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Nina Shabbat

*Thresholds*, nina.shabbat@thresholds.org

Katy Dobbins

*Thresholds*, db.katy@gmail.com


Sonja Seglin

*Thresholds*, sonja.seglin@thresholds.org

Kristin Davis

*Thresholds*, kristin.davis@thresholds.org

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## Measuring patient experience in a safety net setting: Lessons learned

Nina Shabbat, MPH, *Thresholds*, [Nina.Shabbat@thresholds.org](mailto:Nina.Shabbat@thresholds.org)

Katy Dobbins, BA, *Thresholds*\*

Sonja Seglin, MA, LCPC, *Thresholds*, [Sonja.Seglin@thresholds.org](mailto:Sonja.Seglin@thresholds.org)

Kristin Davis, PhD, *Thresholds*, [Kristin.Davis@thresholds.org](mailto:Kristin.Davis@thresholds.org)

*\*No longer an employee of Thresholds at time of publication*

### Abstract

Safety net providers have faced barriers in administering patient experience surveys due to a lack of resources and survey expertise, but this problem has received little attention in the literature. In this manuscript, we offer lessons learned from the administration of a patient experience survey at a mid-size behavioral health care agency serving a safety net population. Specifically, we discuss resource needs, methods of increasing response rate among transient populations, methods for engaging stakeholders and clinical staff in quality improvement initiatives, and considerations for responding to setbacks and challenges dynamically. We also offer insight on the effective dissemination of results within safety net organizations and discuss the role of organizational culture.

### Keywords

Patient experience, safety net, quality improvement, behavioral health

### Introduction

The Affordable Care Act (ACA) has the potential to reduce health disparities not only by increasing access to care but also by improving quality of care for vulnerable and disadvantaged populations. For several years now, hospitals and primary care practices serving commercially insured individuals or Medicare beneficiaries have been using validated survey instruments such as the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) to publically report on patient experience data and to maintain a focus on and create a system that is patient-centered.<sup>1,2</sup> In contrast, some safety net providers have been collecting and reporting on this data in less formalized ways and with a range of survey instruments, many of which are not validated.<sup>3,4</sup> With the ACA's implementation, the use and public reporting of quality care measures related to patient-centeredness is mandated<sup>5</sup> and providers across the health care spectrum will be required to measure experience of care in more formalized ways going forward.

Safety net behavioral health providers in particular will benefit from quality improvement imperatives, as they have for too long lagged behind the general health care system and serve a population that have faced unique barriers to consumer centered care.<sup>6</sup> Moreover, behavioral health safety net providers treat patients with some of the highest costs. While the exact total spending varies among states, individuals with a mental illness account for

significantly higher Medicaid spending than those without a mental illness, with some states reporting that 10% of their beneficiaries account for 60% of their costs.<sup>7-9</sup> In addition, the number of mental health care consumers is expected to increase as a result of the ACA's Medicaid expansion and an additional provision of the law requiring private insurers to cover behavioral health services at parity.<sup>10</sup> To control costs and meet the demands of this population, improving quality care and treatment engagement for these consumers is paramount.

Safety net providers are among those that report logistical barriers in conducting patient experience surveys, including lack of information about survey administration and challenges sustaining organizational support for the initiative.<sup>4</sup> Yet few reports detail strategies for successful implementation of patient experience measurement and quality improvement practices to support safety net providers in undertaking such an endeavor. Instead, the majority of the burgeoning patient experience literature assumes the resources and ability to undertake the survey and reports on quality improvement efforts undertaken based on survey results for commercially insured populations,<sup>11-13</sup> methodological issues related to the survey instrument,<sup>14,15</sup> and to a lesser extent issues related to survey administration.<sup>16</sup>

In this manuscript, we report on phase one of a three-phase quality improvement initiative of administering a patient experience survey to a safety net population at a

mid-size behavioral healthcare organization in the mid-west. The first phase included the planning for and administration of the patient experience survey. The second and third phases will focus on identifying and implementing quality improvement activities and measuring the impact of the quality improvement activities, respectively.

Case studies are well suited for exploring new quality improvement implementation projects<sup>17</sup> and can serve as a heuristic tool for other organizations. To that end, we detail our efforts in building organizational support and achieving organizational buy-in, finding and adapting a suitable measurement tool, increasing response rates, and discuss implications for future quality improvement efforts.

### Context, Setting, and Sample

In addition to our organizational commitment to deliver quality care, we undertook this initiative to prepare for the anticipated influx of consumers seeking mental health services, new reimbursement policies, and expected requirements to standardize and rely on uniform reporting of quality measures.

We administered a modified version of the Experience of Care and Health Outcomes (ECHO) survey at a mid-size psychiatric center that provides team-based outreach services to approximately 3900 individuals with serious mental illness. Most of the 142 teams are Community Support Treatment teams, a step down version of the evidence-based Assertive Community Treatment (ACT) model. ACT is an outreach care model which emerged in the 1970s as a response to the deinstitutionalization of persons with serious mental illness and is marked by providing wrap around services from a multi-disciplinary team *in the community* rather than a clinic.<sup>18</sup>

The majority of agency consumers has a schizophrenia spectrum diagnosis, an average annual income below the poverty line, and is insured through Medicaid. The agency provides basic care management, illness self-management support, access to peer support, and care coordination. Consumers are enrolled in services regardless of their ability to pay. The center is large enough to have infrastructural capacity to administer and report on patient experience data, including both a quality and an evaluation department.

Important to note is that the survey took place within an existing consumer centered organizational culture. The organization was an early adopter of a “recovery orientation,” an orientation which entails ***institutionalizing*** ways to ensure that consumers’ goals for treatment, rather than staff goals, are paramount, that staff demonstrate hope and optimism in their work with

consumers, and that clinical practices strengthen consumer autonomy rather than promote dependency. To oversee and promote this orientation, the organization created a Director of Recovery position in 2003. A recovery steering committee, initiated shortly thereafter oversaw the dissemination of recovery ideas and practices across the teams. To date, the organization has hired more than 50 peer staff, revised documentation practices to allow for consumer participation in care planning, and provided opportunities for psychiatric advance directives, which allow consumers to indicate their instructions should they experience a psychiatric crisis.

### Measure Selection, Modification, and Piloting

Selecting, modifying, and piloting the survey took place over the course of three months. At each phase, we engaged multiple stakeholders to ensure the construct validity of the measure at our agency, and to establish the organizational buy-in needed for successful survey administration, including a commitment to using the results of the survey for quality improvement. First, a steering committee comprised of organizational leaders, internal quality and evaluation staff, and a former consumer of mental health services was formed to select a tool and plan for the use and dissemination of the results. The goal of the selection and modification process was to yield a measure of patient experience that would be both valid for a safety net population receiving mental health services on a team based outreach model and relevant for organizational quality improvement. We utilized a collaborative approach throughout the survey selection and modification process, involving our consumer board, organizational leaders, and frontline staff at each stage of decision-making.

The steering committee decided on the ECHO Survey version 3.0, a product of the Consumer Assessment of Behavioral Health Survey (CABHS) and the Mental Health Statistics Improvement Program (MHSIP) Survey,<sup>19</sup> because it is specific to mental health services, adaptable to a community-based method of service delivery, and feasible to administer to our population. The survey, which is publically available and endorsed by the National Quality Forum, consists of 51 core items that comprise ten single-item measures and seven composite measures.<sup>20,21</sup>

After selecting the ECHO, we undertook a rigorous review and revision process to adapt the survey content for relevance to the organizational setting, method of care delivery, and consumer population while balancing the need to maintain the survey’s scoring and reporting properties. At our agency, the need to adapt the survey items and structure to ensure they were accessible to our consumer population superseded concerns about maintaining the instrument’s psychometric properties. As such, we made a number of modifications to the survey

(see table 1), which were informed by direct feedback from frontline staff, consumers, and agency service goals. We also included four questions from the ECHO supplemental item set, which is available to allow providers to customize their surveys.<sup>22</sup> The final patient experience survey consisted of 42 items, 11 of which were part of one of three composite measures.

Finally, the survey instrument was piloted through in-person interviews and over the phone with members of the consumer population to ensure its usability. A “think-aloud” technique was used during interviews to understand how respondents were interpreting the questions as they responded to the survey. Information gathered during the pilot phase was useful in gauging ease of administration and allowed us to solicit feedback from participants about the survey length, question and rating scale formats, and clarity of the content. The pilot respondents reported that the survey’s length, scales, and content were each accessible. Respondents also noted that the terms used in the survey to refer to case managers needed to be clarified to fit the agency context wherein consumers often work with multiple clinicians at the same time.

We also considered in-person survey administration at several of the agency’s drop in centers, but determined that this option was not feasible due to budgetary constraints, the vast geographic area served by our organization, and the introduction of self-selection bias, as many of those served choose not to use on-site services.

We set a timeline for survey administration that we believed to be realistic and reflective of the challenges common to reaching a safety net population. Assuming that we would need multiple contact attempts to reach most participants, we planned for five months of data collection. A previous study with a similar population achieved a 25% response rate for a telephone survey.<sup>26</sup> Thus, we planned to sample a large number of respondents (roughly 2000 consumers) in order to achieve our desired sample size (500 consumers). We aimed to reach 500 consumers so that we would have a sufficient number of responses to report on the results at the team level meaningfully. Finally, we set a date to reconvene the steering committee after the survey results were in to develop a plan to disseminate and act on the results.

**Table 1: Changes made to the ECHO Instrument**

Modifications	<ul style="list-style-type: none"> <li>Altered question wording to make the survey more accessible to consumers with low levels of literacy</li> <li>Changed phrasing to maintain consistency with the verbiage commonly used by the organization to refer to staff and services</li> </ul>
Additions from ECHO supplemental questions	<ul style="list-style-type: none"> <li>Added items on the topics of:                             <ul style="list-style-type: none"> <li>Perceived improvement of work and/or school status;</li> <li>Perception of level of recovery;</li> <li>Whether providers act as though consumers could improve/recover;</li> <li>Whether the consumer was comfortable raising concerns;</li> <li>Availability of information about medication side effects</li> </ul> </li> </ul>
Original additions	<ul style="list-style-type: none"> <li>Added question about perceived physical health status</li> </ul>
Deletions	<ul style="list-style-type: none"> <li>Removed questions not relevant to the organization’s core mission and services</li> </ul>

**Survey Administration**

We chose to administer the survey by telephone despite literature suggesting that mail surveys<sup>23</sup> or mixed modes (mail and telephone) approaches<sup>24</sup> may be the most effective method of reaching Medicaid populations. We decided against these methods because of low literacy rates and a substantial incidence of mobility in our population, recent research suggesting the high use of mobile devices among people with serious mental illness,<sup>25</sup> and careful consideration of tolerable levels and type of sampling bias. In this case, we weighed non-response and self-selection biases with budgetary and time constraints. Since our population has limited internet access and computer literacy, we eliminated the option of a web-based survey.

**Staffing Needs**

Two telephone interviewers were hired part time to administer the survey. Individuals with strong interpersonal skills and familiarity with the consumer population were selected. Two fulltime staff members with experience in research methodology and data analysis led the project.

**Interviewer Training**

The interviewers participated in a six-hour training session during which they learned about the larger context of the survey and practiced administering the survey using a script to solicit consumer participation. For a period of roughly one week following training, the survey project manager observed the staff administering the survey and

offered constructive feedback to increase consistency of administration between interviewers.

### **Conducting Telephone Interviews**

A randomly selected subset of agency consumers was invited to participate in the survey between April 2014 and September 2014. All current consumers who received services for at least 12 months were eligible for selection, except for those who received services from crisis or mobile assessment teams because such consumers are not regularly engaged in service use. We oversampled from ACT teams because these services are designed for the highest need consumers and we suspected consumers receiving these services would be more difficult to reach because of the greater severity of their illnesses. All consumers who were invited to participate in the survey were provided the opportunity to refuse participation. Each potential participant received at least five contact attempts, except for those who refused participation or who had incorrect or outdated phone numbers in our record system. Data collection required roughly 450 hours of telephone calls over the five months, due in large part to difficulties reaching potential participants. Participants did not receive compensation for taking part in the survey.

### **Lessons Learned**

Despite including multiple stakeholder groups at every stage, modifying the survey to fit organizational context and population, oversampling, and setting a realistic timeline, challenges remained to successful survey administration and dissemination that result in the lessons learned detailed below:

**Create a Vertical Team or Advertise the Project:** The first challenge was reaching survey participants. Issues around accessing reliable contact information are likely to be significant for all safety net providers given the transient nature of their populations. We expected to have some outdated phone numbers in our call list based on background information in the literature,<sup>23</sup> but were surprised by the high number of participants (42%) with non-working numbers. Our clinical staff regularly meets with clients and communicates with them by phone and so we expected our contact information to be more reliable than it would be in a typical medical setting where contact between providers and consumers is generally less frequent.

Because of an idiosyncrasy of our electronic health record that we were not aware of prior to the start of the survey, updating phone numbers is a burdensome task for front-line, clinical staff and is often neglected as a result. Since the survey was not narrowly defined as an evaluation project but rather as an agency wide quality improvement initiative, we were able to contact front-line staff in an effort to obtain updated contact information for

consumers, but we were met with varying levels of success. These issues could be mitigated in future initiatives by reviewing the workflow for updating contact information at the start of the initiative, by partnering with front-line staff to ensure records are accurate, and by advertising the project across the agency to ensure support from clinicians.

**Commit to Responding Dynamically:** Most broadly, we approached the survey administration process with the belief that adapting the protocol as needed throughout the survey process was acceptable. Adaptation is a hallmark of the quality improvement process and an important characteristic that distinguishes quality improvement from research.<sup>27</sup> In this vein, we reacted dynamically to challenges that came up throughout the survey process. For instance, we made changes to interviewer hours and call back time frames to increase response rates because we recognized we were not able to reach some consumers during normal business hours. Interviewers also began to call back participants at the beginning of the month when it was hypothesized they would have the most minutes available on their cellular phone plans.

We also set up a voicemail system for our interviewers as a way to address participants' call screening. We noted that some participants that did not answer the phone called back quickly upon hearing the voicemail left by the interviewers explaining the purpose of the call. By providing a voicemail system for the interviewers, the potential participants were able to communicate their interest in participating even when the interviewers were on other calls or out of the office. As cellular phones (most of which contain caller identification features) increasingly become the primary mode of contact for many people, addressing the issue of call screening will be an important consideration in improving response rates and limiting response biases.

Another challenge was that the survey modifications and mode of delivery did not meet the needs of all survey respondents with respect to literacy, and ability to understand and concentrate on the survey questions. All surveys are vulnerable to participant apathy and the effects of moment-in-time circumstances, but the mental health issues common among our population, including cognitive deficits and auditory hallucinations, heightened the threat.

Interviewers had been trained to read from the script verbatim when administering the survey. Bi-monthly check-ins with interviewers revealed that some participants were having difficulty interpreting some of the survey questions as they were intended. In response, we instructed the survey interviewers to "go off script" to explain the intended meaning of the questions with the hope of increasing the validity of our data. Because internal quality improvement was the goal of this initiative

and no public reporting was required, consistency among our respondents rather than across settings was more important. Research suggests that question comprehension can be increased when interviewers provide clarification in non-standardized ways.<sup>28,29</sup> After implementing this change, our interviewers reported experiencing better rapport with survey participants and receiving responses that seemed on the face to be more thoughtful. We strongly recommend that safety net providers who administer the survey allow for non-standardized communication, particularly if the survey population has barriers to comprehension such as cognitive deficits or limited English proficiency.

Overall, implementing these changes helped increase response rates and survey validity. Based on our experience, we believe that thoughtfully adapting the survey and administration process to the circumstances of individual providers or practices will allow for more successful quality improvement initiatives.

#### **Prepare a Detailed Plan for Disseminating Results at Project Start:**

Planning for reporting the results is particularly important when initiating a new quality improvement program. Detailed planning of who will disseminate the reports signals the importance of this step from the very beginning and also allows dissemination to happen more quickly after the survey has been completed. In addition, early planning on final phases makes it less likely that the inevitable competing priorities will undermine the process. Support for the survey was strong across senior leaders and administrators, but there were a number of competing organizational priorities which could have taken focus away from the last phase of the project—result dissemination and quality improvement planning efforts. In short, to maximize the impact of the survey results, we suggest that organizations undertaking a patient experience survey for the first time make detailed plans at the start for how the project will be finished, and if possible, initiate the project when there are fewer competing improvement initiatives taking place.

#### **Consider Organizational Culture and History of Quality Improvement:**

In administering this survey, we were fortunate to enjoy broad organizational support and to be working within the context of a consumer centered culture. Patient experience surveys and attendant quality improvement activities are likely to be most successful and most useful when they are launched in the context of a culture where patient experience is valued. However, the lack of a well-developed patient-centered culture should not be seen as a barrier to survey administration or quality improvement; rather, the administration of a survey can serve as an opportunity to help providers develop a more patient-centered culture. To the extent that service providers have been skeptical of the value of patient-centered care, working collaboratively to administer a

patient experience survey can facilitate a cultural shift as providers and other stakeholders become more knowledgeable about the topic.

Even though there was strong support for the survey and the values it represents at our agency, we faced some challenges in implementing formalized quality improvement activities. Behavioral healthcare providers have not adopted quality and safety improvement processes to the extent seen in medical settings. Thus, the launching of an eventual large scale improvement project born out of the survey was met with some trepidation. We addressed these concerns by including leaders and stakeholders from many different agency departments in the planning process. We also provided interim reports and carried out the dissemination process as described above such that the timeline unfolded in a predictable manner that allowed administrators time to prepare for the results.

## **Discussion**

This case study suggests that small to mid-size organizations serving a safety net population can successfully measure patient experience outcomes as a first step in systematic quality improvement efforts. Most broadly, we demonstrated the types of pre-survey activities that mitigate challenges in the administration and quality improvement process. Stakeholder input in selecting and adapting the survey, an overall team approach, a flexible approach to data collection that is tailored to the population's circumstances, and the creation of a dissemination plan for results at the very beginning are recommendations for successful administration and dissemination. More specifically, we found that the modified ECHO was a good fit for the majority of our consumers, but that allowing interviewers to offer additional explanation of the survey questions increased comprehension among some consumers. We also found that telephone administration, while feasible, is unlikely to yield high response rates even with a population that uses mobile devices.

Administering the survey within a consumer-centered culture provided us strong administrative and philosophical support. But, we ascribe the success of our survey administration to our use of a collaborative and flexible approach. As such, we believe that surveys can be administered successfully even in settings where a patient-centered culture is less well established and where resources may be less readily available.

Importantly, the case study also suggests that administering a patient experience survey and implementing a quality improvement initiative on a small scale before it is a requirement is worth the organizational investment in time and money. Piloting the process from

beginning to end is both cost-effective and strategically advantageous. While behavioral health care organizations are not yet in the position of being compensated for providing quality care, easing into a new and intensive quality improvement initiative can allow the organization to begin to create a culture of measurement, to identify potential barriers to successful survey administration and quality improvement more broadly, and to achieve a certain level of proficiency in undertaking projects of this nature.

We believe that our experience and recommendations fill an important gap in the patient experience literature for safety net providers. In addition to the documented barriers,<sup>4</sup> safety net providers may be hesitant to implement a patient experience survey because they do not believe they can adequately address potential gaps highlighted by the survey results. Safety net organizations that operate with thin economic margins or that have long histories of a particular kind of service delivery may be resistant to administer the survey knowing that they will be held accountable for implementing changes based on the survey's results. As such, safety net organizations need to be particularly strategic when administering a patient experience survey in order to build internal support for the initiative and maximize the survey's utility.

A potential limitation of the current report, and of case studies more generally, is the ability to generalize to other settings. While this paper reports on the process of implementing a survey at a mid-size organization serving consumers with serious mental illness and is not intended to definitively generalize to other contexts but rather to serve as a heuristic, the lessons learned detailed above can be usefully applied in any setting, including organizations of different sizes and readiness levels. The study offers strategy-level recommendations and potential adaptations for other agencies facing similar demands to measure and report on patient experience. Providing patient-centered care will be one of the most important roles for healthcare providers in the era of health reform. Advancing the quality of this care can only take place in the context of well-executed quality improvement projects.

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