

Parent/Patient Advisory Committee

January 11, 2023

Survey Data:

1. Would be interesting to see patient perspective on the question of “how frequently does your clinic ask patients about their preferences and priorities”
 - a. Jeff said that CWD/FFL could be used to gather responses to this question
2. Expected peds to be higher than adults

Discussion:

1. What would make participating in the PFAC more valuable and meaningful?
 - a. Recruit at FFL, meeting in person, have PI voice why having parent and patients involved make a difference
 - b. Add space on T1D Exchange Website promoting PFAC to people outside the Collaborative
 - c. Social event for parent/patient at Learning Session evening before LS
 - i. Invite comments from other PWD/family members who could not travel to have their opinions shared
2. How can we improve participation in the individual clinical teams?
 - a. Recruit to the collaborative PI to refer a patient or parent

Publication:

1. What would you like the paper to reflect?
 - a. Empower patients to get the most out of visits, addressing major disconnect in priorities between patient and provider
 - b. Can fixing the diabetes and life issues result in better outcomes (A1c, Time in Range etc)
 - c. Audience towards clinicians to understand patient voice/goals
 - i. Tip sheet on how to advocate for yourself (Appendix item?)
2. What is valuable?
 - a. Guidebook on improving the gaps in care between patient priorities and clinical goals
 - b. Motivational interviewing training to help clinicians talk about goal setting with PWD
 - c. Designing as “joint appointments” for strong engagement
3. What does literature say? Group is interested in making something more practical/concrete- la guide that can be followed

Sick Day Guide:

1. What needs to change so this is up to date?

- a. Add in bold (if you vomit assume it is DKA unless proven otherwise)
 - b. Vomiting should result in phone call to care team (even if blood sugars are in range)
 - i. Contact a friend/relative in case care team does not have 24-hour care or can't be reached quickly
 - ii. Add an Emergency contact section for writing in with felt marker
 - c. Move vomiting up to number 1
 - d. Make sure Zophran is listed and keeping fluids down
 - e. Laminate and print as giveaway at events
 - f. Make a QR code so that teens can access easily
2. Do you think that PWD/Parents would like COVID-19 language included?
- a. Sick day is sick day regardless of COVID

Sports Camp: 2/5/2023

www.samfuldt1dsportscamp.com

Link to Recording:

https://us02web.zoom.us/rec/share/q1kOUhp7clalC1qF_kBqPCg82L8MtfCbAnWHf8C8KJZ5G7A3mbAERM9T2KycZHL0.jz29dCLX_ORC9b9Q

Passcode: 2Z5+X32a

Next meeting is scheduled for Wednesday April 12th