Considerations for Accessing, Collecting, and Sharing Data

///AHE Advancing Health Equity
/ Leading care, payment, and systems transformation

Updated March 2023

Purpose

This tool provides guidance on how to plan for data opportunities and challenges that your team may encounter when designing and implementing your health equity care transformation and payment reform initiatives.

This guide will help you answer three overarching questions, with an emphasis on accessing, collecting, and sharing data:

- 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 teams should consider as they begin to design and plan for their care transformation 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, individuals with Medicaid, community members, etc.).c

Data Consideration #1:

Identification of metrics to signal "success" for the initiative

- What specific outcome is your initiative aiming to achieve? Is there agreement across stakeholders?
  - Will achieving this outcome address the identified health disparity or inequity? How?
  - Sometimes projects that are deemed successful per the initially agreed-upon outcomes

Robert Wood Johnson Foundation

will still fail to convince those who have the power to commit to expanding or sustaining the project. It is important to consider all perspectives for those impacted and involved before an initiative starts and anticipate their 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 that would allow them to make a determination regarding the long-term sustainability of the equity-focused, integrated payment and care delivery reforms (e.g., specific health outcomes data, specific financial data). Think about information desired at varying stages such as planning, implementation, midpoint 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 all staff involved in data collection (e.g., front line staff, 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 and what it will not be used for?
- Do all staff have the necessary administrative support, infrastructure, and training to properly collect and report the required data?
  - Certain questions may be sensitive for people to answer for reasons unbeknownst to staff. For example, if staff ask individuals about their sexual orientation and a family member is present, the individual 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 individuals about what data is being collected and why? Have they been trained to be sensitive and discreet when asking potentially sensitive questions?

Data Consideration #3:
Earning buy-in from individuals with Medicaid on data collection is a necessary part of accurate data collection with an equity approach

Individuals with Medicaid should be included in conversations about why you want to collect data from them and have a role in determining how data will be collected, used, and what data will not be used for.

- How will you partner with individuals with Medicaid regarding data collection procedures such as screening for social needs or collection of sensitive demographic information?
  - What concerns might these individuals have regarding the sharing of data? For example, there may be concerns about privacy if you are sharing data with a community-based organization or their health care provider. Have you worked with individuals and community members to identify these concerns?
  - Will there be opportunities for individuals to revoke data they have previously shared?
  - How will you assess and mitigate fatigue some community members may feel with providing data?
- What data and/or outcomes are important to individuals with Medicaid to incorporate into new data collection and reporting efforts?

Robert Wood Johnson Foundation

What data do you need to collect for this initiative?

Most projects will define ongoing process and outcome measures to be able to effectively track the progress of the initiative and make mid-project adjustments. Knowing upfront what data will be required to track process and outcome measures is essential to monitor implementation and evaluate the project.

Data Consideration #4:
Ensuring consistency in the data collection and reporting procedures

Even with comprehensive staff training, there may still be inconsistencies in the way the data is collected and/or reported in the electronic health record (EHR). This is especially true if not all healthcare providers in your network use the same EHR.

- Will all the data be collected the same provider locations? Different provider locations?
  - If data is collected at different locations, will the data be collected and stored in a central place, such as a shared database, for staff to access and record?
- Who is responsible for ensuring the data collection and reporting processes are adhered to?
- How will data be validated? What will be the "source of truth" in cases of conflicting data?

Data Consideration #5:
Data collected may have different definitions or meaning to different people and stakeholders

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 healthcare organizations may collect data on smoking status and consider a "smoker" to only include someone who uses nicotine products, while other healthcare organizations may consider a "smoker" to include someone who uses nicotine or marijuana products.

- If you are collecting demographic information (e.g., race, ethnicity, language, disability status, sexual orientation, gender identity) 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 use the same social needs screening tool? Health risk assessment components?

How will you use that data during the initiative?

Understanding how you will use data 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 having readily available data to continually assess the 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 typically collect.

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

Robert Wood Johnson Foundation

- 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 get an incentive payment as part of the reform, is that data easily accessible and reconcilable?

Data Consideration #7:
Guaranteeing permission to share data throughout the project, beyond the identification stage

While getting access to data in order to identify a health disparity can be time consuming, it is likely that teams will also require continued access to shared data throughout the duration of the initiative. If possible, it may be easier to extend the timeline for Data Use Agreements (DUA) and nondisclosure agreements (NDA) to include the duration of the project. In addition to DUA, HIPAA compliance and compliance with additional regulations related to sensitive topics such as substance use disorders or mental health diagnoses may complicate the ability of stakeholders to share some patient data.

- If you used shared data to identify the health disparity, will you need continual access to that data to track implementation and/or outcomes of the initiative?
  - Do you need a DUA?
  - Are all partner organizations HIPAA compliant?
  - 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., HIV/AIDS diagnoses, substance use disorder diagnosis)?
- How will the identified stakeholders be kept up to date on initiative goals?
  - How will data be pulled and 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 provider, Medicaid managed care organization, state Medicaid agency, community-based organization, and/or other primary or secondary data. Making meaningful use of this data can be time consuming, but impactful.

- If multiple different data sources, such as EHR and claims data, have to be reconciled, which stakeholder will be responsible for merging data?
  - Will you need to merge data sets between multiple provider sites?
  - Will you need to merge any data between state, plan, community-based organization, and/or provider?
  - If so, is a common format agreed upon in advance of data collection?
- What reporting measures are used by stakeholders (e.g., HEDIS, ICD-10 codes, LOINC [Logical Observation Identifiers, Names, and Codes – the database and 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 text, drop down menus, etc.
- If certain data, 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?
  - How will health care organizations receive patient-level data from community-based organizations?
- How will accountability be assessed? For example, how will the community-based organizations be kept accountable to submitting data at regular intervals? How will health care organizations be kept accountable to sharing their data with their communities?

Next Steps and Timeline

Based on the answers to the questions above, list the next high-priority tasks that your team needs to complete, a target data for completion of each task, and the person/people responsible.

Next Steps		
Task	**Target Completion Date**	**Person Responsible**

www.advancinghealthequity.org

Robert Wood Johnson Foundation