

**Attachment D1:  
Brief Citizens' Deliberation  
Facilitator's Guide**

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#### **Objectives:**

1. Provide opportunity for representative groups of community members to engage in informed discussion on the ethical issues and social values inherent in the use of evidence from CER in making individual and societal decisions.
2. Elicit meaningful input from community members on the overall questions for deliberation and on the meta-questions that specifically arise from the case studies being reviewed.
3. Collect data to assess the process and its outcomes.

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### **Characteristics**

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Hours	2 hours in-person
Group size	12 & 24
Experts	none
Breakouts	None; groups of 24 will function the same as groups of 12
Staff	1 facilitator, 1 note taker

Group members get standard set of background materials at time of confirmation.

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### **Facilitator Role**

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1. Leads discussion of smaller and larger groups. This means establishing an environment that:
  - a. Assures participants' understanding of the process and the session's objective.
  - b. Encourages participation from all attendees.
  - c. Promotes frank but respectful interaction among participants.
  - d. Maintains adherence to the meeting schedule.
2. Answers questions about the process and what is covered in the educational materials.
3. Follows the script consistent with the content, but not necessarily in the identical language.
4. Encourages interaction based on the facts presented.
5. Maintains neutrality; does not provide own opinions, even when directly asked.

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### **Note Taker Role**

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1. During group discussions of case studies, takes notes on flipcharts. Notes must capture – as briefly as possible – the essence of each participant's comments.

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2. Seeks direct clarification from individual participant when needed, as coordinated with facilitator.
3. Distributes materials to group members at beginning of the session and as needed throughout.
4. Helps facilitate the logistics of the session, e.g. manage taping
5. Handles informed consents, evaluation surveys and payments to group members.

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## Agenda

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Time	Activity
6:00	Session Begins: Welcome; staff and participant introductions (10 minutes)
6:10	Welcome video, ground rules (5 minutes)
6:15	Context setting (10 minutes including Q&A)
6:25	Review of CER and Slides; over-arching question (10 minutes)
6:35	Presentation/discussion of Hospital Quality, Var. A (30 minutes)
7:05	Presentation/discussion of Variation B (20 minutes)
7:25	Presentation/discussion of Variation C (25 minutes)
7:50	Recap of views: areas of agreement/disagreement (10 min)
8:00	Group ends

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## Meeting Set-Up Instructions

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### Setting up Meeting –Equipment and Supplies

- Ground Rules and over-arching question are posted in room before session starts
- Chairs
- Table (set up very close to sufficient wall space for note-taking)
- Table Name Tents for all participants and facilitator, first name only
- Two easels with self-adhering paper, markers (or writing paper already on near-by walls)
- Pens for participants
- Hosp Quality case study – all variations are in one stack, face down in front of each place
- Laptop, projector, screen or blank wall

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## Checklist of materials

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### Materials

- Informed consent forms (2 copies for everyone – one for us; one to be kept by participant)
- Pre-Knowledge and Attitude Survey (to be completed at the beginning of the session, *only if participant didn't do it on-line*)

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- 1 audio recorder (if group size 24, have multiple microphones)
- Video?
- Background slides/educational materials (copies for everyone) – put together in a packet
- Poster with overarching question
- Poster with ground rules
- Case Study – Hospital Quality. Var. A, B, and C are printed separately on different colored paper.
- Deliberative Experience survey (to be completed by everyone at the end of the session, before they leave)

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### Participant Registration

30 mins

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#### Participant registration

- Informed Consent
- Survey Administration (only if not done online prior to the session)
- Light dinner (can be taken into the room with them)

#### Participant Over-Recruitment

- Facilitator decides in advance who the priority participants are; release extras with incentive and signed receipt.

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### Welcome and Introductions

10 mins

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#### Objective

- Welcome participants to session
- Have participants introduce themselves

#### Example Facilitator Script:

Thank you for joining us here today. We are pleased to have you here and to learn from you. You've received materials in advance about this session, and we'll be summarizing those materials in a few minutes. But first let's do introductions.

My name is [insert name], and I will be helping to lead today's discussion. I am joined by [introduce note-taker(s)], and we're part of the research team at the American Institutes for Research that is leading this project. *Ask participants to introduce themselves, giving their first name, where they are from and how long they have lived in the area.*

We're going to start with a welcome message.

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## Welcome video

5 mins

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### Objective

- Introduce participants to the topics that will be covered during the session

### Example Facilitator Script:

You may also remember that the federal government agency, the Agency for Healthcare Research and Quality, provided the funding for this research because they want to hear what you have to say about health care. Does anyone have any questions about this video or the project?

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## Context-Setting

10 mins

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### Objective

- Review ground rules with participants for the discussion
- Set the context for this session within the broader health care system

### Example Facilitator script:

Though we'll be presenting some basic background information, most of the time today will be spent with all of you talking about your reactions to a particular situation we'll be presenting to you. Since this is about what all of YOU think, there are some points we'd like you to keep in mind:

- **There are no 'right' or 'wrong' answers.** All views and perspectives are important and help us learn; this also means that you can change your mind as the discussion proceeds – tell us if you do.
- **We are here to learn from YOU.** So if we ask certain questions about your views, it is because this is what is most valuable for us to understand your perspective. Please speak your mind, even if you think no one will agree with you.
- **We want to hear from everyone.** Sometimes we may have to interrupt someone to make sure we keep to our schedule.
- **Listen and respond to each other.** We are meeting in a group setting because people learn from each other. So don't be shy about questioning your colleagues here. And, of course, maintaining respect for each other – even when we disagree – is important.

As you can see, we have these summarized on a poster, as a reminder.

Today we will be discussing how to improve health care in the US. Although medicine has made great strides, there is still a lot we don't know about the **best** way to treat, and prevent, a variety of illnesses. Many people believe that once doctors have treatments they prescribe, there is no more research to be done. In fact, there are so many ways now to treat medical problems that we don't always know which ones are best – and that is just as important for people's health as discovering new treatments is.

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So researchers across the country are comparing existing treatments and services to learn more about which ones work best; this research is called Comparative Effectiveness Research, or C-E-R. These can be medications, surgeries, procedures, prevention strategies, hospital quality, and others. These studies ask:

- What gets the best results?
- What causes the fewest problems for patients?
- Does one option work better for some patients than others?
- How does the cost of the treatment affect both the individual patient and society as a whole?
- Do some treatments lead to problems for the community as a whole?

But these questions do not always lead to clear answers. Sometimes the results are not clear-cut or there are trade-offs between them. Today we will be using specific examples to explore your views about some of these trade-offs, which raise questions like:

- Should doctors and patients be able to use any treatment they think will work, regardless of what the research says?
- What happens when treatment decisions affect many people, not just the individual patient?
- What, if any, is the duty of society to protect patients from possible harm?

Are there any questions at this point?

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## Review of CER and Slides

10 mins

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### Objective

- Review content of background materials via background slides
- Make sure participants are introduced to the concept of CER

### Example Facilitator script

You received material about today's session before you arrived here today. I'd like to start with a quick review of the main points that were in the materials.

Let's start with health care quality (SLIDE). The Institute of Medicine, an independent, non-profit organization that provides advice and guidance on health care, says that health care should be safe, effective, timely, patient centered, efficient, and equitable. So when I mentioned earlier that researchers are comparing existing treatments to each other, these are the characteristics that they are comparing. Are there any questions or comments about these six characteristics of quality?

Now that you know WHAT is being studied, it is also important to know that those studies are being done WELL. Like any scientific work, people want to make sure that certain rules are followed when medical research is conducted, so that results are ones you can trust. As you can imagine, medical science has very strict rules because people's lives and well-being depend on reliable, high standards of medical research. (SLIDE)

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The results of medical research that has been done well are called “medical evidence.” And medical evidence is a big part of good quality healthcare because it tells us what is effective, what is safe and what is efficient—and for which patients, which brings into play equity or fairness, timeliness, and patient-centeredness.

**So what's the problem?** What is it that we want YOUR input on? The answer is: even when we have good medical evidence, it is not always followed by doctors and patients—for a variety of reasons. As a result, many Americans do NOT get good quality health care.

So the question that really is at the heart of your participation in this Brief Community Discussion: *Should patients and their doctors be able to make treatment decisions that are not consistent with sound medical evidence – or are there times when society should put limits on this freedom to choose?*

We have posted this question on the wall so you can reflect on to it from time to time.

I mentioned earlier that today's discussion is about research on treatments that already exist, called Comparative Effectiveness Research or C-E-R. In CER, researchers compare two or more different approaches to taking care of the same health problem. This comparison may reveal many differences that are important for patient care. One certainly is 'which is more effective.' That's the main point of CER studies.

Another issue is cost. Often new treatments do not work any better than older ones but they cost a lot more.

Why does cost matter? The fact that health care costs are rising very fast is pretty common knowledge these days. In fact, health care costs have been increasing much faster than the costs for other things we need. As the graph shows, (SLIDE) health costs have risen to 22 times more than what they were in 1970, compared to 5.5 times more for household goods in general.

But people don't always realize that besides paying more for their own health care coverage such as through premiums, as taxpayers, we all help pay for others through public programs like Medicare and Medicaid. This means we all have a stake in helping to control costs to make sure we are getting the best health care results for the money we spend. Are there any questions or comments about this?

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## Presentation/Discussion of Case One, Var. A

30 mins

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### Objective

- Introduce case study, variation A

### Example facilitator script:

Let's begin the discussion by looking at an example of using medical evidence to improve the quality of health care. Please turn over the top page in front of you; read to yourself as I read aloud.

*INSERT FINAL CASE STUDY HERE – Hospital Quality, Var. A*

### What do you think?

Given the significant differences in results for patients in these low- and high-volume hospitals, people might have different responses, such as:

- This seems normal – some hospitals get better results than others and that's to be expected.
- The high-volume hospital is the only one I would go to, and I can't imagine why anyone would do anything else.
- Makes me wonder how many people know which hospitals are the better ones.

Does one of these statements reflect your opinion? Has something else occurred to you? Please check the statement that is closest to your view – or write a different statement.

Let's first get a sense of your responses. How many checked the first statement? The second? The third? Did anyone write in their own statement? (As people raise their hands, F notes on seating chart, what their response was, e.g., with a 1, 2 or 3)

Let's discuss why you voted the way you did. Who would like to start? (Note-taker is at easel, summarizing each point with a separate bullet; clarifies with the participant if something is unclear.)

*As appropriate, facilitator raises the following probes:*

### Progressive probes

- Should doctors be obligated to tell their patients about these different rates? If the doctor practices at the low-volume hospital, is s/he obligated to tell patients that other hospitals gets better results?
- Should physicians do more than simply inform? Should they encourage patients to get care where it will be more effective? Do they have a legal or ethical obligation to do so?
- What reasons can you think of that would cause individuals to choose a hospital that didn't have the "best" results?
- What is the patient's responsibility to seek out information about the results that different hospitals get?
- Should patients be given incentives to make 'good' decisions about where they get their care? Should negative incentives be used?
- Should we require patients to go to the hospital that is going to get the best results?



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- If government knows that some hospital care is poorer quality, should it have standards that hospitals must reach in order to provide the service?

Final question for this segment (**if there is time**):

- Can one of you sum up where you think we have some general agreement?
- Can one of you sum up where you think we have differences of opinion?

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### **Presentation/discussion of Variation B**

**20 mins**

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#### **Objective**

- Introduce case study, variation B

#### **Example facilitator script:**

Okay, now let's go a little deeper and see the financial implications of these different hospitals. Please turn over your next page and read as I read aloud.

#### **Progressive probes**

- What is your reaction to considering 'cost' as part of this discussion about hospital quality?
- How does this information about costs change your views from Part 1? (regarding the role of the doctor, role of patient)
- Since researchers know that lower-quality care often means higher costs, should government (which pays more than 50% of healthcare in this country) try to control how much money is lost through lower quality medical care? Or should it always be left to patients to make the best decision according to their own needs or preferences?
- When patients have insurance, they may not be motivated to consider the cost consequences of their choices. Is it appropriate for those who pay for most of the health insurance in this country (employers, government etc) to provide incentives for patients to make the high-quality, most economical choice?
- What difference would it make if patients realized the cost implications of choosing a lower quality hospital?

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### **Presentation/discussion of Variation C**

**25 mins**

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#### **Objective**

- Introduce case study, variation C

#### **Example facilitator script:**

Now we are going to look at this case study from a different angle. Please turn over your last sheet and read it as I read it aloud.

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**Initial question:** Suppose all of you are on the Springview town council that has to make the decisions on behalf of all the county employees and their families.

*Which health plan would you pick and why?*

### **Progressive probes:**

- As a resident of Springview yourself, what to you is the highest priority? What do you think is the highest priority for the community?
- How would you describe the conflict that Springview faces? What are the main problems that are central to this town council decision?
- Are there additional facts that would help you make this decision?
- As you know from the previous discussion, patients at low-volume hospitals like Springview may be much more costly to treat than if they had gone to University Medical Center. This will likely affect the cost of healthcare insurance. Does this make a difference in your perspective?
- Are there other considerations that haven't been taken into account?
- Who is responsible for deciding which type of care people have access to? Is it the right place for employers/insurance companies to decide? Or, is this role more appropriate for the government?
- How does medical evidence play a role here? How should it play a role? Are there other concerns/considerations that are important than evidence?

When you first saw the over-all differences between low and high volume hospitals, these research findings didn't indicate how many people were actually affected.

Imagine that the town council decided to research the numbers of people affected by going to Springview Community Hospital. They learned that when the total impact on local patients added up, last year 4 residents of Springview (including one child) died that wouldn't have if they had received their care at the high-volume hospital. Several other patients did not recover as quickly or had some long-term problems because of less skilled care.

- Does this figure make your job easier or more difficult?
- Where should society put the brakes on allowing individuals to make decisions that will affect/harm society or themselves?
- Where is the greater harm: reducing access to local medical care services or increasing the risks for patients?

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## **Recap of views**

**10 mins**

### **Objective**

- Summarize main discussion points
- End session

### **Example facilitator script:**

Let's spend just a few minutes summarizing where we have come to. Would anyone like to take a crack at identifying the key points on which people agreed, or the different points of view that

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people have taken over the course of the discussion, especially toward the end. (Note taker) has been taking some notes that you can use.

I want to thank you all for your participation today. Thank you so much for giving all your time, your energy, and your ideas to this discussion. We will be summarizing the input we have gotten from all the group discussions and providing them to AHRQ. We hope you have found this as worthwhile as we have.