

Indigenous peoples

Authors

Sandra Del Pino, Office of Equity, Gender and Cultural Diversity, Pan American Health Organization (PAHO), Washington DC, USA.

Julie Davis, Alex Camacho and **Enrique Perez-Gutierrez**, Department of Health Emergencies, PAHO, Washington DC, USA.

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. Well established exemplars include the Konyak in Nagaland (North East India), the Seminole nation, (Florida, USA) and Māori responses to recent earthquake and flood disasters in New Zealand.

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

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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 Papua New Guinea. 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 (15). Following disaster events, existing community organizations and health personnel are often found to be trusted more than government organizations that have failed to provide necessary aid in the past (13, 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

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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 by national authorities and so was not incorporated into government-led Health EDRM plans, 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 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).

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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 Māori 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), and related amendments to disaster management legislation, signaled.

(Prepared by Associate Professor C. Kenney, Joint Centre for Disaster Research, Massey University, and Dr S. Phibbs, School of Health Sciences, Massey University).

Case Study 5.4.2

Yi-minority Community in Sichuan Province, China

Geographical location plays an important role in explaining ethnic vulnerabilities to disasters in China. There are 55 ethnic minority groups in the People's Republic of China, constituting 8.49% of the country's total population (40). 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, leading to inadequate access to health services as well as to education (41). Evidence from previous disasters shows that these communities have been highly exposed to hazards and demonstrate a low resilience to loss (42–43).

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 (44). 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 health strategies and actions recognize and respond to 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.

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5.4.7 Key messages

- o **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.**
- o **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.**
- o **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.**
- o **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 peoples, 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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