




Medical Monitoring Project 101
June 25, 2009







Overview and History of MMP
A.D. McNaghten
Clinical Outcomes Team Leader






MMP 101 Overview

- Describe the history of MMP
- Describe the sampling design
 - Discuss recruitment
 - Describe data collection and management
- Describe how data will be used at the local and national level





The Medical Monitoring Project, or MMP, is a large, complex project, and it takes many people with very specific roles to meet the goals of the project. With the 2009 data collection cycle underway, we thought it was a good time to provide an overview of the project to enable everyone, no matter what their role with the project, describe MMP to providers, patients, colleagues and others. To accomplish this, we are going to discuss the history of MMP, the sampling design, recruitment methods, data collection and management, and how MMP data will be used at the local and national levels.

We will go through the entire presentation and then follow with time for questions and answers.



HIV/AIDS Surveillance Tools

- Core surveillance
 - HIV/AIDS Reporting System (HARS)
 - Collects a core set of information on all persons with HIV and AIDS
 - Gender
 - Age
 - Race/ethnicity
 - Mode of HIV exposure
 - Provides information on the number of cases and trends in the epidemic

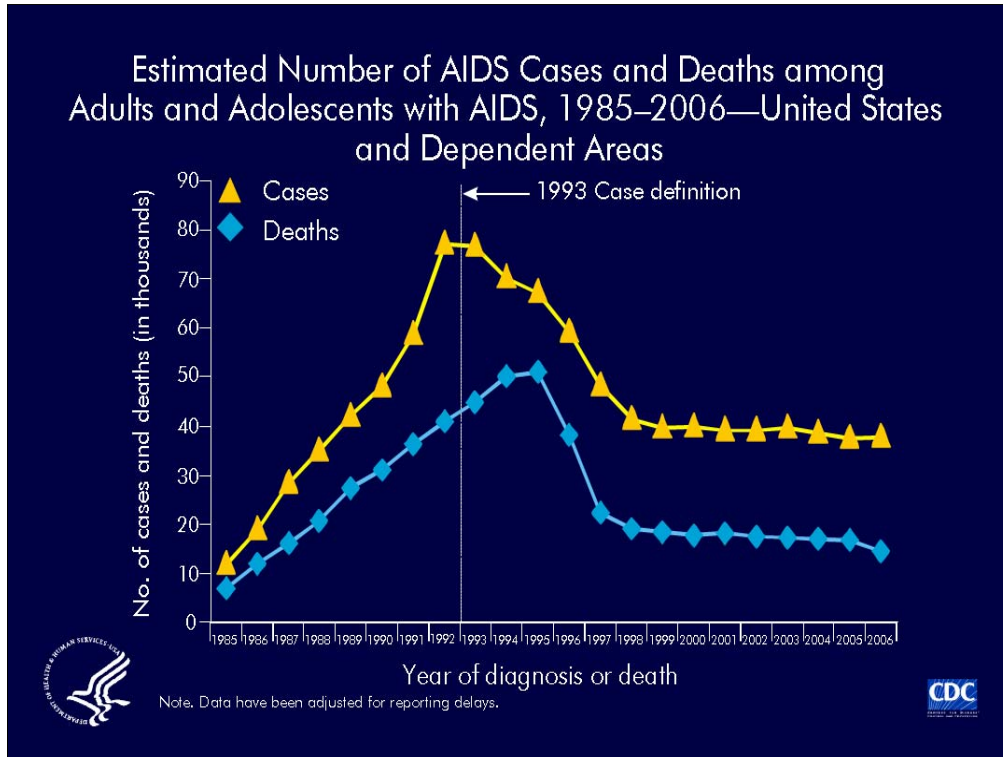


Since MMP is a surveillance project, I'm going to start out by describing what surveillance is.

Most of you are familiar with HIV and AIDS case surveillance, which occurs in all states to collect a core set of information on persons with HIV and AIDS through the HIV/AIDS Reporting System, or HARS.

Core surveillance gathers basic information on everyone reported with HIV or AIDS, such as gender, age, race/ethnicity, and mode of HIV exposure.

Core surveillance provides information on the number of cases and trends in the epidemic.




This is an example of core surveillance data, showing the estimated number of AIDS cases and deaths among adults and adolescents with AIDS from 1985 through 2006 in the US.

The upper curve represents estimated AIDS incidence (number of new cases); the lower one represents the estimated number of deaths.

The peak in 1993 was associated with the expansion of the AIDS surveillance case definition implemented in January 1993. The overall declines in new AIDS cases and deaths of persons with AIDS are due in part to the success of highly active antiretroviral therapies, introduced in 1996.



In recent years, AIDS incidence and deaths of persons with AIDS have leveled.

The data have been adjusted for reporting delays.



What is HIV Surveillance?


- Supplemental Surveillance
 - Gathers detailed information on fewer people
 - Access to and receipt of clinical care and support services
 - Health care seeking and other behaviors
 - Helps explain the reasons for the trends



Supplemental surveillance gathers more detailed information on fewer people compared with core surveillance.



Supplemental surveillance projects are used to examine access to and receipt of care and support services, and health care seeking and other behaviors.

While core surveillance describes the trends in the epidemic, supplemental surveillance helps explain the reasons for the trends. For example, supplemental surveillance would tell you the proportion of persons eligible for antiretroviral therapy who are prescribed therapy, and declines in opportunistic illnesses, which help explain the trends in AIDS incidence and deaths in the graph you just saw.




Surveillance Tools - SHAS

- Supplement to HIV/AIDS Surveillance (SHAS)
 - Interview
 - 19 sites; 1990-2004
 - Risk behaviors of persons with HIV infection
 - Reasons for testing
 - Factors associated with receipt of antiretroviral therapy
 - Adherence to therapy
 - Sex and drug use behaviors





I'm going to tell you briefly about CDC's supplemental surveillance projects that came before MMP.

The Supplement to HIV/AIDS Surveillance, or SHAS project, was an interview project conducted in 19 areas in the US from 1990 through 2004 that focused on risk behaviors of persons with HIV, including their reasons for testing, factors associated with receipt of antiretroviral therapy, adherence to antiretroviral therapy, and sex and drug using behaviors.




Surveillance Tools - ASD

- Adult/Adolescent Spectrum of Disease (ASD)
 - Medical record abstraction
 - 11 sites; 1990-2004
 - Clinical outcomes of HIV infection
 - Trends and risk factors for opportunistic infections
 - Evaluate impact of treatment and prophylaxis on disease progression and survival





The Adult/Adolescent Spectrum of HIV Disease, or ASD project, was a medical record abstraction project that examined clinical outcomes among patients in care in 11 US cities from 1990 through 2004.

ASD allowed us to look at trends and risk factors for opportunistic illnesses and to evaluate the impact of treatment and prophylactic medications on disease progression and survival.




Surveillance Tools - SHDC

- Survey of HIV Disease and Care (SHDC)
 - Medical record abstraction
 - 12 sites; 1999-2001
 - Population based
 - Clinical outcomes, treatment
- SHDC+
 - Abstraction + interview
 - 3 sites in 2004
 - Clinical outcomes, treatment
 - Behaviors





The Survey of HIV Disease and Care, or SHDC, was a population-based medical record abstraction project conducted in 12 areas of the US from 1999 through 2001. It focused on clinical outcomes and treatment, similar to ASD.

SHDC+ was conducted in 3 areas in 2004. It expanded on SHDC by adding an interview component to examine both clinical outcomes and behaviors.



Surveillance Tools

- Limitations
 - ASD and SHAS convenience samples
 - SHDC and SHDC+ population-based but not nationally representative
 - Limited areas participating
- Lack of nationally representative estimates of persons infected with HIV who are in care and
 - Type and quality of care received
 - Behaviors currently engaging in



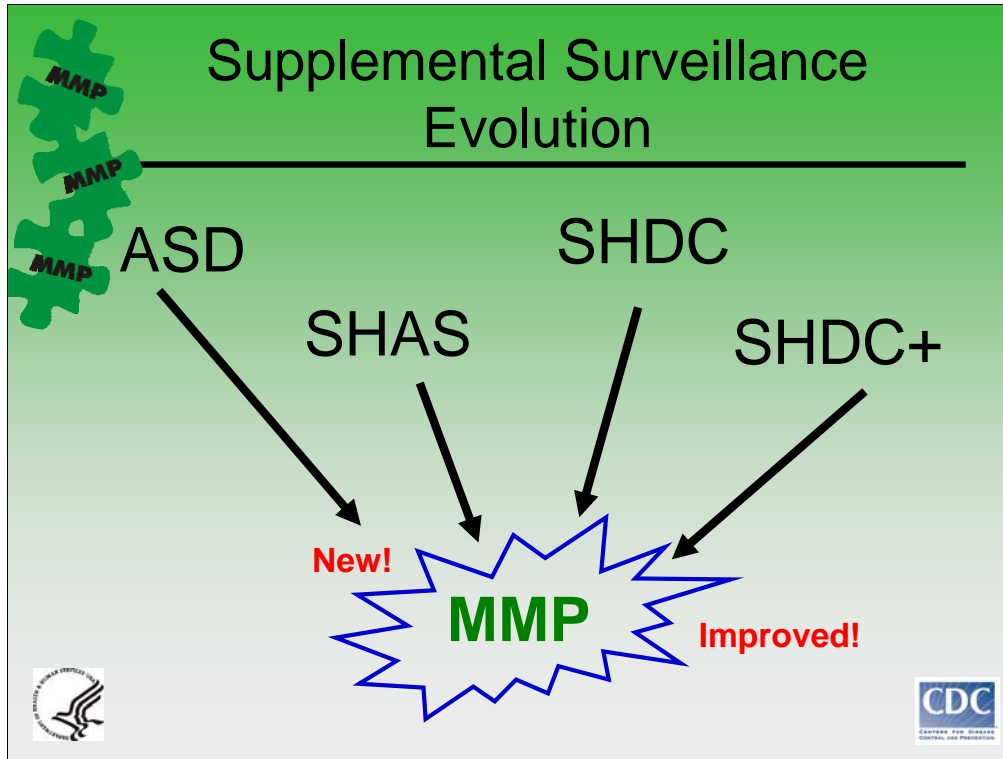
Although these projects provided very useful data, they had their limitations.

ASD and SHAS were convenience samples.


SHDC and SHDC+ were population-based, but not nationally representative.

And all of these projects had a limited number of areas participating.

In addition, we did not have nationally representative estimates of HIV-infected persons in care, the type and quality of care they were receiving, or the behaviors they were engaging in.





ASD, SHAS, SHDC and SHDC+ were all discontinued to make way for MMP, which is comprised of elements from each of these projects.



Surveillance Tools - MMP

- Medical Monitoring Project (MMP)
 - Matched interview and medical record abstraction
 - 26 areas 2004-2008; 23 areas 2009-2013
 - Annual multi-stage probability sample of HIV+ adults in care in the US
 - Locally and nationally representative estimates of HIV infected adults in care

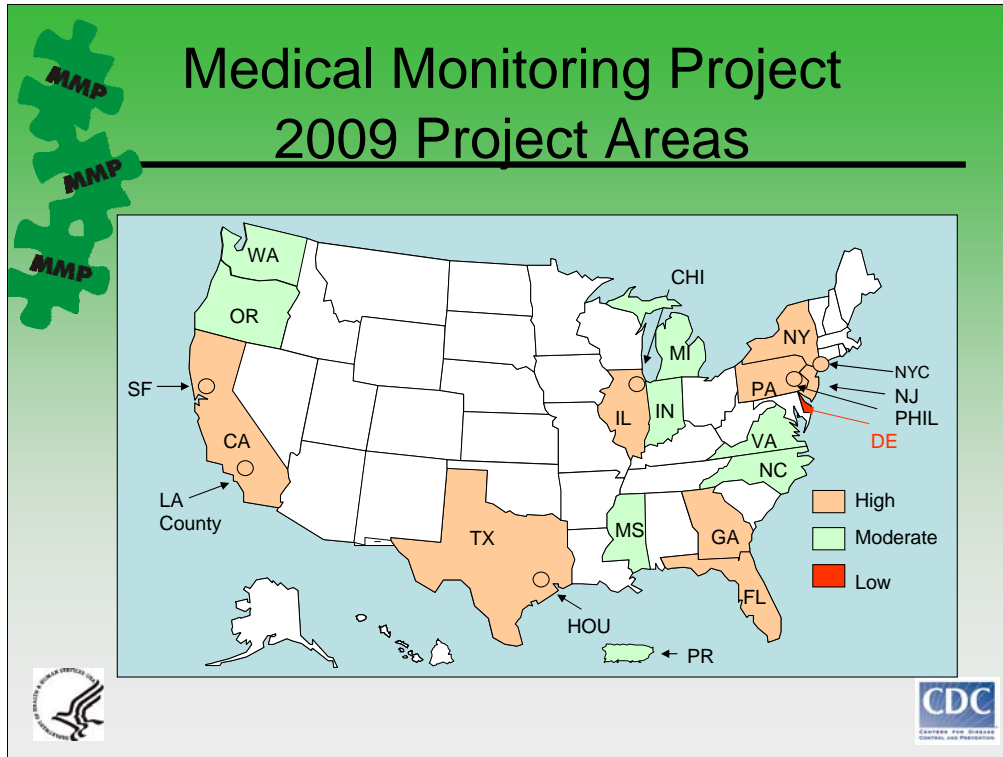


Our new and improved supplemental surveillance project, MMP, collects both interview and medical record abstraction data on HIV-infected patients receiving care.

It was conducted in 26 areas from 2004 through 2008, and will be in 23 areas from 2009 through 2013.

MMP is an annual, multi-stage probability sample of HIV-infected adults receiving care in the US, and we'll talk more about what that means later in this presentation.

The most important feature about MMP, and what makes it really unique, is that it will result in locally and nationally representative estimates of HIV-infected adults in care.



The following are the 23 project areas currently participating in MMP.

Project areas were selected to include different geographic areas, and high, medium and low prevalence areas.

The sampling part of this presentation will tell you more about how these areas, and providers and patients, are selected to participate in MMP.

Collaborators



- Centers for Disease Control and Prevention (CDC)
- State and Local Health Departments
- National Institutes of Health (NIH)
- Health Resources and Services Administration (HRSA)
- National Agencies
- Community and Provider Advisory Boards



There are many collaborators on MMP.

The Centers for Disease Control and Prevention, or CDC, oversees the project nationally and ensures project activities are conducted consistently across all project areas. CDC also draws samples of facilities and patients for each project area.

State and local health departments are responsible for identifying and recruiting sampled facilities and patients and collecting all MMP data.

The National Institutes of Health and Health Resources and Services Administration have provided critical input on what data to collect, and several national agencies that focus on HIV prevention, services and care actively support the project.

Community and Provider Advisory Boards have been part of MMP since the beginning of the project to provide input on project activities and at both the local and national levels and assist with recruitment at the local level.




Provider and Community
Advisory Boards
Nolana Woolfork
Project Coordinator



Hello, I am Nolana Woolfork, Project Coordinator for MMP. I am going to tell you about the activities of the Provider and Community Advisory Boards.





The Provider Advisory Board or PAB plays a vital role in MMP.




Provider Advisory Board (PAB)

- Includes HIV care providers from each project area
- Provide clinical expertise to MMP staff





The PAB is comprised of experienced HIV care providers that represent each of the 23 CDC-funded project areas.

PAB members provide clinical expertise to MMP staff at both the local and national levels.



Provider Advisory Board (PAB)

- Purpose
 - Foster collaborations
 - Promote MMP in the community
 - Guide dissemination of information




The purpose of the PAB is to

Foster collaborations between local and national MMP staff and HIV care providers



Promote MMP in the local community

Guide dissemination of information within medical communities




PAB Local Activities

- Provider Recruitment
 - Contact and persuade providers to participate
 - Assist local MMP investigators with recruitment strategies
- Promotion
 - Educate other providers about MMP
 - Send endorsement letters to providers
 - Present at medical conferences and meetings





The PAB has two roles at the local level: to assist local MMP staff with provider recruitment, and to promote MMP in their community. PAB members frequently play an important role in recruitment by contacting and persuading providers to participate, and helping local MMP staff determine recruitment strategies.

Many PAB members actively promote MMP by educating other providers about the project, putting their name on MMP endorsement letters sent to providers, and presenting information about MMP at meetings and conferences.



PAB National Activities

- Annual National Advisory and/or PAB Meetings
- Bi-annual conference calls
 - Provide project area updates
 - Receive updates on MMP progress
 - Discuss topics of interest
- Input on MMP protocol, data collection instruments, and educational materials




At the national level, PAB members attend an annual Provider Advisory Board meeting to share information with other areas and with CDC.

Also, they participate in bi-annual conference calls to provide updates on progress in their local areas and to stay informed on the progress of MMP at the national level, and to discuss topics of interest, such as provider recruitment.

They also review and provide input on the MMP protocol, data collection instruments, and educational materials.





The Community Advisory Board or CAB also plays a vital role in MMP.




Community Advisory Board (CAB)

- Includes one community representative from each project area
- Serve as a link between patients and MMP staff





The CAB is a national board that includes one community representative from each of the 23 CDC-funded project areas.

They serve as a link between MMP staff and patients who participate in the project.



Community Advisory Board (CAB)

- Purpose
 - Ensure that MMP is effective and respectful
 - Advise local and national MMP investigators
 - Ensure that MMP data supports planning processes
 - Increase awareness of MMP in the community




The purpose of the CAB is to

Review the methods and procedures of MMP and ensure they are effective and respectful, including the recruitment of patients

Advise local and national investigators about the community's perception of MMP



Ensure that the data collected are useful to the local community and support HIV care and prevention community planning

Increase awareness of MMP in the community




CAB Local Activities

- Recruitment
 - Serve as a local resource to answer questions
 - Assist in improving recruitment methods
- Promotion
 - Educate peers about MMP and encourage their participation
 - Send endorsement letters to providers
 - Present at local meetings and conferences





At the local level, MMP CAB members serve as local representatives or resources for MMP to answer questions from persons interested in participating. Also, they work with the local MMP project staff to improve the effectiveness of methods used to recruit providers and patients.

CAB members promote MMP by educating their peers about the project and encouraging their participation, sending endorsement letters to providers, and presenting information about MMP at meetings and conferences.



CAB National Activities

- Annual National Advisory and/or CAB Meetings
- Quarterly conference calls
 - Provide project area updates
 - Receive updates on MMP progress
 - Discuss topics of interest
- Input on MMP protocol, data collection instruments, and educational materials



At the national level, CAB members attend an annual Community Advisory Board meeting to share information with other areas and with CDC.

Also, they participate in bi-annual conference calls to provide updates on progress in their local areas and to stay informed on the progress of MMP at the national level, and to discuss topics of interest, such as patient recruitment.

They also review and provide input on the MMP protocol, data collection instruments, and educational materials.

Next we're going to talk about sampling, so you can learn more about how project areas, providers and patients are selected to participate in MMP.



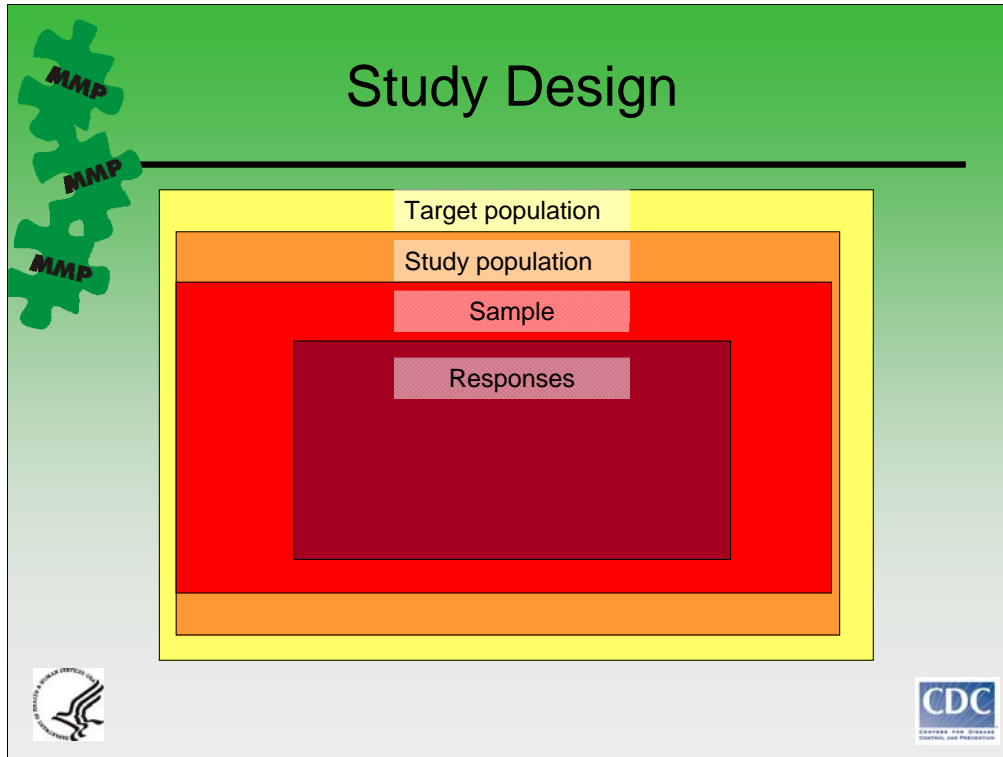
Sampling Design

Chris Johnson

Senior Mathematical Statistician



Hello, My name is Chris Johnson. I'm a survey statistician with the Division of HIV/AIDS prevention, and my major project is MMP. Today I'll talk about what's involved in drawing samples for project areas participating in MMP.



I want to start with some general comments on the designs of surveys. Epi studies often begin by describing a target population, the people you'd like to say something about. The large rectangle is the target population.


The study population is the people we can study and includes those receiving care at an identified provider. Project areas construct a frame, a list that represents that population. People receiving care at facilities left off that list are part of the target population, but not the study population.

Project areas have too many subjects to include everyone, will draw a sample of those eligible from the frame. So within the study population there's the sample.

Some people in the sample won't be interviewed because they can't be located, or they're located but refuse to participate, or otherwise become ineligible. So, we are left with a set of respondents which is the last rectangle nested in the others.



Given that you lose some people you wanted to study at every stage, how can you say that the results you end up with are accurate?

This is the classic set-up for a survey: you have results for respondents only, and analyzing the results requires you to make a series of adjustments to extend the results from respondents to the sample, the sample to the study population, and in some cases the study population to the target population.



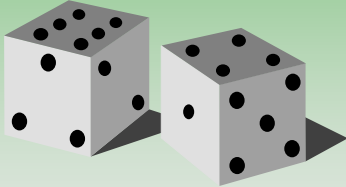

Study Population for MMP

- The study population is
 - HIV–infected adults who received care from known providers of outpatient HIV medical care in the US during a pre-specified time period





Now to focus on the study population for MMP, we defined it as including all HIV-infected adults who received care from known providers of outpatient HIV medical care in the US during a pre-specified time period.

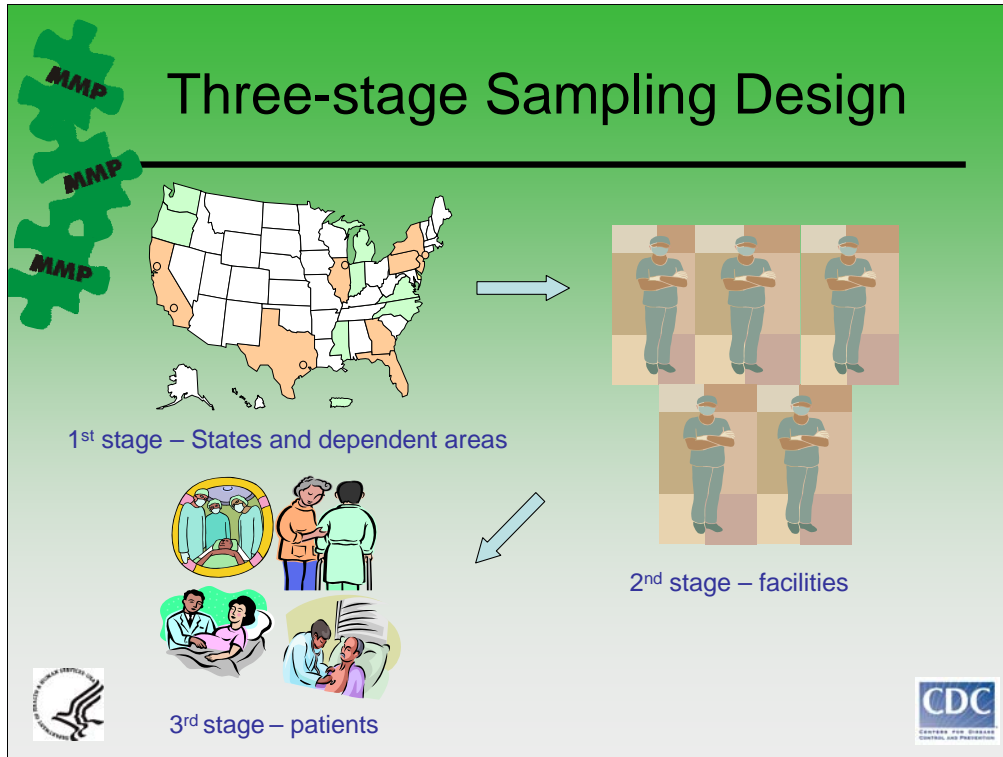
Probability Sample



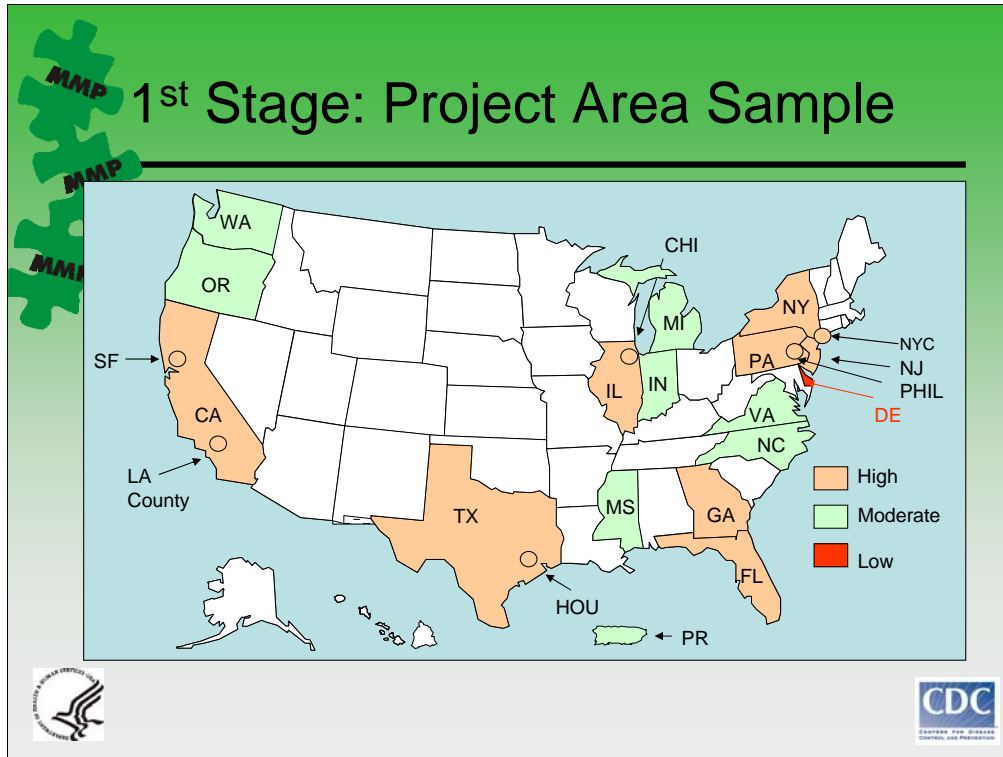
- A sample selected by a process that gives each element in the population a **known, non-zero** probability (chance) of selection



A properly-done survey sample has not only a well-defined study population but also a probabilistic way of choosing the sample. It's harder than just rolling dice. Each element in the population must have a known, non-zero probability (or chance) of selection. To get the adjustments right, you need for them to be of the right magnitude, which is why you have to know what those probabilities were.



MMP uses a stratified cluster sampling design that produces annual cross-sectional probability samples. MMP is designed to be a nationally representative sample of HIV-infected persons in care recruited through three-stage sampling design. The first-stage sampling resulted in selection of 20 states (which included 6 cities). The second stage of sampling selects HIV care providers based on the number of HIV-infected patients seen at the facility. For the 3rd and final stage of sample selection, HIV positive adults receiving medical care during that pre-specified period of time are sampled at participating, selected facilities.






You saw this map in the introduction. It depicts the 23 project areas currently participating in MMP. Project areas were stratified to include different geographic areas, and high, medium and low prevalence areas.

The first-stage sampling resulted in selection of 20 states (which included 6 cities) with selection probabilities proportional to their number of living AIDS cases reported as of December 2002. That was our best proxy measure for the burden of HIV nationally at the time. That sample was fixed for the duration of the project period.

Eligible Facilities

- HIV care: provider performed CD4 or HIV viral load testing or prescribed antiretrovirals
- Facility: any hospital, clinic, health care facility or group or private physicians' practice sharing a medical record unit
- Population Definition Period (PDP): four-month period during which patients presented for care
– January – April 2009
- Estimated Patient Load (EPL): estimated number of patients that received care at a given facility during the PDP




There are some nuances that affect which facilities are eligible and their chance of selection: questions of what, who, when, and how many.

A facility is considered to be providing HIV care if a provider performed CD4 or viral load testing or wrote prescriptions for antiretroviral meds.

A facility is defined as any hospital, clinic, health care facility or group or private physician practice using one medical record unit. A medical record system may be organized among a group of big providers or two providers in the same facility can have a separate medical records system.



The Population Definition Period (PDP) is the four-month period during which patients presented for care. For the MMP 2009 data collection cycle, the PDP is uniform across all project areas and extends from January 1 through April 30, 2009.

The estimated patient load is the expected number of patients receiving care at a particular facility during the PDP.




2nd Stage: Facility Sampling

- A frame is a list that represents the study population
- Needed
 - a complete list (with no duplicates) of facilities that provided HIV care in the specified area during the 12 months prior to the surveillance period
 - accurate estimates of patient load at each identified facility (EPLs)





A frame is a list that represents the target population.

To perform second-stage sampling, project areas need a sampling frame with a complete list of facilities that provided HIV care in the specified area during the 12 months prior to the surveillance period as well as an accurate estimate of patient load at each identified facility.



Facility Samples

- List of eligible facilities comprises frame
- Facilities selected PPS with EPL as measure of size
 - Larger EPL → higher chance of facility selection
 - Smaller EPL → lower chance of facility selection
- Typical facility sample size: 20 – 40 per area



This list of eligible facilities comprises the frame.


From it, facilities are selected with Probability Proportional to Size, with EPL as the measure of size

If a facility has a large EPL, it has a higher chance of facility selection



If a facility has a small EPL, it has a lower chance of facility selection

Typical facility sample sizes range from 20 to 40 per area

Eligible Patients






- Patients seen during PDP
 - HIV-positive adults
 - 18+ years on 1st day of PDP
 - Seen for medical care at facility
 - Facilities: CD4, HIV, VL, ART
 - Patients: any medical care at facility
- Patient lists are collected from participating facilities
- Study ID #s used to de-identify individuals



Each sampled facility is then asked to provide a list of HIV-positive adult patients seen for care during the Population Definition Period. Each patient on the list should have been age 18 or older on the first day of the PDP. Note that for this stage of patient sampling, we use a slightly broader definition of ‘care’ than we did when determining facilities’ eligibility. The operational definition used to identify facilities was providers that performed CD4 or viral load testing, or provided antiretroviral prescriptions. For patient identification, any HIV-positive adult who received medical care at the facility during the PDP is eligible – these medical care visits do not have to include testing or ART prescriptions, since that might not happen at every visit. For reasons of confidentiality, we work with study ID #s to de-identify individuals.


3rd Stage: Patient Sampling

- Lists of eligible patients are concatenated to create a patient frame
- Patient samples are then selected using a computer program





Those patient lists are used in the third stage of sampling. They are combined into one long list, strung together one after another, to create a site's patient frame. Patient samples are then selected using a computer program much like the one depicted here.

Patient Samples



- To give all **patients** an equal chance of selection, the proportion sampled varies
 - Higher chance of facility selection → lower chance of patient selection
 - Lower chance of facility selection → higher chance of patient selection
 - Patient sample sizes by facility are roughly equal
- CDC selects a sample (100 – 800 per area) and returns it to the project area, which begins recruiting those patients



In general, the best sampling design is one that gives everybody in the population an equal chance of being sampled. A PPS design adjusts for the differing selection probabilities assigned to facilities and corrects what would otherwise cause a bias in favor of patients of large facilities. Higher chance of facility selection means a lower chance of patient selection. Lower chance of facility selection implies a higher chance of patient selection.


In an ideal world, if a number of assumptions were met, the design would produce roughly equal sample sizes by facility, which would be convenient logistically. The patient samples range in size from 100 to 800, depending on the burden of HIV in the area.

Once facility and patient samples are drawn and provided back to the project area, recruitment for MMP and data collection can begin. Next, Nolana Woolfork will talk about recruitment.





Facility and Patient Recruitment
Nolana Woolfork
Project Coordinator






Facility Recruitment

- Project area staff approach facilities to enroll in MMP
- Benefits to participation:
 - Contribute to representative estimates
 - Allows their patients to participate
 - Assists in identifying unmet needs in HIV care and informs prevention and care bodies





In facility recruitment, project area staff contact each sampled facility and approach them participation in MMP.

Facility recruitment is essential to the success of MMP and there are many benefits to facility participation. In order to make estimates that are truly representative, it will be necessary to obtain very high participation rates of sampled facilities and patients. Facilities that participate allow for the participation of their patients. Also, facility participation aids in identifying met and unmet needs for HIV care and prevention services to inform prevention and care planning groups, health care providers, and other stakeholders. To be effective, programs must meet the current needs of the population.



Strategies and Best Practices

- Determine best methods for initial contact at facility
 - introductory letters, phone calls, deciding best time to call, appointment setting, using core surveillance for introductions to key staff
- Prepare presentations for facility staff
- Follow-Up: visit facility in person after making initial contact
- Utilize Community and Provider Advisory Board members




Strategies and best practices for facility recruitment depend on facility type and pre-existing relationships fostered between MMP staff and the facility. Some strategies and best practices for facility recruitment include:

Determining the best methods for initial contact such as sending introductory letters, designating a person to make phone calls, deciding the best time to call, setting up appointments by phone, and utilizing core surveillance staff to provide introductions to key facility staff.

Preparing presentations for facility staff.



Visiting facilities in person after initial contact is made.

And utilizing Community and Provider Advisory Board members to provide letters of support, facility contacts, and presentations.



Patient Recruitment

- Two recruitment processes
 - MMP-staff enrollment: MMP staff contact selected patients to offer enrollment
 - Facility-referred enrollment: facility staff contact patients by telephone, in-person, chart-insert, and/or letters




HIV-infected patients are selected from these sampled providers who agree to participate in MMP.

Persons selected for participation in MMP may be offered enrollment through two general recruitment processes: MMP staff-contact enrollment or facility-referred enrollment.



For MMP-staff enrollment, facilities will provide project area staff with contact information for patients who are to be recruited. After obtaining contact information, MMP staff will contact selected patients to describe the project and offer enrollment.

For facility-referred enrollment, patients will initially be contacted by staff of the facility from which they were sampled. This may be done by telephone, in-person, through chart inserts, and/or letters mailed from the facility.



Patient Recruitment

- Benefits to participation:
 - Contribute to representative behavioral and clinical outcomes data of persons in care
 - Opportunity to share experience
 - Receive materials and referrals to prevention and care services
 - Compensation for participation




Patient recruitment is essential to the success of MMP and there are many benefits to participation, such as:

Increasing the likelihood of obtaining behavioral and clinical information that is truly representative of HIV-infected patients in care

Providing each patient that participates the opportunity to share their experiences



The opportunity to receive prevention information and referrals to local prevention and care services

And compensation for participation either in cash or a cash equivalent



Strategies and Best Practices

- Determine which recruitment method is best for initial contact with the patient
- Have the provider introduce MMP to the patient and immediately follow-up
- Make appointments based on availability
- Remind participants of incentives
- Utilize Community Advisory Board (CAB)



IRB requirements, the sampled facilities, and the participants themselves will dictate what type of recruitment strategies and types of contacts will be utilized in each project area.

A few best practices for patient recruitment are:

Having the provider introduce MMP to the patient

Health department MMP staff following-up with the patient immediately after the provider's introduction

Setting appointments based on the patient's availability

Reminding reluctant or hard to reach participants of the incentive for participating in the project

And utilizing the local project area Community Advisory Board in patient recruitment activities


Once patient recruitment has occurred, data collection including patient interview and medical record abstraction can begin. Next, Linda Beer will discuss MMP data collection.



MMP Data Collection
Linda Beer
Epidemiologist





My name is Linda Beer and I'm an Epidemiologist and Project Officer on the Clinical Outcomes Team. I'm going to speak with you today about MMP Data Collection.



2009 MMP Data Collection

- Two components
 - Patient interview
 - Medical record abstraction
- 2009 data collection period
 - May 1, 2009 to April 30, 2010




MMP data collection has two components: a patient interview, followed by a matched medical record abstraction.

Following the end of the 2009 Population Definition Period on April 30, 2009, patient lists are collected from participating facilities and the patient sample is drawn.

The 2009 data collection period begins after project areas receive their patient sample, and will continue until the end of the 2010 MMP cycle's Population Definition Period, April 30, 2010.





First, I'm going to briefly speak to you about the MMP interview. Later, another member of the Clinical Outcomes Team will discuss Medical Record Abstraction.

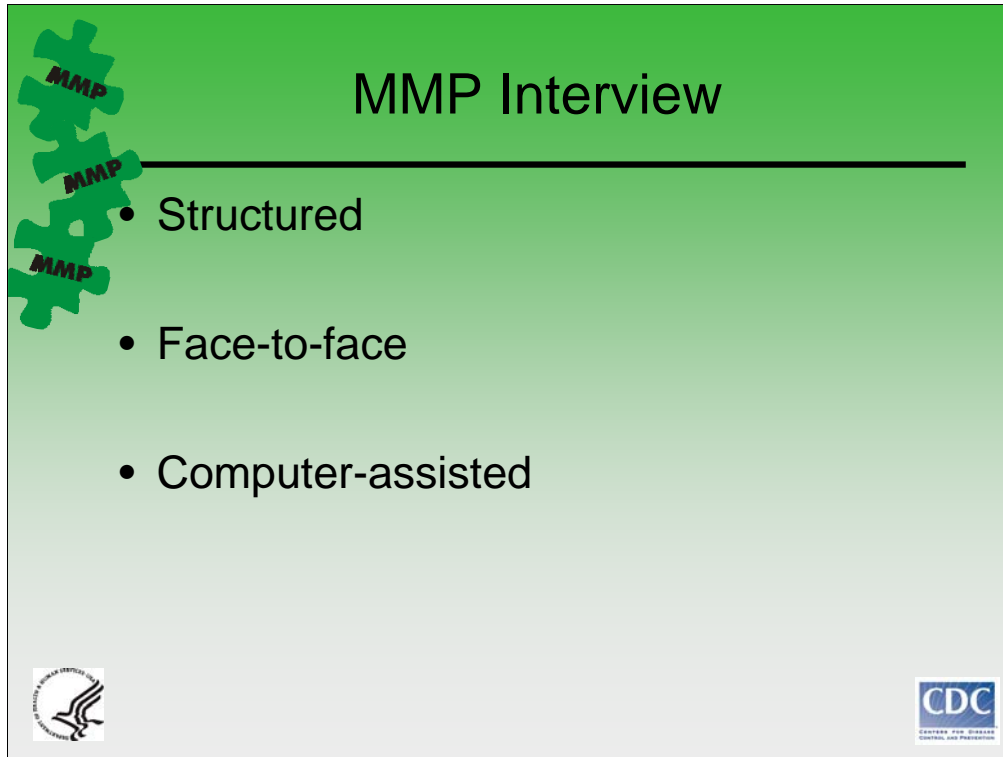


2009 MMP Interview

- Interview Format
- MMP Questionnaire Design
- MMP Administration
- 2009 Questionnaire
- Interview Materials





The MMP interview focuses on the patient's experiences and behaviors during the 12 months prior to the interview date. I'm going to start off by talking about the interview format in general terms, and then move in and focus on the 2009 MMP interview, including the design of the questionnaire, the questionnaire itself and its supplemental materials.




The slide features a green header with the title "MMP Interview" and a horizontal line. On the left side, three green puzzle pieces are stacked vertically, each with the letters "MMP" written on it. Below the title, a bulleted list contains three items: "Structured", "Face-to-face", and "Computer-assisted". In the bottom left corner, there is a circular logo for the National Center for Immunization and Respiratory Diseases. In the bottom right corner, there is the CDC logo with the text "CENTERS FOR DISEASE CONTROL AND PREVENTION".

MMP Interview

- Structured
- Face-to-face
- Computer-assisted





MMP is a structured face-to-face computer-assisted interview. That is easy enough to say, but what exactly does that mean? I'm going to break it down a little bit.



Structured Interview

- Standardized questions provide comparable responses
- All respondents are presented with the same questions in the same order
- Interviewer does not deviate from the script and reads questions as worded




So, what is a structured interview?

Structured interviews have standardized questions that result in responses that can be compared across all individuals completing the interview.



All respondents are asked the same questions in the same order—now with the MMP questionnaire we have skip patterns so that all the **main** questions are asked of everyone in order, but certain follow-up questions that don't apply to an individual's situation are skipped over. For example, if a participant was not taking any antiretroviral medications, they would not be asked questions about adherence to those medications.

Lastly, in structured interviews the interviewer follows a script and reads the questions exactly as they are worded. This eliminates any biases that might occur if the questions were worded differently in different interviews.



Face-to-face Interview


- Higher response rates
- Fewer misunderstood questions and inappropriate responses than self-administered interviews
- Fewer incomplete responses
- Additional information can be collected from the respondent if needed



MMP is a face-to-face interview, meaning that a trained interviewer asks the respondent questions in person. This is in contrast to other studies that may hand out paper questionnaires or conduct an interview over the telephone.



One advantage of face-to-face interviews are that they can produce higher response rates. This is critical since our aim with MMP is to get a representative sample and we need virtually everyone to participate to do that.

Some other advantages of face-to-face interviews are that there are fewer misunderstood questions, there are fewer incomplete responses, and if need be the interviewer can clarify a question or response or collect additional information.



Computer-assisted Interview

- Administered using a laptop or handheld computer device
- Allows for complex skip patterns
- Enables inconsistency and other quality checks on data that are entered
- Eliminates need to decipher handwriting during data entry




Lastly the MMP interview is a computer-assisted interview.

Trained interviewers use laptops or handheld computer devices to administer the questionnaire. The interview data are encrypted, and participants are identified by a study ID number; patient names are not recorded on the interview devices.

Some advantages of computer assisted interviews are that it is easier to administer questionnaires with complex skip patterns, errors can be decreased through the use of quality checks on data that are entered, and that the data do not need to be manually entered into a database for analysis.



Using the computer allows for built-in inconsistency checks. This means that the program won't accept responses that don't make sense. For example, a respondent can't say that they were born in June 2010.

Other advantages of computer-assisted interviews are that the data are electronic (making it easier to read), the program won't let you move forward without answering a question (so all questions have to have a response), and computer administration makes it easier to manage lots of data like we have with MMP.



MMP Questionnaire Design

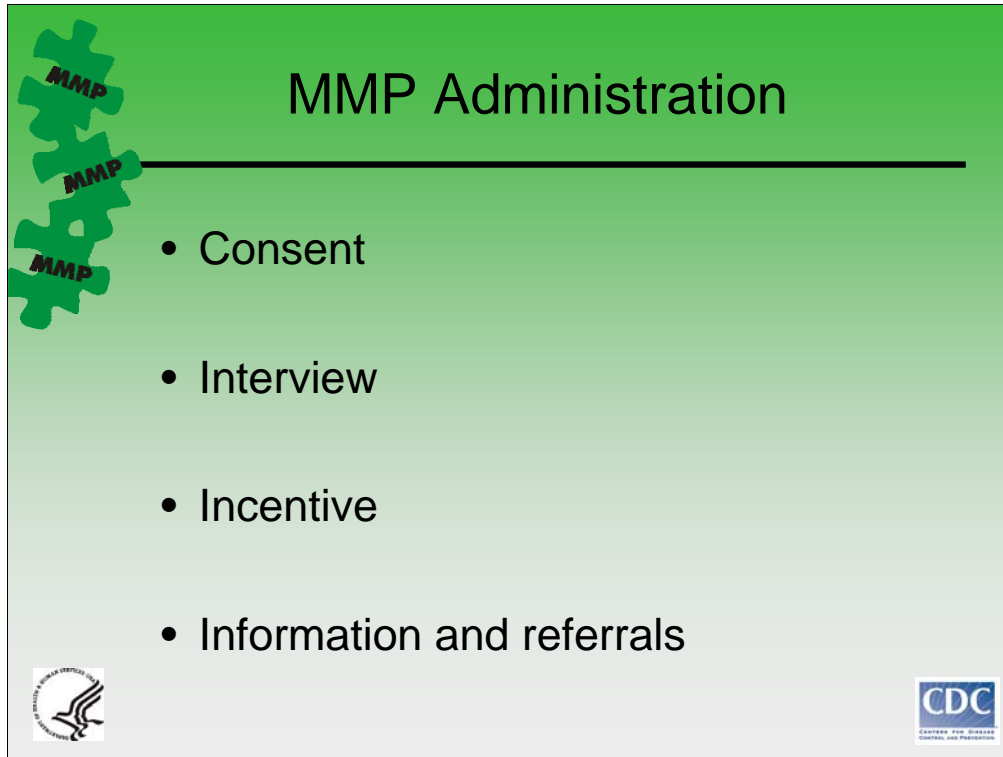
- 2009 questionnaire developed in 2006-2008
- Collaborative effort
 - All participating state and local health departments
 - National PAB and CAB
 - Local CAB members
 - RAND Corporation
 - HRSA and NIH
 - CDC MMP staff and CDC content experts



Now I'm going to talk about the design of MMP.

The questionnaire was developed between 2006 and 2008, and included input on the research questions as well as the content and wording of actual questions in the questionnaire



This was a collaborative effort with many, many folks who provide input. After the questionnaire was developed, it went through a review process at CDC and the Office of Management and Budget, which was about a year-long review process.



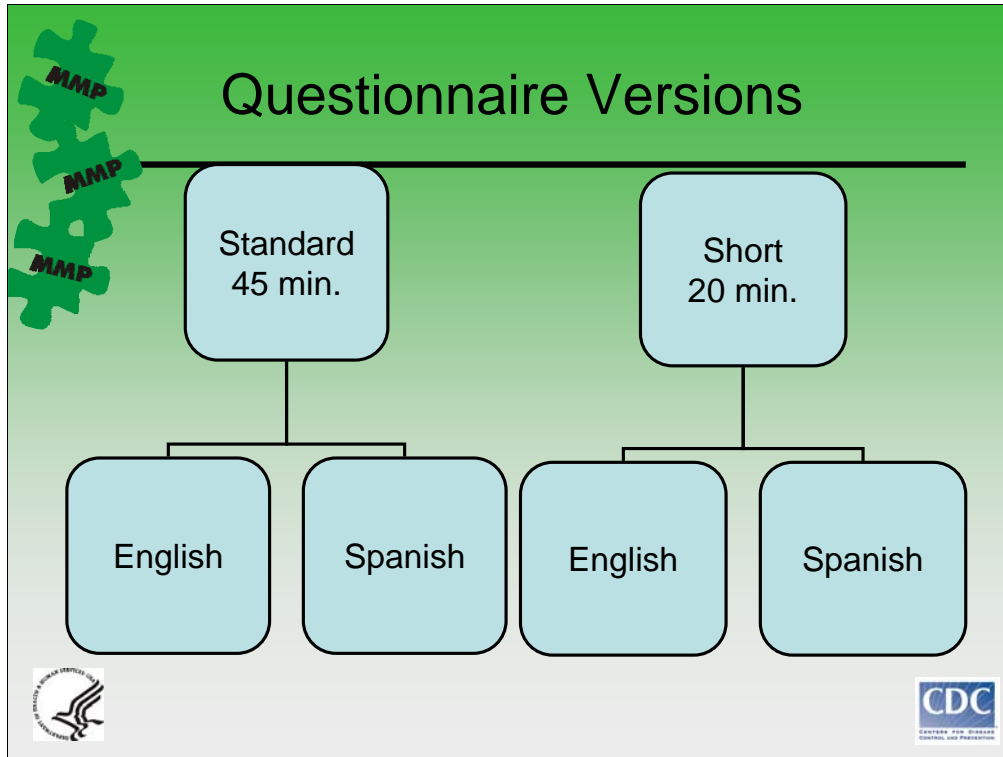
The slide features a green background with a vertical stack of three interlocking puzzle pieces on the left side, each labeled 'MMP'. The title 'MMP Administration' is centered at the top in a large, black, sans-serif font. Below the title is a horizontal black line. A bulleted list of four items is positioned to the right of the puzzle pieces. In the bottom left corner, there is a small circular logo for the University of Michigan. In the bottom right corner, there is a small rectangular logo for the CDC (Centers for Disease Control and Prevention).

MMP Administration


- Consent
- Interview
- Incentive
- Information and referrals



Administration of the interview may vary by project area, so project areas should always refer to their local protocols and local operational procedures. However, the respondent must always consent to the interview before the interview takes place. Consent documents are available in English and Spanish, and local project areas may develop consent in other languages as appropriate for their region. After the interview is over, all participants are provided with a cash or gift card incentive. The interviewer will also have additional educational information and/or referrals available for respondents.





There are 2 versions of the questionnaire, and both versions are available in English and Spanish. Interviewers will almost always administer the standard version of the questionnaire, which takes about 45 minutes to an hour to complete. The short version of the MMP interview is about 20 minutes long and covers critical questions from the standard questionnaire. It is used if a respondent is too ill to complete the standard interview, or if a respondent requires an interpreter.




2009 Standard Questionnaire

- Demographics
- Access to Health Care
- HIV Treatment and Adherence
- Sexual Behavior
- Drug and Alcohol Use
- Prevention Activities
- Anxiety and Depression
- Health Conditions and Preventive Therapy
- Gynecological and Reproductive History
- Optional Module: Acculturation Scale





This is a list of the different sections of the 2009 standard questionnaire. They are listed in order of priority. The interview covers a great deal of information, primarily about health care experiences and health-related behaviors. The interview primarily focuses on the 12 months prior to the interview date. You can find copies of the questionnaires on the CDC Team website.



Local Questions

- State and local health departments may ask additional questions applicable to local settings
- These are administered after the standard questionnaire is completed
- Responses are not sent to CDC



Project areas may add additional questions of local interest to the questionnaire. These are asked after the standard questions have been asked. These data are not shared with CDC.

After completion of the patient interview, the project area will abstract the patient's medical records.



Medical Record Abstraction
Eduardo Valverde
Epidemiologist







Good afternoon, my name is Eduardo Valverde and I'm an Epidemiologist and Project Officer on the Clinical Outcomes Team. I'm going to briefly speak to you about the MMP Medical Record Abstraction component.

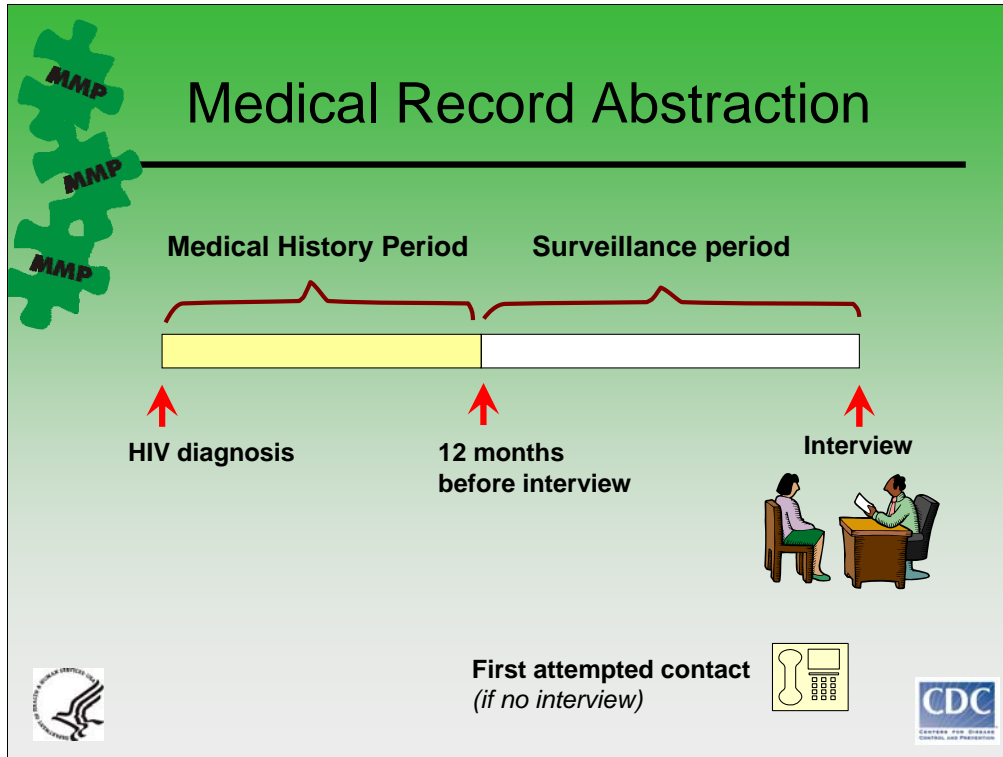
Medical Record Abstraction

Interview → **Participants' experience**


Abstraction → **Documented clinical issues**



As a complement to the information MMP collects through interview about the participants' experiences, MMP also collects information from patients' medical records to provide information about the patient's documented clinical issues.





The MMP medical record abstraction, or MRA, covers two time periods. The surveillance period (or SP) is the 12 month period prior to the MMP interview or the 12 month period prior to the first attempted contact for nonparticipants. The medical history period (or MHP) covers the time since the participant’s HIV diagnosis up to the beginning of the surveillance period.




Medical Record Abstraction

- Surveillance Period (12 months before interview)
 - Surveillance Period Visit Form – each outpatient visit
 - Surveillance Period Inpatient Form – each inpatient visit
 - Surveillance Period Summary Form – selected items
- Medical History Period (HIV diagnosis until Surveillance Period)
 - Medical History Form – baseline information





MRA information is collected by trained abstractors using encrypted laptop computers. MMP collects clinical information using four different electronic MRA forms, three for clinical information that occurred during the Surveillance Period and one for clinical information that occurred during the Medical History Period. The Surveillance Period Visit Form collects information on each outpatient visit that occurred at the facility during the Surveillance Period. The Surveillance Period Inpatient Form collects information from each hospital stay during the Surveillance Period. The Surveillance Period Summary Form contains information that occurs infrequently over the course of the surveillance period (e.g. pregnancy, immunizations). All information that occurs during the Medical History Period is collected on a single form, the Medical History Form.




Medical Record Abstraction (MRA)

- From which facilities is MRA information collected?
 - Highest priority: facility from which patient was sampled
 - Primary HIV care provider (if different from sampled)
 - Acute inpatient care facilities





The first facility an MMP abstractor will go to conduct a Medical Record Abstraction is the facility from which the participant was sampled. Then, if time permits, they will abstract medical record information from the participant's primary HIV care provider, if this is a different facility from where the participant was sampled. If resources are available, the abstractor will also abstract records from any inpatient facilities the participant was admitted to during the surveillance period.




Medical Record Abstraction

- Diagnoses
 - AIDS-defining conditions
 - Other conditions
- Medications
 - Antiretrovirals (ART)
 - Other medications
- Laboratory Results
 - CD4 T-lymphocyte counts, HIV viral loads, ART resistance
 - Infectious disease tests
 - Other lab tests





The MMP MRA covers a wide range of clinical procedures, diagnoses and outcomes. For example the MRA forms capture AIDS defining diagnoses and diagnosis of other conditions and diseases. They also capture information on the types of medications the participant has been prescribed such as antiretrovirals or prophylactic medications; and information on laboratory results such as CD4 counts, HIV viral loads, resistance testing, and tests for other infectious diseases.



Medical Record Abstraction

- Preventive care
 - AIDS opportunistic illness prophylaxis
 - Immunizations
 - Screening tests
- Other services/referrals
 - Case management, social services
 - Counseling: nutritional, medication adherence
 - Dental care, physical therapy, substance abuse treatment
- Others
 - Pregnancies
 - Mortality information



Other information captured in the MRA includes preventive care that the participant may have received such as immunizations or screening tests for conditions such as hepatitis and tuberculosis; and other types of services or referrals such as case management, nutritional counseling, dental care or substance abuse treatment. Finally, the MRA forms also capture information related to pregnancies and their outcomes, and mortality information.


Once data is collected, then data processing and cleaning takes place, which is the topic of our next presentation.



Data Management
Alicia Edwards
Health Scientist





Hello. My name is Alicia Edwards and I am the Project Officer for the Data Coordinating Center. I am going to talk about how MMP data are managed.




Data Coordinating Center

- In 2008 a contract was awarded to ICF Macro to provide data management services for MMP
- ICF Macro developed a Data Coordinating Center (DCC) to organize all aspects of MMP data
- The DCC will begin processing MMP data in July 2009 pending authorization





The Data Coordinating Center was formed to make data management more efficient for both CDC and MMP project areas. Both interview and medical record abstraction data will be managed by the Data Coordinating Center. MMP data is anonymous, personally identifiable information such as names and address are not collected and therefore never sent to the Data Coordinating Center or CDC. The Data Coordinating Center will begin production after receiving an Authorization to Operate from the Office of the Chief Information Security Officer at CDC.

This is the first year the Data Coordinating Center is responsible for managing MMP data.




Data Coordinating Center

- Specific objectives:
 - Receive data from all MMP project areas
 - Process data for quality assurance
 - Create and transfer final data sets to CDC and project areas
 - Provide technical assistance to MMP project areas
 - Provide formal training for MMP project areas
 - Communication to CDC




The Data Coordinating Center is responsible for all aspects of MMP data management. In addition to receiving and disseminating MMP data, the Data Coordinating Center will check the quality of the data, provide technical assistance, and conduct training sessions with project areas. The Data Coordinating Center will conduct the first MMP Data Management Training session in Atlanta July 28th-30th, 2009. The training session will cover all procedures related to sending and receiving data from the Data Coordinating Center.




Data Coordinating Center


- Data collected at local project areas are sent to the DCC via a data portal
- The DCC data portal meets or exceeds all current security measures as outlined in the “Technical Guidance for HIV/AIDS Surveillance Programs – Volume III: Security and Confidentiality”
- The DCC must comply with OMB, HHS and CDC Certification and Accreditation guidelines as outlined in NIST* SP 800-37



* National Institute of Standards and Technology Guide for the Security Certification and Accreditation of Federal Information Systems





MMP data is sent to the Data Coordinating Center via a secure data portal. All MMP data sent through the data portal will be encrypted using 256 bit encryption as required by the Federal government. CDC information technology security staff has toured the location where the servers and Data Coordinating Center are located to make sure all appropriate security measures are in place. For example, backup servers are available and working and all servers are located in locked rooms accessible by a limited number of Data Coordinating Center staff.




Data Coordinating Center

- All DCC and CDC personnel who come in contact with MMP data have been trained in security and confidentiality methods

- Security and Confidentiality statements have been signed as required by CDC





All Data Coordinating Center personnel have experience and training in how to manage highly confidential data. Data Coordinating Center staff, as well as CDC staff, have all signed agreements to follow CDC security and confidentiality guidelines regarding management of sensitive data.



Data Coordinating Center

- DCC will create a data set for each project area
- Each project area will be able to download data for that project area only
- CDC will be able to download data from all project areas
- DCC will create a national dataset for CDC at the conclusion of 2009 data collection



Project areas will only be able to download project area specific data. Project areas will not be able to download any other project area data. The CDC will be able to download data from all project areas. At the end of data collection, the Data Coordinating Center will compile a national dataset which will be used by CDC personnel to analyze 2009 MMP data.


Once data are collected, cleaned, and data sets are created, data is ready for analysis and dissemination as discussed in the next section of the presentation.



Data Analysis and
Dissemination
Janet Blair
Epidemiologist





Hello, I'm Janet Blair and I'm an Epidemiologist and a Project Officer on the Clinical Outcomes Team. I am going to talk about MMP Data Analysis and Dissemination.



Data Analysis Tools

- Goal of project is to analyze data at local and national level
- CDC Data Documentation (2005, 2007 cycles)
- SAS Programs
 - CDC will provide program templates
- Statistical Weighting of MMP Data
 - CDC will advise project areas




The goal of the MMP project is to analyze data at the local and national level. CDC has several data analysis tools that can be used.

CDC has prepared data documentation for the 2005 and 2007 MMP cycles that provides background on the data collection cycles and data elements.



CDC will also provide program templates that can be used by the project areas to produce MMP reports.

In some instances, data analysis techniques may require statistical weighting. In the event that the data are to be weighted, CDC will advise project areas.



Dissemination of Findings


- Findings will be disseminated to providers, patients, and the community
- MMP can inform HIV prevention programs and help guide treatment services
- Data will be used for resource allocation at the local and national level



Findings from MMP will be disseminated to providers, patients, and the community.



Data from MMP can inform HIV prevention programs and help guide treatment services.

Data will be used for resource allocation at the local and national level.



Users of MMP Data

- Consumers
 - Capture experiences of those in care
 - Describe met and unmet needs
- Clinicians
 - Paint broader picture of HIV disease, co-morbidities, disease management and care
 - Demonstrate quality of care delivered
 - Help advocate for treatment guidelines






Several groups or stakeholders, are interested in the findings from MMP. These groups include:

For consumers, MMP captures the experiences of those in care and describes their met and unmet needs.

For clinicians, MMP will paint a broader picture of HIV disease, co-morbidities, disease management and care, demonstrate the quality of care delivered, and help advocate for treatment guidelines.


Users of MMP Data

- Community Planning Groups
 - Demonstrate gaps in services
 - Help to allocate services/resources locally
 - Guide local prevention programs
- Health policy and public health professionals
 - Forecast resource needs and guide allocation
 - Inform development of new prevention initiatives





Users of MMP data also include Community Planning Groups who can use the data to demonstrate gaps in services, help to allocate services/resources locally, and guide local prevention programs.

Health policy and public health professionals can use MMP data to forecast resource needs and guide allocation, and inform development of new prevention initiatives.




Local and National Data Use

- Each project area has responsibility for release of data from their respective areas
- MMP data should be released as aggregated data
 - Facility level data are not representative
 - Facility level or individual data should NOT be released
- Refer to your jurisdiction's guidelines regarding use and release of HIV/AIDS surveillance data
- MMP is considered research in some areas
- National analyses will use CDC guidelines for use and release of HIV/AIDS surveillance data





Each project area has responsibility for release of data from their respective areas. MMP data should be released as aggregated data. Facility level data are not representative, and facility level or individual data should not be released. Please refer to your jurisdiction's guidelines regarding use and release of HIV/AIDS surveillance data. Also, in some areas, MMP is considered research. National analyses will use CDC security and confidentiality guidelines for the use, release, and presentation of HIV/AIDS surveillance data.

Data Dissemination



- Local and national MMP data is reported through multiple conduits such as
 - Local publications
 - Epidemiologic profiles
 - Presentations to local AIDS service organizations, community planning groups, conferences and workshops
 - Publications in peer-reviewed journals
 - Presentations at forums (e.g. continuing medical education courses and seminars)



In terms of data dissemination, local and national MMP data is reported through multiple conduits such as the ones listed here:

Local publications

Epidemiologic profiles

Presentations to local AIDS service organizations, community planning groups, conferences and workshops

Publications in peer-reviewed journals

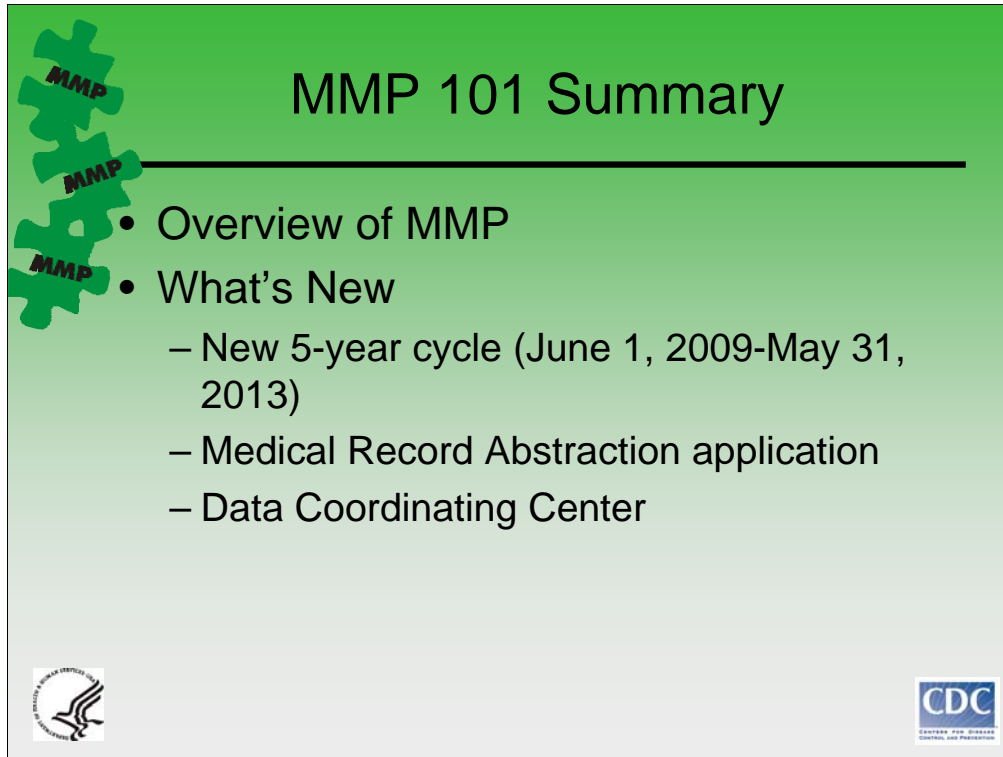
Presentations at forums (e.g. continuing medical education courses and seminars)

Now Nolana is going to provide a summary of today's presentation.



Summary







The slide features a green background with a vertical stack of three interlocking puzzle pieces on the left side, each labeled 'MMP'. The title 'MMP 101 Summary' is centered at the top. Below the title is a horizontal line. The main content is a bulleted list. At the bottom left is the logo for the National Institute of Health, and at the bottom right is the CDC logo.

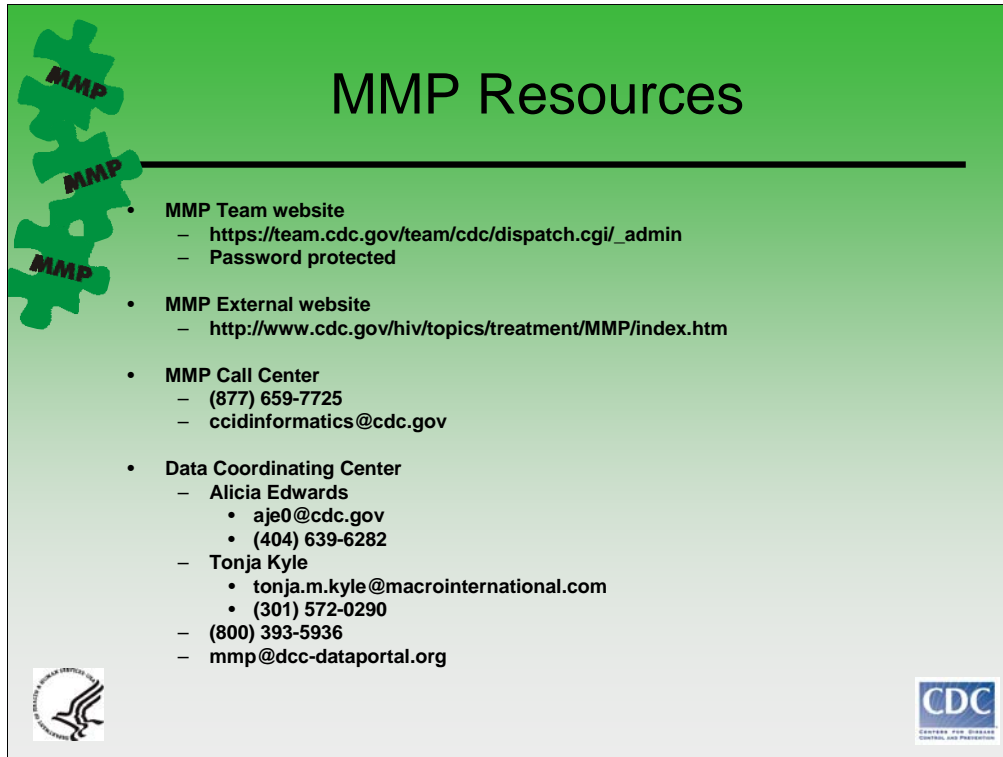
MMP 101 Summary

- Overview of MMP
- What's New
 - New 5-year cycle (June 1, 2009-May 31, 2013)
 - Medical Record Abstraction application
 - Data Coordinating Center



In summary, we provided you with an overview of MMP including history, design, recruitment methods, data collection and uses of data at the local and national level. We also provided you with a glimpse of what is to come – including plans for analysis and dissemination of the data.

These are exciting times for MMP as we have been approved for another 5 years of data collection from June 1, 2009 through May 31, 2013. Also, this June, we deployed the electronic Medical Record Abstraction application to project areas for 2009 data collection. Collecting all MMP data electronically and having the new Data Coordinating Center conduct data management activities should make MMP more efficient so we can answer important questions about unmet needs, access to medical care and services, and behavioral/clinical outcomes on a representative sample of HIV infected patients receiving care in 2009.



MMP Resources

- **MMP Team website**
 - https://team.cdc.gov/team/cdc/dispatch.cgi/_admin
 - Password protected
- **MMP External website**
 - <http://www.cdc.gov/hiv/topics/treatment/MMP/index.htm>
- **MMP Call Center**
 - (877) 659-7725
 - ccidinformatcs@cdc.gov
- **Data Coordinating Center**
 - Alicia Edwards
 - aje0@cdc.gov
 - (404) 639-6282
 - Tonja Kyle
 - tonja.m.kyle@macrointernational.com
 - (301) 572-0290
 - (800) 393-5936
 - mmp@dcc-dataportal.org

Finally, if you would like more information about MMP, you can access the following resources.

The MMP Team website is a CDC-maintained password-protected site used to disseminate information to MMP staff (Principal Investigators, Project Coordinators, Data Managers, Interviewers, and Abstractors) and CAB and PAB members. The CDC MMP Team website has a MMP workspace that includes updated MMP documents and information pertaining to the current project cycle.

CDC maintains an external website that is not password-protected to disseminate general information about MMP to the public. This website includes an overview of the project, project area contact information, brochures, and other marketing materials which may be of interest to providers and patients.

The MMP Call Center is a single point of contact set up for MMP staff in the 23 project areas to document, triage, track, and resolve technical and non-technical questions and problems. Requests for assistance can be via phone or email.

Finally, if you have questions about the Data Coordinating Center, here is the contact information for the CDC Data Coordinating Center Project Officer and the Macro Project Manager.



We'd like to thank you for your time today and answer any questions you might have.