Second Feasibility and Reliability Test of Indicators for Adherence to Antiretroviral Medicine: National Survey in Rwanda, November 27–December 1, 2006

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January 2007

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This report was made possible through support provided by the Swedish International Development Agency, under the terms of Sida contribution 72300310, and the U.S. Agency for International Development, under the terms of cooperative agreement number HRN-A-00-00-00016-00. The opinions expressed herein are those of the author(s) and do not necessarily reflect the views of either the Swedish International Development Agency or the U.S. Agency for International Development.

With thanks and recognition of the team leaders—

Francois Ndamage from the Treatment and Research AIDS Center
Joseph Ntaganira: Local Coordinator
Antoine Gatera: MSH Rwanda
Max Kabalisa: MSH Rwanda

And to the MSH office in Kigali, in particular—

Georges Ntumba
Ingaribe Muziga
Augustine Gatete
Belen Tarrafeta

And to the four teams of data collectors—

Goret Kashama
Aline Muhorakeye
Christian Mukwesi
Florent Rutagarama
Jean Nepo Uwilingiyemungu

Aphrodis Kagaba
Patrick Kairu
Maurice Musoni
Edwin Tayebwa

Eric Kabanda
Placidie Mugwaneza
Dan Rutasingwa
Nadine Umutoni Wa Shema

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Monique Murindahabi
Jean Marie Vianey Havugimana
Jacqueline Uwera

Recommended Citation

Chalker J. 2006. *Second Feasibility and Reliability Test of Indicators for Adherence to Antiretroviral Medicine: National Survey in Rwanda, November 27–December 1, 2006.* Arlington, VA: Center for Pharmaceutical Management, Management Sciences for Health.

Key Words

adherence, antiretrovirals, indicators, HIV/AIDS, Rwanda

CONTENTS

ACRONYMS

ADR	adverse drug reaction
ART	antiretroviral therapy
ARV	antiretroviral
CHUB	University Central Hospital of Butare
CMS	Centre médico-social.
CNLS	Commission Nationale de lutte contre le SIDA
DH	district hospital
FHI	Family Health International
FBO	faith-based organization
GFATM	Global Fund to Fight AIDS, Tuberculosis and Malaria
HC	health center
INRUD	International Network for Rational Use of Drugs
Lux-Development	Luxembourg's development implementing agency
MAP-WB	World Bank Multicountry HIV/AIDS Program
MCAP	Multicountry Columbia Antiretroviral Program
MSF	Médecins Sans Frontières
MSH	Management Sciences for Health
OI	opportunistic infection
PIH	Partners in Health
RPM Plus	Rational Pharmaceutical Management Plus (Program) [MSH]
Sida	Swedish International Development Cooperation Agency
TRAC	Treatment and Research AIDS Center
USAID	U.S. Agency for International Development

BACKGROUND

In collaboration with national AIDS control programs, International Network for Rational Use of Drugs (INRUD) groups conducted a survey to ascertain the current practices in measuring and calculating adherence and defaulting behaviors by patients receiving antiretroviral (ARV) medicines in antiretroviral therapy (ART) programs and to find what data are routinely recorded and where in five East African countries: Ethiopia, Kenya, Rwanda, Tanzania, and Uganda. Overall, interviews were conducted with 24 programs or facility grouping managers that provide ARVs in the five countries and with facility managers or clinicians in 48 facilities with 86,807 patients on ART. These facilities included a wide range of types. Definitions of both adherence and defaulters or dropouts vary considerably, if they exist at all. Fourteen different definitions of defaulting were used. Measurement at individual or facility level is haphazard, using various data sources and various methods of calculation. Nevertheless, much information is recorded at both the clinic and pharmacy locations, so a standardized measurement should be possible.

A regional meeting was held at the Imperial Resort Beach Hotel, Entebbe, Uganda, April 27–29, 2006, in which 38 participants took part. They came from Management Sciences for Health (MSH), the national AIDS control programs, and local INRUD groups who had coordinated the survey. The main objective of the meeting was to discuss findings of the ARV adherence survey and plan work to develop and validate reliable and feasible indicators of adherence.

Candidate indicators were suggested for the following: self-report from interviews or clinical records; nonadherence, based on missed days from pharmacy records; and defaulting, based on information from attendance registers. Other system indicators have been suggested for availability and stock-outs, from pharmacy records; dispensing rate, from exit interviews; patient knowledge rate, from exit interviews; drug labeling rate, from exit interviews; adverse drug event, from exit interviews or clinical records or pharmacy records; clinical or functional status on an accessory form; pediatric indicators; depression screening questions; additional patient indicators; additional facility indicators; and a treatment indicator. A sampling strategy was suggested.

The next step was to test the feasibility and reliability of these candidate indicators in five sophisticated and five basic facilities in two countries. A previous report detailed the first feasibility test in Kenya. This report is on the second feasibility and reliability test, which was conducted in Rwanda from November 27 to December 1, 2006.

PROCEDURES

Facility Sampling

A list of all facilities that treated patients with antiretroviral medicines in the country was obtained through the Treatment and Research AIDS Center (TRAC). Only those facilities treating at least 100 patients with ART in September 2005 were chosen. This criterion reduced the choice to 42 facilities. The sample was 20 from these 42 facilities. They were narrowed down to obtain a mixture of levels of care, different programs, and fit into logistics for data collection teams. The facilities selected are shown in Table 1.

Training

In October, John Chalker visited Rwanda for two days and visited three facilities with two of the team leaders (Francois Ndamage and Joseph Ntaganira) to see the arrangements and plan for the data collection. The other two team leaders had no introduction until the two days of training for the team leaders (November 20–21). These two days were reserved to introduce the team leaders to the data collection instruments and the concepts of sampling.

The forms were very similar to those used in Kenya, with minor modifications. Standard lists of necessary ARVs and key medicines for opportunistic infections (OIs) were drawn up on the basis of national standard treatment guidelines and previous survey data on frequency of OIs.

Three days were then reserved for training the data collectors. For the first day and a half, after a general introduction, each team leader was assigned to introduce one data collection instrument. Each column was discussed in turn with all the variations that one may find. The data collectors and team leaders visited a facility the afternoon of the second day to witness a trial run of the data collection procedure. The groups split up on the morning of the third day for a facility visit to two facilities where they tried whole process. The forms were again reviewed that afternoon in the light of that experience.

Data Collectors

The data collectors were all newly qualified doctors.

Language

Some data collectors spoke English, but others needed translations into French. Discussion therefore was in both English and French. Joseph Ntaganira was able to translate as necessary. The Exit Interview questions were translated into Kinya-rwandan with agreed wording for the adverse drug reactions (ADRs).

Table 1. Site Selection

	Partners							
Geographic Location	***MSF***	***MAP-WB***	***GFATM***	***FHI-FBOs***	***PIH***	***Intra Health***	***Lux-Development***	***MCAP***
North (3 facilities)			Rutongo DH	Ruli DH		Byumba DH		
South (4 facilities)		CHUB Kabutare DH Gikonko HC		Kabgayi DH				
East (4 facilities)			Nyagatare DH	Nyamata DH	Rwinkwavu HC		Rwamagana DH	
West (4 facilities)		Mugonero DH						Gisenyi DH Kabaya DH Kibuye DH
Kigali (5 facilities)	Kimironko HC		King Faycal Referral Hospital Muhima DH Kacyiru HC	CMS Gikondo				
Total number of sites	**1**	**4**	**5**	**4**	**1**	**1**	**1**	**3**

MSF = Médecins Sans Frontières; MAP-WB = World Bank Multicountry HIV/AIDS Program; GFATM = Global Fund to Fight AIDS, Tuberculosis and Malaria; FHI = Family Health International; FBO = faith-based organization; PIH = Partners in Health; Lux-Development is Luxembourg's development implementing agency; MCAP = Multicountry Columbia Antiretroviral Program, Columbia University, New York; DH = district hospital; CHUB = University Central Hospital of Butare; CMS = centre médico-social; HC = health center.

Logistics

Permissions

TRAC sought permission from the Commission Nationale de Lutte contre le SIDA (CNLS) to carry out the survey. The review board did not meet before the data collection dates, but the head of CNLS instructed TRAC to proceed with the survey.

Facilities

TRAC wrote to each facility chosen, informing it of the survey team's visit and requesting collaboration.

TRAC telephoned each facility director to ensure the facility would be open on the planned day of the visit. No HIV/AIDS clinic person was directly contacted to find the best days to visit, however. The team leaders were asked to contact the facilities the day before the visit to arrange times and introduce what they were doing.

Teams and Transport

The 17 data collectors were grouped into four teams after the second day of the trainingfor the third day's trial run. For the data collection vehicles were hired with the capacity to take five or six passengers. As far as possible, MSH booked hotels.

Contracts

Each data collector signed a contract spelling out duties and payments and signing a confidentiality clause.

Communication

All team leaders were given air time for their cell phones. Any problem with process or interpretation was communicated to the research coordinator (John Chalker) for a discussion and so any lesson could be passed on to the other groups. Each evening, all team leaders communicated with the research coordinator.

Stationery

Each group had the following materials—

- A collection of forms (enough for each group member to do each task and a set of forms to give to the facility director if requested)
    - Fifteen facility forms; 10 exit interview procedures; 36 exit interview data forms; 10 recent and 10 long retrospective procedures; 36 recent and 36 long retrospective data forms; 10 recent and 10 long patient identifier forms
    - A copy of the introductory letter from TRAC
- A clipboard for each member for writing on

- Notebooks, pens, and pencils
- A large folder (one for each facility) to keep all forms for each facility
- A laptop computer with data entry forms for each facility

Data Entry

Each team carried a laptop computer. Each evening, the day's data were entered on the computer.

On the Monday after data collection, each group met to finalize their data collection. On the following day (Tuesday), the team leaders all met for a collective debriefing and final checking (sheet by sheet) of the data entry.

Process Recording

Each team leader wrote a short paragraph on his or her experience and problems faced at each facility (appendix 1)

FEASIBILITY AND RELIABILITY SURVEY

Data Collection Instruments

The same four data collection instruments as used for Kenya were slightly modified: facility interviews, patient exit interviews, recent attendance retrospective, and past attendance (long) retrospective.

Facility Interviews

As for Kenya, the Facility Interview forms (see Appendix 2) included questions on the days and hours the clinic is open and whether it is open at convenient times, such as evenings or weekends. The workload per clinician and per support staff was also calculated. The availability of private space for counseling and laboratory services for CD4 and viral load were noted. A list of key ARVs and non-ARV medicines that should be present in a well-functioning clinic had been developed according to national treatment guidelines and the most common opportunistic infections (Tables 2 and 3). Whether these medicines were in stock at the time of the visit and the number of days over the last 90 they had been in stock were noted.

Main Problems

The following problems came up—

- Finding the number of patients a week was often problematic because some facilities had no attendance register or appointment diary. Because most patients attended monthly, ascertaining the number of patients on antiretrovirals and dividing by four gave a rough estimate.

- In Rwanda it is against government policy for nurses to treat patients. Nevertheless, if the returning patient on ARVs saw only the nurse, then the nurse was counted as "clinical staff" for survey purposes.

- Some facilities lacked meaningful stock records (6/20). (This observation may have been more to do with team leaders; one leader missed all five.) In all cases, data collectors could determine whether the medicines were present at that moment.

- The only missing ARV medicine was the second-line choice (Kaletra; lopinavir + ritonavir) when the facility had no one on second line.

- Medicines for OIs are supposed to be covered by Rwanda's community health insurance program; therefore, they often are available at a different location. If that was the case, we judged these medicines to be "not available."

Results

The weekly patient load was less than the sampled facilities in Kenya (188 compared with 313) (Table 4) with a similar spread. The patients per hour per clinician were less than in Kenya, averaging 2.6 (3.2 in Kenya) with a spread of 7.5 to 0.4; whereas patients per week per support staff were very similar at 35 in Rwanda compared with 33 in Kenya. Again,

access to laboratories and private consultation was almost universal. ARVs were all well stocked. Some facilities lacked second-line drugs, such as Kaletra, because they had no patients on second-line treatment. The presence of other key medicines was very variable because they were supplied by a different insurance system at different pharmacy outlets in a number of institutions.

Table 2. Key ARVs for Rwanda

1	Lamivudine 150 mg tablet
2	Stavudine 40 mg capsule
3	Stavudine 30 mg capsule
4	Nevirapine 200 mg tablet
5	Efavirenz 200 mg tablet
6	Efavirenz 600 mg tablet
7	Zidovudine 300 mg tablet
8	Kaletra (lopinavir 133 mg + ritonavir 33 mg) capsule

Table 3. Non-ARV Key Medicines for Rwanda

1	Co-trimoxazole 480 or 960 mg tablets
2	Co-trimoxazole 240 mg/5 ml suspension
3	Fluconazole 150 or 200 mg tablets
4	Ketoconazole 200 mg tablets
5	Erythromycin 250 or 500 mg tablets
6	Nystatin oral drops 10,000 IU/ml
7	Multivitamin tablets

Table 4. Key Results of Facility Questionnaire

	Rwanda			**Kenya**		
Indicator	**Average**	***Maximum***	***Minimum***	**Average**	***Maximum***	***Minimum***
Patient load/week	**188**	*750*	*30*	**313**	*1,525*	*48*
Number hours/week	**36**	*45*	*8*	**38.6**	*49*	*18*
Patients/hour/clinician	**2.6**	*7.5*	*0.4*	**3.2**	*19.6*	*0.6*
Patients/week/support staff	**35.4**	*94*	*10*	**32.6**	*89.5*	*8*
Access to lab services (%)	**100**	—	—	**90**	—	—
Private adherence rooms (%)	**95**	—	—	**90**	—	—
ARVS in stock (%)	**95**	*100*	*87.5*	**93.3**	*100*	*83.3*
% days ARVS in stock in last 90	**96**	*100*	*87.5*	**85.5**	*100*	*58.3*
% key medicines in stock	**71.5**	*100*	*0*	**86.2**	*100*	*37.5*
% days key medicines in stock in last 90	**83**	*100*	*29*	**75.9**	*100*	*16.7*
Convenient operating time (open weekends or evenings)	**One facility**			**One facility**		

Table 5. Rwanda Facility Indicators

Indicators		*11*	*12*	*13*	*14*		*16*	*17*	*18*	*19*	*20*	*21*
	Type of Facility	**% ARVs Now in Stock**	**% Key Medicines Now in Stock**	**Average % Days ARVs in Stock**	**Average % Days Key Medicines in Stock**	**Weekly Number of Patients**	**Number of Hours per Week**	**Convenient Times Y/N**	**Patients/ Hour/ Clinician**	**Patients/ Week/ Support Staff**	**Lab Present Y/N**	**Private Space Y/N**
Facility 1	District Hospital	88	85.7	—	—	100	40	N	1.3	20.0	Y	Y
Facility 2	District Hospital	88	71.4	—	—	30	35	N	0.4	10.0	Y	Y
Facility 3	Health Center	100	71	—	—	185.5	40	N	1.2	23.2	Y	Y
Facility 4	Health Center	100	57	—	—	100	37.5	N	1.3	24.5	Y	Y
Facility 5	Health Center	100	86	—	—	120	45	N	1.7	30.0	Y	Y
Facility 6	District Hospital	100	86	90.0	77.1	232	45	N	5.2	38.7	Y	Y
Facility 7	District Hospital	88	86	79.6	82.3	144	36	Y	4.0	28.8	Y	Y
Facility 8	District Hospital	100	100	90.0	90.0	300	40	N	7.5	50.0	Y	Y
Facility 9	District Hospital	88	43	78.8	38.6	220	40	N	5.5	44.0	Y	Y
Facility 10	Teaching Hospital	100	71	90.0	64.3	150	40	N	3.8	35.0	Y	Y
Facility 11	Teaching Hospital	88	100.0	78.8	90.0	194	40	N	1.6	32.3	Y	Y
Facility 12	District Hospital	88	57	78.8	51.4	67	40	N	0.6	33.5	Y	Y
Facility 13	Health Center	100	100	90.0	90.0	30	8	N	1.9	30.0	Y	N
Facility 14	District Hospital	100	100.0	90.0	90.0	50	40	N	0.4	—	Y	Y
Facility 15	District Hospital	100	100	90.0	90.0	260	40	N	2.2	65.0	Y	Y
Facility 16	District Hospital	88	0	—	—	146	40	N	1.8	48.7	Y	Y
Facility 17	Health Center	100	100	90.0	90.0	750	40	N	6.3	93.8	Y	Y
Facility 18	District Hospital	100	1.0	90.0	84.7	237.5	40	N	3.0	29.7	Y	Y
Facility 19	District Hospital	88	85.7	79.6	77.1	150	40	N	1.9	37.5	Y	Y
Facility 20	District Hospital	100	28.6	90.0	25.7	300	40	N	1.5	33.3	Y	Y
Average or %		**95%**	**71.5%**	**95.7%**	**82.6%**	**188**	**36.45**	**5.0%**	**2.64**	**35.40**	**100.0%**	**95.0%**
Maximum		100.0%	100.0%	100.0%	100.0%	750	45	—	7.5	93.75	—	—
Minimum		87.5%	0.0%	87.5%	28.6%	30	8	—	0.4	10	—	—
Median		100.0%	85.7%	100.0%	92.8%	150	40	—	1.9	33.3	—	—

Exit Interviews

As in Kenya, the intention was to do 30 exit interviews per facility, with the main indicator being a self-report on adherence in recent days, and to collect information on other factors affecting adherence, such as the time to clinic, time spent in clinic, adverse drug reactions, whether medicines are labeled correctly, and whether the patient has correct knowledge on taking medicine. (See Appendix 3 for exit interview instructions.)

A standard introduction in Kinya-rwandan was worked out and practiced. To find out about ADRs, the team chose the same five main ADRs as for Kenya (Table 6). Strategies for asking about these symptoms over the last week were discussed and agreed on. The definition of "properly labeled" included each medicine's being in separate container or envelope with the drug name, dose per time, and number of times per day written on it. The interviews were conducted in Kinya-rwandan.

Table 6. Adverse Drug Reactions

ADR	Symptom to Ask About
Peripheral neuropathy	Pain, numbness, tingling in legs or feet
Rash	Rash
Lipodystrophy	Change of fat distribution, such as enlarged breasts; buffalo hump; loss of fat tissue in face, buttocks, legs
Hepatotoxicity	Jaundice, yellow eyes
Gastrointestinal tract toxicity	Nausea, vomiting, diarrhea

The pharmacist asked the patients to come to be interviewed if they were on ARVs and had not started on that exact day.

Logistical Problems

At several facilities we arrived on days when the clinic did not have many patients. Clearly, contacting the actual people in the clinics is important to find the best days for visits.

Reliability Interviews

Up to three patients were interviewed by two different people in each facility to check for reliability of each question. For this purpose, the record of the interviews had to be compared, which meant that the second interviewer needed to write a patient identifier such as "E6" if it was Edwin's sixth patient, and the like. This method had been used in Kenya to test reliability, and emphasis in training was given to those questions that proved unreliable in Kenya. In particular, asking about ADRs and calculating time in traveling to the clinic and time spent in clinic were areas of concern. These both proved more reliable in Rwanda.

Results

In fact, 285 patients were interviewed at an average of 16 per facility (compared with 373 in Kenya with an average of 20). In seven facilities, very few patients came on the day of the visit (none, three, and five interviews at two facilities each, and six at one facility). If these

seven facilities are discarded, the average of the others is 20 patients per facility, which is the same as in Kenya. Clearly, choosing a day scheduled for treating patients on ARVs is important.

The interviewees were an average age of 35.1 years (maximum 40 and minimum 7), which is almost identical with Kenya. In Rwanda, 68 percent were female (61 percent in Kenya). On average, the had been on treatment for 13.5 months (maximum 27.3; minimum 8), which is again very similar to Kenya.

The self-reported adherence is less in Rwanda with 91 percent (compared with 95 percent in Kenya) reporting full adherence and an average adherence of 91 percent (compared with 97 percent in Kenya), showing that these values vary.

Table 7. Selected Results of the Exit Interviews

Indicator	**Rwanda**			**Kenya**		
	Average	***Maximum***	***Minimum***	**Average**	***Maximum***	***Minimum***
Self-report: Full adherence (**%**)	**91.0**	*100*	*60*	**95.2**	*100*	*80*
Average adherence (**%**)	**91**	*100*	*85*	**97**	*100*	*83.8*
Able to do normal activity (%)	**75**	*100*	*62*	**80.7**	*100*	*33.3*
Average travel time to clinic (minutes)	**108**	*266*	*14*	**167**	*496*	*43*
Average time in clinic (minutes)	**70**	*128*	*15*	**80**	*186.7*	*41*
Know ARV dosage (%)	**97.9**	*100*	*33*	**98.1**	*100*	*86.7*
Medicine properly labeled (%)	**25**	*100*	*0*	**79.1**	*100*	*24.1*
All ARVs dispensed (%)	**100**	*100*	*100*	**100**	*100*	*100*
All non-ARVs dispensed (%)	**80**	*100*	*0*	**75.3**	*100*	*13*
ADR occurrences (%)	**39**	*80*	*0*	**61.7**	*85*	*0*

Table 8. Composite Results of the Exit Interviews

Indicator						*22*	*23*	*24*	*25*	*15*	*15*	*26*	*1*	*2*
Facility	**Number of Interviews**	**Average Age (Years)**	**Average % Female**	**% Can Do Normal Activity**	**Average Months on Treatment**	**Average Time in Travel**	**Average Time in Clinic**	**% Know ARV Dosage**	**% Medicines with Good Labels**	**% ARVS Dispensed**	**% Non-ARVS to Be Dispensed**	**% of ADR**	**% Self-Report Full Adherence**	**Average Adherence (%)**
1	30	34.6	53.3	80.0	12	170	51	100.0	56.7	100.0	90.0	46.7	70.0	65.3
2	12	30.5	66.7	66.7	11	122	104	100.0	100.0	100.0	91.7	33.3	83.3	91.7
3	29	35.5	82.8	62.1	13	200	45	100.0	65.5	100.0	89.7	48.3	100.0	100.0
4	12	40.3	75.0	100.0	23	95	66	100.0	50.0	100.0	83.3	16.7	100.0	100.0
5	22	36.4	86.4	63.6	13	47	68	100.0	0.0	100.0	95.5	40.9	77.3	68.6
6	27	32.1	74.1	85.2	12	215	68	88.9	0.0	100.0	85.2	33.3	85.2	92.3
7	5	37.4	40.0	80.0	9	160	84	100.0	100.0	100.0	100.0	20.0	60.0	80.0
8	17	31.3	64.7	76.5	15	108	69	100.0	29.4	100.0	41.2	41.2	100.0	100.0
9	12	36.8	41.7	100.0	10	101	90	100.0	0.0	100.0	100.0	25.0	100.0	100.0
10	6	38.2	66.7	100.0	15	118	32	100.0	50.0	100.0	100.0	50.0	83.3	66.7
11	15	36.1	73.3	66.7	21	126	88	93.3	0.0	100.0	86.7	66.7	100.0	100.0
12	5	29.4	80.0	80.0	12	265	108	100.0	0.0	100.0	80.0	80.0	100.0	100.0
13	3	7.0	0.0	100.0	27	107	80	33.3	0.0	100.0	0.0	33.3	100.0	100.0
14	—	—	—	—	—	—	—	—	—	—	—	—	—	—
15	22	33.7	86.4	72.7	15	267	51	100.0	9.1	100.0	81.8	63.6	86.4	90.9
16	3	37.7	66.7	66.7	13	14	15	100.0	0.0	100.0	33.3	0.0	100.0	100.0
17	26	37.3	69.2	76.9	8	45	74	100.0	0.0	100.0	23.1	7.7	100.0	100.0
18	23	38.2	60.9	65.2	12	149	66	100.0	4.3	100.0	95.7	43.5	100.0	100.0
19	16	39.0	62.5	68.8	14	112	128	100.0	0.0	100.0	100.0	25.0	100.0	100.0
20	—	—	—	—	—	—	—	—	—	—	—	—	—	—
Average or %	**15.8**	**35.1**	**68.8%**	**75.4%**	**13.5**	**108**	**70**	**97.9%**	**24.6%**	**100.0%**	**80.0%**	**38.9%**	**90.9%**	**91.4%**
Maximum	30	40.3	86.4%	100.0%	27.3	266.6	127.9	100.0%	100.0%	100.0%	100.0%	80.0%	100.0%	100.0%
Minimum	3	7.0	0.0%	62.1%	8.4	14.0	15.0	33.3%	0.0%	100.0%	0.0%	0.0%	60.0%	65.3%
Median	15.5	36.2	66.7%	76.7%	12.6	119.6	68.5	100.0%	2.2%	100.0%	88.2%	37.1%	100.0%	100.0%

Recent Retrospective

The main purpose of the recent retrospective sample is to look at missed appointments and recapture rate (that is, whether the patient who missed an appointment came back within 3 days and within 30 days of the missed appointment. This indicator was a modification of the Kenyan method, where we looked at whether patients who missed appointments had come back within 60 days of their last attended appointment rather than their missed appointment. With some patients being given medicine and appointments for 60 or 90 days, this became difficult to interpret.

In addition, adherence through self-report, pill count, or both can be followed if recorded.

Other aspects of clinical care are noted, including the CD4 testing rate (percentage of patients with documented CD4 test results in last six months); the percentage of patients achieving CD4 count > 300 cells per µl on most recent lab test; the percentage of patients with a documented viral load test in last six months; and the percentage of patients achieving viral load counts < 400 copies per ml on the most recent lab test in the last three months. Also recorded was any adverse drug reaction (as defined by the same criteria as used in the exit interviews) or opportunistic infections. Opportunistic infections were defined as one of the six in Table 9, which are the same as those most commonly recorded in Kenya.

Table 9. Opportunistic Infections

	Condition	Acronym
1	Tuberculosis	TB
2	Oral or esophageal candidiasis	OC
3	Cryptococcus meningitis (Indian ink positive)	CM
4	Pneumocystis cariniae pneumonia	PCP
5	Fungal skin infections	FSI
6	Bacterial skin infections	BSI

The patient identifier sheets were used to record the patient identifier number and date of visit. Three sheets of 40 each were used so that the data-entry clerk could be collecting the first 40 while the others were being selected. In selecting patients for the sample, the data collectors were instructed to find the number of pages in the register of patients attending that month and divide that number into 120 to determine the number of patients to choose randomly per page. The data collectors needed 120 in case the patients were untraceable. Ultimately, a 100-patient sample was needed. If pediatric and adult patients were recorded in different attendance registers, numbers proportional to the relative number on ART in that program were chosen. As discussed in the Results section and Appendix 1, this method was frequently not possible to use in Rwanda.

Reliability Interviews

Five patient records were processed by two different people in each facility to check for reliability of the extraction process.

The reliability surveys showed that as for Kenya some areas of extraction were not reliable. In particular, the judgment of whether a patient had suffered an OI or ADR in the last six months was very varied. This problem seems to be because such data can be written anywhere and needs interpretation as to whether or not symptoms reflect an ADR. As a result, some collectors found relevant data and others did not.

Results of Recent Retrospective

In the 20 facilities, 1,602 records were examined, which is an average of 80 per facility (compared with 1,265 records averaging 63 per facility in Kenya). Of these, 88 percent were classified as experienced patients (> = 3 months) (compared with 77 percent in Kenya). The average age was 37.2 years (range of 39.6–34.4 years), and 64 percent were female (range 73–46.5 percent). These findings were similar to the Kenyan sample, which had an average age of 35 years (range 8–43 years) with 64 percent female (range 38–78 percent).

At the index visit, 4 percent had an OI (9 percent in Kenya) and 11 percent had an ADR in last six months, compared with 20 percent in Kenya since the index visit.

Sixty-four percent (range 99–18 percent) had had a CD4 count in the last six months, with 44 percent (range 67–5 percent) showing more than 300 cells per µl. In Kenya, in the last three months 21 percent had had a CD4 count (range 0–100 percent), with 56 percent (range 100–0 percent) showing 300 cells per µl or more. Only 1.4 percent had had a viral load test (compared with 4 percent in Kenya).

Table 10. Selected Results of the Recent Retrospective

Indicator	**Rwanda**			**Kenya**		
	Average	***Maximum***	***Minimum***	**Average**	***Maximum***	***Minimum***
Attended next appointment	**79%**	*100*	*14*	**78%**	*96*	*46*
If missed, attended in next 3 days (284 patients)	**70%**	*100*	*0*			
If missed, did not attend in next 30 days (284 patients)	**12%**	*67*	*0*	**12% (60 days)**	*100*	*0*
Self-report: (160/1,602 patients)						
Full adherence (%)	**96**	*100*	*29*	**96**	*100*	*87.5*
Average adherence (%)	**99**	*100*	*98*	**99**	*100*	*87.5*
Pill count: (709/1,602 patients)						
Full adherence(%)	**75**	*100*	*47*	**71**	*100*	*57.1*
Average adherence(%)	**96**	*100*	*74*	**96**	*100*	*74*

Problems found were—

- Sampling
    - There was no attendance register. In this case, the pharmacy records or the appointment book was used.
    - There was no pharmacy attendance record or appointment record in either the clinic or the pharmacy. In this case, data collectors looked at all patients who had started on ARVs before the end of July 2006 and selected 120, assuming that most would have attended in July because most patients attended monthly.
    - Records were kept in alphabetical, not numerical, order. In this case, data collectors looked at all patients who had started on ARVs before the end of July 2006, noted their registration numbers, and worked out the proportion that should be samples. Then, the data collector picked all the names beginning with each letter of the alphabet in turn and selected the correct proportion, ignoring any patient with a higher registration number. For example, if 480 patients were registered by August 1, 2006, and they had a certain registration number, the data collectors would take all of each letter and select every fourth patient with a registration number below the number as of August 1.
- Information
    - No data on next appointment: In this case, take the number of days of pills dispensed and assume next appointment is on the last day of pills.
    - No data on next appointment or number of days of pills dispensed: Ask clinic about dispensing/prescribing habits. Often, the clinic was found to always give 28 (or 30) days of pills. The data collectors could assume the date of the next appointment on this basis. If the clinic gave varying number of days of pills and the number of pills was not recorded, then the data collector could not ascertain the date of the next appointment.
    - The teams had difficulties understanding whether data in the notes represented pill counts or self-report. A lot of the “pill counts” may in fact be self-reports.

Table 11. Recent Retrospective

Indicator							*26*	*27*	*28*	*29*	*30*
								In Last Six Months			
Facility	**Number of Patients Recorded**	**Number Experienced Patients**	**Average Months on Treatment**	**Average Age (Years)**	**% Female**	**% OIs**	**% Symptom of ADR (#Ys)**	**% CD4 Test**	**% CD4 > 300 Cells per µl**	**% Viral Load Test**	**% Viral Load < 400 Copies per ml**
1	89	80	10.7	39.5	71.9	22.5	27.0	58.0	30.4	0.0	—
2	73	65	9.5	36.7	60.3	13.7	14.1	78.1	56.9	0.0	—
3	78	77	22.3	35.5	61.5	11.7	23.4	68.8	50.9	18.4	92.3
4	53	53	14.0	35.7	56.6	1.9	5.7	50.0	—	0.0	—
5	81	73	13.5	37.5	60.5	3.7	9.9	70.4	31.6	0.0	—
6	67	58	9.1	36.3	69.2	5.0	1.6	90.9	25.0	4.5	100.0
7	96	79	10.3	38.3	72.9	—	0.0	87.1	21.0	0.0	—
8	100	88	14.8	37.9	62.0	100.0	1.0	88.9	53.4	0.0	—
9	100	72	8.6	36.8	66.0	100.0	0.0	22.0	4.5	0.0	—
10	100	86	13.9	38.4	46.5	2.0	30.0	70.7	34.3	1.0	100.0
11	63	60	20.9	39.6	73.0	1.6	3.2	42.9	66.7	0.0	—
12	58	49	8.0	38.5	69.0	1.7	20.7	69.0	25.0	0.0	—
13	73	73	18.9	36.7	72.6	4.1	11.0	98.6	63.9	0.0	—
14	60	60	15.0	34.2	60.0	0.0	16.7	65.0	48.7	0.0	—
15	74	65	9.1	37.0	58.1		6.8	17.6	61.5	0.0	—
16	100	96	14.4	36.9	71.0	0.0	0.0	39.0	64.1	0.0	—
17	87	68	8.3	34.7	55.2	1.1	6.9	60.9	47.6	0.0	—
18	100	69	9.2	36.8	61.0	7.0	22.0	67.0	60.3	6.0	100.0
19	100	93	13.0	38.8	72.0	0.0	8.0	58.0	36.2	0.0	—
20	50	38	17.6	37.1	50.0	0.0	10.0	92.0	43.5	0.0	—
Average	**80.1**	**70.1**	**12.8**	**37.2**							
Percent		**87.5%**			**63.8%**	**3.9%**	**11.0%**	**63.7%**	**44.2%**	**1.4%**	**90.9%**
Maximum	100	96	22.3	39.6	73.0%	100.0%	30.0%	98.6%	66.7%	18.4%	100.0%
Minimum	50	38	8.0	34.2	46.5%	0.0%	0.0%	17.6%	4.5%	0.0%	92.3%
Median	79.5	70.5	13.3	37.0	61.8%	2.9%	8.9%	67.9%	47.6%	0.0%	100.0%

Indicator	*6*	*7*	*7*	*8*		*1*	*2*			*32*
Facility	**% Attended Next Appointment**	**If Missed, % Attended in Next 3 Days**	**If Missed, % Attended in Next 30 Days**	**If Missed, % Not Attended in Next 30 Days**	**Number of Self-Reported Adherence**	**% Full Adherence**	**Self-Report Adherence Average % Recorded**	**Number of Pill Count Adherence Measures**	**% Full Adherence by Pill Count**	**Pill Count Adherence Average % Recorded**
1	80.9	64.7	88.2	11.8	0	—	—	86.0	57.0	95.1
2	87.7	44.4	88.9	11.1	1	0.0	0.0	71.0	46.5	97.4
3	85.9	64.0	37.5	62.5	0	—	—	55.0	83.6	100.0
4	78.3	70.0	100.0	0.0	0	—	—	28.0	71.4	73.6
5	97.5	0.0	50.0	50.0	0	—	—	80.0	100.0	100.0
6	90.8	66.7	75.0	25.0	36	100.0	100.0	54.0	64.8	98.2
7	95.7	0.0	50.0	50.0	5	100.0	100.0	38.0	92.1	95.9
8	93.9	100.0	100.0	0.0	25	100.0	100.0	0.0	—	—
9	14.0	100.0	100.0	0.0	70	100.0	100.0	0.0	—	—
10	41.0	44.1	91.5	8.5	13	92.3	100.0	0.0	—	—
11	93.7	50.0	100.0	0.0	0	—	—	63.0	85.7	98.2
12	94.8	66.7	100.0	0.0	0	—	—	58.0	93.1	99.0
13	95.9	0.0	33.3	66.7	0	—	—	73.0	95.9	94.1
14	48.3	54.8	80.6	19.4	0	—	—	59.0	50.8	93.0
15	95.9	0.0	33.3	66.7	0	—	—	0.0	—	—
16	92.4	28.6	100.0	0.0	3	100.0	100.0	0.0	—	—
17	—	—	—	—	0	—	—	0.0	—	—
18	77.0	60.9	91.3	8.7	7	28.6	97.9	44.0	52.3	91.9
19	100.0	—	—	—	0	—	—	0.0	—	—
20	100.0	—	—	—	0	—	—	0.0	—	—
Average	—	—	—	—	**8**	—	—	**35.4**	—	—
Percent	**79.0%**	**69.7%**	**88.4%**	**11.6%**	**10%**	**95.6%**	**99.8%**	**45.6%**	**74.6%**	**96.4%**
Maximum	100.0%	100.0%	100.0%	66.7%	70.0	100.0%	100.0%	86.0	100.0%	100.0%
Minimum	14.0%	0.0%	33.3%	0.0%	0.0	0.0%	0.0%	0.0	46.5%	73.6%
Median	92.4%	54.8%	88.9%	11.1%	0.0	100.0%	100.0%	41.0	77.5%	96.7%

Long Retrospective

For the long retrospective, the survey is most interested in the pharmacy records. The main purposes for this sample are to look at the facility's dispensing record over an extended period of time, that is, the percentage of days covered by dispensed medicine. In Kenya, the survey looked at the dispensing record over 12 months (365 days). In Rwanda, the time was shortened to 6 months (184 days) because we were told that the record-keeping system had changed nationally about February 2006. As a result, data collectors selected patients attending during April 2006.

Coupled with this information, the survey is looking at whether the same patients are still on treatment at the end of the time and whether they have had a gap of 30 days or more in their medicine during that period. Whether they attended their next appointment and if not, whether they attended within the next 3 days and within 30 days were also noted.

As for the recent retrospective, clinical information was also gathered, including whether patients have had any ADRs or OIs in the last six months, whether they have had a CD4 or viral load test in the last six months, and if so whether clinical milestones had been achieved. If recorded, data collectors also noted the pill count between the patients' most recent two visits.

Methods and problems in selection were as for the recent retrospective. The difference was that patients attending seven months ago were looked at (so for November 2006, we were looking at patients who attended in April 2006). In one case, the facility had changed its record-keeping system four months before. To accommodate this difference, the same sample was used as for recent retrospective.

Results for Long Retrospective

Data collectors examine 1,532 records, which was an average of 77 per facility (corresponding figures in Kenya were 994 and 50, respectively). Of these, 89 percent were experienced patients (> = 3 months) (59 percent in Kenya).

Their average age was 35 years (range 51–33 years), compared with 33.4 years in Kenya. In Rwanda, 62 percent were female (range 80–51 percent). This figure compares to the same 62 percent in Kenya (range 79–33 percent).

In the last six months; 11 percent had an OI (range 0–23 percent) (in Kenya this was 13 percent, with a range of 0–26 percent) and 14 percent had an ADR (range 0–41 percent) (in Kenya 30 percent, with a range of 5–48 percent).

In Rwanda, 59 percent (range 18–95 percent) had had a CD4 count in the last six months (in Kenya, 46 percent, with a range of 7–88 percent). Of these, 50 percent (range 8–74 percent) were greater than 300 cells per µl (in Kenya, 61 percent, with a range of 20–79 percent). Only 0.4 percent had had a viral load test in the last six months

Table 12. Selected Results of the Long Retrospective

Indicator	Rwanda			Kenya		
	Average	***Maximum***	***Minimum***	**Average**	***Maximum***	***Minimum***
% days covered by medicine dispensed	**96%**	*100*	*88*	**81%**	*99*	*25*
% > 95% days covered by medicine dispensed	**76%**	*98*	*54*	**60%**	*100*	*12*
Gap in medicines of > 30 days	**4%**	*26*	*0*	**25%**	*78*	*0*
Attended next appointment	**78%**	*100*	*38*	**79%**	*100*	*25*
If missed next appointment, attended in next 3 days (281 patients)	**69%**	*100*	*22*	—	—	—
Did not attend in 30 days (60 in Kenya)	**12%**	*50*	*0*	**25%**	*1*	*0)*
Still on treatment at 6 months (12 months Kenya)	**90%**	*100*	*57*	**86%**	*100*	*69*
Pill count: (754/1,532 Rwanda and 116/994 Kenya)						
Full adherence (%)	**71**	*100*	*33*	**76**	*100*	*50*
% achieve 95% coverage	**80%**	*97*	*42*	**60%**	*100*	*12*

Problems with Method

- Sample selection was not always easy because records of who attended were not always clear. The same problems were encountered and solutions adopted as for the recent retrospective.

- Problems were often encountered in calculating number of days' worth of medicines dispensed over the six months. Frequently, no records existed of days dispensed. When the clinic regularly gave the same number of days of medications and attendance dates were present, data collectors calculated number of days' of medicines dispensed on that basis. When no dispensing records were kept and no regular amounts were given, then this calculation was not possible (4 of 20 facilities).

- Checking for months on treatment, OIs, and ADRs sometimes took a particularly long time. In future tests, using a simplified form that excludes OIs and ADRs is recommended; thus, data collectors need only decide whether the patient is new or experienced.

Reliability Survey

The reliability surveys showed that some areas of extraction were not reliable, in particular the following—

- In at least one group, the number of days dispensed and the gap of 30 days was not recorded reliably. This discrepancy may have been caused by lack of training and could be dealt with by better training.

- Again, there was some confusion as to records of pill counts.
- In Kenya, the judgment of whether patients had suffered an OI or ADR was very varied. This problem seems to be because such data can be written anywhere and needs interpretation as to whether it is an ADR or not. As a result, some collectors found relevant data and others did not.

Table 13. Long Retrospective

Indicator							*3*	*26*	*26*	*27*	*28*	*29*	*30*
									In the Last Six Months Any Reported				
Facility	**Number of Patients**	**% Experienced Patients**	**Average Number of Months on Treatment**	**Average Age (Years)**	**% Female**	**% Days Covered by Medicines**	**% Symptom of OI**	**% Symptom of ADR**	**% CD4 Test**	**% CD4 > 300 Cells per µl**	**% Viral Load Test**	**% Viral Load < 400 Copies per ml**
1	100	83.0	8.5	39.5	59.0	94.8	13.0	14.1	90.9	25.8	0.0	—
2	64	89.1	7.1	36.8	67.2	97.8	6.3	4.7	67.2	30.2	0.0	—
3	79	92.4	12.4	33.5	65.4	95.4	22.8	41.8	92.5	48.4	0.0	0.0
4	74	94.6	13.4	38.9	58.1	87.9	14.9	30.5	66.2	8.2	0.0	—
5	75	97.3	11.9	33.0	50.7	98.0	20.0	38.7	83.1	40.3	1.3	100.0
6	84	69.0	6.9	33.9	72.3	94.2	0.0	1.2	—	—	—	—
7	64	87.5	8.3	39.7	71.9	95.3	0.0	9.4	76.6	46.9	0.0	—
8	100	94.0	17.3	37.2	71.7	98.6	2.0	4.0	66.7	57.8	0.0	—
9	100	86.0	8.8	36.6	62.6	97.6	0.0	0.0	—	—	0.0	—
10	61	93.4	13.1	38.0	55.0	95.2	6.6	24.6	75.4	39.1	6.6	100.0
11	61	100.0	19.0	39.5	75.4	98.0	1.6	4.9	34.4	66.7	0.0	—
12	45	86.7	9.0	39.2	80.0	97.1	0.0	9.1	75.6	27.3	0.0	—
13	59	96.6	18.0	35.7	67.8	96.6	5.1	6.8	94.9	67.9	0.0	—
14	60	96.7	12.1	32.9	60.0	92.8	1.7	18.3	61.7	43.2	0.0	—
15	73	61.6	9.2	51.0	58.9	100.0	0.0	6.8	17.8	61.5	0.0	—
16	100	99.0	11.0	37.4	57.0	93.6	0.0	1.0	28.0	64.3	0.0	—
17	80	86.3	7.0	39.1	71.3	—	0.0	0.0	43.8	74.3	0.0	—
18	100	88.0	10.9	36.5	71.0	94.4	0.0	1.0	52.0	65.4	3.0	100.0
19	100	85.0	10.8	39.3	67.0	—	0.0	2.0	55.0	48.2	0.0	—
20	53	86.8	9.5	37.6	73.6	—	0.0	20.8	81.1	51.2	1.9	0.0
Average or %	**76.6**	**88.4%**	**10.5**	**35.3**	**62.1%**	**95.6%**	**10.8%**	**13.9%**	**58.6%**	**49.7%**	**6.1%**	**8.4%**
Maximum	100	100.0%	19.0	51.0	80.0%	100.0%	22.8%	41.8%	94.9%	74.3%	6.6%	100.0%
Minimum	45	61.6%	6.9	32.9	50.7%	87.9%	0.0%	0.0%	17.8%	8.2%	0.0%	0.0%
Median	74.5	88.5%	10.8	37.5	67.1%	95.4%	0.8%	6.8%	66.9%	48.3%	0.0%	0.0%

Indicator		*4*	*5*	*5*	*6*	*7*	*7*	*8*			*31*	*34*
									In Last Two Reported Appointments			
Facility	**% Days Covered by Medicines if Still in Treatment**	**% Days > 95%**	**% with Gap in Medicines > 30 Days**	**% with Gap in Medicines > 30 Days if Still in Treatment**	**% Attended Next Appointment**	**If Missed, % Attended in Next 3 Days**	**If Missed, % Attended in Next 30 Days**	**If Missed, % Did Not Attend in Next 30 Days**	**% Last Dispensing Covered Any of Last 30 Days**	**% Records with Pill Count**	**% of Pill Count Full Adherence**	**% Achieve > 95% Coverage**
1	92.3	54.0	1.0	1.8	71.0	82.8	89.7	10.3	57.0	99.0	53.5	71.7
2	98.1	82.8	4.7	7.3	78.1	81.3	81.3	12.5	64.1	100.0	67.2	81.3
3	96.9	79.5	7.6	4.4	67.1	61.5	80.8	19.2	87.2	100.0	81.0	83.5
4	97.9	55.4	25.7	2.3	83.8	50.0	50.0	50.0	58.1	94.6	71.4	81.4
5	97.8	81.3	1.3	1.4	78.7	75.0	100.0	0.0	98.6	98.7	93.2	91.9
6	88.7	61.3	15.0	12.3	74.1	0.0	100.0	0.0	—	78.6	56.1	71.2
7	96.2	68.8	4.7	3.3	93.8	50.0	100.0	0.0	93.8	57.8	40.5	86.5
8	98.7	95.0	1.0	1.0	91.9	87.5	100.0	0.0	99.0	0.0	—	—
9	97.6	92.0	0.0	0.0	38.0	92.1	98.4	1.6	100.0	0.0	—	—
10	95.9	75.4	0.0	0.0	58.3	44.0	100.0	0.0	93.4	0.0	—	—
11	98.0	93.4	1.6	1.6	93.4	0.0	50.0	50.0	100.0	100.0	100.0	95.1
12	98.1	86.7	2.2	0.0	91.1	33.3	66.7	33.3	86.7	100.0	95.6	91.1
13	96.6	83.1	5.1	5.1	100.0	0.0	—	—	100.0	100.0	96.6	96.6
14	94.4	61.7	13.3	8.9	53.3	64.3	96.4	3.6	93.3	100.0	33.3	41.7
15	100.0	98.6	0.0	0.0	97.3	0.0	100.0	0.0	100.0	0.0	—	—
16	94.1	57.0	11.0	10.4	91.0	20.0	60.0	40.0	96.0	0.0	—	—
17	—	—	—	—	—	—	—	—	—	0.0	—	—
18	95.4	70.7	6.0	6.0	72.0	75.0	100.0	0.0	100.0	40.0	50.0	67.5
19	—	—	—	—	—	—	—	—	—	0.0	—	—
20	—	—	—	—	93.3	100.0	100.0	0.0	100.0	0.0	—	—
Average or %	**96.1%**	**75.7%**	**4.0%**	**4.0%**	**77.8%**	**68.4%**	**90.4%**	**9.2%**	**89.7%**	**49.2%**	**70.6%**	**79.7%**
Maximum	100.0%	98.6%	25.7%	12.3%	100.0%	100.0%	100.0%	50.0%	100.0%	100.0%	100.0%	96.6%
Minimum	88.7%	54.0%	0.0%	0.0%	38.0%	0.0%	50.0%	0.0%	57.0%	0.0%	33.3%	41.7%
Median	96.9%	79.5%	4.7%	2.3%	81.2%	55.8%	98.4%	1.6%	96.0%	68.2%	69.3%	82.5%

Data-Entry Tool

The questionnaires are now formatted in Excel with hidden columns and rows that calculate the indicators for each facility for all patients and for experienced and new patients. When these sheets are loaded into the consolidation forms, indicators for all facilities are automatically calculated. Those summary sheets are the sheets that have been reproduced in this document. When the methods and questionnaires are finalized, these tools will also be finalized.

CONCLUSION

After this second trial of feasibility and reliability with data collection instruments very similar to that used in the first trial, we are in a position to compare and contrast the results and make evidence-based modifications to the instruments.

What is remarkable is the great variety in information systems in the different facilities and the differing amount of information available in the clinical, nursing, and pharmacy notes. Some have no attendance register, no appointment book, and no system of tracing the number of days of pills dispensed to any individual patient. This lack of individual dispensing data would make it difficult to prove any medicines had been stolen.

Usually, attendance at the next appointment and recapture rate can be extrapolated from the data available. The number of days covered by dispensed medication over a set number of days proved possible to measure in all but three facilities, likewise whether a gap in treatment of 30 days or more occurred and whether patients were still in treatment at the end of the period. These findings are the main candidates for proxy indicators of adherence. We will need to test these three indicators for validity in the next phase of the project.

For the dispensing over time: in Kenya this period was a year, while in Rwanda it was six months. As a consequence, in Rwanda the two samples (recent and long retrospective) were only three months apart. This factor often made collecting the two samples of clinical notes conflict with each other. To make only one sample would be a huge advantage.

Self-report is always possible from exit interviews, provided the facility is visited on days when the patient flow is good. This survey failed to visit at an appropriate moment in about a third of facilities, which was a serious error.

In Kenya, about 10 percent of records had pill counts and close to 50 percent had self-report. In Rwanda, the situation was reversed. Because these indicators are not universal, making the two methods complementary indicators only to be used if the particular recording system recorded them might improve data collection.

The percentage of CD4 counts that were greater than 300 cells per µl varied notably from facility to facility. Observationally, this variation seemed to correlate with attendance at next appointment. It would be useful to statistically check this apparent correlation.

We now have formulated instruments, data-entry forms, and analysis spreadsheets. The next step is to carry out a major simplification of the instruments and test them again with less supervision in other of the East African countries.

Indicator Candidates

Following are some thoughts on items that worked well and others that did not and might be candidates for redesign. These are summarized in Table 14.

Attending Next Appointment

This information was easy to find when the next appointment date was noted but needed interpretation if, for example, a standard number of days was given (often 30 or 28). Therefore, an appointment was recorded as missed if more than 30 (or 28) days elapsed between visits. In clinics where no standard number of pills was given and no appointment was recorded, the information could not be obtained.

Dispensing over Time

This indicator worked well where either a system said how many days' worth of medicines was dispensed or when a standard amount was used. Problems arose in one group because patients came back for other reasons and were counted as having received an extra 30 days of medicines. In this survey, days dispensed over six months (184 days) were counted, not a year, because we were told the recording system had changed in February.

Gap in Dispensing of More than 30 Days

This indicator worked reasonably well, but some data collectors found recognizing a 30-day gap in treatment difficult to calculate. We could develop a calendar tool to help the reliability of this indicator.

Still in Treatment after Six Months

This indicator was reinterpreted to mean whether the last dispensing covered any of the last 30 days. It worked well.

Search for OIs, ADRs, and Viral Loads

These indicators yielded little useful or reliable information. Viral loads were extremely rare, and the recording of OIs and ADRs were not picked out consistently.

CD4 Counts

Finding these was a very useful exercise, although only 60 percent or so were findable. In some systems, the CD4 records were in a separate book with no way of linking them to the clinical notes. As mentioned previously, how much the percentage of CD4 counts greater than 300 cells per µl varied from facility to facility was remarkable.

Table 14. Summary of Suggestions

Observations	Suggestion
Pill count and self-report are only in some notes	Make them complementary indicators
Viral load is very rare	Drop it
OIs are very inconsistent	Drop them
ADRs are very inconsistent	Drop them
Months on treatment, age, gender	Retain
CD4: latest in last six months and if > 300	Retain
Days dispensed over six months	Retain
Gap of 30 days	Drop, make a tool for easy recognition, or make complementary
Attended next appointment from three months back and if missed attended in 3 days and 30 days	Retain
Last dispensing covered any of last 30 days	Retain
Exit and facility interviews	Retain

Sampling

As mentioned, the difference between Rwanda and Kenya is that in Kenya the survey sampled at one year and 3 months, and in Rwanda at six months and three months. The method in Rwanda created much more overlap in the samples. With no appointment book or visit register, data collectors sampled from all patients in the clinic who had been started on ARVs by the end of April 2006 and the end of July 2006. This method worked quite well.

To make the sampling less onerous, I would like to suggest taking only one sample (say from six months ago) and doing the dispensing record with this sample, as well as following the same patient forward to July to do missed appointments and reattendance. This change in method would cut down a lot on the data collection demands.

The suggested new procedure is as follows—

- Sample 120 patients either who attended in the month six to seven months ago or who were on treatment by the end of that month.
- Record—
    - Identification number
    - Index visit date in month six to seven months ago
    - Months on ARVs at index visit
    - Age
    - Gender
    - Latest CD4 count in last six months
    - If CD4 count is more than 300 cells per µl

- Number of days dispensed for 184 days after index visit
- From appointment three months ago (if attended), did patient attend next appointment?
- If not, did patient attend in next 3 days and next 30 days?

This information could all be recorded on one side of landscape-oriented paper, 25 patients per side. This system would cut down on rewriting identifier numbers and the like; 100 patients could be back to back on two pieces of paper.

APPENDIX 1. TEAM LEADER DESCRIPTIONS OF THE PROCESS AT EACH FACILITY

		Numbers of Forms Completed			
	Group	Number of Exit Interviews	Number of Exit Reliability Interviews	Recent Retrospective Number Used	Long Retrospective Number Used
Facility 1	1	30	4	89	100
Facility 2	1	12	5	73	64
Facility 3	1	29	5	78	79
Facility 4	1	12	0	53	74
Facility 5	1	22	5	81	75
Facility 6	2	27	0	66	84
Facility 7	2	5	0	96	64
Facility 8	2	17	3	100	100
Facility 9	2	12	0	100	100
Facility 10	2	6	0	100	61
Facility 11	3	15	5	63	61
Facility 12	3	5	3	58	45
Facility 13	3	3	2	73	59
Facility 14	3	0	0	60	60
Facility 15	3	22	5	74	73
Facility 16	4	3	2	100	100
Facility 17	4	26	2	87	80
Facility 18	4	23	0	100	100
Facility 19	4	16	4	100	100
Facility 20	4	0	0	50	53
Average or %		14.3	2.3	80.1	76.6
Maximum		30.0	5.0	100.0	100.0
Minimum		0.0	0.0	50.0	45.0
Median		13.5	2.0	79.5	74.5

Facility 1

How patients per week found	No clinic attendance records so did not go to pharmacy attendance but counted number of notes of patients who attended yesterday and multiplied by 5.
Recent Retrospective	
How were patients selected? Explain system of selection	Used pharmacy attendance records of register of visits. Selected 120. Then pulled clinical and pharmacy records, which were both kept in numerical order.
Long Retrospective	
How were patients selected?	As above
Other comments	Didn't do pill count

Facility 2

How patients per week found	Looked at visit register and counted for a month.
Recent Retrospective	
How were patients selected? Explain system of selection	From the clinical register, we selected 120 patients who came in July. The total number was divided by 120 to get the interval/sequence. Selected clinical dossier and from that pulled pharmacy dossier. No record of numbers of days of pills dispensed. Next appointment was written. 30 days always given so able to calculate from that. Ran out of time.
Long Retrospective	
How were patients selected?	As above but ran out of time

Facility 3

How patients per week found	In pharmacy attendance register.
Recent Retrospective	
How were patients selected? Explain system of selection	A sample of files from 120 patients who came in July 2006 were selected randomly from the Pharmacy register. In the pharmacy register were recorded both the individual number and the group number. The group number was used to find the group of notes and then the individual number to find the individual patient. Group sizes were from 5 to 15. Clinical and pharmacy records were together.
Long Retrospective	
How were patients selected?	As above
Other comments on systems of record keeping	Used MSF clinical files not TRAC format.

Facility 4

How patients per week found	No clinical register of attendance so used pharmacy attendance register. Looked at whole month and divided by 4.
Recent Retrospective	
How were patients selected? Explain system of selection	A sampling of 120 was randomly selected from the pharmacy register. However, clinical records were ordered by name, not by number, so file recovery was very slow. Patient files not being filled in reliably. Often missing. No pharmacy records.
Long Retrospective	
How were patients selected? Explain system of selection	As above. The number of days dispensed could be seen either in the notes or in the register. Appointments were written in the register.
Other comments on systems of record keeping	Some patients seem to have the same identification number, 035/06. This must lead to confusion. Patient files were not filed from July so had to use register. From July some CD4 records were kept in a different, new book that we could not access.

Facility 5

How patients per week found	Used pharmacy register because no clinical register.
Recent Retrospective	
How were patients selected? Explain system of selection	Selected 120 from pharmacy register. Information in three different dossiers: clinical, nursing, and pharmacy records. So needed to pull all three, which were kept in different places. The place for recording pharmacy data was for a time on the TRAC pharmacy cards, but then this method was stopped and the nurses' dossiers were again used. All data had been copied to the nurses' dossier. The locations for the same data were not consistent, sometimes being in the nurses' dossier. The next appointment was recorded.
Long Retrospective	
How were patients selected? Explain system of selection	As above, the number of days dispensed was not recorded, but 30 days were usually but not always given. So what was calculated was the number of days to next appointment.

Facility 6

How patients per week found	Used consultation register, considered the last week of four weeks and pharmacy appointment book.
Recent Retrospective	
How were patients selected? Explain system of selection	Selected from patient register for July 4; two sets of note, clinical and pharmacy, both incomplete
Long Retrospective	
How were patients selected? Explain system of selection	A patient register, 18 pages of patients attended on April 2006 divided by 120, six patients were picked for the first page and seven patients on the next page and so on.
Other comments on: Pharmacy records Reliability Deficiencies	The recording system changed in May 2006, after May no data on number of days dispensed, assuming always 30 days. Only using Pharmacy record card *(Rapport de visite à la Pharmacie).*

Facility 7

How patients per week found	Used consultation register and pharmacy appointment record. Then I took the last page from each register.
Recent Retrospective	
How were patients selected? Explain system of selection	We used pharmacy appointment book and selected every other patient. These were the patients attended in April 2006. After the selection of the patients, we picked up their corresponding clinical note from a cupboard where they are arranged in an ascending order; in addition to clinical note we also used the pharmacy register.
Other comments on: Clinical records Reliability Deficiencies	Because of the change in the files (new pharmacy register) used and the use of ARV dispensing, many files were left unfilled.
Long Retrospective	
How were patients selected? Explain system of selection	We took all patients who attended in July because they were fewer than 120. We used the pharmacy register and ARV dispensing tool to get data we needed; the clinical notes were kept in a cupboard according to ascending order.
Other comments on systems of record keeping	The recording system needs to be improved and updating the ARV dispensing tool is vital in order to have all information for each patient. An integration of clinical and pharmacy data is very essential.

Facility 8

How patients per week found	The facility has no record for consultation; however, the pharmacy staff and the doctor explained to me that they attend to 60 patients a day.
Recent Retrospective	
How were patients selected? Explain system of selection	There were no appointment books or visiting registers in pharmacy or clinic. All nurses' dossiers were kept in order in the dispensing room in cane boxes. The clinic notes were ordered in the same way in the clinic room. There was a register for when each patient started on ARVs and their registration numbers were in ascending order. We therefore knew the number of patients on treatment by the end of April and the end of July. Therefore we selected 10 patients from the basket, picking them randomly from 10 baskets. Ten baskets containing pharmacy registers were kept in a dispensing pharmacy; these were the one we selected first and then picked their corresponding clinical note in another 10 baskets containing clinical notes kept in the consultation room. We selected patients who received medicines in April 2006 and a total of 100 patients were selected.
Other comments on: Clinical records Reliability Deficiencies	The dispensing period was every day for the first one week on treatment, and then every two weeks for three months, and then every 30 days. However, we found differences in some cases. No appointment records were recorded in the notes. If the patient was late it was recorded that the patient was late, but not how late.
Long Retrospective	
How were patients selected? Explain system of selection	Same as in recent retrospective. We selected patients who received drugs in April 2006.
Other comments on systems of record keeping	They need to update their files, both clinical notes and pharmacy register.

Facility 9

How patients per week found	An assumption was made based on the number of patients received in the pharmacy and consultation. About 760 patients on ARVs; almost all of them come at least once a month, This gives an average of 27 patients per day. About 5 patients a day come for consultation; hence 32 patients per day (160 patients per week).
Recent Retrospective	
How were patients selected? Explain system of selection	There was no consultation record or pharmacy register. There was a register for when each patient started on ARVs, and their registration numbers were in ascending order. We therefore knew the number of patients on treatment by the end of April and the end of July. The nurses' dossiers were kept in alphabetical order in wooden compartments where they recorded the patients once they come to take the medicine and register of all patients on ARVs. The clinical records were kept in piles 0–99; 100–199; 200–299 etc. but not in any order. We selected piles of nurses' dossiers and picked patients from 1 to 563 in the order of 1, 4, 8, 12 etc. (number 564 was the first patient registered in August). A new patient has to come to the pharmacy every day for the first week or first two weeks, then after that the patients get ARVs for 30 days. If a patient came a day after 30 days we considered him to have missed his appointment.
Other comments on: Clinical records Reliability Deficiencies	The clinical record was not updated and there were very few clinical records with CD4 counts. However, another register is used to record CD4 for all patients, in which it was very difficult to find individual patients.
Long Retrospective	
How were patients selected? Explain system of selection	There was no consultation record or pharmacy register. We used the *dossier d'infirmière* where they recorded the patients once they come to take the drug and register of all patients on ARVs, number 478 was the first patient registered in May, then we picked patients from 1 to 477 in order of 1, 4, 8, 12 etc. A new patient has to come to the pharmacy every day for the first week or first two weeks, then after that the patients get ARVs for 30 days. If a patient came a day after 30 days we considered him to have missed his appointment.
Other comments on: Pharmacy records Reliability Deficiencies	We were not able to find information on pill count, self-report, age of patient, and sex. We found age and gender from a computer record of patients who had started ARVS.
Other comments on systems of record keeping	The recording system is not good; the files are classified according to the alphabetical order in a box, which also did not follow the alphabetical order. The clinical notes also were classified based on patients with register number greater than 100 and above! Both systems are complicated and it takes more time to find a note. A better system should be put in place whereby a register or clinical note is classified in a chronological order.

Facility 10

How patients per week found	Because the ART department has no consultation register, I assumed that all patients on ARVs at least need to appear once a month, 740/28 = 26.4, and the nurses told me that at least 4 patients come for consultation per day.
Recent Retrospective	
How were patients selected? Explain system of selection	There were no appointments, no appointment or visiting book, no pharmacy register or individual pharmacy records. There were only clinical dossiers that contained visit dates but no appointment dates. They claimed that they gave 15 days for first two weeks and then either 30, 60, or rarely 90 days. We proceeded on the assumption that the next appointment would be after 30, 60, or 90 days. We used the register from the counseling cell, where all HIV patients have to pass before they meet the doctor or the pharmacist. We selected 60 patients from 147 patients who came for ARVs in July. I divided 147 by 60 in order to know how many patients to pick, then the order was 1, 3, 6 etc. We selected 60 files because we had started with the long retrospective, where we had found 40 patients came also in January, and we worked simultaneously in this case. The register helped us pick clinical notes for each patient, which were kept in a box according to the ascending numerical order.
Other comments on: Clinical records Reliability Deficiencies	There is no pill count record or self-report. We were told that they dispense for 30 days or 60 days, and in some files we found 15 or even more than 90 days, which is not clearly defined. There was no appointment date recorded in the clinical note or in the register at the counseling cell.
Long Retrospective	
How were patients selected? Explain system of selection	We used the register from the counseling cell and took all 94 patients who came in for ARVs in April 2006. Then we selected corresponding clinical note from the boxes where they are kept according to their ascending order. We worked simultaneously to fill the long and recent retrospective, because we had found in other sites that there is always a possibility of finding the same patient also came for ARVs in July. At this site the dispensing period is considered to be 30, 60, or 90 days.
Other comments on: Pharmacy records Reliability Deficiencies	There is no pill count record or self-report. The pharmacy does not have any record about who to come and when; they use stock cards to record the patient and a medicine taken, on each stock card of each separate drug. If a patient is taking three separate molecules, he or she will be recorded on three different stock cards. We did not use pharmacy records; instead we used clinical notes.
Other comments on systems of record keeping	A system of updating the records should be put in place, and an appointment for refill should be indicated.

Facility 11

How patients per week found	Patients' files are classified according to the next appointment. The nurse was able to identify those who came for ARVs in October and HIV-positive patients who came only for Bactrim. The total number of patients was 776.
Recent Retrospective	
How were patients selected? Explain system of selection	There is no patient register at both clinic and pharmacy levels. There is a nursing file (*dossier infirmier)* classified according to doctors (6) and to the day of the next appointment. We first identified all the patients who came to the clinic in July 2006, per doctor. We got a total of 491 patients who came in July 2006. We divided it by 120 and we got an interval of 3.7. Then from each doctor's list, we selected every third and fourth patient to have our sample size.
Other comments on: Clinical records Reliability Deficiencies	Nurses are responsible for patient follow-up. Doctors see only patients with a problem, but the day of our visit no patient was referred to the doctor. There is also a *dossier médecin* for the doctors, but it contains very limited information, mainly clinical records at the beginning of the ARV treatment and each time the patient is referred (very rare).
Long Retrospective	
How were patients selected? Explain system of selection	We used the same methodology as for the recent retrospective. We made a list of patients seen in April 2006 for each doctor. We had a total of 491 patients seen in April 2006. We divided the total by 120 and got 4. Then, we selected every fourth patient on our list.
Other comments on: Pharmacy records Reliability Deficiencies	There is no register for pharmacy records. We selected our patients from the *dossier infirmier*.
Other comments on systems of record keeping	They also have a "Rapport des visites" at the pharmacy, but it is only used for Bactrim and not for ARVs. The ARV columns are not filled in. The system is very complicated, using different files for patients.

Facility 12

How patients per week found	We counted the total number of patients who came in October using the appointments register (198) plus the total number of people living with HIV/AIDS who received OI prevention in the same month (65). 198 + 70 = 268.
Recent Retrospective	
How were patients selected? Explain system of selection	There is a patients' register with their appointments. When a patient comes to a visit, there is a "tick" on the date of the appointment. We counted the number of pages (17). 120/17 = 7, that means 7 patients per page. We then selected the patients' files according to the ID selected. However, we found that the patients' files were empty, and we decided to use the "Rapport de visites à la pharmacie" to complete the information.
Long Retrospective	
How were patients selected? Explain system of selection	We have used the same methodology as for the recent retrospective. We combined patient's files and pharmacy records. Because finding the patients' files was difficult, we took all the patients' files and selected every one who came in April 2006.
Other comments on systems of record keeping	Patients' files and the pharmacy records are put away in disorder. It was difficult to find them.

Facility 13

How patients per week found	There is an Excel sheet with all the ARV patients and their attendance for every month. We were able to get the sheet for the period July 2006–November 2006. Every time the patient comes, a tick is made. We have a total number of all the patients who came in November 2006 divided by 4. (ARV clinic open on Monday only.)
Recent Retrospective	
How were patients selected?	Because the total number of patients on ARV is about 100, no sampling was needed. We took all the ARV patients and retained those who came in July 2006.
Long Retrospective	
How were patients selected? Explain system of selection	Same methodology as for the recent retrospective: all the ARV patients, work on patients who came in April 2006. Before July 2006, there was no clinical information in the patient's file. So, we got additional information from the *fiche individuelle* of each selected patient.
Other comments on systems of record keeping	Existing register of patients on ARV + CD4 count, no patient clinical register, no pharmacy register but a very good patient file with all the information that we need since July 2006.

Facility 14

How patients per week found	There is an attendance register with patients who came during the month to get their monthly supply of ARVs (157), a register with new HIV patients (21), and a register for prophylaxis (23). Total number of patients received in November = 201. The number of patients per week is 201/4 = 50.
Recent Retrospective	
How were patients selected? Explain system of selection	The ARV clinic has an attendance register where patients are recorded according to the day of the visit. Although we have names of patients, there is no way to have the patient's file since the ID number is not recorded. The total number of patients who came in July 2006 is 140, and it is close to the total number of patients on ARV in that clinic (221). So, we decided to take them all.
Other comments on: Clinical records Reliability Deficiencies	We used many sources to fill in the questionnaire: patient file, pharmacy file. Patients usually receive an ARV supply for 30 days, but the date of the next appointment is rarely recorded. However, we were told by the staff that the appointment corresponds to the Monday or Tuesday before the end of the ARV supply. Also, when a patient notices that his ARVs are almost finished, he may come to the clinic for a new supply. So, there is no pill count for the remaining pills and the same quantity is always provided.
Long Retrospective	
	Same as for the recent retrospective
Other comments on systems of record keeping	There is no system of tracking defaulters because the files are not kept according to the next appointment. They just record those who came.

Facility 15

How patients per week found	We used the computerized system in place in the hospital. We have the total number of all ARV patients, new and old cases, and people living with HIV receiving prophylaxis for OIs in November (1,041/4 = 260 patients per week).
Recent Retrospective	
How were patients selected? Explain system of selection	The ARV clinic has no patient attendance register, but it has a pharmacy register with dates, patient ID, and the number of pills dispensed on the date. We counted 29 pages in July. We took four or five patients on each page (120/29 = 4.1). After this selection, we noticed that the patient files were empty and not useful. We then decided to use the "Fiche de Rapport des visites à la pharmacie." This document has been used since June 2006 but not always completed properly.
Other comments on: Clinical records Reliability Deficiencies	On the "Rapport des visites à la pharmacie," there is no information on the OIs and the CD4 count. We got the information on the CD4 count from the computerized service (sheet with patient ID in ascending order, date, and CD4 count for the last six months).
Long Retrospective	
How were patients selected? Explain system of selection	Same methodology as for the recent retrospective. However, because the use of the "Rapport des visites à la pharmacie" started in June, our index date was July 2006.
Other comments on: Pharmacy records Reliability Deficiencies	Information on CD4 count was provided by the data manager (computerized system) as for the recent retrospective.
Other comments on systems of record keeping	There is a good computerized system with all the information on patients on ARV: patient ID, starting date, drug regimen, CD4 counts.

Facility 16

How patients per week found	No visit register. Have weekly report of number for consultation and number for pharmacy. So added two for four weeks and divided by 4. This was 285 plus 300, averaging 146.
Recent Retrospective	
How were patients selected? Explain system of selection	25 pages of attendance register and chose patient numbers. This gave us name identifier, but the clinical dossiers were not classified in any order. The pharmacy files were ordered in piles 0–100; 101–200 but patients beyond this not classified. This meant we had to search all.
Long Retrospective	
	As above

Facility 17

How patients per week found	Classification based on group. A group is a number of patients (10–20) who started ARVs at the same time. Each group had one *accompagnateur* per four patients. This was in monthly reports, divided by 4.
Recent Retrospective	
How were patients selected? Explain system of selection	No register, but list of care supporters who came each month. The care supporter is the one who receives medicines for their four or five patients. They had a computer record linking the care supporter and their patients, so from that a list of all patients in July on ARVs could be found. Printed list for April and July. Gave patient name and group identifier. Group identifier gave patient clinical records. From this we could find patient dossier but no data in clinical records. However could not follow care supporter over time. The care supporters carried their own records, which are not recorded anywhere else and may be lost.
Long Retrospective	
	List of all patients in April on ARVs

Facility 18

How patients per week found	Pharmacy attendance register over four weeks.
Recent Retrospective	
How were patients selected?	Pharmacy attendance register to select patient identifiers. Pharmacy records and clinical records in same dossier ordered in sequence.
Long Retrospective	
	As above
Other comments on systems of record keeping	System as we imagined they all would be.

Facility 19

How patients per week found	In monthly report of attendance.
Recent Retrospective	
How were patients selected?	Did this after long retrospective. As below using extra files from those starting in May, June, and July, and choosing from those and remaining files from long selection.
Long Retrospective	
How were patients selected? Explain system of selection	Did this before recent retrospective. No register, but there is a register of new patients placed on ARVs. So took all patient records of patients started before May 1, 2006. Approximated total number (about 300), chose 120 files assuming monthly visit. From 120 checked index visit.

Facility 20

How patients per week found	Monthly summary report, 1,200 came.
Recent Retrospective	
How were patients selected? Explain system of selection	They had Access database of patient attendance in April and July on computer. Difficult because (a) could not print and (b) team leader had other priorities and left early. From the facility gathered patient and pharmacy records, which were together.
Long Retrospective	
	As above

APPENDIX 2. FACILITY INTERVIEW FORM

Final DATA COLLECTION FORM 1A: FACILITY
Facility Questionnaire **# Facility**

Name Facility_____ Programme/System of Care _____

Name of data collector _____ Date _____

Greeting and request for interview

	# Hrs		# Hrs
Mon		Friday:	
Tues		Saturday	
Wed		Sunday	
Thurs			
	Total hours =		

Q1. Which Days of the week and what time is the clinic open? for seeing patients with HIV/AIDS on ARVs

Q2. Is it the same services every day? If not which ones are different?

Q3. Was it the same hours three months ago? Y / N. If n

Q4. Was it the same hours1 year ago? Y / N. If

(Indicator 16: Extent of clinic hours: Number of hours clinic is open per week for routine HIV/AIDS care including ARVs)
(Indicator 17. Convenience of clinic hours: Whether clinic is open at least one evening or weekend day for routine HIV/AIDS care)
(evening means at least a two hour session after five pm) Y ? N

Q5. I am interested to know how many HIV/AIDS patients you see in a week. Can I see the attendance register please?
a) Check register for number in last 4 weeks (28 days) per 2 weeks
b) Divide by 4 to get average number per week =

Note: *If numbering a problem count for last complete week only*
This is all HIV/AIDS patients (not just those on ART)
This is the clinician load, so we need clinic appointment book or record.
This is not the pharmacy record.

Q6. How many Doctors and/or Clinical Officers seeing HIV/AIDS patients do you have during a normal clinic ?
(Check while in the clinic) *(include 'clinical' nurse if doing triage system)*
Divide Q5 by (Q1* Q6) to get average number of HIV/AIDS patients seen per clinician hour =

(Indicator 18. Clinician patient load: Average number of HIV/AIDS patients seen per clinician hour =

Q7. How many of the following staff working directly with HIV/AIDS patients do you have during a normal clinic?
(count one staff only once

social workers		nurses		counsellors	
pharmacists		pharmaceutical technologist		Nutritionist	
Other (specify)		**Total**		**(Check while in the clinic)**	

If community workers or volunteers attached describe here_____
(Indicator 19. Presence of support staff: Average number HIV/AIDS patients
per week per support staff, = Q5/Q7 =

Q8. Do you have access to a laboratory for measuring CD4 counts on the premises or within your progam?
If so is it functioning??
Q9. Do you have access to a laboratory for measuringviral loads on the premises or within your progam?
If so is it functioning??
Q10. Do you have access to a laboratory for measuring CD4 counts within a five minute walk?
If so is it functioning??
Q11. Do you have access to a laboratory for measuring viral loads within a 5 minute walk?
If so is it functioning??
How much do patients have to pay for these tests? _____

(Indicator 20. Presence of laboratory: Whether facility or program has access to a laboratory that is actively measuring CD4 counts or viral loads within program or within 5 minutes walk from the facility, = if Yes to Q8, 9, 10 or 11. = Y)
= Y / N

Q12. Is there private space for Adherence Counseling
(Check while walking around the clinic)
(private space means a discreet area where a conversation with a patient cannot be overheard)
(Indicator 21. Presence of private space for counseling: Whether facility has a private space available for adherence counseling = Y / N from Q 12)

PAGE 1

Final ***DATA COLLECTION FORM 1B: FACILITY***

Q13. Could I see your stock area and supply records for ARVs please?

Take the chosen list of essential ARVs and mark if each drug is in stock today and the number of days present in the last 90.
Make sure you see all supplies of drugs

	If treating children Drug	Y/N	Fixed dose combination Y/N	# days in stock in last 90
1	Lamivudine 150mg tab			
2	Lamivudine syrup 10mg/ml			
3	Stavudine 40 mg			
4	Stavudine 30 mg			
5	Nevirapine 200mg			
6	Nevirapine syrup 10mg/ml			
7	Efavirenz 200mg			
8	Efavirenz 600mg			
9	Efavirenz syrup 30mg/ml			
10	Zidovudine 300mg tab			
11	Zidovudine 100mg tab			
12	Zidovudine syrup 10mg/ml			
	Total			
	Percentage or average			

Q14. Could I see your stock area and supply records for general medicine supply please?

Take the chosen list of key medicines and mark if each drug is in stock today and the number of days present in the last 90.
Make sure you see all supplies of drugs

	Drug	Y/N	# days in stock in last 90
1	Cotrimoxazole tabs 480 or 960mg		
2	Cotrimoxazole susp 240mg/5ml		
3	Fluconazole tabs 150 or 200mg		
4	Ketoconazole tabs 200 mg		
5	Erythromycin tabs 250 or 500mg		
6	Nystatin oral drops 10,000 IU/ml		
7	Multivitamin tabs		
	Total		
	Percentage or average		

APPENDIX 3. EXIT INTERVIEW GUIDE

2. Patient Exit Interview QUESTION SHEET - 1

Standard Greeting, Introduction and request for an Interview

If the patient is a child with a carer: Ask Pre Questions:

1: Is the child responsible for giving themselves the medicine? Y / N
If No ask the carer:
A) Are you the one who usually gives this child his/her medicine? Y / N
B) Who brought the child to the clinic originally and was told how to take medicine? Was it you or another person? Y / N

If the answer to either question A or B is negative, then do not continue the interview and exclude the child from the survey.

For DATA COLLECTION FORM 2 (1): EXIT INTERVIEWS

Clm. C	***Please could I ask you your age?***
Clm. D	Note Gender: Male / Female
Clm. E	***What is your occupation?***
Clm. F	***Are you able to actively continue with your normal activities now with your illness?***
Clm. G	Ask when they started ART and write how many ***months*** on ARV treatment?
Clm. I	Ask how long it took to come to the clinic today from their house or place of work **Calculate total time to travel in minutes**.
Clm. J	Ask what time did they arrive here at the clinic this morning? **Calculate total time in clinic during this visit in minutes.** (If patient doesn't know the time try and relate it to something else such as the beginning of clinic, and calculate the time).
Clm. K-N	TAKE YOUR LIST OF COMMON ADVERSE DRUG REACTIONS and ask in turn whether the patient has suffered any of these symptoms in the last week ASK TO SEE all the ARVS and non ARVS dispensed and the prescription for all drugs prescribed and fill in
Clm. P	Were all ARVS dispensed: Y or N
Clm. Q	Were all Non ARVS dispensed: Y or N

2. Patient Exit Interview QUESTION SHEET – 2

Clm. R: **Look to see if each medicine was dispensed in a separate container or envelope? Does each container or envelope contain: Drug Name, dose per time, number times per day?**

If yes fill Y, otherwise N

For DATA COLLECTION FORM 2 (2): EXIT INTERVIEWS

Say: ***"Some patients find it difficult to take all the medicines every day in exactly the way they are supposed to".***

Clms S-AD Fill in turn: Take each ARV in turn and ask:

How many times a day do you take this medicine?
In the last three days have you missed any?
In the last three days how many times have you missed?

Say: ***"Good luck and Thank you"***

Adverse Drug Events:

ADR	Symptom to ask about
1 Peripheral neuropathy	Pain, numbness, tingling in legs or feet
2. Rash	Rash
3. Lipodystrophy	Change of fat distribution such as enlarged breasts, Buffalo hump, loss of fat tissue in face, buttocks, legs
4. Hepatotoxicity	Jaundice, yellow eyes
5. GIT toxicity	Nausea, vomiting, diarrhea

Opportunistic Infections

	Condition	ACRONYM
1	Tuberculosis	TB
2	Oral or oesophageal candidiasis	OC
3	Cryptococcus meningitis (Indian ink positive)	CM
4	Pneumocystis cariniae pneumonia	PCP
5	Fungal skin infections	FSI
6	Bacterial skin infections	BSI