FROM PROVIDER-ORIENTED TO CLIENT-DRIVEN CARE

Report on the development and testing of a take-home monitoring tool for people living with HIV in Cameroon

CRS
CATHOLIC RELIEF SERVICES

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Report on the Development and Testing of a Take-Home Monitoring Tool for People Living With HIV in Cameroon

Catholic Relief Services
Cameroon Program

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INSTITUTIONAL COLLABORATION

This tool has been prepared through collaboration among people from different institutions who contributed to its design and development. Some participated during the various workshops, while others, particularly the reviewers, contributed by email. This collaboration has resulted in an informal partnership that can be drawn upon to carry out similar and/or related activities. The key institutions were the following:

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- Regional Technical Group for the Fight Against HIV/AIDS for the Northwest Region of Cameroon
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- St. Martin de Porres Catholic Hospital, Njinikom, Cameroon
- St. Elizabeth Catholic Hospital, Shisong, Cameroon
- Central Hospital, Yaoundé, Cameroon
- Social Insurance Hospital, Yaoundé, Cameroon

ACRONYMS

AIDS	Acquired immune deficiency syndrome
ART	Antiretroviral therapy
ARV	Antiretroviral (drugs)
CRS	Catholic Relief Services
HAART	Highly active antiretroviral therapy
HIV	Human immunodeficiency virus
OI	Opportunistic infections
NNRTI	Nonnucleoside reverse transcriptase inhibitor
PLHIV	People living with HIV
TB	Tuberculosis
WHO	World Health Organization

SUMMARY

Traditionally, clinical and biological follow-up of people living with HIV (PLHIV) is provider-oriented. There is little client education and limited involvement in clinical monitoring. This might explain cases of late initiation of therapy, poor adherence to care and treatment, and antiretroviral (ARV) resistance. Faced with this challenge, Catholic Relief Services (CRS) Cameroon decided to develop and test a client-oriented, pocket-size, take-home patient monitoring guide principally for PLHIV. This is a joint report of the two-phase process that covers the period from April 2008 to May 2010.

The tool was designed and developed during three successive workshops that brought together people from various backgrounds with experience offering care to PLHIV. The expert consultative group identified HIV and AIDS indicators understandable to the clients themselves that provide a snapshot of the client's health over time. These indicators included weight, signs and symptoms, CD4 cell counts, ARV regimens, medication refills, medication side effects, nutrition and hygiene. The indicators were incorporated into a 16-page, 14- × 10-cm pocket-size booklet (the tool) to be used mainly by PLHIV in monitoring their own health over a five-year period. Home and facility-based care providers can also complete sections in the booklet.

Three hundred volunteers from four treatment centers in Cameroon were invited to use the tool for three to four months. At the end of the period, 200 participants were interviewed to assess the use of the tool. Another 130 volunteers from the same centers, who did not use the tool, were interviewed to assess the classical

follow-up approach and compare any effects the use of the tool might have produced.

Eighty-five percent of participants used the tool correctly. Illiteracy and low educational levels were one of the main reasons for poor understanding and use. Exposure to the tool significantly increased users' self-management behaviors and practices with specific regard to weight monitoring, CD4 testing and adherence to ARV drugs compared to nonusers. Some key suggestions were made by users to help improve the tool. About 85 percent of nonusers of the tool expressed dissatisfaction over the classical follow-up approach, mentioning lack of understanding by patients of the condition for which they were receiving care, the criteria for initiating treatment and the indicators used for evaluating treatment outcome as the key reasons. Of the 33 percent of nonusers who reported going home with a document outlining their care and treatment, only 15 percent understood the information in the document.

This work possibly presents the first comprehensive self-monitoring tool designed for PLHIV in a resource-limited setting. It provides an opportunity for a critical review of the various systems in place and a transition from provider-oriented to client-driven care that needs further exploration.

INTRODUCTION

Although some reports indicate that the prevalence and incidence of HIV has been curbed in many countries of the world, national epidemics continue to expand in many other parts of the world.[1] The majority of these deaths result from AIDS-defining opportunistic infections (OI) that develop when the immune system is severely damaged by HIV. Proper follow-up and care, as well as timely use of highly active antiretroviral therapy (HAART), are the most effective means of reducing AIDS-related morbidity and mortality. Proper monitoring helps to indicate when to start HAART in treatment-naïve people, ensuring effectiveness among those on treatment and helping to avoid resistance and progress to late stage disease (tertiary prevention).[2]

In Cameroon, as is the case in other developing countries, clinical and biological follow-up of people living with HIV (PLHIV) is provider-oriented. Information is conserved in facility-based records, which are inaccessible to clients. Clients go home with summary notes, often limited to diagnosis and prescription. With the high prevalence of "doctor shopping," poor client education and limited client involvement in clinical monitoring, the current approach to HIV and AIDS care may lead to late initiation of therapy, poor adherence and ARV drug resistance. Faced with this challenge, the Health and HIV Unit of Catholic Relief Services Cameroon (CRS/CM) decided to develop and test a take-home tool that would enable PLHIV to better understand and monitor their health and serve as a link between care providers.

This report presents the conception, development process and testing of the tool in a field setting as well as important recommendations for its use.

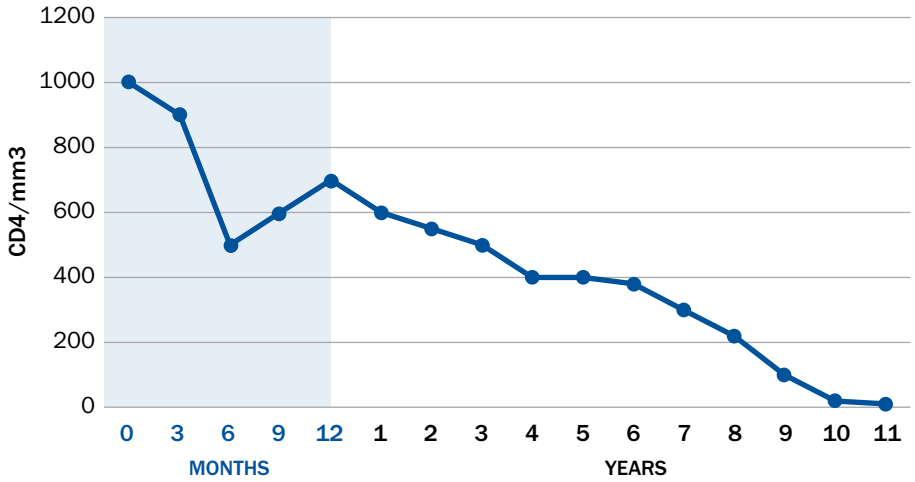
RATIONALE AND CONCEPTUAL FRAMEWORK FOR AN HIV MONITORING TOOL

The transition from the time of infection with the human immunodeficiency virus (HIV) to the development of acquired immune deficiency syndrome (AIDS) is relatively long. The average interval between serologic conversion and full-blown AIDS is estimated to last 7 to 11 years.[3] However the median survival without ART once AIDS sets in has been estimated at 1.6 years.[4] Prior to HAART, the clinical trend was one that usually led to death related to OI that develop as CD4+ T-lymphocyte counts drop (Fig. 1).

1 UNAIDS, *2012 Report on the Global AIDS Epidemic*. (Geneva: UNAIDS, 2012).
2 WHO, *Antiretroviral Therapy for HIV Infection in Adults and Adolescents in Resource-Limited Settings: Towards Universal Access. Recommendations for a Public Health Approach* (Geneva: WHO, 2006)
3 WHO, *HIV/AIDS: Online Q&A, December 2012.* http://www.who.int/features/qa/71/en/index.html
4 Dou, Z., Chen, R., Y., Wang, Z., et al. "HIV-Infected Former Plasma Donors in Rural Central China: From Infection to Survival Outcomes, 1985–2008." *PloS ONE* 5, No. 10 (October 2010): e13737.

Pediatric growth charts for monitoring weight, height and frontal occipital head circumference have been in use since 1977.[5] These have proven to be a powerful preventive tool for childhood illnesses when correctly used. Along these lines, the idea to develop a take-home monitoring tool for PLHIV as a form of prevention was developed by staff of the Health and HIV Unit of CRS/CM. This tool uses simple clinical and biological indicators that the patient can understand.

Figure 1. Natural course of T-lymphocyte CD4+ count in PLHIV



To date, few attempts have been made to conceive and test an appropriate take-home instrument to monitor HIV infection and disease progression in PLHIV in resource-limited settings. In Spain, Cáceres et al. (2001),[6] created and tested a web-based tool for self-monitoring of the medical, psychological and social aspects of PLHIV. They discovered that these patients became more aware and more informed about their health situation than other patients, and the tool also improved their consultations with their care providers. Earlier, Gustafson et al. (1999)[7] had tested in a randomized controlled trial a home-based computerized system called CHESS (Comprehensive Health Enhancement Support System), designed to provide HIV-positive patients with information, decision support, and connections to health care experts and other patients. The study targeted HIV-positive patients in Wisconsin and showed that CHESS was effective in improving the quality of life of its users (active life, negative emotions, cognitive function, social support and participation in health care) and promoting more efficient use of health care.

While both studies did demonstrate that a patient-centered self-monitoring tool can be effective in improving health outcomes of PLHIV, the particular tools

5 Murphy, C. A., Carstens, K., & Villamayor, K. "Electronic Growth Charts: Watching Our Patients Grow." *AMIA Annual Symposium Proceedings* (2005): 1058.

6 Cáceres, C., Gómez, E. J., & Del Pozo, F. *A Patient Monitoring Tool for an HIV/AIDS Integral Care Model*, Grupo Del Bioingeniería y Telemedicina, Universidad Politécnica de Madrid, Spain. Scientific paper presented during the 23rd Anual International Conference of IEEE, October 25, 2001.

7 Gustafson, D. A., Hawkins, R., Boberg, E., Pingree, S., Serlin, R. E., Graziano, F., & Chein, L. C. "Impact of a Patient-Centered, Computer-Based Health Information /Support System." *American Journal of Preventive Medicine* 16, No. 1 (1999): 1–9.

themselves are not likely to be useful in Cameroon and other resource-limited settings. Both tools require the use of computer technology, which is not easily accessible to the majority of people in this part of the world. These earlier works are therefore not culturally relevant to the Cameroonian context necessitating the need for a tool that would be more acceptable, feasible, and affordable by patients in a resource-limited setting.

OBJECTIVES

The overall goal of this project was to better monitor the status of PLHIV who might need to initiate treatment, as well as those who were already on treatment in order to maintain their health. This project had two main objectives, namely:

1. To design and develop a take-home monitoring tool for HIV and AIDS to be used by PLHIV to track identified clinical, biological, immunological and virological variables.
2. To test the use and usefulness of the tool in care and treatment centers in Cameroon.

TOOL DEVELOPMENT AND DESCRIPTION

Design of the Draft Tool

During April 9–11, 2008, an expert consultative group comprising PLHIV, health care providers with experience in HIV and AIDS management, an educator, a graphic artist, a social scientists, and researchers, met in Yaoundé, Cameroon, at a workshop to design the tool. Inspired by a presentation from an expert in the clinical and biological manifestations of HIV and AIDS and follow-up of PLHIV before and during treatment and a collection of existing clinical tools, the consultative group went through a two-step process in designing the tool.

Working in two subgroups, the experts first identified clinical and biological HIV-related indicators currently used by clinicians that could be included in a take-home tool. After identifying these indicators, the group considered different ways of presenting them on paper under the guidance of the graphic artist. Final consensus was on a pocket-size booklet, with the idea that a document that the client could easily slip into the breast pocket for men or handbag for women would minimize stigma. The first draft tool was a 16-page, 14- × 10-cm booklet, with the working title *Patient Monitoring Guide*, that contained the information identified by the taskforce (Fig. 2). The indicators included the following:

1. Identification information.
2. Weight.
3. HIV-related symptoms and signs (fever, night sweats, body rashes, dizziness and weakness, mouth sores, frequent stools, body swellings,

God-fire[8]/zona[9]/shingles, yellow eyes or jaundice, blood in stool, weakness of limbs or paralysis, difficulty breathing, cough, absence of menses, difficulty in swallowing, abnormal behavior, numbness).

4. CD4 count over time.
5. Key laboratory findings (viral load, hemoglobin level, total lymphocyte counts, liver enzymes, creatinine, cholesterol, PPD-intradermal reaction).
6. HAART regimens available in Cameroon, TB treatment and prophylaxis.
7. HAART side effects (excessive tiredness or anemia, abnormal weight changes, sleeplessness, bad or altered dreams, abdominal and/or loin pains, nausea, vomiting, frequent thirst, irregular urinary frequency, decreased urine output). A foreword page with instructions on the use of the booklet and a page providing general advice for healthy living were also included.

Figure 2. First draft of the Patient Monitoring Guide

Review of the Draft Tool

The first draft of the *Patient Monitoring Guide* was sent to 14 reviewers with experience in HIV and AIDS management, public health or research. Nine of the 14 reviewers were from Cameroon, with the remaining five from Germany, Switzerland, Tibet, and the United States. A review table was sent to all the reviewers to facilitate the provision, analysis and subsequent use of feedback. The reviewers were invited to comment on the general presentation of the tool and on each page using a scale with the following scores: 1 = very good, 2 = good, 3 = acceptable, 4 = poor. They were also invited to comment on each of the issues under review and make suggestions for improvement. All reviewers received a PowerPoint electronic presentation of the tool alongside the review table.

8 Common local name for shingles.
9 French for shingles.

Out of the 14 reviewers contacted, feedback was received from 12 (86 percent). All but two feedbacks were sent via email. Nine (75 percent) out of the 12 review feedbacks were based on the scoring scale. The best score was for the foreword page that explained the use and utility of the tool, while the treatment and appointments and advice on nutrition and hygiene sections had the lowest scores (Table 1). The overall grading varied from "very good" to "good."

Table 1. Review Scores from Nine Reviewers Who Used the Scoring Table

ISSUE UNDER REVIEW	NUMBER OF REVIEWERS	TOTAL SCORE	AVERAGE SCORE*
General presentation of booklet	8	9	1.1
Front cover page	9	14	1.6
Inside of front cover page (Foreword)	9	9	1
Page 3 (identification)	9	18	2
Pages 4 and 5 (Weight chart)	9	14	1.6
Pages 6 and 7 (symptoms and signs)	9	15	1.7
Pages 8 and 9 (CD4 chart)	9	15	1.7
Pages 10 and 11 (laboratory follow-up findings)	9	14	1.6
Pages 12 and 13 (treatment)	9	20	2.2
Pages 14 (treatment follow-up indicators)	9	16	1.8
Inside back cover (appointments, nutrition and hygiene)	9	18	2
Back cover	8	9	1.1

*1 to 1.4 = very good, 1.5 to 2.4 = good, 2.5 to 3.4 = acceptable, 3.5 to 4 = poor.

Reviewers also provided qualitative feedback in the form of comments and suggestions on the overall presentation and the content of the document. Some of the comments and suggestions concerned the following:

- The need for explanatory footnotes
- A page on nutrition and hygiene indicators
- Need for a user's guide
- Areas to highlight on the CD4 and other charts
- Disclosure of HIV status
- Overall arrangement of information in the document
- Use of simple or commercial names for ARV drugs
- Confidentiality in recording information
- Use of simple language
- Spelling errors

Finalization of the Tool

A second workshop to finalize the tool was organized in Bamenda, Cameroon, June 19–20, 2008. To ensure relevance of the tool to health care providers, four nurses and one physician from treatment centers in the Northwest region were invited to join the group. As in the previous workshop, PLHIV were part of the working groups that designed and reviewed the tool.

The expert group started with a critical in-depth analysis of the tool before examining the feedback from reviewers. Reviewer comments were grouped under the headings in the review table. The taskforce examined the various comments and decided on those to incorporate into the tool. Some review suggestions, such as the Karnofsky and Disease Stage Scale, were found more appropriate for care provider training sessions, as some care providers were not familiar with them. The present study had no provision for training of care providers.

The information in the identification page of the tool was made more coherent with provision for WHO or CDC (Centers for Disease Control and Prevention) stage upon entering into the follow-up program. Treatment regimens for ART were simplified to include only most frequently used commercial and/or simple chemical names such as nevirapine. The chemical abbreviations d4T, 3TC, LPV/r were all taken out. The section on treatment follow-up (page 14) was shortened to include only symptoms and signs that had not been included under the section with clinical follow-up of HIV-related symptoms and signs (pages 6 and 7). The section on nutrition and hygiene was modified to include balanced diet, habits such as rest and exercise to encourage a healthy lifestyle, and things to avoid such as tobacco and alcohol. Given that the tool was still to be presented to the Ministry of Public Health of Cameroon, a logo of the Cameroon Ministry of Health was taken off the front cover page, leaving only that of CRS. Even then, it was suggested that the size of CRS logo be made slightly smaller to avoid drawing undue attention to the logo, as the tool is meant for all PLHIV irrespective of social, organizational or religious affiliation.

A third workshop was held in Bamenda, on August 5–6, 2008, to familiarize care providers with the tool and prepare a French version of the revised product.

DESCRIPTION OF THE TOOL (BOOKLET)

The French and English versions of the tool were finalized based on the aforementioned process. The final tool is a 16-page; pocket-size booklet about 14- × 10-cm. The booklet is tailored for use by PLHIV in monitoring their health over periods of five years and has the following contents:

- A cover page containing the name of the document: *Patient Monitoring Guide*
- A foreword briefly explaining the use and utility of the tool
- An identification section (page 3) with information about the client and the contact information of the treatment center, but nothing directly referring to the client
- A section to record and plot the weight of the client on a graph, divided into trimesters and covering a period of five years to produce a weight curve (pages 4 and 5)
- A section with common HIV- and AIDS-related symptoms and signs (pages 6 and 7), divided into trimesters and covering a period of five years
- A section to record CD4 with shades to indicate the 200 and 500 cutoff points (pages 8 and 9), divided into trimesters and covering a period of five years
- A section to record frequently used HIV- and ART-related laboratory follow-up investigations (pages 10 and 11), divided in trimesters and covering a period of five years
- A section with ARV regimens available in Cameroon (pages 12 and 13), divided into trimesters and covering a period of five years
- A page with the option to record any ART side effects and special appointments
- General advice in the inside back cover page on maintaining a balanced diet and healthy life style

The various pages of the booklet can be grouped into four sections as displayed in Table 2.

Table 2. Sections of the Monitoring Tool and Key Contents

SECTION	PAGES	KEY CONTENT
General information and identification	Front and back covers (pages 1 and 16)	Title and author contact information
	Foreword (page 2)	Brief guidelines on the use of the tool
	Identification (page 3)	Patient and treatment center identification and some patient parameters
	General advice (page 15)	Advice on nutrition, hygiene and adverse habits like alcohol, tobacco and drugs
Clinical follow-up	Weight chart (pages 4 and 5)	Plot of patient's weight in kilograms on y-axis against time in trimester on the x-axis
	Clinical follow-up indicators (pages 6 and 7)	Chart of HIV-related symptoms and signs on the y-axis against time in trimesters on the x-axis
Para-clinical follow-up	CD4 chart (pages 8 and 9)	CD4 count on the y-axis plotted against time in trimesters on the x-axis
	Laboratory follow-up findings (pages 10 and 11)	Basic laboratory follow-up findings on the y-axis against time on the x-axis
Treatment, side effects and appointments	Prescribed treatment (pages 12 and 13)	ART regimens available in Cameroon on the y-axis against time in trimesters on the x-axis
	Possible ART side effects (page 14)	Common ART adverse effects on the y-axis against dates
	Specific appointments (page 14)	Special appointments against dates

Figure 3 presents pages 8 and 9 of the monitoring tool whereupon CD4 counts are recorded and plotted onto a curve. It permits the client and the care provider to visualize changes in CD4 counts. Figure 4 presents a portion of the section for recording symptoms and signs. Symptoms and signs shown in a darker shade are those that should prompt the patient to see his or her care provider immediately. A separate section was reserved for recording weight (Figure 5), which would enable the client to plot successive recordings onto a curve. Appropriate footnotes have been included to guide the recording and plotting of indicators and assist the client in understanding the significance of the different possible presentations.

Figure 3. Pages 8 and 9 of the Patient Monitoring Guide to record CD4 counts and to plot the figures onto a curve by trimesters for 5 years

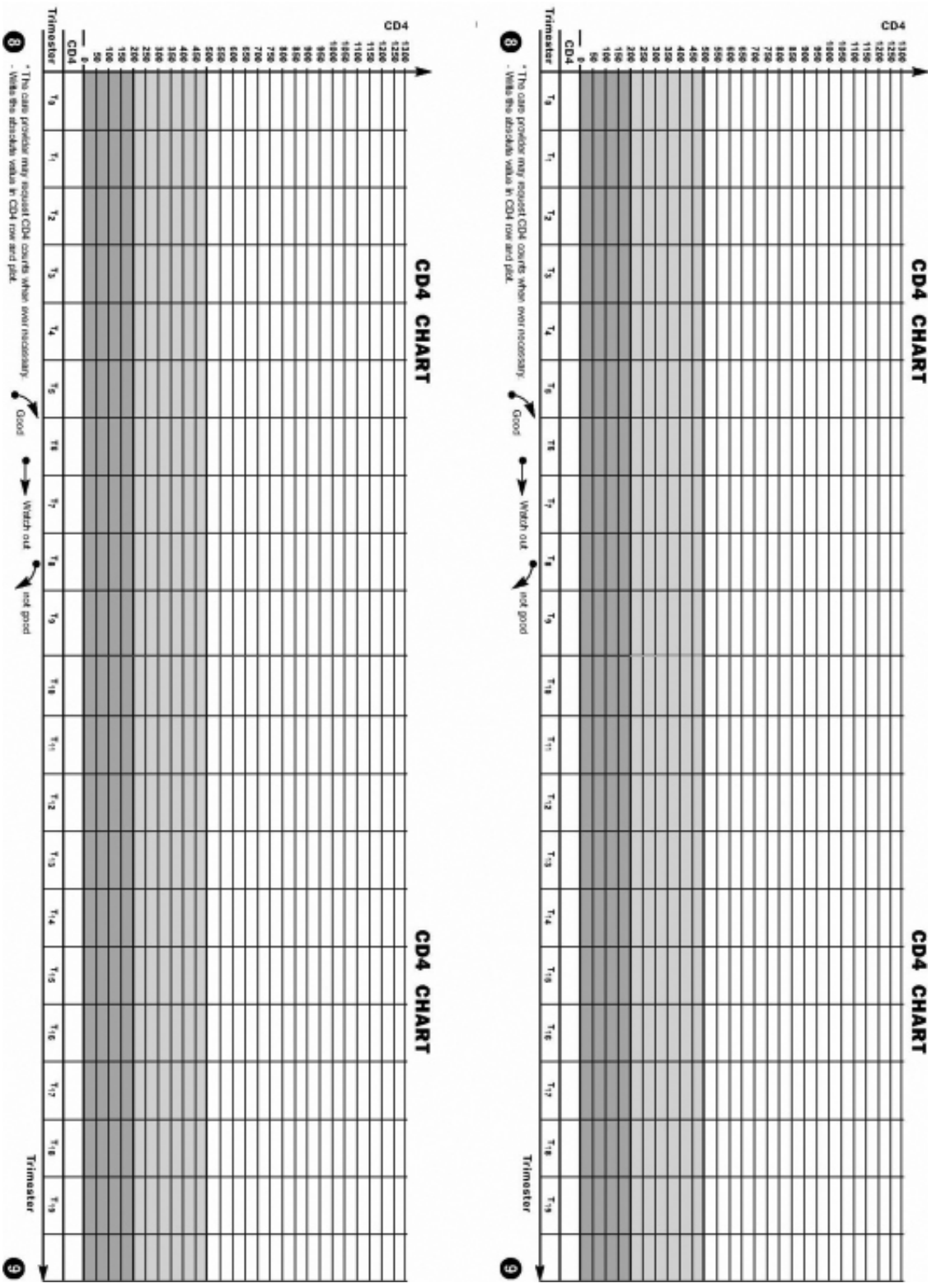
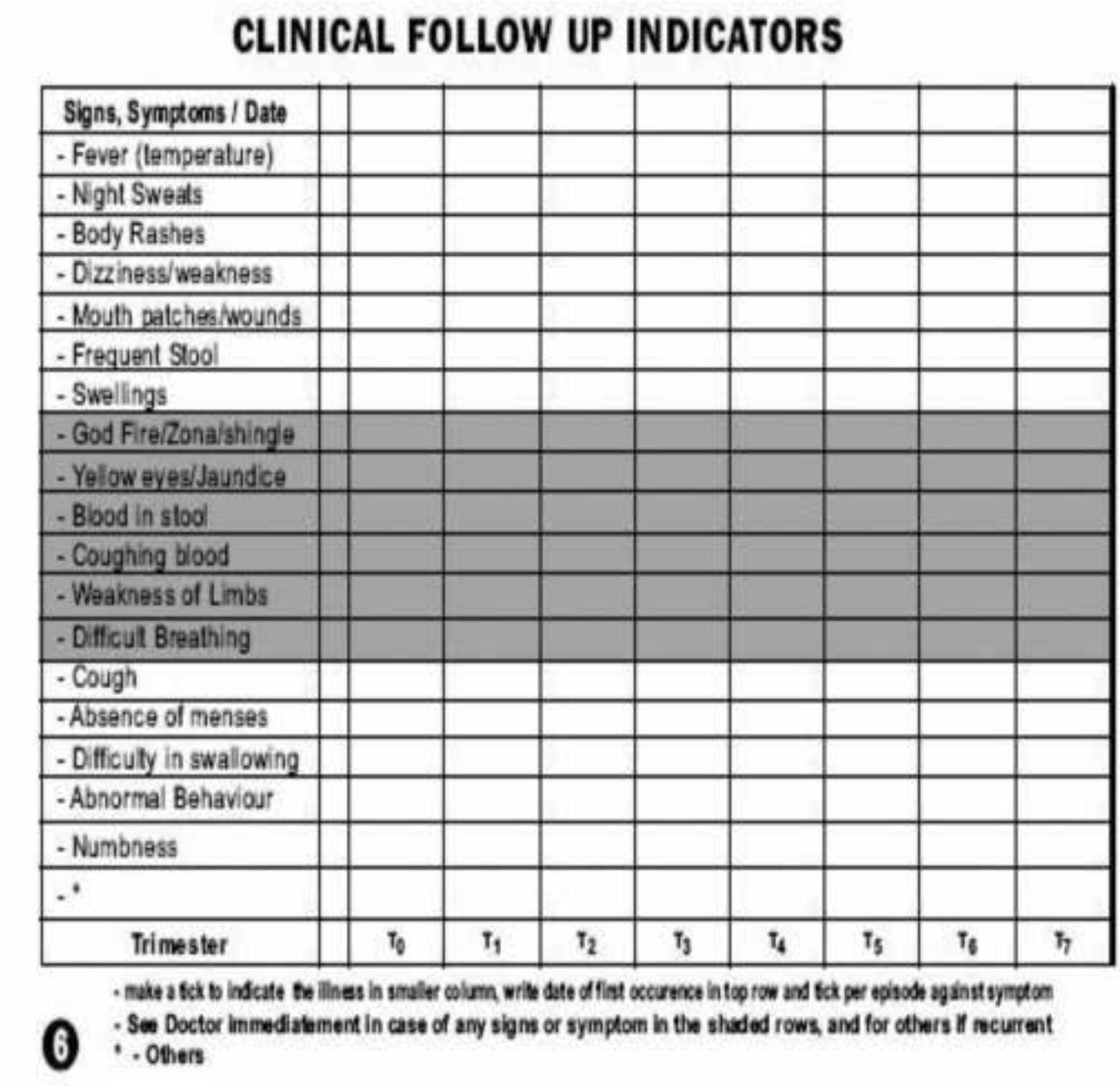


Figure 4. Portion of the clinical follow-up indicators section of the Patient Monitoring Guide to note symptoms



CLINICAL FOLLOW UP INDICATORS

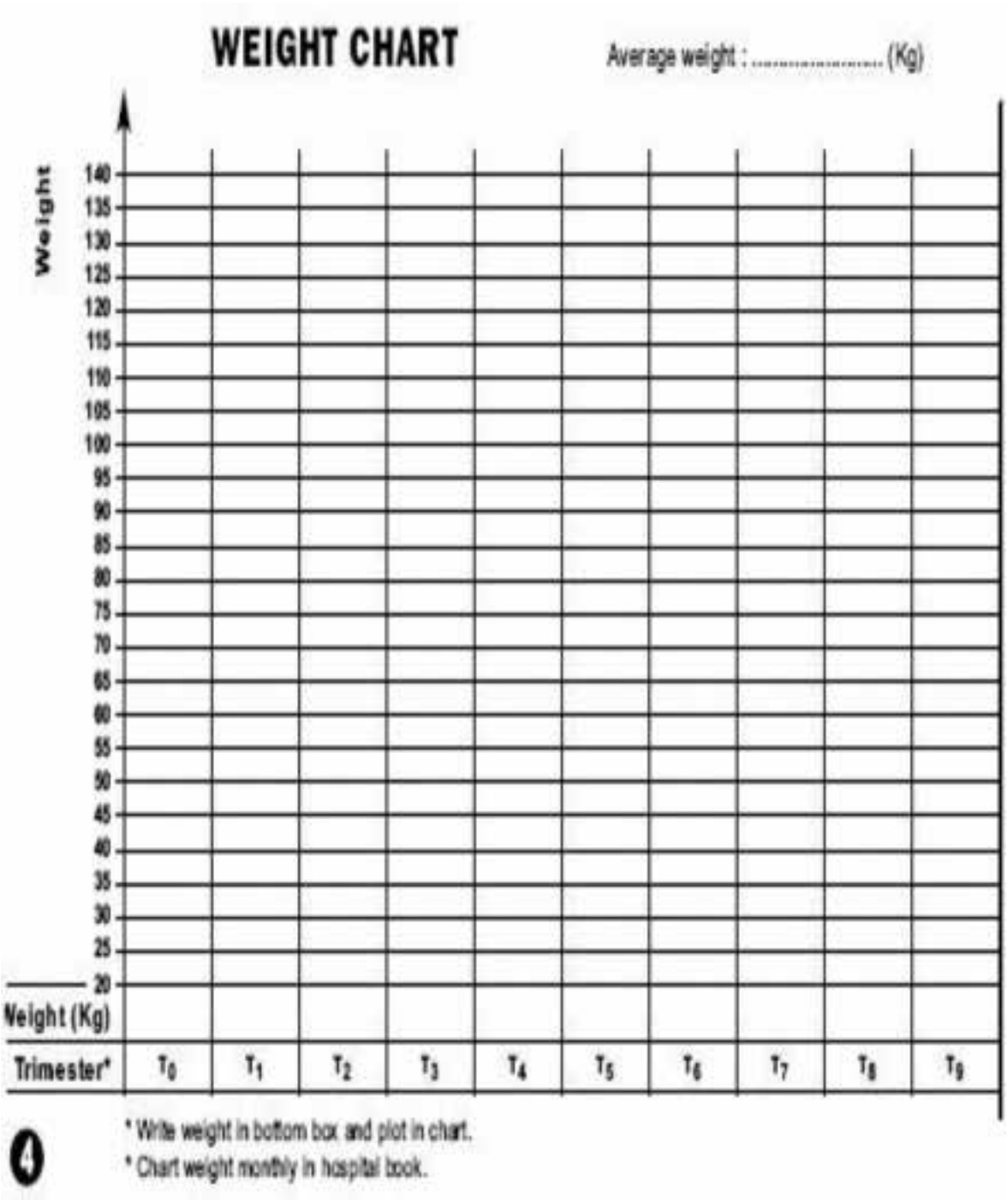
Signs, Symptoms / Date									
- Fever (temperature)									
- Night Sweats									
- Body Rashes									
- Dizziness/weakness									
- Mouth patches/wounds									
- Frequent Stool									
- Swellings									
- God Fire/Zona/shingle									
- Yellow eyes/Jaundice									
- Blood in stool									
- Coughing blood									
- Weakness of Limbs									
- Difficult Breathing									
- Cough									
- Absence of menses									
- Difficulty in swallowing									
- Abnormal Behaviour									
- Numbness									
- *									
Trimester		T_0	T_1	T_2	T_3	T_4	T_5	T_6	T_7

- make a tick to indicate the illness in smaller column, write date of first occurence in top row and tick per episode against symptom
- See Doctor immediatement in case of any signs or symptom in the shaded rows, and for others if recurrent

6

* - Others

Figure 5. Portion of the Patient Monitoring Guide that allows patients to record their weights over a period of five years



TESTING OF THE MONITORING TOOL

In order to achieve the second objective of testing the monitoring tool, the authors opted for an operations research design which had the following specific objectives:

1. Measure the extent to which PLHIV used the monitoring tool to correctly track the identified variables.
2. Measure to what extent PLHIV understood what the changes identified meant for their health and how the recorded information helped the client seek timely care.
3. Determine the extent to which the recorded information influenced decision making by care providers.
4. Assess the usefulness of the monitoring tool in linking up care provider institutions and therapeutics committees that decide on individual treatment regimens in the treatment centers. The therapeutics committees comprise physicians, nurses, psychosocial workers, and the pharmacist.

METHODOLOGY

Study Sites, Population and Design

Four HIV treatment centers were selected for testing the monitoring tool. The four were purposefully selected out of six initially earmarked because of time and resource constraints. Three of the sites were in the English-speaking region, and one was in the French-speaking region. Selection of test sites was based on convenience and easy accessibility to investigators. However, sites were also chosen to reflect the three main sectors that are involved with health care provision in Cameroon: (1) the public (government), (2) private for-profit and (3) private not-for-profit sectors. Both urban and rural settings of the population were represented in the choice of sites. All sites were government-approved treatment centers, and they implemented the national guidelines for care and treatment of PLHIV. The sites included the following:

HIV Treatment Center of the Central Hospital, Yaoundé. A state-owned health facility that was instituted in 1998 as a specialized unit for HIV prevention, care, treatment and support of PLHIV. This treatment center is located in the heart of the city of Yaoundé, the country's capital as well as the city most affected by HIV in the country, with a prevalence of 7.1 percent. The Yaoundé Central Hospital Treatment Center is the largest in the country, with six medical doctors at the time of the study and several other personnel including nurses and laboratory technicians who provide services to clients. It has the capacity to carry out basic laboratory follow-up tests and take CD4 measurements and is situated next to the Centre Pasteur where viral load measurements are carried out.

HIV Treatment Center of the Bamenda Regional Hospital. The regional hospital in Bamenda is one of the oldest state-owned facilities in the country and is

located in the Northwest region, which is the region with the highest prevalence of HIV (8.7 percent) in the country. The HIV treatment center was established as a specialized unit of this hospital in 2002 to prevent and manage HIV infection and also to serve as a referral treatment center to several treatment units that are located across the region. At the time the study was conducted, the treatment center had 10 trained staff, including two physicians. It has facilities to carry out CD4 measurements and routine laboratory follow-up examinations. At the time of this study, it did not have the capacity to perform viral load measurements.

Mezam Polyclinic in Bamenda. This is a private institution with an approved HIV treatment center. In addition, this center runs a home-based care program and provides CD4 count measurements as well as other routine laboratory investigations. This makes it accessible to all patients regardless of their socioeconomic status.

St. Martin de Porres Catholic Hospital, Njinikom. Run by the Catholic Church, this hospital is located in a rural community some 60 km from Bamenda in the Northwest region. It is equipped with facilities to carry out HIV prevention, treatment, care and support of PLHIV, and CD4 testing.

Sample and Sampling

The study population was made up of 300 PLHIV who consented to use the monitoring tool for a period of three to four months and another 130 who were interviewed to assess provision of care based on standard files and hospital booklets or cards.

Sampling was purposive and included people registered in the treatment centers for at least six months prior to the study, were at least 21 years of age, and from whom informed written or verbal consent was obtained for participation in the study. Participants were given the option to choose either French or English versions of the booklet. Given that a member of the participant's household could assist to fill out the booklet, illiteracy (inability to read and write) was not taken into consideration.

Data Collection and Monitoring

Catholic Relief Services assigned the role of monitoring of the field work and data collection to a final-year medical student of the Faculty of Medicine of the University of Yaoundé 1. She trained participants and health care providers on the correct use of the tool, administered surveys, filled out the questionnaire to appraise the use of the tool by each participant, and entered the data into the database prepared on SPSS.

Participants who used the monitoring tool (booklet) were enrolled into the study over a period of two weeks, and they were educated on its use by trained care

providers or, in some instances, by the investigators. After using the tool for a period of three to four months, a survey was conducted with the participants to assess their use and appraisal of the tool. Two questionnaires, which were designed and pretested by the Health and HIV Unit of CRS/CM, were used for the survey. The first focused on appraisal of the tool by the participants, and the second was filled out by trained enumerators to describe the general state of each tool after the period of use. This second questionnaire also enabled investigators to assess the degree to which participants used the tool to monitor their health. This was done through an analysis of reported variables such as weight changes, clinical signs, CD4 count changes and ART adverse effects. The tool was handed back to the participants after the interviews, and participants were encouraged to continue using it to monitor their health. Participants were advised to contact treatment centers in case they experienced HIV-related signs and symptoms in the course of using the instrument.

A different questionnaire was administered to the 130 participants who were assessed on the use of the standard follow-up system. The latter assessment focused on participants' appraisal of the current care centered on clinic-based files. This second group of participants (controls) was identified after a gap of about three weeks from the time the booklets were distributed. In this way the chances of them coming in contact with the users of the tool were minimized.

In order to assess the effect of the tool on knowledge and practice of participants with respect to their health and the care they were receiving, the questionnaires for users and nonusers contained similar questions around the following topics:

- Weight measurement
- Understanding of CD4 test results
- Knowledge about other routine lab tests
- Knowledge of ARV treatment

Data Processing and Analysis

Catholic Relief Services hired the services of two experienced biostatisticians who assisted with data processing and analysis. All the data were entered and processed using SPSS. Microsoft Excel was used to present results. In order to ensure good data quality, recording of the data was carried out first by the lead enumerator (field agent) and then later cross-checked by the consultants. Where there were important discrepancies, the questionnaires were revisited by the research team for clarification.

Proportions were used to describe the extent of use of the booklet by the participants and their understanding of the observed changes of the indicators. In some cases, 95 percent confidence interval (CI) values were calculated to emphasize the relevance of some findings.

Ethical Considerations

The proposal for this study was first presented to the Program Quality and Support Department (PQSD) at CRS Headquarter for approval. The study was designed in keeping with CRS' policy and ethical considerations regarding research in HIV. Once this was approved, ethical clearance and administrative authorization were obtained from the Cameroon National Ethics Committee and the Ministry of Public Health, respectively. After receiving copies of the ethical clearance and administrative authorization, the management of the four treatment centers provided consent for the study to be conducted in their various centers. Written or verbal consent was obtained from all participants.

RESULTS

General Characteristics of Participants (Users and Nonusers)

Of the 300 participants who received the booklets, 200 (66.7 percent) successfully used the booklet ("users") for three months. The reasons for failing to complete the study are summarized in Table 3. All 200 participated in the three-month survey.

Table 3. Distribution of Reasons for Failure of 100 Users to Participate in Three-Month Survey

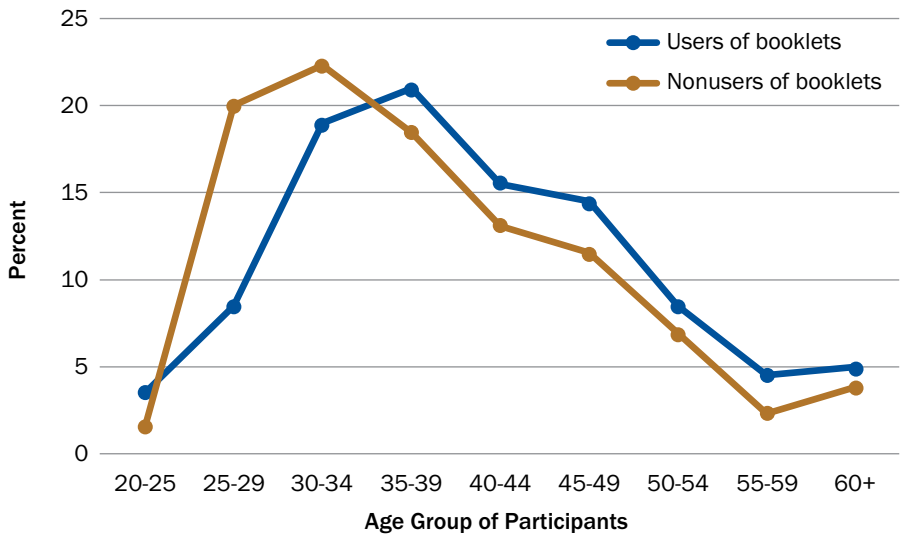
REASONS	DAY HOSPITAL, BAMENDA *N* = 120	DAY HOSPITAL, YAOUNDÉ *N* = 100	MEZAM POLYCLINIC, BAMENDA *N* = 30	CATHOLIC HOSPITAL, NJINIKOM *N* = 50
Booklets were lost	07	05	—	—
Patients were transferred or lost to follow-up	10	12	—	
Deaths (known)	02	03	01	—
Others	31	29	—	—

All 130 controls ("nonusers") were successfully contacted after the three-month period and they agreed to take the survey to assess the standard follow-up approach. They were all contacted during regular clinic visits. All users and nonusers were currently receiving ARV treatment at the time of the study. Age, sex and level of schooling were the main variables, which were used to further describe the participants.

Age Distribution

The mean age of users was 40.1 ± 9.84 years (range: 31.2–50.9) and that of nonusers was 38.7± 9.61 years (range: 29.1–48.2), indicating no significant difference between the groups with regard to age distribution. Most participants were 30–45 years old, as shown in Figure 6.

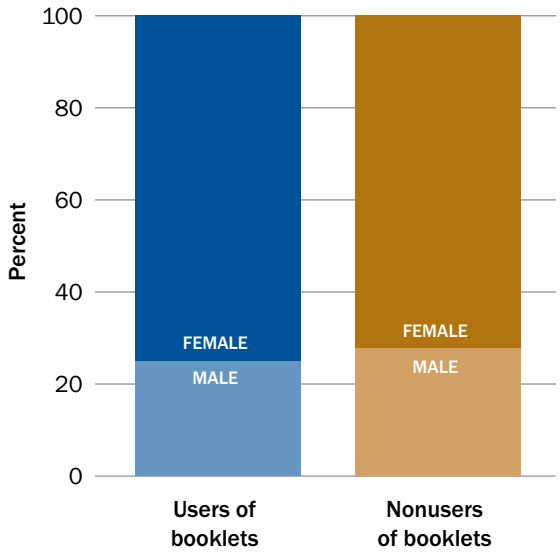
Figure 6. Age distribution of users and nonusers of booklet



Sex Distribution

In both groups, there were more females than males: 75 percent among users and 72 percent among nonusers, respectively (Figure 7).

Figure 7. Distribution of participants by sex

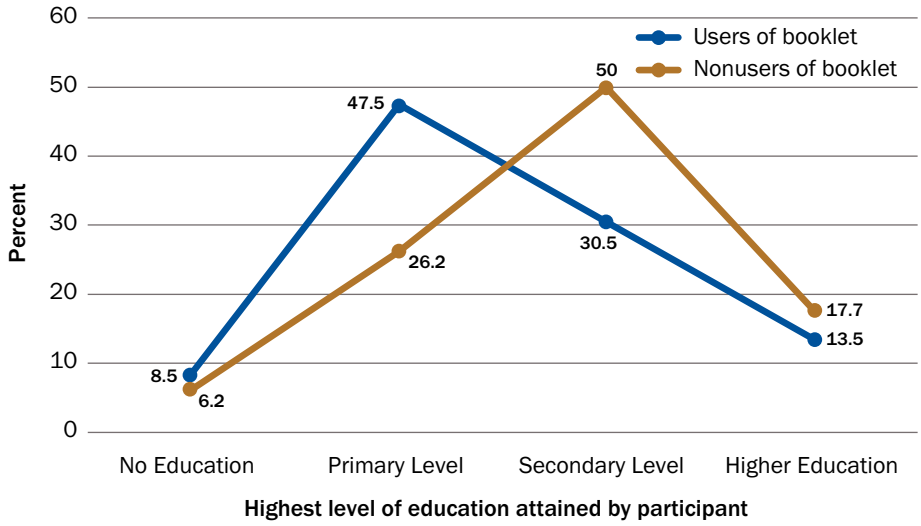


Level of Formal Schooling

The level of literacy of users and nonusers was assessed using four options: primary education, secondary education, higher education and no formal schooling. The aim was to ascertain the proportion of participants who attained some level of primary, secondary or higher education. Within the context of this study, illiteracy is defined as no formal schooling.

The study showed that there was no significant difference between users and nonusers with regard to their level of formal schooling: 78 percent of users and 76 percent of nonusers had attained either primary or secondary school, while only 8.5 percent and 6.2 percent of users and nonusers, respectively, did not have any formal schooling. However, the curve for users presented a right skew, whereas that for nonusers had a left skew, suggesting that there were more educated people among nonusers than users ($p < 0.001$) (Fig. 8).

Figure 8. Distribution of participants by level of formal schooling



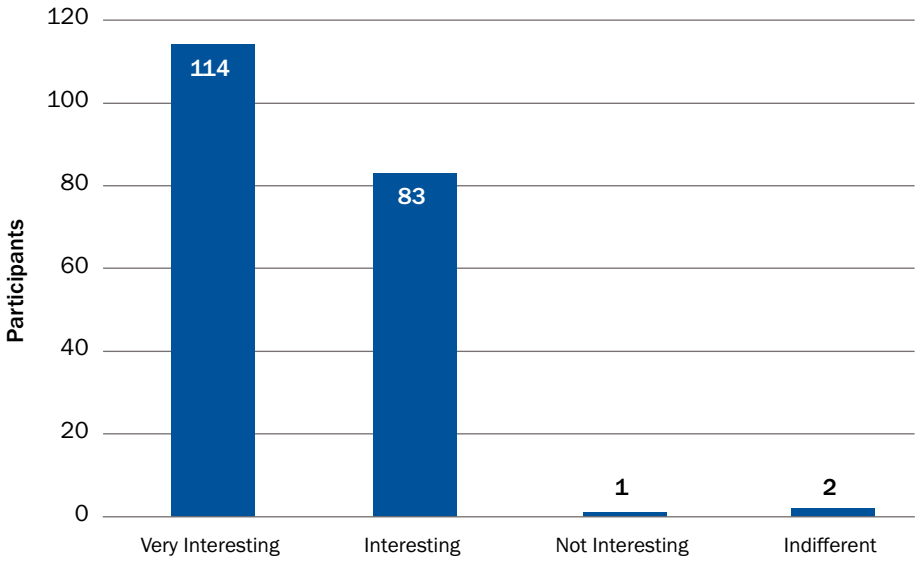
Assessment of the Utilization of the Booklet: Comparison Between Reported and Observed Practice of Users

The utilization of the booklet was assessed in two ways: First, users responding to the survey were asked to assess the usefulness of the tool as well as their understanding of the information on the different aspects of the booklet; second, the enumerators conducted an evaluation of the actual utilization of the booklet by the users in order to validate the information provided by the users. The results of these assessments are presented in this section, and where possible, a comparative analysis of the reported and observed practice of the users has also been presented.

General information and identification (cover page, pages 2 and 3)

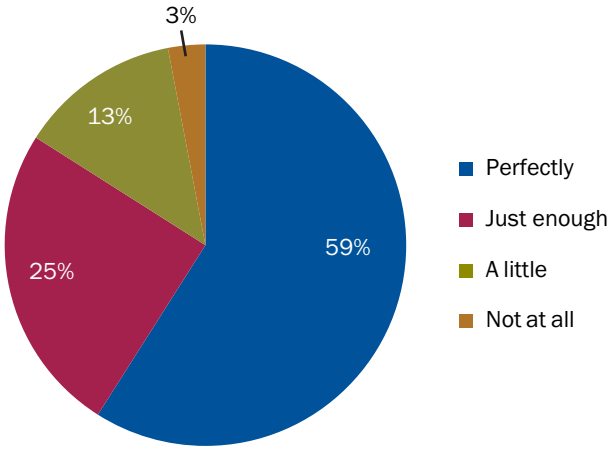
Although 95 percent of participants found the front cover page to be either very interesting or just interesting (Fig. 9), two key suggestions were made to help improve this page. The first was for the color to be dark and the material more solid. The second concerned the word "patient" that appears in the title (*Patient Monitoring Guide*). Several participants wanted "patient" to be replaced with another, less medical, word such as "client," a change that was ultimately made.

Figure 9. Distribution of users by their level of rating of the front cover page of the booklet



The foreword page (page 2) presented basic information to help participants understand and use the tool. It was observed that 16 percent (95% CI: 0.13–0.19) did not understand the message presented (Fig. 10). This figure was significantly higher than the 8.5 percent (95% CI: 0.051–0.095) illiteracy level observed among users ($p < 0.0001$). However, by matching for educational level, illiteracy and low levels of formal education were identified as determinants for the lack of understanding of the message on that page.

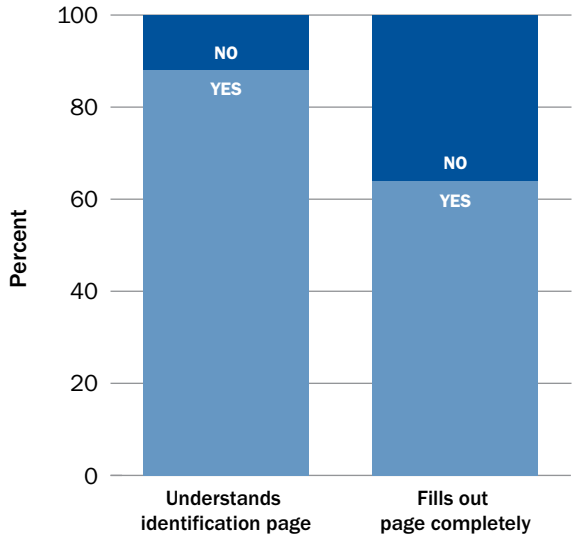
Figure 10. Distribution of users by level of understanding of information contained in the foreword page of the booklet



Only 4 percent of participants wanted some changes to be made to the page; that is, they requested more information concerning the authors of the document and the care providers.

Users' understanding and actual use of the identification page was assessed (Fig. 11). The majority of the users mentioned that they had perfect understanding (52 percent) or enough understanding (36 percent) of the identification page. Assessment of the users' capacity to actually fill out the required information on the identification page revealed that up to 36 percent did not completely fill out the information required on this page. In most cases information on blood group (55 percent) and height (42 percent) was not provided. Most participants did not know their blood groups or heights (even though this information can be obtained from national identity cards owned by every adult in Cameroon).

Figure 11. Comparison between reported knowledge and actual practice of users with respect to providing information required in the identification page of the booklet



There were few comments on the general advice section on nutrition, hygiene and adverse habits (like alcohol, tobacco and drugs), suggesting that the section was probably well understood by participants.

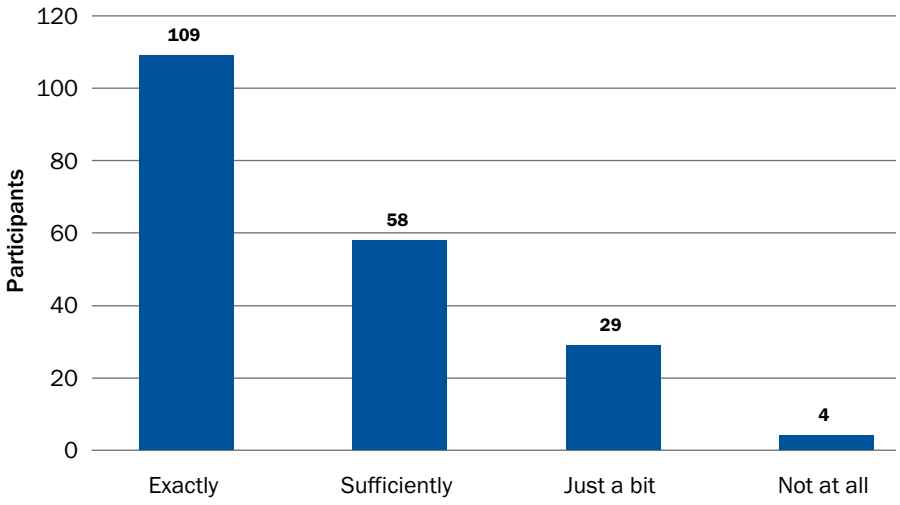
Weight Measurement (Pages 4 and 5)

The study assessed users' knowledge on measuring their weights before requesting if they could understand the use of the weight recording chart in the booklet: 76 percent reported knowing how to measure and read their weights from a weighing scale, while even a higher proportion (84.5 percent) mentioned that they are able to write down their weights once measured. Observation of the booklets revealed that up to 84 percent of users were able to record their weights correctly in the booklet, but slightly less, 71 percent (95% CI; 0.68–0.74), could plot the weights onto a curve to visualize changes over time. It was observed that most patients measured their weights only at the health facility (98 percent) since only 7 percent reportedly owned a weighing scale at home. The majority of weight measurements were taken on a monthly basis (82 percent).

Clinical Follow-up Indicators Page (Pages 6 and 7)

The majority of users (83.5 percent) reported that they had an exact (and enough) understanding of the signs and symptoms listed on this page, as shown in Figure 12. However, 19 percent needed help from either family or care providers to properly fill in the symptoms they experienced during the testing period. A very small proportion of participants (1 percent) observed that the section did not include all the symptoms and signs experienced by PLHIV.

Figure 12. Number of users reporting levels of understanding of signs and symptoms on the clinical follow-up page of the booklet



More than half of the participants (52 percent) reported HIV-related symptoms during the period the tool was used. The three leading symptoms were fever, cough and rash (Table 4). Footnotes in the section advised users to report all symptoms to care providers. They were further instructed to see care providers immediately if they experienced shaded symptoms like blood in sputum, difficulties in breathing and weakness in limbs.

Table 4. Symptoms Reported by Users of the Booklet

SYMPTOMS	NUMBER OF PATIENTS	PERCENTAGE (N = 104)
Fever	47	45.2%
Cough	43	41.3%
Skin disease	20	19.2%
Diarrhea	14	13.5%
Fatigue/tiredness	14	13.5%
Night sweats	12	11.5%
Shingles	6	5.8%
Weakness of limbs	6	5.8%
Blood in stool or in sputum	5	4.8%
Mouth sores	5	4.8%
Difficulties in breathing	4	3.8%
Yellow eyes (jaundice)	2	1.9%

In all, users were quite satisfied with this page of the booklet—98 percent of them felt it was either very interesting or interesting.

Para-Clinical Follow-up (CD4 and Laboratory Follow-up on Pages 8–11)

Although only 66 percent of users confirmed that they were able to correctly record their CD4 results into the CD4 chart of the booklet, observations of the filled booklets indicated that up to 93 percent did record a CD4 result. Just as with the weight chart, users sought assistance from their health care providers in charting the CD4 results into the booklet. The other laboratory tests that users were required to report included the full blood count, fasting blood sugar, liver enzyme tests, pancreatic amylase, body lipids, kidney function test, pregnancy test and HIV viral load. These tests constitute the minimum pretherapeutic and follow-up tests that are often conducted on PLHIV in Cameroon and that are state funded. Other tests or investigations that could be requested, such as tests for sexually transmitted infections, hepatitis, lipids (cholesterol and triglycerides) and cardiopulmonary investigations (chest x-ray, electrocardiograms, etc.), are not state funded. It was observed that majority of users (83 percent) understood all the tests and investigations listed in the booklet. Most (91 percent) of participants knew about other laboratory tests and investigations and when to do them. Many (62 percent) reported knowing why the tests were done, but only 57 percent reported ever receiving any explanation from care providers on the test results.

Observation of the booklets revealed that 87 percent of users commonly recorded results of the following tests in their booklets: (1) liver enzymes tests, (2) fasting blood sugar, and (3) hemoglobin concentration. Information on the other tests that are state funded was not commonly recorded in the booklets. Despite state financial support, 16 percent (95% CI: 0.13–0.19) of patients reported having difficulties going for the routine follow-up tests. However, it was not clear if the difficulties were always financial in nature.

ARV Treatment Refill Chart (Pages 12 and 13)

When using the booklet, 88 percent of users were able to identify the type of ARV medications they were receiving at the time of the study. The main difficulty identified by users in taking medications revolved around respecting the time the medications had to be taken: 178 users (89 percent) correctly recorded the dates of ARV treatment refills in their booklets. The information entered into this page of the booklet was able to track about 9 percent of users who missed a refill date.

Treatment Side Effects and Appointments (Page 14)

A total of 16 percent of patients reported adverse effects. Except for weight gain and frequent urinating, most of the adverse effects seemed to have occurred at the onset of ARV treatment (Table 5). However, the percentage of those reporting these adverse effects might be misleading as the denominator was the whole study population (N = 200) and not just the number starting treatment for the first time.

Table 5. Most Common Adverse Effects Reported

ADVERSE EFFECTS	NUMBER OF PATIENTS	PERCENTAGE (N = 33)
Abdominal pains	10	30.3%
Nightmares	9	27.3%
Nausea and vomiting	7	21.2%
Intense weakness	6	18.2%
Weight gain	3	9.1%
Frequent urinating	2	6.1%

Patients were particularly careful with their dates of pharmacy appointments, with 89 percent indicating correctly the date of the next appointment and 9 percent reported missing a recent appointment.

Overall Use and Handling of the Tool

On average, 83 percent (95% CI: 0.80–0.85) of participants were observed to have used the booklet the way it was meant to be used (Table 6). None of the pages or the content was missing; 3 percent of the booklets were torn and about 20 percent had stains.

Table 6. Overall Use of Tool

	NUMBER OF USERS (N = 200)	PERCENTAGE
Identification correctly provided	128	63.6%
Weight correctly recorded	196	98%
Weight value correctly indicated on the chart	180	89.9%
Weight curve correctly plotted	183	91.4%
CD4 correctly recorded	195	97.5%
CD4 value correctly indicated on the chart	179	89.4%
CD4 curve correctly plotted	163	81.3%
Other tests correctly recorded	87	42.9%
Dates correctly recorded	178	88.9%
Average	177	82.5%

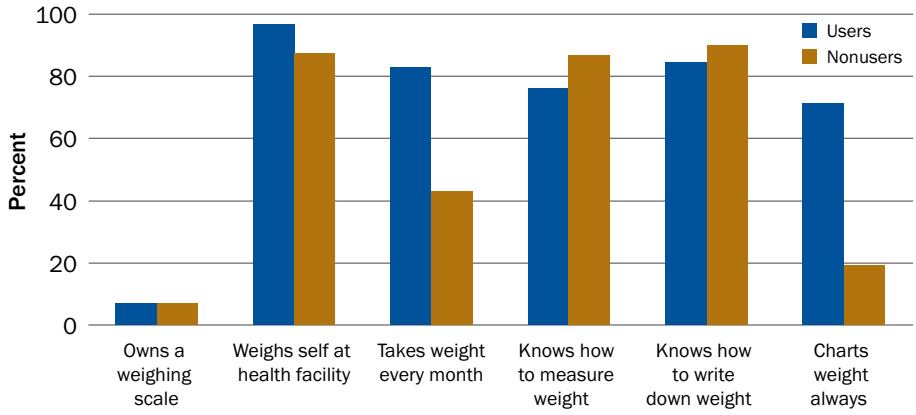
Comparison of Effects of the Tool on Users and Nonusers

In order to further demonstrate the added value this tool could have on care, follow-up and self-management of PLHIV, an analysis of certain effects probably due to exposure to the tool was carried out and presented in this section. This analysis is a result of comparing responses provided by users and nonusers to similar questions in the three-month surveys relating to weight measurement practices, knowledge on CD4 testing, and knowledge on and use of ARV treatment (including adherence).

Differences in Weight Measurement Practice

Users and nonusers were asked to indicate how frequently they recorded their weights. In both groups, although majority reportedly weighed themselves monthly, there was a significant difference in the proportion of users (75 percent) over the proportion of nonusers (36.2 percent) who routinely took their weights every month ($p < 0.01$). A similar difference was equally observed with respect to weight-charting practices. Users were more likely to keep a record of their weights (71.5 percent) than nonusers (19.2%; $p < 0.001$). Apart from these two practices that could be closely linked to the utilization of the booklet, there were no significant differences in the other weight-measuring indicators assessed in this study between users and nonusers, as illustrated in Figure 13.

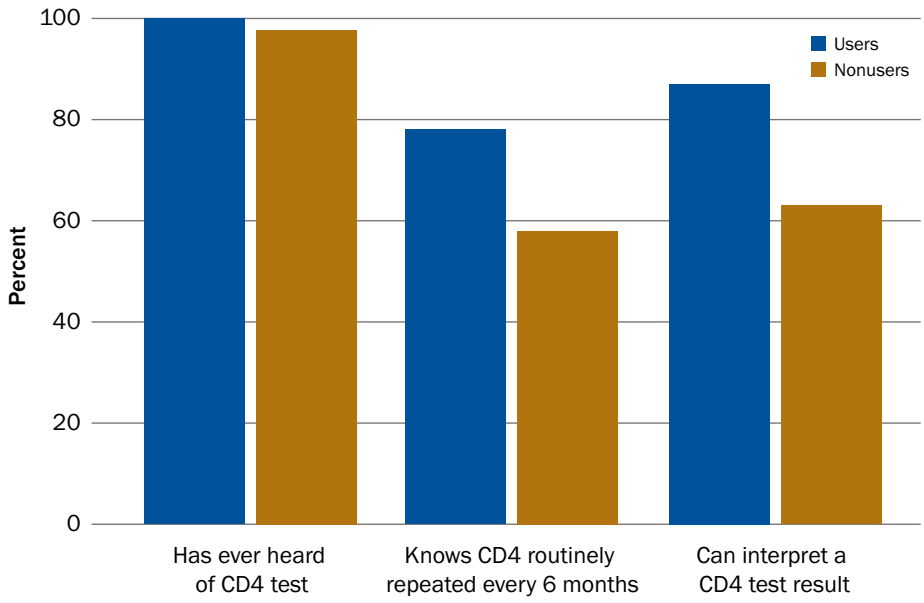
Figure 13. Illustration of weight measurement differences between users and nonusers of the PLHIV monitoring booklet (bars represent only the "yes" responses)



Knowledge of CD4 Count

All participants (users and nonusers) reported knowing about the CD4 count, and the majority (66 percent) knew that it had something to do with the body's defense against disease, which indicated the effect of the virus in the body as well as determining when to start treatment. However, a significantly higher proportion of nonusers (37 percent) compared to 6.5 percent of users ($p < 0.0001$) said they did not know how to interpret CD4 test results. Also, a significantly higher percentage of users (78 percent) mentioned that they knew that the CD4 test should be done every six months as recommended, compared to only 58.2 percent of nonusers ($p < 0.001$).

Figure 14. Illustration of differences in knowledge of CD4 test between users and nonusers of the booklet



Knowledge and Use of ART

It appears that exposure to the booklet increased users' knowledge of the ARV regimen they were placed on, compared to nonusers. A significantly higher proportion of users (88 percent) reported knowing the name of the ARV medications they were receiving, compared to 70 percent of nonusers ($p < 0.001$). The study even further revealed that significantly more users (91 percent) than nonusers (62.2 percent) were compliant to treatment (always took their medications as prescribed).

Standard Follow-up Approach

The 130 nonusers interviewed to assess the standard follow-up approach were all contacted during regular clinic visits. Although most of them had hospital-based files and ambulatory hospital booklets or cards, 85 percent (95% CI: 0.82–0.88) mentioned that they were not satisfied with the current follow-up tools and expressed the need for an instrument that could better help them understand their health status. The majority (62 percent) claimed not to understand what was recorded in the hospital booklets or cards. Only 58 percent of participants reported knowing the names of the ARV medications they were taking, and 10 percent complained that the drugs were not always available.

Discussion

Proper care and treatment with HAART has changed the prognosis of the HIV pandemic in both developed and developing countries.[10,11,12] Despite early apprehension that use of ART in developing countries would be counterproductive, several studies have shown the contrary.[13] Adherence to care and treatment is important to halt progress of HIV to AIDS and reduce AIDS-related morbidity and mortality. Poor adherence has been related to situations such as forgetfulness and being away from home.[14] When patients miss taking their drugs, they run a significant risk of developing major mutations that confer cross-resistance to ARV drug families such as the NNRTIs.[15] Given the chronic nature of HIV and AIDS, there is need to identify appropriate models to support long-term care and delivery of HAART.[16] The aim of the present *Client Monitoring Guide* is to empower the client to actively participate and take the lead in monitoring his/her care and treatment.

In settings with poor access to CD4 counts, clinical monitoring is essential. Proper clinical follow-up and staging, and monitoring of biological variables such as lymphocyte and platelet counts, have been identified as positive predictors of CD4 counts.[17] Given that CD4 testing is not yet widely accessible to many in developing countries, proper monitoring of symptoms and signs will help indicate progress of HIV to AIDS and guide care providers to take prompt action.

Stigma is a major concern in management of HIV and AIDS. The task force that developed this tool was concerned about this and decided on a pocket-size booklet that would be less visible when carried around in a breast pocket or a handbag. Additionally, experience in Haiti and big treatment centers, such as the Yaoundé Central Hospital Treatment Center in Cameroon, indicate that PLHIV will show up once they are sure of receiving good care irrespective of stigma.[18] Therefore, we believe that most patients will want to use this educative tool regardless of any stigma that might result from its use.

To the best of our knowledge, this is the first take-home clinical monitoring tool, designed and developed specifically for PLHIV in Cameroon. It was an original idea

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10 WHO, *Antiretroviral Therapy*.

11 Furber, A. S., Hodgson, I. J., Desclaux, A., & Mukasa, D. S. "Barriers to Better Care for People with AIDS in Developing Countries." *BMJ* 329 (November 27, 2004), 1281.

12 Jaffar, S., Govender, T., Garrib, A., Welz, T., Grosskurth, H., Smith P. G., et al. "Antiretroviral Treatment in Resource-Poor Settings: Public Health Research Priorities." *Tropical Medicine and International Health* 10, No. 4 (April 2005): 295–299.

13 Jaffar et al., "Antiretroviral Treatment."

14 Reynolds, N. R., Testa, M. A., Marc, L. G., Chesney, M. C., Neidig, J. L., Neidig, J. L., et al. "Factors Influencing Medication Adherence Beliefs and Self-Efficacy in Persons Naïve to Antiretroviral Therapy: A Multicenter, Cross-Sectional Study." *AIDS and Behavior* 8, No. 2 (June 2004), 141–150.

15 Parienti, J.-J., Massari, V., Descamps, D., Vabret, A., Bouvet, E., Larouze, B., et al. "Predictors of Virologic Failure and Resistance in HIV-Infected Patients Treated with Nevirapine or Efavirenz-Based Antiretroviral Therapy." *HIV/AIDS* 38 (May 1, 2004): 1311–1316.

16 WHO, *Antiretroviral Therapy.*

17 Ledru, E., Diagbouga, S., Meda, N., Sanou, P.T., Dahourou, H., Ledru, S., et al. "A Proposal for Basic Management of HIV Disease in West Africa: Use of Clinical Staging and Haemogram Data." *International Journal of STD & AIDS* 9 (1998): 463–470.

18 Castro, A., & Farmer, P. "Understanding and Addressing AIDS-Related Stigma: From Anthropological Theory to Clinical Practice in Haiti." *American Journal of Public Health* 95, No 1 (January 2005), 53–59.

of the Health and HIV Unit of CRS/CM that originated from observing PLHIV at treatment centers. It was conceived with input from both health experts and PLHIV. Due to time and resource constraints, the testing of the tool was carried out over a shorter period of time and involved fewer treatment units than initially planned, and a cross-sectional activity rather than a prospective cohort assessment measuring outcome variables over time was conducted. Some important confounders such as length of time on treatment and care, type of service provider (public, faith-based or private), socioeconomic status of patients, which could explain some of the differences observed between users and nonusers, were not examined. The relatively small sample size might have reduced the power of this study. However, these findings provide an overall appraisal and indicate the use and usefulness of the tool to PLHIV. This monitoring tool allows the patient to record his or her weight on a regular basis and to note symptoms and signs indicative of disease progress. It further draws the patient's attention to those symptoms and signs that require immediate action. Documenting symptoms and signs at the individual level is useful in determining their occurrence with respect to CD4 counts. A study in Burkina Faso[19] indicated that PLHIV develop symptoms and signs at higher levels of CD4 counts than is expected from observations in developed countries.[20] Nevertheless, clinical monitoring, coupled with CD4 counts (where possible), has been shown to be most cost-effective in preventing life-threatening illness and determining eligibility to ARV treatment.[21] By recording symptoms at home, along with CD4 counts obtained from facilities, the clients can help the care providers track eligibility for ARV treatment for clients who are not yet receiving ARV medications, given that patients might decide not to consult facilities offering Western care and treatment for certain types of ailments. This is particularly true for Cameroon, where most cases of shingles are treated at traditional healers and at home.

This tool could potentially also help track symptoms and signs of tuberculosis (TB), which is the leading cause of death in PLHIV in developing countries. This is particularly important as pulmonary TB is often a co-infection of HIV occurring at higher levels of CD4 counts.[22] A study in Rwanda showed that symptoms of AIDS and TB are so interwoven that patients often fear having AIDS when suffering from TB only.[23]

Despite the additional use of phone call tracing to try to reach users of the monitoring tool, there was a loss to follow-up of 7.3 percent, and a further 5 percent misplaced their booklets. Interestingly, all these events occurred with patients in the two big state-owned hospitals in the study. This might partly

19 Parienti et al., "Predictors of Virologic Failure."

20 Moatti, J.-P., Spire, B., & Kazatchkine, M. "Drug Resistance and Adherence to HIV/AIDS Antiretroviral Treatment: Against a Double Standard Between the North and the South." *AIDS* 18, Suppl. 3 (2004): S55–S61.

21 Diomandé, F. V., Bissagnéné, E., Nkengasong, J. N., Maurice, C., Monga, B., Laga, M., & Nolan, M. L. "The Most Efficient Use of Resources to Identify Those in Need of Antiretroviral Treatment in Africa: Empirical Data From Cote d'Ivoire's Drug Access Initiative." *AIDS* 17, Suppl. 3 (2003): S87–S93.

22 Furber, "Barriers to Better Care."

23 Ngang, P. N., Ntaganira, J., Kalk, A., Wolter, S., & Ecks, S. "Perceptions and Beliefs About Cough and Tuberculosis and Implications for TB Control in Rural Rwanda." *International Journal of Tuberculosis and Lung Disease* 11, No. 10 (2007): 1108–1113.

reflect the difficulties in tracking and closely monitoring patients in crowded treatment centers. Approximately 8 percent of participants who consented to use the tool were illiterate. This finding highlights the importance of taking into consideration the special needs of people who cannot read and write in planning health education and developing clinical tools.

The Booklet Versus the Standard Follow-up Approach

Assessment of the standard follow-up based on clinic-based files and hospital booklets and cards revealed a communication gap between care providers and the clients. The information recorded in these instruments is aimed at care providers and not client-oriented. This is illustrated by the high percentage of nonusers of the booklet (85 percent) who reported not being satisfied with the follow-up provided in the treatment units and who expressed the need to see things done differently. This short study illustrates that clients are eager and ready to know more about their health and to understand and properly use basic key indicators such as weight and CD4. The study has been able to show that with more exposure to the booklet that provided patients the possibility not only to self-monitor their health, but also to increase communication with caregivers, significant knowledge and practice gaps in key areas such as treatment adherence, weight monitoring and CD4 count measurements can be addressed. While health care providers at HIV treatment centers need to create and spend more time educating clients on these indicators, clients need to be able to take these messages to their homes and actually participate in ensuring that they do things for themselves to monitor their health. The take-home monitoring booklet is one way this link between facility and home-based care can be integrated and complemented.

The difference in knowledge about the CD4 tests and use of ARV treatment between the users of the booklet and nonusers may have stemmed from the exposure of the users to the booklet. In the course of using the booklet, they might have learned more about indicators like weight measurement, CD4 counts, monitoring treatment adherence, and so forth, than the others who were not exposed to the instrument. This shows that in addition to the monitoring role, the use of the tool has an educational component for the client.

General Information and Identification

In the course of conceiving the tool, the expert consultative group was divided over the use of “patient” in the title. Some had suggested the word “client” instead. The study results show that PLHIV themselves do not like to be referred to as patients.

Clinical and Para-Clinical Follow-up

The main challenge observed in the weight and CD4 section was the difficulty of plotting the figures onto a curve on a graph for easy visualization. However, inability to plot a curve should not be a critical setback of this tool, especially

if users are able to understand the individual values of weight and CD4 counts recorded. Given that only 5 percent of users were able to successfully link up the recorded weights and CD4 measurements into a curve, emphasis should be directed toward explaining to clients what the individual values signify and what a decrease or increase may signify. Drawing up smooth curves can be challenging, especially to people with nonartistic abilities. Also, since these parameters are most commonly measured in health facilities, clients may request that their health care providers plot the information in their booklets.

Although testing of the tool lasted only for a short period, over 50 percent of participants reported HIV-related symptoms. Some of the symptoms, such as blood in sputum, required quick attention from care providers, who had to determine if the symptoms were related to some serious disease like TB. This was an additional value of the tool. However, since the study did not have information to determine whether there was an increase in reporting of such symptoms compared to nonusers, it will be interesting in future studies to determine if this tool can indeed increase health service utilization of PLHIV.

Although a good range of laboratory follow-up tests are recommended for PLHIV in this country (about which clients seem to have a fairly good knowledge), only tests with state subvention were frequently performed, indicating that financial considerations may be playing a critical role in limiting the quality of services that PLHIV receive. Care provider–client communication poses a major challenge, as more than 50 percent of participants complained of not receiving any explanations from the providers on their test results. Although this is obviously a difficult task in overcrowded treatment centers with few staff members, there is need to improve dialogue with the client. This booklet could be a good opportunity to initiate the dialogue, because clients will become more aware of the information they need to have to better participate in their self-management of symptoms in particular and their illness in general.

Treatment, Side Effects and Appointments

Participants were able to track several side effects that occur early in treatment. Others, like weight gain, require careful assessment, because they might indicate late adverse effects of some of the ARV medications. Many clients might have adverse events without quickly relating them to the medication.

Users of the booklet were particularly careful with pharmacy appointments. Pharmacy refill irregularity has been shown to be a more powerful predictor of virological treatment failure, compared with CD4 cell count increase at six months or self-reported adherence at one month. The overall utilization of the tool looked encouraging, but the length of the testing might not have permitted us to arrive at definite conclusions.

ANNEXES

RICK D' ELIA FOR CRS

CONCLUSION

Provision of care for HIV and AIDS has so far been provider-centered, with little involvement of PLHIV in monitoring their own care. This study confirms a big communication gap between care providers and clients who are eager to know what is happening to their health. It illustrates that within the limits of literacy levels within the community, clients might be able to participate more in the monitoring of their health than is the case at the moment. Properly guided, they may self-monitor key variables like HIV-related signs and symptoms and changes in weight and CD4 counts.

The present tool provides an opportunity to move from provider-oriented to client-driven care, with the client playing a central role. Properly used, it will further empower the patient and care providers to quickly determine ART eligibility and early warning signs for therapeutic failure. The testing has further brought out findings and suggestions from participants that need to be taken into consideration in improving the general idea of a take-home monitoring tool. Hence, further studies are needed to validate this idea for widespread use in developing countries. It should serve as a major milestone to empower PLHIV to better participate in their day-to-day care. An unintended consequence of the rising awareness among clients about their health might generate increased demands and workload on care providers in already overcrowded treatment centers. The health systems will have to make provision for this eventuality if this tool is adopted for widespread use.

NEXT STEPS

Lessons learned from the piloting of the self-monitoring tool and the suggestions from the participants need to be considered and incorporated into the tool. The final version of the booklet should highlight the cutoff point of 350 for CD4 count (required for initiation of ARV treatment), newly recommended by WHO and now applicable in Cameroon.[24] At the time of developing this booklet, a lower cutoff point for initiation of ARV treatment was applicable in the country.

There is need to address some of the limits through studies with bigger populations, including measurement of outcome variables and, if possible, in other settings to further validate the instrument and the idea. Since this tool also plays the role of predicting the advancement of HIV to AIDS, studies to measure its sensitivity and specificity, as well as its predictive value, are necessary.

24 CNLS, *Plan stratégique national de lute contre le VIH, le SIDA et les IST 2011–2015.* (Yaoundé, Cameroon: Minsante, 2010).

ANNEX I: INFORMATION SHEET TO PARTICIPANTS

Take-Home HIV and AIDS Monitoring Tool Study

Information Sheet to Participants

Background: In Cameroon, most of the key information concerning patients is kept in registers and files at the health facilities. This is especially the case with chronic diseases like hypertension, diabetes, and HIV and AIDS. Patients return home with hospital exercise books or cards that usually contain very meager information. With the high tendency for patients to move from one health institution to the other (doctor shopping), information about the patient is often not easily accessible when needed by health care workers in other centers.

Aim of study: The aim of the present study is to develop a pocket-size booklet in which patients can record important information about their health. This information should help the patient and his or her doctor or nurse make timely decisions to prevent complications and improve health.

Description: The above booklet has been developed by Catholic Relief Services (CRS) Cameroon Program, and we are collaborating with your care provider to test it. Patients will be randomly selected to participate in studying the booklet. About half of those who accept to participate will be randomly selected and provided with the booklet, while the other half will continue with the standard follow-up. At the end of nine months, the study team will meet with each participant for a brief discussion of less than one hour to assess follow-up and compare health variables in both the case cohort (those who used the booklet) and the control cohort (those who did not use the booklet).

Those who decide to participate will be required to leave their contact information at the health facility or hospital in order to permit us to know from time to time how they are doing. **All information provided will be kept confidential and will not be shared with any other person(s) except if the patient ask us to do so. Acceptance or refusal to participate in this study should have no negative effect on the care the patient is or will be receiving at this center**. Patients are **not** required to give their names to people from outside the health facility who might come to talk with them, and all information obtained shall be used solely to improve on the booklet.

Advantage: Participation in this study can contribute in improving the quality of care patients receive. However, you are free not to take part in the study or to stop participating at any time. No additional blood samples shall be drawn from participants for the purpose of the study.

Possible risk: It is possible that some participants might become more conscious of certain situations concerning their health, which they were not aware of before. If this happens to you, please report and discuss your observations with your doctor or nurse. If he or she cannot address certain problems, he or she will provide you with information on other institutions that might offer additional care. However, the care that you will receive will follow the standard system of care that was in place before the study started. This study will not pay for the management of any situation that the study might help you to become aware of. Those using the booklet are not required to and are advised **not to write their names on it**. Other people might find out about their health problems if they write their names on it. They should write instead the telephone number of their treatment center, in case the booklet is missing and then found.

Eligibility: Although this study might provide results that will be useful to all patients in the future, at this point we will include only people 21 years of age and above. People younger than 21 years or who are too old or weak to provide consent will not be included.

* Thank the person and stop and keep the form in a folder for those who refuse. Do not note the person's name in the study register.

ANNEX II: CONSENT FORM

Consent form signed by the participant
(*Participants should sign both forms and go home with one copy and the rest of the information sheet)*

After receiving information concerning the above study:

I freely accept ________ /do not accept* ________ to participate.

I accept to be contacted ________ /do not accept to be contacted* ________ at the end of 4 months to discuss my health during the above period.

Initials of Client ________________ Study code number ________________

Patient's signature ________________________________ (or thumb print)

Treatment center ______________________________ Date ____________

CUT HERE >>- << CUT HERE

After receiving information concerning the above study:

I freely accept ________ /do not accept* ________ to participate.

I accept to be contacted ________ /do not accept to be contacted* ________ at the end of 4 months to discuss my health during the above period.

Initials of Client ________________ Study code number ________________

Patient's signature ________________________________ (or thumb print)

Treatment center ______________________________ Date ____________

ANNEX III: QUESTIONNAIRE FOR PARTICIPANTS WHO ARE USING THE BOOKLETS

Take-Home HIV and AIDS Monitoring Tool Study

Questionnaire for Participants Who Are Using the Booklet

Questionnaire number ___ ___ ___

Do not fill in

General Information

N°	INTERVIEWER	DATE OF THE INTERVIEW
Q01	**Name:** **Code :**	
	INSPECTOR	**DATE OF INSPECTION**
Q02	**Name:** **Code :**	
	SUPERVISOR	
Q03	**Name:** **Code :**	
	PERSON IN CHARGE OF DATA CAPTURE	**DATE OF THE DATA CAPTURE**
Q04	**Name:** **Code :**	
Q05	**Area :** **Province : 1** Center **2** Southwest **3** Northwest **Town:**	

Introduction: My name is _____. I come from _____and work with (or am student at) _____. I am part of a team* and the other member of the team here is _____. We want to learn about your experience using this booklet (show a copy of the *Client Monitoring Guide*) in the past 9 months. The information we get will assist the health services to better take care of the health of the whole population. We would like to ask you some questions and would be happy if you would answer our questions. Your contribution will be very important. In order not to forget important things you say,

*If applicable.

we would like to take some notes in the course of the discussion. Whatever you say will be kept confidential and will be used only for the above purpose. We will not take your name or addresses. Although you were informed of this discussion when you received the tool 9 months ago, you are still free not to participate or to stop the discussion at any time. However, your contribution will be very important in helping us improve on this booklet (show again) and subsequently on the health of many other people that will be using it in the future. Do you have any questions? Can we start?

STRICTLY CONFIDENTIAL AND NOT FOR FISCAL ISSUE

The data collected in this study are strictly confidential as stated by the law n° 91/0223 of December 16, 1991, regarding census and statistical surveys. This law stipulates at its 5th paragraph that "any personal indications on statistical survey questionnaires cannot be used for inspection or economic sanctions."

Circle the matching code when it is provided.

SOCIAL CHARACTERISTICS			
N°	**Questions**	**Answers and codes**	
Q06	Age (in year)		
Q07	Sex	Male Female	**1** **2**
Q08	Education level	None Primary Secondary Higher education	**0** **1** **2** **3**

N°	QUESTIONS	ANSWERS AND CODES		GO TO
General presentation of monitoring booklet and context				
Q09	What is your opinion of the booklet? **(Circle the matching code)**	Very interesting Interesting Not interesting at all Indifferent	**1** **2** **3** **4**	**If 4 → Q11**
Q10	Justify your answer **(List the three most major justifications.)**			
About the front page				
Q11	What is your opinion of the front page? **(Circle the matching code)**	Very interesting Interesting Not interesting at all Indifferent	**1** **2** **3** **4**	**If 4 → Q13**
Q12	Justify your answer **(List the three most major justifications.)**			
Q13	What do you want this front page to look like? **(Circle the matching code)**	The way it is Different	**1** **2**	**If 1 → Q15**
Q14	If you want it to be different, what do you suggest then?			
About the inside of the front cover page (foreword)				
Q15	Do you understand the information on the foreword page?	Exactly Enough Just a bit Not at all	**1** **2** **3** **4**	
Q16	Would you like to add or remove something?	Yes No	**1** **2**	**If 2 → Q19**
Q17	If yes, what would you like to add?			

N°	QUESTIONS	ANSWERS AND CODES	GO TO
Q18	If yes, what would you like to remove?		
	Identification page		
Q19	Do you understand the information in the identification page?	Exactly **1** Enough **2** Just a bit **3** Not at all **4**	
Q20	Would you like to add or remove something?	Yes **1** No **2**	**If 2 → Q23**
Q21	If yes, what would you like to add?		
Q22	If yes, what would you like to remove?		
	Page with the weight chart		
Q23	Do you have a weighing machine (scale balance) at home?	Yes **1** No **2**	**If 1 → Q25**
Q24	If not, how do you weigh yourself? (Circle the matching code)	At health center **1** Mobile weighing man Other _____ **2** **3**	
Q25	How often do you weigh yourself or is your weight taken? (Circle the matching code)	Every day **1** Every week **2** Every month **3** Every three months **4** Every six months **5** yearly **6** No periodicity **7**	
Q26	Do you know how to take your weight yourself?	Yes **1** No **2**	
Q27	Can you write down your weight?	Yes **1** No **2**	
Q28	Do you know how to record your weight on the chart?	Yes **1** No **2**	**1 → Q30**
Q29	If not, who records it for you? (Circle the matching code)	A relative **1** A friend **2** My doctor **3** Whoever I meet **4** other _____ **5**	
	Clinical follow-up indicators page		
Q30	Do you understand the signs and symptoms in this page?	Exactly **1** Enough **2** Just a bit **3** Not at all **4**	
Q31	Do you know how to fill out the chart?	Yes **1** No **2**	**If 1 → Q33**
Q32	If not, who fills out the chart for you? (Circle the matching code)	A relative **1** A friend **2** My doctor **3** Whoever I meet **4** other _____ **5**	

N°	QUESTIONS	ANSWERS AND CODES	GO TO
Q33	How would you rate this chart? **(Circle the matching code)**	Very interesting **1** Interesting **2** Not interesting at all **3** Indifferent **4**	**If 1, 2 or 4 → Q35**
Q34	If you do not like the chart, what are your main reasons for not liking it? **(List the three most major justifications, at most.)**		
	CD4 Chart pages		
Q35	Have you ever heard about the CD4?	Yes **1** No **2**	**If 2 → Q40**
Q36	What do you know about CD4?		
Q37	How often do you do the CD4 count? **(Circle the matching code)**	Every 3 months **1** Every 6 months **2** Yearly **3** No periodicity **4**	
Q38	How has it (CD4) helped you?		
Q39	Do you know how to plot it in the chart to give a curve?	Yes **1** No **2**	
	Other laboratory findings page		
Q40	Do you know the other laboratory tests you had to do?	Yes **1** No **2**	**If 2 → Q45**
Q41	Do you know how often you need to do them?	Yes **1** No **2**	
Q42	Do you understand the laboratory tests listed in your booklet?	Yes **1** No **2**	
Q43	Does your caregiver always explain the test results to you?	Yes **1** No **2**	
Q44	Do you encounter any problems doing your laboratory tests?	Yes **1** No **2**	
	ARV regimens and refills		
Q45	Do you know the names of the drugs you are taking?	Yes **1** No **2**	
Q46	How often do you take them?	Once a day **1** Every morning and evening **2** Three time per day **3** One time every 2 days **4** Others **5**	
Q47	What problems do you encounter getting your drugs?		
Q48	Are your drugs always available in the treatment center pharmacy?	Yes **1** No **2**	
Q49	Do you receive your medications on the dates you are given appointments as recorded in the booklet?	Yes **1** No **2**	
Q50	Has this booklet helped you in remembering your appointments?	Yes **1** No **2**	**2 → Q52**

N°	QUESTIONS	ANSWERS AND CODES	GO TO
Q51	If yes, in what way?		
	Possible side effects of treatment		
Q52	What problems have you encountered taking your antiretroviral drugs?		
Q53	What are some of the possible side effects of your drugs?		
Q54	Which ones did you experience?		
Q55	What did you do?		
Q56	Was the listing of the side effects in your booklet useful to you?	Yes **1** No **2**	**If 2 → 58**
Q57	If yes, in what way?		
	Appointments		
Q58	Do you always come to your appointments?	Yes **1** No **2**	**If 1 → Q60**
Q59	If no, what makes you not to come to them?		
	General advice		
Q60	Did you understand the information given on general advice?	Yes **1** No **2**	
Q61	Did you find the information on general advice useful?	Yes **1** No **2**	
Q62	Did this information help you to **Q62a** Stop smoking? **Q62b** Stop drinking alcohol?	**Yes** **No** 1 **2** 1 **2**	
Q63	Besides these few, what other habits have you given up? **Q63a** Habit 1: **Q63a** Habit 2: **Q63a** Habit 3:		
Q64	Have you visited a traditional healer or gone for any alternative care and treatment for HIV since you knew you were positive?	Yes **1** No **2**	**If 2 → end**
Q65	When?		
Q66	And for what reason(s)		

ANNEX IV: QUESTIONNAIRE FOR PARTICIPANTS WHO ARE NOT USING THE BOOKLET

TAKE-HOME HIV AND AIDS MONITORING TOOL STUDY

Questionnaire for Participants Who Are Not Using the Booklet

General Information

Questionnaire number ___ ___ ___

Do not fill in

General Information

N°	INTERVIEWER	DATE OF THE INTERVIEW
	Name: **Code :**	
	INSPECTOR	**DATE OF INSPECTION**
	Name: **Code :**	
	SUPERVISOR	
	Name: **Code :**	
	PERSON IN CHARGE OF DATA CAPTURE	**DATE OF THE DATA CAPTURE**
	Name: **Code :**	
	Area : **Province : 1** Center **2** Southwest **3** Northwest **Town:**	

Introduction: My name is _____. I come from _____and work with (or am student at) _____. I am part of a team* and the other member of the team here is _____. We want to learn about the care you receive from health institutions. The information we get will assist the health services to better take care of the health of the whole population. We would like to ask you some questions and would be happy if you would answer our questions. Your contribution will be very important. In order not to forget important things you say, we would like to take some notes in the course of the

*If applicable.

discussion. Whatever you say will be kept confidential and will be used only for the above purpose. We will not take your name or address. You are free not to participate or to stop the discussion at any time. However, your contribution will be very important. Do you have any questions? Can we start?

STRICTLY CONFIDENTIAL AND NOT FOR FISCAL ISSUE

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Circle the matching code when it is provided.

SOCIAL CHARACTERISTICS			
N°	**Questions**	**Answers and codes**	
Q06	Age (in year)		
Q07	Sex	Male Female	**1** **2**
Q08	Education level	None Primary Secondary Higher education	**0** **1** **2** **3**

N°	QUESTIONS	ANSWERS AND CODES		GO TO
Existing home-based follow-up instruments.				
	Do you have any document that you take home that has information about your condition?	Yes No	**1** **2**	**2 → 011**
	If yes, please show or describe it to me.			
	Would you want to have another document to help you understand and follow-up your health at home?	Yes No	**1** **2**	
	What type of information will you like to record in the document?			
About the front page				
	If a document to help you monitor your health were to be produced, what information would you like to have on the front cover page?			
About a foreword page				
	What instructions would you like to have at the beginning of such a document?			
Identification page				
	What information would you like to have on the identification page?			
Weight				
	Do you have a weighing machine (scale balance) at home?	Yes No	**1** **2**	**1 → 018**
	If not, where do you weigh yourself?	At the health center Mobile weighing man Never weigh myself Other _____	**1** **2** **3** **4**	
	How often do you take your weight? **Circle the matching code**	Every day Every week Every month Every 3 months Every 6 months Yearly No periodicity	**1** **2** **3** **4** **5** **6** **7**	

N°	QUESTIONS	ANSWERS AND CODES	GO TO
	Do you know how to take your weight?	Yes **1** No **2**	
	Can you record your weight?	Yes **1** No **2**	
	Do you often record your weight?	Always **1** Often **2** Never **3**	
	Clinical follow-up indicators page		
	Do you understand what is written down in the hospital booklet or card that you take home with you?	Exactly **1** Enough **2** Just a bit **3** Not at all **4**	
	CD4		
	Have you ever heard about the CD4?	Yes **1** No **2**	**2 → 033**
	What do you know about CD4?		
	How often do you do the CD4 count?	Every 3 months **1** Every 6 months **2** Once a year **3** No periodicity **4**	
	How has it (CD4) helped you?		
	Do you know how to interpret your CD4 values?	Exactly **1** Enough **2** Just a bit **3** Not at all **4**	
	Would you like it to be presented in the form of a chart in which the CD4 can be plotted and where changes in trend can be visualized?	Yes **1** No **2**	
	Tell us of any other ways you will like the CD4 to be presented		
	Other laboratory tests		
	Do you know the other laboratory tests you had to do?	All **1** Just a part of it **2** None **3**	**3 → 035**
	Do you know how often you need to do them?	Yes **1** No **2**	
	Do you understand the laboratory tests that you do?	Exactly **1** Enough **2** Just a bit **3** Not at all **4**	
	Does your caregiver always explain the test results to you?	Always **1** Often **2** Never **3**	
	Do you encounter any problems doing your laboratory tests?	Yes **1** No **2**	
	ARV regimens and refills		

N°	QUESTIONS	ANSWERS AND CODES	GO TO
	Do you know the names of the drugs you are taking?	All **1** Just some **2** None **3**	
	How often do you take them?		
	What problems do you encounter getting your drugs?		
	Are your drugs always available in the treatment center pharmacy?	Yes **1** No **2**	
	Do you receive your medications on the dates you are given appointments?	Always **1** Often **2** Never **3**	
	What or who helps you to remember your appointments?		
	Would you like to have the names of your medications written in a booklet different from your hospital book or card to help you remember the medications and when you have to go for refills?	Yes **1** No **2**	
	Possible side effects of treatment		
	What are some of the other possible side effects of your drugs?		
	Which ones did you experience?		
	What did you do?		
	Would you like to have the possible side effects of the antiretroviral medications listed in a document that you will carry with you?	Yes **1** No **2**	
	Appointments		
	Do you always come to your appointments?	Yes **1** No **2**	**1 → 048**
	If no, what makes you not to come to them?		
	General advice		
	Have you stopped: Smoking? Alcohol?	**Yes** **No** **Nonvalid** **1** **2** **3** **1** **2** **3**	
	Have you visited a traditional healer or gone for any alternative care and treatment for HIV since you knew you were positive?	Yes **1** No **2**	**2 → End**
	If yes, when?		
	And why? Reason 1 Reason 2 Reason 3		

"Thank you for your cooperation"

ANNEX V: QUESTIONNAIRE TO BE COMPLETED DIRECTLY FROM ASSESSING THE USED TOOL

Take-Home HIV and AIDS Monitoring Tool Study

Questionnaire to be completed directly from assessing the used tool

After conducting the interview with the client, ask his or her permission to take the booklet for a short while. Examine the booklet and answer the following questions.

N°	QUESTIONS	ANSWERS AND CODES	GO TO
General presentation of monitoring booklet			
Q01	Are there any missing pages?	Yes 1 No 2	
Q02	Is the booklet torn?	Yes 1 No 2	
Q03	Is the booklet stained and dirty?	Yes 1 No 2	
About the Front cover page			
Q04	Is the printed information on the cover page intact?	Yes 1 No 2	If 1 → Q06
Q05	If no, what is missing?		
About the inside of the front cover page (foreword)			
Q06	Is the printed information in the inside of the cover page (foreword) intact?	Yes 1 No 2	If 1 → Q08
Q07	If no, what is missing?		
Identification page			
Q08	Was the identification information filled out well?	Yes 1 No 2	If 1 → Q10
Q09	If not, what information was left unfilled?		
Q10	Is any of the printed information in the identification page missing?	Yes 1 No 2	If 2 → Q12

N°	QUESTIONS	ANSWERS AND CODES	GO TO
Q11	If yes, what information is missing?		
Page with the weight chart			
Q12	Is any of the printed information in this page missing?	Yes 1 No 2	If 2 → Q14
Q13	If yes, what information is missing?		
Q14	Were the weights correctly recorded?	Yes 1 No 2	
Q15	Were the weights indicated with spots or crosses at the intersection between the line of the weight and the corresponding trimester column?	Yes 1 No 2	
Q16	Were the spots on the chart connected to form a curve?	Yes 1 No 2	
Q17	Were there places where the curve kept descending over more than two weight measurements?	Yes 1 No 2	
Clinical follow-up indicators page			
Q18	Is any of the printed information in this page missing?	Yes 1 No 2	If 2 → Q20
Q19	If yes, what information is missing?		
Q20	Were any of the symptoms checked?	Yes 1 No 2	
Q21	What were three most frequent symptoms?	1 2 3	
CD4 Chart pages			
Q22	Is any of the printed information in these pages missing?	Yes 1 No 2	If 2 → Q24
Q23	If yes, what information is missing?		
Q24	Were the CD4 values correctly recorded?	Yes 1 No 2	
Q25	Were the CD4 values indicated with spots or crosses at the intersection between the line of the CD4 and the corresponding trimester column?	Yes 1 No 2	
Q26	Were the spots on the chart connected to form a curve?	Yes 1 No 2	
Q27	Were there places where the curve kept descending over more than two CD4 measurements?	Yes 1 No 2	
Other Laboratory findings page			

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