

# PEPFAR Public Health Evaluation – Care and Support –



PHASE I UGANDA

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# Abbreviations

<b>AFB</b>	acid-fast bacillus
<b>APCA</b>	African Palliative Care Association
<b>ART</b>	anti-retroviral therapy
<b>ARV</b>	anti-retroviral
<b>BCP</b>	basic care package
<b>CDC</b>	Centers for Disease Control and Prevention
<b>CHW</b>	community health worker
<b>CSRI</b>	client services receipt inventory
<b>CTX</b>	cotrimoxazole, Septrin
<b>FGD</b>	focus group discussion
<b>FT</b>	full time
<b>HBC</b>	home-based care
<b>HCW</b>	healthcare worker
<b>IGA</b>	income-generating activity
<b>IQR</b>	inter-quartile range
<b>ITN</b>	insecticide treated bednet
<b>KCL</b>	King's College London
<b>LFT</b>	liver function test
<b>MOH</b>	Ministry of Health
<b>NGO</b>	non-governmental organisation
<b>OI</b>	opportunistic infection
<b>OVC</b>	orphans and vulnerable children
<b>PCP</b>	preventive care package
<b>PEPFAR</b>	President's Emergency Plan for AIDS Relief
<b>PHE</b>	Public Health Evaluation
<b>PLWHA</b>	People living with HIV/AIDs
<b>PMTCT</b>	prevention of mother-to-child transmission
<b>PT</b>	part-time
<b>PWP</b>	prevention with positives
<b>SD</b>	standard deviation
<b>SEM</b>	standard error of the mean
<b>TB</b>	tuberculosis
<b>UNAIDS</b>	Joint United Nations Programme on HIV/AIDS
<b>UNC</b>	University of North Carolina
<b>USAID</b>	United States Agency for International Development

<b>USG</b>	United States government
<b>VCT</b>	voluntary counselling and testing
<b>Vol</b>	volunteer
<b>WHO</b>	World Health Organization

# Executive summary

## Rationale

A Public Health Evaluation (PHE) was commissioned to examine HIV care and support funded by the President's Emergency Plan for AIDS Relief (PEPFAR). Phase 1 of this PHE aimed to describe the nature and scope of care and support provision according to the five PEPFAR care and support areas (HIV/AIDS Palliative Care Guidance#1 2006), including the types of facilities, clients seen, and availability of specific components of care.

## Methods

A cross-sectional survey of facility configuration and activity was conducted by collecting quantitative and qualitative descriptive data directly from facilities. Of around 600 PEPFAR-funded HIV care and support facilities in Uganda, 60 (about 10%) were surveyed. At each facility, the following data collection tools were applied: 1) senior staff structured interview, 2) document collection and analysis, 3) pharmacy review, 4) patient focus group discussion (FGD).

## Main findings

### *Facility characteristics*

Nine facilities were hospitals, 27 were health centres, 13 were health posts and 10 provided mainly home-based care (HBC). One facility did not provide health care and was separated from the survey sample for the following analysis. The number of patients seen in the previous three months ranged from 1 to over 16,000 and 65.1% of adult patients were women. On the day of the survey 58% of facilities had electricity and 85% had a safe water supply.

### *Staff characteristics*

Nurses were the most prevalent staff type, working at 86% of facilities. At 75% of facilities there was at least one social worker or Community Health worker (CHW). Many staff were volunteers, particularly CHWs. On average there was one nurse per 69 patients, and for all other staff categories, patient load was considerably higher. Psychological, spiritual and social care were often provided at facilities which had no specialist staff in these areas.

### *Components of care offered*

On average, facilities provided 36 of 69 surveyed components of care onsite and referred out for a further 11. Most services were provided to patients free of charge. Adherence counselling, nutritional advice, family planning counselling, pre- and post-HIV test counselling, treatment for diarrhoea, and treatment for skin rash were the care components most commonly provided or referred. Outward referrals mainly took place for specialist clinical services such as tuberculosis (TB) treatment and cancer management.

Psychological, clinical and prevention care were provided directly or by referral by all 59 facilities in the main analysis, but spiritual care by 58% and social care by only 41%. These are the five areas of PEPFAR care and support.

Forty-six percent of facilities provided antiretrovirals (ARVs) directly, and 32% referred patients outward for ARVs. Toxicity monitoring and treatment failure assessment were available onsite for 89% of the ARV providers.

Management of pain is a cornerstone of HIV palliative care and frequently undervalued. All facilities, with the exception of some HBC facilities, provided or referred for non-opioid analgesics. Opioids were commonly reported to be offered but very rarely found in pharmacies

Pre- and post-test counselling was one of the most widely provided components of care, lacking at only three facilities. It was the most commonly available type of counselling and support included in the survey. Conversely, psychiatric therapy was one of the rarest components, suggesting that although basic psychological care is available, more complex care is difficult to access.

FGD participants revealed that nutritional care and social care were considered to be closely aligned. The ultimate condition of poverty was lack of food, and food shortage, money worries and problems accessing transport were three aspects of the same problem. Nutritional counselling was one of the most widely available care components, but therapeutic feeding for malnutrition was offered or referred at only 44% of facilities. Social care was the least developed area of care, with many components never offered at hospitals or health posts.

The Basic Care Package (BCP, consisting of cotrimoxazole (CTX), insecticide-treated net, water treatment, condoms and family counselling and testing advice), the Ugandan version of the PEP-FAR preventive care package, was provided in full onsite by 24% of facilities. Condoms were the most readily available single item (92%).

Treatment for opportunistic infections (OIs), malaria and TB was more widely available than preventive care. Malaria treatment was widespread, TB treatment not quite as common (85%), and both were more frequently available than were the respective tests used to diagnose them, suggesting that treatment is taking place based on deduction from symptoms and history.

Adherence counselling was provided or referred at all 59 facilities, family planning counselling at 57 and condoms were provided at 54 (see Table 17 above). All five components were provided or referred by 80% of referral hospitals, all district hospitals, 63% of health centre, 38% of health posts and 20% of HBC facilities.

The availability of care to prevent further transmission of HIV was evaluated by examining the availability of five components of care that comprise the 'Prevention with positives' (PWP) package of care (i.e. adherence counselling, family planning counselling, treatment of herpes, patient HIV support groups, and condoms). All facilities offered or referred for at least three of these components and 54% offered or referred for all five.

### *Pharmacy review*

Adult CTX was the most widely available drug, stocked in 68% of facilities. Non-opioid analgesics were stocked at 66% and morphine (in date) at 12%. Stockouts were common, with 25% of all reported drug formulations having a reported stockout in the past six months. Eleven facilities re-

ported providing non-opioid analgesics but had none in stock. Similar discrepancies were recorded for codeine (5 facilities), morphine (6) and CTX (8).

### *Document analysis*

First clinical assessment sheets were used at 66% of facilities and patient records were kept at 92%. Forty-seven percent had care protocols. The content of patient assessment sheets focused mainly on medical needs of patients.

### *Staff views*

Senior staff described the key issues for their facility in terms of regular funding, staff training and investment, and care. They reported a need for a separate place for children's care, development of paediatric counselling, provision of ARVs, drugs to treat infections, school fees for orphans and vulnerable children (OVCs) and provision of food.

## **Patient focus group discussions (FGDs)**

Focus group discussions with patients at 47 facilities revealed that they particularly valued psychological, clinical and social care. The improvements patients wanted were longer opening hours, more training for staff (especially in counselling), a more reliable drug supply, school fees for OVCs, refunds for transport to the facility, and food. To increase uptake of care they suggested outreach activities with drama involving people living HIV/AIDS (PLWHAs), and provision of visible items of clear benefit such as insecticide-treated bednets (ITNs) and food. Sixty per cent of FGD participants had received condoms and 83% received CTX prophylaxis. Reasons given for not receiving these items or other elements of the BCP were that the facility did not have sufficient supplies and that other patients received priority, fear of stigma, unawareness of their existence, allergy to CTX, and stockout.

## **Recommendations**

### *Infrastructure*

- Multidimensional HIV care and support requires more space than other care approaches. Facility staff prioritised a need for private space for counselling sessions and child care.
- More resources should be directed on maintaining/repairing equipment and vehicles in order to avoid costly replacement.

### *Staffing*

- Staff reported delivering care for which they had not been trained, and patients reported dissatisfaction about attending services provided by inadequately trained staff. Increasing specialist training and employing specialist staff to deliver non-clinical aspects of care and support, such as psychological and spiritual care, could widen the availability of specialist care to patients and improve care quality.
- Staff retention was poor because of limited opportunities for development and low pay. High staff turnover is a challenge to quality of care; investment in staff training would result in better care standards.
- Volunteers are more likely to remain at facilities if their contribution is felt to be valuable; reimbursing volunteer travel costs is an important strategy when feasible.

*Care provision*

- Patients prefer HBC care not facilities, which is the most sustainable option. Facilities should develop their HBC support services.
- Social care was found to be the least developed aspect of care and support among survey facilities. More widespread implementation of income-generating activities and home help will improve patient access to clinical care.
- Treatment of TB, malaria and other OIs is more readily available than prevention care, even though prevention is more cost-effective and saves more lives. The BCP consists of prevention interventions and further rollout would be beneficial.

*Drug supplies*

- Reliable drug availability is a significant issue hampering care delivery. Supply chains need to be strengthened by improving communication and responsiveness.
- Staff training in pain management and opioid provision is necessary.

*Documents*

- Insufficient record-keeping limits the potential for a facility to provide integrated care, monitor stock, manage referrals, plan and budget. Large facilities should employ specialist administrative staff to manage data, and train existing staff in record keeping.

# Introduction

In 2003 the United States government (USG) funded a five-year, \$15 billion initiative to combat the global HIV/AIDS epidemic: the President's Emergency Plan for AIDS Relief (PEPFAR). The money was allocated approximately as follows: treatment (55%), prevention (20%), assisting orphans and vulnerable children (10%) and care and support of individuals with HIV/AIDS (15%). PEPFAR has commissioned PHEs in these areas to evaluate programmes.

The evaluation of PEPFAR-funded care and support for HIV was led by King's College London (KCL, Principal Investigator) in collaboration with MEASURE Evaluation at the University of North Carolina (UNC) and the African Palliative Care Association (APCA). The aims, methods and implementation of the evaluation were planned and agreed in consultation with the members of USG Care and Support Technical Working Group, USG staff in country, and representatives of the Ministries of Health in Kenya and Uganda.

## Evaluation Aims and Objectives

The aims of this 2-phase care and support public health evaluation were:

- To describe the nature and scope of HIV care and support provision supported by PEPFAR in two African countries, including the types of facilities available, clients seen, and availability of specific components of care [Phase 1].
- To evaluate how programme components and costs are related to health outcomes [Phase 2].

By meeting these aims, this study will provide detailed description of the care and support services that have been delivered through PEPFAR funding and identify the effective components and costs of the services, to improve the health of patients with HIV. Dissemination of the findings is planned, in conjunction with country teams, to inform effective care and support provision within the two PHE target countries and beyond, where lessons can be transferred to other PEPFAR countries.

In order to address these aims the objectives were:

- To undertake a cross-sectional survey of service configuration and activity by visiting 10% of the facilities being funded by PEPFAR to provide HIV care and support in Kenya and Uganda (aim 1).
- To collect longitudinal prospective quantitative outcome data on 1200 patients at 12 facilities in Kenya and Uganda, measuring both quality of life and core palliative outcomes alongside components of care received (aim 2).
- To conduct qualitative interviews with patients and staff to explore service issues in more depth (aim 2).
- To undertake a cost comparison of care provided including staff costs, overheads and lab costs (aim 2).

As part of the evaluation, results will be disseminated to report lessons learnt and best practices, and to provide recommendations to PEPFAR.

## **Study Overview**

The evaluation design was an observational study in Kenya and Uganda using mixed methods. The design comprised two sequential periods of data collection using mixed methodologies.

- Phase 1 (2007) was a cross-sectional survey of facility configuration and activity using quantitative and qualitative descriptive data.
- Phase 2 (2008) is a longitudinal evaluation of existing care, focusing on patient outcomes of PEPFAR care and support using validated outcome tools. Supplementary interviews with staff, patients and carers aim to provide in-depth understanding of key issues. An additional cost analysis component in this phase will compare patient/family outcomes with their associated costs.

This report focuses on Phase 1 of the evaluation in Uganda. The evaluation was undertaken in Uganda with the support of APCA. A separate report has been written for Phase 1 in Kenya. Phase 2 data collection commenced in January 2008 and is due to be completed by September 2008.

# Methods

## Study design

Phase 1 of the care and support PHE was a cross-sectional survey of facility configuration and activity conducted by collecting quantitative and qualitative descriptive data directly from facilities. The inclusion criterion for facilities to be eligible for selection in Phase 1 was that they received PEPFAR funding to provide HIV care and support during 2006. The exclusion criteria were facilities that were paediatric-only or inaccessible (e.g. insecure, no road access).

## Sampling

Of around 600 PEPFAR-funded HIV care facilities in Uganda, 60 were selected for inclusion in the study (approximately 10% of PEPFAR-funded facilities). Facilities which did not meet the criteria above were replaced using the same random process. These facilities and their reason for replacement are listed in Table 1.

According to routine monitoring patient numbers, the PEPFAR-funded care and support facilities included many smaller facilities. In order to capture a range of facility sizes within the study population, facilities were stratified by number of patients seen for HIV care in the 2006 financial year (according to national PEPFAR records) and divided into three strata (1 to 100, 101 to 500 and >500 patients seen in 2006), resulting in unequal and calculable sampling fractions. Twenty facilities were randomly sampled within each of the strata for the study population.

## Procedure

### *Tool development*

All tools were developed by a multidisciplinary team, including medical professionals, HIV specialists and researchers, in conjunction with USG Care and Support Technical Working Group and the country teams. All tools were piloted in one large and one small Phase 1 facility in Uganda. These facilities were two of the 60 selected, and data from the pilot were used in the final analyses in this report. Following piloting, the wording and structure of the tools were modified and clarified. The tools are presented in Appendices A-D, described below.

Four data collection tools were used:

- Senior staff interview — The researchers interviewed a group of senior staff, including facility managers and senior clinical staff, at each health facility to collect responses to closed and open-ended questions about patient numbers, infrastructure and staffing. This tool also included a version of the Client Services Receipt Inventory (CSRI) (Beecham and Knapp 2001) adapted for the aims of this study and the HIV setting in Africa to collect information about services offered to patients with HIV. The CSRI asked if the facilities offered various specific components of care under the four areas of care: clinical, psychological, spiritual, social and preventive. The tool (Appendix A) was designed for use across the wide range of size and type of HIV care facilities funded by PEPFAR.
- Document collection — In order to study the level of patient-level clinical information management at each facility, the existence, format and language of various clinical documents

relating to care in the facility were recorded (Appendix B). Blank example documents were taken, where available, for content analysis.

- Pharmacy review — Researchers recorded the level and place of drug stock for in-date and expired drugs separately, and if there had been previous stockouts (in-date drugs only) for various formulations of drugs commonly used in HIV care (Appendix C).
- Patient focus group discussions — Researchers led patient discussion groups using the interview schedule (reproduced in Appendix D). The FGDs had two main aims: to act as a validation of the senior staff interview data relating to components of care offered, and to explore aspects relating to patients' care (e.g. which components of care were valued and why, any problems in obtaining medicines).

### *Ethical approval*

Ethical approval to undertake the study in Uganda was received from the Uganda National Council for Science and Technology and the College Research Ethics Committee at KCL. Subsequent tool changes following piloting were also approved. All data were anonymised from patient information and raw data stored separately from consent forms, in a locked filing cabinet in line with ethical guidance and the Data Protection Act. Only anonymised data left the APCA office.

### *Data collection*

Facilities were informed of the planned survey through the Ministry of Health (MOH) in Uganda and were asked to participate. Ugandan researchers attended each sampled site to collect data on a pre-arranged day, between April and August 2007. Data were recorded on two separate sets of identical forms. One set was left with the facility while the other was taken by the researchers for data entry.

Researchers held interviews with senior facility staff (approximately three per facility) to collect staff-reported information on facility structure, service delivery, care offered and asked their views about the services they offer. These staff members were also asked to provide blank service documents (including service aim, referral forms, assessment sheets and patient information sheets), where available, for content analysis.

FGDs were held with existing patients at each facility (inclusion criteria were adult patients who had been under care for at least 6 weeks) who were known (by both the patient themselves and clinical staff) to be HIV positive and gave informed consent to participate (following provision of an information sheet and consent form). Patients were purposively selected by staff with the aim of obtaining a diverse group with respect to gender, age, disease stage and anti-retroviral (ARV) use.

Approximately five patients in each facility were invited to participate in the discussion group, led by the researcher. Researchers made notes on the responses to pre-specified questions on the interview schedule, and the FGD was digitally recorded as a back-up. During each FGD, demographic information was collected on participants' gender, location (urban, rural or peri-urban), age and household size. Participants also stated how many of them in the group had received specific key components of care including daily CTX, a mosquito bednet and nutritional counselling. To complete the pharmacy review, researchers visited the pharmacy to review stocks and stock cards, with the assistance of the pharmacist (or dispenser or other staff who worked in the pharmacy).

### *Data management and entry*

Data were transferred from sampled facilities to the APCA offices immediately after collection. Quantitative data (i.e. closed questions from the senior staff interview and the pharmacy review) were double-entered by two different researchers, and validated, using EpiData v3.1. Errors in data entry and data recording were identified using consistency and logic checks, and followed-up by manual checking of questionnaires. Responses to open-ended questions and FGDs were entered into pre-formatted templates in MS Word 2003. Information from the record of documents available at the facility, and their content, were entered into tables in MS Word 2003 files.

### *Analysis*

- Senior staff interview — Analysis was conducted using Stata v10 (quantitative) and NVivo v7 (open-ended questions). Frequency tables were generated for key responses, grouped by facility type where appropriate. A Spearman's rank test for correlation was conducted to test the reliability of routine data. Patient numbers were weighted to account for the stratified design used to select facilities. Thematic analysis of content was conducted on the responses to the open-ended questions. The principal themes were organised into data categories and then agreed between two researchers.
- Document analysis — To determine the availability of the various types of service documents, a matrix was developed to record the overall number of facilities who reported having such documents, and the number and percentage of facilities that reported having such documents and provided examples. Where the percentage of facilities who provided examples of documents as a proportion of those who reported such documents existed was less than 20%, or where the absolute number of documents was five or fewer, no further analysis was undertaken. Researchers conducted telephone conversations with site representatives in these cases to determine the reason for non-provision. In those instances where the percentage of facilities who provided examples of documents as a proportion of those who reported such documents existed was equal to or greater than 20%, content analysis was undertaken to determine thematic frequency. Data were extracted to common tables, and frequencies described for the number of facilities reporting each type of recording sheet, whether a sample was obtained, the specific nature of the information in the document fields are reported, and subsequently described according to facility type.
- Pharmacy review — Analysis was conducted using Stata v10. Frequency tables were generated for each drug, grouped by facility type where appropriate. Data from the pharmacy review was compared with components of care offered, according to the senior staff interview data.
- Focus group discussions — Information on FGD participants' background and receipt of care items was entered into a predesigned table by the researchers, transferred into an Excel spreadsheet and then merged with the Stata database using a unique identifying variable. The care received by FGD participants was integrated with the facility staff reports of care offered. Analysis of the FGDs was also conducted using NVivo v7. In the same way as for the open-ended questions in the senior staff interviews, thematic analysis of content was conducted on the notes from the FGDs. The principal themes were independently organised into data categories and then agreed between two researchers.

# Results

## Response rate

Of the 60 facilities selected at random, one was found not to meet the selection criteria, and four were in regions where violence broke out, making the area unsafe for travel. A further three facilities could not be found. All of these were replaced with another randomly selected facility from the same stratum as shown in Table 1.

Table 1: Original selected sites that could not be found and their replacements

Original site		Replacement site		Reason for replacement
Name	ID	Name	ID	
Kitintale Diocese Kampala	217	Kadama Pallisa	265	Site non-existent
Kakuka H/C III Bundibugyo	224	Kyenjojo Initiative for Rural Development	278	Insecure region
Rwebisego H/C III Bundibugyo	225	RWIDE Kyenjojo	277	Insecure region
Nakapiripirit	228	Lwamaggwa Rakai	279	Insecure region
Acord Napiripirit	208	Arapai Odudui Soroti	266	Insecure region
Ngora boys PS Soroti	216	Makhai Mbale	263	Exclusively paediatric
Malera Soroti	215	Ngora Dispensary	261	Repetition of facility
Akuja Soroti	201	Rimuli- Bushenyi	269	Site could not be found

All of the facilities approached agreed to take part in the study. The sites that were visited are listed in Appendix E and their geographical distribution is shown in Figure 1. Each facility visit took approximately one day, with many requiring a return visit to complete data collection.

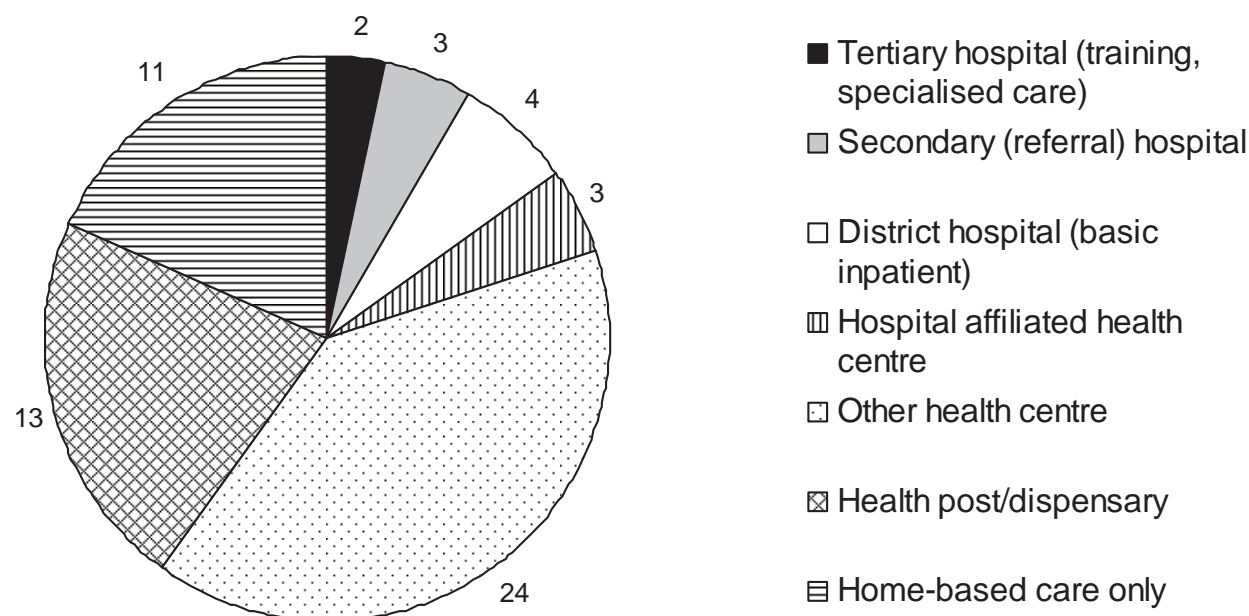
Figure 1: Distribution of facilities visited in Uganda



## Facility types

Facility staff were asked to indicate which type of facility their service was from a list of eight categories. Figure 2 shows that the largest fraction of facilities included in the survey self-reported as 'other health centres'; that is, health centres not affiliated to a hospital.

Figure 2: Types of facilities surveyed



Subsequent analysis is presented by the following facility types: referral hospital (tertiary hospitals and secondary hospitals,  $n=5$ , 8%), district hospital ( $n=4$ , 7%), health centre (hospital affiliated and other health centres,  $n=27$ , 45%), health post (health posts/dispensaries,  $n=13$ , 22%) and HBC only (home-based care facilities only,  $n=10$ , 18%). Seven of the home-based care category facilities did not employ a doctor, nurse or clinical officer.

One facility described itself as offering home-based care, but the survey revealed that in fact it offered no health care at all, being primarily an organisation to help communities improve water delivery. It provided no direct care, did not conduct a FGD, reported no staff and did not have a pharmacy or documentation. For this reason, it has been excluded from the following analysis and all totals sum to 59. Nonetheless, the facility was selected at random from a list of those receiving funding to provide care and support, and passed all the inclusion criteria for the survey. A minimum level of care was not specified for the evaluation. The facility is separated from the other 59 in order to make data more easily interpretable but it remains part of the study.

## Weighted analysis

The largest facilities were selected from a group of 90, so compared to the smallest facilities they had  $315/90 = 3.5$  times the probability of being selected, as shown in Table 2. To reverse this bias, numbers from the smallest facilities were multiplied by 3.5 to restore national representativeness to the sample.

Table 2: Strata for facility selection

Facility size	Definition*	Number of facilities funded by PEPFAR in Uganda	Number of facilities selected	Probability of selection	Weight
Smallest (S)	<100*	315	20	0.06	3.5
Middle (M)	100-500*	136	20	0.15	1.5
Largest (L)	>500*	90	20	0.22	1

\* Number of patients registered at facility in 2006, according to PEPFAR data

Table 3: Weighted analysis – facility type

Facility type	Number of facilities							
	Crude				Weighted			
	S	M	L	Total (%)	S	M	L	Total (%)
Referral hospital	0	1	4	5 (8)	0	1.5	4	9.5 (8)
District hospital	0	0	4	4 (7)	0	0	4	4 (3)
Health centre	8	10	9	27 (45)	28	15	9	52 (43)
Health post	8	3	2	13 (22)	28	4.5	2	34.5 (29)
HBC	4	6	1	11 (18)	14	9	1	24 (20)
Total	20	20	20	60 (100)	70	30	20	120 (100)

After weighting, hospitals made up a smaller proportion of facilities and health posts a greater proportion (Table 3).

## Patients

Patient numbers are based on self-reported data from the facilities. Usually the information was taken from facility records. Researchers specified that the variable of interest was the number of individual patients, not the number of patient visits within a time period.

### *Patient numbers – total*

Table 4 shows that in the selected facilities the number of patients receiving care in the last quarter, as reported by facility staff, ranged from 0 to over 16000. The figures from PEPFAR had a range of 3-17002 patients seen in a year. There is statistically significant correlation between the routine data and the survey data ( $\rho=0.74$ ,  $p<0.0001$ ), meaning higher patient figures provided by PEPFAR matched with higher figures reported by facilities. However, it can be seen from Table 3 that the difference in patient numbers between the two sources can still be considerable.

For 14 facilities (those where the number of new patients is missing), accurate records of patient numbers were unobtainable, and so the figures in the second column were estimates given by facility staff.

Table 4: Patient numbers

Self-reported survey results 2007			PEPFAR routine data FY06	Self-reported survey results 2007			PEPFAR routine data FY06
ID	New patients receiving HIV care in the last three months	All patients receiving HIV care in the last three months	Individuals provided with care and support	ID	New patients receiving HIV care in the last three months	All patients receiving HIV care in the last three months	Individuals provided with care and support
202	139	234	3	241	138	325	648
203	13	26	5	242	401	1950	895
204	13	26	6	243	565	1038	1218
205	7	135	11	244	296	2619	1222
206	30	199	11	245	56	1847	1335
207	Missing	50	19	246	323	3342	1378
209	0	314	25	247	87	1954	1528
210	308	2108	27	248	217	1262	1634
211	Missing	0*	28	249	105	1383	1692
212	10	147	35	250	187	1418	1990
213	14	50*	35	251	8342	16779	2104
214	0	200	35	252	79	2075	3287
218	Missing	80*	51	253	171	205	4618
219	78	436	63	254	138	367	5049
220	20	347	73	255	401	4772	5364
221	37	144	107	256	Missing	500*	8486
222	44	265	136	257	581	5249	9448
223	39	344	137	258	828	9698	10786
226	Missing	50*	150	259	5774	7062	14662
227	95	294	169	260	683	5602	17002
229	14	602	238	261	48	92	52
230	97	208	254	263	Missing	200*	15
231	Missing	200*	263	265	15	47	14
232	39	290	275	266	Missing	70*	16
233	Missing	80*	278	269	Missing	75	12
234	Missing	50*	290	277	35	430	385
235	Missing	500*	379	278	Missing	0*	250
236	111	127	380	279	23	346	169
237	38	371	396				

\* estimate

*Patient numbers – gender and children*

Facilities were asked the number of patients who had used the HIV services in the last quarter in total, and with breakdowns by men, women and children where available. Most facilities provided patient numbers divided into men, women and children. Children were defined as patients under 18 years, in accordance with PEPFAR practice and the advice of country teams.

**Table 5: Gender distribution of patients**

Facility type (n)	Number (%) of facilities with:			
	0-25% female patients	25-<50% female patients	50-<75% female patients	75-100% female patients
Referral hospital (4)	0	0	4	0
district hospital (4)	0	0	4	0
Health centre (21)	0	0	19	2
Health post (7)	0	1	6	0
HBC (8)	0	0	6	2
Total (44)	0	1	39	4

As shown in Table 5, between half and three-quarters of adult patients at facilities were women. In total across all facilities, 65.1% of adult patients were women, and when weighted by facility type, 64.9% of adult patients were women. By facility, a mean of 67% of adult patients were women, with 95% confidence intervals from 64.4% to 69.0%.

**Table 6: Proportion of paediatric patients**

Facility type (n)	Mean n (standard error of mean (sem)) patients who are children	Mean % (sem) patients who are children
Referral hospital (4)	348.5 (117.7)	13.9 (2.3)
District hospital (4)	423.5 (191.3)	9.0 (2.8)
Health centre (20)	95.7 (51.7)	3.1 (0.8)
Health post (7)	11.3 (6.5)	2.8 (1.7)
HBC (8)	43.9 (24.2)	12.7 (6.3)
Total (43)	123.5 (35.5)	6.3 (1.3)

By facility the mean proportion of patients who were children was 6.3%, with a 95% CI from 3.6% to 8.9% (Table 6). In total, 7.2% of patients in all the facilities were children. When weighted by facility type, 6.0% of patients would be children. The proportion of paediatric patients ranged from 0.8% for health centres to 6.3% for HBC facilities, 1.3% of patients overall. Exclusively paediatric facilities were not included in this survey.

Twelve facilities did not provide care for any children and 16 facilities did not have records of how many children they had seen in the last three months.

## Infrastructure

### General

Table 7 shows that approximately one third of all facilities surveyed offered care exclusively to people who were HIV positive, and over two thirds of HBC facilities offered an HIV-only service. Half of facilities were run by the government and the majority of the remainder were run by a non-governmental organisation (NGO), including all the HBC facilities. Facilities commonly reported to more than one authority. Nearly all facilities reported to the MOH, over half reported to PEPFAR (although all facilities receive PEPFAR funding, reporting may be through indirect channels) and just under half reported to an NGO.

Table 7: Infrastructure present at different facility types

		Number of facilities n (%)					
		Referral hospital	District hospital	Health centre	Health Post	HBC	Total
	Total number of facilities of each type	5 (100)	4 (100)	27 (100)	13 (100)	10 (100)	59 (100)
	HIV-only facility	1 (20)	1 (25)	6 (22)	3 (23)	7 (70)	18 (30)
Authority	Government	5 (100)	2 (50)	13 (48)	11 (85)	0	31 (53)
	Private	0	0	3 (11)	0	0	3 (5)
	NGO	0	2 (50)	11 (41)	2 (15)	10 (100)	25 (42)
Reports to	Ministry of Health	5 (100)	4 (100)	27 (100)	13 (100)	3 (30)	52 (88)
	USG/PEPFAR	3 (60)	2 (50)	20 (74)	2 (15)	8 (80)	35 (59)
	NGO	2 (40)	2 (50)	9 (33)	3 (23)	9 (90)	26 (42)
	Private for-profit organisation	0	0	1 (4)	0	0	1 (2)
Place of care	Inpatient	3 (60)	4 (100)	14 (52)	3 (23)	0	24 (41)
	Outpatient	5 (100)	4 (100)	23 (85)	13 (100)	2 (20)	47 (80)
	Home based care	1 (20)	2 (50)	19 (70)	2 (15)	90 (90)	33 (56)
	Medical consultancy	5 (100)	4 (100)	23 (85)	4 (31)	0	36 (61)
	Daycare	1 (20)	1 (25)	12 (44)	2 (15)	1 (10)	17 (29)
	Support groups			17 (63)	4 (31)	10 (100)	37 (62)
General infrastructure	Staff on site 24 hours a day	1 (20)	1 (25)	17 (63)	7 (54)	1 (10)	27 (46)
	Has functioning ambulance	0	3 (75)	18 (67)	2 (15)	4 (40)	27 (46)**
	Has working electricity	5 (100)	4 (100)	18 (67)	3 (23)	4 (40)	34 (58)**
	Has functioning generator, inverter or solar panel	3 (60)	4 (100)	17 (63)	5 (39)	3 (30)	32 (54)**
	Has safe water supply*	5 (100)	4 (100)	25 (93)	8 (62)	8 (80)	50 (85)
	Has functioning toilet	5 (100)	4 (100)	27 (100)	13 (100)	9 (90)	58 (98)

\*'safe' defined as: piped water, a public tap or standpipe, a borehole, protected well or rainwater collection

\*\*In addition there were 5 facilities with an ambulance that did not function, 4 which reported usually having electricity, and 6 with a non-functional generator.

Outpatient care, home-based care, medical consultancy, and support groups were offered by over half of facilities. Outpatient care was the most commonly offered type of care, at over three-quarters of facilities (including all hospitals and health posts and 85% of health centres). One facility in the HBC group did not report offering home-based care. It was found to be primarily an advocacy and support group organisation, although it does provide care in all five areas of PEPFAR care and support (Table 21). The use of self-reported information throughout the survey occasionally leads to situations where facilities give seemingly contradictory answers. For the remainder of this report, the facility in question is included in the HBC group because the overall evidence places it there.

Twenty-four-hour staff coverage was found at fewer than half of facilities, most commonly at health centres. Of 32 facilities reporting having an ambulance (defined as any vehicle for transporting patients), in five facilities the vehicle was not functioning or had no fuel. Likewise, 38 facilities had a generator, of which 16% were not working (n=6). Nearly all facilities had a safe water supply and all but one had a functioning toilet.

### *Time and frequency of appointments*

The median, and most frequent, number of hours per week that patients could see a member of staff was 40, for both non-clinical and clinical staff (Table 8). In this definition, doctors and nurses are clinical staff, all other staff types are non-clinical. Health centres were the types of facility most commonly open more than 40 hours per week.

**Table 8: Hours per week patients can see a member of staff**

Type of appointment	Number of hours per week	Facility type n (%)					Total
		Referral hospital	District hospital	Health centre	Health post	HBC	
	<i>Total number of facilities of each type</i>	5 (100)	4 (100)	27 (100)	13 (100)	10 (100)	59 (100)
Clinical	0	0	0	1 (4)	0	3 (30)	4 (7)
	1-20	2 (40)	0	12 (44)	1 (8)	3 (30)	18 (31)
	21-40	3 (60)	4 (100)	9 (33)	12 (92)	4 (40)	32 (54)
	41-63	0	0	5 (19)	0	0	5 (8)
	0	0	0	0	0	1 (9)	1 (2)
Non-clinical	1-20	1 (20)	0	9 (33)	0	3 (30)	13 (22)
	21-40	4 (80)	4 (100)	12 (44)	13 (100)	6 (60)	39 (66)
	41-63	0	0	6 (22)	0	1 (10)	7 (12)

Table 9: Frequency of appointments

Type of patient, type of appointment	Frequency	Facility type n (%)					
		Referral hospital	District hospital	Health centre	Health post	HBC	Total
	<i>Total number of facilities of each type</i>	5 (100)	4 (100)	27 (100)	13 (100)	10 (100)	59 (100)
Non-ART, clinical	<12/year	2 (40)	1 (25)	8 (30)	3 (23)	0	14 (24)
	12/year	3 (60)	3 (75)	9 (33)	3 (23)	2 (20)	20 (34)
	>12/year	0	0	0	0	0	0
	Appointments as needed	0	0	10 (37)	7 (54)	8 (80)	25 (42)
Non-ART, non-clinical	<12/year	1 (20)	0	7 (26)	2 (15)	0	10 (17)
	12/year	4 (80)	3 (75)	8 (30)	3 (23)	2 (20)	20 (34)
	>12/year	0	0	1 (4)	0	1 (10)	2 (3)
	Appointments as needed	0	1 (25)	11 (41)	8 (62)	7 (70)	27 (46)
ART, clinical	<12/year	0	0	1 (4)	1 (8)	0	2 (3)
	12/year	5 (100)	3 (75)	12 (44)	3 (23)	1 (10)	24 (41)
	>12/year	0	0	3 (11)	0	0	3 (5)
	Appointments as needed	0	1 (25)	11 (41)	9 (69)	9 (90)	30 (51)
ART, non-clinical	<12/year	0	0	3 (11)	1 (8)	0	4 (7)
	12/year	5 (100)	3 (75)	10 (37)	3 (23)	1 (10)	22 (37)
	>12/year	0	0	3 (11)	0	1 (10)	4 (7)
	Appointments as needed	0	1 (25)	11 (41)	9 (69)	8 (80)	29 (49)

Table 9 shows the frequency of regular clinical and non-clinical appointments for HIV patients taking and not taking anti-retroviral therapy (ART), by facility type. Most commonly facilities offered clinical or non-clinical appointments to HIV patients as needed, although monthly appointments were also common. The range was from once every three months to once every two weeks. Hospitals most commonly offered monthly appointments, whereas the other types of facility most commonly offered appointments as needed.

#### *Payment for care*

The totals in Table 10 equal the number of facilities offering each service. Table 10 shows that two facilities charged patients for all their services apart from ART. All the listed services were nearly always free to all patients, if available. Means-testing was rare. ART was the service least likely to be available (see Table 17 below), but if it was available, was most commonly available free of charge.

Table 10: Payment for services

	Type of service						
	Appointment	x-ray	HIV test	ART	Lab work	CTX	Other medicines
Payment routine	Number of facilities (%)						
All pay	2 (4)	2 (10)	2 (6)	0	2 (6)	2 (4)	2 (4)
Free to all	42 (88)	16 (80)	32 (91)	24 (92)	30 (83)	45 (94)	42 (86)
Means- tested	3 (6)	1 (5)	1 (3)	1 (4)	2 (6)	0	3 (6)
Other (unspecified)	1 (2)	1 (5)	0	1 (4)	2 (6)	1 (2)	2 (4)
total	48 (100)	20 (100)	35 (100)	26 (100)	36 (100)	48 (100)	49 (100)

## Facility staff

### *Staffing levels*

Facilities were asked to report the number of paid (full time and part-time) and volunteer staff they had working in their HIV clinic for a number of different staff designations. Tables 11 and 12 show the number of facilities reporting to have each category of each designation of staff, and the median number of staff of each designation reported, by facility type. Staff were recorded by the profession for which they were employed. A nurse who also dispensed drugs and conducted counselling, for example, would be recorded only as a nurse.

Nurses were the most common staff designation present at facilities (88%), and traditional healers the least common, at 7% (Table 11). Over half of facilities had paid (full time or part-time) doctors, clinical officers, nurses, laboratory staff or counsellors. Volunteer staff were rare for most designations of staff, except for CHWs (volunteers at 61% of facilities), where voluntary staff were the most common category.

The widest range of staff numbers was for volunteer counsellors (facilities reported having between 1 and 40 staff members), and commonly facilities reported having only one staff member for every staff designation and category. This data is not shown. Table 12 shows that volunteer counsellors and CHWs were the most common staff reported (median = 7). Seven facilities had no nurses and were staffed entirely by social workers, spiritual leaders, counsellors and volunteer CHWs.

### *Staff categories*

In order to explore the types of specialist care being offered, staff were grouped by the element of care which they provided, as follows: clinical (doctor, clinical officer/medical assistant, nurse, physiotherapist), spiritual (spiritual leader, traditional healer), psychological (counsellor), social (social worker, CHW) and laboratory (lab staff). All groups included full time, part-time and voluntary staff. In terms of PEPFAR care and support, laboratory staff belong with clinical staff, but they were included as a separate group here on the grounds that their training would be very specific and they would not be able to stand in for other clinical disciplines or be replaced by them.





Table 13: Staff categories by facility type

	Facility type n (%)					
	Hospital	District hospital	Health centre	Health post	HBC	Total
<i>Total number of facilities of each type</i>	5 (100)	4 (100)	27 (100)	13 (100)	10 (100)	59 (100)
Clinical	5 (100)	4 (100)	27 (100)	13 (100)	3 (30)	52 (88)
Psychological	3 (60)	2 (50)	19 (70)	3 (23)	8 (80)	35 (59)
Spiritual	1 (20)	1 (25)	9 (33)	3 (23)	5 (50)	19 (32)
Social	4 (80)	3 (75)	23 (85)	5 (38)	9 (90)	44 (75)
Clinical + spiritual + psychological + social	1 (20)	1 (25)	7 (26)	1 (8)	1 (10)	11 (19)
Laboratory	3 (60)	4 (100)	23 (85)	4 (31)	2 (20)	36 (61)

Table 13 shows that all hospitals, health centres and health posts had clinical staff present. The next most common staff group was social (75% of facilities). The HBC facilities were more varied and had no single staff group uniting all of them, although social staff were the most common type of staff found at this type of facility. Health centres most commonly had specialist care providers from each element of care, clinical, psychological, spiritual and social (26% of health centres).

#### *Reliance on volunteers*

Table 14 below shows that CHWs were the staff designation most likely to be represented only by volunteers, followed by spiritual leaders. One facility relied for its clinical staff solely on volunteers, consisting of one doctor, one clinical officer, one pharmacist and two nurses. No other facilities had volunteers of these designations without having paid staff too.

Table 14: Number of facilities where staff represented solely by volunteers, by staff designation

Staff designation	Number of facilities with solely volunteer staff	Staff employment (from Table 11)		
		FT	PT	Vol
Doctor	1	24	12	2
Clinical officer /medical assistant	1	35	7	2
Nurse	1	50	11	5
Pharmacist	1	23	5	1
Laboratory staff	1	34	7	3
CHW	25	11	5	36
Social worker	2	8	1	4
Spiritual leader	9	4	4	10
Traditional healer	2	2	0	3

Staff designation	Number of facilities with solely volunteer staff	Staff employment (from Table 11)		
		FT	PT	Vol
Nutritionist	0	3	3	1
Counsellor	7	27	8	12
Physiotherapist	0	4	0	0

**Table 15: Percentage of staff who were volunteers by facility type**

Facility type	Mean percentage of staff who are volunteers (SEM)
Referral hospital	13.2 (5.7)
District hospital	39.8 (19.3)
Health centre	30.8 (5.6)
Health post	29.3 (9.7)
HBC	88.1 (3.8)

In order to understand the extent to which facilities rely on volunteers, the proportion of voluntary staff of any designation out of the total number of staff (full time, part-time and voluntary, any designation) were calculated for each facility type. The results in Table 15 show that the reliance on volunteers varied from 13% of staff in referral hospitals to almost nine-tenths in HBC facilities (88%).

### *Patient load*

When facilities employed a staff type, and patient numbers were recorded, the number of patients per staff member in a three-month period were calculated. In Table 16 below, part-time and volunteer staff each count as 0.5 of a full-time staff member. Facilities which do not have patient numbers are excluded.

**Table 16: Patient load**

Staff designation	Facilities with staff type (n)	Median patient load (IQR)
Doctor	29	410.0 (222 – 866)
Nurse	51	69.4 (31 – 294)
Clinical officer	30	508.0 (158 – 1040)
CHWs	39	89.7 (18 – 391)
Pharmacist	23	1009.0 (346 – 1950)
Laboratory staff	30	475.0 (178 – 1057)
Social worker	7	1950.0 (47 – 3342)
Spiritual leader	12	393.0 (147 – 1929)
Traditional healer	3	325.0 (218 – 1204)
Nutritionist	5	3342.0 (1458 – 5485)
Counsellor	33	172.0 (158 – 1040)
Physiotherapist	3	1418.0 (49 – 2075)

Table 16 shows that nutritionists had the highest median patient load. Clinical officers had a higher patient load than doctors. Nurses had the lowest patient load, followed by CHWs. This table does not take into account patient contact time or the recommended length of appointments.

## Components of care offered

### *Individual components of care*

Staff were asked to indicate whether the facility offered a variety of components of care that fall under the umbrella of PEPFAR HIV care and support. With reference to components of care, components are described as being ‘provided’ (meaning reported as offered at the facility), ‘referred’ (meaning a patient is formally or informally referred out for the component according to the facility) or ‘provided or referred’ (meaning the component is provided or referred, as before). These components are listed by the five PEPFAR categories of care in Appendix F.

Formal referrals are defined as referrals where there is a process of information to the facility and subsequent feedback. Informal referral consists of a recommendation or directions without further contact. Formal referrals were most common for specialist clinical services, such as physiotherapy (37%), TB treatment (22%), and cancer management (56%). Cryptococcus was also frequently referred (37%). The median number of referrals a facility would make was 7.

Table 17 shows that the components of care most frequently provided, including onsite care and referrals, were

- adherence counselling (100%),
- nutritional advice (98%),
- family planning counselling (97%),
- pre- and post-test counselling (95%),
- treatment for diarrhoea (93%), and
- treatment for skin rash/itching (93%).

The components most rarely provided, including onsite care and referrals, were

- contact with a traditional healer (12%),
- loans/microfinance (12%),
- memory book work (14%),
- circumcision (20%),
- provision of household items (22%), and
- legal services (24%).

Informal referrals were rare but formal referrals more common. Services for which patients were most commonly referred were

- management of cancer (56%),
- treatment for cryptococcus (37%),
- strong opioids (37%),
- physiotherapy (37%),
- psychiatric therapy (37%), and
- liver function test (34%).

Table 17: Components of care

Type	Component of care	Provided here	Referred formally	Referred informally	Not provided n (%)
General clinical	Nursing care	53	1	0	5 (8)
	Adult diagnostic HIV testing	39	11	0	9 (15)
	ARVs	27	19	0	13 (22)
	Weighing	47	4	0	8 (14)
	Assess ARV treatment failure	25	17	0	17 (29)
	Monitor ARV toxicity	25	17	0	17 (29)
	Wound care	48	6	0	5 (8)
	Physiotherapy	9	21	1	28 (47)
Pain management	Assessment of pain	44	7	0	8 (14)
	Strong opioids	12	22	0	25 (42)
	Weak opioids	21	15	0	23 (39)
	Non-opioids	50	3	0	6 (10)
	Treatment for neuropathic pain	28	19		12 (20)
Symptoms	Anxiety/depression treatment	38	14	1	6 (10)
	Treatment for nausea/vomiting	48	4	1	6 (10)
	Treatment for skin rash/itching	48	6	1	4 (7)
	Treatment for diarrhoea	47	8	0	4 (7)
	Laxatives	36	12	1	10 (17)
	Treatment for thrush	42	12	0	5 (8)
	Treatment for oral candidiasis	44	10	0	5 (8)
	Treatment for cryptococcus	28	22	0	9 (15)
	Treatment for other fungal infections	44	9	0	6 (10)
	Treatment for herpes	38	14	0	7 (12)
	Treatment for malaria	47	7	0	5 (8)
	TB detection	36	13	0	10 (17)
	TB treatment	37	13	0	9 (15)
	Therapeutic feeding for malnutrition	12	14	0	33 (56)
	Treatment for other opportunistic infections				
	Management of cancer	4	33	0	22 (37)
	Psychological	Pre- and post-test counselling	54	2	0
Adherence counselling		56	3	0	0
Family planning counselling		53	4	0	2 (3)
Patient HIV support groups		41	2	0	16 (27)
Family care-givers support group		30	3	0	26 (44)

Type	Component of care	Provided here	Referred formally	Referred informally	Not provided n (%)
Psychological con't	Family counselling	48	2	0	9 (15)
	Psychiatric therapy	11	20	2	26 (44)
Spiritual	Visit by pastor	18	2	1	38 (64)
	Prayer with patients	27	1	0	31 (53)
	Contact with traditional healer	6	1	0	52 (88)
Social	Home help	19	0	0	40 (68)
	Transport to care centre	25	1	0	33 (56)
	Employment training	17	0	0	42 (71)
	Provide household items	13	0	0	46 (78)
	Legal services	9	5	0	45 (76)
	Memory book work	8	0	0	51 (86)
	Family home help	16	1	0	42 (71)
	Loans/microfinance	6	1	0	52 (88)
HIV Prevention	Infection control training	50	0	0	9 (15)
	Support for family testing	46	5	0	8 (14)
	Circumcision	11	1	0	47 (80)
	Prevention with positives	52	2	0	5 (8)
Prophylaxis and Preventive care	Multivitamins	34	10	0	15 (25)
	Nutritional advice	57	1	0	1 (2)
	Access to safe drinking water at home	23	4	0	32 (54)
	Septtrin/cotrimoxazole	47	6	0	6 (10)
	Isoniazid	22	13	0	24 (41)
	Condoms	54	0	0	5 (8)
	Mosquito bednets	29	6	0	24 (41)
Laboratory	Liver function test	14	20	0	25 (42)
	Malaria film	34	9	0	16 (27)
	AFB smear	31	10	0	18 (31)
	CD4 count/test	19	18	0	22 (37)
	Rapid HIV test	34	9	0	16 (27)
	Pulse oximetry	10	9	0	40 (68)
	Dried blood spot for HIV diagnosis in newborns	14	10	0	35 (59)
	Viral load	10	19	0	30 (51)
Paediatric	Paediatric ARV	21	14	0	24 (41)
	Infant testing and counselling	20	13	0	26 (44)
	Children testing and counselling	29	12	0	18 (31)

Availability of the most commonly provided or referred components of care, by facility type, is displayed in Table 18 below. Adherence counselling was the only component of care to be provided or referred at all facilities included in the analysis (noting that one facility was excluded because it provides no components of care). It can be seen from Table 18 that adherence counselling and family planning counselling were common across all facility types, but home help was uncommon at hospitals and health posts, and anxiety/depression treatment was lacking at half of HBC facilities.

Table 18: Frequent components of care by facility type

Component of care	Facilities providing or referring for care, n (%)					
	Referral hospital	District hospital	Health centre	Health post	HBC	Total
<i>N</i>	5 (100)	45 (100)	27 (100)	13 (100)	10 (100)	59 (100)
Adherence counselling (clinical)	5 (100)	4 (100)	27 (100)	13 (100)	10 (100)	59 (100)
Anxiety/depression treatment (psychological)	5 (100)	4 (100)	27 (100)	12 (92)	5 (50)	53 (90)
Prayer with patients (spiritual)	2 (40)	4 (100)	10 (59)	3 (23)	9 (90)	28 (47)
Home help (social)	0	1 (25)	9 (33)	0	9 (90)	19 (32)
Family planning counselling (prevention)	5 (100)	4 (100)	26 (96)	13 (100)	9 (90)	57 (97)

#### *Number of components of care offered*

Table 19 shows the mean number of components of care offered at facilities was 36 out of the 69 listed (47 including referrals). District hospitals and health centres offered the most components of care (including referrals), HBC facilities the fewest. Referrals increased the number of components of care potentially accessible at facilities by between 5 and 13.

Table 19: Mean number of components of care offered by facility type

Type of facility	Mean [standard deviation (sd)] of components of care provided onsite	Mean (sd) of components of care provided or referred
Referral hospital	46 (6)	51 (8)
District hospital	49 (4)	57 (6)
Health centre	43 (11)	53 (6)
Health post	28 (11)	41 (9)
HBC	19 (5)	31 (14)
All types	36 (13)	47 (12)

#### *PEPFAR care and support provision*

PEPFAR defines five areas of care and support (Office of the U.S. Global AIDS Coordinator 2006b):

- Clinical care — including HIV counselling and testing, prevention and treatment of opportunistic infections, HIV prevention and behaviour change counselling, alleviation of HIV symptoms and pain, support for malnourishment, monitoring of need and adherence to ARVs, CTX, safe water, nutritional counselling
- Psychological care — including mental health counselling, family care and support groups,

- support for status disclosure, bereavement care, treatment of psychiatric illnesses
- Spiritual care — The interventions should be sensitive to the culture, religion(s) and rituals of the individual and community, and can include (but are not limited to): life review and assessment; counselling related to hopes and fears, meaning and purpose, guilt and forgiveness; and life-completion tasks.
  - Social care — including legal services, links to food support and Income Generating Activities (IGAs)
  - Prevention — including community and clinical-based support groups, condoms and partner testing (HIV/AIDS Palliative Care Guidance#1 2006).

The components of care in Table 17 grouped into areas based on these descriptions, and the proportions of facilities offering care in each area were calculated. The results are presented in Table 20 and the components listed under each heading for this section are listed in Appendix F.

**Table 20: Number of facilities providing or referring for each area of care, by facility type**

Any component provided or referred in area of care	Facility type including referrals, n (%)					
	Referral hospital	District hospital	Health centre	Health post	HBC	Total
<i>N</i>	5 (100)	4 (100)	27 (100)	13 (100)	10 (100)	59 (100)
Clinical	5 (100)	4 (100)	27 (100)	13 (100)	10 (100)	59 (100)
Psychological	5 (100)	4 (100)	27 (100)	13 (100)	10 (100)	59 (100)
Spiritual	3 (60)	4 (100)	15 (56)	3 (23)	9 (90)	34 (58)
Social	1 (20)	1 (25)	11 (41)	1 (8)	10 (100)	24 (41)
Prevention	5 (100)	4 (100)	27 (100)	13 (100)	10 (100)	59 (100)
All care and support	1 (20)	1 (25)	10 (37)	1 (8)	9 (90)	22 (37)

HBC facilities most frequently provided or referred for care from every area (Table 20). All facilities had at least one component of psychological, clinical and prevention care. Social care was the area of care least likely to be provided or referred, followed by spiritual care. HBC facilities were much more likely than other facility types to provide or refer for social and spiritual care, and as a result, to be able to provide or refer for all five areas of care and support.

The presence of the five areas of care was analysed by managing authority, to test the hypothesis that NGOs were more likely than government facilities to provide or refer for a complete package of care involving all five areas. Table 21 below shows that government facilities always provided or referred for clinical, psychological and preventive care, but spiritual care was provided or referred for at only a third of facilities, and social care at 10%. NGOs were much more likely to provide or refer for a complete package of care.

Table 21: Mean components of care by managing authority

Area of care	Number of facilities offering any component of care in area	
	Facilities managed by NGOs	Facilities managed by government
<i>N</i>	25 (100)	31 (100)
Clinical	25 (100)	31 (100)
Psychological	25 (100)	31 (100)
Spiritual	21 (84)	11 (35)
Social	20 (80)	3 (10)
Prevention	25 (100)	31 (100)
All care and support	19 (76)	2 (6)

### *Components of care by themes*

Components of care were grouped by theme to highlight gaps in coverage and explore the provision of integrated care. Some components are repeated under different headings for completeness, for instance thick-film malaria blood test which is shown under malaria (Table 26) and laboratory services (Table 28).

- ART — Of the facilities surveyed, 27 facilities supplied ARVs directly, 19 formally referred and 13 had no provision. All 27 direct providers said they supplied ARVs to everyone who needed them. Two could not provide figures for the number of patients provided with ARVs in the last 3 months. Of the remaining 25 facilities, 3 facilities provided all their patients with ARVs in the last 3 months (one a referral hospital, one a health centre and one an HIV/AIDS focal point for a diocese), based on number of patients supplied, and a mean of 34% of HIV patients was provided with ARVs. Table 22 shows that all hospitals provided comprehensive ART care, and the probability of having toxicity monitoring and treatment failure assessment was closely linked to facility type, declining to 30% in HBC facilities.

Adherence counselling was widely available. Of the 46 facilities that either supplied or referred for ARVs, 43 had adherence counselling onsite. Of the 27 facilities with ARVs provided onsite, all provided assessment for treatment failure and monitored toxicity (24 onsite and 3 referred). The support services for ARVs, toxicity monitoring and treatment failure monitoring, were either both present or both absent. If ARVs were provided by referral (19 facilities), toxicity monitoring and treatment assessment were provided onsite once, referred in 14 cases and not provided in 4.

- Pain management — Management of pain is of particular interest. Pain is a highly prevalent symptom throughout the HIV disease trajectory and pain management is a cornerstone of palliative care. Table 23 below shows that all facility types, with the exception of home-based care facilities, provided or referred for non-opioid analgesics, which were the most frequently available pain medication. Strong opioids were the least likely to be provided or referred. They were more commonly provided or referred at district hospitals and health centres than larger hospitals.

Table 22: ART provision by facility type

ART component	Facilities offering care including referrals, n (%)				
	Referral hospital	District hospital	Health centre	Dispensary	HBC-only
<i>N</i>	5 (100)	4 (100)	27 (100)	13 (100)	10 (100)
ARVs	5 (100)	4 (100)	26 (96)	7 (54)	4 (40)
Adherence counselling	5 (100)	4 (100)	27 (100)	13 (100)	10 (100)
Assessment of ARV treatment failure	5 (100)	4 (100)	24 (89)	6 (46)	3 (30)
Monitor ARV toxicity	5 (100)	4 (100)	24 (89)	6 (46)	3 (30)

Table 23: Availability of components of care relating to management of pain, by facility type

Pain component of care	Facilities offering test including referrals, n (%)					
	Referral hospital	District hospital	Health centre	Health post	HBC	Total
<i>N</i>	5 (100)	4 (100)	27 (100)	13 (100)	10 (100)	59 (100)
Assessment of pain	5 (100)	4 (100)	25 (93)	13 (100)	4 (40)	51 (86)
Strong opioid, e.g. morphine	3 (60)	4 (100)	21 (78)	4 (31)	2 (20)	34 (58)
Weak opioid, e.g. codeine	3 (60)	3 (75)	23 (85)	5 (38)	2 (20)	36 (61)
Non-opioid, e.g. paracetamol	5 (100)	4 (100)	27 (100)	13 (100)	4 (40)	53 (90)
Treatment for neuropathic pain	5 (100)	4 (100)	25 (93)	10 (77)	3 (30)	47 (80)

- Psychological health — The survey included information on several types of counselling and support groups, from which pre- and post-test counselling was selected as the most basic and the first line of care from which others would be referred. Table 24 shows that only two health posts and one HBC facility failed to provide pre- and post-test counselling, one of the most universally offered components of care. Psychiatric therapy was one of the rarest components of care, available through less than half of health posts and HBC facilities and only 56% of health centres. Anxiety and depression are extremely common symptoms in HIV. Treatment for them was widely available at most facility types but at only half of the HBC group.
- Nutrition and social care — Nutrition is an important aspect of HIV care, addressed in the top half of Table 25 below. Nutritional counselling was widely available at all facility types, but therapeutic feeding for malnutrition was provided or referred at only half of district hospitals and health centres, less than a third of HBC facilities and a quarter of health posts. Weighing was provided or referred at almost all facilities except for HBC where only 40% provided or referred for it.

Only four components of care from the survey are included in the PEPFAR definition of social care. They are listed in the bottom half of Table 25. It is clear that this area was much better supported by HBC facilities and health centres than by any other facility type. Referral hospitals, district hospitals and health posts each had only one facility providing or referring

for one component of care out of the four. By contrast, home help, IGA and legal services were each provided or referred by a third of health centres. HBC did even better, with 90% coverage of home help and 70% coverage of employment training/IGA.

**Table 24: Availability of components of care relating to psychological health, by facility type**

Psychological component of care	Facilities offering test including referrals, n (%)					
	Referral hospital	District hospital	Health centre	Health post	HBC	Total
N	5 (100)	4 (100)	27 (100)	13 (100)	10 (100)	59 (100)
Pre- and post-test counselling	5 (100)	4 (100)	27 (100)	11 (85)	9 (90)	56 (95)
Anxiety/depression treatment	5 (100)	4 (100)	27 (100)	12 (92)	5 (50)	53 (90)
Psychiatric therapy	4 (80)	4 (100)	15 (56)	6 (46)	4 (40)	33 (56)

**Table 25: Availability of components of care relating to nutrition and social care, by facility type**

Nutrition component of care	Facilities offering test including referrals, n (%)					
	Referral hospital	District hospital	Health centre	Health post	HBC	Total
N	5 (100)	4 (100)	27 (100)	13 (100)	10 (100)	59 (100)
Weighing	5 (100)	4 (100)	26 (96)	12 (92)	4 (40)	51 (86)
Nutritional counselling	5 (100)	4 (100)	27 (100)	13 (100)	9 (90)	58 (98)
Multivitamins	5 (100)	3 (75)	23 (85)	10 (77)	3 (30)	44 (75)
Therapeutic feeding for malnutrition	4 (80)	2 (50)	14 (52)	3 (23)	3 (30)	26 (44)
Home help	0	1 (25)	9 (33)	0	9 (90)	19 (32)
Loans/microfinance	0	0	3 (11)	0	4 (40)	7 (12)
Employment training/IGA	1 (20)	0	8 (30)	1 (8)	7 (70)	17 (29)
Legal services	0	0	8 (30)	0	6 (60)	14 (24)

- **Opportunistic infections (OIs) and preventive care** — This survey examined the provision of preventive and curative care of general OIs and some specific HIV-related OIs (malaria, TB and STIs) owing to the increased likelihood of contracting these diseases (Barnett & Whiteside 2006, UNAIDS 2008a) and dying from them, especially TB (UNAIDS 2008b). Care components that aimed to prevent patients from contracting OIs and transmitting HIV, and the treatment of OIs were explored. Some care components prevent HIV transmission and the spread of some OIs, e.g. condoms, so these 2 areas were examined together.

1. **Basic Care Package (BCP)** – PEPFAR developed the preventive care package (Office of the U.S. Global AIDS Coordinator 2006a), a number of specified care components which should be considered essential to prevent opportunistic infections, delay disease



2. Malaria and TB – Malaria and TB cause high morbidity and mortality in the HIV-negative population. Both diseases are more likely to affect people with HIV and to be exacerbated by it. The survey included components of care to prevent, diagnose and treat TB and malaria. The prevention interventions (bednets and isoniazid) had the lowest coverage (Table 26). Interestingly, the frequency at which bednets were provided or referred remained about the same in all facility types. All hospitals and health centres provided or referred for treatment for malaria and TB although the respective tests were not universally provided or referred. ‘TB detection’ is more likely to be a series of steps, beginning with screening for symptoms and questions on possible exposure, and ending with a sputum test or x-ray. At HBC facilities, bednets were the care component most likely to be available, with treatment provided or referred for at half of facilities.

Table 26: Availability of components of care relating to malaria and TB, by facility type

Component of care	Facilities offering test including referrals, n (%)					
	Referral hospital	District hospital	Health centre	Health post	HBC	Total
N	5 (100)	4 (100)	27 (100)	13 (100)	10 (100)	59 (100)
Isoniazid to prevent TB	4 (80)	3 (75)	18 (67)	6 (46)	4 (40)	35 (59)
TB detection	5 (100)	4 (100)	26 (96)	9 (69)	5 (50)	49 (83)
TB treatment	5 (100)	4 (100)	27 (100)	9 (69)	5 (50)	50 (85)
Mosquito bednets	3 (60)	2 (50)	18 (67)	6 (46)	6 (60)	35 (59)
Treatment for malaria	5 (100)	4 (100)	27 (100)	13 (100)	5 (50)	54 (92)
Malaria film	4 (80)	4 (100)	26 (96)	8 (62)	1 (10)	43 (73)
AFB test	4 (80)	4 (100)	25 (93)	8 (62)	0	41 (69)

3. Other opportunistic infections – Provision or referral for treatment for opportunistic infections was generally high (Table 27), and was complete at hospitals. Health centres had 93% or higher coverage for all OIs listed and health posts had 77% or higher. There were 6 HBC facilities (60%) which consistently did not provide or refer for clinical care, although some of them provided or referred for management of symptoms such as nausea, diarrhoea and skin rash.
4. Prevention with positives – PEPFAR’s care and support strategy includes ‘prevention with positives’ care. This is an approach promoting healthy living and addressing risky behaviours for people living with HIV/AIDS. The aims of the initiative are improved quality of life and a reduction in HIV transmission to sex partners and infants born to HIV-infected mothers (PEPFAR 2007; IDSA 2007).

Prevention for positives includes providing condoms and promoting their use, counselling HIV-positive persons to prevent transmission, providing STI diagnosis and treatment and prevention of mother to child transmission services (IDSA 2007; PEPFAR 2007) as these aim to reduce risky behaviours. The availability of some of the constituent

components of care was examined in the CSRI, including adherence counselling, family planning counselling, treatment of herpes, patient HIV support groups, and condoms.

All 59 facilities analysed provided or referred for at least three of these five components and over half (n=32) provided or referred for all five. Adherence counselling was provided or referred at all 59 facilities, family planning counselling at 57 and condoms were provided at 54 (see Table 17 above). All five components were provided or referred by 80% of referral hospitals, all district hospitals, 63% of health centre, 38% of health posts and 20% of HBC facilities.

Table 27: Availability of components of care relating to opportunistic infections, by facility type

Treatment for opportunistic infection	Facilities offering test including referrals, n (%)					
	Referral hospital	District hospital	Health centre	Health post	HBC	Total
N	5 (100)	4 (100)	27 (100)	13 (100)	10 (100)	59 (100)
Treatment for nausea/vomiting	5 (100)	4 (100)	26 (96)	13 (100)	5 (50)	53 (90)
Treatment for skin rash/itching	5 (100)	4 (100)	26 (96)	13 (100)	6 (60)	54 (92)
Treatment for diarrhoea	5 (100)	4 (100)	27 (100)	13 (100)	6 (60)	55 (93)
Laxatives	5 (100)	4 (100)	25 (93)	10 (77)	5 (50)	49 (83)
Treatment for thrush	5 (100)	4 (100)	27 (100)	13 (100)	5 (50)	54 (92)
Treatment for oral candidiasis	5 (100)	4 (100)	27 (100)	13 (100)	5 (50)	54 (92)
Treatment for Cryptococcus	5 (100)	4 (100)	26 (96)	11 (85)	4 (40)	50 (85)
Treatment for other fungal infections	5 (100)	4 (100)	27 (100)	13 (100)	4 (40)	53 (90)
Treatment for herpes	5 (100)	4 (100)	27 (100)	12 (92)	4 (40)	52 (88)

- Diagnostic tests — Laboratory services are not specified as an element of care and support but they are necessary in order to prevent and manage infections and monitor HIV progression. All the lab services in the survey were provided or referred at a proportion of hospitals, health centres and health posts, but HBC facilities provided or referred for very few (Table 28). Malaria blood film and rapid HIV test were the most commonly provided or referred lab services, both of them at almost all hospitals and health centres, around two-thirds of health posts and 10% of HBC facilities.

Table 28: Availability of diagnostic tests, by facility type

Laboratory test	Facilities offering test including referrals, n (%)					
	Referral hospital	District hospital	Health centre	Health post	HBC	Total
N	5 (100)	4 (100)	27 (100)	13 (100)	10 (100)	59 (100)
Liver function test	4 (80)	3 (75)	23 (85)	4 (31)	0	34 (58)
Malaria film	4 (80)	4 (100)	26 (96)	8 (62)	1 (10)	43 (73)
AFB smear	4 (80)	4 (100)	25 (85)	8 (62)	0	41 (69)
CD4 count/test	5 (100)	4 (100)	22 (81)	6 (46)	0	37 (63)
Rapid HIV test	4 (80)	4 (100)	26 (96)	8 (62)	1 (10)	43 (73)
Pulse oximetry	1 (20)	2 (50)	12 (44)	4 (31)	0	19 (32)
Dried blood spot for early infant diagnosis	4 (80)	3 (75)	13 (48)	4 (31)	0	24 (41)
Viral load	4 (80)	2 (50)	19 (70)	4 (31)	0	29 (49)

*Care provided and staff available*

Table 29 above shows that in most areas of care, where facilities provided components of care they had specialist staff available in that area, and there were few cases where specialist staff were present but care in that area was not provided. The exception was social care, for which 23 facilities had specialist staff but did not provide any of the five social care components surveyed.

Table 29: Components of care provided onsite and staff available

Area of care	Components of care provided	Number of facilities where specialist staff not working	Number of facilities where specialist staff working
Clinical	None	0	0
	At least one	7	52
Psychological	None	0	0
	At least one	24	35
Spiritual	None	22	3
	At least one	18	16
Social	None	12	23
	At least one	3	21
Prevention	None	0	0
	At least one	3	56
Laboratory	None	20	3
	At least one	3	33

There were few facilities providing clinical components of care without specialist staff. However, there were a large number of facilities providing other specialisms without specialist staff being present. Psychological care was the type of care most likely to be administered by untrained or un-

specialised staff. Pain control and symptom management were not provided at facilities where there were no clinical staff (not shown in table). Nutritional advice was the most commonly reported component of care, but only five facilities employed a nutritionist.

There were only a few facilities where specialist staff were employed but the facility did not provide any components of care in that area (from the ones listed in the CSRI). For example, at three facilities, specialists in spiritual care were available, but none of the listed components of spiritual care were provided there.

### *Number of patients receiving components of care*

Facility staff were asked to report the numbers of HIV patients receiving specific components of care (TB testing, TB treatment, treatment to make water safe, CTX and ITNs). In eight facilities, the number of people recorded to be receiving CTX was greater than the total number receiving care. When this was followed up, facility staff attributed this anomaly to CTX (and other care) in some instances being provided to people who were not registered patients.

In those cases where the numbers of patients receiving care were not higher than the total number of HIV patients, the proportions of patients receiving a number of components of care were calculated.

**Table 30: Proportion of patients receiving components of care**

Care component	Facilities offering component of care onsite, n	Facilities with plausible patient numbers, n	Median proportion of pts receiving the care component in the last quarter, % (IQR)
CTX	47	22	84.0 (57.3-100.0)
Safe water	23	13	28.2 (15.1-50.0)
ITN	29	18	33.0 (21.9-53.9)
TB test	36	22	3.5 (1.0-10.4)
TB treatment	37	31	2.0 (0.6-5.0)

Table 30 shows that, of the facilities offering the components of care listed, several did not have reliable data in order to allow the proportion of patients receiving the care to be calculated. Of those that did have data, the median proportion of patients receiving CTX was 84%, and 10 facilities provided CTX to 100% of patients with HIV at their facility. Safe water and ITNs were each provided to nearly a third of HIV patients. TB testing and TB treatment were offered at more facilities, but to lower proportions of HIV patients.

## **Document analysis**

### *Availability of documents*

The proportion of facilities reporting having specific named documents ranged from 17% for patient charging to 98% for patient information (Table 31). Patient information sheets, patient records, outgoing referral forms and stock control sheets were the only documents to be used by more than 80% of facilities.

Facilities providing examples of their service documents ranged between 4.5-40%, with the least common provided being inward referral criteria, and the most commonly provided being service aim and ongoing assessment sheets.

Table 31: Documents obtained

Document Type	Facilities reporting document in use, n (%)	Facilities from which example document obtained, n (% of those reported)	Further analysis conducted
Service aim	30 (51)	12 (40)	No
Referral criteria (inwards)	22 (37)	1 (5)	No
Incoming referral forms	28 (47)	5 (18)	No
Outgoing referral forms	53 (90)	19 (36)	Yes
Patient charging	10 (17)	1 (10)	No
ARV protocol	25 (42)	5 (20)	No
Care protocols	28 (47)	5 (18)	No
First clinical assessment sheets	39 (66)	14 (36)	Yes
Ongoing contact assessment sheets	35 (59)	14 (40)	Yes
Patient records	54 (92)	9 (17)	Yes
Referral follow-up forms	25 (42)	6 (24)	Yes
Stock control sheet	49 (83)	14 (29)	Yes
Patient information sheet	59 (100)	22 (37)	Yes

Analysed by facility type, for most documents the largest proportion of facilities to provide examples were health centres, which contributed 43% of the total documents provided (Table 32).

As stated in the Methods section, documents were analysed for content if more than five were collected and if the number collected was more than 20% of the facilities reporting use of the document. The exception was the service aim, which was normally very short (e.g. 'Provide care for all, 'Serve Ugandan', 'To treat for life').

Staff were later asked why they had not been able to provide example documents for analysis of content. Reasons given included facilities not keeping some documents in a hand-out form (e.g. service aim), having few or no copies in stock (and in some cases facilities were improvising forms whilst waiting for more copies to arrive) or none spare to hand out, and that documents were confidential.

Table 32: Document examples obtained by facility type

Document type	Number (%) facilities providing example of document					
	Facility type					
	Referral hospital	District hospital	Health centre	Health post	HBC	Total
Service aim	2 (17)	1 (8)	4 (33)	0	5 (42)	12 (100)
Referral criteria (inwards)	0	0	1 (100)	0	0	1 (100)
Incoming referral forms	0	0	4 (80)	1 (20)	0	5 (100)
Outgoing referral forms	0	1 (5)	8 (42)	6 (32)	4 (21)	19 (100)
Patient charging	0	0	1 (100)	0	0	1 (100)
ARV protocol	1 (20)	0	4 (80)	0	0	5 (100)
Care protocols	1 (20)	1 (20)	3 (60)	0	0	5 (100)
First clinical assessment sheets	2 (14)	2 (14)	7 (50)	2 (14)	1 (7)	14 (100)
Ongoing contact assessment sheets	1 (7)	2 (14)	8 (57)	2 (14)	1 (7)	14 (100)
Patient records	0	1 (11)	6 (67)	1 (11)	1 (11)	9 (100)
Referral follow-up forms	0	0	2 (33)	0	4 (67)	6 (100)
Stock control sheet	2 (14)	2 (14)	1 (7)	7 (50)	2 (14)	14 (100)
Patient information sheet	1 (5)	1 (5)	10 (45)	5 (23)	5 (23)	22 (100)

Table 33: Format of documents

Document (Number of facilities using document)	Format used		
	Paper only	Computer only	Both computer & paper
Service aim (n=30)	24	1	5
Referral criteria inwards (n=22)	21	0	1
Incoming referral forms (n=28)	27	0	1
Outgoing referral forms (n=53)	47	1	5
Patient charging (n=10)	5	1	4
ARV protocols (n=25)	22	1	2
Care protocols (n=28)	23	1	4
First clinical assessment sheets (n=39)	32	1	6
Ongoing contact assessment sheets (n=35)	27	1	7
Patient records (n=54)	43	1	10
Referral follow up forms (n=25)	22	1	2
Stock control sheets (n=49)	41	1	7
Information for patients (n=59)	53	1	5

Most facilities, if they had records at all, relied on paper documents (Table 33). Patient records were the information most frequently stored on computer. As a proportion of the total, patient charging forms were the most likely to be stored on computer (50%).

### *Analysis of content*

- Outgoing referral forms — Table 34 shows that fields recording potentially important details of medical history were often not present on outgoing referral forms. The only information which was always present was the facility name, patient's name, the date of referral, and the names of the individuals referring and receiving the patient.

**Table 34: Outgoing referral form contents**

Outgoing referral form features	Number of facilities	
	Information present on form	Information absent from form
Facility details		
Name of facility and location details	19	0
Facility contacts	19	0
Registration details		
Patient clinic number	12	7
Referral number	10	9
Date of referral	19	0
Date of first visit	16	3
Sociodemographic information		
Patient name	19	0
Age	15	4
Sex	15	4
Patient's address	10	9
Medical history		
Diagnosis/ working diagnosis	11	8
Present therapy (ARV, and prophylaxis)	4	15
Treatment given so far	12	7
Previous opportunistic infections (dates)	4	15
WHO staging	4	15
Use of ARV (ARV start date)	4	15
Laboratory investigations done , dates and results	4	15
Patient complaints/ symptoms	12	7
Referral service requested/	17	2
Clinical notes/ remarks	9	10

Outgoing referral form features	Number of facilities	
	Information present on form	Information absent from form
Other details		
Name of officer referring	19	0
Date/Signature of officer referring	19	0
Patient's consent (signature and date)	1	18
Referral response section		
Date of admission	3	16
Date of discharge	3	16
Diagnosis	6	13
Investigations done	6	13
Treatment given	6	13
Remarks	6	13
Officer receiving referral, signature and date	19	0

- Patient records — Only 6 facilities were able to provide a patient record form (Table 35). Again, medical history was not always present. Information on medication the patient had been taking was only mentioned on 2/6 forms.

Table 35: Patient records

Patient record features	Number of facilities	
	Information present on form	Information absent from form
Facility name and contact details	6	0
Facility branch	2	4
Registration details		
Date	6	0
Counsellor's name	2	4
Card number (card does not bear results)	4	2
Facility patient number	4	2
Test number	4	2
Counsellor's code	2	4
Sociodemographics		
Patient name	6	0
Age/ date of birth	6	0
Sex	6	0

Patient record features	Number of facilities	
	Information present on form	Information absent from form
Contact details	6	0
Next of kin	4	2
Company	1	5
Brief medical history		
Case notes	4	2
Investigations and treatment	4	2
Date of next appointment	4	2
Patient medication list		
Prophylaxis medication prescriptions (reason, date dispensed, number of days)	2	4
ARV prescriptions (date, dispensed, number of days)	2	4
Other medications including herbs (date, dispensed, number of days)	2	4

- Referral follow-up forms — Referral follow-up forms were brief and were meant to be additional to the main record, so sociodemographic information was not included (Table 36).

Table 36: Referral follow-up forms

Referral follow-up form features	Number of facilities	
	Information present on form	Information absent from form
Date of arrival	6	0
Diagnosis	6	0
Treatment given	6	0
Treatment or surveillance to be continued	2	4
Name and signature of clinician	6	0
For admissions (admission and discharge dates)	2	4
Confidential footnote and request to return form to facility referring	6	0

- First clinical assessment sheets — The first clinical assessment sheet (sometimes referred to as an HIV care enrolment sheet) is intended for completion by a clinician, who undertakes the physical examination and document patients' medical history for each new patient at their first visit. All reporting facilities captured the core information required by the Ministry of Health: patient socio-demographic information, patient current condition and medical history, previous treatment, adverse reactions and resistance to prior treatment regimens. The MOH recommends collecting information about vital signs, clinical examination and specific laboratory tests to support treatment monitoring, and this information was also present on all the forms. Some facilities captured additional information to address other information needs

(e.g. those involved in research or requiring information on local service providers to avoid service overlap). In terms of the documentation of presenting complaints, only two facilities specifically enquired about pain and only one enquired about patients' mental health.

Table 37: First clinical assessment sheets

First clinical assessment sheet features	Number of facilities	
	Information present on form	Information absent from form
Registration		
Patient ID	14	0
Date of registration	14	0
Confirmed death of patient	2	12
Site / station	3	11
Clinic number	10	4
District, health unit	4	10
Entry point	2	12
Treatment support person	4	10
Home-based care provider	4	10
Free or paying for drugs	4	10
Sociodemographics		
Patient name	14	0
Existing hospital / clinic	2	12
Gender	14	0
Age	14	0
Religion	2	12
Date of birth	14	0
Residence	14	0
Marital status	14	0
Educational level	14	0
Emergency contact	4	10
Literacy	2	12
Disclosure status	12	2
Employment status	14	0
Monthly income	2	12
Number of children	14	0
Distance to facility	2	12
Potential barriers to HIV care	2	12

First clinical assessment sheet features	Number of facilities	
	Information present on form	Information absent from form
Referral		
Who referred you	4	10
HIV History		
Date of HIV diagnosis	14	0
Primary provider	2	12
Diagnosis verification	14	0
Pregnancy	14	0
HIV status	2	12
Number tested in family	2	12
Number HIV positive in family	14	0
Number deceased	2	12
Membership to HIV support group	4	10
History of AIDS defining illness (initial or recurrence)	14	0
Adherence		
Date , doses missed, diagnosis, treatment, change treatment and reason for changing	14	0
Laboratory investigations conducted and results	14	0
Vital signs and medications		
Chief complaints	14	0
Weight, height, temperature, blood pressure, respiratory rate, heart rate, Karnofsky score	14	0
ARV treatment history		
Previous ARV exposure and dates	14	0
Name of drugs and months on treatment	14	0
CD4 prior starting ARV and date	14	0
1st, 2nd and 3rd regimens plus dates	14	0
Viral load prior ARV	14	0
Date started HAART	2	12
ARV eligibility and action taken	14	0
Medical & health history		
Surgical or hospitalisation history or skin, eyes, mouth, pulmonary, neurological problems	14	0
Current non-ARV medications (prophylaxis and contraceptives)	14	0
Liver, kidney, anaemia, drug / alcohol abuse	2	12

First clinical assessment sheet features	Number of facilities	
	Information present on form	Information absent from form
Medication allergies	14	0
Current long-term medications	14	0
TB history and assessment	2	12
If female: pregnancy and connection to preventing mother to child transmission (PMTCT)?	14	0
WHO clinical stage with stages well defined	14	0
Presenting clinical information		
Presenting complaints (pain*, headache, mental health**, new visual problems etc) and their description	14	0
Clinical plan	14	0
Problem list and plan	14	0
Significant positive findings on examination	14	0
Notes, signature of interviewers	14	0
Date of next appointment	14	0

\* 2 sites only \*\* 1 site only

- Ongoing contact assessment sheets — The ongoing contact assessment sheet (Table 38) is intended for completion by a clinician at every clinical appointment. Over 90% of the reporting facilities in Uganda were using similar documents supplied by the MOH. Two of the facilities captured information on the use of herbal medicines, while only four recorded ongoing problems as opposed to only new problems. The sites that captured additional information had similar documentation, suggesting they might be part of the Timetable for Regional Scale-up of ARV therapy (the ‘TREAT’ programme) collaboration, a network of care providers and public, private and faith-based support groups coordinated by the Joint Clinical Research Centre (JCRC, [kampala.usembassy.gov/jcrc](http://kampala.usembassy.gov/jcrc)). Adherence, infections (especially TB), treatment history and ARV monitoring were key areas of focus across all reporting facilities.

Table 38: Ongoing contact assessment sheets

Ongoing contact assessment sheet features	Number of facilities	
	Information present on form	Information absent from form
Registration		
Visit date	14	0
ID	14	0
Existing hospital / clinic	2	12

Ongoing contact assessment sheet features	Number of facilities	
	Information present on form	Information absent from form
Socio-demographic		
Patient name	14	0
Adherence		
Number of doses missed (% adherence)	14	0
Directly observed therapy (DOT)	4	10
Home visits, support group	4	10
Unintended treatment interruption	14	0
Patient reports taking herbal medications	2	12
Vital signs		
Presenting complaints (enquire about sexual activity)	14	0
Last CD4 count and date	14	0
Pregnant? LMP	14	0
Physical examination (temperature, RR, HR, BP, weight, height, pain)	14	0
Clinical assessment	14	0
New problems / diagnoses	14	0
Ongoing problems / diagnoses	4	10
WHO stage, TB status, TB type, TB smear, TB drug	14	0
On ARV side effects	14	0
ARV regimen (start date, end date, change reason, stop reason, ARV source)	14	0
Prophylaxis (drug, strength, frequency, duration, quantity dispensed)	14	0
Opportunistic infection (OI) treatment and other medications	14	0
Assessment (improving, active OI , drug toxicity, non-adherence, WHO stage, CD4, viral load)	14	0
Plan on ARV therapy (change, continue, change regimen, start new treatment etc), regimen	14	0
Next appointment	14	0

- Stock control sheet — A stock control sheet, central to effective stock management systems for drugs used at all levels of the health care system, is ordinarily a small record-keeping system made from cardboard. There is normally one stock card per item, with the card usually retained close to the stock it refers to (e.g. on the same shelf).

As Table 39 shows, the majority of the reporting Uganda facilities documented stock movement information (e.g. quantity issued, received and the actual net balance) and inventory management (e.g. minimum and maximum stock levels). Only half of the reporting facilities documented the drug name on the stock card, and the stock reorder level. In public health fa-

ilities official MOH documents were used; other facility types used documents that included additional details (e.g. adjustments / losses, quantity to order and unit size).

Table 39: Stock control sheet

Stock control sheet features	Number of facilities	
	Information present on form	Information absent from form
Facility details		
Facility name and details	14	0
Program name	9	5
Specifications		
Name of drug	7	7
Item description	10	4
Item code	9	5
Card number	8	6
Unit pack and size	4	10
Formulation	6	8
Strength	9	5
Cost	6	8
Special conditions	7	7
Stock movement		
Date	14	0
Quantity issued	14	0
Quantity received	14	0
Balance at hand	14	0
Quantity to order	7	7
Inventory management		
Average consumption per month or week	7	7
Expiry date	10	4
Remarks (voucher number, other details)	14	0
Re-order level	8	6
Minimum stock level	13	1
Maximum stock level	13	1
To / from	13	1
Losses / adjustments	5	9
Signature	9	5

- Patient information sheets — All facilities with patient information sheets offered information about who they are, what they do and their contact addresses. As Table 40 shows, additionally, all facilities offered information about family planning, positive living and basic information about ART, with the information sheets produced with support from PEPFAR, the MOH, USAID, and Population Services International. Information of child feeding was only provided by 5 facilities.

Among the 59 facilities that reported having information sheets for patients, 57 (97%) had sheets written in English, whilst in 56 sites (95%) information was provided in a minimum of two languages (i.e. English and a local language), 8 sites (14%) provided information in at least 3 languages, and 3 sites (5%) provided information in more than 3 languages.

Table 40: Patient information sheets

Patient information sheet features	Number of facilities	
	Information present on form	Information absent from form
<b>Family planning</b>		
Available contraception options	22	0
How they work	22	0
Advantages and disadvantages	22	0
Other centres offering the service	22	0
PMTCT services	22	0
Services available for PMTCT (comprehensive antenatal care, improved during labour and delivery, postnatal care)	22	0
Expansion strategy	22	0
Actions (feasible alternatives to breast feeding, involvement of development partners, improving coordination between players, increasing spouse involvement)	22	0
Contacts for further information	22	0
<b>Child feeding</b>		
Important information about fresh cow's milk (how to boil it, mixing, preparation, storage and how to give it to the baby)	5	17
Feeding advice for children at different ages	5	17
Child feeding at six months	5	17
Information on what foods to give, in what amounts, form and how	5	17
How to observe hygiene in child care	5	17
<b>Facility information</b>		
Facility mission, aim, goal and objectives	22	0
Facility activities	22	0

Patient information sheet features	Number of facilities	
	Information present on form	Information absent from form
Contact details	22	0
Positive living		
Avoid malaria (sleep under mosquito treated nets)*	22	0
Use daily septrin	22	0
Safe drinking water (use water guard, use a clean container, wash hands with soap before eating or serving food or after using the toilet)	22	0
Do not spread the virus to your lovers (encourage your partners to screen for HIV there is a possibility for discordance, avoid sexual relationships or use a condom, if you get pregnant go for PMTCT services)	22	0
Basics about antiretroviral therapy (meant for HIV+ people)		
By taking ARV you can continue to work and look after your family	22	0
What is ART?	22	0
How does it work?	22	0
Does ART cure AIDS? NO it only helps to lessen the amount of HIV in the body and make it less active. When on ART you can still pass HIV to someone else during unprotected sex.	22	0
When should I start ART?	22	0
What is a CD4 test? A CD4 count of less than 200 in an HIV positive person shows a weak immune system.	22	0
What are ART-related side effects?	22	0
Who should I tell about my HIV status? Tell your sexual partners. It also helps to tell someone you can trust, such a person can remind you to take your ART tablets regularly.	22	0
Is ART expensive? Free drugs are available through ministry of health.	22	0
How long does one take ART? You can start only when you are ready for a life-long commitment.	22	0
What is reinfection? When you are taking ART drugs, you can still get more of the virus or a different HIV strain by having unprotected sex.	22	0

\* Pictorial for illustration on how to use, treat and access mosquito bed nets.

## Pharmacy review

A review of the supply and storage of key drugs for HIV care was undertaken at each facility by visiting the onsite pharmacy.

### *Type, form and amounts of drugs stored*

Adult CTX in tablet form was the most commonly found drug (found at 40 facilities) followed by non-opioid painkiller tablets at 39 as shown in Table 41. Tablets were the most common form of

every drug except paediatric CTX, which was stocked in syrup form in 11 facilities. Twenty-four facilities stocked adult CTX but not paediatric CTX; 16 facilities had both; and one had paediatric CTX but not adult CTX. Owing to the rarity of powder and syrup formulations, of the 21 drug/formulation combinations listed in the pharmacy review, only seventeen were ever found in the 60 facilities visited.

Table 41: Types and amounts of drugs stored at pharmacies

Drug	Formulation	N facilities where in-date drug stocked (expired)	Amount of in-date drug found in pharmacy*		
			Mean	Lowest	Highest
Isoniazid	Tablets	21 (2)	913	70	3610
	Syrup	1 (0)	290	290	290
	Powder	0 (0)	0	0	0
Fluconazole	Tablets	24 (1)	994	40	7154
	Syrup	1 (0)	200	200	200
	Powder	3 (1)	56	7	105
Adult CTX	Tablets	40 (0)	57573	80	84000
	Syrup	3 (0)	70033	500	176000
	Powder	0 (0)	0	0	0
Paediatric CTX	Tablets	10 (0)	2909	42	7630
	Syrup	11 (0)	4570	200	33600
	Powder	1 (0)	100	100	100
Non-opioid analgesic	Tablets	39 (0)	24252	40	29000
	Syrup	10 (0)	17910	200	132000
	Powder	0 (0)	0	0	0
Codeine	Tablets	16 (0)	1101	100	5990
	Syrup	2 (0)	650	300	1000
	Powder	0 (0)	0	0	0
Morphine	Tablets	4 (1)	131	15	236
	Syrup	2 (1)	3930	1190	6670
	Powder	2 (0)	3500	3500	3500
	Injectable	3 (1)	11	10	12

\* Amounts are number for tablets, mls for syrup, grams for powder and number of vials for injectable

The seven facilities with in-date morphine comprised two that stocked syrup, two that stocked tablets, two that stocked tablets and injection, and one that only stocked injectable morphine. One facility had expired syrup but no in-date morphine in stock.

There were four facilities that provided several types of symptom management onsite according to the CSRI data in the staff interview, but had none of the named drugs in stock. This suggests they did not have a pharmacy on site. These facilities were all health centres or health posts. Two of the five identified facilities reported they offered a total of 13 out of a possible 16 components of clinical care. It appears that the facilities must be providing prescriptions only.

Table 42 shows that drug availability is associated with facility type, but district hospitals were on average better stocked than referral hospitals. Morphine was only available at district hospitals and health centres. Non-opioid analgesics and adult CTX had very similar distribution patterns and were the most widely available drugs. HBC facilities have very poor drug stocks. Codeine, a weak opioid, was available at only 60% of referral hospitals and even fewer in all other facility types.

Table 42: Drug availability by facility type

Drug, any formulation, in date	Facilities stocking drug n (%)				
	Referral hospital	District hospital	Health centre	Health post	HBC
N	5 (100)	4 (100)	27 (100)	13 (100)	10 (100)
Non-opioid analgesic	5 (100)	3 (75)	22 (81)	8 (62)	1 (10)
Codeine	3 (60)	1 (25)	10 (37)	3 (23)	0
morphine	0	2 (50)	5 (19)	0	0
Isoniazid	1 (20)	3 (75)	13 (48)	4 (31)	0
fluconazole	4 (80)	3 (75)	16 (59)	1 (7)	0
Adult CTX	5 (100)	3 (75)	22 (81)	9 (69)	1 (10)
Child CTX	2 (40)	1 (25)	12 (44)	2 (15)	0

Table 43 presents a comparison of facilities where drugs were stocked and facilities that said they offered the drug or treatment to HIV patients. Only direct provision rather than referrals are included. The table shows that, for every drug listed, drugs were frequently not in stock on the day of the survey at facilities where the drug was offered as a component of care. Drug availability ranged from 50% of facilities offering morphine having it in stock, to 83% of facilities offering CTX having it in the pharmacy.

There were also cases where the component of care was not reported as offered by the facility to HIV patients, and yet the corresponding drug was in stock. For example, only 71% of facilities stocking isoniazid reported they offered isoniazid prophylaxis to HIV patients.

Table 43: Drugs found in pharmacy compared to care directly offered by facilities

Drug, all forms	Facilities stocking in-date drug (n)	Facilities offering the component of care which requires this drug (n)	Proportion (%) of facilities offering care which have appropriate in-date drug in stock	Proportion (%) of facilities with the in-date drug in stock which offer component of care
Non-opioid analgesic	39	50	39/50 (78)	39/39 (100)
Codeine	17	21	16/21 (76)	16/17 (94)
Morphine	7	12	6/12 (50)	6/7 (86)
Isoniazid	21	22	15/22 (68)	15/21 (71)
CTX (adult or child)	41	47	39/47 (83)	39/41 (95)

**Stock levels and stockouts**

A stock level is the quantity of remaining stock which prompts the facility to make another order. Facilities were asked whether they had a stock level for each drug, and whether they had a record of running out of any drugs in the last 6 months (a recorded stockout).

Table 44: Stock levels

Drug	Formulation	N facilities where stock level reported (% of those where drug stocked)	Stock level (number of packs)		
			mean	minimum	maximum
Non-opioid	Tablets	17 (44)	2.8	1	10
	Syrup	4 (40)	15.8	2	40
Codeine	Tablets	8 (50)	64.8	1	300
	Syrup	0			
Morphine	Tablets	2 (50)	1.0	1	2
	Syrup	1 (50)	20.0		
	Powder	0			
	Injectable	2 (67)	5.5	1	10
Adult CTX	Tablets	20 (50)	7.6	1	50
	Syrup	2 (67)	15.0	10	20
Child CTX	Tablets	5 (50)	5.4	1	10
	Syrup	5 (45)	7.6	6	10
	Powder	0			
Isoniazid	Tablets	4 (19)	9.8	2	25
	Syrup	0			
Fluconazole	Tablets	10 (42)	10.2	2	25
	Syrup	0			
	Powder	1 (33)	5.0		

Table 44 shows that stock levels were given in only about half of cases. In many facilities the stock level was only one pack. Stockouts were frequently recorded. Of the 55 facilities that stocked any of the drugs reviewed, 47% reported a stockout of at least one of the drugs during the past six months. Out of the 40 facilities offering adult CTX tablets, 38% reported a stockout in the last 6 months, and 33% of non-opioid tablet stocks had been empty in the same time.

From the 22 possible formulation combinations which were searched for, 18 were found. Table 45 shows the number of formulation combinations which had had stockouts at each facility in the last 6 months. Four facilities had none of the listed drugs and therefore no risk of stockouts, so the proportion of eligible facilities which had at least one stockout was 26/55 or 47%. The total number of individual drug stocks found (the sum of facilities per drug in Table 44) is 193, and there were 49 stockouts (Table 45), meaning that 25% of all drug formulations recorded at the facilities had suffered a stockout in the previous six months.

**Table 45: Number of stockouts per facility**

<b>Formulations having stockout</b>	<b>Number of facilities (%)</b>
0	33 (56)
1	12 (20)
2	7 (12)
3	5 (8)
4	2 (3)
total	59

Drug stockouts were analysed by facility type to explore whether some facilities were more likely than others to run out of drugs. Table 46 below shows that HBC facilities had no problem with stockouts, largely because they had very few drugs. Health centres had stockouts of the most drug formulations. Non-opioid analgesic tablets and CTX tablets were the drug most likely to be out of stock, partly because these are the most commonly stocked drugs (see Table 42 for denominators for stockout analysis).

### ***Storage***

Table 47 shows that drugs were most commonly kept in locked places, usually locked in clinic or open access in the pharmacy. However, on a number of occasions drugs were found to be kept within easy access of patients. Codeine, CTX, fluconazole and non-opioid painkillers were all openly accessible in the clinic at more than one facility. Morphine should be double-locked, but injectable morphine was openly accessible in the pharmacy in one facility.

Table 46: Drug stockouts by facility type

Drug	Formulation	Number (%) facilities stocking the drug to have recorded stockout in last 6 months				
		Referral hospital	District hospital	Health centre	Health post	HBC
	N	5 (100)	4 (100)	27 (100)	13 (100)	10 (100)
Non-opioid analgesic	Tablets	2 (40)	1 (25)	5 (19)	5 (38)	–
	Syrup	–	1 (25)	1 (4)	–	–
	Powder	–	–	–	–	–
Codeine	Tablets	1 (20)	–	1 (4)	–	–
	Syrup	–	–	1 (4)	–	–
	Powder	–	–	–	–	–
Morphine	Tablets	–	1 (25)	3 (11)	–	–
	Syrup	–	–	1 (4)	–	–
	Powder	–	–	–	–	–
	Injection	–	–	–	–	–
Isoniazid	Tablets	–	1 (25)	4 (15)	1 (8)	–
	Syrup	–	–	–	–	–
	Powder	–	–	–	–	–
Fluconazole	Tablets	1 (20)	2 (50)	1 (4)	–	–
	Syrup	1 (20)	–	–	–	–
	Powder	–	–	1 (4)	–	–
Adult CTX	Tablets	2 (40)	2 (50)	6 (22)	5 (38)	–
	Syrup	–	–	–	–	–
	Powder	–	–	–	–	–
Paediatric CTX	Tablets	–	1 (25)	–	1 (8)	–
	Syrup	–	–	1 (4)	–	–
	Powder	–	–	–	–	–

Table 47: Drug storage

Drug	Formulation	Expiry*	Open access in clinic	Open access in pharmacy	Locked in clinic	Locked in pharmacy
Non-opioid	Tablets	ID	6	16	9	8
	Syrup	ID	2	7	0	1
Codeine	Tablets	ID	2	4	1	9
	Syrup	ID	0	1	1	0
Morphine	Tablets	ID	0	0	1	3
	Tablets	EX	0	0	0	1

Drug	Formulation	Expiry*	Open access in clinic	Open access in pharmacy	Locked in clinic	Locked in pharmacy
Morphine con't	Syrup	ID	0	0	0	2
	Syrup	EX	0	0	0	1
	Powder	ID	0	0	0	1
	Injectable	ID	0	1	1	1
	Injectable	EX	0	0	0	1
Adult CTX	Tablets	ID	5	15	11	9
	Syrup	ID	0	3	0	0
Child CTX	Tablets	ID	2	5	1	2
	Syrup	ID	3	4	2	1
	Powder	ID	0	0	1	0
Isoniazid	Tablets	ID	2	6	6	6
	Tablets	EX	0	1	1	0
	Syrup	ID	0	1	0	0
Fluconazole	Tablets	ID	4	9	2	9
	Tablets	EX	0	0	1	0
	Syrup	ID	0	1	0	0
	Powder	ID	0	1	0	1
	Powder	EX	0	0	0	1

\* ID = in date, EX = expired

### Facility strengths and areas for improvement: staff open-ended questions

The senior staff at each facility were asked to indicate perceived strengths of their facility, ways in which the services offered could be improved, threats to sustainability and their ideas on ways to avoid double-counting of patients. A total of 189 members of staff were involved in the senior staff interviews, a mean of 3.2 people per facility with a range from 1 to 5 (Table 48). The responses are also presented by cross-cutting themes through the range of data sources.

#### Strengths

Nearly all facilities (90%, n=54) named specific provided components of care in their list of strengths. One of the most common was being able to provide CTX to patients. Other aspects of care named were ARVs, VCT, PMTCT, treatment of infections, community mobilisation, peer counselling and home care. Being able to provide services free of charge was mentioned as a strength in itself.

Table 48: Senior staff interviews

Number of participants	Facilities n (%)
1	5 (8)
2	16 (27)
3	15 (25)
4	13 (22)
5	11 (18)

Owning land or buildings, rather than renting, was seen as a strength and a benefit for sustainability. Having a laboratory on-site was often mentioned as a strength. Having a vehicle was a significant strength for staff. Staff said that having transport made it possible to reach new clients, particularly the underserved, via mobile units and home-based care for people too ill to take the bus. Conducting outreach, to publicise the facility's activities and encourage VCT and care uptake, was made easier by transport. Being able to offer home-based care was singled out as a strength.

Some facilities were attempting profit-making enterprises and they saw this as a strength because it would reduce their dependence on outside donors. The facility staff themselves were often considered a strength to the facility. Qualities of the staff mentioned which made them an asset included being committed, motivated, well trained, diverse, and skilled, and having a good relationship with clients. Clinical staff and counsellors were particularly singled out as a staff asset. Psychosocial services were described as a strength when the facility had trained counsellors, who promoted adherence counselling, VCT, positive living, spiritual encouragement and personal testimony.

### *Improvements to care for adults*

One of the most common answers staff gave was the need for more space. In particular, space was associated with counselling rooms, because of the need for privacy. Staff also said they needed space for a laboratory, an enlarged clinic, or simply because they had too many patients and not enough capacity.

Staff said that they would like to provide more mosquito nets, water treatment, drugs and counselling, which are components of the BCP. Additionally they wanted to supply IGA programmes, payment of school fees, transport refunds and ARVs. The most common piece of equipment named which staff would like to have was a CD4 machine. Others said they wanted to be able to conduct HIV tests at the facility rather than having to send samples away for testing. Twenty-two facilities (37%) said better transport would improve the care they could offer. Facilities without vehicles wanted to buy one; those with vehicles wanted funds to pay for fuel.

At some facilities it was said that there were not enough staff to handle the workload, and this caused demoralisation because the workload was too big. Managers wanted to hire more staff, especially community health workers, and provide more training, particularly for counsellors and CHWs. They also wanted to develop training for people living with HIV as peer educators and counsellors. Facilities saw it as important to provide food to patients, or at the very least to provide tea when they came for care. Staff said food provision was needed for three reasons: because many of the patients were malnourished, because the ARVs could not be taken without adequate food, and to reduce illnesses. The stated purpose of IGA was also to improve nutrition. The main reason given for why these improvements had not been carried out was lack of funds.

### *Improvements to care for children*

Many facilities wanted to develop care for children. At 17 facilities staff talked about improvements to the infrastructure, usually building a ward or daycare centre specifically for children, with toys for educational development. It was felt inappropriate to care for children in the same place as adults. This was another instance of the facility needing more building space.

At 15 facilities, the staff wanted training in paediatric counselling. This was the single most commonly expressed training need overall. A further eight staff groups wanted other training for child care. Psychosocial issues were more frequently mentioned in connection with child care than with care of adults.

Nineteen facilities (32%) said that they wanted to provide food for children. Staff said that children were monitored until the age of 6 months, after which their health and growth declined. They wanted to be able to continue following up these children and providing food for them. They also said that carers, who were sometimes very old, could not give the children enough to eat and needed to be supported, and that children were often malnourished.

Some facilities wanted to provide child-specific drugs, and some could only provide ARVs to those aged 15 and over, and had no protocol for paediatric ART. Other suggestions as ways to improve services for children included legal services to prevent child-headed families from losing their possessions to relatives, and provision of school fees and household items. Counselling in schools was suggested as a way to reduce stigma for HIV-infected children. Facilities wanted to develop peer counselling among children but lacked training to do so.

### *Challenges to sustainability*

The most frequently mentioned threat to sustainability was the issue of staff retention (n=38. 63%). Turnover was high, which was seen as damaging to patient care because new staff were less well trained and had not developed the good relationship with patients which was considered an asset to the facility. There were several reasons given for this high turnover. Managers said that many staff were volunteers, who paid for their own transport and food. The fact that they were volunteers meant that managers could not demand as much from them and they could leave at any time. These additional costs of food and transport were felt to be very demotivating to volunteers and staff requested that they should get some remuneration. The unmanageable workload induced lack of motivation and burnout in some staff. Low salaries and lack of training caused staff to leave.

Relying on funding from donors, which is outside the facility's control, was seen as a challenge to sustainability. Twenty-eight facilities (47%) saw funding as a challenge. Staff said that vertical programming, for instance funding specifically for ART or for animal husbandry programmes, limited the ability of the facility to meet its patients' needs. Funding could be terminated at short notice and managers were worried that they would not be able to maintain their services, particularly ART.

Breakdown in drug supply was a serious sustainability issue for 34 facilities (57%). CTX was named in particular as a drug for which the facility had problems maintaining a regular and continuous supply. CTX was also the drug which facilities most commonly identified as a strength if they were able to stock it. Staff said that once drugs were ordered, they often arrived late, making it difficult to manage stock.

Lack of transport was described as a challenge to sustainability by 17 facilities (29%). A vehicle and fuel were required to follow up patients, provide home care, and visit those who could not afford to get to the facility. The patients most in need might be the least able to pay for transport.

Other challenge to sustainability reported included stigma (by 5 facilities, 8%), which was described as 'self-made stigma', i.e. fear of a positive diagnosis preventing potential clients from accessing services. At one facility, religious leaders encouraged followers not to take their ARVs, and staff said this was a significant problem.

### ***Ways to avoid double-counting***

All facilities had suggestions for the reduction of double-counting and no two suggestions were identical, but some common themes emerged. Several staff said the answers were to sensitise patients about the dangers of combining drugs and develop adherence counselling services, using the existing approaches of a drug buddy, sensitisation through drama, peer ambassadors, etc. Also, greater involvement of people living with HIV may help facilities understand why patients moved around. Facilities could also have permanent rather than transient staff, so that patients developed confidence in them and preferred to stay at one place.

Others recommended regional or national databases with unique ID numbers, possibly photo ID cards, a record of drugs dispensed and the date, and stamps to prevent duplication. Two groups said that the reason patients move around was due to irregular drug supply, so the way to prevent it is to ensure the supply is continuous. It was pointed out that patients could be encouraged to bring their children in to collect their own CTX, rather than giving out doses by proxy. This approach may prevent a person receiving double services from the same facility.

Some staff believed the answer was to have each facility as a stand-alone centre, providing all services – social, financial, treatment and care. Conversely, others suggested it would be better for facilities to specialise, with clear catchment areas for their particular speciality. Rather than preventing patients from moving around, this would ensure they got different elements of care from different places, not the same things twice.

Finally, staff suggested improving coordination between facilities and strengthening the referral system, with a strong central role from the Ministry of Health.

### ***Cross-cutting themes from staff open-ended questions***

Space was a very important issue to the staff interviewed. Many staff said they did not have enough space. The most common reason given for needing more space was for counselling, with space equating to privacy.

The overwhelming reason given why services could not be developed was shortage of funds. In addition, funds sometimes arrived late, disrupting planning, and some managers said they spent a lot of their time applying for funds and requested training in how to apply more effectively. There was also the question posed of who would pay for care when a patient cannot afford it. Some facilities could not support all the patients they had, and reported having stopped registering new ones. The good relationship with patients (which staff remarked on as an asset to a facility) could not develop if staff were constantly changing. Managers said that volunteer staff, including themselves, would be more motivated if they had their costs paid such as lunch and transport to the facility.

From the point of view of the staff, transport allowed contact and follow-up with clients. Transport was related to cost in that staff wanted to provide refunds to patients who were prevented from accessing care by the cost of travel, and they also wanted to refund the travel expenses of volunteers. According to the quantitative data, 32 facilities had some kind of vehicle to transport patients, but 5 of these had no fuel or were broken down. Provision of home-based care was a reported strength, and several managers said they wished they had transport so they could provide more.

### *Summary of staff qualitative data*

- Strengths — Staff felt the strengths of their facilities were
  1. clinical care (CTX, ARVs, PMTCT, treatment of infections);
  2. psychological care (adherence counselling, positive living, personal testimony);
  3. spiritual encouragement for patients;
  4. community mobilisation, peer counselling, home based care;
  5. owning land or buildings, owning a vehicle; and
  6. staff who are skilled, motivated, and diverse.
  
- Improving adult care – Staff said that adult care could be improved by
  1. more space, allowing privacy;
  2. providing ITNs, water treatment;
  3. providing ARVs, other drugs, HIV tests onsite;
  4. improved counselling;
  5. IGA, school fees, transport refunds, food;
  6. better transport; and
  7. hiring more staff.
  
- Improving child care — Staff said paediatric care needed
  1. a day care centre or ward for children;
  2. training in paediatric counselling, development of peer-to-peer counselling and school education to counteract stigma;
  3. food from weaning onwards;
  4. child-specific drugs, paediatric ARVs; and
  5. legal services.
  
- Challenges to sustainability — Staff suggested the sustainability of facilities was challenged by
  1. high staff turnover, reducing trust and losing skills;
  2. low salaries and lack of training causing staff to leave;
  3. breakdowns in drug supply;
  4. relying on short-term donor funding;
  5. lack of transport; and
  6. stigma.
  
- Avoiding double-counting — Staff recommended reducing the double-counting problem by
  1. sensitising patients about the dangers of combining drugs;
  2. strengthening the referral system;

3. a national database and ID cards;
4. each facility providing comprehensive care;
5. regular drug supplies; and
6. each patient collecting their own medication.

## **Patient focus group discussions**

### *Sample characteristics*

In Uganda, 47 FGDs were conducted with a total of 228 participants. Each focus group had between 3 and 6 participants, with a mean of 4.9. There were 85 men and 143 women. Four groups were male-only, 10 female-only, the remainder mixed. Participants were aged from 17 to 69 with a mean of 37.8 and median of 37. 151 lived in rural areas, 25 in peri-urban areas and 51 in urban areas. Household size ranged from 1 to 22. At 13 facilities, no FGD was conducted.

### *Services received, comparison of patient data with facility data*

FGD participants were asked if they had received a number of specific components of care from the facility where the FGD was held (CTX, mosquito bed net, test for TB, treatment for drinking water, post-test counselling, nutritional counselling, and family counselling).

During the analysis of the FGD data (both notes and recordings), and facility staff interviews of care offered, it was apparent that many patients responded to these questions without considering whether the care was obtained from the facility where the FGD was being held or by another facility. Therefore, the information in this table can be reliably used only to identify facilities where patients had not obtained the care either at this facility or elsewhere.

Table 49 below summarises the proportion of facilities that identified themselves as offering the specific components of care (from Table 17), and the number of FGD participants reporting themselves as having received that care (now taken to mean from any facility). This table shows that for most components of care, those that are more commonly offered are also more commonly received. The services most commonly offered and received were nutritional counselling (offered by 57 facilities and received by 87% of FGD participants) and post-test advice (offered by 54 facilities and received by 93% of FGD participants). The exceptions to the trend are condoms, which were offered by 54 facilities but received by only 60% of FGD participants, and TB tests, which were offered by 36 facilities and received by 32% of participants.

Table 50 summarises the extent of provision of specific components of care. The category 'some' comprises all the groups where at least one person received the care and at least one person did not. Where all participants reported having received the component of care this may represent it having been received at the facility where the FGD was held or elsewhere. Most notably, counselling and nutritional advice had been received by all the FGD participants at over three-quarters of facilities where the components of care were offered. However, a TB test had not been received by any participants in FGDs at nearly half facilities where the facilities said it was available.

Table 49: BCP care received by FGD participants

BCP component of care	Number of facilities offering care, n (%)	FGD participants receiving care, n (%)
TOTAL	60 (100)	228 (100)
Receives cotrimoxazole, to take every day	47 (78)	188 (83)
Has been given a mosquito bed net (ITN) for personal use	29 (48)	129 (57)
Has been tested for TB by sputum or X-ray	36 (60)	71 (32)
Has received anything to make sure drinking water is clean	23 (38)	127 (56)
Receives counselling about how to prevent transmitting HIV to others	54 (90)	212 (93)
Receives nutritional counselling	57 (95)	199 (87)
Received condoms for self or partner	54 (90)	136 (60)
Been encouraged to bring spouse/children for HIV counselling and testing	48 (80)	187 (82)

Table 50: FGD care received

Care component	Provided or referred by facility	Section of group receiving care, n (%) of FGDs			
		All	Some	None	Total
CTX	Yes	25 (61)	13 (32)	3 (7)	41
	No	4 (67)	2 (33)	0	6
Bednets	Yes	12 (40)	13 (43)	5 (17)	30
	No	4 (24)	7 (41)	6 (35)	17
Water	Yes	12 (52)	9 (39)	2 (7)	23
	No	6 (25)	6 (25)	12 (50)	24
TB test	Yes	1 (3)	18 (49)	18 (49)	37
	No	2 (22)	6 (67)	1 (11)	9
Counselling	Yes	34 (77)	10 (23)	0	44
	No	1 (33)	1 (33)	1 (33)	3
Nutritional counselling	Yes	36 (78)	6 (13)	4 (9)	46
	No	1 (100)	0	0	1
Family VCT	Yes	26 (63)	15 (37)	0	41
	No	3 (50)	2 (33)	1 (17)	6
Condoms	Yes	16 (38)	23 (55)	3 (7)	42
	No	0	3 (60)	2 (40)	5

Reasons for non-receipt of these components of care were explored in the FGDs, and the results of the discussion are presented below.

***Reasons for not receiving BCP services***

Most people reported that they had not had a TB test because they did not have the symptoms (prolonged cough, weight loss, night sweats) whereby a test is recommended. If people did not receive condoms it was either because they had lost interest in sex, said they were too old, or had lost their partner, had been advised to abstain, or they accessed condoms from another facility (frequently an NGO). In two groups people had been told that they would live longer if they abstained from sex. One person did not get condoms from the facility because she believed the counsellor would talk about her and then the patient would be called a prostitute. Another participant said the condoms were too small.

Of the 41 facilities which reported that they provided or referred for CTX, no FGD participants reported having received it at three facilities (7%). Some participants received CTX from another facility and were not aware that the surveyed facility provided it. They said that they accessed CTX from the same source as ART. Reasons for not receiving CTX included being allergic, getting it from another facility, or the facility having run out.

Bednets were reported by staff as being provided or referred at 30 facilities where FGDs were conducted, but at 60% of these, not all participants had got a net, and at five of them (17%), none of the participants had received a net. The usual reason given for not getting water supplies or a bednet was that these things were not available from the facility, or else that there were not enough to go round. Sometimes they were given only to high-risk groups (pregnant women, children under 5), given to new patients, or else simply distributed on certain days until they were all gone.

***Main HIV services and medicines received from the survey facility***

The care components that FGD participants most frequently mentioned that they received were counselling, CTX, treatment for opportunistic infections, malaria treatment, and starter kits including water treatment and bednets. Several IGA programmes were described, including provision of seedlings, hoes and garden equipment, microfinance, chicks and piglets. Some people reported that they had received bicycles, t-shirts and training in peer counselling at the facility.

The elements of counselling services received covered family planning, adherence, nutrition and prevention as topics. Participants reported that some facilities provided material items (such as clothes and household equipment), or food (posho, oil, rice, sugar). One participant reported receiving reflexology, and another reported aromatherapy.

Participants mentioned numerous medicines that they had received from facilities. The medicines most frequently named were antimalarials (particularly Coartem and injectable quinine), non-opioid painkillers, skin rash creams, and magnesium as a mineral supplement. Antibiotics and antifungals were mentioned less frequently, perhaps because there are many different possible formulations and the same ones are not likely to be repeated. Finally, ARVs were specified by name or simply as ARVs, and nevirapine for PMTCT was mentioned several times.

***Best services, areas needing improvement, problems obtaining medicines***

Participants reported many different services that they thought were good. Psychological care services, such as counselling, were mentioned more frequently than clinical care services. The benefits

of counselling reported included mending marriages and relationships, increasing confidence, behaviour change, an HIV test leading to ART and restored health, stigma reduction, helping people protect their families, keeping them going, and mutual support.

The clinical care services that were mentioned as being among the best services received included ART, CTX, infection treatment, malaria treatment and IV drips. Patients said that before they received this care, they had frequently suffered from infections and malaria. Other areas of care commonly valued by patients were ITNs, water guard, food and home based care. For many of the services mentioned, participants valued them highly because they were free of charge.

The importance of the highly valued services above was reinforced at other facilities, as the services not meeting patient satisfaction showed several similarities. Participants at several facilities wanted to receive ARVs. The poor supply of several drugs, particularly CTX, was unsatisfactory to patients.

There were many references made to aspects of staffing, as both strengths and weaknesses of facilities. More staff and better training were called for by patients; more staff to reduce waiting times and allow facilities to be open every day, and better training because counsellors were perceived as not always discreet or respectful. There was a perception that the standard of counselling had declined over time.

Participants thought that facilities would be improved if they provided more ITNs, water guard, IGAs, and food. They said that food made it easier to take the ARVs and also would stop people going hungry while they wait at the facility.

Many patients reported having problems obtaining drugs. Facilities running out of drugs, particularly CTX, were mentioned by patients at many facilities. When pharmacies ran out of stock, patients said that they had to pay to access the drug from elsewhere. Patients also reported that sometimes there were long delays in obtaining drugs from the pharmacy when staff did not turn up and patients had to wait, which they found disrespectful. It reportedly could take 6-8 hours to get a drug dispensed from the pharmacy. Patients also said that they needed to bring their own medical supplies such as cannulae, as these are frequently unavailable on site.

The combination of CD4 tests and transport recurs frequently in people's statements. CD4 tests seem to be regarded as the one aspect of regular care that requires a long journey and there is great demand for decentralisation of CD4 machines.

### ***Services from other facilities***

Almost every FGD produced a list of other health centres and hospitals where people obtained care. Only one mentioned a herbalist (traditional healer). All the rest were biomedical facilities. The list of care received was broadly similar to the care received from the surveyed facility. There was more emphasis on ART, on CD4 counts, and on food, but otherwise there were no notable differences.

***Reasons for visiting other facilities***

The main reasons FGD participants gave for visiting facilities other than the one where the FGD was held were referral, proximity, and availability of services. Some people had been referred to a service which provided ART, often not the nearest to their home, and continued to receive other care, such as counselling, and support, from one closer to where they lived. The place where the CD4 test was conducted may be the place from which ART was provided. In some cases participants also got CTX from the ART provider.

Participants pointed out that if a service was close by, or offered home care, it was cheaper to access, even if it charged for services, because the cost of transport was reduced. Facilities which had longer opening hours were also more accessible. Some patients said their local facility was open only on certain days of the week, so outside that time they travelled further. A couple of participants reported attending private clinics when there was a long wait at the public one.

FGD participants said that other people, men especially, wished to travel further to attend facilities in order to maintain anonymity. Some facilities were recommended to participants by staff or by friends. Facility qualities included availability of drugs, polite staff, confidentiality of counsellors, and food provision. Some participants had specific services that were cheaper for them, such as a military hospital for the families of soldiers, or one facility, which reportedly provided free care to widows. CD4 count machines were rare (many services said they would like to have one); one facility had support groups which contributed money towards bus fares for the members to attend facilities which had CD4 count machines.

***Ways to attract more people, additional services, suggestions***

A number of aspects relating to privacy and confidentiality were suggested as ways to improve the services offered. One of the most frequent and serious complaints about facilities was that counsellors betray patients' confidence. This had reportedly led to family break-ups and job losses, and made people reluctant to come for care. The participants said that patients would go to facilities where the counsellors were well trained. One facility named by participants at several surveyed facilities was well-trusted but only took patients by referral. However, they said they would like to go to that facility directly and be tested there to ensure no-one else found out about the result. At one facility the family planning nurse was male and FGD participants said women were reluctant to talk to him.

Participants made references to several 'concrete', visible aspects of a facility as ways to encourage more people to attend. Offering ITNs, water guard, food, clothes, blankets, and even money were some of the suggestions made.

Participants reported that food was important because the ARVs were 'very strong', and required food in order to take them. Adults preferred to go without ARVs, rather than take them on an empty stomach. Participants said that ARVs increase the appetite of children and make them want more to eat than families can afford, and there is an implication that some elderly or very poor carers may withhold ARVs from children for this reason. Additionally, when patients had to wait for up to six hours at a clinic, there could be a canteen or tea stand for them.

Outreach through drama was described as another way to increase attendance at services. Participants described a combination of peer educators, to publicise their status, and facility staff, to show that they are concerned and able to help, undertaking outreach as most effective. To undertake this work would often require transport, although outreach by radio was another suggested means. Women were more likely to come forward generally, and so participants suggested outreach to be targeted towards men.

Participants reported several groups of people that were discouraging use of HIV services. Participants reported that some religious groups tried to persuade people not to take their ART and instead to have faith that they will be cured, which they had found concerning. Participants felt that politicians had discouraged people from attending services because some had discriminated against people with HIV through policies. Another complaint was that politicians queue-jumped at facilities, compelling staff to treat them first, reporting them to the District Medical Officer if they did not, and leaving insufficient resources for other patients. In this context it is unclear who the politicians are. The important issue to the patients was that some people unfairly had priority access to medicines.

Participants suggested a number of aspects relating to service availability to increase uptake, such as having a clinic open every day, with longer opening hours, and reliable drug supplies. To reduce stigma, participants said there should be a separate clinic for HIV. Participants suggested that having HIV tests available nearby, or offering a reward for being tested, would increase uptake.

Often it was repeated that orphans and vulnerable children need extra help and that the facility should do more to look after children, in particular to feed them. A need for an infant feeding alternative to breast milk was mentioned. Children faced stigma in school, both from staff and other pupils, and participants suggested there should be school education programmes to fight this attitude.

Asked what care they wanted to see, participants said transport, food, home care, IGA, school fees and positive living. School fees, in particular, were repeated. There were several anticipated benefits of providing IGAs. Firstly, IGA was thought necessary to allow people to feed themselves and pay for transport to the clinic. Secondly, participants thought IGA would stop young people becoming involved in prostitution.

A third stated purpose of IGA was to change the public perception of people with HIV as individuals who are dying and cannot think, or plan or do anything. Participants reported that some people with HIV had become dependant on their carer through an assumption on everybody's part that they are no longer capable, so they ceased to make decisions, or even speak for themselves. An IGA programme could be an indication that people were responsible and able to cope. Participants asked to be given the opportunity to prove what they could do. They also wanted representation and access to conferences, and asked for information, for instance about the side effects of the ART. Finally, they wanted love, care and support.

*Cross-cutting themes from patient FGDs*

The components of care that patients most appreciated receiving were counselling and support, ART and clinical care. The care they said should be more developed were provision of bednets and water guard, IGAs and food. IGAs, to some degree, represented food. The IGA programmes were based on gardening or rearing livestock. Patients said that money generated would be spent on food and the programmes themselves would change perceptions of people living with HIV and prevent young people from going into prostitution. Participants suggested that offering visible items like bednets would increase the numbers coming for testing, or indeed that people should be paid to have an HIV test. In all these suggestions there is a sense that behaviour can be changed by the offer of comparatively small incentives.

Several social and cultural issues arose during the FGDs that affected the participants in different ways. Two groups said that religious leaders in the area were discouraging people from taking ARVs, and asked if the facility could do something about it. Common psychosocial issues that patients reported revolved around daily stigmatisation. Their children were bullied at school, politicians discriminated against people with HIV, health staff were perceived as occasionally treating patients badly, and they became dependant on carers.

Aspects of infrastructure were important issues to patients. Several groups reiterated that they wanted a separate clinic for HIV, in order to reduce stigma. They wanted their own place to come for care, with their own staff, which should be open every day. The other main infrastructure issue was drug supply. Stockouts were frequently reported as a problem by patients, but it was just as common for patients to complain about long queues at the pharmacy and “shopping around” between facilities.

The conduct of staff influenced patients in several ways, including which facility patients visit, and whether they go to any at all. Patients often felt keenly that staff do not respect them. Participants said it was important for peer educators and facility staff to conduct outreach together – the peer educators to publicise their status, and the facility staff to show that they cared. Patient said they wanted love, care and support from staff. They praised facilities where staff were polite and discreet. Pharmacy staff were sometimes reported to treat patients poorly, and to arrive late or leave them waiting while they went for lunch.

Whenever distance or transport was mentioned by FGD participants, it was almost always in the context of expense to patients. The impression given was that the cost of public transport to the health facility was a considerable burden. They suggested HIV tests should be more widely available to increase uptake by reducing the need to travel to specific test centres. At one facility, support group members had set up kitties solely for the purpose of paying for transport to obtain a CD4 test.

In summary, the important factors about a facility from the patient’s point of view were the services it provided, the attitude and ability of its staff, and its accessibility in space (distance, cost to reach it) and time (opening hours, length of queues).

### *Summary of focus group discussions*

- Care received — Participants received
  1. clinical care (treatment for malaria and other infections, CTX, ARVs) psychological care (counselling, peer counselling training); and
  2. social care (IGA, food, water treatment, ITNs).
- Best services — Participants liked
  1. psychological care, particularly counselling (restores relationships, behaviour change, led to HIV test, stigma reduction, mutual support);
  2. clinical care (ARVs, CTX, symptom reduction from infections including malaria, IV drips);
  3. social care (ITNs, water guard, HBC, food); and
  4. services that were free.
- Services needing improvement — Participants wanted
  1. more staff, and more training for staff;
  2. longer opening hours, shorter waiting times;
  3. reliable drug stocks;
  4. IGA, food, water guard, ITNs; and
  5. food and school fees for OVCs.
- Reasons for going elsewhere — Participants reported going to other facilities
  1. because referred there
  2. to get ARVs food, a CD4 count
  3. because it was close by (cost of transport
  4. on recommendation from friends
  5. for anonymity
- Suggestions — Patients suggested
  1. improved training;
  2. offering social care (blankets, food, clothes, ITNs);
  3. outreach through drama, peer counselling, radio;
  4. clinic open every day;
  5. infant feeding alternative to breastmilk;
  6. school education programmes to counter stigma; and
  7. IGA to raise self-efficacy and prevent prostitution.

### **Integration of data from staff open-ended questions and patient FGDs**

The comments of staff and FGD participants illustrate similar concerns, from different viewpoints.

Facility staff realised that rapid staff turnover and lack of training was a problem in providing a good HIV service, and patients corroborated this by describing their concerns regarding perceived poor training and demotivated counsellors and clinical staff.

Patients thought that provision of drugs, including CTX, were some of the best services they received, and staff also saw them as one of the strengths of their facilities. Both staff and patients realised drug supply could be a problem, but staff only talked about supply to the facility whereas patients also discussed the difficulties at the facility, such as queuing time at the pharmacies.

Finance was a strong theme to emerge from both staff and patients. Many of the facilities' reported problems, such as staff turnover, lack of training and stockouts, related to funding, and many of the patients' reported problems, such as accessing multiple services, needing food to take with ARVs, and the need for social support from facilities, related to a lack of money.

Staff reported that they could not afford to provide a vehicle, and patients said that they needed it. Transport links were associated with accessibility for patients. Staff thought it was important for the facility to conduct outreach and home-based care using a vehicle. Patients seemed to agree as they found transport to the facility a significant problem.

Patients and staff shared a common idea of what a good service should include. The desired ideal service, perceived problems and consequences of these problems are listed below.

### *Staff*

- Desired: staff who are trained, motivated, multiprofessional and respectful of patients
- Problems: Poor motivation due to low pay, few training opportunities, limited options, volunteer status and lack of remuneration, overwhelming need leading to burnout.
- Consequences: unprofessional behaviour, disrespect towards patients, high staff turnover and poorer quality care.

### *Drug supply*

- Desired: constant supplies of ARVs, antibiotics, analgesics, antifungals, CTX
- Problems: lack of control over stock, staff behaviour as above, insufficient drug supplies
- Consequences: stockouts, long queuing times, patients shopping around, more expense, resistance

### *Transport*

- Desired: HBC for convenience and cost, reimbursement for travel, transport to care centre for the sick, team outreach to rural areas by vehicle
- Problems: shortage of money, vertical programming restricting funds, lack of skills and parts to repair vehicles (sustainability)
- Consequences: no vehicle, or vehicles broken down or without fuel, preventing outreach programmes and HBC

### *Poverty*

- Desired: no hunger, children in school, jobs
- Problems: insufficient food, ARVs increase appetite, no money for school fees especially for OVCs, stigma, ill health, low perceived self-efficacy
- Consequences: refusal of ARVs, children not in school, unemployment, dependence, need for social care

# Discussion

## Selected facilities

Activity data from 2006 provided by PEPFAR demonstrated that there were a large number of facilities which were reported as each providing care for a relatively small number of patients. For this reason, facilities were selected at random from 3 strata based on PEPFAR 2006 attending patient numbers, with the aim of obtaining a sample of facilities that represented the range of facility sizes (defined as patient numbers seen) in the country. The statistically significant correlation between the routine data and the survey data found indicates that higher patient figures provided by PEPFAR matched with higher figures reported by facilities, although there were still substantial differences in patient numbers from the two sources.

## Patient characteristics

In Uganda, UNAIDS estimates that slightly more than half of people aged over 15 with HIV are female (UNAIDS). At the facilities surveyed, 65% of adult patients were women. This suggests that men were less likely than women to access care. Clearly, there are implications for equity of service provision, and public health implications in terms of men either not presenting for testing or for subsequent care that includes prevention with positives. Staff participating in this phase of the evaluation recommended outreach programmes targeted at men.

About 10% of people with HIV in Uganda are thought to be children (defined as under 15 years) and 6% of patients were children (although solely paediatric facilities were excluded from this survey). Twelve facilities did not provide care for any children. The mothers of children with HIV are usually HIV positive themselves. Separating paediatric and adult care requires families to travel greater distances and spend more time on appointments. At facilities which did offer paediatric care, staff frequently stated that these services were underdeveloped.

## Infrastructure

Thirty-two facilities had an ambulance, of which 5 (16%) were not functioning at the time of the survey visit. In the survey an ambulance was defined as any vehicle capable of transporting a patient. Lack of transport was named as a challenge to sustainability at 17 facilities. It hampers outreach to rural communities and raises costs for patients to access care. Home-based care requires transport and this model of care was valued by patients. Home-based care facilities were the most likely to offer social care, the least developed of the five PEPFAR areas, and the one preventing most facilities from offering complete care and support.

Of the thirty-eight facilities with a generator, 6 (16%) were broken down or out of fuel. This reduces the possible care that can be provided and may limit opening hours and increase waiting time, both common complaints. Only 3 facilities lacked a functioning toilet which patients could use, but one of them was a hospital. Ten facilities lacked a safe water supply. Without such basic infrastructure, infection control is likely to be compromised.

## Staffing

Although PEPFAR HIV care and support is seen as holistic, the availability at facilities of staff who specialised in different components of care was variable. Whereas most facilities had clinical staff onsite (especially nurses, and often doctors/clinical officers), traditional healers, social workers and spiritual care staff were rarely employed, even when care in the area was offered.

When all types of care and support staff are considered – i.e. the proportion of facilities that had clinical, psychological, spiritual and social staff of any designation all present – fewer than 20% of facilities had staff of every type. These data show that very few facilities offered professional multidisciplinary holistic care on site, and suggest that staff may have had to meet needs outside their skill base. For example, twenty facilities were providing counselling services without having any designated counsellors. Further, half of facilities had no doctor, a third no clinical officer, over half no pharmacist, four-fifths no social worker, and nearly half no counsellor. These skill shortages necessitate patients attending multiple centres. In particular, patients reported seeking out facilities with a good reputation for counselling. Counselling services were almost universally provided, but in many cases they were delivered by unspecialised staff, leading to a patient-reported inadequate quality of care.

This lack of focus on specialised psychosocial and spiritual care provision is likely to have overburden the clinical appointment times available, as medical and nursing staff deal with problems that present within consultations. It may also fail to resolve (or even compound) patients' problems, either through provision of inadequate psychosocial care by untrained staff or through forcing patients to attend at another facility with the costs and time involved in travel. Psychosocial care provision requires significant investment in time, a very limited resource for overburdened staff with high patient loads. The seven facilities which employed social workers required them to care for a median of almost 2000 patients each.

Further, high patient load and a sense of inability to cope with the level of need can lead to loss of motivation and burnout in staff, causing poor retention with consequent loss of skills and experience. Low motivation was seen as a problem by both staff and patients.

Evidence from multiple sources suggests that the issue of lack of specialist care affected patient experiences. Issues of the management of confidential information on the part of staff had reportedly led to significant negative life events for some patients. Patients reported that they sought out facilities where the counsellors had a reputation for good professional behaviour and confidentiality. Further training on the importance of this issue and appropriate behaviour for counsellors may build trust and attract more people to facilities.

On a more general level, both staff and patients reported a desire for staff to receive further training. In particular, staff themselves acknowledged a need for more counselling training, especially for paediatric counselling. The attitude and behaviour of some staff was of concern to patients. Patients reported in FGDs that one of the main reasons service uptake was not higher, and also a powerful reason to attend another facility, was the behaviour of some staff. There were complaints of indiscretion, ill-mannered behaviour and breaking of confidence, leading to a lack of trust between patients and staff.

Five facilities retained paid spiritual staff, but did not provide any of the spiritual components of care explored. This suggests that they provided other types of spiritual care which were deemed important enough to pay a specialist to offer. The survey did not capture these components of care.

Volunteers were key members of facility staff, but many questions remain about the role of volunteers in care provision. They were often the primary care provider at a facility (particularly HBC-only facilities), but the definition of volunteer, their motivation to volunteer, volunteer staff turnover, the quality of care provided by volunteers and the sustainability of the care they provide are largely unknown. It should be noted that not all staff types were included in the survey and NGO facilities may well have paid administrative or other support staff.

In terms of retention and sustainability, it is notable that across the entire sample, a significant amount of care was provided by volunteers, both professional and lay, including spiritual care provided voluntarily in 17% of facilities, community health workers at 60% of facilities, and counselors at 20%. Volunteering is a positive reflection of commitment to HIV care by a community, and enables facilities to extend their reach with limited resources, but the sustainability of this approach is unclear. Further investigation would enable successful dissemination of methods of training, supervision, and retention to other facilities. This is crucial to quality and continuity, as in health posts and HBC facilities the percentage of staff who were volunteers was 29% and 88% respectively. Staff also raised concern over the sustainability of facilities with such great reliance on volunteers. Volunteers were reported as having a high turnover, and could leave at short notice. Voluntary staff themselves reported being financially disadvantaged as a result of undertaking the work at facilities and desired some recompense for their expenses, thus highlighting that although voluntary staff were not paid, they did incur other costs which they felt should be borne by the facilities employing them.

### **Care provision at facilities**

Care available at facilities was usually provided free of charge to HIV patients, thus maximising access at point of delivery irrespective of ability to pay. However, the cost of transport to get to facilities was an issue for patients, and seemed to be a greater disincentive to patients than the free care available was an incentive. Some patients reported that they paid for drugs which were delivered to their home, because it was cheaper than taking the bus to the free clinic. Long queues and stockouts at the pharmacy were additional problems in accessing care that were frequently reported by patients.

A wide variety of care components were provided onsite at most types of facilities, a mean of 36 offered in all types of facility out of the 69 surveyed. Furthermore, coverage of the different areas of care surveyed was good at the larger types of facility; all hospitals, health centres and health posts provided some element of clinical, preventive, and psychological care. However, social care and spiritual care had much lower coverage throughout all facilities. It may be that these areas were not considered to be a part of health care at some facilities. Multidisciplinary care and support for HIV requires the provision of care in all five areas. Social care, in particular food, school fees, and IGA, were components of care most likely to be named by FGD participants as received elsewhere. Staff also reported that they wanted to develop social care, and that a lack of it was a weakness.

Formal referrals for several components of care, such as physiotherapy, TB treatment, and cancer management, were often available. However, the urban bias (indicated by the geographical distribution of facilities in Figure 2) in the randomly selected sample of facilities means the care components for which referrals were commonly seen are likely not to represent the situation in more rural or remote areas, where fewer other facilities may be available locally to meet additional needs. Further, as cancer is a common presentation of advanced HIV, it is noteworthy that for 23 sites there was no provision or referral. It is unclear whether this is due to lack of local providers or weak referrals. The quality of referral mechanisms is unknown, and systems did not appear to be robust.

## **Components of care by theme**

### ***ART***

Facility staff saw the ability to provide antiretroviral therapy as a strength, and patients in FGDs reported that it was one of the services that they were most pleased with. All the facilities which supplied ARVs onsite reported that they gave them to all patients who needed them. At the same time, some staff reported that they regretted having to ration the number of people who could begin treatment in order to maintain a supply for those already using ARVs. It is possible that when staff reported no restrictions to receipt of ARVs they meant that people were enrolled on a 'first come, first served' basis, rather than by other criteria.

Two facilities could not provide data on the number of patients treated in the last three months. Most patients' documentation sheets did not include information on ART or other drugs. Good record-keeping is essential for an ARV programme to maintain adherence and prevent waste. It is evident from the lack of information in other areas, for example number of patients enrolled and number receiving CTX, that this was a weakness for some facilities. Other support services for ARVs, such as toxicity monitoring, were usually available, although as with all self-reported data, the quality of care provided cannot be ascertained.

### ***Pain management***

Pain is a common (Solano, Gomes & Higginson 2006) and distressing symptom for people living with HIV, which can affect other areas of a person's wellbeing, such as psychological and spiritual wellbeing, mobility and social activities. Yet, it can be cheaply and easily controlled. Uganda is a model country for Africa in terms of morphine availability and usage (Logie and Harding 2005), with the result that 20% of facilities claimed to provide morphine onsite and 37% to refer for it. In the pharmacy, however, only half the facilities which reported providing morphine actually had any in stock, and one of these had only injectable morphine.

People in Africa are commonly cared for at home, and the most effective way to provide opioids is orally, according to the Who Pain Ladder (World Health Organization 1990). It is far less feasible and effective to manage pain through injectable morphine than through oral liquid forms that can be administered by the patient and family.

In general, hospitals and health centres reported good availability of strong and weak opioids, either directly or by referral, while health posts and HBC facilities reported poor availability. Evidence from the pharmacy review proved some of these claims to be overstated. Nonetheless, the reported data show that hospitals and health centres at least were not opposed to the use of opioids.

The fact that reported provision was higher than real provision suggests that more facilities would use opioids if certain barriers were overcome.

The availability of other analgesics was variable. Fifty facilities reported providing non-opioid analgesics but only 39 (78%) had any in stock. At a third of facilities, patients were unable to obtain painkillers of any kind, with the consequent effects on quality of life and functioning. Additionally, some facilities had very low quantities of these drugs, reaching a minimum of only 40 tablets of non-opioid painkiller. These low stock levels for analgesics and the high levels of stockouts recorded for many drugs raise questions about the availability and sustainability of analgesia for patients.

### ***Psychological health***

All facilities provided or referred for at least one component of psychological care, namely adherence counselling, and pre- and post-test counselling was also provided or referred at 56/59 facilities. There is evidence of great psychological distress among patients newly diagnosed as HIV positive, and that these needs continue and change over time (Meursing and Sibindi 2000). FGD participants reported that HIV led to broken relationships and divorce, loss of confidence, internal and external stigma and loneliness, and that counselling helped them tackle all these problems. Therefore, finding broad availability of psychological care is encouraging. However, the evidence suggests this care was often provided by non-specialists. 22 facilities provided psychological care but did not employ any counsellors. This is a potential problem, especially as one of the main complaints of FGD participants was the alleged unprofessional behaviour of counsellors which was believed to be caused by lack of training. Counsellors were reported to have betrayed confidentiality and lost their patients' trust, deterring patients from accessing healthcare. Staff reported feeling a lack of skill and inability to provide adequate counselling, most especially for children.

Treatment for anxiety and depression were rarely available. The prevalence of these symptoms is very high among people with HIV (Ciesla and Roberts 2001), and, as in the general population, women are particularly at risk (Olley et al 2004). Depression is associated with lower ART adherence and hence with faster disease progression and lower quality of life (Campos et al 2008). Appropriate psychotropic medication, in combination with behavioural therapy, has been shown to relieve depression and anxiety for people with HIV (Repetto and Petitto 2008).

### ***Nutrition and social care***

For almost 30 facilities, the single factor preventing them from providing (onsite and by referral) a complete package of care encompassing all five PEPFAR domains was the lack of social care provision. Social care is the least developed PEPFAR care domain in the survey population. This lack is particularly apparent in hospitals, given that they generally had the highest care provision in all other areas. Social care was most often provided at HBC facilities, which generally had the least clinical care. There appears to be a trade-off between these two areas of care, although both are vital for HIV care and support. The most effective way to increase the number of facilities providing a complete package of care would be to invest in social care.

One of the services most frequently requested by FGD participants was food, especially for children. Staff also wished to provide food and felt that their facility was not offering full care without it. Nutritional counselling was widely available, as were multivitamins to a lesser extent, but these

combat vitamin deficiencies, not hunger. Qualitative studies have reported that one of the main deterrents to antiretroviral initiation, and one of the main reasons for low adherence, is the physical pain of hunger caused by increased appetite following ART (Au et al 2006; Hardon et al 2007). FGD participants reported that carers did not put children on ART because they could not afford to satisfy their increased need for food.

Engel's Law is the observation that as income goes up, the proportion of income spent on food goes down; consequently the poorest people spend the highest proportion of their income on food. Rejection of free lifesaving medication on the grounds of inability to afford enough food to stave off pain suggests very severe poverty.

The other financial stressor most frequently mentioned was the cost of transport, also recognised as a major impediment to ART adherence in East Africa (Hardon et al 2007). Income-generating activities were seen by FGD participants as the solution to food insecurity and transport problems, as both stem from limited financial resources.

### ***Opportunistic infections and preventive care***

This survey examined the provision of preventive and curative care of general OIs and some specific HIV-related infections, in particular malaria, TB and sexually transmitted infections. People with HIV are more vulnerable to malaria infection and experience more severe symptoms (Slutsker & Marston 2007). STIs cause high morbidity in the HIV-positive population and are also associated with increased infectiousness and greater probability of HIV transmission (Wasserheit 1992). Coinfection with TB is the single highest cause of mortality for HIV-positive Africans (Corbett et al 2003), while HIV is the single biggest risk factor for activating TB (Bock & Reichman 2004). The synergy between the two has led to TB/HIV being described as a 'dual epidemic'.

- **Basic Care Package** — The purpose of the BCP is to serve as a short list of components of care that every person with HIV should receive as a preventative measure, to protect them from water-borne infections and malaria, and to protect them from transmitting HIV (Mermin et al. 2005). Not all the items are suitable for everyone, for instance families with piped water do not need a water filter. They are a minimum level of immediate care rather than being the best option for all.

Patients said that apart from their primary use in preventing infections, the components of the BCP would encourage retention and uptake of services because prospective patients would see tangible evidence of benefit from care. Staff were keen to provide the BCP and thought it would improve the care they delivered.

Some patients reported that they had not received ITNs and water treatment because there was a limited supply. At other facilities, the FGD participants stated that they were sure these items were not stocked at the facility because they would have been given them if they were available. Eligibility criteria were unclear, and there was a sense that some people were fortunate enough to receive items while others were not. The perceived arbitrariness of receipt encouraged people to access services at numerous facilities. 'Shopping around' is inevitable if the BCP is not available at all facilities.

To maximise the effectiveness of the BCP, it is necessary to examine its availability at facility and patient level, and to evaluate its usefulness and acceptability when delivered as a single entity and as separate components.

- **Malaria and TB** — Malaria treatment was one of the most frequently named services in FGDs when patients listed the services they valued, indicating both that malaria is highly prevalent in this group and that treatment makes a substantial difference to their lives. (It is also possible that ‘malaria’ is used as a generic term for illness, because it is so common.) The interventions to diagnose and treat malaria and TB were more likely to be present or referred at facilities than interventions to prevent them. Prevention of these infections is more effective than treatment. Insecticide-treated bednets, which demonstrably reduce morbidity and mortality from malaria, were not provided or referred at 42% of facilities despite the fact they were a part of the BCP.
- **Opportunistic infections** — Treatment for opportunistic infections and symptoms was widely provided or referred at the larger health facilities, and at about half of HBC facilities. Staff saw the ability to treat infections as a facility strength, and it was rarely an area which they said needed improvement. Six HBC facilities did not provide or refer for symptom management, concentrating on social and psychological care instead. There is an opportunity to provide basic clinical care through these facilities and encourage referral networks for other conditions, linking the home-based social programmes to larger medical facilities. Some treatments are likely to be general, such as skin rash which is often treated with cream, and diarrhoea which is managed with oral rehydration solution. These simple procedures do not require advanced clinical training and could potentially be easily scaled up. Fluconazole was stocked by only 24/59 facilities but other, generic antifungals are more commonly used and were reported at most facilities. FGD participants frequently said they had received topical cream, and seemed to bracket it with analgesics as symptom management rather than solely treatment.
- **Prevention with positives** — Condoms were available at nearly all facilities but individuals reported difficulty obtaining them. One woman was afraid the counsellor would spread rumours about her if she requested condoms. The alleged unprofessionalism of the counsellor, whether justified or perceived, was a barrier to preventive care and this case is a clear demonstration of the importance of training and monitoring for counsellors. Several people had been advised to abstain from sex and some had been told they would live longer if they did so, which is not supported by evidence.

There appears to be a difference between the term ‘PWP’ as understood by facility staff and the PEPFAR definition, as more facilities reported offering PWP than reported offering the separate components of it. It is possible that PWP was interpreted to mean PMTCT, which was not an area of investigation of this survey.

### ***Diagnostic tests***

One of the main reasons for FGD participants to visit other facilities was to obtain a CD4 test, and one of the pieces of equipment staff were most likely to want was a CD4 machine. Nineteen facilities possessed a CD4 machine and 18 referred out for the test. Liver function tests and CD4

counts, which are both necessary for monitoring and treatment assessment, were not always available through ART-providing facilities. In a resource-limited environment, it is not practical for every health facility to be equipped with expensive laboratory equipment, demonstrated by the fact that over 40% of facilities had no electricity at the time of the survey. In some cases, such as dried blood spot test for infants, a sample can be taken at the local clinic and transported to the referral facility, provided a strong referral network exists which allows this kind of arrangement to develop. With facilities referring for a median of 7 out of 69 components of care, the referral network was apparently short of what it could be.

### **Pharmacy supplies**

Some facilities had very small quantities of drugs, for instance 15 morphine tablets or 40 paracetamol tablets. It is possible to provide care with small drug quantities if restocking is frequent and the lead time is short, but evidence from patients of long queues at pharmacies or having to buy drugs elsewhere because facility stocks had run out suggests that the supply chain was often compromised. Part of the issue relating to drug supplies could be due to inadequate monitoring at the facility level. For half the drug formulations, no stock levels were used, and many facilities used the stock level of 1, i.e. they ordered more of a drug when the last pack was opened. This again relies on a short lead time. Eleven facilities had no stock control sheets, and of the 49 who reported using them, only 14 provided a copy, many of which lacked key information. In particular, expiry dates and stock levels were missing more often than not. A pharmacist at one hospital reported that they were allowed to order only a certain amount of each drug per month which was not enough to cover the need, making stockouts inevitable. Forty-seven percent of the facilities which stocked the listed drugs reported at least one stockout in the previous six months.

Although oral morphine is more widely available in Uganda than in most other developing countries, and nurses are able to prescribe it (Harding et al. 2007), morphine was only offered directly at 12 facilities and found in the pharmacy at only 8 of these. One only had an injectable form of morphine, which is not suitable for chronic use.

### **Facility strengths and weaknesses**

Although the patient FGD data, in practice, probably refers to services received from numerous sites, rather than the site at where the FGD was held, this is indicative of “real world” practice and is supported by other data sources on patchy comprehensiveness of components of care, sometimes weak referral networks, and stockouts. If the outcome of interest is receipt of services, rather than source of receipt, then this data is useful when interpreted in light of the other data sources reported and is a usual facet of the multi-methods design. The results indicate that not only did patients access a number of services, but that this was due to both the limited care range available from individual sites and the manner in which it was provided. A survey of this size is too complex to analyse and evaluate at the site level, and further network analysis studies would be appropriate. However, Phase 2 will examine receipt, and sources, of components of care.

The integration of FGD and staff interviews show that although a component of care was described by staff as provided at the facility, it was received by comparatively few respondents of the FGDs (e.g. condoms and water treatment). As this is not a needs analysis (i.e. patients in the group may not have needed those specific interventions, as for example not all patients will need CTX,

TB testing, condoms) the FGD is illuminating in describing why they believe they did not receive a component of care. For example, patients reported limitations placed on eligibility for condoms and bednets which had not been stated in the staff interviews. Further examination of facilities' operational criteria would be useful. There was evidence of condoms being refused by patients for fear of stigmatisation originating from facility staff. Further, as this analysis is of patient receipt of services irrespective of site, the data is useful in that it shows that at some facilities some components of care were not received by any focus group participant- e.g. condoms, water treatment, and bednets.

It is notable that patients most commonly cited the need for social intervention, as this was the area in staff interviews where the biggest lack in dedicated staff was identified. Further, patients requested longer facility opening hours, which supports the finding that in some sites the number of hours for both clinical and non-clinical staff appointments was very low (one third of all sites had clinical time for only up to 20 hours per week).

The need for transport and outreach/mobile clinics is suggestive of rural patients having difficulties attending for care, a problem that would be far worse for those attending sites that do not offer comprehensive care. Patients stated a preference for sites that provided comprehensive care in a single place or provided home-based care. They also preferred a separate unit for HIV patients away from the main health centre.

## **Document analysis**

The main findings were the relative absence of pain and psychological assessments when investigating patients' presenting symptoms. Without an assessment of these aspects it is unlikely that they can be effectively managed.

In general terms, the documentation analysed from the reporting sites were not multi-dimensional in nature (with a number of key domains omitted) or multi-professional from a user perspective (i.e. they were primarily to be used by clinicians and nurses). In order to reflect the provision of holistic HIV care, documentation should include its physical, psychological, social, spiritual and cultural aspects for both the patient and their family. Similarly, providers of such diversified care (including counsellors and spiritual care givers) should be accorded a role within the care giving process, with documentation that can capture role and impact. Only two patient assessment forms recorded religion, the basis for beginning to assess spiritual care need or to ensure appropriate care. Social need was also absent as few forms recorded income, job description, or even literacy.

The study found limited documentation of ongoing as well as new presenting patient problems, and found utility in the ongoing contact assessment sheet that gathers information across a number of key domains to help ensure continuity of care among health care providers.

Most facilities did not record the use of herbal medication, which is widely used among HIV patients in Uganda (Langlois-Klassen et al 2007), and can potentially result in decreased ART bioavailability, treatment interruption, resistance and even failure (Mills et al. 2005). Though currently practised by a few sites, these are areas of good practice that should be replicated elsewhere to further develop the existing integrated model (i.e. traditional and western medicines) approach in HIV care, enhancing uptake of medical services and promoting retention of patients.

## Limitations and strengths

There are a number of limitations to this Phase 1 data. Firstly, the calculation of proportion of patients receiving specific components of care could not be conducted as patient numbers were often missing or seemed unreliable. The information, though basic and essential for monitoring activity, was sometimes difficult to obtain. For instance, 14 facilities (23%) were unable to give a precise figure for the total number of patients they had cared for in the past three months. Others may have taken their figures from the number of people taking ARVs, which have to be monitored closely and may be the best record they have. The lack of monitoring data carries implications for service planning and relates to specific difficulties such as stock-outs. It is difficult to see how a facility could plan effectively without knowing how many people it serves.

Second, under document analysis, despite many documents reportedly being available at the facilities, a large proportion of facilities could not supply the researchers with a blank example document in order to undertake analysis of content. This limited the depth of the analysis of content that could be undertaken and raises the risk of bias. The reasons for this are unclear, and we are following up each facility to identify reasons for non-provision of documents and to retrieve documents where possible.

Third, under the patient FGD, participants were patients who were present at the facility on the day of the visit who were asked to participate by facility staff. The participants were not necessarily representative of the wider HIV positive population, although a purposive sampling frame was proposed to staff. Some patients become peer counsellors and receive training from the facility, but they did not take part in the focus groups. Owing to the large number of FGDs that were undertaken to complete this part of the evaluation (in addition to the pharmacy review and staff interviews) it was not possible to record verbatim, transcribe, translate and analyse the FGDs in the usual way in the time scale available. Instead notes were taken by the researcher during the FGDs, and these were analysed for content. This method is likely to have limitations in their detail which may have meant that some views or opinions were not reported here in depth.

Calculated patient loads are subject to limitations. Firstly, patient contact time was not measured. This may have resulted in over-estimated median patient load values for doctors and clinical officers, for instance, as these staff may in fact undertake only a small amount of clinical work as a proportion of their working day. Secondly, patient load was assessed against job titles, and not job functions. Many staff were found to be undertaking a variety of tasks that would not normally fall under their job title, e.g. nurses who primarily deliver clinical care were also undertaking counselling and dispensing. For these staff, calculated patient loads may be under-estimated.

With respect to the pharmacy review, it is possible that drugs with another label, or a less common formulation than the one asked about, were in use. We reviewed those most commonly used, and identified them through wide consultation. Further, under staffing, we did not record if facilities had dispensers (or other staff that do dispensing), rather than/in addition to pharmacists. Also, pharmacies may have stocked additional drugs not listed in our review sheets, as the study needed to choose common specific drugs, especially as some pharmacies were general medical.

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The PEPFAR categories of care used in the analysis did not contain all the care components captured in the questionnaire. Furthermore, the number of components included within each area of care varied greatly, with most areas containing about four components but clinical care containing over 30. This means the probability of facilities offering any element of clinical care is far higher than their offering any element of the other areas of care. The areas of care were predefined and are not exhaustive. Some components included in the survey were not categorised into any area of care. Additionally, because the survey used a closed-question design, it is likely that some facilities offered additional care which would have been appropriate to one of the areas but for which information was not collected.

Lastly, when research is commissioned to investigate care where resources are scarce, there are always potential desirability biases among respondents who provide that care (Harding et al, 2008). The use of triangulated data (staff, patients and pharmacy) have reduced that bias in the interpretation and the subsequent Phase 2 study will be useful in appraising the effect of the data described here on patient outcomes.

Some of the strengths of the survey are that every facility was visited in person by a Ugandan researcher trained to use the data collection tools. Representatives from all the facilities involved in the study were invited to a dissemination meeting to hear the results of the survey, and the relationship between the facilities and researchers was generally good. The researchers double-entered data into a purpose-designed electronic database, and conducted validation to minimise errors. These steps ensured high quality data collection and entry.

# Recommendations

## Infrastructure

- Multidimensional HIV care and support requires more space than purely medical assessment and intervention. Facilities should increase their physical space for care services, particularly to allow for counselling sessions in privacy and for children's care.
- Availability of resources to ensure existing services such as transport and electricity are required, as many vehicles are not operational and only half of facilities have working generators. Infection control is also compromised in the absence of infrastructure.

## Health management information systems

- As staff recommended, the best way to prevent double counting is to improve coordination and strengthen referral. Smaller facilities cannot provide the holistic, complex care required for HIV without the ability to refer patients.
- Comprehensive records should be kept for all patients, detailing the care they receive including inward and outward referrals and needs assessment.

## Staffing

- It was often found that staff were delivering care for which they felt they had not been adequately trained, and patients reported that they were discouraged from attending services where inadequately trained staff were employed. Increasing specialist training and employing staff specifically to deliver non-clinical aspects of care, such as psychological and spiritual care, could widen the availability of specialist care to patients and improve care quality.
- Staff retention is poor because of limited opportunities for development and low pay, and high staff turnover may damage the quality of care provided. Investment in staff is needed which could benefit both staff and patients.
- Volunteers are more likely to remain at facilities if their contribution is seen to be valuable, for example by reimbursing their travel costs.

## Care provision

- In the absence of data on paediatric-only facilities, skills and facilities for care and support of children need to be enhanced for the 20% of facilities that see no children at all.
- As the model most likely to have staff present across all five areas of care, the holistic provision of healthcare model offered by health centres should be replicated.
- HBC facilities should offer basic clinical care, and provide or refer for treatment for anxiety and depression.
- Social care is the least developed aspect of care in the survey. Income-generating activities and home help need to be implemented more widely to help patients overcome the financial barriers to clinical care.
- The BCP should be rolled out to all facilities, with clear and equitable eligibility criteria and adequate provision for all who need it. While the BCP is available at some facilities but not others, 'shopping around' is unavoidable. Treatment of TB, malaria and other infections is more readily found than prevention care, although prevention is more cost-effective and saves more lives.

## **Drug supplies**

- Reliable drug availability is a significant problem which hampers the delivery of care. Supply chains need to be strengthened by improving communication and responsiveness.
- In addition to improvements in morphine supply, training in pain management and opioid use is needed to increase uptake and usage.

## **Laboratory services**

- Laboratory services, particularly CD4 testing, should be made more widely available. For smaller facilities, referral networks to larger facilities for such services should be efficient.
- All facilities which provide or refer for ART should provide or refer for CD4 tests and LFT, as essential services for ART.

## **Documents**

- Lack of proper records limits the ability of a facility to provide integrated care, monitor stock, manage referrals, plan and budget. Large facilities should have administrative staff specifically employed to handle data management, and train existing staff in record keeping.
- Records forms should be revised and standardised to improve assessment, management and continuity of care and inward/external referral

## **PEPFAR**

- The definition of care and support services should be considered, as the survey found a safe water advocacy group currently falls under this heading in terms of funding.
- Method for identifying patient numbers for PEPFAR routine reporting may require revision. There was often a discrepancy with facility-reported numbers.

## **Further research**

- The survey results are mainly self-reported. A real understanding of the extent and quality of care could only be established by further study and measuring patient outcomes. This will be explored in Phase 2.
- A paediatric care and support PHE is required, although there is currently no validated African outcome tool for children.
- Volunteer staff are an important resource. The motivation and retention of volunteers need to be further understood, particularly at HBC facilities which depend heavily on volunteers.
- Spiritual care needs and provision could be further investigated to determine the care provided by spiritual leaders employed at facilities.
- Further study of barriers to care could explore the difference between reported care offered, and care reported to be received.
- Little is known about the strength and effectiveness of referral networks. A study to assess the comprehensiveness and coordination of the system would require a different design. Topics of interest include reasons for referral, the type and distance of facility referred to, patient uptake and follow-up.

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# Appendix A

## Senior staff interview questionnaire

 Facility name \_\_\_\_\_ ID   

 Date of interview        

Interviewer \_\_\_\_\_

<b>Respondents</b>	Name _____	Position _____
	Name _____	Position _____
	Name _____	Position _____
	Name _____	Position _____
	Name _____	Position _____

A1	facility type	tertiary hospital (training, specialised care) =1 secondary (referral) hospital=2 district hospital (basic inpatient)=3 hospital affiliated health centre=4 other health centre (multiple services)=5 health post/dispensary (few services)=6 walk-in surgery/private doctor's office/clinic = 7 home-based care only=8	<input type="checkbox"/>															
A2	is the facility just for people with HIV or is it also for other people?	HIV only=1 HIV and non-HIV=2	<input type="checkbox"/>															
A3	managing authority	government=1 private for profit=2 private non-profit (eg NGO, faith-based)=3	<input type="checkbox"/>															
	number of patients receiving care in the last quarter	<table border="1"> <thead> <tr> <th></th> <th>A men</th> <th>B women</th> <th>C children</th> <th>D total</th> </tr> </thead> <tbody> <tr> <td>A4 new patients</td> <td><input type="text"/></td><td><input type="text"/></td><td><input type="text"/></td><td><input type="text"/></td> </tr> <tr> <td>A5 all patients</td> <td><input type="text"/></td><td><input type="text"/></td><td><input type="text"/></td><td><input type="text"/></td> </tr> </tbody> </table>		A men	B women	C children	D total	A4 new patients	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	A5 all patients	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	
	A men	B women	C children	D total														
A4 new patients	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>														
A5 all patients	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>														
A6	hours per week when patients can see a clinical member of staff for HIV care		<input type="text"/>															
A7	hours per week when patients can see a non-clinical member of staff for HIV care		<input type="text"/>															
A8	For someone who is HIV-positive but not sick, and <b>does not</b> receive ART, how many times per year would they have regular appointments with clinical staff? <i>777= no regular appointments, as required</i>		<input type="text"/>															
A9	For someone who is HIV-positive but is not sick, and <b>does not</b> receive ART, how many times per year would they have regular appointments with non-clinical staff? <i>777= no regular appointments, as required</i>		<input type="text"/>															
A10	For someone who is HIV-positive but not sick, and <b>does</b> receive ART, how many times per year would they have regular appointments with clinical staff? <i>777= no regular appointments, as required</i>		<input type="text"/>															
A11	For someone who is HIV-positive but is not sick, and <b>does</b> receive ART, how many times per year would they have regular appointments with non-clinical staff? <i>777= no regular appointments, as required</i>		<input type="text"/>															

places of care delivery provided by this facility for HIV positive patients				yes=1, no=2			
A12a	inpatient					□	
A12b	outpatient					□	
A12c	home-based care					□	
A12d	medical consultancy for other facilities					□	
A12e	daycare					□	
A12f	support groups					□	
A13	number of inpatient beds in whole facility:					□ □ □ □ □	
Number of staff in whole facility							
		A full-time paid		B part-time paid		C volunteer	
A14a	doctor	□	□	□	□	□	□
A14b	clinical officer	□	□	□	□	□	□
A14c	medical assistant	□	□	□	□	□	□
A14d	nurse	□	□	□	□	□	□
A14e	pharmacist/dispenser	□	□	□	□	□	□
A14f	lab staff	□	□	□	□	□	□
A14g	community health worker	□	□	□	□	□	□
A14h	social worker	□	□	□	□	□	□
A14i	spiritual leader	□	□	□	□	□	□
A14j	traditional healer	□	□	□	□	□	□
A14k	nutritionist	□	□	□	□	□	□
A14l	counsellor	□	□	□	□	□	□
A14m	physiotherapist	□	□	□	□	□	□
Which patients pay for the following services:				all patients pay=1 means-tested=2 free to patients on ART = 3 free to all patients=4 free to children=5 restricted by other criteria=6 not available=8			
A15a	clinical appointment i.e. to see doctor					□	
A15b	x-rays					□	
A15c	HIV test					□	
A15d	ARVs					□	
A15e	Laboratory work					□	
A15f	cotrimoxazole/Seprin					□	
A15g	other medicines					□	

Does your facility report to:			
A16a	Ministry of Health	yes=1, no=2	<input type="checkbox"/>
A16b	PEPFAR/US agency		<input type="checkbox"/>
A16c	NGO including FBO		<input type="checkbox"/>
A16d	Private for-profit organisation		<input type="checkbox"/>
Infrastructure			
A17	Does your facility have staff available 24 hours a day?	yes, roster observed or staff live onsite=1 yes, no roster and no staff live onsite=2 no=3	<input type="checkbox"/>
A18	does the facility have a functional ambulance, bicycle or other vehicle onsite for patient emergency transport?	yes, functioning (and with fuel)=1 yes, but not functioning or no fuel=2 no=3	<input type="checkbox"/>
A19	Is the electricity working? (Check)	yes=1 usually but not now=2 never have electricity=3	<input type="checkbox"/>
A20	Does the facility have a backup electrical power supply (generator, inverter, solar panels)? (Accept response)	yes, functioning (and with fuel)=1 yes, but not functioning or no fuel=2 no=3	<input type="checkbox"/>
A21	What is the most commonly used source of water for the facility, for all purposes, at this time?	safe (piped, public tap, standpipe, protected dug well, rainwater, borehole)=1 other (unprotected dug well, tanker-truck, cart, jerry can, river/pond surface water etc)=2 bottle water (enough for handwashing)=3 no water source=4	<input type="checkbox"/>
A22	Is there a latrine/toilet available for outpatients to use?(Check)	yes, improved (flush/pour flush to sewer system/ septic tank, pit with slab, VIP, composting)=1 yes, other (flush/pour flush to field, pit without slab, open pit, hanging, bucket)=2 no=3 if F26=3 go to F28	<input type="checkbox"/>
A23	condition of the latrine/toilet	functioning=1 not functioning=2 unable to observe=3	<input type="checkbox"/>

Evaluation (include top 5 for each question)		
<b>A24</b>	What are the strengths of your facility in terms of HIV care service delivery for both adults and children?	
<b>A25</b>	What would improve the way your facility offers services to HIV-infected adults?	
<b>A26</b>	What would improve the way your facility offers services to HIV-infected children?	
<b>A27</b>	As manager, what main challenges do you face in terms of sustainability for your facility?	
<b>A28</b>	What do you think might be potential strategies to avoid patients receiving duplicate HIV-related services at your facility and elsewhere?	





Facility name _____		Facility ID _____	
Interviewer _____		Date	
		d	d
		m	m
		y	y

type of care	service provided? 1=yes, by this facility 2= yes, formally referred 3=yes, informally referred 4=service not provided	currently able to provide to all who need it? yes=1, no=2	# people receiving this care here in the last quarter 9999=missing
Question part: Question number	A	B	C
<b>Support</b>			
B48 wound care	<input type="checkbox"/>	<input type="checkbox"/>	
B49 physiotherapy	<input type="checkbox"/>	<input type="checkbox"/>	
<b>Social</b>			
<b>For the patient</b>			
B50 home help e.g. help with bathing, housework, cooking	<input type="checkbox"/>	<input type="checkbox"/>	
B51 transport to care centre	<input type="checkbox"/>	<input type="checkbox"/>	
B52 employment training/IGA	<input type="checkbox"/>	<input type="checkbox"/>	
B53 provide household items	<input type="checkbox"/>	<input type="checkbox"/>	
B54 legal services	<input type="checkbox"/>	<input type="checkbox"/>	
B55 memory book work	<input type="checkbox"/>	<input type="checkbox"/>	
<b>For the family</b>			
B56 home help e.g. help with bathing, housework, cooking	<input type="checkbox"/>	<input type="checkbox"/>	
B57 loans/microfinance	<input type="checkbox"/>	<input type="checkbox"/>	
B58 infection control training	<input type="checkbox"/>	<input type="checkbox"/>	
<b>Laboratory</b>			
B59 liver function test (LFT)	<input type="checkbox"/>	<input type="checkbox"/>	
B60 malaria film	<input type="checkbox"/>	<input type="checkbox"/>	
B61 AFB smear	<input type="checkbox"/>	<input type="checkbox"/>	
B62 CD4 count/test	<input type="checkbox"/>	<input type="checkbox"/>	
B63 rapid HIV test	<input type="checkbox"/>	<input type="checkbox"/>	
B64 pulse oximetry	<input type="checkbox"/>	<input type="checkbox"/>	
B65 dried blood spot (early infant diagnosis)	<input type="checkbox"/>	<input type="checkbox"/>	
B66 viral load	<input type="checkbox"/>	<input type="checkbox"/>	
<b>Paediatric (0-14 years)</b>			
B67 paediatric ART	<input type="checkbox"/>	<input type="checkbox"/>	
B68 infant testing and counselling	<input type="checkbox"/>	<input type="checkbox"/>	
B69 children testing and counselling	<input type="checkbox"/>	<input type="checkbox"/>	

# Appendix B

## Document analysis record

Facility name \_\_\_\_\_ Date \_\_\_\_\_

Facility ID

Interviewer \_\_\_\_\_

### Document analysis

		If A = 1, complete B-E. Otherwise cross through boxes				
	reported yes=1 no=2	observed yes=1 no=2	format paper=1 computer=2 both = 3	example taken yes=1, no=2	language English=1 other=2	
<b>Question section:</b>	<b>A</b>	<b>B</b>	<b>C</b>	<b>D</b>	<b>E</b>	
<b>Question number</b>						
D1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
D2	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
D3	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
D4	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
D5	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
D6	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
D7	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
D8	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
D9	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
D10	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
D11	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
D12	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
D13	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
service aim	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
referral criteria (inwards)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
incoming referral forms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
outgoing referral forms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
patient charging	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
ART protocols	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
care protocols	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
first clinical assessment sheets	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
ongoing contact assessment sheets	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
patient records	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
referral followup forms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
stock control sheet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
information for patients	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
					Please list all languages:	
					1. _____	
					2. _____	
					3. _____	
					4. _____	
					5. _____	
					<b>E1</b>	
					<b>E2</b>	
					<b>E3</b>	
					<b>E4</b>	
					<b>E5</b>	







# Appendix D

## Patient focus group discussion schedule

Question number	Question	Number
1	Total number in group	
	How many from the group, from this facility:	
2A	Receives cotrimoxazole, to take every day	
2B	Has been given an ITN for personal use	
2C	Has been tested for TB by sputum or X-ray	
2D	Has received anything to make sure your drinking water is clean	
2E	Receives counselling about how to prevent transmitting HIV to others	
2F	Receives nutritional counselling	
2G	Received condoms for you or your partner	
2H	Been encouraged to bring your spouse/children for HIV counselling and testing	

3. How do you feel today?
4. For those of you who did not receive the items mentioned from this service, can anyone tell me a reason why?
5. What are the main HIV services you receive from here?
6. Which services have been the best and why?
7. Are there any services which could be improved?
8. Apart from this facility, where else do you go for HIV services?
9. What are the main HIV services you receive from other places?
10. How do you choose where to go for different things?
11. Which medicines do you get from this facility?
12. Have you had any problems getting medicines from this facility? Please tell us about them.
13. What would you like an HIV care service to do for you, what things would you need?
14. How can this facility attract more HIV-positive people to access services here?
15. Is there anything we haven't asked about that is important to you?

# Appendix E

## Facilities surveyed

ID	District	Name	Facility type
202	Kaberamaido	Ocanoyere P/S	Other health centre
203	Bushenyi	Rugarama HC2	health post/dispensary
204	Bushenyi	Swazi HC2	health post/dispensary
205	Bushenyi	Butoha HC2	health post/dispensary
206	Tororo	Nagongera Boys	hospital affiliated health centre
207	Busia	Busamba	health post/dispensary
209	Kyenjojo	Kyenjojo District PHA Forum	home-base care only
210	Kisoro	Kisoro District PHA Forum	home-base care only
211	Bushenyi	Bushenyi District PHA Forum	home-base care only
212	Kampala	Case Medical Center	other health centre
213	Kumi	Agaria HC II	health post/dispensary
214	Mubende	Mubende District PHA Forum	home-base care only
218	Busia	Buhehe	health post/dispensary
219	Kumi	Nyero HC III	other health centre
220	Rakai	Kifamba	other health centre
221	Kumi	Malera HC III	health post/dispensary
222	Wakiso	Buwambo HCIV	other health centre
223	Rakai	Kasasa	other health centre
226	Mbarara	Kiruhura District	health post/dispensary
227	Bushenyi	Bushenyi TC HC3	other health centre
229	Pallisa	Butesa Community AIDS Initiative	other health centre
230	Rakai	Lyantonde Muslim Health Centre	other health centre
231	Bugiri	UCOBAC	home-base care only
232	Mbarara	Mayanja Memorial Foundation	other health centre
233	Mbarara	Ibanda CDC	other health centre
234	Kampala	Hospice Africa Uganda	other health centre
235	Kampala	Mulago TB-HIV Clinic	training hospital
236	Kumi	Kumi Aids Support Organisation	home-base care only
237	Wakiso	Meeting Point Wakiso Kyamusa Obwongo	home-base care only
238	Kyenjojo	Kyembogo Hc-Kyarusozi	other health centre
239	Kyenjojo	Fp Diocese-Kyembogo	home-base care only
240	Mbarara	Bwizibwera ISS Clinic	health post/dispensary
241	Kumi	Kumi DDHS	other health centre

ID	District	Name	Facility type
242	Bushenyi	Ishaka Hospital	district hospital
243	Kayunga	Kayunga District Hospital	referral hospital
244	Lira	Lira - DDHS	referral hospital
245	Mukono	Nile Treatment Center	health post/dispensary
246	Kabarole	Buhinga Regional Hospital	district hospital
247	Bushenyi	Bushenyi Medical Center, Katungu	other health centre
248	Kampala	Kawempe Health Centre	hospital affiliated health centre
249	Jinja	Jinja Regional Hospital	referral hospital
250	Mukono	Kawolo Hospital	district hospital
251	Apac	Apac Government Hospital	district hospital
252	Kitgum	St. Joseph's Hospital	other health centre
253	Mbarara	AIC Mbarara	health post/dispensary
254	Kitgum	CHAPS	home-base care only
255	Rukungiri	TASO Rukungiri	other health centre
256	Kampala	AIC Kampala	other health centre
257	Mbarara	TASO Mbarara	other health centre
258	Kampala	Mulago Infectious Diseases Clinic	other health centre
259	Kampala	JCRC - Kampala Clinic	other health centre
260	Mbarara	Mbarara Regional Hospital	training hospital
261	Kumi	Ngora Dispensary	other health centre
263	Mbale	Makhai PS	hospital affiliated health centre
265	Pallisa	Kadama	other health centre
266	Soroti	Arapai Odudui	health post/dispensary
269	Bushenyi	Rimuri HC2	health post/dispensary
277	Kyenjojo	RWIDE	home-base care only
278	Kyenjojo	Kyenjojo Initiative For Rural Development	home-base care only
279	Rakai	Lwamaggwa	other health centre

# Appendix F

## Care components categorised for PEPFAR care and support areas

Area of PEPFAR care and support	Care components included from CSRI	Area of PEPFAR care and support	Care components included from CSRI
Clinical	Pre and post test counselling	Psychological	Family care-givers support group
	Adherence counselling		Family counselling
	Nursing care		Psychiatric therapy
	Adult diagnostic HIV testing		Anxiety/depression treatment
	Weighing	Spiritual	Visit by pastor
	Assessment of pain		Staff prayer with patients
	Strong opioids		Contact with traditional healer/herbalist
	Weak opioids		Memory book work
	Non-opioid analgesics	Social	Home help
	Treatment for neuropathic pain		Employment training
	Treatment for nausea/vomiting		Legal services
	Treatment for skin rash/itching		Loans/microfinance
	Treatment for diarrhoea	Prevention	Family planning counselling
	Laxatives		Patient HIV support groups
	Treatment for thrush		Support for family testing
	Treatment for oral candidiasis		Prevention with positives
	Treatment for cryptococcus		Condoms
	Treatment for other fungal infections		
	Treatment for herpes		
	Treatment for malaria		
	TB detection and treatment		
	Therapeutic feeding for malnutrition		
	Treatment for other opportunistic infections		
	Management of cancer		
	Multivitamins		
	Nutritional advice		
Access to safe drinking water at home			
CTX			
Isoniazid to prevent TB			
Mosquito bednets			
Wound care			
Physiotherapy			

# Appendix G

## Results sharing with facilities

### Introduction

Part of the objective of this evaluation is, in conjunction with Measure Evaluation, to build commitment to utilising the findings and lessons learnt from the study. As a step towards meeting this objective a meeting was held in Kampala in May 2008 with the research team and participating facilities. Representatives from all 60 facilities and the country team attended the half day workshop. The purposes of this half-day meeting were

- to share the results of the phase 1 survey with participants;
- to gain insight into the findings from those involved in service delivery and improve the presentation of the findings in the report;
- to discuss the recommendations made, with the option of facilities making additional recommendations if desired; and
- to identify the organisations who may be able to implement the recommendations.

### Meeting outline

Participants were given a summary of the findings. Presentations from the research team explained

- the parties involved and the aims, objectives and design of the evaluation;
- methods and data collection experiences; and
- survey results.

Participants were then divided into 5 groups in order to explore key themes that arose from the data in more detail. In addition to the summary report and presentation handouts already received, each group was given relevant supplementary data (i.e. themed report tables) to aid discussions. Group participants were asked to discuss the main findings relating to the theme allocated. Prompts to aid discussion included: Were any findings surprising? What are the areas where things are doing well or are on track and why? What areas need improvement and why? Participants were then asked to review and discuss the recommendations contained in the summary report, and finally to draft their own set of recommendations for action in this thematic area using the attached format. Discussion summaries were shared with all.

### Meeting feedback- general

Participants expressed their appreciation at being informed of the survey findings, as well as having an opportunity to contribute to the report itself. Although participants were presented with a large amount of data in a short half-day meeting, they were able to form their own views of the findings.

## Meeting feedback — Recommendations from discussion groups

*Components of care by theme: ART, Basic care package, pain management, malaria, TB and other OIs*

Recommended Actions	Supporting data	Beneficiaries	Priority	Lead Organization	Other stakeholders
<p>ART</p> <ul style="list-style-type: none"> <li>• Train lower level units in ART monitoring and assessment of treatment failure.</li> <li>• Increase cover and accessibility</li> <li>• Establish formal linkages between district level and health centre ART programmes</li> <li>• Invest in laboratory infrastructure to support ART monitoring</li> </ul>	Table – ART provision by facility type	Health centres and health care workers	Urgent	MOH	Facilities such as Mildmay, IDI and JCRC
<p>BCP</p> <ul style="list-style-type: none"> <li>• Prioritize distribution of BCP to lower level facilities</li> <li>• Emphasize comprehensive BCP, rather than components</li> </ul>	Figures on availability of elements of BCP	Patients	Urgent	MOH, CDC, USAID	Population services international
<p>OIs</p> <ul style="list-style-type: none"> <li>• Stock all health facilities with CTX.</li> <li>• Evaluate Isoniazid prophylaxis and its implications. A number of sites offered Isoniazid prophylaxis for TB prevention, yet it has been found to cause serious drugs resistance in case of TB. Group members were wondering whether there was any monitoring mechanism in place.</li> </ul>	Table – Availability of components of care relating to opportunistic infections by facility type				
<p>PAIN MANAGEMENT</p> <ul style="list-style-type: none"> <li>• Make opioids available at all referral hospitals.</li> <li>• Strengthen advocacy for clinicians to appreciate the role of palliative care in HIV care programmes</li> </ul>	Table – Availability of components of care relating to pain management by facility type	Patients and health care workers	Urgent	APCA, MOH, Hospice	Palliative care associations

*Components of care by theme: nutrition, social care and psychological care*

Recommended Actions	Supporting data	Beneficiaries	Priority	Lead Organization	Other stakeholders
<p><b>NUTRITION</b></p> <ul style="list-style-type: none"> <li>• Provide health education to create awareness and knowledge about good nutrition</li> <li>• Provide food, and loans to support productivity</li> <li>• Encourage use of local food stuffs instead of nutritional supplements and multivitamins</li> </ul>	<p>Table – Availability of components of care relating to nutrition by facility type</p>	<p>Bed ridden patients and HIV infected and affected children</p>	<p>Urgent</p>	<p>NGOs/ USAID and health facilities</p>	<p>NGOs, CBOs</p>
<p><b>SOCIAL CARE</b></p> <ul style="list-style-type: none"> <li>• Launch awareness campaigns on the need for provision of social care in health centres and hospitals</li> <li>• Set minimum standards for social care in Uganda</li> <li>• Encourage cash circles and other income generating activities to improve on patients productivity and thus self sustenance</li> </ul>	<p>Table – Availability of components of social care by facility type</p>	<p>Patients and health care workers</p>	<p>High</p>	<p>MOH, NGOs and ministry of Finance</p>	<p>USAID, Hospice Africa Uganda</p>
<p><b>PSYCHOLOGICAL CARE</b></p> <ul style="list-style-type: none"> <li>• Promote awareness and availability of psychiatric therapy and encourage proper referrals</li> <li>• Support and build capacity for HBCs to provide psychiatric therapy</li> </ul>	<p>Table – Availability of components of care relating to psychological health by facility type</p>	<p>Patients and health care works</p>	<p>Urgent</p>	<p>MOH, Medical Schools in Uganda</p>	<p>USAID</p>

*Infrastructure and medication stocks, supply and use, laboratory services*

<b>Recommended Actions</b>	<b>Beneficiaries</b>	<b>Priority</b>	<b>Lead Organization</b>	<b>Other stakeholders</b>
<b>INFRASTRUCTURE</b> <ul style="list-style-type: none"> <li>• Increase funding for vehicle repair and availability of ambulances</li> <li>• Establish support groups at district and regional levels</li> </ul>	Patients	Urgent	NGOs/ USAID	MOH
<b>MEDICATION STOCKS , SUPPLY AND USE</b> <ul style="list-style-type: none"> <li>• Train staff in logistics and supplies management</li> </ul>	Patients and population at risk	High	MOH	USAID
<b>LABARATORY SERVICES</b> <ul style="list-style-type: none"> <li>• Avail all diagnostic tests at regional and district hospitals</li> </ul>	Patients	Urgent	USAID	MOH

*Staffing*

<b>Recommended Actions</b>	<b>Beneficiaries</b>	<b>Priority</b>	<b>Lead Organization</b>	<b>Other stakeholders</b>
<b>STAFF RETENTION</b> <ul style="list-style-type: none"> <li>• Improve on staff training and remunerations (especially for volunteers) to reduce staff turnover</li> </ul>	Patients and health care workers	Urgent	MOH, NGOs	CBOs
<b>TRAINING</b> <ul style="list-style-type: none"> <li>• Provide more training to support task shifting where possible. This will support the use of volunteers and traditional healers.</li> <li>• Train and recruit staff to provide spiritual, social and psychological care</li> </ul>	Patients, traditional healers and volunteers	High	MOH, NGOs	USAID
<b>LOGISTICS</b> <ul style="list-style-type: none"> <li>• Provide training in procurement and logistics management</li> </ul>	Patients and pharmacy technicians	Urgent	MOH, Medical Schools in Uganda	USAID

*Cross-cutting issues*

Recommended Actions	Supporting data	Beneficiaries	Priority	Lead Organization	Other stakeholders
<p>STAFFING</p> <ul style="list-style-type: none"> <li>• - Provide training in spiritual care</li> <li>• - Support multi-professionalism at all facilities; medical care should not be the only priority. This may also reduce staff costs where resources are constrained</li> <li>• - Increase staffing levels</li> </ul>	Table – staff categories by facility type	Patients	urgent	MOH	TASO, Mildmay and Hospice
<p>CARE PROVISION</p> <ul style="list-style-type: none"> <li>- Promote referrals for home help and spiritual care</li> <li>- Build capacity for lower level units to provide more types of care since they are more accessible</li> <li>- Sensitise government facilities on the need for care and support in HIV care.</li> <li>- Train community volunteers in counselling and home help to support rolling out of home help</li> <li>- Patients should also be supported to start income generating activities</li> <li>- Increase sensitisation to care and support at Government facilities</li> <li>- Increase results orientation at Government facilities</li> </ul>	Tables - components of care frequently provided or referred, Mean number of components of care provided and referred, Mean components of care by managing authority	Patients and health care workers	Urgent	MOH	TASO, Mildmay, Hospice and APCA

## Amendments to report

Feedback from the discussion groups highlighted some small areas of the report where further explanation of the results was needed to ensure understanding, for instance more detail about water sources.

A principal comment from participants related to the results presented by facility type. Facility type was based on self-reported facility type selected from eight pre-determined categories and later collapsed down to five (referral hospitals, district hospitals, health centres, health posts and home-based care centres). Several people thought their facility was not in the most appropriate group, the term ‘health post’ was not understood, and the different types of health centre in the Ugandan context (health centre 2, 3 and 4) were not reflected in the groups used.

There are numerous ways in which the facilities could be categorised according to different audiences. Furthermore, extensive consultation on Phase 1 analysis had already been undertaken with country teams and MOH representatives, and there was a need to maintain comparable groupings to Kenya to allow cross-country comparisons. Therefore, the study team decided to keep the findings as presented in the main, note the comments from the facility representatives, and supplement the report with additional key tables where facilities are categorised by Ministry of Health-approved type. Our thanks go to Dr Elizabeth Madraa and Dr Saul Onyango from the MOH, and to Dr Umar Ssekabira and Dr Andrew Kambugu from IDI, for assisting us in the process.

The six revised categories consist of:

- Home-based care health centres (HBC)
- Health centre 2 – outpatient only
- Health centre 3 – outpatient, maternity, limited inpatient (<15 beds), lab
- Health centre 4 – blood bank, operating theatre, inpatient
- Hospital – larger inpatient, fully equipped lab, specialties, training
- Referral institution – centres of excellence in a specialised area which do not offer all the facilities of a health centre, e.g. AIC, JCRC and IDI

Five key areas have been reanalysed using this structure and the results are presented below. A comparison between the original and revised category structure is presented in Table 56.

## Key results by Uganda MoH agreed facility type

Table 51 shows that the more developed health centre 4 facilities, hospitals and referral institutions were most likely to have general infrastructure such as an electricity supply. These facilities always report to the MOH, whereas HBC facilities are more likely to report to an NGO. HBC facilities are the most likely to be solely providers of HIV care, and all of them are managed at least in part by an NGO. All types of facility may offer home-based care but only the HBC facilities always do so.

Table 51: Infrastructure

		Number of facilities n (%)					
		HBC	Health centre 2	Health centre 3	Health centre 4	Hospital	Referral institution
	Total number of facilities of each type	9 (100)	8 (100)	17 (100)	5 (100)	12 (100)	8 (100)
	HIV-only facility	5 (56)	2 (25)	6 (35)	0	2 (17)	3 (38)
Authority	Government	1 (11)	6 (75)	9 (53)	5 (100)	7 (58)	3 (38)
	Private	0	0	1 (6)	0	2 (17)	0
	NGO	9 (100)	2 (25)	7 (41)	0	3 (25)	5 (63)
Reports to	Ministry of Health	4 (44)	7 (88)	16 (94)	5 (100)	12 (100)	8 (100)
	USG/PEPFAR	6 (67)	2 (25)	9 (53)	3 (60)	7 (58)	8 (100)
	NGO	8 (89)	4 (50)	5 (29)	1 (20)	5 (42)	3 (38)
	Private for-profit organisation	0	0	0	0	0	1 (13)
Place of care	Inpatient	0	0	7 (41)	5 (100)	10 (83)	2 (25)
	Outpatient	2 (22)	6 (75)	15 (88)	4 (80)	12 (100)	8 (100)
	Home based care	9 (100)	3 (38)	9 (53)	3 (60)	5 (42)	4 (50)
	Medical consultancy	1 (11)	1 (13)	11 (65)	5 (100)	11 (92)	7 (88)
	Daycare	1 (11)	2 (25)	7 (41)	0	4 (33)	3 (38)
	Support groups	8 (89)	2 (25)	8 (47)	3 (60)	8 (75)	7 (88)
General infrastructure	Staff on site 24 hours a day	1 (11)	4 (50)	10 (59)	5 (100)	5 (42)	2 (25)
	Has functioning ambulance	4 (44)	0	8 (47)	2 (40)	6 (50)	7 (88)
	Has working electricity	2 (22)	3 (38)	7 (41)	3 (60)	11 (92)	8 (100)
	Has functioning generator	2 (22)	1 (13)	8 (47)	3 (60)	11 (92)	7 (88)
	Has safe water supply	7 (78)	5 (63)	13 (76)	5 (100)	12 (100)	8 (100)
	Has functioning toilet	8 (89)	8 (100)	17 (100)	5 (100)	12 (100)	8 (100)

\*In addition there were 5 facilities with an ambulance that did not function, 4 which reported usually having electricity, and 6 with a non-functional generator.

Table 52: Staff categories by MOH facility type

		Facility type n (%)					
		HBC	Health centre 2	Health centre 3	Health centre 4	Hospital	Referral institution
	N	9 (100)	8 (100)	17 (100)	5 (100)	12 (100)	8 (100)
	Clinical	3 (33)	7 (88)	17 (100)	5 (100)	12 (100)	8 (100)
	Spiritual	5 (56)	2 (25)	5 (29)	3 (60)	3 (25)	1 (13)
	Psychological	8 (89)	1 (13)	10 (59)	2 (40)	7 (58)	7 (88)
	Social	8 (89)	5 (63)	13 (76)	4 (80)	8 (67)	6 (67)
	Clinical + spiritual + psychological + social	1 (11)	1 (13)	3 (18)	2 (40)	3 (25)	0

Health centre 4s and hospitals are the most likely to have staff who specialise in each area of care and support (Table 52). At HBC facilities, clinical staff are the rarest group, in contrast with the other facility types where clinical staff are nearly always present. Spiritual care staff are least likely to be present at referral institutions, and partly as a consequence, no referral institution has staff in all four areas.

Table 53: Number of facilities providing or referring for each type of care, by MOH facility type

Any component provided or referred in area of care	Facility type including referrals, n (%)					
	HBC	Health centre 2	Health centre 3	Health centre 4	Hospital	Referral institution
N	9 (100)	8 (100)	17 (100)	5 (100)	12 (100)	8 (100)
Spiritual	8 (89)	3 (38)	6 (35)	1 (20)	10 (83)	6 (67)
Psychological	9 (100)	8 (100)	17 (100)	5 (100)	12 (100)	8 (100)
Clinical	9 (100)	8 (100)	17 (100)	5 (100)	12 (100)	8 (100)
Social	8 (89)	2 (25)	4 (24)	0	4 (33)	6 (67)
Prevention	9 (100)	8 (100)	17 (100)	5 (100)	12 (100)	8 (100)
All care and support	7 (78)	2 (25)	3 (18)	0	4 (33)	6 (67)

Referral institutions and HBC facilities are the most likely to offer complete care and support (Table 53), although Table 52 shows that they are the facility types least likely to have trained staff in every area. The limiting factor in offering a complete package seems to be social care, the component which is least often found even though the majority of facilities have social care staff.

Table 54: ART provision by MOH facility type

ART component	Facilities offering care including referrals, n (%)					
	HBC	Health centre 2	Health centre 3	Health centre 4	Hospital	Referral institution
N	9 (100)	8 (100)	17 (100)	5 (100)	12 (100)	8 (100)
ARVs	3 (33)	5 (63)	16 (94)	5 (100)	11 (92)	6 (67)
Adherence counselling	9 (100)	8 (100)	17 (100)	5 (100)	12 (100)	8 (100)
Assessment of ARV treatment failure	2 (22)	4 (50)	15 (88)	4 (80)	11 (92)	6 (67)
Monitor ARV toxicity	2 (22)	4 (50)	15 (88)	4 (80)	11 (92)	6 (67)

The best complete provision of ART in the broad sense is offered by hospitals (Table 54), but health centres type 3 and 4 are more likely to actually have the antiretrovirals. HBC facilities are least likely to offer ART, and two thirds of referral institutions provide it. In all the health centre types, and HBC facilities, at least one facility refers for ARVs without the support structure of toxicity monitoring and treatment failure assessment.

Table 55: Availability of components of care relating to malaria and TB. by MOH facility type

Component of care	Facilities offering test including referrals, n (%)					
	HBC	Health centre 2	Health centre 3	Health centre 4	Hospital	Referral institution
N	9 (100)	8 (100)	17 (100)	5 (100)	12 (100)	8 (100)
Isoniazid to prevent TB	4 (44)	3 (38)	13 (76)	5 (100)	8 (67)	2 (25)
TB detection	5 (56)	4 (50)	15 (88)	5 (100)	12 (100)	8 (100)
TB treatment	5 (56)	4 (50)	16 (94)	5 (100)	12 (100)	8 (100)
Mosquito bednets	5 (56)	4 (50)	11 (65)	3 (60)	5 (42)	7 (88)
Treatment for malaria	5 (56)	7 (88)	17 (100)	5 (100)	12 (100)	8 (100)
Malaria film	1 (11)	4 (50)	15 (88)	5 (100)	11 (92)	7 (88)
AFB test	1 (11)	3 (38)	14 (82)	5 (100)	11 (92)	7 (88)

All facilities in the analysis offer at least one component of clinical care and prevention (Table 53). Malaria and TB are two of the most prevalent and high-morbidity conditions among people with HIV and they are examined in more detail here. Health centre 4 facilities provide the best malaria and TB care as a whole, considering prevention, diagnosis and treatment (Table 55). Referral institutions also have good coverage, with the exception of isoniazid. All hospitals and referral institutions provide treatment but prevention and diagnosis components are not always available. Health centre 2 and HBC facilities frequently do not provide malaria and TB care components.

Table 56: Comparison of self-reported and assigned facility types

Self-reported facility type (main report)	Assigned facility type (appendix)					
	HBC	Health centre 2	Health centre 3	Health centre 4	Hospital	Referral institution
HBC	8	1	1			
Health post		6	4	1	1	1
Health centre	1	1	12	4	3	6
District hospital					4	
Referral hospital					3	2

Table 56 shows that in the main, the category ‘health post’ maps onto ‘health centre 2’, and ‘health centre’ to ‘health centre 3’, and most of the previously designated referral hospitals and district hospitals are assigned to the ‘hospital’ category. The HBC category also remains constant apart from one facility which previously called itself a health centre.

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