## DESIGNING RESEARCH IN DISASTER-AFFECTED SETTINGS

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A training guide informed by The Study on Adolescent Resilience after Disasters



**Collaborators:** 













Collaborating Centre for Oxford University and CUHK for Disaster and Medical Humanitarian Response CCOUC 災害與人道救援研究所

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## CONTRIBUTORS



Elizabeth A. Newnham School of Psychology and Speech Pathology, Curtin University

FXB Center for Health and Human Rights, Harvard University



Jessica E. Tearne School of Psychology and Speech Pathology, Curtin University



Xue Gao School of Psychology and Speech Pathology, Curtin University



Claire Mitchell School of Psychological Science, The University of Western Australia

School of Psychology and Speech Pathology, Curtin University



Samantha Sims School of Psychology and Speech Pathology, Curtin University



Feng Jiao Kunming Medical University



Bhushan Guragain Centre for Victims of Torture, Nepal



Lajina Ghimire Centre for Victims of Torture, Nepal



Satchit Balsari FXB Center for Health and Human Rights, Harvard University



**Emily Chan** 

Collaborating Centre for Oxford University and CUHK for Disaster and Medical Humanitarian Response, The Chinese University of Hong Kong

Centre for Global Health, The Chinese University of Hong Kong



Jennifer Leaning FXB Center for Health and Human Rights, Harvard University



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## WELCOME

On behalf of the investigators, I am delighted to present this research training guide, developed for The Study on Adolescent Resilience after Disasters.

The Study on Adolescent Resilience after Disasters was launched in 2015, with an aim to investigate the specific risks and opportunities that contribute to positive outcomes among young people living in disaster-affected settings. It has been an inspiring and informative two years, as we have learnt from the thousands of young people who contributed to the Study and built partnerships that will foster ongoing advocacy and research in the field.

The Study is a testament to the value of multinational collaborations in applied science. Our partnerships in China, Hong Kong, Nepal, the United States and Australia have strengthened the quality of the research and enabled broad dissemination of the results. Without strong linkages between academia, government agencies and nongovernment organizations, we would not have been able to achieve the meaningful training opportunities and powerful evidence that emerged from the study.

We are in an exciting phase of the research. The Study has reached disaster-affected communities in five districts of Nepal and four districts of China. More than 4,200 adolescents have participated. Findings from the study have been presented at the World Congress on Public Health, the Annual Conference on Disaster Preparedness and Response, the World Congress of Behavioral and Cognitive Therapies, and at research seminars at Harvard University, the Chinese University of Hong Kong, The University of Western Australia and Curtin University. The quality of these papers was exemplified by the Best Paper Award received for a presentation at the Annual Conference on Disaster Preparedness and Response in Hong Kong.

Capacity building is an integral component of the project. Training workshops were conducted at Kunning Medical University, the Centre for Victims of Torture Nepal, and at the Chinese University of Hong Kong. Trainees included undergraduate and postgraduate students, humanitarian professionals, community health workers, and local research assistants working in regional disaster-affected areas. Our ongoing work in analysis and interpretation of the results has broadened opportunities for learning across the research team.

Research findings arising from The Study have informed the development of two policy briefs to date, Responding to Mental Health Needs in Disasters, and The Changing Landscape of Early Warning Systems: Promoting Effective Decision Making and Action. Four academic papers have been submitted to high-impact peer-reviewed journals, with more to follow over the coming year. We are actively promoting the findings through traditional and social media, as well as future community education campaigns.

We are most grateful to our funding partners who supported this work. The Study on Adolescent Resilience after Disasters and accompanying training program were established as part of a generous donation from The Hong Kong Jockey Club Charities Trust. Support was also received from the National Health and Medical Research Council of Australia, the FXB Center for Health and Human Rights at Harvard University, The University of Western Australia and Curtin University. Support and expertise provided by The Hong Kong Jockey Club Disaster Preparedness and Response Institute and the Yunnan Province Centre for Disease Prevention and Control was greatly appreciated. This work would not have been possible without the tireless efforts of our research teams in China, Nepal and Australia, for which we are deeply thankful. Finally, we extend our heartfelt gratitude to our research participants, their families and schools, for their thoughtful insights and valuable perspective.

Yours sincerely,

Eizebet Nenh

Elizabeth Newnham, MPsych., PhD. Principal Investigator, The Study on Adolescent Resilience after Disasters Curtin Research Fellow, School of Psychology and Speech Pathology, Curtin University Research Fellow, FXB Center for Health and Human Rights, Harvard University



### INTRODUCTION TO RESEARCH IN DISASTER SETTINGS

Asia is facing an increasing risk of natural disasters.<sup>1</sup> At a time when climate-related disasters are rising in frequency and severity, evidence is critically needed to understand the health and security effects of humanitarian emergencies across a diverse range of populations and cultures.<sup>2</sup> Humanitarian research spans multiple functions: recording the rate of disaster occurrence, assessing the toll on morbidity and mortality, investigating effective means of responding, and improving associated health, safety, sanitary, logistic and educational programs and policy. While disaster response and humanitarian medicine have become the focus of a growing body of research,<sup>2</sup> the evidence base for preparedness and response policy requires further attention. Accordingly, public health research will play a vital role in determining best practice in emergency settings over the coming years.

The purpose of this training guide is to illustrate ways in which research methods can be employed in the unique context of humanitarian crisis settings. The strategies described in this guide will be useful for studying the effects of disasters on health, and the effectiveness of interventions to improve health outcomes. Fostering an understanding of methodological techniques and challenges is critical to developing evidence-based findings that can inform future policy and practice. This guide is oriented to practitioners, students and novice researchers in the fields of public health, medicine, psychology and allied health sciences who have a strong interest in populations affected by humanitarian emergencies.

Each of the concepts, techniques and challenges described in this guide are issues that we have encountered and addressed in the design and implementation of The Study on Adolescent Resilience after Disasters. From partnership development, through to research design, ethics approvals, data collection and analysis, this guide will explain the processes involved in conducting a research study in disaster-affected settings. We hope that reflection on the lessons learnt in our experience will assist you in developing rigorous, ethical and meaningful research for the benefit of communities in crisis.



#### 5 Deadliest Disasters in A

- 1. Gorkha Earthquake; Ap
- 2. Ludian Earthquake: Au
- 3. North Korea Floods: Au
- 4. Afghanistan Floods: Ap
- 5. India Floods; Novembe



ril 2015 (8,831 deaths) gust 2014 (731 deaths) gust-Septemper 2016 (583 deaths) ril-May 2014 (431 deaths) <sup>r</sup>-December 2015 (325 deaths)

## HOW TO USE THIS GUIDE

PART I

**PART II** 

**PART III** 

**PART IV** 

PART V

The guide comprises five parts:

**First**, challenges associated with conducting research in humanitarian settings are outlined. Disaster research is unique in that teams responding to the scene work under conditions of significant stress, and research often needs to be conducted with a sense of urgency.<sup>3</sup>

The **second** section describes the range of methods and techniques applicable to disaster research. Processes and procedures for developing research questions, applying for ethics approval, and designing qualitative and quantitative research are explained.

The **third** section outlines a range of tools for conducting mental health research in humanitarian settings, with reference to the findings of The Study on Adolescent Resilience after Disasters.

**Fourth**, we highlight considerations for working with special populations, including children and adolescents, diversity of race, religion, gender and sexuality, people with disabilities and those who have suffered trauma and loss

The **final** section illustrates mechanisms for disseminating findings and using evidence to inform policy and practice.

Throughout the guide, relevant sections of the Adolescent Resilience after Disasters study are used as examples of how research has been conducted in disaster-affected settings.



Current Challenges in Disaster Research

Globally, the numbers of people affected by humanitarian crises are reaching unparalleled heights. Forced migration from conflict zones and an increase in the frequency and magnitude of natural hazards<sup>4</sup> are among the causes of recent humanitarian crises. Recent estimates suggest that 65 million people worldwide have been forcibly displaced from their homes and communities due to conflict, with over half of the world's refugees being children.<sup>4</sup> In addition, more than 26 million people have been displaced each year for the last seven years due to natural hazard-related disasters, and over 1.3 million have died as a result of such disasters.<sup>4,5</sup> With climate change and global warming, the frequency and magnitude of natural hazard-related disasters is expected to increase. It is clear that humanitarian responses and resources cannot meet this ever-increasing demand, and that the development of more sustainable and preventative methods are required.<sup>5</sup>

There have been ongoing international efforts over the past two decades to implement global guidelines and frameworks for disaster risk reduction. The World Conference on Disaster Risk Reduction, comprising a series of United Nations meetings, has convened three times since 1994. Two international frameworks have been established following the 2005 and 2015 conferences, including the Hyogo Framework for Action (2005-2015)<sup>6</sup> and the Sendai Framework (2015-2030).<sup>7</sup>

The Sendai Framework details global targets primarily aimed at substantially reducing the impact of disasters (e.g., human loss of life, infrastructure damage), increasing international cooperation to aid national efforts, increasing the number of countries that have risk reduction strategies, and increasing the use and access to multi-hazard early warning systems.<sup>7</sup> With regard to science and research, it requests an increase in the use of scientific findings to inform policy, improve research, and advance risk reduction technologies.<sup>7</sup>

More generally, there has been a shift in emphasis in research from crisis management to building resilience and reducing vulnerability to disasters.<sup>5</sup> It is now deemed crucial that we enhance our understanding of what makes humans resourcefully and psychologically stronger to support early action and prevention to reduce the impact of natural hazards. Indeed, recent years have seen a significant increase in the development of new innovative technologies (including more efficient and action-oriented early warning systems), and more robust infrastructure. Overall, future research should focus on reducing disaster risk and enhancing resilience.





## CHALLENGES IN CONDUCTING RESEARCH IN RESOURCE-CONSTRAINED SETTINGS

The international community has called for an expansion of the evidence base for humanitarian action and policy,<sup>8</sup> yet the challenges inherent in conducting research after disasters have restricted progress. Participants and researchers may be living and working in areas where critical infrastructure is damaged or destroyed, and face an ongoing threat of aftershocks or other disasterrelated events. Partnerships critical to the effective and efficient collection of data may not exist at the time of the disaster, and concentrated efforts to establish strong collaborations are vital.<sup>9</sup> Resources are often limited in the aftermath of disasters, as funding is channelled towards aid programs without allocation to monitoring and evaluation efforts. Despite the considerable benefits of aid, outcomes and scope of impact must be quantified to demonstrate effectiveness.

Disaster-affected populations often face great threats to health, mental health and security, and these may limit their capacity to provide informed consent or to actively engage in research.<sup>10</sup> Further to this, communities may not see a need for research or may already be suffering from participant fatigue (following involvement in multiple research studies that fail to return results or benefits to the community). It is vital that researchers are aware of the heavy toll of participation that has already been sought from a community, and ensure that their own studies do not add to the fatigue and discomfort of an already vulnerable population.

It is also critically important that researchers do not make false promises about the benefits of the research to the community. While the scope of contribution to knowledge may be evident to the research team, participants may require specific assistance, and the team's ability to assist with this must be made clear from the outset. If you are able to secure resources that will assist potential participants, that should be communicated, but if not, there should be no promise of future benefits that may not evolve. False promises disappoint the community, create frustration, and reduce the capacity of future research. Accordingly, welldesigned research that is conducted in collaboration with local partners and government and serves to build capacity in local populations is a welcome resource.<sup>11</sup> This Research Training Guide aims to assist in the development of informed research protocols and contribute to our growing understanding of the impact of disasters on human populations.

Knowledge Check:

- What are three challenges of conducting research in disasteraffected areas?
- What must researchers be conscious of while interacting with participants in vulnerable settings?



Designing Research

### **HOW TO DEVELOP A RESEARCH QUESTION**

Research is a systematic process of collecting, analysing and interpreting data in order to generate new understanding and knowledge of certain interesting topics. A complete research process is typically composed of five steps: (a) identifying the research question(s); (b) developing a clear and detailed research plan including selecting appropriate research methods; (c) collecting research data per your plan; (d) analysing and interpreting the data; (e) and finally reporting and disseminating the results.

A research question is a clear and specific statement of what is to be studied. It is the anchoring point of a research project that guides the planning, development and implementation of a whole research project.

The research question can be developed in three steps: 1) choosing an interesting and important research topic; 2) gathering background information; and 3) narrowing the topic to a focused research question that has potential to generate impactful results. Think about why you want to conduct the research in the first place. In disaster settings, research topics often come from the practical problems in the field, as the purpose of disaster research is to provide evidence for humanitarian practice.

Start with a broader topic that you are interested in and is important in your field of work. For example, a children's service worker may want to study how earthquakes affect children. This is a broad research topic that can be narrowed down. Gather sufficient background information about this topic from various sources. Start with scientific literature from credible research journals, although other organization reports and government data can also provide useful information. This will inform what is known and unknown about this topic and help to choose an appropriate research design and data collection methods.

Finally, a broad research topic can be narrowed down to specific research questions by adding more information about what, when, where and who. Maybe you want to study the mental health effect (what) of the 2015 earthquake on in-school adolescents (who) in Nepal (where) one year after the earthquake (when). This is much more specific now, but could still be further narrowed depending on your resources. It may not be possible to study the whole of Nepal but only a region. Alternatively, you may not have enough resources to study all mental health effects but do have the ability to look at mood disorders. Start to think about the feasibility of the study early in research design, even from the point of developing a research question<sup>12</sup>. Consider how long it will take to complete the research, how much it will cost, what other resources it will need (such as cooperation from other people) and potential ethical constraints. A good research question is a balance of what is feasible and what is important to study.

The focus of The Study on Adolescent Resilience after Disasters was to assess adolescent mental health in disaster-affected areas of the Asia Pacific region. Adolescence is a unique phase in life with rapid physical, neurological, cognitive and emotional development.<sup>13,14</sup> Children and adolescents are more vulnerable during emergencies. Compared to younger children, adolescents are viewed as being at significant risk of negative mental health impacts because of their greater awareness of what is happening and how it could affect the future.<sup>10</sup> On the other hand, they have better problem-solving skills and more coping capacity than younger children.<sup>10</sup>

The Asia Pacific region experiences the highest proportion of disasters<sup>1</sup> in the world, but the experiences of local adolescents are not well described. Our broad research question was to investigate how natural disasters affect adolescent mental health, security and wellbeing in Asia, and to define the specific pathways to resilience. Liaising with local partners, we further specified the focus on study sites in Yunnan province of China and Gorkha, Sindhupalchowk and the Kathmandu Valley in Nepal. In consultation with published literature and local partners' suggestions, we further developed a range of more specific research questions. A few examples include:

- What is the prevalence of post-traumatic symptoms, anxiety and depression among disaster-affected adolescents in target areas of China and Nepal?
- What are the specific indicators of adolescent resilience in disaster-affected areas in China and Nepal?
- What are the risk and protective factors mediating the relationship between disaster exposure and mental health outcomes of adolescents in China and Nepal?

### **CHOOSING AN APPROPRIATE RESEARCH STRATEGY**

After defining your research question, the next step is to select an appropriate research strategy that can answer your question. Think about both the research design and the data collection methods. Depending on the research questions, there are many different research designs that may be suitable.<sup>15</sup> Depending on the type of data to be collected, there are two types of research methods: qualitative and quantitative methods.

Qualitative research methods collect non-numerical data and information through interviews, focus group discussion, or observations including photos and videos to answer questions of what, how, or why. For example, how has life changed for adolescents after an earthquake? Sometimes, you may want to use both qualitative and quantitative research methods to take advantage of each one's strength and build a holistic picture of the studied issue. Qualitative methods provide a depth of understanding not often possible through quantitative methods, but generally do not provide the same breadth of understanding.

**Cross-sectional studies** collect all the data at the same specific point in time. Cross-sectional studies could be descriptive or analytical. An example of descriptive crosssectional study is to measure the prevalence of anxiety symptoms among earthquake survivors one year after the earthquake. An example of analytical cross-sectional study is to compare the prevalence of anxiety symptoms between male and female earthquake survivors one year after the earthquake. **Quantitative research methods** collect measurable data through structured instruments such as a questionnaire, or direct measurement and observation, and employ statistical analysis afterwards to answer questions of how much or how many. For example, what proportion of women reported depression symptoms after the flood? The main types of quantitative research are crosssectional, case-control, cohort, intervention studies and outcome evaluation.

In **case-control studies**, individuals with an outcome of interest (cases) are compared to those who do not have the outcome (controls) with respect to previous exposures to certain factors to examine the relationship between the exposure and the outcome.

In cohort studies, a group of individuals (cohorts) who do not have the outcome of interest at the beginning is followed over time. A number of exposures are measured during the course of the study, and at the end, those who have developed the outcome of interest are compared to those who have not to determine the relationship between these exposures and the outcome. Intervention studies differ from the first three observational study designs by introducing the exposure of interest (the intervention) to the study population. The purpose of an intervention study is to assess the effect of the intervention. The most rigorous design is a randomised controlled trial (RCT). RCTs involve the random allocation of participants to an intervention or control group, and comparison of their outcomes. In field research, sometimes when random allocation is not practical due to ethical or resource constraints, pre- and post-intervention comparison can also be used to estimate the effect, though the interpretation of the results should be made with caution.

In order to evaluate existing services a program of outcome assessment may be implemented. By assessing pre- and post-service outcomes, or other variables of interest, organizations can demonstrate the effect, impact or scope of their programs. **Outcome** assessment data can be highly valuable for evaluating and improving existing services, and demonstrating the impact of donor funds.

### **DETERMINING SAMPLE SIZE**

HOTEL

For some research projects, there may be only a small number of people within the research population. For example, should you wish to study the impact of a landslide in village A that houses 20 families. You may be able to talk to everybody in the village and invite them all to participate. Most of the time, however, it is not feasible to include every person as a participant. Then sampling is necessary. Sampling is the process of selecting a portion of people from the population of interest (a sample) to participate in the research so that by studying the sample you may learn something about the population.

The number of people included in a sample is the sample size. Its determination is a trade-off between being accurate and being affordable. Being too large is a waste of research resources, and being too small may lead to inaccurate conclusions. The approaches of sample size determination vary with the methods of sampling. There are two major categories of sampling methods: probability sampling and non-probability sampling.

Probability sampling employs some form of random selection and each unit of the research population has a known, nonzero probability of being selected. Thus, it is possible to make the inference about the population from the sample. Probability sampling is often used in quantitative research. In probability sampling, sample size calculation varies with the research design, but generally depends on the following aspects:15 the acceptable level of significance, the power of the study, the expected effect size, the baseline event rate in the population, and the standard deviation in the population. The aim is to select an appropriate sample size that allows the researchers to detect a meaningful difference or estimate the population parameter at a desired significance level and power. Free sample size calculators and guides are available online.

In non-probability sampling, the probability of any unit being selected cannot be predetermined. Some elements may have no chance of being selected. Researchers select the sample and determine the sample size based on their own interest or practical conditions. Some examples of non-probability sampling are convenience sampling, quota sampling, purposive sampling, and snowball sampling. Non-probability sampling is often used in qualitative studies, though it can also be used in some quantitative studies. The sample size of non-probability sampling is either decided by the researchers beforehand in the planning phase as in quota sampling, or decided during the data collection process if no further new information can be obtained from more participants (called "saturation").

For The Study on Adolescent Resilience after Disasters, the sample size was determined according to our research strategy, the available time and resources, and the local context. Specifically, in voices of a range of stakeholders relevant to our research questions, including local experts working in adolescent health, security, education or disaster response, community leaders, school teachers, adolescents and their caregivers. Following this framework, our local partners identified a number of potential participants, considering their expertise availability during the planned data collection period, the manpower of our local research team and the logistics for data collection. We employed snowball sampling to broaden the participant sample. Participants were recruited for the study until we reached saturation of the data, within our resources.

For the quantitative survey, in consultation with our local partners, we first determined the specific regions that would be the focus of data collection, considering the disaster exposure experience, the accessibility and local schools' interest in participation (as assessed during the qualitative phase). Then we estimated the sample size and designed a sampling strategy that would be sufficiently rigorous and representative of the region. Our sampling strategy took into account the number of secondary schools in each targeted region, the proportion of government and private schools, the average class size, the manpower of our data collection team, and the available time for data collection. The goal was to achieve a maximum sample size within the limits of resources and time.

In Nepal, the study included government and private schools from Gorkha, Sindhupalchowk, and Lalitpur. Within each participating school, 30 students were randomly selected from an age-appropriate class and invited to participate in the study. In China, the study took place in Changning and Yiliang. In each county, participants between the age of 15 and 19 were recruited from middle schools and high schools closest to the earthquake epicenter. Within each school, two or three classes were randomly selected from each eligible grade (grade 9 to grade 11), and all students in the class were invited to participate in the study. All participants provided informed consent and caregivers' consent was obtained for those under the age of 18.

### TIMEFRAMES: CONDUCTING RESEARCH IN THE DISASTER CYCLE



In terms of risk management, the disaster cycle usually involves four phases (Figure 1):<sup>16</sup> preparedness, response, recovery and mitigation. The <u>preparedness phase</u> focuses on planning how to respond to potential disasters should they occur at any time. It includes activities such as developing a response plan, training response personnel, and establishing a communication system of warnings in the community. The <u>response phase</u> starts immediately after a disaster occurs. In this phase, the plans developed in the preparedness phase are implemented with a primary focus on providing relief: saving lives, meeting the basic needs of those affected (food, water, sanitation, shelter, medical service), and restoring damaged transportation and communication systems. After the emergency phase ends, the <u>recovery phase</u> begins, focusing on getting back to normal. A few examples of activities in this phase include repairing and rebuilding damaged buildings, restoring regular health service, and providing long-term mental health support. The <u>mitigation phase</u> is characterized by actions taken to mitigate the damages of disasters to people and community should they occur again in the future, such as building earthquake-resistant houses. Research can take place in any of the disaster phases depending on the specific research questions (Figure 1). However, there are more challenges associated with conducting research in the response phase, due to logistic constraints and ethical considerations (including obtaining timely ethics approval).



Figure 1. Four phases of the disaster cycle and example research topics<sup>16</sup>

How do you develop a research question?
How do you determine the sample size for your research?
What are the four phases of the disaster cycle?

The identification and engagement of local research partners is crucial to conducting field-based research. International research should only ever be conducted in partnership with local organizations, service providers, government advisors and/or community representatives. As is evident throughout this guide, local research partners are crucial at every stage of the research process, from advising on study feasibility and acceptability, developing methodology, recruitment and sampling, obtaining local research ethics, data collection, guiding analyses, managing risk, and in disseminating and translating findings back to the community. These are essential processes to good quality research and the role of local partners cannot be underestimated. Engaging with local partners also provides an opportunity for reciprocal skills training and capacity building within the international research team. Local and international teams can share strengths and identify areas of need for each other in order to build a cohesive skill set.

It is important to promote an honest and open relationship between partners. Respective roles in study design and methodology, ownership of data, paper authorship and publication plans must be discussed and made explicit at the outset of the research program. Regular team meetings are essential to facilitate this process. Evidence indicates that research partnerships are most successful when teams agree to 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.<sup>17</sup> Without collaboration, research in disaster-affected settings is at risk of drawing false conclusions, duplicating processes or failing to have a meaningful impact on policy and practice.



#### **Knowledge Check:**

- What is the importance of local partnerships?
- What is the importance of international partnerships?
- How can local and international partners collaborate to ensure good quality research?

#### International partnerships

The Study on Adolescent Resilience after Disasters has fostered a number of new international research partnerships and has strengthened existing collaborative efforts. Building upon existing successful collaborations between the FXB Center for Health and Human Rights at Harvard University, The University of Western Australia, Curtin University, and the Collaborating Centre for Oxford University and Chinese University of Hong Kong for Disaster and Medical Humanitarian Response; The Study facilitated new relationships with the Centre for Victims of Torture Nepal and Kunming Medical University. Over the course of the research program, strong partnerships with academics and research staff at both institutions have resulted in reciprocal skill building within the multinational team, and a rigorous, locally relevant, and culturally respectful program of research with clear avenues for dissemination of findings back to the community.

The input of in-country partners in Nepal and China was invaluable to the development of questionnaire design, participant recruitment and engagement, analysis and interpretation of findings, and determining future research questions. At a broader level, the project has resulted in fruitful collaboration with The Hong Kong Jockey Club Disaster Prevention and Response Institute (DPRI), the support of which was crucial to this project. The DPRI provided valuable guidance and strategic vision for the project, and plays a key role in the public dissemination of study results, ensuring that research and practice are closely aligned. The Study on Adolescent Resilience after Disasters has laid foundations for long-lasting research partnerships across Australia, China, Hong Kong, Nepal, and the United States and is a great example of what can be achieved through a shared vision.

## **TRAINING FOR RESEARCH ASSISTANTS**

#### **Essential Components of Training Research Assistants**

The role of a research assistant is to help with the practical tasks that take place while conducting a research project. These may include, but are not limited to, tasks such as making contact with participants; interviewing; translating discussions; facilitating focus groups; collecting, recording, and entering data into systems; and administrative tasks. Selecting and training research assistants in country fosters cultural fidelity in data collection, and builds capacity in partner countries. Throughout this guide, reference is made to a number of topics that are essential components of any training program for research assistants. Outlined below is a summary of these key topics (note that this list is not exhaustive, and should include additional topics of relevance to the individual study as the lead researchers see fit).

#### **Research Aims and Background**

It is crucial to ensure that research assistants are well versed in the aims and hypotheses of the study being conducted, relevant background literature and findings, and the purpose of the study and its relevance to the place in which it is being conducted.

#### Ethics

Research assistants must be well versed in the specific ethical considerations relevant to the study being conducted, as well as receiving training in general principles of ethical research conduct. This preparation is to ensure that the highest levels of research professionalism are upheld, and so that research assistants are very clear on ethical boundaries (e.g. not conducting participants to provide particular answers or to participate, allowing participants to withdraw at any time).

#### **Boundaries and Confidentiality**

Maintaining clear boundaries between participants and researchers, keeping data confidential, and having a thorough awareness of the limits of confidentiality are essential for all researchers so that they may confidently manage situations of risk and effectively negotiate the professional relationship between participant and researcher. Upholding boundaries can be particularly difficult when researchers are working in the community in which they live. Making sure that research personnel have access to good supervision will help them to maintain boundaries.

#### **Risk Management**

When situations of risk arise during the course of data collection, it can be distressing for both participants and researchers. Training research assistants in the management of risk and strategies developed specifically for the study being conducted will help the team to manage situations of risk effectively and ensure safety for the participant and researcher.

#### **Interviewing Techniques**

Research assistants should be trained in effective interviewing techniques for data collection, as well as mechanisms for developing appropriate rapport with participants. Where translation is required, it is essential to ensure that the research assistant understands the meaning of each question and is translating it with fidelity to obtain accurate data. It is also important that researchers understand the possible bias they can introduce into data collection, so that they know how to avoid doing so.

Other suggested topics for training include sensitivity (such as responding in a compassionate manner whilst maintaining boundaries), and the effects of grief and trauma.

#### Key Points of Consideration when Recruiting Potential In-Country Research Assistants:

- Prior to embarking on a selection process, make sure that you have clear expectations of the amount of time research
  assistants will need to work, how much they will be paid (be sure to investigate appropriate rates of pay), what
  time they will be paid for (e.g. will they be paid for travel time?), what expenses you will cover for them, and what
  equipment you will need to provide for them.
- Contact local NGOs or universities for recommendations on who to hire if local research partners aren't in a position to forward their own recommendations.
- Make sure to meet with and screen potential research assistants, assess their expectations, and be clear about your
  expectations.
- Having an open and honest relationship within the research team is crucial for the wellbeing of researchers and
  participants. Make sure to foster a trusting, honest, and collaborative relationship within the research team so that
  problems can be dealt with as they arise.
- Consider whether the gender of research assistants will be important to data collection (e.g. is it important to have male research assistants interview male participants etc.). Other ways in which identity may affect data collection might include the age, caste, religious background, or socioeconomic status of the research assistant

What is the role of a research assistant?

Knowledge Check:

- What are the key topics research assistants must be trained to understand and execute?
- How might one go about recruiting and hiring a research assistant?

## ETHICAL PRACTICES IN HUMAN RESEARCH

The values of respect for human beings, beneficence, justice, and integrity are crucial at all stages of the research process.<sup>18</sup> The following sections briefly discuss the main principles that inform ethical human research based on these values, the role of ethics committees, and working with community advisory boards.

## **PRINCIPLES OF ETHICAL RESEARCH**

#### **Privacy and Confidentiality**

Privacy and confidentiality are important for respecting human rights and minimising harm (e.g., stigma, loss of opportunity, reprisal, feelings of embarrassment or shame) at both an individual and community level.<sup>18</sup>

**Privacy** refers to a participant's sense of control over the degree to which information about themselves, and/or their behaviour, is accessible or observable by researchers and other people. Instances in which privacy must be considered include recruitment methods, participant factors (age, cultural norms, and gender identity), location of assessment or testing, and data collection.

**Confidentiality** is based on the trust relationship between the participant and researcher, and requires that information (data) provided by the participant is not disclosed without their consent to do so. Participants must be informed during the consent process (see next section) about the terms and limits of confidentiality, including how data will be stored and who has access to the data. Some research may be conducted anonymously, but care should still be taken to ensure other identifiable information is secured (e.g., age, date of birth, occupation).

#### Informed Consent

Informed consent requires a person's participation to be voluntary and a result of their free choice to take part. It also requires them to have the capacity to make their own decisions, and that they have adequate knowledge of the research and its implications in order to make their decision. Obtaining informed consent involves explaining the aims, methods, risks and benefits of the research to each potential participant, and providing answers to any questions they may have. Each person approached has the right to agree or reject participants will not experience discrimination or reprisal upon refusing participation. Depending on the nature of the research (e.g., level of risk involved) and participant's individual circumstances, consent can be obtained orally, in writing, or via other means (e.g., implied consent via completion of an online survey). Standard practice involves providing an information sheet and consent form (see Supplementary Materials).

Variations to the informed consent process may occur, depending on the nature of the research, timeframe, laws, and cultural considerations, and must always be approved by an ethics committee. For individuals who may not have capacity to provide informed consent, someone with lawful authority will be required to partake in the consent process on the person's behalf. This process may be suitable for children and young people, people with a cognitive impairment, people with a psychological disorder, and/or people who are highly dependent on medical care, among others. In this case, consent should also be sought from the individual participating in research and their legal caregiver. Participation may also require consent from other organisations or people within certain communities (e.g., families, elders, institutions).

#### The Right to Withdraw or Decline Consent

Individuals are able to decline participation or withdraw their consent to participate at any point during a research study. They are not required to provide a reason, and should not experience prejudice or disadvantage for doing so. Participants should be informed about their right to do so and the consequences of their withdrawal during the initial consent process.

#### Minimising Risk of Harm

Researchers must ensure that any potential risks to participants are minimised, and that any level of risk is justified by the benefits of the research. The term 'risk' refers to the potential or likelihood of any form of harm, inconvenience, or discomfort to participants. The type and nature of risk will differ depending on the research project, and can be physical, psychological, social, legal, or financial. These risks can be to an individual participant, but also to their family, community, and broader population. Researchers must identify potential risks, the likelihood they will occur, their severity, and how they can be minimised/managed. When reviewing projects, ethics committees will also determine whether the benefits outweigh any risks, and whether participants may perceive any risk.

Principles of ethical research were incorporated throughout The Study on Adolescent Resilience after Disasters. During development of the study protocols, the team discussed the data collection procedures, informed consent process and research instruments (e.g. interview guide, questionnaire) with local partners to ensure that they were culturally appropriate, valid, and feasible. Approvals were obtained from the ethics committees of the principal investigator's institutions (the Harvard T.H. Chan School of Public Health, and the University of Western Australia), and the respective ethics committees in our study countries (Nepal Health Research Council and Kunming Medical University Medical Ethics Committee).

Prior to data collection, our research team received training in ethical research practices and risk assessment, and local referral pathways were established should any participants need psychological support. All research assistants received in-depth training and information on referral to services for adolescent participants who were identified as at-risk of harm. Informed consent was obtained from all participants and adult caregivers of adolescent participants under the age of 18. During the consent process, in addition to providing an information sheet, we also discussed the key points with participants verbally, emphasizing their rights to decline to participate and to withdraw from the study at any time, and making sure their questions were immediately answered.

We did not collect personal identifying information from participants, such as name or address. Instead, we assigned a unique ID to each participant. In the qualitative study, any personal identifying information that was accidentally recorded (e.g. sometimes names were mentioned during the interviews or focus group discussions) was removed at the transcription stage. All the hardcopy and digital data were stored safely in locked cabinets and password-protected computers, and were only accessible to the research team and respective ethics committees.

## **WORKING WITH ETHICS COMMITTEES**

Ethics committees are responsible for reviewing, approving, and monitoring research projects, as well as handling any complaints that arise. They ensure that researchers follow the ethical principles detailed above, and that relevant ethical guidelines are followed. Health organisations and educational institutions typically have certified ethics committees with which the researchers must liaise. Such committees typically include individuals with relevant scientific expertise, members of the community, and individuals not affiliated with any sponsors or funding companies. Research teams must submit an initial research proposal to the committee for approval and communicate with the committee throughout the entirety of the project.



## **COMMUNITY ADVISORY BOARDS**

It is crucial to integrate local knowledge and involve community groups (community members, representatives of local organisations, or local government) in the design and implementation of research projects. The creation of community advisory boards provides an important opportunity for researchers and community stakeholders to conduct high quality, relevant, and culturally appropriate research. Furthermore, the board members typically aid in informing the community about the research project, educating the research team on local community and cultural norms, ensuring that the research protocols are ethical and culturally appropriate, and advising the research team of any risks associated with the research. The creation of a community advisory board is strongly recommended, as it opens up communication networks and resources in the community and fosters best research practice. The establishment of community advisory boards should be organised as early as possible in the research process, and involves ongoing collaboration throughout a project.

#### Suggestions for Further Reading and Information:

- For additional information regarding ethical practices please see the following guidelines:
- World Health Organisation (WHO) (2011): Standards and Operational Guidance for Ethics Review of Health-Related Research with Human Participants
- Australian National Health and Medical Research Council (2015): National Statement on Ethical Conduct in Human Research
- Strauss, R. P., Sengupta, S., Quinn, S. C., Goeppinger, J., Spaulding, C., Kegeles, S. M., & Millett, G. (2001). The role of community advisory boards: involving communities in the informed consent process. *American Journal of Public Health*, 91(12), 1938-1943.
- Contact your relevant ethics committee to obtain information about their guidelines and protocols

• What are the main ethical principles that inform ethical human research?

Knowledge Check:

- What is the role of an ethics committee?
- How can you ensure that research is informed by members of the community and culturally appropriate?

#### What is Qualitative Research?

Understanding human thinking, feeling, behaviour, and interaction is an inestimably complex effort, requiring the synthesis of individual perspectives and experiences within a broader social, temporal or regional context. Qualitative research is an invaluable investigative tool, particularly in humanitarian and emergency settings, for eliciting and exploring the experience of individuals and communities. It can stand alone as an in-depth exploration of the experience of a small subset of individuals, or as a complement to quantitative research in which one can infer further meaning from data.

Qualitative research can provide rich, descriptive data. It enables the researcher to engage dynamically with participants and obtain information beyond initial responses and prescriptively obtained answers. Qualitative methods are particularly valuable in emergency settings, as they allow for a deeper understanding of the complex processes associated with responding to and recovering from an emergency. Qualitative methods are useful for cross-cultural studies as they support the collective of culturally specific information and contexts that may be missed in quantitative methods, and are useful for giving social context to the individual responses recorded through quantitative data collection.

#### Methods for Collecting Qualitative Data

There are many ways in which qualitative data can be collected. Central to the collection of qualitative data is the idea that study design is open and flexible to facilitate exploration and elaboration of participants' responses. Where quantitative studies are prescriptive and use structured data collection methods, qualitative studies use semi-structured or unstructured methods to elicit general concepts and detailed responses. Qualitative methods facilitate the development of theoretical explanations for phenomena, and allow for the generation of hypotheses that may further inform data collection.<sup>19</sup> Common methods include observation, individual interviews, and group discussions.

#### Key Informant Interviews

Key informant interviews are detailed interviews with wellinformed participants from the region or community of research interest. Key informants will have first-hand knowledge of the community and will represent a wide range of people, for example community leaders, residents, experts and professionals. Interviews are conducted individually in person or over the phone to enable the participant to elaborate on their own experience, insights, and thoughts. Key informant interviews are particularly suitable when discussing sensitive topics that participants may be disinclined to discuss in a group setting, and for exploring a topic without the influence of others' thoughts and feelings. When developing the sampling strategy, it is important to include a diverse range of key informants to collect data from people of varying experiences and perspectives within the broader community or group of interest.

#### Focus Groups

Focus groups involve interviews with a representative subset of a population of interest. Focus groups facilitate interaction with participants as a group to provide a picture of the broader social context of a topic of interest. Similar to key informant interviews, focus group participants will have particular firsthand knowledge of the community and will represent a wide range of people from the community or group of interest. Focus groups are particularly useful if there are time pressures on the researcher. Groups allow for observing and responding to interactions between community members while collecting verbal data.

#### Sampling

As previously mentioned, only a small subset of a population is selected for a qualitative study. A number of sampling methods can be employed to obtain participants. The most common strategy is purposive sampling, in which sample size is determined by the level of "saturation" in the data; that is, recruitment ceases once no new information is elicited from interviews. This approach necessitates that data collection and analyses are completed in tandem, as data analyses will inform future recruitment to the study. Other methods include quota sampling, in which the numbers of participants are decided during the planning phase of the study, rather than with respect to the data being collected, and snowball sampling, in which participants are enlisted to recruit further participants from their own networks.<sup>20</sup> Some of these methods can be used in combination.

### The Role of the Researcher in Qualitative Data Collection and Analysis

Qualitative analysis necessitates that the researcher's role in the research process is explicitly examined. Researchers are afforded the opportunity to probe and encourage expansion of a participant's answers, and to tailor their questioning to the responses of the participant. This variability means that interviews may not be exactly the same from participant to participant. This also means that the researcher has a great deal of responsibility to be conscious of their own biases, any prior hypotheses, and their influence over the data collection. The researcher must also be aware of their own perspective when it comes to analysing the data, as the researcher/ research team is responsible for extracting themes and meaning from the responses of the participants.

#### **Data Analysis and Interpretation**

Qualitative data analysis is a recursive process which may be guided by a pre-existing theoretical framework (for example, a feminist or political framework guiding the interpretation of the data) or by the data in order to generate a new theoretical framework through which to understand the experience of the participants. Given that multiple theoretical explanations can be derived from the data, it is advisable that analyses of qualitative data be conducted in a team. Data analyses should take place as data are being collected and frequent discussion of the data should occur in order to develop a cohesive framework within which to interpret the results. There are many means of analysing qualitative data. For example texts, we refer readers to Strauss and Corbin's Basics of Qualitative Research and Braun and Clarke's Using Thematic Analysis in Psychology.<sup>19,21</sup> As a broad guide, analyses should proceed through a number of steps, including familiarising oneself with the data, generating and defining themes, reviewing and discussing the themes, and coding the data according to the thematic framework. This process does not progress linearly, but rather happens in a number of iterations ideally with input from various research team members. Crucially, collaboration with local research team members is integral to this process as their experience of the community/regional/cultural context will inform the generation and interpretation of themes, and their perspective and the meaning they make from the data may differ from that of a non-local team member.



We used key informant interviews and focus group discussions to collect qualitative data in the first phase of The Study on Adolescent Resilience after Disasters. Key informant interviews were conducted individually with a wide variety of participants, including local experts working in adolescent health, security, education or disaster response, community leaders, school teachers, adolescents and their caregivers. Additionally, focus group discussions were held with school teachers, adolescents and their caregivers. Additionally, focus group discussions were held with school teachers, adolescents and their caregivers. While key informant interviews could explore individual experience and knowledge in more depth, focus groups could collect data from more participants within limited time. In addition, the interaction among focus group participants may spark more active discussions. We developed a semi-structured interview guide covering our research questions to facilitate the interviews and focus group discussions. The data were transcribed and translated into English, and analysed using thematic content analysis. Team members engaged in active discussion of the themes and analytic structure through all phases of analysis to ensure the consideration of multiple perspectives and cultural fidelity.

#### 1. The psychological state of mind of survivors.

Being through recent disaster is traumatizing and asking questions at such times not only risks causing irritation, stress and undue burden to participants, but may also re-traumatize them. Researchers in earthquake-affected settings should be well trained to work with the survivors of disaster without causing harm.

#### 2. Managing expectations of survivors.

When there is little or no support from the government or NGOs to the survivors of disaster it becomes difficult to ask questions unrelated to the participants' current needs. It is important to connect the participants to existing resources so that their needs may be fulfilled. The availability of existing resources (shelter, food, health, education) must be mapped before starting any research activity in disaster-affected areas so that it is easy to connect survivors to resources. It is also important for researchers to not promise resources that they cannot deliver.

### CHALLENGES COLLECTING SURVEY DATA IN EQ AFFECTED AREAS

There are a number of significant challenges encountered in conducting research in earthquake-affected settings.

#### 3. Obtaining permissions from local

#### authorities is challenging.

However, such permissions are easier to acquire by organizations that have worked in the area for some time and that have contributed in some way to the communities (even before the disaster) as in the case of CVICT in Nepal. Building collaborations with respected local organisations is key to the establishment of a successful project.

#### 4. Risk minimization.

Earthquakes and other disasters are often not singular events. Conducting research and being in disasteraffected areas is risky for the data collector. Researchers and their organizations should be aware and sensitive to the health and safety of staff.

#### 5. Cultural sensitivity.

Research assistants should be trained and made aware of cultural sensitivities while collecting data from culturally diverse communities. Hiring research assistants from affected communities is a useful way of ensuring cultural sensitivity, building credibility, and supporting local livelihoods.



#### What are Quantitative Methods?

As the name suggests, quantitative methods are a group of research methods designed to collect measurable and quantifiable data and use statistical analysis to answer questions of how much or how many. For example, how many adolescents have received mental health support after the earthquake in region A? The data is usually collected from participants directly (primary data) using structured instruments such as questionnaires or direct measurement such as weight and height. In addition, quantitative data can also be obtained through pre-existing sources (secondary data), such as health records or agency reports. Quantitative research often uses large sample sizes so that results may be generalized to a larger population. Quantitative data, if collected rigorously and analysed critically, is generally considered to be objective and reliable.<sup>22</sup> On the other hand, it cannot explore the experience of those affected by disasters in depth, and thus can be complemented by qualitative methods.<sup>23</sup> In disaster research, quantitative methods can be used for quantifying the impact of disasters, assessing the needs of affected-population, establishing the relationship between exposure and outcomes, and evaluating the effects of interventions.

#### **Epidemiological Surveys**

Epidemiological survey is a systematic method to gather information to study the distribution and determinants of health-related states or events within a population. It is often used to collect quantitative data. Depending on the research questions, epidemiological surveys can be used in various study designs, including cross-sectional, case-control, cohort, and intervention studies.<sup>23</sup> Planning for a survey includes several aspects: designing the data collection instrument, selecting the survey administration method, and determining the sampling method.

#### **Designing a Data Collection Instrument**

Epidemiological survey often uses questionnaires as an instrument to systematically collect information from participants. Researchers need to consider the question content, question wording, response format, question placement and the length of the whole questionnaire when constructing the survey instrument.<sup>12</sup> Please refer to other sources<sup>12,24</sup> for detailed guides of questionnaire design. A couple of important considerations<sup>12,24</sup> should be kept in mind:

- 1. Use previously validated questions and measures whenever possible instead of designing your own;
- Include only questions that are absolutely necessary to answer your research question, and keep the questionnaire as short as possible;
- 3. Use a simple and direct language when phrasing the questions to make them concise, specific, easy to understand, and non-offensive;
- 4. Start with easy, nonthreatening questions and put more difficult, sensitive questions near the end;
- Ask about one topic at a time and use a transition when switching topics;
- 6. Thank the participants at the beginning and the end of the questionnaire.

In general, put yourself in your participants' shoes when developing a questionnaire. Finally, always pilot test your questionnaire before embarking on the actual data collection to identify any errors, and improve the wording and translation.

#### Survey Administration

A questionnaire can be completed by the participants on their own without the intervention of the researchers (selfadministered), or through individual or group interviews. Selfadministered questionnaires generally need fewer resources, and give the space for participants to answer more sensitive questions, but they require literacy skills. Questionnaires can be administered in group settings (such as in a school classroom) to increase efficiency.

In interviews, an interviewer directly asks questions to a participant and records the answers. It is important to provide comprehensive training and opportunities for research assistants to rehearse the interviewing process before starting data collection.<sup>12</sup> Consider the literacy level of the participants, the cost and time needed, the skills of your research team when choosing a survey administration method for your research.

#### Sampling

Quantitative research often uses probability sampling to randomly select a small group of participants that are representative of a larger group of people, so that results obtained from the sample can be generalized to a larger population. There are different methods of probability sampling including simple random sampling, systematic random sampling, stratified random sampling, and cluster random sampling.<sup>12,15</sup>

Simple random sampling is the simplest form, in which everyone in the population has an equal, non-zero chance of being selected, and is chosen randomly. In systematic random sampling, individuals in a population are numbered and selected at regular intervals. The interval size depends on the population size and the sample size, and the starting point of selection is chosen randomly. In stratified random sampling, the population is divided into homogenous subgroups (strata) based on specific characteristics, such as gender and age. Then simple random sampling is performed within each stratum to make sure all the subgroups are represented in the selected sample. In cluster random sampling, the units of random selection are not individuals, but clusters, such as a school, or a geographic region. All units from the selected clusters are included in the sample. Finally, the above four sampling methods can be combined in various ways to address the needs of specific research projects more efficiently. This is called *multi-stage* sampling<sup>12</sup>. For example, after the clusters have been randomly selected, simple random sampling can be used to select participants within each cluster.

In practice, the decision on sampling methods is also influenced by practical concerns, including cost, time, and implementation challenges. Sometimes, non-probability sampling can also be used in survey research when the chance of an individual being selected into the sample cannot be estimated beforehand.

#### Analysis and Interpretation

After data collection, data need to be entered and cleaned before any analysis can be done. Ideally, the same set of data should be entered twice independently and cross-checked to minimize data entry errors (i.e. double-data entry). Having a data entry protocol available to the data entry team specifying all the steps can help to improve data quality. Once the data has been entered, further checks should be carried out to ensure data validity and internal consistency. For example, nobody would have a weight of 900KG, and the birth order listed should be within the range of the number of children in a family. The data should be made as clean as possible before any analysis is conducted.

Having an analysis plan at the questionnaire design stage that specifies the research question and the analysis steps is helpful to undertake the analysis in a systematic manner. After data entry and cleaning, the analysis usually begins with simple descriptive analysis of all the items to get an idea of the distribution of responses. Then depending on your research question and analysis plan, different statistical tests can be employed. Bivariate analysis (e.g. correlation) examines the relationship between two variables. Multivariate analysis (e.g. regression) can simultaneously examine the effects of multiple factors to one outcome. Please refer to other statistics textbooks (e.g. Dawson, B., Trapp, R.G., Basic & Clinical Biostatistics, 4th edition, Lange Medical Books / McGraw-Hill, 2004) for details of various statistical tests. Remember to check the underlying assumptions of statistical tests when using them.

The interpretation of statistical analysis results needs to be made with the following considerations in mind:

- 1. Associations do not suggest a causal relationship;
- Be aware of potential systematic errors (biases) in the processes of sampling and data collection that could lead to incorrect conclusions;
- 3. A statistically significant result does not necessarily mean it is significant in practice.

Involving local researchers in data interpretation is particularly helpful as they can assist with interpretation of the results in a manner more relevant to the local context.



In the second phase of The Study on Adolescent Resilience after Disasters, we conducted a cross-sectional survey with inschool adolescents in disaster-affected areas of China and Nepal. The questionnaire assessed a variety of domains (please see Supplementary Materials) and most of the questions were adapted from previously published questionnaires and validated measuring scales. The questionnaire design was largely informed by themes identified in the earlier qualitative study, and facilitated by published literature and local partners' suggestions. In consultation with our local partners, we translated the questions into Chinese and Nepali if a local version was not already available. In depth discussion among the research team further refined the translations. We then pilot-tested the questionnaire in both study sites and further revised some wording and expressions per the feedback.

Depending on the local circumstances, our sampling strategy and survey administration method varied slightly between the China and Nepal sites. In China, as the concerned disasters only affected a limited region, we recruited participants from schools closest to the disaster-affected areas. Classes were randomly sampled from participating schools, and all students in the sampled class were invited to participate. The questionnaire was self-administered in a class setting. In Nepal, the 2015 earthquakes affected a wide region and hundreds of secondary schools. We randomly selected schools from the affected areas, and then randomly sampled students from those schools. Depending on the participant's literacy level, the questionnaire was filled in by each participant either on his/her own or with a research assistant reading out each question, in a small group of 5 to 7 students. The data collected by paper questionnaires were then entered into pre-designed electronic data entry templates. Further cleaning and validation were conducted to prepare the data for analysis.



# PART II

Assessing Mental Health After Disasters

## **MENTAL HEALTH RESPONSES TO DISASTERS**

Each individual will be affected in different ways by exposure to disasters and emergency situations. Their emotional response will depend upon a great number of factors, both intrinsic and extrinsic, such as the type and severity of trauma, their pre-existing mental and physical health, their level of social and economic support, the skills they use to cope with difficult situations, their age, and their exposure to other traumatic events in their lifetime.<sup>25,26</sup> A range of psychological responses after trauma have been observed, including acute stress, anxiety, fear, horror, helplessness, sadness, grief, panic, guilt, and disorientation.<sup>27,28</sup> For most individuals exposed to a traumatic event, their level of distress will reduce with time and they will develop helpful coping strategies and supports to enable them to reconcile their experience.<sup>27</sup>

#### Common Acute Reactions to Trauma<sup>29</sup>

- Physical symptoms: headaches, fatigue, loss of appetite, aches and pains
- Crying, sadness
- Grief
- Anxiety, fear
- Exaggerated startle response
- Difficulty sleeping, insomnia, nightmares
- Irritability, anger
- Guilt and shame
- · Confusion, problems with memory and concentration
- Withdrawal, anhedonia
- Disorientation
- Problems with activities of daily living

In the general population, most adults are exposed to at least one traumatic event in their lifetime, but only a very small number go on to experience severe or disabling psychological symptoms.<sup>30</sup> The case is similar after disaster exposure- in a small but significant minority of cases, pathological psychological responses will occur.<sup>27</sup> Some individuals will develop new psychological disorders, and others may experience a relapse or escalation of pre-existing mental health problems. These problems may be induced or exacerbated by contextual factors related to the disaster, such as separation or displacement, loss of safety, loss of livelihoods and resources, inadequate shelter, hygiene and privacy, and escalation of pre-existing inequities such as belonging to a marginalised group. A comprehensive review of approximately 60,000 victims of disaster found that the most commonly occurring diagnoses following disaster exposure are post-traumatic stress disorder, major depressive disorder, generalised anxiety disorder, and panic disorder.<sup>31</sup>

#### **Common Symptoms of PTSD**

*Intrusive symptoms:* Recurrent and involuntary memories of the event; nightmares; flashbacks to the event; prolonged distress and arousal; strong reactions to trauma-related stimuli

**Avoidance symptoms:** Avoidance of cues that remind someone of the traumatic event, including thoughts, feelings, certain places, people, or activities, and conversations about the trauma

**Mood symptoms:** Sadness, guilt, fear, horror, anger, shame; negative beliefs about self, others, and the world; diminished interest in previously enjoyable activities; difficulty experiencing positive emotions

**Arousal symptoms:** Hypervigilance; startle response; irritability and/or anger; sleep disturbance; difficulty concentrating



#### Assessing and Treating Mental Health Symptoms Post-Disaster

Researchers have advocated for a stepped-care model of mental health service delivery post-disaster in order to maximise existing resources and ensure provision of appropriate and effective intervention for those in need. A stepped-care model encapsulates a graduated response from services beginning with population-based information and education, escalating to focused mental health treatments and specialised psychological care for those experiencing severe psychological Symptoms.<sup>32</sup> As part of a stepped care model, Psychological First Aid (PFA) is recommended as a first response.<sup>25,33</sup> PFA is a means of assessing basic needs and providing support and connection with local services.<sup>25</sup> It can be delivered in low-resource settings and provides a means of triaging distressed individuals to the appropriate level of care in the community.



#### Time Course of Psychological Responses After Disaster

Psychological distress is common in the months immediately following disaster, and will mostly resolve in subsequent weeks and months. Symptoms that develop within four weeks of the traumatic event fall under the diagnosis of acute stress disorder, whereas symptoms persisting longer than four weeks are categorised as PTSD.<sup>27</sup> Symptoms of PTSD are considered chronic if they persist for three months or longer.<sup>27</sup>

### Considerations For Working with People Affected by Psychological Disorders

In terms of research ethics, persons affected by mental health problems are considered a vulnerable group. As with all research participants, it is crucial to respect their safety, dignity, and rights when inviting them to take part in research. Participants should be made aware of the rationale of the study, the benefits and risks of participation, and the way their data will be stored and used (and if appropriate, the limits to the confidentiality of their data).

It is imperative that in the course of developing a research plan, partnerships with local researchers, mental health professionals, and other health services are made so that participants can be directed to appropriate services should the need arise. Researchers must also be well versed with acute risk assessment and management should a situation of risk be disclosed in the course of research (see Risk Assessment section of this guide for further detail).

Figure 2: Stepped Care Model for Mental Health Services<sup>32</sup>

#### **Cultural Considerations and Expressions of Mental Health**

Although there is evidence that mental health diagnoses have similar and recognisable symptoms all over the world, it is crucial to consider that expressions and manifestations of mental health may differ between cultures.<sup>34</sup> Patients may describe their symptoms in ways that are culturally acceptable for them (for example, complaining of physical but not emotional symptoms), or ascribe different meaning to their symptoms (for example, attributing symptoms to a religious or supernatural cause).<sup>34,35</sup>

As a researcher, one must carefully consider the culture of the place in which they are conducting research and conduct themselves in a respectful manner, by considering local understandings of mental health, important beliefs and practices, and considering issues such as gender, age, and language when planning and conducting research activities. It is also important for this reason to have strong ties to a local research partner who can advise on cultural matters and assist with the interpretation of research findings in a culturally sensitive manner.

#### **Responsible Interpretation and Dissemination of Findings**

Researchers have an ethical responsibility to ensure that the potential benefits derived from conducting research outweigh any possible risks to the participant. Broader reaching benefits of research are contingent upon responsible and accurate interpretation of research data, and upon translating the findings to the public. As previously mentioned, the role of local collaborations in ensuring accurate and sensitive cultural conduct and interpretation of findings cannot be underestimated. Local counterparts can also assist in communicating research findings to communities from which participants are drawn. There are many ways in which researchers can disseminate their findings beyond traditional academic products such as book chapters and journal articles, which while important, may not reach the subjects of their research. Mechanisms such as community forums and discussions, media engagement, research reports, and policy briefs are all excellent avenues for communicating findings and effecting change.





The Study on Adolescent Resilience after Disasters was designed to investigate the specific mental health needs and security risks facing male and female adolescents affected by natural disasters in Asia. Focusing on disaster survivors in Yunnan Province, China, and Kathmandu Valley, Nepal, the study aimed to determine the mechanisms underpinning resilience and highlight the challenges unique to adolescents at each site. A mixed methods approach was employed, with qualitative assessments conducted in 2015, and a large scale quantitative assessment conducted in 2016. The study represents an active and ongoing collaboration between the FXB Center for Health and Human Rights at Harvard University, Curtin University, Kunming Medical University, the Centre for Victims of Torture Nepal, The University of Western Australia and the Chinese University of Hong Kong.

#### **Demographics**

The sample comprised more than 4000 adolescents of both genders, with ages ranging from 13-20. All participants were in school at the time of assessment. Within the quantitative assessment, ages ranged from 15-20 (see figure).



## **DISASTER EXPOSURE**

All participants had experienced a disaster, with a range of trauma exposures described across the sample. Most participants had survived earthquakes, and many reported exposure to landslides, severe storms and floods.

"Yunnan is one of the provinces in the whole country where earthquakes happen most frequently."

- Female, 50, China.

"The earthquake has traumatised all people, including adolescents, children... People are worried and fear living in their house".

- Male, 52, Nepal

### **DAILY HARDSHIPS**

Social determinants played a significant role in disaster recovery. Pre-existing hardships were compounded by the experience of trauma, and poverty mediated post-disaster difficulties. Disasters created unsafe physical environments through damaged buildings and infrastructure (including the destruction of roads and communication services) and potential secondary hazards such as landslides and floods, in both China and Nepal. Indirectly, the challenging social environments that arose following disasters put adolescents at risk for violence, harassment, neglect and trafficking. Displacement was common, and many adolescents described separation from their parents.

Adolescents demonstrated an acute awareness of the economic consequences of disasters, and the effect that hardship will have on their future.

### THE Adolescent Resilience PROJECT



"I now live with others in the village, but with the feeling of no home..."

- Female, 16, China

"In the way earthquake has lowered the economic status of our country, I think that has an impact on the future of all the adolescents"

– Male, 15, Nepal.

"Sexual violence, psychosocial problems, economic problems... these are daily life crises... [the] earthquake made these crises bigger"

- Male, 33, Nepal

#### Mental Health Effects of Disaster

There were significant mental health impacts for adolescents affected by disasters. Participants described symptoms that reflected post-traumatic stress, anxiety disorders and depression. A range of risky behaviours and somatic complaints were also noted. Within the qualitative interviews, a number of participants highlighted growing concerns with the increased rate of suicide among young people.

"... We are seeing clearly some kids who've been really withdrawn, kind of fearful not going to school, and directly correlated to the earthquake... I see their behaviour has changed since the earthquake"

- Male, 46, Nepal

"The stress we felt after the earthquake is stress about whether it will come again, stress about whether or not we will live"

- Male, 13-15 years, Nepal

"After the earthquake, she seemed to, like what they said, have fear. Especially when we were on the road, when the big truck passed by, it reminded her of that feeling again."

- Female, 38, China



#### Humanitarian Services

While many participants had received aid in the aftermath of natural disasters, the range of support services varied. In Nepal, large numbers of adolescents reported receiving food, cash or medical assistance, whereas the proportion of services were smaller in China. This is likely due to the differing scale of disasters across the two sites.

The findings of The Study will inform development and implementation of psychological interventions. Outcomes of the study will also be used to design policy recommendations and service needs for adolescents in China and Nepal. For further detail on the dissemination of findings, see Part V.

## **CONDUCTING RISK-ASSESSMENTS**

In the course of conducting research in the field, a participant may disclose information that suggests that they may be at risk of harm from themselves or someone else, or at risk of harming another person. If this situation arises, it is important to discuss the information within the research team so that appropriate strategies can be enacted to ensure the participant's safety.

Uncovering information such as this can also be distressing for the researcher. Risk assessment and management strategies must be discussed and documented prior to commencing field research so that management plans can be quickly enacted both for the safety and security of the participant, and to minimise distress for the research team. It is also important to have a good working knowledge of local mental health services and to map out potential options for referral should a member of the research team come across a situation of risk.

#### What is Risk?

Risk is complex and multi-faceted. At its core, risk (as it is thought about in psychological assessment) encapsulates the idea that someone may be likely to harm themselves, be harmed by another person, or harm someone else. Risk also considers factors existing in a person's life that may influence the likelihood that they will come to or enact harm, how quickly it is likely to happen, and how life-threatening the situation may be should it occur. Common risks seen during psychological assessments may include non-suicidal self-injury (or self-harm), thoughts of suicide, substance abuse, threats of violence (toward self or others), and disclosures of abuse (such as physical or sexual acts).

#### How is Risk Assessed?

Should someone make a disclosure of risk or if it is suspected that someone is at risk, a health professional or trained member of the research team should conduct a thorough risk assessment. It is important to remember that discussing risk has not been found to increase a person's risk of coming to harm, and can provide an important opportunity for a person to feel heard and understood, potentially reducing their likelihood of future harm.<sup>36</sup> It is also important to maintain composure and a non-judgemental stance when discussing risk with a person.

The key elements of a risk assessment include finding out about the person's intent and plans for harm, their previous exposure to harmful acts, and other factors that may elevate or decrease their level of risk. It is crucial to consider that risk levels often fluctuate and are dependent upon the context the person is in. Below are some examples of ways questions about risk can be asked.

Open and closed ended questions can also be useful for eliciting further information. An open-ended question is one which encourages the person to elaborate and provide more information. Closed ended questions invite short responses, such as a yes or a no or specific information.

#### Example Questions to Ask About Suicidal Ideation or Self-Harm

- Have you thought about ending your own life?
- How severe are these thoughts? How often do you have them?
- Do you have any plans for ending your own life?
- Do you have access to what you need to carry out this plan?
- Have you ever tried to end your life before?
- Have you ever made a plan about ending your life in the past?
- Do you think about hurting yourself intentionally, without intending to end your life?
- Have you ever acted on these thoughts?
- Have you hurt yourself intentionally in the past?

#### **Example Questions to Ask About Harm to Others**

- Have you thought about harming someone else?
- How severe are these thoughts? How often do you have them?
- Do you have a plan for how you might harm this person/these people?
- Have you ever harmed someone else deliberately in the past?
- Was this planned or did it happen in the moment?
- Have you ever made a plan about harming someone else?

#### Example Questions to Ask to Assess Other Risk Factors

- Do you use drugs or alcohol?
- How often do you use these substances? How much do you use/how many drinks do you have at a time?
- Have you ever felt really sad/anxious/hopeless like this in the past?
- Are there any stressful things happening with your family/ friends/school/etc. at the moment?
- How do you see the future?
- What stops you from harming yourself? (E.g. family, friends, religion)

#### Example Questions to Ask About Everyday Functioning

- How is school?
- Do you work?
- What is that like?
- What do you like to do in your spare time?
- Does the way you feel currently stop you from doing things you'd normally do like going to school or work?
- Have you noticed any changes in your ability to do things you like to do?

None	Low	Moderate	High	Severe
-No thoughts of harm to self/others	-Fleeting thoughts of harm to self/others -No plan -Low/no drug or alcohol use	-Current thoughts -Past history of actions without intent or plans -Moderate drug or alcohol use	-Current thoughts, some plans -Past impulsive actions -Increased drug or alcohol use	-Current thoughts with expressed intentions or plans -Past history -Means available -High drug or alcohol use/current intoxication
Problems	with Everyday Func	tioning		
None	Low	Moderate	High	Severe
-No impairment above what would normally be expected	-Some difficulty in social/work/schoo l functioning -Difficulty coping without assistance	-Significant impairment in social/work/ school functioning	-Significant impairment across a number of domains	-Impairment in most/all areas -Extreme distress

#### Managing Risk After a Disclosure

Prior to commencing field research, it is crucial to speak with local partners and develop a clear referral pathway, tailored to the study location, so that the actions that will be taken should someone make a disclosure of risk are clearly documented. Prior to commencing data collection, it is recommended that contact is made with local clinicians and mental health interventionists, doctors, and/or hospitals in order to establish clear lines of referral for at-risk persons. Where appropriate, participants should be informed at the outset that if they disclose risk, the research team has an obligation to ensure their safety and that they may enlist the assistance of outside professionals.

After a disclosure of risk is made, it is vital to let the participant know that what they have disclosed is important and is taken seriously by the researcher/s. They should be informed that other members of the research team will be informed. It is crucial to be open, honest, and specific about the actions that will be taken (for example, "I am going to tell my research team leader and together we will contact your doctor because I am concerned for your safety and wellbeing").

#### **Ethical Considerations**

Familiarity with the IRB ethics requirements for the intended study is also key when it comes to managing risk. Conducting psychological research can uncover sensitive information for participants, and their dignity and rights must be maintained at all times. Each study will have different ethical stipulations regarding confidentiality and when to disclose information to other researchers or third party professionals. It is the responsibility of each researcher on the team to familiarise themselves with the ethics associated with the study so that they know what information must be kept confidential and what must be disclosed to others. All questions regarding ethical considerations should be discussed with the research team leader- if in doubt, ask.

#### Managing Researcher Stress

Talking about topics such as suicide, self-harm, and violence can be distressing for the researcher as well. Discussing disclosures of risk with the research team leader or other team members is not only important for the participant's safety, but also for the wellbeing of the research team. It is also important to have a clearly developed plan of how disclosures of risk will be managed so that each member of the team can feel confident in their decision making in the event of a disclosure.



#### Risk assessment training in China and Nepal

As part of our commitment to upholding the highest standards of ethical practice, as well as to providing skills training to our in country research assistants, members of the core Adolescent Resilience After Disasters research team delivered in-depth assessment and ethics training program to research assistants in China and Nepal. In addition to training on the research program, interviewing skills, teamwork, and research ethics, research assistants received thorough training in assessing risk in study participants. A unique risk assessment protocol with locally-relevant referral pathways was developed and discussed in detail during the training so research assistants could feel confident in their ability to manage at risk participants during the study should the need arise. Assistants were also trained in the principles of Psychological First Aid, a gold-standard approach to providing psychosocial assistance to persons affected by traumatic events such as disasters. Training in the aforementioned skills is valuable not only for the specific purposes of The Study on Adolescent Resilience after Disasters, but to the studies and careers of the research assistants. These skills are highly generalizable and will be applicable to a broad range of research and clinical pursuits.

### USING SELF-REPORT MEASURES IN MENTAL HEALTH RESEARCH

Self-report measures are commonly used in disaster research to collect information that is not readily observable, but directly reported by the participants themselves, such as their thoughts, feelings and behaviours. While such methods of data collection are relatively cheap and easy to implement, researchers should be aware of the limitation that participants' own reports may not be very accurate. Participants may exaggerate some answers, forget some details or give desired answers. When using self-report measures, researchers need to consider the following aspects.

#### Forward and Back-Translation

To ensure the translated questionnaire is conceptually equivalent to the original version (often in English), forward and back-translation is routinely adopted in the field. Forward translation is ideally conducted by a translator who is familiar with the topic measured by the original questionnaire and the original language, but whose native language is the primary language spoken by the targeted population. WHO recommends the following guidelines for this process<sup>41</sup>:

- Translators should always aim at the conceptual equivalent of a word or phrase, not a word-for-word translation
- Translators should strive to be simple, clear and concise in formulating a question
- The target language should aim for the most common audience and avoid the use of any jargon
- Translators should consider issues of gender, age and cultural applicability and avoid any terms that might be considered offensive to the target population

Back-translation is similarly conducted by an independent translator using the same approach as in forward translation, but from the target language to the original language. Then back-translated questionnaire is compared with the original version. Any conceptual discrepancies should be discussed by the researchers and translators together, and the translation is modified to reach a satisfactory version.

#### **Pilot Testing**

After the translation, it is necessary to pilot-test the translated questionnaire on the target population before the actual data collection starts.<sup>37</sup> Ideally, participants of pilot testing should be recruited from those who can represent the target population, but will be excluded from the main study. Participants in pilot testing should represent various characteristics of the target population as much as possible such as age and gender. The questionnaire will be administered to these testing participants following the pre-designed protocol to be used in the study. Then the participants will be asked about their thoughts on the questionnaire and administration process, such as if they understood the instructions clearly, what they thought the question was asking, if there was any phrase they did not understand or found ambiguous, how they gave their answer, whether they found any expression offensive or unacceptable, what other alternative expressions they might find easier to understand. A written record of the pilot testing process should be kept to facilitate further revision of the questionnaire.

#### **Reliability and Validity**

Reliability and validity are two related indicators to assess the usefulness of the assessment instruments used in epidemiological surveys, such as a questionnaire. Reliability indicates the extent to which an instrument can produce stable and consistent results. Validity describes how well an instrument measures what it claims to measure.

A good way to understand these two concepts and their relationship is using shooting at a target as an illustration<sup>12</sup> (Figure 3). Imagine that the centre of the target is the concept your instrument intends to measure, and each shot is one measurement. There are four possible scenarios as shown in the picture below. In the first one, the measurements are reliable - all the shots consistently hit the same area on the target, but not valid - far away from the centre of the target. In the second one, the measurements are not reliable-the shots spread all over the target, but on average they are aiming at the centre of the target. In this case, you can get a valid group estimate, but the individual measurements are not reliable. In the third scenario, the shots are neither concentrated at one spot, nor on average located at the centre of the target-the measurements are neither reliable nor valid. In the last case, all the shots are consistently at the centre area of the target, and that's what an ideal instrument aims to be, both reliable and valid. In practice, there are different types of reliability and validity that can be examined. More details will be described in "Using self-report measures" in Part III.



Figure 3. Graphical depiction of reliability and validity

The reliability of a self-report measure is commonly assessed by test-retest reliability and internal consistency reliability.<sup>12</sup> Test-retest reliability is estimated by administering the same instrument to the same group of individuals at two different timepoints. The results from the two timepoints can then be compared and correlated to evaluate the reliability of the test over time. The internal consistency reliability evaluates how well different items of the instrument that are intended to reflect the same concept produce similar results. There are a variety of ways to describe internal consistency, including average inter-item correlation, average item-total correlation, split-half reliability, and Cronbach's Alpha (Table 1).<sup>12</sup> Cronbach's Alpha is a most often used indicator that can be calculated by most statistical software. A Cronbach's Alpha larger than 0.7 is generally considered as acceptable.

Methods of estimating internal reliability		
Estimates of internal	Description	
consistency reliability		
Average inter-item correlation	The average of the correlation between the scores of each pair of items.	
Average item-total correlation	The average of the correlation between the score of each item and the total instrument score.	
Split-half reliability	The items of an instrument are randomly split to two halves, and the total score of the items in each half is calculated. The split-half reliability is the correlation between these two scores.	
Cronbach's Alpha	Can be calculated by most statistical software. A value larger than 0.7 is generally considered as acceptable.	

There are two broad categories of validity<sup>38</sup> that can be assessed: contentrelated and criterion-related. Content-related validity looks at if the instrument contains appropriate content that can measure what it intends to measure. Criterion-related validity assesses how one instrument performs compared to other related measures (criterions). The different types of criterion-related validity include predictive validity, concurrent validity, convergent validity and discriminant validity.<sup>12</sup>

#### Knowledge Check:

- How do you conduct a translation of a self-report measure?
- What might you ask the participants in pilot-testing of a self-report measure?
- What are the different types of reliability and validity that are often used to assess a self-report measure?

# PART IV

**Special Populations** 

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## **WORKING WITH CHILDREN AND ADOLESCENTS**

#### **Developmental Considerations**

Children and adolescents have distinct challenges and needs from those of adults in disasters. To safeguard and promote their wellbeing, it is essential to assess needs and required services from their viewpoint. As children and adolescents differs from adults physiologically and psychologically, any interaction during the research process needs to be attentive to their level of cognitive, emotional, behavioural, psychosocial, and linguistic development.

Data collection methods should also be adapted to the stage of development. Self-administered questionnaires are not recommended for children under the age of 12 unless the researchers are present to provide support<sup>39</sup>. Younger children have short attention spans, and thus the length of interview should be minimized or more frequent breaks provided. For focus groups, consider stratifying groups by age and gender.<sup>39</sup> Keep the age range in a single group within 2 to 3 years. In addition, a "question and answer" format that works well for adults may not be effective to engage with children and adolescents, and participatory approaches could be particularly helpful in this regard (See Textbox). Please refer to other resources<sup>39,40,41</sup> for more detailed guidelines on working with children and adolescents.

Children and adolescents often report different perspectives from adults. Their participation in different stages of the research process, from research design to results dissemination, can be particularly useful to ensure sustainable uptake of the results. As early as the design stage, children and adolescents can be involved as advisors.<sup>39</sup> For example, they can suggest preferred time and location to conduct research, advise on how to recruit other participants like themselves, comment on the wording of questions or the layout and structure of questionnaires, or even propose innovative ideas for eliciting data. They can also be involved in developing the dissemination plans, especially with regards to disseminating results to other children and adolescents.

As previously detailed in the Ethical Practices chapter, informed consent is an important ethical principle that all researchers must follow. Children and young people across different developmental stages vary significantly in their ability to make informed decisions and thus provide informed consent.<sup>42</sup> Regardless of cognitive capacity, attempts should always be made to explain the project in a developmentally appropriate way to a child or young person. In most circumstances, informed consent is required (when possible) from both the child and their lawful caregiver. It is important to liaise with your appropriate ethics committee in order to review the project, potential risks, and the level of consent required from the young person and their caregiver.

Depending on the research question and design, the assessment of children and young people is typically accompanied by a caregiver assessment. This systematic process involves obtaining information (or data) from the caregiver about a range of areas relevant to the caregiver, child, and their broader socio-cultural context. The information obtained is typically focused on the research question, but can include a range of domains that are informative to the child and caregiver's overall functioning: needs, strengths, resources, environment, family functioning, medical history, and emotional/behavioural/social functioning of the caregiver assessment is typically combined, and compared with, information obtained through an assessment of the child/young person.

Involving Children and Adolescents

in Research Design

Informed Consent- Child and Caregiver

#### **Caregiver** Assessment



### What activities can children and adolescents be involved with in research design?

- What factors must be considered in determining whether a child or young person can provide informed consent?
- What are some examples of areas or domains assessed in a caregiver assessment?

**Participatory Approaches For Engaging Young People in China** Each research project targeting adolescents should integrate adolescents' participation. This is not only to safeguard adolescents' rights, but also to sustain the running of the project in an effective manner.

**Knowledge Check:** 

When we talk about "adolescent participation", it is not only about adolescents' participation in research activities, or adolescents being informed of relevant research information. More importantly, we need to engage with adolescents mentally and emotionally, enabling them to share the research work and results, and develop a sense of ownership of the research work.

To promote adolescents' active participation in research, we can work from the following aspects:

1. Use a language that adolescents can understand to explain the aim and significance of research work.

2. Do our best to understand and respect the local youth culture, including the culture of ethnic groups and some youth subcultures. Maintain cultural sensitivity and a non-judgmental attitude, and shorten the distance between researchers and adolescents as much as possible.

3. Minimize boring research activities, and try to design the activities in flexible and diverse ways that would interest adolescents. For example, matrix scoring, key events mapping, and seasonal calendar from participatory rapid appraisal (PRA) are all good choices.

4. After completing the research, share the results with adolescents in a simple manner so that the results can have a direct impact on them. This would be helpful to encourage them to participate in other similar research projects.

### **CONDUCTING RESEARCH IN SCHOOLS**

Schools are a popular venue for conducting research about children and adolescents. Obtaining cooperation from schools is essential, but could be difficult due to various reasons: many consuming primary demands are placed on schools already; concerns about affecting students' normal study schedule; concerns about perpetuating distress and postponing recovery in disaster-affected children; and bureaucratic complexities of the education system. In most cases, permission from the local education bureau should be sought before approaching individual schools. The education bureau can help to liaise with individual schools in the region and introduce the researchers to the schools. Sometimes, having staff from the local education bureau accompanying the researchers' visits to schools can greatly improve communication efficiency. Researchers should be prepared to explain the study clearly in simple language to the local education bureau and the schools' principals before speaking with students and teachers.

Another consideration is the types of schools to be included in studies. Most children and adolescents attend public schools, but those from private schools or vocational schools may differ from the general school sample in various ways, such as their family background or academic performance. Even among public schools, there may be different categories depending on the local circumstances. Researchers should consider these issues and determine a sampling plan accordingly.

When conducting research in schools, researchers should always try to minimize the impact on students' normal school schedule. Meeting with teachers ahead of time is essential to solicit input regarding the data collection process and to find a least interrupting time for data collection, such as at a freeactivity class.

**Knowledge Check:** 

- What populations may researchers gain access to via research in schools?
- What are the potential difficulties of obtaining cooperation from schools?
- What are a few considerations to be aware of regarding the impacts of research on students?

### WORKING WITH RACE, ETHNICITY, CASTE AND RELIGIOUS MINORITIES

Race, Ethnicity, and Religious Disparities in Research: An Overview Diversity of race/ethnicity and religious background are important factors for researchers to consider when interacting with global communities. Minority populations face distinct challenges, and thus require special consideration as partners and participants in research efforts. Intersecting identities such as race and religion often put individuals at risk of discrimination and inequity, which is demonstrated by higher rates of poverty, lack of access to essential resources, and discrepancies in treatment and care.43,44 Researchers should develop an understanding of the range of health and social issues that racially and religiously diverse individuals experience. This understanding should also include identification of the strengths and protective factors for each community, which may entail factors such as social structures, unique spiritual guidance systems, and community support frameworks. Research questions, design, and implementation should make sure to identify, acknowledge, build upon and promote these strengths within the community.

In order to ensure the needs of marginalized communities are being met, it is important for researchers to collaborate closely with group members to identify needs within the community and to establish means through which the research will be most beneficial. Inherent in this practice is an obligation on behalf of the research team to examine their own motivations for conducting research. Researchers must consider their own intentions and whether a tangible benefit to the community/ group of interest outweighs any possible risk, distress, or harm that may be caused due to participation in a study. As mentioned throughout this guide, building in-country partnerships, preferably with knowledge of or membership to the ethnic or religious group of interest, is essential when working with these groups so that their needs and voices are accurately represented, and to ensure maximal impact of the research back to the community of concern.

#### **Strengths**

Identifying the specific strengths and resilience manifest in minority groups provides an important foundation for the development of research protocols and future interventions.<sup>45</sup> It is essential to work with communities to identify unique assets, such as in-depth knowledge, social support, community structures, and health management, prior to the commencement of any research. Representatives of social groups will provide important insights into the specific capacities and needs of their community, which should drive the focus and design of the study. These processes are vital to any research design, but particularly in areas where race, religion, ethnicity or caste have traditionally resulted in systematic disadvantage.

#### Vulnerability

Disasters do not affect all populations equally. Those who already experience the effects of disadvantage, such as the elderly, impoverished, migrants and refugees, homeless, women and girls, certain religious groups, and ethnic minorities, are demonstrably more vulnerable at all stages of the disaster cycle.<sup>46</sup> More specifically, many instances of

systematic disadvantage have their roots in prejudice and racism, and occurrences such as natural disasters serve to amplify already present social disparities.<sup>47</sup> Individuals within marginalized groups may be more likely to reside in isolated regions, locations with poorer structural integrity, or areas with less access to the proper resources to safeguard their communities.<sup>43</sup> When disasters strike these populations, they are less prepared to deal with the crisis, less likely to survive, and less likely to recover<sup>46</sup>. Research with these groups is thus extremely important so that their needs and vulnerabilities are considered in disaster response and in planning for future disasters. However, a careful balance must be struck between obtaining needed information and placing unnecessary burden upon the already socially vulnerable. Having a strong ethical foundation and framework to guide your research program and a clear plan for advocating for the communities you work with (whether it be through intervention, dissemination of findings, or promoting their needs and rights) are two ways in which working with vulnerable communities can be beneficial to all involved.

#### Services

Often services to minority populations are overlooked. The rate and extent of recovery services is an important consideration as people from different races and religious backgrounds may be less likely to receive services during and after a disaster.<sup>43</sup> In conjunction with their pre-existing vulnerabilities mentioned above, marginalized individuals often face enhanced challenges and require more nuanced care during and after a disaster. It is important that issues regarding race and religious identity are not neglected, so that any existing disparities can be tackled head on to protect the health and wellbeing of these diverse communities. The "Building Back Better" principle of disaster recovery is key here, and attention should be given to rebuilding services that are accessible to all, not just a few. Research is a crucial avenue through which the rights of the marginalised can be advocated for, and through which needs and recommendations can be highlighted.

### Practical considerations for conducting research with ethnically or religiously diverse populations

- Take care when recruiting participants to ensure accurate representation of all groups, including ethnically diverse populations and religious groups. Researchers should keep in mind the ethical principle of justice, which holds that the benefits of research should reach all members of a community equally.
- Mechanisms to minimise any participant's vulnerability must be addressed, such as taking care to obtain the participant's consent and making sure of their awareness that their participation is voluntary and they will not be discriminated against or punished for refusing to participate or withdrawing. Researchers should take care not to assume that all participants are aware of these fundamental rights.
- Devote time to ensuring that participants understand the purpose of the research, are aware of the limits of confidentiality and anonymity, and that all questions regarding their participation are answered. Researchers should be mindful of the influence of their relative position of power over participants' willingness to participate and to provide accurate data.

- Consider who is conducting the research- what cultural or religious mores do you need to respect in conducting research? For example, consider whether the gender of a research assistant will impact upon data collection, or whether certain clothing should be worn to avoid embarrassment and to protect the dignity of the participant.
- Team members must be committed to valuing and respecting cultural diversity, and should take care not to let their own belief systems influence their reactions to and interpretation of participant responses. Researchers can achieve this by asking for clarification and elaboration from participants, checking their responses have been understood accurately, and by conferring with local partners to enhance their own understanding.
- Identify strengths and capacities of minority groups to inform valid protocols and meaningful research outcomes.
   Data related to minorities is often framed in terms of deficit, disadvantage, and difference. Focusing on strengths will shift the dialogue.<sup>45</sup>

### WORKING WITH DIVERSITY OF GENDER AND SEXUALITY

#### **Diversity in the Global Context**

Concepts, attitudes, laws, and issues relating to gender and sexuality differ significantly between, and within, different cultures. Some countries and cultures are more accepting of gender and sexuality diversity, while others may not acknowledge, or discriminate against, individuals with a gender identity or sexuality that differs from the culturally accepted norm. Sexuality, gender identity and expression can be profoundly affected by and interact with other aspects of a person's identity (e.g., race/ethnicity, socioeconomic status, immigration status, disability status, and spiritual and/or religious affiliations).<sup>48,49</sup>

It can be very difficult to compare and/or translate concepts of gender and sexuality cross-culturally.<sup>50</sup> For this reason, it is important to become familiar with the attitudes, laws, and issues relating to gender and sexuality in the culture, region, and/or country you are conducting research in. Furthermore, researchers should develop an understanding of the range physical health, mental health, and social issues that individuals who are diverse in their gender or sexuality often experience.

#### Stigma and Discrimination

Stigma and discrimination based on a person's gender and/ or sexuality is prevalent worldwide, and frequently results in marginalisation. Awareness of the stigma, discrimination, and other relevant issues relating to gender and sexuality is important in research for reasons including: (i) conducting research in an ethical manner, especially respect and minimising harm, and (ii) avoiding incidental discrimination.

#### Terminology

It is important to be familiar with the terminology relating to gender and sexuality diverse populations. Distinctions between biological sex, gender identity, gender expression, and sexual orientation should be acknowledged. Note that there may be different meanings or words for particular types of gender or sexuality between, and within, countries and cultures.

#### Methodological Considerations and Suggestions

The methods in which data is collected should acknowledge the diversity of gender, gender presentation, and sexuality (as well as biological sex for those who are intersex). More often than not, researchers may accidentally discriminate in regards to gender and sexuality, such as only acknowledging binary gender and/or heterosexuality in forms and surveys. Thus, data collection should aim to be inclusive and sensitive to gender and sexuality diversity, and use appropriate terminology (e.g., response options only acknowledge binary gender).



The term "disability" refers to any continuing condition (permanent or likely to be so) that results in some form of restriction in daily activities (e.g., communication, learning, and mobility) and requires ongoing support services.<sup>51</sup> Impairments that result in disability can include physical, cognitive, intellectual, neurological, psychiatric, or sensory impairments (or a combination of these).<sup>52</sup> Below are some examples of ethical and methodological considerations to take into account when potential or recruited participants have a disability. While there are many different types of disability, as well as individual differences, many of the ethical issues that arise are similar.<sup>42</sup>

#### Ethical Considerations

#### Capacity to Consent

Depending on the type of disability, it is important to consider an individual's capacity to provide informed consent and participate in the study. Participation can also be affected by other factors such as medication, fluctuations in the condition, physical discomfort, and psychological distress.<sup>42</sup> All efforts should be made to explain the project and its potential outcomes to the participant, and there should be a discussion surrounding what will happen regarding consent if the person's capacity fluctuates or changes. As with any participant, people with a disability have the right to refuse participation or withdraw at any time. However, it is important that people with a disability are not systematically excluded from research that would be enriched by their participation. Research teams need to explicitly state in their proposal to an ethics committee how they will assess capacity in individuals with a disability.<sup>42</sup>

#### **Minimising Harm**

Particular types of disability (e.g., cognitive impairment, physical conditions, and psychiatric disorder) may sometimes increase a person's likelihood that they will experience some form of distress or discomfort. These risks should be determined and managed appropriately, and if risks are present, they should be justifiable and outweighed by the benefits of the research.

#### **Advisory Boards**

Depending on the nature of the research project, the involvement of an advisory board (that includes representatives with lived experience) is recommended. This will ensure that a collaborative and respectful approach is implemented.

#### Consider the following in developing methodologies:

- The processes needed to determine a person's capacity to consent
- The effects of medication, cognitive impairment, and fluctuations in certain conditions
- Accessible testing locations and appropriate equipment (e.g., for sensory impairments, physical impairments)
- Testing length (e.g., one full sessions or several shorter sessions)
- Reading ability (e.g, specific learning disorders may impact how you deliver information)



#### Knowledge Check:

 What are some different types of disability?
 What are some ethical considerations when working with someone with a disability?

#### Gender-Specific Security and Health Issues in Disasters

There is evidence to show that females (particularly adolescent girls) are disproportionately affected by disasters. Women and children are up to fourteen times more likely to die during a disaster, and are more likely to be killed at an earlier age.<sup>53</sup> Aside from exposure to risk, differences in gender are also evident at other levels of disaster exposure such as risk perception, preparedness, psychological and physical health impacts, and recovery and reconstruction.<sup>54</sup> Women are less likely to have the information they need to appraise the risk associated with disasters and to obtain help when they need it. They're less likely to receive warnings that a disaster is coming, and are often not included or valued in recovery efforts.

There are many factors that influence the way disasters impact upon women's health and wellbeing. These may include biological factors (for example, pregnant, lactating, and menstruating women have unique healthcare and infrastructure needs that may be difficult to obtain after a disaster), and social factors such as sociallydetermined gender roles (for example, exposure to the elements, illness, and injury whilst providing care for the sick, and through gathering food and water; less likelihood of or opportunity to join in rescue efforts or preparedness education; and less likelihood of being rescued due to families needing sons to carry on the family line).53,55 Disasters are known to exacerbate pre-existing risks for marginalised groups, and for women in times of disaster this has often meant increased rates of gender-based violence, early marriage, sexual assault, trafficking, sex work, and harassment, and well as diminished access to resources and livelihoods.<sup>56</sup>

There is a clear mandate for the consideration of gender in disaster risk management, preparedness, and response efforts. Encouraging women and girls to participate in disaster risk reduction programs, including them in education efforts, and considering their unique health, safety, and security needs in the wake of a disaster are all means of encouraging resilience and fostering safety in this vulnerable population.

Gender risks in context: Viewpoints from Nepal

The Study on Adolescent Resilience after Disasters has illuminated a number of valuable insights into the experience of women and girls during and after the Nepal earthquakes of 2015. Our participants highlighted a unique set of health and security risks for females in the wake of the earthquakes such as increases in the rates of trafficking and physical, sexual, and domestic violence. An overwhelming number of participants noted a lack of resources for managing women's health needs and recommended that future disaster response give consideration to the provision of private changing spaces and sanitary supplies so women can manage their health safely and with dignity. An important finding to emerge from this study is that the effects of the Nepal earthquakes amplified existing inequalities with regard to the position and rights of Nepali women in society, and highlighted the importance of Nepal's continued efforts to achieve gender equality at all levels of society. The use of qualitative research methodology, as outlined earlier in this guide, was crucial in gleaning an in depth understanding of the experience of disaster for women and girls in our sample.



**Dissemination of Findings** 

Disasters create unique research challenges. To advocate for the health, safety and support of affected populations, evidence is vital. As funding bodies and individual donors become more focused on the efficient and effective use of funds, providing reliable information about the level of need, specific risk factors, and impact of humanitarian aid will become increasingly valuable.

The future of humanitarian practice and policy is evidencebased. Rigorous research conducted by multidisciplinary and multinational teams will ensure that improvements in health, medicine and technological advancement continue to be designed and implemented for the benefit of local communities. To do so, the collaborative engagement of local governments, non-government organizations, community groups and special representatives will be vital.<sup>57</sup> The uptake of results and sustainability of new initiatives is dependent on the early engagement of partners. Therefore, we urge the international community of researchers to focus efforts on building incountry partnerships and developing plans for dissemination of results prior to the commencement of any research protocol. In collaborating with local partners, research protocols are more likely to be designed in ways that are clearly defined, relevant to the community, and ethically conducted. Results may be received with greater interest should the community be invested in the process.

To optimise uptake of the study results, a targeted strategy for dissemination and promotion should be developed early in the research process. Working with local and international partners, organisations, media and government bodies will enable a broader outreach, and critical evaluation. Scientific manuscripts can be complemented by presentation of the results at international conferences, seminars, workshops, press briefings, through policy recommendations and importantly, community hall events. A multilevel strategy for communicating the findings has potential to engage multiple stakeholders and promote sustainable change.



Dr Jessica Tearne Receives Best Paper Award at the Annual Conference on Disaster Preparedness and Response 2016

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To ensure that the results of The Study on Adolescent Resilience after Disasters are broadly publicised, we designed a strategy for dissemination of results and publication of findings early in the partnership. The research team have held regular Skype calls throughout the term of the project to discuss research design, data collection, analysis and then write-up of the results. We plan to continue these calls as we proceed with analyses and dissemination of the quantitative findings.

At multiple points during the study we met in person (in Kunming, Kathmandu and Perth), to review the preliminary analyses of the qualitative and quantitative results, develop a plan for manuscripts and discuss next steps. By presenting the findings at conferences and research seminars together, we further refined our key messages.

The results of The Study on Adolescent Resilience after Disasters have informed two policy briefs, 'Responding to Mental Health Needs in Disasters', and 'The Changing Landscape of Early Warning Systems: Promoting Effective Decision Making and Action'. Four academic papers have been submitted to high-impact peer-reviewed journals, with more to follow over the coming year. Important next steps include communication of the findings locally, regionally and at an international level, through community groups in our network, social media platforms and traditional media outlets.

By highlighting the effects of trauma exposure and resulting hardships for adolescents, we have identified key risk and protective factors that impact young people in the aftermath of disasters. Efforts to improve adolescent health and security are vital, and should include family reunification, increasing speed of access to medical care, minimising disruptions to education and improving delivery of high-quality psychological services.

Accordingly, our aim is to build on the findings of The Study on Adolescent Resilience after Disasters to develop and implement interventions that will improve psychological outcomes, family strengthening, and adolescent engagement in school. We are currently exploring interventions that will have a positive impact on the specific risks identified in our study, and plan to expand the research program over the next year.

Adolescents are disproportionately represented in nations vulnerable to humanitarian crises, and consideration of their needs is crucial as nations strive to build back better. We hope that the findings of The Study on Adolescent Resilience after Disasters will amplify the voices of adolescents whose knowledge, experience and unique perspective will guide more sophisticated response strategies and inform vital services in the aftermath of disasters.

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