The Medical Monitoring Project (MMP) is a national surveillance project designed to provide information about the experiences and needs of people receiving care for HIV. It is sponsored by agencies in the U.S. Department of Health and Human Services—the Centers for Disease Control and Prevention (CDC), National Institutes of Health, and Health Resources and Services Administration—and is currently being implemented by 26 state and local health departments.

MMP contributes to HIV/AIDS case surveillance by providing comprehensive clinical and behavioral information on a patient sample carefully selected to represent everyone receiving medical care for HIV in the United States. The goals of the project are to (1) provide local and national estimates on behaviors and clinical outcomes for persons in care for HIV; (2) describe health-related behaviors; (3) determine accessibility and use of prevention and support services; (4) increase knowledge about the care and treatment provided; and (5) examine variations by geographic area and patient characteristics. State and local health departments have identified all HIV care facilities in their respective areas. A representative sample of the facilities was chosen, and representatives were contacted by the health department. An equal probability sample of patients was then selected from those facilities.

MMP has two primary data collection components: a personal interview and medical record abstraction. MMP staff members coordinate with providers to invite each selected patient to participate in a face-to-face interview. The interview takes approximately 45 minutes and includes questions concerning the patient’s medical history, use of medical and social services, and risk behaviors. Participants are compensated for their time. Trained MMP medical record abstractors then collect additional information from the patient’s medical chart, which complements the data from the interview.

Health department staff members are taking measures to ensure the project is not burdensome to participating providers or patients. State and local health department representatives conduct all data collection activities to avoid disrupting providers, their staff, or services to their patients. All personal and health care information collected during the project is secure and confidential. Names of facilities, providers, or patients are not sent to CDC.

Q & As

Is the collected information kept confidential?
Yes, all collected information will be kept confidential, including facility, provider, and patient names. Facility, provider, and patient names are not sent to CDC and will not be used in any reports.

Can patients decline or withdraw?
Yes, patients may decline or change their minds about participating at any time. However, patients selected represent other patients in care, so their participation is important.

Who is conducting the project in local areas?
State and local health department staff members conduct all data collection activities.

Where can I learn more about MMP?
Patients and providers can contact their state or local health department for more information about MMP or visit the Web site at: http://www.cdc.gov/hiv/topics/treatment/mmp/index.htm
What’s New with MMP

**MMP Staff News**

New staff members have joined the Clinical Outcomes Team at CDC. We would like to extend a warm welcome to the following:

- Emma L. Frazier, PhD, MS, Senior Data Manager
- Andrea Polk-Stephenson, MS, MSR, Project Coordinator
- Catherine Carroll, MA, Project Coordinator
- Jian Zhang, PhD, Data Manager

**Presentations**

- Exarchos, A. Factors associated with antiretroviral adherence in Washington State. Presented at: the 2nd Annual International Conference on HIV Treatment and Adherence; 2007 March; Jersey City, NJ.

### MMP Project Areas

<table>
<thead>
<tr>
<th>States</th>
<th>Territory</th>
<th>Cities</th>
</tr>
</thead>
<tbody>
<tr>
<td>California</td>
<td>New Jersey</td>
<td>Puerto Rico</td>
</tr>
<tr>
<td>Delaware</td>
<td>New York</td>
<td>Houston</td>
</tr>
<tr>
<td>Florida</td>
<td>North Carolina</td>
<td>Los Angeles</td>
</tr>
<tr>
<td>Georgia</td>
<td>Oregon</td>
<td>New York City</td>
</tr>
<tr>
<td>Illinois</td>
<td>Pennsylvania</td>
<td>Philadelphia</td>
</tr>
<tr>
<td>Indiana</td>
<td>South Carolina</td>
<td>San Francisco</td>
</tr>
<tr>
<td>Maryland</td>
<td>Texas</td>
<td></td>
</tr>
<tr>
<td>Massachusetts</td>
<td>Virginia</td>
<td></td>
</tr>
<tr>
<td>Michigan</td>
<td>Washington</td>
<td></td>
</tr>
<tr>
<td>Mississippi</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Provider Advisory Board (PAB)

Chris Zebley, ANP-BC, MSN, AAHIVS, Delaware

I received a Bachelor of Science in Nursing from Widener University in Chester, Pennsylvania in 1993. Following that, I completed a Master of Science in Nursing at the University of Delaware in 2001. Currently, I work as an adult nurse practitioner specializing in oncology/immunodeficiency at Christiana Care Health Services HIV Community Wellness Program, Brandywine Counseling, Inc. This program is an outpatient substance abuse treatment center located in the heart of Wilmington—traditionally the hardest hit area in the state in terms of infection rates. Our clients are, in large part, unable to afford basic health care and we see any effort to increase access or quality of care to HIV- and AIDS-diagnosed patients as an effort worth being involved in. I collaborate closely with the primary infectious disease specialist in Delaware, Dr. Susan Szabo, who served previously as our Medical Monitoring Project Provider Chair.

Dr. Szabo has an extremely large HIV- and AIDS-diagnosed patient load, which prompted her to ask me to step in and represent the provider community in Delaware for this project. The program is now receiving two different levels of provider representation within the state. I am involved in a very active community clinic setting and am able to coordinate closely with other similar clinic settings within the state. Dr. Szabo is also available to help coordinate efforts in larger infectious disease treatment settings, if needed.

I am the medical coordinator for Safety Net Services, which is a program for clients who are women with children and also persons who are ex-offenders within the past 2 years. This program offers HIV testing, HIV medical management, mental health services, opiate treatment, counseling, case management, and transitional housing services.

“The (MMP) program allows for surveillance of treatment services made available in each state. It also provides an important look at the trends in data, treatment deficiencies, and most importantly, we hope the program results in the discovery and allowance of new treatment options nationwide.”

Chris Zebley, Delaware PAB member
Here are a few of my recent achievements according to the Academy of HIV Medicine, 2007–2009:

I served as the 2007 delegate from Delaware at the “Physicians for Human Rights Organization Campaign.” This effort involved advocating on Capital Hill for comprehensive services for IV drug users to decrease HIV infection globally.

I am a member of the Steering Committee in Delaware for the 5-year pilot “Needle Exchange Program.” Our efforts expose the community and intravenous drug users to the program and encourage unrestrained use of available resources. The committee is also involved in building a legislative case for continued program operation beyond the initial 5-year period.

I am a faculty staff member within the AIDS Education Training Center (AETC), representing physician assistants, nurse practitioners, and registered nurses, AETC’s program, in coordination with Ryan White services, is a network of regional and national centers that train health care providers to treat persons with HIV/AIDS. As the clinical training component of the Ryan White Program, AETC seeks to improve health outcomes for people living with HIV/AIDS through training on clinical management of HIV disease in areas such as use of antiretroviral therapies and prevention of HIV transmission. The program targets providers who treat minority, underserved, and vulnerable populations in communities most affected by the HIV epidemic. Innovative training methods—skill-building workshops and clinical practice placements—augment traditional didactic education. AETC also provides clinical consultation and decision support to clinicians regarding care and use of antiretroviral therapies, and technical assistance to improve service delivery at the organizational level. My MMP activities are a natural fit within these lines of duty.

Although I am relatively new to the MMP, I have been an active participant since the program started. I assisted the MMP interviewers in locating and meeting with patients who are being treated both on and off site. I have given full training sessions to MMP investigators on the diverse set of medical terminology, explaining the significance of test results and medical chart navigation, and helped with promoting the MMP program to gain media exposure at special community events related to HIV/AIDS patient care. Those of us in the Delaware HIV/AIDS medical provision community believe that all medical providers, along with public health community, must provide the same quality and standards of care and epidemiological education across the country. The level of data we are given for analysis will directly drive how we act in our future fight of this epidemic.

My statement, above, directly reflects the importance of MMP. The program allows for surveillance of treatment services made available in each state. It also provides an important look at trends in data, treatment deficiencies, and most importantly, we hope the program results in the discovery and allowance of new treatment options, nationwide.
“People go to their doctors and may not be truthful about monogamous relationships; the doctors do not always follow through with questions, which creates gaps. Sometimes, it’s just too difficult to talk to the doctors. There is very little attention paid to the anniversary month of someone’s diagnosis. Doing so may help people celebrate their medical successes.”

Gregg Fordham, CAB member, Virginia

Community Advisory Board (CAB)

Gregg Fordham, Virginia

My name is Gregg Fordham, and I am currently serving as a representative on the MMP CAB. I believe that everyone is supposed to help someone along the way. When dealing with HIV/AIDS, people need to know they are not more unique or different than anyone else just because they are living with HIV/AIDS. I have been living with HIV for 17 years, and I am fortunate to be able to help people. It is not courage that propels me forward. I do it because helping is the right thing to do. Real courage is taking the test for HIV/AIDS.

I was born in Orlando, Florida. My father served in the Air Force and I was the typical “military brat.” We were lucky enough to live in Japan when I was 12–15 years old. That experience taught me a lot, including respecting others for their differences, mainly because I was different; I was tall in a culture that was not the same as me.

Like my father who served in the military, I joined the Navy. I was stationed on a ship and was responsible for running the ship’s store, barber shop, laundry, etc. My favorite part of serving in the Navy was the opportunity to travel to so many wonderful places including Oslo, Halifax, St. Maarten, St. Thomas, Spain, Italy, Greece, and Egypt. I love people and I love to travel. My favorite thing was to experience the heat and water in St. Thomas.

In 1990, I was diagnosed with HIV. The first thing I remember asking my doctor was “how long do I have to live?” My doctor’s response was, “You could go outside and get hit by a bus and die, so I cannot tell you because nobody can ever tell you how long you really have to live.” He had no idea how relevant his answer would be. Thirteen years later on December 12, 2003, I was in a car accident and almost died. They say I blacked out in the car. When I woke up several weeks later, it was January 2004, and my left leg had been amputated above the knee. They were still trying to save my right leg. Both of my arms had been crushed in the accident, the right side of my body was severely burned, and I had a C2 neck fracture. In the end, I lost my right leg, and now I am medically labeled a “bilateral above-the-knee amputee.” One might think this was a huge challenge for me; however, I joke a lot about myself these days. I used to be very tall and have long arms. I was 6 ft ½ inches tall.
I am one of the only people who can tell you what it feels like to be both short and tall! In fact, I have tall and short pictures of myself! Today, my friends love to go places with me because I can get wheelchair access. I consider it a ‘ perk.’ Center court at a basketball game is my favorite place! At first, people would tell me “God had a plan for me.” Now, I know that to be true and I know that I need to keep doing what I am doing to help others with HIV/AIDS.

When I was in high school, I played basketball and was good at it. I played into my adult years and continued to play while in the Navy. Today, I still play, albeit a totally different way. I currently play center forward with the Virginia Sun Wheelers basketball team. I continue to play for fun just as I did when I was in school. It’s encouraging to know that even though my life has changed dramatically, I can still do the things that have been fun for me throughout my entire life. The guys on the Sun Wheelers taught me stuff that no therapist could ever teach me, like how to pop off little curbs in my chair instead of looking for cut-ins, and how to take some risk and have some faith.

After my HIV diagnosis, I needed to figure out my issues of disclosure. I didn’t feel that I had anything to hide, but I wasn’t sure what to tell my family. I began by telling my sister, in what I thought was “strictest confidence.” And she said, “It’s like you have a cold that you can’t get rid of and there is nothing different about you.” Before I knew it, Mom and everyone else knew about it, but they didn’t say anything directly to me. My Mom first started talking about it by asking me how I “felt,” and I realized that I was happy she was talking about it. I became known as Mr. HIV to my family up and down the East Coast. To my family, it is not a big issue. I visit with my family, go to conferences, and enjoy helping people along the way.

“Once I told my family, it was okay to tell the world.”
Gregg Fordham, CAB Member, Virginia

I am the luckiest man and have the greatest support system in the world. When I got out of the hospital after the accident, all my friends wanted to take care of me, and for that I was thankful. However, I told them I needed to learn to do stuff on my own. I have friends who tell me they are having a bad day, but, I don’t believe in bad days. I do believe that if God allows you to open your eyes, what you do with the rest of your day is totally up to you.

My role model was my granddad. I saw how hard he worked. He taught me the value of working hard and of respect. Granddad had four girls and put two of them through college and one through nursing school. He earned the respect of everyone in his community in Orlando. Today, people tell me that I am their role model. I am just trying to work hard and do what is right, like my granddad. In Tidewater, I am Chair of the Community Planning Group. I also serve on the Ryan White Planning Council and various other committees. I coordinate and attend town hall meetings to bring issues and education to people who are living with HIV/AIDS.

I have been active in the Campaign to End AIDS and am organizing the initiation of a statewide affiliation to the national movement. I arranged a caravan for People Living with HIV/AIDS to travel to Myrtle Beach, South Carolina, for a political debate.

For MMP, I participate as a CAB member and help implement interviews in our community. MMP will make a difference by taking snapshots of what HIV care looks like in communities throughout the country. MMP also helps us determine gaps in care. For me, when I was first diagnosed, the shock was significant and lasted 2–3 weeks. For others, the shock lasts even longer. I believe this is why some people don’t follow up with medical care quickly enough or right after their initial diagnosis. Doctors talk in a language that is foreign to most people, especially when those people are already in shock about the diagnosis. There is a big gap in which providers are supposed to be talking to patients about safe sex practices and risk reduction techniques. People go to their doctors and may not be truthful about monogamous relationships; the doctors do not always follow through with questions, which creates gaps. Sometimes, it’s just too difficult to talk to the doctors. There is very little attention paid to the anniversary month of someone’s diagnosis. Doing so may help people celebrate their medical successes.

I try to have positive energy. I have always believed in helping others, even before my accident. Seven or eight years ago, I created a couple of prevention youth groups for teenagers to show others how to prevent HIV/AIDS. We got creative and developed different strategies for prevention education that helped keep kids engaged in learning—Sex Court, Sex Hunters, and Girltalk. We talked about abuse, HIV, STDs, etc. We did corny things, and people jumped right in to participate.

One of the barriers was that kids “aged out” of the group and had to stop attending. Luckily, three of those original kids are getting ready to graduate and today I still keep in touch with them. At the same time I worked with the youth group, I also started a Gay Youth Group. We participated in retreats, including the Advocates for Youth in Washington, DC. This retreat continues today, and it’s encouraging to see the growth and continuity.

MMP is one project that I thoroughly enjoy. I like to share information with people. People on CAB must be dedicated and committed to be involved. When we have a conference call, there are approximately 15–20 people from across the country participating. That says something strong about the process. I look forward to the MMP conferences in Atlanta where I meet all these people face to face. They inspire me because they are doing so much.
Spotlight on Virginia

"During the interview process, most of the participants show a lot of support for the project and provide their point of view about programs that can assist persons living with HIV/AIDS."

Betty Vines, MMP Interviewer/Abstractor, Virginia

The Virginia MMP team consists of eight staff members: Dena Bensen (principal investigator), Carmen B. Roman (program coordinator), Betty Vines (interviewer/abstractor), Lanisha Childs (interviewer/abstractor) Stephanie Lewis (interviewer/abstractor), Gregg Fordham (lead CAB member and temporary interviewer), Anushree Vichare (temporary medical record abstractor), and Shankar Krishnappa (MPH internship student/temporary abstractor). The total number of facilities sampled in Virginia for 2007 was 23; 18 agreed to participate.

During December 2007, MMP staff initiated contact with the sampled facilities to prepare for interviewing participants. Of the 18 participating facilities, 15 have worked together with MMP staff in recruiting their patients. Only three of the selected facilities have shown poor participation in the project. To further these facilities’ participation, help has been requested from Virginia’s Provider Advisory Board member to draw on his experience and knowledge about the project and motivate these facilities to continue with their participation.

As of April 8, 2008, Virginia MMP has completed 128 interviews and has started medical record abstractions. The active collaboration and participation of the CAB and PAB members has been a great help in disseminating information about MMP throughout Virginia. One of our MMP interviewer/abstractors, Betty Vines, stated that: “During the interview process, most of the participants show a lot of support for the project and provide their point of view about programs that can assist persons living with HIV/AIDS.”

MMP Staff Spotlight

Tyler Smith, Oregon MMP Staff

Tyler has extensive experience doing HIV counseling and testing in marginalized communities.

Tyler Smith is an interviewer and abstractor for the Oregon MMP. In addition to interviewing and abstracting, he also works on participant recruitment and abstractor trainings. He has been working in the public health field for 8 years, primarily providing direct services in homeless medical clinics. He is a naturopathic physician and is currently working toward his MPH degree in Portland. Besides working with the MMP, he runs a transgender (trans) health clinic serving low-income and homeless trans people. He has been involved with trans health activism for 10 years, and, in addition to directly providing health care to transgendered people, has provided trainings for health care providers and organizations on transgender health issues. In the HIV field, Tyler has extensive experience doing HIV counseling and testing in marginalized communities. On the personal side, Tyler is getting married this year to his partner of almost 5 years. They live a great life together with their 4 cats and a black lab.
Eduardo Valverde, MPH, CDC MMP Project Officer

Currently, Eduardo is the MMP project officer for Florida, Maryland, Pennsylvania, Philadelphia, Puerto Rico, and Virginia. He also coordinates the MMP Provider Survey, serves as project officer for Philadelphia in the Never in Care (NIC) project, and represents the Behavioral and Clinical Surveillance Branch in CDC’s Hispanic Latino Executive Committee.

Originally from Lima, Peru, Eduardo Valverde came to the United States in his early 20s. He settled in Miami, Florida, where, for the next 20 years, he was involved in public health education and research. In Miami, he also completed a bachelor’s degree in sociology and anthropology, a master’s in public health, and began studies towards a Ph.D. in medical sociology.

Eduardo became involved in the HIV/AIDS epidemic in 1991, when he started working for one of the first community-based organizations in Miami funded to provide HIV/AIDS education to high-risk heterosexuals. As a health educator with this community-based organization, he conducted hundreds of HIV prevention presentations in homeless shelters, substance abuse treatment centers, public schools and other community settings. He later coordinated the HIV/AIDS Prevention Program of the American Red Cross Greater Miami Chapter, where he had the opportunity to train and direct the activities of dozens of Hispanic and African American HIV/AIDS instructors. Later, he worked for 5 years for the Florida Department of Health (DOH) as a Program Manager coordinating HIV sero-surveillance activities in the south Florida area in settings such as STD clinics, drug treatment centers, TB clinics, homeless shelters, and correctional facilities. With the Florida DOH he also had the opportunity to work in other HIV related studies such as the Homeless and Runaway Youth Survey and the Young Men’s Survey.

Before joining CDC in September 2006, Eduardo worked for 6 years at the University of Miami, Miller School of Medicine, directing behavioral interventions designed to improve access to HIV medical care and reduce high risk behaviors among HIV-positive populations. In his position as senior research associate at the University of Miami, he also led an international collaboration with one of the largest HIV primary care clinics in Argentina, conducting quantitative and qualitative HIV epidemiological studies with HIV-positive persons living in Buenos Aires.

Currently, Eduardo is the MMP project officer for Florida, Maryland, Pennsylvania, Philadelphia, Puerto Rico, and Virginia. He also coordinates the MMP Provider Survey, serves as project officer for Philadelphia in the NIC project, and represents the Behavioral and Clinical Surveillance Branch in CDC’s Hispanic Latino Executive Committee. Eduardo is married and has two children. He spends his free time collecting Latin American art, cooking, and being chased by his two boys around the house.

MMP Upcoming Events

CAB Quarterly Conference Call
Date for the next CAB call is September 8, 2008, at 1 pm (EST)

PAB Quarterly Conference Call
Date for the next PAB call is in June 19, 2008, at 3pm (EST)

To be “Spotlighted” in the MMP Newsletter contact:
Andrea Polk-Stephenson, MS, MSR
Project Coordinator/Health Research Analyst III
Northrop Grumman Information Technology CITS Contract
Centers for Disease Control and Prevention
E-mail: fuo3@cdc.gov  Tel: 404-639-6165  Fax: 404-639-8640