



Challenges to asking about
health knowledge...

lessons learned

and values

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Making health care decisions

- What do patients know?
- What do they care about?
- Who makes the decisions?



Shared Decision Making

Patients should be informed

- Knowledgeable about condition
- Be aware of risks and benefits of treatment choices



Shared Decision Making

Decision should:

- Take into account goals and concerns of the patient
- Be made with the patient's input



How would these questions be used?

- Before a decision gets made:
 - Used to better understand the knowledge and values
- After a decision is made:
 - To help assess the quality of decision making and to see whether patients understand key facts and whether their choices reflect their preferences



Original rounds of cognitive testing

- 80 cognitive interviews
- 16 health conditions
- Recruited through newspapers, online ads, flyers, and word-of-mouth
- 20% non-white; 29% less than High School education; average age 54.5



Questionnaires – 4 sections

- Facts about the medical condition;
- Values of the respondent in regard to choices that must be made about the condition;
- What treatment choices were offered & what choices were made; and
- Background information/demographics



Challenges

- Asking about generalized knowledge
- Use of “don’t know” option
- Asking about risks and benefits of treatment options
- Question formatting
- Asking about how personal goals and concerns influence treatment choices



Asking about generalized knowledge

- Respondents wanted to personalize questions
 - “I never had this side effect”
- Didn't believe that the questions were about facts – especially death and recurrence rates
- Did not understand that facts came from research studies
 - Didn't know what a “research study” was



The (original) introduction

Section title:

Understanding your treatment choices

Introduction:

These first questions ask about

your understanding of treatment choices for early stage prostate cancer.



Try #2

Section title:

Facts

Introduction:

The first set of questions asks about depression and the options for treating it. The correct answers are based on medical research and practice. Please do your best to answer each question, even if you did not have the symptoms or treatments discussed in the question.



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Better introduction

Start this
section here

Questions C1 to C18 are about some of the facts that doctors think are important to know about heart disease and how to treat it. The correct answers are based on medical research. ***Please do your best to answer every question, even if you are not sure about the answer.***



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Making sure questions are as general as possible

- What is the best plan for managing early stage prostate cancer?
 - For most men, what is the best plan for managing early stage prostate cancer?
- Is xxx a side effect of radiation after lumpectomy?
 - Do some women have xxx as a side effect of radiation after lumpectomy?



Change order of questions

- Respondents personalized the instrument.
 - Assumed that all of the questions were about them – including the knowledge questions.
- By reordering the questions so that the respondent first talks about him or herself, (what they've done, their choices and beliefs) the fact questions are more likely to be seen as having a different focus.



ORIGINAL order

- Facts
- Values
- Treatment choices
- Background

REVISED order

- Values
- Treatment choices
- Facts
- Background



Question Formatting: Yes/No

Which of the following are symptoms of BPH?

		Yes	No	Unsure
a.	Bladder feels like it does not empty	[]	[]	[]
b.	Frequent urges to urinate	[]	[]	[]
c.	Stopping and starting when urinating	[]	[]	[]
d.	Problem with erections	[]	[]	[]



For each of the following, please mark whether or not it is a possible complication of weight loss surgery.

a.	Vomiting	<input type="checkbox"/> Yes	<input type="checkbox"/> No
b.	Swelling in the legs	<input type="checkbox"/> Yes	<input type="checkbox"/> No
c.	Infection at the surgery site	<input type="checkbox"/> Yes	<input type="checkbox"/> No
d.	Diarrhea	<input type="checkbox"/> Yes	<input type="checkbox"/> No



Best Option

C7. Can hormone therapy help relieve **night sweats**?

Yes

No

C8. Can hormone therapy help relieve **tiredness**?

Yes

No

C9. Can hormone therapy help relieve **vaginal dryness**?

Yes

No

C10. Can hormone therapy help relieve **joint pain**?

Yes

No



Numeric Questions

- Out of 100 people who are diagnosed with colon cancer, how many will die of colon cancer?
 - You may not know the exact number, but please take your best guess. Out of 100 people who are diagnosed with colon cancer, how many will die of colon cancer?



People consider many things when deciding about treating BPH. Please rate how important each of the following is to you, using any number from 0 to 10, where 0 is not at all important and 10 is extremely important. Mark one box for each question.

B1. What number would you use to rate how important it is to you to improve or relive your BPH symptoms quickly?

0	1	2	3	4	5	6	7	8	9	10
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not at all important										Extremely important

B5. What number would you use to rate how important it is to you to avoid taking medicine for BPH?

0	1	2	3	4	5	6	7	8	9	10
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not at all important										Extremely important

A1. People consider many things when thinking about how to treat their depression. **We would like to know what is important to you.** Please rate each of the items below using any number from 0 to 10, where 0 is not at all important, 5 is somewhat important, and 10 is extremely important.

	Not at all important					Extremely important					
	0	1	2	3	4	5	6	7	8	9	10
...to feel better as quickly as possible?	[]	[]	[]	[]	[]	[]	[]	[]	[]	[]	[]
...to be able to return to your regular activities?	[]	[]	[]	[]	[]	[]	[]	[]	[]	[]	[]
...to minimize out-of-pocket costs?	[]	[]	[]	[]	[]	[]	[]	[]	[]	[]	[]

A2. When thinking about how to treat their depression, sometimes there are things that people specifically want to **avoid**. In the last 12 months, how important was it to you ...

	Not at all important			Somewhat important				Extremely important			
	0	1	2	3	4	5	6	7	8	9	10
...to avoid taking anti-depressant medicine?	0 []	1 []	2 []	3 []	4 []	5 []	6 []	7 []	8 []	9 []	10 []
...to avoid the side effects of anti-depressant medicine?	0 []	1 []	2 []	3 []	4 []	5 []	6 []	7 []	8 []	9 []	10 []
...to avoid going to depression counseling or therapy?	0 []	1 []	2 []	3 []	4 []	5 []	6 []	7 []	8 []	9 []	10 []



Ongoing Challenges



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Belief in “facts”

- Idea of “research” and where the data come from is not well understood
- There’s always an exception
 - “I know someone who...”
- Nothing is pure – everything has a slant
 - “That’s not true – it’s just what the drug companies want you to believe”



Getting Rs to attend to the actual question (when thinking about treatment choice)

In the last 12 months, when you were thinking about how to treat your depression, how important was it to you ...

- To get relief from your symptoms of depression
- To feel better as quickly as possible
- To be able to return to your regular activities
- To minimize out-of-pocket costs
- To avoid taking anti-depressant medicine
- To avoid the side effects of anti-depressant medicine
- To avoid going to depression counseling or therapy



- Asking about treatment R did not/can not have
 - “How important is it to avoid the serious side effects of hormone therapy?”
- Asking about avoiding doing things
- Are these the correct questions to ask
 - Ask individually
 - Weighing issues



Thank you



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