Lived Experience and Data Management: Trauma-Informed Approaches and Perspectives

Background

Federally Qualified Health Centers (FQHCs) manage large amounts of data collected about patients and services. The data collected is used routinely to inform healthcare providers and FQHC organizational leadership about patient outcomes and health center performance. Health center patients are asked to complete and repeat paperwork, surveys, and assessments at their first and subsequent visits. It has been reported by some patients and providers that the repetition of collecting the same data points can be discouraging and appear as though the routine of data collection outweighs the patients' needs and undervalues their experiences. In some cases, repeating one's entire medical, housing, and personal histories can even create harm and re-traumatization for patients and providers alike.

This publication will explore why and how lived expertise must be sought and valued by health centers and allied organizations to improve every stage of the data management process from collection and analysis to data sharing, access, and decision-making. Additionally, we will discuss the nexus of racial equity and lived expertise in data management, and how data used improperly or carelessly have the potential to both harm and help perpetuate inequities. Finally, we provide recommendations and practices that can be implemented in the short, medium, and long term to use data to reduce the chances of re-traumatization.

Data Collection and Potential for Harm

Health data collection is an inescapable fact of the process for providing health care. Data collection is critical to understand the health conditions of patients and provide them with the appropriate care and establish medical history, as well as for billing purposes to state Medicaid or managed care organizations. However, FQHCs must recognize how much is too much.

Increasingly, social determinates of health (SDOH) data are an important facet of providing care to patients. Briefly, SDOH are those social, economic, and environmental factors that impact one's health. SDOH may include things like education level, income, housing status, and zip code. There are several popular assessments for SDOH in use at many FQHCs [e.g., Protocol for Responding to and Assessing Patient Assets, Risks, and Experiences (PRAPARE)]. Other FQHCs use the ICD-10 codes (called the Z-codes) for tracking SDOH conditions. These tools go beyond individual diagnoses to encompass the whole person and, arguably, allow practitioners better insight into a patient's day-to-day, contextualizing chronic conditions, identifying other factors that may worsen conditions or put a patient at risk of additional illnesses.

Overall, it is a net positive for FQHCs to collect on SDOH factors outside their "traditional" scope to understand patients' health outcomes in context – so long as *something* is done with the data to assist both the individual patient's health outcomes and the organizational goals to improve service delivery. A common mindset among some practitioners is to avoid noting in a patient file SDOH conditions if they cannot personally do something to address them. To shift away from this mindset, FQHCs must engage with staff and patients to recognize that beyond individual health care practitioners, there should be a network of partners and providers who help address a patient's SDOH needs.

While PRAPARE and the ICD-10 Z-codes are excellent tools for SDOH collection, even the perfect collection instrument will do nothing for patients or FQHCs without a framework to carry data forward to analysis and decision making, grounded in the insights, recommendations, and decisions of patients with lived experience in positions of power and agency at the point of their own care and as part of a board or committee setting. Patients who must repeat their story, their histories, their traumas, each time they visit their provider for needed services and seemingly getting nothing back is a strong disincentive to return. Collecting and storing data for funding requirements, to "check-the-box" and not use them for analysis not only creates work for FQHC staff, but it also opens patients up to potential harm.

Organizational Data Collection Improvements

FQHCs should seek to review, make changes, and decide what parts of their data collection apparatus need to be adjusted or even overhauled completely. The framework offered below may help organize these review efforts.

- Policies: All things flow from good policies. FQHCs should have written policies on data collection, analysis, and sharing that are periodically reviewed, updated, and approved to meet the need. Included in these policies are the legal and funding requirements that FQHCs are obliged to follow. Policy development and review should be an organization-wide effort and feedback should be actively solicited from staff and patients.
- Process (or procedure): How are the established policies operationalized? Processes should clearly define how data is collected, when, and from whom. It is strongly advisable to create a flow chart that illustrates how data flows across the organization and how it is used.
- Paperwork: Data collected from patients and providers - from data collection forms and assessments to intake forms, billing, authorizations and consents, and releases of information - must align with the established process and policies. Moreover, all paperwork should be in plain language, to the extent possible, and either supplemental written guidance provided along with the forms, or individualized assistance offered at patient request. Finally, and importantly, this is the key part of data collection where patients should know the 'why' of data collection and the value to them personally and to the organization to provide their data. This should include what will and will not be done with patient data, when and where it will be stored, and what agency patients have over their own data (e.g., deletion, withdrawing consent).
- Patient experience: How people interact with data collection and their experiences regarding ease of use, amount collected, timing, and accessibility are key factors in getting quality data. FQHCs should establish multiple avenues to solicit feedback. These include basic asynchronous feedback opportunities through customer satisfaction surveys and comment cards, but also extend to focus groups and patient-provider working groups on data collection improvements.

Performance: Finally, FQHCs must establish performance baselines and goals to understand how data collection is functioning across the organization. Connecting all the previous pieces, what does data quality and completeness look like for the organization? How does patient experience impact data collection and desired outcomes? How can the FQHC work collaboratively with staff and patients to set goals, monitor performance and equity, and adjust and course correct as necessary?
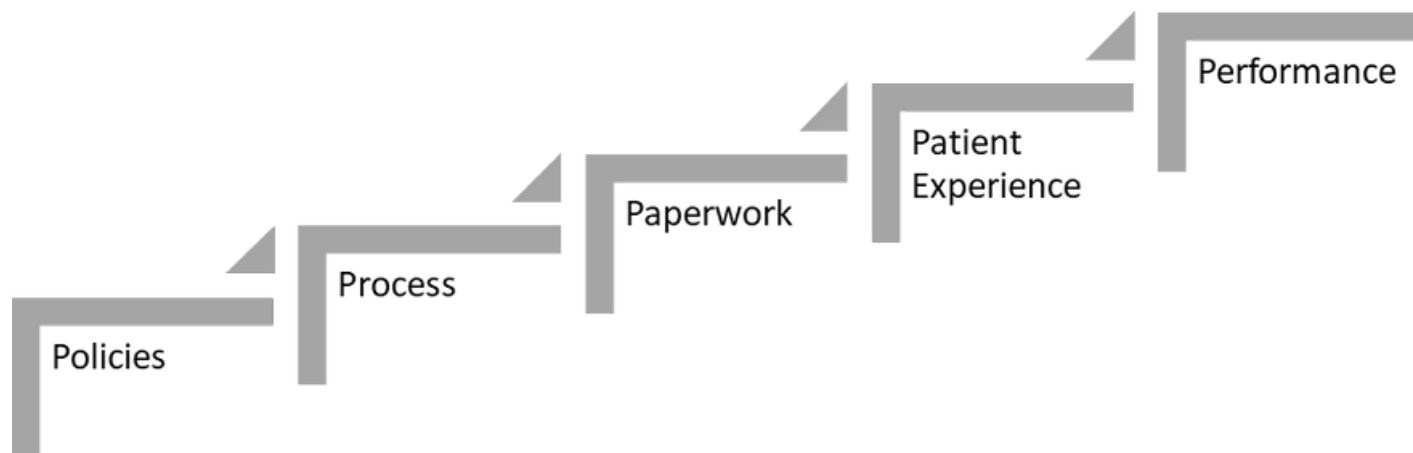

Data Management and Lived Experience

Building an Inclusive Data-Informed Community Culture

Data management is the collection, storage, analysis, and interpretation of data. These activities are only one-third to one-half of the equation to becoming a data-informed organization. There is some debate about the terms "data-informed" and "data-driven." For many the words seem outwardly interchangeable. For others, being "data-informed" is a more inclusive term that seeks to be informed by not only data, but also qualitative experiences and contextualizing factors (i.e., everything else) whereas data-driven connotes excluding all but quantitative data to "drive" the conversation, organization, and decision-making. FQHCs should be aware of these subtleties as use of specific language conveys understanding of the nuances, organizational values and emphasis, and, often slowly, shifts organizational culture even among the most data-averse patients and staff.

In building a data-informed culture, one of the most key facets will be inclusion of qualitative data collection and meaningful engagement with patients. Data is often a poor substitute for the direct questions, "What do you want?" and "What does this look like for you?"

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Hallmarks of a Data-Informed Culture
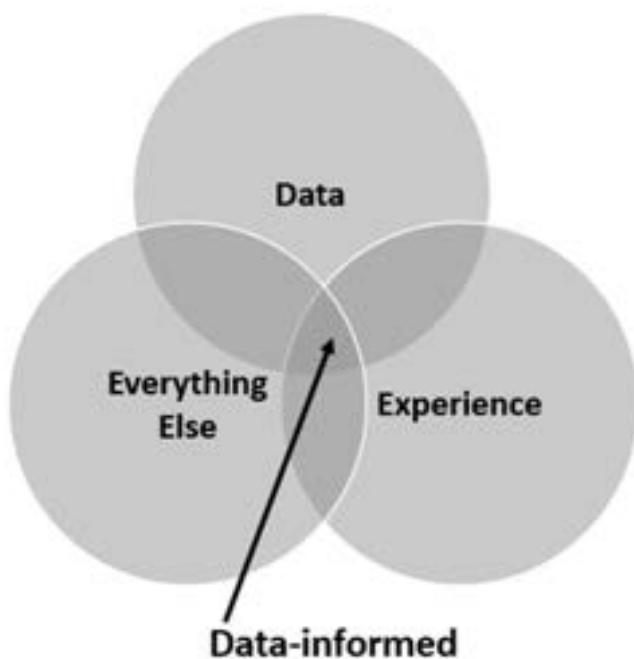
- Gathering **broad** and **deep sets of quantitative data**
- Ironclad commitment to **observe data about system access, needs,** and **outcomes** disaggregated by demographics such as race/ethnicity, gender, age, family composition, and disabling conditions
- Yielding to **experience** and **perception** of **system health** and **quality** – even if quantitative data points in another direction
- Contextualizing **external events** (deadlines, NOFOs, political shifts, etc.) into **data analysis**
- Focuses on what success looks like and **Continuous Quality Improvement (CQI)**

Data-Informed Means Being Trauma-Informed

As FQHCs journey toward becoming a data-informed organization, it is vital that the trauma-informed practices that should be ingrained into service provision are also embedded throughout these data processes. FQHCs must recognize that data inherently creates a dividing line between those with knowledge (and often power) and those without. This dynamic runs a high risk of creating harm. Merely recognizing this dynamic is the first step to mitigating the risk of re-traumatization.

The Urban Institute recommends some key tenets on qualitative research and trauma-informed practices, summarized here:

1. Reflect on relationships and power dynamics;
2. Full transparency about process and results before, during, and after every engagement;
3. Patients have every right to make informed decisions and have autonomy and agency over their participation in data collection and not have their choice (for or against participation) impact their continued access to quality services;
4. FQHCs collecting quantitative feedback have a responsibility to patients to meet them where they are, to be flexible, nimble, and responsive to what patients offer.

Once data is collected, how do FQHCs produce a clear and comprehensive analysis? Moreover, how should these analyses be communicated to patients, staff, leadership, and the broader service network of the FQHC and to what ends?

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This paper references patients with lived experience to refer to patients with any number of chronic conditions or histories that FQHCs must bear in mind when making organizational and service decisions. All patients have a distinctive lived experience that should be heard. FQHCs are encouraged to define lived experience as broadly as possible to include special populations such as those with lived experiences of homelessness and housing instability, those with experiences of discrimination, and those with health and behavioral health conditions. When engaging with patients with lived experience, FQHCs must ask the question whether the qualitative data received is reflective of their larger patient population.

Data Analysis and Interpretation: Racial Equity and Health Equity

FQHCs have a responsibility to know about and review how data is collected, stored, deleted, analyzed, shared, and interpreted across the organization. Not only will this better enable the health center, through the data, to work with patients to improve their health care outcomes, it will better inform organizational performance management and improvement as well as highlight racial and other disparities in service access and outcomes. Included in this responsibility is actively seeking a broad range of perspectives from patients of color, and in particular patients who identify as Black, and patients with lived experience of homelessness about how to evaluate process and procedure to make improvements.

When analyzing FQHC data, it must be disaggregated on demographic features to best observe, monitor, and mitigate disparities. The analysis framework FQHCs should implement is two-pronged: 1) structural/functional; and 2) substantive. Structural/functional analysis is about the data itself, analyzing the sources and collection methods and opportunities for implicit or explicit biases. Substantive analyses seek to better understand the 'why' and incorporate qualitative data to contextualize insights, provide history and detail, and can be used as quick checks to determine if insights comport with people's experiences.

Incorporating patient experience into data analysis takes time. It is not advisable to simply pull together a group of patients and show them some charts. Rather, engaging with patients for data analysis requires FQHC staff and data analysts to explain the process, context, and requirements of why and how the data is collected. This skill-building or "leveling-up" will allow patients to provide greater insight and strengthen their associations with their experiences from what they see in the presented data. Improving data literacy for patients and staff is a practice that requires a consistent cycle of communication of data, results, and feedback for improvement.

One way to bring this kind of consistency is to use a Continuous Quality Improvement (CQI) framework. CQI is a recognized, data-informed method that focuses data, analysis, and process to achieve organizational goals. Approaches to data analysis and CQI are meant to be ingrained into the everyday work of an organization and is not an add-on once a month or quarter. Starting with a problem, develop suggestions on how it could be improved, implement key suggestions, collect data, decide on success, and repeat. This cycle is described as "Plan, Do, Study, Act (PDSA)" and is the engine under the CQI hood.

PLAN	• Define the problem and scope • Collect data on what is known about it • Develop and prioritize strategies to address it
DO	• Implement the strategies • Correct course as necessary • Make observations and collect additional data
STUDY	• Analyze data from the 'do' phase • Determine success of strategies • Make any necessary changes to improve on all strategies, even successful ones
ACT	• Implement strategies • Create additional policies, procedures, and structures • Train staff and inform patients of changes • Monitor performance and come back around to 'plan'

Data Sharing Considerations and Consequences

FQHCs routinely share patient data with other teams within the organization as well as with others working in health care, housing, and other community services. Ironically, the routine nature of sharing data may lead some to treat it with less scrutiny. FQHCs must take care that they share only what is necessary to advance patient outcomes or better understand their performance and system. Put simply, just because data can be shared legally does not always mean that data must be shared. For example, an FQHC with a partnership with a food bank may have a data sharing agreement for which patients are informed of and sign off on during intake. The sharing agreement is mostly boilerplate and contains identifying information such as name, date of birth, and social security number along with various patient conditions that may or may not be relevant to the food bank's services. Sharing all this information may be largely unnecessary and may open itself up to legal ramifications and misuse.

While sharing data has potential to cause harm, it also may serve as a trauma-informed way to provide services. Using the same example of the food bank, consider a patient diagnosed with diabetes who is uncomfortable sharing their diagnosis or is traumatized by repeating their story with other providers outside the FQHC. The FQHC, in partnership with the food bank and the patient, may share information only pertinent to their diabetes diagnosis so that the food bank may be prepared for the patient's specific dietary needs. It may not be necessary to share other information such as service histories, other conditions or medication prescriptions for which the patient has no diet requirements or sensitivities and other personal identifiable information that has no bearing on the services being provided.

While seemingly more onerous for the FQHCs and partner organizations, data sharing must be narrowly tailored to the needs and decisions of the patient who has authorized such sharing. Organizations sharing data must negotiate this sharing related to the specific services offered and for the data elements that are strictly "need to know." Even if this slows down administration of data, FQHCs must place a higher value on patient privacy and service provision than on easing data management and administration.

Building and Managing Trust and Privacy

So much about working with data is based on trust. Trust in the data itself, trust between patient and provider, between colleagues, between organizations, and within the community. With sharing data this trust is a chain and only as strong as the weakest link. The same tenets described to collect data apply in sharing as well: Focus on relationship, radical transparency, agency and consent, and flexibility. Building trust means building relationships. It means providing explanations in plain language to patients about to whom their data will be shared, for what purpose, and how it will explicitly help them in their health goals.

Ceding Power: Models That Work

Harm-reduction and trauma-informed approaches the FQHC implements should be extended to both staff and patients alike. The models below, though geared primarily toward patients, are techniques that an FQHC should consider for peer workers and other FQHC staff. Incorporating lived experience in FQHC operations and data means everyone's lived experience. The more perspective an FQHC gains, the better able it will be to make decisions, reduce harm, and improve patient health outcomes.

Consumer Advisory Boards (CABs)

The FQHC Consumer Advisory Board (CAB) model has been around for many years and is a wonderful way to embed patient and consumer feedback in not only data conversations, but FQHC policy, performance, and day-to-day operations. The CAB model is a collaborative partnership and involves the FQHC ceding some power and decision-making responsibilities. The most successful CABs can make requests for data from FQHC staff and expect the same level of care as if the staff were reporting to any other organizational oversight.

There are many good templates for operationalizing a CAB. The National Healthcare for the Homeless Council (NHCHC) published a detailed manual to assist FQHCs in getting started. Likewise, the Center for Health Care Strategies (CHCS) released a blog post about the CAB model, including national examples.

Focus groups

Another tried and tested approach is conducting focus groups. Focus groups are typically small conversations centered on a few select topics or questions with facilitators. Focus groups should ideally have at least two facilitators and five to seven participants. While larger groups are possible, it can prevent the group from covering a lot of ground or not allow for follow-ups and unpacking as facilitators try to include all participants. For larger groups of potential focus group participants, consider holding more than one session.

The logistical work of planning focus groups sessions is where there is the most opportunity to cause or reduce harm. How group participants are selected, what the expectations are, what will (and will not) be done with patients'/participants' feedback, how to ensure confidentiality, and what will the compensation look like are all important factors that should be worked out by the facilitators before meeting with any focus group.

During focus groups, facilitators should anticipate the types of reactions from participants given the content or questions. Even the most outwardly innocuous topic may bring something up for someone and they may need to express themselves or step back from the group. This is why it is so critical that there are at least two facilitators, so that one can work with someone with strong reactions to ensure they have what they need and are, frankly, safe.

Peer and Staff Support at Intake and Through Point of Care

Research has shown that peer support is a major influence in patient satisfaction, trust, and, ultimately, in seeing positive health outcomes. FQHCs would do well to establish a comprehensive peer and staff support system and if one exists to double down on the organizational support and training they receive.

Peer-provided services factor strongly in the data collection and management space as well. If a patient needs assistance with forms, paperwork, or process, having a peer worker to walk through the steps and address questions will increase the likelihood of better data quality in collection, leading to better analysis, and decisions about that patient's health care.

Asynchronous Feedback: Follow-Ups and Satisfaction Surveys

The most low-barrier way to engage patients is to offer self-paced opportunities to provide feedback in the form of follow-up connections and satisfaction surveys. Surveys should be reasonably short and tailored to the patient's experience. The design, questions, and responses to surveys should be co-developed with patients based on their experiences and part of the data collection structure of the FQHC.

Follow-up phone calls post-visit is another way to collect data on patient experience as well as strengthen the connection between the FQHC and the patient, though more resource-intensive for the agency. It has the benefit of person-to-person communication and will likely yield more results than a passive and optional satisfaction survey. The FQHC should, to the extent possible, separate the functions of the staff calling the patient with the services received to promote a franker assessment of their visit. Patients should also be fully informed about how their data and feedback will be used and that their observations will be held in confidence.

Note About Compensation

When asking patients for their time and insight for intense and continuous activities, particularly for focus groups or CABs, FQHCs must offer compensation. Moreover, compensation must be fair and appropriate to the work done and be in the form of money and bear little difference to the process of paying any other contractor or vendor with whom the FQHC works. It is important that the type of payment (check, direct deposit) and amount of money looks no different as this sends a clear message to patients about the value of their work and that their experiences are expertise.

Compensation is a tough issue for many organizations working with people with lived experience. There are many concerns about benefits and tax implications when paying patients rather than providing gift cards or other non-cash compensation. While these are thorny issues, they can be worked out with proper accounting policies and procedures, as well as engaged staff who are committed to supporting and compensating patients.

To be clear, paying for patients' time and insight in real, actual cash is simply non-negotiable at this stage. And, if an FQHC is unable or unwilling to compensate patients in this way, it is better to stick to the low impact, low risk methods of passive qualitative data collection such as satisfaction surveys and staff observations. This work is work and takes an emotional toll on all involved, that must be recognized and compensated appropriately.

Recommendations / Next Steps

Review data collection structure of the FQHC

1. Gather data collection instruments from intake through aftercare
2. Inventory questions asked, from whom, if connected to funding requirements, and what is done with these data elements
3. Map data collection in a flow chart, noting when data elements are collected

Develop or update policies, process, paperwork for data collection structures

1. Determine what policies and procedures exist for data collection and sharing
2. Cross reference with data collection structure, needs of patients, and trauma-informed practices
3. Co-develop updates or new policies with patients

Evaluate how patients experience incorporated FQHC data and operations

1. Review how patients' experiences play a role in decision-making and data analysis in the FQHC
2. Plan for creation of a CAB or CAB-like group, outlining responsibilities, decision-making authority, and structure
3. Ensure compensation policies align with best practices and are appropriate to the work the CAB will provide

Start analyzing FQHC data and making some insights

1. Conduct some exploratory analysis on data collection, service use, and disparities
2. Start with UDS reporting, disaggregated
3. Observe where disparities are showing up between patient population, services provided, and outcomes observed
4. Ask more questions, and solicit compensated insights from patients

Resources And Additional Reading

Presenting complaint: use of language that disempowers patients. | PSNet (ahrq.gov) – Use of language, plain language in forms and processes

Medicare And Telehealth: Delivering On Innovation's Promise For Equity, Quality, Access, And Sustainability | Health Affairs – New technology and impact on equity, perpetuating or reducing disparities

Policy Spotlight: One-On-One with Meena Seshamani | Health Affairs

Improving The Measurement Of Structural Racism To Achieve Antiracist Health Policy | Health Affairs

Assessment of bias in patient safety reporting systems categorized by physician gender, race and ethnicity, and faculty rank: a qualitative study. | PSNet (ahrq.gov)

Employee silence in health care: charting new avenues for leadership and management. | PSNet (ahrq.gov)

Person-Centered Practices Self-Assessment (acl.gov)

Introducing the NCAPPS Person-Centered Practices Self-Assessment - YouTube

Does racism impact healthcare quality? Perspectives of Black and Hispanic/Latino patients. | PSNet (ahrq.gov)

Establishing the Framework for Health Equity at CMS | CMS

Addressing Health Equity through Health and Housing Partnerships - CSH

Health care quality and safety in a correctional system: creating goals and performance measures for improvement. | PSNet (ahrq.gov)

Resources And Additional Reading

Community Support to Gather Feedback on Proposed Changes to HMIS Data Elements - HUD Exchange

Health Equity Tourism: Ravaging the Justice Landscape - PubMed (nih.gov)

Data Integration Best Practices for Health Centers & Homeless Services - CSH

The How, What and Why of Housing Data Collection - CSH

Connections to Housing: Everything you need to know on HMIS and becoming a Coordinated Entry Access Point - CSH

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