Monitoring HIV Care in the United States: A Strategy for Generating National Estimates of HIV Care and Coverage

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Morgan A. Ford and Carol Mason Spicer, Editors; Committee to Review Data Systems for Monitoring HIV Care; Board on Population Health and Public Health Practice; Institute of Medicine

MONITORING HIV CARE IN THE UNITED STATES

A Strategy for Generating National Estimates of HIV Care and Coverage

Committee to Review Data Systems for Monitoring HIV Care

Board on Population Health and Public Health Practice

Morgan A. Ford and Carol Mason Spicer, *Editors*

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Willing is not enough; we must do."
—Goethe

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This report has been reviewed in draft form by individuals chosen for their diverse perspectives and technical expertise, in accordance with procedures approved by the National Research Council's Report Review Committee. The purpose of this independent review is to provide candid and critical comments that will assist the institution in making its published report as sound as possible and to ensure that the report meets institutional standards for objectivity, evidence, and responsiveness to the study charge. The review comments and draft manuscript remain confidential to protect the integrity of the deliberative process. We wish to thank the following individuals for their review of this report:

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Although the reviewers listed above have provided many constructive comments and suggestions, they were not asked to endorse the conclusions or recommendations nor did they see the final draft of the report before its release. The review of this report was overseen by **Kristine M. Gebbie,** Flinders University, and **Stephen E. Fienberg,** Carnegie Mellon University. Appointed by the National Research Council and Institute of Medicine, they were responsible for making certain that an independent examination of this report was carried out in accordance with institutional procedures and that all review comments were carefully considered. Responsibility for the final content of this report rests entirely with the authoring committee and the institution.

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Abbreviations and Acronyms

ACA	Patient Protection and Affordable Care Act
ACSUS	AIDS Cost and Services Utilization Survey
ADAP	AIDS Drug Assistance Program
AHRQ	Agency for Healthcare Research and Quality
AIDS	acquired immune deficiency syndrome
ART	antiretroviral therapy
BRFSS	Behavioral Risk Factor Surveillance System
CCW	Chronic Condition Data Warehouse
CDC	Centers for Disease Control and Prevention
CMS	Centers for Medicare & Medicaid Services
CNICS	CFAR [Center for AIDS Research] Network of Integrated Clinical Systems
FPL	federal poverty level
GDP	gross domestic product
HARS; eHARS	HIV/AIDS Reporting System; Enhanced HIV/AIDS Reporting System
HCSUS	HIV Cost and Services Utilization Study
HHS	Department of Health and Human Services
HIV	human immunodeficiency virus
HIV RNA	viral load

HIVRN	HIV Research Network
HMO	health maintenance organization
HRSA	Health Resources and Services Administration
IOM	Institute of Medicine
IRB	institutional review board
IT	information technology
MAX	Medicaid Analytic eXtract
MEPS	Medical Expenditure Panel Survey
MHF	Medical History Form
MMP	Medical Monitoring Project
MRA	medical record abstraction
MSIS	Medicaid Statistical Information System
MSM	men who have sex with men
NA-ACCORD	North American AIDS Cohort Collaboration on Research and Design
NCHS	National Center for Health Statistics
NHANES	National Health and Nutrition Examination Survey
NHAS	National HIV/AIDS Strategy
NHID	Normative Health Information Database® (Ingenix)
NHIS	National Health Interview Survey
NHSS	National HIV Surveillance System
NIH	National Institutes of Health
NSDUH	National Survey on Drug Use and Health
OMB	Office of Management and Budget
ONAP	Office of National AIDS Policy (White House)
PCIP	Preexisting Condition Insurance Plan
PDP	population definition period
ResDAC	Research Data Assistance Center
RSR	Ryan White HIV/AIDS Program Services Report
RTS	real-time sampling
SP	surveillance period
SPIF	Surveillance Period Inpatient Form
SPSF	Surveillance Period Summary Form
SPVF	Surveillance Period Visit Form
SSDI	Social Security Disability Insurance

TrOOP	true out-of-pocket
USPSTF	U.S. Preventive Services Task Force
VHA	Veterans Health Administration
VL	viral load

Summary[1]

In September 2010, the White House Office of National AIDS Policy commissioned an Institute of Medicine (IOM) committee to respond to a two-part statement of task concerning how to monitor care for people with HIV. The IOM convened a committee of 17 members with expertise in HIV clinical care and supportive services, epidemiology, biostatistics, health policy, and other areas to respond to this task. The committee's first report, *Monitoring HIV Care in the United States: Indicators and Data Systems*, was released in March 2012. The report identified 14 core indicators of clinical HIV care and mental health, substance abuse, and supportive services for use by the Department of Health and Human Services (HHS) to monitor the impact of the National HIV/AIDS Strategy (NHAS) and the Patient Protection and Affordable Care Act (ACA) (P.L. 111-148) on improvements in HIV care and identified sources of data to estimate the indicators. The report also addressed a series of questions related to the collection, analysis, and dissemination of data necessary to estimate the indicators.

In this second report, the committee addresses how to obtain national estimates that characterize the health care of people with HIV within the context of the ACA, both before 2014 and after 2014 when key provisions of the ACA will be implemented (see Box S-1, Statement of Task).

The ACA will provide care coverage to millions of previously uninsured Americans, including many people with HIV. Some provisions of the ACA

[1]This summary does not include references. Citations to support text, conclusions, and recommendations made herein are given in the body of the report.

BOX S-1
Statement of Task

How do we obtain national estimates that characterize the health care of people living with HIV in public and private settings?

a. How can we obtain data from a nationally representative sample of HIV-positive individuals in the United States to establish a baseline for health insurance and health care access status prior to 2014?
b. If it is not possible to obtain a nationally representative sample of people living with HIV, are there other alternatives (including using multiple existing data sources or requiring a complete accounting of all positive persons in care) to obtain data on care and utilization beyond those individuals enrolled in the Ryan White HIV/AIDS Program?
c. How do we continue to regularly obtain data from a large sample (nationally representative or otherwise) of HIV-positive individuals after 2014 to monitor the impact of the Patient Protection and Affordable Care Act on health insurance and health care access?

that will improve access to health coverage and care for people with HIV include expansion of the Medicaid program in some states[2] to include non-Medicare-eligible individuals with incomes up to 133 percent of the federal poverty level[3]; closure of the Medicare Part D prescription drug coverage gap; increased access to private health insurance and consumer protections; and expansion of coverage for preventive services. This report addresses how to monitor the anticipated changes in health care coverage, service utilization, and quality of care for people with HIV within the context of the ACA. The committee's two reports, although distinct, do overlap in certain ways. For example, it will be important to monitor care quality using indicators such as those recommended in the committee's first report in addition to tracking the movement of individuals into and among different sources of health coverage, which is the focus of the present report.

[2]On June 28, 2012, the U.S. Supreme Court ruled that the Medicaid expansion provision of the ACA, which would withhold federal funding for Medicaid from states that failed to comply, was unduly coercive, meaning that states cannot be penalized for choosing not to participate in the new program by taking away existing Medicaid funding. As a result, states are likely to exhibit greater variation than anticipated in the scope of eligibility in their Medicaid programs.

[3]A standard 5 percent income disregard effectively increases the limit to 138 percent of the federal poverty level.

COMMITTEE'S APPROACH TO ITS CHARGE

For its first report, the committee requested information from 29 data systems on the types of data collected (e.g., data on demographics, access to care, need for supportive services) to identify best sources of data to estimate the committee's recommended core indicators. The committee revisited these data sources for this second report to identify those that capture data relevant to monitoring the care experiences of people with HIV within the context of the ACA, such as health care coverage and utilization. The committee considered which data collection efforts could best produce nationally representative estimates of people with HIV in the United States and which best capture data on health coverage and utilization at the state level. The committee also considered the extent to which the various data sources capture information to estimate indicators of care quality for people with HIV. Care quality will be important to monitor as the ACA is implemented because continuity of care may be disrupted and the range of benefits available to individuals may shift as they move among sources of care coverage.

The committee reviewed several existing national population-based health surveys as potential sources of data on health care coverage and utilization for a nationally representative sample of people with HIV, including the National Health Interview Survey, the Medical Expenditure Panel Survey; the National Health and Nutrition Examination Survey; the Behavioral Risk Factor Surveillance System; and the National Survey on Drug Use and Health. These surveys capture data relevant to monitoring care within the context of the ACA, for example, on sources of care coverage, care utilization, and demographic information. However, due to the relatively low prevalence of HIV in the general U.S. population, the number of people with HIV included in a given sample will be too small for meaningful analysis. In addition, population-based health surveys were not designed to generate representative estimates for people with specific diseases. Including questions about HIV serostatus and additional questions on HIV care experiences for HIV-infected individuals in national surveys, therefore, would not be adequate to generate nationally representative estimates of their health care coverage and utilization.

Although the statement of task refers generally to "people living with HIV," the committee chose to focus this report on people living with a diagnosis of HIV in the United States. The committee did not interpret its charge to include people with HIV who are undiagnosed as there is no practical way to obtain a "large sample (nationally representative or otherwise)" of people living with HIV that includes such individuals. In addition, the committee limited the population under consideration to adults and adolescents (ages 13 and older). The use of antiretroviral therapy to reduce or prevent

perinatal transmission of HIV has resulted in a relatively small number of newly diagnosed pediatric HIV cases in the United States each year

COMMITTEE'S CONCLUSIONS AND RECOMMENDATIONS

How to Establish a Baseline of Health Care Coverage and Utilization Prior to 2014

There currently is no single source of data to generate a nationally representative baseline of care coverage and utilization for people with HIV prior to 2014. In considering the statement of task for this report, the committee felt that the first, overarching, question about how to obtain "national estimates that characterize the health care of people living with HIV in public and private settings" had been addressed in its first report. That report identified 12 data systems, including public and private and HIV-specific and non-HIV specific systems, that the committee concluded could serve as a collective platform for evaluating access to continuous and high-quality care in all populations of people with HIV. Although none of these systems are designed to be nationally representative, together they can provide a reasonably accurate baseline of care coverage and utilization before 2014.

Recommendation 1. Given that there currently is no single data collection system that can be used to establish a baseline for health care coverage and utilization for a nationally representative sample of people with HIV in the United States, the Office of National AIDS Policy should use multiple existing data sources to establish this baseline prior to 2014. These data sources might include

- **National HIV Surveillance System**
- **Medical Monitoring Project**
- **Ryan White HIV/AIDS Program**
- **Medicaid and Medicare**
- **Veterans Health Administration**
- **Housing Opportunities for Persons with AIDS**
- **North American AIDS Cohort Collaboration on Research and Design**
- **CFAR Network of Integrated Clinical Systems**
- **HIV Research Network**
- **Private insurers**

As the committee concluded in its first report with respect to the estimation of its recommended indicators for clinical HIV care and supportive services,

combining data from multiple data systems presents a range of analytic and logistical challenges that will change over time and need to be revaluated periodically. To that end, the committee reiterates its recommendation from the first report pertaining to periodic reevaluation of mechanisms for combining relevant data elements and identification of and approaches to addressing barriers to the efficient analysis of data, including relevant statistical methodologies.

How to Continue to Obtain Data to Monitor Health Care Coverage and Utilization After 2014

The committee's first report describes a number of challenges to collecting and combining data from multiple sources to create a picture of the overall care experiences of people with HIV in the United States. For example, the various sources of care and care coverage have their own health information technology systems with disparate architectures and vocabularies that impede the sharing of data across systems. Development of a unique mechanism for capturing relevant information would simplify the collection and analysis of data and could also provide more detailed and representative data than currently exist to monitor care coverage and utilization among people with HIV.

The Medical Monitoring Project (MMP) was initiated in 2005 partially in response to the IOM report *Measuring What Matters: Allocation, Planning, and Quality Assessment for the Ryan White CARE Act*, which described a need for nationally representative data on the care and preventive service needs of individuals with HIV in the United States. Conducted by the Centers for Disease Control and Prevention (CDC) through cooperative agreements with health departments located in 23 project areas (17 states and 6 cities), MMP is a population-based surveillance system designed to assess the clinical and behavioral characteristics of a nationally representative sample of adults with HIV who are in care. After reviewing multiple data systems, the committee found that MMP is a promising resource for the generation of nationally representative estimates of care coverage and utilization for people with HIV. MMP already collects data on central dimensions of health care reform, such as sources of health coverage; access to HIV care and unmet need for supportive services; quality and comprehensiveness of care; receipt of recommended clinical and preventive services (e.g., screenings and immunizations); and the organizational context and structure of care. MMP also collects data on patient age, race and ethnicity, country of birth, sex at birth, gender, sexual orientation, and education and income, allowing for analyses of disparities in health care coverage and utilization. MMP's repeated (annual) cross-sectional design permits new questions to be added to the data collection instruments as information

needs change at different phases of ACA implementation. MMP data are reflective of the experiences of patients who receive care in a variety of settings, public and private, and whose care is covered by a variety of payers, including Medicaid, Medicare, the Ryan White HIV/AIDS Program, and private insurance, among others. This makes MMP a useful source of data to track care utilization and quality in different care organizational models and the distribution of health coverage among people with HIV during and following implementation of the ACA.

Although MMP provides a promising basis upon which to build, the committee raised a number of concerns about its current ability to generate nationally representative data, including concerns about MMP's current response rate and its representation of vulnerable populations. Although MMP's response rate has improved over time, the overall patient response rate for 2010, the most recent year for which data are available, was 56 percent. Another concern is that MMP does not currently include people who have a diagnosis of HIV infection but who are not in care, many of whom stand to benefit from provisions of the ACA that will improve access to health care coverage. Adolescents (ages 13-17) are also excluded by design, leaving a gap in representative data on health care coverage and utilization for this age group. It is also important to ensure adequate representation of populations, such as immigrants, people who are homeless or unstably housed, people with mental and substance abuse disorders, and people who flow in and out of the corrections system, who are more likely to experience gaps in health care coverage and care.

Expansion of MMP to include new populations is likely to generate the need for additional staffing resources. Substantial resources and expertise are also required to achieve adequate response rates, including from vulnerable populations, and to support data collection, analysis, and dissemination activities. Training and technical support for staff in the 23 MMP project areas will continue to be critical to the success of the project. It is important that funding for MMP is commensurate with these activities.

Recommendation 2. By 2015, the Centers for Disease Control and Prevention (CDC) should improve the Medical Monitoring Project (MMP) to ensure higher response rates and increased sample representativeness. CDC should expand MMP to include representative numbers of HIV-diagnosed individuals not in care, adolescents, and those in the criminal justice system and take particular care to ensure adequate representation of vulnerable populations, including, but not limited to immigrants; individuals who are homeless or unstably housed; and people with mental or substance use disorders.

The committee encourages CDC to continue to test strategies for improving MMP sample completion and representation of vulnerable populations of people with HIV who are not in care. Such strategies might include using the National HIV Surveillance System (NHSS) for participant sampling; using a dual-frame sampling approach that combines medical facility-based sampling to identify individuals in care and NHSS-based sampling to identify individuals not in care; implementing real-time sampling within select facilities; and extending the time period for participant recruitment and data collection.

Recommendation 3. The Office of National AIDS Policy and the Department of Health and Human Services should use the Medical Monitoring Project, once improved, to obtain nationally representative data on health care coverage and utilization for people with HIV.

Historically, priorities for HIV surveillance have shifted with changes in the distribution of HIV burden among people living with HIV, new knowledge about transmission risk, clinical indicators of health for people with HIV, HIV treatment guidelines, and other factors. Surveillance priorities inevitably will continue to shift within the context of the ACA. Similarly, new questions may emerge over time with respect to access to and receipt of quality care by people with HIV as the ACA is implemented. For example, researchers and policy makers may want to gather information on reasons for changes in care quality consequential to shifts in care coverage and the range of benefits available to people with HIV. A mechanism should be established for periodic evaluation of MMP to ensure that data collected are responsive to changes in the HIV epidemic and ACA-related informational needs.

Recommendation 4. The Department of Health and Human Services should convene and fund a multidisciplinary task force responsible for designing improvements in the Medical Monitoring Project and for ensuring that it remains responsive to changes in the epidemic and the health care environment.

Although designed to be nationally representative, the MMP does not collect data on individuals with HIV in all U.S. states and territories. Similarly MMP is not designed to provide an in-depth look at care coverage and utilization within coverage sources of particular importance for HIV-infected individuals. Data from Medicaid and the Ryan White HIV/AIDS Program, because they are captured for all states and territories, can serve as useful sources of state-level information on care coverage and utilization to supplement findings from MMP. Medicaid and the Ryan White HIV/

AIDS Program, along with Medicare, are also currently the most common sources of care coverage for people with HIV. More than half of those living with diagnosed HIV infection in the United States are covered by these programs. Although not generalizable to all HIV-infected individuals in the United States, analysis of data from these specific programs, in addition to data from MMP, is essential to highlight how ACA provisions that affect program eligibility and coverage of services impact the care experiences of people with HIV. These data and analyses are especially important given the wide variation in eligibility and benefits across state Medicaid programs, as well as differences in implementation of the health insurance exchanges under the ACA.

Although they are often proprietary, private health insurer data should also be used to monitor the care experiences of people with HIV within the context of the ACA. Currently, almost one in five individuals with HIV has private health insurance. Many more individuals with HIV are likely to enroll in private health insurance with the implementation of new benefits and protections in the private health insurance market, such as the establishment of health insurance exchanges in states to help consumers purchase health insurance and the elimination of preexisting condition exclusions.

Recommendation 5. In addition to data from the Medical Monitoring Project, the Office of National AIDS Policy and the Department of Health and Human Services should use data from Medicaid, Medicare, the Ryan White HIV/AIDS Program, and private insurers to monitor the impact of the Patient Protection and Affordable Care Act on health care coverage and utilization at the state and program level.

Although health care reform will increase access to care coverage for people with HIV, it does not guarantee linkage to, retention in, and receipt of quality care. Individuals with HIV who transition across sources of health insurance coverage could experience disruptions in their continuity of care and the array of services that are available to them at any given time. For example, the Ryan White HIV/AIDS Program model of care provides a range of supportive services in addition to clinical care within a single "medical home." Care for many people with HIV will likely shift from the Ryan White HIV/AIDS Program to other sources of care as the ACA expands other programs, particularly Medicaid, to cover adults who were previously uninsured. This change could affect the range of services available to individuals previously enrolled in the Ryan White HIV/AIDS Program and the quality of care that they receive. By bringing previously uninsured individuals into the health care system, the ACA will also place demands on the health care workforce to provide care to a greater number of individuals. Provider shortages and delays in service provision could

impact care quality. Thus, it will be important to monitor both trends in care quality for individuals with HIV and enrollment among the various sources of care coverage as the ACA is implemented. In its first report, the committee identified core indicators to monitor the impact of the NHAS and the ACA on HIV care as well as care quality. These or similar indicators could be used to measure care quality within the context of the ACA.

Recommendation 6. The Office of National AIDS Policy, working with the Department of Health and Human Services, should ensure the collection and linkage of data on core indicators[4] to monitor quality of care for people with HIV during and following the implementation of the Patient Protection and Affordable Care Act.

Data tracking health care coverage sources, enrollment, service utilization, and core outcomes among people with HIV are important for monitoring the impact of the ACA and the NHAS on access to and quality of HIV care in the United States over time. The data may be used to identify any difficulties encountered as individuals with HIV transition among sources of care coverage and to inform future planning related to the health care workforce and possible redistribution of resources to improve the quality and efficiency of care and reduce HIV-related health disparities. Reporting the data at least once every 2 years will permit stakeholders, including policy makers, health care coverage programs and plans, organizations of health care professionals, and others, to anticipate future needs and make appropriate midcourse corrections to advance the goals of the NHAS and maximize access to quality HIV care under the ACA.

Recommendation 7. The Department of Health and Human Services should produce and disseminate a report at least once every 2 years on the care of people with HIV. This report should characterize trends and identify gaps in coverage and care during and following the implementation of the Patient Protection and Affordable Care Act.

[4]Fourteen core indicators for monitoring access to clinical HIV care and mental health, substance abuse, and supportive services were recommended by the committee in its first report, which includes discussion of the collection and linkage of data needed to estimate the indicators. HHS currently is in the process of implementing the use of seven common core indicators for HIV diagnosis, treatment, and care services across HHS-funded programs (http://blog.aids.gov/2012/08/secretary-sebelius-approves-indicators-for-monitoring-hhs-funded-hiv-services.html). This recommendation is not intended to duplicate federal efforts to monitor HIV care and supportive services but to ensure that such monitoring occurs in conjunction with the tracking of changes in enrollment patterns and benefit packages among different sources of coverage for HIV care.

Sufficient resources will be required for the collection and analysis of data from MMP, Medicaid, Medicare, the Ryan White HIV/AIDS Program, and other sources to monitor trends in access to care and care coverage for people with HIV as well as to assess the quality of care for this population. The production and dissemination of a report at least once every 2 years summarizing the care experiences of people with HIV based on analysis of data from these sources will also require adequate staff and funding.

1

Introduction

Approximately 1.1 million people in the United States currently are living with HIV (CDC, 2012d; Hall et al., 2012). Of these individuals, only about 82 percent have been diagnosed (CDC, 2012d,f; Hall et al., 2012)[1]; fewer still are receiving clinical care for HIV, including antiretroviral therapy (ART); and only 19 to 25 percent have achieved viral suppression (Burns et al., 2010; CDC, 2012d; Gardner et al., 2011; Hall et al., 2012). In July 2010, the White House Office of National AIDS Policy (ONAP) released its National HIV/AIDS Strategy (NHAS), the primary goals of which are to (1) reduce the number of people who become infected with HIV, (2) increase access to care and optimize health outcomes for people with HIV, and (3) reduce HIV-related health disparities (ONAP, 2010). The NHAS identifies action steps for each of the three primary goals and sets quantitative targets to be achieved by 2015 (see Box 1-1).

In September 2010, ONAP commissioned the Institute of Medicine (IOM) to establish a committee of experts to review public and private data systems that capture information on the care of people with HIV and to recommend ways to utilize and supplement existing data to track the impact of the NHAS and the Patient Protection and Affordable Care Act (ACA) (P.L. 111-148) on improving HIV care in the United States. In response to this charge, the IOM convened the 17-member Committee to Review Data Systems for Monitoring HIV Care composed of experts in clinical HIV care, mental health, health services research, private health insurance, health

[1]Eighteen percent undiagnosed in 2009 is an improvement over the 20 percent of people living with undiagnosed HIV in 2006 (CDC, 2012f).

BOX 1-1
National HIV/AIDS Strategy Action Steps and Targets

Reducing New HIV Infections

Action Steps
- Intensify HIV prevention efforts in communities where HIV is most heavily concentrated.
- Expand targeted efforts to prevent HIV infection using a combination of effective, evidence-based approaches.
- Educate all Americans about the threat of HIV and how to prevent it.

Targets
By 2015,
- lower the annual number of new infections by 25 percent.
- reduce the HIV transmission rate, which is a measure of annual transmissions in relation to the number of people living with HIV, by 30 percent.
- increase from 79 to 90 percent the percentage of people living with HIV who know their serostatus.

Increasing Access to Care and Improving Health Outcomes for People Living with HIV

Action Steps
- Establish a seamless system to immediately link people to continuous and coordinated quality care when they are diagnosed with HIV.
- Take deliberate steps to increase the number and diversity of available providers of clinical care and related services for people living with HIV.
- Support people living with HIV with co-occurring health conditions and those who have challenges meeting their basic needs, such as housing.

Targets
By 2015,
- increase the proportion of newly diagnosed patients linked to clinical care within 3 months of their HIV diagnosis from 65 to 85 percent.

policy, housing policy, the Ryan White HIV/AIDS Program, biostatistics, epidemiology, health disparities, and biomedical informatics (see the Appendix, Biographical Sketches of Committee Members).

The committee, which was given a two-part statement of task (Box 1-2), released its first report, *Monitoring HIV Care in the United States: Indicators and Data Systems*, in March 2012 (IOM, 2012). Responding to the first part of the committee's statement of task, the report identifies core and additional indicators related to continuous clinical HIV care and access

- increase the proportion of Ryan White HIV/AIDS Program clients who are in care (at least two visits for routine HIV medical care in 12 months at least 3 months apart) from 73 to 80 percent.
- increase the percentage of Ryan White HIV/AIDS Program clients with permanent housing from 82 to 86 percent.

Reducing HIV-Related Health Disparities and Health Inequities

Action Steps

- Reduce HIV-related mortality in communities at high risk for HIV infection.
- Adopt community-level approaches to reduce HIV infection in high-risk communities.
- Reduce stigma and discrimination against people living with HIV.

Targets

By 2015,

- increase the proportion of HIV diagnosed gay and bisexual men with undetectable viral load by 20 percent.
- increase the proportion of HIV diagnosed Black Americans with undetectable viral load by 20 percent.
- increase the proportion of HIV diagnosed Latinos with undetectable viral load by 20 percent.

Achieving a More Coordinated National Response to the HIV Epidemic in the United States

- Increase the coordination of HIV programs across the federal government and between federal agencies and state, territorial, local, and tribal governments.
- Develop improved mechanisms to monitor and report on progress toward achieving national goals.

to supportive services, such as housing, food and nutrition, and transportation, as well as 12 public and private data collection efforts the committee concluded would be the most useful for estimating the indicators in order to monitor the effect of the NHAS and the ACA on access to and provision of quality HIV care.

The report discusses how data can be used to estimate the committee's recommended indicators and describes potential barriers to and the role of health information technology in the collection and linkage of data pertain-

BOX 1-2
Statement of Task

The White House Office of National AIDS Policy has requested that the Institute of Medicine (IOM) convene a committee of experts to assess available public and private data systems that capture information about HIV care to investigate ways to maximize their usefulness and recommend approaches for supplementing current data sources and to identify and provide recommendations for the most critical data and indicators to gauge the impact of the National HIV/AIDS Strategy and the Patient Protection and Affordable Care Act in improving HIV/AIDS care.

The committee will address the following questions in its first consensus report:

1. What are the best sources of data (and which data elements should be used) from public and private HIV care databases to assess core indicators related to continuous care and access to supportive services, such as housing, for people living with HIV?
   a. What data collection items need to be revised or reconsidered in existing databases of care and services provided to people living with HIV and in demographic data about populations receiving these services? Are there proposed changes that can provide necessary data without adding additional burden to data collection?
   b. What is the difference between claims data and clinical data found in medical records and do these differences encompass gaps in measures for HIV care?
2. What similar data collection or standardization efforts are currently under way by public agencies or private industry that should be tapped?
3. How do we regularly obtain data (core indicators) that capture the care experiences of people living with HIV without substantial new investments?
4. What situations may impose barriers to the collection of core indicators?
   a. What policies, reimbursement issues or reporting issues need to be addressed to collect necessary data?

ing to HIV care, as well as the possibilities and challenges of combining data from different data systems to estimate the indicators identified by the committee.

The current report, which responds to the remaining portion of the committee's charge, addresses how to monitor the changes in health care coverage, service utilization, and quality of care for people with HIV that are anticipated under the ACA. Almost 30 percent of people with HIV in the United States have no source of health care coverage and only 17

b. How can data be collected in a way that will not significantly increase provider burden?

5. How can federal agencies efficiently analyze care indicators and disseminate data to improve HIV care quality?
6. What models or best practices in data system integration can be gleaned from public agencies or private industry to make existing data systems and core indicators interoperable?
   a. Which among these models or combination of models would be most cost effective?
7. How should health information technology (including electronic medical records) be utilized and configured in order to improve the collection of comprehensive data describing the care experiences of people living with HIV?

In a second consensus report, the committee will address the following question:

1. How do we obtain national estimates that characterize the health care of people living with HIV in public and private settings?
   a. How can we obtain data from a nationally representative sample of HIV positive individuals in the United States to establish a baseline for health insurance and health care access status prior to 2014?
   b. If it is not possible to obtain a nationally representative sample of people living with HIV are there other alternatives (including using multiple existing data sources or requiring a complete accounting of all positive persons in care) to obtain data on care and utilization beyond those individuals enrolled in Ryan White?
   c. How do we continue to regularly obtain data from a large sample (nationally representative or otherwise) of HIV-positive individuals after 2014 to monitor the impact of the Affordable Care Act on health insurance and health care access?

percent have private insurance; the remaining 53 percent are covered by government programs such as Medicaid, Medicare, and the Ryan White HIV/AIDS Program (HHS, 2012a). Many aspects of health reform under the ACA, including expansion of Medicaid eligibility requirements, elimination of preexisting condition exclusions, and lifting of annual and lifetime dollar limits on care, should substantially decrease the number of people with HIV who have no health care coverage and possibly result in changes to sources of coverage for others.

THE COMMITTEE'S APPROACH TO ITS CHARGE

The committee's two reports complement one another. In considering the statement of task for the current report, the committee thought that the first, overarching, question about how to obtain "national estimates that characterize the health care of people living with HIV in public and private settings" had been addressed already in its first report. One of the questions posed in the statement of task for the first report asks about how to "obtain data (core indicators) that capture the care experiences of people living with HIV without substantial new investments," and the first report focuses primarily on the identification of indicators and data systems for and approaches to estimating the indicators and monitoring the quality of clinical HIV care and access to mental health, substance abuse, and supportive services for people with diagnosed HIV in the United States. Although the statement of task for the first report does not specifically mention "national" or "nationally representative" estimates, the committee was mindful of this goal in its approach to the first report, including its identification of public and private data collection efforts for estimating the recommended indicators.

The present report focuses on the collection of data on health coverage status and data systems needed to address the current statement of task subquestions (a) through (c) pertaining to the establishment of "a baseline for health insurance and health care access status prior to 2014" and to monitoring "the impact of the [ACA] on health insurance and health care access" following its implementation in 2014. The committee considered subquestions (a) and (b) to be linked. The first asks how to obtain a nationally representative sample of people living with HIV in the United States prior to 2014, and the second poses a conditional question about alternative ways, including the use of "multiple existing data sources or requiring a complete accounting of all HIV-positive persons in care," to obtain "data on care and utilization beyond those individuals enrolled in the Ryan White HIV/AIDS Program" if it is not possible to obtain a nationally representative sample.

The committee interpreted this conditional question to apply to the acquisition of necessary data to establish a baseline for health care coverage and utilization status prior to 2014, if it concluded it were not currently possible to collect these data from a nationally representative sample of HIV-diagnosed individuals in the United States. The committee understood subquestion (c) to be a forward-looking opportunity to recommend an ongoing, dynamic strategy for capturing data from a nationally representative sample of HIV-diagnosed individuals in the United States. Given the challenges discussed in the committee's first report of collecting and combining data from disparate systems to generate an overall picture of the care

experiences of people with HIV in the United States (IOM, 2012, Chapters 4-6), development of a unique mechanism for capturing relevant information would simplify the collection and analysis of data and provide more detailed and representative data than currently exist to monitor the impact of the ACA on health care coverage and utilization for people with HIV.

The committee recognized that the development and maintenance of a successful, ongoing, dynamic strategy for capturing data from a nationally representative sample of HIV-diagnosed individuals in the United States will require sufficient funding. However, it determined that a detailed cost analysis and budgetary recommendation was beyond the scope of its charge.

The committee's two reports, although distinct, do overlap in certain ways. For example, as discussed in later chapters, it will be important to monitor care quality using indicators such as those recommended in the committee's first report in addition to tracking the movement of individuals into and among different sources of health coverage, which is the purview of the present report. In addition, the first report examined how best to obtain data to estimate the indicators using existing data systems and "without substantial new investments." The same ongoing mechanism recommended in the present report to capture data from a nationally representative sample of HIV-diagnosed individuals in the United States "to monitor the impact of the ACA on health insurance and health care access" potentially could also be used to simplify the collection and analysis of data to generate a national estimate of the indicators recommended in the first report.

Although the statement of task refers generally to "people living with HIV," for the purpose of this report, the committee interpreted this phrase as referring to people living with *a diagnosis* of HIV in the United States, since there is no practical way to obtain a "large sample (nationally representative or otherwise)" of people living with HIV that includes individuals with undiagnosed infection.[2] In addition, the present report limits the population under consideration to adults and adolescents (ages 13 and older). The use of ART to reduce or prevent perinatal transmission of the virus has resulted in a relatively small number of newly diagnosed pediatric HIV cases in the United States each year (CDC, 2012a, Table 1a). Although there

[2]The availability of rapid home-based HIV testing in the wake of the U.S. Food and Drug Administration's approval of an over-the-counter rapid HIV test in July 2012 "has the potential to identify large numbers of previously undiagnosed HIV infections especially if used by those unlikely to use standard screening methods" (FDA, 2012). Availability of such testing may affect timely reporting of individuals newly diagnosed through home-based testing to public health authorities for surveillance purposes and timely linkage of those individuals to care, as well as related measures pertaining to HIV diagnosis and linkage to care. Speculation on specific ways in which home-based testing may affect these measures is premature and beyond the scope of the committee's charge.

is a similarly low rate of new HIV diagnoses among 13- to 14-year-olds (CDC, 2012a, Table 1a), adolescents age 13 and older fall within the same HIV screening and treatment guidelines as adults (Branson et al., 2006; HHS, 2012b) and therefore are included with the adult population. For ease of reference, however, the report generally uses variations of "people with HIV" to refer to *adults and adolescents living with a diagnosis of HIV*. Where it is important to distinguish among diagnostic status and age groups (e.g., in the epidemiology section of this chapter), the committee took care to do so.

In considering the statement of task, the committee interpreted the term "health insurance" broadly to include all types of private and public plans or programs that cover health care and related services, including private health insurance; federal programs (e.g., Medicaid, Medicare, Ryan White HIV/AIDS Program, military health care, Indian Health Service); and individual state health plans. Since not all of the programs that cover care for people living with HIV (e.g., Ryan White HIV/AIDS Program, Veterans Health Administration) are insurance, this report preferentially uses the term health care "coverage."

For its first report, the committee considered more than 30 data systems and data collection efforts, including some that are HIV specific and others that are not but capture information on people living with HIV. The committee then requested information from 29 public and private data systems on the types of data collected (e.g., data on demographics, access to care, need for supportive services) to identify best sources of data to estimate core indicators of HIV care. The committee revisited these data sources for this second report to identify those that capture data relevant to monitoring health care coverage and utilization for people with HIV within the context of the ACA. Data of particular interest include enrollment and demographic information; sources of health coverage; and utilization of care, preventive, and supportive services. The committee considered which data collection efforts, including convenience samples (e.g., North American AIDS Cohort Collaboration on Research and Design [NA-ACCORD], CFAR [Centers for AIDS Research] Network of Integrated Clinical Systems [CNICS], HIV Research Network [HIVRN]) and national health-related surveys (e.g., National Health Interview Survey [NHIS], National Health and Nutrition Examination Survey [NHANES], National Health Care Surveys), could best capture data on health care coverage and utilization for a nationally representative sample of people with HIV in the United States and which best capture these data at the state level. The committee also took into account the findings from its first report on the extent to which various data sources capture information to estimate indicators of care quality and outcomes for people with HIV. Care quality and outcomes are important to monitor as

the ACA is implemented because continuity of care may be disrupted and the range of benefits available to individuals may change as they move into and among sources of care coverage.

REPORT ORGANIZATION

The remainder of Chapter 1 discusses the current epidemiology of the HIV epidemic, provides background on clinical HIV care and supportive services, and discusses the importance of an ongoing strategy for monitoring health care coverage and utilization for people with HIV in the United States. The chapter also highlights some examples of current and past broad-based data collection efforts. Chapter 2 gives a selective overview of the ACA; discusses ways in which implementation of the ACA is likely to affect people with HIV in the United States; and highlights some of the challenges of implementing the ACA. Chapter 3 provides background information to support the committee's conclusions and recommendations for how to establish a baseline for health care coverage, utilization, and quality prior to the implementation of the ACA; how to obtain relevant data from a nationally representative sample of people with HIV in the United States; and how to continue to monitor the impact of the ACA on these outcomes. The chapter first provides background information on the limitations of national health-related surveys for collecting data on specific diseases such as HIV and the sampling design and methodology used in the HIV Cost and Services Utilization Study (HCSUS), the first nationally representative study of HIV-infected adults in care in the United States. Referring to the committee's first report, it then notes the challenges and possibilities that attend establishing a baseline of health care coverage and utilization prior to 2014. The chapter next describes and discusses the strengths and limitations of the Medical Monitoring Project, a surveillance project conducted by the Centers for Disease Control and Prevention (CDC) that is currently designed to obtain nationally representative estimates of the clinical and behavioral characteristics of HIV-diagnosed individuals in care. The chapter also discusses how data from programs most apt to be affected by health reform, particularly Medicaid, Medicare, and the Ryan White HIV/AIDS Program, will be needed to monitor changes in health care coverage and utilization for people with HIV in the context of the ACA at the state and programmatic level. Chapter 4 contains the committee's conclusions and recommendations for monitoring health care coverage, utilization, and outcomes for people with HIV prior to and following full implementation of the ACA in 2014.

STUDY CONTEXT

Epidemiology of HIV

The epidemiology of the HIV epidemic is important for evaluating how representative different data collection efforts are of the national HIV-diagnosed population and for highlighting areas in which they may need to improve. As outlined in this section, differences in the racial and ethnic distribution of HIV-infected individuals among different regions of the country, differences in transmission category between men and women, and differences in prevalence trends among age groups illustrate the complexity of the HIV epidemic in the United States. Such variations, along with other factors such as differences in socioeconomic status, highlight the need for careful attention to sampling in any effort to obtain a nationally representative sample of people living with HIV in the United States.

There has been a significant shift in the HIV epidemic in the United States since the first cases were reported in the 1980s. In the early years of the epidemic, the virus that leads to AIDS had not yet been identified and treatments were limited, resulting in an epidemiologic focus on AIDS diagnoses and deaths. Within 11 years, the number of people diagnosed with AIDS grew rapidly from about 300 in 1981 to more than 75,000 in 1992, and the disease accounted for more than 50,000 deaths in 1995 (CDC, 2012c). In recent years, the annual rate of new AIDS diagnoses has decreased from 11.5 per 100,000 in 2007 to 10.8 per 100,000 in 2009 and 2010, while the death rate has held steady at 5.8 per 100,000 (CDC, 2012a, Tables 2b and 12a). Advances HIV diagnosis and treatment have contributed to the decrease in AIDS diagnoses as well as increased prevalence of non-AIDS HIV cases. With the advent of highly active antiretroviral therapy, HIV has become a chronic disease, and infected individuals are living longer, healthier lives. Although the number of newly HIV-infected individuals has stabilized at approximately 50,000 per year in the past few years (CDC, 2012c), the number of people estimated to be living with HIV in the United States has increased 8 percent from 2006 through 2009 (CDC, 2012f, Table 5b) because there are fewer deaths than new infections each year. In addition, increased testing and resultant diagnoses have contributed to a 9 percent increase in the number of people living with diagnosed HIV infection in the same time period. By the end of 2009, an estimated 1,148,200 people 13 years of age and older were living with HIV/AIDS in the United States, including an estimated 207,600 people with undiagnosed HIV/AIDS (CDC, 2012f, Table 5a). The increase in HIV prevalence has important resource implications for the diagnosis and care of people living with HIV.

Geographic Variations

The prevalence of individuals living with diagnosed HIV varies among U.S. regions and among racial and ethnic groups within the regions (Table 1-1).[3] In addition, there have been geographical shifts in the distribution of HIV in the United States. The burden of the epidemic, which was initially concentrated in major metropolitan areas such as San Francisco and New York City, has expanded over time to include more rural areas and the Southeast. In 2009, the southern region had the highest percentage of reported individuals with diagnosed HIV; 43 percent of people living with diagnosed HIV in the United States were living in the South (CDC, 2012a, Table 21; see Figure 1-1). In addition, the South had the highest percentage (45 percent) and the second highest rate (13 per 100,000) of newly diagnosed AIDS cases in the United States in 2010 (CDC, 2012f, Table 4a). The Northeast has the next highest percentage of people living with diagnosed HIV (26 percent) and of new AIDS diagnoses (24 percent), but the highest rate of newly diagnosed AIDS cases (14.2 per 100,000) (CDC, 2012a, Table 21; 2012f, Table 4a). The West accounts for 19 percent of people living with diagnosed HIV and of new AIDS cases, and the Midwest accounts for 12 percent and 13 percent of each respectively (CDC, 2012a, Table 21; 2012f, Table 4a).

The CDC also reports data for the U.S. dependent areas of American Samoa, Guam, Northern Mariana Islands, Puerto Rico, Republic of Palau, and U.S. Virgin Islands (CDC, 2012a, Table 21). The U.S. Virgin Islands and Puerto Rico have the highest rates of adolescents and adults living with diagnosed HIV (approximately 633 and 556 per 100,000 respectively).

Racial and Ethnic Variations

Overall, racial and ethnic minorities are disproportionately affected by HIV (Figure 1-2). Although blacks/African Americans accounted for 14 percent of the U.S. population in 2009, they represented 43 percent of people living with diagnosed HIV in 2009 and 46 percent of new HIV diagnoses in 2010 (CDC, 2011a, 2012a, Tables 1a and 15a). The rate of

[3]The CDC (2012a, p. 14) divides the country into four geographic regions—Northeast, South, Midwest, and West. States that comprise the *Northeast* are Connecticut, Maine, Massachusetts, New Hampshire, New Jersey, New York, Pennsylvania, Rhode Island, and Vermont. Areas of residence that comprise the *South* are Alabama, Arkansas, Delaware, District of Columbia, Florida, Georgia, Kentucky, Louisiana, Maryland, Mississippi, North Carolina, Oklahoma, South Carolina, Tennessee, Texas, Virginia, and West Virginia. States that comprise the *Midwest* are Illinois, Indiana, Iowa, Kansas, Michigan, Minnesota, Missouri, Nebraska, North Dakota, Ohio, South Dakota, and Wisconsin. States that comprise the *West* are Alaska, Arizona, California, Colorado, Hawaii, Idaho, Montana, Nevada, New Mexico, Oregon, Utah, Washington, and Wyoming.

TABLE 1-1 Number and Rates (per 100,000) of People Living with a Diagnosis of HIV in the United States by Regions and Race/Ethnicity, Year-End 2009

Region	Race/Ethnicity	Number	Rate per 100,000[a]
Northeast	American Indian/Alaska Native	216	101.5
	Asian	2,121	69.3
	Black/African American	98,296	1,500.7
	Hispanic/Latino	60,655	867.5
	Native Hawaiian/Other Pacific Islander	69	335.7
	White	58,587	154.1
	Multiple race	5,285	487.5
	Regional	209,600	384.3
South	American Indian/Alaska Native	862	93.3
	Asian	1,509	47
	Black/African American	205,786	935.2
	Hispanic/Latino	43,464	238.5
	Native Hawaiian/Other Pacific Islander	163	196.6
	White	106,627	155.2
	Multiple race	3,926	184.0
	Regional	358,411	314.3

[a]The rate per 100,000 was for this table was determined by dividing the reported number of HIV-infected individuals (CDC, 2012a) by the total ethnic/racial populations for each of the regions (Ennis et al., 2011; Hixson et al., 2011, 2012; Hoeffel et al., 2012; Norris et al, 2012; Rastogi et al., 2011; U.S. Census, 2012a) and multiplied by 100,000.

blacks/African Americans living with diagnosed HIV is seven times that of whites (951.9 compare to 143.9 per 100,000) (CDC, 2012a, Table 15a). Hispanics/Latinos accounted for 16 percent of the U.S. population but 19 percent of people living with diagnosed HIV in 2009 and 20 percent of new HIV diagnoses in 2010 (CDC, 2011b, 2012a, Tables 1a and 15a). The rate of Hispanics/Latinos living with diagnosed HIV is 319.9 per 100,000, more than two times that of whites (CDC, 2012a, Table 15a). Multiracial individuals also are more likely to be living with an HIV diagnosis than whites (286.4 compared to 143.9 per 100,000) (CDC, 2012a, Table 15a).

Even though the rates of American Indians/Alaska Natives and Native Hawaiians/Other Pacific Islanders living with a diagnosis of HIV (130.8

TABLE 1-1 Continued

Region	Race/Ethnicity	Number	Rate per 100,000[a]
Midwest	American Indian/Alaska Native	420	91.6
	Asian	821	47.5
	Black/African American	44,467	639.7
	Hispanic/Latino	9,161	196.5
	Native Hawaiian/Other Pacific Islander	56	189.5
	White	43,138	82.8
	Multiple race	1,494	130.1
	Regional	98,063	148.4
West	American Indian/Alaska Native	1,655	123.8
	Asian	4,476	67.1
	Black/African American	26,100	762.5
	Hispanic/Latino	42,766	207.6
	Native Hawaiian/Other Pacific Islander	554	136.1
	White	82,762	217.8
	Multiple race	1,414	53.8
	Regional	158,313	219.8

SOURCE: Based on CDC, 2012a, Table 21; Ennis et al., 2011, Table 2; Hixson et al., 2011, Table 4, 2012, Table 2; Hoeffel et al., 2012, Table 2; Norris et al., 2012, Table 2; Rastogi et al., 2011, Table 5; U.S. Census, 2012a (following the guidelines in U.S. Census, 2012b).

and 184.5 per 100,000, respectively) are comparable to that of whites (CDC, 2012a, Table 15a), their rates of HIV and AIDS diagnoses in 2010 were significantly greater. Although American Indians/Alaska Natives are 10 percent more likely than non-Hispanic whites to have ever been tested for HIV (Schiller et al., 2012, Table 41), they were 30 percent and 60 percent more likely than whites to be diagnosed with HIV and AIDS (CDC, 2012a, Tables 3a and 4a). Native Hawaiians/Other Pacific Islanders were 260 percent and 220 percent more likely than whites to have been diagnosed with HIV and AIDS (CDC, 2012a, Tables 3a and 4a) yet were 20 percent less likely to have ever been tested (Schiller et al., 2012, Table 41). In addition, both groups were estimated to have a higher percentage of

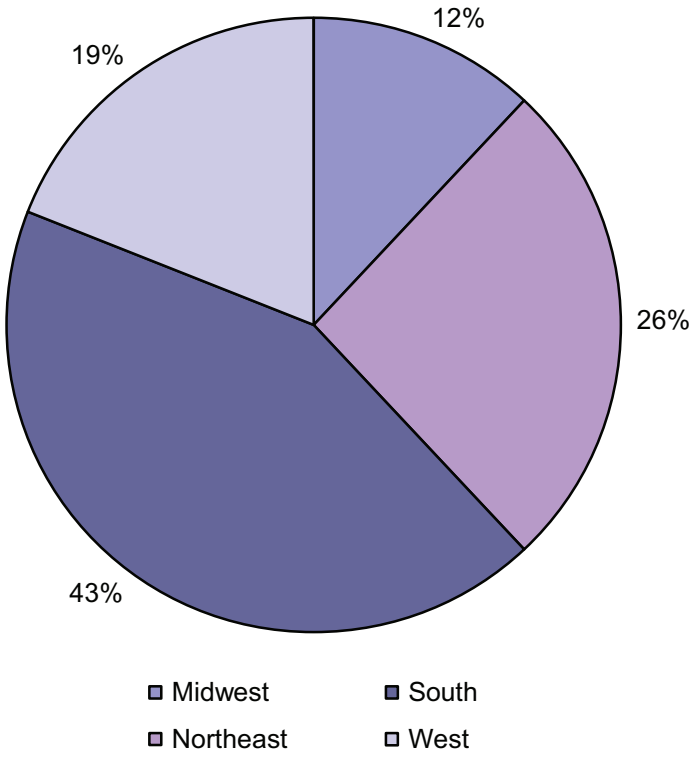

FIGURE 1-1 Total percentage of people living with a diagnosis of HIV in the United States by region, year-end 2009.

people living with undiagnosed HIV infection in 2009 compared to whites (CDC, 2012f, Table 5b).

Asian Americans were 10 percent less likely than non-Hispanic whites to have ever been tested for HIV (Schiller et al., 2012, Table 41). In addition, an estimated 27.4 percent of Asian Americans living with HIV in 2009 were undiagnosed, the highest percentage of undiagnosed individuals among all racial and ethnic groups (CDC, 2012f, Table 5b).

Variations by Sex

The proportion of people living with HIV in the United States also varies by sex. Approximately 75 percent of people living with diagnosed HIV in the United States are male (CDC, 2012a, Table 15a). In addition, there

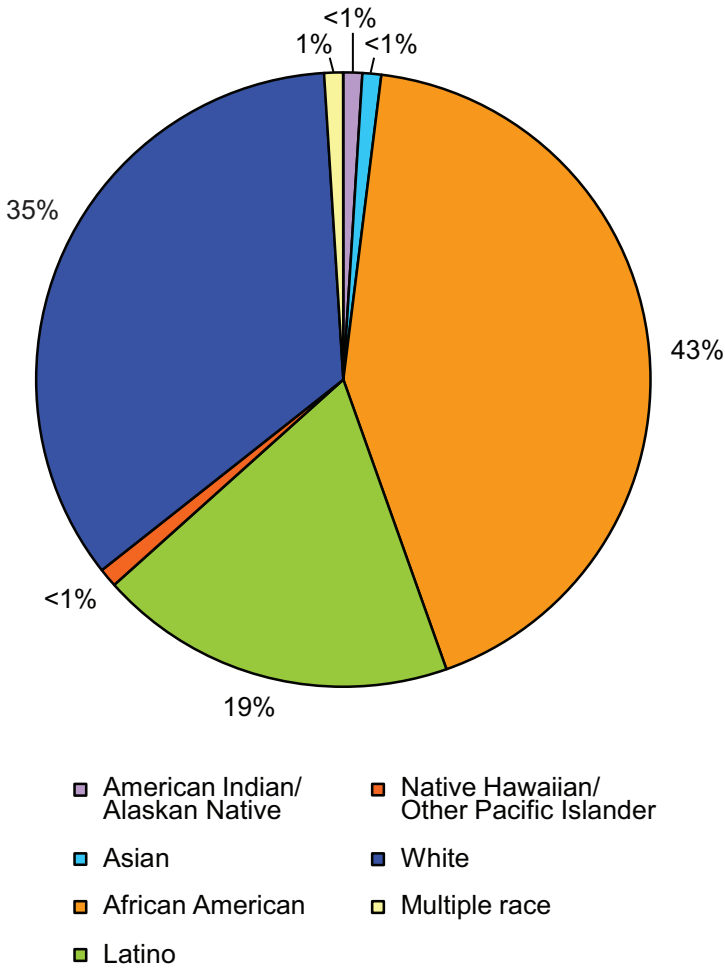

FIGURE 1-2 Percentage of racial and ethnic populations living with a diagnosis of HIV, year-end 2009.
SOURCE: CDC, 2012a, Table 15a.

are differences between males and females in the distribution of HIV transmission categories as well as race and ethnicity (see Table 1-2; Figure 1-3).

Sixty-eight percent of diagnosed HIV infections among men are acquired through male-to-male sexual contact (CDC, 2012a, p. 9, Table 15a), even though men who have sex with men (MSM) account for just 5.2 percent of sexually experienced men 18 to 59 years of age in the United

TABLE 1-2 Females and Males in the United States Living with a Diagnosis of HIV, by Race and Ethnicity, Year-End 2009

	Female Estimated			Male Estimated			
Race or Ethnicity	Number	Rate (per 100,000)	Percent of HIV-Diagnosed People	Number	Rate (per 100,000)	Percent of HIV-Diagnosed People	Total Estimated Number
American Indian/ Alaska Native	782	83	<1	2,218	245	<1	3,000
Asian	1,457	27	<1	6,816	138	1	8,273
Black/African American	114,721	764	61	214,464	1,612	37	329,185
Hispanic/Latino	31,753	190	17	117,101	647	20	148,854
Native Hawaiian/ Other Pacific Islander	108	83	<1	498	383	<1	606
White	36,587	44	19	235,610	297	40	272,197
Multiple race	3,083	225	2	7,908	617	1	10,991
Total[a]	188,688	154	24	585,197	496	76	773,885

[a]Because column totals include persons of unknown race and ethnicity, the values in each column may not sum to the column total.
SOURCE: CDC, 2012a, Table 17a.

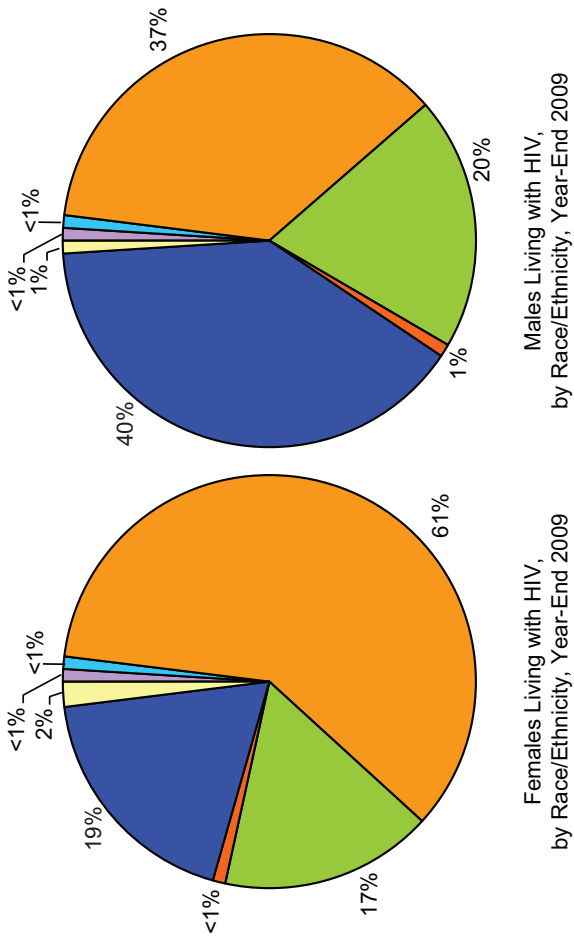

FIGURE 1-3 Percentage of females and males living with a diagnosis of HIV in the United States by racial or ethnic group, year-end 2009.
SOURCE: Based on CDC, 2012a, Table 17a.

States (Xu et al., 2010). MSM accounted for 51 percent of people living with HIV in the United States in 2009 and an estimated 61 percent of new HIV diagnoses in 2010 (CDC, 2012a, Tables 1a and 15a). Young black/African American MSM (13-29 years of age) had a 48 percent increase of new HIV infections from 2006 to 2009, making it the only risk group to have a statistically significant increase in new HIV infections during that period (Prejean et al., 2011).The remainder of diagnosed infections among males can be attributed to injection drug use (13 percent), heterosexual contact (11 percent), and combined MSM contact and injection drug use (8 percent) (CDC, 2012a, p. 9, Table 15a). The racial and ethnic distribution of males diagnosed with HIV in 2009 is similar to that of the entire population of diagnosed individuals in the United States (see Figures 1-2 and 1-3).

In contrast to the male population, 74 percent of women living with diagnosed HIV in 2009 were infected through heterosexual contact with a person known to have or to be at high risk for HIV infection (CDC, 2012a, p. 9, Table 15a). There is also a significantly different racial distribution among women with diagnosed HIV compared to HIV-diagnosed men. Black/African American females comprise 61 percent of females in the United States with an HIV diagnosis, whereas black/African American males account for 37 percent of males living with an HIV diagnosis (CDC, 2012a, Table 17a; see Figure 1-3). White females account for only 19 percent of females diagnosed with HIV in the United States, while white males represent 40 percent of the diagnosed male population (CDC, 2012a, Table 17a; see Figure 1-3).

Age Variations

The proportion of individuals living with HIV varies by age group, and there has been a change in the age distribution over time (Table 1-3). The prevalence of HIV among children under 13 years of age, and among adolescents 13 to 14 years of age, has declined significantly due to routine HIV testing of pregnant women and administration of ART to HIV-infected women. Between 2007 and 2009, the number of individuals living with a diagnosis of HIV in each age group decreased by 21 and 17 percent respectively (Table 1-3; CDC, 2102a, Table 15a). In addition, there is a significant increase in the number of people living with diagnosed HIV between the 13- to 19-year-old and the 20- to 29-year-old age groups (Table 1-3; CDC, 2102a, Table 15a).

The age groups that had the largest increase in the number of people living with an HIV diagnosis between 2007 and 2009 were the 50-to-59 and the 60-and-older groups due to increased survival among people in care, as well as to new infections. From 2007 to 2009, the number of HIV-diagnosed individuals in those age groups increased 20 and 31 percent

TABLE 1-3 People Living with a Diagnosis of HIV in the United States by Age Group, 2007-2009

	2007 Estimated		2008 Estimated		2009 Estimated	
Age at End of Year	Number	Rate	Number	Rate	Number	Rate
<13	3,729	7.4	3,318	6.5	2,945	5.7
13-14	1,459	18.4	1,362	17.4	1,218	15.7
15-19	6,611	32.2	6,947	33.7	6,983	34.1
20-24	21,047	104.1	23,374	115.1	25,866	126.1
25-29	42,992	214.7	44,701	218.8	46,394	224.7
30-34	61,326	332.8	62,330	335.4	63,541	335.6
35-39	101,426	508.4	96,619	487.3	91,523	468.2
40-44	145,078	700.0	140,427	692.1	134,215	673.8
45-49	139,947	647.2	148,956	688.4	155,757	719.0
50-54	100,497	505.0	108,914	535.2	117,290	567.7
55-59	59,313	343.1	66,005	374.9	73,759	409.3
60-64	27,935	203.5	32,581	227.5	37,066	246.9
≥65	21,688	60.2	24,816	67.3	28,143	74.8

SOURCE: Based on CDC, 2012a, Table 15a.

respectively.[4] In contrast, the number of people aged 35 to 44 years living with diagnosed HIV decreased by 8 percent in the same time period, and the number of 30- to 34-year-olds increased by only 3 percent (Table 1-3; CDC, 2012a, Table 15a).

Clinical HIV Care and Supportive Services

The advent of highly active antiretroviral therapy in the mid-1990s changed the face of the HIV epidemic. HIV care has been transformed from acute and palliative end-of-life care into chronic disease management. With appropriate treatment, infected individuals on ART can live long and relatively healthy lives. Studies have shown that the life expectancy of people with HIV who are receiving ART is similar to that of uninfected individuals who engage in unhealthy behaviors such as the heavy use of alcohol or cigarettes (ART-CC, 2009; May et al., 2011; Nakagawa et al., 2012), although life expectancy is lower among injection drug users and individuals who are diagnosed with HIV at later stages of the disease or who delay treatment (ART-CC, 2008; May et al., 2011; Nakagawa et al., 2012). Appropriate use of ART also reduces morbidity among people with HIV, as indicated by a reduction in the incidence of opportunistic infections and AIDS-defining illnesses (Iwuji et al., 2011; Mocroft et al., 1999; Moore and Chaisson, 1999; Palella et al., 1999).

In addition, awareness of one's HIV-infected status can lead to behavior changes that reduce the risk of transmitting the virus to others, and appropriate use of ART also reduces infectivity. Initial results from the recent HIV Prevention Trials Network HPTN 052 clinical trial, funded by the National Institutes of Health, indicate that early initiation of ART reduces sexual transmission of HIV in serostatus-discordant couples by 96 percent (Cohen et al., 2011). The U.S. Department of Health and Human Services (HHS) *Guidelines for the Use of Antiretroviral Agents in HIV-1-Infected Adults and Adolescents* issued in March 2012 recommend the initiation of ART for all HIV-infected individuals, although the strength of the recommendation varies based on the individual's CD4+ T-cell count (HHS, 2012b, p. E-1). In practice, the movement in the United States toward universal treatment for people with HIV had begun prior to the release of the current HHS *Guidelines*. In April 2010, the San Francisco and, in December 2011, the New York City departments of health already were recommending

[4]Individuals age 50 years and older now comprise more than 30 percent of the HIV-diagnosed population in the United States (Table 1-3; CDC, 2012a, Table 15a). Reflecting the increasing number of older adults with diagnosed HIV and the special concerns that attend HIV infection in that population, the U.S. Department of Health and Human Services added a new section on "HIV and the Older Patient" to the March 27, 2012, revision of its treatment guidelines (HHS, 2012b, pp. I-27-I-32).

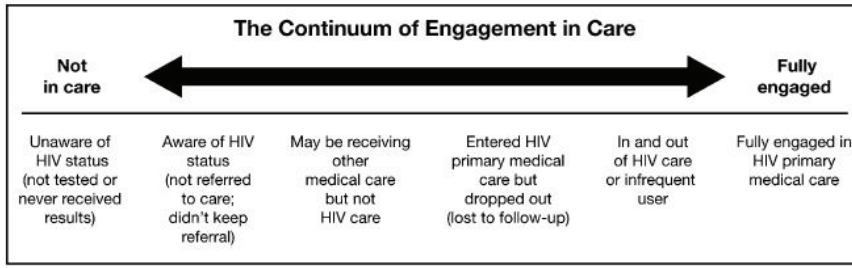

FIGURE 1-4 Continuum of engagement in care.
SOURCE: Cheever, 2007.

initiation of ART regardless of individuals' CD4 count (Charlebois et al., 2011; NYC DOHMH, 2011).

Despite the importance of appropriate antiretroviral use for reducing HIV-related morbidity and mortality and viral transmission, many people with HIV are not on ART. The goal of ART is to reduce individuals' viral load below the level of detection. According to estimates for the United States, although approximately 77 to 80 percent of individuals being treated with ART have an undetectable viral load, only 24 to 33 percent of people with HIV are receiving ART and only 19 to 25 percent of people with HIV overall have an undetectable viral load (CDC, 2012d; Gardner et al., 2011). Primary barriers to optimal outcomes for people with HIV include late diagnosis, delayed linkage to care, poor retention in care, delayed initiation of ART, and poor adherence to ART (i.e., discontinuing or intermittent ART), as well as untreated non-HIV comorbidities and unmet basic needs (Castilla et al., 2002; Gardner et al., 2011; Justice, 2006; Lo et al., 2002). Figure 1-4 shows the continuum of engagement in HIV care and Figure 1-5 shows the number and percentage of people lost to care at various points along the care continuum.

A number of factors, including mental health symptoms and disorders, substance abuse, and difficulty securing and maintaining basic needs of housing, food, and access and transportation to medical care and supportive services, have been shown to have a significant, negative impact on the health status and outcomes of people with HIV (see, e.g., Conviser and Pounds, 2002a,b; Gaynes et al., 2007; Kidder et al., 2007; Leaver et al., 2007; Lo et al., 2002; Pence, 2009; Royal et al., 2009; Stall et al., 2003; Weiser et al., 2009a,b).

Furthermore, significant disparities exist among racial, ethnic, and sexual minorities with respect to access to and continuity of care and treatment (Espinoza et al., 2008; Gebo et al., 2005; Hall et al., 2008; Mays et al., 2011; Prejean et al., 2008, 2011; Robison et al., 2008). Several stud-

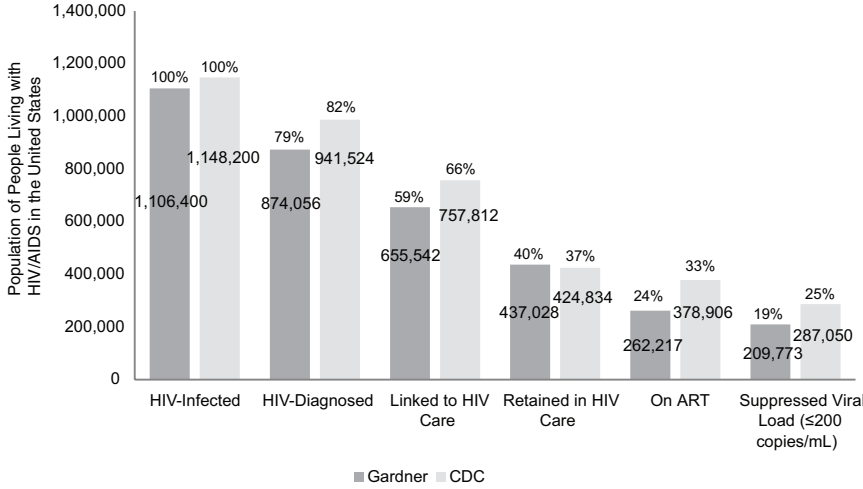

FIGURE 1-5 Engagement in HIV care cascade.
NOTE: The numbers shown are estimates and in some cases are extrapolated from single time points. For example, the CDC linkage to care estimate is based on people who were diagnosed with HIV in 2009.
SOURCES: Adapted from CDC, 2012d; Gardner et al., 2011; Hall et al., 2012.

ies report differences in the care experiences of racial or ethnic minorities compared to whites, including differences in access to health care services due to lack of health coverage, differences in the presentation of health care information and advice as a function of patient–provider interactions, and perceived bias and discrimination, although the mechanisms of how these work are not well understood (Baicker et al., 2004; Cooper-Patrick et al., 1999; Doescher et al., 2001; Garland et al., 2010; Johnson et al., 2004a,b; Korthuis et al., 2008; Schneider et al., 2002). In addition to race and ethnicity, individuals' country of origin and citizenship status are factors that may be related to HIV-related disparities (Chen et al., 2010; Garland et al., 2010). Age, sex, and socioeconomic and health coverage status are other demographic characteristics associated with disparities in HIV care (Agwu et al., 2011; Aziz and Smith, 2011; Meditz et al., 2011; Mugavero et al., 2007; Wohl et al., 2011).

Access to HIV care also varies based on geographic area of residence, in terms of rural, urban, and suburban populations and region of the country (South, Northeast, Midwest, West) (Krawczyk et al., 2006a,b; Moon et al., 2001; Qian et al., 2006; Reif et al., 2005). People living in rural areas face barriers to accessing quality HIV care, including greater stigma regarding

HIV infection; increased fear of HIV status being disclosed; reduced availability of local HIV-knowledgeable providers; and difficulty traveling to obtain HIV care elsewhere (Heckman et al., 1998; Krawczyk et al., 2006a,b; Mays et al., 2011; Meditz et al., 2011; Moon et al., 2001; Ohl et al., 2010; Qian et al., 2006; Reif et al., 2005, 2011; Schur et al., 2002; Vermund et al. 2010; Weis et al., 2010).

The vital role of appropriate HIV care (including medical and supportive services) and the use of ART in reducing HIV morbidity, mortality, and transmission—in conjunction with the number of people with HIV who either are never engaged in or are lost to HIV care and the significant disparities in HIV care and outcomes among different demographic groups—highlights the need to monitor health care coverage, service utilization, and quality of care for people with HIV in the United States.

In its first report, the committee recommended 14 core indicators of HIV care (9 for clinical HIV care; 5 for mental health, substance use, and supportive services) for monitoring HIV care in the United States (IOM, 2012, pp. 75-77; see Table 1-4). The committee also identified 15 additional indicators (10 for clinical HIV care; 5 for mental health, substance use, and supportive services) that provide a more comprehensive assessment of quality HIV care (IOM, 2012, Chapter 2). The committee used critical benchmarks along the HIV care continuum; NHAS targets (ONAP, 2010); and existing indicators (HHS, 2010; PEPFAR, 2009), quality measures (Horberg et al., 2010; NQF, 2011), and treatment standards (HHS, 2011)[5] as a basis for the HIV care indicators. In addition, the committee took account of mental health, substance use, and the need for supportive services, such as housing, food, and transportation, as mediators of HIV care in its formulation of the relevant indicators. Figure 1-6 shows the core and additional HIV care indicators mapped to the continuum of HIV care.

MONITORING HIV IN THE UNITED STATES

Development of an ongoing strategy for monitoring HIV in the United States is important for a variety of reasons: (1) monitoring the incidence of new HIV infections; (2) acquiring data on the numbers and demographic characteristics of people lost to care at various points along the HIV care continuum; (3) tracking HIV-related disparities and health inequities; (4) helping to inform potential redistribution of resources to improve the

[5]In its first report, the committee followed the HHS panel's then-current recommended CD4+ T-cell count threshold of 500 cells/mm^3 in formulating a core indicator for the initiation of ART. The committee further noted that if future HHS guidelines were to recommend universal treatment for people with HIV (as they now do), the committee would support a similar revision of its ART-initiation indicator or an alternate indicator tracking the time from HIV diagnosis to ART initiation (IOM, 2012, pp. 47-48).

TABLE 1-4 Core Indicators for Clinical HIV Care and Mental Health, Substance Abuse, and Supportive Services, with Rationale

Core Indicators for HIV Clinical Care
Proportion of people newly diagnosed with HIV with a CD4+ cell count >200 cells/mm^3 and without a clinical diagnosis of AIDS Rationale: Improve health outcomes by reducing the number of people living with HIV/AIDS (PLWHA) with late diagnosis.
Proportion of people newly diagnosed with HIV who are linked to clinical care for HIV within 3 months of diagnosis Rationale: Timely linkage to care improves individual health outcomes and reduces transmission of the virus to others.
Proportion of people with diagnosed HIV infection who are in continuous care (two or more visits for routine HIV medical care in the preceding 12 months at least 3 months apart) Rationale: Continuous HIV care results in better outcomes, including decreased mortality, and reduced transmission of the virus to others.
Proportion of people with diagnosed HIV infection who received two or more CD4 tests in the preceding 12 months Rationale: Regular CD4 testing permits providers to monitor individuals' immune function, determine when to start antiretroviral therapy (ART), and assess the need for prophylaxis for opportunistic infections.
Proportion of people with diagnosed HIV infection who received two or more viral load tests in the preceding 12 months Rationale: Regular viral load (plasma HIV RNA) testing is important for monitoring clinical progression of the disease and therapeutic response in individuals on ART.
Proportion of people with diagnosed HIV infection in continuous care for 12 or more months and with a CD4+ cell count ≥350 cells/mm^3 Rationale: Achieving and maintaining a CD4+ cell count ≥350 cells/mm^3 reduces the risk of complicating opportunistic infections and cancers.
Proportion of people with diagnosed HIV infection and a measured CD4+ cell count <500 cells/mm^3 who are not on ART* Rationale: Appropriate initiation of ART improves individual health outcomes and reduces transmission of the virus to others.
Proportion of people with diagnosed HIV infection who have been on ART for 12 or more months and have a viral load below the level of detection Rationale: The goal of ART is durable virologic suppression, which improves health outcomes and reduces transmission of the virus.

All-cause mortality rate among people diagnosed with HIV infection*
Rationale: Mortality rate is the ultimate outcome measure for people diagnosed with HIV infection. Mortality among PLWHA should be inversely related to the quality of overall care delivered.

Core Indicators for Mental Health, Substance Abuse, and Supportive Services

Proportion of people with diagnosed HIV infection and mental health disorder who are referred for mental health services and receive these services within 60 days**
Rationale: Untreated mental health disorders can negatively affect maintenance in care, adherence to treatment, and health outcomes for PLWHA and may increase the risk of transmitting the virus to others.

Proportion of people with diagnosed HIV infection and substance use disorder who are referred for substance abuse services and receive these services within 60 days**
Rationale: Untreated substance use disorders can negatively affect maintenance in care, adherence to treatment, and health outcomes for PLWHA and may increase the risk of transmitting the virus to others.

Proportion of people with diagnosed HIV infection who were homeless or temporarily or unstably housed at least once in the preceding 12 months*
Rationale: Homelessness and housing instability negatively affect maintenance in care, adherence to treatment, and health outcomes for PLWHA and may increase the risk of transmitting the virus to others.

Proportion of people with diagnosed HIV infection who experienced food or nutrition insecurity at least once in the preceding 12 months*
Rationale: Food insecurity affects maintenance in care, adherence to treatment, and health outcomes for PLWHA and may increase the risk of transmitting the virus to others. Poor nutrition affects absorption of medications and can contribute to diet-sensitive comorbidities.

Proportion of people with diagnosed HIV infection who had an unmet need for transportation services to facilitate access to medical care and related services at least once in the preceding 12 months*
Rationale: Unmet need for transportation to access HIV health care and related services negatively affects treatment access, service utilization, and health outcomes for PLWHA and may increase the risk of transmitting the virus to others.

*In contrast to the other indicators, the estimates for these indicators should decrease with improved access to care and supportive services.
**Receipt of care within 30 days would reflect optimal care, but 60 days is more realistic given the current limited capacity of many providers to see new patients within a shorter time frame. Urgent cases should be seen as soon as possible.

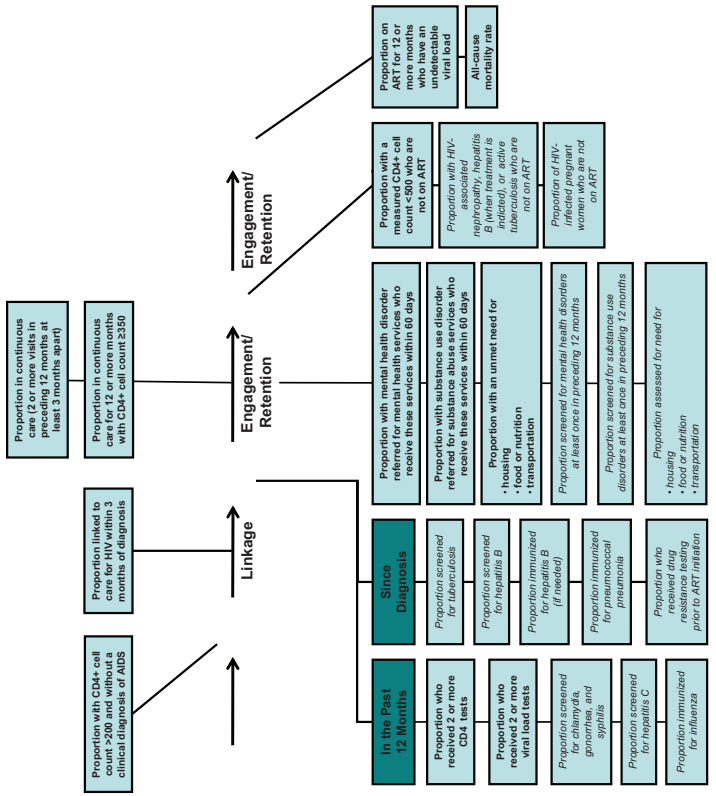

FIGURE 1-6 Continuum of HIV care arrow mapped to indicators for HIV care and supportive services.
NOTE: Indicators written in bold text correspond to the committee's recommended core indicators; the indicators written in italics correspond to the additional indicators identified by the committee
SOURCE: Adapted from Das, 2011.

efficiency and quality of care and reduce health disparities; (5) permitting assessment of the impact of the NHAS and the ACA on health care coverage, utilization, and quality for people with HIV, facilitating identification of any difficulties encountered, and informing future planning; and (6) providing a real-time window into national health policy.

HIV is an expensive, chronic infectious disease, for which treatment of infected individuals has important public health consequences. Increased survival resulting from more effective treatments has led to a greater number of people with HIV in the United States. In addition, although the number of new HIV infections occurring annually has leveled off in recent years, an estimated 50,000 people in the United States were newly infected with HIV each year from 2006 through 2009 (Prejean et al., 2011). In addition to improving health outcomes for people with HIV who are treated, the movement toward universal treatment of HIV-infected individuals with ART may help to reduce the incidence of new infections. Reductions in the overall morbidity and mortality associated with new HIV infections in conjunction with decreases in HIV incidence could reduce HIV-related health care costs over time, although this benefit will not be realized for some time, given the lifespan of people being effectively treated for HIV. Each new HIV infection detected generates a responsibility to treat and monitor an additional patient, at an average cost of $19,912 per year in 2006 (Gebo et al., 2010) or $23,000 in 2010 dollars (CDC, 2012b). Based on a lifetime cost estimate discounted to the time of infection, the potential savings in HIV-related health care costs per HIV infection prevented is $303,100 in 2004 dollars for an adult initiating ART at a CD4+ cell count <350/mm^3 (Schackman et al., 2006) or $379,668 in 2010 dollars (CDC, 2012b).

Earlier diagnosis and improved linkage to HIV care may help to improve health outcomes (ART-CC, 2008; Iwuji et al., 2011; May et al., 2011; Mocroft et al., 1999; Moore and Chaisson, 1999; Nakagawa et al., 2012; Palella et al., 1999), reduce new transmissions, and reduce the additional costs associated with late entry into care.[6] In addition to late diagnosis and linkage to care, poor retention in care, delayed initiation of ART, and poor adherence to ART (i.e., discontinuing or intermittent ART) contribute to suboptimal outcomes for people with HIV. The fact that only 19 to 25 percent of people with HIV in the United States have an undetectable viral load in an era of effective treatment (CDC, 2012d; Gardner et al., 2011) is alarming. Monitoring health care coverage, utilization, and quality for

[6]Studies have shown that HIV treatment costs are significantly higher for individuals who enter treatment with lower CD4+ cell counts (e.g., <350/mm^3) than for those who enter treatment earlier in the course of their disease (e.g., CD4+ cell counts >500/mm^3) (Fleishman et al., 2010; Krentz and Gill, 2012). Notably the cost differential remains significant even among those remaining in care for 7 to 8 years, despite improved CD4 counts (Fleishman et al., 2010; Krentz and Gill, 2012).

people with HIV would provide data on the numbers and demographic characteristics of people who never enter care, are lost to care at various points along the care continuum, or receive suboptimal care. It also would permit the assessment of progress not only in improving health outcomes for all people with HIV, but also in reducing HIV-related disparities. These data could help inform potential redistribution of resources and identify progress and challenges associated with implementation of the ACA.

Although implementation of the ACA is expected to improve access to health care coverage and services and reduce health disparities among people with HIV, at least in states that choose to implement the Medicaid expansion provision, these outcomes are not guaranteed. For example, access may be reduced if new sources of health coverage limit the number of medications covered per month or reimbursement for substance abuse, mental health, and supportive services that were previously covered under the Ryan White HIV/AIDS Program. In particular, it will be important to assess how the care people receive under new public and private insurance and other sources of coverage compares to care they previously received under the Ryan White HIV/AIDS Program and other discretionary and entitlement programs. In this vein, monitoring the service utilization and quality of care for people with HIV in the wake of the ACA not only will permit assessment of the impact of the ACA on the amount and quality of care received by people with HIV, but also will facilitate identification of difficulties encountered during ACA implementation and inform planning, including future funding, workforce, or service needs.

In order to take maximum advantage from any strategy for monitoring health care coverage and utilization for people with HIV, it is important to ensure that the monitoring process is living and dynamic rather than static, allowing it to be modified as needed to collect the most useful and relevant data. Development of a strategy for monitoring HIV care coverage and utilization also may provide a window into national health care policy, such as interstate disparities. Furthermore, the system for monitoring health care coverage and utilization for HIV might facilitate the development of strategies for monitoring other chronic conditions, such as diabetes and heart disease.

Use of Nationally Representative Samples for Monitoring Health Care Coverage and Utilization Among People with HIV

In monitoring health care coverage and utilization for people with HIV in the United States, the use of nationally representative sampling is important to ensure that all subgroups within the U.S. HIV-infected population are included in the results. As discussed previously, HIV disproportionately

affects "vulnerable populations,"[7] which contributes to the health disparities experienced by many people with HIV. In addition, a majority of people with HIV in the United States also must confront actual or perceived stigma and discrimination based on their sexual orientation or practices, further contributing to health disparities within this population.

The NHAS targets improvements in the care and health outcomes of individuals at the greatest risk for poor outcomes and unmet basic and health care needs, and the ACA is expected to significantly improve access to health care coverage and services for low-income people with HIV. Consequently, a monitoring system requires proportionate attention to groups that often are the most difficult to assess, including individuals with mental and substance use disorders, homeless individuals, those living in rural areas, and undocumented immigrants, which makes the task of developing a "representative national sample" particularly challenging.

As discussed in the committee's first report, data relevant for monitoring progress toward meeting the goals of the NHAS and ACA currently are being collected by a number of public and private data systems, some specific to HIV and others not, each of which has limitations. The committee identified 12 data systems in particular that can serve as a collective platform for evaluating the use of continuous and high-quality care in all HIV-infected populations in the United States (Box 1-3; IOM, 2012, p. 167). As discussed in detail below, two of these data collection efforts, the National HIV Surveillance System (NHSS) and the Medical Monitoring Project (MMP), both under the auspices of the CDC, are either relatively comprehensive or designed to be nationally representative of people in the United States who have been diagnosed with HIV. Other data collection efforts, such as NA-ACCORD, CNICS, and HIVRN, draw from convenience samples. Although convenience samples may be demographically diverse, they are not necessarily nationally representative of the population of interest (Shapiro et al., 1999). NA-ACCORD, CNICS, and HIVRN, for example, draw data primarily from cohorts or sites in urban areas. Therefore, the data may not reflect the experiences of people with HIV in rural areas (IOM, 2012, Chapter 3). Data from health plans (e.g., Kaiser Permanente, Veterans Health Administration) or other sources of health care coverage (e.g., Medicaid, Medicare, Ryan White HIV/AIDS Program), including private insurers, also are not nationally representative, including data only from enrollees in their plans or programs. Data

[7] "Vulnerable populations are groups that are not well integrated into the health care system because of ethnic, cultural, economic, geographic, or health characteristics. . . . Commonly cited examples of vulnerable populations include racial and ethnic minorities, the rural and urban poor, undocumented immigrants, and people with disabilities or multiple chronic conditions" (Urban Institute, 2012).

BOX 1-3
Data Collection Activities for Monitoring HIV Care

HIV Care-Specific Data Systems

Public

- National HIV Surveillance System
- Medical Monitoring Project
- Ryan White Services Report
- Ryan White AIDS Drug Assistance Program Reports

Private

- North American AIDS Cohort Collaboration on Research and Design
- CFAR Network of Integrated Clinical Systems
- HIV Research Network

Data Systems with Information That Includes People with HIV

Public

- Medicaid Statistical Information System
- Medicare Chronic Condition Data Warehouse
- Clinical Case Registry: HIV
- National Vital Statistics Information System

Private

- Kaiser Permanente

from these sources, although useful in many ways, have other limitations as well (IOM, 2012, Chapter 3; Shapiro et al., 1999). National health-related surveys (e.g., NHIS, NHANES), which draw data from multistage probability-based samples of households, generate nationally representative data, but are neither apt to capture a statistically significant number of people with nor designed to capture detailed information about any given disease (Shapiro et al., 1999).

Examples of Broad-Based Data Collection for Monitoring Health Care Coverage and Utilization Among People with HIV

Population-based surveillance of the HIV epidemic in the United States began in 1981 when the first cases of opportunistic illnesses caused by what later would be identified as HIV were reported. Early in the epidemic, CDC, as well as state and local bodies, used AIDS case reporting to track the epidemic, rather than reports of newly diagnosed persons. The advent of

highly active antiretroviral therapies in the mid-1990s led to an increase in the time from HIV infection to AIDS diagnosis and thereby rendered AIDS case reporting insufficient to track the epidemic overall and to provide adequate information about prevention and care service needs (Fleming et al., 1999). In 1985, states began to institute HIV case reporting in addition to AIDS case reporting. In 1994, CDC integrated its AIDS and HIV reporting systems into a single, unified system, the NHSS (CDC, 2012e).[8]

Although surveillance data are vitally important for monitoring many aspects of the HIV epidemic, they traditionally have been relatively limited in scope. The NHSS, as a comprehensive national surveillance system, contains data on virtually all people diagnosed with HIV in the United States. However, surveillance data are not designed to describe HIV care and utilization in the United States as would be captured by the core indicators recommended by the committee in its first report (IOM, 2012, pp. 89-90, 110-118; see Table 1-4). Other large-scale HIV data collection efforts, such as the AIDS Cost and Services Utilization Survey (ACSUS), HIV Cost and Services Utilization Study, and MMP, have attempted to collect a broader range of data about health care coverage and utilization as well as supportive service needs, use, and experiences among people with HIV.

National HIV Surveillance System

The NHSS is a population-based census of all persons in the United States diagnosed with HIV infection and reported to CDC, including individuals receiving HIV care and those who are not in care, approximately 942,000 individuals (CDC, 2011d).[9] CDC funds and assists state, territorial, and local health departments to collect HIV surveillance data and report them to CDC using Adult and Pediatric HIV Confidential Case Report forms. The state, territorial, and local HIV surveillance systems represent valuable additional sources of data pertinent to HIV care utilization.[10] By

[8]Since 2008, CDC also conducts HIV Incidence Surveillance in 25 jurisdictions disproportionately affected by the disease and, since 2004, Variant, Atypical, and Resistance HIV Surveillance, to collect HIV genetic sequence data, in 11 jurisdictions (CDC, 2012c). Another CDC initiative, National HIV Behavioral Surveillance, collects data on "behavioral risks for HIV, HIV testing behaviors, access to and use of prevention services, and HIV testing results" in 20 AIDS-prevalent jurisdictions (CDC, 2012c).

[9]The national surveillance system is meeting its completeness standard of ≥85 percent for all diagnosed cases being reported to the system (CDC response to IOM request for information, April 4, 2011).

[10]These HIV surveillance systems may include additional data elements not captured on the CDC case report forms, as well as data from code-based reports initiated prior to name-based reporting and anonymous results that have not been name ascertained and hence are not included in the NHSS. The proportion of these uncounted cases can be calculated precisely by the reporting areas that have made the transition to name-based reporting.

April 2008, all 50 states and the District of Columbia, as well as American Samoa, Guam, Puerto Rico, the U.S. Virgin Islands, the Northern Mariana Islands, and the Republic of Palau—one of three freely associated states that report HIV surveillance data to CDC[11]—had implemented confidential, name-based HIV reporting (CDC, 2011c). Although the data for all reporting areas are included in CDC's annual *HIV Surveillance Report*, 2012 marks the first year that all states have sufficiently mature reporting systems to permit CDC to statistically adjust the data for reporting delays and missing information (CDC, 2012e).[12]

In terms of data elements of interest for tracking the impact of the ACA, the NHSS includes date of HIV/AIDS diagnosis, information on CD4+ T-cell count and plasma HIV RNA (viral load) closest to diagnosis, and optional fields for HIV and substance abuse treatment referral, pregnancy status, and ART status at the time of reporting. Demographic data captured in the NHSS can be used to monitor health disparities among people with HIV with regard to race, ethnicity, sex, gender, age, geographic area, and country of birth.[13] Most jurisdictions also report all CD4 count and viral load results,[14] which permits the tracking of individuals' health status over time.

AIDS Cost and Services Utilization Survey

Although not designed to be nationally representative of people with HIV, ACSUS (1991-1992) was the first large-scale and broadly representative effort, beyond surveillance, to collect data on HIV-infected individuals. Sponsored by the Agency for Health Care Policy and Research, now the Agency for Healthcare Research and Quality (AHRQ), ACSUS focused on people receiving HIV care and provided longitudinal data on health care services use, expenditures, and sources of payment for care of adults and children at various stages of HIV infection, and the ways in which those

[11]The Federated States of Micronesia and the Republic of the Marshall Islands are the other two freely associated states.

[12]The *HIV Surveillance Report* for 2012, to be issued in 2014, will be the first to include aggregate data from all 50 states (CDC, 2010).

[13]The full set of data elements captured in the NHSS can be obtained from the Adult and Pediatric Confidential HIV Case Report forms (available at http://www.odh.ohio.gov/pdf/IDCM/frm5042a.pdf; http://www.odh.ohio.gov/pdf/IDCM/frm5042b.pdf [accessed June 13, 2012]).

[14]As of June 15, 2010, 33 of 59 reporting areas (50 states, District of Columbia, 5 U.S. dependent areas, and 3 freely associated states) were reporting all CD4 and viral load test result, including 30 states, District of Columbia, Guam, and Puerto Rico (Personal communication, Amy Lansky, Centers for Disease Control and Prevention, October 6, 2011). More states are moving toward reporting all CD4 and viral load test results. Massachusetts, for example, mandated that all CD4 and all HIV viral load results be electronically reported by clinical and commercial laboratories as of January 2012 (Massachusetts Department of Public Health, 2012).

variables changed over the course of the illness (Berk et al., 1993; Fleishman et al., 1994).

The study collected data on 2,090 HIV-infected adults and children receiving clinical HIV care from spring 1991 through fall 1992. Participants (or their proxies) were interviewed in person quarterly for a total of six interviews (Berk et al., 1993; Hsia et al., 1995). Interview data were supplemented by medical, service utilization, billing, and other data obtained from the providers of inpatient, ambulatory, and home health care, as well as pharmacy data and Medicaid, and Health Care Financing Administration claims records (Berk et al., 1993). Data also were collected from nonmedical providers, including community-based organizations that offer supportive services, podiatrists, and alternative therapy providers.[15]

Interview data were gathered on participants' age, sex, race and ethnicity, educational level, employment history, income sources, insurance type, stage of illness, route of exposure, and clinical trials participation. Information also was collected on participant's living arrangements and social support network; experience of barriers to the receipt of services; functional status; and psychological affect and experience of pain (Berk et al., 1993; Hsia et al., 1995; Niemcryk et al., 1998). During each interview, participants were asked to give a full accounting of all providers from whom they had received services since the previous interview. With permission, those providers were contacted to obtain clinical and laboratory data, as well as data on service utilization, charges, and source of payment (Berk et al., 1993). Such data were collected on hospital admissions, emergency department use, outpatient services, drug and alcohol treatment, dental treatment, and counseling or support group services (Niemcryk et al., 1998), in addition to data on pharmacy and home health service utilization (Berk et al., 1993).

HIV Cost and Services Utilization Study

HCSUS (October 1994-September 2000) was the first major research effort to collect information on a nationally representative sample of adults receiving care for their HIV infection (AHRQ, 1998; RAND, 2011). Designed to collect and analyze data on medical and nonmedical cost and service utilization for adults with HIV, HCSUS was a cooperative effort conducted by a public-private consortium based out of the RAND Corporation and funded by a number of public agencies and private entities, through an agreement between AHRQ and RAND (RAND, 2011).

HCSUS was a prospective observational study that collected data

[15]Providers of dental services were not contacted directly due to concern about exposing patients' HIV status.

through three serial interviews with a national probability sample of HIV-infected adults receiving regular medical care in the first 2 months of 1996 and interviews with providers and caregivers. Additional data were collected through health, dental, pharmacy, and billing record abstraction (Bozzette et al., 1998; Frankel et al., 1999; Shapiro et al., 1999). Participants were identified using a three-stage probability design with population-proportion-to-size sampling in which cases were randomly selected based on geographic location, provider, and patient (RAND, 2011). Of 4,042 eligible participants, 76 percent were interviewed (Andersen et al., 2000), yielding data on approximately 3,000 HIV-infected persons receiving care in hospitals, clinics, HMOs, or private practices who were living in urban areas or clusters of rural counties in the contiguous United States. The study population included racial and ethnic minorities, adult males and females with varying levels of education, routes of HIV infections, and health care service coverage (see Shapiro et al., 1999).

HCSUS consisted of a core study that explored the "cost, use, and quality of care; access to and unmet needs for care; quality of life; social support; knowledge of HIV; clinical outcomes; mental health; and the relationship of these variables to provider type and patient characteristics" and seven supplemental studies (RAND, 2011). In addition to interviews, participants' medical, financial, and pharmaceutical records were abstracted, and a subset of participants had blood drawn to measure CD4+ T-cell count, viral load, and the presence of genotypic and phenotypic sequences associated with antiviral resistance (RAND, 2011).

Medical Monitoring Project

Initiated in 2005 in response to the IOM report *Measuring What Matters: Allocation, Planning, and Quality Assessment for the Ryan White CARE Act* (IOM, 2004), MMP is a CDC-sponsored population-based surveillance system currently designed to collect comprehensive clinical and behavioral services need, utilization, and outcomes data on a nationally representative sample of adults (≥18 years of age) living with HIV/AIDS who are receiving medical care from outpatient facilities in the United States and Puerto Rico (Blair et al., 2011). Approximately 480,000 of the 942,000 diagnosed HIV-infected individuals in the United States are retained in clinical HIV care (CDC, 2011d). It is this population from which MMP draws. MMP is the first project since HCSUS that is designed to obtain comprehensive information about HIV care from a nationally representative population of people with HIV who are in care. As discussed in greater detail in Chapter 3, MMP employs a probability proportional to size sampling design to obtain cross-sectional probability samples of its target population. Data are obtained from individual patient interviews and medical record

reviews. MMP also includes a minimum data set of core surveillance data from NHSS for all individuals sampled.

Limitations of Nationally Representative Studies

Although nationally representative studies hold promise for providing an overarching picture of health care coverage and utilization among people with HIV in the United States, they are generally not useful for generating comparisons among subgroups where stratification results in subgroups too small for meaningful analysis. For example, nationally representative studies such as MMP may not be sufficiently large to permit state-by-state analysis and comparisons of health care coverage and utilization.[16] Yet, monitoring health care coverage and experiences at the state level is important because of state variations in implementation of the ACA (discussed in Chapter 2), Medicaid eligibility and benefits, and health care coverage requirements and available options, as well as state and regional disparities in access to health care by people with HIV. Similarly, it will be important to monitor changes in enrollment and in some cases benefits that are expected to occur in various sources of health coverage as the ACA is implemented.

All studies designed to be nationally representative face the difficulty inherent in including marginalized, hard-to-reach populations (e.g., individuals with mental and substance abuse disorders, those in correctional facilities, the homeless). The funding and labor necessary to ensure that all populations are sufficiently represented can be high. Adequate funding and careful attention to sampling and recruitment methods are necessary to ensure the collection of sufficient data for all subpopulations.

REFERENCES

Agwu, A. L., J. A. Fleishman, P. T. Korthuis, G. K. Siberry, J. M. Ellen, A. H. Gaur, R. Rutstein, and K. A. Gebo. 2011. Disparities in antiretroviral treatment: A comparison of behaviorally-HIV-infected youth and adults in the HIV Research Network. *Journal of Acquired Immune Deficiency Syndromes* 58(1):100-107.

AHRQ (Agency for Healthcare Research and Quality). 1998. *HCSUS Fact Sheet. HIV Cost and Services Utilization Study*. http://www.ahrq.gov/data/hcsus.htm (accessed March 26, 2012).

Andersen, R., S. Bozzette, M. Shapiro, P. St Clair, S. Morton, S. Crystal, D. Goldman, N. Wenger, A. Gifford, A. Leibowitz, S. Asch, S. Berry, T. Nakazono, K. Heslin, W. Cunningham, and the HCSUS Consortium. 2000. Access of vulnerable groups to antiretroviral therapy among persons in care for HIV disease in the United States. *Health Services Research* 35(2):389-416.

[16]In addition, MMP data are limited to 17 states.

ART-CC (Antiretroviral Therapy Cohort Collaboration). 2008. Life expectancy of individuals on combination antiretroviral therapy in high-income countries: A collaborative analysis of 14 cohort studies. *Lancet* 372(9635):293-299.

ART-CC. 2009. Mortality of HIV-infected patients starting potent antiretroviral therapy: Comparison with the general population in nine industrialized countries. *International Journal of Epidemiology* 38(6):1624-1633.

Aziz, M., and K. Y. Smith. 2011. Challenges and successes in linking HIV-infected women to care in the United States. *Clinical Infectious Diseases* 52(Suppl 2):S231-S237.

Baicker, K., A. Chandra, J. S. Skinner, and J. E. Wennberg. 2004. Who you are and where you live: How race and geography affect the treatment of Medicare beneficiaries. *Health Affairs* (Suppl Variation, October):VAR33-44, doi: 10.1377/hlthaff.var.33.

Berk, M. L., C. Maffeo, and C. L. Schur. 1993. *Research Design and Analysis Objectives*. AIDS Cost and Services Utilization Survey (ACSUS) Reports, No. 1. AHCPR Publication No. 93-0019. Rockville, MD: Agency for Health Care Policy and Research.

Blair, J. M., A. D. McNaghten, E. L. Frazier, J. Skarbinski, P. Huang, and J. D. Heffelfinger. 2011. Clinical and behavioral characteristics of adults receiving medical care for HIV infection—Medical Monitoring Project, United States, 2007. *Morbidity and Mortality Weekly Report Surveillance Summaries* 60(11):1-20.

Bozzette, S. A., S. H. Berry, N. Duan, M. R. Frankel, A. A. Leibowitz, D. Lefkowitz, C. A. Emmons, J. W. Senterfitt, M. L. Berk, S. C. Morton, and M. F. Shapiro. 1998. The care of HIV-infected adults in the United States. HIV Cost and Services Utilization Study Consortium. *New England Journal of Medicine* 339(26):1897-1904.

Branson, B. M., H. H. Handsfield, M. A. Lampe, R. S. Janssen, A. W. Taylor, S. B. Lyss, and J. E. Clark. 2006. Revised recommendations for HIV testing of adults, adolescents, and pregnant women in health-care settings. *Morbidity and Mortality Weekly Report* 55(RR14):1-17.

Burns, D. N., C. W. Dieffenbach, and S. H. Vermund. 2010. Rethinking prevention of HIV Type 1 infection. *Clinical Infectious Diseases* 51(6):725-731.

Castilla, J., P. Sobrino, L. De La Fuente, I. Noguer, L. Guerra, and F. Parras. 2002. Late diagnosis of HIV infection in the era of highly active antiretroviral therapy: Consequences for AIDS incidence. *AIDS* 16(14):1945-1951.

CDC (Centers for Disease Control and Prevention). 2010. *Summary of Changes to the National HIV Surveillance Report*. National Center for HIV/AIDS, Hepatitis, STD, and TB Prevention. http://www.cdc.gov/hiv/topics/surveillance/resources/factsheets/pdf/summary_changes.pdf (accessed October 20, 2011).

CDC. 2011a. *HIV among African Americans*. November. http://www.cdc.gov/hiv/topics/aa/PDF/aa.pdf (accessed July 3, 2012).

CDC. 2011b. *HIV among Latinos*. November. http://www.cdc.gov/hiv/resources/factsheets/pdf/latino.pdf (accessed July 3, 2012).

CDC. 2011c. *HIV Infection Reporting*. http://www.cdc.gov/hiv/topics/surveillance/reporting.htm (accessed July 2, 2012).

CDC. 2011d. Vital signs: HIV prevention through care and treatment—United States. *Morbidity and Mortality Weekly Report* 60(47):1618-1623.

CDC. 2012a. Diagnoses of HIV infection and AIDS in the United States and dependent areas, 2010. *HIV Surveillance Report*. Volume 22. March. http://www.cdc.gov/hiv/surveillance/resources/reports/2010report/index.htm (accessed July 3, 2012).

CDC. 2012b. *HIV Cost-Effectiveness*. http://www.cdc.gov/hiv/topics/preventionprograms/ce/index.htm (accessed May 10, 2012).

CDC. 2012c. *HIV in the United States: At a Glance*. http://www.cdc.gov/hiv/resources/factsheets/PDF/HIV_at_a_glance.pdf (accessed July 3, 2012).

CDC. 2012d. *HIV in the United States: The Stages of Care*. http://www.cdc.gov/nchhstp/newsroom/docs/2012/Stages-of-CareFactSheet-508.pdf (accessed September 10, 2012).

CDC. 2012e. *HIV Surveillance Supported by the Division of HIV/AIDS Prevention*. http://www.cdc.gov/hiv/topics/surveillance/resources/factsheets/pdf/HIV_surveillance.pdf (accessed June 11, 2012).

CDC. 2012f. Monitoring selected national HIV prevention and care objectives by using HIV surveillance data—United States and 6 U.S. dependent areas—2010. *HIV Surveillance Supplemental Report*. Volume 17, Number 3 (Part A). http://www.cdc.gov/hiv/surveillance/resources/reports/2010supp_vol17no3/index.htm (accessed July 31, 2012).

Charlebois, E. D., M. Das, T. C. Porco, and D. V. Havlir. 2011. The effect of expanded antiretroviral treatment strategies on the HIV epidemic among men who have sex with men in San Francisco. *Clinical Infectious Diseases* 52(8):1046-1049.

Cheever, L. W. 2007. Engaging HIV-infected patients in care: Their lives depend on it. *Clinical Infectious Diseases* 44(11):1500-1502.

Chen, N., E. Erbelding, H. C. Yeh, and K. Page. 2010. Predictors of HIV testing among Latinos in Baltimore City. *Journal of Immigrant and Minority Health* 12(6):867-874.

Cohen, M. S., Y. Q. Chen, M. McCauley, T. Gamble, M. C. Hosseinipour, N. Kumarasamy, J. G. Hakim, J. Kumwenda, B. Grinsztein, J. H. S. Pilotto, S. V. Godbole, S. Mehendale, S. Charjvalertsak, B. R. Santos, K. H. Mayer, I. F. Hoffman, S. H. Eshelman, E. Piwowar-Manning, L. Wang, J. Makhema, L. A. Mills, G. de Bruyn, I. Sanne, J. Eron, J. Gallant, D. Havlir, S. Swindells, H. Ribaudo, V. Elharrar, D. Burns, T. E. Taha, K. Nielsen-Saines, D. Celentano, M. Essex, and T. R. Fleming. 2011. Prevention of HIV-1 infection with early antiretroviral therapy. *New England Journal of Medicine* 365(6):493-505.

Conviser, R., and M. B. Pounds. 2002a. Background for the studies on ancillary services and primary care use. *AIDS Care* 14(Suppl 1):S7-S14.

Conviser, R., and M. B. Pounds. 2002b. The role of ancillary services in client-centred systems of care. *AIDS Care* 14(Suppl 1):S119-S131.

Cooper-Patrick, L., J. J. Gallo, J. J. Gonzales, H. T. Vu, N. R. Powe, C. Nelson, and D. E. Ford. 1999. Race, gender, and partnership in the patient-physician relationship. *Journal of the American Medical Association* 282(6):583-589.

Das, M. 2011. *Intensifying HIV Prevention in the Communities Where HIV Is Most Heavily Concentrated*. PowerPoint presentation at the 2011 National HIV Prevention Conference, Atlanta, GA, August 15.

Doescher, M. P., B. G. Saver, K. Fiscella, and P. Franks. 2001. Racial/ethnic inequities in continuity and site of care: Location, location, location. *Health Services Research* 36(6 Pt 2):78-89.

Ennis, S. R., M. Ríos-Vargas, and N. G. Albert. 2011. *The Hispanic Population: 2010*. Economics and Statistics Administration. http://www.census.gov/prod/cen2010/briefs/c2010br-04.pdf (accessed September 12, 2012).

Espinoza, L., H. I. Hall, R. M. Selik, and X. Hu. 2008. Characteristics of HIV infection among Hispanics, United States, 2003-2006. *Journal of Acquired Immune Deficiency Syndromes* 49(1):94-101.

FDA (U.S. Food and Drug Administration). 2012. *FDA Approves First Over-the-Counter Home-Use Rapid HIV Test*. http://www.fda.gov/NewsEvents/Newsroom/PressAnnouncements/ucm310542.htm (accessed September 10, 2012).

Fleishman, J. A., D. C. Hsia, and F. J. Hellinger. 1994. Correlates of medical service utilization among people with HIV infection. *Health Services Research* 29(5):527-548.

Fleishman, J. A., B. R. Yehia, R. D. Moore, K. A. Gebo, and HIV Research Network. 2010. The economic burden of late entry into medical care for patients with HIV infection. *Medical Care* 48(12):1071-1079.

Fleming, P. L., J. W. Ward, R. S. Janssen, K. M. DeCock, R. O. Valdiserri, H. D. Gayle, in collaboration with J. L. Jones, J. S. Lehman, M. L. Lindegren, A. K. Nakashima, P. S. Sullivan, P. A. Sweeney, P. M. Wortley, E. M. Seiler, and H. W. Jaffe. 1999. Guidelines for National Human Immunodeficiency Virus Case Surveillance, including monitoring for human immunodeficiency virus infection and acquired immunodeficiency syndrome. *Morbidity and Mortality Weekly Reports* 48(RR13):1-28.

Frankel, M. R., M. F. Shapiro, N. Duan, S. C. Morton, S. H. Berry, J. A. Brown, M. A. Burnam, S. E. Cohn, D. P. Goldman, D. F. McCaffrey, S. M. Smith, P. A. St. Clair, J. F. Tebow, and S. A. Bozzette. 1999. National probability samples in studies of low-prevalence diseases. Part II: Designing and implementing the HIV Cost and Services Utilization Study sample. *Health Services Research* 34(5, Part 1):969-992.

Gardner, E. M., M. P. McLees, J. F. Steiner, C. Del Rio, and W. J. Burman. 2011. The spectrum of engagement in HIV care and its relevance to test-and-treat strategies for prevention of HIV infection. *Clinical Infectious Diseases* 52(6):793-800.

Garland, J. M., A. S. Andrade, and K. R. Page. 2010. Unique aspects of the care of HIV-positive Latino patients living in the United States. *Current HIV/AIDS Reports* 7(3):107-116.

Gaynes, B. N., A. J. Rush, M. H. Trivedi, S. R. Wisniewski, G. K. Balasubramani, D. C. Spencer, T. Petersen, M. Klinkman, D. Warden, L. Nicholas, and M. Fava. 2007. Major depression symptoms in primary care and psychiatric care settings: A cross-sectional analysis. *Annals of Family Medicine* 5(2):126-134.

Gebo, K. A., J. A. Fleishman, R. Conviser, E. D. Reilly, P. T. Korthuis, R. D. Moore, J. Hellinger, P. Keiser, H. R. Rubin, L. Crane, F. J. Hellinger, and W. C. Mathews. 2005. Racial and gender disparities in receipt of highly active antiretroviral therapy persist in a multistate sample of HIV patients in 2001. *Journal of Acquired Immune Deficiency Syndromes* 38(1):96-103.

Gebo, K. A., J. A. Fleishman, R. Conviser, J. Hellinger, F. J. Hellinger, J. S. Josephs, P. Keiser, P. Gaist, and R. D. Moore. 2010. Contemporary costs of HIV healthcare in the HAART era. *AIDS* 24(17):2705-2715.

Hall, H. I., R. Song, P. Rhodes, J. Prejean, Q. An, L. M. Lee, J. Karon, R. Brookmeyer, E. H. Kaplan, M. T. McKenna, and R. S. Janssen. 2008. Estimation of HIV incidence in the United States. *Journal of the American Medical Association* 300(5):520-529.

Hall, H. I., E. L. Frazier, P. Rhodes, D. R. Holtgrave, C. Furlow-Parmley, T. Tang, K. M. Gray, S. M. Cohen, and J. Skarbinski. 2012. *Continuum of HIV care: Differences in Care and Treatment by Sex and Race/Ethnicity in the United States*. Oral abstract presented by H. I. Hall, XIX International AIDS Conference, Washington, DC, July 27, 2102.

Heckman, T. G., A. M. Somlai, J. Peters, J. Walker, L. Otto-Salaj, C. A. Galdabini, and J. A. Kelly. 1998. Barriers to care among persons living with HIV/AIDS in urban and rural areas. *AIDS Care* 10(3):365-375.

HHS (U.S. Department of Health and Human Services). 2010. *Healthy People 2020 Summary of Objectives*. http://www.healthypeople.gov/2020/topicsobjectives2020/pdfs/HIV.pdf (accessed April 23, 2012).

HHS. 2011. *Panel on Antiretroviral Guidelines for Adults and Adolescents. Guidelines for the Use of Antiretroviral Agents in HIV-1-Infected Adults and Adolescents*. October 14. http://aidsinfo.nih.gov/contentfiles/AdultandAdolescentGL002534.pdf (accessed July 2, 2012).

HHS. 2012a. *How Does the Affordable Care Act Impact People Living with HIV/AIDS*. http://aids.gov/federal-resources/policies/health-care-reform/ (accessed July 16, 2012).

HHS. 2012b. *Panel on Antiretroviral Guidelines for Adults and Adolescents. Guidelines for the Use of Antiretroviral Agents in HIV-1-Infected Adults and Adolescents*. March 27. http://aidsinfo.nih.gov/contentfiles/lvguidelines/adultandadolescentgl.pdf (accessed July 2, 2012).

Hixson, L., B. B. Hepler, and M. Ouk Kim. 2011. *The White Population: 2010*. Economics and Statistics Administration. http://www.census.gov/prod/cen2010/briefs/c2010br-05.pdf (accessed September 12, 2012).

Hixson, L., B. B. Hepler, and M. Ouk Kim. 2012. T*he Native Hawaiian and Other Pacific Islander Population: 2010*. Economics and Statistics Administration. http://www.census.gov/prod/cen2010/briefs/c2010br-12.pdf (accessed September 12, 2012).

Hoeffel, E. M., S. Rastogi, M. Ouk Kim, and H. Shahid. 2012. *The Asian Population: 2010*. Economics and Statistics Administration. http://www.census.gov/prod/cen2010/briefs/c2010br-11.pdf (accessed September 11, 2012).

Horberg, M. A., J. A. Aberg, L. W. Cheever, P. Renner, E. O'Brien Kaleba, and S. M. Asch. 2010. Development of national and multiagency HIV care quality measures. *Clinical Infectious Diseases* 51(6):732-738.

Hsia, D. C., J. A. Fleishman, J. A. East, and F. J. Hellinger. 1995. Pediatric human immunodeficiency virus infection: Recent evidence on the utilization and costs of health services. *Archives of Pediatric and Adolescent Medicine* 149:489-496.

IOM (Institute of Medicine). 2004. *Measuring What Matters: Allocation, Planning and Quality Assessment for the Ryan White CARE Act*. Washington, DC: The National Academies Press.

IOM. 2012. *Monitoring HIV Care in the United States: Indicators and Data Systems*. Washington, DC: The National Academies Press.

Iwuji, C. C., B. N. Mayanja, H. A. Weiss, E. Atuhumuza, P. Hughes, D. Maher, and H. Grosskurth. 2011. Morbidity in HIV-1-infected individuals before and after the introduction of antiretroviral therapy: A longitudinal study of a populations-based cohort in Uganda. *HIV Medicine* 12(9):553-561.

Johnson, R. L., D. Roter, N. R. Powe, and L. A. Cooper. 2004a. Patient race/ethnicity and quality of patient-physician communication during medical visits. *American Journal of Public Health* 94(12):2084-2090.

Johnson, R. L., S. Saha, J. J. Arbelaez, M. C. Beach, and L. A. Cooper. 2004b. Racial and ethnic differences in patient perceptions of bias and cultural competence in health care. *Journal of General Internal Medicine* 19(2):101-110.

Justice, A. C. 2006. Prioritizing primary care in HIV: Comorbidity, toxicity, and demography. *Topics in HIV Medicine* 14(5):159-163.

Kidder, D. P., R. J. Wolitski, S. Royal, A. Aidala, C. Courtenay-Quirk, D. R. Holtgrave, D. Harre, E. Sumartojo, and R. Stall. 2007. Access to housing as a structural intervention for homeless and unstably housed people living with HIV: Rationale, methods, and implementation of the housing and health study. *AIDS and Behavior* 11(2 Suppl):149-161.

Korthuis, P. T., S. Saha, J. A. Fleishman, M. M. McGrath, J. S. Josephs, R. D. Moore, K. A. Gebo, J. Hellinger, and M. C. Beach. 2008. Impact of patient race on patient experiences of access and communication in HIV care. *Journal of General Internal Medicine* 23(12):2046-2052.

Krawczyk, C. S., E. Funkhouser, J. M. Kilby, and S. H. Vermund. 2006a. Delayed access to HIV diagnosis and care: Special concerns for the southern United States. *AIDS Care* 18(Suppl 1):S35-S44.

Krawczyk, C. S., E. Funkhouser, J. M. Kilby, R. A. Kaslow, A. K. Bey, and S. H. Vermund. 2006b. Factors associated with delayed initiation of HIV medical care among infected persons attending a southern HIV/AIDS clinic. *Southern Medical Journal* 99(5):472-481.

Krentz, H. B., and M. J. Gill. 2012. The direct medical costs of late presentation (<350/mm^3) of HIV infections over a 15-year period. *AIDS Research and Treatment* 2012:757135.

Leaver, C. A., G. Bargh, J. R. Dunn, and S. W. Hwang. 2007. The effects of housing status on health-related outcomes in people living with HIV: A systematic review of the literature. *AIDS and Behavior* 11(2 Suppl):85-100.

Lo, W., T. MacGovern, and J. Bradford. 2002. Association of ancillary services with primary care utilization and retention for patients with HIV/AIDS. *AIDS Care* 14(Suppl 1):S45-S57.

Massachusetts Department of Public Health. 2012. Letter to clinical laboratories. February 28.

May, M., M. Gompels, V. Delpech, K. Porter, F. Post, M. Johnson, D. Dunn, A. Palfreeman, R. Gilson, B. Gazzard, T. Hill, J. Walsh, M. Fisher, C. Orkin, J. Ainsworth, L. Bansi, A. Phillips, C. Leen, M. Nelson, J. Anderson, and C. Sabin. 2011. Impact of late diagnosis and treatment on life expectancy in people with HIV-1: UK Collaborative HIV Cohort (UK-CHIC) Study. *British Medical Journal* 343:d6016.

Mays, V. M., R. Maas, J. Ricks, and S. D. Cochran. 2011. HIV and African American women in the South: Employing a population-level HIV prevention and interventions. In *Handbook of Health Psychology, Second Edition*, edited by A. Baum, T. Revenson, and J. Singer. London: Psychology Press.

Meditz, A. L., S. MaWhinney, A. Allshouse, W. Feser, M. Markowitz, S. Little, R. Hecht, E. S. Daar, A. C. Collier, J. Margolick, J. M. Kilby, J. P. Routy, B. Conway, J. Kaldor, J. Levy, R. Schooley, D. A. Cooper, M. Altfeld, D. Richman, and E. Connick. 2011. Sex, race, and geographic region influence clinical outcomes following primary HIV-1 infection. *Journal of Infectious Diseases* 203(4):442-451.

Mocroft, A., C. A. Sabin, M. Youle, S. Madge, M. Tyrer, H. Devereux, J. Deayton, A. Dykhoff, M. C. I. Lipman, A. N. Phillips, and M. A. Johnson. 1999. Changes in AIDS-defining illnesses in a London clinic, 1987-1998. *Journal of Acquired Immune Deficiency Syndromes* 21(5):401-407.

Moon, T. D., S. H. Vermund, T. C. Tong, and S. D. Holmberg. 2001. Opportunities to improve preventions and services for HIV-infected women in nonurban Alabama and Mississippi. *Journal of Acquired Immune Deficiency Syndromes* 28(3):279-281.

Moore, R. D., and R. E. Chaisson. 1999. Natural history of HIV infection in the era of combined antiretroviral therapy. *AIDS* 13(14):1933-1942.

Mugavero, M. J., C. Castellano, D. Edelman, and C. Hicks. 2007. Late diagnosis of HIV infection: The role of age and sex. *American Journal of Medicine* 120(4):370-373.

Nakagawa, F., R. K. Lodwick, C. J, Smith, R. Smith, V. Cambiano, J. Lundgren, V. Delpech, and A. N. Phillips. 2012. Projected life expectancy of people with HIV according to time of diagnosis. *AIDS* 26(3):335-343.

Niemcryk, S. J., A. Bedros, K. M. Marconi, and J. F. O'Neill. 1998. Consistency in maintaining contact with HIV-related service providers: An analysis of the AIDS Cost and Services Utilization Study (ACSUS). *Journal of Community Health* 23(2):137-152.

Norris, T., P. L. Vines, and E. M. Hoeffel. 2012. *American Indian and Alaskan Native population: 2010*. Economics and Statistics Administration. http://www.census.gov/prod/cen2010/briefs/c2010br-10.pdf (accessed September 11, 2012).

NQF (National Quality Forum). 2011. *NQF—Endorsed Standards*. http://www.qualityforum.org/Measures_List.aspx?#k=HIV&p=2&s=n&so=a (accessed April 23, 2012).

NYC DOHMH (New York City Department of Health and Mental Hygiene). 2011. *2011 Advisory #27: Health Department Releases New HIV Treatment Recommendations*. http://home2.nyc.gov/html/doh/downloads/pdf/cd/2011/11md27.pdf (accessed December 19, 2011).

Ohl, M., J. Tate, M. Duggal, M. Skanderson, M. Scotch, P. Kaboli, M. Vaughan-Sarrazin, and A. Justice. 2010. Rural residence is associated with delayed care entry and increased mortality among veterans with human immunodeficiency virus infection. *Medical Care* 48(12):1064-1070.

ONAP (Office of National AIDS Policy). 2010. *National HIV/AIDS Strategy for the United States*. http://www.whitehouse.gov/sites/default/files/uploads/NHAS.pdf (accessed January 6, 2012).

Palella, F. J., K. M. Delaney, A. C. Moorman, M. O. Loveless, J. Fuhrer, G. A. Satten, D. J. Aschman, A. D. Holmberg, and the HIV Outpatient Study Investigators. 1999. Declining morbidity and mortality among patients with advanced human immunodeficiency virus infection. *New England Journal of Medicine* 338(13):853-860.

Pence, B. W. 2009. The impact of mental health and traumatic life experiences on antiretroviral treatment outcomes for people living with HIV/AIDS. *Journal of Antimicrobial Chemotherapy* 63(4):636-640.

PEPFAR (President's Emergency Plan for AIDS Relief). 2009. *Next Generation Indicators Reference Guide*. http://www.pepfar.gov/documents/organization/81097.pdf (accessed April 23, 2012).

Prejean, J., R. Song, Q. An, and H. I. Hall. 2008. Subpopulation estimates from the HIV incidence surveillance system—United States, 2006. *Morbidity and Mortality Weekly Report* 57(36):985-989. http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5736a1.htm (accessed December 20, 2011).

Prejean, J., R. Song, A. Hernandez, R. Ziebell, T. Green, F. Walker, L. S. Lin, Q. An, J. Mermin, A. Lansky, and H. I. Hall. 2011. Estimated HIV incidence in the United States, 2006-2009. *PLoS One* 6(8):e17502.

Qian, H. Z., R. D. Taylor, H. J. Fawal, and S. H. Vermund. 2006. Increasing AIDS case reports in the South: U.S. trends from 1981-2004. *AIDS Care 18*(Suppl 1):S6-S9.

RAND. 2011. *HIV Cost and Services Utilization Study (HCSUS)*. http://www.rand.org/health/projects/hcsus.html (accessed March 26, 2012).

Rastogi, S., T. B. Johnson, E. M. Hoeffel, and M. P. Drewery. 2011. *The Black Population: 2010*. http://www.census.gov/prod/cen2010/briefs/c2010br-06.pdf (accessed September 11, 2012).

Reif, S., C. E. Golin, and S. R. Smith. 2005. Barriers to accessing HIV/AIDS care in North Carolina: Rural and urban differences. *AIDS Care* 17(5):558-565.

Reif, S., K. Whetten, E. Wilson, and W. Gong. 2011. *HIV/AIDS Epidemic in the South Reaches Crisis Proportions in Last Decade*. Durham, NC: Duke Center for Health Policy and Inequalities Research (CHPIR), Duke University. http://globalhealth.duke.edu/news/2011/ResearchReportFinal3-12.pdf (accessed May 8, 2012).

Robison, L. S., A. O. Westfall, M. J. Mugavero, M. C. Kempf, S. R. Cole, J. J. Allison, J. H. Willig, J. L. Raper, C. M. Wilcox, and M. S. Saag. 2008. Short-term discontinuation of HAART regimens more common in vulnerable patient populations. *AIDS Research and Human Retroviruses* 24(11):1347-1355.

Royal, S. W., D. P. Kidder, S. Patrabansh, R. J. Wolitski, D. R. Holtgrave, A. Aidala, S. Pals, and R. Stalle. 2009. Factors associated with adherence to highly active antiretroviral therapy in homeless or unstably housed adults living with HIV. *AIDS Care* 21(4):448-455.

Schackman, B. R., K. A. Gebo, R. P. Walensky, E. Losina, T. Muccio, P. E. Sax, M. C. Weinstein, G. R. Seage III, R. D. Moore, and K. A. Freedberg. 2006. The lifetime cost of current human immunodeficiency virus care in the United States. *Medical Care* 44(11):990-997.

Schiller, J. S., J. W. Lucas, B. W. Ward, and J. A. Peregoy. 2012. Summary health statistics for U.S. adults: National Health Interview Survey, 2010. National Center for Health Statistics. *Vital Health Statistics* 10(252).

Schneider, E. C., A. M. Zaslavsky, and A. M. Epstein. 2002. Racial disparities in the quality of care for enrollees in Medicare managed care. *Journal of the American Medical Association* 287(10):1288-1294.

Schur, C. L., M. L. Berk, J. R. Dunbar, M. F. Shapiro, S. E. Cohn, and S. A. Bozzette. 2002. Where to seek care: An examination of people in rural areas with HIV/AIDS. *Journal of Rural Health* 18(2):337-347.

Shapiro, M. F., M. L. Berk, S. H. Berry, C-A Emmons, L. A. Athey, D. C. Hsia, A. A. Leibowitcz, C. A. Maida, M. Marcus, J. F. Perlman, C. L. Schur, M. A. Schuster, W. Senterfitt, and S. A. Bozzette. 1999. National probability samples in studies of low-prevalence diseases. Part 1: Perspectives and lessons learned from the HIV Cost and Services Utilization Study. *Health Services Research* 34(5, Part 1):951-968.

Stall, R., T. C. Mills, J. Williamson, T. Hart, G. Greenwood, J. Paul, L. Pollack, D. Binson, D. Osmond, and J. A. Catania. 2003. Association of co-occurring psychosocial health problems and increased vulnerability to HIV/AIDS among urban men who have sex with men. *American Journal of Public Health* 93(6):939-942.

Urban Institute. Health Policy Center. 2012. *Vulnerable Populations*. http://www.urban.org/health_policy/vulnerable_populations/index.cfm (accessed May 11, 2012).

U.S. Census Bureau. 2012a. *State by age, sex, race, and Hispanic origin: 6 race groups—5 race alone groups and one multiple race group*. Economics and Statistics Administration. http://www.census.gov/popest/data/state/asrh/2011/files/SC-EST2011-alldata6-ALL.csv (accessed September 12, 2012).

U.S. Census Bureau. 2012b. *State by age, sex, race, and Hispanic origin: 6 race groups—5 race alone groups and one multiple race group (file layout)*. Economic and Statistics Administration. http://www.census.gov/popest/data/state/asrh/2011/files/SC-EST2011-ALLDATA6.pdf (accessed September 12, 2012).

Vermund, S. H., S. L. Hodder, J. E. Justman, B. A. Koblin, T. D. Mastro, K. H. Mayer, D. P. Wheeler, and W. M. El-Sadr. 2010. Addressing research priorities for prevention of HIV infection in the United States. *Clinical Infectious Diseases* 50(Suppl 3):S149-S155.

Weis, K. E., A. D. Liese, J. Hussey, J. J. Gibson, and W. A. Duffus. 2010. Associations of rural residence with timing of HIV diagnosis and stage of disease at diagnosis, South Carolina 2001-2005. *Journal of Rural Health* 26(2):105-112.

Weiser, S. D., D. R. Bangsberg, S. Kegeles, K. Ragland, M. B. Kushel, and E. A. Frongillo. 2009a. Food insecurity among homeless and marginally housed individuals living with HIV/AIDS in San Francisco. *AIDS and Behavior* 13(5):841-848.

Weiser, S. D., E. A. Frongillo, K. Ragland, R. S. Hogg, E. D. Riley, and D. R. Bangsberg. 2009b. Food insecurity is associated with incomplete HIV RNA suppression among homeless and marginally housed HIV-infected individuals in San Francisco. *Journal of General Internal Medicine* 24(1):14-20.

Wohl, A. R., W. H. Garland, J. Wu, C. W. Au, A. Boger, R. Dierst-Davies, J. Carter, F. Carpio, and W. Jordan. 2011. A youth-focused case management intervention to engage and retain young gay men of color in HIV care. *AIDS Care* 23(8):988-997.

Xu, F., M. R. Sternberg, and L. E. Markowitz. 2010. Men who have sex with men in the United States: Demographic and behavioral characteristics and prevalence of HIV and HSV-2 infection. *Sexually Transmitted Diseases* 37(6):399-405.

2

Implications of Health Care Reform for People with HIV in the United States

Health spending in the United States reached $2.79 trillion (seasonally adjusted annual rate) in April 2012, approximately 18 percent of the gross domestic product (GDP) (Center for Sustainable Health Spending, 2012), up from $2.59 trillion, 17.9 percent of the GDP, in 2010 (CMS, 2012, Table 1). U.S. health expenditures are the highest among 13 industrialized nations, whose health expenditures accounted for 12 percent or less of their GDPs in 2009 (Squires, 2012). Despite much higher spending, health care quality in the United States is not significantly better than that provided in less expensive systems (Squires, 2012). Higher health spending in the United States is likely a result of higher prices and, perhaps, more accessible technologies and greater levels of obesity (Squires, 2012).

At the same time as U.S. health expenditures continue to soar, 48.6 million people nationally (15.7 percent) lacked health insurance in 2011 (DeNavas-Walt et al., 2012),[1] and 29 million adults under 65 years of age

[1] "For reporting purposes, the U.S. Census Bureau broadly classifies health insurance coverage as private coverage or government coverage. Private health insurance is a plan provided through an employer or a union or purchased by an individual from a private company. Government health insurance includes such federal programs as Medicare, Medicaid, and military health care; the Children's Health Insurance Program (CHIP); and individual state health plans. [Types of insurance are not mutually exclusive; people may be covered by more than one during the year.] People were considered 'insured' if they were covered by any type of health insurance for part or all of the previous calendar year. They were considered 'uninsured' if, for the entire year, they were not covered by any type of health insurance" (DeNavas-Walt, 2012, p. 21).

were underinsured in 2010 (Schoen et al., 2011).[2] Although the number and percent of uninsured decreased between 2010 and 2011, millions of people in the United States, including approximately one-third of those with HIV, still lack health insurance (HHS, 2012a). It is against this background that the Patient Protection and Affordable Care Act (ACA) (P.L. 111-148), as amended by the Health Care and Education Reconciliation Act of 2010 (P.L. 111-152), was signed into law on March 23, 2010. This chapter is not designed to provide a comprehensive and detailed review of all aspects of the ACA that have implications for people living with HIV but rather to highlight the aspects of the ACA that the committee anticipated would be most pertinent to its task, such as those that are likely to effect changes in sources of health coverage for that population and to establish the basis for the selection of data systems that would be most relevant to tracking the impact of the ACA on health coverage and care for people with HIV (e.g., Medicaid, Medicare, Ryan White HIV/AIDS Program, private insurers).

AFFORDABLE CARE ACT

The ACA has the potential to significantly improve access to and quality of health care for the majority of people living with HIV in the United States. The law sets out numerous provisions that will be implemented over time, with major changes occurring in 2014. Most notably, the law includes both a provision that most citizens and legal residents of the United States must have qualifying health insurance coverage by 2014 or pay a tax penalty and a provision for the expansion of Medicaid coverage to most non–Medicare eligible individuals under age 65 with incomes less that 133 percent of the federal poverty level (FPL) (KFF, 2011a).[3] The ACA includes additional provisions of particular importance to people with HIV, such as increased access to private health insurance and consumer protections, establishment of state or regional health insurance exchanges (the legislation uses the term "health benefit exchange"), gradual elimination of the Medicare Part D prescription drug coverage gap, and development of an "essential health benefits package" and improved coverage for preventive care services.[4]

[2]Individuals were identified as underinsured if they had health insurance for the full year but also had very high medical expenses relative to their income (Schoen et al., 2011). In this study, "health insurance" referred to private health insurance, Medicaid or some other type of state medical assistance for low-income people, Medicare, and "health insurance through any other source, including military or veteran's coverage" (Commonwealth Fund, 2010, Questionnaire).

[3]A "mandatory income disregard" equal to 5 percent of the FPL will make the "effective income limit 138 percent of the FPL" (Natoli et al., 2011).

[4]Other major provisions of the ACA are not discussed here, including the development of accountable care organizations, increased payments for primary care providers, and expanded

In response to enactment of the ACA, Florida and 25 other states, the National Federation of Independent Business, and other interested parties filed suit challenging the constitutionality of the health insurance coverage requirement ("individual mandate") and the Medicaid expansion, questions that were ultimately appealed to the U.S. Supreme Court. The Court heard oral arguments pertaining to the case in late March 2012 and issued its ruling upholding the insurance coverage requirement on June 28, 2012, finding that Congress has the authority to levy a tax on individuals who choose to forgo such coverage. With respect to the Medicaid expansion provision, the Court ruled that "Congress is not free … to penalize States that choose not to participate in that new program by taking away their existing Medicaid funding" but that "[n]othing in our opinion precludes Congress from offering funds under the Affordable Care Act to expand the availability of health care, and requiring that States accepting such funds comply with the conditions on their use."[5]

In practice, the Court ruling makes it optional for the states to adopt the Medicaid expansion provision. Although some states already have taken steps to expand Medicaid before 2014 (as permitted by the ACA), other states, in the wake of the Supreme Court ruling, may choose not to do so at all. A compilation of statements by lawmakers, press releases, and media coverage indicates that as of September 12, 2012, 12 states and the District of Columbia had opted to expand Medicaid and 6 states had elected not to do so (Daily Briefing, 2012).

The six states identified as not participating in Medicaid expansion under the ACA had uninsurance rates above the national average of 44 percent for adults 19 to 64 years of age with incomes less than 139 percent of the FPL in 2010 (KFF, 2012e). One of the concerns raised by the variation in state adoption of Medicaid expansion is the potential lack of health coverage options for individuals who remain ineligible for Medicaid in states that opt out of Medicaid expansion but who have incomes below the level of eligibility for federal subsidies to purchase insurance coverage through the state exchanges (KFF, 2012a).

Despite the uncertainty surrounding what states ultimately might do, a number of the ACA's provisions are expected to improve access to health care coverage not only for people living with HIV, but also for individuals living with other chronic medical conditions, such as diabetes, hypertension, rheumatoid arthritis, and the like. Several of these provisions have

service capacity at community health centers, including federally qualified health centers, which are an important source of care for people living with HIV who are less able to access traditional sources of medical care.

[5]National Federation of Independent Business v. Sebelius, 567 U.S. ___ (2012), 55, slip opinion.

been implemented already, and others are slated for implementation in 2014.[6]

HEALTH REFORM AND PEOPLE WITH HIV

Among people with HIV in the United States, almost 30 percent have no health care coverage and only 17 percent have private insurance: the remaining 53 percent are covered by government programs such as Medicaid, Medicare, and the Ryan White HIV/AIDS Program (HHS, 2012a). As the ACA is implemented, most people with HIV in the United States will move into or shift between sources of care coverage. Figures 2-1, 2-2, and 2-3 depict the pathways to care coverage for people with HIV before, during, and following implementation of the ACA. As shown in Figure 2-2, as of 2010, the ACA gave states the option to expand Medicaid coverage to low-income adults up to 133 percent of the FPL regardless of disability or other status, which some states have done. In addition, individuals without access to employer-based coverage or who cannot purchase insurance in the individual market and are not eligible for Medicaid or Medicare can now purchase insurance through Preexisting Condition Insurance Plans (PCIPs) created under the ACA. PCIPs are high-risk pools operated by states or the federal government to provide insurance for individuals who are U.S. citizens or reside legally in the United States, have a preexisting condition, and have been without health coverage for at least 6 months.[7] As depicted in Figure 2-3, beginning in 2014, low-income adults up to133 percent of the FPL become a new Medicaid-eligible group, although the Supreme Court has limited the authority of the federal government to enforce this provision, and therefore, eligibility for Medicaid coverage is likely to vary across states. Individuals without access to employer-based coverage who are not eligible for Medicaid or Medicare but are eligible for tax credits to purchase insurance and/or can afford to pay for health insurance may do so through state health insurance exchanges established to facilitate the purchasing of health insurance by qualified individuals and employers. As it did prior to the enactment of the ACA, the Ryan White HIV/AIDS Program continues to serve as a payer of last resort for people with HIV who are under- or uninsured. Federal funding is provided to states, cities, and providers but does not always match the number of people who need services or the cost of their care.

[6]Some provisions of the ACA apply to all health care plans, others (e.g., coverage for preventive care without cost sharing) do not apply or apply differently for grandfathered plans (i.e., those in which an individual was enrolled on March 23, 2010, the date the ACA was enacted).

[7]These criteria apply to people living in states served by the federally run PCIP (HHS, 2012b). State-run PCIPs have their own eligibility criteria.

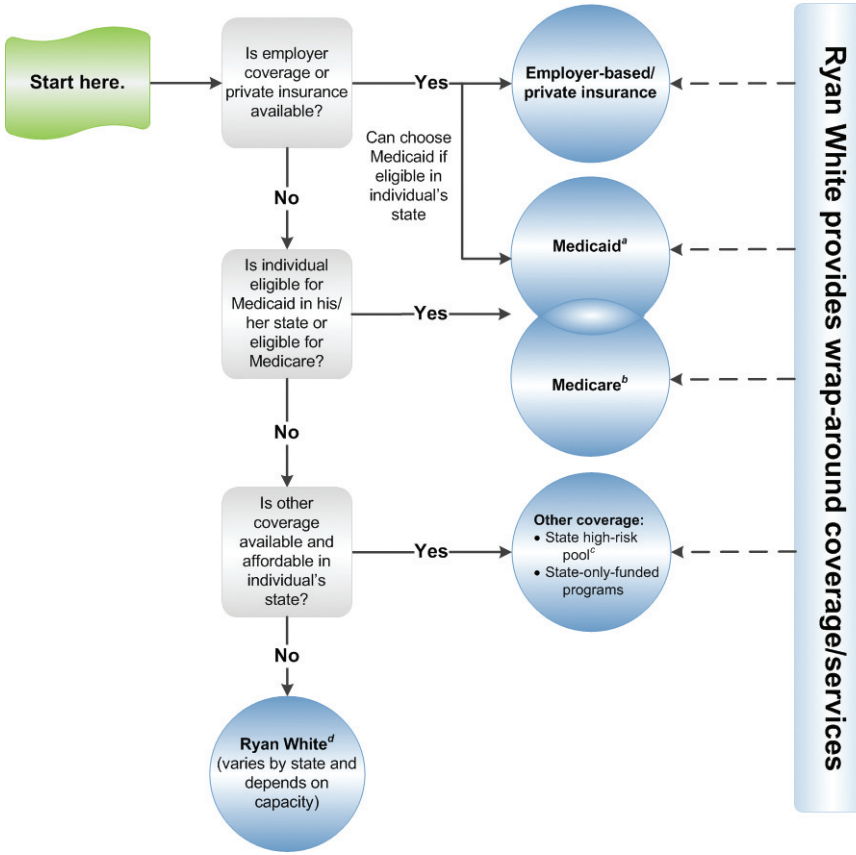

FIGURE 2-1 Pathways to coverage for people with HIV: Prior to the ACA, before 2010.

[a]Medicaid eligibility (state-based): low-income and categorically eligible (disabled, pregnant women, children, medically needy); states may seek waivers to cover other groups (such as nondisabled, childless adults); must be a U.S. citizen or legal resident for at least 5 years. For current state eligibility requirements, see Kaiser Family Foundation (KFF), State Health Facts, *Medicaid Income Eligibility Limits for Adults as a Percent of Federal Poverty Level*, http://statehealthfacts.org/comparereport.jsp?rep=130&cat=4. For more information on Medicaid, see KFF, *Medicaid: A Primer*, http://www.kff.org/medicaid/7334.cfm.

[b]Medicare eligibility (national): ≥65, disabled (Social Security Disability Insurance [SSDI]) or end-stage renal disease; must be a U.S. citizen or legal resident for at least 5 years. For more information on Medicare, see KFF, Medicare: A Primer, http://www.kff.org/medicare/7615.cfm.

[c]State high-risk insurance pools: Prior to the ACA, health plans were permitted to deny coverage to individuals with pre-existing conditions or to charge them higher

premiums. Because of this, several states operate high-risk insurance pools, which provide health insurance to residents who are considered medically uninsurable and are unable to buy coverage in the individual market. See KFF, State Health Facts, *State High Risk Pool Programs and Enrollment*, http://www.statehealthfacts.org/comparetable.jsp?ind=602&cat=7.

[d]Ryan White: The Ryan White HIV/AIDS Program, the single largest federal program designed specifically for people with HIV in the United States, provides care and services for people with HIV who are uninsured or underinsured, serving as payer of last resort. It includes the AIDS Drug Assistance Program (ADAP). Federal funding is provided to states, cities, and providers but may not match the number of people who need services or the cost of their care. For more information, see KFF, *The Ryan White Program*, http://www.kff.org/hivaids/7582.cfm.

SOURCE: Adapted from KFF, 2012b.

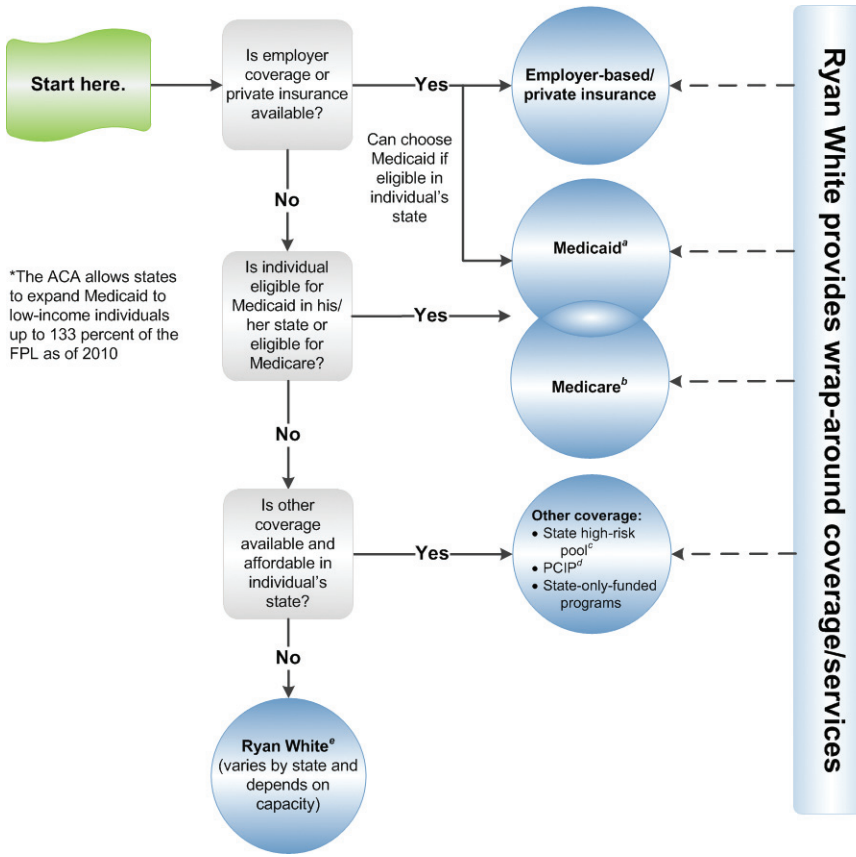

FIGURE 2-2 Pathways to coverage for people with HIV: ACA transition period, 2010-2013.

NOTE: The ACA provides new dependent coverage for children up to age 26 for all individual group policies. In addition, insurers are prohibited from denying coverage to children with preexisting conditions.

[a]Medicaid Eligibility (state-based): low-income and categorically eligible (disabled, pregnant women, children, medically needy); states may seek waivers to cover other groups (such as non-disabled, childless adults); must be a U.S. citizen or a legal resident for at least 5 years. As of 2010, the ACA gave states the option to expand coverage to low-income individuals up to 133 percent of the federal poverty level (FPL), regardless of disability or other status (which some states have done). For current state eligibility requirements and information on which states have moved to expand Medicaid as permitted by the ACA, see, Kaiser Family Foundation, State Health Facts, *Medicaid Income Eligibility Limits for Adults as a Percent of Federal Poverty Level*, http://statehealthfacts.org/comparereport.jsp?rep=130&cat=4. For more information on Medicaid, see, Kaiser Family Foundation, *Medicaid: A Primer*, http://www.kff.org/medicaid/7334.cfm.

[b]Medicare Eligibility (national): ≥65, disabled (SSDI), or end stage renal disease; must be a U.S. citizen or a legal resident for at least 5 years. Medicare beneficiaries are getting discounts on drugs while in the Medicare coverage gap and preventive services are covered without cost sharing. For more information on Medicare, see, Kaiser Family Foundation, *Medicare: A Primer*, http://www.kff.org/medicare/7615.cfm.

[c]State High-Risk Insurance Pools: Prior to the ACA, health plans were permitted to deny coverage to individuals with pre-existing conditions or to charge them higher premiums. Because of this, several states operate state high risk pools which provide health insurance to residents who are considered medically uninsurable and are unable to buy coverage in the individual market. See Kaiser Family Foundation, State Health Facts, *State High Risk Pool Programs and Enrollment*, http://www.statehealthfacts.org/comparetable.jsp?ind=602&cat=7. In addition, the ACA created the temporary PCIP program in 2010 (see below).

[d]Pre-Existing Condition Insurance Plan (PCIP): Created by the ACA, PCIP is a temporary program that runs from 2010-2014 to provide health coverage to individuals with pre-existing medical conditions who have been uninsured for at least six months. The plan will be operated by the states or the federal government. For more information on the current status of PCIPs, see, Kaiser Family Foundation, State Health Facts, *Pre-Existing Condition Insurance Plan: Operation Decisions and Preliminary Funding Allocations*, http://www.statehealthfacts.org/comparemapreport.jsp?rep=67&cat=17.

[e]Ryan White: The Ryan White HIV/AIDS Program, the single largest federal program designed specifically for people with HIV in the United States, provides care and services for people with HIV who are uninsured or underinsured, serving as payer of last resort. It includes the AIDS Drug Assistance Program (ADAP). Federal funding is provided to states, cities and providers but may not match the number of people who need services or the cost of their care. For more information, see, Kaiser Family Foundation, *The Ryan White Program*, http://www.kff.org/hivaids/7582.cfm.

SOURCE: Adapted from KFF, 2012b.

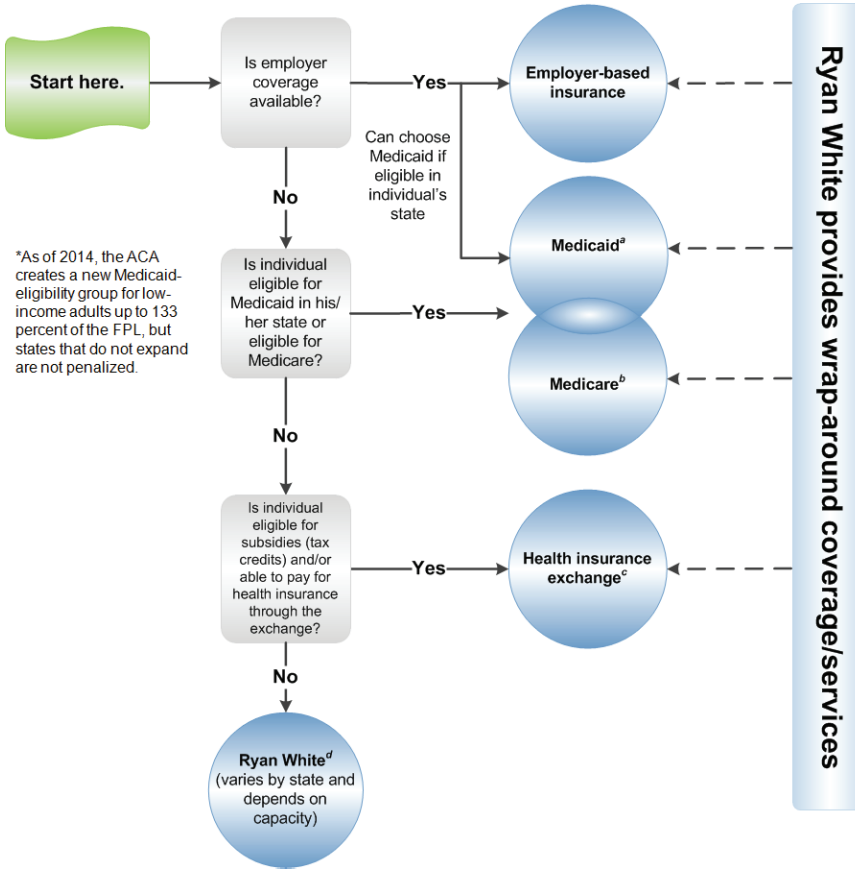

FIGURE 2-3 Pathways to coverage for people with HIV: Full implementation of the ACA, 2014 and beyond.

NOTE: The ACA provides new dependent coverage for children up to age 26 for all individual and group policies. Also, as of 2014, the ACA prohibits health plans from being able to deny coverage to people with pre-existing health conditions. Individuals with pre-existing conditions will be able to obtain insurance in the exchange or non-group market (the temporary PCIP program will no longer be needed).

[a]Medicaid eligibility (state-based): low-income and categorically eligible (disabled, pregnant women, children, medically needy); states may seek waivers to cover other groups (such as nondisabled, childless adults); must be a U.S. citizen or legal resident for at least 5 years. Under the ACA, as of 2014, low-income adults up to 133 percent of the FPL become a new Medicaid-eligibility group. The Supreme Court has limited the authority of the federal government to enforce this provision, making it uncertain whether all states will comply. For current state eligibility requirements and information on which states have moved to expand Medicaid as permitted by the ACA, see KFF, State Health Facts, *Medicaid Income Eligibility*

Limits for Adults as a Percent of Federal Poverty Level, http://statehealthfacts.org/comparereport.jsp?rep=130&cat=4. For more information on Medicaid, see KFF, *Medicaid: A Primer*, http://www.kff.org/medicaid/7334.cfm.

[b]Medicare eligibility (national): ≥65, disabled (SSDI) or end-stage renal disease; must be a U.S. citizen or legal resident for at least 5 years. For more information on Medicare, see KFF, *Medicare: A Primer*, http://www.kff.org/medicare/7615.cfm.

[c]Health insurance exchange: A key component of the ACA, exchanges are entities that will be set up in states to facilitate the purchasing of health insurance by qualified individuals and employers. All legal, non-incarcerated residents are eligible to purchase insurance through the exchanges. Additionally, all legal, non-incarcerated residents are eligible for subsidies, in the form of tax credits, if they do not have access to employer-sponsored insurance, Medicaid, or Medicare, and their incomes are between 100 and 400 percent of the FPL. In addition, if an employer plan does not cover at least 60 percent of average health expenses or the employee must pay more than 9.5 percent of his/her income for the premium, individuals, depending on income, may be eligible for a tax credit to offset premiums for coverage purchased through an exchange. Exchanges are required to be fully operational in every state by 2014. See KFF, State Health Facts, *State Action Toward Creating Health Insurance Exchanges*, http://www.statehealthfacts.org/comparemaptable.jsp?ind=962&cat=17.

[d]Ryan White: The Ryan White HIV/AIDS Program, the single largest federal program designed specifically for people with HIV in the United States, provides care and services for people with HIV who are uninsured or underinsured, serving as payer of last resort. It includes ADAP. Federal funding is provided to states, cities, and providers but may not match the number of people who need services or the cost of their care. For more information, see KFF, *The Ryan White Program*, http://www.kff.org/hivaids/7582.cfm.

SOURCE: Adapted from KFF, 2012b.

The provisions of the ACA discussed in the following sections are likely to have the greatest impact on care and care coverage for people with HIV.

Pre-Existing Conditions, Rescission, and Limits on Coverage

Currently, children with pre-existing medical conditions (e.g., HIV/AIDS, diabetes) no longer can be denied health care insurance coverage (Keith et al., 2012; KFF, 2011a).[8] Beginning in 2014, insurers also will no longer be able to deny coverage to or charge higher premiums for adults

[8]In addition, coverage must now be extended for dependent children on parental policies up to age 26 (Keith et al., 2012; KFF, 2011a). Since young adults, ages 20 to 29, have the highest rates of new HIV diagnoses among all age groups in the United States (CDC, 2012, Table 1a), extension of coverage for older dependent children is a potentially important source of coverage for HIV care for this population.

with pre-existing conditions. In the interim, adults with pre-existing conditions who have been without health coverage for at least 6 months are eligible to purchase coverage through federal or state-run, high-risk PCIPs (Figure 2-2; KFF, 2011a). In addition, insurance providers no longer can rescind coverage due to health status, except in cases of fraud or intentional misrepresentation (Keith et al., 2012; KFF, 2011a). The ACA also prohibits the imposition of lifetime dollar limits on coverage for essential health benefits and restricts and phases out annual dollar limits on coverage for essential health benefits, unless waived by the Department of Health and Human Services (HHS).[9] Waivers for annual dollar limits on coverage will be discontinued in 2014, eliminating annual dollar limits on coverage for all plans in small- and large-group markets (Keith et al., 2012).

Medicaid Expansion

Medicaid currently is the largest single source of health care coverage for people living with HIV, providing coverage for 47 percent of HIV-infected individuals estimated to be receiving regular medical care (Kates, 2011, p. 1). In fiscal year 2007, 212,892 Medicaid beneficiaries were HIV-positive (Kates, 2011, p. 1). In states that choose to expand their Medicaid program as allowed under the ACA, Medicaid eligibility will be extended to most "non-Medicare eligible individuals under age 65 (children, pregnant women, parents, and adults without dependent children)" with incomes up to 133 percent of the FPL (Figure 2-3; KFF, 2011a).[10] Currently, most Medicaid beneficiaries with HIV (74 percent) qualify through the disability pathway, meaning their disease is sufficiently advanced to preclude them from working (Kates, 2011, p. 4). With Medicaid expansion, as passed by law under the ACA, low-income individuals who have HIV, including those without dependent children ("childless adults"), will be eligible for Medicaid before their disease becomes disabling. For those who become newly eligible for Medicaid, the federal government will assume 100 percent of Medicaid costs during 2014-2016, phased down to a minimum of 90 percent thereafter.

Where Medicaid is expanded, particularly if coupled with more effective enrollment of currently eligible individuals, it is expected that there could be as many as 11.6 million new people entered into the Medicaid system in 2014 and 20 million by 2019, representing 21 and 34 percent increases, respectively, over pre-ACA projections (CMS, 2010). It is anticipated that the majority of individuals with HIV who currently receive clinical or related

[9]A discussion of "essential health benefits" is included later in the chapter.

[10]Recent (less than 5 years in the United States) and undocumented immigrants will remain ineligible for Medicaid.

supportive service care and prescription drug assistance through the Ryan White HIV/AIDS Program (>500,000) will become eligible for Medicaid in 2014 (KFF, 2011b; NASTAD, 2012b; Project Inform, 2012). The implications of this coverage shift are discussed later in this chapter.

Health Insurance Exchanges

The ACA also mandates the establishment of state or regional health insurance exchanges by January 2014 (Figure 2-3). The exchanges are meant to provide a marketplace in which eligible individuals and small businesses (less than 100 employees) can easily obtain and compare information on different health insurance options and purchase insurance coverage (KFF, 2011a). Individuals and families with incomes between 100 and 400 percent of the FPL will be eligible for federal subsidies to help cover insurance premiums and out-of-pocket health care costs (KFF, 2011a).

Medicare Part D Drug Coverage Gap

Medicare Part D prescription drug plans currently contain a coverage gap ("donut hole") that can impose significant financial burdens on enrollees. Prior to the enactment of the ACA, Medicare Part D beneficiaries were required to pay the full cost of their prescription drugs while in the coverage gap between the time they and their drug plans spent a specified dollar amount on covered drugs and the time beneficiaries' "true out-of-pocket" (TrOOP) costs reached the threshold catastrophic coverage. Of importance specifically for people with HIV, AIDS Drug Assistance Program (ADAP) benefits now count toward Medicare Part D recipients' TrOOP costs for medications, allowing them to move through the coverage gap more quickly. Additional ACA provisions will ease the burden of out-of-pocket drug costs for all individuals in the donut hole. Currently, pharmaceutical manufacturers are required to provide a 50 percent discount on prescriptions of brand name medications filled in the gap, and the beneficiary coinsurance rate will be reduced from 100 percent to 25 percent by 2020 (KFF, 2011a).

Essential Health Benefits Package and Preventive Care

The ACA charges HHS with establishing an "essential health benefits package" within specified parameters whose scope "is equal to the scope of benefits provided under a typical employer plan, as determined by the [HHS] Secretary" (P.L. 111-148, Sec. 1302 [42 U.S.C. 18022]). At a minimum, the essential health benefits package must include items and services in 10 areas of care: ambulatory patient services; emergency services; hospitalization; maternity and newborn care; mental health and substance use

disorder services, including behavioral health treatment; prescription drugs; rehabilitative and habilitative services and devices; laboratory services; preventive and wellness services and chronic disease management; and pediatric services, including oral and vision care (P.L. 111-148, Sec. 1302 [42 U.S.C. 18022]). HHS decided to allow each state the flexibility to select a plan from several options to serve as the benchmark for the essential health benefits package in that state.[11] Services covered by the benchmark plan in each of the 10 mandated areas become the essential benefits for plans in that state (Cassidy, 2012).

Health plans within and outside of the health insurance exchanges, except grandfathered plans, must provide, at a minimum, coverage for the essential benefits package of at least 60 percent of the actuarial value of the covered benefits, with limits on annual cost sharing (KFF, 2011a). Medicaid programs within states that implement the expansion provision of the ACA also must provide benefits comparable to those in the essential health benefits package to newly eligible adults (KFF, 2011a).

As of 2010, the ACA improves preventive care coverage by eliminating cost sharing within Medicare for preventive services recommended by the U.S. Preventive Services Task Force (USPSTF) (i.e., services rated A or B) and requiring health plans to provide the same services without cost sharing, as well as recommended immunizations, pediatric and adolescent preventive care, and preventive care and screenings for women (KFF, 2011a). The ACA also offers incentives to states in which Medicaid covers USPTF A- and B-rated services and recommended immunizations without cost sharing (KFF, 2011a).

STATE IMPLEMENTATION

Although the ACA establishes federal mandates and standards regarding health insurance, states are among those entities responsible for implementing some of the most significant changes, such as establishment of state health insurance exchanges and whether to accept the Medicaid expansion provision.[12] Box 2-1 lists some of areas in which state variation in implementation of the ACA is anticipated.

[11]States may choose as their benchmark "one of the three largest small group plans in the state by enrollment, one of the three largest state employee health plans by enrollment, one of the three largest federal employee health plan options by enrollment, or the largest health maintenance organization (HMO) plan offered in the state's commercial market by enrollment" (Cassidy, 2012).

[12]Most of the consumer protection and insurance reform provisions of the ACA apply to the U.S. territories as well as states and the District of Columbia, although there are some differences (NASTAD, 2012a). People residing in the territories are exempt from the individual mandate, and the territories are not required to establish health insurance exchanges, although

BOX 2-1
Possible Variation in Patient Protection and Affordable Care Act Implementation Across States

- Expansion of Medicaid to childless adults up to 133 percent FPL[a]
- Specific services included in "essential benefits" packages
- Restrictions on Medicaid-covered services[b]
- Federal versus state oversight of pre-existing conditions insurance plans
- Federal versus state oversight of health benefits exchanges
- Mechanisms (e.g., websites) to facilitate client enrollment into public and private insurance
- Inclusion of pilot programs[c]
  1. Regionalized Systems for Emergency Care Pilots: Sec. 3504
  2. Healthy Aging, Living Well Pilot Program: Sec. 4202
  3. Environmental Health Hazards Primary Pilot Program: Sec. 10323
  4. National Pilot Program on Payment Bundling: Sec. 3023

[a]Eligibility requirements currently vary widely from state to state and likely will continue to do so. Some states have programs with FPL cutoffs higher than 133 percent, and others will continue to have less generous eligible criteria.

[b]This already occurs, such as limits on the number of prescriptions per month, or pre-authorization for specific medications.

[c]The implementation of pilot programs is not subject to state choice.

Some states are in a better starting position than others to implement the ACA. Massachusetts, for example, enacted health reform legislation in 2006 that is similar to the ACA, including an individual mandate, Medicaid expansions, subsidized private insurance coverage, and a purchasing pool (Long and Masi, 2009). Vermont enacted single-payer health care legislation in 2011. Although the Vermont system, when implemented, may provide benefits equivalent to or better than those provided under the ACA, the state has also established a health insurance exchange to fulfill the ACA mandate until it can apply for a waiver once the single-payer system is implemented (Hsiao et al., 2011; KFF, 2012d, Vermont). New York State already has in place a number of the protections for health insurance

tablish an insurance exchange will receive additional funding for their Medicaid programs. Medicaid programs in the territories operate under broad federal guidelines but with different funding and coverage requirements. The ACA does increase the amount of federal Medicaid cap in these areas, resulting in more federal money for their Medicaid programs. Among the U.S. territories and dependent areas, health reform in Puerto Rico and the U.S. Virgin Islands will have the greatest effect on people living with HIV due to the high prevalence of HIV in those areas.

consumers included in the ACA (NYS, 2012), such as guaranteed issue. In 1974, Hawaii became the first state to create a near universal health care system, requiring most employers to provide health care coverage to eligible employees and setting minimum standards for the coverage benefits (State of Hawaii, 2012).

States have used waivers to extend Medicaid benefits to at least some portion of their "childless adult" population (MACPAC, 2012, pp. 108-110, Table 10). In addition, states have different income thresholds for eligibility, ranging from well below 100 percent of the FPL to well above 133 percent of the FPL, although in some cases the benefits covered may be more limited than those provided under the regular state plan (KFF, 2012f). Among the states that choose to implement the Medicaid expansion provision of the ACA, those that already have more generous Medicaid eligibility requirements may experience fewer changes in their programs than those that have not. State Medicaid programs also vary in the scope of their benefits. For example, some states limit the number of prescriptions covered per month or require preauthorization for certain medications.

States also are at different stages regarding implementation of their health insurance exchanges. Table 2-1 summarizes state action on establishing exchanges as of November 19, 2012. At that time, seventeen states and the District of Columbia had established exchanges; six states had decided to pursue the establishment of a federal–state partnership exchange; and sixteen states had defaulted to a federal exchange (KFF, 2012c). Eleven states were still undecided (KFF, 2012c).[13]

OPPORTUNITIES, CHALLENGES, AND LIMITATIONS

The ACA offers great opportunities for significant expansion of access to health care, improved health outcomes, and emphasis on preventive care for millions of Americans including most of the almost 30 percent of people living with HIV who currently lack any form of health care coverage (CMS, 2010; HHS, 2012a). States such as Massachusetts and Vermont have enacted sweeping health reform initiatives independent of the ACA, and many other states have taken various actions to increase access to health care. Despite their promise to increase access to health care and improve the health of people living with HIV, health reform efforts under the ACA also raise numerous challenges.

Economic sustainability is one challenge of health reform efforts that include expanded access, guaranteed coverage, and the removal of dollar limits on benefits. The requirement that most individuals be insured or pay

[13]Detailed health exchange profiles for each state are available at http://healthreform.kff.org/State-Exchange-Profiles-Page.aspx (accessed June 26, 2012).

TABLE 2-1 State Action Toward Creating Health Insurance Exchanges, November 19, 2012

Declared State-Based Exchange (17 + DC)	Planning for Partnership Exchange (6)	Default to Federal Exchange (16)	Undecided (11)
California, Colorado, Connecticut, Hawaii, Iowa, Kentucky, Maryland, Massachusetts,[a] Minnesota, Mississippi, Nevada, New Mexico, New York, Oregon, Rhode Island, Vermont, Washington District of Columbia	Arkansas, Delaware, Illinois, Michigan, North Carolina, Ohio	Alabama, Alaska, Georgia, Kansas, Louisiana, Maine, Missouri, Nebraska, New Hampshire, North Dakota, Oklahoma, South Carolina, South Dakota, Texas, Wisconsin, Wyoming	Arizona, Florida,[b] Idaho, Indiana, Montana, New Jersey, Pennsylvania, Tennessee, Utah,[a] Virginia, West Virginia

[a]Passed laws prior to the enactment of the ACA in March 2010, but not yet decided on implementing an ACA-compliant exchange.
[b]Although not compliant with the ACA, Florida is proceeding with plans that predate passage of the ACA to establish an insurance marketplace for small businesses (KFF, 2012d, Florida).
SOURCE: KFF, 2012c.

a tax is designed to bring young and healthy individuals into the insurance pools, which will help to offset the increased costs associated with expanded access and increased benefits. To be economically sustainable, sufficient numbers of such "low-risk" individuals will have to enter the insurance pools or the tax levied on those who fail to do so will have to be sufficient to offset the additional cost burden.

Another challenge raised by health care reform is that increased access to health care coverage under the ACA will facilitate but not ensure linkage to, retention in, and provision of quality clinical HIV care for people living with HIV. Although the number of uninsured HIV-infected individuals will decrease, people near the eligibility borders may be expected to "churn" (i.e., move back and forth) between different sources of coverage, which may affect the continuity of their care and the package of benefits for which they are eligible at any given time. Such movement may be especially pronounced between Medicaid and state insurance exchanges, affecting individuals at 125 to 135 percent of the FPL. Ensuring continuity of clinical HIV care and supportive services throughout movement across sources of coverage is important for improving individual health outcomes and reducing the risk of transmitting the virus to others. Maintaining formerly incarcerated individuals in clinical HIV care as they transition from the prison health care system to mainstream sources of health coverage is similarly important.

Movement of individuals from the Ryan White HIV/AIDS Program (as their primary source of coverage for HIV care) into Medicaid or other sources of coverage may affect the scope of services they receive. Given the significant interstate variation in Medicaid benefits, for example, some Ryan White HIV/AIDS Program clients might experience a reduction in services under Medicaid. In addition, the Ryan White HIV/AIDS Program covers many nonclinical services, such as food and nutrition, transportation, child care, and case management services, that are important to the success of clinical HIV care. To the extent that individuals no longer receive such supportive services when they move to other sources of coverage, their clinical service utilization and health outcomes may be negatively affected.

In addition to concerns about individuals maintaining access to continuous, high-quality clinical HIV care and supportive services, some people living with HIV in the United States, such as recent and undocumented immigrants, will remain ineligible for health coverage under the ACA and will continue to face challenges in accessing needed health care services.

Another challenge pertains to the availability of sufficient health care services to meet the anticipated increase in demand. The influx of new patients into the health care system, especially individuals with chronic diseases such as HIV who were previously unable to obtain coverage, can be expected to place additional burdens on an already strained system. A

2011 Institute of Medicine report assessing the capacity of the U.S. health care system to accommodate increased HIV testing and provision of care found that the HIV health care "workforce is decreasing relative to the number of individuals expected to require care" (IOM, 2011, p. 39). The number of HIV-infected individuals needing care will continue to grow with ongoing new infections; increases in HIV testing, diagnosis, and linkage to care; increased survival; and increased access to care as a result of health reform efforts. At the same time, many professionals engaged in HIV care are nearing retirement, and insufficient numbers of new practitioners proficient in HIV care are entering the workforce to accommodate the growing need (HRSA, 2010; IOM, 2011). Fiscal constraints are further decreasing the system's capacity to provide care for more people with HIV (IOM, 2011).

The possibility of "churning" between coverage sources, the movement of individuals from the Ryan White HIV/AIDS Program into other subsidized programs, and concerns about the availability of competent health care services sufficient to meet the needs of people living with HIV underscore the importance not only of tracking changes in health care coverage for people with HIV but also of monitoring service utilization and care quality using indicators such as those recommended in the committee's first report (IOM, 2012).

REFERENCES

Cassidy, A. Health Policy Brief: Essential health benefits. *Health Affairs*, April 25. http://healthaffairs.org/healthpolicybriefs/brief_pdfs/healthpolicybrief_68.pdf (accessed July 17, 2012).

CDC (Centers for Disease Control and Prevention). 2012. Diagnoses of HIV infection and AIDS in the United States and dependent areas, 2010. *HIV Surveillance Report*. Volume 22. March. http://www.cdc.gov/hiv/surveillance/resources/reports/2010report/index.htm (accessed July 3, 2012).

Center for Sustainable Health Spending, Altarum Institute. 2012. *Health Sector Economic Indicators.SM Insights from Monthly National Health Expenditure Estimates through April 2012*. Spending Brief #12-06: April 2012 Data (June 7). http://www.altarum.org/files/imce/CSHS-Spending-Brief_June%202012_060612.pdf (accessed June 20, 2012).

CMS (Centers for Medicare & Medicaid Services). 2010. *2010 Actuarial Report on the Financial Outlook for Medicaid*. https://www.cms.gov/ActuarialStudies/downloads/MedicaidReport2010.pdf (accessed March 29, 2012).

CMS. Office of the Actuary, National Health Statistics Group. 2012. *National Health Care Expenditures Data*. https://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/NationalHealthExpendData/downloads/tables.pdf (accessed June 20, 2012).

Commonwealth Fund. *The Commonwealth Fund 2010 Biennial Health Insurance Survey*. http://www.commonwealthfund.org/Surveys/2011/Mar/2010-Biennial-Health-Insurance-Survey.aspx (accessed August 16, 2012)

Daily Briefing. 2012. *Where Each State Stands on ACA's Medicaid Expansion: A Roundup of What Each State's Leadership Has Said About Their Medicaid Plans*. http://www.advisory.com/Daily-Briefing/2012/07/05/Where-each-state-stands-of-the-Medicaid-expansion (accessed September 17, 2012).

DeNavas-Walt, C., B. D. Proctor, and J. C. Smith. 2012. *Income, Poverty, and Health Insurance Coverage in the United States: 2011*. U.S. Census Bureau, Current Population Reports, P60-243. Washington, DC: U.S. Government Printing Office.

HHS (U.S. Department of Health and Human Services). 2012a. *How Does the Affordable Care Act Impact People Living with HIV/AIDS*. http://aids.gov/federal-resources/policies/health-care-reform/ (accessed July 16, 2012).

HHS. 2012b. *Who's Eligible for PCIP Coverage?* https://pcip.gov/Who's_Eligible.html (accessed September 17, 2012).

HRSA (Health Resources and Services Administration). 2010. Workforce capacity in HIV. *HRSA Care Action* (April):1-12.

Hsiao, W. C., A. G. Knight, S. Kappel, and N. Done. 2011. What other states can learn from Vermont's bold experiment: Embracing a single-payer health care financing system. *Health Affairs* 30(7):1232-1241.

IOM (Institute of Medicince). 2011. *HIV Screening and Access to Care: Health Care System Capacity for Increased HIV Testing and Provision of Care*. Washington, DC: The National Academies Press.

IOM. 2012. *Monitoring HIV Care in the United States: Indicators and Data Systems*. Washington, DC: The National Academies Press.

Kates, J. 2011. *Medicaid and HIV: A National Analysis*. Washington, DC: Henry J. Kaiser Family Foundation. http://www.kff.org/hivaids/upload/8218.pdf (accessed January 11, 2012).

Keith, K., K. W. Lucia, and S. Corlette. 2012. Implementing the Affordable Care Act: State action on early market reforms. *Issue Brief 6* (March). Publication 1586. Commonwealth Fund.

KFF (Kaiser Family Foundation). 2011a. *Focus on Health Reform: Summary of the New Health Reform Law*. Publication 8061. http://www.kff.org/healthreform/upload/8061.pdf (accessed March 30, 2012).

KFF. 2011b. *The Ryan White Program*. HIV/AIDS Policy Fact Sheet. Publication 7582-06. http://www.kff.org/hivaids/upload/7582-06.pdf (accessed June 26, 2012).

KFF. 2012a. *Focus on Health Reform: A Guide to the Supreme Court's Affordable Care Act Decision*. Publication 8332. http://www.kff.org/healthreform/upload/8332.pdf (accessed July 18, 2012).

KFF. 2012b. *How the ACA Changes Pathways to Insurance Coverage for People with HIV*. http://healthreform.kff.org/notes-on-health-insurance-and-reform/2012/september/how-the-aca-changes-pathways-to-insurance-coverage-for-people-with-hiv.aspx (accessed September 18, 2012).

KFF. 2012c. *State Action Toward Creating Health Insurance Exchanges, as of November 19, 2012*. http://statehealthfacts.kff.org/comparemaptable.jsp?ind=962&cat=17 (accessed November 20, 2012).

KFF. 2012d. *State Health Exchange Profiles*. http://healthreform.kff.org/State-Exchange-Profiles-Page.aspx (accessed June 27, 2012).

KFF. 2012e. *State Health Facts: Health Insurance Coverage of Adults (19-64) with Incomes Under 139% of the Federal Poverty Level (FPL), States (2009-2010), U.S. (2010)*. http://www.statehealthfacts.org/comparetable.jsp?ind=779&cat=3 (accessed July 18, 2012).

KFF. 2012f. *State Health Facts: Income Eligibility Limits for Working Adults at Application as a Percent of the Federal Poverty Level (FPL) by Scope of Benefit Package, January 2012*. http://www.statehealthfacts.org/comparereport.jsp?rep=54&cat=4#notes-1 (accessed March 29, 2012).

Long, S. K., and P. B. Masi. 2009. Access and affordability: An update on health reform in Massachusetts, Fall 2008. *Health Affairs* 28(4):w578-w587.

MACPAC (Medicaid and CHIP Payment and Access Commission). 2012. *Report to the Congress on Medicaid and CHIP*. March. http://www.macpac.gov/reports (accessed September 5, 2012).

NASTAD (National Alliance of State and Territorial AIDS Directors). 2012a. *Frequently Asked Questions on Health Reform, August 2012*. http://www.nastad.org/Docs/014950_NASTAD,%20Health%20Reform%20FAQs%20August%202012.pdf (accessed September 17, 2012).

NASTAD. 2012b. *National ADAP Monitoring Project Annual Report*. http://www.nastad.org (accessed June 26, 2012).

Natoli, C., V. Cheh, and S. Verghese. 2011. Who will enroll in Medicaid in 2014? Lessons from Section 1115 Medicaid waivers. *Medicaid Policy Brief* (1). Mathematica Policy Research.

NYS (New York State). 2012. *Federal Health Care Reform in New York State: Summary of Health Care Reform*. http://www.healthcarereform.ny.gov/summary (accessed March 29, 2012).

Project Inform. 2012. *Frequently Asked Questions: Health Care Reform and People Living with HIV*. http://www.projectinform.org/pdf/hcr_faq.pdf (accessed March 30, 2012).

Schoen, C., M. M. Doty, R. H. Robertson, and S. R. Collins. 2011. Affordable Care Act reforms could reduce the number of underinsured U.S. adults by 70 percent. *Health Affairs* 30(9):1762-1771.

Squires, D. A. 2012. Explaining high health care spending in the United States: An international comparison of supply, utilization, prices, and quality. *Issues in International Health Policy* 10 (May). Publication 1595. Commonwealth Fund.

State of Hawaii. Department of Labor and Industrial Relations. 2012. *About PrePaid Health Care*. http://hawaii.gov/labor/dcd/aboutphc.shtml (accessed September 17, 2012).

3

How to Obtain National Estimates of Health Care Coverage and Utilization for People with HIV in the United States

This chapter provides information to support the committee's conclusions and recommendations, presented in Chapter 4, for how to establish a baseline of health insurance and health care access for people with HIV in the United States prior to 2014 when key provisions of the Patient Protection and Affordable Care Act (ACA) (P.L. 111-148) are scheduled to be implemented (Statement of Task, subquestions a and b), and for how to continue to obtain data from a large sample of people with HIV to monitor the impact of the ACA on access to health insurance and health care access after 2014 (Statement of Task, subquestion c). In the context of describing how to monitor the impact of the ACA after 2014, the committee discusses an existing surveillance project conducted by the Centers for Disease Control and Prevention (CDC) called the Medical Monitoring Project (MMP) that is designed to obtain nationally representative estimates of the clinical and behavioral characteristics of HIV-diagnosed individuals in care. The committee presents an overview of the project's design and its strengths and weaknesses for generating nationally representative estimates of HIV care and coverage for people with HIV. The committee also discusses how data from Medicaid, Medicare, and the Ryan White HIV/AIDS Program, which are currently the most common sources of health care coverage for people with HIV, as well as data from private health insurers, might be used to characterize the health care experiences of people with HIV.

The HIV Cost and Services Utilization Study (HCSUS) was the first study designed to produce nationally representative estimates of people with HIV regularly receiving medical care (Shapiro et al., 1999). Active from 1994 to 2000, the HCSUS was a prospective cohort study involving

approximately 3,000 participants. HCSUS participants were interviewed several times over a 3-year period (a baseline interview with follow-up interviews at 6 and 12 months). In addition to the interview, participants' medical, pharmacy, and financial records were abstracted and a subset of participants had their blood drawn for laboratory testing. Among the study's main objectives was to guide policy decisions on the allocation of health care resources by providing reliable national estimates of the health care services received by people with HIV and on the costs of those services (RAND, 2011). The HCSUS offers a number of insights and lessons learned concerning the generation of nationally representative estimates of the care experiences of people with HIV, several of which have been incorporated into the MMP protocol. The committee uses HCSUS as a reference throughout its discussion of MMP in this chapter's section on how to continue to regularly obtain data to monitor health care coverage and utilization after 2014.

The committee reviewed several existing national population-based health surveys as potential sources of data on health care coverage and utilization for a nationally representative sample of people with HIV. These include the National Health Interview Survey (NHIS), which is the principal source of information on the health of the non-institutionalized U.S. population (CDC, 2012a); the Medical Expenditure Panel Survey (MEPS); the National Health and Nutrition Examination Survey (NHANES)[1]; the Behavioral Risk Factor Surveillance System (BRFSS); and the National Survey on Drug Use and Health (NSDUH). Although these surveys capture data relevant to monitoring care within the context of the ACA (for example, on sources of care coverage, care utilization, and demographic information), the number of people with HIV included in a given sample will be small because the prevalence of HIV in the general U.S. population is less than 1 percent (Shapiro et al., 1999; UNAIDS, 2010). A 2007 study that combined 2002-2004 MEPS data to evaluate the relationship between Ryan White HIV/AIDS Program service utilization and patient characteristics identified 125 people with HIV (Rein, 2007). Even the NHIS, which interviews between 75,000 and 100,000 individuals each year, will not include sufficient numbers of people with HIV to draw meaningful conclusions about their care experiences. Furthermore, while these population-based surveys are designed to be representative of the general U.S. population, they are not designed to be representative of people with any specific disease (CDC, 2010d; Shapiro et al., 1999). Including questions about HIV serostatus and

[1]In addition to an interview component, the NHANES includes an examination involving medical, dental, and physiological measurements and the administration of laboratory tests, including HIV antibody tests. Findings from the NHANES are designed to determine the prevalence of and risk factors for diseases (CDC, 2011a).

additional questions on HIV care experiences for HIV-infected individuals in national surveys would not be adequate to generate nationally representative estimates of their health care coverage and utilization. Thus, the committee did not consider national surveys as practical sources of data to establish a nationally representative baseline of health care coverage and utilization for people with HIV prior to 2014, nor to continue to obtain such data after 2014.

HOW TO ESTABLISH A BASELINE OF HEALTH CARE COVERAGE AND UTILIZATION PRIOR TO 2014

There currently is no single source of data to generate a baseline of care coverage and utilization for people with HIV. MMP is an ongoing federal supplemental HIV surveillance project designed to obtain nationally representative estimates of the care experiences of adults with HIV in care that collects data pertinent to monitoring the impact of the ACA on health coverage and utilization. However, as discussed in the following section, MMP currently has limitations to its design and participant response rate that raise concerns about the representativeness of the data. Combining data from multiple data sources is the most viable option for generating a baseline of care coverage and utilization prior to 2014.

In its first report, the committee identifies 14 core indicators to monitor the impact of the ACA and National HIV/AIDS Strategy (NHAS) on improvements in HIV care (see Table 1-4 in Chapter 1). The committee also identifies sources of data to estimate the indicators, including HIV-specific data sources (e.g., the National HIV Surveillance System, the Ryan White HIV/AIDS Program, and ongoing epidemiologic studies of people with HIV) as well as data sources that are not HIV-specific but that collect data relevant to monitoring care for people with HIV (e.g., Medicaid, Medicare, Veterans Health Administration, and private health insurer data). The committee revisited these data sources for this second report and found that many capture data pertinent to monitoring the impact of the ACA on care for people with HIV such as health coverage and service utilization information and receipt of recommended preventive health services. While none of these systems are designed to be nationally representative, together they can provide a reasonably accurate baseline of care coverage and utilization before 2014. As is outlined in the committee's first report, these data systems also provide a collective platform for estimating indicators of care quality and, thus, can be used to generate estimates of care quality before full implementation of the ACA (IOM, 2012).

HOW TO CONTINUE TO OBTAIN DATA TO MONITOR HEALTH CARE COVERAGE AND UTILIZATION AFTER 2014

Medical Monitoring Project

MMP was initiated by CDC in 2005 in response to the Institute of Medicine (IOM) report *Measuring What Matters: Allocation, Planning, and Quality Assessment for the Ryan White CARE Act*, which described a need for representative data on the care and preventive service needs of individuals with HIV in the United States (CDC, 2012e; IOM, 2004). MMP utilizes a repeated (annual) cross-sectional design to obtain data from a national probability sample of HIV-diagnosed adults in care to

- describe the clinical and virologic status of these persons;
- describe the prevalence of comorbidities related to HIV disease;
- describe HIV care and supportive services received and the quality of such services; and
- identify met and unmet needs for HIV care and prevention services to inform prevention and care planning groups, health care providers, and other stakeholders (CDC, 2012c).

MMP is the only study since HCSUS (Bozzette et al., 1998; RAND, 2011) that is designed to be nationally representative of HIV-diagnosed adults in care in the United States. Whereas MMP employs a cross-sectional design, however, HCSUS was a prospective study that followed a cohort of individuals in care for HIV over time (RAND, 2011). MMP is conducted through cooperative agreements between CDC's Division of HIV/AIDS Prevention-Surveillance and Epidemiology and state and local health departments in participating MMP project areas (CDC, 2012c).

Current Sampling Methodology

MMP uses three-stage, probability proportionate to size sampling for the selection of (1) project areas, (2) facilities that provide outpatient HIV medical care in selected project areas, and (3) HIV-infected adults who receive medical care at selected facilities (Figure 3-1). A similar sampling methodology was used in HCSUS to identify a cohort of people with HIV in care. The national population of inference for each MMP data collection cycle is HIV-infected adults age ≥18 years who received care from known providers of HIV medical care in the United States during a predefined population definition period (PDP).[2] The PDP has been January 1 through

[2]For local estimates in MMP project areas, the population of inference is HIV-infected adults who received care from known providers of HIV care in the project area during the population definition period (CDC, 2012c).

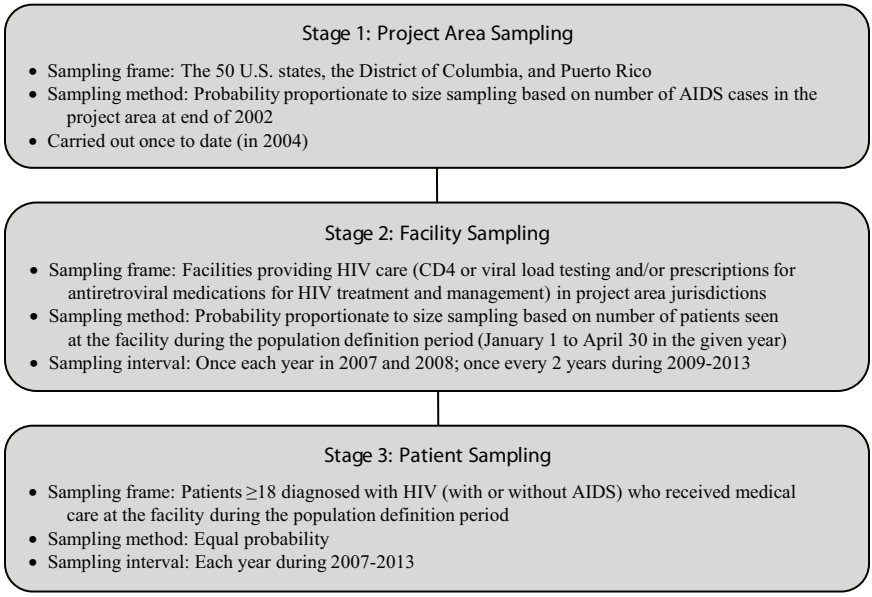

FIGURE 3-1 MMP sampling design.
SOURCE: Adapted from CDC, 2012c; McNaghten et al., 2007.

April 30 for each full year of MMP data collection thus far (CDC, 2012c,e). The first full year of MMP data collection was 2007; 13 project areas were funded to pilot data collection on patients who were in care in 2005,[3] and CDC did not collect data on patients in care in 2006 due to delays in the Office of Management and Budget's (OMB's) clearance of MMP activities[4] (CDC, 2010a).

Project Area Sampling

Project area sampling took place in early 2004. Consistent with the goal of MMP to obtain a national probability sample of adults in care for HIV infection, all 50 U.S. states, the District of Columbia, and Puerto Rico were eligible for selection. Probability proportionate to size sampling was used to select primary geographic sampling units where the measure of size

[3]The 13 project areas were Delaware, Florida, Houston (Texas), Illinois, Los Angeles (California), Maryland, Michigan, New Jersey, New York City (New York), Philadelphia (Pennsylvania), South Carolina, Texas, and Washington (CDC, 2012c).

[4]The Paperwork Reduction Act of 1980 requires Office of Management and Budget approval of federally sponsored data collection activities (HHS, 2012a) such as MMP.

was the total number of people living with AIDS at the end of 2002.[5] Based on available funding for MMP, 20 primary geographic sampling units were selected (19 states and 1 territory); 6 municipal jurisdictions located within the selected project areas and separately funded for HIV/AIDS surveillance were also selected, resulting in a total of 26 project areas. All of the project areas agreed to participate in MMP (CDC, 2012c,e).[6]

Of the 26 project areas initially sampled, 23 have been funded to conduct MMP since 2009. States and territories currently funded for MMP are California (other than Los Angeles and San Francisco), Delaware, Florida, Georgia, Illinois (other than Chicago), Indiana, Michigan, Mississippi, New Jersey, New York (other than New York City), North Carolina, Oregon, Pennsylvania (other than Philadelphia), Puerto Rico, Texas (other than Houston), Virginia, and Washington. Municipal project areas currently funded for MMP are Chicago, Illinois; Houston, Texas; Los Angeles County, California; New York, New York; Philadelphia, Pennsylvania, and San Francisco, California. In addition to the areas noted above, the project areas funded for the 2007 and 2008 data collection cycles included Maryland, Massachusetts, and South Carolina (CDC, 2012c,e). While maintaining a nationally representative system, these states were removed from the project area sample in 2009 to reduce project costs and improve operational efficiency (Personal communication, Jacek Skarbinski, CDC, August 27, 2012).

CDC's 2012 HIV Surveillance Report includes data from 46 states and 5 dependent areas that have used confidential name-based HIV (in addition to AIDS) reporting since at least January 2007. Although MMP project area sampling was conducted in 2004, data from the report indicate that about 80 percent of the 800,784 people ≥13 reported to be living with a diagnosis of HIV infection in 2009 resided in the 19 states and 1 dependent area that are the current MMP project areas (CDC, 2012b).[7]

[5]The results of MMP are intended to be generalizable to adults with diagnosed HIV infection who are in care, and not limited to those whose infection has progressed to AIDS. However, when project area sampling was carried out in 2004, there was no data system from which to reliably estimate the number of people in the United States with diagnosed HIV infection; several states and dependent areas did not yet use confidential name-based reporting to collect HIV infection data. The estimated number of people diagnosed with AIDS was used as an indirect measure of size to sample project areas because reporting of AIDS diagnoses had been implemented nationally (CDC, 2010b, 2012c,e). All U.S. states, the District of Columbia, and six dependent areas had implemented confidential name-based HIV reporting as of April 2008 (CDC, 2011c).

[6]Please see CDC, 2012c (Appendix A) for a fuller description of the project area sampling methodology.

[7]2009 is the most recent year for which estimates of the total number of people living with a diagnosis of HIV infection by state and dependent area are available (CDC, 2012b).

Facility Sampling

The second stage of sampling involves the selection of facilities from each project area. Facility samples were drawn each year in 2007 and 2008 and are being drawn every other year during 2009 to 2013. A comprehensive list of eligible facilities providing HIV medical care within a project area jurisdiction serves as the facility sampling frame (CDC, 2012c,e). Compiled by health department staff in the project area (i.e., "project area staff"), the facility sampling frame is composed of facilities that reported patients to the HIV/AIDS Reporting System (HARS) or Enhanced HIV/AIDS Reporting System (eHARS), databases used by health departments to collect, manage, and report state or local HIV/AIDS surveillance data to CDC.[8] Project area staff may also consult state or local laboratory reporting databases or prescription drug lists, which contain information on providers who order laboratory tests and prescribe antiretroviral medications, to identify eligible facilities (CDC, 2012c,e).

Outpatient facilities, including hospital-affiliated and freestanding clinics, health care institutions, and private and group physician practices that are providing HIV medical care in the jurisdiction, and that have a centralized medical record system, are eligible for MMP. HIV medical care for purposes of constructing the facility sampling frame is defined as "conducting CD4 or HIV viral load testing and/or providing prescriptions for antiretroviral medications in the context of treating and managing a patient's HIV disease" (CDC, 2012c, p. 9) (Figure 3-2). Facilities that do not provide medical care (e.g., those that exclusively provide HIV counseling and testing services or that obtain CD4 count and viral load information for referral purposes only) are not eligible. Also ineligible are facilities that only provide inpatient care (e.g., hospices); emergency departments; facilities located outside the project area; correctional and work-release facilities; tribal facilities; and facilities located on military installations.[9] Veterans Health Administration (VHA) facilities are eligible to participate in MMP and it is a requirement that they are included on the facility sampling frame (CDC, 2012c).

For each facility included on the facility sampling frame, MMP proj-

[8]eHARS is a browser-based system created by CDC and deployed at health departments. CDC developed eHARS as a replacement for the older HARS to help expedite and standardize reporting of HIV/AIDS information (CDC, 2009a).

[9]According to the 2012 MMP protocol, inpatient facilities and emergency departments are excluded because the medical care provided to people with HIV in these settings may not be HIV-related. Furthermore, some providers in inpatient hospital facilities, such as medical residents, may not be known providers of HIV care and thus not be eligible to carry out MMP patient contact and recruitment activities. Hospices may provide HIV medical care but are excluded from MMP because they are not considered to be known regular providers of such care (CDC, 2012c).

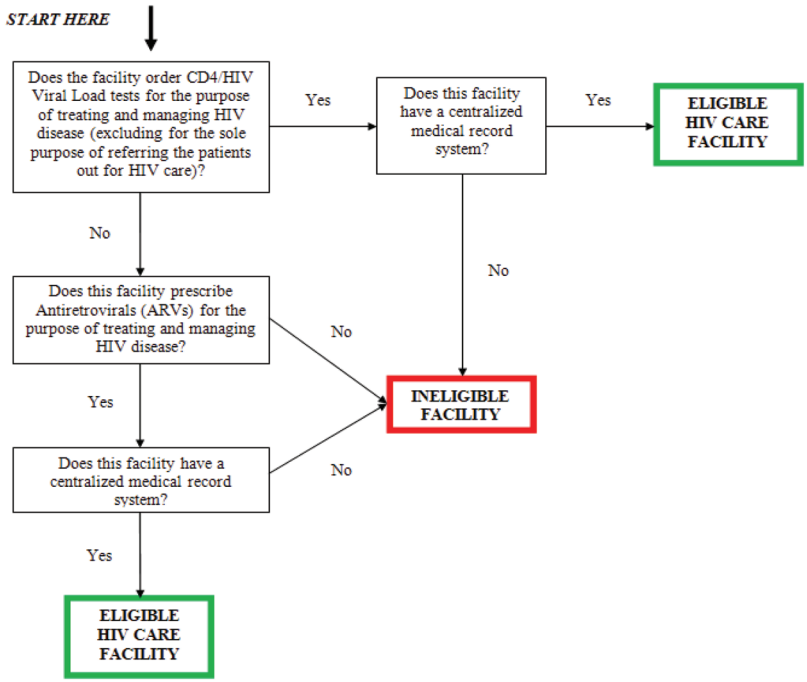

FIGURE 3-2 MMP facility eligibility determination algorithm.
SOURCE: CDC, 2012c.

ect area staff identifies an estimated patient load—a best estimate of the total number of eligible patients who receive care at the facility during the PDP. The estimated patient load is based on data provided directly by facilities, for example, based on patient data runs or another record-based source. Data from HARS, eHARS, state or local laboratory databases, or prescription drug lists may be used to estimate a facility's patient load in cases where information cannot be obtained from facilities (CDC, 2012c). CDC uses the patient load information reported by facilities to select facilities using probability proportionate to size sampling, where facilities with higher estimated patient loads are more likely to be selected. According to the 2012 MMP protocol, between 25 and 50 facilities were selected in most project areas for the 2011 and 2012 data collection cycles (CDC, 2012c,e).

As discussed below, CDC is pilot testing the feasibility of using the National HIV Surveillance System (NHSS) as a patient sampling frame in select MMP project areas during the 2012 and 2013 data collection cycles. If the pilot study is successful and NHSS-based sampling is implemented, facility sampling could be reduced or eliminated (CDC, 2012e).

Patient Sampling

The third stage of sampling involves the selection of patients from each participating facility. To be eligible for MMP, patients must (1) be diagnosed with HIV (with or without AIDS) any time prior to the end of the population definition period or PDP (between January 1 and April 30 of the given year); (2) be at least 18 years of age at the beginning of the PDP; and (3) have received medical care during the PDP. Medical care for purposes of patient sampling is defined as "any visit to the facility for medical care or prescription of medications, including refill authorizations and vaccinations" (CDC, 2012c, p. 14).[10] Patients must also be able to provide informed consent and cannot have already participated in MMP during the current data collection cycle to be eligible for participation. Patient sampling is carried out on an annual basis (CDC, 2012c).

Patients are selected for MMP using list-based sampling. Each participating facility provides local project area staff with a list of HIV-infected adults who received medical care at the facility during the PDP. After project area staff have received patient lists from all participating facilities within the jurisdiction, a master file is transmitted to CDC for patient sampling. Sampling is performed so that all patients who were seen during the 4-month sampling period have an equal probability of selection. The identification numbers of selected patients are returned to project areas for patient recruitment (CDC, 2012c,e). CDC determined that 400 is the minimum sample size for a state to obtain population estimates with an acceptable level of precision, including patients sampled in a municipal jurisdiction or statewide project area. Patient sample sizes across all facilities in a project area ranged from 100 to 800 during 2012. Approximately 9,400 participants were sampled in total (Table 3-1; CDC, 2012c).

CDC pilot tested real-time sampling (RTS) in two large facilities in the Philadelphia project area in 2011. RTS can improve coverage, response rates, and data timeliness, including among harder-to-reach populations since study participants are recruited when they come for services (Iachan et al., 2011). In the MMP pilot study, "office period units" were selected using probability proportionate to size sampling where size was the patient flow during a particular time of day in a particular office within the selected facility. Patients believed to be eligible for MMP (as determined by facility staff) with scheduled appointments during the selected office period units comprised the sampling frame. Patients were selected from this sampling frame using systematic random sampling (Iachan et al., 2011). Results from

[10]Note that this is different from the definition of medical care used for facility sampling (i.e., "conducting CD4 or HIV viral load testing and/or providing prescriptions for antiretroviral medications in the context of treating and managing a patient's HIV disease") (CDC, 2012c, p. 9).

TABLE 3-1 MMP Patient Sample Sizes by Project Area, 2012

Project Area	Patient Sample Size
California (excluding LA, SF)	500
Los Angeles County	400
San Francisco	400
Delaware	400
Florida	800
Georgia	400
Illinois (excluding Chicago)	100
Chicago	400
Indiana	400
Michigan	400
Mississippi	400
New Jersey	500
New York State (excluding NYC)	200
New York City	800
North Carolina	400
Oregon	400
Pennsylvania (excluding Philadelphia)	100
Philadelphia	400
Puerto Rico	400
Texas (excluding Houston)	400
Houston	400
Virginia	400
Washington	400
Total	9,400

SOURCE: CDC, 2012c.

the pilot study were promising with regard to sampling completion. HCSUS also used RTS in select sites to good advantage to address several implementation challenges also faced by MMP (Frankel et al., 1999; Shapiro et al., 1999). However, due to additional burden on MMP staff to manage the sampling process and provide statistical assistance, CDC decided not to continue using RTS for the remainder of the 2009-2013 funding cycle (Iachan et al., 2011; Personal communication, James Heffelfinger, CDC, June 11, 2012).

Facility and Patient Recruitment

Facilities sampled for MMP are recruited by project area staff. No substitutions are made for facilities found to be ineligible during recruitment or that decline to participate because doing so could invalidate the project sampling design. Given that the success of MMP is heavily dependent on a high facility response rate, CDC advises that project areas have a plan in place to maximize facility participation based on previous experience with

TABLE 3-2 MMP Facility and Patient (Interview) Response Rates, 2009 and 2010

	Facility Response Rate	Patients Sampled	Interviews Completed	Raw Response Rate[a]	Adjusted Response Rate
2009	76%	9,038	4,620	51%	56%
2010	80%	9,300	4,981	54%	56%

[a]Before adjustment for patients sampled who are later identified as ineligible.
SOURCE: Personal communication, Jacek Skarbinski, CDC, September 12, 2012.

MMP and similar projects, as well as discussions (e.g., on conference calls, at meetings) among staff in the various project areas (CDC, 2012c). The facility response rates for the 2009 and 2010 data collection cycles were 76 percent and 80 percent respectively (Table 3-2) (Personal communication, Jacek Skarbinkski, CDC, September 12, 2012).

Patients may be recruited either by facility or project area staff. The decision of which of the two methods to use is based on local facility preference and state or local project area Institutional Review Board (IRB) requirements. Project area staff is responsible for scheduling interviews (discussed below) for all patients who are eligible and agree to participate in MMP (CDC, 2012c,e). The adjusted response rate for the interview portion of the study in 2010, the most recent year for which data are available, was 56 percent (Table 3-2) (Personal communication, Jacek Skarbinksi, CDC, September 12, 2012). By comparison, the HCSUS interviewed 76 percent of individuals sampled (Shapiro et al., 1999). The interviewer-administered NHIS household survey averages a 90 percent response rate each year, although the response rate for the sample adult core component of the NHIS, which collects information on health conditions and access to and utilization of health care services for one adult per household, was about 61 percent in 2010 (Schiller et al., 2012). The unweighted response rate for the 2009-2010 NHANES interview was 79 percent (CDC, 2011d). The NSDUH, which collects sensitive health information, such as on use of illegal drugs, alcohol, and tobacco by the U.S. civilian, noninstitutionalized population aged 12 or older via face-to-face interviews, achieved a 75 percent response rate in 2010 (SAMHSA, 2011). MMP participants are compensated in either cash or cash equivalent (e.g., personal gifts, gift certificates, bus or subway tokens) for the interview.[11] The compensation was valued to be about $25 for the 2012 data collection cycle, with the exact amount varying by project area (CDC, 2012c).

[11]Non-cash reimbursements are provided in project areas where local regulations prohibit cash reimbursements (CDC, 2012c).

An MMP Provider Advisory Board and a Community Advisory Board are in place to support facility and patient recruitment. The Provider Advisory Board consists of one provider representative from each project area as well as members of national HIV provider organizations. Members serve as a resource for providers who are approached about participating in MMP and also provide significant input to MMP staff on facility and patient recruitment strategies. The Community Advisory Board is made up of one community representative from each project area and members of national organizations of people living with HIV. It serves as a link between MMP staff and patients invited to enroll in MMP and works with participating health departments to make sure that patients' rights and privacy are protected. Members of both the Provider Advisory Board and Community Advisory Board consult on barriers to participation in MMP, study methods and data collection instruments, the usefulness of collected data, and best methods for dissemination of study data (CDC, 2009b,c, 2012c).

Other activities to facilitate patient recruitment include bimonthly conference calls with interviewers and annual interviewer trainings hosted by CDC that address recruitment challenges and strategies to ensure that patient participation is maximized. To better enable participation of patients in rural areas, interviewers travel to conduct interviews in patients' preferred locations. Optional telephone interviewing, which has been implemented in all project areas as of 2012, also makes it more convenient for patients to participate in MMP (Personal communication, James Heffelfinger, CDC, June 11, 2012).

Data Collection

Core MMP data collection activities include interviewing sampled patients and abstracting their medical records. A minimum data set of basic core surveillance information is also obtained for all sampled patients. Data collection activities are carried out by health department staff in each of the project areas (CDC, 2012c).

The 2012 standard MMP questionnaire includes modules in each of the following areas: Demographics; Access to Care (HIV testing and care experiences, sources of care, and met and unmet needs); Stigma and Discrimination; HIV Treatment and Adherence; Sexual Behaviors; Drug and Alcohol Use (cigarette and alcohol use, non-injection drug use, and injection drug use); Prevention Activities; Anxiety and Depression; Gynecological and Reproductive History; and Health Conditions and Preventive Therapy. The questionnaire also includes an optional module on acculturation that project areas may use to assess patients' native language, languages spoken and read, language used as a child, language spoken at home and with friends, and language used when thinking (CDC, 2012f). The questionnaire

is administered either face-to-face or by telephone by a trained interviewer who is affiliated with the project area health department. Interviewers utilize a handheld-assisted personal interview (HAPI) on a personal digital assistant device or computer-assisted personal interview (CAPI) software on a laptop computer to administer the questionnaire. Paper versions of the questionnaires are also provided to interviewers to use if needed. Face-to-face interviews take place at a location mutually agreed upon by the patient and project area staff where the confidentiality and security of the patient's information can be guaranteed, such as a medical facility or the participant's home. A short MMP questionnaire that includes abridged versions of the demographics, access to care, and HIV treatment and adherence modules is available for interview of patients who are too ill to complete the longer standard questionnaire or who do not speak English or Spanish and require an interpreter to complete the interview.[12] The standard and short questionnaires take approximately 45 minutes and 20 minutes to complete, respectively (CDC, 2012c).

After patients complete the MMP questionnaire, their medical records are abstracted by trained abstractors using an electronic medical record abstraction (MRA) application. The medical records of patients who do not complete the interview may also be abstracted in certain circumstances, as discussed below. The range of information abstracted is based on the patient's clinical condition and experiences and may consist of diagnoses of opportunistic illnesses and other HIV-related conditions, provision of preventive care, prescription of antiretroviral and other medications, laboratory results, and health services utilization. Demographic and insurance status data are also collected (CDC, 2012c).[13] Beginning in 2012, the MRA focuses on data contained in the medical record at the care facility where

[12]There are English and Spanish versions of the questionnaire. With respect to interviews requiring an interpreter (i.e., for non-English, non-Spanish speaking participants), project areas are encouraged to anticipate what languages they are likely to encounter and to make arrangements to have an interpreter available when needed. CDC's guidelines for MMP interpreters include demonstration that the interpreter is capable of conveying information in both languages and orientation and training in interpretation and interviews, ethical considerations, and confidentiality (CDC, 2012c).

[13]Medical record information is collected in four linked forms including a Surveillance Period Summary Form (SPSF), Surveillance Period Visit Form (SPVF), Surveillance Period Inpatient Form (SPIF), and Medical History Form (MHF). The SPSF, SPVF, and SPIF are used to abstract clinical data for events that occurred during the "surveillance period" (SP), which is the 12 months prior to the interview for patients who complete an interview and the 12 months prior to the first attempt to contact the patient for interview for patients who do not complete the interview. The MHF is used to abstract clinical data for events that occurred from the date of first medical care for HIV documented in the patient's medical record through the date prior to the first day of the SP. For patients found to be deceased, the MRA covers the 12 months prior to the date of death (CDC, 2012c).

the patient was sampled. This includes any information from outside facilities (e.g., inpatient records, lab results) that is available in the patient's medical record at the facility (CDC, 2012c; Personal communication, Jacek Skarbinski, CDC, June 12, 2012). In previous MMP cycles, in addition to information in the medical record at the facility where the patient was sampled, the MRA could include clinical data contained in medical records at other facilities where the patient had received care (CDC, 2010c), but this is no longer part of the protocol.[14]

The MRA may be conducted for patients who decline to participate in the interview or who cannot be located for interview in project areas with surveillance authority to perform MRA without explicit patient consent. (This is not possible in project areas with more narrow definitions of surveillance that do not include MRA.) A waiver of consent to complete the MRA for patients known to have died may be obtained in project areas where MMP is considered by the local IRB to be research (CDC, 2012c; HIPAA Privacy Rule 45 CFR 164.512[1][1][iii]).

Multiple measures have been implemented to ensure the collection of quality interview and MRA data. Edit checks are built into the software that interviewers use to record patient responses to interview questions. In addition, 5 percent of patient interviews are observed by MMP principal investigators, project coordinators, or other supervisory staff to ensure data completeness and quality. A standardized checklist for structured interviews is provided by CDC for this purpose (see Box 3-1). The MRA modules are reviewed for quality by project area supervisory staff before submission to CDC. Five percent of MRAs completed are re-abstracted by an independent reviewer and compared with the original MRAs for discrepancies and completeness (CDC, 2012c).

To facilitate the completeness of MMP data, project areas may collect data on patients who have moved and are no longer receiving care in the project area and facility from which they were sampled. For example, staff in the jurisdiction from which the patient was sampled may abstract the medical records of patients who have moved to an area that is not conducting MMP to the extent allowed by surveillance authorities, although an interview is not completed for these patients. For patients who have relocated to areas that are conducting MMP, the new project area may conduct an interview if consent requirements and recruitment protocol specifications are agreed upon by MMP principal investigators in both project areas. Staff

[14]In the 2011 MMP protocol, for example, CDC recommended that project areas give priority, in decreasing order, to the abstraction of clinical data from (1) the facility where the participant was sampled, (2) the facility reported by the participant as being his or her primary source of medical care for HIV, and (3) facilities where the participant received inpatient care during the surveillance period (CDC, 2010c).

BOX 3-1
Criteria from Checklist for Observation of MMP Interviews[a]

Preparation

- Interviewer had all necessary materials.
- Confidential materials were stored in a locked container before and after the interview.
- Interviewer greeted participant in a friendly manner.

Consent Process

- Interviewer followed all aspects of informed consent according to local protocol.
- Interviewer provided the participant with a copy of the consent form to follow along.
- Interviewer gave the participant a personal copy of the consent form.
- Interviewer inquired about and, if applicable, addressed any questions or concerns about the consent form.

Questionnaire Administration

- Interviewer read questions exactly as written.
- Interviewer read questions at an appropriate pace.
- Interviewer avoided leading participant to a particular response.
- Interviewer demonstrated a neutral attitude.
- Interviewer followed instructions ("Read choices" and "Do not read choices").
- Interviewer read Say Boxes verbatim.
- Interviewer used all response cards when indicated.
- Interviewer used the calendar to aid with time reference changes.

Interviewer Comments

- (If applicable) Interviewer used "Interviewer Comments" function to record additional comments.

Rapport

- Interviewer established a good rapport with the participant at beginning of interview and maintained it throughout interview.

Closing

- Interviewer provided educational materials and referrals when appropriate.
- (If applicable) Interviewer clarified any factual errors expressed by the participant during the interview.
- Interviewer reimbursed the participant according to local protocol.

[a]The individual observing the interview may indicate "Yes," "Needs improvement," or "Not done."

SOURCE: CDC, 2012c.

in the original project area completes the MRA to the extent allowed by surveillance authorities (CDC, 2012c).

All project areas collect a minimum dataset for all patients sampled for MMP regardless of level of participation. This dataset consists of demographic information; transmission category (i.e., how the individual acquired HIV); primary source of reimbursement at the time the individual was diagnosed with HIV and/or AIDS; and clinical information, including CD4 count and HIV viral load test results. These data generally are extracted from project areas' HARS or eHARS, but may be collected directly from facilities in cases where they cannot be extracted from these systems (CDC, 2012c). Since the information included in the minimum dataset is consistent with that reported to CDC for national HIV/AIDS surveillance, it may be collected without patient consent under project areas' surveillance authority. MMP obtained a minimum data set for 88 percent of all sampled patients in the 2009 data collection cycle, with a project area completion range of 72 to 100 percent (Personal communication, James Heffelfinger, CDC, June 11, 2012). As is discussed below, CDC recently expanded the linkage of MMP with NHSS by adding additional data elements to the minimum data set to allow prospective monitoring of MMP participants' HIV disease progression and receipt of care (CDC, 2012c).

Funding

As of the writing of this report, CDC had received OMB approval for MMP operations through May 31, 2015. The cost of the project for 2012-2015 is estimated to be about $44.1 million or $14.7 million per year. The majority of funds are to support cooperative agreements with health departments in project areas which, as indicated previously, carry out the MMP data collection activities (CDC, 2012d).

Recent Major Developments in the Medical Monitoring Project

In a report to the committee on the use of MMP data to monitor implementation of the ACA, CDC reported that it is carrying out a demonstration project during the 2012 and 2013 data collection cycles to explore the feasibility of using the NHSS as a participant sampling frame which would expand MMP's population of inference to include individuals with diagnosed HIV who are not in care (CDC, 2012e).[15] In the dem-

[15]Population-based studies conducted in the United States show that 45 to 55 percent of individuals with diagnosed HIV infection fail to receive care in any given year (Gardner et al., 2011; Ikard et al., 2005; Olatosi et al., 2009; Perkins et al., 2008). In addition, several cohort studies have shown that 25 to 45 percent of people with diagnosed HIV are completely lost

onstration project, a subset of MMP project areas will draw a sample of eligible individuals from local HIV surveillance data, assess eligibility and offer enrollment, and conduct the interview and MRA for participants who consent to participate. The capacity of project areas to obtain current contact information and informed consent from individuals sampled from NHSS and, therefore, to achieve adequate response rates will be evaluated. The project will also assess whether oversampling of individuals who are recently diagnosed with HIV can be used to collect information for improving linkage to HIV care and for enhancing HIV prevention interventions (CDC, 2012e). If the pilot study is successful and NHSS-based sampling is implemented, MMP's sampling methodology would be simplified as the need for stage two facility sampling would be reduced or eliminated (CDC, 2012e; Personal communication, Amy Lansky, CDC, March 19, 2012).

As noted previously, project areas extract a minimum data set from HARS or eHARS for each individual in the jurisdiction who is sampled for MMP. Beginning with the 2012 data collection cycle, CDC modified the linkage of MMP data with NHSS by adding 56 new data elements to the minimum data set. This modification was implemented to supplement incomplete data due to delays in reporting to complete the interview and MRA as well as to permit longitudinal monitoring of MMP participants' HIV disease progression and care utilization (CDC, 2012c,e).

Other recent changes relate to data collection. CDC implemented telephone interviews as an alternative to face-to-face interviewing to improve patient response rates and operational efficiency. After a period of pilot testing in select project areas in 2010 and 2011, telephone interviewing is now an option for patients in all project areas. In addition, CDC has made changes to the MRA process to improve the efficiency of data collection while maintaining the ability to collect detailed clinical data. Revisions include simplification of the MRA data collection instruments and possible modification of the existing software application for the collection of MRA data. As noted previously, beginning in 2012 the MRA is limited to information contained in the patient's medical record at the facility from which he or she was sampled, whereas previously the MRA was expected to include medical records from any facility where the patient received care. CDC also noted that the MRA is being streamlined to collect data relevant to (1) clinical indicators linked to prevention that are included in the NHAS and (2) selected quality-of-care measures that have been proposed

to care in many settings, although many of them eventually reenter care (Arici et al., 2002; Coleman et al., 2007; Hill et al., 2010; Mocroft et al., 2008).

by various expert panels and cross-federal-agency efforts[16] in the areas of viral load suppression, prescription of antiretroviral therapy (ART), retention in care, appropriate health screening, prophylaxis against opportunistic infections, and immunizations (CDC, 2012e).

Strengths and Limitations of the Medical Monitoring Project to Generate Nationally Representative Estimates of Health Care Coverage and Utilization

MMP is the only ongoing study that is designed to provide nationally representative estimates of the clinical and behavioral characteristics of HIV-infected individuals. Comparison of MMP participant data from 2007, the most recent year for which published data are available, with national data from NHSS shows similarities across characteristics of sex, age, and race and ethnicity (Table 3-3) (CDC, 2012b,e). However, MMP may be less representative of the general population of people with HIV for other characteristics. For example, while it is estimated that 17 percent of people living with diagnosed HIV in the United States have private health insurance (HHS, 2012b), 37 percent of MMP participants reported having private health insurance or a health maintenance organization (HMO) as a source of health coverage during the past 12 months (Appendix Table 3-1).

MMP provides an annual "snapshot" of the health care experiences of HIV-diagnosed adults that can be used to monitor trends in health care coverage and utilization over time. As is characteristic of survey research, new questions and variables can be developed, piloted, and added to MMP data collection instruments in response to changing information needs. This is a valuable mechanism for researchers and policy makers as questions about HIV care quality and access are likely to emerge in future stages of ACA implementation. MMP data are currently used to monitor several national initiatives such as the NHAS and Healthy People 2020 HIV-related indicators (CDC, 2012e) and could play a similar role to monitor the impact of the ACA on care coverage and utilization of people with HIV.

There are advantages and disadvantages to a cross-sectional study design, as is primarily used in MMP, and a prospective study design, as was used in HCSUS, to study the care experiences of people with HIV. Cross-sectional surveys are useful for providing information about the characteristics of a population at a specific point in time. Such data can be of great value to policy makers and public health administrators for assessing the

[16]Such entities include a National Committee for Quality Assurance-sponsored HIV/AIDS Expert Panel Work Group, the American Medical Association, the Health Resources and Services Administration, the Infectious Disease Society of America, and the HIV Medicine Association (CDC, 2012e).

health status and health care needs of populations, as well as for resource allocation, and is the approach used in population-based health surveys such as the NHIS and NHANES. Cross-sectional studies can be used to generate descriptive statistics (e.g., source of care coverage for various demographic groups) but generally are not useful for making inferences about relationships between exposures and outcomes, although MMP was not designed for this purpose. In contrast, prospective studies follow the same cohort of individuals over a period of time. Because the temporal sequence between exposures and outcomes is more clearly established, prospective studies permit the testing of hypotheses (Hennekens and Buring, 1987).[17] A prospective design could be used to monitor changes in care coverage and utilization in a cohort of people with HIV at various stages of ACA implementation, which may allow for more meaningful inferences about the patterns of these changes. A drawback to prospective studies, however, is that they require substantial investment in participant retention to prevent loss to follow-up of study participants (Hennekens and Buring, 1987; Hunt and White, 1998; Shapiro et al, 1999). In addition, although MMP's cross-sectional design permits the selection of a study population that is reflective of changing trends in the characteristics of people with HIV because a participant sample is drawn each year, a prospective study risks becoming less representative over time unless participant entry and study completion is staggered. In both cross-sectional and prospective studies, differences in the characteristics of participants who respond and who do not respond can bias study results (Hunt and White, 1998; Shapiro et al., 1999). The planned linkage of MMP participant data to NHSS to obtain an expanded minimum data set and to track clinical markers of HIV disease progression and maintenance in medical care will add a prospective element to MMP's design. Although it is still unclear for how long participants will be followed, data from this linkage could potentially be used to monitor trends in care coverage and utilization for the same individuals over time.

MMP in its current design excludes people with HIV who are not in care but who stand to benefit from the ACA through provisions (e.g., Medicaid expansion) that will improve access to health coverage and care. As noted previously, CDC is undertaking a demonstration project to pilot test the use of NHSS as a participant sampling frame. If NHSS-based sampling is implemented, MMP would provide data on access to health coverage and care for individuals who are not actively seeking care and would help

[17]A number of ongoing HIV-related observational cohort studies examine exposures associated with care and treatment among people with HIV. Such studies include various individual U.S. cohorts as well as the North American AIDS Cohort Collaboration on Research and Design (NA-ACCORD), which is a collaboration of a number of HIV-related cohorts in the United States and Canada (McNaghten et al., 2007).

TABLE 3-3 Comparison of National HIV Surveillance System and Medical Monitoring Project Population by Select Characteristics

	National HIV Surveillance Report, 2007 (estimated)[a]		National HIV Surveillance Report, 2009 (estimated)[a]		Medical Monitoring Project, 2007	
Characteristic	No.	%	No.	%	No.	%
Sex						
Male	556,477	75	597,928	75	2,633	72
Female	183,805	25	194,656	25	959	26
Transgender	NA		NA		47	1
Age group (yrs)						
<13	3,799	<1	2,987	<1	NA	
13-14	1,497	<1	1,249	<1	NA	
15-19	6,817	<1	7,155	<1	NA	
18-24	NA		NA		73	2
20-24	21,464	3	26,329	3	NA	
25-29	44,022	6	47,328	6	143	4
30-34	62,951	8	65,161	8	219	6
35-39	103,850	14	93,780	12	481	13
40-44	148,610	20	137,477	17	720	20
45-49	143,314	19	159,418	20	807	22

50-54	102,937	14	120,082	15	589	16
55-59	60,784	8	75,575	9	340	9
60-64	28,720	4	38,067	5	161	4
≥65	22,478	3	29,164	4	110	3
Race						
Black/African American	313,012	42	336,144	42	1,438[b]	40
White	259,665	35	273,883	34	1,272[b]	35
Asian	7,129	<1	8,422	1	19	<1
Native Hawaiian/Pacific Islander	497	<1	620	<1	11	<1
American Indian/Alaska Native	2,826	<1	3,040	<1	19	<1
More than one race	10,941	1	11,213	1	119	3
Unknown (NHSS)/other (MMP)	778	<1	770	<1	61	2
Ethnicity						
Hispanic/Latino	156,396[c]	21	169,679[c]	21	699	19
Total	751,244[d]		803,770[d]		3,643	

[a]Based on data from 46 states and 5 U.S. dependent areas with confidential name-based reporting since at least June 2007.
[b]Non-Hispanic.
[c]Hispanic/Latino of any race.
[d]Because column totals for estimated numbers were calculated independently of the values for the subpopulations, the values in each column may not sum to the column total.
SOURCES: CDC, 2012b,e.

to elucidate the availability and accessibility of HIV care and supportive services to individuals not currently in care (CDC, 2012e).[18] Information about individuals who have a diagnosis of HIV but who are not in care is currently limited (Fagan et al., 2010). A CDC-funded Never in Care (NIC) project used surveillance data to identify individuals with HIV who had never been in care and to describe their demographic characteristics and barriers and facilitators of HIV medical care, among other factors. Individuals identified as never in care were younger and more likely to be African American and Hispanic than those for whom there was evidence of care entry (Fagan et al., 2010). The expansion of MMP to include individuals who are not in care could improve understanding of factors that influence care utilization and the development of interventions to improve access to care for all people with HIV.

MMP also does not currently include adolescents who have unique HIV care and treatment needs. Psychosocial issues, such as coping with a new HIV diagnosis and disclosure to friends and family, and frequently occurring comorbidities of mental illness and substance abuse, can complicate HIV disease management among adolescents. Many adolescents with HIV are recently infected (Catallozzi and Futterman, 2005; CDC, 2011b; Spiegel and Futterman, 2009). For these reasons it is important to monitor adolescents' linkage to and engagement in care. The exclusion of adolescents from MMP leaves a gap in information concerning health care coverage and utilization for people with HIV in this age group. While MMP does include individuals with a history of homelessness or housing instability, it is unclear that there is adequate representation of immigrants, people with mental and substance abuse disorders, and people who flow in and out of the corrections system. These populations are more likely to experience gaps in coverage and care (Altice et al., 2010; Baillargeon et al., 2010; Chen et al., 2011; Dang et al., 2012; Mellins et al., 2009; Springer et al., 2011).

Another limitation of the current MMP design is that the sampling frame is limited to HIV-diagnosed adults who receive care during the PDP of January 1 to April 30 of the given year (CDC, 2012d). If there are systematic differences in the characteristics of patients seen for care during this 4-month period and patients seen for care at other times during the calendar year, the study population may not be fully representative of HIV-diagnosed adults in care. In addition, as was noted about the 2-month PDP used in HCSUS, the 4-month PDP will result in the exclusion of some patients who are infrequent users of care (Shapiro et al., 1999).

[18]For example, MMP's standard questionnaire asks if participants had unmet needs for services (e.g., medicines through the ADAP, dental health care, mental health services, etc.) in the past 12 months and, if so, the reason the participant was not able to get the service (e.g., waiting list too long, transportation problems, lack of insurance) (CDC, 2012f).

The MMP questionnaire may be administered either face-to-face or via telephone by a trained interviewer. Research on mode of questionnaire administration has shown that face-to-face interviews are often less burdensome for respondents because they usually only require that respondents speak the language in which the questions are being asked and have basic verbal and listening skills (Bowling, 2005). Reading skills are not required to the extent required for self-administered questionnaires. In addition, trained interviewers can help to maintain motivation with longer questionnaires, such as the MMP questionnaire, and utilize techniques to aid participant recall of past events and behavior. Although costly in terms of staffing and training requirements, face-to-face interviews often achieve higher response rates than other methods of survey administration (Bowling, 2005; Kelley et al., 2003). Telephone interviews can be more burdensome (e.g., because visual aids cannot be used) and make greater auditory demands on respondents than face-to-face interviews (Bowling, 2005). Nevertheless they are a useful alternative to the face-to-face interview to increase response rates of MMP participants who are unable to complete the interview in person. Self-administered questionnaires are most burdensome because they require that respondents are literate in reading the language of the survey, do not have visual impairments, and have the dexterity to respond to questions (e.g., tick a box on a paper questionnaire, key in responses on a computer-based questionnaire). Respondents may also need the ability to follow routing and skipping instructions on paper questionnaires (Bowling, 2005).

As with all epidemiologic studies based on self-reported data, patients' inability to accurately recall information during the MMP interview has the potential to result in measurement error that can lead to inaccurate inferences from the interview data (Coughlin, 1990). In MMP, clinical information such as laboratory values, history of vaccinations, and other medical information may be particularly difficult for patients to recall (Blair et al., 2011). Inaccurate recall is a threat to the validity of findings based on clinical information captured solely via patient interview. However, an important advantage of the MMP protocol is that the MRA allows for checking of self-reported data against data in the medical record for agreement. Another potential limitation of self-reported data is the possibility for social desirability response bias, where socially undesirable behaviors (such as drug use or certain sexual behaviors) are underreported and socially desirable behaviors (such as condom use) are overreported (Blair et al., 2011; Bowling, 2005; Coughlin, 1990). Interviewer-administered surveys have several advantages over self-administered questionnaires, as noted above. Yet, some research on the reporting of sensitive and stigmatized behavior has shown that surveys that require social interaction with an interviewer, either face-to-face or by telephone, are more susceptible to social desirability bias than self-administered surveys (Bowling, 2005; Butler et al.,

2009; Drapeau et al., 2011; Tourangeau and Smith, 1996; Tourangeau et al., 1997). Currently, MMP study participants do not have the option to self-administer any parts of the interview. In its first report, the committee noted that allowing patients who participate in MMP to directly enter their responses to sensitive questions into a computer or on the questionnaire may be one way to counteract the potential for social desirability bias (IOM, 2012).

MMP collects a minimum set of data consistent with information collected for national HIV/AIDS surveillance on all patients enrolled in MMP regardless of level of participation. In addition to providing a core set of data for the majority of patients sampled, the minimum data set can be used to support quality control (e.g., ensure patients were not sampled for participation more than once). Because the minimum data include information on patient demographics and other characteristics, they also may be used to evaluate potential nonresponse bias for data collected through the interview and MRA (CDC, 2012c).

A significant concern with MMP is its low response rate (IOM, 2012). The facility and patient response rates in 2010 were 80 percent and 56 percent, respectively (Table 3-2). Without an adequate response rate, MMP becomes a convenience sample study of those willing to be interviewed (Groves et al., 2006; Shapiro et al., 1999). In a response to an inquiry from the committee on the most common reasons for nonparticipation in MMP, CDC indicated that direct facility refusals are low. When facilities do refuse to participate, it is most often due to a lack of time or bureaucratic barriers such as the need for IRB review and Veterans Administration regulatory restrictions for VHA facilities. Furthermore, a number of facilities that do agree to participate are subsequently unable to do so because they cannot provide access to sampled patients (e.g., due to IRB approval delays). With respect to patients, CDC stated that many who do not participate cannot be located or do not respond to attempts at contact made by facility or project area staff. Some project areas and facilities prefer, or have IRB mandates that require, facility staff to recruit and enroll patients. Patients may not be recruited when facilities are not persistent enough in their recruiting efforts, such as calling patients at different times and searching for updated contact information (Personal communication, James Heffelfinger, CDC, June 11, 2012). Measures have been implemented to improve patient participation starting with the 2009 data collection cycle. One change was that the time between patient sampling and recruitment was narrowed to expedite location of patients for interview after receipt of care at participating facilities

(Blair et al., 2011).[19] Also, as noted earlier, MMP implemented telephone interviewing as an alternative to the in-person interview in all project areas in 2012.

The study timeline submitted to OMB for approval of MMP through April 2015 notes that project areas have 4 to 5 months to recruit participants and to complete the MRA (CDC, 2012d). Expansion of the window for recruitment and data collection could help to increase both facility and patient participation because facilities would have more time to secure local IRB approval and to work out a site-specific protocol for contacting sampled participants.

A potential protocol change that CDC has considered but not implemented to improve patient response rates is real-time sampling (RTS), a variety of time-space sampling where a random sample of patients with appointments scheduled during the busiest times of day is recruited for participation in MMP. CDC's pilot study demonstrated that the use of RTS in two large facilities had a positive impact on patient response rates, showed potential to reach participants who are hard to reach using traditional recruitment methods, and was less burdensome to the participating facilities, which may in turn increase facility participation. CDC expressed concern that using RTS would place additional burden on MMP staff to manage RTS and provide statistical assistance (Personal communication, James Heffelfinger, CDC, June 11, 2012). However, the methodological gains resulting from a more complete and thus more representative sample may warrant further consideration of using RTS sampling in select facilities. Similar sampling approaches have been used in a number of studies to identify hard-to-reach populations such as individuals who use drugs and young MSM (Choi et al., 2005; Forney et al., 2012; Grov et al., 2009; Lo et al., 2012; Parsons et al., 2008). In describing lessons learned from HCSUS, the study investigators noted that list-based sampling saved on up-front costs because a staff person did not need to be located on site to perform RTS, but that broader use of RTS (which was used in select HCSUS sites) ultimately would have reduced the expense of participant location and recruitment (Shapiro et al., 1999).

CDC reported that MMP activities require substantial staff and financial resources to produce nationally representative estimates but that possible changes to the sampling design as well as recent changes to the data collection, described previously, could help to reduce current resource needs (CDC, 2012d). The HCSUS investigators also reported a large investment to achieve nationally representative estimates from a sample of HIV-

[19]Contacting patients more quickly after receipt of care might increase the likelihood of having up-to-date contact information and, therefore, the location of individuals for recruitment and participation (Blair et al., 2011).

diagnosed individuals in care, but felt that this investment was justified if the data obtained are unbiased and of high quality (Shapiro et al., 1999).

As discussed in Chapter 2, many of the key changes resulting from the ACA—such as expansion of the Medicaid program, phasing out the Medicare Part D prescription drug coverage gap, increased access to private health insurance (e.g., through elimination of preexisting condition exclusions) and consumer protections, and expansion of coverage for preventive health services—are expected to increase the number of people with HIV who have health care coverage and access to benefits and services. Among MMP's strengths to monitor the health experiences of people with HIV in the context of the ACA is that it already collects data on dimensions of HIV care that correspond to key areas of health care reform (CDC, 2012e). For example, MMP data can be used to evaluate the following:

- sources of health care coverage and the distribution of different sources of coverage (e.g., private health insurance, Medicaid, Ryan White HIV/AIDS Program, Tricare or CHAMPUS, VHA coverage) among study participants;
- primary method of payment for prescription medications for HIV and related illnesses;
- access to HIV care and met and unmet need for supportive services (e.g., HIV case management, AIDS Drug Assistance Program [ADAP] services, dental care, mental health services, housing assistance), including for persons with different types of care coverage;
- the quality and comprehensiveness of HIV care, such as receipt of recommended clinical (e.g., use of ART) and preventive (e.g., immunizations, screening examinations) interventions; and
- the organizational context and structure of HIV care, including where care is provided (e.g., community health centers, hospital-affiliated outpatient clinics), who is providing that care (e.g., infectious disease physicians, nurse practitioners), and whether care is occurring in the context of new organizational models intended to improve service coordination (e.g., patient-centered medical homes, accountable care organizations).

MMP also collects detailed demographic information (age, race and ethnicity, country of birth, sex at birth, gender, sexual orientation, education, and income) that can be used to monitor health care coverage and utilization for subpopulations of people with HIV and to identify and address disparities. MMP project area sample sizes allow national estimates at an acceptable level of precision for subpopulations as small as 5 percent of the total population of interest (CDC, 2012c).

Increased access to health insurance and health care under the ACA

will not ensure linkage to, retention in, and the provision of quality care for people with HIV. For some individuals, movement among sources of care coverage may disrupt the continuity of care and the package of benefits available to them at any given time. For this reason, it is important to monitor care quality and outcomes in addition to care coverage and utilization in the context of ACA implementation. In its first report, the committee identifies 14 core indicators to monitor the impact of the NHAS and ACA that are also measures of HIV care quality (see Table 1-4 in Chapter 1); these include 9 indicators for clinical HIV care and 5 indicators for mental health, substance abuse, and supportive services (housing, food, and transportation assistance), which are important mediators of access to care for people with HIV (Anema et al., 2009; Buchanan et al., 2009; IOM, 2012; Kalichman et al., 2011; Sarnquist et al., 2011).[20] MMP captures many of the data elements needed to estimate these indicators. Appendix Table 3-2 maps the committee's core indicators with questions from the MMP questionnaire and MRA forms that might provide the data needed to estimate the indicators. Once laboratory reporting of CD4 and viral load results is implemented in all states, the NHSS may be the most robust source of information to estimate indicators for individuals who are recently diagnosed with HIV, such as the proportion of people who are newly diagnosed who have clinical diagnosis of AIDS.[21] Since MMP's current sampling methodology involves sampling participants from care facilities, it is less likely to select individuals who are recently diagnosed with HIV who do not yet have an HIV care provider. However, MMP's capacity to generate nationally representative estimates for these indicators should be improved if CDC implements NHSS-based sampling. MMP does not currently provide all of the data needed to estimate the committee's recommended indicators for mental health and substance abuse, but it is one of only a few sources of data, along with the Ryan White HIV/AIDS Program, that captures information to estimate indicators of need for housing, food, and transportation assistance (IOM, 2012).

ADDITIONAL DATA SOURCES

Although designed to be nationally representative, MMP does not collect data on individuals with HIV in all U.S. states and territories. Data from Medicaid and the Ryan White HIV/AIDS Program, because they are captured for all states and territories, can serve as useful sources of state-

[20]The committee also identified additional (noncore) indicators that could be used for more comprehensive assessment of HIV care quality (IOM, 2012).

[21]Currently, there is some variation among states in the specific values of CD4 and HIV viral load that are required to be reported.

level information on care coverage and utilization to supplement findings from MMP. Medicaid and the Ryan White HIV/AIDS Program, along with Medicare, are also currently the most common sources of care coverage for people with HIV (HHS, 2011, 2012b). Although not generalizable to all HIV-infected individuals in the United States, analysis of data from these specific programs, in addition to data from MMP, is essential to highlight how ACA provisions that affect program eligibility and coverage of services impact the care experiences of people with HIV. Provisions of the ACA will not be implemented by states uniformly, resulting in variation among states in eligibility for health coverage and, consequently, access to health care (IOM, 2012). State-by-state monitoring of the care experiences of people with HIV will be important for this reason.

Medicaid Program Data

The Medicaid program is currently the largest single source of care coverage for people with HIV in the United States. Forty-seven percent of people with HIV in regular care in FY 2007 were enrolled in Medicaid (Kates, 2011). The ACA expands the Medicaid program to include non-Medicare eligible individuals under age 65 with incomes up to 133 percent of the federal poverty level (FPL) (a standard 5 percent income disregard effectively increases the income limit to 138 percent of the FPL). The ACA also calls for the removal of categorical eligibility requirements, such as being disabled.[22] This means that people with HIV will no longer be required to have a diagnosis of AIDS or other disability to qualify for Medicaid. Disability is currently the most common pathway to Medicaid for those with HIV, with about three in four such individuals qualifying on the basis of being disabled (Kates, 2011). Medicaid expansion is expected to considerably reduce the number of people who are uninsured in the United States. However, in June 2012 the U.S. Supreme Court ruled that the federal government cannot penalize states that choose to opt out of Medicaid expansion by withholding state Medicaid funding (*National Federation of Independent Business v. Sebelius,* 567 U.S. ____ [2012]). Because many states are not likely to comply with Medicaid expansion in the wake of the Supreme Court's ruling, the impact of this provision may not be as significant as earlier anticipated (Daily Briefing, 2012).

Analysis of data from the Medicaid program is essential to monitoring access to health coverage and utilization for people with HIV because of the large proportion of people with HIV who are currently enrolled in

[22]Prior to the passage of the ACA, in addition to meeting income eligibility requirements, individuals were required to be "categorically eligible" for Medicaid. Categorical eligibility groups include the disabled; parents, children, and pregnant women; the elderly; and other groups.

the program and the anticipated increase in program enrollment starting in 2014. The nature of Medicaid as a source of care coverage for low-income individuals makes it a useful source of data for tracking the care experiences of people with HIV who are economically disadvantaged and who are more likely to have multiple care and supportive service needs. In addition, Medicaid data will encompass the care experiences of a greater number of HIV-infected individuals from racial and ethnic minority groups since racial and ethnic minorities disproportionately rely on the program as a source of health coverage. States administer the Medicaid program under broad federal guidelines and have some independence in determining income and other eligibility requirements. Program data are reported by states to the Centers for Medicare & Medicaid Services (CMS) and can be used for both state specific and inter-state analyses of Medicaid enrollment and care utilization.

As discussed in the committee's first report, the Medicaid Statistical Information System (MSIS) is the primary source of Medicaid data. MSIS is a claims processing system that captures utilization and management information on medical care and services provided to Medicaid beneficiaries. MSIS is populated with data reported by states on a quarterly basis, including eligibility and demographic characteristics of each person enrolled in Medicaid, and claims adjudicated for drugs, long-term care services, inpatient stays, and other services during the quarter (CMS, 2012b,c). MSIS data are also available through the Chronic Condition Data Warehouse (CCW), created by CMS, to approved researchers and certain government agencies through the Research Data Assistance Center (ResDAC, a CMS contractor). These files are called "Medicaid Analytic eXtract" (MAX) files and are formatted in a way to facilitate research and public policy needs. MAX files include a person summary file with enrollment information, as well as inpatient hospital, long-term care, prescription drug, and other services files (ResDAC, 2012). Both MSIS and MAX files provide data that could be used to monitor the impact of the ACA on health care coverage and utilization for people with HIV. Comparison of Medicaid enrollment data pre- and post-2014, and beyond 2014, could be used to track how many additional people with HIV gain access to this source of health coverage over time. Analysis of Medicaid data also could be used to track beneficiary receipt of preventive and care services, including benefits outlined in a package of essential health benefits that states will be required to provide most newly eligible Medicaid beneficiaries starting in 2014 (KFF, 2010).[23]

[23]These benefits include ambulatory patient services; emergency services; hospitalization; maternity and newborn care; mental health and substance use disorder services, including behavioral health treatment; prescription drugs; rehabilitative and habilitative services and devices; laboratory services; preventive and wellness services and chronic disease manage-

In addition to the strengths of Medicaid data for monitoring the care experiences of people with HIV noted above, MSIS data should have lower occurrence of reporting inaccuracies than patient-reported information since data come from claims submitted by providers (although providers may inaccurately report data due to coding and other errors). MSIS uses unique identifiers to link information across time for individuals, permitting longitudinal evaluation of their care experiences. Data are collected quarterly (moving to monthly within 2 years), which allows for regular updating of the data (IOM, 2012).

There are a few limitations to MSIS data. Many people with HIV who are enrolled in Medicaid should be identifiable by diagnostic code for HIV/AIDS. However, the diagnostic code may not be recorded for some individuals (e.g., because they were diagnosed with HIV before they enrolled in Medicaid and the new provider failed to enter the diagnosis). Use of a combination of codes for diagnoses, procedures (e.g., CD4 counts, viral load tests), and prescription drugs (e.g., antiretrovirals used to treat HIV) may be the best way to identify Medicaid beneficiaries with HIV with the greatest positive predictive value (Crystal et al., 2007; IOM, 2012; Koroukian et al., 2003). Another challenge is fluctuating eligibility requirements for Medicaid, which cause people to shift in and out of coverage so that any medical care they receive during the period they are not enrolled in Medicaid will not be recorded in MSIS. In addition, some services that Medicaid beneficiaries receive may not be recorded in the claim record (for example, if the service was carved out to another provider) and, therefore, not available in MSIS.

As noted previously, the data contained in MSIS are reported by states to CMS. It can take states a year or more to complete their reporting resulting in an approximately 2-year lag time for MSIS files to be created. The lag time is longer (2.5-3 years) for MAX data files because the raw MSIS data must be extracted and consolidated. A built-in lag time of at least 13 to 14 months is required to ensure that claims for most services delivered in a given calendar year are captured, and another 9 to 10 months is needed to validate the data (ResDAC, 2006). This delay should not preclude the use of Medicaid data for monitoring access to health insurance and health care for people with HIV. Data that are currently available could be used to establish a baseline of the number of Medicaid beneficiaries with HIV and their receipt of preventive and other services of interest (Kates, 2011); data available after 2014 (starting in 2016, given the approximately 2-year lag time) could be used for longitudinal monitoring.

Care for most Medicaid beneficiaries is provided through managed

ment; and pediatric services, including oral and vision care (Affordable Care Act of 2010, Sec. 1302[b]).

care arrangements where states contract with managed care organizations to provide Medicaid services. Under this model, providers are paid a capitated (i.e., fixed) rate per enrolled Medicaid beneficiary. Similar to Medicaid claims for services provided on a fee-for-service basis, encounter data serve as the primary record of services provided to program beneficiaries enrolled in capitated managed care (HHS, 2009). Although many states with Medicaid managed care have collected, used, and reported encounter data for a number of years, CMS has not enforced the reporting of encounter data as it has for fee-for-service claims data (Byrd and Verdier, 2011). Studies have shown that encounter data are not always reported as required or that reporting may be delayed, limiting the usefulness of MSIS (and MAX) data for research and policy analysis (HHS, 2009; Klein, 2002). Missing Medicaid encounter information may further limit the usefulness of MSIS data going forward to the extent that states rely on managed care for Medicaid expansion.

With respect to indicators to measure care quality, MSIS might provide data to estimate the indicators recommended in the committee's first report for continuity of care (two or more visits for routine HIV medical care in the preceding 12 months at least 3 months apart) and regular CD4 and viral load testing (two or more tests in the preceding 12 months). These data would be available from claims for office visits submitted by providers with HIV listed as one of the diagnostic codes and claims submitted for CD4 and viral load tests. All claims capture dates of service to determine when beneficiaries received a service. Medicaid claims do not record the results of CD4 and viral load tests and thus cannot be used to calculate indicators of clinical HIV care that require such measures, such as the proportion of people with HIV with a CD4+ cell count <500 cell/mm^3 who are not on ART (IOM, 2012). MSIS captures date of death and could provide data to calculate the mortality rate of individuals with HIV enrolled in Medicaid. MSIS includes data on screening and visits for mental health and substance abuse services covered by Medicaid, but it does not specifically capture the dates of diagnosis or referral and first visit for services to assess the mental health and substance abuse indicators. MSIS also does not collect data on the housing, food, and transportation needs of beneficiaries to estimate indicators of these supportive services. The demographic data collected would permit estimation of indicators for racial and ethnic subpopulations and by sex, age, and location of residence (IOM, 2012).

Medicare Program Data

Medicare is a public health insurance program for individuals age 65 or older, people under age 65 with certain disabilities, and people of all

ages with end-stage renal disease.[24] Approximately one in five individuals with HIV is a beneficiary of the program. The majority of people with HIV who are enrolled in Medicare are under age 65 and qualify on the basis of disability. A small share qualify as seniors. The number of people with HIV who are enrolled in Medicare has grown over time. This growth is likely to continue as a result of advances in treatment that allow people with HIV to live longer lives (KFF, 2009).

The ACA eliminated Medicare Part B (Medical Insurance) coinsurance and deductibles for recommended preventive services beginning in January 2011 (HHS, 2012d). Covered preventive services include screenings for conditions that frequently co-occur with HIV, such as diabetes, sexually transmitted infections, and depression, as well as immunizations for seasonal influenza, hepatitis B, and pneumonia.[25] Medicare also now pays for an annual wellness visit that focuses on helping enrollees establish and maintain a personalized prevention plan (CMS, 2012d). Also relevant to people with HIV who are enrolled in Medicare is the closure of the Medicare Part D prescription drug coverage gap (IOM, 2012). Continuous access to prescription medications is a vital component of HIV care. For example, people with HIV who are on and adherent to ART are more likely to achieve and maintain viral suppression and thus have improved health outcomes. They are also less likely to transmit the virus to others (Cohen et al., 2011; Granich et al., 2009). Prior to the passage of the ACA, individuals enrolled in Medicare Part D were required to pay out-of-pocket for the full cost of prescription drugs while in a coverage gap spanning the time between when enrollees and their drug plans had spent a certain amount for covered medications and the initiation of catastrophic coverage.[26] The ACA has begun phasing down this coverage gap so that, by 2020, beneficiaries will be responsible for 25 percent of the costs for brand name and generic drugs while in the coverage gap (CMS, 2012a). This change makes drugs more affordable for people with HIV who have Medicare Part D prescription drug coverage. Prior to the ACA, many individuals with HIV had expenditures within the coverage gap unless they were receiving low-income subsidies (KFF, 2006). As of January 2011, ADAP benefits are considered contributions to out-of-pocket spending for Medicare beneficiaries. This will help low-income Medicare beneficiaries with HIV move through the

[24]HIV disease and some HIV treatments are associated with renal complications. Some individuals with HIV may qualify for Medicare because they have end stage renal disease (KFF, 2009).

[25]Some preventive services are available to beneficiaries who meet age, risk factor, or other eligibility requirements, while others are available to all Medicare enrollees; see CMS, 2012e.

[26]In FY 2012, the Part D prescription drug coverage gap began at $2,930 and catastrophic coverage began after an individual paid $4,700 in out-of-pocket expenses for prescription medications (CMS, 2012a).

Part D coverage gap and into catastrophic coverage more quickly (HHS, 2011; KFF, 2012a).

Medicare data are available in a format to support research through the CCW. CCW contains enrollment and fee-for-service claims data for all Medicare beneficiaries. Fee-for-service claims include data on outpatient care, preventive services, and a variety of other services that could be used to assess the care experiences of beneficiaries with HIV. As of June 2008, CCW makes Part D prescription drug enrollment and utilization data available to researchers for approved studies (Schneider et al., 2010). Prescription drug events are available for all filled prescriptions that are covered by the Part D benefit. Researchers may choose to have event characteristics, such as drug name (brand or generic), appended to the prescription drug event file (Schneider et al., 2010). These data may be useful for monitoring dispensing of ART or other prescription drugs to people with HIV enrolled in Part D as the prescription drug coverage gap is phased down. Basic demographic data captured should allow for analysis of program data by age, sex, race and ethnicity, and Medicare status (i.e., whether an individual qualified for Medicare based on age or disability).

Weaknesses of Medicare data are similar to those of Medicaid. For example, it may be difficult to extract data for all enrollees with HIV. One recent study evaluated the effectiveness of algorithms to identify data from the CCW for individuals who were diagnosed with chronic conditions prior to enrolling in Medicare. The CCW algorithm identified about 70 percent of individuals with preexisting diabetes, but just 17 percent of individuals with preexisting arthritis. The study authors speculated that conditions needing less frequent health care utilization (e.g., because they are not identified by the Medicare provider) may be underestimated (Gorina and Kramarow, 2011). As a condition that requires continuous treatment and regular visits with providers, HIV may be less susceptible to problems of data extraction than other conditions. As with Medicaid data, there is a delay of a couple of years for Medicare data to be made available through the CCW. Medicare is funded in part by payroll taxes paid by most employees. To qualify for Medicare on the basis of age, individuals or their spouses must have 10 or more years of Medicare-covered employment. Thus, program data will not include information for people with HIV age 65 or older who do not meet this eligibility requirement, unless they qualify based on disability.

Medicare is similar to Medicaid in terms of data collected to estimate indicators of care quality. Since Medicare claims capture dates of services, program data can inform indicators related to continuity of care and regular CD4 and viral load testing. Medicare does not collect data to estimate clinical HIV care indicators requiring specific CD4 or viral load values. Program data can be used to measure the mortality rate of people with HIV who are Medicare beneficiaries. Medicare does not have data on

screening for mental health disorders or substance use, but it does capture service utilization information on diagnosis of and covered treatment for these conditions. The data generally do not allow for calculation of the time between referral and receipt of mental health and substance abuse services, although an approximation might be made if the first visit is covered by Medicare. As with Medicaid, Medicare does not collect data on housing, food, or transportation to estimate indicators for these supportive services (IOM, 2012).

Ryan White HIV/AIDS Program Data

The Ryan White HIV/AIDS Program is the largest federal program designed specifically to serve the health care needs of people with HIV. Administered by the Health Resources and Services Administration (HRSA), the Ryan White HIV/AIDS Program provides medical and supportive services to more than 550,000 people each year.[27] The program often serves as a wrap around program to pay for medications and supportive services (e.g., case management, housing services, psychosocial support services) that are not paid for through other sources of health care coverage. The program has been reauthorized every 3 to 5 years since it was established in 1990 (Ryan White Care Act, P.L. 101-381), with the next reauthorization scheduled for 2013. Ryan White HIV/AIDS Program funding is provided to cities, states and territories, providers, and other organizations. Given variations in the nature of the HIV epidemic and service needs across geographic areas and providers, program grantees are given discretion to determine client eligibility and service priorities (HRSA, 2012a; KFF, 2011b).

As noted in the committee's first report, the Ryan White HIV/AIDS Program model of care helps to overcome barriers to care posed by the fragmented health care system in the United States, because clinical and supportive services are coordinated within a single "medical home" (IOM, 2012). The expansion of the Medicaid program, changes in access to private health insurance, and other ACA provisions are expected to reduce

[27]In order to most effectively execute the services necessary, the Ryan White HIV/AIDS Program developed five "Parts," each of which is designed to help accommodate the needs of people living with HIV in the United States: Part A provides emergency assistance to Eligible Metropolitan Areas and Transitional Grant Areas that are most severely affected by the HIV epidemic; Part B provides grants to all 50 states, the District of Columbia, Puerto Rico, Guam, the U.S. Virgin Islands, and 5 U.S. Pacific Territories or Associated Jurisdictions; Part C provides comprehensive primary health care in an outpatient setting for people living with HIV; Part D provides family-centered care involving outpatient or ambulatory care for women, infants, children, and youth with HIV; Part F provides funding for a variety of programs, including the Special Projects of National Significance Program, the AIDS Education and Training Centers Program, the Dental Programs, and the Minority AIDS Initiative (HRSA, 2012a).

the number of people with HIV who are uninsured and, therefore, who require medical services through the Ryan White HIV/AIDS Program (HHS, 2012c). Although the long-term impact of health care reform on the Ryan White HIV/AIDS Program remains to be seen, the program will likely continue to play an important role in filling gaps in care. Many individuals, such as legal and undocumented immigrants, will remain uninsured even after the ACA is fully implemented (Buettgens and Hall, 2011). In addition, for people with HIV who are currently enrolled in or who transition to other sources of care coverage, the Ryan White HIV/AIDS Program may serve as a source of medical and supportive services not covered by public and private insurance (HHS, 2012c). The program may also have new roles in assisting clients with health insurance premiums, deductibles, copays, and other out-of-pocket costs (Cross, 2011; Martin and Schackman, 2012).

Ryan White HIV/AIDS Program data may be useful for evaluating the ACA. For example, program data may provide insights into shifts in enrollment into other sources of health care coverage. Data can also be used to assess changes in utilization patterns for specific services in order to measure care quality in the context of the ACA. Program data can provide information on an important at-risk and underserved population, as most of clients have incomes at or below the FPL. In addition, the majority of Ryan White HIV/AIDS Program clients are racial and ethnic minorities (HRSA, 2010).

One source of Ryan White HIV/AIDS Program data is the *Ryan White HIV/AIDS Program Services Report* (RSR). This report is submitted to HRSA by program grantees and service providers on an annual basis to report information on their programs and the clients they serve (HRSA, 2012d). The RSR collects a number of data elements relevant to monitoring the impact of the ACA on the Ryan White HIV/AIDS Program as well as care for people with HIV who are enrolled in the program. Such information includes provider organization information; types of services delivered by the agency during the reporting period (e.g., core medical and supportive services,[28] HIV counseling and testing); and client-level data,

[28] *Core medical services* include outpatient/ambulatory medical care; local AIDS pharmaceutical assistance (not ADAP); oral health care; early intervention services; health insurance premium and cost sharing assistance; home health care; home and community-based health services; hospice services; mental health services; medical nutrition therapy; medical case management, including treatment adherence; and substance abuse services (outpatient). *Support services* include non-medical case management; child care; pediatric development assessment/early intervention services; emergency financial assistance; food bank/home-delivered meals; health education/risk reduction; housing services; legal services; linguistic services; medical transportation; outreach services; permanency planning; psychosocial support services; referrals; rehabilitation services; respite care; substance abuse services (residential); and treatment adherence counseling.

including demographic information, number of visits for core medical services for each quarter in the reporting period, and supportive services received for each quarter in the reporting period. Client-level demographic information includes sources of health insurance allowing for analysis of types of Ryan White HIV/AIDS Program services that continue to be utilized by individuals with other types of health coverage (HRSA, 2012d). Outpatient and ambulatory care providers report clinical information, such as laboratory test results, prescription of ART, and receipt of preventive screenings and immunizations. These data can be used to assess care quality for program clients. For example, clinical data captured in the RSR permit the calculation of indicators recommended by the committee for continuity of HIV care, regular CD4 and viral load testing, and ART initiation. The RSR collects client housing status as well as receipt of housing, food, and transportation assistance, making it one of the few sources of data available, along with MMP, to estimate need for these supportive services. The demographic data collected permit analyses of data by race and ethnicity, sex, age, gender identity, sexual orientation, and location of residence (HRSA, 2012d; IOM, 2012).

The ADAP is a component of the Ryan White HIV/AIDS Program that provides HIV-related prescription drugs to low-income people with HIV who have limited or no prescription drug coverage. ADAPs are a major source of prescription drug coverage for people with HIV; they provided services to about one-third of people with HIV in care in 2010 (KFF, 2012a). With the passage of the ACA, ADAPs are legislatively required to report drug assistance provided to clients with Medicare Part D prescription drug coverage. Consequently, ADAP data can be used to monitor the extent to which ADAP funds are used to fund out-of-pocket expenses for ADAP clients receiving Medicare Part D benefits who fall into the drug coverage gap. Other data reported by ADAPs that may be useful for monitoring prescription drug access under the ACA are enrollment information, demographic characteristics of clients served, and limits applied to the program (e.g., enrollment caps, waiting lists) (HRSA, 2012b). Data are currently reported in aggregate on a quarterly basis. Beginning in 2013, ADAPs will report client-level information on a semiannual basis. Information collected will be expanded to include additional information relevant to evaluate the role of ADAPs under ACA such as client sources of health insurance, reasons for disenrollment from ADAP, and more detailed payment information. The new report will also collect CD4 and viral load test dates and results which can be used to assess indicators of care quality for ADAP enrollees (HRSA, 2012c; IOM, 2012).

In June 2012, the HHS Office of the Assistant Secretary for Planning and Evaluation submitted a request for OMB approval of a Ryan White HIV/AIDS Program Modeling Study to understand changes in Ryan White

HIV/AIDS Program services utilization and funding needs under the ACA. To supplement the analysis of quantitative data from the Ryan White HIV/AIDS Program, Medicaid, and NHSS, the study would involve the collection of interview data from program grant managers, administrators, and providers. The interviews would assess HIV service needs and use; Ryan White HIV/AIDS Program funding prioritization and allocation processes; factors that influence regional variation in HIV care costs and Ryan White HIV/AIDS Program funding needs; third-party payment policies and reimbursement for HIV services; and methods of ensuring quality care under the ACA (HHS, 2012c). Findings from the study might be an additional source of information to evaluate the continuing role of the Ryan White HIV/AIDS Program.

Private Health Insurer Data

Approximately 17 percent of individuals with HIV have private health insurance (HHS, 2012b). It is likely that many more individuals with HIV will gain access to private insurance under the ACA. In 2014, a guaranteed availability of insurance provision ensures the issuance and renewability of health insurance regardless of health status and without increased premiums for individuals with preexisting conditions, such as HIV. Currently, temporary preexisting insurance plans with subsidized premiums are available to adults with preexisting conditions who have been uninsured for at least 6 months. In addition, low- to middle-income individuals with HIV will have improved access to private insurance through health insurance exchanges, slated to be in place in states by 2014,[29] that will serve as points of access to commercial health insurance for individuals and employers.[30] Health plans offered under the exchanges will be required to cover services in the essential benefits package for newly eligible individuals.

Monitoring the enrollment of individuals with HIV in private health

[29]The ACA sets broad parameters for the exchanges. However, states are given flexibility on a number of aspects of the exchanges, such as governance structure and administration; key functions and responsibilities; whether to establish their own exchange or rely on the federal government to do so; and how the exchange will interact with the state's Medicaid program (Carey, 2010). Fifteen states and the District of Columbia had established health insurance exchanges as of August 1, 2012. A few states have chosen to allow the federal government to set up their exchanges. Other states have slowed or halted their exchange preparations due to legal challenges to the ACA and uncertainty about the fate of the exchanges. This means that fewer states may meet the timeline for implementation and will default to a federal or federal–state partnership exchange (KFF, 2012b).

[30]The Kaiser Family Foundation projects that the 2019 exchange population would be somewhat older, less educated, lower income, and more racially diverse than current privately insured populations. In addition, most individuals in this population will have transitioned from being previously uninsured (KFF, 2011a).

insurance plans and their receipt of relevant health care services would provide a fuller picture of the impact of the ACA on health care coverage and utilization for this population. MMP, which tracks private health insurance as a source of health care coverage for study participants, is one source of these data. Although they are proprietary, private health insurer enrollment and claims data could be used for larger-scale analyses. One source of such data is the Ingenix Normative Health Information Database® (NHID). NHID contains de-identified Health Insurance Portability and Accountability Act-compliant claims data from commercial health insurers, self-funded employer group plans, and Medicare Advantage plans. The commercial health insurer data consist of transaction-level claims data for more than 14 million covered lives annually from all 50 states and the District of Columbia. Of all individuals in the database at any time during 1994-2010, 67,929 had a diagnosis of HIV/AIDS. NHID includes claims-level information in the following categories that may be relevant to monitoring care for people with HIV under the ACA: care provided in physician offices or other outpatient ambulatory care settings such as urgent care or Minute-Clinics inpatient hospital stays; care provided at ambulatory centers, hospital clinics, and emergency rooms; self-administered prescription drugs; laboratory, imaging and diagnostic services; and goods or services related to specific episodes of care, such as reimbursed transportation (Dore, 2011).

CHALLENGES OF COMBINING DATA FROM DIFFERENT SOURCES

As discussed in detail in the committee's first report, combining data from multiple data systems presents a range of analytic and logistical challenges. One challenge is the lack of interoperability among health information technology (IT) systems. Interoperability—the ability of different IT systems and software applications to communicate, exchange, and use information—is not fully possible in the United States at this time due to a lack of infrastructure to support it. For the most part, the various sources of health coverage and care for people with HIV have their own health IT systems with disparate architectures and vocabularies, posing a challenge to the exchange of data across systems (IOM, 2012).

A second challenge is the multiplicity of federal and state privacy laws designed to protect patient health information. The privacy and security of health information is particularly important to people with HIV and their providers. HIV continues to be a stigmatized disease (Sengupta et al., 2011). Besides HIV status, other patient information contained in health IT systems (e.g., information on drug use, sexually transmitted diseases, etc.) may be considered sensitive information and, if released, could potentially be used to discriminate against an individual. The current lack of an

infrastructure to support the secure exchange of health information across health IT systems (e.g., electronic health records) and organizations heightens privacy and security concerns because the accessibility of information may increase the potential for access and misuse by authorized and unauthorized users. Concern for patient privacy has led to numerous federal laws and state statutes and regulations on the proper use and disclosure of patient information with which care providers and data collection systems must contend. Although important to patient privacy, the often inconsistent nature of these protections, which leave the decision of whether or not to disclose requested patient information open to various interpretations, may result in discrepancies in data sharing and reporting across states and providers. Such discrepancies may influence the availability and quality of data needed to monitor trends in health care coverage and utilization.

A third challenge to combining data from multiple data systems relates to differences in the way that the systems operationalize data elements or define concepts to allow them to be measured. In addition, linkage between sources at the individual subject level may be uncertain or impossible, and even when linkages with high levels of certainty are possible, all of the relevant information may not be available on all subjects. Furthermore the level of precision of information may not be equal across studies and optimal estimation may have to take this into account as well (IOM, 2012).

Despite significant challenges such as these, advances are being made in the linkage and analysis of data from multiple disparate data systems. A number of large data linkage initiatives are under way, including linkages between the MSIS and the Current Population Survey; MSIS and NHIS; MSIS and the MEPS; survey data from the National Center for Health Statistics (NCHS) and death certificate records from the National Death Index; and survey data from NCHS and claims data from CMS (O'Grady and Mahmud, 2011).

On a smaller scale, the Louisiana Public Health Information Exchange (LaPHIE), described in the committee's first report (IOM, 2012, Chapter 5), overcame technical and privacy barriers to implement electronic exchange of electronic medial record data and surveillance data between the Louisiana State University Health Care Services Division and the Louisiana Office of Public Health in order to identify people with HIV who have not been linked to or have fallen out of care (Herwehe et al., 2012). On a more general level, the Indiana Network for Patient Care has established the feasibility of linking records across different systems by successfully linking data from hospitals, public health departments, and state Medicaid programs (McDonald et al., 2005).

Ongoing research to develop "new" methodologies to address the statistical challenges of combining data sets, as well as financial and policy support, will be needed to ensure the sustainability of current linkage initia-

tives and to facilitate the development of new ones. Cross-agency efforts by the federal statistical agencies to examine potential linkage opportunities might accelerate developments in this area.

An alternative to combining data sets quantitatively for statistical analysis is the qualitative synthesis of data found in "public health triangulation," "an iterative process in which key questions and hypotheses that potentially explain them are formulated, examined and reexamined as additional data become available" (Rutherford et al., 2010, p. 4). Such a process may permit the synthesis and interpretation of HIV-related data from disparate sources (e.g., surveillance, programs, research studies) for use in public health decision making, especially in the absence of or as a supplement to traditional intervention research and metaanalysis (Rutherford et al., 2010).

REFERENCES

Altice, F. L., A. Kamarulzaman, V. V. Soriano, M. Schechter, and G. H. Friedland. 2010. Treatment of medical, psychiatric, and substance-use comorbidities in people infected with HIV who use drugs. *Lancet* 37:6367-6387.

Anema, A., N. Vogenthaler, E. A. Frongillo, S. Kadiyala, and S. D. Weiser. 2009. Food insecurity and HIV/AIDS: Current knowledge, gaps, and research priorities. *Current HIV/AIDS Report* 6(4):224-231.

Arici, C., D. Ripamonti, F. Maggiolo, M. Rizzi, M. G. Finazzi, P. Pezzotti, and F. Sutter. 2002. Factors associated with the failure of HIV-positive persons to return for scheduled medical visits. *HIV Clinical Trials* 3(1):52-57.

Baillargeon, J. G., T. P. Giordano, A. J. Harzke, G. Baillargeon, J. D. Rich, and D. P. Paar. 2010. Enrollment in outpatient care among newly released prison inmates with HIV infection. *Public Health Reports* 125(Suppl 1):64-71.

Blair, J. M., A. D. McNaghten, E. L. Frazier, J. Skarbinski, P. Huang, and J. D. Heffelfinger. 2011. Clinical and behavioral characteristics of adults receiving medical care for HIV infection—Medical Monitoring Project, United States, 2007. *MMWR Surveillance Summaries* 60(11):1-20.

Bowling, A. 2005. Mode of questionnaire administration can have serious effects on data quality. *Journal of Public Health* 27(3):281-291.

Bozzette, S. A., S. H. Berry, N. Duan, M. R. Grankel, A. A. Leibowitz, D. Lefkowitz, C. A. Emmons, J. W. Senterfitt, M. L. Berk, S. C. Morton, and M. F. Shapiro. 1998. The care of HIV-infected adults in the United States: HIV Cost and Services Utilization Study Consortium. *New England Journal of Medicine* 339(26):1897-1904.

Buchanan, D., R. Kee, L.S. Sadowski, and D. Garcia. 2009. The health impact of supportive housing for HIV-positive homeless patients: A randomized controlled trial. *American Journal of Public Health* 99(Suppl 3):S675-S680.

Buettgens, M., and M. Hall. 2011. *Who Will be Insured After Health Insurance Reform?* http://www.rwjf.org/files/research/71998.pdf (accessed August 6, 2012).

Butler, S. F., A. Villapiano, and A. Malinow. 2009. The effect of computer-mediated administration on self-disclosure of problems on the addiction severity index. *Journal of Addiction Medicine* 3(4):194-203.

Byrd, V. L. H., and J. Verdier. 2011. *Collecting, Using, and Reporting Medicaid Encounter Data: A Primer for States*. http://www.cms.gov/Research-Statistics-Data-and-Systems/Computer-Data-and-Systems/MedicaidDataSourcesGenInfo/Downloads/MAX_PDQ_Task_X_EncounterDataPrimerforStates.pdf (accessed August 20, 2012).

Carey, R. 2010. *Health Insurance Exchanges: Key Issues for State Implementation*. http://www.rwjf.org/files/research/70388.pdf (accessed July 12, 2012).

Catallozzi, M, and D. C. Futterman, 2005. HIV in adolescents. *Current Infectious Disease Reports* 7:401-405.

CDC (Centers for Disease Control and Prevention). 2009a. *DHAP News*. http://www.cdc.gov/hiv/resources/newsletter/dhap_news/102009/index.htm#link11 (accessed September 11, 2012).

CDC. 2009b. *Q and A for Consumers*. http://www.cdc.gov/hiv/topics/treatment/mmp/resources/patient.htm (accessed September 11, 2012).

CDC. 2009c. *Q and A for Professional Partners*. http://www.cdc.gov/hiv/topics/treatment/mmp/resources/provider.htm#pab (accessed September 11, 2012).

CDC. 2010a. *Clinical and Behavioral Characteristics of Adults Receiving Medical Care for HIV Infection: Medical Monitoring Project, 2005 Pilot Data Collection Cycle*. HIV Special Surveillance Report 6. http://www.cdc.gov/hiv/topics/surveillance/resources/reports/pdf/MMP_2005_Report_6.pdf (accessed September 11, 2012).

CDC. 2010b. *Medical Monitoring Project*. http://www.cdc.gov/hiv/topics/treatment/mmp/index.htm (accessed September 11, 2012).

CDC. 2010c. *Medical Monitoring Project 2011 protocol*.

CDC. 2010d. *National Health Interview Survey. The Principal Source of Information on the Health of the U.S. Population*. http://www.cdc.gov/nchs/data/nhis/brochure2010January.pdf (accessed August 30, 2012).

CDC. 2011a. *About the National Health and Nutrition Examination Survey*. http://www.cdc.gov/nchs/nhanes/about_nhanes.htm (accessed August 30, 2012).

CDC. 2011b. *HIV among Youth*. http://www.cdc.gov/hiv/youth/pdf/youth.pdf (accessed August 31, 2012).

CDC. 2011c. *HIV Infection Reporting*. http://www.cdc.gov/hiv/topics/surveillance/reporting.htm (accessed September 11, 2012).

CDC. 2011d. *NHANES Response Rates and CPS Totals*. http://www.cdc.gov/nchs/nhanes/response_rates_cps.htm (accessed August 26, 2012).

CDC. 2012a. *About the National Health Interview Survey*. http://www.cdc.gov/nchs/nhis/about_nhis.htm/ (accessed August 26, 2012).

CDC. 2012b. *HIV Surveillance Report. Diagnoses of HIV Infection and AIDS in the United States and Dependent Areas, 2010*. Volume 22.

CDC. 2012c. *Medical Monitoring Project 2012 protocol*.

CDC. 2012d. *Medical Monitoring Project. Supporting Statement Part A*. http://www.reginfo.gov/public/do/PRAViewDocument?ref_nbr=201203-0920-011 (accessed September 18, 2012).

CDC. 2012e. *Report on the Use of Centers for Disease Control and Prevention's Medical Monitoring Project to Monitor the Implementation of the Affordable Care Act*. Submission to committee. January.

CDC. 2012f. *Standard Questionnaire for Medical Monitoring Project, 2012*.

Chen, N. E., J. P. Meyer, A. K. Avery, J. Draine, T. P. Flannigan, T. Lincoln, A. C. Spaulding, S. A. Springer, and F. L. Altice. 2011. Adherence to HIV treatment and care among previously homeless jail detainees. *AIDS and Behavior* (November 8). DOI 10.1007/s10461-011-0080-2.

Choi, K. H., W. McFarland, T. B. Neilands, S. Nguyen, G. Secura, S. Behel, D. Mackellar, and L. Valleroy. 2005. High level of hepatitis B infection and ongoing risk among Asian/Pacific Islander men who have sex with men, San Francisco, 2000-2001. *Sexually Transmitted Diseases* 32(1):44-48.

CMS (Centers for Medicare & Medicaid Services). 2012a. *Closing the Coverage Gap*. http://www.medicare.gov/publications/pubs/pdf/11493.pdf (accessed September 11, 2012).

CMS. 2012b. *Medicaid Statistical Information System*. http://www.cms.gov/Research-Statistics-Data-and-Systems/Computer-Data-and-Systems/MSIS/index.html (accessed September 11, 2012).

CMS. 2012c. *Medicaid Statistical Information System (MSIS) State Summary Datamart*. http://www.cms.gov/Research-Statistics-Data-and-Systems/Computer-Data-and-Systems/MedicaidDataSourcesGenInfo/MSIS-Mart-Home.html (accessed September 11, 2012).

CMS. 2012d. *Prevention—General Information*. http://www.cms.gov/Medicare/Prevention/PrevntionGenInfo/index.html?redirect=/PrevntionGenInfo/ (accessed September 11, 2012).

CMS. 2012e. *Quick reference information: Preventive services*. https://www.cms.gov/Medicare/Prevention/PrevntionGenInfo/Downloads/MPS_QuickReferenceChart_1.pdf (accessed September 11, 2012).

Cohen, M. S., Y. Q. Chen, M. McCauley, T. Gamble, M. C. Hosseinipour, N. Kumarasamy, J. G., Hakim, J. Kumwenda, B. Grinsztein, J. H. S. Pilotto, S. V. Godbole, S. Mehendale, S. Charjvalertsak, B. R. Santos, K. H. Mayer, I. F. Hoffman, S. H. Eshelman, E. Piwowar-Manning, L. Wang, J. Makhema, L. A. Mills, G. de Bruyn, I. Sanne, J. Eron, J. Gallant, D. Havlir, S. Swindells, H. Ribaudo, V. Elharrar, D. Burns, T. E. Taha, K. Nielsen-Saines, D.Celentano, M. Essex, and T. R. Fleming. 2011. Prevention of HIV-1 infection with early antiretroviral therapy. *New England Journal of Medicine* 365:493-505.

Coleman, S., U. Boehmer, F. Kanaya, C. Grasso, J. Tan, and J. Bradford. 2007. Retention challenges for a community-based HIV primary care clinical and implications for intervention. *AIDS Patient Care STDs* 21(9):691-701.

Coughlin, S. S. 1990. Recall bias in epidemiologic studies. *Journal of Clinical Epidemiology* 43(1):87-91.

Cross, J. 2011. *Pre-existing Condition Insurance Plans (PCIPs)*. July 13. http://prod.nastad.dotnet-web1.advansiv.com/Docs/094424_presentation_NASTAD_PCIP_July2011.pdf (accessed August 30, 2012).

Crystal, S., A. Akincigil, S. Bilder, and J. T. Walkup. 2007. Studying prescription drug use and outcomes with Medicaid claims data: Strengths, limitations, and strategies. *Medical Care* 45(10 Suppl 2):S58-S65.

Daily Briefing. 2012. *Where Each State Stands on ACA's Medicaid Expansion: A Roundup of What Each State's Leadership Has Said About Their Medicaid Plans*. http://www.advisory.com/Daily-Briefing/2012/07/05/Where-each-state-stands-of-the-Medicaid-expansion (accessed September 11, 2012).

Dang, B. N., T. P. Giordano, and J. H. Kim. 2012. Sociocultural and structural barriers to care among undocumented Latino immigrants with HIV infection. *Journal of Immigrant and Minority Health* 14(1):124-131.

Dore, D. 2011. *Commercial Health Insurance Claims Data for Studying HIV/AIDS Care*. 2011. Presentation to committee. April 28.

Drapeau, A., R. Boyer, and F. B. Diallo. 2011. Discrepancies between survey and administrative data on the use of mental health services in the general population: Findings from a study conducted in Quebec. *BMC Public Health* 11:837.

Fagan, J. L., J. Bertolli, and A. D. McNaghten. 2010. Understanding people who have never received HIV medical care: A population-based approach. *Public Health Reports* 125(4):520-527.

Forney, J. C., R. L. Miller, and City Project Study Team. 2012. Risk and protective factors related to HIV-risk behavior: A comparison between HIV-positive and HIV-negative young men who have sex with men. *AIDS Care* 24(5):544-552.

Frankel, M. R., M. F. Shapiro, N. Duan, S. C. Morton, S. H. Berry, J. A. Brown, M. A. Burnam, S. E. Cohn, D. P. Goldman, D. F. McCaffrey, S. M. Smith, P. A. St. Clair, J. F. Tebow, and S. A. Bozzette. 1999. National probability samples in studies of low-prevalence diseases. Part II: Designing and implementing the HIV cost and services utilization study sample. *Health Services Research* 345(5, Part 1):969-992.

Gardner, E. M., M. P. McLees, J. F. Steiner, C. del Rio, and W. J. Burman. 2011. The spectrum of engagement in HIV care and its relevance to test-and-treat strategies for prevention of HIV infection. *Clinical Infectious Diseases* 52(6):793-800.

Gorina, Y., and E. A. Kramarow. 2011. Identifying chronic conditions in Medicare claims data: Evaluating the Chronic Condition Data Warehouse algorithm. *Health Services Research* 45(5):1610-1627.

Granich, R. M., C. F. Gilks, C. Dye, K. M. De Cock, and B. G. Williams. 2009. Universal voluntary HIV testing with immediate antiretroviral therapy as a strategy for elimination of HIV transmission: A mathematical model. *Lancet* 373(9657):48-57.

Grov, C., B. C. Kelly, and J. T. Parsons. 2009. Polydrug use among club-going young adults recruited through time-space sampling. *Substance Use and Misuse* 44(6):848-864.

Groves, R. M., M. P. Couper, S. Presser, E. Singer, R. Tourangeau, G. P. Acosta, and L. Nelson. 2006. Experiments in producing non-response bias. *Public Opinion Quarterly* 70(5): 720-736.

Hennekens, C. H., and J. E. Buring. 1987. *Epidemiology in Medicine*. Boston, MA: Little Brown and Company.

Herwehe, J., W. Wilbright, A. Abrams, S. Bergson, J. Foxhood, M. Kaiser, L. Smith, K. Xiao, A. Zapata, and M. Magnus. 2012. Implementation of an innovative, integrated electronic medical record (EMR) and public health information exchange for HIV/AIDS. *Journal of the American Medical Informatics Association* 19(3):448-452.

HHS (U.S. Department of Health and Human Services). 2009. Office of the Inspector General. 2009. *Medicaid Managed Care Encounter Data: Collection and Use*. http://oig.hhs.gov/oei/reports/oei-07-06-00540.pdf (accessed August 20, 2012).

HHS. 2011. *How the Affordable Care Act Helps People Living with HIV/AIDS: 2011 and Beyond*. http://www.healthcare.gov/news/factsheets/2011/11/hiv-aids11092011a.html (accessed September 11, 2012).

HHS. 2012a. *Frequently Asked Questions About PRA/Information Collection*. http://www.hhs.gov/ocio/policy/collection/infocollectfaq.html#4 (accessed September 11, 2012).

HHS. 2012b. *Health Care Reform and HIV/AIDS*. http://aids.gov/federal-resources/policies/health-care-reform/ (accessed September 11, 2012).

HHS. 2012c. *Ryan White HIV/AIDS Program Modeling Study*. Paperwork Reduction Act Supporting Statement Part A. http://www.reginfo.gov/public/do/PRAViewDocument?ref_nbr=201206-0990-003 (accessed August 6, 2012).

HHS. 2012d. *The Affordable Care Act: Strengthening Medicare in 2011*. http://www.cms.gov/apps/files/MedicareReport2011.pdf (accessed September 11, 2012).

Hill, T., L. Bansi, C. Sabin, A. Phillips, D. Dunn, J. Anderson, P. Easterbrook, M. Fisher, B. Gazzard, R. Gilson, M. Johnson, C. Leen, C. Orkin, A. Schwenk, J. Walsh, A. Winston, A. Babiker, and V. Delpech. 2010. Data linkage reduces loss to follow-up in an observational HIV cohort study. *Journal of Clinical Epidemiology* 63(10):1101-1109.

HRSA (Health Resources and Services Administration). 2010. *Going the Distance: The Ryan White HIV/AIDS Program*. http://www.impactmc.net/downloads/samples/writing/Going-the-Distance-20-years-of-the-Ryan-White-HIV-AIDS-Program.pdf (accessed September 11, 2012).

HRSA. 2012a. *About the Ryan White HIV/AIDS Program: Legislation*. http://hab.hrsa.gov/abouthab/aboutprogram.html (accessed September 11, 2012).

HRSA, 2012b. *AIDS Drug Assistance Program. Quarterly Data Report*. http://hab.hrsa.gov/manageyourgrant/adap/adapformfeb08.pdf (accessed August 6, 2012).

HRSA. 2012c. *Crosswalk of Changes between the Proposed ADAP Data Report (ADR) Client Report and the ADAP Quarterly Report (AQR)*. http://hab.hrsa.gov/manageyourgrant/files/adraqrcrosswalk.pdf (accessed August 7, 2012).

HRSA. 2012d. *The Ryan White HIV/AIDS Program Services Report*. http://hab.hrsa.gov/manageyourgrant/clientleveldata.html (accessed August 6, 2012).

Hunt, J. R., and E. White. 1998. Retaining and tracking cohort study members. *Epidemiologic Reviews* 20(1):57-70.

Iachan, R., T. Kyle, and D. Farrell. 2011. Real time sampling in patient surveys. Joint Statistical Meetings—Section on Government Statistics.

Ikard, K., J. Janney, L. C. Hsu, D. J. Isenberg, M. B. Scalco, S. Schwarcz, L. Beer, D. A. Wendell, P. E. Franks, and J. G. Kahn. 2005. Estimation of unmet need for HIV primary medical care: A framework and three case studies. *AIDS Education and Prevention* 17(6 Suppl B):26-38.

IOM (Institute of Medicine). 2004. *Measuring What Matters: Allocation, Planning, and Quality Assessment for the Ryan White CARE Act*. Washington, DC: The National Academies Press.

IOM. 2012. *Monitoring HIV Care in the United States: Indicators and Data Systems*. Washington, DC: The National Academies Press.

Kalichman, S.C., J. Pellowski, M.O. Kalichman, C. Cherry, M. Detorio, A. M. Caliendo, and R. F. Schinazi. 2011. Food insufficiency and medication adherence among people living with HIV/AIDS in urban and peri-urban settings. *Prevention Science* 12(3):324-332.

Kates, J. 2011. *Medicaid and HIV: A National Analysis*. Washington, DC: Henry J. Kaiser Family Foundation. http://www.kff.org/hivaids/upload/8218.pdf (accessed September 11, 2012).

Kelley, K., B. Clark, V. Brown, and J. Sitzia. 2003. Good practice in the conduct and reporting of survey research. *International Journal for Quality in Health Care* 15(3):261-266.

KFF (Kaiser Family Foundation). 2006. *The Role of Part D for People with HIV/AIDS: Coverage and Costs of Antiretrovirals Under Medicare Drug Plans*. http://www.kff.org/hivaids/upload/7548.pdf (accessed September 11, 2012).

KFF. 2009. *Medicare and HIV/AIDS. HIV/AIDS Policy Fact Sheet*. February. http://www.kff.org/hivaids/upload/7171_04.pdf (accessed September 11, 2012).

KFF. 2010. *Explaining Health Care Reform: Questions About Health Insurance Exchanges*. http://www.kff.org/healthreform/7908.cfm (accessed September 11, 2012).

KFF. 2011a. *A Profile of Health Insurance Exchange Enrollees*. http://www.kff.org/healthreform/upload/8147.pdf (accessed September 11, 2012).

KFF. 2011b. *The Ryan White Program. HIV/AIDS Policy Fact Sheet*. November. http://www.kff.org/hivaids/upload/7582-06.pdf (accessed August 6, 2012).

KFF. 2012a. *AIDS Drug Assistant Programs (ADAPs). HIV/AIDS Policy Fact Sheet*. May. http://www.kff.org/hivaids/upload/1584-11.pdf (accessed September 11, 2012).

KFF. 2012b. *State Health Facts. State Action Toward Creating Health Insurance Exchanges*, August 1, 2012. http://statehealthfacts.kff.org/comparemaptable.jsp?ind=962&cat=17 (accessed September 11, 2012).

Klein, J. 2002. *Report on the Use of Medi-Cal Managed Care Encounter Data for Research Purposes*. http://www.dhcs.ca.gov/dataandstats/statistics/Documents/Report%20on%20the%20Use%20of%20Medi-Cal%20Managed%20Care%20Encounter%20Data%20for%20Research%20Purposes.pdf (accessed November 5, 2012).

Koroukian, S. M., G. S. Cooper, and A. A. Rimm. 2003. Ability of Medicaid claims data to identify incident cases of breast cancer in the Ohio Medicaid population. *Health Services Research* 38(3):947-960.

Lo, Y. C., G. Turabelidze, M. Lin, and Y. Friedberg. 2012. Prevalence and determinants of recent HIV testing among sexually active men who have sex with men in the St. Louis metropolitan area, Missouri, 2008. *Sexually Transmitted Diseases* 39(4):306-311.

Martin, E.G., and B. R. Schackman. 2012. What does U.S. health reform mean for HIV clinical care? *Journal of Acquired Immune Deficiency Syndrome*. 2012 May 1;60(1):72-6.

McDonald, C. J., J. M. Overhage, M. Barnes, G. Schadow, L. Blevins, P. R. Dexter, B. Mamlin, and the INPC Management Committee. 2005. The Indiana Network for Patient Care: A working local health information infrastructure. *Health Affairs* 24(5):1214-1220.

McNaghten, A. D., M. I. Wolfe, I. Onorato, A. K. Nakashima, R. O. Valdiserri, E. Mokotoff, R. A. Romaguera, A. Kroliczak, R. S. Janssen, and P. S. Sullivan. 2007. Improving the representativeness of behavioral and clinical surveillance for persons with HIV in the United States: The rationale for developing a population-based approach. *PLoS One* 2(6):e550. doi:10.1371/journal.pone.0000550.

Mellins, C. A., J. F. Havens, C. McDonnell, C. Lichtenstein, K. Uldall, M. Chesney, E. K. Santamaria, and J. Bell. 2009. Adherence to antiretroviral medications and medical care in HIV-infected adults diagnosed with mental and substance abuse disorders. *AIDS Care* 21(2):168-177.

Mocroft, A., O. Kirk, P. Aldins, A. Chies, A. Blaxhult, N. Chentsova, N. Vetter, F. Dabis, J. Gatell, and J. D. Lundgren. 2008. Loss to follow-up in an international, multicentre observational study. *HIV Medicine* 9(5):261-269.

O'Grady, M. J., and A. Mahmud. 2011. *The Next Generation of Data Linkage Projects: Priority Areas for SNACC under the ACA*. http://www.shadac.org/files/SNACCDataLinkageBrief_1of3.pdf (accessed September 12, 2012).

Olatosi, B. A., J. C. Probst, C. H. Stoskoph, A. B. Martin, and W. A. Duffus. 2009. Patterns of engagement in care by HIV-infected adults: South Carolina, 2004-2006. *AIDS* 23(6):725-730.

Parsons, J. T., C. Gov, and B. C. Kelly. 2008. Comparing the effectiveness of two forms of time-space sampling to identify club drug-using young adults. *Journal of Drug Issues* 38(4):1061-1081

Perkins, D., B. E. Meyerson, D. Klinkenberg, and B. T. Laffoon. 2008. Assessing HIV care and unmet need: Eight databases and a bit of perseverance. *AIDS Care* 20(3):318-326.

RAND. 2011. *HIV Cost and Services Utilization Study (HCSUS)*. http://www.rand.org/health/projects/hcsus.html (accessed July 17, 2012).

Rein, D. B. 2007. *Should Patient Characteristics be Included in a Severity of Need Index for Ryan White Program, Part A Services? An Evaluation Based on the Medical Expenditure Panel Survey* http://hab.hrsa.gov/manageyourgrant/severityofneed/supppatient.pdf (accessed August 30, 2012).

ResDAC. 2006. *Medicaid Analytic eXtract (MAX) data FAQ*. www.resdac.org/medicaid/FAQs-draft-08172006.doc (accessed June 20, 2012).

ResDAC. 2012. Medicaid data available. http://www.resdac.org/Medicaid/data_available.asp (accessed June 20, 2012).

Rutherford, G. W., W. McFarland, H. Spindler, K. White, S. V. Patel, J. Aberle-Grasse, K. Sabin, N. Smith, S. Taché, J. M. Calleja-Garcia, and R. L. Stoneburner. 2010. Public health triangulation: Approach and application to synthesizing data to understand national and local HIV epidemics. *BMC Public Health* 10:477.

SAMHSA (Substance Abuse and Mental Health Services Administration). 2011. *Results from the 2010 National Survey on Drug Use and Health: Summary of National Findings*. http://www.samhsa.gov/data/nsduh/2k10nsduh/2k10results.htm#TabB-5 (accessed November 5, 2012).

Sarnquist, C. C., S. Soni, H. Hwang, B. B. Topol, S. Mutima, and Y. A. Maldonado. 2011. Rural HIV-infected women's access to medical care: Ongoing needs in California. *AIDS Care* 23(7):793-796.

Schiller, J. S., J. W. Lucas, B. W. Ward, and J. A. Peregoy. 2012. Summary health statistics for U.S. adults: National Health Interview Survey, 2010. National Center for Health Statistics. *Vital Health Statistics* 10(252).

Schneider, K., B. O'Donnell, J. O'Donnell, and C. Powers. 2010. *Technical Guidance for Researchers Summarizing and Describing Prescription Drug Utilization*. http://www.ccwdata.org/cs/groups/public/documents/document/ccw_part_d_tech_guidance.pdf (accessed July 12, 2012).

Sengupta, S., B. Banks, D. Jonas, M. S. Miles, and G. C. Smith. 2011. HIV interventions to reduce HIV/AIDS stigma: A systematic review. *AIDS and Behavior* 15(6):1075-1087.

Shapiro, M., M. L. Berk, S. H. Berry, C. Emmons, L. A. Athey, D. C. Hsia, A. A. Leibowitz, C. A. Maida, M. Marcus, J. F. Perlman, C. L. Schur, M. A. Schuster, J. W. Senterfitt, and S. A. Bozzette. 1999. National probability samples in studies of low prevalence diseases. Part I: Perspectives and lessons learned from the HIV Costs and Services Utilization Study. *Health Services Research* 34(5, Part 1):951-968.

Spiegel, H. M. L., and D. C. Futterman. 2009. Adolescents and HIV: Prevention and clinical care. *Current HIV/AIDS Reports* 6(2):100-107.

Springer, S. A., A. C. Spaulding, J. P. Meyer, and F. L. Altice. 2011. Public health implications for adequate transitional care for HIV-infected prisoners: Five essential components. *Clinical Infectious Diseases* 53(5):469-479.

Tourangeau, R., and T. W. Smith. 1996. Asking sensitive questions: The impact of data collection mode, question format, and question context. *Public Opinion Quarterly* 60:275-304.

Tourangeau, R., K. Raskinski, J.B. Jobe, T. W. Smith, and W. F. Pratt. 1997. Sources of error in a survey of sexual behavior. *Journal of Official Statistics* 13:341-365.

UNAIDS. 2010. *UNAIDS Report on the Global AIDS Epidemic 2010*. http://www.unaids.org/GlobalReport/Global_report.htm (accessed August 30, 2012).

APPENDIX TABLE 3-1 Number and Percentage of Participants, by Selected Characteristics, Using Unweighted Data—Medical Monitoring Project, United States, 2007

Characteristic	No.[a]	%[b]
Gender[c]		
Male	2,633	72
Female	959	26
Transgender	47	1
Self-reported sexual orientation		
Heterosexual or straight	1,791	49
Homosexual, gay, or lesbian	1,514	42
Bisexual	278	8
Race/Ethnicity[d]		
Black, non-Hispanic	1,438	40
White, non-Hispanic	1,272	35
Hispanic or Latino	699	19
American Indian/Alaska Native	19	<1
Asian	19	<1
Native Hawaiian/Pacific Islander	11	<1
Multiracial	119	3
Other	61	2
Age at time of interview (yrs)		
18-24	73	2
25-29	143	4
30-34	219	6
35-39	481	13
40-44	720	20
45-49	807	22
50-54	589	16
55-59	340	9
60-64	161	4
≥65	110	3
Education		
<High school	790	22
High school diploma or GED credential	987	27
>High school	1,865	51
Country/territory of birth		
United States	2,984	82
Puerto Rico	281	8
Mexico	103	3
Other	273	8
Time since HIV diagnosis		
≥5 yrs	2,836	78
<5 yrs	785	22
Homeless at any time during past 12 months[e]		
Yes	280	8
No	3,363	92

continued

APPENDIX TABLE 3-1 Continued

Characteristic	No.[a]	%[b]
Health insurance or coverage during past 12 months		
Yes	3,040	84
No	599	16
Type of health insurance or coverage during past 12 months[f]		
Medicaid	1,366	45
Private health insurance or HMO	1,136	37
Medicare	896	30
Other[g]	475	16
Primary method of paying for prescription medications for HIV and related illnesses during past 12 months[b]		
Medicaid/Medicare	1,509	41
Private health care coverage	896	25
AIDS Drug Assistance Program	915	25
Not taking any prescription medications for HIV or related illnesses	187	5
Paid for medications themselves (i.e., out of pocket)	194	5
Received medications from a public clinic	88	2
Received medications from an AIDS service organization	50	1
Participated in a clinical trial or research study that provided medications	12	<1
Applied for public assistance during past 12 months		
Yes	708	19
No	2,932	81
Received any form of public assistance including SSI or SSDI during past 12 months		
Yes	1,798	49
No	1,843	51
Primary source of money or financial support during past 12 months		
SSI or SSDI	1,463	40
Salary or wages	1,403	39
Spouse, partner, or family	244	7
Public assistance	211	6
Pension or retirement fund	81	2
No income or financial support	43	1
Friends	35	1
Savings/investments	28	<1
Total	**3,643**	**100**

NOTE: GED = general equivalency degree; HMO = health maintenance organization; SSDI = Social Security Disability Insurance; SSI = Social Security Supplemental Income.

[a]Numbers might not add to total because of missing data. Analyses limited to persons with diagnosis of HIV infection for at least 12 months before the interview. Values exclude categories with fewer than five responses, responses of "don't know," and skipped (missing) responses.

APPENDIX TABLE 3-1 Continued

[b]Percentages may not add to 100% because of rounding.

[c]Participants were classified as transgender if sex at birth and gender reported by the participant were different or if the participant chose transgender in response to the question about self-identified gender.

[d]Hispanics or Latinos might be of any race.

[e]McKinney-Vento definition of homelessness: living on the street, in a shelter, in a single-room occupancy hotel, temporarily staying with friends or family, or living in a car. A person is categorized as homeless if that person lacks a fixed, regular, adequate nighttime residence or has a steady nighttime residence that is (1) a supervised publicly or privately operated shelter designed to provide temporary living accommodation, (2) an institution that provides a temporary residence for persons intended to be institutionalized, or (3) a public or private place not designed for or ordinarily used as a regular sleeping accommodation for human beings (e.g., in an automobile or under a bridge) (Stewart B. McKinney Homeless Assistance Act, 42 U.S.C. § 11301, et seq.; 1987).

[f]Among 3,040 participants who reported having health insurance or coverage during the past 12 months. Participants could select more than one response.

[g]Includes Tricare/CHAMPUS, Veterans Administration coverage, and insurance classified as "other" health insurance.

[h]Participants could select more than one response.

SOURCE: Submission to committee, January 2012.

APPENDIX TABLE 3-2 Committee's Recommended Core Indicators Mapped to Questions from MMP Questionnaire and Medical Record Abstraction Forms

Indicator	Does MMP Adhere to Indicators?	Question ID	Questions Collecting Data Related to Indicator
Proportion of people newly diagnosed with HIV with a CD4+ cell count >200 cells/mm^3 and without a clinical diagnosis of AIDS	Yes		**From questionnaire:**
		A1	• What month and year did you first test positive for HIV? Tell me when you got your result, not when you got your first test. (MM/YYYY; Refused to answer; Don't know)
		C2a	• What was the result of your **most recent** CD4 count? (0-49; 50-99; 100-199; 200-349; 350-499; 500 or more; Refused to answer; Don't know)
		C8	• Have you **ever** been told by a doctor, nurse, or other health care worker that you had PCP [*Pneumocystis jirovecii* pneumonia]? (No; Yes; Refused to answer; Don't know)
			From medical record abstraction forms:
			• Is there documentation that any AIDS defining opportunistic illnesses (AIDS OI) were diagnosed prior to the SP start date? (If yes, abstractor checks which AIDS OI was diagnosed and enters the date of first diagnosis) (MHF)
			• Is there documentation of CD4 cell count test results prior to the SP start date? (If yes, abstractor enters lowest CD4 count and date of lowest CD4 count) (MHF)
			• Is there documentation of any new or existing diagnoses of AIDS defining opportunistic illnesses (AIDS OI) during this visit? (If yes, abstractor checks which AIDS OI was diagnosed) (SPVF)
			• Is there documentation of CD4 cell count done at this visit? (If yes, abstractor enters value) (SPVF)

			• Is there documentation of any new or existing diagnoses of AIDS defining opportunistic illnesses (AIDS OI) during this inpatient stay? (If yes, abstractor checks which AIDS OI was diagnosed) (SPIF) • Is there documentation of CD4 cell count test results during this inpatient stay? (If yes, abstractor enters value) (SPIF)
Proportion of people newly diagnosed with HIV who are linked to clinical care for HIV within 3 months of diagnosis	Yes	A1 A5	**From questionnaire:** • What month and year did you first **test** positive for HIV? Tell me when you got your result, not when you got your first test. (MM/YYYY; Refused to answer; Don't know) • Since testing positive for HIV, what month and year did you **first** visit a doctor, nurse, or other health care worker for HIV medical care? (MM/YYYY; Refused to answer; Don't know) **From medical record abstraction forms:** • (Newly diagnosed) Is there documentation of the first positive HIV test result, or laboratory test results for CD4 cell count, or HIV viral load, prior to the SP start date? (If yes, abstractor enters date of first positive test result). (MHF)
Proportion of people with diagnosed HIV infection who are in continuous care (two or more visits for routine HIV medical care in the preceding 12 months at least 3 months apart)	Yes	A8 A10 A10a A10b	**From questionnaire:** • During the **past 12 months**, was there one usual place, like a doctor's office or clinic, where you went for most of your HIV medical care? (No; Yes; Refused to answer; Don't know) • What is the name of this place where you went for most of your HIV medical care during the past 12 months? • Did you get any sort of care at ***[USE FACILITY NAME]*** between ***[INSERT START DATE]*** and ***[INSERT END DATE]***? (No; Yes; Refused to answer; Don't answer) • Between ***[INSERT START DATE]*** and ***[INSERT END DATE]***, how many times had you been to ***[USE FACILITY NAME]*** for any sort of care? (__ __ __; Refused to Answer; Don't know)

continued

APPENDIX TABLE 3-2 Continued

Indicator	Does MMP Adhere to Indicators?	Question ID	Questions Collecting Data Related to Indicator
			From medical record abstraction forms: Dates of visits for medical care and dates of laboratory test results, etc.
Proportion of people with diagnosed HIV infection who received two or more CD4 tests in the preceding 12 months	Yes	C3	**From questionnaire:** • During **the past 12 months,** how many CD4 counts have you had? (__ __; Refused to answer; Don't know) **From medical record abstraction forms:** • Is there documentation of CD4 cell count done at this visit? (If yes, abstractor enters value) (SPVF) • Is there documentation of CD4 cell count test results during this inpatient stay? (If yes, abstractor enters value) (SPIF)
Proportion of people with diagnosed HIV infection who received two or more viral load tests in the preceding 12 months	Yes	C6	**From questionnaire:** • During the past 12 months, how many viral load tests have you had? (__ __; Refused to answer; Don't know) **From medical record abstraction forms:** • Is there documentation of HIV viral load test done at this visit? (If yes, abstractor enters value) (SPVF) • Is there documentation of HIV viral load test results during this inpatient stay? (If yes, abstractor enters value) (SPIF)

Proportion of people with diagnosed HIV infection in continuous care for 12 or more months and with a CD4+ cell count ≥350 cells/mm^3	Yes	C2a	**From questionnaire:** • What was the result of your **most recent** CD4 count? (0-49; 50-99; 100-199; 200-349; 350-499; 500 or more; Refused to answer; Don't know)
		A8	• During the **past 12 months**, was there one usual place, like a doctor's office or clinic, where you went for most of your HIV medical care? (No; Yes; Refused to answer; Don't know)
		A10	• What is the name of this place where you went for most of your HIV medical care during the past 12 months?
		A10a	• Did you get any sort of care at ***[USE FACILITY NAME]*** between ***[INSERT START DATE]*** and ***[INSERT END DATE]***? (No; Yes; Refused to answer; Don't know)
		A10b	• Between ***[INSERT START DATE]*** and ***[INSERT END DATE]***, how many times had you been to ***[USE FACILITY NAME]*** for any sort of care? (__ __ __; Refused to Answer; Don't know)
			From medical record abstraction forms: • Dates of visits for medical care and dates of laboratory test results, etc. • Is there documentation of CD4 cell count test results prior to the SP start date? (If yes, abstractor enters lowest CD4 cell count and date of lowest CD4 count) (MHF) • Is there documentation of CD4 cell count done at this visit? (If yes, abstractor enters value) (SPVF) • Is there documentation of CD4 cell count test results during this inpatient stay? (If yes for CD4 count, abstractor enters value) (SPIF)

continued

APPENDIX TABLE 3-2 Continued

Indicator	Does MMP Adhere to Indicators?	Question ID	Questions Collecting Data Related to Indicator
Proportion of people with diagnosed HIV infection with a measured CD4+ cell count <500 cells/mm^3 who are not on ART	Yes	C2a T4	**From questionnaire:** • What was the result of the **most recent** CD4 count? (0-49; 50-99; 100-199; 200-349; 350-499; 500 or more; Refused to answer; Don't know) • Are you **currently** taking any antiretroviral medicines for your HIV? (No; Yes; Refused to answer; Don't know) **From medical record abstraction forms:** • Is there documentation of CD4 cell count test results prior to the SP start date? (If yes, abstractor enters lowest CD4 cell count and date of lowest CD4 count) (MHF) • Is there documentation of CD4 cell count done at this visit? (If yes, abstractor enters value) (SPVF) • Is there documentation of CD4 cell count results during this inpatient stay? (If yes, abstractor enters value) (SPIF) • Is there documentation of prescription of antiretroviral therapy (ART) prior to the SP start date? (If yes, abstractor enters date of first prescribed ART) (MHF) • Is there documentation of prescription or continuation of antiretroviral therapy (ART) during this visit? (If yes, abstractor enters the type of ART prescribed) (SPVF) • Is there documentation of prescription of antiretroviral therapy (ART) during this inpatient stay? (If yes, abstractor enters the type of ART prescribed) (SPIF)

Proportion of people with diagnosed HIV infection who have been on ART for 12 or more months and have a viral load below the level of detection	Yes	C5b	**From questionnaire:** • What was the month and year of your **most recent** viral load? (MM/YYYY; Refused to answer; Don't know)
		C5c	• What was the result of your **most recent** viral load test? (Below the level of detection, undetectable; detectable, but less than 5,000 viral copies/ml; 5,000 to 100,000 viral copies/ml; Greater than 100,000 viral copies/ml; Refused to answer; Don't know)
		T3	• When was the first time you **ever** took any antiretroviral medicines for your HIV? (MM/YYYY; Refused to answer; Don't know)
		T4	• Are you **currently** taking any antiretroviral medicines for your HIV? (No; Yes; Refused to answer; Don't know)
		T14	• During the **past 12 months**, have you taken any antiretroviral medicines? (No; Yes; Refused to answer; Don't know)
		T16	• During the **past 12 months**, have you ever purposefully taken a "drug holiday" from your antiretroviral medicines that wasn't recommended by your doctor? That is, did you plan to not take any doses of one or more of your antiretroviral medicines for at least two whole days in a row? (No; Yes; Refused to answer; Don't know)

continued

APPENDIX TABLE 3-2 Continued

Indicator	Does MMP Adhere to Indicators?	Question ID	Questions Collecting Data Related to Indicator
			From medical record abstraction forms: • Is there documentation of prescription of antiretroviral therapy (ART) prior to the SP start date? (If yes, abstractor enters date of first prescribed ART) (MHF) • Is there documentation of the first positive HIV test result, or laboratory test results for CD4 cell count, or HIV viral load, prior to the SP start date? (If yes for viral load, abstractor enters date of most recent undetectable result) (MHF) • Is there documentation of prescription or continuation of antiretroviral therapy (ART) during this visit? (Yes; No) (SPVF) • Is there documentation of any of HIV viral load test done at this visit? (If yes, abstractor enters value) (SPVF) • Is there documentation of prescription of antiretroviral therapy (ART) during this inpatient stay? (Yes; No) (SPIF) • Is there documentation of any HIV viral load test during this inpatient stay? (If yes, abstractor enters value) (SPIF)
All-cause mortality rate among people diagnosed with HIV infection	Yes	Section XI	**From medical record abstraction forms:** • Is there documentation that the patient died during the SP? (Yes/No) If yes: o Date of death during the Surveillance Period (MM/DD/YYYY) o Cause of death (accident, homicide, suicide, natural, other (specify), cause not documented) (SPSF)

Proportion of people with diagnosed HIV infection and mental health disorder who are referred for mental health services and receive these services within 60 days	No	A18 A26a A26b	**From questionnaire:** • During the **past 12 months**, were you enrolled in an inpatient mental health facility? (No; Yes; Refused to answer; Don't know) • During the **past 12 months**, did you get mental health services? (No; Yes; Refused to answer; Don't know) • During the **past 12 months**, have you needed mental health services? (No; Yes; Refused to answer; Don't know) **From medical record abstraction forms:** • Is there documentation of any of the following mental illnesses prior to the SP start date? (Anxiety disorder [generalized anxiety disorder, GAD], Bipolar disorder, Depression [major depression, depressive disorder], Psychosis) (MHF) • Is there documentation of any of the following referrals during the SP? (Responses include referrals for mental health services) (SPSF) • Is there documentation of any new or existing diagnoses of conditions other than AIDS OI during this visit? (If yes, abstractor enters the type of diagnosis which may include anxiety disorder, depression diagnosed by physician, and psychosis including schizophrenia) (SPVF) • Is there documentation of any new or existing diagnoses of conditions other than AIDS OI during this inpatient stay? (If yes, abstractor enters the type of diagnosis which may include anxiety disorder, depression diagnosed by physician, and psychosis including schizophrenia) (SPIF)

continued

APPENDIX TABLE 3-2 Continued

Indicator	Does MMP Adhere to Indicators?	Question ID	Questions Collecting Data Related to Indicator
Proportion of people with diagnosed HIV infection and substance use disorder who are referred to substance abuse services and receive these services within 60 days	No	A19 A27a A27b	**From questionnaire:** • During the **past 12 months**, were you enrolled in an inpatient drug or alcohol treatment facility? (No; Yes; Refused to answer; Don't know) • During the **past 12 months**, did you get drug or alcohol counseling or treatment? (No; Yes; Refused to answer; Don't know) • During the **past 12 months**, have you needed drug or alcohol counseling or treatment? (No; Yes; Refused to answer; Don't know) **From medical record abstraction forms:** • Is there documentation of reported or suspected alcohol abuse or other non-prescribed use of substances, including counseling or treatment for alcohol and/or substance use/abuse prior to the SP? If yes: o Is there documentation of alcohol abuse prior to the SP? o Is there evidence of any injection substance use (e.g., track marks) documented prior to the SP? (If yes, abstractor enters the type of substance and type of use [e.g., injection, non-injection]) (MHF) • Is there documentation of any referrals for substance abuse prevention services during the SP? (Yes; No) (SPSF)

- Is there documentation of reported or suspected alcohol abuse or other non-prescribed use of substances, including counseling or treatment for alcohol and/or substance use/abuse, during the SP? If yes:
  - Is there documentation of alcohol abuse during the SP?
  - Is there evidence of any injection substance use (e.g., track marks) documented during the SP? (If yes, abstractor enters the type of substance and type of use [e.g., injection, non-injection]) (SPSF)
- Is there documentation of any new or existing diagnoses of conditions other than AIDS OI during this visit? (If yes, abstractor enters the type of diagnosis which may include alcoholism) (SPVF)
- Is there documentation of any new or existing diagnoses of conditions other than AIDS OI during this inpatient stay? (If yes, abstractor enters the type of diagnosis which may include alcoholism) (SPIF)

continued

APPENDIX TABLE 3-2 Continued

Indicator	Does MMP Adhere to Indicators?	Question ID	Questions Collecting Data Related to Indicator
Proportion of people with diagnosed HIV infection who were homeless or temporarily or unstably housed at least once in the preceding 12 months	Yes		**From questionnaire:**
		D10	• During the **past 12 months**, have you o lived on the street? (No; Yes; Refused to answer; Don't know) o lived in a shelter? (No; Yes; Refused to answer; Don't know) o lived in a Single Room Occupancy (SRO) hotel (No; Yes; Refused to answer; Don't know) o lived in a car? (No; Yes; Refused to answer; Don't know)
		A30a	• During the **past 12 months**, did you get shelter or housing services? (No; Yes; Refused to answer; Don't know)
		A30b	• During the **past 12 months**, have you needed shelter or housing services? (No; Yes; Refused to answer; Don't know)
			Housing Status data also captured in the following questions:
		A6	• What was the main reason you did not go to a doctor, nurse, or other health care worker for HIV medical care **within 3 months** of testing positive for HIV? ("Experienced homelessness" is a response option)
		A7a	• What was the main reason you didn't visit a doctor, nurse, or other health care worker for HIV medical care during the **past 6 months**? ("Experienced homelessness" is one of the response options)
		T2	• What is the main reason you have **never** taken any antiretroviral medicines? ("Homeless" is a response option)
		T4a	• What is the main reason you aren't **currently** taking any antiretroviral medicines? ("Homeless" is a response option)
		T10	• The **last time** you missed taking your antiretroviral medicines, what were the reasons? ("Homeless" is a response options)

			From medical record abstraction forms: • Is there documentation of any of the following referrals during the SP? (If yes, abstractor enters the type of referral which may include food and housing support services) (SPSF)
Proportion of people with diagnosed HIV infection who experienced food or nutrition insecurity at least once in the preceding 12 months	Yes	A31a A31b A36a A36b	**From questionnaire:** • During the **past 12 months**, did you get meal or food services? (No; Yes; Refused to answer; Don't know) • During the **past 12 months**, have you needed meal or food services? (No; Yes; Refused to answer; Don't know) • During the **past 12 months**, did you get nutritional services? (No; Yes; Refused to answer; Don't know) • During the **past 12 months**, have you needed nutritional services? (No; Yes; Refused to answer; Don't know) **From medical record abstraction forms:** • Is there documentation of any of the following referrals during the SP? (If yes, abstractor enters the type of referral which may include food and housing support services) (SPSF)

APPENDIX TABLE 3-2 Continued

Indicator	Does MMP Adhere to Indicators?	Question ID	Questions Collecting Data Related to Indicator
Proportion of people with diagnosed HIV infection who had an unmet need for transportation services to facilitate access to medical care and related services at least once in the preceding 12 months	Yes		**From questionnaire:**
		A33a	• During the past 12 months, did you get transportation assistance? (No; Yes; Refused to answer; Don't know)
		A33b	• During the past 12 months, have you needed transportation assistance? (No; Yes; Refused to answer; Don't know)
			Transportation data also captured in the following questions:
		A6	• What was the main reason you did not go to a doctor, nurse, or other health care worker for HIV medical care **within 3 months** of testing positive for HIV? ("Unable to get transportation" is a response option)
		A7a	• What was the main reason you didn't visit a doctor, nurse, or other health care worker for HIV medical care during the **past 6 months**? ("Unable to get transportation" is a response option)

NOTE: Although the indicators for clinical HIV care and mental health and substance abuse recommended in the committee's first report are targeted toward adults, they apply to adolescents (≥13 years) as well (IOM, 2012). The Medical Monitoring Project does not include children or adolescents; the population of inference is individuals with HIV ≥18 who are in care. Therefore, as currently designed the MMP does not provide data to estimate indicators for individuals under the age of 18. MHF = Medical History Form; SP = Surveillance Period; SPIF = Surveillance Period Inpatient Form; SPSF = Surveillance Period Summary Form; VL = Viral Load.

4

Conclusions and Recommendations

Question (a) from the committee's statement of task asks how to obtain data from a nationally representative sample of people with HIV to establish a baseline for access to health coverage and care prior to 2014, by which time several of the provisions of the Patient Protection and Affordable Care Act (ACA) (P.L. 111-148) should be fully implemented. The committee concluded that there currently is no single data collection effort that can provide a baseline prior to 2014, nor is there a system that can be modified quickly enough to serve this purpose. Given this conclusion, the committee considered question (b) from the statement of task about alternatives, including the use of data from multiple existing data sources for obtaining data on health care coverage, access, utilization, and outcomes for a large sample of people with HIV. The committee's first report identified 12 data systems that it concluded could serve as a collective platform for evaluating access to continuous and high-quality care in all populations of people with HIV (IOM, 2012, p. 167). Together, these data systems can provide a reasonably accurate baseline for health care coverage and utilization prior to 2014. Most of these systems capture some data on health coverage status.

Recommendation 1. Given that there currently is no single data collection system that can be used to establish a baseline for health care coverage and utilization for a nationally representative sample of people with HIV in the United States, the Office of National AIDS Policy should use multiple existing data sources to establish this baseline prior to 2014. These data sources might include

- **National HIV Surveillance System**
- **Medical Monitoring Project**
- **Ryan White HIV/AIDS Program**
- **Medicaid and Medicare**
- **Veterans Health Administration**
- **Housing Opportunities for Persons with AIDS**
- **North American AIDS Cohort Collaboration on Research and Design**
- **CFAR Network of Integrated Clinical Systems**
- **HIV Research Network**
- **Private insurers**

As the committee concluded in its first report with respect to the estimation of its recommended indicators for clinical HIV care and supportive services, combining data from multiple data systems presents a range of analytic and logistical challenges that will change over time and need to be revaluated periodically. To that end, the committee reiterates its recommendation from the first report pertaining to periodic reevaluation of mechanisms for combining relevant data elements and identification of and approaches to addressing barriers to the efficient analysis of data, including relevant statistical methodologies (IOM, 2012, p. 315).

Question (c) from the committee's statement of task asks about how to regularly obtain data from a nationally representative sample of people with HIV to monitor the impact of the ACA on health care coverage and utilization after 2014. The committee saw this as an opportunity to recommend a dynamic strategy for capturing data from a nationally representative sample of people with diagnosed HIV. Given the challenges discussed in the committee's first report of collecting and combining data from disparate systems to generate an overall picture of the care experiences of people with HIV in the United States (IOM, 2012, Chapters 4-6), development of a unique mechanism for capturing relevant information would simplify the collection and analysis of data and provide more detailed and representative data than currently exist to monitor the impact of the ACA on health care coverage and utilization for people with HIV.

After reviewing multiple data systems, the committee concluded that the Medical Monitoring Project (MMP) is a promising resource for the generation of nationally representative estimates of health care coverage and utilization for people with diagnosed HIV. Since people with HIV comprise less than 1 percent of the U.S. population, it is unlikely that national population-based health surveys will include a sufficient sample of people with HIV to generate nationally representative data on the care experiences of this population. In contrast, MMP focuses specifically on people with HIV. MMP was designed by the Centers for Disease Control

and Prevention (CDC) as an HIV surveillance tool that would supplement the National HIV Surveillance System (NHSS) by providing detailed and nationally representative information about the care experiences and needs of adults ≥18 years with diagnosed HIV who are in care.

MMP collects data on dimensions of care that correspond to major components of health care reform, such as source of health coverage and the distribution of different sources of coverage; access to HIV care and unmet need for supportive services (including for people with different types of coverage); the quality and comprehensiveness of care; receipt of recommended clinical and preventive interventions (e.g., screenings and immunizations); and the organizational context and structure of care (e.g., where care is provided, who is providing that care, and whether care is occurring in the context of new organizational models intended to improve service coordination [e.g., patient-centered medical homes, accountable care organizations]). In addition, MMP captures clinical data needed to estimate indicators of care quality within the context of the ACA. Along with the Ryan White HIV/AIDS Program, MMP is one of only a few data systems that can be used to assess unmet need for housing, food, and transportation assistance for people with HIV. Due to MMP's repeated (annual) cross-sectional design, there is regular opportunity for questions to be added to the data collection instruments should information needs change as the ACA is implemented. Collection of data through patient interview, abstraction of patients' medical records, and extraction of core surveillance data on each patient through the NHSS allows for corroboration of data and the collection of at least minimal data for most patients (CDC, 2012a,b).

Despite its promise, there are aspects of MMP that the committee concludes need to be improved before MMP can be used to generate nationally representative estimates of health care coverage and utilization for all people with diagnosed HIV. One concern is MMP's current patient response rate. Although it has improved over time, the patient response rate in 2010, the most recent year for which data are available, was 56 percent. Another concern is that MMP's current population of inference does not include the people living with diagnosed HIV who are not in care and who stand to benefit from ACA provisions that will improve access to health care coverage. CDC is pilot testing the use of the NHSS for patient sampling which would expand the study population to include individuals who are not in care. If redesigned in this way, MMP can provide data on characteristics of HIV-diagnosed adults who are not in care and on the availability and accessibility of health care coverage and utilization to these individuals (CDC, 2012a,b).

MMP also does not include, or lacks adequate representation of, particular subgroups for whom it is critical to monitor access to care and care coverage. For example, black/African American MSM (men who have sex

with men) ages of 13 through 29 are the only risk group to have had a statistically significant increase in the number of new HIV infections between 2006 and 2009 (CDC, 2011a). Because MMP's current population of inference is limited to individuals ages 18 and older, however, it cannot be used to monitor health care coverage and utilization of adolescents 13 to 18 years of age. Adolescents have unique HIV care and treatment challenges and many are recently infected. Thus, it is important to monitor their linkage to and engagement in care (CDC, 2011b; Spiegel and Futterman, 2009). It is also crucial to ensure adequate representation of vulnerable populations such as immigrants, people who are homeless or unstably housed, people with mental and substance abuse disorders, and people who flow in and out of the corrections system. These populations are more likely to experience gaps in health coverage and care (Altice et al., 2010; Baillargeon et al., 2010; Chen et al., 2011; Dang et al., 2012; Mellins et al., 2009; Springer et al., 2011).

Expansion of MMP to include new populations such as adolescents and people not in care may generate the need for additional staffing resources, for example, to locate and recruit potential participants. Substantial resources and expertise are also required to achieve adequate response rates from a nationally representative sample of people with HIV, including those from vulnerable populations, and to support data collection, analysis, and dissemination activities. Training and technical support for staff in the 23 MMP project areas will continue to be essential to the success of the project. It is important that funding for MMP is commensurate with these activities.

Recommendation 2. By 2015, the Centers for Disease Control and Prevention (CDC) should improve the Medical Monitoring Project (MMP) to ensure higher response rates and increased sample representativeness. CDC should expand MMP to include representative numbers of HIV-diagnosed individuals not in care, adolescents, and those in the criminal justice system and take particular care to ensure adequate representation of vulnerable populations, including, but not limited to immigrants; individuals who are homeless or unstably housed; and people with mental or substance use disorders.

The committee encourages CDC to continue to test alternative strategies for improving MMP sample completion and representation of vulnerable populations of people with HIV who are not in care, such as using NHSS as the overall sampling frame (as is currently being tested); using a dual-frame approach, combining facility-based sampling to identify individuals in care with NHSS sampling to identify individuals not in care; implementing real-time sampling, rather than list-based sampling, to sample patients within

select facilities; and extending the time period for participant recruitment and data collection.

Recommendation 3. The Office of National AIDS Policy and the Department of Health and Human Services should use the Medical Monitoring Project, once improved, to obtain nationally representative data on health care coverage and utilization for people with HIV.

HIV surveillance needs shift over time. For example, following the introduction of effective antiretroviral therapy (ART) in the mid-1990s, surveillance requirements expanded to include the extent to which providers prescribe ART as indicated, patient adherence to ART, and met and unmet need for care given the demand on the health care system to treat a growing number of people living with HIV (McNaghten et al., 2007). Similarly, new questions may emerge over time with respect to access to and receipt of quality care by people with HIV as the ACA is implemented. For example, researchers and policy makers may want to gather information on possible causes of changes in care quality resulting from shifts in care coverage and the range of benefits available to people with HIV. A mechanism for periodic evaluation of MMP to ensure that data collected are responsive to changes in the HIV epidemic and in ACA-related informational needs over time should be established.

Recommendation 4. The Department of Health and Human Services should convene and fund a multidisciplinary task force responsible for designing improvements in the Medical Monitoring Project and for ensuring that it remains responsive to changes in the epidemic and the health care environment.

Although an improved MMP will be able to provide an overall picture of trends in health coverage and utilization, additional data sources will be needed to more fully assess trends at the program and state level. Provisions of the ACA, in particular Medicaid expansion, subsidized health coverage for other low-income individuals, increased coverage of preventive care services, and the phasing out of the Medicare Part D prescription drug coverage gap, will affect enrollment and benefits within Medicaid, Medicare, and the Ryan White HIV/AIDS Program, each of which is a source of coverage for a substantial proportion of people with HIV in the United States. Fifty-three percent of people with HIV in the United States are covered by government programs such as these. In addition, the ACA will increase access to health care for many of the almost 30 percent of people with HIV in the United States who currently do not have any source of health care coverage (HHS, 2012a). Data from these programs can provide important

insights into the ACA's impact on access to health coverage and health care for people with HIV.

Because MMP does not include patients in every state it cannot be used for state-by-state analysis of health care coverage and utilization. Data from Medicaid, Medicare, and the Ryan White HIV/AIDS Program are necessary to provide information about differences in care coverage and utilization within and across states. Since not all states will comply with the Medicaid expansion provision of the ACA, monitoring Medicaid eligibility and benefits and service utilization at the state level will be important. In addition, jurisdictional variations, such as those among health insurance exchanges and Ryan White HIV/AIDS Program services, add to the need for monitoring at the state and local level.

Roughly one in five individuals with HIV currently has private health insurance (HHS, 2012a). The proportion of people with HIV who have private health insurance may grow under the ACA due to the creation of state health insurance exchanges that will help employers and individuals purchase health insurance and the establishment of protections that will prevent individuals from being denied coverage due to preexisting conditions, such as HIV or AIDS, or having their coverage rescinded. Although private insurer data are often proprietary, to the extent feasible they should be used in concert with data from MMP and public sources of care coverage to monitor shifts in the care experiences of people with HIV in the context of the ACA.

Recommendation 5. In addition to data from the Medical Monitoring Project, the Office of National AIDS Policy and the Department of Health and Human Services should use data from Medicaid, Medicare, the Ryan White HIV/AIDS Program, and private insurers to monitor the impact of the Patient Protection and Affordable Care Act on health care coverage and utilization at the state and program level.

Increased access to health care through expanded coverage under the ACA will facilitate but not ensure linkage to, retention in, and provision of quality clinical HIV care for people living with HIV. For example, although the number of uninsured HIV-infected individuals will decrease, people near the eligibility borders may be expected to "churn" (i.e., move back and forth) between different sources of coverage (e.g., Medicaid, subsidized insurance through health benefit exchanges), which may affect their continuity in care and the package of benefits for which they are eligible at any given time.

Movement of individuals from the Ryan White HIV/AIDS Program (as their primary source of coverage for HIV care) into Medicaid or other subsidized insurance coverage may affect the scope of services they receive.

The Ryan White HIV/AIDS Program covers many nonclinical services, such as food and nutrition, transportation, child care, and case management services, that are important to the success of clinical HIV care. To the extent that individuals no longer receive such supportive services when they move to other sources of coverage, their clinical service utilization and health outcomes may be negatively affected.

It is important not only to monitor changes in access to health care coverage for people living with HIV but also to monitor any concurrent changes in service utilization and outcomes through the collection of necessary data and estimation of core indicators of HIV care for the populations most affected by coverage changes under the ACA, including Medicaid, Medicare, Ryan White HIV/AIDS Program, and private insurance.

Recommendation 6. The Office of National AIDS Policy, working with the Department of Health and Human Services, should ensure the collection and linkage of data on core indicators[1] to monitor quality of care for people with HIV during and following the implementation of the Patient Protection and Affordable Care Act.

Data tracking health care coverage sources, enrollment, service utilization, and core outcomes among people with HIV are important for monitoring the impact of the ACA and the National HIV/AIDS Strategy (NHAS) on access to and quality of HIV care in the United States over time, facilitating identification of any difficulties encountered, and informing future planning with respect to the health care workforce and the potential redistribution of resources to improve efficiency and quality of care and reduce health disparities. Such data will be of interest and use to policy makers, health care coverage programs and plans, and organizations of health care professionals, among others. Periodic reporting of the data will permit stakeholders to anticipate future needs and make midcourse corrections as needed to advance the goals of the NHAS and maximize access to quality HIV care under the ACA.

[1]Fourteen core indicators for monitoring access to clinical HIV care and mental health, substance abuse, and supportive services were recommended by the committee in its first report, which includes discussion of the collection and linkage of data needed to estimate the indicators (IOM, 2012). HHS currently is in the process of implementing seven common core indicators for monitoring HIV diagnosis, treatment, and care across HHS-funded programs (HHS, 2012b). This recommendation is not intended to duplicate federal efforts to monitor HIV care and supportive services but to ensure that such monitoring occurs in conjunction with the tracking of changes in enrollment patterns and benefit packages among different sources of coverage for HIV care.

Recommendation 7. The Department of Health and Human Services should produce and disseminate a report at least once every 2 years on the care of people with HIV. This report should characterize trends and identify gaps in coverage and care during and following the implementation of the Patient Protection and Affordable Care Act.

Sufficient resources will be required to implement the committee's recommendations. These resources include staffing and funding to support collection and analysis of data from MMP, Medicaid, Medicare, and the Ryan White HIV/AIDS Program to monitor trends in access to health insurance and health care for people with HIV; collection and analysis of data from MMP, Medicaid, Medicare, the Ryan White HIV/AIDS Program, and other data sources to estimate core indicators and assess care quality for people with HIV; and the production and dissemination of a report at least once every 2 years describing the care of people with HIV based on analysis of data from these sources.

REFERENCES

Altice, F. L., A. Kamarulzaman, V. V. Soriano, M. Schechter, and G. H. Friedland. 2010. Treatment of medical, psychiatric, and substance-use comorbidities in people infected with HIV who use drugs. *Lancet* 37:6367-6387.

Baillargeon, J. G., T. P. Giordano, A. J. Harzke, G. Baillargeon, J. D. Rich, and D. P. Paar. 2010. Enrollment in outpatient care among newly released prison inmates with HIV infection. *Public Health Reports* 125(Suppl 1):64-71.

CDC (Centers for Disease Control and Prevention). 2011a. *Estimates of New HIV Infections in the United States, 2006-2009*. http://www.cdc.gov/nchhstp/newsroom/docs/HIV-Infections-2006-2009.pdf (accessed July 18, 2012).

CDC. 2011b. *HIV Among Youth*. http://www.cdc.gov/hiv/youth/pdf/youth.pdf (accessed August 31, 2012).

CDC. 2012a. *Medical Monitoring Project 2012 Protocol.*

CDC. 2012b. *Report on the Use of Centers for Disease Control and Prevention's Medical Monitoring Project to Monitor the Implementation of the Affordable Care Act*. Submission to committee. January.

Chen, N. E., J. P. Meyer, A. K. Avery, J. Draine, T. P. Flannigan, T. Lincoln, A. C. Spaulding, S. A. Springer, and F. L. Altice. 2011. Adherence to HIV treatment and care among previously homeless jail detainees. *AIDS and Behavior* (November 8). DOI 10.1007/s10461-011-0080-2.

Dang, B. N., T. P. Giordano, and J. H. Kim. 2012. Sociocultural and structural barriers to care among undocumented Latino immigrants with HIV infection. *Journal of Immigrant and Minority Health* 14(1):124-131.

HHS (U.S. Department of Health and Human Services). 2012a. *Health Care Reform and HIV/AIDS.* http://aids.gov/federal-resources/policies/health-care-reform/ (accessed July 13, 2012).

HHS. 2012b. *Secretary Sebelius Approves Indicators for Monitoring HHS-Funded HIV Services*. http://blog.aids.gov/2012/08/secretary-sebelius-approves-indicators-for-monitoring-hhs-funded-hiv-services.html (accessed August 30, 2012).

IOM (Institute of Medicine). 2012. *Monitoring HIV Care in the United States: Indicators and Data Systems*. Washington, DC: The National Academies Press.

McNaghten, A. D., M. I. Wolfe, I. Onorato, A. K. Nakashima, R. O. Valdiserri, E. Mokotoff, R. A. Romaguera, A. Kroliczak, R. S. Janssen, and P. S. Sullivan. 2007. Improving the representativeness of behavioral and clinical surveillance for persons with HIV in the United States: The rationale for developing a population based approach. *PLosOne* (6):e550.

Mellins, C. A., J. F. Havens, C. McDonnell, C. Lichtenstein, K. Uldall, M. Chesney, E. K. Santamaria, and J. Bell. 2009. Adherence to antiretroviral medications and medical care in HIV-infected adults diagnosed with mental and substance abuse disorders. *AIDS Care* 21(2):168-177.

Spiegel, H. M. L., and D. C. Futterman. 2009. Adolescents and HIV: Prevention and clinical care. *Current HIV/AIDS Reports* 6(2):100-107.

Springer, S. A., A. C. Spaulding, J. P. Meyer, and F. L. Altice. 2011. Public health implications for adequate transitional care for HIV-infected prisoners: Five essential components. *Clinical Infectious Diseases* 53(5):469-479.

Appendix

Biographical Sketches of Committee Members

Paul A. Volberding, M.D. (*Chair*), is a professor in the Department of Medicine and Director of the AIDS Research Institute at the University of California, San Francisco (UCSF). He is also co-director of the UCSF-GIVI Center for AIDS Research and Director of Research, Global Health Sciences, at UCSF. Dr. Volberding received his medical degree from the University of Minnesota and finished training at the University of Utah and UCSF, where he studied for 2 years as a research fellow in the virology laboratory of Dr. Jay Levy, later a co-discoverer of HIV. Dr. Volberding's professional activities initially centered at San Francisco General Hospital where he established a model program of AIDS patient care, research, and professional education. His research career began with investigations of HIV-related malignancies, especially Kaposi's sarcoma. His primary research focus, however, shifted to clinical trials of antiretroviral drugs. He was instrumental in testing many compounds but is best known for groundbreaking trials establishing the benefit of treatment in early stage HIV infection. Dr. Volberding has written many research and review articles. He is coeditor in chief of the *Journal of Acquired Immune Deficiency Syndromes* and is the founder and chair of the board of the International AIDS Society-USA and a past president of the International AIDS Society (IDSA). He was president of the HIV Medicine Association of the Infectious Diseases Society of America. He is a fellow of the American Association for the Advancement of Science, the American College of Physicians, and of IDSA, and he is a member of the Institute of Medicine, where he has served on several committees addressing the HIV epidemic.

Angela A. Aidala, Ph.D., is an associate research scientist at the Joseph L. Mailman School of Public Health at Columbia University in the Department of Sociomedical Sciences. Her primary interest is the intersection of economic, social, and cultural influences on health and illness among disadvantaged populations. Dr. Aidala's work focuses on research, teaching, and service delivery strategies to work effectively with harder–to–reach or "hidden" populations in urban settings, including the homeless, mentally ill, substance users, HIV–infected adults, and youth. Dr. Aidala has directed more than 20 collaborative community health or services research projects. Her recent work is studying housing/lack of housing and HIV prevention and care and methodological and statistical approaches to improve "practice-based" evidence. Dr. Aidala is coprincipal director and study director of the Community Health Advisory & Information Network (CHAIN), an ongoing study of persons living with HIV or at high risk of infection in New York City, now in its eighteenth year. CHAIN is conducted in collaboration with the HIV Planning Council and the New York Health Department of Health and Mental Hygiene and is a main source of data for service planning in the region. Formerly she directed the Multiple Diagnoses Initiative, a Department of Housing and Urban Development–Department of Health and Human Services joint initiative that worked with housing providers to better understand the reciprocal relationship between housing and health care among persons living with HIV/AIDS who also struggle with mental illness and/or chronic substance abuse problems. Dr. Aidala received her Ph.D. in sociology from Columbia University.

David D. Celentano, Sc.D., M.H.S., is professor and Charles Armstrong Chair of the Department of Epidemiology in the Johns Hopkins Bloomberg School of Public Health, with joint appointments in medicine; international health; and health, society, and behavior. His research integrates behavioral science theory and research with epidemiologic methods in the study of behavioral and social epidemiology. Although originally trained in a chronic disease paradigm (alcoholism and cancer control), he began his research in HIV/AIDS and sexually transmitted diseases (STDs) in the early 1980s. He has worked on some of the major cohort studies (AIDS Link to the Intravenous Experience [ALIVE], Multicenter AIDS Cohort Study [MACS]) in HIV epidemiology, as well as conducted intervention research in the United States for heterosexual men and women, injection drug users, and young men who have sex with men. He began international HIV research in 1990 through a long-term collaboration with Chiang Mai University in northern Thailand. He has worked on and directed numerous HIV/AIDS and STD epidemiological investigations and preventive interventions. He and his collaborators demonstrated that a behavioral intervention with young military conscripts led to a sevenfold reduction in incident STDs and halved the

HIV incidence rate. In addition, the role of STDs and alcohol use in HIV acquisition has been shown. His research group conducted a prospective study of hormonal contraception in relation to HIV seroconversion and elucidated the epidemiology of human papillomavirus prevalence, incidence, and clearance—a study with significant family planning policy and health implications. Today, he is the principal investigator of four studies in Thailand supported by the National Institutes of Health, focusing on interventions to influence the association between drug use, sexual risk, and HIV treatment in HIV transmission. Additional research is being conducted in Vietnam, India, South Africa, and Tanzania.

Moupali Das, M.D., M.P.H., is director of research in the HIV Prevention Section at the San Francisco Department of Public Health and assistant clinical professor in the Divisions of Infectious Diseases and HIV/AIDS at San Francisco General Hospital, at the University of California, San Francisco. She is a board-certified infectious disease clinician-HIV specialist with research expertise in implementation science and evaluation research, in particular, using routinely collected HIV surveillance data to evaluate the impact of a comprehensive public health approach to HIV, including multilevel HIV prevention interventions. Dr. Das coauthored a key modeling study using San Francisco's surveillance data to evaluate the effect of expanding access to antiretroviral therapy on the HIV epidemic among MSM. She has developed a novel population-based biologic indicator, community viral load, for monitoring the HIV epidemic prevention and control. Her manuscript on community viral load (Das, *PLOS One* 2010) has been cited as the basis for measuring community viral load in President Barack Obama's National HIV/AIDS Strategy (NHAS) and provides the framework for the NHAS recommendation that community viral load be used as an outcome measure to evaluate the effectiveness of the strategy. Dr. Das has examined geographic and sociodemographic disparities in community viral load as well as the relationship between community viral load and new HIV infections. She is evaluating the relationship between differences in community viral load among different subpopulations in San Francisco and corresponding disparities in HIV incidence. Dr. Das is currently refining the community viral load methodology and exploring using community viral load as a marker for multiple planned multilevel HIV prevention trials. Dr. Das has been honored by invitations to participate in the Department of Health and Human Services and the Office of Management and Budget consultations on developing a parsimonious set of harmonized indicators to evaluate the impact of the NHAS and health care reform. Dr. Das has been privileged to mentor junior investigators to support publication of their manuscripts on community viral load (Castel, *AIDS* 2011).

Victor G. DeGruttola, Sc.D., M.S., is a professor of biostatistics and chair of the Department of Biostatistics at the Harvard School of Public Health. His research activities focus on developments of statistical methods required for appropriate public health response to the AIDS epidemic both within the United States and internationally. The aspects of the epidemic on which he has worked include transmission of, and natural history of infection with, HIV, as well as research on antiretroviral treatments, including the development and consequences of resistance and other adverse consequences of treatments. The broad goals of his research include developing treatment strategies that provide tolerable and durable virologic suppression while preserving treatment options after failure and evaluating the community-level impact of packages of prevention interventions, including antiviral treatment itself. He served as the director of the Statistics and Data Analysis Center of the Adult Project of the AIDS Clinical Trials Group during the period in which highly active antiretroviral treatment was developed, and he was instrumental in designing and analyzing studies of the best means of providing such therapy. Most recently, he has been engaged in development and application of methods for prevention of HIV infection.

Carlos del Rio, M.D., is the Hubert Professor and Chair of the Hubert Department of Global Health at the Rollins School of Public Health and professor of medicine in the Division of Infectious Diseases at the Emory University School of Medicine. He is also codirector of the Emory Center for AIDS Research. He has held numerous leadership roles including executive director of the National AIDS Council of Mexico, the federal agency of the Mexican government responsible for AIDS policy in that country; program director and principal investigator of the Emory AIDS International Training and Research Program; and member of the Board of the International AIDS Society–USA, the HIV Medicine Association, and the Infectious Diseases Society of America. Dr. del Rio's research interests include the epidemiology of opportunistic infections in HIV and other immune deficiencies, the epidemiology and transmission dynamics of HIV and other sexually transmitted diseases, HIV testing, access to and retention in care, and compliance with antiretroviral drug regimens. He is also interested in the impact of HIV in developing countries and the optimal use of antiretroviral drugs in limited-resource settings. Dr. del Rio is associate editor of *AIDS Clinical Care* and senior clinical editor for *AIDS Research and Human Retroviruses* and is a member of the editorial board of *Journal of AIDS* and *Global Public Health*. He has coauthored more than 150 scientific papers.

Marshall Forstein, M.D., is an associate professor of psychiatry at Harvard Medical School and director of Adult Psychiatry Residency Training at the

Cambridge Health Alliance. He attended the College of Medicine, University of Vermont, after a career of teaching high school English, where he developed a lifelong interest in teaching and education. He completed an internship at Presbyterian Hospital, Pacific Medical Center in San Francisco, and a residency in psychiatry at Massachusetts General Hospital. For 12 years he served as Medical Director of Mental Health and Addiction Services of the Fenway Community Health Center in Boston, a dedicated center for the care of sexual minorities and people at risk for and living with HIV infection. Dr. Forstein teaches medical students and is a core faculty member in the Division of Palliative Care at Harvard Medical School. Dr. Forstein has been treating people with HIV since the beginning of the epidemic, and he cofounded an integrated medical/psychiatric HIV clinic that has been treating a diverse population of people infected with HIV for more than 25 years. He served as a member of the board of directors of the AIDS Action Committee of Massachusetts. Dr. Forstein has been a principal investigator on an HIV Education and Training Grant through the federal Center for Mental Health Services and later served as a member of the Advisory Board of the Center for Mental Health Services of the Substance Abuse and Mental Health Service Administration. He teaches and has published on the neuropsychiatry and psychosocial aspects of the HIV/AIDS epidemic. He currently chairs the Steering Committee on HIV Psychiatry for the American Psychiatric Association for Research and Education. He is a distinguished fellow of the American Psychiatric Association and is currently serving on the Residency Review Committee for Psychiatry of the Accreditation Council for Graduate Medical Education.

Carmine Grasso, M.S.W., M.P.H., is currently a consultant working on HIV policy and funding issues. He recently retired from public service from the New Jersey Department of Health and Senior Services where he served as Director of the Care and Treatment Unit, which oversees the development of integrated systems designed to address the care and treatment needs of persons living with HIV in New Jersey. This unit serves as the Ryan White Part B grantee in New Jersey and oversees CARE Act activities, which include the AIDS Drug Distribution Program, the HIV Home Care Program, the Health Insurance Continuation Program, and regional HIV Care Services. Mr. Grasso has served as a consultant for the Centers for Disease Control and Prevention Global AIDS Program and the National Alliance of State and Territorial AIDS Directors. From 1979 to 1981, Mr. Grasso served as a Peace Corps volunteer in the Republic of Kiribati, where he worked as an outer island health education and sanitation worker in a primary health care program sponsored by the World Health Organization. Mr. Grasso received his M.P.H. and M.S.W. degrees from Columbia University.

Shannon Houser, Ph.D., M.P.H., RHIA, is an associate professor in the Health Information Management Program in the Department of Health Services Administration, School of Health Professions of the University of Alabama at Birmingham (UAB). Dr. Houser works on many research studies at UAB, mostly large national studies of epidemiology, health behavior, health information technology, data management, and program evaluation. She brings her expertise in health information management, the Health Information Portability and Accountability Act Privacy Rule, and electronic health record implementation and evaluation. She has published widely in professional journals. Dr. Houser has been appointed as an adviser to Project HOPE and provides technical advice on program monitoring and evaluation for most ongoing HOPE-sponsored projects in China. Dr. Houser serves as a member of the American Health Information Management Association's Education Strategy Committee and Research Committee and the Healthcare Information and Management Systems Society's Scholarship Committee and Electronic Health Record Usability Task Force. She has served on the editorial review board and is currently a reviewer of the journal *Perspectives in Health Information Management*. Dr. Houser also develops courses and teaches in the undergraduate and graduate Health Information Management Programs for both traditional classroom courses and online or distance learning courses.

Jennifer Kates, Ph.D., M.A., M.P.A., is vice president and director of Global Health & HIV Policy at the Henry J. Kaiser Family Foundation (KFF), where she oversees the foundation's policy analysis and research focused on the U.S. government's role in global health and on the global and domestic HIV epidemics. Widely regarded as an expert in the field, she regularly publishes and presents on global health issues and is particularly known for her work on analyzing donor government investments in global health; assessing and mapping the U.S. government's global health architecture, programs, and funding; and tracking key trends in the HIV epidemic, an area in which she has been working for more than 20 years. Prior to joining KFF in 1998, Dr. Kates was a senior associate with the Lewin Group, a health care consulting firm, where she focused on HIV policy, strategic planning and health systems analysis, and health care for vulnerable populations. Before that, she directed the Office of Lesbian, Gay, and Bisexual Concerns at Princeton University. Dr. Kates also serves on numerous federal and private sector advisory committees on global health and HIV/AIDS issues. She is a former member of the Institute of Medicine (IOM) Committee on Planning the Evaluation of Global HIV/AIDS Programs Implemented Under the U.S. Global Leadership Against HIV/AIDS, Tuberculosis, and Malaria Reauthorization Act of 2008, as well as the IOM Committee on HIV Screening and Access to Care. Dr. Kates received her Ph.D. in health

policy from the George Washington University, where she is also a lecturer. She holds a bachelor's degree from Dartmouth College, a master's degree in public affairs from Princeton University's Woodrow Wilson School of Public and International Affairs, and a master's degree in political science from the University of Massachusetts.

Erika G. Martin, Ph.D., M.P.H., is an assistant professor of public administration and policy at the Rockefeller College of Public Affairs and Policy and an institute fellow at the Nelson A. Rockefeller Institute of Government, State University of New York at Albany. She teaches undergraduate and graduate courses on policy analysis methods and health policy. Dr. Martin has examined the fairness and flexibility of the federal allocation formula for the Ryan White HIV/AIDS Program, interstate variation in state AIDS Drug Assistance Program formularies, and the budget impact of expanded HIV screening on government testing, discretionary, and entitlement programs. Current projects include using system dynamics modeling to evaluate the new HIV testing law in New York State, analyzing the effects of the recently repealed ban on federal funding for syringe exchange programs, and assessing how health reform may affect AIDS Drug Assistance Programs. In addition to her research on HIV and substance abuse policy, Dr. Martin is actively involved in various projects that examine the public health effects of state vaccination laws and the way media influence public policy and public health practice. Dr. Martin received her B.A. from Brown University, her M.P.H. in epidemiology from the University of Michigan, and her Ph.D. in health policy and administration from Yale University.

Kenneth H. Mayer, M.D., is the director of HIV Prevention Research at Beth Israel Deaconess Medical Center and a visiting professor in medicine at Harvard Medical School. Previously, Dr. Mayer was professor of medicine and community health and director of the AIDS Program at Brown University and an attending infectious disease physician at Miriam Hospital. He is medical research director at Fenway Community Health in Boston and codirector of the Fenway Institute. Dr. Mayer has conducted studies of HIV's natural history and interventions to interrupt transmission since the beginning of the epidemic. He was one of the first clinical researchers in New England to care for patients living with AIDS. Dr. Mayer has lectured at many international conferences and symposia on biological and behavioral approaches to HIV prevention research and the development of community-based clinical research. He coedited *The Emergence of AIDS: Impact on Immunology, Microbiology, and Public Health* (APHA Press); *HIV Prevention: A Comprehensive Approach* (Academic Press); and *The Fenway Guide to Lesbian, Gay, Bisexual and Transgender Health* (ACP

Press). He has served as a member of the Data and Safety Monitoring Board of NIH's AIDS Clinical Trials Group and sits on several editorial boards of scientific publications. Dr. Mayer has co-authored more than 450 articles, chapters, and other publications on AIDS and related infectious disease topics.

Vickie M. Mays, Ph.D., M.S.P.H., is a professor in the Department of Psychology in the College of Letters and Sciences, as well as a professor in the Department of Health Services at the University of California, Los Angeles (UCLA) School of Public Health. She is also the director of the UCLA Center on Research, Education, Training and Strategic Communication on Minority Health Disparities. She teaches courses on health status and health behaviors of racial and ethnic minority groups; research ethics in biomedical and behavioral research on racial and ethnic minority populations; research methods in minority research; mental health policy and mental health services; and the social determinants of mental disorders and psychopathology. She holds a Ph.D. in clinical psychology and an M.S.P.H. in health services, with postdoctoral training in psychiatric epidemiology, survey research as it applies to ethnic minorities (University of Michigan), and health policy (RAND). Professor Mays's research focuses on the mental and physical health disparities affecting racial and ethnic minority populations. She has a long history of research and policy development in the area of contextual factors surrounding HIV/AIDS in racial, ethnic, and sexual minorities. This work ranges from looking at barriers to education and services to understanding racially based immunological differences that may contribute to disparities in health outcomes. Other areas of research include looking at the role of perceived and actual discrimination in mental and physical health outcomes, particularly as these factors impact downstream disease outcomes. Her mental health research examines the availability, access, and quality of mental health services for racial, ethnic, and sexual minorities and effective and efficient methods for integrating behavioral health of these populations into primary care systems. She is the co-principal investigator of the California Quality of Life Survey, a population-based study of more than 5,000 Californians on the prevalence of mental health disorders and the contextual factors associated with those disorders. Her recent work in mental health includes the provision of mental health disaster response, recovery, and preparedness as the director of a Kellogg-sponsored project in New Orleans, "Helping Hands, Healing Hearts," which designed training for mental health providers and religious leaders. Dr. Mays has provided testimony to a number of congressional committees on her HIV, mental health, and health disparities research findings. She was chair of the Subcommittee on Populations of the National Committee on Vital and Health Statistics. There she helped develop a report

on the role of the collection of data on race, ethnicity, and primary language to reduce health disparities. She has received a number of awards, including one for her lifetime research on women and HIV from the American Foundation for AIDS Research, a Women and Leadership Award from the American Psychological Association, and several distinguished contributions for research awards.

David P. Pryor, M.D., M.P.H., is West Coast medical director for NBC Universal, where he oversees medical services provided to company employees, promotes the corporate–wellness agenda, and serves as a subject matter expert on legal and production-related health and safety issues. Previously, Dr. Pryor was medical director for Aetna, one of the largest health benefits companies in the United States, where he was responsible for a number of medical management activities that resulted in the coordination of quality, cost-effective care on behalf of Aetna members. He also proactively used data analysis to identify new opportunities to increase the effectiveness and efficiency of care. Prior to joining Aetna, Dr. Pryor was an associate medical director at WellPoint, where he was fortunate to have been actively involved with almost all aspects of medical management, including utilization management, medical policy, disease management, and program development. Dr. Pryor maintains a strong commitment to impacting health disparities and serves as the president and founder of BlackWomensHealth.com, one of the leading Internet sites dedicated to improving the health and wellness of African American women. Additionally, he serves on the IOM Roundtable on the Promotion of Health Equity and the Elimination of Health Disparities and was a featured speaker on the Congressional Black Caucus Foundation's Black Health Empowerment Tour. A native of California, Dr. Pryor received a B.S. in biology from Stanford University and completed his medical degree at the University of California, San Diego. He is board-certified in internal medicine and also has a master's degree in public health from the University of California, Berkeley.

Sten H. Vermund, M.D., Ph.D., is Amos Christie Chair in Global Health and professor of pediatrics at Vanderbilt University and director of the Vanderbilt Institute for Global Health. With interests in adolescence, cervical cancer prevention, and prevention of mother-to-child transmission of HIV, he has focused on issues of special relevance to women and HIV. Dr. Vermund served as chief of the Vaccine Trials & Epidemiology Branch in the National Institutes of Health (NIH) Division of AIDS at the National Institute of Allergy and Infectious Diseases from 1988 to 1994 and was awarded the Superior Service Award of the U.S. Public Health Service in 1994 for his work in HIV vaccine clinical trial development. Dr. Vermund founded the Centre for Infectious Disease Research in Zambia in 2000,

now a major research venue and President's Emergency Plan for AIDS Relief implementer. In 2007, he founded Friends in Global Health, LLC, to spearhead HIV prevention, care, and treatment in rural Mozambique and Nigeria. He served from 2006 to 2012 as principal investigator for the HIV Prevention Trials Network, with sites in the United States, Africa, Asia, and South America. His collaboration with the Chinese Center for Disease Control and Prevention seeks to implement a "test and linkage to care" initiative for HIV-infected men who have sex with men; the dual goal is to reduce community transmission and, at the same time, improve the quality of life for HIV-infected persons. His training initiatives include the Gorgas Course in Clinical Tropical Medicine in Lima, Peru; an AIDS International Training and Research Program in Zambia, Mozambique, India, Pakistan, Bangladesh, and China; and the Fogarty International Clinical Research Scholars and Fellows Support Center, with 472 trainees and alumni over 5 years in 45 developing-country sites doing 1-year mentored overseas research training. Dr. Vermund is co-principal investigator of the Medical Education Partnership Initiative award to the University of Zambia to build manpower capacity in HIV control. Dr. Vermund sits on U.S. and European university, WHO, U.S. Agency for International Development, and NIH advisory committees.

Adam B. Wilcox, Ph.D., is an associate professor in the Department of Biomedical Informatics at Columbia University and the director of clinical databases for New York Presbyterian Hospital. His primary interest is the application of health information technology in transforming the research, discovery, and delivery of health care. He currently leads a project to create a research infrastructure that incorporates data from multiple institutions and includes patient-reported data, with the goal of supporting comparative-effectiveness studies of multiple diseases. He has worked in supporting the use of data from existing clinical systems for research and manages an electronic health record at Columbia University Medical Center. He also directed the development of a community-centered health information exchange in Washington Heights, New York City, with the goal of improving care in a medically underserved immigrant population. Previously at Intermountain Healthcare and as faculty at the University of Utah, Dr. Wilcox led the design and implementation of electronic health records in the primary care and emergency department settings and was the principal investigator of a project studying the comparative effectiveness of care management in ambulatory care. He received his Ph.D. in medical informatics from Columbia University.

Douglas Wirth, M.S.W., is president and chief executive officer of AmidaCare, a nonprofit Medicaid HIV Special Needs Plan specifically designed for

persons living with HIV/AIDS that works with its members and providers to improve access to and retention in care. He is the former executive director of the People with AIDS Coalition of New York, a past chairperson of the New York AIDS Coalition, and former health policy adviser to New York City Mayors Dinkins and Giuliani where he served as chair of Strategic Planning and Evaluation for the NYC HIV Planning Council. As a senior faculty member of the American Psychological Association Office of AIDS' HOPE Project, he provided continuing education, health, and mental health training from coast to coast. Mr. Wirth completed his master's degree in social work at Hunter College, City University of New York. He is presently a board member of the Association for Community-Affiliated Plans.