5.1 Disaster mental health research

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5.1.1 Learning objectives

To understand the importance of the following for mental health research relevant to health emergency and disaster risk management (Health EDRM):

1. Mental health consequences of disasters;
2. Research methods appropriate for assessing mental health;
3. The importance of partnerships to support mental health research in disaster settings;
4. The role of culture in defining the experience and expression of distress.

5.1.2 Introduction

The accelerating risk of complex emergencies arising from climate change and human conflict will have major implications for mental health, making this an important aspect of Health EDRM. Exposure to trauma during disasters and conflict, together with the cascading effects of bereavement, forced displacement, injury and resource loss has the potential to cause long-term psychological distress *(1–3)*. Urbanization often compounds disaster risk, particularly in low-resource areas, where population density presents significant threats to health, social capital and community resilience in humanitarian emergencies *(4–5)*.

Despite high levels of need, mental health is a relatively neglected area in Health EDRM, with little focus on services funding, human resources or research in the field *(6–7)*. Consequently, there is tremendous opportunity to improve disaster mental health risk reduction through rigorous research and informed policy. This chapter presents an overview of methods applied in recent research and important considerations for developing rigorous protocols in mental health assessment.

5.1.3 Psychological responses to trauma

In the face of crisis, people naturally react with fear, horror, sadness and grief *(8)*. For most people, this early trauma response resolves over time *(9–10)*; and the provision of psychosocial and community support during the early stages of recovery will likely reduce the incidence of more severe psychological issues *(11–13)*. However, in a sizeable minority of cases, psychological distress remains high for months and even years *(1, 14)*. In fact, it is typical for PTSD and other forms of psychological distress to develop some time after the acute crisis. Despite the definition of mental health as a second-wave issue in disasters, its later timing does not lessen the severity of need *(15)*. However, the secondary surge in demand for health care and other forms of psychosocial support often occurs when attention has shifted away from the disaster, and funding for health services has already been channelled into the treatment of injuries, infectious diseases and pre-existing chronic conditions. Addressing mental health in the aftermath of disasters therefore requires careful long-term planning and substantial knowledge of the pattern of response across affected populations. These issues are similarly important for research design: early assessment will illustrate elevated patterns of distress across the population, which is likely to diminish over time for the vast majority. Thus, targeted and well-timed research is required to reliably demonstrate the mental health impacts of disasters.

Exposure to trauma has potential to induce a range of psychological and neuropsychiatric disorders. The rates of psychological disorders following disasters vary widely *(16)*, but consistent evidence indicates that up to one third of survivors develop PTSD, and one quarter report depression *(11)*. Substance use disorders are less likely to be caused by trauma, but may be exacerbated *(17)*. Less attention has been paid to the rates of anger disorders, suicide, psychosis, and traumatic brain injury following disasters *(18–20)*. Key risk factors for the cause or maintenance of psychological distress among survivors include severity of trauma exposure, female gender, pre-existing psychological conditions and the presence of ongoing chronic stressors in the post-disaster environment *(11, 18)*. Trauma related to interpersonal violence and conflict leads to poorer mental health outcomes than natural or technological disasters *(16)*. Research in this field has largely focused on the effects of exposure to earthquakes *(21)*, bushfires *(1)*, windstorms *(22)*, floods *(23)*, terrorism *(24)*, and war *(25)*. As climate change shapes the patterns of disaster risk and conflict globally, a greater focus on the consequences of extreme temperatures, water insecurity, trade disputes, civil unrest, and the compounding and interacting effects of pre-existing vulnerabilities will be needed.

5.1.4 Assessing mental health in disaster-affected areas

Research methodologies relevant to the assessment of mental health after disasters have expanded to include increasingly innovative techniques. These approaches can be applied to examine the full spectrum of psychological response, including examinations of resilience, subclinical mental health issues, acute reactions and long-term psychological distress and dysfunction. Research methods are discussed in greater detail in Section 4, but the following examples highlight ways in which quantitative and qualitative methods can be applied to the investigation of mental health issues.

5.1.5 Quantitative research

Quantitative research designs seek to answer questions related to the prevalence of mental health problems, their correlates, symptom course, and effects of intervention. The vast majority of disaster mental health studies have used cross-sectional survey designs, employed to report the rate of mental health issues evident in affected populations; however, a growing number of longitudinal and cohort studies have shed light on the trajectory of psychological response to disasters and the risk and protective factors associated with outcomes (Chapter 4.4) *(13, 26-27)*. For example, the English National Study of Flooding and Health, the Queensland Flood Study in Australia, and Project Ice Storm in Canada, have established important findings on the long-term consequences of disaster exposure across the lifespan, including the longitudinal effects of prenatal disaster stress *(28-30)*. Cohort studies are less common in conflict and post-conflict settings, although the Longitudinal Study of War-Affected Youth has illustrated the specific risk and protective factors associated with mental health trajectories for youth in Sierra Leone *(9)*. More recently, a range of innovative analytic techniques has emerged in the field. For example, various statistical methods have been employed in disaster mental health research (see also Chapters 4.2 and 4.4), including the use of time series data analysis to assess psychiatric hospital admissions associated with hot temperatures *(31-32)*, multilevel longitudinal analysis to determine the mental health effects of group involvement following bushfires *(26)*, latent class analyses to assess the psychological factors associated with urban evacuation preparedness *(33)*, and geospatial patterning of vulnerabilities after hurricanes *(34)*.

5.1.6 Disaster mental health services research

Understanding the likely and locally presenting mental health impacts of disasters is crucial to the design of strategies to reduce mental health risks and inform the delivery of effective support measures and services that optimally facilitate recovery *(35)*. As our scientific knowledge base regarding the mental health consequences of disasters consolidates, disaster mental health service research can play a vital role in furthering its effective translation into quality disaster mental health response and support services *(36–37)*. In this context, disaster mental health service research has been instrumental in monitoring ongoing mental health care needs, service demand and equitable service access of disaster-affected populations *(38)*, whilst capturing important intervention outcomes *(39-40)* and key lessons to enhance the quality and organization of future disaster responses *(41)*. Evidence-based elements for effective disaster mental health response include: the effective coordination of multiple disaster response agencies and support services across varying sectors and jurisdictions *(42)*; the integration of enhanced disaster mental health services within existing support structures, such as primary care *(43)*; facilitation of ready access to care *(44-45)* and creation of pathways between different levels of care *(46)*; targeted capacity building for disaster responders in evidence-informed and scalable interventions *(47)*; as well as timely and transparent communication among all involved stakeholders and the wider community. Importantly, data from additional sectors, including schools (48-49), non-profit organizations *(50)*, and community groups *(51-52)* will augment services data to highlight the short- and long-term community needs and treatment outcomes. However, not all sectors or settings will have capacity for data collection and record keeping, particularly in the context of extensive damage to infrastructure and loss of human resources (Chapter 2.4). In such cases, it may be more appropriate to implement alternative techniques of inquiry, such as mixed methods research (Chapter 4.13).

The integration of health service research and evaluation into disaster preparedness and response is essential to develop the evidence base for effective interventions and critical to ensuring that the supports put in place are well-coordinated and are reaching those most affected. While each disaster context is unique, and there are psychosocial disaster response guidelines that can be tailored to local circumstances, comparative disaster mental health services research is now starting to elevate our understanding beyond the locally unique and allow the incorporation of what works well both within and across contexts *(42, 53-54)*, thereby establishing the key elements for more effective disaster mental health responses and proactive risk reduction efforts in future.

5.1.7 Qualitative research

Qualitative research presents an opportunity to gather in-depth or exploratory data on topics not always assessable via quantitative methods. As discussed in Chapter 4.12, qualitative research may be used to investigate sensitive or taboo topics related to mental health and to broaden inclusivity to populations not often included in the evidence base *(55)*. Often characterized by the use of smaller, purposive samples and collection of narrative data, qualitative research enables a deep exploration of meaning and relationships. Although a variety of approaches and analytic techniques are available, qualitative methods are usually focused on describing, exploring and interpreting the participants' frame of reference and worldview *(56-57)*. These methods are particularly relevant to disaster research. Recent applications have included the rapid assessment of needs following exposure to trauma *(58-59)*, social network analysis in communities preparing for hazards *(60)*, and the exploration of mental health symptoms among cultural groups rarely represented in the literature *(55, 61–62)*.

5.1.8 Participatory action research

Participatory action research (PAR) engages study participants in active co-researcher roles to broaden the scope of research with novel perspectives, disrupt dominant paradigms, and champion inclusive approaches (see examples in Chapters 3.1 and 4.15) *(63)*. Working within a co-design framework fosters ownership of the process and findings within the community, and supports innovative, meaningful outcomes. By disrupting the power imbalance between researcher and participant, PAR fosters a sense of agency among community members. PAR with children and adolescents affected by disasters has sought to dispel the perception of children as passive and vulnerable, instead recognizing their right to contribute to the decisions affecting their lives *(64)*. Similarly, PAR has been used to develop more inclusive policies and practices for marginalized groups and minorities across a range of disaster settings *(65–66)*. An example of PAR for mental health research is given in Case Study 5.1.1.

Case Study 5.1.1
Working with communities to assess the effects of disasters *(67)*

A participatory approach can add value to disaster research in many ways, including unique insights from community members and shared ownership of outcomes – but there are also many ways it can go wrong. The post disaster environment is chaotic, communication and social networks are often fractured, and the social bonding that can occur in response to a shared disaster experience can also deteriorate over time into disagreements and conflict. The ethical and academic implications for researchers are fraught, and need to be managed with care.

The Beyond Bushfires: Community Resilience and Recovery study was conducted in Victoria, Australia following the February 2009 bushfires, commonly referred to as the 'Black Saturday' bushfires because the worst of the fires occurred on Saturday 7 February *(68)*. The six-year study involved a cross-disciplinary team of academic investigators who valued cross-sectoral input and so invited a range of government, emergency, and health sector partners to attend all investigator/partner study meetings for shared decision making. Community expertise was also considered essential, and the lead investigators from the University of Melbourne began with a series of community visits to seek advice on the study methodology, recruitment locations and contextual differences. Twenty-five rural communities accepted the invitation to become study sites representing high, medium and low impact communities. It very quickly became clear to the investigators that there were so many diverse and sometimes conflicting views within and across those communities that it would be unhelpful and offensive to simply have a few community spokespersons join the investigator/partner study meetings held in the city to contribute to decision making. Instead, the lead investigators committed to ongoing community visits throughout the study, calling and visiting people for chats, attending local meetings and presenting emerging findings at local seminars. They maintained connections with a wide range of individual and organizational contacts and channelled the feedback and insights provided to the investigator/partner meetings to ensure community influence on study decision making occurred at all stages of the research process and that it was sufficiently nuanced to reflect the complexity of individual and community level experiences. This approach resulted in continuing adjustments to the study, including the study name, adjustment to the recruitment boundaries, the sampling strategy, communication methods, survey questions, focus of data analyses, interpretation of findings, study output and dissemination strategies. These continual responses to feedback demonstrated the investigator commitment to a participatory approach and greatly enhanced the relevance and impact of the findings *(67)*. As one community member noted about the Beyond Bushfires study "Most importantly, it has provided a safe, supportive environment for us to explore the lived experience of bushfire recovery" *(67)*. This shows the value of a participatory approach for those involved but also the potential for harm if the participatory efforts are merely tokenistic. A participatory approach requires genuine commitment on the part of the investigators to adapt to the realities of a post-disaster environment. If that can be achieved, the research quality and the study impacts are likely to exceed a traditional approach to research.

5.1.9 Considerations for working with disaster-affected populations

Conducting research with traumatized populations

Mental health research often requires engaging with people who are actively experiencing distress or are required to remember difficult times. Accordingly, participating in research has the potential to exacerbate stress, irritation or fatigue, but is still valued by participants and, if carefully managed, is unlikely to contribute to further trauma *(69)*. Investigators working with disaster survivors must be mindful of the way they conduct their research to ensure that participants are protected from distressing or ethically compromised protocols. Possible means to address this concern might include:

- ensuring comprehensive training is provided for the research team, with a focus on research ethics, confidentiality, sensitivity, risk assessment and building rapport;
- developing a referral network prior to the commencement of research, so that higher risk cases may be referred to specialist care;
- engaging community stakeholders to guide research design and data collection.
- speaking with participants about their social support networks and ways that they can access further information and assistance.

Mental health stigma

The stigma associated with mental illness calls for thoughtful planning for conducting research and disseminating findings. The use of scientific evidence presents an important opportunity to reduce stigma around psychological responses to trauma, if done well. Discussions of mental illness that inadvertently reinforce community concerns (such as associations between psychological symptoms and weakness or danger) can reinforce stigma *(70)*. Challenging stereotypes through positive messages of change, associating help-seeking with strength, and normalizing trauma reactions has significant potential to mitigate stigma among survivors *(71)* and first responders *(72)*.

Cultural expressions of distress

Culture plays an important role in the expression of distress. Cultural expectations and socialization processes shape the norms for psychological and behavioural phenomena, which are dynamic and vary with time (for further detail, see Case Study 5.1.2). Using qualitative research to explore common descriptions of stress, mood and behaviour change may illuminate meaningful symptom clusters and idioms of distress *(73-74)*. In addition, adoption of a 'cultural lens' is required to effectively interpret the influence of gender, family composition, coping, social determinants, and developmental stages in the expression and experience of psychological distress *(75)*. Using culturally and (where suitable) developmentally appropriate terms to describe psychological expressions will significantly improve the validity of the research. Without careful consideration of culture, our research paradigms, sampling strategies, methods of data collection and interpretation of findings will be significantly flawed *(75)*.

Case Study 5.1.2
Expressions of distress among disaster-affected adolescents in China and Nepal *(74)*

China and Nepal have recently experienced devastating earthquakes. Both nations have large adolescent populations, for whom traumatic stress has potential for significant effects on mental and physical health, development and education *(59)*. To address these issues, it is vital that we understand the specific experiences of young people affected by disasters.

The Study on Adolescent Resilience after Disasters sought to investigate the range of expressions of psychological distress and any behavioural changes arising from exposure to natural disasters *(74)*. Ethnographic research in Nepal has illustrated a multifaceted model of psychological trauma, with particular emphasis on interpersonal relationships, social identity and loss *(61, 76)*. In China, mental health is conceptualized within a holistic systems approach with greater integration of the concepts of mind and body *(77)*. However, diversity in the conceptualizations of psychological distress in both countries, and a lack of attention to child and adolescent experiences warranted in-depth assessment *(74)*.

Key informant interviews and focus group discussions were conducted with adolescents, caregivers, teachers and experts in disaster-affected districts of Yunnan Province, China (n=79), and Kathmandu Valley, Nepal (n=62). A thematic analysis revealed that key indicators of distress emerged across four domains: anxiety and stress, mood difficulties, somatic complaints, and changes in behaviour. Young people frequently described fear of the earthquake recurring, anxiety triggered by trauma reminders, nightmares and hypervigilance. An adolescent participant from Nepal said "They say the sound of people shouting when the houses collapsed haunts them… I have not seen, but my friends say they are afraid to go anywhere in the dark, the sound of people shouting is heard" *(74)*. The magnitude of the Nepal earthquakes was associated with a sense of existential worry among adolescents who were forced to examine their future in light of new and worsened hardships. Concurrently, post-traumatic growth and strengthened connections between adolescents and their families were described in both settings. A number of participants described a sense of coping, mastery and self-efficacy arising from their experience *(74)*.

Many of the symptoms described by adolescents and their families reflect diagnostic criteria for PTSD, depression and anxiety, perhaps due to an increasingly globalized communication of mental health *(74)*. However, the nuanced descriptions of psychological distress highlight a significant need for psychological and community services that promote evidence-based interventions tailored to culturally specific understandings of mental health and the unique capabilities of adolescents.

5.1.10 Establishing research partnerships

Identifying and engaging local partners is crucial to conducting field-based research. International studies should always be conducted in partnership with local organizations, service providers, government advisors, and/or community representatives. Such partnerships are also advisable when working in the researcher's home setting, where there may be opportunities to establish working relationships prior to the onset of a disaster. Local research partners play a vital role at multiple levels of the research process, from advising on study feasibility and acceptability, developing methodology, recruitment and sampling, obtaining ethics approvals, data collection, managing risk, interpreting results and disseminating findings within and beyond the community. Whether working in high-, middle- or low-income nations, building capacity in the mental health workforce (across both clinical and non-clinical settings) should be incorporated in the planning.

Successful partnerships are dependent on open communication, inquisitiveness, trust, humility and follow-through on decisions *(78)*. Regular team meetings and agreements regarding data ownership, respective roles in data collection and paper authorship facilitate this process *(79)*. Furthermore, an understanding of the political, economic, social, environmental and technical realities that shape interactions will foster stronger relationships *(80)*. Research partnerships are most successful when teams agree on a strong research plan, have respect for each other's capacities, engage in transparent and effective communication, clearly delegate roles and responsibilities, and develop a shared vision for the project *(79)*. Without collaboration, research conducted in disaster-affected settings is at risk of duplicating processes, drawing false conclusions, or failing to have a meaningful impact on policy and practice.

5.1.11 Dissemination and impact

The uptake of results and sustainability of new mental health initiatives are dependent upon the early engagement of partners and community members. An early process of joint decision making aiming to achieve multiple research project outcomes to meet the needs of all partners will support community engagement and research validity. In addition, it is important to foster progressive development of a knowledge translation plan to ensure wide dissemination of the findings and outputs tailored to different audiences and contexts. Scientific manuscripts and academic products can be complemented by community seminars and workshops, promotion through social and traditional media, and creating opportunities for partners to present findings in community forums. As funding bodies and individual donors become more interested in the efficiency of resources, providing reliable evidence on the level of need and effectiveness of humanitarian interventions will become increasingly valuable.

5.1.12 Conclusions

Mental health research plays a critical role in determining the health needs, trajectories of adjustment and treatment outcomes for disaster-affected populations. It has an important part to play in Health EDRM. Both clinical and non-clinical supportive services in the acute recovery phase have potential to support population-level improvements for adult and child mental health *(12)*. Rigorous research that pays careful attention to inclusive sampling, ethical processes, social determinants of risk and cultural considerations has the potential to expand the evidence base and highlight important areas for service development. Collaborative partnerships are vital: where possible, mental health researchers should seek to work in partnership with other agencies and local community members to guide the research and build capacity in the settings in which they work. The tremendous potential for research to inform and prevent mental health difficulties and deliver timely, evidence-based intervention will support the long-term resilience of disaster-affected communities.

5.1.13 Key messages

- **Rigorous mental health research is needed to determine the specific needs of disaster-affected populations and effectiveness of interventions in the months following a disaster.**
- **Consideration of the timeframe for psychological adjustment, sample characteristics and cultural expressions of distress will inform the research design.**
- **Partnerships with local community stakeholders, agencies and research collaborators are vital for valid research, capacity building and long-term uptake of results in Health EDRM.**

5.1.14 Further reading

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5.2

Crowdsourcing to gather data

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5.2.1 Learning objectives

To understand the fundamentals of crowdsourcing and its relevance to Health EDRM, including:

1. What crowdsourcing is;
2. How crowdsourcing differs from related terms;
3. Strengths and limitations of crowdsourcing;
4. Things to consider when designing a study that would use crowdsourcing to gather data.

5.2.2 What is crowdsourcing?

Crowdsourcing, which is a method to harness the knowledge, creativity, or sheer manpower of a large number of people at once, has existed as a concept for hundreds of years, although the term itself was only coined a decade ago *(1–5)*. The term 'crowdsourcing' first emerged in a *Wired Magazine* article, and was described as a method of outsourcing tasks to an undefined, and generally large number of people using an open call. A commonly cited, classic example demonstrates the power of crowd wisdom in guessing the weight of an ox at a fair (Case Study 5.2.1). In the past decade, uses of crowdsourcing in research and practice have increased greatly, although many authors still feel the method is underutilized and underexploited *(6–9)*. This chapter explores the potential of crowdsourcing to help with research relevant to Health EDRM.

Case Study 5.2.1
A historical example of crowdsourcing

In 1907, Francis Galton wrote an article in *Nature* describing an experiment he conducted in Plymouth, West of England, where a crowd was invited to judge the weight of an ox. Some 787 votes were collected, and the average of these was incredibly close to the actual weight of the ox – within 1% of the real value *(10)*. Indeed, Buecheler et al. argue that individuals are biased towards the correct answer and that, because of this, if one million people contributed to solving a problem using crowdsourcing there would be a 97.7% likelihood that the crowd would arrive at the correct answer *(11)*.

Although technology is not a requirement for crowdsourcing, advances in technology have facilitated the impact and feasibility of crowdsourcing as a method. For example, at least 70% of the world's population has access to a mobile phone *(12)*. These devices can collect photo, video, acoustic, gyroscopic (measuring orientation), accelerometric (measuring acceleration), and proximal information, and can also be paired with external sensors such as air pollution sensors, or a wearable device such as a "smart watch" that will collect both gyroscopic and accelerometric information to track fitness by combining speed and location *(13)*. Mobile phones can also produce geographic information system (GIS) data (see Chapter 4.8), which are especially valuable in emergency situations *(14)*. Advances in artificial intelligence (AI) and machine learning algorithms provide new ways of processing the large amounts of data obtained through crowdsourcing (for example through receipt of many submissions, or through wearable sensors or mobile phone data).

Crowdsourcing can provide answers to questions that may be impossible or not feasible to answer otherwise by considerably lowering operational and data collection costs, while exponentially increasing sample size, and enabling researchers to receive data in real time *(14–20)*. As research in disaster situations faces time, funding, and logistical constraints – including staff and equipment – crowdsourcing may offer a desirable alternative or complement to traditional research methods *(8, 15, 21–28)*. However, as the crowd is often self-selected, there are concerns about the generalizability of samples. In cases where the information requested is sensitive, security and data protection issues also need to be considered. Efforts need to be made to design studies that can combat false submissions (from malicious contributors, for example, or if on a platform such as Amazon Mechanical Turk, malicious workers). Finally, concerns about the representativeness of the sample when crowdsourcing studies have very few contributors doing most of the 'work' or access to technology, age, and other demographic factors may affect who is able to contribute *(14, 29)*.

There are several different models of crowdsourcing, as well as similar and overlapping terms. While there is disagreement on the scope, categories, and types of models of crowdsourcing *(4)*, four basic and comprehensive categories emerge: crowd processing, crowd rating, crowd solving and crowd creation. These are outlined below.

Crowd processing

Crowd processing is the use of large numbers of people to process information independently, which become partially aggregated for quality assurance. This is described as a ‘divide and conquer’ approach. Examples of these include ReCAPTCHA, GalaxyZoo and the BioGames example provided later in this chapter.

Crowd rating

Crowd rating is the use of large numbers of people to vote or provide their opinion (such as TripAdvisor or Hollywood Stock Exchange).

Crowd solving

Crowd solving is the use of a large numbers of people to solve a problem, where the best submission is the ‘winner.’ Example of this are FoldIt, Crowdmed and Innocentive.

Crowd creation

Crowd creation *(30)* is the use of large numbers of people to co-create, such as Threadless.

In addition to the above four categories, crowdsourcing needs to involve a clear call for submissions or tasks, which can be voluntary or remunerated, and is usually conducted using some technology to enable low-cost and speedier data transmission. The crowd can be formed of laypersons or experts, but who the study is targeting should be decided for each problem. Responses may be aggregated or could be compared against each other in competition form. A comprehensive description of types of crowdsourcing can be found elsewhere *(4)* and some of the relevant terminology is shown in Table 5.2.1.

Table 5.2.1 Terms related to crowdsourcing and their definitions

Term	Definition
Participatory epidemiology	Using participatory methods in epidemiology, which could range from designing the study to participatory methods in data collection (the latter would likely be in line with crowdsourcing) *(31)*.
Wisdom of the crowd (that is, collective intelligence)	A phrase coined by Surowiecki *(32)*, describing a form of crowdsourcing that relies on having an intelligent crowd and follows four ‘rules’ to ensure crowd intelligence: diversity, aggregation, decentralization and independence. Not all crowdsourcing requires a wise crowd, but all ‘wisdom of the crowd’ activities are crowdsourcing.
Citizen science	Non-professionals conducting science-related activities *(33)*. While crowdsourcing refers to *how* the activity is conducted, citizen science refers to *who* is doing it, and *what* they are doing. Often, crowdsourcing and citizen science are performed in tandem.
Health 2.0	The use of Web 2.0 technologies to actively participate in one’s health *(33)*. These could facilitate crowdsourcing (for example, through using wearable sensors to transmit data en masse), but may also be used individually for personal tracking.
Open-sourcing or peer production	Open sourcing is the development of data or materials that will become freely available, where there is often no clear ‘call’ to work. In crowdsourcing, an organization would initiate the work *(15)*.
Outsourcing	Crowdsourcing can be defined as a niche form of outsourcing *(2)*. However, unlike outsourcing more generally, there is no contract for crowdsourced work *(9)*.

5.2.3 Use of crowdsourcing in health research and emergency situations

Although, as noted above, some have argued that crowdsourcing has not been used to its full potential *(5–9)*, there are several notable examples that show the power of this innovation.

For instance, BioGames, uses the power of large crowds and gamification to analyse malaria smears. An online game, accessible via an Android device or computer, was created. The game has players ‘kill’ malaria parasites on blood smears using a syringe and collect healthy cells, after a short tutorial. Gamers have been able to reach 99% accuracy *(34–35)*. An educational version of this game was also created, which used a diagnostician to provide feedback to the gamers. In this version, gamers were more easily able to identify infected cells than healthy ones. The authors suggest that in future, gamers or machine-learning algorithms could pre-screen positive or negative marked cells and send questionable ones to experts for diagnosis *(36)*.

The OpenZika Project called for people around the world to volunteer their spare computing power, helping the project run simulations of potential drug candidates for Zika *(37)*. By using computing power from volunteers around the world, this project ran 92 000 simulations. All data from this project is open access.

Crowdsourcing is often used for disease surveillance in emergency settings (Chapter 2.2). Several open-source participatory epidemiology programmes exist, including Frontline SMS and Ushahidi. Participatory epidemiology is the use of people to gain epidemiological data (and is, by definition, a form of crowdsourcing). Frontline SMS enables users to request needs, such as supplies and logistical challenges, via SMS. It has been used in the Republic of Malawi, Republic of Burundi, Bangladesh, and the Republic of Honduras. Ushahidi creates individual reports using web, SMS, and email, which are classified, translated and geotagged *(19–20, 38)*. Ushahidi was initially created to respond to election violence in Kenya, but has since been used in many countries around the world, and most famously, to respond to the aftermath of the Haitian earthquake, as described in Case Study 5.2.2.

Case Study 5.2.2
The use of Ushahidi in Haiti

In January 2010, a 7.0 magnitude earthquake struck Haiti causing mass destruction in populous areas. Ushahidi, an open-source crowdsourcing platform, was deployed within four days of the earthquake. It provided vital information to responders. Ushahidi opened an SMS service for Haitians to text their needs, including food, aid, and medical needs, to a free SMS number, which was visualized geographically using cell phone tower triangulation, Google Earth, and Google Street Maps. Reports were triaged, and volunteers were able to text back. Translation was done by volunteers. Over 25 000 text messages were received. Of these, almost 3 600 were actioned, most relating to needs for vital services *(20, 39)*.

Other recent examples of Ushahidi's use include reporting violence after the US election, sharing geolocation information for flood help in Chennai, reporting earthquake damage in Puebla, Mexico using geolocation and photos, and tracking logistics after a terrorist attack *(38–41)*

In humanitarian or disaster relief settings, perhaps the most common use of crowdsourcing is for mapping. Ushahidi, Frontline SMS, Missing Maps and Humanitarian Open Street Maps either create maps for disaster preparedness or are able to work with crowdsourced maps (such as Open Street Maps) to enhance mapping capabilities, and to use these in coordinating a response. In many countries prone to disasters, there may be a lack of accurate maps containing basic geographic information, so efforts to create accurate maps in advance can be essential to responding effectively (see Case Study 5.2.3) *(38, 41)*.

Case Study 5.2.3
Open Cities for disaster risk management in Nepal

In addition to being one of the countries most exposed to natural hazards, the majority of houses in Nepal's capital, Kathmandu, do not meet minimum requirements for earthquake safety. As a proactive approach, local stakeholders in Nepal began using Open Street Map in 2012 to collect exposure data and map schools and health facilities. In Kathmandu 2256 schools and 350 health facilities were mapped. In April and May 2015, two high magnitude earthquakes hit Nepal. While these halted the initial Open Cities project, the existing information was crucial in informing humanitarian responders and supporting recovery efforts *(42)*.

MoBuzz, a participatory epidemiology application to combat dengue in Sri Lanka, is a good example of a multi-component crowdsourcing application. It uses predictive surveillance, civic engagement and health communication to reduce the exposure of the Sri Lanka population to dengue. The application uses predictive technology and machine learning algorithms to determine weather, vector and human data and produce hotspot maps for public and health officials. Civilians are engaged to report breeding sites, symptoms and bites, which are in turn reflected on the hotspot map. Finally, this information is communicated widely to the public and health officials *(43)*. Similar campaigns to this, or that reported more recently by Bartumeus and colleagues *(44)*, could be employed in emergency situations using this as a model.

Geographical sciences have also used crowdsourcing and these applications could be easily adapted for use in Health EDRM. One application, Sapelli, has successfully used citizen science and crowdsourcing to map poaching in sub-Saharan Africa through icon interfaces on a smartphone application *(45–46)*. The Sapelli application is icon-based and suitable for use by people with low literacy. It, or a similar application called CyberTracker *(47)*, and their underlying participatory methodology, could be tailored to report a variety of relevant health outcomes, such as disease monitoring, water and sanitation hygiene risk factors, or violence.

5.2.4 What to consider when designing a study using crowdsourcing

When designing a research study that will use crowdsourcing, there are several factors to consider, as discussed below.

Crowd composition and crowd knowledge

It is important to consider what type of crowd is needed to conduct the task. For example, the task might require specialist knowledge (such as when gathering expert or specialist opinion), or might rely on information from laypersons. Health-related crowdsourcing exercises requiring specialist knowledge include Innocentive or Crowdmed, where complex pharmaceutical or medical problems are crowdsourced by a large crowd, and the winner is rewarded with a large sum of money. Laypersons can be extremely accurate at problem solving or conducting crowd processing tasks, such as in the case of BioGames, or for GIS solutions that require large numbers of people to report and map locations, such as OpenStreetMap. It is also important to consider the diversity of the crowd that is likely to be obtained. The more diverse the crowd, the higher the probability of obtaining a 'smart' crowd *(32, 48)*.

Platform to host the call

It is important to consider the platform to host the call (or semi-open call, if choosing an expert call) for crowdsourcing submissions. Globally several platforms exist to reach laypersons, such as Amazon Mechanical Turk and Crowdflower, and other software such as Ushahidi is at least partially open-source *(38, 41)*. If people affected by the emergency are being targeted, it will be important to consider whether they are able to access the platforms without difficulty (for example, they may have limited access to mobile phones or computers with internet connections). Applications that can be considered include SMS (which may be most appropriate for those impacted), specialist data collection tools (such as using Open Data Kit) for first responders, or OpenStreetMaps for remote helpers. Finally, it is important to consider whether the data generated from the chosen platform is comparable with current data management and storage systems, and whether these can be merged if desired (*49)*.

Crowd accessibility

The accessibility of the crowd is an important consideration. For example, the crowd may be located in a hard-to-reach area. If the target population is difficult to access, this may be challenging when advertising the call using word of mouth, online advertising or targeted enrolment. There may be barriers to entry, such as cultural sensitivities, or challenges related to reaching specialist communities with the needed knowledge (for example, diaspora communities with the ability to read messages from the affected population).

Remuneration

Crowdsourcing in humanitarian settings primarily uses volunteered information. However, the use of platforms such as Amazon Mechanical Turk to process tasks (such as annotating images) may require some remuneration to the crowd. If members of the crowd are to be paid for their contribution, it is important to consider that the study or programme may receive many submissions over a short period of time and a pilot study may be helpful for adequately predicting and budgeting for submissions.

Desired output

As with any research study, a study or programme that will use crowdsourcing needs to have a clear question or purpose (Chapter 3.5). This would include careful consideration of the type of task and the best way to combine submissions (for example, aggregation or selection of the best submission). There may be ethical issues (Chapter 3.4) relating to the sensitivity of the data to be collected (for example, data on violence experienced, corruption) and care will be needed in how such data are collected, processed, stored and analysed.

Advertising the call

When considering the advertisement of the call it is essential to ensure that the right crowd is reached effectively. The call could be issued through a mass media campaign, word of mouth, or targeted enrolment – it should be considered which of these is most likely to reach the target population. Important factors include literacy, local customs and culture, and the reach of different media modalities.

Study design and analysis

In determining whether crowdsourcing is appropriate for a particular study, the balance between precision, speed and cost must be considered. It is also important to be confident that crowdsourcing is an appropriate way to generate a reliable answer to the research question.

Quality Assurance

Methods for quality assurance in crowdsourcing studies differ from those in traditional studies. Often, it is important to obtain multiple measurements of the same thing, and to triangulate these to verify one another. In addition, surveys might need to include questions designed specifically to identify 'malicious participants' (such as those who are answering survey questions at random).

5.2.5 Conclusions

Crowdsourcing is a method that uses crowds to solve problems, whether it be through harnessing knowledge of large numbers of people, capitalizing on a group of people's unique positioning to a problem (for example, through GPS-tagged submissions), or the sheer volume of a crowd and its ability to process information at a rapid scale. Existing crowdsourcing platforms are available, such as Ushahidi. Designing a programme, response or study that uses crowdsourcing will require initial thought and understanding of the questions being answered, the population forming the crowd (and how best to reach them), and whether it is the optimal method, considering trade-offs such as precision in reporting to time and cost. Crowdsourcing has been used in disaster response, and examples from outside the humanitarian context can be adapted to Health EDRM. When it is the appropriate methodology, crowdsourcing can reduce costs and improve response time, making it particularly well suited to emergency or humanitarian situations.

5.2.6 Key messages

- **Although crowdsourcing is still a nascent field, it has huge potential for Health EDRM *(4, 5, 50).***
- **Crowdsourcing can be a low-cost, rapid alternative to traditional data collection methods.**
- **There are several different problems that crowdsourcing can be used to solve, including crowd processing, crowd rating, crowd solving, and crowd creation.**
- **Several open-source applications exist which can be used for crowdsourcing studies.**

5.2.7 Further reading

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5.3

Refugees and internally displaced populations

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5.3.1 Learning objectives

To understand the following key aspects of research with refugees and Internally Displaced Persons (IDPs):

1. The nature and characteristics of refugees and IDPs;
2. Ethical concerns surrounding migration research and approaches to address these;
3. Linguistic and cultural challenges facing refugees and the critical role of interpreters when conducting research or providing care;
4. Mental health issues of refugees and IDPs in different settings and appropriate and ethical research methods to address their needs;
5. Importance of evidence-based interventions to properly manage acute conditions and the challenges of conducting research among refugees or IDPs with acute conditions.

5.3.2 Introduction

The traditional role of the health sector during emergencies and disasters is response-focused on addressing and managing a single hazard. The Health EDRM framework requires the active collaboration and participation of an array of sectors and stakeholders across different levels of society to implement an approach focusing on the full spectrum of hazards, including but not limited to natural, biological, technological, and societal *(1)*. A consequence of these hazards is forced migration, which is discussed in this chapter.

Populations who have been forced to flee their homes and lands are heterogeneous in nature, and have complex reasons behind their displacement, and the destination of their fleeing journey *(2)*. Armed conflict, financial circumstances, disasters caused by natural hazards, and a lack of sufficient resources are all reasons behind forced migration. Refugees are individuals who reside outside the country of their nationality due to a well-founded fear of persecution based on their race, religion, nationality, membership of a particular social group or political opinion *(3)*.

IDPs represent those who have been forced to leave their homes and lands due to conflict, violence, disasters, or resource insecurities, but remain inside the internationally recognized borders of their home country *(2)*. At the end of 2017, there were an estimated 40 million IDPs and nearly 20 million refugees globally *(3–4)*. It is worth noting that, due to their location or circumstances, it can be more challenging to provide humanitarian support to IDPs than to refugees, which makes IDPs one of the most vulnerable populations around the world *(4)*.

Evidence-based research includes collecting, analysing, and implementing best available evidence to enhance the decision-making process *(5)*, improve the provision of health care and provide scientific evidence for Health EDRM programmes. This chapter discusses four specific topics to consider in evidence-based research among refugees and IDPs: humanitarian ethics, language and interpretation, mental health and acute care.

5.3.3 Humanitarian Ethics

Refugees and IDPs have been forcibly uprooted from their lands and cultures. Therefore, scholars argue that investigating and understanding their living conditions is an act of social justice. These populations continue to experience vulnerability and structural violence due to race and ethnicity, legal status and identity, as well as socioeconomic status and linguistic difficulties. Although migrants may benefit from participating in research that improves their health and wellbeing *(6)*, it is the responsibility of researchers to ensure that their investigation is conducted under humane conditions and using ethically-sound approaches.

Alongside the more general issues of ethics in Health EDRM discussed in Chapter 3.4, conducting research among refugees and IDPs carries the potential for specific ethical concerns that may arise especially during or after emergencies and disasters. Linguistic and cultural barriers may lead some refugees to engage in research without understanding its objectives, outcomes and possible risks. The variation in power between refugees and researchers might drive these vulnerable individuals, out of fear or illiteracy of their rights, to engage in research involuntarily. Furthermore, research carries the risk of causing harm to refugees and IDPs if certain population-specific considerations are not properly addressed. For example, if the investigation is conducted in a low- or middle-income country in which refugees are temporarily residing without the same rights or equal treatment as regular citizens, the privacy of their personal information might not be protected, and their safety might be unknowingly jeopardized. Indeed, refugees might be exploited, persecuted and deported should their legal status be compromised due to ongoing or previous research.

Conducting research that involves direct engagement with humans requires following certain ethical practices, such as obtaining an informed consent (Chapter 3.4). The principle strategies of informed consent are disclosure, comprehension, capacity, voluntariness and consent *(7)*. Ensuring the integrity of these four strategies while obtaining an informed consent from refugee and IDP participants may be challenging. Refugees may have limited language skills and high illiteracy rates, making it difficult or unfeasible to adequately inform them about the research procedures or to require them to read and sign informed consent forms. The heterogeneity of health literacy levels between and within refugee populations could affect the process of explaining the outcomes of the research they intend to be involved in, and any adverse effects of their involvement should these arise. Research personnel who lack adequate cultural sensitivity training may also be unable to appropriately inform refugee participants about the nature of the research, which could thereby compromise the integrity of the informed consent process.

Before starting a research study among refugees and IDPs, researchers should comprehensively assess the benefits of undertaking the study for this specific population, the participants undergoing the assessment and the society as a whole. They also need to recognize the importance of protecting the confidentiality and privacy of their participants. Essential identity and demographic data such as names, dates of birth and current residences should only be collected when the benefits of this procedure far outweigh the harms. If such data are collected, anonymization or pseudonymization procedures should be used to protect participants and ensure their confidentiality. Hard copies should be kept in secure areas and personal data should be safeguarded by comprehensive safety systems or separated physically from other collected materials. All electronic files should be encrypted and protected by passwords, and access to these files should be limited to personnel who are conducting the particular research study.

Finally, the leaders of the research have the responsibility of adequately training their staff and interpreters to use culturally sensitive approaches when explaining the nature of their research and to conduct the informed consent and data collection processes adequately, while avoiding any cognitive biases that might affect the quality of the research.

Case Study 5.3.1
Example of important cultural issues in a research project with Syrian refugees in Lebanon

A doctoral student was undertaking a qualitative migration research project as part of her dissertation. She planned to go to Lebanon and conduct semi-structured interviews with Syrian refugees to understand their lived experiences during a transitional period.

Upon arrival in Lebanon, she recruited an Arabic-speaking research assistant to help with the field work and the interpretation processes, but the assistant voiced concerns about privacy and confidentiality. She recognized why collecting names of participants might jeopardize their privacy and safety. She made the ethically-sound decision not to collect their names and decided to perform a sex- and gender-based analysis instead.

5.3.4 Language and interpretation

Language and cultural barriers disrupt communication between medical practitioners and refugees, limiting their access to and maintenance of treatment, increasing their use of emergency services, and reducing their health-related quality of life. Caring for refugees is challenging due to the complexity of their communication barriers, health conditions and their limited health system literacy *(8-11)*. Limited local language proficiency may lead to poorer treatment adherence *(12)*, impede refugees' access to fundamental services and life necessities such as housing *(13)*, and negatively impact their social capital, because the majority find themselves unable to reach out and extend their social networks beyond those who speak their mother tongue *(14)*. In Canada, limited local language proficiency was associated with a rapid decline in the health status of newly arriving refugees and other immigrants *(15)*. Some of these communication difficulties are related to cultural differences and possibly fear of physicians *(16)*. Emergency practitioners, however, can mitigate the harms of communication barriers experienced by refugees through enhancing the appropriateness of the health care they provide *(17-18)*.

High-income countries have attempted to implement interpretation services within their social and healthcare systems to aid refugees and other migrants with poor language skills. This approach helped refugees access, navigate and maintain social and healthcare services *(19)*. Interpreters act as a liaison between both ends of the conversation and play a pivotal role in overcoming language barriers. They should possess certain attributes that are fundamental to their role, such as the ability to fluently communicate in the native tongue of the refugee as well as the official language of the healthcare or social service provider. Furthermore, evidence shows that medical interpreters should receive proper training in medical terminology and interpretation to ensure the quality of their work *(20)*. Interpreters should not take a central role of the conversation but rather maintain their position of support to the quality and accuracy of this interaction. It is preferable for them to have background or cultural resemblances to that of the refugee so that they are able to understand and properly interpret the indirect gestures and expressions which could be specific to this background or culture. However, local interpreters are very likely to be recruited from the same community as the study participants, a practice that could bias the interview process and give rise to confidentiality concerns and misinterpretations generated by cultural assumptions or taboos. Finally, interpreters should be trained on the importance of respecting the confidentiality of their clients and the application of procedures that protect their privacy and the privacy of the information they exchange.

In the field of migration research, using interpreters can improve the quality of the evidence. In qualitative research (Chapter 4.12), interpreters narrow the gap between the perceptions of refugee participants and the understanding of the researchers conducting the investigation. In quantitative research, interpreters facilitate the exchange of data from and to refugee participants. However, there are several limitations to using interpreters in migration research. For example, certain refugee or IDP populations might have an unconscious mistrust of locally recruited interpreters and would be suspicious of any enquiries, which might make them feel uncomfortable about participating in research. Moreover, the lack of human and timely resources may impede the data collection process, and therefore the quantity of interpreters becomes a determinant to the quality of the research. The accuracy of interpretation may also affect the quality of evidence, mainly because verification of responses is limited. Finally, interpreters could allow their cognitive biases to interfere in the process of exchanging information, which, in return, affect the quality of the data collected.

5.3.5 Mental health research

Disasters and humanitarian crises negatively impact the mental health status of affected populations (Chapter 5.1). Mental health problems could be the result of pre-existing illnesses, emergency-induced disorders or conditions caused by the humanitarian response to disasters. Therefore, a sound and effective response to a health emergency or disaster should consider addressing, investigating and managing the mental health conditions of affected populations. Refugees and IDPs who experience or witness traumatic events or violence before their resettlement are at a higher risk for developing mental health conditions such as depression, anxiety or PTSD *(21-23)*. Such events could have been witnessed or experienced before fleeing (when individuals have to give up their properties, jobs, education, as well as family and social networks), during their migration journey (when some may be faced by precarious events and substandard living conditions), or after their arrival to the host country (where they may undergo prolonged asylum-seeking processes, stigmatization, and barriers to accessing their fundamental life needs) *(13, 24)*.

Conducting mental health research among refugees or IDPs poses several challenges that must be addressed adequately to ensure the proper conduct of research among these vulnerable populations. Firstly, the physical environment surrounding refugee participants might be inadequate or unavailable to conduct research. Secondly, some researchers may resort to employing the services of family members as interpreters. This practice gives rise to ethical concerns because family members cannot be objective interpreters, especially when discussing frequently stigmatized issues such as mental health problems. Thirdly, the limited time availability of refugees and IDPs because of work or family health issues could lengthen the research process and require further funding. Furthermore, investigating past traumatic events by regular research staff or interviewers may cause some participants to relive these events, which could ignite their psychiatric symptoms and cause them harm *(25)*. Lastly, externally validating or “generalizing” the findings of mental health research to broader refugee or IDP populations is challenging because those who are willing to participate in a study examining their mental health problems may be radically atypical of the wider population.

Multiple procedures must be followed when conducting research among refugees or IDPs. Researchers must ensure that their research is performed in a secure and quiet setting with adequate privacy measures that the participants feel comfortable about. Offering participants a monetary compensation for their time should not be the sole reason for their participation in research without understanding its nature. Therefore, declaring the provision of any financial or other incentives for participation should occur after explaining the research procedures and outcomes intended. It may be beneficial for researchers to explore proxies for psychological distress, such as sleep disturbance or decreased social functionality, especially in cultures where mental health problems are highly stigmatized. Moreover, when applying for funding (Chapter 6.3), researchers should explain that the process may take longer than expected, leading to a need for more funding to ensure the completion of the proposed study. All interview procedures must be concise and preferably conducted somewhere close to the participant's residence. Lastly, professional psychologists or physicians with expertise in dealing with trauma-induced mental health conditions must be present during the questioning process to ensure the proper management of acute mental health symptoms should they arise.

When conducting research using existing studies, systematic reviews and meta-analyses represent the most feasible and accurate approach to consider when dealing with this vulnerable population (Chapter 2.6). A systematic review is a research methodology that aims to identify, critically appraise and synthesize all the empirical evidence that meets pre-specified eligibility criteria to answer a research question *(26)*. Meta-analyses usually accompany systematic reviews and provide more clear-cut and explicit estimates of the effects of studied interventions *(27)*. However, conducting systematic reviews may present some challenges: the process is time consuming and may not be suitable for answering a question that has not yet been studied. Furthermore, the accuracy and certainty of findings depend heavily on the searches done by the reviewers' and the quality of the studies they review.

Case Study 5.3.2
Use of a systematic review to assess psychosocial services and programmes for refugees and IDPs *(28)*

There is a large body of literature on psychosocial services and programmes. However, evidence on the effectiveness of these interventions among refugees and asylum seekers is sparse and not adequately quantified. Therefore, Nosè and colleagues *(28)* conducted a systematic review and meta-analysis on the effectiveness of such services.

To ensure a robust and systematic review of literature, they set inclusion criteria that answered their research question and defined the population, interventions, comparisons, and outcomes of interest. They searched for controlled trials of adult refugees and asylum seekers in high income countries that had compared the effects of a psychosocial intervention versus no intervention, usual care, or minimal interventions, to assess post-traumatic and depressive symptoms.

The findings showed that psychosocial interventions such as narrative exposure therapy (NET) were effective in decreasing PTSD symptoms as well as depressive symptoms compared to control groups. However, these findings are limited to adult refugees and asylum seekers in high-income countries and cannot be generalized to IDPs, migrant children, or refugees in low- and middle-income countries. Furthermore, the definition of refugees differed across studies, which could camouflage certain population specificities that should be considered.

The inability to generalize findings due to population heterogeneity may limit the evidence-informed decision making process. Therefore, groups such as the Grading of Recommendations, Development and Evaluation (GRADE) recommend decreasing the certainty of evidence should researchers detect any indirectness affecting the effectiveness of a certain intervention *(29)*.

5.3.6 Acute Care

Although refugees and migrants are likely to be in good health prior to fleeing, their health status might be jeopardized while in transition or living in substandard conditions after departure from their homes and lands *(24)*. The interaction of overcrowded environments, contaminated water, poor sanitation and low access to health services such as vaccination serves as a breeding ground for illnesses to re-emerge. Communicable diseases make up almost 90% of consultations in refugee settlements *(30)*. Diphtheria is an example of a vaccine-preventable disease with rare occurrence rates, even in low- and middle-income countries. The pathogen behind diphtheria, however, has spread among Rohingya refugees in Bangladesh due to their congested and overcrowded living conditions, and the lack of vaccination coverage among them *(31)*. Cholera is another example of an opportunistic water diarrhoeal disease that spread among Yemeni children because of limited access to clean water and sanitation resources *(32-34)*.

Managing acute conditions among vulnerable populations requires evidence-based interventions that are proven to be rapid and effective.

New research among refugees and IDPs with acute conditions should only be undertaken if it addresses a critical issue with high prevalence among this population, and assesses a research question that a review of existing research or data does not provide an answer to (Chapter 3.6). Research protocols must be well designed to reflect the logistical and ethical challenges of conducting research among refugees and IDPs, as well as the proposed practices to ensure the success of techniques such as randomization (Chapter 4.1) and recruitment among patients with acute conditions. Moreover, protocols must describe, in detail, the use of privacy methods to ensure the confidentiality of participants in an emergency environment.

When conducting the investigation, researchers must acknowledge the critical physiological and cognitive conditions that refugees and IDPs might experience. Their condition might mean that they are in pain, frightened, unaware of their rights within a new healthcare system, illiterate of their health conditions, or unable to explain their symptoms due to language barriers. They might also have impaired cognition, preventing them from giving an informed consent. Refugees and IDPs may also think that treatment is contingent to their participation in the research study. The researcher, therefore, must have sound and culturally appropriate communication skills to help inform potential participants about the nature of research, the benefits and harms of undergoing it, and their right to refuse participation without any penalty. If capacity to provide an informed consent is jeopardized due to cognitive impairment, the researchers must obtain an “a priori” approval from an ethics board or committee to employ other methods of consent-acquiring processes such as proxy, prospective or deferred consent (Chapter 3.4). Nonetheless, researchers must always act in the best interest of the participant. Lastly, equity considerations must be addressed and strict rules must be imposed to prevent researchers, interpreters, or outcome assessors from discriminating against participants based on their gender, ethnicity, religion, sexual orientation or political opinion.

Case study 5.3.3 Identifying acute health needs in refugees and IDPs *(35)*

Refugee populations frequently move together in large heterogenous groups. These groups will often reach a political border or face a natural barrier that will lead to the formation of a temporary camp. The United Nations High Commissioner for Refugees (UNHCR) plays a major role in supporting the road, tent and health infrastructure for these camps. Nonetheless, the sub-standard living conditions and congestion in these camps is a risk factor for developing acute illnesses and conditions.

Rapid needs assessment surveys (Chapter 2.1) can play an important and timely role of mitigating acute health conditions. These detect the demographics of the populations, pregnant women, elderly, young children and cases of acute diarrhoea and acute respiratory infection or other communicable disease outbreaks. Multiple survey tools now exist online such as EPI Info from the US Centers for Disease Control and Prevention (CDC), which provides support for researchers and public health professionals as they prepare the questionnaire, enter data and conduct rapid analysis *(36)*. Most rapid surveys are done in collaboration with local staff.

Hurricane Katrina forced many families to move from their homes into other cities, such as Denver, Colorado. Ghosh and colleagues conducted a rapid needs assessment survey to identify and examine the acute and contextual medical and non-medical needs of these populations that moved following the hurricane. Certain unique needs emerged, such as the necessity to educate individuals on the high altitude of the city of Denver, and what they can do to overcome altitude-related symptoms *(35)*.

5.3.7 Conclusions

Conducting research for refugees and internally displaced populations can be rewarding both for vulnerable migrants and for health practitioners. Although research engagement can bring evidence-based practices and programmes for migrant specific conditions, researchers need to be vigilant for any ethical concerns that may arise. Training research staff on cultural sensitivity and adapting a comprehensive and explicit informed consent process are good practices to follow when conducting research with vulnerable populations. Field research for mental illness and acute care conditions should only be undertaken when the need for such investigation outweighs any potential harms. Knowledge syntheses such as systematic reviews and meta-analyses may improve the precision of research, reduce bias and limit unnecessary harms to local populations.

5.3.8 Key messages

- **Researchers need to consider population-specific ethical concerns when conducting research among refugees or IDPs, such as obtaining a comprehensive informed consent.**
- **The linguistic barriers that refugees face require the services of interpreters when providing care or conducting research. Researchers need to acknowledge the confidentiality challenges and cognitive biases that may arise when using interpreters and work to overcome them.**
- **Refugees and IDPs are at a disproportionately higher risk of psychiatric disorders. Mental health research among these vulnerable populations is challenging and requires ethical research methods.**
- **Efficient management of acute care conditions among refugees and IDPs requires evidence-based research. Researchers should be transparent when planning their research and should have sound communication skills to explain its nature to refugees and IDPs.**

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5.4

Indigenous peoples

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5.4.1 Learning objectives

To understand the following:

1. Methodologies addressing the health needs of indigenous peoples;
2. The contributions of indigenous knowledge and practices to research and evidence in Health EDRM;
3. Key inputs from prior research to support effective inclusion of Health EDRM approaches among indigenous communities.

5.4.2 Introduction

Indigenous peoples have faced the risks of emergencies and disasters for generations and have applied indigenous knowledge and practices in efforts to reduce the risks and impacts of these events, and build the resilience of their communities. The Sendai Framework for Disaster Risk Reduction 2015-2030, which was adopted by UN member States at the Third UN World Conference on Disaster Risk Reduction, gives emphasis to the integration of traditional indigenous and local knowledge and practices, to complement the development and implementation of disaster risk management policies, strategies, plans and programmes tailored to localities and context *(1)*.

Indigenous peoples are dedicated to persevering, developing, and transmitting their land and ethnic identities to future generations to further their existence as communities with distinct cultures, institutions, and governance *(2)*.

Indigenous communities may be disproportionately impacted by a variety of emergencies and disasters *(3)*. They often endure multiple forms of discrimination and exclusion, resulting in significant inequities, including high levels of poverty and violence, and consequently, the denial of their individual and collective rights *(4)*. The social and economic disadvantage that some communities face leads to decreased access to health services and to poor infrastructure, posing a long-term challenge to resilience. Although indigenous peoples have close relationships with the land, these regions may be compromised due to human- activities such as resource mining, forestry and agriculture, which may leave them vulnerable to the impacts of emergencies and disasters. On the other hand, there are numerous examples of indigenous communities having enhanced adaptive capacity and thus resilience in disaster settings despite socioeconomic deprivation.

Chapters 3.4 and 6.4 discuss ethical issues relevant to research; additional ethical considerations must be put into place to ensure effective inclusion and respect for the rights of indigenous peoples and the use of indigenous knowledge and practices in Health EDRM. There are critical adaptive capacities, networks and bonds among indigenous peoples, as well as additional vulnerabilities, such as social, economic, physical, and environmental factors, that need to be considered in methodological approaches to undertaking research in partnership with indigenous peoples.

In response to the challenges faced by indigenous peoples, the PAHO Member States approved the first PAHO Policy on Ethnicity and Health in 2017. Representatives from indigenous peoples, Afrodescendants, and Roma populations, among others, participated in the development of this policy and committed to supporting its implementation. This policy is aimed at improving, among other things, the health of indigenous peoples in the Americas, while acknowledging the different situations and challenges of these populations in diverse contexts. It is based on recognizing the need for an intercultural approach to health and equal treatment of the different groups from the standpoint of equality and mutual respect. The policy focuses on five lines of action to address the health of ethnic groups: a) the production of evidence; b) the promotion of policy action; c) social participation and strategic partnerships; d) recognition of ancestral knowledge and traditional and complementary medicine; and e) capacity development at all levels. The PAHO Policy on Ethnicity and Health acknowledges the importance of adopting an intercultural approach to address inequities in health *(4)* and is often used as a policy reference at the global level.

This chapter outlines key methodologies and examples to support effective research with indigenous communities, while highlighting the need for any such collaboration to take into account important cultural differences and be based on mutual respect and benefit to both parties. The PAHO Policy on Ethnicity and Health, along with the Sendai Framework for Disaster Risk Reduction and the WHO Health EDRM Framework, are taken into consideration throughout this chapter.

5.4.3 Production of evidence

Understanding the health needs of indigenous peoples is important for the implementation of Health EDRM, in particular for the assessment of risks, including the analysis of exposure, vulnerabilities and capacities. The health data on indigenous peoples may be non-representative, in part due to the lack of disaggregation of data by ethnic origin, and misclassification and underestimation remain key challenges to effective measurement and understanding of indigenous health status. While governments, UN organizations and researchers have made efforts to disaggregate data by ethnic origin, these methods have not always been systematically implemented. The varying definitions of ethnicity across censuses and health records can cause inaccuracies in typical data collection methods (such as national registries), contributing to the lack of health data available among indigenous populations and so significant gaps in data remain.

Different approaches are being employed to improve data and evidence on the health needs of indigenous communities. Data linkage methodologies that collate and cross-reference data from various sources are increasingly being used to improve the accuracy of existing data. Variables such as their recognition of ancestral lands, the main language spoken at home, financial stress over the last year, and self-assessed health status have been used among Aboriginal populations in Australia to compare against census data, and to assess national data compared with qualitative collection *(5)*. Qualitative data collection methods, as discussed in Chapter 4.12, can help enhance understanding of the health needs and experiences of indigenous peoples, and some authors have demonstrated that conducting semi-structured interviews have produced useful insights into the needs of the communities in Health EDRM *(5–6)*. Meanwhile, interactive and collaborative methods of participatory research have shown success in other settings. These techniques include mapping, timeline assessments, trend analyses, daily activity schedules, seasonal diagrams, and likelihood analyses *(7)*.

Participatory research can provide meaningful insight into indigenous health needs. However, outside researchers should ensure they are not imposing their own theoretical and methodological frameworks into participatory activities. It is critical that research is viewed as a partnership, and that an interviewer's relationship with the communities is not a superficial one or just for the sole purpose of data collection *(8)*. This could be perceived as disrespectful and may be damaging to the goal of exchanging information and equitable co-production of research. Instead, such methods should always be based on meaningful consultation, be of clear mutual benefit, and recognize and respect indigenous approaches to health and to emergencies, including disease outbreaks. It is important to collect information on the potential for disease outbreak within these communities. This should include an assessment of what taboos or differing perceptions may exist around certain diseases and how to address them in a culturally appropriate context *(9)*. Meaningful participation of community members in data collection and use is important, as well as ensuring the representation of both women and men of all ages, recognizing the potential impact of gendered and intersecting vulnerabilities in Health EDRM *(4)* .

5.4.4 Social participation and strategic partnerships

PAHO's Policy on Ethnicity and Health *(4)* states that it is essential to promote social and strategic partnerships in line with the national context, while ensuring an accurate representation of both men and women in the process of preparing for health-related activities. This area of intervention seeks to promote effective participation, joint efforts, commitment and strategic partnerships among health authorities, other state institutions, local organizations and the general population to foster action to increase inclusion, equity and equality. In turn, this can better guide research practices in a respectful and effective manner.

While the methodology of data collection is crucial in assessing the needs of indigenous peoples in Health EDRM, it is also imperative that the existing institutions and organizations within these communities are included in the decision-making process, in partnership with national and international organizations *(10)*. Indigenous peoples are best placed to make an assessment of the needs of their community, and this perspective is crucial in managing the risk of emergencies prior to their occurrence. These communities are often marginalized. Researchers have described a denial of their right to self-determination by a postcolonial "developmentalist narrative" in which indigenous peoples are systematically refused and excluded from participation in sustainable development projects *(11–12)*. This leaves their land and resources especially vulnerable to hazards during disasters, yet partnering with them in preparedness actions has been shown to improve post-disaster responses.

Policies only enacted at the governmental level, without the meaningful inclusion and participation of indigenous bodies, have been shown to further enable the cycles of colonization and marginalization *(11)*. Drawing on research examining pre- and post-disaster conditions among indigenous peoples in New Zealand, three types of participation groups can be considered when implementing disaster-based policies: participation led by government, participation led through pre-existing community organizations, and participation through the grassroots movements that arise situationally *(13–14)*. Furthermore, it is important to consider public-private partnerships that stem from co-governance agreements, which are becoming increasingly common between indigenous collectives and central and local government in disaster settings *(13, 15–16)*. There are many examples of indigenous communities assuming leadership in these situations, establishing their own emergency plans and actions to then collaborate with outside governing bodies.

Research has shown that effective processes in promoting the involvement of indigenous organizations within the community in Health EDRM, including both preparedness and response capacities, often include assessments of physical infrastructure *(17)*. Community members are more aware of the areas for improvement than outside organizations, who may be unfamiliar with their infrastructure and systems *(18–19)*. This need becomes even greater with the increasing impacts of climate change and its effect on indigenous communities. In order to properly assess the needs of the communities in vulnerable terrains, researchers should take care to ensure they are fostering indigenous participation in sharing knowledge of how nature has impacted their people in previous generations as well *(19–20)* . As outlined in the Sendai Framework, community-based approaches may need to be modified to address vulnerable groups such as the elderly in disaster situations *(1)*.

5.4.5 Recognition of ancestral knowledge and traditional and complementary medicine

The recognition of ancestral knowledge aims at promoting knowledge dialogue to facilitate the development and strengthening of intercultural health models as a way of achieving people- and community-centered health care *(4)*, including disaster risk reduction plans.

A widely-accepted practice of improving Health EDRM among indigenous peoples is the incorporation of indigenous knowledge into planning for emergencies and disasters. Indigenous knowledge has been defined in a variety of ways. UNESCO describes local and indigenous knowledge as follows:

The understandings, skills and philosophies developed by societies with long histories of interaction with their natural surroundings. For rural and indigenous peoples, local knowledge informs decision-making about fundamental aspects of day-to-day life. This knowledge is integral to a cultural complex that also encompasses language, systems of classification, resource use practices, social interactions, ritual and spirituality. These unique ways of knowing are important facets of the world's cultural diversity, and provide a foundation for locally-appropriate sustainable development *(21)*.

This information can improve scientific knowledge and increase the acceptance of policies within the community by drawing on this understanding of the interaction between culture, resources, and the environment *(22–25).*

Before the 2004 tsunami in the Indian Ocean, the importance of indigenous knowledge was largely underestimated even though indigenous knowledge of how to respond to signs of incoming tsunami waves had saved many indigenous lives *(26–27)*. Elsewhere, purposive sampling of indigenous members within a region of the Republic of Zimbabwe prone to extreme flooding revealed that their study of cloud patterns and the restlessness of a specific species of bird had been studied and this knowledge passed down as a warning sign for imminent heavy rains *(28)* . The Tikopia Island population in the Solomon Islands were prepared for Cyclone Zoe in 2002 by their use of traditional sturdy housing structures that had been part of the cultural knowledge for generations, as well as knowing the locations of overhanging rocks to use as shelter when the storm hit *(29)*. These examples demonstrate that indigenous communities have been drawing on indigenous knowledge to ensure resilience in the face of environmental hazards for long periods of time, and that much remains to be done to effectively incorporate these insights into disaster preparedness and response strategies.

Bridging traditional knowledge and western science is more impactful when they are viewed not as two separate ways of managing risks of emergencies and disasters, but as a collaborative sharing of information from several sources that can provide successful plans of action *(30–31)*. This also applies to the different perceptions that researchers and indigenous communities may have regarding the definition and description of a hazard. Certain events may be viewed as a potential disaster by some scientific communities, while for an indigenous community, the same events may be perceived as something that they have developed the knowledge to handle routinely over generations *(12, 32–33)*. Consequently, researchers and policymakers should take care that proposed actions are shaped in consultation with the community – and be guided by the community's insights as to what would be considered hazardous. This has been referred to as the process of "guided discovery", in letting the communities highlight the areas of importance, in order for researchers to then collaborate in developing a plan for disaster risk reduction *(7)*. Research has shown that it is an effective practice to subdivide groups within the community by type of knowledge and who is best served to communicate this into emergency and disaster planning *(32)*. This includes knowledge such as usage of the land, input from elders within the community, or even the division by gender if appropriate within the community's culture ,so that people feel they can speak freely *(32)*.

It is through "knowledge dialogues" that indigenous peoples can lead the conversation and provide information from their own perspective regarding emergencies and disasters. Furthermore, through continuous knowledge dialogues, indigenous peoples can gradually determine whether they need to modify or transform their practices, living conditions, and knowledge of the risks they have in the community.

It is also recommended to involve knowledge stemming from oral traditions of indigenous peoples, particularly since these are not frequently documented ,and thus sometimes discredited by researchers *(32)*. For populations maintaining oral knowledge traditions, rather than written, previous research has found that immersive fieldwork provides an effective approach to learn from oral tradition about the nature of past events and to be able to document them for future collaboration *(33–34)*. As storytelling related to indigenous knowledge of disaster risks, situations and practice comes embedded in the ways of life within communities, methodologies that respectfully analyse and record these stories with the involvement of elders support more culturally relevant disaster risk management *(12, 33)*.

While there has been improved documenting of the implementation of indigenous knowledge and practices, particularly in relation to natural and environmental hazards and more recently climate change related disasters, there is still work to be done to mainstream this into policy approaches. Therefore, research outcomes recommend that the strategic partnerships established in response to previous emergencies and disasters work towards greater implementation of indigenous knowledge and traditions. This can be used, for example, in disseminating warnings before events in both traditional scientific language and through the medium of indigenous language and cultural norms as well *(34)*.

Case Study 5.4.1

Kaupapa Māori - Indigenous Research Methodology and Health in Disasters

Kaupapa Māori research is a New Zealand-based indigenous research approach that combines indigenous research theory, methodology and design *(35)*. Research is developed by and for Māori, addresses Māori concerns, and is implemented by Māori researchers in accordance with Māori cultural values and research practices *(36–37)*.

A qualitative research project was developed to identify cultural attributes that enhanced the wellbeing of Māori during and after the 2010-2011 Canterbury Earthquakes. A Māori research methodology, Te Whakamāramatanga *(38)*, underpinned by cultural values and practices, shaped project implementation, facilitating a research partnership between the researchers and Māori partners, Ngāi Tahu. Tribal connections and external relationships were leveraged to recruit participants. Institutional ethical requirements and the tribe's cultural imperatives were met. Acknowledgment of the tribe's Mana motuhake (self-determination and autonomy), their collective authority, agency, action and accountabilities in relation to the research, generated community trust. Whakaritenga (negotiation) and whakaaetanga (acceptance, agreement, consent) were continually actioned. Data collection explored Māori views of the response to the earthquakes and 70 participants' narratives were collected during interviews and hui (group meetings). Interview topics were jointly agreed, while interviews were transcribed verbatim and member checked. Māori cultural concepts framed narrative analyses of participants' talk. Investigator and theoretical triangulation processes reduced data misinterpretation. Researchers liaised with participants to ensure themes reflected Māori experiences.

Thematic results included the effectiveness of Māori responses to the earthquakes; concerns (such as invisibility of Māori concerns and health needs) and cultural beliefs, values and practices contributed to Māori recovery and could enhance community resilience. Participants' recommendations for Māori planning for disaster preparedness were also documented. Results highlighted the speed and effectiveness of the Māori response to community needs. Māori resources encompassed mobile emergency medical teams, primary care, and psycho-social services, financial supplements, shelters, food, clothing and fresh water as well as free legal guidance regarding government benefits and insurance *(38)*. Results also drew attention to the ways formal emergency management othered Māori in the earthquake response *(12)*. Publications were co-authored with Maori partners who retained intellectual property rights over cultural knowledge, and shared property rights for new knowledge with the researchers.

Findings have informed changes to emergency management policies and practices. The role of Māori in facilitating community resilience to disasters, has also been acknowledged by central government *(39, 40)*, and related amendments to disaster management legislation, signaled.

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Case Study 5.4.2
Yi-minority Community in Sichuan Province, China

Geographical location plays an important role in explaining ethnic vulnerabilities to disasters. There are 55 ethnic minority groups in the People's Republic of China, constituting 8.49% of the country's total population *(41)*. They have different dialects, cultural practices, livelihoods, and social traditions within the boundary of China; nevertheless, most of them are also characterized by the remoteness of their settlements, which has been associated with inadequate access to health services as well as to education. Evidence from previous disasters shows that these communities have been highly exposed to hazards and demonstrate a low resilience to loss *(42)*.

A survey undertaken to inform a Health EDRM programme for the Yi-minority community in Sichuan province, showed that the Yi population, who live in a mountainous landscape with poor road conditions, lacked disaster preparedness *(43)*. It also found that previous disaster experience, including a major flood in 2012, had not been a good predictor for future disaster preparedness – despite an increasing risk of disaster in this rural mountainous area. Informed by these findings, a number of health measures were designed in order to strengthen villagers' disaster preparedness. This included the preparation of household disaster kits and oral rehydration solution recipes. These interventions were tailored to the need of the community and implemented in a way that was culturally acceptable – with a focus on providing the necessary tools for self-empowerment and improved resilience.

To truly address the need of these communities before, during and after emergencies and disasters, it is of utmost importance that research informs health strategies and actions about potential differences between ethnic and non-ethnic minorities. Factors to take into account may include diversities in demographic patterns, literacy rate, language and occupation. Effective risk communication (see Chapter 4.11) must be tailored to the literacy rate and languages (mostly dialects) of the community, while age and occupation will be key predictors of health status and responsiveness to the risks and impacts of disasters.

5.4.6 Conclusions

In summary, existing research methodologies concerning Health EDRM among indigenous peoples are scarce and often non-representative. Such methodologies can benefit from certain advances, such as the Sendai Framework, the Health Emergency and Disaster Risk Management Framework and incorporation of lines of action addressed in the 2017 PAHO Policy on Ethnicity and Health. They may also benefit from being modified to include collection of disaggregated data and to encourage participation and community engagement – which are crucial in any action that may seek to strengthen Health EDRM among indigenous peoples.

5.4.7 Key messages

- **Indigenous peoples must be meaningfully included in the development and implementation of Health EDRM policy, planning, practice and research to ensure that the approaches used are culturally and linguistically relevant.**
- **True partnership with indigenous peoples and effective engagement of indigenous peoples in Health EDRM is crucial. It is important to assess what aspects of communication, among other areas, need to be improved upon to meet the community's needs.**
- **It is critical that research is viewed as a partnership which respects the leadership, empowerment and full consent of indigenous peoples. Indigenous people are best placed to make an assessment of the needs of their community, and this perspective is crucial in risk management and research.**
- **International and national agencies and other organizations need to be held accountable in including indigenous peoples in Health EDRM initiatives, particularly the recognition of knowledge, practice and needs of indigenous peoples, collaboration with indigenous people. and incorporation of indigenous knowledge and practice into regional, national, and international emergency and disaster risk management strategies and plans.**

5.4.8 Further reading

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