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

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MONITORING HIV CARE
IN THE UNITED STATES
INDICATORS AND DATA SYSTEMS

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

ABC	Abacavir
ACA	Patient Protection and Affordable Care Act
ADAP	AIDS Drug Assistance Program
ADR	*ADAP Data Report*
AI/AN	American Indian or Alaskan Native
AIDS	acquired immune deficiency syndrome
AMPATH	Academic Model Providing Access to Healthcare
APR	Annual Progress Report
ARRA	American Recovery and Reinvestment Act of 2009
ART	antiretroviral therapy
ARV	antiretroviral
ASPR	Assistant Secretary for Preparedness and Response
BC	British Columbia
BEMR	Bureau of Prisons Electronic Medical Record
BOP	Federal Bureau of Prisons
CAH	critical access hospital
CAPER	Consolidated Annual Performance Evaluation Report
CCR	Clinical Case Registry
CCW	Chronic Condition Data Warehouse
CD4	CD4+ T cell
CDC	Centers for Disease Control and Prevention
CDS	clinical decision support
CFAR	Centers for AIDS Research

CFR	Code of Federal Regulations
CHC	community health center
CLIA	Clinical Laboratory Improvement Amendments
CMS	Centers for Medicare and Medicaid Services
CNICS	CFAR Network of Integrated Clinical Systems
CNS	central nervous system
CPOE	computerized physician order entry
CRS	Clinical Reporting System
ECHPP	Enhanced Comprehensive HIV Prevention Planning Project
EHR	electronic health record
ELR	electronic laboratory reporting system
EMR	electronic medical record
eRx	e-prescribing
FDA	Food and Drug Administration
FPL	federal poverty level
FQHC	federally qualified health center
FQHCLA	federally qualified health center “look-alike”
HAART	highly active antiretroviral therapy
HAB	HIV/AIDS Bureau
HBV	hepatitis B virus
HCCI	Health Care Cost Institute
HCV	hepatitis C virus
HEARTH	Homeless Emergency Assistance and Rapid Transition to Housing Act of 2009
HHS	U.S. Department of Health and Human Services
HIE	health information exchange
HIPAA	Health Insurance Portability and Accountability Act
HIRD®	HealthCore Integrated Research Database
HITECH	Health Information Technology for Economic and Clinical Health
HITSP	Healthcare Information Technology Standards Panel (HHS)
HIV	human immunodeficiency virus
HIVRN	HIV Research Network
HMIS	Homeless Management Information System
HMO	health maintenance organization
HMS	HIV Management System
HOPWA	Housing Opportunities for Persons with AIDS
HPTN	HIV Prevention Trials Network

HPV	human papillomavirus
HRSA	Health Resources and Services Administration
HUD	U.S. Department of Housing and Urban Development
ICD-9	International Classification of Diseases, Ninth Revision
IDU	injection drug use
IHS	Indian Health Service
IOM	Institute of Medicine
IQA	Information Quality Act/Data Quality Act
IPW	inverse-probability weighting
IT	information technology
KFF	Kaiser Family Foundation
KP	Kaiser Permanente
LaPHIE	Louisiana Public Health Information Exchange
LSU HCSD	Louisiana State University Health Care Services Division
MAX	Medicaid Analytic eXtract
MCBS	Medicare Current Beneficiary Survey
MCO	managed care organization
MMP	Medical Monitoring Project
MoCA	Montreal Cognitive Assessment scale
MSA	metropolitan statistical area
MSIS	Medicaid Statistical Information System
MSM	men who have sex with men
NA-ACCORD	North American AIDS Cohort Collaboration on Research and Design
NASTAD	National Alliance of State and Territorial AIDS Directors
NHAS	National HIV/AIDS Strategy
NHSS	National HIV Surveillance System
NIH	National Institutes of Health
NJDHSS	New Jersey Department of Health and Senior Services
NQF	National Quality Forum
NRC	National Research Council
NVSS	National Vital Statistics System
NwHIN	Nationwide Health Information Network
NYC DOHMH	New York City Department of Health and Mental Hygiene

OASIS	Outcome and Assessment Information Set
OCR	Office of Civil Rights
OI	opportunistic infection
OMB	Office of Management and Budget
ONAP	White House Office of National AIDS Policy
ONC	Office of the National Coordinator for Health Information Technology
PACHA	Presidential Advisory Council on HIV/AIDS
PCIP	Primary Care Information Project (NYC DOHMH)
PCP	*pneumocystis jiroveci pneumonia*
PEPFAR	U.S. President's Emergency Plan for AIDS Relief
PHI	protected health information
PHR	personal health record
PHS	Public Health Service
PLWHA	people living with HIV/AIDS
PRO	patient-reported outcome
QSOA	qualified service organization agreement
RHIO	regional health information organization
RNA	ribonucleic acid
RPMS	Resource and Patient Management System
RSR	*Ryan White HIV/AIDS Program Service Report*
SPNS	Special Projects of National Significance
STD	sexually transmitted disease
STI	sexually transmitted infection
SUN	Study to Understand the Natural History of HIV/AIDS in the Era of Effective Therapy
TB	tuberculosis
UAB	University of Alabama at Birmingham
USDA	U.S. Department of Agriculture
USPSTF	U.S. Preventive Services Task Force
VA	U.S. Department of Veterans Affairs
VHA	Veterans Health Administration
VL	Viral load
VistA	Veterans Health Information Systems and Technology Architecture

Summary[1]

BACKGROUND

The number of people living with HIV/AIDS (PLWHA) in the United States is growing each year largely due both to advances in treatment that allow HIV-infected individuals to live longer and healthier lives and to a steady number of new HIV infections each year. The U.S. Centers for Disease Control and Prevention (CDC) estimates that there were 1.2 million people living with HIV infection in the United States at the end of 2008, the most recent year for which national prevalence data are available. As a disease that disproportionately affects populations who already have a range of care and supportive service needs, now more than ever HIV requires continuous and coordinated quality care. Furthermore, there continue to be challenges to curbing the toll of the epidemic. Each year, approximately 16,000 individuals die from AIDS despite overall improvements in survival, and 50,000 individuals become newly infected with HIV. In 2011, the CDC estimated that about three in four people living with diagnosed HIV infection are linked to care within 3 to 4 months of diagnosis and that only half are retained in ongoing care. Treatment with antiretroviral therapy (ART) can help to reduce the level of HIV virus in the blood, sometimes to viral suppression (i.e., to an undetectable level), resulting in improved health outcomes for PLWHA as well as reduced risk of HIV transmission. Yet, only 19–28 percent of PLWHA are virally suppressed.

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

The National HIV/AIDS Strategy and the Patient Protection and Affordable Care Act

In the context of the continuing challenges posed by HIV, the White House Office of National AIDS Policy (ONAP) released a National HIV/AIDS Strategy (NHAS) for the United States in July 2010. The primary goals of the NHAS are to

- reduce HIV incidence;
- increase access to care and optimize health outcomes for PLWHA; and
- reduce HIV-related health disparities.

Federally run HIV programs traditionally have been administered in a siloed fashion due to differences in the missions of the agencies within which they originate or in funding stream requirements. Meeting the NHAS objectives will require increased synergy of HIV programs across federal agencies, and among federal agencies, states, and other jurisdictions. As such, the NHAS includes a fourth objective to increase coordination of HIV program activities across levels of government. Subsumed within this objective is the development of improved mechanisms to monitor progress in achieving the NHAS goals. In the agency operational plans for the NHAS, this Institute of Medicine (IOM) report is named as one of the activities that ONAP is undertaking to address existing gaps in the collection, analysis, and integration of data on the care and treatment experiences of PLWHA.

The NHAS is intended to build upon the Patient Protection and Affordable Care Act (ACA), which—if implemented as originally planned—is expected to bring millions of uninsured individuals, including many PLWHA, into the health care system. Examples of provisions of the ACA that may increase access to care for PLWHA include changes in eligibility requirements for public (e.g., Medicaid) and private health insurance, reduced out-of-pocket costs for Medicare Part D prescription drugs, expansion of coverage for preventive health services, and increased care capacity in community health centers.

CHARGE TO THE COMMITTEE

ONAP requested that the IOM convene a committee to identify critical data and indicators related to continuous HIV care and access to supportive services, as well as to monitor the impact of the NHAS and the ACA on improvements in HIV care. In addition, the committee was tasked with identifying public and private data systems that capture the data needed to estimate these indicators. The committee was also asked to address a series of specific questions related to the collection, analysis, and dissemination of such data (Box S-1). The IOM convened a committee of 17 members with expertise in HIV clinical care and supportive services, health policy, data collection and analysis, informatics, and other relevant areas to respond to this charge.

COMMITTEE'S APPROACH TO ITS CHARGE

NHAS targets for increasing access to care and improving health outcomes for PLWHA and for reducing HIV-related health disparities by 2015 (Box S-2) provided the basis for several of the indicators recommended by the committee.[2] The committee also reviewed existing indicators of HIV care and measures of HIV care quality. These include Healthy People 2020 objectives and President's Emergency Plan for AIDS Relief (PEPFAR) indicators that pertain to HIV care and supportive services, as well as performance measures for HIV care that were endorsed by the National Quality Forum, an organization that sets national consensus standards of performance in health care. The committee also reviewed current guidelines for HIV treatment. The committee identified indicators linked to benchmarks along the continuum of HIV care, from diagnosis through virologic suppression (Figure S-1).

The committee compiled a list of 32 public and private data systems and data collection agencies, including ones highlighted in the project proposal from ONAP and others identified by the committee as potentially important sources of information on HIV care and supportive services. The committee reviewed both HIV-specific data systems and data collection activities, such as epidemiologic studies of PLWHA and Ryan White HIV/AIDS Program data, and those that are not HIV specific but capture information on care received by PLWHA, such as Medicaid and Medicare claims data. The committee requested information from individuals who are familiar with the data systems and data collection activities in the areas of HIV testing and linkage to care, clinical care, access to care, treatment and adherence, financial security, need for supportive services, demographics, risk behavior assessment, and patient experience with care. The committee then compared the compiled information against the data elements needed to estimate the indicators to identify the best sources of

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[2] The committee interpreted its charge as focusing on the population of people living with HIV/AIDS (PLWHA) who have been diagnosed with HIV. Therefore, the committee did not identify indicators to monitor the National HIV/AIDS Strategy (NHAS) objective related to reducing the occurrence of new HIV infections, although some of the indicators promote reduced HIV transmission as well as improved health outcomes for PLWHA.

BOX S-1
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.

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 support 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?
    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 or configured in order to improve the collection of comprehensive data describing the care experiences of people living with HIV?

BOX S-2
National HIV/AIDS Strategy Targets

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

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.
- 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.

Targets for Reducing HIV-Related Health Disparities and Inequities

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.

data for gauging the impact of the NHAS and ACA on improvements in HIV care.

The committee's information gathering for the remaining aspects of its charge consisted of presentations before the committee during its open sessions and review of the research literature.

COMMITTEE'S RECOMMENDATIONS

Core Indicators Related to Continuous HIV Care and Access to Supportive Services

The committee concluded that the primary challenges to optimal health outcomes for PLWHA include late diagnosis, delayed linkage to care for HIV, poor retention in care, delayed initiation of ART, and poor adherence to ART (i.e., discontinuing or intermittent use of ART), as well as untreated non-HIV comorbidities (e.g., substance abuse, hepatitis C), and unmet basic needs (e.g., housing, food, or transportation assistance needs). The commit-

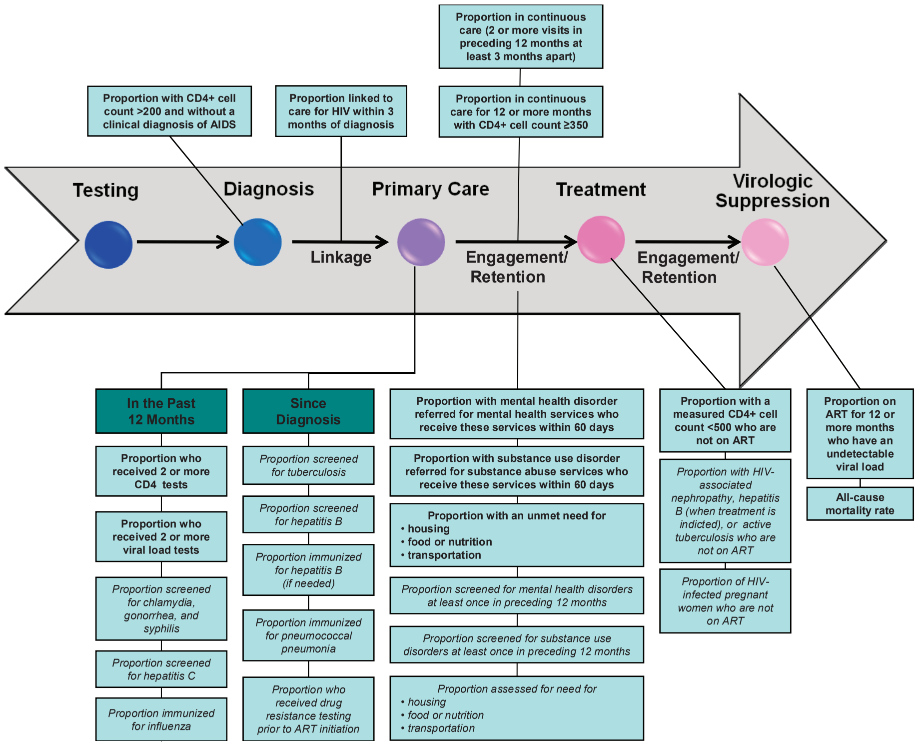

FIGURE S-1 Continuum of HIV care arrow mapped to indicators of HIV care and supportive services.
NOTE: Indicators in bold text correspond with the committee's recommended core indicators, while the indicators in italics correspond with the additional indicators. More information on the committee's selection of both core and additional indicators can be found in Chapter 2.

tee identified a set of core indicators that can be used to measure the degree to which these challenges are being addressed across the continuum of HIV care and to monitor the impact of the NHAS and ACA on improvements in HIV care (Table S-1 provides the committee's rationale for each of the core indicators).

> **Recommendation 2-1. The Department of Health and Human Services should use the following core indicators to assess the impact of the National HIV/AIDS Strategy and the Patient Protection and Affordable Care Act on improving HIV/AIDS care and access to supportive services for individuals with HIV:**
>
> ***Core Indicators for Clinical HIV Care***
>
> > **Proportion of people newly diagnosed with HIV with a CD4+ cell count >200 cells/mm^3 and without a clinical diagnosis of AIDS**
> >
> > **Proportion of people newly diagnosed with HIV who are linked to clinical care for HIV within 3 months of diagnosis**
> >
> > **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)**
> >
> > **Proportion of people with diagnosed HIV infection who received two or more CD4 tests in the preceding 12 months**
> >
> > **Proportion of people with diagnosed HIV infection who received two or more viral load tests in the preceding 12 months**
> >
> > **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**
> >
> > **Proportion of people with diagnosed HIV infection and a measured CD4+ cell count <500 cells/mm^3 who are not on ART**
> >
> > **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**
> >
> > **All-cause mortality rate among people diagnosed with HIV infection**

Core Indicators for Mental Health, Substance Abuse, and Supportive Services[3]

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[4]

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[5]

Proportion of people with diagnosed HIV infection who were homeless or temporarily or unstably housed at least once in the preceding 12 months[6]

Proportion of people with diagnosed HIV infection who experienced food or nutrition insecurity at least once in the preceding 12 months[7]

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[3] As discussed in Chapter 2, the committee found that the indicators for supportive services may be particularly difficult to measure. However, there is evidence from research that addressing need for housing, food security, and other supportive services is effective for retention in care and improving health outcomes among people with HIV. In addition, the committee was specifically asked to address core indicators relating to "access to support services, such as housing," as well as those relating to continuous care. The fact that indicators for supportive services may be difficult to estimate did not preclude the committee from including them as core indictors.

[4] 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.

[5] See footnote 4 above.

[6] The U.S. Department of Housing and Urban Development's Homeless Management Information System (HMIS) Data Standards provide guidance for classifying housing status in four categories: *literally homeless* (e.g., lack a regular nighttime residence, staying in an emergency shelter), following the McKinney-Vento Homeless Assistance Act (42 U.S.C. 11302, Sec. 103) definition of homelessness, as amended by the Homeless Emergency Assistance and Rapid Transition to Housing (HEARTH) Act of 2009 (P.L. 111-22, div. B, Sec. 1003); *imminently losing housing* (e.g., being evicted or being discharged from an institution with no housing options identified); *unstably housed and at-risk of losing housing* (e.g., temporarily doubled up with others, moving frequently for economic reasons); and *stably housed* (http://www.hudhre.info/documents/FinalHMISDataStandards_March2010.pdf, accessed March 12, 2012).

[7] According to the U.S. Department of Agriculture, households with *high food security* have "no reported indications of food-access problems or limitations"; households with *marginal food security* have "one or two reported indications—typically of anxiety over food sufficiency or shortage of food in the house [with] little or no indication of changes in diets or food intake"; households with *low food security* have "reports of reduced quality, variety, or desirability of diet [with] little or no indications of reduced food intake"; and households with *very low food security* have "reports of multiple indications of disrupted eating patterns and reduced food intake." The lower two levels indicate food insecurity (http://www.ers.usda.gov/briefing/foodsecurity/labels.htm#cnstat, accessed March 12, 2012).

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

In addition to the core indicators, the committee identified a set of additional indicators based on more granular process measures to provide a comprehensive assessment of the quality of HIV care. These additional indicators are included in Figure S-1 and discussed in detail in Chapter 2 of the report.

Demographic data on PLWHA have to be collected to monitor the impact of the NHAS and ACA on improvements in HIV-related health disparities. The committee found that many crucial data elements, such as gender identity, sexual orientation, sexual risk behaviors, geographic marker of residence, income, primary means of reimbursement for medical services, and level of acculturation as reflected in primary language are not routinely collected in many of the federal data systems that it reviewed. Data on race and ethnicity often are not collected with a sufficient level of detail to make nuanced distinctions among the health needs of different racial and ethnic groups. On October 31, 2011, the U.S. Department of Health and Human Services (HHS) issued new guidance on minimum standards for collection of data on race, ethnicity, sex, primary language, and disability status in national population health surveys that are sponsored or conducted by HHS. The guidance mandates the collection of more granular data on race and ethnicity, as well as data on "biologic sex" and English proficiency as a measure of primary language. HHS is also developing a plan to integrate the collection of data on sexual orientation and gender identity into HHS national surveys, and to collect data on socioeconomic status.

Recommendation 2-2. The Department of Health and Services and the Office of Management and Budget should continue to expand the demographic data elements to be captured by federal data systems relevant to HIV care to permit calculation of the indicators for subgroups of the population of people with diagnosed HIV infection, including, but not limited to, the following:

Age

Race

Ethnicity

Sex (assigned at birth)

Gender identity (e.g., male, female, transgender [male-to-female, female-to-male], bigender, gender queer)

TABLE S-1 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.

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*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.

Sexual orientation (e.g., heterosexual, homosexual, bisexual)

Current geographic marker of residence (e.g., current address, zip code, partial zip code, census block)

Income or poverty level

Primary means of reimbursement for medical services (including Medicaid, Medicare, Ryan White HIV/AIDS Program, private insurance or health maintenance organization, no coverage)

In addition, HHS should, to the extent practicable, extend its expanded data collection standards beyond national population-based health surveys to all HHS-sponsored data collection activities.

Sources of Data on HIV Care to Assess Core Indicators and Access to Supportive Services

Data on HIV care and supportive services are currently being collected by a number of public and private data systems. Although no single data system on its own provides all of the data needed to estimate the indicators recommended by the committee (listed above), these data systems as a whole are collecting relevant information that can serve as a collective platform for evaluating access to continuous and high-quality care in all populations of PLWHA. The committee identified 12 data systems in particular that collect data of use for estimating the core indicators to monitor progress toward meeting the goals of the NHAS and ACA:

National HIV Surveillance System (CDC)

Medical Monitoring Project (CDC)

Ryan White Services Report (Health Resources and Services Administration [HRSA])

Ryan White AIDS Drug Assistance Program Reports (HRSA)

Medicaid Statistical Information System (Centers for Medicare and Medicaid Services [CMS])

Chronic Condition Data Warehouse (CMS)

North American AIDS Cohort Collaboration on Research and Design

CFAR Network of Integrated Clinical Systems

HIV Research Network

Clinical Case Registry: HIV (Department of Veterans Affairs)

Kaiser Permanente

National Vital Statistics System

The committee identified two additional data systems that provide information of use in tracking the impact of the NHAS and ACA on care for two small but important subpopulations of PLWHA (American Indians and Alaskan Natives; federal prisoners), and a third that provides information relevant to housing assistance and other supportive services for PLWHA:

Resource and Patient Management System (Indian Health Service)

Bureau of Prisons Electronic Medical Record

Housing Opportunities for Persons with AIDS (U.S. Department of Housing and Urban Development)

The committee's review showed that each data system has limitations. For example, few contain all of the data elements needed to estimate all of the indicators recommended by the committee, especially those for mental health, substance abuse, and supportive services (housing, food security, transportation). In addition, most of the data systems are not fully representative of the population of PLWHA in the United States. In many cases (e.g., Ryan White HIV/AIDS Program, Medicaid Statistical Information System [MSIS], Chronic Condition Data Warehouse [CCW], Clinical Case Registry: HIV), the population represented in the data system is defined by program eligibility and cannot be expanded. Similarly, the purposes for which the data systems were designed preclude expansion of the data elements they collect to include all of those needed to estimate all of the indicators identified by the committee. Modest changes in individual data systems, however, could improve the usefulness of their data for tracking changes in HIV care and access to supportive services for PLWHA. For example, a given data system might add one or more data elements or modify an existing data element to allow the system to provide data for estimating a subgroup of the indicators identified by the committee, such as those pertaining to supportive services, or to simplify identification of data representing HIV-infected individuals (e.g., flagging HIV/AIDS as a chronic condition in the CCW). In cases where the population represented in a data system is not constrained by the program it serves (e.g., Medical Monitoring Project), steps might be taken either to make the population more representative of the national population of PLWHA or to include groups (e.g., homeless) who are less apt to be represented in other data systems.

Recommendation 3-1. The Department of Health and Human Services, the Department of Veterans Affairs, the Department of Housing and Urban Development, and other relevant federal agencies should review and, to the extent practicable, modify the federal data systems identified by the committee to better enable them to be used for monitoring progress toward achieving the goals of the National HIV/AIDS Strategy.

Currently there is variation among CDC reporting areas with respect to longitudinal reporting of CD4 and viral load test dates and results. Uniform longitudinal reporting of CD4 and viral load test dates and results from all jurisdictions would facilitate the use of data from the National HIV Surveillance System (NHSS) to estimate the core indicators for HIV care identified by the committee. In addition, collection of longitudinal data on the initiation and ongoing prescription or dispensing of antiretroviral therapy for individuals diagnosed with HIV would provide the remaining data elements necessary to use the NHSS as a source of data to estimate all of the core clinical HIV care indicators. Use of NHSS data would permit estimation of the indicators for the majority of the population diagnosed with HIV in the United States, as well as for subpopulations based on race, ethnicity, sex, gender, age, geographic area, and country of origin. Capturing information on sexual orientation, sources of coverage for medical treatment, and current geographic area of residence would facilitate use of NHSS data for evaluation of indicators for specific subpopulations identified in the NHAS.

Recommendation 3-2. The Centers for Disease Control and Prevention should take steps to enhance the National HIV Surveillance System including

- **issuing guidelines or criteria for National HIV Surveillance System reporting to include all CD4 and viral load test results**
- **capturing longitudinal data pertaining to the initiation and ongoing prescription or dispensing of antiretroviral therapy for individuals diagnosed with HIV (e.g., through pharmacy-based reporting)**
- **obtaining information on sexual orientation and sources of coverage for medical treatment (including, but not limited to, Medicaid, Medicare, Ryan White HIV/AIDS Program, other public funding, private insurance or health maintenance organization, no coverage) and obtaining and employing current geographic marker of residence (e.g., current address, zip code, partial zip code, census block) for individuals in the National HIV Surveillance System**

Clinically based electronic health record (EHR) systems, such as those used by the Veterans Health Administration (VHA) and Kaiser Permanente, capture all, or most, of the data elements needed to estimate the clinical HIV care indicators recommended by the committee. They also generally capture at least some of the information needed to estimate the indicators pertaining to mental health and substance abuse, but they do not routinely capture data needed to estimate the indicators pertaining to supportive services. Another limitation of provider-based EHR systems is that individually each represents only one segment of the population of PLWHA in the United States (e.g., those who receive care in the VHA system, Kaiser Permanente enrollees). Other data systems represent larger proportions of PLWHA nationally (e.g., NHSS, MSIS) and may contain information on mental health, substance abuse, and supportive services (e.g., Ryan White HIV/AIDS Program, MSIS), but they contain limited or no clinical data. The National Health Information Network Exchange is an example of a partnership between public and private entities to exchange health information for a variety of purposes. It could serve as a model for or a foundation upon which to build a broader data sharing partnership among public and private data systems both to permit better estimation of the indicators identified by the committee and to return information to private health care systems and providers for the purpose of improving health care for individuals with HIV. Building upon existing data sharing partnerships would help to reduce costs associated with implementation of such partnerships for the exchange of information relevant to the provision of HIV care.

> **Recommendation 3-3. The Department of Health and Human Services, the Department of Veterans Affairs, the Indian Health Service, the Federal Bureau of Prisons, and other relevant federal agencies should use existing data from private data systems, including data from electronic health records, to monitor the impact of the National HIV/AIDS Strategy and the Patient Protection and Affordable Care Act on improving HIV care. Federal agencies also should share data pertaining to HIV care with private health care systems and providers to improve the quality of care for individuals with HIV. Methods might include the development of a data sharing partnership between public and private data systems that include data pertaining to HIV care.**

Barriers to the Collection of HIV Care Data

Grantees of federally funded HIV/AIDS programs are a vital source of HIV care and supportive services data, but are currently overburdened by the many reporting obligations they are required to fulfill as a condition of program funding. The reporting requirements for core and supplemental

HIV/AIDS programs administered by health departments are often project specific, even across related programming (e.g., HIV prevention and HIV/AIDS care), requiring staff to modify their reporting practices for each grant. Reporting is further complicated by the fact that programs operate on different grant cycles so that reports for related programs are due at different times during the year. According to the Presidential Advisory Council on HIV/AIDS, the current reporting requirements for grantees of federally funded HIV/AIDS programs have not resulted in a set of metrics by which to thoroughly monitor the HIV epidemic or to evaluate federal HIV/AIDS programs. A smaller number of metrics that are aligned with NHAS goals could be used across federal agencies to monitor progress in managing the epidemic. As it was preparing this report, the committee learned that there is an effort under way by HHS to identify a set of HIV-related metrics to be used across funding agencies and reduce reporting burden for program grantees. The committee supports this current effort and recommends that it be maintained so that data needs can be periodically reprioritized based on changes in the HIV epidemic and to facilitate continued minimization of grantee reporting burden.

> **Recommendation 4-1. The Department of Health and Human Services should maintain and institutionalize the existing effort to streamline data collection and reduce reporting requirements for federally funded HIV/AIDS programs. This will allow for periodic reprioritization of data needs, based on changes in the HIV epidemic that occur over time, and ensure the continuous availability of data to effectively monitor HIV care while minimizing reporting requirements for grantees. The data reprioritization should involve health departments, HIV provider organizations, and federal agencies that are major funders of HIV/AIDS programs, including HHS, the Department of Veterans Affairs, and the Department of Housing and Urban Development.**

Providers of HIV care and supportive services contend with numerous federal laws and state statutes and regulations on the proper use and disclosure of patient information. 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 estimate indicators of HIV care and supportive services.

Recommendation 4-2. The Department of Health and Human Services should issue guidance to the HIV care community to clarify what is permissible patient information to share given federal and state privacy laws.

The Role of Health Information Technology and Data System Integration in the Collection of HIV Care Data

Increased exchange of health-related information across providers of HIV care and supportive services has the potential to improve care coordination and longitudinal tracking of care. Some integrated health care systems, such as the VHA and Kaiser Permanente, effectively manage information across providers within their networks, but most PLWHA receive care and supportive services outside of these networks, and many receive care across multiple organizations. The committee identified local efforts in health information exchange that have resulted in improved monitoring of patient care and outcomes. However, these efforts have not been scaled broadly among entities serving PLWHA.

Recommendation 5-1. The Department of Health and Human Services should review existing mechanisms for the confidential and secure exchange of health information to provide a platform to increase the exchange of such information among entities serving individuals with HIV. These entities may include, but are not limited to, state and local health departments, government agencies, and community-based organizations funded to provide medical care, substance use and mental health services, and housing and other supportive services.

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 care and care coverage for PLWHA have their own health IT systems with disparate architectures and vocabularies, posing a challenge to the exchange of data across systems.

Recommendation 5-2. The Department of Health and Human Services and the Office of the National Coordinator for Health Information Technology should provide technical assistance and policy guidance to state and local health departments, clinical providers, and other agencies serving individuals with HIV to improve the interoperability of data systems relevant to monitoring HIV care and supportive services.

Efficient Analysis of HIV Care Indicators and Dissemination of Data by Federal Agencies

Estimation of the committee's recommended indicators for clinical HIV care and mental health, substance abuse, and supportive services will often require combining data from multiple data systems. Making valid inferences about the indicators across different populations and over time using data from multiple data systems presents a range of analytic and logistical challenges. Such challenges will change over time and will have to be reevaluated periodically.

> **Recommendation 6-1. At least once every 2 years, the Department of Health and Human Services should reevaluate mechanisms for combining data elements to estimate key indicators of HIV care and access to supportive services, analyze the combined data, and identify and address barriers to the efficient analysis of such data, including relevant statistical methodologies. To facilitate this process, HHS should engage a center of excellence representing broad areas of expertise that include information technology, statistical methodologies for combining data, and data system content.**

Information on the indicators recommended by the committee will be of interest to a variety of stakeholders, including policy makers, health departments, HIV care providers, patients, and researchers. The disseminated information can be used in numerous ways—from informing policy decisions to supporting the development of research projects—that have the potential to improve HIV care quality.

> **Recommendation 6-2. The Department of Health and Human Services should report to the public at least once every 2 years on indicators of HIV care and access to supportive services to foster improvements in the quality of HIV care and in monitoring progress toward meeting the goals of the National HIV/AIDS Strategy.**

The reporting interval of at least once every 2 years allows for regular reporting of the indicator data to monitor the NHAS while minimizing reporting burden and associated costs.

1

Introduction

In September 2010, the White House Office of National AIDS Policy (ONAP) commissioned the Institute of Medicine (IOM) to convene a committee of experts to assess available public and private data systems that capture HIV care information; investigate ways to maximize the usefulness of, and recommend approaches for supplementing, existing data systems; and provide recommendations for the most critical data and indicators to help gauge the impact of the National HIV/AIDS Strategy (NHAS) and the Patient Protection and Affordable Care Act (ACA, P.L. 111-148) on HIV care.

The committee was asked to address seven additional questions in its response to this charge, which are as follows:

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?
   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?

The Committee to Review Data Systems for Monitoring HIV Care was formed to carry out this study. The 17-member committee comprises experts in clinical HIV care, mental health, health services research, private health insurance, health policy, housing policy, the Ryan White HIV/AIDS Program, biostatistics, epidemiology, health disparities, and biomedical informatics (see Appendix A, Biographical Sketches of Committee Members).

This is the first of two reports to be prepared by this committee. In a forthcoming report, also requested by ONAP, the committee will address the broad question of how to obtain national estimates that characterize the health care of people living with HIV/AIDS (PLWHA) in the United States. The second report will include discussion of challenges and best practices from previous large scale and nationally representative studies of PLWHA as well as other populations.

STUDY CONTEXT

The number of PLWHA in the United States is increasing every year in large part due to the availability of effective antiretroviral therapy (ART), which has allowed PLWHA to live longer and healthier lives (CDC, 2011b), and to a steady number of new HIV infections occurring each year. Nearly 1.2 million individuals age ≥13 were living with HIV infection (both AIDS and non-AIDS cases) at the end of 2008, the most recent year for which national prevalence data are available (CDC, 2011c). The total prevalent cases represent a 6.5 percent increase in the number of PLWHA from the estimate for 2006 (CDC, 2008, 2011c). Despite overall improvements in survival, there continue to be many challenges to curbing the HIV epidemic. For example, an estimated 50,000 people in the United States were newly infected with HIV each year from 2006 through 2009 (Prejean et al., 2011), and approximately 16,000 people with AIDS die each year (CDC, 2011c). Many PLWHA remain undiagnosed; 20 percent of the prevalent cases estimated for 2008 were among those whose infection was undiagnosed. The Centers for Disease Control and Prevention (CDC) estimates that 77 percent of people who are diagnosed are linked to care within 3 to 4 months and that only 51 percent are retained in ongoing care (CDC, 2011c). ART can help to reduce the level of HIV virus in the blood, sometimes to viral suppression (i.e., to an undetectable level), resulting in improved health outcomes for PLWHA and reduced risk of HIV transmission (Cohen et al., 2011; Granich et al., 2009).[1] Yet, only 19–28 percent of PLWHA are virally suppressed (Gardner et al., 2011).

The evolving and often complex health care needs of PLWHA highlight the importance of making available continuous and coordinated quality HIV care. It is estimated that by 2015, more than half of PLWHA in the United States will be 50 or older (Effros et al., 2008; Justice, 2010). With improved survival and the aging of the population of PLWHA, there is a need for care models that address changing patterns of comorbidity that include increasing rates of chronic "non-AIDS" conditions, such as cardiovascular disease, diabetes, hypertension, certain cancers, and psychosocial comorbidities, and the influence of HIV infection and long-term treatment on the etiology and progression of disease (Chu and Selwyn, 2011; Justice, 2010; Mugavero et al., 2011; Shiels et al., 2011).

HIV care should also be oriented to address the full range of care and supportive service needs of PLWHA so that they may better manage their HIV infection. HIV disproportionately impacts populations with care and supportive service needs that, when unmet, reduce access and adherence to HIV care and treatment (Robertson et al., 2004; Weaver et al.,

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[1] Being in HIV care may help to reduce risk of HIV transmission in ways besides having a reduced viral load as a result of being on antiretroviral therapy (ART). For example, provider counseling and linkage to supportive services may help to promote behaviors (e.g., consistent use of ART, safer sex, use of clean syringes) that reduce risk of HIV transmission (Parashar et al., 2011; Sikkema et al., 2010).

2009). The provision of wraparound services such as case management, mental health services, substance abuse treatment, and transportation and housing assistance for PLWHA improves linkage and retention in care (Ashman et al., 2002; Mugavero et al., 2011). To help reduce disparities among subgroups of PLWHA, care should also be responsive to the diversity of the population by taking into account demographic variables such as sex, gender, age, socioeconomic status, race and ethnicity, and sexual orientation (Bhavan et al., 2008; Bogart et al., 2010; Christopoulos et al., 2011; Moore, 2011).

To monitor and improve HIV care and address care disparities, data on the care experiences of PLWHA have to be collected and analyzed. Several organizations, such as the New York State Department of Health AIDS Institute, Kaiser Permanente, the Veterans Health Administration, and the Ryan White HIV/AIDS Program (a federally funded program, administered by the Health Resources and Services Administration (HRSA), which is considered a payer of last resort for low-income, uninsured, and underinsured PLWHA), have developed measures to assess the quality of their HIV care delivery (Horberg et al., 2010). However, these efforts have not been coordinated, resulting in several unaligned measures of HIV care quality. Development of a more standard set of measures that could be applied across a variety of care delivery platforms would allow for better comparisons and longitudinal tracking of care (Horberg et al., 2010).[2]

Sources of care and coverage for PLWHA are important to consider for assessing the impact of the insurance reform that is occurring as a result of the ACA (described later in this chapter) on HIV care. An analysis of data from a convenience sample of 20,555 PLWHA attending high-volume HIV care sites participating in the HIV Research Network showed that Medicaid was the source of insurance at first outpatient visit for the largest proportion of patients (32 percent) followed by the Ryan White HIV/AIDS Program (24 percent). Commercial health insurance and Medicare were the source of insurance at first outpatient visit for 17 percent and 14 percent of patients, respectively (Table 1-1) (Fleishman and Gebo, 2012).[3]

A recent analysis of older data from the Medical Monitoring Project

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[2] Recognizing the need for aligned HIV care quality measurement, in 2007 the National Committee for Quality Assurance in partnership with the American Medical Association, HRSA, and the Infectious Diseases Society of America and HIV Medicine Association established "a single set of aligned HIV quality measures for care processes and intermediate outcomes for external accountability and individual quality improvement" (Horberg et al., 2010). Chapter 2 describes these measures in more detail.

[3] Data are from care sites located in Baltimore, Maryland; Tampa, Florida; Dallas, Texas; New York, New York (three sites); Rochester, New York; Philadelphia, Pennsylvania; Detroit, Michigan; San Diego, California; Oakland, California; and Portland, Oregon.

TABLE 1-1 Insurance at First Outpatient Visit for Patients Attending Adult Care Sites in the HIV Research Network, CY2010

Insurance	Number of Patients (%)
Commercial	3,580 (17)
Medicaid	6,652 (32)
Medicare	2,946 (14)
Dual (Medicaid and Medicare)	970 (5)
Uninsured (self pay)	544 (3)
Ryan White	4,955 (24)
Other/Unknown	908 (4)
Total number of patients	20,555

SOURCE: Fleishman and Gebo (2012).

(MMP), a national survey of the health care experiences and needs of adult PLWHA receiving medical care in the United States, showed that 84 percent of participants (3,040 of 3,643) had one or more types of health insurance coverage during the 12 months prior to the survey. Of those with health insurance, 45 percent had Medicaid, 37 percent had private health insurance or coverage through a health maintenance organization, and 30 percent had Medicare (Blair et al., 2011).[4] There will likely be growth over the next few years in the number of PLWHA on Medicare as a result of the aging of this population and ACA provisions related to the Medicare Part D drug benefit (described later in this chapter).

Continuous access to medications is an important component of HIV care. As noted above, ART is vital to help PLWHA achieve and maintain viral suppression and thereby improve health outcomes and reduce HIV transmission (Cohen et al., 2011; Granich et al., 2009). Continuous access to and adherence to ART also may decrease the occurrence of HIV drug resistance (Gardner et al., 2010; Sethi et al., 2003). The AIDS Drug Assistance Program (ADAP), a component of the Ryan White HIV/AIDS Program administered by states to cover the costs of Food and Drug Administration (FDA)-approved prescription drugs, is a common source of prescription drug coverage for low-income PLWHA. ADAPs provided medications to more than 135,000 clients in 2010 (NASTAD, 2011). In the MMP survey described previously, ADAPs were the primary method of payment for prescription medications for 25 percent of participants. Medicaid or Medicare and private health care coverage were the primary method of payment for 41 percent and 25 percent of participants, respectively (Blair et al., 2011).

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[4] Survey respondents could select more than one source of health insurance coverage (Blair et al., 2011).

The National HIV/AIDS Strategy and the Patient Protection and Affordable Care Act

ONAP is tasked with coordinating efforts of the federal government to reduce the number of HIV infections in the United States (ONAP, 2011a). Noting the continuing challenges to curbing the domestic HIV epidemic, ONAP released its NHAS in July 2010. The primary goals of the NHAS are to (1) reduce the number of people who become infected with HIV; (2) increase access to care and optimize health outcomes for PLWHA; and (3) reduce HIV-related health disparities (ONAP, 2010). The NHAS identifies action steps for each of the three primary goals and identifies quantitative targets to be achieved by 2015 (see Box 1-1).[5]

Because increased coordination and collaboration among HIV care programs is necessary to meeting the goals of the NHAS, the strategy also includes an objective to achieve a more coordinated national response to the epidemic among federal, state, territorial, local, and tribal governments (ONAP, 2010). As described in the IOM report *Crossing the Quality Chasm: A New Health Care System for the 21st Century*, the U.S. health care system as currently structured is uncoordinated and inefficient. Care providers often operate as silos "providing care without the benefit of complete information about the patient's condition, medical history, services provided in other settings, or medications prescribed by other clinicians" (IOM, 2001). HIV care in particular is provided through a patchwork of payers with different eligibility requirements that cause many PLWHA to shift in and out of eligibility for care coverage over the course of their illness (IOM, 2005, 2011b). Better coordination and communication across HIV providers and programs could improve continuity of care for PLWHA, who often have complex, long-term treatment and supportive service needs (Mugavero et al., 2011). The work of this IOM committee is named in the operational plans for the NHAS as one of the key activities that ONAP is undertaking "to address gaps in data collection, analysis, and integration of the care and treatment experiences of people living with HIV" within the NHAS goal to achieve a more coordinated national response to the HIV epidemic (ONAP, 2011b).

The NHAS is intended to complement the implementation of the ACA (ONAP, 2011b). If implemented as originally designed, the ACA will pro-

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[5] In addition, an overview of the operational plans for lead agencies implementing the National HIV/AIDS Strategy (NHAS), including the departments of Health and Human Services and its subagencies, Housing and Urban Development, Justice, Labor, Veterans Affairs, and the Social Security Administration, was released in February 2011 (ONAP, 2011b). The report outlines key activities that agencies are undertaking for each of the three NHAS goals as well as to increase coordination of HIV programs and improve mechanisms to monitor and report on progress toward achieving national goals.

vide health coverage to over 30 million uninsured citizens by 2021 (CBO, 2011), including many PLWHA, and will establish private insurance market regulations. A few of the changes from the ACA that are likely to impact PLWHA are as follows:

- *Expansion of the Medicaid Program:* The Medicaid program, currently the largest single source of care coverage for people with HIV, will eliminate current categorical eligibility requirements such as being pregnant or disabled. Coverage will be expanded to include all non-Medicare eligible individuals with incomes up to 133 percent of the federal poverty level (FPL) beginning in 2014. People living with HIV who meet the new income threshold will no longer have to wait for an AIDS diagnosis or other diagnosis of disability to become eligible for Medicaid (KFF, 2011; NASTAD, 2010).[6]
- *Phasing out the Medicare Part D Prescription Drug Coverage Gap:* Medicare Part D prescription drug benefit recipients must pay out-of-pocket for the full cost of prescription drugs while in a coverage gap (i.e., between the time recipients and their drug plans have spent a certain amount of money for covered medications and the time catastrophic coverage begins).[7] Prior to the ACA, PLWHA on ART were likely to have expenditures within the coverage gap unless they were receiving low-income subsidies (KFF, 2006). The ACA gradually phases down the 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, 2012; KFF, 2011), making medications more affordable to PLWHA who have Medicare Part D drug coverage. In addition, starting in 2011, ADAP prescription drug benefits began counting toward enrollees' Medicare Part D "true-out-of-pocket" (TrOOP) spending limit, which determines when catastrophic coverage begins. This change will shift some of the costs of prescription drugs from ADAP to Medicare (HRSA, 2010).
- *Increased Private Health Insurance Access and Consumer Protections:* The ACA will increase access to private health insurance and protect beneficiaries from being denied coverage and other unfavor-

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[6] As of April 2010, states had the option to phase in expansion of Medicaid to the newly eligible as long as the state does not offer coverage to (1) individuals with higher income before those with lower income or (2) to parents, unless their children are enrolled in Medicaid or other coverage. A cost-neutrality requirement for the expansion of Medicaid to nondisabled persons with HIV through a waiver process (i.e., that it cost the federal government no more than it would have with the waiver) has been a barrier to states taking up this option (NASTAD, 2010).

[7] Up to $4,700 in out-of-pocket costs in 2012 (CMS, 2012).

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.
- 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.

BOX 1-1 Continued

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.

SOURCE: ONAP, 2010.

able industry practices. Beginning in 2010, private health insurers were no longer able to deny coverage to children with preexisting conditions such as HIV/AIDS (KFF, 2011). 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 people with preexisting conditions. In the meantime, temporary preexisting insurance plans with subsidized premiums are available to adults with a preexisting medical condition who have been uninsured for at least 6 months (KFF, 2011). Also starting in 2014, states will set up health insurance exchanges designed to make health coverage easier to buy and more affordable. Premiums for insurance will be offered on a sliding scale for people at 133 to 400 percent of the FPL who are not eligible for Medicaid based on income. Private insurance companies could no longer cancel or rescind coverage (except in the case of fraud) or impose a lifetime cap on the amount of coverage an individual can receive starting in 2010 (HHS, 2011b; KFF, 2011).[8]

- *Expansion of Coverage for Preventive Health Services:* As of September 2010, the ACA requires new private health insurance plans to cover the cost of preventive services that have been determined by the U.S. Preventive Services Task Force (USPSTF) to have high or moderate certainty of substantial or moderate net (population) benefit (USPSTF, 2010) and of immunizations recommended by the Advisory Committee on Immunization Practices (CDC, 2011a). The ACA also requires coverage for an annual wellness visit under Medicare, eliminates cost sharing for recommended preventive services covered by Medicare, and gives state Medicaid programs financial incentives to cover preventive services (Cassidy, 2010). Preventive services recommended by the USPSTF that are of particular interest to PLWHA include screening examinations for sexually transmitted infections (STIs), certain cancers, depression, diabetes and other conditions, as well as several vaccinations (USPSTF, 2010).[9] In response to recommendations outlined in the IOM report *Clinical Preventive Services for Women: Closing the Gaps* (IOM, 2011a), in August 2011 the U.S. Department of Health and Human Services (HHS) announced new guidelines for health insurers and health plans specifying that women receive certain preventive services without copayment, coinsurance, or deductible. The guidelines, which go into effect in August 2012 with changes becoming effective for most new health plans on January 1, 2013, build on the ACA provisions to increase access to preventive services for all Americans. The new guidelines require full coverage for HIV screening and counseling for all sexually active women, human papillomavirus (HPV) testing, STI counseling,

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[8] It is important to note that while some of the provisions of the Patient Protection and Affordable Care Act (ACA) apply to all health plans, certain requirements (e.g., coverage of preventive services without cost sharing) are not applicable to a grandfathered plan as long as the plan or insurance coverage remains a grandfathered plan. A grandfathered health plan is a group health plan or insurance coverage in which an individual was enrolled on March 23, 2010, the date the ACA was enacted.

[9] Furthermore, an "essential benefits package" that is planned to go into effect in 2014 would require all qualified health benefits plans to offer at least the benefits in the package, which will include items and services in the following 10 categories: (1) ambulatory patient services, (2) emergency services, (3) hospitalization, (4) maternity and newborn care, (5) mental health and substance use disorder services, including behavioral health treatment, (6) prescription drugs, (7) rehabilitative and habilitative services and devices, (8) laboratory services, (9) preventive and wellness services and chronic disease management, and (10) pediatric services, including oral and vision care (KFF, 2011; H.R. 3590, SEC 1302).

and FDA-approved contraceptive methods and counseling, among other services (HHS, 2011a).

- *Expansion of Care Capacity at Community Health Centers:* Community health centers (CHCs), including federally qualified health centers (FQHCs),[10] are an important source of care for PLWHA who may be isolated from traditional forms of medical care (e.g., undocumented and recent immigrants,[11] people living in rural areas), as well as people who are low income, uninsured, and members of racial and ethnic minority groups. To increase access to preventive care and primary health care, the ACA provides funding to increase the service capacity of CHCs/FQHCs from 20 million to 40 million patients by 2015 (McKay, 2011).

As noted in the operational plans for the NHAS, federal agencies and their state, local, and community partners need to ensure that HIV health care providers and PLWHA are included in initiatives to improve quality of care and integration of care services as the ACA is implemented (ONAP, 2011b). The ACA will help to address several features of the current health system that restrict access to care and care coverage for PLWHA.[12] This will occur by expanding access to Medicaid, Medicare (prescription drug coverage), and private insurance programs, as well as by increasing access to preventive services and bolstering support to CHCs. It is important to

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[10] Federally Qualified Health Centers (FQHCs) include health centers funded under Section 330 of the U.S. Public Health Service (PHS) Act; FQHC "look-alikes," or FQHCLAs, that have been identified by the Health Resources and Services Administration and certified by the Centers for Medicare and Medicaid Services (CMS) as meeting the definition of "Health Center" under Section 330; and outpatient health programs or facilities operated by tribal organizations.

[11] Some qualified immigrants are not eligible for Medicaid until they have been in the United States for 5 years (CMS, 2012).

[12] While preparing this report, the committee was mindful that provisions of the ACA that would impact access to care for PLWHA may not be implemented as originally planned. However, the indicators and data systems identified by the committee in this report to monitor the impact of the ACA on HIV care remain valid even if the ACA is not fully implemented. Indeed the committee's charge was to identify indicators to gauge the impact on HIV care not only of the ACA but also of the NHAS, for which implementation plans developed by applicable federal agencies currently are underway. Furthermore, many states have already expanded access to health insurance for their residents in response to ACA provisions, and states may maintain these changes even in the absence of national-level reforms. For example, the ACA allowed states the option to begin phasing in Medicaid expansion to cover non-elderly individuals with income up to 133 percent of the federal poverty level (FPL) beginning in April 2010, and many states have done so. The committee's recommended indicators could be used to monitor improvements in HIV care within states over time as a result of these changes, even if such changes do not occur nationally. The indicators are also applicable to state-specific policies, such as shifts to Medicaid managed care, and New York's current Medicaid redesign, which will include a new payment structure.

note that changes resulting from the ACA will not benefit all PLWHA—for example, undocumented immigrants who are ineligible for many key provisions of the legislation.

The Ryan White HIV/AIDS Program is an example of an effective integrated model of care for PLWHA. Primary and specialty care as well as psychosocial services are coordinated within a single "medical home." Therefore, the Ryan White HIV/AIDS Program model of care helps to overcome challenges posed by the fragmented health care system that may impede retention in care for many PLWHA (Gallant et al., 2011). Care for many PLWHA will likely shift from the Ryan White HIV/AIDS Program to Medicaid as the ACA expands Medicaid to cover adults who were previously uninsured. However, the Ryan White HIV/AIDS Program and other safety net providers will continue to fill gaps in medical and social services not covered by Medicaid. The Ryan White HIV/AIDS Program also will continue to be an important source of care and supportive services for PLWHA who remain uninsured under the ACA (such as undocumented immigrants).

The Role of Health Information Technology and Data System Integration

When applied appropriately, health information technology (health IT) can help to improve health care quality, prevent medical errors, reduce health care costs, and increase administrative efficiencies (HHS, 2011c; IOM, 2001). The Health Information Technology for Economic and Clinical Health (HITECH) Act, a key component of the American Recovery and Reinvestment Act of 2009 (ARRA, P.L. 111-5) , has allowed HHS to establish several programs to improve health care delivery through investment in health IT, such as electronic health records (EHRs) (HHS, 2011d). For example, incentive funds authorized under the ARRA are helping eligible primary care as well as medical and surgical specialists with high EHR implementation costs that have been an obstacle to their widespread use (Hogan and Kissam, 2010). The health IT infrastructure being established as a result of the HITECH Act is key to carrying out goals of the ACA to improve quality of care through expanded measurement and reporting, reduce costs and improve efficiency of care delivery and administrative processes, and improve access to care and coverage (Buntin et al., 2010).

Although the government investment in health IT is encouraging, implementation has thus far occurred at a slow pace. For health IT to be used to its fullest capabilities to monitor HIV care, several barriers to adoption and utilization in settings that provide care and services to PLWHA have to be addressed. These include costs and staffing needed to implement and maintain IT applications, privacy and confidentiality concerns, and a variety of other factors described in more detail later in this report. Most importantly, the benefits of health IT cannot fully be realized without system interoperability or an infrastructure that supports the secure exchange of health information across providers, including physician practices, insurance providers, hospitals, and other entities (Edwards et al., 2010).[13] To a large extent, the health IT systems currently employed in clinician and provider offices capture patient information in different ways (e.g., using different terminology standards) and thus cannot "talk" to each other. The existence of heterogeneous HIV data systems makes understanding interoperability essential. The exchange of health information across care sites is especially important for PLWHA who may transition across programs throughout the course of their illness (as previously described) and see different types of providers for the management of HIV and comorbid conditions.

THE COMMITTEE'S APPROACH TO ITS CHARGE

The committee reviewed information from a number of sources during the course of its deliberations, including the scientific literature, previous IOM reports, and presentations by experts invited to speak with the committee on topics pertaining to its charge. As described in greater detail in the following chapters, the committee also reviewed existing HIV care indicators and measures of HIV care quality to inform its selection of core indicators. The committee requested information from individuals who work with various sources of data on HIV care and supportive services about the information collected to identify the best sources of data for estimating indicators. The committee reviewed data systems that are HIV specific (e.g., epidemiologic studies of PLWHA), as well as data systems that are not HIV specific (e.g., Medicaid, Medicare, private health insurance data systems) that include data relevant to monitoring HIV care.

Consistent with the NHAS objective to increase access to care and improve health outcomes for PLWHA, the committee focused on identifying core indicators and data systems to track linkage and access to appropriate HIV care and related supportive services among diagnosed PLWHA. The committee also considered how indicators could be used to monitor HIV-related health disparities. Reducing the occurrence of new HIV infections, another NHAS objective, is critical to curbing the HIV epidemic in the United States. However, this report does not identify indicators and data systems to monitor reductions in new HIV infections because the committee interpreted its charge to apply to the population of PLWHA with diagnosed

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[13] In health care, interoperability refers to the ability of different information technology systems and software applications to communicate; to exchange data accurately, effectively, and consistently; and to use the information that has been exchanged (HHS, 2008).

HIV infection. In addition, the committee chose to focus this report on adult PLWHA, although the core indicators for clinical HIV care and mental health and substance abuse could be applied to adolescents as well.[14]

As the committee was preparing this report, there was a concurrent effort under way by HHS to identify domain areas from which standardized indicators can be identified to monitor federally funded HIV/AIDS prevention, treatment, and care services.[15] The project was motivated by a need to develop a common set of metrics to streamline the collection of data to measure NHAS objectives and reduce reporting requirements for grantees of federally funded HIV/AIDS programs (Forsyth et al., 2011; Valdiserri and Forsyth, 2011). Because the aims of the HHS effort overlapped with the charge to the committee to identify core indicators to gauge the impact of the NHAS and ACA on HIV care, the committee deemed it necessary to include the HHS effort in its information gathering. HHS representatives who are familiar with the HHS effort were invited to one of the committee's meetings to discuss the types and sources of indicators under consideration. The committee also received periodic updates on HHS's progress over the course of the study.

Providers of HIV care and supportive services are required to meet many reporting obligations related to compliance with federal grants, disease surveillance, and other activities. These reporting obligations require substantial staff time and may constrain provider capacity to engage in other activities such as the provision of HIV care and supportive services (IOM, 2010, 2011b). Taking into account the ongoing effort by HHS to streamline data reporting requirements for HHS grantees, the committee made an effort to be parsimonious in its identification of core indicators to gauge the impact of the NHAS and ACA on improvements in HIV care.

REPORT ORGANIZATION

Chapter 2 of this report addresses the parts of the committee's statement of task that pertain to data elements and core indicators related to continuous care and access to supportive services for PLWHA. The relative merits of each type of data are discussed, as well as whether the differences among data types (in particular, claims data and clinical data) encompass

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[14] Although new cases of HIV in children (i.e., individuals under age 13) continue to occur, their frequency has diminished substantially with the implementation of routine HIV screening of pregnant women and the provision of ART to HIV-infected pregnant women, which greatly reduces the risk of mother-to-child transmission (Branson et al., 2006; CDC, 2002).

[15] As of January 24, 2012, these domain areas included HIV+ diagnosis; early HIV diagnosis; initial linkage to care; sustained engagement in care; initiation of antiretroviral treatment; viral load suppression; and housing (personal communication, Andrew Forsyth, Department of Health and Human Services, January 24, 2012).

gaps in measures for HIV care. The chapter also presents the committee's choice of core indicators related to continuous HIV care and access to supportive services and identifies and recommends the most critical data and indicators to gauge the impact of the NHAS and the ACA. Chapter 3 discusses sources of data for estimating the core indicators identified in Chapter 2, considers ways to maximize their usefulness, and recommends approaches for supplementing current data systems to gauge the impact of the NHAS and the ACA on HIV care. Chapter 3 also discusses similar data collection and standardization efforts that should be utilized, as well as how to regularly obtain data to capture the care experiences of PLWHA without substantial new investments. Chapter 4 discusses potential barriers to the collection of the data needed to estimate the core indicators recommended by the committee, including policy, reimbursement, and reporting issues that must be addressed to collect the necessary data. The chapter also considers how core indicator data can be collected without significantly increasing provider burden. Chapter 5 discusses ways in which health IT can be utilized and configured to improve the collection of HIV care data, as well as models and best practices in data system integration to make existing data systems that capture HIV care data interoperable. Chapter 6 describes how federal agencies can efficiently analyze indicators of HIV care and disseminate data to improve the quality of HIV care. Each chapter ends with the committee's conclusions and recommendations pertaining to aspects of the statement of task discussed in that chapter.

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2

Indicators Related to Continuous HIV Care and Access to Supportive Services

This chapter addresses the committee's charge to "provide recommendations for the most critical data and indicators to gauge the impact of the National HIV/AIDS Strategy (NHAS) and the Patient Protection and Affordable Care Act (ACA) in improving HIV/AIDS care" in the United States (statement of task). The chapter presents the committee's choice of core and additional indicators related to continuous HIV care and access to supportive services, such as housing, for people living with HIV/AIDS (PLWHA); the process by which the committee identified and prioritized the indicators; the committee's rationale for selecting each indicator; and the data (elements) needed to measure the indicators. The committee recognizes the importance of efforts to increase access to HIV testing and the number of HIV-infected individuals who are aware of their serostatus (IOM, 2010, 2011b,c), as well as the need to reduce the transmission of HIV through efforts to reduce risk behaviors among all persons. Based on its statement of task, however, the committee focused its attention on linkage and access to and provision of appropriate HIV care and related supportive services for people already diagnosed with HIV/AIDS.[1]

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[1] Although the committee did not focus on indicators specifically related to reducing the transmission of HIV by people in care for HIV (e.g., condom use), some indicators, such as those related to undetectable viral load, also promote transmission reduction. Preliminary results from a large HIV Prevention Trials Network randomized clinical trial (HPTN 052) indicate that early use of antiretroviral therapy (ART) in PLWHA reduces sexual transmission of HIV to an uninfected partner by 96 percent (Cohen et al., 2011). Likewise, the committee did specifically address the use of ART to reduce mother-to-child transmission in pregnant women with HIV as part of the prenatal care provided to HIV-infected pregnant women.

The chapter also discusses different types of data relevant to patient care and their usefulness for evaluating the continuity (and quality) of HIV care and access to supportive services. The relative merits of each type of data are discussed, as well as whether the differences among data types (in particular claims data and clinical data) "encompass gaps in measures for HIV care" (statement of task question 1b). The chapter ends with the committee's conclusions and recommendations for "the most critical data and indicators for gauging the impact of the National HIV/AIDS Strategy (ONAP, 2010) and the Patient Protection and Affordable Care Act [P.L. 111-148] in improving HIV/AIDS care."

INDICATORS OF CLINICAL HIV CARE AND ACCESS TO MENTAL HEALTH, SUBSTANCE ABUSE, AND SUPPORTIVE SERVICES

The Institute of Medicine (IOM) letter report *Leading Health Indicators for Healthy People 2020* (IOM, 2011d, p. 8) defined the term "indicator" as "a measurement" and "leading health indicators" as "quantitative expressions of health-related concepts that reflect major public health concerns." For the purposes of the present report, indicators of HIV care and access to supportive services are defined as quantitative expressions (measurements) pertaining to the state of HIV care and the availability of supportive services for PLWHA (and subgroups thereof) in the United States. "Core indicators" are those indicators deemed by the committee to be fundamental both to assessing the extent to which persons diagnosed with HIV are connected to appropriate medical care, are maintained in care over time, and have access to needed supportive services in the United States and to gauging the impact of the NHAS and the ACA in improving HIV/AIDS care.

Indicators may include process measures and outcome measures. Process measures pertain to processes of care, such as regular visits for routine care, lab tests and screening performed, and therapies initiated. Outcome measures pertain to the actual health outcomes or status of patients. Mortality and morbidity are ultimate outcome measures for tracking access to quality HIV care for people diagnosed with HIV. Intermediate outcome measures include CD4+ T-cell counts (CD4 counts) and plasma HIV RNA levels (viral loads), which reflect disease progression and infectivity. Process measures are important indicators of quality of care and treatments received, which research has shown are directly associated with good clinical outcomes (Kitahata, 1996; Kitahata et al., 2000, 2003; Landon et al., 2005). For example, regular monitoring of CD4 counts implies good-quality HIV care, with the expectation of good outcomes.

Indicators often are defined in terms of a percentage, proportion, or other relative measure and are not synonymous with the data elements necessary to assess them. Multiple data elements may be required to generate an indicator. For example, "the proportion of PLWHA in the United States who have a CD4+ cell count above *X*" is an indicator, while the data needed to assess that indicator are CD4 counts (specifically the number of people with a CD4+ cell count above *X*) and the total number of HIV-infected individuals in the United States.

Background

A number of important sets of performance measures (Horberg et al., 2010), health objectives (HHS, 2010), and indicators (PEPFAR, 2009) related to HIV screening and care have been developed or revised in recent years. The NHAS also identifies several specific targets, in addition to its three general goals of "reducing the number of people who become infected with HIV; increasing access to care and optimizing health outcomes for people living with HIV; and reducing HIV-related health disparities" (ONAP, 2010, p. 1). These sources provide a basis for the committee's development of a set of indicators for measuring HIV care and access to mental health, substance abuse, and supportive services in the United States (Appendix Table 2-1).[2]

HIV Care Quality Measures

Michael Horberg and colleagues (2010) describe the development of a set of 17 performance measures for HIV care (Table 2-1), most of which have been endorsed by the National Quality Forum (NQF), a nonprofit organization that sets national consensus standards on performance in health care (see NQF, 2011a).

The measures represent a consensus among members of a working group of experts convened by the National Committee for Quality Assurance, in conjunction with the Health Resources and Services Administration (HRSA), the Physician Consortium for Performance Improvement of the American Medical Association, and the HIV Medicine Association of the Infectious Diseases Society of America. The effort to produce a single set of

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[2] All indicators considered by the committee are population-aggregated individual measures, such as the proportion linked to care within 3 months of diagnosis and mortality rate. The committee recognizes the importance of system-level indicators, such as the structural dimensions of system comprehensiveness, capacity, integration, and accessibility described in the Health Resources and Services Administration (HRSA) System Assessment Project (Conviser, 2007). System-level indicators are important because they are related to getting diagnosed individuals linked to, engaged in, and retained in care. However, the committee understood its charge to be recommendations for indicators to measure the quality as well as the continuity of HIV care received by PLWHA in the United States.

TABLE 2-1 HIV Care Quality Measures

Measure	Level of Care Impacted[a]	Level of Evidence[b]
Process of care		
1. Retention in care (seen at least twice annually at least 60 days apart)	P	Level II and QM
2. CD4+ cell count measurement (measured at least twice annually)	P	Level II and QM
Screening		
3. Gonorrhea/chlamydia screening (at least once)	P	Level II
4. Syphilis screening (annually)	P	Level II and QM
5. Injection drug use screening (annually)	P	Level II
6. High-risk sexual behavior screening (annually)	P	Level I and QM
7. Tuberculosis screening (at least once)	P	Level I and QM
8. Hepatitis B screening (at least once)	P	Level III and QM
9. Hepatitis C screening (at least once)	P	Level III and QM
Immunization		
10. Influenza immunization (annually)	B	Level III
11. Pneumococcal immunization (at least once)	B	Level II and QM
12. Hepatitis B vaccination first dose received (if appropriate)	P	Level II and QM
13. Hepatitis B vaccination series completed (if appropriate)	S	Level II and QM
Prophylactic therapy		
14. PCP prophylaxis if CD4+ cell count <200 cells/μL	B	Level I and QM
ART prescription		
15. Appropriately prescribed ART	P	Level I and QM
Viral control (at least 6 months post-ART initiation)		
16. Achieving maximal viral control if prescribed ART	S	Level II and QM
17. Achieving maximal viral control if prescribed ART or treatment plan documentation if maximal viral control not achieved	P	Level II and QM

NOTE: ART, antiretroviral therapy; PCP, *Pneumocystis jiroveci pneumonia*.

[a] Levels of care are as follows: P, physician; S, system; B, both.

[b] Levels of evidence are as follows: I, evidence from ≥1 randomized controlled trial; II, evidence from ≥1 clinical trial, multiple cohort studies, or multiple times series or dramatic results of uncontrolled experiments; III, expert opinion only; QM, previous quality measure data indicating gaps in care.

SOURCE: Adapted from Horberg et al., 2010, Table 1.

national performance standards for HIV care was precipitated by a proliferation of HIV performance measures developed by different bodies over a number of years (Horberg et al., 2010)[3] and heeds the call from the 2004 IOM report *Measuring What Matters: Allocations, Planning, and Quality Assessment for the Ryan White CARE Act* for a standard set of quality measures that are applicable across the range of delivery systems (IOM, 2004). Most of the performance measures endorsed by NQF are process measures. Research has shown that patients who receive more routine office visits; appropriate initiation and prescription of antiretroviral therapy (ART); and appropriate screenings, prophylaxis, and immunizations have better outcomes than those who do not (Kitahata, 1996; Kitahata et al., 2000, 2003; Landon et al., 2005).[4] However, other factors (e.g., untreated non-HIV comorbidities, including mental illness; contextual factors such as food and/or housing insecurity) can result in poorer outcomes even under conditions of the most expert care and perfect treatment adherence. For this reason, outcome measures (e.g., the results of CD4 counts, mortality) are more definitive markers of successful management of HIV disease, although even with outcome indicators there are numerous factors that can affect HIV quality care and may not be able to be assessed. In addition, despite their usefulness, outcome measures generally are more difficult to obtain than process measures, although the increasing use of electronic health records (EHRs) has significantly advanced the collection of health outcomes data.

Taken together, process measures and outcome measures provide a strong basis for the development of associated HIV care indicators and are important for assessing the impact of the NHAS and ACA in improving HIV/AIDS care in the United States. With appropriate care and treatment, HIV is a chronic disease with long disease progression time. Policies that improve HIV care may have an immediate impact on some process indicators (such as frequency of CD4 testing), but a delayed impact on certain outcome indicators (particularly mortality and secondary infections). The goal of any public health intervention is to improve outcomes, but process indicators can provide early feedback about whether the policy guiding

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[3] See, e.g., New York State Department of Health AIDS Institute, HIV Quality of Care Program, (NYSDHAI, 2011); Veterans Health Administration, HIV-QUERI (Bozzette et al., 2000); Kaiser Permanente (Horberg et al., 2011); Ryan White Program, HRSA, HIV/AIDS Bureau, HIVQUAL (HRSA, 2011a,b).

[4] Studies such as these suggest that provider experience in caring for PLWHA improves quality of care and patient outcomes. As the number of individuals with HIV who are in care continues to increase, and with the evolution of HIV as a chronic condition, there will be a continued need for HIV care to move away from infectious disease (HIV) specialists toward nonspecialist primary care providers who have experience in treating HIV patients (IOM, 2011c).

that intervention works. This may be especially important for particular subpopulations of PLWHA, for whom conditions may moderate the effect of a given intervention. For example, a particular group might be linked to care sooner and receive more quality care, but have less change in mortality (compared to other groups) due to chronic housing and social service needs or even different sets of HIV-related risk environments or risk clusters.

Process indicators also can provide insights into why a policy is or is not working. If mortality remains the same despite improvements in certain areas (e.g., linking people to care, routine CD4 testing, appropriate ART initiation), the collection of additional process indicators may highlight other areas that need to be addressed (e.g., screening and immunization for certain coinfections).

Healthy People 2020 Objectives

Healthy People 2020 is the most recent incarnation of an initiative begun more than 30 years ago to identify data-based objectives for improving health among Americans (HHS, 2011a). Healthy People 2020 identifies 18 objectives relating to HIV: 14 relate to HIV prevention, testing, and diagnosis, and 4 relate to health care, survival, and death following diagnosis (HHS, 2010). In keeping with the committee's focus on HIV care following diagnosis, three of the latter four objectives (HIV.9, HIV.10, and HIV.12), in addition to one pertaining to mother-to-child transmission (HIV.8), served as a basis for associated HIV care indicators (see Box 2-1).

PEPFAR Indicators

Indicators developed by the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) provided another basis for the indicators recommended by the committee. Originally authorized by the U.S. Congress in 2003 and reauthorized in 2008, PEPFAR is an unprecedented federal government investment to address the HIV/AIDS epidemic around the world. Now a cornerstone of President Obama's Global Health Initiative, PEPFAR provides support for national programs and strategies in more than 85 host countries to treat adults and children currently living with HIV/AIDS and to reduce the transmission of HIV (PEPFAR, 2011). PEPFAR has developed a set of essential reported indicators to gather information for planning, monitoring, and management purposes (PEPFAR, 2009).

The PEPFAR indicators that pertain to the treatment of PLWHA and the provision of supportive services, such as food assistance, also provided a basis for the committee's development of core indicators related to continuous care and access to supportive services for PLWHA in the United States (Box 2-2).

BOX 2-1
Healthy People 2020 Summary of Objectives: HIV

Diagnosis of HIV Infection and AIDS

[HIV-1–HIV-7]

HIV-8. Reduce the number of perinatally acquired HIV and AIDS cases

Death, Survival and Medical Healthcare After Diagnosis of HIV Infection and AIDS

HIV-9. Increase the proportion of new HIV infections diagnosed before progression to AIDS

HIV-10. Increase the proportion of HIV-infected adolescents and adults who receive HIV care and treatment consistent with current standards

HIV-11. Increase the proportion of persons surviving more than 3 years after a diagnosis with AIDS

HIV-12. Reduce deaths from HIV infection

SOURCE: HHS, 2010.

NHAS Goals

As discussed in Chapter 1, the NHAS lists three primary goals: (1) reduction of HIV transmission; (2) increased access to care and optimized health outcomes for PLWHA; and (3) reduction of HIV-related health disparities (ONAP, 2010, p. 1). Within these three general goals, the NHAS identifies a number of specific measurable objectives to be met by 2015. Of particular interest for the committee's work are the specific targets pertaining to increased access to HIV care, improved health outcomes, and reduced HIV-related health disparities.

The NHAS (ONAP, 2010, p. 21) lists three targets regarding increased access to care:

- Increase the proportion of newly diagnosed patients linked to clinical care within 3 months of their HIV diagnosis from 65 to 85 percent.
- Increase the proportion of Ryan White HIV/AIDS Program clients who are in continuous 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. (This serves as a measurable proxy of [ONAP's] efforts to expand access to [U.S.] Department of Housing and Urban Development [HUD] and other housing supports to all needy people living with HIV.)

Although the NHAS does not specify it explicitly, the text makes clear that the continuous care target for Ryan White clients serves as a measurable proxy of efforts to ensure that all diagnosed HIV-infected persons are maintained in care (ONAP, 2010, pp. 23-25).

The NHAS (ONAP, 2010, p. 31) also lists three targets in support of the goal of reducing HIV-related health disparities:

BOX 2-2
PEPFAR Essential Reported Indicators

Prevention

P1.2.D Number of HIV-positive pregnant women who received antiretrovirals to reduce risk of mother-to-child transmission

Care

C2.1.D Number of HIV-positive adults and children receiving a minimum of one clinical service

C2.4.D Percentage of HIV-positive patients who were screened for tuberculosis (TB) in HIV care or treatment settings

C2.5.D Percentage of HIV-positive patients in HIV care or treatment (pre-ART or ART) who started TB treatment

C5.1.D Number of eligible clients who received food and/or other nutrition services

Treatment

T1.2.D Number of adults and children with advanced HIV infection receiving ART [CURRENT]

SOURCE: Adapted from PEPFAR, 2009, Table 1.

- Increase the proportion of HIV-diagnosed gay and bisexual men with undetectable viral load by 20 percent.
- Increase the proportion of HIV-diagnosed blacks with undetectable viral load by 20 percent.
- Increase the proportion of HIV-diagnosed Latinos with undetectable viral load by 20 percent.

As discussed in more detail later, these six specific strategy targets provided the basis for several of the indicators recommended by the committee. Since the issue of continuity of care clearly is not limited to Ryan White HIV/AIDS Program clients, the continuity-of-care indicator identified by the committee is directed toward the general population of PLWHA but can also be applied to Ryan White HIV/AIDS Program clients or any other subpopulation. The same is true for the indicators relating to permanent housing and undetectable viral load.

Selection of Indicators of HIV Care and Access to Supportive Services

In addition to the HIV-related performance measures, health objectives, indicators, and NHAS goals discussed in the preceding sections, the committee's selection of core indicators "to gauge the impact of the National HIV/AIDS Strategy and the Patient Protection and Affordable Care Act in improving HIV/AIDS care" (statement of task) was informed by the identification of two overarching goals for the provision of HIV care: (1) to optimize health outcomes for PLWHA and (2) to reduce the risk of transmitting the virus to others. These goals of HIV care are best achieved through full engagement of PLWHA in clinical HIV care, as depicted in Figures 2-1 and 2-2.

Primary barriers to optimal outcomes for PLWHA 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 2-3 shows the number of people lost to care at various points along the care continuum. Identification of benchmarks and points at which diagnosed PLWHA are lost along the continuum of engagement in HIV care from diagnosis to death served as a basis for the committee's selection of process and outcome indicators of quality clinical HIV care. Throughout its deliberations, the committee, in keeping with its charge to recommend indicators that "capture the care experiences of people living with HIV without substantial new investments" and mindful of the need not to increase reporting burden unduly, sought to balance the numerous facets of quality HIV care against the need for parsimony in its selection of core indicators;

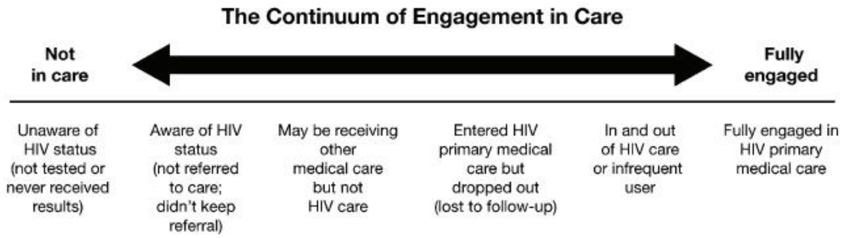

FIGURE 2-1 Continuum of engagement in care.
SOURCE: Cheever, 2007.

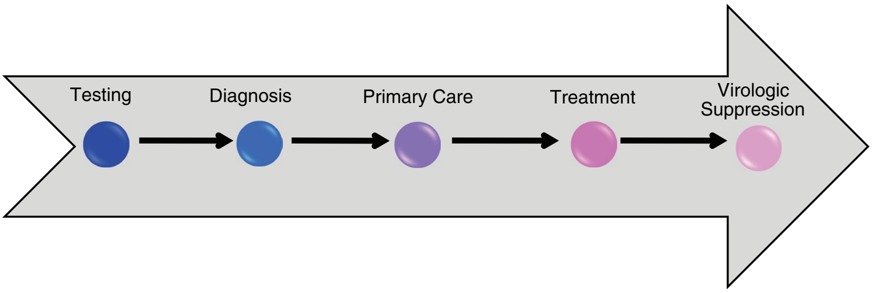

FIGURE 2-2 Continuum of HIV care arrow.
SOURCE: Adapted from Das, 2011.

hence, the core indicators reflect more general aspects of clinical HIV care, while more specific aspects are included in the additional indicators. In addition, the committee was specifically asked to address indicators related to access to supportive services, such as housing. Consideration of significant mediators of continuous engagement and optimal health outcomes in HIV care, including receipt of needed mental health and substance abuse services, homelessness and housing instability, food insecurity, and lack of transportation needed to access medical and supportive services, informed the committee's selection of core and additional indicators in these areas.

A recent series of IOM reports discusses policies, facilitators, and barriers surrounding expanded HIV testing and access to care (IOM, 2010, 2011b,c). The present report focuses on adults who have been diagnosed with HIV and on indicators pertaining to the provision of HIV care and supportive services from diagnosis forward. Although the indicators for clinical HIV care and mental health and substance abuse are targeted toward adults, they apply to adolescents (≥13 years) as well. There are tens of thousands of new diagnoses annually among the group of individuals

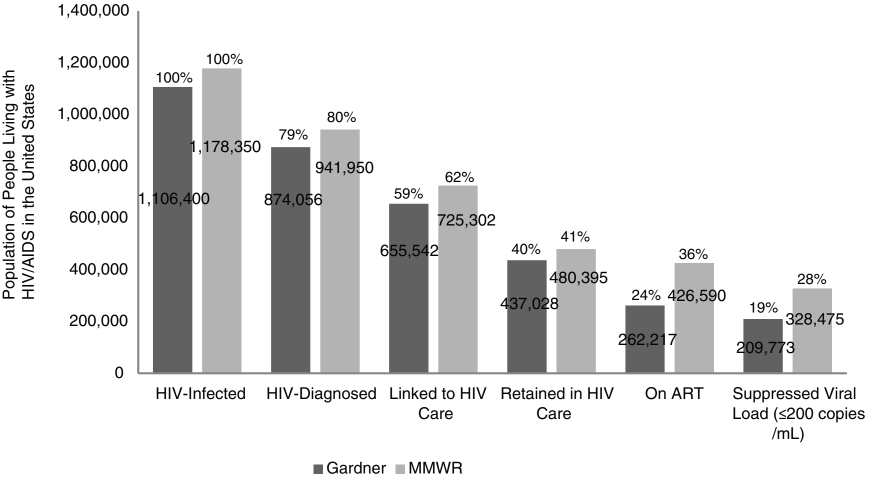

FIGURE 2-3 Engagement in HIV care cascade.
SOURCE: Adapted from CDC, 2011c; Gardner et al., 2011.

13 and older, with the highest rates between the ages of 20 and 49 years (CDC, 2012, Table 1a).[5] In contrast, 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. In 2008, 218 children under the age of 13 were diagnosed with HIV; by 2010, the number had dropped to 185 (CDC, 2012, Table 1a).

Although some of the indicators, such as screening for sexually transmitted infections (STIs) and mental health and substance use disorders, generally do not apply to children under the age of 13, others, such as mortality rate, apply equally to all ages; indicators that reflect treatment guidelines apply to children as well, once they are adapted to reflect pediatric guidelines for HIV care (HHS, 2011e).

The indicators crafted by the committee reflect the current science and guidelines for the practice of HIV care at the time of writing. Although the specific details of the indicators (e.g., threshold CD4+ cell counts) may evolve over time as the science and practice of HIV care changes, the prin-

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[5] Although there is a low rate of new HIV diagnoses among 13- to 14-year-olds (CDC, 2012, Table 1a), adolescents 13 and older fall within the same treatment guidelines as adults (HHS, 2011d) and therefore are included in the group. In addition, the current Centers for Disease Control and Prevention HIV screening guidelines also focus on individuals age 13 and older (Branson et al., 2006).

ciples embodied in the indicators (e.g., early diagnosis, linkage and retention in care, timely initiation of ART) continue to pertain.[6]

Core Indicators Related to Clinical HIV Care

Diagnosis

The first benchmark along the continuum of HIV care is diagnosis. Although the number of persons diagnosed with HIV earlier in the course of their infection has increased (CDC, 2009), there is evidence that many PLWHA continue to be diagnosed late. For example, the Centers for Disease Control and Prevention (CDC) estimates that in 2009 32 percent of all HIV cases reported by 46 states with confidential name-based reporting received a diagnosis of AIDS less than 12 months after their initial HIV diagnosis (CDC, 2012, Table 10a). CDC also estimates that approximately 20 percent of PLWHA in the United States are unaware that they have HIV (CDC, 2011a,b),[7] putting them at risk for being diagnosed late, by which time symptoms may have already developed and treatment may not be as effective. Given the importance of care and treatment for improving health outcomes, timely diagnosis is a crucial first step in the provision of quality HIV care. In addition, research shows that individuals who are aware that they have HIV are less likely to transmit the virus to others (Pinkerton et al., 2008).

At the time of HIV diagnosis, patients should be evaluated to assess the stage of the disease and establish a baseline to help determine management plans and goals (HHS, 2011d, p. 4), including the need for mental health and substance abuse treatment and supportive services. Newly diagnosed patients also should receive recommended testing and screening, including CD4 and viral load testing, screening for concurrent infections and antiretroviral (ARV) drug resistance, and routine laboratory tests (Aberg et al., 2009, p. 662, Table 5; HHS, 2011d, p. 4; Kaplan et al., 2009).

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[6] The committee considered guidelines for HIV treatment in its development of the indicators for clinical HIV care, including the U.S. Department of Health and Human Services *Guidelines for the Use of Antiretroviral Agents in HIV-1-Infected Adults and Adolescents*, dated October 14, 2011, that were current at the time the report went to press (HHS, 2011d). A revised version of the *Guidelines* was issued March 27, 2012, and readers may wish to take account of the revised *Guidelines* when considering the indicators.

[7] Michael Campsmith and colleagues (2010) used an extended back-calculation approach based on the number of HIV diagnoses by calendar year and disease severity (i.e., whether the individual received an AIDS diagnosis in the same calendar year as the HIV diagnosis) to estimate the total number of infections (known diagnosed cases plus estimated undiagnosed cases). They then subtracted the estimated number of deaths (obtained from national HIV/AIDS surveillance data) to arrive at an estimated prevalence of undiagnosed cases (232,700 95% CI = 221,200-244,200).

CD4 count at diagnosis provides a baseline against which subsequent tests can be compared. Along with the presence or absence of an AIDS defining illness, it serves as an indicator of the health status of the individual at HIV diagnosis. Higher CD4 counts at diagnosis indicate better health status and a shorter time between infection and diagnosis. Early diagnosis results in better health outcomes and decreased likelihood of viral transmission.

The committee recommends the following indicator as a measure of the health status of individuals at diagnosis and the timeliness of diagnosis.

- **Proportion of people newly diagnosed with HIV with a CD4+ cell count >200 cells/mm^3 and without a clinical diagnosis of AIDS**

The indicator also can be used as a measure of the success of testing efforts within a population: an increase in the rate of early diagnosis indicates more successful testing efforts. Aggregate measures, such as median CD4 counts at diagnosis, also may be used to track the success of expanded testing efforts within a given population, with higher median CD4 counts being indicative of more people being tested sooner following infection.

Linkage to and Continuity of Care

Timely linkage to care following diagnosis is the second benchmark in HIV care. Currently only 64 to 77 percent of individuals newly diagnosed with HIV are linked to HIV care within 3 to 4 months of diagnosis (see CDC, 2011c; Gardner et al., 2011; Marks et al., 2010; Torian and Wiewel, 2011). A study of time-limited case management intervention focused on linkage to HIV care demonstrated improved linkage to care over the standard-of-care arm, which received only passive referral to a local HIV care provider in addition to information about HIV and local care resources (Gardner et al., 2005). The more quickly newly diagnosed individuals enter HIV care, the better their health outcomes are apt to be. ART may be initiated more promptly, with an attendant reduction in viral load, which leads to improved health outcomes and a reduction in HIV transmission. In addition, prompt receipt of prevention services, such as screening and treatment for STIs and mental health and substance use disorders, risk reduction counseling and behavioral interventions, assistance with partner notification, and housing assistance and other supportive services, is important for reducing transmission of the virus and improving health outcomes among PLWHA (CDC, 2010b; Crepaz, et al., 2006; Kamb et al., 1998; Shain et al., 1999; Weinhardt et al., 1999; Wolitski et al., 2005). The NHAS sets a target of linkage to care within 3 months of diagnosis (ONAP, 2010, p. 21), as does CDC's HIV Prevention Strategic Plan (CDC, 2007). Although newly diagnosed PLWHA ideally would be linked to care within 1 month of diagnosis, the 3-month time frame is more realistic and dovetails with existing literature and public health goals.

Given the importance of timely linkage to HIV care in optimizing health outcomes of PLWHA and in reducing transmission of the virus, the committee recommends the following core indicator.

- **Proportion of people newly diagnosed with HIV who are linked to clinical care for HIV within 3 months of diagnosis**

Retention in or continuity of care is another key aspect of engagement in HIV care. As previously noted, regular office visits for ongoing care, appropriate initiation and monitoring of ART, and monitoring of CD4 and viral load levels, as well as provision of recommended screening, prophylaxis, and treatment for comorbid conditions, are important for ensuring optimal health outcomes for HIV-infected individuals. Missed visits during the first year of care are associated with an increasing risk of death as the number of missed visits increases (Giordano et al., 2007; Mugavero et al., 2009; Park et al., 2007). Given that approximately 50 percent of diagnosed PLWHA are not engaged in regular care (CDC, 2011c; Gardner et al., 2011; Giordano et al., 2007), increasing the proportion of diagnosed HIV-infected individuals in continuous care is important to the success of the NHAS.

Measuring continuity of care requires specifying what constitutes appropriate ongoing care. However, clinical care guidelines may not be consistent and may also evolve over time to reflect updates in clinical practice. HIV Care Quality Measures recommend HIV-infected patients be seen at least twice within a 12-month period, at least 60 days apart, and receive CD4 testing at least once every 6 months (Horberg et al., 2010). With regard to Ryan White HIV/AIDS Program clients, the NHAS defines continuous care as at least two visits within a 12-month period at least 3 months apart (ONAP, 2010, p. 21).

Regular HIV-related laboratory tests, such as CD4 and viral load testing, provide evidence of continuity of clinical HIV care (Perkins et al., 2008). U.S. Department of Health and Human Services (HHS) guidelines recommend CD4 and viral load testing every 3 to 6 months prior to initiating ART and extend the interval to every 6 to 12 months in clinically stable patients with a suppressed viral load on ART (HHS, 2011d, p. i). Although not directly representative of office visits, because patients may have office visits in addition to those associated with laboratory testing or receive laboratory testing independent of an office visit, regular monitoring of patients' CD4 and viral load levels can serve as proxies for care visits when evaluating continuity of care.

The committee recommends the following core indicator for tracking retention in HIV care.

- **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)**

Improvements in linkage to and retention in care are particularly important for a number of subpopulations of PLWHA that are at heightened risk for delayed entry into and poor retention in care, although the at-risk groups do not reflect consistent racial, ethnic, or sex differences (CHAIN Fact Sheet, 2004; Dennis et al., 2011; Meditz et al., 2011; Mugavero et al., 2007), because the individuals affected often vary with local resources and considerations. However, groups of particular concern, including homeless and unstably housed individuals, HIV-infected adolescents, those living in rural areas of the South, and some racial or ethnic minorities, are often burdened with a set of complex social factors such as a lack of resources (Denning and DiNenno, 2010); fears about their HIV status being revealed and the resultant stigma and discrimination (Sayles et al., 2009); or distrust of the medical system (Bogart et al., 2010; Whetten et al., 2006a).

Quality of HIV Care

Quality of HIV care is distinct from continuity of care, since a patient might be seen regularly but not receive quality HIV care—that is, care in accordance with accepted practice guidelines or measures. A number of the indicators identified by the committee could serve to measure quality of care as well as linkage to and continuity of care. For example, regular monitoring of patients' CD4 and viral load levels (discussed in the previous section) can provide information about their continuity of care, as well as about the quality of their HIV care. The core indicators that relate to quality of care and health outcomes are presented in the following discussion.

CD4 and Viral Load Testing As process measures, CD4 and viral load testing in accordance with recommended guidelines not only demonstrate continuity of care but also are acceptable indicators of quality HIV care. Regular CD4 testing improves health outcomes in PLWHA by permitting providers to monitor individuals' immune function, determine when to initiate ART, assess immunologic response to ART, and assess the need for initiation or discontinuation of prophylaxis for opportunistic infections (OIs) (HHS, 2011d, p. 7). Regular viral load testing is also important for monitoring clinical progression of the disease, particularly therapeutic response in individuals on ART (HHS, 2011d, p. 9). Decreased viral load, or undetectable viral load in individuals on ART, is associated with improved health outcomes and reduced transmission of the virus.

The appropriate number and intervals for "regular" CD4 and viral load testing vary with the health status and needs of each individual. *HHS Guidelines for the Use of Antiretroviral Agents in HIV-1-Infected Adults and Adolescents* recommend testing every 3 to 6 months, with additional testing at the time of ART initiation or modification (HHS, 2011d, pp. 6-10).[8] The interval between tests may be increased to every 6 to 12 months for clinically stable individuals on ART with viral suppression. For the purpose of tracking the impact of the NHAS and the ACA on HIV care in the United States, the committee chose to define regular testing as two or more tests in the preceding 12 months. Although the committee recognizes that one test per year could serve as a minimum standard to identify individuals who clearly have fallen out of care, in most cases it would be inappropriate to consider this frequency of testing to be indicative of optimal treatment.

Accordingly the committee recommends the following core indicators for regular CD4 and viral load testing.

- **Proportion of people with diagnosed HIV infection who received two or more CD4 tests in the preceding 12 months**
- **Proportion of people with diagnosed HIV infection who received two or more viral load tests in the preceding 12 months**

ART Initiation and Adherence Appropriate initiation of ART, the third benchmark of quality HIV care, is crucial to increased longevity and reduced morbidity among PLWHA and important for reducing transmission of the virus to others (HHS, 2011d). For this reason, a significant measure of the quality of HIV care is the proportion of PLWHA who are started on the correct drug regimen at the appropriate time. Although approximately 77 to 80 percent of individuals being treated with ART have an undetectable viral load, many PLWHA are not on ART (CDC, 2011c; Gardner et al., 2011). According to estimates, only 24 to 36 percent of PLWHA are receiving ART and only 19 to 28 percent of PLWHA overall have an undetectable viral load (CDC, 2011c; Gardner et al., 2011). As indicated in Figure 2-3, the gap lies in undetected cases of HIV infection, inadequate linkage to and retention in care for those who are diagnosed, and delayed or absent initiation of ART.

The current HHS *Guidelines* (HHS, 2011d, p. 27) specify that indi-

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[8] The *Guidelines* also recommend viral load testing 2 to 8 weeks following ART initiation or modification and, if needed, every 4 to 8 weeks thereafter until suppression to <200 copies/mL (HHS 2011d, p. 6).

viduals with a CD4+ cell count below 350 cells/mm^3 or those who have a history of an AIDS-defining illness should be started on ART. The *Guidelines* further recommend that ART be initiated in people whose CD4+ cell counts are between 350 and 500 cells/mm^3, but the HHS panel was divided on whether to recommend ART for patients with CD4+ cell counts greater than 500 cells/mm^3. In formulating a core indicator for initiation of ART, the committee followed the HHS panel's recommended threshold of 500 cells/mm^3.

- **Proportion of people with diagnosed HIV infection and a measured CD4+ cell count <500 cells/mm^3 who are not on ART**

Initial results from the HIV Treatment Prevention Network's HPTN 052 clinical trial funded by the National Institutes of Health indicate that early initiation of ART in PLWHA reduces sexual transmission of HIV in serostatus-discordant couples by 96 percent (Cohen et al., 2011). In an August 2011 letter to HHS Secretary Kathleen Sebelius, the Presidential Advisory Council on HIV/AIDS (PACHA) emphasized the importance of these "treatment as prevention" findings, stating that "HHS-supported HIV clinical treatment guidelines must be revised to reflect these findings" (PACHA, 2011). If HHS were to revise its guidelines according to PACHA's recommendation, the committee would support similar revision of its ART-initiation indicator. Movement toward universal treatment for PLWHA has begun. The San Francisco and, more recently, New York City departments of health now recommend initiation of ART regardless of individuals' CD4 count (Charlebois et al., 2011; NYC DOHMH, 2011). If a policy of universal treatment becomes widespread, a more appropriate indicator of ART initiation would be the time from diagnosis to ART initiation.

With the advent of more potent antiretroviral drugs, the goal of ART is durable virologic suppression, the fourth benchmark of quality HIV care. Adherence to a prescribed antiretroviral drug regimen is an important factor in successful treatment with ART. Failure to take antiretroviral medications as prescribed not only decreases the drugs' effectiveness in reducing individuals' viral load but also may increase the risk of HIV transmission to others and may lead to the emergence of ARV-resistant strains of the virus, undermining the durability of the present drug regimens. People on ART may fail to take their drugs as prescribed for a variety of reasons, including inability to pay for the medications, undesirable side effects, serious mental illness, lack of food, stigma, and forgetfulness. It is important to work with nonadherent patients to identify and address the causes of nonadherence (Cooperman et al., 2012; de Bruin et al., 2010; Henderson et al., 2011; HHS, 2011d, pp. 122-125; Reisner et al., 2009; Simoni et al., 2006, 2010).

Although adequate adherence is an important factor in achieving viral suppression, viral suppression itself is the most important outcome measure for successful ART. HIV-infected individuals with a viral load below the level of detection experience significantly improved health outcomes (HHS, 2011d, p. 9). In addition, as reinforced by the results of the HPTN 052 clinical trial, individuals with virologic suppression are much less likely to infect others (Cohen et al., 2011). Current estimates indicate that 13 to 20 percent of individuals on ART still have a detectable viral load (CDC, 2011c; Gardner et al., 2011). Imperfect viral load suppression among treated individuals motivates the committee's identification of the following core indicator of successful treatment with ART.

- **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**

This indicator serves not only as a measure of the status of the epidemic in terms of optimal health outcomes and decreased risk of HIV transmission but also as a surrogate measure of treatment adherence and the prescription of effective drug regimens. An alternate indicator would be the time from diagnosis to virologic suppression.

Additional Outcome Indicators In aggregate, CD4 and viral load test results provide information about the status of the epidemic nationally or in specific subpopulations or geographic areas. Although virologic suppression is the primary outcome indicator for individuals on ART, the committee recommends two additional outcome indicators for monitoring the provision of quality HIV care to PLWHA.

Maintaining a CD4+ cell count ≥350 cells/mm^3 reduces the risk of complicating OIs and cancers among PLWHA (HHS, 2011d, pp. 28-31). Since 64 to 76 percent of PLWHA currently are not on ART (CDC, 2011c; Gardner et al., 2011), the following indicator serves as an outcome measure for this group, as well as for those who are on ART, but have not achieved virologic suppression.

- **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**

If a large number of previously undiagnosed individuals with late-stage HIV disease entered care, the CD4+ cell count ≥350 cells/mm^3 indicator might drop, suggesting poor system performance. However, this change could be interpreted correctly in the full context of all the indicators.

Mortality rate is the ultimate outcome measure for people diagnosed with HIV infection and serves as another aggregate-level measure of HIV care. Mortality among PLWHA should be inversely related to the quality of overall care delivered. To avoid the difficulties inherent in identifying and reporting which deaths among PLWHA resulted directly or indirectly from HIV infection, the committee recommends the use of all-cause mortality in the following indicator.

- **All-cause mortality rate among people with diagnosed HIV infection**

Taken together, the committee recommends the preceding indicators as core indicators related to continuous and quality clinical care for PLWHA. Core indicators pertaining to mental health, substance abuse, and supportive services, such as housing, that affect the health outcomes of PLWHA are discussed in the following section.

Core Indicators Related to Mental Health, Substance Abuse, and Supportive Services

A number of factors, including mental health symptoms and disorders, substance abuse, lack of well-being, and poor quality of life, as well as 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 health outcomes of PLWHA (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). The committee identified screening and treatment for mental health and substance use disorders, as well as access to needed housing, food, and transportation assistance, to be sufficiently important facilitators of improved health outcomes for PLWHA to recommend as indicators of HIV care. Obtaining data to estimate these indicators, especially those pertaining to supportive services, poses challenges different from those that attend the clinical HIV care indicators, nevertheless they are amenable to objective quantification.

Mental Health and Substance Abuse

Substantial evidence indicates that mental health symptoms and disorders, including neurocognitive disorders, and substance use disorders are significantly increased in people with HIV (see Hinkin et al., 2002; Lansky et al., 2009; Milloy et al., 2010; Owe-Larsson et al., 2009; WHO, 2008), and these disorders affect treatment adherence to antiretroviral medications (Ettenhofer et al., 2009; Hinkin et al., 2002; Tucker et al., 2003; Waldrop-Valverde et al., 2006) and continuity of care, secondary transmission, and overall health outcomes (Samet et al., 2007; Ulett et al., 2009; Zaller et al., 2007). For this reason, screening HIV-infected patients for mental health and substance use symptoms and disorders is essential to providing care that will lead to the best health outcomes.

"Mental health disorders" refers to a broad range of conditions that might affect treatment and health outcomes for PLWHA, including anxiety and mood (e.g., depression) disorders, psychoses, and subthreshold conditions (i.e., mental conditions not meeting full diagnostic criteria for mental disorders). Mental health symptoms refer to conditions of psychological distress, which may be acute or chronic and are known to be related to negative health outcomes. Moderate to severe depression is particularly prevalent among PLWHA and is associated with failure to access ART, failure to adhere to ART, increased morbidity and mortality, and potentially increased HIV-related risk behavior (Crepaz and Marks, 2002; Horberg et al., 2008; Kalichman, 2000; Kumar and Encinosa, 2010; Penzak et al., 2000). The prevalence of HIV-associated neurocognitive disorders is greater than 50 percent, and perhaps higher in older HIV patients (Valcour et al., 2011), making age-specific analysis of relevant indicators particularly informative. Even mild symptomatic cognitive impairment is associated with non–central nervous system (non–CNS) morbidity and overall HIV mortality (Vivithanaporn et al., 2010). Early detection and treatment of depression, psychological distress, and cognitive impairment among PLWHA are important because they often negatively impact daily routine functioning and the ability to efficaciously adhere to medication routines. In addition, symptomatic impairment, whether mild neurocognitive disorder or asymptomatic neurocognitive impairment, has been linked to all-cause mortality (Valcour et al., 2011). More serious HIV-related neurocognitive disorders can result in dementia, which can also impede good health outcomes without necessary interventions.

Mental health disorders and symptoms can be associated with HIV in two ways: first, individuals with mental health disorders may be at greater risk for acquiring, as well as transmitting, HIV; second, HIV-infected individuals are at greater risk for developing neurocognitive disorders. In addition, HIV-infected patients, as they live longer and age, increasingly have high rates of medical comorbidity associated with the normal aging process as well as side effects from their ART (Bisson et al., 2003; Goulet et al., 2007). There is evidence as well that mental health and neurocognitive disorders are increased among older PLWHA (Justice et al., 2004; Valcour et al., 2011), making screening especially important for this subpopulation. Although some HIV-related cognitive disorders have decreased in incidence or severity with the use of ART, the overall prevalence is increased among older PLWHA.

With evidence mounting that mental health and neurocognitive disorders are common in spite of ART, screening for depression and other mental health disorders as well as changes in cognition and the accompanying functional impairments may be an important factor in achieving sufficiently high adherence rates to maintain undetectable viral load and immunologic competency. Since many medical comorbidities, such as hepatitis C (and other) infection in the central nervous system (CNS), endocrine disorders, advanced cerebrovascular disease, and medications, can cause cognitive changes, the screening for medical causes of cognitive dysfunction is also imperative in order to maximize health outcomes. Although complete mental health and neuropsychological testing often are not clinically available outside of academic HIV treatment centers, a number of user-friendly screening tools are available for use in the clinic to help identify patients who should be referred to specialty services or for more extensive evaluation. Basic screening tools include the nine-item Patient Health Questionnaire (PHQ-9) for depression (Pfizer, 2011), the Modified HIV Dementia Scale (AETC, 2011, Figure 1) and the culture neutral International Dementia Scale (Sacktor et al., 2005, Figure 1), the Montreal Cognitive Assessment scale (MoCA, 2011), and the Exit 25 for severe cognitive disorders (UTHSC, 2011).

Unhealthy substance abuse or misuse behaviors, such as chronic and heavy intake of alcohol and illicit drug use, particularly injection drug use, are significantly related to the acquisition of HIV infection and for some PLWHA serve as a way to cope with and manage HIV-related symptoms (Brion et al., 2011). Heavy and chronic abuse of alcohol and other substances is also significantly related to increased risk of acquiring new HIV infections, since they can impair judgment and reduce inhibitions, potentially resulting in unsafe sex and other HIV-related transmission risk behaviors. Substance abuse is also linked with poorer health outcomes for HIV-infected individuals (Carrico, 2011), complicates health care outcomes, and decreases adherence to ART regimens. In a prospective cohort study of 140 HIV-infected patients at a county hospital HIV clinic during the year following initiation of highly active antiretroviral therapy (HAART), Carol Golin and colleagues (2002) found that nearly all of the patients' adherence levels were suboptimal and that interventions that assessed and treated substance abuse and incorporated assistance with antiretroviral adherence were more likely to result in optimal care levels. Not only can substance use negatively affect treatment adherence and hence outcomes (Tucker et al., 2003); the use of certain substances, such methamphetamine, also has been shown to increase HIV viral replication in animal models (Gavrilin et al., 2002) and to increase neuronal damage and cognition impairment in humans (Langford et al., 2003; Rippeth et al., 2004). Judith Cook and colleagues (2008) found that the use of crack cocaine was associated with a faster progression of HIV.

Recent studies have found that multidisciplinary approaches to care that address psychiatric conditions and substance abuse and its sequelae, such as hepatitis C coinfection, resulted in improved access to and retention in care and better uptake rates of initiation of ART (Litwin et al., 2005; Palepu et al., 2006; Sherer et al., 2002). Screening, Brief Intervention, and Referral to Treatment (SBIRT) and Alcohol, Smoking, and Substance Involvement Screening Test (ASSIST) are user-friendly screening tools that permit early diagnosis and intervention in alcohol and drug use disorders in HIV and other health care settings (Babor et al., 2007; Humeniuk et al., 2008; SAMHSA, 2011). Other tools such as the Alcohol Use Disorders Identification Test (AUDIT) or CAGE (an acronym derived from its four questions that stands for "*cut* down," "*annoyed*," "*guilty*," and "*eye*-opener") questions also can be used to screen for alcohol dependency (NIAAA, 2005). Use of such tools in conjunction with a complete alcohol and drug history, including over-the-counter and alternative medicines as well as illicit drugs, is vital for increasing optimal antiretroviral treatment, reducing secondary HIV transmission, elucidating cognitive changes, and identifying individuals who might benefit from specialized adjunct treatment in addition to the management of their HIV disease.

The committee recommends two core indicators relating to mental health and substance abuse.

- **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**
- **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**

Studies have shown that referrals for mental health and substance abuse services that can be accessed in a short period of time after they have been recommended have some of the best outcomes and high levels of patient satisfaction (Kowal et al., 2011). In cities such as Baltimore and San Francisco, treatment on demand for substance use has been instituted to reduce the human and economic harm associated with alcohol and illicit drug use and to increase the benefits of better treatment (Drug Strategies, 2000; Friedmann et al., 2003; Sears et al., 2009). Detroit found that treatment on demand reduced homicides and larceny and resulted in high rates of patient satisfaction (Trent, 2004). The committee considered receipt of specialty mental health and substance abuse services within 30 days of referral, with urgent cases being seen as soon as possible, to reflect optimal care because it is anticipated that individuals with sufficiently severe mental health or substance use disorders to merit referral should receive those services in a short window of time to reduce the likelihood of suboptimal adherence to ART and to decrease the risk for secondary transmission of HIV infection (and preventable new infections). However, the committee concluded that receipt of specialty services within 60 days was more realistic given the current limited capacity of many providers to see new patients within a shorter time frame.

Housing, Food Security, and Transportation

Assessment of food and housing needs and referral to appropriate services are essential to improving HIV care, improving health outcomes, and reducing health disparities among the HIV-infected population (Anema et al., 2009; McMahon et al., 2011; Reily et al., 2011; Weiser et al., 2009a,b). Studies suggest that as many as half of all persons diagnosed with HIV in the United States will face homelessness or experience an unstable housing situation at some point over the course of their illness (Aidala et al., 2007; Song, 1999). Estimates indicate that 140,000 PLWHA currently are in need of housing assistance (NAHC, 2012). Needs assessments have found that rates of food insecurity and nutritional needs range from 20 to more than 50 percent among samples of PLWHA in medical care or social service settings, with rates higher among PLWHA who are not in care.

For the purpose of this report, "housing instability" refers to homelessness, imminent risk of homelessness, and unstable housing as defined for reporting in HUD's Homeless Management Information Systems (HMIS), which are used by all jurisdictions receiving HUD funding to address homelessness and risk of homelessness (HUD, 2010). The broad distinction is between persons who have stable, permanent housing in the community and individuals or families who lack the resources or support networks to retain or obtain permanent housing. Guidance is provided for classifying housing status in four categories: *literally homeless* (e.g., lack a regular nighttime residence, staying in an emergency shelter);[9] *imminently losing housing* (e.g., being evicted or being discharged from an institution with no housing options identified); *unstably housed and at-risk of losing housing* (e.g., temporarily doubled up with others, moving frequently for economic reasons); and *stably housed* (HUD, 2010, pp. 54-56). HUD currently is taking the lead in interagency efforts to develop a common vocabulary of homelessness and to standardize housing status questions among several

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[9] This category is based on the McKinney-Vento Homeless Assistance Act (42 U.S.C. 11302, Sec. 103) definition of homelessness, as amended by the Homeless Emergency Assistance and Rapid Transition to Housing (HEARTH) Act of 2009 (P.L. 111-22, div. B, Sec. 1003). HUD issued its final rule for the definition of homelessness on December 5, 2011 (*Federal Register* 76[233]:75944-76019).

federal agencies, including HHS (e.g., Centers for Medicare and Medicaid Services, HRSA) and the Department of Veterans Affairs.

"Food insecurity" refers to the U.S. Department of Agriculture (USDA) definition as "limited or uncertain availability of nutritionally adequate and safe foods or limited or uncertain ability to acquire acceptable foods in socially acceptable ways" (ERS, 2009, citing Anderson, 1990). Since 2006, the USDA has applied four classifications to the range of food (in)security. *High food security* means "no reported indications of food-access problems or limitations"; *marginal food security* means "one or two reported indications—typically of anxiety over food sufficiency or shortage of food in the house [with] little or no indication of changes in diets or food intake"; *low food security* means "reports of reduced quality, variety, or desirability of diet [with] little or no indications of reduced food intake"; and *very low food security* means "reports of multiple indications of disrupted eating patterns and reduced food intake" (ERS, 2011). Persons who are classified with low and very low food security are considered food insecure (ERS, 2011).

Housing instability, food insecurity, and other supportive service needs affect HIV outcomes in direct and indirect ways. Lack of shelter or severely inadequate housing increases exposure to infectious agents, allergens, and neurotoxins that compromise health (Shaw, 2004). Poor nutrition affects the ability to maintain healthy body weight and increases the risk or complicates the management of other chronic diseases such as heart disease, diabetes, and cancer. In addition, some ARVs need to be taken with food, and diarrhea, which is often associated with homelessness, is associated with underabsorbtion of ARVs (Brantley et al., 2003; Bushen et al., 2004; Dillingham et al., 2011).

As the NHAS points out, persons who face daily challenges meeting their basic needs for housing and food are much less likely to maintain a stable HIV treatment regimen (ONAP, 2010, p. 28). Housing instability is one of the major factors limiting access to and maintenance in HIV care and adherence to treatments (Aidala et al., 2007; Ghose et al., 2011; Kidder et al., 2007; Leaver et al., 2007). Persons who are food insecure are also less likely to be in care, stay in care, or be adherent to treatment than their counterparts whose food and nutrition needs are met (Anema et al., 2009; Ashman et al., 2002; Riley et al., 2011).

Whether via physiological or psychosocial mechanisms, homelessness or unstable housing is associated with lower CD4 counts, higher viral loads, and higher rates of comorbidities among PLWHA, controlling for a wide range of individual and medical care variables (Clements-Nolle et al., 2008; Kidder et al., 2007; Knowlton et al., 2006; LeGrand et al., 2010). Homelessness has been an independent predictor of mortality in all studies that have investigated the impact of housing status on the survival of

HIV-infected persons (Lieb et al., 2002; McMahon et al., 2011; Riley et al., 2005a,b; Schwarcz et al., 2009; Walley et al., 2008). Food insecurity also is associated with poor clinical outcomes and higher mortality in the United States, as well as in low-resource countries (Campa et al., 2005; Hendricks and Gorbach, 2009; Kalichman et al., 2010; McMahon et al., 2011; Vogenthaler et al., 2010; Weiser et al., 2009a,b).

However, research has also shown that addressing the need for housing and other supportive services is both effective and cost-effective for improving health care access and health outcomes of HIV-infected people. A systematic review of 17 housing-related studies (Leaver et al., 2007) found a significant positive association between increased housing stability and better health-related outcomes, including connection to HIV medical care and adherence to treatment. In a randomized trial commissioned by the CDC and HUD, provision of rental assistance was associated with reduced emergency room use and improved mental health and clinical health outcomes for HIV-infected clients (Wolitski et al., 2010). Food and nutrition programs have improved adherence to and the effectiveness of HIV medications among food-insecure patients. Nonmedical supportive services including food assistance can serve to attract clients who need other services and can facilitate their entry into and maintenance in HIV medical care (see Ashman et al., 2002; Conover and Whetten-Goldstein, 2002; Conviser, 2007; Conviser and Pounds, 2002a,b; Messeri et al., 2002).

Another crucial supportive service for many PLWHA is transportation. Lack of reliable transportation has long been recognized as limiting access to and utilization of medical care, especially the use of prevention services and medical monitoring of chronic conditions (see, e.g., Arcury et al., 2005; Baldwin et al., 2004; Littenberg et al., 2006; Valet et al., 2009). Lack of transportation is a major barrier to regular and timely health care visits for PLWHA as well, especially in rural areas where distances to providers are often very long and public transportation is absent (Conover and Whetten-Goldstein, 2002; HRSA, 2009; Napravnik et al., 2006; Reif et al., 2005; Sarnquist et al., 2011; Stewart et al., 2011).

In rural areas, particularly in the southern United States, which accounts for almost 70 percent of all rural cases of HIV, transportation can be a significant barrier to care, including quality HIV-related medical services (Arcury et al., 2005; Cohn et al., 2001; HRSA, 2009; Kempf et al., 2010). HIV care providers can be as much as 2 hours away in rural West Virginia and as much as 200 miles away in parts of Montana (NRHA, 2006). Long travel hours, inclement weather, and lack of travel resources may be critical issues for PLWHA in rural areas and need to be addressed for these individuals to achieve timely linkage to and continuity of care (Krawczyk et al., 2006b; Weis et al., 2010). Transportation concerns are especially important in southern states because the greatest number of new infections in African

Americans, particularly women, is occurring there (Mays et al., 2011). Studies of HIV in the South have indicated the need for transportation, particularly since some individuals seek care further from their neighborhoods in order to avoid stigma and discrimination (Mays et al., 2011; Reif et al., 2005; Vermund et al., 2010).

Transportation issues often pose barriers to appropriate care for PLWHA in urban areas as well. Services research in Boston (Lo et al., 2002), Chicago (Kenagy et al., 2003), Detroit (Andersen et al., 2007), Minneapolis–St. Paul (Othieno, 2007), New York City (Halkitis et al., 2008; Messeri et al., 2002), and several multisite studies covering diverse geographic areas (Ashman et al., 2002; Cunningham et al., 1999; Rumptz et al., 2007) has shown that transportation needs are consistently associated with failure to keep scheduled medical appointments and generally worse engagement with HIV primary care. Medicaid beneficiaries and Ryan White HIV/AIDS Program clients may be eligible for transportation assistance for medical visits. However, costs are seldom fully covered and there are other medical transportation barriers as well. Public transportation may have restricted coverage and times of operation, require long walks or some other form of transport to bus stops or transit stations, and have long wait times in potentially inclement weather. Transportation services for medically fragile or wheelchair-bound individuals may be limited, and clients often face scheduling challenges. Reliance on social networks for help with transportation to HIV care or services may be closed to PLWHA due to stigma and fear of disclosure associated with visits for HIV care or services (HRSA, 2009).

Routine assessment of transportation needs and provision of transportation assistance are effective for promoting timely entry into care and retention in care for persons living with HIV (Ashman et al., 2002; Chin et al., 2009; Conover and Whetten-Goldstein, 2002; Messeri et al., 2002; Rumptz et al., 2007). Transportation assistance also facilitates appropriate follow-through and use of mental health and substance abuse services (Whetten et al., 2006b). Because their transportation needs tend to be greater, assistance with transportation shows greater impact on medical care outcomes among HIV-infected women, ethnic minorities, and recently incarcerated individuals (Andersen et al., 2007; Burks et al., 2011; Halkitis et al., 2010; Kenagy et al., 2003; Sarnquist et al., 2011; Scheyett et al., 2010). Medical and social service providers recognize transportation assistance as an effective mechanism for promoting retention in care for PLWHA (Amico, 2011).

Given the importance of adequate housing, food, and transportation to the health outcomes of PLWHA, the committee identified three core indicators related to access to services that promote housing stability, food security, and transportation. Tracking the proportion of PLWHA who require assistance to meet their needs in these areas provides information about whether available services are meeting those needs. The committee recommends the following indicators.

- **Proportion of people with diagnosed HIV infection who were homeless or temporarily or unstably housed at least once in the preceding 12 months**
- **Proportion of people with diagnosed HIV infection who experienced food or nutrition insecurity at least once in the preceding 12 months**
- **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**

Additional Indicators Related to Clinical HIV Care

In addition to the core indicators for HIV care, the committee identified a number of additional indicators, based on other, more granular, process measures, that provide a comprehensive measure of the quality of HIV care (Appendix Table 2-1).

Testing and Screening for Concurrent Infections

In addition to CD4 and viral load testing, individuals newly diagnosed with HIV should receive a complete medical workup (Aberg et al., 2009; HHS, 2011d), including testing for tuberculosis (TB); STIs, in particular, syphilis, as well as gonorrhea and chlamydia (by nucleic acid amplification test); and hepatitis B and C. Testing for these concurrent infections is important because HIV-infected individuals may be more likely to transmit HIV and other STIs to others and because comorbid conditions are more likely to affect the health of PLWHA. For this reason, the committee identified the following additional indicators pertaining to testing and screening.

- **Proportion of people with diagnosed HIV infection who have had a documented tuberculosis screening test with results interpreted at least once since HIV diagnosis**
- **Proportion of people with diagnosed HIV infection who have had documented chlamydia, gonorrhea, and syphilis screenings at least once in the preceding 12 months**
- **Proportion of people with HIV infection who have had hepatitis B screening performed at least once since HIV diagnosis or for whom there is documented immunity**

- **Proportion of people with diagnosed HIV infection who have had hepatitis C screening performed at least once in the preceding 12 months.**

The time frame specified for repeat testing or screening varies among diseases and the risk of infection. STI screening is recommended annually for sexually active individuals. Hepatitis B screening is recommended only once since diagnosis because immunity is conferred either by previous infection or by vaccination subsequent to a negative screening test, precluding the need for repeat screening. Routine testing or screening should continue to be administered at appropriate intervals in accordance with recommended treatment guidelines (CDC, 2010b) and recognized performance measures (Horberg et al., 2010; NQF, 2011b).

PLWHA also should receive recommended screening and routine primary care in accordance with accepted practice guidelines (see, e.g., Aberg et al., 2009). In particular, quality HIV care should include monitoring for a number of co-occurring, chronic medical conditions associated with HIV infection or treatment, including hyperlipidemia, diabetes, osteoporosis, renal disease, cancers, and depression. PLWHA are at increased risk for such conditions, and as HIV-infected individuals live longer, screening, monitoring, and treatment of these chronic conditions have become increasingly important elements of HIV care. Although the committee recognizes the importance of screening, monitoring, and treating such conditions in the provision of quality HIV care, it did not include indicators related to these practices, since the number of co-occurring conditions made specification of indicators for every condition impracticable and the practice guidelines for the conditions are the same for individuals with and without HIV. Oral health is another important aspect of care for PLWHA. Oral problems can be caused by either a weakened immune system or by certain types of ART, resulting in discomfort; potential difficulty with eating, maintenance of good nutrition, and adherence to ART; and potential psychosocial problems (Chapple and Hamburger, 2000; Coulter et al., 2002; NYSDHAI, 2001). Appendix Table 2-3 lists some of the co-occurring conditions most commonly associated with HIV, along with their etiologic cofactors and references to published guidelines for optimal management.

Immunizations and Prophylaxis

Appropriate immunizations and prophylaxis are other important elements of quality HIV care. The effect of HIV infection on the immune system places PLWHA at greater risk for serious complications of seasonal influenza, pneumococcal pneumonia, and the occurrence of OIs, including pneumocystis pneumonia, TB, and viral hepatitis. Immunosuppression in

PLWHA increases susceptibility to OIs, which not only increase morbidity and mortality among PLWHA but also may cause an increase in HIV viral load, thereby further weakening the immune system (Lawn et al., 2001). Although the use of ART greatly reduces the risk of acquiring OIs (Candiani et al., 2007; Kaplan et al., 2000; Ledergerber et al., 1999), PLWHA should receive appropriate immunizations and prophylactic measures in accordance with recommended guidelines to maximally protect individuals against OIs and their sequelae (Aberg et al., 2009; Kaplan et al., 2000, 2009). Because of the large number of OIs, the committee chose not to develop indicators specific to OI prophylaxis, opting instead to emphasize the importance of following established guidelines for the management of OIs (Kaplan et al., 2009).

The committee did, however, identify the following indicators pertaining to recommended immunizations for PLWHA (HHS, 2009; Horberg et al., 2010; Kaplan et al., 2009, p. 77).

- **Proportion of people with diagnosed HIV infection who have received an influenza immunization during the preceding 12 months**
- **Proportion of people with diagnosed HIV infection who have received a pneumococcal immunization at least once since HIV diagnosis**
- **Proportion of people with diagnosed HIV infection who have received a hepatitis B vaccination, or who have documented immunity**

The need for revaccination varies with the effectiveness of the vaccine at preventing future infection.

Additional Indicators for ART Initiation

In addition to providing guidance for initiating ART based on CD4 count (one of the core indicators recommended by the committee), HHS *Guidelines* specify that ART should be initiated in patients with HIV-associated nephropathy and in patients coinfected with hepatitis B virus (HBV) when treatment for HBV is indicated (HHS, 2011d, pp. 27, 30).[10] The *Guidelines* also recommend initiation of ART in patients with active TB within 2 to 4 weeks of starting treatment for TB for patients with CD4+ cell counts ≤500 cells/mm^3, and 8 weeks for those with CD4+ cell counts >500 cells/mm^3 (HHS 2011d, p. 118).

The *Guidelines* further specify that combination ART should be initiated in pregnant women with HIV (regardless of CD4 count) to help

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[10] Guidance for initiation of ART in response to hepatitis C coinfection is more ambiguous (HHS, 2011d, pp. 114-116; Kaplan et al., 2009, p. 89; Shafran, 2007).

prevent mother-to-child transmission of HIV (HHS, 2011d, pp. 27, 32; 2011f, p. 8). In conjunction with caesarian instead of vaginal delivery and avoidance of breastfeeding, the use of ART during pregnancy has reduced the rate of perinatal HIV transmission from 25-30 percent to less than 2 percent (CDC, 2006).

In keeping with the HHS *Guidelines*, the committee identified the following additional indicators for the initiation of ART.

- **Proportion of people with diagnosed HIV infection and HIV-associated nephropathy, hepatitis B (when treatment is indicted), or active tuberculosis who are not on ART**
- **Proportion of pregnant women with diagnosed HIV infection who are not on ART**

ARV Resistance Testing

The HHS *Guidelines* also indicate that ARV drug resistance testing should be performed prior to the initiation of ART, or if previously performed, repeat testing should be considered (HHS, 2011d, p. 11). A 2006 study showed that 15 percent of individuals newly diagnosed with HIV experience antiretroviral drug resistance (Wheeler et al., 2010), which is one barrier to effective treatment. Drug resistance testing prior to the initiation of ART helps to determine the appropriate treatment regimen and therefore improves health outcomes and reduces viral transmission. HHS *Guidelines* (HHS, 2011d, p. 42) list additional factors that influence selection of individual ART regimens, including the presence or absence of

> comorbid conditions (e.g., cardiovascular disease, chemical dependency, liver disease, psychiatric disease, renal diseases, or tuberculosis); potential adverse drug effects; potential drug interactions with other medications; pregnancy or pregnancy potential; . . . gender and pretreatment CD4 count if considering nevirapine (NVP); HLA-B*5701 testing if considering abacavir (ABC); coreceptor tropism assay if considering maraviroc (MVC); patient adherence potential; and convenience (e.g., pill burden, dosing frequency, and food and fluid considerations).

Since the decision about which ART regimen is appropriate varies among patients and would be impossible to quantify and because new therapies may be developed, the best measure of whether appropriate therapy has been prescribed is the individual's response to it. Nevertheless, the importance of ARV drug resistance testing as a first step in selecting an ART regimen led the committee to identify the following indicator of quality HIV care.

- **Proportion of ART-naïve people with diagnosed HIV infection who receive drug resistance testing (genotypic) prior to ART initiation**

Additional Indicators Related to Mental Health, Substance Abuse, and Supportive Services

Unlike the additional clinical HIV care indicators, which supplement the core indicators by tracking other important aspects of HIV care, the additional indicators for mental health, substance abuse, and supportive services are directly related to the core indicators in that they track identification of PLWHA who have a need for those services through annual screening.

- **Proportion of people with diagnosed HIV infection who were screened for mental health disorders at least once during the preceding 12 months**
- **Proportion of people with diagnosed HIV infection who were screened for substance use disorders at least once during the preceding 12 months**
- **Proportion of people with diagnosed HIV infection who were assessed for need for housing at least once during the preceding 12 months**
- **Proportion of people with diagnosed HIV infection who were assessed for need for food or nutrition at least once during the preceding 12 months**
- **Proportion of people with diagnosed HIV infection who were assessed for need for transportation at least once during the preceding 12 months**

Summing Up

Taken together, the core and additional indicators for clinical HIV care and mental health, substance abuse, and supportive services identified by the committee provide a means for assessing the impact of public health policies across the HIV care continuum. Figure 2-4 shows the continuum of care arrow depicted in Figure 2-2 with the indicators mapped to it.

Appendix Table 2-2 also maps the indicators (and the related data elements) to the continuum of care and indicates which indicators relate to outcome measures, process measures, or both. Appendix Table 2-1 provides a summary of the indicators, including the data elements (and proxy/alternative data elements) needed to estimate them and a brief rationale for each.

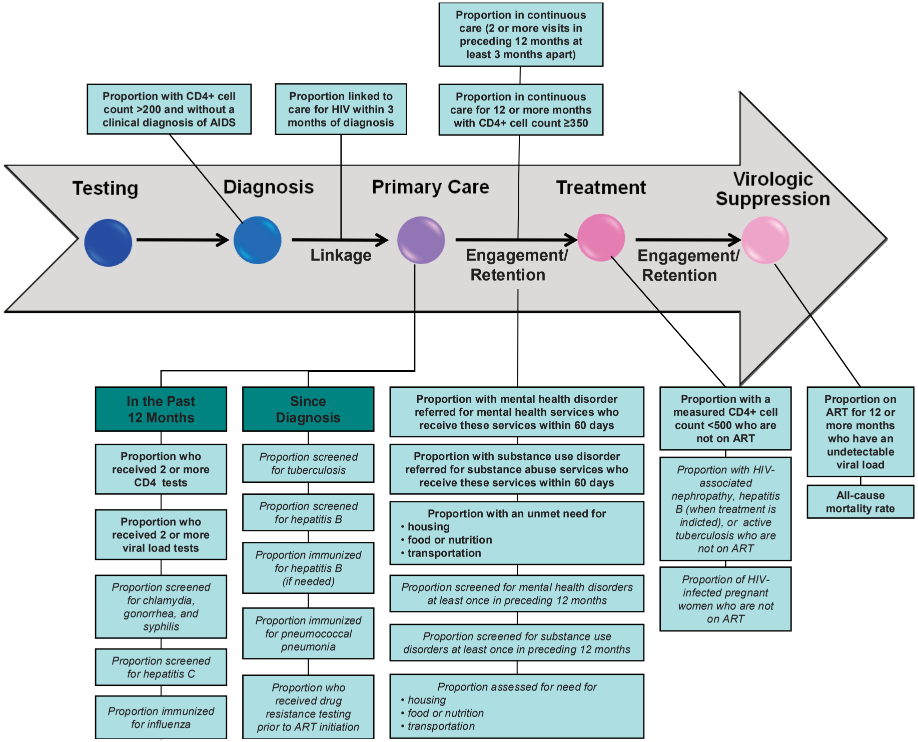

FIGURE 2-4 Continuum of HIV care arrow mapped to indicators for HIV care and supportive services.
SOURCE: Adapted from Das, 2011.
NOTE: Indicators written in bold text correspond to the committee's recommended core indicators; the indicators written in italics correspond to the additional indicators identified by the committee.

HEALTH-RELATED DISPARITIES

As indicated by the NHAS targets (Box 1-1), subpopulations of PLWHA, including Ryan White HIV/AIDS Program clients, black Americans, Latinos, and gay and bisexual men, are of particular interest when evaluating HIV care. Other important subpopulations include additional vulnerable populations of race and ethnicity, sex and gender, age, lower socioeconomic status, high mobility, and those in certain geographic areas. Significant disparities exist among racial, ethnic, and sexual minorities with respect to HIV risk, incidence, and 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 studies report differences in the quality of care received by racial and ethnic minorities compared to whites (Garland et al., 2010; Korthuis et al., 2008). Differences exist in the care experiences of these groups, including differences in access to health care services; 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; Johnson et al., 2004a,b; Schneider et al., 2002). Blacks are more likely to receive care from health care facilities that have fewer clinical resources and to have longer travel times to care; they also are less likely to see the same provider in follow-up care visits (Doescher et al., 2001; Probst et al., 2007). In studies comparing the care experiences of African Americans and whites, African Americans rate their care visits as less participatory and more dominated by their provider (Johnson et al., 2004b).

In addition to race and ethnicity, an individual's country of origin and citizenship status are factors that may be related to HIV-related disparities. For example, in 2006, almost one-quarter of all new HIV infections in Latinos living in the United States were among Puerto Ricans. This finding may indicate a higher risk of HIV for Puerto Ricans or higher rates of HIV detection. Puerto Ricans may have had higher rates of testing secondary to higher rates of health insurance and access to health care when compared to other subpopulations of Latinos (Garland et al., 2010). Latinos from Mexico and Central America have been found to have higher rates of late diagnosis of HIV infection (Garland et al., 2010). Research has shown that foreign-born or unacculturated Latinos are less likely to have been tested for HIV, not only because of less access to health care but also due to a lack of knowledge about HIV as a disease (Chen et al., 2010).

Evidence also suggests that culturally and linguistically specific care increased adherence to treatment among Latinos, which then significantly improved CD4 counts and decreased viral loads (Oh et al., 2009; Silverberg et al., 2009; Sullivan et al., 2007). Good results with adherence have been noted with urban foreign-born Latinos from Mexico and Central America when culturally appropriate care was delivered by bicultural and bilingual health care staff (Enriquez et al., 2008). It therefore appears that knowledge of linguistic and cultural differences among subpopulations of PLWHA can make a difference in the design of appropriate care approaches that can aid in adherence.

Age, sex, and geographic location are other demographic characteristics associated with disparities in HIV care. Studies have reported disparities in the receipt of HAART by age (Agwu et al., 2011; Wohl et al., 2011). Women, racial minorities, and people without private health insurance are less likely to keep an initial appointment for HIV care and therefore are less likely to establish care (Mugavero et al., 2007). Another study suggests that although white women with HIV began ART sooner than other groups, there is some evidence that women tended to have a higher incidence of HIV-related and AIDS-defining illnesses than men, with nonwhite women experiencing higher morbidity than those in other groups (Meditz et al., 2011). The study also showed a correlation between geographic location (southern United States) and higher morbidity. There is some evidence that the socioeconomic position of nonwhite women in the South is a determinant of increased morbidity in that group (Aziz and Smith, 2011; Meditz et al., 2011).

To the extent that lower socioeconomic status plays a role in racial, ethnic, and gender disparities in access to HIV care and better outcomes, implementation of the ACA may be expected to reduce disparities by increasing access to health care within certain of those subpopulations. Medicaid provides coverage for 47 percent of PLWHA estimated to be receiving regular medical care, making it the largest single source of coverage for HIV care in the United States (Kates, 2011). By raising the income threshold to qualify for Medicaid coverage to 133 percent of the federal poverty level, the ACA will significantly increase access to Medicaid, with an anticipated increase in health care utilization and improved health outcomes (Finkelstein et al., 2011). However, undocumented and recent immigrants will remain ineligible for Medicaid coverage, which may increase health disparities by citizenship.

All of the indicators identified by the committee for tracking clinical HIV care and mental health, substance abuse, and supportive services can be applied to specific subpopulations of PLWHA to evaluate and track disparities among those groups. For example, several indicators and subpopulations are specifically targeted in the NHAS under the primary goal of reducing HIV-related disparities and health inequities (ONAP, 2010, p. 1). The NHAS specifies targets for increasing the proportion of PLWHA with an undetectable viral load among black Americans, Latinos, and gay and bisexual men by 2015 (ONAP, 2010, p. 31; see also Box 1-1). Indicators specific to these NHAS targets can be generated by applying the relevant core indicator identified by the committee—that is, the 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—to these subpopulations.

- Proportion of black Americans with diagnosed HIV infection who have been on ART for 12 or more months and have a viral load below the level of detection
- Proportion of Latinos with diagnosed HIV infection who have been on ART for 12 or more months and have a viral load below the level of detection
- Proportion of gay and bisexual men with diagnosed HIV infection who have been on ART for 12 or more months and have a viral load below the level of detection

Other indicators, such as a continuity-of-care indicator—that is, the 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)—could be applied to these and other subpopulations of interest. For example, applying the continuity-of-care indicator to the population of Ryan White HIV/AIDS Program clients would generate the information to track the NHAS target of increasing "the proportion of Ryan White HIV/AIDS Program clients who are in care (at least 2 visits for routine HIV medical care in 12 months at least 3 months apart) from 73% to 80%" by 2015 (ONAP, 2010, p. 21). Similarly, applications of the committee-identified indicators to different racial or ethnic, foreign-born, gender, and socioeconomic subpopulations would be of interest as well.

Access to quality 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, etc.) (Krawczyk et al., 2006a,b; Reif et al., 2005). People in rural areas, for example, have a more difficult time accessing appropriate HIV care. Barriers to accessing HIV care for people in rural areas include 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; Mays et al., 2011; Ohl et al., 2010; Reif et al., 2005; Schur et al., 2002; Vermund et al., 2010). Barriers to accessing quality HIV care can result in poorer health outcomes for PLWHA in rural areas. A recent study of individuals initiating HIV care within the Veterans Health Administration (VHA) found that delayed entry into care accounted for higher mortality among PLWHA in rural areas compared to those in urban areas, although, once in care, care utilization was equivalent between the two groups (Ohl et al., 2010). PLWHA in the southern United States also have been shown to be less apt to initiate treatment than those from other regions of the country. Lower socioeconomic status may play a role in these differences (Krawczyk et al., 2006a,b; Meditz et al., 2011; Weis et al., 2010).

Indicators for tracking health disparities in rural areas (and different geographic regions) can be derived from those identified by the committee. Examples of such indicators include the following:

- Proportion of people living in rural areas and newly diagnosed with HIV who are linked to clinical care for HIV within 3 months of diagnosis
- Proportion of people with diagnosed HIV infection who are living in rural areas and have been on ART for 12 or more months and have a viral load below the level of detection
- Proportion of people with diagnosed HIV infection who are living in rural areas who are in continuous care (two or more visits for routine HIV medical care in the preceding 12 months at least 3 months apart)

Equivalent framing of any of the other indicators pertaining to HIV care and needed services in terms of different subpopulations of PLWHA would help to inform both the evaluation and the impact of policies on disparities in those areas as well.

DATA ELEMENTS TO GAUGE THE IMPACT OF THE NHAS AND THE ACA

The committee identified three general groups of data elements for gauging the impact of the NHAS and the ACA in improving HIV care. Although the data elements identified include those needed to estimate the previously discussed indicators that capture the care experiences of PLWHA, the lists are not identical. The committee recognized some data elements, such as stigma, discrimination, and patient satisfaction with care, to be important but did not recommend related indicators because of the difficulties in defining, objectively quantifying, and measuring those elements.[11] The three groups of data identified by the committee are health

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[11] Although obtaining data to estimate indicators for housing, food, and transportation poses challenges, those needs are objectively quantifiable using standardized definitions such as those provided in the text. By contrast, experiences of stigma, discrimination, and satisfaction with care are not quantifiable in the same way.

care data, including data on diagnoses, test results, and health care service utilization; data pertaining to access to housing, food, and transportation; and demographic data, which, as in the case of zip code, can provide information regarding risk environment, permitting those areas to be targeted in terms of linkage of care, STI services, and the like. Health care data inform indicators related to linkage to and continuity of care, as well as quality of care. Data pertaining to supportive services inform indicators related to access to those services. Demographic and other personal data inform indicators related to payer sources and disparities (racial, ethnic, and sexual minorities; geographic) in HIV-related health care.

The following section provides an introduction to the primary types of health care, supportive services, and demographic data and lays the foundation for the later discussion of the data elements necessary for assessing each of the indicators identified by the committee.

Types of Data

The health, service utilization, and demographic data elements needed to assess the indicators are found in several general data types, including claims data, clinical data, surveillance and vital records data, and survey or interview data. Relevant data may be used for financial, legal, or epidemiologic purposes, such as billing third-party payers, certifying birth or death, and disease tracking to establish public health interventions, as well as the provision of individual patient care.

Claims Data

Claims data, also known as billing data, are records of interactions between patients and various parts of the health care system designed to solicit reimbursement from private or public third-party payers (e.g., private health insurance, Medicare, Medicaid). These data include patient-identifiable demographic data (e.g., patient address, sex, date of birth), diagnosis and procedure codes, claims for laboratory tests and other types of studies, and some claims for prescription drugs.

There are numerous advantages to the use of claims data for health care research and the evaluation of performance measures (Ferver et al., 2009; Jollis et al., 1993). They represent a large quantity of data that is relatively easy and inexpensive to obtain. The large amount of data is especially useful for compiling information on rare conditions and may facilitate the identification of trends or practices that would otherwise be missed. Some claims data systems include demographic information, such as income level and employment status, that is not generally available from other health care data systems. Claims data also are, or easily can be made, anonymous and hence can be used without patient authorization. The anonymity of the data also make claims data particularly good source of data pertaining to sensitive diagnoses such as HIV/AIDS or mental illness. Claims data also are available electronically, which facilitates their use for research.

Claims data have a number of disadvantages as well. One major disadvantage is that claims data are designed for billing and not for use in health care research (Ferver et al., 2009; Jollis et al., 1993). Only the data necessary to file the claim are captured, which leaves the data lacking in sufficient clinical detail to be maximally useful in research on health outcomes for example. There is a single *International Classification of Diseases, Ninth Revision* (ICD-9) code for prostate cancer, for example, which indicates the diagnosis but provides no information as to the stage of the disease at the time of diagnosis or treatment (see, e.g., West et al., 2010). Likewise, claims data cannot directly provide information on disease progression, treatment failure, or treatment intention (e.g., therapeutic or palliative) (Jollis et al., 1993). With respect to HIV, for example, claims data may provide reasonable information on how many CD4 and viral load tests are performed in a given period, but they will not provide information on the results of those tests and so are not of use in identifying treatment failure or tracking the effect of various therapeutic interventions on CD4 counts and viral load over time. For chronic conditions the "date of onset" may be listed as the date of service at each subsequent visit or the visit may be attributed to one medical problem (diagnosis) when several in fact are present. Similarly, several procedures may be "bundled" into a single claim (Ferver et al., 2009).

Since the purpose of claims data is to generate reimbursement, there is a financial disincentive to capture any data that are not directly related to that end (Ferver et al., 2009). If itemizing diagnoses or procedures will not increase the amount of reimbursement, there is no incentive to do so; indeed, the additional reporting time required creates a disincentive. This may be especially problematic for patients with multiple comorbid conditions, including HIV. Similarly, data on procedures not submitted for reimbursement may not be captured. For example, data on HIV testing may be underrepresented if the test kits are paid for by a health department. Conversely, there is an increased incentive to include tests and procedures that can be reimbursed, which also must be taken into account when interpreting the data.

Another significant disadvantage of using claims data for research is how labor intensive it can be to analyze the data. It often requires someone with strong training in data management to perform the necessary recoding and data manipulation. For example, the rows of data may be patient records and some patients have multiple records (rows). Extensive recoding is needed to reformat the data into the patient or episode level. In addition, it may be necessary to use sample records (e.g., rather than analyzing all Medicaid records) because it would be too computationally taxing to run all of the data. Again, this type of sampling requires someone with very strong technical skills.

Other disadvantages arise with claims data as well. Coding inaccuracies of various types may render the data problematic for research purposes. Not only may typographical coding errors occur, but misunderstandings about diagnoses and incorrect or misreported diagnoses also may occur. In addition, questionable billing practices can lead to inaccurate coding or "upcoding" in order to increase reimbursement in certain cases (Ferver et al., 2009). All of these factors are potentially problematic for the use of claims data to generate estimates of the percentage of individuals with a specific condition or receiving certain tests or procedures.

Clinical Data

Clinical data are collected for or pertain directly to the health and welfare of individual patients. The primary source of clinical data is individuals' personal health records compiled by health care providers during the course of caring for those individuals. Health records include information on individuals' health status, findings from physical examinations, and information on individuals' medical history. The records also document diagnoses, tests or studies that are ordered and the results, diagnostic and therapeutic procedures, medications prescribed, when medication was administered (for inpatients), information on allergies or side effects, and the like. Health records also may contain information concerning consultations and referrals. Health records commonly include certain demographic information, such as address, date of birth, sex, and insurance status. However, certain types of demographic information, including race and ethnicity, gender identity, and sexual orientation, may not be recorded at all; may be based on provider observation rather than patient self-report; or may be reported or recorded in different ways, making it difficult to code uniformly. In addition, medical records generally do not include information on individuals' socioeconomic position (e.g., income, wealth, education) (Krieger, 1992).

Medical records provide more detailed information, such as laboratory test and treatment results, than that available through claims data and hence are preferable for use in health care research, especially research focusing on quality of care and health outcomes. In addition, clinical data are apt to give a more accurate picture than claims data of patients' health status (Roos et al., 1991; Tang et al., 2007).

Although medical records may provide more detailed and comprehensive information about the health care received by specific individuals, they also have a number of disadvantages from a research perspective. One problem lies in the accuracy and completeness of the health record. Clinicians vary not only in their accuracy regarding diagnoses but also in the accuracy and completeness of the information they elicit and record from a patient's medical history and physical examination (Roos et al., 1991). Nevertheless, there is good reason to believe that the accuracy and comprehensiveness of the clinical information are greater than found in claims data (Roos et al., 1991).

Other difficulties involve the extraction of pertinent data from patient health records and the challenge of linking individual-level data across providers for patients with multiple providers (e.g., primary care provider, HIV specialist, mental health provider). This process can be labor intensive, expensive, and time consuming, which makes claims data an attractive surrogate for medical records data in health care research. The increased use of EHRs, especially following enactment of the Health Information Technology for Economic and Clinical Health (HITECH) Act, as part of the American Recovery and Reinvestment Act of 2009 (P.L. 111-5), has simplified the process of data extraction, although challenges remain for extraction as well as for data linking and system interoperability across providers. Integrated care systems with comprehensive EHRs, such as Kaiser Permanente (KP) and the VHA, avoid these challenges to a certain extent. EHRs can pose other difficulties as well, such as system failures, decreased interdisciplinary communication, and overreliance on checkboxes (in lieu of critical thinking) (NIH, NCRR, 2006).

Despite such potential drawbacks, EHRs also can improve the quality of documentation, increase the accuracy of shared information, and improve patient safety (e.g., through checking for possible drug interactions) (Tang et al., 2007). Use of EHR data for quality measurement also reduces provider burden by reusing clinical data already being entered as part of patient care (Tang et al., 2007). However, providers' notes remain as "free text" that needs to be combed to find pertinent pieces of clinical information. This information extraction may be done manually, adding time and expense to the project as well as potentially introducing inaccuracies from errors during the extraction process. In some cases, it also is possible to mechanize the extraction of data from free text.

Pharmacy records are a source of data on prescriptions that have been filled. Although claims data may also provide this information, pharmacy data are available even when patients lack prescription drug coverage. Although filling a prescription does not ensure that the medication actually is being taken or taken as directed, there is some correlation between refill data and treatment adherence (Pladevall et al., 2004). As is the case with claims data, the extraction of person-level (rather than record-level) data is technically difficult. People may visit multiple pharmacies, which would make it difficult to compile data at the patient level. In addition, there is apt to be variation in the use and interoperability of electronic record systems.

The challenges may be mitigated, but not eliminated, for pharmacies that are integrated into health care systems such as KP or the VHA.

Surveillance and Vital Records Data

Disease registries and surveillance systems, such as the CDC's National HIV Surveillance System (NHSS), a population-based registry of individuals diagnosed with HIV in the United States (CDC, 2010a), are useful sources of certain health and demographic data. Such population-based registries serve epidemiologic and public health functions, permitting the tracking of a disease's prevalence and incidence over time and within specified geographic areas. Disease registries and surveillance systems include demographic and health data relevant to their function, including, for example, disease diagnosis and staging, risk factors, individual's name, address, age, sex, and race and ethnicity. In addition, some HIV surveillance systems include selected clinical test results and drug treatment information. Since the NHSS and state and local HIV surveillance systems as a group are inclusive of the majority of individuals diagnosed with HIV in the United States and contain a wealth of information relevant to HIV care, they are important sources of data on PLWHA.

Vital records, which include information on births and deaths, are another source of data. Of particular interest for HIV care are mortality data on PLWHA. Although vital records systems may have developed procedures for uniform reporting on cause of death, challenges to the accuracy of cause of death information persist. Whether the proximate cause of death is attributable to a secondary or tertiary cause of interest, such as HIV, may be subject to diagnostic or reporting errors or not recorded at all. For this reason, all-cause mortality may provide a more accurate measure of mortality with in a population diagnosed with a particular disease.

Survey and Interview Data

Surveys or interviews are additional sources of data that can be used to evaluate health care quality and outcomes. Well-designed surveys can be used to help track and identify trends in health insurance, health services, hospitalizations, cost, access, and quality of care; to capture patients' experiences with their health care services; and to evaluate the ability of the nation's health system to meet the public's health needs (NCHS, 2012). In addition, they can be used as tools in clinical care to assist providers in delivering needed health services and as quality measurement tools to assess clinical performance (Kass-Bartelmes, 2002).

There are a number of advantages to using surveys for data collection (Marsden and Wright, 2010). A well-designed sampling scheme allows data gathering on a good cross-sectional snapshot of all residents, including those who are not in care (i.e., those who are by definition excluded from clinical and administrative data sets). Surveys also permit collection of data on indicators or variables that are not recorded in claims, clinical, surveillance, or other types of data (e.g., barriers to accessing care) and systematic assessment of data elements that providers may not uniformly report (e.g., socioeconomic position, educational attainment) for all patients. Questions can be tailored to fit information needs (e.g., a consistent measure of homelessness, food security, or education, rather than relying on the different ways in which clinicians may collect that information in their clinical records). In addition, interviews can elicit qualitative data about complex issues that are hard to quantify objectively, such as stigma, discrimination, or reasons some subpopulations are less likely to access care. New surveys can be fielded to collect data on emerging issues, and long-term trends can be assessed using panel data.

There are disadvantages to the use of surveys and interviews as well (Marsden and Wright, 2010). Losses to follow-up and nonresponse, which may be more common among hard-to-reach populations such as those who are homeless or unstably housed or struggling with mental health or drug use problems, may introduce bias and compromise the representativeness of results. In addition, it may be difficult to collect accurate self-reported data for a variety of reasons, including forgetfulness and reluctance to disclose sensitive information (although some survey modes such as computer-assisted questionnaires may help in that regard). Finally, primary data collection can be costly and labor intensive, although there are ways to make it less so (e.g., adding modules to existing surveys such as the National Health and Nutrition Examination Survey, contracting with companies that have existing sample pools).

Summary

The differences between clinical data such as test results and claims data can result in gaps in measures of HIV care. Claims data provide information about the number of PLWHA who are in care and the frequency with which they are seen, although it may not always be possible to gauge whether a visit for an unrelated health concern also included HIV care, nor are claims data designed to measure care quality. Claims data also can yield information about what tests and other procedures are being provided to an individual and the frequency with which they are being done. However, claims data provide no information on the results or outcomes of the tests or procedures. Similarly claims data or pharmacy records may provide information about whether prescriptions for ART medications are being filled and at what interval, but such information serves only as a proxy for data on treatment adherence.

Claims data provide important, although potentially incomplete, information about quality of HIV care with regard to continuity of care (frequency of visits), provision of appropriate screening and monitoring (types and frequency of laboratory tests), and, to a certain extent, timely initiation and prescription of appropriate ART (medical and pharmacy records). Such data are important for assessing whether PLWHA are receiving quality HIV care. Other factors, such as substance use, mental health disorders, housing instability, and food insecurity, can negatively affect health outcomes even when individuals receive and adhere to quality HIV care and treatment. For this reason, clinical data pertaining to health outcomes, such as lower viral loads and higher CD4 counts, are important for tracking the overall success of HIV care in improving health outcomes for PLWHA and controlling the epidemic. Such clinical data (e.g., CD4 count results) also are currently needed to supplement other types of data when assessing the timeliness of ART initiation.

Data from surveys and interviews can fill additional data gaps by providing information on hard-to-reach populations, such as homeless individuals and PLWHA who are not in care, and permitting collection of data not routinely collected by health care providers, such as need for and access to supportive services and subjective experiences of stigma and discrimination and satisfaction with care providers.

For these reasons, different types of data (e.g., claims, clinical, surveillance, survey) are needed to estimate the core indicators related to continuous, quality clinical HIV care and access to mental health, substance abuse, and supportive services for people living with HIV and hence to assess the impact of the NHAS and the ACA in terms of improving care for PLWHA. Because the data needed to estimate the indicators identified by the committee are likely to come from different sources, attention to the use of consistent definitions (e.g., homelessness, food insecurity, race, ethnicity, gender) in the collection of data is important.

Data Elements for Assessing Indicators

Appendix Table 2-1 lists the data elements needed to estimate each of the indicators identified by the committee. Many of the data elements are used to estimate more than one indicator, making the total number of required data elements fewer than it might initially appear. In some cases, suitable proxies may exist that can be substituted for the specified data elements when they cannot be obtained from a specific data system of interest. The following sections discuss the data elements in groups pertaining to their use.

Denominators

All of the indicators rely on the population of PLWHA or a subpopulation thereof (e.g., a clinical marker of some type, such as ART or pregnancy status) for their denominators. The goal is to select as comprehensive and nationally representative a population of PLWHA as possible when assessing indicators for the full population of PLWHA in the United States. Discussion of the current availability of nationally representative data for the population of PLWHA in the United States follows in Chapter 3. Similarly, when assessing indicators for specific subpopulations of PLWHA, the goal, again, is to begin with as comprehensive and nationally representative a population as possible and then to apply the limiting element, such as race or ethnicity, to the group.

As noted, blacks, Latinos, gay and bisexual men, and Ryan White HIV/AIDS Program clients are subpopulations specifically identified in NHAS targets. Additional subpopulations of interest include other racial and ethnic groups, women, individuals living in rural areas or different geographic areas, individuals of varying socioeconomic position or levels of acculturation, and individuals with different payer status. Demographic data needed to assess the application of indicators to such subpopulations include race and ethnicity; gender identity; sexual orientation; zip code or other identifier for current geographic area of residence; payer status (e.g., private, Medicaid, Medicare, VA, Ryan White HIV/AIDS Program); socioeconomic position; and level of acculturation (e.g., primary language spoken). These data can be collected, based on individual self-report, in clinical records, surveys, and administrative records for claims or program eligibility records.

One difficulty faced in evaluating, tracking, and reporting on the quality of the care and treatment of these subpopulations is the lack of data collected on a number of these demographic characteristics. Although data systems relating to HIV care generally capture data on age, sex assigned at birth, and certain information on race and ethnicity and current area of residence, many fewer capture complete information on payer status, sexual minority status, gender identity, nativity status, and primary language preferred.

It is important that complete data on both race and ethnicity be collected not only to evaluate and track health disparities but also because of the essential role they play in clinical care decisions. For example, Latinos, African Americans, American Indians, and some subpopulations of Asian and Pacific Islanders are at higher risk for diabetes and its complications than are whites, raising concerns about the use of some ARVs with higher associations of metabolic syndromes. In a small study of 43 ART-naïve Latinos, Latinos were found to have greater unfavorable changes in metabolic parameters and body composition in response to ART initiation than either blacks or whites (Gibert et al., 2009). Also since some Latinos present late in the course of the HIV disease continuum, they are more likely to have OIs related to their countries of origin (Garland, 2010).

Standardization of the collection of data on race and ethnicity is important to permit the collection and sharing of this information across federal agencies and other bodies. In 1997, the Office of Management and Budget (OMB) issued revised minimum standards for the collection of race and ethnicity data, specifying five racial (American Indian or Alaska Native, Asian, black or African American, Native Hawaiian or other Pacific Islander, and white) and two ethnic (Hispanic or Latino; not Hispanic or Latino) categories in an effort to increase standardization of race and ethnicity data in administrative reporting and statistical activities within federal agencies (OMB, 1977, 1997b). In addition, OMB encourages the collection of more granular data on ethnicity when they can be aggregated back to the minimum categories (OMB, 1997a). This effort has improved the collection of such data within many health information systems, but not all nonfederal data collection activities use these categories (IOM, 2009) or even require the collection of data on race and ethnicity. In addition, there may be differences in the way these data are collected. For example, race may be collected by providers based on their observations, which can differ from a patient's description of his or her race. Furthermore, OMB does not specify standardized collection of more granular data, for example, pertaining to country of origin, which is important for clinical decision making and nuanced monitoring of health disparities.

In response to Section 4302 of the ACA, new HHS guidance on data collection standards for race, ethnicity, sex, primary language, and disability status, effective October 31, 2011, set minimum standards for the collection of such data in population-based health surveys conducted or sponsored by HHS (HHS, 2011g). The HHS data standards mandate the collection of more granular data on race and ethnicity as specified in the guidance, as well as the collection of data on "biologic sex" and English proficiency as a measure of primary language. The guidance also recommends the wording for collection of data on the specific language spoken at home should an agency wish to collect such data.[12]

HHS is also in the process of developing a national progression plan to integrate the collection of data on sexual orientation and gender identity into its national surveys (HHS, 2011c,g) and to collect data on socioeconomic status. Collection of standardized demographic data on gender

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[12] The guidance includes a data standard for the collection of disability status, which might apply to PLWHA in cases when the disease process results in one or more of the disabling conditions specified.

identity and sexual orientation is important to track access to, and quality of, HIV care among sexual minority subpopulations of PLWHA—for example, by estimating the proportion of gay and bisexual men with an undetectable viral load as specified in the NHAS (ONAP, 2010, p. 31). A 2011 IOM report assessing the current state of knowledge about the health of lesbian, gay, bisexual, and transgender people provides working definitions of gender identity and sexual orientation (IOM, 2011a, pp. 25-29). "*Gender identity* refers to a person's basic sense of being a man or boy, a woman or girl, or another gender (e.g., transgender, bigender, or gender queer—a rejection of the traditional binary classification of gender)" (IOM, 2011a, p. 25). "*[S]exual orientation* refers to an enduring pattern of or disposition to experience sexual or romantic desires for, and relationships with, people of one's same sex, the other sex, or both sexes" (i.e., homosexual, heterosexual, bisexual) (IOM, 2011a, p. 27). Although useful and important, these categories will not capture the group of MSM who do not self-identify as homosexual or bisexual or gender different. For this reason, the collection of data on sex of sexual partner(s) is also important.

Minimizing the burden of data collection is an important consideration, but it must be balanced against the importance of the information for clinical decision making and the evaluation and monitoring of treatment and care, which may differ in quality based on many of the aforementioned demographic data elements. The committee supports the HHS efforts to increase the scope and granularity of demographic data collected in national population-based health surveys and recommends that the expanded data collection standards be extended to all HHS-sponsored data collection activities to the extent practicable.

Although OMB and HHS standards apply to federal data collection, private health insurance plans vary in their collection of these data. KP, discussed in more detail in Chapter 3, collects data on race and ethnicity and sexual orientation. Although the data are incomplete, KP is actively working to complete the missing data (KP response to IOM request for information, March 30, 2011). The Ingenix Normative Health Information Database®, which includes claims from private commercial insurance plans, self-funded employer group health plans, and Medicare Advantage plans, also contains data on race and ethnicity, but the data are incomplete. These data are available for 50 to 94 percent of private commercial and self-funded employer group beneficiaries, depending on plan, but no information on race and ethnicity is available for Medicare Advantage plans. Ingenix does not capture data on sexual orientation (Ingenix response to IOM request for information, April 27, 2011). The HealthCore Integrated Research Database (HIRD®), which includes longitudinal administrative claims data representing commercially insured members of 15 Blue Cross Blue Shield health plans across the United States, does not contain data on race and ethnicity or sexual orientation. Although the HIV/AIDS epidemic has disproportionately affected traditionally disadvantaged and vulnerable populations, who are generally covered by public insurance, the reduction in work disability with the advent of ART makes employer-based insurance an increasingly relevant source of information on PLWHA. As such, the routine collection of standardized data on race and ethnicity, as well as sexual orientation and gender identity, by private insurers would facilitate their usefulness for tracking changes in access to and the provision of HIV care.

Core Indicators for Clinical HIV Care

The data elements required to assess the core indicators for clinical HIV care are date of HIV diagnosis, date of first visit for HIV care, dates of subsequent routine HIV care visits, dates and results of ongoing CD4 and viral load tests, date of diagnosis of AIDS or AIDS-defining condition (if applicable), dates of ART initiation and ongoing prescription or dispensing of drugs, and date of death. Most of these data are available through surveillance or claims data systems, although some clinical data might have to be obtained from patient medical records.

The date of first visit for HIV care may be difficult to obtain. Claims data capture office visits for HIV care if they are coded as such, but data sources generally only capture the date an individual was first seen for HIV care within a given system, not the first-ever date of HIV care (see Chapter 3 for additional discussion). Individuals' medical records may contain the approximate date of first HIV care, but the information is apt to be incomplete, and the process of mining it is time consuming.

The date of first CD4 and viral load tests may be used as a proxy for the date of first visit for HIV care. One difficulty with this approach arises when the tests are not recorded on the same date that the first appointment occurred. For the purpose of measuring linkage to care, however, the difference of a day or two between the date of the first visit and the test date is seldom important. A more significant problem occurs when the tests are ordered at the time of diagnosis. In this case, the first CD4 or viral load test date is less likely to reflect linkage to care. Although the date of first visit for HIV, as well as lab test dates, can be obtained from claims data, the lab test dates also are available from surveillance data, which may make them preferable since most of the other data elements required to assess the core indicators can be obtained from surveillance data as well (see Chapter 3).

As indicated in Chapter 3, a number of data systems collect information for a specified reporting period. In such cases, yes/no documentation of CD4 or viral load tests, use of ART, or diagnosis of AIDS within the reporting period can be used if specific test, prescription, or diagnosis dates are not available. Documentation of CD4 or viral load tests also may serve as a proxy for HIV care visits to indicate continuity of care.

Outside of medical records, in particular EHRs, obtaining data on ART initiation is challenging, because it requires linking evidence of ART prescription or dispensing with CD4 test results. When specific dates for CD4 counts and ART prescription or dispensing are not available, some combination of results using the most recent CD4 test within the reporting period and yes/no documentation of whether the individual is on ART within the reporting period can be used.

Additional Indicators for Clinical HIV Care

Assessment of the additional indicators for HIV care requires a number of the same data elements needed to assess the core HIV care indicators: date of HIV diagnosis, CD4 test results at diagnosis or first visit for HIV care, date of ART initiation, and dates of ART prescription or dispensing. Data elements that are specific to the additional HIV care indicators include dates and results of TB tests; dates of chlamydia, gonorrhea, and syphilis screenings; date of hepatitis B screening or date of documented immunity; dates of hepatitis C tests; dates of influenza immunizations; date of pneumococcal immunization; and date of hepatitis B vaccination or date of documented immunity. Test or screening and immunization dates (or a close proxy) may be obtained from either clinical or claims databases. The information needed is documented evidence that the specified screenings and immunizations took place after HIV diagnosis and, where relevant, at the appropriate intervals. Clinical data on TB test results and documentation of hepatitis B immunity would have to be obtained from medical records or, in the case of TB, possible linkage with public health surveillance systems.

Other data elements needed to assess additional indicators relating to ART include dates of drug resistance testing, diagnosis or test results for HIV-related nephropathy, and pregnancy test results (or documentation of pregnancy). Dates or evidence of drug resistance testing may be obtained from claims databases, but diagnosis of nephropathy and documentation of pregnancy are not available from claims data. Yes/no documentation of these conditions may be obtained from other administrative data systems, as well as from EHRs or other medical records. Evidence of concurrent ART usage is needed as well to evaluate the relevant indicators.

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

Data elements for assessing the core indicators for mental health and substance abuse include dates of mental health screening, as well as dates of diagnosis or referral and first visit for mental health services, and the equivalent dates for substance abuse screening, referral, and first visit for services. Referral dates for mental health and substance use disorders are not readily available outside of EHRs and other medical records, and dates of first treatment may be difficult to acquire because individuals may be referred to outside providers or the services may be "carved out" (i.e., fee-for-service, provided by a different managed care plan than the rest of the individual's medical care, or paid out of pocket). Suitable proxies for estimating the relevant indicators include evidence of assessment for mental health or substance abuse disorders and any visits for treatment services during the same reporting period. Pharmacy data showing evidence of prescriptions relevant to the treatment of mental health or substance abuse disorders also may serve as a proxy for receipt of care for these conditions. As discussed in Chapter 4, privacy laws may pose particular challenges for obtaining data to estimate the core indicators for access to mental health and substance abuse services.

Data elements for assessing the core indicators for supportive services include housing and food security status (e.g., as previously defined) and need for transportation services to access medical care and related services. Obtaining data to estimate the indicators for supportive services is particularly challenging since most data systems related to HIV care do not capture this type of data and have no reporting requirement in these areas. Evidence of reported need for (or access to) housing, food, or transportation assistance during the reporting period can be used if information about housing instability, food insecurity, or unmet transportation need is not available. Surveys are promising vehicles for obtaining data to estimate the supportive services indicators.

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

The additional indicators pertaining to mental health, substance abuse, and supportive services for housing, food, and transportation assistance involve documentation of assessment of need for relevant treatment or supportive services. If assessment dates are not available, then yes/no documentation of assessment (e.g., within a specified reporting period) would be a suitable proxy.

Additional Data Elements of Interest

As previously noted, the committee identified several data elements that reflect important aspects of the care experiences of PLWHA but are not required to estimate the indicators related to continuous HIV care and access to supportive services. These additional data elements include access to dental care, emergency department or inpatient use, sexual risk behaviors, and partner HIV status (see Appendix Table 3-2f).

Other data elements pertain to individuals' experience of discrimination or stigma as PLWHA (Sengupta et al., 2011), individuals' level of satisfaction with their HIV care experience, and individuals' assessment of their health-related quality of life (HHS, 2011a,b). Such experiences are important to the success of treatment and health outcomes of PLWHA, since they can affect the willingness of individuals to enter and remain in care and adhere to ART (see, e.g., Valdiserri, 2002). They also may affect individuals' mental state and the likelihood that they will initiate or continue substance use (Mays and Cochran, 2001).

Stigma and discrimination, along with numerous other factors (e.g., housing instability, food insecurity), are major sources of chronic stress, which can precipitate or exacerbate mental health and substance use disorders. Stress also can compromise immunological functioning and may alter the progression of HIV disease. Studies of HIV samples have confirmed the relevance of stress-influenced biomarkers in physiological mechanisms of HIV (Glover et al., 2010; Kopnisky et al., 2004; Kumar et al., 2003). For example, norepinephrine, a neurotransmitter of the autonomic nervous system released in response to stress, has been shown to accelerate HIV replication (Chipimo et al., 2011; Cole, 2008; Miles et al., 2011).

The NHAS highlights HIV stigma and discrimination, calling for a reduction of stigma and discrimination against PLWHA as one of its action steps (ONAP, 2010, p. 35). Data on subjective experiences such as these are difficult to quantify objectively, however, which complicates the collection and meaningful application of data in these areas. Surveys and interviews can be particularly effective collection tools for this type of data, which can be used to supplement data obtained from clinical and administrative sources.

CONCLUSIONS AND RECOMMENDATIONS

- Measures of continuous HIV care as well as access to and quality of care can be monitored by a limited number of core indicators. Primary challenges to optimal outcomes for PLWHA include late diagnosis, delayed linkage to care for HIV, 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. Core indicators can measure the extent to which these challenges are being addressed across the care continuum and can be used to gauge the impact of the NHAS and the ACA in improving HIV/AIDS care in the United States.

Recommendation 2-1. The Department of Health and Human Services should use the following core indicators[13] to assess the impact of the National HIV/AIDS Strategy and the Patient Protection and Affordable Care Act on improving HIV/AIDS care and access to supportive services for individuals with HIV:

Core Indicators for Clinical HIV Care

Proportion of people newly diagnosed with HIV with a CD4+ cell count >200 cells/mm^3 and without a clinical diagnosis of AIDS

Proportion of people newly diagnosed with HIV who are linked to clinical care for HIV within 3 months of diagnosis

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)

Proportion of people with diagnosed HIV infection who received two or more CD4 tests in the preceding 12 months

Proportion of people with diagnosed HIV infection who received two or more viral load tests in the preceding 12 months

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

Proportion of people with diagnosed HIV infection and a measured CD4+ cell count <500 cells/mm^3 who are not on ART

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

All-cause mortality rate among people diagnosed with HIV infection

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[13] The rationale for each of the indicators is summarized in Appendix Table 2-1.

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[14]

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[15]

Proportion of people with diagnosed HIV infection who were homeless or temporarily or unstably housed at least once in the preceding 12 months

Proportion of people with diagnosed HIV infection who experienced food or nutrition insecurity at least once in the preceding 12 months

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

- The differences among clinical, claims, and other types of data can result in gaps in measures for HIV care. Both clinical and claims data are needed to provide a complete picture of the quality of HIV care. Data from surveys and interviews can fill additional data gaps by providing information on hard-to-reach populations, such as homeless individuals and PLWHA who are not in care, and permitting collection of data not routinely collected by health care providers, such as need for and access to supportive services, and data on subjective experiences, such as HIV stigma and discrimination. Various types of data are needed to estimate the core indicators related to continuous, quality HIV care and access to mental health, substance abuse, and supportive services for people living with HIV, and hence to assess the impact of NHAS and ACA on improving HIV/AIDS care.

- Demographic data are essential to fully understanding HIV care challenges especially among groups disproportionately affected

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[14] 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.

[15] See footnote 14.

by the HIV epidemic. Many of these crucial data elements, such as gender identity, sexual orientation, sexual risk behaviors, geographic marker of residence, income, primary means of reimbursement for medical services, and level of acculturation as reflected in primary language, are not routinely collected. Other data elements such as race and ethnicity often are not collected with a sufficient level of detail to make nuanced distinctions among the health needs of different racial and ethnic groups. New HHS guidance, effective October 31, 2011, on minimum data collection standards for race, ethnicity, sex, primary language, and disability status mandates the collection of more granular data on race and ethnicity, as well as the collection of data on "biologic sex" and English proficiency as a measure of primary language. These standards apply to all national population health surveys sponsored or conducted by HHS. HHS is also in the process of developing a national progression plan to integrate the collection of data on sexual orientation and gender identity into HHS national surveys and to collect data on socioeconomic status.

Recommendation 2-2. The Department of Health and Human Services and the Office of Management and Budget should continue to expand the demographic data elements to be captured by federal data systems relevant to HIV care to permit calculation of the indicators for subgroups of the population of people with diagnosed HIV infection, including, but not limited to, the following:

Age

Race

Ethnicity

Sex (assigned at birth)

Gender identity (e.g., male, female, transgender [male-to-female, female-to-male], bigender, gender queer)

Sexual orientation (e.g., heterosexual, homosexual, bisexual)

Current geographic marker of residence (e.g., current address, zip code, partial zip code, census block)

Income or poverty level

Primary means of reimbursement for medical services (including Medicaid, Medicare, Ryan White HIV/AIDS Program, private insurance or health maintenance organization, no coverage)

In addition, HHS should, to the extent practicable, extend its expanded data collection standards beyond national population-based health surveys to all HHS-sponsored data collection activities.

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APPENDIX TABLE 2-1 follows on next page

APPENDIX TABLE 2-1 Core and Additional Indicators for Clinical HIV Care and Mental Health, Substance Abuse, and Supportive Services

Core Indicators for Clinical HIV Care			
Indicator	**Data Elements Needed**	**Proxy/Alternative Data Elements**	**Rationale**
Proportion of people newly diagnosed with HIV with a CD4+ cell count >200 cells/mm^3 and without a clinical diagnosis of AIDS	• Date of HIV diagnosis • CD4 test results at diagnosis/first visit for HIV care • No diagnosis of AIDS or AIDS-defining illness (e.g., OIs)	Reported rates of cases newly diagnosed with HIV and a CD4+ cell count >200 cells/mm^3 and no clinical diagnosis of AIDS within time period can be used if specific CD4 test dates and results are not available.	Early diagnosis improves health outcomes and reduces transmission of the virus to others.
Proportion of people newly diagnosed with HIV who are linked to clinical care for HIV within 3 months of diagnosis	• Date of HIV diagnosis • Date of first visit for HIV care	Date of first/second CD4 or viral load test can be used if date of first visit for HIV care is not available.	Timely linkage to clinical HIV care for PLWHA who are newly diagnosed 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)	• Dates of routine HIV-care visits	Dates of CD4 or viral load tests can be used if dates of visits for routine HIV care are not available.	PLWHA who are in continuous HIV care experience better health outcomes, including decreased mortality, and are less apt to transmit the virus to others.
Proportion of people with diagnosed HIV infection who received two or more CD4 tests in the preceding 12 months	• Dates of CD4 tests	Yes/no documentation of CD4 tests within 12-month reporting period can be used if specific dates of CD4 tests are not available.	Regular CD4 testing improves health outcomes in PLWHA by permitting providers to monitor individuals' immune function; determine when to start antiretroviral therapy (ART)

			in untreated patients; assess immunologic response to ART, and assess the need for initiation or discontinuation of prophylaxis for opportunistic infections.
Proportion of people with diagnosed HIV infection who received two or more viral load tests in the preceding 12 months	• Dates of viral load tests	Yes/no documentation of viral load tests within 12-month reporting period can be used if specific dates of viral load tests are not available.	Regular viral load (plasma HIV RNA) testing is important for monitoring clinical progression of the disease and therapeutic response in individuals on ART. Decreased viral load, and undetectable viral load in individuals on ART, is associated with improved health outcomes and reduced transmission of the virus.
Proportion of people with diagnosed HIV infection in continuous care for 12 or more months and with a CD4+ cell count $\geq$350 cells/mm^3	• Dates of routine HIV-care visits • Dates of CD4 tests • Results of at least one CD4 test within time period specified	Dates of CD4 or viral load tests can be used if dates of visits for routine HIV care are not available.	Achieving and maintaining a CD4+ cell count $\geq$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*	• Dates of CD4 tests • Results of CD4 tests • Dates of ART prescription or dispensing	Results from most recent CD4 test within reporting period can be used if specific dates of tests not available. Yes/no documentation of whether on ART can be used if prescription/ dispensing dates are not available.	Appropriate initiation of ART improves health outcomes and reduces transmission of the virus to others.

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*In contrast to the other indicators, the estimate for this indicator should decrease with improved access to care and supportive services.

continued

APPENDIX TABLE 2-1 Continued

Indicator	Data Elements Needed	Proxy/Alternative Data Elements	Rationale
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	• Dates of ART prescription or dispensing • Dates of viral load tests • Results of viral load tests	Results from most recent viral load test within reporting period can be used if specific dates of tests not available. Yes/no documentation of whether on ART can be used if prescription or dispensing dates are not available. Rates of undetectable viral load among all persons diagnosed with HIV infection can be used as system level indicator.	With the advent of more potent antiretroviral drugs, the goal of ART is durable virologic suppression. An undetectable viral load improves health outcomes for PLWHA and reduces transmission of the virus.
All-cause mortality rate among people diagnosed with HIV infection*	• Date of death	Mortality rate within states or jurisdiction	Mortality is the ultimate outcome measure for assessing HIV/AIDS care among PLWHA. Mortality should be inversely related to the quality of overall care delivered.

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

Indicator	Data Elements Needed	Proxy/Alternative Data Elements	Rationale
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[a]	• Date of diagnosis or evidence of mental health disorder • Date of mental health referral • Date of first visit for mental health services	Evidence of mental health assessment and any visits for mental health services during the same reporting period can be used if specific dates of mental health referral and mental health visits are not available.	Untreated mental health disorders can negatively affect maintenance in care, adherence to treatment, and health outcomes for PLWHA, reducing treatment effectiveness and increasing 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[b]	• Date of diagnosis or evidence of substance use disorder • Date of referral for substance abuse services • Date of first visit for substance abuse services	Evidence of substance use assessment and any visits for substance abuse services during the same reporting period can be used if specific dates of substance abuse referral and substance abuse visits are not available.	Untreated substance use disorders can negatively affect maintenance in care, adherence to treatment, and health outcomes for PLWHA, reducing treatment effectiveness and increasing risk of transmitting the virus to others.
Proportion of people with diagnosed HIV infection who were homeless or temporarily or unstably housed[c] at least once in the preceding 12 months*	• Housing status	Evidence of reported need for housing assistance during the reporting period can be used if information about housing status is not available.	Housing instability can negatively affect maintenance in care, adherence to treatment, and health outcomes for PLWHA, reducing treatment effectiveness and increasing risk of transmitting the virus to others.

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*In contrast to the other indicators, the estimate for this indicator should decrease with improved access to care and supportive services.

[a] Receipt of services within 30 days would be the ideal for optimal care, and more urgent cases should be seen sooner.

[b] See footnote *a* above.

[c] The U.S. Department of Housing and Urban Development's *Homeless Management Information System (HMIS) Data Standards* provides guidance for classifying housing status in four categories: literally homeless (e.g., lack a regular nighttime residence, staying in an emergency shelter), following the McKinney-Vento Homeless Assistance Act (42 U.S.C. 11302, Sec. 103) definition of homelessness, as amended by the Homeless Emergency Assistance and Rapid Transition to Housing (HEARTH) Act of 2009 (P.L. 111-22, div. B, Sec. 1003); imminently losing housing (e.g., being evicted or being discharged from an institution with no housing options identified); unstably housed and at-risk of losing housing (e.g., temporarily doubled up with others, moving frequently for economic reasons), and stably housed (http://www.hudhre.info/documents/FinalHMISDataStandards_March2010.pdf, accessed March 12, 2012).

continued

APPENDIX TABLE 2-1 Continued

Indicator	Data Elements Needed	Proxy/Alternative Data Elements	Rationale
Proportion of people with diagnosed HIV infection who experienced food or nutrition insecurity[d] at least once in the preceding 12 months*	• Food security status	Evidence of reported need for food assistance during the reporting period can be used if information about food security status is not available.	Food insecurity can negatively affect maintenance in care, adherence to treatment, and health outcomes for PLWHA, reducing treatment effectiveness and increasing 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*	• Transportation need	Evidence of reported need for transportation assistance during the reporting period can be used if information about access to transportation is not available.	Unmet need for transportation to access clinical HIV care and related services can negatively affect treatment access, service utilization, and health outcomes for PLWHA, reducing treatment effectiveness and increasing risk of transmitting the virus to others.
Additional Indicators for Clinical HIV Care			
Indicator	**Data Elements Needed**	**Proxy/Alternative Data Elements**	**Rationale**
Proportion of people with diagnosed HIV infection who have had a documented tuberculosis (TB) screening test with results interpreted at least once since HIV diagnosis	• Date of HIV diagnosis/treatment or documentation of infection prior to test • Date and results of TB screening	Yes/no documentation of TB test and results in medical record or yes/no documentation of TB test results within reporting period can be used if specific dates of HIV diagnosis and TB screening are not available.	All PLWHA with diagnosed active tuberculosis should receive ART to improve health outcomes. Screening for TB permits earlier diagnosis and initiation or ART.

Proportion of people with diagnosed HIV infection who have had documented chlamydia, gonorrhea, and syphilis screenings at least once in the preceding 12 months	• Date of chlamydia, gonorrhea, and syphilis screenings	Yes/no documentation of chlamydia, gonorrhea, or syphilis screening within reporting period can be used if specific dates of screening tests are not available.	Infection with co-occurring sexually transmitted infections (STIs) increases the risk of transmitting HIV to others. Screening for STIs permits earlier diagnosis and risk reduction.
Proportion of people with diagnosed HIV infection who have had hepatitis B screening performed at least once since HIV diagnosis or for whom there is documented immunity	• Date of hepatitis B screening or date of documented immunity	Yes/no documentation of hepatitis B screening within reporting period or documented immunity can be used if specific dates of HIV diagnosis and hepatitis B assessment are not available.	Individuals coinfected with HIV and hepatitis B virus are at greater risk for developing chronic hepatitis and for accelerated liver damage and serious liver-related morbidity and mortality. Early detection of hepatitis B coinfection permits earlier treatment and improved outcomes. Individuals who are screened and negative for immunity should be vaccinated, eliminating the need for repeated screening.
Proportion of people with diagnosed HIV infection who have had hepatitis C screening performed at least once in the preceding 12 months	• Date of hepatitis C screening	Yes/no documentation of hepatitis C screening within reporting period can be used if specific dates of screening tests are not available.	HIV and hepatitis C coinfection is associated with accelerated liver damage. Early detection of co-occurring hepatitis C coinfection permits earlier treatment and improved outcomes.

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*In contrast to the other indicators, the estimate for this indicator should decrease with improved access to care and supportive services.

[d] According to the U.S. Department of Agriculture, households with high food security have "no reported indications of food-access problems or limitations"; households with marginal food security have "one or two reported indications—typically of anxiety over food sufficiency or shortage of food in the house [with] little or no indication of changes in diets or food intake"; households with low food security have "reports of reduced quality, variety, or desirability of diet [with] little or no indications of reduced food intake"; and households with very low food security have "reports of multiple indications of disrupted eating patterns and reduced food intake." The lower two levels—low and very low food security—refer to food insecurity (http://www.ers.usda.gov/briefing/foodsecurity/labels.htm#cnstat, accessed February 3, 2012).

continued

APPENDIX TABLE 2-1 Continued

Indicator	Data Elements Needed	Proxy/Alternative Data Elements	Rationale
Proportion of people with diagnosed HIV infection who have received an influenza immunization during the preceding 12 months	• Date of influenza immunization	Yes/no documentation of influenza immunization within reporting period can be used if specific date of influenza immunization is not available.	HIV-infected individuals are considered to be at greater risk for serious influenza-related complications. CDC recommends annual prophylactic vaccination (inactive) for influenza.
Proportion of people with diagnosed HIV infection who have received a pneumococcal immunization at least once since HIV diagnosis	• Date of HIV diagnosis/treatment or documentation of infection prior to immunization • Date of pneumococcal immunization	Yes/no documentation of pneumococcal immunization in medical record or yes/no documentation of pneumococcal immunization within reporting period can be used if specific dates of HIV diagnosis and pneumococcal immunization are not available.	HIV-infected individuals are considered to be at greater risk for contracting and developing serious complications from pneumococcal pneumonia. CDC recommends prophylactic vaccination as soon as possible following diagnosis, followed by a one-time revaccination 5 years later.
Proportion of people with diagnosed HIV infection who have received a hepatitis B vaccination, or who have documented immunity	• Date of hepatitis vaccine/date of documented immunity	Yes/no documentation of hepatitis B vaccination or documented immunity can be used if specific dates of HIV diagnosis and hepatitis B vaccination are not available.	HIV and hepatitis B coinfection is associated with accelerated liver damage and the development of chronic hepatitis and serious liver-related morbidity and mortality. CDC recommends prophylactic vaccination against hepatitis B for susceptible individuals with HIV.

Proportion of ART-naïve people with diagnosed HIV infection who receive drug resistance testing (genotypic) prior to ART initiation	• Date of drug resistance testing • Date of ART initiation	Documentation of drug resistance testing for persons receiving ART can be used if dates of drug resistance testing and/or ART initiation are not available.	Drug resistance testing prior to the initiation of ART permits the identification of the appropriate treatment regimen and therefore improves health outcomes and reduces viral transmission.
Proportion of people with diagnosed HIV infection and HIV-associated nephropathy, hepatitis B (when treatment is indicted), or active TB, who are not on ART*	• Diagnosis or test results for HIV-associated nephropathy, hepatitis B, and TB • ART status (whether on ART or ART prescription/dispensing dates)	Number of people with any of these conditions who are not on ART can be used if information about all three conditions is not available.	HHS recommends that HIV-infected individuals with HIV-associated nephropathy, hepatitis B virus coinfection (when treatment is indicated), or active TB receive ART to improve health outcomes.
Proportion of pregnant women with diagnosed HIV infection who are not on ART*	• Pregnancy status • ART status (whether on ART or ART prescription/dispensing dates)	Number of births during reporting period to women not on ART can be used if complete information about pregnancy status is not available.	Use of combination ART in HIV-positive pregnant women significantly reduces mother-to-child transmission of the virus.
Additional Indicators for Mental Health, Substance Abuse, and Supportive Services			
Indicator	**Data Elements Needed**	**Proxy/Alternative Data Elements**	**Rationale**
Proportion of people with diagnosed HIV infection who were screened for mental health disorders at least once during the preceding 12 months	• Date of mental health screening	Yes/no evidence of screening for mental health disorders or referral for treatment during reporting period can be used if dates of mental health screening are not available.	Undiagnosed, and therefore untreated, mental health disorders can negatively affect adherence to treatment and health outcomes for PLWHA and increase their risk of transmitting the virus to others.

*In contrast to the other indicators, the estimate for this indicator should decrease with improved access to care and supportive services.

continued

APPENDIX TABLE 2-1 Continued

Indicator	Data Elements Needed	Proxy/Alternative Data Elements	Rationale
Proportion of people with diagnosed HIV infection who were screened for substance use disorders at least once during the preceding 12 months	• Date of screening for substance use	Yes/no evidence of screening for substance use disorders or referral for treatment during reporting period can be used if dates of substance use screening are not available.	Undiagnosed, and therefore untreated, substance use disorders can negatively affect adherence to treatment and health outcomes for PLWHA and increase the risk of transmitting the virus to others.
Proportion of people with diagnosed HIV infection who were assessed for need for housing at least once during the preceding 12 months	• Date of housing needs assessment	Yes/no evidence of housing assessment or referral for housing assistance during reporting period can be used if dates of housing assessment are not available.	Assessment of housing stability is important because housing instability can negatively affect adherence to treatment and health outcomes for PLWHA and increase the risk of transmitting the virus to others.
Proportion of people with diagnosed HIV infection who were assessed for need for food or nutrition at least once during the preceding 12 months	• Date of food security assessment	Yes/no evidence of food security assessment or referral for food or meal assistance during reporting period can be used if specific dates of assessment are not available.	Assessment of food security is important because food insecurity can negatively affect adherence to treatment; effectiveness of treatment, including ART; and health outcomes for PLWHA and increase the risk of transmitting the virus to others.
Proportion of people with diagnosed HIV infection who were assessed for need for transportation at least once during the preceding 12 months	• Date of transportation needs assessment	Yes/no evidence of assessment for transportation need or referral for transportation services during reporting period can be used if specific dates of assessment are not available.	Assessment of transportation need is important because an unmet need for transportation to access clinical HIV care and related services can negatively affect treatment access and health outcomes for PLWHA and increase the risk of transmitting the virus to others.

APPENDIX TABLE 2-2 follows on next page

APPENDIX TABLE 2-2 Indicators of Clinical HIV Care and Mental Health, Substance Abuse, and Supportive Services, Mapped to Entry and Engagement in Care

	Diagnosis	Linkage	Engagement & Retention	Primary Care
Indicators and Type (Process/Outcome)				
	- Process/ Outcome	- Process	- Process/ Outcome	- Process
	- **Proportion with a CD4+ cell count >200 cells/mm^3 and without a clinical diagnosis of AIDS**	- **Proportion linked to care for HIV within 3 months of diagnosis**	- **Proportion in continuous care (two or more visits in the preceding 12 months at least 3 months apart)** - **Proportion in continuous care for 12 or more months with CD4+ cell count ≥350 cells/mm^3**	<u>In the preceding 12 months</u>: - **Proportion who received two or more CD4 tests** - **Proportion who received two or more viral load tests** - Proportion screened for chlamydia, gonorrhea, and syphilis - Proportion screened for hepatitis C - Proportion immunized for influenza <u>Since diagnosis</u>: - Proportion screened for tuberculosis - Proportion screened for hepatitis B - Proportion immunized for hepatitis B (if needed) - Proportion immunized for pneumococcal pneumonia - Proportion who received drug resistance testing (genotypic) prior to ART initiation

NOTE: The committee's recommended core indicators are written in bold text.

Treatment	Virologic Suppression	Mediators	Disparities
• Process	• Outcome	• Process/Outcome	• Process/Outcome

• **Proportion with a measured CD4+ cell count <500 cells/mm^3 who are not on ART**
• Proportion with HIV-associated nephropathy, hepatitis B (when treatment is indicated), or active tuberculosis who are not on ART
• Proportion of HIV-infected pregnant women who are not on ART
	• **Proportion on ART for 12 or more months who have an undetectable viral load**
	• **All-cause mortality rate**
		• **Proportion with mental health disorder referred for mental health services who received these services within 60 days**
		• **Proportion with substance use disorder referred for substance abuse services who receive these services within 60 days**
		• **Proportion with an unmet need for**
		  • **housing**
		  • **food**
		  • **transportation**
		In the preceding 12 months:
		• Proportion screened for mental health disorders
		• Proportion screened for substance use disorders
		• Proportion assessed for need for
		  • housing
		  • food
		  • transportation
			• All indicators related to diagnosis, linkage, engagement and retention, primary care, treatment, and virologic suppression, stratified by subpopulation
			• All mediators, stratified by subpopulation

continued

APPENDIX TABLE 2-2 Continued

	Diagnosis	Linkage	Engagement & Retention	Primary Care
Data Elements				
	• Date of HIV diagnosis • CD4 test results at diagnosis/first visit for HIV care • Diagnosis of AIDS or AIDS-defining illness (e.g., OIs)	• Date of HIV diagnosis • Date of first visit for HIV care (or proxy of first or second CD4 or viral load test date)	• Dates of routine HIV-care visits • Dates of CD4 tests • Results of at least one CD4 test within time period specified	• Dates of CD4 tests • Dates of viral load tests • Date of HIV diagnosis/ treatment or documentation of infection • Dates of chlamydia, gonorrhea, and syphilis screenings • Date of hepatitis C screening • Date and results of tuberculosis screening • Date hepatitis B screening or date of documented immunity • Date of influenza immunization • Date of pneumococcal immunization • Date of hepatitis vaccine/date of documented immunity • Date of drug resistance testing • Date of ART initiation

Treatment	Virologic Suppression	Mediators	Disparities
• Dates of CD4 tests • Results of CD4 tests • Dates of ART prescription or dispensing • Diagnosis or test results for HIV-associated nephropathy, hepatitis B, and tuberculosis • Pregnancy status	• Dates of ART prescription or dispensing • Dates of viral load tests • Results of viral load tests • Date of death	• Date of diagnosis or evidence of mental health disorder • Date of referral for mental health services • Date of first visit for mental health services • Date of diagnosis or evidence of substance use disorder • Date of referral for substance abuse services • Date of first visit for substance abuse services • Housing status • Food security status • Transportation need • Date of mental health screening • Dates of screening for substance use • Dates of housing, food security, and transportation needs assessment	• All data elements for indicators and mediators • Additional data elements pertaining to subpopulations: • Race • Ethnicity • Sex • Gender identity • Sexual orientation • Date of birth • Zip code/other geographic marker

APPENDIX TABLE 2-3 Co-Occurring Conditions and Etiological Cofactors with Link to Guidance for Optimal Management

Condition	Etiological Cofactors	Guidance for Optimal Management
Cervical/anal dysplasia	Human papillomavirus (HPV); HIV*	• Guidelines for Prevention and Treatment of Opportunistic Infections in HIV-Infected Adults and Adolescents (http://www.aidsinfo.nih.gov/contentfiles/Adult_OI.pdf)
Chronic obstructive pulmonary disease	Cigarette smoking	• Chronic obstructive pulmonary disease and HIV (http://www.hiv.va.gov/provider/manual-primary-care/copd.asp)
Diabetes	HIV*; highly active antiretroviral therapy (HAART)*; diet; genetics; exercise	• Clinical Practice Recommendations (http://care.diabetesjournals.org/content/31/Supplement_1.toc)
Hepatoma	Hepatitis B virus; hepatitis C virus	• European AIDS Clinical Society (EACS) Guidelines for the Clinical Management and Treatment of Chronic Hepatitis B and C Coinfection in HIV Infected Adults (http://onlinelibrary.wiley.com/doi/10.1111/j.1468-1293.2007.00535.x/pdf) • EASL Clinical Practice Guidelines: Management of Chronic Hepatitis B (http://www.easl.eu/assets/application/files/b73c0da3c52fa1d_file.pdf) • Care of Patients with Chronic Hepatitis B and HIV Co-Infection: Recommendations from an HIV-HBV International Panel (www.hem-aids.ru/system/files/attachments/1659/aids_aids_pdf_183.pdf)
Hyperlipidemia	HIV; HAART; diet; genetics; exercise	• Third Report of the Expert Panel on Detection, Evaluation, and Treatment of High Blood Cholesterol in Adults (ATP III Final Report) (http://www.nhlbi.nih.gov/guidelines/cholesterol/atp3_rpt.htm) • Guidelines for the Evaluation and Management of Dyslipidemia in Human Immunodeficiency Virus (HIV)-Infected Adults Receiving Antiretroviral Therapy: Recommendations of the HIV Medicine Association of the Infectious Diseases Society of America and the Adult AIDS Clinical Trials Group (http://cid.oxfordjournals.org/content/37/5/613.full)

APPENDIX TABLE 2-3 Continued

Condition	Etiological Cofactors	Guidance for Optimal Management
Osteoporosis	HIV[*]; HAART[*,**]; lack of sun exposure; genetics; diet; substance use	• Primary Care Guidelines for the Management of Persons Infected with Human Immunodeficiency Virus: 2009 Update by the HIV Medicine Association of the Infectious Diseases Society of America (http://cid.oxfordjournals.org/content/49/5/651.full)
Renal disease	Hypertension; HAART[**]; HIV	• Guidelines for the Management of Chronic Kidney Disease in HIV-Infected Patients (http://cid.oxfordjournals.org/content/40/11/1559.full)
Hypogonadism	Advanced HIV disease	• Primary Care Guidelines for the Management of Persons Infected with Human Immunodeficiency Virus: 2009 Update by the HIV Medicine Association of the Infectious Diseases Society of America (http://cid.oxfordjournals.org/content/49/5/651.full)
Hepatitis	Chronic hepatitis B or C; antiretroviral hepatotoxicity	• Primary Care Guidelines for the Management of Persons Infected with Human Immunodeficiency Virus: 2009 Update by the HIV Medicine Association of the Infectious Diseases Society of America (http://cid.oxfordjournals.org/content/49/5/651.full) • European AIDS Clinical Society (EACS) Guidelines for the Management and Treatment of Chronic Hepatitis B and C Coinfection in HIV-Infected Adults (http://onlinelibrary.wiley.com/doi/10.1111/j.1468-1293.2007.00535.x/pdf)
Sexually transmitted infections	Syphilis; gonorrhea; chlamydia; herpes simplex; enteric infections (via fecal contact)	• Sexually Transmitted Diseases Treatment Guidelines, 2010 (http://www.cdc.gov/std/treatment/2010/STD-Treatment-2010-RR5912.pdf)
Tuberculosis and other opportunistic infections	HIV-associated immunodeficiency	• Guidelines for Prevention and Treatment of Opportunistic Infections in HIV-Infected Adults and Adolescents (http://www.aidsinfo.nih.gov/contentfiles/Adult_OI.pdf)

continued

APPENDIX TABLE 2-3 Continued

Condition	Etiological Cofactors	Guidance for Optimal Management
Mental health disorders	Anxiety, depression, post-traumatic stress; stigma; discrimination	• HIV and Mental Health (http://www.hivguidelines.org/clinical-guidelines/hiv-and-mental-health/) • Mental Health Disorders Among Substance-Using HIV-Infected Patients (http://www.hivguidelines.org/clinical-guidelines/hiv-and-substance-use/mental-health-disorders-among-substance-using-hiv-infected-patients/)
Substance use disorders	Anxiety, depression, post-traumatic stress; stigma; discrimination	• HIV and Substance Use (http://www.hivguidelines.org/clinical-guidelines/hiv-and-substance-use/) • Mental Health Disorders Among Substance-Using HIV-Infected Patients (http://www.hivguidelines.org/clinical-guidelines/hiv-and-substance-use/mental-health-disorders-among-substance-using-hiv-infected-patients/)
Oral health	Candida; oral hairy leukoplakia; herpes simplex	• HIV and Oral Health (http://www.hivguidelines.org/clinical-guidelines/hiv-and-oral-health/)

* Connection between condition and cofactor not proven.
** Tenofovir most commonly associated with this finding.

3

Sources of Data on HIV Care to Assess Indicators of HIV Care and Access to Supportive Services

In this chapter the committee describes data from public and private data systems to assess the indicators for HIV care and mental health, substance abuse, and supportive services identified in Chapter 2. The chapter identifies what the committee determined to be the best sources of data for assessing the indicators, discusses ways to maximize their usefulness, and recommends approaches for supplementing current data systems to gauge the impact of the National HIV/AIDS Strategy (NHAS) and the Patient Protection and Affordable Care Act (ACA) in improving HIV care (statement of task heading text and question 1). The chapter also describes other data collection and standardization efforts that could be utilized to monitor improvements in HIV care and how to regularly obtain data that capture the care experiences of people living with HIV/AIDS (PLWHA) without substantial new investments (statement of task questions 2 and 3). The chapter ends with the committee's conclusions and recommendations.

IDENTIFICATION OF DATA SYSTEMS

To identify the best public and private sources of data to estimate the indicators related to continuous HIV care and access to services for PLWHA, the committee first compiled an initial list of 32 public and private data systems or data collection agencies, including those that are HIV specific and those that are not HIV specific but include information on PLWHA. The list included data collection efforts and systems highlighted in the project proposal as well as others identified by committee members as important or potential sources of information on PLWHA, including care and services provided to them. Box 3-1 summarizes the data systems and collection activities identified by the committee for further consideration.

Requests for information were sent to individuals familiar with 29 of the data systems and agencies. Several other potential sources of data—accountable care organizations, the Enhanced Comprehensive HIV Prevention Planning (ECHPP) Project, and the 12 Cities Project—were still being implemented at the time of the inquiry.[1] Information was obtained from 27 of the data systems or agencies contacted. The committee was unable to obtain information from Aetna and the HMO (Health Maintenance Organization) Research Network. The Substance Abuse and Mental Health Services Administration provided information on several data collection activities. In total, the committee reviewed information on 31 different data collection activities. The committee requested background information (e.g., the population for which data are collected; the method and frequency of data collection; whether the data are public, private, or proprietary) and details about the data elements captured by each of the data systems in the areas of HIV testing and linkage to care, clinical care, access to care, treatment and adherence, financial security, demographics, risk behavior assessment, and patient experience with care.

The data systems vary with respect to their design; the size, nature, and representativeness of population; the source and type of data; and the specific data elements included. The committee took account of these factors when considering which data systems, individually and in aggregate, would be most helpful for estimating the indicators presented in Chapter 2 and for assessing the impact of the NHAS and the ACA in improving HIV care in the United States.

The committee identified 12 data systems it considered to be most useful for tracking the impact of the NHAS and the ACA on HIV care in the United States:

- National HIV Surveillance System
- Medical Monitoring Project
- Ryan White Services Report
- Ryan White AIDS Drug Assistance Program Reports
- Medicaid Statistical Information System
- Chronic Condition Data Warehouse
- North American AIDS Cohort Collaboration on Research and Design
- CFAR Network of Integrated Clinical Systems
- HIV Research Network
- Clinical Case Registry: HIV

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[1] Complete descriptions of ECHPP and the 12 Cities Project are provided later in this chapter.

BOX 3-1
Data Collection Activities Considered by the Committee

HIV Care–Specific Data Systems

Public

- National HIV Surveillance System
- Medical Monitoring Project
- Ryan White HIV/AIDS Program (Ryan White Services Report; Ryan White AIDS Drug Assistance Program Reports; Ryan White Dental Services Report)
- Clinical Case Registry: HIV
- Housing Opportunities for Persons with AIDS
- Minority AIDS Initiative
- HIV Outpatient Study
- Study to Understand the Natural History of HIV/AIDS in the Era of Effective Therapy
- Enhanced Comprehensive HIV Prevention Planning Project
- 12 Cities Project

Private

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

Data Systems with Information that Includes People Living with HIV

Public

- Medicaid Statistical Information System
- Chronic Condition Data Warehouse
- Resource and Patient Management System
- Bureau of Prisons Electronic Medical Record
- Bureau of Primary Health Care–Federally Qualified Health Center Uniform Data System
- Substance Abuse and Mental Health Services Administration
- Healthcare Cost and Utilization Project
- National Ambulatory Medical Care Survey
- National Hospital Ambulatory Medical Care Survey
- National Vital Statistics System

Private

- Private health insurers (Aetna, Kaiser Permanente, United Health [Ingenix Normative Health Information Database®], Wellpoint [HealthCore Integrated Research Database®])
- MarketScan Research Databases
- HMO Research Network

- Kaiser Permanente
- National Vital Statistics System

Two additional data systems provide useful information for tracking the impact of the initiatives on HIV care for two small but important subpopulations of HIV-infected individuals (American Indians and Alaska Natives; federal prisoners) and a third provides information relevant to housing assistance and other supportive services for PLWHA:

- Resource and Patient Management System
- Bureau of Prisons Electronic Medical Record
- Housing Opportunities for Persons with AIDS

Appendix Table 3-1 provides an overview of the data systems, including their strengths and limitations, potential enhancements to consider, and implications of the ACA for each. Although no single data system can fully track the progress of the NHAS and the ACA, the committee concluded that a combination of these 15 data systems can provide a collective platform for helping to evaluate these initiatives and for estimating the indicators identified to measure the quality of HIV care and access to supportive services. Appendix Tables 3-2a through 3-2e show which of the data elements associated with the indicators are available in each data system. Appendix Table 3-2f shows which data systems capture additional data elements that were identified by the committee to be of interest, but not required to estimate the indicators. Appendix Tables 3-3a through 3-3d summarize the indicators that can be estimated using information available from each of the data systems. Some of the data collection instruments are publicly available on the Internet (see Appendix Table 3-4); these provide more complete information on the data captured by the relevant data system.

SOURCES OF HIV CARE DATA

National HIV Surveillance System

The Centers for Disease Control and Prevention (CDC) maintains the National HIV Surveillance System (NHSS), which provides data about the HIV/AIDS epidemic for program planning and resource allocation. Started in 1981, the surveillance system is conducted in all 50 states and the District of Columbia, as well as American Samoa, Guam, Puerto Rico, the U.S. Virgin Islands, and the Northern Mariana Islands. In addition, the three freely associated states (the Federated States of Micronesia, the Republic of the Marshall Islands, and the Republic of Palau) report HIV surveillance data to CDC. CDC funds and assists state and local health departments to collect the information, and the state and local HIV surveillance systems represent valuable additional sources of data pertinent to HIV care.[2] The NHSS is a population-based census of all persons diagnosed and reported with HIV infection in the United States, including both those individuals receiving HIV care and those who are not in care.[3]

Since April 2008, all 50 states and the District of Columbia, as well as American Samoa, Guam, the Northern Mariana Islands, Palau, Puerto Rico, and the U.S. Virgin Islands, have been using the same confidential name-based reporting standards for newly diagnosed cases of HIV. Although the NHSS only includes data from those confidential name-based reporting systems that have been collecting HIV data for at least 4 years in the national aggregate numbers it publishes (CDC, 2010),[4] all states and areas report HIV surveillance data to CDC, and the data for each reporting area are included in the annual *HIV Surveillance Report*. As such, the population in the surveillance system is one of the most nationally representative and provides the largest available sample of diagnosed PLWHA in the United States.

Another advantage of the NHSS is the use of standardized definitions of variables and reporting methods. In terms of data elements of interest to the committee,[5] the system includes date of HIV/AIDS diagnosis; information on CD4+ cell count and plasma HIV RNA (viral load) closest to diagnosis; and optional fields for HIV and substance abuse treatment referral, pregnancy status, and antiretroviral therapy (ART) status at the time of reporting. Data gathered also can be used to monitor disparities with regard to race, ethnicity, sex, gender, age, geographic area, and country of birth.

In addition, most jurisdictions report all CD4 count and viral load lab

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[2] State, territorial, and local HIV surveillance systems may include 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.

[3] 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).

[4] The 2009 national aggregate data published in 2012 includes data from the 46 states and 5 dependent areas that had implemented confidential name-based reporting by January 2007 (CDC, 2012, Commentary). Two additional states will be represented in the national aggregate data reported next year. 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).

[5] Although the data systems considered by the committee capture many useful data elements, only those data elements identified by the committee to be of specific interest for tracking the impact of the NHAS and ACA are discussed in the text. Appendix Table 3-4 lists the publicly available data collection instruments for the data systems discussed, which provide a comprehensive picture of the data elements captured by each.

results,[6] which permits the tracking of individuals' health status over time. In those cases, additional information can be extrapolated or calculated from available data. For example, the time between diagnosis and initial (or second) CD4 and viral load test can serve as a surrogate for the length of time between diagnosis and entry into care, and the number of routine HIV care visits per year may be estimated from the number of HIV-related lab reports per year. One limitation of the NHSS, as noted in the NHAS (ONAP, 2010, p. 18), is the fact that although most jurisdictions report all lab results, such as CD4 and viral load results, not all do. Another limitation is the problem of incomplete or inaccurate reporting by clinicians treating PLWHA and by state and local health departments. Studies have raised questions about the accuracy and completeness of NHSS data. A study comparing self-reported dates of HIV diagnosis with those reported to the NHSS indicates that 56 percent of the date pairs agreed on the year of diagnosis, with another 17 percent differing by 1 year and 19 percent by 3 or more years (Hall et al., 2005). Thirty percent of self-reported dates were earlier than those reported in surveillance data (Hall et al., 2005). Another study comparing date of first diagnosis based on self-report, medical record, and surveillance system data showed 51 percent agreement between self-reported year of diagnosis and the surveillance system and 70 percent agreement between the years reported in medical records and in surveillance (McCoy et al., 2010). Another 21 percent of self-reported dates differed by 1 year, while 23 percent differed by 3 or more years (McCoy et al., 2010). On average the self-reported dates were earlier than those recorded in the surveillance data (McCoy et al., 2010).

According to one study of reporting completeness, 81 percent of HIV diagnoses are reported within 12 months of diagnosis (Hall et al., 2006). This figure corresponds with the observation of McCoy and colleagues that only 81 percent of the cases in their study could be matched to surveillance data (McCoy et al., 2010). Incomplete reporting may be explained by lack of timeliness in reporting, failure to comply with case reporting, or an assumption that previously diagnosed cases already had been reported (McCoy et al., 2010). Structures are in place to improve the accuracy and

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[6] 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 results (see Appendix Table 3-5), including 30 states, District of Columbia, Guam, and Puerto Rico (Personal communication, Amy Lansky, Centers for Disease Control and Prevention, October 6, 2011). One additional state (Kentucky) reported all CD4 results, but only detectable viral load results, and 7 additional states reported all viral load results, but not all CD4 results. More states are moving toward reporting all CD4 and viral load test results. Massachusetts, for example, mandated 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).

timeliness of reporting. For example, increased use of electronic laboratory reporting is expected to increase the completeness and timeliness of HIV surveillance reporting (Overhage et al., 2008).

Despite current gaps in accuracy and reporting, the NHSS is one of the most representative HIV data systems that exists and offers a wealth of information. In terms of the data elements required to assess the core indicators for clinical HIV care, the NHSS, as previously noted, currently captures the individual's date of diagnosis and the dates and results of the individual's first and most recent viral load test and the CD4 test at, or closest to, the date that the individual was determined to be HIV-infected or to have AIDS (see Appendix Table 3-2a), as well as the first CD4+ cell count <200 cells/mm^3. The ongoing CD4 and viral load test dates available for most reporting areas may be used as a surrogate for dates of first and ongoing visits for routine HIV care in those jurisdictions. These data permit estimation of the indicators for linkage to and continuity of care, regular CD4 and viral load testing, and individuals in care who achieve or maintain a CD4+ cell count of greater than 350 cells/mm^3 (see Appendix Table 3-3a).

A revised version of the Adult HIV Confidential Case Report was approved by the Office of Management and Budget (OMB) in June 2011. The form includes a section that asks whether the individual "has ever taken any antiretrovirals (ARVs)," ARV medications taken, and dates ARVs were taken (date begun, date of last use). This information, which is collected "if required by Health Department," is required for state and local health department that participate in CDC's HIV Incidence Surveillance (HIS) and Variant, Atypical and Resistant HIV Surveillance (VARHS) activities and is optional for all other surveillance areas (CDC response to IOM request for information, October 20, 2011). When available, the ARV information may permit estimation of the core indicators pertaining to ART initiation and subsequent durable virologic suppression. However, there currently is no mechanism by which the NHSS can routinely capture ARV usage longitudinally. Longitudinal individual-level ART data in conjunction with longitudinal CD4 and viral load test dates and results would more reliably permit calculation of the relevant core indicators. Enhancement of NHSS data in this way would allow its use to evaluate all of the core HIV care indicators for the majority of the population diagnosed with HIV in the United States.[7] Information is also captured on pregnancy status at the time the form is completed, which may be used to estimate the additional clinical

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[7] Since the NHSS captures date of death, it can provide the data necessary to calculate the core indicator pertaining to all cause mortality among PLWHA. However, as discussed in more detail later in this report, the National Vital Statistics System also collects and calculates annual data on HIV mortality.

care indicator pertaining to proportion of pregnant women with HIV who are receiving ART.

NHSS data also permit calculation of the core HIV care indicators for subpopulations of PLWHA based on age, race and ethnicity,[8] sex assigned at birth, current gender identity, geographic distribution, and country of birth. Although CDC does not currently capture information specifically about individuals' sexual orientation, which relates to the NHAS target and associated indicator pertaining to the proportion of diagnosed gay or bisexual men with undetectable viral load, combining data on sex assigned at birth with data collected on sex of sexual partner(s) (sex with male) can serve as a close proxy.

As is common with disease surveillance in the United States, the HIV surveillance system also does not collect information about income level. Unlike the previous version of the Adult HIV Confidential Case Report form, which included an optional section asking about the individual's primary source of reimbursement for medical treatment (Medicaid, private insurance or HMO, no coverage, other public funding, clinical trial or government program, unknown), the current form does not collect that information. Collection of such data, especially if the Ryan White HIV/AIDS Program were added to the list of reimbursement source checkboxes provided on the form, would permit the use of NHSS data to estimate the indicators for the subpopulations specifically identified in the NHAS and would help to facilitate the evaluation of data across data systems as discussed in Chapter 6.

Uniform reporting to CDC of ongoing CD4 and viral load test dates and results from all jurisdictions and collection of longitudinal information on ARV usage would permit the use of data from the NHSS to assess all of the core indicators for HIV care identified by the committee. Use of national surveillance system data would permit evaluation of the indicators for the vast majority of the population diagnosed with HIV in the United States, as well as for subpopulations based on race, ethnicity, sex, gender, age, and country of origin. In addition, capturing information on sexual orientation and maintaining current geographic areas of residence for HIV-infected individuals in the system would further enhance the ability of the NHSS to be used to evaluate the impact of the NHAS and health care reform on HIV care in the United States.

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[8] Like the other federal data systems, NHSS captures data on race and ethnicity as specified by OMB (1977, 1997a,b).

Medical Monitoring Project

Initiated in 2005 in response to an Institute of Medicine (IOM, 2004) report, the Medical Monitoring Project (MMP) is a CDC-sponsored population-based surveillance system designed to collect comprehensive clinical and behavioral service 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). MMP is the first project since the HIV Cost and Services Utilization Study (Bozzette et al., 1998) almost 15 years ago that is designed to obtain comprehensive information about HIV care from a nationally representative population of PLWHA who are receiving care. MMP employs a probability proportional to size sampling design to obtain cross-sectional probability samples of its target population. A sample of about 400 individuals from each of 26 project areas (approximately 10,400 people) was selected each year for the 2007 and 2008 data collection cycles.[9] Data are obtained from individual patient interviews and medical record review.

MMP captures most of the data elements needed to assess all of the indicators identified by the committee (see Appendix Tables 3-2a to 3-2e and 3-3a to 3-3c), including data on supportive services, which makes it an attractive source of data. In terms of demographic data, the interview component of MMP captures self-reported data on race, ethnicity, sex at birth, gender identity (male, female, transgender), and sexual orientation (homosexual, heterosexual, bisexual). In addition to the comprehensiveness of the data currently captured, the nature of the interview component of MMP allows flexibility to modify the questionnaire to capture different data elements that are subsequently determined to be useful. Starting with the 2011 cycle, for example, MMP is capturing data on stigma and discrimination, making it the only data system to do so among those examined by the committee.

An additional strength of MMP is its design to generate results that are nationally representative of the population of HIV-infected adults in care in the United States, which makes it a potentially valuable tool for tracking changes in access to and quality of HIV care in the country. Although MMP only includes HIV-infected individuals who are in care, the sample is not limited to those receiving care through a specific payer (Medicaid, Medicare, Veterans Health Administration [VHA], private or HMO) as is the case with a number of other data systems.

Despite its strengths, MMP also has several limitations. One significant

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[9] Details of the sampling method are described in the MMP 2009 protocol (CDC, 2009) and summarized in Blair et al. (2011) and on the MMP website (CDC, 2011b).

concern about MMP is its low participation rate. For the 2007 data collection cycle, 10,192 individuals were determined to be eligible for participation. The median participation rate was 40 percent, ranging from 3 to 76 percent depending on the project area. Interview data ultimately were reported for 3,643 of the 3,944 participants interviewed; medical record abstraction data were not reported (Blair et al., 2011). As a result of the low participation rate, the data for the 2007 collection cycle may not be nationally or locally representative of HIV-infected adults receiving care in the United States. Steps have been taken to improve participation rates beginning with the 2009 collection cycle, and CDC anticipates that future data will permit nationally representative results (Blair et al., 2011).[10] It is not clear, however, that the efforts will completely resolve the issues of nonresponse bias. For example, studies have found that PLWHA who are harder to reach and/or engage for study participation are more likely to be homeless or unstably housed; to be struggling with mental health or drug use problems; to be socially isolated; and to have high rates of missed appointments. Specific efforts to engage such populations are needed to ensure their representation in the study.

A second concern about MMP is the potential for social desirability response bias in the responses to the interview questions. Since many of the the interviews are conducted "in person," respondents may be reluctant to answer accurately if doing so means providing what they perceive to be less "socially appropriate" responses to sensitive questions (Blair et al., 2011). Providing participants with a means to enter their responses to sensitive questions directly into the computer or on the response form is one way to help counteract social desirability response bias. This approach would avoid the necessity of sharing their responses with the interviewer and could improve the accuracy of the information collected (Carr et al., 1983; Greist et al., 1973; Kobak et al., 1996; Lawrence et al., 2010; Lucas et al., 1977; Metzger et al., 2000; Petrie and Abell, 1994; Waruru et al., 2005; Willig, 2011), although a study of clients at an addiction treatment center found no significant differences in the reliability of information on drug, alcohol, or tobacco use collected through computerized interviews, face-to-face interviews, or self-report formats (Skinner and Allen, 1983).

A third concern is the potential inaccuracy of clinical data (lab values, vaccinations, ART prescription) collected through participant self-report (Blair et al., 2011). Although a problem for reports of findings based on clinical information obtained solely from interviews (e.g., Blair et al. 2011), medical record abstraction is another component of MMP (CDC, 2009, pp. 22-25), which permits comparison with and corroboration of

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[10] Some interview and medical record abstraction data from MMP's 2009-2010 cycle have been reported (CDC, 2011d).

the self-reported clinical data. It is important that data from the medical record abstraction component of the protocol be available to permit such cross-checking and confirmation of self-reported information. The 2009 MMP protocol specifies that in project areas that have the surveillance authority to abstract medical records of selected patients without their consent, medical record abstraction should be completed for all sampled patients, including those who decline to participate in the interview or who cannot be located for interview (CDC, 2009, p. 25). In project areas with a more narrow definition of surveillance, where record abstraction cannot be completed without patient consent, minimal data can be collected on all sampled patients. The minimum data set contains the same fields as the NHSS case report form, and therefore these data can be collected in all project areas under HIV/AIDS surveillance authority.

Despite its current limitations, the research infrastructure, design, and implementation efforts that are in place make MMP a promising tool for monitoring care among HIV-infected adults receiving care in the United States. The committee supports the current efforts of CDC to improve individual participation and completion rates. Other strategies to increase participation might include providing additional incentives for study participants[11] and participating clinics or reducing the time required to complete the full interview by selectively eliminating certain questions.[12] In addition, implementation of the "minimum data set" records abstraction could help to provide some data for individuals who decline to participate.

Beginning with the 2012 data collection cycle, medical record abstraction will focus only on the 12 months preceding the interview; earlier clinical data will no longer be captured (Personal communication, Amy Lansky, Centers for Disease Control and Prevention, October 20, 2011). Although limiting medical record abstraction to the preceding 12 months likely will expedite collection of the data, certain data elements required to estimate some HIV care indicators may no longer be captured. For example, data on hepatitis B screening, vaccination, and immunity would not be captured if the relevant testing and immunization took place more than 12 months prior. Another option for reducing the number of questions in the standard interview without undermining the breadth of information provided might be to eliminate (some of) the self-reported clinical data if the same infor-

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[11] The 2009 MMP protocol specifies that individual participants will receive approximately $40 in cash or cash equivalent for participating in the interview (CDC, 2009, p. 21).

[12] Currently the MMP protocol offers two interview instruments: the Standard Questionnaire, which is the default and takes approximately 45 minutes to complete, and the Short Questionnaire, which is reserved for individuals who speak neither English nor Spanish or are too sick to respond to the Standard Questionnaire and takes approximately 20 minutes to complete.

mation already is being harvested through medical record abstraction. In addition, as electronic health records (EHRs) become more prevalent, MMP may be able to increase the scope of medical abstraction while retrieving and processing the data in a timely way. Such enhancements would help to make MMP better able to fulfill its promise as an expanded surveillance system for monitoring HIV care in the United States.

The potential for MMP to provide comprehensive information for tracking improvements in access to and quality of HIV care and supportive services in the United States is great; however, the low completion rate to date and the potential for nonresponse bias raise concerns about the representativeness of the data, especially for the homeless or unstably housed population and those with mental health and/or substance use disorders. Implementation of strategies to improve participation rates, especially among hard-to-reach populations, and to expedite the processing and availability of the data obtained through medical record abstraction would significantly increase the value of the project.

Ryan White HIV/AIDS Program Data

According to the Health Resources and Services Administration (HRSA), approximately 529,000 people currently receive at least one medical, health, or related support service through the Ryan White HIV/AIDS Program each year (HHS, 2011a). The AIDS Drug Assistance Program (ADAP), under Part B of the Ryan White Program, reported 213,764 clients enrolled during FY 2009, including 33,672 new enrollees, and 190,936 clients served (NASTAD, 2011, Table 5). The Ryan White Program is the third-largest federally funded program serving PLWHA (after Medicare and Medicaid) and the largest that serves only PLWHA (KFF, 2009b). Twenty-nine percent ($5.4 billion) of federal spending for HIV care was allocated to the Ryan White Program in FY 2011 (Kates, 2011, p. 1). The majority of Ryan White Program clients are low income, with approximately 70 percent at or below the federal poverty level (FPL) (HRSA, 2010, p. 45, Table 6).

HRSA launched a new reporting scheme in 2009, replacing the *Ryan White HIV/AIDS Program Annual Data Report* with the *Ryan White HIV/AIDS Program Service Report* (RSR). The RSR captures individual client-level data annually for individuals who receive one or more Ryan White–funded services (client report), as well as grantee and service provider information (grantee report and service provider report). The RSR client report generates a unique client identifier for every Ryan White HIV/AIDS Program client based on the client's name, birth date, and other characteristics; the identifier is then encrypted before being sent to HRSA, further protecting the client's privacy. Use of unique client identifiers not only permits tracking of individual clients across providers, generating more accurate client counts, but also permits the capture of individual-level demographic, clinical, and service utilization data, which can be used to assess quality of care received.[13]

The client report captures many of the data elements needed to assess the core clinical HIV care indicators identified by the committee (Appendix Tables 3-2a, 3-3a). The client report captures the year of birth (but not the full date); date of death; dates of ambulatory or outpatient HIV care visits; and the dates and results of all CD4 counts and viral load tests within the reporting period. In addition, the client report captures the year, but not the full date, of HIV diagnosis and whether the individual has been prescribed ART at any time within the reporting period, but not the date of ART initiation or subsequent prescriptions. Finally, the client report records the date of the client's first ambulatory or outpatient care visit with the provider. However, the visit need not be for HIV care, nor is it necessarily the client's first HIV care visit following diagnosis, which is required to assess the indicator pertaining to linkage to care.

The RSR client report also captures data relevant to the indicators related to mental health, substance abuse, and supportive services (see Appendix Tables 3-2b, 3-3b, 3-3d): screening for both mental health and substance use within the reporting period; number of mental health service visits; number of substance abuse service visits (inpatient and outpatient) in each quarter of the reporting period; housing status (stable permanent, temporary, unstable); and receipt of housing, food, and (medical) transportation services in each quarter of the reporting period (HRSA, 2011). The report does not provide information on referral for mental health or substance abuse services (e.g., whether the services were received within 60 days of referral); direct (e.g., dates) assessment of housing, food, or transportation need; or the proportion of clients who are food insecure or have an unmet need for transportation services, although such information might be inferred from the number of clients who are receiving food or transportation services.

The client report also collects data specific to a number of the additional clinical HIV care indicators (Appendix Tables 3-2c, 3-3c). These data include whether a client has been screened for tuberculosis (TB) during the 12-month reporting period or since being diagnosed with HIV; whether a client was screened for syphilis during the reporting period (excluding those under 18 years of age who are not sexually active); whether a client was screened for hepatitis B and C during the reporting period or since diagnosis

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[13] Although the Ryan White client-level data will be de-duplicated, the process will identify some false negatives and false positives, as is the case with any identifier based on personal characteristics.

with HIV; and whether a client has completed the hepatitis B vaccination series. In addition, data are collected on the pregnancy status of HIV-infected female clients, the stage of pregnancy at which they entered prenatal care, and whether they were prescribed ART to prevent maternal-to-child transmission of HIV. Data relevant to the additional clinical HIV care indicators that are not captured by the client report include dates of chlamydia and gonorrhea screenings; dates of influenza and pneumococcal immunizations; and data pertaining to ART drug resistance testing and ART initiation in individuals with HIV nephropathy, hepatitis B or C, or TB.

Although the data elements collected by the client report are not identical to those enumerated for the indicators identified by the committee, they provide information that may serve as a proxy for estimating many of the indicators. In addition, the RSR client report captures demographic data that specify subpopulations within Ryan White HIV/AIDS Program clients including race and ethnicity; gender (male, female, transgender, unknown; and for transgender, male-to-female, female-to-male, unknown); geographic code (first three digits of client zip code); income as a percentage of the FPL; and sources of health insurance.

ADAPs independently report data to HRSA, and ADAP reporting also is undergoing revision. The October 1, 2012 through March 31, 2013, data collection period is the first to capture individual client-level data for the *ADAP Data Report* (ADR), replacing the *ADAP Quarterly Report*. Like the RSR, the ADR will employ unique client identifiers using the same algorithm and encryption process as those used for the RSR. The encrypted client identifiers are meant to carry across the reports. In the future, although the reports will remain separate, client-level data from the RSR and the ADR will be merged into a single system, and the two reports will be linked for those clients receiving ADAP and other Ryan White–funded services (Personal communication, Faye Malitz, Health Resources and Services Administration, October 25, 2011).

Appendix Tables 3-2a through 3-2e summarize the data elements pertaining to the committee's indicators that are captured by the *ADAP Quarterly Report* and the ADR, including those that are new for the ADR. Appendix Tables 3-3a through 3-3d map the committee's indicators to the various data elements that are or will be captured by the ADAP reports.[14] The ADAP reports do not supplement the data already captured in the RSR in terms of those needed to evaluate the committee's indicators. However, for the population of ADAP clients who do not receive other Ryan White

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[14] No data elements from the *ADAP Quarterly Report* that are pertinent to the committee's indicators will be dropped in moving to the ADR, although new data elements of interest will be added. The committee refers to "the ADAP reports" jointly when it is unnecessary to distinguish between them.

services, the ADR in particular can provide data to estimate a few of the core clinical HIV care indicators, such as the proportion of ADAP clients who have received CD4 and/or viral load testing in the past year (Appendix Table 3-3a). The ADR also may be able to provide the data to estimate the indicators pertaining to the proportion of clients with a CD4+ cell count that is less than 500 cells/mm^3 who are on ART; the proportion of clients on ART for 12 or more months who have an undetectable viral load; and the proportion of female ADAP clients who are pregnant and on ART. However the data for these indicators are limited to ART drugs that are fully ADAP funded. If a client is not receiving at least one such drug, that person will not be identified as being on ART.

The ADAP reports capture no data pertaining to mental health or substance use screening or services or to the need for or use of supportive services for housing, food, and transportation. Demographic data captured in the ADAP reports are more limited than those captured by the RSR, limited to race and ethnicity, gender (as in RSR), and for the *ADAP Quarterly Report*, percentage of clients with an annual household income less than 200 percent of the FPL. The ADR includes year of birth and insurance status or type, as well as income as a percentage of the FPL.

As a stand-alone data system, the ADAP reports are of limited usefulness in providing the data needed to estimate the indicators identified by the committee for tracking the provision of HIV care and mental health, substance use, and supportive services in the United States. However, ADAP data may prove useful for assessing waiting time for access to ART drugs and the proportion of people who need, but do not have access to, ART. The committee supports HRSA's intention to merge the client-level data from the RSR and the ADR into a single system.

Ryan White HIV/AIDS Program data are an important source of information for monitoring access to quality HIV care and supportive services because of the population represented and the importance of the program in providing care and services to many disadvantaged populations. By increasing health insurance options and extending Medicaid coverage to nondisabled individuals who meet the expanded income criteria, implementation of the ACA is expected to reduce the dependency of a portion of current Ryan White HIV/AIDS Program clients on the program to meet their health care service needs, although the Ryan White HIV/AIDS Program likely will continue to serve an important role in providing HIV care to individuals who remain uninsured. Reduction in the use of Ryan White funds for medical care would permit the redirection of funds to other vital Ryan White–funded services. The Ryan White HIV/AIDS Program has an established role in providing a comprehensive array of services beyond medical care, including medical case management and treatment adherence counseling, mental health and substance abuse treatment services, oral care, food assistance, medical transportation, and psychosocial support (IOM, 2011, p. 20). Increased emphasis on such services through continued funding of the Ryan White HIV/AIDS Program and decreased demand for medical care among clients would continue to advance the goals of the NHAS in important ways, for example, by supporting PLWHA "who have challenges meeting their basic needs, such as housing" (ONAP, 2010, p. 21). As one of the few data systems examined by the committee that capture data on housing, food, and medical transportation need, an increase in Ryan White funding available for such supportive services would make it an even more valuable source of data on those services.

Although the population of PLWHA receiving services through the Ryan White HIV/AIDS Program is a large and important one, it is not nationally representative of PLWHA, and use of Ryan White data to estimate the indicators will only permit tracking of the indicators for that group. Another difficulty with Ryan White HIV/AIDS Program data is that data pertaining to medical and supportive services received are reported only when the services were funded with Ryan White dollars. Such services include mental health and substance abuse treatment visits and housing, food, and transportation services. An organization might receive funding from a number of different sources, and if a client were to receive some services funded, at least in part, through the Ryan White HIV/AIDS Program and other services funded exclusively by another source, only the former would be reported to HRSA. Ryan White–funded services vary widely among and within states, depending on how state and local jurisdictions tailor services to meet the needs of local communities (Rawlings and Hopson, 2009). There are persistent dollar-per-case federal allocations to states (Martin and Keenan, 2011), which are associated with the size and scope of ADAP drug formularies (Martin and Barry, 2011). If other sources of state and local funding are used to provide these additional services, they will not appear on the client's record. To obtain a comprehensive picture of access to needed services within the Ryan White HIV/AIDS client population, it would be helpful to have information on all pertinent services received by clients regardless of funding source, as is the case for clinical data. The clinical information reported by providers who receive Ryan White HIV/AIDS Program funding includes all of the data requested for each Ryan White HIV/AIDS Program client, regardless of how the service was paid for and who delivered it. Thus, all of a given client's outpatient or ambulatory care visit dates, CD4 and viral load counts, and the like within the reporting period are included.

Along with MMP, the RSR is one of two data systems to provide information on the need for and utilization of supportive services for housing, food, and transportation, as well as HIV medical care and mental health and substance use services.[15] The data's usefulness is limited by the reporting only of those supportive services that are funded through the Ryan White HIV/AIDS Program. Just as all pertinent clinical data are reported by Ryan White–funded providers for clients regardless of payment source, reporting of complete data for supportive service utilization would provide more robust information for tracking the impact of the NHAS and health care reform on the provision of these services. Absent reporting of all supportive service utilization, an indication of whether clients had received any non-Ryan White-funded services would allow analyses of Ryan White HIV/AIDS Program data to be stratified accordingly.

Medicaid Statistical Information System

Medicaid is the largest safety-net health insurance program in the United States, providing health and long-term care coverage to more than 59 million low-income and disabled beneficiaries (KFF, 2011a). Although PLWHA represent less than 1 percent of the total Medicaid population, in FY 2007 Medicaid provided coverage for 47 percent of PLWHA estimated to be receiving regular medical care: 212,892 Medicaid beneficiaries were HIV infected (Kates, 2011, p. 1). Medicaid is financed jointly by the federal and state governments and represents the largest expenditure on health care coverage for PLWHA when federal and state funds are combined. Together, federal and state Medicaid expenditures totaled $9.3 billion in FY 2011, accounting for 51 percent of federal spending for HIV care (Kates, 2011, p. 1). Medicare accounts for another $5.4 billion (29 percent) of federal funding for HIV care (Kates, 2011, p. 1). Approximately 29 percent of Medicaid beneficiaries with HIV were dually eligible for Medicare in FY 2007 (Kates, 2011, p. 1).

The Medicaid Statistical Information System (MSIS) is the claims processing system for Medicaid, which captures utilization data and management information pertaining to medical care and services provided to Medicaid recipients. MSIS includes the full population of people with HIV/AIDS enrolled in Medicaid in the United States,[16] and, given Medicaid's prominent role in HIV care (covering 47 percent of PLWHA estimated to be in care), it not only captures a significant share of PLWHA but also is a critical source of care and coverage that should be assessed. Currently,

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[15] Housing Opportunities for Persons with AIDS (HOPWA) is a federal program under the U.S. Department of Housing and Urban Development (HUD) that provides short- and long-term housing assistance to PLWHA and their families (HUD, 2011b). HOPWA data, discussed later in the chapter, provide important information on housing needs and services for PLWHA, but are focused primarily on housing.

[16] It does not include information on individuals who are eligible for, but not enrolled in, Medicaid.

to qualify for Medicaid individuals must be low income and be "categorically eligible." 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). The anticipated expansion of Medicaid under the ACA will remove the categorical eligibility requirement and extend eligibility to most people under the age of 65 who have incomes less than 133 percent of the FPL (Kates, 2011, p. 4). The resulting increase in Medicaid's role in covering care for PLWHA makes MSIS a particularly important source of data for tracking the impact of the ACA on HIV care.

States are required to report Medicaid beneficiary and claims data quarterly to the Centers for Medicare and Medicaid Services (CMS) through the Medical Management Information System (MMIS).[17] These data, which include demographic and monthly enrollment data for each person covered by Medicaid in the quarter (eligible files) and adjudicated claims data (paid claims files), are captured in MSIS. Claims files are categorized by inpatient, long-term care, prescription drug, and noninstitutional services and include data on types and dates of services, providers, costs and types of reimbursement, and epidemiological variables (CMS, 2011c).

MSIS data are available in two forms: MSIS files and Medicaid Analytic eXtract (MAX) files. MSIS files are organized quarterly for the federal fiscal year (October–September) and by transaction or claims adjudication date. They cover all enrollment transactions, including retroactive enrollment and corrections, as well as all interim claims records, including originals, voids, credits, debits, and the like. MAX files contain data extracted from the MSIS files and formatted to facilitate research and public policy needs. They are organized chronologically by calendar year, based on date of service, and MSIS claims records (initial, interim, voids, and adjustments) are combined or consolidated to generate final records for specific services covered by Medicaid as accurately as possible (CCW, 2011c; CMS, 2011a,d). MAX files include a person summary file, as well as inpatient hospital, long-term care, prescription drug, and other services files.[18]

MAX files are available to approved academic researchers and certain government agencies through the CMS Chronic Condition Data Warehouse (CCW). MAX files currently are available for 1999 through 2008, although 2008 data are not yet available for all states (ResDAC, 2011a).[19] MSIS files

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[17] CMS plans to move to monthly collection of data within 2 years (CMS response to IOM request for information, April 8, 2011).

[18] More detailed descriptions of MSIS and MAX files, and the differences between them, are available from CMS (2011d). See also RESDAC (2011b), CCW (2011b), and CMS (2010).

[19] Data are currently missing for Hawaii, Missouri, North Dakota, Pennsylvania, Utah, Wisconsin, and the District of Columbia, although these data were expected to be available on or about October 31, 2011 (CMS, 2011a).

are available through FY 2009 (48 states) and for 22 states for FY 2010 (CMS, 2011b). Although most states complete their reporting within a year, not all do, resulting in about a 2-year lag time for MSIS data files. The lag time is somewhat longer (2.5-3 years) for MAX data files because the raw MSIS data must be extracted and consolidated (CCW, 2011c). A built-in lag of at least 13 to 14 months is needed to ensure that claims for most services delivered in a given calendar year are captured, and another 9 to 10 months are needed to validate and process the data (ResDAC, 2011b).[20]

Advantages of MSIS as a source of data for HIV care include the large number of HIV-infected individuals represented (although enrollees with HIV are identifiable only if they have a diagnosis for HIV entered in the system); strong representation of "vulnerable populations," including racial and ethnic minorities; regular collection of data over time (currently quarterly, moving to monthly within 2 years [CMS response to IOM request for information, April 8, 2011]), linkage of data to unique personal identifiers, and an existing data processing and data retrieval structure. In addition, diagnostic and treatment information is reported by providers, which may reduce inaccuracies inherent in patient self-report, although nonclinical factors can affect provider reporting also. For example, changes in disease recognition, treatment, and prescription patterns, as well as billing or reimbursement considerations, may have an impact on provider reporting (Crystal et al., 2007). Inaccurate reporting (errors, coding variation, designation) is another nonclinical factor that can affect the accuracy of the data available from MSIS or MAX. MSIS and MAX data include eligibility and claims data and limited demographic data. As is the case with all claims databases, information is available to chart "quality of care" based solely on medical service and medication utilization. Dates of service, diagnosis and procedure codes, and provider codes are available, but core outcome measures such as CD4 and viral load test results are not. Some negative outcome indicators would be available, such as treatment for an opportunistic infection or mortality, based on date of death. Assessment for mental health treatment needs or medical comorbidities would be indicated only if a diagnosis code appears in the case file to justify treatment or medication. Appendix Tables 3-2a through 3-2e summarize which data elements of interest to the committee are captured in MSIS.

One challenge of using MSIS or MAX data is identification of the population of PLWHA who are Medicaid beneficiaries. Variations in diagnostic and other service coding may adversely affect the usefulness of any particular group of codes for accurately identifying the Medicaid population with a given condition. Therefore, use of a combination of diagnosis

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[20] Although 22 to 24 months has been reported as the minimum lag time for MAX data (RESDAC, 2011b), it appears that 30 to 36 months may be more realistic.

codes (for HIV/AIDS), common procedure codes (CD4 counts; HIV RNA tests), and prescription drug codes (ARVs) is likely the best way to identify the maximum number of PLWHA among Medicaid recipients with the greatest positive predictive value (see Crystal et al., 2007; Koroukian et al., 2003). Difficulties other than those related to coding also limit the ability to identify the full population of PLWHA within Medicaid. The fluctuating eligibility of some beneficiaries causes those individuals to move in and out of coverage during the course of a year, meaning any medical care they receive in the period during which they are not covered is not captured by Medicaid claims data. Dual eligibility with Medicare also causes claims covered by Medicare not to be captured in Medicaid data. Each of these situations makes it probable that MSIS or MAX data on encounters will not provide a complete accounting of medical services received by individuals in the group (Koroukian et al., 2003). Not only may some Medicaid recipients with HIV not be identified at all, but a number of others within these groups will have incomplete encounter data in MSIS, resulting in an underestimation of the indicators for the population of Medicaid recipients (Crystal et al., 2007).

Similar to the cases in which Ryan White HIV/AIDS Program data include only Ryan White–funded services, even if the MSIS data were complete and accurate, state variation in covered services beyond a set of "mandatory" services required to receive matching federal funds and service payment structure (fee-for-service versus prepaid plans) would mean those data still would not provide a complete accounting of service utilization by individual recipients. For example, MSIS may include data pertaining to a given type of service for some beneficiaries (those residing in a state in which the service is covered) but not capture data on the provision of the same type of service for Medicaid beneficiaries residing in a state where the service is not covered. In addition, states may place limits on the number of occurrences (prescriptions, inpatient days, provider visits) that Medicaid will cover. In both types of case, Medicaid claims data will not provide a complete picture of service utilization by individual beneficiaries.

In other cases, MSIS data may not be complete or accurate. Fee-for-service plans generate fairly complete utilization data because reimbursement depends on filing a claim for each covered service. However, in FY 2007, 71 percent of Medicaid beneficiaries with HIV received some covered services through managed care plans (Kates, 2011). Although states are required to report utilization for beneficiaries in prepaid plans (HMOs, preferred health plans), the accuracy and completeness of these data are suspect (CCW, 2011c; Crystal et al., 2007). Both situations (variations in Medicaid coverage, incomplete or inaccurate Medicaid data) may result in incomplete service utilization data being available from MSIS on specific individuals. Identification of the most common service providers for individuals with variable Medicaid eligibility or of services not covered by Medicaid (e.g., Ryan White HIV/AIDS Program) would permit use of data from these additional sources to gain a more complete measure of the full set of services received by these individuals. Likewise, combined Medicare and Medicaid data for individuals dually eligible for both programs also would provide a more complete picture of service usage. As discussed in Chapter 6, although combining data from multiple data systems to generate a more complete measure of service utilization for the purpose of estimating the recommended indicators is a theoretical ideal, doing so in practice poses numerous statistical challenges.

Demographic data of interest are limited to date of birth, date of death, gender (male, female), race and ethnicity, and zip code. MSIS also collects limited information on private payer status. Income (as a percentage of the FPL) is an optional field, although information about income level could be inferred based on eligibility criteria. Also, data are collected on whether the beneficiary received Temporary Assistance for Needy Families benefits during the month. MSIS links data to unique individual identifiers (either MSIS generated or Social Security number, depending on the state), so that information may be tracked across time for individuals, permitting evaluation of their longitudinal care experiences to the extent permitted by claims data. The demographic data collected would permit assessment of indicators for racial and ethnic subgroups of interest, as well as subgroups based on location of residence and payer status. Since data on sexual orientation are not collected, MSIS data do not permit estimation of the indicators for the NHAS-targeted subgroup of gay and bisexual men, although separate assessments could be made for men and women with data based on sex. With respect to the core indicators of HIV care, MSIS could be expected to provide the data needed to assess the indicators pertaining to continuity of care and regular CD4 and viral load testing, based on claims submitted for office visits with HIV listed as one of the diagnosis codes and claims submitted for CD4 and viral load tests, all of which capture dates of service (see Appendix Table 3-3a). However, any services received by an individual that were not reported to CMS would not be included in MSIS, resulting in gaps in the information available. MSIS captures date of death and so could provide data to calculate the mortality rate within its population of PLWHA.

MSIS captures neither the date of HIV diagnosis nor the date of first visit for HIV care; thus it cannot be used to assess the linkage-to-care indicator. Also, since MSIS does not capture clinical data, such as the results of CD4 counts and viral load tests, it cannot independently provide the information needed to assess the remaining core indicators of clinical HIV care, even though it collects data on the prescription and (re)fill dates for ART drugs, when claims are submitted.

MSIS captures data pertaining to screening and visits for mental health and substance use services covered by Medicaid, but it does not specifically capture the dates of (hence, the time between) diagnosis or referral and first visit for services. With regard to supportive services, MSIS collects data on the provision of social work or case management services, but specific information pertaining to housing, food, and transportation needs is not captured (see Appendix Tables 3-2b, 3-3b).

For the additional indicators (see Appendix Tables 3-2c, 3-3c), MSIS could provide data to assess the clinical HIV care indicators relating to TB, sexually transmitted infections (STIs), and hepatitis B and C screenings, along with influenza, pneumococcal pneumonia, and hepatitis B immunizations, although clinical information about whether the TB test results were interpreted or hepatitis B immunity was documented would not be available. Data would also be available to assess the indicators pertaining to drug resistance testing and the proportion of HIV-infected pregnant women on ART, although pregnancy status would have to be extrapolated from related diagnostic or service codes. Data to assess indicators relating to timely diagnosis of HIV infection and those involving clinical markers for ART initiation would not be readily available.

Despite the importance of data from the Medicaid population for tracking the impact of the NHAS and the ACA on HIV care, MSIS and MAX data have some limitations. As previously noted, the lag time from service utilization to reporting completion (especially for MAX data) may be problematic for time-sensitive policy evaluation. In addition, Medicaid data alone may not provide a complete accounting of service utilization by beneficiaries who receive services from multiple funding sources, and strategies must be employed to help correct for that additional encounter data. Stephen Crystal and colleagues (2007) list some “best practices” for working with Medicaid data. Development of methods for combining data from or analyzing data across additional relevant data systems (e.g., Medicare, Ryan White HIV/AIDS Program) might provide more complete information on service utilization for individuals receiving services through two or more of the programs. One such effort is the database of linked Medicaid and Medicare data developed by CMS in 2009, which contains service utilization and expenditures data for 9 million dually eligible beneficiaries (CHCS, 2010). CCW assigns a unique beneficiary identification number for the MAX and Medicare records of dually eligible beneficiaries to permit tracking and analysis of data across programs (CCW, 2011c, p. 4).

Chronic Condition Data Warehouse

Although not representing as large a patient population as Medicaid, Medicare accounted for 29 percent of federal spending on HIV in FY

2011 (Kates, 2011), the largest source of federal spending on HIV care.[21] Medicare is a federal program providing health care coverage to disabled individuals and those age 65 and older. Approximately 100,000 Medicare beneficiaries are HIV-infected, representing about 20 percent of HIV-infected individuals estimated to be receiving care in the United States (KFF, 2009a). The majority of PLWHA currently receiving Medicare qualified through the disability pathway. With the evolution of HIV into a chronic condition, many PLWHA are living longer and increasingly are expected to qualify for Medicare on the basis of age, resulting in an increase in the number Medicare beneficiaries with HIV. Given Medicare's Part D prescription drug coverage and the increasing number of Medicare-eligible PLWHA, Medicare plays an important role in HIV care coverage.

The CCW contains fee-for-service[22] claims data for 100 percent of Medicare beneficiaries from 2005 to 2009[23] and Part D drug event data from 2006 to 2009 (CCW, 2011a, About). As such, it includes fee-for-service utilization data for all PLWHA who are enrolled in the Medicare program. To expedite delivery and maximize cost efficiency, data sets are available for predetermined cohorts representing 21 chronic conditions. Although HIV/AIDS is not presently one of the predefined cohorts, it currently is under consideration for addition to the list of flagged conditions (CCW, 2011a, Chronic Conditions).

Medicare uses a unique beneficiary identification number and collects the basic demographic data of interest: date of birth, date of death, OMB-defined race and ethnicity, gender (male, female), and zip code. The Medicare Current Beneficiary Survey (MCBS) of a representative national sample of Medicare beneficiaries is used to generate two files (Access to Care; Cost and Use) each year. The Access to Care file "contains summaries of use and expenditures for the year from Medicare files along with survey data on insurance coverage, health status and functioning, access to care, information needs, satisfaction with care, and income" (CCW, 2011b, p. 10). Although MCBS data are not automatically linked to Medicare beneficiary identification numbers, information is available upon request to permit MCBS data to be merged with other CCW data at the beneficiary level. Medicare also requires assessments for beneficiaries receiving care in nursing facilities, inpatient rehabilitation facilities, and home care. These assessments provide data on certain aspects of beneficiaries' health status, as well as other relevant information (e.g., the safety and sanitary condition of the individual's

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[21] Federal spending on Medicare is greater than that on Medicaid (if the state share is not included) and the Ryan White HIV/AIDS Program (KFF, 2011b).

[22] Most services for Medicare recipients in managed care are not captured in the CCW.

[23] The CCW also contains data on a random 5 percent sample of Medicare beneficiaries for 1999 forward.

home for those receiving home care) and likely will increase in importance as the population of PLWHA ages and individuals with HIV enter home and institutional nursing care in greater numbers.

As a source of claims data, Medicare is similar to Medicaid in terms of the data available to assess the core indicators of HIV care. It should be able to inform indicators related to continuity of care, regular CD4 and viral load testing, and mortality rate, but it does not contain the information necessary to evaluate the linkage-to-care indicator or the clinical data needed to assess the other core HIV care indicators. ART drug prescription and (re)fill data are available for Medicare Part D beneficiaries. The availability of Medicare data to assess the additional indicators for HIV care is similar to that of MSIS data as well.

Although Medicare does not have data on screening for mental health disorders or substance use, it does capture service utilization data on the diagnosis of and covered treatment for these conditions, but as with Medicaid, the data do not specifically permit calculation of the time between treatment referral and receipt of services. Medicare does not collect data on housing, food, or transportation needs, although questions pertaining to housing adequacy are included in the assessment for home health beneficiaries (OASIS).

As previously noted, efforts to link Medicare and Medicaid data for dually eligible beneficiaries will provide a more complete picture of service utilization for that group of individuals. In addition, inclusion of HIV/AIDS in the list of predetermined chronic condition cohorts for which CCW data sets are available should expedite delivery of these data for research and policy use.

North American AIDS Cohort Collaboration on Research and Design

The North American AIDS Cohort Collaboration on Research and Design (NA-ACCORD) captures data from 22 single and multisite clinical and classical epidemiologic HIV cohorts, which represent most of the HIV/AIDS cohort studies in North America, including the CFAR Network of Integrated Clinical Systems (CNICS) and the HIV Research Network (HIVRN) discussed in the following sections. Although NA-ACCORD includes data from CNICS and HIVRN, not all of the data elements captured by those systems are represented in NA-ACCORD.

NA-ACCORD collects data on more than 100,000 HIV-infected adults from more than 60 academic research and hospital- and community-based clinical sites throughout the United States (44 states and the District of Columbia) (Kitahata, 2011; NA-ACCORD, 2011; NA-ACCORD response to IOM request for information, March 30, 2011). NA-ACCORD is designed to be widely representative of HIV care in the United States,[24] and the population of PLWHA represented is similar to that reported by the CDC in terms of age and sex, but it includes somewhat fewer minorities[25] (Kitahata, 2011; NA-ACCORD response to IOM request for information, March 30, 2011).

NA-ACCORD data pertaining to the core clinical HIV care indicators include date of diagnosis (although these data are not complete); date of first visit at the clinical site and whether the individual was previously seen at another site (but not always the date of first-ever visit for HIV care); dates of routine HIV care visits; CD4 and viral load test dates and results; dates that individual ARVs were started or stopped; year of birth; and mortality information (date and cause of death) (Appendix Tables 3-2a, 3-3a). For the additional indicators of clinical HIV care, NA-ACCORD also includes dates of ART drug resistance testing; diagnoses of AIDS-defining conditions; diagnoses of and/or laboratory results relevant to renal disease (nephropathy), hepatitis C, and hepatitis B; dates of hepatitis C and hepatitis B screening; and dates of TB testing (Quantiferon-TB tests). As of 2012, NA-ACCORD collects information on pregnancy status. NA-ACCORD does not currently collect dates of screening for chlamydia, gonorrhea, and syphilis or dates of vaccination or immunization for hepatitis B, influenza, or pneumococcal pneumonia (see Appendix Tables 3-2c, 3-3c).

Information on diagnosis or referral for mental health disorders and substance abuse is included in NA-ACCORD, but not data on screening for those disorders or on first visit for mental health or substance abuse treatment, although it will capture visits for psychiatry, psychology, and counseling, beginning in 2012. NA-ACCORD does not include data pertaining to housing stability, food security, or access to transportation but could add such data to the extent they are collected by social workers in the clinical practice setting (Appendix Tables 3-2b, 3-3b).

Demographic information available in NA-ACCORD includes age, sex, race and ethnicity, and the first three digits of zip code, as well as metropolitan statistical area (MSA), and, as of 2012, country of birth. Data on

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[24] Since urban areas are heavily represented among the cohorts, NA-ACCORD may not be representative of the care experience of PLWHA in rural areas.

[25] A comparison of 2007 data for NA-ACCORD and the population of PLWHA indicates that NA-ACCORD had a lower proportion of non-Hispanic blacks (40 percent versus 46 percent) and Latinos (14 percent versus 20 percent), as well as a higher proportion of non-Hispanic whites (41 percent versus 32 percent) (Kitahata, 2011). Older (2005) data reported for the NHSS (33 states and U.S. dependent areas with confidential name-based reporting) and NA-ACCORD for HIV transmission risk factors suggest that, at the time, NA-ACCORD had a lower proportion of men who have sex with men (33 percent versus 44 percent) and a higher proportion of injection drug users (27 percent versus 20 percent) and individuals infected through heterosexual contact or other means (40 percent versus 30 percent). (See CDC, 2007, Table 8; Gange et al., 2007, Table 3.)

sexual orientation, gender identity, income, and insurance status are not collected. (See Appendix Table 3-2d.)

Data collected by NA-ACCORD can be used to estimate all of the core indicators of clinical HIV care. The data system is less useful for estimating the additional clinical care indicators and much less so for indicators pertaining to mental health, substance abuse, and supportive services. A strength of NA-ACCORD is that new data elements can be added relatively easily if they are collected by the participating cohorts.

CFAR Network of Integrated Clinical Systems

The CFAR Network of Integrated Clinical Systems comprises a network of eight Centers for AIDS Research (CFAR) sites[26] that have implemented point-of-care electronic data collection systems. CNICS data are collected prospectively through these systems on PLWHA in care at the site and, therefore, characterize the rapidly changing course of HIV disease management. The CNICS cohort includes more than 23,000 individuals and represents a diverse population of patients with regard to sex, race, ethnicity, age, risk factor for HIV transmission, and geographic distribution, although the CFAR sites are located in urban areas and the data may not be representative of PLWHA in rural areas (CNICS, 2011, CNICS sites; Kitahata, 2011).

CNICS currently maintains data on 10 unique domains: (1) disease diagnoses; (2) laboratory data (viral load, CD4 count, viral hepatitis, hematologic, kidney, and chemistries or metabolic markers); (3) medication data; (4) demographics (sex, race and ethnicity, age, and risk factor for HIV transmission); (5) health care utilization (initial patient enrollment, primary care visits, and hospitalizations); (6) vital status (death date, source, and cause of death); (7) patient-reported outcomes[27]; (8) antiretroviral drug resistance; (9) biological specimens; and (10) census block data (CNICS, 2011, Data elements).

According to the project website, an important distinction between

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[26] These are Case Western Reserve University; University of Alabama at Birmingham; University of California, San Francisco; University of Washington; University of California, San Diego; Fenway Community Health Center of Harvard University; University of North Carolina; and Johns Hopkins University. Although the Johns Hopkins University site is no longer CFAR-funded, it has continued to collaborate with other CNICS sites.

[27] Most sites collect patient-reported outcomes data from consenting patients using touchscreen tablets or PCs that are connected to a wireless network. Data are captured on depression and anxiety; adherence; smoking, alcohol, drug use; HIV transmission risk behaviors; symptom burden; physical activity level; body morphology; and quality of life. As of August 2010, there were approximately 8,000 completed assessments in the central database (CNICS, 2011, Data elements).

CNICS and other cohorts is the ability to provide peer-reviewed open access to data for research from a system that prospectively collects comprehensive patient data including validated outcomes, longitudinal resistance data, and PROs (CNICS, 2011).

CNICS includes much of the data needed to calculate the core clinical HIV care indicators (Appendix Tables 3-2a, 3-3a), including dates of first and ongoing visits for HIV care, CD4 and viral load test dates and results, and dates of starting and stopping specific ARVs. Information on date of diagnosis is collected by CNICS, but these data are not available for some individuals. For the additional clinical HIV care indicators (Appendix Tables 3-2c, 3-3c), CNICS collects data on diagnosis of AIDS-defining conditions; hepatitis B and C; chlamydia, gonorrhea, and syphilis screening; ART drug resistance testing; and diagnosis of renal disease. Data also are collected on TB testing using QuantiFERON-TB tests. As of 2012, data on pregnancy status is collected, and collection of immunization information for hepatitis B, influenza, and pneumococcal pneumonia is proposed. If all these data are collected, CNICS will capture the data needed to estimate all of the core and additional indicators for clinical HIV care.

CNICS also collects certain data on mental health and substance abuse disorders, including dates of screening and diagnosis or referral. Although CNICS does not specifically capture the date of first visits for mental health treatment services, it does capture visits for psychiatry, psychology, and counseling. Since it also captures date of screening, a proximate visit for services would suggest date of first visit, but it would not be flagged as such. CNICS captures whether an individual received substance abuse treatment in the past year, but not specific dates of service. CNICS does not currently include data on housing, food, and transportation needs assessment or status, but data on housing stability (stable or permanent, temporary, unstable, and homelessness) are collected in the clinical practice setting and could be added to CNICS (CNICS response to IOM request for information, April 11, 2011).

Demographic data captured in CNICS include age, sex, race, and ethnicity. Data on sexual orientation and gender identity are not currently collected. CNICS collects MSA of residence and is adding the three initial numbers of individuals' zip codes, which provide state and at least county of residence, as permitted by the Health Insurance Portability and Accountability Act. Country of birth is collected beginning in 2012. Insurance status is collected, and income data are collected and could be added to CNICS. PROs provide an opportunity to collect qualitative data on satisfaction with provider care and on stigma or discrimination, as well as other information of interest, including food security and transportation needs.

HIV Research Network

The HIV Research Network compiles data electronically from health records and through manual medical record review in order to obtain, analyze, and disseminate current information on the delivery of services to PLWHA. HIVRN captures these data longitudinally to assess trends in areas such as accessibility, quality, utilization, safety, and costs of HIV-related health care services. HIVRN is primarily supported by the Agency for Healthcare Research and Quality with additional support from other agencies of the U.S. Department of Health and Human Services (HHS).

HIVRN represents a consortium of 16 academic and community-based sites that provide primary and subspecialty HIV care in 13 cities throughout the United States, with 8 in the eastern United States, 1 in the Midwest, 3 in the South, and 4 in the West (HIVRN, 2011). Data are collected annually on the clinical and demographic characteristics of approximately 21,000 adults, adolescents, and children receiving HIV care at the participating sites (HIVRN response to IOM request for information, March 30, 2011). (Five of the sixteen sites are devoted to pediatric care.) The data from each site are sent to the data coordination center at the Johns Hopkins School of Medicine, where they are consolidated into a single uniform database.

HIVRN data can be used to estimate all of the core clinical HIV care indicators identified by the committee. In addition, data for estimating the core indicators for mental health and substance abuse are available for a subset of the participating sites. HIVRN does not collect data on the dates of screening for mental health or substance abuse disorders, nor does it collect any data pertinent to the committee's core or additional indicators for housing, food security, or unmet need for transportation. As with NA-ACCORD and CNICS, HIVRN data are collected from urban areas and may not be representative of PLWHA in rural areas.

Clinical Case Registry: HIV

The Veterans Health Administration within the Department of Veterans Affairs is the largest provider of HIV care in the United States, serving more than 24,000 veterans with HIV in 2010 (VA, 2011). The Clinical Case Registry (CCR): HIV is an administrative and clinical database containing population-based data on HIV-infected individuals who receive care through the VHA.[28] Local reporting allows clinicians with access to the database to monitor clinical outcomes and resource utilization. The national database permits quality of care, as well as outcomes and utiliza-

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[28] A second CCR collects data on veterans with hepatitis C who receive care in the VHA system.

tion, monitoring. Data on all veterans with a confirmed diagnosis of HIV/AIDS in VHA care during the calendar year are included in the database. The sample is limited to those veterans who receive care within the VHA system and is older and predominantly male, compared with the overall population of PLWHA in the United States (VHA response to IOM request for information, April 11, 2011).

The VHA has a sophisticated EHR system that captures utilization and outcomes data. Data needed to calculate all of the core clinical HIV care indicators and most of the additional clinical care indicators are available from the EHR if the services are performed within the VHA system (Appendix Tables 3-2a, 3-2c, 3-3a, 3-3c). Date of diagnosis, CD4 count at diagnosis, and date of first visit for HIV care are all available for individuals diagnosed and treated within the VHA, but for those who transfer into the system following diagnosis, data on linkage to care and stage of disease at diagnosis are not available. Information on prescriptions and refills written by VHA providers is available as are dispensing data for prescriptions (re)filled through the VHA pharmacy system.

Although prenatal care is covered by the VHA, prenatal care services are provided outside the system by community providers. Although the VHA EHR does not capture data from external providers, the information pertaining to ART prescription for pregnant women would be available for prescriptions filled through the VHA pharmacy system.

Data pertaining to screening for mental health disorders and substance use are not captured in the VHA data system (VHA response to IOM request for information, April 11, 2011), but it does include data on diagnosis of or referral for mental health and substance abuse disorders, as well as date of first visit for treatment services if they occur in the VHA. Data pertinent to the supportive services indicators are not collected, although some data pertaining to social work or case management are captured. (Appendix Tables 3-2b, 3-3b). Demographic data collected include age, sex, race, ethnicity, and address. Data on gender identity, sexual orientation, income, insurance status, and country of birth are not collected. (See Appendix Tables 3-2d, 3-2e.)

As an EHR, the VHA data system contains comprehensive clinical data on test and treatment services provided within the system, including prescription and pharmacy dispensing data, although information on services provided outside the system is not reliably captured.[29] As an integrated health care system, the VHA is well poised to respond to challenges raised by the NHAS, as demonstrated by its recent efforts to implement routine

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[29] A uniform notation in the EHR indicating whether a patient reports having received health care services outside of the VHA system could facilitate research on health care services provided by the VHA.

HIV testing. Although the population of PLWHA served by the VHA is disproportionately male and older compared to the national population of PLWHA, recent collaborative efforts between the VHA and Kaiser Permanente (KP) (discussed in the following section) may be the first step in addressing concerns about representativeness.

Kaiser Permanente

Kaiser Permanente is one of the largest not-for-profit health plans in the United States, providing coverage to more than 8.7 million members in nine states and the District of Columbia (KP, 2011). Health outcome and utilization data are collected on all members through EHRs and databases. The second-largest private provider of HIV care in the United States in 2006, with more than 16,000 HIV-infected individuals in care, KP data represent a diverse population of individuals with private insurance in California, Hawaii, and selected metropolitan areas, including Baltimore, Maryland; Washington, DC; and Atlanta, Georgia. Analyses have shown that KP is representative of the HIV-infected population in California (KP response to IOM request for information, March 30, 2011), a state with more than 6.5 million KP members (KP, 2011), and as the largest provider of HIV care in Hawaii, KP is representative of the population there as well (KP response to IOM request for information, March 30, 2011).

KP has a sophisticated EHR system that facilitates the capture and retrieval of detailed clinical data. A major benefit to a robust EHR system is the availability of data on both service utilization and clinical outcomes. KP captures all of the data elements necessary to assess the core indicators of clinical HIV care, although the date of HIV diagnosis is only captured for individuals diagnosed within the KP system (Appendix Tables 3-2a, 3-3a). Thus, the linkage-to-care indicator can be calculated reliably only for those in the system at the time of diagnosis. KP also captures the data needed to assess the additional indicators for clinical HIV care (Appendix Tables 3-2c, 3-3c). Data on the prescription of ART drugs are available, as are most pharmacy (re)fill data. No data are available on prescriptions (re) filled at pharmacies outside of the KP system.

KP also records data on screening for mental health disorders and substance abuse, although the screenings are performed as indicated and not according to a predetermined schedule. Data on referral for services for mental health disorders and substance abuse are included in individuals' EHRs, as are data on receipt of treatment services that are provided within the KP system. Data relevant to supportive services indicators are not routinely collected within the KP system.

As an integrated health care system with a comprehensive EHR system, KP, like the VHA, captures comprehensive clinical test and treatment data for services provided within the system. Although the population of PLWHA served by KP is not nationally representative, it is representative of the privately insured HIV-infected population in areas of the United States with access to Kaiser (Hawaii; California; Oregon; Mid-Atlantic region, including the District of Columbia; Atlanta, Georgia).

In December 2009, KP and the VHA launched a pilot project in San Diego, California, for electronically sharing EHR files of individuals who receive care from both systems with patient permission (KP, 2009). Now part of the Nationwide Health Information Network Exchange project (NwHIN Exchange, 2011), this type of data sharing not only should improve patient care but also could permit the capture of similar types of data from a larger and more diverse population than those represented by the individual participating systems.

National Vital Statistics System

Most of the data systems reviewed by the committee collect date of death. In particular, the NHSS would serve as the most nationally representative source of data for estimating the committee's recommended mortality indicator: all-cause mortality rate among PLWHA. As indicated in Chapter 2, the committee selected all-cause mortality for the indicator because of the inherent difficulties in determining and recording in every instance whether deaths among PLWHA were related to the disease or another cause. Mortality rate due to HIV nevertheless may be a useful measure for some purposes. In such cases, the National Vital Statistics System (NVSS) is the best source of data for estimating mortality related to HIV infection. Although some of the data systems examined by the committee, such as NA-ACCORD, record information on cause of death, the NVSS regularly calculates HIV mortality. NVSS operates under the auspices of CDC's National Center for Health Statistics, which collects vital statistics data through contracts with the registration systems in jurisdictions that are legally responsible for recording vital events, such as births and deaths (NVSS, 2011a). Mortality data from the NVSS provide uniform, nationwide demographic, geographic, and cause-of-death information for individuals who die in the United States (NVSS, 2011b). Standard forms (e.g., death certificate) and model procedures are developed and recommended for nationwide use to promote the collection of uniform national data. The death certificate requires a single immediate (final) cause of death and allows for as many as three underlying causes of death to be listed sequentially (CDC, 2011c). Although reporting errors of various types may occur for cause of death, CDC provides extensive information on writing cause-of-death statements for death certificates (NVSS, 2011c). Preliminary HIV mortality data currently are available for 2009 (Kochanek et al., 2011).

ADDITIONAL DATA SYSTEMS FOR MONITORING HIV CARE

The committee identified three additional systems that provide data to help evaluate the impact of the NHAS and the ACA on HIV care and access to supportive services for PLWHA in the United States. The Indian Health Service (IHS) and the Federal Bureau of Prisons (BOP) have data systems that capture health care data for two small but important subpopulations of HIV-infected individuals: American Indians and Alaska Natives (AI/ANs) and federal prisoners. The Housing Opportunities for Persons with AIDS (HOPWA) program collects data pertinent to the program's funding of assistance for housing and other supportive services for its beneficiaries.

Resource and Patient Management System

Nationally, AI/ANs represent less than 1 percent of PLWHA (between 3,039 and 3,083 individuals in 2009) (CDC, 2012, Commentary, Table 15a). Yet, AI/ANs are disproportionately burdened by the epidemic in several ways. The rate of HIV diagnoses among AI/ANs was 9.7 (per 100,000) in 2010, compared with 6.5 for Asians and 7.3 for whites (CDC, 2012, Table 1a).[30] Compared with other racial and ethnic groups, AI/ANs also have one of the shortest timelines from AIDS diagnosis to death (CDC, 2012, Commentary, Table 14a; Hall et al., 2005). Impoverishment and conditions such as alcoholism and diabetes that occur at higher rates among AI/ANs (Chartier and Caetano, 2010; IHS, 2008) may complicate care and adherence to treatment.[31] The IHS is the federal agency responsible for providing comprehensive health care services to approximately 2.0 million AI/ANs representing 566 federally recognized tribes (IHS, 2012). Most IHS facilities are primary care clinics. Two IHS-funded hospitals together treat the majority of HIV patients in the lower 48 states (Personal communication, Lisa Neel, Indian Health Service, October 13, 2011). Combined with an additional two sites, these facilities account for 61 percent of the IHS HIV/AIDS case load (Personal communication, Lisa Neel, Indian Health Service, October 13, 2011). Although some IHS clinics provide limited HIV care services, most refer their HIV clients to outside providers for HIV care (GAO, 2007; IHS response to IOM request for information, March 28, 2011). As of June 2011, there were 289 HIV/AIDS patients on record at federal IHS health care service sites, of which 224 were "active," having received CD4 and viral load testing within the preceding 12 months. Patients receiving care in tribally operated and urban Indian health care programs are not included in

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[30] Black or African Americans and Native Hawaiian and other Pacific Islanders had higher rates of diagnosis (CDC, 2012, Table1a).

[31] In addition, an estimated 25 percent of AI/ANs with HIV infection are undiagnosed (CDC, 2011a).

these numbers due to administrative constraints (Personal communication, Lisa Neel, Indian Health Service, February 29, 2012).

The IHS uses an electronic record system called the Resource and Patient Management System (RPMS) to manage clinical, administrative, and financial information on patients and resources and improve the quality of care provided at federal, tribal, and urban IHS facilities throughout the United States (Cullen, 2006). Data are entered into RPMS by providers during patient visits.[32] An optional automated module within RPMS called the HIV Management System (HMS) may be used by HIV care providers and case managers in the IHS system to capture data related to HIV/AIDS and to assist nonspecialist providers with decision making through the use of clinical reminders, provider guidelines, and quality-of-care audit reports. HMS captures HIV-specific information such as date of HIV diagnosis, CDC classifications, and ART status. Lab, radiology, and pharmacy data are available through linkage with RPMS. HMS also may be used to report HIV/AIDS cases to public health authorities through a state surveillance form and report (Cullen, 2006). HMS was first implemented in 2006, and personnel at 12 IHS facilities had been trained in how to use the system by October 2007 (GAO, 2007). In 2009, it was integrated into RPMS (IHS, 2011a, Home, Tech Support), but HMS usage is not mandatory (IHS, 2011d). Although 283 IHS facilities have downloaded HMS as part of the RPMS update, only the two large hospitals that treat the majority of HIV-infected patients are known to use the system and contribute to its ongoing development (Personal communication, Lisa Neel, Indian Health Service, October 13, 2011).

Another component of the RPMS, called the Clinical Reporting System (CRS), is used for national, local, and area monitoring of clinical performance measures. The CRS draws from local RPMS databases to create printed or electronic reports of clinical performance measures, including HIV screening and HIV quality of care, as well as a number of other conditions (e.g., STI, depression, and alcohol screening) that may be relevant for monitoring HIV care (see IHS, 2011c). According to 2011 guidance on the CRS, HIV screening information is reported nationally (IHS, 2011b,c). Reported information includes data on HIV screening among pregnant women and among patients age 13 to 64 with no recorded HIV diagnosis prior to the report period, broken down by gender and age groups, as well as the percentage of patients with documented HIV screening refusals (IHS, 2011b,c). In addition, information is reported on the percentages of patients with positive, negative, or indeterminate test results and on the

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[32] Although the IHS is a federal agency, tribal data require special permission to access, since the data belong to the tribe and not to the federal government (IHS response to IOM request for information, March 28, 2011).

number of HIV tests given to patients during the report period where the patient was not diagnosed with HIV anytime prior to the screening (IHS, 2011b). HIV screening is also incorporated into a syphilis, gonorrhea, chlamydia, and HIV screening measure where diagnosis of one of these STIs prompts screening for the other three (IHS, 2011b).

CRS also captures HIV quality-of-care data for the user population of patients age 13 and older with at least two direct care visits (i.e., visits within the IHS system) during the report period with HIV diagnosis *and* one HIV visit in the last 6 months (IHS, 2011c). These measures are not reported nationally, however. The quality-of-care measures assessed are (1) the percentage of patients who received the CD4 test only (without HIV viral load) during the report period; (2) the percentage of patients who received HIV viral load only (without CD4) during the report period; (3) the percentage of patients who received both CD4 and HIV viral load tests during the report period; and (4) total numerators 1, 2, and 3 (IHS, 2011c). The first collection period for these variables was July 2010–June 2011 (Personal communication, Lisa Neel, Indian Health Service, October 13, 2011). IHS recently added "newly diagnosed HIV" to CRS, but the measure has not yet been validated (Personal communication, Lisa Neel, Indian Health Service, October 13, 2011).

As with other clinically based EHR systems (e.g., KP, VHA), the IHS collects all of the data needed to calculate the core clinical HIV care indicators for services provided within the IHS (Appendix Tables 3-2a, 3-3a), and the HMS attempts to include historical data about tests and services provided outside of IHS facilities. Similarly, the IHS captures the data pertinent to the additional clinical HIV care indicators (Appendix Tables 3-2c, 3-3c). Even if certain data (e.g., date of influenza vaccination) are not currently captured in the HMS, they may apply to quality measures for other subpopulations (e.g., individuals ages 50 and older, individuals with diabetes) (IHS, 2011c). In addition, data would be captured at the patient level and could be applied to HIV-specific indicators in the future.

Data for calculating the mental health and substance abuse indicators also are captured by the IHS (Appendix Tables 3-2b, 3-3b, 3-3d). Information pertaining to the need for and provision of supportive services may be recorded in the provider narrative section of the EHR. Demographic data collected include age, sex, race, ethnicity, and locality of residence. Data on gender identity and sexual orientation are not routinely collected but might be recorded in the provider narrative section of the EHR.

IHS captures the data necessary for estimating most of the indicators identified by the committee, which could be used to track improvements in HIV care and access within the population of HIV-infected individuals receiving care in IHS facilities. The limited number of IHS facilities providing comprehensive HIV care can affect the size of the HIV-infected population represented in the data system. Facilities that transition from federal to tribal management no longer automatically report data to IHS. In addition, some tribal facilities have moved from IHS to private-vendor EHRs, making data sets incompatible.

Bureau of Prisons Electronic Medical Record

When both state and federal prisons are considered, 21,987 inmates (1.5 percent of total inmates) were HIV infected or had confirmed AIDS as of the end of 2008. Of those inmates, 1,538 were federal prisoners (Maruschak, 2010).

The BOP, which is responsible for ensuring access to health care services for the almost 217,000 individuals incarcerated in federal correctional institutions throughout the United States (BOP, 2011), uses the Bureau of Prisons Electronic Medical Record (BEMR), a point-of-care direct entry web-based system record, to collect health information on inmates housed at 116 federal correctional institutions (BOP response to IOM request for information, April 14, 2011). The BEMR includes a fully integrated pharmacy capability (computerized order entry through prescription administration records, BEMRx) as well as a dental module (DOJ, 2011; Price, 2011). The BEMR tracks CD4 count and viral load for prisoners with HIV/AIDS. Other information contained in the BEMR that may be useful for tracking HIV/AIDS care received by prisoners includes demographic, prescription drug, substance use, and mental health data. The BOP is in the process of enhancing the BEMR by programming key HIV data elements for the extraction and analysis of HIV data that currently are available only in individuals' records (BOP response to IOM request for information, April 14, 2011).

Due to the much larger number of HIV-infected inmates in state prisons, it would be necessary to track HIV care data from the state inmate population as well in order to gain a more complete picture of HIV care within the U.S. corrections system. Gathering and integrating data from the individual state systems poses a significant challenge, however. A 2007 survey of state electronic health initiatives found that although 22 of 42 states responding had implemented some sort of health information technology use in their state prison systems, only 3 states reported the use of EHRs and/or electronic medical records (Smith et al., 2008). Kentucky had implemented an EHR system across all of its state-operated correctional facilities. Virginia had planned implementation of an EHR system for its correctional facilities, and Washington State was exploring the feasibility of a single, integrated EHR for all of its correctional institutions, including state prisons, city and county jails, and juvenile corrections facilities (Smith et al., 2008).

Integrating EHRs across all types of correctional institutions would provide a rich source of data for tracking the provision of HIV care in the incarcerated population. For individuals already diagnosed with HIV, linkage to and maintaining continuity of care and treatment adherence upon release is a significant challenge. Development of methods for capturing data on the provision of transitional services and associated outcomes for HIV-infected prisoners upon release would be important in this regard (Rich et al., 2011).

Housing Opportunities for Persons with AIDS

The HOPWA program, managed by the U.S. Department of Housing and Urban Development's (HUD's) Office of HIV/AIDS Housing, provides funds for housing assistance and other supportive services. The additional supportive services most relevant to the indicators identified by the committee include meals and nutritional services, transportation services, mental health services, and alcohol and drug abuse services, as well as approved health, medical, and intensive care services (HOPWA, 2011a,b). HOPWA programs provide assistance to low-income households with one or more PLWHA along with other members of the household. By the end of FY 2010, HOPWA had provided resources for housing assistance to 60,669 unduplicated households (HOPWA response to IOM request for information, April 4, 2011). The population served by HOPWA is generally representative of low-income PLWHA (HOPWA response to IOM request for information, April 4, 2011).

HOPWA grantees report aggregated data on program performance outcome measures related to maintenance of housing stability, improved access to care and support, and reduced risk of homelessness for low-income persons and their families living with HIV/AIDS. HOPWA Competitive Program grantees submit an Annual Progress Report (APR) and Formula Program grantees submit a Consolidated Annual Performance Evaluation Report (CAPER) measuring performance outcomes.

APR and CAPER (HOPWA, 2011a,b) report information on the number of households with an unmet need for housing assistance,[33] as well as the type of subsidy assistance needed. They also report on the number of households served by HOPWA and other funding sources that provide housing assistance and support to PLWHA and their families and the number of households that received other supportive services through HOPWA funds (e.g., meals or nutritional services, transportation, mental health

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[33] These data are for "the number of HOPWA-eligible households that require HOPWA housing subsidy assistance, but are not served by any HOPWA-funded housing subsidy assistance in [the] service area" (HOPWA, 2011b, p. 8).

services, alcohol and drug abuse services). Aggregate data are reported on the number of PLWHA who qualified their household to receive HOPWA housing assistance, their prior living situation, the number of other PLWHA who reside with the HOPWA-eligible individuals, and the number of persons not diagnosed with HIV who reside with the eligible individuals. The reports also record the number of HOPWA-eligible individuals and other beneficiaries by race and ethnicity, as well as by sex (male, female) and gender (transgender male to female, female to male) within given age ranges. Additional information reported includes number of households that demonstrated "a housing plan for maintaining or establishing stable on-going [sic] housing"; contact with a case manager or benefits counselor as specified in the client's individual service plan; contact with a primary health care provider as specified in the client's individual service plan; access to and maintenance of medical insurance or assistance; and sources of income. The reports also include the number of households receiving assistance by percentage of area median income.

In addition to the aggregate data reported by HOPWA grantees, HUD developed the Homeless Management Information System (HMIS) to store longitudinal standardized individual-level data on persons receiving housing assistance and homeless prevention services through Continuum of Care programs. Program-level data on homeless service usage is reported as well. Aggregate HMIS data provides information about the size, characteristics, and needs of the homeless population at the local, state, and national levels. Although HMIS is not an HIV-specific data system, one of the client-level universal data elements it captures is "disabling condition," which includes AIDS and AIDS-related conditions.

HUD requires the collection in HMIS of a minimum set of data elements from all individuals receiving homeless assistance and prevention services. These data are required to generate unduplicated estimates of the number and basic demographic characteristics of individuals accessing services and patterns of service use. These "universal data elements" include, among others, name, date of birth, race, ethnicity, gender (male, female; transgender male to female, female to male), presence of a disabling condition, residence prior to program entry, zip code of last permanent address, and housing status (HUD, 2010, pp. 40-63). Additional "program-specific" data elements are variously required from specified homeless assistance programs, including those funded through HOPWA. The program-specific data elements include the amounts and sources of income, if any, in the preceding 30 days; receipt of noncash benefits (e.g., Medicare, Medicaid, Supplemental Nutrition Assistance Program); and information on physical and developmental disability, chronic health conditions, HIV/AIDS, mental health, substance abuse, domestic violence, and destination upon program exit (HUD, 2010, pp. 64ff.). Optional program-specific data elements, not required for APR reporting, include employment status, education, general health status, and pregnancy status (HUD, 2010, pp. 93ff.).

The data from HOPWA's APR and CAPER and those captured in HMIS provide important information about access to housing and other supportive services for PLWHA, including an assessment of unmet housing needs for HOPWA-eligible households (i.e., those with income below 80 percent of the area median income and documented HIV/AIDS status) (HUD, 2011a). The unmet needs assessment is limited, however, to those individuals identified as being HOPWA-eligible and may not represent the full scope of need for housing assistance among PLWHA. In terms of access to other supportive services (e.g., nutrition or food, transportation), the data are limited to households receiving HOPWA-funded services and do not reflect need or access to services among other PLWHA.

The collection of longitudinal individual-level data in HMIS permits assessment of patterns of housing service usage and outcomes over time. In addition, a number of the client-level data elements captured may allow for linkage or cross-matching to additional information in other pertinent data systems (e.g., MSIS, CCW, Ryan White HIV/AIDS Program).

SIMILAR DATA COLLECTION EFFORTS

Several additional data collection efforts are under way that will provide useful information for assessing the impact of the NHAS and ACA on HIV care, including CDC's Enhanced Comprehensive HIV Prevention Planning Project, HHS's 12 Cities Project, and the Nationwide Health Information Network Exchange.

Enhanced Comprehensive HIV Prevention Planning Project

Launched in September 2010 in response to the NHAS, the ECHPP Project is a 3-year demonstration project funded by the CDC's Division of HIV/AIDS Prevention. The program targets the 12 MSAs that have the highest AIDS prevalence, cumulatively accounting for 44 percent of cases in the United States (DHAP, 2011).[34] Following the NHAS, the overarching goals of the project are to maximize the impact of HIV prevention strategies in these geographic areas, reduce the incidence of HIV infections, improve the quality of HIV care, and reduce HIV health disparities.

The 12 ECHPP grantees are evenly divided between state or territorial health departments and directly funded local health departments. During

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[34] The 12 MSAs are Atlanta, Georgia; Baltimore, Maryland; Chicago, Illinois; Dallas, Texas; District of Columbia; Houston, Texas; Los Angeles, California; Miami, Florida; New York City; Philadelphia, Pennsylvania; San Juan, Puerto Rico; San Francisco, California.

the first year of the project, each grantee was required to conduct a local situational analysis, taking account of available resources, epidemiologic profiles, priority areas, and cost and cost-effectiveness data for specific interventions and strategies. Based on these analyses, the grantees created a set of goals and strategies that would best aid in the accomplishment of NHAS goals. These enhanced prevention plans, which have been approved by CDC, include interventions and public health strategies designed to prevent new HIV infections and to promote HIV care and treatment. By the end of 2011, the jurisdictions had begun implementing their plans and had submitted funding applications for the second and third years of the project.

Although prevention of new infections is the primary emphasis of ECHPP, seven of its nine required prevention strategies for PLWHA address treatment concerns such as linkage to care, retention or reengagement in care, provision of ART consistent with current guidelines, adherence to antiretroviral medications, STI screening, prevention of perinatal transmission, and linkage to other medical and social services (DHAP, 2011). ECHPP has a comprehensive evaluation plan that incorporates process, outcome, and impact indicators to assess progress in these prevention and treatment areas that will be collected in the 12 MSAs, as well as supplemental data from a subset of the cities (Fisher and Hoyte, 2011).

12 Cities Project

Created by HHS to work in conjunction with CDC's ECHPP initiative, the 12 Cities Project is a demonstration project designed to promote prevention and treatment of HIV in the 12 cities (MSAs) disproportionately affected by the epidemic through cross-agency collaboration and coordination with state and local health departments and other organizations (HHS, 2011b). Ultimately the lessons learned through the 12 Cities Project will help to improve HIV care in other jurisdictions. The project expands upon the foundation laid by ECHPP, engaging additional federal partners and increasing focus on HIV care and treatment. Whereas ECHPP's emphasis is on local plans to improve prevention and care in the 12 jurisdictions, the 12 Cities Project emphasizes better coordination of services and funding of federal efforts to improve HIV prevention and care within the jurisdictions and the development of a common set of measures (indicators), in conjunction with streamlining reporting requirements, to evaluate the efforts with respect to the goals of the NHAS.

Motivated by the need to develop common metrics for tracking program outcomes for the 12 Cities Project, HHS undertook a broader effort to develop a streamlined set of cross-agency, core indicators that can be used to monitor the prevention, treatment, and care services of all federally funded programs providing HIV/AIDS services. HHS identified the need for indicators in seven domains: HIV+ diagnosis, early HIV diagnosis, initial linkage to care, sustained engagement in care, initiation of ART, viral load suppression, and housing (Valdiserri and Forsyth, 2011; Personal communication, Andrew Forsyth, Department of Health and Human Services, January 24, 2012). The committee has recommended indicators in each of these areas. Although the jurisdictions included in the 12 Cities Project represent a large percentage of the U.S. population of PLWHA, use of a common set of core indicators across all federally funded HIV/AIDS programs nationwide will generate a more complete picture of HIV care in the United States.

Nationwide Health Information Network Exchange

Developed under the auspices of the Office of the National Coordinator for Health Information Technology, the Nationwide Health Information Network (NwHIN) Exchange is a public-private partnership designed to promote the exchange of health information from patient health records (ONC, 2011). Federal agencies participating in NwHIN Exchange include CDC, Department of Veterans Affairs, and Department of Defense. Nonfederal entities include KP, various hospitals, health information organizations, and state health information exchanges.

Health Care Cost Institute

Another type of data sharing partnership is the Health Care Cost Institute (HCCI), launched in September 2011. The HCCI is an independent, nonprofit entity whose goal is to create a comprehensive database of health care cost and service utilization data to promote and support research on the drivers of escalating health care costs and utilization. HCCI will make available de-identified claims records from four of the largest private health insurers in the United States (Aetna, Humana, Kaiser Permanente, United-Healthcare), as well as Medicare Advantage data from each of those plans (HCCI, 2011). Currently the HCCI database contains more than 5 billion medical claim records from over 5,000 hospitals and 1 million service providers from 2000 through the present (Merrill, 2011). Eventually HHCI plans to add data from additional private insurers, as well as public payers such as Medicaid (Merrill, 2011). This type of cooperative arrangement among private insurers and between the private insurance industry and the public serves as another example of the type of data sharing enterprise that would help to expand the pool of data available to estimate the indicators beyond those available from any individual data system.

CONCLUSIONS AND RECOMMENDATIONS

- Currently data are being collected by a number of public and private data systems, some specific to HIV and others not, each of which has limitations. These data systems are collecting relevant information that can serve as a collective platform for evaluating access to continuous and high-quality care in all populations of PLWHA. The committee identified 12 data systems in particular that collect data of use for estimating the core indicators to monitor progress toward meeting the goals of the NHAS and ACA:

  National HIV Surveillance System

  Medical Monitoring Project

  Ryan White Services Report

  Ryan White AIDS Drug Assistance Program Reports

  Medicaid Statistical Information System

  Chronic Condition Data Warehouse

  North American AIDS Cohort Collaboration on Research and Design

  CFAR Network of Integrated Clinical Systems

  HIV Research Network

  Clinical Case Registry: HIV

  Kaiser Permanente

  National Vital Statistics System

  Two additional data systems provide information of use in tracking the impact of the initiatives on care for two small but important subpopulations of HIV-infected individuals (AI/ANs; federal prisoners), and a third provides information relevant to housing assistance and other supportive services for PLWHA:

  Resource and Patient Management System

  Bureau of Prisons Electronic Medical Record

  Housing Opportunities for Persons with AIDS

- The committee's review of federal data systems relevant to HIV care showed they capture a wealth of data that can be used to estimate the indicators identified by the committee for monitoring the impact of the NHAS and the ACA in improving HIV/AIDS care in the United States. Each data system has limitations, however. Few contain all of the data elements needed to estimate the indicators, especially those pertaining to mental health, substance abuse, and supportive services. In addition, most of the data systems are not fully representative of the population of PLWHA in the United States. In many cases (e.g., Ryan White HIV/AIDS Program, MSIS, CCW, VHA), the population represented in the data system is defined by program eligibility and cannot be expanded. Similarly, the purposes for which the data systems were designed preclude expansion of the data elements they collect to include all of those needed to estimate all of the indicators identified by the committee. Furthermore, such expansion would entail significant increases in cost and reporting burden. The committee concluded, however, that more modest changes in individual data systems could improve the usefulness of their data for tracking changes in HIV care and access to supportive services for people living with HIV. For example, a given data system might add one or more data elements or modify an existing data element to allow the system to provide data for estimating a subgroup of the indicators identified by the committee, such as those pertaining to supportive services (housing, food security, transportation), or to simplify identification of data representing HIV-infected individuals (e.g., flagging HIV/AIDS as a chronic condition in the CCW). In cases where the population represented in a data system is not constrained by the program it serves (e.g., MMP), steps might be taken either to make the population more representative of the national population of people living with HIV or to include groups (e.g., homeless) who are less apt to be represented in other data systems.

Recommendation 3-1. The Department of Health and Human Services, the Department of Veterans Affairs, the Department of Housing and Urban Development, and other relevant federal agencies should review and, to the extent practicable, modify the federal data systems identified by the committee to better enable them to be used for monitoring progress toward achieving the goals of the National HIV/AIDS Strategy.

- Uniform longitudinal reporting of CD4 and viral load test dates and results from all jurisdictions and data on the initiation and ongoing prescription or dispensing of antiretroviral therapy would facilitate the use of data from the NHSS to assess all of the core indicators for clinical HIV care identified by the committee. In addition, collection of data on sexual orientation, sources of coverage for medical treatment, and maintaining current geographic area of residence for individuals in the NHSS would facilitate use of national surveillance system data for evaluation of indicators for specific subpopulations identified in the NHAS.

Recommendation 3-2. The Centers for Disease Control and Prevention should take steps to enhance the National HIV Surveillance System including

- **issuing guidelines or criteria for National HIV Surveillance System reporting to include all CD4 and viral load test results**
- **capturing longitudinal data pertaining to the initiation and ongoing prescription or dispensing of antiretroviral therapy for individuals diagnosed with HIV (e.g., through pharmacy-based reporting)**
- **obtaining information on sexual orientation and sources of coverage for medical treatment (including, but not limited to, Medicaid, Medicare, Ryan White HIV/AIDS Program, other public funding, private insurance or health maintenance organization, no coverage) and obtaining and employing current geographic marker of residence (e.g., current address, zip code, partial zip code, census block) for individuals in the National HIV Surveillance System**

- The committee's review of data systems relevant to HIV care showed that clinically based EHR systems (e.g., VHA, KP, IHS, BOP) capture all, or most, of the data elements needed to estimate the clinical HIV care indicators identified by the committee. They also generally capture at least some of the information needed to estimate the indicators pertaining to mental health and substance abuse, but they do not routinely capture data needed to estimate the indicators pertaining to supportive services. Another limitation of provider-based systems is that individually they represent only one segment of the population of PLWHA in the United States (e.g., veterans, KP enrollees, AI/ANs, federal prisoners). Other data systems represent larger proportions of PLWHA nationally (e.g., NHSS, MSIS) and may contain information on mental health, substance abuse, and supportive services (e.g., Ryan White HIV/AIDS Program, MSIS), but they contain limited or no clinical data. The NwHIN Exchange is an example of a partnership between public and private entities to exchange health information for a variety of purposes. It could serve as a model for or a foundation upon which to build a broader data sharing partnership among public and private data systems both to permit better estimation of the indicators identified by the committee and to return information to private health care systems and providers for the purpose of improving health care for individuals with HIV. Building upon existing data sharing partnerships would help to reduce the costs associated with implementation of such partnerships for the exchange of information relevant to the provision of HIV care.

Recommendation 3-3. The Department of Health and Human Services, the Department of Veterans Affairs, the Indian Health Service, the Federal Bureau of Prisons, and other relevant federal agencies should use existing data from private data systems, including data from electronic health records, to monitor the impact of the National HIV/AIDS Strategy and the Patient Protection and Affordable Care Act on improving HIV care. Federal agencies also should share data pertaining to HIV care with private health care systems and providers to improve the quality of care for individuals with HIV. Methods might include the development of a data sharing partnership between public and private data systems that include data pertaining to HIV care.

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APPENDIX TABLE 3-1 follows on next page

APPENDIX TABLE 3-1 Summary of Data Systems for Monitoring HIV Care Identified by the Committee

Design	Population Covered	Source of Data	Number	How Representative
National HIV Surveillance System (Centers for Disease Control and Prevention)				
• Public health surveillance, state-mediated mandatory reporting by all jurisdictions • Longitudinal from time of diagnosis	• All persons diagnosed with HIV/AIDS	• Clinician reports of diagnosis • Lab reports of CD4 counts and viral load • State health department reporting	• 808,090 (803,771)[a] —2009 data for 46 states and 5 U.S. dependent areas with confidential name-based reporting	• Wide coverage of diagnosed PLWHA • Includes PLWHA out of care

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[a] Estimated number following statistical adjustment for reporting delays and missing risk-factor information, but not for incomplete reporting (http://www.cdc.gov/hiv/surveillance/resources/reports/2010report/pdf/2010_HIV_Surveillance_Report_vol_22.pdf#Page=52, accessed March 21, 2012).

Strengths	Limitations	Potential Enhancements	ACA Implications
• Population-based census • Includes individuals not in care • Not limited to one type of payer • Definitions of variables and reporting methods standardized • Trend data routinely available • Many highest priority indicators can be calculated • Can be used to monitor disparities re: gender, race/ethnicity, region • Possible to link with other data systems maintained at local level (e.g., Ryan White Services Report; Homeless Management Information System)	• Clinical data elements limited to CD4 and viral load tests, with optional fields for ART and pregnancy status • Not all jurisdictions report lab results longitudinally • Inability to track individuals across reporting areas • Inaccurate/incomplete reporting • Not yet complete for jurisdictions without mature name-based reporting	• Addition of payer information • Addition of employment status, income, sexual orientation • Addition of ART status (whether receiving) • Work with states to extend reporting of all CD4 and viral load lab results to all jurisdictions	• Number may increase and become more comprehensive as more individuals with HIV/AIDS are identified with increased access to health care coverage

continued

APPENDIX TABLE 3-1 Continued

Design	Population Covered	Source of Data	Number	How Representative
Medical Monitoring Project (Centers for Disease Control and Prevention)				
• Multistage probability proportional to size sampling design • Repeated cross-sectional probability sample	• Adults (≥18 years) diagnosed with HIV/AIDS and receiving outpatient care	• Self-reported behavioral and selected clinical data • Medical record abstraction	• 3,643 HIV-infected adults (2007 cycle) • 4,217 HIV-infected adults (2009 cycle)[b]	• Repeated cross-sectional probability samples of adult PLWHA receiving outpatient medical care in United States and Puerto Rico

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[b] The 2009 collection cycle data were weighted to estimate nationally representative percentages of HIV-infected adults receiving medical care in the United States.

Strengths	Limitations	Potential Enhancements	ACA Implications
• Most indicators can be calculated • Includes data on supportive services • 2009 data cycle weighted to estimate nationally representative percentages of adult PLWHA in care • Not limited to patients receiving care through a specific payer	• Low individual participation rate in 2007 cycle • 2007 data unweighted • Possibility of social desirability response bias for in-person interviews • Some clinical information (e.g., date of HIV diagnosis and date of first entry into care) is self-reported • Stratification by certain characteristics produced numbers too small for reliable interpretation • Only includes individuals who are in care	• Take steps to improve participation rates and make sample more nationally representative particularly among hard to reach populations such as homeless • Create a mechanism to allow supplemental questions to be added as needed to capture salient data (e.g., with specific ACA implementation issues and how they might affect patients)	• Sample may be expected to reflect greater number of PLWHA not previously in care, as number of persons in care increases

continued

APPENDIX TABLE 3-1 Continued

Design	Population Covered	Source of Data	Number	How Representative
Ryan White Services Report (Health Resources and Services Administration)				
• HRSA/HAB mandatory reporting for Ryan White HIV/AIDS Program grantees and contracted service providers	• HIV-infected individuals receiving at least one Ryan White service	• Ryan White grantees and contracted service providers • *Grantee Report*: summary of RW providers in the jurisdiction and services they offer • *Service Provider Report*: basic information about the organization; lists service provider contracts for reporting period • *Client Report*: client-level demographic information; HIV clinical information; HIV medical, health care, and support services received	• >500,000 HIV-infected individuals	• Representative of clients receiving Ryan White funded services • Not representative of national population of PLWHA in the United States

Strengths	Limitations	Potential Enhancements	ACA Implications
• Most indicators (or a proxy) can be calculated • Includes data on supportive services, such as need for and use of housing, food, transportation services for people served by Ryan White HIV/AIDS Program • Grantee data can be used to monitor changes at service system level	• Grantees/providers are not required to report client service data for services not paid for by the Ryan White HIV/AIDS Program (may result in client-level data gaps) [Full clinical data are reported regardless of funding source] • Difficult to compare data across jurisdictions due to interstate variation in programs	• Report all client service data regardless of funding source	• Anticipated shift in clientele and services • Reduced dependency on program to meet health service needs • Redirection of funds to other vital services (e.g., housing, case management)

continued

APPENDIX TABLE 3-1 Continued

Design	Population Covered	Source of Data	Number	How Representative
Ryan White AIDS Drug Assistance Program (ADAP) Reports (Health Resources and Services Administration)				
ADAP Quarterly Report				
• HRSA/HAB mandatory reporting for ADAP grantees and contracted entities	• Aggregate data on ADAP clients enrolled/served	• ADAP grantees and contracted entities such as Pharmacy Benefits Management organizations • ADAP Quarterly Data Report (aggregate data)	• 213,764 ADAP clients enrolled (FY2009) • 190,963 ADAP clients served (FY2009)	• ADAP clients are HIV-positive, low income, and uninsured or underinsured
ADAP Data Report (NOTE: First data collection period is April 1–September 30, 2012)				
• Proposed HRSA/HAB mandatory reporting for ADAP grantees and contracted entities	• Client-level data on ADAP clients enrolled/served (proposed)	• ADAP grantees and contracted entities such as Pharmacy Benefits Management organizations • ADAP Data Report (proposed) (client-level data) • Demographic variables may be self-reported • Clinical data must be from lab report, clinical documentation, or HIV surveillance program	• 213,764 ADAP clients enrolled (FY2009) • 190,963 ADAP clients served (FY2009)	• ADAP clients are HIV-infected, low income, and uninsured or underinsured

Strengths	Limitations	Potential Enhancements	ACA Implications
	• Data are aggregate • Contains only limited data, mostly demographic • Scheduled to be replaced by ADAP Data Report beginning with April 1–September 30, 2012, collection period		
• Client-level data	• Provides information only on medications that are fully funded by ADAP	• Capture dispensing information for all ADAP formulary drugs regardless of funding source	

continued

APPENDIX TABLE 3-1 Continued

Design	Population Covered	Source of Data	Number	How Representative
Medicaid Statistical Information System (Centers for Medicare & Medicaid Services)				
• Health care claims and eligibility	• HIV-diagnosed individuals enrolled in Medicaid	• Claims and eligibility data reported by states • Eligible file • Inpatient claims • Long-term care claims • Other claims • Prescription drug claims Claim types: • Fee-for-service • Capitated payments • Encounter claims • Service-tracking claims (some states)	• 212,892 HIV-infected individuals (FY2007)	• Representative of PLWHA enrolled in Medicaid (estimated 47 percent of PLWHA in care) • Enrollees most likely to be black males over the age of 19 • 74 percent qualify for Medicaid as disabled (therefore not currently representative of non-disabled population of PLWHA)

Strengths	Limitations	Potential Enhancements	ACA Implications
• Represents largest single source of care coverage for PLWHA: Medicaid enrollees account for 47 percent of PLWHA estimated to be in regular care	• Utilization data only: No clinical outcome data • No data on housing, food, transportation services • Challenging to identify HIV-positive Medicaid recipients • Incomplete data on services for beneficiaries in managed care • Diagnostic and service information dependent on codes entered on claims potentially resulting in incomplete data • Variations in Medicaid eligibility resulting in enrollment lapses		• Anticipated increase in enrollment with increased eligibility provisions in ACA: magnitude likely to vary greatly across states

continued

APPENDIX TABLE 3-1 Continued

Design	Population Covered	Source of Data	Number	How Representative
Chronic Condition Data Warehouse (Centers for Medicare & Medicaid Services)				
• Health care claims	• HIV-diagnosed individuals enrolled in Medicare	• Claims data submitted by health care providers	• Approximately 100,000 HIV-infected individuals	• Approximately 20 percent of PLWHA estimated to be receiving care in the United States • PLWHA who are disabled or age 65 or older • 29 percent of HIV-infected Medicaid enrollees are dually eligible for Medicare

Strengths	Limitations	Potential Enhancements	ACA Implications
• Represents approximately 20 percent of PLWHA in care • Number expected to increase with aging population of PLWHA	• Primarily fee-for-service utilization data • Limited data on services for beneficiaries in managed care • Limited/no clinical outcome data or data on supportive services • May provide better information on drug coverage than other systems (with Part D enrollees)	• Designate HIV/AIDS as one of the predefined chronic condition cohorts	• Potentially more claims for Medicare Part D • Eventual elimination of Part D “donut hole”

continued

APPENDIX TABLE 3-1 Continued

Design	Population Covered	Source of Data	Number	How Representative
North American AIDS Cohort Collaboration on Research and Design				
• Clinical cohorts collect data in the course of routine medical practice at each of the contributing clinical sites • Classical epidemiologic HIV interval cohorts collect data at visits scheduled every 6 months	• HIV-infected adults at 60+ clinical and academic research sites in the United States and Canada	• Electronic data provided by contributing clinical and interval cohorts • Clinical cohorts collect data from electronic health records, interview questionnaires, chart review, and other data collection systems • Interval cohorts collect data from structured interview, questionnaires, and other data collection systems	• Approximately 100,000 HIV-infected individuals	• Demographics (including age, sex, and transmission risk group) are similar to those reported by the CDC for the United States, but with somewhat fewer minorities; includes individuals from all but three U.S. states, but not all areas of each state represented

Strengths	Limitations	Potential Enhancements	ACA Implications
• Represents about 20 percent of PLWHA in care • New data elements can be added if they are collected by individual cohorts	• Data are private/proprietary, but may be available upon submission of proposal for research/policy use • No common protocol for timing and standardization of data elements across sites • Limited data on supportive services • PLWHA receiving care primarily in academic medical centers may show little change in already high standard of care in response to ACA or NHAS implementation		• No change anticipated

continued

APPENDIX TABLE 3-1 Continued

Design	Population Covered	Source of Data	Number	How Representative
CFAR Network of Integrated Clinical Systems				
• Clinical cohorts • Longitudinal record while in care in a selected Center for AIDS Research (CFAR)	• Individuals receiving HIV care at 8 selected CFAR sites across the United States[c]	• Electronic health records • Electronic patient-reported outcomes using standardized questionnaire • Chart review and other data collection systems	• 23,197 HIV-infected adults	• Representative of PLWHA in the geographic regions of the selected CFAR sites
HIV Research Network				
• Clinical cohorts • Longitudinal record while in care at a participating site	• Adults, children, and adolescents in care at hospital and community-based outpatient clinics throughout the United States	• Data supplied electronically and through medical record review	• Approximately 21,000 HIV-infected patients in care	• Demographics (including age, sex, race/ethnicity, and transmission risk group) are similar to those reported by the CDC

[c] University of Alabama at Birmingham (UAB); University of California at San Francisco (UCSF); University of Washington (UW); Case Western Reserve University (CWRU), Cleveland, OH; Lifespan/Tufts/Brown University CFAR (Fenway), Boston, MA/Providence RI; the University of California, San Diego (UCSD); the University of North Carolina at Chapel Hill (UNC), and Johns Hopkins University (JHU), Baltimore, MD.

Strengths	Limitations	Potential Enhancements	ACA Implications
• Much of the data needed to calculate indicators, except for supportive services • New data elements, such as housing stability, can be added if they are collected in the clinical practice setting • Patient reported outcome questionnaire could be used to ask about basic needs, stigma, discrimination	• Data are private/proprietary, but may be available upon submission of proposal for research/policy use • Population not nationally representative of PLWHA in the United States		• No change anticipated
• Much of the data needed to calculate indicators, except for supportive services • New data elements, such as housing stability, can be added if they are collected in the clinical practice setting	• Data are private/proprietary, but may be available upon submission of proposal for research use		

continued

APPENDIX TABLE 3-1 Continued

Design	Population Covered	Source of Data	Number	How Representative
Clinical Case Registry: HIV (Department of Veterans Affairs)				
• Longitudinal record while in care in system	• HIV-diagnosed veterans receiving care in Veterans Health Administration (VHA) facilities	• Electronic health records	• 23,463 HIV-infected individuals (2008)	• Population is predominantly male and older compared to all PLWHA in the United States

Strengths	Limitations	Potential Enhancements	ACA Implications
• Outcome and utilization data • Largest provider of HIV care in the United States	• Population not nationally representative of PLWHA in the United States • Only captures data within VHA system • No data on supportive services or mental health/ substance abuse screening		• No change anticipated

continued

APPENDIX TABLE 3-1 Continued

Design	Population Covered	Source of Data	Number	How Representative
Kaiser Permanente				
• Longitudinal record while in care in system	• HIV-diagnosed individuals enrolled in Kaiser	• Electronic health records	• >19,000 HIV-infected individuals (2009); regional variation +/- 200 to >6,600 • HIV registry of 17,000+ (2010)	• Largest private provider of HIV care (2010) • Representative of the insured HIV-positive population in the U.S. areas with Kaiser access (Hawaii, California, Oregon, Mid-Atlantic region, Atlanta, GA) • Majority Caucasian MSM • Greater percentage of Latinos on West Coast and greater percentage of blacks on East Coast • 12% female, but greater percentage on East Coast

Strengths	Limitations	Potential Enhancements	ACA Implications
• Outcome and utilization data • Represents one of the largest groups of privately insured PLWHA in the United States	• Data are private/ proprietary • Only captures data within Kaiser system • No data on supportive services • Younger and marginally employed individuals may not remain in system due to insurance status		• Possible increase in enrollees as more people with low/ moderate incomes (133–400% of federal poverty level) gain access to private insurance • Possible increase in private insurance enrollees with elimination of preexisting condition clauses

continued

APPENDIX TABLE 3-1 Continued

Design	Population Covered	Source of Data	Number	How Representative
Resource and Patient Management System (Indian Health Service [IHS])				
• Longitudinal record while in care in system	• American Indians/ Alaska Natives receiving HIV care within IHS	• Electronic health records	• A minority of the estimated 2,385 HIV-positive American Indian/ Alaska Native individuals (2008) receive HIV care in IHS facilities	• American Indian/ Alaska Native individuals account for <1 percent of PLWHA • Not representative of national (or native) population of PLWHA
Bureau of Prisons Electronic Medical Record				
• Longitudinal record while in care in system	• Federal prisoners diagnosed with HIV/ AIDS	• Electronic health records	• 1,538 HIV-infected individuals (December 31, 2008)	• Not representative of national population of PLWHA

Strengths	Limitations	Potential Enhancements	ACA Implications
• Utilization and outcome data • Optional HIV-specific module in electronic health record system • Important subpopulation	• Very small subpopulation of PLWHA (even within native population) • Data from tribal facilities require special permission to access • Data on supportive services are not routinely captured		• No change anticipated
• Developing capability to extract HIV data that currently are only available at individual level • Important subpopulation	• Very small subpopulation of PLWHA (even among incarcerated population in the United States)		• No change anticipated

continued

APPENDIX TABLE 3-1 Continued

Design	Population Covered	Source of Data	Number	How Representative
Housing Opportunities for Persons with AIDS (Department of Housing and Urban Development)				
• HUD-mandated reporting for Housing Opportunities for Person with AIDS (HOPWA) Competitive Program and Formula Program grantees	• Aggregate data on HOPWA beneficiaries and households served and unmet need for housing based on HOPWA-eligible households not served by HOPWA-funded assistance in service area	• HOPWA grantees: information on program accomplishments in maintaining housing stability, improving access to care, and reducing risk of homelessness • Competitive Program grantees file *Annual Progress Report* • Formula Program grantees file *Consolidated Annual Performance Evaluation Report*	• 60,669 unduplicated households (by end of FY2010)	• Generally representative of low-income PLWHA

Strengths	Limitations	Potential Enhancements	ACA Implications
• Includes data on unmet need for housing among HOPWA-eligible households not receiving HOPWA housing assistance • Includes data on supportive services, such as housing, food or nutrition, and transportation, as well as mental health and substance abuse services funded through HOPWA • Grantee data can be used to monitor changes at service system level	• Data are aggregated • Supportive services information limited to HOPWA-funded services		

APPENDIX TABLE 3-2a Data Elements for Core Clinical HIV Care Indicators

	Date of HIV diagnosis [or first evidence of HIV infection]	Date of first visit for HIV care [or date of first/second CD4/viral load test]	CD4 count at diagnosis/first visit for HIV care	Dates of routine HIV-care visits
National HIV Surveillance System	Yes	Yes (CD4/VL)	Yes	Yes (CD4/VL test dates: most reporting areas)
Medical Monitoring Project	Yes	Yes	Yes	Yes
Ryan White Services Report	No	Yes (at present RW provider agency)	No	Yes
Ryan White ADAP Reports	No	No	No	No
Medicaid Statistical Information System	No	No	No	Yes
Medicare Chronic Condition Data Warehouse	No	No	No	Yes
North American AIDS Cohort Collaboration on Research and Design	Yes, but data are not complete	Yes	Yes	Yes
CFAR Network of Integrated Clinical Systems	Yes, but data are not complete	Yes	Yes	Yes

Dates of CD4 counts	CD4 counts	Dates of viral load tests	Viral load results	ART prescription/ dispensing dates	Date of death
Yes (most reporting areas)	Yes (most reporting areas)	Yes (most reporting areas)	Yes (most reporting areas)	Whether ever taken ARV, ARV taken, and dates taken (not required in all areas)	Yes
Yes	Yes	Yes	Yes	Yes	Yes (during surveillance period)
Yes	Yes	Yes	Yes	Whether prescribed within 12-month reporting period	Yes
Yes (most recent in past 12 months)	Yes (most recent in past 12 months)	Yes (most recent in past 12 months)	Yes (most recent in past 12 months)	Yes (in reporting period: only fully ADAP-funded drugs)	No
Yes	No	Yes	No	Yes	Yes
Yes	No	Yes	No	Yes	Yes
Yes	Yes	Yes	Yes	Yes (dates of starting and stopping individual drugs)	Yes
Yes	Yes	Yes	Yes	Yes (dates of starting and stopping individual drugs)	Yes

continued

APPENDIX TABLE 3-2a Continued

	Date of HIV diagnosis [or first evidence of HIV infection]	Date of first visit for HIV care [or date of first/second CD4/viral load test]	CD4 count at diagnosis/first visit for HIV care	Dates of routine HIV-care visits
HIV Research Network	Yes (> 60% of patients)	Yes	Yes	Yes
Clinical Case Registry: HIV (VHA)	Yes (in VHA)	Yes (in VHA)	Yes (in VHA)	Yes
Kaiser Permanente (KP)	Yes (at KP)	Yes (at KP)	Yes (at KP)	Yes
Indian Health Service (IHS)	Yes	Yes	Yes	Yes (in IHS)
Federal Bureau of Prisons	Yes (if during incarceration)	Yes (if during incarceration)	Yes (not discrete data in EHR)	Yes (while incarcerated)
Housing Opportunities for Persons with AIDS	No	No	No	Households that had contact with primary provider as specified in client's plan

Dates of CD4 counts	CD4 counts	Dates of viral load tests	Viral load results	ART prescription/ dispensing dates	Date of death
Yes	Yes	Yes	Yes	Yes	Yes
Yes	Yes	Yes	Yes	Yes	Yes
Yes	Yes	Yes	Yes	Yes	Yes
Yes (in IHS)	Yes (in IHS)	Yes (in IHS)	Yes (in IHS)	Yes (in IHS)	Yes
Yes (while incarcerated)	Yes	Yes (while incarcerated)	Yes	Yes	Yes (if during incarceration, separate database)
No	No	No	No	No	No

APPENDIX TABLE 3-2b Data Elements for Core Mental Health, Substance Abuse, and Supportive Services Indicators

	Date of mental health diagnosis or referral	Date of first visit for mental health services	Date of substance use diagnosis or referral
National HIV Surveillance System	No	No	No
Medical Monitoring Project	Whether diagnosed/referred in 12-month surveillance period, but not date/prior diagnosis	Whether received services in 12-month surveillance period, but not date	Whether diagnosed/referred in 12-month surveillance period, but not date
Ryan White Services Report	No	Number of visits in 12-month reporting period, but not date	No
Ryan White ADAP Reports	No	No	No
Medicaid Statistical Information System	No	Visits, but not first visit specifically	No
Medicare Chronic Condition Data Warehouse	Yes (in past 12 months)	First visit covered by Medicare	Yes (in past 12 months)
North American AIDS Cohort Collaboration on Research and Design	Yes	2012, will collect visits, but not first visit specifically	Yes
CFAR Network of Integrated Clinical Systems	Yes	Visits, but not first visit specifically	Yes
HIV Research Network	Yes (for a subset of sites)	Yes (for a subset of sites)	Yes (for a subset of sites)
Clinical Case Registry: HIV (VHA)	Yes	Yes (in VHA)	Yes
Kaiser Permanente (KP)	Yes	Yes (at KP)	Yes
Indian Health Service (IHS)	Yes	Yes (in IHS)	Yes
Federal Bureau of Prisons	Yes (while incarcerated)	Yes (while incarcerated)	Yes (while incarcerated)
Housing Opportunities for Persons with AIDS (HOPWA)	No	Whether received HOPWA-funded services	No

Date of first visit for substance abuse services	Housing status	Food security status	Transportation status
No	No	No	No
Whether received services in 12-month surveillance period, but not date	Yes	Yes	Yes
Number of visits in 12-month reporting period, but not date	Yes, also whether received RW-funded services	Whether received RW-funded services	Whether received RW-funded services
No	No	No	No
Visits, but not first visit specifically	No	No	No
First visit covered by Medicare	No	No	No
No	No	No	No
Whether received services in past year	No	No	No
Yes (for a subset of sites)	No	No	No
Yes (in VHA)	No	No	No
Yes (at KP)	No	No	No
Yes (in IHS)	Variable (provider narrative)	Variable (provider narrative)	Variable (provider narrative)
Yes (while incarcerated)	N/A	N/A	N/A
Yes, also whether received HOPWA-funded services	Whether received HOPWA-funded services	Whether received HOPWA-funded services	Whether received HOPWA-funded services

APPENDIX TABLE 3-2c Data Elements for Additional Clinical HIV Care Indicators

	Diagnosis of AIDS or AIDS-defining illness	Dates and results of TB tests	Dates of chlamydia, gonorrhea, and syphilis screening	Date of hepatitis B screening or date of documented immunity	Dates of hepatitis C tests
National HIV Surveillance System	Yes (optional)	No	No	No	No
Medical Monitoring Project	Yes	Yes	Yes	Yes (2007–2011 cycles only)*	Yes (2007–2011 cycles only)*
Ryan White Services Report	Yes	Yes	Yes (syphilis within 12-month reporting period)	Whether screened within 12-month reporting period	Whether screened within 12-month reporting period
Ryan White ADAP Reports	HIV/AIDS status at end of reporting period	No	No	No	No
Medicaid Statistical Information System	Yes	Test dates	Yes	Yes (screening)	Yes
Medicare Chronic Condition Data Warehouse	No	Test dates	Yes	Yes (screening)	Yes

*Starting with the 2012 data collection cycle, medical record abstraction focuses on the 12 months preceding the interview. Earlier clinical data is no longer captured.

Date of influenza immunization	Date of pneumococcal immunization	Date of hepatitis B vaccination/ date of documented immunity	Dates of ART resistance testing	Date of ART initiation	ART prescription/ dispensing dates	Diagnosis/ test results for HIV nephropathy, hepatitis B, TB
No	No	No	Yes (optional)	Yes (self-report, not required in all areas)	Whether ever taken ARV, ARV taken, and dates taken (not required in all areas)	No
Yes	Yes	Yes (2007–2011 cycles only)*	Yes (during surveillance period)	Yes	Yes	Yes
No	No	Whether vaccination series is completed	No	No	Whether prescribed within 12-month reporting period	No
No	No	No	No	Proposed (in reporting period: only fully ADAP-funded drugs)	Proposed (in reporting period: only fully ADAP-funded drugs)	No
Yes	Yes	Yes (vaccination)	Yes	No	Yes	Diagnosis captured if claim filed with appropriate ICD-9 codes
Yes	Yes	Yes (vaccination)	Yes	No	Yes	No

continued

APPENDIX TABLE 3-2c Continued

	Diagnosis of AIDS or AIDS-defining illness	Dates and results of TB tests	Dates of chlamydia, gonorrhea, and syphilis screening	Date of hepatitis B screening or date of documented immunity	Dates of hepatitis C tests
North American AIDS Cohort Collaboration on Research and Design	Yes	Yes	No	Yes	Yes
CFAR Network of Integrated Clinical Systems	Yes	Yes	Yes	Yes	Yes
HIV Research Network	Yes	For a subset of sites	Yes	Yes	Yes
Clinical Case Registry: HIV (VHA)	Yes	Yes	Yes	Yes	Yes
Kaiser Permanente (KP)	Yes	Yes	Yes	Yes	Yes
Indian Health Service (IHS)	Yes	Yes	Yes	Yes	Yes
Federal Bureau of Prisons	Yes (if during incarceration)	Yes	Yes	Yes	Yes (may not be in EHR)
Housing Opportunities for Persons with AIDS	No	No	No	No	No

Date of influenza immunization	Date of pneumococcal immunization	Date of hepatitis B vaccination/ date of documented immunity	Dates of ART resistance testing	Date of ART initiation	ART prescription/ dispensing dates	Diagnosis/ test results for HIV nephropathy, hepatitis B, TB
No	No	No	Yes	Yes	Yes, dates of starting and stopping individual drugs	Yes
Proposed for 2012	Proposed for 2012	Proposed for 2012	Yes	Yes	Yes, dates of starting and stopping individual drugs	Yes
For a subset of sites	For a subset of sites	For a subset of sites	For a subset of sites	Yes	Yes	For a subset of sites
Yes	Yes	Yes	Yes	Yes (in VHA)	Yes	Yes
Yes	Yes	Yes	Yes	Yes (at KP)	Yes	Yes
Yes	Yes	Yes	Yes	Yes	Yes (in IHS)	Yes
Yes	Yes	Yes	Yes (if during incarceration)	Yes (if during incarceration)	Yes	Yes
	No	No	No	No	No	No

continued

APPENDIX TABLE 3-2c Continued

	Pregnancy status
National HIV Surveillance System	Yes
Medical Monitoring Project	Yes
Ryan White Services Report	Yes
Ryan White ADAP Reports	Yes
Medicaid Statistical Information System	Not specifically, but may be extrapolated from related diagnosis/service codes
Medicare Chronic Condition Data Warehouse	No
North American AIDS Cohort Collaboration on Research and Design	Yes (as of 2012)
CFAR Network of Integrated Clinical Systems	Yes (as of 2012)
HIV Research Network	No
Clinical Case Registry: HIV (VHA)	Yes
Kaiser Permanente	Yes
Indian Health Service	Yes
Federal Bureau of Prisons	Yes (via ICD-9 codes)
Housing Opportunities for Persons with AIDS	No

APPENDIX TABLE 3-2d follows on next page

APPENDIX TABLE 3-2d Data Elements for Additional Mental Health, Substance Abuse, and Supportive Services Indicators

	Date of mental health screening	Date of screening for substance abuse	Dates of housing needs assessment	Dates of food security assessment	Dates of transportation needs assessment
National HIV Surveillance System	No	No	No	No	No
Medical Monitoring Project	Yes	Yes	Whether received/ needed services, but not date	Whether received/ needed services, but not date	Whether received/ needed services, but not date
Ryan White Services Report	Whether screened within 12-month reporting period, but not date	Whether screened within 12-month reporting period, but not date	No	No	No
Ryan White ADAP Reports	No	No	No	No	No
Medicaid Statistical Information System	Yes	Yes	No	No	No
Medicare Chronic Condition Data Warehouse	No	No	No	No	No
North American AIDS Cohort Collaboration on Research and Design	No	No	No	No	No
CFAR Network of Integrated Clinical Systems	Yes	Yes	No	No	No
HIV Research Network	No	No	No	No	No

APPENDIX TABLE 3-2d Continued

	Date of mental health screening	Date of screening for substance abuse	Dates of housing needs assessment	Dates of food security assessment	Dates of transportation needs assessment
Clinical Case Registry: HIV (VHA)	No	No	No	No	No
Kaiser Permanente	Yes	Yes	No	No	No
Indian Health Service	Yes	Yes	No	No	No
Federal Bureau of Prisons	Yes	Yes	N/A	N/A	N/A
Housing Opportunities for Persons with AIDS (HOPWA)	No	No	Number of HOPWA-eligible households with unmet need for housing assistance	No	No

APPENDIX TABLE 3-2e Data Elements to Estimate Indicators for Subpopulations

	Race	Ethnicity	Sex (M/F)
National HIV Surveillance System	Yes	Yes	Yes (sex at birth)
Medical Monitoring Project	Yes	Yes	Yes
Ryan White Services Report	Yes	Yes	Yes (male/female under gender)
Ryan White ADAP Reports	Yes	Yes	Yes (male/female under gender)
Medicaid Statistical Information System	Yes	Yes	Yes
Medicare Chronic Condition Data Warehouse	Yes	Yes	Yes
North American AIDS Cohort Collaboration on Research and Design	Yes	Yes	Yes
CFAR Network of Integrated Clinical Systems	Yes	Yes	Yes
HIV Research Network	Yes	Yes	Yes
Clinical Case Registry: HIV (VHA)	Yes	Yes	Yes
Kaiser Permanente	Yes	Yes	Yes
Indian Health Service	Yes	Yes	Yes
Federal Bureau of Prisons	Yes	Yes (in separate database)	Yes
Housing Opportunities for Persons with AIDS	Yes	Yes	Yes

Gender identity	Sexual orientation	Date of birth	Zip code/ other geographic marker	Country of birth
Current gender identity (optional)	No (but captures sexual history)	Yes	Yes (at diagnosis of HIV and AIDS)	Yes (optional)
Yes	Yes	Yes	Yes (optional field for local use only)	Yes
Yes	Yes	Yes (year)	Yes (first 3 digits)	No
Yes	No	Yes (year)	No	No
No	No	Yes	Yes	No
No	No	Yes	Yes	No
No	No	Yes	Yes (first 3 digits)	Yes (as of 2012)
No	Sex of patient and current partner collected semiannually	Yes	Yes (first 3 digits)	Yes (as of 2012)
Yes (transgender persons who self-identify)	Yes	Yes	No	No
No	No	Yes	Yes	No
No	Yes (but data are not complete)	Yes	Yes	No
No	No	Yes	Yes	No
No	No	Yes	N/A	Yes (in separate database)
Yes	No	No	Yes	No

APPENDIX TABLE 3-2f Additional Data Elements for Monitoring HIV Care

	Stigma	Discrimination	Emergency department/ inpatient use	Sexual risk behaviors
National HIV Surveillance System	No	No	No	Yes
Medical Monitoring Project	2011 cycle	2011 cycle	Yes	Yes
Ryan White Services Report	No	No	No	Yes
Ryan White ADAP Reports	No	No	No	No
Medicaid Statistical Information System	No	No	Yes	No
Medicare Chronic Condition Data Warehouse	No	No	Yes	No
North American AIDS Cohort Collaboration on Research and Design	No	No	Yes (as of 2012)	No
CFAR Network of Integrated Clinical Systems	No	No	Yes	Yes
HIV Research Network	No	No	Yes	Yes
Clinical Case Registry: HIV (VHA)	No	No	Yes	Variable
Kaiser Permanente (KP)	No	No	Yes	Yes
Indian Health Service	No	No	No	No
Federal Bureau of Prisons	No	No	No	Yes (not as a discrete data element)
Housing Opportunities for Persons with AIDS	No	No	No	No

*KP Northwest is the only provider of dental services in the KP system. Only dental services provided within the system are captured.

Partner HIV status	Access to dental care	Income	Employment status	Insurance status/type
Yes (only for persons reporting heterosexual risk)	No	No	No	Yes (optional)
Yes	Yes	Yes	No	Yes
No	Yes (RW-funded)	Percent of federal poverty level (FPL)	No	Yes
No	No	Percent of FPL Current: percent of clients <200% FPL	No	Yes
No	Yes	No	No	Yes
No	No	No	No	Yes (only Medicare and Medicaid)
No	No	No	No	Yes (as of 2012)
Yes (current partner status semiannually)	No	No	No	Yes
No	No	No	No	Yes
No	Yes (in VHA)	No	No	No
No	At KP Northwest (Oregon) only*	No	Yes	Yes
No	No	No	No	No
No	Yes	N/A	N/A	N/A
No	No	Yes	Yes	Yes

APPENDIX TABLE 3-3a Data Systems Mapped to Core Clinical HIV Care Indicators

	Proportion with CD4+ cell count >200 and without a clinical diagnosis of AIDS	Proportion linked to care for HIV within 3 months of diagnosis	Proportion in continuous care (2 or more visits in preceding 12 months at least 3 months apart)	Proportion who received 2 or more CD4 tests in past 12 months
National HIV Surveillance System	Yes (most reporting areas)	Yes	Most reporting areas: proxy using CD4/VL test dates	Yes (most reporting areas)
Medical Monitoring Project	Yes	Yes	Yes	Yes
Ryan White Services Report	No	No	Yes	Yes
Ryan White ADAP Reports	No	No	No	Yes (most recent date)
Medicaid Statistical Information System	No	No	Yes	Yes
Medicare Chronic Condition Data Warehouse	No	No	Yes	Yes

Proportion who received 2 or more viral load tests in past 12 months	Proportion in continuous care for 12 or more months and with CD4+ cell count ≥350	Proportion with a CD4+ cell count <500 who are not on ART	Proportion on ART for 12 or more months who have an undetectable viral load (VL)	All-cause mortality rate
Yes (most reporting areas)	Possible using CD4 test dates as proxy, but not all jurisdictions report all results	No/Variable (minimal data on ART status; variable jurisdictional reporting of CD4 counts)	No (no longitudinal data on ART status; variable jurisdictional reporting of VL results)	Yes
Yes	Yes	Yes	Yes	Yes (during surveillance period)
Yes	Yes	Yes (within 12-month reporting period)	Possible: depends on availability of longitudinal data on ART status	Yes
Yes (most recent date)	No	Possible for future, but only for fully ADAP-funded ARVs	Possible for future, but only for fully ADAP-funded ARVs	No
Yes	No (no CD4 results)	No (no CD4 results)	No (no VL results)	Yes
Yes	No (no CD4 results)	No (no CD4 results)	No (no VL results)	Yes

continued

APPENDIX TABLE 3-3a Continued

	Proportion with CD4+ cell count >200 and without a clinical diagnosis of AIDS	Proportion linked to care for HIV within 3 months of diagnosis	Proportion in continuous care (2 or more visits in preceding 12 months at least 3 months apart)	Proportion who received 2 or more CD4 tests in past 12 months
North American AIDS Cohort Collaboration on Research and Design	Yes	Yes (but date-of-diagnosis data are not complete)	Yes	Yes
CFAR Network of Integrated Clinical Systems	Yes	Yes (but date-of-diagnosis data are not complete)	Yes	Yes
HIV Research Network	Yes	Yes	Yes	Yes
Clinical Case Registry: HIV (VHA)	Yes (diagnosed in VHA)	Yes (in VHA)	Yes	Yes
Kaiser Permanente (KP)	Yes (diagnosed at KP)	Yes (at KP)	Yes	Yes
Indian Health Service (IHS)	Yes (in IHS)	Yes	Yes (in IHS)	Yes (in IHS)
Federal Bureau of Prisons	Yes (if diagnosed while incarcerated	Yes (if diagnosed during incarceration)	Yes	Yes
Housing Opportunities for Persons with AIDS	No	No	Proportion following client-specific schedule for contact with provider	No

	Proportion who received 2 or more viral load tests in past 12 months	Proportion in continuous care for 12 or more months and with CD4+ cell count ≥350	Proportion with a CD4+ cell count <500 who are not on ART	Proportion on ART for 12 or more months who have an undetectable viral load (VL)	All-cause mortality rate
	Yes	Yes	Yes	Yes	Yes
	Yes	Yes	Yes	Yes	Yes
	Yes	Yes	Yes	Yes	Yes
	Yes	Yes	Yes	Yes	Yes
	Yes	Yes	Yes	Yes	Yes
	Yes (in IHS)	Yes (in IHS)	Yes (in IHS)	Yes (in IHS)	Yes
	Yes	Yes (if incarcerated during that period)	Yes	Yes	Yes (in separate database for those who die while incarcerated)
	No	No	No	No	No

APPENDIX TABLE 3-3b Data Systems Mapped to Core Mental Health, Substance Abuse, and Supportive Services Indicators

	Proportion with mental health disorder referred for mental health services who receive these services within 60 days	Proportion with substance use disorder referred for substance abuse services who receive these services within 60 days
National HIV Surveillance System	No	No
Medical Monitoring Project	No (no dates for diagnosis/referral or services)	No (no dates for diagnosis/referral or services)
Ryan White Services Report	No	No
Ryan White ADAP Reports	No	No
Medicaid Statistical Information System	No	No
Medicare Chronic Condition Data Warehouse	Yes, if first visit covered by Medicare	Yes, if first visit covered by Medicare
North American AIDS Cohort Collaboration on Research and Design	Possible, if a service date is proximate to referral date	No
CFAR Network of Integrated Clinical Systems	Possible, if a service date is proximate to referral date	No
HIV Research Network	Yes (for a subset of sites)	Yes (for a subset of sites)
Clinical Case Registry: HIV (VHA)	Yes (in VHA)	Yes (in VHA)
Kaiser Permanente (KP)	Yes (at KP)	Yes (at KP)
Indian Health Service (IHS)	Yes (in IHS)	Yes (in IHS)
Federal Bureau of Prisons	Yes (while incarcerated)	Yes (while incarcerated)
Housing Opportunities for Persons with AIDS	No	No

Proportion who were homeless or temporarily or unstably housed at least once in the preceding 12 months	Proportion who experienced food or nutrition insecurity at least once in the preceding 12 months	Proportion who had an unmet need for transportation services at least once in the preceding 12 months
No	No	No
Yes	Yes	Yes
Yes, also whether received RW-funded services	Whether received RW-funded services	Whether received RW-funded services
No	No	No
No	No	No
No	No	No
No	No	No
No	No	No
No	No	No
No	No	No
No	No	No
Variable (incomplete data)	Variable (incomplete data)	Variable (incomplete data)
N/A	N/A	N/A
Yes	No	No

APPENDIX TABLE 3-3c Data Systems Mapped to Additional Clinical HIV Care Indicators

	Proportion screened for TB since diagnosis and results interpreted	Proportion screened for chlamydia, gonorrhea, and syphilis	Proportion screened for hepatitis B since diagnosis	Proportion screened for hepatitis C	Proportion immunized for influenza
National HIV Surveillance System	No	No	No	No	No
Medical Monitoring Project	Yes	Yes	Yes (2007–2011 cycles only)*	Yes (2007–2011 cycles only)*	Yes
Ryan White Services Report	Yes (but lacks diagnosis date)	Syphilis within 12-month reporting period	Yes (within 12-month reporting period)	Yes (within 12-month reporting period)	No
Ryan White ADAP Reports	No	No	No	No	No
Medicaid Statistical Information System	Yes (but lacks diagnosis date; TB test results)	Yes	Yes (but lacks diagnosis date)	Yes	Yes
Medicare Chronic Condition Data Warehouse	Yes (but lacks diagnosis date; TB test results)	Yes	Yes (but lacks diagnosis date)	Yes	Yes

*Starting with the 2012 data collection cycle, medical record abstraction will focus on the 12 months preceding the interview. Earlier clinical data will no longer be captured.

Proportion immunized for pneumococcal pneumonia since diagnosis	Proportion immunized for hepatitis B (if needed)	Proportion who receive drug resistance testing prior to ART initiation	Proportion with HIV-associated nephropathy, hepatitis B (when treatment is indicated) or active TB who are not on ART	Proportion HIV-infected pregnant women who are not on ART
No	No	No	No	Yes (when pregnancy and ART status captured)
Yes (during surveillance period)	Yes (2007–2011 cycles only)*	Yes (during surveillance period)	Yes	Yes
No	Whether vaccination series is completed	No	No	Yes (ART prescribed in last 12 months)
No	No	No	No	Data only for fully ADAP-funded drugs
Yes (but lacks diagnosis date)	Yes	Yes (if covered and identifiable by code; lacks ART initiation date)	Yes (if claims filed with proper diagnosis code/s)	Yes (if pregnancy captured by relevant diagnostic code/s)
Yes (but lacks diagnosis date)	Yes	Yes (but lacks ART initiation date)	No	No

continued

APPENDIX TABLE 3-3c Continued

	Proportion screened for TB since diagnosis and results interpreted	Proportion screened for chlamydia, gonorrhea, and syphilis	Proportion screened for hepatitis B since diagnosis	Proportion screened for hepatitis C	Proportion immunized for influenza
North American AIDS Cohort Collaboration on Research and Design	Yes	No	Yes (date-of-diagnosis data incomplete)	Yes	No
CFAR Network of Integrated Clinical Systems	Yes	Yes	Yes (date-of-diagnosis data incomplete)	Yes	Proposed for 2012
HIV Research Network	Yes (for a subset of sites)	Yes	Yes	Yes	Yes (for a subset of sites)
Clinical Case Registry: HIV (VHA)	Yes (in VHA)	Yes	Yes	Yes	Yes
Kaiser Permanente (KP)	Yes (at KP)	Yes	Yes	Yes	Yes
Indian Health Service (IHS)	Yes (in IHS)	Yes	Yes	Yes	Yes
Federal Bureau of Prisons	Yes	Yes	Yes	Yes (although data may not be available in EHR)	Yes
Housing Opportunities for Persons with AIDS	No	No	No	No	No

Proportion immunized for pneumococcal pneumonia since diagnosis	Proportion immunized for hepatitis B (if needed)	Proportion who receive drug resistance testing prior to ART initiation	Proportion with HIV-associated nephropathy, hepatitis B (when treatment is indicated) or active TB who are not on ART	Proportion HIV-infected pregnant women who are not on ART
No	No	Yes	Yes	Yes (as of 2012)
Proposed for 2012 (date-of-diagnosis data incomplete)	Proposed for 2012	Yes	Yes	Yes (as of 2012)
Yes (for a subset of sites)	Yes (for a subset of sites)	Yes (for a subset of sites)	Yes (for a subset of sites)	No
Yes	Yes	Yes	Yes	Yes
Yes	Yes	Yes	Yes	Yes
Yes	Yes	Yes	Yes	Yes
Yes	Yes	Yes (may not be available)	Yes (would require record abstraction and verification)	Yes
No	No	No	No	No

APPENDIX TABLE 3-3d Data Systems Mapped to Additional Mental Health, Substance Abuse, and Supportive Services Indicators

	Proportion screened for mental health disorders at least once in the past 12 months	Proportion screened for substance use disorders at least once in the past 12 months	Proportion assessed for need for housing at least once in the past 12 months	Proportion assessed for need for food or nutrition at least once in the past 12 months	Proportion assessed for need for transportation at least once in the past 12 months
National HIV Surveillance System	No	No	No	No	No
Medical Monitoring Project	Yes	Yes	No (whether received/needed services, but not date)	No (whether received/needed services, but not date)	No (whether received/needed services, but not date)
Ryan White Services Report	Yes	Yes	No	No	No
Ryan White ADAP Reports	No	No	No	No	No
Medicaid Statistical Information System	Yes	Yes	No	No	No
Medicare Chronic Condition Data Warehouse	No	No	No	No	No
North American AIDS Cohort Collaboration on Research and Design	No	No	No	No	No
CFAR Network of Integrated Clinical Systems	Yes	Yes	No	No	No
HIV Research Network	No	No	No	No	No
Clinical Case Registry: HIV (VHA)	No	No	No	No	No

APPENDIX TABLE 3-3d Continued

	Proportion screened for mental health disorders at least once in the past 12 months	Proportion screened for substance use disorders at least once in the past 12 months	Proportion assessed for need for housing at least once in the past 12 months	Proportion assessed for need for food or nutrition at least once in the past 12 months	Proportion assessed for need for transportation at least once in the past 12 months
Kaiser Permanente	Yes	Yes	No	No	No
Indian Health Service	Yes	Yes	No	No	No
Federal Bureau of Prisons	Yes	Yes	N/A	N/A	N/A
Housing Opportunities for Persons with AIDS	No	No	Yes	No	No

APPENDIX TABLE 3-4 Publicly Available Data Collection Instruments and Information

Data System	Collection Instrument/s
National HIV Surveillance System	1. Adult HIV/AIDS Confidential Case Report
Medical Monitoring Project	1. 2010 Medical History Form* 2. 2010 Surveillance Period Inpatient Form* 3. 2010 Surveillance Period Summary Form* 4. 2010 Surveillance Period Visit Form* 5. 2010 Standard Questionnaire* 6. 2011 Medical Monitoring Project Response Cards
Ryan White AIDS Drug Assistance Program (ADAP) Reports	1. AIDS Drug Assistance Program (ADAP) Data Report—Final Client-Level Data Variables (Effective October 1, 2012) 2. ADAP Data Report: Grantee Report: Summary of Changes to the Grantee-Level Variables 3. ADAP—Quarterly Data Report (Phasing out this year)
Ryan White Services Report	1. Data Elements for Client-Level Data Export (Effective for the 2010 Annual RSR)
Medicaid Statistical Information System	1. Medicaid Analytic eXtract Files (MAX) User Guide 2. Medicaid and CHIP Statistical Information System (MSIS): File Specifications and Data Dictionary
Medicare Chronic Condition Data Warehouse	1. Chronic Condition Data Warehouse User Guide 2. Summary Statistics 3. Data Dictionaries 4. Chronic Conditions 5. Analytic Guidance
CFAR Network of Integrated Clinical Systems	1. CNICS Data Elements
Indian Health Service	1. HIS Clinical Reporting System (BGP): Selected Measures (Local) Report Performance Measure List and Definitions
Federal Bureau of Prisons	1. Management of HIV: Federal Bureau of Prisons Clinical Practice Guidelines—May 2011
Housing Opportunities for Persons with AIDS	1. Annual Progress Report (APR): Measuring Performance Outcomes 2. Consolidated Annual Performance Evaluation Report (CAPER): Measuring Performance Outcomes 3. Homeless Management Information System (HMIS) Data Standards, Revised Notice—March 2010

*Link to 2009 version of MMP data collection materials.

Link/s
1. http://health.utah.gov/epi/forms/Adult%20HIV.AIDS%20Report%20Form.pdf
1. http://www.cdc.gov/hiv/topics/treatment/MMP/pdf/MMP_2009_MRA_MHF_v400_OMB_Race_Jan5_2009.pdf 2. http://www.cdc.gov/hiv/topics/treatment/MMP/pdf/MMP_2009_MRA_SPIF_v400_Jan5_2009.pdf 3. http://www.cdc.gov/hiv/topics/treatment/MMP/pdf/MMP_2009_MRA_SPSF_v400_Jan5_2009.pdf 4. http://www.cdc.gov/hiv/topics/treatment/MMP/pdf/MMP_2009_MRA_SPVF_v400_Jan5_2009.pdf 5. http://www.cdc.gov/hiv/topics/treatment/MMP/pdf/2009MMPStandardEnglish.pdf 6. http://www.cdc.gov/hiv/topics/treatment/mmp/pdf/2011_english_response_cards.pdf
1. http://hab.hrsa.gov/manageyourgrant/files/habadrclientlevelvariables.pdf 2. http://hab.hrsa.gov/manageyourgrant/files/adrgranteeleveldatavariablesfinal.pdf 3. http://hab.hrsa.gov/manageyourgrant/adap/adapformfeb08.pdf
1. http://hab.hrsa.gov/manageyourgrant/files/clientleveldatafields.pdf
1. http://www.ccwdata.org/cs/groups/public/documents/document/ccw_max_user_guide.pdf 2. https://www.cms.gov/msis/downloads/msisdd2010.pdf
1. http://www.ccwdata.org/cs/groups/public/documents/document/ccw_userguide.pdf 2. http://www.ccwdata.org/summary-statistics/index.htm 3. http://www.ccwdata.org/data-dictionaries/index.htm 4. http://www.ccwdata.org/chronic-conditions/index.htm 5. http://www.ccwdata.org/analytic-guidance/index.htm
1. http://www.uab.edu/cnics/data-core/cnics-data-elements
1. http://www.ihs.gov/cio/crs/documents/crsv11/SelectedMeasuresV11_1.pdf
1. http://www.bop.gov/news/PDFs/mgmt_hiv.pdf
1. http://www.hudhre.info/documents/APR_HOPWA.docx 2. http://portal.hud.gov/hudportal/documents/huddoc?id=hopwa_caper_10312014.doc 3. http://www.hudhre.info/documents/FinalHMISDataStandards_March2010.pdf

APPENDIX TABLE 3-5 CD4 and Viral Load Reporting by HIV Surveillance Reporting Area (as of June 15, 2010)

CD4 count (cells/μL)	
Reportable Level All Values	Reportable Level <200
Alaska, Arkansas, California, Delaware, Florida, Georgia, Hawaii, Illinois, Indiana, Iowa, Kentucky, Louisiana, Maine, Maryland, Massachusetts,* Michigan, Minnesota, Mississippi, Missouri, Nebraska, New Hampshire, New York, North Dakota, Oregon, South Carolina, South Dakota, Texas, Utah, Virginia, Washington, West Virginia, Wyoming	Alabama, Arizona, Connecticut, Idaho, New Jersey, New Mexico, North Carolina, Ohio, Pennsylvania, Rhode Island, Tennessee, Vermont, Wisconsin
District of Columbia	
Guam, Puerto Rico	U.S. Virgin Islands

Viral Load	
Reportable Level Any Result	Reportable Level Detectable
Alaska, Arkansas, California, Colorado, Connecticut, Delaware, Florida, Georgia, Hawaii, Illinois, Indiana, Iowa, Louisiana, Maine, Maryland, Massachusetts*, Michigan, Minnesota, Mississippi, Missouri, Nebraska, New Hampshire, New Jersey, New Mexico, New York, North Dakota, Oklahoma, Oregon, South Carolina, South Dakota, Texas, Utah, Vermont, Virginia, Washington, West Virginia, Wisconsin, Wyoming	Arizona, Idaho, Kansas, Kentucky, Montana, Nevada, North Carolina, Ohio, Pennsylvania, Rhode Island, Tennessee
District of Columbia	
Guam, Puerto Rico	U.S. Virgin Islands

*As of January 2012.

SOURCES: Personal Communication, Amy Lansky, Centers for Disease Control and Prevention, October 6, 2011; Massachusetts Department of Public Health, 2012.

Reportable Level <500	No Reporting
Colorado, Kansas, Nevada, Oklahoma	Montana
	American Samoa; Marshall Islands; Micronesia, FS; N. Mariana Islands; Palau

	No Reporting
	Alabama
	American Samoa; Marshall Islands; Micronesia, FS; N. Mariana Islands; Palau

4

Barriers to the Collection of HIV Care Data

This chapter addresses question 4 from the committee's statement of task on barriers to the collection of data to measure core indicators for clinical HIV care and for mental health, substance use, and supportive services. The committee was specifically asked to describe policy, reimbursement, and reporting issues that need to be addressed to collect necessary data (statement of task question 4a). Because the reimbursement and reporting barriers to the collection of data are sometimes linked to policies, the chapter begins with a discussion of those barriers and then describes other policy barriers to the collection of data. The chapter addresses how data can be collected in a way that will not significantly increase burden (statement of task question 4b) within the section on reporting barriers. The chapter ends with the committee's conclusions and recommendation pertaining to this portion of its charge.

POTENTIAL REIMBURSEMENT-RELATED BARRIERS TO THE COLLECTION OF HIV CARE DATA

Reimbursement-related barriers to the collection of data on care and supportive services received by people living with HIV/AIDS (PLWHA) are to a large extent specific to claims data, as providers enter services rendered into claims systems in order to receive reimbursement for those services. As described in Chapter 2, there are several advantages to the use of claims data for health care research. For example, claims data represent a large quantity of data, can be made anonymous and used without patient authorization, and are available in an electronic format for easier transmission. Claims data are an especially important source of information on care received by PLWHA given the large number who are Medicaid beneficiaries: an estimated 47 percent of PLWHA who were receiving regular medical care were Medicaid beneficiaries in FY 2007 (Kates, 2011). As more PLWHA become eligible for Medicaid and commercial health insurance as a result of the Patient Protection and Affordable Care Act (ACA, P.L. 111-148), claims data are likely to become an even more useful source of data for monitoring HIV care. Despite the many advantages of claims data, the influence of reimbursement policies needs to be taken into consideration when using claims data for health services research (Crystal et al., 2007).

Health plan reimbursement policies may "carve out" certain services such as behavioral health, transportation, dental, and pharmacy benefits so that a separate organization is responsible for payment. As a result, the primary insurer may not have a record of the carved-out service in its claims data (Hicks, 2003; Joins et al., 2007). Carve-out arrangements are often used in the Medicaid program when Medicaid managed care organizations (MCOs) contract with other entities to provide services to which beneficiaries are entitled, as per the state Medicaid agencies' contract with the MCO.[1] An MCO may decide to carve out a benefit because it lacks in-house expertise to meet a particular patient need or because it does not have the infrastructure necessary to administer a benefit (e.g., transportation services) (Joins et al., 2007). Carve-out arrangements parse benefits out to multiple entities, and it is often challenging for these entities to communicate and exchange data with one another in order to coordinate patient care effectively (Joins et al., 2007).[2] Carve-outs may also make it difficult to combine data at the patient level for research or monitoring purposes. Carve-out arrangements may pose a challenge to the estimation of indicators that require prescription drug dispensing data, or data on receipt of mental health or transportation services, since these services are among those that are most likely to be carved out of a health plan.

A health plan's claims data also will not contain data on care for which

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[1] In FY 2007, 71 percent of Medicaid enrollees with HIV had some of their care paid for through Medicaid managed care (Kates, 2011).

[2] The Lewin Group performed an assessment of carve-out and carve-in arrangements for pharmacy benefits within Medicaid MCOs (Joines et al., 2007). Among the advantages to MCOs with carve-in arrangements were that providers were more likely to have real-time access to pharmaceutical data to help prevent potential drug interactions and polypharmacy (unwanted duplication of drugs), identify inappropriate use of drugs, monitor controlled substance usage, and other interventions. Some representatives of carve-out MCOs reported that they do not always have access to real-time claims data to determine what medications patients are taking. The report noted the importance of data system integration to ensure real-time transfer of pharmaceutical information, both for MCOs that carve their pharmaceutical services out to other entities and for carve-in MCOs who may contract with a pharmacy benefits management group to manage pharmacy benefits (Joines et al., 2007).

a patient pays out of pocket or for which a claim is submitted before a deductible is exceeded (Hicks, 2003). In other cases, services may not be documented because they are provided by nonphysicians or by contract practitioners and providers who cannot be reimbursed for the service. Some state Medicaid agencies limit the types of providers and practitioners that can bill and receive reimbursement, for example (Bachman et al., 2006). Furthermore, some states limit the number of services that can be billed to Medicaid on the same day (e.g., state Medicaid restrictions on same-day billing for a physical health and a mental health service or visit), which may result in inaccurate or incomplete documentation (Kautz et al., 2008).

Another general source of inaccuracy in claims data that is tied to reimbursement is inappropriate or incomplete coding. Providers may not use all applicable codes as a way to reduce administrative burden,[3] exaggerate condition severity by entering alternate coding as a way to ensure payment, or enter alternate diagnoses for sensitive conditions such as mental illness or HIV in order to protect patients' confidentiality and insurability (Hicks, 2003).

As will be discussed in greater detail in Chapter 5, effective use of health information technology (health IT) can make for easier collection and exchange of care delivery data. To reap its full benefits, health IT will have to be adopted across insurers and a growing number of providers. However, a number of surveys show that adoption of electronic health records (EHRs) and other health IT products is occurring slowly in settings where PLWHA receive care.[4] The cost to implement and maintain health IT systems is a frequently cited barrier to adoption (Lardiere, 2009; Rao et al., 2011; Reardon and Davidson, 2007). A 2011 study estimated the cost of implementation of an EHR into a physician practice to be $162,000 during the first year (Fleming et al., 2011).

The Health Information Technology for Economic and Clinical Health (HITECH) Act, a component of the American Recovery and Reinvestment Act of 2009 (ARRA, P.L. 111-5), helps to reimburse providers for some of the costs for implementation of EHRs by authorizing incentive payments through Medicare and Medicaid to health care professionals and

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[3] Surveys of physicians show that there is substantial administrative burden associated with reimbursement processes under Medicaid and Medicare (AMA, 2010; Cunningham and O'Malley, 2009). This administrative burden includes payment delays, rejection of claims because a billing form was completed incorrectly or the physician was not able to verify a patient's eligiblity, and complex rules and regulations on how claims are to be filed (Cunningham and O'Malley, 2009).

[4] An electronic health record (EHR) is an electronic record of health-related information on an individual that conforms to nationally recognized interoperability standards and that can be created, managed, and consulted by authorized clinicians and staff across more than one health care organization (HHS, 2008).

hospitals that implement certified EHRs and demonstrate certain usage requirements.[5] This support is likely to increase EHR usage by HIV care providers owing to the large number of PLWHA who have Medicare and/or Medicaid coverage. A continuing obstacle to EHR adoption may be the inability of some providers to cover the upfront costs of implementation, however, since providers are reimbursed after demonstrating usage requirements. Some have argued that under current provider reimbursement models, the larger share of the monetary benefit from health IT goes to health care payers (e.g., insurers) and that often the users of health IT (e.g., HIV care providers) do not experience much in the way of financial benefit (e.g., Johnston et al., 2003; PCAST, 2010; Sittig and Singh, 2011). This could be a barrier to implementation or continued use of EHRs. In addition, questions remain about the role of commercial health insurers, who are major payers in many care settings, in funding health IT implementation (Sittig and Singh, 2011). Although most HIV care is financed through public programs, the number of PLWHA who are eligible for commercial health insurance is likely to grow under the ACA.

POTENTIAL REPORTING-RELATED BARRIERS TO THE COLLECTION OF HIV CARE DATA

The ability to monitor trends in HIV care depends on accurate and timely reporting of data by HIV care providers, laboratories, health departments, and other entities. For example, estimation of several of the committee's recommended indicators for clinical HIV care require accurate estimates of the number of people living with diagnosed HIV infection in the United States, as well as CD4 and viral load testing information, reported for state and local as well as national HIV/AIDS surveillance purposes.

As of April 2008, all 50 states, the District of Columbia, and 6 dependent areas had implemented confidential name-based HIV case reporting (in addition to AIDS case reporting), where the names of individuals who test positive for HIV are reported to state or local public health authorities (CDC, 2010) (Table 4-1). Some research has shown underreporting of HIV/AIDS cases by health care providers and laboratories to public health authorities (Hall et al., 2006). Past studies conducted in different geographic

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[5] Under a Medicare EHR incentive program, eligible health professionals can receive as much as $44,000 over a 5-year period. Incentive payments for hospitals and critical access hospitals (CAHs) are based on a number of factors and begin with a $2-million base payment. Under a Medicaid EHR incentive program, eligible health professionals can receive up to $63,750 over 6 years. As under the Medicare program, incentive payments for hospitals and CAHs under the Medicaid program are based on a number of factors and begin with a $2-million base payment (CMS, 2012).

areas and years show a range of AIDS case reporting completeness of 60 to 98 percent (Buehler et al., 1992; Doyle et al., 2002; Greenberg et al., 1993, Jara et al., 2000; Rosenblum et al., 1992; Schwarcz et al., 1999). These studies were limited in that they assessed completeness of reporting for a specific geographic area or for an isolated time period (Hall et al., 2006). Attempting to address the weaknesses of previous studies, Hall and colleagues (2006) used capture-recapture methods to assess the completeness of HIV and AIDS case data reported to surveillance programs during October 1, 2002 to September 30, 2003. Over the 1-year period, 11,266 HIV diagnoses were reported to surveillance programs in four states and two cities. The estimated completeness of reporting of HIV diagnoses was 76 percent when allowing 6 months of reporting delay and increased to 81 percent with 12 months of follow up. The estimated completeness of AIDS diagnoses reported to seven states and two cities (11,079 AIDS diagnoses were reported) was 77 percent when allowing 6 months of a reporting delay (Hall et al., 2006). Based on this research, in part, the CDC estimates the completeness of reporting of HIV infection to be more than 80 percent (CDC, 2010).

Barriers to the reporting of notifiable diseases, including HIV/AIDS, may include lack of awareness of reporting requirements and procedures on the part of providers, human error, lack of motivation, and poor system processes (Lazarus et al., 2009; Overhage et al., 2008; Turnberg et al., 2010). Evidence suggests that automated electronic reporting facilitates more accurate and complete reporting of notifiable diseases to public health authorities. For example, Overhage and colleagues (2008) found that use of an automated electronic laboratory reporting (ELR) system to report notifiable conditions to health departments serving Indianapolis, Indiana, identified 4.4 times as many cases of such conditions as traditional, spontaneous, paper-based methods, likely by helping to overcome some of the barriers noted above. The ELR system also identified cases about 8 days earlier than spontaneous reporting (Overhage et al., 2008). Despite substantial progress in the implementation of electronic reporting, some reporting mechanisms still depend on practitioner-initiated manual data entry and submission, which are more likely to result in delayed and inaccurate data (Lazarus et al., 2009).

State and local HIV/AIDS surveillance systems collect additional laboratory information on established, reported cases of HIV/AIDS, such as CD4 and viral load counts. These data are used for surveillance purposes, such as to verify existing cases of HIV/AIDS, to identify potential new cases, and to evaluate unmet medical need (CSTE, 2009). HIV diagnostic CD4 count and HIV viral load test results are reportable from clinical, hospital, laboratory, or other authorities in all but a few U.S. states and territories (CSTE, 2011). However, as is discussed in Chapter 3, states currently vary

TABLE 4-1 HIV Testing and Reporting Policies

State or Territory	C/A	HIV Reporting	Name Reporting Implementation	State or Territory	C/A	HIV Reporting	Name Reporting Implementation
Alabama	C	Name	1988 Jan	New Hampshire	C, A	Name	2005 Jan
Alaska	C, A	Name	1999 Feb	New Jersey	C, A	Name	1992 Jan
Arizona	C, A	Name	1987 Jan	New Mexico	C, A	Name	1998 Jan
Arkansas	C, A	Name	1989 Jul	New York	C, A	Name	2000 Jun
California	C, A,	Name	2006 Apr	North Carolina	C	Name	1990 Feb
Colorado	C, A	Name	1985 Nov	North Dakota	C	Name	1988 Jan
Connecticut	C, A	Name	2005 Jan	Ohio	C, A	Name	1990 Jun
Delaware	C, A,	Name	2006 Feb	Oklahoma	C, A	Name	1988 Jun
District of Columbia	C, A	Name	2006 Nov	Oregon	C, A	Name	2006 Apr
Florida	C, A	Name	1997 Jul	Pennsylvania	C, A	Name	2002 Oct
Georgia	C, A	Name	2003 Dec	Rhode Island	C, A	Name	2006 Jul
Hawaii	C, A	Name	2008 Mar	South Carolina	C	Name	1986 Feb
Idaho	C	Name	1986 Jun	South Dakota	C	Name	1988 Jan
Illinois	C, A	Name	2006 Jan	Tennessee	C	Name	1992 Jan
Indiana	C, A	Name	1988 Jul	Texas	C, A	Name	1999 Jan

Iowa	C	Name	1998 Jul	Utah	C, A	Name	1989 Apr
Kansas	C, A	Name	1999 Jul	Vermont	C, A	Name	2008 Apr
Kentucky	C, A	Name	2004 Oct	Virginia	C, A	Name	1989 Jul
Louisiana	C, A	Name	1993 Feb	Washington	C, A	Name	2006 Mar
Maine	C, A	Name	2006 Jan	West Virginia	C, A	Name	1989 Jan
Maryland	C, A	Name	2007 Apr	Wisconsin	C, A	Name	1985 Nov
Massachusetts	C, A	Name	2007 Jan	Wyoming	C, A	Name	1989 Jun
Michigan	C, A	Name	1992 Apr	American Samoa	C, A	Name	2001 Aug
Minnesota	C, A	Name	1985 Oct	Guam	C, A	Name	2000 Mar
Mississippi	C	Name	1988 Aug	North Mariana Islands	C, A	Name	2001 Oct
Missouri	C, A	Name	1987 Oct	Palau	C	Name	2005 Oct
Montana	C, A	Name	2006 Sept	Puerto Rico	C, A	Name	2003 Jan
Nebraska	C, A	Name	1995 Sept	U.S. Virgin Islands	C	Name	1998 Dec
Nevada	C	Name	1992 Feb				

NOTE: A = anonymous; C = confidential.
SOURCE: Adapted from KFF, 2011.

with respect to the level at which viral load and CD4 test results are reportable. In several states, CD4 cell counts of less than 500 or 200 cells/mm^3 are reportable, whereas in other states all CD4 values are reportable. In addition, some states do not report undetectable viral load results (see Chapter 3, Appendix Table 3-5) (Personal communication, Amy Lansky, Centers for Disease Control and Prevention, October 6, 2011). The variability in the legislation and regulations for reporting may result in differences in the completeness of data and make it difficult to compare these measures across states and territories. The committee recommends (see Recommendation 3-2 in Chapter 3) that CDC take steps to enhance HIV/AIDS surveillance by issuing guidelines or criteria for National HIV Surveillance System reporting to include all CD4 and viral load test results.

Non-reporting of HIV/AIDS cases identified at anonymous testing sites may be another barrier to the completeness of surveillance data. Health departments introduced anonymous HIV testing early in the HIV epidemic because of the unique stigma attached to HIV and concern that fear of potential breaches in confidentiality might deter individuals from testing (Markovitz et al., 2011). Unlike confidential HIV testing where an individual's name is recorded with her or his test result, in anonymous HIV testing a number or code is linked to the test, and only the individual being tested knows the code. Individuals who test positive for HIV at anonymous testing sites are not reported to state or local health departments unless they choose to have their test results converted from anonymous to confidential (CDC, 2011b). Anonymous testing is an important service. Research has shown that it contributes to earlier testing as well as medical care (as defined by the average number of days in HIV-related medical care before an AIDS diagnosis) (Bindman et al., 1998). A recent study of public testing sites in Colorado and Washington state showed that anonymous testers were significantly more likely to have CD4+ cell counts >500 cells/mm^3, suggesting an earlier stage of HIV infection. Yet because anonymous tests are not reported to confidential HIV/AIDS surveillance systems, surveillance data may not be representative of individuals who are tested at anonymous testing sites (CDC, 1999, 2011b).[6] Research on the demographic characteristics of anonymous testers shows that they are often MSM and younger, more often white, and more likely to report more years of education than individuals who receive confidential testing (Markovitz et al., 2011). Most U.S. states and territories currently offer both anonymous and confidential HIV testing, although some have only confidential testing (Table 4-1).

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[6] In addition, in a 2007 survey of HIV/AIDS surveillance capacity in health departments, only 20 percent of health departments responded that it is permissible in their jurisdiction for a provider or laboratory to report a new HIV or AIDS case without a name or other personal identifier (CSTE, 2009).

Many cases of HIV/AIDS identified at anonymous testing sites, along with CD4 count and viral load information, are added to surveillance after individuals enter care.

One of the core functions of health departments in response to the HIV epidemic is the collection and analysis of data on the number of PLWHA and demographic data on individuals who receive services through federally funded HIV/AIDS programs within a jurisdiction (NASTAD, 2007). The data are compiled and analyzed at the local and national levels and serve as the basis for decision making about funding to state and local health departments to support HIV/AIDS programs. Sharing of identifiable health information across health departments is often necessary to link data for individuals who receive HIV care and supportive services across multiple jurisdictions. However, local laws designed to protect identifiable information may inhibit data sharing among state public health authorities, compromising the accuracy of the analysis of and conclusions drawn from the data (Hodge et al., 2011; Personal communication, Carmine Grasso, New Jersey Department of Health and Senior Services, August 9, 2011).[7]

Funding mechanisms can result in inadequate resources within health departments to support activities related specifically to data collection and analysis. When data collection and analysis activities are funded, they may be lumped into the category of administrative costs, which may result in inadequate allocation of financial and staff resources to these activities. For example, due to budget constraints that impede the employment of staff with expertise in data collection and analysis, health departments may delegate data collection and analysis activities to support staff who may not be sufficiently trained to perform these activities (Personal communication, Carmine Grasso, New Jersey Department of Health and Senior Services, August 9, 2011).

Reducing Provider Reporting Burden

Grantees of federally funded HIV/AIDS programs are an important source of HIV care and supportive services data. To comply with funding requirements, grantees must generate and submit to federal agencies numerous programmatic reports. These reports contain program information that can inform how well the clinical care and supportive services needs of PLWHA are being met locally and nationally. The range of data contained in such reports includes, but is not limited to, the number and demographics of PLWHA within a specific jurisdiction or provider setting who receive

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[7] The CDC issued guidance on standards for data security, confidentiality, and use across surveillance and program areas for HIV, viral hepatitis, STD, and TB prevention in state and local health jurisdictions in December 2011 (CDC, 2011a).

medical services, pharmaceutical assistance, and supportive services such as housing assistance, as well as information on the provision of care and supportive services to communities that are disproportionately affected by HIV.

As the recipients of numerous core and supplemental HIV/AIDS grant awards, health departments are central to the collection and reporting of data to monitor progress in achieving NHAS goals. However, health departments are currently overburdened with myriad grant-related administrative activities. The scope of reporting requirements for state health departments in 2010 included 96 reports for core and supplemental (e.g., STD and viral hepatitis) HIV/AIDS grant awards (Figure 4-1). Reporting includes several hundred specific variables (NASTAD, 2011; PACHA, 2011). Furthermore, the National Alliance of State and Territorial AIDS Directors (NASTAD) reports that the current requirements for reporting on program planning, progress, and performance measures are project specific and inconsistent across related programming (e.g., HIV prevention and STD prevention and control; HIV prevention and HIV/AIDS care). Thus, health departments must modify their reporting practices to meet the specifications of each grant. Projects also operate on different grant cycles, which further complicates reporting. There is also substantial duplication in reporting practices owing to differences in the schedules for reporting on program progress and for local disease reporting and service data collection and validation. Health departments often must submit incomplete or inaccurate data on program progress, and then resubmit the data after local data are updated (to ensure the accuracy and completeness of program progress reports) (NASTAD, 2012).[8]

According to the Presidential Advisory Council on HIV/AIDS (PACHA), the current reporting requirements for grantees of federally funded programs have not resulted in a set of metrics by which to thoroughly monitor the HIV epidemic. Nor have they yielded data of sufficient quality to effectively evaluate and manage federal HIV/AIDS programs (PACHA, 2011). A smaller number of key metrics that are relevant to NHAS goals could be used across federal agencies to monitor progress in managing the epidemic. Use of metrics that are comparable across funding agencies would also help to streamline reporting requirements for grantees (PACHA, 2011). While the committee was preparing this report, there was an effort under way by the U.S. Department of Health and Human Services (HHS) to identify a uniform set of HIV-related metrics to be used across funding agencies and reduce reporting burden (HHS, 2011; Valdiserri and Forsyth,

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[8] In addition, many health departments currently face staff challenges that affect reporting capacity. Budget cuts in many states' HIV/AIDS and other infectious disease programs in health departments have resulted in hiring freezes and the elimination of staff positions, resulting in less capacity for the completion of the required reports (NASTAD, 2010).

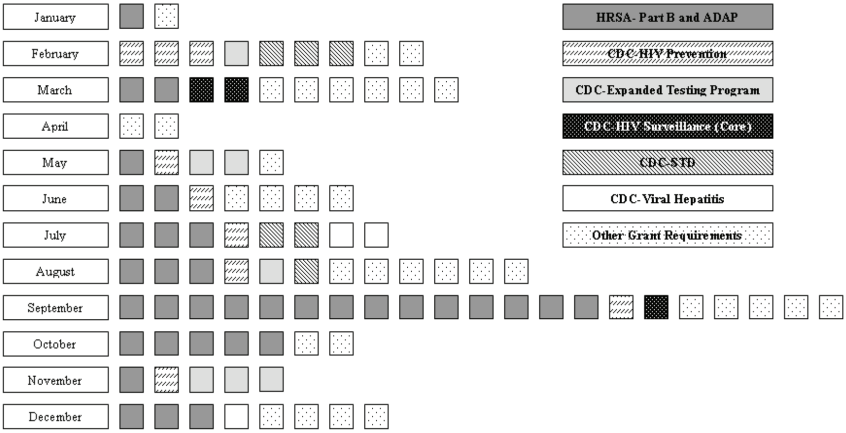

FIGURE 4-1 Federal reporting requirements for core and supplemental HIV/AIDS grant awards administered by state health department HIV/AIDS directors.
SOURCE: Adapted from NASTAD, 2011.

2011). The committee supports this current effort and recommends that it be maintained and institutionalized (see recommendation 4-1 at the end of this chapter) so that data needs can be periodically reprioritized based on changes in the HIV epidemic and to facilitate continued minimization of grantee reporting burden.

Legislative action may also be necessary to reduce reporting burden in certain instances because some of the overlapping and duplicative reporting activities are delineated in federal legislative or appropriations language. For example, per its authorizing legislation, the Ryan White HIV/AIDS Program contains multiple parts. Each part includes several different funding components and requirements that are often in conflict, duplicative, and may be burdensome for grantees.

In addition to health departments, sites that provide direct clinical care and supportive services to PLWHA could stand to benefit from the use of a streamlined set of metrics for HIV monitoring. Such entities, such as community health centers (CHCs), may themselves be the direct grantees of federally funded HIV/AIDS core or supplemental programs and report program data to funding agencies, or they may provide data to health departments that are then incorporated into reports for federal agencies.

Providers of HIV clinical care and supportive services have many competing responsibilities and restrictions (e.g., budget or expertise related) on the amount of staff time that can be devoted to reporting activities. As potential users of the collected data, the various providers of HIV care and supportive services can be involved in decision making about what data are important to collect as well as processes for collecting them. Early and continuous dialogue with providers about the data collection process can help to identify and address any concerns in a timely fashion, and perhaps help to reduce reporting burden later on. Some federal HIV/AIDS data collection efforts are already informed by such input. As one example, proposed data variables for the Health Resources and Services Administration's (HRSA's) AIDS Drug Assistance Program Data Report were vetted with Ryan White HIV/AIDS Program grantees (CareActTarget.org, 2011).

OTHER POLICY BARRIERS TO THE COLLECTION OF HIV CARE DATA

Several other laws and policies may present obstacles to the collection of data elements needed to estimate the committee's recommended core indicators. These include federal and state policies that result in a fragmented health care system, as well as federal and state policies pertaining to the disclosure of health information.

Federal and State Policies That Result in a Fragmented Health Care System

There are multiple sources of care and care coverage for PLWHA in the United States. PLWHA who are insured and in the health care system rely heavily on public insurance programs (i.e., Medicaid, Medicare, both) to finance their care. PLWHA who are uninsured or underinsured rely on safety net programs such as the Ryan White HIV/AIDS Program, CHCs, and public hospitals. Other PLWHA are privately insured. Care for many PLWHA is financed through multiple sources (KFF, 2004).

The multiple sources of care and care coverage are uncoordinated, making it difficult for patients to navigate care. Furthermore, eligibility for these programs depends on factors such as health or disability status, family status, employment status and income, and assets that will vary over time for any given individual (Table 4-2). Eligibility for programs also varies widely by state, particularly for Medicaid and the Ryan White HIV/AIDS Program. Thus, a person may be eligible for a program in one state but not in another, and not all states have the same coverage and care programs (KFF, 2004).[9] As PLWHA lose access to care or move from one source of

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[9] Many PLWHA migrate to different jurisdictions following an HIV diagnosis. One study of migration patterns after HIV diagnosis among 760 HIV-infected adults residing in the southern United States found that 226 (30 percent) moved after testing HIV positive (Agee et al., 2006). In another study involving a national probability sample of 3,014 PLWHA, 17 percent of respondents made a move to a different state or noncontiguous county following an HIV diagnosis. These findings suggested that PLWHA are more likely to move than non-infected

care or care coverage to another, there may be gaps or losses in care data, or duplicate records, which can complicate collection of data needed to estimate the indicators recommended by the committee.

Some provisions of the ACA will not be implemented by states uniformly, resulting in state variation in eligibility of PLWHA for health insurance and, by consequence, access to health care. One of several examples relates to the establishment of health insurance exchanges that will serve as points of access to commercial health insurance for individuals and employers. The ACA sets broad parameters for the exchanges, but states are given flexibility on several features, such as 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). In many states, legislation has been proposed to alter or oppose provisions of the ACA. Resulting differences in access to health care by state will have to be taken into consideration for the collection and use of program data for purposes of monitoring the impact of the ACA on improvements in HIV care.

In the current fragmented health care system, the various sources of care and care coverage often have their own policies relating to the sharing of data. Data from private sources, such as commercial health insurers, may be proprietary, for example. As noted earlier in this chapter, local privacy laws and lack of data sharing mechanisms among state and local public health authorities can impede the collection and analysis of surveillance data (Personal communication, Carmine Grasso, New Jersey Department of Health and Senior Services, August 9, 2011).

Federal and State Laws Pertaining to the Disclosure of Health Information

Privacy of personal health information is a concern for many PLWHA. Fears of breaches in confidentiality and resulting HIV stigma can result in individuals not accessing or adhering to care and treatment (Kempf et al., 2010; Whetten-Goldstein et al., 2001). When personally identifying information is disclosed, it can result in stigma, embarrassment, and discrimination. Without some assurance of privacy, people may be disinclined to provide honest and complete disclosures of sensitive information, even to their physicians (IOM, 2009). This section discusses federal and state privacy laws designed to protect patient health information and how these laws may influence the collection of HIV care data for purposes of estimating the core indicators recommended by the committee.

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persons in the general population and are almost twice as likely to move out of state (Berk et al., 2003). Reasons for moving, especially for PLWHA in small or rural communities, may be to gain access to better HIV medical care, to obtain financial assistance, or due to fear of stigma and confidentiality issues (Agee et al., 2006; Berk et al., 2003).

TABLE 4-2 Potential Eligibility Criteria for Care Coverage for PLWHA, by Major Payer/Source

	Medicaid	Medicare	Private (employer)	Private (individual)	Ryan White
	Both low income and categorically eligible	Seniors or under-65 disabled	Job-based	Individual market-based	Low income and uninsured or underinsured
Income/asset test	Yes	No	N/A, but costs involved	N/A, but costs involved	Yes
U.S. citizen	Yes	Yes	Not necessarily	Not necessarily	No
Preexisting condition limit	No	No	Some limits	Yes, in most states	No
State variation	Yes	No	Yes	Yes	Yes
Capped funding	No	No	Yes	Yes	Yes
HIV-specific program	No	No	No	No	Yes

NOTE: N/A = Not applicable.
SOURCE: KFF, 2010.

Health Insurance Portability and Accountability Act Privacy Rule

At the federal level, the sharing and use of people's health information is governed primarily by the Health Insurance Portability and Accountability Act (HIPAA, P.L. 104-191), which was enacted by Congress in 1996 with the goals of making health care delivery more efficient and increasing the number of Americans with health insurance. The HIPAA Privacy Rule was developed under administrative simplification provisions of the HIPAA, instructing the HHS Secretary to issue regulations concerning electronic transmission of health information, which was increasing in the early 1990s (IOM, 2009). The Privacy Rule standardizes requirements for disclosure of individually identifiable protected health information (PHI) related to "an individual's past, present, or future physical or mental health condition; the provision of health care to the individual; or, the past, present, or future payment for the provision of health care to the individual" (HHS, 2003).

PHI includes names, all geographic subdivisions smaller than a state, all elements of dates (except year) directly related to an individual, Social Security numbers, and other information.[10] Data elements to estimate indicators of HIV care that are recommended by the committee (see Chapter 2) that may be considered PHI include zip code, several date-based elements (e.g., date of HIV diagnosis, dates of viral load and CD4 counts), and age.

The Privacy Rule applies to health plans, health care providers, and health care clearinghouses that electronically transmit health information in connection with certain health care transactions[11] (HHS, 2003). These entities are collectively designated as "covered entities" (Box 4-1). Covered entities, which include providers of care and care coverage to PLWHA, are required to obtain patient authorization before using or disclosing PHI to third parties, except under the following circumstances:

- To the individual (unless required for access or accounting of disclosures);
- For treatment, payment, and health care operations;

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[10] The full list of PHI includes the following: names; postal address information, other than town or city, state and zip code; telephone numbers; fax numbers; electronic mail addresses; Social Security numbers; medical record numbers; health plan beneficiary numbers; account numbers; certificate or license numbers; vehicle identifiers and serial numbers, including license plate numbers; device identifiers and serial numbers; web Universal Resource Locators (URLs); Internet Protocol (IP) address numbers; biometric identifiers, including finger- and voiceprints; and full face photographic images and any comparable images. 45 CFR § 164.514(e)(2) (HHS, 2003).

[11] These transactions include claims, benefit eligibility inquiries, referral authorization requests, or other transactions for which HHS has established standards under the HIPAA Transactions Rule (HHS, 2003).

- To provide an individual the opportunity to agree or object to uses and disclosures of PHI (informal permission);
- For purposes of an incident to an otherwise permitted use and disclosure (i.e., a secondary use or disclosure that cannot reasonably be prevented, is limited in nature, and occurs as a result of another permitted use or disclosure);
- For public interest and benefit activities; and
- For a Limited Data Set for the purposes of research, public health or health care operations (HHS, 2003).

The permitted use and disclosure of PHI without patient authorization for "public interest and benefit activities" is particularly relevant to the public health goal of monitoring improvement in HIV care. Under this exception, covered entities may disclose PHI for public health activities—for example, to public health authorities as required by law to prevent and

BOX 4-1
HIPAA Privacy Rule–Covered Entities

Health Care Provider

- Doctors
- Clinics
- Psychologists
- Dentists
- Chiropractors
- Nursing Homes
- Pharmacies

Health Plans

- Health insurance companies
- Health maintenance organizations (HMOs)
- Company health plans
- Government programs that pay for health care, such as Medicare, Medicaid, and the military and veterans health care programs, and the Indian Health Service

Health Care Clearinghouses

This includes entities that process nonstandard health information they receive from another entity into a standard (i.e., standard electronic format or data content), or vice versa.

Other

- Researchers employed by a covered entity
- Some universities (or parts of universities, such as health centers)
- A public health clinic that is part of a public health agency

SOURCES: HHS, 2003; IOM, 2009.

control disease (such as HIV/AIDS), injury, and disability. Public health activities include, but are not limited to, "reporting of disease, injury, and vital events, and conducting public health surveillance, investigations, and interventions" (CDC, 2003). Examples of public health authorities include the CDC and state and local health departments, which is why providers are permitted to report new HIV and AIDS cases with patient identifying information to area public health authorities.[12] PHI also may be disclosed to health oversight agencies for activities such as audits and investigations necessary for administration of the health care system and government benefit programs (HHS, 2003). Disclosure of PHI by covered entities to HRSA's HIV/AIDS Bureau (HAB) for purposes of monitoring and assessing its grants is permitted under the health oversight exception, for example (HRSA, 2010). PHI may also be released for research, defined as "a systematic investigation, including research development, testing, and evaluation, designed to develop or contribute to generalizable knowledge" [45 CFR. §164.501] (HHS, 2003).

The collection of data for purposes of monitoring HIV care may also occur under the Limited Data Set permitted use and disclosure, which may be used for public health, health care operations, or research activities (HHS, 2003). A Limited Data Set is PHI that excludes direct identifiers of an individual, her or his relatives, employers, or household members, but may include the following:

- Geographic data other than street address (town, city, state, zip code);
- Dates relating to an individual (dates of birth, admission, and discharge); and
- Other unique identifying characteristics or codes not listed as direct identifiers (HHS, 2003).

Covered entities are required to condition their disclosure of a limited data set to third parties on establishment of a data use agreement.[13]

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[12] "Public health authorities" are "legally authorized to collect or receive the information for purposes of preventing or controlling disease, injury, or disability." They include any "entity working under a grant of authority from a public health authority, or when directed by a public health authority, to a foreign government agency that is acting in collaboration with a public health authority" (CDC, 2003).

[13] A data use agreement establishes the permitted uses and disclosures of such information by the recipient, consistent with the purposes of research, public health, or health care operations; limits who can use or receive the data; and requires the recipient to agree not to reidentify the data or contact the individuals. The agreement must contain assurances that the recipient will use appropriate safeguards to prevent use or disclosure of the data other than as permitted by HIPAA and the data use agreement, or as required by law (OCR, 2003).

HIPAA-covered entities may not disclose data on "small cells" or for data elements for which there is a very small number of observations. For example, there may be a small number of HIV cases among a subpopulation in a geographic area, and release of the data could reveal an individual's identity. This could be an impediment to analysis of subpopulations of PLWHA.

The Privacy Rule does not apply to health information that has been de-identified in accordance with the Privacy Rule (HHS, 2003).[14] Limited data sets differ from de-identified information in that they may contain dates and some geographic information associated with an individual that are absent from de-identified information.

Several of the data systems identified in Chapter 3 as important for monitoring indicators of HIV care are maintained within HIPAA-covered entities (i.e., Medicaid Statistical Information System [MSIS], CMS Chronic Condition Data Warehouse [CCW], Kaiser Permanente, North American AIDS Cohort Collaboration on Research and Design [NA-ACCORD], CFAR Network of Integrated Clinical Systems [CNICS]). In cases where PHI-linked data are requested from these data systems for purposes of estimating core indicators, the reasons for use of the data may be required to fall within the permitted uses and disclosures of the Privacy Rule (listed above), which may include the public health and limited data set exceptions.

Even with the permitted uses and disclosures of PHI and the allowable use of de-identified data from HIPAA-covered entities, the Privacy Rule and its varying interpretations may impede data collection (Gostin and Nass, 2009). In an evaluation of the collection of race, ethnicity, and language data in medical practices with five or fewer physicians, Hasnian-Wynia and colleagues found practices worried that asking questions about race or ethnicity could be a violation of patient privacy rights under the HIPAA, even though the collection of race and ethnicity data from patients in health care settings does not violate the HIPAA Privacy Rule and is legal under both federal and state law (Hasnian-Wynia et al., 2010). In another study, health information managers reported increases in the public's misunderstanding about release of patient information under HIPAA to be a major barrier to the release of such information. Lack of an umbrella policy or regulation defining infractions and enforcement and challenges in control-

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[14] The Privacy Rule designates two ways in which a covered entity can determine that health information is de-identified. Under the "Safe Harbor" approach, a covered entity may consider data to be de-identified if that entity removes identifiers and has no reason to believe that the remaining information could be used to identify a person. Alternatively, a covered entity may consider data to be de-identified if "a qualified statistical or scientific expert concludes, through the use of accepted analytic techniques, that the risk the information could be used alone or in combination with other reasonably available information, to identify the subject is very small" (HHS, 2010).

ling safeguards related to the release of information with increased use of health IT, such as electronic health records, were other major barriers (Houser et al., 2007).

The implementation of the Privacy Rule has changed the way in which covered entities manage health information. Concerned about compliance with the Privacy Rule, many providers have reevaluated the manner in which patient data are stored and disseminated (Wilson, 2009). As noted previously, the Privacy Rule permits the release of PHI without patient permission for public health purposes. Yet the terms of release are unclear and leave room for interpretation as to whether disclosure is permitted. Covered entities and their attorneys (whose job is to minimize clients' risk rather than improve public health) may decide not to release requested information, given that the release of PHI under the public health exception is permitted but not mandatory (Wilson, 2009). Public health officials have found success in gaining access to personal health data to be mixed and note that covered entities cite the Privacy Rule as a reason not to provide data to researchers and health departments (Stoto, 2008). Concern that reported data may reveal aspects of a person's lifestyle such as health status (e.g., HIV) or behaviors (e.g., unsafe sex or needle sharing) may result in reluctance to disclose PHI among both patients and providers (Gostin, 2002).

A potential disincentive to reporting is that covered entities that do release PHI for certain public health activities are required to record such disclosures and make an accounting of the disclosures available to patients who request them (Wilson, 2009).[15] Reporting of patient information to authorities can create tensions between physicians, whose primary role is to protect their patients' interests, and public health, whose primary role is to protect the population's interests (Gostin, 2002; Wilson, 2009).

As noted in Chapter 3, epidemiologic studies are a useful source of data on HIV care. Researchers who conduct epidemiologic studies on PLWHA often have to obtain patient information from hospitals and clinics that are HIPAA-covered entities (Houser et al., 2007). A few studies conducted after the Privacy Rule became effective in 2003 suggested that the HIPAA Privacy Rule had a negative impact on the conduct of health research, including research related to public health surveillance (e.g., Armstrong et al., 2005; Linet, 2003; Ness, 2007). A 2007 study showed that the Privacy Rule had little impact on a researcher's ability to obtain patient medical records. A likely by-product of HIPAA, however, was the refusal of 10 percent of facilities to accept a HIPAA-compliant release form other than their own,

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[15] Where data are released for public health activities, HIPAA-covered entities are required to make a listing of all disclosures of an individual's protected health information made by the covered entity or its business associates for up to 6 years preceding the request (HHS, 2003).

adding delay time, increasing participant burden, and creating a possible loss of study outcomes (Houser et al., 2007).

Confidentiality of Alcohol and Drug Abuse Patient Records Regulation

HIV-infected drug users have increased prevalence and frequency of medical, substance use, and psychiatric disorders that result in increased morbidity and mortality (Altice et al., 2010). Left untreated, these comorbid disorders can complicate treatment by impeding adherence to antiretroviral therapy, which is critical to maintaining suppression of viral replication (Altice et al., 2010; Fiellin, 2004). Therefore, screening and referral for substance abuse treatment are important components of HIV care.

Confidentiality has been fundamental to the practice of substance abuse treatment in the United States for more than four decades. In 1975, Congress enacted the Confidentiality of Alcohol and Drug Abuse Patient Records Regulation[16] (see 42 CFR § Part 2 or "Part 2") after it recognized that the stigma associated with substance abuse, as well as fear of prosecution, might deter individuals from entering treatment (Fenner, 2009; SAMHSA, 2004). The regulation, hereafter referred to as "Part 2," establishes confidentiality requirements for patient records maintained in connection with application for or receipt of services provided by federally assisted programs that provide alcohol and drug treatment, diagnosis, and referral services programs.[17]

Part 2 has been described as "powerfully preemptive" of both lesser state laws and HIPAA (Rosenbaum et al., 2009). Part 2 generally requires patient consent for disclosure of identifying information that reveals that a patient is in, has been in, or has applied for substance abuse treatment.[18] It also prohibits health care providers and plans that receive information from disclosing it to another entity without patient consent. Most substance abuse treatment programs are subject to both Part 2 and the Privacy Rule and must comply with both. According to guidance for alcohol and substance abuse programs developed by SAMHSA, this generally means that

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[16] "Records" refer to "any information, whether recorded or not, relating to a patient received or acquired by a federally assisted alcohol or drug program" (SAMHSA, 2004).

[17] Broadly defined, "federally assisted" programs are those that receive direct federal funding, but also have a tax-exempt status from the Internal Revenue Service (White and Daniel, 2009). For-profit drug and alcohol treatment programs and private practitioners who do not receive federal assistance are not subject to the requirements of Part 2, unless state law requires them to comply with Part 2 (SAMHSA, 2004, 2010).

[18] This may include name, address information, Social Security number, fingerprint, photograph, or similar information by which the identity of a patient can be determined with reasonable accuracy and speed either directly or by reference or through verification with another party (42 CFR 2.11).

programs will follow Part 2 and not disclose information unless they receive patient consent or can point to an exception that permits the disclosure. Then programs confirm that the disclosure is also allowed under the Privacy Rule (SAMHSA, 2004).

There are instances in which patient identifying information can be disclosed without patient consent under Part 2, such as (42 CFR Part 2, Subpart D—Disclosures without patient consent):

- to medical personnel in case of a medical emergency;
- to qualified personnel to conduct research, management audits, financial audits, or program evaluation (e.g., through a qualified service organization agreement [QSOA]);[19]
- for communications within a program; and
- for communications between a program and an entity having direct administrative control over the program.

Unlike the Privacy Rule, which usually permits the disclosure of PHI without patient consent for treatment, payment, or health care operations purposes, Part 2 typically requires patient consent for such disclosures (see 42 CFR §§ 2.3, 2.12, 2.13). As with the Privacy Rule, Part 2 does not apply to data that have been de-identified (SAMHSA, 2004).

Part 2 does not prohibit drug and alcohol treatment programs from meeting state-mandated communicable disease reporting and follow-up responsibilities. Therefore, programs can report cases of HIV/AIDS and other communicable diseases without patient consent to local public health authorities, such as through a QSOA with the local public health department or by some other mechanism. Reported cases of HIV/AIDS would probably not be linked to substance abuse treatment information; however, most states require reporters to identify themselves (which may disclose that the information is coming from a drug and alcohol abuse treatment program) (SAMHSA, 2004).

Part 2 may impede the collection of data on date of diagnosis for substance use disorder, date of referral for substance abuse services, and date of first visit for substance abuse services. These data elements are needed to estimate the 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, one of the core indicators recom-

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[19] A qualified service organization provides services to a Part 2 program, such as data processing, bill collecting, dosage preparation, laboratory analyses, or legal, medical, accounting or other professional services, and has entered into a written agreement with a program under which that person acknowledges that in receiving, storing, processing or otherwise dealing with any patient records from the programs, it is fully bound by these regulations (SAMHSA, 2010).

mended by the committee. Most drug and alcohol treatment programs receive federal assistance (SAMHSA, 2010) and therefore are required to be in compliance with Part 2. PLWHA in need of substance abuse treatment, especially those who are low income and under- or uninsured, are apt to receive such treatment from federally assisted programs.

Clinical Laboratory Improvement Amendments

Several of the committee's recommended indicators require data from laboratory testing results. Clinical laboratory testing performed on humans in the United States is regulated by the federal Clinical Laboratory Improvement Amendments (CLIA). CLIA may apply to HIV and other tests (e.g., CD4 count, viral load, drug resistance testing, tuberculosis testing, and STD and hepatitis screenings) received by PLWHA that are processed by clinical laboratories. CLIA regulations allow clinical laboratories to disclose test results to individuals who are authorized under state law to order or receive test results and, if applicable, to the person responsible for using the test results and the referring laboratory, in the case of reference labs (Pritts et al., 2009a; 42 CFR § 493.2). In the absence of state guidance, CLIA allows clinical laboratories to release laboratory results to "the individual responsible for using the test results and the laboratory that initially requested the test" (42 CFR § 493.1291[f]). Who is responsible for using the test results is not defined under CLIA, however (Purington et al., 2010). Laboratory reporting of HIV, CD4, and viral load information to public health authorities is required in virtually all U.S. states (although, as discussed earlier, the level at which CD4 count and viral load reporting is required varies by state) (Personal communication, Amy Lansky, Centers for Disease Control and Prevention, October 6, 2011). While the CLIA provisions suggest that test results may be furnished to providers who order tests, whether clinical laboratories may directly provide results to health care providers who did not order the test or to patients varies by state (Pritts et al., 2009b; Purington et al., 2010). The role of state laws on clinical laboratory reporting is discussed in the following section.

State Health Privacy Laws

In addition to federal laws, state statutes and regulations govern the disclosure of health information. In general, a state health privacy law that is more stringent about the privacy of individually identifiable health information takes precedence over federal law (Pritts et al., 2009b). State health privacy laws also are the primary laws governing entities that hold health information but are not covered under federal privacy laws (e.g., health care providers who do not electronically transmit health information in connection with health care transactions). The landscape of state health privacy laws is uneven because states are diverse in the rights and protections that they provide.

Because it was peripheral to the study charge, the committee did not conduct an independent review of current laws for all U.S. states and territories pertaining to the privacy of health information needed to estimate the core indicators of HIV care, behavioral health, and supportive services recommended in this report (although, such a review might be helpful to gain a better sense of the full extent to which state laws are barriers to the collection of necessary data). Instead, the committee consulted existing reviews of state health privacy laws and independently reviewed code pertaining to the privacy of health information for a few select states.

State Laws Pertaining to HIV and Other Communicable Disease Reporting Consistent with federal notifiable disease reporting, many states' laws articulate that HIV test results, as well as results from tests for other communicable diseases, may be reported without patient permission to public health authorities. Under current New York State law, for example, a person who obtains confidential HIV-related information may not disclose such information except to "a federal, state, county or local health officer when such disclosure is mandated by federal or state law" (New York State Article 27-F, HIV and AIDS Related Information).

Similarly, under Illinois law, no person is permitted to disclose the identity of a person who receives HIV testing or the results of the test in a manner that permits the identification of the person, except to "the Department or the local health authority, in accordance with rules for reporting and controlling the spread of disease, or as otherwise provided by State law" (Illinois Title 77: Public Health, Subchapter K: Communicable Disease Control and Immunizations).

Disclosure of Health Information to Other Health Care Providers for Treatment Purposes The exchange of health information among providers for treatment purposes is essential both for the provision of coordinated care for PLWHA and for accurate and complete data collection.

A review of state law requirements for the disclosure of health information that is often considered "sensitive" and provided heightened legal protections showed that almost all U.S. states and territories have statutes or regulations that specifically address disclosure of HIV-related information or communicable diseases including HIV (Pritts et al., 2009b). The scope of state laws governing disclosure of HIV-related information between care providers includes information related to HIV test taking and results, other (i.e., non-HIV testing) HIV-related information, and/or the redisclosure of

TABLE 4-3 Scope of State and Territorial Statutes and Regulations Governing HIV-Related Information

	Number of States and Territories
Information related to HIV test taking and results	41
Other information related to HIV	19
Recipient expressly prohibited from redisclosing information[a]	15

SOURCE: Adapted from Pritts et al., 2009a.

[a] Does not include statutes and regulations that, as a general rule, apply to holders of HIV-related information. Includes only provisions that expressly restrict recipient's redisclosure of information.

HIV-related information (i.e., from a recipient to someone else) (Table 4-3). As of 2008, when the review of state health information laws was conducted, laws in 41 U.S. states and territories addressed information related to HIV testing and results. At least 19 of these states had HIV-specific laws that apply to a wide range of HIV-related information and limit disclosure of all information that identifies, or could identify, a person as having HIV/AIDS. Laws in 15 states and territories expressly prohibited recipients of HIV-related information from redisclosing the information (Pritts et al., 2009a).[20]

Pritts and colleagues (2009b) note that the scope of the laws in states that address the disclosure of HIV-related information beyond HIV testing appear broad enough to possibly include valuable care information, such as information on antiretroviral medications. For example, the code for one of these states, New York, defines "confidential HIV-related information" as:

> any information, in the possession of a person who provides one or more health or social services or who obtains the information pursuant to a release of confidential HIV related information, concerning whether an individual has been the subject of an HIV related test, or has HIV infection, HIV related illness or AIDS, or information which identifies or reasonably could identify an individual as having one or more of such conditions, including information pertaining to such individual's contacts (Part 63 HIV/AIDS Testing, Reporting and Confidentiality of HIV-Related Information).

Some states permit the disclosure of HIV-related information for treatment purposes without patient permission absent any qualifying conditions. In many states, the disclosure of information without patient permission is

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[20] States expressly prohibiting redisclosure of HIV-related information were Arizona, California, Connecticut, Delaware, Florida, Hawaii, Maine, New Mexico, New York, Ohio, Oregon, Pennsylvania, Washington, West Virginia, and Wisconsin.

allowed under specified circumstances, such as for continuing or emergency care purposes or when necessary for treatment, and is subject to various interpretations. As of 2008, five states, the District of Columbia, and four U.S. territories did not allow the disclosure of HIV-related information for treatment purposes without patient permission (Pritts et al., 2009b). States that require patient permission to disclose HIV-related information often require that the permission be in writing, although in some of these states, separate permission is not required for each release of information. A current provision of Massachusetts public health law on the disclosure of HIV testing results, for instance, states that no health care facility, physician, or health care provider shall "disclose the results of such test to any person other than the subject thereof without first obtaining the subject's written informed consent; or identify the subject of such tests to any person without first obtaining the subject's written informed consent" (Massachusetts Laws Ch.111 70F).

Almost every state has a statute or regulation that governs the disclosure of information related to substance abuse treatment. State laws generally impose confidentiality requirements on both substance abuse treatment records as well as the patient's identity. The laws also focus primarily on patient information and records generated by substance abuse treatment programs and facilities, rather than those generated in the context of clinical care. The entities covered by statutes and regulations vary across states (e.g., in some states the law applies to programs that operate under or who have a contract with the state while other states' laws have broader application) (Pritts et al., 2009b). As of 2008, laws in more than 30 states incorporate the federal standards (Part 2) for protection of confidentiality in federally funded programs and/or state-funded programs. Pritts and colleagues noted that in at least one state (Pennsylvania) restrictions on the disclosure of substance abuse treatment-related information for treatment reasons appear to be more restrictive than Part 2. A number of states' laws specify the circumstances under which providers may disclose substance abuse treatment-related information without patient permission, such as for continuity-of-care purposes (Pritts et al., 2009b).

While there is no federal equivalent, nearly every state also has a statute or regulation that governs the disclosure of information maintained by mental health treatment facilities that provide inpatient treatment.[21] The scope of entities covered varies; in some states the law applies to services provided by state, local, or county government, while in others the law applies to any establishment that provides mental health treatment. Most states' mental health laws allow inpatient mental health treatment facilities

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[21] At the federal level, mental health treatment information is protected under the HIPAA Privacy Rule, which addresses all types of health care information.

to disclose health information for treatment reasons but for very limited circumstances. Some states have limitations on disclosures that may be made for treatment, such as restricting the type of information that can be shared and with whom. In several states, recipients are prohibited from further disclosure of the information except as authorized under the terms of the law. A few states' mental health laws treat mental health information the same as other types of health information and generally permit disclosure without patient permission for treatment purposes. (The review did not include outpatient mental health treatment facilities.)

With respect to general clinical information, Pritts and colleagues (2009b) found that the HIPAA Privacy Rule sets the standard for disclosure of information by hospitals and medical doctors in many states (either expressly or implicitly). In other states, statutory or regulatory provisions independently allow for disclosure of health information without patient permission for treatment purposes. A handful of states have laws that either limit disclosures to providers who previously provided treatment to the patient, or allow patients to opt out of such disclosures (Pritts et al., 2009b). Under the Texas Health and Safety Code, for example, disclosure of a patient's health care information by hospitals without the patient's authorization is permitted only:

> to a health care provider who is rendering health care to the patient when the request for the disclosure is made . . . [or] . . . to a prospective health care provider for the purpose of securing the services of that health care provider as part of the patient's continuum of care, as determined by the patient's attending physician (Texas Health and Safety Code § 241.153).

Most states' laws appear to permit pharmacists to disclose general clinical information for treatment reasons without patient permission. However, a few states indicate that the decision as to whether to provide such information is based on the pharmacists' own professional judgment. In other states, pharmacists may disclose clinical health information without patient consent only to specific types of care providers (Pritts et al., 2009b).

Disclosure of Information Maintained by Clinical Laboratories State law controls who is authorized to receive the results of tests performed by clinical laboratories, as described in the discussion of CLIA above. A survey of state laws on the release of clinical laboratory test results by independent (rather than public health) laboratories showed that clinical laboratory licensing laws often restrict the release of test results to the person who ordered the test or the person authorized to use the test (Pritts et al., 2009a). Most states do not expressly allow results to be released to other providers.[22,23] In addition, a few states have laws that limit the release of test results to health care providers who are licensed to practice within the state, presenting obstacles to the provision of care across state lines.

Pritts and colleagues (2009a) observe that states that provide heightened confidentiality for specific medical conditions such as HIV/AIDS impose an additional layer of complexity on the manner in which clinical laboratories may release test results. It is not always apparent whether clinical laboratories are subject to these statutes and regulations, which are written to cover a broad range of entities. As of 2008, laws in a handful of states with HIV/AIDS confidentiality laws that are broad enough to possibly include independent clinical laboratories expressly indicate that HIV test results must or may be provided to the person who ordered the test. In about half of the states, HIV/AIDS confidentiality laws appear to permit the disclosure of HIV test results to health care providers and health care facilities for treatment reasons without the patient's permission. Some states have a "need-to-know" standard on the release of HIV test results, perhaps leaving disclosure open to various interpretations (Pritts et al., 2009a). For example, Ohio's code on the disclosure of HIV test results to providers states:

> The results of an HIV test or a diagnosis of AIDS or an AIDS-related condition may be disclosed to a health care provider, or an authorized agent or employee of a health care facility or a health care provider, if the provider, agent, or employee has a medical need to know the information and is participating in the diagnosis, care, or treatment of the individual on whom the test was performed or who has been diagnosed as having AIDS or an AIDS-related condition (OhioRev.Code.Ann.3701.243 [B]).

Privacy Issues in State Public Health Agencies The Public Health Data Standards Consortium conducted a survey of past, present, and future privacy-related issues faced by public health agencies in 2008. Among current issues, public health agencies identified the need for a standardized way to ensure data de-identification, because statutes (federal and state) have different definitions of de-identification. Agencies also identified the need for secure and reliable methods for linkages across databases. How to handle data breaches and identity theft in an environment where more

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[22] As of 2008, about half of the states had laws that expressly allowed or required clinical laboratories to release test results to authorized providers who requested the test. In some of these states, test results may be released only to the person who ordered the test; in other states, the law enumerates the health care providers who are authorized to order tests and receive results (Pritts et al., 2009a).

[23] Where state law does not specify who is authorized to receive test results, clinical laboratories may send results only to persons who ordered the test or who are responsible for using the test (Pritts et al., 2009a).

information is being collected electronically was another concern. Privacy officers in public health agencies noted challenges to ensuring privacy and security-related training and education of the workforce as well as a need for clarification on oversight responsibilities and enforcement. One HIV-specific issue noted by privacy officers was the new federal requirement to report HIV/AIDS data to states with identifiable information (name), which required amendments to regulations as well as assurances to PLWHA that their data will be protected (PHDSC, 2008).

Participating health agencies also noted several new and emerging health information privacy issues. Privacy officers in health agencies identified the need to develop state public health privacy frameworks to simplify understanding and documentation of privacy regulations pertaining to the reporting of health information. The growing demand for identifiable information for research purposes that is occurring as a result of increased availability of data in electronic form creates greater opportunity for linking data across systems and tracking individual-level data longitudinally. However, privacy officers reported that these changes present more complex privacy issues for state agency institutional review boards and raise ethical challenges in balancing increased access to data for research and ensuring the privacy and security of health information (PHDSC, 2008).

CONCLUSIONS AND RECOMMENDATIONS

Reimbursement-Related Barriers to the Collection of HIV Care Data

- Reimbursement policies and practices can result in the dispersal of care information across multiple entities. For example, care services that are carved out of a health plan (e.g., behavioral health, transportation, dental, and pharmacy benefits) may not be recorded in the primary insurer's claims records. Therefore, the primary insurer's records will not provide a complete medical history of the patient. Means to link data across reimbursement systems will be required to gain access to a complete medical history for many PLWHA.

Reporting-Related Barriers to the Collection of HIV Care Data

- Several of the core indicators recommended by the committee require estimates of the total number of people diagnosed with HIV in the United States, as well as dates and values of CD4 count and viral load tests. Incomplete HIV/AIDS case reporting by providers to public health authorities; variability in the levels at which CD4 counts and viral loads are reportable across states; and a lack of mechanisms for health departments to share data across jurisdictions may influence the comprehensiveness and accuracy of reported data. Staffing, administrative, and budgetary constraints are other potential barriers to reporting for health departments and other providers of HIV care and supportive services.

- Current national estimates of the number of people who are tested for HIV at anonymous sites were not available at the time of this report. Most states do offer anonymous HIV testing, however. Although anonymous testing should be acknowledged as a minor barrier to the completeness of HIV surveillance data, its benefits may outweigh this drawback since the availability of anonymous testing may promote testing among individuals who are concerned about potential breaches in the confidentiality of their testing information.

Reducing Data Reporting Burden

- Grantees of federally funded HIV/AIDS programs are a vital source of HIV care and supportive services data, but are currently overburdened by the many reporting obligations they are required to fulfill as a condition of program funding. The reporting requirements for core and supplemental HIV/AIDS programs administered by health departments are often project specific, even across related programming (e.g., HIV prevention and HIV/AIDS care), requiring staff to modify their reporting practices for each grant. Reporting is further complicated by the fact that programs operate on different grant cycles so that reports for related programs are due a different times during the year. According to the Presidential Advisory Council on HIV/AIDS, the current reporting requirements for grantees of federally funded HIV/AIDS programs have not resulted in a set of metrics by which to thoroughly monitor the HIV epidemic or to evaluate federal HIV/AIDS programs. A smaller number of metrics that are aligned with NHAS goals could be used across federal agencies to monitor progress in managing the epidemic. As it was preparing this report, the committee learned that there is an effort under way by HHS to identify a set of HIV-related metrics to be used across funding agencies and reduce reporting burden for program grantees. The committee supports this current effort and recommends that it be maintained so that data needs can be periodically reprioritized based on changes in the HIV epidemic and to facilitate continued minimization of grantee reporting burden.

Recommendation 4-1. The Department of Health and Human Services should maintain and institutionalize the existing effort to streamline data collection and reduce reporting requirements for federally funded HIV/AIDS programs. This will allow for periodic reprioritization of data needs based on changes in the HIV epidemic that occur over time, and ensure the continuous availability of data to effectively monitor HIV care while minimizing reporting requirements for grantees. The data reprioritization should involve health departments, HIV provider organizations, and federal agencies that are major funders of HIV/AIDS programs, including HHS, the Department of Veterans Affairs, and the Department of Housing and Urban Development.

- Engagement of health departments, HIV care clinicians, and other stakeholders in the planning of an HIV/AIDS data collection effort can help to identify what data are most important to collect (since these groups are often users of the collected data) as well as processes for collecting those data. Involvement of stakeholders may foster greater investment in data collection and reduce reporting burden since the data collected will be more closely aligned with stakeholders' own data needs.

Other Policy Barriers to the Collection of HIV Care Data

- The various sources of care and care coverage in the United States each have their own eligibility requirements. As a result, many PLWHA shift in and out of care and change providers over the course of their illness, which creates opportunities for gaps or losses of patient data and impedes longitudinal tracking of care. Improved exchange of data across systems maintained by insurers and providers would help to address this problem, as discussed in Chapter 5.

- Several provisions of the ACA are being implemented differently by states. Resulting differences across states in access to health insurance and health care will have to be taken into consideration for purposes of monitoring the improvements HIV care resulting from the ACA and more generally.

- Providers of HIV care and supportive services contend with numerous federal laws and state statutes and regulations on the proper use and disclosure of patient information. The inconsistent nature of these protections, which often 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 estimate indicators of HIV care and supportive services.

Recommendation 4-2. The Department of Health and Human Services should issue guidance to the HIV care community to clarify what is permissible patient information to share given federal and state privacy laws.

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5

The Role of Health Information Technology and Data System Integration in the Collection of HIV Care Data

This chapter describes potential improvements in the collection of HIV care and supportive services data from health information technology (health IT) and data system integration. Specifically, the chapter addresses how health IT can be utilized and configured to improve the collection of comprehensive data describing the care experiences of people living with HIV/AIDS (PLWHA) (statement of task question 7), and discusses models and best practices in data system integration to make existing data systems and core indicators interoperable (statement of task question 6). The chapter ends with the committee's conclusions and recommendations on these aspects of its charge.

UTILIZATION AND CONFIGURATION OF HEALTH INFORMATION TECHNOLOGY TO IMPROVE THE COLLECTION OF HIV CARE DATA

Health IT generally refers to the various computer technologies that are used by providers, consumers, payers, insurers, and other groups to manage and transmit health information (PCAST, 2010). Some of the more common health IT applications are computerized physician order entry (CPOE), clinical decision support (CDS), and electronic prescribing (Table 5-1). These applications are often housed in an electronic medical record (EMR), an electronic record of a patient's health information created, managed, and consulted by providers, or an electronic health record (EHR) that generally has the same features as an EMR but conforms to nationally recognized

TABLE 5-1 Descriptions of Health IT Products and Functionalities

Product or Functionality	Description
Electronic health record (EHR)	An electronic record of health-related information on an individual that conforms to nationally recognized interoperability standards and that can be created, managed, and consulted by authorized clinicians and staff across more than one health care organization
Electronic medical record (EMR)	An electronic record of health-related information on an individual that can be created, gathered, managed, and consulted by authorized clinicians and staff within one health care organization
Personal health record (PHR)	An electronic record of an individual's health-related information that is managed, shared, and controlled by the individual. May conform to nationally recognized interoperability standards. Health-related information may be drawn from multiple sources (e.g., providers, insurance claims, pharmacy data).
e-prescribing (eRx)	Enables a physician to transmit a prescription electronically to the patient's pharmacy. Also enables physicians and pharmacies to obtain information about the patient's eligibility and medication history from drug plans. May come with alerts for drug-drug, drug-allergy, and drug-disease interactions
Computerized physician order entry (CPOE)	A computer-based system of ordering medications and other tests. Physicians enter orders into a computer system that can have varying levels of sophistication. Basic CPOE ensures standardized, legible, complete orders and thus primarily reduces errors due to poor handwriting and ambiguous abbreviations
Clinical decision support (CDS)	Any system designed to improve clinical decision making related to diagnostic or therapeutic processes of care. Addresses activities ranging from the selection of drugs or diagnostic tests to detailed support for optimal drug dosing and support for resolving diagnostic dilemmas. Often incorporated as part of CPOE or EMR-EHR systems

SOURCE: Adapted from Detmer et al., 2008; HHS, 2008; Moiduddin and Moore, 2008.

interoperability[1] standards and can be used by providers across more than one health care organization (HHS, 2008). Personal health records (PHRs) are electronic records of a patient's health-related information that are controlled by the patient and can be shared with others, such as providers and family members. PHRs are usually web based so that patients may access

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[1] In health care, interoperability refers to the ability of different IT systems and software applications to communicate; to exchange data accurately, effectively, and consistently; and to use the information that has been exchanged (HHS, 2008).

their information remotely. Some PHRs can be populated with information from a variety of sources (e.g., provider EHRs, insurance claims, pharmacy data) to provide a more complete picture of the patient's health-related information (Table 5-1) (CMS, 2012a; Detmer et al., 2008; HHS, 2008).

The full benefits of health IT cannot be realized without an infrastructure that supports the secure exchange of health information beyond an individual provider or health care delivery system. Health information exchange (HIE) enables the electronic sharing of patient-level health information across organizations and health IT products (principally EHRs and PHRs) using nationally recognized interoperability standards (HHS, 2008). HIE is a solution to barriers to the exchange of health information across organizations posed by the fragmented health care system (HHS, 2008; Vest et al., 2011). HIE gives providers access to more accurate and complete information on their patients and, thus, may help to improve the safety and quality of care (CBO, 2008; Vest et al., 2011; Wright et al., 2010). A number of regional health information organizations (RHIOs) across the country have developed networks to enable secure HIE among local clinicians, provider organizations, pharmacies, laboratories, health departments and other entities (Shapiro et al., 2011).

When used appropriately, health IT has the potential to generate savings. For example, health IT could result in savings by lowering the costs of providing health care, eliminating unnecessary services (e.g., duplicate tests), and improving care quality in a way that may reduce costs. Savings may be internal in the form of reductions in the costs of providing care for health care providers directly. Savings also can be external, meaning the savings accrue beyond individual providers to other providers, patients, health insurance plans, or others—for example, from increased ability of participants to engage in HIE (CBO, 2008). As discussed below, compared with large integrated health organizations, small provider groups may be less likely to internalize the financial benefits from health IT because there is less incentive for improvements in administrative efficiency and because costs are distributed across a smaller number of providers and patients (PCAST, 2010).

Uses of Health Information Technology for the Collection of HIV Care Data and Management of HIV Care

Clinical data needed to monitor indicators of HIV care are often contained in EHRs or EMRs. As discussed in Chapter 2, clinical data include information on individuals' health status, findings from examinations, and medical history information. EHRs and EMRs also document patient demographic information such as sex, date of birth, insurance status, and race and ethnicity. Stand-alone and EHR- or EMR-embedded CPOE applications contain data on pharmacy, laboratory, and other types of provider orders. E-prescribing features also provide prescription drug information. Because the clinical data are maintained in an electronic format, they can be more easily retrieved and transmitted. Some IT systems can be used to compile and summarize information from patients' medical records to identify trends in a specific population or to track compliance with clinical standards or other quality measures. They also may be used to generate reports such as to identify no-show rates for HIV patients or to monitor trends in laboratory test results. Such features can help HIV care providers comply with mandated reporting requirements (HRSA, 2011). Integrated EHRs can organize patient information across providers (within or across organizations) and facilitate faster distribution of data so that providers can obtain up-to-date views of a patient's health information (PCAST, 2010). This is important for PLWHA who often receive care and supportive services across several providers and organizations over the course of their illness.

Another benefit of EHRs and EMRs in HIV/AIDS care is supporting research. EHRs and EMRs have become a rich source of data for both retrospective and prospective cohort studies, which can improve understanding of PLWHA and their health care. As discussed in Chapter 3, the CFAR Network of Integrated Clinical Systems (CNICS) is an EMR-based research network containing data collected at point of care on more than 23,000 PLWHA. Research using CNICS data has helped to inform several important questions in HIV care, including, but not limited to, factors associated with linkage to and retention in care and the comparative effectiveness of different HIV treatment strategies (Kitahata, presentation to IOM, April 28, 2011; UAB, 2012).

Preliminary research from the Louisiana Public Health Information Exchange (LaPHIE)—a partnership between the Louisiana Office of Public Health and the Louisiana State University Health Care Services Division (LSU HCSD)—shows that the electronic exchange of EMR and surveillance data can be used to identify PLWHA who have not been linked to care or who have fallen out of care (Herwehe et al., 2012). Using a secure bidirectional HIE linking state public health surveillance data with medical record data, LaPHIE sends alerts to LSU HCSD care providers when individuals who have not received CD4 or viral load monitoring for more than a year present to care for non-HIV-related conditions (Herwehe et al., 2012). Over a 2-year period, LaPHIE issued alerts for 488 patient encounters and identified, matched, and exchanged messages on 345 unduplicated PLWHA who were in need of treatment. The majority of the individuals identified followed up with care within the study period; 82 percent received one or more CD4 counts within the 18-month follow-up period, and 62 percent had at least one HIV specialty visit. Both providers and patients were accepting of the exchange. A patient acceptability evaluation showed that patients preferred the sharing of their information to be limited to public health authorities and health care providers when there is benefit to the patient and/or the community. The evaluation also showed that the health care delivery setting is the preferred environment for communication about the need for follow-up, as opposed to community-based outreach methods traditionally used by public health (Herwehe et al., 2012).

One limitation of EHRs and EMRs is that, like hard copy medical charts, the completeness and quality of data they contain, and therefore their usefulness for research and patient monitoring, depend on the inputting of data by users. Some research has shown data to be frequently missing from EMRs (Lau et al., 2011). Incomplete and inaccurate information can also diminish the potential for improvements in patient safety and quality resulting from health IT. For example, drug alerts and CDS functions will be of little use if the relevant data in the EMR or EHR to activate such functions are not complete and accurate.

A data-related benefit of PHRs is that providers may use them to document and verify a patient's health-related information (e.g., in the EHR), thus improving data quality (Detmer et al., 2008). PHRs may include clinical data populated from a provider EHR, and some PHRs allow patients to input information such as demographic and emergency contact information, diagnoses, drug allergies, immunizations, and other information. Some PHRs also include features that allow patients to schedule and receive reminders about their appointments, refill prescriptions, research medical conditions, and communicate with their providers. Like EHRs, many PHRs conform to nationally recognized interoperability standards and therefore can be used in HIE (HHS, 2008).

Because PHRs allow patients to view and manage their own health information, they are thought to facilitate better patient engagement in care (CHF, 2010; HHS, 2008; Kahn et al., 2010; McInnes et al., 2011).[2] PHRs may be especially useful to individuals with chronic conditions such as HIV as well as for those with comorbidities because they help patients manage information across multiple care providers, appointments, and medications (HHS, 2009; Kahn et al., 2009, 2010). A recent study evaluated PHR usage patterns of 211 patients attending San Francisco General Hospital's HIV/AIDS clinic (Kahn et al., 2010). Data retrieved from the PHR website log showed that participants commonly accessed their PHRs to view CD4 count and viral load information (891 visits by 110 persons, and 542 visits by 104 persons, respectively) as well as office visits, medical conditions,

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[2] Adherence research has shown that patients, including HIV/AIDS patients, who perceive themselves to be more highly engaged with their health care providers have better adherence to medication, provider advice, and appointments (Bakken et al., 2000; Osterberg and Blaschke, 2005).

and medications. Of 51 patients who completed a usage survey, 80 percent agreed that the PHR helped them to manage their medical conditions (Kahn et al., 2010). Results from a national consumer survey on health IT showed that PHR users who had less education and lower incomes, and those with chronic illnesses, derive the most value from PHRs (CHF, 2010). Web-based PHRs may aid in continuity of care for PLWHA as they change providers or relocate.

Electronic laboratory reporting (ELR), the electronic reporting of communicable diseases and laboratory test results to public health authorities for surveillance, is another health IT tool that is relevant to the collection of HIV-related data. As discussed in Chapter 2 of this report, several of the data elements (e.g., HIV/AIDS cases, CD4 counts and viral load information) needed to estimate the committee's core indicators come from surveillance data. Evidence suggests that methods for electronic reporting of communicable disease information facilitates more accurate and complete reporting of data to public health authorities (CDC, 2011; Nguyen et al., 2007; Overhage et al., 2008), while provider-initiated, manual systems often provide delayed and inaccurate data with many omissions and errors (Birkhead et al., 1991; Jajosky and Groseclose, 2004; Ward et al., 2005).[3]

A Special Projects of National Significance (SPNS)-sponsored project identified key considerations in the adoption of health IT for HIV care providers based on the experiences of 6 HIV care sites conducting comprehensive evaluations of health IT interventions between 2002 and 2005 (Magnus et al., 2007). The project encompassed care delivered to 24,232 clients by 700 providers. Each site was implementing a different type of health IT ranging from a web-based information tool for HIV care providers to an application to allow HIV patients to complete a questionnaire on medication adherence, depression, and substance abuse via touch screen computers prior to meeting with their health care provider. The investigators identified 6 key considerations for IT adoption across the SPNS sites. These were: programmatic capacity (e.g., assessment of computer resources and existing IT infrastructure); elucidating stakeholder expectations of the value added by IT; participation (the involvement of all key stakeholders in the development of the IT plan); organization models (whether the IT effort was pioneered by leadership, support staff, or was self-contained within a specific HIV clinic); end-user types (assessment of the various ways that end users will interact with the IT system); and consideration of the challenges to adoption under different care models (see Box 5-1). The project also showed that it is essential to have an evaluation process in place to monitor

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[3] Although there has been substantial progress in the use of electronic reporting, many surveillance mechanisms still depend on manual data entry and submission (CDC, 2005; Lazarus et al., 2009; Lober et al., 2003).

BOX 5-1
Key Considerations for the Adoption of Health IT by HIV Care Providers

Programmatic Capacity

Prior to implementation of new health IT strategies, it is important to assess computer resources and explore existing IT infrastructure to see whether new capabilities can be added in to it, rather than implementing a completely new system. The IT intervention should be developed with future growth and sustainability in mind. Selection of well supported software that protects the confidentiality of patient data, is capable of addressing current and future compatibility standards, and has ongoing technical assistance is also important.

Expectations

It is important to determine whether stakeholder expectations of the value added by IT are realistic and address system needs, or barriers to IT utilization may result. Understanding the reasons for suboptimal care, and the ability of IT to improve them prior to implementation of the IT intervention, helps to ensure that the IT will address system needs.

Participation

All key stakeholders, including providers, end users, ancillary staff, clients, patients, and other community members, should be consulted and involved in the IT creation and implementation processes.

Organizational Models

Grantees noted that IT interventions were implemented in one of three models: (1) top-down, in which the administration identified IT as a means of overcoming a systemic difficulty; (2) ground-up, in which users identified the need for the program and were champions of its adoption; or (3) stand-alone, where the intervention was self-sufficient in a preexisting context of care, not requiring extensive organizational support.

End-User Types

End users often interact with the same IT program in different ways. Therefore, during the preadoption phase, it is important that each potential user be consulted and their usage assessed to understand the relative value of the system for them and how they expect to use it. This information can help to identify the scope of the IT or, if the assessment determines that the proposed IT is not an ideal solution, determine that other changes may be necessary.

continued

BOX 5-1 Continued

Challenges

It is important to be aware of challenges to the implementation of IT under a particular organizational model. For example, in top-down models, frontline staff and providers may resent a particular system being imposed upon them and resist using the system, while in a ground-up model IT may not have administration support and resource commitment for sustainability. Knowledge of the model at work can be used to address barriers to success of the IT intervention.

SOURCE: Magnus et al., 2007.

IT use and its impact on patient outcomes. Feedback from the evaluation can improve IT implementation and provide data that may assist with sustainability (Magnus et al., 2007).

Challenges to the Adoption of Health Information Technology

Despite its potential benefits, evidence suggests that adoption of health IT is occurring at a slow pace in settings where PLWHA receive care, such as physician offices, hospitals, and community health centers (CHCs). Data from a nationally representative survey of office-based physicians show that 25 percent of physician offices were using a basic EHR or EMR system in 2010, up from 22 percent in 2009. Ten percent of physicians were using a fully functional system in 2010, compared with 7 percent in 2009 (Hsiao et al., 2010).[4] A report on progress in EHR adoption by acute care, non-federal hospitals in the first year following passage of the 2009 American Recovery and Reinvestment Act (ARRA; P.L. 111-5), which authorized incentive payments through Medicaid and Medicare to providers who implement certified EHRs, found only small gains in EHR adoption. The proportion of hospitals (N=3,101) meeting criteria for a basic EHR rose from 7.2 to 9.2 percent between 2008 and late 2009 while the proportion

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[4] A "basic" EHR or EMR system as defined in the study has functionalities for patient history and demographics, patient problem lists, physician clinical notes, medications taken by patients, computerized orders for prescriptions, and viewing laboratory and imaging results. A "fully functional" EHR or EMR system has each of the basic functionalities as well as functionalities for prescription and test orders, warnings of drug interactions or contraindications, highlighting of out-of-range test levels, and reminders for guideline-based interventions or screening tests (Hsiao et al., 2010).

of hospitals meeting criteria for a comprehensive EHR increased from 1.5 to 2.7 percent. Hospitals likely to serve more disadvantaged populations (e.g., critical access, public, nonteaching, and rural hospitals) were among the least likely to have adopted even a basic EHR in the 12 months preceding the survey. Eighty-nine percent and 74 percent of hospitals, respectively, did not have key meaningful use functions for engagement in HIE and the ability to report quality measures to the state or to the Centers for Medicare and Medicaid Services (CMS) (Jha et al., 2010). In a 2008 survey of 362 federally qualified health centers (which include CHCs), 23 percent responded that they use an "all-electronic" EHR. None of the health centers met the criteria for a fully functional EHR (Lardiere, 2009).[5] The practice of HIE, or the exchange of health care information across organizations, also remains the exception rather than the rule (PCAST, 2010; Vest, 2009; Vest et al., 2011; Wilcox et al., 2006). The national health IT consumer usage survey mentioned above found that just 7 percent of respondents were using a PHR (CHF, 2010).

Part of the explanation for the lack of broad adoption and use of health IT is linked to the organizational and economic structure of the U.S. health care system (PCAST, 2010). Many physicians, including those who provide care to PLWHA, practice in small groups and are reimbursed for care on a fee-for-service basis. Physicians who practice in this type of environment may not garner the benefits of health IT, such as increased sharing of patient information, enhanced coordination of care, or the ability to aggregate care data. Therefore, there is little incentive for these providers to invest in health IT. Adoption of health IT has occurred at a faster pace in large health care organizations, such as in the Veterans Health Administration (VHA) and Kaiser Permanente, that directly gain from health IT and have a greater incentive to provide care efficiently and reduce duplication of services. Large organizations are also better situated to shoulder the costs of implementing health IT, since costs are spread across a larger number of patients and providers (PCAST, 2010).

Besides the costs of installing and maintaining health IT systems, a number of other barriers and challenges to the adoption of health IT have been described in the research literature. These include the inability to integrate new and existing systems (Lardiere, 2009; PCAST, 2010); concerns about the security and privacy of data (PCAST, 2010); productivity loss (e.g., during transition to a new EHR) (Lardiere, 2009; PCAST, 2010; Poon et al., 2006; Reardon and Davidson, 2007; Shields et al., 2007); lack of support from providers (Bhattacherjee and Hikmet, 2007; Lardiere,

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[5] "Fully functional" was defined as having functionalities for collection of patient demographic information, electronic prescribing, computerized physician order entry, clinical notes, clinical decision support, and public health reporting (Lardiere, 2009).

2009; Liu et al., 2011); and perceived incompatibility with work processes (Bhattacherjee and Hikmet, 2007; PCAST, 2010). Some providers may be concerned about the potential liabilities associated with use of health IT and participation in HIE. For example, it has been suggested that since integrated EHRs can store large amounts of instantly accessible information on several aspects of care, providers may be more likely to be found responsible for missing critical details in a given patient's EHR that affect treatment decisions (Sittig and Singh, 2011).

Providers who care for the underserved may face additional barriers to the implementation of health IT. In CHCs, which disproportionately serve patients who are low income, for example, the integrated service approach to care may make health IT implementation more complicated (Moiduddin and Moore, 2008). Health IT can improve care quality when used effectively. Therefore, these unique challenges must to be addressed to ensure that health disparities are not exacerbated by uneven adoption and use of health IT.

The benefits of health IT, both within a practice and for purposes of monitoring care on a broader scale, may not be evident to many providers. Education on possible functions and benefits of health IT is important for implementation and use (Gibbons, 2011; Samentaray et al., 2011; Torda et al., 2010). Surveys of physicians have reported that financial incentives for the purchase and use of health IT systems, receipt of technical assistance, and protections from personal liabilities would facilitate adoption and use (DesRoches et al., 2008; Patel et al., 2011). There may be a particular need for improved incentives to smaller providers who are less likely to internalize the financial benefit from health IT.

Although adoption of health IT has occurred at a slow pace thus far, the financial incentives and technical assistance being provided as a result of the ARRA could help to promote broader use of EHRs among HIV providers in coming years. The Health Information Technology for Economic and Clinical Health (HITECH) Act, a component of the ARRA, supports adoption and use of EHRs by authorizing incentive payments through Medicare and Medicaid, major payers of care for PLWHA, to physicians and hospitals that use EHRs and demonstrate their "meaningful use" (Jha et al., 2010).[6] The three main components of meaningful use for the first phase of the HITECH Act, which began in 2011, are the use of certified

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[6] Under the Medicare EHR incentive program, eligible health professionals can receive as much as $44,000 over a 5-year period. Incentive payments for hospitals and critical access hospitals (CAHs) are based on a number of factors and begin with a $2-million base payment. Under the Medicaid EHR incentive program, eligible health professionals can receive up to $63,750 over 6 years. As under the Medicare program, incentive payments for hospitals and CAHs under the Medicaid program are based on a number of factors and begin with a $2-million base payment (CMS, 2012a).

EHRs (1) in a meaningful manner (e.g., for electronic prescribing); (2) for secure electronic exchange of health information to improve the quality of health care; and (3) to submit clinical quality and other measures (CMS, 2011). Because providers must use an EHR that has been certified to support objectives of meaningful use to qualify for the incentive, a possible outcome of meaningful use is the increased development of functions in EHRs to document various clinical quality measures and other health data.[7,8] HITECH Act programs also offer technical support to providers that are in particular need of assistance (e.g., solo and small group practices, CHCs, critical access hospitals) to attain adoption and meaningful use of EHRs, including assistance with implementation, workforce training, and HIE (ONC, 2011a).

The array of data contained in health IT systems is largely limited to clinical care data. Resources to support effective use of health IT are particularly lacking among mental health and supportive services providers who were not eligible for EHR meaningful use incentives under ARRA (SAMHSA, 2011). Efforts to expand the use of health IT by behavioral health providers and to address barriers to the inclusion of behavioral health information in HIE would improve the availability of data to monitor indicators for referral for and receipt of mental health and substance abuse services among people with diagnosed HIV infection, as well as for other populations (SAMHSA, 2011).

Data Privacy and Security Considerations

As noted previously, some of the existing ambivalence about integrating health IT into the health care system is related to concerns about privacy

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[7] The criteria by which meaningful use of EHRs will be determined is being rolled out in three phases. Phase 1 (2011 and 2012) "sets the baseline for electronic data capture and information sharing" (CMS, 2011). It is anticipated that future stages of meaningful use will be increasingly rigorous. For example, by 2015, in order to qualify for meaningful use of EHRs, providers will have to demonstrate greater use of decision support tools, higher levels of information exchange, and improvement in care coordination and patient outcomes (PCAST, 2010).

[8] Since the HITECH Act was passed, the Office of the National Coordinator for Health Information Technology (ONC) has moved forward on several additional activities that will help to improve the health IT infrastructure. One of these activities, the Nationwide Health Information Network (NwHIN), is composed of standards, services, and policies to enable secure health information exchange over the Internet. The NwHIN is meant to help achieve the goals of the HITECH Act by enabling "health information to follow the consumer, be available for clinical decision making, and support appropriate use of health care information beyond direct patient care so as to improve population health" (ONC, 2011b). This project has convened stakeholders and created an appropriate forum for the discussion of options to improve the health IT infrastructure (PCAST, 2010).

and security of information (PCAST, 2010). The privacy and security of health information is particularly important to PLWHA and their providers. HIV continues to be a stigmatized disease (Sengupta et al., 2011). Besides HIV status, other information about PLWHA 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 PLWHA. Increased use of health IT and HIE heightens privacy and security concerns because the accessibility of information may increase the potential for access and misuse by authorized and unauthorized users. A lack of protections to keep health information private and secure would undermine trust in health IT as a means for data collection and storage and its ability to improve care (NRC, 1997; ONC, 2011a).

The federal government has initiated several efforts to improve privacy and security protections that are relevant to increased use of health IT. For example, the HHS Office of Civil Rights (OCR) is fulfilling HITECH Act obligations to modify privacy and security rules under the Health Information Portability and Accountability Act (HIPAA), which establishes a federal floor of protection for health information, to strengthen the privacy and security of health information and the enforcement of penalties for violating HIPAA rules.[9] OCR and ONC are working with providers and consumers of health IT to educate and inform them of the importance of health IT security and ways to ensure that personal health information is kept secure (ONC, 2011a).

Lessons from the Veterans Health Administration and Kaiser Permanente on the Use of Integrated Electronic Health Records

Although not representative of other health care organizations, the experiences of large integrated care organizations, such as VHA and Kaiser Permanente (KP), provide important lessons on the uses and limitations of integrated EHRs. The Veterans Health Information Systems and Technology Architecture (VistA) integrated EMR system has enabled VHA to provide a highly regarded level of information technology that supports better

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[9] See Chapter 4 for a fuller discussion of HIPAA. The HIPAA Privacy Rule regulates the use and disclosure of identifiable health information held by health plans, health clearinghouses, and health care providers who engage in administrative electronic transactions. In general, the Privacy Rule permits the disclosure of identifiable health information for treatment, payment, and health care operations without written patient permission. The Privacy Rule also permits the disclosure of identifiable information for research and public health purposes without patient permission as long as certain conditions are met. However, the Privacy Rule does not supersede state laws that are more stringent, such as those that require patient permission to exchange health information.

care (Asch et al., 2004; PCAST, 2010). For instance, VistA enabled VHA to reduce medication errors to a rate of 7 per million prescriptions, compared to a national average of 1 error in 20 prescriptions. Use of electronic reminders and performance measurement to improve pneumonia vaccination rates for veterans with emphysema is estimated to have saved the lives of thousands of VHA patients (PCAST, 2010). KP's HealthConnect system connects all KP members over nine states and the District of Columbia to throusands of physicians in hundreds of medical offices and hospitals. Physicians can retrieve data on patient care received from anywhere within the network. In addition to providing alerts to providers on overdue preventive screenings, KP's system also produces quality measures and feedback for providers. Data from the system can be aggregated to track adverse events and trends (PCAST, 2010). Improved quality and efficiency of care have been attributed to patient access to KP's system via the Internet. One study showed that patients' use of secure messaging and scheduled phone visits enabled by HealthConnect resulted in a 26.2 percent decrease in total office visits over 4 years (Chen et al., 2009).

The VistA and HealthConnect systems were expensive to implement, and they require substantial resources to maintain and to extract and utilize the information (PCAST, 2010). As noted previously, there is often little incentive for providers outside of integrated networks, which may include care sites such as CHCs where many PLWHA receive care, to invest in integrated EHRs. Both VistA and HealthConnect are currently limited with regard to interoperability or the ability to share patient information with other providers. The lack of interoperability means that a complete record of patient care often will not be available, even for many PLWHA in large integrated health networks.

In a presentation before the committee, Jamie Ferguson, vice president of Health IT Strategy and Policy at Kaiser Permanente, described a partnership between KP and the VHA to share data on patients who receive care in both systems. The exchange was the first Nationwide Health Information Network exchange conducted for treatment purposes. Information exchanged included patient demographics, medications, lab results, immunizations, allergies, and vital sign information. Participating patients opted into the exchange and were permitted to opt out at any time. An important lesson learned from the exchange was that the Healthcare Information Technology Standards Panel (HITSP) specifications to enable interoperability were much easier to implement than expected. Patient ID matching was the biggest unresolved issue. Mr. Ferguson also noted that operational processes for patient opt-in need to be streamlined and automated. Key success factors for the exchange were the alignment of incentives (quality of care and patient safety as drivers for participation in the exchange); a data use agreement (describing the permitted purposes for data exchange; breach notification, privacy and security requirements; and dispute resolution, liability, and governance terms); and data content (use of HITSP specification enabled interoperability) (Ferguson, 2011).

MODELS AND BEST PRACTICES IN DATA SYSTEM INTEGRATION

The committee was asked to identify models and best practices in data system integration to improve interoperability of data systems and core indicators. In health care, "interoperability" is generally defined as "the ability of different IT systems and software applications to communicate, exchange data accurately, effectively, and consistently, and to use the information" (HHS, 2008). Interoperability is not fully possible in the United States at this time (ONC, 2011a). For the most part, the various sources of care and care coverage have their own health IT systems with their own digital language. Systems also vary in their complexity, length, and technical vocabulary and are run using different information architectures, protocols, and software programs (Edwards et al., 2010). As PLWHA move through the health care system, each provider's health IT system captures a portion of the patient information, and care data cannot easily be tracked across these systems. Methods of data system integration can help to address challenges of interoperability.

Some examples of data system integration involve direct information exchange across settings, which simply makes information available between systems. The Indiana Network for Patient Care has been an operational statewide health information exchange for more than 10 years, linking hospitals, public health departments, and state Medicaid data to deliver clinical data to care settings throughout Indiana and has served as a model of HIE across the nation. New York State in 2006 began a significant investment in health data integration with the Healthcare Efficiency and Affordability Law for New Yorkers (HEAL-NY) capital grant program (Kern et al., 2009). Initially this program distributed $53 million to 26 RHIOs across the state, each of which pursued a specific implementation of health IT and exchange. Although most of the recipients focused more heavily on health IT adoption, among the RHIOs were prominent examples that facilitated direct information exchange, such as the Bronx RHIO, Brooklyn Health Information eXchange (BHIX), Long Island Patient Information eXchange (LIPIX), and the New York Clinical Information eXchange (NYCLIX). Other information exchange initiatives have also been developed in other states.

Other examples go beyond just data integration to actually monitor patient populations. The Academic Model Providing Access to Healthcare (AMPATH) medical record system is used specifically to monitor HIV patients and was implemented to support HIV care in sub-Saharan Africa

(Tierney et al., 2007). AMPATH includes standard EHR components, as well as data entry capabilities for clinical observations relevant to HIV care. From the system, data can be extracted and reported to national AIDS programs or funding agencies. The data in structured form can also support research queries. The New York City Department of Health and Mental Hygiene's (NYC DOHMH's) Primary Care Information Project (PCIP) promoted EHR adoption in clinics and doctors' private offices, with technology supporting both CDS and electronic reporting of required health measures to public health organizations. Data exchange focused more on reporting than on access across providers, which created an information-supported centralized data model at the DOHMH (Mostashari et al., 2009). This allowed the use of the PCIP infrastructure for the NYC DOHMH in population monitoring. Integrated delivery networks with extensive information systems, such as Kaiser Permanente, Geisinger, and Intermountain Healthcare, have created patient monitoring systems by gathering data from multiple sites of care. Common examples are the various diabetes or chronic disease registries, which can be used to both monitor patient status with accepted guidelines and prompt care providers to bring patients back into care.

National research registries have also exchanged health information—but to support research rather than to direct patient care. The National Registry for Myocardial Infarction collects health information for patients in multiple institutions to monitor the effectiveness of various treatments and patient outcomes. Other examples include the Surveillance, Epidemiology and End Results (SEER) program, a source for cancer statistics in the United States, and the National Program of Cancer Registries.

Various lessons learned throughout these examples might be applied to a strategy of data monitoring for HIV care. Most of these examples are focused on HIE, and integration is done through the clinicians only on individual cases. Data integration does exist for patient monitoring, but usually this is done within delivery networks where systems are already integrated and/or incentives can better justify data integration. These examples are relevant to PLWHA in these systems, but most PLWHA receive care outside of integrated delivery networks. AMPATH was applied directly to HIV/AIDS care, but that was in an environment where the disease prevalence was sufficiently high to promote monitoring systems. Lessons learned from AMPATH are thus best applied to settings where the prevalence of HIV/AIDS in the patient population is high enough to standardize the integration of data, such as specialty HIV/AIDS clinics. The PCIP project was interesting in that it centered data exchange with the public health organization. Data reporting was facilitated, and data integration could occur within a centralized system. Since public health reporting is ubiquitous among sites where PLWHA receive care, this is the most relevant example for patients outside of integrated delivery networks and specialty clinics. A final lesson is learned from research registries. Many registries require manual abstraction of data from patient records at the institutions providing data. Where this information is available electronically, registry reporting can be more efficient, but only when the data are collected consistently. Indicators of care are more efficient when they can be based on data that are collected consistently and are available electronically.

As noted in the ONC's Federal Information Technology Strategic Plan for 2011–2015, future stages of meaningful use for EHRs may become more rigorous—for example, by requiring that providers not only adopt health IT but use it to exchange health information (ONC, 2011a). If implemented as planned, these changes could help to lay the groundwork for increased data system interoperability and to simplify the assessment of the state of HIV care at the national level. The federal government is currently developing a standards and interoperability framework (S & I Framework) to broaden interoperability across different organizations and federal agencies.[10] To support health IT adoption and information exchange for public health and populations with unique needs, ONC is working with CDC, CMS, the National Institutes of Health (NIH), the Food and Drug Administration (FDA), the Assistant Secretary for Preparedness and Response (ASPR), and the Health Resources and Services Administration (HRSA) to ensure that meaningful use of certified EHRs supports the needs of public health agencies. In particular, these agencies are working to ensure that EHRs include capabilities to submit electronic syndromic surveillance data, immunization registries, and electronic lab reporting (as based on current stage 1 meaningful use criteria). This may help set the stage for two-way communication between providers and public health agencies (ONC, 2011a).

Data System Linkage

One means of data system integration is data linkage. Data linkage refers to the bringing together of information from one or more disparate data sources for the same individual, family, event, or place, removing the need to extract data from several sources. Data linkage has been used frequently for medical and population health research (Brook et al., 2008; Herzog et al., 2007; Jutte et al., 2011; Karmel and Rosman, 2008). Rather than initiating new data collection efforts, linkage allows researchers to

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[10] The framework will focus on identifying transport standards (that enable one provider to exchange data with another provider, or one system with another system, securely); content standards (that allow data to be packaged or "read" in a way that is useful for the provider); and vocabulary and terminology standards and value sets (to achieve semantic interoperability at the level of individual data elements) (ONC, 2011a).

make better use of data that are already collected for other purposes (e.g., claims or registry data) (Jutte et al., 2011). Data linkage can improve the cost-effectiveness of data collection, can reduce the amount of time needed for data collection in research, and has the potential to improve the quality of the data collected—for example, through the detection of duplications that otherwise may not have been identified (Herzog et al., 2007; Holman et al., 2008).

Methods for record linkage are described elsewhere in the research literature (see Fellegi and Sunter, 1969; Herzog et al., 2007). In general, linkage is achieved using individual identifiers to reliably identify an individual across two or more data systems (Jutte et al., 2011; Tromp et al., 2011).[11] Identifiers may include Social Security numbers, names, dates of birth, zip codes, and other information. The use of a unique individual identifier (e.g., Social Security number, patient medical record number) across data sources can help to overcome problems of inaccuracies in identification of matches across systems based on other types of identifiers. However, in the United States, unique identifiers are not applied ubiquitously across the various sources of care and care coverage for PLWHA.

Some of the best examples of successful data linkage while maintaining patient privacy and confidentiality come from the international realm (Jutte et al., 2011). For the most part, countries that have demonstrated successful data linkages for most of their residents have single-payer health care systems that do not face the same administrative and legal barriers to sharing of health information encountered within the U.S. health care system (see Chapter 4). In Sweden, the MigMed2 database was developed by linking data from several national registers, including those containing population, death, hospital discharge, multigenerational (i.e., identities of the biological and adopted parents), and immigration data. The national 10-digit civic registration identification number that each person uses for her or his lifetime are used to link individual-level data across registers. Prior to inclusion in the database, the identification numbers are replaced with serial numbers to ensure anonymity. MigMed2 has been used for research in a number of areas including, but not limited to, prostate cancer mortality and patterns of breast cancer survival within families (Hemminki et al., 2008; Ji et al., 2010; Li et al., 2011). Population Data BC (British Columbia), formerly the British Columbia Linked Health Database, contains data on nearly every person in British Columbia and links individual-level health care utilization, population demographics and vital statistics,

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[11] The two primary methods for data linkage are deterministic linkage and probabilistic linkage. In deterministic linkage, a predefined subset of linking variables have to agree to be considered a match and linked. In probabilistic linkage, record pairs are linked based on the probabilities of agreement of a set of identifiers (Tromp et al., 2011).

cancer registry, and occupational and early childhood information for use in research. Population Data BC uses identifiers (e.g., names, birth dates) to link data, but it does not store data in a linked format, and data are reported only at an aggregate level to protect confidentiality. This resource has been used by researchers to identify determinants of health for the entire population of BC as well as for health disparities research (Population Data BC, 2012). Other international examples of successful record linkage for population-based research include the Scottish Record Linkage System, the Oxford Record linkage Study, and the Western Australia Data Linkage System (Holman et al., 2008; Jutte et al., 2011).

In keeping with the fragmented nature of the U.S. health care system, a number of successful examples of data linkage in the United States have occurred more locally. One example involving PLWHA is the HIV/AIDS Cancer Match Study, which uses anonymized data collected by state and regional HIV/AIDS and cancer registries to study cancer in PLWHA. The study data are pulled from computerized linkages between databases that are maintained by study sites in 13 states and the District of Columbia (NCI, 2012). Data from the linked registries have helped to identify cancers that occur more often among PLWHA; describe changes in cancer burden among PLWHA over time; and identify predictors of cancer outcomes for PLWHA (Shiels et al., 2010, 2011a,b; Simard et al., 2011). The results from the study provide important information on the impact of HIV on cancer risk and trends in morbidity and mortality to the National Cancer Institute and other policy makers (NCI, 2012). Data linkage has been used in several HIV-related research studies carried out in the United States to improve the completeness of data for surveillance and for monitoring HIV care. A study of linkage of HIV/AIDS surveillance data in the District of Columbia Department of Health with death registries showed that the linkage improved the accuracy of estimation of the prevalence of individuals living with HIV/AIDS (CDC, 2008). In the LaPHIE study described earlier in this chapter, state public health surveillance data was linked to real-time EMR data to successfully identify PLWHA who had fallen out of care (Herwehe et al., 2011).

Efforts are under way to improve data linkage among sources of care and care coverage for PLWHA. As discussed in Chapter 3, the *AIDS Drug Assistance Program (ADAP) Data Report* will begin to capture client-level data during the April 1 through September 30, 2012, data collection period and will employ a unique client identifier using the same algorithm and encryption process as is currently used for the *Ryan White Services Report*. Eventually the systems will be merged to link data for Ryan White clients who are receiving ADAP services (Personal communication, Faye Malitz, Health Resources and Services Administration, October 25, 2011). In 2009, the CMS developed a database of linked Medicaid and Medicare data to improve tracking and coordination of care for individuals who are enrolled in both programs (CHCS, 2010).

Further enhancements in linkages among data systems could enhance the completeness of data for monitoring HIV care. Examples include, but are not limited to, linkage of surveillance systems that collect CD4 and viral load information to other public health data systems. For example, linking surveillance data with the Medical Monitoring Project (described in Chapter 3) could enhance understanding of the transition from newly diagnosed HIV infection to chronic clinical outcomes. Other linkages to more comprehensive data collection systems such as CNICS and the North American AIDS Cohort Collaboration on Research and Design ([NA-ACCORD] described in Chapter 3) could provide rich data but may require new data-use agreements given that the data for these studies were obtained via informed consent.

CONCLUSIONS AND RECOMMENDATIONS

- When used effectively, health IT can facilitate the collection of health care data and directly improve patient care. Although little research has been conducted on the use and configuration of health IT for the collection of HIV care data in particular, general improvements in the collection and exchange of data resulting from health IT would increase the availability of data to monitor HIV care. Education for HIV care providers on the potential uses and benefits of health IT for their own practices, technical assistance, and financial incentives (including, but not limited to, that being offered to providers who demonstrate meaningful use of EHRs under the HITECH Act) could help to promote more widespread use of health IT.

- Increased exchange of health-related information among providers of HIV care and supportive services has the potential to improve care coordination and longitudinal tracking of care. Some integrated health care systems, such as the Veterans Health Administration and Kaiser Permanente, effectively manage patient information across providers within their networks, but most PLWHA receive care and supportive services outside of these networks and many receive care across multiple organizations. The committee identified local efforts in health information exchange that have resulted in improved monitoring of patient care and outcomes. However, these efforts have not been scaled broadly among entities serving PLWHA.

Recommendation 5-1. The Department of Health and Human Services should review existing mechanisms for the confidential and secure exchange of health information to provide a platform to increase the exchange of such information among entities serving individuals with HIV. These entities may include, but are not limited to, state and local health departments and government agencies or community-based organizations funded to provide medical care, substance abuse and mental health services, and housing and other supportive services.

- 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 care and care coverage for PLWHA have their own health IT systems with disparate architectures and vocabularies, posing a challenge to the exchange of data across systems.

Recommendation 5-2. The Department of Health and Human Services and the Office of the National Coordinator for Health Information Technology should provide technical assistance and policy guidance to state and local health departments, clinical providers, and other agencies serving individuals with HIV to improve the interoperability of data systems relevant to monitoring HIV care and supportive services.

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6

Efficient Analysis of HIV Care Indicators and Dissemination of Data by Federal Agencies

In this chapter the committee describes how federal agencies can efficiently analyze indicators and disseminate data to improve the quality of HIV care (statement of task question 5). The chapter begins with an overview of the challenges to the analysis of indicators, including those related to combining data drawn from multiple sources, and how to address those challenges. The committee then describes how federal agencies can efficiently disseminate HIV care data to improve care quality. The chapter ends with the committee's conclusions and recommendations.

EFFICIENT ANALYSIS OF HIV CARE INDICATORS BY FEDERAL AGENCIES

As discussed in Chapter 3, no single data system can be used to gauge the impact of the National HIV/AIDS Strategy (NHAS) and the Patient Protection and Affordable Care Act (ACA) on improvements in HIV care. Rather, estimates of the indicators of clinical HIV care and mental health, substance use, and supportive services recommended by the committee often will require the use of data elements from two or more data systems. Combining data from multiple systems may also be necessary to compensate for the weaknesses of any individual data system, such as a lack of representativeness of the population of people living with HIV/AIDS (PLWHA) or incompleteness of data (e.g., due to a low response rate).

The committee was asked to describe how federal agencies can efficiently analyze indicators. The data systems described in Chapter 3 that are maintained by federal entities represent a mix of surveillance (e.g., the

National HIV Surveillance System [NHSS]), claims (e.g., Medicaid Statistical Information System), and programmatic (e.g., Ryan White HIV/AIDS Program) data sources, as well as epidemiologic studies of PLWHA (e.g, the Medical Monitoring Project). Efficient analysis of the indicators will require overcoming challenges to combining data across these disparate systems.

One analytic challenge to the efficient analysis of indicators relates to differences in the way that data systems operationalize data elements or define concepts to allow them to be measured. An area in which this may be relevant is in the calculation of indicators for subgroups of PLWHA, because data systems may vary in how they define certain demographic data such as income, geographic marker of residence, race or ethnicity, and sex or gender. Another challenge is differences across data systems in the periodicity for particular data elements. Although claims systems will have continuous data on dispensing of antiretroviral drugs, the Ryan White HIV/AIDS Program collects information on whether antiretroviral drugs were prescribed within a 12-month reporting period. This presents an obstacle to combining data from these systems for purposes of estimating the proportion of PLWHA who were or were not on antiretroviral therapy (ART) during a given period. Although technically difficult, there are approaches to deal with the analytic challenges of combining data, as discussed below.

Additional impediments to the efficient analysis of the indicators by federal agencies that relate to combining data from multiple systems include the current lack of an infrastructure to support the secure exchange of health information across health information technology systems (e.g., electronic health records) and organizations, and other barriers to data sharing. These issues are discussed in Chapters 4 and 5 of this report.

An Example of Challenges to the Efficient Analysis of an Indicator for Clinical HIV Care

One of the core indicators for clinical HIV care recommended by the committee (see Recommendation 2-1 in Chapter 2) is the **proportion of people with diagnosed HIV infection and a CD4+ cell count <500 cells/mm^3 who are not on ART** among all patients who receive such counts. To define this indicator more precisely, one must take timing into account. For example, one might ask: What proportion of individuals who received a CD4+ cell count measurement of <500 cells/mm^3 in 2011 also received ART at any point in 2011. Although this definition is clear, it suffers from the problem that those who received such a count late in 2011 had less opportunity to receive ART in that year. Therefore, it may make more sense to rephrase the question: How many individuals who received a CD4+ cell count <500 cells/mm^3 in 2011 received ART treatment within a fixed window of time (e.g., 6 months) of receipt of that measurement. In addition to estimating a population average, there is also interest in estimating the effects of demographic factors or insurance status on this indicator.

To estimate such an indicator requires information on date of measurement and level of CD4 count as well as date of ART prescriptions given or filled. Some data sources, such as health maintenance organizations (HMOs; e.g., Kaiser Permanente), the Department of Veterans Affairs (VA), and federal prisons provide all of the relevant information needed, permitting a relatively straightforward estimation for subsets of the population. However, analytic issues arise from the fact that patients may leave these systems at any point—possibly after a CD4+ cell count <500 cells/mm^3 is measured but before the prescription is provided or 6 months have elapsed. Furthermore, delays in reporting (e.g., of HIV/AIDS cases, CD4 counts) must be taken into account, particularly if the goal is to investigate trends over time. In addition, patients may die within 6 months of receiving a CD4 count—a situation that makes it impossible to obtain the indicator. For patients who leave a system before their contribution to the indicator can be assessed, it is important to make use of the available partial follow-up information in an attempt to avoid, or at least reduce, bias. This is fairly straightforward using methods for failure-time data if the loss to follow-up is not informative (i.e., unassociated with greater or lower risk of starting treatment). If it is informative, appropriate methods must be used to minimize bias; however, unbiased estimation is possible only if all potentially confounding variables are available (a very unlikely situation). To investigate the effect of demographic and other factors on the risk of not receiving appropriate ART, regression methods can be used. Limitations arise from losses to follow-up, as described above, as well as from the fact that with the exception of the NHSS, which captures data on the vast majority of people identified with HIV/AIDS in the United States, none of the data sources is representative of either the American population as a whole or any particular demographic group.

The limitation of representativeness can be addressed by making use of other sources of data that have broader coverage. To do so, however, one must make use of data systems that provide only part of the necessary information by combining them in some way. For example, the NHSS provides dates of measurements and CD4 counts but not (reliably) the time of receiving ART. By contrast, Medicare and Medicaid databases provide information about dates of ART prescriptions filled but not CD4 counts. In the absence of unique identifiers, no direct linkage between databases can be made. However, combining across sources is still feasible through linkage by demographic factors. For example, suppose one knew that for one demographic group in a given state, 400 people had CD4+ cell counts <500 cells/mm^3 at some point in 2011 among 600 people who had CD4+ cell counts drawn. Suppose one also knew for this group that 300 people received or filled prescriptions for ART. One then would know that at a minimum, there had to be 100 patients who should have been on ART but were not. In fact, however, the number might be considerably greater because some of the ART use may have been among patients who had CD4+ cell counts of 500 cells/mm^3 or greater. However, if one could estimate this number from other sources (for example, from people within HMO-type systems who are similar in demographic category to those under study), the estimate could be refined further. Suppose that of the 200 people who never had a CD4+ cell count <500 cells/mm^3 during the year, one estimates, from some other data source, that about 100 of them were on ART. Then one could estimate that about 200 of the 400 patients who should have been receiving ART were not.

The above discussion illustrates the underlying logic for making inference but does not address the question of uncertainty in estimation. Of course there would be errors associated with all of these estimates. How to calculate the variability in estimates obtained by combining data from different sources is an area of active research. Bayesian methods have been used in a variety of settings to characterize the uncertainty associated with such estimates, reflecting the limitations of the data and the need to combine across sources. Similarly, Bayesian methods can also be used to conduct regression analyses that would allow for estimation of the effect of demographic factors on risk of receiving inadequate treatment.

Issues in Combining Information

Many problems can bedevil analyses of data sets that are derived from clinical program or public health systems and from which treatment or intervention effects are being estimated; these include missing data, unknown population sizes and denominators, and sampling bias. Analysis of randomized studies generally also suffers from these challenges, since they are subject to some level of participant attrition, unplanned crossovers, and inadvertent unblinding. Combining sources of information can help to overcome shortcomings in each source but creates new challenges for the analyst, as described in the illustration above. These challenges arise from the fact that 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 factor into account as well. A large and growing body of work regarding strategies and methods for combining information is now available.

In 1992, the National Research Council issued an important report titled *Combining Information: Statistical Issues and Opportunities for*

Research which described many of the principles and methods associated with combining information (NRC, 2002). Since that time, a number of developments in methods for combining data from different sources have occurred that could be applied to HIV research. For example, Bayesian two-stage hierarchical models have been employed in environmental health studies that relate air pollution to mortality. The first stage of such studies estimates the impact on mortality of air pollution for different cities of interest, after controlling for confounding factors. The second stage combines the estimates across cities using a Bayesian hierarchical model (Lindley and Smith, 1972; Morris and Normand, 1992) to obtain an overall estimate and to explore whether some of the geographic variation can be explained by site-specific explanatory variables (Dominici et al., 2000). Such techniques would also be useful if, for example, there was interest in relating community-level factors—such as prevalence or incidence of disease, access to health care, poverty or homelessness rates—to such health outcomes as HIV morbidity or mortality.

Many of the problems that arise in combining information can be viewed as related to the issue of missing data. For example, the indicator for a link between individuals may be seen as missing. Missing data are handled in a wide variety of ways from the ad hoc (analyze only complete cases) to sophisticated methods for accommodating incomplete observations.

One approach to dealing with missing data is imputation—replacement of the missing observation with the best estimate of what it would have been had it not been missing. Such methods, however, tend to underestimate the uncertainty that arises from the missing data. Multiple imputation addresses this concern using Bayesian methods (Little and Rubin, 1987). Likelihood-based methods are also useful; these involve the development of a likelihood for just the observed data. In either case, one must have a statistical model for the generation process of the data, including the probability of its being observed. Given the importance of such models, considerable effort has been made to expand their flexibility, by allowing not only fully parametric but also semiparametric models (Tsiatis, 2006).

In some cases it may be possible to make inferences about the sizes of populations of interest using capture-recapture methods; these are useful in settings when collection of complete data (i.e., a full enumeration of the populations) is not feasible or affordable. For example, as described below, these have been used to estimate the size of an injection drug-using population.

In addition to the problem of missing data, analyses of observational data intended to produce causal estimates of the impact of factors, such as demographics or insurance status, on outcomes must take into account confounding factors. There is an enormous literature on adjustment for confounding factors, as well as increased interest in causal modeling for this purpose. One approach—use of marginal structural models—has received increasing attention because of its ability to handle confounding factors that vary over time (Suarez et al., 2008). All of these techniques are relevant to the charge to the committee to explore the opportunities and limits of data sources for HIV program and outcome evaluation in the United States, but they by no means capture the breadth of methodology available to cope with data limitations that may bias or confound results and distort conclusions.

Multiple Imputation for Missing Data

Missing data can arise from settings in which people are asked about sensitive personal data, when resource constraints limit the completeness of data collection, or when certain items of information are not routinely collected. When a given variable is essential for a particular evaluation, analyses only of complete cases introduces many threats to inference: (1) bias can be introduced because persons with missing data may be systematically different from those with complete data; (2) statistical power can be reduced when many cases are deleted from analyses due to missing data; (3) resources can be wasted—for example, when 95 percent of data are collected on someone, but due to the 5 percent missing data, the entire data block is left unused; and (4) ethical obligations to research subjects can be compromised when they have inconvenienced themselves under the assumption that they were doing this for biomedical or behavioral research, but the investigator discards their data due to missing variables.

Data on sensitive topics such as sexual risk behaviors or drug use may be limited by nonresponse bias or biases stemming from socially sensitive responding. These biases present a special challenge to the collection of data for surveillance and for epidemiologic research studies where sexual behaviors or drug use may be relevant (Fenton et al., 2001). Multiple imputation helps to circumvent the need to eliminate subjects with partially observed data imputing (predicting) values for missing variables. Such imputation requires a statistical model for the complete data (including the unobserved portions) and for the process that led to the observed pattern of missing observations. This model is used to predict the missing observation based on the individuals for whom the data were observed. The posterior distributions of the unobserved values given the observed data can then be calculated. Since such calculations may be difficult, Little and Rubin (1987) propose a resampling-based approach for their calculation. Like any approach for handling missing data, its validity depends on the correct specification of a model for the process that generated the missing data.

Capture-Recapture Methods

When the population of interest has not been enumerated and a survey of the prevalence of a condition or size of a subgroup in a community is impractical or otherwise unfeasible, the capture-recapture method may be used. This technique derived from the field of population ecology (Stephen, 1996). For example, one can capture mosquitoes, dust them with harmless florescent material, and release them. The proportion of recaptured mosquitoes in a day or two (allowing sufficient time for remixing but not allowing time for significant mortality) can be used to estimate the total number of mosquitoes in the local population, assuming random mixing and equal probability of selecting labeled and unlabeled mosquitoes. Similarly, small mammals may be trapped, tagged, and released, and then a second trapping recaptures new and old (tagged) mammals, enabling a population estimate.

In human biology and epidemiology, the completeness of population ascertainment can be indirectly estimated using capture-recapture, as with estimations of persons who need HIV therapy, drug addiction services, or other social or medical services. Thus, persons must be "captured" and "marked," to borrow the ecology model, such that they are available for recapture after release. Sometimes in epidemiology, this is literal, as with prisoners who are injection drug users (IDUs), who are arrested but released after a short time in jail. The proportion who return to jail may be used to estimate the proportion of drug users at risk of being arrested (presumably a large proportion of IDUs); combined with population HIV estimates, the absolute number of HIV-infected drug users can be estimated (Drucker and Vermund, 1989; Dunn and Ferri, 1999).

One may estimate the size of a population from just two samples or through multiple samples. Capture histories may be analyzed to estimate migration, life span, or size in the population of interest. A simple formula reflects the core principle of the basic capture-recapture approach. This simple model requires strong assumptions such as full mixing of persons who have been "captured" and "released" (as with hospitalized patients who go home) with the general population. The time-to-recapture estimation must be long enough to permit remixing and short enough for estimation to be relatively unaffected by deaths, out- and in-migrations, and failure to identify "marks." The latter may occur, for example, when rehospitalized patients use different names when entering an institution. If the assumptions are met, the formula is expressed as: $N = MC/R$ (where N = total population size estimated; M = total number of persons "captured" and "marked" [i.e., identified] on the first occasion; C = total number of persons "captured" on the second visit; and R = number of identified persons "marked" from the first occasion that were then reidentified on the second occasion) (Chao et al., 2001; Hook and Regal, 1995; International Working Group for Disease Monitoring and Forecasting, 1995a,b; Stephen, 1996).

Marginal Structural Methods and Models

Marginal structural models estimate treatment or intervention effects in observational studies by statistical strategies of controlling for selection bias and confounding variables (Robins, 1999). The fundamental concept behind marginal structural modeling can be explained as follows: Suppose one wishes to compare exposures A and B, which may vary over time, in some population and suppose that, at each time, one could create an identical copy of each study subject. If the actual subject had exposure A at a given time, we would give the copy exposure B and vice versa. One could then compare each subject to his or her copy. We refer to the outcomes for each of the imaginary copies as "counterfactuals" and treat them as missing data. Inverse-probability weighting (IPW) is an approach to handling missing data that reweights observations by the inverse of the probability that they are made. Marginal structural models use IPW to deal with the unobserved ("missing") counterfactuals. Using IPW and marginal structural model procedures reweight data sets so that treatment and covariates are not confounded.

In "confounding by indication," an "exposure" is linked to a true causal exposure (e.g., condom use and commercial sex work) but does not itself contribute to the outcome. For example, condom use may be statistically and positively linked to HIV risk, which is counterintuitive (Holmes et al., 2004), but this association may arise because of confounding by indication (e.g., disproportionate use of condoms by sex workers in the population studied). When this occurs in an observational study, the association of the putative risk factor cannot be accurately attributed to the outcome of interest unless one has measured all of the exposures and the relevant confounding factors.

Estimation of causality must take into account time-dependent confounding, and marginal structural models can address selection bias and/or confounding in such analyses. However, inclusion of such factors as time-varying covariates in longitudinal models does not correct for this bias. Such bias occurs most often when "(1) conditional on past treatment history, a time-dependent variable is a predictor of the subsequent outcome and [is] also a predictor of subsequent treatment; and (2) [when] past treatment history is an independent predictor of the time-dependent variable" (Suarez et al., 2008).

Marginal structural models can be used for causal inference even from nonexperimental designs, comparing treatments or interventions, as long as information is reasonably accurate, all confounders are measured, and censoring either is noninformative or can be modeled accurately as a function of known covariates. Better control of confounding than available from simple parametric regression models alone may bring some observational data closer to values that would be measured in a randomized controlled clinical trial. One recent example comes from a study showing that hormonal contraception is a risk factor for HIV acquisition in African women (Heffron et al., 2011). Marginal structural model analyses were used to assess the validity of the Cox proportional hazards regression from this large observational couples study.

Here the committee describes only a few of the challenges that arise in the use of observational data to make inferences about outcomes or service coverage (Teresi, 1994) and the approaches to dealing with them. Nonetheless, the committee seeks to illustrate a few modern statistical methods to make surveillance and programmatic data more useful for evaluation purposes and to illustrate the inherent challenges, both to data collection and to analyses. Correct application of these and other relevant techniques can improve the chances that inferences drawn from imperfect data are valid.

Analysis of Indicators Involving Small Subgroups of People Living with HIV/AIDS

Tracking reductions in HIV-related health disparities will require analysis of indicators by race and ethnicity, sexual orientation, and other demographic variables. The NHAS is aimed at improving access to care and health outcomes for PLWHA and reducing HIV-related health disparities at the national level. Yet, analysis of indicators may occur at a local level, such as to disseminate information to local health departments and HIV care providers on the status of the HIV epidemic in their jurisdictions. In some communities of the United States, the number of individuals who comprise a specific demographic group (e.g., racial and ethnic minority men who have sex with men) may be small. Because the statistical power of an indicator estimate is linked to the number of observations in a sample, small subgroups limit the precision of estimates of care indicators and the ability to compare them with other subpopulations of PLWHA. In epidemiologic studies, investigators may have little choice but to pool very small subpopulations with the larger study population because there is insufficient power to extract the effects of defining subgroup characteristics. With respect to the NHAS, however, this would defeat the purpose of using indicators to track improvements in HIV-related disparities.

Statistical methods for inference may be used for the analysis of indicators involving small subgroups of PLWHA. In general, Bayesian methods are useful for combining information about prevalence, incidence, or treatment effects across different population subgroups (Han and Chaloner, 2005). Group-specific Bayesian estimates are "shrunk" toward (moved closer to) the mean of the quantity of interest over the population included in the combined data set. Because the amount of shrinkage depends on the amount of available information, the smaller the size of the subgroup, the greater will be the reliance on the estimate of the mean. In addition, group-specific Bayesian estimates are sensitive to assumptions regarding the distributions of the random effects; the most common approach of assuming normal distributions leads to the greatest shrinkage. Using other types of random effects distributions, such as Student *t* or mixtures, can reduce the amount of shrinkage, since they have longer tails and, therefore, allow for a greater probability of outlying values. As an alternative, one can base inference on nonparametric approaches, which can achieve the same goal. Posterior distributions may also tend to be flatter—implying lower precision in estimates—because the strong normal assumption can convey a sense that there is more information on which to base inference than is truly the case if the distributions are nonnormal. While Bayesian methods provide posterior distributions for any subgroup, no matter its size, the inference for that group will rest most heavily on the mean and on underlying assumptions if the subgroup is small. More advanced statistical methods, such as those that do not require parametric assumptions for the distributions of the random effects, can provide more reliable and robust results in this setting.

Growing numbers of studies indicate that social status modifiers such as race and ethnicity, nativity (place of birth), sexual orientation, geographic location, and drug use status often have an impact on important measures of HIV care (e.g., Kempf et al., 2010; Lillie-Blanton et al., 2009; McGowan et al., 2011). For these subpopulations, among whom social status contributes to their risk environment (Farley, 2006; Rhodes, 2009) and treatment access, assumptions of normality of the distribution of random effects may be especially problematic, and approaches that allow for the existence of outliers are particularly needed. One potential consequence of overshrinkage is underestimation of the impact of indicators of social status, such as geographic location, economic status, or drug status, on care experiences. And so although parametric approaches can provide some care data on individuals in these subpopulation groups, they lie within a more restrictive set of assumptions that could temper the use of the results for policy changes.

Epidemiologic studies are an important source of data on care and supportive services received by PLWHA. Health research in general has historically been plagued by an inability to recruit and retain large numbers of racial and ethnic and socioeconomically diverse populations, particularly of sexual minorities or the homeless (Levkoff and Sanchez, 2003; Moreno-John et al., 2004; Sengupta et al., 2000), although studies of PLWHA may do better than studies of other populations in terms of representativeness. Although helpful, statistical methods cannot make up for a lack of sufficient data to estimate indicators for small populations of PLWHA. The development of precise indicator estimates would be facilitated to a greater degree by inclusion of those groups in greater numbers in HIV-related studies.

In a given community, there may be subpopulations of PLWHA that are small in number and have complex health care and supportive service needs for whom the ability to maintain health care regimens depends on access to supportive services. Improvements in linkages between data systems that collect information on clinical care and those that collect information on supportive services (e.g., housing and transportation services) would help to ensure the availability of the full range of data needed to estimate indicators for these subpopulations. Although data system linkages will not address the problem of low statistical power in analyses designed specifically to provide estimates for small subpopulations of PLWHA, nonparametric methods can be used to provide some insights into care needs.

Increased support for training of HIV/AIDS researchers in statistics and methodologies may facilitate the development of expertise in the analysis of data for subpopulations of PLWHA. Such investment could speed the provision of effective treatment to all communities and thereby improve control of HIV transmission.

DISSEMINATION OF DATA TO IMPROVE HIV CARE QUALITY

Analysis of the HIV care and related indicators identified by the committee will generate data of interest to a number of stakeholders, including federal and state agencies and policy makers, state and local health departments, health care systems (e.g., HMOs, VA, prisons), individual providers, consumers (patients), and academic researchers. Properly presented, the information provided to each audience has the potential to improve the quality of HIV care in the United States. Policy makers, agencies, and health departments may use the information to direct resources and policies toward areas that are most problematic (e.g., access to health care or mental health, substance use, or supportive services to improve linkage to or retention in care). Health care systems and individual providers may use the information to inform their provision of quality HIV care and to target patient education efforts. Individual patients, patient groups, and patient advocates could use the information to direct personal and group advocacy efforts for access to needed services. Academic researchers could use the information to support research proposals and projects that might generate additional information to further improve the quality of HIV care.

The committee's review of the existing systems that capture data relevant to HIV care shows that many data on various aspects of HIV care currently exist. However, existing data often are not used to the fullest extent possible. Although government agencies and some state and local health departments make some de-identified data available publicly, in other cases the data reside with the agencies that require the reporting and are not made accessible to the public (HHS, 2010), including to the programs and providers who reported the data in the first place. Not only is broad dissemination of data on HIV care important for improving care by engaging as many stakeholders as possible; the return of information to reporting programs and providers increases the collaborative nature of the relationship, provides them with useful feedback, and may motivate them to further increase reporting compliance (CDC, 2011, p. 5-32).

Data Dissemination by Federal Agencies

Federal agencies, including the Centers for Disease Control and Prevention (CDC), the Health Resources and Services Administration (HRSA), and the National Institutes of Health (NIH), have been disseminating health-related information for decades. Until the advent of the Internet, which enabled agencies to disseminate large amounts of information, dissemination had primarily involved making paper copies of documents available to the public (OMB, 2011). In the context of increasing federal information dissemination, Congress passed the Information Quality Act (IQA), also referred to as the Data Quality Act, in December 2000. The IQA required the Office of Management and Budget (OMB) to issue guidance to federal agencies to ensure the “quality, objectivity, utility, and integrity” of information disseminated to the public. In response, the OMB issued *Guidelines for Ensuring and Maximizing the Quality, Objectivity, Utility, and Integrity of Information Disseminated by Federal Agencies*, effective October 2001. These guidelines require that information quality be treated as an integral step in the information development process. Federal agencies must adopt a basic standard of quality as a performance goal and take steps to incorporate information quality criteria into agency information dissemination. In addition, agencies are to develop a process for reviewing the quality of information before it is disseminated. OMB designed the guidelines to apply to a variety of government dissemination activities and to be generic enough to fit all media (HHS, 2006a).

The IQA also required that government agencies issue their own information quality guidelines and establish mechanisms to allow individuals to seek correction of information maintained and disseminated by federal agencies that does not comply with OMB guidance (OMB, 2011). Therefore, *Guidelines for Ensuring the Quality of Information Disseminated to the Public* have been issued for several agencies of the U.S. Department of

Health and Human Services (HSS). These guidelines describe the types of information disseminated by the agency to the public; types of dissemination methods; agency standards for ensuring the quality of information disseminated; agency administrative complaint procedures; influential scientific, financial, and statistical information; and any special considerations for agency dissemination. As one HIV-specific example, the types of information disseminated by HRSA listed in its guidelines include HRSA HIV/AIDS Bureau State Profiles that describe spending and service information for Ryan White HIV/AIDS Programs, including provider characteristics (e.g., the number and types of organizations in the state that receive Ryan White HIV/AIDS Program funding), client demographic information, service utilization information (e.g., number of patient visits for core medical services), and characteristics of AIDS Drug Assistance Program clients (HHS, 2006b; HRSA, 2012). Under "dissemination methods" the guidelines say that the state profiles are available through the HRSA HIV/AIDS Bureau website and that further requests or feedback can be made by phone or email (HHS, 2006c). Within CDC, dissemination guidance applies to HIV/AIDS Surveillance Reports and reports for other infectious and noninfectious conditions (HHS, 2006b).

Considerations in Data Dissemination

Effective and efficient dissemination of data requires careful attention to several considerations, including audience, definition and presentation of the message, data quality and interpretation, and method of dissemination (CDC, 2009; Marriott et al., 2000; Sofaer and Hibbard, 2010a,b).

In HRSA guidelines for ensuring the quality of information disseminated to the public, CAREWare, a software package used by Ryan White HIV/AIDS Program providers to track clients and services, is listed as a means to ensure the quality of information disseminated to the public (HHS, 2006c). According to the guidelines, CAREWare helps to ensure the quality of data because it contains consistency and edit checks on input data. HIV/AIDS Bureau State Profiles, which present state-level data derived from these data, provide—for each data element—information on data limitations, rounding, and restrictions where appropriate (HHS, 2006c). CDC guidance notes that surveillance information is often obtained from third parties, such as states and grantees, which places limits on quality assurance. However, the accuracy, completeness, and timeliness of the information are subject to sample audits, site visits, and an "evaluation for completeness and consistency with trends and external controls" (HHS, 2006b).

Audience

Defining and understanding the target audience is one of the first steps in developing a plan for data dissemination (Marriott et al., 2000; Sofaer and Hibbard, 2010b). Potential audiences for data derived from the full set of HIV care indicators identified by the committee already have been identified (federal and state agencies and policy makers, state and local health departments, health care systems, individual providers, consumers [patients], and academic researchers). Selection of the appropriate audience involves consideration of what the data show, the purpose for which the data are being disseminated, and the message that is to be conveyed.

Federal, state, or local policy makers and agencies would be the primary target audience/s if the purpose is to increase or redirect the allocation of resources or to affect policy changes, including the development of new programs to address specific areas of need. Such programs could focus on points in the HIV care continuum that the data might indicate are particularly problematic (e.g., continuity of care) or mediators known to affect those areas (e.g., access to stable housing). Information about improvements on indicators would be useful as well, by showing which current policies and programs are working.

Public and private health care systems, as well as individual providers, might be interested in the data for the purpose of evaluation of, and possible changes in, the HIV care they provide. Such information could permit systems and providers to identify their areas of strength, as well as areas for improvement, in the provision of quality HIV care. Research indicates that dissemination of clinical practice guidelines alone has a minimal effect on provider knowledge and performance, while combination strategies, including those with an education component, are more effective (Marriott et al., 2000). Results of performance indicators also may be more effective in changing provider behavior (Marriott et al., 2000).

PLWHA, and advocacy groups for PLWHA, are other potential audiences for the information on indicators. The information could be used to educate individuals regarding areas in which increased attention and advocacy could improve HIV care.

Depending on what the data show, the dissemination process might target any of these general audiences or a more specific audience within a group, such as policy makers representing a particular region of the United States, HIV care providers who serve patients in a specific demographic group, or patients of a particular race or ethnicity. Ultimately, audience selection should depend on the applicability of the data for that audience and the purpose the data serve (Sofaer and Hibbard, 2010b). Once the audience is defined, the message and the remainder of the dissemination process should be geared to that audience (CDC, 2009).

Definition and Presentation of the Message

Another critical consideration in effective data dissemination is the message to be conveyed. Many audiences are not equipped to understand and process vast quantities of data (Sofaer and Hibbard, 2010a). Data provided without the expertise to interpret them can cause more harm than good. Even the language used to present the information may result in unanticipated misinterpretation (Hibbard and Sofaer, 2010). It is important therefore for an agency to have a clear understanding of the message it wants to transmit and then relay that message to the target audience clearly and concisely, along with the data to support it (Hibbard and Sofaer, 2010; Marriott et al., 2000; Sofaer and Hibbard, 2010a). The details of the message may vary depending on the target audience, as will the way in which the message is presented.

Presentation of the message in the most appropriate way for the target audience is critical to ensure that the message the agency wants to convey is the one that is received by the audience (CDC, 2009; Marriott et al., 2000). Considerations of health literacy and numeracy are important when preparing information for dissemination (Hibbard and Sofaer, 2010; IOM, 2004). Presentations of data from the HIV care and supportive services indicators and trends in the quality of HIV care over time will use different language depending on the audience (e.g., clinical care professionals, policy makers, program administrators, members of the public). Clinical indicators of HIV care that are fully comprehensible to HIV care providers may be incomprehensible to patients or to policy makers. It is important to make the information relevant to what the audience understands and the purpose for which it will use the data. Three papers on “best practices in public reporting” on health care performance data, prepared for the Agency for Healthcare Research and Quality, discuss a number of the pitfalls in and solutions to presenting performance data to health care consumers (Hibbard and Sofaer, 2010; Sofaer and Hibbard, 2010a,b). Although the papers focus on a specific type of data and target audience, the concepts presented may be generalized to other audiences and types of information.

Data Quality and Interpretation

As discussed, the IQA mandates that federal agencies develop quality assurance guidelines for information releases to the public, and a number of HHS agencies have issued *Guidelines for Ensuring the Quality of Information Disseminated to the Public*. Although it is important for agencies to present the message clearly, concisely, and in language that is understood by and resonates with the target audience, it is also important that they include information about the quality of the data that support the message and the methods used to interpret them (Sofaer and Hibbard, 2010a).

Factors affecting data quality include the source of the data, quality within the system, coverage of the data, confidence range, use of proxies, and analytic methodology applied. The challenge lies in providing sufficient information to permit independent assessment of the data, while not overwhelming the target audience with information that it cannot or will not use (Marriott et al., 2000; Sofaer and Hibbard, 2010a). One approach is to include with the disseminated information a summary, presented in language accessible to the target audience, of the data and the data analysis, including discussion of limitations or gaps in the data and any other relevant information that would enhance the audience's understanding and evaluation of the data (HHS, 2006b; Marriott et al., 2000; Sofaer and Hibbard, 2010a). At the same time, the agency could make available to interested parties full information on the data set and the methodologies used to assess it (Sofaer and Hibbard, 2010a). CDC, for example, clearly documents and makes publicly available the statistical processes and methodologies used to derive published information, which allows independent statisticians to replicate the results (HHS, 2006b).

Evidence suggests that an audience's acceptance of data is affected by its perception of the credibility of the data source and the source reporting the information (e.g., professional medical journal versus popular press), as well as proximity of the source to the target audience (Marriott et al., 2000; Sofaer and Hibbard, 2010a). Information intermediaries can help in this regard. Engagement with organizations knowledgeable about and trusted by the target audience may assist in the dissemination of information and help to support the credibility of the information and its source (Sofaer and Hibbard, 2010b).

Methods of Dissemination

A final consideration for effective and efficient data dissemination is selection of the most appropriate and cost-effective method of dissemination. As previously mentioned, federal agencies have a variety of dissemination methods at their disposal, including traditional print media (e.g., reports, peer-reviewed articles, fact sheets, newsletters), electronic media (e.g., websites, podcasts), and public forums (e.g., conferences, planned meetings) (CDC, 2009), and frequently more than one method may be employed.

The target audience and the message and data to be conveyed are factors in the choice of dissemination method. An agency might choose to prepare a report or paper for a peer-reviewed professional journal if the goal is transmit the information to health care systems or providers. Reports, newsletters, and fact sheets might be more effective in reaching policy makers or other agencies. Websites will reach a larger and broader audience, including members of the public. The type of information and style of presentation used for a professional journal will differ markedly from that prepared for dissemination on the agency website. The speed or urgency with which a message needs to be conveyed is another consideration in the selection of dissemination method.

CONCLUSIONS AND RECOMMENDATIONS

- Estimation of the committee's recommended indicators for HIV care and supportive services will often require combining data from multiple data systems. Making valid inferences about the indicators across different populations and over time using data from multiple data systems presents a range of analytic and logistical challenges. Such challenges will change over time and will have to be reevaluated periodically.

  Recommendation 6-1. At least once every 2 years, the Department of Health and Human Services should reevaluate mechanisms for combining data elements to estimate key indicators of HIV care and access to supportive services, analyze the combined data, and identify and address barriers to the efficient analysis of such data, including relevant statistical methodologies. To facilitate this process, HHS should engage a center of excellence representing broad areas of expertise that include information technology, statistical methodologies for combining data, and data system content.

  The center of excellence might also include experts in epidemiology and surveillance; laws and policies that affect access to HIV-related data; health services research, including insurance; medical informatics, including integration of public and private data sources to estimate population-level parameters; clinical HIV care and relevant social services; and community and patient perspectives.
  The center of excellence could address questions such as the extent to which proxy data elements can be used to estimate indicators; whether knowledge of an indicator for a subpopulation rather than the whole cohort of PLWHA might be acceptable for some indicators; and the level of accuracy to be demanded for any given indicator (e.g., whether estimates are needed within 1, 5, or 10 percentage points) given the potential costs of data collection and of obtaining very accurate indicator estimates.

- Information on the indicators recommended by the committee will be of interest to a variety of stakeholders, including policy makers, health departments, HIV care providers, patients, and researchers.

The disseminated information can be used in numerous ways—from informing policy decisions to supporting the development of research projects—that have the potential to improve the quality of HIV care.

Recommendation 6-2. The Department of Health and Human Services should report to the public at least once every 2 years on indicators of HIV care and access to supportive services to foster improvements in the quality of HIV care and in monitoring progress toward meeting the goals of the National HIV/AIDS Strategy.

The reporting interval of at least once every 2 years allows for regular reporting of the indicator data to monitor the NHAS while minimizing reporting burden and associated costs. To facilitate understanding and use of the indicator information by stakeholders, dissemination products and strategies may vary depending on the target audience and message to be conveyed. Information about the quality of the indicator data (e.g., confidence ranges for indicators estimates, use of proxy data elements) might be included in the dissemination product so that stakeholders are aware of the limitations of the data.

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Appendix

Biographical Sketches of Committee Members

Paul A. Volberding, M.D. (*Chair*), is a professor in the Department of Medicine and codirector of the Center for AIDS Research at the University of California, San Francisco (UCSF). He 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. He was president of the HIV Medicine Association of the Infectious Diseases Society of America (IDSA). 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-positive adults, and youth. Dr. Aidala has directed over 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 18th 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 men who have sex with men. 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 socio-demographic 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 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 Hubert Chair and Professor of Global Health in the 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 boards 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 boards 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 over 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. The Care and Treatment Unit oversaw the development of integrated systems designed to address the care and treatment needs of persons living with HIV in New Jersey. This unit served as the Ryan White Part B grantee in New Jersey and oversaw CARE Act activities, which included 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. Currently she is a 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. She is a former member of the IOM Committee on HIV Screening and Access to Care. Dr. Kates received her Ph.D. in Health Policy from 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 the National Institutes of Health'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 Institute of Medicine 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 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 Institute 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 serves 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 advisory committees for U.S. and European universities, the World Health Organization, U.S. Agency for International Development, and NIH.

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 Amida-Care, 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.