

# Reducing Health Information Inequities in the Caribbean

## Why is this study needed?

Precision medicine is a new approach for disease prevention and treatment that considers an individual's genetic information, environmental conditions, and lifestyle. This approach depends on health information systems sharing data from a range of sources. In many settings, however, there are structural inequalities that limit the usefulness of previous data collection efforts. This project describes how the ECHORN data sharing workgroup is trying to advance health data sharing in the Caribbean.

## Who was involved?

The ECHORN data sharing work group includes representatives who come from civil society, public health, health policy, and academic institutions, and community settings. This work group is part of the same research network that hosts the ECHORN cohort study, which looks at risk and protective factors for non-communicable diseases in the Caribbean population.



## Study approach:

- The broad goals of the ECHORN data sharing workgroup are to find public health data for the Caribbean, build an accessible data sharing platform, and foster data sharing efforts in the Caribbean.
- The first project is to build a free public web site to share population-level data from the ECHORN cohort study with community residents. This web site will allow users to conduct simple analyses with the data. The site will adhere to ethical standards for protecting privacy and confidentiality.

## Future Impact:

*The ECHORN data sharing workgroup uses regional collaboration to improve data sharing in the Caribbean. The workgroup includes members from different backgrounds to understand a range of perspectives and increase the reach of how information is shared. The workgroup's first major project will be to create a web site to share data from the ECHORN cohort study. This is an important step in the broad goal of contributing to research and advocacy efforts that improve Caribbean health outcomes.*

Citation: Wang K, Hambleton I, Linnander E, Marenco L, Hassan S, Kumara M, Fredericks LE, Harrigan S, Hasse TA 2nd, Brandt C, Nunez-Smith M; ECHORN Writing Group. Toward Reducing Health Information Inequities in the Caribbean: Our Experience Building a Participatory Health Informatics Project. *Ethn Dis.* 2020 Apr 2;30(Suppl 1):193-202.