# SPARCSdm Updates

*Standardized Process Assessment of Relationship-Centered Shared Decision-Making*

## Valuing Our Care Partners

This newsletter focuses on the invaluable contributions that informal care partners make in the lives of those they care for and in rehabilitation research and practice. We are fortunate to have two care partners, Paige Ford and Trisha Kot, as members of our team. Their lived experiences of caring for persons in disordered states of consciousness have enhanced our understanding of the complex treatment contexts in which rehabilitation care takes place.

In SPARCSdm and at the Advanced Metrics Lab (AML), care partner perspectives are incorporated into all aspects of the research process including methodology design, data analysis and dissemination activities. We dedicate time to increase their capacity to engage with us as members of our research team.



An informal care partner is an individual who provides emotional and instrumental support to someone experiencing physical or mental health challenges, disabilities, or chronic illnesses. Care partners may be family members or friends, and their responsibilities often encompass a wide range of tasks, including assisting with daily activities, offering companionship, managing medical needs, and providing overall care and advocacy. IIn Trisha's words, "Caregiving is all consuming. You have to have so many hats: nurse, doctor, insurance, but firstly to always be his mom and to care." Similarly, Paige also describes being a care partner as being "all consuming." Paige elaborates saying that caregiving is "giving support mentally, physically, and emotionally. It is more than just medicine and feeding, you have to be there for them in every way."

In the field of medical rehabilitation for persons in disordered states of consciousness, care partners can play a crucial role in enhancing the well-being and quality of life their loved ones. By listening and including their lived experiences, care partners provide crucial perspectives into the multifaceted challenges faced by patients and those who care for them, and guide the development of patient-centered approaches.

In the current SPARCSdm project, Trisha and Paige have supported our Relationship-Centered Shared Decision-Making Process Model by co-designing with us, reviewing various iterations of our work on micro-decisions during clinical encounters, and disseminating with various member of our research team and advisory board.
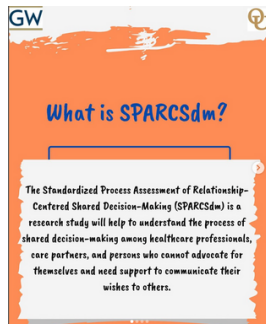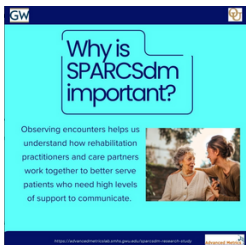
# Team Member Spotlight

## Trisha Kot

Trisha has been involved with the AML since 2016, beginning with the No One Listens to Me project. She remembers feeling intimidated traveling to DC to meet the team for the first time at a conference, but was immediately relieved by realizing there's a crucial need for her perspective. Trisha found reward in helping others, hoping her experiences caring for her son Nick, would resonate with fellow care partners. Her perspective emphasized the importance of care partners being directly involved in research, as their unique experiences contribute to a collective learning process, benefiting others facing similar challenges.

## Paige Ford

Paige's involvement since 2016 began when she was a care partner for her son Trey. Her role as both a mother and a care partner has offered a comprehensive view of the various hats care partners wear, from managing medical responsibilities to navigating complex insurance systems. Paige became involved in the interview process and her participation helped to make interviewees feel more comfortable and understood. She understands the importance of practitioners hearing care partners' side of the story, because as she says, "the more the practitioners know, the better we can both care for them". Paige's insights have become an integral part of gathering qualitative data, providing a nuanced perspective that betters the lab.

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## Project Updates

- We have received IRB approval to conduct data collection at TIRR Memorial Hermann in Houston, Texas. We anticipate this opportunity will provide us with abundant and diverse data!
- Our team is creating innovating analysis procedures to properly and insightfully identified micro-decisions.

SPARCSdm

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