



THE AIDS INSTITUTE

PUBLIC COMMENT

by

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before the

FEDERAL COORDINATING COUNCIL ON COMPARATIVE EFFECTIVENESS RESEARCH

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Good afternoon ladies and gentlemen. My name is James Sykes, Director of Global Programs, Policy, and Advocacy at The AIDS Institute, a national nonprofit public policy research and advocacy organization located in Washington, DC. Thank you for the opportunity to address this esteemed body during this listening session.

The AIDS Institute is concerned about domestic and global health policy, particularly as it relates to healthcare and the impact of policy on the lives of patients living with disease and their access to care. In January, while the Senate was considering the economic stimulus package which contains the funds for comparative effectiveness research, we wrote Senator Lautenberg et al, asking that the legislation

- Ensure that the funds be used for comparative clinical effectiveness research which would ensure that the mission of CER be limited to clinical effectiveness and not cost effectiveness.
- Not allow a new CER agency or board to make coverage decisions or recommendations.
- Give patients and providers an active role in the entire research process – from setting research priorities to disseminating research results.

In February, we wrote to Speaker Pelosi, Majority Leader Hoyer, Minority Leader Boehner, and their respective Whips, asking that the House adopt the language approved by the Senate Appropriations Committee that ensured CER would focus on medical outcomes and contain the flexibility to take into account variations among different patient populations and to take the steps necessary to ensure transparency of the research by including patients and providers in the process.

I offer this as background because The AIDS Institute has been extremely interested in this process and has sought to provide constructive input. We appreciate this opportunity to ask you to consider the needs of patients with HIV/AIDS and to protect their full access to all necessary medications and offer some suggestions where comparative effectiveness research can be useful to people with HIV/AIDS. We ask that, first and foremost, you protect the existing Public Health Service's Treatment Guidelines

for the treatment of HIV/AIDS and opportunistic infections. These guidelines are well established and periodically reviewed by experts in the field. We do not want any CER to limit treatment regimens that would interfere with these guidelines. People with HIV/AIDS must be ensured access to all drugs for the treatment of HIV/AIDS, which today includes combination antiretroviral therapy. After time, people often build up resistance to a certain medication and then they must move to a new treatment. People with HIV/AIDS frequently experience multiple conditions and receive treatment for such other illnesses such as Hepatitis, Hypertension, Diabetes, Depression, and other diseases and conditions. No two patients are alike and everyone must have access to those medications that will best help them.

If you do choose to conduct CER in the area of HIV/AIDS, we offer the following suggestions, in which it can be useful,

- The role of Support Services, such as case management offered through the Ryan White Program, in the health outcomes of people with HIV/AIDS;
- A comparison of how HIV healthcare is provided – either by a HIV or infectious disease specialist or a primary care provider;
- A comparison of healthcare outcomes for HIV/AIDS patients between states with differing AIDS Drug Assistance Programs or Medicaid programs;
- The impact of other co-morbid conditions on certain drug regimens;
- Models to improving adherence to taking medications; and
- The impact of certain medications on those who are aging.

We also believe that CER can be useful in prevention strategies. For example, you may want to utilize it for HIV testing – specifically, you may want to examine differing models of programs that connect people who test positive to care and treatment. Additionally, you can study various models that encourage people to take an HIV test or various models that encourage providers to offer their patients an HIV test.

The AIDS Institute appreciates the opportunity to offer these comments to you. We hope you will respect the treatment guidelines that are well established for HIV/AIDS and consider conducting CER in the areas we have suggested in order to improve care and treatment to people living with HIV/AIDS in order to improve their quality of life and live longer lives.

Thank you.

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