# National Institutes of Health (NIH)

# National Institute of Child Health and Human Development (NICHD)

# INvestigation of Co-occurring conditions across the Lifespan to Understand Down syndromE (INCLUDE) Project

# Diversity, Equity, Inclusion, and Accessibility (DEIA) Webinar Series

# Value of Diverse Perspectives in Down Syndrome (DS) Research

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## Background

This webinar was designed to explore the importance of engaging diverse communities in research and to learn how to apply successes from other programs to DS research

Dr. Watson described the Research Program and its efforts to engage underrepresented communities and researchers in biomedical research, discussed how participant data reflects intersectionality within underrepresented communities, and highlighted what has achieved with its Researcher Workbench and data.

## A Precision Medicine Initiative

uses its resources to engage populations that have been historically underrepresented in biomedical research (UBR). The program has been intentional in addressing DEIA, and it emphasizes the intersectionality of research across the life span for UBR (and all) participants. has also been successful in achieving a diverse researcher network by collecting a large amount of data from diverse communities.

In 2015, the

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the science of engagement, retaining participants, equipping researchers, and creating a return-of-value cycle.

currently has 14 national engagement awardee organizations representing historically UBR populations: the American Association on Health and Disability (AAHD), Baylor College of Medicine, the Asian Health Coalition, Delta Research and Education Foundation, FiftyForward, the National Alliance for Hispanic Health, Pyxis Partners, the University of Utah, the National Baptist Convention USA, the Network of the National Library oT0 i0T /TT0 12 Tf(y)]pre (n)- (of t)3 w4.y7 (k)5 ( )-

highest grade level achieved of ninth through eleventh grade (5.8%), who are not covered by health insurance (6.5%), and who have been worried or concerned about not having a place to live within the last six months (16.3%). Connecting social information with genetic, biological, and environmental factors may allow researchers to better understand intersectionality across the life course and ask research questions that address health disparities. data could someday be used to build better tools for detecting health conditions, to determine how environment, lifestyle, and genes impact health, and to identify who is more likely to develop a disease. The cohort also includes UBR participants who identify into sexual and gender minority (SGM) groups (about 10%), report living with a disability (16.1%), and live in a rural community (7.1%).

One of the program's community partners, AAHD, invites participants living with disabilities to contribute to research to advance individualized treatment and care for all. With the vision statement of "Nothing About Us Without Us," AAHD has been instrumental helping develop disability definitions and metrics and brainstorm ways to include more populations, including people with intellectual disabilities. Stanford University PRIDEnet has been instrumental in helping engage with the SGM community and has provided education to ensure that researchers understand the correct language and cultural values to use when highest concentrations of Latinos (44%) are in Texas and California, but Hispanic/Latino populations are growing in every state. Even the northern states are seeing increases in Hispanic populations (North Dakota 135%, South Dakota 74%, Montana 72%). The Latino community's major challenges include lower levels of education and income, higher rates of poverty, and poor access to healthcare.

## Latino Clinical Trial Participation

The outcome was the development of a system-wide, mandatory minority accrual plan for all clinical trials. Now, any investigator who opens a clinical trial at the cancer center must write a minority accrual plan for enrolling as many participants as possible from the service area and must use a checklist to develop tools for the recruitment of minorities. Program coordinators translate informed consent forms and informational videos and help implement the many ways listed on the checklist to encourage clinical trial participation. These

Latinos are among the largest users of social media, the program has been successful using Facebook and webinars to reach its target audience.

To improve clinical trial enrollment, the UT cancer center uses the Salud America! model to develop bilingual, bicultural clinical trial educational resources. Latinos who have participated in a clinical trial are interviewed and asked about whether clinical trial participation is important and what kind of a difference participating has made in their life. Latino physicians are interviewed about their experiences and feelings on clinical trials. Beyond participation in clinical trials, the program promotes the need for biospecimen donation to speed research discoveries. The program also promotes NIH websites with clinical trial information and open trials available locally.

Furthermore, to ensure that providers do not make decisions for Latino patients, the UT cancer center is working to increase health care workers' knowledge of implicit bias. An educational program for providers, the "Find If You Have Implici/TT0 12 Tf -nHr Td ( )Tj Eave m6 (lic)3 (116.782 Tf 0.012 Tc .

long. It was hard to stay awake. Dr. Thrower: Jaia's first research experience was at Children's Hospital. The researcher was wonderful. It was hard for Jaia to stay awake, because at that time she was not sleeping well and would wake up in the middle of the night. So by the time we got to the appointment, she was extremely tired. The researchers had to figure out the best ways to keep her engaged.

important to think creatively about research designs that make sense. For example, Jaia was talking about research with Shequanna. During that study, Jaia was getting distracted. Jaia was tired but noticed that Shequanna had a pretty scrunchie in her hair. Shequanna said, "Next time I will bring you a scrunchie," and she did. She remembered, and she brought it. Shequanna was open to accommodating us with breaks and snacks; she was flexible and made accommodations that fit within the confines of the study. My concerns are that sometimes researchers are so stringent that they will not make accommodations.

Dr. Thrower: I always tell people about the best research study in which I participated. It included all the items listed on this slide: focus groups, bridge, no political agenda, compensation, flexibl-4 (h)0 612 792 re W*n BT 226.04 615.34 Td [(I a)-28.-3 (M)-4 (y co)12 792 r9e ab