The Comparative Impact of Patient Activation and Engagement on Improving Patient-Centered Outcomes of Care in Accountable Care Organizations

Contract Number: IHS-1310-06821

Principal Investigator: Stephen M. Shortell, PhD, MPH, MBA

University of California, Berkeley

Patient Survey Consent Form

April 6, 2016
CONSENT TO PARTICIPATE IN STUDY
ACTIVATE Study

Introduction

Professors Stephen Shortell and Hector Rodriguez are leading a team at the University of California at Berkeley School of Public Health to conduct a study of how the extent of patient activation and engagement (PAE), or patients’ involvement in their health care, influences their health outcomes. The study is funded by the Patient Centered Outcomes Research Institute, a non-profit research organization focused on improving health outcomes for patients. You are being invited to participate in this study because you have been chosen by your health care organization as one of their ongoing patients who is being treated for health conditions.

Purpose

The purpose of this study is to determine your understanding of your role in the care process and whether you feel you have the information, ability, and confidence to take on that role. Your participation will make a valuable contribution.

Procedures

If you agree to be in this study, we will ask you to do the following:

• Complete a survey describing the experiences of care you have received for your chronic condition(s) over the past 6 months.

Study time: The survey will take a total of approximately 30 minutes to complete.

Study location: All study procedures will take place by mail, or, if you prefer, you may complete this survey by phone by calling CSS at xxx-xxx-xxx

Benefits

There is no direct benefit to you anticipated from participating in this study. However, it is hoped that the information gained from the study will help physicians and other health professionals better understand how care can be improved for patients with chronic conditions.

Risks/Discomforts

• Breach of confidentiality: As with all research, there is a chance that confidentiality could be compromised; however, we are taking all precautions to minimize this risk.

Confidentiality

The information you provide will be handled in a confidential manner. If results of this study are published or presented, individual names and other personally identifiable information will not be used. Analysis will be based on aggregate data only.
To minimize the risks to confidentiality, we will store your data in encrypted files on password protected servers at UC Berkeley to which only a limited number of approved researchers and staff will have access.

Retaining research records: When the research is completed, we may save the data collected from these
surveys for use in future analyses done by our team and other researchers. We will retain this study information indefinitely after the study is over. The same measures described above will be taken to protect data confidentiality.

**Compensation**

In return for your time, we have enclosed a $10 Target gift card. You will also receive a second $10 Target gift card for completing the enclosed survey. The card will be mailed to you about six weeks after we have received your completed survey.

**Rights**

*Participation in research is completely voluntary.* You have the right to decline to participate or to withdraw at any point in this study without penalty or loss of benefits to which you are otherwise entitled.

**Questions**

If you have any questions or concerns about this study, or wish not to participate, you may contact Professor Stephen Shortell at (510) 643-5346 or shortell@berkeley.edu or Project Director Patty Ramsay at (510)643-8063 or pramsay@berkeley.edu

If you have any questions or concerns about your rights and treatment as a research subject, you may contact the office of UC Berkeley's Committee for the Protection of Human Subjects, at 510-642-7461 or subjects@berkeley.edu.

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**CONSENT**

You have been given a copy of this consent form to keep.