

Measuring the Impact of Targeted Food Assistance on HIV/AIDS-Related Beneficiary Groups

*With a Specific Focus on
TB, ART, CI and PMTCT Beneficiaries*

M&E Indicators for Consideration



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The views and opinions expressed in this document are those of the authors, and not necessarily of the individual C-SAFE member agencies.

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This research was supervised and guided by Kate Greenaway, regional technical advisor for HIV/AIDS, and the document was edited by Kara Greenblott, regional programming section manager.

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Acronyms

ARV	Anti-retroviral
ART	Anti-retroviral Therapy
BIA	Bioelectrical Impedance Analysis
BMI	Body Mass Index
CDC	Center for Disease Control and Prevention
CHAZ	Churches Health Association of Zambia
CHS	Community and Household Surveillance
CIDRZ	Center for Infectious Disease Research in Zambia
CRS	Catholic Relief Services
C-SAFE	Consortium for Southern Africa Food Security & Emergency
CSB	Corn Soy Blend
CSM	Corn Soy Milk
DAP	Development Assistance Program
ECOG	Eastern Cooperative Oncology Group
EHFIS	Experiential Household Food Insecurity Scale
EGPAF	Elizabeth Glaser Pediatric AIDS Foundation
EUM	End Use Monitoring
HAART	Highly Active Anti-retroviral Therapy
HAI	Household Asset Index
HDD	Household Dietary Diversity
I-LIFE	Improving-Livelihoods through Increasing Food Security
MDRTB	Multi-Drug Resistant Tuberculosis
MOS	Medical Outcome Survey
MSF	Medecins Sans Frontieres
NAC	National AIDS Council
NFNC	National Food and Nutrition Commission (Zambia)
PDM	Post Distribution Monitoring
PLHA	People living with HIV/AIDS
PMTCT	Prevention of Mother To Child Transmission
PPTCT	Prevention of Parent To Child Transmission
PVO	Private Voluntary Organization
QOL	Quality of Life
ROL	Review of Literature
TB	Tuberculosis
TB-DOTS	Tuberculosis – Directly Observed Treatment, Short-course
TFA	Targeted Food Assistance
VCT	Voluntary Counseling and Testing
WHO	World Health Organization
WVI	World Vision International
ZNAN	Zambia National AIDS Network

I. Executive Summary

The purpose of this study is to assist C-SAFE members and other interested stakeholders to better measure the impact of Targeted Food Assistance (TFA) on people living with HIV/AIDS (PLHA). Specifically, this study focuses on four HIV/AIDS-related beneficiary groups: the Chronically Ill (CI), TB patients, individuals receiving ART and individuals enrolled in PMTCT. It is intended to facilitate an improved understanding of various options for measuring impact of TFA on these groups, and prompt discussion, debate and further research around the use of various indicators.

Initiated by C-SAFE Learning Spaces in November 2004, this study began with a literature review (December 2004) which was released, and has been available on the C-SAFE website, since early 2005. The literature review was then followed by field research in Malawi, Zambia and Zimbabwe (February 2005). Documents were reviewed from a wide variety of sources and in the field, information was gathered through key informant interviews, group discussions, observational visits and collection of current monitoring and evaluation tools from over 66 individuals and 29 different organizations.

A key finding of this research is that there is a dearth of documented evidence, both in the literature and the field, showing the impact of food aid on these HIV/AIDS related beneficiary groups. Despite the lack of *documented* evidence, numerous *testimonials* from HIV positive beneficiaries and program staff gave anecdotal examples of the impact of food aid on the chronically ill, and TB, PMTCT and ART program participants. No one interviewed expressed any doubt about the importance of food aid as a key component of comprehensive HIV/AIDS services.

According to the review of the literature and field research, the key changes expected from food aid at the household and individual level are:

- increase in daily food consumption by all household members
- increase in money available for other needs
- increase in household food security

These improvements generate subsequent changes in the individual and household that are believed to result in increases in weight, energy, treatment adherence, school attendance, immunity, medical treatment, quality of life, productive capacity and ultimately, survival; in addition to an anticipated increase in program uptake. Given that many of the existing indicators are difficult to collect and interpret, this paper proposes a short list of indicators for consideration. The following list is by no means exhaustive, nor does C-SAFE purport that they are the most appropriate in all cases. They are simply the indicators thought by the interviewees and the researchers to be generally the most feasible and relevant given C-SAFE's operating environment and capacity constraints.

Table 1: Indicators for Consideration when Measuring the Impact of TFA by Program Type¹

Indicators for Consideration in Measuring Impact	Program Type				
	TB	ART	CI	PMTCT	
				Mother	Child
1. Anthropometrics					
BMI	X	X	X	X	
Percentage of Weight Change		X	X	X	
MUAC				X	
Weight for Age					X
Weight for Height					X
2. Treatment Adherence	X	X		X	
3. Risky Coping strategies		X	X	X	
4-6. Quality of Life					
Mental Health	X	X	X	X	
Activities of Daily Living	X	X	X	X	
Productive capacity	X	X	X	X	
7. Need for Caregivers		X	X		
8. Program Uptake	X			X	

While the opinions of the people who contributed to this paper are valid and insightful, neither the ROL nor the field interviews and discussions found significant evidence of where the direct impact of TFA is being measured. With this in mind, it should be noted that the indicators selected for presentation in this paper are not a reflection of validated research, but rather the most promising ideas from technical staff currently working with TFA programs. To this end, the following recommendations are made to with regards to furthering our collective understanding how to measure impact of TFA on chronically ill, and TB, PMTCT and ART beneficiaries.

- Pilot the eight indicators listed above and articulated in the Discussion section of this document at select sites of C-SAFE, I-LIFE and similar NGO food aid programs targeting these groups to measure program impact. Indicators measuring program inputs, activities, and outcomes are also needed as monitoring tools and to help interpret impact indicators, but are not discussed in this document.
- Include some of the suggested indicators into future C-SAFE and I-LIFE surveys, and eventually integrate them into future project M&E systems;
- In established EUM, PDM and CHS collection tools, link data already collected such as coping strategies, school participation, and program uptake to participation in food aid programs;
- Establish M&E partnerships between health centers, district level, central governmental authorities and food aid programs serving the same populations and determine information of mutual interest which could be shared;
- Share lessons learned among C-SAFE partners, the wider UN/NGO network and local health service providers.

¹ As is presented in this paper, further research is needed to assess the validity and to further understand the sensitivity and specificity of these indicators. Details on each indicator are found in Annex C.

II. Background, Objectives and Methodology

Background

In October 2005, the Consortium for the Southern Africa Food Security Emergency (C-SAFE) transitioned to its fourth and final year of a regional ‘developmental relief’ program. Members in Zambia and Zimbabwe had completed three full years with the regional Consortium and the Lesotho members had joined in Year 3. C-SAFE Malawi left the regional consortium at the end of Year 2, and transitioned to a five year Development Assistance Program (DAP) entitled Improving-Livelihoods through Increasing Food Security (I-LIFE). C-SAFE and I-LIFE continued to collaborate on this specific learning activity given their common objectives of improving M&E for HIV/AIDS related beneficiary groups. C-SAFE’s strategic objectives included: 1) to improve/maintain nutritional status; and 2) to protect productive assets; and 3) improve community resilience to future food security shocks.

The term **Targeted Food Assistance** (TFA) is used by the C-SAFE members as an umbrella term which may include individual or household rations, dry or wet distribution methods, and includes/overlaps with ‘supplemental’ and ‘complementary’ feeding. TFA is distinct from general food distributions (GFD) and Food for Assets (FFA) and is used to refer to targeted feeding to specific vulnerable groups such as the chronically ill (a proxy for HIV/AIDS).

As part of its Targeted Food Assistance (TFA) program, C-SAFE provides food assistance to four HIV/AIDS related beneficiary groups. The chronically ill (CI) is used by all three members as a proxy for HIV/AIDS², and several of C-SAFE’s members also link TFA to medically oriented interventions such as PMTCT, TB-DOTS and Antiretroviral Therapy (ART).³ Throughout project implementation, the issue of how to measure the impact of food aid on individuals receiving ART or TB drugs, mothers and infants enrolled in PMTCT programs and the chronically ill has been discussed and debated. While C-SAFE regularly monitors *household food security* using variety of tools and systems, and in some programs measures the nutritional status of children under five; measuring the impact of food on these four HIV/AIDS related groups remains a significant challenge.

To date, for individuals receiving ART or TB drugs, and those in PMTCT programs, C-SAFE members monitor whether or not food was received, but generally do not gather much additional information. Many clients are being weighed regularly by health service providers, and a range of other indicators are being used to monitor progress, though C-SAFE staff have not generally taken advantage of this information, nor systematically applied other (livelihoods or nutrition) indicators to measure whether there is demonstrable change as a result of food aid. The most common measure of ‘success’ has been attached to program uptake and treatment adherence. The monitoring of the chronically ill is similar, with limited or no data gathered to try demonstrate the direct impact of food aid on the affected individual.

As C-SAFE members and other agencies expand their involvement in this type of programming, it becomes increasingly important that we attempt to build an evidence-based understanding of the attribution of food aid to the quality of life and physical status of these beneficiaries, not only to better justify the provision of such assistance, but as importantly, to improve the design and implementation of targeted food assistance programs to these beneficiaries.

To assist Consortium members to begin to ‘unpack’ this complex issue, a study was commissioned by C-SAFE Learning Spaces⁴ in November, 2004. A review of the literature was completed in December 2004 and field research in Malawi, Zambia and Zimbabwe in February 2005. The two researchers were asked to summarize current knowledge and practices and advise C-SAFE and other stakeholders about appropriate, practical methods for monitoring the impact of targeted food assistance on HIV/AIDS related beneficiary groups.

² To date, C-SAFE has used chronic illness as a proxy for AIDS as defined by *an individual experiencing persistent and recurring illness lasting three months or more, which has reduced that person’s level of productive capacity.*

³ A summary of C-SAFE’s better practices in TFA, which cites examples of these types of programs, was published by the C-SAFE Learning Center in 2005. The document also provides Guidance for linking food aid with medical interventions. *Targeted Food Assistance in the Context of HIV/AIDS* is available at www.c-safe.org.

⁴ Learning Spaces was housed by the Regional Program Unit of C-SAFE through September 2005. This initiative provided a vehicle for learning among consortium members and other stakeholders on key themes such as HIV/AIDS and food security, food aid targeting, and lessons learned from working in a consortium format.

Objectives

The overall objective of this research was to investigate current practices for measuring the impact of TFA on four HIV/AIDS related beneficiary groups: 1) the chronically ill (CI); 2) women and infants engaged in PMTCT programs; 3) individuals on ART; and 4) individuals on TB treatment. This was done through a review of the literature followed by interviews and observational visits of HIV/AIDS-related food aid programs in Malawi, Zimbabwe and Zambia. Recommendations for monitoring and evaluating the direct impact of TFA are provided based on the literature review and analysis from the fieldwork.

The specific objectives of the investigation were as follows:

- Identify current knowledge and practices of assessing the impact of Targeted Food Assistance (TFA) on people living with HIV/AIDS (PLHA) through a literature review;
- Review and examine C-SAFE programming for CI, TB, PMTCT and ART in Malawi, Zimbabwe and Zambia and document current practices in measuring impact;
- Interview key technical staff and stakeholders in the regional office and the three C-SAFE countries to solicit opinions and experience with measuring the impact of food on CI beneficiaries;
- Recommend effective and appropriate indicators to be used in measuring the impact of TFA in CI, TB⁵, PMTCT and ART programming;
- Develop a set of tools/questionnaires and simple guidance notes on their use in programming that will make the tools accessible to field staff;
- Recommend sites and processes most appropriate for piloting the tools, in order that the C-SAFE M&E team can move forward on operationalization.

Methodology

The literature review included a search of PUBMED, AEGIS, the Cochrane Database of Systematic Reviews and the search engines of major food relief and development agencies. Agencies reviewed included The World Bank, FAO, IFAD, World Food Program (WFP), FANTA, USAID, AED, Save the Children and IFPRI. The following key word combinations were used in combination with HIV&AIDS:

- Food and medicine
- Food relief
- Food supply
- Hunger and medicine
- Medical and interventions and food and relief
- Nutrition and medicine
- Nutrition and surveys and medicine

Searches were further refined through the screening of reference lists of relevant papers. When saturation of the literature was achieved, each paper was scrutinized for information on nutritional status and the impact of TFA in the context of HIV&AIDS. Since the literature is limited in this area, a wider review of literature was then done, including disease progression and nutrition, impact of treatment, and psychosocial issues. Due to the lack of available papers in peer-reviewed journals, the "grey" literature was also reviewed and is presented here.

In the field, information was gathered through key informant interviews, group discussions, observational visits and collection of current monitoring and evaluation tools. In each study country, a local representative identified appropriate field sites to visit and stakeholders to interview. For each intervention type, analysis focused on objectives, strengths and weaknesses of current practices, gaps, and recommendations for integrating impact measurements into future activities. During the visits, the researchers pursued additional interviews and site visits as time and transport allowed.

⁵ Since chronic illness is used as a proxy for AIDS, and TB patients make up a significant sub-set of the chronically ill, targeting TB patients was intended to capture those who are HIV positive without the stigmatizing effect of requiring an HIV test. While C-SAFE acknowledges that HIV negative TB patients are also captured through this mechanism, this is not considered an inclusion error, as they are also chronically ill.

The following questions guided the interview process:

1. In your work plan or proposal, what is the stated impact you plan to achieve?
2. Program design:
 - a. How did you design your ration package to attain this impact?
 - b. How did you design your distribution system to achieve this impact?
3. How did you design your M & E to assess this impact? (EUM, PDM, CHS)
4. Do you think your food aid program is having an impact? YES/NO
5. Is YES what is the impact?
 - a. Are these the intended impacts (Q. 1)?
 - b. Were there additional impacts? What were they?
 - c. If the intended impacts were not achieved, why not?
6. How do you think your program could be designed to increase impact?
7. Ration targeting
 - a. To meet nutritional deficit?
 - b. To encourage uptake? (Smaller incentive ration—can't be both, if too much concern re: selling off)

Regarding tools used to measure impact:

8. What are you doing now to measure impact?
9. How would you like to change this? {Recommendations for evaluating impact}
10. Do you know of any studies or have access to any data which is assessing impact?
11. What are your reactions to the following indicators? (feasibility, comfort level, training needs, enumerators)
 - Weight
 - Height
 - Hand grip strength
 - Diarrhea incidence
 - CD4 count
 - Accessing health information
 - QOL assessment

A total of 66 individuals from 29 different agencies were interviewed across the three countries. A list of interviewees / organizations consulted are included in Annex A.

III. Results

A. Review of the Literature

This work highlights the paucity of studies addressing provision of TFA to PLHAs, and almost complete void of documentation on measuring impact of food aid on PLHAs. Although HIV-related confidentiality and stigma are extensively discussed, practical tools to assess TFA's impact on households and ultimately nutritional outcomes for PLHA are not widely available.

During the review of literature (ROL), over 75 documents were reviewed from a wide variety of sources. The review began with AEGIS.COM news briefs from June 2002 (Wall Street Journal, Associated Press, UN, BBC News, South African Sunday Times, Reuters, Inter Press Service and the International Federation of Red Cross and Red Crescent) [1-16]. Common themes included:

- Food relief (supplements) as long-term care or recovery
- The concept of a “new variant famine”
- Chronic illnesses' negative impact on household food security
- The unmet needs of Orphans and Vulnerable Children (OVC)
- Multiple targets and entry points
- Issues of denial and stigma
- Gender inequity (women as caregivers, girls leaving school to care, etc.)

While many organizations advocate for incorporating food aid into HIV/AIDS programming, there is a serious lack of empirical evidence on how best to evaluate the impact of programs on participants who are HIV positive or living with AIDS [18,21,24,25,34]. Despite the lack of experience in how to evaluate the impact of TFA on HIV/AIDS participants, this literature review has identified a number of important starting points and potential indicators to pilot for use in measuring impact changes from TFA programs. Findings geared to two levels (Individual and Household) are outlined below.

1. Assessing Individual Impact

a) Nutritional status: Traditional anthropometric measures (weight, height and age) are important aspects of assessments and are one of the few quantitative measurements that are practical for field measurement. Anthropometric measurements give evidence of the nutritional status of someone with HIV/AIDS and, tracked over time, can show nutritional improvement or decline.

The literature provides some guidance on how best to use anthropometric indicators to monitor and measure the impact of programs. Miller (2003) suggests that nutritional status can be basically assessed through vigilant monitoring of weight status and that disease progression can be monitored through serial measurements of MUAC, triceps skin folds and other anthropometry[36]. These recommendations are supported by the HAART and HARVEST program in Kenya which monitors weight in an effort to link food security with antiretroviral therapy (ART) outcomes [31].

In the few research studies measuring the impact of food aid on PLHA, body mass index (BMI)⁶, mid-upper arm circumference (MUAC) and weight measurements were the most common indicators, though head circumference, weight for height, BIA, body circumferences and skin-fold measurements were also used to measure nutritional impacts of TFA programs [64-67]. A few organizations are also experimenting with handgrip strength as an easily administered proxy for nutritional status using a mechanical handgrip dynamometer. Used primarily to date with elderly populations, handgrip has been found to be positively correlated to BMI, MUAC and arm muscle area [68].

⁶ Body mass index is calculated as kg/m²

HIV/AIDS brings additional problems in interpretation of anthropometric measurements that compromise the value of these traditional measures as indicators of the impact of TFA programs. For example, it is known that even in ideal conditions where HIV positive children receive well over the recommended daily allowance (RDA) of calories and protein, inferior growth may be seen and HIV positive adults with no enteric pathogens have shown diminished skin fold thickness and lower weight than HIV negative adults despite equal food intake [36]. Nutritional status and growth may be impaired because of malabsorption and a metabolism which can exceed one's ability (or appetite) to consume, so while the food aid may be enhancing the food security of the family and even helping the PLHA nutritionally, the BMI or MUAC measurements would not reflect any positive change. Without substantial years of data to refer to, it is difficult to interpret anthropometric measurement trajectories as impact from TFA may be reduced weight loss versus weight gain as is expected in TFA programs targeting HIV negative individuals.

Anthropometric indicators also are trailing indicators and generally show change subsequent to other sub-clinical measures of health, so by the time there are measurable changes, other important health changes have already occurred and the impact of food aid may not be detectable. In relation to MUAC, lipodystrophy may make that measurement unreliable for PLHA who are on ART.

In consideration of the above, the ROL shows that anthropometric measurements are useful components of a tool to measure impact, but used in isolation would not provide the level of understanding needed to assess a TFA program and potentially could be misleading. They can provide information on nutritional status and be helpful in assessing disease progression, but need to be interpreted in context. Clearly, what is required are program indicators that are sensitive to a variety of HIV/AIDS effects[17].

b) Strength and stamina: The return of strength and ability to be involved in routine and income generating activities are possible general indicators of TFA impact [22]. As with other measures, it would be important to control for the availability and use of medical treatment including ART, tuberculosis (TB) treatment and for the treatment of opportunistic infections. A mechanical handgrip dynamometer could be used to measure changes in strength due to TFA programs, though little has been published to test this instrument with PLHA.

c) Diarrhea prevalence: Diarrhea prevalence in young children (under 24 months of age) is another possible proxy measure of health and improved food security [27]. Another study supports a significant association between malnutrition and diarrhea incidence [73].

d) Treatment uptake and efficacy: For individuals on TB treatment or ART, a commonly mentioned impact of TFA programs was an increase in treatment uptake and a decrease in default rates.

e) Treatment completion (Tuberculosis) and Treatment adherence (ARV therapy for HIV/AIDS).

For PLHA's on TB treatment or ART, a commonly mentioned impact of TFA programs was an increase in treatment acceptability and ease of adherence with drug regimens. One study has shown that amongst a small sample of treatment interrupters, lack of money for food is seen as a barrier to treatment adherence [80]. Despite this, further studies are urgently needed to better understand and document the impact of food security on TB treatment completion and adherence to HAART.

f) Quality of life (QOL): Current literature abounds with studies on quality of life among PLHAs and recent interviews with health workers and TFA field staff support exploring the use of QOL as a measure of the impact of TFA. Quality of life is a multi-faceted concept, which considers the impact of impairments, function, perceptions and social opportunities [42]. Quality of life measures may prove promising in the assessment of improved food security. Numerous studies have been done using QOL measures with HIV positive persons, [47-49] and a number of tools exist [44-46, 69, 73]. Unfortunately, however, there are no published studies that look directly at the impact of food assistance on QOL for PLHAs. One unpublished pilot study has been done in South Africa on QOL and food, while another has looked at ARV-related nutritional problems and QOL [50]. QOL measures offer a richer assessment of the impact of TFA, including physical, social and psychological components. These benefits will need to be weighed against time needed to complete QOL assessments (minimum 20 minutes) and level of translation and training required.

Scales such as the Karnofsky and Disease Stage Scale and the WHO/Zubrod or ECOG Scale (Eastern Cooperative Oncology Group) that were originally developed to measure physical functioning levels for patients with cancer [74-75], now are being used to assess health and physical ability of PLHAs. Karnofsky uses a 0-100 scale in 10 point intervals, 100% signifying perfect health and 0 % indicating death. The ECOG Scale has only six values, 0 being asymptomatic and 5 signifying death. They are more focused on physical functioning and the ability to conduct daily activities than tools such as the HRQOL-HIV or MOS-HIV. There is a scale used in medical oncology for children that is based more on observation called the Lansky scale, but it does not appear in research conducted in the developing world context related to HIV/AIDS [76]. WHO recommends Karnofsky as a tool to use to monitor clinical status for patients on ARV treatment [77].

Strength and stamina issues addressed in section ‘b’ above are often incorporated into QOL indices.

2. Assessing Household Impact

Even for programs that target individuals, it is acknowledged that food aid impacts all household members as the individual and household are intrinsically linked, which is reflected in the fact that C-SAFE provides household or expanded sized rations. For this reason, traditional food aid programs usually measure household level impact as does C-SAFE and other food aid programs targeting PLHAs. However, demonstrated impact at the household level does not necessarily imply that there is also impact for the targeted individual.

The link between HIV/AIDS and household food insecurity has been discussed and demonstrated in several C-SAFE documents⁷. Therefore, while there are not tested examples presented in the literature, the level of household food insecurity is a potential indicator to use to measure the impact of food aid on PLHA. In addition to using individual level measurements (e.g. BMI) of all household members to measure household impact, a composite measure of the food security or insecurity level of the household has traditionally been used to measure impact of food aid. Known household responses to food insecurity that could potentially be used to track the impact of food aid programs targeting households affected by HIV/AIDS include sale of assets (both productive and non-productive), dietary changes, hiring in and out of household labor, and withdrawal of children from school [29]. Swindale has identified multiple household indicators to measure food insecurity such as dietary diversity, asset retention, as well as anthropometry, demographics and diarrhea prevalence in young children [27].

Another distinction which could be made would involve categorizing households based on the type of AIDS impact, e.g. chronic illness or death or support of orphans. This could be further broken down into impacts on human, financial, social, physical and natural capital [32]. Indicators that are already included in many data collection tools measuring food security include number of meals eaten per day, quantity or number of foods eaten in the past 24 hours, dietary diversity indices, consumption of luxury items, amount of land planted, and expenditure on food could be used to look at household impact of PLHA TFA programs. Examples of indices or composite tools which may be useful are: the *Experiential Household Food Insecurity Scale (EHFIS)*, *Household Dietary Diversity (HDD)*, *Household Asset Index (HAI)*[27] and *Coping Strategy Index* [78].

An issue to be considered when assessing household impact is the bi-directional nature of chronic illness and food security. Chronic ill-health may serve as a *cause* of food insecurity as well as a *consequence* of food insecurity [23]. HIV disease is related to food security at the individual, household and community levels. For example, during times of food insecurity individuals may skip meals which potentially could exacerbate chronic illness. In turn, subsequent infection and illness reduce an individual’s ability to improve their household food security.

⁷ Documents include ‘Targeted Food Assistance in the Context of HIV/AIDS,’ ‘Food Aid and Chronic Illness: Insights from the Community and Household Surveillance Surveys,’ and others.

B. Results of Field Research

1. Current Practices and General Impressions of Impact Measurement

As in the ROL, the primary finding of the field investigation was that indicators and methods to measure the direct impact of food aid on PLHA are not prevalent. While C-SAFE partners have a great deal of experience monitoring receipt of food aid and food security status of targeted households, most do not have indicators or formalized systems to measure the impact of food aid on PLHA.

Although anthropometric, clinical and performance measures are collected at the clinic level, they do not inform food programming and often the information is only collected on a qualitative or anecdotal basis. C-SAFE partners are collecting fairly extensive information on household coping strategies, assets, use of food aid, and vulnerability levels. However, this information generally is not gathered or analyzed in a manner that is able to tease out the direct impact of food aid on particular sub-groups of beneficiaries. In general, C-SAFE programs are not analyzing individual health outcomes, survival, quality of life or nutritional status, but focused rather on information at the household level. Considerable anecdotal information exists in relation to the impact of food aid on the individual and household, but neither agencies nor health facilities have systems of sufficient rigor or regularity to support reported observations. This is not necessarily due to the lack of capacity or interest, as staff stated they wanted to learn more about the impact of food aid on CI beneficiaries, but C-SAFE was neither mandated nor funded to collect this level of data, so M&E frameworks were not designed to do so.

Although no quantitative data exists to demonstrate the impact of food aid on PLHA in C-SAFE programs, almost all beneficiaries and stakeholders interviewed gave anecdotal evidence of positive impacts of food aid, most often citing increased weight, improved health and increased food consumption. Beneficiaries reported that after receiving food they experienced a noticeable improvement in body weight, strength, ability to work and overall well-being. For example, a middle-aged HIV positive woman with Kaposi's Sarcoma in Bangwe, Malawi who participated in a Salvation Army Home-based Care program with targeted food assistance through World Vision reported:

It was good to receive [the food aid]. I ate three meals a day compared to once a day before. [Before], I was dependent on visitors to bring food. I could not have employed someone to do the gardening. [With food aid], I had money to spare for other things, to buy fish, eggs, vegetables, and relishes. I was able to plant beans and maize.

A husband and wife on ART from MSF in Thyolo, Malawi who received targeted food assistance from World Vision that stopped in August 2004 reported:

Before food aid I had many challenges. I was sick, had stomach aches, heart palpitations, headaches and pneumonia. I started on ARVs and then got C-SAFE food. With drugs and food my physical problems decreased, I had less diarrhea, I gained a lot of energy and could move around and get involved. I had enough strength to mold bricks and construct a house. I could increase the gardening. [Since the food has been stopped] I have an increased problem taking the medications and my weight has decreased.

Before food support the wife's reported weight was around 40kg, with the ART and food support, she went to 61kg. She is still on ART, but with no food support, now weighs 47kgs.

Clinical staff reiterated similar experiences of the impact of food aid on patients' health, treatment adherence and nutritional status. For example, Sister Maggie Mutopo, Matron of St. Paul's Musami Hospital in Zimbabwe commented on participants in a HIV-positive support group that she leads [none of whom are on ART]. CSB was provided by CRS until October 2004 for the program.

I could see improvement in their general disposition and less complaints about their conditions. I also noticed people gaining weight. Now, at TB days each month, weight has dropped and there are less people attending [since food aid stopped in October].

As examples of specific indicators that could be used to measure the impact of food aid, both on the individual and household, most interviewees mentioned weight and/or body mass index (BMI). While BMI was consistently proposed as a useful measure of impact, interviewees did raise concerns regarding the capacity and equipment to accurately collect BMI, particularly height. While weight is routinely measured, the knowledge of how to measure height is not as common, and cultural issues around measuring height lying down (e.g. the belief that the only reason to be measured lying down is to determine coffin size) plus the lack of appropriate measurement equipment may compromise the collection of accurate BMI values. The quality of weight scales (reported as often being bathroom scales, both in the field and in clinics) was also questioned raising questions about the validity of data.

Indicators tracking health status, program uptake, drug efficacy and strength or stamina data such as return to productive capacity were also commonly mentioned along with household food security measures. When queried about quality of life issues such as mental health and ability to conduct daily activities, interviewees felt that these were things that food aid does impact, but that aren't normally tracked. Most all expressed an interest in having tools to measure these areas. No one mentioned handgrip strength, BIA, head circumference or skinfold measurements.

The work involved in collecting additional information to properly examine the impact of food aid on PLHA would not be extensive as much of it is already being collected or being partially collected. Many clinics routinely collect weight, symptoms, frequency of visits, treatment regimes, clinical outcomes and information that could be adapted to performance indicators such as the Karnofsky, ECOG and WHO scales. In general, it did not appear that this information is being retrieved or utilized by NGO food aid programs. Although cooperation between medical service providers and NGOs exist at the implementation level (such as clinics providing beneficiary lists to NGOs), there are few examples of linkages between monitoring and evaluation systems and sharing of data. Both clinics and NGOs see the value of integrating their information and expertise, but little partnership is currently happening.

2. Field Practices and Proposed Indicators by Program

a) Targeted Food Assistance to Tuberculosis Programs

Interviewees proposed the following indicators to measure the impact of food aid on TB patients:

- Mortality
- Adherence to TB drug regime/reduction in default rate
- Weight/BMI
- Morbidity/Symptoms (e.g. persistence of cough)
- Productive capacity levels
- Length of hospital stay

Interviewees across the three countries felt that attaching food to TB drug treatment programs is very desirable. A major expected impact of food aid, particularly in Malawi, is a reduction in mortality. Unlike most of the other program groups, some research has been conducted on the impact of food aid on TB programs. According to Dr. Salaniponi, the Head of the Malawi TB Program, food aid is a major priority in the treatment of tuberculosis and in reducing mortality rates. In research done with MSF in Thyolo, Malawi, the TB department found that 57% of TB patients were malnourished upon admission. With food aid, there was a dramatic reduction of mortality in the first four months of treatment compared to situations without food aid [70].

Using food as an incentive to increase the adherence of patients and reduce the default rate of the TB drug regime was mentioned by several practitioners. As the TB treatment regime is 8-9 months long, the default rate is historically high as people are likely to stop taking the powerful drugs once they feel better and have negative sputum tests. In Zimbabwe, WFP is specifically looking at adherence to TB treatment as an effect of food aid. In Malawi, while the importance of food aid was stressed, according to Salaniponi, the national default rate is below 7%, so the feeling was that food aid could not be expected to significantly reduce the rate since it already is so low.

Most of the NGO representatives interviewed reported that their programs classified people with TB as chronically ill. As with other chronically ill people, the impact expected from food aid were increased weight gain, reduced symptoms and enhanced productive capacity. Sister Maggie at St. Paul's Hospital in Musami, Zimbabwe reported

visible weight gain in chronically ill patients (including TB patients) when they were receiving CSB from CRS through the C-SAFE program. Increased weight gain combined with elimination of TB was also predicted to have an improvement in the productive capacity of patients. Dr. Salaniponi, among others, mentioned that while TB patients may complete the treatment, many of them are still so malnourished that without food aid they are too weak to farm or actively return to daily activities.

Another treatment related indicator mentioned was a decrease in hospital stay. The TB program at Chikankata Hospital in Zambia has found that malnutrition upon admission significantly increases the length of stay for TB patients, and staff anticipates that food aid -- along with proper medical intervention -- would be a significant contribution to a quicker recovery.

b) Targeted Food Assistance to ART Programs

Indicators mentioned by interviewees that could potentially be used by programs to measure the impact of food aid on ART recipients included:

- Mortality/prolonged survival
- Adherence to drug regime
- Efficacy of drugs
- Weight/BMI
- Morbidity/Symptoms (e.g. diarrhea)
- Productive capacity levels
- Quality of life

Several interviewees mentioned the relationship between nutritional status (usually measured through BMI) and survival. Previous research by UNC in Malawi showed that a BMI less than 16 was predictive of high mortality (50% of patients died within 6 months of going on ART) when coexisting with anemia, poor functionality and CD4 below 50⁸. It was implied in many discussions that nutritional status could be enhanced through food aid, thus when coupled with ART, there would be a synergistic positive result. Several interviewees, however, pointed out that nutritional status is interrelated to treatment and it will be difficult to distinguish between the impact of treatment and the contribution of food aid.

As with the TB drugs, the use of food aid as an incentive to increase adherence to ART regimes was frequently mentioned. Field staff reported communities asking “how are we to take these drugs if we have nothing in our stomachs?” implying that without food, they couldn’t take the prescribed drugs because the drugs wouldn’t work or they would get sick. When the issue was proposed to medical professionals and beneficiaries, though, their opinion was that generally people are so grateful to be on ARVs and feel the benefits are so substantial that adherence is already very high. Dr. Libamba, the head of HIV/AIDS at the MoH in Malawi said that from crude adherence monitoring (measuring the number of pills left in bottles brought back each month by patients), the default rate in the government sponsored ART program is less than 5%. Before ART was free in Malawi, default rates were much higher due to the cost of drugs. Now, in the free drug schemes in Zambia and seemingly in Malawi, eligibility criteria includes previous drug and appointment history as well as participation in educational sessions on the importance of adherence. In addition, the fact that regulations stipulate that patients can be dismissed from the program for not taking drugs also ensures that adherence rates remain high.

Several interviewees predicted an enhanced *uptake* or efficacy of ARV drugs with the availability of food. Again, most clinical practitioners did not support this suggestion, but did say they were not aware of research to refute it. Drs. Libamba and Hosseinipour, for example, both pointed out that the drugs used in Malawi were deliberately chosen because they don’t need to be taken with food and shouldn’t be affected by the food security status of the patient. Several practitioners mentioned that even for severely malnourished patients, the recommendation is not to wait for weight gain, but to concurrently treat malnutrition with therapeutic care while giving ART since experience has shown that the drugs are still very effective even when the patient is malnourished.

Weight gain measured through BMI was commonly suggested as something that should be measured to show the impact of food aid on ART program participants. Interviewees did not feel that collection of information on weight

⁸ Personal communication with Dr. Mina Hosseinipour, UNC Project, Tidziwe Clinic, Lilongwe Central Hospital, Lilongwe, Malawi

would be very burdensome. As some of the ART drugs prescribed are dosed according to weight, patients are weighed regularly at the clinics and recorded on master cards which could be easily accessed. National guidance in Malawi calls for BMI to be measured on ART patients to determine if they should be referred to feeding programs (for BMI is less than 16, patients are referred to therapeutic feeding; for BMI 16-18.5, they are referred to a supplemental feeding program, though these referral options may not reliably exist) so again it was felt BMI should be easy to gather, at least by those interviewed in Malawi.

Symptoms, productive capacity levels, and quality of life scales were posed as additional indicators to demonstrate the impact of food support on people receiving ART. Those interviewed felt that many PLHA live in such food insecure situations that although ART is a key intervention, nutritional support is also needed to fully benefit from improved CD4+ counts. ART protocols consistently identify 'good nutrition' as an integral part of a comprehensive package of care. In order to start taking care of themselves, resume productive activities and reduce reliance on caregivers, improved nutrition is required, something food aid should be able to address. Symptoms, especially diarrhea, were predicted by interviewees to decline with the addition of food aid to the ART regime. Return to productive capacity and ability to conduct daily activities as a result of food aid, particularly when combined with ART, were widely recommended for inclusion in an M&E system. Finally, when probed, most interviewees felt that quality of life indicators that included daily activities, mental outlook and productive capacity would also be appropriate, well received and informative.

c) Targeted Food Assistance to the Chronically Ill

A number of potential indicators for measuring the impact of food aid on the chronically ill were mentioned by C-SAFE and I-LIFE stakeholders, including:

- Weight change/BMI
- Symptoms (e.g. diarrhea)
- Productive capacity levels
- Quality of life
- Household asset levels
- Coping strategies
- Attendance and performance in school by children in affected households
- Need for caregiver

Weight change was the primary indicator that stakeholders proposed for measuring impact of food aid on the chronically ill. Chronically ill beneficiaries themselves reported impacts of food aid such as; "*giving strength*" and that "*(I have) gained weight, my skin is healthier, (I have) strength to walk.*" Issues related to collecting weight and BMI data were similar to those mentioned previously. If patients are well enough to get to a health center, weight will be recorded on the patient retained clinic card, but for homebound patients, there may be access, equipment and data collection constraints. The quantity of clinic data depends on how regularly the PLHA seeks treatment. In programs where the CI beneficiary collects food at the clinic, data is collected quite regularly so would be viable information, while clinic data on CI beneficiaries not receiving regular treatment or having incentives to go to the clinic on a regular basis, and thus may be less useful.

Reduction in symptoms, particularly diarrhea, was also cited as something field workers felt would result from food aid. Not everyone agreed, however, as some medical practitioners felt the reduction in symptoms was more likely the result of treatment than food.

As mentioned under TB and ART program impacts, quality of life issues (e.g. productive capacity, coping strategies, household assets and mental health) were mentioned as important indicators of the impact of food aid. It was predicted that with food aid, PLHA would be able to get out of bed, take care of themselves, and help out with household tasks and farm work. Individuals mentioned that the ability to buy sugar, soap, and other basic household goods and foodstuffs also enhanced daily life and improved the mental health of recipients. The assurance of continued food assistance also reportedly reduced worry by the targeted beneficiary and stress within the household.

In addition to individual impacts, household level impacts from TFA were frequently identified. As a result of food aid, caregivers were not needed as much and were able to return to work, reducing the sale of assets and increasing

household production/income. Food security and coping strategy indicators were also recommended, as were increased attendance and performance at school due to improved ability of the household to pay for school fees and incidental expenses, better nutrition, and decreased need for children to assist at home.

CRS in Zambia has a study underway to investigate the impact of nutritional supplementation on the quality of life and anthropometric status of HIV+ home based care (HBC) program clients over a six month period. Dependent variables include BMI, quality of life scores, MUAC and dietary diversity. The results from Zambia will provide insight to other programs.

d) Targeted Food Aid to PMTCT Clients

With regard specifically to PMTCT programs, participants proposed the following indicators:

- Weight change/BMI
- Symptoms (e.g. diarrhea)
- Productive capacity levels
- Quality of life
- Coping Strategies
- Program uptake (increased testing, disclosure, attendance at counseling sessions)
- Maternal weight change, BMI and MUAC
- Birth outcomes and infant weight
- Level of mixed feeding
 - Exclusive breastfeeding
 - Weaning (timing and success)
- Length of exclusive breastfeeding
- Duration of the weaning period

M&E systems have already been developed for PMTCT programs regionally. However, most of these systems focus on program uptake and outcomes (# women receiving VCT, # mother-infant dyads receiving Nevirapine and number of children testing positive at 18 months) and don't focus on impact of the food assistance. Respondents felt there is a need to substantially improve monitoring of non-drug prevention measures and include nutritional and behavioral indicators in the current PMTCT M&E plans.

It was widely agreed in field interviews that food aid attached to PMTCT programs would increase program uptake as food would bring women into PMTCT sites and increase the number of women counseled and tested. If food aid were linked to HIV status, disclosure would also be inadvertently increased, though this raises ethical issues on the use of food.

As with all food aid interventions, it was predicted that PMTCT participants would gain weight and improve their nutritional status. As there are links between maternal nutritional status and birth outcomes, numbers of LBW children born to HIV-positive mothers, weight gain during pregnancy, BMI during lactation and infant growth were all mentioned as potential indicators to measure food aid impact.

Infant feeding practices such as the level of mixed feeding, length of exclusive breastfeeding, and accelerated weaning behavior are a great concern to many involved in PMTCT. Insufficient energy for the mother to continue to exclusively breastfeed, lack of household food security, and low availability of proper weaning foods were examples of inhibitors to exclusive breastfeeding and accelerated weaning, thus increasing the risk of vertical transmission, all issues that could potentially be addressed by TFA. Indicators of food aid impact on PMTCT could therefore include incidence of mixed feeding and duration of the weaning period (e.g. duration of mixed feeding) for HIV positive mothers. Indicators proposed would largely be based on the type of PMTCT food assistance and the counseling support provided. Currently, there are no indicators which measure the duration of exclusive breastfeeding or quality of weaning practices being used.

Other impacts mentioned previously for other programs such as enhancement in quality of life, higher productive capacity, improved mental health and reduced risky coping strategies were also brought up by PMTCT stakeholders as indicators that could be used to examine food aid impact on PMTCT participants.

3. Issues That Could Affect Measurement

A number of general concerns were raised that could affect collection of data and measurement of impact:

- a) Sufficient time - issues related to staff having sufficient time to collect the data were repeatedly raised.
- b) Proper equipment (e.g. rulers instead of measuring tapes or height boards) - improper or low quality equipment could impact the comparability or validity of the data collected.
- c) Appropriate training and experience – insufficient training of staff responsible for collecting data could result in poor quality of data or non-collection of data.
- d) Existence of indicators and assessment tools – the tools to measure some expected impacts either don't exist or have not been fully tested. For example, the need to be realistic about the long term and potentially cyclical needs of CI households was discussed. For this reason, some NGOs are trying to develop assessment tools which identify when to intervene with food support and when to “pull back”. The concept of identifying a ‘trigger point’ for both safe graduation and increased vulnerability appears promising.
- e) Presence and availability of staff who can adequately design, supervise and analyze studies of the complexity that will be necessary to show causal attribution of food aid to individual and household impacts.

IV. Discussion

A. Proposed Indicators

A key finding of this research is that there is a dearth of documented evidence, in the literature as well as in the field, that shows the impact of food aid on PLHA. Current M&E systems of C-SAFE programs are also not designed to evaluate this impact. Despite the lack of documented evidence, there were numerous testimonials from HIV positive beneficiaries and program staff that gave anecdotal examples of various impacts of food aid on the chronically ill, and TB, PMTCT and ART program participants. No one interviewed expressed any doubt about the importance of food aid as a key component of comprehensive HIV/AIDS services. Using the literature review⁹, extensive discussions with technical staff, and experience from traditional food aid evaluations, this study proposes a framework of suggested indicators to be used in measuring the impact of food aid on individuals and households living with HIV/AIDS.

According to the review of the literature and field research, key improvements expected from food aid at the household and individual level are:

- increase in daily food consumption by all household members
- increase in money available for other needs
- increase in household food security

These improvements generate a cascade of subsequent changes at the individual and household levels that are believed to result in increases in weight, energy, treatment adherence, school attendance, immunity, medical treatment, quality of life, productive capacity and ultimately survival. In addition, there is an anticipated increase in programmatic uptake as a result of providing food aid. This is articulated in Figure 1.

Given that many of the indicators in existence are difficult to collect (and to interpret), this paper proposes a short list of indicators for consideration. This list is by no means exhaustive, nor does C-SAFE purport that they are the most appropriate in all cases. They are simply the ones thought by the interviewees and the researchers to be generally the most feasible and relevant given C-SAFE's operating environment and capacity constraints. These indicators are highlighted in Figure 1 and defined more thoroughly in Annexes B and C. They are:

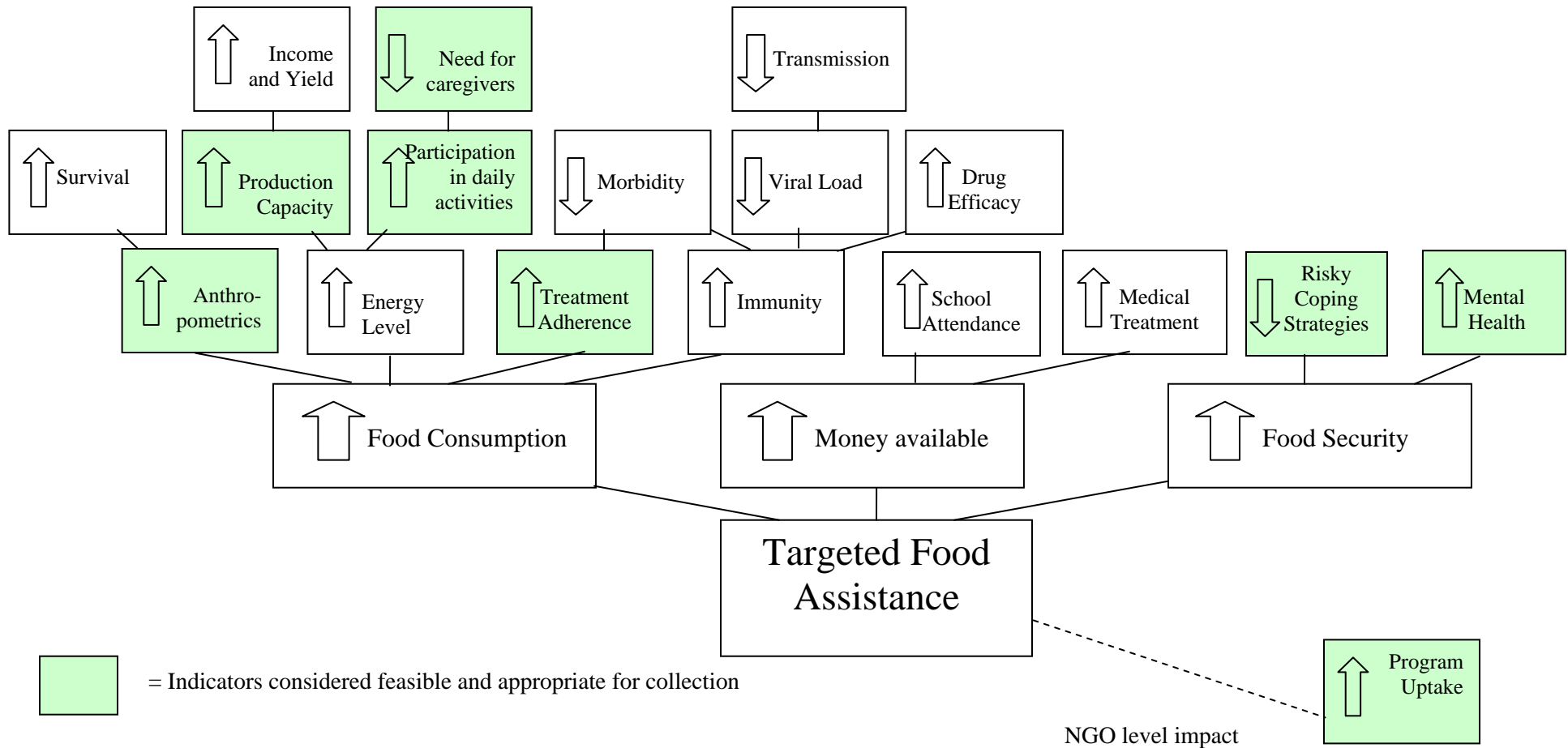
- Anthropometrics: BMI, MUAC, weight for age and % weight change
- Treatment Adherence/Default Rates: TB and ART drugs and infant feeding protocols
- Risky coping strategies
- Mental Health
- Production capacity
- Ability to perform daily living activities
- Need for caregivers
- Program uptake

A decision as to which of the indicators to use will depend upon:

- ✓ the degree of relationship with food aid
- ✓ the cost of collecting indicators
- ✓ proven biological plausibility
- ✓ their perceived feasibility for C-SAFE and similar partners to collect

⁹ A limitation of this work was the lack of published research available at the time of this study. A review of the grey literature was therefore used and thus the exploratory nature of this work and the recommendations that emanate from it are acknowledged.

Figure 1: POTENTIAL IMPACT OF FOOD AID ON PLHA



Some of the medically-oriented impacts such as HIV transmission, viral load, drug uptake and immunity were not included as they would require extensive clinical examinations and/or analysis of samples that was not deemed to be in the financial or physical reality of most partners. Obviously, if this data is easily available from local sources for the target population, it could be used. Other medically oriented impacts suggested by interviewees in the field such as reduction in diarrhea and increase in drug efficacy from food aid directly were not included since the biological plausibility of these changes is under debate.

With indicators that are high up the flow chart of Figure 1, it will be particularly difficult to separate out the impact of food aid from the numerous other factors influencing that variable, so in general, the farther away the potential impact is listed away from food aid, the less likely an indicator measuring those impacts would be recommended. The impact of increased money available to the household (since less money is being spent on food) is more difficult to attribute directly to food assistance, as there are many other reasons why a household has more money available to it besides receiving food aid. School attendance, for example, was not recommended for collection due to the difficulty in collecting quality data and the number of other factors that could influence the final numbers.

It is not feasible or appropriate to use all of the potential indicators in every NGO M&E system. Each implementer will have to examine the specific program objectives and available capacities to determine what indicators would be most appropriate. Indicators recommended by program type are given in Table 1. Lesser known and more experimental indicators such as handgrip strength, BIA, and head circumference were not included as it was felt most partners did not have the equipment or capacity to use such tools. This is not to say that these indicators could not or should not be piloted by partners with more capacity.

Table 1: Indicators for Consideration to Measure Impact of TFA by Program Type

Indicators for Consideration in Measuring Impact	Program Type				
	TB	ART	CI	PMTCT	
				Mother	Child
1. Anthropometrics					
BMI	X	X	X	X	
Percentage of Weight Change		X	X	X	
MUAC				X	
Weight for Age				X	X (<6m)
Weight for Height					X (>6m)
2. Treatment Adherence	X	X		X	
3. Risky Coping Strategies		X	X	X	
4-6. Quality of Life					
Mental Health	X	X	X	X	
Activities of Daily Living	X	X	X	X	
Productive capacity	X	X	X	X	
7. Need for Caregivers		X	X		
8. Program Uptake	X			X	

B. Challenges to Evaluating Impact

Establishing a framework to measure the impact of food aid on PLHA, and modify M&E systems respectively, is not a simple task. Constraints include (but are not limited to) institutional cultures, data collection capacity, available time, the complexity of study design and analysis necessary to document impact, financial resources and current limited understanding of the interplay between HIV, micro and macro nutrients. As the C-SAFE TFA programs are all dry distributions, intra-household distribution, sales and sharing of food will all be uncontrollable variables.

Proving causal attribution of impact to food aid is also going to be difficult due to the complexities of the HIV disease and the multiple factors that are influencing beneficiaries' experiences. For example, conditions such

as morbidity, mortality, number of visits or length of stay at medical centers and community ability to care are influenced by so many different factors that only a very extensive and rigorous evaluation design could sort out impact that was related to food aid versus rainfall, government policy, quality of local medical facilities and similar issues.

Given the multi-factoral and complex interplay between HIV disease and nutrition, potentially confounding factors must be identified from the outset and collected in baseline and monitoring tools, particularly if using a cross-sectional survey design versus a baseline-evaluation model. Research is needed to better understand all the independent variables that would be relevant to collect to show causal attribution of food aid on PLHA. One potentially confounding variable is the issue of continued wasting even for beneficiaries on ART [36, 38]. Other variables include ART side impacts such as nausea and vomiting, metabolic complications of treatment (derangement of lipid and glucose metabolism) [39] and prolonged recovery times [40]. Key control variables include, but are not limited to: standard demographic information, program inputs, the medical treatment the beneficiary is receiving (e.g. ART or TB medication), the stage of disease of the beneficiary (determined either by CD4 count or WHO stage classification), and the signs/symptoms the beneficiary has experienced during the period in question. If these variables are not collected and controlled for in the analysis, it will not be possible to determine what impact came from food aid and what came from other sources.

Box 1: Key Control Variables

1. Demographic information (e.g. gender, age, ethnicity, location, household size)
2. Program inputs (e.g. quantity of food and commodities received and for what duration)
3. Treatment received (e.g. ARVs, breastfeeding counseling, cotrimoxazole)
4. Stage of Disease/CD4 count at onset and completion of research period
5. Signs/symptoms experienced by PLHA during research period

Sample tools that can be used to gauge control variables of the stage of disease and relevant signs and symptoms of disease are included in Annex C (3,4, & 5) -- the Karnofsky and Disease Stage Scale, the ECOG scale and the WHO stages respectively.

V. Recommendations

A. Overall Recommendations

While the opinions of the people who contributed to this paper are very valid, neither the ROL or the field research found significant evidence of where the direct impact of TFA is being measured. Therefore, what is presented here does not reflect documented validated research; but rather, thoughts and ideas from technical staff from TFA programs regarding indicators that they believe offer potential towards measuring the impact of TFA on the four PLHA sub-groups mentioned in this study. To this end, the following recommendations are made to advance these efforts:

- Pilot the eight indicators noted in the Discussion section of this document at select sites of C-SAFE, I-LIFE and similar NGO food aid programs targeting PLHAs to measure program impact. Indicators measuring program inputs, activities, and outcomes are also needed as monitoring tools and to help interpret impact indicators, but are not discussed in this document.
- Include some of the suggested indicators into future C-SAFE and I-LIFE surveys, and eventually integrate these indicators into future project M&E systems.
- In established EUM, PDM and CHS collection tools, link data already collected such as coping strategies, school participation, and program uptake to participation in food aid programs.
- Establish M&E partnerships between health centers, district level, central governmental and food aid programs serving similar populations and determine mutual areas of interest in order to share information.
- Share lessons learned among C-SAFE partners, the wider UN/NGO network and health service providers.

B. Research Specific Recommendations

Due to the lack of existing research on the impact of food aid on PLHA, and the complexities involved with showing causal attribution, it is highly recommended that C-SAFE and other organizations identify specific pilot studies that can be conducted to test indicators and evaluate the potential impact of TFA on these groups.

A key piece of ongoing operational research that should be closely followed is the CRS SUCCESS Program Palliative Care Nutritional Supplementation Targeted Evaluation taking place in Zambia. This study is comparing QOL and anthropometric (BMI and MUAC) measures among three arms of home based care clients: those receiving a ration of high-energy protein supplement and oil, a ration of bulgar wheat and beans and a control group. C-SAFE is providing the beans and bulgar ration. Other institutions are conducting similar research such as the impact of food aid on ARV patients (CIEDRS in Zambia) and lactating women (UNC in Malawi), which should also be monitored by C-SAFE partners.

The literature review identified two broad research priorities for evaluating the impact of food aid on PLHA:

1. Mixed (qualitative and quantitative) studies of optimal dietary advice with the outcomes such as *quality of life, morbidity, disease progression and survival time* [58]
2. Quantitative studies of optimal nutrition support and outcomes such as *body composition, morbidity (esp. diarrhea), CD4 counts, viral load, disease progression, survival time and MTCT (rate)*[58].

C-SAFE has several sites which offer the programming infrastructure and beneficiary access required for operations research. Examples of where pilot research could take place are included in Annex D. With the phase out of the regional C-SAFE Learning Spaces initiative, however, it will be necessary to integrate operational research into follow-on DAPs or emergency funding or source external technical support to assist in establishing a sound research protocol and to provide the necessary training.

Issues to consider for operational research include:

1. Relationship between quality of life indices and food aid.
2. Use of handgrip strength as a proxy for nutritional status and strength
3. Impacts of varying quantities and quality of food aid on various HIV-affected populations
4. Validity of MOS-QOL in evaluating quality of life issues, identifying modifications and additions.

ANNEX A:
List of Interviewees and Organizations

1: Names by Country and Organization

<u>Name</u>	<u>Position</u>	<u>Organization</u>
Malawi		
Dr. Salaniponi	Head of TB Program	Ministry of Health
Dr. Libamba	Head of HIV/AIDS Unit	Ministry of Health
Catherine M Kangama	Chief Nutritionist	Ministry of Health
Prof. Cameron Bowie	Department of Community Health	University of Malawi
Claire Bowie	Bangwe Home based care program	Salvation Army
Allison Zakaliya	M & E officer	ActionAid
Mr. Chimwemwe		World Vision
Felix Mtonda		Oxfam
Overton Mgemezula		Oxfam
Nixon Khembo	Deputy Director	Center for Social Research
MacPherson Gondwe	M & E Coordinator	Family Health International
Ethel Kapyepye	National HIV/AIDS Coordinator	World Vision
Cosby Nkwazi	Head of Planning, M & E	National AIDS Commission
Dr. Mina Hosseinipour		X Clinic, X Hospital, Malawi University of North Carolina Project
Lola Castro	Deputy Country Director	World Food Program
Dr. Katie Cummings	Consultant	Valid International
Dr. Paluku Bahwele	Staff	Valid International
Bena Musembi	Program Manager	I-LIFE
Dr. S. Jayasuriya	Deputy Director	I-LIFE
Jennifer Lentfer	Technical Advisor, M & E	CRS
Emily Movall	Deputy Head of Programming	CRS
Kathryn Lockwood	Health & Nutrition Program Manager	CRS
Charlotte Walford	Staff	UNICEF
Roger Mathieson	Staff	UNICEF
Helen Jones	E.I. I-LIFE Program Manager	Emmanuel International
Andrew Mellen	Relief Program Manager	Emmanuel International
Zimbabwe		
Anna Miller	Technical Advisor	EGPAF
Barbara Reed	Food for Peace Officer	USAID
Valerie Guarnieri	Deputy Country Director	WFP
Mumtaz Osman	Nutritionist	WFP
L. Maboreke	Program Officer Planning, M & E	NAC
A. Mpofo	M & E Manager	NAC
Jean-Baptiste Nkusi	Program Manager	World Vision
Sinini Masuku	HIV/AIDS Coordinator	World Vision
Sr. S. Ngwenya	Sister	Gwanda Clinic
Dr. Peter Iliff	Medical Director	ZVITAMBO
Dr. Alexandre Boon	Project Coordinator	MSF
Ben Mountfield	Head of Delegation	ICRC
Winfreda Chandisarewa	Project Director	ZAPP-CTA
S. Tinarwo	Staff	JF Kapnek Trust
C. Marangwanda	Project Director	JF Kapnek Trust
Sister Maggie Mutopo	Matron	St Paul's Hospital Musami
Theresa Ndoró	PMTCT Coordinator	Murhewa Hospital (ISPED)

T.Z. Sithole	District Nursing Officer	Murhewa Hospital
Tendai Chikumba	Mvuma sub-office	CARE
Abel Whande	Mvuma sub-office	CARE
Maria Tokwani	HIV/AIDS Sector Coordinator	CARE
Janelle Zwier	C-SAFE coordinator	World Vision

Zambia

Linda Lovick	Program Manager-SUCCESS	CRS
Maurice Pengele	M & E Officer	CRS
Jennie Munthali	Program Manager, AIDSRelief	CRS
Lynn Tamba	TB Specialist	CHAZ
Mr Kandeke	ARV Specialist	CHAZ
Mr. C Makasa	ARV Specialist	CHAZ
Rosemary Zimba	PMTCT M & E	CHAZ
Benson Sichone	ARV Program	Chikankata Hospital
Clare Ntinda	PMTCT Program	Chikankata Hospital
Mrs. E. Mataka	Executive Director	ZNAN
Beyant Kabwe	M & E	ZNAN
Patrice Charpentier	Program Manager/ C-SAFE	CARE
Dr. A Mwinga	Assoc. Director, Scientific Operations	CDC
John Imbwae	Executive Director	KARA Counseling
Yvette McFarlane	PMTCT M & E	CIDRZ
Catherine Nguni	PMTCT M & E	CIDRZ

2: List of Interviewees (organizations) by Program Type

	Malawi	Zimbabwe	Zambia
National TB program	X		
HIV/AIDS	X	X	
PMTCT			
Nutrition	X	X	X (Food & Nutrition Commission)
AIDS Council	X (NAC)	X (NAC)	
Targeted Food Assistance	CARE, World Vision, CRS, Action Aid, WFP, Salvation Army, Emmanuel International,	CARE, World Vision, CRS, WFP	CARE, World Vision, CRS
Hospice / Home-based care	Beneficiaries, Salvation Army (Bangwe)	Beneficiaries, International Federation of Red Cross and Red Crescent	Kara Counseling
Support Groups	University of Malawi (Department of Community Health)		
TB/ ARV programs	Family Health International, University of North Carolina (Tiziwe Center), Beneficiaries	MSF	CDC Global AIDS Program (PEPFAR), CIDRZ, CRS Chikankata Hospital
PMTCT programs		The JF Kapnek Trust, University of Zimbabwe (ZAPP), ISPED, EGPAF Zvitambo, USAID, Beneficiaries	Chikankata Hospital, Churches Hospital Association of Zambia (CHAZ)

ANNEX B

Definitions and Examples of Recommended Indicators

1. **Anthropometric indicators:** BMI, percentage of weight change, MUAC, weight for height and weight for age are all commonly used anthropometric indicators. Other indicators such as handgrip strength, head circumference and BIA are being tested in pilot programs, but not recommended for general programming due to the current lack of interpretability and comparability of the measurements. Find formulas and collection criteria listed in Annex C.
2. **Treatment Adherence and Program Default Rates:**
Adherence and default are two sides of the same issue regarding how people are participating in the program. Programs usually collect whichever is easier and most meaningful to them. 'Adherence' addresses compliance of patients in following prescribed dosages e.g. *% of patients successfully taking correct dosages during month*. 'Program default' addresses the percentage of patients that failed to complete the treatment e.g. *number of patients who failed to complete the treatment program / number of patients who began program – number of patients who died*
3. **Risky Coping Strategies:** As mentioned in the review of the literature, several tools exist to measure coping strategies. As coping strategies vary between countries and target groups, each program should establish lists and scales of risky coping strategies. Since not all coping strategies are harmful, it is important to rate strategies regarding level of usage, severity and risk. It is useful to evaluate whether individual PLHAs and households of PLHAs receiving food aid engage in less risky or severe coping strategies than before they received food aid or compared to those households without food aid. Indicators can measure specific risky coping strategies or one of several risky coping strategies e.g. *% of PLHA households selling productive assets over year* or *% of PLHA households engaged in risky coping strategies (selling productive assets, non-seasonal migration, or skipping whole days of food) during year*. Coping strategy composites can also be developed with assigned values according to the evaluated risk and a score calculated for each household can be tracked over time or compared to a control group who are not receiving food aid e.g. *Mean coping strategy score for PLHA households*. The Coping Strategy Index is one frequently used approach to measuring in this manner.
- 4-6. **Quality of Life** (mental health, activities of daily living and production capacity): While individual indicators can provide information on various aspects of a PLHA's quality of life, several can also be combined in a composite indicator that presents a more complete picture. Several QOL scales exist including PARSE, Medical Outcome Survey-HIV (MOS-HIV), WHO-QOL, and QOL by the AIDS Clinical Trial Group. Many of these, however, are very long and/or have not been adapted to resource-poor settings. The quality of life composite that seems most appropriate/feasible for programs discussed here is the MOS-HIV. This survey encompasses mental health, productive capacity, and return to daily living activities in addition to measuring mental functioning. More testing of this tool and compilation of similar QOL composite tools to address HIV/AIDS in the developing country context is needed. Other useful tools to measure physical fitness, production capacity and activities of daily living include the ECOG Scale and Karnofsky and Disease Stage Scale. Individual indicators can be used to measure production capacity e.g. *number of days of farming enterprise and person days engaged in income generating activities*. See Annexes C2, C3, and C4 for the MOS-HIV questionnaire, the Karnofsky & Disease Stage Scale, and ECOG.
7. **Need for Caregivers:** The need for caregivers or the need to give care measures the health and capacity of the PLHA, in addition to providing information on the loss of labor to a household that occurs when someone needs to remain with the PLHA rather than contribute to the household economy. Potential versions of this indicator could include *% of PLHA requiring 24 hour/regular caregivers, # of household members unable to farm or perform regular productive activities due to care giving duties*.
8. **Program Uptake:** Unlike the other indicators which measure the impact of food aid programs on households and/or individuals, program uptake is related to the impact food aid has at the NGO or activity level, and examines the increase in participants in a program. In programs such as PMTCT and TB-DOTS treatment, pre-food aid enrollment numbers can be compared to post-food aid numbers to see if food aid significantly influenced more people to attend, test, receive counseling or obtain treatment. An indicator that could be is *% average monthly increase in intake of new program participants*.

**ANNEX C:
Indicators and Tools for Consideration**

1. Anthropometric Indicators

	Indicator/Formula	Target Population	Analysis	Advantages and Disadvantages
1. Body Mass Index (Que'telet's index)	Weight (kg)/ height ² (m)	Adults (including lactating mothers, but not pregnant women) Adolescents	<u>Common cutoffs</u> >30 = obese >25 = overweight >/18.5 = normal >/16.5 = moderate malnutrition <16.5 = severe malnutrition <u>ACF</u> ¹⁰ >/18.5 = normal 17-18.4 marginal energy deficiency 16-17 moderate energy deficiency <16 Severe energy deficiency	- Wt and ht relatively easy to collect - Only need one ht. measurement - Cut-offs are not overly robust - Varies according to stature of individuals - Recommended by WHO as anthropometric measurement for adolescents, though BMI varies greatly particularly at puberty - Math skills needed to do calculation - Correlation between BMI, fat mass, wt and ht less marked in adults under 30 - BMI varies by age and population group
2. Percentage of Weight Change	% of weight change over baseline weight	- Adults incl lactating and pregnant women - Adolescents	5-10% loss = stage 2 AIDS ¹¹ >10% loss = stage 3	- Easy to collect - Not always possible to get baseline when still healthy - Not extensive scales for comparison
3. Mid Upper Arm Circumference (MUAC)	Mm or cm circumference of distance around the middle of the upper arm (loosely hung left arm, mid-point between elbow and shoulder)	Children over 1 year or 75cm Adults including pregnant women	ACF: Children ¹² : >/125–135mm = mod risk >/120 - <125 = serious risk >/110 – 120mm = mod malnutrition <110 mm = severe malnutrition Adults moderate/at risk: -Females: <220mm -Males: <230mm Collins: Adults <185 = moderate malnutrition ¹³ <160 mm = severe malnutrition Children: <130 and >110 = mod. malnutrition <110 = severe malnutrition	- Good indicator of body mass - Better predictor of mortality than wt/age or wt/ht - Requires minimal equipment and training to measure - High inter and intra measurement error - No internationally recognized thresholds – Unknown variation in MUAC between populations - Lipodystrophy in patients on ARVs may make inaccurate - Inaccurate for children <1 yr or <75cm in length - Biased towards younger children - Usually used for screening; use for program evaluation has not yet been validated.

¹⁰ Prudhon, C., *Assessment and Treatment of Malnutrition in Emergency Situations*, ACF, Paris, 2003

¹¹ WHO Classification (Annex C.5)

¹² Prudhon, C., *Assessment and Treatment of Malnutrition in Emergency Situations*, ACF, Paris, 2003

¹³ Collins, S., *Using middle arm circumference to assess severe adult malnutrition during famine*, Journal of American Medical Association 1996, 276, 291-95.

<p>4. Underweight (Weight for Age)</p>	<p>1) % of median weight for age group ([weight recorded x 100]/median reference weight) 2) Standard deviation or z-score ([weight recorded – median reference weight]/ standard reference deviation)</p>	<p>Children 0-59 months Adolescents</p>	<p>Percent of the median: <80% = moderate malnutrition <70% weight for height or <60% weight for age = severe malnutrition Z-scores: <-2 and >-3 = moderate malnutrition <-3 = severe malnutrition</p>	<ul style="list-style-type: none"> - Easy to collect - Commonly collected in growth monitoring programs - References exist for adolescents - Misrepresents short but healthy and tall but thin children - Accurate age needed - Does not account for oedema
<p>5. Wasting (Weight for Height)</p>	<p>1) % of median weight for age group ([weight recorded x 100]/median reference weight) 2) Standard deviation or z-score ([weight recorded – median reference weight]/ standard reference deviation)</p>	<p>Children 6-59 months Adolescents</p>		<ul style="list-style-type: none"> - More sensitive than wt/age - Age not needed - Preferred measurement for adolescents by some NGOs (e.g. ACF) - Reference measurements not available for <49cm - Infant wt/ht may not reflect growth, rather prenatal care - Not accurate for BF babies <6 months - WHO reference tables for adolescents do not exist, but tables based on reference data of wt/age and ht/age have been developed

2. Quality of Life – MOS-QOL Questionnaire (AIDS CARE January 2004 16 (81-94))
 (INTERVIEWER: Q1 - Q14 ARE PROMPTED)

1. In general, would you say your health is:	Excellent	1						
	Very good	2	[]					
	Good	3	{Q1}					
	Fair	4						
	Poor	5						
2. How much <i>bodily</i> pain have you generally had during the past thirty days?	None	1						
	Very mild	2						
	Mild	3	[]					
	Moderate	4	{Q2}					
	Severe	5						
	Very severe	6						
3. During the past thirty days, 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	{Q3}					
	Quite a bit	4						
	Extremely	5						
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					
a. The kinds or amounts of <i>vigorous</i> activities you can do like, digging, fetching water from a well, carrying a big bunch of bananas, splitting firewood.	1	2	3	[]			{Q4a}	
b. 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}	
c. Walking up hill, climbing stairs.	1	2	3	[]			{Q4c}	
d. Bending, lifting light objects or kneeling.	1	2	3	[]			{Q4d}	
e. Walking a distance, like the length of a football pitch, about 100 meters.	1	2	3	[]			{Q4e}	
f. Eating, dressing, bathing or using the latrine.	1	2	3	[]			{Q4f}	
5. Does your health <i>keep</i> you from working at a job, doing work around the house or attending school?	Yes	1	[]				{Q5}	
	No	2						
6. Have you been unable to do <i>certain kinds or amounts</i> of work, housework or schoolwork, because of your health?	Yes	1	[]				{Q6}	
	No	2						
7. How much of the time, during the past thirty days, has your <i>health limited your social activities</i> , like visiting with friends or family?	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A little of the Time	None of the Time	[]	{Q7}
	1	2	3	4	5	6		
8. How much of the time, during the past thirty days:								
a. Have you been a very nervous person?	1	2	3	4	5	6	[]	{Q8a}
b. Have you felt calm and peaceful?	1	2	3	4	5	6	[]	{Q8b}
c. Have you felt depressed?	1	2	3	4	5	6	[]	{Q8c}
d. Have you been a happy person?	1	2	3	4	5	6	[]	{Q8d}
e. Have you felt so depressed that nothing could cheer you up?	1	2	3	4	5	6	[]	{Q8e}

9. How often during the past thirty days:

a. Did you feel full of life and energy?	1	2	3	4	5	6	<input type="checkbox"/>	Q9A
b. Did you feel totally without energy?	1	2	3	4	5	6	<input type="checkbox"/>	Q9B
c. Did you feel tired?	1	2	3	4	5	6	<input type="checkbox"/>	Q9C
d. Did you have enough energy to do the things you wanted to do?	1	2	3	4	5	6	<input type="checkbox"/>	Q9D
e. Did you feel weighed down by your health problems?	1	2	3	4	5	6	<input type="checkbox"/>	Q9E
f. Were you discouraged by your health problems?	1	2	3	4	5	6	<input type="checkbox"/>	Q9F
g. Did you feel despair over your health problems?	1	2	3	4	5	6	<input type="checkbox"/>	Q9G
h. Were you afraid because of your health?	1	2	3	4	5	6	<input type="checkbox"/>	Q9H

10. How often during the past thirty days:	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A little of the Time	None of the Time		
a. Did you have difficulty reasoning and making decisions, for example, making plans or learning new things?	1	2	3	4	5	6	<input type="checkbox"/>	{Q10a}
b. 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="checkbox"/>	{Q10b}
c. Did you have trouble keeping your attention on any activity for long?	1	2	3	4	5	6	<input type="checkbox"/>	{Q10c}
d. Did you have difficulty doing activities involving concentration and thinking?	1	2	3	4	5	6	<input type="checkbox"/>	{Q10d}

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).

	Definitely TRUE	Mostly TRUE	Don't KNOW	Mostly FALSE	Definitely FALSE		
a. You are somewhat ill?	1	2	3	4	5	<input type="checkbox"/>	{Q11a}
b. You are as healthy as other people you know?	1	2	3	4	5	<input type="checkbox"/>	{Q11b}
c. Your health is excellent.	1	2	3	4	5	<input type="checkbox"/>	{Q11c}
d. You have been feeling bad recently.	1	2	3	4	5	<input type="checkbox"/>	{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	<input type="checkbox"/>
	Good and bad parts about equal 3	{Q12}
	Pretty bad 4	
	Very bad; could hardly be worse 5	

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	<input type="checkbox"/>
	About the same 3	{Q13}
	A little worse 4	
	Much worse 5	

3. Karnofsky and Disease Stage Scale

**SPNS Cooperative Agreement Evaluation
Module 73: Karnofsky and Disease Stage Scale
National Evaluation by The Measurement Group**

ID Letters	ID Numbers	Site	Sub-Provider	Date
<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> / <input type="text"/> / <input type="text"/> <small>Month Day Year</small>

Staff <input type="text"/>	Client Gender <input type="radio"/> Male <input type="radio"/> Female	1. In general, how would you rate the patient's overall health; would you say that it is: <input type="radio"/> Excellent <input type="radio"/> Good <input type="radio"/> Fair <input type="radio"/> Poor <input type="radio"/> Very Bad <input type="radio"/> Terrible <input type="radio"/> Don't Know
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<p>2. HIV-DISEASE PROGRESSION CURVE Instructions: Darken the bubbles corresponding to any signs that the patient is currently manifesting.</p> <p>2a. ENTER CD4-CELL COUNT (CU MM) <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> </p> <p style="text-align: center;">→ <input type="text"/> <input type="text"/></p> <p>2b. Enter (estimate if needed) the number of years since initial exposure and infection <small>*Indicates conditions that are observed over a broad range of CD4-cell counts.</small> </p>	<p>3. THE KARNOFSKY RATING SCALE</p> <p>Instructions: Darken the bubble corresponding to the patient's current disease stage.</p> <table border="1" style="width: 100%; border-collapse: collapse;"> <thead> <tr> <th style="width: 5%;">%</th> <th style="width: 95%;">Description</th> </tr> </thead> <tbody> <tr> <td>100</td> <td><input type="radio"/> Normal; no complaints; no evidence of disease.</td> </tr> <tr> <td>90</td> <td><input type="radio"/> Able to carry on normal activity; minor signs or symptoms of disease.</td> </tr> <tr> <td>80</td> <td><input type="radio"/> Normal activity with effort; some signs or symptoms of disease.</td> </tr> <tr> <td>70</td> <td><input type="radio"/> Cares for self; unable to carry on normal activity or to do active work.</td> </tr> <tr> <td>60</td> <td><input type="radio"/> Requires occasional assistance but is able to care for most of own needs.</td> </tr> <tr> <td>50</td> <td><input type="radio"/> Requires considerable assistance and frequent medical care.</td> </tr> <tr> <td>40</td> <td><input type="radio"/> Disabled; requires special care and assistance.</td> </tr> <tr> <td>30</td> <td><input type="radio"/> Severely disabled; hospitalization indicated although death not imminent.</td> </tr> <tr> <td>20</td> <td><input type="radio"/> Very sick; hospitalization necessary; active, supportive treatment necessary.</td> </tr> <tr> <td>10</td> <td><input type="radio"/> Moribund, fatal processes progressing rapidly.</td> </tr> <tr> <td>0</td> <td><input type="radio"/> Dead.</td> </tr> </tbody> </table>	%	Description	100	<input type="radio"/> Normal; no complaints; no evidence of disease.	90	<input type="radio"/> Able to carry on normal activity; minor signs or symptoms of disease.	80	<input type="radio"/> Normal activity with effort; some signs or symptoms of disease.	70	<input type="radio"/> Cares for self; unable to carry on normal activity or to do active work.	60	<input type="radio"/> Requires occasional assistance but is able to care for most of own needs.	50	<input type="radio"/> Requires considerable assistance and frequent medical care.	40	<input type="radio"/> Disabled; requires special care and assistance.	30	<input type="radio"/> Severely disabled; hospitalization indicated although death not imminent.	20	<input type="radio"/> Very sick; hospitalization necessary; active, supportive treatment necessary.	10	<input type="radio"/> Moribund, fatal processes progressing rapidly.	0	<input type="radio"/> Dead.
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4. ECOG (Zubrod) Scale¹⁴

ECOG Grade (PS)	Definition
0	Fully active, able to carry on all predisease 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)

5: WHO disease staging system for HIV Infection and Disease in Adults and Adolescents¹⁵

Clinical Stage I:

1. Asymptomatic
2. Generalized lymphadenopathy

Performance scale 1: asymptomatic, normal activity

Clinical Stage II:

3. Weight loss,
4. Minor mucocutaneous manifestations (seborrheic dermatitis, prurigo, fungal nail infections, recurrent oral ulcerations, angular cheilitis)
5. Herpes zoster within the last five years
6. Recurrent upper respiratory tract infections (e.g. bacterial sinusitis)

And/or performance scale 2: symptomatic, normal activity

Clinical Stage III:

7. Weight loss, > 10% of body weight
8. Unexplained chronic diarrhoea > 1 month
9. Unexplained prolonged fever (intermittent or constant), > 1 month
10. Oral candidiasis (thrush)
11. Oral hairy leucoplakia
12. Pulmonary tuberculosis
13. Severe bacterial infections (e.g. pneumonia, pyomyositis)

And/or performance scale 3: bedridden

Clinical Stage IV:

14. HIV wasting syndrome
15. Pneumocystis carinii pneumonia
16. Toxoplasmosis of the brain
17. Cryptosporidiosis with diarrhoea > 1 month

¹⁴ Performance Status of the Eastern Cooperative Oncology Group (ECOG) for Patients with Cancer (Zubrod Scale)

¹⁵ WHO (2002) Scaling Up Antiretroviral Therapy In Resource-Limited Settings Guidelines For A Public Health Approach

18. Cryptococcosis, extrapulmonary
 19. Cytomegalovirus disease of an organ other than liver, spleen or lymph node (e.g. retinitis)
 20. Herpes simplex virus infection, mucocutaneous (>1 month) or visceral
 21. Progressive multifocal leucoencephalopathy
 22. Any disseminated endemic mycosis
 23. Candidiasis of esophagus, trachea, bronchi
 24. Atypical mycobacteriosis, disseminated or lungs
 25. Non-typhoid Salmonella septicemia
 26. Extrapulmonary tuberculosis
 27. Lymphoma
 28. Kaposi's sarcoma
 29. HIV encephalopathy
- And/or performance scale 4: bedridden > 50% of the day during last month

Footnotes: HIV wasting syndrome: weight loss of > 10% of body weight, plus either unexplained chronic diarrhoea (> 1 month) or chronic weakness and unexplained prolonged fever (> 1 month). HIV encephalopathy: clinical findings of disabling cognitive and/or motor dysfunction interfering with activities of daily living, progressing over weeks to months, in the absence of a concurrent illness or condition other than HIV infection which could explain the findings.

ANNEX D:

Possible C-SAFE Pilot Study Areas

During the course of field research, the following possibilities for pilot studies were identified. These are examples of the types of opportunities that C-SAFE and other agencies should look for to address the PLHA food aid research priorities.

1. Malawi

a. TB-DOTS

National TB Control Program (Dr. Salaniponi) and I-LIFE

Dr. Salaniponi was eager to be involved in evaluation research. This program is said to be a model program regionally with low MDRTB and default rates. In collaboration with colleagues, Salaniponi has studied early treatment mortality among TB patients. Zachariah et al (2002) showed that increased levels of malnutrition (especially BMI < 17.0) and HIV positive status were significantly associated with early mortality. There is great potential and interest to expand on this body of knowledge through a careful assessment of targeted food support to TB patients and impact on early mortality rates.

b. ART

i. World Vision and MSF in Thyolo. World Vision is supporting home-based care programs within which people are benefiting from MSF ARV treatment. This program appears to have highly motivated home care volunteers who would be an asset to any evaluation research. A study of the impact of TFA on ARV patients' quality of life and weight seems possible and potentially very informative.

ii. ActionAid: contact: allisonzakaliya@yahoo.co.uk

The Strategies for Action program (SFA HIV AIDS) has been recruited for the CHANGES project which provides grants to CBO's providing either 1.) Prevention, 2.) Impact Mitigation or 3.) Treatment, care and support, (ARVs, HBC) activities. This is a new project which began in August '04 to build CBO capacity. ActionAid would like CBOs to have tools for collecting data but currently they do not have checklists or registers to use. The goal is to develop indicators for measuring which can contribute to the NAC database.

Most of these CBOs have a feeding component, through income generating activities, which provide food to PLHA, CI and orphans. Funding from MASAF for maize meal, agricultural inputs (seeds, fertilizer and gardening tools) some small grants for food and clothing. Current M&E forms are limited to the NAC activity report form. Although this is an important start, there is a great deal of opportunity to expand on this and develop M&E systems that better serve the CBOs' needs. ActionAid is just beginning to implement expanded M&E systems regarding HIV (they have started in at least five CBOs in each district and have seven districts total) and are open to improving this process.

iii. Center for Social Research – University of Malawi (Based in Zomba) Nixon Khembo (Deputy Director) nskhembo@yahoo.com HIV/AIDS Alister Munthali

This center is well positioned to be a mentor/partner with the I-LIFE program. It has a food security and livelihoods department and an HIV/AIDS specialist on faculty. The center provides both qualitative and quantitative research with seven PhD's and numerous Master's prepared faculty. They have been involved in coordinating research nationally since 1979, and although they have no current studies which sound similar to the needs of this report, they are open to work in these areas.

2. Zimbabwe

a. PMTCT: The national PMTCT and Nutrition initiative offers considerable potential for pilot studies on the impact of TFA on PMTCT beneficiaries. Although the ration size as currently proposed is not adequate to measure a nutrition impact on women other impact measures could be developed such as program uptake, exclusive breastfeeding duration, timing and duration of weaning period as well as weight gain and disease incidence in children from 6 months of age.

Possible sites are numerous and involve all CTA partners including ISPED, Zvitambo, Kapnek and ZAPP.

- i. Murehwa District Hospital PMTCT program (ISPED rural site)
 - ii. Chitungwiza Health Center (ZAPP peri-urban site)
- b. TB:** A small retrospective yet useful study could be done at St Paul's Musami. This hospital has a TB register available with weights of patient while on food assistance as well as when food assistance not available. (contact: Sister Maggie Mutopo- Matron)
- c. Chronic Illness: Gwanda**
This is a World Vision Site with both a CI TFA program as well as a food for assets program. Both groups are eager to share their experiences.

3. Zambia

- a. ART- Catholic Relief Services is the lead agency for the PEPFAR ARV program in Zambia. Following discussions with CDC and CRS in Lusaka, it was clear that there is no routinely collected data on nutrition. Given CRS's experience in food aid and their currently expanding role in ARV roll out, this would be an opportune time to work towards improved assessment of TFA on ARV recipients. Although a small-scale pilot would be warranted at first, the potential is to expand as the ARV roll out program expands.

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