

Motivations Study - Exploring the experience of participating in a Patient Oriented Research Study

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Abstract

Derived from our experience of recruiting children with medical complexity for research studies, the “Motivations Study” will help us understand the complex barriers to research participation for parents of a child with a serious illness. In this qualitative research study we are asking parents important questions about what research means to them and why or why not they have chosen to participate in it. This line of questioning moves beyond the standard feedback form that asks participants whether their experience in a study was positive or negative, towards a deeper understanding of how research participation is understood and experienced from the point of view of a parent deeply engaged in the health care of their medically complex child.

We recognize that only a qualitative methodology will enable us to gain a deeper understanding of this issue. We have chosen a qualitative research approach, known as Interpretive Phenomenological Analysis (IPA) as the foundation for this study. This methodology will allow us to reflect on the deeper meaning of participating in research through the collection of individual narratives of such experiences. We are conducting semi-structured interviews with 15 families to gather a plethora of rich stories about these individual’s experiences participating in research or perhaps - not participating.

Importantly, we have also chosen for our staff Family Liaison, a parent-partner in our larger program of research, to be the study lead. Our Family Liaison plays an invaluable role in bridging clinical and academic research agendas with the realities of the families that enter our research program. As our Family Liaison is herself the parent of a child with medical complexity and carries with her years of experience navigating the health care system, she is uniquely positioned to connect with study participants from a shared context. We believe that this shared context will create meaningful conversation and allow us a deep understanding of what moves parent to give their time, energy and medical charts for the benefit of researchers, or prevents them from doing so.

Institution

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