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Identifying and engaging high-risk groups in disaster research

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2.5.1   Learning objectives

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

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

2.5.2   Introduction

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

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

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

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

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

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

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

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

2.5.3   High-risk populations

The vulnerabilities and resiliencies of populations may shift depending on the disaster scenario (Chapter 3.2), with different disasters distinctively heightening specific risks. For example, in a disaster in which evacuation is necessary, careful planning will be required for those with mobility issues – such as people with physical disabilities that inhibit movement, functionally limited elderly and other homebound persons. Similarly, those who are less well connected to mainstream communication services due to language restrictions, education level, migration status or other means of marginalization, may not receive adequate guidance on disaster risk management or access to health services. In heatwaves, cold-waves, heavy rainfall and flooding events, which require populations to stay indoors, the homeless and those living in compromised housing are at increased vulnerability and may require appropriate shelter. It is important that research defines and addresses issues relevant to high-risk populations to support evidence-informed DRR practices and policies. The following section addresses some common factors that have potential to increase vulnerability.   89

2.5.4 Age and developmental stage

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

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

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

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

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

Semi-structured, in-depth key informant interviews and focus group discussions were conducted with a total sample of 69 adolescents and 72 adults across both countries. Five major themes were identified in the

analysis of data on DRR for adolescents: (i) the importance of adolescent safety and security post-disaster; (ii) adolescent participation in disaster preparedness; (iii) disaster response tailored to adolescents' needs; (iv) the need for evidence-based psychosocial support; and (v) acknowledgement of adolescent participation in disaster risk management *(10)*. The qualitative process identified not only the strengths and weaknesses of current practice, but also recommendations voiced by participants, particularly adolescents.

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

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

2.5.5 Gender and sexual identities

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

services. Menstruating and lactating women require regular access to private settings and provision of menstrual hygiene resources.

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

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

2.5.6   Pre-existing chronic conditions

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

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

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

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

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

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

2.5.7 Persons with disabilities

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

2.5.8 Other marginalized groups in the community

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

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

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

Sampling

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

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

There are limitations and biases that occur with each sampling method, which may affect the research results. Selection bias is introduced by the way individuals are chosen as participants. For example, sampling chronic disease patients at local public hospitals would exclude those who attend

private clinics only, or those who do not seek treatment for their conditions. Non-response bias occurs when those who participate in the study are inherently different from those who refuse to participate. This can occur with telephone surveys, mail-surveys, internet sampling, and is of particular concern in follow-up studies. Gatekeeper bias, where participation is limited by those who provide entry into the community groups, may restrict the types of participants that can be involved in the study. Addressing biases through a more comprehensive or open sampling strategy is important to ensure the rigor of the study.

Recruitment

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

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

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

2.5.10 Data collection

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

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

2.5.11 Ethics Approvals and Considerations

Chapters 3.4 and 6.4 discuss key aspects of the ethics of research and obtaining ethics approval. However, when working with high-risk groups it is especially important to be vigilant about possible ethics violations, intended or unintended. A systematic review of published guidelines on research ethics in disaster settings highlighted the importance of obtaining formal approvals, but also addressing issues of vulnerability in research protocols *(58)*. Among the vulnerability factors identified, reducing risks of physical harm, retraumatization, manipulation, exploitation, unrealistic expectations and stigmatization were central to ethical research processes *(58)*. It is important to obtain informed consent from all participants. Consent can be obtained on multiple occasions, including at the end of data collection, and from multiple agencies, such as the community, parent and participant, to empower informed decision making *(59)*. For people

with less access to education, language restrictions, severe mental health issues or cognitive difficulties, information about the research purpose and the participant's rights must be presented in a format tailored to promote comprehension *(60)*. Space should be given to participants to refuse the study without pressure or persecution, and to ask questions about the research activities.

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

2.5.12 Conclusions

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

2.5.13 Key messages

o   **Health EDRM research with an inclusive focus on high-risk populations should be conducted across the entire disaster cycle and may vary according to the characteristics of the disaster and community.**

o   **Children, elderly, gender and sexual minorities, those with pre-existing chronic conditions or disabilities, ethnic minorities, migrants, displaced persons and other marginalized groups are common high-risk groups to be considered. Intersectionality plays a significant role in capacities and heightened vulnerabilities.**

o   **High-risk populations may be difficult to reach, which can affect sampling, recruitment and data collection.**

o   **Inclusive and ethically responsible research protocols must consider the impact of research on high-risk populations and guide reliable and thoughtful dissemination of findings.**

2.5.14 Further reading

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