

**SEVERITY OF NEED INDEX PROJECT
PANELIST BRIEFING DOCUMENT**

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I. Overview of the HIV/AIDS Severity of Need Index

The HIV/AIDS Bureau (HAB) of the Health Resources and Services Administration (HRSA) directs the Ryan White HIV/AIDS Treatment Modernization Act (the Ryan White Program) funds to areas in the greatest need of financial assistance through several discretionary grant programs, including Part A supplemental awards, Part B AIDS Drug Assistance Program (ADAP) supplemental awards, and Part C and Part D awards.

In contrast to formula awards, which are based exclusively on estimates of living AIDS cases, these grants take into account other factors affecting severity of need (SON). 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 socio-economic circumstances of the populations to be served.”

The approach that HRSA has been using to calculate SON for Part A supplemental award applications is based on three equally weighted components: (1) HIV/AIDS epidemiology; (2) comorbidity, poverty, and insurance information; and (3) evidence of the existence of populations with special needs. This approach, while it is based on explicit criteria to evaluate resource needs and allocate Part A supplemental grants, has proved problematic for several reasons: no consistent indicators have been used to evaluate *relative* need, the data are largely qualitative, and much of the evaluation process is subjective.

A systematic review of existing methods of estimating unmet need for HIV care, conducted by the University of California, San Francisco, included measures used by all 51 Part A-eligible metropolitan area (EMA) grantees and showed that:

- There was significant variation in the definitions and measures used for unmet need
- Many sampling techniques were applied
- While the quantitative measures applied were the most useful, variability in data quality and samples reduced the usefulness of the measures
- Qualitative studies that assessed population characteristics were not very useful for quantifying unmet need, especially where these did not include the size of affected populations and did not focus on clinical outcomes.

An Institute of Medicine (IOM) Committee, based on this review and other analyses and consultations, recommended that HRSA adopt a new approach to allocating Part A supplemental awards based on standardized, quantitative indicators of resource needs in different jurisdictions. Furthermore, the Committee suggested that there are other factors, aside from those typically

reported in supplemental requests, that determine resource needs. These indicators and measures would comprise a SON Index with the following characteristics:

- A quantitative scale, relying on fewer measures, transparent, reliable, and valid
- Data elements should be available for all Ryan White Program grantees (therefore available at the county level) and should be periodically updated, readily available, contain sufficient variation, and be free of measurement error that would influence SON.

The IOM conceptualized SON in terms of the following function:

$$\text{Severity of Need} = (\text{Disease Burden}) \times (\text{Cost of Care}) - (\text{Available Resources})$$

Four distinguishable conceptual elements influence this equation. They are:

- **Area Characteristics** – structural characteristics of an area that make the care of HIV/AIDS more resource-intensive in one area than another
- **Patient Coverage and Need** – the medical care available to patients and the level of need that infected patients have for services
- **Patient Characteristics** – characteristics of infected patients that result in a greater need for resources for some populations than for others
- **Associated Costs** – regional variation in medical costs that affect the cost of HIV care.

The SON initiative has organized four panels of experts, each of which is charged with investigating one of these elements. The role of the panels will be to define precisely how each element contributes to resource needs and determine appropriate data to measure that element. The work of the panels will be used to shape a severity of need index that is quantitative.

II. Structure and Activities of the HIV/Severity of Need Project

The overarching objective of the project is to develop a conceptual framework to improve HAB's ability to assess the severity of need for Ryan White programs and services and distribute the funds according to quantifiable measures.

The following section provides an outline of the collaborative structure – involving Federal representatives from HRSA and other agencies, the Altarum (formerly HSR)/RTI team, and key national specialists – and provides an overview of how those involved will contribute to the development of the framework. It also describes and reviews a proposed timeline for the activities specific to the panels, which include several consultation meetings, a series of conference calls, and the creation of panel reports.

A. Collaborative Structure

The SON collaboration includes the SON Collaborative Council, Health Resources and Services Administration’s (HRSA) HIV/AIDS Bureau (HAB) SON Workgroup, the Project Contractor – Altarum (formerly Health Systems Research, Inc.) and RTI International (RTI), and the four Specialists’ Panels.

1. **SON Collaborative Council Representation** – Composed of representatives from eight agencies and offices. Provides a structure for input from Departmental agencies and offices. Provides expertise and feedback to Altarum/RTI, including recommendations of staff to participate on Specialists’ Panels.

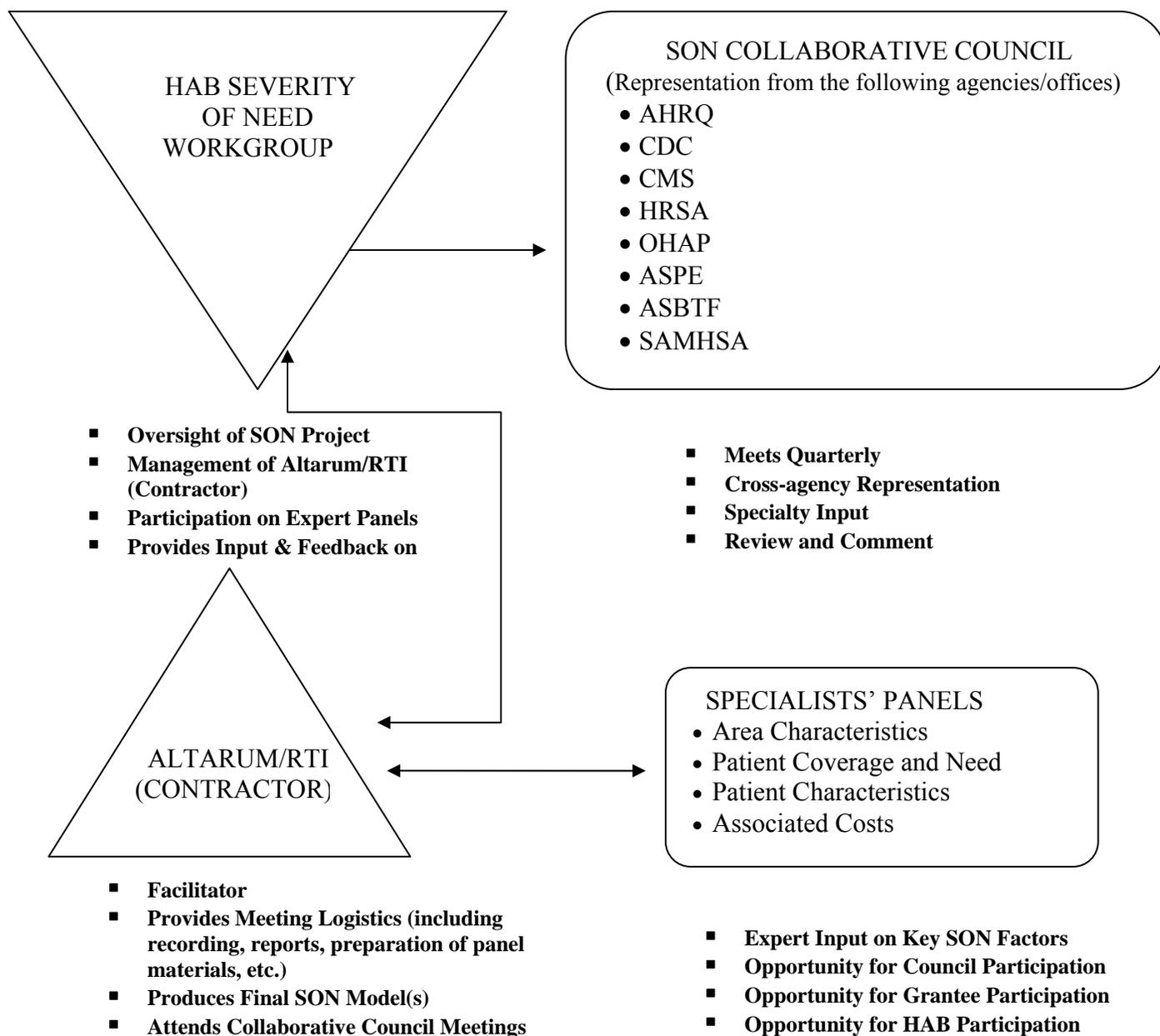
The following agencies and offices have agreed to serve as collaborators in the development of the SON model(s):

1	Agency for Healthcare Research and Quality (AHRQ)
2	Centers for Disease Control and Prevention (CDC)
3	Centers for Medicare and Medicaid Services (CMS)
4	Health Resources and Services Administration (HRSA)
5	Office of HIV/AIDS Policy (OHAP)
6	Assistant Secretary for Planning and Evaluation (ASPE)
7	Assistant Secretary for Budget, Technology, and Finance (ASBTF)
8	Substance Abuse and Mental Health Services Administration (SAMHSA)

2. **HAB SON Workgroup** – Composed of representatives from all HAB Divisions. Intricately involved in the SON process. Participants work closely with the Altarum/RTI team to ensure that the timeline proceeds as scheduled. Representation on all expert panels. Provides input and feedback for the final SON model(s).
3. **Altarum/RTI** – Functions as the facilitator of all panels. Identifies experts for Specialists’ Panels. Provides logistical support for Specialists’ Panels. Develops SON model(s) from recommendations of the Specialists’ Panels. Analyzes strengths and weaknesses of proposed model(s) and writes up methods and findings.
4. **Specialists’ Panels** – Convened by Altarum/RTI and composed of national experts as well as staff from across the Department, each committee investigates and compiles information on the following specific quantitative measures to be used by Altarum/RTI in the SON model(s):

1	Area Characteristics
2	Patient Coverage and Need
3	Patient Characteristics
4	Associated Costs

Organization and Workflow Of The Severity Of Need Collaboration



B. Project Activities and Timeline

The collaborating partners will be involved in a number of critical tasks in order to develop the conceptual framework, as outlined below. Providing both logistical and technical support, the Altarum/RTI will work closely with each of the panels.

Proposed Project Schedule							
Activity	2005				2006		
	Sep	Oct	Nov	Dec	Jan	Feb	Mar
1. Orientation conference calls		●					
2. First consultation meeting (Oct. 31)		□					
3. Working group conference calls			●	●	●	●	●
4. Written panel reports						▲	
5. Final panelist meeting							□

□ Meeting/Briefing ▲ Report ● Conference Call

Orientation conference calls – Altarum/RTI, with assistance from the HAB SON Workgroup, has conducted orientation conference calls with the intention of familiarizing experts with the overall project aims, preliminary findings, project timeline, and panelist roles and responsibilities. In order to accommodate busy schedules, panelists were given a choice of three possible dates.

First consultation meeting – A one-day, face-to-face consultation meeting with the panelists, HAB Workgroup, and Altarum/RTI will be held on October 31st. This meeting will provide an opportunity for the panels to begin working collaboratively on each of the specific areas of concentration and determine a schedule and process for future communication and the development of the panel report.

Panel conference calls – Although the process for each panel will be distinct, each panel may need to meet regularly via conference call during the months of November through March. The Altarum/RTI Project Team will assist with call scheduling and coordination, facilitation, written summaries, and provision of any requested background materials.

Written panel reports – By the end of February, each panel should create a written report for the data elements examined. Altarum/RTI will work with the panels to coordinate and create the documents as needed.

Final panelist meeting – A final meeting of the panels will be held in the spring of 2006 to share the findings of each group, clarify any questions, and discuss next steps.

III. Panelist Responsibilities

The role of each panel is to add structure and specificity to previous conceptual discussions held regarding SON. The job of the panelists is to determine specific items that could be included in a SON index (specific panelist tasks are described below). The results of the deliberation and research should be compiled into a written report. Members of the HRSA/HAB Workgroup and the Altarum/RTI Project Team have been assigned to each panel to provide assistance as needed (see page 13).

Panelist Tasks	
Task	Detail
Defining Components	<ul style="list-style-type: none"> Examine the proposed set of variables Define the meaning of each variable and how it influences a component of the SON equation (disease burden, cost of care, or available resources) Add and remove variables, with documented justification
Identifying data elements, their sources, and availability	<ul style="list-style-type: none"> Determine and report on data sources for each variable and whether they are available at the county level If data are available only at the State level, consider whether it is reasonable to use State-level data for county-level estimates Determine how frequently data for each measure are compiled Determine the availability (cost, necessary use agreements) of each data element If measures are limited for data elements, are there measures which can be used as proxies? If so, consider the same issues for proxy measures Determine the uniqueness and importance of each variable. Does the variable measure some unique component of the panel's subject area that relates to resource needs?
Identifying problems	<ul style="list-style-type: none"> Assess reliability of measures. Are elements measured in a similar way across units of analysis? Assess validity of measures. Do elements measure the intended underlying concept or phenomenon? Assess the measurement error of the data element. Is measurement error systematic in a way that it would bias resource allocations to the benefit of certain areas? If issues of reliability, validity, or systematic measurement error exist, are they resolvable with statistical adjustments? Do the measurement problems of the variable outweigh its information value? Do any other problems preclude the use of this variable?
Creating final variable list	<ul style="list-style-type: none"> List variables for inclusion Provide justification for each included variable Indicate data sources and measures for each variable
Weighting	<ul style="list-style-type: none"> Recommend relative weights for each measure used to indicate a variable (for example, different measures used to indicate disease burden) Recommend relative weights for each variable used to indicate a component (for example, weight for each variable – disease burden, availability of health care resources, etc. – used to indicate a component) Articulate a rationale for the weights

IV. Panel Operations

This section is intended to help each panel get started as easily as possible. As outlined below, each panel is staffed with members from four areas. Panelists were chosen on the basis of their ability to contribute particular expertise, but with the hope that their contributions would not be limited to their areas of expertise.

Panel Representatives and Their Recommended Roles	
Type of Representative	Recommended Role
Subject Matter Experts	To introduce the main challenges of measuring SON from an academic and research perspective
Ryan White Program Representatives	To provide input from an experiential or contextual perspective in the SON index development process
HHS and HRSA/HAB Representatives	To provide input and act as a resource in the SON index development. A HAB representative will serve as co-chair for each panel.
Altarum Contract Staff	To receive input from panels and HRSA on SON model(s). To facilitate meetings and conference calls, and coordinate communications, travel arrangements, reimbursements, and payments of honoraria
RTI International Contract Staff	To synthesize the content of discussions between meetings and raise clarifying questions to ensure that panel recommendations can be translated usefully into a quantifiable index

Initiating discussion – Each panel may want to begin with a discussion of its specific area, as outlined on the corresponding chart (page 9 - Area Characteristics; page 10 – Patient Coverage and Need; page 11 – Patient Characteristics; and page 12 – Associated Costs). Once the overall conceptualization has been addressed, it may be helpful to move to a discussion of the first variable, based on the following questions:

- How did the IOM Committee define the variable? (An abbreviated definition is provided in the tables included in this section; full definitions are included in Appendix B.)
- What is missing in this description?
- How exactly does this variable influence SON?
- What would be an ideal measure of this variable?
- Realistically, what variables are likely to be available?
- What are the specific measures and what are their sources?
- For each variable, are data available at the county level? If not, is it reasonable to use State-level data? How frequently are data compiled? Are selected data sources available for free? If measures are limited for data elements, are there measures that can be used as proxies?

Panels then can repeat this process for all variables in the section, using the questions as a guide, as appropriate. At the meeting's conclusion, the Altarum/RTI team will summarize the session notes and forward these to the panel for approval. Panelists will have the opportunity to propose changes to the notes. The session notes then will serve to document the process.

Electing a panel chair – To ensure that all variables are covered, that panelists' views have been adequately addressed, and that the group progresses as intended, panelists should elect a co-chair to work directly with HAB and Altarum/RTI. Each panel will also have a HRSA/HAB co-chair.

The panel co-chairs are ultimately responsible for insuring that the panel arrives at recommendations that are usable by the contractor to generate a Severity of Need index. At the end of the expert panel deliberations each panel has the responsibility to submit the following to the contractor:

- A completed data template for each variable included in the model
- A document explaining the rationale for the inclusion of each variable on the list.

The panel co-chairs are responsible for finalizing the document and delivering it to the contractor. Although unanimous consensus among panel members regarding the contents of their recommendations is desirable, it is not required for finalization. The panel co-chairs should strive to reach a broad consensus among panelists whenever possible. The co-chairs are encouraged to call for votes among the panelists to resolve difficult issues, and the nature of all controversies should be documented in the panel's final report.

The specific roles and responsibilities of the panel co-chairs are:

- To set the agenda for each conference call
- To facilitate the division of tasks among panel participants
- To forward formal requests for technical assistance to the contractor
- To call for votes to resolve controversial issues
- To deliver a completed data template and written documentation of the groups decisions to the contractor.

Voting – Panelists will be asked to vote on the group's recommendations as a whole, and the work of the panel will not be considered complete until it is ratified by a majority of panel members. The panel chair is empowered to call votes to resolve disagreements and to forward the process. Only panel members (excluding the Altarum/RTI contractors) are empowered to vote to resolve disputes. The Altarum/RTI contractors, interested members of other panels, and delegates of named panel member should be allowed to freely offer input on the panel deliberations, but are not empowered to vote.

Organizing additional work – Panelists likely will find that there is more work to be done than can be completed at the one-day meeting on October 31st. To facilitate completion of the project, we suggest having a panel member(s) volunteer to be responsible for coordinating the response for individual variables. Altarum/RTI and HRSA/HAB representatives can also assist panelists.

Reporting results – The intended end product from each panel is a written report that outlines the information described above for each data element examined. This is due by the end of February. If needed, the Altarum/RTI and HRSA/HAB representatives are available to assist with the creation of these documents.

V. Areas of Concentration

The following section outlines the IOM’s conceptualization of the four SON components, featuring a chart listing the variables in each component and a brief explanation of each.

A. Area Characteristics

Area characteristics refer to structural characteristics of an area that make the care of HIV/AIDS more resource-intensive in one area than another. The primary example of this is disease burden, which refers to the number of HIV-infected patients in an area. All other things being equal, areas with many infected patients will require more resources than areas with few. However, fundamental questions exist regarding how to measure disease burden. Other structural differences that may affect the need for Ryan White Program funding include the type of health care staff available in an area, physician availability, the availability of services to those who need them, the number of people living in poverty, and an area’s urban/rural composition.

Area Characteristics	
Component	Notes
Disease burden - HIV incidence - HIV/AIDS prevalence - HIV to AIDS Case Ratio, and or disease stage information	<ul style="list-style-type: none"> Commonly measured by the incidence or prevalence (point or period prevalence) of a disease Current Ryan White Program allocation formulas use estimated AIDS prevalence to quantify disease burden Including HIV burden estimates in Ryan White Program allocation formulas would be likely to shift funds to recently infected populations and away from areas with established epidemics The quality of HIV data is not consistent across States and EMAs; uniform methodology for data collection unavailable Defined by the CDC based largely on symptoms (e.g., AIDS-defining clinical conditions such as pulmonary tuberculosis, or recurrent pneumonia) or CD4+ cell counts (AIDS case surveillance definition CD4+ cell count < 200) Resource needs for patients in care vary significantly by disease stage – recently infected individuals generally require fewer resources than infected individuals at later disease stages
Poverty & economic considerations	<ul style="list-style-type: none"> Poverty status (typically reported as average per capita income or percentage of population below the Federal poverty level [FPL]) in an area is likely to affect available resources in calculating total resource needs
- Measures collected from the census - FPL - Urban/rural	<ul style="list-style-type: none"> Provides county-level information which grantees typically report in quantifying severity of need (e.g., estimating the size of special populations and reporting socioeconomic needs) Disadvantage: Census data are not specific to HIV/AIDS Measure updated annually by Census Bureau to estimate the number of Americans living in poverty (differs by number of persons in family unit) Commonly used to determine eligibility for programs such as Head Start, National School Lunch, Food Stamps, etc. HRSA/HAB asks grantees to provide estimates of the no. of people living at or below 300 percent of FPL (majority of estimates come from Census data or State Health Departments) Highly affected urban areas defined by EMA status (population greater than 500,000 with more than 2,000 reported AIDS cases w/in last 5 years) – Title I grants created to provide immediate relief to urban areas overwhelmed by concentrated case loads

B. Patient Coverage and Need (for Services)

Patient coverage and need for services refers to estimates of the medical care available to patients and the level of need that infected patients have for services. These include both measures of the number of people already in care (Estimated Patient Load); indicators of unmet need, such as waiting lists for ADAP services or proxy measures for poor access; and social area analyses of basic needs for medical services.

Patient Coverage and Need (for Services)	
Component	Notes
Estimates of persons in care/not in care	<ul style="list-style-type: none"> • Three HIV populations addressed by the Ryan White Program: undiagnosed and not in care; diagnosed and not in care; diagnosed and in care. Efforts typically have focused on diagnosed populations. The number of undiagnosed people not in care is difficult to estimate without HIV incidence data • Estimates from the literature suggest between 42 and 59 percent of all people with HIV/AIDS are not in regular care
Unmet needs	<ul style="list-style-type: none"> • Typically defined as eligible individuals not receiving care for HIV/AIDS – can include support services such as case management in addition primary medical care (which generally includes access to highly active antiretroviral therapy [HAART]) • May be quantified using findings from the HIV Cost and Services Utilization Study (HCSUS), which included questions on use of HAART drugs and needs related to income assistance, housing, home health care, mental health care and alcohol/drug treatment
ADAP waiting list	<ul style="list-style-type: none"> • ADAP provides funding primarily for medications, but it also supports treatment adherence counseling and purchases private insurance with prescription drug benefits • Financial eligibility requirements and drug coverage varies across States – increasing treatment costs and State budget shortfalls have forced many States to implement restrictions such as enrollment caps, limits on access to antiretroviral treatment, and expenditure caps • ADAP Supplemental Awards: 3% of ADAP funds earmarked for States with severe need (defined by FPL, medical eligibility, or a lack of access to or availability of drugs/health care)
Regional variations in need	<ul style="list-style-type: none"> • IOM Committee estimated preliminary models (termed social area analysis) of patient need (in addition to receipt of HAART) as a function of area characteristics, using data from the Census and HCSUS • Persons reported more needs if they lived in areas with fewer college-educated persons, fewer general practitioners, and more medical specialists
Need for core services	<ul style="list-style-type: none"> • Need for specific Ryan White Program-funded services that have been termed “core services.” Although the list of “core services” has not been finalized, it certainly includes primary medical care and medications. However, it could be substantially shorter than the list of all services that Ryan White Program programs currently provide.
Hospital discharge data	<ul style="list-style-type: none"> • May be used to indicate unmet need in that hospitalization may be avoidable with adequate primary care. Hospital discharge data can also be used in active reporting (along with death records and other administrative data) to identify previously unreported cases based on HIV/AIDS-related discharge codes

C. Patient Characteristics

“Patient characteristics” refers to aspects of people infected with HIV that are expected to influence resource needs. For example, poor and uninsured HIV/AIDS patients are likely require more Ryan White Program-funded services than more affluent patients. The presence of comorbid conditions such as TB, substance abuse, hepatitis C, and mental health problems likely make caring for HIV/AIDS more resource-intensive. The age of the epidemic in a geographic area and the distribution of patients among disease stages are also likely to affect resource needs, given the different medical complications associated with different stages. Concentrations of patients with high-risk characteristics may also lead to increases in cases in the future.

Patient Characteristics	
Component	Notes
Patient characteristics related to need	<ul style="list-style-type: none"> HCSUS study: Persons with HIV on Medicaid or uninsured, along with women and racial/ethnic minority groups, did more poorly on a variety of access measures than individuals who were privately-insured, male, or white
Sociodemographics (race/ethnicity, gender, age)	<ul style="list-style-type: none"> Area sociodemographic characteristics likely to be related to HIV resource needs as identified by the IOM Committee in preliminary analyses include: Percentage of the population that is African American, foreign born, living in urban areas, living in poverty, and college graduates
Comorbidities	<ul style="list-style-type: none"> Main comorbid conditions include: TB, syphilis, gonorrhea, hepatitis C, injection drug use, other substance abuse, mental illness, homelessness Large variation in the source, validity, reporting period and definitions used by EMAs to document comorbidities (e.g., homeless during the past year vs. month) Estimates largely reported among the general population instead of the HIV-infected population due to data limitations
Risk factors	<ul style="list-style-type: none"> Serving a large poverty-stricken IDU population with high rates of no insurance may be more costly than having an affluent largely MSM population with great health benefits. States often require documentation of associated risk factors in case reporting – completeness varies across States

D. Associated Costs

Associated costs refer to elements that make medical care more costly in one area than in another. These primarily include regional differences in the cost of medical services but may include other factors as well, such as State Medicaid reimbursement rates and information on the proportions of people with and without health insurance (and for those with insurance).

Associated Costs

Component	Notes
Regional variations in cost	<ul style="list-style-type: none"> Total cost of providing comparable care across areas may vary geographically due to differences in wage rates for health care workers, local costs of medical supplies and per capita income Costs also may vary depending on levels of efficiency in providing care and economies of scale (e.g., areas with concentrated case loads or established epidemics) Adjusted Average Per Capita Cost: controversial measure used by Medicare to adjust capitation rates for regional variations in cost
Resource needs estimation based on health system quality	<ul style="list-style-type: none"> Defined as the product of disease burden and cost of care minus available resources Resource needs = (Disease burden * Cost of care) – Available resources
Availability of healthcare resources - Physician shortage data	<ul style="list-style-type: none"> Structural measures (e.g., measures which address the characteristics or resources – training, supplies, staff, etc. – of an area or organization) thought to be associated with the quality and cost of care. The effects of staffing mix, physical surroundings, and availability of services on care are poorly understood Health Provider Shortage Areas (HPSA). Defined as a geographic area, population group, or medical facility that HHS determines to be served by too few health professionals of particular specialties. Physicians who provide services in HPSAs qualify for Medicare bonus payments. HPSA information is county-specific and may be used in analyses to account for general availability of medical personnel in an area
- Insurance coverage - Medicaid generosity	<ul style="list-style-type: none"> HRSA/HAB asks grantees to provide estimates of the number of people without insurance, including those without Medicaid insurance The level at which State Medicaid programs currently provide benefits for HIV/AIDS services

VI. Logistical Information

In an effort to help the project run smoothly, the following section includes information concerning Altarum /RTI roles and responsibilities, conference call logistics, payment of honoraria, and arrangements and reimbursement for meeting travel.

Altarum/RTI roles and responsibilities – Altarum will serve as the prime contractor, with responsibility for the overall coordination of contract activities, the development and support of the expert panel and workgroup process, and the design and conduct of the consultation meetings. RTI will take the lead role in the creation of datasets, refinement of the original severity of need model, and creation of the summary report of the final model.

Conference call logistics – Beginning in November, the Altarum/RTI Project Team will work collaboratively with the chair of each panel to assist with call scheduling and coordination, facilitation, and written summaries. The team also will work with the HAB SON Workgroup to provide any requested background materials. A password-protected Web site will be created to facilitate the conference call and report generation processes.

Payment of honoraria – When appropriate, panelists will receive a daily rate for their efforts. (Please note that Ryan White Program grantee representatives and Federal Staff are not eligible to receive honoraria.) Consulting agreements with a generalized scope of work will be drawn up by Altarum and provided to participants for signature and approval. Final workloads may vary due to the role and responsibilities of the panelists, but generally, consulting agreements may include 2 days for consultation meetings and 8 days for conference calls and background work, for a total of 10 days.