



Organizational-Level Consumer Engagement: What It Takes

Case Study: *Hudson River Health Care*



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Introduction

Person-centered, value-driven health care delivery includes patients and families as partners in all aspects of decision-making about their health care. In practice, however, most health care delivery falls far short of achieving this goal. Yet health care systems are increasingly seeing the value in engaging patients not only in direct patient care, but to guide organizational decisions about that care. And while there is growing interest among health care organizations in taking meaningful steps to improve patient engagement, there is a knowledge gap and activation barrier to achieving this change and making sure the voice of the patient is incorporated at all levels of organizational decision-making.

The purpose of this project was to learn from organizations that have made a commitment to engaging patients and families at the organizational and system levels, recognizing that even highly committed health care organizations are at varying stages of maturity when it comes to implementing structures to actualize their goals in this area. In particular, we were interested in learning with more specificity about the engagement structures organizations have employed, what it takes for organizations to operate those structures, and what has been the impact of these structures both on the organizations and on the people and communities they serve.

Interviews were conducted with staff, patients and families at three health care organizations that have undertaken concerted efforts to meaningfully engage consumers at the system level:

- Children's Mercy Kansas City
- Hudson River Health Care
- Trinity Health

The resulting case studies describe the patient and family engagement strategies adopted (or in the process of being adopted) by these organizations and estimate the resources that are needed to initiate and sustain these strategies. By sharing this level of detail, the intent is to help spur broader adoption of meaningful consumer engagement strategies by other health care providers.

To learn more about the project's methodology and findings or to read the other case studies, please visit the [project webpage](#).

Terminology

This document preferentially uses the following terms as they are defined below. Where the health care organizations studied used specific terminology to describe their objectives, activities and programs, their preferred terminology is used within their respective case studies.

Patient is used as an umbrella term to represent an individual or their authorized representative – such as a parent of a minor or an adult child of an aging parent – who interacts with the health care system. A patient may also be referred to as an individual, person, consumer, member, beneficiary, caregiver or resident.

The terms **family** and **caregivers** are used in certain contexts to refer to patient-authorized individuals involved in providing care or decision-making support for a patient. Caregivers may include family members, friends, authorized representatives, community-based supporters or others authorized by the patient to support them in their care.

Patient and family engagement is the act of partnering with patients and families in defining, designing, participating in and assessing the care practices and systems that serve them to assure they are respectful of and responsive to individual patient preferences, needs and values.

Person-centered and family-centered care refer to health care planning, delivery and evaluation that sees patients, families and caregivers as equal partners in making sure care meets their goals, needs and preferences. This can also be referred to as people-centered or patient-centered care.

Patient experience is a component of health care quality that encompasses the interactions that patients have with the health care system.

Sources: CMS, Institute for Patient- and Family-Centered Care, AHRQ, National Academy of Medicine, Center for Consumer Engagement in Health Innovation, Health Care Transformation Task Force



Background

Hudson River Health Care (HRHCare) is a network of Federally Qualified Health Centers (FQHC) located throughout New York’s Hudson Valley, New York City and Long Island. Its mission is to increase access to comprehensive primary and preventive health care and to improve the health status of our community, especially for the underserved and vulnerable.

HRHCare started as a movement in 1971 with four mothers from Peekskill, New York, then one of the Hudson River Region’s poorest cities, who could not get adequate care for their children. Inspired by Reverend Martin Luther King, Jr. to take action, these “founding mothers” worked with fellow community members and religious leaders to address this lack of accessible and affordable health care services, ultimately leading to the opening in 1975 of the first FQHC in Peekskill.

Today, HRHCare serves over 225,000 patients annually at 43 Community Health Centers located in urban and rural communities across its service areas.

HRHCare provides comprehensive primary and preventative care, behavioral health services including Substance Use Disorder (SUD) treatment, dentistry, specialty services such as podiatry, optometry and nutrition, care management, and urgent care.

The majority of HRHCare’s patients are enrolled in Medicaid (44 percent) or uninsured (29 percent). Among the special populations served are people who are homeless, those with HIV or AIDS, those that live in public housing and agricultural workers.

“Founding Mothers”



(left to right) Willie Mae Jackson, Pearl Woods, Rev. Jeannette Phillips and Mary Woods with HRHCare CEO Anne K. Nolon (second from right)





Data Collection Methods

Ten individuals were interviewed for this case study and provided insight into HRHCare's patient engagement strategies. Individuals included a variety of leadership and staff with varying degrees of responsibility for patient engagement – Deputy Executive Officer and Chief Financial Officer, Chief Operating Officer and Executive Vice President, Chief Medical Officer, Chief of Patient Experience and Staff Development, Director of Planetree, Manager of Patient Experience, Director of Quality, Assistant Vice President of Care Management, Vice President of Quality Management and a Patient Advisor. In addition to these interviews, this case study also was informed by the review of a range of HRHCare engagement materials.

Findings

Engagement Strategies and Structures

HRHCare defines itself as a person-centered organization and in 1996 became the first affiliated FQHC. HRHCare is currently seeking Planetree certification, meaning that it will have met a set of rigorous criteria for “cultivating a culture of continuous improvement and consistently orienting care around patients, families, and communities.” This culture informs the organization's approach to patient engagement.

Governance

Board of Directors (Board): As an FQHC, HRHCare is required to have a Board, the majority of which (at least 51 percent) must be patients who “represent the individuals who are served by the health center in terms of demographic factors, such as race, ethnicity, and gender.”¹ In addition to these factors, HRHCare also aims to ensure that special populations – e.g., farm workers, homeless/formerly homeless people, people with HIV or AIDS – are represented.

The Board has responsibility for reviewing and providing guidance on all aspects of the organization and engages in activities such as:

- Reviewing incidents and patient complaints
- Evaluating activities and services for patients, including outreach and education
- Reviewing staff training plans and activities
- Evaluating staff satisfaction surveys and responding to the results
- Reviewing patient satisfaction and focus group data and making suggestions on action steps
- Reviewing and approving the annual budget and monthly financial reports
- Establishing strategic aims and measures, including one around patient experience
- Shaping major decisions (e.g., merging with Brightpoint; seeking Planetree certification)
- Recruiting, hiring and evaluating the CEO

¹ Health Resources and Services Administration (HRSA) Health Center Program Requirements, Chapter 20: Board Composition <https://bphc.hrsa.gov/programrequirements/compliancemanual/chapter-20.html>



Patients also sit on Board committees including the Quality and Personnel Committees. While they do not have a role in hiring staff beyond the CEO, patients have worked with the human resources department to establish hiring standards. In this way, patients inform the values HRHCare looks for when they hire any new staff member.

Finally, though not required, some patient members of the Board have taken an active role in HRHCare programs, such as the Health Promotoras Program and the HIV Community Programs. The resources required to support patient participation in the Board include, as needed, interpreter services, transportation and childcare.

Informing Projects and Improvement

Patient Focus Groups: For the past 15 years, HRHCare has been hosting an annual focus group at each of its health center sites. The focus groups are comprised of a randomized group of patients who have visited the site in the previous three months. Staff recruits these patients using a prepared script with the goal of having at least 10 patients for each focus group.

High-level members of HRHCare’s Patient Engagement Team lead the focus groups, which last approximately one hour. In order to elicit feedback on their experiences with the health center, facilitators ask participants three open-ended questions: what they like about the health center, what they don’t like about the health center and what they’d like to see added or changed.

Following each focus group, HRHCare staff conduct a “walk-through” of the site with the participants. The walk-throughs are another means of collecting concrete improvement data. They allow HRHCare staff to see the health centers “through the patients’ eyes” and understand what they are seeing and hearing at the site. The focus groups facilitator is responsible for writing a summary, which is shared with the head of the Patient Engagement Team, who then shares it with the senior leadership team and the leadership of the site. The Patient Engagement Team then works with operations staff and building management to address any identified concerns.

Aside from the regular focus groups, HRHCare has convened special focus groups to address specific issues raised by the Patient Experience Team, the Planetree Committee, local site leadership, community outreach groups or patient complaint. For example, after hearing that African-American patients at one of the health centers reported feeling disrespected, HRHCare convened a focus group with a randomly selected set of patients from the health center. The focus group helped to identify some of the underlying issues contributing to patient dissatisfaction. In this case the patient base for this health center had historically been predominately African-American, however, in recent years there had been a large influx in Spanish-speaking patients. To respond to the changing demographics, the health center had hired Spanish-speaking front desk staff which resulted in some of the African-American patients feeling underrepresented. With this information in hand, HRHCare met with the health center staff, shared its findings and made a recommendation to hire front-desk staff who were fully representative of the community the clinic served. HRHCare’s focus group strategy requires an investment of resources that

“Once we’re aware of an issue, focus groups allow us to ‘dig down deeper.’ Who can tell you better but the patient?”



includes providing \$25 gift cards for participants, offering refreshments, printing costs, paying for staff travel and providing, as needed, interpreter services, transportation and childcare.

Community Advisory Councils: HRHCare currently operates several community advisory councils (CACs) that provide the system with additional feedback from patients served at their clinics. The first set had its origins in six clinics in Suffolk County that became part of HRHCare in 2014. The CACs, which were previously the Boards for each of the clinics, receive support from HRHCare's community liaison who is responsible for recruiting members and facilitating meetings.

The second set has its origins in New York City clinics that only recently became part of HRHCare as a result of the merger with Brightpoint. This set is made up of a Central CAC that is open to any patient that participates in any service across the system and meets every other month, as well as a CAC made up of elected members of the client councils that operate at three adult day center sites in Brooklyn, Queens and the Bronx. Generally speaking, these CACs review and comment on all drafts of patient-facing materials before they are finalized. These materials have included a survey of patients to understand their experience with stigma, a form used by providers to create a safety plan with patients at increased risk of suicide, a code of conduct for all clinic visitors, and, more recently, a script for helping to explain to patients the changes occurring as a result of the merger between HRHCare and Brightpoint.

Currently, HRHCare Quality Improvement (QI) staff organizes and facilitates CAC meetings, but they envision a future in which the CACs are more autonomous. In addition, HRHCare leadership attends every CAC meeting. Though this was not always the case, Central CAC members now meet in HRHCare's New York City executive offices (though they also provide a videoconference option for members who are unable to attend in person). HRHCare's QI staff report that, contrary to some expectations, the shift to a professional setting has improved attendance and motivated CAC members to take on their roles with renewed vigor.

The responsibility for oversight and follow-up with the CACs falls under the Chief of Patient Engagement. The staff members assigned to the CACs work collaboratively with her and the Associate Vice President of Operations to assign identified issues, whether they are operational or opportunities for new programming, to the appropriate staff people for follow-up. The types of resources required to support HRHCare's CAC strategies include refreshments; printing costs and transportation for participants.

Monitoring and Improving Quality

Phone Surveys: Using a third-party vendor, Crossroads Group, HRHCare conducts a phone survey of a random selection of approximately 3,000 patients from across the network per quarter.² In order to get feedback on all aspects of care at HRHCare, there are surveys tailored for primary care, women's health, dental, behavioral health and urgent care. Crossroads conducts the surveys in the patient's primary language as listed in the medical record. The resources required to conduct the surveys are not insignificant: HRHCare pays the third-party vendor \$12 per completed survey.

² Providers who work part-time have 12 patients selected per quarter whereas providers who work full-time have 20 patients selected per quarter.



Genesis Community Advisory Boards (CAB): HRHCare runs three CABs specific to its Genesis Program, which “connects patients who have HIV/AIDS and their families with the primary health care and specialized services they need.” The CABs are made up of patients living with HIV who meet on a monthly basis to give the Genesis Program input on ways to improve the quality of its services. New CAB members are nominated and elected by current CAB members, and they participate in accordance with a set of written guidelines and a code of conduct. Each CAB is co-chaired by two members, oftentimes a patient and a staff member who serves as a peer educator. At the CAB members’ insistence, senior staff always attends meetings in order to provide rapid responses and decisions.

On a quarterly basis, Genesis Program staff brings quality improvement (QI) data to the CABs to discuss its meaning and potential solutions to identified issues. In addition, periodically, CAB consumer members will attend their region’s monthly QI meeting to talk about the aggregate data and to discuss strategies to address identified issues. In addition, the CABs often implement special projects. For example, the Genesis Program CABs led the implementation of the 3-year Consumer Lens project which sought to explore HIV positive health users’ ideas about quality of care, as well as how and why such ideas are meaningful. The CABs were responsible for reviewing draft survey instruments, reviewing the data responses, and developing recommendations. Finally, CAB members are offered multiple opportunities throughout the year to deepen their understanding of, and hone their skills around, quality improvement. These include direct and educational-level-appropriate training on quality improvement, weekend retreats, annual HRHCare staff conferences and an annual conference sponsored by the Latino Commission on AIDS.

Feedback from the Genesis CABs is woven into the Program’s quarterly quality management meeting, which examines trends in all systems, guidelines and policies. The Program also discusses patient engagement as part of its annual organization assessment.

To support the CABs, HRHCare invests in printing costs, providing meals and, as needed, transportation and childcare. It also pays the registration fees for CAB members to attend training.

Employee and Trainee Education

Patient Participation at Planetree Staff Retreats: Ten times each year, HRHCare holds a two-day retreat for all new staff, no matter their role (executives, facilities, providers, etc.) that have completed their initial 90-day employment period. On the first day of the retreat, a panel called “Quality from the Patient’s Perspective” is held in which an HRHCare staff person facilitates a conversation with two or three patients who share what is important to them, as well as their experiences with their health center and answer questions from retreat participants. Patient videos are also used as part of the curriculum in order to tie patient experience with quality metrics. On the second day of the retreat, participants visit the HRHCare-run Farmworkers Community Center, which distributes both food and clothing and serves as a social setting for farmworkers and their families. From there, staff participants travel in outreach vans to the fields to see where farm workers are working and living. Participants also hear from outreach workers about the needs of this community. The resources required

“I think providing patients with the opportunity to share their stories and to be trainers for staff also empowers them to come up with some solutions.”



to support this strategy are relatively modest: HRHCare provides each patient-panelist a \$25 gift card, lunch and, as needed, transportation.

Key Resources Needed to Implement and Operate Strategies

As described in each strategy above, HRHCare has a sophisticated and varied approach to establishing and operating its patient engagement strategies and to ensuring that the feedback they receive makes its way to system leaders and that patients learn what happened as a result of their feedback. However, there are a few cross-cutting central office bodies that ensure this feedback happens.

The most critical body is the Patient Experience Team, which oversees all patient engagement strategies. The head of this team, the Chief of Patient Experience and Staff Development, has a highly visible role within the organization. This person serves as the “glue” for patient engagement across the organization with a high level of participation in all of the structures and strategies. Even more critical, however, is that this person is a member of the executive cabinet, the highest level of the organization, where key decisions are made.

“It’s absolutely essential to have somebody in leadership who can speak directly to what’s happening with patients. Without that voice, patient experience can get lost, especially as an organization grows. If you don’t have that voice at the table that’s making the bigger decisions, you’re really in trouble.”

The Board of Directors serves as another central office hub for patient feedback in that it receives data from each of the various patient engagement strategies. For example, trends from the focus groups are shared on a quarterly basis with the Board of Directors, or more frequently if requested. Similarly, staff responsible for the CACs submit meeting minutes to the QI sub-committee of the Board. And, feedback from the Genesis Program CAB makes its way to the Board in a semi-annual QI presentation from the Medical Director for HIV/Hepatitis C. The Chief of Patient Engagement also attends Board retreats to report on emerging issues from the CACs and CABs.

Finally, patient engagement at HRHCare is also supported by at least two central office topical committees that receive and resolve patient feedback: the first is the Cultural Competency Committee, which handles any patient (or staff, for that matter) feedback related to the provision of culturally appropriate and sensitive care throughout the system. The second is the LGBTQ Committee, which handles feedback related to the care of the system’s LGBTQ patients.

All told, the HRHCare interviewees estimated that the organization spends approximately \$300,000 on an annual basis on its patient engagement strategies. Aside from the direct costs listed above for each strategy, this total also includes portions of time from a mix of HRHCare senior level leadership and project managers and, to a lesser extent, site staff. Senior leadership includes the Chief of Patient Experience and Staff Development, the Director of Planetree, the Manager of Patient Experience, the Director of Quality, Assistant Vice President of Care Management and Vice President of Quality Management. Site staff includes the site manager and front-line staff (including peer educators) who are responsible for managing the logistics of focus groups or CAB or CAC meetings. Additional costs include \$15,000 per year for Planetree membership and a \$20,000 fee for certification.



Examples of Impacts and Successes

HRHCare has realized important impacts and successes that directly emerged from its patient engagement strategies and structures. Several examples follow:

- **Phone System:** Through surveys and focus groups, HRHCare staff had fielded numerous complaints from patients about major problems with the phone system. For example, patients found it difficult to make appointments, felt that call wait times were too long and reported calls simply not getting through. The feedback went to the Board who became deeply engaged in thinking about the structure of the call center. As a result, HRHCare made a major investment (\$500,000) in establishing a new and improved centralized telephone call center.
- **Reducing Stigma Around HIV/AIDS:** The Genesis Program CAB was asked to review the results of a staff questionnaire around stigma. CAB members reviewed the data and discovered that while the vast majority of staff did not hold stigmatizing or value-laden views of people with HIV or AIDS, there was still work to be done to reduce stigma. CAB members made themselves available for staff sensitivity training and worked with the LGBTQ Committee to identify systemic changes to address the issue.
- **Administering Patient Questionnaires:** HRHCare learned from staff that administering certain patient questionnaires, e.g., those on the topics of sexual health or social determinants of health, were quite challenging. Staff led focus groups on the issue and heard that patients found that completing questionnaires in-person with a provider was extremely uncomfortable or off-putting. This feedback led to a project that aimed to move the questionnaire administration to an electronic format. Extensive patient feedback on the first iterations ultimately led to the creation of an easy-to-use survey tool that patients can confidentially complete (in English or Spanish) using an iPad.
- **Health Center Appearance:** Through patient focus groups and surveys, staff became aware of a negative trend about the appearance of some of the health centers. To learn more about the exact nature of the problem, HRHCare leadership went to the health centers and offered patients in the waiting area \$25 gift cards to do a comprehensive walk-through of the health center and to describe what they saw. The findings from these walk-throughs was that there were too many signs, fliers and educational materials posted on the walls. While these findings surprised staff, who thought they were successfully educating patients about important health topics with these materials, they were able to work with sites to reduce the clutter.
- **LGBTQ representation:** HRHCare was interested in comparing patient experience for LGBTQ patients vs. non-LGBTQ patients and convened a special focus group of LGBTQ patients. They asked participants what they would want to see when they walk into their clinic. Among the answers they received were that they would like to see art and brochures with individuals, couples and families that looked like them. This feedback was taken back to HRHCare's Cultural Competence Committee, which worked with the marketing team to make these changes happen. HRHCare then followed up with focus group participants to let them know that their feedback produced concrete results.



- **Improving Wait Times:** The Central CAC noticed there was a trend of patient complaints about wait times. A member of the CAC suggested that part of the problem might be that providers were being tied up in unnecessary appointments to review normal laboratory results with patients when many of these results could be reported by phone or mail. As a result of the feedback and the CAC member's suggestion, the system changed its protocol so that an appointment following lab work is not automatic, but rather, scheduled at the discretion of the provider (or at the request of the patient), depending on the lab results.

Challenges

- **Time and Resources:** Perhaps unsurprisingly, the top challenge identified by nearly all interviewees was a shortage of both time and resources. This was especially true at the time of this case study because of the transition the organization was going through following its merger. The impact of a lack of time and resources was keenly felt by HRHCare staff in terms of not being able to dig in as deeply as they would like to better understand patient comments.
- **Early Engagement:** Another identified challenge is simply remembering to prioritize patient engagement early in the process and taking the time it requires to do it well. Senior leadership acknowledged that patient engagement can be hard to do but that they know they will ultimately realize benefits, both in terms of time saved and improved products, further down the road. As one interviewee noted, “without that patient engagement, we may not actually be solving the right problem or solving it in the way that’s going to be most effective. You can get all the way to your final product, tie it up with a nice bow, only to find that when you go to deploy it, you don’t end up accomplishing what you set out to accomplish.”
- **Fear of Negative Feedback:** A third identified challenge is psychological. Getting negative feedback can be difficult for people who work hard every day to improve the health and well-being of their patients, so it is natural for people to avoid seeking feedback. As one interviewee commented “Everyone wants an A, and sometimes people will avoid getting feedback because they don’t want to, potentially, get a lower grade.”
- **Diverse Representation:** A final challenge relates to diversity of representation, particularly of the HRHCare Board. While HRHCare is required as an FQHC to have 51 percent of its Board members be patients who are representative of their patient population, recruiting can be challenging. This is especially true of patients from more transient populations, such as those who are homeless or farmworkers.

Considerations for Replicating and Scaling Work

- **Good focus group facilitation is essential.** According to interviewees, focus group facilitators must be highly skilled in facilitation. They must be confident in group management and be able to quickly establish a comfortable and safe environment for participants to respond with openness and honesty. Having central office staff facilitate the focus groups, rather than site staff, and assuring participants that all feedback is confidential, helps to create this open conversation. Facilitators



avoid asking leading questions instead asking open-ended questions in order to gain a deeper understanding of a participant's comments. For instance, once, a focus group participant said that the wait time was too long, and the facilitator then asked participants what kind of wait-time was acceptable to them only to discover that there was quite a bit of variation in opinion.

- **Survey data does not tell the full story.** You have to create opportunities to ask patients open-ended questions. Interviewees emphasized the importance of using strategies outside of simply conducting patient surveys. For instance, a recent focus group among teenage children of migrant workers revealed their desire for mental health counseling and support groups. As the Chief of Patient Experience observed, "That probably wouldn't come up in a phone survey but it comes up loud and clear in person."
- **Don't move forward with new projects without getting patient input.** Proactively seek feedback, e.g. the Patient Engagement Team recently pulled together a focus group to meet with an architect and ask for their thoughts on ways improve the existing health center, but also ideas on how they would design a new health center.
- **Patients can be both teachers and learners, and systems need to invest in both.** Make space for patients to share their experiences directly with staff, for example, through staff training sessions. Health care organizations should also invest the resources necessary to train patients on topics (e.g. quality improvement, financial reports) that will enhance their ability to contribute to the bodies on which they serve.
- **Ensure that a strong and informed voice for patients is a visible leader at the senior levels of the organization.** Ensure that with responsibility for patient engagement are not siloed off from leadership within the organization. To maximize organizational buy-in, staff should be visible at key meetings and in daily encounters. Some organizations may consider placing patient engagement staff offices close to those of the C-Suite leaders.
- **Supplement formal strategies with informal strategies.** Formal strategies for patient engagement are essential but should be supplemented by informal strategies such as monitoring social media for patient comments and trends. Patient engagement staff, to the extent possible, should strive to be present within the community the organization serves, e.g. by attending local meetings on relevant topics such as substance use disorders, domestic violence or childhood trauma.

"It does take time to engage with patients in the way [we do]. But it can ultimately save time in terms of what we build and what we end up moving forward with."