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BRINGING INVISIBLE POPULATIONS TO LIGHT:
METHODS FOR AN INCLUSIVE POPULATION HEALTH
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>> SANDRO GALEA: Good afternoon, good morning, good evening, wherever you are in the world, everybody. Welcome. My name is Sandro Galea. I have the privilege of serving as Dean of the Boston University School of Public Health. On behalf of our school, welcome to this public health conversation. These events are meant as spaces where we come together as a community to discuss, debate, and engage with issues of consequence for health. We are guided in these discussions by expert speakers from both within and outside the field of public health. Together, we aim for a deeper understanding of issues that shape a healthier world. Thank you for joining us for today's event. In particular, thank you to the Dean's Office and the Marketing and Communications team, without whose efforts these conversations would not take place.

Victor Hugo, of "Les Mis," wrote: "Those who do not weep do not see." In public health, we are centrally concerned with improving the health of populations because we see all too well how far we are from a world that supports the health of all. To see this is to be moved to do something about it, to create a world that's truly healthy. However, we recognize that there are remaining groups who we do not fully see, whose health remains poor in no small part because of the conditions that have kept them less visible.

Incomplete data complicate our efforts to understand and meet needs of all populations. Improving health means shaping new methods to capture and better understand these data. We are pleased today to be joined by distinguished guests who will help us think through how we can better see all populations towards a more inclusive, effective pursuit of health. I very much look forward to learning from all of our speakers today.

I am now pleased to turn the event over to today's moderator, Professor Scarlett Bellamy, Chair of our Biostatistics Department here at the School of Public Health. Our original moderator, Liam Messin, unfortunately took ill today and had to step aside. I am very grateful to Professor Bellamy for stepping in. Professor Bellamy, the floor is yours. Thank you. I think you're on mute, Scarlett.

>> SCARLETT BELLAMY: We can't say that enough, can we?

>> SANDRO GALEA: Excellent.

>> SCARLETT BELLAMY: Thank you, President Galea, for that introduction. It is my pleasure to step in today and I'm going to get straight to the program. I'll start by introducing our speakers for the afternoon and evening, and we'll move right into the program from there.

First, we will hear from Renice Bunde. Renice works with the Kenya National Bureau of Statistics as an Assistant Manager of Governance, Peace, and Security Statistics. She handles statistics on human rights for the vulnerable populations, especially for persons with disabilities, who are forcibly displaced, women and girls, children, street families, and the elderly.

Next, we will hear from Forrest Crawford. Dr. Crawford is an Associate Professor of Biostatistics, Statistics and Data Science, Operations, and Ecology and Evolutionary Biology at Yale University. He is affiliated with the Center for Interdisciplinary Research on AIDS, the Institute for Network Science, the Computational Biology and Bioinformatics Program, and the Public Health Modeling Concentration.

Next up will be Paul Wesson. Dr. Wesson is an Assistant Professor of Epidemiology and Biostatistics at the University of California San Francisco School of Medicine. His work focused on quantifying the health burdens of and disparities related to hard-to-reach and socially marginalized populations, particularly as they relate to infectious diseases. His research expertise includes developing and using data-driven methods for sampling hard-to-reach and hidden populations, population size estimation methods, and using advanced epidemiologic and statistical techniques to study the social determinants of health.

Finally, we will hear from Louisa Yasukawa. Ms. Yasukawa is a researcher at the Internal Displacement Monitoring Center, IDMC, where she focuses on the socioeconomic impacts of internal displacement. She currently leads the IDMC's research programs on gender, children, youth and education, and people with disabilities. Renice, the floor is yours.

>> RENICE BUNDE: Yeah, thank you very much. Unfortunately, I won't be seen clearly. I'm very sorry for that, but I hope you will hear me clearly. As you've been told, I'm Renice Bunde from Kenya National Bureau of Statistics. So, I work in the Directorate of Population and Social Statistics, and specifically under Governance, Peace, and Security Statistics, where we deal with the inclusion or making the groups left behind to be visible. So, thank you for this opportunity. I hope my screen can be clearly seen.

>> We can see your screen clearly, thank you.

>> RENICE BUNDE: Thank you. I will talk about how we can bring invisible populations to light through official statistics. So, I'm trying to move. It is a bit slow. It's not moving. Sorry for that. Next. Thank you.

Now, about Kenya National Bureau of Statistics. This is a national statistical organization in Kenya in charge of collecting official statistics, and it is mandated by the Act of Parliament to collect, collate, analyze, and even program data or statistics within the national statistical system. So, all media sources of data, we have census, population and housing census. We also have various censuses like census of agriculture, so we normally do that. We also carry out surveys and we know in order to complement censuses which are not carried out frequently, we need surveys. And we also get data from administrative records. But currently, we are considering to include data that is citizen-generated, especially from civil societies or institutions that have a lot of data but have not yet been recognized as official. So, we are really trying to do that.

So, as an institution, we've managed to come up with about 29 groups left behind. So, some of them, we have persons with disabilities, children with disabilities or women with disabilities, and we also have specifically persons with albinism, because we all know they are of interest, especially when it comes to human trafficking. We also have persons with mental health, which is also coming up; internally displaced persons, among others. So, we have quite a number. And we came up with this together with the Human Rights Commission, among other stakeholders, and we realized that some of these groups, yes, they are among the common groups, but if we don't collect their data or we don't really look at them when we are collecting the data, then they are likely to be forgotten or to be omitted.

So, maybe I will tell you some of the examples thereafter. So, some of the strengths that we've had -- I'm sorry for the noise. Kenya has done relatively well in ensuring that various invisible groups are visible using human rights-based approach. And the reasons for the success is because we have good coordination tools; we have a National Strategy for the Development of Statistics, which is used to strengthen collaboration between stakeholders within the national statistical system.

We also have a framework that is meant to ensure that we have quality statistics, and our stakeholders have been taken through. Then we also have what we call technical working committees, and we have specific ones like Governance Peace, and Security, Gender, Health Education, Disability, among others, which address the groups left behind either directly or indirectly.

Then we also have partnerships with various agencies, like UN. And through the partnerships, we've managed to have memorandum of understanding. Like for example, we have one between our office and the National Commission on Human Rights, which was signed in 2017 and renewed this year. And out of the partnership, we've really done a lot, including some of the groups that have been left behind in our censuses, like the intersex, among other groups.

Then, we are also members of various international groups like Expert Group on Refugees, IDPs, and Statelessness Statistics EGRISS; Washington group on Disability, we are in the steering group committee among others, which has built upon capacity and made us also think beyond the mathematics, beyond the figures that we normally come up with and to learn best practices on how to bring invisible groups into existence or into light.

Then, we also have existence of inter-agency coordinating committees, like one on disability, migration, where we also get to build our capacities. Because you know, like as statisticians, we can't know everything, but at least from these inter-agency coordinating committees, we get to learn more about how to bring these groups that have been left behind.

Then, we are co-signatory to the Inclusive Data Chart, which promotes the disaggregation of data and also inclusion of various groups that have been left behind; specifically, disaggregation by sex, age, disability status, religion, geographical location, migratory status, nationality, among others. And we've really tried to ensure that we adhere to that.

I hope I'm not too fast. And we have examples of data that we've collected. We did our last population and housing census in 2019. And we managed to include the following modules or variables, like when it comes to sex, it was the first time that we included the intersex. And for us to include this, we had to bring the Human Rights Commission on board. They had to even bring some few people who are intersex, and they took us through what they go through or what they undergo, and we really saw the need that these groups like the intersex have been left behind, especially when it comes to access to health, education, among others. They even drop out of school. When they go to the health facilities, even when they want to be treated, some of them are being treated like female, while the active hormones are male, and some of the medical or practitioners normally chase them away. So, they had very, very good cases or scenarios which really convinced us that we really need to include even the basic information about these groups.

We also have children, youth, elderly. We also have a disability module. We collected something on ethnicity in Kenya. We have, like, over 40 tribes, quite a number of tribes. And another interesting bit, we also had something on nationality. Yes, it is common, but we asked like for the migrants, reasons for migration. And from there, we go to refugees and asylum seekers, and we also got to establish the number of stateless. And maybe I highlighted stateless, because from this number, at least it triggered various institutions, plus our institution, to carry out a survey for specific communities, which as we speak, currently they are now citizens of Kenya. And out of the surveys that we did, or the inclusion in the census alone, at least more information could be collected, and they are now accessing some of their rights, among others. We have a lot.

And out of the census, we have generated quite a number of analytical reports which can be read there in our website, but they are specific. And as you can see, we have one on gender, disability, migration, elderly, that are addressing those groups left behind.

We've also done census on the street families. You know, this group has also been left behind for long. So, out of this census data, a bill on the intersex has been drafted. We're just waiting for the Parliament to pass it so that at least it can assist our people who are intersex to access some of their rights. And three stateless communities have got their citizenship. So, it has really helped.

And maybe also to include something on the surveys that we've done, we all know the demographic and health survey. And out of that, we have a module like the module on disability which was never collected before, and as a section within the institution, we really fought to ensure that we have this so people can now generate information related to maybe disability and other health and demographic indicators.

We also touched something on women empowerment, domestic violence, which is now bringing out some of the gender parities or other vulnerabilities. Among others. We also had a survey on violence against children, and we are planning to include a module in our next Kenya Integrated Household Budget Survey, which is meant to bring out indicators on poverty to have something on refugees and asylum seekers. You know, this population is normally forgotten, especially when you look at our national sampling frame. We normally forget this group. And also, we are planning for a National Disability Survey come next year. I'm trying to be fast. Sorry for that.

Another step that we've made as an institution or as a section, we have what we call -- we have two annual reports: Economic Survey and Statistical Abstract. And out of that, we've really tried to include more indicators on governance, peace, and security, to bring out the situation of some of the groups left behind, and some of them are here. The number of registered refugees, registered persons with disabilities, cash transfers, participation in decision-making, child protection, among others. So, out of that, people have come to appreciate that. We really need more information, including prisoners who have been left behind and to know their cases, like for women compared to men.

Now, we have challenges. In this area, I can tell you for sure that little research has been done for some of the groups left behind, and especially when it comes to the socioeconomic and health status, so a lot needs to be done. And because there are few, most of these invisible groups are few. So, statistically, they really require a huge sample size or a lot of funds is required to carry out a stand-alone service. So, more often, we just incorporate questions or variables or options in other surveys.

Then, when it comes to disaggregation, going up to lower level, maybe beyond national, is also a challenge because of the number. Then, during some of these exercises, we've realized that we really need to do targeted publicity, for example, for persons with disabilities, and even intersex, to make them know the importance of giving the information.

Then, after collecting some of the information, then most of our users at times do, like, reject our findings, like disability prevalence. They need huge numbers, or in terms of proportion, they want the big figures, while in terms of methodology, we can only get a small figure. So at times, we don't accept. But we've realized that when we build that capacity or boost sensitization, they get to know the importance. Sorry for going so fast.

Then, different sources of data giving different results, like for census and what we have for registered numbers of refugees. We had some discrepancies among others.

Now, in terms of recommendations -- I'm almost done. Data on the invisible groups should be collected continuously, because like for the intersex, we did it during census. We are planning to do more research or more studies, but we are not yet there. More disaggregation needs to be done to bring out the groups left behind. And then, data collected should be used for the right purpose without infringing into the rights of the target population, and that's what we've been trying as a country. We go beyond data and push. There are bills that can be drafted or policies so that at least they can access their data.

So, thank you very much.

>> SCARLETT BELLAMY: Thank you, Renice. Just a quick reminder, if we haven't said it at the top of the hour. I see some questions are starting to come through in the Q&A, which is great. And as we transition over to Professor Crawford, just a reminder as an order of business, that we will collect the questions and we will sort of, you know, ask them collectively at the end of all of the presentations from the panelists.

So, Professor Crawford, whenever you are ready, the floor is yours.

>> FORREST W. CRAWFORD: Thank you very much. I'm just going to make sure... All right. Full screen. Okay. Thank you very much. My name is Forrest. I work at the Yale School of Public Health, and I'll be talking today about the ways -- one of the ways that public health researchers and epidemiologists learn about hidden and hard-to-reach populations by sampling their social networks.

So, for the purpose of this presentation, a hidden population or hard-to-reach population is one for which a representative sample cannot be obtained. That means that census might not be feasible; there may be no sampling frame, like an exhaustive list of members of the population from which a sample could be drawn. Subjects may fear exposure by participation in a study like that. You can't put a sign on the telephone pole that says "all injection drug users come to the clinic on Wednesday" because the police may show up as well in some places, in some settings, and people who are members of that population may fear exposure.

In addition, administrative data can be unrepresentative. Think about interaction with social services, arrests, or hospitalizations. These may not be representative sources of information about the populations that are at greatest risk for health issues.

The population itself in a hidden population is often characterized by stigmatized or criminalized behavior or identity. Some examples include sex workers, people who use drugs, unhoused people, sexual and gender minorities, trafficking victims. Many of our most important public health interventions are specifically targeted at hidden and hard-to-reach or stigmatized groups, but biased at convenience samples can lead to biased inferences about characteristics and risk factors of those same groups, and these things can contribute to lack of effective policies and interventions.

Here I've drawn a little cartoon of the network, the social network connecting members of a hidden population. And then, suppose that we sample these four individuals represented by nodes in this network. The characteristic represented by the gray nodes here has population prevalence in the whole population of 7 out of 13, but in the sample, it's zero. And this is what we might call an unrepresentative sample of this particular population. If this was your sample, then you would have failed to learn about the distribution of this important characteristic represented by the gray nodes here in this population. If this was HIV, you would get an HIV prevalence in the sample of zero, and this would not be an accurate, defensible, representative inference about that population.

The way that epidemiologists and public health researchers have mostly studied hidden and hard-to-reach populations in public health research is to leverage the study population's social network for recruitment of individuals who meet the study inclusion criteria. The most popular method, still widely used, is called respondent-driven sampling, or RDS. The idea is to start with a couple individuals who are members of the target population. They are called seeds. They're chosen mostly by convenience. You give these people a small reward for being interviewed and a couple of coupons tagged with a unique ID. They recruit other people who are also in that same population by giving them a coupon, and then new recruits are identified with a recruiter who gets a reward. Those people are interviewed, then the process repeats. And so, it is a social network sampling method that radiates outward in a social network connecting members of the hard-to-reach population, and thereby, obtaining a sample for public health researchers. These are some examples of coupons that are used in respondent-driven sampling studies.

Here's a little cartoon showing you how respondent-driven sampling works and the data that it reveals to public health researchers. So, on the left you see a true population social network. This is obscured from researchers. The population is hidden. They can't see this, but they know about one person and call that person number 1. This is what the researcher sees. That person has two friends. And then they recruit someone else. And then that person recruits someone else, and this process continues here until we get eight recruits, which is a subset of the population. And the researchers who conduct this study, they get to see the characteristics of the eight people that they recruited along with the social network links along which a recruitment event occurred and these parts of links are edge stubs that might connect these people to others who may or may not also be in the sample. And that's what recruiters get from the respondent-driven study, this sample on the right.

And it turns out, you can represent this object in a regular data table that public researchers may be used to seeing. And along with the network topological information, the subject ID, the time at which they were recruited, the recruiter's ID, their social network degree or ego-centric network side, the number received, and you can get what you received in the study, in this case, HIV status. So, this is what is revealed by respondent-driven sampling studies of hidden and hard-to-reach populations.

This procedure, RDS, started out as a recruitment protocol and it was viewed as a approximation for survey sampling but became a set of statistical tools as well for looking at HIV prevalence, population size, network features, associations, during regression to link risk factors with health outcomes for members of these populations. And now, RDS is a standardized recruitment procedure for surveillance in high-risk groups. CDC uses RDS to conduct the national HIV behavioral surveillance in the U.S. and WHO and UNAIDS uses it worldwide. It's quite popular.

There are a few problems with respondent-driven sampling. The population features that public health researchers most care about, which are population averages, things like HIV prevalence, are not non-parametrically or statistically identified using RDS without assumptions. So, in particular, it's not a sample design with specified marginal sampling specificities, meaning it's hard to collect RDS samples for selection bias in the way we would in survey research. This precludes the most popular estimator's averages, including HIV prevalence. In general, it doesn't reveal enough information about the network that binds together the members of the hard-to-reach population for us to make reliable inferences about network functions, in particular, homophily or the tendency of disease status or health outcomes to cluster within a network. So, this is kind of bad news. This is something known explicitly or implicitly throughout, I think, HIV epidemiology. People usually don't talk about it, though.

There are a number of perspectives on these issues for respondent-driven sampling, most popular design for learning about hidden and hard-to-reach populations. I think it's fair to say that members of the populations targeted by RDS benefit or would benefit from representative inferences that lead to rigorous epidemiological research, but there are a diversity of views of RDS and it's controversial among epidemiologists. Some think it's a miracle. Some think it's an authentic sampling design for rigorously surveying people from previously unreachable groups. Some think it's always bad, nothing more than glorified convenience sampling. And they believe they are fooling themselves from the small RDS samples. I take the third perspective, which is that RDS is interesting, it's useful, but problematic. It's not exactly a sampling design, but the recruitment design and the data have a tremendous amount of structure, and there is a lot more that public health researchers and epidemiologists and statisticians can do to improve RDS as a sampling design and to help make more valid and representative inferences. So, briefly go out over a couple of examples of this third, middle-way perspective.

The first thing you can do with the RDS data is learn a tremendous data about the social network or epidemiological network, connecting the people who are actually in the study. Under some fairly defensible assumptions, you can reconstruct the social network of people in the study and then you can learn about that. You can study that and do regression, network-based regression to learn about the relationship between risk factors and outcomes. We did this in a large, a very large study of injection drug users in St. Petersburg, Russia, a few years ago.

You can learn about network characteristics like homophily and preferential recruitment during the RDS study. You can learn about these in a way that is agnostic to the edges or network links that you don't see. And we did a study like this to learn about these characteristics and the clustering of gender characteristics, drug use, and homelessness within a very large social network of injection drug users in Hartford, Connecticut. This was a few years ago.

The last example that I'll give here is population size estimation. It may be possible under some circumstances to learn about the size of a hidden population without actually sampling everybody in it from data that is revealed by respondent-driven sampling.

This is the last slide. I think members of hidden and hard-to-reach populations deserve public health advocacy and resources and interventions that are based on accurate research. I think RDS mostly fails to deliver accurate inferences that are needed to do this. Because it's not really a sampling design. It doesn't have marginal sampling probabilities that you can learn about reliably from the data. And the assumptions required to make RDS samples representative are quite heroic. They are things difficult to believe if you know about the sampling design.

On the other hand, RDS is really important, still. It's very useful for obtaining large samples of people who meet study inclusion criteria and RDS samples themselves contain a lot of structural information, and this can be exploited to learn in a statistical way about network properties, population size, potentially prevalence of characteristics throughout the network, and the relationship of those networks to risk factors. So, I think there's a tremendous amount of methodological, public health, and epidemiological research to be done on methods for learning about hidden and hard-to-reach populations. And I'm very excited to be doing some of that and also to hear from our next speaker. So, that's all I have to say about that. Thank you very much.

>> SCARLETT BELLAMY: Great! Thank you, Forrest. Now we will transition to Paul. And Paul, whenever you are ready, the floor is yours.

>> PAUL WESSON: Great, thank you. Let me just go ahead and share my screen. If you can please just confirm that you can see this.

>> SCARLETT BELLAMY: We see the version with your speaker notes.

>> PAUL WESSON: Oh, okay. Try again.

>> SCARLETT BELLAMY: Yes.

>> PAUL WESSON: Okay, great.

>> SCARLETT BELLAMY: Perfect.

>> PAUL WESSON: Thank you. Awesome, thank you. All right. Thank you to the organizers of this event for the opportunity to present on the sampling methodology for the California Statewide Study of People Experiencing Homelessness on behalf of my colleagues. I have no conflicts of interest to declare.

Much of our existing knowledge of homelessness comes from studies and surveys with limited external validity that because they are either convenience or probability-based samples that are tied to service utilization. The last large-scale representative survey of people experiencing homelessness was conducted by the Urban Institute in the 1990s, but was also tied to service utilization and no longer reflects the shifting dynamics of homelessness, such as unsheltered homelessness.

The biannual Point in Time count and surveys related to that lend consistency over time but is limited to the more visible population of people experiencing homelessness on a single night of the year. In California, it's estimated that there are 171,000 people experiencing homelessness, which is more than double the number in the next highest state, which is New York at 75,000. This estimate represents 30% of the U.S. homeless population and 50% of the U.S.'s unsheltered population.

So, my colleagues and I at the UCSF Benioff Homelessness and Housing Initiative sent out a survey of people experiencing homelessness in California to understand the characteristics of this population, the common causes of homelessness and identify potential opportunities to prevent and end homelessness.

We used a multistage sampling design with randomization at three levels, the county, the venue, and the individual. To start off, we divided California into eight geographic regions loosely based on the California Air Resource Board, which reflected the geographic diversity of the state. We then sampled one county from each region and compared the demographic and economic distribution of the general population and the population of people experiencing homelessness from the eight sampled counties to the demographic and economic distribution of the state as a whole, using data from the American Community Survey and the 2019 Point in Time survey. We then repeated this process for 200 possible samples and chose the sample of eight counties with the lowest route mean squared error that was the set that was most representative of the state.

Next, we randomly sampled venues within each county to match the expected proportion of sheltered and unsheltered residents in that county. Working with community stakeholders and persons with lived experiences, we constructed a venue sampling frame that included overnight congregate and non-congregate shelters, such as emergency shelters, non-shelter venues, such as free and low-cost meal programs, free shower locations and community daytime drop-in centers, and encampments or unsheltered areas with at least five people experiencing homelessness overnight in vehicles, tents or other makeshift structures not intended for human inhabitation. And we used probability size to sample from this frame.

Lastly, our field team followed randomization protocols for each venue based on the number of people experiencing homelessness there and the target number of surveys to complete at the venue. We completed 3,045 surveys through venue-based samplings, mostly in English and Spanish, and all participants were compensated with either a $30 visa gift card or a $35 Safeway gift card of their choice for participation in the study.

As a supplement to the venue-based sampling arm, we also employed respondent-driven sampling to reach people we might be less likely to find through venue-based sampling. RDS, as we've learned from the last presentation, is a peer referral method in which participants recruit other participants from their social network, receiving both a primary incentive for completing the survey and a secondary incentive for each successful referral.

Studies in HIV epidemiology have shown that RDS can be successful in reaching the more hidden members of a population compared to venue-based sampling. So, we, therefore, used RDS to specifically target and sample people experiencing homelessness who are also farm workers and day laborers, domestic violence survivors, transitional age youth and members of the LGBTQ+ community. Participants were given either physical or digital coupons to recruit members from their social network. Digital coupons were received on their phone and they could text to other members of their social network. And RDS interviews took place either in person or by telephone.

Here on the left, I'm showing preliminary results from the RDS recruitment chains, color coded by county. And as you can see, some of the chains are fairly long, which could be a sign of successful penetration in social networks of people experiencing homelessness, although many of them are short. And on the right, I'm displaying differences in the sociodemographic characteristics of the RDS sample and the venue-based sample. RDS tended to recruit people who were younger and a higher proportion of gender diverse individuals and members of the LGBTQ community.

Sample weights were constructed in four steps. First, initial inverse probability weights were calculated based on the probability of selection for the county, the venue, and the individuals in the venue-based sampling arm. These were known or knowable by design.

Second, we modeling non-response using logistic regression with perceived individual characteristics such as age, race, gender, disability status, and intoxication, as well as venue characteristics such as county or the category of the venue, such as shelter or encampment.

Third, we combined both the RDS and the venue-based samples by estimating each participant's overall inclusion probability using recent methods to incorporate non-probability samples, such as web-based surveys, with probability samples.

And finally, we used post stratification adjustments to county-level benchmarks from the 2022 Point in Time count survey of sheltered and unsheltered population to tie survey weights to regional population totals. These sample weights were used to correct for venue sampling frames known in advance to be incomplete for individuals living in unsheltered settings.

Data collection included 3200 staff-administered surveys measuring demographics, participants of current episodes of homelessness, housing trajectories, and health and health care utilization, among many other domains. Based on survey responses, participants were flagged for in-depth qualitative interviews for a deeper understanding of incarceration among many other domains.

Here are just a few examples of some of the key findings from the survey. People experiencing homelessness in California are Californians. Nine out of ten participants lost their last housing in California, and 75% of participants lived in the same county as their last housing. Participants have been homeless for prolonged periods. 39% of participants were in their first episode of homelessness. The median length of homelessness was 22 months. And 36% met the federal criteria for chronic homelessness.

Physical and sexual victimization throughout the life course was, unfortunately, common. Nearly three-quarters experienced physical violence in their lifetime and 24% experienced sexual violence. And most participants were unsheltered. More than three-quarters noted that they had spent the most time while homeless in the prior six months in unsheltered settings, 21% reporting in a vehicle, and 57% reporting without a vehicle. I invite you to visit our website for a more detailed policy report that describes these findings and many more.

In closing, there are a few points I would like to highlight. First, this is the largest survey of homelessness conducted in California and the first large-scale representative survey that is not limited to service utilization. What we feel we've gained in representativeness through our complex sampling design may have come at the cost of larger design effects that then inflated the variance of our estimates, but this is still being explored.

RDS is not often used to sample people experiencing homelessness. We have demonstrated some successes here, but are also in the process of deconstructing our challenges in order to improve future applications. Despite these limitations, we believe that this study represents promising and successful novel applications of sampling methods to generate data and inference on people experiencing homelessness and will motivate additional rigorous research with this vulnerable and marginalized population to produce evidence-based solutions.

I just want to acknowledge the hundreds of people who contributed to this effort with a special shout-out to our field team, study participants themselves who trusted us with their deeply personal stories, and to our funders. And I thank you for your time and attention.

>> SCARLETT BELLAMY: Thanks, Paul. Now we will transition to our last speaker in the series, Louisa. Whenever you are ready, the floor is yours.

>> LOUISA YASUKAWA: Okay, thank you very much, Scarlett! My name is Louisa Yasukawa, and I'm a researcher at the Internal Displacement Monitoring Center, which is based in Geneva. And we operate under a UN-endorsed mandate to be a global source of

data and analysis on internal displacement.

Okay. I thought I'd start first by saying and explaining what internal displacement is. So, a person who is internally displaced is someone who's been forced to leave their homes due to conflict, violence, human rights violations, or disasters, but they remain within their own country. And many people aren't familiar with the term itself, but actually, we see every day examples of internal displacement in the news. So, we're seeing people displaced within Ukraine since the invasion in February. We've seen people displaced by the devastating earthquake in Syria and Turkiye, and more recently, we've seen displacement linked with flooding in Libya.

And internal displacement broke new records in 2022. So, there was 71.1 million people living in internal displacement worldwide due to conflict, violence, and disasters at the end of 2022. And there are more internally displaced people than refugees and asylum seekers, but they tend to get less attention in the media, in academia, and in political discourse. And so, for that reason, they're often referred to as the invisible majority.

So, as you can imagine, when people are displaced within their own countries, not only are they separated from their homes, but they're also separated from their livelihoods, schools, networks, health services. And this can have severe, media, and long-term consequences on various aspects of their lives, including their health.

So, as a very starting point, to try to bring to light some of the experiences of IDPs, which are too often hidden, at IDMC, we've developed an original household survey tool to measure the socioeconomic impacts of displacement. And the tool is designed to interview displaced and non-displaced households to collect quantitative data on the impacts of displacement on various areas. And we have a dedicated module on health. The data that we collect is disaggregated by sex, age, disability status, and we've used it in about 16 contexts so far, to survey between 300 and 600 IDPs and the same proportion of non-displaced residents as well. And we complement the quantitative data with key informant interviews with local NGOs and health professionals.

In terms of the health module, I should start by saying that it's really a top-line assessment. So, we've heard of very interesting, rigorous, in-depth methodologies by the other panelists today, and our approach is really just to get a sense of what are some of the health impacts of displacement. So, we look at the perceived physical health and psychosocial well-being of respondents that access and barriers to health care, their access to food and coping mechanisms, changes in the cost of health care and the availability of specialized health care. And for each of these areas, we asked respondents to compare their situation before displacement compared with now, and we compare the results amongst the IDP sample and the non-IDP sample.

So, we've already heard from Renice of the important data that's being collected by the National Bureau of Statistics in Kenya. And I thought I'd just share a couple of the key findings from a study we recently conducted on drought displacement in Garissa County in Kenya.

So, here you can see we asked respondents to compare their physical health before displacement and after and see whether or not it had worsened, improved, or stayed the same. So, you can see on the left that the majority of respondents in red said that their physical health had worsened, but we did still see that 16% have improved. And respondents in this study came from pastorous backgrounds and had been displaced because of the doubt due to death of their livestock and cattle and food and water insecurity as well, which made them abandon their pastorous lifestyles and led to their displacement.

So, the top three reasons cited by IDPs for the deterioration in their physical health were: Less access to food; less access to health care; and less access to water. And so, what's interesting here is we see food and water scarcity as both a driver and a consequence of displacement.

We also interviewed local health workers who explained that malaria and cholera are very common amongst IDPs. And although the non-displaced population living in the same area do face similar health challenges, they said they're exacerbated amongst IDPs, given their poorer housing conditions.

Because we disaggregated the data, it was also interesting to see some of the differentiated impacts. So, we saw that a high proportion of women said that their health had worsened than men. And this is something that we hope to investigate further, and we're actually going to hold a workshop soon with humanitarian actors who are operating in the area to better understand some of these dynamics, though some key informants mentioned lack of access to maternal health care is one of the reasons why women maybe face greater barriers to health care, and also childrearing responsibilities and difficulties accessing livelihoods can also impinge on their physical health.

We also saw that all of the IDPs in the sample said that their physical health had worsened, though I note here that it was a relatively small amount of respondents who were identified as having a disability using the Washington group's short set, but it was nonetheless interesting to see that all of them did report a deterioration, and that's consistent with the results that we've seen in other contexts when we've disaggregated by disability status.

So, on that note, another interesting study we conducted was on flood displacement in the town called Beledweyne in Somalia. This is a town that's regularly affected by flooding, and it's become such a recurring cycle that people in the town prepared to move from low ground to high ground when the floods occur. And in fact, some humanitarian responders are already prepared in the higher ground to provide a tent and other services for IDPs.

So, in this case, we saw that 25% of displaced households included at least one member with disabilities, which is a relatively high proportion, particularly given we know that the global average disability rate is about 15%. But while identifying disability prevalence is important, and of course, is useful in trying to make visible populations that are too often invisible, it's important that quantitative data and disability prevalence isn't enough, and we really need to complement this with qualitative data to better understand some of the barriers that they face.

So, here I've pulled out a quote from a representative of people with disabilities that we interviewed who explained that floods affect people with disabilities the most in this town. Almost 30% have to crawl to reach their destination. There are no vehicles to transport them. There are no wheelchairs that can withstand the water, and people are not well informed of their needs.

And this finding is consistent with, as I said, other surveys that we've conducted. So, in fact, across 12 countries, we asked IDPs who are identified as having a disability, a set of follow-up questions about their specific barriers that they face, as well as the type of support that they received. And out of 131 IDPs we surveyed, only 15 had received specialized health care adapted to their needs during displacement.

So, in terms of further information and resources, you can find the studies that we've already conducted on our website. If you go to our page on the socioeconomic impacts of internal displacement. And importantly, safely and ethically sharing data is really important to not only to make sure that the research that we conduct is impactful, but also to make sure that we avoid over-researching the same groups. So, in that spirit, we're working to publish our anonymized data sets from recent studies we've conducted in Kenya, Mali, Cameroon, and Niger. And so, we're hoping to publish them later this year on our website, so stay tuned for that.

So, I'll leave it there and stop sharing my slides, but thank you very much again to the Boston University School of Public Health for the opportunity to join the panel today.

>> SCARLETT BELLAMY: Thank you, Louisa. If I could please ask the panelists to please join us again by turning back on your videos, and we'll start the Q&A portion of the hour.

While people are coming on board, I'll get us started with the first question, if I might. So, this question, or this theme of trust is sort of one of the ones that is sort of running through many of the questions that are coming up from our audience members. And so, I'm wondering if anybody would like to sort of speak to how trust sort of, you know, enters the process for engaging with folks who are for reasonably, sort of you know, for good reason, you know, hard to reach and sort of maybe for all kinds of reasons, sort of less enthusiastic about engaging in research.

>> FORREST W. CRAWFORD: I'll start. I think historically, social network link tracing study designs were invented to solve this problem, because they don't require participants to reveal identifying information about themselves, nor do they require participants to reveal identifying information about their social network contacts who also meet the study inclusion criteria, who are members of the same hidden or hard-to-reach or stigmatized or criminalized population.

There have been pros and cons historically from that decision, for public health to focus on those types of recruitment methods. The pros are that participants can, in many cases, participate without fear of being exposed directly by the researchers who are conducting the research, so that if the police raid the clinic where the research is being done, that no information will be found that identifies them as a member of the population. So, that has been very helpful for improving recruitment of hidden and hard-to-reach populations.

The pitfalls are as I tried to describe in my presentation, that we have lost in doing this the ability to make generalizable inferences about those same populations, and I fear sometimes that some of our ability to make rigorous inferences and to do very good services delivery to those same populations has been hampered by doing this.

>> SCARLETT BELLAMY: Thank you, Forrest. Renice, you had a hand up. Did you want to add to that?

>> RENICE AKINYI BUNDE: Yeah, maybe to add to that, we also

have a snowball sampling method which also works for the hard-to-reach population, so it can also be applied along that where you identify a few of them from the few. It's more like networking but statistically tested, so it's also another method that can be used. Thank you.

>> PAUL WESSON: I'll also add that I think in addition to the different scientific methodologies of how to design the sampling process and design the study itself to try to protect participants' identities and protect them from further stigma, using community advisory boards are also really important, and that was something that was really impactful in the study that I presented on where the main organizers of the study, the principal investigators and others, spent a lot of time with different community advisory boards all throughout the state, people with lived experience of homelessness on appropriate methods to reach people who are currently experiencing homelessness, how to interact with people during the interviews, how to frame certain questions so that we're not perpetuating past trauma.

And I've heard from other members of my team, just the positive reception that this report has received from people who are currently experiencing homelessness and seeing the report and seeing themselves genuinely represented in the report and seeing that the team had listened in terms of how to conduct the study and the interview guide.

>> SCARLETT BELLAMY: Thank you, Paul. Louisa, did you have a hand up to add?

>> LOUISA YASUKAWA: Yeah. I just wanted to add another important consideration in terms of trust and making sure that participants feel comfortable is, of course, your approach to the numerators that you use, so really important to use, where possible, numerators who are from the local area. And when it comes to asking questions about disability, it's also a great practice to be involving organizations of persons with disabilities themselves, not only in the design of the research, but also as numerators. And there's some really useful guidance produced by the Stakeholder Group of Persons with Disabilities about how researchers can work with those kinds of organizations to ensure that they're actually involved in the production of data as well.

>> SCARLETT BELLAMY: That's great. So, I like that the responses have ranged from the technical to the practical, so I appreciate that from the panelists.

In a similar vein, there's a question in the Q&A that is sort of related in the sense that since we are, you know, asking sort of, you know, these populations that have a whole host of challenges, both as it relates to the work that you or we are trying to do as researchers, but you know, probably in addition to those, there are a whole host of things that may be challenging in their lives that aren't directly related to our research.

And so, the question, with that as the backdrop, is can you speak to sort of, you know, additional resources that you potentially can provide to folks while you do have them as a captive audience in those moments where you are engaging with them?

So, more specifically, while you're thinking of your response. For example, if there is a need that is expressed for which you haven't anticipated, how frequently can you provide some sort of a resource to meet that need?

>> FORREST W. CRAWFORD: I guess I'll say a few words. I think service provision is often a pretty important part -- or linking to services and care is a very important part of a lot of research in general in hard-to-reach populations; in particular what I'm most familiar with is surveys in the HIV risk behavior and the context of HIV epidemiology. So, like anybody who comes in for an HIV survey from any sampling design who gets an HIV test, if that test comes out positive, then they will be referred to care.

People who participate in surveys, people who inject drugs, for example, might be linked to a needle exchange clinic or resources for opiate substitution therapy, things like that, so a lot of harm reduction engagement happens during the process of gathering scientific information as part of, you know, a biomedical and public health study.

At the same time, I'll give like maybe another type of response. At the same time, I think strongly linking service provision to non-representative sampling designs can be somewhat dangerous, because it is almost by definition inequitable to link service provision to being friends with someone who's already got the service. It's precisely what we avoid trying to do -- what we avoid doing in many other types of public health service provision, where we say, you can get the thing that might help you, but only if you're good friends with someone else who's also got it, who is proximal socially or geographically to the clinic where that service is provided or you're easy for our outreach workers to find. I think it's very difficult to do equitable service provision for hidden and hard-to-reach populations by definition because we don't know where it is or how to reach them. But I think we shouldn't be complacent in thinking that because we have sampling designs that can penetrate hard-to-reach populations that those designs themselves are the ones that we ought to use for service provision.

>> SCARLETT BELLAMY: Thank you. Any additional thoughts?

>> PAUL WESSON: I'm still thinking over that last point by Dr. Crawford. I think that's a really interesting point. I think maybe I would add to that by saying, especially in the context of RDS, which tends to in theory reach the more hidden members of the population, those study participants are not exclusively being offered these additional services. I would imagine that in many contexts, the services that are being provided are widely provided across the population, but there may be certain people who are less likely to access it for a variety of reasons. And so, you could think about RDS as a way of reaching people who are even more removed from these service provisions and providing them with direct access or linking them -- more strongly linking them to these services. Just as another thought.

But I would also add that for, I would imagine, all of these studies that are based in academia, part of our application is also a plan for how would we approach coming across different information about abuse or trauma and which services are available within that context that we could then directly link someone to or provide them with the contact information or resources to access that service.

>> SCARLETT BELLAMY: Thanks, Paul. Since you brought it up, there was also a question that was directly related to your last comment, specifically around navigating IRBs in the context of these sampling designs like respondent-driven sampling. And so,

I'm wondering if any of the panelists can sort of, you know, address that, either you know, your own experiences or, you know, some sort of, you know, specific strategies or things that, you know, IRBs are typically interested in having researchers address when the survey design or the experimental design involves RDS.

>> PAUL WESSON: I think probably Dr. Crawford could probably speak best to this, but my advice regarding IRB is always first and foremost to pick up a phone and talk to an IRB analyst as soon as possible. My experience has been that the IRB is great and they're not trying to impede the research but just to make sure that it's done in the most ethical way possible and the way that protects participants appropriately. I have found that when I had that conversation with the IRB, where I talk with the analysts about the goals of the study, the study design and they understand what we're trying to do, they know that it's based in the scientific literature, there's a precedent for it, and that they then understand it and become partners with me in, and what questions I need to specifically address in order to make sure that they are comfortable with what I'm trying to do.

>> FORREST W. CRAWFORD: I'll say a few words. So, in the academic setting, it's usually fairly easy for academic public health researchers to get respondent-driven sampling or snowball sampling approved by IRBs in schools of public health or schools of medicine because they're not intervention studies. As long as you're not doing surgery or giving people pills that may change the way their body works, it looks okay, you know. It looks very low risk from the IRB perspective.

I think in reality, the main risks for most participants in studies like this is exposure in the sense that they will be individuals who will be linked to study data that identifies them as members of a stigmatized or criminalized population. And so, there could actually be legal consequences for someone who has identified as participating in a study, whose inclusion criteria is that they're doing something that is against the law or something like that. So, that can be very dangerous, and it is a very big hazard in some international settings in particular places where gender and sexual minorities, maybe their identities may be criminalized. So, this is a major concern.

I think IRBs are sensitive to the idea of names and addresses and phone numbers being exposed. They don't think very careful or systematically of the idea of network data being exposed. I think we need to be very careful about exposing information about social links between people, even when we don't expose the identities of the people embedded in that network. And the reason is there are theoretical results but also empirical results that say, sort of, if you know a lot about the social network that binds people together, then if you can deidentify one node in that network, you might be able to learn a lot about the people around them in the network and possibly many more people in the network. So, it makes a risk -- a small risk of disclosure kind of multiplies across the network that researchers have collected, and I think IRBs maybe could be a little more sensitive to restricting the disclosure of social network information that might increase risk of disclosure.

>> SCARLETT BELLAMY: Thanks for that. If there's nothing to add on that topic, I'm going to switch gears, perhaps quite dramatically. And Louisa, I think this is a question that's

primarily directed towards you, or perhaps I'll ask for you to respond to it first. Sort of just a more practical question around how is it that you conduct sort of survey-related research in theaters of war? One of your examples, at least, you know, included, you know, Ukraine, perhaps, as an example. And if you just want to speak to that broadly.

>> LOUISA YASUKAWA: Sure. Thanks for the question. So, yeah, I find Ukraine as an example that we're seeing, of course, on the news. And we actually just concluded a study in Ukraine looking particularly at the gender dynamics of internal displacement. And the original survey tool that I mentioned in my presentation is designed for house-to-house survey collection. But in the context of Ukraine, we thought that given security considerations, it would be better suited to an online survey.

So, we partnered with a company called Ruey, which basically offers an innovative technology to run anonymous, random surveys to people while they're browsing the Internet on their desktop or app devices. And we managed to engage a wide sample, and we had 18 questions in total in our survey and 2,945 respondents completing all questions.

So, the focus of this survey wasn't specifically on health, though we did ask respondents about their access to health care and including specialized health care, and we disaggregated the results by men, women, nonbinary respondents, as well as enabling respondents to identify as an LGBTQI+ as well. So, this was an example where we used a different approach, a different methodology, because we thought that would be quite suited to the context because the survey could be run in all parts of the countries that have Internet access, and it is a country that has quite a high penetration of Internet usage. So, yes. So, that's how we went about it in that context. But we have, of course, collected data on displacement linked with conflict and violence in house-to-house, in-person surveys. But of course, that also depends on accessibility, and it's something that we work quite closely with local researchers in determining where would be the most appropriate place to conduct the data collection.

>> SCARLETT BELLAMY: Thanks, Louisa. In the same spirit, I'm going to ask a very different question next. So, there's a question in the Q&A, and effectively, the spirit of the question is -- I like these questions -- these are the "so what" questions. If anybody would like to sort of speak to, you know, based on what you've learned, what are your sort of future steps, perhaps sort of intervention development, policy development, based on what you've learned about, you know, any one of these hidden populations that sort of might have informed how your results sort of translates into, you know, like I said, either interventions, policies, et cetera, that would sort of benefit their health.

>> RENICE BUNDE: Maybe if I can --

>> PAUL WESSON: Sorry, go ahead.

>> SCARLETT BELLAMY: Please, Renice.

>> RENICE AKINYI BUNDE: Thank you very much. Maybe for the example for Kenya for the bill that's been drafted. You know first of all people didn't know about intersex for example. But inside the bill, you will have some of the basic access to basic rights and health. So maybe after the bill is passed, then they now will be accepted, for example. You know, people get stigmatization or discrimination, even from health practitioners

themselves who maybe fail to understand that they equally have their rights.

So, from Kenya, yes, we would have policies drafted after data collection or after doing some studies and realizing that we have got some gaps, and for sure, they are working. So, even for the academia, you can as well have your research paper for various interventions and I believe once they get access to these interventions, they will equally be happy. So, as an institution, we've managed to do that. At the end of the day, we don't just end at producing results, but we follow up with our stakeholders to see, like what's next for our policymakers? What can they do beyond the data that we've produced? And at the end of the day, we have various groups that are accessing their rights. That's what I can say for now.

>> SCARLETT BELLAMY: Thank you. Paul, did you want to?

>> PAUL WESSON: Yeah, I'll add a little bit based off of our experience. So, we collected a lot of data, and you know, over the next year, there are quite a number of academic publications that we have planned. But I love the "so what" question, because the study itself was really designed to have that so-what implication and to try to answer, well, what are the causes of homelessness in our state and what might be some intervention points to prevent this in the future?

So, our PI on the study, Dr. Margo Kushel, spent a lot of time since the publication of the policy report earlier this summer, in Sacramento talking to politicians, and politicians in D.C. as well, about the results of this survey to see, you know, what are potential policy implications for that. What about, like, you know, monthly stipends or one-off stipends to prevent homelessness? What are the reasons people entered into homelessness? And can we, if we better understand that, can we institute certain policies to prevent that in the future?

For example, people who entered into homelessness after leaving an institutional setting, less than 17% of them were offered any kind of resources for housing or other health care or social services as they were leaving those institutions, such as jail or prison. So, that is also a direct intervention point of strengthening those linkages to community resources as people are leaving a carceral setting.

>> SCARLETT BELLAMY: That's great. There was actually a related question around sort of linking this to sort of incarcerated populations. So, thank you, Paul, for touching on both of those. Louisa, please.

>> LOUISA YASUKAWA: Yeah. So, the work that we've been conducting has the aim of trying to inform humanitarian programming. So, at the research design phase, in each of the contexts where we are carrying out these surveys, we try to engage with local partners who are working on programming on displacement in those areas. And then, as I mentioned in the presentation, once we collect the data, we then hold workshops with public authorities, humanitarian actors, and local NGOs to not only present the findings, but most importantly, gather further insights from them that can assist us in understanding and analyzing the findings and identifying further gaps.

And in terms of the sort of "so what," I think it's been interesting to see, even if we take the most-recent studies we've done in Kenya and Mali, for instance, the actual implications of the findings are quite different. So, in the case of Kenya, because of time period, I didn't really get to go too much into the details of the findings. But given the severity of the drought, we saw that health needs were also high amongst the non-displaced population, as you can imagine, particularly in terms of access to food. And so, although in that case we did see that IDPs were still facing greater challenges, in that scenario, because we could contrast between the two groups, it really would highlight the need for more area-based interventions, so also including the non-displaced population in programming as well.

Whereas, the similar study we conducted in Bamako in Mali, we were looking at IDPs living in a more formalized settlement compared with a local non-displaced community, and there we saw a very big disparity between the needs of the two groups, which just goes to show the importance of dedicating more services that are close to those settlements that can specifically target IDPs.

>> SCARLETT BELLAMY: Thank you. Any additional thoughts on that last question?

>> FORREST W. CRAWFORD: Sure. In terms of work and research frontiers on the methodological side, I've spent a lot of time thinking about clever things to do analytically that would make the data from respondent-driven sampling and other linked tracing designs better for public health purposes. And I think now my opinion is that dumber might be better and that we should think really carefully about using public health resources and public health money, in particular, NHR01-level funding not to run tiny surveys of a small number of people, but to do census-like enumeration.

We talk in abstractions about hidden and hard-to-reach populations, but in many American cities, the people we care most about, there's not more than a few million of them, or even 100,000 or maybe only 10,000. And we could totally meet and do brief interviews for a very large fraction of those populations for $1.5 million.

Instead, what we do is so sample maybe 50 or 100 or maybe 200 of those people and subject them to three-hour interviews in which a lot of information is revealed. This is getting very controversial. But I think that larger sample sizes and near census-like enumeration two do better for the credibility of public health inferences about the most vulnerable populations in our societies than the current orientation towards smaller studies with more exhaustive socio-behavioral characteristics of a small number of individuals.

So, I think, like, the methodological domain -- the frontier in the methodological domain is simpler studies of more people for better understanding and better services delivery.

>> SCARLETT BELLAMY: That is a controversial -- a bit of a controversial position, but for the sake of, you know, for discussion, I think that is a compelling argument. Yeah. Thank you for bringing that into the conversation.

So, again, sort of putting my statistician hat on, I do think that, you know, that sort of simple methods often get dismissed for the new, hot thing, and that doesn't necessarily mean that, you know, the simpler method is inferior in any way. So, again, just thank you for bringing that into the conversation.

>> PAUL WESSON: If I could just add to that last point. I think that that also depends on the audience. I think that the simpler method may get maybe more often dismissed in academic audience where there's more of a temptation to go to the more complicated statistical methods, but in terms of policy

applications, I think that you're more likely to get much further with simpler methods that are much easier to grasp and display.

>> SCARLETT BELLAMY: Yep. So, Paul, that's actually a nice segue to the next question that I had in mind. And again, it sort of gets back to this, you know, once the work is done, there's a question in the Q&A around researchers' sort of abilities to go back and share their findings with survey participants. I think it's particularly relevant in this context, where the participants were sort of hard to reach the first time around, and sort of if people can speak to processes and/or strategies for potentially re-engaging them so that you can share back what you've learned, you know, in an aggregate sense from the research in which, you know, potentially they've just sort of, you know, contributed to.

>> PAUL WESSON: Yeah, I think that's a great question. I think it's something that we don't do enough of as academic researchers. And I'm guilty of that as well, in terms of doing the report back.

I think that perhaps one of the first steps in that report back is, especially if you have engaged a community advisory board or lived experience advisory board to return to that group and share the report with them or the findings with them, and if there's a possibility for some kind of gathering to more formally share those results that may be complicated with the nature of the populations that we're working with. Many of them are stigmatized and in some contexts criminalized, so there would need to be a lot of thought put in beforehand of exactly how you disseminate those findings specifically to that group if you're trying to form some kind of gathering, but I do think that it's important and just respectful to try to very deliberately share those findings with the population themselves who, again, took time to share their very deeply personal, sometimes traumatizing experiences with the research team.

>> SCARLETT BELLAMY: Thanks for that. Renice, did you have a hand up?

>> RENICE BUNDE: Yeah, maybe from the statistical organization, just the same way we go to them when we need the information, it's also our mandate to ensure that we disseminate the same information to them. But we can't really reach out to all the respondents, so we normally reach out to them through their networks, through their leaders, through the national administration, even religious organizations, through media. From our side, it's mandatory that we really, really have to share that information with them.

Because more often when it comes to interpretation of the information, because of late, quite a number of these groups have been sensitized or enlightened, and they really dig much into those reports. So, when it comes to interpretation and how to use some of those information, we really find it, like it's mandatory, and we normally do it, even using local channels among other methods. So, it's doable. From national statistical side.

>> SCARLETT BELLAMY: If I could ask one more question sort of related to that. Louisa, I believe in your talk, you mentioned this idea of ethical data sharing. Could you just sort of explain a little bit more about sort of, you know, what that means to you, what that means to your organization?

>> LOUISA YASUKAWA: So, in terms of the humanitarian sector (?) is really leading the way through its humanitarian data

exchange platform, the idea being that it encourages organizations, UN agencies, to share anonymized data sets with other organizations to inform their work. So, we're working to, as I said, to publish our data sets on the platform as well that we take for ethical practices, we try as much as possible to avoid duplicating research, so always conducting thorough literature reviews prior to conducting studies. And as I said, engaging with local partners at the research design stage is a really useful way of doing that, and then we take into account various factors when designing our research methods so, particularly sensitive to, for instance, even the language that we translate surveys into and which backgrounds the enumerators come from, again, to make sure that we can build that trust amongst respondents, and we don't collect any personally identifiable information.

So, the drawback on that being that we can't follow up after we've conducted these surveys, but the advantage being we're protecting their anonymity. And that actually links to the previous question that was raised, which is something that we have really hoping to work more towards, so avoiding that extractive approach to research where we survey people and then don't kind of share it back with them. So, we're trying to work out the best ways we can do that with the communities that we survey. So, as I said, we have the workshops with particularly the humanitarian community in those areas, but we're thinking about ways where we can even publicize it in community centers or areas where we know that the respondents that we engaged are likely to be so that once the study is published, they can access the findings. But at the moment, all we do is provide information of the organization and where they can find out more information on our research. So, yes, if anyone has more suggestions on ways we can do that, we definitely welcome any advice.

>> SCARLETT BELLAMY: Thank you for that. So, I'm looking at the clock here. And while this has been a wonderful and engaging discussion, we are nearing the end of our time together. I just want to formally thank each of the panelists for sharing their time and their thoughts with us this afternoon. And while I am sort of -- I regret that Liam became ill, I'm actually happy that I had a chance to sort of jump in and join you and moderate this afternoon. So, with that, I will turn it over to Dean Galea.

>> SANDRO GALEA: Thank you, Professor Bellamy, and thank you to our panelists, Louisa, Paul, Forrest, Renice. We spent a year thinking about how to construct this panel because it's a difficult topic to think about how to bring invisible populations to light. It's one of those topics that we knew is really important but we couldn't quite figure out an angle on it. And when we settled on this combination of panelists, I think we felt like we actually had the right frame to look at this topic from multiple directions. And the panel not only did that, but far exceeded expectations. I feel like I was learning from all of you as I was listening to your presentations and I was learning from all of you during the Q&A. Thank you. I'm really grateful to you all. I'm grateful to our audience always for participating in these events and I thank you once more to Professor Bellamy, who, of course, moderated last minute and did an outstanding job at it. Everybody, thank you for all you do for public health. Everyone have a good afternoon, good evening, or good day if it's morning where you are. Take good care.

(Session concluded at 2:28 p.m. ET)