We at PCORI view the patient-centered comparative effectiveness research (CER) we fund as critical for improving the quality of patient care. But what does the rest of the healthcare community think of CER and of engaging patients and clinicians in the research process? In December 2012 we conducted a month-long survey of patients, caregivers, and primary-care clinicians in an effort to find out. For more information please see the PCORI Blog (http://pcori.org/Blog/Attitudes-Towards-CER).

Q1a. The most recent time you looked for information about health or medical topics, where did you go? Check all that apply.
   a. Family
   b. Friend/co-worker
   c. Doctor or other healthcare provider
   d. Internet
   e. Television; radio; newspaper; or magazines
   f. Telephone information number of disease focused group such as the American Cancer Society or the American Heart Association
   g. Complementary; alternative or unconventional practitioner
   h. Other (please specify in the comments below)
   i. I have never looked for information about health or medical topics

   Comments:
   

Q1b. The most recent time you looked for information about health or medical topics, where did you go first?
   a. Family
   b. Friend/co-worker
   c. Doctor or other healthcare provider
   d. Internet
   e. Television; radio; newspaper; or magazines
   f. Telephone information number of disease focused group such as the American Cancer Society or the American Heart Association
   g. Complementary; alternative or unconventional practitioner
   h. Other (please specify in the comments below)
   i. I have never looked for information about health or medical topics

   Comments:
Q2. **In the past 12 months**, which of the following internet sources have you used to get information about health or medical topics? *Check all that apply.*
   a. Website for government health agency
   b. Websites; chat rooms; message boards or other online community for patients or caregivers dealing with the same health condition
   c. Website sponsored by your health insurance company (health plan)
   d. Website for disease focused groups such as the American Cancer Society or the American Heart Association
   e. None of the above

Q3. In general, how much do you trust information about health or medical topics from each of the following?

| a. Doctor | • Not at all  
|          | • A little  
|          | • Some  
|          | • A lot  |
| b. Other healthcare provider (nurse; pharmacist; or other professional who provides care) | • Not at all  
|          | • A little  
|          | • Some  
|          | • A lot  |
| c. Family or friends | • Not at all  
|          | • A little  
|          | • Some  
|          | • A lot  |
| d. Online community for patients or caregivers dealing with the same health condition | • Not at all  
|          | • A little  
|          | • Some  
|          | • A lot  |
| e. Disease focused groups such as the American Cancer Society or the American Heart Association | • Not at all  
|          | • A little  
|          | • Some  
|          | • A lot  |
| f. Your health insurance company (health plan) | • Not at all  
|          | • A little  
|          | • Some  
|          | • A lot  |
| g. Internet | • Not at all  
|          | • A little  
|          | • Some  
|          | • A lot  |
| h. Television; radio; newspaper; or magazines | • Not at all  
|          | • A little  
|          | • Some  
|          | • A lot  |
| i. Government health agencies | • Not at all  
|          | • A little  
|          | • Some  
|          | • A lot  |

PCORI Patient Engagement Survey
Q4. Medical treatment decisions are choices about your health such as which medication to take or whether to have surgery. When did you last make a medical treatment decision related to your health?
   a. In the last month
   b. More than 1 month ago but less than 12 months ago
   c. More than 12 months ago
   d. I have never made a medical treatment decision related to my health

Q5. Think about the last time you made a medical treatment decision related to your health. Rate how much you agree with each statement.

   a. I knew all of the treatment options that were available to me
      - Strongly disagree
      - Somewhat disagree
      - Neither agree nor disagree
      - Somewhat agree
      - Strongly agree

   b. I knew the benefits of each treatment option
      - Strongly disagree
      - Somewhat disagree
      - Neither agree nor disagree
      - Somewhat agree
      - Strongly agree

   c. I knew the risks and side effects of each treatment option
      - Strongly disagree
      - Somewhat disagree
      - Neither agree nor disagree
      - Somewhat agree
      - Strongly agree

   d. I had information that applied to me
      - Strongly disagree
      - Somewhat disagree
      - Neither agree nor disagree
      - Somewhat agree
      - Strongly agree

Q6. Have you heard of the following organizations?

   a. NIH (National Institutes of Health)
      - Yes
      - No
      - I’m not sure

   b. PCORI (Patient-Centered Outcomes Research Institute)
      - Yes
      - No
      - I’m not sure

   c. AHRQ (Agency for Healthcare Research and Quality)
      - Yes
      - No
      - I’m not sure

   d. FDA (Food and Drug Administration)
      - Yes
      - No
      - I’m not sure

   e. CDC (Centers for Disease Control and Prevention)
      - Yes
      - No
      - I’m not sure

   f. CMS (Centers for Medicare & Medicaid Services)
      - Yes

PCORI Patient Engagement Survey
Medical research looks for ways to treat medical problems. There are many types of medical research.

Q7. Have you ever heard about medical research in which...

| a. Patients try an experimental new medication | • Yes • No • I’m not sure |
| b. Two or more medications are compared to see which works best | • Yes • No • I’m not sure |
| c. Information from patients’ medical records is used for a study | • Yes • No • I’m not sure |
| d. Patients and/or caregivers help the researchers choose what the study will be about | • Yes • No • I’m not sure |
| e. Patients and/or caregivers help researchers decide how to ask people questions about their health | • Yes • No • I’m not sure |

Q8. How much do you agree with this statement:

Research on medical treatment choices can help patients make better treatment decisions.
- Strongly disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Strongly agree

Sometimes patients work directly with medical researchers. For example, patients may help researchers decide what to study or how to collect information from other patients.

Q9. Have you ever worked with medical researchers?
- Yes
- No
- I’m not sure

Q10. Which of the following make you want to work with medical researchers? Select all that apply.

Please list any other reasons that would make you want to work with medical researchers (optional).

- Helping others with my medical condition
- Helping the next generation
- Getting paid for the time I spend helping with the research
- Learning how research works
- Learning about my health
- Helping researchers decide what to study
- Making research studies more meaningful to patients
h. Having my health provider recommend that I participate
i. Getting family support for my participation
j. None of the above

Comments:

Q11. Which of the following would keep you from working with medical researchers? Check all that apply.

Please list any other reasons that would keep you from working with researchers (optional).

- a. Work; school; or caregiving commitments
- b. Lack of time
- c. Transportation issues
- d. Distrust of researchers
- e. Concern about my privacy
- f. Lack of payment for my time
- g. Lack of interest in research
- h. Lack of training in research
- i. I don’t think research will improve my health or the health of others
- j. None of the above

Comments:

Q12. How much do you agree with the following statements:

| a. Patients working directly with researchers can improve the value of medical research. | • Strongly disagree • Somewhat disagree • Neither agree nor disagree • Somewhat agree • Strongly agree |
| b. Patients working directly with researchers can improve health care. | • Strongly disagree • Somewhat disagree • Neither agree nor disagree • Somewhat agree • Strongly agree |

Comments:

Q13. Would you ever be interested in working directly with medical researchers in the future?

- Yes
- No
- I’m not sure

Q14. Some medical research helps patients make better medical treatment decisions.
Thinking about research, how important are each of the following to you?

| (a) Research that measures things that patients care about like daily functioning | • Not at all important  
| • Slightly important  
| • Moderately important  
| • Very important |
|---|---|
| (b) Research that answers questions that health care providers care about | • Not at all important  
| • Slightly important  
| • Moderately important  
| • Very important |

Comments: