

Investigation of Co-occurring conditions across the Lifespan to
Understand Down syndrome (INCLUDE)

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generalizable data. Simply having a translator is naïve. More measures for culturally appropriate behavioral phenotyping and behavioral science research are needed.

- A researcher suggested utilizing remote online programs that can be adapted and disseminated to different communities. During the pandemic, her group adapted burdensome activities, such as completing questionnaires, to be online activities. Outside programs could be used to translate questionnaires or consent forms to other languages to get a more diverse sample of community participants as well as global population samples.
- A researcher said that research participants grew tired of meeting researchers and investigators without any follow-up on the outcomes and how the research would help their lives. Also, some Asian communities have some stigma against children with

transportation, which a participant's parent or sibling would normally do. This was expensive, so ways to relieve the need for a consistent study partner would help.

- *A researcher said that bridging transportation gaps would help build a larger diverse sample. His team used DS-Connect® to recruit participants and had many responses from across the United States and one from another country. Lack of transportation was the primary barrier for not accepting these people, many of whom came from minority populations with no access to similar research in their hometowns.*
- *A researcher stated that his team often works with rare conditions and needs to recruit nationally. The team has partnered with advocacy groups and national organizations, but most of these groups are not diverse and provide the same pools of participants. He suggested thinking about ways that research organizations, perhaps including NIH, could help these organizations become more diverse.*
- *A researcher said it is important to budget for adequately compensating families and participants*

intentional collaborations have been successful in

and researchers. NIH can support efforts to increase diversity by melding clinical care with research, including community support in funding, and addressing the role of medical devices geared toward inclusion. Diversity, community-building, and technological solutions should be considered in the evaluation of every scientific study.

Attendance

23 Researchers

8 NIH

3 Unknown