

Patients and Family Members of PFACS: Questions

Good afternoon everyone. Thank you for your time and for being willing to talk to me.

However before we begin, here are some details about me. My name is James Harrison and I am a researcher at the University of California San Francisco (UCSF) and I work with hospitalists, or general internal medicine doctors, whose focus is to care for people who are admitted to the hospital. The research topics of the projects I work on relate to Hospital Medicine.

By Hospital Medicine research projects, I mean projects that are aiming to understand, and find the best solutions, to improving the care and experiences of hospitalized patients, their families and caregivers. This includes the time of admission to the hospital, during hospitalization and the through the transition to home or another care setting.

The purpose of today's discussion is for me to learn from you all about how we can best involve patients and families in Hospital Medicine research projects seeking to improve the hospital experience.

I am planning to create a PFAC that will advise on these Hospital Medicine research projects. I want to understand what you, as PFAC members, would need so you can participate and provide your perspectives on these projects. I also want to you think about what researchers such as myself need to do to effectively partner with PFAC members.

Now before we begin some housekeeping and other information for you.

- Please feel free to eat during this meeting or go to the restrooms.
- This discussion today is part of a research study has been approved by the Institutional Review Boards of UCSF/BWH and Christiana Care.
- Your participation is entirely voluntary and you do not have to participate if you do not wish to.
- As part of this discussion we will audio record our conversation. We will be recording this session so that we can accurately capture the suggestions and comments that you have shared with us today.
- The audiotape will then be transcribed and any identifying information about you that comes up in the recording (such as your name) will be removed. The audio recording will then be destroyed.
- There are no right or wrong answers, what is important to me are your opinions, experiences and perspectives. You do not have to have any experience working or advising on a research project. Your perspectives as a PFAC member and as a patient, family member or caregiver are what are important.

- The goal is for everyone to have the opportunity to share his or her opinion. To accomplish this, I may need to ask you to limit your time in order to give someone else a chance to speak, do not take this personally.
- Your comments and feedback today remain confidential and will not be linked to your name. Your opinions will not be shared with any of your existing care at BWH/Christiana Care/UCSF providers and will not affect any current or future care you receive.
- If any of you have detailed questions, feedback, or concerns, I am happy to discuss with you now, after the meeting or at another time.
- Now before I begin I need to ask everyone to verbally let me know they agree to participate in this focus group by saying yes or I agree.
- Again, thank you all for your time.

Questions

1. I thought we could first go around the room to introduce each other and tell each other a little bit about ourselves and what PFACs you are involved.
2. Before we start the main discussion, I wanted to give everyone an overview of the phases of a research project so we are all on the same page. JAMES to explain and ask if anyone has any questions.
3. Now thinking about your time on this PFAC, and any experiences that you have may had working on a research project. What was the research project about? In what ways did you contribute or provide your perspective?
4. We are interested in how patients, family members, caregivers and researchers engage in research. By engagement we mean meaningful involvement of patients, family members and caregivers throughout the research process – this includes from topic selection, through design of a study, through implementation, to sharing of results or findings with the public. Why do you think it is important to engage patients, family members or caregivers as team members of research projects that are seeking to improve care delivery and the patient experience in the hospital?
5. What are the barriers or challenges for you as PFAC members in engaging and contributing your perspectives to a research project?
6. What types of information or tools would you, as PFAC members, need to fully engage, feel comfortable and contribute your perspectives to a research project?
7. Finally, tell me are there things we haven't discussed yet that I should be aware of as we are planning training for researchers, patients and families, to make their partnership in Hospital Medicine research most productive?

