Transcript: Communities Leveraging Evidence for Action and Resources

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Title Slide 1
Hi. I'm Danielle German. I'm super happy to be here with you today to share with you our Communities Leveraging Evidence for Action and Resources, otherwise known as CLEAR.

First, I'd like to acknowledge our project team and those responsible for these slides that I am going to be able to share with you today. Those folks include Brendon Holloway, August Cason, Kevi Smith-Joyner, Elizabeth Gall, Mannat Malik, and Jennifer Glick. Additionally, we have within our co-investigator team Merrick Moses, Molly Gribbin, Jean-Michel Brevelle, and Colin Flynn; and a fantastic combination of Community Advisory Board [CAB] members. Together this team of people and their dedication and commitment and expertise, is extremely valuable and important for the project that I am going to be sharing with you.

Slide 2 – Who is CLEAR?
So, CLEAR was created in 2018 to better understand health, social, and service needs of trans people in the Baltimore Metro Area, which includes 8 different counties in and around Baltimore City. As you see in our mission, we were designed to identify the strengths and assets, and understand health, social, and service needs of transgender and nonbinary individuals living in and around Baltimore City. We are considered to be a sister-project of BESURE…

Slide 3 – Who is BESURE?
…which some of you may be familiar with.

BESURE is part of CDC's National HIV Behavioral Surveillance System [NHBS]. It is implemented across the country in about 25 different places. We are a community health project designed to directly inform program planning to address community needs and fight the spread of HIV. We … our primary purpose is to be able to assess prevalence and trends in HIV risk behaviors, testing behaviors, service utilization, and also an annual survey on social issues, health and well-being, across different populations in Baltimore.

BESURE focuses on people who inject drugs, men who have sex with men, and people at increased risk for heterosexual transmission. But notably, the NHBS system was not designed to be particularly well inclusive of trans people, and thus, there are important gaps in the available data.

CDC has recently implemented a survey that focuses on trans women, but it is not inclusive of other trans and nonbinary identities.

So CLEAR was created as a partnership between Johns Hopkins and the Maryland Department of Health, with funding from the Maryland Department of Health, to help to address these gaps.

Slide 4 – Prioritizing community in the work
When CLEAR started, it was a priority to make sure that we were hiring individuals who were part of the rans and nonbinary communities, with the hope that participants and community members would see themselves reflected in our staff and all across the project. Currently, the majority of our staff identify as trans or nonbinary; part of our [co-investigator] team is trans, and all of our CAB members are trans as well.

Slide 5 – Overview of CLEAR project components
CLEAR has three primary project components: Research, Service Linkage, and Capacity Building. All of them are separate, but were designed to intersect and inform each other, to provide a holistic and cohesive experience of using data to support community members.

The Research component prioritizes actionable data collection that will directly impact the trans community; and our plan and hope it to share findings with a range of diverse audiences, but explicitly with trans community members seeking to use the data and whose lives are reflected within the information we are collecting.

We also include within the Service Linkage component a variety of mechanisms to help individuals access resources on a more immediate basis, and I'll tell you in the next couple of slides a bit more about that.

And then the Capacity Building component focuses on community engagement and building partnerships throughout the community, recognizing that we will be collecting information about what community members need, and aim to problem-solve based on that.

Our overall goal is to be able to maximize the use of the information to be able to inform how better for the trans community to be able to access resources and supports that they need in an affirming and accessible way.

Slide 6 – Service Linkage
A bit more about the Service Linkage component…

Slide 7 – What is service linkage?
Service Linkage includes the development of a database of trans-affirming services and resources. This has been development with an assessment of organizations, determining the extent to which they are trans-affirming, and then using this database to be able to facilitate referrals for individuals based on an assessment of their own needs and assets, and what it is that they are looking for.

To support this on an ongoing basis, the Service Linkage Team will also follow up with individuals after they have visited a referred organization, to ensure that their experience was, in fact, affirming.

We also want to highlight that the Service Linkage component was built on the principles of harm reduction and trauma informed care, and that we are aiming to ensure that individuals are met with affirming and positive experiences at referral locations.

Slide 8 – How service linkage works
In general, the Service Linkage is available to any trans and nonbinary community members in the Baltimore Metro Area, regardless of whether they have participated in the research components. Essentially, individuals just need to make an appointment by calling or by email – we're also doing video chats in the context of COVID – and within an initial conversation, we'll go through a quick needs and strengths assessment, to better understand what they are looking for and what their goals are, and then make a referral based on that.

Slide 9 – Research Overview
Within the Research component, I'll share with you some of what we're doing, thinking about, and what is…

Slide 10 – Our research plan
…likely to be coming next.

From the beginning of CLEAR, the priority has been to ensure that the data are actionable, useful, and wanted by trans community members. To do this we have had a variety of steps. We've had meetings with trans people to identify what gaps are. In 2018, we held an event to summarize the results of early conversations, plans about the project, with trans community members. There we about thirty people within that meeting, who then provided their feedback.

We ended up hearing from that [meeting] some specific gaps that currently exist in Baltimore in regards to locally-specific data needs that we were able to then use to inform our adaptation of the existing NHBS BESURE survey to better meet local needs.

Slide 11 – Identified knowledge gaps
So, these include the topics that are on this slide. We have continued to reassess the extent to which these remain priorities as time has gone on, and for the most part they still do.

Reading from left to right, top to bottom, what we identified was need for information on Health Literacy and Health Access; Experiences with Gender Affirming Surgeries; Hormones Use Experiences; Conversion Therapy; Stigma and Discrimination; Social Relationships and Social Stability; Housing Challenges and Opportunities; Experiences Related to Passing; Individual and Community Experiences with Violence; Family Life and Fertility Goals; General Life Goals and Achievements; and, Role of Religion and Faith.

Essentially, our team is committed to doing research that helps to address these different areas.

Slide 12 – Formative Research
We included quite a bit of early-stage formative work that helped us to create the survey and other data collection tools, as well as just some of how we operate as a team.

Slide 13 – Primary data report (PDR) background
The first thing that we did was to summarize existing information about trans people in the local area, and then to have a series of individual meetings and small group discussions with trans people and stakeholders who work in and with the trans community. We held about 13 small group discussions, 15 in-depth interviews, and through these discussions we essentially laid the foundation for our project and what we were aiming to do.

We identified needs and strengths of community members, based on their personal experiences and stories; were able to identify gaps in existing research; and we were explicitly intentional about reaching and including diverse groups within the trans community. Some of these included Black trans men, trans people who were engaged in sex work, nonbinary community members, and trans people in professional and organizational roles, as well as diverse combinations of all these different identity and experiential groups.

Within the Primary Data Report, we were able to highlight three main things that I will briefly talk about next.

Slide 14- PDR: Strengths and assets of the community
The first thing was the strengths and assets of the community. Within the small group discussions, we learned that mentorship and individual relationships were identified as key sources of community support. For example, many trans women spoke about their experiences as being mothers to other trans people, and they would often provide housing, food, and stability for their chosen children.

Another strength that came up quite often was resilience that was enacted through social support. So, due to a lack of family support, trans people reported often helping to cover housing costs or funeral costs, and to be involved in organizing rallies, including against police brutality; offering resources and recommendations for providers that were particularly strong.

Slide 15 – PDR: Social determinants of health
We also heard a lot about social determinants of health. Within the small group discussions, housing, employment, and violence were priority topics. These were also affirmed by the Community Advisory Board, who has identified these as key issues to focus on in order to better understand community experiences.

Slide 16 – PDR: Service needs and barriers to accessing care
The final theme was service needs and barriers to accessing care.

Within discussions with trans people, they identified three different tiers of service needs: on an Individual Level, housing, employment, healthcare, transportation and legal services; at the Provider Level, cultural competency training, in order to support trans people in being able to access affirming care, and; on an Organizational Level, increased funding for organizations that

are affirming to hire more staff, and more of an institutional commitment to competency trainings and capacity building.

We also just heard a lot about within the organizations that are affirming, challenges to access such as wait-lists, and generally more of a lack of knowledge about specific trans community needs, and experiences of intersectionality or combined marginalized identities and how affects people's lives and experiences.

Slide 17 – Key informant interviews
We also started to explore how we could best learn from others about the most effective practices for trans and nonbinary research. We have been interviewing trans and allied researchers and stakeholders across the country, who have experience with trans health research, especially community-engaged work, and you see some of the areas that we've focused on in those interviews reflected on this slide.

Slide 18 – Key informant interviews; Key themes
Some of the key things that have emerged from that are, that at the individual level, it's important to use research to address immediate needs of community members; and that flexibility is important to ensure participation and inclusivity.

At the community level, it's critical that researchers appreciate the histories and legacy of exploitation of trans community members within HIV research, and learn about strategies that can be used effectively within this context to collect useful data that reflects community priorities.

At an organizational level, there's a strong need for trans and nonbinary people to be part of all of the different aspects of a project team, so not only staff but other layers within the project, such as co-investigators and community advisory board.

And at a structural level, the need to address hiring barriers and create pipelines for trans peole to enter into this work, and have a career path that is supportive.

Slide 19 – Upcoming Research
In terms of our Research component, we have a variety of different aspects that are in progress.

Slide 20 – The core survey
Firstly, our primary component is the core survey, which is an adaptation of the NHBS/BESURE activity. We have done that adaptation and, in fact, were just about ready to launch that component right before COVID-19 put us all on, into a different reality. So we are doing some adaptations to that, that will hopefully allow us to be able to launch relatively soon, so please keep an eye out for announcements about that, and ways to be able to be part of that activity.

Slide 21 – COVID-19 experiences
We also have been working on a component that will allow us to understand trans and nonbinary people's experiences related to COVID-19 and the preventative measures that have been in place. To goal is to under stand community's experiences through qualitative research, to inform

community needs and future policies as the pandemic continues, and other emergency response measures that might come up. We will be asking about a range of different topics, which you can see here reflected on the slide. We are hoping to be able to launch this – we're still pending IRB review, but are definitely seeing this as a priority, so hope to have this in place over the next period of time.

And then we are also working in a qualitative component that focuses on housing experiences. This is currently under review by the IRB, and it focuses on two different groups: first is the experiences of trans community members who have experienced housing instability; and then also service providers and community members who provide either informal or formal housing services to trans people. The goal is to be able to understand needs, barriers, and challenges that trans people are facing when accessing housing. We are also hopeful that we can learn how we can better advocate for and support housing providers who provide services, again, informally or not within the trans community.

Slide 22 – Housing experiences
[Content for this slide was explored in the previous slide, second paragraph.]

Slide 23 – Thank you!
So, with that I will say, thank you very much. We would have really loved to have been there with you in person, but we appreciate you [dog barks] being here with us, even is it's [dog barks] virtual, and if you'd like to connect more with us you can find us through all of these different social media channels. And we also have a newsletter that you can sign up for. Please feel free to reach out to us; we'd love to hear from you. If you'd like to be involved in the project, one way or another, we'd really love to hear from you as well and hope you'll be as excited as we are for the upcoming Research components and the data we'll be able to generate to support overall an improved landscape for trans health within the Baltimore Metro Area.

Thanks so much for giving us this opportunity to share this project.

End Title – [Video: Danielle German smiling].

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