**Epi CASE Toolkit Considerations**

When disaster strikes, public health and safety officials who lack training in disaster response and epidemiology could be at a loss for what to do. Several different tools, outlined below, are available to support them. Becoming familiar with these tools ahead of time, through trainings such as the Disaster Responder Exposure Assessment and Monitoring (DREAM) course is important during the preparedness phase. By monitoring surveillance data and the media, the alert public health practitioner might be able to detect chemical, biological, radiological, nuclear, explosive, or natural incidents when they occur. Using the Epi CASE Decision Support Tool will help guide you through the process of determining when to use the Epi CASE survey tool, and when to consider a registry as an option. (A registry generally requires a longer commitment to systematically collect standardized data about each person in an affected population.)

When an incident occurs, you should quickly assess the situation to decide whether the Epi CASE survey tool, a part of the Epi CASE tool kit (<https://www.atsdr.cdc.gov/epitoolkit/index.html>) is appropriate. You need to determine the extent of the public health problem to guide action. You can then determine if you need to issue public health messages or allocate resources for the people affected by the incident. For some incidents, such as the following, you will want to assess people and will need to deal with associated concerns:

* Confirmed exposure, and short-term or long-term health outcomes are possible or unknown
* Confirmed disease or environmental cause is plausible or possible
* Significant public health outcome or a rare exposure
* Significant political or public pressures to collect data
* Potential for significant public health knowledge gains

In these types of incidents, you can use the Epi CASE survey to quickly identify persons who have been exposed (responders and general population), the extent of exposure, and response needs. After assessing each person, you need to consider potential follow-up activities.

Epi CASE provides an Epi-Info™ (<https://www.cdc.gov/epiinfo/index.html>) tool to characterize assessed persons and how they have been affected. This information can be shared with decision makers to determine potential relief and service needs of the affected population. Providing a summary to everyone involved, including the affected community, is an important step in building trust through transparency. Healthcare providers will need situational awareness to help them prepare. All of this must occur while the incident is ongoing or subsiding to identify affected people efficiently.

Also consider training to use post-incident disaster epidemiologic tools in preparation for future incidents.

The Assessment of Chemical Exposures (ACE) program (<https://www.atsdr.cdc.gov/ntsip/ace.html>) has a toolkit of materials you can easily adapt to most exposure scenarios. If you have identified affected people with Epi CASE, you might then want to survey them using the more in-depth ACE tools. It might also be helpful to go to hospitals to interview the staff and collect medical chart information to make comparisons with self-reported Epi CASE data.

* If you decide from the Epi CASE analysis that you need household-based community health and basic needs information, conduct a **Community Assessment for Public Health Emergency Response (CASPER)** (<https://www.cdc.gov/nceh/hsb/disaster/casper/default.htm>). CASPER uses valid statistical methods to quickly collect reliable, empirical data for public health and emergency managers to make informed decisions.
* **Emergency Responder Health Monitoring and Surveillance™ (ERHMS™)** (<https://www.cdc.gov/niosh/erhms/default.html>) is a tool workers can use before, during, and after deployment in an incident response. ERHMS™ prepares workers to respond to an incident, ensures the health and safety of all workers during an incident, and helps an organization determine if any workers will need short-term or long-term follow-up after an incident.
* **The Epi CASE data** would be a starting point to begin contacting workers who were not already assessed in ERHMS™.
* A good supplementary data collection activity is to validate and enhance what was collected in **Epi CASE using surveillance tools** (<https://www.cdc.gov/disasters/surveillance/index.html>).
* **Several tools** can be used to rapidly assess shelter conditions during emergencies and disasters. For example, you can easily modify the Shelter Assessment Tool (<https://emergency.cdc.gov/shelterassessment/index.asp>) to meet local needs.
* **The Disaster-Related Mortality Surveillance Form** (<https://www.cdc.gov/disasters/surveillance/pdf/disaster-mortality-form.pdf>) can be used to conduct surveillance for deaths resulting from the incident. Ask medical examiners, coroners, hospitals, nursing home, or funeral homes to fill out the form during a disaster.
* **The Natural Disaster Morbidity Surveillance Individual Form** (<https://www.cdc.gov/disasters/surveillance/pdf/naturaldisastermorbiditysurveillanceindividualform.pdf>) can be used to assess illness and injuries after natural disasters, you can use the. Use the form to obtain individual-level active surveillance of medical conditions in acute care facilities such as hospitals or shelters with health care workers. It provides timely, detailed, patient-level information for response efforts.
* **Monitoring poison control center data** might help you identify emerging or established public health concerns following the incident. The area poison control center director might be able to help develop a monitoring plan. The **National Poison Data System (NPDS),** the data warehouse for the nation’s 55 poison control centers, could also help.

Long-term health evaluation

You might use one or more disaster epidemiology tools after the incident. However, if you need a way to evaluate long-term health outcomes that might take significant time to develop, then more thought has to go into whether an exposure assessment, health study, or health registry are needed. Examples of such purposes include the following:

* Potential to reduce disease or death among the exposed
* Potential to improve the delivery of health services to the affected population
* Potential to justify a public health intervention
* Ability to better identify any populations at risk

If your main interest is maintaining situational awareness, then a registry or health studies might not be needed.

However, if you identify a potential need for a registry, it must be considered carefully; a registry is a long-term resource commitment. These criteria must be considered before launching a registry:

* Are there adequate data to assess exposure?
* Can data be collected in a reasonable period?
* Will the sample size be sufficient to produce meaningful results?
* Is there sufficient long-term funding, considering that the registry might require many years?
* Is there sufficient staffing to complete data collection, entry, analysis, and long-term maintenance?
* Are there adequate communication channels to relay information and results to the registrants?
* Is there political or popular support (or at least no opposition)?

If you meet these criteria, you can consider developing a health registry. The most important step is to first assess the people who were exposed. You may then develop more in-depth surveys of the exposure and outcomes if needed. Remember that Institutional Review Board (IRB) approval most likely will be needed.

If you meet *some* of the criteria, you may be able to conduct a health study. Advantages of conducting a health study include a shorter period before results are generated and a generally lower resource commitment.

The minimum requirements for a successful health study include the following:

* Confirmed exposure and adequate data to assess individual exposure
* Clearly identified exposed population of sufficient size to assure sufficient statistical power
* Sufficient staffing and funding

The design of health studies varies, depending on the affected population, the health effect and exposure(s) of interest, and temporal factors associated with the exposure. Health studies require IRB approval and Office of Management and Budget Paperwork Reduction Act clearance. That means health studies, particularly those conducted by federal government agencies, can take substantial time to complete, although usually not as long as registries.

If you do not learn of an exposure until after an incident, you might want a less resource-intensive way to see if there have been some measurable health effects (e.g., adverse birth outcomes, death, cancer, etc.). You might be able to use existing registries to do a health statistics review to see if the exposed population is having increased levels of illness and death.

The World Trade Center (WTC) Health Registry (<https://www1.nyc.gov/site/911health/index.page>) is an example of a relatively recent and successful registry.

*Justification*

Creating a registry to track health effects resulting from the WTC event was justified for the following reasons, among others:

* This was an unprecedented terrorist mass casualty incident of great public and governmental interest
* The incident caused exposure to a mixture of many noxious and potentially unknown substances with uncertain public health effect initially and long-term

*Approach*

The exposed population for the registry was restricted to recovery workers and responders to the terrorist attacks of September 11, 2001 (9/11). It also included people who lived, worked, studied, or went to school and were present during the attack at the WTC site in lower Manhattan. The WTC Health Registry was established to accomplish the following:

* Identify and register people who were exposed to toxic substances
* Assess the occurrence of physical injuries and mental health effects among survivors
* Monitor the health of registrants over time
* Share findings and recommendations
* Develop and share disaster preparedness and public policy information for response to future incidents

*Practicality: How it met the criteria*

The registry had a *sufficient sample size*, of 71,437 people.

The WTC Health Registry effort had *reasonable timeliness*. Registry efforts started in July 2002, 10 months after the incident, and data collection began in September 2003.

The registry had *sufficient funding* — approximately $23.5 million initially — and *appropriate staffing* to begin operation. Additional and substantial funding has since been allocated to keep the registry running.

A contractor was assigned to promote the registry and conduct outreach. This provided adequate communications and registrant follow-up through several mechanisms, including telephone, in-person, and web-based interviews. Information was shared through multiple channels, including a comprehensive website, annual reports, e-newsletters, brief videos, social media, targeted mailings, health information sheets, press announcements, and stakeholder meetings.

WTC Health Registry Outcomes

WTC registry data were used to identify increased reporting of newly diagnosed health issues, including respiratory symptoms, asthma, post-traumatic stress disorder, and serious psychological distress. One significant finding to come from the registry was that WTC rescue and recovery workers who wore respirators were less likely to report respiratory problems 5–6 years after 9/11 than were those who went without adequate respiratory protection. These findings have influenced preparedness and planning efforts regarding respirator use during the response to future incidents. The registry continues to be used to monitor the health of registrants by conducting surveys of them every 3-4 years.

Conclusion

Registries are a powerful tool for post-incident data collection and follow-up. They can provide valuable information when the health consequences of certain environmental exposures are uncertain or will likely take a long time to develop. Certain diseases can have environmental causes that are not completely well defined, and long-term data collection via a registry could provide important insights.

Before deciding to create a registry, you will need to evaluate many considerations. The final decision should be based on a careful consideration of the reasons, clear methods, and practicality of creating and maintaining a registry.

References

1. Antao VC, Muravov OI, Sapp J 2nd, et al. Considerations before establishing an environmental health registry. Am J Public Health 2015;105(8):1543–51.

2. Paranthaman K, Catchpole M, Simpson J, Morris J, Muirhead CR, Leonardi GS. Development of a decision framework for establishing a health register following a major incident. Prehosp Disaster Med 2012;27(6):524–30.