

FHCQ | Social Needs and Health Equity Steering Committee

Storing and Sharing Data Workgroup
September 13th, 2022 | 8:00 – 9:00 a.m.
Virtual

MEMBERS PRESENT

Dwayne Taylor, One Health Port
LeAnn Blanco, Washington Health Benefits
Exchange

Ryan Williams, Molina Healthcare
Ginny Weir, MPH, Foundation for Health Care
Quality

STAFF AND MEMBERS OF THE PUBLIC

Nick Locke, MPH, Bree Collaborative
Karie Nicholas, MSc, Bree Collaborative

WELCOME

Nick Locke, Bree Collaborative, welcomed the group to the Storing and Sharing Data workgroup, an ad-hoc workgroup of the Social Needs and Health Equity Steering Committee. Members briefly introduced themselves. Mr. Locke introduced August minutes and requested changes via email.

REVIEW: DELIVERABLES

Mr. Locke briefly reviewed the group's three buckets of deliverables:

- Report/Discussion: the workgroup will identify best practices for data collection as advancing personal and public health, regulations governing data sharing, and data ethical principles
- Data Outline/Capabilities Best Practices: the workgroup will identify common use cases, capabilities required for each use case, and best practices/potential standards for meeting each capability.
- Implementation Considerations: the workgroup will identify major barriers/concerns for implementing new data architecture and offer solutions.

Workgroup members affirmed their goals/deliverables.

DISCUSS: USE CASES AND NEXT STEPS

Mr. Locke shared potential use cases drawing on the Gravity Project's previous work. The three use cases borrowed from the Gravity Project include: patient interface to input social needs, communication of social need for closed loop referrals, and communication of aggregate social need information for data analytics. The workgroup members discussed use cases and what to do next.

- Workgroup members discussed including demographic (race/ethnicity, sexual orientation/gender identity, disability) data in the common capabilities. The workgroup decided to start smaller with social need information and not endorse standards for demographic data beyond what is already required by ONC.
- Workgroup members discussed other use cases developed by the Gravity Project, including related to public health and business use cases. We may want to address this use cases throughout our capabilities work.
- Many of the use cases are a combination of use case and capabilities. They will draw from a similar data architecture/flow. Perhaps it will be more useful to develop an outline of steps and capabilities and work from there?

Workgroup members agreed that the best next step would be to develop an outline of common capabilities in a broad data framework. From there, the workgroup can see what recommendations/standards already exist (especially borrowing from various Gravity Project workgroups), and offer solutions for organizations to reach those standards/recommendations.

- Mr. Taylor offered to draft an outline of the important capabilities.
- Mr. Locke and Ms. Nicholas will review the capabilities and map them to existing recommendations.
- The entire workgroup will reconvene to review the outline at the October meeting.

Before closing, the workgroup discussed premises/assumptions to guide the work. Mr. Williams suggested two assumptions to inform the standards.

- Assumption 1: all programs have an electronic health record. We know this isn't the case, and perhaps we can include some language in the implementation section about how to use existing resources to develop EHR systems. For our data architecture outline, however, we should assume that organizations storing and sharing data have an EHR.
- Assumption 2: we will align with guidance from CMS/ONC when available. This specifically means that we will be recommending FHIR resources for alignment. Again, not all organizations have adopted FHIR yet, but this is the direction that healthcare is moving, and it will help facilitate alignment with other programs.
- Workgroup members discussed other premises to consider:
 - Our goal is to ensure data collection is as integrated with EHRs as possible to facilitate ease of use.
 - Another assumption we should put forward is that each organization agrees to use established statutes for ethical standards related to consent management, data autonomy, and others. We will need to do more work to define what ethical standards we want to uphold.

PUBLIC COMMENT AND GOOD OF THE ORDER

Mr. Locke thanked workgroup members for attending and discussed next steps. Between this meeting and October, the workgroup will develop an outline of capabilities to meet the intended use cases and cross-walk the use cases with existing recommendations. The workgroup will reconvene to discuss the outline at their October meeting. The workgroup's next meeting will be held on Tuesday, October 11th from 8:00 – 9:00 AM.