



Lessons from the Camden Coalition care team efforts to improve Healthy Days data collection

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Abstract

After several attempts to collect patient-reported data through the Center for Disease Control's (CDC) Healthy Days measures, care teams at the Camden Coalition of Healthcare Providers found that data collection, even when using validated measures, can be difficult to implement in the context of providing care. This brief shares the hurdles care teams faced in their attempts to collect accurate and sustained data from the patients they serve, the results of a rapid cycle Plan-Do-Study-Act (PDSA) project we undertook to attempt to improve data collection, and lessons learned.

Introduction

The Camden Coalition of Healthcare Providers (Camden Coalition) is a multidisciplinary nonprofit working to improve care for people with complex health and social needs. The individuals we work with have multiple chronic physical and mental health conditions, often alongside challenges like substance use disorders, homelessness, and social isolation. For many of these individuals, access to appropriate and effective care in the community has been constrained by social determinants of health such as racism, poverty, and related structural barriers to health and wellness.

The Camden Coalition takes a person-centered approach to addressing these barriers. One prime example of the work that we do is our signature care management intervention, the **Camden Core Model**, in which an interprofessional care team assists patients with identifying and achieving goals that are important to them, managing their medication, and connecting them to needed social services and healthcare providers in the community.

Throughout the intervention, customized care planning and follow-up visits take place in both the home and community. During each visit, our care teams practice active listening and motivational interviewing to engage patients on a more personal level to identify their barriers to health and wellness. They use strength-based frameworks to build trusting, authentic healing relationships with patients and empower them to reach long-term health management. Through this work, we've come to better recognize the variety of factors that drive patient outcomes — whether these factors reside at the individual,

Authentic healing relationships is the term we use to describe the secure, genuine, and continuous relationships that our care team members build with patients, and that complex care teams more generally should strive to build with the individuals they serve. The term comes from this [qualitative research](#) paper published by the Camden Coalition.

family, community, or system level — and understand the importance of considering the whole person when providing care and assessing intervention impact.

Like many who seek to improve care for people living with complex health and social needs, we at the Camden Coalition, always question how our model of care is making a difference in our intervention participants' lives.

In this brief we describe our care teams' experience administering a particular set of questions to assess our participants' health-related quality of life (HRQoL) using the Center for Disease Control's (CDC) "Healthy Days" measures, and our efforts to improve data collection for these measures. Our purpose is to illustrate and share lessons about the challenges facing frontline staff when administering questions that are critical for evaluation purposes from the organization's perspective, but may be viewed by care teams as a barrier to engaging authentically with their patients, particularly if the purpose of collecting the data is not clear.

Background: the CDC's Healthy Days measures

The CDC's Healthy Days measures provide a comprehensive summary of physical and mental health (i.e., perceived sense of well-being) over time. This is assessed through the implementation of four questions asking patients to self-rate their health and identify the number of days in the previous month when their physical and mental health were not good, and the number of days their activity was limited due to poor physical or mental health (CDC, 2000).

According to the CDC, the Healthy Days measures offer researchers, policymakers, and practitioners a national standard for identifying disparities and tracking both the physical and mental health of adults (CDC, 2000). The Healthy Days questions have been widely adopted due to confirmation of their validity — a critical indication that a set of questions are useful and measure what they're supposed to across multiple sub-populations — when measured against established self-perceived health measures such as the 36-item Short Form Survey (SF-36) (CDC, 2000; Slabaugh, et al., 2017) as well as their brevity. Per the CDC, an additional advantage to their inclusion in clinical assessments is their practical and straightforward measurement of medium- and long-term effects of care (CDC, 2000).

Adopting the CDC's Healthy Days measures

The Camden Coalition was first introduced to the Healthy Days measures in 2012 after receiving a healthcare innovation award from the Centers for Medicare & Medicaid Services (CMS).

The award included a request for the implementation of an evaluation plan for our core care management intervention (Camden Core Model). CMS shared a list of preferred measures along with the recommendation to use either the SF-36 or CDC Healthy Days measures to track longitudinal changes in patients' health and functional status. Both SF-36 and Healthy Days are well-known, valid measures of health-related quality of life with very similar assessments of physical and mental health constructs (Barile et al., 2016); the two HRQoL measures even share the same self-rated general health question.

After thorough review of the SF-36, the evaluation team concluded that it would not be useful for the Camden Coalition's patient population at the time. The main concern was the length and insufficient sensitivity of the tool for individuals who start at a low baseline for health and functional status. The Healthy Days measures, however, appeared to have more sufficient sensitivity and seemed ideal for tracking changes in our patients' health status over time as they were validated for use within vulnerable patient populations.

To evaluate our intervention and assess our participants' self-rated health and well-being, we added the following core Healthy Days measure questions to our participant assessment forms:

- *Would you say that in general your health is: excellent, very good, good, fair or poor?*
- *Now thinking about your physical health, which includes physical illness and injury, how many days during the past 30 days was your physical health not good?*
- *For how many days during the past 30 days was your mental health not good?*
- *During the past 30 days, for about how many days did poor physical or mental health keep you from doing your usual activities, such as self-care, work, or recreation?*

The questions were typically administered by a nurse during the first patient home visit to gather their baseline health status. The questions were asked again 30 days and 60 days after enrollment into the intervention to assess short-term improvements in health status. To assess long-term health improvements, care team staff asked the Healthy Days questions six months post-enrollment. For a while, data collection was fairly consistent and patients were responding well to the Healthy Days questions. The care teams felt that the information gathered was useful in gauging how patients view and set goals for their own health.

Healthy Days data collection over time

At the onset of the data collection period, care team staff were given clear objectives and direction for administering the Healthy Days questions, which helped to maintain their data collection momentum. Yet we found that over time, Healthy Days data collection began to decrease. This was concerning given the importance of having complete data for quality

improvement and evaluation purposes. At this time, the data and evaluation teams considered removing the Healthy Days questions from participant assessments but decided to attempt to increase data collection first.

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The evaluation team began engaging in listening sessions with the care teams to learn more about their experience implementing the Healthy Days measures and to plan for a quality improvement project. Early conversations between the care and evaluation

teams revealed that several people were happy to “take a break” from asking these questions because they were awkward and burdensome to ask at times. Care teams were dealing with more high-stakes cases and felt that urgent needs — emergency housing, access to food, and reliable transportation to medical appointments — took priority and didn’t leave room to ask participants about Healthy Days. A care team staff member described the situation with the following comment: “When you’re in a visit with a patient that sleeps under a bridge, your priorities shift...the measures don’t seem as important.”

Efforts to improve Healthy Days data collection

In an effort to collect more HRQoL data and to better understand the challenges our care teams face administering the Healthy Days questions, we implemented a rapid cycle Plan-Do-Study-Act (PDSA) quality improvement (QI) project. This approach was ideal to meet our goal of learning and adapting our measurement processes quickly. The evaluation team began meeting with select staff from the care teams in June 2019 to develop a course of action for the next few months.

Step 1: “PLAN”

Listening sessions with care team staff members were a key part of the QI planning process. After discussing the lessons from these sessions, the decision was made for care teams to proceed with their regular participant engagement workflow with slight changes to the assessment forms and follow-up cadence. The plan was to collect assessment data over a three-month period and analyze the Healthy Days responses on a monthly basis. Findings would be reported regularly to internal care team managers and staff. After reviewing the completeness of the Healthy Days data collection, the evaluation team then gathered additional feedback from the care team staff to determine the usefulness of these measures for understanding our participants’ self-perceived health and well-being.

Step 2: “DO”

PDSA data collection occurred over a three-month period in 2019. The following changes were made prior to the start of data collection:

I. Removed the Client Perceptions of Coordination Questionnaire (CPCQ) questions from the participant assessment forms

These questions were initially included in participant assessment to measure patient-centered care and care coordination from a consumer perspective. However, care team staff expressed that these questions were difficult and burdensome to ask, and confusing for patients to respond to. In addition, the data collected from the questions were never used to evaluate the participant’s perspective of care. As a result, the CPCQ questions were eliminated from the assessment form for the PDSA.

II. Adjusted the timing of follow-up assessments

The intervention survey questions were previously asked at enrollment, 30 days post-enrollment, 60 days post-enrollment, and 180 days post-enrollment. For this PDSA, intervention questions were asked at:

1. Enrollment (30-day completion window)
2. 60 days post-enrollment follow-up (50-80 day post-enrollment completion window)
3. Graduation (completion window of up to 2 weeks post-graduation)
4. 6 months post-graduation follow-up (6- to 8-month post-graduation completion window)

The follow-up assessment timeframe was adjusted to allow more time for engagement and intervention activities to occur before a participant was asked to reflect on his or her health status. Changing the timing of follow-ups also set clear checkpoints for tracking progress throughout the intervention. Prior to the start of the PDSA, care team staff indicated that if they missed a follow-up time point (e.g. 30 days post-enrollment) they did not attempt to make up that assessment. Because of this reason, it was determined that an explicit window for completing the assessment was needed to provide flexibility around when the questions could be asked to ensure data was being collected at all specific time points.

III. Tracked follow-up attempts

The evaluation team realized that the number of times a care team member attempted to contact a participant was not explicitly being tracked prior to the PDSA. A checkbox labeled “follow-up survey related encounter” was added to the participant data tracking table of the Camden Coalition’s care management data platform. This enabled us to differentiate between data not collected as a result of a missed appointment versus an active choice on the part of the care team not to ask the questions.

IV. Created a paper version of the follow-up assessment form

A paper version of the assessment questionnaire was developed to solve any technology difficulties that may occur during an enrollment or follow-up encounter, such as interruptions in WiFi connectivity that resulted in data not being stored when using WiFi-enabled devices. The plan was for each care team member to always have a paper copy of the survey on hand, and enter the data from the completed form into the data platform as soon as possible.

Step 3: “STUDY”

Despite their previous hesitations, our care teams were motivated to resume asking the Healthy Days questions based on their desire to collect more robust data that would help elucidate their impact on participants’ health-related outcomes. A staff member told us, “We knew that these questions were a priority due to the clear objective, instruction, and organization around rolling out the PDSA.”

However, even though data collection was improving, care team staff were still not thrilled about the Healthy Days questions. This was clear about one month into the PDSA when the evaluation team joined a Population Health Initiatives department meeting to ask a few questions about the changes made for the PDSA. Everyone seemed to agree that removing the CPCQ questions from the enrollment and graduation assessments was a positive change. Staff remarked that the follow-up form felt shorter and more straightforward, freeing up time to ask about Healthy Days. Even so, the care teams continued to be frustrated with the Healthy Days questions, believing they were poorly worded and vague. The evaluation team also learned that, although the paper version of the assessment form had originally been included as a back-up tool, several care team staff preferred to use it in lieu of an electronic version during visits with participants as technical difficulties were common when collecting data using tablets or phones.

Healthy Days data collection results

When compared to the pre-PDSA findings, the PDSA enrollment assessment results showed that the completion rate on the assessment form doubled to 67% during the PDSA compared with pre-PDSA data collection.

While it was encouraging to see a higher overall completion rate after the PDSA, debriefing sessions with care team staff revealed that challenges remained with administering the questions. The evaluation team learned that care team staff still felt uncomfortable asking people to answer the Healthy Days questions, often because they felt overburdening the patient would interfere with the goal of building a relationship with a new intervention participant:

“The patient is already overwhelmed so we may try to ask the bare minimum of questions, especially during the first visit.”

Another significant barrier to complete and accurate Healthy Days data collection was participants' difficulty assigning a number to reflect the amount of recent days their health was "not good." Comments from care team staff illuminating this theme included:

"The hardest part is for people to pinpoint the number of days."

"Patients were having difficulty with the number 30. It's hard to put a number to your health."

"There are people who would say, 'all of them' and some would say, 'a couple.'"

Step 4: "ACT"

The PDSA results highlighted the importance of understanding the needs of *all* stakeholders (i.e., patients and care team members) when implementing measures into care management workflows. Taking the time to learn how all parties involved interpret the survey questions and addressing all implementation concerns will lead to more positive measurement experience and impact.

In light of this feedback and after careful review of the PDSA results and consultation with care management leadership, we chose to remove the Healthy Days questions from the assessment forms. The evaluation team also suggested the following action steps:

- Determine what measurement-related challenges may be lingering from the PDSA and plan to address them going forward.
- Prioritize new metrics to implement for our care management interventions and build out PDSA cycles to pilot them.
- Continue to reference and revise the quality improvement tools we have been utilizing (e.g., logic models, project charter, PDSA template) to support ongoing improvement efforts.

Putting the Camden Coalition's experience with Healthy Days in context

Our care teams are not the only ones to have experienced challenges administering quality-of-life measures. Researchers have found that it is common for patients to struggle to assess their own quality of life due to cognitive and/or communication impairments as well as any challenges related to the chronic illnesses they are living with. It may not be as easy for those with significant health or functional limitations to provide a discrete number of days for

their assessment of their own health and well-being compared to someone with fewer health impairments (Sneeuw et al., 1998, as cited Addington-Hall and Kalra, 2001). Further, a CDC finding that many respondents to the Healthy Days questions tend to give a more general response versus an account of days (CDC, 2000) reinforces the information shared by care team members about our intervention participants' responses to the Healthy Days questions. Other identified challenges in HRQoL measurement include (from Larson 1998, Moum 1998, Beatty 1996, and Schechter 1998, as cited by CDC, 2000):

- Difficulty interpreting the question and/or determining what an appropriate response would be
- Issues with various survey administration methods
- Older participants are less likely to respond within the given question format
- Older participants are more likely to have a hard time recalling information from memory and translating it into the specified response categories

These examples describe just some of the barriers to collecting complete and accurate health and well-being data in complex care populations. Organizations, including ours, should not be discouraged by these challenges, as measuring outcomes is a necessary practice to better patients' quality of care and improve care programs. Instead, we must continue to learn and adapt to the barriers we face.

Lessons for other organizations

There is much to take away as we reflect on our experience implementing the CDC's Healthy Days measures. In the course of this quality improvement project, we found that patient-reported outcome measures, particularly Healthy Days, assume that patients can recall health history with ease. Tools that are not suitable for the particular patient population may negatively affect the patient-provider relationship because the provider could appear to be insensitive to their patient's needs. In essence, a measure being valid doesn't mean it's appropriate.

This experience at the Camden Coalition highlighted the importance of also considering the potential for burden on the person who is administering the measurement tool(s). The work we do with patients is relationship-based. Many of us focus on capturing the patient perspective in our work and thus may be more sensitive to respondent burden. Incorporating measures into

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complex assessment workflows is especially challenging when care team staff are so often working through crises with their patients, which makes the tool less of a priority. If this reality is not given adequate attention, data quality and team morale may suffer.

While there is no simple solution to the challenges of survey administration, organizations can take steps to improve their measurement implementation, such as:

- **Regularly following up with those administering the measures — in this case, care teams.** When a research study or quality improvement project ends, it is essential that organizations share the data and the implications back with staff so they understand the impact of their work and can maintain data-collection momentum. In other words, evaluation teams should not just expect things to keep going and running smoothly after one round of a measurement pilot — or even after several years of implementation — without ongoing communication and feedback. It is also important to make staff aware of all changes that are made as a result of PDSAs or other evaluations.
- **Bring care team staff, program participants, and other important stakeholders into the evaluation and QI work from the beginning and support them throughout the measurement process.** Care team expertise — in terms of how to engage participants — is valuable. It is just as important to consider the effects of measurement questions on care team staff and their workflow as on participants.
- **Review best practices for effective survey administration and discuss approaches to asking measurement questions in challenging situations.** (e.g., participant is having a hard time understanding the questions; a participant feels that the questions have been asked already; being rushed for time during an engagement).

We are currently developing new approaches to **measuring patient-reported outcomes** for our care management interventions. Some of the priority areas for measurement include alternatives for measuring self-reported health and well-being; social connections; medication adherence; and health literacy. As we begin to pilot new measures, we will ensure that care team staff and intervention participants are comfortable with them.

We hope that our experience serves as inspiration for complex care organizations to continuously devote time and effort to address the often challenging, but always necessary, work of evaluating their programs and improving processes to create authentic and mutually beneficial relationships within and across teams and with the individuals served by the program.

References

1. Centers for Disease Control and Prevention. Well-being concepts: Health-related quality of life. 2018. <https://www.cdc.gov/hrqol/wellbeing.htm>.
2. Addington-Hall, J. Kalra, L. Who should measure quality of life? British Medical Journal. 2001. <https://doi.org/10.1136/bmj.322.7299.1417>.
3. Centers for Disease Control and Prevention. Measuring healthy days: population assessment of health-related quality of life. 2000. <https://www.cdc.gov/hrqol/pdfs/mhd.pdf>.
4. Bynum, J. Measuring what matters most to people with complex needs. Health Affairs Blog. Health Affairs. June 26, 2018. <https://www.healthaffairs.org/doi/10.1377/hblog20180622.306574/full>.
5. Barile, J., Horner-Johnson, W., Krahn, G., Zack, M., Miranda, D., DeMichele, et al. Measurement characteristics for two health-related quality of life measures in older adults: The SF-36 and the CDC Healthy Days items. Disability and Health Journal. 2016. <https://doi.org/10.1016/j.dhjo.2016.04.008>
6. Slabaugh, S., Shah, M., Zack, M., Happe, L., Cordier, T., Havens, E., et al. Leveraging health-related quality of life in population health management: The case for healthy days. Population Health Management. 2017. <https://doi.org/10.1089/pop.2015.0162>.



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About the Camden Coalition of Healthcare Providers

We are a multidisciplinary nonprofit working to improve care for people with complex health and social needs in Camden, NJ, and across the country. The Camden Coalition works to advance the field of **complex care** by implementing person-centered programs and piloting new models that address chronic illness and social barriers to health and wellbeing. Supported by a robust data infrastructure, cross-sector convening, and shared learning, our community-based programs deliver better care to the most vulnerable individuals in **Camden** and **regionally**.

Through our **National Center for Complex Health and Social Needs (National Center)**, an initiative of the Camden Coalition, we connect complex care practitioners with each other and support the field with tools and resources that move complex care forward. The National Center's founding sponsors are the Atlantic Philanthropies, the Robert Wood Johnson Foundation, and AARP.