Roundtable Discussion:
Community Centered Data Practice

November 19, 2021

Hosted by the Social Policy Institute at Washington University in St. Louis, in partnership with the Mastercard Center for Inclusive Growth, the St. Louis Regional Data Alliance, and data.org.
Who’s in the Zoom?

Please post into the chat:

○ Your name

○ Organization/Affiliation
OBJECTIVE: Develop a set of trainings and resources for St. Louis social sector organizations seeking to utilize data more effectively to increase impact and promote equitable outcomes.
How Can a Data-Informed Social Sector Amplify Impact in St. Louis?

Roundtable participant + Advisory Committee feedback

Mapping Your Data Journey from Vision to Impact
Using Data to Promote Equitable Outcomes
Community-Centered Data Practice

DSSI Trainings and Resource Development
Roundtable goals:

• Facilitate dialogue about data governance by centering two critical questions: Who benefits and who decides?
• Gather feedback about what tools and resources would help social sector organizations move forward in this area

Roundtable format:

• Speakers will share some thoughts and frameworks for thinking about data governance through an equity lens
• Participants join in the discussion in breakout groups and dive deeper together
• Report back and key takeaways
Roundtable Presenters

Paul Sorenson, Director, St. Louis Regional Data Alliance

Riisa Rawlins-Easley, Chief of Staff, St. Louis Regional Health Commission
Community-Centered Data Practice

Data Protection, Data Sharing, & Who Benefits

Riisa Rawlins-Easley, St. Louis Regional Health Commission
Paul Sorenson, St. Louis Regional Data Alliance
Governance!

**Defined:** “[The] process of... overseeing the control and direction of something” (Merriam-Webster)

- Centering Community
- Data Protection
- Data Sharing
- Who Benefits
Data Governance!

**Defined:** “The process of establishing and ensuring the freedoms, constraints, and incentives that determine how two or more parties agree to conduct the ingress, storage, protections, use, and egress of data, tools, methods, and knowledge amongst themselves and with others.”

*(Sage Bionetworks)*
Data Governance??

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*(Sage Bionetworks)*

**Questions:**

- Who has what rights and how will those rights be asserted?
- How does this process get established? How are stakeholders represented in that process?
- Which parties?? How does one become a party??
- How do we know what needs to be protected??
- Under what circumstances will parties be removed? How?
- By what criteria? How will the results be evaluated?
- What happens when everyone acts as they agreed but something still goes wrong??
- Which parties??
Key Questions for Today

What needs to be governed above & beyond “data”?

What systems need to be in place for effective data governance to occur?

How do we ensure that these systems are equitable in process and outcome?
Governance IRL

- Clients and Patients
- Social Services
- Healthcare Providers
- "Backbones"
- Community Leaders
- Funders
- Technology Platforms
- Local Governments
Primary Components of “Community Information Exchanges”

RESOURCES DATA EXCHANGE
- ORGANIZATIONS
- LOCATIONS
- SERVICES

CLIENT DATA EXCHANGE
- Shared Vocabularies
- Balance of Health and Social Service Context

COMMUNITY DATA GOVERNANCE
- Impact on INDIVIDUALS
- Impact on SERVICE PROVIDERS
- Impact on COMMUNITIES

STANDARDS AND PROTOCOLS
- IDENTIFY
- CONTEXT
- ACTIVITIES
- CONSENT

OPEN ACCESS INFRASTRUCTURE

bit.ly/socialcaredatapdf
Community-Centered Governance

- Who Benefits?
- Who Decides?

- Impact on Individuals
- Impact on Providers
- Impact on Communities
The St. Louis Regional Health Commission

The RHC is a network of individuals with responsibility and commitment to improve health in St. Louis.

The mission statement of the RHC is to increase access to health care for people who are medically uninsured and underinsured, reduce health disparities and improve health outcomes among populations in the St. Louis City and County region.
Transition Task Force

**CHARGE:**
As appointed by the Chair of the Commission, the goal of the St. Louis Regional Health Commission Transition Task Force is to lead the strategic planning and branding efforts for the next phase of the RHC.

The charge of the task force is to:
- Review healthcare coordination landscape in the St. Louis region and complete an analysis of the gaps and needs in the healthcare system.
  - Determine the need of the RHC for the future
- Develop recommendations for the strategic direction of the RHC post the implementation of Medicaid Expansion.
- Develop recommendations for branding changes to the RHC, as needed.

The RHC Transition Task Force will solicit input and feedback from the Commission, Ad Boards, and the boards of partner organizations, as needed.
Stakeholder Representation

- Policy/Advocacy
- Community Advocates
- Board Members
- Partner Organizations
- Public Health Departments
Opportunity Statement

Because the STLRHC is transitioning its operations to understand the underinsured and uninsured landscape in the context of Medicaid expansion in the state of Missouri, our approach is designed to empower the commission and its stakeholders to create and execute strategic priorities in becoming the national leader in regional health advocacy.
VISION
We envision the St Louis region committed to achieving zero health disparities through a community driven approach that yields health equity in all policy and outcomes.

MISSION
The RHC will serve as a regional model for bi-directional relationship building and shared decision making that harnesses the power of systems and communities to foster accountability and improve equitable healthcare access and outcomes particularly for communities of color.
## Vision
We envision the St. Louis region committed to achieving zero health disparities through a community-driven approach that yields health equity in all policy and outcomes.

## Mission
The RHC will serve as a regional model for bi-directional relationship building and shared decision making that harnesses the power of systems and communities to foster accountability and improve equitable healthcare access and outcomes particularly for communities of color.

### Transformational Impact
- Regional Coordination
- Increased Access
- Zero Health Disparities
- Community-driven Policy Change
- Responsive Systems
- Improved Workforce Capacity
- Shared Data System

### How?
- Champion solutions
- Translate information
- Change and inform policies
- Harness collective power/shared power

### With whom?
- Strategic Partners
- Healthcare Organizations
- Public Health Departments
- Community Organizations
- Government Sector
- Elected Officials
- Business Sector
- Criminal Justice Sector

### Drivers
- Equity
- Community-centered
- Power sharing
- Bi-directional Communication
- Choice
- Accountability
- Anti-racism
- Relationships
Action Plan

- Regional Coordination and Communication
  - To execute equity-centered agenda for Health and Well-Being

- Shared Data Reporting
  - To measure efforts to achieve zero health disparities and foster accountability

- Community-Driven Policy Change
  - For Health Equity and Well-Being

- Increased Workforce Wellness and Capacity
  - To address Emerging Needs
Community-Centered Governance

- Who Benefits?
- Who Decides?

- Impact on Individuals
- Impact on Providers
- Impact on Communities
Contact Info

Riisa Rawlins-Easley: reasley@stlrhc.org
Paul Sorenson: sorensonp@umsl.edu
We want to hear from you! You will be automatically assigned. Your breakout facilitator will be with you shortly.
• Where is there a disconnect between those impacted and those deciding?

• How is data implicated by such decision making?
Thank You!

Three Things You Can Do:

1. **Share your thoughts and ideas with us!**
   - Fill out a 5 minute survey on this roundtable series (link in chat)
   - Get in touch by emailing jenrose@wustl.edu

2. **Bring the conversation back to your organization.**
   - How is your organization grappling with these important questions: who benefits and who decides?

3. **Become a member of the St. Louis Regional Data Alliance.**
   - Visit https://stldata.org/ to learn more!