March 12, 2009

Dr. Harvey V. Fineberg, M.D., Ph.D.
President, Institute of Medicine
500 Fifth Street NW
Washington, DC 20001

Dr. Steven A. Schroeder
Chairman, Board on Health Care Services

Dr. Roger Herdman
Director, Board on Health Care Services

Dr. Robert Ratner
RWJF Health Policy Fellow and Project Officer

Subject: The IOM Panel on Recommendations on the National Priorities for Comparative Effectiveness Research in Health Care (IOM-HCS-09-01)

Dear Sirs,

The undersigned consumer, patient and public health advocacy organizations are pleased that the American Recovery and Reinvestment Act of 2009 appropriated $1.5 million to the Institute of Medicine to study and make recommendations for the most productive use of portions of the $1.1 billion allocated for comparative effectiveness research.

The initial roster of 16 nominees to the committee signals a positive start to this effort. We congratulate you on selecting many fine individuals and organizations to serve on this advisory committee. However, we write today to strongly urge you to add additional consumer and patient groups, and representatives of ethnic/minority communities, to the committee so that it is properly balanced. To ensure their independent perspectives and substantive contributions, these representatives should have a solid understanding of research methodology and not have financial ties to companies that make medical products or provide medical treatment.

Specifically, ARRA requests “input from stakeholders.” We interpret that to imply that the common practice of FACA and other federal advisory bodies be followed: that is, that a representative balance of stakeholders be achieved that is appropriate to the task at hand. In this case, we believe you have achieved a fair balance of leading research, industry, and provider stakeholders, but the end-users of health care research and practice – consumers and patients – are under-represented.

For example, the roster includes three members from the insurance industry, several who represent provider networks, five clinicians representing various specialties, and three who have been intimately involved in conducting technology assessments. We believe the consumer and patient perspective needs to be given comparable weight. Specifically, we would request an additional three slots added for patient/consumer representatives with at least one of those going to a group representing minority population interests.

Thank you for consideration of these views.

Respectfully and Sincerely,
Center for Science in the Public Interest
Consumers Union
National Women’s Health Network
WomenHeart: The National Coalition for Women with Heart Disease
The TMJ Association
Breast Cancer Action
The Title II Community AIDS National Network
Woodymatters
Our Bodies Ourselves
ABC/African-American Community Health Group of the Central Coast (CA)
National Coalition for Cancer Survivorship
Florida Breast Cancer Coalition Research Foundation
Government Accountability Project
National Partnership for Women and Families
Rhode Island Breast Cancer Coalition
The Endometriosis Association
Annie Appleseed Project
SafeMinds
National Research Center for Women and Families
Community Catalyst
Childbirth Connection