

Testimony of  
Dorothy A. Jeffress, MBA, MSW, MA  
Executive Director, Center for Advancing Health  
IOM Committee on Comparative Effectiveness Research Priorities Process

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Drs. Sox and Greenfield, Committee members, thank you for inviting the Center for Advancing Health to participate in this important undertaking.

I am Dorothy Jeffress, the Center's Executive Director. Since our founding in 1992, our work has been guided by three principles:

- That scientific **evidence**, while always evolving, offers the best guide for positive changes in the health of the individuals and the nation.
- That individuals, sick or well, will only benefit from the expertise of health professionals and available technologies if they have the knowledge, skills, judgment and willingness to **engage** in their health and health care over time.
- That minimizing the social and behavioral barriers to people's engagement in their health and health care will contribute to **equity** of opportunity for health for all.

Determining priorities for comparative effectiveness research (CER) comes at a time in our nation of great uncertainty, but also a time of enhanced scientific and political opportunity. At the CFAH, we recognize the complexity and significant challenges that this committee faces at this critical time in our history.

Rather than nominating one condition over another (which is outside the core expertise of the Center), we simply offer that priorities for CER should be on high volume and/or high cost conditions for which there exist significant variations in practice AND multiple treatment or diagnostic options. Research priorities and methodology should also factor in any systematic variations in disease prevalence or treatment response across different populations, as well as consider known health disparities in treatment provision.

In preparation for today's comments, we noted that in the description of this committee on the IOM website, it was stated that "substantial effort will be expended to disseminate and build public interest in, and understanding of, the results of the project."

It is, therefore, our primary recommendation that your effort to advance public understanding of CER and even more critically, develop TRUST in the value and output of a institute devoted to CER, be as important as a debate about "who's on first" with regard to selecting priority areas of study.

At the Center we recognize that as a society we have often been lulled into believing that new scientific discoveries, that "wonder pills" and technology are the keys to living well. And that more treatment and/or more costly treatments are frequently equated with quality. This expectation and preference for the latest, often "high-price" option means that apparent advances in the number and variety of treatment options creates both a solution AND a problem.

However, we also know that advances in scientific knowledge can only increase health and quality of life IF people are able to make informed decisions about their health care. In addition, people must be willing to change life-long habits and manage complicated medical regimens. The success or failure of modern medicine is increasingly dependent on an individual's ability to engage more fully in their own health.

For example, here are some observations of our president and founder, Jessie Gruman, when she conducted over 200 interviews with patients and their families about their experience with health care for her book *AfterShock, What to do When the Doctor Gives You - or Someone You Love a Devastating Diagnosis*. She learned that the vast majority of them were surprised at what they were expected to know and do, and overwhelmed when they grasped (however dimly) that their actions and their choices could make the difference between receiving good care and bad and could even contribute substantially to the quality and even the length of their lives. She also learned that they often felt abandoned in their attempts to find the right care and administer it for themselves or their loved one. Surprised, overwhelmed and abandoned...not exactly criteria associated with making sound decisions. If CER is to meet its potential, we must address an already compromised patient.

So we would like to offer five potential strategies to engage the public:

1. Align early and often with trusted public advocacy groups and spokespersons to disseminate basic information about the need for and the value of CER.
2. Institutionalize the participation of consumers and patient advocates in the reviews and dissemination of findings.
3. Be fully transparent about the selection and study process for treatment reviews.
4. Make all findings directly available to the public in accessible formats.
5. Share potential outcomes and/or consequences of CER reports in various "real-life" scenarios for the average patient and physician (downside & upside from each perspective).

Lastly, it is of great concern to the Center that opponents of CER have grabbed rhetorical high ground with negatively framed language specifically designed to frighten people. Thoughtful perspectives from a variety of trusted sources are urgently needed to provide the public with a more balanced understanding.

Thank you again for this opportunity to add input to your important process.

**Dorothy A. Jeffress**