



CHEJ Unequal Response Unequal Protection Meeting Notes- March 18, 2021

Attendees:

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

Discussion Part 1: Reactions to Latest Draft Document

Question 1: What are your reactions to the revisions we've made to the draft framework?

- Liked the outline given about case definition, but in thinking about the practical reality of the way the circumstances evolve, is sometimes more about a clear exposure than known health effects. Wants the opportunity to allow for the investigation process to start from a different perspective (Marilyn Howarth).
 - Doesn't have to be a formal case definition → develop further over the course of the investigation.
- Industry is a big topic that's missing. How do we see industry as a part of this process? They can either hinder the process or they could help it. The oversight group has to have enough teeth if industry is seen to be the root cause of exposures (Sharon Croisant). We need to think about what power the entity should have and what the role of industry should be (Stephen Lester).
 - We should have a human health impact assessment in addition to environmental impact assessment. Also, take a look back to see what policies could have prevented everything in the first place and which existing structures are harmful (Sharon Croisant).
- Part of the preparation may be existing agencies to which we refer to in the draft document (like ATSDR testing/analysis). Could help put teeth on the protocols by

adding in an agency from the Department of Justice. It would be good to have a framework in the document that defines/explores the legal process of why we're doing this (Lou Zeller).

Question 2: What areas need more work?

- In section 3, is it the scientific method that is not effective or the policy that isn't effective? (Lou Zeller). It's more on the methods of epidemiology that aren't sensitive enough to answer the questions people have (Stephen Lester).
 - Is it that existing science is not yet appropriately applied to policy in order to take action on behalf of communities? This shouldn't cast aspersions on the scientific method as it's helpful, it's just that in some areas it hasn't been applied (Marilyn Howarth).
 - It's more about if the scientific method is or isn't done correctly (Frank Bove).
- Change can happen quite often for exposure, it's not a static situation (Wilma Subra). We can't just look at regulated chemicals, we have to look at everything that people are exposed to (Stephen Lester).
- If we have a set of criteria to determine whether to investigate communities, people may feel that they aren't taken seriously because of bias (Frank Anastasi).
- For the Response Team, there's already environment and public related disaster-response teams out there. This could be an expansion of it, by including on-going chronic pollutants and acute exposures (Erin Haynes).
- Include other agencies that have information/resources already. For example, a call to the EPA would be helpful in gathering more data (Marilyn Howarth).
 - Has to be a coordinated response with multiple agencies (Erin Haynes)
- Grammatical suggestion: section 3, there's an overabundance of the use of "/" in the text. If it's overused, it can lead to confusion. At some point, eliminate all the "/" in the slash in order to make it more understandable (Lou Zeller).

Discussion Part 2: Science Challenges

Question 1: Initiating a Health Investigation

- Who is the community? How do you define community? It doesn't have to be an organization, shouldn't be limited to a non-profit or 501(3)(c) (Erin Haynes).
- Reviewing the current literature and having access to information is important, should be shared. We should consider poison control center/trained environmental health exposure individuals (Erin Haynes and Stephen Lester).
 - Review existing evidence for chemicals of interest.

- Some of the calls might come from incidences/interactions that haven't yet been well studied or are misunderstood. These could be opportunities for scientific discovery. The bases shouldn't be limited by existing scientific literature/understanding. (Yanna Lambrinidou)
 - Agrees, adds that they should have the best information available. Should also encourage the community to call in and give local knowledge (Frank Bove).
- Possible Criteria to Initiate a Health Investigation:
 - Human health impacts (Wilma Subra).
 - Number of complaints ex.) 1 call from a community → anonymous? Every phone call deserves some sort of investigation (Erin Haynes).
 - Data collection process begins right after phone calls.
 - Phone calls are too easily dismissed. Need to make sure this doesn't happen (Teresa Mills).
 - Would be helpful to have a hotline and mapping of the calls (Erin Haynes).
 - Agency actions depend on information of the person calling in. We should come up with the information needed to decide on what to do → what tools do we need? (Frank Bove).
 - Have had situations where they should have been moving on before phone calls occurred. If think about responding, are almost always too late (Sharon Croisant).
 - Illnesses.
 - Already identified EJ communities.
 - Information coming in from a community should be transparent, along with what the response team is planning to do (Yanna Lambrinidou).
 - One mechanism to help with communities being a part of this is being transparent about what the initial complaints are and how many there are so that community members who suspect what's going on can check what other community members are reporting even if they're not connected to them (Yanna Lambrinidou).
 - "Decision tree" - range of different decisions depending on exposure scenario
 - Offers communities understanding of how the investigation will unfold to involve communities in all steps of the process
 - If we develop something (even if it's dynamic and can/should change) we should share it with the community so that they know what's going on and can understand it (Sharon Croisant).

- Part of the problem is that people are sent away for their concerns. Every concern should receive some level of attention. Something should be done to investigate everything (Marilyn Howarth).
- Prioritize information needed by the agency over criteria → information needed depends on the scenario.

Question 2: Case Definitions

- Case definitions work when chemical effects are known, but there are very few scenarios in which all contaminants are known (Marilyn Howarth and Stephen Lester).
- Should have certain questions you should ask yourself: what kind of exposure, timing of exposure, level of exposure, how far in the past did the exposures occur, pregnancy, age, etc. Help decide what you might want to look at. Work with the community and come up with a list of biomarkers you want to look at. Differs by the community and the situation (Frank Bove).
- When people believe they have health effects from chemical exposure, can make people feel that they're excluded if the case definition is made too early (Marilyn Howarth).
- Should include a list of health effects that people have had. Define the range of health effects, is it reasonable to think that exposure might contribute to these health outcomes? (Marilyn Howarth)
- Don't think we need a term (case definition). Case definition is a problem, don't use this term. Think rather about what we're investigating and why. This is good enough (Frank Bove).
 - We're limited where case definition doesn't make sense (Marilyn Howarth).
- Anecdotal information may be useful to define a case and what went wrong and right/what the outcome was (Lou Zeller).
- Don't let our perceived notions of case deter investigation in situations with multiple/unknown chemicals (Sharon Croisant).
- Citizens would be more receptive if we didn't have a case definition → we're not exposed to one chemical at a time. Be transparent with the community about what you're doing and why you're doing it (Teresa Mills).
- Might be better to call it affected individuals (Thomas Dydek).

Question 3: Public Health Surveillance System

- Change the word surveillance (Teresa Mills).
- Try to integrate environmental and health databases in a way that's better than previous programs, such as the NCEH tracking program. NCEH focuses too

much on national data, needs to be more localized. NCEH is available to community members (Frank Bove).

- Could call it exposure tracking/tracing and disease tracking/tracing as opposed to surveillance (Thomas Dydek).
- Don't just examine hospitalizations to track health impacts → ex. People don't report asthma, but respiratory problems are important to know about (Sharon Croisant).
- It's more about proactive surveillance as opposed to reactive surveillance. Look for exposures/environmental health problems via a bioinformatics approach. Can find things in communities that can be used as markers to see what's going on → how much cough medicine sold could help with when the flu is happening (Marilyn Howarth).

Question 4: Post Investigation Evaluation

- Did you interrupt the exposure? Did you interrupt it on a temporary or permanent basis? (Wilma Subra)
- Have to figure out if there's a need for ongoing/intermittent reevaluation (Marilyn Howarth).
 - Superfund sites get 5 year reviews → periodic check-ins.

Next Steps:

- Possibly have a lawyer look at the document at some point.
- CHEJ will send out draft 3 (combination of community and scientist comments).
- Joint meeting (community leaders and scientists) to discuss the draft document.
 - April 8
- Discuss how we intend to use the document.