

A Roadmap to Inviting, Engaging, and Including Patient/Family Partners in Quality Improvement and Other Health-related Initiatives



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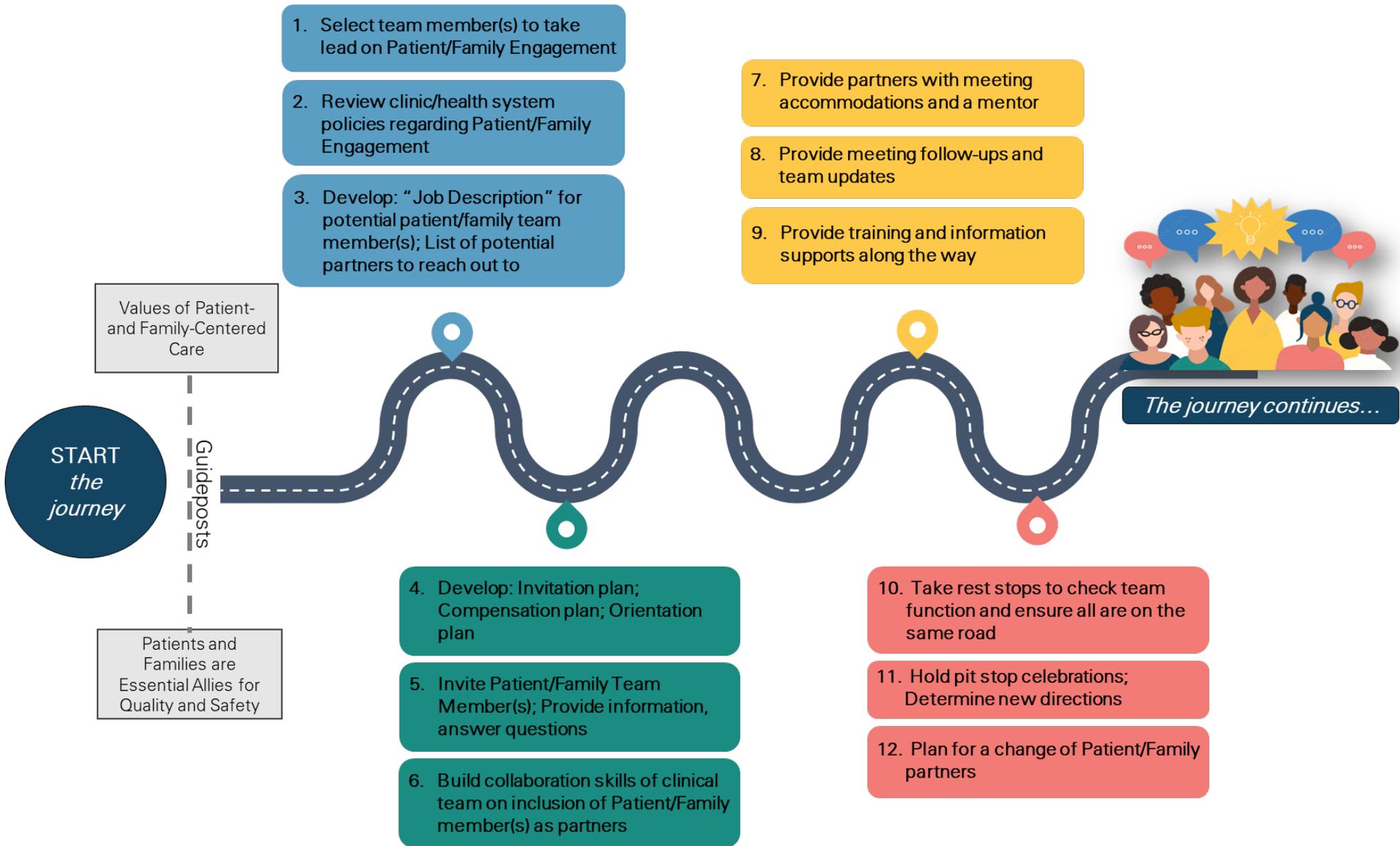
Introduction

Patient and family engaged care is an essential element of health equity. There are a variety of miles to cover and turns to take on the journey of effective engagement and inclusion of a Patient/Family Partner (PFP) onto a work group, advisory council, Quality Improvement (QI) team, or other clinical or health systems initiatives. Pre-planning is likely needed in advance of inviting PFPs to join in on the journey. While the 12 stages of this roadmap are listed in sequence, some points along the way may occur simultaneously, some might need to be returned to over time, and others may need to be consistent and continuous throughout.

This roadmap is a guide, and the exact order of the trip will differ from one organization to another. Travels will need to be personalized based on the organization, the initiative at hand, the team a PFP will be invited into, and the experience level of the organization and team members in engaging with PFPs.

Enjoy the trip while keeping your destination in mind—improving and advancing the practice of patient- and family-centered care, especially for children and youth with special health care needs.

So, start your engine where you are, with the key word being “start”!



Guideposts



Values of Patient- and Family-Centered Care

- **Dignity and Respect.** Health care practitioners listen to and honor patient and family perspectives and choices. Patient and family knowledge, values, beliefs, and cultural backgrounds are incorporated into the planning and delivery of care.
- **Information Sharing.** Health care practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete, and accurate information in order to effectively participate in care and decision-making.
- **Participation.** Patients and families are encouraged and supported in participating in care and decision-making at the level they choose.
- **Collaboration.** Patients, families, health care practitioners, and health care leaders collaborate in policy and program development, implementation, and evaluation; in facility design; in professional education; and in research; as well as in the delivery of care.



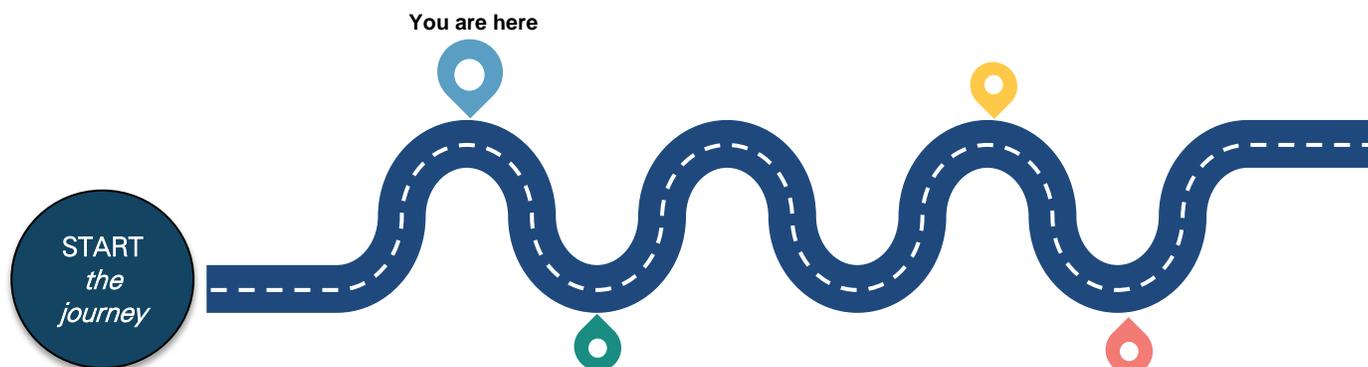
Patients and Families are essential allies for quality and safety

“Patient- and family-centered care is an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families. It redefines the relationships in health care by placing an emphasis on collaborating with people of all ages, at all levels of care, and in all health care settings. In patient- and family-centered care, patients and families define their “family” and determine how they will participate in care and decision-making. A key goal is to promote the health and well-being of individuals and families and to maintain their control.”

“This perspective is based on the recognition that *patients and families are essential allies for quality and safety*—not only in direct care interactions, but also in quality improvement, safety initiatives, education of health professionals, research, facility design, and policy development.”

~ Institute for Patient- and Family-Centered Care (IPFCC). Adapted from: Johnson, B. H. & Abraham, M. R. (2012). “Partnering with Patients, Residents, and Families: A Resource for Leaders of Hospitals, Ambulatory Care Settings, and Long-Term Care Communities” Bethesda, MD.

Roadmap Expansion



1 Select one or two clinical team or staff liaison member(s) to take lead on Patient/Family Engagement (PFE).

- a. A designated one or two clinical or staff liaison member(s) can take lead and review what is already in place regarding PFE and develop a framework for PFE based on the review (i.e., check with Human Resources, PFE Coordinator, Patient and Family Advisory Council, Volunteer Services Coordinator, and/or your organization's Director of Patient Experience or Patient-and Family-Centered Care (PFCC)).
- b. The lead member(s) can then coordinate recruitment and orientation of new PFPs.
- c. The lead member(s) might also coordinate ongoing liaison and support work with PFPs.

2 Review clinic/health system policies regarding Patient/Family Engagement.

- a. Assess the extent to which PFCC concepts and strategies are currently implemented within your clinic/health care system.
- b. Determine a process for clinical and staff members to learn about patient- and family-centered care, PFE and collaborating in partnership with patient/family advisors (see #6).
 - Resource: [Better Together- Partnering with Families: Strategies for Educating Staff](#); source: IPFCC
- c. Maintain considerations for recruitment of diverse and historically underrepresented partners, and the use of cultural competency/humility tenets throughout the planning, development, and inclusion of PFPs.
 - Resource: [Strengthening Diversity in Research Partnerships](#); source: IPFCC
 - Resource: [Trauma Informed Approaches to Partnering with Families](#); source: Ohio Statewide Family Engagement Center at the Ohio State University
- d. Determine how you may want to measure PFE and partnerships, evaluate processes, and assess the outcomes of collaborations.
 - Resource: [Family Engagement in Systems Assessment and Toolkit](#) (FESAT); source: Family Voices

3 Develop: "Job description" for potential patient/family team member(s); List of potential PFPs to reach out to.

- a. Identify roles for PFPs (i.e., Focus group; Advisory role; Active team member; Co-design and development).
- b. Determine qualities and skills that PFPs serving in the above roles are preferred to possess.
 - Resource: [Advancing the Practice of PFCC](#); source: IPFCC

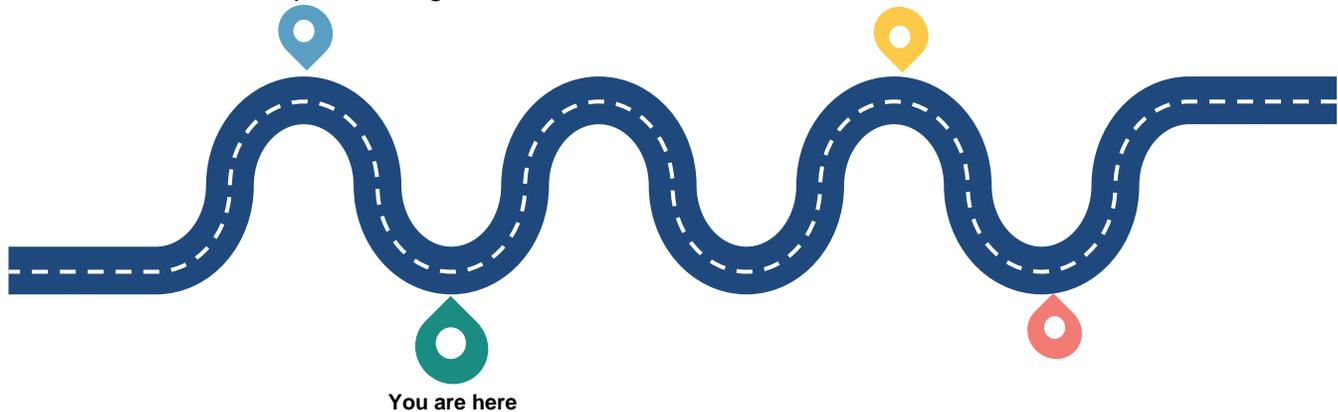
NOTE: This 2016 booklet from the IPFCC has a list on page 8. There are a variety of other related resources for recruitment and engagement of PFEs.

- c. Gather a list of names from clinicians and staff, from the clinic or health system PFE Coordinator, Volunteer Services Coordinator, from the Patient and Family Advisory Council, and from community-based or condition-based organizations.

- Resource: [Greater Plains Collaborative Patient Advisor Role](#); source: Patient-Centered Outcomes Research Institute (PCORI)

NOTE: An example job description template for a PFP in an advisory role.

- Resource: [REACHnet Patient-Consultant: Roles & Scope](#); source: PCORI
- NOTE: This is an in-depth “Roles & Scope” document for PFPs who may be more extensively involved in a project, research, etc. This resource includes a short compensation guide.



4

Develop: Invitation plan; Compensation plan; Orientation Plan.

- a. Invitation plan – considerations:

- Develop a patient/family advisor recruitment and selection plan and supporting items for the process (i.e., will you use an application process or provide a direct invitation? Who interviews or reviews possible PFPs and makes final selection decisions?).
- Post a notice for the position at the clinic, in news and online bulletins, give notices to patient/family members at appointments.
- Alternately, develop a letter of invitation to send to specific potential members, extend the invitation by phone call, or present the opportunity during a scheduled, in-person clinic visit.

- Resource: [Working with Patients and Families as Advisors](#); source: Agency for Healthcare Research and Quality (AHRQ)

NOTE: Department of Health and Human Services AHRQ guidebook and sample templates and resources were initially developed in 2008; however, there are a variety of templates to view as support at this Web page.

- b. Compensation plan – considerations:

- In appreciation of a PFP's time, expertise, and willingness to be vulnerable in sharing information, budget for compensation from the beginning.
- Consider babysitting and travel/parking costs; loss of work or family time; sharing of personal information and lived experiences; other skills and capacity based on the member's education, job, and related life activities; and networking capacity.

- Resource: [Preparing for Research Partners: Compensation for Patient/Family Advisors](#); source: IPFCC

- Resource: ["Patient partner compensation in research and healthcare: the patient perspective on why and how"](#); source: *Patient Experience Journal*

- If there is a barrier to providing direct stipend, honoraria, or compensation pay, strive for creative alternatives for compensation, such as: Collaborating with a stakeholder organization that has a direct relationship and interest in your clinic/work to provide stipend support; provide parking vouchers and gift cards; give useful material goods such as a notebook and pen, electronic support items, etc.; provide access to trainings and conferences; tap compensation resources from your health care system’s Volunteer Services Office and/or PFCC Coordinator; and, always provide refreshments at in-person meetings.
- c. Orientation packet – considerations:
 - Forms to be completed (confidentiality forms, memo of understanding, etc.).
 - Letter of invitation.
 - Outline of expectations, roles, responsibilities of team members, and typical meeting “norms” for your team (dress code; if titles are used in meetings such as Dr. Smith, versus John; if members raise hands to speak, or is it free flow discussion).
 - A roster of all team members, possibly including brief bio or background information on each member.
 - Clinic/health system policies, mission, values.
 - Health Insurance Portability and Accountability Act (HIPAA) information, and the importance of privacy and confidentiality (check with Volunteer Services or similar entity for HIPAA training or informational resources).
 - Information pertinent to the team initiatives.
 - Glossary of terms and acronyms consistently used by the team, clinic, and health system, and those specifically related to the project. Below are two examples of comprehensive glossaries that will likely not be necessary to use in full but provide a starting point to create a more personalized and succinct glossary.
 - Resource: [Serving on Groups Glossary](#); source: Family Voices of Wisconsin
NOTE: A general glossary from Wisconsin’s Family Voices “Serving on Groups” learning modules.
 - Resource: [CHAMPS QI Glossary](#); source: Community Health Association of Mountain/Plains States
NOTE: Many of the terms and acronyms in this QI-related glossary were compiled and shared by health center teams that participated in a Health Disparities Collaborative, which focused on improving care for specific chronic conditions.
 - Consider holding an in-person or virtual orientation prior to the PFP’s first meeting.



Invite Patient/Family Team Member(s); Provide information, answer questions.

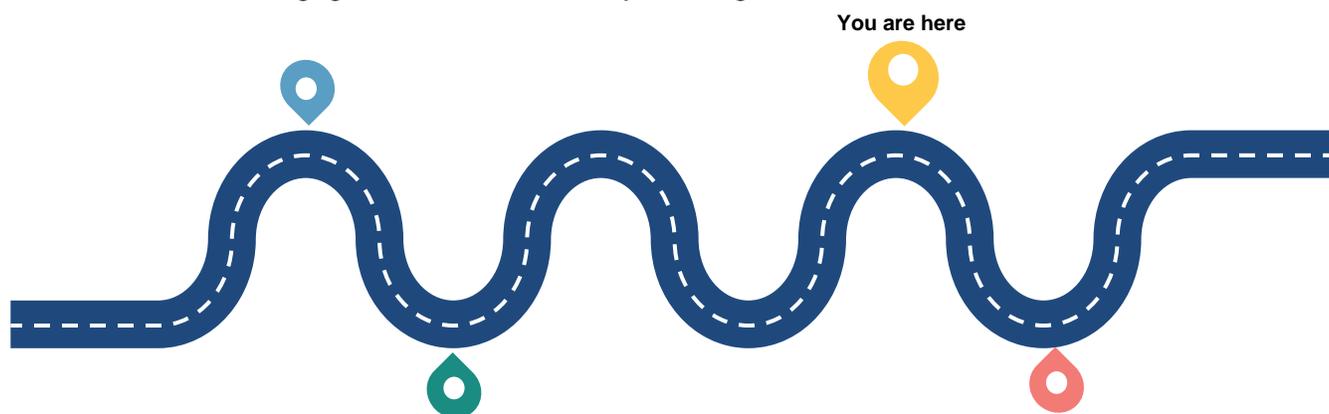
- a. When extending the invitation, be prepared to give ample time to provide further information and answer questions.
- b. Offer information or resources on where the PFP can learn more about the specific team initiative (i.e., information on QI; information on purpose/goals).
 - Resource: [QI 101 Webinar](#); source: National Institute for Children’s Health Quality (NICHQ)
NOTE: This interactive course teaches the fundamentals of QI and how to use this methodology to create effective, beneficial change.
 - Resource: [Increasing Patient-Community Capacity to Engage on Quality of Health Care](#); source: National Health Council
NOTE: A six-module online educational series addresses why quality is important in the current health care environment and how patients and patient organizations can be strong advocates for quality and engage in quality programs and measurement. Each module is 10-15 minutes in length.
- c. Offer the opportunity to connect with and/or be mentored by another PFP.

- d. Consider offering a potential new PFP an option to visit during a team meeting.

6

Build collaboration skills of clinical team on inclusion of Patient/Family member(s) as Partners.

- a. Implement a process for leadership, clinical, and staff members to learn about working with PFPs.
- b. Work to alleviate institutional and attitudinal barriers toward inclusion of PFPs as allies and team contributors.
- c. Provide research, resources, and training on collaborative communication and co-design skills.
 - Resource: [Group Processes](#); source: Serving on Groups
NOTE: See specifically the section on “Processes Groups Use.”
 - Resource: [Health Systems Guidance Modules](#); source: Anderson Center for Health Systems Excellence at Cincinnati Children’s Hospital.
NOTE: The Anderson Center Learning Network Program helps to build and support sustainable collaborative networks that measurably improve health outcomes. They produced a series of six learning healthcare system modules to guide organizations interested in developing a learning network—see specifically Module 5 for “Engagement and Community Building.”



7

Provide PFPs with: Meeting accommodations; A Mentor.

- a. Consider meeting accommodations to support a PFP, such as:
 - Time of meetings and place where meetings are held—might these need to be adjusted?
 - If meetings are virtual, check in advance on their technology access and ability to use the platform or other technologies used by the team; provide training and/or easy-read guides as needed.
 - Inquire in advance about the need for interpretation services and provide as needed.
 - Provide the agenda and meeting materials in advance and provide the same materials that everyone else on the team receives.
 - Hold a pre-meeting check-in to answer any questions regarding the agenda.
 - If the meeting is in-person, have someone greet the PFP and make them feel welcome, guide them to the meeting space, introduce them to others as folks settle in, and arrange seating for the PFP beside someone they may already know.
 - Hold formal, round-robin introductions by everyone at the start of all meetings, until the PFP is comfortable with who is at the table.
 - If the PFP is quiet during the meeting, create comfortable opportunities throughout the meetings for them to share perspectives and ask questions (but allow the PFP to “pass” if they don’t have a specific comment).

- At meeting's end, have a brief check-in to get feedback and answer any questions the PFP may have.
 - Resource: [REACHnet's Agenda Template for Stakeholder Inclusion](#); source: PCORI
NOTE: Example agenda with explanatory commentary.
- b. Consider providing a mentor or ally who can carry out some of the accommodations mentioned above. This liaison service can facilitate building the comfort of the PFP, as well as support and sustain their involvement with the team.

8

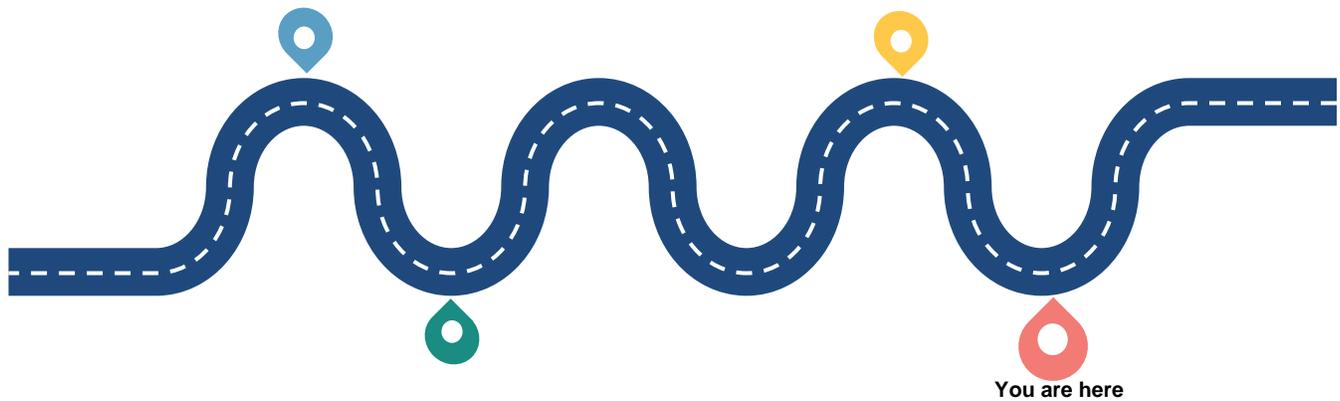
Provide meeting follow-ups and team updates.

- a. Include PFPs in any follow-up information, related new resources, “homework” items, etc. from team meetings. Include meeting reminders of dates, times, and locations of upcoming meetings. Strive to adhere to scheduled meeting times and venues and alert the PFP as soon as possible if a change must be made. Last minute cancellations can be a source of frustration for a PFP who has traveled to the meeting and arranged their schedule to attend (this also includes virtual meetings).
- b. If interesting or helpful learnings come out of daily/weekly internal QI related activity in which the PFP may not be directly involved, perhaps send a short update or “FYI” note, or suggest they review newly posted entries in any group-held communications platform (CoLab; Google Docs; SharePoint, etc.). PFPs may need guidance on the access and use of a group-held communications platform.

9

Provide training and information supports along the way.

- a. Keep PFPs abreast of opportunities for increasing skills and broadening their scope of knowledge related to serving with your team, as well as offer the opportunity to attend training events with the team, as appropriate. This might include a free webinar, self-paced course, IT support session, or a learning opportunity offered by your health system. However, also make it clear they should only attend such activities based on their interest and as their schedule allows.
 - Resource: [Vimeo Shorts Series on QI](#); source: Cystic Fibrosis Learning Network
NOTE: The Community Innovators team in the Cystic Fibrosis Learning Network made a series of brief videos introducing QI to patients and families. This series could also support step #5.b. See this introductory Vimeo recording for access to the whole series.
 - Resource: [QI 102 Webinar](#); source: NICHQ
NOTE: Building on QI 101, this interactive course provides further insight into the QI best practices needed to create effective change. The course is the next step in gaining the knowledge to create a real culture of change that fosters improvement for all.
 - Resource: [Family Leadership Training Modules](#); source: Family Voices of Indiana
NOTE: “Family Leadership Training Modules” give families access to the tools they need to be empowered to lead, advocate, and engage as partners in the systems that serve their children. The modules are accessed online at Indiana Licensing and Education Depot (I-LEAD)—where one must register first, then will gain access to these modules and more for free.



10

Take rest stops to check team function and ensure all are on the same road.

- a. It is good practice to take time out and assess how the whole team is doing—a “temperature check” of team function and communication. This reflective activity can include using an assessment questionnaire and/or holding a facilitated discussion and is best supported by using your team’s meeting guidelines as reference. This can be a quick process at the end of all meetings, or a more occasional planned, in-depth conversation.
 - Resource: [Team Effectiveness Questionnaire](#); source: Adapted from: “Team Effectiveness Diagnostic” created by London Leadership Academy, National Health Service

NOTE: This is one example of a “Team Effectiveness Questionnaire.” There are a variety of such tools available online. Similar items may also be available through your human resources department.
- b. Ensure a clear understanding of where the group is on the project journey. It is helpful to review the goals and mission of the project along with timelines or benchmarks that were set at the start of the project. Having this discussion as an agenda item each quarter will help manage staying on target (McCrea Coaching).
- c. Just as important are individual checks with the PFP, to hold a deeper debrief as a “rest stop” check in, beyond the short end-of-meeting checks mentioned in #7.a.

11

Hold pit stop celebrations; Determine new directions.

- a. Everyone enjoys time to celebrate successes and milestones large and small, as well as completion of a project journey. Consider making celebrations a purposeful part of your team’s interactions and be certain to include your PFP in these moments.
- b. When a project ends, acknowledge and thank a PFP’s participation. Share any final data and reports that may come out of the project. If there is a presentation or publication opportunity stemming from the project, consider including the PFP as a co-presenter or co-author.
- c. If new directions related to the project arise, such as a similar QI initiative or further steps of the original project, consider asking PFPs to continue on with the next journey.

12

Plan for a change of Patient/Family Partners.

- a. At any time, a PFP may need to bow out of the team. Or, as a project ends, a PFP may decide to move on to another opportunity elsewhere. Knowing this, consider keeping a running list of potential new PFPs to invite into the process. Also ask your current PFP if they might know of others who would like to be involved.
- b. Remember to update and finalize the measurement or evaluation of PFP engagement, as determined in #2.a.

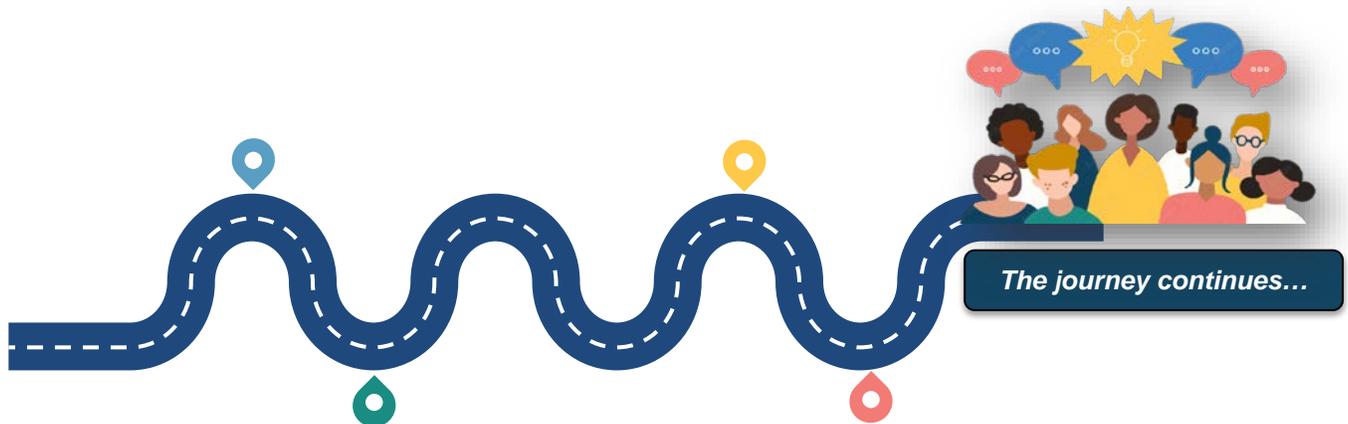
- c. Consider conducting an exit interview with your PFP or have them complete an evaluation of their time spent with the team. Ask for their suggestions for improvement in outreach and inclusion of new PFPs. Also ask if they might be willing to speak to possible new PFP team members to answer questions, and/or to provide written information and endorsement regarding working with the team.
 - Resource: [Exit Interview Sample](#); source: New Hampshire Center for Non-Profits
NOTE: General exit interview tool for non-profit boards.

Admiring and Acquiring (i.e., stealing shamelessly) Along the Way, Regarding Family/Community Engagement from the Field of Education

“Family Engagement is a full, equal, equitable partnership among families, educators, and community partners to promote children’s learning and development from birth through college and career.”
~ Commissioners Roundtable for Family and Community Engagement in Education Report: “Full, Equal and Equitable Partnerships with Families: Connecticut’s Definition and Framework for Family Engagement,” State of Connecticut Department of Education (December 18, 2018)

On moving Family and Community Engagement from “Nice to Necessary” . . .

“We’ve seen it [Family/Community Engagement] go from a backburner, add-on, compliance type of strategy to one where mindsets have been shifted to understand that family and community engagement needs to be a core strategy for whole school improvement,” Dr. Karen Mapp* says.
~ Emily Boudreau, “Effective Family Engagement Starts with Trust,” Harvard Graduate School of Education (April 30, 2020)
* Karen L. Mapp, Ed.D, Senior Lecturer, Harvard Graduate School of Education; Researcher and Co-Designer of the “Dual Capacity-Building Framework for Family-School Partnerships



Appendix

Resource List:

1. Select one or two clinical team or staff liaison member(s) to take lead on Patient/Family Engagement (PFE).
2. Review clinic/health system policies re Patient/Family Engagement.
 - [Better Together- Partnering with Families: Strategies for Educating Staff](#); source: Institute for Patient-and Family-Centered Care (IPFCC)
 - [Strengthening Diversity in Research Partnerships](#); source: IPFCC
 - [Trauma Informed Approaches to Partnering with Families](#); source: Ohio Statewide Family Engagement Center at the Ohio State University
 - [Family Engagement in Systems Assessment and Toolkit \(FESAT\)](#); source: Family Voices
3. Develop: “Job description” for potential patient/family team member(s); List of potential PFPs to reach out to.
 - [Advancing the Practice of Patient- and Family-Centered Care](#); source: IPFCC
 - [Greater Plains Collaborative \(GPC\) Patient Advisor Role](#); source: PCORI
 - [REACHnet Patient-Consultant: Roles & Scope](#); source: PCORI
4. Develop: Invitation plan; Compensation plan; Orientation Plan.
 - [Working with Patients and Families as Advisors](#); source: Agency for Healthcare Research and Quality (AHRQ)
 - [Preparing for Research Partners: Compensation for Patient/Family Advisors](#); source: IPFCC
 - ["Patient partner compensation in research and healthcare: the patient perspective on why and how"](#); source: Patient Experience Journal
 - [Serving on Groups Glossary](#); source: Family Voices of Wisconsin
 - [CHAMPS QI Glossary](#); source: Community Health Association of Mountain/Plains States
5. Invite Patient/Family Team Member(s); Provide information, answer questions.
 - [QI 101 Webinar](#); source: National Institute for Children’s Health Quality (NICHQ)
 - Resource: [Increasing Patient-Community Capacity to Engage on Quality of Health Care](#); source: National Health Council
6. Build collaboration skills of clinical team on inclusion of Patient/Family member(s) as Partners.
 - [Group Processes](#); source: Serving on Groups
 - [Health Systems Guidance Modules](#); source: The James M Anderson Center for Health Systems Excellence at Cincinnati Children’s
7. Provide PFPs with: Meeting accommodations; A Mentor.
 - Resource: [REACHnet's Agenda Template for Stakeholder Inclusion](#); source: PCORI
8. Provide meeting follow-ups and team updates.
9. Provide training and information supports along the way.
 - [Vimeo Shorts Series on QI](#); source: Cystic Fibrosis Learning Network
 - [QI 102 Webinar](#); source: NICHQ
 - [Family Leadership Training Modules](#); source: Family Voices of Indiana
10. Take rest stops to check team function and ensure all are on the same road.
 - [Team Effectiveness Questionnaire](#); source: Adapted from: “Team Effectiveness Diagnostic” created by London Leadership Academy, National Health Service
11. Hold pit stop celebrations; Determine new directions.
12. Plan for a change of Patient/Family Partners.
 - [Exit Interview Sample](#); source: New Hampshire Center for Non-Profits

Additional Resources:

- [Family Engagement Guide](#); source: Family Voices Massachusetts and NICHQ
NOTE: This guide was produced after a Learning Collaborative with 13 pediatric practices in Massachusetts. It includes an extensive set of information with similar perspectives as this roadmap. Note that some of the links within this guide are broken or no longer available.
- [Team Engagement for QI Welcome Booklet](#); source: Wisconsin Department of Health Services and Center for Patient Partnerships – Wisconsin CYSHCN Program and Partners
NOTE: An easy-read example of a welcome and orientation guide.
- [Partnering with Youth & Families in Research](#); source: CYSHCNet, a HRSA-funded network
NOTE: A resource booklet with extended information on the type/levels of family and youth partnership and suggested compensation, a resource list of family and community organizations, and an extensive glossary of research terms.
- [Website for PFCCpartners: https://pfccpartners.com/partner-resources/resource-materials/](https://pfccpartners.com/partner-resources/resource-materials/); source: The Patient and Family Centered Care Partners
- NOTE: The Patient & Family Centered Care partners (PFCCpartners) is an organization focused on improving quality, safety, and experience of healthcare through authentic partnerships. It is connected to both the IPFCC and to the Patient Family Advisors Network (PFAnetwork). There are four different entry point pages under the “Resources” section of the PFCC website, with each page listing multiple resources related to patient- and family-centered care, engagement, and partnership. One especially helpful video for both PFPs and QI team members is a short 4-1/2 minute video on being a Patient Family Advisor – see the last item at the “Patient Family Centered Practice Resources” tile, or go to this YouTube video link: [PFCCpartners and the PFAnetwork, Core Competencies Training - YouTube](#).

The roadmap guide was developed by Linda Hampton Starnes, Statewide Family Leader, Title V Children and Youth with Special Health Care Needs Program, Office of Children’s Medical Services (CMS), Florida Department of Health, in collaboration with CMS’s Learning and Action Network (LAN) partner, the National Institute for Children’s Health Quality (NICHQ). Lead Editor was Eliza Williamson, Senior Project Manager, NICHQ, with supplemental editing by: Sandra Widland, NICHQ and CMS LAN Project Director; Joni Hollis, Bureau Chief, Office of CMS; Kelli Stannard, Nursing Consultant, Office of CMS; and Angela Miney, Family Partner, University of Florida Health Pediatric Pulmonology Center.