

Chapter 8: Monitoring and Evaluation Program Design Steps

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Key Concepts

- 8.1 Considerations in M&E for Food Assistance Programs in an HIV Context
- 8.2 Key Elements of M&E for Food Assistance Programs in an HIV Context
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In This Chapter

This chapter brings together what has been learned to date about monitoring and evaluation (M&E) of food assistance programs in an HIV context and provides specific direction for monitoring and evaluating HIV-related activities such as PMTCT, ART, TB, OVC, and care and support programs that integrate food and nutrition.

The chapter identifies several significant issues that distinguish M&E for food assistance programs in areas of high HIV prevalence from M&E in a non-HIV context. These differences include the need for greater interaction with and reliance on health services, the variation among beneficiaries of integrated programs, and the issues presented by stigmatization of HIV-positive individuals and affected families. In highly affected areas, it also becomes increasingly important to monitor contextual issues influencing the relationship between food insecurity and HIV.

Next, the chapter describes the key elements of food assistance M&E systems. These include the information requirements for effectively monitoring and evaluating project activities and changes among beneficiaries and target populations, the identification of appropriate indicators and determination of program targets, as well as approaches to data collection and analysis.

The chapter then discusses some of the challenges that remain in adapting food assistance M&E systems to an HIV context. Among the more technically demanding challenges of M&E in highly affected areas are interpreting standard anthropometric measures, determining the validity of proxy indicators in differing contexts and adapting traditional sampling methods.

Despite the guidance this chapter provides on adapting M&E systems to account for the impacts of HIV, there are many potential areas for investigation that are beyond the capacity of a single program's M&E system. Many such questions and issues are better addressed through operations research. Where appropriate and feasible opportunities exist, programs may consider integrating an operations research component. However, in most cases, program M&E should remain focused on measuring and using information from program-specific indicators that staff can collect and analyze and should not be expected to address broader research questions.

Considerations in M&E for Food Assistance Programs in an HIV Context

Several key considerations make M&E of food assistance programs in an HIV context different from—and often more challenging than—in a non-HIV context. Some of the significant issues to consider include:

Differing objectives. The objectives of food-based interventions in an HIV context may be different from those in a non-HIV context; therefore indicators used to measure results require adaptation. For example, whereas the objective in non-HIV contexts may be to improve nutritional status of targeted vulnerable groups, for individuals who are chronically ill the objective may be simply to maintain nutritional status or slow its decline. Food may also be used for entirely different reasons than in traditional programs (e.g., to improve adherence to or mitigate side effects of ARVs, or increase use of PMTCT services). Relevant indicators appropriate for beneficiary groups being targeted should be developed and measured for these objectives (see **Chapter 5: Targeting**).

Attention to stigma. Stigma and discrimination should be considerations in M&E just as they are for targeting and other aspects of program planning. In many cases proxy indicators may be required (e.g., using chronic illness as an indicator because stigma may prevent people from identifying themselves as being HIV-positive). Also, beneficiaries who are afraid of being stigmatized may not properly register (e.g., give a false name or address) or not appear for regular follow-up, making it difficult to track progress. Program activities must include mechanisms for maintaining confidentiality when targeting PLHIV to guard people's privacy and reduce the possibility of discrimination or resentment among non-beneficiaries.

Variation among beneficiaries. While there is variation among beneficiaries in all food security programs, the variation may be much greater in HIV contexts. Individuals and households affected by HIV may face different and stiffer constraints to improved food security and may experience smaller improvements in food security from interventions than non-affected individuals and households do. Among HIV-infected individuals, there may be wide variation in outcomes depending on the stage of disease and their treatment status. These variations can have implications for the targets that a program sets and for data disaggregation and analysis.

Documentation of learning. To date, quantitative data demonstrating the outcomes and impacts of food assistance on PLHIV are weak or non-existent, though anecdotal evidence abounds. Both beneficiaries and clinical staff report that they observe positive impacts from food assistance, most often citing increased weight, strength, ability to work, increased food consumption and overall well-being.¹ Finding creative ways and reliable indicators to measure and document these improvements remains a challenge and an opportunity for learning. Where possible, opportunities to attach operations research to current programming should be identified and implemented to build the knowledge base about effective programming. However, such operations research efforts should not come at the expense of the programs' primary objective of effective implementation.

Greater interaction with and reliance on health services. Data collection, analysis and interpretation in an HIV context may require greater interaction with and reliance on health service providers than is usually the case for traditional food assistance programming. For example, clinical records may be a more prominent source of data than household-level surveys. Furthermore, since optimal programming may involve integrating food security and HIV interventions, M&E systems need to be planned carefully to collect necessary information on both food security and HIV outcomes, and to integrate data collection

systems to avoid duplicating efforts. Information sharing systems should provide program staff involved in clinical issues related to HIV with relevant food security information and should provide staff addressing food security issues with relevant HIV-related information.

Emphasis on capacity building. M&E of food assistance programming in an HIV context is still a relatively new area. Food assistance agency M&E staff, partners and health care providers may require significant training and capacity building on how to adapt and modify M&E systems to this context. As this area is evolving rapidly, capacity building in M&E should be considered an ongoing need and should be budgeted accordingly.

Attention to contextual issues. Tailoring program design to a particular setting in terms of local social, cultural, political, environmental or other factors is especially important in an HIV context. Given that vulnerability to the combined impact of food insecurity and HIV can be greatly influenced by issues such as migratory patterns, civil conflict and gender inequity, M&E systems in highly affected areas should pay specific attention to monitoring changes in context within the program area.

Key Definitions in M&E²

Inputs: Resources (e.g., staff, financial resources, space, equipment) utilized to accomplish the project's objectives

Processes: Specific activities (e.g., training, program design, planning) to which resources are allocated to pursue project objectives

Outputs: Products (e.g., number of trainees, immunized children, activities implemented) that result from the combination of inputs and processes

Outcomes: Beneficiary and population-level changes in knowledge, practices and attitudes (e.g., improved health practices, increased knowledge of nutrition) resulting from the intervention

Impacts: Long-term changes at the beneficiary and population level (e.g., improved food access, improved nutritional status, increased resiliency to shocks, reduced labor migration) resulting from changes in knowledge, practices and attitudes

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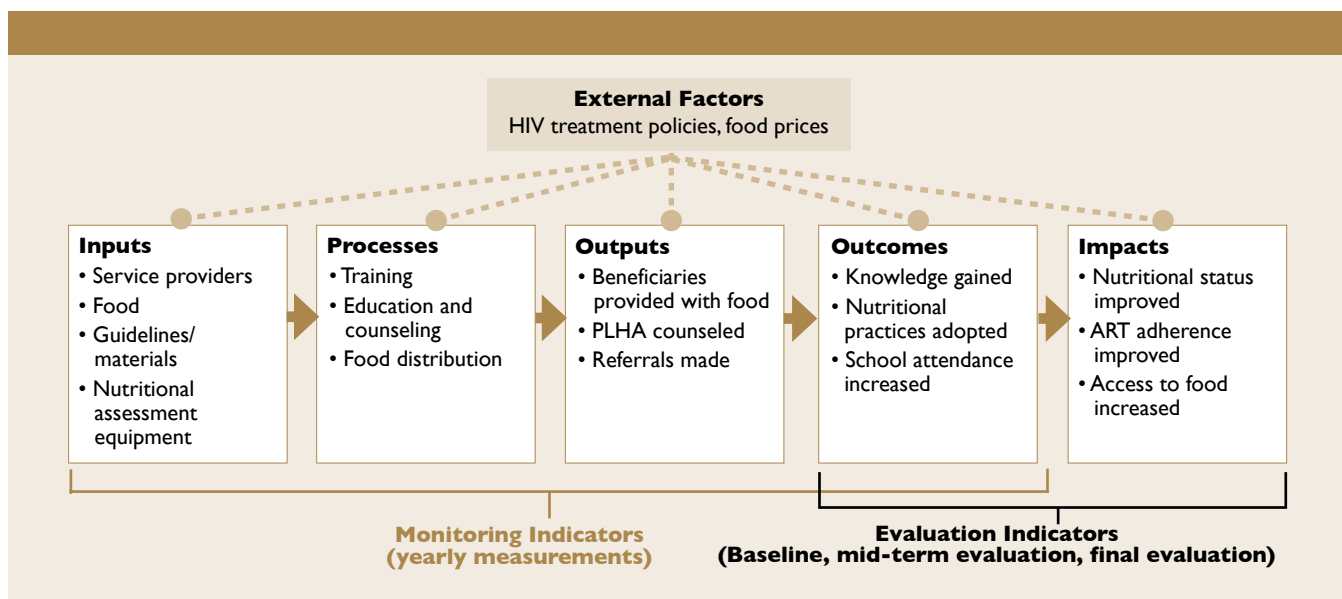
Key Concept

Key Elements of M&E for Food Assistance Programs in an HIV Context

While the core elements for designing an M&E system in an HIV context are the same as in a non-HIV context, there are specific issues and adjustments to consider to ensure that M&E systems are responsive to the information needs of the implementing organization and other stakeholders. This Key Concept discusses differences and adaptations to consider in an HIV context for the five main components of an M&E system:

1. Information needs
2. Indicators
3. Targets
4. Data collection and analysis
5. Uses of information

Figure I: M&E Framework for Food Aid–HIV Programs



Adapted from Bergeron et al. *Monitoring and Evaluation Framework for Title II Development-oriented Projects*. Technical Note 10. Washington, DC: FANTA Project, Academy for Educational Development, 2006.

Information Needs

There are two principal questions to ask about information needs: What are the purposes of collecting information? What information is needed to meet these purposes?

The primary purpose of collecting M&E information is typically to assess whether a program is achieving what it set out to do at the various stages of the program cycle, which are represented in the form of *inputs*, *processes*, *outputs*, *outcomes* and *impacts*. These stages are depicted in Figure I, which has been adapted to an HIV context. Information on a program's progress and achievements is used for program management, reporting, learning what interventions work best, and advocacy.

Information can be organized into two categories: information on the progress of program activities and information on changes among beneficiaries.

Information on Program Activity Progress

Information on the progress of program activities—generally drawn from input, process and output indicators—should address these questions:

- ▶ Is implementation occurring at the planned levels and pace (inputs, outputs)?
- ▶ What is the quality of food-assisted services (inputs, processes)?
- ▶ Are beneficiaries accessing services? At what level of participation (outputs)?

In an HIV context, information about program progress can be critical. For instance, it may be important to know how many women have been referred to food assistance programs through involvement in PMTCT activities. In an FFA program, implementers may want to find out how well the program design and ongoing management adheres to GIPA guidelines. For nutrition education and counseling services, managers may want to know how well counselors are assessing clients' diets, educating clients and creating plans to address

nutritional concerns. Programs that support gender mainstreaming may want to monitor performance in incorporating and addressing concerns of women and men in their activities and assess any differences in how each group's concerns are addressed. (See Figure 2 for examples of input, process and output indicators for nutrition education and counseling.)

Information About Changes Among Beneficiaries and the Target Population

Information about changes among beneficiaries and target populations—generally measured with outcome and impact indicators—should address these questions:

- ▶ Have beneficiaries' knowledge, practices and attitudes improved (outcomes)?
- ▶ Has the nutritional status improved among beneficiaries and the target population (impacts)?
- ▶ Has access to food increased among beneficiaries and the target population (impacts)?

For example, in a PMTCT program, managers may want to know if women are following guidance on exclusive breastfeeding or learn how women's health and nutritional status have changed since enrolling in the program. For an FFA program, managers may want to find out how a community garden developed to provide food for PLHIV and OVC has contributed to these groups' household dietary diversity. In a nutrition education and counseling program, managers may want to know whether PLHIV are eating more frequently, are knowledgeable about using nutrition practices to manage symptoms, and have improved their nutritional status.

Figure 2: Example of the Input-Impact Sequence for Nutrition Education and Counseling (NEC) for PLHIV

Inputs	Processes*	Outputs	Outcomes	Impacts
Trained service providers	Flow of clients to counselor or educator through referrals and other systems	Provision of NEC as part of HIV treatment and care services	Changes in PLHIV knowledge, dietary practices and related behaviors (for example, food purchase and preparation, water and sanitation, availing food supplementation, dietary response to symptoms, management of drug-food interactions)	Nutritional status (weight, nutrient deficiencies)
Educational and counseling materials		Receipt by PLHIV of NEC services, such as individualized nutrition counseling and weight monitoring		Daily functioning and physical activity
Adequate space for nutrition education and counseling	Quality of counseling: counselor behavior, assessment, provision of information, identification and planning of options for PLHIV	Receipt of follow-up nutrition counseling by PLHIV		Severity, frequency and duration of symptoms
Nutrition assessment equipment (e.g., scales), tools and documentation materials	Quality of group education			Response to treatment, severity of side effects, and adherence

*These indicators could also be considered outcome indicators where the project is measuring systemic change in the quality of the health care system as a prerequisite to change in knowledge and behavior among targeted beneficiaries.

Source: FANTA Project. *A Guide to Monitoring and Evaluating Nutrition Education and Counseling for People Living with HIV/AIDS*. Draft. Washington, DC: Academy for Educational Development, 2006.

Identifying Appropriate Indicators

Once the specific information needs have been established, the next step is to identify reliable and measurable indicators for the information needs at each stage of the program cycle (input, process, output, outcome and impact). It may not be possible to collect all the data desired because of limitations of time, resources and staff capacity available for M&E. In such cases programs should prioritize their information needs, carefully balancing the need for information on program progress (to ensure the program is well-managed with effective service provision) with the need for information on individual changes (to ensure the program is having the intended effect on beneficiaries). Programs should also include indicators at each stage of the program cycle so that gaps can be easily identified and implementation processes refined where necessary.

M&E of food assistance programs in an HIV context is still a nascent field, and there is not yet a consensus about standard indicators. Still, much has been learned and documented in recent years to help practitioners select indicators. A number of groups are conducting pilot exercises and operations research to test various indicators and contribute to our understanding of what works. When selecting indicators, programs should consider:

- ▶ What the program expects to achieve
- ▶ How these achievements—and the processes leading up to them—can be measured
- ▶ The expected uses of the information collected
- ▶ The likelihood that the food assistance program will cause changes in indicators
- ▶ The cost and feasibility of collecting the data needed
- ▶ The expertise required to collect, analyze and interpret data generated by indicators
- ▶ Program staff capacity to collect, analyze and interpret the information
- ▶ Information currently being collected and existing data collection systems that may incorporate additional indicators

Figure 3 provides examples of indicators for food assistance programs in HIV contexts that are drawn from various sources, including FANTA, WFP and C-SAFE. These indicators reflect a range of interventions and program information needs and are intended to illustrate the various types of indicators that can be used. Programs should select their own indicators based on their specific objectives, interventions, expected uses of information and feasibility constraints.

Types of Outcome and Impact Indicators

There are various types of impact and outcome indicators, and in selecting which ones to use, programs should consider what changes the program interventions are expected to bring about and what can be feasibly collected. While some indicators must be collected by health care professionals because they require specialized expertise, food security program staff still should understand the indicators. Outcome and impact indicators that can be used in food assistance programs in HIV contexts include:

Anthropometrics. Anthropometric indicators use physical measurements to assess a person's nutritional status. They include BMI, percentage weight change, mid-upper arm circumference (MUAC), weight-for-age (W/A), height-for-age (H/A), weight-for-height (W/H),

Figure 3: Example Indicators for Food Assistance Programs in HIV Contexts

Input	<ul style="list-style-type: none"> Number or percentage of program sites with functional weighing scales Number or percentage of program sites with at least one service provider trained in nutritional care and support of PLHIV Number of staff trained in nutritional care and support for PLHIV Number of metric tons resourced
Process	<ul style="list-style-type: none"> Percentage of food rations distributed on time Percentage of beneficiaries aware of ration entitlement Percentage of beneficiaries satisfied with food quality Number of sensitization sessions conducted to inform beneficiaries about the purpose of the program and the criteria for participation Percentage of nutrition counseling sessions that meet a fixed criterion for quality (e.g., a counseling quality checklist)
Output	<ul style="list-style-type: none"> Number of metric tons of food distributed through each distinct food support activity Number of OVC (or ART clients or other targeted group members) receiving food Number of chronically ill individuals receiving food Percentage of care and treatment sites providing nutrition counseling with food Percentage of planned beneficiaries who actually receive food assistance, disaggregated by sex and age group Number of HBC groups formed Number of households affected by chronic illness that are provided inputs and training in labor-saving agricultural production techniques or household gardens Number or percentage of PLHIV who received nutrition counseling in the past three months
Outcome	<ul style="list-style-type: none"> Percentage of PLHIV beneficiaries consuming food the recommended number of times per day on the previous day Percentage of PLHIV beneficiaries who know appropriate dietary responses to symptoms and medication side effects Percentage increase in enrollment in PMTCT or ART services Percentage of households affected by chronic illness that are using labor-saving agricultural production techniques or household gardens Percentage increase in school attendance by OVC
Impact	<ul style="list-style-type: none"> Percentage of adult PLHIV beneficiaries with BMI < 18.5 Percentage of new ART clients with BMI < 18.5 who have BMI > 18.5 after six months of treatment Average percentage weight change among adult beneficiaries over the past three months Prevalence of malnutrition (weight/age) among children under five years of age born to HIV-infected mothers who were enrolled in the PMTCT program Percentage of beneficiaries still on ART 12 months after initiating treatment Percentage of beneficiaries performing moderate to intense physical activity (activities to be defined locally) for a fixed period of time (e.g., 45 minutes) on the previous day Percentage change in average quality of life (QOL) scores among beneficiaries

Adapted from 1) FANTA Project. *A Guide to Monitoring and Evaluating Nutrition Education and Counseling for People Living with HIV/AIDS*. Draft. Washington, DC: Academy for Educational Development, 2006; 2) Egge, K., and Strasser, S. *Measuring the Impact of Targeted Food Assistance on HIV/AIDS-related Beneficiary Groups With a Specific Focus on TB, ART, CI and PMTCT Beneficiaries*. Johannesburg: C-SAFE Learning Spaces Initiative, 2005; 3) World Food Programme (WFP). *Proposal for Development of Monitoring and Evaluation Tools for HIV/AIDS Food-Assisted Programmes*. Draft. WFP, 2005.

skin fold thickness and others. Anthropometric indicators are widely used to measure the nutritional status of individuals or populations in HIV and non-HIV contexts.

Adherence/default. Treatment adherence or default rates are two sides of the same issue regarding people's participation in treatment services. Adherence measures patients' compliance in following prescribed dosages, while program default measures the percentage of patients who do not continue treatment. Programs usually choose the indicator that is easier to collect and most meaningful to them.

Program uptake. In programs such as PMTCT and TB-DOTS, enrollment before introduction of food assistance can be compared to enrollment after food assistance to see if the food assistance significantly influenced people to participate and receive counseling, treatment or other services.

Food access. Food access indicators measure individual or household access to food and include household dietary diversity, months of inadequate food provisioning, coping strategies, asset wealth, household food insecurity access scale, and others. Indicators and tools used to measure food access appear in Annex 1.

Illness/disease status. Illness indicators reflect the state of disease and opportunistic infections. Illness indicators include clinical symptoms and appearance, clinical events such as hospitalizations, and counts of CD4+ T-cells and viral load. Other indicators include scales such as the Karnofsky Scale, the Eastern Cooperative Oncology Group (ECOG)/ Zubrod Scale and the WHO HIV Stage Scale. The ECOG and WHO scales appear in Annexes 2 and 3.

Functioning. These indicators measure an individual's physical strength and ability to perform certain tasks. To measure a person's functional status, programs use hand grip strength, physical activity records, ability to perform daily activities, capacity to return to work, the extent of need for a caregiver, and Activities for Daily Living (ADL) questionnaires. A few organizations are experimenting with handgrip strength, using a mechanical handgrip dynamometer, as an easily administered measure of functioning. Used primarily with elderly populations, handgrip strength has been found to be positively correlated to BMI, MUAC and arm muscle area.³

Quality of life. Quality of life (QOL) is a multifaceted and subjective concept that considers the impact of impairments, function, perceptions and social opportunities. QOL measures can offer a rich assessment of the impact of food assistance programs, including physical, social and psychological status. There are a variety of tools for measuring QOL, including the Standard CDC Health-Related Quality of Life (HRQOL) 14-item Measure, the HRQOL-HIV scale and the MOS-HIV scale. The MOS-HIV scale appears in Annex 4.

There are specific factors in an HIV context that may affect indicators for coverage of services. For example, stigma could decrease coverage by preventing some beneficiaries from accessing services, while having a strong set of services could increase coverage by encouraging people to come forward.

Setting Targets

Targets are commitments made by implementing agencies about the level of inputs and activities to be implemented and about the extent and timing of a particular program's results. Typically, a target will be defined by a specific indicator value to be accomplished by a particular date in the future.⁴

The process of setting targets in the HIV context should carefully consider the operating environment and limitations. For example, in non-HIV contexts, programs may aim to increase a household's accumulation of productive assets. In an HIV context, the target may

be a specific number or percentage of households that have maintained productive assets. Similarly, where coping strategies are being monitored as a measure of food security, the target in a high HIV prevalence context may simply be to prevent a certain number or percentage of households from engaging in negative coping strategies in the short term.

In some contexts, it may be most appropriate to set targets for recovering assets or health conditions or maintaining them at normal, pre-shock levels (e.g., pre-drought, civil unrest, pre-HIV epidemic levels). Data from earlier DHS surveys (www.measureDHS.com) and UNICEF Multiple Indicator Cluster Surveys (MICS) (www.childinfo.org) may be good sources of information on what is “normal” in a specific country.

In an HIV context, indicators often focus on changes that may not be easy to describe in quantitative terms, for example, improvements in the quality and delivery of nutritional care services through HBC. Appropriate performance indicators for such programs may include new HBC functions that participating organizations can perform and a set of standards for each of these functions. In such cases, descriptive, or qualitative, targets may provide more depth and contextual information than quantitative data. Qualitative targets are difficult to aggregate, but it is possible to transform qualitative information into quantitative scales against which targets can be set.

Examples of Expressing Targets in Food-Assisted HIV Interventions⁵

Targets may express quantity (how much), quality (how good) or efficiency (least cost) to be achieved within a specific timeframe. Ways to express targets include:

- ▶ Absolute level of achievement, e.g., 1,000 chronically ill individuals trained in positive living by 2007
- ▶ Change in level of achievement, e.g., ART adherence rates increased by 10 percentage points between 2006 and 2007
- ▶ Change in relation to the scale of the problem, e.g., percentage of food-insecure ART patients receiving food support increased by 10 percentage points by 2007
- ▶ Change in cost-efficiency of service, e.g., cost of PMTCT services (per individual) reduced by five percent between 2006 and 2007
- ▶ Proportion reaching a certain level of quality, e.g., proportion of HIV care sites meeting minimum standards for quality nutritional care based on a standardized checklist
- ▶ Creation or provision of something new, e.g., anti-stigma campaign conducted throughout the district by the end of 2006

Setting appropriate targets for food assistance programs addressing HIV can be challenging because there is little long-term experience with these programs and because many other factors affect program outcomes. These sources can help in setting realistic program targets:

Baseline survey. If secondary data of sufficient quality are available, organizations may be able to use them to establish baselines. Otherwise, agencies may need to collect primary data to establish baseline values. For individual or household indicators, baselines should disaggregate data by relevant target groups (e.g., gender; chronically ill, households caring for orphans) to help set disaggregated targets.

Transforming the Qualitative to Quantitative⁶

To measure an intermediate result that emphasizes improvements in quality of maternal and child health services, USAID/Yemen devised a scale that transforms qualitative information about services into a rating system that can be used to set targets. Similar scales can be developed for food assistance and HIV services.

0 points = Service not offered

1 point = Offers routine antenatal care

1 point = Offers recognition and appropriate management of high-risk pregnancies

1 point = Offers routine deliveries

1 point = Offers appropriate management of complicated deliveries

1 point = Offers postpartum care

1 point = Offers neonatal care

Score: Total actual service delivery points

Illustrative target: Increase average score to 5 by Year 3

Beneficiary expectations of progress. It is important to solicit input from community members (including HIV-related service organizations and the PLHIV and HIV-affected households who will be assisted by the interventions) to understand their preferences, needs and expectations for project activities. This information will help set relevant and realistic targets. Information collection may involve formal interviews, rapid appraisals or informal conversations with relevant groups or their representatives.

Trends observed before program implementation. Underlying historical trends in selected indicators may help provide a fuller picture than baseline values alone. Determining patterns of change with respect to individual performance indicators (e.g., recent increases/decreases, spreading geographic trends) can inform the process of setting targets.

Expert judgments. It is also useful to solicit expert opinion on what is feasible regarding a particular indicator or within a given context. As always, experts who are familiar with HIV-related issues—such as those from HIV coordinating bodies within the government as well as those directing HBC, VCT, PMTCT and other services—should be included.

Accomplishments of comparable programs. This may be especially helpful in an HIV context because many organizations are piloting/experimenting with different approaches. Gauging other organizations' progress with programs with similar contexts, resources and other factors may provide an effective means of setting targets.

Data Collection and Analysis

Data collection and analysis in an HIV context require flexibility, time and resources to adapt existing tools and approaches and to develop new systems as needed. Some issues to consider in adapting data collection and analysis processes to HIV contexts are noted below.

Data Collection Approaches

Programs may need to adapt existing data collection approaches to the specific constraints of HIV contexts. For example, stigma or confidentiality issues may make it difficult or

Progress Is Not Always a Straight Line

While it is easy to establish annual targets by picking an acceptable final performance level and dividing expected progress evenly by the number of years, such linear thinking about progress is often inconsistent with the way development programs really work, especially in HIV contexts.

In many cases, no real progress—in terms of measurable outcomes or impacts—may be evident during the start-up period or the early years, and most of the impacts occur in the final year or two. In a high

HIV prevalence context, programs may have to be extremely conservative in setting expectations about the planned increases in beneficiary outcomes. In some cases, progress may be indicated by a relatively flat line instead of an incline, demonstrating that the intervention prevented an imminent decline.

On the other hand, for input and output indicators (such as coverage), the greatest increase may occur during the early stages of a project and plateau after that.

unethical to visit households to collect data from HIV-affected beneficiaries. An alternative approach could be collecting data at health care sites or collaborating with health care or HBC providers to solicit input from PLHIV. Illness may also interfere with normal data collection processes by limiting beneficiaries' availability. Programs could collect information from other household members instead, if stigma and confidentiality issues allow. Rapid changes in individuals' health because of treatment and infections may also affect the timing of data collection needed to obtain representative information.

Interaction With Health Care Providers

One significant difference in data collection and analysis in an HIV context is that there may be a need for greater interaction with and reliance on health care providers and clinical records. This may be obvious in cases where food programmers and clinical staff coordinate closely because food contributes to treatment adherence or reduced transmission rates among PLHIV. However, other food programs can also benefit from using clinical records.

Many NGOs collect fairly extensive information about household coping strategies, assets, use of food assistance and vulnerability levels, yet few use the anthropometric, clinical and performance measures collected by health staff to help make program decisions.⁷ However, while health care providers can be a rich source of information, implementing agencies should take measures to protect the confidentiality of medical records, including restricting staff access to such information.

Information should also flow from food assistance programmers to health care staff and counselors because nutrition and household food security data may strengthen the delivery of health care services. **Chapter 5: Targeting** presents some complementary data collection tools for food assistance targeting adapted to an HIV context.

Resources for Measuring Illness, QOL and Functioning Indicators

There are several standardized indicators and data collection tools to measure illness, QOL and functioning, some of which have been adapted for use in an HIV context. In deciding whether to use these measures, the usefulness of the information should be weighed against the time and money needed for training, data collection, translation and analysis.

For example, because QOL indicators are subjective, substantial training is required to use them properly. Three tools used in HIV contexts to collect data on QOL, functioning and illness are included in Annexes 2–4: the ECOG Zubrod Scale (functioning), the WHO disease staging scale (illness) and MOS-QOL.

Incorporating Additional Indicators Into Existing Tools and Approaches

Given the time and resource constraints typically associated with M&E and food assistance programs, indicators and data collection processes should be integrated into existing M&E systems where possible, rather than creating entirely new systems. For example, additional questions could be added to end-use monitoring (EUM) or post-distribution monitoring (PDM) systems, if those tools are in use. While this may add several minutes to questionnaire implementation, it is generally less expensive than establishing a separate system for collecting the information.

Adapting Sampling and Disaggregation of Data

The sampling unit for many surveys in food assistance programs has been the household, with data typically disaggregated by the household wealth ranking and the sex of the household head, among other factors. For programs working in high HIV prevalence contexts, it may be useful to categorize households according to the effect HIV has on them, such as:

- ▶ HIV-affected households where a member is either ill or has died from AIDS-related diseases

Adapting End-Use Monitoring Tool to Changing Needs and Contexts⁸

End-use monitoring (EUM) is a tool that Title II CSs use to verify that commodities, processes and services provided during a food distribution meet expectations and are of the highest possible quality.

Used at food distribution sites as beneficiaries receive rations, the EUM questionnaire reflects the issues that program managers grapple with and is updated as needed. The data are analyzed directly after collection so program adjustments based on the new information can be made as quickly as possible.

Though not often used for this purpose, EUM can help provide insights on other programmatic issues. For example, in one country, EUM revealed that long distances to distribution sites forced beneficiaries to travel by night, exposing them to risks such as attacks and theft. In another location, EUM showed that “under-the-tree registrations” were excluding

the poorest of the poor, who felt they did not have adequate clothing for attending these meetings.

C-SAFE adapted EUM when C-SAFE members wanted to better understand how food rations were affecting the chronically ill and households hosting the chronically ill. Several questions on these issues were developed in focus groups by C-SAFE Malawi. The questions were pilot tested in the EUM tool in Zimbabwe, revised and then rolled out in a finalized EUM tool to the other C-SAFE countries, Lesotho and Zambia.

EUM was again adapted when C-SAFE Zimbabwe needed to monitor its recently expanded FFA program, school feeding, and general food distribution. In addition, C-SAFE Zambia added questions to its EUM tool to find out what community members knew and thought about the upcoming closing of the C-SAFE program and the program’s exit strategies.

- ▶ Households where members are not infected but have been affected by HIV (e.g., through the diversion of household resources to support an HIV-affected extended family member; the death of an extended family member who contributed resources to the household, or orphans joining the household)
- ▶ Households where members are unaffected by HIV either directly or through related households⁹

A recent UNICEF guide for M&E of OVC programs recommends that data comparing orphans with non-orphans be collected and disaggregated by age to account for differences in behaviors and opportunities for young orphans compared to older ones. The report provides guidance on estimating sample size for surveys measuring indicators for OVC and provides instructions on defining a sample frame and methodology.¹⁰

Using Information

As in other contexts, M&E information collected from food assistance and HIV programs has three primary uses:

1. To serve as a management tool for planning, implementing, and adjusting activities
2. To enable reporting and accountability to management and donors
3. To support advocacy and provide information about effectiveness of interventions to donors, host governments and other stakeholders

As food assistance programming in an HIV context is still relatively new, strong M&E systems are particularly relevant to provide evidence, document effective approaches and support learning in this area. M&E staff should document proven measurement techniques for use by the larger food assistance and HIV communities. In addition, food assistance programs can benefit by building on what is already being collected in HIV programs.

Tracking the progress and effectiveness of efforts to support food-insecure PLHIV and HIV-affected households and communities can help programmers adjust current programs and design future ones. Program staff should use the information to verify that their targeting criteria are correct and are being properly applied, as well as to do periodic reverification exercises and adjust the programs as needed. In particular, information from M&E systems can make program staff more sensitive to gender issues and ensure that program benefits are addressing these issues effectively. As in other program contexts, information flow systems should provide program managers and other staff with the critical information they need to make decisions and refine their activities.

Prioritizing the Use of Information

Different programs prioritize the uses of information differently. For example, at the Mildmay Centre in Uganda, the primary purpose of collecting data is to monitor patients' progress and to guide program and service provider decisions about their medical and nutritional care. In Zambia, CRS's SUCCESS and the

WV-led RAPIDS consortium programs collect data primarily to assess the impact of their interventions as part of a larger evaluation that aims to contribute to the evidence base about how food programs can address the needs of HIV-affected communities.¹¹

8.3

Key Concept

Challenges of M&E for Food Assistance Programs in an HIV Context

Monitoring and evaluation of food assistance programs in the context of HIV faces many of the same challenges as M&E in other types of programming—M&E efforts are often underbudgeted, often require greater technical skills or time availability than project staff have and are sometimes neglected or underemphasized in work plans and job descriptions. However, food-based programs in a high HIV prevalence context pose additional challenges to M&E, a number of which are listed below.

Anthropometrics. While anthropometric indicators have considerable value in assessing the impact of food assistance in various settings and circumstances, their usefulness may be more limited in an HIV context. In a non-HIV context, prevalence of wasting, underweight and stunting of children aged 0–5 is a good indicator of a population’s health and nutritional status. However, in an HIV context the nutritional status of children aged 0–5 may be less reflective of the entire population because HIV infection affects adults most directly.

On an individual level, anthropometric measurements can provide an incomplete picture of the nutritional status of PLHIV if used in isolation. For example, improvements that occurred due to food and nutrition support may be masked by other effects of the disease.

Unintended household use of food assistance. Households might not use food assistance in the way it is intended. For example, a household might share food intended for PLHIV, or it may trade or sell food to pay for household expenses. This can substantially dilute food assistance impacts on targeted individuals.

Causal attribution is generally not possible, even in non-HIV contexts. Attributing specific changes in outcomes to food assistance is extremely difficult even under less complicated conditions. In HIV contexts, indicators such as morbidity, mortality and even nutritional status are influenced by many program and non-program factors besides food assistance. Therefore, without a very rigorous evaluation design—which programs are not expected to employ—it is not possible to isolate how much of observed impact is due to food assistance. Donors generally acknowledge these limitations, and programs should still try to measure outcomes and impacts to the best of their ability, while examining and acknowledging any changes in assumptions regarding the operating environment.

Validity of proxies. The validity of some indicators may be context-specific and defy straightforward interpretation. For example, area of cultivated land is an indicator that is predicted to decrease with the loss of productive household labor. However, a study in Kenya showed that the correlation between family size and land cultivated required two additional indicators—gender of deceased household member and type of crop being cultivated. Specifically, the death of an adult male may reduce cash crop production, and increase production of low-labor root crops. Understanding these relationships will help guide the inclusion of specific questions—in this case, questions about gender and type of crop—into M&E tools for more accurate analysis and interpretation of data.¹⁴

Validity of traditional sampling units. Some of the assessment or sampling methods traditionally used in food assistance programming may not be valid in HIV-affected areas. In particular, the household may not be an appropriate basic sampling unit because of adult death, household dissolution and large numbers of beneficiary orphans on the street or in institutional care.¹⁵ In areas where most services are facility-based, clinics may not know which households their beneficiaries come from, making population-based sampling difficult. In addition, people who go to clinics may not be representative of the infected population, meaning that a programmer would not be able to generalize clinic-based samples to the

general population in the program's targeted area. Programs may need to adjust sampling methods to reflect the demographic situation and be transparent about a sample's limitations if the sampling frame is neither complete nor representative.

Dietary recall. Unreliable responses from caregivers and patients about food consumption and treatment adherence are a concern. In addition, dietary recall by a small number of participants may not accurately reflect actual dietary patterns across all participants.

Lack of proven assessment tools. There are few tried and true tools to measure some outcomes and impacts of food assistance in HIV contexts. These include tools for proven methods of assessing the impact of pre-existing malnutrition on disease progression and tools that can demonstrate causal attribution of food assistance provided to PLHIV.^{16, 17}

Staff skills. Inadequate training and experience in data collection, especially where tools have to be adapted for HIV contexts, can result in poor quality data. In addition, there is a lack of staff who can design, supervise and analyze evaluations with the complexity needed to measure food assistance outcomes and impacts on individuals and households in an HIV context.

Tool for Monitoring the Use of M&E Systems

In 2003, C-SAFE in Zimbabwe found that its M&E systems were increasingly complex and grew concerned that unnecessary data may be generated, resulting in waste and inefficiency. To monitor the utility of various M&E tools, project managers were asked to provide feedback on how they had used information

generated by the system. Their feedback was reported quarterly and discussed at M&E meetings in order to streamline systems. The M&E monitoring and feedback tool was later used in all three C-SAFE countries, Lesotho, Zambia and Zimbabwe.

Using Anthropometrics in an HIV Context

In a C-SAFE review of literature and field experiences on the impact of food assistance on PLHIV, the most common indicators found were BMI, MUAC and change in weight.¹² Other indicators used include head circumference, W/H, body circumferences, skin-fold measurements and biometric impedance analysis (BIA).

The review noted that even in ideal conditions where HIV-positive children receive well over the RDA of calories and protein, inferior growth may be seen, and HIV-positive adults with no enteric pathogens show diminished skin fold thickness and lower weight than HIV negative adults despite equal food intake. Furthermore, lipodystrophy may make MUAC unreliable for PLHIV who are on ART. This suggests that in HIV contexts, differences in anthropometry indicators do not necessarily imply differences in food intake.

Nutritional status and growth may be impaired because of malabsorption or metabolism that exceeds one's appetite or ability to consume. In such cases food assistance may be enhancing the food security of the family and even supporting the PLHIV's nutritional status, but the BMI or MUAC measurements may not reflect as large a positive change as expected.

Despite the need for caution in using BMI to assess nutritional status among HIV-positive individuals, C-SAFE Malawi field staff suggested BMI as a promising indicator for measuring the impact of food assistance on ART program participants. Staff did not feel collection of information on weight would pose additional burdens, as some of the ART drugs

prescribed are dosed according to weight and patients are weighed regularly at the clinics. In fact, national guidance in Malawi calls for BMI to be measured for ART patients to determine if they should be referred to food assistance programs (for BMI < 16, patients are referred to therapeutic feeding; for BMI 16-17, they are referred to a supplemental feeding program, though these referral options may not always reliably exist).¹³

While change of weight is a common and important measure of changes in nutritional status, participants in a recent FANTA review pointed out some of its limitations:

- ▶ Weight alone may not provide sufficient information about nutritional practices; for example, a person may gain weight but still not be eating a sufficiently nutritious diet.
- ▶ Weight change may not be comparable across a population because a given weight change can have different implications for people of different weights.
- ▶ Food and nutrition interventions may not be effective in helping a person with AIDS to gain weight once the disease is in an advanced stage. The intervention may be helping to manage symptoms or improve the individual's quality of life, and weight alone may be an inappropriate measure of the intervention's benefits.
- ▶ Weighing an adult in community or home-based settings can be difficult because of the logistics of accessing accurate and reliable scales.

Annex I: Food Access Indicators

Below are five indicators/indices that can be used to measure food access:

Months of Adequate Household Food Provisioning (MAHFP)

The MAHFP indicator is a measure of household food access that captures changes in the household's ability to access food by examining its food supply over the past year and assessing to what extent that level of supply was sufficient to meet household needs. Measuring MAHFP can capture the combined effects of a range of interventions and strategies, such as improved agricultural production, storage and interventions that increase the household's purchasing power. Guidance on using MAHFP can be found at www.fantaproject.org/downloads/pdfs/MAHFP_Jun07.pdf.

Household Dietary Diversity Score (HDDS)

HDDS is another indicator of household food access that assesses the number of different food groups consumed over a given reference period. Unlike the MAHFP, this indicator uses the diversity of the diet as a measure of household food consumption. One of these two indicators (MAHFP and HDDS) is required for all USAID FFP Multi-Year Assistance Programs (MYAP) that aim to improve food access. Guidance on using HDDS can be found at www.fantaproject.org/downloads/pdfs/HDDS_v2_Sep06.pdf.

Coping Strategies Index (CSI)

The CSI is a relatively simple and efficient indicator of household food security that correlates well with other more complex measures of food insecurity. Developed by CARE and field tested by WFP and CARE, the CSI has been used for early warning and food security monitoring in eight African countries and several Middle Eastern countries. It measures the frequency of use and the severity of a household's coping strategies for addressing shortfalls in food supply. Guidance on using CSI can be found at www.fao.org/crisisandhunger/root/pdf/cop_strat.pdf.

Household Food Insecurity Access Scale (HFIAS)

Developed by FANTA in collaboration with Cornell University and Tufts University, the HFIAS is a set of nine questions that distinguish food-insecure from food-secure households across different cultural contexts. These questions represent universal domains of the experience of insecure access to food that can be used to assign households and populations along a continuum of severity of food insecurity. Guidance on using HFIAS can be found at www.fantaproject.org/publications/hfias_intro.shtml.

Food Consumption Score (FCS)

The FCS represents a proxy for the diversity of the household diet and is calculated based on the household's reported diet over the three days before the survey. Each food type is allocated a score based on its nutrient density, and the maximum possible FCS score is 48. The higher the FCS score, the more nutritionally dense the diet is. The tool is described in *CHS Regional Analysis: Household Vulnerability and the Impact of Food Aid*,¹⁸ available at: www.reliefweb.int/library/documents/2005/csafesouafr-28feb.pdf.

Annex 2: ECOG (Zubrod) Scale

This scale can be used by doctors, clinical staff and M&E personnel to assess the progression of disease in individuals and its impact on their daily activity. It may also be helpful in determining appropriate care and treatment responses as well as potential options for food assistance (if needed).

ECOG Grade (PS)	Definition
0	Fully active, able to carry on all pre-disease activities with restriction (KS 90-100)
1	Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature (KS 70-80)
2	Ambulatory and capable of all self-care but unable to carry out any work activities. Out of bed > 50% (KS 50-60)
3	Capable of only limited self-care, confined to bed or chair > 50% waking hours (KS 30-40)
4	Completely disabled, cannot carry on any self-care, totally confined to bed or chair (KS 10-20)

Source: Eastern Cooperative Oncology Group (ECOG). *ECOG Performance (Zubrod Scale)*. As published in *American Journal of Clinical Oncology*: Oken, M.M., Creech, R.H., Tormey, D.C., Horton, J., Davis, T.E., McFadden, E.T., and Carbone, P.P. "Toxicity And Response Criteria of The Eastern Cooperative Oncology Group," *American Journal of Clinical Oncology* 5 (1982):649-655.

Annex 3: WHO Disease Stages of HIV/AIDS

WHO Clinical Staging of HIV/AIDS for Adults and Adolescents with Confirmed HIV Infection	
Clinical Stage 1	<ul style="list-style-type: none"> ▶ Asymptomatic ▶ Persistent generalized lymphadenopathy
Clinical Stage 2	<ul style="list-style-type: none"> ▶ Unexplained moderate weight loss (<10% of presumed or measured body weight) ^a ▶ Recurrent respiratory tract infections (sinusitis, tonsillitis, otitis media and pharyngitis) ▶ Herpes zoster ▶ Angular cheilitis ▶ Recurrent oral ulceration ▶ Papular pruritic eruptions ▶ Seborrhoeic dermatitis ▶ Fungal nail infections
Clinical Stage 3	<ul style="list-style-type: none"> ▶ Unexplained ^b severe weight loss (>10% of presumed or measured body weight) ▶ Unexplained chronic diarrhea for longer than one month ▶ Unexplained persistent fever (above 37.6°C intermittent or constant, for longer than one month) ▶ Persistent oral candidiasis ▶ Oral hairy leukoplakia ▶ Pulmonary tuberculosis (current) ▶ Severe bacterial infections (e.g., pneumonia, empyema, pyomyositis, bone or joint infection, meningitis, bacteremia) ▶ Acute necrotizing ulcerative stomatitis, gingivitis or periodontitis ▶ Unexplained anaemia (<8.g/dl), neutropaenia (<0.5 x 10⁹ per liter) and/or chronic thrombocytopaenia (<50 x 10⁹ per liter)
Clinical Stage 4 ^c	<ul style="list-style-type: none"> ▶ HIV wasting syndrome ▶ Pneumocystis pneumonia ▶ Recurrent severe bacterial pneumonia ▶ Chronic herpes simplex infection (orolabial, genital or anorectal of more than one month's duration or visceral at any site) ▶ Oesophageal candidiasis (or candidiasis of trachea, bronchi or lungs) ▶ Extrapulmonary tuberculosis ▶ Kaposi's sarcoma ▶ Cytomegalovirus infection (retinitis or infection of other organs) ▶ Central nervous system toxoplasmosis ▶ HIV encephalopathy ▶ Extrapulmonary cryptococcosis including meningitis ▶ Disseminated non-tuberculous mycobacterial infection ▶ Progressive multifocal leukoencephalopathy ▶ Chronic cryptosporidiosis (with diarrhea) ▶ Chronic isosporiasis ▶ Disseminated mycosis (coccidiomycosis or histoplasmosis) ▶ Recurrent non-typhoidal Salmonella bacteremia ▶ Lymphoma (cerebral or B-cell non-Hodgkin) or other solid HIV-associated tumors ▶ Invasive cervical carcinoma ▶ Atypical disseminated leishmaniasis ▶ Symptomatic HIV-associated nephropathy or symptomatic HIV-associated cardiomyopathy

a - Assessment of body weight in pregnant woman needs to consider the expected weight gain of pregnancy.

b - Unexplained refers to where the condition is not explained by other causes.

c - Some additional specific conditions can also be included in regional classifications (such as reactivation of American trypanosomiasis [meningoencephalitis and/or myocarditis] in the WHO Region of the Americas and disseminated penicilliosis in Asia).

Source: World Health Organization (WHO). *WHO Case Definitions of HIV for Surveillance and Revised Clinical Staging and Immunological Classification of HIV-Related Disease in Adults and Children*. Geneva: WHO, August, 2006.

Annex 4: MOS-QOL Questionnaire for HIV-Infected Individuals

This survey is taken from Mast, T.C., Kigozi, G., Wabwire-mangen, F., et al. "Measuring Quality of Life Among HIV-Infected Women Using a Culturally Adapted Questionnaire in Rakai District, Uganda," *AIDS Care* 16 (1) (2004): 81-94.

Quality of Life								
Now, I would like to ask you a few questions about your health. [INTERVIEWER: Q1 - Q13 ARE PROMPTED]								
1.	In general, would you say your health is:	Excellent...1 Very good...2 Good...3 Fair...4 Poor...5					_ {Q1}	
2.	How much <i>bodily</i> pain have you generally had during the <i>past thirty days</i> ?	None...1 Very mild...2 Mild...3 Moderate...4 Severe...5 Very severe...6					_ {Q2}	
3.	During the <i>past thirty days</i> , how much did <i>pain</i> interfere with your normal work, including both work outside the home and housework?	Not at all...1 A little bit...2 Moderately...3 Quite a bit...4 Extremely...5					_ {Q3}	
4.	The following questions are about activities that a person might do during a typical day. Does your <i>health now limit you</i> in the following activities? If so, how much?	YES, limited a lot	YES, limited a little	NO, not limited at all				
4a.	The kinds or amounts of <i>vigorous</i> activities you can do like, digging, fetching water from a well, carrying a big bunch of matooke, splitting firewood.	1	2	3	_ {Q4A}			
4b.	The kinds or amounts of <i>moderate</i> activities you can do like washing clothes, moving a jerrican of water or moving a bundle of firewood from one place to another.	1	2	3	_ {Q4B}			
4c.	Walking up a hill, climbing stairs.	1	2	3	_ {Q4C}			
4d.	Bending, lifting light objects or kneeling.	1	2	3	_ {Q4D}			
4e.	Walking a distance, like the length of a football pitch, about 100 meters.	1	2	3	_ {Q4E}			
4f.	Eating, dressing, bathing or using the latrine.	1	2	3	_ {Q4F}			
5.	Does your health <i>keep you</i> from working at a job, doing work around the house or attending school?	Yes...1	No...2	_ {Q5}				
6.	Have you been unable to do <i>certain kinds or amounts</i> of work, housework or schoolwork, because of your health?	Yes...1	No...2	_ {Q6}				
For each of the following questions, please tell me the answer that comes closest to the way you have been feeling in the past thirty days.		All of the time 1	Most of the time 2	A good bit of the time 3	Some of the time 4	A little of the time 5	None of the time 6	
7.	How much of the time, during the past thirty days, has your <i>health limited your social activities</i> , like visiting your friends or family?	1	2	3	4	5	6	_ {Q7}
8.	How much of the time, during the past thirty days:							
8a.	Have you been a very nervous person?	1	2	3	4	5	6	_ {Q8A}
8b.	Have you felt calm and peaceful?	1	2	3	4	5	6	_ {Q8B}
8c.	Have you felt depressed?	1	2	3	4	5	6	_ {Q8C}
8d.	Have you been a happy person?	1	2	3	4	5	6	_ {Q8D}

8e.	Have you felt so depressed that nothing could cheer you up?	1	2	3	4	5	6	<input type="text"/> {Q8E}
9.	How often during the past thirty days:							
9a.	Did you feel full of life and energy?	1	2	3	4	5	6	<input type="text"/> {Q9A}
9b.	Did you feel totally without energy?	1	2	3	4	5	6	<input type="text"/> {Q9B}
9c.	Did you feel tired?	1	2	3	4	5	6	<input type="text"/> {Q9C}
9d.	Did you have enough energy to do the things you wanted to do?	1	2	3	4	5	6	<input type="text"/> {Q9D}
9e.	Did you feel weighed down by your health problems?	1	2	3	4	5	6	<input type="text"/> {Q9E}
9f.	Were you discouraged by your health problems?	1	2	3	4	5	6	<input type="text"/> {Q9F}
9g.	Did you feel despair over your health problems?	1	2	3	4	5	6	<input type="text"/> {Q9G}
9h.	Were you afraid because of your health?	1	2	3	4	5	6	<input type="text"/> {Q9H}
		All of the time 1	Most of the time 2	A good bit of the time 3	Some of the time 4	A little of the time 5	None of the time 6	
10.	How often during the past thirty days:							
10a.	Did you have difficulty reasoning and making decisions, for example, making plans or learning new things?	1	2	3	4	5	6	<input type="text"/> {Q10A}
10b.	Did you forget things that happened recently, for example, where you put things or when you had appointments?	1	2	3	4	5	6	<input type="text"/> {Q10B}
10c.	Did you have trouble keeping your attention on any activity for long?	1	2	3	4	5	6	<input type="text"/> {Q10C}
10d.	Did you have difficulty doing activities involving concentration and thinking?	1	2	3	4	5	6	<input type="text"/> {Q10D}
		Definitely true 1	Mostly true 2	Don't know 3	Mostly false 4	Definitely false 5		
11.	Please tell me the answer that comes closest to describing whether the following statement is true or false for you. The answers are: [INTERVIEWER: READ RESPONSES ABOVE]							
11a.	You are somewhat ill.	1	2	3	4	5		<input type="text"/> {Q11A}
11b.	You are as healthy as other people you know.	1	2	3	4	5		<input type="text"/> {Q11B}
11c.	Your health is excellent.	1	2	3	4	5		<input type="text"/> {Q11C}
11d.	You have been feeling bad recently.	1	2	3	4	5		<input type="text"/> {Q11D}
12.	How has the quality of your life been during the <i>past thirty days</i> ? That is, how have things been going for you?	Very well; could hardly be better...1 Pretty good...2 Good and bad parts about equal...3 Pretty bad...4 Very bad; could hardly be worse...5						<input type="text"/> {Q12}
13.	How would you rate your physical health and emotional condition now compared to <i>thirty days ago</i> ?	Much better...1 A little better...2 About the same...3 A little worse...4 Much worse...5						<input type="text"/> {Q13}

Endnotes

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