



## **CHEJ Unequal Response Unequal Protection Meeting Notes- January 28, 2021**

### **Attendees**

- Lou Zeller
- Wilma Subra
- Erin Haynes
- Yanna Lambrinidou
- Charles Powell
- Sharon Petronella-Croissant
- Frank Bove
- Thomas Dydek
- Marilyn Howarth
- (Various CHEJ Staff)

### **Question 1: Mihir talked about the importance of having a response team, a low trigger bar, and others. How is this process different from your experiences with investigations in communities with chemical contamination.**

- Lou: Controlling the outbreak is a sticking point
- Sharon: Lack of uniform case definitions - people have different symptoms
  - Need infrastructure for reporting environmental exposure
- Yanna: Elements of precautionary principles needs to be present. Taking action before we know the true extent of them
- Reaction speed
- (Stephen asked how often we see hypotheses generated in a toxics investigations)
- Frank: Community has to generate the hypothesis themselves before the health agency comes in
  - (ATSDR) identifies a cluster and has an idea of why it was caused, way before an agency gets in there)
  - For food investigations, an implicit hypothesis already exists.
  - For toxics, there could be many diseases and situations of exposure. Depends on the context for which the problem is happening.
  - Same with occupational
- Marilyn: Acute vs. chronic nature of the problem.

- There is a disease investigation group that exists in the CDC for environmental problems, but it is geared towards long-term exposure.
  - Diversity of outcomes and impacts on people
  - No confirmatory test for environmentally-associated health problems
- Erin: People go to physicians for diagnosis → change. Doctors cannot diagnose these types of problems with a swab.
  - Might need specialty tests and labs
  - Environmental problems don't have one bacteria, but many unique chemical compounds occurring over time
- (Mihir asked whether it's possible to build that infrastructure or if it's too complicated or specialized)
- Erin: Depends on technology. Would require us to improve the speed to which we get results. We'd also need funding for this
  - Could we send samples directly to CDC?
- (Stephen reiterated the importance of funding for testing and a structure for testing people. Family doctors don't have the resources to address this.)
- Sharon: Many doctors don't have experience with environmental assessment or what to test for
  - They're not thinking of environmental issues in the context of public health
  - We can't just look for extreme cases. People aren't going to the emergency room for asthma
  - We need a reporting system for communicating environmental exposure. Would allow people to report these less extreme methods of seeking treatment. This could work when there is a large environmental event
- Wilma: Monitor industry reports for accidents and repetition of particular toxins over time
- Marilyn: Surveillance to detect sources, not just health
- Lou: Need group of doctors who are knowledgeable about the connection to be part of entity
- (Stephen said that the CDC has a team for other environmental disasters and asked which professionals should be part of the response team)
- Wilma: Consider biomonitoring once/before exposure is detected
- Charles: Agency tries to put the burden to prove exposure & cause and effect on the community
  - Community needs to be heard and community concerns taken seriously.
  - Contamination identified by community and given to physicians. CDC didn't learn about issues until it was conveyed to them by nurses.
- Yanna: We routinely dismiss community expertise.
  - Social scientists need to consider power balances and strive to elevate community voices

- Frank: This is why investigations aren't working.
  - When there's a catastrophic accident, there is an emergency response group
  - ATSDR has one
  - The challenge is situations where there's a number of possible exposure scenarios and associated health impacts. No team for that.
- Teresa: Missing from CDC protocol: Once it's determined that there's a problem, what happens next? So what? Often, nothing ever comes from initial first step.
- Erin: There needs to be follow up. CDC's goal is to determine "the outbreak is over"
- (Stephen says that even if you can't solve the problem completely, there are steps that can be taken, such as outreach).
- Frank: During an investigation, goal should be to shut down pollution sources even if there is no direct link to health impacts
- (from chat) Diana Rohlman: Who owns and has access to the data? How can the data be used? How and what data sources do you use to focus your investigation? The community often knows where to look, but what existing data is there to help drive the investigation?

**Question 2: What elements from the foodborne-illnesses case study do we want to see in a new model? What tools would be helpful?**

- Marilyn: We need a central place where science is being done that is readily accessible and affordable to communities
- (Stephen stated how health investigations are currently triggered by outraged community)
- Frank: Health agency just does a cluster-analysis and says the result isn't statistically significant
  - Instead, professionals should enter communities and collaborate with residents directly: understand their work, environment, life to identify pollution sources and occupational hazards
- Lou: Wishes he was able to get water/air tested for other potentially related compounds
  - Need more data- negative data is as useful as positive data
- Frank: Reiterated the importance of having focus for testing using community knowledge
- Marilyn: No proactive surveillance of legacy sites that would have created environmental hazards during use
  - Automatic testing could significantly reduce community exposure
  - Could be expensive but essential for precautionary approach

- Implement proactive testing into regulation
- Sharon: Implement citizen science to expedite data collection.
  - Used for disasters sometimes.
  - This will foster community participation
  - Will require developing appropriate technology.
- Yanna: Funding for investigations needs to come through CDC
  - Citizen science and community science – what are the histories and differences? This is an important discussion for later.
- Teresa: Warns community groups to be careful of what they ask for.
  - Citizens will have problems with testing methodology and the way it's presented
  - We need citizen science but it must be legitimate science
- Frank: Agency arbitrarily decides conditions of investigation.
  - There are many implicit hypotheses that are “a black box to the community”
  - Scientists and residents should develop a hypothesis together that implements community concerns. Example: use a questionnaire
  - It's too easy for anyone to quickly think up a bad hypothesis, not find anything, and leave
- Lou: Diversity in who's developing hypotheses
- Marilyn: Community questions may not be the same as what science can reveal. Design investigations based on what communities care about
- (Stephen and Teresa emphasized this point and how it has been a focal point of our community meetings)

**Question 3: What do you see as the role of the community in the investigation?**

- Yanna: Community must define the problem, the questions to address, and what they envision as solution
- Frank: Needs to be a mechanism to allow agencies to implement expertise. I.e. Community assistance panel
- Marilyn: Engage community members to find out how they're interacting with the environment
  - Outsiders often make wrong assumptions about how people are being exposed. Only community can know that
- Wilma: Consider what's being brought in externally. Example: Workers may bring occupational hazards home and impact surrounding people.
- Charles: Meet with the community to identify sources.
  - ATSDR assumes problem without taking close examination of the actual community
  - Can be done by understanding people's lived experiences

- Need a good representation of the community
- Erin: Involve community in all steps of the process
- Frank: Community needs to be involved with data interpretation
  - Political organizing in the community is a crucial piece of this. Get funding through a legislator and pass policies
- Yanna: Need a broader structure to combat other social, political, and policy problems beyond the extent of the science
- (Stephen: We are going to develop an outreach plan in addition to the document we develop in order to broaden our audience)
- Marilyn: Involve the community in how information is distributed to public
  - Only they know how they want their information to be distributed (flyers, electronic messages, etc.)
  - Will allow us maximize our outreach in communities
- Lou: Community should be the trigger
  - Need routine surveillance and way to report

**Question 4: How do we define the community?**

- (Stephen states how EPA advisory groups is often composed of people with with interests at odds with impacted residents)
- Frank: For ATSDR's CAP: Ask communities to provide representatives who are already interested in the effort
  - Transparent process
- Marilyn: Members of organizations and non members are 2 different groups
  - We need an inclusive grassroots approach to represent everyone who cares, not just the people who are engaged in the effort
- Teresa: ATSDR often tries to limit amount of community members involved
  - Community members on CAP need to equal or outnumber agency professionals
- Marilyn: Start with community questions and find people based on these questions
- Yanna: It can be risky to pick representatives from the outside because they know that grassroots-sounding groups have histories of betrayal.
  - Find a broad number of stakeholders who represent the diversity of the community
  - Community definition may transcend geographic boundaries