DISASTER PSYCHOSOCIAL ASSESSMENT AND SURVEILLANCE TOOLKIT

(Disaster-PAST)

_Methods to Enhance Disaster Preparedness, Response and Recovery

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TABLE OF CONTENTS

Introduction	5
Definitions	8
Acronyms	9
Utilization	10
Collaboration and Relationships	15
Partnerships with Community Stakeholders	15
Partnerships with Governmental Agencies and Local Universities	16
Partnerships across Regions	
Ethics and Privacy in Psychosocial Assessment	26
Health Insurance Portability and Accountability Act (HIPAA)	
Institutional Review Boards (IRB)	
Data Collection	43
Forms of Data Collection	43
Modes of Data Collection	
Who to Assess	
Data Management	54
Assessment and Surveillance Timeline	
Immediate Screening – Phase 1	
Recovery Screening – Phase 2	
Extended Screening – Phase 3	
Psychosocial Assessment and Surveillance as an Evaluation Tool	
Outcome Evaluation	65
Using the Screening Tool for Outcomes	65
Domains of the Screening Tool	68
Demographic Domain	68
Risk Factor Domain	
Psychosocial Domain	71
Mental Health Sub-Domain	72
Resilience and Self-Efficacy Sub-Domain	74
Quality of Life Sub-Domain	
Special Considerations for Children and Adolescents	76
References	80

Appendices

Appendix A – Screening Tool Example	92
Appendix B – Evaluation and Services Tool Example	101
Appendix C – Child and Adolescent Screening Tool Example	105

LISTING OF FIGURES AND TABLES

Figure 1:	Overview of Disaster-PAST Procedures	pg. 7
Table 1:	The 18 Public Health Identifiers	pg. 31
Table 2:	Sample Size Examples	pg. 49
Table 3:	Database Example	pg. 53

Introduction

This Disaster Psychosocial Assessment and Surveillance Toolkit (Disaster- PAST) was designed for surveillance of community mental health and psychosocial functioning following disasters for the purpose of informing distribution of services by public or private entities and better understanding the ongoing need in recovering communities. Having empirically informed knowledge of mental health needs can aid in attaining an appropriate level of services to people and places that are most in need. The toolkit can be used to understand the following regarding mental health after a disaster:

WHO–Mental health screening will help to explain which communities and populations are most in need of mental health services following a disaster, as well as to what extent they have been affected. It can also allow for identification of certain demographic and risk factors that may serve as risks for developing certain types of mental health problems such as depression or posttraumatic stress symptoms following a disaster.

WHAT–Data-informed knowledge can help to determine what levels of services are needed. This can allow a funding source to direct an appropriate level of services to those in need. Some areas may need different levels of intervention following a disaster including: community level psychoeducation (paper materials describing how to recognize mental health symptoms and instructions for self-care distributed at community events), disaster-specific trainings for mental health providers already located in the disaster area, brief crisis intervention provided by trained paraprofessionals, or individual and group psychological or psychiatric treatment provided by trained and licensed mental health providers such as social workers, counselors, psychologists, or psychiatrists.

WHERE–Using assessment and surveillance techniques will help to determine where services are most needed and where they are most utilized by the population. By tracking demographic information such as zip codes and area of residence (or another location identifier) prior to the disaster, it can also aid in anticipating where services will be needed once individuals begin returning home in the cases of mass migration due to a disaster.

WHEN–The toolkit provides recommendations of when it may be helpful to conduct psychosocial assessment and surveillance following occurrence of a disaster. In cases of a nationally declared disaster in the United States, psychosocial surveillance can inform services provided within the timeline of Federal Emergency Management Agency (FEMA) Crisis Counseling Assistance and Training Program (CCP) services. The Disaster-PAST toolkit also provides a recommended timeline of when to conduct psychosocial assessment and surveillance in the event a national disaster is not declared or in international disasters. Finally, the screening tool in the toolkit can be used for ongoing evaluation of mental health services and for long-term surveillance of mental health needs following a disaster. Additionally, all measures recommended in the toolkit are publically available and free to use.

HOW–Information in the toolkit provides recommendations on how to conduct psychosocial surveillance following a disaster, including how to construct an appropriate screening tool, how to sample individuals to participate in the assessments, and guidelines for how to use the information to inform provision of services.

The Disaster-PAST toolkit was designed to be adapted to varying types of disasters. Disasters have been defined as "event[s] marked by destruction, death, physical injury, and human suffering that cause permanent changes to human societies, ecosystems, and the environment [and]... expose unselected populations to trauma" (Braga, Fiks, Mari, & Mello, 2008). Individuals in communities affected by a disaster can be directly impacted, indirectly impacted, or vicariously exposed to trauma (Braga et al., 2008). Disasters can include many different types of events with differing causes. Some examples are Natural Disasters (e.g., hurricane, tornado, tsunami, flooding, earthquake, volcanic eruption, landslide, wildfire or forest fire); Technological Disasters (e.g., oil spill, nuclear disaster); and Mass Violence (e.g., terrorism, community violence, school shooting). Recommendations for constructing a screening tool that addresses issues specific to different types of disaster can be found in the Domains of the Screening Tool section (page 68).

The toolkit provides information needed to conduct community assessment and surveillance in order to better understand the psychosocial and mental health needs in a community. The information obtained from psychosocial assessment and surveillance using the Disaster-PAST can yield a more complete and accurate understanding of the psychosocial and mental health needs of communities recovering from a disaster. This can ultimately result in efficient distribution of mental health services and resources to those communities that are most in need. Knowledge gained from psychosocial assessment and surveillance can also aid in the understanding of the psychosocial effects of disasters and help guide future disaster preparedness. Figure 1 provides an overview of the Disaster-PAST process.



Figure 1: Overview of Disaster-PAST Procedures

Definitions

Definitions presented are in specific relation to topics found in the Disaster-PAST toolkit.

Assessment -a structured questionnaire that gathers information concerning a person's mental health, social status, and functional capacity within the community. information collected for reference or analysis. Data --Data collection a term used to describe a process of preparing and gathering -data the statistical data describing a population, especially those Demographics -showing average age, income, education, etc. event[s] marked by destruction, death, physical injury, and Disaster -human suffering that cause permanent changes to human societies, ecosystems, and the environment [and]... expose unselected populations to trauma Domains major sections of the screening tool --Measures a group of questions that aim to explain a single construct or -mental health condition (e.g. depression, anxiety or posttraumatic stress). Often referred to as assessment instruments or scales. Mental Health a state of emotional and psychological well-being --Protective Factors something associated (e.g. social support) with an increased -protection from a negative outcome or mental health condition Population a particular section, group, or type of people living in a -specified area (e.g. all members of a community affected by a disaster) Psychosocial of or relating to the interrelation of social factors and individual -thought and behavior **Risk Factors** any characteristic of a person (such as age), a situation (such -as the severity of a traumatic event), or a person's environment (such as family life) that increases the likelihood for a negative outcome or mental health condition Sample a smaller subset of people from and used to describe -characteristics of the population Screening Tool -the physical or electronic questionnaire, compiled of demographics, risk factors and psychosocial domains, that is used to collect assessment and surveillance data. Surveillance the act of observing through use of a structured questionnaire --(interchangeable with the word assessment)

Acronyms

Crisis Counseling Assistance and Training Program	CCP
Louisiana Department of Health and Hospitals	DHH
Deepwater Horizon Gulf Oil Spill	DWH
Federal Emergency Management Agency	FEMA
Health Insurance Portability and Accountability Act	HIPAA
Louisiana State University Health Sciences Center	LSUHSC
Louisiana Spirit	LA Spirit
Institutional Review Board	IRB
Posttraumatic Stress Disorder	PTSD
Substance Abuse and Mental Health Services Administration	SAMHSA
SAMHSA Emergency Response Grant	SERG

Measures Acronyms

Center for Epidemiologic Studies Depression Scale	CES-D
Center for Epidemiological Studies Depression Scale for Children	CES-DC
Connor–Davidson Resilience Scale	CD-RISC
Generalized Anxiety Disorder Scale	GAD-7
Kessler Psychological Distress Scale	K6
Physical Health Questionnaire	PHQ
Post-Traumatic Stress Disorder Checklist	PCL
Self-Report for Childhood Anxiety Related Disorders	SCARED
Short PTSD Rating Interview	SPRINT
University of California at Los Angeles Posttraumatic Stress	UCLA-RI
Disorder Reaction Index	
World Health Organization Quality of Life	WHOQOL

Utilization

The toolkit is designed to guide assessment and surveillance of psychosocial and mental health needs following a disaster. Surveillance can begin immediately following the disaster and can continue years after the disaster to monitor changes throughout the recovery process. It can also be used to evaluate effectiveness of an ongoing services program. This section will discuss recommendations for building an appropriate screening tool, recommendations for how to use the toolkit to conduct psychosocial assessment and surveillance for several different disaster situations and purposes, as well as recommendations of when to use the toolkit following a disaster.

Uses of the Toolkit

The domains included in the screening tool can be used either as a stand-alone assessment of mental health needs or can be used in conjunction with a more general surveillance following a disaster. As a stand-alone assessment of psychosocial and mental health needs, one can obtain information regarding several mental health issues including severe mental illness, posttraumatic stress symptoms, depression symptoms, anxiety symptoms, resilience, and quality of life. All of the recommended measures were chosen to allow for a reliable and valid measure of the psychosocial and mental health domains while keeping the screening tool as brief as possible to avoid over burdening potentially distressed respondents recovering from a disaster. The scales were also chosen because they are available in the public domain and can be used free of charge. When designing a screening tool using this toolkit, one should keep in mind the balance between information obtained (i.e., length of the survey) and burden on the respondent.

As a comprehensive psychosocial needs assessment, you can gain information about several different domains related to psychosocial functioning following a disaster. The three primary domains are demographic factors, risk factors, and psychosocial factors. The demographic domain allows the opportunity to obtain demographic information that can be helpful in determining to whom and where services would be best directed. Suggestions for which measures to use and which demographic factors to include are located in the Domains of the Screening Tool section (see page 68). The risk factors domain assesses factors that may be either risk factors for poor psychosocial adjustment or protective factors following a disaster: these can include level of trauma exposure and loss, and concerns about effects of the current disaster, among others. The psychosocial domain assesses psychosocial and mental health symptoms following a disaster; this domain will assess mental health needs and other psychosocial factors such as resilience and quality of life. The toolkit provides guidance as to how to design an appropriate needs assessment screening tool to collect data at varying time periods following a disaster (e.g., immediately after disaster, recovery phase, long-term recovery). This information is located in the Assessment and Surveillance Timeline section (see page 58).

If one has the goal of using materials to supplement a broader, more general survey following a disaster, this toolkit can be used to create a mental health screening component. A mental health component can assess just one dimension of psychosocial needs (e.g., resilience, posttraumatic stress symptoms, and depression) or several, along with relevant psychosocial risk factors. However, conducting psychosocial assessment and surveillance following a disaster allows the focus to be on psychosocial needs. Through this, one is able to obtain a depth of detailed information that can be used to accurately inform where and to whom mental health services are most needed. When psychosocial needs are a component of a larger survey, it is often limited to only a few questions. Because psychosocial and mental health adjustment following disasters is a large and multi-faceted issue, including only a small component of mental health is likely to provide only a superficial picture of the needs in a community and may overlook several important needs. Therefore, the focus of this toolkit will be to guide assessment and surveillance focusing on psychosocial needs following a disaster.

Purposes of the Toolkit

Information obtained in a mental health survey can serve many purposes. Whether you are using the survey as a comprehensive, stand-alone screening of psychosocial needs or to supplement a larger survey, information gained from a psychosocial screening can help guide the following tasks—assessment of needs, assessment of mental health impact of a disaster, distribution of services immediately following and during recovery following a disaster, and evaluation of ongoing mental health services provided. In assessing the mental health needs of a community, one can gain knowledge of how the disaster has affected individuals in the community. By using sampling techniques described in the Data Collection section (page 42), it is possible to measure the mental health needs of a few individuals and then make estimates about the population in general. This can allow you to accurately describe the mental health impact of a disaster. Surveillance can also lend information about what risk factors may be leading to more or different types of mental health problems.

Once the psychosocial and mental health needs are known, they can be used to inform distribution of mental health services coinciding with the needs in certain areas. Additionally, if demographic data on location before and after the disaster is collected, it can be used to show where services are needed. For instance, if the survey includes questions about zip code (or a common location identifier) before and after the disaster occurred, it is possible to tell which communities were most heavily impacted by the disaster, where the individuals from those communities went (e.g., evacuated, shelters, staying with out of town relatives, stayed in home, temporary housing), and where services are currently needed. If there was a large disaster forced migration and individuals are not able to return to their homes or communities, it is possible to anticipate which areas will be in need of services once individuals are allowed to return. Furthermore, assessment can inform what level of services would be beneficial in certain areas. For instance, individuals in areas heavily impacted by the disaster may need intensive individual and group mental health services provided by trained mental

health professionals, while areas less impacted would benefit from brief crisis counseling provided by paraprofessionals hired and trained to work after a specific disaster. Other communities may benefit from psychoeducation, or printed information about recognizing mental health problems and self-care, or providing disaster-specific training to mental health professionals that are already located in the disaster area. Having an accurate picture of the mental health needs in different communities will help to inform which services are most appropriate for each area.

Having relationships with community stakeholders can be helpful in navigating the process of when and where it would be most helpful to collect surveys. Some suggestions for how to form relationships with community stakeholders is located in the Collaborations and Relationships section of the toolkit (page 15). Information obtained through these collaborations can aid in understanding the culture and needs of a community, as well as how needs may change throughout the recovery process. If surveys are collected as part of an ongoing service program, they can be completed by recipients of services and used to assess the ongoing need and measure how mental health needs change over time. A shortened form of the screening tool (see the example in Appendix B) can also be used to evaluate effectiveness of a mental health services program following a disaster on reducing mental health symptoms. More information on using the screening tool for evaluation can be found in the Psychosocial Assessment and Surveillance as an Evaluation Tool section (see page 65).

As a note of caution, while the measures in the toolkit will provide a valid and reliable measure of mental health symptoms at the population and community level, mental health treatment planning and diagnosis on the individual level should be conducted by a trained mental health professional. Therefore, the toolkit alone should not be used as a diagnostic tool to assess whether a specific individual meets diagnostic criteria for depression, posttraumatic stress disorder, or any other mental health disorder. However, psychosocial and mental health assessment and surveillance is an effective way to measure mental health symptoms in the population and community following a disaster.

When to Use the Toolkit

This section briefly describes how mental health screening can be used at different time points following a disaster. The time points follow the United States FEMA CCP timeline following disaster which includes immediate, recovery, and extended. For more detailed information about what types of surveillance should occur at each time point, refer to the Assessment and Surveillance Timeline section (see page 58).

Immediate Phase

The immediate phase following a disaster includes the time period within two months of when the disaster occurs. In cases of a nationally declared disaster in the United States, this coincides with the FEMA CCP Immediate Services Program (FEMA, n.d.). Information collected during this time period should be basic information to gain a

general sense of what areas were most impacted by the disaster and the risk of mental health effects using an immediate screening tool (see Assessment and Surveillance Timeline section (page 58) that can be widely distributed while individuals are still evacuated, in shelters, or in their homes, and still coping with the immediate effects of the disaster. It is recommended that data collection in this phase use purposive sampling to focus on individuals and areas likely to be highly impacted by the disaster, as using random techniques such as telephone sampling may not be effective if individuals are not in the home or are still in an acute crisis response mode coping with immediate disaster repercussions. See the Data Collection section (page 43) for more information on sampling.

Recovery Phase

The recovery phase includes the time period from one month to one year following the occurrence of a disaster. Due to additional time, surveys can be more thorough than in the previous stage and can be used to assess multiple psychosocial domains. Assessments can be collected using a variety of sampling techniques, including inperson interviews, telephone, web-based, paper-and-pencil, or through ongoing services programs. For more information on choosing a sampling technique, see the Data Collection Section (see page 43). In cases of a nationally declared disaster in the United States, this time period can also coincide with FEMA CCP Immediate Services Program extension or the FEMA CCP Recovery Services Program (FEMA, n.d.). Data collected in this time period or in the earlier time period can help to determine what and where services should be provided under those guidelines.

Extended Phase

The extended phase includes the time period of one year or longer following the occurrence of disaster. Although in the United States, FEMA CCP Recovery services typically lasts 1 year following national declaration of a disaster, a community's recovery can last much longer (Arnberg, Eriksson, Hultman, & Lundin, 2011; Brackbill et al., 2009). Literature has shown that recovery following a disaster can last months, years, and even decades afterward (Brackbill et al., 2009; Meewise, Olff, Kleber, Kitchiner, & Gersons, 2011E). For example, after the terrorist attacks on the World Trade Center occurring in New York City on September 11, 2001 (9/11), the city did not complete recovery and build new memorial structures until 10 years later (Dobnik, 2011), and studies suggest that the psychological effects in the community and country still have an impact (Brackbill et al., 2009). In this time period one year or longer after the disaster, it is helpful to monitor how communities are recovering and how the mental health needs change over time. Again, sampling during this phase can include many different techniques depending on the funding and availability of resources (see Data Collection section, page 43, for detailed sampling information).

The Mental Health Assessment and Surveillance Team

The Disaster-PAST toolkit has been developed for anyone that has a need to better understand the mental health effects of a disaster. Critical attention should be given to individuals selected to comprise the mental health assessment and surveillance team. A variety of skills and knowledge bases will contribute to more successful and useful results. A subset of individuals on the team should have knowledge in the areas of: basic research, general mental health, data management, local resources, cultural factors, and the local disaster recovery process. These individuals are often located in entities such as: state departments of mental health or human services departments; universities; local non-government organizations; non-profit agencies, etc; for more information see section entitled Collaborations and Relationships (page 15). The above team members will be important throughout the entire assessment and surveillance process. Depending on the resources and knowledge of the above team members and the purpose, extent, and methods of the assessment, it may be necessary to consult and recruit additional work force or consultants as needed.

In some circumstances it may be necessary to consult or hire an individual or agency that specializes in data management, analysis, and interpretation (see section Data Management page 54). A consultant that has expertise in participant privacy may also be needed due to the sensitive nature of mental health information (see section Ethics and Privacy in Psychosocial Assessment, page 26). Depending on the data collection method, it may be necessary to recruit or hire additional personnel to administer (see section Data Collection, page 43) or enter (see section Data Management, page 54) the screening tools. Finally, because of its impact on current mental health symptoms additional consultation on the local culture and history is highly recommended (see section Collaborations and Relationships, page 15).

Collaboration and Relationships

Having knowledge about local culture and history is helpful when constructing a screening tool that accurately reflects the mental health and psychosocial needs for an area following a disaster. This knowledge can guide the choice of relevant demographics and risk factors to include in a survey, as well as cultural factors that would be relevant to the functioning level for individuals in a community (i.e. religious involvement and social supports). Prior history about a community is also important to keep in mind, particularly previous traumatic events. Depending upon how the community coped and how they perceived the level of care provided in previous traumatic events or disasters, individuals in communities may be guarded or have specific concerns about the current disaster. These are important to assess regarding their applicability to mental health needs. Knowledge about local culture and history, in addition to expertise related to assessment and surveillance, can be obtained through collaborations and relationships with local entities such as community stakeholders, governmental agencies, and local universities.

Partnerships with Community Stakeholders

Relationship building is an extremely important aspect of the assessment and surveillance process. These relationships serve as the groundwork for an ongoing trauma informed system. Often these relationships will be derived out of need for response to a disaster or crisis; however, if properly developed, these relationships can also serve to help prepare organizations for future disasters and continuing crises.

When looking for partnerships in the community, the first step in the relationship building process is to identify key stakeholders in the community. These stakeholders may include: public and private school administrators, counselors, social workers, teachers, case workers, physicians, physicians assistants, nurses, child care workers, home health care workers, and non-profit and government agency staff and administration. If possible, we recommend teams establish contact with at least two people from each site due to staff turnover and changing job requirements and to ensure feasibility.

Even for teams working in the area prior to the disaster, community partnerships provide something additional that may otherwise be absent. These stakeholders are going to be most familiar with their community and can provide valuable information and insight into various issues in that area. Stakeholders can also provide general information about people's adjustment and needs following disaster. Community partners can educate teams about cultural factors or trauma histories specific to that community. All of this information will prove to be invaluable to teams wanting to conduct surveillance.

Once identified, the next step in partnerships is outreach to these identified stakeholders either through face-to-face, email, or telephone contact. During this contact, it is important to demonstrate how participation in surveillance can help serve their community and improve functioning of their agency or program. It is important for

teams to emphasize the reciprocity of the relationship and highlight any incentives individuals will receive in exchange for their participation. These incentives can include tokens like money, gift cards, or coupons, or information like local resource lists or materials on recognizing symptoms of trauma or effective coping strategies after disaster. Based on our experiences conducting a psychological needs assessment following the Deepwater Horizon Oil Spill, we had the greatest success conducting surveillance by attending events where community members were already assembled for another purpose. These events included community dinners, fishing rodeos, commodities distributions, farmer's markets, and a variety of other gatherings. We found this was the best way to connect with individuals living in impacted areas and also to gather information about the general functioning of the community following the disaster.

Teams should contact community agencies, provide information about their surveillance, and inquire about possibilities to connect with individuals at agency sponsored events. Once invited to an event, it is extremely important for teams to follow through and attend as arranged whenever possible. If circumstances change and your team is no longer able to attend an event, it is the team's responsibility to notify their contact person. A few days before an event, the team should get in touch with their contact person to confirm the time and location of the event and verify that they will be attending the event to conduct surveillance. Prior to the day of the event, teams should prepare the necessary materials (e.g., paper surveys, pens/pencils, clipboards, electronic equipment) and discuss logistics like transportation arrangements and departure time. On the day of the event, teams should plan to arrive at least 30 minutes in advance in case of unforeseen delays and also to allow time for set up at the event. Following the event, teams should reach out to their contact person and thank them for the opportunity to attend the event.

Once teams have invested time and energy into connecting with a particular organization or group, attention should be given to preserving this valuable link. Teams should make efforts to maintain ongoing contact with their community partners. Maintaining a mutual trust and respect with stakeholders can be extremely valuable both for a team's present intention and for future endeavors (Bromet & Havenaar, 2006). It is also important to remember that these existing relationships will often lead to other contacts and additional opportunities for surveillance. Offering trainings and/or consultation to stakeholders or community members is another great way to maintain these relationships. These efforts can establish the groundwork for an ongoing trauma informed system.

Partnerships with Governmental Agencies and Local Universities

Partnerships between governmental agencies and local universities can be particularly beneficial in mental health surveillance following disasters. This type of partnership can strengthen the abilities of the governmental agency and the university since both have sets of expertise that complement the other. More importantly, this mutually beneficial relationship can yield better and more informative mental health surveillance data than either entity could achieve on its own. Generally, universities have expertise relevant to making mental health surveillance more applicable to current and past academic literature (e.g., more consistent with past literature, knowledge to improve methodological soundness, make screening data more relevant and useful for academic literature on disasters). Governmental agencies, on the other hand, typically have expertise on how to make surveillance data more useful for immediate purposes such as service provision following a disaster and ensuring that data collected will accurately inform public policies and proceedings following the current disaster that are often decided on a regional level. Additionally, both universities and governmental agencies may have pre-existing relationships with community stakeholders that can be combined to better form positive relationships with communities, and both universities and governmental agencies will have access to resources such as staff, software, and office space and supplies that can be combined to benefit the goal of mental health needs screening following a disaster.

Resources/Expertise of Universities

University departments are able to provide knowledge, materials, and resources about research, mental health, and surveillance methodology. University departments that would be helpful to partner with for the purposes of mental health surveillance following a disaster can include departments of Psychiatry, Psychology, Counseling, Social Work, Sociology or other mental health related fields. These departments are likely to have professors who are knowledgeable about how to perform, analyze, interpret, and publish mental health data. Many universities have professors on faculty that specialize in mental health effects of disasters, including focusing their research in this area and having knowledge about the effects of disasters from academic research conducted by other institutions. In areas that are prone to multiple disasters or where disasters have occurred in the past, you are likely find researchers who specialize in disaster or trauma, whether they were recruited by the university following a disaster or because researchers at the university re-specialized to address the needs of the local community.

However, regardless of the extent of prior work with disasters, professors in university departments of mental health related fields generally have expertise with research that is relevant to conducting mental health surveillance. This research expertise can include prior experience with IRB application and approval, knowledge about how to appropriately use and protect mental health data, and knowledge about statistics, interpretation, and application of data obtained through mental health assessment and surveillance. They may also have prior experience with academic literature about disasters, which can aid in making the screening tool for the current mental health needs surveillance relevant and meaningful for immediate purposes and for informing the global community about mental health effects of disasters. Additionally, many professors are actively involved in research and are able to effectively plan for the logistics of running a research study including how to recruit and contact participants, how to train individuals to administer screening tools, and how to store data in a way that legally and ethically protects participants. They should also be familiar with how to

implement ethical guidelines for the release of mental health data, including how to appropriately control who has access to data, how to translate data into meaningful terms that can accurately inform the need for services, and how to report data in aggregate terms that is detailed enough to be accurately informative but general enough to maintain participants' privacy and confidentiality.

University departments also have access to resources and local knowledge that can benefit surveillance following disasters. Resources common in university settings are access to online databases and literature to become familiar with the mental health effects of similar disasters, access to an Institutional Review Board (IRB) office (see section on Ethics and Privacy in Psychosocial Assessment, page 26 for more information), and computers with statistical software such as Statistical Package for Sciences (SPSS: 2011; http://www-Social IBM, 01.ibm.com/software/analytics/spss/products/statistics/) or Statistical Analysis Software (SAS; http://www.sas.com/software/sas9/) for setting up, maintaining, and analyzing datasets. In addition to knowledge about how to maintain and report data in a fashion that is compliant with maintaining participants' confidentiality, universities will often have physical space that is appropriate for maintaining this compliance (e.g., locked rooms with restricted access appropriate to store data). University departments that are local to where the disaster occurred will also have knowledge about the local area such as critical events and disasters in the past, how the community perceived governmental response and cultural variables that may be relevant. When designing the screening tool used for mental health surveillance, university personnel can help in choosing relevant variables following a particular disaster based on their knowledge of both local events and measurement knowledge about how to reliably and accurately measure the relevant risk factors and effects. Finally, university departments may have existing relationships with community stakeholders that are helpful for the collection of mental health surveillance data and the needs of the community. In past work, we have found that these existing relationships with the community are helpful in making both organizations in the community and individuals feel more comfortable when conducting mental health surveillance because they feel they can more easily trust the confidentiality and commitment to the community due to their previous experiences with the university.

Resources/Expertise of Governmental Agencies

Governmental agencies often have specific knowledge and resources following disasters that local universities may not. They are also often charged with the task of distributing mental health resources, such as information on treatment facilities, and hiring temporary employees to help with the disasters. Agencies are left to distribute these important resources following disasters without any specific data-driven knowledge about the needs of the community. Knowledge of governmental agencies can ensure that data obtained from mental health screenings accurately informs distribution of resources following a disaster. Resources often specific to governmental agencies agencies can include access to federally funded grants for immediate service delivery,

access to temporary workers that can help with both surveillance and meeting treatment needs informed by mental health surveillance, and information about the needs of the community to inform development of relevant risk factors and demographic variables to include in the psychosocial screening tool.

Due to the breadth of communication with community stakeholders and other governmental agencies, local governmental agencies can be particularly helpful in aiding collaborations across regions, universities, and communities for the purpose of mental health screening to inform distribution of post-disaster resources. In this way, they can make introductions and help the process of making the first "hand-shake" between a university department participating in surveillance and a community or governmental agency that can help with collection of data for mental health surveillance. These partnering agencies can include mental health or educational programs funded by the government, community action agencies, and community members that are politically involved.

Example: Partnership between Louisiana State and LSUHSC in Hurricane Katrina and DWH Oil Spill

With the monumental task of recovering from one of the most devastating natural disasters in United States history, The Louisiana Department of Health and Hospitals (DHH) Office of Behavioral Health contacted The Department of Psychiatry at Louisiana State University Health Sciences Center (LSUHSC) to begin collaboration just after the Hurricane Katrina made landfall in August of 2005. The original goal of this partnership was to provide services to communities throughout Louisiana by working together to improve the efficiency and quality of mental health service distribution. Specifically, LSUHSC Department of Psychiatry helped the DHH Office of Behavioral Health by guiding recovery programming, training their temporary workers and clinicians on brief crisis management, supervision of counseling services, and providing evaluation for their Louisiana Spirit Specialized Crisis Counseling Services program. The DHH Office of Behavioral Health and LSUHSC Department of Psychiatry collaboration also included members from national organizations such as the National Child Traumatic Stress Network and the National Center for Post Traumatic Stress. Resources were combined together in a central team entitled the Practice Directorate where experts in the field pooled their knowledge about how to address mental health needs following the uniqueness of Hurricane Katrina and build on previous relationships with community stakeholders, educational systems, and governmental agencies. Rather than being a one-time collaboration for a singular purpose, this relationship was maintained throughout the long-term recovery phase of Hurricane Katrina and for several projects related to the region's recovery of additional disasters including Hurricanes Rita, Gustav and Ike.

Only five years later, the occurrence of the Deep Water Horizon (DWH) Gulf Oil Spill on April 20, 2010, signaled the need for accurately identifying the mental

health impacts of the disaster as well as meeting the mental health needs of affected communities. Calling upon the previously established collaboration between DHH Office of Behavioral Health and LSUHSC Department of Psychiatry was a natural fit for serving both of these purposes. When the state was approached by the Substance Abuse and Mental Health Services Administration (SAMHSA) to conduct a federally funded study of the impact of the oil spill on Louisiana communities, partnership with LSUHSC Department of Psychiatry was employed. A primary component of studying the mental health needs of Southern Louisiana communities was conducting psychosocial assessments in communities that were impacted by the DWH oil spill. The collaboration between the state office and university department allowed both parties to pool their resources to improve mental health surveillance across the impacted region. The university designed the screening tool to reliably and accurately indicate the psychosocial needs in the communities. The state provided access to the temporary crisis counselors that were providing crisis counseling services under the program entitled Louisiana Spirit (LA Spirit).

LA Spirit crisis counseling offered outreach services to help further mitigate the incidence of post-traumatic stress symptoms and long-term psychological effects in those affected by the Gulf Oil Spill disaster. Services included providing supportive listening, crisis intervention, education and referrals and ongoing community-based psychological support and substance abuse programs through:

• **Outreach** to residents and businesses including door-to-door visits, participation in community events and/or meetings, and distribution of educational materials.

• Short-Term Individual/Group Counseling conducted with residents identified as needing short-term crisis intervention or case management services. A dyad comprised of a mental health professional and resource linkage coordinator conducted individual sessions with residents within their homes or community settings to address identified needs. Licensed addiction counselors were available for substance abuse screening and referrals to the appropriate local service providers.

• Stress Management sessions were offered to individuals or groups including schools and businesses. The sessions included stress reducing techniques, team building activities, and/or basic stress management educational presentations.

• Long-Term Individual/Group Counseling was also available to individuals or groups identified as needing at least six sessions. These sessions were led by licensed master's level mental health professionals and a resource linkage coordinator. Groups were formed to address specific needs identified by community members. Session content included discussion of substance use, grief and loss, domestic violence, children's issues, cultural issues, etc.

By collaborating, both temporary crisis counselors and university faculty used the same screening tool for mental health surveillance. This allowed for a much larger sample size and direct comparisons of mental health needs across many different impacted areas of the state. To ensure that data was collected in a reliable and consistent way, LSUHSC held trainings for the employees of the state instructing them on how to use the screening tool and how to properly collect surveillance in a non-coercive manner that was not burdensome to community members. These trainings also included techniques for brief crisis intervention following disasters and how to provide resources for distressed individuals identified when completing the screening tool.

Mental health surveillance was also streamlined and improved by this collaboration. The LA Spirit temporary crisis counselors were able to reach many impacted communities that the LSUHSC might not have had the resources to reach on its own. Furthermore, in many rural areas where community members felt overburdened by research and multiple research studies, being associated with LSUHSC was helpful because people were familiar with the local university and trusted that they had the best interest of the community in mind. Also, many individuals were glad to hear of the DHH state involvement, and said that they realized the information they were providing was not just for data information purposes, but also had the potential to directly benefit their community by increasing services and delivering them to community stakeholders from both the state and the university, many introductions and collaborations were formed to benefit both the psychosocial assessment procedures and mental health services distribution.

The collaboration between LSUHSC Department of Psychiatry and DHH Office of Behavioral health has been a mutually beneficial relationship that has positively impacted the communities in Southern Louisiana by making psychosocial needs assessments more accurate and relevant to the mental health needs of the communities. In addition to mental health surveillance, the state and university have collaborated in providing trainings, providing recovery services programs, and evaluating these services programs. Having a relationship that is ongoing also allows for future collaborations and early intervention when future disasters occur.

Partnerships across Regions

Rarely does a disaster affect a singular, specific region. For example, Hurricane Katrina in 2005 affected a geographic region approximately the size of Great Britain (Handy, Kimball, & Winbourne, 2006). Although this is not the case for all disasters, one only has to think for a few minutes to generate several examples such as the tsunami and subsequent nuclear disaster in Fukushima, Japan in 2011—in which the tsunami flooded an areas of 561 km (348 mi) and the radiation damage remains unknown in

some areas (INPO, 2011; McCurry, 2011). Thus, assessment of post disaster needs in circumscribed, specific regions can often leave an incomplete picture of the full extent of a disaster's impact. Even in well-funded studies of mental health effects following disaster, it is often unrealistic for researchers or agencies to collect mental health data beyond a certain region. Collaborations with agencies and researchers in surrounding regions is often a good way to extend assessment resources and knowledge to enable comparisons of effects in a wider area. Regions can be areas that are geographically, politically, or practically defined as separate. In the United States, collaborations can be made across regions such as states or counties. In other parts of the world, collaborations could be made across countries or areas with different cultural backgrounds. This collaboration process can lead to a more complete picture of mental health effects and levels of psychosocial needs in areas affected by the disaster.

Collaborating with other regions has a number of other benefits in addition to gaining a more complete picture of mental health effects and psychosocial needs in affected communities. First, partnering with other experts in the field will provide you with a more informed and better designed study of the mental health effects. It will also enable you to better understand how cultural factors in different areas affect mental health following disaster and how risk factors may change across geographic regions related to a variety of factors including how the region was physically affected by the disaster, cultural differences in the regions, and distance from the epicenter or most impacted area of the disaster. Collaboration can also protect individuals in different communities from feeling as though they are "over-researched" since different agencies will all be using the same screening tool. It will also make these participants' responses more informative since you will be able to make direct comparisons of their responses with individuals from different communities affected by the disaster. Finally, collaborating to do a larger scale assessment of mental health effects will better inform future disasters and disaster response.

How to Collaborate in a Meaningful Way

The first step in the collaboration process is to decide who would be best to partner with. Ideally, collaborators should have similar or related goals. In the instance of psychosocial screening, collaborating parties could be interested in understanding the psychosocial needs or mental health effects in communities following a disaster. Collaborators will likely work independently in their own region, but be actively engaged in the partnership of working toward the goal of a more widespread study of disaster recovery. It is recommended that collaborators set up regular meetings, which may be more frequent in the phase of designing the screening tool and planning how to collect data. These meetings could then be held less frequently given the means and needs of the collaborating parties. Additionally, given technological advances, there are many means for meeting across regions, including teleconferences, webinars, and conference calls, in addition to traditional in-person meetings. Further, collaboration can take place and be helpful at any assessment phase following a disaster. The collaboration could begin immediately following the disaster, once assessment has begun but before it is finished, or even after surveillance has commenced to work together to interpret the

result in terms of the larger region. Additionally, collaboration following disasters can be helpful for reasons beyond assessment of psychosocial needs. It can be used to assess how needs differ across regions, how different areas responded to the disaster, and how to work together in the recovery of the current disaster. Finally, collaboration can be helpful for establishing plans to have partners come to each other's aid in the event of future disasters.

In deciding how to best collaborate, it may be helpful to have some common domains that are collected in all regions for direct comparisons. Generally, we would recommend that demographics, risk factors, and psychosocial domains (such as depression, anxiety, or posttraumatic stress symptoms) be collected in all areas, although this will also depend on what each party feels is most important given the anticipated needs and circumstances surrounding the disaster. Depending upon where the assessment is taking place, it may also be important to consider the language of the Several measures are available in multiple languages; however, screening tool. collaborators may need to keep this in mind if they are assessing areas where individuals will not be able to complete the screening tool due to language barriers. The more similar screening tools and methodology are, the easier it will be to directly compare mental health effects in different regions. It will also enable you to more easily generalize results across the areas and speak about impact in a way that applies to many different regions instead of just one. However, it is important to balance this need for generalizability with the need to inform specific regions about their own needs as well.

In many instances, different communities experience disasters in different ways and certain risk factors may be more or less relevant to specific local regions. For instance, following Hurricane Katrina, the destruction on Mississippi's Gulf Coast was primarily damage from wind and storm surges in which homes and neighborhoods were flattened (FEMA, 2006; Fritz et al., 2007), while the experiences in the city of New Orleans were those in which the structures remained intact but there was mass flooding (80% of the city flooded) and consequent problems such as mold in homes in addition to wind and storm surge damage in coastal regions of Louisiana (FEMA, 2006). Thus using identical screening tools in both of these regions would not have given an accurate depiction of disaster experiences for individuals in those communities. When determining this balance, also bear in mind the need to not overburden participants with lengthy screening tools and to avoid having participants complete items that are not relevant to their experiences. In many cases, it may be helpful for different regions to have different screening tools, but agree on several demographics, risk factors, and psychosocial measures included in each of the screening tools if possible. One way to do this may be to decide on a "core screening tool" that each region will collect, and then have additional risk factors and other domains included in their screening tool that are more suited to that area's needs, history, and variations of disaster experiences.

Example: Tri-State Collaboration Following DWH Oil Spill

An example of regional collaboration for assessment of mental health needs following a disaster was the tri-state collaboration following the Deep Water Horizon (DWH) oil spill in April 2010. As part of a SAMHSA Emergency Response Grant (SERG), governmental bodies and university departments collaborated across the tri-state region of Louisiana, Mississippi, and Alabama to assess the mental health needs resulting from the DWH oil spill disaster. In each state, a governmental department or office partnered with a local university. In Louisiana, the DHH Office of Behavioral Health partnered with the LSUHSC Department of Psychiatry. In Mississippi, the state government partnered with the University of Southern Mississippi, Department of Social Work and in Alabama, the state government partnered with the University of South Alabama, Department of Psychology. The distribution of expertise across different departments ultimately led to more thorough consideration of factors relevant to mental health and disasters throughout the collaboration and psychosocial screening process.

The goal of the grant and the collaboration was to gain fast and readily available knowledge of psychosocial needs in each area and across the larger region resulting from the DWH disaster. Once the collaborations between states and universities were made, the relationships across the three states grew over time and with each subsequent meeting of the six parties across the state lines. The three states met on a quarterly basis for the first year following the disaster. Each state operated independently of the others in a partnership with its corresponding university. This yielded several different methodologies for collecting mental health needs data that were unique to each area and were designed to assess unique needs and risks in that state. States also tended to utilize several different methodologies for assessment to ensure that all relevant information was being collected—some of these methods included partnering with local agencies such as domestic violence shelters to share data, working with governmental agencies to access suicide hotline call data, and monitoring and evaluating youth services programs. Each state incorporated screening psychosocial needs assessment of the population as part of their methodology at some stage. The collaborations across the three states were strengthened with time. Across the states, there were several domains common to each state. including similar demographic items, risk factors, and mental health symptom scales that were directly comparable such as using the CES-D to screen for depression symptoms.

Several important lessons were learned about regional collaborations throughout this process. First, we were able to gain more regional knowledge about mental health effects of the disaster both for our individual states, as well as for the Gulf Coast region as a whole. For instance, each state realized that many areas were still in the recovery process from Hurricane Katrina when the DWH oil spill occurred. This was apparent in all states, but presented in differing ways given

the differences in how each was affected by the hurricane and the stage of the recovery process from Hurricane Katrina the community was in when the DWH disaster occurred. We also learned the importance of collaboration across the tri-state region and the importance of understanding mental health effects throughout all areas affected by a disaster to be able to better understand how they differ in relation to cultural factors, previous disaster history, and local and governmental response. The collaboration has also been helpful in interpretation of each state's data. In presenting results at tri-state collaboration meetings with representatives from all state agencies and universities attending, we are able to interpret data from one state in light of data presented from all other states. In this way, experts from three different mental health fields were able to contribute to understanding the effects of the disaster in a more global context across the field of mental health. Finally, this collaboration has been helpful in establishing tri-state partners for response to future events for expanding our ability to study and address the mental health needs across all three states. Because the Gulf Coast is in an area prone to natural disasters such as hurricanes, tornados, and seasonal flooding, each state and university department has agreed to continue this tri-state partnership, which will enable us to act quickly and call upon each other's aid in the event of another disaster in the future.

Ethics and Privacy in Psychosocial Assessment

Psychosocial assessment and surveillance involves the collection of personal information about a person's mental health history, family history, and other potentially private details about one's life. Because this information is so personal, the surveillance team should treat it with more sensitivity and protection than would be required for other surveillance procedures. This will involve taking additional precautions to protect personal information of respondents throughout the surveillance process including data collection, data analysis, and reporting of survey results to ensure the privacy of respondents. These protections should be a proactive effort by the surveillance team not only to prevent disclosures of personal information to inappropriate personnel, but also to prevent accidental disclosures that may negatively impact assessment respondents.

Mental health information is important to protect for many reasons. Among these is the potentially stigmatizing nature of mental health information and the potential for participation in mental health assessment and surveillance to be damaging to respondents if their information is not treated appropriately. For instance, if an individual's personal information is accidentally made public, this could impact future job opportunities if employers know about mental health problems they have had in the past. Potential harm to respondents resulting from participation in any surveillance should be avoided using all reasonable procedures available to the surveillance team. Additionally, if the surveillance team members administering screening tools are not able to give reasonable assurance of their privacy, many individuals will not be willing to participate in the surveillance process. Following disasters, it is especially important that the protection of respondents' personal information be kept private since disaster survivors may be more vulnerable than the general population. Disaster survivors may also be in the process of filing for provision of resources or compensation for damage claims to multiple entities such as governmental departments, insurance companies, or private companies. If their personal information is accidentally released to these payment entities, it may negatively impact respondents' receipt of resources or compensation. The surveillance team should be mindful of this, and should be aware of how this might impact potential respondent's decisions of whether or not they want to participate in a psychosocial assessment if their protection cannot be assured.

Issues of respondents' privacy impacting litigation and compensation were seen in the proceedings following the Exxon Valdez oil spill in Alaska in 1989. Litigation for residents' claims from Exxon Valdez lasted twenty years (Picou, 2009). During the litigation process, data that were originally collected for research on mental health effects following the oil spill were subpoenaed in court. Although the researchers had no intention of sharing this information with the public at the time of data collection, once it was subpoenaed, they were forced to turn their records over to the court (Picou, 2009). Mental health symptoms from individuals who participated in the assessment and surveillance that also had legal claims against Exxon Valdez were closely scrutinized. In some cases, respondent's answers were held against them as reason for why they should not receive compensation for their personal damages (Picou, 2009).

The handling of this data in the litigation process highlights the importance of protecting respondent's privacy. To avoid negative impacts to your respondents, surveillance teams should avoid collecting more information than they need to fulfill the purpose of the assessment and surveillance, as well as to be proactive about storing both the hard copies of screening tools and electronic databases in a way that cannot identify who the responses belong to in case they are ever subpoenaed (Palinkas, 2010). To avoid these negative impacts on assessment respondents, the surveillance team should make active efforts to avoid release of respondent's information at every step in the assessment and surveillance process. This requires the surveillance team to be mindful of how responses are collected, who has access to responses once they are collected, and taking reasonable precautions against accidental disclosures to individuals who should not have access to this personal information.

When designing a screening tool, the surveillance team should not collect unnecessary information. For instance, if there is not a specific reason why names and dates of birth need to be collected, they surveillance team should strongly consider not including these on their screening tool. Any items or questions included on the screening tool should be included for a specific reason that will help the surveillance team discover the psychosocial and mental health needs of communities recovering from the disaster. In addition to collecting the minimum information necessary to serve the purposes of the assessment and surveillance, any questions included on the screening tool should be carefully considered before it is added to the survey. From an ethical standpoint, each question or measure included on the screening tool should go through a risk/benefit consideration. So the benefits of including the question or measure on the screening tool should outweigh the risks to respondents and the community.

The surveillance team also needs to assure ethics and privacy when collecting data. First, participation in any assessment and surveillance should be voluntary. Individuals should be given all information about the potential benefits and potential risks of completing the screening tool, and should then be given an opportunity to ask guestions and make an informed decision about whether or not they want to participate in the The surveillance team should be as transparent as possible when assessment. explaining risks and benefits of participation so that respondents will understand and be able to make an informed choice. This may include explaining the purpose of the assessment and surveillance, funding sources, how personal information will be protected, and how information obtained through the surveillance and assessment will be used. Following a disaster, an important consideration is whether or not it is in the individual's best interest to complete the screening tool. Research has shown that individuals have different patterns of recovery following traumatic events and disasters, with talking and thinking through the trauma being beneficial for some individuals and contraindicated in others (Bonnano, 2004, 2006). Thus, if individuals who do not want to talk about the disaster are encouraged to against their better judgment, this may interfere with their recovery process and negatively impact their mental health adjustment. Although participation in psychosocial assessments should always be considered, potential negative mental health impacts are most important to consider in the weeks and months immediately following the disaster.

When administering screening tools in groups, extra precautions should be taken to protect against accidental disclosure of one respondent's information by another respondent seeing his or her screening tool. Techniques to help with this may include spacing people so that they cannot see each other's answers, or having individuals cover their answers as they work so that others cannot see their personal information. Once a screening tool is completed in a group setting, it should be stored in a place where other respondents or individuals working with the surveillance team would not be able to see it. This may be accomplished by keeping the completed screening tools face-down in a box where that box can be monitored by the surveillance team at all Team members should not look through completed screening tools at the times. assessment and surveillance site and should keep them secured and monitored. Even when checking for imminent risk (e.g., indication of suicidal ideation), this question should be reviewed in a discrete manner and as soon as the relevant responses are reviewed, the screening tool should be secured. Once a screening tool is completed, transporting it to a place where privacy can be assured should be done as soon as possible. Completed screening tools should be kept secured throughout transportation to a secure location and throughout the entire surveillance process. More specific recommendations for maintaining data in a manner consistent with ethical practices can be found in the Data Management section (page 54).

Governing Bodies of Protection and Privacy

In addition to the personal responsibility of surveillance teams to protect privacy of respondents, there are also governing bodies that have regulations that surveillance teams must comply with. In the United States, two of the primary governing bodies relevant to psychosocial assessment and surveillance are the Health Insurance Portability and Accountability Act (HIPAA) of 1996 and Institutional Review Boards.

Generally, HIPAA provides guidelines that must be upheld for health plans, health care clearinghouses, and certain health care providers, and IRBs provide guidelines for conducting research. This section of the toolkit gives a brief overview of HIPAA and IRBs as they relate to psychosocial assessment and surveillance; however, these reviews are not exhaustive. We strongly recommend that surveillance teams contact their local government agencies, carefully review all HIPAA guidelines, and contact a local IRB if they have any questions about requirements for compliance in their assessment and surveillance procedures. In countries outside of the United States, there may be additional governing bodies for psychosocial assessment and surveillance for their local areas where they plan to conduct psychosocial assessment and surveillance following a disaster. The World Health Organization (WHO) provides resources and guidelines for collecting any type of human health data around the world. These resources can be found on their website:

http://www.who.int/ethics/research/en/index.html

Health Insurance Portability and Accountability Act (HIPAA)

The Health Insurance Portability and Accountability Act (HIPAA) of 1996 established legally binding guidelines for protecting the privacy of personal health information. Entities that must comply with HIPAA are health plans, health care clearinghouses, and certain health care providers. Depending upon the funding source and the composition of the surveillance team, psychosocial assessment and surveillance may fall under the guidelines of HIPAA. If you are unsure of whether you comprise an entity that must comply with HIPAA, you can visit their website at:

http://www.hhs.gov/ocr/privacy/hipaa/understanding/index.html.

The discussion of HIPAA in this toolkit is not exhaustive but, rather, is meant to give a brief overview of HIPAA guidelines as they may relate to psychosocial assessment and surveillance in maintaining compliance regarding the privacy of respondents.

The United States Department of Health and Human Services (HHS) established the HIPAA guidelines for the purpose of maintaining the privacy of personal health information. The guidelines are meant to uphold the protection of any type of personal health information while not interfering with the ability to carry out good patient care across settings. Two parts of HIPAA that are most relevant to psychosocial assessment and surveillance following disasters are the Privacy Rule (also known as *Standards for Privacy of Individually Identifiable Health Information*) and the Security Rule (also known as Security Standards for the Protection of Electronic Protected Health Information).

The Privacy Rule establishes conditions under which health plans, health care clearinghouses, and certain health care providers (i.e., the "covered entities") may use and/or disclose certain individually identifiable information called "protected health information" (PHI) collected and held by covered entities. Although the Privacy Rule does not directly regulate independent research conducted by organizations that are not covered entities, researchers who receive research data from a covered entity may be required to comply with the Privacy Rule as well. The Security Rule establishes a minimum set of security standards that covered entities must implement to protect certain health information" or e-PHI). Such security standards include technical and non-technical safeguards.

Definitions Specific to HIPAA

Covered Entity. Covered entities are those that are required to comply with HIPAA in the United States. Covered entities can be a health plan, a health care clearinghouse, or a health care provider who collects, houses, or transmits health information, including psychosocial information, in electronic form in connection with a transaction for which HHS has adopted a standard (See 45 C.F.R § 164.104).

Protected Health Information (PHI). Under HIPAA, PHI is any individually identifiable health information "(i) transmitted by electronic media; (ii) maintained in electronic media; or (iii) transmitted or maintained in any other form or medium." (45 C.F.R § 160.103). For purposes of psychosocial assessment and surveillance, this is any personal information that can be reasonably tied back the respondent who provided it.

Health Information. Health Information means "any information, whether oral or recorded in any form or medium, that: (1) is created or received by a health care provider, health plan, public health authority, employer, life insurer, school or university, or health care clearinghouse; and (2) relates to the past, present, or future physical or mental health or condition of an individual; the provision of health care to an individual; or the past, present, or future payment for the provision of health care to an individual" (45 C.F.R § 160.103). For psychosocial assessments, this would be any information that is collected through the assessment process.

Individually Identifiable Health Information. Individually identifiable health information means "a subset of health information, including demographic information collected from an individual, and: (1) is created or received by a health care provider, health plan, employer, or health care clearinghouse; and (2) relates to the past, present, or future physical or mental health or condition of an individual; the provision of health care to an individual; or the past, present, or future payment for the provision of health care to an individual; and (i) that identifies the individual; or (ii) with respect to which there is a reasonable basis to believe the information can be used to identify the individual" (45 C.F.R. §160.103). An example of this would be a psychosocial screening tool that collected identifying demographic information as well as responses to the screening tool in one place.

Research. Under HIPAA, research is defined as any "a systematic investigation, including research development, testing, and evaluation, designed to develop or contribute to generalizable knowledge." (45 C.F.R § 164.501). This definition of research will typically apply to psychosocial assessment and surveillance following a disaster. So if you are a covered entity that must comply with HIPAA, you will likely need to comply with the guidelines for research.

Use and Disclosure of Protected Health Information for Research

The Privacy Rule allows a covered entity to use or disclose PHI for research purposes in the following circumstances:

• If the PHI has been de-identified in accordance with the provisions of the Privacy Rule, in which case, the health information is no longer PHI. Requirements for what constitutes de-identification are further discussed below.

- If the covered entity receives appropriate documentation issued by an IRB (see IRB section, page 34) or Privacy Board waiving or altering the authorization.
- If the information is disclosed as a limited data set, with certain identifiers removed, and with a data use agreement between the covered entity and the researcherrecipient. For psychosocial assessment and surveillance following disasters, you will likely maintain your own datasets. We recommend leaving this as a limited dataset. Also, if you choose to consult with another entity for data purposes such as statistics, they should be given a dataset that only includes the needed information. Typically, they will not need more than a limited dataset to run these analyses.

De-identified Health Information

De-identified health information is not considered PHI, and thus can be used and disclosed by a covered entity without authorization or restrictions on use or disclosure. Section 164.514 of the Privacy Rule permits a covered entity to de-identify PHI in two ways. The first way, the "safe-harbor" method, requires the removal of all 18 elements that could be used to identify the individual or the individual's relatives, employers, or household members. Data that are stripped of these 18 identifiers are deemed de-identified, unless the covered entity has actual knowledge that it would be possible to use the remaining information alone or in combination with other information to identify the subject. The 18 identifiers that must be removed to have de-identified data are presented in Table 1.

Because these public health identifiers have the potential to allow identification of respondents, we recommend that you avoid collecting these unless there is a specific need or reason (such as for a longitudinal population assessment, for evaluation purposes, or for payment purposes). If any of these identifiers are collected, they should be separated from the rest of the screening tool as soon as is reasonably possible (see Data Management section, page 54, for recommended procedures) and stored in a separate location. For instance, the majority of screening tool responses would be stored with non-identifying numbers, and the names and other identifiers would be stored in a separate database that does not contain the rest of the screening tool responses.

Table 1: The 18 Public Health Identifiers

Identifiers

- 1. Name**
- 2. All geographic subdivisions smaller than a state, including street address, city, county, precinct, ZIP code, and their equivalent geographical codes, except for the initial three digits of a ZIP code if (a) the geographic unit formed by combining all ZIP Codes with the same three initial digits contains more than 20,000 people; or (b) the initial three digits of a ZIP Code for all such geographic units containing 20,000 or fewer people are changed to 000
- 3. All elements of dates (except year) for dates directly related to an individual, including birth date, admission date, discharge date, date of death
- 4. Telephone numbers**
- 5. Facsimile numbers**
- 6. Electronic mail addresses**
- 7. Internet protocol (IP) address numbers
- 8. Social security numbers**
- 9. Medical records numbers**
- 10. Health plan beneficiary numbers**
- 11. Account numbers**
- 12. Certificate/license numbers**
- 13. Vehicle identifiers and serial numbers, including license plate numbers**
- 14. Device identifiers and serial numbers**
- 15. Web universal resource locators (URLs) **
- 16. Biometric identifiers, including fingerprints and voiceprints**
- 17. Full-face photographic images and any comparable images**
- 18. Any other unique identifying number, characteristic, or code, unless otherwise permitted by the Privacy Rule for re-identification. **

Note. **must be excluded for limited data set agreements, see page 33 for more information.

Research Use and Disclosure with Authorization

Section 164.508 of the Privacy Code permits covered entities to use and disclose PHI with research participants' authorization. This means that if you are to release this information to anyone, you would need to get specific written permission from each responded whose information you intend to release in which they agree what you will release, for what purpose, and to whom. An authorization is an individual's signed permission allowing a covered entity to use or disclose the individual's PHI to the stated recipient. The covered entity must provide a copy of the signed authorization to the individual signing it and retain the signed authorization for six years from the date of creation or the date it was last in effect, whichever is later. A valid authorization must be written in plain language and contain at the minimum the following specific core elements and required statements. This will typically not be part of assessment and surveillance following a disaster. However, for more information about core elements and statements required to be part of an authorization, please see the HIPAA website at:

http://www.hhs.gov/ocr/privacy/hipaa/understanding/summary/index.html

Research Use and Disclosure without Authorization

The Privacy Rule allows covered entities to use and disclose PHI for research purposes without authorization in the following circumstances: under a waiver of the authorization requirement, as a limited data set with a data use agreement, for activities preparatory to research, and for research on decedents' information. For more information about these disclosures, please see the above website.

Limited Data Set and Data Use Agreement

Section 164.514 of the Privacy Rule permits a covered entity to use and disclose a limited data set, without obtaining authorization or documentation of a waiver or an alternation of authorization. Limited data sets are not de-identified health information under the Privacy Rule and thus may include information such as addresses other than street name or street address, dates, and unique codes or identifiers not listed as direct identifiers. A limited data set contains the health information of the individual, or individual's relatives, employers, or household members that exclude 16 direct identifiers. A list of identifiers that must be excluded are marked with ** in Table 1 and postal address information, other than town or city, state, and ZIP code.

A covered entity is required to enter into a data use agreement with the researcher-recipient before disclosing a limited data set. The data use agreement must contain the following provisions:

- Specific permitted uses and disclosures of the limited data set by the recipient consistent with the purpose for which it was disclosed
- Identification of persons permitted to use or receive the limited data set
- Stipulations that the recipient will (a) not use or disclose the information other than permitted by the agreement or otherwise required by law; (b) use appropriate safeguards to prevent the use or disclosure of the information except as provided for in the agreement; (c) report to the covered entity any uses or disclosures in violation of the agreement of which the recipient becomes aware; (d) hold any agent of the recipient (including subcontractors) to the standards, restrictions, and conditions stated in the data use agreement with respect to the information; and (e) not identify the information or contact the individuals.

Security Safeguards of Protected Health Information

The Security Rule requires covered entities to put in place certain administrative, physical, and technical safeguards to protect PHI that are transmitted by or maintained on electronic media ("electronic protected health information" or e-PHI). Section 164.306 of the Security Rule requires the covered entities to:

- Ensure the confidentiality, integrity, and availability of all e-PHI they create, receive, maintain, or transmit;
- Identify and protect against any reasonably anticipated threats or hazards to the security or integrity of such information;
- Protect against any reasonably anticipate, impermissible uses or disclosures; and
- Ensure compliance by their workforce.

Covered Entities may use a flexible approach to implement the above requirements; however, in deciding which security measures to use, a covered entity must consider the following factors: the size, complexity, and capabilities of the covered entity; the covered entity's technical infrastructure, hardware, and software security capabilities; the costs of security measures; and the probability and criticality of potential risks to electronic protected health information.

Section 164.308 of the Security Rule requires covered entities to institute a contingency plan for responding to an emergency (for example, fire, vandalism, system failure, and natural disaster). Such contingency plan must include data backup plan, disaster recovery plan, and emergency mode operation plan.

Section 164.310 of the Security Rule requires a covered entity to implement physical safeguards that include limited physical access to its electronic information systems and the facility housing e-PHI, while ensuring that properly authorized access is allowed. A covered entity must also establish policies and procedures regarding the transfer, removal, disposal, and re-use of electronic media.

Section 164.312 of the Security Rule requires covered entities to implement specific technical safeguards that include, among other things, the following:

- Access control: allowing only authorized persons to access e-PHI;
- Audit control: implementing hardware, software, and/or procedural mechanisms to record and examine access and other activity in information systems that contain or use e-PHI;
- Integrity control: implementing policies and procedures to ensure that e-PHI is not improperly altered or destroyed;
- Transmission security: implementing technical security measures to guard against unauthorized access to e-PHI that is being transmitted over an electronic communications network.

Many of the procedures for protecting personal health information under the Security Rule that are highlighted here also constitute good practices for maintaining the privacy of assessment respondents, even for surveillance teams that are not covered entities under HIPAA. If a surveillance team is unsure of how to protect the personal psychosocial data they collect during assessment and surveillance following disasters, we recommend that they visit the Department of Health and Human Services website:

http://www.hhs.gov/

Institutional Review Boards (IRB)

This section reviews the purpose of an institutional review board (IRB) in post-disaster surveillance, when it is needed, and how to obtain IRB approval for disaster surveillance. This section will also review situations in which IRB approval may not necessary for psychosocial assessment and surveillance. This section provides a brief overview of how IRB may apply to psychosocial surveillance following a disaster; however, it is not exhaustive. For more information on whether or not your surveillance requires IRB approval, please contact a local IRB office or consult with the website for the Department of Health and Human Services, Office of Human Research Protection:

http://www.hhs.gov/ohrp/index.html

The goal of an institutional review board (IRB) is to evaluate whether human subjects research is ethical and to evaluate whether the benefits of a particular research study outweigh the potential risks. IRBs can be non-profit (usually affiliated with academic institutions) and for profit (usually an outside agency or organization with oversight from the United States Federal Government) and typically consists of a group of professionals from different disciplines. When a study is under review, the IRB evaluates all aspects of ethical obligations and limitations in a study. They also evaluate whether the benefits to a study outweigh the risks. In disaster research, this can include

weighing the ethics of burdening disaster survivors by having them complete multiple studies that yield redundant information or studies that in and of themselves place a strong burden on participants. In some disasters, such as the Oklahoma City bombing in 1995, all studies were approved and coordinated by the IRB at the local university to ensure that victims of the disaster were not overburdened and that studies did not collect redundant information (Fleischman, Coolgan, & Tuma, 2006). However, this level of coordination is often not acquired. Following disasters, many areas are prone to being over researched by interested and well-intentioned researchers from all over the country and sometimes the world. It is important to determine if there is an entity such as a local IRB or state or national office that is overseeing and approving disaster surveillance and research.

IRB Categories

Whether or not assessment and surveillance procedures should be approved by an IRB depends upon what the information will be used for. Several instances are exempt from IRB approval and can be completed without going through this process. Any type of research can be regarded by an IRB as exempt from needing approval, eligible for expedited review, or subject to full review. Each of these categories will be discussed within the context of disaster research. This section provides a brief overview of IRB categories; however, for more information on whether or not your surveillance requires IRB approval, please contact a local IRB office or consult with the website for the Department of Health and Human Services, Office of Human Research Protection:

http://www.hhs.gov/ohrp/index.html

Exempt from IRB Review

Studies exempt from IRB approval include those for which IRB approval is not necessary. In these instances it is not necessary to submit an IRB application. However, if you are working with a university or agency that has an IRB, it is recommended that you complete an application for exempt research to ensure that your study does not need to be submitted for expedited or full review. There are several instances which are exempt from IRB approval.

The first is research on normal educational practices or research on practices that are performed, established, and commonly accepted by educational settings including preschool, school-age, high school, and college settings. This category only includes common practices in educational settings or measures and screening tools that are given by teachers and/or the school board. If a non school affiliated researcher has children in a school complete research that is not typically part of the curriculum, the research is often not exempt. Thus, unless it is a common practice or deemed necessary by school administration, the addition of psychosocial assessment in a school setting may require IRB approval.
The second category for IRB exemption is research involving the use of educational tests (cognitive, diagnostic, aptitude. achievement), survev procedures, interview procedures or observation of public behavior. For research to fit this category, data must be collected anonymously, potentially identifiable information should not be collected, and any information collected cannot place the participants at risk of criminal or civil liability or be damaging to the participants financial standing, employability, or reputation. For a list of variables or information that is potentially identifying, see Table 1. Those most relevant to disaster surveys include geographic information smaller than a state, all elements of dates except year (including birthdays, move/evacuation dates, and dates of admission or discharge), as well as any personally identifying numbers such as telephone numbers, addresses, or social security numbers. Additionally, public behavior includes behavior that takes place in settings in which individuals are not expected to have privacy.

Data using pre-existing data or publicly accessible data is also typically exempt, providing that the data is collected in a non-identifiable way. Additionally, if a survey is expected to cause more than minimal risk to participants or cause distress, it may not be exempt from IRB approval. Finally, surveys that are collected for non-research purposes are also typically exempt from IRB review. These include evaluation of publically or privately run programs, information collected for purposes of quality improvement or quality assurance, and interviews regarding transportation or crime. Information collected for public forums regarding neighborhood development or land use is also exempt; however, this may not apply to post-disaster mental health screenings. Mental health surveys that may be exempt following disasters could include a program evaluation, model curriculum, or a needs assessment, which does not lead to research activities such as field testing, and cannot be generalized to the larger community (meaning that the results will be delivered only to one school or agency for the purpose of quality improvement, and will not be compared with other assessments, etc.).

If you feel that your mental health surveillance may meet criteria for exemption from IRB review, please review the following resources:

Belmont Report:

http://ohsr.od.nih.gov/guidelines/belmont.html

Department of Health and Human Services:

http://answers.hhs.gov/ohrp/categories/1564

Department of Health and Human Services, Office of Human Research Protection:

http://www.hhs.gov/ohrp/index.html

It is ultimately the ethical responsibility of the researcher to ensure that studies are done in an ethically consistent manner, including IRB approval if indicated. If you are still unsure of whether or not your study meets criteria, it is advised that you consult with a local IRB office to help determine this.

Expedited IRB Review

Ultimately, it is the decision of the IRB whether a study meets criteria for expedited or full review. However, this section will give an overview of disaster studies that typically meet criteria for expedited review. The first criterion is that most studies that qualify for expedited review pose no more than minimal risk to participants and do not aim to include at risk populations such as children, fetuses, elderly, or prisoners in the sample. This category applies to most research employing survey, interview, oral history, focus groups, program evaluation, human factors evaluation, or quality assurance methodologies. Thus, it would likely apply to post-disaster survey research if it is not eligible for exemption. Additionally, information collected cannot reasonably be expected to put participants at risk regarding their financial standing, employability, insurability, reputation, or be stigmatizing. Even so, attempts must be made to protect participants' privacy and confidentiality. For research that is not exempt from IRB, including both expedited and full review, researchers will need to develop an informed consent procedure with participants.

Full IRB review

Again, it is important to stress that the decision of whether a study qualifies for expedited or full review is ultimately the determination of the IRB reviewing body (typically by a subset of individuals who serve on the IRB board). Research on mental health surveillance following a disaster may fall into this category if the study intends to include at risk populations such as children, elderly individuals, disabled individuals, or prisoners or if the study asks questions which constitute more than minimal risk. This could include questions that have the potential to put participants at risk such as questions about substance use or violent acts, or questions that are uncomfortable for participants to answer such as history of suicide attempts or current suicidal ideation.

For complete guidelines on whether or not a study is eligible for exemption, expedited, or full IRB review, see

http://www.hhs.gov/ohrp/policy/index/index.html.

Relevant links include: Exempt Research and Research That May Undergo Expedited Review; Categories of Research that may be Reviewed Through an Expedited Review Procedure.

How to Construct an IRB Application for Disaster Research

This section will provide details and suggestions for how to construct an application for IRB review following a disaster. This discussion is tailored for survey research assessing mental health needs following disasters. Although the information may be useful for constructing any IRB application for other disaster research, it will be particularly useful for applying for survey research on mental health needs with adults following a specific, identifiable disaster. Finally, there has been discussion of the possibility of having a pre-approved IRB for research that would have standing approval for a specified purpose and would be implemented or enacted upon national declaration of a disaster. This procedure has not yet been approved but has been discussed in research forums as a possibility for future disaster research.

IRB application

Each IRB has its own application form; however, there are several parts that tend to be consistent across many different boards. We will review several sections commonly found in IRB applications; however, persons using the toolkit to conduct research should check with their local IRB for specific requirements before beginning the application process.

Primary Investigator. In IRB applications, a primary investigator must be identified. This should be a person with expertise and ideally previous experience in the field of disasters, mental health, or surveillance procedures. The primary investigator will be responsible for leading the team that conducts the study, for seeing that all aims and procedures of the study are carried out as planned, and for ensuring the ethical integrity of the study. Commonly, it will be a professor at a university, and some IRBs may even require this. There may also be co-investigators identified on the IRB application; however, this is typically not a requirement. The role of co-investigators is to aid the primary investigator in carrying out the work. They may also be involved in the planning and implementation of the study.

Title of Study. The title of the study should accurately and concisely describe the purpose of the study. In disasters, it should include the name of the specific disaster and the purpose of the assessments. An example for a mental health needs assessment via survey methods for the Deepwater Horizon Oil Spill would be "Deepwater Horizon Event Psychosocial Needs Assessment." The study title should be "fully explanatory on its own," and it is recommended that it be no more than 12 words (APA, 2010).

Abstract of Study. The abstract of a study is a brief description of the purposes of a study, the rationale for the study, the planned study procedures, and the expected outcomes. It should be able to stand on its own, be concisely written, and provide information about the planned study. The recommended length for an abstract is typically between 150 to 250 words; however, individual IRBs may have specific requirements concerning the length of the abstract (APA, 2010).

Rationale for Current Study. Although rationale should be briefly addressed in the abstract, IRB applications often require a more detailed rationale for the study. The rationale should be a persuasive paragraph citing past literature and clearly illustrating the importance of information collected in the study. In cases of mental health surveillance following disasters, this can be accomplished effectively by citing mental health needs in past disasters of the same or similar types, expressing reasons why having an accurate determination of the psychosocial needs of the current disaster will help affected individuals, and explaining how the methodology (surveillance procedures) used is an effective way to obtain information in a way that balances the need for information without being overly burdensome or invasive to participants.

Study Procedures. This section typically requires several elements including a description of the target population, recruitment procedures, data collection and sampling procedures, and how data will be kept secure and participants' confidentiality will be protected. When presenting the population you intend to study, it is important to keep in mind the justification for inclusion of any at-risk groups, including children, the elderly, prisoners, and pregnant women and fetuses. In recruitment, you will need to discuss where recruitment will take place (e.g., evacuation shelters, communities, random telephone sampling), who will be recruited, and how they will be recruited. When discussing recruitment procedures, include details of how measures will be taken to avoid coercion for participation and ensure that participation is voluntary. In data collection and sampling procedures, discuss the methods of data collection including telephone surveys, paper-and-pencil surveys, web-based surveys, or in-person interviews. If using in-person interviews, also discuss what level of training individuals who administer the interviews will have and what resources participants will have should they become distressed or request additional services while participating. More information on how to decide which sampling and study procedures to use can be found in the Data Collection section (see page 43) of this toolkit. In the IRB application, you will likely need to include specific procedures of how data security and privacy of participants will be ensured. This includes how data will be stored, who it will be released to and in what form (aggregate data summaries or raw data), and how it will be de-identified if used by outside parties. More information about how to properly store and handle data, including a brief overview of HIPAA guidelines on handling personal health information, can be found on page 29 of this toolkit.

Additional Information. Depending upon the requirements of the particular IRB, additional information and documentation may be requested. This can include a list of funding sources for the study, whether or not participants will be compensated for participation and conflicts of interest for researchers. IRB applications will also typically request copies of all materials used for the study including flyers for recruitment, surveys, telephone scripts, and the informed consent document, which is discussed in further detail below.

Informed Consent

Informed consent is required for most studies. Informed consent is a process which usually involves a minimum of an oral explanation of the study, discussion with potential participants about the study, giving potential participants the opportunity to ask questions about the study to a researcher, and then freely consenting to participate without coercion. Documentation of informed consent is usually required in addition to these procedures. There are several situations in which written documentation of informed consent is not required; however, whether or not it is required will be determined by the IRB. Situations in which documentation of informed consent is not required are generally when 1) having the participant sign an informed consent would put the person at risk, such as if consent is the only identifying part of the study and they are reporting on information that would put them at risk if identified, and 2) you are using study methods for which informed consent is not typically required (e.g., observational techniques in a natural setting, telephone surveys).

Documentation of informed consent is a written form which explains the nature and purpose of the study, as well as other information considered to be necessary for making an informed decision about whether or not to participate. It is signed by the participant after going through the informed consent process. As stated above, simply having a participant sign a document of informed consent is not sufficient for acquiring informed consent. Participants should only be asked to sign the document after the study has been explained in clear language, all information that would be required to make an informed decision has been explained, and the participant has had an opportunity to ask questions about the study and what participation would entail. A necessary part of this process is to stress to the participant that their participation is voluntary and that they will not be penalized in any way for refusing to participate, refusing to answer questions they are uncomfortable with on the survey, or withdrawing after participation has begun. The informed consent document should be written in plain, readable language that is free from scientific jargon. For surveillance studies on adults in the general United States population, it is recommended that language should not be above the 4th to 8th grade level.

According to the United States Department of Health and Human Services, minimum requirements of an informed consent are:

1. A description of any potential risks or discomforts

- 2. A description of any possible benefits to the participant or to others as a direct result of the study
- 3. Options for alternatives to participation. In surveillance, this would typically be the option of not participating.
- 4. How the participant's confidentiality will be protected, including how the data will be protected and maintained, what personal information may be released to outside parties, and a possible ways that confidentiality may be accidentally release as a result of participating in the study.
- 5. Whether compensation will be given, what the compensation is, and how it will be delivered to the participant.
- 6. Contact information for researchers or the local IRB office should a participant have questions about the study.
- 7. A statement that participation is voluntary, and that they will not be penalized in any way for refusal to participate (http://answers.hhs.gov/ohrp/categories/1566).

IRB offices can require additional information to be included on the informed consent document such as the study title, where the study will take place, names and contact information for investigators of study, contact information for the IRB office, description and purpose of the study, the process of how to withdraw from the study, and separate signatures for the participant, a witness, and a reader if the participant is unable to read on his or her own. Many IRB offices have a general informed consent form for you to use as a guide.

Assent

Individuals can only provide informed consent to participant in a study if they are able to legally represent themselves. Thus, populations that are not able to do so (e.g., children, gravely disabled) must have a legal representative provide informed consent for them to participate. If you are using a population that cannot provide informed consent, it is recommended and sometimes required that researchers obtain informed assent from participating individuals. Informed assent is documented in a similar fashion as informed consent. Participation should be voluntary, and the study should be explained in a way appropriate to the developmental level of the potential participant. Thus, if participants are children, the assent document should be explained and written in language appropriate to the child's level of understanding using grade- and ageappropriate language.

For more information on informed consent, please see the following websites:

http://answers.hhs.gov/ohrp/categories/1566

http://www.hhs.gov/ohrp/policy/ictips.html

Data Collection

When approaching data collection following a disaster, it is important to consider who is being studied, what is being assessed, when it is being assessed, and why the study is being conducted (North & Norris, 2006). Other important considerations include availability and allocation of resources, including funding and personnel. This toolkit will discuss specific guidelines and recommendations for collecting data after a disaster. This section will outline the different forms and modes of data collection and describe the advantages and disadvantages of each method. Common modes of data collection include in-person, telephone, and online/web-based surveys. When developing a plan for data collection, it is important to take into account that different modes can affect how people respond and different factors (e.g., length of survey, time of day, etc.) can impact respondents' willingness to participate. To ensure proper administration, each team member must receive training on data collection methods and be thoroughly familiar with the screening tool in order to understand what is being assessed in each question.

Forms of Data Collection

There are two choices for data collection: paper forms or electronic forms. Paper forms are the most accessible form of data collection, particularly when in incidents of disaster you may not have access to electronic equipment or resources may be compromised or are limited.

Paper Forms

Paper forms of data collection have the advantage of being easy to use and generally require little training for team members. Paper forms are very portable and do not require electricity, the internet, or other electronic devices at the time of collection. In this way, they can be useful for individuals less comfortable with electronic devices or in situations where these resources are limited. However, this method requires materials, such as hardcopies of the screening tool, pens, and a hard surface to write on such as tables or clipboards. Teams must prepare an adequate number of paper forms in advanced to avoid shortages while in the field and the potential of missing an opportunity to collect valuable data. Paper forms are not protected from the elements (e.g., rain) and can be easily misplaced or inadvertently mixed in with other paperwork. Teams must consider the costs of generating copies of paper forms, including the expense of photocopying, along with the additional time and labor required to prepare the forms. One major disadvantage to using paper forms to collect data is the added step of data entry. Any data collected in paper form must eventually be entered into a database, which can prove to be a very labor-intensive process. Manually transferring the data from the paper forms to the electronic database also introduces an element of human error. Scanning machines provide a way to minimize the amount of time spent on data entry, but the machines themselves can be very costly (upwards of \$10,000 US) and this method requires special formatting for paper forms. Even with the barriers

of data entry, paper forms of data collection are the most common following disasters as they are not reliant on access to electronic equipment when resources are limited.

Electronic Forms

Electronic forms of data collection offer many conveniences, including real time data entry and portability. Electronic forms require the use of equipment such as laptops, tablet computers, or Personal Digital Assistants (PDAs), which can be expensive for teams to purchase (DHHS/CDC, 2009). While the costs of electronic equipment and internet access are decreasing, the expense of using computers is not always economical and may be cost prohibitive for many teams (Galliner et al., 2008).

Even teams who can afford the equipment and technology must face the added reality that in instances of disaster, they may be limited by the inaccessibility of resources to power the equipment, internet and cell phone access. Additionally, this equipment requires regular maintenance care, and technology support. Data collected in electronic form offers the benefit of being easily transferable into a database, eliminating the timeconsuming extra step of having to manually enter this information. However, this method does not eliminate the possibility of human error. Mistakes can be made at any point during the data collection; team members can incorrectly enter respondents' information or respondents less familiar with electronic formats may have difficulty entering their responses correctly.

Modes of Data Collection

The most common modes of data collection are in-person/face-to-face, telephone, and online/web-based surveys. One of the most important considerations in determining the mode of data collection is maximizing response rate. Response rate is the number of people that complete your assessment divided by the number you attempted to collect data from. In some cases it is difficult to determine your response rate because the number attempted is unknown; however, the goal of any assessment is to increase the likelihood that a potential participant will respond. For example: are your potential participants more likely to responds to an in-person, telephone, or web-based assessment? Before selecting a mode of data collection, it is important to consider cultural factors and aspects of the study environment that may affect how easy or difficult these modes of data collection would be to implement. By making informed decision regarding data collection modes, teams can drastically increase their response rates.

In-person Assessments

In-person surveys can either be administered by an interviewer, often referred to as face-to-face interviews, from the team or independently completed by the respondent. In-person surveys can be particularly useful following a disaster when telephone and mail services may be unavailable. One main advantage of in-person surveys is that they offer a more personal approach to data collection and give team members an opportunity to gain trust and establish a connection with respondents. Team members

are able to clarify items on the survey and answer respondents' questions. In-person surveys also allow team members to easily provide respondents with additional information, such as local resources and educational materials on mental health or disaster recovery. Response rates with this method tend to be very good (Rubin & Babbie, 2010). Additionally, in-person modes are typically very costly and time-consuming once you factor in the expenses of labor and travel. For teams trying to sample a very specific population, in-person assessments are the recommended mode of data collection. Teams should also be aware of the potential for in-person assessments to increase the potential for interviewer bias or the effect characteristics about the interviewer can have on a respondent's answers (Rubin & Babbie, 2010). Research shows that factors like the interviewer's race (Hill, 2002), gender (Catania et al., 1996; Huddy et al., 1997) or item wording (Catania et al., 1996) on sensitive topics (e.g., mental illness, sexual behavior, criminal activity) can influence responses. This occurrence is often attributed to social desirability or a respondent's attempt to present a positive self-image to the interviewer.

Conducting in-person assessment and surveillance after disaster presents a number of unique challenges and requires a considerable amount of planning. Areas that are normally accessible may be difficult to reach following disaster, for example roads may have restricted access or may be physically limited by debris. In spite of these challenges, the richness and depth of in-person interviews provides invaluable and practical knowledge for the entire assessment and surveillance team. For example being on the ground in a recovery area allows team members to gain knowledge from interacting with individuals directly affected; which can include gualitative anecdotal reports and important risk factors that may not be included on the screening tool. This feedback received can serve as an important guide when updating and editing the screening tool and when interpreting the results from the data. Team members' presence in a disaster recovery area also provides an opportunity to build rapport with community residents, stakeholders and organizations (Bromet & Havenaar, 2006). Partnering with temporary crisis workers or other recovery field workers, as in the LA Spirit example on page 20, can be an efficient way to address some of the challenges with conducting in-person assessments in disaster areas.

Telephone Assessments

Compared to other methods of data collection, telephone surveys are fairly cost effective (Rubin & Babbie, 2010). Teams can easily collect telephone surveys with few resources and smaller numbers of team members. Telephone surveys allow teams to reach respondents that may otherwise be inaccessible using other methods (Galea et al., 2006). One notable disadvantage is that data collection via telephone excludes rural areas where telephone service is not developed and areas where telephone service is unavailable after disaster. In addition, because telephone surveys rely on intact landline and/or cellular service, calls can be unexpectedly disconnected or dropped. If this occurs in the process of completing an assessment, the interviewer may be unable to subsequently reach the respondents to clearly hear the interviewer which could lead to

misunderstandings or misinterpretations of information. Teams considering utilizing phone surveys must consider the high rate of call screening and the possibility that phone calls from team members may be mistaken as telemarketer calls. Phone surveys allow team members to speak directly with respondents, which provides an opportunity for them to clarify items on the survey and answer respondents' questions. In spite of this, it may be difficult to establish rapport with respondents and gain their trust. Additionally, some respondents may be reluctant to provide information to team members over the telephone.

In order to conduct telephone assessments one must have access to a list of telephone numbers. These can be publicly available at no charge or available for purchase. Publicly available phone lists are often provided free of charge by land based telephone service providers, either in hardcopy form or accessible online. Fee based phone lists can be purchased from a telephone service provider or private agency, which often includes cellular phone lists. Importantly, costs for these cellular phone lists can be prohibitively expensive and total more than \$10,000 US dollars. A growing number of people depend solely on cellular phones for telephone communication, especially for younger respondents (Rubin & Babbie, 2010), thus depending on your resources, the costs of purchasing a cell phone list may be a worthwhile investment.

Web-based Assessments

The use of web-based assessments has increased considerably in recent years (Vehovar & Lozar Manfreda, 2008) and this data collection mode can be especially useful following disaster (Schlenger & Cohen Silver, 2006). While web-based surveys require respondents to have both computer and internet access, these resources are becoming increasingly more common, even in rural areas. For people who do not have internet access at home, computers are available at various public locations (e.g., libraries, schools, etc.) and community agencies. Despite this accessibility, online surveys may be best used with respondents who are familiar with and already use the internet on a regular basis. Online surveys are thought to be the most cost effective form of data collection and the time period required for data collection is generally shortened. In most cases, once web-based surveys are created, additional expenses are minimal. Cost effective web-based assessment companies, like Survey Monkey (http://www.surveymonkey.com) are widely available to teams and streamline the process of survey design (Galliner et al., 2008; Rubin & Babbie, 2010). Even teams with very few members and resources can easily collect data using web-based surveys. Online surveys allow respondents to work at their own pace and give respondents flexibility of where and when to complete the survey. Respondents may also find the process less intrusive. Online surveys offer the added convenience of automatic data entry, which allows the team to directly proceed to analysis of the data. Web-based data collection also provides a great amount of flexibility and surveys can be designed to automatically skip questions that do not apply to a respondent.

One disadvantage with this data collection mode is that because respondents interact directly with the survey, questions cannot be clarified and respondents may experience

problems understanding directions or answering questions. Teams must consider the possibility for multiple submissions which may skew survey results. Because online surveys rely entirely on technology, they can be completely disabled by technical problems or glitches. If this occurs while respondents are in the middle of completing a survey, the data may be lost. Respondents who encounter this problem while trying to begin a survey may not return to complete the screening tool.

Following disaster, rapid response is needed to assess people's degree of exposure and post-disaster adjustment (Schlenger & Cohen Silver, 2006). Web-based surveys can be an effective way to implement surveillance and measure these domains. Although online surveys allow teams to reach large numbers of respondents, it may be difficult to identify these individuals or locate them to notify them about the assessment. There is also the very real possibility that internet services may be unavailable following a disaster. Without the necessary resources, even well-designed web-based assessments could be stalled, delaying the ability to gather crucial information. One possibility following natural disasters may be to provide web-based assessments at a shelter or other areas where survivors are located in groups.

Administering Assessments

Individuals administering and distributing surveys will typically consist of staff, faculty, junior staff, students, volunteers, additional workforce, or in some cases temporary employees that have been hired to administer brief services following a disaster. These assessment administers can be sent to locations or make phone calls for telephone surveys. Temporary employees can also be accessed by contracting with call centers, often associated with psychology and sociology departments at universities or polling centers. They should be trained in methods of assessment administration, including how to administer informed consent and ensure that participation in the assessment and surveillance, individuals who administer these either in person or via phone should have basic training on or supervision from someone familiar with recognizing mental health risk factors, how to provide basic support, and how to refer for local mental health services when indicated or requested by survey respondents.

If a survey includes questions about suicidal ideation or intent, individuals administering the survey should be trained or supervised by someone trained in how to do a suicide assessment and how to immediately connect individuals who are imminently at risk to appropriate services, including hospitalization if necessary. For questions that directly assess suicidal ideation, it is imperative that an appropriate response protocol is developed and in place to address endorsement. The World Health Organization has an information resource guide for prevention and recommended crisis intervention procedures (WHO, 2006).

http://whqlibdoc.who.int/publications/2006/9241594314_eng.pdf

If a protocol cannot be ensured, omitting any questions referring to suicide ideation is recommend due to the ethical limitations of not being able to assure the respondents safety. Regardless of whether suicidal ideation is directly addressed, staff administering surveys should be aware of social and cultural expectations and norms in the area and should be trained to administer surveys without bias.

The safety of assessment administers must always be emphasized and given priority over data collection. It is important for the assessment and surveillance team to maintain communication throughout the data collection process. In a disaster recovery situation it may be important to consider potential communication difficulties in the field due to telephone and internet outages. Many universities have official field safety guides and safety requirements; the link below provides an example of a guide specifically for field research from the University of Texas at Austin (Safety Guidelines, 2010).

http://www.utexas.edu/safety/ehs/fieldguide/field_guide.pdf

Payment or Compensation of Participants

Payment or compensation for time and effort is a common practice for research projects. The payment should not be so large that the respondent would view the payment as coercive (Rubin & Babbie, 2010). Whether you choose to or can pay participants will depend on your purpose, logistics, and/or available funding. Additionally, offering incentives to respondents (e.g., money, gift cards, coupons, etc.) and designing a survey with a low level of difficulty can also increase response rates. As an important note, it is often required to collect personal information, such as names and social security numbers, in order to fulfill payment and avoid duplicate assessments. While compensation may increase response rates, requiring personal information may be a deterrent toward participation. Money is not the only form of compensation; snacks, bottles of water, pens, T-shirts, vouchers etc. can also be useful incentives for individuals to consider participation in your assessment and surveillance.

Who to Assess

Selecting a population of interest is a fundamental part of the assessment and surveillance procedures (North & Norris, 2006). The population of interest is a target group of individuals that you want to identify the post disaster mental health needs of. In disaster research, populations of interest generally fall into three categories of exposure: 1) communities, populations, and schools, 2) victims and survivors, and 3) rescue and recovery workers (North & Norris, 2006). Common population indicators following a disaster may include: people directly affected by the disaster; people indirectly affected; distance from the disaster; first responders; displaced individuals; temporary housing/shelter locations; refugee camps; medical facilities; providers; relief aid distribution sites; and community or religious events targeted toward survivors. Teams should also consider various methods to define population groups, including

geographical areas (e.g., political boundaries like a country, county/parish/province, city/town/village) or exposure to the disaster (e.g., first responders, individuals living closest to the scene of the disaster). Populations can also be further classified according to demographics (e.g., by age group, by racial/ethnic/tribal categories) (DHHS/CDC, 2009; Siegel, Laska, & Meisner, 2004). Following disaster, many teams may also be interested in assessing whether the incidence of certain mental health domains are significantly higher in exposed as compared to unexposed populations (Bromet & Havenaar, 2006). In such cases you may want to include unaffected individuals in your population of interest to use as a comparison group. It is important for teams to consider who is being studied and what is being assessed when identifying their population of interest. Even studies that use an appropriate screening tool can yield studies that misrepresent the needs if the respondents are not part of the population of interest.

Sampling

Once you have decided on your population of interest, the next step is to consider sampling or selection of a small portion of the population of interest to assess. Sampling can be very useful following disaster when the population of interest is very large and/or not directly tied to mental health service provision. In these cases, teams should seek a representative sample, or one that reflects a snapshot of the larger population of interest. Samples can also be understood as a smaller subset of the population that represents the larger population. With a representative sample, teams can make generalizations about findings that apply to the entire population. Sampling can decrease costs, time, and effort on the part of both the surveillance team and the respondents. With sampling there is no need to assess everyone in the population of interest. For more in-depth discussions on how a sample allows one to estimate toward the general population of interest (i.e. central limit theorem), please refer to the link below (Garrison, 2009).

http://faculty.chass.ncsu.edu/garson/PA765/sampling.htm

Teams need to make careful decisions about sampling and make efforts to collect surveys from respondents that are part of the target population; otherwise this method can produce a non-representative sample. The effects of poor sampling can create faulty assumptions about the true needs of the population (Rubin & Babbie, 2010).

Sample size

As discussed earlier, it is not necessary or likely that teams would be able to survey every individual impacted by a disaster. When designing your assessment and surveillance procedures, it is important to consider how large your sample needs to be (i.e. sample size). It is important to consider sample size because you want to make sure that your sample is large enough to accurately estimate the population of interest. Conversely it is also important to know how small your sample can be as to not overburden the surveillance team, resources, and respondents. Once a sample has reached a size that it can estimate the population of interest, additional resources may be better used elsewhere. In such cases, when a pre-identified sample size has been met, additional assessments reach a point of diminishing return where additional respondents will do very little to increase your knowledge about mental health needs.

Sample size depends on a number of factors; however, for population assessments, there are free and publicly available sample size calculators available on the internet. The major components of determining sample size include the size of the population of interest, the desired confidence interval, and the desired confidence level. A common way to estimate the size of a population of interest is to use census data, popular website to locate this data can be found at:

- <u>http://www.census.gov/</u>
- http://factfinder2.census.gov/faces/nav/jsf/pages/searchresults.xhtml?refresh=t
- http://www.census.gov/population/international/data/idb/informationGateway.php

In some disaster circumstances and for specialized populations of interest it can be very difficult to estimate the population size. In these instances, it may not be possible or desirable to predetermine your sample size.

The confidence interval gives the range for where the entire population would likely be. Confidence intervals are often pre-set at either ± 5 or ± 1 . For example, if 71% of your respondents reported damage to their homes due to the disaster, with a confidence interval of ± 5 , you can assume that if you had sampled the entire target population 66-76%, would have experienced damage to their homes due to the disaster. Similarly the confidence level refers to how confident the researchers can be that the population would have chosen an answer within with confidence interval. Generally, confidence levels are set at 90%, 95%, or 99%, with the higher percentage meaning higher confidence. The population size, confidence interval, and confidence level are predetermined by the surveillance team. These will be entered into a sample size calculator, a number of these are available for free on the web and we have provided a link to one below.

http://www.surveysystem.com/sscalc.htm

Example of population sizes and the required sample size needed to estimate the answers of your survey to the entire population of interest are provided below (see Table 2).

Population	100	200	500	1,000	2,500	5,000	20,000
Sample size needed	80	132	217	278	333	357	377

Table 2: Sample Size Examples

Note. confidence level = 95%; confidence interval = 5.

Probability Sampling

Probability sampling involves random sampling—a precise procedure for selecting respondents for a sample that guarantees equal probability of selection from the entire population of interest. Random sampling ensures that a sample will be representative of a population (Rubin and Babbie, 2010). For example in the Louisiana State University Health Sciences Center telephone surveillance following the Deepwater Horizon Oil Spill, the population of interest was organized using telephone directories from impacted regions. Systematic random sampling was conducted within these directories by contacting every sixth (number in population / number of samples) nonbusiness/residential listing and inviting the adult who answered the call to participate in the assessment. One notable limitation of this method is that telephone directories only include households and businesses with listed landline phone numbers. Survey Sampling, Inc. (1990) estimates that only about two-thirds of all U.S. households have a listed telephone number. Similarly the project could not afford cellular phone directories and was again limited to landline participation only. Other types of random sampling include cluster sampling (see paragraph below on CASPER) and stratified sampling, where mutually exclusive groups (i.e. sex, age, socioeconomic status) are determined and random sampling of these groups is conducted.

Non-Probability Sampling

Often in disaster assessments, random samples are not feasible or desired. In these instances purposive, or convenience, non-probability sampling techniques can be used (Rubin & Babbie, 2010). Surveillance teams collect assessments on anyone available that is known to include their population of interest. For example following the Deepwater Horizon Gulf Oil Spill in 2010, Louisiana State University Health Sciences Center (LSUHSC) conducted a psychosocial assessment using purposive sampling in order to reach individuals who were directly impacted such as individuals in the fishing and seafood industry, oil related industry, hospitality and tourism, and coastal communities. Team members attended events (e.g., community dinners, commodity distributions, ports) in highly impacted regions to conduct surveillance with individuals most affected by the oil spill. Purposive sampling can give you a better description of a specific subset of individuals that may be difficult to reach with random sampling techniques. With purposive sampling, teams are able to get information about specific facets of the population that can be generalized to other individuals who fit similar parameters, but cannot be generalized to the larger population.

Community Assessment for Public Health Emergency Response (CASPER)

The method described in the Community Assessment for Public Health Emergency Response (CASPER) provides an example of how to use sampling procedures following disaster. In an effort to standardize public health assessment procedures after disaster, the Division of Environmental Hazards and Health Effects, Health Studies Branch (DEHHE/HSB) at the Centers for Disease Control and Prevention (CDC) developed the CASPER toolkit (DHHS/CDC, 2009). CASPER was designed to provide quick, low cost, accurate, and reliable information about communities impacted by public health emergencies (DHHS/CDC, 2009). CASPER provides guidelines on physical health tool development, sample selection, training, data collection, analysis, and report writing (DHHS/CDC, 2009). The complete CASPER toolkit can be found at:

http://emergency.cdc.gov/disasters/surveillance/pdf/CASPER_toolkit_508%20COMPLIA NT.pdf

Using CASPER sampling procedures, teams are able to collect public health and basic need information from specific areas or populations affected by a disaster (DHHS/CDC, 2009). The sampling methods described in CASPER can also be used for mental health assessment and surveillance. The methodology detailed in CASPER allows for rapid data collection from a sample of households that can be reliably generalized to the entire community, country, or region (DHHS/CDC, 2009). CASPER provides the following steps for community and regional sampling.

- 1. define the geographic area
- 2. determine what type of sampling method to use
- 3. cluster sampling
- 4. households within each cluster
- 5. one household member to respond for each household

Step 1. Define the geographic area.

The geographic area for the assessment should be well defined before the assessment can begin. This will likely be determined by a local official and may be divided politically (district, city, county), geographically (roads or bodies of water), or by specific subpopulations. Once these boundaries have been determined, detailed information about the population can be obtained from the U.S. Census Bureau to aid the sampling process.

Step 2. Determine the Proper Sampling Method.

If resources are available to assess every housing unit within the defined geographic area, then no sampling is necessary. However, this can require large amounts of time, labor, and money, which may not be available immediately following a disaster. When reaching out to every affected housing unit is not feasible, information from a sample of households is used to represent all households in a geographic area. CASPER suggests the use of a multistage cluster design because disaster situations may limit the amount of information available to utilize proper random, systematic or stratified sampling techniques.

Step 3. Cluster Sampling.

Cluster sampling is a two-stage sampling procedure in which *clusters* are defined as "non-overlapping subpopulations" within the affected area and are typically composed of street blocks (.05 of a mile or .08 kilometer). In the first stage, 30 different clusters are randomly selected from the affected area. Each cluster will encompass a certain number of housing units proportional to the total number of housing units in the affected area and may be larger or smaller than a city block depending on the geographic area. For United States samples, CASPER recommends using freely available data from the U.S. Census Bureau to identify clusters (census blocks) in the affected area, and using random number generators to randomly select thirty clusters from this list. After the 30 clusters are selected, they can be mapped with roads and landmarks through the "Map It" function on the U.S. Census Bureau website or other freely available internet mapping applications. More detailed directions and links are available through the CASPER link above.

Step 4. Households within each Cluster.

In the second stage of cluster sampling, seven housing units are randomly selected from each of the 30 clusters identified in the first step. This can be accomplished through three different approaches. After creating a complete list of housing units from each cluster and assigning numbers to each of the units, seven numbers can randomly be selected and the corresponding housing units chosen for interviews. A second method for randomly choosing housing units involves randomly choosing global positioning system (GPS) points within each cluster and selecting the home at or closest to each point. The third method takes place once the interview team has reached the cluster. Once in the center of the cluster, a team member chooses a direction by spinning an object (pen, pencil) and walking in the direction indicated until reaching the first house. From there, the interview team would continue the assessment by travelling to housing units closest to the previous home in sequential order until seven houses have been selected within that cluster.

Step 5. Choose eligible persons to interview.

There are no rules regarding gender, race, ethnicity or religion when choosing who is eligible to interview. Eligible household members should be over 18 years of age and understand that he or she is responding to questions on behalf of the entire household. If more than one adult is present in the home at the time of the interview, either can respond to the interview or the interviewer can choose the person with the birth date closest to the assessment date.

Data Management

At some point in conducting assessment and surveillance, one has to decide what to do with the information. These procedures are referred to as data management and can include data entry, storage, and analysis.

Data Entry

Data entry involves the act of entering data (information on the screening tool) into a database which may include Microsoft Excel or other statistical software (e.g., SPSS, SAS). All responses should be entered into single electronic databases for ease of management and reference. This may include directly entering the data from hard copy version of the screening tool or downloading responses from an electronic source. In typical databases, each row represents a respondents and each column represents a question or item from the screening tool. Table 3 presents a database example.

ID	Question1_sex	Question2_age	Question3_disaster_survivor
Respondent 1	Male	23	Yes
Respondent 2	Male	44	No
Respondent 3	Female	31	Yes

Table 3: Database Example

The process of data entry, especially from hardcopies to electronic system, increases error. To reduce this error, one option is to verify the data. This requires the added steps of entering the information a second time, comparing the two entries, and then correcting any errors. However, the process of verifying the data is often not realistic due to the additional time and labor required and the increased potential for additional human error in the form of duplicate entries of the same survey in a single database.

Removal of Identifying and Private Health Information

At the earliest possible time (typically at data entry), identifying information should be removed and stored separately from the remaining information. For example, the first page of the screening tool, which contains private health information (see example in Appendix A, page 92), can be removed from the remaining sheets at the time of data entry. Informed consents or other documents bearing respondents' signatures, which can also be used to identify respondents, should also be removed. In the event that identifying information is needed (e.g., for making payment to respondents or longitudinal study), respondents' identifying information should be kept separately from their responses and separate databases should be created.

A non-identifying number should be assigned to both the page containing identifying and private health information and the remaining contents of the questionnaire. This non-identifying number is often referred to as the respondent's ID (see column 1, Table 3) A non-identifying number cannot be linked by initials or any of the above identifying information. This arbitrary number (e.g., 1,234, next respondent 1,235, etc.), should be the only link for private health information and the remaining contents of the questionnaire - both sheets should be stored separately in a secure location as described below.

Data Storage

This section provides information on how to manage your data and how to safeguard the privacy of your respondents. Specifics on formal privacy protection can be found on page 26 in the Ethics and Privacy of Psychosocial Assessment section. Do not implement these guidelines until you have investigated whether or not you are a "covered entity" as described under the United States Health Insurance Portability and Accountability Act of 1996 (HIPAA) guidelines, which can be found at

http://www.hhs.gov/ocr/privacy/hipaa/understanding/index.html

We also encourage you to contact a local Institutional Review Board, non United States equivalent in governing research, or university to better understand what your specific privacy requirements are. The data management section is written to guide you in helping maintain the privacy of your respondents, but should not be viewed as the ultimate authority on privacy policies. Because demographic and personal health information that identifies or can be used to identify respondents may be obtained, it is of utmost importance to follow privacy regulations with proper data management techniques.

If possible, it is best to work with de-identified data, which would include not collecting the following information:

- name;
- all geographic subdivisions smaller than a state, including street address, city, county, precinct, ZIP code, and their equivalent geographical codes, except for the initial three digits of a ZIP code if (a) the geographic unit formed by combining all ZIP Codes with the same three initial digits contains more than 20,000 people; or (b) the initial three digits of a ZIP Code for all such geographic units containing 20,000 or fewer people are changed to 000;
- all elements of dates (except year) for dates directly related to an individual, including birth date, admission date, discharge date
- telephone numbers;
- facsimile numbers;
- electronic mail addresses; and
- internet protocol (IP) address numbers (often collected inadvertently though private online surveys).

However, due to the nature of disaster research, the above information, especially geographic subdivisions, may be of particular interest when trying to determine severity

of impact or where services are most needed. When collecting any of the above information, a proactive stance should be taken to ensure that respondents' health information and privacy are protected throughout the entire process, from collection of data to maintenance of databases.

Prior to engaging in surveillance activities, training should be conducted on the importance of maintaining respondents' privacy. These trainings would include information on safe temporary storage and the process for submitting the questionnaires in an efficient manner.

Generally, data should be stored in a double locking system (i.e. locked filing cabinet/closet behind a locked door) for hardcopies, or a password protected system for electronic copies (see Ethics and Privacy in Psychosocial Assessment section on page 26 for more information on electronic safeguarding of data). When collecting screening tools at events or public places, measures should be taken to prevent against accidental disclosure of identifying and protected health information. Specifically, completed questionnaires should be kept in a safe, secure, and discreet manner and location (e.g., face down in a closed or locked box). Review of critical items (e.g., suicidal ideation) on the questionnaires should be carried out quickly and discreetly and once it has been determined that the respondents are not in imminent danger, the questionnaires should be immediately stored in the manner described above. Safeguards should also be placed while the data is in transit (e.g., in a locked box in a locked trunk) and every attempt should be made to transport data to a secure location as soon as possible after the data has been collected. For web-based or computer-based questionnaires, caution should be taken to ensure that the previous respondent's information and responses are closed prior to beginning to conduct a survey with a new respondent. Access to completed questionnaires should be limited to only researchers and/or members of surveillance team.

Electronic database should also be securely safeguarded. At the minimum, access to such databases should be password protected and only members of the surveillance team should be allowed access. Data encryption may also be considered (see Ethics and Privacy in Psychosocial Assessment section on page 26 for more information on electronic safeguarding of data).

Minimum Necessary Standard

The identifying data should only be viewed by individuals directly involved with the surveillance or research; however, the de-identified data or reports on the results may be presented to individuals outside of the direct surveillance or research team. The HIPPA guidelines require—and as a general privacy rule—that reasonable efforts should be made to limit the use or disclosure of private health information to the minimum necessary amount to accomplish the purpose.

Data Analysis

Data analysis is defined as when information from the screening tool (data) is processed (Rubin & Babbie, 2010) in a concise manner to help answer the questionwhat are the mental health needs of individuals affected by the disaster? This can include ensuring there are no errors in the database (often referred to as cleaning the data) and conducting the necessary statistical procedures. It would be helpful for a person on the surveillance team to be knowledgeable about how to set up and maintain databases in statistical software such as Excel by Microsoft, SPSS (IBM, 2011; http://www-01.ibm.com/software/analytics/spss/products/statistics/), SAS or (http://www.sas.com/software/sas9) and have the ability to run analyses using basic syntax. However these more advanced statistical skills can usually be contracted out to a consulting agency. Basic reports often include descriptive statistics which include the frequency (count) and percentages of responses to each question. When frequency and percentages do not enhance readability, such as reporting 3 (1.2%) of respondents were age 43, 2 (0.7%) of respondents were age 44, etc., mean and standard deviations should be used, the mean (average) age of respondents was 36 (SD = 9.4). For more information on the definitions and how to calculate these using Microsoft Excel, please consult Elementary Data Analysis Using Excel (Meehan & Warner, 2012).

Knowledge dissemination is also an important step in the assessment and surveillance process. Knowledge dissemination is important to inform service provision, aid in the understanding of the psychosocial effects of disasters, and to help guide future disaster preparedness. Individuals choosing to complete the screening tool often do so in an effort to help the disaster recovery cause. Therefore, the collective effort of your respondents should be presented in a public manner. At a minimum this is often conducted in a report back to the surveillance funding agency(ies), but it is also important to consider dissemination at professional conferences, academic journals, news papers, websites, etc. Following privacy considerations outlined in the Ethics and Privacy in Psychosocial Assessment section (page 26) information that could identify a single individual in any way should be avoided. For example, a sentence describing the impact of a disaster on a single mother of three young children whose home was destroyed on Somewhere Street, would potentially violate that respondent's privacy; thus, this level of specificity should be avoided. Instead, consider sentences such as 80% of houses in the [large geographic area] were destroyed or 20% of respondents met the PCL-C cut-off for posttraumatic stress.

Assessment and Surveillance Timeline

The Disaster-PAST is designed to capture individual and community mental health effects during disaster recovery. The recovery period can be categorized into three main phases— Phase 1, Immediate, Phase 2, Recovery, and Phase 3, Extended. The first two phases coincide with the United States Federal Emergency Management Agency (FEMA) Crisis Counseling Assistance and Training Program (CCP) grant funding timeline (FEMA, n.d.). Phase 1 coincides with the Immediate Services Program (ISP) and Phase 2 coincides with the Regular Services Program (RSP). Phase 3 extends beyond the CCP timeline to monitor long term community recovery and how the mental health needs change over time. For more information on FEMA CPP, please visit the guidance manual located at:

http://www.dmh.ca.gov/Disaster/CCPToolkit/docs/CCPProgramGuidance.pdf

Each screening phase, along with its purpose, scope, and timeframe, is detailed below.

Immediate Screening – Phase 1

The Immediate Screening Phase extends up to 60 days following the date of the disaster or crisis and overlaps with the Immediate Services Program (ISP; which spans 14-60 days post-disaster). The main purpose of assessment and surveillance of this phase is to quickly assess initial exposure and mental health need for immediate resource allocation and psychological relief efforts.

Due to the high distress and disorder immediately following a disaster, it is recommended that the screening tool is kept short in length (one page or less). The brief tool will streamline the administration process to quickly and efficiently obtain the most essential information about immediate mental health needs.

The immediate screening tool is likely to consist of limited non-identifiable demographic information and questions targeted to capture severe mental health effects. Sample demographics are limited to include age, sex, race/ethnicity, pre-disaster and current zip code (zip code is a type of regional identifier used in the United States), pre-existing mental health condition, and pre-existing physical problem/disability, along with risk categories resulting from the disaster, such as:

- Injured or physically
 Life was threatened harmed
 - Witnessed death/injury
- Evacuated prior to the incident

• Assisted with rescue

- Staying with family or friends
- Separated from family Victimized

- Family missing or dead
- Friends missing or dead
- Staying in shelter or temporary housing
- Witnessed violence

In conjunction with the above demographics, the K-6 (Kessler et al., 2002), which was designed for use in the United States National Health Interview Survey, is a recommended measure to briefly screen for mental health distress in an effort to capture the presence of serious mental illness. The scale does not aim to discern specific mental diagnoses, but instead serves to identify the presence of broad mental health problems that are severe enough to cause moderate to severe impairment in social or occupational functioning. The K-6 is particularly useful for immediate screening as it consists of only 6 items, asking respondents to rate how often in the last 30 days (based on responses of 0 = None of the Time, 1 = A little of the time, 2 = Some of the time, 3 = Most of the time, and 4 = All of the Time) they had felt:

- 1. Nervous
- 2. Hopeless
- 3. Restless or Fidgety
- 4. So depressed that nothing could cheer the respondent up
- 5. That everything was an effort
- 6. Worthless

To score the scale all items are summed to create a total score, with scores of 13 or higher indicating the possible presence of mental illness (Kessler, et al., 2003).

The K-6, coupled with the aforementioned demographics and risk categories, can provide quick insight into the patterns of distress severity across impacted areas and populations.

Recovery Screening – Phase 2

Assessing disaster impact over time is critical, as common physical, emotional, cognitive, and behavioral responses have been shown to change as communities progress from pre-disaster to reconstruction stages. For instance, affected persons may initially report restlessness and being on edge in the days following a disaster, but may report different or additional symptoms, such as physical exhaustion or substance abuse, over time.

The Recovery Screening Phase immediately follows the Immediate Screening Phase and takes place 60 days to 1 year post-incident, which corresponds to the Regular Services Program (RSP) timeline. The primary goal of this phase is to obtain more detailed information to fully understand the psychosocial impact of the disaster and to further guide early recovery efforts. In this phase, collection of identifying information (i.e., name and contact information) may be helpful to link respondents with existing mental health services, payment of participants, and to facilitate future follow-up assessment with original populations.

The length of the recovery screening tool depends on a variety of factors. Because you have more time to prepare for phase 2, and possibly more resources, this allows you to expand upon the information collected in phase 1 and to obtain more detailed

information to guide the understanding of mental health needs. However, it is still important to consider the point of respondent frustration and exhaustion; therefore the screening tool should be limited to no more than 8 pages. Please note that some individuals may find that 8 pages is still too long and may be unwilling to participate in the assessment. This will be an important consideration when deciding what information is essential for your assessment and surveillance, balanced with overburdening your responders.

In assessing psychosocial need in the recovery phase following the Deepwater Horizon Gulf Oil Spill, completion time for the 8-page screening tool used (see Appendix A) averaged approximately 30-40 minutes for literate respondents. For those with more limited literacy, screeners were often read aloud, thus requiring greater time and one-on-one administrator involvement. Therefore, amount of information (i.e., number of items and scales included) must be weighed against contextual factors such as the reading level of participants, administration format, and resources.

Regardless of page length, the recovery screening tool should aim to expand upon the domains--demographic, risk category, and psychosocial—in the immediate screening tool. Inclusion of domains should be relevant to the specific culture, current disaster and significant stressors. For example, in assessments following the Deepwater Horizon Gulf Oil Spill in 2010, risk factors included prior hurricane experiences. Although hurricane experiences were not related to the oil spill, many communities were still recovering from Hurricanes Katrina and Rita in 2005, and thus, it had the potential to impact psychosocial needs.

Demographics Domain

The items below are examples of demographics that could be included for a recovery phase screening tool. Demographics in bold are those that were not included in the immediate screening tool and provide a more comprehensive understanding of the recovering population and landscape.

- Name
- Contact Information
- Age
- Sex
- Race/ethnicity
- Current zip code
- Pre-disaster zip code
- Highest Level of Completed Education
- Occupation/Employment Status and Tenure
- Annual Household Income (from the most recent full year)
- Years of Residency in the Affected Area
- Pre-existing Health Problem/Disability
- Pre-existing Mental Health Condition

Risk Categories Domain

The items below are examples of risk categories that could be included for a recovery phase screening tool. Risk categories in bold are those that were not included in the immediate screening tool and provide a more comprehensive understanding of the recovering population and landscape.

- Injured or physically harmed
- Assisted with rescue
- Evacuated prior to the incident
- Separated from family
- House destroyed or damaged
- Loss of property (other than house)
- Loss of business, income, job opportunities

- Life was threatened
- Witnessed death/injury
- Staying with family or friends
- Victimized (i.e., robbed, assaulted)
- Became seriously ill
- Loss of usual way of life or leisure activities
- Pre-disaster traumatic experience

- Family missing or dead
- Friends missing or dead
- Staying in shelter or temporary housing
- Witnessed violence
- First responder
- Post-disaster traumatic experience
- Witness community destruction

Psychosocial Domain

The recovery screening tool should include a variety of psychosocial domains to assess the mental health and psychosocial needs of disaster survivors in a more comprehensive way than in the immediate screening tool. Additional psychosocial domains, or sub-domains, can allow you to further specify the mental health needs (e.g. depression, substance use, post traumatic stress, anxiety, etc.) for service provision as well as identify psychosocial strengths such as resilience and social capital. Relevant domains, along with measures that assess them, are suggested below.

Mental Health

Mental health is one of the most important domains to include in psychosocial assessments and surveillance. A review of 160 samples of disaster victims found psychological symptoms to be one of six major post disaster problems. In fact, significant psychological problems were identified in 121 (77%) of those samples, with posttraumatic stress symptoms, depression, and anxiety, being most prevalently represented. More specifically, Post Traumatic Stress Disorder (PTSD) was identified in 68% of the studies, followed by depression in 36% and anxiety in 20% (Foa, Stein, & McFarlane, 2006). Therefore, in addition to the K-6 from the initial screening phase, which examines the presence of serious mental

illness, symptom scales directly addressing posttraumatic stress, depression, and anxiety should be considered. The Posttraumatic Symptom Checklist for Civilians (PCL-C), Generalized Anxiety Disorder Scale (GAD-7), and the Center of Epidemiologic Studies Depression Scale (CES-D), which are more fully reviewed in the Domains of the Screening Tool section (see page 68), are examples of brief measures for possible inclusion in the recovery phase screening tool. If the purpose is to link respondents with mental health services in the area, an additional question to consider for the mental health domain is whether the survivor would be interested in speaking with a counselor if services were offered.

Physical Health

While the purpose of mental health and psychosocial assessments is primarily to gain an understanding of psychological and social well-being, physical health can be closely related. These are often referred to as psycho-somatic complaints— when physical symptoms are caused by mental health problems. For example an individual with high levels of depression may also experience real physical symptoms of back aches, stomach aches, or lethargy. Health-related symptoms may be important to include, as they are a "component of the disaster-reactive psychopathological repertoire" (p. 966) and may also reflect, in some disasters, the effects of unsanitary conditions that follow such crises (Escobar, Canino, Rubio-Stipec & Bravo, 1992). Physical health can be measured with the Physical Health Questionnaire (PHQ), assessing symptoms such as gastrointestinal problems, headaches, sleep disturbances, and respiratory illness (see Domains of the Screening Tool section, page 68).

Aggression and Personal Conflict

Aggression, anger, hostility and personal conflict often increase following exposure to trauma (Ulrich & Wieland, 2006) and may be a domain worth including in the recovery screening tool. For example, in the psychosocial assessments following the Deepwater Horizon Gulf Oil Spill, six descriptive questions regarding anger, aggression and personal conflict (including suicidal ideation) were included. Additionally, questions regarding current suicidal ideation and plan would have to be closely monitored, and addressed, if endorsed at the time of administration by a trained and qualified individual. The World Health Organization (WHO) provides resources and guidelines for collecting any type of human health data around the world. These resources can be found on their website (WHO, 2006):

http://www.who.int/ethics/research/en/index.html

Alcohol Use

As a coping method, many individuals may increase the use of alcohol following disaster (Brymer et al., 2006; United States Department of Veterans Affairs National Center for PTSD, 2007; Vlahov et al., 2002) and individuals with a history of disordered alcohol use are at increased risk of relapse (Foa, et al., 2006). Thus, it may be useful to gauge pre- and post-disaster consumption, such as frequency and amount. A scale like the CAGE (see Domains of the Screening Tool section, page 68), a 4-item self-report scale, can also supplement these items to quickly assess for the presence of an alcohol usage problem. Depending on legality, cultural context, and common practices, assessment of differing types of harmful substance usage may be needed.

Resilience and Self-Efficacy

Resilience has shown to be a protective (Bonanno, 2004; Bonanno, Galea, Bucciarelli, & Vlahov, 2006) and mitigating factor for adverse mental health outcomes following a disaster (Osofsky, Osofsky, & Hansel, 2011). Thus, the domain of resilience may be another domain worth assessing in the recovery screening tool. The Connor-Davidson Resilience Scale is a widely used tool to capture the domain of resilience and can be shortened to include only items regarding one's ability to "adapt to change" and "bounce back from setbacks" (see Domains of the Screening Tool section for more information, page 68).

Self-efficacy, a component of resilience, has been shown to be a protective factor in terms of mental health outcomes following a disaster (Osofsky, Osofsky, & Hansel, 2011; Masten & Obravadic, 2008) and is ideal to assess as well. Additional use of questions derived from Albert Bandura's work (Bandura, 1997) may provide a complementary brief assessment of the respondent's perceived self-efficacy, a related domain that has also been shown to mediate psychological outcomes (Benight & Harper, 2002).

Quality of Life

Finally, incorporation of a culturally relevant quality of life assessment instrument is also useful, as it looks generally at the respondent's social capital, personal goals, standards, and concerns in the context of their value systems. The World Health Organization Quality of Life (WHOQOL-BREF) is an example of this type of measure. The WHOQOL-BREF assesses psychosocial areas including satisfaction with physical health, psychological health, social relationships, and the environment, and is available in multiple languages (World Health Organization, 2012).

Extended Screening – Phase 3

Surveillance should also be considered at time periods following the Recovery Screening Phase, as mental health effects are likely to change over time (FEMA, n.d.). Psychological problems may also persist over years (e.g., Havenaar et al., 1997), warranting, in some cases, resource allocation beyond that originally provided. Assessment and surveillance over time can thus provide insight into both type and duration of need.

Assessment and surveillance during the Extended Recovery Phase aim to better understand the changing psychological landscape of the affected areas. Some surveillance teams may choose to re-sample individuals that completed the assessments in the recovery phase, while others may choose to assess different individuals in the affected areas using similar sampling methods as in the recovery phase. This decision may depend on the particular questions being asked about mental health status during disaster reconstruction or recovery and/or logistical factors (i.e., funding, timing of extended programming/resource allocation). If possible, it is recommended to use the same measures from the recovery phase or used in previous assessments of the same disaster, for consistency and to increase comparability.

Psychosocial Assessment and Surveillance as an Evaluation Tool

Post-disaster psychosocial needs assessments typically seek to estimate the prevalence of mental disorders; identify vulnerable groups, mental health needs and available resources; and plan mental health and psychosocial interventions and services (Mollica et al., 2004; Parry & Kraaikamp, 2006). Evaluation with a screening tool can be used to justify needs for mental health services (formative evaluation), track progress and effectiveness of mental health services program (summative or outcome evaluation) or guide changes in program delivery as the needs of the population change (process evaluation). Evaluation of long-term outcomes and impacts of psychosocial and mental health interventions are currently limited (Parry & Kraaikamp, 2006). In this section, we illustrate how to use your psychosocial assessment and surveillance as an evaluation tool, particularly in services outcome assessment.

Outcome Evaluation

Outcome evaluation is essential in gauging the quality and effectiveness of health care and social services (Schalock, 2001). An outcome evaluation measures benefits or changes that occur in individuals as a result or consequence of the intervention or service (McNamara, 2012; Schalock, 2001; United Way of America, 1996; James Bell Associates, 2008; Myers & Barnes, 2005). An outcome evaluation can provide more information about participants' needs as well as data that can help strengthen and improve existing services (Myers & Barns, 2005; United Way of America, 1996).

Outcomes may be short, intermediate, or long term and may relate to behavior, skills, knowledge, attitudes, values, condition, or other attributes (Schalock, 2001; United Way of America, 1996). Success or positive aspects of mental health programs can be tracked by outcome indicators, which describe observable, measurable characteristics (Myers & Barnes, 2005). For example, a desired outcome for a mental health service program is to reduce participants' anxiety and depression symptoms. The number and percent of participants who demonstrate reduction of symptoms (as measured by the screening tool) are indicators of the program's performance with respect to the outcome.

Using the Screening Tool for Outcomes

As part of the overall psychosocial assessment and surveillance process, completing the initial assessment can be a convenient baseline (pre-measure/test) for individuals receiving mental health services. The initial assessment would be conducted prior to or at the beginning of service provision. Then the same screening tool would be completed by the same individual at regular intervals (e.g. every 3 or 4 months) while receiving services (WHO, 2000). The follow-up (post-measure/test) measures are then compared to the baseline measures to determine whether participants changed or improved on the outcome measure (James Bell Associates, 2008).

This is often referred to in the literature as a pre-post test design (Field, 2005; Rubin & Babbie, 2010). Pre-post test designs can determine if treatment objectives are being met, identify the type of participants who improved most or least, and determine if the improvement varies with the amount or type of treatment received (WHO, 2000). Although this design can show the stability of outcomes being achieved, an extra effort is required to maintain contact with the sample of participants being followed-up (WHO, 2000). Ideally, everyone (or as many people as possible receiving mental health services) at your agency or organization would complete the evaluation procedures. Pre-post test design is well suited as a basic evaluation tool even for treatment services or systems with limited experience or resources (World Health Organization, 2000).

For example, in a number of programs following Hurricanes Katrina and Rita and the Deepwater Horizon Gulf Oil Spill, the recovery screening tool (see Appendix A on page 92) was used to obtain information on mental health including measures for anxiety, posttraumatic stress, depression, resiliency, and quality of life for individuals impacted by the disaster. The recovery screening tool was based on the LA Spirit Specialized Crisis Counseling evaluation model following Hurricanes Katrina and Rita (Hansel et al., 2011; SCCS, 2006). The mental health measures obtained from the full screening tool were then used as baseline data for treatment of individuals referred for mental health services. Once they were in treatment, a shortened version of the full screener (the "service tool") was used to assess changes in individuals' mental health while receiving treatment. See Appendix B (page 101) for a sample of a service tool. A shortened version of the screening tool, including basic information about treatment (such as number of sessions, date of service, treatment type) and the measure, was used to reduce burden on clients because demographic and risk factors were not likely to change. While in treatment the services tool was completed as a follow-up measure, at regular intervals. The length of regular intervals depends on the length and type of treatment. During Hurricane Katrina, services were more supportive-based and a similar follow-up services tool was completed every third visit/session; for the Deepwater Horizon Gulf Oil Spill, services were more comprehensive/therapeutic, and the follow-up services tool was completed every eight to twelve weeks.

Most commonly, baseline or initial needs assessment mean/average scores are compared to the final follow-up services tool available. This can be done by a simple comparison of how many individuals receiving treatment have improved on their measure scores. For example if you have 100 clients and 75 clients improved on at least one measure, a very basic measure or program effectiveness would be to suggest a 75% success rate.

Another option would be to conduct a paired sample *t*-test. Excel by Microsoft Word provides a free data analysis add-on that will enable users to conduct the pre-post comparison (paired sample *t*-test). For more information on how to use excel for statistical purposes, please see *Elementary Data Analysis Using Excel* (Meehan & Warner, 2010). These can also be calculated by hand with instructions provided at: <u>http://simon.cs.vt.edu/SoSci/converted/T-Dist/</u>. Further explanations of *t*-tests and other statistical procedures can be found in the books *Applied Statistics for the Behavioral*

Sciences (Hinkle, Wiersma, & Jurs, 2002) and Discovering Statistics for SPSS (Field, 2005).

A more sophisticated statistical procedure which requires statistical software such as SPSS or SAS, is to conduct a repeated measures analysis of variance (ANOVA) using more of the follow-up tools (i.e. baseline vs. 2nd month follow-up, vs. 4th month follow-up vs. final 6th month follow-up). It is recommend that at least one of the surveillance team members is familiar with ANOVA or consult with a statistician to implement these statistical procedures.

The domains of the screening tool are provided to guide the basic components necessary for a comprehensive understanding of the psychosocial and mental health needs following a disaster. The components and questions used in each domain will depend largely on the timeline following disaster (see Assessment and Surveillance Timeline, page 58), culture, language, type of disaster, and purpose of the screening. The domains include: demographics, risk factors, and psychosocial. Within the psychosocial domain, there are a number of sub-domains representing mental health, physical health, aggression and personal conflict, alcohol use, resilience and selfefficacy and quality of life. You may choose to include many or some of the subdomains depending on the purpose of your assessment and surveillance. Constructing your screening tool depends on a number of factors including how many psychosocial sub-domains you choose; however, keep in mind the page limit and redundancy. Hardcopy versions of screening tools can be made using Microsoft Word or another type of word processing system. It is important to note that when using a valid measure one should not change the set of questions, wording, or response choices. Instead of making changes to the structure of a measure consider changing margin or font size to accommodate the entire measure. Font styles and sizes should be kept in common cultural norms, for English this is usually 10-12 point size readable font in Arial, Calibri, Times New Roman, Georgia, etc. Guidance for constructing screening tools during different phases following disaster can be found in the Assessment and Surveillance Timeline section (see page 58); an example of a recovery screening tool and necessary components can be found in Appendix A (page 92).

Demographic Domain

Demographics are the describing characteristics of your population of interest. These may include questions regarding age, gender, sex, marital status, race and ethnicity, highest level of education, occupation and length of employment, household size and income, and years residing in the community. These will be dependent on cultural, location, or disaster specific factors. When deciding on the content of your demographic domain, questions should be brief and understandable by the respondent. The language and syntax of each question should not exceed the minimum education or knowledge level in your population of interest. Questions should be specific and rarely include open-ended questions. For example, when asking about sex, respondents should be able to select from specific choices such as male, female, transgender, instead of writing in their own response. This will alleviate much frustration when analyzing results. It is also important to ask some type of the pre-disaster and current regional identifier, for example in the United States this is often one's zip code. Demographic examples can be found in the Assessment and Surveillance Timeline, section (see page 58) or Appendix A (page 92).

Risk Factor Domain

Risk factors are the describing characteristics that can increase one's vulnerability to negative mental health outcomes. A few risk factor examples following a disaster may include displacement, injury, or separation from friends/family. This can aid in understanding not only the experiences of your disaster survivors, but also what risk factors particular to your disaster may increase the chances of negative psychosocial adjustment and need for services. The risk factors associated with natural disasters (hurricanes, tsunamis, earthquakes, tornados) may differ from risk factors of technological disasters (oil spills, nuclear meltdown) or mass violence (Norris, Friedman, & Watson, 2002). Additionally, it is important to understand not only the current disaster effects, but also pre-disaster risk factors (Bromet & Havenaar, 2006), such as a previous traumatic experience, as this type of complex trauma can be a risk factor in and of itself. Unique risk factors associated with several types of disasters are listed below; assessments of risk can be guided by the suggestions listed in each category, but each list is not exhaustive.

Natural Disasters (Hurricane, Tornado, Tsunami, Flooding, Earthquake, Volcanic Eruption, Landslide, Wildfire or Forest Fire);

- Home destroyed
- Home damaged
- Personal injury
- Loss of business
- Loss of income
- Family member injured
- Family member killed
- Loss of personal property (other than house)
- Serious illness
- Victimized (i.e. robbed, assaulted)
- Friends/Family members house destroyed/damaged
- Friends injured
- Friends killed
- First responder

Tsunami Specific (Neuner & Schauer, 2006; Tang, 2007)

- Saw wave
- Caught by wave
- Fled from wave
- Saw people struggling for life

Earthquake Specific (Wang, Gau, Shinfuku, Zhang, Zhao, Shen, 2000)

- o Perceived level of threat to life during and immediately after the earthquake
- Level of fear of earthquake recurrence
- o Felt aftershocks

Hurricane Specific (NCTSN, 2005)

- Evacuated prior to event
- o Rescued

Technological Disasters (Oil Spill, Nuclear Disaster)

- Loss of personal or family business
- Loss of job opportunities
- Relocation
- Loss of tourism
- Loss of usual way of life
- Damage to wildlife/environment
- Personal health effects
- Health concerns about food from local sources
- Participated in recovery

Nuclear Disaster Specific (Havenaar et al., 1996; Dohrenwend et al., 1981)

- o Exposure or perceived exposure to contamination
- Evacuated during the event

Oil Spill Specific (Arata, Picou, Johnson, and McNally, 2000; Palinkas, Petterson, Russell, Downs, 1993; Picou, Marshall, Gill, 2004):

- o Forced to sell possessions to compensate for losses due to the spill
- Second job taken to compensate for loss
- Adverse effect on community
- Loss of time due to involvement in litigation
- Loss of recreation activities
- Loss of damaged property

Mass Violence (Terrorism, Community Violence, School Shooting) (DiGrande et al., 2008; Galea et al., 2002; Galea et al., 2003)

- Sustained personal injury
- Directly witnessed terrorist/violent event
- Stranded/Caught in building/location during event
- Perceived threat to life during event
- Death of friends or relatives during the event
- Evacuated home
- Relocated residence after event
- Lost job because of event
- Lost possessions or property because of event
- Involved in rescue efforts
- Involved in recovery work

Psychosocial Domain

Within the psychosocial domain there are a number of sub-domains including mental health, physical health, aggression and personal conflict, alcohol use, resilience and self-efficacy and quality of life. The sub-domains of physical health, aggression and personal conflict, and alcohol use are described in more detail in the section Assessment and Surveillance Timeline (page 58) under recovery screening. This section focuses primarily on valid measures of psychosocial sub-domains of mental health, resilience and self-efficacy and guality of life. Validated measures are important for describing psychosocial needs because they have been well tested and researched in various populations. This is often referred to as a measure having good psychometrics, standardization, reliability and validity (Rubin & Babbie, 2012). A valid measure is a set of questions asked in a specific way to confidently measure a given construct, such as depression or anxiety. Therefore, when using a valid measure, one should not change the set of questions, wording, or response choices. This will allow for increased accuracy, confidence that you are measuring what was intended, readability by the respondents, and most importantly comparability to other populations and disaster assessments that have used the same valid measure.

This toolkit provides a variety of free self-report valid measures which can be included in the screening tool as the surveillance team sees fit. For example, there are two valid measures of posttraumatic stress presented below; however, it is not necessary or advised to include both for your screening tool. Additionally, the scales presented below represent only a handful of the valid measures available, but these have been chosen for their utility, brevity, available use, and past use with disaster recovery assessments.

Mental Health Sub-Domain

General Psychological Distress.

K6. The Kessler Psychological Distress Scale (K6) was designed to screen for psychological distress in a brief format. The scale does not aim to discern specific mental diagnoses, but instead serves to identify the presence of broad mental health problems that are severe enough to cause moderate to severe impairment in social or occupational functioning. The K6, which contains six questions, can be completed within 2-3 minutes. Answers to each question range from 0 none of the time to 4 all of the time. To score the scale all items are summed to create a total score, with scores of 13 or higher indicating the possible presence of mental illness (Kessler, et al., 2003); however, this cut-off may only be valid in U.S. populations (Kessler et al., 2010). Both scales have been demonstrated to have strong psychometric properties and the ability to identify DSM-IV disorders across major sociodemographic subsamples. The K6 has been translated into Arabic, Mandarin Chinese, Dutch, French, Hebrew, Italian, Japanese, Sinhalese, Cantonese, German, Portuguese, Spanish, and Swahili, all of which can be downloaded from the National Comorbidity Survey webpage within Harvard's School of Medicine (Kessler et al., 2002). An example of the K6 can be found in Appendix A, page 97 or online at:

http://www.hcp.med.harvard.edu/ncs/k6_scales.php

Post traumatic Stress.

SPRINT. The Short PTSD Rating Interview (SPRINT) assesses the core symptoms of PTSD as well as somatic complaints, distress from stressful events, and interference in daily activities and relationships. The eight question assessment can be completed within 5-10 minutes. Item responses are rated on a 5-point scale from 0 not at all to 4 very much, with a possible maximum score of 32, indicating the worst possible symptoms. Total scores between 11 and 14 indicate the presences of posttraumatic stress, depending on intended sensitivity (Connor & Davidson, 2001). The Short Post-Traumatic Stress Rating Interview-Expanded (SPRINT-E) is a modified version of the SPRINT for use in crisis situations. It is a 12-item scale, with the first 11 items assessing for disasterrelated PTSD, depression, functional impairment, and perceived need for assistance. These 11 items are also scored on a 5-point scale, with an "intense reaction" label given to guestions answered with guite a lot or very much; respondents who report 7 or more intense reactions are considered likely to suffer from PTSD. The twelfth question assesses for suicidal thoughts and may be included in the scale as an indicator that immediate psychiatric attention is needed. SPRINT-E is preferred to SPRINT in situations where respondents' perceived need for professional mental health care should be assessed (Norris et al., 2006). SPRINT shows good psychometric properties and responsiveness to symptom changes across time periods (Connor & Davidson, 2001; Norris et al.,
2006). The scales are available in English and Korean (Kim et al., 2008). Permission to use the SPRINT can be obtained by contacting Dr. Jonathan Davidson. For more information on the SPRINT and SPRINT-E visit:

http://www.ptsd.va.gov/professional/pages/assessments/sprint.asp

PCL. The Post-Traumatic Stress Disorder Checklist (PCL) measures symptoms of PTSD from the DSM-IV. The 17 questions take about 5-10 minutes to complete. Questions ask about symptoms during the past 30 days and are rated on a 5-point response scale ranging from 1 not at all to 5 extremely. Total possible scores range from 17 to 85, with a recommended cut-off score of 50 to indicate a probable diagnosis of PTSD. The PCL has been amended slightly for use with military populations (PCL-M) including questions referring to a stressful military experience; with civilian populations (PCL-C) including questions referring to a stressful experience from the past; and for participants who may have experienced a specific stressful experience (PCL-S; Weathers, 1993). Scoring is the same for each of these versions. The PCL has shown good reliability and validity, and demonstrates sensitivity to assessing treatment outcomes. Bosnian, Chinese and Spanish languages are available, in addition to English. Information and contact details for these editions can be found at International Society for Traumatic Stress Studies webpage (www.istss.org). Use of the PCL-S, PCL-M, or PCL-C may require permission; further information is available at the National Center for PTSD (www.ptsd.va.gov). An example of the PCL-C can be found in Appendix A, page 96 or online at:

http://www.mirecc.va.gov/docs/visn6/3_PTSD_CheckList_and_Scoring.pdf

Depression.

CES-D. The Center for Epidemiologic Studies Depression Scale (CES-D) measures frequency and severity of depressive symptoms experienced by the respondent. The original 20-item CES-D was shortened, creating the 10-item CES-D. The 10-item scale takes approximately 5 minutes to complete, with respondents answering questions about their experiences during the past week on a response scale from 0 *rarely or none of the time* to 3 *most of the time*. Both scales have good reliability and validity, but the 10-item scale has higher feasibility due to its length (Kim et al, 2011; Nishiyama et al, 2009). The CES-D has been translated into 50 different languages and the scales tend to have good psychometric properties (Nezu, Nezu, McClure, & Zwick, 2002); however, researchers are warned to use caution in the interpretation of results and cut-off points due to item response bias among different ethnic groups and cultures (Mui, Kang, Chen, & Domanski, 2003). An example of the CES-D can be found in Appendix A, page 97. The CES-D is widely and freely available on the internet; the CESD-R can be accessed at the CESD-R webpage:

http://cesd-r.com/

Anxiety.

GAD-7. The Generalized Anxiety Disorder Scale (GAD-7) effectively measures anxiety symptoms in the general population and is helpful in monitoring symptom severity across time (Löwe et al. 2008). Frequency of anxiety symptoms are assessed through 7 questions, each on a scale from 0 not at all to 3 nearly every day, with total scores of 5, 10, and 15 are taken as the cut off points for mild, moderate, and severe anxiety, respectively. When used as a screening tool, further evaluation is recommended when the score is 10 or greater (Spitzer, Kroenke, Williams, Löwe, 2006). The GAD-7 has good reliability and validity (Löwe et al, 2008). A brief version, the GAD-2, was created as a shorter version of the measure, incorporating the first 2 questions. The GAD-7 has also been translated into Arabic Afrikaans, Bulgarian, Cebuano, Chinese, Croatian, Czech, Danish, Dutch, Filipino, Finnish, French, German, Greek, Gujarati, Hebrew, Hindi, Hungarian, Indonesian, Italian, Kannada, Korean, Lithuanian, Malay, Malayalam, Marathi, Norwegian, Polish, Portuguese, Punjabi, Romanian, Russian, Slovakian, Spanish, Swedish, Tamil, Telugu, Thai, Turkish, Ukrainian, and Urdu. Versions of these translations are available on the Patient Health Questionnaire webpage (www.phgscreeners.com) and require no permissions to use, reproduce, or distribute; however, few of these languages other than English have been psychometrically validated. An example of the GAD-7 can be found in Appendix A, page 96 or online at:

www.phqscreeners.com

Resilience and Self-Efficacy Sub-Domain

CD-RISC. The Connor-Davidson Resilience Scale (CD-RISC) measures the multidimensional characteristics of resilience. The 25 questions assess characteristics of resilience during the past month on a 5-point response scale, from 0 not true at all to 4 true nearly all the time with higher total scores indicating greater resilience (Connor & Davidson, 2003). The original CD-RISC has been abbreviated and simplified to a 10-item version (Campbell-Sills & Stein, 2007) and a 2-question version (Vaishnavi, Connor, Davidson, 2007), The 25 question scale can be completed in about 5-10 minutes: the 10 and 2 question scales can be completed in about 1-5 minutes. All three versions have sound psychometric properties and have been found to have sensitivity when evaluating treatment outcomes. CD-RISC has been translated into many languages, each of which has been demonstrated to have good reliability and validity: Afrikaans, Arabic, Bahasa Indonesian, Chinese, Dutch, Farsi, Finnish, French, German, Hindi, Italian, Japanese, Kiswahili, Korean, Norwegian, Portuguese, Quechua, Russian, Serbian, Spanish, Turkish, and Urdu. These translations and guidelines for obtaining permission to use the CD-RISC can be found on the Connor-Davidson Resilience Scale webpage (www.connordavidson-resiliencescale.com). An

example of the CD-RISC 2 item version can be found in Appendix A, page 99 or online at:

www.connordavidson-resiliencescale.com

Quality of Life Sub-Domain

WHOQOL-BREF. World Health Organization Quality of Life assessment (WHOQOL-100) is a cross-culturally valid assessment of general well-being. WHOQOL-BREF is a brief measure including 26 questions extracted from the original WHOQOL which can be used when there are time limitations and when quality of life is only one of several sub-domains being measured. Each item is answered on a 5-point response scale from 0 *not at all* to 4 *completely* and can be completed in as little as 5 minutes. The WHOQOL-BREF assesses respondents' satisfaction of their position in life across four constructs relevant to quality of life: Physical, Psychological, Social Relationships & Environment (WHOQOL Group, 1998). WHOQOL-BREF has good variability and reliability; it also performs well as a cross-cultural assessment (Skevington, Lotfy, O'Connell, 2003). WHOQOL is available in most of the world's major languages, and many of the versions as well as scoring directions can be found on the World Health Organization's webpage (http://www.who.int). An example of the WHOQOL-BREF can be found in Appendix A, pages 99-100, or online at:

http://www.who.int

Special Considerations for Children and Adolescents in Psychosocial Assessment and Surveillance

Many of the psychosocial assessment procedures outlined in Disaster-PAST, can also apply to children and adolescents (survivors under the age of 18). Child and adolescent survivors often do not receive enough attention in the disaster recovery process (Masten & Osofsky, 2010); however, there is a growing body of literature and research on the post disaster needs of working with this special population (La Greca, Silverman, Vernberg, & Roberts, 2002; Masten & Obradovic, 2008; Osofsky, Osofsky, & Harris, 2007; Sagi-Schwarz, Seginer, & Abdeen, 2008). Psychosocial assessment and surveillance procedures with younger populations are important, given that their mental health needs may differ from adult populations.

Unlike adult populations, child and adolescent populations are often easier to locate due to the concentration of this population in school settings. A primary concern for schools in disaster recovery zones and schools receiving a high number of displaced students is often the mental health needs of their student population. Schools are also frequently called upon in disaster recovery situations to provide mental health services, due to the natural fostering of supportive relationships through classmates, teachers, and school staff interactions (LaGreca, Vernberg, & Silverman, 1996; Pina et al., 2008). For these reasons, it is recommended to collaborate with schools if identifying child and adolescent mental health needs is part of your assessment and surveillance purpose. Collaboration with school systems will allow the surveillance team insight into developing the surveillance tool and the appropriate level of readability, difficulty level, and length that their students can complete. Given that child and adolescents are defined as a vulnerable population, special consideration should be paid to ethical and privacy practices when assessing this population (see Ethics and Privacy in Psychosocial Assessments section, page 26).

The domains of the screening tool will be the same for child and adolescent respondents; these include demographic, risk factors, and psychosocial domains. What will change is the content and question style for each domain. An example of a screening tool used following Hurricanes Katrina and Rita is provided in Appendix C, page 105.

Child and Adolescent Measures

A major difference between adult and child/adolescent screening tools are the measures. Given that the adult measures are developed, validated and standardized on adult populations, it is important to select appropriate measures that were developed, validated and/or standardized on child and adolescent populations. This is important to aid in readability and comprehension for younger populations.

Assessment and Referral Tool

NCTSN Hurricane Referral Tool. The National Child Traumatic Stress Network (NCTSN) Assessment and Referral Tool was developed for use following the September 11, 2001 Attacks on the World Trade Center in New York (NCTSN, 2002). It was modified as the NCTSN Hurricane Referral Tool following hurricanes in Florida and in the Gulf Coast region to assist front line workers in evaluating children and adolescents after hurricane exposure (NCTSN, 2005). It includes an assessment of risk categories of exposure, nature and severity of post-hurricane reactions and behavior. The NCTSN Hurricane Referral Tool is a self report for children in grades 4 through 12 (approximately ages 10 to 18) and parent report for school children in Pre-Kindergarten through 3rd grades (approximately up to age 9). The post-hurricane reactions and behavior index consists of 22 question for the child self report version and an additional 7 questions specifically for parents of young children. The questions are based on the UCLA PTSD Reaction Index and include a number of depressive symptoms. Responses for each question are scored on a 5 point Likert scale where, 0 =None, 1 = Little, 2 = Some, 3 = Much, 4 = Most. One point is given for each response of 3 or 4 and total scores of 4 or more suggest the need for mental health referral.

http://www.nctsnet.org/nctsn_assets/pdfs/intervention_manuals/referraltool.pdf

Depression

CES-DC. The Center for Epidemiological Studies Depression Scale for Children (CES-DC) is a 20-question self-report depression inventory for children and adolescents age 6 to 17. Each response to a question is scored as: 0 = Not At *All*; 1 = A Little; 2 = Some; 3 = A Lot, with a possible total score that can range from 0 to 60. It is important to note that questions 4, 8, 12, and 16 are phrased positively, and should be scored in the opposite order: 3 = Not At All; 2 = A Little; 1 = Some; 0 = A Lot. Higher CES-DC scores indicate increasing levels of depression and a cut-off score of 15 suggests the presence of significant levels of depressive symptoms (Weissman, Oryaschel, & Padian, 1980). There are English and Spanish versions of the CES-DC and the scales have shown good reliability and validity.

http://www.brightfutures.org/mentalhealth/pdf/professionals/bridges/ces_dc.pdf

http://www.edwardpierce.net/super/CES_D.htm

PTSD

UCLA-RI. The University of California at Los Angeles Posttraumatic Stress Disorder Reaction Index (UCLA-RI) is one of the most widely used instruments for the assessment of traumatized children and adolescents (Steinberg, Brymer, Decker, & Pynoos, 2004). It has been used around the world after major disasters and catastrophic violence as an integral component of public mental health response and recovery programs.

There are three versions: child, adolescent and parent's report. The test takes around 20-30 minutes to complete depending on age, reading ability and method of administration. The UCLA-RI has demonstrated good reliability and validity in both English and Spanish versions.

There is a score sheet available for the UCLA-RI which provides instructions for calculating a total PTSD severity score, and severity scores for each of the DSM-IV B, C, and D symptom clusters. A cut-off of 38 or greater on the total PTSD score, for a single traumatic event, has the greatest sensitivity and specificity for detecting posttraumatic stress symptoms (Rodriguez, Steinberg, Saltzman & Pynoos, 2001a, 2001b).

http://kb.nctsn.org/SPT/SPT--FullRecord.php?ResourceId=295

www.irct.org

Anxiety

SCARED. The Self-Report for Childhood Anxiety Related Disorders (SCARED) screens children and adolescents age 8 to 18 for anxiety disorders. The SCARED has both child and parent report versions and both versions contain 41 questions that measure five factors: general anxiety, separation anxiety, social phobia, school phobia, and physical symptoms of anxiety. Severity of symptoms for the past three months is rated using a 0 to 2-point Likert rating scale with 0 meaning *not true or hardly ever true*, 1 meaning *sometimes true*, and 2 meaning *true or often true*. A total score of 25 or higher may indicate significant anxiety symptoms; scores higher than 30 have more specificity. The SCARED is available in Arabic, Chinese, English, French, German, Italian, Portuguese, Spanish, and has shown good reliability and validity (Birmaher et al., 1999).

http://psychiatry.pitt.edu/sites/default/files/Documents/assessments/SCARED%2 0Child.pdf

Example: Mental Health Assessment for Children and Adolescents Following Hurricane Katrina

Immediately following Hurricanes Katrina and Rita in 2005, through Louisiana state and local recovery meetings, it became apparent that there was the great concern for young survivors. In partnership with local school systems, the Louisiana State University Health Sciences Center (LSUHSC) Department of Psychiatry began conducting psychosocial assessments to better understand the mental health needs of children and adolescents affected by the hurricanes.

Schools administered a modified National Child Traumatic Stress Network (NCTSN) Hurricane Assessment and Referral Tool (NCTSN, 2005). Input was obtained from national experts, school administrators, parents and students to ensure relevance and cultural sensitivity. Students were assessed each school year for mental health needs beginning immediately after Hurricane Katrina (2005) and continuing to the most recent school year. The assessment was administered confidentially, but not anonymously, so that it was possible to report back to the schools and follow-up with students who scored above the cut-off for mental health symptoms as well as those students who requested a meeting with a counselor. The results from the assessment were used to help identify students who were having difficulties and required evaluation for mental health services as well as to provide culturally sensitive trauma informed services. Students were given the opportunity to refuse participation on all or parts of the assessment at their discretion.

Over 25,000 assessments have been collected in southeastern Louisiana and 45% met the cut-off in 2005, 37% met the cut-off in 2006, 30% met the cut-off in 2007, 33% met the cut-off in 2008 and 28% met the cut-off in 2009. Analyses are currently being conducted on the 2010 and 2011 data to assess the impact of the Deepwater Horizon Oil Spill. Reports, including compilations of students' responses, were given to the schools in order to provide them with more information about student's concerns in an effort to improve services and enhance the school environment. Based on these reports many schools were able to secure funding for additional mental health services and all children meeting cut-off or requesting services received a brief follow-up evaluation. Results from the assessments have also been used to improve understanding of child and adolescent hurricane survivors (Kronenberg et al., 2010; Osofsky, Osofsky, Kronenberg, Brennan & Hansel, 2009).

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Appendix A

Screening Tool Example

DWH Deepwater Horizon Event Psychosocial Needs Assessment

You have been selected to participate in a needs assessment on people living in parishes affected by the recent oil spill. The needs assessment will be conducted by the Louisiana State University Health Sciences Center (LSUHSC) Department of Psychiatry in partnership with the Louisiana Department of Social Services.

The needs assessment will help us understand the current needs of people in these communities and how we can direct both state and federal assistance to the well-being

of community members.

Today you will be participating in an interview, which should take 20-30 minutes. Participation is voluntary and there will be no reimbursement. **If you do not wish to participate, you may stop at any time. Responses will be confidential and your name will not appear on any reports.** Data will be stored in a secured location and all identifying information will be removed. There are minimal risks associated with this assessment, which may include psychological distress. You may stop at anytime during the assessment. Benefits may include improved and informed mental health services to the communities affected by the oil spill. Taking part in this assessment is your agreement to participate.

Thank you for agreeing to participate in the Deepwater Horizon Event Psychosocial Needs Assessment.

If you would like a copy of this letter for your records, please give me your email address and I will email you a copy. If you have any questions regarding this assessment please contact, Howard Osofsky, (504) 568-6004 at 1542 Tulane Avenue, 2nd Floor, New Orleans, LA 70112. Thank you again for your help.



	SECTION A: TELL US ABOUT YOURSELF								
A1.	How old are you?		18-21 〇	22- C		26-30 〇	31-35 O	36-40 〇	41 + O
A2.	What is your marita	I status?	Married	Ν	lever m O	arried	Divorced	Separated	Widowed
A3.	Are you living with	someone i O No	n a marria	ge-l	ike rel	ationsh	hip? (If marrie	ed, answer "	No".)
A4.	Are you male or fen	nale?		0	Male	O F	emale		
A5.	Are you Spanish/Hispanic/Latino?				Yes	O N	lo, not Spanish,	/Hispanic/Lati	no
A6.	What is your race? (Mark all that apply.) White Asian (e.g., Chinese, Filipino, Indian) Black or African American American Indian or Alaskan Native Other (Please specify) 								
Α7.	What is the highest level of education you completed? Some education but no diploma or GED Post-HS technical certificate or degree (e.g. EMT) GED or equivalent 2-year college Associate Degree High school diploma 4-year college degree (BA, BS, or equivalent) Some post-HS education, but no certificate or degree Graduate or professional study					-			
A8.	 What is your occupation/employment st Management, Business, Sales and Finance Community and Social Service Education, Training, and Library Healthcare Personal Care and Service Military Hospitality and Tourism Seafood Related Industry Construction and Maintenance Disability/ SSI recipient Other (<i>Please specify</i>) 				Food F Cleanin Transp Office Farmin Fishing Oil/dri Home	ng and M portation and Adm ng and Fc g lling Supp maker	on and Service laintenance and Moving inistrative Supp prestry port Industry ot currently em		
A9.	How many years ha Less than 1 year	1-5 years	en in the o 6-10 years	ccuț	-	/employ 11-20 years	yment status 21-30 years O) More	i n A8? e than 30 years 〇
A10.	Is the occupation/e		nt status yo	ou re	eporte	d in A8	, your occup	ation of ch	bice?
	🔿 Yes	🔿 No							
A11.	If no to A10, what ((Please sp		pation wou	ıld y	ou pre	efer?			

A12. What was your annual income for 2009?

- \$61,000-\$80,000 Under \$20,000 \bigcirc
- \$21,000-\$40,000
- \$41,000-\$60,000
- \$81,000-\$100,000
 - More than \$100,000 \bigcirc

A13. How many years have you and your family lived in South Louisiana?

Less than 1	1-5	6-10	11-20	21-30	More than 30
year	years	years	years	years	years
Õ	Ó	0	0	0	0

A14. Please indicate any of the following you experienced as a result of the recent hurricanes (i.e. Katrina, Rita, Gustav, Ike): (Check all that apply)

		Yes	No			Yes	No	
a.	House Destroyed	0	0	h.	Loss of personal property other than house	0	0	
b.	House Damaged	0	0	i.	Became seriously ill	0	0	
c.	Injured	0	0	j.	Victimized (i.e. robbed, physically assaulted)	0	0	
d.	Loss of Business	0	0	k.	Friends/Family Members House Destroyed/Damaged	0	0	
e.	Loss of Income	0	0	١.	Friends Injured	0	0	
f.	Family Members Injured	0	0	m.	Friends Killed	0	0	
g.	Family Members Killed	0	0	n.	First Responder	0	0	

A15. What concerns do you have about the impact of this oil spill (Check all that apply)?

		Yes	No			Yes	No
a.	Loss of personal or family business	0	0	f.	Damage to wildlife and the natural environment	0	0
b.	Loss of job opportunities	0	0	g.	Health concerns about food sources from local waters	0	0
c.	Needing to relocate	0	0	h.	Personal health effects	0	0
d.	Loss of tourism	0	0	i.	Other concerns	0	0
e.	Loss of usual way of life	0	0	j.	Participated in recovery	0	0

A16. Did you apply for financial assistance from BP following the oil spill? O Yes No О

A17. If yes to A13, have you received all of your financial assistance yet? O Yes Ο No

A18. Using a 0 - 4 scale where 0 represents "not at all" and 4 represents "extremely"; please mark ONE circle for each scale...

	Not at all	Mildly	Moderately	Markedly	Extremely			
	0	1	2	3	4			
 The oil spill has disrupted your work*/school work: 	0	0	0	0	0			
	* Work includes paid, unpaid volunteer work or training							
	0		orked /studied at a ated to the oil spill.	ll during the p	ast week for			
The oil spill has disrupted your social life/leisure activities:	0	0	0	0	0			
The oil spill has disrupted your family life / home responsibilities:	0	0	0	0	0			

Adapted from the Sheehan Disability Scales

SECTION B: YOUR MENTAL HEALTH

B1. Below is a list of problems and complaints that people sometimes have in response to stressful experiences. Please read each one carefully, then check how much you have been bothered by that problem <u>past 30 days</u>.

		Not at all	A little bit	Moderately	Quite a bit	Extremely
1.	Repeated, disturbing memories, thoughts, or images?	0	0	0	0	0
2.	Repeated, disturbing dreams?	0	0	0	0	0
3.	Suddenly acting or feeling as if events were happening again (as if you were reliving it)?	0	0	0	0	0
4.	Feeling very upset when something reminded you of events or an incident?	0	0	0	0	0
5.	Having physical reactions (e.g. heart pounding, trouble breathing, sweating) when something reminded you of the event?	0	0	0	0	0
6.	Avoiding thinking about or talking about an incident or avoiding having feelings related to the incident?	0	0	0	0	0
7.	Avoiding activities or situations because they reminded you of an incident?	0	0	0	0	0
8.	Trouble remembering parts of the incident?	0	0	0	0	0
9.	Loss of interest in activities that you used to enjoy?	0	0	0	0	0
10.	Feeling distant or cut off from other people?	0	0	0	0	0
11.	Feeling emotionally numb or being unable to have loving feelings for those close to you?	0	0	0	0	0
12.	Feeling as if your future somehow will be cut short?	0	0	0	0	0
13.	Trouble falling or staying asleep?	0	0	0	0	0
14.	Feeling irritable or having angry outbursts?	0	0	0	0	0
15.	Having difficulty concentrating?	0	0	0	0	0
16.	Being "super-alert" or watchful or on guard?	0	0	0	0	0
17.	Feeling jumpy or easily startled?	0	0	0	0	0

Posttraumatic Stress Checklist (PCL-C)

B2. How often in the past 30 days, have you been bothered by the following problems?

	Not at all	Several days	Over half the days	Nearly everyday
1. Feeling nervous, anxious, or on edge	0	Ŏ	0	Ŏ
2. Not being able to stop or control worrying	0	0	0	0
3. Worrying too much about different things	0	0	0	0
4. Trouble relaxing	0	0	0	0
5. Being so restless that it's hard to sit still	0	0	0	0
6. Becoming easily annoyed or irritable	0	0	0	0
7. Feeling afraid as if something awful might happen	0	0	0	0

Generalized Anxiety Disorder Scale (GAD-7)

B3. During the past 30 days, how often did you feel...

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
1nervous?	0	0	0	0	0
2hopeless?	0	0	0	0	0
3restless or fidgety?	0	0	0	0	0
4so depressed that nothing could cheer you up?	0	0	0	0	0
5that everything was an effort?	0	0	0	0	0
6worthless?	0	0	0	0	0

K-6

Rarely Some Occasionally Most B4. During the past week... or none of or a little or a moderate of the time of the time amount of the the time (< 1 day)(1-2 days) time (3-4 days) (5-7 days) 1. I was bothered by things that usually don't bother me. Ο Ο Ο Ο 2. I had trouble keeping my mind on what I was doing. Ο Ο Ο Ο 3. I felt depressed. Ο Ο Ο Ο 4. I felt everything I did was an effort. Ο Ο Ο Ο 5. I felt hopeless about the future. Ο Ο Ο Ο 6. I felt fearful. Ο Ο Ο Ο 7. My sleep was restless. Ο Ο Ο Ο 8. I was unhappy. Ο Ο Ο Ο 9. I felt lonely. Ο Ο Ο Ο 10. I could not get "going." Ο Ο Ο Ο

Center for Epidemiologic Studies Depression Scale (CES-D)

SECTION C: Anger and Personal Conflict

C1. How often in the <u>past 30 days</u>, did you have attacks of anger when all of a sudden you lost control and...

		Every/ nearly every day	3-4 days/ week	1-2 days/ week	<1 day/ week	Never
1.	yelled, insulted, or swore at someone?	0	0	0	0	0
2.	broke or smashed something worth more than a few dollars?	0	0	0	0	0
3.	hit or tried to hurt someone?	0	0	0	0	0
4.	threatened to hit or hurt someone but didn't do it?	0	0	0	0	0

C2. Do you <u>CURRENTLY</u> have...

	Yes	Νο
1thoughts of killing yourself?	0	0
2a plan of how to kill yourself (e.g., exactly how, where, and when)?	0	0

SECTION D: Physical Health

D1. How often in the past 30 days have you had each of the following health problems?

		Not bothered at all	Bothered a little	Bothered a lot
1.	Stomach pain	0	0	0
2.	Back pain	0	0	0
3.	Pain in your arms, legs, or joints (knees, hips, etc.)	0	0	0
4.	Menstrual cramps or problems with periods (Women only)	0	0	0
5.	Headaches	0	0	0
6.	Chest pain	0	0	0
7.	Dizziness	0	0	0
8.	Fainting spells	0	0	0
9.	Feeling your heart pound or race	0	0	0
10.	Shortness of breath	0	0	0
11.	Pain or problems during sexual intercourse	0	0	0
12.	Constipation, loose bowels or diarrhea	0	0	0
13.	Nausea, gas, or indigestion	0	0	0
14.	Feeling tired out or low in energy	0	0	0
15.	Trouble sleeping	0	0	0

Patient Health Questionnaire (PHQ)

	SECTION E: Alc					
E1	. <u>Prior to the oil spill</u> , when you drank alcohol	Never	Several times per year	Monthly	Weekly	Daily
1.	how often did you drink?	0	0	0	0	0
2.	how many drinks did you consume in one setting? (1 drink = one 12 oz. beer, 1 glass of wine, 1 shot/cockta		drinks			
E2	. <u>Currently</u> , when you drink alcohol	Never	Several times per year	Monthly	Weekly	Daily
1.	how often do you drink?	0	0	0	0	0
2.	how many drinks do you consume in one setting? (1 drink = one 12 oz. beer, 1 glass of wine, 1 shot/cockta	ail)			drinks	
E3	. In the <u>past 30 days</u>			Yes		No
1.	Have you ever felt you should cut down on your drinking	?		0		0
2.	Have you ever been annoyed when people have commen	ted on	your drinking?	0		0
3.	Have you ever felt guilty or badly about your drinking?	0		0		
4.	Have you ever had an eye opener first thing in the morni nerves or get rid of a hangover?	ng to s	teady your	0		0

SECTION F: Resilience and Self Efficacy

F1. The next questions are about your ability to handle stress. How true are the following statements?

	Not true	Rarely true	Sometimes true	Often True	True nearly all of the time
a. are you able to adapt to change?	0	0	0	0	0
b. do you tend to bounce back from setbacks?	0	0	0	0	0

Adapted from the Connor-Davidson Resilience Scale

F2. Rate your degree of confidence by circling a number from 0 to 100 using the scale below:

Ca	0 nnot do at all	10	20	30	40	5 Moderate	-	n do	60	70	D	80	90	Highl	10 y Cert)0 tain ca	an do
											Conf	idenc	e (0-10)0)			
1.	Keep tough	problen	ns from	getting	g you d	own	0	10	20	30	40	50	60	70	80	90	100
2.	Bounce back	after yo	u tried y	our best	t and fai	led	0	10	20	30	40	50	60	70	80	90	100
3.	Get yoursel really bad	f to kee	o tryin <u>c</u>	y when	things a	are going	0	10	20	30	40	50	60	70	80	90	100
4.	Keep up you	ur spirit	s when	you su	ffer har	dships	0	10	20	30	40	50	60	70	80	90	100
5.	Keep from b	peing ea	sily rat	tled			0	10	20	30	40	50	60	70	80	90	100
6.	Overcome of seems to we		gement	when	nothing	you try	0	10	20	30	40	50	60	70	80	90	100

Provided by Al Bandura

SECTION G: Quality of Life

G1. Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the <u>past 30 days</u>.

	Very poor	Poor	Neither poor nor good	Good	Very good
1. How would you rate your quality of life?	0	0	0	0	0
	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2. How satisfied are you with your health?	0	0	0	0	0
The following questions ask about how much	you have exp Not at all	erienced cer A little	r <mark>tain things in</mark> A moderate amount	the <u>past :</u> Very much	30 days. Extremely
3. To what extent do you feel that physical pain prevents you from doing what you need to?	0	0	0	0	0
4. How much do you need any medical treatment to function in your daily life?	0	0	0	0	0
5. How much do you enjoy life?	0	0	0	0	0
6. To what extent do you feel your life to be meaningful?	0	0	0	0	0
7. How well are you able to concentrate?	0	0	0	0	0
8. How safe do you feel in your daily life?	0	0	0	0	0
9. How healthy is your physical environment?	0	0	0	0	0

The following questions ask about how completely you experience or were able to do certain things in the past 30 days.

	Not at all	A little	Moderately	Mostly	Completely
10. Do you have enough energy for everyday life?	0	0	0	0	0
11. Are you able to accept your bodily appearance?	0	0	0	0	0
12. Have you enough money to meet your needs?	0	0	0	0	0
13. How available to you is the information that you need in your day-to-day life?	0	0	0	0	0
14. To what extent do you have the opportunity for leisure activities?	0	0	0	0	0

The following questions ask about how completely you experience or were able to do certain things in the past 30 days.

	Very poor	Poor	Neither poor nor good	Good	Very good
15. How well are you able to get around?	0	0	0	0	0
	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
16. How satisfied are you with your sleep?			ulocullonou		
17. How satisfied are you with your ability to perform your daily living activities?	0	0	0	0	0
18. How satisfied are you with your capacity for work?	0	0	0	0	0
19. How satisfied are you with yourself?	0	0	0	0	0
20. How satisfied are you with your personal relationships?	0	0	0	0	0
21. How satisfied are you with your sex life?	0	0	0	0	0
22. How satisfied are you with the support you get from your friends?	0	0	0	0	0
23. How satisfied are you with the conditions of your living place?	0	0	0	0	0
24. How satisfied are you with your access to health services?	0	0	0	0	0
25. How satisfied are you with your transport?	0	0	0	0	0
	Never	Seldom	Quite often	Very often	Always
26. How often do you have negative feelings such as blue mood, despair, anxiety, depression?	0	0	0	0	0

World Health Organization Quality of Life (WHOQOL - BREF)

Thank you for your participation!

Are you willing to be contacted again for additional information?

🔿 Yes 🔿 No

Would you like to be sent a copy of the report?

O Yes O No

Appendix B

Evaluation and Services Tool Example

	Today's Date:
DWH	
Deepwater Horizon Event Services Interview	Month Day Year

The following questions are in regards to your well being and will be used to assess service implementation. The data related to this evaluation are available to sponsoring agencies. Responses will be confidential and your name will not appear on any reports. Data will be stored in a secured location and all identifying information will be removed.

Name:						_ F	Phor	ne:						
Birth date: Month]— Day]-[vider	Year GO T	-	GE 2	Coc	-) W					
				r										
Provider Name:														
Date of Last Interv	iew:	Mont	 h	- Day		_	Y	ear						
Session Number:	8 9 〇 〇	10 O	11 O	12 O	16 0			1 8 0	19 〇	20 〇	24 〇	25 〇	26 〇	27 〇
Other N	Number o	f Sess	sions	0		(1	Pleas	se sp	ecif	y)				
Is this the last sess	sion? (i.e.	treatr	nent	closur	e, ter	minat	ion,	refe	rral)) () Ye	es () No	
Please mark the nu	mber and	l type	of s	ervice	es ree	ceive	d sin	ice	date	e of la	ast int	erviev		_
Туре	•	0	1 2	2 3	4	56	7	8	9	10	11	12	Provi but unkne	#
Counseling Group Treatmo Family Therap Psychotherapy Psychiatric Se Medication Ma	y / rvices	0 0 0 0 0 0 0		0 0			0000000	000000	000000	000000	000000	000000		

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Referral

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Below is a list of questions regarding your problems, complaints, feelings and self confidence. Please read each question carefully.

Please check how much you have been bothered the following problems in the past 30 days.

	Not at all	A little bit	Moderately	Quite a bit	Extremely
18. Repeated, disturbing memories, thoughts, or images?	0	0	0	0	0
19. Repeated, disturbing dreams?	0	0	0	0	0
20. Suddenly acting or feeling as if events were happening again (as if you were reliving it)?	0	0	0	0	0
21. Feeling very upset when something reminded you of events or an incident?	0	0	0	0	0
22. Having physical reactions (e.g. heart pounding, trouble breathing, sweating) when something reminded you of the event?	0	0	0	0	0
23. Avoiding thinking about or talking about an incident or avoiding having feelings related to the incident?	0	0	0	0	0
24. Avoiding activities or situations because they reminded you of an incident?	0	0	0	0	0
25. Trouble remembering parts of the incident?	0	0	0	0	0
26. Loss of interest in activities that you used to enjoy?	0	0	0	0	0
27. Feeling distant or cut off from other people?	0	0	0	0	0
28. Feeling emotionally numb or being unable to have loving feelings for those close to you?	0	0	0	0	0
29. Feeling as if your future somehow will be cut short?	0	0	0	0	0
30. Trouble falling or staying asleep?	0	0	0	0	0
31. Feeling irritable or having angry outbursts?	0	0	0	0	0
32. Having difficulty concentrating?	0	0	0	0	0
33. Being "super-alert" or watchful or on guard?	0	0	0	0	0
34. Feeling jumpy or easily startled?	0	0	0	0	0

Posttraumatic Stress Checklist (PCL-C)

During the past 30 days, how often did you feel

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
7nervous?	0	0	0	0	0
8hopeless?	0	0	0	0	0
9restless or fidgety?	0	0	0	0	0
10so depressed that nothing could cheer you up?	0	0	0	0	0
11that everything was an effort?	0	0	0	0	0
12worthless?	0	0	0	0	0

How often in the past 30 days, have you been bothered by the following problems?

	Not at all	Several days	Over half the days	Nearly everyday
8. Feeling nervous, anxious, or on edge	0	Ŏ	Ó	Ŏ
9. Not being able to stop or control worrying	0	0	0	0
10. Worrying too much about different things	0	0	0	0
11. Trouble relaxing	0	0	0	0
12. Being so restless that it's hard to sit still	0	0	0	0
13. Becoming easily annoyed or irritable	0	0	0	0
14. Feeling afraid as if something awful might happen	0	0	0	0

Generalized Anxiety Disorder Scale (GAD-7)

During the <u>past week</u>	Rarely or none of the time (< 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of the time (3-4 days)	Most of the time (5-7 days)
11. I was bothered by things that usually don't bother me.	0	0	0	0
12. I had trouble keeping my mind on what I was doing.	0	0	0	0
13. I felt depressed.	0	0	0	0
14. I felt everything I did was an effort.	0	0	0	0
15. I felt hopeless about the future.	0	0	0	0
16. I felt fearful.	0	0	0	0
17. My sleep was restless.	0	0	0	0
18. I was unhappy.	0	0	0	0
19. I felt lonely.	0	0	0	0
20. I could not get "going."	0	0	0	0

Center for Epidemiologic Studies Depression Scale (CES-D)

Rate your degree of confidence by circling a number from 0 to 100 using the scale below:

0 Cannot do at all	10	20	30	40	5 Moderate	-	n do	60	7(D	80	90	High	10 ly Cert		an do
										Conf	idenc	e (0-10	00)			
7. Keep tough	probler	ns from	gettin	g you d	own	0	10	20	30	40	50	60	70	80	90	100
8. Bounce back	after yo	u tried y	our bes	t and fai	led	0	10	20	30	40	50	60	70	80	90	100
9. Get yoursel really bad	f to kee	p trying	g when	things a	are going	0	10	20	30	40	50	60	70	80	90	100
10. Keep up yo	ur spirit	s when	you su	ffer har	dships	0	10	20	30	40	50	60	70	80	90	100
11. Keep from I	being ea	asily rat	tled			0	10	20	30	40	50	60	70	80	90	100
12. Overcome o seems to w		gemen	t when	nothing	you try	0	10	20	30	40	50	60	70	80	90	100

Provided by Al Bandura

Appendix C

Child and Adolescent Screening Tool Example

LSUHSC DEPARTMENT OF PSYCHIATRY & LOUISIANA RURAL TRAUMA SERVICES CENTER DISASTER INTERVIEW

Modification of NCTSN Assessment and Referral Tool for Children and Adolescents

Self Report for Grades 4 through 12

Nan	ne:			Date:			
Date of Birth:				Age:			
Ger	nder:	Male	_ Female				
1.	Who do you	currently live with? (pl	ease check al	l that apply)			
		Mother		Other adult(s)			
		Father		By myself			
		Grandparent(s)		Friends your own age			
		Other adult relative(s)				
2.	Where are you living now? (please check all that apply)						
		Relative's house		Tent			
		Friend's house		Apartment			
		My house		A new house			
		Other (please describ	be):				
3.	Were you inj	ured during the hurrica	ane/flood/evad	cuation?	Yes	No	
4.		embers of your family i od/evacuation?	njured during	the	Yes	No	
	4a. Who w	vas injured? (please cl	heck all that a	pply)			
		Mother		Friend			
		Father		Other adult relative			
		Grandparent		Other adult			
5.	Did any of your family members/friends die because of the earthquake/				Yes _	No	
	5a. Who w						
		Mother		Friend			
		Father		Other adult relative			
		Grandparent		Other adult			
6.	Did you see	Did you see anyone get injured during the hurricane/flood/evacuation?				No	
7.	Did you help	Did you help rescue people during the hurricane/flood/evacuation?			Yes _	No	
8.	Did any of your relatives rescue people during the hurricane/flood/evacuation?			Yes	No		
9.		e to leave your pet beh od/evacuation?	ind during the	9	Yes	No	
	9a. If yes,	were you able to find	your pet?		Yes _	No	
10	Did you lose	any clothes or toys be	cause of flood	ding at your house?	Yes _	No	

			107
11	Was your home damaged because of the hurricane/flood/evacuation?	Yes	No
12	Was your home destroyed because of the hurricane/flood/evacuation?	Yes	No
13	Did you see your neighborhood destroyed or badly damaged?	Yes	No
14	Did you see other areas destroyed or badly damaged?	Yes	No
15	Have you been back to your community since the earthquake/ tsunami?	Yes	_ No
16	How many schools have you attended since the hurricane/flood/evacuation?		
17	Did you have to change schools because of the hurricane/flood/evacuation?	Yes	_ No
18	Did you have to live away from your caregivers or parents because of the hurricane/flood/evacuation?	Yes	_ No
	18a If yes, are you still living away from your parents?	Yes	No
19	Are extra family members or guests currently staying in your home because of the hurricane/flood/evacuation?	Yes	_ No
20	Did your parent/caregiver lose their job because of the hurricane/flood/evacuation?	Yes	_ No
21	Have you seen a mental health counselor or therapist since the hurricane/flood/evacuation?	Yes	_ No
	21a If yes, are you still seeing the counselor or therapist?	X	
~~		Yes	_ No
22	Have you seen a doctor since the hurricane/flood/evacuation?	Yes	_ No
23	If services were offered, would you like to speak privately with a counselor about your thoughts and feelings since the hurricane/flood/evacuation?	Yes	_ No
24	Before the hurricane/flood/evacuation, had <u>you</u> ever experienced any major losses or traumas (really bad things that happened)?	Yes	_ No
	If yes, please describe:		
25	Since the hurricane/flood/evacuation have <u>you</u> experienced any major losses or other traumas <i>(really bad things that happened)</i> ?	Yes	No
	If yes, please describe:		

26 Does you have any of the following problems or worries (check all that apply)?

____ Financial problems

_____ Housing problems

_____ Family problems

_____ School problems (Bad grades or getting into trouble)

Problem with friends

_____ Neighborhood violence

We are interested in your feelings and thoughts about the Hurricane/flood/evacuation and how much they are causing problems <u>now</u>. Think about your thoughts, feelings and behavior

DURING THE LAST MONTH

For each question choose ONE of the following responses and circle the number of your choice for that question.

(1) Not at all (2) A little bit (3) Quite a bit (4) Very much

1.	Do you get upset, afraid or sad when something makes you think about the hurricane/flood/evacuation?	1	2	3	4
2.	Do you have bad dreams or nightmares about what happened?				4
3.	Do you have upsetting thoughts or pictures that come to mind about what happened?	1	2	3	4
4.	Do you try not to think about or talk about what happened?	1	2	3	4
5.	Do you stay away from places, people, or things that make you remember the hurricane/flood/evacuation?	1	2	3	4
6.	Since the hurricane/flood/evacuation, especially in the past four weeks, do you feel that nothing is fun any more or that you just aren't interested in anything?	1	2	3	4
7.	Do you have difficulty falling asleep at night or wake up in the night because of what happened?	1	2	3	4
8.	Do you often feel jumpy or nervous?	1	2	3	4
9.	Since, the hurricane/flood/evacuation, do you find it harder to concentrate or pay attention to things?	1	2	3	4
10.	Since the hurricane/flood/evacuation, especially in the past four weeks, do you worry about what is going to happen?	1	2	3	4
11.	Do you often feel irritable or grouchy?	1	2	3	4
12.	Do you often feel sad, down or depressed?	1	2	3	4
13.	Has your appetite changed?	1	2	3	4
14.	Do you have headaches or stomachaches?	1	2	3	4
15.	Do you have less energy than usual?	1	2	3	4
16.	Do you find it harder to get your schoolwork done?	1	2	3	4
17.	Do you worry about something bad happening to you?	1	2	3	4
18.	Since the hurricane/flood/evacuation, especially in the past four weeks, do you have a harder time getting along with family or friends?	1	2	3	4
19.	If in a new school, are you having a hard time making new friends?	1	2	3	4
20.	Are you finding it harder to do or enjoy activities?	1	2	3	4
21.	How bothered are you by these questions?	1	2	3	4
22.	Have you used drugs or alcohol since the hurricane/flood/evacuation?	1	2	3	4

Thank you!!

For questions or more information regarding the contents of the Disaster-PAST toolkit please contact the Louisiana State University Health Sciences Center Department of Psychiatry.

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