ATTACHMENT H

SSLA— IN-DEPTH TELEPHONE INTERVIEWS WITH PATIENTS AND CONSUMERS

MATHEMATICA
Policy Research, Inc.

SOCIETAL STAKEHOLDER LEVEL OF ANALYSIS (SSLA)
INTERVIEW PROTOCOL FOR PATIENTS/CONSUMERS

Description of the Protocol

The purpose of the in-depth stakeholder telephone interviews is to collect information on the three primary domains of interest—knowledge and skills, attitudes and beliefs, and behaviors and experiences—in an effort to understand what processes stakeholders use to engage in CER. The interviews will also follow up on issues raised in other data collection activities. We will collect this information from each *key* stakeholder group—those that are directly involved in CER decision-making or are CER users, including: (1) physicians, (2) consumers/patients, and (3) health care organizations. We will also collect this information from each *additional* stakeholder group—those that contribute to CER but are not directly involved in point-of-care decision making that use CER, including: (4) employer/payers, (5) researchers and (6) developers of innovation. This will allow us to examine differences in CER-relevant knowledge and skills, attitudes and opinions, and behaviors and experiences held by various stakeholder groups. We will use the data we collect from the telephone interviews to help answer SSLA evaluation questions as well as inform other levels of analysis. (Please see the stakeholder-specific section of the draft approach for more detail.)

The expectation is that we will conduct 8 to 10 interviews for each of the 6 stakeholder groups, for a total of up to 60 hour-long interviews.

For the patient/consumer interviews, we will primarily recruit patients with chronic or acute conditions, persons seeking information on CER for preventative care, and family caregivers.

Prepared by Mathematica Policy Research   2

The total burden of this interview protocol is 10 hours.

I.   **GENERAL INTRODUCTION** (<5 minutes)

We appreciate you taking the time to speak with us today. Before we begin, let me introduce myself and tell you a little bit about the work we are conducting for the Office of the Assistant Secretary for Planning and Evaluation (ASPE), which is part of the Department of Health and Human Services. My name is _____, and I work for an independent policy research firm called Mathematica Policy Research (Mathematica). *[If note taker, introduce him/her as well.]*

We are helping ASPE learn more about what people know and think about comparative effectiveness research, which is often called CER for simplicity. I will use this term, CER, during our discussion today as well. To do this work, we are talking with patients and consumers to learn how people think about and use health care information to make decisions about their health. We received your name from [insert name of sampling frame]. Our discussion today is private, and you will not be identified personally in any of our reports. My colleague is taking notes so that I don't forget anything that we talked about. We will combine what you say with comments of other people we talk with in order to learn what people know and think about comparative effectiveness research.

The results of our discussion will be synthesized in a final report and only general themes that emerge from our discussions will be reported. We will not attribute specific comments or quotes to named individuals without permission and your individual answers will be kept private to the extent permitted by law. Only the Mathematica evaluation team will have access to individually identifiable information.

We expect this discussion to take about an hour.

Before we begin, do you have any questions?

II. BACKGROUND QUESTIONS - HEALTH CARE EXPERIENCES AND BEHAVIORS
(5-10 minutes)

First, I'd like to learn about your health care experiences.

A. Health Care Experiences

1. Do you currently have health insurance?

   - *If yes, what kind do you have? Is it through your employer or a spouse's employer, is it purchased directly, or is it a state or federal plan, such as Medicare, Medicaid, or VA?*

   - *If yes, what type of plan is it, (e.g. PPO or HMO)?*

      1a. What do you think about your health insurance? Are you able to get the care you need when you need it? Can you give an example?

2. How often did you visit the doctor in the past 12 months? This can include visits in an office, a clinic, or other location like a hospital or emergency room.

   ▪ **Probe:** often, infrequent? Can you give an estimated number within the past year?

3. What type of place do you typically go to when you are sick or need preventive care?

   ▪ **Probe:** a doctor's office, clinic, emergency room, hospital outpatient setting, etc.?

4. Would you say that your experiences with receiving health care have been generally positive, generally negative, or neutral? Can you give an example?

   4a. What is your opinion, in general, about your doctor and the quality of care you receive? Why?

B. Seeking CER findings for use in decision-making

1. [Behavior]: How often do you look for information on different health treatment options that your doctor is considering to see which one might be better?

   [If doesn't look], do you think your doctor looks up different treatment options when deciding which ones to discuss or recommend for you? Where do you think your doctor typically looks for such information?

2. [Behavior] [Attitude]: Where do you typically look for such information? What do you think is the best way to get information comparing different treatment options?

   ▪ **Probe:** from friends? Online? Brochures?

3. [Behavior]: What type of information that compares different health treatment options do you trust the most to help you make decisions about your health care? For example, this could be information from large studies that tested a treatment with a large number of people, or it could be information from websites like WebMD, or information from your doctor, or advice and experience from friends and family?

- **Probe:** Do you feel that you can get your hands on this type of information, that is, information that compares different treatment options that helps you with health care decisions?

4. [Behavior]: How often do you use information that compares different treatment options when you make decisions about health care?

- **Probe:** Please give an example of how you have used this kind of information to make a decision about your health care?

5. [Behavior]: Do you talk with your doctor about the pros and cons of different treatment options before you make a health care decision? Does your physician ever show you materials about the pros and cons of treatment options (like pamphlets or website information)?

III. KNOWLEDGE ABOUT CER (10-15 minutes)

Now, let's talk about comparative effectiveness research (CER).

A. Awareness/Understanding of CER

1. [Awareness]: Have you ever heard the term "comparative effectiveness research (CER)" or "patient-centered outcomes research?"

   - *If yes*, *could you describe what it means in your own words? (Could you give an example?)*

   - *If no, what do you think it means?*

     I'm going to read you a definition of comparative effectiveness research (the AHRQ Definition) [READ IT SLOWLY WITH PAUSES]: ***Comparative effectiveness research is a type of health care research that compares the results of one approach for managing a health problem to the results of other approaches****. For example, if you had diabetes, you and your doctor might use research about different ways to treat diabetes to help you decide if you should change your diet and exercise to lose weight or if you should go on medication.*

2. [Awareness]: Different people interpret definitions differently. What would you say the definition I read means to you, in your own words?

3. [Awareness]: Please describe some recent examples of CER:

4. [Awareness]: Do the terms "comparative effectiveness research" and "patient-centered outcomes research" mean the same thing to you or do they mean something different?

   - *If they are different*, *is one more positive or negative than the other? Why do you think that?*

B. Knowledge/Understanding of CER

[Knowledge] [Attitudes]: I would like to ask you about some specific aspects of comparative effectiveness research and how important these are for improving health care.

1. How important is it that this kind of research responds to the information that patients, doctors and other decision makers need? Why or why not?

2. How important is it that this kind of research looks at how well treatments work for different types of patients? For example:

    - **Probe:** Should it look at how well it works for different age groups? Why or why not?

    - **Probe:** Should it look at how well it works for different ethnicities and races? Why or why not?

3. How important is it that this kind of research looks at a variety of ways to manage a health problem? For example:

    - **Probe:** Should it look at medications? Why or why not?

    - **Probe:** Should it look at procedures like surgical and screening procedures? Why or why not?

    - **Probe:** Should it look at medical and assistive devices and technologies? Why or why not?

    - **Probe:** Should it look at behavioral change strategies like strategies to help you monitor your own health conditions? Why or why not?

4. How important is it that this kind of research looks at a range of health-related results? For example, should this research look at whether a surgery makes you healthier as well as whether it makes you happier or more satisfied? Why or why not?

5. Could you please rank the four things we talked about for comparative effectiveness research by how important they are to you (1= most important, 4=least important)?

IV. KNOWLEDGE, ATTITUDES, BEHAVIORS REGARDING ELEMENTS OF COMPARATIVE EFFECTIVENESS RESEARCH (10-15 minutes)

A. Using CER in Health Decision Making

Now let's talk about how you might use information from this type of research to make decisions about your health care. Let's pretend that your doctor just told you that you have a medical condition, for example, diabetes, and told you about several treatment options for how to treat this condition that you need to consider and decide which would be best for you.

1. [Self-efficacy]: How confident are you that you would know where to look for information about the pros and cons of different treatment options? On a scale of 1 to 10, with 1 being not at all confident and 10 being completely confident, where would you be?

2. [Self-efficacy]: How confident are you that you could understand information about the pros and cons of different treatment options? On a scale of 1 to 10, with 1 being not at all confident and 10 being completely confident, where would you be?

3. [Self-efficacy]: How confident are you that you could make a treatment decision together with your doctor? (For example, deciding whether to take prescription drugs for diabetes versus trying to lose weight?) On a scale of 1 to 10, with 1 being not at all confident and 10 being completely confident, where would you be?

4. [Attitude]: Do you think this kind of research, that is, comparative effectiveness research, would help or hinder your ability to make the best health care decisions for yourself? Why do you say that?

    ▪   **Probe:** Do you think it will restrict your freedom to choose treatments recommended by your doctor? Do you think it will restrict your doctor's freedom to recommend treatments to you?

B. Tools for using CER

1. [Awareness]: Are you familiar with any tools that would help doctors and patients use information that compares different health treatment options to make decisions about health care?

    - *If yes*, which ones? Any new ones?

      [Give one or two examples: An example of tools to help with decision-making includes:

      1)

      And

      2)]

    -   *If no, an example of a tool could be a computer program or website that helps you think through your preferences as you decide on a treatment ([IF FEMALE:] like what kind of surgery would be appropriate for breast cancer [IF MALE:] like what kind of treatment would be appropriate for prostate cancer)*

2. [Behavior]: IF YES, Do you use these kinds of tools or resources to make health care decisions? If yes, please describe what tools you use?

3. [Self-efficacy]: How confident are you in using computer-based tools or other tools to help you think through treatment options before making a health care decision?

    For example, a computer program or website that helps you think through your preferences as you decide on a treatment *([IF FEMALE:]* like what kind of surgery would be appropriate for breast cancer *[IF MALE:]* like what kind of treatment would be appropriate for prostate cancer).

4. [Attitude]: What are your thoughts about approaches or tools for assisting doctors and patients in their use of comparative effectiveness research in clinical decision-making?

    ▪   **Probe:** for example, using tools like we just described?

V. **GENERAL ATTITUDE TOWARD CER** (5-10 minutes)

[Attitude]: Now that we've talked about the different elements and possible uses of comparative effectiveness research, I would like to get your thoughts on how this type of research might affect health care and how it is practiced more broadly.

1. How might this kind of research affect health care in the US?

2. If more providers used this kind of research to make health care decisions, how might that affect health care in the US?

3. If more patients used this kind of research to make health care decisions, how might that affect health care in the US?

4. If more health insurance companies used this kind of research, how might that affect health care in the US?

VI. **WRAP UP** (<5 minutes)

Those are all the questions I have.

Are there any other thoughts about comparative effectiveness research that you would like to share before we end?

(Check with note taker to see if anything was missed or if s/he has follow-up questions.)

Thank you for taking the time to speak with us. Your comments have been very helpful. Have a nice day/evening!