103 Patients and family partners can become leaders on their quality improvement teams

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Background: Patient and family partners (PFPs) collaborate with their cystic fibrosis (CF) center’s health care team to provide their perspective and improve patient health and overall care. PFPs can rise to the level of quality improvement (QI) leaders on the team, which requires open dialogue, support of team members, and participation in the PFP workgroup. The CF center at Columbia University Medical Center (CUMC) has locations in New York City and Stamford, Connecticut. The center’s QI team consists of two PFPs, a lead physician, a registered nurse, a nurse practitioner, two social workers, a registered dietitian, and an integrative medicine physician. The team meets weekly for 1 hour to collaborate on QI.

Methods: A PFP who became the CF care team’s PFP in 2017, when CUMC joined the Cystic Fibrosis Learning Network (CFLN), formed a relationship with the lead CF physician who cared for the PFP’s child. They began attending the PFP workgroup meetings each month to learn about QI tools, privacy requirements, and team meeting protocols, in addition to filling out the monthly required PFP ladder of engagement survey (Figure 1). The QI team members, including the PFP, joined the Quality Improvement Measurement Intensive (QIMI) meetings to learn QI techniques necessary to advance their work. The team reported revisions of their plan-do-study-act (PDSA) to the CFLN weekly and completed all required surveys.

Results: As the PFP took on more responsibilities in their role, they became more comfortable assuming a greater leadership position on the team. In 2019, the QI team expanded, when it promoted two team members (the PFP and the integrative medicine physician) to the roles of co-QI leaders to better assist the lead physician in accomplishing their goals. As a QI leader, the PFP assisted the team in producing PDSA cycles for four initiatives, sent weekly reminders including dates and times of upcoming CFLN engagements and expectations, kept the QI team focused, and helped new team members and another PFP understand their roles, all while showing frequent gratitude to team members for the exceptional work they do for the CF community. Through teamwork and communication, this team has accomplished many of its QI goals. In 2021, the team published four abstracts on which the PFPs were co-authored for the North American Cystic Fibrosis Conference.

Conclusions: By being part of a team that encourages a collaborative environment that fosters autonomy and growth, a PFP can rise to the position of QI leader in the CFLN. Attending monthly PFP workgroups, collaborating with teammates, and showing leadership skills are all necessary components of being a valuable member of the QI team. Encouraging more PFPs to take on leadership positions on their QI teams is a necessary component to having the greatest influence possible on CF-related patient care.

Acknowledgements: CFLN; Cystic Fibrosis Foundation grant.

104 Provider involvement in research conversations with patients: Quality improvement

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Background: Clinical research is essential to advancing cystic fibrosis (CF) clinical care [1]. With new pursuits into therapies for those not eligible for CF transmembrane conductance regulator (CFTR) modulators, research teams may need to modify previously successful processes to best meet the needs of those that have been ineligible for clinical trials. These patients may have experienced lack of recognition and engagement from research. Patients consistently rate their physicians as the most trusted source of information [2]. A relationship between investigators, patients, and providers is conducive when engaging and recruiting minority populations [3]. The purpose of this project is to assess how often providers discuss research with patients in the clinical care setting.

Methods: As a larger quality improvement (QI) project examining the culture of research at a large adult CF center, 10 CF providers (7 doctors, 2 nurse practitioners, 1 PhD) were asked, “When do you talk to your patients about clinical research?” Respondents were given the opportunity to elaborate, allowing for quantitative and qualitative results.

Results: Nine (90%) of those surveyed responded. Although none of the providers responded “never,” only two (22%) answered, “at every clinic visit.” Other responses were “when the patient brings it up” (33%), “when I know there is a study for my patient” (44%), and “when I think there is a study for my patient” (55%). Multiple answers were allowed, as well as the opportunity to explain them. Four (44%) responded that they rely on “someone else” to bring up research. Another four (44%) reported being unfamiliar with research studies available and therefore did not discuss it at every clinic visit.

Conclusions: As providers continue to deliver innovative care, it is imperative to identify barriers to provider-patient research discussions. Research teams and clinical care providers can work together to build trust and provide resources to address systemic barriers to participation in clinical research for underrepresented minority groups [4]. Following eQUIP-CR design, the research QI team will prioritize educating providers, encouraging these conversations between people with CF and providers, and re-analyzing.

References