Preparing for Return of Results from Wastewater Surveillance: Stakeholder Perspectives and Ethical Considerations

Jennifer Deegan[1], Shannon-Claire Barnes[2], Christi Guerrini[2], Jill Robinson[2], Faith Fletcher[2], Rosalia Guerrero[1], Mary Majumder[2], Olive Pertuit[2], Amy McGuire[2]

[1]The University of Texas Health Science Center at Houston, [2]Center for Medical Ethics and Health Policy, Baylor College of Medicine
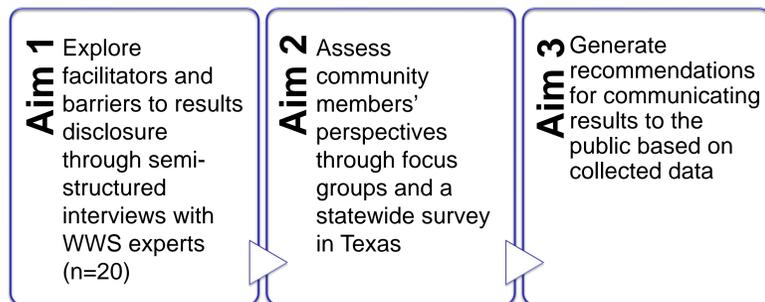
Introduction

- COVID-19 brought renewed attention to wastewater surveillance (WWS), which has been used to track and respond to infectious disease outbreaks since the polio epidemic in the 1940s.
- The potential for expanded applications of WWS raise important ethical, legal, and social questions.
- No currently available ethical guidelines focus on the complexities around communication of results.
- Many public health programs are using public-facing dashboards to communicate WWS results.
- Our NIH-funded EMPOWER (Engaging community Members to Plan for dissemination Of Wastewater Epidemiology Results) project aims to create a strategy for reporting wastewater surveillance results in Texas that aligns with community values and perspectives.

Project Overview

Aim 1 Explore facilitators and barriers to results disclosure through semi-structured interviews with WWS experts (n=20)

Aim 2 Assess community members' perspectives through focus groups and a statewide survey in Texas

Aim 3 Generate recommendations for communicating results to the public based on collected data

Aim 1 Interview Methods

- Audio-recorded 60-minute virtual interviews (total n=20)
- Recruited via email using purposive and snowball sampling
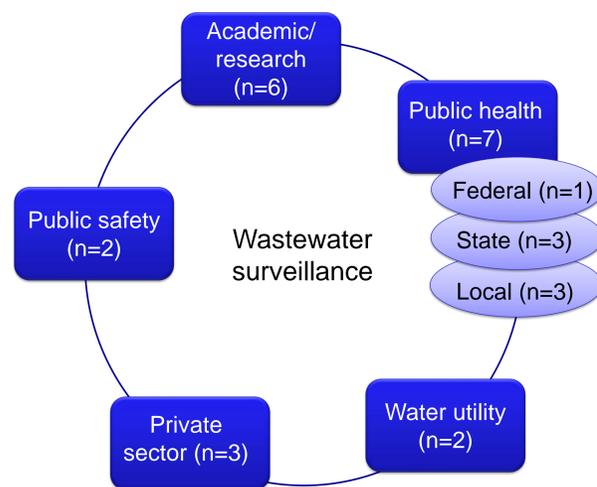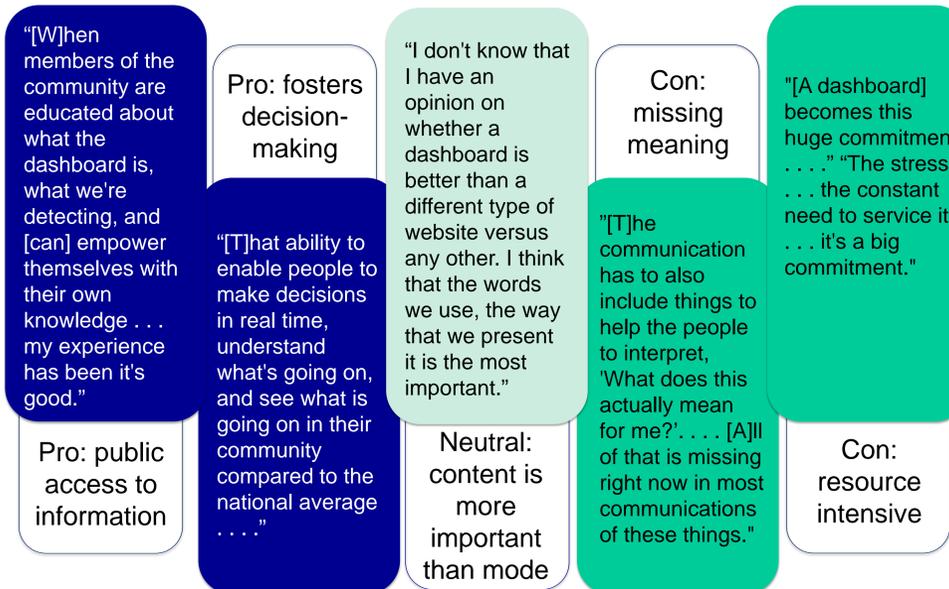- Offered $100 compensation
- Thematic content analysis of transcripts

Wastewater surveillance

- Academic/research (n=6)
- Public health (n=7)
  - Federal (n=1)
  - State (n=3)
  - Local (n=3)
- Water utility (n=2)
- Private sector (n=3)
- Public safety (n=2)

Figure 1. Stakeholder groups interviewed

Preliminary Results from Interviews

Pros and cons of communicating results via a public dashboard

Pro: public access to information
"[W]hen members of the community are educated about what the dashboard is, what we're detecting, and [can] empower themselves with their own knowledge . . . my experience has been it's good."

Pro: fosters decision-making
"[T]hat ability to enable people to make decisions in real time, understand what's going on, and see what is going on in their community compared to the national average . . . ."

Neutral: content is more important than mode
"I don't know that I have an opinion on whether a dashboard is better than a different type of website versus any other. I think that the words we use, the way that we present it is the most important."

Con: missing meaning
"[T]he communication has to also include things to help the people to interpret, 'What does this actually mean for me?'. . . . [A]ll of that is missing right now in most communications of these things."

Con: resource intensive
"[A dashboard] becomes this huge commitment . . . ." "The stress. . . . the constant need to service it . . . it's a big commitment."

Special considerations of communicating different categories of test results

Uncertain results	**Consistency in communication** "So communication internally before you go and communicate it externally. And I think that's the most important thing because if you're not saying the same thing, then people don't know who or what to believe and you lose trust."	**Public misunderstanding** "Here's the issue, okay, some other entity reports something that they find, and it doesn't make people sick, but it gets everybody all worked up, then the health department, they're tasked with doing a lot of communication to try to undo or understand or if they have differing results than the outside entity, that creates problems and confusion."
Results from infectious disease testing	**Providing information builds trust** "I feel communicating with the public early, often, and giving them the information that they need to take action is important. It's the way to build trust . . . ."	**Privacy concerns and unclear actions** "[I]n certain cases, sharing with the public may not be appropriate if it is at a really small scale. . . . [B]alancing the benefits of sharing that data publicly with the risks if there's a smaller population or if it's a pathogen that maybe is emerging and the public health action isn't super clear yet . . . ."
Results from illicit substance testing	**Educating communities in need** "[With the WWS data] we're able to shift our resources to those areas where they're needed . . . . [E]ducation, education, education. I'm big about investing in preventive measures rather than the reactive. . . . We've had a huge campaign [aimed at] reducing our overdose rate. We've been highly successful."	**Stigmatization of communities** "If a certain area in the county has a high level of [substances], then there could be a stigma. . . . [W]e don't know that actually that level of . . . substance use or alcohol, et cetera, has increased in this area. And then we put that on a website and everyone thinks, 'Well, this is where all the people of X, Y, Z live.'"

Interview Participant Characteristics

Participants (N=20)	
Characteristic	**n (%)**
Age, in years	
< 39	5 (25%)
40-49	4 (20%)
> 50	6 (30%)
Unconfirmed	5 (25%)
Race and Ethnicity	
Black or African American	1 (5%)
Hispanic or Latino	4 (20%)
Two or more	1 (5%)
White or European	9 (45%)
Unconfirmed	5 (25%)
Gender	
Man	6 (30%)
Woman	9 (45%)
Unconfirmed	5 (25%)
Residence[a]	
U.S. Midwest	0 (0%)
U.S. Northeast	1 (5%)
U.S. South	13 (65%)
U.S. West	1 (5%)
Unconfirmed	5 (25%)

[a] As defined by the U.S. Census Bureau

Conclusion & Next Steps

- Initial analysis suggests dashboards are a common but resource-intensive approach to communicating WWS results
- Stakeholders should consider the ways that information are communicated to ensure understanding and promote public trust
- It is critical to provide clear public health actions and avoid inciting panic and stigmatization of communities when communicating WWS results
- **Next steps:**
  - Continue analyzing Aim 1 interviews
  - Conduct focus groups and administer a Texas statewide survey to identify what types of information and modes of communication are most important to community members and why

Acknowledgments