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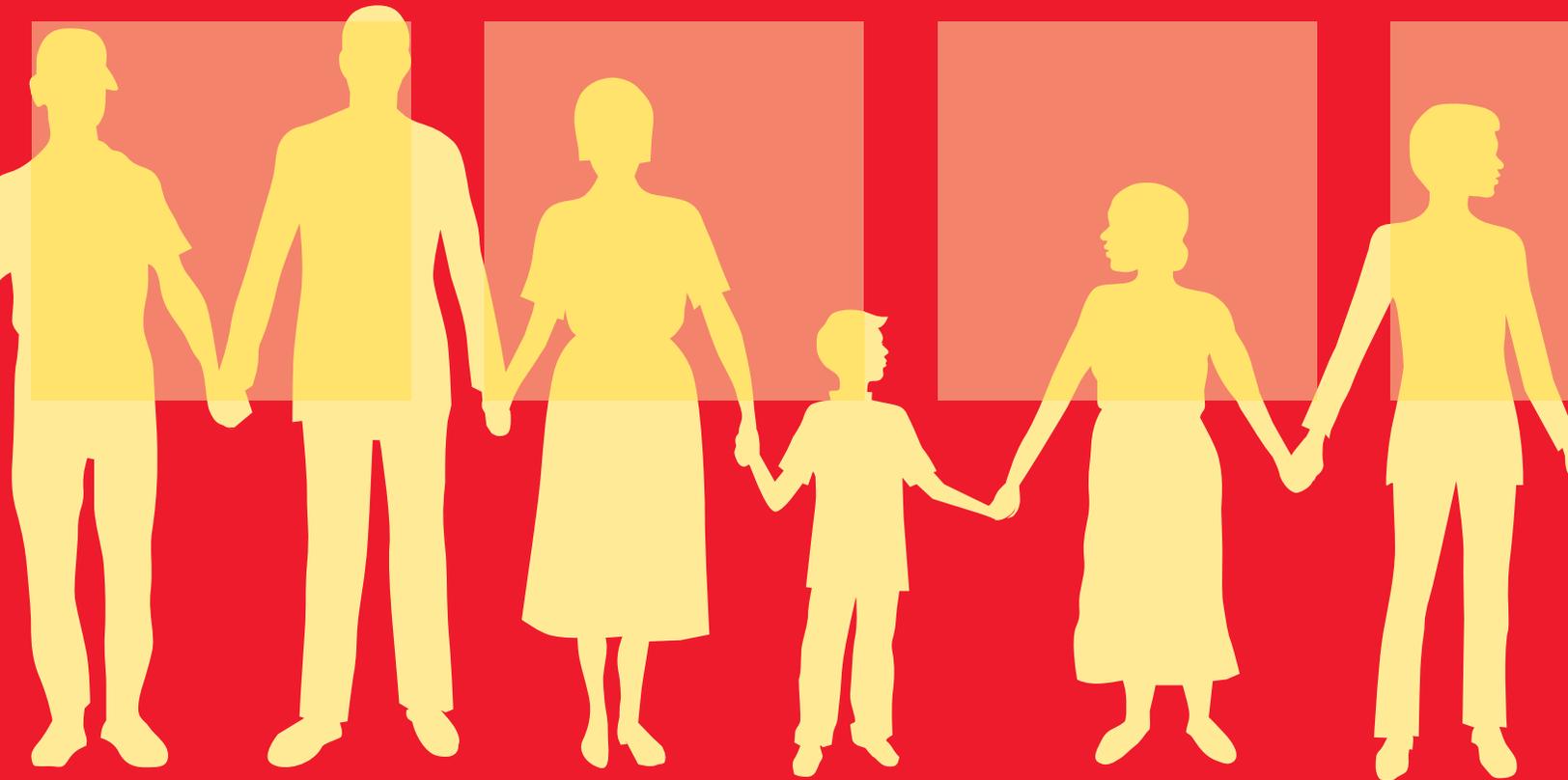
# Outcomes Evaluation Technical Assistance Guide

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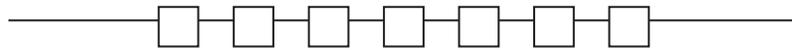
## *Getting Started*

*Titles I and II of the Ryan White CARE Act*



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# Outcomes Evaluation: Technical Assistance Guide



## *Getting Started*

*Titles I and II of the Ryan White CARE Act*



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## *Purposes of the Guide*

### **This guide has two main purposes:**

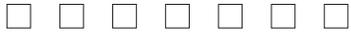
- To support outcomes evaluation efforts of Title I and II and other Ryan White Comprehensive AIDS Resources Emergency (CARE) Act grantees, planning bodies, and providers that generate information useful in planning, priority setting, and resource allocation and meet CARE Act requirements.
- To provide specific information and tools that will help the CARE Act community\* undertake outcomes evaluation, effectively involve stakeholders, and set up the systems to facilitate ongoing evaluation efforts.

The guide provides suggested steps for a CARE Act program to use in planning, testing, and institutionalizing an outcomes evaluation process, from the development of outcomes indicators and data elements to the implementation of ongoing systems for collecting, reporting, analyzing outcomes data. It includes worksheets and other aids, a glossary of frequently used outcomes evaluation terms, and suggested tasks, roles, and responsibilities. Focus is on providing an easy-to-understand, step-by-step process that can be used by programs with limited outcomes evaluation experience.

This guide is part of an evolving process of building CARE Act community capacity to evaluate the results of CARE Act programs. The HIV/AIDS Bureau (HAB) Division of Service Systems (DSS) and other HAB divisions within the Health Resources and Services Administration (HRSA) are producing other documents to help programs conduct outcomes evaluation and other evaluation efforts. For example, HAB has completed guides providing sample outcomes indicators for primary care and case management, and HAB's Office of Science and Epidemiology (OSE) is publishing a monograph series on evaluation. This guide complements these efforts.

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\* The terms "CARE ACT community" and "CARE ACT programs" are used throughout the guide to mean grantees, planning bodies, providers, people living with HIV/AIDS, and other CARE Act stakeholders.



## *Background and Rationale*

### **Legislative Requirements**

After more than a decade of CARE Act services, program evaluation is receiving increasing emphasis. The CARE Act legislation requires that Title I and Title II programs evaluate program “effectiveness,” which means conducting outcomes evaluation. Legislative language on evaluation is more limited for the other two titles, but program guidances require evaluation. In addition, the 2000 Amendments call for quality management programs to be established by all programs. These requirements are summarized below.

The CARE Act Amendments of 1996 included specific evaluation requirements for Titles I and II, which have been retained and slightly modified in the 2000 Amendments:

- Each Title I planning council shall establish priorities for the allocation of funds based on factors including the “demonstrated (or probable) cost effectiveness and outcome effectiveness of proposed strategies and interventions, to the extent that data are reasonably available”; and may, at its discretion, “assess the effectiveness, either directly or through contractual arrangements, of the services offered in meeting the identified needs.” [Section 2602(a)(4)(C)(ii)]
- Each Title II consortium is required to submit to the State an application that “(D) demonstrates that the consortium has created a mechanism to evaluate periodically—(i) the success of the consortium in responding to identified needs; (ii) the cost-effectiveness of the mechanisms employed by the consortium to deliver comprehensive care; and (E) demonstrates that the consortium will report to the State the results of the evaluations described in subparagraph (D) and shall make available to the State or the Secretary, on request, such data and information on the program methodology that may be required to perform an independent evaluation” [Section 2613(c)(1)(D-E)]. State grantees are required to provide for “periodic independent peer review to assess the quality and appropriateness of health and support services provided by entities that receive funds from the State” [Section 2617(b)(4)(C)] and may spend up to 10% of grant funds on “planning and evaluation activities.” [Section 2618(b)(3)]

- Title III programs may spend no more than “7.5 percent, including planning and evaluation of the grant for administrative expenses with respect to the grant...”[Section 2664(g)(3)]
- Each Title IV program is required by the Secretary to: “(2) directly or through contracts with public and private entities, provide for evaluations of programs carried out pursuant to subsection (a).” [Section 2671(h)(2)]

The CARE Act Amendments of 2000 maintain the previous requirements while adding a new section establishing quality management programs applicable to all titles:

- The Amendments require grantees under all four titles to “establish a quality management program to assess the extent to which HIV health services provided to patients under the grant are consistent with the most recent Public Health Service guidelines for the treatment of HIV disease and related opportunistic infections, and as applicable, to develop strategies for ensuring that such services are consistent with the guidelines for improvement in the access to and quality of HIV health services.”
- Title I and II grantees may allocate up to the lesser of 5% of the total grant amount or \$3 million for quality management activities. Funding limits are not specified for Titles III and IV.

Guidance from HAB indicates that quality management programs are intended to help grantees evaluate and improve the quality of primary care and health-related supportive services provided under the CARE Act. In order to meet the purpose of continuously improving systems of care for individuals and populations, HAB expects evaluations of quality of care to consider the quality of each of the following:

- service inputs (*e.g.*, staffing, resources)
- the service delivery process
- service outcomes

The focus and ultimate goal of quality management is improved health status. Moreover, quality management programs should look beyond clinical services to consider both supportive services and outcomes specific to each grantee’s population and location.

Since many providers have funding from more than one title, there is a need for shared evaluation approaches as well as common evaluation terms, outcomes indicators, and data elements across titles.



## Need for Outcomes Evaluation

Many factors in addition to CARE Act legislative requirements contribute to a need for outcomes evaluation. All Federal programs are now expected under the Government Performance and Results Act (GPRA) to document progress towards specific measurable objectives. Documentation of results is necessary to demonstrate program quality and effectiveness and to support CARE Act appropriations and reauthorization. The Inspector General has recommended the establishment of systems at the national, State, and local levels to support outcomes evaluation.

Grantees and planning bodies need outcomes evaluation data to support their work at the State and local levels. Both grantees and lead agencies need guidance on data requirements to include in their Requests for Proposals (RFPs) and in provider contracts so they can document results. Planning bodies need outcomes data as input to their planning and priority setting. States and municipalities often require documentation that programs are making a difference, whether they are supported solely through CARE Act resources or by a combination of funding sources, public and private. Providers need to be able to document program outcomes as they seek public and private funds and as they work to improve and coordinate services.

### Key Evaluation Terms

Evaluation terms used frequently in this guide are briefly defined and described below for use in reading this document. For more detailed definitions and examples, see the Glossary.

**Outcomes** are benefits or other results (positive or negative) for clients that may occur during or after program participation. Outcomes can be classified as **initial**, **intermediate**, and **longer-term** based on how soon they occur after program participation begins.

**Client-level outcomes** are results or benefits for an individual client, including biological measures such as improved CD4 count or viral load or morbidity measures such as reduction in opportunistic conditions; **system-level outcomes** are results for all clients receiving services, such as reduced morbidity or mortality rates.

**Outcome indicators or measures** are observable, measurable data sets—such as changes in CD4 counts or non-injury-related emergency room visits over time—that are used to track a program’s success in reaching desired outcomes.

**Data elements** are the specific items of information—such as CD4 counts or non-injury-related emergency room visits by clients during a specific period—that are collected and aggregated in order to make measurements using the indicators.

**Targets** are measurable objectives stating the desired level of outcome achievement for a program, such as “to have a perinatal transmission rate below X% for women receiving antiretroviral prophylaxis to prevent perinatal transmission.”

**Outputs** are measures of the direct products or volume of program operations such as the number of service units that a program delivers; primary care examples include the number of clients served, CD4 and viral load tests completed, or specialty care consultations provided.

Evaluation of the CARE Act program at the national level is overseen by the HAB Office of Science and Epidemiology. OSE evaluation efforts can support State and local evaluation activities by documenting national outcomes and assessing the relationship between the provision of quality care and outcomes (*e.g.*, showing that following HIV-related treatment guidelines leads to reductions in morbidity and mortality). These national evaluation studies require standardized local data that record how standards of care are being met and document specific program outcomes.

### HAB Evaluation Questions

HAB has established five key evaluation questions to guide CARE Act evaluation efforts (see box). They address many of the same evaluation questions that Title I and Title II grantees and planning bodies are likely to want answered. These questions address access to care, program processes, quality, and outcomes.

Outcomes evaluation of primary care services directly addresses two aspects of Evaluation Question #4, *Providing Quality Care*:

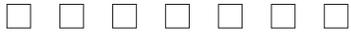
- Evaluation based on the standards of care specified in the HIV-related treatment guidelines measures program quality. Meeting such treatment guidelines contributes to positive treatment outcomes.
- Using outcomes indicators related to primary medical care provides direct information regarding changes in morbidity and mortality and in health-related quality of life.

Outcomes evaluation of other CARE Act services addresses two other evaluation questions:

- Determining outcomes of supportive or enabling services can address the extent to which these services are helping to remove barriers to care and to enroll and retain clients in primary health care (Evaluation Question #2, *Removing Barriers to Care*).
- As client-level outcomes evaluation data become more available and evaluation becomes more systems-oriented, models and combinations of care can be evaluated (Evaluation Question #3, *Optimizing Local Service Delivery Systems*).

Outcomes evaluation is usually linked to other types of evaluation, such as process evaluation, and is likely to further address one evaluation question:

- Grantees will generally want to know not only what client outcomes have been achieved, but also for what clients—which means reviewing client demographic data (which addresses Evaluation Question #1, *Assessing Unmet Need*).

**HIV/AIDS Bureau Evaluation Questions\***

1. **Assessing Unmet Need.** To what extent are CARE Act grantees and Titles I and II providers identifying HIV infected populations who are not in primary health care (not accessing available services)? To what extent are grantees identifying HIV-infected populations who are not remaining in primary health care and the reasons for this lack of continued service utilization?
2. **Removing Barriers to Care.** Are grantees determining the specific reasons why individuals are not in care and removing barriers to their care? What are grantees/providers doing to enroll and retain identified underserved populations in primary health care?
3. **Optimizing Local Service Delivery Systems.** Have CARE Act grantees identified the most effective combinations or models of integrated services that improve the use of primary health care, taking into account the characteristics of local health care delivery systems and affected populations?
4. **Providing Quality Care.** To what extent are CARE Act grantees/providers providing quality care to clients as defined by Public Health Service and other care standards? Is this care having optimal effects on morbidity and mortality, and is it improving health-related quality of life?
5. **Adapting to Change.** To what extent are CARE Act grantees adapting their service priorities and allocations to a changing and sometimes chaotic health delivery and reimbursement environment?

\* These evaluation questions were revised by the HIV/AIDS Bureau in 2000.

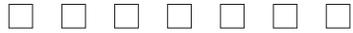
**Using this Guide**

This guide explains how to get started in designing and implementing outcomes evaluation. It is designed for people with limited experience with outcomes evaluation, such as grantees that do not have professional evaluators on staff but are committed to determining the outcomes of their CARE Act programs.

HAB does not require a specific type of outcomes evaluation; this guide provides suggested approaches, not requirements. Every grantee and planning body may determine for itself what outcomes indicators and approaches it will use in evaluating program results. However, many CARE Act programs have indicated a need for guidance from HAB on outcomes evaluation; the guide was developed to address this need.

Use the guide to learn about:

- what is meant by “outcomes evaluation” and how it is different from other types of evaluation
- common evaluation terminology
- the range of different approaches that can be used to obtain outcomes evaluation data
- the importance of working towards evaluation of systems of care, not just individual services, and determining how a variety of services contribute to positive client outcomes—activities that may require special funding and expertise
- many factors that need to be considered in planning and carrying out outcomes evaluation
- ways to involve a range of local or State “stakeholders” in planning and implementing outcomes evaluation
- a step-by-step process that can be used to plan, implement, and refine an outcomes evaluation system
- how to plan and implement outcomes evaluation, directly or through hiring and supervising an outcomes evaluation consultant
- how to use evaluation technical assistance personnel effectively
- references and resources that can support the evaluation process



## Types of Evaluation

There are many types of evaluation. Usually, CARE Act programs will want to conduct more than one kind. This guide focuses on outcomes evaluation, but it is useful to be familiar with other types of evaluation and how they are used. There is no one term or definition for each type of evaluation, but the list in Figure 1 is typical.

Closely related—and complementary—to outcomes evaluation is quality assurance or quality improvement. While outcomes evaluation focuses on determining program results, quality improvement is based on ensuring that minimum standards of care are met. Programs that have already carried out quality improvement efforts have a major head start in doing outcomes evaluation: they have developed standards of care for their services, and usually have defined units of service as well. Both are extremely useful in outcomes evaluation. Only if there are consistent definitions for service units (*e.g.*, what constitutes a case management visit or a primary care examination) can outcomes of those services be combined and analyzed across providers.

### Figure 1: Types of Evaluation\*

#### Design or Formative Evaluation

- Often used before a program is fully implemented, to determine adequacy of program design or identify needed changes in design
- Also used to answer the question, “Which works better?”
- Focuses on ways of improving or enhancing programs rather than judging overall effectiveness

#### Process Evaluation

- Answers the question, “What services are actually being delivered and to whom?”
- Compares program work plan with actual implementation, including the extent to which programs actually operate consistent with the objectives and procedures originally devised for them
- Assesses whether program has met its “task” or “process” objectives
- Can address quality or participant satisfaction with the program

#### Quality Improvement

- A formal and systematic process of identifying problems in service delivery, designing activities to overcome these problems, and following up to ensure that corrective actions have been effective and no new problems have developed
- Usually focuses on ensuring that minimum standards of care are met

#### Outcomes Evaluation

- Answers the question, “Did the program make a difference?”
- Usually addresses initial outcomes such as increased knowledge (*e.g.*, appropriate treatment during pregnancy can minimize the probability of perinatal transmission), awareness (treatment is available), or skills (how to access services), or intent to change behavior (*e.g.*, adhere to medications)
- Also addresses intermediate outcomes such as success in obtaining services (*e.g.*, client is obtaining regular primary medical care) and actual behavior change (*e.g.*, improved adherence), and longer-term client benefit (*e.g.*, substance user has been drug-free for three months), or measures of improved health status (*e.g.*, improved CD4 count or viral load, fewer HIV-related hospitalizations)
- Can include evaluation of longer-term results or impact, *i.e.*, the program’s ultimate impact on morbidity or mortality among clients living with HIV/AIDS, results that generally cannot be measured immediately after program interventions begin.

#### Cost-Effectiveness Evaluation

- Compares program costs with expected benefits, or compares the cost differences of alternative program strategies
- Helps determine which program strategies provide the greatest benefits for the least money
- Assesses the value of a service relative to its cost

\* Based on/revised from an excerpt from *Evaluating HIV/AIDS Prevention Programs in Community-Based Organizations*, Washington, D.C.: National Community AIDS Partnership, September 1993.



## *Issues and Challenges in Outcomes Evaluation*

Outcomes evaluation presents a number of interrelated issues and challenges, including those listed below. Many are already being addressed by HAB; most require continued attention by HAB and by the CARE Act community.

- **Outcomes data involve client status and behaviors; such information must come directly or indirectly from the client.** Provider-based records of services delivered document outputs (*e.g.*, level of services) but not outcomes (changes in clients). Some outcomes data can be obtained through client interviews, while others must be obtained through medical or other tests. Sometimes the client is unaware of his/her own status. For example, the client may be able to report on his/her own ability to carry out daily activities such as employment or school work. Clinical data such as CD4 counts and viral loads are based on laboratory testing and should be obtained from the primary care provider to ensure accurate reporting. Confidentiality provisions and client consent forms help determine when and how such information may be shared among providers.
- **Providers of supportive or enabling services want to be able to demonstrate that their services are linked to improved client health status; however, they are unlikely to be able to obtain data about those health outcomes.** Clinical health data may be made available by the primary care provider to the grantee (*e.g.*, a State or local health department). However, such information is rarely available to a provider of enabling services—those services designed to enable clients to increase access to and retention in primary care, such as transportation or child care. Providers of supportive services may be able to determine the direct outcomes of their own services (*e.g.*, weight gain for nutrition programs, reduced homelessness for a housing project). However, they, too, are unlikely to have access to clinical measures of client health status. Other, less demanding, outcomes-related measures are needed (*e.g.*, a reduction in missed primary care appointments for transportation, increased adherence to treatment for a housing project).

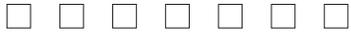
- **Successful implementation of outcomes evaluation requires not only skill in outcomes evaluation design and implementation but also cooperation and agreements among providers, grantees, and planning bodies.** For example, outcomes evaluation of a Title I or Title II program or other CARE Act program with multiple providers depends upon:
  - ▼ agreement on what outcomes will be measured
  - ▼ agreement on what indicators should be used to measure these outcomes
  - ▼ agreement on what outcomes will be measured
  - ▼ agreement on necessary data elements
  - ▼ appropriate provider procedures for the consistent collection, aggregation, and reporting of the required data
  - ▼ willingness of providers to collect data in ways that make possible comparisons across providers
  - ▼ willingness of providers to report and share these data
  - ▼ resources for data collection and reporting

### Obtaining Clinical Data on Client Health Status and Links to Primary Care

HIV/AIDS care is now based largely on a medical model of service delivery designed to reduce morbidity and mortality. Determining the effectiveness of CARE Act services therefore requires understanding whether, overall, such services are helping clients to access and remain in primary care and realize improved health status. This means that outcomes evaluation for almost any CARE Act-supported service category, from case management to transportation, needs to include an indication of whether program participation can demonstrate linkages to primary care—which, in turn, contributes to improved clinical outcomes. Most providers lack access to data on client health status, but they can document their ability to link clients to primary care (*e.g.*, helping them enter primary care, keep appointments, and adhere to medications).

Obtaining clinical data on client health status from primary care providers can be very challenging. Primary care providers typically collect and maintain such data as part of client medical records. However, such data are not always recorded consistently and may not be aggregated or reported on a regular basis. Client medical records are less likely to be available for review and/or providers are less likely to modify their recordkeeping systems to meet CARE Act needs in locations and situations such as the following:

- where most primary care services are not paid for with CARE Act funds so medical records of CARE Act clients are not being maintained by CARE Act-funded providers



- in rural or low-prevalence areas where each primary care provider serves a relatively small number of CARE Act clients and therefore receives limited CARE Act funds
- where primary care and other services are being supported through different CARE Act titles and reported through different data systems
- where the grantee and providers are not using a client-level data system with unique client identifiers
- where there is no computerized system in place to report aggregate clinical data on clients
- where the grantee has a number of primary care providers with different recordkeeping systems and types of medical records

Because the CARE Act is supposed to be the “provider of last resort,” a great deal of primary care for CARE Act clients is supported through Medicaid, and some clients receive primary care through the Veterans Administration or through private insurance. Obtaining client-based clinical data from such sources is a particular challenge, and providers of other services need to identify other types of outcomes data that are more accessible.

### Evaluating Systems of Care

CARE Act programs, especially Title I and Title II programs, typically help to support a system of HIV/AIDS services, and grantees and planning bodies want evaluation data that can guide decision making about program priorities and resource allocation. Ideally, this means understanding the outcomes associated with not just one category of services (*e.g.*, primary medical care or case management) but rather a combination of primary care and supporting and enabling services—or an entire system of care.

Evaluation linking supportive or enabling services to health outcomes often requires some form of system-level evaluation. This is extremely challenging for several reasons:

- If the evaluation is to link outcomes to particular services or a mix of services, a unique client identifier is needed as well as an area-wide client-level data system; without them, determining what services an individual client has received is very difficult.
- To evaluate the contributions of supportive and enabling services to client clinical outcomes, providers of such services or the program as a whole will need access to clinical data collected by the primary care provider or substitute measures such as access to and retention in care. Unless there is a client-level data system, such information can be obtained only if support services providers can find ways to obtain data linking their services to primary care access, retention, and/or medical outcomes.

## Time and Resources

Establishing procedures to collect and report outcomes data takes considerable time and resources for many of the reasons identified above. States and EMAs have estimated that it takes 18 months to two years to fully implement the systems needed for outcomes evaluation—systems needed for collecting and reporting common data elements. This includes time to:

- work with providers and planning bodies to decide on appropriate outcomes and indicators
- develop, test, and implement provider recordkeeping systems that collect needed data
- develop and test client records abstraction or other methods of aggregating and reporting such data

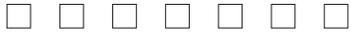
These efforts require human and financial resources. Prior to the 2000 CARE Act Amendments, administrative caps could make it difficult for grantees and planning bodies—especially those in low-incidence States and small EMAs—to carry out evaluation with CARE Act funds. The 2000 Amendments specifically permit the use of grant funds for evaluation as a part of the required quality management programs. Title I and Title II grantees may spend up to 5% of grant funds or \$3 million, whichever is less, on quality management programs. In addition, planning bodies are permitted to prioritize evaluation as a program support function and allocate non-administrative funds if they feel that this is a high priority use of CARE Act funds. Title II includes a provision to support planning and evaluation activities up to 10 percent of the grant award, or up to a total of 15 percent in combination with administrative costs. Some grantees use State or local funds or do fundraising to obtain additional resources for evaluation. HAB provides a small amount of competitive funding for local evaluation through special requests for proposals.

## Data Reporting versus Sampling Methods

Many grantees have indicated that primary care providers collect much of the information needed for outcomes evaluation but do not aggregate or report these data on a regular basis. A

long-term solution is to develop a computerized client-level or provider-based data system that can report clinical data. Other, more immediate, approaches include abstraction of data from a sample of client records or special studies utilizing a sample of selected providers or clients.

Valuable outcomes data can be obtained without 100% reporting by providers. If providers collect needed outcomes data and record them in client medical or case management records, the grantee can use client records abstraction procedures to sample clients from various providers and generate outcomes data without requiring providers to regularly aggregate and report their outcomes data. Similarly, the grantee can conduct special studies involving collection of data from a sample of providers.



The CARE Act community needs to decide how best to obtain data needed for outcomes evaluation, with attention given to both immediate and longer-term methods. A desirable approach is to work towards the establishment of systems for consistent reporting of outcomes data, while using records abstraction or special studies as an interim approach.

### Data Systems

Outcomes data are most easily reported through client-level data systems. To meet the needs of grantees and providers, HAB has supported the development of a computerized database, RW CAREWare. This new software package is designed to provide grantees and providers with a clear and easy-to-use tool for collecting, managing, and reporting Annual Administrative Report (AAR) data. RW CAREWare allows users to collect client-level, encounter-based data that can be used to support outcomes evaluation. A built-in “Crosstab Wizard” enables users to conduct extensive analyses of the data to address their own needs. RW CAREWare allows client-level analysis of data at the local level, and the software package also contains modules that will summarize and aggregate data to create the AAR.

### Consistent Indicators across Titles

Providers often receive funds from multiple CARE Act titles. Outcomes evaluation is most efficient if the same clinical indicators and data elements can be used across titles. Because a small number of clinical status data elements are regularly collected for CARE Act clients, it is not difficult to select indicators that are consistent across titles. The outcomes and indicators suggested in this guide are consistent with those being developed by HAB for use by all CARE Act grantees. These suggested outcomes and indicators have also been included in RW CAREWare.

### Obtaining Clinical Data from Clients

Clinical data on clients are best obtained from medical records. However, in situations where medical records are not available to CARE Act grantees, alternative data are needed. In some cases, case managers or other providers can obtain access to clinical data. Some clinical data may be available for clients whose medications are paid for with ADAP funds. Sometimes specific clinical data can be released to clients and then shared with the case manager. Where providers believe that they cannot obtain reliable and valid data using such methods, an alternative approach is needed, such as the use of validated instruments for obtaining client-reported quality of life data.

## *Suggested Steps for Beginning Outcomes Evaluation*

The experiences of CARE Act programs provide approaches for getting started in outcomes evaluation. The following steps represent one way to carry out an initial outcomes evaluation process and establish systems for ongoing outcomes evaluation. No CARE Act program should feel under any pressure to use this approach. However, if you want to begin outcomes evaluation and are unsure how to proceed, this process may help. It may serve as a guide in finding a process that works for you and in using evaluation consultants. Included are alternative evaluation tools.

### **Suggested Outcomes Evaluation Steps**

1. Agree on what you want to accomplish through the outcomes evaluation effort.
2. Establish a group to oversee the evaluation process.
3. Become familiar with evaluation concepts.
4. Assess your outcomes evaluation readiness.
5. Prepare an evaluation plan and timeline.
6. Agree on outcomes and indicators to be used.
7. Plan methods of obtaining and reporting data.
8. Test your process.
9. Analyze and report findings.
10. Use results.
11. Refine and institutionalize the outcomes evaluation system and process.



***1. Agree on what you want to accomplish through the outcomes evaluation effort.***

The first step is to agree on why you want to do outcomes evaluation, including how you expect to use the results in decision making. The primary reasons for outcomes evaluation should relate to ensuring effective services for clients—not “meeting HAB requirements” related to outcomes evaluation. You may want to:

- find out whether the program is contributing to improved client health status and other positive client outcomes
- understand the extent to which specific services are contributing to positive outcomes for particular types of clients
- test various methods of obtaining needed data for outcomes evaluation
- address some or all of the HAB evaluation questions
- obtain data for use in planning and decision making, especially with regard to setting priorities and allocating resources
- meet expectations or requirements of funders, public and private
- determine the need for improved data collection and reporting systems

### Agreeing on Outcomes Evaluation Purposes

Members of the CARE Act community may share a belief that outcomes evaluation is necessary but may not know exactly what they want the evaluation to accomplish. One way to reach consensus is to bring together as many key “stakeholders” in evaluation as possible—the individuals and organizational representatives that have an interest in the process. The following process could be used at a planning body meeting.

1. Divide participants into small groups of 4-6 people.
2. Have each group choose a **facilitator** to coordinate the work of the group and participate as well, a **recorder** to write down group responses on a big piece of paper from an easel pad, and a **reporter** to summarize the work of the small group for the full group.
3. Ask each group to answer the following questions:
  - a. *Why do we need to begin doing outcomes evaluation?*
  - b. *What specific results are most important to achieve through this process?*
4. First ask each participant to think individually about each question and write down his/her responses—at least three responses to each question.
5. Each participant then provides ONE answer to the first question. Then the next person provides ONE answer, and so on. The recorder should write down each response. There should not be questions except as necessary to understand what the group member means by his/her response. Keep going around the group until all responses have been shared.
6. Review the list and agree on the 3-5 most important reasons. Mark those.
7. Go through the same process with the second question.
8. Have the reporter prepared to use the newsprint lists to summarize the work of the small group to the full group.
9. Compare the responses of each group. Discuss similarities and differences in responses. Then develop a master list of responses and agree on the most important reasons for doing outcomes evaluation and the results the group most wants to achieve from the evaluation process. You can do this by voting—with each person permitted to vote for up to three desired reasons or results—or through consensus. Write down the desired results and refer to them regularly as you design and implement the evaluation, so you can be sure these results are reached.

## 2. Establish a group to oversee the evaluation process.

Now you are ready to convene a group to coordinate the entire evaluation effort. Whether the actual evaluation work will be done by staff, volunteers, or consultants, an oversight group is needed. Its members need a common understanding of their roles and responsibilities. Be sure the process used reflects the agreement reached in Step 1.

**Form an evaluation committee.** Experience suggests that a grantee’s first outcomes evaluation effort is usually time-consuming and demanding. For this reason, it can be helpful to form a committee responsible solely for outcomes evaluation, rather than making evaluation one of multiple committee responsibilities. If the task is given to a committee with other roles, be sure that evaluation is its primary responsibility for the period of the evaluation effort—which is likely to be 18 months or more.



**Have diverse membership:** Committee composition needs to be diverse, including grantee, planning body, provider, and consumer representation, plus other stakeholders as appropriate. It is extremely important that providers—including primary care providers—be well represented on the committee; they will have a key role in ensuring access to outcomes data. The committee generally should include grantee staff who will be involved in the evaluation effort and are familiar with provider contractual requirements for collecting and reporting data and grantee resources and capacity for evaluation. The skills and knowledge represented will, of course, depend upon the location. Conscious planning and outreach will help ensure that the committee includes individuals with diverse experience and the ability to help gain wide support for the evaluation process.

**Clarify the required time commitment:** Be sure committee members understand that this will be a long-term effort. It is likely to involve periods of intense activity and other periods when most of the work may be done by consultants or by provider or grantee staff. It may be helpful to agree on a committee member position description.

#### **Position Description: Evaluation Committee Member**

**Responsibilities:** Each member will be expected to:

- attend regular meetings to plan and oversee an outcomes evaluation process for the program
- review materials provided before and between meetings, and come to meetings ready for discussion and decision making
- serve as a liaison to specific providers or communities
- participate in the selection of outcome indicators
- participate in the selection of an evaluation consultant
- help ensure support of the evaluation process throughout the CARE Act community

**Skills and Experience:** Members should have several of the following:

- familiarity with specific service categories
- understanding of the overall service system supported by the CARE Act
- experience in planning and conducting evaluations or related activities such as service documentation, development of standards of care, or quality improvement
- knowledge of specific populations or communities
- knowledge of the provider network

### 3. Become familiar with evaluation concepts.

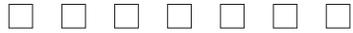
Before your committee agrees on an evaluation process, work plan, and timeline, members need shared background knowledge about evaluation. This includes an understanding of the basics of outcomes evaluation, familiarity with HAB and grantee expectations for evaluation, recognition of the challenges you face in establishing an outcomes evaluation system, and acquaintance with some approaches to outcomes evaluation.

Start by reviewing this guide and other evaluation materials to become familiar with HAB expectations and frequently used evaluation methods. The references in the box may be especially helpful.

#### Useful References

If members of your committee are not experienced in evaluation, the following evaluation guides may be particularly useful background reading. See the References and Resources section for how to obtain them; also check the HIV/AIDS Bureau website for new evaluation materials (<http://www.hab.hrsa.gov>).

- **Become familiar with frequently used primary care and case management outcomes indicators:** Review *Outcomes Evaluation Technical Assistance Guide: Primary Medical Care Outcomes*, prepared by the HIV/AIDS Bureau, Division of Service Systems, 1999, which includes suggested outcomes indicators for primary medical care. Also see *Outcomes Evaluation Technical Assistance Guide for Case Management Services*, 2001, which includes suggested outcomes indicators for case management and information on validated quality of life instruments.
- **Become familiar with evaluation terms and approaches:** Use *A Practical Guide to Evaluation and Evaluation Terms for Ryan White CARE Act Grantees*, Report #4 of the HIV/AIDS Monograph Series, prepared by the Office of Science and Epidemiology, September 1999.
- **Understand the difference between “outcomes” and “outputs” and look at a popular outcomes evaluation model:** Review *Measuring Program Outcomes: A Practical Approach*, prepared for United Way of America, 1996.
- **If you plan to hire a consultant to help carry out the evaluation:** Obtain *Choosing and Using an External Evaluator*, Report #1 of the HIV/AIDS Monograph Series, prepared by the Office of Science and Epidemiology, 1997.



Once committee members have reviewed these documents, discuss what you have learned.

If you are unfamiliar with evaluation, you may feel, after reviewing these materials, that you need some initial training or more technical assistance. If so, examine possibilities for obtaining training or more extensive technical assistance. Think carefully about what information you are seeking. You may need any or all of the following:

- an orientation to outcomes evaluation, perhaps through a training session that addresses such topics as definitions and terminology, typical approaches and models, examples of outcomes indicators, practical benefits of outcomes evaluation, and HAB expectations and suggestions
- more intensive training and technical assistance, including help in agreeing on a process for evaluation, developing outcomes indicators for selected service categories, and deciding how to collect or report outcomes data
- ongoing assistance from a local university or consultant, throughout the evaluation process

Once you have decided what you need:

- Request a briefing from grantee staff, provider evaluation specialists, or another local evaluation expert who is familiar with CARE Act programs and requirements.
- Seek more intensive assistance from these sources or from a local university or evaluation consultant.
- Contact your Project Officer and ask for advice and guidance. S/he may be able to provide an orientation to familiarize your evaluation committee or your entire planning body with evaluation needs and approaches.
- Request technical assistance from the Ryan White Technical Assistance Contract (TAC) through your Project Officer. You may need only a single site visit from someone who can clarify HAB expectations and provide a briefing about outcomes evaluation, or more extensive assistance.

#### **4. Assess your outcomes evaluation readiness.**

Once you understand evaluation models and HAB expectations, you are ready to consider the context of your evaluation effort. You need to know how much outcomes evaluation is already being done and what needed data are already being collected or reported. Be sure to explore the following:

**Outcomes Evaluation Technical Assistance Guide**

- **How available and accessible are outcomes data?** For example, are clinical data from primary care providers accessible to the grantee through reports or medical records abstraction? (This is a particularly important question if most primary care is provided through Medicaid funds or from providers that do not receive CARE Act funds.) What are the current contract requirements for primary care providers regarding reporting health status or other outcomes data? For allowing appropriately trained personnel to abstract data from medical or other client records, with client consent and appropriate confidentiality protections? Do providers already obtain written consent forms from clients that enable them to provide such data to others at a client level, or will a new consent process need to be established?
- **Does the State or EMA have a computerized client-level data system through which all or most funded providers report information about clients?** If so, does it include outcomes data (*e.g.*, clinical status data such as CD4 count, viral load, HIV-related hospitalizations, non-injury-related emergency room visits)?
- **Does the State or EMA have a unique client identifier** so that individual clients can be tracked to determine the mix of services they receive and link this information to outcomes? If not, is there any way to determine the mix of services obtained by individual clients?
- **Are there existing standards of care** for most or all service categories supported through your CARE Act funding? Clearly defined units of service?
- **What resources are available for evaluation?** Will the work be done by staff or consultants with committee oversight? Or will the committee be directly involved in the process?

If you plan to use a consultant, hire someone at the beginning of the evaluation process to help develop the evaluation plan. Be sure the consultant has outcomes evaluation experience, an understanding of HIV/AIDS services and the CARE Act, and is comfortable working with and reporting to an evaluation committee. A cadre of consultations has been trained by HAB to provide outcomes evaluation; contact your Project Officer for information about these consultants. (For additional guidance on using consultants to assist in evaluation, see *Choosing and Using an External Evaluator*, HIV/AIDS Evaluation Monograph Series, Report #1, in the Resources and References section.)

Once you have answered these questions, you are ready to begin planning your evaluation effort.



### ***5. Prepare an evaluation plan and timeline.***

The purpose of this step is to develop an agreed-upon evaluation plan and timeline, including assignment of responsibilities for all the tasks and activities.

To develop your evaluation plan, you need to review the desired results of your evaluation effort and agree on an evaluation approach. CARE Act programs vary in how they approach outcomes evaluation. HAB does not recommend any specific model as most appropriate. You may want to use one model or combine approaches from several.

**United Way Logic Model:** An increasing number of CARE Act grantees report using a “logic model” developed by United Way of America. This model provides a clear, easy-to-understand, step-by-step process for outcomes evaluation. Particularly helpful aspects include:

- the distinction made between outputs (volume of services such as number of primary care examinations completed or number of case management plans prepared) and outcomes (the benefits or other results, positive or negative, for clients during or following program participation such as improved access to services or improved health status)
- the concept of initial, intermediate, and longer-term outcomes
- the logic-flow of charting a program’s inputs, activities, outputs, and outcomes

Because a number of grantees have found the logic model useful, this guide provides two figures that demonstrate how this model can be used in outcomes evaluation. Figure 2 shows how the United Way Logic Model categorizes the work of a service agency; examples provided are appropriate for an HIV/AIDS primary care provider. Figure 3 shows how to use the logic model approach to develop three levels of client-level outcomes related to primary care. Two types of primary care programs are used as examples: primary care services for adults with HIV and treatment to prevent perinatal transmission of HIV.

Figure 2: United Way Logic Model

Inputs	Activities	Outputs	Client-Level Outcomes	Program-Level Outcomes
<p><b>Resources</b> dedicated to or consumed by the program</p> <ul style="list-style-type: none"> <li>› money</li> <li>› staff</li> <li>› volunteers</li> <li>› equipment and supplies</li> <li>› medications</li> </ul> <p><b>Constraints</b> (if any)</p> <ul style="list-style-type: none"> <li>› laws</li> <li>› regulations</li> </ul>	<p><b>Services</b> - what the program does with inputs to fulfill its mission</p> <ul style="list-style-type: none"> <li>› outreach</li> <li>› medical examinations</li> <li>› tests</li> <li>› primary care physician visits</li> <li>› medications and therapy</li> <li>› specialty visits</li> <li>› other direct services</li> <li>› recordkeeping</li> <li>› administrative tasks</li> </ul>	<p><b>Products</b> of program activities</p> <ul style="list-style-type: none"> <li>› intake</li> <li>› primary care visits completed</li> <li>› clients served</li> <li>› tests completed</li> <li>› medications prescribed</li> <li>› treatments provided</li> <li>› referrals made</li> </ul>	<p><b>Benefits</b> to or changes in participants during or after involvement in program activities</p> <p><b>Initial:</b></p> <ul style="list-style-type: none"> <li>› new knowledge</li> <li>› increased skills</li> <li>› changed attitudes or values <i>(e.g., awareness of HIV perinatal treatment; HIV/AIDS diagnosis; knowledge of CD4 count and viral load)</i></li> </ul> <p><b>Intermediate:</b></p> <ul style="list-style-type: none"> <li>› modified behavior <i>(e.g., adherence to medication and improved clinical status as demonstrated by CD4 count and viral load)</i></li> </ul> <p><b>Longer-term:</b></p> <ul style="list-style-type: none"> <li>› improved health and social condition or status <i>(e.g., reduced HIV-related morbidity; slowed disease progression; completion of perinatal treatment; HIV-negative infants)</i></li> </ul>	<p><b>Program-level benefits</b> to participant group during or after program involvement</p> <p><b>Initial:</b></p> <ul style="list-style-type: none"> <li>› new knowledge</li> <li>› increased skills</li> <li>› changed attitudes or values <i>(e.g., number of women informed about available treatment; number of clients informed of their CD4 count and viral load)</i></li> </ul> <p><b>Intermediate:</b></p> <ul style="list-style-type: none"> <li>› modified behavior <i>(e.g., percent of primary care clients who adhere to medications, percent with improved clinical status as indicated by increased CD4 count, decreased viral load; percent of women contacted/educated who enter HIV perinatal treatment)</i></li> </ul> <p><b>Longer-term:</b></p> <ul style="list-style-type: none"> <li>› improved health and social condition or status <i>(e.g., reduced HIV-related morbidity rates; percent of clients with slowed disease progression; percent of women completing perinatal treatment; rate of perinatal transmission among their infants)</i></li> </ul>



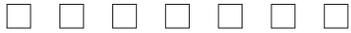
**Beginning outcomes evaluation of selected service categories:** CARE Act Title I and Title II programs often support a large number of service categories. It can be extremely challenging to develop outcomes and indicators and conduct outcomes evaluation of all these service categories at once. Many CARE Act grantees have found that the most practical way of initiating outcomes evaluation is to review the range of funded service categories and then divide them into two or three groups—then focus on one group at a time. This “segmented” approach allows the program to learn and test the process on one-third to one-half of its funded service categories, often a more manageable task than trying to address them all at once. For each group of service categories, the evaluation committee agrees on outcomes to be used for evaluation, develops outcome indicators, and agrees on data elements to be collected. A pilot test is then conducted, using these services and indicators. Once the process has been tested and refined based on one group of services, it is repeated with other service categories, using lessons learned from the earlier experience.

If you decide to use this segmented process, consider the following:

- Primary medical care is the centerpiece of CARE Act services. Moreover, national treatment guidelines providing standards of care already exist for primary medical care. Therefore, primary medical care should generally be included in the first group of service categories to be evaluated.
- Try to group service categories in some logical way. For example, you might want to focus first on primary care and other categories of health services plus those enabling services most directly linked to getting people into care. Or you might want to ensure that several of the service categories that receive the most CARE Act funding are included in the first group. If you feel that cooperation needed for outcomes evaluation will be particularly difficult to obtain with regard to certain services, put them in the second or third group, so you can address them after you have gained experience in obtaining support for the evaluation process.
- It is easiest to develop outcomes indicators for services in which there are clearly defined standards of care and units of service. If you are in the process of developing standards of care for certain service categories, begin outcomes evaluation of those services after the standards of care have been developed.
- Provider support and assistance are extremely important in developing evaluation procedures and outcomes indicators, and ensuring that needed data are obtained. In selecting service categories for your initial effort, include some categories where key providers are a part of the evaluation committee and supportive of the evaluation effort.

**Methods of obtaining data:** Evaluation data can be obtained in many different ways, depending on the systems in place in your area. Most often, you will begin by obtaining outcomes evaluation through one or more of the following methods:

- **Data from a client-level data system.** Where data systems already include client-based service and outcomes data—hopefully including some health status data—outcomes evaluation will focus on choosing the data to be aggregated, based on agreed-upon outcomes and indicators. Such systems may permit analyses of outcomes by population and service mix.



- **Program-level reporting by providers.** Where aggregate outcomes data are reported regularly by each provider, it is important to determine whether the same data elements are being reported for each service category where there are multiple providers. If data are consistent across providers and can be aggregated by service category, the evaluation will focus on data aggregation and analysis of existing data. If data elements vary by provider, providers may need to agree on some common data elements they will all report as a part of the outcomes evaluation effort.
- **Medical or case management records abstraction.** Providers may be asked to abstract data from all or a sample of client files, then aggregate and report these data. Sometimes, the grantee may want to hire professionals to carry out the records reviews and data abstraction. Arrangements will be needed to ensure client consent and confidentiality of data, including the use of unique identifiers.
- **Sampling methods.** In programs with large numbers of clients, outcomes evaluation may be carried out using data from a sample of clients. This may involve records abstraction from a sample of client records or periodic reporting of data from a sample of clients. Probability sampling can be used so that findings can be generalized to the entire client population.
- **Client-reported quality of life data.** Client-reported clinical data are often unreliable. However, there are validated instruments that can be used to obtain self-reports of health status, mental health status, ability to perform activities of daily living, and other quality of life information. Service providers, particularly case management programs, sometimes use such instruments to assess client outcomes. These instruments are sometimes used at intake and then re-administered at regular intervals such as every six months. Sometimes similar measures are used in special client surveys; some programs use surveys designed to meet both evaluation and needs assessment purposes.

#### Outline for an Evaluation Plan

1. Overview
2. List of Evaluation Phases
3. Outcomes Evaluation Chart of Outcomes, and for each outcome:
  - *Indicators*
  - *Data Elements*
  - *Sources of Data*
  - *Methods for Obtaining Data*
4. Work Plan Chart of Tasks, and for each task:
  - *Individual or group responsible*
  - *Starting and completion date*
  - *Product or result*

Prepare the evaluation plan, including:

- **Evaluation phases**, which might include a segmented process using groups of service categories, or simply stages including the various steps in planning, agreement on outcome indicators and data elements, data collection and/or reporting, analysis, and refinement of the evaluation process.
- **Methods for obtaining outcomes data for each agreed-upon outcome measure.** This might include a combination of provider-level reporting, records abstraction, sampling methods, client-reported quality of life data, and special studies, or might require only one method such as obtaining data from a client-level data system.
- **Tasks** to be completed, specified in detail and in chronological order.
- **Responsibilities** of the grantee, planning body, committee, providers, consultants, etc., for each task.
- **Timeline** for carrying out the first outcomes evaluation cycle—including development of outcomes indicators, testing of data collection and reporting, use of results in planning and decision making, and refinement of the process based on experience. You will probably need at least 6-8 months to test the evaluation process with the first group of service categories, and about 18 months to complete the initial outcomes evaluation. It may take 2-3 years to complete the process with all service categories, including establishing an ongoing system for outcomes evaluation.

## 6. Agree on outcomes and indicators to be used.

Identify and agree on the specific outcomes and indicators to be used in your initial evaluation effort. Include outcomes and indicators for each of the service categories that you have selected for inclusion in the initial evaluation effort. Be sure to consider the following types of outcomes and indicators:

### Remember:

**Desired outcomes** are the results for clients you choose to use in evaluating your program—such as slowing or prevention of disease progression among primary care clients.

**Indicators** are the observable, measurable sets of data you will use to track your program's success in reaching the desired outcomes—such as improved or maintained CD4 counts or viral loads for clients, as measured over a specific time period.

**Clinical or other health status outcomes:** Since CARE Act services are based on a medical model, it is important to consider how CARE Act services contribute to positive health outcomes for clients. Primary care providers can measure this directly, while providers of supportive or enabling services rarely have the ability to obtain clinical data. Where primary care providers



receive funding from several CARE Act titles, cooperation with outcomes evaluation efforts is likely to be greatest where a set of clinical outcomes and indicators can be agreed upon and used across titles. Figure 4 provides a set of suggested primary care outcomes and indicators. Quality of life measures also provide useful information on client-reported health status. A number of quality of life measures have been validated with AIDS clients, as described in the References and Resources section.

**Linkages to primary care:** There is wide agreement that outcomes for all service categories should include some evidence of linkages to primary care. Usually, these measures address access to primary care—helping clients overcome barriers and assisting them to find and/or to maintain a regular source of primary care. Data might include the number of clients entering primary care who were not previously in care, percentage of missed appointments, number of clients who receive regular primary care, and reported adherence to medications. Measures should be appropriate to the service category; a case manager might document referral completions that result in clients entering care, while transportation services may focus on whether appointments are kept. Because of the importance of the entire continuum of care, it is also important to determine how each service leads to other outcomes that contribute to positive health outcomes, such as ensuring that basic survival needs such as housing and food are met, etc. In selecting outcomes indicators, be sure to consult with providers to see what outcomes indicators they are already using, provide some choice about indicators, and agree on some common indicators (especially access to and retention in primary care). Figure 5 provides a set of suggested case management outcomes and indicators.

In developing outcomes and indicators:

- **Decide whether you prefer “broad” or “narrow” outcomes.** You may prefer to state a larger number of narrow outcomes (*e.g.*, increase average CD4 counts, reduce average viral loads), or to identify a smaller number of broader outcomes that can be measured through the use of several different indicators (*e.g.*, reduce AIDS-related morbidity, improve client-reported quality of life). While the broader outcomes may seem more meaningful, they require more complicated analyses.
- **Include quality of care indicators.** In addition to clinical outcomes, it is useful to include outcomes based on standards of care measures (*e.g.*, evidence from client charts that appropriate treatment was offered at specific stages of the disease, completed referrals to needed services). Meeting standards of care represents a way of achieving outcomes, because studies have demonstrated a link between those standards and positive client health and quality of life outcomes. Figures 4 and 5 provide several examples of indicators based on quality of care.
- **Include indicators involving linkages to primary care.** Evidence that an enabling or supportive service helps to link clients with primary care is a legitimate outcomes indicator for the same reasons as quality of care indicators. Studies have shown that if people living with HIV or AIDS enter and remain in primary care, they are much more likely to receive needed medications, which in turn contributes to positive clinical outcomes.

**Figure 4: Recommended Core Outcomes, Indicators, Data Elements, and Data Sources for Primary Care Programs**

Client and Program-Level Outcomes	Indicators	Data Elements and Sources
<b>Biological Markers</b>		
<p>Slowing/prevention of disease progression</p> <p><b>Program-level outcome:</b> Disease progression among CARE Act clients is slowed or prevented over time</p>	<p>Improved or maintained average CD4 counts, viral loads for clients as measured over a specified time period</p>	<p>Test results needed to calculate changes in CD4 counts, viral loads for individual clients over a specified time period</p> <p>Source: client medical records (or, where possible, from case management records where clients receive primary care through non-CARE Act-funded providers)</p>
<b>Morbidity and Mortality Outcomes and Indicators</b>		
<p>Reduced incidence of AIDS-defining opportunistic conditions</p> <p><b>Program-level outcome:</b> Incidence of opportunistic conditions among CARE Act clients decreases over time</p>	<p>Change in frequency of occurrence of AIDS-defining opportunistic conditions among clients over a specified time period</p>	<p>Number of cases of AIDS-defining opportunistic conditions, incidence of preventable conditions (<i>e.g.</i>, PCP, MAC) among individual CARE Act clients over a specified period</p> <p>Source: client medical records</p>
<p>Reduced number or rate of AIDS-related emergency room visits</p> <p><b>Program-level outcome:</b> Rates of emergency room visits among clients decrease over time</p>	<p>Change in the rate of AIDS-related emergency room visits among clients over a specified period of time</p>	<p>Number of clients who make non-injury-related emergency room visits and the total number of non-injury-related emergency room visits made by these clients during a specified time period</p> <p>Source: client medical records</p>
<p>Reduced number or rate AIDS-related hospitalizations</p> <p><b>Program-level outcome:</b> Hospitalization rates among clients decrease over time</p>	<p>Change in the rate of AIDS-related hospitalizations among clients over a specified period of time</p>	<p>Number of clients having AIDS-related hospitalizations and the total number and days of AIDS-related hospitalizations for these clients during a specified time period</p> <p>Source: client medical records</p>



Figure 4 Continued: Recommended Core Outcomes, Indicators, Data Elements, and Data Sources for Primary Care Programs

Client and Program-Level Outcomes	Indicators	Data Elements and Sources
<p>Reduced mortality rates</p> <p><b>Program-level outcome:</b> Mortality rates among clients served by Ryan White CARE Act providers are reduced over time</p>	<p>Change in the percent of clients dying from AIDS-related conditions over a specified time period</p>	<p>Number and percent of deaths from AIDS-related conditions during specified time periods</p> <p>Source: client medical or case management records</p>
<p>Reduced rates of perinatal transmission</p> <p><b>Program-level outcome:</b> Rates of perinatal transmission among pregnant clients served by CARE Act providers decrease over time</p>	<p>Change in percent of infants born to HIV-positive mothers who are HIV-infected 3-6 months after birth over a specified time period</p>	<p>Number and percent of pregnant HIV-positive women entering and completing perinatal treatment regimen; number and percent of infants born to HIV-positive women who enter and complete infant perinatal treatment regimen; number and percent of infants who are HIV-infected 3-6 months after birth; requires data on total number of women entering the program and total number of infants born to such women</p> <p>Source: mother and infant medical records</p>
<b>Quality of Care Standards and Indicators</b>		
<p>HIV-related treatment guidelines met</p> <p><b>Program-level outcome:</b> Primary care services meet HIV-related treatment standards for adults/adolescents, for pediatric cases, for pregnant women</p>	<p>Change in percent of primary care clients for whom HIV-related treatment standards are being met</p>	<p>Number and percent of clients whose flowcharts reflect types, sequence, and frequency of primary care services provided — examinations, tests, treatment regimens—that meet treatment guidelines during specified time period</p> <p>Source: client medical records</p>

**Figure 5: Suggested Non-Clinical Outcomes, Indicators, Data Elements, and Data Sources and Methods for Case Management Programs**

Client and Program-Level Outcomes	Indicators	Data Elements and Sources
<b>Service Outcomes and Indicators</b>		
<p>Increased number of clients accessing primary health care services</p> <p><b>Program-level outcome:</b> Number of clients accessing primary health care services increases over time</p>	<p>Change in the number of clients who accessed primary health care programs after a specified time period</p>	<p>Number and percent of HIV-positive clients who did not have primary health care and accessed primary health care during specified time periods</p> <p>Sources: (1) follow-up communications with individual clients and/or providers or (2) follow-up communications with a sample number of clients or their providers</p>
<p>Increased number of clients maintaining their primary health care services</p> <p><b>Program-level outcomes:</b> Number of clients maintaining their primary health care services increases over time</p> <p>Change in the number of clients who maintained their primary</p>	<p>health care services after a specified time period</p>	<p>Number and percent of HIV-positive clients who maintained their primary health care services during specified time periods</p> <p>Sources: (1) follow-up communications with individual clients and/or providers or (2) follow-up communications with a sample number of clients or their medical providers</p>
<p>Change in the number of clients who obtained support services</p>	<p>Number and percent of HIV-positive clients who obtain support services during specified time periods</p> <p>Sources: Sources: (1) follow-up communications with individual clients and/or providers or (2) follow-up communications with a sample number of clients or their providers</p>	<p>Increased number of clients accessing support services that facilitate their access to primary medical care</p> <p><b>Program-level outcomes:</b> Number of clients accessing support services that facilitate their access to primary medical care increases over time</p>

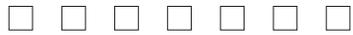


Figure 5 Continued: Suggested Non-Clinical Outcomes, Indicators, Data Elements, and Data Sources and Methods for Case Management Programs

Client and Program-Level Outcomes	Indicators	Data Elements and Sources
<p>Increased number of clients completing service plan objectives</p> <p><b>Program-level outcomes:</b> Number of clients completing service plans objectives increases over time</p>	<p>Change in the number of clients who successfully complete the objectives contracted by client and case manager in service plans after a specified time period</p>	<p>Number and percent of HIV-positive clients who completed service plan objectives and number and percent of objectives met by clients</p> <p>Sources: (1) follow-up communications with individual clients and/or other providers or (2) follow-up communications with a sample number of clients or their other providers</p>
<p>Increased number of clients completing substance abuse treatment services</p> <p><b>Program-level outcomes:</b> Number of clients completing substance abuse treatment services increases over time</p>	<p>Change in the number of clients who enter substance abuse treatment services and complete them after a specified time period</p>	<p>Number and percent of clients who enter substance abuse treatment services and complete the program</p> <p>Sources: (1) follow-up communications with individual clients and/or their provider or (2) follow-up communications with a sample number of clients or their providers</p>
<p>Increased number of clients adhering to HIV medication regime</p> <p><b>Program-level outcomes:</b> Number of clients adhering to HIV medication regime increases over time</p>	<p>Change in the number of clients who adhere to their HIV medication regime after a specified time period</p>	<p>Number and percent of HIV-positive clients who adhere to their HIV medication regimen</p> <p>Sources: (1) follow-up communications with individual clients and/or their medical providers; (2) follow-up communications with a sample number of clients or their medical provider; (3) client medical records</p>

## Outcomes Evaluation Technical Assistance Guide



Figure 5 Continued: Suggested Non-Clinical Outcomes, Indicators, Data Elements, and Data Sources and Methods for Case Management Programs

Client and Program-Level Outcomes	Indicators	Data Elements and Sources
<b>Psychosocial Outcomes and Indicators</b>		
<p>Quality of life is improved or maintained</p> <p><b>Program-level outcomes:</b> Quality of life of CARE Act clients is improved or maintained over time.</p>	<p>Improved or maintained human functional status as measured over a specified time period.</p>	<p>Initial measurement of human functional status (taken at the time of intake using quality of life instruments) is compared to measures taken over specified periods of time (e.g. every six months)</p> <p>Sources: Standardized quality of life instruments and case management records</p>
<b>Quality of Care Standards and Indicators</b>		
<p>Case management care standards are met</p> <p><b>Program-level outcome:</b> Case management services meet the program's case management standards for clients</p>	<p>Change in percent of case management clients for whom HIV-related service needs are being met</p>	<p>Number and percent of clients whose service plans show attainment of requested services</p> <p>Sources: (1) follow-up communications with individual clients and/or other providers; or (2) follow-up communications with a sample number of clients or their other providers</p>
<b>Biological Markers*</b>		
<p>Slowing/prevention of disease progression</p> <p><b>Program-level outcome:</b> Disease progression among CARE Act clients is slowed or prevented over time</p>	<p>Improved or maintained average CD4 counts, viral loads for clients as measured over a specified time period</p>	<p>Test results needed to calculate changes in CD4 counts, viral load for individual clients over a specified time period</p> <p>Sources: (1) follow-up communications with individual clients and/or medical providers; (2) follow-up communications with a sample number of clients or their medical providers; (3) client medical records</p>

\* Use only when clinical data from primary care providers are not available.



- **Include initial, intermediate, and longer-term outcomes.** Recognize that initial and intermediate outcomes indicators are available sooner and are often easier to collect. Initial outcomes may seem more like outputs. To become comfortable with the distinction, focus on changes in the client, but recognize the need for flexibility. Intermediate and longer-term measures provide more information about the effects of services on client health status, such as slowed disease progression and reduced mortality rates. Attached is a sample chart demonstrating how to specify three levels of outcomes, plus a blank chart for your use (See Figures 6 and 7).

Figure 6: Identifying Three Levels of Outcomes

Program	Initial	Intermediate	Longer-Term
<b>Program: HIV Perinatal Transmission Therapy for Pregnant Women</b>	<p>Pregnant women who are HIV-positive are aware of the existence of the program.</p> <p>Pregnant women who are HIV-positive are knowledgeable about the risk of perinatal transmission.</p> <p>Pregnant women who are HIV-positive understand that perinatal treatment can significantly reduce the probability of perinatal transmission of HIV to their infants.</p>	<p>Pregnant women who are HIV+ enter treatment.</p> <p>Women in the program take antiretrovirals as prescribed.</p>	<p>Pregnant women complete the HIV perinatal transmission treatment regimen.</p> <p>Infants of mothers who complete the treatment regimen are HIV-negative.</p>
<b>Program: Primary Care for Adults/ Adolescents with HIV</b>	<p>Specific targeted populations of adults with HIV enter primary care.</p> <p>Adults with HIV receive appropriate diagnostic tests as specified in the HIV-related treatment guidelines.</p> <p>Adults become aware of their health status, including their CD4 count and viral load.</p>	<p>Adult patients receive antiretroviral therapy where appropriate.</p> <p>Adult patients adhere to prescribed therapies.</p> <p>Adults receiving appropriate therapies have improved or stabilized CD4 counts and viral loads.</p> <p>Adults receiving appropriate therapies have reduced incidence of opportunistic conditions.</p>	<p>Adult patients report reduced non-injury-related emergency room visits.</p> <p>Adult patients report reduced AIDS-related hospitalizations.</p> <p>Adult patients have reduced or stabilized mortality rates.</p>



Figure 6 Continued: Identifying Three levels of Outcomes

Program	Initial	Intermediate	Longer-Term
<b>Program: Case Management for Adults/Adolescents with HIV</b>	<p>Specific targeted populations of adults with HIV enter case management service</p> <p>Adults with HIV receive intake, psychosocial assessment, and needs assessment.</p> <p>Adults understand that primary health care and support services can increase their health status.</p>	<p>Adult patients receive referrals to primary health care and support services.</p> <p>Adult clients complete referrals to primary health care and support services.</p> <p>Adult clients complete goals documented on client service plan.</p>	<p>Adult clients maintain their primary health care and support services.</p> <p>Adult clients research available services on their own and advocate for themselves.</p> <p>Adult clients report improved functional status.</p>

**Figure 7: Format for Identifying Three Levels of Outcomes**

Program	Initial	Intermediate	Longer-Term
Program:			
Program:			



Figure 7 Continued: Format for Identifying Three levels of Outcomes

Program	Initial	Intermediate	Longer-Term
Program:			

## 7. Plan methods of obtaining and reporting data.

Agree on and decide how to implement specific methods and procedures for obtaining the new data or reporting existing data required for outcomes evaluation.

In developing a work plan (Step 5), the evaluation committee will have outlined methods to be used to obtain needed data. Now that outcomes and indicators have been selected, detailed plans can be made for obtaining needed data elements. A number of factors should be considered:

- **Contract requirements regarding provider data reporting.** Some grantees require providers to collect, aggregate, and report aggregate data on client outcomes. It is important to understand existing data systems and required reporting, the extent to which requirements are being met, and the quality and completeness of the data.
- **Whether needed data are already being collected and if so, how these data can be accessed.** For example, if the program has a client-level data system that includes outcomes data, this is usually the easiest and most useful source of outcomes data. Such systems permit comparisons based on client characteristics, types of services received, and other factors. However, most States and EMAs do not have a client-level data system. Some outcomes data such as clinical data on client health status are likely to be available in client medical records and perhaps in medical case management records. Quality of life data, as well as other outcomes data such as information about completed referrals providing access to care, may already be routinely collected and maintained by case managers. If needed data are already collected, and if data reporting is required, access may be relatively simple. Even if reporting has not been required, providers may be able to aggregate and report data they already collect. However, sometimes it is difficult to gain access to existing data. For example, primary care providers are likely to have the most complete clinical data on clients, but if the CARE Act is not a major source of funds for primary care, these providers may not be willing to report such data; confidentiality issues may also be a major factor.
- **Data limitations.** A major limitation is likely to be the lack of a client-level data system or a unique client identifier. If there is no way to determine which clients received what mix of services, then there will be limits on the extent to which client outcomes can be linked to supportive or enabling services, and it will be extremely difficult to look at the service system. Sometimes other limitations exist, such as differences in the way program and outcomes data are documented and reported. If there are no shared standards of care for the State or EMA, it will be difficult to determine whether a specified standard of care that can be linked to outcomes has been met.
- **What data need to be collected for the first time.** Some data may exist in medical, case management, or other records, and need to be reported. Other data may not be collected at all. For example, there may be no information about which primary care clients receive transportation assistance. Such data can be collected with provider agreement, but this will require adding items to client records and ensuring that someone is responsible for collecting and reporting such data.



- **Costs and other resource requirements for accessing available data or collecting new data.** Carefully consider the effort required to implement your outcomes data system, including the efforts required of providers. If your providers do not use the same client flow charts or other shared recordkeeping systems, you will need to agree on specific data elements and a consistent format and procedure for collecting and reporting these clinical data. The frequency of reporting or records review and abstraction will need to be determined. Providers need not use the same forms, but should be recording the same data elements. If flow charts or other medical records forms are to be used to track compliance with HIV-related treatment guidelines, different flow charts will be needed for adults/adolescents, pediatric cases, and pregnant women to reflect specific treatment standards. A phase-in period will be required to test and refine the methods to be used in periodic medical records abstraction or aggregation and reporting of data.
- **Alternatives to 100% reporting.** It may be extremely expensive to aggregate and report data on all clients, especially when there are numerous providers and clients and no client-level data base or regular provider reporting of needed data. Other data reporting and/or collection methods may be less costly. For example, providers might be asked to report data from a sample of client files, to collect data on a sample of clients for a specified period of time, or to permit client records abstraction by a trained professional with appropriate consent and confidentiality arrangements. The time and other costs of alternative approaches needs to be determined.
- **Ensuring the data relate to the planned analyses.** Be sure you have already planned your analyses when you agree on plans for data collection and reporting. Otherwise, you may find that you do not have the client demographics or other supporting data needed for meaningful evaluation. For example, be sure you have made provisions to collect and aggregate data both overall and by population group (including the underserved populations identified in your service area), geographic area, and, where possible, level and mix of services received.

Based on these considerations, the evaluation committee can agree on the data collection and reporting methods to be used for all needed data elements.

You will probably want to report data for a specified time period, such as a calendar quarter. This provides a manageable amount of data and makes possible comparisons of client outcomes over time.

### **8. Test your process.**

Now you are ready to test the outcomes evaluation process you have developed. This may include any or all of the following:

- have providers report data using the selected indicators, data elements, forms, process, and timeline
- aggregate data already being generated through an existing client-level database
- carry out medical records extraction

**Outcomes Evaluation Technical Assistance Guide**

- conduct special studies

Once you have obtained the data, you have two equally important responsibilities:

- Review the data for quality and completeness.
- Assess how the process worked in terms of data availability, access, and time and costs required.

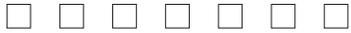
Several approaches and tools can help you manage the testing process:

- Several weeks into the data collection and reporting process, bring together participating providers to identify and resolve problems that have arisen.
- At the end of the process, once again bring together everyone who participated in the outcomes evaluation process to find out how much time and effort were required, identify difficulties in providing needed data, and determine whether the process needs refinement.
- If you hired professionals to extract data from existing medical or other client records, debrief to find out the extent to which needed data were included in the client records and in what format, and identify limitations or problems in extracting the data. Determine whether access to needed data was denied, and if so, for what reasons.

To facilitate this process, consider developing and using Reaction Forms through which providers and professional data gatherers (such as those doing medical records extraction) can report their experiences in collecting, aggregating, extracting, and/or reporting the data. Forms should address time required, missing data, problems with data formats, issues of data access, and other aspects of the experience. The box provides sample questions.

**A Reaction Form Might Ask for Information About:**

- What data were you collecting or reporting?
- Were you able to obtain/report the expected data? Were any data missing? If so, what?
- How much time did it take to collect/report the data? Was this more/less/about the same amount of time expected?
- Was the reporting format appropriate? If not, how should it be changed?
- Were the data requirements appropriate? If not, how should they be changed?
- Did you have appropriate consent forms for clients, if needed? If not, what is needed?
- Did you have appropriate confidentiality protections? If not, what needs to be changed?
- Overall, what went well?
- What did not go well?
- Identify specific actions needed to improve the process for ongoing use.



## 9. Analyze and report findings.

Tabulate, analyze, and report your outcomes data in a format useful to the planning body, grantee, and providers.

Outcomes evaluation reports should be designed for easy use by those responsible for planning, setting priorities, and allocating resources. Data should provide an understanding of both overall client outcomes and the extent to which these outcomes vary by population and other factors (e.g., race/ethnicity, gender, age, location).

Carry out additional levels and types of analysis if appropriate data and resources are available. For example, if a client-level database, unique client identifier, or special study makes it feasible:

- Compare outcomes for clients who have and clients who have not received a particular type of service.
- Compare services received by specific populations and link this information to differences in outcomes

At a minimum, your analysis should:

- **Specifically address your stated outcomes.** For example, if one of your outcomes is that clients receiving appropriate therapies have improved or stabilized CD4 counts, then you will want to summarize the data about CD4 counts for these clients and see to what extent this outcome was achieved.
- **Use accepted statistical methods.** Get help as needed to ensure that the data are aggregated and analyzed using widely accepted statistical procedures. Staff or consultant analysts should be asked to document and explain analytic procedures.
- **Identify missing data or data limitations.** If missing data meant limited information was reported in relation to some indicators, be sure to clearly state those limitations. If the data are so limited that the results are not meaningful, document the problems and then do not include these data as evaluation findings.
- **Present findings visually wherever possible.** Use bar charts, line charts showing trends or changes, or other easy to read charts rather than just presenting numbers visually or using complex tables.
- **Provide baseline data that can be compared to future outcomes data to determine changes and trends.** Baseline data (the evaluation data obtained during your first reporting period) will not only provide useful information about program outcomes, but also provide information that can be compared with future findings.

**10. Use results.**

The purpose of this step is to ensure that findings from the evaluation are used in program decision making. Providers and planning bodies should be able to use evaluation findings in determining the effectiveness of services, deciding what actions might be needed to improve services, and—for the planning body—to set priorities and allocate resources for services.

At a minimum, grantees are expected to:

- Provide planning bodies with core outcomes evaluation data in consistent and clear formats each year, in time for review and use in priority setting and other decision making.
- Ensure that planning bodies use outcomes data in planning and priority setting.

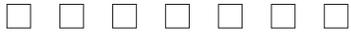
Evaluation reports should be designed and results presented so they meet the needs of users—planning bodies and providers. Use of results is likely to be enhanced if:

- the group overseeing the evaluation consults with the group that will be doing the priority setting and other decision making to determine what information is needed, by what date, and in what format
- evaluation results are summarized and/or charts developed so that findings are clear and understandable to people who do not have a research or evaluation background
- representatives from the evaluation group make themselves available along with staff or consultants for an oral presentation of evaluation results, including any limitations the decision makers need to understand before they use the data for decision making
- providers have an opportunity to learn evaluation results related to their service categories and to share them with staff, volunteers, and board members (special presentations for providers, overall and by service category, might be offered by the group responsible for the evaluation)
- evaluation efforts are linked to needs assessment and comprehensive planning, so that client surveys conducted for needs assessment include evaluation questions that complement information available from providers, and evaluation findings are used to help focus needs assessment questions.

**11. Refine and institutionalize the outcomes evaluation system and process.**

The purpose of this step is to review the entire outcomes evaluation process as tested and refine it for ongoing use within the CARE Act system. If you used a segmented approach (*i.e.*, developed outcomes indicators for a subset of service categories), you will want to make these refinements before you develop indicators for additional service categories.

Based on the testing period and your assessment of the experience and results, you can decide what changes are needed in:



- outcomes and indicators
- methods of data collection and aggregation
- reporting forms and procedures
- responsibilities for data collection and reporting
- data aggregation
- other aspects of the evaluation process

You can use this information to “institutionalize” the system so that outcomes evaluation data are regularly reported, analyzed, compared with results from prior periods, and used for planning and decision making. Give special attention to the following:

**Ensuring reasonable time and resource demands.** Carefully consider the ongoing time and effort required to collect, maintain, and aggregate desired client-level data. Unless you have a client-level data system, even an ongoing, well established system will require regular data abstraction from medical or other records, use of special studies, and/or new provider-based reporting systems. In planning your approach, consider not just development time and efforts but also the resources required to maintain the data collection, records abstraction, and/or reporting systems. For example, you might plan for regular use of staff or consultants to carry out medical records abstraction for a sample of providers and clients using standardized forms (See the References and Resources section for how to obtain a sample medical records abstraction form). This will reduce the burden on providers; they will need to collect outcomes data, but aggregating and reporting data will be done by others.

**Contract requirements.** The evaluation process may help grantees to identify the specific requirements that should be incorporated into future contracts with providers. This might include data collection, aggregation, and reporting requirements, as well as requirements for access to client records with appropriate consent form and confidentiality requirements. HAB recommends that every grantee or other designated lead agency:

- Include requirements in provider contracts that they collect, maintain, and report outcomes-related data.
- Include as standard language in provider contracts a form permitting reviews of client records by either grantee representatives or a professional consultant or review organization under contract to the grantee, with appropriate confidentiality protections and client consent.
- Conduct contract monitoring sufficient to ensure compliance with stated provider requirements including collection and reporting of outcomes data (e.g., patient record audits).

**Addressing confidentiality and consent issues.** Collecting data for outcomes evaluation may involve abstracting client medical or case management records and/or obtaining client consent to share information with other service providers. The Department of Health and Human Services

and many States and local jurisdictions have laws and policies protecting client privacy and ensuring the confidentiality of client data. However, it is possible to obtain needed information for evaluation while protecting client confidentiality and meeting Federal and other requirements. The box summarizes issues that need to be considered. Grantees and providers need to ensure that appropriate requirements are in place and are met by evaluation activities.

### Confidentiality and Consent Issues

The following information first addresses confidentiality and consent issues from a substance abuse counselor or case manager perspective and then indicates requirements for obtaining client consent. The material below and additional information on these issues are available in *Substance Abuse Treatment for Persons With HIV/AIDS*, Treatment Improvement Protocol (TIP) Series 37, Center for Substance Abuse Treatment, Substance Abuse and Mental Health Services Administration.

#### Confidentiality

“Confidentiality raises issues of consent, disclosure, and release of information. Because linkages and referrals for needed resources are part of the client’s overall treatment plan, the client should not be surprised that other treatment providers will be contacted and that releases of information will be needed. The client might have fears about disclosure—talking about this fear with the client is important. The counselor and client must develop a partnership that places the client in an active, empowered position so that she understands the value of connecting with other agencies. Eligibility for services at another agency may be based on need, and the agency may inquire about the client’s condition to ascertain whether it pertains to the agency’s services.”

#### Consent and Disclosure

“The counselor should also understand the difference between the terms ‘informed consent’ and ‘consent.’ ‘Informed consent’ refers to a client’s consent to begin treatment after s/he understands his/her treatment options and the advantages and disadvantages of each option. ‘Consent’ refers to the client’s consent to allow confidential information to be disclosed as needed.” (Chapter 5)

“The Federal regulations regarding consent are strict, somewhat unusual, and must be carefully followed....A general medical release form...is not acceptable.”

“One exception to the general rule prohibiting disclosure without a client’s consent permits programs under certain conditions to disclose information to auditors and evaluators. DHHS has written two opinion letters that approve the use of the audit and evaluation exception to report HIV/AIDS-related information to public health authorities. (Information about consent forms and how to locate the two DHHS letters is provided in Chapter 9.)



**Program-level objectives or targets:** Ideally, each outcome needs a measurable program-level objective or target of performance. After you have gained some experience with measuring client-level outcomes, you may be ready to add such program-level objectives or targets—for example, not just “to reduce AIDS-related mortality” but “to reduce AIDS-related mortality by X% among population Y.” If your outcome involves completion of antiretroviral therapy by pregnant women, your target might be to have 85% of women who begin treatment complete prescribed antiretroviral therapy. It is usually very difficult to decide what level of performance you should try to attain during the first year of outcomes measurement, but once you have some results that provide baseline data, you should be able to set obtainable standards for programs. To establish a challenging but achievable outcome target, get a year of experience in measuring outcomes at the individual client level, then aggregate the information to see program-level outcomes. If the program does not collect client-level data and you are not using records abstraction, review program-level outcomes data by service category. Comparable information from other programs, national data, or Public Health Service standards can help you determine or adjust your targets.

**Summary report formats.** Programs have found that clear, easy-to-understand outcomes data summary forms encourage support for the evaluation process and use of data by planners and providers. Think carefully about how you want providers to report data, and also about how aggregated data should be reported back to them. Some programs have developed reporting formats that chart data over time, so changes and trends are easily identified. For example, if data are reported every six months, outcome indicators such as the percentage of missed primary care appointments, mean changes in CD4 counts, or percent of pregnant women reporting completion of perinatal treatment can be charted every six months and trends shown as part of a summary report on outcomes data.

**Regular review and refinement of the outcomes evaluation process.** Many programs will develop their outcomes evaluation over a period of several years, using their experience with a selected group of service categories to repeat the process with additional service categories. Experience will lead to many ideas for improving the outcomes evaluation system, from refining outcomes and indicators to considering major changes such as adoption of a unique client identifier and/or client-level data system. Building in regular review and refinement of the outcomes evaluation process, perhaps annually, helps ensure that lessons are shared and applied, and that the program’s capacity to plan and conduct outcomes evaluation is continuously increased.

## References and Resources

Following are some references and resources that may help in developing and implementing outcomes evaluation.

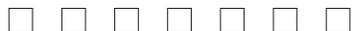
Unless otherwise indicated, referenced HAB materials are available through the HRSA Information Center, telephone 888-ASK-HRSA, TTY 1-877-4TY-HRSA, website <http://www.ask.hrsa.gov>. Many of these documents can also be downloaded from the HRSA website: <http://www.hab.hrsa.gov>.

### HAB Guides on Evaluation

*Outcomes Evaluation Technical Assistance Guide: Primary Medical Care Outcomes*, developed for the HIV/AIDS Bureau, Division of Service Systems, 1999. Provides sample outcomes and indicators for primary medical care and clarifies HAB expectations regarding outcomes evaluation of services funded under Title I and Title II of the CARE Act.

**HIV/AIDS Evaluation Monograph Series**, developed under the coordination of the Office of Science and Epidemiology:

- *Choosing and Using an External Evaluator*, Report #1, September 1997. Describes a seven-step process for defining the purpose and scope of an evaluation, selecting an external evaluator, and working with the evaluator to plan and implement a methodologically sound study. (Adapted by Community Health Solutions, Inc., from a report prepared by IOX Assessment Associates for the CDC, Division of Adolescent and School Health.)
- *Using Data to Assess HIV/AIDS Service Needs: A Guide for Ryan White CARE Act Planning Groups*, Report #2, August 1998. Designed for use in training community members of CARE Act planning bodies, including PLWH, on basic statistics terms and methods and needs assessment, so they can participate actively in activities involving the use of statistics and research reports. Includes self-tests. (Adapted from a manual written by Mosaica for the National Council of La Raza, with funding from the Centers for Disease Control and Prevention.)

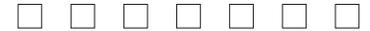


- *Cost and Performance-Based Contracting: A Guide for Ryan White CARE Act Grantees*, Report #3, October 1998. Designed to introduce grantees and planning bodies to the concepts of cost and outcome effectiveness and the ways in which cost and performance indicators can be incorporated into priority setting, resource allocation, and procurement processes. Includes useful definitions as well as guidance on developing performance-based provider contracts and monitoring service providers to identify fiscal and performance problems and facilitate quality improvement.
- *A Practical Guide to Evaluation and Evaluation Terms for Ryan White CARE Act Grantees*, Report #4, September 1999. Designed to help CARE Act grantees become familiar with the language of evaluation. Defines basic terms associated with the planning, implementation, and analysis of evaluation studies: Part I defines evaluation and explains how it differs from needs assessment, monitoring, research, and continuous quality improvement. Part 2 describes nine steps in evaluation design, implementation, and analysis and defines the terms associated with each step. Part 3 defines terms related to quality management and improvement. Includes an alphabetical index of terms.
- *An Approach to Evaluating HAART Utilization and Outcomes in CARE Act-Funded Clinics*, Report #5, June 2000. This report describes the approach used by two Title III-funded clinics to evaluate the therapeutic benefits and resource requirements of implementing highly active antiretroviral therapy (HAART). Study findings are presented, but the primary focus of the report is on the process of designing and conducting an outcomes evaluation, the problems encountered, and the “lessons learned.”
- *Delivering HIV Services to Vulnerable Populations: What Have We Learned?*, Report #6, October 2000. This report summarizes recent research on the accessibility, quality, and outcomes of health and support services provided to low-income and medically underserved populations with HIV/AIDS. The focus is on evaluation and research studies that have received financial support from the HIV/AIDS Bureau or Ryan White CARE Act grantees.

### HAB and HRSA Evaluation Materials and Aids

“Evaluation of Local HIV Service Delivery: Issues, Approaches & Strategies Under Title I, the Ryan White CARE Act,” report of a meeting sponsored by the Division of HIV Services and Office of Science and Epidemiology, May 1996.

**The Primary Care Assessment Tool (PCAT)**, an evaluation tool originally developed for Title III and updated in 1998 by a cross-title working group coordinated by the Primary Care Services Branch, Division of Community Based Programs, HIV/AIDS Bureau. Includes modules that focus on clinical services, administration, finance, and support services. Designed for use by a

**Outcomes Evaluation Technical Assistance Guide**

multidisciplinary team making a site visit to a primary care site funded through the CARE Act to assess whether it is meeting legal requirements, HIV-related treatment guidelines, grantee requirements, and other accepted quality standards. Can be downloaded from the HRSA website: <http://hab.hrsa.gov> click on Publications, then look under Quality Assurance/Improvement.

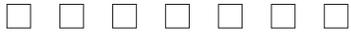
**Medical Records Abstraction Form and Instructions.** The Office of Science and Epidemiology has developed a form and instructions that can be used to abstract client demographic and medical data, including outcomes data, from medical records. “Impact of RWCA Title I Funding in Newly Funded EMAs: Medical Record Abstraction Form-Phase I” and “Instructions for Completing the Ryan White EMA Record Abstraction Form” are now available on the HIV/AIDS Bureau website: <http://hab.hrsa.gov>.

**RW CAREWare.** Includes the CAREWare software, manual, and data dictionary for Ryan White CARE Act grantees and providers. Available from Office of Science and Epidemiology, HRSA/HAB, Parklawn Building, Room 7-90, 5600 Fishers Lane, Rockville, MD 20857 or download from <http://hab.hrsa.gov/careware>.

**HIVQUAL Software System:** Several computerized systems have been developed to document and aggregate data on client services and outcomes. Among them is the HIVQUAL software system, now being tested in the Title III HIV-Qual Demonstration Project. This project collects information on several items identified as required outcomes data elements, including CD4 and viral load counts, and a number of data elements needed to assess whether treatment guidelines are being met. Many of these same outcomes data elements will be collected by Title IV grantees participating in a voluntary medical outcomes study. Available are the “HIVQUAL Manual Data Collection Sheet,” a chart showing application of basic algorithms (showing how questions and responses are interconnected within the system) and the sampling methodology for the demonstration project. The system provides a model for recording and abstracting medical data including outcomes data on persons with HIV/AIDS. To obtain information about HIVQUAL, visit the HRSA website or contact John Milberg at [jmilberg@hrsa.gov](mailto:jmilberg@hrsa.gov).

**Substance Abuse and Mental Health Administration Treatment Improvement Protocol**

Center for Substance Abuse Treatment, Substance Abuse and Mental Health Services Administration, *Substance Abuse Treatment for Persons With HIV/AIDS*, Treatment Improvement Protocol (TIP) Series 37. Includes extensive information on confidentiality and client consent. Can be downloaded from <http://treatment.org/externals/tips.html>.



## Materials to Assist Grantees in Collecting Client-Reported Quality of Life Data

Following are quality of life tools and supporting information:

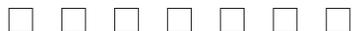
- **Medical Outcomes Trust Instruments:** The following instruments from the Medical Outcomes Trust can be used to obtain client-reported health-related quality of life data. Copies and permission to use these questionnaires can be obtained from the Medical Outcomes Trust, 20 Park Plaza, Suite 1014, Boston, MA 02116, telephone (617) 426-4046; website <http://www.outcomes-trust.org>.
  - ▼ “Health and Opinions Questionnaire.” Available are three client-reported health status instruments that have been tested and found to be reliable and valid. The SF-12 consists of 12 items addressing client views about their own status and the health care they receive. Also available are the SF-20 and the SF-36.
  - ▼ “MOS-HIV Health Survey.” The questionnaire adapted from the Medical Outcomes Study (MOS) for persons diagnosed with HIV/AIDS assesses client-reported health-related quality of life. See Wu, et al., below, for information about the uses and validation of this study.
  - ▼ “Quality of Well-being Scale.” The instrument measures well-being in individuals based on the social preferences that society generally associates with an individual’s level of functioning at a specific point in time, the scale rates: mobility, physical activity, and social activity, and rates symptomatic complaints that might inhibit function.
- **Karnofsky Performance Scale.** An assessment tool used to assist clinicians and caretakers to measure the patient’s ability to carry out activities of daily living. Client’s ability to carry out activities of daily living is assessed by provider and documented in client records at each visit. The scale is available through the Southeast AIDS Training and Education Center as part of the manual: *Clinical Management of the HIV-infected Adult: A Manual for Mid-level Clinicians*. The manual and scale can be accessed online at <http://www.seatec.emory.edu/default/htm> or ordered through the Southeast AIDS Training and Education Center, Emory University School of Medicine, Department of Family and Preventive Medicine, 735 Gatewood Road NE, Atlanta, GA 30322-4950, e-mail: [seatec@emory.edu](mailto:seatec@emory.edu), telephone (404) 727-2929, fax (404) 727-4562.
- **Multidimensional Quality of Life Questionnaire for Persons with HIV (MQOL-** A brief questionnaire that measures ten major quality of life domains (physical function, medical care, social support, physical health, cognitive functioning, intimacy, social functioning, finance, sexual functioning, and mental health) and addresses issues especially relevant for people with HIV and AIDS. The MQOL-HIV can be used as a supplement to clinical measures such as immune status and viral load. Available through the New England Research Institutes, e-mail [Media@neri.org](mailto:Media@neri.org), telephone (617) 923-7747 x560, fax (617) 923-4176.

- **WHOQOL-100 and WHOQOL-BREF.** Two quality of life measurement instruments designed by the World Health Organization (WHO). The core WHOQOL instruments can assess quality of life in a variety of situations and population groups. Additional modules are being developed that concentrate on specific population (e.g., people living with HIV/AIDS). Information is available from Dr. Donald Patrick, Department of Health Services, F-346, Health Sciences Centre, SC-37, Seattle, Washington 98195, telephone (206) 543-8866, fax (206) 543-3964, e-mail [uswhoqol@u.washington.edu](mailto:uswhoqol@u.washington.edu).
- **The American Thoracic Society (ATS) Database.** A detailed database on many different quality of life instruments and resources including those listed above. For more information contact ATS at 1740 Broadway, New York, NY 10019, telephone (212) 315-8700, fax (212) 315-6498, or access the ATS webpage at <http://www.atsqol.org>.
- **Using Health-Related Quality of Life Measures:** Article providing guidance on how to use health-related quality of life measures and questionnaires: A.W. Wu, R.D. Hays, S. Kelly, F. Malitz, and S.A. Bozzette, "Applications of the Medical Outcomes Study: Health-Related Quality of Life Measures in HIV/AIDS," *Quality of Life Research*, Vol. 6, 1997. This article describes health status measures from the Medical Outcomes Study (MOS) and other studies, providing a reference for researchers in selecting an instrument to use, comparing health-related quality of life findings from different studies, or interpreting and analyzing the use of these measures in studies of HIV.

#### Guides providing "how-to" information on outcomes evaluation:

*Measuring Program Outcomes: A Practical Approach.* Alexandria, Virginia: United Way of America, 1996. 169 pp. Item number 0989; available from Sales Service/America, (800) 772- 0008 for \$5. This is the "how-to" guide presenting the United Way Logic Model of evaluation. Excerpts from the guide and other practical materials are available through United Way's Outcome Measurement Resource Network, <http://national.unitedway.org/outcomes>.

*W.K. Kellogg Foundation Evaluation Handbook.* Battle Creek, Michigan: W.K. Kellogg Foundation, 1998. Provides practical information on evaluation, including project-level, cluster, and program-level evaluation using several models including logic models. Available as item 1203 from Collateral Management Company, 1255 Hill Brady Road, Battle Creek, MI 49015, (616) 964-0700 or download from the Foundation's website, <http://wkkf.org/Publications/evalhdbk>.



## Glossary

This glossary defines and describes key evaluation terms using explanations and examples designed to make them useful for providers and other non-researchers. For more detailed definitions, see *Glossary of Evaluation Terms for Ryan White CARE Act Grantees*, Report #4 of the HIV/AIDS Evaluation Monograph Series, prepared for the HIV/AIDS Bureau by the Office of Science and Epidemiology, September 1999.

**Average** - a way of describing the typical value or measuring the “central tendency” among a group of numbers, such as average age or average income. See **mean**.

**Bar Chart or Bar Graph** - a visual way to show and compare scores or values for different categories of variables; for example, a bar chart might be used to show the number of reported AIDS cases who are from each major racial/ethnic group; the taller the bar, the larger the number of AIDS cases.

**Case Fatality Rates** - the percent of deaths reports among persons whose cases were diagnosed and reported during a specified period; for example, AIDS case fatality rates might specify the percent of deaths among AIDS cases diagnosed during the past five years.

**Causality** - to establish a cause and effect relationship between the program or intervention and the observed outcomes; to be able to document that the program was the cause (or a cause) of the outcome. This is very difficult. If national studies—such as those conducted by universities or by the HAB Office of Science and Epidemiology—show that ensuring that patients follow an approved HIV-related treatment regimen contributes to positive health outcomes, then it is acceptable for individual grantees and providers to assume that positive longer-term outcomes are at least partially a result of the services provided.

**CD4 Count** - refers to a person’s T-lymphocyte count, the results of an HIV antibody test used to measure the effect of the virus on the immune system. An HIV-positive person with a CD4 count below 200 is considered by the CDC to have AIDS.

**Coding** - the process of “translating” data from one format to another, usually so the information can be entered into a computer to be tabulated and analyzed; often, coding involves assigning numbers to all the possible responses to a question, such as Yes = 1, No = 2, Not Sure = 3, No Response = 0.

**Continuous Quality Improvement (CQI)** - an ongoing process that involves individuals within an organization in monitoring and evaluating its resources and other service “inputs,” processes, and outputs in order to continuously improve service delivery. CQI focuses on preventing problems and maximizing quality of care. It is a model for improving service delivery that is closely related—and complementary—to program evaluation.

**Cumulative Incidence** - the total number of new cases of a disease that have been diagnosed and reported from the time reporting began to the most recent reporting date.

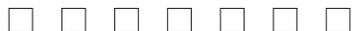
**Data Analysis** - careful, rigorous study of data; usually involves studying various elements of information and their relationships.

**Data Elements** - the specific items of information that are collected and aggregated in order to make measurements using the indicators. For example, to determine whether the rate of non-injury-related emergency room visits by clients is decreasing over time, required data elements would be the number of non-injury-related emergency room visits by clients during specific periods. To determine whether CD4 counts are being maintained or improved, data elements would be CD4 counts for clients at specific intervals during the stated time period.

**Enabling Services** - non-health care related services that are designed to enable clients to access and maintain participation in primary care and supportive services, such as transportation and child care.

**Exposure Category** - in describing HIV/AIDS cases, same as **transmission categories**; how an individual may have been exposed to HIV, such as injecting drug use, men who have sex with men, and heterosexual contact.

**Frequency Distribution** - a tally of the number of times each score or response occurs in a group of scores or responses; for example, if 20 women with HIV provided information about how they were infected with the virus, the frequency distribution might be 8 = injection drug use, 5 = heterosexual contact with an injection drug user, 3 = other heterosexual contact, 1 = blood transfusion, and 3 = don't know.



**Generalizability** - the extent to which findings or conclusions from a sample can be assumed to be true of the entire population from which the sample was drawn; findings can be generalized only when the sampling procedure and the data meet certain methodological standards.

**Goals** - descriptions of desired long-term program impact. It often takes a long time and many programs to achieve a goal. Outcomes objectives measure progress towards goal attainment. For example, one typical goal of Title I and Title II CARE Act programs is to reduce AIDS-related mortality; an outcome objective is to reduce the mortality rate for clients in care.

**Incidence** - the number of new cases of a disease that occur in during a specified time period.

**Incidence rate** - the number of cases of a disease per population per specified time period, often expressed per 100,000 population. AIDS rates are often expressed in this way.

**Mean** (average value)- arithmetic average, calculated by adding up all the values or the responses to a particular question and dividing by the number of cases; for example, to determine the mean age of 12 children in a pediatric AIDS program, add up their individual ages and divide by 12.

**Median** (middle value)- a measure of central tendency or location which calculates the central value, the one that falls in the middle of all the values when they are listed in order from highest to lowest; for example, if the annual incomes of seven families were \$37,231, \$35,554, \$30,896, \$27,432, \$24,334, \$19,766, and \$18,564, the median would be \$27,432. To determine the median of an even number of values, average the two central values (that is, add them together and divide by two).

**Mode** (most common value) - a measure of central tendency or location which identifies the most frequently observed value; for example, suppose an adolescent project included 13 youth of the following ages: 17, 17, 16, 16, 15, 14, 14, 14, 14, 13, 13, 12, 12; the mode would be 14, which occurs four times.

**Opportunistic Infections or Conditions** - diseases that occur when a patient's immune system is weakened, as is the case with persons living with AIDS; the presence of certain opportunistic infections is used as an indicator that a person has AIDS.

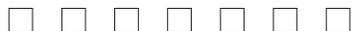
**Outcomes** - Benefits or other results (positive or negative) for clients that may occur during or after their participation in a program. **Client-level outcomes** are results for an individual client; examples include biological markers (*e.g.*, improved CD4 count) or morbidity-related outcomes (*e.g.*, reduction in opportunistic conditions or infections).



**System-level outcomes** are results stated in terms of all clients receiving services from CARE Act providers, such as reduced rates of perinatal HIV transmission or reduced mortality rates for clients within a particular State or EMA. Outcomes can be categorized along a time continuum, as **initial**, **intermediate**, or **longer-term**; the shorter-term outcomes lead to the longer-term ones. (The Aids for Outcomes Evaluation section includes a sample chart showing the three categories of outcomes that might be expected for two types of primary care services.) Specifically:

- **Initial outcomes** are the first benefits or changes experienced by clients, usually involving changes in knowledge, skills, or attitudes. For example, initial outcomes for a pregnant woman with HIV might be knowledge that treatment is available that can help reduce the transmission of HIV to an unborn child and understanding that she can reduce the probability of perinatal transmission by adhering to and completing this treatment. An initial outcome for an adult entering primary medical care might be to become aware of his/her disease status through determining initial clinical indicators such as viral load and CD4 count.
- **Intermediate outcomes** occur after the initial outcomes and link them to the longer-term outcomes desired for clients. They often involve behavior change. For example, for the pregnant woman with HIV, an intermediate outcome would be beginning or following the treatment regimen to reduce perinatal transmission. An intermediate outcome for an adult in primary care might be compliance with combination antiretroviral therapy. System-level outcomes might include the percentage of pregnant women who adhere to the specified treatment regimen or improved rates of client adherence to combination antiretroviral therapy.
- **Longer-term outcomes** are measurable client results that take longer to achieve such as changes in their condition, clinical health status, or quality of life. They are the long-term results the program was established to accomplish, often related to morbidity and mortality. For example, desired longer-term outcomes for the pregnant woman include completion of the treatment regimen to reduce perinatal transmission and, ultimately, determination that the infant is HIV-negative. System-level longer-term outcomes for primary medical care might include reducing perinatal transmission of HIV, reducing HIV-related mortality, and slowing disease progression (as measured by CD4 count, viral load, or reduced incidence of opportunistic conditions).

**Outcomes Indicators or Measures** - the observable and measurable data that are used to measure and track a program's progress in achieving desired outcomes or results. For example, the following individual client-level outcomes indicators might be used by a primary care program to track reductions in morbidity and mortality: biological markers such as changes in CD4 counts and viral loads over time, morbidity indicators such as incidence of new AIDS defining opportunistic conditions, and mortality indicators such as survival during a specified time period. System-level indicators might include reduced rates of non-injury-related emergency room visits or reduced percent of clients dying from AIDS-related conditions over a specified time period.



**Outcome Objectives or Outcome Targets** - numerical objectives stating the desired level of outcome achievement for the program, such as for all primary care providers or all clients served by a Title I or Title II program. Outcome targets are usually stated for the program rather than for individual clients and are sometimes referred to as **system-level or program-level objectives**. For example, an outcome target might be to have 80% of HIV-positive pregnant women complete their treatment regimen or to ensure that 72% of adult clients take their medications consistently. In developing outcome targets, it can be helpful to start with targets reached by non-CARE Act providers, or targets specified by the U.S. Public Health Service or other CARE Act grantees. If targets from other locations are used, it is important that they be based on epidemiologic profiles similar to those of your service area.

**Outputs** - measures of the products or volume of program operations such as the number of service units that a program delivers—the number of clients served, medical examinations provided, CD4 or viral load tests completed, or specialty care consultations provided, etc. For example, a desired output for a primary care program might be to provide primary medical care for 150 adults with HIV disease during the year, or to provide 35 medical examinations for HIV-positive adults each month. Outputs do not measure changes in clients, but without outputs or service units, outcomes would not occur. Sometimes it is difficult to tell the difference between an output and an initial outcome, so judgment is required. It is easier to tell the difference between outputs and intermediate or longer-term outcomes since the latter clearly involve client changes or benefits.

**Overrepresentation/Underrepresentation** - terms often used to indicate that a particular subpopulation makes up a larger proportion—or a smaller proportion—of a particular group than would be expected, given its representation in the total population; for example, Hispanics and African Americans are both overrepresented among AIDS cases, compared to their percentage in the U.S. population, while Asians/Pacific Islanders are underrepresented.

**Oversampling** - a procedure in stratified random sampling in which a larger number of individuals from a particular group (or **stratum**) are selected than would be expected given their representation in the total population being sampled; this is done in order to have enough subjects to permit separate tabulation and analysis of that group; for example, minorities are often oversampled to permit separate analysis of data by racial/ethnic group as well as comparisons among racial/ethnic groups.

**Percent** - literally, per hundred; a proportion of the whole, where the whole is 100; percent is calculated by dividing the part of interest by the whole, and then multiplying by 100; for example, if you want to know what percent of recently reported AIDS cases are women, take the number of women AIDS cases (the part of interest), divide by the number of total AIDS cases (the whole), and multiply by 100; if your community has a total of 70 recently reported AIDS cases and 14 are women, divide 14 by 70 ( $=.2$ ) and multiply by 100, and you get 20%.

**Percentage Point** - one one-hundredth; term used to describe numerical differences between two percents without comparing relative size; for example, if 16% of AIDS cases are Hispanic and 32% are African American, the difference is 16 percentage points (32 minus 16).

**Prevalence** - The total number of persons living with a specific disease or condition during a given time period.

**Prevalence Rate** - the total case rate of a disease or condition in a given population at a given time (compared to the **incidence rate**, which refers to new cases; often expressed as cases per 100,000 population).

**Primary Source Data** - original data that you collect and analyze yourself.

**Probability** - the likelihood that a particular event or relationship will occur.

**Probability Value** - the probability that a statistical result—an observed difference or relationship—would have occurred by chance alone, rather than reflecting a real difference or relationship; statistical results are often considered to be significant if the probability or **p value** is less than .05, which means that there is less than a 5% chance (5 out of 100) that the result would have occurred by chance alone.

**Proportion** - a number smaller than one, which is calculated by dividing the number of subjects having a certain characteristic by the total number of subjects; for example, if 35 new AIDS cases have been reported in the community in the past year and 7 of them are women, the proportion of female AIDS cases is 7 divided by 35 or  $1/5$  (.2).

**Public Health Surveillance** - an ongoing, systematic process of collecting, analyzing, and using data on specific health conditions and diseases, in order to monitor these health problems, such as the Centers for Disease Control and Prevention surveillance system for AIDS cases.



**Quality Assurance** - a formal and systematic process of identifying problems in service delivery, designing activities to overcome these problems, and following up to ensure that correction actions have been effective and no new problems have developed. The emphasis is usually on ensuring that minimum standards of care are met. It is an approach for improving service delivery that is closely related—and complementary—to program evaluation.

**Raw Data** - data that are in their original form, as collected, and have not been coded or analyzed; for example, if a woman participating in an HIV nutrition workshop is tested to determine her knowledge of nutrition needs and gets a score of 11, that is her raw score; if the score represented 11 correct answers out of 20, then the score could be converted to 11 divided by 20 times 100 or 55%, which is no longer a raw score.

**Reliability** - the consistency of a measure or question, in obtaining very similar or identical results when used repeatedly; for example, if you repeated a blood test three times on the same blood sample, it would be reliable if it generated the same results each time.

**Representative** - term used to indicate that a sample is similar to the population from which it was drawn, and therefore can be used to make inferences about that population.

**Rounding** - presenting numbers in more convenient units; rounding is usually done so that all numbers being compared have the same level of precision (one decimal place, for example); usually numbers under 5 are rounded down while 5 and over are rounded up; for example, you would round 3.08 to 3.1 and 4.14 to 4.1.

**Sample** - A group of subjects selected from a total population or universe with the expectation that studying the group will provide important information about the total population.

**Secondary Analysis** - analysis of data or other information collected by someone else; for example, you might obtain data on AIDS cases in your metro area from the Centers for Disease Control and Prevention, and carry out some additional analysis of those data.

**Secondary Source Data** - information that was collected by someone else, but which you can analyze or re-analyze.

**Self-Administered Survey** - refers to a questionnaire that is mailed or given to an individual, to be completed independently by the individual and then returned, rather than having an interviewer ask the questions and record the answers.

**Supportive Services** - non-health care service categories funded under the CARE Act that are designed to support clients and contribute to improved health status and other positive client outcomes; examples include housing and case management.

**Statistical Significance** - a measure of whether an observed difference or relationship is larger or smaller than would be expected to occur by chance alone; statistical results are often considered to be significant if there is less than a 5% chance—5 out of 100—that they would have occurred by chance alone.

**Statistics** - Information or data presented in numerical terms; quantitative data; often refers to numerical summaries of data obtained through surveys or analysis.

**Stratified Random Sample** - a random sample drawn after dividing the population being studied into several subgroups or **strata** based on specific characteristics; subsamples are then drawn separately from each of the strata; for example, the population of a community might be stratified by race/ethnicity before random sampling.

**Surrogate Measures** - substitute measures, used to help understand a situation where adequate direct measures are not available; for example, it may be difficult to obtain good HIV surveillance data on teenagers, but incidence rates of sexually transmitted diseases (STDs) among teenagers can be used as surrogate measures of high-risk sexual behavior, since HIV is an STD, and people get STDs when they engage in unprotected sex.

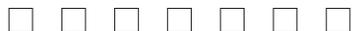
**Survey Research** - research in which a sample of subjects is drawn from a population and then interviewed or otherwise studied to gain information about the total population from which the sample was drawn.

**System-level or program-level objectives** - see **outcome objectives** or **outcome targets**.

**Tabulation of Data** - ordering and counting of quantitative data to determine the frequency of responses, usually the first step in data analysis; typically involves entering data into a computer for manipulation through some form of data analysis program.

**Target Population** - the population to be reached through some action or intervention; may refer to groups with specific demographic characteristics (*e.g.*, race/ethnicity, age, gender, socioeconomic status) or in specific geographic areas.

**Transmission Categories** - in describing HIV/AIDS cases, same as **exposure categories**; how an individual may have been exposed to HIV, such as injecting drug use, men who have sex with men, and heterosexual contact.



**Trend** - movement in a particular direction in the value of variables over time.

**Trend Charts** - line charts which show changes or movement in the values of a particular variable over time; usually, values are recorded periodically as points on a graph, and then connected to show how the values are changing; often used to provide comparisons, such as separate lines showing reported AIDS cases among different population groups over time.

**Universe** - the total population from which a sample is drawn.

**Validity** - the extent to which a survey question or other measurement instrument actually measures what it is supposed to measure; for example, a question which asks PLWHs with TB whether they are taking their medication every day is valid if it accurately measures their *actual level* of medication use (as with directly observed therapy programs in which they are observed taking the medication), and it is not valid if they are not giving honest answers, and the question is really measuring the extent to which they realize that they *should* take their medication.

**Value** - individual response or score; for example, if people responding to a survey are asked to state their age, each age is a value.

**Variable** - a characteristic or finding that can change or vary among different people or in the same person over time; for example, race/ethnicity varies among individuals, and income varies for the same individual over time.



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