Measuring Severity of Need for HIV Care and Treatment Resources

Ryan White CARE Act Training and Technical Assistance Grantee Meeting

August 29th, 2006
Washington, DC

Overview of the Project

Project Purpose

To develop a conceptual framework to improve HAB's ability to:

- Assess the severity of need for CARE Act programs and services
- Distribute the funds according to quantifiable measures

Defining “Severity of Need”

HRSA/HAB defines “severity of need” as:

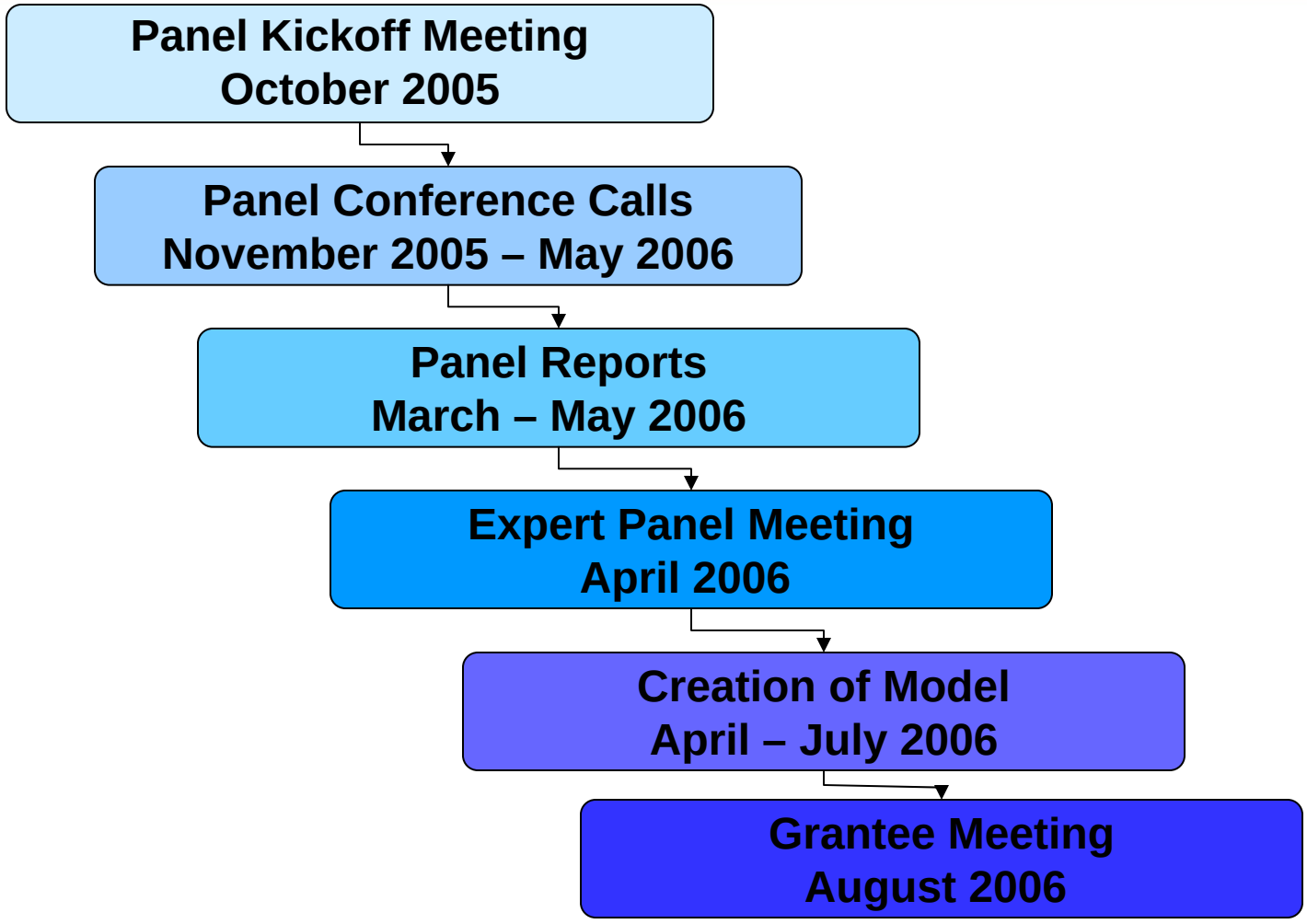
“...the degree to which providing primary medical care to people with HIV disease in any given area is more complicated and costly than in other areas based on a combination of the adverse health and socioeconomic circumstances of the populations to be served”

Developing a New Model

The Institute of Medicine (IOM) Committee recommended a new approach with several key characteristics

- Quantitative scale that:
  - Relies on fewer measures
  - Is transparent, reliable, and valid
- Data elements that should:
  - Be available, periodically updated, and readily available
  - Contain sufficient variation
  - Be free of measurement error that would influence SON

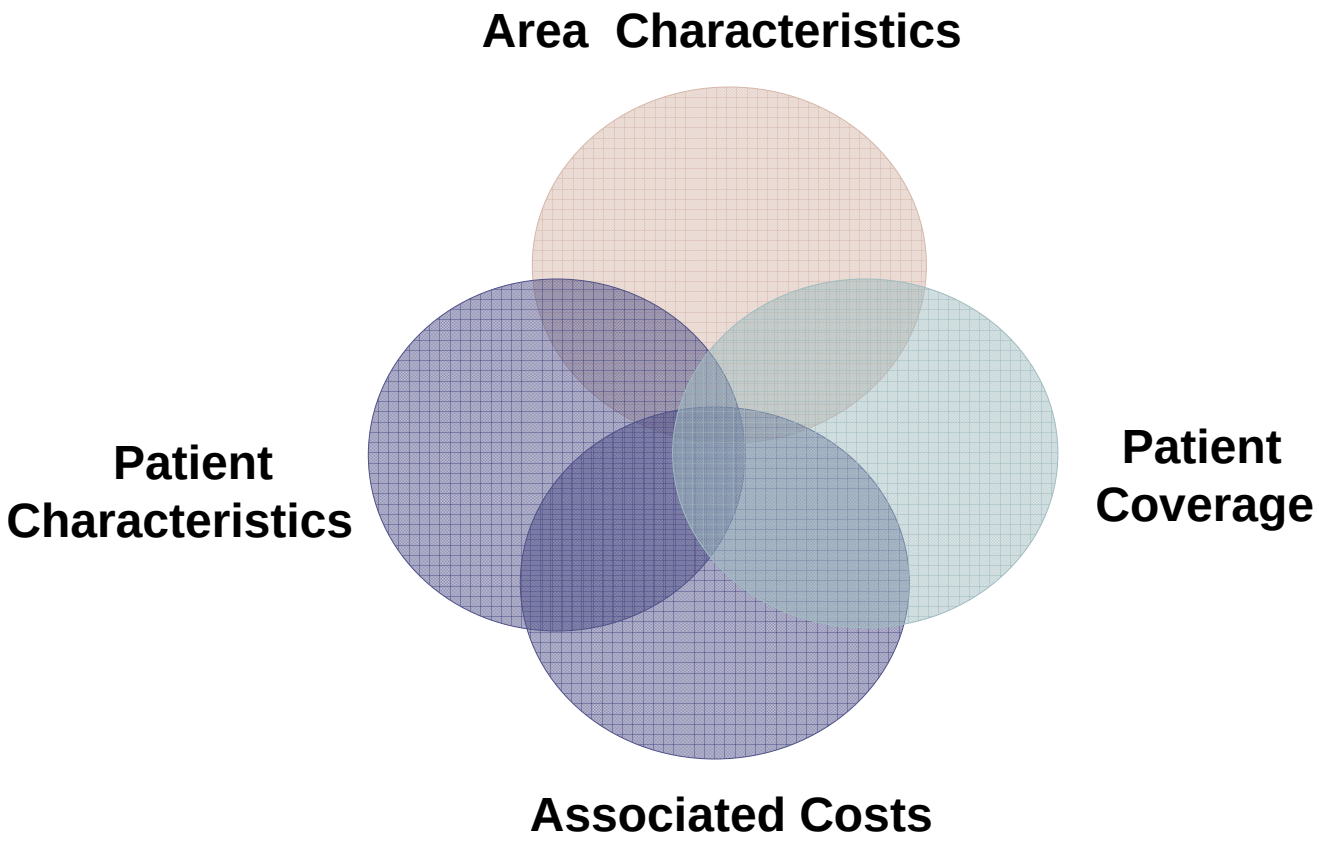
Project Process



Overview of Accomplishments

- 4 panels, 47 panelists, 5 contractors
- More than 100 panel and workgroup panel calls
- Consideration of at least 56 variables, with many more issues discussed
  - 19 variables forwarded for consideration in an index
  - 21 variables identified as important but lacking sufficient data
  - 16 variables eliminated
- Important to note that panelists struggled with not having enough data, but that this was seen as comprehensive of a process as feasible at the time

Defining Four Conceptual Elements



Area Characteristics Panel Co-Chair Report

Area Characteristics Panel Members

- Jill Ashman (HRSA)
- Matthew Bramlett (NCHS)
- Celia Gabrel (HRSA)
- Jo Ann Hilger (NYC)
- Scott Holmberg (RTI)
- Andy Jordan (HRSA)
- Faye Malitz (HRSA)
- Kathleen McDavid (CDC)
- Chuck Nelson (US Census Bureau)
- David Rein (RTI)*
- Ebony Ross (HSR)*
- Mona Scully (NYS)
- Pat Sweeney (CDC)
- Ella Tardy (Miss.)

* Non-voting coordinators

We Considered Three General Categories of "Area Characteristics" That Would Determine Need:

- "**Burden" of disease—**actual AIDS and HIV cases
- **Health infrastructure**—how well could an area accommodate HIV/AIDS patients
- **Poverty** and other indices of need (how many HIV/AIDS patients needed but could not get care)

Panelists' Priority Scores*

HIV/AIDS Disease Prevalence	1.08
Poverty Rate	1.69
Uninsured Rate	1.77
Access to Primary Care Providers	2.62
Median Income	2.62
Unemployment Rate	3.08
HRSA Supported Clinics	3.38
STI Burden	4.08

*1 (most important) - 5 (least important)

"Burden" of Disease: **AIDS Cases Only**

Advantage: • One of the best surveillance systems in the world (completeness, reliability, etc.)	*Disadvantage*: • Does not measure all HIV patients needing care (e.g., pre-AIDS diagnosis); many reported HIV cases would not be counted/considered
Advantage: • Available and reasonably up-to-date from every locality on living AIDS cases (reported, minus deaths)	*Disadvantage*: • Measures past HIV incidence, so localities with recent epidemic "under-measured"

"Burden" of Disease: **AIDS *and HIV*** **Cases**, as Reported to CDC

Advantage: • Much more complete description of living HIV patients in a given locality	*Disadvantage*: • Not all states have name-based reporting and some states' HIV reporting is still recent/"immature"
Advantage: • Available and reasonably up-to-date from every locality	*Disadvantage*: • Penalizes states that have not yet started name-based HIV reporting

"Burden" of Disease: **AIDS/HIV Cases, Adjusted** for States Without, or With Recent, HIV Reporting

Advantage: • Fairer to states with recent or no HIV reporting	*Disadvantage*: • CSTE has looked at this and considers such adjustment "invalid"
Advantage: • Still collects all living HIV/AIDS cases	*Disadvantage*: • Gives a "pass" to states that do not comply with recent national recommendations for name-based reporting

Our Group's Decision

- We recommended counting all cases reported through CDC's national AIDS and HIV reporting

- An important caveat: the "final arbiters" may decide to use an adjustment for the minority of states with recent or no HIV reporting systems

Next Variable for Consideration: **Health Infrastructure**

- Area capabilities to care for current HIV/AIDS cases
- Difficult, as there is no direct measurement of this (such as surveillance or census data)

Area's Ability to Provide HIV Care for Those Needing It

Primary care providers **(#s and locations)** ***Advantage***: Proxy for provision of health/ med. care needs for HIV pts.	**Primary care providers** **(#s and locations)** *Disadvantage*: Same as for any "proxy" measurement
HRSA supported clinics and providers ***Advantage***: Clearly located in areas of need	HRSA supported clinics and providers *Disadvantage*: "Self-fulfilling prophecy"

Variables Forwarded for Possible Inclusion

Working Group	Variables Suggested for Use in the SON Index	Variables with Sufficient Rationale for Inclusion, but Insufficient Data	Variables with Insufficient Rationale for Inclusion
Health infrastructure	• Access to primary care providers	• Number of homeless assistance providers • Number of people without conventional housing	• Hospital location and capacity • HRSA supported clinics and providers

Variables Forwarded For Possible Inclusion

Working Group	Variables Suggested for Use in the SON Index	Variables with Sufficient Rationale for Inclusion, but Insufficient Data	Variables with Insufficient Rationale for Inclusion
Poverty and Census Characteristics	• Percent below 100% federal poverty level • Percent with no health insurance • Median household income • Population* (*variable needed to for other variables; not itself an index of SON)	• Percent < 200% federal poverty level • Cost of living adjustment (COLA)-- federal locality pay adjustment • COLA, using regional CPIs* • % underinsured	• % with other forms of insurance • Personal income • % unemployed

* Consumer Price Index

Issues

- Group consensus good on the vast majority of issues
- Larger, recurrent issues:
  - How to count AIDS/HIV cases potentially needing care under RW Care act
  - Some measures are of the same parameter (e.g., several variables are linked to poverty)—which is best?
  - Political realities

Patient Coverage and Need Panel Co-Chair Report

Patient Coverage and Need Panel Members

- Ruth Finkelstein (NY)
- Gunther Freehill (DC)
- Emily Gantz McKay (DC)
- Celia Hayes (HRSA)
- James Kahn (CA)
- Doug Morgan (HRSA)
- David Paltiel (MA)
- Ebony Ross (HSR)*
- Beth Scalco (LA)
- Walt Senterfitt (CA)
- David Thompson (SAMHSA)
- Kathleen Wirth (RTI)*
- Steven Young (HRSA)

* Non-voting coordinators

Purpose of the Panel

The Patient Coverage Panel was responsible for identifying variables that describe the degree of medical care currently infected HIV/AIDS patients can expect to have access to in the absence of the CARE Act program

Overview of Panel Findings

Variables Forwarded for Further Consideration for Use in an SON Index	Variables Placed on Hold	Variables Not Forwarded Due to Insufficient Data	Variables Not Forwarded Due to Insufficient Rationale for Inclusion
• Case fatality rate among reported living AIDS patients • Medicaid adequacy • Percentage of Federal poverty level (FPL) required for eligibility for the Medicaid Medically Needy program • AIDS Drug Assistance Program (ADAP) adequacy	• Medicaid enrollment • Rapid progression to AIDS diagnosis • Receipt of highly active antiretroviral therapy (HAART) (pharmaceutical data) • Social Area Indicator Analysis based on the Morbidity Monitoring Project (MMP)	• Unmet need for HIV primary medical care • Unmet need for substance abuse treatment	• Phencyclidine (PCP) incidence • Hospital discharge data

Variables Forwarded for Inclusion

- **Case fatality rate among reported living AIDS patients -** serves as a proxy indicator for severe cases of unmet need for primary medical care services
- **Medicaid adequacy -** measures the ability of a State Medicaid program to meet the health care needs of patients with HIV/AIDS
- **Percentage of Federal poverty level (FPL) required for eligibility for the Medicaid Medically Needy program -** measures the presence or absence of such a program in a State and the relative generosity of its eligibility requirements
- **AIDS Drug Assistance Program (ADAP) adequacy -** measures the ability of a State ADAP program to meet the medication needs of patients with HIV/AIDS

Variables Considered Important and Placed On Hold

Several variables were placed on hold for future consideration because the data:

- Was currently unavailable but likely to be available in the near future, or
- Was currently available, but its validity and reliability could not be accurately assessed given the time constraints of this panel's work

These variables included:

- Medicaid enrollment
- Rapid progression to AIDS diagnosis
- Receipt of highly active antiretroviral therapy (HAART) (pharmaceutical data)
- Social Area Indicator Analysis based on the Morbidity Monitoring Project (MMP)

Variables with Good Rationale but Not Forwarded Due to Insufficient Data

- Unmet need for HIV primary medical care
- Unmet need for substance abuse treatment

Variables Not Forwarded Due to Insufficient Rationale

Several variables not recommended for inclusion because they:

- Were correlated with one of the variables recommended for inclusion
- Did not have a sufficient impact on the SON yet, or
- Could not be accurately measured by the publicly available data yet

These variables included:

- Phencyclidine (PCP) incidence
- Hospital discharge data

Issues

- The panel weighed concerns about creating disincentives or perverse rewards (e.g., penalizing States that make significant financial contributions) through the inclusion of variables related specifically to Medicaid and ADAP against the need to provide health care for needy patients in States that may stint on care

  They recognized the inherent difficulty in identifying a revenue-neutral way to ensure adequate care for all needy patients nationwide without, to some degree, penalizing areas that invest State resources in caring for HIV/AIDS patients

Issues

- The panel discussed at length the need for a standardized measure of undiagnosed HIV patients that could be applied without State/grantee input (e.g., they wanted to avoid the scenario of “We can’t identify persons with HIV because we don’t have any money”
- The panel considered assessing only Federal contributions to specific programs, such as ADAP and Medicaid, as opposed to the program’s entire funding including State and local contributions

Patient Characteristics Panel Co-Chair Report

Patient Characteristics Panel Members

- Bruce Agins (NY)
- Kathleen Clanon (CA)
- Michael Evanson (HRSA)
- Jamie Hart (HSR)*
- Lisa Hirschhorn (JSI)
- Margaret Korto (OMH)
- Alice Kroliczak (HRSA)
- A.D. McNaghten (CDC)
- José Morales (HRSA)
- David Rein (RTI)*
- Anna Satcher (CDC)
- Fikirte Wagaw (IL)
- Tia Zeno (HRSA)

* Non-voting coordinators

Purpose and Process of the Panel

- Identifying specific characteristics of HIV/AIDS patients that result in a greater need for services and for which adequate data exist
- Established three subpanels:
  - HIV Clinical Characteristics
  - Comorbidities
  - Sociodemographic Characteristics

Overview of Panel Findings

Patient Characteristics Subpanel	Variables Forwarded for Further Consideration for Use in an SON Index	Variables Not Forwarded Due to Insufficient Data	Variables Not Forwarded Due to Insufficient Rationale for Inclusion
Clinical Characteristics	• HIV/AIDS disease progression	• Drug resistance	• Non-IDU HIV exposure categories
Comorbidities	• IDU exposure category*	• Age-related comorbidities • Hepatitis C • Mental illness • Substance abuse	• Gonorrhea • Syphilis • Tuberculosis (TB)
Demographic Characteristics	• Age • Race/ethnicity • Sex	• Educational status • Socioeconomic status (SES) • Immigration status	• Urban-rural differences

*surrogate for substance use and related comorbidities

Variables Forwarded for Inclusion

- **HIV/AIDS disease progression** – to adjust for patients with more advanced destruction of their immune system would require greater resources

- **IDU exposure category** – to adjust for increased costs related to:
  - Increased need for substance abuse services
  - The likelihood of extremely high rates of hepatitis C
  - The tendency to enter care at a late stage of disease progression
  - The overall cost of primary care

Variables Forwarded for Inclusion

- **Age** – to adjust for increased need treatment of comorbidities that occur with advanced age and subsequently increase the cost of care
- **Race/ethnicity** – to adjust for lack of access to care due to racial disparities in the quality and quantity of health services
- **Sex** – to adjust for differences in cost of care and complexity of care for women due to associated gynecological conditions and obstetric issues

Variables with Good Rationale but Not Forwarded Due to Insufficient Data*

- Drug resistance
- Other HIV exposure categories
- Age-related comorbidities
- Hepatitis C
- Mental illness
- Substance abuse
- Educational status
- Socioeconomic status (SES)
- Immigration status

*ongoing work to identify other sources

Variables Not Forwarded Due to Insufficient Rationale for Impact on Utilization

- Non-IDU HIV risk behaviors
- Gonorrhea
- Syphilis
- Tuberculosis (TB)
- Urban-rural differences

Areas for Further Discussion

- Several variables could not be forwarded because current data sources do not measure them adequately
- In particular, the panel was concerned about the absence of data on:
  - Mental illness and substance abuse because of their heavy impact on cost of care
  - Including IDU risk as a variable without also adjusting for need for other substance abuse services (active substance use)
  - HIV drug resistance
- Therefore, panel strongly suggested that the substance abuse and mental illness variables should be considered in the future when better data become available
- Similarly sources of area data which measure drug resistance across populations in care will also be critical

Associated Costs Panel Co-Chair Report

- Kevin Cranston
  - Massachusetts Department of Public Health

Associated Costs Panel Members

- Karyn Kai Anderson (CMS)
- Arlene Bincsik (NC)
- Eli Camhi (NY)
- Richard Conviser (HRSA)
- Kevin Cranston (MA)
- Lois Eldred (HRSA)
- Boyd Gilman (RTI)*
- Jamie Hart (HSR)*
- Fred Hellinger (AHRQ)
- Richard Moore (MD)
- Idalia Sanchez (HRSA)
- Stephanie Sansom (CDC)
- Bruce Schackman (IN)
- Adelle Simmons (ASPE)
- Rich Stevens (MA)

* Non-voting coordinators

Purpose of the Panel

- Developing a set of geographic price indices for labor and nonlabor inputs for the delivery of HIV primary care services funded under Titles I and II
- Developing and assigning cost weights to a group of patient attributes considered to be important and independent determinants of the cost of care under Titles I and II

Overview of Panel Findings

Patient Characteristics Subpanel	Variables Forwarded for Further Consideration for Use in an SON Index	Variables Not Forwarded Due to Insufficient Data	Variables Not Forwarded Due to Insufficient Rationale for Inclusion
Geographic Variables	• Geographic labor adjustment • Nonlabor inputs	• Health insurance – ADAP programs	
Clinical Variables	• Substance abuse (IDU risk factor)	• HIV stage • Hepatitis C • Diabetes • CVD	
Sociodemographic Variables		• Poverty • Age • Sex	• Race/ethnicity

List of Core Services

- **Medical services**
  - Ambulatory/outpatient medical care
  - Specialty care (e.g., dermatology, radiology)
  - Drug assistance or medication programs
  - Substance abuse services – outpatient
  - Mental health services
  - Oral health care
- **Support services**
  - Housing assistance and services
  - Transportation services
  - Food bank/home-delivered meals
- **Case management services**

Variables Forwarded for Inclusion

- **Geographic labor adjustment** – to adjust per capita funding allocations for state and EMA-level differences in the wages of health care professionals common to HIV primary care programs
- **Nonlabor inputs** – to adjust for regional variation in the cost non-labor inputs, most notably, rent and facility costs
- **Substance abuse (IDU risk factor)** – to compensate for the incremental treatment costs associated with substance abuse as a comorbid condition

Variables with Good Rationale but Not Forwarded Due to Insufficient Data

- HIV stage
- Hepatitis C
- Diabetes
- Cardiovascular disease
- Health insurance – ADAP programs
- Poverty
- Age
- Sex

Variables Not Forwarded Due to Insufficient Rationale

- Race/ethnicity

Areas for Further Discussion

HIV disease progression – the panel felt that:

- The true cost-driver associated with disease progression was whether an individual was on ARV or not, not AIDS diagnosis or CD4 count
- There is no consistent and current information on ARV prevalence at the State or local level
- HRSA should continue to monitor the cost and consider including this variable in the SON index in the future if the evidence suggests it is important

Areas for Further Discussion

Age-related comorbidities and demographic characteristics – the panel felt that:

- The incremental costs of age-related comorbidities are not yet sufficiently large to warrant inclusion
- The incremental costs of HIV care associated with age and gender are not sufficiently large to warrant inclusion
- There was less consensus about race/ethnicity and poverty. However, the underlying rationale for including race/ethnicity in the severity of need index is better captured by poverty
- HRSA should continue to monitor the cost and consider including these variables in the SON index in the future if the evidence suggests they are important

Areas for Further Discussion

- **Drug prices** – the panel felt that:
  - Grantees should not be compensated for any observed differences in drug prices because of States' eligibility to participate in the 340B drug pricing program
- **ADAP health insurance purchasing and maintenance program** – the panel felt that:
  - Adjustments for per-enrollee HIP expenditures should be deferred until more States implement the program and more consistent data are available
- **Medicaid generosity** – the panel felt that:
  - The SON index should not create a disincentive to expand Medicaid eligibility and enhance covered services
  - This issue should be deferred until the recommendations of the patient coverage panel become available

Findings and Next Steps

Objective and Timing of Severity of Need Index

- Objective: To develop a quantitative index that links differences in grantee attributes to needs for CARE Act resources
- Timing:
  - Developed over a number of years
  - Piloted before implementation
  - Timed to inform 2010 reauthorization
- SON Index will not affect 2007 allocations

Progress – Identification of Variables

Content Area	Variables with Measures Now	Potential Future Variables
Disease Burden	- AIDS Cases - HIV Cases for most areas	- HIV Cases for all areas
Regional Costs	- Labor Costs - Rent	- None
Patient Case Mix	- Age - Gender - Race - HIV/AIDS status - Exposure category	-Substance abuse status - Immigration status - Patient income - Receipt of HAART - Hepatitis C - Mental illness - Age-related comorbidities
Poverty and Access to Care	-Percent population <100% FPL -Percent uninsured at state level -Death rate among people diagnosed with AIDS -Primary care providers per capita	- None
Program Characteristics and Area Resources	- Medicaid eligibility criteria - Medicaid adequacy - ADAP eligibility criteria	- Special programs for PLWHA - Rules governing capitation

Index Framework

Allocation Per Jurisdiction = Disease Burden X Funds Available Per Case

- With adjustments related to
  - **Cost**
    - » Regional Costs
    - » Patient Case Mix
  - **Need**
    - » Poverty and Access to Care
    - » Program Characteristics and Area Resources

Current Progress

- Work of expert panels is complete
- Identified relevant variables and discussed their rationale for inclusion
- Data to measure these variables has been collected for all those with available measures

Next Steps

- Important data will be available in the near future
- Collaborations with HRSA's agency partners to obtain additional and/or alternative data are being explored
- Additional research initiated to link variations in need components to differences in grantee resource needs

Linking Variables to Need

- Regional costs
  - Completed
    - Bureau of Labor Statistics (BLS) data on wages for medical professionals
    - Housing and Urban Development (HUD) data on average rent and facilities costs
  - Updated annually on an ongoing basis

Linking Variables to Need

- Patient case mix
  - Regression analyses linking patient characteristics to variations in CARE Act reimbursable costs controlling for confounding factors.
    - HIV Research Network Data
    - Other sources of medical claims data (Medicaid)

Linking Variables to Need

- Poverty and access to care
  - Limit list of variable to those most important
  - Explore studies using CDC's Morbidity Monitoring Project (MMP) data
  - Explore primary data collection from selected grantee sites
- Program characteristics and area resources
  - Explore collaborations with agency partners to obtain better and more recent data

Questions