



An Advocate's Guide to the DAIDS Trial Networks Funding Recompensation Process

What is DAIDS?

The US government is, by far, [the world's biggest funder of HIV research](#). In the US government, the Division of AIDS (**DAIDS**) is part of the National Institute of Allergy and Infectious Diseases (**NIAID**), which is one of the 27 Institutes of National Institutes of Health (**NIH**). NIH controls the largest pot of funding for HIV/AIDS research.

And now DAIDS is close to making a big funding decision based on what they think they know about the kinds of prevention products people want. If this concerns you, read below for a breakdown of what you need to know and how to make your voice heard in this decision.

Since 2000, NIH has been the world's biggest funder for development of HIV prevention options, including an HIV vaccine, pre-exposure prophylaxis (PrEP) and microbicides. Between 2000 and 2016, over US\$3 billion was spent globally on microbicide research and four times that amount — close to US\$12.7 billion — on vaccine development. Since 2000, the US public sector has accounted for three-fourths of the world's vaccine funding at US\$9.4B. US investments in microbicide research made up 84 percent of total funding in 2016, of which NIH was the largest donor at US\$97 million. ***You might be asking:***

Why does DAIDS matter to me, especially if I don't live in the United States?

The US government is the largest funder of HIV research worldwide. This includes:

- Research to make new and better HIV drugs to treat people living with HIV
- Looking for a cure for HIV
- Lab-based work known as “basic science”
- Studying how HIV works in infants and children
- Finding ways to prevent HIV

Scientists solve these questions by doing research trials (or studies) in places where there are high rates of HIV. Some of these places are in the US; many are not. DAIDS-funded research is going on all over the world and especially in East and Southern Africa. The clinic or hospital down the street from you may not have a US flag on it or anything at all that says “DAIDS”. But if it is doing a trial on HIV prevention or treatment, it is likely that money from DAIDS is paying for some of their research costs, equipment, salaries, pills and more.

So DAIDS funding is likely at work somewhere in your community. Who decides what that funding gets spent on? People in the US and partners in your country and community. But you have a voice, too! Whether or not you are in a trial, you have a right to say what money should be spent on in your community.

Okay, so DAIDS *does* matter. What's happening right now?

Clinical trials and other research studies try to answer questions. The first questions are about whether the tested product is safe and whether it works to treat or prevent HIV. But questions about whether people prefer one kind of a product or another are also very important—because people are unlikely to use something they do not like. Different kinds of questions need different kinds of studies. DAIDS funds different “clinical trial networks” that work on the topics listed above (HIV treatment, cure, prevention, etc.). And every seven years, DAIDS decides whether the networks are pursuing the right research agendas, studying promising enough products and are organized in the right way. That decision is happening right now.

Why should I care?

For the past seven years, in the prevention space there has been a network focused on research on microbicides, another on HIV prevention more broadly and one on HIV vaccines. Now DAIDS is proposing to combine the microbicide and prevention networks into one network, while keeping the vaccine network separate.

The leadership of DAIDS says this approach will help DAIDS find the next set of products people need to prevent HIV. Carl Dieffenbach, the director of DAIDS, has also said that the primary focus of these networks would be making HIV prevention products that are both long-acting (work in the body for six months or longer) and systemic (they affect the whole body and protect against all routes of infection, like through the vagina, rectum, blood and breastmilk). Vaccines and long-term injectable PrEP meet this definition. But microbicides do not.

But wait a minute!! People can choose whether to use a pill or a coil or an injectable for birth control. Why can't we have the same choices for HIV prevention?

The answer from DAIDS is that the prevention trials done so far show that people don't want HIV prevention products that they have to take every day or even every month. They have said that the data from microbicide and oral PrEP trials show that women "run from" these products. Their proposed structure would focus on products that he and other scientists believe are what people *do* want.

Is this really what people want?

No one knows. There are scientific reasons why a long-acting product could be very effective against HIV. But there are many reasons why some people might not want an HIV prevention injection if it existed. And there are lots of reasons why people might want daily oral PrEP or a microbicide gel at different times in their lives. Results from Phase III efficacy trials have provided important insights, but these findings may say more about trial participation than about actual product use in the real world. There are different kinds of research that can tell us what people do and don't want outside of the clinical trials—and yet now DAIDS is close to making a big funding decision based on what they think they know before we have these more robust findings outside of Phase III trials.

I want to have a say about what people in my community do—and don't—want. What do I do?

Now is the time to tell DAIDS that they can't decide what people will or won't use without asking us. And that, when they ask us, they need to listen to us about the best ways to get answers. They need to work in partnership with us on trials and studies that really try to figure out what types of products work and what we need at different points in our lives. These are some of the specific things we are asking DAIDS to do:

- Make a cross-cutting agenda (not divided up by networks) for doing research on women and key populations.
- Continue funding non-systemic products like gels, rings and films, that could reduce risk of getting HIV from vaginal and anal sex.
- Fund more of the kinds of research that shows us what people *actually* want.

DAIDS has agreed to accept public input and comments on their future directions and their proposed funding priorities for the 2021-2027 cycle until. Input is due by 30 November 2017. This is the time to comment on their agenda—ACT NOW!

Please make your voice heard on this issue!

Let DAIDS know you want research on all types of methods for all types of people to continue. And that decisions about HIV prevention priorities need to be made by the people most affected by HIV as well as scientists, health workers, peer educators and more.

- Comment today at <https://www.niaid.nih.gov/research/HIV-Research-Enterprise>.
- Download a sign-on statement (<http://bit.ly/2zBUrSE>) that outlines specific demands for microbicides—one of the tools at greatest risk of being dropped from further research if DAIDS' proposed restructuring happens.