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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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

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

Catalogue HHS indicators, data collection, and reporting requirements

⬇

Consider gaps, guidelines, data needs, and external comments

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Develop a parsimonious set of sound, feasible, harmonized indicators

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Submit recommendations to HHS OS by Dec. 2011

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
- Identity 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
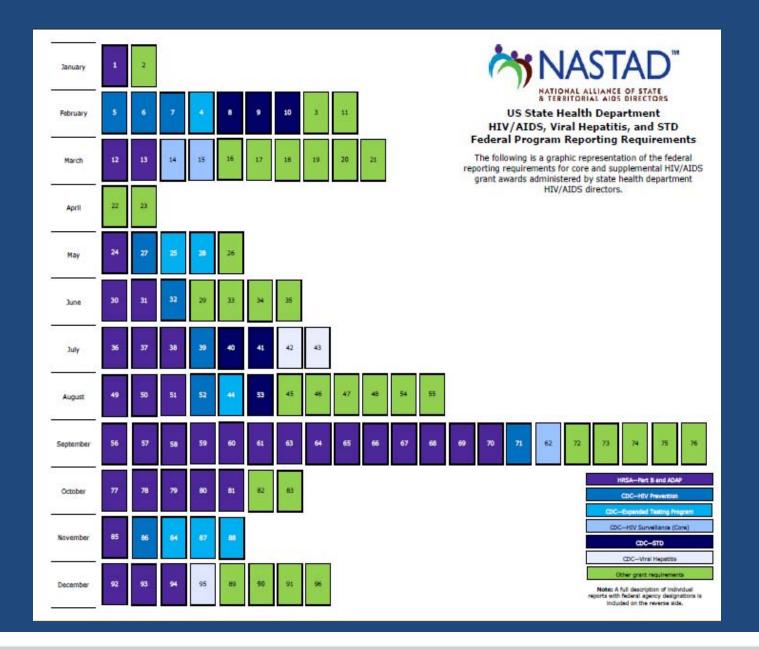
U.S. Department of **Health & Human Services**

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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

U.S. Department of **Health & Human Services**