Research Summary: Data sharing in the context of community-engaged research partnerships

- The National Institute of Health (NIH) **implemented a policy to improve the sharing of research data** in January 2023.
- The Rapid Acceleration of Diagnostic Testing in Underserved Populations (RADx-UP) initiative was an **opportunity to provide a community perspective on data sharing.**

Scan QR code to read the full paper!

WHO PARTICIPATED

- Community-engaged researchers from the Implementation Science Center for Cancer Control Equity (ISCCCE).
- The Massachusetts League of Community Health Centers.
- RADx-UP Community Advisory Board.

WHAT WE DID

- During the two-year RADx-UP study:
  - We **held meetings with members** of the study partnership and RADx-UP Community Advisory Boar**d** to gather multiple views on sharing community-level data.
  - We **learned from the experiences of the Mass League informatics team** in sharing community-level data.

WHAT WE RECCOMMEND

Without effective community engagement and rich contextual knowledge, biases resulting from data sharing can remain unchecked.

Several recommendations would allow **better community engagement** related to data sharing:

- Create community-informed, simplified and collaborative Data Use Agreements (DUAs)
- Ensure community understanding of data use and outcomes
- Ensure researcher understanding of community context
- Track data use
- Ensure benefit sharing
- Develop models for evaluating impact

ISCCCE | IMPLEMENTATION SCIENCE CENTER FOR CANCER CONTROL EQUITY