

Improving Pediatric Care Through Patient and Family Engagement Assessments

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TAKEAWAYS

- Patient and family engagement assessments are useful tools to help pediatric care teams understand the effectiveness of existing engagement strategies, how patients and families experience care, and patients' and families' priorities for improving health care services.
- A thoughtful and sustainable approach to patient and family engagement requires ensuring long-term funding, dedicated staff time, and leadership buy-in.
- This tool outlines practical considerations to help pediatric care teams implement patient and family engagement assessments and offers insights on selecting the right assessment method.
- Though this tool focuses on patient and family engagement assessment in a pediatric context, the strategies are applicable to providers with patients of all ages.

Across the nation, pediatric practices and health systems are investing in efforts to create better and more equitable health outcomes for pediatric patients. Meaningfully engaging patients and their families can provide critical information to design more person-centered, strengths-based, and effective pediatric care. As the recipients of care, patients and families have an important perspective on how care delivery can best meet their needs. Meaningful patient and family engagement, however, is often challenging for pediatric practices to pursue due to a lack of time and resources for both patients and the pediatric care team, as well as patient and family distrust of the medical system, particularly for families of color, due to historical and [current biased treatment](#).

Conducting patient and family engagement assessments can help pediatric practices, health systems, and community-based organizations (CBOs) understand patient and family perspectives; uncover opportunities to engage patients and families in advisory roles; and inform activities that shift care to be more holistic, strengths-based,

What is meaningful engagement?

Meaningful patient and family engagement can look different for patients, families, and medical care teams, but at its core, it is an equitable partnership where patients and families are involved from the very beginning of a change or improvement initiative, their experiences and feedback are valued and acted upon, patient and family preferences are honored in all decision-making, and they are fairly compensated for their contributions and time.

and anti-racist. These assessments can identify the effectiveness of existing engagement strategies, how patients and families experience care, and patients' and families' priorities for change. Patient and family engagement assessments can be used to inform transformation strategies over time, working toward an environment where patient and families co-design improvement initiatives alongside medical care teams.

This tool aims to support pediatric practices, health systems, and CBOs interested in fostering more authentic engagement with patients and their families. It outlines practical considerations to help stakeholders: (1) [understand considerations for implementing a patient and family assessment](#); and (2) [choose the best tool to meet the needs of the population served](#). It draws from the expertise of patient and family engagement leaders and pediatric sites participating in [Accelerating Child Health Transformation](#), a national initiative led by the Center for Health Care Strategies with support from the Robert Wood Johnson Foundation, and includes pilot site examples to illustrate existing efforts to improve patient and family engagement. Though this tool focuses on patient and family engagement assessment in a pediatric context, the strategies are applicable to providers with patients of all ages.

Implementation Considerations for Pediatric Care Teams Conducting Patient and Family Engagement Assessments

Prior to selecting a tool and conducting a family engagement assessment — whether in the form of a survey, an interview, or a listening session — pediatric care teams may consider the following:

- ✓ ***Do we have sufficient resources to conduct the assessment, including funding for dedicated staff time and family compensation?*** Employees involved in assessment efforts are often more successful if they have dedicated time for this work. If resources allow, it may be useful to hire new staff with dedicated time for the assessment and overall patient and family engagement efforts. It is also important to compensate patients and families adequately for time they spend in assessment efforts. See a [related brief](#) for considerations on compensating community members, including youth.
- ✓ ***Do we have leaders who support our desire to improve patient and family engagement and will prioritize this work?*** Having leadership buy-in is essential to support long lasting change. Additionally, leadership can help ensure staff time is protected and ensure needed resources for engagement work are available.
- ✓ ***Do we have the ability to enact long-term changes in engagement practices, if needed?*** Organizations may choose to seek out grant funds from local or regional foundations to support assessment efforts and subsequent family engagement work. Practices that have connections with academic institutions may be able to work with undergraduate, graduate, or medical students to provide support for this work.

Engagement assessments can be conducted in a variety of ways (as described in the following section) and can uncover information about how patients and families experience health care systems and engage with care teams, as well as opportunities for improvement. Following are considerations for care teams when beginning a new assessment process to identify opportunities for improving engagement.

- **Establish the purpose of the assessment.** It is important that all assessment participants, including the practice team and families, understand and align on the goals of the assessment and how the results will be used to inform improvements in patient and family engagement practices. It can be useful to meet with family participants early in the process — prior to selecting a tool — to collaboratively agree on the purpose of the assessment. Clearly defining the purpose upfront will help ensure that the assessment elicits meaningful feedback related to how and why the practice can improve family engagement.
- **Identify staff who will develop the assessment process.** This may involve using existing tools or creating in-house questions and processes. Organizations may lean on family advisors, community health workers, social workers, family navigators, and case managers to help inform the design of the assessment.
- **Consider how to administer the assessment.** It is important to establish how and when families will take a survey, participate in an interview, or join a group discussion, as well as who will administer each component of the assessment. The process should seek to avoid overburdening staff who are involved in assessment activities and reduce participation hurdles for patients and families.
- **Determine who is best suited to conduct the assessment.** Organizations may work with a CBO that is trusted within the community to conduct the assessment. Ensuring patients and their families feel comfortable in the assessment setting allows for more honest responses about their challenges with the practice without fear of experiencing negative consequences. Ideally, the individuals who conduct the survey/interviews/focus groups are unbiased individuals with lived expertise who do not provide care in the practice. Additionally, questions in the assessment may evoke memories of traumatic experiences for the participant. Individuals who conduct the assessment may need to provide additional support in the moment and refer participants to external supports as needed.
- **Recruit a diverse set of participants.** Assessment efforts are most useful when participating families are representative of the overall patient population. While it is often easiest to recruit families who have already expressed positive feelings toward the practice, are English-speaking, and are of higher socioeconomic status (and therefore assumed to have the resources to spend time engaging in this process), it is critical to include patients and families who are from historically marginalized groups, such as families of color, families with children who have disabilities, families from immigrant or refugee communities, and LGBTQ+ families.

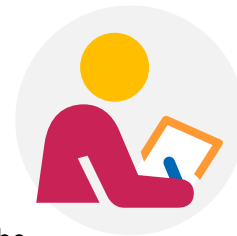
- **Address any ethical concerns related to gathering participants' insights.** It is important to protect the anonymity of participants, as it may help families answer honestly without fear of decreased quality of care. If needed, the institution can obtain [Institutional Review Board](#) approval, which can provide a helpful framework to conduct assessment efforts in an ethical way.
- **If needed, translate the assessment and recruitment materials for accessibility.** Components of the assessment, such as surveys, interview guides, flyers, and group discussion guides, can be made available in the most common languages that families at the practice speak, which may involve partnering with a translator to conduct the assessment. Additionally, using [plain language](#) can make questions more accessible to participants. Partnering with culturally competent CBOs to co-design or review potential language can help ensure accessible language is used.
- **Understand families' preferred mode(s) of communication.** Families may prefer being contacted via phone call, text, or during in-person appointments. If staff do not know patients' and families' preferred methods for communication, the practice can conduct a brief initial survey or ask families during a patient visit or in existing flyers or newsletters. If practices are interested in hearing directly from pediatric patients, they may consider how to engage youth through platforms they are most comfortable with, such as using QR codes or social media platforms.
- **Identify ways to share findings with participants.** It is critical to have a clear feedback loop to ensure that those who provide feedback understand how the information they provide is used, what they are helping to inform, and how to interpret the aggregate results. There are many ways to do this, such as drafting a one-page summary of the survey findings and making it available to families in the practice, e-mailing a summary of findings or including them in a newsletter, or hosting a meeting with families who participated in the survey to describe the trends uncovered and what steps the practice may take based on the data received. Practices may wish to designate an individual from the team to manage the feedback loop.
- **Ensure the assessment process fits into the practice's overall patient and family engagement strategy.** Meaningful patient and family engagement requires maintenance, attention, and continuous reinforcement. The assessment can be the starting point of building partnerships with patients and families where pediatric practices can build on the assessment process by considering ways to engage patients and families over the long term to ensure the practice understands the specific and evolving needs of patients and their families.

Selecting the Right Family Engagement Assessment Method

There are several methods for assessing the baseline level of patient and family engagement — and the effectiveness of engagement over the long term. Below is a list of methods to obtain feedback from families and staff about current engagement strategies, including through staff self-assessment, surveys, one-to-one interviews, and group discussions. Once a clear purpose for an assessment is identified, a practice can determine the best method of capturing engagement data for the patients they serve. Practices may also choose to use multiple methods to gather a diverse set of perspectives (see sidebar, next page).

1. Staff Self-Assessment

Self-assessments offer opportunities for staff to provide feedback about how they engage patients and families via written survey or through group discussions. Such assessments often encourage internal examination of staff attitudes, readiness of staff members to begin patient-centered transformation efforts, and level of leadership buy-in. Self-assessments may be time consuming, but they can be broken down into specific areas of interest to limit scope. Self-assessment tools can be used at regular intervals to measure progress over time and track progress during transformation efforts.



EXAMPLE: Pediatrics Northwest

To assess their policies and practices, Pediatrics Northwest in Tacoma, Washington, created a care transformation committee of providers and staff who went through the Family Engagement in Systems Assessment Tool (FESAT). Through this self-assessment, they determined the need to revise practice policies to reflect family voice, which the team recognizes is an ongoing process of engaging patients and families and incorporating feedback. As a next step, Pediatrics Northwest is establishing relationships with family advisors to support revising policies.

The FESAT supported discussions on where we are helped us ensure our mission, vision, and policies reflect incorporating family voice. We were able to create goals for where we'd like to be as a practice so that we can 'grow to feel comfortable with being uncomfortable.'

— Rachel Lettieri, Director of Care Coordination, Pediatrics Northwest

EXAMPLE: AtlantiCare

AtlantiCare, a federally qualified health center in Atlantic City, New Jersey, used a tool designed by the Institute for Patient- and Family-Centered Care (IPFCC) to assess their family-centered practices and policies. A group of social workers and administrative staff used the assessment to review patient engagement efforts related to: (1) leadership commitment; (2) signage and facility design; (3) patient and family participation in care and decision-making; (4) patient and family access to information, education, and support; and (5) education of staff, clinicians, students, and trainees. The AtlantiCare team used worksheets from the [Advancing the Practice of Patient- and Family-Centered Care in Primary Care and Other Ambulatory Settings tool](#) to develop action steps to create a family advisory board.

Examples of Family Engagement Assessment Tools

Below are examples of tools that support medical care teams to assess effectiveness of current patient and family engagement strategies and outline opportunities to improve engagement.

[Family Engagement in Systems Assessment Tool \(FESAT\)](#), developed by [Family Voices](#): This tool provides a comprehensive framework to evaluate and enhance family engagement practices with the goal of ensuring that families can be active participants in their care experience. The FESAT covers five categories, and organizations may choose to focus on one of its five categories at a time: (1) communication; (2) participation; (3) collaboration; (4) support; and (5) policy and advocacy. Each category seeks to identify how the practice is currently performing and opportunities for improvement. Family Voices offers technical assistance for sites who are interested.

[Advancing the Practice of Patient- and Family-Centered Care in Primary Care and Other Ambulatory Settings](#), developed by the [Institute for Patient- and Family-Centered Care](#): This guide is designed to help providers assess and improve their patient- and family-centered care practices. In Appendix A, health care teams can find a self-assessment to be completed by staff, providers, and family advisors that covers topics including: (1) leadership commitment; (2) advisory programs; (3) leadership opportunities for families; (4) decision-making around care; (5) access to information; and (6) education about medical care. Appendix A requires respondents to indicate the priority level of each section, and Appendix B outlines action steps toward improving the prioritized areas.

[Family Engagement Guide](#), developed by the [National Institute for Children’s Health Quality](#): This guide can support providers in assessing the readiness of their practice to work with patients and families as quality improvement partners. There are five steps in the guide: (1) examine the role and benefits of family health partners; (2) build practice readiness for partners as team members; (3) involve partners in training and orientation; (4) build communication and leadership skills; and (5) evaluate, sustain, and improve engagement and the health partner role. There are two assessments embedded in the guide — one helps practices understand leadership and staff readiness, and the second is a checklist to assess how the organization involves families as advisors and partners.

[Partnering with Families in Children’s Hospital](#), developed by the [Institute for Patient- and Family-Centered Care](#): This short organizational self-assessment can help staff understand current policies that impact families. This simple but effective tool also provides a mechanism for staff to prioritize areas of transformation based on assessment responses.

[Community Tool Box](#), developed by the [Center for Community Health and Development at the University of Kansas](#): This online resource for organizations interested in community assessments offers tools related to [conducting interviews](#), [listening sessions](#), and [surveys](#), among other strategies. Resources include preparation guidelines, example templates, and checklists. These tools are not family engagement-specific, but can inform a practice’s development of assessments, surveys, interview guides, and listening sessions.

[Partnership Assessment Tool for Health](#), developed by the [Nonprofit Finance Fund](#) and the [Center for Health Care Strategies](#): This tool is designed for organizations interested in assessing existing partnerships with community-based organizations. The tool features four categories: (1) internal and external relationships; (2) service delivery and workflow; (3) funding and finance; and (4) data and outcomes. While not specific to patient and family engagement, the tool can provide inspiration for practices interested in assessing the success of patient and family engagement work.

2. Surveys

Surveys may be a helpful strategy for assessing the effectiveness of current patient and family engagement. As with other family engagement efforts, staff bandwidth and an established feedback loop for sharing results with respondents should be in place prior to beginning. There are many existing survey tools, including the assessment tools mentioned above, that practices can use off-the-shelf or use as inspiration to create a survey tailored to their needs.

Practices may consider asking families questions that are parallel to those asked on a staff self-assessment to obtain a complementary and comparative set of responses from staff and family members. Being able to compare responses from staff members and families allows for a better understanding of where staff should focus their transformation efforts and whether or not staff priorities align with the families they serve.

If creating a new survey, practices can work with families to co-design questions, which allows families to influence what information is captured and ensures that the survey is written in plain language.

Surveys can be completed using whichever medium is best for providers and families, including tablets, paper forms, or conducting surveys verbally — either on the phone, in-person, or during a visit. If surveys are conducted in written form, respondents should be able to submit their answers anonymously. If surveys are conducted verbally, it is important to carefully select who will conduct the survey to ensure that families' responses are not swayed by the person administering the survey and that answers are kept confidential and non-identifiable if determined necessary.

EXAMPLE: Center for Collaborative Primary Care at St. Christopher's Hospital

When the Center for Collaborative Primary Care at St. Christopher's Hospital for Children in Philadelphia sought to ensure their services aligned with families' priorities, they created a survey to solicit family feedback. The survey was conducted using tablets during or after in-person visits as well as via phone. Participants received a gift card as compensation. With guidance from family advisors, the care team drafted survey questions covering a broad array of topics. Using the survey data as background, the team then hosted group discussions with families on themes that emerged to refine desired best practices for sharing resource referrals and what level of behavioral health support families wanted from their medical team.

3. One-to-One Interviews

Interviews allow for in-depth understanding of the experiences, perspectives, and desires of patients and families. Interviews can provide flexibility and allow interviewers to pivot their questions based on the responses, rather than adhering to a set list. If a practice is interested in this type of interaction, it is important to be intentional when picking the interviewer. As mentioned in the previous section, the interviewer should ideally be a patient/family advocate or member from the community and preferably have shared experiences and cultural ties to ensure families feel comfortable speaking freely.



Interviews also allow for gathering personal stories, which help illustrate positive and negative care experiences, and shed light on the importance of needed practice change. Additionally, some patients and families prefer to provide feedback verbally rather than in written form or may prefer a one-to-one environment over a group setting, making interviews a useful option.

Interview questions can be pulled from existing resources, such as the assessments highlighted in the sidebar on page 6, or can be developed by the practice. Practices may benefit from consulting a patient and family engagement expert to determine questions that are appropriate for the audience, [trauma-informed](#), and stated clearly and in plain language.

EXAMPLE: Cincinnati Children’s Hospital Medical Center Academic Pediatric Primary Care

The Cincinnati Children’s Hospital Medical Center Academic Pediatric Primary Care team sought to better understand patients’ and families’ opinions about continuity of care in their practice. In addition to collecting data that showed how often families had appointments with the same provider, the team hired a peer researcher, who was also a parent of a child in their practice, to conduct interviews with families. The peer researcher strengthened Cincinnati Children’s information-gathering, as she was able to speak directly to patient and family experience, which helped the interviews flow smoothly, providing qualitative data that made the case for additional improvement projects. While there was a set of 15 questions the peer researcher used throughout each interview, there was a subset of questions she could use depending on the discussion. Interviews were conducted virtually to provide flexibility for the interviewees and allowed the team to transcribe the interviews, which helped streamline the analysis.

4. Group Discussions/Listening Sessions

Practices may choose to host group discussions or listening sessions independently, alongside, or in follow-up to self-assessments, surveys, and interviews. Group discussions are often an efficient use of time as many perspectives can be captured during a single meeting. Additionally, participants may raise an issue that another person had not thought to mention. These discussions work best when someone outside of the clinical team facilitates to help patients and families feel protected and that their feedback is confidential.



An unexpected positive aspect of bringing families together for small group discussions is that they often elicit sharing of strengths and resources across families, which can facilitate relationship building across families at the practice. Depending on family and staff preference, these conversations can occur virtually or in-person. As with all other types of assessments, compensating those who participate is critical — and if participants join in person, covering costs for transportation, meals, parking, and child care is strongly recommended.

EXAMPLE: University of New Mexico Health Sciences Center’s ADOBE Program

Leadership staff at the University of New Mexico Health Sciences Center’s [ADOBE program](#) — which provides wrap-around services for juvenile justice-involved youth and their families — was interested in learning how they could better support ADOBE family navigators and educational liaisons as care team members. Many of these support staff have lived expertise and form close connections with patients and families. But through that work, the staff also have to process a lot of secondary trauma. The leadership team worked with a family advocate, unaffiliated with the practice, to facilitate a virtual listening session with ADOBE family navigators and liaison staff. The family navigators and liaisons shared an appreciation of their close-knit and trust-based work relationships as well as the value of reflective supervision to build trust, reduce burnout, and decrease staff turnover, which reinforced ADOBE leadership’s commitment to continue to foster this type of environment for staff.

Conclusion

Patient and family engagement offers pediatric practitioners an invaluable opportunity to understand what is working well in their care settings and where opportunities for improvement can be best focused. As the recipients of pediatric care, patients and their families have the most direct perspective on care delivery and can therefore provide suggestions, based on their own experiences, for where transformation is needed most. However, to date, many pediatric settings have not invested systematically in these types of engagement efforts, and likely have opportunities to build their capacity to engage patients and families more effectively. Pediatric care teams can use a variety of existing resources to assess their patient and family engagement efforts, or they can create their own assessment tools. Regardless of the method of data collection, it is critical that pediatric care teams are thoughtful about how they engage with patients and their families with the ultimate goal of informing better and more equitable care delivery and outcomes for all patients served.

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