

Presidential Advisory Council on HIV/AIDS (PACHA)

46th Meeting

L'Enfant Plaza Hotel

Ballroom C & D

480 L'Enfant Plaza, S.W.

Washington, DC 20024

May 16 and 17, 2012

Council Members Present

Nancy Mahon, J.D., PACHA Chair

Douglas Brooks, M.S.W., Co-Chair, Disparities Subcommittee

Cornelius Baker

Dawn Averitt Bridge, Co-Chair, Global Subcommittee

Humberto Cruz, M.S.

Patricia Garcia, M.D., M.P.H.

Robert Greenwald, J.D., Co-Chair, Access to Care Subcommittee

Kathie M. Hiers, Co-Chair, Disparities Subcommittee

David Holtgrave, Ph.D., Co-Chair, Incidence Subcommittee

Michael Horberg, M.D., M.A.S., FACP, FIDSA, Co-Chair, Access to Care Subcommittee

Naina Khanna

Douglas Michels, M.B.A.

Mario Pérez, Co-Chair, Incidence Subcommittee

Rev. Vanessa D. Sharp, M.Div., M.A.C.M., M.A.T.M.

Phill Wilson

Council Members Absent

Praveen Basaviah

Rev. Dr. Calvin Otis Butts III, D. Min., M.Div.

Ernest Darkoh, M.D., M.P.H., M.B.A.

Kevin Robert Frost, Co-Chair, Global Subcommittee

Ejay Jack, M.S.W., M.P.A.

Jack Jackson, Jr.

Anita McBride

Rosie Perez

Sandra Torres-Rivera

Staff Present

B. Kaye Hayes, M.P.A., Executive Director, PACHA, U.S. Department of Health and Human Services (HHS)
Melvin Joppy, Committee Manager, HHS
Vera Yakovchenko, M.P.H., Public Health Analyst, Office of HIV/AIDS and Infectious Disease Policy (OHAIDP), Office of the Assistant Secretary for Health (OASH), HHS

Presenters

Mayra Alvarez, M.H.A., Director, Public Health Policy, Office of Health Care Reform, HHS
Douglas Brooks, M.S.W., Co-Chair, Disparities Subcommittee, and PACHA Liaison to the CDC/ HRSA¹
Advisory Committee on HIV, STD, and Viral Hepatitis Prevention and Treatment (CHAC)
Grant Colfax, M.D., Director, Office of National AIDS Policy (ONAP), the White House
Andrew D. Forsyth, Ph.D., Senior Science Advisor, OHAIDP, OASH, HHS
Antigone Hodgins Dempsey, M. Ed., CHAC Liaison to PACHA and CHAC Co-Chair
Caya Lewis, Counselor to the Secretary, HHS
Howard Koh, M.D., M.P.H., Assistant Secretary for Health, HHS
John O'Brien, J.D., Senior Advisor, Disabled and Elderly Health Program Group, Center for Medicaid and CHIP Services, Centers for Medicare and Medicaid Services (CMS), HHS
RADM Deborah Parham Hopson, Ph.D., R.N., FAAN, U.S. Assistant Surgeon General and Associate Administrator, HIV/AIDS Bureau (HAB), HRSA, HHS
Adelle Simmons, Senior Policy Analyst, Office of the Assistant Secretary for Planning and Evaluation (ASPE), Office of Health Policy, HHS
Ronald Valdiserri, Deputy Assistant Secretary for Health, Infectious Diseases, and Director, OHAIDP, HHS

Day 1

MORNING SESSION

Welcome

PACHA Chair Nancy Mahon welcomed everyone to PACHA's 46th full Council meeting, which also is her second full Council meeting. She said she is lucky to be Chair and wants to thank all her colleagues on PACHA for the amount of work they have accomplished between meetings.

Ms. Mahon said that what is terrific about PACHA, for one thing, is that it brings to the national agenda an incredible competency and very valuable points of view.

This meeting has a packed agenda designed to retrieve very important information and to provide an opportunity to look at PACHA and its role in ending the HIV/AIDS epidemic in the United States.

Ms. Mahon asked "How can we maximize that role?" There will be a Public Comments period later today as well.

¹ Centers for Disease Control and Prevention/Health Resources and Services Administration

Ms. Mahon said she is very interested in how to optimize this session “and make sure we are being responsive.”

Ms. Mahon welcomed the first speaker of the day, Howard Koh, Assistant Secretary for Health at HHS. Dr. Koh is “America’s doctor and PACHA’s doctor.” He is “many people’s doctor.” We “are blessed by the fact that he has treated those living with HIV and also served in public office in Massachusetts prior to coming to the HHS.” Ms. Mahon thanked Dr. Koh for all the work he has done on and for PACHA, for he is a “great listener and leader.”

Ms. Mahon extended a warm welcome to Grant Colfax, the new ONAP Director at the White House. She noted that Dr. Colfax is not new to HIV as a provider and as a leader in HIV work on an international level. Dr. Colfax has had particularly fantastic success in treatment outcomes in San Francisco.

Remarks by Howard Koh, M.D., M.P.H., Assistant Secretary for Health, HHS

Dr. Koh applauded Ms. Mahon’s appointment as PACHA’s new Chair. “What a joy to have her energy, vision, passion, creativity, and dedication. And the fact that she is a fellow Yalie is a big plus.”

Dr. Koh noted that in the past few months, Ms. Mahon has put much energy into PACHA and “all our work.” He continues to thank her for her commitment to PACHA, ending the epidemic, and implementing the National HIV/AIDS Strategy (NHAS or Strategy).

Just this morning, Dr. Koh was reflecting on how much has happened in the United States in less than 2 years. He noted that most of those around the table were in the White House in July 2 years ago when the Strategy was released, and “we have all been sprinting ever since to implement that and harness the energy of as many colleagues around the country as possible to make it real.”

Dr. Koh took a moment to extend particular thanks to Ronald Valdiserri. To great applause, Dr. Koh noted Dr. Valdiserri’s absolute tirelessness. Dr. Valdiserri, he said, is a national and global expert in infectious disease who is 1,000 percent committed to making the Strategy work. It was a year ago that HHS unveiled the first-ever hepatitis strategy, and Dr. Valdiserri has taken that on, as well as blood safety responsibility. He does not have a big staff, “but he has an overwhelming depth of commitment and dedication.” Today, “we will hear more from him and from Andrew Forsyth about the fact that HHS is about to go down to seven common indicators for reporting, which is just short of miraculous. “This project and its advancement show our department trying to work together in a way it never has before.”

Dr. Koh stated that over the course of PACHA’s meeting, members will see much transition in the way of new colleagues and steadfast dedication to the mission. “We all know,” Dr. Koh continued, “of Dr. Colfax’s background, and we are thrilled to have him and Caya Lewis, a new counselor to the Secretary, who also will speak later this morning.” There are four counselors to the Secretary, Dr. Koh explained, and they serve as extremely important colleagues in informing the department’s leadership. Ms. Lewis worked for the late Sen. Ted Kennedy (D-Mass.) in the U.S. Senate and on PACHA even before that. She is “a young person with a great deal of experience.”

This year, the Affordable Care Act (ACA) also passed its second anniversary, and next year, the Ryan White CARE Act comes up for reauthorization. There has been a meeting at HHS to guide and navigate the reauthorization “in this very complex environment.” And, Dr. Koh said, “HHS is going to need your help.”

Dr. Koh also noted that he is thrilled to have John O’Brien here to speak today about Ryan White and Medicaid expansion for people living with HIV/AIDS (PLWHA). “We are always trying to bring the Centers for Medicare and Medicaid to the table. They have so much influence in many ways.” It is good, Dr. Koh added, that Mr. O’Brien has a strong background in public health, mental health, and the law.

In closing, Dr. Koh noted that former PACHA Executive Director Christopher Bates, “whom we all respect so much,” is helping with planning for the international AIDS meeting this summer. He is working at the State Department on this effort and continues to serve as a liaison to HHS. Dr. Koh congratulated Mr. Bates for holding yet another important post. He then formally welcomed B. Kaye Hayes as PACHA’s new Executive Director. He noted her tremendous background in policy and the fact that she is one of the most positive human beings he has ever met. “There is no challenge she can’t overcome. Kaye has already made an impact.”

Dr. Koh also welcomed to the meeting Mayra Alvarez, who is Director of Public Health Policy for HHS’s Office of Health Reform. “There are many high-energy folks at the department committed to health reform and prevention, and Mayra is one of them. She too has much Congressional experience.”

These “true leaders” want to hear from PACHA at this critical time for public health, Dr. Koh concluded. PACHA’s “expertise and energy are something we value tremendously.”

Ms. Mahon asked for a shout-out to Mr. Bates and Ms. Hayes.

Ms. Mahon then introduced Dr. Colfax, who will talk about the view from ONAP and will answer Council questions on the Strategy and the status of implementation and where he “sees us in coming months going forward.”

“Moving Forward: Continuing Implementation of the National HIV/AIDS Strategy,” by Grant Colfax, M.D., Director, ONAP, the White House

Dr. Colfax noted that he too is new, having been in the White House at his current post for 7 weeks. He thanked Dr. Koh for his introductory remarks and noted what a pleasure it has been to work with HHS and Ms. Mahon. “This really is a transformative time, and we have lots of tools to help us move forward.” The legacy of HIV, he continued, is “having community and expert voices helping us figure this out together. We really need to figure this out together, using that legacy and energy. I know all of you on PACHA have other roles and responsibilities in addition to this.”

Dr. Colfax then gave a slide presentation focused primarily on epidemiology, resource allocation, measurement, and operationalizing implementation.

PACHA Priorities for NHAS Implementation Submitted February 28, 2012

Slide 3 lists these priorities as they were presented to the President and as provided to the NHAS Implementation Subcommittee. Dr. Colfax said ONAP “is dedicated to being as responsible and transparent as possible.” In terms of his time and moving forward, he wants PACHA to know that addressing stigma is a priority. After all, he noted, “We have a President who just announced he is personally in favor of gay marriage.” This, he added, “is huge.”

Epidemiology

Over the next few slides, beginning with slide 4, Dr. Colfax emphasized epidemiology. Slide 4 shows how AIDS diagnoses based on 2009 data are distributed differently across the country. A large number are in the Northeast and the South, as well as the West Coast, particularly California. “As we continue to move forward with implementation, it will vary according to disease burden and the geography in which we are working.”

Next (slide 5), Dr. Colfax noted new infections data that came out relatively recently (2011), after the Strategy was published. It shows that the United States continues to have about 50,000 new infections annually, 64 percent of which are among men who have sex with men (MSM), with a large increase among young black MSM. A disproportionate burden also is being carried by women, particularly black women. Latinos are disproportionately affected compared to whites. “This is where the U.S. epidemic is and where it remains and where we need to focus our effort.”

Dr. Colfax noted that young African American youth “are by far the greatest number of newly diagnosed” in the 13–24-year-old age group (Slide 6). By risk group (transmission category), “MSM youth represent the greatest number of newly diagnosed sexual contacts” (slide 7).

Improving Our National Response: Funding Resources and Allocation

Dr. Colfax said questions such as “is funding equitable?” are the kinds of questions that “need to be asked.” Slide 8 shows NIH FY 2010 HIV/AIDS funding for behavioral and social science research by risk group in the amount of \$441,000,000. “This is just an example,” Dr. Colfax said. Breaking down the NIH funding in this category, Dr. Colfax commented that “this funding is only 16 percent recent focused on MSM.”

Showing slide 9, Dr. Colfax said “great progress has been made in aligning resources with the epidemic.” He went on to say that the CDC has shifted resources to living HIV cases. When the CDC Funding Opportunity Announcement (FOA) is fully implemented, HIV prevention resources will closely match the geographic burden of HIV. “This is a huge shift,” Dr. Colfax noted, and it “very much follows the data and is in keeping with equity.”

Dr. Colfax noted that he comes from a jurisdiction (San Francisco) that dramatically lost resources in this shift.” Given all this, “we all will need to figure out how to address the situation on the ground.” There is “lots of change, and it is a challenge.” If “we would say everything is set in a jurisdiction and ask how do we shift that, that would be one thing. But there is more than that going on in a dynamic, changing environment.”

Slide 10 shows the U.S. Department of Housing and Urban Development's (HUD's) Housing Office for People With AIDS' (HOPWA) 2011 formula jurisdictions and awards to 137 grantees in 40 States, Puerto Rico, and 93 Metropolitan Statistical Areas. Dr. Colfax said that the way HOPWA has distributed grants is an ongoing issue. HOPWA "is looking hard at realigning challenges, and I expect this will be moving forward fairly quickly," he added.

Prevention

With slide 11, Dr. Colfax turned to prevention and a fairly long list of tools "that work in preventing HIV." Let us, he said, "be thoughtful about what we know works." Of the tools that work, the most dramatic tools are the clinical trials outcomes, the pre-exposure prophylaxis (PrEP) studies, and the U.S. Food and Drug Administration (FDA) panel recommendation for moving forward with specific drugs for PrEP. In addition, "we just had an FDA vote on testing technology." The tool chest has many tools, but "I go back to getting the basic things right." He said while we know what works, "there is always a caveat—that the best combination of HIV prevention approaches that will have a population-level impact for specific populations is unknown—and all epidemics are local." The "science needs to be followed," Dr. Colfax said, but in terms of other factors like relationships and community, "how do we implement while continuing to align with the core principles of the Strategy?"

Modeling Test and Treat: Annual Number of New HIV Infections

On slide 12, Dr. Colfax showed key elements of what he called a complicated paper (by Sorensen, 2012), but the main point, he said, is if we continue with current practices in a steady-state fashion, that is one thing, but if we engage in "intermediate combinations, we achieve more progress, more quickly," and "we meet four out of five of the main Strategy goals." Dr. Colfax noted the bottom line on the slide's graph. It represents the greatest amount of reduction in annual number of new HIV infections. This line would be the result of engaging in "optimal combinations." However, Dr. Colfax said, "We don't have the capacity to go all the way."

Showing slide 13, Dr. Colfax said there are many ongoing challenges to implementing the Strategy, and "many of us are dealing with them." Obviously, "the cost issues are up front and center for us." The Administration "has been very supportive, with an \$800 million proposed increase in the Presidential budget." Dr. Colfax also gave a shout-out to HHS for bringing the agencies together in a coordinated fashion with respect to metrics, FOAs, and tackling traditional siloed approaches. However, various challenges exist in coordination among Federal, State, and local entities, including "little understanding of issues on the ground, and inadequate funding or staffing at the local level."

The ability of organizations to adapt to a changing environment is important, Dr. Colfax said, adding that as a provider who sees Ryan White clinic patients, he sees one aspect of the changing environment that deals with the intersection of community-based organizations and community health clinics. Having the "political will to place funds where the epidemic is" also is critical, and "the CDC has led that effort." Last but not least in the list of ongoing challenges is capacity. "How do we scale up what works and scale down what does not work? This is particularly challenging. We have to be humble and acknowledge that sometimes it is time to make a change."

We Must Do Better: HIV Treatment Cascade

Showing the HIV treatment cascade on slide 14, Dr. Colfax noted that, according to this cascade, only 28 percent of those with HIV infection in this country are maximally suppressed. “Now we have a metric, a baseline, and the cascade continues to be a priority as we move forward in implementation. We have to do better across the continuum.”

Addressing the Cascade: Federal Coordination

Showing slides 15 and 16, Dr. Colfax said that at ONAP, “we’re looking at the research,” which is in the planning stages. Also, “we need an inventory to see what efforts are aligned and complementary and get to the communities most in need.”

HIV Infection

Showing slide 17, HIV infection by socioeconomic indicators, Dr. Colfax said “Upstream factors are very important. It has been said before but can’t be said enough that HIV follows the fault lines of social-economic inequality in the United States.” All the Y-axis coefficients, from no high school education to homelessness, “are closely associated with infection.” This fact “requires broad thinking, for this is not a health issue alone. We need to keep the big picture in mind.”

AIDS Mortality by Race

This slide (18) is “one of the most concerning slides to me,” Dr. Colfax said. “The point is that AIDS deaths have declined least in the antiretroviral therapy (ART) era among people of color.” It is “a remarkably striking disparity that, in fact, mortality has increased among people of color with HIV/AIDS in the post-HAART [highly active antiretroviral therapy] era despite our treatment effort and efficacy.”

Social, Economic, and Clinical Differences Among KP (Kaiser Permanente) Cohort of PLWHAs

Showing slide 19, Dr. Colfax asked members to take a look at the main bullet points and “these sobering data,” but slide 20 shows “some very hopeful data, also from Kaiser, and thanks to some of you in this room who have assisted in this.”

What really stands out in slide 20, Dr. Colfax said, are data about time to AIDS-related events or death that “suggest that having comprehensive and meaningful health care can address some of the disparities we talk about.”

Structural Change: The ACA

Showing slide 21, Dr. Colfax said the ACA is “one piece of structural change that is already having a meaningful effect.” Highlights include:

- 54 million additional Americans now receiving preventive services
- Hundreds of PLWHA now covered under preexisting condition insurance plans
- Insurers not able to rescind coverage except in cases of fraud or intentional misrepresentation
- In 2014, no denial of coverage for preexisting conditions and expansion of Medicaid eligibility to 133 percent of the Federal poverty level (FPL).

Moving from the big, national-policy-level picture, Dr. Colfax said some local implementation efforts need to be examined for how they can be sustained and adapted. Slide 22 depicts a Washington, D.C., example, the purpose of which is to reengage PLWHA in care who have been “lost to care.” Methods include primary medical care providers sending a list of clients not seen in their clinics for more than 6 months to the local public health department. These lists are then matched to HIV databases. This, Dr. Colfax said, “is potentially one of those scale-up models,” in part because “it uses resources we already have.”

Implementation Takes Time: the San Francisco HIV Prevention Shift

Showing slide 23, Dr. Colfax briefly outlined the time it has taken San Francisco to shift to different interventions and different agencies as it prepares for a reduction in its CDC contract. The point is, “it takes time.”

At the Ground Level

Implementation at the ground level requires asking and trying to answer a number of questions (slide 24), including:

- Are resources being allocated to the populations at greatest risk?
- Are these populations being reached? (“This second bullet is something we need to discuss more.”)
- Are the interventions evidence-based, scalable, sustainable, and effective?
- Do we have and use metrics to measure program success? (“Thanks to Dr. Valdiserri for his leadership in bringing this to the table.”)
- How long do we take to declare success or failure of a program?

NHAS Implementation Dialogues

Showing slides 25 and 26, Dr. Colfax noted that ONAP has conducted a number of implementation dialogues, the results of which will be published in a report summary. He provided select quotes from participants in these dialogues, emphasizing the need not only to expand the primary care workforce but to think about other providers who work with PLWHA and “how to shift skill sets to modernize our efforts.” Also, “how do we keep patients engaged?” In addition, there is “the need to talk about what jurisdictions can do to scale with limited resources.”

Ongoing Implementation Needs

On slide 27, Dr. Colfax emphasized technical assistance (TA) as “an incredibly important part of ownership of the Strategy and its goals, because it is clear none of us can do this alone.” That is, “the Federal Government is necessary but not sufficient.” We also “need to support the shift from process- to outcome-oriented metrics.”

Measuring HIV-Related Outcomes

This past March, the Institute of Medicine (IOM) issued an ONAP-supported report regarding measuring HIV-related outcomes. Some of the principles in the report are: parsimony of metrics; harmony of

metrics (“which is a challenge at every level”); sustainability of metrics; and usability of metrics (“how to make sure the data collected are used to inform our efforts”).

Private/Public Efforts

On slide 29, Dr. Colfax noted a number of private efforts, including the We Are Greater Than AIDS campaign. Many foundations “are working with us, including MAC [the MAC AIDS fund], to bring forth a campaign that is meaningful and aligned with the Strategy in increasing awareness and also flexibility in terms of local health departments.” An outstanding question “is how we continue to support these private/public efforts.”

Estimated Rate of New HIV Infections by Race and Gender, 2009

Dr. Colfax noted the estimated rate of new HIV infections by race and gender on an easily understood graph on slide 30, adding that the differences depicted “are real.”

Presidential Memorandum Establishing a New Working Group

Dr. Colfax noted that last March, the President issued a memorandum establishing an inter-agency working group on the intersection of HIV/AIDS, violence against women and girls, and gender-related health disparities. ONAP is now supporting specific efforts based on this memorandum, including pulling the working group together, which will have representatives from the Departments of Justice, Interior, HHS, Education, Homeland Security, Veterans Affairs, HUD, and the Office of Management and Budget (OMB). “We will move forward with this Federal effort to look particularly hard at women of color and the domestic epidemic.” In addition, Dr. Colfax noted that the working group will seek input from key stakeholders, including PACHA members (slide 31).

Upcoming White House Consultations: June 2012

There will be two separate White House consultations in the near future (slide 32), the draft goals of which are:

- To determine if Federal and other investments in the epidemic are aligned with epidemiologic data
- To meaningfully engage implementers to use evidence-based, community-supported, culturally competent, and effective interventions
- To determine the needs and capacities of organizations serving blacks and Latinos to adapt to the changing HIV prevention and care environment
- To discuss building and sustaining black and Latino leadership in addressing national and local HIV epidemics.

Dr. Colfax invited PACHA to stay tuned for more information about this.

AIDS 2012

Last, Dr. Colfax noted the fact of the upcoming International AIDS Conference (IAC) in Washington, D.C., in July of this year. Dr. Colfax said the meeting will be held in the United States “largely thanks to the Administration’s lift of the entry ban.” He promised that important information will be forthcoming

at the conference, which is the target date for release of both the ONAP implementation update and the HHS Implementation Progress Report.

Dr. Colfax acknowledged PACHA and his HHS and ONAP colleagues, including James Albino, who is present today, adding that he is here and “here to listen.”

Discussion/Comments/Questions and Answers

Robert Greenwald congratulated Dr. Colfax for an “incredible” presentation, as you have highlighted most of the really important factors we need to look at in meeting the Strategy.” In particular, Dr. Colfax “encouraged us to look at new incidence by geography, significantly at evidence around the South.” Mr. Greenwald added that Dr. Colfax also noted the cascade, calling for a look “at where we are on the cascade by gender and geography.”

Dr. Colfax thanked Mr. Greenwald, adding that “looking at the data is always important.”

Kathie Hiers said one thing she noticed in Dr. Colfax’s good presentation is that under prevention, there is no mention of comprehensive sex education or peer support and services. Therefore, she would like feedback on how important those things are to keeping people in care. In addition, on the testing slide, she would like to know what “intermediate combination” means, as in intermediate combination “of what?”

Dr. Colfax responded that “a comprehensive approach to health and wellness, including sexual health, is incredibly important, and it is on the trajectory.” With regard to intermediate combination, he is referring to different percentages of diagnosed versus undiagnosed, and said that he would be happy to discuss this further offline.

Naina Khanna thanked Dr. Colfax for a very comprehensive presentation that “hits a lot on where we are in the epidemic.” Given that Dr. Colfax just told PACHA about ONAP’s implementation update and that a working group has been convened, “how do you see that process fitting in?” Also, Ms. Khanna asked where the working group is in terms of being convened, as a deadline for that is coming up.

Dr. Colfax responded that ONAP has asked agencies to identify those in the working group, and he hopes to have the first meeting sometime before June 1 and to start addressing the issues. Many Federal leads on this are very excited about moving forward and having a meaningful dialogue, Dr. Colfax said, adding that “metrics must look at HIV-related outcomes among women.”

ACTION ITEM

Michael Horberg asked if PACHA can get the Sorenson article Dr. Colfax referenced. Ms. Mahon asked if PACHA has it. If not, “we’ll track it down.” She also asked Dr. Colfax to release his slides, as PACHA members do not have copies. Ms. Mahon noted that PACHA has requested a breakdown of the cascade from the CDC.

Dr. Valdiserri said he sent Ms. Mahon an e-mail, which he can resend, on how the CDC is working on this breakdown. “They do not have the information yet. When they do, they will publish the breakdown in

peer-reviewed literature and share it with PACHA shortly before publication.” Dr. Valdiserri added that “we could ask for a specific timeline on this.” Ms. Mahon asked, “Can we?,” and Dr. Valdiserri reconfirmed that PACHA can ask for a specific timeline.

Remarks on HHS Planning and Implementation of the Affordable Care Act, by Caya Lewis, Counselor to the Secretary, HHS; and Mayra Alvarez, M.H.A., Director, Public Health Policy, Office of Health Reform, HHS

Speaking without slides or notes, Ms. Lewis noted that she has spent most of her career working on public health. She said it is very important for the Administration to hear from PACHA at this very important time. She noted that Mayra Alvarez “is the latest expert on planning and implementation of the ACA.”

Ms. Lewis said the Secretary has been very focused on “making sure we turn our sights to the domestic epidemic. On World AIDS Day, the President made a \$35 million commitment to the AIDS Drug Assistance Program (ADAP) due to several concerns about ADAP’s health, including around waiting lists.” Meanwhile, Dr. Valdiserri and other colleagues are meeting regularly trying to address a number of challenges, including how to reach the most affected populations.

The Secretary “wants us to think about what we can do now with the partners we have, knowing the fiscal scene is difficult at all levels of Government. “ At CMS, HRSA, and the CDC “we have been strategic on how we can work together, with the ACA.” We “know there is a lot of opposition to ACA, and we also know there are many concerns around Ryan White and what changes there might be and what it will look like in 2014.”

At CMS, “we began to think about all that immediately, from the day the ACA bill passed.” Ms. Lewis added “we want to continue to work with you on that.” She noted that PACHA will hear more today from Adelle Simmons, Senior Policy Analyst, ASPE, Office of Health Policy, HHS, and Deborah Parham Hopson, U.S. Assistant Surgeon General and Associate Administrator, HAB, HRSA, on research that is underway “to ensure that the transition can work well.” Ms. Lewis added that members should feel free to contact her.

In terms of the IAC, Ms. Lewis has been working closely with the White House and representatives to the international community. A very good slate of U.S. representatives, including Secretary Sebelius and Secretary of State Clinton, will speak. Also, “some of our agencies have cutting-edge research on prevention and so on to present.” Leading up to the conference, the Secretary has convened groups of funders and pharmaceutical companies “to think together how we can move forward on the domestic agenda through private/public partnerships,” and “we hope to have an announcement around that that we can work with you on.”

Also speaking without slides or notes, Ms. Alvarez said that in the implementation of the ACA, “much of our focus has shifted to doing more around public health education around ACA, to make sure that those who need these policies know about them.” Goals include doing away with the worst abuses, using benefits more wisely, and improving access to care.

Ms. Alvarez said that HHS is busy eliminating insurance/benefit exclusions, including for HIV/AIDS. “We are also doing away with lifetime limits. And the bridge plan is making a difference.”

HHS also is emphasizing “wiser spending.” Through the new 80/20 rule, which is one aspect of the act itself, “as most of you know, we’re requiring insurance companies to use your dollars on actual services, and the Kaiser Family Foundation has estimated that \$1.3 billion will go back to you because of that.” In terms of rate review, in States across the country, insurance companies must publicly justify why they have increased a premium 20 percent or more. Premiums are still going up, but at a slower rate, and some rate increases are slowing down. In some States, like Nevada, policyholders are even seeing a rate decrease.

In terms of Medicare, “many on Medicare are living with HIV/AIDS sustainably.” HHS is “doing way with the cost-sharing provision and reducing drug expense.” In 2011, several million people saved \$3 billion in cost sharing because they escaped the Medicare donut hole.

Last, in terms of access to care, 54 million people across the country “no longer have to worry about cost sharing on preventive screening.” The opportunity to put health care first “is a real change that ACA is making happen.” In 2012, women will be provided with specific services “across their lifetimes.” This is not just for women defined as high risk but for healthy women, too, with wellness visits provided for annually. Another key service is “a free domestic violence screen.” We are “trying to shift the conversation on prevention and what we need to live a healthy life.”

HHS is investing in community health centers (CHCs) across the country in underserved communities and improving services in existing health centers. HRSA has issued a FOA that links Part C providers with CHCs “so we can figure out how we can work together.” A key question is what expertise Ryan White providers have “that we can integrate into the health centers,” and “how can Ryan White providers share their expertise with the centers?”

Ms. Alvarez said it is “a challenge and an opportunity to figure out how to do better in terms of HIV/AIDS care.”

Ms. Alvarez also mentioned the CMS Innovation Center, which issued its first round of innovation awards last week and is preparing for a second round. These awards are to model programs “that are making a difference so that we can replicate those successes.” Ms. Alvarez is “hoping that the second round will contain opportunity for PLWHA—if not that round, a future round.”

Discussion/Comments/Questions and Answers

Mr. Greenwald said one HHS interpretation he and PACHA’s Access to Care Subcommittee are concerned about is the notion that the ACA makes it impossible for States to regulate utility management, which will have “a huge impact on our ability to have controls over prior authorization and other restrictions for access to essential medications.” In short, “this seems like a strict interpretation.”

Ms. Alvarez replied that she can ask others about that; she knows some sections of the law better than others.

Mr. Greenwald said in turn “it still means we have to do the work State by State.”

Ms. Alvarez then responded that, in general with the exchanges, whether they are State-based or Federal, the opportunity is to create a health insurance marketplace where those plans will compete. “We should explore opportunities for health plans to sell products that better cater to the needs of populations buying the insurance.”

We Need Federal Leadership

Mr. Greenwald said “you could create a separate benchmark plan with HIV/AIDS, but that is not realistic. We need the Federal government to take leadership in defining a floor. In many States, it will be a race to the bottom and will continue disparities.”

Mr. Pérez invited Ms. Alvarez to think about the successes of Ryan White at the local level in general and its success in suppression in particular. As “we migrate out of Ryan White and to different plans under ACA, in Los Angeles, we have been motivated to create some incentives and some sticks to drive performance.” So, “what opportunities do you see to drive performance with health plans supported by ACA so that we don’t see viral suppression drop among poor folks?”

Ms. Alvarez replied that in the future, HHS will be adding information on the ratings of health plans so that consumers can purchase health plans with different ratings. Healthcare.gov provides information on how often a health plan is rescinding coverage, so information on that type of transgression lets consumers know what that plan’s priorities are.

HHS Needs Help With Quality Factors Specific to PLWHA

Ms. Lewis responded that the concepts of health reform and a focus on health care quality reform within HHS are built into the law. The department is dedicated to quality, so we need to get with you on quality factors specific for PLWHA as we are building quality measures and standards for the insurance market.”

Ms. Alvarez added that HHS just launched a new health standards tool yesterday on “how these measures are changing and how we’re doing on that score.” Ms. Lewis added that “we also need to know if we are measuring things in the correct way.”

Cornelius Baker said he applauds the Administration on the ACA and on integrating its implementation with Ryan White. He has a few thoughts and questions. First, in terms of health care quality and the Agency for Healthcare Research and Quality (AHRQ), “what is on healthcare.gov is very complex.” When he looks at the epidemic in the United States, it is increasingly dominated by black men, but very few of the dot-gov presentations are about that epidemic. Among these men, there are high levels of unemployment, incarceration, and isolation from the health care system. So “how are we going to bring them in? What is the departmental thinking on how to end that?” Second, “how do the social services system and community-based system get integrated into a health system that has not often cared for

them very well?” We “have success on the front end, testing, but where we have an enormous dropoff is in the clinical system, where we don’t retain, even when there is equal access.”

Mr. Baker continued. “The messages coming out are not very clear. It doesn’t tell these men their place within the change. And the CMS analysis of innovative systems: Is that really going to look at what community-based structure is necessary, so we know what kind of services we need to get retention with populations with a poor history with the system?”

Ms. Alvarez responded that this is complex, “but rightfully so.” It is clear, from the Secretary on down, “just how big a challenge we’re facing in 2014. There are millions of children eligible for CHIP [Children’s Health Insurance Program], for example, but not enrolled. Now we can reach 30 million more, and it would be a missed opportunity if we don’t meet those challenges.” In terms of innovation changes, “half of the 26 awards are for integrating community health workers into the traditional system,” because “the traditional health model does not give evidence to that efficacy.” With respect to the 30 million who need to be reached, “It is that type of outreach we need, for walking into a fancy building will not work for some of these people.”

HHS also is looking at social networks. Ms. Alvarez said “black people across the country are more likely to have a Twitter account than cable TV. ‘Text for Baby’ is a text program. Even low-income women have 30-day text phone plans, and they auto-sign up for Text for Baby right away. We need to think to learn from your expertise.”

Ms. Lewis said she heard from Mr. Baker a general sense, still, of the need to focus on the most vulnerable communities “and the disparities we know exist.” To that end, the Secretary has a racial and ethnic health disparities action plan and also has the Strategy as an action plan. At CMS, “we spend a lot of time monitoring that.” There is “much appreciation at the department on the disparities we still have. And while that is not specific to HIV/AIDS, we know them. Along with the National Strategy, we have things very aligned at the department to continue to figure out how to reach the most vulnerable and how to close the gap on health disparities overall.”

Ms. Lewis added that “black men are where the numbers are. And we are focusing on the numbers.”

Ryan White CARE Act Reauthorization Update

Ms. Mahon noted that the Secretary has asked PACHA to form a Subcommittee related to the intersection of Ryan White and the ACA. She said PACHA needs to look at the successes in Ryan White and how to retain them and to better understand the ACA.

“Ryan White HIV/AIDS Program Reauthorization and the Affordable Care Act,” by RADM Deborah Parham Hopson, Ph.D., R.N., FAAN, U.S. Assistant Surgeon General and Associate Administrator, HAB, HRSA, HHS

The first thing Dr. Parham Hopson said was that the “Ryan White program is still alive and well.” She then provided a brief legislative history of this public health service law, noting that its current authorization expires September 30, 2013, but the program does not sunset; that is, the program can continue without authorization, as long as it receives appropriations.

Slide 3 indicates ACA provisions with immediate impact on Ryan White. These are:

- The pre-existing conditions insurance plans: as of December 31, 2011, just under half of the States were using AIDS Drug Assistance Program (ADAP) funds to enroll individuals in these new insurance plans—2,393 clients total.
- ADAP counting toward true-out-of-pocket expenses for Medicare: as of January of last year, ADAP costs can now cover eligible patients in the Medicare Part D “donut hole,” and then Part D assumes costs. States are calculating cost savings at this time. Dr. Parham Hopson said HRSA has seen “some movement into the hole and then out.”

ACA Provisions With Long-Term Impact on Ryan White

ACA provisions with long-term impact on Ryan White are:

- Medicaid expansion to 133 percent of the FPL
- Subsidies via health insurance exchanges for 133 percent to 400 percent of the FPL
- Private market reforms that require a ban on health insurance rescissions and elimination of lifetime and annual caps.

Understanding the Impact of ACA Implementation

HRSA is working closely with CMS and Ms. Alvarez’s office to examine the rollout of State plans, and HRSA supported CMS release of the State Medicaid Director Waiver Tool Kit, including training and TA. HRSA made sure the kit was applicable to Ryan White programs.

Two studies funded in FY 2011 are assessing gaps anticipated in care once the ACA is fully implemented. One of these studies will be completed in August of this year, and Dr. Parham Hopson will address it then. Adelle Simmons will discuss these studies further later this morning.

HRSA is examining State insurance plans to understand their impact on Ryan White.

The Future of Ryan White

- The implementation of the ACA does not eliminate the need for the Ryan White program.
- Gaps in coverage will remain, both in terms of Medicaid and private insurance. This will be the case for coverage of oral health and substance abuse treatment services and support services that link clients to care.
- There will be a need to continue training and retraining of providers through AIDS Education and Training Centers (AETCs). HRSA has 11 regional AETCs.

Positioning Ryan White Grantees for Anticipated Changes in the Health Care Environment

- The ACA addresses medical homes. Some Ryan White programs meet that definition; some do not.
- Maintaining/enhancing Ryan White delivery systems is a goal.
- The National Cooperative Agreement funded in 2011 is meant to address capacity building.
- CHCs are expanding in number. Ryan White grantees are already partnering with existing health centers or becoming health centers. Some, Dr. Parham Hopson said, decided “to say no thank

you.” She added that there are real concerns on both sides. However, six HIV-based organizations did receive Bureau of Primary Health Care (BPHC) planning grants in 2011.

Improving HIV Care Capacity in Primary Care

- Released last year were AETC cooperative agreements for building capacity in minority communities.
- Also released last year were BPHC policy assistance letters in testing and care and treatment.
- There also is a BPHC national cooperative agreement to increase lesbian, gay, bisexual, and transgender (LGBT) cultural competence in CHCs.
- BPHC is partnering with the Substance Abuse and Mental Health Services Administration (SAMHSA) to increase behavioral health capacity within CHCs.
- BPHC is involved in building the primary care workforce.

Reauthorization of Ryan White

- The Administration is working toward reauthorization of the Ryan White program.
- HHS and HRSA leadership are working to determine needed changes in the program that may be driven by the ACA.
- HAB is spearheading a plan to solicit stakeholder feedback on reauthorization.
- The current authorization ends in 2013. There is much discussion about when reauthorization should occur, 2013 or 2014. “The decision will be made above my pay grade.”

HAB Ryan White Reauthorization Outreach Efforts

- A series of meetings are being held with representatives from major national HIV/AIDS advocacy groups to discuss the future of the program and challenges going forward. The next meeting is May 31, 2012.
- HAB also will request stakeholder feedback from the HIV/AIDS community, including grantees, on changes and ways to improve the program going forward.
- “We are taking a page out of Jeff Crowley’s book that he used for the Strategy.”

How Stakeholders Can Weigh In

- Now open to anyone is a site for comments on Ryan White. Go to <http://hab.hrsa.gov/reauthorization/> to submit comments on Parts A–F of the program.
- Stakeholders can participate in regional virtual listening sessions (Webinar conference calls) to ask questions and offer feedback about the program. Check <http://hab.hrsa.gov/reauthorization/>.
- At the end of July, HAB will collate the information received and be ready to go forward with reauthorization. “So far, we are moving forward as if reauthorization will take place in 2013.”

Moving Ahead

HRSA will be:

- Working to build partnerships across Federal and national partners
- Prioritizing services
- Utilizing other resources in the community
- Improving quality
- Distributing limited resources equitably
- Documenting results and disseminating best practices.

“HAB is willing to do this by geography and different populations.”

Discussion/Comments/Questions and Answers

Ms. Mahon said she wants to link the PACHA Web site to the URLs provided by Dr. Parham Hopson. She encouraged members of the Council to get the word out and Melvin Jopy to send out helpful hints about this.

Humberto Cruz said that, for the most part, the New York State Department of Health has been a good partner in Ryan White and through some challenging times. Through those challenging times, he said, addressing Dr. Parham Hopson, “you were skillful in addressing critical issues.” Now he asks, should “we reauthorize now or wait until the future?”

Mr. Cruz noted that Dr. Parham Hopson indicated HAB will be ready for this in 2013. He noted that he himself has been very vocal about waiting a little bit “until we know more fully what will happen with health reform.” The issue is “a concern related to the dramatic and systematic change that is occurring across the delivery system. We are seeing how health care reform is doing this. And yet it is an election year.” We “need to consider how providers across the board are being affected by all the changes that are happening at the same time. We need to consider the capacity of the system to respond.”

Mr. Cruz continued. “I have concern...because if you undermine the system’s structure, the end result may be that entities that have reached great levels of success will not be able to continue.”

Mr. Cruz finished by noting that he and Dr. Parham Hopson will be meeting next Tuesday to talk about the “monetary standard.” The “issue is how all the different delivery systems have to report, and these activities are increasing.”

Dr. Parham Hopson said she is not sure she heard a question. Ms. Mahon said “that was a statement.”

Douglas Brooks asked if HAB and the BPHC convened CHC leadership and Ryan White providers to discuss barriers, facilities, and opportunities to integrate Ryan White into the health centers where appropriate “because the money is going into the centers, which, I think, is a good thing in many ways.” Mr. Brooks said he is making a suggestion.

Dr. Parham Hopson responded “we have done that for many years.” The National Advisory Council on the National Health Service Corps has a Subcommittee on HIV, and “we go to that meeting every year. Many programs have been Ryan White providers for a long time, and they try to do peer-to-peer dialogue.” In terms of primary care and HAB, “we say that provision of HIV care is not just the responsibility of HAB and Ryan White but all HRSA programs, no matter where you enter.” We “are talking a broader view that everyone should contribute.”

Dr. Parham Hopson then asked Mr. Brooks if he is suggesting that “we do something different.”

Mr. Brooks replied, “Maybe use some sticks, because what is different this time is the dollars and the amount of money being put into the centers. They don’t have an option. The mandate should be, HIV care is care, and you don’t have an option to become proficient, you must become proficient, and is there a way for this body to support you? If there is a way, I think it would.”

Mr. Greenwald suggested that activists look at a program in Texas and replicate that model. He said he knows that HRSA funds it.

Mr. Greenwald also noted that his center at Harvard has produced two germane reports. One estimates the impact of the transition by State for all States, and the second details findings and estimates relative to health reform in the State of Massachusetts and the ongoing role of Ryan White there. In the Massachusetts report, an estimate of savings is given relative to reduced incidence in the State and the way health reform and Ryan White programs there are working together.

ACTION ITEM

Mr. Greenwald will provide the two reports and information on the Texas grant to Dr. Parham Hopson.

Responding to a question from Ms. Khanna, Dr. Parham Hopson said that some public health departments are Ryan White providers. HRSA just completed a study on primary care and linking that to public health. The study was exploring the challenges public health departments and the public health system face, and what opportunities exist to support public health departments so that they can be providers of primary care “for all our populations.”

Dr. Parham Hopson said she will be happy to take further comments by e-mail and/or PACHA member ideas on how public health departments can be strengthened to provide services to PLWHA.

Ms. Khanna said she was referring to more guidance on transition planning, but she will send Dr. Parham Hopson a follow-up e-mail.

“Medicaid and CHIP in 2014: A Seamless Path to Affordable Coverage,” by John O’Brien, Senior Advisor, Disabled and Elderly Health Program Group, Center for Medicaid and CHIP Services, CMS, HHS

Mr. O’Brien said he would make his presentation short to encourage discussion.

Mr. O’Brien began by noting that two-thirds of the nonelderly uninsured are low income, with a total of 49.1 million uninsured (slide 2).

CMS is trying to come up with a seamless system of eligibility and enrollment, including submission of a single application to an insurance exchange or Medicaid/CHIP, a streamlined way of getting eligibility determined and verified, and tools to assist enrollment in affordable coverage (slide 3). A proposed final rule related to seamless and affordable coverage expands access to affordable coverage, simplifies Medicaid and CHIP, and ensures a seamless system of coverage (slide 4).

“What we are trying to come up with,” Mr. O’ Brien said “is a seamless system, but regulations can only go so far, so we are also trying to come up with additional guidance to the States.” What is critical is enrollment.” With “the funding we’re giving to the States, enrollment will be easier than it was in Massachusetts initially.”

More on Expanding Medicaid Access to Coverage With Significant Federal Support

Federal support eliminates gaps in eligibility by expanding to 133 percent FPL for individuals under age 65; enables States to consolidate a large number of eligibility categories in four main groups— children, pregnant women, parents, and disabled adults; allows enrollment in the new income-based category without having to first screen for other eligibility groups (the rule is “enroll first”); and enables those with disabilities and those needing long-term care services and support to enroll in the group that best meets their needs (slides 5 and 6).

Simplifying Medicaid and CHIP

Along these lines, CMS is moving to a modified adjusted gross income (MAGI), which confers the following benefits:

- Replaces complex rules in place today (TA will be available to States for converting current standards to MAGI.)
- Modernizes eligibility verification rules to rely primarily on electronic data
- Ensures that the Federal Government will perform some of the data matches for States, relieving State administrative burden
- Will not require a return form if eligibility can be renewed based on available data.

Slides 9, 10, 11, and 12 provide more details on eligibility, including for individuals needing long-term care services and supports, enrollment, and how coverage plays out for various levels of FPL.

Slide 13 outlines key elements of CMS’s interim final rule, with comments on eligibility and coverage. Slide 14 notes facilitations for enrollment in insurance affordability programs under the interim final rule, with comment. For example, an insurance exchange, which may be State, Federal, or nongovernmental, can make Medicaid/CHIP MAGI eligibility determinations using State Medicaid/CHIP rules/standards, or an exchange can make an initial assessment of eligibility, with State Medicaid and CHIP agencies making the final eligibility determination.

Next Steps

- The interim final rule was published in the *Federal Register* on March 23, 2012.
- The 45-day comment period closed on May 8, 2012.

- The comment period allowed for comments on safeguarding information, timeliness standards, and coordination.
- CMS is now working on operational guidance, streamlined application, and data and performance standards in collaboration with States and other stakeholders.
- CMS is working with other Federal agencies to ensure coordination across programs (such as the Supplemental Nutrition Assistance Program).
- State Operations and Technical Assistance (SOTA) teams are being put into place to provide TA to the States.
- SOTA also will work on benchmarks and other issues.

Mr. O'Brien concluded that important strategies are needed to reach those who have not been interested or eligible. He urged PACHA members to review the two URLs provided on his last slide (slide 18), which link to more information on the final rule and information provided through Webinars.

Discussion/Comments/Questions and Answers

Ms. Mahon asked about PACHA's role and the role of exchanges run by nongovernmental entities.

Mr. O'Brien said there is a role in making sure that PACHA members are trying to influence what the exchanges are doing. This can be done by members getting themselves elected to exchange advisory groups. Bringing issues to these groups will be critically important, as exchanges could get so focused on the "plumbing" that they lose sight of the 133 percent FPL and below. "Some States are thinking of this as a homogenous crowd, yet there are different ways they will need to get them enrolled and construct their benefit plans."

Mr. Baker noted the process of selecting one's insurer and being assisted in decisionmaking by various Web sites, then asked how CMS is working with AHRQ on the standardization of reports available for decisionmaking and also the indicators used. His understanding is that CMS's only standard so far is testing.

Mr. Baker then stated "we now have the Gardner Cascade as a framework, so what is CMS considering as corrective action to improve that quality of care?" He added that there are still ADAP providers "who are providing lower-quality medications."

Mr. O'Brien said "the first part of Mr. Baker's questions may entail a longer offline conversation about the second part." However, first, as Ms. Alvarez said, "a number of individuals who have never been insured will now get insurance, so how to help them think about the plan they choose is important. A few of the important items are that individuals should make sure they choose plans that actually cover their needs, and that individuals are part of a plan or network that actually covers their needs. Navigator programs help people ask the right questions, and this includes specific populations in the expanded groups."

Mr. O'Brien said he is uncertain about the depth of information "we'll be able to get on individual providers, but right now, we are primarily focused on plan and network information and quality information." He proposed talking offline about the rest.

Essential Benefits/Enforcing Nondiscrimination

Mr. Greenwald said CMS has a monumental task and agreed that enrollment is critical. He asked about essential benefits and State flexibility. “Are we making any progress articulating the ACA mandates, including nondiscrimination, to ensure needs are met?”

Mr. O’Brien said he is concerned about that, “but one of the things we need to know—and you are helping us—is what we need to tell the States about how they are looking at this coverage and what we expect.” But there are other issues, such as drugs, “that we need to put on their radar screens so that they know this is part of their plans, too, as needs for specialized populations.” Mr. O’Brien said he hopes they create specialized plans, which they could do.

Mr. Greenwald asked about putting in the records three or four things that need to be in those specialized plans.

Mr. O’Brien said he does not know the answer to this, but he is seeing good lines of communication between some advocates and CMS. However, “I’m concerned about relations with some of the State policymakers. We need reinforcement from the advocacy areas.”

Need More of a Federal Mandate

Mr. Greenwald responded that “Federal guidance will really inform advocacy and State plans. We need more of a Federal mandate.”

Dr. Horberg said he wants to follow up on Mr. Baker’s and Mr. Greenwald’s questions regarding quality care and quality metrics. “We know if there is not good quality care, because lack of it is a key problem in retention.” Therefore, workforce is a key to Medicaid, and yet Medicaid reimbursement rates are significantly lower than for Medicare and private insurance, “so how does that play into your thinking?”

The “Sufficiency” Concept

Mr. O’Brien said thing one thing CMS is paying a lot of attention to is trying to find “sufficiency,” not just number of providers and whether they are offering services consistent with good care. “So we are hoping to continue guidance to the States to help them understand our expectations around sufficiency. We will probably get some pushback, but it is the right kind of conversation to have with them at this time.”

Rev. Sharp asked if clients are being asked what is sufficient. Mr. O’Brien said “we are open to the right questions we need to ask. There are some things we can look at in terms of access but not experience of care, so we’re in the process of exploring the right questions around experience of care. On the enrollment side, we are open to good ideas on that.”

Rev. Sharp said “you need to walk in someone else’s shoes.” She suggested “modifying the 13-page process—cut it, in short—and focus on the most pertinent questions, then gradually increase the questions as the person is in the program so that all the t’s are crossed and i’s dotted.”

Mr. O'Brien said that is important. "That much we've learned from Massachusetts. But it won't be perfect when it happens."

A lunch break was scheduled here, but Ms. Mahon asked that Adelle Simmons give her presentation before lunch.

Ryan White Care Act Reauthorization Update Continued

"Ryan White Modeling Study Overview," by Adelle Simmons, Senior Policy Analyst, ASPE, Office of Health Policy, HHS

Ms. Simmons, who previously served in ONAP, explained that ASPE is conducting a study on Ryan White and the ACA transition to support HRSA as required by the Senate's FY 2011 Appropriations bill report (slide 3). ASPE also is conducting the study to help inform future policy development concerning the Ryan White program. "We know," Ms. Simmons said, "that there will continue to be a need for Ryan White."

Purpose of Study

The major goals of the ASPE study are:

- To examine current use of Ryan White program services
- To estimate shifts in demand for Ryan White program services across jurisdictions after the ACA coverage expansions are implemented.

In short, as Ms. Simmons explained, "we are trying to project what the transition will look like."

Coordination

The study is co-funded by ASPE and ONAP and was designed with input from ONAP, HAB, and OHAIDP. ASPE's study complements HRSA's study on potential gaps and the potential impact of the ACA on Ryan White.

Data

Data will come from:

- The Ryan White HIV/AIDS program and HRSA grantee expenditure reports
- Medicaid enrollment and claims, because Medicaid is such a large provider of HIV services
- HIV surveillance on future needs
- Micro simulation estimates of future Medicaid and State exchange transitions
- Qualitative data based on grantee interviews (210 Ryan White providers and program administrators).

Ms. Simmons commented that it is very important to have local input about client populations and input from those "on the ground."

Data Limitations

Some estimates are available only at the national level, but it will be useful to get the State-to-State report coming from Mr. Greenwald. ASPE will certainly look at that. In addition, there is the data limitation that assumptions must be made for a range of unknowns, such as State policies on essential health benefits and on Medicaid expansion coverage benefits.

Other Study Components, Including Preliminary Findings

The study will include an analysis of HIV provider payment models, a technical expert meeting to solicit input from subject matter experts, and preliminary findings in spring 2013. Preliminary findings will be discussed in a public meeting

Discussion/Comments/Questions and Answers

Mr. Cruz said “areas of most need” is a departure from the way Ryan White funds are allocated today, because today, “they are allocated to the whole Nation, and almost everyone gets funding.” It seems Ryan White is following the CDC prioritization, and “this creates a concern.” Many States and localities have had successes in combating the epidemic. “We built an infrastructure that enabled those successes, but some may lose that.” He is thinking about the switch of emphasis to New York City from the State, by which the State lost 80 percent of its previous funding.

Ms. Simmons asked if she could respond.

Mr. Cruz said his brain “loses track, so now the use for your study.” He “likes the sources, but the study is lacking in some critical parts, including the shift in demand for Ryan White when other services are available.” Also, “you don’t have the unmentionables, the underinsured, and also the full structure that is necessary for people to get services, such as mental health services.” Mr. Cruz is fearful that in a study “done with good intentions, when one captures only one subset of those who influence demand, the end result could be a negative impact on States in terms of receiving resources.”

Ms. Mahon noted that all agree a study is needed, “but there is a great deal of anxiety in the field, so we want to ensure that data is included so that the study is as fully informed as possible.” She continued, “how could PACHA inform the data collection process to ensure that everyone is included?”

The unmentionables, Ms. Simmons said, “Are being taken care of in the micro simulations.” If “there are specific data sources you could add, we would welcome that.” Ms. Simmons said that her team “is still in the process of assessing the data it has and “how we will work with that.” We “need to use the best data we have at this time. It is an ambitious job to project the future.”

PACHA Members Are Offering To Help

Dr. Horberg noted that PACHA members are offering to help Ms. Simmons. “We are talking specifically how this will impact Ryan White through the health exchanges.” Valuable information could come from the network that represents 19 integrated care systems in the United States, from the HIV Medicine Association, and from the Ryan White Coalition. All of these “would partner with you, as well as Kaiser Permanente, which would also be happy to help you.”

Ms. Simmons responded that a *Federal Register* notice announced the planned grantee interviews, and from that, ASPE did get good feedback and comments, so now her team is refining data collection instruction based on that. “We hope to use that as a way to get into special population and special needs, for example.”

Ms. Hiers said that, historically, Ryan White has given more funding to urban areas. She suggested that ASPE look at mortality and incidence rates as well. Also, as regards the slide addressing other components of the study, Ms. Hiers said “I’m sure provider payment is like copayment, but are you looking at the Ryan White supportive services that aren’t being provided at community health centers?” Ms. Hiers observed that “in overhauling the entire medical system as we know it, we’ll have cracks and will need Navigator.”

Ms. Simmons responded that in terms of the HIV provider models, “we are looking at HIV medical providers, as well as Ryan White support services, in terms of hidden costs and ends associated with Ryan White programs; what the current use of those services is; and what one would expect to be covered through those services and not elsewhere.”

Study Timeline: Hoping Study Will Inform Decisionmaking on Reauthorization

Ms. Mahon asked about timeline for the study, to which Ms. Simmons replied that her team is waiting for HRSA data, including duplication. “That is a work in progress.” Once she gets OMB clearance on the grantee interviews, it is expected that those interviews could be fielded in the fall. Then “the hope is to have the quantitative and qualitative analysis as preliminary findings to be discussed in the spring of 2013.”

Ms. Mahon asked whether the data will inform the reauthorization strategy, to which Ms. Simmons replied “we’re hoping it will be available to inform decisionmaking.”

Mr. Brooks asked if the Federal Government will articulate a Government position in a coordinated fashion. “Are the silos talking with each other?”

Ms. Simmons said “we are coordinating with HRSA.”

Dr. Valdiserri said there is coordination at least across HHS. The Secretary was briefed on Ryan White reauthorization about 2 weeks ago. HRSA Administrator Mary Wakefield, Dr. Koh, Dr. Parham Hopson, and representatives from ASPE were present. Dr. Valdiserri stated that he does not want to imply that a single briefing resolved all the complexities, but put on the table from the HHS perspective were two major issues—what reauthorization will look like when the ACA is implemented, and what information HHS does and not have.

Dr. Valdiserri continued that one of the items the Secretary asked for was a timetable back to the point of coordination within HHS of what activities need to happen when, particularly in terms of studies underway and some of the legislative approaches that could be taken. “This has not been resolved, but the initial briefing with the Secretary and key department staff was about thinking how we move forward with the strategy.”

Lunch

AFTERNOON SESSION

Reconvening

Reconvening the Council after lunch, Ms. Mahon said that when she met with the Secretary and asked her what she would like PACHA to focus on, “she very specifically said Ryan White and the ACA.” In particular, the Secretary “wanted us to form a Subcommittee ensuring that HIV benefits from the ACA fully and that Ryan White continues, and there are improved health outcomes.”

The Subcommittee: PACHA Input?

Ms. Lewis is in charge of those from HHS who will be on the Subcommittee. Ms. Mahon’s first request is to include Ms. Alvarez on it. “So now we need to determine how we can be best used. There is a lot going on in Ryan White and the ACA. We can have input. Based on this morning’s presentations, what do you feel the Subcommittee focus should be?” One issue, Ms. Mahon continued, is “coordination of various Government actions.”

Ms. Mahon said PACHA has about 1 hour for this discussion. Mr. Greenwald has suggested PACHA mount or be part of a state of the science summit, so if time allows, PACHA will discuss that as well.

Discussion

Mr. Cruz asked if PACHA could consider the issue of having systemic changes underway when, it seems, there is no process at the Federal level to assess the impact on services and the ability to meet HIV/AIDS standards.

Ms. Mahon said this is a great suggestion. “How would PACHA tackle it? Everything is a moving target, from Ryan White data to a Supreme Court decision on the ACA not expected until June. In addition, rules are underway on essential benefits.”

Mr. Cruz said that “so far, we have had the Government making decisions from the top down. I think bottom up information is needed. At least that could be one step in the direction of being able to assess systemic change in different forces at play at the State level.”

Ms. Mahon asked what the focus would be on, to which Mr. Cruz responded, “from the point of view of grantees/service providers, because it is too early to see what is happening to the clients themselves.”

Ms. Mahon asked if PACHA could work from what Ms. Simmons is overseeing or something different, to which Ms. Hayes replied that she is “waiting on clearance for that piece of it.”

Mr. Cruz said the National Association of State and Territorial AIDS Directors (NASTAD) has done an analysis on the impact on grantees—“who won/who lost.” That, he said, “is a second mechanism, getting information from entities doing this level of analysis and putting that into a single document so we could see it.” There is, Mr. Cruz added, an organization on the impact of health care reform across

the States, “so let’s begin with something to see if we could have a picture of what is happening in the field.”

Back to the Secretary’s Request

Mr. Greenwald said it is great that the Secretary is interested in having PACHA have a more engaged role, “so the question is, how will the agenda get set, who sets it, who is on the committee, and so on.”

Mr. Greenwald said he believes “now is the time to put tremendous pressure on the Federal Government to create a floor that will protect PLWHA in every State.” The Secretary “feels pressure to talk to us about the States,” but “I’m a little unclear about the committee.” For one, “who is on it?”

Mr. Greenwald continued. “Caya has this elevated role, and Mayra is focused on workforce/prevention and not engaged in the day-to-day, so who is making decisions? If we are going to have a committee of the more political people, I’m not sure how much we’ll move the needle on the substance.”

Mr. Greenwald said that he “wants to respond to the Secretary’s request, but what is the agenda and who are the players, unless we’re saying we’ll tell them what they want.”

Ms. Mahon said what the Secretary wants the Subcommittee to do is “engage in a more granular focus on Ryan White and the ACA.” Mr. Greenwald responded “the people you mentioned so far are the political, big-picture folks.” Ms. Mahon said she is confused about the objection.

Mr. Greenwald said, “What are the four major things involved but for making sure essential benefits work, making sure the patient navigation system helps, and so on. It is the list we produced for the Secretary that focused on access to care. So who are the people who can move that agenda in the Federal Government. I wouldn’t want to knock out Caya and Mayra.”

Ms. Mahon responded that the Secretary received PACHA’s letter, and basically, “she is asking us to prioritize.” Ms. Mahon urged PACHA to “take this as an invitation and define it,” adding she is “not clear on the resistance.”

Mr. Greenwald said that this “is characterized as a new opportunity, but it is exactly what we’ve been doing.” The Access to Care Subcommittee “has had two foci—ACA implementation and the future of Ryan White—in a very granular way.” If “we are saying this is a new opportunity, I haven’t heard a new definition of what the work is.”

Mr. Greenwald added that he is not opposed to taking on this new opportunity, “but I’m not sure that what we are being asked to do is in any way different than what we’ve been doing—maybe reframing it?”

Ms. Mahon said she knows there has been a great deal of consternation in the past about the lack of dialogue between PACHA members and others, “but this is only my second meeting.”

Dr. Horberg said his concern is that this new committee “has added value.” Perhaps “the best thing we can do is convene a dialogue between those in HHS who are required to evaluate Ryan White and the greater community, and look at the treatment cascade on how each section is impacted by Ryan White,

and bring in people in the field.” The “best thing we can do as PACHA and the best service to the public is to convene a discussion/a dialogue. It complements the work we’ve been doing here. It doesn’t supplant it.”

Mr. Cruz said that Dr. Horberg “took my words.” Mr. Cruz said he has been thinking that “we’re talking conceptually, when some States have been engaged in health care reform very forcibly. Likewise, we haven’t brought to the table those entities that have done the work. If we want to look at what is happening, we need to bring in those who have implemented and those who have reluctance and bring that into a discussion for making a recommendation or two, because Ryan White is so critical to this discussion.”

Mr. Cruz continued. “We have the beginning of an assessment of Ryan White through ACA reform, so let’s look at the local level in a positive manner, and use this as an opportunity to see what is going on.”

Ms. Mahon noted that PACHA has asked for a breakdown of the treatment cascade, so could the CDC also name the top three reasons “for the fall-off in each bar?” She added that she “hears that is of interest and also local models and the state of the epidemic.”

Dr. Horberg responded “yes and no.” He said that when he thinks of the treatment cascade in this discussion, “these groups deal with various elements of the cascade.” And “that is what Humberto is saying. We don’t see these elements as dissonant.”

Ms. Mahon said “it is hard to gauge from this perspective to what extent there are holes, that PACHA may see holes in what is being focused on in a top-down way, so look across the buckets at what is being done so you can say ‘this is the bucket of work PACHA could focus on.’” The first piece would be “really assessing who is working on Ryan White in the context of the ACA and what are they working on. Then, PACHA finds out the missing pieces we can inject into the discussion.” There is a limit. “We have Ms. Hayes and Mr. Joppy, and they have other jobs, although we have Dr. Valdiserri as our right hand.”

So, Ms. Mahon asked, “what gap information can we inject?”

Set of Outcomes: Have They Been Identified?

Mr. Brooks said that is something valuable. “Dr. Colfax has talked about outcomes. Has the Secretary identified a set of outcomes she wants from the newly formed group? Is the creation of the group an indication that she hasn’t been getting what she needs from us? The important question is the outcomes for the group.”

ACTION ITEM

Ms. Mahon said that is a terrific question, and that she “can go back and tell the Secretary that PACHA feels it has been working on these issues in the past and that it would be good to get specific outcomes that would particularly bring PACHA’s expertise to bear.”

Request for the Cascade Breakdown

David Holtgrave said that he has “talked with Irene Hall, and the CDC will try to transmit its cascade breakdown as a late breaker for the AIDS conference. He thinks this will happen “sooner rather than later.”

How Will This Work, Structurally?

Dr. Holtgrave also is wondering about the issue of the preexisting Access to Care Subcommittee working so hard. Is the Secretary’s request for two Subcommittees or a hybrid of one? “Can we enlist the work that has already been done and then bring in what has been discussed today? Do we rename the Subcommittee?”

Ms. Mahon responded that the Federal Advisory Committee Act (FACA) requires a charter. Yet “let’s not get so focused on the structural. It is less important the being than the doing.” She then asked that “if there is past thinking that hasn’t been trickled up, that doesn’t negate or erase it. This is an opportunity to share it.”

Need for More Information

Ms. Khanna said she agrees that this is more about doing than being. “As a Council, we want to be useful in the best possible way on this very important and timely issue. We need to know more, such as timeframe and constraints under FACA. It would behoove us to engage with our Federal partners in a different way, and we need to know more about the opportunity. We want to move the agenda as strategically as we can, but we need more information.”

Mr. Baker agreed with Ms. Khanna. He has been in Australia and therefore absent from the Council for a while, but two elements stand out for him. First, it is unclear, structurally, what this means for PACHA’s expectation of work going forward, and, so, “how should we engage in the discussion?” He is respectful of the Access to Care Subcommittee, and he is not sure whether it needs to determine how to adapt this into the work it has been doing or engage the rest of PACHA. “It would be useful to have a framework that is more useful to us and a dynamic that doesn’t feel so political.”

Mr. Baker continued. “Obviously, we were framed around the Strategy,” so Ms. Mahon, as PACHA’s Chair, “should directly and clearly understand our role.” Mr. Baker feels “that the Secretary has put suggestions on the table, but it is not clear how that directly informs our work. The whole private/public partnership issue keeps coming up, as well. If we don’t have the appropriate structure to deliver, then we should look at the structure and members to see what we really can deliver.”

Three-Legged Entity and Struggle for Balance

Mr. Baker continued. “This is a push-pull. We are a three-legged entity. The President has outlined a National Strategy. HHS has real tactical implementation issues, such as the ACA, Ryan White, and all sorts of issues which, because we are also responsive to the Secretary, we could drill deeply into and leave aside big picture issues.” Then, “there are our own representations, and they need to rise to a higher level of national focus.” Mr. Baker concluded by saying he “feels a real struggle right now about the balance between these three legs.”

Dr. Valdiserri's Observations

Dr. Valdiserri asked to make some observations. Part of the struggle, he began, is not that someone is holding something back. "Frankly, there was a desire expressed by the Secretary to have a focus on this issue. As an HHS employee, and given that you are special Government employees here, I like to see it as an opportunity."

Dr. Valdiserri said he "gets it" that the Access to Care Subcommittee has not been oblivious to this issue, but if there is a lack of clarity "why doesn't PACHA come forward with what you would like to suggest?" And, second, perhaps this is more a statement to the Subcommittee, human behavior has a lot to do with being ready for action, so when you provide information to someone "and they're not ready to act on it, they're not ready to act on it," even though this can be hard to accept.

The good news is that "time has moved." All of a sudden, "people are saying the Ryan White CARE Act is up for reauthorization, and we have the ACA. Whatever this group ends up being part of, it will, I suspect, go back to the fundamental work the Access to Care Subcommittee has done and keep that as a base." But now, "the higher levels of leadership are ready to engage in it because they are ready for it."

Dr. Valdiserri continued. The "Office of the Secretary is interested in bringing additional voices into the discussion. This is my interpretation of the events." Last, "there is another way of looking at this group, whatever it ends up being. There is a difference in product, generally. My sense is that the Subcommittee raises a lot of question and generates recommendations. Maybe part of what we have to think of, sincerely, is the Office of the Secretary asking for something more in those recommendations. This gets back to the granular thing. As in 'look at this and tell me, is there something we should be doing policy wise that we're not doing?'"

Concluding, Dr. Valdiserri said "you don't have to be the entity to fill the gap. Your first job is to identify the gap, as in 'is anyone in the department doing x, y, and z.'" Ask yourselves, he added, "'Is there something we are asking for that is actionable or immediately actionable?'"

Ms. Averitt Bridge said her thoughts are "morphing" after Dr. Valdiserri's observations. The agenda calls this section of the meeting "addressing care issues, but does that mean the conversation around the ACA and Ryan White is not as broad therefore?"

Ms. Mahon said, "Yes," adding "how can PACHA be of greater use to the Secretary?" She said that "at this point, I said [to the Secretary] that there is a trove of expertise not necessarily being tapped." The Secretary "could amend the charter, which she has the power to do, and incorporate a formal structure where members of the new Subcommittee would actually be members of the Council and part of the Subcommittee." This "seemed to be a terrific invitation, and I've tried to be as transparent as possible." In short, "I think it is a terrific project."

Ms. Averitt Bridge said she asked to speak because she was thinking about the agenda and iterations of the cascade but also thinking that what seems very relevant to her and the goals of the Strategy is how the gaps are identified specifically related to the cascade. However, "there is also important cross-

cutting work across all the PACHA Subcommittees. The cascade has given us great models to highlight gaps and opportunities. We're uniquely positioned to be able to do this."

Dr. Horberg said he sees this as a great opportunity, and he agrees with Dr. Valdiserri, for "time has moved on, and many new players are involved. So how do we get from the concept of opportunity to a plan of action?" He said he was hoping there would be some plan today, so he has a recommendation for formation of a small group, with representatives from a number of different Subcommittees, who would meet with Ms. Mahon and maybe even Ms. Lewis to come up with a plan of action. "That is mainly what we've been struggling with."

Ms. Mahon asked "how we can be most useful is the plan." Dr. Horberg reiterated his proposal. Ms. Mahon said "Sure." Ms. Mahon noted that the proposed discussion needs to take place publicly.

Mr. Pérez said in the spirit of partnership and taking advantage of the opportunity, "We need to sort through a few things." The Access to Care Subcommittee is not just about ACA implementation. "The fact is, getting even more folks into Ryan White and the ACA are critical parts of access, with Medicaid the third wheel in that spoke." If "we move forward with this evolving Subcommittee, the first order of business needs to be a review of the state of implementation of these various parts. Maybe here we can lean on the Harvard reports. At different levels, there are very different levels of appetite, readiness, resource bases, and in many cases, not enough resources. Even with resources, there is just not sufficient capacity."

Mr. Pérez continued. "In California, we've been trying for the past year to get the three relevant partners on the phone together." So the opportunity here is to have "folks roll up their sleeves and come together. After we review the Strategy implementation review report, we look at the essential benefit issue on the table, and either we have the political will at the Federal level or we don't. There are important issues around navigation. We are just not moving people along. This needs to be part of the recommendation review. Also, we need some conversation on pharmacy access and on mental health. Once we did this work, in 120 days, we could begin to establish a framework for Ryan White 2.0. Although some States, like California, have done this, many are looking at 1/1/14 as being the date."

Working Group, Not a Subcommittee?

Mr. Baker said the new group under discussion could be allowed by the PACHA charter as a working group, not a Subcommittee. "We wouldn't need to amend the charter if the Secretary appointed a working group."

Ms. Hayes responded that on that particular nuance, "we will need to consult with our FACA expert."

Mr. Baker said "if we establish this as a working group under the leadership with the Subcommittee, folks might be ready to move on." The issues that Mr. Pérez outlined are big picture issues, "and we're not interested in losing those issues off of our agenda. Dr. Horberg and Mr. Greenwald would need to figure this out. Value-added is important."

Mr. Baker continued. “We should take the opportunity the Secretary has given. We should respond to it and find a way to address it, but there are big, critical issues, as the cascade shows, that need to be addressed.”

Ms. Hayes said “the meat on the bones needs to be done in public.”

Ms. Mahon said “the group could be outside PACHA, if the group is saying, ‘why don’t we have it outside of PACHA.’”

Mr. Greenwald said he has not heard anyone say that. Mr. Baker said “it is really about how much we get done that is value-added.” Mr. Greenwald added that “if the FACA person was here and said the workgroup can be formed, we’d be able to move forward.”

Ms. Hayes said she will scope out the FACA question, “but this does not negate the fact that we can look toward discussion on fleshing the meat on the bone.” Mr. Greenwald responded “nothing precludes us from having a small group put the meat on the bone.”

Dr. Horberg said Dr. Valdiserri “gave us a very good framework. Maybe this is a case where we define the projected outcomes and you would work back to what you need. I want to be very clear that this group would need to have a laser focus on the intersection of the ACA and Ryan White. We could talk about a lot of other things like social determinants of health and the cascade.”

Dr. Holtgrave mentioned there is a working group precedent; PACHA has had a Metrics Working Group.

Ms. Mahon said the word the Secretary used was “Subcommittee.” So “would members not agree to that?”

Mr. Greenwald said “we want to take the opportunity the Secretary is offering. Period. Mr. Baker had a positive way of communicating this back. That is, ‘We thank you for this opportunity, and we have formed a working group.’ I’m sure the Secretary didn’t know the difference.”

Decision Point?

Mr. Brooks said “we have a working group on disclosure with PACHA members, CHAC members, and other external members. I’m certain that Mr. Bates did due diligence on that.” Meanwhile, “a tremendous amount of work has already been done, and it will be easy for you to comb through all the recommendations you’ve already made that are tangible, clear, and instructive about what their implementation would lead to. Then present the results of your combing through.”

Ms. Mahon said, “Great. We’re clear.”

Public Comments

Reading from a list of public attendees who signed up to speak today, Ms. Hayes called Carl Schmid’s name. Mr. Schmid gave his testimony later. Amanda Lugg was next.

Amanda Lugg, with the African Services Committee in New York, said the HIV epidemic in the United States disproportionately affects communities of color, but it has not been so clear how the epidemic affects the foreign-born black community in the United States. Now there is a new report by African Services at Mt. Sinai on Africans in the United States. It is being published by the *Immigrant Minority Health Journal*.

Ms. Lugg said if PACHA is interested, someone should get in touch with her, and she will e-mail a PDF. She said the report is well-written and includes data on “the quite staggering prevalence rates” on the Continent and documents immigrant trends in the United States. For example, the number of African immigrants in the United States grew by 700 percent from 1999 to 2010.

Mariel Selbovitz’s name was called, with no response. David Miller’s name was called, with no response. Ernest Hopkins said he would pass. Sarah Audelo was next.

Sarah Audelo, from Advocates for Youth, read a statement that focused on a recent addition to the HHS Office of Adolescent Health’s list of science-based education programs entitled “Heritage Keepers Abstinence Education,” characterizing it as a “fear and shame-based abstinence-only-until-marriage program that denies young people life-saving information about condoms and contraception and promotes harmful gender stereotypes.”

Ms. Audelo said the Office of Adolescent Health’s list is used not only by Tier 1 Teen Pregnancy Prevention Initiative grantees but also by others trying to determine the best programs for prevention of unintended pregnancy, HIV, and sexually transmitted infections (STIs) in their communities.

The Administration “has taken so many positive steps that it is disappointing it would endorse such a harmful program,” Ms. Audelo said, and she asked PACHA to ask HHS to remove the program from the list and adopt standards criteria to be applied in the future. Ms. Audelo also reiterated an earlier request that young people be appointed as members of PACHA.

Ms. Mahon asked what constitutes an evidence-based program, to which Ms. Audelo responded “one that discusses delay in initiation and increased use of contraception, among other things.”

Mr. Greenwald asked if the program was newly added, to which Ms. Audelo responded in the affirmative and offered to share more information. Mr. Greenwald thanked her, and Ms. Mahon said “we would like to respond quickly and decisively.”

William McColl, from AIDS United, provided a written statement, the focus of which was asking PACHA to send the President a letter about making syringe exchange a top Administration priority, “as it has been in the past.” He said he was speaking on behalf of an ad hoc coalition of 87 public health, HIV/AIDS, viral hepatitis, and harm reduction organizations “that are extremely concerned about syringe exchange.”

Mr. McColl also asked that PACHA focus on syringe exchange at its next meeting, and offered the coalition’s assistance in that effort. A list of members of the coalition was attached to his statement.

Mr. Brooks asked if Mr. McColl had a letter prepared, to which Mr. McColl replied that he could have a letter on Mr. Brooks' desk tomorrow.

Mr. Brooks said, "If we are going to respond, now is the time, while we are in session."

Ms. Hiers said she would draft a letter and send it around tonight, including to Mr. Brooks.

Mr. Greenwald asked if this will be turned into a resolution of some sort, to which Mr. Brooks responded that this is a letter because that is what was requested.

Ms. Mahon said so far PACHA is responding to two things from Public Comments, the abstinence only program and syringe exchange, adding that both of these matters could be addressed in a letter or a resolution. Ms. Hiers said the youth resolution comes up for a vote tomorrow, so that would be a place to add PACHA's objection to this new curriculum. Ms. Mahon said "we'll run it up the flag pole in either form."

Daniel Raymond, from the Harm Reduction Coalition, said syringe exchange looks very different in this decade; thanks to education and advocacy, legitimization has been occurring in several States, such as North Carolina, which has programs and successes, and Colorado, which has its own syringe exchange. However, at the same time, there has been a "destabilization of funding, a cascade effect of State budget deficits and cuts in public funding complemented by shifts in CDC funding."

Stephanie Arnold Pang, from the National Coalition of STD Directors (NCSO), spoke in her written statement to "two important issues for the future success of stemming the HIV epidemic in this country: the rise of drug-resistant gonorrhea and Federal budget cuts to youth-focused HIV and STD [sexually transmitted disease] prevention."

First, NCSO and its member health departments across the country are very concerned about the rise of multi-drug-resistant gonorrhea and its implications for increases in HIV acquisition. "We are on the verge of a highly untreatable gonorrhea epidemic, for gonorrhea has developed resistance to every class of antibiotics. We are now on our last line of defense to treat this STD, which can facilitate HIV transmission, with no new drug in the pipeline."

According to the CDC, gonorrhea incidence could increase fourfold over 7 years due to antimicrobial resistance, and over those 7 years, "the CDC estimates that antibiotic-resistant gonorrhea will result in nearly 800 additional HIV cases and add... \$780 million in total direct lifetime medical costs to our health care system."

To deal with this, NCSO has asked for an additional \$26 million for the CDC's STD prevention efforts for FY 2013, which "is not nearly enough, but flat funding at CDC's Division of STD Prevention and declining resources for public health departments on the front lines...require immediate increased investment."

NCSO also remains concerned about the 25 percent cut in funding sustained last year by the Division of Adolescent and School Health (DASH). "This cut threatens the Strategy goal to reduce the number of new HIV infections in the United States." NCSO would like to thank the Council for considering a youth

and HIV resolution that addresses the importance of effective comprehensive sex education programs. DASH's funding "needs to be fully restored...and we have joined colleagues in asking for an additional \$20 million for DASH for FY 2013."

Responding, Ms. Mahon said the Council can amend the youth resolution to address this tomorrow.

Mr. Cruz said the CDC will be recompeting these funds again in 2 years, so "this is part of the added stresses in the system, the first of which was from the prevention FOA; now the surveillance FOA is here, and then the STD FOA is to come." All of that "will be changing, and it is unknown what the priorities will be in terms of funding. This is a critical issue we need to keep in mind."

Leo Rennie's name was called, and he did not respond. Daria Boccher-Lattimore's name was called, and she passed. The last one to give public comment was Carl Schmid.

Carl Schmid, from the AIDS Institute, provided a written statement, the focus of which was two related issues, "both having to do with providing proper tools and resources so that the ACA can be implemented to provide care and treatment to people with HIV/AIDS and to help prevent HIV."

Two years after passage of the ACA and after a few meetings between HRSA and the HIV community, "Ryan White grantees still have little direction on how to proceed with health reform implementation, and the clock is ticking."

When fully implemented, "the ACA can provide greater access to care and treatment for people with HIV, many of whom do not have access today, while many do under the Ryan White program. Over half a million low-income people depend on the Ryan White program for their care, and nearly 200,000 rely on ADAP for their life-saving medications. A dependable system of care has been established with specialized providers, caseworkers, and buildings and administrative staff. PLWHA are relying on this system to receive their care and treatment."

"Health reform will drastically change things. Most Ryan White clients will be able to access their care and treatment paid for by Medicaid, and some will be able to buy health insurance through the exchanges. While most health reform changes will not occur until 2014, some elements have already begun, and planning to make sure it works for people with conditions like HIV is well underway. There is much uncertainty out there, and not all is known, but we are concerned with the lack of dialogue and planning that is occurring between HRSA and its outside partners."

Last year, the AIDS Institute suggested that a small, ongoing workgroup composed of outside partners and HRSA HAB staff be formed to work together to ensure health reform "goes as smoothly as possible for people with HIV. Since then we have had a few meetings, but there has been no evidence that grantees will receive any direction on how to proceed anytime soon. Instead, we see further discussion on reauthorization of the Ryan White HIV/AIDS Program. While this discussion must occur, it should be done so in light of ACA implementation. Discussions of and progress on implementing the ACA must occur first."

Continuing, Mr. Schmid said health reform is a great transformative moment for us, “but if not done correctly, our entire system of care for people with HIV can be dismantled. It is not going to be an easy process, and huge changes must occur. Understandably, there is a huge level of angst out there, and there is an urgent need for leadership. Together, let’s help fill that void.”

The other area in need of tools and resources is on reimbursement for HIV testing. Under the ACA, certain preventive services, including testing, can be reimbursed by various payers, including Medicare, Medicaid, and private insurers. “But the CDC has provided limited information to its grantees on how to take advantage of these new coverage options, many of which are already in effect. In this time of tight budgets at all levels, it is especially important to develop these reimbursement mechanisms as soon as possible so that appropriated dollars can be used to test people outside of medical settings, individuals who do not have access to a payer, or for those nonreimbursable preventive services. If the U.S. Preventive Services Task Force recommends a positive grade for routine HIV testing later this summer, then the need will be even greater.”

Adjournment

Ms. Hayes moved to adjourn the public meeting and noted that PACHA members are scheduled to meet again tomorrow at 9:00 a.m. in this room. She then noted that there are a few follow-ups, as hands were raised, and Ms. Khanna noted that there are other public comments from those who did not register to speak.

Public Comments Period Continued

Phil Crud, who identified himself as a citizen, said he had a comment on the ACA and that he is concerned about the cost of prescription medicine, which cost him \$137.50 last year and \$966.00 for 3 months of this year. Every 3 months now, he has to weigh paying rent against paying for his medication. He has many friends here in Washington, D.C. who have the same problem.

Dr. Holtgrave said Leo Rennie, who signed up to make a comment, had e-mailed him because he wanted Dr. Holtgrave to call attention to the American Psychological Association’s new recommendations on biobehavioral guidelines.

State of the Science Summit

Dr. Holtgrave then asked for a few minutes to discuss the state of the science summit concept before members go into Executive Session. Ms. Mahon said this was fine. She noted the lack of program staff for PACHA and asked, therefore, “How we would execute a summit.”

Mr. Greenwald responded that PACHA could take advantage of the IAC as one forum for a meeting on the impact science has had on achieving the goals of the Strategy and the ongoing role for PACHA. “This may be one of those leadership opportunities that looks at what the impact is of some of the more recent scientific research and that uses some of that to drive access to care and other Strategy goals.”

Ms. Mahon noted that at PACHA’s last meeting, members talked about space and other possible needs or constraints.

Dr. Holtgrave said he really supports this idea and “looking at the cascade in terms of what we know about the best ways of getting from bar to bar on the cascade.” There is literature and public health management to be tapped on the early and latter parts of the cascade. “What is needed now is to do some review of the middle and bring the meeting together as quickly as possible.”

Dr. Valdiserri asked if Dr. Colfax had mentioned that ONAP is planning at least a piece of that review, to which Mr. Greenwald responded “he did say that.” Dr. Valdiserri advised keeping that in mind.

Ms. Mahon asked if Mr. Greenwald and Dr. Holtgrave want to further develop this idea and have it go through the Access to Care Subcommittee. Dr. Holtgrave said he would be happy to do it in partnership. As to Dr. Valdiserri’s statement, “if there was a White House meeting on linkage, that would be good to build on.” There also is another conference on adherence. “We need to bring that all together and figure out how many people and what kinds of costs.”

Dr. Horberg said “added value for us would be to talk about the scalability of those findings.”

Ms. Mahon said “our attendance is very low, and honestly, I have a sense we are talking to ourselves against what we are trying to achieve. Maybe we go to them, as it were. Let’s really think about who we are trying to convince and make sure they are in the room.”

Final Adjournment

Ms. Hayes adjourned the meeting at 2:55 p.m. and called for a 15-minute break for members before the beginning of the members-only Executive Session.

Day 2

MORNING SESSION

Welcome and Opening Remarks

There was brief discussion about whether the meeting could start without a quorum, as seven members were present, but PACHA Chair Nancy Mahon; PACHA Executive Director B. Kaye Hayes; and Ronald Valdiserri, Deputy Assistant Secretary for Health, Infectious Diseases, and Director, OHAIDP; agreed that the meeting could begin. Ms. Mahon welcomed everyone.

PACHA Report on National HIV/AIDS Strategy Implementation

Ms. Mahon said that members had a healthy and good discussion during the members-only Executive Session yesterday related to the PACHA report. Ms. Mahon explained that it was the goal of the Council to issue a report in the fall. To achieve that, the report must be written over the summer. The structure will be sections by Subcommittees, and each Subcommittee’s Co-Chairs will work on the content of their Subcommittee’s section. The result of that is “what we will preview or in part present at the International AIDS Conference.”

Ms. Mahon said “we are working to schedule on that report and will have public comment on the report. “

During yesterday's Executive Session, Ms. Mahon continued, Patricia Garcia led a discussion on being responsive to the public and to Public Comments made during full Council meetings. Therefore, "we will follow up today on Public Comments received yesterday."

Next on the Agenda

Next on the agenda is the Women and HIV Resolution, to be presented by Dr. Garcia and Ms. Khanna from the Access to Care Subcommittee, but, at present, a quorum of members is lacking.

It was noted that Antigone Dempsey, the CHAC liaison to PACHA and the CHAC Co-Chair, is here, so it might be possible to put the Women and HIV and Youth and HIV resolutions to the side for the moment and go to the next agenda item. This was agreed.

Safe and Voluntary Disclosure of HIV Status in the United States

"PACHA/CHAC Disclosure Workgroup: Safe and Voluntary Disclosure of HIV Status in the United States," by Douglas Brooks, M.S.W., Disparities Subcommittee Co-Chair and PACHA Liaison to CHAC; and Antigone Hodgins Dempsey, M.Ed., CHAC Liaison to PACHA and CHAC Co-Chair

Background

The White House released the National HIV/AIDS Strategy in 2010, and it set out a number of action steps for Federal agencies, as well as PACHA and CHAC.

Subsequently, the Strategy's implementation plan provided directives for PACHA and CHAC:

- PACHA will be tasked with developing recommendations for ways to promote and normalize safe and voluntary disclosure of HIV status in various contexts and circumstances.
- CHAC will solicit public input and make recommendations for normalizing and promoting individuals' safe, voluntary disclosure of their HIV status. HRSA will publish the recommendations.
- There have been several phone and a few in-person meetings between CHAC and Mr. Brooks, PACHA's liaison to CHAC, to discuss the matter.

Mr. Brooks emphasized in slide 4 that there are no simple answers to address how to normalize and promote individuals' safe and voluntary disclosure and their HIV status. "It is not even easy for folks to have a conversation about this. Lack of conversation is a huge piece."

Those who are positive are affected by a host of things:

- HIV criminalization laws, stigma, discrimination, and denial cause significant barriers for people and create unsafe environments for disclosure.
- Safe and voluntary disclosure is affected and influenced by individuals' past experiences with disclosing, stigma and discrimination, and one's family norms; race and ethnicity;

socioeconomic/educational status; gender; sexual orientation; gender identity; and the intersection of syndemics, such as substance abuse and violence.

Disclosure is an ongoing and fluid experience that affects many domains of a person's life (e.g., friends, family, sexual partners, work, medical providers, and school). This complex task needs a nuanced and carefully planned approach, with outcomes that do not cause unintended negative consequences.

Proposed Approach

Mr. Brooks said, all the above considered, "we've come up with the idea of a 2½-day Disclosure Summit" (see slide 6). The idea is to provide a format that has well-formulated and-considered outcomes, with a maximum of 20 invitees, including some members of CHAC, Ms. Khanna, Mr. Brooks, and Sandra Torres-Rivera. Authorities also would be invited to make some policy recommendations.

Mr. Brooks noted that CHAC went back and forth on who the audience would be for the deliverables, and concluded that it would be not only those living with HIV but policy advisory bodies, as "we felt the deliverables need to be policy recommendations." (slides 7 and 8)

Using the format of the summit, the anticipated outcomes would be a set of principles for safe and voluntary disclosure of HIV status in the United States, and a set of five (two short-term and three long-term) policy recommendations for promoting safe and voluntary disclosure. The proposed timeline for release of preliminary principles and recommendations would be at the IAC in July 2012. Therefore, the summit would be held in late June 2012.

Mr. Brooks noted that other members of the summit working group include representatives of the U.S. Department of Justice and others with legal orientations. In addition, Dr. Valdiserri "was hugely helpful by encouraging us to start by thinking about principles."

Concluding, Mr. Brooks noted that having the summit by the end of June is ambitious, but it was strongly felt that a presentation should be ready for the IAC. "We shall see."

Discussion/Comments/Questions and Answers

Ms. Mahon asked about international perspectives and epidemiological data that might tie impact, such as decreases in incidence, to safe and voluntary disclosure.

Ms. Dempsey said those working on this project are including international perspectives. "We have done an exhaustive literature review and have abstracts for committee members to review so that we can know what the literature says. There has been a lot of global work, and we can learn from it." In terms of epidemiology, this "will be part of the expertise in the room. It is an important perspective."

Ms. Mahon asked if Mr. Brooks and Ms. Dempsey are looking for funding from PACHA for this project.

Mr. Brooks said that the group is working loosely with Ms. Hayes, and "we're not asking for any action by PACHA on this. This is just an update." Ms. Dempsey added that recommendations and principles will be shared when the group has developed them.

Dr. Garcia congratulated Mr. Brooks and Ms. Dempsey. “What a great job the two of you have done, with thoughtful sensitivity to the discussion.” She asked that the paradigm include the perinatal issue. Disclosure is a particularly important part of that, as it is a time when new infections are diagnosed, and the confluence “makes disclosure unique and eventful, and the lack of disclosure significantly impacts adherence to post-exposure prophylaxis for neonatal care.” When there is not disclosure, “it is very hard to give an infant neonatal syrup.”

Ms. Dempsey said simply, “I know.” Mr. Brooks said “we are both HIV-positive people. Antigone’s Mom has gone through that.”

Dr. Garcia said “we see the pediatric community at odds with the maternal community.” The pediatric community “insists on disclosure to the father, while we in the maternal community are trying to protect the confidentiality of the mother. I love my pediatric colleagues, but we are advocating for different parts of the dyad.”

Mr. Wilson said there is a need for PACHA action if this is going to be a joint PACHA/CHAC event to achieve “that kind of branded, added value, official function of PACHA.” Mr. Wilson said “it is important to look at the policy issues, but it is also important at this point to look at public campaigns and encourage them. There are many of us who can disclose, and this could be very important for other people to disclose.”

Mr. Brooks apologized for not raising Mr. Wilson’s point earlier, for public awareness was on the list “of what we talked about.” Much like “Starbucks takes on issues, would we use something very public in that form?” Mr. Brooks added that he and Ms. Dempsey will get together with Dr. Valdiserri and Ms. Hayes to find out if more needs to be done in terms of PACHA action.

Ms. Mahon said she looks forward to further information.

Ms. Mahon asked if we have a quorum now. Mr. Wilson said “we have 13 now,” and Ms. Hayes agreed, with Mr. Cruz on the line.

Mr. Brooks then proposed that PACHA take action on the summit now, if it can.

Motion and Vote on the Disclosure Summit

Mr. Brooks made an official motion that PACHA agree to move forward with the Disclosure Summit in conjunction with CHAC. A first and second were heard. A vote was taken. It was stated that the majority ruled.

Further Discussion on the Disclosure Summit

Mr. Greenwald asked how the summit will obtain a perspective “different from ours.” Mr. Brooks said that is a good question, so “one of the workgroup members has already suggested that we have a medical ethicist.” That is “one field that could be involved.” Mr. Greenwald said “that is great.”

Dr. Horberg also asked about disclosure officers for some of the larger counties, such as Los Angeles, who deal with those very unwilling to disclose.

There was further discussion about having a State official discuss the criminalization front. Ms. Mahon said “allies are fine, but someone in favor of criminalization would be of value, too.” Mr. Greenwald agreed. Mr. Brooks also agreed, adding that he regrets Anita McBride “not coming to these meetings.”

Women and HIV Resolution

Ms. Khanna said that now that there is a quorum, she would like to introduce, on behalf of the Access to Care Subcommittee, the Women and HIV Resolution, a draft of which is in the member packets.

Ms. Khanna said this resolution “has been a while in coming, as there has been some public comment at PACHA meetings to increase focus on women’s issues and the Strategy.” Some of the issues addressed by the resolution are very similar to issues members heard raised at the full Council meeting focused on women and HIV.

Ms. Khanna then began to address the resolution point by point, noting in particular that the resolution includes transgender women but does not make many specific recommendations for them, so it has been suggested that transgender women could be addressed in another resolution.

Dr. Garcia noted that the members who helped pull this resolution together had many discussions based on the women and HIV session presentations. Also, in the Access to Care Subcommittee, “we tried to distill it down to focus on issues we felt needed movement, including the need to measure progress as relates to women and transgender women.” She asked if she and Ms. Khanna really had to read it out loud and suggested instead that they respond to questions.

Discussion/Comments/Questions and Answers

Ms. Mahon thanked Ms. Khanna and Dr. Garcia and said she has questions. First, overall, “how would this resolution relate to the Subcommittee [workgroup] dealing with domestic violence that Dr. Colfax mentioned yesterday?” She asked whether “we defer or ask for coordination, as it would seem that ONAP would be the major coordinating body on this.”

Ms. Khanna responded that this resolution “is complementary to what was in the Presidential Memorandum Dr. Colfax mentioned yesterday. The nuts and bolts are here—gender-sensitive care, support and services, data collection needs, research, and being able to evaluate the Strategy’s effectiveness, which is what the workgroup was charged with doing.” If the Access to Care Subcommittee agrees, a new “Be it resolved” could be added to the effect that PACHA will work with the Federal agency workgroup, “which is charged with working with us as appropriate anyway.”

Mr. Wilson said he wishes that Ejay Jack were here today, as PACHA has had a lot of conversations about transgender needs and issues, and he is concerned that much of it “is lip service.”

Mr. Wilson continued to address this subject. “The issues of transgender people seem to me to be somewhat complex, so I feel we’ve not been getting to the issues but, rather, we’re just checking the box for political correctness. Is there value to distinguishing between transgender and different issues? We are in a room. Do we not have a commitment to have a transgender conversation?”

Mr. Wilson said he is “not putting pressure on this resolution, but he is not sure how we move from where we are.”

Ms. Khanna said she totally agrees, and “that was my sense in the workgroup on women and the Access to Care Subcommittee.” One of the recommendations at the women’s meeting was to have another PACHA agenda specifically focused on the needs of the transgender community. “You are right that the issues are so complex.”

Dr. Horberg said Ms. Khanna “said it better than I could.” Mr. Greenwald said “we also said we need to address it briefly here and that it would also be good to have another PACHA meeting on this.”

Mr. Greenwald continued. In terms of Ms. Mahon’s question about the new workgroup, he proposed adding new language to the first “Be it resolved,” which Ms. Mahon accepted. Mr. Greenwald asked if the resolution should say that PACHA wants to be part of the workgroup as well, and there was agreement on this.

Discussion continued regarding amendments to the resolution, including pinning down how much of the domestic HIV burden women actually bear; adopting more precise language about access to care and essential support services to indicate that it is more difficult for women; and preparing amendments to the “Be it resolved” section to make it clear who has the power to amend the Strategy and/or the Strategy implementation plan. Key discussion items on the latter point included Ms. Mahon stating that while she supports the concept of the resolution and the resolution itself, she has heard pushback on it outside this room and heard Ms. Averitt Bridge asking for amending language to make clear or at least point to PACHA’s desire “for tangible action.” The critical piece “is to see some things move, and we want to be engaged in however that takes shape.”

As members worked through amendments and wordsmithing, Mr. Greenwald and Dr. Horberg worked with Ms. Khanna and Dr. Garcia to capture changes. After some research, Dr. Horberg said according to the CDC, HIV prevalence among women in the United States is 24.7 percent per 100,000 population, or “nearly a quarter.” Dr. Valdiserri offered to look at the new surveillance report as well. On this point, Mr. Brooks said he wanted to make sure the record shows that raising the point about the number is “not oppositional.” Everyone said they understood that and that no one intends to replicate past miscommunications on this point.

Mr. Pérez asked that CDC and SAMSHA “not be left off the hook” on the last “Be it resolved”; asked if HEDIS [Healthcare Effectiveness Data and Information Set] measures should be mentioned or “something systematic that raises the bar for the quality of HIV medicine available for women”; and added his voice to the earlier discussion about transgender women. “The issues are so complex—the stigma, the access, the rates of infection, the violence, and more—so numerous and multilayered that a single mention in this document doesn’t do justice to those issues.” Therefore, Mr. Pérez proposed a separate resolution that addresses the needs of transgender women in this country.

Dr. Garcia said she and others who worked on this resolution “totally agree that quality of care is important both for men and for women,” so if language needs to be changed to show that, she is in

agreement. She also agrees “with all the comments on transgender.” So, she asked, “does PACHA resolve to have another meeting and generate a separate resolution, or do we say here somewhere that we mean inclusive of transgender women?”

Agreement on Separate Resolution for Transgender Women/Also Include Them in This Resolution

There seemed to be agreement that those around the table want both a separate resolution at a future meeting and also to indicate that this resolution is inclusive of transgender women.

Dr. Garcia said just because transgender is addressed briefly in this resolution “does not preclude our paying attention in the future. It should be tied to a broader look at women’s issues, but that is not sufficient.”

Presidential Memorandum

Dr. Valdiserri noted that he has asked a staff member to pull up the Presidential Memorandum referred to earlier. On the basis of language there, he and Ms. Khanna worked through some language changes in the “Be it resolved” section of the resolution.

Continued Discussion on Transgender Populations

Mr. Baker said he appreciates Mr. Brooks’ comments and that he was considering not speaking to this resolution “because I didn’t want to sound like I was oppositional.” He would remove mention of transgender because “they are not being spoken to accurately here.” Second, “Resolution on the Needs of Women” should be the title. Also, in the third and fourth “Whereas,” a comparison is needed, “but we need to be careful about it.” We could compare with men, but that includes white men, when the environment and situation is particularly black.”

Mr. Baker continued. “For those of us in the organization I belong to, there are consequences around language, including with the Campaign 30 for 30. This resolution says women of color. A lot of these disparities are between white and black, not just gender. We don’t really call out the racism in the system. I want clarity on where we want to see the needle move.”

Mr. Greenwald asked for help, and Mr. Baker suggested “a reference to the disproportionate burden among African American women who experience the pressures of racism, putting their lives in the context of community.” Ms. Khanna noted public comment on country of origin, so could the term “black” be used? Mr. Baker replied that he “is always open to using black.”

Ms. Mahon noted the first and second “Be it resolveds” and asked if PACHA wants to add anything “more specifically on the ONAP report, as this will be a critical time.” That is, “is there a specific demand we can make with regard to that report?” Various suggestions were made, and the resolution as voted upon and provided below reflects those agreed upon. Ms. Mahon explained that she wants the resolution to be as strong and “bulletproof” as possible, but at the end of the day, “you can’t do everything,” so she asked for discussion to begin to come to a close.

Mr. Wilson said he does not understand how PACHA will get a chance to vote on this today. Ms. Mahon asked that the changes be noted, adding there has been some deepening of the language. “The Subcommittee did such a great job, so let’s not push this over to the fall meeting.”

Ms. Khanna asked if the resolution could be worked on until after the next break, then presented “while we still have a quorum.”

Mr. Wilson noted that this is an example where members got a draft in advance, and he too is guilty, but these are the issues “we have to take responsibility for in advance so we can move on this.” Ms. Mahon said she understands. Dr. Garcia said she was sure the transgender discussion could be distilled as well as other comments, so she would like to project a new version for members after the break.

Ms. Dempsey asked for consideration of specific terms such as “Latina” so that women can see themselves here.

Addressing process, Mr. Brooks pointed out that in the past, PACHA has voted for resolutions with the understanding that the workgroup would make corrections as noted. He advocated taking the vote on this resolution. Ms. Mahon suggested the group go on to the Youth and HIV Resolution, take a break, and then vote. She asked if anyone was leaving. It did not seem so, although whether Mr. Cruz was still on the line was not clear.

A round of applause was given to those who worked on the Women and HIV Resolution.

Transgender

Ms. Averitt Bridge said, with all due respect to Mr. Baker’s comments, that “transgender needs to be addressed in this resolution. For the past 20 years, I have linked arms with transgender women. They have said ‘we want to be included when you talk about women.’ We have a responsibility to address that, and I feel strongly we need to call out.”

Mr. Baker said, “If we do, then do it in a more comprehensive way, express concern, and also acknowledge the range of issues. You can put that in a ‘Whereas’ that addresses a range of issues, from lack of good data gathered about their condition, to unemployment, violence, and their care. Address the whole person, not just lack of adherence.”

Ms. Khanna noted that some of what Mr. Baker suggests was in an earlier version of the resolution.

Ms. Mahon said, “put the ‘Whereas’ in there, and we’ll vote on it.”

Mr. Wilson said that “our comments here are a contribution to this, so let the minutes show that. Also, if there is a way, we should make sure we make transgender part of our future agenda.”

Ms. Mahon asked for someone to make a recommendation for how to take on Mr. Wilson’s suggestion in a constructive way. Dr. Horberg said Mr. Jack would be the one to get involved, and he is a member of the Disparities Subcommittee. Ms. Mahon said “OK.”

Youth and HIV Resolution

Ms. Hiers noted that most of the comprehensive sex education references in this resolution “are a no-brainer.” The problem at the HHS Office of Adolescent Health mentioned yesterday is something to discuss. Outside of that, Ms. Hiers said she is not sure there is anything controversial about the resolution’s contents. She invited members to wordsmith.

Dr. Holtgrave said he is very much in support of this resolution, but when it comes to naming a specific curriculum in this resolution—such as the one mentioned yesterday as a problem—“we need to lay eyes on it. We need to get a copy of it and to be able to say we reviewed it.”

Ms. Hiers said she would commit to read all 60 pages. Ms. Mahon said “we need formally to request a copy.” Dr. Holtgrave said it seems difficult to locate. Someone from the audience said their New York office has a copy and can get it to PACHA members. Mr. Greenwald affirmed that this was heard and thanked the public attendee.

After a bit of discussion about whether to leave reference to the curriculum in or out of the resolution, Mr. Greenwald suggested that PACHA vote provisionally to leave it in, provided that the actual curriculum actually “says the things that are cited.” Dr. Valdiserri noted an alternative, which is to name the kinds of issues offensive “in any curriculum.” Meanwhile, he agrees with Dr. Holtgrave, “HHS issues aside.” To talk about curricula that promote gender stereotypes and stigmatize based on sexual orientation “gives longevity to the matter.”

Decision Point

After a bit more discussion of the matter, it was decided that it would be, as Mr. Wilson said, “highly inappropriate and dangerous for us to call the particular program out without having time to review it, so using Dr. Valdiserri’s suggestion would be better.”

Meanwhile, Mr. Wilson added he is really concerned about how it even happened that such a curriculum was put on what seems to be an approved list. “What is happening in these review processes that people are totally ignoring what’s in the Strategy and other bodies of work?”

How to Prevent Approval of Such Curricula?

Ms. Mahon asked what PACHA could ask for procedurally to help prevent this, to which Dr. Valdiserri responded, “You can ask HHS what was the process by which this particular curriculum was reviewed and approved. We’re still trying to find that out in my office.” Dr. Valdiserri has received a brief, which he shared with Ms. Hayes, but his understanding is that the review was conducted by an independent contractor with a set of criteria, so “we need to see what the criteria are.” It also would be appropriate to ask the department what the process is. Meanwhile, he and Ms. Hayes need more information.

Ms. Hiers noted that Ms. Audelo is here and has some information about how it happened. Ms. Audelo said “there are no content standards for a program to be placed on the evidence-based list.” If “you look at the Office of Adolescent Health Web site, there are three standards. If you meet one of those standards, you could get on the list.”

Ms. Mahon asked if PACHA can get a presentation on standards for its next meeting.

Mr. Greenwald said he does not want to delay things. He does think this is important. Having the Office of Adolescent Health come, “having us really read the program over, and having some teeth to this resolution, might make sense.”

Rev. Sharp asked when the evaluation was done. Someone who works with Ms. Audelo said “the evaluation was done in 2005, and the curriculum was written in 2004.”

Ms. Hiers said she would rather take specific reference to the curriculum in question out than not vote on the resolution.

Other Aspects of the Resolution

Dr. Horberg said the first “Be it resolved” is not specific enough. “If we’re talking about a cut in programs, we need to give a dollar amount.” Ms. Hiers said “the reason not to is that at the last PACHA meeting, people didn’t want to put line items in without a more systemic approach to the budget.”

Dr. Holtgrave suggested that the last “Be it resolved” be changed so that PACHA is asking that “the programs on the HHS list of evidence-based programs be reviewed again with these criteria in mind.”

Mr. Pérez said he agrees with Dr. Holtgrave’s amendment. He made some more minor suggestions, which Ms. Hiers accepted; Mr. Pérez then said he is not sure that it is PACHA’s role, as relates to one of the “Be it resolveds,” to ask for DASH to be continued as a standalone. He also pointed out some adjustments he felt were needed in the “Whereas” section. He asked if he could work with Dr. Horberg at the break on some of these concerns.

Ms. Hiers said she did not want to put off a vote on this resolution again.

PACHA Will Vote Up or Down on This Today

Ms. Mahon indicated that the Council would be voting up or down today.

Ms. Hiers asked why DASH should be removed from the language. Mr. Pérez responded “I’m not sure what our role is there.” Dr. Horberg said he agrees with Mr. Pérez on this. “The goal is what outcomes we want, not to dictate the process to get there per se. What we want is increased accurate information to youth about sexual health. Do they do this through a standalone DASH, or does CDC feel it could be done a better way?”

Ms. Mahon said, assuming this resolution passes close to this form, “what we do going forward with it is important. I’m not sure what we would do with DASH. In many ways, having a standalone division may disadvantage HIV issues. Sexuality is across the life span. Maybe these elements should be folded together.” Ms. Mahon then asked for members’ thoughts about what PACHA does with this resolution going forward. She asked the same question with regard to the Women and HIV Resolution.

Mr. Brooks said he agrees with Mr. Pérez and Dr. Horberg. “Our role is to advise on policy, not operations and management.”

Ms. Hiers said the controversial provision is now out of the resolution. Ms. Averitt Bridge said, just take out “standalone.” Ms. Hiers confirmed that is what is out. Dr. Valdiserri said the problem is that the D in DASH means “division. That means you keep it as a division. What I suggest is that you think about calling on the CDC or the National Center in which DASH resides to keep a strong programmatic and policy focus on adolescent health issues. You don’t have to say how they do it.”

Dr. Horberg said that is precisely the way to handle it. He said that PACHA also wants to make sure “there is specific targeted funding for those outcomes.” As a side note, Dr. Horberg said the CDC is developing a coalition on sexual health.

Ms. Hiers asked if it is the will of the Council to put the dollar amount back into the resolution. Dr. Holtgrave said if the Council puts dollar amounts back in, he is in favor of increased funding. “It helps when we do put dollar amounts in. Then people know what it is they are buying with that increase.” Ms. Hiers said that will go in the first “Be it resolved.”

Ms. Mahon asked to break for 15 minutes. When the Council returns, resolution sponsors/writers will have redrafted the resolution and will project the redraft. “Then this will be e-mailed to the full Council.” Also, Andrew Forsyth is here, “so after we vote, he will be put on before lunch instead of after.”

Break

Reconvening

Ms. Mahon noted that Mr. Cruz is no longer on the phone, so she needs every member possible back in the room.

Youth and HIV Resolution Redraft

It was noted that 12 members are now present.

Ms. Mahon said Mr. Wilson’s comments about members, including himself, having had plenty of time to consider and suggest amendments before today “are well taken.” Therefore, “unless you have an amendment that would change your vote, keep that amendment to yourself.”

Ms. Hiers projected the resolution and read through the sections that were changed. She asked members to speak up “if there is a problem.”

Members seemed to have no objection to the changes made. Ms. Hayes asked for a language change to indicate that “programs on the evidence-based list housed in the Department of Health and Human Services be reviewed again with these criteria in mind.”

Vote

Members were asked to indicate by voice if they are in favor. It was stated that the resolution passed with a voice vote. It was not clear if some members abstained or voted against the resolution.

The resolution as it was adopted appears here.

Presidential Advisory Council on HIV/AIDS

Health Disparities Subcommittee

Adopted Motion

Support Comprehensive Sex Education for Our Nation's Youth

WHEREAS, young people ages 13–29 make up one-third of new HIV infections, the largest share of any age group, and the Centers for Disease Control and Prevention (CDC) shows that this is the only age group where HIV incidence is increasing, driven by an increase in new infections primarily among young black men who have sex with men;

WHEREAS, the National HIV/AIDS Strategy goal of reducing new infections by 25 percent demands that we achieve a substantial reduction in new HIV infections among persons ages 13–29;

WHEREAS, comprehensive sex education programs give young people the information and tools they need to make healthy and responsible decisions about their sexual health, not only in their adolescence, but throughout their lifetimes;

WHEREAS, the finalized Fiscal Year (FY) 2012 funding included a devastating \$10 million cut to the CDC's Division of Adolescent and School Health (DASH), the only Federal funding dedicated to HIV, sexually transmitted infection (STI), and unintended pregnancy prevention in our Nation's schools;

WHEREAS, the FY 2012 budget also includes \$5 million in funding for abstinence-only-until-marriage programs that a preponderance of studies has shown are ineffective and that do not meet the HIV-prevention needs of young people or HIV-positive young people;

WHEREAS, abstinence-only-until-marriage programs were zeroed out in FY 2010 and FY 2011, as well as in the President's Request for the FY 2013 budget, after more than \$1.5 billion in Federal and State funding has been spent on these ineffective programs;

WHEREAS, the Teen Pregnancy Prevention Initiative was created in FY 2010 to implement evidence-based teen pregnancy prevention interventions and to build upon the existing body of evidence of teen pregnancy prevention programs by funding innovative approaches;

WHEREAS, the Personal Responsibility Education Program was created through the Affordable Care Act to provide States with funding to implement sex education programs that educate young people about abstinence, contraception, and adult preparation subjects, such as healthy relationships and communication and decision-making skills;

WHEREAS, the Title V Abstinence-Only Program was reauthorized in the Affordable Care Act even though a 2007 congressionally-mandated study of Title V abstinence-only-until-marriage programs showed funded programs to have no impact on delay of sexual activity—the primary intended purpose of the programs;

WHEREAS, leading medical, scientific, and public health organizations, including the American Medical Association, American Academy of Pediatrics, American Congress of Obstetricians and Gynecologists, and the Society for Adolescent Health and Medicine, support comprehensive sex education and have called for an end to Federal funding for abstinence-only-until-marriage programs;

WHEREAS, evidence-based and medically accurate interventions give States and organizations a starting point to find the best programs for their communities but are not held to comprehensive sex education content standards;

WHEREAS, this past World AIDS Day, the President boldly announced his Administration's commitment "...to ending the AIDS pandemic once and for all..." and pledged to fight HIV "...today, tomorrow, every day until we get to zero"; and

WHEREAS, each day presents our Nation's schools and community-based organizations with the opportunity to play a critical role in reaching 56 million young people (2010 U.S. Census projected number of students to be enrolled in the nation's elementary through high schools), providing them with information about health and giving them the opportunity to practice the skills that promote life-long, healthy behaviors;

BE IT RESOLVED that the Presidential Advisory Council on HIV/AIDS requests that the Federal Government provide adequate resources to increase HIV prevention efforts with young people and that all Federally funded sex education programs be informed by the best scientific information available and aim to reduce unintended pregnancy and sexually transmitted infections, including HIV; promote safe and healthy relationships; and promote and uphold the rights of young people to have access to information in order to make healthy and responsible decisions about their sexual health.

BE IT RESOLVED that the PACHA supports the expansion of adolescent sexual health efforts in the National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention (NCHHSTP), building on the current activities of the Division of Adolescent and School Health, and that the CDC maintain a strong programmatic and policy focus on adolescent school health and ensure that funding remain dedicated to State, Local, and Territorial education agencies as well as to the non-governmental organizations that support their efforts.

BE IT FURTHER RESOLVED that all Federally funded sex education programs should be built on characteristics of effective programs and expand the existing body of evidence on comprehensive sex education programs through program evaluation.

BE IT FURTHER RESOLVED that no Federal funds should be used for health education programs that withhold life-saving information about HIV; are medically inaccurate or have been scientifically shown to be ineffective; promote gender stereotypes; are insensitive and unresponsive to the needs of sexually active adolescents; are insensitive and unresponsive to the needs of lesbian, gay, bisexual, or transgender youth or are inconsistent with the ethical imperatives of medicine and public health; and ask that the Department of Health and Human Services' list of evidence-based programs be reviewed again with these criteria in mind.

Women and HIV Resolution Redraft

Vote

Dr. Garcia and Ms. Khanna projected changes to the draft, in red. After a few minutes, someone made a motion in support of this draft. It was supported, a vote was called for, and a vote was taken. It seemed to be a voice vote. Ms. Mahon said all were in favor. No one spoke as opposed.

Here is the resolution as passed.

Presidential Advisory Council on HIV/AIDS

Access to Care Subcommittee

Motion as Adopted

Resolution on the Needs of Women at Risk for and Living With HIV

WHEREAS, we are at a critical moment in the HIV epidemic and cannot end the epidemic without addressing the specific needs of all affected communities;

WHEREAS, women bear nearly a quarter of the domestic HIV burden;

WHEREAS, the HIV epidemic has a disproportionate impact on women of color, with rates of new infection among Black women fifteen times that of white women, and among Latina women over three times the rate of white women;

WHEREAS, there is limited data available concerning HIV rates among transgender women, yet several studies have shown disproportionately high HIV rates, particularly among transgender women of color;

WHEREAS, racial disparities persist in incidence, access to testing, access to quality care, and in health outcomes especially for Black, Latina, and transgender women;

WHEREAS, women living with HIV enter late into HIV care, have impaired access and adherence to antiretroviral therapy, suffer many HIV-related illnesses, and have high mortality rates;

WHEREAS, accessing care and essential support services, including housing, is especially challenging for women living with HIV, as they are disproportionately low income and are likely to have caretaking responsibilities;

WHEREAS, the primary mode of HIV acquisition for woman is heterosexual contact, and female-controlled prevention methods are not yet available;

WHEREAS, transgender women are especially vulnerable to violence, poverty, homelessness, and discrimination and because they experience a lack of access to high-quality, competent care face challenges in adhering to treatment regimens;

WHEREAS, women most at risk for or living with HIV are likely to experience sexual or intimate partner violence one or more times in their lives;

WHEREAS, the Affordable Care Act (ACA) provides numerous opportunities to increase access to care for women living with and at risk for HIV, including expanding access to private and public insurance coverage;

WHEREAS, sustained success in perinatal prevention efforts requires unfettered access to prenatal care;

WHEREAS, access to reproductive health services is essential to decrease the occurrence of unplanned pregnancies and to promote safe conception;

BE IT RESOLVED that the PACHA requests participation in the newly created Working Group on the Intersection of HIV/AIDS, Violence against Women and Girls and Gender-Related Health Disparities.

BE IT FURTHER RESOLVED that the PACHA recommends that the Secretary of Health and Human Services request all relevant Federal agencies, the newly created Working Group on the Intersection of HIV/AIDS, Violence against Women and Girls and Gender-Related Health Disparities, along with the White House Office of National AIDS Policy and the HHS Office of HIV/AIDS and Infectious Disease Policy, to update the National HIV/AIDS Strategy (NHAS) and its implementation plan to ensure they envision and achieve specific, targeted, and measurable goals and objectives for reducing HIV incidence and HIV-related health disparities and improving health care access and health outcomes for women living with HIV.

BE IT FURTHER RESOLVED that the PACHA recommends that the National HIV/AIDS Strategy (NHAS) implementation plan be updated to address the needs of women in the following ways:

- 1) To evaluate the effectiveness of the first two years of the National HIV/AIDS Strategy (NHAS) in addressing the needs of women living with HIV, especially for Black, Latina and transgender women, using all available data (such as those related to late diagnosis, retention in care, viral suppression, HIV-related and reproductive health outcomes);
- 2) To make quality and effective gender-sensitive care for women living with HIV more widely and readily available through the integration of HIV care and prevention services with sexual and reproductive health care and intimate partner violence prevention and counseling;
- 3) To expand and expedite the provision of housing and services that facilitate linkage to and retention in care for women with HIV;
- 4) To produce and make available by January 2013 more refined data (as noted above in 1)) that analyze the unique health and service needs of women with HIV; and
- 5) To produce expanded research into the development of women-controlled prevention methods.

BE IT FURTHER RESOLVED that the PACHA recommends that routine HIV testing and screening and counseling for intimate partner violence and sexually transmitted infections be covered as required Medicaid preventive services for women, just as these services are now required to be covered by private insurance plans without cost sharing.

BE IT FURTHER RESOLVED that the PACHA recommends that ONAP work with HHS, the Health Resources and Services Administration (HRSA), the Center for Medicare and Medicaid Services (CMS), the Centers for Disease Control and Prevention (CDC), and the Substance Abuse and Mental Health Services Agency [*sic*] (SAMHSA) to develop an Affordable Care Act implementation plan that ensures that the full prevention, care, and treatment needs of women living with and at risk for HIV are met.

HIV/AIDS Core Indicators Update

“Implementing Common Core Indicators, Streamlining Data Collection, and Reducing Reporting Burden for HHS-Funded HIV Programs: An Update,” by Andrew D. Forsyth, Ph.D., OHAIDP, OASH, HHS

Objectives of This Presentation

The objectives of the presentation are:

- An update of recent OASH/OHAIDP activities
- Discussion of new developments
- Preview of immediate next steps
- Open discussion.

Dr. Forsyth stressed that he would welcome PACHA’s input and advice going forward, “as always.” He noted it is important that the IOM inform HHS implementation efforts. He has briefed PACHA’s Incidence Subcommittee on this, and he can discuss it more, if desired.

Moving quickly through his slides, Dr. Forsyth noted the Strategy’s goals to achieve a more coordinated national response to the HIV epidemic (slide 4). He also noted key aspects of the implementation plan to achieve these goals, including engaging PACHA’s Incidence Subcommittee (slide 5).

On slide 6, Dr. Forsyth noted OASH recommendations for common core indicator domains:

- HIV diagnosis
- Early HIV diagnosis
- Initial linkage to care
- Sustained engagement in care
- Initiation of ART
- Viral load suppression
- Housing.

Dr. Forsyth noted OASH recommendations for data streamlining and reducing undue reporting burden (slide 7), including aligning with IOM indicator recommendations. He noted that in April 2012, the HHS Secretary issued a memorandum requiring that (slide 9):

- Within 90 days, relevant parties work with OASH to finalize a set of common core HIV/AIDS indicators
- In the subsequent 90 days, relevant parties finalize plans with OASH to implement core indicators, streamline data collection, and reduce reporting burden by at least 20–25 percent for HIV grantees
- Operational plans be fully deployed by the beginning of FY 2014.

IOM Report: Monitoring HIV Care in the United States—Indicators and Data Systems

In slide 10, Dr. Forsyth noted key aspects of the IOM report process, and in slide 11, the IOM report’s key recommendations, including providing guidance for improving the interoperability of data systems.

In slide 12, Dr. Forsyth reviewed the IOM report’s implications for HHS, including elements to be resolved. These “to be resolved” elements include:

- How best to align IOM recommendations with HHS efforts
- How all HHS-funded programs can report specific elements, given limited capacity
- How interoperability of data systems can best be improved
- How reporting obligations legislated by Congress can be navigated.

Dr. Forsyth noted that a request for information has been released to service providers on what it would take to develop a system to improve interoperability of data systems.

ONAP Update

ONAP is “very supportive of indicators, streamlining, and burden reduction, and considers 20–25 percent reduction of burden as a minimum.” In addition, Dr. Forsyth said, there is a “real possibility that it will extend these efforts to other relevant departments, such as HUD, and so on.”

Immediate Next Steps

Phase I, as outlined on slide 15, is what “has happened.” Dr. Forsyth emphasized that an initial HIV/AIDS Indicators Implementation Group meeting is scheduled for June 7, 2012. Invitations to attend have been extended to Drs. Holtgrave, Horberg, and Garcia as representatives of PACHA.

Dr. Forsyth indicated that there will be one or two post-meeting calls. “We’ve worked hard to get to the June 7 meeting.” The goals are specified at the end of slide 15.

Discussion/Comments/Questions and Answers

Dr. Forsyth said a lot of progress was made just as soon as the Secretary’s memorandum was issued. “It took us some time to convene a meeting, but we are set up to achieve goals in our timeline.”

Dr. Valdiserri thanked Dr. Forsyth for his excellent overview. He has a few clarifications. Three PACHA members have been identified to work with this group, as reported, but because of time constraints,

“we had to pick a meeting date without consultation.” He extended to any PACHA member an invitation to share any ideas or thoughts about the process directly with him or Dr. Forsyth. Two Federal-Government-only phone meetings have been held. The first major open meeting will be June 7, 2012. “We probably will have a telecom before that to reach out to non-Federal partners.”

Dr. Valdiserri said that Dr. Forsyth’s presentation referred to external consultants. They are two paid consultants under contract to Dr. Koh; one is a medical epidemiologist.

New Data Indicators for LGBT Populations

Mr. Baker thanked Dr. Forsyth for a great presentation and good progress. He has questions. In terms of the implementation group/consultation, “do you have interface with the Healthy People group and the new data indicators for LGBT populations, especially transgender populations?” Is AHRQ participating, “as they are thinking about public reports for the future of the ACA”? Mr. Baker had the same question about the CDC National Center for Health Statistics.

Dr. Forsyth said the group has been working to reach out to all Federal partners across the Government and “to be mindful of progress in development of core indicators around LGBT. This is an important priority for HHS.” Dr. Forsyth said he has not been as directly engaged with the LGBT group that has been associated with this. Rather, the mechanisms have been informal, and Dr. Valdiserri may want to say more. The same is true of AHRQ, as they have some 600 indicators in their warehouse.

Mr. Baker’s Suggestions Are Good Ones

Dr. Valdiserri said Mr. Baker’s suggestions are good ones. An important nuance is that the proposed consolidated set of measures “is not meant to be the alpha and omega.” We “recognize that other offices and agencies will need to collect information about other important metrics that are not part of the core set. We want to put everything on a diet. We want to be mindful to ask for information that is necessary, not just information for information’s sake.” The goal is that “we want to be able to look across all HHS programs at shared measures for late diagnosis of HIV,” for example, but “these will not be the only measures you could ever use.”

Dr. Valdiserri reiterated his appreciation of Mr. Baker’s suggestions.

Need for Broader Sense of LGBT Populations

Mr. Baker said “part of our situation is that agencies have developed these measurements in isolation.” AHRQ is engaged in considerable investment and work on public reports, yet “there are no HIV indicators in these public reports right now.” The “HRSA database is extremely difficult to manipulate.” In short, “if you don’t get in now at the front end, you will have this wonderful set you have developed that, in a year and a half, will have no relevance.” Meanwhile, “how do we begin to collect a range of data on those populations to get a broader sense of LGBT populations?”

Work Has Been Done in This Area

Vera Yakovchenko said “we recently updated the AHRQ performance measure in our office around the ACA issue. We are currently fielding language on transgender sexual orientation and working with SAMHSA on that. In terms of Healthy People, we helped to standardize those measures with the

Strategy's goals in the summer and fall of 2010. You can see that rates have been adjusted to align with the Strategy."

End User Involvement?

Mr. Brooks expressed to all involved that this work is exciting and important "for folks in programs every day and having to report on grants." How "wonderful it will be when the effects of this work flow to those on the ground." He does have a question, and that is, "Does it make sense at some point to have one or two end users involved in the process?"

Dr. Valdiserri responded "Yes," and this is "exactly what I meant when I said we would be reaching out to NASTAD and the Urban Coalition on HIV/AIDS Prevention Services. We definitely want those user perspectives."

Dr. Holtgrave echoed what Mr. Brooks said, adding that the work done so far "has been terrific." He also indicated some concern about IOM recommendations, as he worries about "the perfect getting in the way of the extremely good." Dr. Holtgrave then noted that his recent work with linkage and retention in 13 cities "is probably the hardest thing I've ever worked on."

Behavioral Indicators

Dr. Forsyth noted that he and Dr. Holtgrave and others talked last week during the Incidence Subcommittee conference call about adding additional indicators (additional to one metric on unprotected risk behavior and sero status in discordant relationships). "We've explored this topic often, and we believe it is important to include a behavioral indicator in the final core set, but for now, we are concentrated on the charge before us." He can "see the value of several suggestions that have been made. This is not a one-time effort, and, as the IOM recommended, this process will take place every 2 years or so. It will be important to stratify the cascade data in terms of LGBT. It will also allow us to look at women and racial and ethnic minorities."

PACHA Has Been Very Involved in This Work

Dr. Horberg said the work on this is "wonderful," adding that "PACHA has been very involved in this." For all of us, "this is a tremendous product." Echoing conversations he has had with Dr. Forsyth and others on behavioral issues "as we go forward with meaningful use and electronic health records, behavioral issues are difficult to extract here. It may be necessary but not necessarily cheaper."

Rev. Sharp said she was struck by the public comment yesterday regarding the 700 percent increase in African immigration to the United States. Rev. Sharp noted that the speaker offered a report. She asked what Dr. Valdiserri and his staff have to say about that.

Ms. Yakovchenko responded that her office has conducted an inventory of demographic characteristics, and "we ask about foreign-born status. We are considering that to be a somewhat core indicator that needs to be standardized over time as well."

Dr. Garcia thanked staff for the great job on this so far, adding she "strongly endorses outcomes related to behaviors, such as STI rates and unintended pregnancy rates. It is so critical to include those."

It was indicated that there would be no lunch or any other kind of break until PACHA finished today's agenda.

Drug Injection Letter

Ms. Hiers introduced what was referred to as the "drug injection letter" regarding syringe exchange stemming from Public Comments yesterday.

Mr. Pérez said the letter, to the President, contains several grammatical errors. He does want to endorse it, however.

Discussion/Comments/Questions and Answers

Dr. Horberg asked if letters from PACHA are signed by PACHA or Ms. Mahon. Ms. Hayes said Ms. Mahon, as Chair, signs the letters.

Mr. Pérez raised an issue that generated quite a bit of discussion, which was the letter's reference to a coalition of 91 organizations. "We've heard from one person who spoke on behalf of these organizations, but reference to stakeholders and providers is what is needed here." He had many other comments, so many that he offered to sit at the lunch break and make changes.

Ms. Hiers said in response to a query about international trends that syringe exchange is used in Vietnam, where the epidemic "is half IDU [injection drug use]."

Vote, Then Attend to Grammar?

Mr. Wilson asked to have a conversation about the concept and then vote, and allow for things like grammatical changes to take place afterwards. Ms. Mahon endorsed that approach.

Mr. Wilson added that he very much supports the concept of the letter, but a reference to data in this letter is far from the strongest reference, so he asked that this reference simply be struck, "as it goes to a place we don't have to go." Mr. Pérez indicated he would like to work with Ms. Hiers to clarify what the most recent prohibition on syringe exchange in the United States specifically applied to.

Mr. Baker said he has a tactical question and an appropriateness question, the latter first. He said he does not know "whether it is appropriate for us to send the President a letter that is pretty much a sign-on letter. It misrepresents our process. We haven't done a deliberative process. It's not a big deal, but it would be better to say that this is an issue of concern to PACHA, on its own. We don't know how the community sign-on was conducted. We shouldn't be involved in that."

Requested Change Made

Ms. Hiers changed the last paragraph of the letter to be responsive to Mr. Baker's concern and also struck the list of sign-on organizations appended to the draft. Dr. Horberg said the letter is now stronger, and it will be well if the coalition of sign-on organizations also sends a letter.

Mr. Brooks said he is wondering about the efficacy of the letter. "Does it add more power that we have heard from the public? Otherwise, I wonder where this thing lands, anyway."

What Can the Administration Do?

Ms. Mahon asked whether, procedurally, “We are asking the Administration something they can do.” “At some point, our side caved on this and other issues in the appropriations process. What are we actually asking them to do? There was no way the President could ‘X’ the ban portion of the appropriations bill out. Is there something more specific the Administration could do quickly?”

Dr. Horberg said he feels bad that he cannot directly answer Ms. Mahon’s question. He agrees with Mr. Baker that the letter is more effective as a standalone. “Our minutes will reflect that we had public comment on that and that we’ve acted on the public comment and taken the action of producing a letter. The coalition’s request was not necessarily to sign on to their letter but to use the strength of PACHA to request change. We don’t need to echo that group.”

PACHA Has Discussed This Subject Often

Ms. Khanna said one reason PACHA could respond so quickly is that the Council has talked quite a bit about this subject, and “it fits into science-based policies, which is consistent with PACHA’s values. Part of our agenda is trying to prioritize and move issues. We can say there is strong community support for this.”

Mr. Wilson said “all we really need to say is that this is an issue that came up in public comment but not add the list. We can make a statement that this public testimony is consistent with PACHA all along.”

Mr. Wilson added that Ms. Mahon is correct that the ban occurred at the Congressional level, “but you are also right that the Administration did cave. So the point of this is PACHA recommends the Administration not cave in the future and that we add to the body of evidence when this argument comes up again. It can be said that the ‘experts on this issue’ have said this about syringe exchange the next time it comes up. This could have influence on the negotiation even before the appropriations bill comes up.”

Ending the Ban Is the Request

Ms. Hiers agreed with Ms. Mahon that she buried the lead in this draft of the letter “because isn’t ending the ban the ‘ask’?”

Ms. Mahon asked if there is a way to get this out of the appropriations process. “We’ve spent so much money on exchange, and now we’re back to the ban. This is money that could have been used for other measures.”

Mr. Pérez suggested “marrying our long-time support for syringe exchange with how this was amplified recently for us by public testimony.”

To Mr. Pérez’s point, Dr. Holtgrave asked if this letter could reference the letter PACHA sent to the President in August 2011, which mentioned this issue as well. “Also, can we copy the Congressional HIV Caucus? How far can we go?”

ACTION ITEM

Ms. Hayes said Dr. Holtgrave's question was "a great question," and she will follow up.

Dr. Garcia said "this is a point at which we need to weigh in on this issue, but, realistically, it is not our job to weigh in on the political solution. It would be an abdication of our responsibilities not to weigh in on the health implications. We need to do it appropriately and respectfully."

The Cost of Not Ending the Ban

Mr. Greenwald agreed. "There is benefit in supporting this and even to add from the fiscal perspective the cost of needle exchange versus the lifetime cost of HIV treatment."

Mr. Brooks said he had consulted a legislative expert, who said "There is no mechanism for getting around the appropriations process."

Mr. Greenwald noted that States and local communities have moved forward, and part of the Congress has endorsed syringe exchange. Private foundations also have endorsed it.

Ms. Mahon said on the private side, given the size of the CDC budget cut, "We do not have funding to keep the door open."

Ms. Mahon asked what can be accomplished on this in the next hour. Ms. Hiers said she will work with Dr. Holtgrave and Mr. Pérez on an altered draft. She asked if the PACHA Web site would have all the historic resolutions. She asked if staff could look through the reports.

Vote Now?

Mr. Brooks said he trusts Ms. Hiers, Dr. Holtgrave, and Mr. Pérez to come up with a good version, so could PACHA take a vote now on the letter "in its essential form?" Ms. Mahon said PACHA could do this.

Include List of Organizations?

Ms. Hiers asked if PACHA could first vote on whether to mention or include the list of 91 organizations. Mr. Wilson said that Mr. Pérez has already provided a solution. "We did not hear from 91 organizations." Merge "that this is a consistent position of the Council and that we receive public comment on this on a regular basis," Ms. Khanna suggested. Mr. Baker said "Citing 91 organizations doesn't have any political value, and you diminish your stature when you say this."

Vote on the Drug Injection Letter

A vote was called on the letter, with the understanding that Ms. Hiers, Dr. Holtgrave, and Mr. Pérez will change parts of it to reflect PACHA member comments. The vote was unanimously in favor, Ms. Mahon stated.

The redraft of the letter was e-mailed to members after the meeting. That redraft follows.

Draft PACHA Syringe Exchange Letter to President Obama

May 17, 2012

The Honorable Barack H. Obama

The White House

1600 Pennsylvania Ave., N.W.

Washington, DC 20500

Dear Mr. President,

As members of the Presidential Advisory Committee on HIV/AIDS, we would like to thank you for your previous support for use of federal funds for syringe services programs (SSPs), and we request your continued leadership on behalf of the critical role that SSPs play in achieving the goals of the National HIV/AIDS Strategy (Strategy).

As stated in the Strategy, "...studies show that comprehensive prevention and drug treatment programs, including needle exchange, have dramatically cut the number of new HIV infections among people who inject drugs by 80 percent since the mid-1990s." The Strategy additionally states that access to sterile needles and syringes is one of five "...scientifically-proven biomedical and behavioral approaches that reduce the probability of HIV transmission..." and further states that "...several studies have found that providing sterilized equipment to injection drug users substantially reduces risk of HIV infection, increases the probability that they will initiate drug treatment, and does not increase drug use."

In December 2009, you signed into law the Consolidated Appropriations Act 2010, ending a two-decade ban on federal funding for syringe exchange programs contained in the Labor, Health and Human Services, Education, and Related Agencies Appropriations bills. This policy allowed local jurisdictions to invest Federal funds for syringe exchange as a component of comprehensive HIV/AIDS and viral hepatitis prevention services and substance abuse treatment and recovery programs. Unfortunately, Congress imposed a complete ban on use of Federal funds for SSPs for FY 2012. This reversal represents a major setback in achieving the goals of the Strategy at a pivotal time in the course of the epidemic. The funding restriction also diminishes our credibility and leadership on HIV/AIDS globally and our advocacy efforts to support effective, evidence-based strategies to combat the HIV/AIDS epidemic internationally.

Ending the ban on the use of Federal funds for syringe services programs remains an urgent priority for the public health, HIV/AIDS, viral hepatitis, and harm reduction communities. Sustaining and expanding access to sterile syringes and comprehensive services for people who inject drugs is of vital importance to disease control efforts, as State and local jurisdictions struggle to adequately resource these programs as they confront new challenges and growing demand. We are extremely concerned that the FY 2012 federal funding ban may worsen access to HIV testing and prevention interventions for this key

risk group, exacerbate HIV-related racial and ethnic health disparities among injection drug users, and jeopardize our ability to meet the goals of the Strategy.

We support your FY 2013 budget language that would allow for the use of federal funds to support SSPs:

“SEC. 505. None of the funds contained in this Act may be used to distribute any needle or syringe for the purpose of preventing the spread of blood borne pathogens in any location that has been determined by the local public health or local law enforcement authorities to be inappropriate for such distribution.”

This language is consistent with our longstanding position on this issue and is further amplified by a recent statement made to the PACHA reiterating strong community support for evidence-based efforts.

We encourage the Administration to continue its support for this language, to prioritize restoring local flexibility in funding syringe services programs during negotiations around the FY 2013 Appropriations bills, and to clearly convey this priority to Congress.

Again we thank you for maintaining your Administration’s focus on syringe services programs.

Respectfully yours,

Nancy Mahon, Chair

Presidential Advisory Council on HIV/AIDS

PACHA Subcommittee Updates

Subcommittee Co-Chairs gave very brief reports on the activities of their Subcommittees.

Access to Care Subcommittee

Mr. Greenwald emphasized, as he has consistently for several meetings, that the Subcommittee is focused in large part on the intersection of the ACA and Ryan White and on Ryan White reauthorization, and also how the intersection of the ACA and Ryan White relates both to the upcoming IAC and PACHA’s report.

Mr. Greenwald said he still thinks a state of the science summit “is something we could do and would be helpful.” He asked if the Incidence Subcommittee “could work that up.”

Disparities Subcommittee

Ms. Hiers noted that she had been very involved in the needle exchange letter, which PACHA just voted to approve, and, likewise, the Youth and HIV Resolution, which PACHA just voted to approve. She noted a meeting with HUD on HOPWA modernization, “and no one thinks it will happen this year.”

Mr. Brooks noted that the Subcommittee continues to examine the issue of condoms being criminalized.

Global Subcommittee

Ms. Averitt Bridge said the Subcommittee has had no recent conference calls. She noted that some of the Subcommittee’s members are outside the United States and not here that often. She asked PACHA

members interested in working with the Subcommittee to let her or Kevin Frost know “so that we can assess what we are going to be working on in the remaining months of this year” in addition to global funding issues.

Incidence Subcommittee

Dr. Holtgrave noted that the Subcommittee continues to be involved in metrics and also behavioral measures. Near-term future work will involve FDA decisions regarding PrEP and at-home testing. He continues to advocate for a state of the science summit. Praveen Basaviah has joined the Incidence Subcommittee.

Dr. Holtgrave added that “we could help influence the agenda at the AETC meeting.” Dr. Horberg said that the AETC “has not historically dealt with what you advocate.”

CHAC Update

Ms. Dempsey said CHAC met last week, and a few resolutions came out of that meeting; a workgroup was established on Ryan White reauthorization; CHAC members accepted a definition of sexual health; and CHAC will write the Secretary a letter regarding establishment of a viral hepatitis working group. CHAC’s title and charter were recently changed to include viral hepatitis.

In addition, CHAC discussed youth and peer review of youth programs. There was much discussion about this topic.

Joint PACHA/CHAC Sexual Health Framework Letter Approved

PACHA voted to approve a joint PACHA/CHAC letter to the Secretary, with copies to CDC Director Thomas R. Frieden and HRSA Administrator Mary Wakefield. Mr. Brooks noted that PACHA members had much opportunity to vet the letter’s contents, and that the letter basically provides background on the importance of a sexual health framework in providing a unifying theme with a focus on health, rather than disease, “that may counter the forces of stigma and provide a positive, life-affirming approach.”

The letter, dated March 14, 2012, also contains a recommendation from PACHA and CHAC that “HHS, CDC, and HRSA leadership support the development and implementation of a public health approach to advancing sexual health in the United States,” and then provides specific suggested points of action.

May Is Viral Hepatitis Month

Dr. Valdiserri noted that May is “Hepatitis Awareness Month.” He knows that PACHA has not discussed extensively how coinfection is a major undertaking for his office, but there is a national plan on viral hepatitis that is a year old, under which HHS is putting together a plan for how to do a better job of diagnosing coinfections, particularly chronic infections. He invited members to look at the notice in their packets about this. The first-ever testing day is this Saturday (May 19, 2012).

ACTION ITEM

Mr. Brooks noted that at the previous CHAC meeting, this was identified as one of three or four areas “where we could and should be working together.” He will send more information to PACHA members.

IAC: Update/Discussion on PACHA Involvement

Ms. Mahon said that, as regards the ACA and Ryan White, “we have to clarify whether we can have external civilians on the PACHA, so if you yourself want to be on this or make suggestions about Federal actors to be on this, send those suggestions to Ms. Hayes in the next week.” Also, she added, “we talked about trying to do a scan of what is already happening, so we need to know what groups already exist and also about external groups. We have funds for that.”

Mr. Wilson said, as a process note, that he asked for 2 hours of space, and “whatever they respond with, we will have to go with that.” He will take responsibility for informing those who need to know. At this point, whatever the time is, “some of us are going to be booked.”

Next PACHA Full Council Meeting

Ms. Mahon said that members should e-mail dates of conferences being held in the fall so that PACHA can “try to involve more folks who may be attending those conferences in PACHA’s next full Council meeting, in the fall.”

Initial Closing Remarks

Attendance

Ms. Mahon thanked everyone for being here. She said she and Ms. Hayes will be looking at attendance and “hoping to write a letter about, if you are on PACHA, you have to be here.” This was an “excellent meeting, and we appreciate the attendance of members of the public.”

Can PACHA Handle a Potential New Subcommittee?

Rev. Sharp asked about a potential new Subcommittee and whether PACHA has the ability to “handle that, in terms of manpower.”

Chair to Check With Mr. Frost on Reception Space

ACTION ITEM

Ms. Mahon said she will check with Mr. Frost on the reception space.

Rev. Sharp asked if PACHA members “will have to be the ones who do stuff, not bartending.”

Full Council Fall Meeting Dates

When queried about full Council fall meeting dates, Ms. Mahon said, “This depends on where others are.”

Ms. Hayes said she wants to establish the date as soon as possible, so members can put it on their calendars. Dr. Garcia asked if we “are trying to avoid or maximize attendance?” Ms. Mahon said, “Maximize both Federal attendance and PACHA member attendance.”

Agenda for the Fall Meeting

Focus on Transgender Populations/Presentation by the Office of Adolescent Health

Dr. Garcia asked if the fall meeting will have a focus on transgender populations. Ms. Mahon responded in the affirmative. Ms. Hayes added that there should be a presentation by the HHS Office of Adolescent Health.

Mr. Baker asked if we are talking about a meeting with more public people attending, adding that “this is probably easy to do. Identifying a meeting where there are Federal officials might be more difficult to do, particularly since Federal officials have such restrictions on travel.”

Ms. Hayes said part of this exercise is “trying to hold a date early so as to get it on Federal officials’ calendars early.”

Syringe Exchange Letter to the President

Ms. Hiers asked as a matter of process that although PACHA passed the syringe exchange letter to the President, “I didn’t capture all the changes, so when are we going to do this?” Mr. Pérez responded that this should be done now.

Fall Meeting Topics Continued

Finalizing PACHA’s Report

Dr. Holtgrave noted topics for the fall meeting that have been brought up, adding that “if we finalize and vote on PACHA’s report, we need a day to do that, to pass the whole report. This could happen on the afternoon of the first day and the morning of the second day. We need to do that work.”

Dr. Horberg responded that PACHA could have conference calls, “with public notice.”

Ms. Mahon asked if this is at odds with working on a transgender agenda. Ms. Hiers said “no, as that will require 2 or 3 hours.” She added that Mr. Jack needs to be the point person on that.

Adjournment

Ms. Mahon adjourned the meeting at 12:47 p.m., with a shout-out for Ms. Hayes, Mr. Joppy, and Dr. Valdiserri’s staff.