



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

Attendees:

- Lou Zeller
- Wilma Subra
- Erin Haynes
- Yanna Lambrinidou
- Diana Rholman
- Frank Bove
- Thomas Dydek
- Marilyn Howarth
- Jill Johnston
- (Various CHEJ Staff)

General Questions/Comments:

- 27 February, intrastate pipeline in Florence → virtual public forum. If anyone's interested, let Lou know (Lou Zeller)
- Note: every step in the protocol process is done with community support. (Mihir Vohra)
- People are mad that they aren't involved in decision making. There's avenues for listening to the community, but not engaging with them as of now. (Stephen Lester)
 - Have a community engagement core, and have to wait for government to put out an RFA that fits with what the community needs. Can't just have government fund study right away. There should be a type of robust mechanism that deals with this. (Marilyn Howarth)
 - Diana strongly agrees with Marilyn. So many funding agencies talk about community engagement, but often they expect the research question will come from academia and be aligned with the funders research interests, so there are few avenues to actually address community needs and interests. (Diana Rholman)
 - Yanna thinks that we are up against pretty strong institutional forces that systematically exclude communities as knowers or capable knowledge

makers. Is this something we should be thinking about more in this process? (Yanna Lambrinidou)

- Do we have until the 25th to comment on the document? (Yanna Lambrinidou) Stephen says yes, would be happy to give everyone another week to comment. Eventually will share this document with community members.
- Lou is uncertain which is the latest draft of the document, because had two in his inbox. (Lou Zeller) Stephen said later one is just focused on the protocol, while the earlier version was focused more towards community members (broader).
- Teresa did most of the communication with community groups, says that a lot of the groups felt like they were fighting their own government. State health department, EPA agencies, ATSDR weren't saying yes to community groups. This is why community groups wanted a private entity as opposed to a governmental entity (Teresa Mills)
 - Something that might be helpful is an accountability mechanism for the governmental groups. (Frank Bove)
- Believes that involving community at the ground floor is great. Addresses shortcomings in CDC guidelines. (Frank Bove)
- Is this initiative something that has been tried before? What's the history here? (Yanna Lambrinidou) Stephen believes this is the first effort that takes it to this extent, while previous reports just identify the problem.

Discussion Question 1: What's your reaction to the draft protocol?

- Language and semantics → difference between community participation vs leadership? Yanna realizes that some of the harm happens because residents don't have leadership in decision making processes, so it is important to focus on how we create the opportunity for communities to be actively leading some of this stuff. Social scientists and historians can be helpful. (Yanna Lambrinidou)
- Community goals can go beyond scientific investigation, and can go towards political/justice issues. Do we want in this process to understand more holistically what the community is thinking about and what the short/long term goals are? (Yanna Lambrinidou). Stephen thinks this is a good point, we should bring in more people to get a broader perspective.
- Section 1: National headquarters with analytical lab capabilities → duplicative nature of recreating a set of analytical capabilities that are largely available in the country. Will be a monetary limitation. Would rather additional exposure assessment/monitoring/human studies. (Marilyn Howarth)

Discussion Question 2: Are there any components of the framework that are unclear?

- Area needs fleshing out: defining area of concern (impacted by contamination). Lou sent a note about this, but wants to emphasize defining the area of concern is most critical because decisions made here determine what actions can/can't follow. Doors should be open to revisiting decisions. (Lou Zeller)
- Area fleshed out → what kind of information should the community provide in order to go forward with investigation? Needs to be a definition of what kinds of information the agency wants in the first place. Further, how do they make the decision to investigate or not (what's the criteria?). CDC methods may be useful. (Frank Bove)
- TAG grants, one person? Other groups have multiple technical experts, could have/need more than one. (Frank Bove).
- Clarity on interagency jurisdiction: thinks that people can work with communities to investigate problems, but a successful approach relies on good communication with those who have existing data (ex. CDC, ATSDR, etc.). Not just that team has authority, but that there's an established and collaborative working relationship with those who have needed information. (Marilyn Howarth). Stephen says we're addressing a different question here: if left to the state to invite agencies in, people don't want the agencies to come in. But agrees that we should amend what we've written to have a collaborative working relationship. Want a spirit of let's figure out what's going on here.
- Case definition issue. Needs to be a literature review. Case definition should be effected by what the exposure is/how it occurred/time period etc. Need to keep in mind these aspects. (Frank Bove)
 - Marilyn thinks that case definition may be more constraining for this approach than we'd like. There are plenty of chemicals we haven't explored enough to know, so don't want to be constrained by the scope of research. In order to be more inclusive, we want to think about how we could handle these sorts of situations. (Marilyn Howarth)
- Issue of ownership/confidentiality of the data. What data specifically? Do they get personal identifying information? That might not be a good idea. (Frank Bove) Stephen believes it's not about personal data, but more so about results of testing around the neighborhood.
 - Is there interest in thinking about this issue more broadly in terms of coming together with communities of experts? There can be unintended consequences and harm along the way. Patient protections may be useful in thinking about community protections/rights, which would include and go beyond data ownership. (Yanna Lambrinidou)
 - Citizens should get final say on what happens with data and testing when/if numbers are released. Agrees that citizens cannot own personal health data, only the individual can own that. (Teresa Mills)

Discussion Question 3: What are the strengths of the draft protocol?

- Likes emphasis on interviews, understanding the community members, harnessing community knowledge. (Yanna Lambrinidou)
- Emphasis on precautionary principle. 50:50 standard is also a great idea. Emphasis of transparency and participation are very good. (Frank Bove)
- Surveillance program for toxic exposures and sources. It's missing from the current process. Can identify more people who were affected. (Marilyn Howarth)
- Highlights and makes up for deficiency in community engagement that other agencies have. Good to involve community at every step. Prior legislation and policy haven't made community action in agencies actionable. (Marilyn Howarth)
- Lou has highest regard for the Community Leadership Team and centrality of it with equal standing in the decision making process, ownership of data, etc. in establishing an entity that listens and addresses local concerns. (Lou Zeller)

Discussion Question 4: What are the weaknesses of the draft protocol?

- What is an initial evaluation? Could eliminate communities who don't meet the criteria → criteria could be too restrictive. (Wilma Subra)
- A lot of the incidents are exposure, and so it may never be over. Need a new descriptor for "the incident" and when it's over. (Wilma Subra). Stephen agrees, not every situation is like a spill that can be cleared up. Need a new descriptor.
- Small political problem. Could be different based on different administrations and could affect what the new entity could face, like funding. What will give the entity the ability to survive different administrations? (Lou Zeller). Stephen agrees, says we need more conversation around this. How do we get this accepted in the mainstream? → need more support of this from communities around the country before we take it to Washington.

Discussion Question 5: What's missing?

- We don't have anything in here that engages issues that involve wells, etc. Model focuses too much on EPA, need to include agencies that combat other environmental problems (Wilma Subra)
- Historical reconstruction of exposure, in order to understand what cumulative exposure is. It's important to look at PFAS. Biomonitoring could be mentioned as well (Frank Bove) Stephen thinks this is very important, along with tying case definition to the exposure.
- Need to identify areas where we do need to have more research. Need to understand these uncertainties more (Stephen Lester)
- Something that might be helpful is an accountability mechanism for governmental groups (Frank Bove)