

## 2.2 Improving Surveillance

**Research Need: Improve surveillance of human exposure and disease.**

**Lead Author:** George Luber (Email: gcl4@cdc.gov)

**HARRNESS Recommendation:** Same (HARRNESS, 57).

The prevalence of human illness due to exposure to HABs is not well understood, primarily due to the lack of human cases identified and reported to state and local health departments. This is in part a result of failure to link health effects with exposure pathways (e.g., swimming, boating, or fishing), but is also likely the result of the lack of a uniform and accessible manner for reporting potential human and animal illnesses associated with HABs. There is a critical need to develop a reporting system for state and local health officials that can facilitate the collection and dissemination of reports of possible human and animal cases of HAB-related illness.

Responding to this need, federal and state public health officials have developed an online reporting system for HAB-related illnesses that is designed to combine human and veterinary case information and environmental data relevant to HABs in one location. The Harmful Algal Bloom Information System (HABIS) is a secure, web-based system that allows state health and environmental departments to enter and update information related to cases status, HAB environmental factors, and associated animal illnesses or deaths.

While the technical challenges of such a system are significant, equally challenging is the need to understand stakeholder needs and requirements in order to ensure that data are captured in the most efficient and accurate manner possible. We propose undertaking a rapid ethnographic assessment of stakeholder, or end-user, perceptions of barriers and facilitators to the successful implementation of the HABIS surveillance system. This formative research will help ensure that the proposed surveillance system will provide an accurate picture of the true burden of disease posed by HABs.

### Research Objectives

1. *Identify stakeholder perceptions of barriers and facilitators to the successful implementation of the HABIS surveillance system.*
2. *Identify additional sources of information that can assist in reporting HAB cases. These might include sportfishing and recreational groups such as birdwatchers, boaters, and wildlife enthusiasts.*

### Example Project

#### **Rapid Ethnographic Assessment of Stakeholder Acceptance of the HABIS Surveillance System**

**Description:** This project will explore stakeholder and “end-user” perceptions of barriers and facilitators to using an electronic web-based system like HABIS for the collection and dissemination of information pertinent to human and animal illnesses related to HAB exposures.

**Methods:** This project employs a Rapid Ethnographic Assessment (REA) methodology which relies primarily on a qualitative approach. The REA approach is designed to be adaptive and iterative, relying on the refinement or revision of questionnaires and focal domains as the research progresses. The REA approach relies on the flexible use of a variety of approaches, including focus groups, key informant interviews, semi-structured and unstructured interviews, and participant observation. At the core of the approach is that the investigator begins with a limited set of pre-defined domains that are explored and elucidated in a time-limited manner.

**Outcomes:** This assessment is designed to assist in the development of the HABIS system and will ultimately be evaluated by the number of users, the frequency of use, and the quality of the data that is entered into the system.

**Challenges:** Close collaboration and buy-in from state and local health departments, environmental protection officials, and private veterinarians is key to gaining access to stakeholder perceptions.

**Expertise Needed:**

- An investigator familiar with the collection and analysis of qualitative data is essential. In addition, as this is an iterative methodology, expertise in a variety of ethnographic methods would be ideal (i.e., participant observation, focus groups,

pile-sorts, triads testing, and cognitive domain elicitation).

- Close collaboration and buy-in from state and local health departments, environmental protection officials and private veterinarians would be key to gaining access to stakeholder perceptions.

**Timeline:** The REA approach is intended to be formative in nature and guide the development of the final HABIS product. Therefore, the REA should be conducted over a time period of no greater than one month.

**Estimated Cost:** Fieldwork expenses, travel, and transcription costs should not exceed \$20,000.

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## 2.3 Developing Epidemiological Methods

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**Research Need:** Develop new, cost effective epidemiological methods appropriate to HAB issues that will enhance capacity to develop primary public health and prevention activities.

**Lead Author:** Lorraine Backer (Email: lbacker@cdc.gov)

**HARRNESS Recommendation:** “Develop new, cost-effective epidemiological methods that are appropriate to HAB issues” (HARRNESS, 57).

Traditional epidemiologic methods available to investigate environmental health issues are labor intensive, expensive, and time-consuming. Case definitions for HAB-related illnesses vary from agency to agency or are simply nonexistent. There is typically no way to clinically verify HAB-related exposures or illnesses. Also, there are no resources to conduct the prospective studies needed to fully assess the chronic effects from acute or chronic exposures to HABs and HAB-related toxins. Identifying and applying alternative methods for data collection and analysis will enhance our ability to develop timely and effective public health activities and exposure- and disease-prevention strategies.

disease incidence. It would also help public health agencies target response and prevention activities.

2. *Develop alternative methods to analyze and present environmental data that provide the public with information they can understand, accept, and use to make personal decisions about potential exposures.* There should be some consistent response to HAB-associated events that those responsible for communicating with the public develop and agree to disseminate.

### Research Objectives

1. *Investigate or develop alternative strategies for case-reporting, including those that do not require the patient to interact with the medical community.* Additional case-finding would help the public health community identify the individual variations in response to toxins and help assess true

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