

Appendix

Exhibit 1.

Types of Focus Groups

2 Pilot groups
2 groups included English-speaking, adults with dependents
2 groups included English-speaking, low-income groups with dependents
2 groups included English-speaking, middle-aged, adults
2 groups included English-speaking, low income, middle-aged adults
2 groups included English-speaking, retired, adults
2 groups included English-speaking, low-income, retired adults
2 groups included English-speaking, young adults
2 groups included English-speaking, low-income, young adults
1 group included Spanish-speaking adults with dependents
1 group included Spanish-speaking, middle-aged adults
1 group included Spanish-speaking, retired adults,
1 group included Spanish-speaking, young adults.

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Recruitment Protocol
Discussing Costs in the Doctor-Patient Encounter
Focus Groups
April 2011

PARTICIPANT INFO SUMMARY

PARTICIPANT

NAME: _____

SEX: M / F

AGE: _____

PARTICIPANT'S MAIN LANGUAGE: SPANISH ENGLISH

RACE/ETHNICITY:

- White
- African American
- Asian
- Native Hawaiian or Other Pacific Islander
- American Indian or Alaskan native
- Other

HISPANIC: Y / N

ORIGIN:

- Mexican
- Puerto Rican
- Cuban
- Dominican
- Central American (country: _____)
- South American (country: _____)

ADDRESS: _____

PHONE NUMBER(S): DAY: _____

EVENING: _____

RECRUITED FOR: DATE: _____

TIME: _____

CONFIRMATION LETTER SENT? DATE: _____

REMINDER PHONE CALL? DATE: _____

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CALL HISTORY

| CALL ATTEMPT # | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
|----------------|---|---|---|---|---|---|---|---|---|----|
| DATE | | | | | | | | | | |
| TIME | | | | | | | | | | |
| RESULT | | | | | | | | | | |
| INTERVIEWER | | | | | | | | | | |

General Recruitment Instructions:

- Recruit a mix of ages but all participants must be 18 years old or older
- All participants must be able to speak and understand either English or Spanish
- All participants must be able to provide informed consent
- Aim to recruit an equal number of men and women if possible (would like some males to the extent possible)
- All participants must have health insurance at the time of recruitment (be enrolled in a health plan such as Medicare, Medicaid, or fee for service plan).
- Recruitment goals: Recruit participants with the following varied characteristics: age (working adults with and without dependents and retirees); ethnic/racial groups (African American, Latino, Non-Hispanic whites); varied economic status (incomes below 300% of the Federal poverty threshold, and above).
- Screen out participants who work in a doctor's office, clinic, or hospital (current or profession when retired)
- Exclude participants who are uninsured or who are not able to provide informed consent or speak English or Spanish well enough to participate in the focus group.
- OK to recruit individuals who know each other.
- OK to recruit individuals who have participated in prior RAND groups or interviews as long as the topic was not health care or health insurance.
- Recruit and schedule 12 candidates per focus group.

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- Los Angeles focus groups: Participants must come to RAND's offices at 1776 Main St., Santa Monica, CA and ask for Brianne Mingura or Beverly Weidmer. Please provide participants with a map and detailed instructions for coming to RAND. Participants will receive a \$75 cash honorarium.
- Washington DC focus groups: Participants must come to [LOCATION TO BE DETERMINED]. Please provide participants with a map and detailed instructions for coming to RAND. Participants will receive a \$75 cash honorarium.
- **Focus Group dates:** Focus groups will be held on the following days/times: [DATES] Please allow two hours for each focus group.

RECRUITMENT SCRIPT

1. RAND is conducting a study of people's experiences in talking with their doctors about the costs of illness and medical care. I'd like to ask you a few questions to see if you are eligible for this study. Let's start with age. How old are you?

IF NEEDED: Since we need to include people who are a mix of different backgrounds and experiences, there are some requirements that I have to check on for all of the people that we bring in to participate. I need to ask you a few questions to see if you meet the requirements for participating in the interview.

IF NEEDED: NIH and RAND researchers are conducting focus groups about experiences with in talking with doctors about the costs of their medical care. These focus groups will provide valuable information that will be useful in providing doctors with information on patient preferences for discussing this topic with their patients.

ENTER AGE: _____

OR

_____ REFUSE → THANK R FOR TIME, END OF INTERVIEW

NOTE: IF THIS RESPONDENT IS UNDER AGE 18, THANK R AND TERMINATE. ALL OTHERS, CONTINUE.

2. What language do you usually speak at home?

(Check One Answer)

_____ English

_____ SPANISH

3. FOR SPANISH-SPEAKERS ONLY: How well would you say you speak English? *(Check One Answer)*

_____ Very well (thank and end script)

_____ Well (thank and end script)

_____ Not very well

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_____ Not well at all

3a. What is your country of origin?

[Write in Name of Country:] _____

[IF **NOT** MEXICO, CUBA, PUERTO RICO, DOMINICAN REPUBLIC OR OTHER CENTRAL OR SOUTH AMERICAN COUNTRY, [**THANK AND END**]

4. What is your current occupation? (IF RETIRED: What was your occupation at the time you retired?)

ENTER

OCCUPATION: _____

NOTE: IF WORKING OR WORKED IN A DOCTOR'S OFFICE OR CLINIC NOW OR BEFORE RETIRING, THANK R AND TERMINATE. ALL OTHERS, CONTINUE.

6. Gender. (Confirm if needed.)

_____ MALE

_____ FEMALE

7. Are you of Hispanic or Latino origin or descent?

_____ Yes

_____ No

8. What is your race? Please mark one or more.

_____ White

_____ Black or African American

_____ Asian

_____ Native Hawaiian or Other Pacific Islander

_____ American Indian or Alaskan Native

_____ Other

9a. At this time, are you personally covered by any type of health insurance?

_____ Yes

_____ No

9b. What type of health insurance do you have?

- ¹ Private health insurance
- ³ Medicare, federal health insurance for people over 65 and some others
- ⁴ Medicaid, state health insurance for low-income persons
- ⁵ Some other type of health insurance plan not mentioned above (Do not include "free care" from a hospital, health center, or other place)

10. How many people are there in your family or household?

Note if clarification is needed: a 'household' is roughly defined as a family, on a broad definition of family (i.e., including civil unions, life partnerships, etc.). The household does include financially dependent children and financially dependent seniors, even if they do not reside in the same house. The household does not include: divorced or separated partners no longer living in the same house; children or seniors who are financially independent and file their own taxes; roommates or housemates who are financially independent of one another; and so on.

ENTER NUMBER: _____

11. Is your household's total yearly income more or less than [READ ANNUAL OR WEEKLY INCOME FROM TABLE BELOW DEPENDING ON ANSWER TO QUESTION 10]?"

Circle answer to question 10 is:

| | Annual income | Weekly income: |
|---|---------------|----------------|
| 1 | \$33,000 | \$600 |
| 2 | \$44,000 | \$850 |
| 3 | \$56,000 | \$1050 |
| 4 | \$67,000 | \$1300 |
| 5 | \$79,000 | \$1500 |
| 6 | \$90,000 | \$1750 |
| 7 | \$101,000 | \$1950 |
| 8 | \$113,000 | \$2200 |
| 9 | \$124,000 | \$2350 or more |

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Note if clarification is needed: Household income includes income from all sources for everyone in the household. Household income *does* include: a dependent student's parent's income; alimony payments from a divorced parent no longer in the household; payments from the government; and so on. Household income *does not* include: an independent student's parent's income; income of a divorced parent no longer in the household, except what is paid as alimony; and so on.

INVITATION IF INDIVIDUAL MEETS RECRUITING CRITERIA:

Thank you for answering all of my questions. I'd like to invite you to participate in an focus group at [location]. We have several dates available. Would you like to take part in this study?

AS NEEDED: You should plan to be at the focus group for two and a half hours. At the end of the group meeting you will receive \$75 as a thank you for your participation plus \$25 to cover your transportation or other costs.

AS NEEDED: I will send you a letter to confirm your appointment and a map and directions of how to get to place where the focus group will be held.

Let me double-check the spelling of your name, and your address, and phone number. {Record information.}

Name: _____ Telephone: _____

Address: _____

City,
State: _____ Zip: _____

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Let me just mention three things that you need to know before you come to the interview:

- 1) If you wear reading glasses, please be sure to bring them, as you may be asked to read some materials during the interview;
- 2) Please be aware that RAND has a no-smoking policy; and
- 3) If you care for children please do not bring them with you because there is no child-care available at RAND.

If you have any questions or find that you can't attend, please call us right away at *{insert phone number}* so that we can find a replacement.

Thank you for your time and for agreeing to help. We look forward to meeting you on [DATE] at [TIME].

Additional Comments from Focus Group Participants

(1) *Nothing less than the best*

You know, when it comes to your health, there really is no value on it.

If I have a problem, I go right to the doctor, I don't care what it takes, blood work, whatever, I'll pay it and done, I don't mess with my health, it's not something I gamble with...I paid \$600 a month in insurance for my son and myself, it's ungodly but I don't care, health is more important than other stuff.

Maybe people have no money or have a lot of money, but if they don't have good health, then they don't have anything. In the end, that's the most important thing.

I think that we're programmed to think more is better.

Participant 1: You know, a headache could be anything. It might be a tumor.

Participant 2: Absolutely. That's the first thing I would think.

Participant 3: It could be the oncoming of an aneurism.

Participant 4: It could be a stroke that's waiting to happen.

I'm a big fan of mitigating risk and I believe that if I have my health, I can provide, I just believe I can hustle, whatever it takes, I'm going to provide, so I'm about eliminat[ing] risk.

I had a younger brother that had a brain tumor that unfortunately took his life, so in my perspective...I figure if I'm not surviving, the money part wouldn't be that tantamount to the situation.

How many times do you turn on the news, and they did this test instead of this one, and they missed this. And now a baby's dead, and all that. I don't want to be on the news the next day. Sorry.

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(2) *Unaccustomed to making tradeoffs between health and money*
Cheaper things turn out to be more expensive in the long run.

It's like buying a cheap dress. Okay, is it going to tear by next week, or should I pay a few dollars extra and have it for a while?

Why is the other one so much cheaper? Is it because it's an inferior test?

Moderator: Would you be receptive to your doctor talking about choosing a less expensive option?

Participant: If it's as effective, yes.

But I don't want to necessarily have to kind of diagnose myself and say okay, which one? Because my thing is, you're the doctor. So which one do you think I need?

I just don't think doctors should have to think about the costs.

Sometimes you're treated based upon what you can afford, and that's not fair because they should treat you based upon the illness and not what's in your pocket.

Participant: Personally, I wouldn't care.

Moderator: Why wouldn't you care?

Participant: Because that's what they're in business for, and why should I worry about how much they're going to be paying? I'm going to be worried more about how much I'm going to have to pay for this.

I don't care what they have to pay. You tell me my out-of-pocket cost.

I'd want to know how it's affecting my care. Why are you telling me about the insurance company? I want to know what I have to pay.

If it's going to cost my health plan, I don't care.

I don't care if it's going to cost them more or less. What is best?

They don't have any problem taking my premiums every two weeks.

If they don't care what it costs me, I'm not going to care about them.

They're my insurance. I paid them to cover me, and it's their responsibility. Let them pay it. I don't care how much they have to pay.

I don't care. I want my doctor to recommend what he thinks is best. And if the government or Medicare or whatever has to pay extra money, that's not my concern. That's why I pay insurance premiums. It costs me \$100 a month for my Medicare insurance premium and that's why I'm paying it.

That's why you get the [negative] response when you say, "Oh, we're going to help the healthcare." Why? They don't help us for crap.

I want to know what's recommend[ed] but if they're both basically equal I want to go with the less expensive one because everyone choosing the more expensive one, the next year the [Cigna] comes back and says guess what, here's your new premium. And it comes back on my lap anyway.

Well, if it's your insurance at work, it's good to protect it. But I'm still not going to say to the doctor, "You know what? I have a headache, but just give me an aspirin so that my insurance doesn't send me somewhere where they have to pay more." My health comes first.

I want to know what treatment will give me the best results and I don't want, in the back of my head, a cash register working.

I don't believe that cost should be put into a medical discussion.

(3) Lack of interest in or concern about costs borne by private insurers, Medicare, and Medicaid

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a. Skepticism that cost-consciousness is necessary.

Medicare and the government is spending a lot of money on ridiculous paperwork.

Why doesn't the government put some of that money [for ethanol subsidies] into the general mass fund for health care so we could not have to pay so much premiums for health care?

b. Lack of personal responsibility.

The money is not going to be a factor, especially if I'm not paying for it.

These costs are something that we don't have a part in, so in order for us to reduce them seems really offensive.

c. Antagonistic attitudes toward insurers and/or government.

Participant 1: [When choosing the more expensive option], you don't think of CareFirst?

Participant 2: I care first about myself

I want to know what treatment will give me the best results and I don't want, in the back of my head, a cash register working.

I don't believe that cost should be put into a medical discussion.

I don't have any empathy for the insurance companies. The insurance companies are a for-profit industry, regardless of what they say. And they're concerned with their bottom line. So, if they have to pay more, they're going to pass down those costs to the public...If having the CT would resolve the problem, then let's do that instead of spending another \$500 that is unnecessary, because that eventually is going to come back to bite me anyway.

I don't care what the insurance is paying. I pay my - you know, it goes through my check. They got my money. It's time to pay back.

(4) *Collective action problem*

To be kind of nonchalant about "I don't care what my insurance company pays" is ridiculous because the cost is going to come back to you.

No one thinks about cost when you have to go to the doctor for some kind of catastrophic ailment.

If you're hurting bad enough, you don't care what it costs right then. It's like, you're going to cut my arm off? All right, I'll pay for it.

I would think it would depend on how severe the problem is. If it's an emergency problem, I don't want to be sitting there discussing cost when something has to be done right away.