

# Monitoring HIV Care in the United States

2012 National Summit on HIV and Viral Hepatitis  
Diagnosis, Prevention and Access to Care  
November 28, 2012



INSTITUTE OF MEDICINE  
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# White House Office of National AIDS Policy Charge to IOM

## Report 1



- Identify core indicators and data elements for HIV care and supportive services to monitor impact of NHAS and ACA on HIV care
- Identify best sources of data (public and private) to assess core indicators
- Identify potential barriers to data collection
- Discuss role of health information technology
- Address analysis and dissemination of data

## Report 2



- Address how to obtain nationally representative estimates to monitor the impact of the ACA on care coverage and utilization for people with HIV

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# IOM Committee Membership

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**DAVID P. PRYOR**, NBC Universal

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**DOUGLAS WIRTH**, AmidaCare

# REPORT #1

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# Committee's approach to its charge

- Use NHAS targets and existing indicators (PEPFAR, HP 2020), quality measures (NQF), and treatment standards (HHS Guidelines) as a basis for recommended indicators
- Review public and private data systems pertinent to HIV care
- Identify critical points along care continuum (“treatment cascade”)
- Review the literature, expert presentations
- Minimize reporting burden and cost
- Limit scope to those with diagnosed HIV infection, adults/adolescents (ages 13+)

# Recommendations Report #1

## Recommendation 1.

HHS should use the following core indicators to assess the impact of the NHAS and ACA on improving HIV care and access to supportive services for individuals with HIV

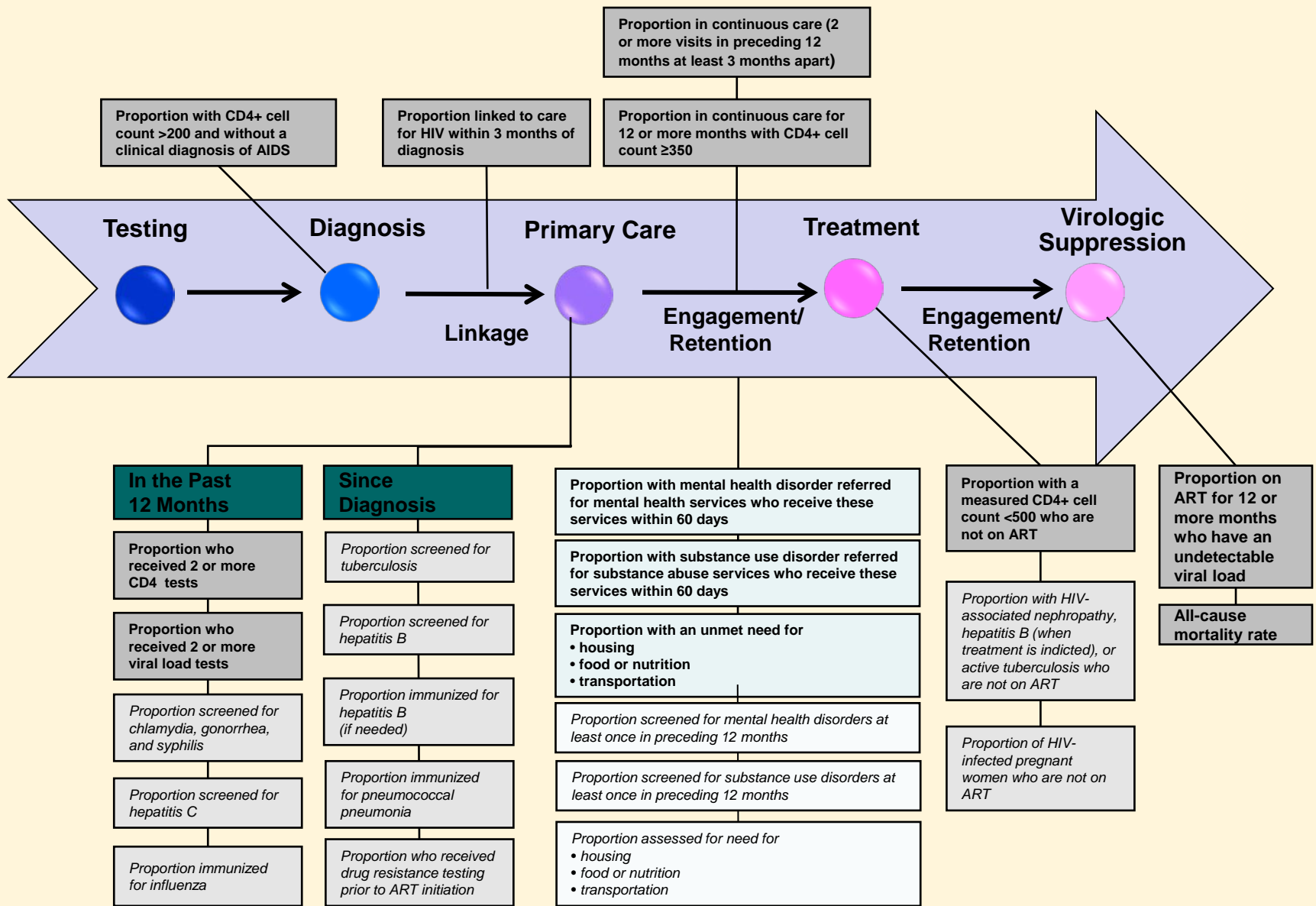
### – 14 Core Indicators

- 9 indicators for clinical HIV care
- 5 indicators for mental health, substance use, and supportive services

### – Also, identified 15 Additional Indicators (for more comprehensive assessment of care quality)

- 10 clinical HIV care indicators
- 5 mental health, substance use, and supportive services indicators





# Recommendations Report #1, cont.

## Recommendation 2.

HHS and OMB 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 (age, race/ethnicity, sex, gender identify, sexual orientation, current geographic marker of residence, income/poverty level, payer)

## Recommendation 3.

HHS, VA, HUD, and other federal agencies should **review/modify federal data systems to better enable them to be used for monitoring progress** toward achieving the NHAS goals.

## Recommendation 4.

**CDC should enhance the National HIV Surveillance System** (e.g., issue guidelines/criteria for reporting CD4 and viral load, obtain data on payer status)



# Recommendations Report #1, cont.

## Recommendation 5.

HHS, VA, IHS, Bureau of Prisons, and other federal agencies should **use existing data from private data systems to monitor the impact of the NHAS** and ACA 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.

## Recommendation 6.

HHS should maintain and institutionalize the existing effort to **streamline data collection and reduce reporting requirements** for federally funded HIV/AIDS programs.

## Recommendation 7.

HHS should issue guidance to the HIV care community to **clarify what is permissible patient information to share given federal and state privacy laws.**

# Recommendations Report #1, cont.

## Recommendation 8.

HHS should review existing mechanisms for confidential and secure **exchange of health information** to provide platform to increase exchange of such information among entities serving individuals with HIV.

## Recommendation 9.

HHS and the Office of the National Coordinator for Health Information Technology should **provide TA and policy guidance to improve the interoperability of data systems.**

## Recommendation 10.

**At least once every 2 years, HHS should reevaluate** mechanisms for combining data elements to estimate key indicators of HIV care and access to supportive services, analyze combined data, and identify and address barriers to the efficient analysis of such data.

## Recommendation 11.

**HHS should report to the public at least once every 2 years on indicators of HIV care and access to supportive services.**

# REPORT #2

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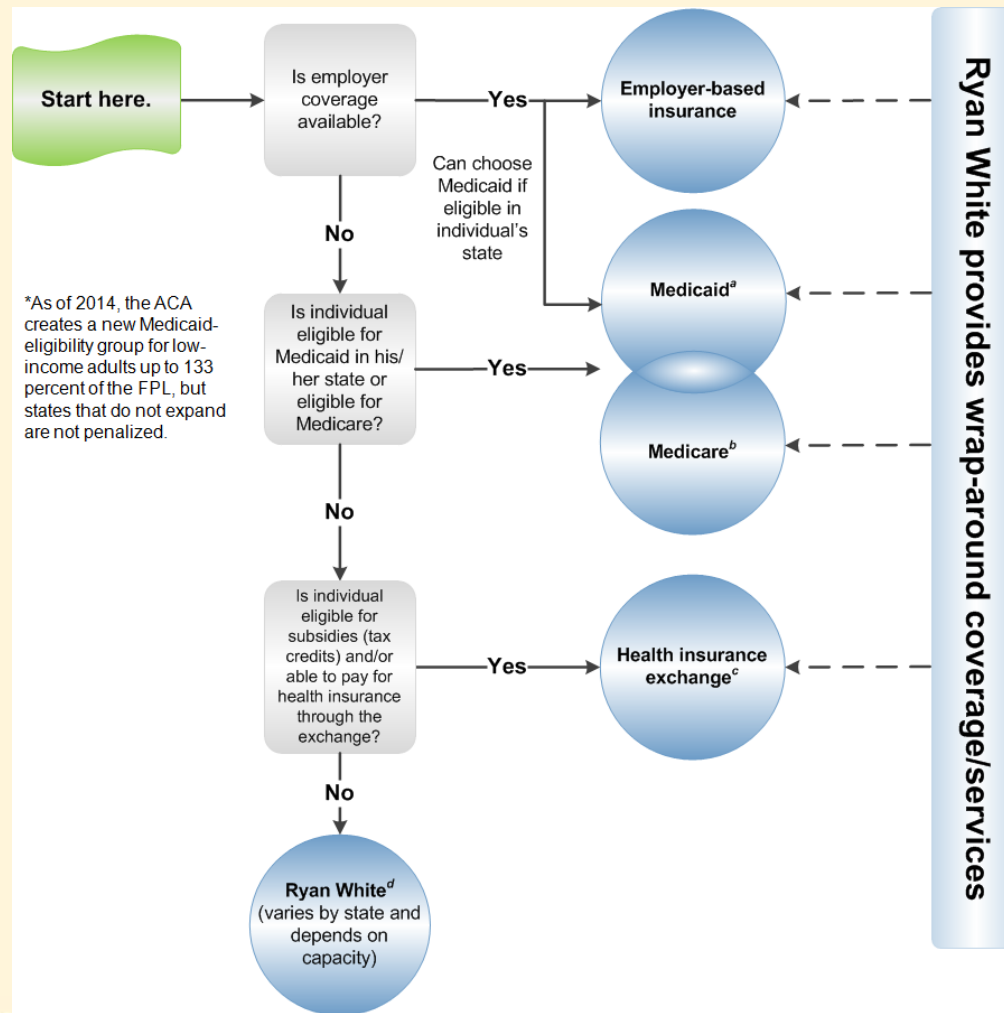
# Committee's approach to its charge

- **Identify pathways for the movement of individuals into and among different sources of health coverage and patterns of service utilization during and following implementation of ACA**
- **Need for national-, state-, and local-level monitoring**
- **Revisit 29 public and private data systems reviewed for Report 1**
- **Continue to monitor quality (Report 1) along with changes in coverage sources scope of benefits**
- **Limit scope to those diagnosed with HIV, adults/adolescents (ages 13+)**

# Examples of How the ACA Affects Access to Care for People with HIV

- **Increased Private Health Insurance Access and Consumer Protections**
  - Children cannot be denied coverage based on pre-existing conditions
  - Young adults allowed to stay on parents' health plan until age 26
  - Adults with pre-existing conditions currently eligible to purchase coverage through federal or state-run high risk, PCIPs. Beginning in 2014, insurers will be prohibited from denying and rescinding coverage to adults based on pre-existing conditions.
- **Medicaid Expansion**
  - In 2014, Medicaid eligibility will be extended to individuals with incomes up to 133% FPL; categorical eligibility requirements, such as being disabled, will be removed (Supreme Court decision effectively makes this a state option).
- **Medicare Part D Drug Coverage Gap**
  - Gradually phases out Part D coverage gap
  - ADAP Rx expenses now count towards TrOOP (to reach catastrophic coverage level).
- **Essential Health Benefits, including Preventive Services**
  - Starting in 2014, health plans will be required to offer a package of essential benefits, including services rated A&B by USPSTF (new recommendation for routine screening); implications for Medicaid, Medicare.

# Pathways to coverage for people with HIV in 2014 and beyond





# Findings

- **Currently no single source of data to generate a nationally representative baseline before 2014**
- **The 12 data systems identified in the committee's first report, most of which capture data on health coverage status, together can provide a reasonably accurate baseline**
- **Medical Monitoring Project (MMP) only ongoing data system designed to obtain nationally representative estimates of care experiences of people with HIV, but has limitations**
- **ACA will be implemented differently across the country, will therefore need to assess state-level variation; need data from multiple sources**
- **Although ACA improves access to care coverage, it does not guarantee linkage to, retention in, and receipt of quality care. Thus, it will be important to monitor care quality as the ACA is implemented.**

# Recommendations Report #2

## Recommendation 1.

ONAP should use multiple existing data sources to establish a baseline for health care coverage and utilization prior to 2014.

## Recommendation 2.

By 2015, the CDC should improve the Medical Monitoring Project (MMP) to ensure higher response rates and increased sample representativeness.

## Recommendation 3.

Once improved, ONAP and HHS should use MMP to obtain nationally representative data on health care coverage and utilization for people with HIV.

## Recommendation 4.

HHS should convene a multidisciplinary task force to design improvements in MMP and ensure that it remains responsive to changes in the epidemic and health care environment.

# Recommendations Report #2, cont.

## Recommendation 5.

ONAP and HHS should use data from Medicaid, Medicare, the Ryan White HIV/AIDS Program, and private insurers to monitor the impact of the Patient Protection and Affordable Care Act on health care coverage and utilization at the state and program level.

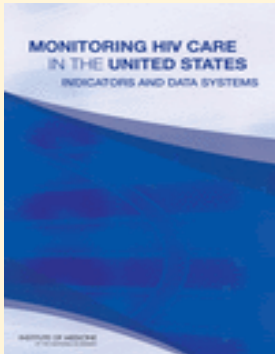
## Recommendation 6.

ONAP and HHS should ensure the collection and linkage of data on core indicators to monitor quality of care for people with HIV during and following the implementation of the Patient Protection and Affordable Care Act.

## Recommendation 7.

HHS should produce and disseminate a report at least once every 2 years on the care of people with HIV that characterizes trends and identifies gaps in coverage and care during and following the implementation of the Patient Protection and Affordable Care Act.

# For more information:



- <http://www.iom.edu/Reports/2012/Monitoring-HIV-Care-in-the-United-States.aspx>
- <http://www.iom.edu/Reports/2012/Monitoring-HIV-Care-in-the-United-States-A-Strategy-for-Generating-National-Estimates-of-HIV-Care-and-Coverage.aspx>

