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Ask the Experts: HIV Testing Kaiser Family Foundation Broadcast Studio June 26, 2007

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JILL BRADEN BALDERAS, M.P.H.: Good day. I'm Jill Braden Balderas, with kaisernetwork.org. Thanks for tuning in to "Ask the Experts," our regular live Web show that provides in-depth discussion of current health policy issues, and allows you to interact directly with top experts.

Tomorrow is National HIV Testing Day, which more than a decade ago was started and continues to be led by the National Association of People with AIDS. At present, there are an estimated 1 to 1.2 million people in the United States with HIV or AIDS, and about one quarter of those don't know their status.

In an effort to make voluntary HIV screening a routine part of medical care and increase the number of people who know if they're HIV-positive, the Centers for Disease Control and Prevention now recommends testing for all patients ages 13 to 64. The idea is that regular testing and early HIV diagnosis can lead to improved treatment and prevention, as well as reduce the stigma associated with testing.

Today, we're going to look at the implementation of the CDC's testing recommendations, as well as examine broader efforts to improve HIV testing in the U.S. As always, we'd like to include you, our viewers, in the discussion. So please e-mail us your questions to ask@kaisernetwork.org.

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Joining us in studio are Dr. Bernard Branson, associate director of the Laboratory Diagnostics Division of HIV/AIDS Prevention at CDC; Jennifer Kates, vice president and director of HIV Policy at the Kaiser Family Foundation; and Murray Penner, deputy executive director of Domestic Programs with the National Alliance of State and Territorial AIDS Directors.

Bernie Branson, I will start with you. First of all, thanks to all of you for joining us. Can you just explain to us what the difference is in the current recommendations that were issued in September 2006 to the previous recommendations from the CDC about HIV testing?

BERNARD BRANSON, M.D.: Sure. Previously, actually since 1993, CDC has recommended HIV testing for patients in high prevalence acute care inpatient and outpatient hospital setting - that prevalence threshold was 1-percent - and then testing for people based on risk assessment in other places. We found that recommendations were really not being followed or adopted in most places.

Health care settings didn't know what their prevalence was, very often providers didn't have time, or patients didn't like going through a risk assessment. And so in September 2006, we issued recommendations suggesting that all patients age 13 through 64, when they encounter the health care system, should receive an HIV test in order to

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find out what their HIV status was. And the way it should be offered is the so-called opt-out method, which is that people are told that HIV testing is a routine part of the care. They should have the opportunity to decline testing if they'd rather not, but otherwise testing should be conducted as part of their routine health care visit.

JILL BRADEN BALDERAS, M.P.H.: So can you walk us through what a patient should experience when they go to the doctor or in a health care setting under these new recommendations?

BERNARD BRANSON, M.D.: What we've seen from the demonstration projects is there are several different ways to actually implement this, but in general, a patient when they go to their health care setting should be either told or there should be signs posted that HIV testing is available, and that all patients are encouraged to know the HIV status. They should receive information that could either written or verbal that HIV testing will be carried out and information about HIV itself.

They should be told they have the opportunity to decline testing when they go through. But then, unless they have questions to ask, or unless they prefer not to be tested, the testing should be done as part of - for example, on a regular health care visit when they order your routine

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blood work, or your cholesterol check, HIV test should be added to the list.

JILL BRADEN BALDERAS, M.P.H.: Okay. And what are the testing options available to people, and how do they work?

BERNARD BRANSON, M.D.: Conventional testing is when you draw your blood and have it sent off to the lab. That's the way, certainly in doctor's offices, most testing is done. And then the test is done at a centralized laboratory. If the initial screening test is positive, they immediately do a confirmatory test before they send the result back.

More recently, rapid HIV tests have become available and this allows what's called point-of-care testing, which is immediately in the office or the emergency department, or even an outreach setting where a person can take a finger prick blood specimen or an oral fluid specimen and have a test result in 20 minutes or less from that. But that result is preliminary, and if it should be positive from a rapid test, a confirmatory test still needs to be done, and that still requires a specimen to be sent to the laboratory to confirm whether or not the rapid screening test was correct.

JILL BRADEN BALDERAS, M.P.H.: So, Jen Kates, I move on to you. Can you talk about, just set up first of all what we know, since these tests are now going to be made available

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to the general public, what do we know about the general public's knowledge of HIV in general?

JENNIFER KATES, M.A., M.P.A.: Well, the Kaiser Family Foundation conducts regular surveys of the American public every couple of years, trying to get a sense of what people think of HIV, what they know about HIV. Our last survey was conducted just before the implementation of these recommendations. And at that time, this was in 2006, what we found, and it's been a trend that we've seen, in general people in the U.S. have a pretty good basic knowledge about HIV.

They know about HIV, they're concerned about HIV, but what we do continue to find is misperceptions still exist, so people have misperceptions about HIV transmission thinking that HIV can be transmitted by sharing a drinking glass, for example. This is of concern because those people who tend to have misperceptions like that also tend to be more uncomfortable working and living with people with HIV. So we think if that could be a connection between not having the knowledge and maybe stigma.

So that's one issue that we find. The other is when we ask people, do you have the information you need about HIV testing? Do you want to know more? People want to know more. They want to know about the tests that are available to them, they want to know about where to get tested, they

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want to know about what test results mean. So the public is very hungry for more knowledge about HIV testing, and then the recommendations came out and we're going to go back into the field in a few months and we'll be able to see hopefully how people are - if they're hearing anything differently about testing when they go to the doctor.

JILL BRADEN BALDERAS, M.P.H.: Now can you set up for us all the different players that are involved in actually implementing these recommendations for HIV testing?

JENNIFER KATES, M.A., M.P.A.: Sure. Now the recommendations as Dr. Branson mentioned are really focusing on health care settings. So the first obvious partners are all of the health care partners that are out there. That's everyone from public partners, clinics, community-based organizations, private physicians, doctors, hospitals, emergency rooms, pretty much anywhere where an individual would come into contact with the health care system.

But beyond that, there are many other partners. The states clearly are a major partner in this. The states are responsible for HIV prevention at the state level, and provide much of the prevention and testing. So states are a key partner.

People Living with HIV and AIDS are a key partner. In fact, National HIV Testing Day was started by the National Association of People Living with AIDS in recognition of the

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key role that people living with HIV play in HIV prevention and testing.

The other type of partner that's really critical are people that reach consumers. So whether it's an employer, or the media, insurance companies, other ways that consumers are going to get information or interact with the healthcare system are also critical partners.

JILL BRADEN BALDERAS, M.P.H.: Now, Jen mentioned the state, so Murray Penner, I'd like to go to you. Your organization, NASTAD, just recently surveyed about 65 cities and states and territories in the U.S. about their HIV testing policies. So before we get to some of the findings, can you explain to us, what was the information you were actually soliciting in this survey?

MURRAY PENNER: Sure. Thanks. We did survey all 65 states, territories and directly funded cities through the CDC. We received an 85-percent response rate, so we got really good results back from 49 states, the District of Columbia and five of the six directly funded cities.

What we were looking for were, first of all, the legal and regulatory environments for HIV testing. We wanted to examine what states were experiencing in that realm. Secondly, the current Health Department efforts on screening, what they were doing in their own settings as well as then as what their future plans were.

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Now, we also took a look at the impact of the recommendations on programs and so that was one of the areas that we also examined through the process of this survey. Just briefly, what we found were that many of the states or jurisdictions were already doing routine screening in the public health setting, such as STD clinics, those kinds of settings where you would expect there would be some routine screening. So many of the jurisdictions were already doing that.

We also found that many of the jurisdictions had specific consent requirements and they had managed to work around those requirements to do their routine screening in those public facilities. And so it really does speak to the fact that we need to take a look at whether or not that was an actual barrier, the consent was an actual barrier in some jurisdictions to implementing routine recommendations or whether states have figured out how to manipulate and to work around those particular regulations or statutes. And so it's something that we want to certainly take a look at.

We also found that over a third of the jurisdictions were planning to do some kind of change policy, change pursuing regulatory change or statute changes based on the recommendations. And so there is a willingness on the part of states to really adapt and try to figure out ways in which

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to make sure that routine screening does become more prevalent in their facilities.

JILL BRADEN BALDERAS, M.P.H.: And what were some of the barriers that you found in the survey that states were experiencing? Just in HIV testing in general, but then also specific to the recommendations implementing those?

MURRAY PENNER: Well, certainly when you look at this, and you look at health care settings, you hear the argument that we're intending this to be in other health care settings, but certainly public health is an important part of the infrastructure in supporting the widespread implementation of routine testing in health care settings, and so funding is certainly a key. From the public health perspective, the infrastructure necessary to support the health care implementation of routine screening was one of the major barriers that we found, as well as a concern that health departments expressed in being able to support and implement these recommendations.

JILL BRADEN BALDERAS, M.P.H.: So, Bernie Branson, I'll turn it back to you in terms of the funding and building this infrastructure. How is the CDC working with states to try and prove this infrastructure?

BERNARD BRANSON, M.D.: I think there are a couple of features that I related to it. One, of course, is the recent funding announcement that CDC has made available additional

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money to help support testing, especially in the 26 high-priority jurisdictions which have experienced the largest number of cases of AIDS among African-Americans.

Clearly, we need to do more in those places. In December we published an NNWR, for example, from South Carolina where they were able to look at their people with HIV and AIDS who have been reported, and found out that 73-percent of them had passed through healthcare facilities but never had an HIV test before they were diagnosed.

And I think nearly 80-percent of those cases, their healthcare visits had been to emergency departments, and so we clearly see there's a place where people can go and get HIV tested and then of course the states will need to play a role in helping to do follow-up, helping to do partner counseling and referral services. And I think a lot of states, as Murray pointed out, have certain infrastructures. They just need to extend that in terms of partnering with a lot of their health care facilities that are not traditional public health facilities, in order to help provide certain assistance, perhaps provide some information to those places, but mostly work cooperatively.

CDC's been working with some of the institutions directly by conducting a series of regional strategic planning workshops for emergency departments, and we invite the Health Department to each one of those and find that very

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often, these are unfamiliar partnerships. They're not used to working directly with some of the health care institutions. They are more focused on their public health aspect. And I think facilitating the communication has been an important role.

JILL BRADEN BALDERAS, M.P.H.: Now we actually had an e-mail from a viewer about testing in emergency rooms and some of the confidentiality issues with that and kind of how to implement that in a successful way. So do you have any recommendations for somebody in terms of getting in touch with the CDC, in this setting, in the emergency room setting?

BERNARD BRANSON, M.D.: As you know, the CDC doesn't run emergency rooms, and so I don't think we have recommendations. What we're relying on are the experiences from our demonstration projects.

We had several demonstration projects that were conducted in emergency departments across the country and they're taking different approaches, but in one in particular in Oakland, they looked at several different models of asking people about HIV testing, about obtaining consent, communicating negative results, communicating positive results. And their experience was that most patients felt completely comfortable with the idea of being offered a test or providing consent for a test in a situation that was not entirely confidential. And they were also very comfortable

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and high degrees of satisfaction in receiving their negative test results in a setting that was not entirely confidential.

An emergency department is a very busy place. Sometimes you're separating another patient cubicle by curtains, so that experience was instructive for us and we're encouraging other emergency departments to gather that kind of information to see what their individual experience is going to be like, because it may depend very much on their patient population and on their specific set-up.

JILL BRADEN BALDERAS, M.P.H.: Now an emergency department is obviously a big place for implementing this testing, but there's also plenty of others, so Murray Penner, can you talk about the traditional and the non-traditional settings that states are using in order to implement increased [interposing]?

MURRAY PENNER: Sure. I do want to point out the emergency departments from those state health departments' perspective, because we did find in our survey that nearly half of the jurisdictions that we surveyed did anticipate going into emergency rooms and working with emergency rooms, and I think it's critical in all of these settings, not just in emergency departments, but as these settings look at implementing routine HIV screening that health departments experiences in working with statutes and regulations and their own experiences in HIV testing are very critical to the

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process of implementation of these programs in various settings, including emergency departments.

And so I appreciate Dr. Branson's discussion about the health departments being invited into those discussions about emergency department implementation. The health departments really have the experience. And we found through some consultations that we've done that some of the most successful projects have been where health departments and emergency departments have partnered together in making sure that can happen, based on the experience that the health department has, bringing in the regulatory and the consent and all that into the emergency departments and being able to implement that.

I mean, it applies to other settings as well, just to answer your question about the non-traditional settings, that it's really key that health departments be involved in that process of determining what works, what doesn't work, where the successes are, where the failures are and where we can learn and move forward.

JILL BRADEN BALDERAS, M.P.H.: So what are some examples of other settings where HIV screening is being implemented?

MURRAY PENNER: Certainly family planning clinics, correctional facilities, community health clinics, TB clinics, substance abuse facilities. Those are some of the

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key ones, I think, that probably come up and those may not be non-traditional, they may be traditional in the sense of it seems obvious that that's where you're going to be screening. But certainly I think health departments are really looking at various areas where they can expand their reach, and want to be supportive of the various aspects of CDC's recommendations when they move forward.

JILL BRADEN BALDERAS, M.P.H.: Now, going back a little bit to the funding issue, there's some stuff going on in Capitol Hill in terms of funding these recommendations and giving the states the ability to actually implement them. So can you talk a little bit about what's going on on Capitol Hill?

MURRAY PENNER: Well, first of all, we're very pleased that CDC has identified \$35 million to put towards this new testing initiative for 26 jurisdictions. And the ability for jurisdictions to be able to go into health care settings primarily and identify those that do not know their status.

One of the things that we are certainly hopeful on and some of the things that we continue to hear is that for fiscal year 2008 that Congress would allocate those funds again to ensure that those particular projects would be able to continue. Right now, as it stands, the \$35 million has

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been allocated for fiscal year '07 and we certainly support those funds continuing into fiscal year 2008.

I think the other piece that we're hearing a lot of concern about is some particular language in the preliminary bills in Congress about the early diagnosis treatment grants through the Ryan White Program, which would require that CDC set aside \$30 million of existing funding to go to states based on particular testing policies that they have in place.

And from our perspective, I think it's concerning that there are potential cuts to health departments for not only testing programs, but also just vital prevention programs through these \$30 million in cuts that could happen if that is enacted. So we're hearing lots of concerns about that, and we're certainly watching that very closely.

JILL BRADEN BALDERAS, M.P.H.: And another side of this is the whole insurance side, so Jen Kates, could you talk a little bit about what we know? Some people thought that these recommendations from the CDC would actually spur insurance companies on to cover these tests. What do we know about that?

JENNIFER KATES, M.A., M.P.A.: Well, I think the short answer is that when you talk about insurance, particularly private insurance, most people have insurance through their employers who are privately insured, and that varies considerably from plan to plan, from employer to

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employer. So what the situation is is very hard to assess across the country.

However, when you have the CDC coming out with recommendations that say this is an important part of healthcare and should be a routine screening test, it really does help insurance companies understand that, and we already know that several big insurance companies have taken steps to be explicit about that and make sure that that's very explicit in the requirements and programs that they are involved in. It doesn't mean that all of them have, but it certainly - I would think that it's happening more as a trend.

The other thing is that to the extent that insurance companies are already covering routine screening tests, this should be considered a screening test. Again, that may vary and when somebody is facing a barrier with that, it's probably related to the larger barrier around what's covered under screening in their plan. And if that were to happen to somebody, unfortunately they could rely on publically funded testing sites. But I think the hope is that by having these recommendations, more and more, both insurance plans and employers that work with those plans will understand the critical need to incorporate testing as a routine part, a routine screening test when you go to get your health care, as everyone should.

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The other issue still, is public payers, Medicaid, Medicare, and then people who are uninsured. And there's also some variation there and this is another kind of challenge because we have CDC saying here are the recommendations, and then we have government-funded payers over here and they're not always in sync yet.

And so for Medicare, for example, routine screening of HIV testing is not a reimbursable service at this point. For Medicaid it's a little more complicated, because Medicaid's a partnership with the states and the federal government, and it's something that can be reimbursed but states have to, in many cases, be proactive about wanting that to be a reimbursable service.

Certainly for those who are uninsured, there are many options for getting low, or no-cost testing. And Ryan White, actually the Ryan White Program will cover testing for some populations of people at risk.

BERNARD BRANSON, M.P.H.: I would like, if I could, to add a little bit to what Jen was saying.

I think, first of all, one of the circumstances is that 75-percent of the testing, of HIV testing in the U.S. already occurs in health care institutions, so when you look at the National Health Interview survey and ask people where were you tested, the most common answer is by my doctor, in

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my HMO, in my hospital, in an emergency department, in an outpatient clinic the last time I went.

The problem is that according to our information of the people diagnosed with HIV, half of them have their first HIV test within a year of developing AIDS. And so what we'd like to see is for the reimbursement of the tests to be moved up earlier, so that you're going to pay for the test now, or you're going to pay for the test later. If the person is sick, it's a medically necessary test and all insurance covers things that are medically necessary.

The distinction right now is paying for it as a screening test, and the issue really that we are seeking to happen is to make sure that people get tested earlier, when they can have access to lifesaving therapy, instead of late in the course of their disease when they potentially had missed many opportunities for beneficial care and when they might have put other people at risk that they wouldn't have done had they known they were HIV infected.

As Jen was talking about, Medicare, for example, requires a specific act of Congress in order to provide coverage for screening because they had very explicit rules. On the other hand, our recommendations call for testing people ages 13 to 64, so most of them aren't Medicare-eligible. What we're really looking at now is for private insurance and for Medicaid to consider this and to recognize

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that they're already underwriting a lot of HIV testing in the U.S.

JENNIFER KATES, M.A., M.P.A.: And I want to add one other thing, which is it sort of links of states again, with their role as educating insurers and providers. I know that several states are working with their HMO's and local insurance companies, as well providers and employers to educate them about the recommendations and the importance of screening and what that might be.

JILL BRADEN BALDERAS, M.P.H.: I just want to bring up this e-mail question because it kind of hits on the syncing between different organizations and the CDC's recommendations. This one was e-mailing in about the CDC and then the U.S. Prevention Services Task Force, and having these discordant policies on routine HIV testing. So she wants to know, are you working with the USPSTF to revise their April 2007 statement regarding HIV testing? So can you first of all talk a little bit about what was in their 2007 statement and then how that links up with the CDC?

BERNARD BRANSON, M.D.: Sure, the Preventive Service Task Force last did an update of their review of HIV screening both for high risk persons, for people in the general population and for pregnant women in 2005. And after CDC's recommendations came out, they sort of took a second look because the recommendation in 2005 which is one that

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remains is they do recommend testing in high prevalence, that is in settings greater than 1-percent or for high-risk persons, and high risk may be defined either by the nature of the setting or a persons individual risk factor.

And so that is given a strong recommendation that screening should be conducted. With respect to people that they describe as without specific risk factors are lower prevalence setting, they gave it a call. It's called the C recommendation, which is that there is insufficient evidence to recommend either for or against.

So first of all, I want to sort of correct the misimpression that it's not entirely concordant. I think our recommendations are relatively close together, the CDC and the Preventive Services Task Force. Because in fact, when they re-review the information, what they've said is that they had recommended it in higher-prevalence settings, but most people don't know what their prevalence is. And one way to find out your prevalence is to start screening and to see what happens.

This was very much the same situation that existed with respect to screening of pregnant women in 1995. CDC recommended screening all pregnant women at that point in time. The U.S. Preventive Services Task Force recommended screening only high-risk pregnant women, and in fact they

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didn't change that recommendation until 2005 when they came out with their most recent review.

The Preventive Services Task Force really requires some very evidence in order to make recommendation, and that's the way it should be. They're evidence-based recommendations. CDC sometimes needs to rely on the best available evidence in order to move things forward, and as was the case with pregnant women, that recommendation proved very effective, to screen all pregnant women resulted in a 95-percent reduction of vertically transmitted or mother-to-child transmission of AIDS cases and in fact, that also generated the evidence of that the Task Force needed to change their recommendation.

So we are hoping the similar circumstance will come right now, but it's not like we're trying to twist the arm of the Preventive Services Task Force and say hey our recommendations ought to be the same so.

JILL BRADEN BALDERAS, M.P.H.: Now, Jen Kates, if you could talk about the new WHO UNAIDS guidelines that they issued on HIV testing, because this move towards opt-out testing is not just in the United States.

JENNIFER KATES, M.A., M.P.A.: Right. I think it's very important to understand that this is really a global shift that's been developing for a while, and thinking about how to tackle the epidemic. And many of the issues that CDC

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was seeking to address in issuing these recommendations are even more pronounced globally, so one of the issues in the U.S. is a certain percentage of people, one in four not knowing that they're HIV-positive. Globally, that's more like eight in 10.

Another issue, people finding out quite late in their diagnosis, globally that's a much worse problem. And treatment access and all of these things that we wanted to address here in the U.S. are clearly global issues. UNAIDS and WHO have been working for a while with various policy statements about this, and came out in May with guidance that has a lot of similarities to what CDC's recommendations say. There are some differences, largely because WHO and UNAIDS are speaking to the world, and speaking to very different situations in mostly low- and middle-income countries.

But essentially what that guidance said was we now are recommending what they call provider-initiated HIV testing, which is opt-out testing from in health care settings, moving from client-initiated testing, which is opt-in. So that's essentially what the CDC was saying before the onus was really on the person wanting to get tested and seeking that testing out, and now the recommendation from WHO and UNAIDS is really healthcare settings, defined differently in different locations, really need to adopt a routine screening approach that is going to provide HIV testing

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that's voluntary with consent, but offer it. And again, the patient can refuse, but the hope there is that we'll increase uptake and there's actually country evidence and experience of that happening, and it's helped with access to treatment, et cetera.

So it's a very similar message overall. And the other thing, one thing that is a little different but I think it relates to an issue here in the U.S., there's a real recognition in the guidelines and the guidance about the fact that there's treatment access while getting better is still very low in most of the hard-hit parts of the world.

And so there's a delicate balance between finding out you're positive and then treatment access. Where do you start with that? Is it better to know you're positive if you can't get treatment than not knowing you're positive because there's prevention benefits and other things you can do besides accessing antiretroviral treatment? But clearly that's critical. So the guidance talks about that and talks about that as a potential, a big issue to consider in implementation and provides some suggestions in that regard.

BERNARD BRANSON, M.D.: [Inaudible] actual guidance though also distinguishes sort of the stages or different types of epidemics, so that their provider initiated testing and counseling, they didn't recommend to the whole world run out and do it. They definitely think that places that have

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generalized epidemics, that have high prevalence, ought to be testing everyone.

With respect to countries like the U.S., where you don't have a generalized epidemic, it is either sort of more concentrated or unevenly distributed, they do recommend that you take other circumstances into consideration before you make a recommendation. So they're not recommending that all countries in the world adopt this approach, but just sort of grading it on the basis on what the extent of the epidemic is, whether there's availability of treatment and also whether there's protection from discrimination, because we all recognize that an advantage we have in the U.S. with Americans with Disability Act, with other protective measures is that we perhaps overcome some problems that other countries have not in respect to discrimination that people might face when they're diagnosed with HIV.

JENNIFER KATES, M.A., M.P.A.: The guidance talks at length about that, and about stigma, about protection, about confidentiality, about ensuring that that environment is in place because that is clearly critical.

JILL BRADEN BALDERAS, M.P.H.: And now... oh, please go ahead.

MURRAY PENNER: I just wanted to echo the bringing it home a little bit to the United States and our access to treatment, because clearly putting these guidelines in place

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is intended to bring more people into care. And certainly the resources necessary to make sure that individuals have access to the treatment that is necessary is critical in this. And we know today that there's over 500 individuals in AIDS drugs assistance programs waiting for medication.

And so, it's not necessarily the fact that we have all the resources necessary publically to support treatment that's necessary for individuals that we find. And so as we continue to implement these guide lines, that's a critical piece, in the United States as well, certainly there are varying degrees of that across the world, but even in the United States.

JILL BRADEN BALDERAS, M.P.H.: So what are states doing to get prepared for more people needing treatment?

MURRAY PENNER: Well, I think many states have put their own resources into their treatment programs, in particular AIDS drug assistance programs, have put their own resources to match the federal resources to make sure that they can continue to treat individuals that come in.

Certainly if we identify all these individuals that we need to identify, and get those into care, that's going to be a tremendous burden on a system that's pretty stretched already publicly, from the public perspective. And so states are concerned about that and I know that there are many of them that are looking at ways to either trim their costs or

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make sure that they can allow more individuals into the programs.

BERNARD BRANSON, M.D.: And I want to point out that it's also not just a matter of money. We definitely need funding for adept programs for other care, but one thing that people have been sort of worrying about is that the supply of providers who take care of HIV-infected patients, and it's sort of a sub-specialty where you need to have some expertise in juggling different medications and that.

That has not really been increasing, so a lot of providers are saying look we're at capacity in our clinic and it's not easy for me to hire somebody to bring it on. And so we at CDC, as well as some of our partners, like the American Academy of HIV Medicine and HIV Medicine Association, are seeking to attract more providers to this area, to make sure there is sufficient training, and part of the management of patients probably needs to be monitored over a long period, but perhaps don't need medications yet, could also be conducted on a broader range of settings than it has been in the past.

JILL BRADEN BALDERAS, M.P.H.: And what... oh.

MURRAY PENNER: I think that applies not only to private medical associations but also to the public health work force. I mean, certainly we're seeing public health work force shortages and demands on the public health system

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as well, and so it's very applicable there too. And certainly that's a necessity.

I just want to segway a little bit into the necessity for these guidelines and provider education is very important. One of the things that we found in our survey was that the necessity for providers to understand these guidelines, consent requirements, all the various things that are required at the various state levels are very important as well.

JILL BRADEN BALDERAS, M.P.H.: And so what are states doing to - I'd actually like to ask both of you this question, but what are states actually doing to educate providers?

MURRAY PENNER: One of the things that we found in our survey was that nurses are critical to the information necessary for HIV screening and testing mechanisms, and so one of the things that states are starting to do is work, not only with medical provider organizations, but all with nurse organizations in the states. And so I think that expanding it necessarily beyond just the medical doctors is important.

I think the nurse organizations are certainly important as well, but we really have seen that it's an overall process that states need to work with all providers in implementing the guidelines.

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JILL BRADEN BALDERAS, M.P.H.: And I imagine the CDC would agree.

BERNARD BRANSON, M.D.: Well, the CDC agrees and I think that, I do want to point out though that it is also a two-way street, which is states working to educate providers and sometimes providers working to educate states. I mean the California Medical Association, for example, has been very active in working with their legislature, some of the other physician association have something called White Coat Day where the providers go to meet with legislators or with other political bodies in order to communicate the nature of the problem.

And I think that HRSA, the Health Resources and Services Administration, finds that AIDS education and training centers and as part of this new initiative, I know that Murray talked about CDC providing \$35 million, well, actually this year, it's \$45 million. Some of that money is going for provider education through the ATCs, some of it is going for social marketing campaigns in order to try to reach patients and to reach providers and so there's a multi-faceted approach in order to try to sustain each part of the enterprise that we need to move forward in order to get more people tested and to help identify more HIV-infected persons and get them into care.

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JENNIFER KATES, M.A., M.P.A.: Yes, I would just, as a [inaudible] main HIV provider organizations, one of which was mentioned, the American Academy and the other, the HIV Medicine Association have also been working with their networks to let them know about the recommendations but also to use the power of convening providers to reach out to some of the non-HIV specific provider networks out there, including a meeting I believe that happened at CDC with AMA and many others to really talk about this.

And as an example of something that I know about, because we tried to help with this here in D.C., the D.C. Department of Health AIDS office was very interested in helping to bridge the provider community with what the recommendations say and convened a meeting here and we helped do this with HIV providers. Because the idea is that HIV providers, as experts in the field, first they should know about the guidelines and many of them actually are doing routine screening in their practices, but they can provide important peer support, and peer connections to their community in D.C.

And I think that's a model that others around the country can adopt. In D.C., D.C. was actually starting a push on routine screening a little bit about the same time as the recommendations so they were ready to start thinking about that.

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JILL BRADEN BALDERAS, M.P.H.: One element that I would imagine that would be important in this education would be the idea of the fact that these tests need to be voluntary. While their routine, it's opt-out, but voluntary, so can you, Jen Kates, talk a little bit about what some of the issues were at the beginning as these recommendations were being developed with de-linking the written consent for getting tested, but at the same time ensuring that they are voluntary. What were some of the concerns in the community?

JENNIFER KATES, M.A., M.P.A.: Well, part of the concern was not knowing the full, I think implications or what it meant to de-link or to say that the written consent was changing. What really I think the recommendations say is that explicit separate written consent for an HIV test are no longer needed. It's not that it shouldn't be, but their not needed. And the idea there was that if a provider, in the health care setting - this is health care setting, if a provider, and this is heard from providers, had to actually get specific consent from a patient for this specific consent from a patient for this specific test, it almost became a barrier, both to that provider and others to implementing this important intervention in the context of a medical visit. Because we all know how sometimes our medical visits are concaded, so one of the concerns was that requiring that

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separate explicit written consent for HIV testing could really inhibit a broader availability of testing.

So what the recommendations actually say is that there needs to be consent, somebody needs to understand that HIV test will be performed and they should have total control of knowing what that means and saying they don't want it. But that general medical consent, the kind that we all infer upon our doctors when we go see them, should be enough, should be sufficient to also allow for consent of this test.

Again, the provider should be talking to the patient and saying we're going to do these tests, including an HIV test, but the step that does not have to take place according to the recommendations is the patient to say, I agree to that test. The patient will have had to agree to medical care from that provider.

The concern was that, and it's really just a broader concern that will always be the case, and we've seen it from our surveys that people don't always understand testing, what does consent really mean? Do people understand what they are consenting to? Because there are implications to a positive test result, many implications. Many would say it's better to know that you're HIV-positive, but there are important implications.

There's still a stigma in our country. There still is issue of discrimination. There still are a lot of

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challenges that people will face if they have a positive diagnosis, there's certainly tremendous advantages to knowing you're HIV-positive, both from a prevention and treatment perspective, but that was one concern. So are people understanding what they're consenting to?

And even if they're negative, what does it mean to consent to a test? And I think the other issue that was always raised was are certain people going to get, certain groups that maybe always don't get information that they need in the healthcare setting going to suffer disproportionately, and not get the information they need to really consent to this test. So that is still a concern. Consent is a big issue.

BERNARD BRANSON, M.D.: I don't want to point out necessarily that, results on one of the Kaiser surveys to Jim from Kaiser, but in the last survey, when they asked the question, they asked people whether they find anything special should be required. And two-thirds of the people said no for an HIV test, that they shouldn't have to go through a special procedure. One third of people said that yes, you still should require something special.

I think there are a lot of state-to-state differences in terms of what's required. In our perspective, first of all, in a health care setting there is something called a doctrine of informed consent, all right? You can't do

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anything to anybody without getting their consent and so this issue of being voluntary, that's never been a question.

The question has been whether you have to have a separate process, a separate procedure, a separate form and I don't think that there is a complete consensus in the country yet on whether that's necessary or whether its not. There's no question people should know they're being tested for HIV, and they should have an opportunity to say no thank you. So that we completely agree with, consent is an integral part of the process.

Jen mentioned that some providers felt there was a barrier, that they were reluctant to obtain this extra consent or it was a problem, but we've also seen that some patients say hey, why should I have to sign this separate piece of paper? I mean what's different about this? And then they get worried, and they get some anxiety or they feel there may be some stigma that's associated with going through this process, and they feel differently when it's this thing that oh, well, everybody is recommended to get it.

That was clearly demonstrated with prenatal screening for pregnant women that when you went through the opt-out approach and you had to sign a separate form, at least in one randomized control trial, only 45-percent of the women agreed. When we just changed it to the we recommend this routinely for everybody, testing went up to 88-percent. And

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so it's not just a provider issue. I think it's a patient perception issue.

And one of the intentions of the recommendations was to destigmatize HIV testing because risk-based testing missed a lot of people who were HIV-infected but didn't acknowledge or realize that they had some risk behavior. But also, it tended to discourage people from getting tested because you had to have basically some risk factor to be eligible for an HIV test and people didn't feel comfortable with that, it really stigmatized the process of testing.

JENNIFER KATES, M.A., M.P.A.: Now I want to pick up on something you said, also people do not always recognize that they have risk behaviors.

BERNARD BRANSON, M.D.: Right.

JENNIFER KATES, M.A., M.P.A.: That's a big issue. There have been several studies the CDC has conducted and others with people finding out that they are positive and asking how many of them think that they are at risk. These are people who are HIV-positive, high percentages saying, I'm not at risk. So a lot of people are very, don't want to believe that they may be at risk for something, so just a risk based approach in all settings is not always going to be the best approach. It is an important approach in some settings.

JILL BRADEN BALDERAS, M.P.H.: Now... go ahead.

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MURRAY PENNER: I want to speak a little bit about the consent as well, because one of the things we did find in our study is that there are a majority of states that do have some kind of consent requirement, varying tremendously from state to state as Dr. Branson pointed out. But certainly states have also implemented routine screening in many of those jurisdictions and so they have figured out ways to make that work and it really is a state-by-state kind of decision as to what works and what they're able to maneuver around in order to make sure that this happens. I think our goal is, as you said, very much the same. And that is to get as many people tested and into care as possible so that they know their status, so that they can prevent new infections, et cetera.

So there is the consent issue but it shouldn't necessarily be the barrier if states are able to work together and figure out ways to partner and provide peer technical assistance to each other in figuring out ways to overcome some of those barriers that may be in place.

JILL BRADEN BALDERAS, M.P.H.: Did you find any evidence of states needing to change their laws to actually implement the recommendations?

MURRAY PENNER: There are certainly some states that are considering changes to their laws in order to implement it. I believe it's about a third that are saying we need to

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do some changes, we feel that we've got to make some changes in order to have that happen. Certainly they're pursuing that, but there are others that are pursuing other mechanisms besides just changing their laws.

BERNARD BRANSON, M.D.: And I want to be careful to reiterate what Jen said earlier that while the majority of states have some regulations with respect to consent, it is not a majority of states that require separate written, informed consent.

MURRAY PENNER: That's correct.

BERNARD BRANSON, M.D.: It's actually a minority of states, and several states, for example Illinois, both the House and Senate has already passed legislation changing that requirement, there's another bill that's going through the legislature in California. It's passed the Assembly, it's gone to the Senate with respect to the separate written consent. But that is really a minority of states.

With respect to the other issues related to consent, again we all agree that people need to be tested voluntarily and so I don't think that people are going to ever pass the law that says you don't need consent for an HIV test in any of the states. And so some of it has to do with removing what were impediments because of some of the regulations being basically too involved or too complicated in order to facilitate easy screening in health care settings.

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JILL BRADEN BALDERAS, M.P.H.: So can you talk a little bit about what role counseling plays in the new recommendations and how perhaps it might be a little bit different from previous recommendations and why counseling is so important?

BERNARD BRANSON, M.D.: Sure, I think that in the past you never said HIV testing without mentioning counseling, it was sort of like bike and exercise, sort of always went together in that circumstance. And we still feel very strongly at CDC that counseling is an important intervention, both for HIV-negative and certainly for HIV-positive people.

In 2003, CDC did in announcing the advancing HIV prevention initiative, changed a lot of it's emphasis to focusing more on finding HIV-positive persons, getting them into treatment and conducting prevention interventions, including counseling with HIV-positive persons. In the new recommendations, we still strongly recommend prevention counseling for HIV-negative persons with known risk factors.

The difficulty with respect to a routine screening program is that requiring counseling, requiring risk assessment in all those settings was, frankly, impractical. If you have an emergency department that has 100,000 visits a year, adding 15 minutes to every one of those visits in order to provide counseling would require you to hire eight people

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in order to do that. And providers were saying, look, this is not feasible for us.

And so our position with respect to counseling is that it's not the test that ought to prompt counseling. Getting a test is not the reason you need counseling. Having a risk, having a risk behavior, being treated for an STD are all good reasons for which you should get counseling whether or not you get an HIV test at the time. And so the idea is people need counseling, people need testing, they don't always need them together. And I think that's the idea we're promoting.

JILL BRADEN BALDERAS, M.P.H.: And what is the state perspective on this, from based on what you found in the survey, about the importance of counseling?

MURRAY PENNER: Well, I think certainly, I think we would agree that counseling in high risk situations is absolutely necessary. From a perspective of the larger general screening, I think it varies depending on the prevalence of the jurisdiction as well, I think when you're looking at very low prevalence jurisdictions where you probably do not have the risk that you would have in some of the higher-prevalence jurisdictions.

You really would want to look at the importance of counseling and whether or not that was necessary. That also speaks to the cost effectiveness of regular HIV screening in

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low-incidence jurisdictions. It's another piece that we've been looking at in our study, about what in particular if you want to consider prevalence or incidence, where do you draw the line? Where is the cost effectiveness in the importance of regular routine screening? Is it necessary in all jurisdictions? Maybe not.

JILL BRADEN BALDERAS, M.P.H.: And is that something that either states or the CDC are looking into, of what is that point-of-cost effectiveness?

BERNARD BRANSON, M.D.: Well, there have been several cost effectiveness studies that have been published. And they have shown that one time screening is cost effective down to a prevalence of 0.1-percent, and in fact CDC's recommendations say that places should start screening and if you find fewer than one infected person per 1,000 persons screening that it's not worth continuing to screen. So our recommendations very much take into account this whole issue of the cost effectiveness threshold.

The problem was in our consultation, we were told in no uncertain terms not to make a prevalence-based recommendation because nobody knows what their prevalence is. And when this screening proceeds, I think we'll have some idea in many places, and certainly in many more states will know what the prevalence is in different environments and then perhaps we'll be able to make some decisions about

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repeat screening, about what the periodicity is because at the current time we are not saying that everybody should get screened every year, or everybody should get screened every three years. Right now, CDC is saying everybody should know their HIV status, and persons with known risk factors should get screened or tested at least once a year.

JILL BRADEN BALDERAS, M.P.H.: Now Jen Kates, earlier you talked about the major players in implementing these recommendations and one of the elements was the media. And businesses, can you talk a little bit about the Kaiser Family Foundations partnerships and the new ad campaign, the PSA that we're doing to promote getting tested?

JENNIFER KATES, M.A., M.P.A.: Well, certainly the media are a critical partner for anything related to information about HIV. One of the things that we see on our surveys everytime we do a survey, most people in America are getting information about HIV from the media. More so than their doctors, more so than schools. I mean those are important sources, but the main source is the media.

So what they're hearing, what they're learning is critical. So one of the things we've done at Kaiser is try to, and we have developed a new model of working with the media, which is seeing the media as a partner. And partnering directly with media companies to provide them with information about HIV and let them do what they do best,

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which is figure out the creative and important ways to reach consumers.

We've been doing this for over a decade with MTV, with BET, with CBS. We're now doing this work globally, and one of the key things that we have found in the media can be very, very helpful to is information about HIV testing, because it's something the public wants to know about, it's important from a public health perspective. People need information, and the media can be a great source of information to provide, to do that and also to destigmatize testing.

So one of the things that we've recently launched, and we have a lot of efforts around testing in our media partnerships, we just started a partnership with HBO and the NBA and the Global Business Coalition on HIV/AIDS and CDC was a partner as well, to find a way to bring all those players together, literally and figuratively, and promote HIV testing.

Jamie Foxx and Queen Latifah were part of this effort, and we launched this new PSA campaign called "Testing 411" with these partners. And it has NBA players in it, it has Jamie Foxx in it, and the idea is that if you see people that, especially young people can really relate to, talking about testing as something that's important in people's

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lives, hopefully more people will understand the importance of testing.

And also just know that there are places to get information about testing, it drives people to information sources. And I'm also happy to say that other media companies that aren't part of the HBO network, that are separate like MTV and BET and others, are going to air these PSAs. So the idea was the information is what's important, and these groups came together, businesses, media companies, NBA players and entertainment industry to really help make a difference.

JILL BRADEN BALDERAS, M.P.H.: And we would actually show you that PSA, and so you can understand why Jen Kates said players, both literally and figuratively. So, if we have that queued up?

[RECORDING] PSA: Did you know most people living with HIV today don't know it? Testing one, two, three, testing one, two, three. I know in your status you protect yourself and those you love. Imagine the possibility of an HIV free generation. No fear, no shame, no doubt, do the right thing.

So get on the ball. Get tested today.

It begins with you.

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JILL BRADEN BALDERAS, M.P.H.: So we hope you enjoyed that PSA. It began airing, I believe last week, is that right?

JENNIFER KATES, M.A., M.P.A.: Yes. And it's going to air beyond National HIV Testing Day, which is tomorrow as you said, but yes, these are... and they're available to other media companies.

JILL BRADEN BALDERAS, M.P.H.: We actually received an e-mail questions from the New York City Health Department wanting to know, do we actually have rates on how many people are getting tested? Do we have a good understanding? So we kind of know the base line where we're starting, and then how hopefully the recommendation can improve HIV testing rates?

BERNARD BRANSON, M.D.: The information that we have, that we rely on for testing right now comes from usually several different surveys, so the behavioral risk factor surveillance survey, the National Health interview survey, the National Survey of Family Growth are all places where they conduct vast questions about testing and we get rates.

Right now, it's estimated that between 16 and 22 million people get tested for HIV per year. This is prior to the recommendations. We expect this next cycle in the survey is going to give us some information probably by the middle of next year, on basically what's happened compared to what the earlier rates are from that.

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JILL BRADEN BALDERAS, M.P.H.: Is there a goal for the number of people to get tested?

BERNARD BRANSON, M.D.: Well, under the new testing initiatives the CDC has coming out, the goal is with this \$45 million total is to test an additional 1.5 million people. Obviously our goal ultimately is to try to diagnose as many of the estimated 250- to 300,000 persons who are infected but don't know it, as possible. We do expect it will take several years.

JENNIFER KATES, M.A., M.P.A.: I would just add, another survey is the one that we do where we do ask people on have you been tested. And that data is more recent, but it finds basically the same thing. One thing we have seen, and this is again before the recommendations came out, is there's a growing share of the population in the U.S. that has been tested for HIV at some point, which makes sense over time.

But in terms of being tested in the last year, that share hasn't changed that much, so that is one thing we'll be looking at. Are people now getting tested more recently? So not just at some point in their life. And that will be a good measure I think.

JILL BRADEN BALDERAS, M.P.H.: And is there a way also that you can measure the effectiveness of these public service announcements?

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JENNIFER KATES, M.A., M.P.A.: Clearly, understanding the role of the media in helping people get information and leading to protective behavior is critical. I think it's first important to understand the media is one part of a comprehensive approach to HIV prevention. If you have great interventions but nobody knows about them, that's a problem. But if you just have information and there's nothing to go to, that's a problem. So these two have to work together.

And there have been many, many studies actually throughout the world looking at the role of the media, finding that the media campaigns, public health campaigns through mass media, lead to increased knowledge, reduced risk behavior, more likelihood to use condoms during sex, so things that we would want to have happen.

In the context of our campaigns, what we try to do is assess how those campaigns are reaching the intended audience. We do that through surveys, which is one measure. One way we try to measure this and we find is a very, very high recognition of the campaigns, we do it through, not just recognition of those campaigns, but do people say they learn something? They intend to do something differently, like talk to a partner, reduce their risk, get tested.

We also, because we work so closely with CDC - in fact, everything that we do in the U.S. context with the media drives people to the CDC's hotline and testing database

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- so people can find out where to get tested. We can actually see with some of the campaigns, spikes in calls to the CDC hotlines, and requests for information when those air. So we think that's a pretty good reflection of the reach.

MURRAY PENNER: I'd like to jump in just real quickly about, and commend CDC for the heightened national response on HIV, which actually looked at non-traditional ways and suggested non-traditional ways in reaching populations that had not been reached, particularly African-Americans that are impacted heavily by HIV disproportionately.

And certainly the media is a big part of that and I believe that some of CDC's outside-the-box thinking is so necessary in this. It's not just about testing, it's about sometimes figuring out ways to get into communities that you normally would not reach, and you normally would not get into that are providers that we think of, don't have the mechanisms to get into. So everytime we can think beyond the traditional ways, the media, other mechanisms to actually reach individuals that don't know their status, I think it's important.

The other piece of it is that we can't just think about testing. We have to think about the arsenal of prevention activities that jurisdictions, health departments, CBOs have to actually prevent new infections. And so it's

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not just about testing, and yes, we certainly recognize that testing is a major part of this in getting people into care, but also prevention is important.

JILL BRADEN BALDERAS, M.P.H.: Well we have very quickly passed an hour, so I just want to close with one question. And Murray Penner, if you don't mind, I'll start with you, the same question to all of you. Where do you hope we'll be this time next year in terms of testing and improvements that will have been made in the next year?

MURRAY PENNER: Well, certainly we're definitely moving in the direction of getting more people to know their status, and I think from the perspective of state health departments, we want people to know their status. We want people in care so that we can prevent new infections, and certainly if we can reach the kinds of individuals that we're trying to reach through these new pilot projects with this new funding, we will identify new people, and that's the goal. I wouldn't throw out a number necessarily, but the goal is certainly to increase the number of people that know their status and are actually in care.

JILL BRADEN BALDERAS, M.P.H.: Jen Kates?

JENNIFER KATES, M.A., M.P.A.: I mean, that's the goal that I think we all share. We want people who are risk to know what risk means, we want people who are HIV-positive to know their status, and I think the only piece that I would

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add is therefore, the partners that we talked about throughout. We want those partners to be educated too, and make changes that they need to make to facilitate this everyone.

BERNARD BRANSON, M.D.: I may regret this, but I will throw a number, I guess. Anyway I think that in general, CDC sees between 40- and 45,000 new diagnosis a year. With this new initiative, we are hoping to diagnose an additional 20,000 people, and so a year from now, that's what I'd like to see, that we've accomplished that goal and we've been able to help 20,000 more people find out that they're HIV-infected, people who don't know it now and are probably suffering for it.

JILL BRADEN BALDERAS, M.P.H.: Well, thanks to all three of you for being with us today. We've been joined by Dr. Bernard Branson of the U.S. Centers for Disease Control and Prevention, Jennifer Kates with the Kaiser Family Foundation, and Murray Penner with the National Alliance of State and Territorial AIDS Directors. And thanks to all of you for tuning in. We appreciate all of your questions. I'm sorry we couldn't get to all of them.

We'll see you next time on kaisernetwork.org's "Ask The Experts."

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¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

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