## Purpose:

This discussion guide will help you anticipate and investigate data challenges related to collecting, sharing, and analyzing data throughout the various stages of a healthcare delivery transformation and payment reform initiative. This document will help your team answer overarching questions related to project sustainability, stakeholder interest, and data usage such as:

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

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

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

After your team has reviewed the sections that correspond with the questions below, they should set aside time to work together to complete the Considerations for Collecting, Sharing, & Analyzing Data Worksheet.

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

This is perhaps the most important question 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—internal and external—are necessary for project sustainability. As you plan your initiative, consider all internal and external stakeholders. For example, do the provider teams, Medicaid-managed care organizations, and community-based organizations all define success the same way? 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 a successful initiative.

Sometimes projects that are deemed successful according to specific outcomes still fail to convince those with the power to determine whether a project is sustained or expanded over the long-term. It is important to consider their perspectives before a project starts, anticipate their particular information and data requirements, and, if possible, gain agreement across stakeholders about project goals.

What specific outcome is your project aiming to achieve? How will achieving that outcome address the identified health disparity?

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

2. Identify the specific information required by each stakeholder listed in the previous question 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 the 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.

1. Although a program's merits may be widely recognized or acknowledged, you still may have trouble achieving staff buy-in. Once your organizations have decided what existing data you want to use, and/or if there is new data to be collected, consider if staff will be required to do anything different or new regarding data collection and reporting and their comfort level with those tasks. For example, if they are going to ask members for sensitive information related to sexual orientation, consider (re)training staff on how to collect data in a culturally responsive manner. Do mid- and upper-level managers agree that the data is important to collect? At what points do they diverge?

2. Do staff at all levels understand what the data will be used for?

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

4. Have all staff received the necessary training and resources to help them communicate with members that preserves their privacy and autonomy as individuals regardless of age, language, race, gender, disability, or sexual orientation?

## 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. For example, members might let you know that collecting data via phone surveys is not preferred and will offer up alternative options.

1. How will you engage with Medicaid Members regarding data collection procedures such as screening for social needs or collecting sensitive demographic information?
2. What concerns might Members have regarding how and with whom data is shared?
3. How will your team determine what data and/or outcomes are important to Members? How will you illustrate that you've taken their concerns seriously?

## What data do you need to collect for that initiative?

Most teams will set aside time to define ongoing process and outcomes measures to be able to effectively track the initiative's progress and make any mid-project adjustments. Knowing upfront what data will be required to track process and outcomes measures is essential to monitoring collection of data for the project's analysis and implementation.

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

Despite staff training, there may still be inconsistencies in the way the data is collected from Members and/or reported in the electronic health record (EHR). This is especially true if health care providers in your network use different EHRs.

1. Will all the data be collected at the same or different provider locations?
2. Will the data collected and stored in a central place, such as a shared database, for staff to access and record?

3. Who is responsible for ensuring that data collection and reporting processes are followed?

### 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 define a smoker as someone who uses nicotine products, while other sites may define a smoker as someone who uses nicotine **and/or** marijuana products.

1. 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?

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

3. Will all stakeholders collect data using the same tools? If not, how will you anticipate and mitigate potential data collection problems?

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

Understanding how you will use data collected in various stages of the initiative requires an understanding of which data is collected, who will require the data and in what format. Although it may be time consuming, making the effort during the initial planning stages to understand permissions associated with sharing data from various sources, the specifics of Data Use Agreements (DUA), and how data will be pulled and shared will ultimately be beneficial for your initiative.

### Data Consideration 6: A project's success may rely on readily available data needed for continual assessment.

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.

1. Have the required ongoing reports already been created? If not, can they be built in a timely manner? Who will build them?

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

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

It is likely that teams will require continued access to shared data throughout the duration of the project. If possible, consider extending the timeline for DUAs to include the duration of the project. Apart from DUAs, some data (such as a substance use disorder or mental health diagnosis) may preclude stakeholders from sharing patient data.

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1. If you used shared data to identify the disparity, will you need continual access to that data to track implementation and/or outcomes?
2. Do you need a DUA?
3. Do you have permission to share all data from shared sources?

4. Will any of the data shared or received from shared sources contain sensitive information (e.g. AIDS diagnoses, SUD diagnoses, mental health, etc.)?

5. Are all partners—including CBOs—HIPAA compliant? If not, how will that impact your next steps?

6. How will the identified stakeholders be kept up to date on projects goals?

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

When working on complex projects (such as the AHE Learning Collaborative) it is likely that data will be drawn from several sources, and may include information from the health care providers, Medicaid managed care organization, State Medicaid agency, and/or CBOs. Consider having stakeholders agree upon a common format in advance of collection as well as keeping a record of which reporting measures are used for stronger communication among teams.
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1. If multiple different data sources, such as EMR and claims data, have to be reconciled, which stakeholder will be responsible for the merge? Will you need to merge data sets from multiple provider sites or among states, plans, and/or providers?

2. What reporting measures are used by each stakeholder (i.e. HEDIS measures or ICD-10 Codes)?
3. Consider formatting issues that if left ignored, could potentially complicate how data is interpreted from person to person (e.g. text boxes, free form text, drop down lists, etc.
4. If certain data points, such as closed-loop referrals, depend on external data from community-based organizations, who will manage the data?
5. How will you receive patient-level data from stakeholders and how will they be held accountable to data submission timelines?