for the planning, implementation, and evaluation of public health practice. Such surveillance can serve as an early warning system for an impending outbreak, help target response efforts, document the impact of an intervention, monitor and clarify the extent of health problems and allow priorities to be set and public health policy and strategies to be implemented based on quantitative evidence. For example, surveillance of vaccine-preventable diseases, such as measles, is vital for managing a potential outbreak, as well as in disaster or conflict settings, in order to understand the functioning of the wider health system and recognize weaknesses early.

Disasters and other complex emergencies often increase the risk of transmission of infectious diseases and make other health problems (such as severe malnutrition) more likely. An effective disease surveillance system is essential to detecting disease outbreaks quickly before they become difficult to control. However, if the routine system is adversely affected by the impact of the disaster or is not designed to gather information relating to the health consequences of the hazards that led to the disaster or arise in its aftermath, a more specialized system may be needed.

A recent example of the development of one such specific surveillance tool is WHO's Early Warning, Alert and Response System (EWARS) (see Case Study 2.2.1). This was designed to improve disease outbreak detection in emergency settings, such as in countries experiencing an outbreak in another part of the country, in conflict or following a disaster caused by natural hazards *(7)*.

'EWARS in a box' was developed by WHO to strengthen the gathering of health data in outbreaks, disasters and other emergencies, and may provide an important means of gathering the data needed for epidemiological research. It is an emergency kit containing the equipment needed to rapidly establish early warning, alert and response activities, particularly in difficult and remote field settings without reliable internet or electricity. It has been used across the world, including in the response to cyclone Idai in the Republic of Mozambique in 2019 *(8)*.

The box contains 60 mobile phones, laptops and a local server to collect, report and manage disease data. A solar generator and solar chargers allow the phones and laptops to be powered without mains electricity. Each health facility can be allocated a mobile phone with a disease reporting app that will allow health workers to enter data on patients with symptoms of priority diseases or conditions such as acute diarrhoea, cholera, measles, acute flaccid paralysis, fever, malaria and jaundice. The app uploads the information to a server, where the data is used to generate real-time reports. This allows a rapid response to emerging diseases as well as allowing aggregated reports from health facilities, automatic triggering and investigation of alerts, collation of lists of all known and suspected cases (line lists) during outbreaks and recording of verification and risk assessment activities.

Where possible, health surveillance should rely on existing systems and processes as, when these are functioning, they can provide the most reliable and timely information (*9–10*). Such systems gather information on a routine basis from hospitals, primary care settings and laboratories, but may need amendments or augmentations to enable them to rapidly detect diseases of the highest priority and consequence in a disaster, which may differ markedly from those the systems were established to detect.

Healthcare surveillance systems make it possible to measure demand for services and identify where emergency or other healthcare resources may become stretched or overrun. Syndromic surveillance systems (see Chapter 4.9), such as England’s National Ambulance Surveillance System, can be used to reveal early information about unfolding incidents and outbreaks *(11)*. Monitoring of calls to poison centres may allow identification of public exposure or concern about chemicals or other environmental hazards *(12)*.

However, although such systems may be a feature of high-income countries, they may not be in place in some low- and middle-income countries, or they may be particularly susceptible to the impact of disasters on staffing and infrastructure. For example, recurring outbreaks in the African region have led to recognition of the need for outbreak response tools that can be implemented during complex emergencies when existing national public health surveillance systems may be underperforming, disrupted or non-existent. Existing national public health surveillance systems may quickly become overwhelmed and unable to meet the surveillance information needs of a large-scale outbreak, conflict or disaster. In addition, existing tools may not be sufficiently comprehensive, or address requirements in the field during emergencies, which can lead to proliferation and fragmentation of data collection at the frontline. This can make it especially important for those designing epidemiological research to take particular account of the quality of the data, and decide whether the data from routine health and health facility surveillance systems is sufficiently reliable.

To illustrate how epidemiological research needs to use methods that supplement routine data, Case Study 2.1.1 describes how a variety of epidemiological studies were used to estimate the number of deaths caused by Hurricane Maria in Puerto Rico.

Case Study 2.1.1
Mortality estimates from Hurricane Maria in Puerto Rico

Puerto Rico is a part of the USA in the northeast Caribbean Sea, with a population of approximately 3.3 million.

Hurricane Maria, a category 4 hurricane, hit Puerto Rico on 20 September 2017. Widespread damage affected the healthcare system and caused power outages. By the end of 2017 the number of deaths was estimated as 64 *(13)*, but this only considered deaths for which a “hurricane related” cause of death was recorded on the person’s death certificate. Although this would be a standard epidemiological technique for using routine data to determine the number of deaths due to a specific cause, this method of measurement may be unreliable in the disaster context.

For example, a study published in May 2018 *(14)* estimated the number of excess deaths to be close to 6000, with most of these deaths resulting from the interruption of services such as health care, electricity, and water access. This epidemiological study gathered its data through a household survey, extrapolated the household mortality rate to the complete population and compared this to the mortality rate for the same period in 2016.

In a subsequent study *(15)*, data from before Hurricane Maria were used to estimate an average number of expected deaths per month. This generated a conservative estimate of 1139 excess deaths, with levels returning to the pre-hurricane range by December 2017, three months after the hurricane.

Finally, an independent review commissioned by the government used the official, national statistics to estimate the total excess number of deaths after the disaster. This reported that there were 1427 more deaths in the four months after the hurricane than the number expected using data from the previous four years *(16)*.

These different ways of estimating the number of deaths caused by the hurricane illustrate the potential impact of using different techniques for epidemiological research. They vary from counts based on death certificates in the immediate aftermath of the hurricane to estimates based on comparisons with the same months in previous years. This is important when considering the implications of epidemiological research — the updated estimate from the government-commissioned review prompted the government to undertake a major review of its preparedness, which should help to inform future planning and the public health preparation and response to such a disaster in the future.

2.1.5 Outbreak investigations and other incident reports

Outside the context of disasters from natural hazards, conflicts and other emergencies, epidemiological methods are used to investigate disease outbreaks, employing both descriptive and analytical techniques to understand the source of a disease or infection, how it may be spreading and how best to control it. This may allow interventions to be put in place to prevent further morbidity and mortality. These studies include assessments of the prevalence of biological and pathogenic hazards and of the health consequences already known to be caused by them, as well as investigations that test the association between hazards and health outcomes to investigate whether these hazards lead to the health outcomes.

These epidemiological methods can also be important in disasters from natural hazards where, for example, population movements or damage to healthcare infrastructure can lead to the more rapid spread of infectious diseases. Epidemiological studies can use exposure data to determine the presence of these risk factors and assess the effects of an intervention. For example, case control studies in the Republic of Haiti in 2012-14 found that a reactive cholera vaccination programme provided protection from four to 24 months after vaccination. This was important because vaccination is a key component of efforts to control cholera epidemics *(17).*

In some cases, investigations may take place long after the acute disaster phase, as health impacts and the research needed to investigate them may take some time to be identified. For example, epidemiological techniques such as case control and cohort studies were employed to look for risk factors for traumatic injury after an earthquake in California. These longer term studies found that peak ground acceleration, perceived shaking intensity, building characteristics, and individual characteristics were important risk factors for injury *(18–19)*.

Case Study 2.1.2 provides an example of how epidemiological methods were used to study long-term environmental contamination and the outbreak investigation mechanisms needed to determine cause and effect, as well as the control systems that had to be put in place.

Case Study 2.1.2
Minamata Bay and organic mercury poisoning

Between 1932 and 1968, it was reported that an estimated 27 tons of mercury was released into Minamata Bay *(20)*.

In the 1950s, initial reports of poisoning involved local cats, birds and fish *(20)*. By the middle of the decade, symptoms started to appear in humans: these included loss of fine motor control, stumbling while walking, and violent tremors *(21)*. Using a wide range of epidemiological techniques including surveys, case interviews and descriptive and analytical epidemiological studies, a link was made with consumption of contaminated fish *(22)*.

Organic mercury was identified as the cause in 1959.

The findings of these studies contributed to a global treaty, the Minamata Convention on Mercury, seeks to protect human health and the environment from the adverse effects of mercury *(23)*.

2.1.6 Databases holding disaster data

Some of the epidemiological research relevant to emergencies and disasters is able to draw on data included in disaster databases. These present exciting opportunities for disaster epidemiology but also highlight some challenges. Despite containing large amounts of data from emergencies and disasters that can be analysed and reported, they reflect the shortcomings in the data itself. These include a lack of standardization in collection methodologies and definitions, and the absence of a single reliable source of verified data *(24)*. Moreover, the databases are hosted by a variety of organizations, with different disciplinary affiliations and scientific traditions. Individual databases are usually set up with distinct objectives, which may be inconsistent with those of other databases. This makes it difficult to compare outputs across databases, as has been shown in several comparisons *(25–26)*. This lack of a shared focus makes it difficult to come to a consensus on the range and magnitude of impacts and, as a result, to have confidence in the estimates presented *(27)*. Described below are two of the main disaster databases (EM-DAT, from CRED, and the Desinventar), followed by information on the Sendai Framework Monitor (SFM), which has recently been developed with the intention of providing a more complete and shared global database on disasters, aligned with the targets of the Sendai Framework for Disaster Risk Reduction 2015-2030 *(28)*.

CRED and EM-DAT (Emergency Events Database)
The Centre for Research on the Epidemiology of Disasters (CRED) was established in 1973 as a non-profit institution, with international status under Belgian Law. It is located in the School of Public Health of the Université Catholique de Louvain in Brussels. In 1988, **CRED** launched the Emergency Events Database (EM-DAT). This widely used and cited database was until recently fully accessible to the public. It provides information on the human impact of disasters, including the number of people killed, injured or affected; as well as economic damage estimates and disaster-specific international aid contributions.

For a disaster to be entered into the database, at least one of the following criteria must be fulfilled:

- At least ten people reported killed
- At least 100 people reported affected
- Declaration of a state of emergency
- Call for international assistance.

EM-DAT contains core data on the occurrence and effects of more than 15 700 disasters from 1900 to present, including those caused by natural and technological hazards. The database is compiled from various sources, including UN agencies, non-governmental organizations, insurance companies, research institutes and press agencies. However, the eligibility criteria for EM-DAT mean that it does not include data on the large number of smaller events that occur each year that do not meet at least one of the four eligibility criteria. It is also hampered by the issues surrounding disaster data generally, namely the challenges of capturing data on all disaster events and the potential unreliability of data and reports on health impacts, including mortality.

DesInventar: a Disaster Loss Database
In the early 1990s, groups of researchers, academics, and institutional actors in Latin America linked to the Network of Social Studies in the Prevention of Disasters in Latin America (Red de Estudios Sociales en Prevención de Desastres en América Latina - LA RED) worked together to develop DesInventar, a conceptual and methodological tool for generating National Disaster Inventories and constructing databases of information on damage, losses and other effects of disasters on specific countries. Subsequently, UNDP and UNISDR sponsored implementation of DesInventar in the Caribbean, Asia and Africa. Desinventar includes:

- Methodology (definitions and help in the management of data)
- Database with flexible structure
- Software for input into the database.

The information in DesInventar inventories is spatially disaggregated in order to show (and later analyse) the effects of disasters at a local level. The minimum disaggregation level recommended for country-level disaster inventories is equivalent to municipality, which is usually one or two levels below the country's first-level administrative or political division (province, state or department depending on the country). A list of the available databases from reporting counties is available on the DesInventar website and DesInventar has been linked to reporting for the Sendai Framework Monitor.

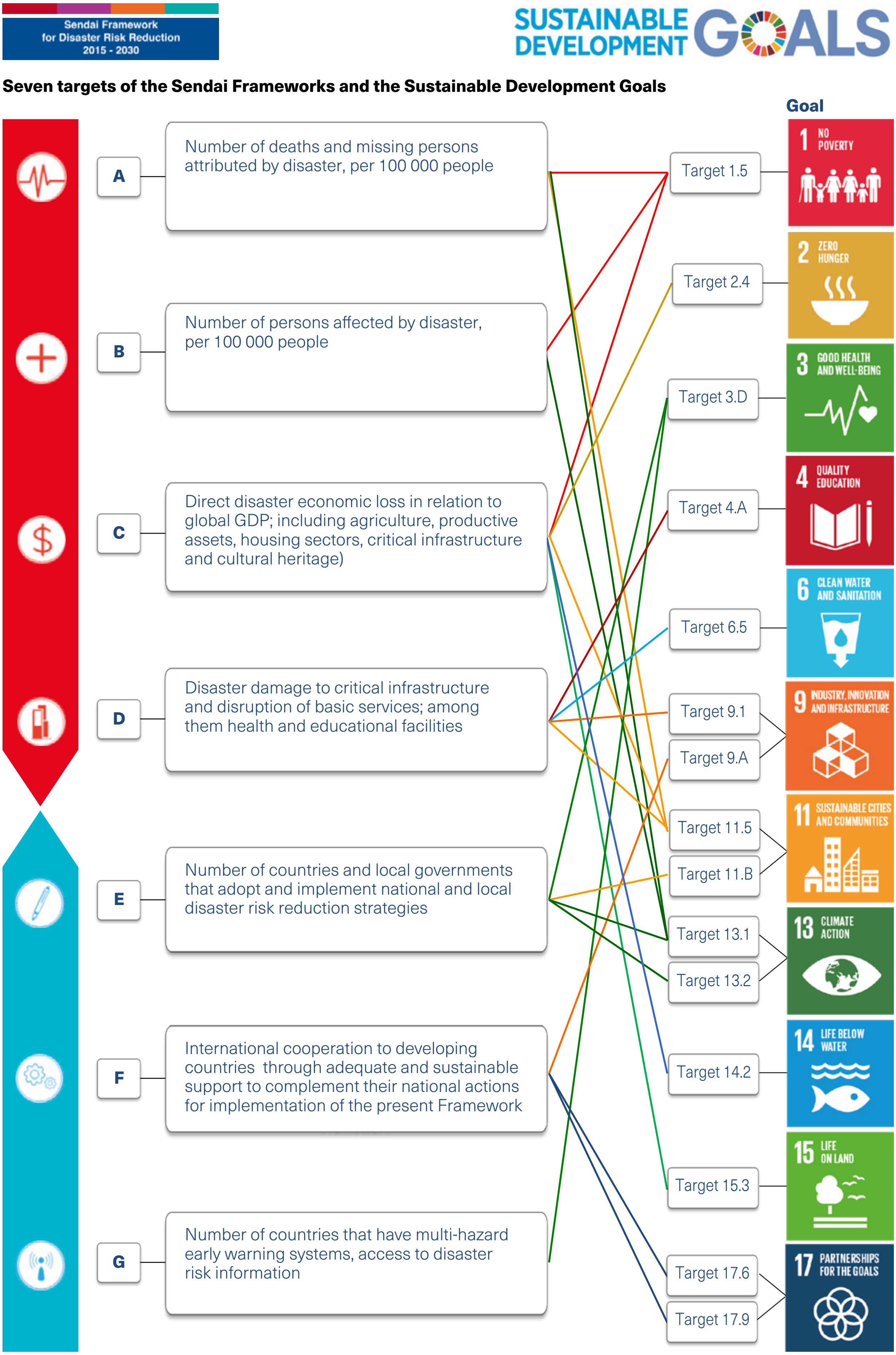
Sendai Framework Monitor

UNDRR has identified strong accountability as a corner stone of the Sendai Framework for Disaster Risk Reduction 2015-2030 *(28)*. A set of 38 indicators, recommended by an intergovernmental expert working group, are being used to track progress in implementing the seven targets of the Sendai Framework, as well as its related dimensions reflected in the Sustainable Development Goals (Figure 2.1.1). The Sendai Framework Monitor will also function as a management tool to help countries document their disasters, in order to facilitate their understanding of which disaster risk reduction strategies may be beneficial, assist in risk-informed policy decisions and inform the allocation of resources to prevent new disaster risks.

UNDRR is implementing a system to determine progress in implementing the Sendai Framework and this will be assessed every two years. As of March 2018, UN member states must use the online Sendai Framework Monitor to report against the indicators for measuring the global targets of the Sendai Framework. A detailed timeline has been developed and shared for the key milestones of the process and 84 of 195 countries had started to report as of August 2019.

The Sendai Framework Monitor is a major outcome of the Sendai Framework for Disaster Risk Reduction, which should provide more complete systematic information about the occurrence of all disasters, including those of small and medium impact. It should provide disaggregated data about the effects of large scale disasters that has not previously been available for most countries.

Figure 2.1.1 Links between Sendai Framework reporting and the Sustainable Development Agenda



Seven targets of the Sendai Frameworks and the Sustainable Development Goals

A Number of deaths and missing persons attributed by disaster, per 100 000 people

B Number of persons affected by disaster, per 100 000 people

C Direct disaster economic loss in relation to global GDP; including agriculture, productive assets, housing sectors, critical infrastructure and cultural heritage)

D Disaster damage to critical infrastructure and disruption of basic services; among them health and educational facilities

E Number of countries and local governments that adopt and implement national and local disaster risk reduction strategies

F International cooperation to developing countries through adequate and sustainable support to complement their national actions for implementation of the present Framework

G Number of countries that have multi-hazard early warning systems, access to disaster risk information

2.1.7 Value of disaster epidemiology for research

Epidemiological research can be used to generate knowledge long after a disaster response effort has passed. It might help to fill evidence gaps that are identified by the evaluation of the response, as well as identify further gaps that need to be filled. Although many public health and other disaster responders may have no or few resources to commit to formal epidemiological studies or research, the role of initial needs assessments, surveillance and incident investigations is vital in informing the later strategy for knowledge generation. By using existing data from, for example, surveillance systems or disaster databases as mentioned above, researchers can minimize the research waste that might arise from them conducting their own data gathering, such as through new surveys. Researchers need to be part of collaborations between responding agencies, academic institutions, government agencies and funding bodies to help them to understand the benefits and shortcomings of using existing data and to identify priority areas for new research. These partnerships are critical to ensuring that opportunities to improve future disaster response are taken. By way of illustration, Case Study 2.1.3 shows how epidemiological research provided important evidence on the mental health impacts of flooding in the United Kingdom.

Case Study 2.1.3
Measuring mental health impacts of flooding

After widespread flooding in England in 2013-14, a multi-year National Study of Flooding and Health was established to examine the long-term impact of flooding on the mental health of people living in flood-affected areas.

The methodological complexities of measuring mental health impacts of flooding meant that collecting data on a range of personal factors was essential. A year after the flooding, the epidemiological research showed psychological morbidity was elevated among both flooded participants (prevalence of depression 20.1%, anxiety 28.3%, PTSD 36.2%) and those who were disrupted but without floodwater entering their homes (prevalence of depression 9.6%, anxiety 10.7% PTSD 15.2%) *(29)*. The prevalence of depression, anxiety and PTSD among unaffected respondents living in the same area were 5.8%, 6.5% and 7.9% respectively.

Furthermore, flooded participants who reported disruption to domestic utilities (such as electricity, gas or water) or to health care were more likely to have developed symptoms of one of these mental health problems than other flooded participants. For example, after adjusting for the depth and duration of floodwater in the home, the odds of probable depression were 1.7 times higher for participants who were displaced compared with those who were not *(30)*. The amount of warning received appeared to be a protective factor amongst those who were displaced, with those receiving no warning before flooding reporting more symptoms of depression and PTSD than those who were forewarned.

2.1.8 Conclusions

Public health research is essential in determining and understanding health impacts from disasters and other emergencies. Epidemiological research provides the evidence to help decision makers plan for future disasters, showing both the causes and consequences of hazards that cause disasters and arise from them. Key epidemiological techniques for disaster research include assessments of need, health surveillance, registries of affected populations and new studies into outbreaks and other cascading hazards that may follow the initial event. Tools such as the IASC NATF Multi-Cluster/Sector Initial Rapid Assessment (MIRA) and the WHO's Early Warning, Alert and Response System (described above) can contribute to reliable research in Health EDRM.

2.1.9 Key messages

- **The principles of epidemiology for emergencies and disasters are critical to understanding risk factors and health impacts of disasters and informing strategies for health emergency and disaster risk management.**
- **Disaster databases are important sources of data but have limitations that need to be recognized by researchers and it is hoped that the Sendai Framework Monitor will help overcome some of these problems**
- **Health impacts of disasters can be both immediate and long term; the long-term impact has been relatively under-studied and thus the burden on a population is likely to be under-estimated and inadequately addressed.**

2.1.10 Further reading and resources

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2.2

Measuring the health impacts of disasters

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2.2.1 Learning objectives

To understand the following key factors relating to measuring the health impacts of disasters:

1. The importance and relevance of measuring the health impacts of disasters.
2. The variety of indicators that characterize the health impacts and risks of emergencies and disasters.
3. Systems and methodologies that can be used to measure health impacts.
4. Challenges and issues in measuring the health impacts of disasters.
5. Strategies to cope with these issues.

2.2.2 Introduction

Between 2008 and 2017, disasters from natural hazards registered in international databases affected, as an annual average, nearly 200 million people, causing nearly 70 000 deaths and leading to economic losses of more than US$ 160 billion *(1)*. A further 172 million were affected by conflict *(2)*. From 2012 to 2017, WHO recorded more than 1200 outbreaks, including outbreaks of new or re-emerging infectious diseases, in 168 countries. In 2018, WHO tracked 352 infectious disease events, including Middle East respiratory syndrome coronavirus (MERS-CoV) and Ebola virus disease. Given the tendency of international disaster data to focus on large-scale events, such data usually omit the large numbers of small- to medium-scale events that also have substantial health, economic, social and environmental effects *(2)*. Measuring the effects of emergencies and disasters and building systems that can facilitate in-depth investigation both of their causes and of their effect on people is imperative to enabling us to better reduce the risks of emergencies and disasters and their ensuing human impact.

Measuring the health impacts of disasters can help in determining the scale and scope of response needed, defining the 'big picture' operationally, quantifying the magnitude of urgent needs, ensuring the response is appropriate and timely, assessing progress, and allowing comparisons to be made among different emergencies and disasters. Epidemiology provides a good foundation for measuring, studying and using indicators that are critical to reducing risks in emergencies and disasters, and helping to ensure that health impacts and outcomes are measured systematically. Epidemiological methods may be used to characterize affected populations, especially vulnerable groups, and assess their vulnerability and exposure, as well as to quantify impacts and generate evidence for public health interventions before, during and after emergencies (See Chapter 2.1).

Public health decision-making for emergencies and disasters relies critically on information about the anticipated or actual health impacts of these events. The ability to measure health impacts should therefore be an integral part of any Health EDRM system. The development of capacities in public health surveillance, epidemiological investigation, laboratory testing and other related technical areas – responsibility for which belongs to the public health sector – supports measurement of the health impacts of disasters, which is crucial to being able to prevent, prepare for and respond to these events appropriately.

Indicators that can be used to describe the impacts of emergencies and disasters are an important area for study. Conventionally, such indicators are measured in terms of human impacts or fatalities, physical impacts through property damage and effects on critical infrastructure, as well as socioeconomic impact indicated by financial losses. Table 2.2.1 shows the indicators that can be used to quantify the impacts of sudden-impact disasters from natural hazards specifically in relation to health (see also Chapter 2.4).

Table 2.2.1. Common health indicators used to quantify sudden-impact health impacts from natural hazards *(3)*

Effect	Health indicator	Application
Death	Number of deaths among the population	Rough assessment of disaster severity
	Number of impact-related deaths among the population of a given age	Identification of vulnerable groups for further Health EDRM planning
	Number of deaths and number of houses destroyed	Assessment of building structure safety Evaluation of predisaster community rescue training
	Number of impact-related deaths per unit of time after the disaster among the population	Evaluation of self-reliance of community
Hospital admission	Number of casualties among the population	Evaluation of predisaster prevention, mitigation and preparedness measures Evaluation of warning adequacy
	Distribution of reasons for hospital admission	Estimation of emergency care available and relief needs Identification of critical services to be maintained in emergency
	Hospital bed occupancy and duration of stay in hospital	Monitoring of health facilities and medical care needs
	Geographical origin of hospitalized patients	Needs assessment for relief supplies, including field hospitals
Health-seeking behaviour	Number of consultations among the surviving population	Estimation of type and volume of medical relief and resources
	Time distribution of consultations	Scheduling of medical relief

To ascertain health impacts of disasters, it is useful to examine health impacts as a function of risks –that is, the probability and negative consequences of exposure of individuals, communities and the population to a wide range of hazards. Risks may be compounded by vulnerabilities intrinsic to individuals (such as extremes of age, weak immune status, strong familial history of disease) or characteristic of communities (low income level, low educational attainment, poor sanitary practices) and by limited capacities of health systems (weak governance, poor coordination mechanisms, suboptimal investments). Conversely, health risks and impacts can also be reduced by the capacities that can be built into the health system and other sectors at the individual, community and population levels.

Case Study 2.2.1
New technologies to detect and track outbreaks: Early Warning, Alert and Response System in the People's Republic of Bangladesh

Between late August and mid-December 2017, an estimated 655 000 Rohingya women, men and children fled to Bangladesh. In tackling an outbreak of diphtheria among the Rohingya refugees, WHO utilized both old and new public health tools. Contact tracing was used to find all the people who may been exposed to the disease. Diphtheria treatment centres were established to take care of those affected and keep the disease contained. A newly developed computer program known as the Early Warning, Alert and Response System (EWARS) allowed the quick collection of field data, geographical location and affected populations (see also Chapter 2.1). This allowed the response teams to act promptly. EWARS was developed by WHO specifically for humanitarian and emergency settings and is designed to be used by local people in at-risk communities. It works even without an internet connection.

The importance of surveillance systems in Health EDRM cannot be overemphasized. Public health surveillance applied to Health EDRM encompasses continuous, systematic collection, analysis and interpretation of disaster and health data crucial for planning, implementation and evaluation of public health interventions in emergencies and disasters. During emergencies and disasters, health assessments to measure health outcomes make it possible to determine needs and identify related services in the immediate, short and long term. Activation of surveillance systems, and use of relevant data are essential to Health EDRM. Case Study 2.2.1 provides an example of how such surveillance can help.

Although the value and benefits of measuring health outcomes are clear, emergencies and disasters by their very nature present numerous challenges to the functionality of surveillance systems. Starting with the physical effects of disasters on the affected communities, power and communication may be affected by the destruction of lifelines; critical infrastructure such as roads, bridges and airports might also be damaged. Health infrastructure such as hospitals, clinics, laboratories and public health offices might be damaged or destroyed, along with their equipment, materials and supplies. Disasters can also affect healthcare providers and those responsible for health surveillance. Other impacts include high population mobility as a result of displacement and the breakdown of other vital services and insecurity. All of these can constrain the effective, efficient and timely use of epidemiological data for evidence-based action in emergencies and disasters. Methodological issues can also arise because of the lack of baseline data or sample sizes that are too small to provide generalizable findings.

However, the most important challenge may be the resulting prioritization of emergency response and relief operations over assessment and measurement activities. This may mean that public health interventions are not guided by sound evidence, and further health risks may be realized instead of being prevented. However, it is possible to undertake both tasks at the same time, and this should be encouraged.

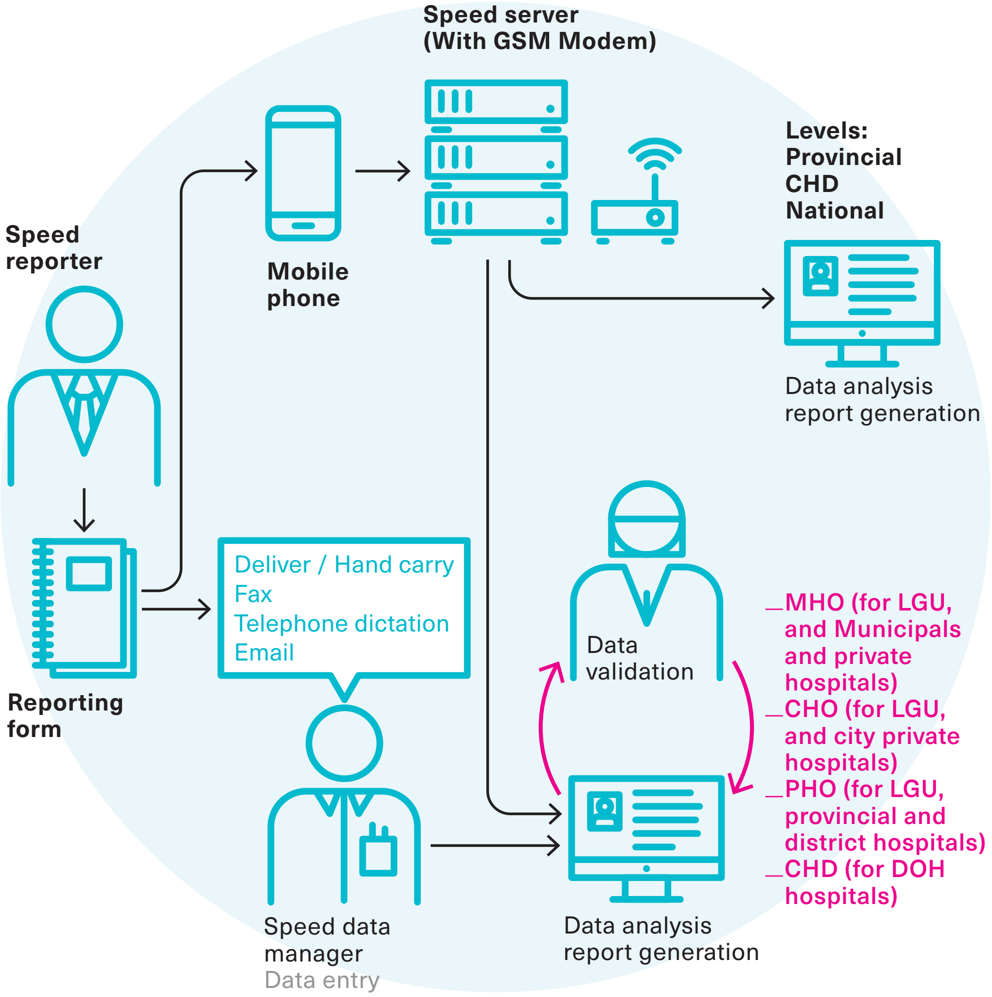
It is also important to evaluate the preparedness of public health systems to conduct real-time surveillance, and measure and count health outcomes and indicators during emergencies and disasters. In some low and middle-income countries, it may be difficult to organize and maintain surveillance and reporting systems. In some cases, baseline data may not be available, there could be significant variation in data that are collected, or it may not be possible to institutionalize surveillance systems because of insufficient technical capacity, or human resource or logistics issues.

2.2.3 SPEED in the Philippines

The Surveillance in Post-Extreme Emergencies and Disasters (SPEED) programme in the Philippines provides an illustrative example of an actual system used by public health authorities to measure and manage the health risks of a disaster to a population. SPEED is an early warning and alert system developed by the Department of Health in the Philippines, which was born out of the country's experience with a range of emergencies and disasters that caused a significant public health burden to the country (see Chapter 1.3 for a description of how a modified version of SPEED was used in Japan). Firstly, it describes the type of health issues emerging in the communities and in temporary shelters after huge population displacements, secondary to the disaster, across the timeline from post-disaster response to recovery. Secondly, it shows how SPEED as a system draws an "operational picture" of the disaster and so guides appropriate public health interventions to manage the health risks that have been measured. This highlights the critical function of such a system not only in measuring but also in managing these health risks. Lastly, this example brings to light some common issues encountered in utilizing the system in the context of emergencies, in order to underscore the importance of prevention and preparedness strategies that aim to build robust health information systems during normal times to support response when it is needed.

SPEED is an early warning surveillance system that monitors consultations for health conditions arranged in syndromes. It assesses health trends and uses web-based software that receives data via short messaging service (SMS) and converts data into customizable reports.

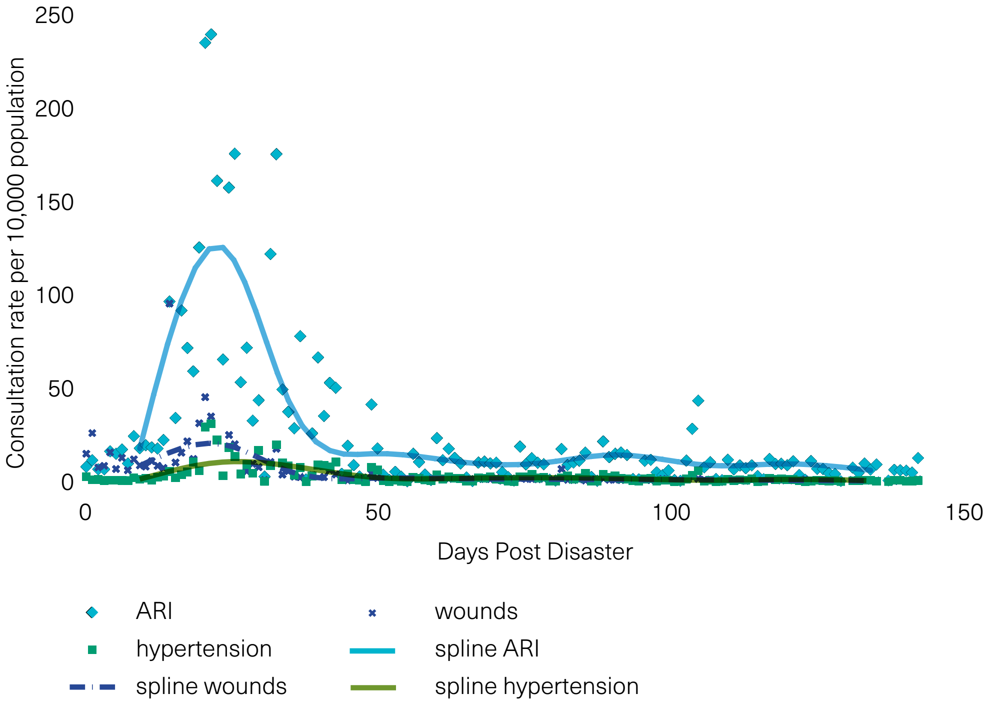
Figure 2.2.1 The SPEED Reporting System *(4)*



Key: MHO Municipal Health Officer; LGU Local Government Unit; CHO City Health Officer; PHO Provincial Health Officer; CHD: Center for Health Development; DOH Department of Health

In November 2013, Typhoon Haiyan – one of the strongest category typhoons ever to make landfall in the Philippines – ravaged six of the country's 17 regions. Strong winds, heavy rainfall and storm surges led to an unprecedented impact: 6300 dead, 1061 missing and 26 689 injured. The typhoon damaged all health facilities in its path, affected many healthcare workers and disrupted critical infrastructure (water, power, communication). This impaired the delivery of health services to the affected population. As soon as local and international emergency medical teams arrived and started to provide their services, SPEED was activated. The Department of Health prioritized SPEED after having seen the value of early warning systems after extreme events, and implemented it despite several obstacles (such as poor network and communication, lack of health human resources, logistical concerns), using the data and findings it collected to plan the response activities. This led to an analysis of health impacts and gave a clear picture of diseases that ensued in different timeframes. It showed that the most common morbidities were communicable diseases in children and injuries and non-communicable diseases in adults. Important public health interventions such as mass vaccination for vaccine-preventable diseases, logistics and medical supply augmentation for hypertension and diabetes were undertaken to decrease preventable morbidity and mortality after the disaster. SPEED data indicated that the focus of interventions should be on primary health care rather than specialist care, which helped in team deployment decisions. Furthermore, as well as depicting the severity and magnitude of disruption to the health system (which was fully apparent within two months after the typhoon), it delineated a recovery phase that signalled the transition of the health system from response to recovery. This guided the main recommendation to authorities that external medical teams were no longer needed, because local capacities were sufficient to address the long-term needs.

Figure 2.2.2 Consultation rates per 10 000 individuals for acute respiratory infections, wounds, and hypertension in Typhoon Haiyan, Philippines, 2013 *(5).*



As reported by WHO, there was no outbreak of communicable diseases among the communities affected by Typhoon Haiyan. This was attributed to the contribution made by SPEED to facilitating early and appropriate actions and interventions that reduced health risks after the disaster.

SPEED was also used in the Zamboanga Siege in the Philippines in 2013. It demonstrated its usefulness as an early warning tool for disease prevention during this armed conflict situation on Mindanao Island.

2.2.4 Obstacles to implementation of SPEED during Typhoon Haiyan

Typhoon Haiyan destroyed or badly damaged many of the aspects of the health system that are crucial for measuring and counting (that is, epidemiology and surveillance). Hospitals, laboratories and public health offices were damaged, as were computers, mobile phones, reporting forms and other supplies. Lifelines (that is, communications, networks and power) were out of service for a week after the typhoon. Many healthcare workers were affected. Some were killed by the typhoon, some had their houses damaged, and some had family members or friends missing. Consequently, the routine surveillance system was paralyzed. Besides which, the immediate priority was to save lives, manage the dead and missing, and attend to the needs of the displaced population in evacuation centres, rather than measuring and counting health impacts. The Department of Health, aware of the value of SPEED, activated it. To circumvent problems with power and the communication network, it defaulted to the paper mode of SPEED, using manual documentation and processing. To address the shortage of healthcare workers, the Department of Health oriented and deployed international medical teams to gather SPEED data. It also sought the help of partners to report health data from the SPEED system.

The use of SPEED proved to be greatly advantageous in this context and subsequent enhancements were made. These included revision of criteria for activation and deactivation, inclusion of disease syndromes and revision of thresholds, updating of the format for SMS, revision of data entry and online reporting forms, and enhancement of maps and graphs.

It is also apparent that many predisaster strategies and systems are needed to support SPEED. For example, SPEED should be operationalized in such a way as to complement routine surveillance systems, as analysis of predisaster data and baseline information alongside SPEED data would provide a richer context for planning. There is also a need for continuous training to address the rapid turnover of SPEED-trained personnel. Software and hardware developments are also a priority in order to improve SPEED.

2.2.5 Conclusions

Measuring the diverse health impacts of different types of emergencies and disasters at health system, population and individual levels is critical in order to understand how people's health and health systems are affected by the interaction of hazards with their respective exposures, vulnerabilities and capacities. This understanding provides vital information to develop and implement Health EDRM strategies to reduce the risks and consequences of emergencies and disasters. The use of health trends in different post-disaster settings across time has helped guide public health managers in planning and implementing the response to, and recovery from, the affected population's varying health needs. The examples of WHO's EWARS and the Philippines' SPEED show the importance of measuring and managing the health risks of a disaster as an important public health function. Likewise, the examples show the effects of emergencies and disasters on the functioning of the health system and the need to make necessary adjustments and find solutions to address these challenges and assure continued functionality.

2.2.6 Key messages

- **Measuring the health impacts of disasters at health system, population and individual levels is critical in order to enable appropriate and timely public health interventions in emergencies and disasters.**
- **Various indicators should be measured to characterize the health impacts and risks of emergencies and disasters. Relevant data should be collected and analysed so that it can be used for various purposes and actions before, during and after emergencies and disasters.**
- **It is crucial to build capacities for epidemiology, laboratory testing, public health surveillance and information management as part of Health EDRM as these will provide the foundation for accurately measuring health impacts during emergencies and disasters.**
- **Although the effects of an emergency or disaster may make measuring health impacts particularly difficult, putting in place predisaster prevention and preparedness measures, operational readiness, back-up systems and contingency plans can prevent or overcome these obstacles.**

2.2.7 Further reading

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2.2.8 References

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2.3

Disease burden: generating evidence, guiding policy

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2.3.1 Learning objectives

To understand the basic concept of disease burden and its potential in identifying and understanding the health issues surrounding a disaster, in particular:

1. The strength of the burden of disease concept.
2. How to quantify the burden of disease from mortality and disability.
3. The content of three case studies using the burden of disease concept.

2.3.2 Introduction

A pivotal foundation to prioritizing policy planning and interventions for health emergency and disaster risk management (Health EDRM) is the availability of comprehensive and comparable evidence of mortality and disability, and the risk factors that may contribute to them (see Chapter 3.2). The burden of disease is a globally recognized concept that provides a methodological framework to quantify and compare population health using a summary measure of both mortality and disability: the disability-adjusted life year (DALY) *(1–2)*.

A major strength of the burden of disease concept is that it allows comparisons to be made between health losses due to mortality and disability, and those due to different diseases or injuries. DALY combines in one measure the time lost due to individuals' premature death from each disease or injury and the time lived with disability, taking into account the degree of severity of disability associated with different states of poor health caused by each disease and injury *(3)*. DALYs are therefore a useful measure for examining which diseases and injuries make the largest contribution to health loss in a given population group (by age, gender, location and so on) at a given time, as well as for identifying and understanding key health problems and prioritizing health policy concerns, such as resource allocation, interventions, service providing, research, and advocacy.

Disasters and hazards are major causes of injuries which lead to mortality and disability. The threat of both natural and human-induced health emergencies and disasters adds an even greater sense of urgency to the need to hasten efforts for risk management on an 'all hazards' basis *(4)*. Rapid and unplanned urbanization, along with climate change, widespread poverty and insecurity, social inequality, political instability, and economic stagnation, have all helped to increase the risks and harmful consequences of health emergencies and disasters. For example, more than 50% of the world's population now lives in urban areas, and this is expected to increase to 66% by 2050 *(5)*. These heavily urbanized areas are frequently also located in disaster prone regions, with 80% of the world's largest cities vulnerable to earthquakes and 60% at risk from storm surges and tsunamis *(6)*. Today, natural disasters cause annual economic losses of US$ 520 billion worldwide, and cause about 26 million people to fall into poverty *(7)*. Investing in disaster risk management can reduce the disaster impact in terms of both economic losses and burden of diseases, conserve resources, and protect development progress. Some studies have estimated that for every dollar spent on well-targeted and effective DRR, approximately US$ 7 will be saved from a reduction in economic losses *(8)*.

The adoption in 2015 of the Sendai Framework, the SDGs, and the Paris Agreement (with DRR interlinked between them) reflects national, regional, and global commitments to disaster risk management, presenting an unparalleled opportunity for action. The burden of disease concept is a powerful research tool in this context – for generating evidence, guiding policy, planning, and investing strategically on disaster risk management. This chapter provides a guide as to how DALYs are defined and calculated, describes their use in practice, gives a snapshot of the Global Burden of Disease Study (GBD) (the world's largest systematic, scientific effort to produce comparable estimates of disease burden), and concludes with three case studies illustrating how the burden of disease concept has been used in professional practice.

2.3.3 Quantifying the burden of disease from mortality and disability

The DALY measures the difference between the actual situation and an ideal situation in which everyone lives to the standard life expectancy and is in perfect health. DALYs associated with hazards as health risks include not only direct injuries and deaths, but also indirect health effects and their spillover effects due to the deterioration of health resources and social capital *(9)*. One DALY represents a one-year loss of 'healthy' life due to disease or injury. DALYs for a specific cause of disease or injury are calculated as the sum of the Years of Life Lost (YLL) due to premature death from that cause and the Years Lived with Disability (YLD) for people living in states of less than perfect health resulting from a specific cause:

$$DALY = YLL + YLD$$

The YLLs metric essentially corresponds to the number of deaths multiplied by the standard life expectancy at the age at which death occurs. The basic formula for YLL for a given cause, age, and gender is the following:

$$YLL = N \times L$$

where N denotes the number of deaths and L is standard life expectancy at age of death (in years). The standard life table (on which the standard life expectancy calculation is based) is a key component of the burden of disease concept. It corresponds to the ideal or aspirational life span for an individual in perfect health, but is not necessarily the actual life table of the population of interest. For example, a standard life table can be constructed from the lowest observed mortality rate in the latest year among all countries for each age and gender *(10)* or might be based on the life tables for countries with the highest longevity.

There are two methods of calculating the YLD for a particular cause in a particular time period: the incidence-based or prevalence-based approaches *(11)*. Prevalence looks at existing cases, while incidence looks at new cases. For incidence-based YLD, the number of incident cases in a given period is multiplied by the average duration of the disease or injury and a disability weight. This weight factor reflects the severity of the disease or injury on a scale from 0 (perfect health) to 1 (dead). The basic formula for incidence-based YLD is:

$YLD = I \times DW \times L$

where I denotes the number of incident cases, DW is the disability weight and L is average duration of the case to remission or death (in years). For prevalence-based YLD, the number of prevalent cases during a given period is also multiplied by a weight factor and the basic formula is:

$YLD = P \times DW$

where P is the number of prevalent cases and DW is disability weight. The disability weights for YLD are based on subjective measures. The conceptual and methodological basis for estimation of disability weights have been developed through various iterations *(12-14)*, and there is debate over their validity *(15-17)*. A large set of global disability weights estimated by the Global Burden of Disease and for the European population by Haagsma and colleagues can be found elsewhere *(13- 14)*. Further details of the methods used for estimating YLLs, YLDs, and DALYs are provided in the Global Burden of Disease study *(10, 18)*.

2.3.4 Use of DALYs in Health EDRM

By quantifying the burden of disease associated with health emergencies and disasters, DALYs are a valuable metric for setting disaster research and policy priorities. If the data allow, DALYs can be calculated for different socioeconomic groups (by gender and age group) or geographic areas (by country and region), providing a more detailed perspective on the impact of emergencies and disasters. For example, by regularly updating DALYs estimates based on the best available data, trends in DRR policies can be monitored over time to assess the impact of macro-level policy interventions. As a result, DALY can be an important tool to support Health EDRM policies aimed at improving the resilience of the general population and particular population groups and reducing disparity in damage.

2.3.5 GBD 2017 reporting: a snapshot

The Global Burden of Disease (GBD), which has been affiliated with WHO and the World Bank and is now housed in the Institute for Health Metrics and Evaluation (IHME) at the University of Washington in the USA, is produced by a global network of more than 3600 collaborators from universities, research institutes and government units. Most of these are in low- and middle-income countries *(19)*. Using published studies and available data worldwide, the most recent study as of 2019 *(18)*, GBD 2017, covered 195 countries and territories, with subnational assessments for 16 countries (Brazil, China, Federal Democratic Republic of Ethiopia, India, Islamic Republic of Iran, Japan, Kenya, United Mexican States, New Zealand, Norway, the Russian Federation, South Africa, Sweden, United Kingdom and USA), and calculated DALYs and other health metrics for each year from 1990 until 2017. Data are disaggregated by age, gender, location and year. The study assessed 359 diseases and injuries, and 84 risk factors or combinations of risks *(20)*.

Table 2.3.1 shows seven hazards addressed in GBD 2017. The grouping of diseases and injuries used by the GBD is based on the International Statistical Classification of Diseases and Related Health Problems (ICD-10).

Table 2.3.1 Hazards currently covered in the GBD projects

WHO classification of hazards	GBD cause group	ICD10 codes mapped to GBD causes
Natural	Exposure to forces of nature	X33-X38
Natural	Environmental heat and cold exposure	L55-L55.9, L56.3, L56.8-L56.9, L58-L58.9, W88-W99, X30-X32, X39
Human-induced	Fire, heat, and hot substances	X00-X06, X08-X19
Human-induced	Exposure to mechanical forces	W20-W38, W40-W43, W45-W46, W49-W52
Human-induced	Interpersonal violence	X85-Y08, Y87
Human-induced	Conflict and terrorism	Y36-Y36.9, Y89.1
Human-induced	Executions and police conflict	Y35-Y35.9, Y89.0

The GBD synthesizes a large number of data sources to estimate burden of diseases. Country vital registration data are the primary data source for mortality due to these hazards. The Centre for Research on the Epidemiology of Disasters' International Disaster Database (EM-DAT) (see also Chapter 2.1) served as the GBD's primary non-vital registration source of mortality data due to exposure to forces of nature, and to fire, heat, and hot substances *(21)*. Data sources for conflict and terrorism include the Uppsala Conflict Data Program (UCDP) *(22)*, International Institute for Strategic Studies *(23)*, Robert S. Strauss Center for International Security and Law *(24)*, the Global Terrorism Database (GTD) *(25)*, and the RAND Database of Worldwide Terrorism Incidents *(26)*. Other data sources can be explored via the Institute for Health Metrics and Evaluation's GBD 2017 Data Input Sources Tool *(27)*.

The case studies below illustrate how the burden of disease concept can be interpreted and used for Health EDRM, using data from the GBD 2017. The data in Case Study 2.3.1 can be compared with that for another case of a major natural disaster in Japan, the Great Hanshin Earthquake in Kobe (magnitude 7.3), in January 1995. This shows a similar picture. The earthquake killed 6434 people, of whom 99.5% were residents of Hyogo Prefecture. Many structures were irreparably damaged by the earthquake, including nearly 400 000 buildings *(30)*. The most frequent cause of death was asphyxia due to direct compression of the chest or from being buried under the debris of houses *(30)*. The second most frequent cause of death was severe crush injury.

Figure 2.3.2 shows the age-specific mortality rate (per 100 000) due to natural disasters in 1995 in Hyogo Prefecture. As with the 2011 data for Miyagi Prefecture, the highest mortality rate was observed in the older population at the age of 90–94 years, at 487 (95% uncertainty intervals: 319 to 711) per 100 000 people, 5 to 10 times higher than among those aged under 50 years. However, as with the tsunami in Miyagi, when the burden of the earthquake was measured as a DALYs rate, the burden was highest among both the older population and young children.

These findings imply that, although mortality captures the likelihood (or risk) of dying due to a particular cause, DALYs capture the magnitude of health losses caused by a particular cause. Using a metric of DALYs in measuring the health impact of a disaster, it is clear that young children are more prominently affected. This is in part due to the fact that the burden of a disaster disproportionately affects younger populations, who lose greater healthy lifetime than the older population.

Case Study 2.3.1
DALYs produce a different picture of health impact of a disaster

The devastating magnitude 9.0 Great East Japan Earthquake that struck north-eastern Japan on 11 March 2011 and the subsequent tsunami killed more than 16 000 people. There was no major structural damage due to the earthquake itself. In Miyagi, the earthquake is said to have been directly responsible for the deaths of at least four people, but the largest number of tsunami deaths were recorded in this coastal prefecture, accounting for about 60% of total deaths. The nature of a tsunami is such that it usually causes fewer non-fatal injuries than an earthquake, but, rather, is a matter of life-or-death for those who live on the coastline in its path.

Many previous studies indicate that the older population are more likely to die or suffer serious injuries when involved in hazardous events *(28)*. The 2011 disaster in Japan is no exception. Figure 2.3.1 shows the age-specific mortality rate (per 100 000) due to 'exposure to forces of nature' (that is, natural disasters) in 2011 in Miyagi Prefecture. The highest mortality rate was observed in the age group over 90 years of age, at 1913 (95% uncertainty intervals 1249 to 2840) per 100 000 people. This is 5 to 10 times higher than among those aged under 50 years. DALYs produce a different picture of the burden of the natural disaster than that the mortality rates: in terms of DALYs rate, the highest burden of the natural disaster was observed in children under five years of age, followed by older age groups (Figure 2.3.1).

Figure 2.3.1 Age-specific mortality and DALYs rate per 100 000 people due to natural disaster in Miyagi Prefecture in 2011 (Source: *(27)*)

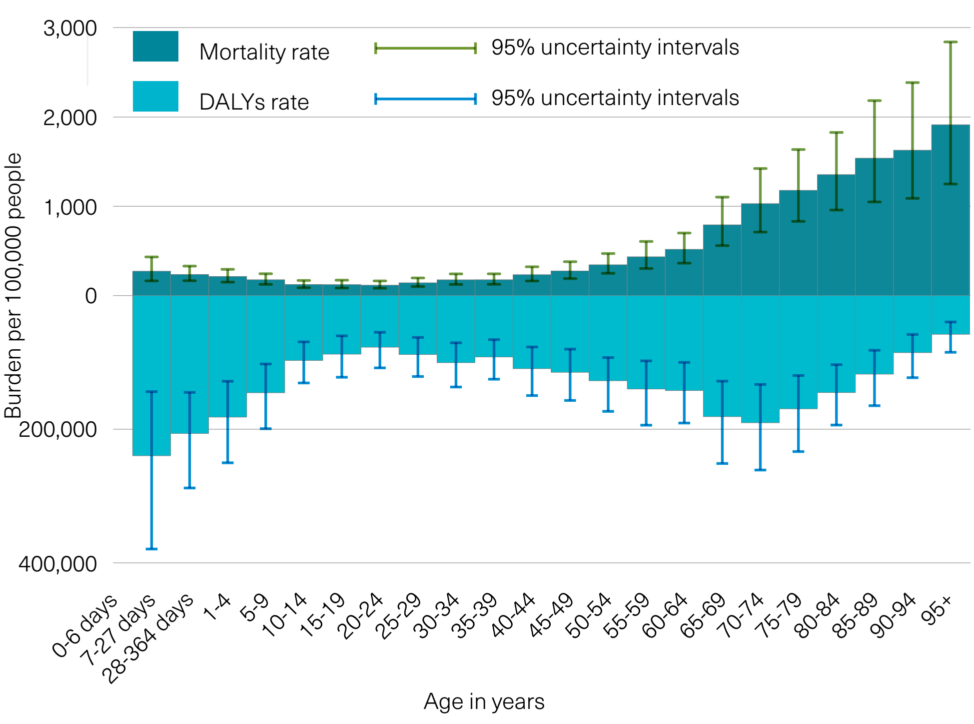
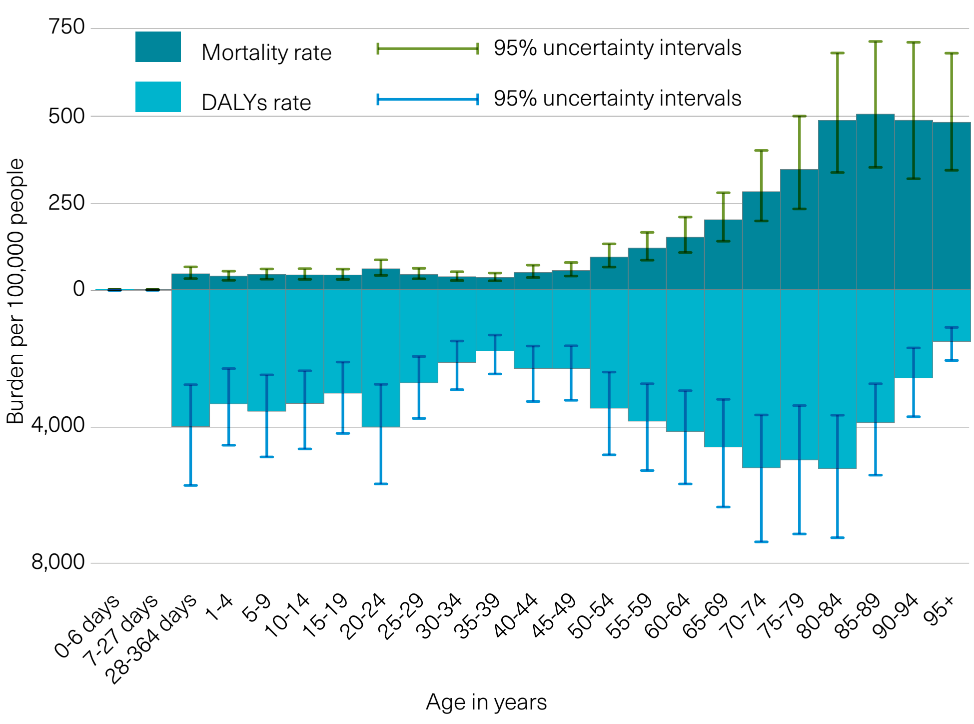


Figure 2.3.2 Age-specific mortality and DALYs rate per 100 000 people due to natural disaster in Hyogo Prefecture in 1995 (Source: *(27)*)

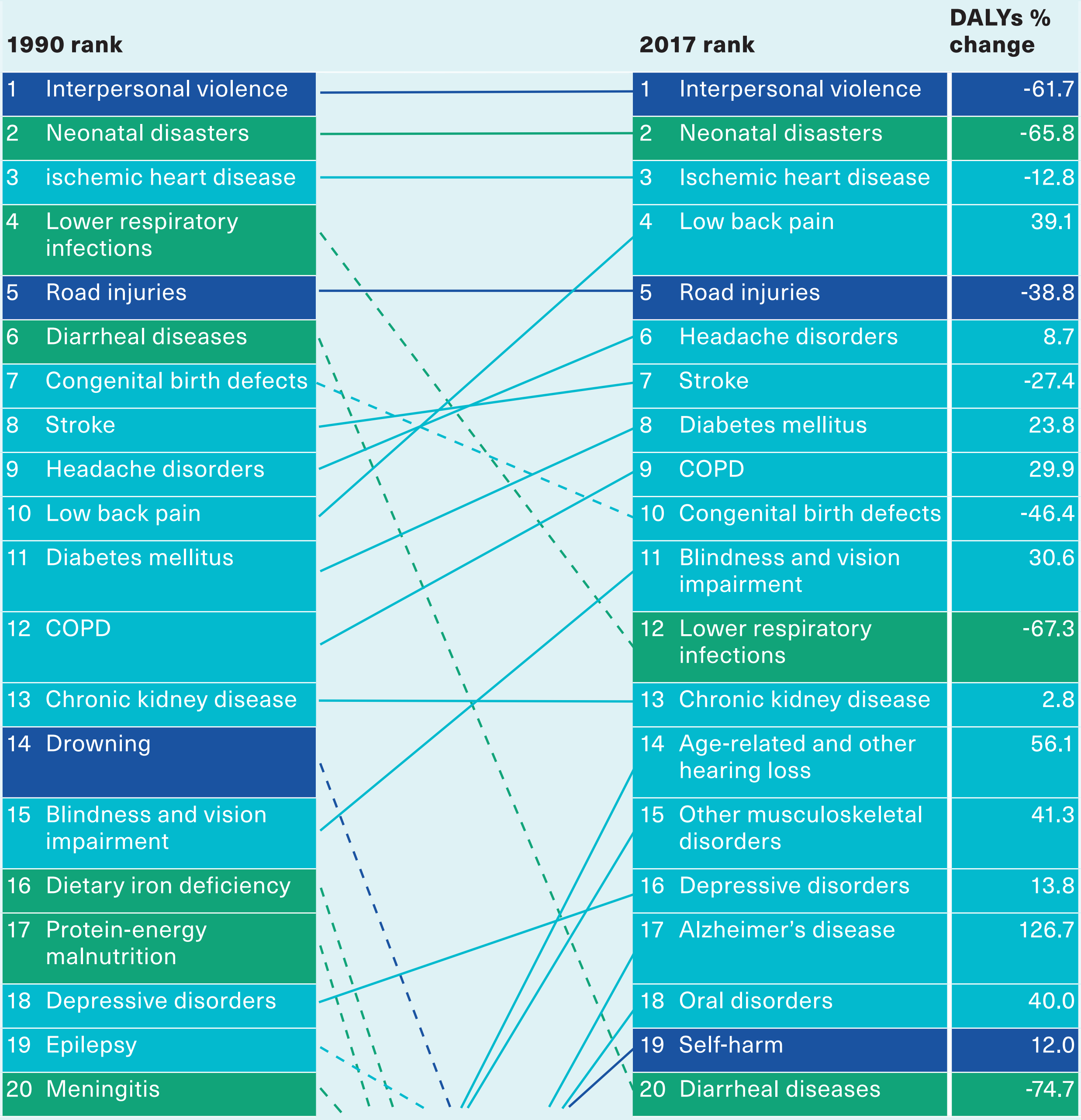


Case Study 2.3.2

Political violence has persisted in the Republic of Colombia despite several peace processes

In Colombia, the top three causes of DALYs in 2017 were interpersonal violence, neonatal disorders and ischemic heart disease (Figure 2.3.3). These rankings have not changed since 1990, although DALYs due to these causes have decreased by 61.7%, 65.8%, and 12.3%, respectively.

Figure 2.3.3 Ranking of DALYs in Colombia in 1990 and 2017 for both sexes combined, all ages *(27)*



1990 rank	2017 rank	DALYs % change
1 Interpersonal violence	1 Interpersonal violence	-61.7
2 Neonatal disasters	2 Neonatal disasters	-65.8
3 ischemic heart disease	3 Ischemic heart disease	-12.8
4 Lower respiratory infections	4 Low back pain	39.1
5 Road injuries	5 Road injuries	-38.8
6 Diarrheal diseases	6 Headache disorders	8.7
7 Congenital birth defects	7 Stroke	-27.4
8 Stroke	8 Diabetes mellitus	23.8
9 Headache disorders	9 COPD	29.9
10 Low back pain	10 Congenital birth defects	-46.4
11 Diabetes mellitus	11 Blindness and vision impairment	30.6
12 COPD	12 Lower respiratory infections	-67.3
13 Chronic kidney disease	13 Chronic kidney disease	2.8
14 Drowning	14 Age-related and other hearing loss	56.1
15 Blindness and vision impairment	15 Other musculoskeletal disorders	41.3
16 Dietary iron deficiency	16 Depressive disorders	13.8
17 Protein-energy malnutrition	17 Alzheimer's disease	126.7
18 Depressive disorders	18 Oral disorders	40.0
19 Epilepsy	19 Self-harm	12.0
20 Meningitis	20 Diarrheal diseases	-74.7

🟦 Non-communicable diseases

🟩 Communicable, maternal, neonatal and nutritional diseases

■ Injuries

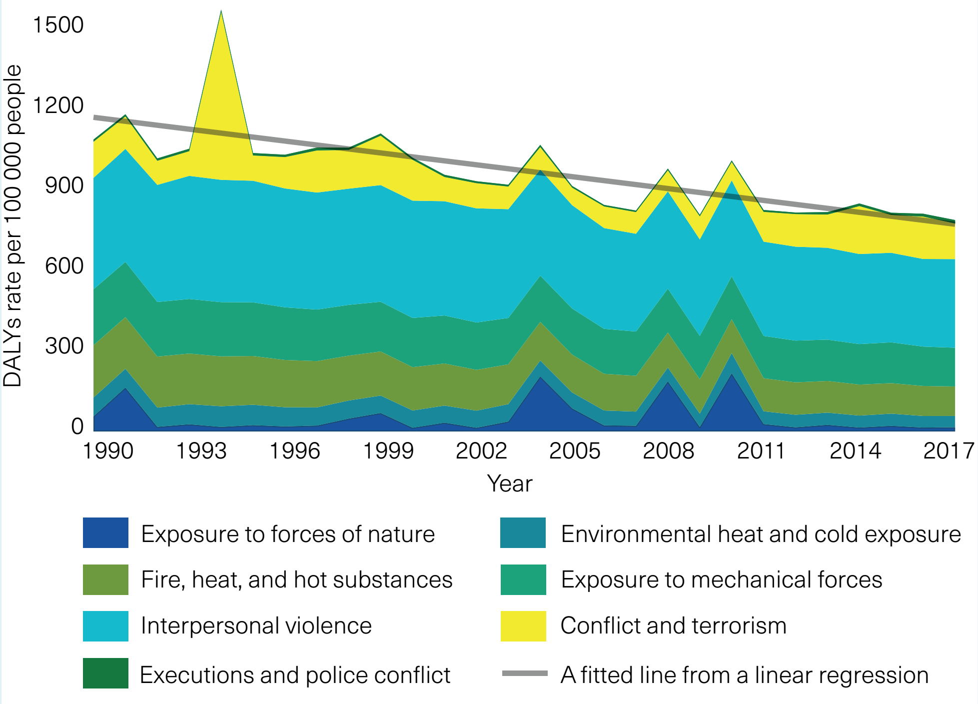
Interpersonal violence, the leading cause of DALYs in 2017, is mainly attributed to homicides related to drug trafficking, illegal firearms and alcohol. The violence primarily affects the younger population, which leads to higher numbers of YLLs and YLDs. Young males in particular suffer from a high mortality rate due to interpersonal violence. It is worth noting that, although rates in Colombia remain high, from 1990 to 2017 DALYs declined by 61.7%, in part due to militaristic and social economic policies aimed at ending armed conflict and eradicating drug trafficking *(31)* which resulted, in 2016, in the end of a 53 year-long civil war through a peace agreement between the Colombian Government and the Revolutionary Armed Forces of Colombia (FARC). Other notable initiatives include banning of carry permits for guns, which started out as a time and occasion specific ban in major cities in the early 1990s, and a general ban in the capital, Bogotá, in 2012 and became nationwide in 2015 *(32-34)*. Furthermore, given the complexity of the relationship between police, crime and communities in Columbia, addressing interpersonal violence through means such as alcohol regulation, which was associated with a lower risk of homicide in the city of Cali, may be an effective intervention *(35)*.

Research points to violence repeating itself, in that children who experience abuse or violence as they grow up are prone to demonstrating and solving conflict with violence as adults *(36)*. In order to halt this cycle of violence, the mayor of Cali, Rodrigo Guerrero, who is a public health expert, stressed the need for Colombia to pursue a profound cultural change, beginning from the very earliest stages of life, so that violence ceases to be a culturally accepted way of resolving conflicts.

Case Study 2.3.3
Global DALYs due to the seven hazards are declining

Figure 2.3.4 shows stacked cumulative age-standardized DALY rates per 100 000 people globally due to the seven hazards defined in Table 2.3.1. Among these seven hazards considered in GBD 2017, interpersonal violence has been the main cause of DALYs in recent decades (41.0% on average between 1990 and 2017), followed by exposure to mechanical forces (18.3%); fire, heat, and hot substances (15.4%); conflict and terrorism (13.1%); environmental heat and cold exposure (6.2%); exposure to forces of nature (5.1%); and executions and police conflict (0.8%).

Figure 2.3.4 Trends in age-standardized DALYs rate per 100 000 people due to exposure to the seven hazards in Table 2.3.1 (Source: *(27)*)



The grey line on Figure 2.3.4 is an ordinary least squares regression line based on the total age-standardized DALYs rate from 1990 and 2017. This shows a temporal trend in DALYs due to the seven hazards. Between 1990 and 2017, there was a large reduction in the age-standardized DALYs rate, which fell by 34%. The peaks on the figure represent shock events: the 1991 Bangladesh cyclone (exposure to forces of nature), the 1994 Rwandan genocide (conflict and terrorism), the 2004 Indian Ocean earthquake and tsunami (exposure to forces of nature), the 2008 Cyclone Nargis in the Republic of the Union of Myanmar (exposure to forces of nature), and the 2010 Haiti Earthquake (exposure to forces of nature).

2.3.6 Conclusions

Disasters and other health emergencies cause substantial mortality and disability. Reliable evidence on the scale of this mortality and disability and how different populations groups are affected is vital to policy planning and the prioritization of interventions in Health EDRM. Using the burden of disease concept helps to provide the comprehensive and comparable data necessary for this. The burden of disease concept is globally recognized as a methodological framework to quantify and compare population health, using the DALY as a summary measure of both mortality and disability. When used in Health EDRM, burden of disease and DALYs allow policy makers and researchers to compare and contrast the health impacts of different events across countries and regions, and over time. This provides them with a foundation for the assessment of programmes and policies and for the planning and analysis of research.

2.3.7 Key messages

- **A key foundation for prioritizing policy planning and interventions in Health EDRM is comprehensive and comparable evidence on mortality and disability.**
- **A burden of disease approach quantifies and compares health loss due to mortality and disability for different diseases and injuries.**
- **DALY is a summary measure of population health that integrates mortality and disability.**
- **DALY allows comparisons between different health hazards and offers the ability to assess the impact of DRR strategies.**

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2.4

Databases and registers as tools for disaster epidemiology

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2.4.1 Learning objectives

To understand the three major types of databases and registers available to disaster epidemiology researchers, and their associated strengths and weaknesses by:

1. Characterizing the salient differentiating features of these database and register types.
2. Providing case studies and examples to illustrate these and their usage.
3. Highlighting the strengths and weaknesses of each, and providing a global overview.

2.4.2 Introduction

The *exposome* is defined as "the totality of human environmental exposures", in other words, all the non-genetic exposures which shape individuals' life-course trajectories *(1)*. Quantification of this all-encompassing concept is challenging at a single point in time, and is even more complex over time – particularly in the context of health emergency and disaster risk management (Health EDRM) when people may be exposed to the risks or consequences of emergencies and disasters. An individual's exposure begins before birth and includes insults from multiple sources. In the normal course of events, genetics has been found to account for only about 10% of diseases, while the remaining causes appear to be from life histories and environment *(1)*. Significant insults from emergencies and disasters have even a greater impact.

A key factor in describing and understanding the exposome and a person's resultant life-course trajectory is the ability to accurately measure germane factors and exposures, and their effects. Databases and registers – due to their rapid evolution, availability, and the ability for them to be linked to other information sources – are increasingly being used by researchers to improve this understanding. Building on the discussion of disaster epidemiology in Chapter 2.1, this chapter outlines three major types of databases and registers that are useful for epidemiological investigations in the disaster context:

- Ongoing population-based databases and registers (typically comprising routinely collected administrative data);
- Pre-existing subpopulation databases and registers (often available from ongoing cohort studies initiated prior to the emergency or disaster event); and
- Post-disaster databases and registers (studies and databases initiated and established after the event and therefore containing no (or little) pre-event information).

2.4.3 Ongoing population-based databases and registers

Today's world is increasingly digitized with a vast amount of data produced daily. In 2018, it was estimated that 2.5 quintillion bytes of data were created each day, and this is rapidly accelerating *(2)*. Some 90% of the world's data were generated in the last two years alone *(2)*. Data are being routinely and more frequently collected from increasingly varied sources and archived. The promise of Big Data and machine learning and data science, then, is to map the exposome, and ascertain the contribution of events and exposures. However, much work remains to be done – although initiatives such as New Zealand's Integrated Data Infrastructure (IDI) *(3)* are helping. The IDI is a large national research database holding microdata about all New Zealand people and households. It links detailed data from health, education, justice, income and work, population and many other sources over time. Such databases can provide a holistic detailed baseline account and history of individuals in an emergency- and disaster-affected region, and the resultant effects on those who stay or flee, included on those who were unaffected. Because these data are prospectively collected and provide complete population coverage, they are likely to provide robust and less biased epidemiological estimates of factors and exposures before, during and after an emergency or disaster. However, they are limited by the scope and quality of the data that are actually collected *(4)* and administrative data typically lack important qualitative information. This is because administrative data collected by government agencies are generally for the purposes of registration, transaction, monitoring and record keeping, rather than for research or research-related objectives *(5)*. How these types might be used in Health EDRM research is discussed in Chapter 4.4.

Such broad-based, comprehensive, linked population-based datasets remain uncommon internationally, although this is changing rapidly. For example, in Republic of Estonia, an efficient, secure and transparent nationwide digit ecosystem has been built that includes integrated data from different healthcare providers to create a common record for every patient (https://e-estonia.com). Within the domain of health, medical databases are often massive repositories of routinely collected detailed information and may serve as a robust research tool *(6)*. For example, patient registries with complete nationwide coverage and individual-level linkage potential have existed in the Republic of Finland since 1969, Denmark since 1978, Sweden since 1987, the Republic of Iceland since 1999 and Norway since 2008 *(7)*. These health registers can be used to provide baseline information and to track the impact of emergencies or disasters. Case Study 2.4.1 provides one example in which routinely collected information from Christchurch Hospital in New Zealand is used to assess the impact of the 2010-2011 Christchurch earthquakes and a change in their healthcare service delivery model.

However, routine databases and registers are often not appropriately designed for specific disaster research purposes or do not lend themselves to this. At times, they absorb considerable resources for very little scientific gains *(4)*. Furthermore, the precise exposures or confounders that researchers wish to explore or account for are frequently absent from these databases *(10)*. This, in part, motivated the development of the REporting of studies Conducted using Observational Routinely collected health Data (RECORD) statement to aid transparency and improve research reporting (www.record-statement.org). Although, for hazards that have slow onset but long duration, such as deforestation and air pollution, the ongoing population-based databases designed with long term broad-based measures may be advantageous over post-disaster tailored databases.

Case Study 2.4.1

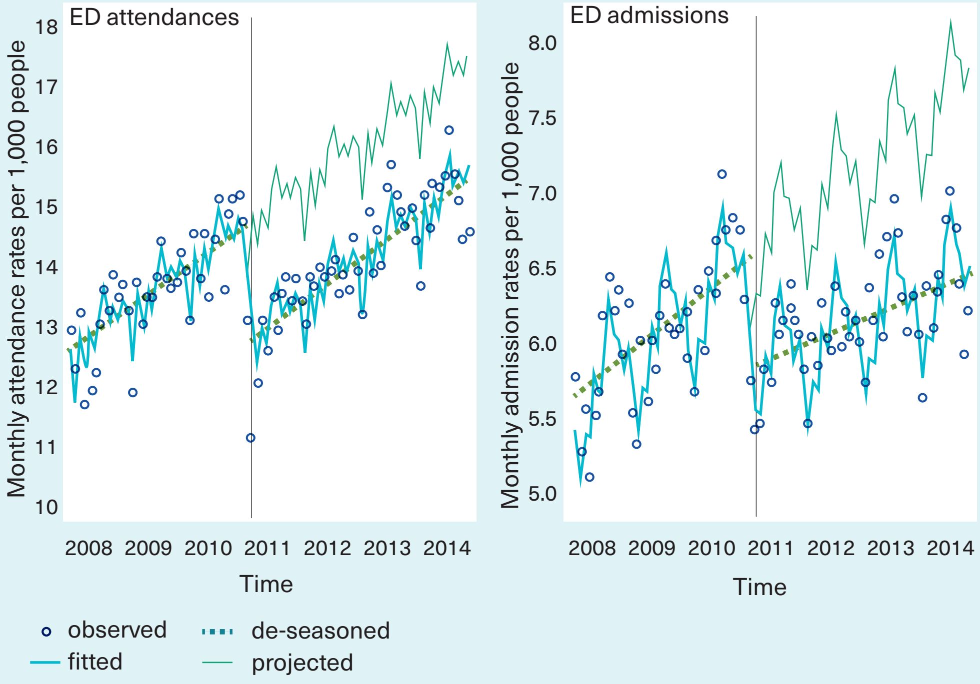
Measuring the impact of integrated health system changes on emergency department attendances and acute admission, precipitated by an earthquake *(8)*

Hospital systems routinely collect data on a number of activities, including emergency department (ED) attendances and acute admissions. These attendances and admissions are costly and often preventable. Moreover, in many countries, the healthcare service provision is increasingly recognized as being unsustainable. In response, the Canterbury District Health Board initiated a shift to an integrated person-centred healthcare model *(9)*. However, the 2010–2011 Christchurch earthquakes and aftershock series (the most devastating of which occurred on 22 February 2011, resulting in 185 deaths, more than 6500 injuries, an estimated 10 600 people relocating to outside of Christchurch, and costing NZ$ 40 billion – or 19% of New Zealand's Gross Domestic Product) compromised infrastructure and disrupted services, so that this new healthcare delivery model was rapidly implemented. While conceptually appealing, the evidence base for such a service model is relatively weak, and the empirical impact it had within the Canterbury District Health Board was unknown. By interrogating the routinely collected ED attendance and admission records for Christchurch Hospital, the single tertiary hospital in the region serving approximately 500 000 people, one important component of the earthquake impact and change in service delivery model could be measured.

Figure 2.4.1 presents the observed, fitted, de-seasoned and projected standardized population emergency department attendance and acute admission rates, derived from models using Bayesian change-point methods. The 'projected' line gives the predicted rates based on pre-earthquake and pre-existing healthcare delivery model, while the 'fitted' line gives the actual rates derived from the routinely collected data. The demonstrative change post-earthquake, together with the significantly decreased rate of growth in emergency department admissions is also depicted. These findings support the conclusion that, after the earthquake, the Canterbury District Health Board's integrated health systems transformations have resulted in a dramatic and sustained reduction in emergency department attendances and acute hospital admissions.

Figure 2.4.1 shows scatter plots of observed Canterbury District Health Board standardized monthly Emergency Department (ED) attendance rates (left) and Emergency Department admissions (right) per 1000 people (hollow circles), together with a superimposed fitted lined from the full time-series model (solid line), the estimated de-seasoned trend line (heavy dashed straight line) and the extrapolated projected line (grey line). The vertical line denotes the 22 February 2011 earthquake.

Figure 2.4.1 Scatter plots of observed Canterbury District Health Board standardized monthly Emergency Department attendance and admission rates per 1000 people.



2.4.4 Pre-existing sub-population databases and registers

Another rich source of exposome data arises from serendipitous pre-existing cohort or longitudinal studies that were already being conducted in an area affected by an emergency or disaster. These studies often contain pre-event information from multiple health, social and environmental domains; invariably using instruments with excellent research-orientated psychometric properties. Moreover, participants in these studies commonly have their data augmented by information collected from other sources. This reduces responder burden, and also harnesses a greater information landscape. One such example is the Avon Longitudinal Study of Children and Parents, which was established to understand how genetic and environmental characteristics influence health and development in parents and children *(11)*. Other examples include the nationally representative Demographic and Health Surveys which are regularly conducted in various African, Asian, European, Oceanian, Latin American and Caribbean countries *(12)*, the China Health and Retirement Longitudinal Study *(13)*, and the Nurses' Health Study in the USA *(14).*

A similar study exists in Christchurch – the Christchurch Health and Development Study, which follows 1265 children born in 1977. At the time of the 2010-2011 Christchurch earthquakes, the Christchurch Health Development Study cohort participants were aged 34 years, with just over 50% exposed to the earthquakes and the remainder unexposed (forming a non-randomized control group). The comprehensive pre-event data, combined with the different earthquake exposure levels, provides a powerful mechanism to understand the disaster impact: the study presented as Case Study 2.4.2, for example, explored the role of peri-traumatic stress in predicting major depression symptoms. Pre-existing longitudinal studies with data linkage capabilities to population-based registers can also provide new possibilities for analysing peri- and post-traumatic stress symptoms following a disaster. For example, when combined with health service use data, a more comprehensive view of the impact of physical and mental trauma on individuals across a longer time span can be gained.

Case Study 2.4.2
Understanding the role of peri-traumatic stress and disruption distress in predicting symptoms of major depression following exposure to a natural disaster (15)

Few studies have examined the contribution of specific disaster-related experiences to symptoms of depression. This study investigated this among an existing cohort of individuals exposed to the 2010-2011 Christchurch earthquakes and associated major aftershocks. One of the perennial challenges associated with disaster epidemiology research is the availability of detailed pre-event data. However, Christchurch is home to the long-running Christchurch Health and Development Study, a birth cohort of 1265 children born in 1977. This cohort has now been studied repeatedly from birth to age 35 years, has maintained high retention (79% of those surviving) and the resultant database contains a large repertoire of life-course information. More than 50% of the study cohort were exposed to the earthquakes, and at age 35 years, those exposed were interviewed about their experiences of these earthquakes.

The strengths of this study include the availability of data from a well-studied cohort and the use of a model which tests for both peri-traumatic and post-event distress simultaneously. Pre-earthquake covariates included cognitive ability, prior history of mental disorder and familial socioeconomic status measures. Previous studies which report that major depression is related to post-event factors have not looked at confounders of this association. The study found that peri-traumatic stress is an under-recognized predictor of major depressive disorder following a disaster caused by natural hazards.

2.4.5 Post-disaster databases and registers

Pre-existing population-based databases and registers or research-based studies are often inadequate or insufficient to understand the health impacts and service gaps on a population following an emergency or disaster. In such instances, post-disaster databases or registers are needed. These are flexible and tailored to contain instruments and tools that are most pertinent to the specific population and situation. However, critical gaps in observational research instruments still exist, such as the monitoring of long-term mental health or psychosocial risk of people in both a clinical and community setting *(16)*. Moreover, the clear disadvantage of this approach is that predisaster information must be recalled or retrieved retrospectively, which can suffer from important biases, such as selection bias and information bias. Practical and ethical considerations are also paramount. These include interference with emergency responses or recovery, participant safety and sensitivity and ensuring that truly informed consent can be obtained (see also Chapter 3.4). Nonetheless, this is a common and important approach taken by researchers and agencies alike. Examples include the World Trade Center Health Registry *(17)* described in Case Study 2.4.3, the 1995 Oklahoma City Bombing Injuries Database *(18–20)* and the Canterbury Earthquake Recovery Authority Wellbeing Survey *(21)*.

Case Study 2.4.3
World Trade Center Health Registry (17) and the longitudinal determinants of depression among World Trade Center Health Registry enrollees, 14 to 15 years after the 9/11 attacks *(22)*

The World Trade Center Health Registry is now the largest registry in UnS' history to track the health effects of a disaster. It tracks the impact of the 9/11 attacks, a series of four coordinated attacks by the terrorist group al-Qaeda on 11 September 2001. The attacks killed 2996 people, injured more than 6000 others, and caused at least US$ 10 billion in infrastructure and property damage, with other dying of 9/11-related cancer and respiratory diseases in the months and years after the attacks. The World Trade Center Health Registry was established post-disaster, and enrolment was voluntary for people who lived, worked or went to school in the area of the disaster, or who were involved in rescue and recovery efforts. To enrol, participants completed a confidential "Wave 1" health survey in 2003 or 2004. More than 71 000 people enrolled, including 4000 survivors of the collapsed World Trade Center towers. Multiple measurement waves have followed, with surveys in 2007, 2011 and 2015. The results of these surveys help determine the extent to which physical and mental health conditions have persisted, and whether any new symptoms and conditions have emerged.

Another important goal is to identify and help address gaps in physical and mental health treatment. For example, in Jacobson and colleagues (2018) study, the longitudinal determinants of depression among different PTSD levels were examined for 21 258 enrollees who had completed four questionnaires over 14 years of follow-up. They found that 18.6% experienced depression, and it was more common among those who had ever experienced PTSD (56.1%) compared with those who had not (5.6%). These findings highlight the substantial burden of depression in a trauma-exposed population 14 to 15 years after the disaster, especially among those with PTSD. Many World Trade Center Health Registry research outputs have been published *(23)*. Moreover, like many bodies (such as the Integrated Data Infrastructure in New Zealand), the World Trade Center Health Registry welcomes proposals for new studies from external researchers. Upon approval, researchers can request de-identified survey data or request that the Registry facilitate recruitment of enrollees into a study.

2.4.6 Conclusions

Disaster epidemiology researchers are able to use a variety of health-related databases and registers when studying topics of relevance to Health EDRM. A broad overview of the important strengths and weakness typically associated with databases and registers is presented in Table 2.4.1. However, each specific dataset and scenario may have other important strengths and weaknesses and requires careful critique and evaluation before it is used in research.

Table 2.4.1 Important strengths and weakness typically associated with databases and registers used as tools for disaster epidemiology

Major register types	
Strengths	**Weaknesses**
Ongoing population-based databases and registers:	
Cost: usually relatively inexpensive; Coverage: usually population wide; Predisaster information available; Time: relatively quick to undertake.	Not designed for disaster research; Important instruments or variables may be missing or have poor psychometric properties; Database linking may be difficult or impossible; Selection bias may mean that those missing from the register are importantly different from those included; Data are often aggregated or grouped in ways that lead to findings suffering from the ecological fallacy; Big Data datasets require data storage systems, computation capacity and performance, and analytical techniques that are (currently) often beyond the scope of many individual researchers.
Pre-existing sub-population databases and registers:	
Cost: potentially inexpensive if ‘added-on’ to an existing study; Predisaster information available Typically cover subject matter in-depth; Capability to augment with qualitative information; Instruments normally designed for research purposes and often tested for psychometric properties and reliability.	Not originally designed for disaster research, so may miss important factors or exposures; Recruitment or retention to the existing study may limit the external validity of finding; Study participant sample size may lack statistical power.
Post-disaster database and registers:	
Designed and tailored for disaster and population of interest.	Cost: usually expensive; Predisaster information is limited; Potentially time consuming and resource or expertise intensive; Timely collection of data may be unethical; If a multi-agency, multi-sector research collaboration then competing interests may exist and hamper the scope.

2.4.7 Key messages

- **There are multiple and growing sources of data available for disaster epidemiology research. Knowledge of the exposome can be extended and developed by using and linking these data, and exploring how emergencies and disasters affect people's likelihood of mortality, morbidity and life-course trajectories.**
- **The expediency of using routinely collected data is often offset by the coverage, depth and quality of the variables available to researchers. This often requires initiation of a post-disaster study, that is both specifically and contextually relevant to the disaster and the population affected.**
- **As more better quality and richer data are collected, Big Data, machine learning and data science are likely to play an increasingly important role in disaster epidemiology research. However, possible avenues to augment these quantitative data with qualitative information still need to be explored.**

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2.5

Identifying and engaging high-risk groups in disaster research

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2.5.1 Learning objectives

To understand how to identify and support high-risk groups in disaster research by:

1. Describing high-risk groups in the community.
2. Addressing barriers to inclusion through strategies for sampling, recruitment and data collection.
3. Engaging co-researchers or community advisors within the population of interest to ensure inclusive, ethically responsible research processes, and valid findings.

2.5.2 Introduction

The growing frequency and intensity of disasters will leave more people vulnerable to physical and mental health risks than ever before. The consequences of a changing climate will exacerbate existing inequalities in health and broaden the geographic and social patterns of disparity *(1)*. High-risk groups are defined by disadvantages resulting from the characteristics and intersection of age, gender and sexual identities, race, culture, religion, disability, socio-economic status, geographical location, or migration status. Importantly, it is not only the stand-alone identities, but the intersection of different identities that can create or worsen risk *(2)*. These groups may have a history of marginalization, stigmatization, existing health conditions, or developmental vulnerability that amplifies health risk when intersected with disaster exposure. An individual's disaster vulnerability is dependent on contextual factors and timing, which means their level of resilience may be depleted at times, but strengthened at others (Chapter 3.2). However, several risk factors have been identified that contribute to consistent patterns of disaster risk. It is therefore critical that health services and DRR policies be informed by the growing evidence base to ensure that services cater to the specific needs and capacities of high-risk groups.

Health EDRM strategies seek to prevent and mitigate risks among those most vulnerable in all phases of the disaster cycle (Chapter 3.2). It is important that research protocols are designed to be inclusive of groups that may be high risk and understand their needs across all these phases. The following examples highlight potential research topics that engage high-risk groups across each of the four phases of the cycle:

i) Prevention/mitigation: Identifying specific disaster risk perceptions among low-income migrant and seasonal farmworkers *(3)*.

ii) Preparedness: Assessing preparation for medication access fluctuations or knowledge of accessible evacuation routes among people with chronic disease *(4)*.

iii) Response: Examining psychological perspectives and reactions among adolescents affected by earthquakes *(5-6)*.

iv) Recovery: Determining the processes of restoration and barriers to recovery among persons with disabilities *(7).*

When conducting population-based research, it may be easy to miss the distinct vulnerabilities of high-risk communities hidden by political or social status, or those who are at risk of being marginalized, stigmatized or persecuted if identified. Accordingly, targeted research that is sensitive to the political and social context will provide greater representation and deeper understanding for the circumstances of specific communities.

Groups considered to be high-risk will simultaneously demonstrate specific strengths. Individual resilience, strong family or peer attachments, preparedness knowledge, established connections within the community, and experience of earlier disasters will influence a person's capacity to respond and recover from a disaster. It is vital that disaster research investigates and promotes both the heightened risk and evidence of resilience for high-risk populations. Research will thus play an important role in informing the equitable delivery of services in a context where resources are often severely limited. This chapter presents a concise literature review, with case studies from high-, middle- and low-income countries, to provide guidance in conducting inclusive and ethically responsible research.

2.5.3 High-risk populations

The vulnerabilities and resiliencies of populations may shift depending on the disaster scenario (Chapter 3.2), with different disasters distinctively heightening specific risks. For example, in a disaster in which evacuation is necessary, careful planning will be required for those with mobility issues – such as people with physical disabilities that inhibit movement, functionally limited elderly and other homebound persons. Similarly, those who are less well connected to mainstream communication services due to language restrictions, education level, migration status or other means of marginalization, may not receive adequate guidance on disaster risk management or access to health services. In heatwaves, cold-waves, heavy rainfall and flooding events, which require populations to stay indoors, the homeless and those living in compromised housing are at increased vulnerability and may require appropriate shelter. It is important that research defines and addresses issues relevant to high-risk populations to support evidence-informed DRR practices and policies. The following section addresses some common factors that have potential to increase vulnerability.

2.5.4 Age and developmental stage

Both young and old age present potential risks in disasters. Children and adolescents (aged 0-19 years) are vulnerable because at early ages they often depend on caregivers to supply their basic needs and support their wellbeing *(8)*. Their age-specific needs, such as an uninterrupted supply of infant formula, identification of safe routes to school or distribution of developmentally appropriate disaster preparedness information, may be easily overlooked in disaster risk management activities *(9)*. During later adolescence, the dependence on parents will diminish but family support often remains a critical protective factor following trauma *(10)*. Adolescent girls in particular begin to have reproductive health needs that should be supported through comprehensive education and services.

Short and long-term separation from parents during a disaster is a particularly important stressor for children. Short-term separation may occur if a disaster strikes while children are at school or home alone, whereas long-term separation results from displacement or the death of parents *(9)*. Without caregivers, children are at increased risk of abuse, neglect or trafficking *(11)*. Although many children and adolescents report considerable resilience and post-traumatic growth after emergencies; high levels of disaster exposure, loss of resources, security risks, and separation play a significant role in the potential development of psychological and physical trauma *(10, 13)*. Case Study 2.5.1 provides further detail on adolescents' needs and engagement in DRR strategies in China and Nepal.

Case Study 2.5.1
Conducting mixed methods disaster research on adolescent engagement in DRR in China and Nepal

Despite the increasingly active role that young people are taking in DRR and climate action, the specific needs and roles of adolescents are often overlooked. The collaborative Study on Adolescent Resilience after Disasters was conducted in Nepal and south-western China to understand adolescents' disaster-related risks, mental health needs, and engagement in DRR *(10)*. Key partnerships with local organizations were established to inform the development of the study, support access to the target population, lead data collection, and guide the interpretation of results and dissemination of findings. In addition to the participation of adolescents aged 13 to 19 years affected by disasters, the study included a wide range of stakeholders involved in adolescent development such as parents, teachers, healthcare professionals and community leaders.

Using a mixed methods design (see Chapter 4.13), the study comprised an in-depth qualitative study of risks, strengths and opportunities for adolescents affected by disasters, followed by a large-scale quantitative assessment. For the qualitative study, purposive and snowball sampling were used to recruit the target population, ensuring access to participants beyond the researchers' networks. Informed consent was sought for all participants and from caregivers for those under 18 years of age.

Semi-structured, in-depth key informant interviews and focus group discussions were conducted with a total sample of 69 adolescents and 72 adults across both countries. Five major themes were identified in the analysis of data on DRR for adolescents: (i) the importance of adolescent safety and security post-disaster; (ii) adolescent participation in disaster preparedness; (iii) disaster response tailored to adolescents' needs; (iv) the need for evidence-based psychosocial support; and (v) acknowledgement of adolescent participation in disaster risk management *(10)*. The qualitative process identified not only the strengths and weaknesses of current practice, but also recommendations voiced by participants, particularly adolescents.

Adolescents had been active participants in the disaster risk reduction process in both China and Nepal. While coping with their own experience of trauma and loss after disasters, many reported involvement in delivering first aid, participating in rescue efforts, promoting preparedness strategies, arranging security surveillance in temporary camps, and caring for family members *(10)*. The study therefore highlights the importance of recognizing co-existing resiliencies and threats for high-risk groups, revealing a need for DRR programming that supports adolescent safety and empowerment after a disaster *(10)*.

Similarly, although not all elderly are at higher risk during disasters, older age does typically come with greater health needs and vulnerabilities. Elderly people (defined as 60 years and above) *(13)* may have deteriorating physical abilities and in some cases, experience difficulty performing activities of daily living (ADL) *(14)*. "Activities of daily living" comprise a person's basic functional ability, including bathing, dressing, eating, getting in and out of beds and chairs, using the bathroom and mobility in the home. Instrumental Activities of Daily Living (IADL) comprise the ability to live independently within a community, including capacity to prepare meals, manage money, shop, use the telephone, take prescribed medicines correctly, complete light housework and travel outside. Older persons may also have diminished sensory capacities or ability to regulate body temperature and pre-existing medical conditions, such as dementia and mental health conditions *(14–15)*. These impairments may present as vulnerabilities in disasters, requiring the provision of additional functional assistance and care.

2.5.5 Gender and sexual identities

Women, girls and people with non-binary gender can be disproportionately affected by disasters, because of societal barriers, restrictions on freedom of movement or access to prevention, response and recovery services, specific health needs and higher risk of domestic and sexual violence *(16)*. Depending on the cultural context, women and girls may hold a lower social status in the community and have reduced access to resources such as education, income or health services *(8, 17)*. Furthermore, their capacity to take desired preventative actions in disasters may be hindered by unequal power dynamics and differing risk perceptions between genders *(18–19)*. They may have roles of caretaking and responsibilities that reduce their mobility and increase their workload *(8)*. There are also specific health and resource needs of women who are pregnant, menstruating or lactating *(21)*. Pregnant women may have reduced mobility, heightened nutritional needs, and require prompt access to healthcare services. Menstruating and lactating women require regular access to private settings and provision of menstrual hygiene resources.

In post-disaster settings, women have a higher risk of experiencing sexual abuse and domestic violence *(21–22)*. In a study of 82 cases of violence against women and children following the 2011 Great East Japan Disaster, Yoshihama and colleagues *(23)* found that domestic violence increased in severity in the year following the disaster. Similarly, non-partner violence occurred when perpetrators were able to exploit the victims' financial or social vulnerability, particularly in insecure settings such as evacuation centres or temporary housing *(23)*. These findings are consistent with reports of exacerbated domestic and sexual violence following Hurricane Katrina *(22)*, Australian bushfires *(21)*, and the Indian Ocean tsunami *(18)*.

In many settings, members of the Lesbian, Gay, Bisexual, Transgender, Queer, and Intersex (LGBTQI) communities are at risk of experiencing stigma and discrimination both before a disaster and during the response and recovery periods, heightening their disaster vulnerability and restricting access to health-related services. For example, in evaluations of prior disaster response programmes, same sex couples and people with non-binary gender have experienced exclusion from shelter and aid due to policies that use traditional definitions of family *(24)* or gender *(25)*. Furthermore, members of the LGBTQI community may fear violence or discrimination should their identity be revealed as a result of accessing health services *(26– 27)*. It is important that Health EDRM researchers consider the broad spectrum of gender and sexuality, and how existing policies may impact the development of assessment protocols, interventions and systems of evaluation. For example, training packages recently developed by the International Organization of Migration (IOM) were designed to support effective assistance for LGBTQI people in humanitarian emergencies and have relevance for the development of inclusive research protocols *(28)*.

2.5.6 Pre-existing chronic conditions

Pre-existing chronic conditions can be exacerbated by disaster-related disruptions to medication supply, routine health care and critical infrastructure. Survivors of heart disease and stroke, or people with hypertension and diabetes require regular access to medications *(29)*. Disrupted treatments for those with cancer or chronic kidney disease could affect their health, and cause patients to have weakened immune systems and be at higher risk of infections and injury *(30)*. Home-based treatments could be affected by loss of electricity, such as oxygen therapies for patients with severe respiratory diseases *(30)*. Furthermore, those with pre-existing psychological difficulties are at risk of poorer mental health outcomes after a disaster *(31–32)*. Case Study 2.5.2 demonstrates the impacts of disrupted treatments for people with chronic disease.

Case Study 2.5.2
Assessing the impact of Hurricane Katrina on persons with chronic disease *(33)*

Hurricane Katrina, a category 4 storm, landed in the south-eastern USA in August 2005 causing more than 1600 deaths and the displacement of 1.3 million people *(34, 35)*. While chronic disease patients are known to suffer disproportionately in disasters, the extent to which treatments are disrupted is not well known. A study was conducted to assess the causes and extent of chronic disease treatment disruption among hurricane survivors *(33)*. A large population-based sample of English-speaking adults over 18 years of age participated from January to March 2006, five months after the disaster *(33)*. Two sampling frames were used: a telephone bank of households located in counties impacted by the hurricane, as defined by the USA Federal Emergency Management Agency, and cellular and land-based telephone numbers from an application for requesting American Red Cross assistance. These sampling frames were examined and found to be relatively robust, especially since many displaced households forwarded their pre-hurricane numbers to reachable numbers. The sampling strategies included random digit dialing from the telephone lists and oversampling of the New Orleans area, which was severely impacted by the hurricane. A prescreening questionnaire was used to determine eligibility based on pre-hurricane residence, after which 1043 participants were included in the final sample, with a 41.9% response rate *(33)*. Information was gathered on demographics, residence, social network, chronic conditions and treatment. Weights were applied to reduce potential overlap of the two sampling frames and to adjust for differences of the sampling method with the general affected population.

The study revealed that 73.9% of participants reported chronic conditions prior to the hurricane, and among those, 20.8% reported disrupted treatment after the hurricane *(33)*. Treatment disruptions were more common for mental disorders, diabetes and cancer, where the lack of treatment had asymptomatic consequences, rather than chronic conditions that would become symptomatic without regular treatment, such as respiratory, cardiovascular and musculoskeletal conditions *(33)*. Treatment was more likely to be disrupted among those who were under 65 years of age, with fewer close friends and family nearby, and for those who experienced more residential instability after the hurricane. Common reasons for treatment disruption included lack of access to physicians, lack of access to medication, and problems with finance, insurance, transportation or demands on time *(33)*.

The use of a telephone sampling methodology would have excluded those unreachable by telephone and possibly the most disadvantaged or most seriously ill. Furthermore, landline telephone surveys were more likely to recruit older participants, which may account for the high rate of chronic conditions in the sample. Although the study did not comprehensively collect data on all chronic conditions, or include details on disease severity, extent of treatment cutbacks and their clinical outcomes, it highlights the importance of treatment continuity for people with chronic disease affected by disaster.

Overall, recommendations were made to anticipate chronic care needs in disaster management plans and enable continuation of treatment by ensuring timely reestablishment of primary healthcare systems, access to medical records, and activation of portable emergency insurance coverage.

2.5.7 Persons with disabilities

Persons with disabilities “include those with long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” *(36)*. This is not a homogeneous group, and their vulnerabilities, which cover a diverse range, are likely be exacerbated differently depending on the hazard. Specific disabilities may include acquired brain injury, blindness, deafness, neurological conditions, spinal cord injury, reduced limb use and amputation which may hinder one’s ability to receive or act on disaster information *(37–38)*. For example, in an UNDRR survey on persons with disabilities, a respondent described that “Because I can’t hear sirens, when there is severe weather, I have to stay awake to watch storms until they are all gone” *(39)*. If an evacuation is required, those with mobility issues within the evacuation parameters would be at increased risk. Persons with disabilities are often overlooked in receiving assistance *(37)*. Compounding factors that increase barriers to assistance include isolation, stigma, inaccessible resources and services, communication difficulties and cognitive impairment *(40)*. Furthermore, people with a disability can be especially vulnerable if they have lost their usual supports during or after the disaster, because they may be deprived of the care that they need *(8)*.

2.5.8 Other marginalized groups in the community

Other marginalized groups in the community may include migrants, Indigenous and First Nations peoples, undocumented persons, displaced persons, those living in poverty and the homeless. Marginalization may prevent access to health care, resources, or information *(41)*. In some disaster settings, marginalized groups (such as people living in poverty) may comprise the majority of the population. People at risk of discrimination and inequity may also be more likely to reside in risky living conditions *(42–43)*. For example, despite the high quality health care available in parts of the Eastern Mediterranean region, refugees residing in those countries may be less likely to be able to access health services and obtain pharmaceuticals due to policy, social or economic disadvantage *(44)*. Furthermore, literacy, language, different abilities or cultural differences may prevent people from receiving and understanding disaster warning messages, particularly if the messages are only provided in the dominant language or via mainstream communication channels *(37)*. People living in geographically remote communities may be similarly vulnerable due to poor communication pathways, road access and distance from disaster prevention, preparedness, response or health services.

2.5.9 Barriers and strategies in conducting research with high-risk groups

Once high-risk populations have been identified, the research process might encounter challenges in sampling, recruitment and data collection. High-risk groups may overlap with hard-to-reach groups that are difficult for researchers to access. For some, it may be dangerous to self-identify, especially those with illegal status, mistrust in authorities or those susceptible to stigma and discrimination *(45)*. High-risk groups can also be low in numbers within the population or geographically dispersed.

Sampling

Sampling can be one of the main barriers to conducting rigorous research with high-risk groups. A regular random sampling method is often inadequate to acquire sufficient sample sizes (that is, statistical power) of those who are hard-to-reach *(45)*. The list of all potential participants in the population of interest, also known as the sampling frame, might be unknown, preventing the use of probability sampling to help ensure that results are representative. Alternative non-probability sampling methods may be used depending on the research study *(45)*. These include convenience sampling, which selects participants that are accessible and eligible for participation. Purposive sampling selects participants that fit a certain inclusion criterion relevant to the study purpose. This may be complemented by 'snowball' sampling or respondent-driven sampling, where participants assist in recruiting more participants from their social networks, enabling an expansion of the sample group beyond the researchers' links. Low prevalence population sub-groups can also be oversampled in order to obtain more data for minorities *(46)*. Other more complex sampling methods include targeted sampling or venue-based time-location sampling, where participants are sampled from an exhaustive list of venues that the target population frequents *(47)*. High-risk groups can be located in places that they commonly attend, such as schools, clinics, community events or certain residential neighbourhoods *(48)*. A combination of sampling strategies can be used to best reach the high-risk group.

Sampling should be conducted in collaboration with community organizations that have access to the target population. Stronger research outcomes can be achieved by partnering with organizations led by members of the high-risk group, or that have direct access to such groups, through service delivery or advocacy *(49)*. It is important to include relevant stakeholders in the research, such as community group members, hospital staff, informal caretakers of patients, and guardians of children, as they may add insight or a different perspective into the circumstances of the target population (see also Chapter 4.12). Community advisory boards also play an important role in guiding the development of research protocols, sampling strategies and the interpretation of findings. Working with partner organizations and community advisory boards can help to build trust, which is critical to the research process and will assist with the following stage of recruitment.

There are limitations and biases that occur with each sampling method, which may affect the research results. Selection bias is introduced by the way individuals are chosen as participants. For example, sampling chronic disease patients at local public hospitals would exclude those who attend private clinics only, or those who do not seek treatment for their conditions. Non-response bias occurs when those who participate in the study are inherently different from those who refuse to participate. This can occur with telephone surveys, mail-surveys, internet sampling, and is of particular concern in follow-up studies. Gatekeeper bias, where participation is limited by those who provide entry into the community groups, may restrict the types of participants that can be involved in the study. Addressing biases through a more comprehensive or open sampling strategy is important to ensure the rigor of the study.

Recruitment

Low recruitment rates are often highlighted as a challenge for researchers working with high-risk communities. Lack of trust in the researchers and the fear of being mistreated or exploited are important considerations that may present potential barriers to recruitment *(45)*. For example, a follow-up study on PTSD in the 2 to 3 years after the September 11 terrorist attacks in New York described the limitations of potential self-selection and nonresponse bias, despite having used a large registry and multiple recruitment methods *(50)*.

Such issues could be addressed from the outset by devoting sufficient time and resources to building community relationships. Long-term partnership with the community can in turn foster interest and engagement among potential participants. Trust can be developed by working with and engaging the support of community, religious leaders and local authorities, employing members of the high-risk group as research investigators, staff or translators, and involving community groups in the research process *(45)*. Engagement can be fostered with the use of culturally and linguistically appropriate materials, social marketing strategies such as media and advertisements, and providing reimbursements for participants' time and travel expenses *(45)*. Furthermore, increased sense of ownership can assist recruitment, particularly if the research is community-driven and the results are shared back to the community *(45)*.

The most effective methods of recruitment vary, including personalized outreach and online recruiting. For example, a study in a multi-ethnic neighbourhood in south England found that local advertisements were found to recruit more white participants, while ethnic minorities were recruited more effectively using interpersonal contacts and institutional contacts, respectively *(51)*. A study in the Philippines after Typhoon Haiyan explored both the usefulness and disadvantages of Facebook as a recruitment tool in the general population *(52)*. Social media is an efficient recruitment tool that supports participant independence and geographical diversity, enabling engagement in areas outside the researcher's physical reach. However, online recruitment is self-selecting, vulnerable to noise, and may not be representative of the general population *(52)*. What works in one population group may not work in the next, and so an in-depth understanding of the worldview, preferred communication networks, and interests of the group of interest is critical.

2.5.10 Data collection

The methodology used for data collection may differ depending on the study design. Qualitative research, as discussed in Chapter 4.12, may capture greater complexity and enable deeper involvement of high-risk group members. In contrast, quantitative research may enable greater generalizability through measurable data. A combination of quantitative and qualitative methods in a mixed-methods study design, as discussed in Chapter 4.13, may allow for both complexity and greater generalizability. Case Study 2.5.1 illustrates this. Longitudinal research presents opportunities to examine trajectories of change after disasters, and the impact of interventions within communities. Researchers, however, may experience difficulty in retaining participants in longitudinal assessments, especially among more transient populations such as migrants, nomads, and those who are homeless. Thus, flexibility is needed to cater to participants' circumstances. Pilot testing of the research materials is also necessary to ensure that the research questions and measures are relevant and appropriate to the high-risk group.

Participatory action research (PAR) (as discussed in Chapters 3.1 and 5.1), which engages participants as co-researchers, challenges traditional power relationships and knowledge through an emphasis on equity and participation *(53)*. Participatory action research (and complementary approaches such as critical participatory action research and youth participatory action research) provides an opportunity for more targeted and critically valid research that includes groups less often represented in the scientific literature. In studies relevant to DRR and climate change, participatory action research has been used to engage typically marginalised groups and promote important messages of risk and disaster management *(54–55)*. The use of participatory action research in the Torres Strait Islands has promoted the combination of different types of expertise, intergenerational knowledge transfer, and community engagement in climate action and DRR *(56)*. Alongside these approaches, working with a culturally-secure lens such as the adoption of an Aboriginal worldview when working with Indigenous people *(57)*, and decolonising research strategies, will support stronger and more trusting relationships with participants, more reliable measurement, and accurate interpretation of the data.

2.5.11 Ethics Approvals and Considerations

Chapters 3.4 and 6.4 discuss key aspects of the ethics of research and obtaining ethics approval. However, when working with high-risk groups it is especially important to be vigilant about possible ethics violations, intended or unintended. A systematic review of published guidelines on research ethics in disaster settings highlighted the importance of obtaining formal approvals, but also addressing issues of vulnerability in research protocols *(58)*. Among the vulnerability factors identified, reducing risks of physical harm, retraumatization, manipulation, exploitation, unrealistic expectations and stigmatization were central to ethical research processes *(58)*. It is important to obtain informed consent from all participants. Consent can be obtained on multiple occasions, including at the end of data collection, and from multiple agencies, such as the community, parent and participant, to empower informed decision making *(59)*. For people with less access to education, language restrictions, severe mental health issues or cognitive difficulties, information about the research purpose and the participant's rights must be presented in a format tailored to promote comprehension *(60)*. Space should be given to participants to refuse the study without pressure or persecution, and to ask questions about the research activities.

It is vital that ethics approval is obtained from the researcher's appropriate ethics committee or institutional review board, as well as ethics boards relevant to the research setting (such as national ethics committees, local institutions, or protective bodies for more vulnerable populations).

2.5.12 Conclusions

Health EDRM seeks to prevent and mitigate disaster risks particularly among the most vulnerable in society (Chapter 3.2). Identifying the factors that may elevate a group's risk during or after disasters, and working with the community to create inclusive research protocols will improve the equity of disaster risk management. Consideration of diversity within and between groups is important, as is attention to the role of intersectionality. Health EDRM research has an important role to play in expanding the evidence base on best practice for high-risk groups that are too often neglected in policy and programming. A robust evidence base will support the effective and equitable delivery of disaster prevention, preparedness, response and recovery services in environments that are often severely resource constrained. Research should support decision making to determine *who* is best served by *which* services, and *when (61)*. Consideration of the factors that heighten risk, as well as the unique capabilities and strengths that support resilience is critical. Furthering our understanding of each group's specific disaster risks, resilience, preparedness and responses, will enable the formulation of inclusive and holistic disaster risk management plans, effective leadership, and equitable policies beneficial to health.

2.5.13 Key messages

- **Health EDRM research with an inclusive focus on high-risk populations should be conducted across the entire disaster cycle and may vary according to the characteristics of the disaster and community.**
- **Children, elderly, gender and sexual minorities, those with pre-existing chronic conditions or disabilities, ethnic minorities, migrants, displaced persons and other marginalized groups are common high-risk groups to be considered. Intersectionality plays a significant role in capacities and heightened vulnerabilities.**
- **High-risk populations may be difficult to reach, which can affect sampling, recruitment and data collection.**
- **Inclusive and ethically responsible research protocols must consider the impact of research on high-risk populations and guide reliable and thoughtful dissemination of findings.**

2.5.14 Further reading

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2.6

The current state of the evidence: Mapping the evidence and systematic reviews

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2.6.1 Learning objectives

To understand the importance of the following when considering the current state of the evidence and systematic reviews as a source of information for research in health emergency and disaster risk management (Health EDRM):

1. The essential elements of Health EDRM as they pertain to various stages of the emergency management continuum.
2. The current level of research and available evidence to standardize the application and practice of these essential elements in Health EDRM.
3. The optimal modalities for generating additional evidence for elements currently deemed deficient.
4. The barriers and difficulties in conducting systematic reviews and research during emergencies and disasters.

2.6.2 Introduction

The impact of natural hazards in human and economic costs has increased considerably in the past two decades, raising a global alarm. Furthermore, there are concerns about the adverse effects of extreme weather and climate change, which call for an all-hazards approach to emergency and disaster risk management. The United Nations (UN) Secretary-General's Special Representative for Disaster Risk Reduction (DRR), Mami Mizutori, said on 23 July 2018: "Every year disasters cost the global economy an estimated US$ 520 billion, displacing millions of people and pushing many of them into poverty. Reducing economic losses from disasters has the power to transform lives" *(1)*. Health EDRM research has an important role to play in meeting these challenges and concerns.

The public health impact of emergencies and disasters includes direct and indirect mortality and morbidity, trauma, injuries and disability. Health systems are also adversely impacted through damage to health infrastructure *(2)* and over-burdening of health systems in the wake of increasing demand for a variety of health services. Due to the urgent nature of emergencies or disasters, health behaviours and actions surrounding them tend to be adaptations of regular practices during non-emergencies. Issues arise when the existing infrastructures, communications, and resources are disrupted, and application of those regular practices become unrealistic, impractical or unfeasible. While best practices should be the gold standard during times of crises, it is crucial to identify lessons learned and evaluate which are most beneficial *(3)*.

Current literature is largely focused on individual emergency events and short-term consequences, and tends to be limited to only one sector. The shift in paradigm from reactive to proactive Health EDRM, applied through the lens of an all-hazards approach and multi-sectoral perspectives, means evidence has to be systematically generated and validated in order to support a whole-of-society and risk-based approach *(2)*. Despite Health EDRM being at the intersection of heath and DRR, it is still an emerging field in both practice and academia (Chapter 1.2). It encompasses emergency and disaster medicine, DRR, humanitarian response, health systems resilience and community health resilience *(4)*. Furthermore, policies and programmes which cover the disaster management cycle are not always fully evidence-supported. For example, the Humanitarian Response Review *(5)* commissioned by the UN identified serious gaps in humanitarian action and made recommendations to ameliorate the situation.

Given that all humanitarian interventions occur in inadequate circumstances, a critical factor that compounds knowledge and evidence-generation is the partial or total collapse of the systems for routine information collection and analysis (Chapter 2.4). This is commonly observed in events of structural, social, and political instability *(6)*. The poor reliability and validity of information coming from compromised or incomparable information systems within an affected area further hampers the ability to monitor trends to determine the effectiveness of interventions, and be able to prioritize reliably and allocate resources efficiently (Chapter 2.7). There is also rarely sufficient real-time evidence to show whether the humanitarian situation is improving at the level of the crisis as a whole *(6)*. Table 2.6.1 gives an overview of health response topics which are currently supported by evidence; table categories are adapted from an invited paper published by the WHO Regional Office for the Eastern Mediterranean *(7)*.

Table 2.6.1 Delineated interventional areas across Health EDRM by current status of the evidence base

Status:	Essential element of Health EDRM programmes:
Operational and fully standardized	Water and sanitation
	Nutrition
	Communicable diseases/surveillance/EWARS
	Essential medicines
	Partners/cluster coordination
	Humanitarians accountability
	Surveillance
	EWARS/Outbreak investigation and control
Not fully operational	Assessments
	Sexual reproductive health
	Human rights and protection
	Mental health
	Education and training (humanitarian services providers)
	Emergency preparedness
	Risk prevention and mitigation
	Hazards/vulnerability analyses
	Emergency risk communication
	Sexual harassment in humanitarian programmes and service delivery (staff and services' beneficiaries)
	Psychosocial first aid
	All-hazards approach
Seriously deficient	Real-time evaluation
	Health systems resilience/recovery
	Operational readiness
	Ethics of research in health emergencies and disasters
	Inter-sectoral coordination (health sector with others)
Absent/Missing	International Health Regulations (IHR 2005)
	Disaster and development paradigm and linkages

Unfortunately, it is wrongly assumed that all disaster risk management has been, and will be, based upon scientific evidence *(7)*. Further complicating the global application of knowledge is when the evidence generated is region-specific, the peculiarities may not be applicable to other cultures. Furthermore, where 'lessons learned' exercises and epidemiological research based on individual projects or crisis-led efforts do exist, and may be beneficial, a lack of systematic reviews makes it difficult to validate and assess the strength and direction of evidence for applicability in other disaster scenarios.

2.6.3 Research Rationale

Randomized trials are the most reliable way of generating evidence on the effects of interventions to guide and improve policy and outcomes in health (Chapter 4.1). Unfortunately, controlled experiments have inherent limitations and challenges for humanitarian settings, arising from, for example, the immediacy of urgent, life-saving health needs, security concerns, and marginalized status of affected populations make it difficult to gather informed consent. Nevertheless, repeated occurrence of humanitarian crises and use of remedial interventions do provide opportunities for 'practice-based evidence'. However, this does not guarantee learning or improvements for the next crisis because no two crises are exactly alike. Cultural variations may also render interventions with documented successes in one crisis, inapplicable in the next. Furthermore, without explicit practice and training to create change, people may resort to old practices, even when these are not supported by evidence.

Systematic reviews can help to identify the most efficient and effective practices during different phases of the disaster management cycle. Providing standardized summaries of the vast volume of existing studies can enable evidence-based practices for preparedness and operational readiness plans to be introduced for on-the-ground responders, field coordinators, funding bodies and policymakers to incorporate into action *(6–8)*. This is especially relevant to disaster literature as it is largely made up of observational and descriptive studies (such as cross-sectional or case control studies) which may not determine causality *(9–10)*. Traditional hierarchies of evidence are heavily influenced by biomedical experimental designs, but some of these study designs may be unsuitable for disasters due to the lack of a controlled environment and ethical implications (Chapter 3.4). Gaps in practices can also be identified to guide future research, establish standardized methods of data collection and seek out methods for information dissemination *(6, 10)*. Systematic reviews can also help with the engagement of different sectors by identifying key roles in how they directly and indirectly impact health *(11)*.

2.6.4 What are systematic reviews?

Systematic reviews are robust studies which identify existing research to comprehensively answer a research question. This is done by methodically identifying eligible studies through critical appraisal to distinguish high from low quality evidence. The use of stringent guidelines and checklists can reduce selection and publication bias, validate statistical associations and causality and identify research gaps. The overall balance of evidence is essential for good decision making because a single study may be too specific in terms of its sample population, context, and the time it was undertaken to provide a more general application.

Three main types of systematic review are discussed in this chapter: quantitative synthesis (via meta-analysis), narrative systematic reviews and qualitative synthesis. Whichever type of review is chosen, two important sources of methodological guidance should be considered: Cochrane (Case Study 2.6.1) and the Joanna Briggs Institute *(12–13)*.

Case Study 2.6.1
Cochrane and the Cochrane Database of Systematic Review (CDSR)

Cochrane (formerly known as the Cochrane Collaboration) is an international organization that promotes evidence-informed health decision-making. It is internationally recognized as one of the leaders in the production of high-quality systematic reviews. It does not accept commercial or conflicted funding for any of its reviews and has four goals: producing evidence; making evidence accessible; advocating for evidence; and building an effective and sustainable organization. It produces well-respected and widely used guidance on the conduct of systematic reviews *(14)*.

As of January 2020, there were more than 8000 full systematic reviews available in the Cochrane Database of Systematic Reviews (CDSR) *(15)* which is available at www.cochranelibrary.com. There are five main types of Cochrane Review:

- Intervention reviews, which assess the benefits and harms of interventions used in health and social care and policy.
- Diagnostic test accuracy reviews, which assess how well a diagnostic test performs in diagnosing and detecting a particular disease.
- Methodology reviews, which address issues relevant to how systematic reviews and clinical trials are conducted and reported.
- Qualitative reviews, which synthesize qualitative evidence to address questions on aspects of interventions other than effectiveness.
- Prognosis reviews, which address the probable course or future outcomes of people with a health condition.

It is crucial that guidance is followed throughout the systematic review to maintain its rigor and to distinguish it from general or scoping reviews. Table 2.6.2 lists the key steps for a systematic review.

Table 2.6.2 Steps and tools for a systematic review

Process	**Factors to consider**	**Common Tools and Resources**
Defining the question	Specify the inclusion and exclusion criteria: population, intervention, exposure, outcome, methodology, time of publication, time of data collection, language, geographic location, etc.	PICO mnemonic: Problem/Patient/Population Intervention/Exposure Comparator Outcomes
Conduct the literature review	A search criterion: Search dates, language, location, study designs, synonyms, integrate/ controlled vocabulary Information source (Chapters 3.7 and 6.2): Databases, funding agencies, trial registries, citation lists Paywalls Unpublished or grey literature Reference management	General: CENTRAL; EMBASE; EM-BIB; Google Scholar; MEDLINE; PubMed; PsycINFO; Scopus; Web of Science Disaster specific: DisDAT; EM-DAT; ReliefWeb Reference management: EndNote; Mendeley; RefWorks; Zotero
Apply inclusion and exclusion criteria	Remove duplicates Apply specific to titles and abstracts Obtain full articles for those potentially eligible Further apply criteria to the full articles	PRISMA flow chart ENTREQ ConQual COREQ JBI Review's Manual Cochrane Handbook *(14)*
Create data abstraction and analysis	Critically appraise the studies: internal validity; study methods; participant number, reliability, (comparison) interventions Analysis: effect measure, significance, certainty (such as confidence intervals, p-value), pooled estimates, subgroup analysis (if appropriate)	AGREE II (appraisal) R SAS SPSS STATA Qualitative tools
Presentation and findings	Risk of Biases within study Directness of evidence Heterogeneity Publication bias Journal, conference, oral presentations	GRADE Framework (Grading of Recommendations, Assessment, Development and Evaluations)

2.6.5 Statistical meta-analysis

Quantitative synthesis (via meta-analysis) involves pooling the quantitative data from multiple independent studies to provide a *cumulative* aggregation of findings about, typically, the effects of an intervention compared with an alternative. In order to aggregate data, homogeneity is a crucial component, whether it is in terms of the population, intervention, comparators or outcomes covered. Regarding analysis, the results are often presented as a forest plot *(16)*, which shows the precision of each independent study and the cumulative findings. Case Study 2.6.2 provides an example of a meta-analysis of mental health and psychosocial support, including forest plots (Figures 2.6.1 and 2.6.2).

Case Study 2.6.2
The impact of mental health and psychosocial support interventions on people affected by humanitarian emergencies *(17)*

In 2017, a systematic review was commissioned by the Humanitarian Evidence Programme, a partnership between Oxfam Great Britain and the Feinstein International Center at the Friedman School of Nutrition Science and Policy, Tufts University in the USA. It describes the impact of mental health and psychosocial support (MHPSS) interventions on people affected by humanitarian emergencies, using both meta-analysis and qualitative synthesis methods.

Figure 2.6.1 shows the statistical meta-analysis of the impact of MHPSS on PTSD. Some studies show MHPSS interventions have a better impact than the control situation, while other studies suggest the reverse. The cumulative estimate of effect indicates that when the data from the 21 studies were pooled, the MHPSS programmes have a positive but small effect on PTSD. In contrast, Figure 2.6.2 shows that the cumulative estimate of effect of MHPSS interventions on anxiety, based on six evaluations, is neutral. This led the authors of the meta-analysis to conclude that these programmes have no impact on anxiety.

The review's narrative synthesis analysis on gender showed that "overall, the findings reported from these studies were mixed, with no clear pattern across types of intervention or outcome". It summarized eight studies narratively, comparing and contrasting their findings.

Qualitative synthesis was also conducted, and five themes were identified which can influence the effectiveness of MHPSS interventions: community engagement, sufficient number of trained MHPSS providers, experience of programme activities, benefits of group-based programmes, and building trust and supporting relationships. This identification of areas which are influential can help future interventions be better implemented and point out areas for greater emphasis by service providers.

Figure 2.6.1 Forest Plot and Pooled Standardized Mean Difference (SMDs), 95% confidence interval (CI) and weight (W) of 21 controlled evaluations of the impact of MHPSS interventions on PTSD amongst people affected by humanitarian emergencies

Measure: continuous: d (Hedges g)
Heterogeneity: Q = 206; df = 27; p = 0; I^2 =86.9%; tau-squared = 0.29
Random effects model: -0.463 (-0.689, -0.237)

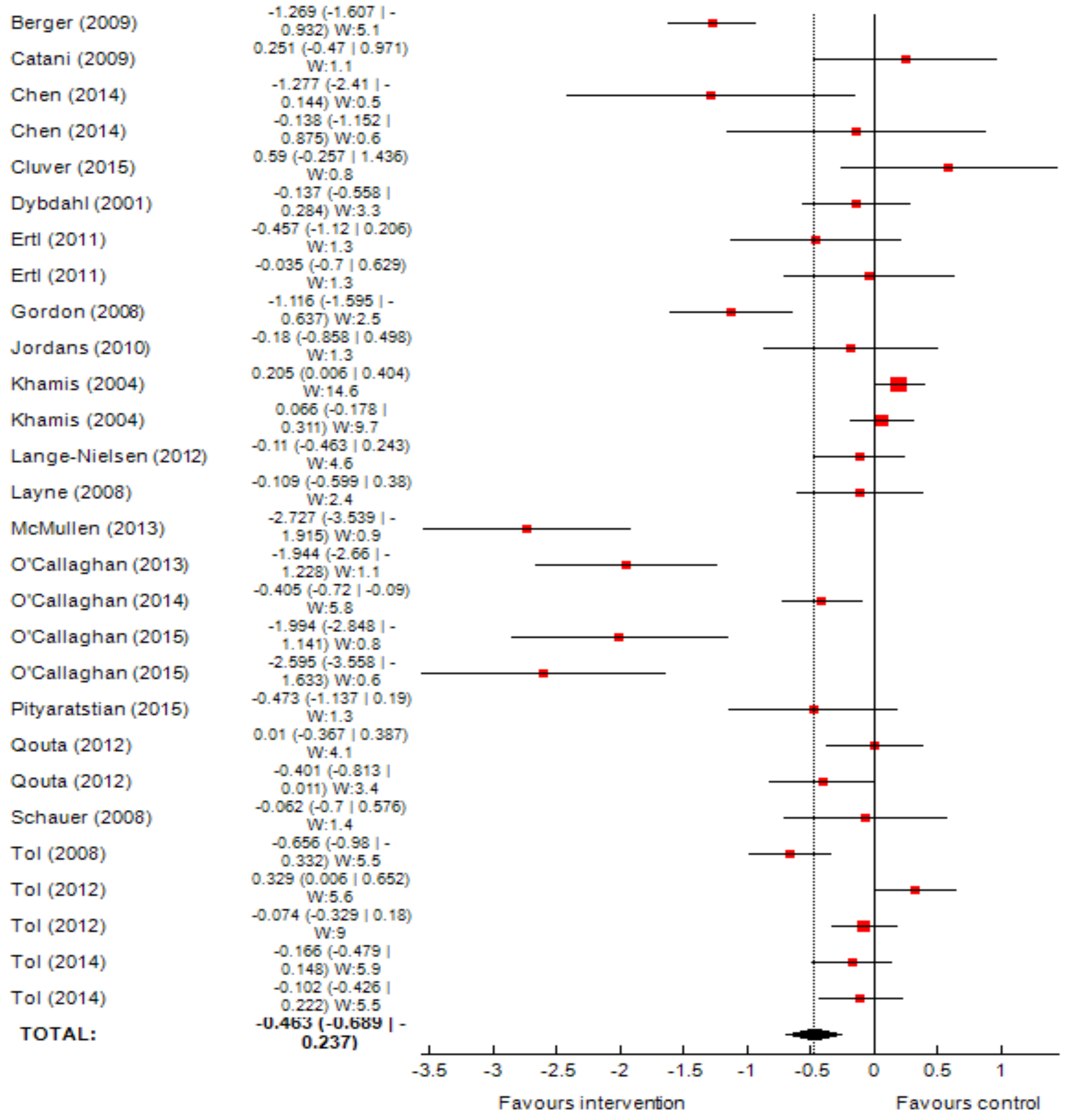
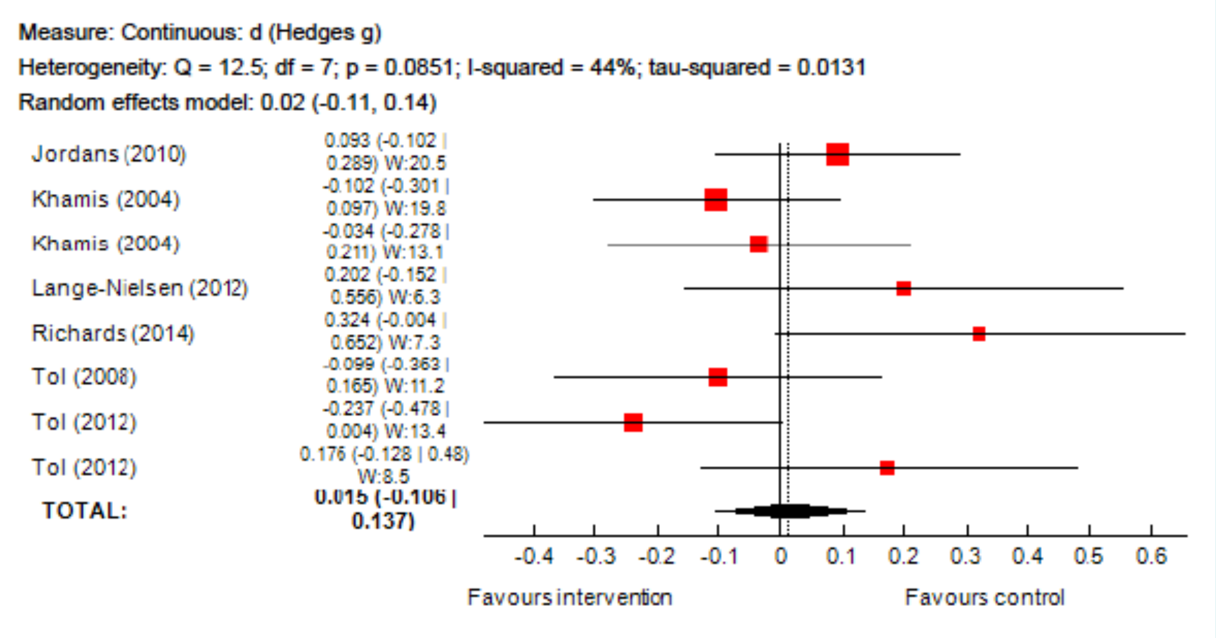


Figure 2.6.2 Forest Plot and Pooled Standardized Mean Difference (SMDs), 95% confidence interval (CI) and weight (W) of 8 controlled evaluations of the impact of MHPSS interventions on anxiety amongst people affected by humanitarian emergencies



In a forest plot (such as those in Figures 2.6.1 and 2.6.2), the solid vertical line represents no difference between the effects of the intervention and the comparator ('the trunk') and each study ('leaf') is shown to be either side of it. Each study is represented by a square to estimate the effect size for the intervention and a horizontal line for its 95% confidence interval. The cumulative estimate of effect, represented by the black diamond shape at the bottom of the figure, indicates the overall balance of the evidence from all pooled results of the individual studies.

Although most meta-analyses of the effects of interventions rely on randomized trials (Chapter 4.1), some use other evaluation designs that have varying risk of bias. These include quasi-experimental designs such as interrupted time series analysis, matched comparisons, regression discontinuity design, and difference-in-differences (Chapter 4.5) *(18–19)*.

2.6.6 Narrative systematic reviews

If the studies collected for a systematic review do not meet the criteria of homogeneity, they are often analysed using more descriptive and narrative methods of synthesis. Narrative systematic reviews use words and text (rather than cumulative statistical estimation) to summarize and explain the findings of the included studies. In effect, they 'tell the story' of the available evidence by describing and analysing the population, intervention, comparator and outcomes measured, and by undertaking descriptive and inferential statistics on each study individually. They might also help to develop a theory of how the intervention works, why and for whom, and can often provide preliminary synthesis of the findings of included studies *(20)*. This method of systematic review is prevalent in disaster literature due to the variety of stakeholders surrounding disasters, accessibility of data sources and a lack of comparable research tools.

2.6.7 Qualitative Synthesis

Evidence from qualitative studies are systematically reviewed using analytical methods of synthesis appropriate to qualitative methods and data *(21–24)*. Qualitative synthesis reviews evidence that has been gathered using in-depth interviews, focus groups, observational studies, ethnography, documentary analysis, oral histories, and case studies (Chapters 4.12 and 4.13). Rather than seeking statistical generalizations, it identifies common themes, concepts and principles across different studies *(25)*. It also gives detailed attention to the contexts in which studies were undertaken and tries to identify the contextual specificity of findings, including those that influence or determine the effectiveness of an intervention. By providing evidence from the viewpoints of providers and recipients of an intervention, local and cultural factors that influence the uptake, implementation, and impact of an intervention may be identified. Such information can help users to understand why, how, and under what conditions an intervention is likely to achieve the desired outcomes, as well as the barriers to, and facilitators of, achieving those outcomes.

2.6.8 Health elements: the current state of evidence

Most systematic reviews in Health EDRM use narrative or qualitative synthesis. This is largely because of the heterogeneity of the study methodologies and the small sample sizes, which limit the data available to be pooled. Even within the same topic, different definitions, measuring tools, and timeframes mean that studies cannot be directly compared *(26–27)*. While the lack of high quality data is often attributed to the volatile nature of disasters, it may also be due to the sensitive nature of the contents (such as gender-based sexual violence) or limited by language, whether the definition of terminology or differences in the language spoken/written. Some of the common themes and barriers to researching violence in disaster and humanitarian settings are described in Case Study 2.6.3.

Case Study 2.6.3
Existing evidence from systematic reviews on violence in disasters

The topic of violence is complex, especially when the trauma may still be ongoing. Studies on physical violence have found that men have repeated exposure to violent acts, whereas women and children tended to witness the violence – although this relationship changes for sexual violence *(28–29)*. Women are the main victims of gender-based sexual violence (GBV), but a scoping study showed there is insufficient evidence on how to support men who are sexually victimized *(30)*.

Research on child abuse and family violence may provide suggestions on prevention and intervention strategies. For example, parental trauma experience, substance abuse, mental disorder and history of child abuse were found to be risk factors for parents abusing their own children. The intergenerational cycle of violence, such as the use of physical discipline, coupled with environmental stressors such as disruption of family structure, food and shelter insecurity, and poverty all contribute to abusive behaviour *(31–33)*.

Common barriers for systematic reviews on violence are the lack of consensus and definition in terminology, which includes terms like 'torture', '(sex) trafficking', 'sexual exploitation', and abuse *(29– 30)*. Studies tend to be small because of the associated stigma and willingness to disclose such events and there is inconsistent use of validated outcome measurement tools making it difficult to compare, contrast and combine studies. Health outcomes of violence are also mostly about mental health, and physical health outcomes such as injury or disabilities are rarely reported; there are few evaluations of GBV interventions *(31, 34)*. A single study of sexual exploitation by humanitarian workers that studied peacekeepers across 36 international missions suggested that sexual exploitation and abuse was more likely to be reported for host countries with lower GDP per capita *(35)*.

A scoping search of systematic reviews published after 2005 using the key words: health, disaster, and emergencies, found that most were carried out in the Global North and only included papers written in English. Exceptions were on earthquakes (Asia), armed conflicts/humanitarian crises (Middle East and Africa), and H1N1 (China) *(36–38)*. Disasters that garnered wide media attention also dominated the available research, such as Hurricane Katrina, the 9/11 World Trade Center Attacks and the Wenchuan Earthquake. Reviews on natural hazards are largely focused on physical health outcomes, while human induced or complex humanitarian emergencies focus on mental health and psychosocial wellbeing. Only four meta-analyses were identified: two on mental health interventions; one on sexual exploitation and abuse among peacekeepers; and one on earthquake-related injuries *(17, 35, 38–39)*.

The most common contents in the reviews are health epidemiology and outcome. These include prevalence and incidence of disease, injury and mortality, particularly for natural hazards such as earthquakes, floods, and storms *(40–41)*. Mental health research has also seen a large increase in recent years, especially on the prevalence of PTSD. More attention has also been given to disaster responders *(42–43)*, and there has been a shift from research on refugees and internally displaced peoples in armed conflicts towards their health during seeking asylum and resettlement *(28, 44–45)*. Reviews on topics which have established response protocols, such as communicable diseases, have fewer recent systematic reviews unless they are about disease outbreaks (such as Ebola). Topics highlighted by the Sendai Framework, such as non-communicable and chronic disease, have garnered more publications but few systematic reviews and a reliance on observational studies *(46)*.

2.6.9 Barriers

One of the main barriers to conducting systematic reviews is the shortage of high-quality studies to review. A lack of transparent methodology, terminology definitions and rigorous criteria cause many studies to be excluded from the final analysis *(47)*. The difficulty of doing large studies is a constant disadvantage for research in a disaster, and this coupled with inconsistencies in the reported outcomes makes meta-analyses difficult or impossible. The availability of personnel to conduct field research is another barrier. In many cases, those who are responding to the disasters are also the researchers. This division of labour often means that research becomes a secondary priority *(9)*. To make it a top priority, dedicated research personnel should be established separately and well before a disaster's onset to ensure both priorities are met. As a field-based topic, Health EDRM should also consider publications from the grey literature, such as reports from non-governmental and inter-governmental organizations (Chapter 6.2).

This may be particularly true for research done within organizations, because the findings of such research are usually kept in-house. Dissemination through academic journals and conferences are primarily channels for researchers, and systematic reviewers will need to look for relevant evidence in other communication channels, including in languages other than their own.

2.6.10 The future of systematic reviews for Health EDRM

The future of systematic reviews for Health EDRM lies in identifying the most efficient methods of data collection, which includes having standardized data collection tools. Since systematic reviews provide a less biased and more statistically powerful analysis of currently available evidence, there should also be a consensus as to how often reviews on the same topic should be updated. Research should be tailored to the needs of the affected communities. For example, mental health is a broad topic that has international traction, and the focus on PTSD may exclude other aspects of mental health (such as anxiety-related diseases or other psychosocial comorbidities) that are associated with exposures to multiple hazards.

2.6.11 Conclusions

Humanitarian crises are growing in frequency, magnitude, and scale, in addition to the increasing globalization connectivity, and premature urbanization. When coupled with warnings over the hastening of adverse impacts from climate change, there is an increasing imperative that remedial elements and corresponding interventions along the emergency continuum are evidence-based, predictable, standardized, and afford the maximum efficiency and effectiveness. There also needs to be accountability if and when the interventions are not properly implemented. However, the evidence base for Health EDRM is currently variable at best, affecting standardization and predictability and which hampers accountability. To have a standardized Minimum Data Set for core outcomes will greatly facilitate interoperability across different health systems and nations by hastening data availability. That in turn will lead to a more optimal application of sound and effective interventions in health emergencies, All of which should be based on reliable and timely evidence from systematic reviews of good quality research.

Despite limitations and challenges posed by paucity of information, and concerns over the reliability and validity of information available, a large body of literature has been produced on project and crises-specific interventions covering various elements of Health EDRM and their impact. Systemic reviews need to be done to assess the strength, relevance, and utility of this body of literature for improving Health EDRM.

2.6.12 Key messages

- **Many challenges hamper the generation of evidence and its accurate and consistent application in Health EDRM. Practitioners who are aware of evidence limitations may not have the necessary training or skills to design, plan, implement and evaluate their programmes. They may also lack the training to discern programmatic and practice-based problems that could be turned into research questions for new studies (Chapter 3.5).**
- **People in low-income, resource-poor countries and settings may disproportionately suffer from the 'double jeopardy' of lacking the critical mass of trained researchers and practitioners, coupled with limited or non-existent opportunities for interaction between researchers and practitioners in Health EDRM.**
- **Strong leadership will be required from global and regional entities, including donors, with a strong stake in Health EDRM to bring together the main groups required for the generation and use of evidence: the Health EDRM practice community to identify needs and problems requiring research; the academic sector to conduct high quality research; and agencies and donors to bridge the science into practice and application gaps.**
- **Systematic reviews provide the means to bring together existing evidence to inform these processes and to place the findings of new studies in the context of the totality of the evidence. They will allow decision makers in Health EDRM to make use of the best available evidence.**

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2.7

Prioritization of research

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2.7.1 Learning objectives

To understand the key factors to consider when preparing, developing and evaluating a research prioritization exercise in health emergency and disaster risk management (Health EDRM), including:

1. The importance of careful selection of priorities for research.
2. Practical steps in setting priorities.

2.7.2 Introduction

Research prioritization is usually defined as an interpersonal activity that leads to the selection of the topics to be studied and the methods to be used in research *(1)*. The results of the exercise do not always directly match the final decisions that are made by governments or organizations as to what research to conduct, but they can be useful for guiding such decisions. A level of flexibility may be needed to be responsive to important political issues that arise, meaning that pre-set priorities may be amended to take account of the situation.

In Health EDRM, priority setting might be done at the level of the research group trying to develop a specific research question, or at an organizational level – such as within a nongovernmental or governmental organization or UN agency that is trying to develop a broader research area, which might then be refined to one or more specific research questions.

The objective of a research prioritization exercise depends on the context in which it is conducted, the political, social and organizational processes that led to its initiation and the managers, professionals, practitioners, policy makers and ultimate beneficiaries of the process (often referred to as stakeholders). Some examples in Health EDRM include:

- Evidence Aid's priority setting exercise to identify thirty priorities for up-to-date systematic reviews of the effects of interventions, actions and strategies on health outcomes, which would be particularly relevant to those involved in disaster risk prevention, preparedness, response and recovery (Case Study 3.5.3 in Chapter 3.5) *(2)*.

- WHO's gathering of healthcare practitioners to identify key research priorities around the role of nurses and midwives in emergency responses *(3)*.

There is no consensus as to the scope or depth of a research priority. It may be broad (such as "more research on tropical diseases") or specific (such as "the cultural drivers of the spread of the Ebola virus in the DRC in 2019"). However, there is consensus about various elements that are likely to support a quality research prioritization exercise (Figure 2.7.1). These elements can be grouped into three steps: things to do *before* the priority setting exercise (preparation), things to do *during* the exercise, and things to do *after* the exercise.

Figure 2.7.1 Elements to support a research prioritization exercise

Step 1 Preparation	a) Leadership team b) Understand context and collect necessary data c) Identify and engage with stakeholders d) Collecting background information
Step 2 Shaping a Priority Setting Exercise	a) Identify research questions b) Deciding on use of criteria c) Ranking the research questions d) Disseminate/implement priorities research questions
Step 3 After the Priority setting exercise	a) Conduct prioritized research projects b) Implement findings of research projects c) Evaluating impact of research findings d) Report and Publish the priority setting exercise e) Evaluate the process and outcome of the exercise f) Feed the results back to revise future exercises

2.7.3 Step 1: Preparing for a research prioritization exercise

Step 1a Leadership team

The prioritization exercise will need a team to design, lead and monitor its implementation. The team needs to identify people, skills and resources required to complete the project. Technical skills, such as managing information, visualization or effective data collection, are important. However, interpersonal skills are also crucial, including effective communication, relationship building with those involved in disaster risk management including response, disaster research and the ultimate beneficiaries of the research and service, coordinating and chairing discussions, and the ability to analyse political situations in order to decide on appropriate strategies and tactics.

Step 1b Understand context and collect necessary data

Before embarking on a new prioritization exercise, it is important to understand the context for it, including whether there are any other similar or otherwise relevant exercises, any high level strategic priorities that have already been set, or any critical political decisions that have been made, which should influence or inform the exercise.

Viergever and colleagues *(4)* categorize the contextual issues affecting the process of research prioritization as available resources, focus of the exercise, values of those involved and the underpinning health, research and political environment. For example, a specific contextual issue relevant to Health EDRM research is the underlying causal factor that might influence how badly a disaster affects the community. This includes the degree of exposure and vulnerability of the society (Chapters 1.3 and 3.2) *(5)*.

Step 1c Identify and engage with stakeholders

As part of the preparation for the prioritization exercise, the team needs to identify who should be involved in setting the priorities, including the people, organizations and governments, remembering that each of these has many different layers. For example, government might be at the local, regional or national level. WHO's report on research for health also mentions civil society organizations, philanthropic bodies and industry as important stakeholders in a prioritization exercises *(6)*. Others who might need to be involved include patients, the general public, universities and research institutes.

Some key questions that should be considered in choosing the individuals to engage in the process are:

- Who are the individuals who will benefit or use the results of the prioritized research?
- Who are the individuals who have knowledge and oversight of the major issues that are likely to have an impact on those affected, or have influence and impact (such as politicians or managers of humanitarian aid organizations)?
- Who are the individuals who have direct knowledge of what happens in the field and in routine practice (such as healthcare workers in disaster areas, those who were directly affected and those providing support for them after a disaster or those who have local knowledge)?

- Who are the individuals who have a key role in supporting or implementing the research (such as academic organizations, philanthropic bodies and industry)?
- Who are the individuals who have a key role in moving the results of the research into policy and practice (such as healthcare professionals and workers, politicians and policy makers)?

In order to ensure proper engagement of stakeholders in the process, it is important to consider how they are involved, to ensure true involvement and avoid tokenism. The series of questions in Table 2.7.1 can help to guide these decisions *(7)*.

Table 2.7.1 Using an equity lens to set research priorities: questions to consider

1. Are a variety of stakeholders who might be affected by the choice of research topics involved in the prioritization process (such as people who differ in age, sex, sexual orientation, disability, ethnicity, religion, place of residence, occupation, education, socioeconomic status, and social capital)? In which steps are they involved? It is important to have an audit process to ensure that those communities impacted are included in the process.
2. Does the prioritization project consider reducing inequity as part of its objectives?
3. Are the methods and tools selected to identify prioritize, implement, disseminate and communicate research topics understandable, transparent and relevant for different stakeholders? For example, if the target population is multi-lingual and the researchers only use tools that are in English, this will not provide equal opportunities for the whole population to be involved – translation or using images might help to address it. It is important to consider that the readiness, availability and tendency of the stakeholders to respond to the survey or data collection is variable. Some might respond quickly and in a timely manner while others may need more time. Some may require evidence that their contribution is taken seriously or require support and empowerment before dedicating time and resources to contribute to the process.
4. Have specific strategies been considered to minimize the barriers to participation by disadvantaged or less accessible populations (this can be physical accessible such as population living in remote areas or other aspect of accessibility such as population that speaks a less known or used language)?
5. Does any situation analysis (such as evaluating current research coverage, identifying gaps and evaluating healthcare needs) consider the differences in the prevalence, severity and urgency of health problems along with potential differences in the impact or value of the interventions assessed across different subgroups?
6. Do the criteria for prioritization consider potential differences in the severity and urgency of health problems in disadvantaged populations or less accessible groups, as opposed to the health problems in privileged populations? Criteria refer to factors that individuals use to rank the research topics and questions. These criteria might be predefined or defined during the process.
7. Do the criteria for prioritization consider the potential differences in the impact of an intervention in disadvantaged populations, as opposed to the problems in privileged populations?

8. Do the criteria for prioritization consider that different population groups might have different values and preferences? This does not only refer to individuals' values with regard to health issues but the larger impact of research on cultural values.
9. Are different stakeholder groups provided with an opportunity to provide feedback and appeal the methods and results of the prioritization process?
10. Did the prioritization result in research topics that are relevant to disadvantaged groups? This can be topic areas that are relevant to the daily life of disadvantaged groups (on an individual level) or reducing inequity (on a community level) – or topics that cover both areas.
11. Does the dissemination and implementation strategy increase the likelihood that funders and research institutes become aware of the prioritized research topics and consider them as part of their research agenda or strategic planning?
12. Does the dissemination and implementation strategy increase the likelihood that prioritized research topics of relevance to disadvantaged groups get funded and conducted?
13. Does the dissemination and implementation strategy increase the likelihood that researchers who work with disadvantaged groups will conduct or get involved in the prioritized research projects?
14. Does the dissemination and implementation strategy increase the likelihood that disadvantaged groups or decision makers or practitioners who work with disadvantaged groups get involved in the prioritized research?
15. Does the dissemination and implementation strategy increase the likelihood that policy makers and decision makers who work with disadvantaged groups will use the findings from the prioritized research?
16. Did the results of the prioritized research topics change policies, legislation or clinical practice in favour of disadvantaged groups?
17. Did the appeal and enforcement strategy increase the likelihood that disadvantaged groups or decision makers, researchers and practitioners who work with disadvantaged group will provide feedback and comments on the prioritization process or its results?

For all the individuals involved in the priority setting process, it is important to consider how they may have different values and preferences based on their characteristics, background, knowledge and skills and how these will be represented, including different socioeconomic or racial groups. The acronym PROGRESS PLUS can be useful in identifying pockets of vulnerabilities within the beneficiaries of the research. PROGRESS PLUS defines axes of potential disadvantage: Place of residence, Race/ethnicity/culture/language, Occupation, Gender/sex, Religion, Education, Socio-economic status, Social capital and other characteristics ('Plus') such as sexual orientation, age and disability.These characteristics identify whether certain communities of populations are disadvantaged due to "social, political and legal structures and processes". During the preparation phase for the exercise, the lead team should identify all groups and communities, including disadvantaged groups, that are relevant to the topic area and ensure that individuals involved in the priority setting process represent those dimensions *(8)*. Case Study 2.7.1 highlights how the values and preferences of stakeholder groups can differ.

Case Study 2.7.1
Values and preferences of different stakeholders: research priorities for mental health and psychosocial support in humanitarian settings

A research prioritization exercise for mental health and psychosocial support in humanitarian settings was conducted in the Republic of Peru, Uganda and Nepal, with 114 participants. These included policy makers, academic researchers and humanitarian aid workers; covering a range of disciplines (psychiatry, psychology, social work, child protection, and medical anthropology) and organizations (governments, universities, non-governmental organizations and UN agencies).

The team conducted focus groups with each stakeholder group separately, to identify their priorities, before comparing and contrasting these priorities.

Although some priorities for research were similar between the groups (such as the prevalence and burden of mental health and psychological distress), there were areas of disparity. For example, academics gave more priority to research about improving methods and processes and obtaining long-term results, while aid workers and policy makers were more interested in projects that could be interpreted quickly and would have immediate results. Some aid workers even raised concerns that research could be a waste of time. This suggests that it may be important to identify and prioritize research questions that include both the long-term impact of Health EDRM and short term results in order to increase engagement with field and aid workers *(9)*.

People who study or conduct research prioritization often fail to report in adequate detail how the values of individual stakeholders affected the interpretation and use of data in the process. For example, the US National Academy of Medicine Committee on Health Care Technology recommends collecting or estimating "data for the prevalence of specific conditions, the unit cost of the relevant technology, various uses of the technology, the burden of illness addressed by the technology, and the potential of the results of technology assessments to affect health outcomes and costs". The difficulty with this approach is that the collection, analysis and presentation of data are buried under layers of assumptions and value judgements that may not account fully for the true values and perceptions of different stakeholders. This variation can justify different decisions about collecting or analysing data. For example, different approaches to defining the burden of illness can lead to different decisions on research priorities. It is therefore important that the reporting of the results of the prioritization exercise should be as detailed and specific as possible about the data that were used, the methods that were applied and who was involved in different stages of the process *(10–11)*.

Step 1d Collecting background information

Research prioritization should be evidence-based and guided by reliable information. When preparing for a prioritization exercise, it is important to identify and access relevant routinely collected data and studies that have already been conducted, and use interviews, case study materials or surveys to gather up-to-date knowledge, information from the stakeholders and missing information. The most difficult part may be to identify the key operational questions from field workers and examples about what has helped or hindered them in past responses, as field workers will be under pressure to deal with the imminent needs of those affected by an emergency or disaster and research is unlikely to be a priority for them. This highlights how research into the preparedness of different parts of the disaster response system may be a priority. For example, a paper by Rosner and colleagues describes in detail how the preparedness to shift public health services in response to an emergency helped in the 9/11 attacks on the World Trade Centre, how the different services responded afterwards and how this might be improved in future *(12)*.

Ideally, part of the exercise should include systematic searches to explore whether the identified research questions are indeed real research gaps or needs (Chapters 2.6, 3.6 and 3.7).

The prioritization process should also consider current sources of research funding (Chapter 6.3) and research capacity for the specific topic and setting. This can also provide information on research that has been done or is currently being conducted, what advances are most achievable, and what is most likely to be supported in the future. Moreover, it can highlight reasons for research gaps (Chapter 3.7) and how these might be addressed. For example, some donors and funders might place restrictions on how their money can be used and research gaps may exist because of these restrictions. It may also be important to consider whether the focus of the research should be on a specific event or type of emergency or disaster or use a holistic approach to study the impact of emergencies and disasters generally. For example, some areas in the Philippines are dealing with repeated disasters of different types that impact on efforts to rebuild the community *(13)* .

2.7.4 Step 2: Shaping a priority setting exercise

A simple way to conduct a research prioritization exercise is to bring people with relevant knowledge together in a meeting and help them to achieve consensus on the most important things to study. However, these group conversations are known to have strong biases and errors (due to undue influence by individuals who are most vocal, for example). Therefore, tools and methodologies have been developed to guide organizers of priority setting exercises. Examples of tools are object mapping and the use of images to facilitate storytelling *(14, 15)*.

The methodologies that have been developed to guide priority setting all adhere to the same set of steps, depicted in Figure 2.7.1. This section describes steps 2a, 2b and 2c, which help to make the prioritization process itself more systematic, transparent and evidence-based.

Step 2a Identifying research options

The first step of the priority process itself is to identify all relevant research options within the scope of the priority setting exercise (bearing in mind that the team should have already defined the scope of the exercise under Step 1: Preparation). There are many different ways in which the team can identify research options.

Conduct a literature review in the field that is the scope of the priority setting exercise on:

- the current state of knowledge
- current research
- research gaps
- previously established research priorities.

Ask stakeholders what they think are research options:

- in questionnaires or interviews ahead of the meetings where consensus on a list of priorities is established
- at the start of those meetings
- or a combination of these two.

It can be elegant to include larger groups of stakeholders in the early stages of the priority setting exercise to ask them about research options. For example, in a research priority setting exercise for a health condition, the organizing team might send out surveys before any meeting is organized to ask patients, healthcare practitioners and researchers to suggest research options. The options that arise from these surveys might be organized by the team according to different levels of granularity. Interviews could be held to deepen descriptions of stakeholders' views on the research options and a literature review could provide a stronger evidence base for them. The list of research options that follows from this might then be reviewed, refined and finalized during a meeting of a smaller group of stakeholders.

Step 2b Deciding on use of criteria

The team leading the prioritization exercise might decide to define and use criteria to prioritize each research option. These criteria would help all those involved in the exercise to differentiate and rank topics. The use of criteria is generally considered to be good practice in priority setting exercises. The organizing team might predefine the criteria based on literature review or involve stakeholders in setting these criteria. In the latter case, it is advisable to ask stakeholders what factors informed their decisions. Examples of criteria include whether alternative interventions are available, budget impact, health impact, amount of controversy around the intervention or the topic area, disease burden, economic impact, ethical implications, legal implications, psychosocial implications, underlying evidence, expected level of interest and variation in rates of use of the intervention *(15–16)*. If multiple criteria are used to inform the prioritization decisions, a performance matrix might be a useful approach to frame and guide the process, and to rank the priorities and guide discussions in a consensus meeting *(17)*.

Step 2c Prioritizing the research options

There are a variety of methods for asking individuals and organizations (stakeholders) to 'judge' each research option and to achieve a list of research *priorities*. These include surveys (such as of those affected by a disaster, practitioners, policy makers or managers), consensus methods (such as Delphi), face-to-face meetings and participatory workshops to discuss and agree on the priorities *(18–19)*. Often, a combination of these methods is used. As part of the development of the process, the prioritization team need to decide which individuals should have their knowledge and values recorded and incorporated in the process and whose knowledge and values need to be used to define key decisions in the process (such as ranking and prioritization). The latter might be used to shape the group that will be involved in choosing the final set of priorities.

It is important to be aware of the key issues that can affect the dynamics of stakeholder interactions during the research prioritization process. Developing good relationships with individuals can help to understand their interests, values and preferences as well as power relations between the different groups and how this can affect stakeholder engagement. If a consensus meeting will be held, it is recommended to have an independent and experienced facilitator to manage the meeting who is aware of these issues *(1, 20-21)*. It may also be important to have a mechanism in place to identify and report financial and non-financial conflicts of interest of stakeholders.

The organizers of a priority setting exercise need to consider that attending meetings may be difficult financially for some stakeholders and that this might affect their presence and attendance. Some stakeholders might be less comfortable with disagreeing with some of the other participants in meetings for fear this might affect their future working relation or access to funding.

2.7.5 Step 3: After the priority setting exercise

After the priority setting exercise, six things are important:

Step 3a Conduct the prioritized research projects: because priority setting exercises are intended to ensure that the right research is conducted, it is important to consider how the prioritized research projects may be best initiated.

Step 3b Implement the findings of research projects: research can sometimes be "blue-skies research", but more often research is done to inform health practice or policies directly. A plan should be made as to how the findings of the prioritized research projects may be translated into practice, policy or both.

Step 3c Evaluate the impact of research findings: a plan is also needed as to how the research that will be done as a result of the priority setting exercise might be evaluated.

Step 3d Report and publish the priority setting exercise: it is important to both disseminate the results of a prioritization exercise and ensure that the relevant researchers and funders have access to the results and a clear report of how the exercise was done. There is a reporting guideline (Chapter 6.6), REPRISE, to help with this *(22)*.

Step 3e Evaluate the process and outcome of the exercise: the evidence base for the quality of priority setting exercises will be improved if more exercises are evaluated systematically. For example, papers by Viergever and colleagues *(4)* and Nasser and colleagues *(7)* provide frameworks that can inform the building and implementation of an evaluation framework. This includes looking back at the process and outcomes of the priority setting exercises and asking: What went well? What could have gone better? What should the organizers of the next priority setting exercise on this topic do differently? What lessons were learned? This information should be included in the report or publication.

Step 3f Feed the results back to revise future exercises: priority setting is an iterative process that might keep running and changing, based on what research gaps remain and need to be addressed. Therefore, the prioritization exercise may need to provide opportunities for periodic review of the priorities that were agreed, and for appeal and feedback on these. Such reviews also provide opportunities for stakeholders to challenge the results of a prioritization exercise, or provide feedback to the group on the priority decisions they made, which will improve the acceptability and, as a result, legitimacy of the exercise. Thus, there should be a plan as to when the priority setting exercise will be repeated and how the information gleaned in Step 3 will be used to inform future exercises.

Lastly, a note on funding: prioritization exercises may be used to inform decisions about the allocation of funding that might otherwise be used on other aspects of Health EDRM. This makes it especially important to demonstrate accountability towards the stakeholders and evaluate the success of the exercise.

2.7.6 Conclusions

Several different approaches have been used to set priorities for research to adapt to the variety of contextual issues for which these priorities are needed. The approach to take depends on the objective of the prioritization exercise, underlying principles, ethical frameworks, and social, political and contextual issues. There are also different ways to categorize the purpose of the prioritization exercise. It might be categorized as identifying current uncertainties or be more future oriented, seeking to address issues that will arise in the future.

Some have defined steps in research prioritization as predominantly technical, including the interpretive and consultative methods used to identify data and encourage stakeholder's involvement. However, research prioritization exercises do not always clearly belong to one category. For example, those that emphasize involving stakeholders and using qualitative methods to gather information from them, will probably still use quantitative data to inform the decision-making process, while those that are predominately data driven (for example that emphasize the value of information analysis) will require people to make value-driven assumptions when interpreting these data to inform their decision making *(1, 23)*.

Across health research generally, it is important to identify the topics that are the highest priorities for new studies. This is if anything even more important in Health EDRM, where funding and resources put into research might otherwise have been used directly for risk prevention, preparedness, response, and recovery to strengthen resilience. In setting the priorities for new research, it is important to follow a process that is equitable, involves all the key stakeholders and uses an evidence-based approach to identify the areas of greatest need that are most amenable to research. This chapter has outlined some of the key steps for doing this.

2.7.7 Key messages

- **Prioritization of research in Health EDRM will help ensure that the research that is most needed gets conducted and make efficient use of resources that might otherwise be used for implementing interventions.**
- **Those undertaking prioritization exercises should use an evidence-based approach and ensure that key stakeholders are involved. Several methodologies are available to help do this.**
- **Reports of prioritization exercises should be clear about the outcomes, the methods used in the exercise, the underlying assumptions made before or during the process to support the decision making process (such as political, social and economic views underlying support or funding decisions), and how the various sources of information were used, in order to allow those who might act on the priorities to judge the quality and relevance of the exercise that led to them.**

2.7.8 Further reading

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