

Name: Patti Ephraim, MPH

Project Role: Project Director (JHU)

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Personal Statement: I have 20 years of experience in the development and execution of multi-site randomized clinical trials. My research has focused on behavioral interventions aimed at improving the health of patients with chronic disease and disability, with particular emphasis on increasing knowledge and self-efficacy, reducing barriers, and improving shared-decision making. For the past 7 years, I have worked with Dr. Boulware, participating in the development of decision-aids to support patients and families in shared-decision making and overseeing the management of RCTs to test the efficacy and effectiveness of intervention of these materials in patients with chronic kidney disease and end-stage renal disease. I have extensive experience in the areas of questionnaire design; evaluation studies; development of protocols and execution of training project staff; supervision of mail, telephone and in-person data collection efforts; and cleaning, editing, and analysis of survey data.

Hobbies/Interests: cooking, travel, and spending time with my family

Why this project is important to me: I know from personal experience how important it is that patients with kidney disease have the information they need to make an informed choice about which kidney treatment is best for them. In 2009, my 72 year-old grandfather Max Ephraim was diagnosed with kidney cancer. We learned that he only had one functioning kidney – a surprise to him as well as us and probably a condition he had lived with for much of his life. He received treatment at one of the premier academic medical centers in the country, but what was missing from his care were conversations about which treatment for kidney failure might be best for him. He eventually went on in-center hemodialysis, spent a few weeks in misery, and then asked to be withdrawn from dialysis and died soon after at home. I'm committed to working with patients and their families to develop a program that will help them to start conversations early and provide support for their decisions.