

Farrell Adrian, President of NAMI Washington State  
Comments to PCORI  
September 19, 2011

My name is Farrell Adrian, and I am the President of the Washington State affiliate of the National Alliance on Mental Illness (NAMI). NAMI is a member of the Partnership to Improve Patient Care (PIPC). As you know from hearing from my colleague Andrew Sperling in the past, NAMI was very engaged in the advocacy effort that created PCORI and is very supportive of its mission to create a patient-centered program for conducting comparative clinical effectiveness research. The patients that NAMI represents rely on us to be their advocates for sound policies that truly put the needs of patients first.

I have just a couple of comments for the PCORI Board today related to your most recent work on the definition of “patient-centered outcomes research” and the Tier 1 projects.

On the definition, NAMI believes it has a number of strong attributes, in particular the set of patient-focused questions, and recognition of the differences in individual patient's needs and preferences. Yet, we are concerned that the first part of the definition refers to “people” as opposed to patients. NAMI urges PCORI to replace the word “people” with “patients and family caregivers” to ensure the definition captures PCORI's core mission to be “patient-centered.”

NAMI's comments also urged PCORI to recognize the role of patients and family caregivers, including their representative organizations, throughout the research process. PCORI must understand that often patients rely on NAMI to be their advocates, and to participate in this process on their behalf so that they can focus on their own care and treatment. How loud the voice of mentally ill patients may be in the PCORI process will depend largely on PCORI's protocols for seeking NAMI's input.

There has also been much discussion about the role of cost in PCORI's research, which in the opinion of NAMI, has no place in PCORI. The statute creating PCORI has a stated purpose and a consistent focus on clinical comparative effectiveness and patient health outcomes.

NAMI also submitted comments to PCORI on their Tier 1 Research Priorities. In general, we support the eight areas of interest for the initial projects.

Nevertheless, it is vital that the Board understand the unique vulnerabilities and challenges of major mental illness as you begin to determine research priorities. As an example, one of the most difficult challenges is a condition known as anosognosia, or literally, the inability to see one's own illness. Anosognosia dramatically reduces medication adherence, and occurs in about half of people with serious psychiatric illnesses. This condition also called lack of insight and is virtually exclusively a concern in our population. Anosognosia makes research about adherence strategies especially crucial for this population. NAMI believes that this should be a major priority for comparative effectiveness, especially in the context of serious mental illness.

Our comments to PCORI on Tier 1 Projects urged research to identify and address gaps in existing evidence that impact underserved and vulnerable populations and the complexity of shared decision-making tools. A related concern would be an examination of strategies to achieve better outcomes for people with guardians that need to buy into the choice that they can legally make. In looking at predictive outcomes instruments, NAMI recommended to PCORI that this include self-assessment techniques. With regard to research on “behaviors, lifestyles and choices within patient control that may influence their outcomes,” NAMI recommended this area be expanded to include a focus on resilience and coping strategies.

In conclusion, NAMI looks forward to being a resource to you as you seek input on the research questions that mentally ill patients care about most. We are pleased that PCORI is here today seeking our input, and hope to establish a strong relationship with the Institute’s staff as we work together to determine the best strategies to ensure the patient voice is not just heard but truly incorporated into your work.