

REPORT

Research Advocacy Network

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What Do Advocates Know About Comparative Effectiveness Research?

Results of A Survey Conducted By Research Advocacy Network (RAN)

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What Do Advocates Know About Comparative Effectiveness Research?

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Introduction

Comparative effectiveness research compares the effectiveness, benefits, and harms of different treatment options such as different drugs, medical devices, or chemotherapy regimens. It can also be used to determine whether it is better to give different treatments to subgroups of patients who have a given biomarker, or whether it is better to initially give everyone the same treatment. The goal of comparative effectiveness research is to provide evidence for healthcare policy and clinical decisions so that physicians do not have to guess which treatment might be best for their patients.¹

At Research Advocacy Network (RAN), we believe that advocates who are knowledgeable about comparative effectiveness research play an important role as liaisons between patients and researchers. Advocates work with researchers to advance patient-oriented study and with patients to ensure that their voice is incorporated into the research. As advocates, we are also dedicated to helping patients get the best care possible, which comparative effectiveness research can enable.

In order to facilitate the discussion and implementation of comparative effectiveness research, advocates must have a strong working knowledge of the topic. Toward this end, Research Advocacy Network is developing educational materials designed for advocates that will provide information and examples on comparative effectiveness research. As part of this process, we conducted a survey to determine the current state of knowledge and perceptions that advocates have about comparative effectiveness research.

Survey Description

We developed a survey consisting of 12 open-ended or yes/no questions. Four of the questions came from an article by Kristin Carman and colleagues entitled “Evidence that consumers are skeptical about evidence-based health care,” published in *Health Affairs* in 2010.² We developed other questions based on discussions with advocates about personalized medicine, scientific discovery, and improving healthcare for individuals and populations.

Respondents

The survey was sent to 200 advocates across the United States identified through participation in Research Advocacy Network training programs. A total of 51 surveys were returned, for a response rate of approximately 25%. As shown in the following table, nearly all respondents were female and more than half came from the breast cancer community. The majority of respondents had worked in advocacy for more than 5 years and the sample came from all parts of the United States.

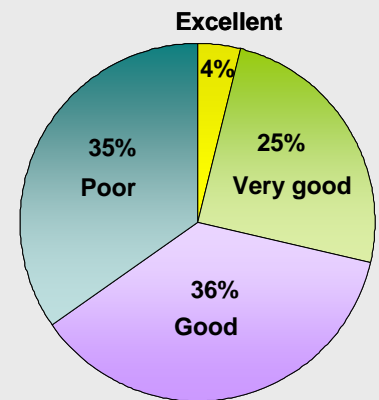
Characteristics of Advocate Survey Respondents	
<i>Characteristic</i>	<i>% of Respondents (N=51)</i>
Female	92%
Age range	
31-45 years	16%
45-60 years	40%
60-75 years	44%
Primary cancer type	
Breast	61%
Lung	8%
Colon/gastrointestinal (GI)	6%
Pancreatic	6%
Gynecologic	4%
Prostate	4%
Other	10%
Geographic location	
Northeast	33%
Midwest	18%
West	18%
Southwest	16%
Southeast	12%
Not specified	3%
Years in advocacy	
1-5	28%
5-10	24%
10-15	22%
15-20	22%
>29	4%

Survey Results

Most respondents indicated that their knowledge of comparative effectiveness research was poor (35%) or good (36%). From this question we learned that there is definitely a need for advocate education in this area, as most advocates do not have a great deal of knowledge about comparative effectiveness research or are not confident in that knowledge.

Most advocates felt they had a poor (35%) or good (36%) knowledge base of CER.

Self-Rated Current Knowledge of Comparative Effectiveness Research



Many respondents indicated positive perceptions of comparative effectiveness research. These perceptions centered primarily on its evidence-based orientation (e.g., its ability to help determine efficacy and compare different therapies or regimens), as well as its potential for standardization across populations and physicians. Here are some of the advocates' positive perceptions of comparative effectiveness research:

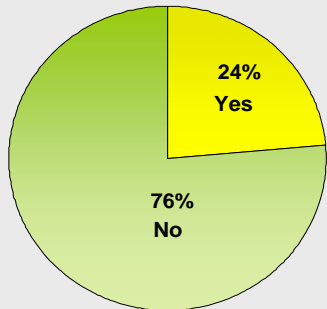
- Knowledge about what works
- Looks at collective bodies of evidence and entire populations
- Provides evidence-based medicine for patient and physician decision-making
- Reduces over and under treatment
- May reach more community doctors
- Conducts research that wouldn't otherwise be conducted – compares therapies, dosages

However, advocates also had a number of negative perceptions about comparative effectiveness research. The negatives centered on how comparative effectiveness research could potentially be used in the future rather than how it has been used in the past or how it is intended to be used. In particular, advocates were concerned that comparative effectiveness research would preclude adequate consideration of individual differences and patient choice. Here are some of the advocates' negative perceptions of comparative effectiveness research:

- Does not account for individualized information, such as why one patient might have done better on a "less effective" treatment than the majority of patients
- May limit payments and patient choice, especially if patient has unique needs
- Does not apply well to smaller disease states/smaller sub-populations
- It has the potential to create a one-size-fits-all cheapest solution for reimbursement
- This method is only as good as the people interpreting the data
- The initiative is broad in scope, and will require the cooperation of a number of constituencies

These negative perceptions showed us that it is important to address issues surrounding individual care in our discussion about comparative effectiveness research. We believe that this is an opportunity for education and plan to structure our educational materials accordingly.

Have You Heard Concerns From Patients About Comparative Effectiveness Research?



Most advocates who took the survey indicated that they had not heard any concerns from patients about comparative effectiveness research.

The following are examples of concerns that advocates had heard from patients about comparative effectiveness research.

- May be performed primarily or "only" to compare costs, with the purpose of rationing services
- Will be used to limit treatments, access to treatments or payment for treatments
- "Death panels"
- Won't be able to access treatments that are no longer considered "effective" because they do not lengthen life
- Will eliminate the smaller population of people who may have the opposite experience (positive or negative) with a treatment from the greater numbers reflected in a study (e.g., Avastin®)
- My individual information will be lost in the majority of patients

Again, these examples illustrate concerns that comparative effectiveness research and the evidence it provides focus on the patient population as a whole to the relative exclusion of the individual's needs and preferences.

The survey also asked advocates whether they agreed with a series of specific questions about comparative effectiveness research. As can be seen from the results in the following table, more than half of the advocates surveyed agreed that cost effectiveness research would improve the quality of care for the population of the United States and advance scientific discoveries into clinical practice. However, nearly half believed that it would appear to ration care based on cost and limit the treatment choices a provider can offer. Most advocates did not agree that cost effectiveness research would inappropriately interfere with a physician's recommendations for treatment. It is possible to interpret these results as suggesting that physicians may be more limited in their treatment choices, but this would not necessarily be inappropriate (i.e., the limitations might be appropriate). Moreover, nearly half of the advocates surveyed indicated that cost effectiveness research would improve an individual patient's quality of care.

Do You Feel That Comparative Effectiveness Research Will . . .

Limit who patients can choose as a provider?	19%
Limit the treatment choices the provider can offer?	44%
Inappropriately interfere with physician's recommendations for treatment?	23%
Appear to ration care based on cost?	44%
Stand in the way of personalized medicine?	27%
Increase access to care for more patients?	40%
Improve an individual patient's quality of care?	48%
Improve the quality of care for the population of the United States?	63%
Advance scientific discoveries into clinical practice?	56%
Be a barrier to scientific discovery?	25%

Conclusions

Overall, the RAN advocate survey illustrated the need for additional education on comparative effectiveness research and highlighted some of the perceptions that surround this concept. Results indicated that, although advocates believe comparative effectiveness research is beneficial for the population as a whole, they also believe that it has the potential to negatively impact individual patients by limiting options. The latter concern was echoed by patients who had expressed concerns about comparative effectiveness research to advocates. In order to counteract these negative perceptions, we believe that examples of what comparative effectiveness research has done and how it has been used are critical.

From this survey, we also learned that comparative effectiveness research has relevance for patients primarily at the time when they are making treatment decisions. This suggests an opportunity to educate advocates who can inform patients at the time they need it – when they are making treatment decisions.

We have identified three actions that would support patient engagement in comparative effectiveness research. First, engage research advocates. Advocates are trusted by both patients and researchers and are dedicated to advancing good science. Second, develop a feedback process and methodology. Such a process should be ongoing and must demonstrate that input from patients was acted upon. Finally, include evaluation of communication messages and strategies. It is important to know whether comparative effectiveness research was part of the treatment decision-making process for patients.

Overall, the survey provided valuable information that we plan to use in developing our advocate educational materials on comparative effectiveness research. The responses have helped us identify areas where advocates could benefit from more knowledge, and have illustrated positive perceptions that we can reinforce, as well as negative perceptions that we can attempt to mitigate.

References

1. Carman KL, Maurer M, Mathews Yegian J, Dardess P, McGee J, Evers M, Marlo KO. Evidence that consumers are skeptical about evidence-based health care. *Health Affairs* 2010;29:1400-1406.
2. Garber AM, Tunis SR. Does comparative-effectiveness research threaten personalized medicine? *N Engl J Med* 2009; 360:1925-1927.