

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.**



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WHO PARTICIPATED



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

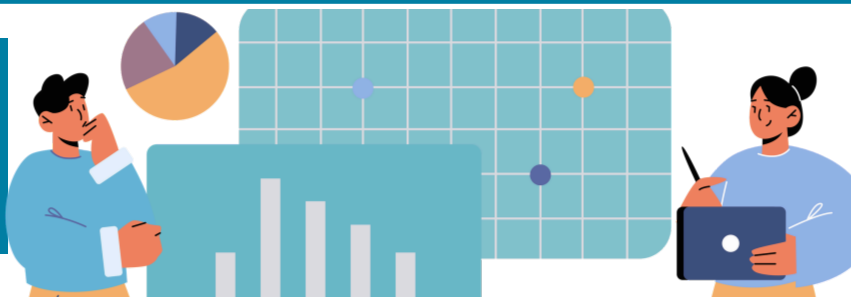
WHAT WE DID

During the two-year RADx-UP study:

- We **help meetings with members** of the study partnership and RADx-UP Community Advisory Board to gather multiple views on sharing community-level data.
- We **learned from the experience of Mass League** informatics team in sharing community-level data.

WHAT WE RECOMMEND

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 User 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

