

Steps for Engaging Patients and Community Members in Data-Driven Quality Improvement

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TAKEAWAYS

- Data is a powerful tool to guide health care improvement efforts, so it matters how health systems use data and who they engage as partners in that process.
- Partnering with patients and community members throughout data-driven quality improvement efforts keeps health systems focused on what matters most to patients and their communities.
- It is important to engage patients and community members throughout all stages of using data, from clarifying goals through collecting and analyzing data, making sense of what information means, and taking action in response.
- This tool outlines practical considerations to help health care organizations partner more effectively with patients and community members on data-driven quality improvement projects.

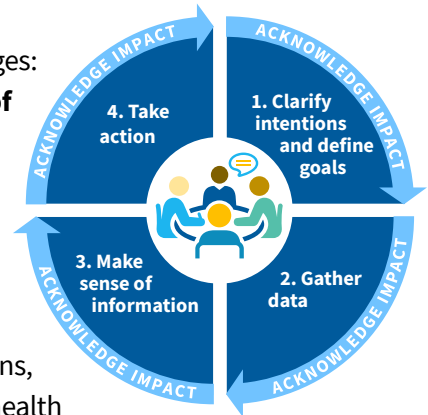
Hospitals and clinics use data to guide quality improvement efforts, monitor progress toward goals, demonstrate accountability for care quality, and highlight successes. It is important that health systems engage patients throughout these data-driven efforts to build trust and transparency, focus on what matters most to patients' health, and get a holistic view of what care teams are doing well and where to make improvements.

This tool provides guidance for how health care organizations can strengthen data-driven quality improvement efforts by partnering with patients and community members. It includes key steps, discussion questions, conversation starters, and a practical example to help hospitals and clinics partner with patients throughout the process of using data to improve care. The tool was developed as part of [*Engaging Patients of Color to Advance Health Equity*](#), an initiative led by the Center for Health Care Strategies with support from the New York Health Foundation.



Partner with Patients at Every Stage

Using data to guide a quality improvement project includes four main stages: (1) **clarify intentions and define goals**; (2) **gather data**; (3) **make sense of information**; and (4) **take action**. Even with clear intentions, using data to guide improvement efforts can result in unintended consequences. Across all four stages, it is important to acknowledge impact — both benefits and harm.



Below is guidance for partnering with patients at each stage of using data to improve care. Each stage includes key questions to discuss with clinicians, administrators, patients, and community members to ensure that how a health care organization uses data ultimately benefits patients without causing unintended harm. See conversation starters on page 4 for tips on how to best communicate with patients and community members.

1. Clarify Intentions and Define Goals

Before using any data to guide quality improvement efforts, first clarify goals and how using data will ultimately benefit patients. Spell out intended benefits for specific patient and community groups. Engage patients as members of committees, advisory councils, and governing boards to define why you are using data and how it will ultimately benefit patients. Key questions to explore include:

- *What is the goal of using data? What questions are we trying to answer and why?*
- *How will using data benefit patients? Which patients and in what ways?*

2. Gather Data

Co-design data collection with patients to ensure surveys, forms, and processes are convenient, easy-to-understand, and culturally tailored. Share and adjust analysis plans to address any community concerns. Key questions to explore include:

- *What data (both quantitative and qualitative) are most important and why?*
- *What information is already available? How can it guide action?*
- *If additional data are needed, what are the best ways and times to collect it?*

3. Make Sense of Information

Share preliminary findings with patients via community forums and town halls to make sense collectively of what data mean. Seek out alternative viewpoints and interpretations. Key questions to explore include:

- *What stories are the data telling?*
- *How do these stories differ by perspective?*
- *Whose perspectives are missing? How can we bring patients, community members, and other partners with those perspectives into the conversation?*

4. Take Action

Work with patients on committees, advisory councils, and governing boards to decide what actions to take in response to data. Key questions to explore include:

- *Based on the data, what actions are necessary to realize intended benefits and address unintended harm?*
- *Who will take those actions? When?*

Acknowledge Impact

Throughout each of these four stages, it is important to acknowledge risks alongside intended benefits, monitor for unintended consequences, and address harm when it occurs. One of the most important harms to consider is the potential for using data in ways that reinforce or amplify inequities already built into the U.S. health care system. To decrease the risk of unintended harm while making intended benefits more likely, engage patients and community members from marginalized populations to explore what harm might arise from using data, and for which communities. Work with patients and community members to monitor for potential harm and make corrections when harm occurs.

Engaging patients and community members and acknowledging impact throughout all these stages will keep the effort focused on what matters most to patients and reduce the potential for harm.

Example In Practice

To improve blood pressure management for residents in the neighborhood around its clinic, a federally qualified health center (FQHC) designed a program to provide patient education and offer free blood pressure checks and low-fat recipes at a local food bank. To guide the improvement project, the clinic tracked blood pressure readings within patient medical records during the six months before and six months after the program started. Clinic staff were excited to see that since starting the program, more patients had well-managed blood pressure.

But, by relying only on medical record information, the clinic missed the most underserved residents — those who were not receiving care at all. The clinic unintentionally perpetuated the inequities that led to these residents being underserved in the first place. As a result, the clinic missed the opportunity to improve blood pressure management for residents who already had the most unmet health care needs.

To address this unintended harm, the clinic convened an advisory group of patients and community members. Together, the clinic, advisors, and food bank staff designed a process to gather anonymous data from the free blood pressure readings offered at the food bank. After a few months, the clinic shared aggregated data from both medical records and the food bank at a series of community meetings. Residents, community leaders, and clinicians collectively decided on how to improve the program to connect more residents with care.

Conversation Starters: How to Begin Talking with Patients and Community Members About Data

It takes time to build trusting relationships with patients and community members before engaging in data-driven quality improvement projects. Start small with a conversation, listen with humility, and earn trust by acting on what patients share. Build on initial conversations by inviting patients to play a larger role over time.

Tips for Relationship-Building Conversations

As you talk with patients and community members about using data to improve care, try these approaches:

- **Lead with respect** for patients' time and views. Ask first if they're willing to engage.
- **Share the purpose** of the conversation. Integrate open-ended questions into this sharing and listen more than you talk.
- **State intentions, then ask about impact.** Be prepared to say more about the kind of role and time commitment you are hoping patients would play as partners, then ask how patients would like to engage and collaborate. Be open to rethinking your approach.
- **Listen to learn.** Resist the urge to explain intentions or defend current plans. Try responses such as, “*I hadn't thought of that;*” “*Thank you, we'll have to give that more thought;*” and “*Tell me more about that.*”
- **Share power in the conversation.** Invite patients to ask their own questions and speak to questions you hadn't thought to ask.
- **Recognize contributions** by [budgeting for partners' financial compensation](#). Also plan to provide additional patient supports, such as technology, transportation, or child care.

Try out some of these prompts to start a conversation:

- “*We want to work with patients and community members to improve how we deliver care. Would you be willing to share some of your thoughts to help shape our plans?*”
- “*Our team at _____ is working to _____. What could accomplishing this goal mean to you and others in your community? Are there other goals you feel would be more important?*”
- “*We're seeking to benefit _____ by using data to _____. Who else should we seek to help through this work? What other benefits should we think about? How might these benefits show up in your life, or in the life of others in your community? How would you know?*”
- “*What potential harm do we need to consider? How might that show up for you or others in your community?*”
- “*What questions do you have for me? What should we think about that I haven't yet asked?*”
- “*Would you be willing to work with us to design our project in ways that create the most benefit and least harm for patients?*”

Conclusion

Partnering with patients keeps health systems' data-driven quality improvement efforts focused on what matters most to patients and their communities. Working with patients helps health systems understand where improvements are most needed while earning trust through transparent decision-making. Partnership is important at every stage of using data, from clarifying intentions and defining goals, to gathering data, making sense of information, and taking action. Across all four stages, it is important to acknowledge impact by monitoring for and mitigating unintended harm arising from data use. Building partnerships with patients and community members begins with relationship-building conversations, inviting collaboration, and staying flexible.



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ABOUT ELLEN SCHULTZ CONSULTING

Ellen Schultz helps clients from across health and human services align measurement with what matters most to the people they serve. She helps researchers, policymakers, and change agents partner with patients and community members to design measurement strategies that re-orient systems around people. Learn more by contacting Ellen.Schultz@EMSchultzconsulting.com.