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TO: Joanna E. Siegel, ScD and Doris Lefkowitz, PhD

FROM: Jessica Waddell and Kristin Carman

RE: Community Forum, Use of deliberative methods to enhance public engagement in

the Agency for Healthcare Research and Quality's Effective Healthcare Program and Comparative Effectiveness Research Enterprise, Response to comment from Ronald

Falk, President, American Society of Nephrology

DATE: March 22, 2012

Please find below our recommended response to the comment from Ronald Falk.

Thank you for your recommendation that "AHRQ determine where affected people find interest and value in research, identify strategies to engage patients and their families as research participants, and focus on closing knowledge gaps that prevent optimal delivery of patient care."

AHRQ, through its Community Forum project which involves two major components, is undertaking a variety of initiatives that address your recommendations. The first component involves engendering stakeholder input in all aspects of the Comparative Effectiveness Research process, including participation in research studies. This first component of Community Forum project includes methods to innovate and expand upon AHRQ's existing stakeholder engagement activities, which explicitly includes patient groups. The project team has conducted an extensive review of the literature and consulted with experts in stakeholder engagement to identify emerging trends and strategies to effectively engage stakeholders, including patient groups. Updates from their efforts will be posted on AHRQ's Effective Healthcare Program website: http://www.effectivehealthcare.ahrq.gov/.

The second component is the deliberative methods experiment outlined in the 30-day Federal Register Notice. This is a study to identify the most effective methods in public deliberation for eliciting input from lay people that accurately reflects their values, ethics, principles, and preferences and will inform the broader field of public consultation and engagement regarding how and when public deliberation, or deliberative methods, are most appropriately and effectively used.

Because participants in the deliberative methods will consider the issue of how medical evidence can and should be used in healthcare decision-making – both at the individual and societal level, this study, by design, will enable us to learn:

- People's values in terms of research and evidence (e.g., which topics, interventions, and populations warrant more research, and why?);
- What other considerations (e.g., equity, quality of life) should be taken into consideration in healthcare decision-making; and

• How AHRQ and other research-generating entities can best disseminate evidence and use evidence to improve quality of care and the optimal delivery of healthcare overall.

Thus, this project will uncover where people find interest and value in research and provide insights that could ultimately improve patient care.

We appreciate your interest and comments on this project.