Study Title: Planning for the Care You Want

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Title of Research: Planning for the Care You Want

(IRB Study #032013-051)

Funding Agency/Sponsor: Agency for Healthcare Research and Quality and the Palliative Care Research

Cooperative

Study Leader: Ramona Rhodes, MD

Research Team: Bryan Elwood, Kimberly Williams, and Tori Knox-Rice

Why is this study being done? Parkland and UT Southwestern Medical Center are looking for better ways to help African American patients understand their options for care.

Why am I being asked to take part in this research study? We are inviting adult patients who are hospitalized at Parkland and their caregivers to participate by answering survey questions. We expect about 96 people to participate.

What is involved in this study? If you agree to participate, we will ask you survey questions about your experience with your illness and your medical care and your thoughts and feelings about each. This survey takes about 30 minutes. If you have a caregiver, we will ask them to answer some survey questions, too. At the end of the survey, we will give you a \$10 Target gift card as our thanks. If your caregiver completes the survey, that person will also get a \$10 Target gift card. Some participants will be invited to watch an educational video about options for planning for the care you want and talk with one of our team members about it. Not everyone will be asked to watch this video. That's part of the design of the study. Then, everyone will get a call from someone on our team to ask you some survey questions again in one month, then again in three months, and one last time in six months. Each of these follow-up surveys will take about 20 minutes. After each survey, we will mail you a \$10 Target gift card as our thanks. There are no tests or treatments related to participation. We hope participating in this study will be a good experience for you. However, there may be no direct benefit to you for participating.

What if I do not want to participate? That is okay. You do not have to take part in this study. If you begin the study and change your mind, you can stop at any time. Whether or not you take part in this study will not effect the healthcare you receive at Parkland. By answering these questions and completing the survey, you will give consent and agree to let our research team access information about your health in your medical record. There are no costs to you or your insurance company for participating.

What are the risks of the study? There are minimal risks related to participating in this study. Some questions may make you feel uncomfortable. You may refuse to answer any question, take a break, or stop participating. Like any research study, there is the small potential for loss of confidentiality. The information you provide will only be shared with members of the research team. Some of your information may also be viewed by the UT Southwestern Institutional Review Board, the funding agencies, and government agencies responsible for keeping research safe for participants. No reports or publications will use your name or other information that could identify you.

Whom do I call if I have questions or problems? Please call Dr. Ramona Rhodes at 214-648-9012 if you have any questions or concerns. If you get her voicemail, she will call you back during regular business hours. You may also call the study coordinator, Bryan Elwood, at 214-648-8487. For questions about your rights as a research participant, contact the UT Southwestern Institutional Review Board (IRB) Office at 214-648-3060.