

T1DX-QI Advisory Committee's Clinic Practice Guide to Engaging People with Diabetes in Quality Improvement Initiatives



Purpose:

Engaging with people with diabetes (PWD) and parents can improve clinical care processes and benefit your practice with better engagement, communications, and outcomes.

This guide has been designed with the T1DX-QI Advisory Committee to act as a resource for clinics beginning the process of engaging with PWD and their families so that their voices and perspectives can be a part of care improvement.

Background:

T1DX-QI coordinates a partnership of clinical teams, setting quality improvement aims together and implementing QI interventions to improve care processes and health outcomes for people living with diabetes.

The multidisciplinary clinical teams that work together on quality improvement projects include endocrinologists, nurses, psychologists, social workers, nutritionists, educators, social workers, quality improvement specialists, pharmacists, and data analysts.

In September 2022, T1DX-QI completed an annual survey with member centers, asking questions about care teams and practices. Thirteen clinics, or 22%, reported that they had at least one patient advisor collaborating with their care team. The Advisory Committee set a goal of increasing that number by 25%. The Committee also organized a qualitative study to learn more about the steps that the 13 clinics took to bring PWD/family advisors into their team work.

Definitions:

Below are definitions to help your team better understand stakeholder engagement. PCORI defines Stakeholders in healthcare as:

A broad range of communities have a stake in generating useful and relevant healthcare research evidence. The term "research partner", includes individuals who have experience living with, caring for, advocating for, and/or treating those with a condition. These individuals are included on research teams to share their knowledge and perspectives to ultimately enhance the relevance and use of the research. PCORI champions "patient partners" who are representative of the population of interest in a particular study, as well as their family members, caregivers, and the organizations that represent them. Other stakeholder partners include members of constituencies based on professional experience including clinicians,

community members, healthcare purchasers, payers, industry, hospitals and other health systems, policy makers, training institutions, and researchers.

Person-Centered Care vs Patient-Centered Care

In 2019, Jakob Eklund¹ published an analysis of the differences between person-centered care and patient centered care and identified nine common themes of:

- (1) Empathy
- (2) Respect
- (3) Engagement
- (4) Relationship
- (5) Communication
- (6) Shared decision-making
- (7) Holistic focus
- (8) Individualized focus
- (9) Coordinated care

The analysis showed that two distinct goals emerged between the two, with person-centered care working to support a meaningful life; and patient-centered care working to support a functional life, concluding that person-centered “broadens and extends the perspective” and considers the “whole life of the patient.” (1) We recognize and see value in all nine themes and we encourage teams to work towards providing person-centered care by collaborating with PWD and families who are receiving care in practice. Teams can help PWD lead meaningful lives by addressing the functional needs of their diabetes health and the “whole person” needs of the individual. Recognizing these distinctions, we encourage teams to use the language of “person-centered” and “people with diabetes” instead of “patient-centered” and “patients.”

Family-Centered Care

Family-centered care considers the health and well-being of PWD and their families through mutually respectful family-clinical partnerships. Recognizing and respecting the strengths and working with themes of:

- 1.) Empathy and compassion
- 2.) Respect for Cultures, Traditions, Diversity, and Plurality

¹ Håkansson Eklund J, Holmström IK, Kumlin T, Kaminsky E, Skoglund K, Högländer J, Sundler AJ, Condén E, Summer Meranius M. "Same same or different?" A review of reviews of person-centered and patient-centered care. *Patient Educ Couns.* 2019 Jan;102(1):3-11. doi: 10.1016/j.pec.2018.08.029. Epub 2018 Aug 26. PMID: 30201221.

3.) Recognition of the expertise and the lived experience that PWF and families bring to the stakeholder engagement relationship ([Family Voices](#) website²)

In the context of pediatric centers, family-centered care and family voices often include parents and caregivers. In adult centers, caring for a spectrum of PWD, from teenagers to older adults 85+, family voices include spouses/partners, caregivers, and children.

PWD Advisors

PWD Advisors: are people who are receiving care at your practice and/or their family members, who want to be involved in improving health care at your clinic. Many advisors have extensive experience either as a person receiving care, family member or caregiver; others have worked professionally in the health system. They are a heterogeneous group who are passionate about improving the care experience.

Clinical Teams: We define clinical teams as individuals or organizations seeking to include PWD and family voices to improve the systems of care. In the context of this guide, Clinical Teams are T1DX-QI member centers, but the recommendations are applicable for all clinical teams who are setting goals to provide more person-centered care.

These core principles can be helpful in grounding and setting the tone for PWD engagement work:

Guiding Principles for PWD Engagement	
1. Co-design and co-produce	Involve people with diabetes and their families (PWD) at the beginning/at idea generation. It will ensure that decisions reflect what is meaningful for them.
2. Offer PWD compensation for their time & contributions	Demonstrate to PWD that you value their time by offering payments, gift cards, parking vouchers, food, and other incentives. Compensating PWD for their time and providing resources is one way of supporting more diversity in PWD advisor representation. In grants applications, request financial support for PWD time and contributions.
3. Make the engagement role accessible	Make meetings/feedback opportunities more accessible by reducing barriers. Set mutually agreeable times for meetings to encourage PWD attendance. For meetings, cover food, childcare, transportation, parking costs; and offer virtual meeting options. Make written materials

² Family Voices website, accessed 9/1/2023 [Family Voices will partner in AAP's new center to improve systems of care - Family Voices](#)

	and the physical meeting space accessible for all ages. Increasing accessibility is another way of supporting diversity in PWD advisor representation.
4. Be transparent & humble	Be humble and transparent in your approach. Bravely share real numbers/data with poor results. They can help the team change course towards improvement.
5. Respect & empower PWD & families	Use language that is respectful and empowering. Using Person-Centered Care and inviting PWD engagement as part of the team acknowledges their lived experience that extend beyond the brief window of time when they are visiting the clinic for care.
6. Lead with health equity	Have BIPOC clinicians leading and speaking on the equity work. They can speak from their personal experience and represent it in an authentic way. Involve PWD in health equity work. They can also speak from their personal experiences and help the team reduce bias and identify what is most important.
7. Communicate roles and decision- making clearly	Start the PWD engagement process by communicating clearly how decisions will be made and how PWD feedback will be incorporated. Take time to explain acronyms and hospital policies/ procedures to help PWD understand the systems that the clinic is operating in.
8. Be flexible and responsive in how PWD can participate	Encourage and support PWDs to participate in the care team at the level they choose. Consider setting time-bound terms. Continue to check in with them and offer them opportunities to contribute at the level they are comfortable with. Some families may need to take “breaks” but may appreciate an open-door policy, to allow them future opportunities to contribute.
9. Communicate and celebrate improvements w/PWD as team members	Continuously share updates on how the improvements/feedback/processes are being incorporated so that PWD can see and celebrate their contributions in action. Invite them to co-author, co-present, or attend conferences.

Appendix of resources*

1. University of Michigan Teen Update (questions to help guide conversation for next visit) [U-M Teen Update.pdf - Google Drive](#)
2. University of Michigan’s Longitudinal Interprofessional Family-based Experience course matches student teams with patients/families living with chronic illness to see firsthand their life experience. Below is an example text shared with families:
 - a. I am excited to invite you personally to participate in a new educational program and research opportunity with the [UM Center for Interprofessional Education](#). This course, titled “Longitudinal Interprofessional Family-based Experience” (aka “LIFE”) will match student teams with patients/families who experience chronic illness. Student teams will

meet virtually with the patient and family twice over the course of the semester to learn about the patient and family's experiences.

- b. Each student team will consist of students from different health professional programs (such as pharmacy, nursing, dentistry, and social work) who will be immersed in learning about interprofessional collaboration and practice, as well as the social determinants of health that impact a patient/family's experience with the health care system and community.
- c. If you are interested in participating, please read below for the details about the commitment, and qualifications. We are seeking 8-9 patients/families to participate. If possible, **please reply at your earliest convenience** to let us know if you are able to participate!
- d. You would be a great fit for this if you:
 - i. Have a chronic medical condition that significantly impacts your life on a daily basis
 - ii. Can commit to meet virtually for one hour in February and one hour in March with your interprofessional student team (time to be scheduled with the team) and completing short follow-up surveys after your meetings
 - iii. Have experienced healthcare visits for treatment of illness, with different disciplines (e.g. doctors, nurses, social workers, therapies, etc.)
 - iv. Have a willingness to share experiences about your illness and life

*T1DX-QI would like to add more resources to this appendix. Please share resources from your clinic with your QI coach and QI@t1dexchange.org.