Considerations for Collecting, Sharing, & Analyzing Data

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It is important to anticipate data challenges that may be encountered when designing and implementing integrated healthcare delivery transformation and payment reform initiatives on multi-stakeholder teams.

This guide will help you answer three overarching questions:

/ Whose buy-in do you need to sustainably scale up a successful initiative?

/ What data do you need to collect to address all stakeholder interests?

/ How will you use that data during various stages of the initiative?

Whose buy-in do you need to sustainably scale up a successful initiative?

This is perhaps the most important question multi-stakeholder teams should consider as they begin to design and plan for their healthcare delivery and payment reform initiatives. While teams typically think about who is instrumental for the implementation of projects, often what is missed is a discussion about which stakeholders, both internal and external, are necessary for the sustainability of the project.

For example, if a project is 'successful' according to the provider team, does that also mean success for Medicaid managed care organizations, or would they use a different set of criteria? Consider all internal and external stakeholders who will decide whether or not to implement and continue the project (e.g. state Medicaid agency personnel, hospital administrators, community organization partners, etc.).

Data Consideration 1: Lack of agreement or understanding from the team on what metrics signal 'success' for the initiative.

/ What specific outcome is your project aiming to achieve? Is there agreement across stakeholders?
   o Will achieving this outcome address the identified health disparity? How?

Sometimes projects that are deemed successful per the outcomes outlined in question 1 will still fail to convince those who have the power to determine whether or not to commit to expanding or sustaining the project over the long-term. It is important to consider all perspectives for those impacted and involved before a project starts and anticipate their sometimes unique information and data requirements.

/ Whose buy-in at the provider, community, managed care, and state Medicaid levels is required for short-, mid-, and long-term sustainability?

/ Identify the specific information required by each of the stakeholders listed in question 2 that would allow them to make a determination regarding the long-term sustainability of the equity-focused, integrated payment and health care delivery reforms (e.g., specific health outcome variables, specific financial data). Think about information desired at varying stages such as planning, implementation, mid-point check-ins, and evaluation.

Data Consideration 2: Staff and organizational buy-in is necessary for the collection and reporting of new and existing data.

Consider what staff are going to be asked to do and if they are required to do anything different or new regarding data collection and reporting. Once your organizations have decided what existing data you want to use, and/or if there is new data to be collected, here are a set of questions to help you think through common data challenges pertaining to staff buy-in:

/ Do mid- and upper-level managers agree that this data is important to collect?

/ Do staff at all levels understand what this data will be used for?

/ Do all staff have the necessary administrative support and training to properly collect and report the required data?

Certain questions may be sensitive for Members to answer for reasons unbeknownst to staff. For example, if staff ask Members about their sexual orientation and a family member is present, the Member may not feel comfortable or safe in providing an honest answer.

/ Have all staff received the necessary training and resources to help them communicate with members for why they are collecting data if a member were to ask?

Data Consideration 3: Medicaid Member buy-in on data collected directly from Members is a necessary part of accurate data collection with an equity lens.

Members should be included in conversations about why you want to collect data from them and have a role in determining how it will be collected and used.

/ How will you engage with Medicaid Members regarding data collection procedures such as screening for social needs or collection of sensitive demographic information?
   o What concerns might Members have regarding the sharing of data? For example, Members may be concerned about their privacy if you are sharing data with a community-based organization.
   o What data and/or outcomes are important to Members?

What data do you need to collect for this initiative?

Most projects will define ongoing process and outcomes measures to be able to effectively track the progress of the initiative as well as be able to make any mid-project adjustments. Knowing upfront what data will be required to track process and outcomes measures will be essential to monitoring collection of data for the implementation and analysis of the project.

Data Consideration 4: Despite staff training, there may be a lack of consistency in the data collection and reporting procedures.

Regardless of providing staff training, there may still be inconsistencies in the way the data is collected from Members and/or reported in the EHR. This is especially true if not all health care providers in your network use the same EHR.

/ Will all the data be collected at the same provider locations? Different provider locations?
  o If data is collected at different locations, will the data collected and stored in a central place, such as a shared databased, for staff to access and record?

/ Who is responsible for ensuring the data collection and reporting processes are adhered to?

Data Consideration 5: Data collected may have different definitions or meaning to different people.

Definitions are important. They are even more important when we are drawing conclusions from data that depends on the same meaning of words or categories. For example, some sites may collect data on smoking status, and consider a "smoker" to only include someone who uses nicotine products, while other sites may consider a "smoker" to include someone who uses nicotine or marijuana products.

/ If you are collecting demographic information (i.e. racial, ethnic, sexual orientation, gender identity, or language) and are sharing the data, do other partners use the same definition/criteria?

/ For any outcomes relevant to the initiative, will partners use the same definition/criteria?

/ Will you collect data using the same tools? For example, will all stakeholders be using the same social needs screening tool? Health risk assessment components?

How will you use that data during varying stages of the initiative?

Understanding how you will use data collected requires an understanding of not only what data is collected, but who will require the data and in what format for various stages of the initiative.

Data Consideration 6: The success of a project may rely on readily available data needed to continually assess project.

In addition to process and outcomes measures, stakeholders who are instrumental in determining the sustainability of your initiative may require different data than what you are collecting.

/ Do the required ongoing reports necessary for your healthcare delivery transformation and payment reform initiative already exist? If not, can they be built in a timely manner? Who will build them?

/ What data will you need in an ongoing basis in order to process any new payment reform initiatives? For example, if staff have to report new data in order to get an incentive as part of the payment reform, is that data easily accessible and reconcilable?

Data Consideration 7: Permission to share data throughout the project, beyond the identification phase, is often required, but overlooked.

While getting access to data in order to identify a disparity can be time consuming, it is likely that teams will also require continued access to shared data throughout the duration of the project. If possible, it may be easier to extend the timeline for Data Use Agreements (DUA) to include the duration of the project. In addition to DUAs, some data such as a substance use disorder or mental health diagnosis may preclude stakeholders from sharing patient data.

- If you used shared data to identify the disparity, will you need continual access to that data to track implementation and/or outcomes of the initiative?
  - o Do you need a data use agreement (DUA)?
  - o If sharing with community-based organizations, are these organizations HIPAA compliant?
  - o Do you have permission to share all data from shared sources?

- Will any of the data shared or received from shared sources contain sensitive information (e.g. AIDS diagnoses, SUD diagnoses, mental health, etc.)?
  - o Are all partners HIPAA compliant?

- How will the identified stakeholders be kept up to date on projects goals?
  - o How will data be pulled/shared?

Data Consideration 8: Shared data may come from different sources.

When working on complex projects such as this Learning Collaborative, it is likely that data will be drawn from several sources, and may include data from the health care providers, Medicaid managed care organization, State Medicaid agency, community-based organizations, and/or other primary or secondary data. Making meaningful use of this data can be time consuming, though impactful.

- If multiple different data sources, such as EMR and claims data, have to be reconciled, which stakeholder will be responsible for the merge?
  - o Will you need to merge data sets from multiple provider sites?
  - o Will you need to merge any data between state, plan, and/or provider?
  - o If so, is a common format agreed upon in advance of collection?

- What reporting measures are used by stakeholders? (i.e. HEDIS measures, ICD-10 Codes, LOINC (Logical Observation Identifiers Names and Codes, database & universal standard for identifying medical lab observations), SNOMED (Systematized Nomenclature of Medicine)?

- Are the data in a consistent place and format? (Consider formatting such as text boxes, free form text, drop down pick list, etc.)

- If certain data points, such as closed-loop referrals, depend on external data from community-based organizations, who will merge the data? Is the data format agreed upon in advance?
  - o How will you receive patient-level data from community-based organizations?

- How will the community-based organizations be kept accountable to submitting the data at regular intervals?