



# Developing Core Indicators for HIV/AIDS Prevention, Treatment, & Care Services

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DHHS/OHAP Consultation on HIV/AIDS Core Indicators, Data Streamlining,  
& Federal Reporting Requirements

September 19, 2011



# Summary of NHAS Targets for 2015

## Reduce New Infections

- Reduce new infections (25%)
- Reduce transmission rate (30%)
- Increase awareness of HIV+ serostatus (90%)

## Improve access to and outcomes of care

- Link PLH to care w/in 3 mo of diagnosis (80%)
- Increase continuous care for RW clients (80%)
- Increase access to permanent housing for RW clients (86%)

## Reduce HIV-related health disparities

- Increase undetectable viral load by 20% in MSM, Blacks, and Latinos



# Summary of NHAS Targets for 2015 (Cont'd)

## Achieve a more coordinated national response

- Ensure coordinated programs
- Promote equitable resource allocation
- Streamline and standardize data collection
- Evaluate programs and reallocate resources for maximal impact



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- Promote equitable resource allocation
- **Streamline and standardize data collection**
- Evaluate programs and reallocate resources for maximal impact



# Common Metrics Needed

“... we must identify a set of common metrics that can be used across HHS-funded HIV/AIDS activities to measure program outcomes in the 12 Cities Project. **Developing a streamlined set of common metrics that can be used by all federally funded programs** providing HIV/AIDS services makes good sense, will reduce inefficiencies, and will ultimately decrease costs.”

DHHS Secretary Kathleen Sebelius

January, 2011



# National HIV Testing Goals Report to Congress

“Contributing federal organizations reported four common challenges and barriers in achieving the annual national HIV/AIDS testing goal: 1) limited state, local, and federal financial resources for HIV testing and prevention; 2) discordant federal HIV testing guidelines; 3) **lack of standardized data collection systems and limitations associated with existing systems**; and 4) limited staff and time in clinical and non-clinical settings.”

Thomas R. Frieden, MD, MPH  
Director, Centers for Disease Control and Prevention  
July, 2011



# Developing Core Indicators of Federally funded HIV Prevention, Treatment, and Care Services



# Plan for Developing Core HIV/AIDS Prevention, Treatment, & Care Indicators

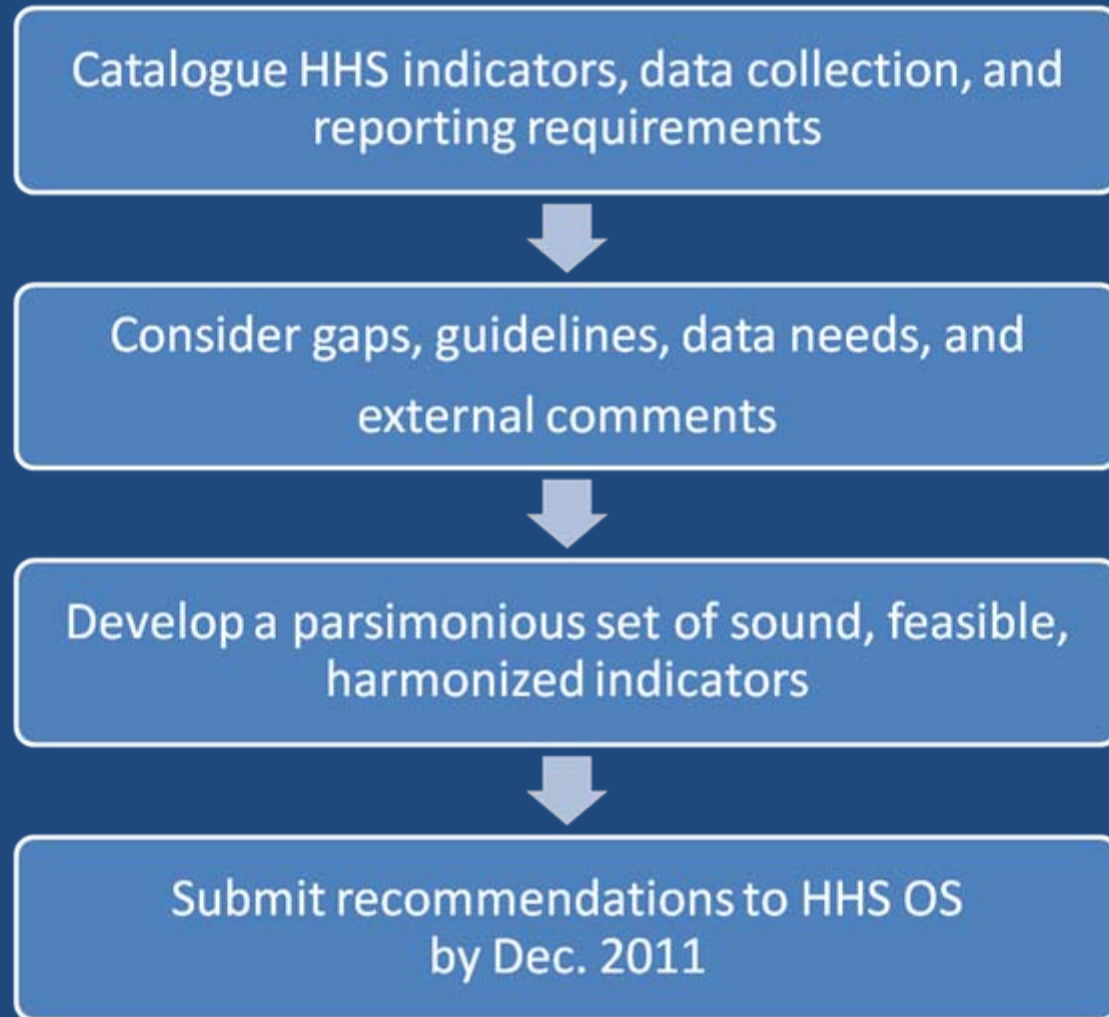
OHAP will lead cross-agency Indicators WG to:

- Finalize a core set of common indicators
- Define data elements (numerators, denominators, exceptions)
- Review current Federal reporting requirements (elements, frequency)
- Find opportunities to remove redundant data elements
- Explore options for increasing data system interoperability
- By Dec. 15, 2011, provide recommendations to the HHS/OS, via HHS/OASH, for core indicators, streamlining data collection, & reducing reporting requirements





# Plan for Developing Core Indicators



# HIV/AIDS Prevention, Treatment, & Care Indicators

- 12 Cities SC Metrics Subgroup **catalogued** HHS HIV-related indicators for ECHPP/12 Cities (Feb - May, 2011)
- OHAP subsequently:
  - **Reviewed indicators** deployed by other Federal and non-Federal partners (e.g., VA, Kaiser Permanente; Jun, 2011)
  - **Examined guidelines** and performance standards (e.g., NQF; Jul, 2011)
  - **Proposed a strategy** to 12 Cities SC for developing common indicators, streamlining data collection, & reducing reporting burden (July, 2011)
  - **Convened a cross-agency** WG to review indicators, data collection, and Federal reporting requirements (Sep, 2011)
  - **Hosted an Indicators Consultation** (Sep, 2011)



# Consultation Goals & Objectives

Goal: To offer recommendations by December 2011 to the HHS OS, via the OASH, for:

- Implementing a core set of indicators to monitor federally-funded HIV/AIDS prevention, treatment, and care services
- Streamlining data collection
- Reducing reporting requirements on federal grantees

Consultation Objectives:

- Review progress in the development of cross-agency, core indicators
- Discuss a set of proposed HIV/AIDS indicators for relevance, feasibility, and impact
- Examine opportunities to streamline data collection and reporting requirements for HHS grantees
- Identify next steps for developing recommendations to the HHS/OS



# Three Types of Indicators of Interest

- **Process:** Short range effects of program implementation (e.g., client satisfaction, activity counts).
- **Outcome:** Moderate range effects of program activities (e.g., changes in behavior, access, policies)
- **Impact:** Longer range, cumulative effects over time and programs (HIV infection, morbidity, mortality)

Source: Rugg et al., 2004



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# Principles for Developing Cross-Agency Core Indicators

- Align with NHAS goals
- Collaborate with federal and non-federal partners
- Find smallest set of core measures
- Use existing data/indicators to the extent possible
- Augment core indicators, as needed
- Reduce grantee burden
- Standardize definitions, reporting (demographics, etc)
- Remove redundant indicators and data elements
- Strive for interoperability of data systems



# Five Proposed Core HIV/AIDS Prevention, Treatment, & Care Indicators

- HIV Testing
- Late HIV diagnosis
- Linkage to care
- Retention in care
- Viral load suppression



# Survey of Core HIV/AIDS Prevention, Treatment, & Care Indicators

Core Indicators	CDC/ DHAP	CMS	HRSA/ BPHC	HRSA/ HAB	IHS	SAMHSA/ CSAT	NQF*
HIV Testing	Y	-	Y	Y	Y	Y	Y
Late Diagnosis	Y	-	-	-	-	-	-
Linkage to Care	Y	-	-	Y	-	-	Y
Retention in Care	-	Y	-	Y	Y	-	Y
Viral Suppression	Y	-	-	Y	-	-	Y

Sources: HHS Catalogue of HIV-related indicators for 12 Cities/ECHPP; HIV Testing at CDC-Funded Sites, United States, Puerto Rico, and the U.S. Virgin Islands, 2008-2009; 2011 CMS Physician Quality Reporting System (Physician Quality Reporting) Measures List; HRSA/HAB HIV Performance Measures; \*National Quality Forum HIV Performance Measures, for comparison.





# Key Questions: Developing Core Indicators

- Are these the right core indicators?
- Who can or should collect these?
- Are they feasible?
- How frequently should they be collected?



# Streamlining and Federal Reporting Requirements



“Contributing federal organizations reported four common challenges and barriers in achieving the annual national HIV/AIDS testing goal: 1) limited state, local, and federal financial resources for HIV testing and prevention; 2) discordant federal HIV testing guidelines; 3) lack of standardized data collection systems and limitations associated with existing systems; and 4) limited staff and time in clinical and non-clinical settings.”

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# Data Streamlining Challenges

- Absence of common data types, definitions, & policies (FOAs)
- Lack of interoperability of Federal data systems
- Legal mandates that constrain degrees of freedom
- Striking an appropriate balance between organizational centralization and decentralization among Federal partners





# Key Questions: Data Streamlining and Reducing Federal Requirements

- What are acceptable target reductions?
- How best to achieve them?
- What barriers and challenges will need attention?



# Preliminary Findings: Indicators

- Revise core set (e.g., HAART initiation, CD4 @ dx, risk behaviors)
- Must develop common, time-linked indicators across Fed
- Assess both population-based and program level outcomes
- Focus less on process, more on outcomes/impacts
- Need indicators for the full spectrum (Prev, Tx, Care)
- Align with consensus development organizations (e.g., NQF)
- Changes will not be resource-neutral
- Attributing change to specific Federal funds will be challenging



# Preliminary Findings: Streamlining and Requirements

- Identify critical questions data should answer
- Integrate data systems to reduce duplicative reporting
- Develop a hierarchy of data sources (e.g., record abstraction vs. direct reporting)
- Consider requiring single annual progress reports
- Explore security, confidentiality, and unique identifiers for de-duplication
- Provide technical assistance and build capacity, as needed
- Balance reducing burden on need to respond to inquiries
- Learn from past efforts to streamline
- Make better use of surveillance data for individual level data





# Next Steps

- Finalize report and internal discussions
- Standardizing definitions and reporting frequencies
- Hold regular Fed WG meetings re: indicators, requirements
- Consult experts re: existing data
- Explore IT solutions for data collection/reporting



# Progress Implementing the NHAS

- Strategy is at work through federal agencies (Ops Plans)
- New strategic investments (ECHPP, ADAP, MAI)
- Necessary policy changes (funding formulas, HD FOA)

## Next steps

- Strengthen new state, city, local, and tribal partnerships
- Empower communities to implement NHAS
- Define common metrics to measure progress
- Streamline administrative burden while maintaining accountability

Source: [http://aids.gov/federal-resources/policies/national-hiv-aids-strategy/hiv\\_aids\\_july\\_2011.pdf](http://aids.gov/federal-resources/policies/national-hiv-aids-strategy/hiv_aids_july_2011.pdf)

