# Data Sharing in the Context of Community Engaged Research

## Community Engaged Scholarship Forum
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On behalf of The Pittsburgh Study Core Team, which includes Jamil Bey, Val Chavis, Felicia Savage Friedman, Bob Gradeck, Elizabeth Miller, Deb Moore, Judith Navratil, and Amy Snider.

# Community-Engaged Research has set new expectations

- CER is carried out **in collaboration with community** members

- **Academic researchers must build trust** by demonstrating that the work will be done transparently and in line with community needs and interests

- Community members can expect some level of **reciprocity**

- **Access to scientists and research tools** can provide communities with evidence needed for changes in policy / practice

- Community involvement improves the **validity, feasibility, and impact** of science

# What is Data Sharing?

- Increasingly, research funders and publishers **require** data sharing
- Data is **collected and analyzed** by individual studies
- The **investigator makes the data available** to the research community via website/ institutional process
- Data can be **examined and re-analyzed** by other researchers

# NIH Data Sharing policy requires that:

Starting Jan 2023, data sharing will be:

- The **default** practice (not sharing must be justified!)

- **Responsibly** implemented

- Prospectively **planned** for at all stages of the research process

A CER research team, led by a university professor in collaboration with community members, carries out a study of drug use and educational attainment among teens. Neighborhoods are randomized to offer programming designed to prevent drug use or to offer other activities as a 'control' treatment. Survey data is collected from participants at recreation centers at study baseline and end-of-program. Changes in reported attitudes and behaviors across these timepoints are compared across neighborhoods by assigned treatment group. The research team also compiles local education and crime data, by neighborhood, as secondary outcomes. At the end of the trial, the research team analyzes the data and presents findings which show no effect of the intervention program on reported drug use among teens. An outside researcher requests the data.

*What concerns do you have about sharing this data?*

*What practices or policies could be put in place to address concerns?*

# Conflicts between CER and Data Sharing

- Will researchers understand local data outside of its context?

- Will their work misrepresent or stigmatize the communities involved in the study?

- Will sharing data harm the relationships and trust that the primary researchers have worked to build?

- How can the community or the participants benefit from secondary analyses of data?

# Issues with data sharing (individual)

- Risk of **reidentification**
- Data **security**
- Appropriate **consent** processes

# Issues with data sharing (group)

- No established **relationship**
- **No processes** for consent/engagement at community level
- Risk of **stigmatization**

# When preparing a grant, researchers will put together a data plan

▪Decide which data should be collected

▪Decide which data should be shared

▪Make plans and a budget for management, deidentification, sharing of data

*Grant application*

*Consent form*

▪Community should be involved early on to take part in these decisions

# We must develop

- New Norms for Secondary Analyses
- New Models for Participant and Community Involvement
  *Consent and re-consent*
  *Engagement and reciprocity*
    *Share-backs at community and individual levels*
    *Data analysis and interpretation*
    *Dissemination and action*
- New processes and infrastructure for long term relationships with communities and participants
  *Block chain or registry based models to allow ongoing consent, information sharing*

"Do not mistake the availability of the data as permission to remain at a distance."

All data are local by Yanni Alexander Loukissas

# Questions or Comments?