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Re: HealthHIV Comment on PCORI's Draft Research Priorities and Research Agenda

HealthHIV is a national, 501 (c) (3) non-profit working with organizations, communities and professionals to advance effective prevention, care and support for people living with, or at risk for, HIV/AIDS through education and training, technical assistance and capacity building, advocacy, and health services research and evaluation. HealthHIV supports primary care providers treating HIV, as well as community and faith-based organizations involved in HIV prevention, care and treatment. We appreciate the opportunity to provide comments to the Patient-Centered Outcomes Research Institute's (PCORI) draft research priorities and research agenda.

HealthHIV was actively engaged in advocacy activities supporting the legislation that created PCORI and we are a member of the Partnership to Improve Patient Care (PIPC). HealthHIV's involvement and interest in comparative effectiveness research (CER) - cognizant of the potential benefits to people living with or at-risk of HIV infection - demands that we share specific comments regarding PCORI's draft priorities and research agenda. HealthHIV believes:

- **PCORI should set national research priorities based on the specific conditions, interventions, and health outcomes that matter most to patients, providers, and caregivers.**

We are concerned that the lack of specificity about the types of research priorities. The draft research priorities and agenda are overly broad and will not allow patients or providers in a particular disease area to provide meaningful input about the interventions or outcomes that matter most to them.

HealthHIV feels that we must reiterate our opposition to looking at factors related to cost. **PCORI's national research priorities should focus on comparative clinical effectiveness research, not cost.** HealthHIV, along with many other organizations representing patients, from the very beginning of discussions about CER and PCORI, opposed the inclusion of cost analysis in any new national program for comparative clinical effectiveness research. We believed then, as now, that cost consideration would skew findings toward cost savings and not to better health outcomes.

Finally, HealthHIV believes that the research agenda should be patient-centered. The essence of patient-centered healthcare is that the healthcare system is designed and delivered to address the healthcare needs and preferences of patients so that

health-care is appropriate. PCORI must have an open, public process for gaining comments and input from patients, providers and clinicians on specific research topics and questions. Without this process, PCORI will not be able to define a research agenda and answer the research questions that matter most to patients.

HealthHIV strongly supports PCORI's mission and looks forward to continued engagement directly with PCORI or through our membership in PIPC. We will continue to provide input and feedback to PCORI on behalf of the 1.2 million people in the U.S. living with HIV/AIDS.

Sincerely,

Brian Hujdich  
Executive Director

James Sykes, MPH  
Advocacy Manager