PEPFAR Public Health Evaluation
– Care and Support –

PHASE 2 KENYA

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Abbreviations

ANOVA	analysis of variance
APCA	African Palliative Care Association
ART	antiretroviral therapy
ARV	antiretroviral
BMI	body mass index
C&S	care and support
CBO	community based organisation
CHW	community health worker
CSRI	client services receipt inventory
CTX	cotrimoxazole
DHS	demographic and health survey
ECOG	Eastern Cooperative Oncology Group
Fac	facility
HCW	health care worker
IGA	income generation activity
IQR	inter-quartile range
IRIS	immune reconsititution inflammation syndrome
ITN	Insecticide-treated net
KCL	King's College London
KEHPCA	Kenya Hospice and Palliative Care Association
KEMRI	Kenya Medical Research Institute
MOH	Ministry of Health
MOS-HIV	Medical Outcomes Scale for HIV
OI	opportunistic infection
ORS	oral rehydration solution
PCP	preventive care package
PEPFAR	President's Emergency Plan for AIDS Relief
PHE	public health evaluation
PMTCT	prevention of mother to child transmission
POS	Palliative Outcomes Scale
PWP	prevention with positives
SD	standard deviation
Se	standard error
Sem	standard error of the mean
STI	sexually transmitted infection
TB	tuberculosis
UNC	University of North Carolina
USAID	U.S. Agency for International Development
USG	United States government
VCT	voluntary counselling and testing
WHO	World Health Organization

1 Executive Summary

1.1—Rationale

A Public Health Evaluation (PHE) was commissioned to examine PEPFAR-funded care and support. Phase 2 of this PHE aimed to evaluate how PEPFAR care and support programme components and costs are related to health outcomes in Kenya.

1.2—Methods

Phase 2 was completed using three methods: a longitudinal quantitative observational study of patient care and health outcomes over three months; qualitative interviews with patients, informal carers and staff; and a costing study to estimate facility-level costs of providing care and support. Six facilities receiving PEPFAR Care and Support funding were selected from those which had completed Phase 1. In the longitudinal study, self-reported health outcomes were measured using the MOS-HIV and the APCA African POS, and patient care using a modified Client Services Receipt Inventory.

1.3—Main Findings of Longitudinal Quantitative Study

1.3.1—Facility Characteristics

The facilities (numbered 155–160) were all HIV outpatient clinics. Four were based in public hospitals, one in an NGO hospital, and one was a health centre.

1.3.2—Participant Characteristics

Six hundred ninety-six people were recruited to the study, and interviewed at a mean of 30.2 day intervals for four months. One hundred four participants did not complete all four interviews; nine died, thirty left the facility, three were unable to continue, and sixty-two did not identify a reason. Participants were aged 18–69 (mean 35), 31% were male and 97% had some primary education. Median time from HIV diagnosis to recruitment was 36 days and their median CD4 count was 276 at the beginning of the study. At baseline 12% were accompanied by an informal carer.

1.3.3—Care Delivery

Of 52 components of care and support included in the questionnaire, participants received a mean of 12 per month and 20 altogether during the study. The most commonly provided were adherence counselling, prevention with positives and CTX, each received by over 90% of participants. Of the five categories of PEPFAR Care & Support (clinical, psychological, spiritual, social and preventive), 99% of participants received clinical care and 94% prevention. Psychological care was the least commonly delivered (58%).

In general participants received clinical care from the facility, social and spiritual care from other sources. Symptom management was obtained both from the facility and from elsewhere. During the study 76% of participants received ART at least once. Receipt of CTX increased over time, until by the end of the study period 85% were receiving daily CTX and 95% had taken it the previous day.

Forty-one percent of participants were recruited to the study within two weeks of their HIV diagnosis. The care they most commonly received was, in order from the highest prevalence, pre- and post-test counselling, adherence counselling, prevention with positives, CTX, multivitamines, and nutritional advice. During the study 56% received family VCT information, 67% improved drinking water supplies, 47% an ITN, 65% condoms and 92% CTX. These are the components of the preventive care package. Participants who had been diagnosed more than two weeks before recruitment received the preventive care package components with similar frequency.

1.3.4—Physical and Mental Health and Palliative Care Related Problems

At baseline, participants had a mean self-reported physical health score of 46.1 and mean mental health score of 48.1 as measured using the MOS-HIV, with 100 being the best possible health and 0 the worst. Their lowest scores on the multidimensional care scale

(APCA African POS) were for not being able to share their feelings with anyone, and not having enough help and advice for the family to cope.

1.3.5—Differences between Facilities

Facilities differed in the relative wealth of their participants and in the proportion who were newly diagnosed (defined as within 14 days of recruitment). Facility 157 had 64% new participants while facility 156 had 13%. The facilities with poorest participants were 155 and 160. Median CD4 count ranged from 332 at facility 156 to 221 at facility 158. Provision of clinical care was high at all facilities, and provision of social care was always low, but the proportion to receive pain management, nursing care or spiritual care varied widely.

1.3.6—Participant Characteristics and Health

Older people, and poorer people, reported lower physical health at baseline, but mental health was not associated with age or relative wealth. There was no difference in mental or physical health between men and women, or between those with different levels of education. Participants with a low CD4 count reported lower physical health and, as a consequence, lower mental health. Whether participants were receiving ART at baseline was not associated with health outcomes. Participants taking ART had similar physical and mental health to those not prescribed ART (and probably with less advanced disease).

1.3.7—Changes in Health Over Time

Over time participants' mean physical and mental health improved and care needs decreased, after accounting for the bias that people with lower health were more likely to drop out of the study. Those with the lowest scores also experienced improvement. Facility 156 showed much less improvement in physical score than average; early gains in physical health then stabilised after the end of the first month. Older participants experienced less gain in health than younger, and wealthier participants experienced more than poorer. Gender, education, and ART status were not associated with change. Participants receiving TB treatment had the same gains in mental health as those not receiving TB treatment, but less improvement in physical health.

1.4—Main Findings of Qualitative Interviews

Patients reported feeling pain, fatigue and anxiety; invisible, chronic problems. Their main worries and those of carers centred on poverty, realised in difficulty paying for food, transport, drug costs and school fees. They made great efforts to find fruit and vegetables but there was often not enough for the family.

Patients greatly appreciated the quality of care they received and, in most cases, the courteous behaviour of staff. They objected to waiting for a long time to see a health care worker, with opportunity costs and risk of infection in the waiting bay. Staff reported that increasing patient numbers were difficult to manage and that the quality of care was perceived to decline when they were overloaded. Patients gave each other social and spiritual support, which usually did not come from the facility. There were schemes such as travel reimbursement and provision of soap for home care, sometimes carried out by the facility and sometimes by the individual health worker. Family carers received little support.

Care focused on clinical problems, and standard assessment and monitoring forms included only clinical measures, not emotional wellbeing. Patients were advised not to have too many thoughts, as they reported worry and many thoughts burdening them. They were encouraged to participate in social life and to discipline themselves against feelings of isolation and ostracism.

1.5—Main Findings of Costing Study

There was wide variation in costs per patient per year, ranging from $77 at Facility 157 to $1160 at Facility 159. Facility 159 was much more expensive than the others; the next largest cost was $418. The largest contribution to costs was staff salaries at three facilities, ART at two and lab costs at one. Clinical staff contributed much more to costs than did non-clinical staff. Patient loads were extremely high for non-clinical staff. There were economies of scale, so that facilities with more patients had lower costs per patient.

1.6—Recommendations

1.6.1—For Health Professionals

- People with HIV have physical and mental health needs throughout the trajectory of illness, and mental health in particular is not related to HIV progression but can be a problem at any stage. All patients referred with HIV should be assessed for psychological need on a regular basis. Emotional wellbeing should be a core component of patient assessment in HIV monitoring upon registration and throughout patient care

- The needs of carers should be included in the patient care encounter. Including carers early on the care trajectory would demonstrate the value of the carer role in the eyes of facilities, improve social care for patients and could help to identify patient needs that are not acknowledged by the patients themselves.
- Participants established on ART were able to further improve their physical and mental health over three months. Care and support, complementary to ART, can help to optimise health.

1.6.2—For Health Facility Managers

- Health facilities should have a clear policy regarding delivery of social care, food support and financial refunds, so that the burden of decision making and payment does not fall on health delivery staff.
- Staff need to be supported and protected from risk of burnout to maintain valuable skills in health care and reduce turnover
- There should be sufficient numbers of non-clinical staff to ensure a manageable patient load for counsellors, nutritionists, social workers and community health workers, and high quality patient care. The areas addressed by these professions are a severe cause of need for people with HIV.
- Sufficient space is essential to providing confidential counselling services and meeting patient needs

1.6.3—For Policymakers

- Many participants were initiated onto ART within weeks of their HIV diagnosis, showing that they could have benefited from treatment at an earlier stage. Testing needs further encouragement so that people with HIV are identified as early as possible in the disease trajectory and gain the maximum benefit from care and support services including ART.
- No problems were reported with the supply of ARVs but supplies of other drugs were frequently unreliable, causing expense to patients and delays to care. Supply chain systems should adopt the best practices of the ART delivery system.
- Chronic hunger is not adequately managed by short-term interventions. Food shortage caused by poverty is a significant problem which inhibits delivery of HIV care. Health facilities should work towards sustainable, adequate food supply for all patients to help maintain health and adherence.
- Policy makers should advocate for increased use of appropriate analgesics, including opioids, to manage chronic pain.

1.6.4—For Researchers

- The evaluation model used here could be replicated in other countries.
- Facility staff who had hosted research projects for years expressed a wish to learn skills and conduct their own research. Future research programmes should include building of knowledge and capacity in host settings.
- A study of care and outcomes for children should be undertaken to explore the multidimensional problems of this important population, particularly the expanding group of HIV positive older children for whom optimal care is still being developed.
- Shortage of non-ART drugs delayed patient care and was a common complaint, but the cause of these shortages is unclear. Examination of the barriers to drug delivery and a more detailed investigation of how drugs are supplied would be beneficial in terms of care delivery and patient satisfaction.
- A longer follow-up period would be beneficial to explore whether care and outcomes are maintained over a period greater than three months.
- A study of how different staff working in care and support of HIV patients spend their working hours would enable an examination of how care costs relate to patient outcomes.
- Further study of referral networks from individual facilities would help understand where, as well as why, patients obtain care that is not provided at the principal facility of study.

2 Introduction

In 2003 the United States government (USG) authorised 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: provision of antiretroviral (ARV) treatment for people living with HIV/AIDS (55%), programmes to prevent HIV (20%), assisting orphans and vulnerable children (10%) and provision of palliative care services for individuals with HIV/AIDS (15%). PEPFAR has commissioned PHEs in these areas to evaluate funded programmes. Palliative care was subsequently redefined as care and support by OGAC.

2.1—Aim

The aims of the evaluation were to (a) 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); and (b) evaluate how PEPFAR care and support programme components and costs are related to health outcomes (Phase 2). By meeting these aims, this study was designed to provide detailed descriptions 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.

2.2—Objectives

To address these aims, the study 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;

» undertake a longitudinal prospective study of 600 patients newly diagnosed with HIV or who presented with a new problem attending PEPFAR care and support services. Data collected included self-reported quality of life, core palliative outcomes, and components of care received;

» conduct qualitative interviews with staff, patients, and carers in order to explore and understand service issues and care provision in more depth; and

» undertake a cost comparison of care provided, including staff, overhead and laboratory costs.

2.3—Study overview

The evaluation design, an observational study in Kenya and Uganda, was comprised of two sequential periods of data collection using mixed methodologies. Phase 1 (2007) was a cross-sectional survey of 10% of facilities providing care and support services and documented facility configuration and activities using quantitative and qualitative descriptive data.

Phase 2 (2008) was a longitudinal evaluation of care and support services focusing on patient outcomes using validated outcome tools. Qualitative interviews with staff, patients and carers provided in-depth understanding of key issues. An additional cost analysis component in this phase compared patient/family outcomes with their associated costs. Patient data collection took place between January and September 2008, with data collection for the costing component being completed in January 2009. This report focuses on Phase 2 of the evaluation in Kenya. Reports for Phase 1 in Kenya (**1**) and Uganda (**2**) have been published separately.

This 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 Country Teams, and representatives of the Ministries of Health in Kenya and Uganda.

3 Phase 2 Methods

3.1—Study Design

Phase 2 of the care and support PHE was a mixed method prospective evaluation of PEPFAR-funded care and support services. The main component was a longitudinal study of how care components potentially related to HIV patient palliative and general health outcomes over time. In-depth interviews with staff, patients and carers explored in-depth service issues. Descriptive cost data were collected to compare patient outcomes with cost of providing services. There were three parts to Phase 2 of this evaluation, including (a) a quantitative longitudinal study; (b) patient and staff interviews; and (c) a costing survey.

3.2—Rationale for the Study Design

The aim of the study was to evaluate how PEPFAR Care and Support programme components and costs are related to health outcomes. The PEPFAR programme was country-wide and had been implemented for several years before the evaluation was commissioned. Therefore it was not possible to conduct a before-and-after study. One option was to compare outcomes at facilities receiving PEPFAR funding with those which did not, but this design would have been difficult as there are few large facilities in the target countries which have never received PEPFAR funding. Little information exists regarding the quality of life of Kenyan populations, which could have been used as a comparison sample. Facilities did not have stated targets against which their performance could be compared.

A cross-sectional study would only be able to identify differences between facilities, which might be caused by population factors as well as variations in care and support delivery. A longitudinal cohort study design was selected to allow the effect of care over time to be examined. This design offered the best option for evaluation of outcomes, although it was not possible to remove the effects of previous contact with PEPFAR Care and Support.

Patient self-reported health was selected as the outcome of interest because care and support aims to improve quality of life, and could not be properly assessed without measuring this outcome. A mixed-methods design incorporating both quantitative and qualitative methods allowed triangulation and greater understanding of the data and its context.

3.3—Protocol Development

The protocol was developed by a multidisciplinary team, including medical professionals, HIV specialists and clinical and academic researchers, with review and comment from the USG Care and Support Technical Working Group and the country teams in Kenya and Uganda. All tools were piloted in one facility in Uganda. Following piloting, the wording and structure of the tools were modified and clarified. The tools are presented in Appendices A–D, and described below.

3.3.1—Longitudinal Quantitative Study

The data collection tools for the longitudinal study were four questionnaires, one of them (demography) used only once per person and the others used four times at monthly intervals. The time points, each one month apart, were designated T0 (entry to the study), T1, T2 and T3. A "patient pack" was created for data collection, consisting of all the tools bound in the order they should be used, with the pages colour coded by time point, and preceded by a log page to complete the dates of interviews and a front cover with the participant's ID number. For each facility, questionnaire packs were prepared in two languages; English and a common local language. All the documents were translated into local languages from the English versions twice, independently, by two local researchers. Each of these versions was translated back to English by a third researcher, with any discrepancies discussed amongst the group and an agreed translation decided.

Demographic and medical questionnaire (Appendix A): Basic demographic and medical details were collected using a brief questionnaire administered at T0 (recruitment to study). In addition, four clinical questions were asked at T1: WHO stage, date and result of most recent CD4 test, and date of beginning ART.

The African APCA Palliative Outcome Scale (POS) and Eastern Co-operative Global Performance Scale (ECOG) (Appendix B): The APCA African POS is an adapted version of the original POS, which was developed at KCL to address the multidimensional problems of patients with incurable progressive disease and subsequently adapted around the world (3;4). The APCA African POS was validated in ten centres in six Sub-Saharan African countries in 2006 (**5**). Its ten items address the primary physical, emotional and spiritual concerns of patients and families and employs scoring methods appropriate for a range of literacy skills. It was administered at each of the four time points. The validation study demonstrated its properties included sensitivity to change, and it has high levels of patient and clinician acceptability.

The ECOG is a clinician-rated single item measure of physical performance, with no psychosocial indices of quality of life, also at administered at all four time points (**6**). Scores range from 0 (normal activity) to 4 (unable to get out of bed). The ECOG is the most widely used performance measure (**7**).

Medical Outcome Scale-HIV (MOS-HIV) (Appendix C): The MOS-HIV is a very widely used quality of life measure and has been culturally adapted to the East African HIV setting (**8, 9**). The 35 items, asked at all four time points, address the domains of role function, pain, physical functioning, cognitive functioning, overall health perception, mental health, and vitality. The weighted subscores in these domains are then combined to produce two summary scores measuring physical health and mental health.

Client Service Receipt Inventory (Appendix D): This tool was a version of the Client Services Receipt Inventory (CSRI) (**10**) adapted for the aims of this study and the HIV setting in Africa in order to collect information about services received by patients in the study. Every month the CSRI recorded receipt of 52 components of physical, psychological, spiritual, social and preventive care, and whether they were received at the facility or from elsewhere.

3.3.2—Qualitative Interviews

Interview schedules (Appendices E, F and G) were designed to gain greater understanding of service use and provision from the views of the patients, their carers and the staff. The principal themes for patients and carers were experience of facility care, choice of facility, the nature and content of clinical encounters, and principal needs. Interviews addressed medical, psychological, spiritual and social domains. Initial interview transcripts were reviewed and question wording amended where needed to improve clarity of questions and fully explore key issues. The interview schedules, information sheets and consent forms were translated into local languages from the English versions twice, independently, by two local researchers. Each of these versions was translated back to English by a third researcher, with any discrepancies discussed amongst the group and an agreed translation decided.

3.3.3—Costing Study

Because the provision of care is such a complex area there are potentially a number of cost components that could be accounted for. Due to funding constraints on this study only the following key cost elements were examined: (a) labour—by staff type, staff salaries; (b) medicines—ARVs, pain medicines, antibiotics, CTX, other—and their inventories—buffer stock; (c) laboratory items—supplies and equipment; (d) buildings—rent per month or estimated rental value—and utilities; and (e) capital inputs—high end equipment and vehicles.

Because only the major cost drivers were included, the costs in this report are likely to be an underestimate of the real costs of providing care. Cost elements that may be significant, but which were not accounted for include: costs of developing training and HMIS systems, training of health providers, supervision, monitoring and evaluation including HMIS systems, clinic administrative costs, drug and commodities management and maintenance and depreciation on capital assets.

As HIV care and support is provided in a clinical setting in which other non-HIV services are provided, it was necessary to estimate the proportion of some cost elements which are measured for all clinical services and attribute a share for care and support. This is a common issue with the costing of services that are provided in an environment where several medical specialities are simultaneously provided separately at one facility. For labour costs, only staff who were involved in providing care and support services were included so there was no allocation difficulty with staff costs.

To estimate non-ARV drug costs, facilities reported the use of their three most common analgesics, of strong and weak opioids, CTX, the three most commonly prescribed antibiotics for OIs, and TB treatment. The cost of these was divided by the proportion of facility patients who were HIV positive, as a proxy for drug use. Similarly, capital and building costs were allocated to HIV care and support using the proportion of all patients accounted for by HIV patients. Tools were piloted and revised to maximise validity of the data collected and ease of data provision for facilities.

3.4—Ethical Approval and Data Storage

Ethical approval to undertake the study in Kenya was received from the Kenya Medical Research Institute (Ref KEMRI/RES/7/3/1) and the College Research Ethics Committee at KCL (Ref CREC/06/07-140). Subsequent tool changes following piloting were also approved.

During longitudinal data collection all questionnaires were stored separately from consent forms, in a locked filing cabinet at the facility. Upon completion of the study, anonymised questionnaires were taken from the facility to Nairobi for storage in locked filing cabinets. These arrangements were in line with ethical guidance and the Data Protection Act.

3.5—Selection and Recruitment

3.5.1—Health Facilities

In Phase 1, the approximately 600 facilities receiving PEPFAR Care and Support funding in Kenya were divided into three strata based on the number of patients treated in the past year, and 20 facilities were selected at random from each stratum. From these 60 facilities, the largest six were selected to participate in Phase 2. The inclusion criteria for Phase 2—which applied in addition to those for Phase 1—were that facilities recruited at least 30 new HIV patients a month, had sufficient staff with essential skills to conduct data collection, offered ongoing care and support to enable longitudinal data collection, and had sufficient capacity to engage in the study. The six largest facilities were selected because they were the most likely to meet the inclusion criteria listed above.

3.5.2—Participants

Longitudinal quantitative study: Consecutive patients who met all of the following criteria were approached for participation in the longitudinal study: (a) patients were 18 years of age or over; (b) patients were diagnosed HIV positive; (c) patients knew of their diagnosis; (d) patients had sufficient cognitive ability (estimated by health care workers) to answer the questions for the study; and (e) patients were either new to service or presenting with a new problem (social, psychological, spiritual or physical).

Participants gave informed consent to participate following provision of an information sheet and consent form. These documents were translated into local languages, and were read aloud by the health care worker if the patient was nonliterate. Participants were reimbursed travel expenses to the facility of US$5 per visit. Each facility recruited about 100 participants for a total of 600.

Qualitative interviews: Any staff member working at the facility who was involved in the care of patients was eligible to participate in the staff interviews. A purposive sampling strategy was undertaken in order to interview a variety of staff designations. The aim was to complete seven patient interviews, three carer interviews and five staff interviews per facility.

Eligible participants for the patient qualitative interviews were patients of the facility who had already been diagnosed as HIV positive, over 18 years of age, had been under care for at least six weeks, and were not involved in the longitudinal study (so as to minimise study burden). These patient participants were asked for consent to approach an identified adult informal carer (i.e., family member or friend who provides assistance/support) in order to undertake a separate qualitative interview.

Patient, carer and staff participants gave informed consent to participate following provision of an information sheet and consent form, which was read aloud to the interviewee by the health care worker if the interviewee was nonliterate.

3.6—Data Collection

Facilities were informed of the planned survey through the MOH in each country.

3.6.1—Longitudinal Quantitative Study

Data collection took place between January and September 2008, with recruitment to the longitudinal quantitative study ending in June to allow all the interviews to be completed. With the exception of CD4 counts, data for the longitudinal quantitative study were self-reported by the participants, and recorded in the questionnaire packs provided by health care workers (HCWs) already employed at each facility.

HCWs recruited patients and completed questionnaires in the course of their regular duties. Funding was provided to the facility directors to support data collection, including purchase of a computer. HCWs were trained by APCA staff in the process of seeking informed consent and the completion of the questionnaires. A researcher maintained contact with each facility through regular visits which would include observing data collection, checking the use of appointment diaries and regular data entry, and delivering additional training as necessary.

Data collection was conducted at recruitment (T0) and at three subsequent interviews about one month apart, which coincided with clinical appointments where possible. Once participants had completed the longitudinal study, CD4 counts were extracted from patient records by the HCWs, or by the researchers themselves under the supervision of HCWs.

Early in data collection it became apparent that participants could not always remember the date and result of their last CD4 count. Less than 50% of participants were able to provide a CD4 count and it appeared that these were biased towards people who were more ill or concerned about their health. Accordingly, permission was granted by the ethics board overseeing the study to search patients' records for CD4 counts. Researchers visited each facility after the longitudinal quantitative study data collection had been completed, and copied CD4 counts for the study participants into a specially designed form which preserved anonymity while allowing records to be linked to participants. CD4 count was the only piece of information obtained in this way. The decision to refer to patient records was taken because the researchers knew the information was collected by facilities, and participants had been informed of their result, but simply could not remember the information.

One questionnaire pack contained all the data for one individual. The pages were colour-coded to indicate time points. The front cover of the pack was blank apart from the participant's name. When the final time point was complete, this page was torn out, making the data unidentifiable. The second page included metadata logging the progress of data collection and management at each timepoint.

3.6.2—Qualitative Interviews

The interviews took place between February and September 2008. Single qualitative interviews with staff members, patients and informal carers were conducted by trained APCA staff and were digitally recorded. Interviews were carried out in several languages including English, Swahili and Luo. Interviews were conducted in private, usually in consulting rooms at the care facility.

Most participants were not accompanied by a carer and the few who were accompanied were often very ill, needing the carer's constant presence. As a result, recruitment of sufficient carers for qualitative interviews was difficult. Researchers identified family carers through community outreach teams operating from the care facilities, where available. In this way, a more representative sample of carers of patients at all disease stages could be interviewed.

3.6.3—Costing Study

A data collection instrument (Appendix H) was designed and tested to capture the identified cost elements in each of the Phase 2 facilities in which participants were being followed. Facility level data included number of patients seen by staff category in a typical day, hours spent with HIV patients per week and hours worked per week by staff category; number of staff by category involved in HIV care; quantities of medications dispensed in the last three months by kind of drug; numbers of laboratory tests conducted in the last three months; information on physical buildings such as space and an equivalent in rental value of the space; utility costs per month including water, electricity, generator fuel, communications, waste disposal etc.; transport costs, fuel, costs of drivers, maintenance; clinical consumable costs per month, including gloves, syringes, cotton wool swabs, plasters, soap, sterilizing solution etc.; amount spent on volunteer staff including training, travel reimbursements, payment in kind in past 3 months.

Researchers gathered the information required for the instrument with information provided by key informants at each facility. Key informants varied by facility but generally included the HIV clinic director, hospital administrator or manager, the accountant, clinicians, nurses and pharmacists. In some cases, more than one site visit was required in order to interview all relevant respondents and to complete the questionnaire.

Unit costs were required for some cost elements. These included staff (i.e., full salaries including allowances), prices of medicines and unit costs of laboratory tests. Salary data were obtained from the Kenyan Ministry of Health and from some of the facilities as well as from one of the USAID projects that supports some of the facilities. Drug costs were largely obtained from international sources such as the WHO and the International Drug Price Indicator Guide while laboratory test costs were obtained from ATC.

3.7—Data Management and Entry

3.7.1—Longitudinal Quantitative Study

Immediately after collection, data were entered into a pre-designed EpiData v3.1 database with conditional checks for internal consistency. Data entry was conducted at the health care facility by an administrative staff member who had been trained in the use of the tools and the database. When participants had completed the study, the completed data collection tools were transferred to the KEHPCA office. There research staff conducted a second round of all data entry and validation of the two rounds. Discrepancies identified were corrected by manual checking of questionnaires and results were revalidated until the two datasets were identical. The CD4 information from patient records was entered into a separate EpiData database and merged into the main dataset.

3.7.2—Qualitative Interviews

Interview recordings were transcribed verbatim into MS Word 2003 in the language in which they were conducted. If the interview was not conducted in English, two independent translations into English were then performed, either by the researchers or by identified native-speaker health professionals. A team of three then reconciled the two independent translations, referring back to the taped interview if necessary, and agreed upon a final version. After the final translation had been agreed, the tapes were destroyed. A table containing background information on the participant was added to the beginning of each transcript. These data were extracted from interviews and entered into Excel tables.

3.7.3—Costing Study

The data were entered into predesigned Excel spreadsheets. Analysis, including creation of graphs and linear regression, was conducted in Excel workbooks with data drawn together from the different sheets. Clinical staff were defined as doctors, nurses and clinical officers.

4 Analysis Plan

An analysis plan was developed and circulated to all contributors for comment after data collection was completed. The three main sources of data (longitudinal quantitative study, qualitative interviews and costing) were analysed separately. Analysis plans are outlined below, with the research questions in boxed text.

Following the implementation of the analysis plans, the results were integrated. The six participating facilities are designated by numbers in this report to preserve anonymity. The same identifying numbers were used in the Phase 1 report so that reference can be made between the two.

4.1—Longitudinal Quantitative Study

Analysis was conducted using Stata v10.

4.1.1—Outcome Measures

The main outcome measures were the MOS-HIV (health related quality of life) and APCA African POS (palliative care related problems). In order to reduce multiple significance testing, for the purposes of this evaluation the MOS-HIV was used as the primary outcome measure, owing to its previous use in longitudinal HIV research in Africa (**11**).

MOS-HIV: The 35 MOS-HIV items contribute to eight multi-item subscales (health perceptions, physical function, role function, cognitive function, pain, mental health, energy/fatigue, and health distress) and two single-item subscales (social function and quality of life). Subscales were computed by summation of individual item scores and conversion to a score out of 100, with 0 indicating the poorest health and 100 indicating the best health. Two summary scores for physical health and mental health were calculated by weighting each subscale score with standard coefficients, then aggregating the weighted scores across subscales, which were also scored out of 100 (**12**). These summary scores were the principal outcomes used from the MOS-HIV.

The physical health score comprises the physical function, pain, role function and social function subscales, with a smaller component from the energy and general health perceptions subscales. The mental health score comprises mostly mental health, health distress, quality of life, cognitive function and energy subscales, with smaller contributions from social function and general health perception subscales. Both scores are standardised so that the mean is 50 and the standard deviation is ten (**12**). Point differences of three to five are considered clinically significant (**11**).

APCA African POS: For the APCA African POS, the scores for the first three items (pain, symptoms and worry) were reversed so that for all items, zero represented the worst situation and five the best. Three items are addressed to the main carer of the patient. The POS is designed to be a multidimensional scale for progressive disease (**13**) and it is unlikely that all the items form a single factor. The POS items are commonly used separately for clinical audit (**5**). In this study, data from the instrument were used to give more detailed information on the problems of participants attending care facilities, and a total score was created using the seven patient items, but because of its limitations as a single scale it was not used as one of the main outcome variables.

4.1.2—Section A: Cross-Sectional Descriptive Analysis

Facility Characteristics

1. What are the six facilities like in terms of infrastructure and care offered?

Information from the cross-sectional survey in Phase 1 of the evaluation was used to provide a summary of facility characteristics for the six Phase 2 facilities. The location, number of patients per year, type and referral system for inpatients, number and type of fulltime, part-time and volunteer staff at each facility, and the components of care offered were detailed. This information was self-reported by a small group of senior staff at each facility.

Participants and Interview Numbers

2. How many people were there in the study?
3. How far apart were the interviews?
4. How many people dropped out and why did they leave?

Time points were designated T0 (study entry or baseline), T1, T2 and T3. Ideally these would each be one month apart but any data collection within two weeks either side of that point was acceptable, in order to minimise the burden of additional travel for participants. Some recoding of timepoints took place. If a participant was recorded to have completed T0, T2 and T3 but missed T1, then T1 was deleted from the record and T2 and T3 were renumbered T1 and T2, to obtain a continuous series of three points. Compressing timepoints in this way made the most efficient use of the data.

An alternative would have been to consider that timepoint was defined by time elapsed since T0, rather than by number of interviews completed. However, as explained above, the time between interviews was not precisely one month and in some cases was considerably more. Using exact time as the definition of a timepoint would have necessitated either renumbering some interviews to T4, T5 and so forth, or dropping them from analysis.

The median, maximum, minimum and inter-quartile range for time between interviews was calculated. A flowchart was produced indicating the loss to followup at each data collection point. The number of people recruited, completion rate and mean time between interviews was tabulated by facility.

Participant Characteristics

5. What kind of patients come to these six facilities for PEPFAR Care & Support services?
6. How long have they known they were HIV-positive?
7. Why do they come?
8. How advanced is their HIV disease?

The study group was described in terms of age, gender, number of dependants, and reason for attending the facility. The length of time between the date of HIV test result and the beginning of the study was calculated.

The variables from the demography questionnaire which related to socioeconomic status were incorporated into a principal components analysis to generate a single factor. This factor was then split into five quintiles of equal size, to create a categorical variables for relative wealth (**14**). The socioeconomic variables were presented by wealth quintile to portray the characteristics of each level of relative wealth.

The variables included were those used in the DHS surveys: (a) material used to make the walls/roof/floor of the house; (b) type of toilet; (c) main source of drinking water; (d) fuel used for cooking; and (e) household ownership of car/bicycle/refrigerator/television/mobile phone/radio.

Reason for attending the facility was a closed question in the demography questionnaire. Individuals whose HIV test date was in the 14 day period prior to joining the study were recoded so that their reason for attending was 'new HIV test result'. A free text option was provided for those who reported they came because of referral, a new illness or for another reason. The answers in the free text boxes were used to recode some responses. In particular, those who reported that they had been referred from VCT were recoded as having an HIV test result. Reason for joining were tabulated and presented by percentage.

CD4 count is the best measure of the progression of HIV disease commonly in use. CD4 count was used for two purposes: to establish a baseline measure of HIV disease severity at the time of the study, and to observe change in CD4 count over the course of three months. During data collection it was discovered that very few participants had two CD4 counts so close together to enable the examination of change over the course of the study. The first purpose of CD4 count (i.e., measure of disease severity) accordingly came to be the main one.

Available CD4 count data was categorised by time. CD4 T1 was fixed within the range from one year prior to the beginning of the study (T0) to the time of the second interview, designated T1. CD4 T3 was in the range from the third interview (T2) to three months after T3. These time ranges were set after consultation with clinicians as to the rate at which CD4 count changed over time and assessment of the data available in patient records. It was important to get a valid count from as many people as possible. If the time period was too short not enough counts would be included, and if it was too long the result would no longer be valid. To balance these competing demands, one year before T1 was agreed as the boundary.

For those individuals who had two CD4 counts to compare, change in CD4 counts from T1 to T3 was analysed using a paired t-test. The two other measures of illness severity, WHO stage and ECOG physical function score, were also analysed. ECOG at the beginning of the study was tabulated and WHO stage at each timepoint was presented by facility.

Care Participants Received

9. What kinds of Care & Support do people receive?
10. What kind of care do they get from the PEPFAR-funded health facility and what do they get from other places?
11. What are the five categories of PEPFAR Care & Support?
12. Which of these five categories are people most likely to get?
13. What care do people get immediately after being diagnosed HIV positive?
14. What is the Preventive Care Package and how many people get it?

The frequency of ever receiving each of the 52 care components listed in the CSRI was calculated. People who responded "don't know" when asked whether they received a component of care were grouped in the "no" category. Care receipt was reported separately for components received at the study facility and those received elsewhere. The main figures presented were proportion receiving a care component at a particular time point (as a percentage of those completing the timepoint), and proportion ever receiving the care component (defined as receiving it at least once and up to four times, calculated as a percentage of all study participants).

PEPFAR Care & Support services consist of five categories: clinical, psychological, spiritual, social and preventive care. The 52 components were ordered into these categories based on existing guidelines (15) and the percentage of people receiving each category was calculated.

The 267 participants (of 696) whose positive HIV test took place in the two weeks before entering the study were analysed separately in order to explore the care which newly diagnosed people received.

PEPFAR encourages the development of a country-specific Preventive Care Package (PCP) of prophylactic items such as ITNs, water filters and multivitamins. In Uganda a five-item PCP has been evaluated and is being rolled out across the country. Kenya has not produced a definitive list of PCP items, so the Uganda PCP was used in this study. The five elements of the Uganda Preventive Care Package were examined, for newly registered patients (who should be assessed for need of each component) and existing patients.

Care Themes

15. What kind of problems do care components address?
16. What are the themes and patterns of care provision?
17. How many people get antiretroviral therapy and how regularly do they get it?
18. How many people get CTX and do they take it every day?

Care components were grouped into themes according to the issues they addressed and the way in which they were provided. This approach allowed more detailed analysis of the relationships between care components. The care themes were also used in later analysis as an average of the number of people receiving care by facility. For this section, components of care which were very rare (received by fewer than 10% of participants at any time) were removed from the themes, because as outliers they could have unwarranted effects on the results. Each care theme was tabulated. Further analysis is described below by care theme.

Spiritual: Involves a visit by a religious leader, prayer with patients, and contact with traditional healer. Spiritual care is a distinct aspect of PEPFAR Care & Support. Staff praying with patients and a visit from a religious leader are the most common types of spiritual care provided through health facilities in Kenya. Many people with HIV visit traditional healers (**16**) and the care delivered by them fits the PEPFAR definition of spiritual care being sensitive to individual and community culture (**15**).

Counselling and Advice: Involves pre-and post-test counselling, adherence counselling, family planning counselling, patient HIV support groups, family counselling and psychiatric therapy. This theme comprises all "talking therapies." It is sometimes difficult to distinguish counselling as listening and responding to the patient's worries and concerns from counselling as didactic imparting of information. VCT, for example, is a strategy of both prevention and care, assessed for its efficacy in reducing risk behaviour and HIV transmission (**17**). While these are valuable goals, they are a departure from the usual purpose of counselling which is improved health for the individual.

Nursing: Involves wound care and other nursing care. Nursing is a specific discipline and its status may vary between facilities.

Pain Management: Is an assessment of pain and provision of strong and weak opioids or non-opioid analgesics and treatment for neuropathic pain. Pain is a common symptom in HIV (**18**) and all five components in this theme are necessary for its relief. The WHO pain ladder (**19**) outlines the need for non-opioid and opioid analgesics until pain has been controlled. Neuropathic pain, which is particularly common in HIV (**20**) is caused by damage to nerves and does not respond to traditional, non-opioid and opioid analgesic pain medication.

Symptom Management: Involves treatment for anxiety/depression, nausea/vomiting, skin rash/itching, diarrhoea, laxatives, thrush, oral candidiasis, cryptococcus, other fungal infections, herpes, malaria and other opportunistic infections.

The components in this theme were usually defined by the symptom treated, rather than the underlying cause or pathogen, because the cause of a symptom is often not known in HIV disease (**21**). All these physical symptoms and conditions are common in HIV (**21, 22**).

Nutrition: Includes food, multivitamins, nutritional advice, safe drinking water, therapeutic feeding for malnutrition. As part of Phase 1 of the evaluation, patient focus group discussions revealed that food was one of the most commonly requested components of care. Poor nutrition comprises two problems: lack of macronutrients (wasting, malnutrition) and lack of micronutrients (vitamins and minerals). Both of these predispose individuals with HIV to infections and ill health. Lack of food is the most fundamental level of poverty.

Social: Involves employment training/income generation activity (IGA), home help, household items, legal services, memory book work, loans/microfinance. The social theme components were selected after advice from USG country mission teams. Phase 1 qualitative data indicated that the purpose of IGA and microfinance programmes was not only to increase income for families, but to reverse the myth that people with HIV are incapable of acting for themselves. Memory book work was allocated to the social care theme because it aims to reduce internalised stigma and improve relations between family members.

Prevention: Involves prevention with positives, condoms, ITNs, infection control training, isoniazid for TB prophylaxis. This theme includes both components to protect the person with HIV from other infections, and components to prevent them from infecting others with HIV. Prevention with positives is the general name for a package of care designed to encourage behaviour change (condom use, reduction of partners, and revealing HIV status). Condoms prevent further infection and also protect the individual from other strains of HIV and from other STIs such as herpes. Insecticide-treated nets protect against malaria, which is more common and more aggressive in people with HIV (**23**), and the TB drug isoniazid can be used as a prophylactic for those at high risk of TB.

ART: Involves ARVs and assessment of ARV treatment. Antiretroviral therapy consists of more than ARVs. It includes regular assessment to observe signs of developing resistance, toxicity and side effects. Receipt of antiretroviral therapy was tracked over time using a decision tree. Receipt of ARVs and of assessment was compared by facility and timepoint.

CTX: CTX is a broad-spectrum antibiotic proven to reduce morbidity and mortality in people with HIV (**24, 25**). At each interview participants were asked whether they had taken CTX on the previous day and whether they had been given daily prophylactic CTX in the last month. These answers were compared to test adherence.

TB: TB treatment was listed separately from treatment for other symptoms and infection, for two reasons. Firstly, it is the leading cause of death for people with HIV in Africa (**26**). Secondly, the course of treatment lasts for four to six months, long after symptoms have resolved. The full course of treatment must be completed to prevent resistance and recurrence. TB testing was not included as it would not, in itself, improve outcomes.

Health at the Beginning of the Study

19. What level of physical and mental health do people have at the beginning of the study?
20. What kinds of multidimensional problems do people have?
21. What needs do informal caregivers and family members have?

Physical and mental health summary scores were calculated from the MOS-HIV as described above. The summary scores at the beginning of the study were grouped into blocks of 50 to present as histograms, and analysed for mean, median and standard deviation.

Multidimensional problems were collected in the APCA African POS. Each of the seven patient-completed items was graphed individually and all items were analysed for median and inter-quartile range. These were used rather than the mean and standard deviation because scores were not expected to be parametric. The scores of the seven patient items were added together to create an APCA African POS total score, which was presented as a histogram.

How Participants Differ by Facility

22. Do the six facilities care for different kinds of people?
23. Are the people at some facilities more ill than at others?
24. Do people at different facilities get different kinds of care?
25. Do people at different facilities get all the five categories of PEPFAR Care & Support?
26. Are people at some facilities more likely to get care from elsewhere?
27. How do physical health and mental health vary by facility?

The demographic characteristics of participants were compared according to the facility with which they were registered. Gender split, mean age, median number of dependants and median time to travel to the facility were compared visually. Relative wealth and reason for attending were tabulated by facility. Illness severity was explored by tabulating ECOG scores and mean CD4 count by facility.

The mean, standard deviation, minimum and maximum number of care components received by individuals at each facility was calculated, along with the proportion of participants by facility receiving each of the 52 components of care. The proportion of participants ever to receive each of the five PEPFAR C&S categories was compared between the six facilities. The proportion of participants receiving care from the facility and from elsewhere was also calculated by facility, and a series of stacked bar charts was produced showing the mean number of care components received from each location by facility and time. Finally, mean and standard deviation of physical and mental health scores and total APCA African POS scores were calculated at baseline for each facility, and the extent of the difference was analysed using Kruskal Wallis tests.

Participant Characteristics and Health

28. Do men and women have the same physical and mental health?
29. Do older people have the same physical and mental health as younger people?
30. Does education or wealth make a difference to physical and mental health?
31. Do people whose HIV is more advanced have worse physical or mental health?
32. Do people receiving ART or TB treatment have different physical or mental health?
33. Do patients accompanied by a carer have different physical or mental health?

The association of baseline physical and mental health with demographic characteristics was analysed using appropriate statistical tests, with a significance level of 5% throughout. Mean health scores for men and women were compared using t-tests. The ordinal variables, education, and wealth quintile, were analysed using ANOVA, and the continuous variable age was analysed using linear regression.

CD4 count at T1 was used to represent illness severity. CD4 count was converted into an ordinal variable with four categories which are most commonly referred to for clinical decision-making (**27**) and epidemiological studies (**28**). The categories were (a) 0–50: increased mortality risk (**29**); (b) 51–200: severe immunosuppression; (c) 201–350: immunosuppression; and (d) above 350. The association of health scores with CD4 category was analysed using ANOVA. In addition, linear regression was used to identify whether mental health was associated with CD4 count after controlling for physical health.

Mean physical and mental health, with standard error, was calculated for people who received antiretroviral therapy at T1 compared to those who did not. CD4 counts for T1 (and the year preceding it) were also compared according to receipt of ART. The hypothesis was that in this observational, non-randomised study of an outpatient population, participants not receiving ART would be those in earlier stages of illness who had not yet been prescribed it. Accordingly, people receiving ART at T1 would have a lower CD4 count (which is one of the criteria for beginning ART), and lower physical and mental health due to their more advanced disease. These hypotheses were tested using t-tests with a 5% significance level. The same analysis was repeated for TB treatment.

It was hypothesised that participants with lower physical health would be more likely to be accompanied by a carer, but the same would not be true of mental health. To test this hypothesis, linear regression was used to separate the associations of carer presence with physical and mental summary scores at T0.

4.1.3—Section B: Longitudinal Analysis

Longitudinal multilevel modelling is an approach which makes the most efficient use of data collected over time. Unlike most statistical tests, longitudinal modelling includes all timepoints at once, which both reduces the number of tests to be carried out (making false positive results less likely) and allows change to be modelled as a continuous effect. This means that rather than simply finding variables which are associated with any change in outcome, the magnitude of the change can also be considered.

A common problem in longitudinal studies of health outcomes is that patients with the worst health are the most likely to be lost to follow-up, so that a comparison between the beginning and end of the study could find improved outcomes only because a proportion of those with poor health would not contribute to the later timepoint. Longitudinal analysis does not have this bias because all participants can be included whether they complete the study or not.

Additionally, longitudinal analysis can reveal patterns over time which would not be identified using traditional methods such as t-tests. For example, in this population a cross-sectional study at any time would have found that people with greater relative wealth had higher health scores. Longitudinal analysis showed that although this was true, wealth was not associated with change in outcomes over time. Rich and poor gained equally from the care they received, and the difference in health scores was due to poorer participants arriving at the facility with a lower level of health, not to any disparity in care.

The technique adopted in this study was multilevel mixed-effects linear regression, selected because it allowed data to be clustered at two levels, by individual and by facility.

34. Were people with worse health at the beginning of the study more likely to drop out?

The question of whether people with lower health scores at the beginning of the study were more likely to be lost to follow-up was a very important one. Many longitudinal studies suffer from the bias caused by the most unwell individuals being most likely to leave the study. To determine whether this bias was present, t-tests were used to compare the mean physical and mental health scores of those who completed all four observations with those who missed at least one. Traditional analysis of longitudinal data involves comparing the earliest observation with the last, so any difference in the scores of completers versus non-completers would bias the findings.

In addition, the same tests were used to compare the mean scores of those who only completed a single observation with those who completed two or more. This was to test the suitability of multi-level modelling, which is explained below. Multi-level modelling uses all data points except the first one, so anyone who only completed one observation would be excluded and it was necessary to test whether this would also cause a bias.

Changes in Health Over Time

34. On average, does participants' health improve, stay the same or get worse during three months of care?
35. On average, do participants' multidimensional problems improve, stay the same or get worse?
36. Do the people with the worst physical and mental health at the beginning of the study get better, stay the same or get worse?
37. Do all six facilities find their participants' physical and mental health changes by the same amount?

Mean, standard deviation and 95% confidence intervals of physical and mental health at each timepoint were calculated and graphed. The change in mean health score from T0 to T3 was calculated, with its standard deviation, and checked for clinical significance.

Comparing mental and physical health score change at different facilities was accomplished using graphs rather than statistical analysis, because graphs were sufficient for the purpose and provided clarity on exactly how facilities varied. Change in outcomes over time was calculated separately for each participant at each timepoint. Mean change over time was reported as the mean of all individual score changes, rather than mean health score at one time point subtracted from mean health score at another. For example, mean change in mental health score from T0 to T2 was derived by finding the change in health score for each person who had completed both T0 and T2, and then taking the average of these, rather than by subtracting mean mental health at T0 from mean mental health at T2. This method removes the risk of bias due to non-response.

To test whether physical and mental health summary scores changed significantly over time throughout the course of the study, a multilevel modelling method was adopted (**30**). The methods are detailed in Appendix I. This analysis was repeated with the 20% of participants (n=128) who had the lowest physical health score at T0, and with the 20% who had the lowest mental health score at T0, to determine whether the effect of improved outcomes over time extended to those in greatest need. For the APCA African POS, score distribution at each timepoint was tabulated for those who scored 0 (worst possible problem) on the items relating to pain and symptoms. This simple approach was adopted because very few people scored 0 on these items and mean scores could have been biased by a single outlier. The items for pain and symptoms were selected because people with complex, intractable problems in advanced disease may not experience improvement although average scores for the population increase.

Changes in Health Over Time in Detail

38. Do men and women experience the same improvements in physical and mental health?
39. Does, age, education or wealth have any effect on whether a person's physical and mental health improves?
40. Do people taking ART or having TB treatment experience the same improvement in physical and mental health as people who don't?
41. Does being at a facility which offers certain kinds of care have an effect on whether physical and mental health improves?

Differences between Individuals

To identify whether demographic variables were associated with different changes in physical or mental health over time, the multi-level models developed earlier were now rerun with the addition of each demographic variable (age, gender, education level and wealth quintile), one by one. The models were run exactly as before, except that each contained one demographic covariate. This process of univariate analysis was adopted because it is more careful and the methods were new, to remove the risk of finding unwarranted associations. Education level and wealth quintile were treated as continuous variables for this analysis, because each of them had enough categories of sufficient size to approximate to a continuous distribution.

ART and TB treatment were considered particularly important variables to model over time, for several reasons. Both of them must be maintained over time (for TB treatment, usually for six months; for ART, usually indefinitely), both of them are lifesaving treatments which are associated with side effects, possible drug resistance, and the need for monitoring. Multilevel models were developed to show the association of physical and mental health with ART and with TB treatment over time.

These covariates, unlike any others studied so far, varied over time. Time-invariant characteristics such as age and relative wealth were only measured once and remain constant for each individual. Care availability, discussed below, is constant by facility. By contrast, receipt of ART or TB treatment was elicited at every timepoint and so each of the (maximum of three) observations an individual contributes to the model has its own value.

It was necessary to include CD4 count at T1 in the model as well, because previous analysis had shown that CD4 count was lower in people receiving ART or TB treatment at T1, and it was possible that any effect on health scores could be confounded by lower CD4 count and its consequences. The intention had been to analyse CTX using the same techniques, but this was not carried out because CTX provision reached almost 100%, meaning that those few individuals who for some reason did not receive it could have been different from the rest in ways which would bias the findings.

Differences between Facilities

Examining the relationship between health outcomes and care received was complicated by the potential bias that those in the worst health would probably receive the most care, whereas a lack of care could mean either no need of it, or lack of appropriate provision. To avoid this problem, a variable representing available care needed to be developed, which might have a closer association with health outcomes than the level of care individually received. Availability of care was defined as the percentage of individuals at a facility who received care in a particular theme. Care themes were used rather than individual components in order to reduce the number of variables needed in the model and ensure stability. For example, the variable "psychological care," contains information on the percentage of people, per facility, who received at least one component of psychological care at T1, T2 or T3. T0 was excluded because the model analysed change from T0 onwards.

Each of the eight remaining care themes (counselling/advice, nursing care, spiritual care, prevention, nutrition, social care, pain management and symptom management) were included one by one in a univariate multi-level model to identify which ones were associated with mental or physical health over time. As before, multilevel mixed-effects linear regression was used with repeated measures at the individual level and individuals clustered within facilities. The outcomes were mental health score and physical health score. Additional covariates included the baseline value of the other outcome variables (i.e., if mental health score was the outcome of the model, both T0 mental health score and T0 physical health score would be individual-level covariates) and any demographic covariates which had been identified as associated with the outcome. Both T0 outcome scores were included because a separate piece of analysis (Appendix I) showed that the two scores were closely associated and that in some cases an apparent association with mental health score was in fact entirely confounded by physical health score.

All variables had fixed coefficients, with the exception of interview number which was allowed to vary at the individual level. All individual-level and facility-level covariates which were associated with outcome at the 10% level in univariate analysis were taken forward into a multivariate model and eliminated in a downward stepwise procedure if the association was lost. It is usual to use 10% as the acceptance level with stepwise downward regression to avoid dismissing variables too early.

4.2—Qualitative Interviews

The interview transcripts were imported from Word into NVivo 7 for coding and analysis. Information on interviewees' age, gender, household location, family size, profession (for staff), relationship to patient (for carers) and whether they were receiving ART (for patients) was extracted into an Excel table, subsequently imported into NVivo. Identifying information such as names of individuals or care facilities was removed from transcripts. Thematic analysis of content was conducted concurrently on the patient, carer and staff interviews to enable multiple perspectives on each coded theme.

42. How do facilities provide HIV care and what is the nature of the care they provide?
43. What is the experience of participants receiving care and their families?

4.2.1—Development of Coding Frame

Two coding frames were developed and subsequently combined into a single version used for the remainder of the coding. One coding frame was developed in Kenya by the team of APCA researchers at KEHPCA who had conducted the interviews. The other coding frame was developed at KCL in London. The intention was to explore cross-cultural differences and similarities in coding.

In both three-person teams, each researcher coded eight randomly selected interviews (three with a patient, three with a member of staff and two with a carer), creating hierarchical codes. The team members agreed on a coding frame by discussion, comparison and consensus. At a meeting in Kampala, Uganda, the two coding frames were compared and found to be similar in many respects. A unified coding frame was developed, combining the strengths of both country-level frames. Each code was reviewed for internal consistency and given an agreed definition to ensure it was applied using a standard meaning by each researcher. The Kenya researchers were trained in the use of NVivo 7 and in application of the new coding frame, which was applied to the entire dataset.

Each of the APCA researchers coded three interviews which were checked for consistency at KCL. The APCA researchers then proceeded to code all remaining interviews.

4.3—Costing Study

44. What is the cost of supplying the HIV care received by study participants?
45. What are the main cost drivers of HIV care and support?
46. Are there economies of scale in HIV care and support delivery?

The costing study makes it possible to understand what factors influence costs per patient. For example the capital costs of rural facilities might be expected to be less than those in urban settings. Similarly if a facility tends to use relatively inexpensive providers it may be less expensive in providing the same service as a facility that has lots of trained physicians. Facilities that do not provide ART or do not provide testing may also have lower costs per patient. We might also expect to observe economies of scale with larger facilities (judged by numbers of patients) registering lower per patient costs than smaller ones.

Another possible use of costing data is to guide resource allocation. If two programmes have similar outcomes but different costs it may be possible to reallocate resources to the lower cost programme with no loss in health benefits or the less efficient programme might change the way it allocates resources so as to emulate the more efficient programme. This cost-effectiveness analysis, however, was not part of the present study.

Analysis was carried out using an Excel spreadsheet. Most data were collected in local currency (Kenyan shillings), and converted to US dollars at the current exchange rates. Since only six facilities per country were included and these facilities were not meant to be statistically representative, all results are reported per facility without aggregation across the sample. The average costs per patient for one year of care and support were calculated using aggregated average costs per patient for each of the main components of care for a year. Scatter plots of per-staff member patient load against staff costs, and of per-patient costs against number of patients, were used to investigate economies of scale.

5 Results of Longitudinal Quantitative Study Section A

5.1—Facility Characteristics

The facilities taking part in Phase 2 of this PHE also took part in Phase 1 (the facility survey). Phase 1 data collection took place between April and August 2007. Some of the key results from Phase 1 are presented here to provide context with respect to the nature and scope of HIV care and support provision at the Phase 2 facilities.

Of the six facilities taking part in Phase 2, all but one were government-run facilities (Table 1). Three facilities were secondary or tertiary hospitals, two were district hospitals, and one was a non-governmental health centre. The facilities had between 1126 and 5975 HIV positive patients registered in 2008, of whom between 246 and 796 were newly registered in that time. Registered HIV patients were between 25.8% and 48.2% male.

All facilities had full time doctors, although four facilities did not have any specialist spiritual staff and four did not have any specialist psychological staff. Five facilities had a small number of volunteer staff, and one facility employed 40 of their 99 staff members on a voluntary basis. All facilities provided between 50 and 54 of the 69 components of care examined. Facilities 157, 159, and 160 all provided at least one component of care under each domain of the PEPFAR care and support guidelines (clinical, psychological, spiritual, social and prevention).

Table 2 shows facilities' self-reports of the care components they provided, either directly or by referral. "Yes" has been abbreviated to "Y" to make the other responses stand out more clearly. Most symptom management care components were reported at all facilities, but social care and opioid drugs were often not reported.

Table 3 shows the number of staff of several key professions working at each facility as reported in Phase 1. Fulltime, part-time and volunteer staff were reported separately. Facilities 156, 157 and 159 had large numbers of fulltime clinical staff, while only Facilities 155, 158 and 160 employed community health workers.

5.2—Participant and Interview Numbers

Of the 728 patients approached to participate at the six facilities, 696 gave consent and were recruited to the study (response rate=95.6%). Of the 696 participants recruited, 634 (91.1%) completed more than one interview and 592 (85.1%) completed all four. The most common reason given for leaving the study was leaving the facility (attributed to 30 of the 104 participants who were lost to follow up). Figure 1 displays the loss to follow-up over time, after recoding of timepoints as described in the Methods section. The median (IQR) number of days between each subsequent interview was 28 (28–31). The responses by interview month and facility are shown in Table 4.

Table 1: Characteristics of Facilities

Facility	Type	Location	No. Patients in 2007	No. New Patients in 2007
155	HIV clinic of public hospital	Rural	N/K	246
156	HIV clinic of public hospital	Urban	3031	377
157	HIV clinic of public hospital	Urban	4334	463
158	NGO	Urban	1126	796
159	HIV clinic of public hospital	Urban	4963	547
160	HIV health centre	Rural	5975	422

Table 2: Facility Self-Reported Care Provision from Phase 1 Survey

Type	Component of Care	Service Provided					
	Facility	*155*	*156*	*157*	*158*	*159*	*160*
General clinical	Nursing care	Y	Y	Y	Y	Y	Y
	ARVs	Y	Y	Y	Y	Y	Y
	Weighing	Y	Y	Y	Y	Y	Y
	Assess ARV treatment failure	Y	Y	Y	Y	Y	Y
	Monitor ARV toxicity	Y	Y	Y	Y	Y	Y
	Wound care	Y	Y	Y	Y	referred	Y
	Physiotherapy	Y	Y	Y	No	referred	Y
Pain management	Assessment of pain	Y	Y	Y	Y	Y	No
	Strong opioids	No	No	No	No	No	No
	Weak opioids	No	No	No	Y	No	No
	Non-opioids	Y	Y	Y	Y	Y	Y
	Treatment for neuropathic pain	Y	Y	Y	Y	Y	Y
Symptoms	Anxiety/depression treatment	Y	Y	Y	Y	Y	Y
	Treatment for nausea/vomiting	Y	Y	Y	Y	Y	Y
	Treatment for skin rash/itching	Y	Y	Y	Y	Y	Y
	Treatment for diarrhoea	Y	Y	Y	Y	Y	Y
	Treatment for constipation/laxatives	No	Y	Y	Y	Y	Y
	Treatment for thrush	Y	Y	Y	Y	Y	Y
	Treatment for oral candidiasis	Y	Y	Y	Y	Y	Y
	Treatment for cryptococcus	Y	Y	Y	Y	Y	Y
	Treatment for other fungal infections	Y	Y	Y	Y	Y	Y
	Treatment for herpes	Y	Y	Y	Y	Y	Y
	Treatment for malaria	Y	Y	Y	Y	Y	Y
	TB detection	Y	Y	Y	Y	Y	Y
	TB treatment	Y	Y	Y	Y	Y	Y
	Therapeutic feeding for malnutrition	Y	Y	Y	Y	Y	referred
	Treatment for other opportunistic infections	Y	Y	Y	Y	Y	Y
	Management of cancer	referred	Y	referred	Y	Y	Y
Psychological	Pre- and post-test counselling	Y	Y	Y	Y	Y	Y
	Adherence counselling	Y	Y	Y	Y	Y	Y
	Family planning counselling	Y	Y	Y	Y	Y	Y
	Patient HIV support groups	Y	Y	Y	Y	Y	Y
	Family care-givers support group	No	Y	Y	Y	No	No
	Family counselling	Y	Y	Y	referred	No	Y
	Psychiatric therapy	referred	Y	Y	No	referred	referred

Table 2: Facility Self-Reported Care Provision from Phase 1 Survey

Type	Component of Care	Service Provided					
	Facility	*155*	*156*	*157*	*158*	*159*	*160*
Spiritual	Visit by faith leader	No	No	No	No	Y	No
	Prayer with patients	No	Y	Y	No	No	Y
	Contact with traditional healer	No	No	No	No	No	No
Social	Home help	Y	No	No	No	No	No
	Transport to care centre	Y	No	No	Y	Y	Y
	Employment training	Y	No	No	Y	Y	Y
	Provide household items	Y	No	No	referred	No	No
	Legal services	No	No	Y	No	No	referred
	Memory book work	No	No	No	No	No	No
	Family home help	Y	No	No	No	No	No
	Loans/microfinance	No	No	No	No	No	Y
	Infection control training	Y	Y	Y	Y	Y	Y
Prophylaxis/ preventive care	Support for family testing	Y	Y	Y	Y	Y	Y
	Prevention with positives	Y	Y	Y	Y	Y	Y
	Multivitamins	Y	Y	Y	Y	Y	Y
	Nutritional advice	Y	Y	Y	Y	Y	Y
	Access to safe drinking water at home	Y	No	Y	Y	Y	No
	CTX	Y	Y	Y	Y	Y	Y
	Isoniazid	No	No	No	Y	No	Y
	Condoms	Y	Y	Y	Y	Y	Y
	ITNs	No	No	No	Y	No	No
Laboratory	Malaria film	Y	Y	Y	Y	Y	Y
	AFB smear	Y	Y	Y	Y	Y	Y
	CD4 count test	Y	Y	Y	Y	Y	referred

Table 3: Staff Working at Each Facility *(FT=full-time, PT=part-time, Vol=volunteer)*

Facility	***155***			***156***			***157***			***158***			***159***			***160***		
Staff Type	**FT**	**PT**	**Vol**	**FT**	**PT**	**Vol**	**FT**	**PT**	**Vol**	**FT**	**PT**	**Vol**	**FT**	**PT**	**Vol**	**FT**	**PT**	**Vol**
Doctor	2	0	1	51	0	0	20	0	0	2	2	0	16	0	0	1	0	0
Clinical officer	10	1	0	24	0	0	22	0	0	5	0	0	30	0	0	16	0	0
Nurse	48	0	0	294	0	0	216	0	0	25	0	0	124	0	0	26	0	0
Lab staff	5	0	0	15	0	0	19	0	0	5	0	2	5	0	0	4	0	0
CHW	4	2	2	0	0	0	0	0	0	10	0	30	0	0	0	0	30	0
Social worker	0	0	0	1	0	1	2	0	0	0	0	0	2	0	0	2	0	0
Spiritual leader	0	0	0	0	0	1	0	0	0	0	0	0	0	0	1	0	0	0
Nutritionist	1	0	0	5	0	0	7	0	1	2	0	0	4	0	0	2	0	1
Counsellor	0	0	0	0	0	0	0	0	0	3	0	8	0	0	0	7	0	0
Physiotherapist	1	0	0	8	0	0	5	0	0	0	0	0	6	0	0	1	0	0

Table 4: Participant Numbers and Interview Details

	Facility						**Total**
	155	**156**	**157**	**158**	**159**	**160**	
No. recruited, baseline (T0)	109	111	120	120	125	111	696
No. completing two timepoints	107	105	106	107	104	105	634
No. completing three timepoints	106	104	100	102	101	100	613
No. completing four timepoints	103	101	100	93	99	96	592
No. dropouts	6	10	20	27	26	15	104
Mean time between interviews (days)	28.6	28.2	30.2	32.6	31.4	30.5	30.2

Figure 1: Flowchart of Study Participation

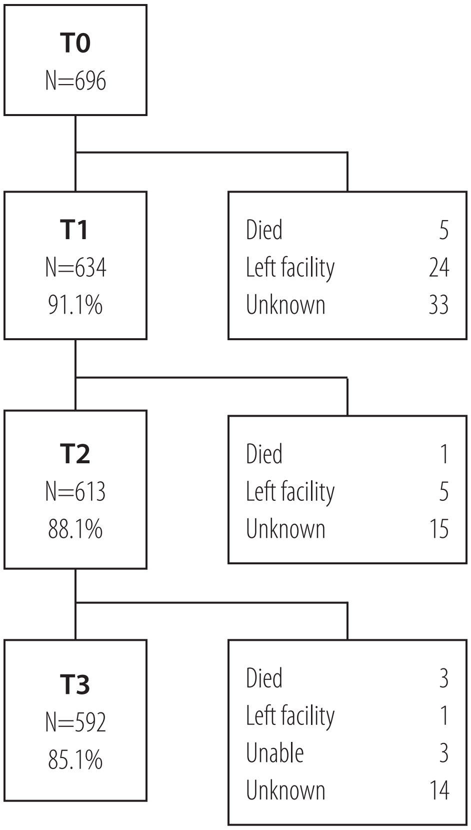


Figure 2: Age of Participants

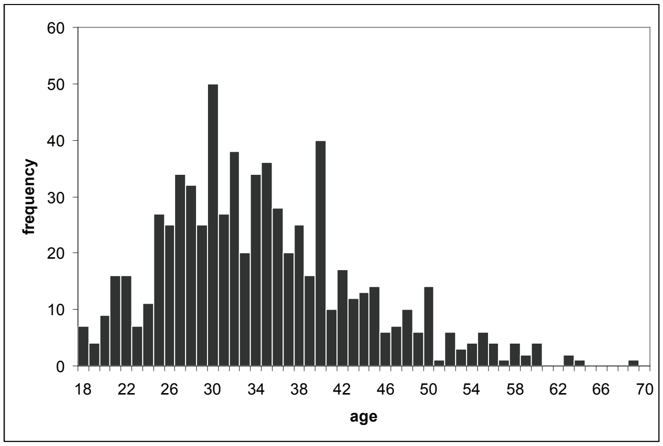


Table 4 shows that the loss to follow-up was highest at facilities 158 and 159. These facilities also recruited more participants than average. All facilities had a mean time between interviews that approximated one month (range 28.2–32.6 days).

5.3—Participant Characteristics

5.3.1—Demography

Participants were 31% male. Participants' mean age was 34.6 years (sd 9 years, range: 18–69 years). Female participants were on average slightly but significantly younger than male participants, with a mean of 33.4 years compared to 37.2 years (t=10.00, p<0.01). The age range of female participants was also younger (18–64 years) than males (21–69 years). The age distribution of participants is shown in Figure 2.

Participants travelled for a median of 60 minutes (IQR 30–90 minutes, range from two minutes to 12 hours) to attend the facility and had a median of three dependants (range=0–18). Women had on average 3.3 dependants and men 4.6.

For the majority of the population, the highest education level attended was primary (53.6%, Table 5). Approximately a third of respondents lived in homes with walls made of thatch/mud and pole walls and another third with stone/burnt bricks walls. The majority of participants' houses had cement/concrete floors (55.8%), and corrugated roofs (82.3). The most common water source was pipe-borne outside the house (38.1%), and fuel source was firewood (48.9). Nearly half (47.4%) of participants lived in a house with a private latrine.

5.3.2—HIV Diagnosis and Reason for Attending the Clinic

At the first interview, participants gave their reason for coming to the facility that day (Table 6). Participants who reported the date of their HIV positive diagnosis within the 14 days prior to beginning the study were coded as coming because of a new HIV test result. This was done because some facilities recorded these people as referred from VCT.

The reason most commonly given by participants for attending the clinic was because they had recently

Table 5: Population Demographic Characteristics

Population Characteristic	**N (Total=696)**	**%**	**Population Characteristic**	**N (Total=696)**	**%**
Highest Level of Schooling Attended			*Wall Material*		
None	21	3.0	Thatch/mud and poles	234	33.6
Began Primary	373	53.6	Mud/unburnt bricks	39	5.6
Began secondary	249	35.8	Metal sheet/cement block	179	25.7
Diploma +	52	7.5	Stone/wood/burnt bricks	244	35.1
Floor Material			*Roof Material*		
Earth	291	41.8	Natural	78	11.2
Cement/concrete	388	55.8	Corrugated iron	572	82.3
Other finished	17	2.4	Finished	45	6.5
Source of Drinking Water			*Fuel Source*		
Pipe-borne inside/bottle	79	11.4	Electricity/gas	34	4.9
Pipe-borne outside	265	38.1	Paraffin/coal	122	17.5
Other, safe	138	19.8	Charcoal	200	28.7
Other, unsafe	214	30.8	Firewood/straw/grass	340	48.9
Personal Property			*Type of Toilet*		
Car	82	11.8	Private flush	74	10.6
Bicycle	25	39.5	Private latrine	330	47.4
Fridge	84	12.1	Public/shared/outside	292	42.0
T.V.	317	45.6			
Mobile Phone	522	75.0			
Radio	609	87.5			

Table 6: Reasons for Attending Facility at Recruitment to Study

Participant-Reported Reason	**N**	**(%)**
HIV diagnosis within past two weeks	267	38.4
HIV diagnosis more than two weeks ago	61	8.8
Referred	34	4.9
Obtain medication or lab test result	172	24.7
New illness	148	21.3
Other	14	2.0

been diagnosed as HIV positive (38.4%, Table 6). At the time of recruitment to the study the median time since having been diagnosed as HIV positive for a participant was 36 days, and participants most commonly had been registered at the health facility involved in the study for about a week.

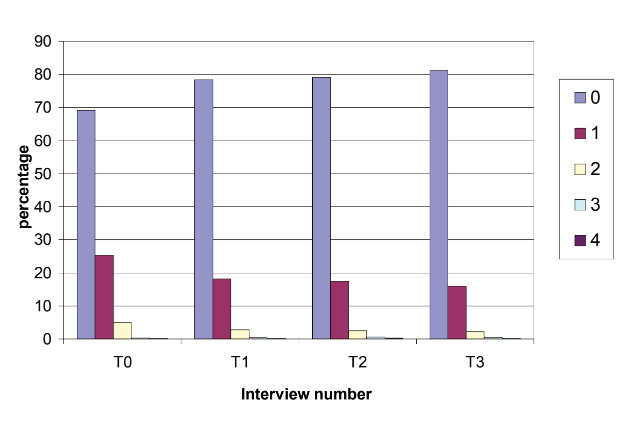
5.3.3—Relative Wealth

The information presented above on home construction, fuel, water and sanitation use, ownership of goods and education was used in a principal components analysis to generate a factor which was then split into equal wealth quintiles. Table 7 presents the percentage of participants reporting assets by quintile. Details of how each component loaded onto the factor are presented in Appendix I.

Table 7: Percent of Participants in Each Quintile Reporting the Assets Surveyed *(1=poorest, 5=richest)*

Asset	Wealth Quintile				
	1	2	3	4	5
Floor Material					
Earth	100.0	84.6	22.0	1.5	0.0
Cement	0.0	15.4	75.2	95.6	93.5
Finished	0.0	0.0	2.8	2.9	6.5
Wall Materials					
Thatch/mud and poles	91.6	51.5	14.9	7.3	1.4
Bricks—mud or unburnt	6.3	7.4	6.4	5.8	2.2
Metal sheet/cement block	0.7	8.1	33.3	36.5	50.4
Stone/wood/burnt bricks	1.4	33.1	45.4	50.4	46.0
Roof Material					
Natural	50.7	0.7	2.1	1.5	0.0
Corrugated iron	49.3	98.5	97.2	97.8	69.8
Finished	0.0	0.7	0.7	0.7	30.2
Type of Toilet					
Public/shared/outside	51.4	37.5	34.0	55.5	30.9
Latrine	48.6	62.5	65.3	40.9	20.1
Private flush	0.0	0.0	0.7	3.7	48.9
Source of Drinking Water					
Bottle/piped inside	0.0	0.7	4.3	6.6	45.3
Piped outside	2.8	30.9	35.5	72.3	50.4
Other, safe	27.5	27.2	29.1	11.7	3.6
Other, unsafe	69.7	41.2	31.2	9.5	0.7
Source of Cooking Fuel					
Electricity/gas	0.0	0.0	0.7	2.2	21.6
Paraffin/coal	0.0	5.2	7.8	30.7	44.6
Charcoal	2.1	22.1	37.6	53.3	29.5
Firewood/straw/grass	97.9	72.8	53.9	13.9	4.3
Personal Property					
Car	0.7	6.6	9.9	10.2	31.7
Bicycle	39.4	44.9	37.6	35.0	40.3
Refrigerator	0.0	1.5	4.3	8.0	46.8
Television	2.8	22.1	48.2	63.5	92.1
Mobile phone	47.2	71.3	78.0	83.2	96.4
Radio	85.2	85.3	87.9	85.4	93.5

Figure 3: Health worker-rated participant ECOG values



5.3.4—Illness Severity

ECOG (physical function): The ECOG (Eastern Co-operative Oncology Group) is a measure of physical function, from fully active at 0 to dead at 5. In this study, the relevant range was from 0 to 4 (completely disabled, cannot carry on any self care). Participant physical function was high at all timepoints. The percent of participants rated with an ECOG of 0, i.e., fully active, increased slightly from 69.3% at T0 to 81.2% at T3 (Figure 3).

WHO staging: There was great variation in the availability of a participant's WHO HIV status by facility. Nearly all participants at two facilities had a WHO stage recorded, whereas over half of participants at another three facilities did not have a WHO status recorded. Such variation in the availability of the measure made it unsuitable for inclusion in further analysis. The existing data (Table 8) show that WHO levels 2 and 3 were the most common.

CD4 counts: Table 9 shows that 90% of participants had a CD4 count recorded in the thirteen months before T1. Twenty-four participants who had a count at T3 did not have a count at T1. Recorded CD4 counts ranged widely, from 0 to over 1100. The distributions of CD4 counts at T1 and T3 for participants completing T3 are shown in Figure 4. When examining change in counts over time there was found to be a mean increase in CD4 count of 45.1 (standard error of the mean 10.7) for participants who had counts at T1 and T3.

Table 8: Participant WHO Stage by Facility

Facility	Stage 1		Stage 2		Stage 3		Stage 4		Unknown/Missing	
	N	%	N	%	N	%	N	%	N	%
155	9	8.4	34	31.8	44	41.1	20	18.7	0	0.0
156	15	14.3	52	49.5	17	15.3	0	0.0	21	20.0
157	6	5.7	10	9.4	17	16.0	0	0.0	73	68.9
158	12	11.4	6	5.7	8	7.6	0	0.0	81	75.7
159	19	18.3	14	13.5	15	14.4	1	1.0	55	52.9
160	29	27.6	27	25.7	40	38.1	7	6.7	2	1.9
Total	90	13.0	143	20.7	141	20.4	28	4.1	290	41.9

Table 9: CD4 Count Statistics

Group	N	%	Median	Mean	SD	95% CI
All CD4 T1 counts	628	90.2	276	322.3	244.4	303.2–341.5
All CD4 T3 counts	250	35.9	312	346.0	205.8	320.4–371.7
CD4 T1 for those with two counts	226	32.5	269	304.1	222.1	319.6–373.4
CD4 T3 for those with two counts	226	32.5	312	346.5	205.4	320.4–371.7

Figure 4: CD4 Counts at T1 and T3 of Participants Completing T3

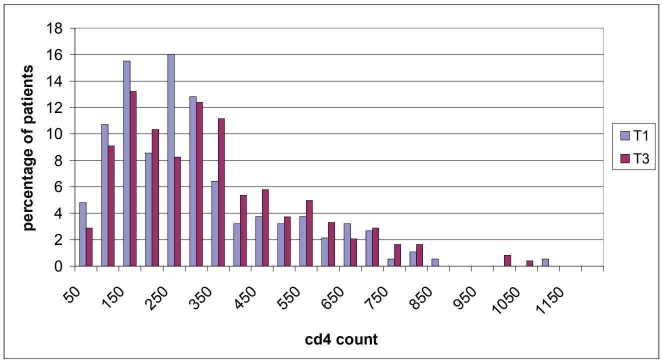
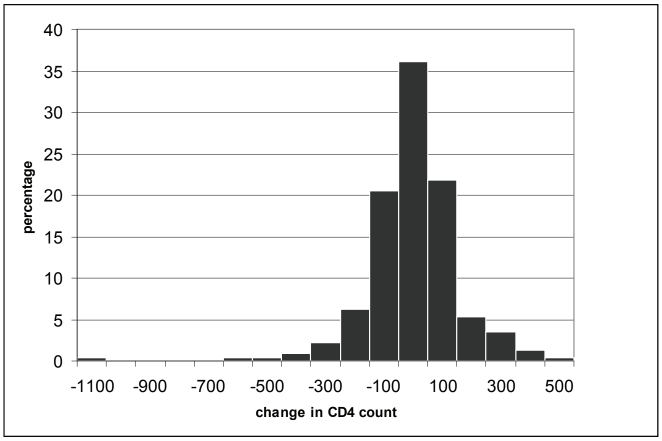


Figure 5: Change in CD4 Count from T1 to T3 for Those Completing T3



As shown by the median and mean, and illustrated in Figure 5, the distribution was approximately parametric with a tail to the left. Paired t-test analysis showed the mean count at T3 to be statistically significantly higher than the mean count at T1 for those participants (t= -4.2, p<0.001).

As only 35% of participants had CD4 counts at both T1 and T3 and 90% of participants had a count at T1, for subsequent analysis the T1 CD4 counts only were used as an indicator of illness severity. T1 counts were grouped according to clinical definitions (**28**) into <50, 51–200, 201–350 and >350. The distributions of T1 CD4 counts in these groups are shown in Table 10. The table shows that in the year before T1 about a quarter of participants had CD4 counts of between 51–200 and 210–350. In the same time period fewer than 10% of participants had CD4 counts below 50, and 37.1% of participants had CD4 counts of over 350.

Validation of CD4 counts: A lowered CD4 count is associated with disease progression and poorer physical function. The T1 CD4 counts were compared by ECOG score to establish whether this expected association was confirmed in the study sample, and validate the use of CD4 in later analysis. As shown in Table 11, there was a clear trend with higher ECOG being associated with lower CD4 count, but the confidence intervals overlapped for most ranges. A t-test was used to compare the distributions for those scoring 0 and 1 on the ECOG scale, and found a highly significant association between ECOG and CD4 count(t=3.96, p<0.001). Other ECOG values were not used in a test due to low numbers.

Table 10: Participant CD4 Counts at T1, Grouped

CD4 Count Group	Description of CD4 Group	Participants Completing T1	
		N	%
<50	High risk of mortality	57	9.0
51–200	Severe immunosuppression	151	26.3
201–350	Immunosuppression	155	24.4
>350	–	212	37.1
Total	–	573	100.0

Table 11: T1 CD4 Count Statistics by ECOG Score

ECOG Score	N	Median	Mean	95% CI
0—fully active	439	308	353.4	329.3–377.5
1—restricted	153	208	262.6	230.8–294.4
2—ambulatory	33	152	199.2	146.3–252.0
3—limited self care	2	141	141.0	101.7–180.3
4—completely disabled	0	–	–	

5.4—Care Participants Received

5.4.1—All Care Components

Out of the 52 care components examined, a mean of 11.9 components of care (sd=6.5) was received by a participant in the month preceding each data collection time point, and a mean of 9.6 (sd=6.1) of those were received at the facility the participant was attending. There was little variation in the number of care components received per month (lowest was T0 (mean 11.7, sd 7.1), highest T3 (mean 12.2, sd 5.7). The highest number of items received in a month preceding any time point was 40. The maximum number of care components received by a single individual in the course of the study was 44 and the minimum was zero, with a mean of 20.1 and median of 20 (Figure 7).

Ten components of care (adherence counselling, prevention with positives, CTX, assessment of ART treatment, multivitamins, pre and post test counselling, nutritional advice, non-opioids, ART/ARV and assessment of pain) were received at least one time point during the study by over 75% of participants (Table 12). The components of care most commonly received in the month before T0, before recruitment to the study (i.e., the month before testing positive or developing a new problem), were pre and post test counselling, adherence counselling and prevention with positives.

The most common opportunistic infection treatment received was for malaria (received by 50% of the study population on at least one time point). Non-opioids were the most commonly received analgesic, received by over 75% of participants on at least one time point. Eighteen components of care were received by less than 10% of the study population at every time point.

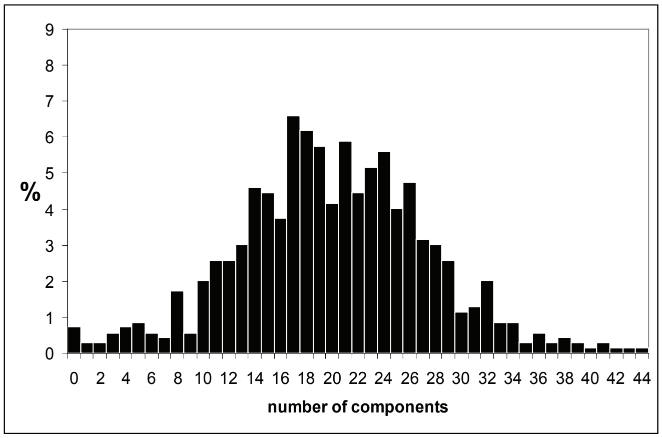
Table 12: Percent of Participants Receiving Each Component of Care During the Study (in Descending Order of Most Commonly Ever Received)

Component of Care	T0 (n=696)	T1 (n=634)	T2 (n=613)	T3 (n=592)	Ever (n=696)
Adherence counselling	63.7	79.7	74.0	71.5	90.8
Prevention with positives	65.1	72.2	67.7	71.0	90.2
CTX to take every day	60.1	84.9	84.5	85.1	89.1
Assess ART treatment	45.8	66.7	67.4	67.6	84.2
Multivitamins	51.1	77.4	77.1	76.9	83.5
Pre- and post-test counselling	70.5	57.1	44.1	40.5	82.5
Nutritional advice	42.9	64.5	59.7	56.8	80.5
Non-opioid analgesics	46.9	43.6	41.4	41.3	78.3
ART/ARV	44.7	58.5	63.4	67.4	76.1
Assessment of pain	42.4	46.9	43.4	43.2	75.9
Visit by religious leader	43.2	40.4	40.5	43.9	67.7
Condoms	34.3	42.3	43.3	42.9	64.5
Access to safe drinking water at home	37.3	44.5	40.5	47.8	63.9
Other nursing care	32.6	38.6	42.8	42.1	63.4
Family planning counselling	30.7	38.6	36.8	36.5	61.8
Patient HIV support groups	31.3	39.0	34.7	43.6	60.2
Wound care	27.4	33.3	37.3	41.2	58.8
Family counselling	28.3	29.0	29.4	31.9	54.6
Treatment for other opportunistic infections	28.9	25.4	21.2	23.7	53.9
Treatment for malaria	33.3	15.9	12.6	16.2	50.0
Prayer with staff	19.7	26.7	22.6	22.1	46.8
ITNs	21.3	22.4	25.3	24.7	46.1
Infection control training	29.0	25.9	21.4	16.1	45.8
TB testing	27.3	21.0	14.2	12.0	40.5
Food	15.4	21.0	17.0	14.4	35.1
Treatment for skin rash/itching	18.0	14.0	11.1	10.8	31.9
Treatment for other fungal infections	14.7	14.0	8.3	5.9	26.1
Memory book work	6.2	13.3	8.5	7.3	23.4
Treatment for nausea/vomiting	11.4	9.5	6.9	5.2	23.0
Treatment for diarrhoea, including ORS	12.7	8.0	7.0	5.2	22.4
Employment training/IGA	10.4	8.0	8.0	6.8	20.7
Home help	11.7	6.6	5.1	5.7	20.0
TB treatment	12.4	12.9	13.7	12.8	19.5
Treatment for genital thrush	8.2	8.5	5.9	5.4	18.1

Table 12: Percent of Participants Receiving Each Component of Care During the Study (in Descending Order of Most Commonly Ever Received)

Component of Care	T0 (n=696)	T1 (n=634)	T2 (n=613)	T3 (n=592)	Ever (n=696)
Treatment for oral thrush/candidiasis	7.8	10.3	5.1	4.2	16.8
Physiotherapy	6.3	6.3	5.4	5.6	15.1
Treatment for neuropathic pain	6.2	5.7	4.1	4.4	14.2
Loans/microfinance	8.2	5.1	3.1	4.4	14.2
Legal services	4.6	3.5	3.1	3.0	11.8
Treatment for constipation/laxatives	5.5	3.9	2.0	2.7	10.9
Contact with traditional healer or herbalist	7.9	2.8	2.0	0.8	10.8
Treatment for herpes (e.g. acyclovir)	7.2	4.1	1.6	2.0	10.2
Therapeutic feeding for severe malnutrition	5.5	3.6	1.3	1.2	9.5
Anxiety/depression treatment	4.5	3.6	1.5	1.5	8.9
Provide household items	4.3	1.6	2.0	1.7	7.8
Psychiatric therapy	5.1	3.0	1.5	0.2	7.5
Weak opioids	3.2	1.6	1.5	0.0	5.3
Isoniazid (INH) to prevent TB	2.3	1.9	1.8	1.2	5.0
Strong opioids	2.5	1.7	0.8	0.0	4.5
Treatment for cryptococcal meningitis	1.3	1.4	0.3	0.2	2.4
Management of cancer	0.9	0.8	0.7	0.7	2.4

Figure 6: Number of care components Ever Received by an Individual During the Study



5.4.2—Care Received from a Different Facility

Table 13 shows the proportion of patients who received each component of care at the facility where data collection was carried out, and the proportion who received each component from another source, reported at each timepoint. The majority of care items were more commonly received at the facility than elsewhere. The exceptions were a visit from a religious leader, ITN, home help, loans and microfinance, IGA programmes, household items, and contact with traditional healer. Apart from ITNs, these are components of social and spiritual care. Frequency of receipt of care components from other sources generally declined over time.

5.4.3—PEPFAR Care and Support Categories

The CSRI components were grouped according to the PEPFAR categories of clinical, spiritual, social, psychological, and prevention (of new HIV infections) as listed in Appendix J. This grouping was carried out

Table 13: Percentage of People Receiving Care at the Facility and Elsewhere

Component of Care	T0 n=696		T1 n=634		T2 n=613		T3 n=592	
	Fac	Else	Fac	Else	Fac	Else	Fac	Else
CTX	53.3	6.6	83.3	1.6	83.4	1.0	84.0	1.2
Adherence counselling	55.6	7.9	76.7	3.0	72.6	1.3	69.3	2.2
Multivitamins	45.0	5.9	75.6	1.9	74.9	2.1	74.3	2.5
Prevention with positives	52.3	12.5	67.7	4.6	64.6	2.9	66.6	4.4
Assess ART treatment	42.2	2.3	65.6	0.9	66.2	1.0	66.4	1.2
ART/ARV	40.5	4.0	57.3	1.3	62.2	1.1	65.9	1.5
Nutritional advice	36.2	6.6	61.5	3.0	57.9	1.6	53.5	3.2
Pre and post test counselling	53.9	16.4	50.3	6.8	41.6	2.4	38.0	2.5
Assessment of pain	31.2	11.1	42.7	4.1	40.5	2.8	40.0	3.2
Non-opioids	24.9	21.6	31.9	11.5	29.7	11.6	28.9	12.3
access to drinking water	24.9	12.4	34.1	10.4	35.2	5.2	37.3	10.5
Visit by faith leader	1.7	41.4	1.1	39.3	2.0	38.5	1.9	42.1
Condoms	26.4	7.6	37.9	4.4	38.0	5.2	39.2	3.7
Other nursing care	24.1	8.3	35.5	3.2	40.5	2.3	39.5	2.5
Patient HIV support groups	23.0	8.2	32.8	6.2	30.0	4.6	35.8	7.8
Family planning counselling	21.7	8.9	32.2	6.5	32.6	4.1	32.4	4.1
Wound care	20.0	7.3	29.8	3.5	35.4	1.8	38.9	2.4
Family counselling	18.8	9.3	20.3	8.7	20.2	9.1	21.5	10.5
Treatment for other OIs	21.3	7.3	22.6	2.8	18.8	2.3	21.3	2.4
ITNs	9.3	11.9	10.9	11.5	13.7	11.6	12.5	12.2
Infection control training	22.1	6.8	22.2	3.6	19.1	2.3	14.5	1.5
Prayer with staff	4.9	14.7	14.8	11.8	15.0	7.5	15.5	6.6
Treatment for malaria	15.8	17.4	10.7	5.2	8.3	4.2	9.8	6.4
TB testing	20.7	6.5	18.8	2.2	13.4	0.8	11.1	0.8
Food	9.2	6.2	18.1	2.8	15.5	1.5	12.0	2.4
Treatment for skin rash/itching	12.1	5.9	12.8	1.3	10.4	0.7	10.1	0.7
TB treatment	8.2	4.2	10.3	2.7	11.7	2.0	10.5	2.4
Treatment for fungal infections	7.5	7.2	11.8	2.2	7.0	1.3	5.4	0.5
Memory book	1.6	4.6	11.0	2.2	7.2	1.3	6.1	1.2
Treatment for diarrhoea	7.0	5.6	6.6	1.4	5.9	1.1	4.1	1.2
Treatment for nausea/vomiting	6.5	4.9	8.4	1.1	5.7	1.1	4.7	0.5
IGA	1.9	8.3	2.7	5.4	2.6	3.9	1.7	5.1
Home help	0.6	11.1	0.8	5.8	0.8	4.2	0.3	5.4
Treatment for genital thrush	5.3	2.9	7.7	0.8	5.5	0.3	5.2	0.2

Table 13: Percentage of People Receiving Care at the Facility and Elsewhere

Component of Care	T0 n=696		T1 n=634		T2 n=613		T3 n=592	
	Fac	Else	Fac	Else	Fac	Else	Fac	Else
Treatment for oral thrush	5.5	2.3	9.9	0.3	4.2	0.8	3.9	0.3
Physiotherapy	4.2	2.2	5.4	0.9	5.1	0.3	4.7	0.8
Loans/microfinance	0.3	7.9	1.1	3.9	0.7	2.4	0.3	4.1
Treatment for neuropathic pain	3.9	2.3	4.7	0.9	3.8	0.3	3.5	0.8
Treatment for herpes	3.3	4.0	3.5	0.6	1.5	0.2	2.0	0.0
Legal services	0.7	3.9	1.4	2.1	2.4	0.7	2.0	1.0
Treatment for constipation/laxatives	2.9	2.6	3.3	0.6	1.8	0.2	2.5	0.2
Contact with traditional healer	0.3	7.6	0.2	2.7	0.2	1.8	0.0	0.8
Therapeutic feeding for malnutrition	3.9	1.6	3.3	0.3	1.3	0.0	1.2	0.0
Treatment for anxiety and depression	2.6	1.9	3.2	0.5	1.3	0.2	1.2	0.5
Psychiatric therapy	4.0	1.0	2.4	0.6	1.0	0.5	0.2	0.0
Household items	1.0	3.3	0.3	1.3	0.8	1.1	0.0	1.7
Isoniazid	1.9	0.4	1.7	0.2	1.6	0.2	1.2	0.0
Weak opioids	1.6	1.6	1.1	0.5	1.1	0.3	0.0	0.0
Strong opioids	1.4	1.0	1.1	0.6	0.7	0.2	0.0	0.0
Treatment for cryptococcal meningitis	0.6	0.7	1.3	0.2	0.3	0.0	0.2	0.0
Cancer management	0.6	0.3	0.6	0.2	0.5	0.2	0.5	0.2

during Phase 1 analysis and circulated to country teams and other stakeholders for review. ART, with assessment of ART treatment, was kept as a separate care component. The three CSRI items not included in Phase 1 were grouped under the PEPFAR categories as (a) food=social; (b) provision of household items=social; and (c) infection control training=clinical.

Table 14 shows that there was little variation in the proportion of participants receiving care over time in the areas of clinical, psychological and spiritual care. The percent of participants receiving any element of social care decreased from 34.1% at T0 to 26.9% at T2. The percent of participants receiving any component of preventive care increased from 75.6% at T0 to 81.9% at T3.

Nearly all participants received some element of clinical care during the course of the study. The area of care least received by participants was psychological care; 57.6% of participants received an element of psychological care during the course of the study.

Table 14: Percent of Participants Receiving Care within PEPFAR Care and Treatment Categories, by Timepoint

Area of Care	T0	T1	T2	T3	Ever
n	*696*	*634*	*613*	*592*	
Clinical	96.8	99.8	99.2	99.5	98.9
Psychological	30.9	32.5	31.0	32.6	57.6
Spiritual	56.5	59.0	56.0	57.4	82.6
Social	34.1	33.9	26.9	28.0	60.1
Prevention	75.6	80.9	80.3	81.9	93.7

Table 15: Percent Newly Diagnosed Participants Receiving Each Component of Care During the Study (in Descending Order of Most Commonly Ever Received)

Component of Care	T0 n=267	T1 n=233	T2 n=219	T3 n=208	Ever n=267
Pre and post test counselling	86.9	68.7	49.5	41.8	93.6
Adherence counselling	58.8	82.8	79.4	70.2	89.9
Prevention with positives	62.9	81.1	76.1	74.5	88.4
CTX	41.6	83.3	88.5	84.6	85.0
Multivitamins	32.6	79.8	79.8	76.9	80.1
Nutritional advice	33.3	67.8	61.9	56.7	77.5
Assessment of pain	39.3	47.2	45.9	42.3	76.8
Assess ART treatment	23.2	59.2	62.4	60.1	75.7
Non-opioid analgesics	46.1	39.9	38.1	38.0	74.9
ART/ARVs	25.8	41.6	52.8	59.1	65.9
Condoms	27.3	45.9	45.9	44.7	62.9
Access to safe water supply	33.0	46.4	45.4	46.6	59.2
Visit by faith leader	36.3	36.5	34.9	38.9	58.4
Patient HIV support groups	23.2	36.5	38.1	43.8	57.7
Family planning counselling	24.3	38.2	36.7	34.1	56.2
Treatment for malaria	39.0	15.9	16.1	14.9	55.4
Wound care	25.8	36.9	40.8	41.8	55.1
Other nursing care	28.5	38.2	47.2	41.3	54.3
Family counselling	24.3	29.2	31.2	27.9	53.2
Treatment for other OIs	25.5	27.9	19.7	20.7	50.2
ITNs	19.1	22.7	28.0	24.5	45.3
Infection control training	30.3	24.9	23.9	14.4	43.8
TB testing	30.0	25.8	16.1	12.0	43.4
Prayer with staff	15.0	25.3	26.1	25.0	40.8
Food	10.5	21.0	16.5	11.5	32.6
Treatment for skin rash/itching	16.1	10.3	12.4	10.6	30.3
Treatment for fungal infections	14.6	16.3	5.5	6.7	26.2
Memory book work	3.4	11.6	8.3	10.6	22.8
Treatment for diarrhoea	12.0	6.9	7.3	4.8	22.5
Treatment for genital thrush	8.6	9.4	7.3	6.3	20.2
TB treatment	10.9	14.6	16.1	13.9	18.4
Treatment for nausea/vomiting	7.1	7.7	5.5	4.3	18.0
Treatment for oral thrush	5.2	13.3	6.4	3.8	17.6
Contact with traditional healer	11.6	4.7	3.2	1.4	16.5

Table 15: Percent Newly Diagnosed Participants Receiving Each Component of Care During the Study (in Descending Order of Most Commonly Ever Received)

Component of Care	T0 n=267	T1 n=233	T2 n=219	T3 n=208	Ever n=267
Home help	9.0	5.2	3.7	2.9	14.6
Physiotherapy	3.7	6.9	6.4	3.8	13.5
IGA	7.5	6.0	6.9	2.9	13.1
Loans	9.0	3.9	3.7	2.9	13.1
Legal services	3.7	3.4	4.1	4.3	12.4
Treatment for neuropathic pain	4.9	2.1	2.3	5.8	10.9
Treatment for constipation/laxatives	3.4	3.4	1.8	1.4	9.0
Treatment for herpes	6.4	3.0	0.5	2.4	8.6
Therapeutic feeding	5.2	4.3	0.5	0.5	8.6
Treatment for anxiety and depression	3.0	3.0	0.5	0.5	6.4
Psychiatric therapy	4.1	1.7	0.5	0.0	5.6
Weak opioids	2.6	1.7	0.9	0.0	4.5
Household items	2.6	0.4	1.4	1.0	4.5
Strong opioids	0.7	1.7	0.5	0.0	2.6
Isoniazid for TB prophylaxis	0.4	0.9	0.9	1.0	1.9
Treatment for cryptococcal meningitis	0.4	0.9	0.0	0.0	1.1
Cancer management	0.4	0.9	0.5	0.0	1.1

5.4.4—Care for People Newly Diagnosed with HIV

Participants whose positive HIV test was dated less than two weeks before beginning the study were designated "newly diagnosed." The most commonly received components of care for people newly diagnosed as HIV positive were pre and post-test counselling, adherence counselling, prevention with positives, CTX, multivitamins, nutritional advice, pain assessment, assessment of ART treatment and non-opioid analgesics, which were received by over 70% of newly diagnosed participants at some point during the study (Table 15).

The receipt of a number of care components changed dramatically after T0. The proportion of patients receiving pre- and post-test counselling was highest at T0 (86.9%), which decreased to 41.8% of patients by T3. Receipt of other components showed increases after T0. The proportion of patients receiving adherence counselling, CTX, multivitamins, assessment of ART treatment and nutritional advice each increased by 25 percentage points or greater between T0 and T1. There was a similar decrease in the proportion of newly diagnosed patients receiving malaria treatment as there was for the whole study population, from 39.0% at T0 to 15.9% at T1, remaining at this level for the rest of the study. Other components of care that showed notable decreases were infection control training (30.3% at T0 to 14.4% at T3), contact with a traditional healer (11.6% at T0 to 1.4% at T3) and loans (9.0% at T0 to 2.9% at T3).

5.4.5—Preventive Care Package

PEPFAR developed the concept of the Preventive Care Package (PCP), a number of specified care components which should be considered essential to prevent opportunistic infections, delay disease progression and prevent HIV transmission (**31**). A defined PCP was not developed for Kenya but in Uganda this concept was refined into the Basic Care Package (BCP), which

Table 16: Components of the PCP Ever Received by New and Existing Patients, at the Facility or From Anywhere

Component of Care	Newly Diagnosed, n=267		Diagnosed Previously, n=429	
	facility	anywhere	facility	anywhere
Family VCT information	39.3	53.2	43.4	55.5
Access to safe water supply	50.2	59.2	50.1	66.9
ITN	30.7	45.3	29.1	46.6
Condoms	58.8	62.9	57.8	65.3
CTX	82.0	85.0	90.7	91.6
Two components	10.9	13.1	20.8	16.6
Three components	14.6	14.6	20.1	16.8
Four components	24.0	24.0	22.8	31.5
Five components	15.4	24.7	11.4	21.0

consists of CTX prophylaxis, an ITN, water disinfection, family VCT information and condoms (**32, 33**). In Table 16, the five elements of the BCP are presented by location of care delivery and time since diagnosis. Table 16 shows that there was little difference in the probability of receiving elements of the BCP for newly diagnosed and previously diagnosed participants. Less than a quarter of participants in either group received all five elements during the study, but each component apart from an ITN was received by more than half.

Table 17: Percent of Participants Receiving Spiritual Care Theme Components Over Time

Component of Care	T0	T1	T2	T3	Ever
n	*696*	*634*	*613*	*592*	*696*
Visit by religious leader	43.2	40.4	40.5	43.9	67.7
Prayer with staff	19.7	26.7	22.6	22.1	46.8
Contact with traditional healer	7.9	2.8	2.0	0.8	10.8

Table 18: Percent of Patients Receiving Counselling and Advice Care Theme Components Over Time

Component of Care	T0	T1	T2	T3	Ever
n	*696*	*634*	*613*	*592*	*696*
Adherence counselling	63.7	79.7	74.0	71.5	90.8
Patient HIV support groups	31.3	39.0	34.7	43.6	60.2
Family planning counselling	30.7	38.6	36.8	36.5	61.8
Family counselling	28.3	29.0	29.4	31.9	54.6
Pre and post test counselling	70.5	57.1	44.1	40.5	82.5
Psychiatric therapy	5.1	3.0	1.5	0.2	7.5

5.5—Care Themes

The components of care were grouped into eight themes as described in the Methods section.

5.5.1—Spiritual Care

Receiving a visit from a religious leader was the most common component of spiritual care that patients reported receiving (Table 17). The proportion of participants praying with staff increased from 19.7% at T0 to 26.7% at T1, after which the proportion remained at just over a fifth. Contact with a traditional healer was reported by 7.9% of participants in the month before T0, and this decreased to 2.8% by T1 and 0.8% by T3.

5.5.2—Counselling and Advice

Except for psychiatric therapy, all types of counselling were received by the majority of participants, with adherence counselling the most commonly received (Table 18).

Table 19: Percent of Participants Receiving Nursing Care Theme Components Over Time

Component of care	T0	T1	T2	T3	Ever
n	*696*	*634*	*613*	*592*	*696*
Other nursing care	32.6	38.6	42.8	42.1	63.4
Wound care	27.4	33.3	37.3	41.2	58.8

Table 20: Percent of Participants Receiving Pain Management Care Theme Components Over Time

Component of Care	T0	T1	T2	T3	Ever
n	*696*	*634*	*613*	*592*	*696*
Non-opioid analgesics	46.9	43.6	41.4	41.3	78.3
Assessment of pain	42.4	46.9	43.4	43.2	75.9
Treatment for neuropathic pain	6.2	5.7	4.1	4.4	14.2
Weak opioids	3.2	1.6	1.5	0.0	5.3
Strong opioids	2.5	1.7	0.8	0.0	4.5

Table 21: Percent of Participants Receiving Symptom Management Care Theme Components Over Time

Component of Care	T0	T1	T2	T3	Ever
n	*696*	*634*	*613*	*592*	*696*
Treatment for other OIs	28.9	25.4	21.2	23.7	53.9
Treatment for malaria	33.3	15.9	12.6	16.2	50.0
Treatment for skin rash/itching	18.0	14.0	11.1	10.8	31.9
Treatment for genital thrush	8.2	8.5	5.9	5.4	18.1
Treatment for fungal infections	14.7	14.0	8.3	5.9	26.1
Treatment for nausea/vomiting	11.4	9.5	6.9	5.2	23.0
Treatment for diarrhoea	12.7	8.0	7.0	5.2	22.4
Treatment for anxiety/depression	4.5	3.6	1.5	1.5	8.9
Treatment for oral thrush/candidiasis	7.8	10.3	5.1	4.2	16.8
Treatment for herpes	7.2	4.1	1.6	2.0	10.2
Treatment for constipation/laxatives	5.5	3.9	2.0	2.7	10.9
Treatment for cryptococcal meningitis	1.3	1.4	0.3	0.2	2.4

Table 22: Percent of Participants Receiving Nutrition Care Theme Components Over Time

Component of Care	T0	T1	T2	T3	Ever
n	*696*	*634*	*613*	*592*	*696*
Nutritional advice	42.9	64.5	59.7	56.8	80.5
Multivitamins	51.1	77.4	77.1	76.9	83.5
Access to drinking water	37.3	44.5	40.5	47.8	63.9
Food	15.4	21.0	17.0	14.4	35.1
Therapeutic feeding for malnutrition	5.5	3.6	1.3	1.2	9.5

5.5.3—Nursing

Nursing and wound care were each received by around a third of participants at any time point, and around two-thirds of participants received these two care items in the course of the study (Table 19).

5.5.4—Pain Management

Non-opioid analgesics were received by over three-quarters of participants during the study and a similar proportion had their pain assessed (Table 20). Receipt of other pain medication was rare. The overall trend in receipt of analgesics was decreasing over the course of the study.

5.5.5—Symptom Management

The single symptom for which participants most commonly received treatment was malaria (50.0% of all participants) and, as noted previously, malaria treatment was most commonly received in the month before recruitment to the study (Table 21). Treatment for skin rash or itching was received by about a third of participants. Although treatments for the other single symptoms examined were not commonly received, over half of participants reported receiving treatment for other unspecified opportunistic infections.

5.5.6—Nutrition

Care relating to nutrition was commonly received by participants in the study (Table 22). The majority of participants received nutritional advice (80.5%), multivitamins (83.5%) and help with access to drinking water (63.9%) at some point during the study. Furthermore a third of participants received food during this time.

Table 23: Percent of Participants Receiving Social Care Theme Components Over Time

Component of Care	T0	T1	T2	T3	Ever
n	*696*	*634*	*613*	*592*	*696*
Employment training/IGA	10.4	8.0	8.0	6.8	20.7
Loans/microfinance	8.2	5.1	3.1	4.4	14.2
Legal services	4.6	3.5	3.1	3.0	11.8
Memory book work	6.2	13.3	8.5	7.3	23.4
Home help	11.7	6.6	5.1	5.7	20.0
Household items	4.3	1.6	2.0	1.7	7.8

Table 24: Percent of Participants Receiving Prevention Care Theme Components Over Time

Component of Care	T0	T1	T2	T3	Ever
n	*696*	*634*	*613*	*592*	*696*
Prevention with positives	65.1	72.2	67.7	71.0	90.2
Condoms	34.3	42.3	43.3	42.9	64.5
ITNs	21.3	22.4	25.3	24.7	46.1
Infection control training	29.0	25.9	21.4	16.1	45.8
Isoniazid for TB prevention	2.3	1.9	1.8	1.2	5.0

Table 25: Percent of Participants Receiving ART Care Theme Components Over Time

Component of Care	T0	T1	T2	T3	Ever
n	*696*	*634*	*613*	*592*	*696*
ARVs	44.7	58.5	63.4	67.4	76.1
Assess ART treatment	45.8	66.7	67.4	67.6	84.2

5.5.7—Social Care

The most common form of social care received by participants was memory book work (23.4% ever received) and the least common was household items (7.8% ever received, Table 23). With the exception of memory book work, all social care items were most commonly received in the month before T0.

5.5.8—Prevention

Components of care aimed at preventing infections relating to HIV were commonly received (Table 24). Nearly all (90.2%) participants received prevention with positives counselling at some point during the study. Nearly 65% of participants received condoms. Over 45% of participants received ITNs and the same proportion reported receiving infection control training.

5.5.9—ART

The proportion of participants receiving ART increased after each study interview from 44.7% at T0 to 67.4% at T3 (Table 25). Over three-quarters of participants received ART at some point during the study. A similar proportion of patients received assessment of their ART treatment as received ART itself, although overall the former was received by more participants during the course of the study.

Table 26 shows that the proportion of participants receiving ART who also received support and monitoring was highest at T2. At Facilities 155 and 159, the probability of receiving support and monitoring increased over time, but at Facility 156 it decreased and Facility 157 peaked at T2. In general, at all time points the proportion of ART patients to receive support and monitoring was between 83% and 91%; high, but not universal.

Table 26: Number and Percent of People Who Received ARVs to Also Receive ART Support and Monitoring, by Facility and Timepoint

	155		156		157		158		159		160		Total	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%
T0	48	67	63	84	9	90	41	85	67	96	29	83	257	83
T1	59	79	62	79	39	98	67	97	64	86	35	97	326	88
T2	61	82	60	78	50	100	68	100	65	96	48	94	352	91
T3	61	84	62	79	53	93	66	100	66	90	44	81	352	88

5.5.10—CTX

About three fifths of participants received CTX in the month before T0 (Table 27) but this proportion rapidly increased between T0 and T1, and then remained stable. CTX was one of the most widely received components of care during the study.

Table 28 shows the number of participants who reported receiving daily prophylactic CTX compared to the number who reported taking it on the previous day. Numbers rather than percentages are reported, because both the proportion of CTX recipients to take the medication and the proportion of CTX takers to be prescribed it as a prophylactic are of interest. Bearing in mind that the number of active participants decreased over time, the proportion of participants to be prescribed CTX increased over time, as did the number of people to have taken it on the day before the interview.

Table 27: Percent of Participants Receiving CTX Over Time

T0 n=696	T1 n=634	T2 n=613	T3 n=592	Ever n=696
60.1	84.9	84.5	85.1	89.1

Table 28: Adherence to CTX

	T0		T1		T2		T3	
Took CTX Yesterday	**yes**	**no**	**yes**	**no**	**yes**	**no**	**Yes**	**no**
Has daily CTX	321	96	507	31	496	21	484	20
Does not have daily CTX	32	245	28	68	26	69	13	75

5.5.11—TB Treatment

TB testing was dropped from analysis on the grounds that it was not a component of care in itself. It had been thought all participants would receive TB screening. This does happen, but it emerged that screening consists of checking for signs of TB (persistent cough, night sweats and weight loss), and asking about these symptoms was not recorded as a TB test. Only people showing symptoms were sent for a sputum test (a "TB test"). The proportion of participants to receive TB treatment varied very little over time from entry to the study (Table 29), although the proportion to ever receive it was slightly higher, showing that many recipients, but not all, were treated at each time point.

Table 29: Percent of Participants Receiving TB Treatment Over Time

T0 n=696	T1 n=634	T2 n=613	T3 n=592	Ever n=696
12.4	12.9	13.7	12.8	19.5

5.5.12—All Care Themes

The proportion of participants receiving any component of spiritual care, counselling/advice, prevention care or TB treatment varied by less than five percentage points over the course of the study (Table 30 and Figure 7). The proportion of participants receiving nursing care, nutrition, ART or CTX to take every day increased for each subsequent month of the study. Conversely the proportion of participants receiving pain management, symptom management or social care decreased over the course of the study (the latter two groups showing slight increases in T3 compared to T2).

Table 30: Percent of Participants Receiving Care Within Selected Themes, by Timepoint

Care Theme	T0	T1	T2	T3	Ever
n	***696***	***634***	***613***	***592***	***696***
Spiritual	51.7	52.1	52.0	55.1	78.2
Counselling/advice	86.1	87.1	82.7	82.4	96.6
Nursing	38.1	43.5	45.7	47.3	67.5
Pain management	59.2	59.5	55.3	54.2	87.2
Symptom management	58.5	52.7	43.6	44.9	82.8
Nutrition	67.0	87.2	86.1	86.8	93.5
Social	17.5	13.1	10.3	11.3	20.7
Prevention	75.9	80.6	77.0	80.4	93.8
ART	44.7	58.5	63.4	67.4	84.2
CTX to take every day	60.1	84.9	84.5	85.1	89.1
TB treatment	12.4	12.9	13.7	12.8	19.5

Figure 7: Proportion Receiving Each Care Theme Over Time

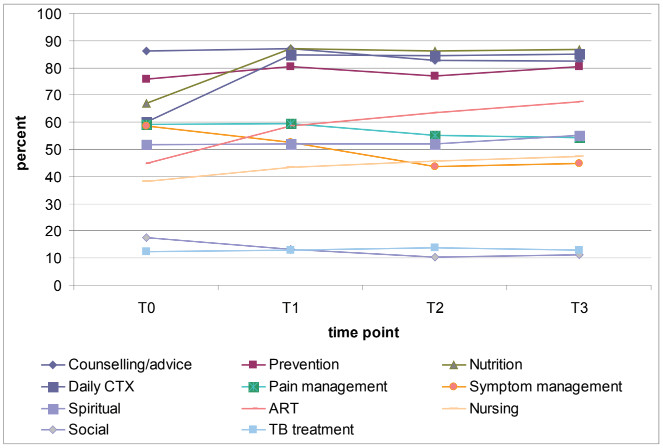


Figure 8: Physical Health Score at Baseline

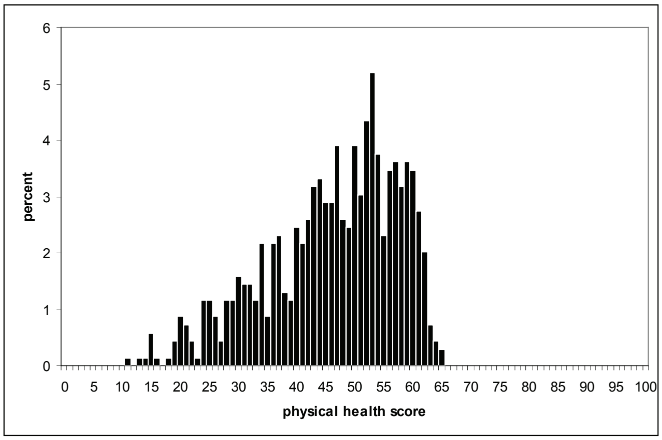


Figure 9: Mental Health Score at Baseline

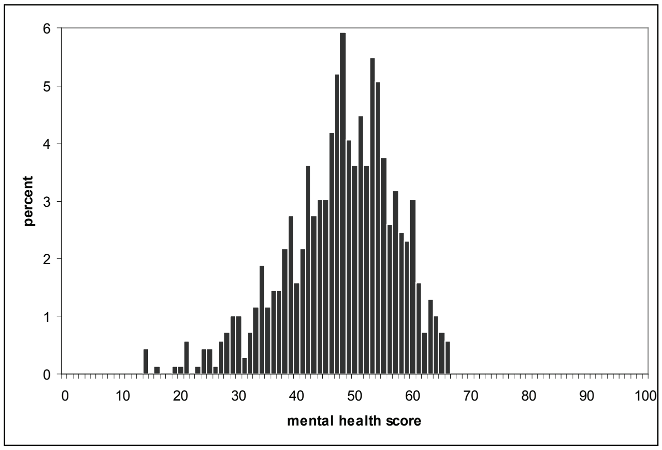


Table 31: APCA African POS Item Distributions, at Baseline (T0) (N=696)

Item	Median	IQR
Pain	3	3–5
Symptoms	4	3–5
Worry	4	3–5
Share	1	0–3
Worthwhile	4	3–5
Peace	4	2–5
Help	1	(0–3

5.6—Health at the Beginning of the Study

5.6.1—Physical and Mental Health Scores

The raw responses to the MOS-HIV at baseline are displayed in Appendix L. These were converted into the two outcome variables, physical health score and mental health score, each with possible values from 0=worst possible health to 100=best possible health. The physical health score of the study population at baseline ranged from 10.7 to 65.4, with a mean of 46.1 (sd 11.3, Figure 6). The mental health score of the study population at baseline ranged from 14.2 to 66.8, with a mean of 48.1 (sd 9.5, Figure 9).

5.6.2—Multidimensional Care Scores

Each outcome in the APCA African POS is scored from 0 to 5. The scores were reversed for some items, such that in all cases 0 represented the worst situation and 5 the best. This direction was used because it corresponds to the MOS-HIV, where a higher score corresponds to a better quality of life.

At baseline the items on which participants reported most problems in relation to their HIV diagnosis were being unable to share how they felt with others (median=1) and feeling that they and their family were not getting enough help to plan for the future (median=1) (Table 31). Participants had low levels of worry, were not feeling greatly affected by their symptoms, felt life was worthwhile and felt at peace (median=4 for all). The distributions of APCA African POS items in the study population at baseline are shown in Figures

Figure 10: APCA African POS at T0: Please Rate Your Pain During the Last Three Days

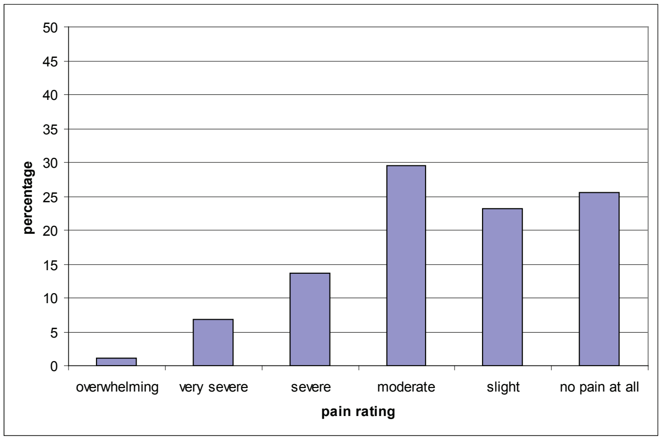


Figure 11: APCA African POS at T0: Have Any Other Symptoms Been Affecting How You Feel?

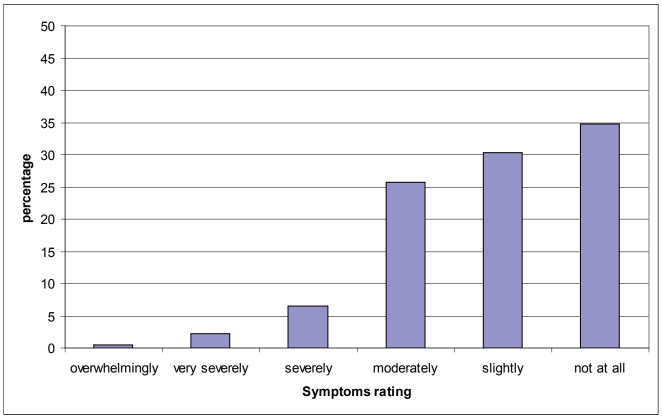


Figure 12: APCA African POS at T0: Have You Been Feeling Worried About Your Illness?

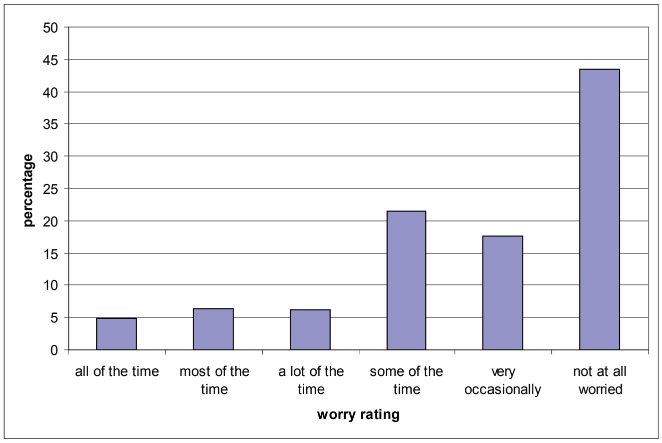


Figure 13: APCA African POS at T0: Over the Past Three Days Have You Been Able to Share How You Feel?

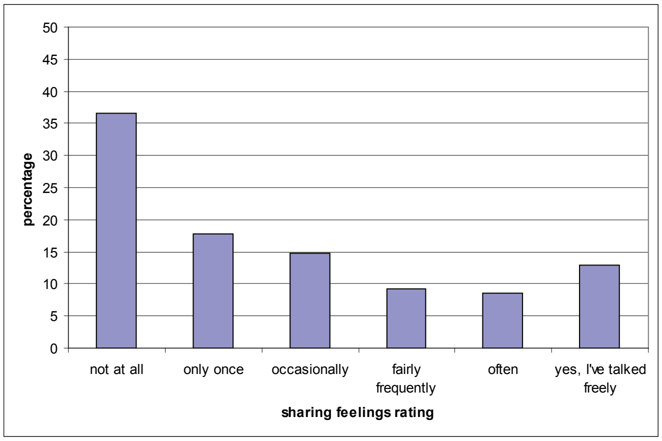


Figure 14: APCA African POS at T0: Over the Past Three Days Have You Felt that Life Was Worthwhile?

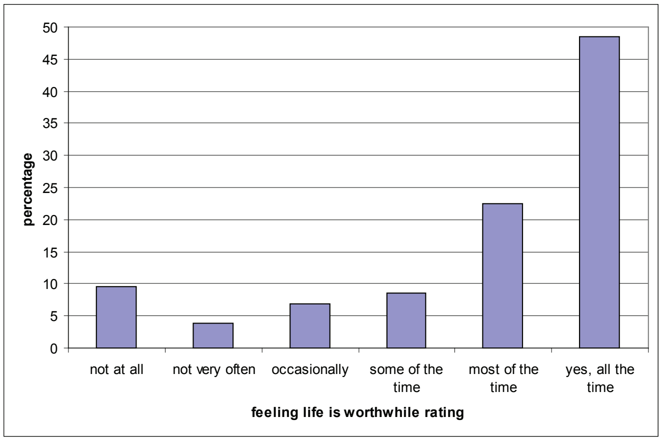


Figure 15: APCA African POS at T0: Over the Past Three Days Have You Felt at Peace?

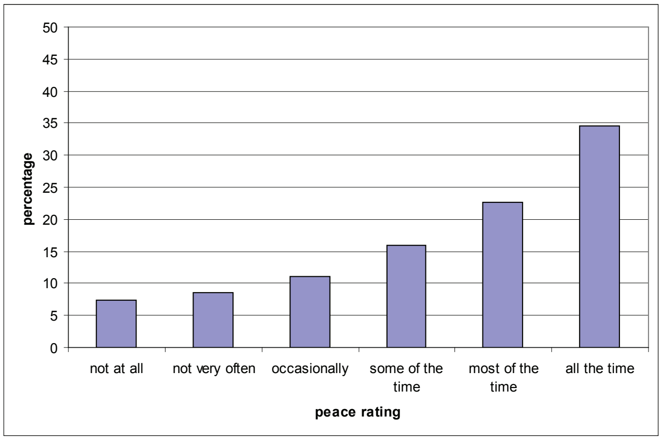


Figure 16: APCA African POS at T0: In the Past Three Days Have You Had Enough Help and Advice for Your Family to Plan for the Future?

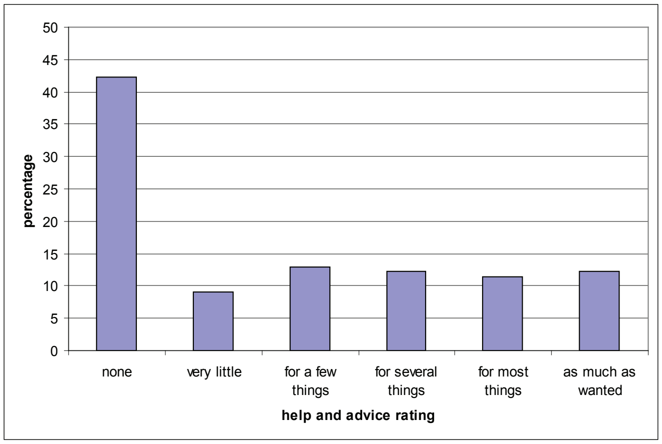


Figure 17: APCA African POS Total Score at T0

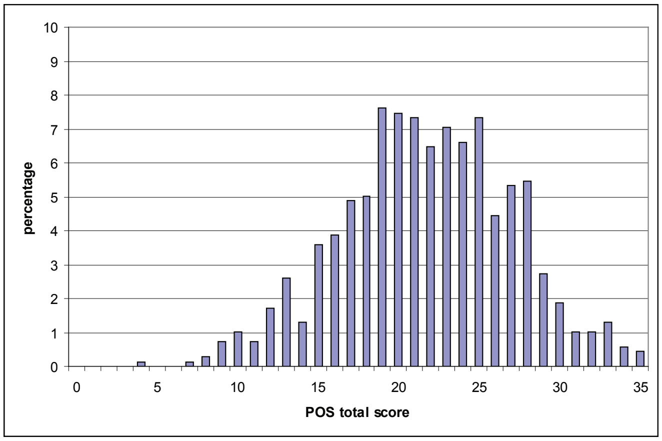


Table 32: APCA African POS Carer Item Responses

Carer Item	T0		T1		T2		T3	
	Median	IQR	Median	IQR	Median	IQR	Median	IQR
Information	3	1–5	4	2–5	4	3–5	4	2–5
Confidence	4	2–5	4	3–5	5	4–5	4	3–5
Worry	5	3–5	5	3–5	5	4–5	5	3–5

12–15. The sum of the responses to the seven POS items was calculated to create an APCA African POS score with a possible range of 0–35. At baseline participants APCA African POS summary score ranged from 4 to 35, with a mean of 21.7 (sd= 5.3) (Figure 17).

5.6.3—Problems Facing Family Caregivers

The APCA African POS contains three items for informal carers accompanying the participant to answer (Appendix B). APCA African POS domains for carers were frequently not completed as carers were often not present at the participant's clinical appointment. Of the number of participants completing each timepoint, 83 (11.9%) carers completed all three APCA African POS carer questions at baseline, 43 (6.8%) at T1, 23 (3.8%) at T2 and 20 (3.4%) at T3. Owing to the small proportion of completed carer questions, responses to these items are described here but were not included in further analyses.

Table 32 shows that the amount of information received by the carer was the area with the lowest score (median at baseline=3, quite a lot of information received, increased to a median of 4, a great deal of information received, at all subsequent timepoints), but they were not worried about the participant (median=5, not at all worried, at all time points).

5.7—How Participants Siffer by Facility

5.7.1—Participant Characteristics at Different Facilities

The facilities included in the study are from different parts of the country. The characteristics of the facilities themselves have been studied in detail in Phase 1 and summarised in section E1. In addition, the variety of locations of the facilities is likely to mean the characteristics of the participants attending vary also.

The variations in participants' key demographic characteristics by facility are shown in Table 33. At all facilities the majority of participants were female. The facility with the greatest proportion of male participants was 160 (42.3%) and the lowest was 156 (25.2%). The facility with the youngest participants was 155 (mean age 33.0 years) and the oldest was 156 (mean age 38.6 years). There was little variation in the median

Table 33: Demographic Characteristics of Participants, by Facility

Facility	Males		Age		Dependants		Minutes to Facility		Attended Secondary School	
	N	%	Mean	SD	Median	IQR	Median	IQR	N	%
155	34	31.2	33	10.8	4	2–6	60	37.5–120	24	22.2
156	28	25.2	38.6	8.9	3	2–4	60	30–90	43	38.7
157	41	34.2	33.9	8.5	3	1–4	60	30–82.5	37	30.8
158	33	27.5	33.5	8.4	3	1–4	30	20–60	45	37.5
159	37	29.6	34.8	8.1	4	2–6	60	30–120	58	46.4
160	47	42.3	33.7	8.4	4	2–6	60	30–90	42	37.8

Table 35: Reasons for Attending Facility at Recruitment to Study

	155		156		157		158		159		160	
	n	%	n	%	n	%	n	%	n	%	n	%
New HIV test result	43	39.5	4	3.6	77	64.2	66	55.0	38	30.4	39	35.1
HIV test result >14 days ago	10	9.2	10	9.0	0	0.0	3	92.5	12	9.6	26	23.4
Referred	5	4.6	2	1.8	12	10.0	2	1.7	8	6.4	5	4.5
Medication or lab test	4	3.7	69	62.2	24	20.0	39	32.5	8	6.4	28	25.2
New illness or problem	46	42.2	26	23.4	5	4.2	3	2.5	56	44.8	12	10.8
Other	1	0.9	0	0.0	2	1.7	7	5.8	3	2.4	1	0.9

Table 34: Percentage of Participants Coded to Each Quintile, by Facility

Facility	Wealth Quintile (1=poorest; 5=richest)				
	1	2	3	4	5
155 (n=109)	51.38	22.94	20.18	4.59	0.92
156 (n=111)	3.60	31.53	28.83	18.92	17.12
157 (n=120)	8.33	24.17	13.33	24.17	30.00
158 (n=120)	1.67	4.17	11.67	34.17	48.33
159 (n=125)	19.20	12.00	31.20	23.20	14.40
160 (n=110)*	41.82	24.55	16.36	10.91	6.36
Total (n=695)	20.43	19.57	20.29	19.71	20.00

*Demographic information missing for one participant

number of dependents or time to reach the facility by facility. Nearly half of participants attending facility 159 had attended secondary school, compared to 22.2% of participants at facility 155.

The wealth quintiles indicate that participants attending facility 155 were the poorest relative to the rest of the study population, and participants attending facility 158 were the richest (Table 34).

The highest proportion of newly diagnosed participants recruited was at facility 157 (64.2%), and the lowest at facility 156 (3.6%) (Table 35). Over 40% of participants from facility 155 and 159 reported a new illness at the time of recruitment. Facility 156 was the only one at which the majority of participants (62.2%) attended to receive medication or the results of a lab test.

5.7.2—Illness Severity at Different Facilities

The proportion of participants who had a CD4 count recorded from a year before T0 up to T1 was very high

Table 36: CD4 Count by Facility

Facility	Those Completing T1 with CD4 Count at T1		CD4 Count at T1		Those Completing T3 with CD4 Count at T3		CD4 Count at T3		Those Completing T3 with CD4 Count at T3 and T1		Change in CD4 Count	
	N	%	Mean	sem	N	%	Mean	sem	N	%	Mean	sem
155	95	88.8	349.4	29.9	16	15.5	475.9	70.4	12	11.7	25.6	112.3
156	95	90.5	353.5	19.0	74	73.3	403.5	23.3	72	71.3	43.4	12.2
157	92	86.8	304.3	28.3	34	34.0	292.6	37.2	28	28.0	37.8	40.0
158	104	97.2	266.1	21.1	44	47.3	290.2	29.3	42	45.2	66	20.6
159	95	91.3	354.4	24.6	40	40.4	319.4	26.1	38	38.4	25.9	17.8
160	95	90.5	343.4	27.3	23	24.0	345.5	38.7	19	19.8	140.5	35.5
Total	576	90.9	327.9	10.3	231	39.0	350.3	13.7	207	35.0	51.7	11.0

Table 37: Mean Number of Components of Care Received by Participants at Each Facility During the Study

Facility	Any Location		On Site	
	mean	sd	mean	sd
155	15.5	6.0	13.5	5.7
156	11.5	6.2	8.3	5.7
157	8.4	4.9	7.1	5.0
158	15.8	6.7	13.3	6.4
159	10.1	5.8	7.4	5.0
160	9.9	5.1	8.0	4.7

for all facilities (from 87.5 to 100% of participants, Table 37). Over a third (37.8%) of participants who completed T3 had a CD4 count at both T1 and T3, although there was a wide variation in proportions by facility. The facility with the largest proportion of participants having CD4 counts at both time periods was 156 (74.2%), and the lowest was 155 (15.5%).

At T1 participants at facility 156 had the highest mean CD4 count (358.9) and those at facility 158 the lowest (210.6). At each facility the mean CD4 count increased over the study period and the overall increase was significant. Participants at facility 160 showed the greatest increase in CD4 count between the 2 time-points (a mean increase of 124.5 counts), and facility 159 the lowest (mean increase of 2.4 counts).

5.7.3—Care Received at Different Facilities

Table 37 shows that the mean number of care components received per month ranged from 8.4 at facility 157 to 15.8 at facility 156, out of the 52 surveyed. Participants attending facility 157 received the lowest number of components of care, both on site (7.1) and when including care received from elsewhere (8.4).

Table 38 shows there was great variety in the proportion of participants receiving many components of care over the course of the study. Variations in the receipt of the some of the key components are described here. Nearly all participants in the study at facility 155 took ART at some point during the study (95.4%) compared to just over half of participants at facility 157 (52.5%). CTX and multivitamins were received at least once during the study by the vast majority of participants at all facilities, except for facility 160 (53.2% and 33.3% respectively).

By facility there was great variety in the proportion of participants ever receiving an ITN (from 31.7 at facility 157 to 82.5% at facility 158) or safe water treatment (from 35.0 at facility 157 to 98.2% at facility 155). Almost no participants received strong opioids, except at facility 159 where 21.6% of participants received them at some point during the study. A similar pattern of receipt was seen for weak opioids, with many more participants attending facility 159 reporting receipt of this medication than at the other facilities. Nearly a quarter of participants attending facility 155

Table 38: Percent of Participants Ever Receiving Components of Care by Facility

Care Component	155	156	157	158	159	160
Visit by religious leader	78.9	76.6	45.8	51.7	67.2	89.2
Prayer with staff	62.4	33.3	65.8	10.8	50.4	59.5
Contact with traditional healer	18.3	5.4	3.3	9.2	16.8	11.7
Pre- and post-test counselling	87.2	63.1	90.0	99.2	56.8	100.0
Adherence counselling	98.2	90.1	75.0	99.2	84.0	100.0
Family planning counselling	92.7	68.5	37.5	76.7	44.0	55.0
Patient HIV support groups	93.6	53.2	32.5	91.7	28.8	65.8
Family counselling	84.4	56.8	20	64.2	60.0	44.1
Psychiatric therapy	24.8	9.0	0.0	6.7	2.4	3.6
Prevention with positives	99.1	85.6	85.0	95.0	80.8	97.3
Wound care	90.8	45.0	12.5	90.8	40.0	77.5
Other nursing care	99.1	46.8	7.5	89.2	60.8	80.2
ART/ARV	95.4	88.3	52.5	71.7	87.2	63.1
Assessment of ART treatment	94.5	85.6	70.8	68.3	90.4	97.3
Assessment of pain	94.5	46.8	70.0	84.2	68.8	91.9
Strong opioids	0.0	0.9	0.0	2.5	21.6	0.0
Weak opioids	3.7	3.6	1.7	4.2	17.6	0.0
Non-opioids	82.6	65.8	65.8	86.7	80.8	88.3
Treatment for neuropathic pain	14.7	4.5	8.3	11.7	23.2	22.5
Anxiety and depression	13.8	11.7	5.8	10.0	8.0	4.5
Nausea/vomiting	25.7	19.8	16.7	30.8	26.4	18.0
Treatment for skin rash/itching	34.9	22.5	31.7	46.7	35.2	18.9
Treatment for diarrhoea	27.5	19.8	17.5	22.5	20.0	27.9
Treatment for constipation/laxatives	9.2	10.8	4.2	18.3	12.0	10.8
Treatment for genital thrush	15.6	3.6	25.0	30.8	16.8	15.3
Treatment for oral thrush	14.7	9.9	23.3	25.0	17.6	9.0
Treatment for cryptococcal meningitis	3.7	5.4	1.7	2.5	1.6	0.0
Treatment for fungal infections	18.3	21.6	25.8	50.0	30.4	8.1
Treatment for herpes	6.4	6.3	10.8	17.5	14.4	4.5
Treatment for malaria	69.7	18.9	37.5	59.2	55.2	59.5
TB testing	42.2	31.5	31.7	68.3	24.8	45.0
TB treatment	22.9	19.8	19.2	25.8	13.6	16.2
Therapeutic feeding	11.9	10.8	3.3	21.7	4.0	5.4
Treatment for other OIs	54.1	45	28.3	76.7	64	54.1
Cancer management	2.8	6.3	0.0	4.2	0.8	0.9
Physiotherapy	50.5	16.2	0.8	16.7	3.2	6.3

Table 38: Percent of Participants Ever Receiving Components of Care by Facility

Care Component	155	156	157	158	159	160
Food	56.9	42.3	25.0	46.7	19.2	22.5
Multivitamins	99.1	97.3	90.0	97.5	82.4	33.3
Nutritional advice	99.1	89.2	87.5	92.5	41.6	76.6
Access to drinking water	98.2	74.8	35.0	95.0	41.6	42.3
CTX	99.1	98.2	90.8	98.3	93.6	53.2
Isoniazid	7.3	6.3	0.0	3.3	12.0	0.9
Condoms	90.8	67.6	56.7	82.5	51.2	39.6
ITNs	46.8	44.1	31.7	82.5	35.2	36.0
Household items	14.7	16.2	1.7	8.3	3.2	3.6
Home help	33.9	32.4	5.0	22.5	16.0	11.7
IGA	44.0	32.4	2.5	10.0	20.8	17.1
Transport to care centre	17.4	8.1	20.0	11.7	6.4	7.2
Legal services	18.3	13.5	38.3	13.3	50.4	2.7
Memory book work	14.7	17.1	4.2	22.5	22.4	3.6
Loans	85.3	46.8	17.5	78.3	32.0	17.1
Infection control training	78.9	76.6	45.8	51.7	67.2	89.2

Table 39: Percentage of People Ever Receiving Care at the Facility and Elsewhere, by Facility

Component of Care	155		156		157		158		159		160	
	fac	else	fac	else	fac	else	fac	else	fac	else	fac	else
Visit by religious leader	6.4	78.9	14.4	73.0	5.0	41.7	3.3	50.8	0.8	67.2	4.5	88.3
Prayer with staff	37.6	40.4	17.1	17.1	61.7	17.5	1.7	10.0	16.0	38.4	28.8	42.3
Contact with traditional healer	0.9	17.4	0.9	4.5	0.0	3.3	0.0	9.2	0.0	16.8	1.8	10.8
Pre and post test counselling	81.7	15.6	50.5	17.1	73.3	29.2	96.7	30.8	44.0	16.0	100.0	10.8
Adherence counselling	98.2	14.7	89.2	19.8	74.2	8.3	97.5	7.5	84.0	8.8	100.0	9.0
Family planning counselling	91.7	9.2	62.2	23.4	33.3	11.7	65.8	30.8	44.0	12.8	48.6	13.5
Patient HIV support groups	90.8	18.3	30.6	31.5	30.0	7.5	90.8	7.5	17.6	16.0	59.5	13.5
Family counselling	80.7	20.2	42.3	27.0	15.0	8.3	58.3	15.8	26.4	52.0	31.5	20.7
Psychiatric therapy	22.9	1.8	4.5	4.5	0.0	0.0	4.2	2.5	1.6	0.8	2.7	0.9
Prevention with positives	99.1	13.8	76.6	21.6	85.0	11.7	95.0	26.7	73.6	24.0	93.7	18.0
Wound care	90.8	9.2	33.3	18.0	7.5	7.5	90.0	20.8	35.2	8.0	73.0	7.2
Other nursing care	99.1	7.3	33.3	18.9	4.2	3.3	87.5	17.5	55.2	15.2	74.8	13.5
ART/ARV	95.4	4.6	86.5	10.8	52.5	7.5	70.8	2.5	85.6	7.2	63.1	4.5
Assessment of ART treatment	94.5	5.5	81.1	9.9	70.8	5.8	68.3	1.7	90.4	6.4	97.3	0.9
Assessment of pain	91.7	8.3	38.7	11.7	63.3	19.2	83.3	8.3	61.6	24.0	86.5	28.8
Strong opioids	0.0	0.0	0.9	0.0	0.0	0.0	1.7	0.8	13.6	8.0	0.0	0.0
Weak opioids	1.8	1.8	2.7	0.9	0.8	0.8	4.2	0.0	9.6	8.8	0.0	0.0
Non-opioid analgesics	65.1	44.0	32.4	42.3	44.2	35.0	75.0	35.8	68.0	39.2	78.4	39.6
Treatment for neuropathic pain	11.9	2.8	4.5	0.0	5.0	3.3	6.7	5.0	17.6	6.4	21.6	4.5
Treatment for anxiety and depression	11.9	1.8	8.1	3.6	3.3	2.5	7.5	2.5	4.8	3.2	2.7	1.8
Treatment for nausea/vomiting	20.2	8.3	12.6	9.0	10.8	5.8	26.7	6.7	20.8	6.4	12.6	6.3
Treatment for skin rash/itching	29.4	9.2	19.8	2.7	25.0	10.0	41.7	8.3	28.0	12.0	15.3	4.5
Treatment for diarrhoea	20.2	8.3	17.1	3.6	10.8	8.3	15.0	10.8	12.8	8.8	18.0	9.9
Treatment for constipation/laxatives	6.4	3.7	9.0	2.7	2.5	1.7	13.3	5.8	9.6	3.2	9.0	3.6
Treatment for genital thrush	13.8	2.8	2.7	1.8	23.3	3.3	28.3	3.3	14.4	4.8	10.8	5.4
Treatment for oral thrush	13.8	2.8	8.1	2.7	22.5	2.5	20.0	5.8	16.8	3.2	8.1	0.9
Treatment for cryptococcal meningitis	1.8	2.8	4.5	0.9	1.7	0.0	1.7	0.8	0.8	0.8	0.0	0.0
Treatment for fungal infections	17.4	3.7	14.4	8.1	15.8	14.2	43.3	14.2	25.6	11.2	6.3	3.6
Treatment for herpes	4.6	3.7	6.3	0.9	6.7	5.0	10.0	8.3	9.6	5.6	1.8	2.7
Treatment for malaria	51.4	29.4	12.6	8.1	13.3	27.5	27.5	40.8	40.0	24.8	39.6	28.8
TB testing	38.5	5.5	29.7	3.6	21.7	15.0	60.8	17.5	23.2	4.0	40.5	5.4
TB treatment	20.2	3.7	18.9	3.6	15.0	8.3	16.7	18.3	13.6	0.0	15.3	3.6
Therapeutic feeding	7.3	4.6	9.9	0.9	2.5	0.8	19.2	3.3	3.2	0.8	4.5	0.9
Treatment for other OIs	49.5	6.4	36.0	9.9	19.2	10.8	71.7	15.8	58.4	15.2	46.8	14.4
Cancer management	0.9	1.8	4.5	1.8	0.0	0.0	3.3	0.8	0.8	0.0	0.9	0.0

Table 39: Percentage of People Ever Receiving Care at the Facility and Elsewhere, by Facility

Component of Care	155		156		157		158		159		160	
	fac	else	fac	else	fac	else	fac	else	fac	else	fac	else
Physiotherapy	47.7	3.7	13.5	3.6	0.8	0.0	10.0	7.5	1.6	1.6	3.6	3.6
Food	56.0	2.8	23.4	24.3	23.3	4.2	44.2	5.8	5.6	15.2	16.2	6.3
Multivitamins	99.1	7.3	97.3	11.7	90.0	10.8	97.5	5.8	79.2	15.2	27.9	5.4
Nutritional advice	99.1	5.5	82.9	33.3	85.8	7.5	92.5	5.0	38.4	7.2	75.7	5.4
Access to drinking water	98.2	10.1	36.9	60.4	31.7	5.8	92.5	19.2	12.8	32.8	32.4	17.1
CTX	99.1	2.8	97.3	13.5	90.0	11.7	97.5	4.2	89.6	13.6	49.5	7.2
Isoniazid	7.3	0.0	4.5	2.7	0.0	0.0	2.5	0.8	12.0	0.0	0.9	0.0
Condoms	89.9	9.2	55.0	24.3	54.2	9.2	79.2	18.3	40.0	22.4	32.4	10.8
ITN	37.6	22.0	22.5	29.7	28.3	8.3	45.0	67.5	24.8	17.6	19.8	20.7
Household items	4.6	11.0	0.9	15.3	0.0	1.7	5.0	3.3	0.8	2.4	0.9	2.7
Home help	4.6	32.1	0.9	31.5	1.7	3.3	4.2	20.8	0.0	16.0	0.9	11.7
IGA	17.4	33.9	7.2	28.8	0.8	1.7	1.7	8.3	4.8	16.0	11.7	6.3
Legal services	0.9	16.5	2.7	5.4	17.5	2.5	8.3	3.3	0.0	6.4	1.8	5.4
Memory book work	9.2	12.8	3.6	10.8	36.7	2.5	5.8	7.5	46.4	8.8	1.8	0.9
Loans	1.8	12.8	0.9	16.2	0.0	4.2	6.7	20.0	1.6	20.8	0.9	2.7
Infection control training	80.7	11.0	39.6	13.5	17.5	2.5	74.2	15.0	21.6	17.6	10.8	6.3

Table 40: Percent of Participants at T1 to Receive Care Theme in T1–T3, by Facility

Care Theme	Facility					
	155	156	157	158	159	160
Spiritual	83.2	74.3	79.2	47.7	69.2	92.4
Support/Counselling	100.0	94.3	93.4	100.0	93.3	100.0
Preventive	100.0	97.1	92.5	100.0	84.6	93.3
Nursing	98.1	50.5	9.4	98.1	66.3	77.1
Pain	93.5	70.5	74.5	93.5	81.7	89.5
Symptoms	76.6	56.2	72.6	88.8	84.6	75.2
Nutrition	100.0	100.0	99.1	100.0	97.1	72.4
Social	41.1	46.7	3.8	19.6	28.8	13.3

had received psychiatric therapy, compared to less then 10% of participants at each of the other facilities.

Participants at facility 160 reported the lowest level of receipt of several key care components, such as CTX, multivitamins and weak opioids, many of these levels being much lower than all the other facilities.

5.7.4—Care Themes

Receipt of care for the themes to be used in later analysis also varied by facility, but as Table 40 shows, there were no trends in which facilities had the highest or lowest proportion of participants receiving care. For example, some component of spiritual care was received by 47.7% of participants at facility 158 and 92.4% of participants at facility 160. Receipt of support and counselling care was received by all participants at facilities 155, 158, and 160, and over 90% at the other three facilities. The widest variation in receipt of care by facility was for nursing care, which ranged from 9.4% of participants ever receiving some form of nursing care at facility 157 to 98.1% at facilities 155 and 158. The care themes included care reported at T1, T2 or T3 only, because they were used to predict change in health scores from T0. The denominator was the number of participants to complete T1.

5.7.5—PEPFAR Care and Support Categories

Looking at the proportion of participants ever receiving a component of care from each of the PEPFAR care and support categories of care by facility (Table 41), it can be seen that nearly all participants at every facility received some form of clinical care during the course of the study, and over 85% of participants at all facilities received some component of preventive care. The other areas of care showed more variation. The proportion of participants receiving some component of psychological care ranged from 24.2% at facility 157 to 89.0% at facility 155. Social care receipt ranged from 24.3% of participants at facility 160 to 62.4% at facility 155. It is important to note that Table 40 refers to only three timepoints, and Table 41 to all four.

Table 41: Percent of Participants Ever to Receive PEPFAR Care Categories, by Facility

Care category	Facility						
	155	**156**	**157**	**158**	**159**	**160**	**Total**
N	***109***	***111***	***120***	***120***	***125***	***111***	***696***
Clinical	99.1	99.1	97.5	100.0	96.8	100.0	98.7
Psychological	89.0	59.5	24.2	68.3	61.6	45.0	57.6
Spiritual	88.1	79.3	77.5	56.7	79.2	90.1	78.2
Social	62.4	60.4	29.2	46.7	49.6	24.3	45.3
Prevention	99.1	97.3	86.7	95.8	87.2	97.3	93.7

5.7.6—Health at Baseline at Different Facilities

At baseline there was greater variation in physical health score than mental health score by facility, although the variation was statistically significant for both (p<0.001 and p=0.018 respectively using Kruskal Wallis tests). The highest and lowest means for the two scores were reported by the same facilities (Table 42). Mean scores ranged from 42.6 (sd 11.2) for physical health score and 46.4 (sd 8.6) for mental health score at facility 160 to 49.5 (sd 9.2) for physical health score and 49.7 (sd 8.2) for mental health score at facility 156. Although there was little variation in APCA African POS total scores at baseline by facility, with scores ranging from 20.6 (sd 5.2) at facility 159 to 22.6 (sd 5.5) at facility 155, this variation was statistically significant (p=0.012).

Table 42: Mean Physical and Mental Health Score at Baseline (T0), by Facility

Facility	Physical Health Score		Mental Health Score		APCA African POS Total	
	mean	**sd**	**mean**	**sd**	**mean**	**sd**
155	43.1	12.8	47.0	10.1	22.6	5.5
156	49.5	9.2	49.7	8.2	22.1	4.9
157	47.4	11.6	47.5	10.2	20.9	5.5
158	46.7	11.8	48.4	9.5	22.4	4.9
159	47.1	9.6	49.5	9.7	20.6	5.2
160	42.6	11.2	46.4	8.6	22.0	5.8

5.8—Participant Characteristics and Health

5.8.1—Gender

Mean physical health score was 45.5 in males and 46.4 in females. Mean mental health score was 48.5 in males and 47.9 in females. The difference between males and females was not significant for either score (p=0.348 and p=0.414 respectively).

5.8.2—Age

The association of age with the MOS summary scores was tested using linear regression. Treating age as a continuous variable, outcomes at the intercept (where age=0) were 48.4 for physical health score and 45.7 for mental health score. Physical health score declined by 1.4 per increasing year of age, but this was not significant (p=0.162). Mental health score increased by 1.73 with each increasing year of age, but this also was not significant (p=0.084).

Table 43: Mean Health Scores at Baseline for Different Levels of Education

Education Level	Physical Health Score		Mental Health Score		APCA African POS Total Score	
	Mean	sd	Mean	sd	Mean	sd
None	40.5	12.3	46.5	9.2	21.4	5.2
Begun primary	45.8	11.2	47.8	9.6	21.4	5.2
Begun secondary	46.8	10.7	48.3	9.4	21.9	5.5
Diploma or higher	47.7	13.5	50.0	8.8	23.8	4.8
F	2.49		1.04		3.50	
p	0.060		0.375		0.015	

Table 44: Mean Health Scores at Baseline for Different Level of Wealth *(1=poorest, 5=wealthiest)*

Wealth Quintile	Mean Physical Health Score		Mean Mental Health Score		Mean APCA African POS Total Score	
	Mean	sd	mean	sd	mean	sd
1	44.1	11.3	46.7	9.7	21.8	5.3
2	45.1	11.8	47.4	10.0	21.1	5.2
3	45.7	11.4	48.3	9.0	21.6	5.8
4	48.0	9.8	48.8	8.9	21.3	5.0
5	47.9	11.7	49.5	9.5	22.9	5.2
F	3.25		1.91		2.55	
p	0.012		0.108		0.038	

5.8.3—Education

Mean physical health score and mental health score scores increased for each increasing level of education completed by the participants (Table 43). This variation in scores according to education level was not significant for either score (one way ANOVA p=0.060 and 0.375 respectively). Mean APCA African POS total score increased with education and the variation was significant at the 5% level (p=0.015).

5.8.4—Relative Wealth

Participants who reported greater relative wealth also reported better physical and mental health at baseline (Table 44). This variation in outcomes by wealth quintile was significant for physical health score (p=0.012) but not mental health score (p=0.108) using one way ANOVA. Mean physical health score was associated with wealth quintile, with participants in the wealthier quintiles having a higher mean physical health score (p=0.012).

The same effect was not observed for mental health score. The ANOVA test showed an association between APCA African POS total score and wealth quintile (p=0.038) but without a clear directional trend.

5.8.5—Illness Severity

The association between outcomes and illness severity were explored using the first CD4 counts collected, which relate to T1 and up to 12 months prior and the participant outcomes at T1. From Table 45 it can be seen that participants with higher CD4 counts tended to report higher physical and mental health scores, and there were significant differences in both scores between the four groups (p<0.001 and p=0.059 respectively). There was little variation in APCA African POS total score between participants who had differ-

Table 45: Physical Health Score, Mental Health Score and Total APCA African POS Total Score at T1 by CD4 Groupings

CD4 group	<50	51–200	201–350	>350	One way ANOVA
N at T1	57	151	155	213	p
Mean (sd) physical health score at T1	45.5 (12.3)	48.1 (11.3)	52.4 (9.0)	52.2 (8.8)	<0.001
Mean (sd) mental health score at T1	49.9 (9.1)	51.7 (8.3)	52.9 (8.9)	53.0 (7.9)	0.059
Mean (sd) POS total score at T1	24.4 (4.8)	24.6 (5.0)	25.0 (4.8)	24.7 (4.6)	0.851

Table 46: A Comparison of Outcomes Between Participants Receiving and Those Not Receiving Specific Care Components at T1

Received	Physical Health			Mental Heath			CD4 Count		
	n	mean	se	n	mean	se	n	mean	se
TB treatment									
Yes	82	46.04	1.46	82	51.45	0.99	77	217	21
No	552	50.91	0.42	552	52.36	0.36	499	344	11
ART									
Yes	371	50.54	0.63	371	52.22	0.45	339	285	13
No	263	50.10	0.55	263	52.28	0.51	237	388	17

ent CD4 counts, and this variation was not statistically significant.

Linear regression was used, with CD4 count as a continuous variable, to explore the effect of CD4 on mental health score adjusting for physical health score, and vice versa. The results (in Appendix I) showed that after adjusting for physical health there was no association between mental health and CD4 count. The same did not apply when physical health was adjusted for mental health, proving that the result was not simply due to close correlation between the two health scores.

Very few participants were accompanied by a caregiver. To explore whether outcomes predicted having a caregiver, linear regression was used to model each health score associated with carer presence, and with carer presence plus the other health score (Appendix I). The results showed that having a carer was associated with lower physical health, but after adjusting for physical health there was no association between mental health and presence of a caregiver.

5.8.6—Individual Care Components

Owing to their importance in HIV care, the receipt of certain individual care components was examined for their association with outcomes at baseline. The mean and standard error of physical health, mental health and CD4 count are presented in Table 46. Participants who had received TB treatment in the month before baseline had lower physical and mental health scores and a lower CD4 count than those who had not.

The differences in mean physical score (t= -4.00, p<0.001) and CD4 count (t= -4.25, p<0.001) were both statistically significant but the difference in mental health score was not (t= -0.90, p=0.366). Participants who received ART in the month before baseline had almost identical scores for physical and mental health, and a lower CD4 count, compared to those who had not. CD4 count showed a significant difference (t=4.99, p<0.001), but physical health and mental health were not associated with receipt of ART (t=0.53 and p=0.597 for physical, t=0.084 and p=0.933 for mental).

6 Results of Longitudinal Quantitative Study Section B

6.1—Association of Outcomes with Loss to Follow-Up

To determine whether missing data were missing at random with relation to the outcomes, or whether the outcomes were associated with the probability of loss to follow-up, mean physical and mental health scores at T0 for completers and non-completers were compared using t-tests.

Table 47 shows that the 60 participants who only completed the first observation had a mean score two points lower than the mean for the remaining participants, and the difference was not statistically significant (t=1.30, p=0.194). However, the 104 who left the study before completion had a significantly lower mean physical health score at the 5% level than those 588 who completed all four observations (t= –2.15, p=0.032).

In Table 48, the participants who only completed one observation did not have significantly lower scores than those who completed more than one (t=0.28, p=0.78). The 104 participants who dropped out at some point during the study had lower mean mental health scores than the 588 who completed all observations but this difference was also not statistically significant (t= –1.49, p=0.14).

The implication of these results is that any analysis which only included people who had completed all four observations would be biased towards a higher level of physical health than was visible in the whole study population. On the other hand, analysis which included all participants except the 60 who only completed an interview at T0 would not bias the result. Therefore, multilevel modelling, which operates using all observations except the first, is a more appropriate way of exploring change over time in this study than traditional techniques which often exclude non-completers.

Table 47: Mean Physical Health Scores at T0 by Number of Observations Completed

Observations completed	N	Mean	sd	95% CI
One	60	44.32	11.53	41.33–47.29
More than one	632	46.30	11.28	45.42–47.18
Less than four	104	43.93	11.71	41.65–46.21
Four	588	46.51	11.20	45.61–47.42

Table 48: Mean Mental Health Scores at T0 by Number of Observations Completed

Observations Completed	N	Mean	sd	95% CI
One	60	47.77	10.85	44.97–48.81
More than one	632	48.13	9.32	47.40–48.86
Less than four	104	46.83	10.63	44.77–48.90
Four	588	48.33	9.23	47.58–49.07

Table 49: Mean MOS Summary Score Changes Over Time

	T0	T1	T2	T3
Mental health summary score	48.10	52.24	54.22	54.98
Physical health summary score	46.13	50.28	51.96	53.35

6.2—Changes in Health Over Time

6.2.1—Physical and Mental Health Scores

Table 49 shows both mean health summary scores at each timepoint. From observation, mean scores increased over time for both physical and mental health.

Mental and physical health score values at T3 were significantly higher than at T0 (both p<0.001) as illustrated in Figures 18 and 19. The mean increase from baseline to T3 was 6.6 (sd 9.9) for mental health score and 6.8 (sd 11.9) for physical health score, which are both clinically significant (**11**). The greatest increase for both physical and mental health occurred between T0 and T1. Mixed methods analysis accounting for repeated measures on individuals and the clustering of

Figure 18: Change in Average Physical Health Score Over Time

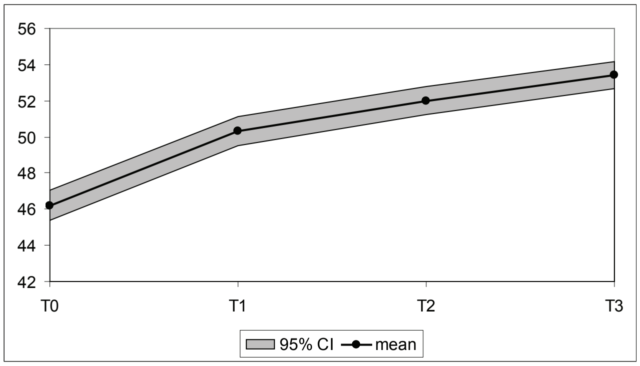


Figure 19: Change in Average Mental Health Score Over Time

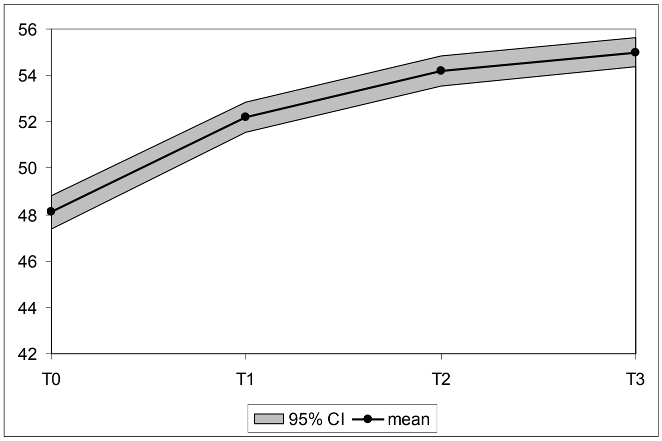


Table 50: Mixed-Effects Model of Physical Health Score Adjusting for Physical Health at T0 and Time

	Coefficient	Standard Error	p	95% CI
Baseline physical health score	0.4	0.0	<0.001	0.4–0.5
Interview number	1.4	0.2	<0.001	1.0–1.8
constant	28.8	1.3	<0.001	26.3–31.4

Table 51: Mixed-Effects Model of Mental Health Score Adjusting for Mental Health at T0 and Time

	Coefficient	Standard Error	p	95% CI
Baseline mental health score	0.4	0.0	<0.001	0.3–0.4
Interview number	1.3	0.2	<0.001	1.0–1.6
constant	33.7	1.3	<0.001	31.2–36.3

Table 52: Median APCA African POS Scores for Items (All 0–5)

APCA African POS Item	Median (IQR)			
	Baseline	T1	T2	T3
Pain	3 (2–4)	4 (3–5)	4 (3–5)	4 (3–5)
Symptoms	4 (3–5)	4 (3–5)	4 (3–5)	5 (4–5)
Worry	4 (3–5)	4 (3–5)	5 (3–5)	5 (3–5)
Sharing	2 (0–4)	2 (0–4)	2 (1–4)	2 (0–4)
Life worthwhile	4 (3–5)	4 (3–5)	5 (4–5)	5 (3–5)
Peace	3 (2–4)	4 (3–5)	4 (3–5)	4 (3–5)
Help and advice	1 (0–3)	2 (1–3)	2 (1–4)	3 (1–4)

individuals at facilities also showed that the increase in the mental and physical health summary score were significant (p<0.001, Tables 50 and 51).

6.2.2—Multidimensional Care Scores

According to the domains measured in the APCA African POS, at all time points participants rated their symptoms, worry and feeling that life was worthwhile to be relatively lesser problems, but obtaining help for their family and sharing their problems were the areas with the lowest score (Table 52). Participants' reported ability to share feelings with others showed no change over the course of the study, even though the median score was low at baseline (2 [IQR 0–4]). Participants' reported rating of feeling that had received enough help and advice was the lowest scoring APCA African POS item at baseline (median 1 [IQR 0–3]), and also showed the greatest increase by T3 (median 3 [IQR 1–4]). The remaining items showed modest increases over the course of the study.

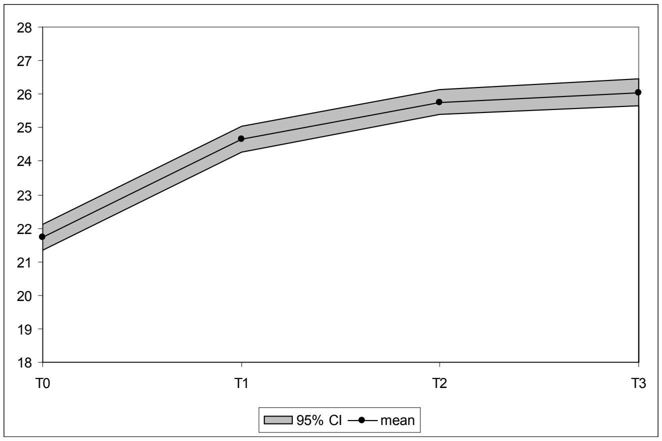
Table 53 presents a different summary of the same information. The proportion reporting “severe” (the worst two scores) and “moderate” (the middle two scores) problems on each item are reported by time. The results show that the reduction in median scores shown in Table 52 had clinical meaning. In most cases the proportion experiencing either severe or moderate problems decreased, particularly between T0 and T1 when the largest reduction in severe problem scores occurred. The exception to this rule was in the two items causing most need at baseline; not being able to share feelings and not having enough help and advice for the family to cope. In these areas, severe problems were apparently reduced only to the status of moderate problems, causing an increase in the proportion to report moderate problems.

Figure 20 and Table 54 show the change in APCA African POS total score over time. APCA African POS total score increased, reflecting a reduction in multidimensional problems. The multilevel model in Table 54 shows that the average increase between time points was 0.68 and the improvement over time was statistically significant (p<0.001).

Table 53: Proportion Reporting Severe and Moderate Problems by Multidimensional Item Over Time

		T0 n=696	T1 n=634	T2 n=613	T3 n=592
Pain	severe	8.1	2.5	2.6	2.0
	moderate	43.3	27.1	22.0	22.8
Symptoms	severe	2.7	1.1	0.7	0.8
	moderate	32.2	16.4	18.3	15.0
Worry	severe	11.2	3.3	2.1	3.2
	moderate	27.7	19.1	16.2	15.2
Share feelings	severe	54.5	49.7	42.4	40.9
	moderate	24.0	28.1	37.7	34.8
Life worthwhile	severe	13.4	8.4	5.6	4.2
	moderate	15.5	10.3	8.5	10.1
Peace	severe	15.8	8.5	7.3	6.3
	moderate	27.0	19.9	17.0	17.1
Help and advice	severe	51.3	39.0	29.9	30.2
	moderate	25.1	35.2	33.6	32.8

Figure 20: Change in APCA African POS Total Score Over Time



6.3—Participants with the Most Need at Baseline

It is of particular concern that individuals with the most severe problems relating to their HIV status should receive appropriate care. It is possible that the most intractable problems are not dealt with sufficiently, and that an average improvement in scores hides this. For this reason the participants with the worst outcomes at baseline were examined to see how their outcomes changed over time.

Table 54: Mixed-Effects Model of APCA African POS Total Score Adjusting for Baseline APCA African POS Total Score and Time

	Coefficient	Standard Error	Z	P	95% CI
Baseline total POS score	0.239	0.025	9.39	<0.001	0.189–0.288
Interview number	0.684	0.111	6.14	<0.001	0.466–0.902
Constant	18.883	0.847	22.30	<0.001	17.223–30.543

Table 55: Mixed-Effects Model of Physical Health Score Adjusting for Baseline Physical Health Score and Time for the 20% with the Lowest Physical Health Score at Baseline

	Coefficient	Standard Error	p	95% CI
Baseline physical health score	0.6	0.2	<0.001	0.3–0.9
Interview number	3.6	0.6	<0.001	2.5–4.7
Constant	21.3	4.7	<0.001	12.0–30.6

Figure 21: Mean Physical Health Score Over Time for the 20% with the Lowest Physical Health at T0

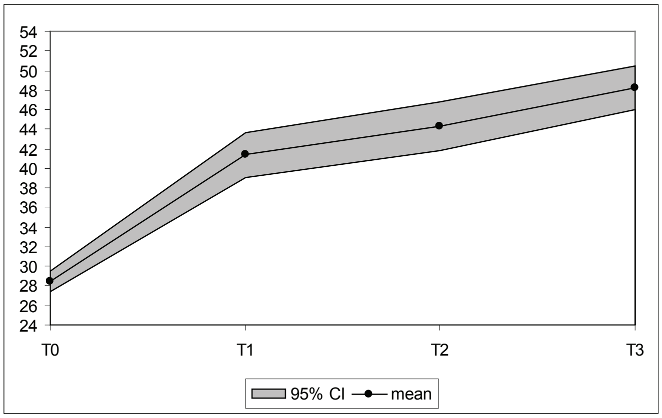
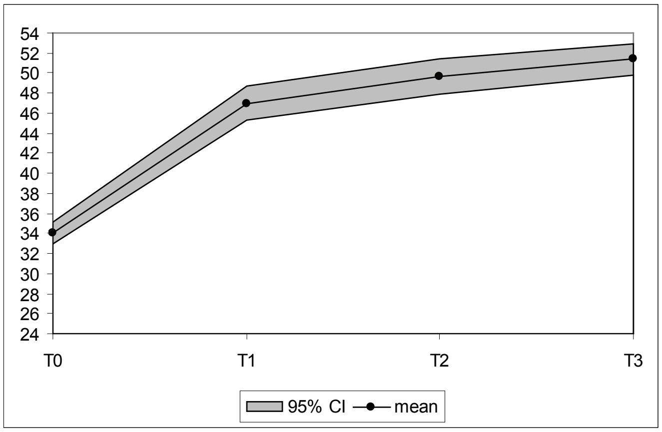


Table 56: Mixed-Effects Model of Mental Health Score Adjusting for Baseline Mental Health Score and Time for the 20% with the Lowest Mental Health Score at Baseline

	Coefficient	Standard Error	p	95% CI
Baseline mental health score	0.3	0.1	0.022	0.04–0.50
Interview number	2.5	0.4	<0.001	1.7–3.4
constant	34.6	4.1	<0.001	26.6–42.6

Figure 22: Mean Mental Health Score Over Time for the 20% with the Lowest Mental Health Score at T0



6.3.1—Physical and Mental Health Scores

Participants who scored in the lowest 20% of the mental health score and the physical health score at baseline (T0) were examined separately to see how their outcomes changed during the time of the study.

The mean physical health score of participants in the lowest 20% physical health score of the population (n=138) was 28.2 (sd 5.9) at baseline (T0), and a mean of 48.1 (sd 11.7) at T3. This was a mean increase of 19.8 (sd 12.6), which was clinically and statistically (p<0.001) significant and shows that participants with poorest physical health at baseline also improved during time under care (Figure 21 and Table 55).

The mean mental health score of participants in the lowest 20% of the population (n=552) was 34.0 (sd 6.1), and a mean of 51.4 (sd 8.1) at T3. This was a mean increase of 17.3 (sd 9.5). The increase over time was statistically significant (Table 56 and Figure 22), although the baseline value of mental health score was less predictive of change than was the case for physical health score, shown by the wide 95% confidence limits and higher (but still significant) p-value.

6.3.2—Multidimensional Care Scores

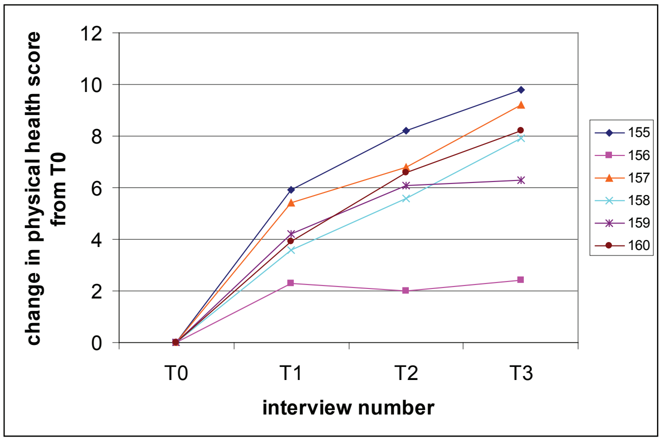
Severe pain and symptoms are sometimes complex and intractable. The scores over time for those who reported either overwhelming or very severe pain and symptoms at T0 were analysed to determine whether these problems were resolved.

Table 57 shows that, for both pain and symptoms, most participants with the worst problems at T0 showed improvement.

Table 57: Pain and Symptom APCA African POS Item Scores Over Time for Those Who Experienced the Worst Two Scores at T0

	Pain				Symptoms			
	T0	T1	T2	T3	T0	T1	T2	T3
Overwhelming (0)	9	0	1	0	3	0	0	0
Very severe (1)	48	2	2	3	16	0	0	0
Severe (2)	–	6	2	3	–	3	0	1
Moderate (3)	–	17	13	14	–	4	3	4
Slight (4)	–	16	9	12	–	8	4	4
None (5)	–	11	23	16	–	3	9	7
Total	56	52	50	48	19	18	16	16

Figure 23: Change in Mean Physical Health Score Over Time for Each Facility



6.4—Variation by Facility

Multilevel models of the health outcomes over time without covariates showed that the great majority of variance was between individuals rather than between facilities (results in Appendix I). For physical health, the variance was 52.1 (se 4.0) between individuals and 2.9 (se 2.3) between facilities. Nonetheless there was a measurable difference between facilities, which is explored in the following section.

Table 58 and Figure 23 show that the mean physical health score increased at all facilities over the course of the study. Facility 156 had the highest mean physical health score at baseline (49.5), and Facility 160 the lowest (42.6). Participants at Facility 155 showed the largest increase in physical health score (an increase of 9.8 by T3). Participants at facility 156 had the smallest increase in physical health score (2.4 by T3) and also showed little increase in mental health score after T1. Mean physical health score for all facilities except 156 and 159 showed steady increases with each subsequent month.

Table 59 and Figure 24 show that the mean mental health score increased at all facilities over the course of the study. Facility 156 had the highest mean mental health score at baseline (49.7), and Facility 160 the lowest (46.4). Participants at Facilities 157 showed the largest increase in mental health score (9.9 by T3) and participants at facility 156 the lowest (4.7 by T3). The trajectory of change in mental health score varied by facility. Participant mean mental health score at facili-

Table 58: Mean Physical Health Score by Timepoint and Facility

Facility	T0		T1		T2		T3	
	mean	sd	mean	sd	mean	sd	mean	sd
155	43.1	12.8	49.0	11.7	51.3	11.7	52.9	10.0
156	49.5	9.2	51.8	9.3	51.5	9.6	51.9	9.8
157	47.4	11.6	52.8	9.4	54.2	8.6	56.6	7.4
158	46.7	11.8	50.3	10.3	52.3	8.9	54.6	6.9
159	47.1	9.6	51.3	9.1	53.2	7.8	53.4	7.7
160	42.6	11.2	46.5	11.3	49.2	11.5	50.8	11.5

Table 59: Mean Mental Health Score by Timepoint and Facility

Facility	T0		T1		T2		T3	
	mean	sd	mean	sd	mean	sd	mean	sd
155	47.0	10.1	53.6	8.4	55.1	6.8	55.7	6.2
156	49.7	8.2	51.8	9.1	53.3	9.0	54.4	7.9
157	47.5	10.2	53.1	9.0	55.0	7.8	57.4	7.0
158	48.4	9.5	51.5	8.5	53.3	8.0	55.2	7.9
159	49.5	9.7	52.2	8.2	56.0	6.6	54.7	7.4
160	46.4	8.6	51.2	7.8	52.6	8.9	52.5	8.9

Figure 24: Change in Mean Mental Health Over Time for Each Facility

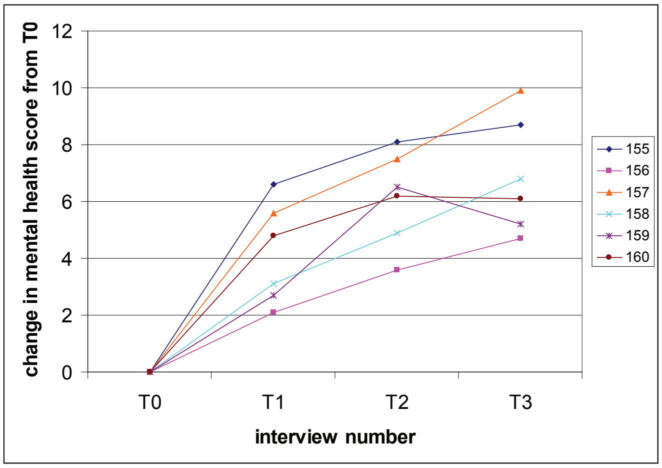


Table 60: Association of Physical Health Score with Demographic Variables (One at a Time), Using Fixed Effects

Variable	Coefficient	Standard Error	z	p	95% CI
Gender	0.829	0.599	1.38	0.166	-0.345 to 2.003
Age	-0.065	0.031	-2.10	0.036	-0.125 to -0.004
Education	-0.166	0.390	-0.43	0.670	-0.931 to 0.599
Wealth	0.562	0.219	2.56	0.010	0.132 to 0.992
CD4 count	0.003	0.001	2.11	0.035	0.000 to 0.005

Table 61: Association of Mental Health Score with Demographic Variables (One at a Time), Using Fixed Effects

Variable	Coefficient	Standard Error	z	p	95% CI
Gender	0.030	0.489	0.06	0.951	-0.928 to 0.987
Age	-0.041	0.025	-1.63	0.103	-0.090 to 0.008
Education	0.418	0.317	1.32	0.188	-2.036 to 1.040
Wealth	0.589	0.185	3.19	0.001	0.227 to 0.951
CD4 count	0.001	0.001	0.63	0.530	-0.001 to 0.003

ties 155 and 160 showed rapid increases between T0 and T1, which subsequently levelled off. Participant mean mental health score at facilities 156, 157 and 158 showed steady increases from month to month. At Facility 159 mean mental health score increased from T0 to T2, but then decreased at T3.

6.5—Participant Characteristics

The two outcomes, physical and mental health score, were modelled with each of the five demographic covariates gender, age, education, wealth quintile and CD4 count, one by one. The relationships between each outcome and each covariate and presented in Tables 60 and 61. Table 60 shows that age, poverty quintile and CD4 count were individually associated with change in physical health score over time at the 5% level. Table 61 shows that poverty was associated with change in mental health score over time. These variables were carried forward into the multivariate analysis.

Table 62: Multi-level Mixed-Effects Models of Physical Health Over Time Adjusting for Individual Care Received

		No Treatment			TB Treatment			ART		
		coeff	**se**	**p**	**coeff**	**se**	**p**	**coeff**	**se**	**p**
	Intercept	28.500	1.378	<0.001	29.232	1.433	<0.001	28.285	1.437	<0.001
Time-invariant	Physical health score at T0	0.431	0.027	<0.001	0.420	0.028	<0.001	0.431	0.027	<0.001
	CD4 at T1	0.003	0.001	0.035	0.002	0.001	0.053	0.003	0.001	0.030
Time-varying	ART	–	–	–	–	–	–	0.257	0.477	0.590
	TB treatment	–	–	–	-1.349	0.758	0.075	–	–	–
	Time	1.245	0.206	<0.001	1.246	0.206	<0.001	1.234	0.207	<0.001
		var	**se**		**var**	**se**		**var**	**se**	
Random	Between facilities	1.014	0.968		1.140	1.046		1.024	0.975	
	Between individuals	22.741	3.371		22.156	3.350		22.778	3.374	
	Time slope	3.069	0.719		3.028	0.714		3.063	0.719	
	Residual	40.273	1.912		40.506	1.925		40.292	1.912	

6.6—Antiretroviral Therapy and TB Treatment

Having established that receipt of TB treatment at baseline was associated with lower physical health, while receipt of ART was not associated with either outcome, longitudinal analysis was used to investigate the association of care with outcomes over time.

Table 62 shows the results of three models of physical health over time, all of them including CD4 count and physical health score at the beginning of the study. In addition, one model includes the receipt of TB treatment and the other includes ART. The table shows that TB treatment was weakly associated with physical health score over time (coefficient= -1.35, p=0.075). There is some evidence that people receiving TB treatment had lower physical health score and experienced less improvement in physical health score over three months, although it does not meet the previously established criteria for significance. By contrast, there was no association between receipt of ART and physical health score, either at baseline or over time (coefficient=0.26, p=0.590). CD4 count was positively associated with physical health over time. Table 62 also reveals that the majority of unexplained variance was between individuals rather than between facilities.

Table 63 shows the results of the same analysis using mental health score as the outcome. Only time and baseline mental health score were associated with the outcome; on average, mental health improved, and initial score was a good predictor of improvement. Neither TB treatment nor ART was associated with change in mental health score over time (TB treatment coefficient = -0.55, p=0.383, ART coefficient=0.014, p=0.974).

6.7—Care Availability

Each of the eight care themes was included in a multilevel model to identify which ones were associated with mental or physical health over time. In the tables below, each row refers to a different model including the named coefficient. These models also included T0 physical health score, T0 mental health score and time, and the demographic variables which were associated with the outcome (age, poverty quintile and CD4 count for physical health score, poverty for mental health score).

Table 64 shows that mental health score was not significantly associated with any care variables when they were modelled individually with wealth quintile and baseline outcome values.

Physical health score was not associated with any care theme variables at the 10% level when each care theme was modelled separately (Table 65). Only baseline CD4 count, baseline physical health score, and mental health score were associated with the outcome.

Table 63: Multi-level Mixed-Effects Models of Mental Health Over Time Adjusting for Individual Care Received

		No treatment			TB treatment			ART		
		coeff	**se**	**p**	**coeff**	**se**	**p**	**coeff**	**se**	**p**
	Intercept	34.205	1.387	<0.001	34.391	1.403	<0.001	34.194	1.432	<0.001
Time-invariant	Mental health score at T0	0.350	0.026	<0.001	0.348	0.026	<0.001	0.350	0.026	<0.001
	CD4 at T1	0.001	0.001	0.530	0.001	0.001	0.619	0.001	0.001	0.535
Time-varying	ART	–	–	–	–	–	–	0.014	0.416	0.974
	TB treatment	–	–	–	-0.553	0.633	0.383	–	–	–
	Time	1.289	0.177	<0.001	1.288	0.177	<0.001	1.288	0.178	<0.001
		var	**se**		**var**	**se**		**var**	**se**	
Random	Between facilities	0.980	0.835		0.996	0.845		0.983	0.837	
	Between individuals	19.393	2.576		19.399	2.572		19.406	2.578	
	Time slope	0.185	0.478		0.172	0.477		0.186	0.478	
	Residual	34.270	1.549		34.307	1.551		34.290	1.550	

Table 64: Mixed-Effects Models of Mental Health Score Over Time with Individual Care Themes

Covariate	Coefficient	Standard Error	Z	P	95% CI
Pain management	2.637	7.234	0.36	0.715	-11.541 to 16.815
Spiritual care	4.856	4.210	1.15	0.249	-3.396 to 13.108
Counselling/advice	0.776	20.764	0.04	0.970	-39.922 to 41.473
Nursing care	-0.325	2.153	-0.15	0.880	-4.546 to 3.896
Symptom management	1.066	6.368	0.17	0.867	-11.414 to 13.546
Nutrition	2.164	6.489	0.33	0.739	-10.555 to 14.883
Social care	-0.054	4.399	-0.01	0.990	-8.675 to 8.567
Prevention care	-0.911	12.379	-0.07	0.941	-25.173 to 23.351

6.8—Multivariate Modelling

The only covariates to be associated with change in health outcomes were demographic variables which did not change over time. For mental health, only wealth was associated with outcome. Three demographic variables (age, CD4 count at baseline, and relative wealth) were associated with change in physical health. These are modelled below in Table 66. In Model A, the association of change in physical health with the CD4 count was just under significance (p=0.051) so Model B was developed without including CD4 count.

Table 66 shows that all covariates in Model B showed significant association with the outcome, but Model A had less unexplained variance and missed significance on one covariate by only 0.1%. In both models, higher baseline health scores, greater relative wealth and younger age were associated with better physical health and greater improvement in physical health score over time. The great majority of variance was between individuals rather than between facilities.

Table 65: Mixed-Effects Model of Physical Health Score Over Time with Individual Care Themes

Covariate	Coefficient	Standard Error	z	p	95% CI
Pain management	-2.574	5.528	-0.47	0.642	-13.408 to 8.261
Spiritual care	0.650	3.759	0.17	0.863	-6.717 to 8.017
Counselling/advice	-14.625	14.281	-1.02	0.306	-42.614 to 13.365
Nursing care	-1.580	1.470	-1.07	0.282	-4.461 to 1.301
Symptom management	0.721	4.992	0.15	0.884	-8.926 to 10.368
Nutrition	5.985	4.168	1.44	0.151	-2.184 to 14.154
Social care	-1.071	3.368	-0.32	0.751	-7.673 to 5.531
Prevention care	-3.683	9.317	-0.40	0.693	21.944 to 14.577

Table 66: Multi-level Mixed-Effects Models for Physical Health Over Time

	Model A			Model B		
Fixed Effects	**coeff**	**se**	**p**	**coeff**	**Se**	**p**
Time	1.240	0.206	<0.001	1.371	0.196	<0.001
Physical health at T0	0.373	0.034	<0.001	0.370	0.031	<0.001
Mental health at T0	0.094	0.039	0.017	0.113	0.037	0.002
Relative wealth	0.643	0.228	0.005	0.532	0.217	0.014
Age	-0.075	0.032	0.020	-0.072	0.031	0.019
CD4 count at T1	0.002	0.001	0.051	-	-	-
Random Effects	**variance**	**se**		**variance**	**se**	
Facility	0.743	0.787		0.875	0.840	
Individual—time slope	3.044	0.716		2.392	0.669	
Individual	21.366	3.318		23.658	3.201	
Residual	40.435	1.922		41.241	1.870	

7 Results of Qualitative Interviews

The coding frame is presented below. Italicised phrases are examples and explanations of the codes. This frame was derived from two independently developed frames, one in Kenya and one in the UK, which are presented in Appendix K. Patient, carer and staff interviews were all coded using the same frame.

7.1—Agreed Coding Frame

- Unmet needs—*not what is provided, but what is self-identified as needed*
    - staff
    - carer
    - patient
        - social/financial
            - food
        - clinical (*e.g., CD4, pain, skin rash, diarrhoea*)
        - emotional/psychological (*e.g., stigma, worry, bereavement, anxiety, desire for child*)
        - preventive (e.g., *ITNs, safe water, condoms*)

- Components of care provided—*what facilities say they actually do and what patients say they got*
    - bereavement/care of dying
    - carers
    - spiritual
    - socio-economic
    - psychological and emotional (*e.g., information and advice*)
    - clinical (*e.g., VCT, RCT,ART, curative, lab services*)
        - adherence counselling
    - preventive (*e.g., ITNs, CTX, condoms, water*)

- Experiences of delivering and receiving care—*staff, patient, and carer views*
    - experiences of receiving care—*patient and carer only*
        - positive
        - negative
    - facility strengths and challenges
        - strengths
            - best practice and lessons learned
        - challenges
    - suggestions for improvement

- Multiple identities: patient, staff and carer roles—*description of how patients perform multiple patient, staff and carer roles*

- Access to care—*factors associated with starting care and choice of facility*
    - health seeking behaviour—*reason for initiating care*
    - process of choosing facility—*including being given referral letter*
    - eligibility criteria
    - retention/shopping around
    - costs to patient

- Clinical standards—*care processes and protocols*
    - process of enrollment
    - frequency of contact
    - monitoring and documentation
    - referral mechanisms and reasons
    - education and training of staff
    - supervision of staff

The data are presented by each coding frame category in turn, and then the broad themes are reviewed and integrated. Each data theme is illustrated using a direct quote from the transcripts and the anonymous identification for each respondent is given. The inclusion of identification numbers demonstrates the selection of data from across the sample. The number represents the facility ID, and P=patient interview, S=Staff interview and C=family carer interview.

7.2—Description of Sample

At each facility, seven patient interviews and five staff interviews were conducted. Four of the facilities hosted five carer interviews each, and there were three at facilities 156 and 159. Patients were 67% (n=28) female, aged from 20 to 56 with a median of 34. The majority (n=23) lived in rural areas, the mean household size was 4.7 and 71% (n=29) were receiving ART. Just over half of carers (n=14) were female, aged from 20 to 72 with a median of 37, living in households of a mean 5.6 people. By self-described relationship to the patient they consisted of four mothers, one father, one sister, one brother, two daughters, two sons, two wives, six husbands, three aunts, one friend and one cousin.

These terms may be more expressive of social than blood relationship; one carer introduced himself as a patient's father but later explained he was her uncle. The staff interviewed had worked at the facility for a median of two years, ranging from two months to 26 years. They were six clinical officers, four nurses, four nutritionists, two nurse counsellors, two doctors, two community nurses and ten staff of other grades.

7.3—Unmet Needs

The data category of unmet needs demonstrate that patients and families reported having multidimensional needs across domains. Further, the clinical staff identified their own professional needs to enhance care.

7.3.1—Staff Needs

A wide range of professional needs to be able to perform their roles were described. Firstly, they had a number of training and education needs that were broadly non-clinical and managerial by nature, encompassing administration, management and IT:

> "we handle a lot of logistics, I would wish to do logistic management . . . I use computer also in dispensing, so programming sometimes become a problem; you log a patient and it is just bringing its own things, it is not bringing you what you want. That requires more knowledge of computer." —S001 155

Second, the clinical management of paediatric HIV and patients was identified as a staff need:

> "I would like to learn more on dosage and care for children who are HIV positive and also on the issue of disclosure to children about their status." —S001 156

Third, general clinical updates were identified, including ART, palliative care, nutrition, and PMTCT to keep clinical skills up to date:

> "You know in training you are supposed to be updated so these should be continuous. It's a long time since I attended a training to update me on HIV/AIDS treatment and management. It's good to attend such training so that you can update yourself because may be there are new drugs or therapy in the market and there is need for one to be updated on this." —S005 156

> "I think ART is a new area and I think there is always a lot to learn. I have always wished to go and do an in depth course." —S001 159

> "Training on dealing with co morbidity because sometimes we have patients who present with hypertension, diabetes, are HIV positive and are taking a myriad of drugs." —S002 156

> ". . . the palliative care. Sometimes we have the very sick ones with the pains, Kaposi's and all that. So I would want. I have something small but I feel I need to know more of how to assist them with these pains." —S003 157

Fourth, training needs were described in general psychosocial care, including death and dying:

> "I would like to be trained in psychosocial issues and also on how to help HIV/AIDS patients die a peaceful death i.e., so that one does not die cursing their next of kin or partner." —S003 156

> "I want to be trained in psychology. I am dealing in paediatric, the adolescent age is a very difficult age; they want to become sexually active and they realise they are HIV positive and disclosure is a challenge to me because when the child reaches the age of 10–12 years, some children even refuse to take the medicine; in fact I wanted to be trained on paediatrics and psychology on how to go about it." —S004 158

Fifth, staff were keen to be able to engage meaningfully in research within their facility, to be able to collaborate with overseas research partners and to lead research locally:

> "I think I can do some research work better that is what I feel and think especially related to HIV. I have been in the field for the last 4 years and I think I can do research better." —S004 158

> "The way we are here at [name], we can be able to do our own research other than having outsiders like from New York coming to tell us to do certain things. We can sit as ourselves here at [name] and decide because whatever the New York people are trying to collect, these are the things that we are doing here. When they come they just write the information that we have. We are lacking the methodologies."—S002 158

7.3.2—Family/Carer Needs

Family/carer needs focused on the socioeconomic problems of feeding and caring for the patient, enabling them to attend clinical care, and on the psychological challenges of being a carer:

> "We have had money related problems; we have to look for money to enable us attend her clinical appointments. . . I would say is that my biggest problem is how to get money to bring her to the clinic."—C001 156

> "But they could be assisted through issuing of loans. This could really improve their lives."—C001 158

> "That is the burden which I have because I have to work hard, I am forced to borrow or take a loan so as to provide food for him. The other issue is transport. . . What I would like to say is that I have clients who are sick, this patient being one of them, although he stays separately. I have other whom I stay with. How can the government assist me so that I am encouraged as I take care of these clients since I was not blessed with children but He gave me a helping heart to help those in need?"—C001 160

> "Again, she has school-going children and school fees then also becomes a problem. So that is where the problem is."—C002 159

Family poverty is compounded by caring for their HIV positive family member:

> "You see when I am offering assistance to [name], it is not easy but I have to try real hard and I don't come from a very good background. . . For instance my parents died when I was very young so I am also have been struggling in life. So when I am looking for my own support I have to look into her needs as well."—C003 156

> "We can work hard to get our daily needs like food but we may only be getting one type of food. If we could get things like fruits, it would be very good. Sometimes I can get an orange but when I cut it into pieces for everyone including my children, I may feel like I am giving the patient a small piece. This is because the patient cannot eat alone while the child is just watching."—C004 158

However, the psychological needs of family carers were also described:

> "I don't think there is any other thing I can say. Otherwise I don't want to look that I am sick and I don't want my wife to be stressed. What we need is the home based care people to come and see us; you know when you come and talk to us, we feel that we are with you, but when we are alone we feel lonely"—C003 155

> "I have had emotional problems; sometimes one gets disturbing thoughts and you find that her illness also affects me because I have to keep thinking about her constantly."—C003 156

7.3.3—Patient Needs

The multidimensional needs of patients spanned the social/financial (especially food), the clinical/medical, the emotional/psychological and preventive care needs:

> "The biggest problem is food because sometimes we are on drugs and we need to get the diet as claimed, because you know sometimes we are sick and we are not on payroll. This forces us to look for what we can eat"
> —C003 155

> Respondent: "As a parent, I have financial problems because the kids are not going to school."
> Interviewer: "Are there some children who have dropped out of school?"
> Respondent: "Some have dropped out and some are not in school, in fact most of them are not in school."—C003 155

> "I am a sister to her mother and my husband died and I am unable to provide; so if they could assist us in whichever way, because she needs to eat well. At times you may get something to eat and other times you may not get something to eat. But we know that God is there."—C004 157

The ability to attend and benefit from a clinic is challenged by poverty even if the patient is able to pay for transport to attend:

> "When we come here, we should at least be given something to drink. Because at times you can be waiting to be attended to until 1pm and may be you don't even have some money to buy a cup of tea."—P001 157

> "I am unemployed. When I am asked to buy some medicines, I don't have the money. There was a time when I was prescribed for some eye drops that were about five hundred and something shillings and I was unable to buy it. When I came back to the clinic for my next appointment, I told them that I had not purchased the medicine."—P001 157

> "Yes, even last week I was told by someone who was in the pharmacy that, 'we don't have these drugs for the stomach; Go and buy these drugs.' "—P004 159

Patients' clinical and medical needs focused mainly around the ability to obtain prescribed medications. Stock-outs in pharmacies necessitate patients going elsewhere to purchase medicines to relieve problems:

> Interviewer: "Are there times you have had to buy?"
> Respondent: "Yes, several times. They seem to miss Dapsone so much but foliate and multi vitamin they do have."
> Interviewer: "So Dapsone, many times you have to go and buy.
> Respondent: "Yes, I have to go and buy and sometimes also foliate I used to buy."—P002 156

This was verified by staff interview data:

> "Also as much as we have drugs, they are not enough for patients. Occasionally we run out of drugs especially the Opportunistic Infection drugs." —S003 155

> "The two or I would say three key drugs which we usually buy but they are never enough for our patients are Pyridoxine, amitriptyline or other tricyclic antidepressants which most of the time is not well supplied. We also need acyclovir because we discovered that it is a very expensive drug and we use it frequently; so most of the time even if we prescribe it, the patients are not able to buy."—S003 155

The most commonly reported patient physical problem was pain:

> Respondent: "And my chest is painful and uncomfortable; I am coughing and producing very black/dark saliva and thus I am wondering why. . . I have painful joints and especially when I am sleeping.
> Interviewer: "So you have painful joints?"
> Respondent: "Yes, whenever I lie down, it becomes difficult to rise up." —P003 159

> "My whole body hurts and I spend a lot of time in bed; I have no energy and I am not able to get out of bed."—P006 159

Emotional and psychological care needs were underlined by the experience of living with the diagnosis, made more difficult by the stigma, which may originate within the family:

> "I used to live with my sister and I don't get along with her. When she heard that I have the HIV virus, she chased me away. I now live with other ladies and I don't work." [Starts to cry] —P002 158

> "It's that if your family does not accept you, you have to suffer; but if your family realise that you are a part of them, they will help you."—P002 156

The discrimination was also reported as originating from within the wider community:

> "Also the society; the society does not accept someone who is HIV positive; they still fear; they still talk about you and many patients are affected by the stigma."—P002 156

> "I can stay without telling anybody about it; also I do not disclose to people that I have the HIV virus because I fear if I disclose to anyone, they will look at me differently and then start discriminating me in front of other people, so I just say I will die with it in my heart."—P002 159

Emotional problems were multifaceted- both as a result of living with the knowledge of diagnosis and related to the financial problems experienced as a result of the diagnosis:

> "At times when I start having a lot of thoughts my head throbs."—P002 159

> "The other problem is, you come to town; you try to find a job; you don't get; you go home; you are so troubled; my heart sometimes go down; psychologically, I am so much affected."—P002 156

Patients and families had a number of preventive care needs, and these were broadly representative of the preventive care package (prevention of transmission, nutrition, ITNs) plus the recurring issue of food and finance.

> "Buying for her fruits is also a challenge since people do not grow fruits in my village and thus one has to go looking for them with lack of money also being a challenge and it was during the dry season."—C003 156

> "The assistance that we would like to get is provision of bed nets especially to those of us who cannot afford because there are a lot of mosquitoes at our place."—P005 158

Patients described a wide range of discussions that centred on infection and transmission control, however a small number had not received this:

> Interviewer: "You know this disease is not only transmitted through sexual intercourse; you can also infect other people through other ways; so whenever you come here, do they ever tell you how you can prevent infecting others?"
> Respondent: "I have never gotten someone to ask me what you are asking me now."—P005 156

7.4—Components of Care Provided

When staff, patients and families were asked about the care they have specifically delivered and received, prompts were given for the multidimensional possible areas of care.

7.4.1—Bereavement Care and Care of the Dying

The provision of bereavement care appeared rare in this sample, most likely due to research interviews taking place in the outpatient setting:

> Interviewer: "What happens to dying patients?"
> Respondent: "Dying patients; well. . . we have not received such most of them are in the ward. Most people who walk up to here are able. . . It could be their relatives who come and pick the drugs for them, but we don't quite encounter them"—S001 155

> "Who are referred on to wards, although some work is done to prepare for death after we have seen the patient for sometime, and we realise that this patient is definitely not coming up, we do counsel them. When the patient is at a very advanced stage of HIV and they open up, that's the time we counsel the family members and tell them to be prepared. Again, because it's a chronic disease and our patients are generally out patients, we don't take the really sick patients in our clinic. The only people we counsel are their family members."—S001 158

> "We have not had any arrangement of that kind in the [name] program, but normally when we get cases that are reported in the clinic that has passed away, there is little we can do because we don't have any funds for that. The only thing we can do is just to close the file and say 'we are sorry'. If willingly you as a person you have something that you can give them, you can either chip in or give as an individual. But for the [name] they have not put in any program of that kind."—S002 160

There was recognition that acceptance of death should be advanced:

> "Like they need to know that; yes we are giving them hope or I as a counselor/ nutritionist am giving them hope but they also need to know that they will be dead sometimes. But actually, so as to say, there is no formula for death; whether one has HIV or no HIV, there is death. And so, I would really like to go ahead and encourage them and actually make them know that death will come and it is good if they also had it in their minds. And if they know this, then they should also prepare for it and if possible if they are brave enough, they will discuss with the family members."—S002 159

When it was delivered, end of life care could have appeared rudimentary:

> Interviewer: "What about bereavement? That is things to do with death and dying."
> Respondent: "Rarely. . . I tell them that it's God's wish and am sorry about it."—S001 156

When terminal and bereavement care was provided, it appeared to be about preparation for death rather than palliation:

> "We haven't talked much about it although we tell them to take photos for their young ones. But we tell them it's not like they are going to die, because even us we take photos. We tell them it's so that their children can have a look at the photos and see how their mum looked like. We also talk about legal things like how they can write a will so that their property is not taken by other people."—S001 157

The (erroneous) perceived cost of palliative drugs was offered as a reason for lack of provision:

> Interviewer: "What happens with the dying patients?"
> Respondent: "They need more palliative drugs. The cost is very expensive."
> —S001 157

There is a reluctance to talk about, and to hear, the topic of end of life apart from those with advanced disease and HIV-related cancers:

> Interviewer: "OK. Do you talk about bereavement?"
> Respondent: "Not that much. It's a painful subject that people sometimes are afraid to discuss not unless you have talked with a patient may be three or four times and you have developed some rapport. Otherwise it would be rather negative the first time you see a patient and you are talking about death and bereavement. It's like you are not giving them any hope whereas in this clinic we are trying to say there is hope because we offer ARVs. So unless you have been with a patient for long, this is only when then you can sit down and say "you know this can actually happen [meaning death]. May be there are two or three patients who have come our way who are HIV positive and have got cancers and these are the ones we have tried to prepare and tell them "yes, I think we can do something about the HIV but for this cancer, I think we are stuck and this is may be what is going to happen". I have had an opportunity to prepare one or two patients like these."—S001 159

Those clinicians able to broach the topic of death and dying were seen as "brave":

> "I was saying, in this set up since its just like a normal ward set up, we have not put any extra effort as in we just want to give life support. If you find that there is a brave clinician in the ward, then he/she can be able to prepare the relatives and tell them 'this person I do not think we will be able to save them and we are just waiting for time. Have you done one, two things, three and four?' But then there aren't very many health care workers who are able to do this."—S001 159

Some appropriate clinical intervention and concepts of palliation were well described, and the lack of inpatient space seen as limiting end of life care potential:

> "we admit the patients because they might need oxygen or something which they can't get at home. At the same time the general condition might be poor so the patient can't even take oral medicine so they are given food using IG tubes or IV infusion. They are given analgesics. We try to make their last days not as painful or as stressful as it would have been. Sorry to say that... but in the wards there is a problem. The space limits our efforts." S002 157

7.4.2—Family Carers

The focus on carers within clinical time was described to be as a means to ask questions about the patient rather than carer wellbeing:

> Interviewer: "And do the HCWs ever ask you whether you have any problems as you provide care to [name]?"
> Respondent: "Yes, they usually ask me because I am the one who brings her here most of the times."
> Interviewer: "What questions do they usually ask you?"
> Respondent: "They usually ask me how she is doing and I tell them."—C002 159

> "The advice that I am mostly given is on how to live with and take care of my patient."—C003 159

> Interviewer: "When you come here and meet with the HCWs (health care workers), what are some of the things that you discuss with them? What do they tell you?"
> Respondent: "Nothing."
> Interviewer: "They don't ask you questions?"
> Respondent: "No."—P005 157

This lack of focus on family carers was confirmed by staff:

> Interviewer: "Do you ever see their families, the families of these patients?"
> Respondent: "Ahhh... Not really unless the patient is incapacitated or the patient is unable or is not adhering well to the drugs."—S001 155

> Interviewer: "Do you offer any support to these families?"
> Respondent: "None at all."—S001 156

There were, however, some examples of good practice in care for family carers:

> "Support in terms of our advice, counselling, that's the support we give the family members. We have a comprehensive family program where we send letters of invitation to the family members through the patient himself. We invite the family members to come to the clinic. They are seen by the counsellors. He talks to them about the kind of care expected by the positive member of the family and the kind of support they should give him in terms of nutrition general support about positive living and we also encourage them to test themselves in order for them to know their status. If they are willing to test, they test and if they are positive, they are free

> to enroll in the program. If they are negative, then they are counselled on how to continue living as HIV negative people and about prevention of HIV from the positive ones."—S001 158

7.4.3—Spiritual Care

Facility staff often encouraged patients and families to keep hope through spiritual belief:

> "They tell us to lay our hopes in God."—C002 159

> "The HCW will also counsel from a biblical point of view and tell us that these problems are common and that one must persevere."—P003 159

> "Sometimes when we are sitting at the waiting bay, someone may come and start preaching to us and eventually we pray together."—P001 156

> "Since February, we started singing at the waiting area. We then pray and if you have a question, you can ask before you are treated and you are answered."—P002 157

However, it was slightly more common that patients/families were never spoken to about spiritual wellbeing by their clinical team:

> "We only talk about clinical matters. I haven't heard anything to do with spirituality."—P001 158

As well as providing support and meeting patients needs for spiritual wellbeing, religious observance is also instructed as part of clinical advice:

> "They tell me, and especially the matron who has just left, "that we must trust God; this a problem in this world and there is nothing we can do; but just continue taking your medicine. So go to church, pray all the time; pray in the evening before you sleep; pray before you eat."—P004 159

> "They tell us that we have to pray to God."—P004 158

This element of religious instruction as part of clinical guidance was confirmed by staff:

> "Not so often but apart from talking about their disease of course one must always acknowledge that we as human beings can only do a certain amount and that there is somebody else who can definitely do much more-God."—S001 159

7.4.4—Socio-economic Care

Interestingly, social support seems to be gained from fellow patients:

> Interviewer: "Do you discuss social issues with the health care worker?"
> Respondent: "No but a lot of these things we discuss amongst ourselves when we meet at the clinic."—P001 156

It was not common for facility staff to ask about socioeconomic problems, and patients were sustaining themselves:

> Interviewer: "What about financial issues?"
> Respondent: the health workers?
> Interviewer: "Yes."
> Respondent: "No they don't. When you have been treated, you just go and pick your medicines and go home. That's it."—P001 157

> Interviewer: "What about social and financial issues, do you talk about them?"
> Respondent: "We have not talked about it yet neither have talked it with us."—P001 160

Patients and families had rarely discussed their socioeconomic problems with facility staff or been asked about them. Several did mention having discussed and found support through their community, micro finance from a bank project, and their Church. The most common intervention appeared to be advice and encouragement to be self sufficient:

> "Yes, they advice to work for myself and not to always think that I am sick and that I cannot be able to work. They advice me to go out and look for work to do; say in a week I should try and work for two days."—P006 156

Some patients did report being able to ask for transport cost reimbursement occasionally and to waive drug fees, and this was confirmed by staff who described their attempts to meet the needs of those with fewest resources:

> "Our health facility normally deals with very poor people. I am not saying that we don't deal with people who can afford; but in most cases our clients who come to this facility are very poor they can't afford; some cannot even afford a meal per day. Like now most of them are being cared for by

> their grandmothers, especially the paediatrics, and others are retrenched and they can't go to work because they are sick. So we give priority to those who cannot take care of themselves."—S004 158

> "The transport reimbursement. At the pharmacy if there are drugs that they need to buy, they can be waived."—S001 157

Example of an employment opportunity and income generation skills training were also given:

> "We have a small farm where people who are strong can actually be employed on casual basis"—S001 159

> "Our patients also have support groups and within the support groups we assist them on knowledge on how to conduct income generating activities."—S003 155

> "For those who think that they cannot do anything, I encourage them to look for something small. A business; something that can keep them going instead of just sitting down and waiting for handouts. For those who say that they don't know how to start, I have some connections with some people who teach people about business and what have you. I tell them "go and see this person, this person will help you, you will understand how to start a business and how to help yourself."—S003 158

Referral on to appropriate agencies was also reported:

> "They know that I deal with welfare issues and when patients are referred to me, I offer the necessary assistance. For instance in the case of orphaned and Vulnerable Children (OVC), I refer the very needy cases to children's homes or advice them accordingly. Point number two, if a patient has no finances; they are referred to me and I am able to organize for a waiver system with the finance department."—S003 156

7.4.5—Psychological and Emotional Care

Provision of psychological care is both integrated and offered as a stand-alone intervention:

> Respondent: "Yes, and I kept wondering, 'now whom shall I talk to?' But everytime I felt weighed down by stress, I just used to come to the [facility] and they were always welcoming."
> Interviewer: "So you sometimes you just come for counselling?"
> Respondent: "Yes, for only."—P003 156

Although the psychological problems associated with an HIV diagnosis was a common problem, and it was often described as a component received and highly valued, it was not routinely provided to patients and families:

> Interviewer: "Do you ever discuss issues around stress with the HCWs?"
> Respondent: "No, we do not discuss such things."—C001 156

> Interviewer: "And what about you personally; were you given some encouraging words?"
> Respondent: "No."—C002 156

A common coping strategy cited by patients as being the psychological care advice received was to avoid "thinking", which could be seen as a cheap and effective intervention or as lacking a true component of psychological care:

> Interviewer: "What about psychological care?"
> Respondent: "No they don't. The only time that we discussed with them is during that time when I was diagnosed with the virus. They told me to avoid having very many thoughts."—P003 158

The provision of information was highly valued by family carers in being to cope psychologically:

> "I can say the service here is good because it as helped me with a lot of information which has reduced the mental anguish that I had been having for a long time."—C002 156

Patients were encouraged to improve their psychological wellbeing through engaged in activities of daily living and social engagement:

> "You should join a support group; they really insist that one should join a support group. If there is a wedding somewhere, you try to get involved; if there are some celebrations around, get involved. That is, you should try to be in the company of other people; you should not stay alone. That is the first thing that they tell you when you come here. It is something that you should discipline yourself. They tell us to not ever think like other people are isolating us. This is the first thing that they tell us."—P003 158"

The concept of "counselling" in HIV care in Africa is worthy of exploration to understand what is sought and delivered in this area of care. Interestingly, it appears to have a broader content than in Western cultures, and includes medical advice:

> Interviewer: "And during these sessions; what do the HCWs tell you/do they give you any counselling?"
> Respondent: "Yes they counsel me. In the first place I ask them questions such as; whether my weight is okay; whether my CD4 count is okay; and then I tell them how I am getting on with the medicine—if it has given me any side effects or its okay with me." —P001 159

> Interviewer: "What are you told during counselling?"
> Respondent: "We are told about the proper time to take your medicines, the kind of food that you should eat; a balanced diet. Things like that." —P001 157

The support groups facilitated by clinics were highly valued:

> Interviewer: "And what do you do during your support group meetings?"
> Respondent: "During our meetings together with our HCWs, every person speaks out about their problems. There are times they visit us and we also tell them our problems. And there are times that even us, those who are HIV positive visit each other say, once per week we visit each other; educate each other; share experiences; talk to each other; encourage each other; and if we see one of us is down emotionally we try to uplift them." —P001 159

Psychological wellbeing is enhanced through religious support even when stigma has arguably reduced perceived community support:

> "Even now that my neighbours do not come to visit me, I just feel contented because I am born again (saved); my children are born again too and they also come to console me. My husband is also born again and men from the church also come to visit him and we share the word of God together; so I feel contented even when neighbours shun me. And in any case, most of these people from the community will only visit with bad intentions of going to spread bad messages about a sick person." —P005 156

7.4.6—Clinical and Medical Care

Attendance for routine phlebotomy and to collect antiretrovirals was the core clinical and medical activity:

> "There is nothing else apart from being prescribed for medicine; dispensing to us medicine after which we just go home." —C002 159

This was enhanced by very frequent description of advice on adherence:

> "They try to tell us about taking the medications and problems which may occur due to non adherence or not taking medicine." —C001 160

> "We have been told that if she adheres to her medication and follows the doctor's instructions, she will be okey with these. And that, things can only be bad if she fails to follow the doctor's instructions." C003 156

> "They tell us to use our medicine correctly and consistently; because if we stop, it can have effects on our bodies/health." —P001 159

Being able to express problems is an essential component of HIV care, and patients also valued this opportunity and the feeling of being able to express their problems:

> "They greet us; welcome us and they tell us to be comfortable; and to relax when we go to see the doctors and to explain whatever we are suffering from . . . to pour out just what we are suffering from." —P001 156

> "You know there are doctors that when you go to see them you get scared of telling them your problem, but these ones I can tell them everything that I want. I am free and I can say anything in case I don't like something or I feel that what was done is not professional." —P002 158

7.4.7—Preventive Care

Core preventive activities were reported such as provision of condoms:

> "As we have decided, I with my two wives have decided that we don't want any more child, If I am out of my stock of the condoms, they give me all those." —P001 155

Provision of prophylactic antibiotics:

> "The first day I came, the fact that I had already been confirmed that I was positive, I explained to them and that is why they first gave me septrin to see how it was going with my body. When I came back for the second time they found that I was improving, so they've continued giving me septrin up to date." —P001 155

Nutritional advice:

> "Most of the time we talk about feeding habits, how to live positively and the importance of disclosure to ones family. Usually the health worker gives me good advice and am able to relate well with my family and they take me just the way I am. They also tell me that if I get sick, I should just go back to them because they are in a position to understand my problems." P001 156

> "We talk about nutrition, the food that I am supposed to eat, fruits, any problems that I could be experiencing as a result of taking the medicines, any side effects, and things like those . . . they tell you about a balanced diet, about vitamins, carbohydrates, proteins, things like those . . . carbohydrates like rice, ugali (meal made from maize flour); proteins like fish; fruits like paw paws, passion fruits and bananas."—P003 157

Prevention of transmission:

> "When you finish using the condom, wrap it with tissue paper and dispose it off in a pit latrine so that your partner cannot get infected with the virus. If you have a wound somewhere and your partner doesn't have, if you want to help, put on gloves and help in washing the wound. When you are assisting someone to give birth, for someone like me who has the virus, I must put on gloves. I cannot help the lady who s giving birth without wearing gloves. They teach us all that."—P005 158

7.5—Experience of Delivering and Receiving Care

7.5.1—Patient and Carer Experiences of Receiving Care

Positive experiences: The vast majority of respondents reported positive experiences of being under care. The three factors that appeared to constitute a positive experience were good staff attitude, availability of drugs, and short waiting times. A good staff attitude was associated with being welcoming, and an ability to effectively communicate needs and experiences to clinicians:

> Respondent: "They talk to us very nicely. And you know nurses talk very rudely."
> Interviewer: "Talking very nicely is like telling you what?"
> Respondent: [laughs] "You know you can ask a nurse something and she doesn't respond. But these ones listen to you and give you a response."
> —P001 157

> "According to me, I find the facility okay . . . Because people are treated well."—P003 159

> "OK, when we get in here, let me say nowadays we really thank God because the CCC staff supports us even in the way they approach us; they welcome us well; they say hallo and then ask you, 'yes, my friend, how are you?' and this helps to build the relationship further. So, this helps us to open up with anything that we may want to tell the HCW because it makes us fell like we have been to this person for long."—P003 156

> "There is no pushing while getting the drugs, the nurses don't insult us. Here they have very good intentions of helping us. Even if you are so helpless, they assist you."—P004 158

Several patients made comments that the staff attitude could sometimes vary:

> "What delights me is the fact that, for instance those people whom we find at the reception, apart from the one who was rude to me who I also did not feel so bad about because probably she also had other issues bothering her; I do not see anything about this place. Even at the pharmacy, the first time I went to get my ARVs I was treated well."—P003 160

> "The other good thing about this place is that usually they receive us very well and show us love."—P006 156

> "There are some who talk to us badly and some talk to us nicely."— P007 155

The second factor associated with a positive experience was the availability of medicines:

> "I tried in Nairobi, but the kind of services I get from those people is different from the kind of services I get here. On the other side they just provide you with medication without checking on your health. Yes, To me their service is perfect. That is why I would come out of my way to spend transport to come here every two months. What I would say why I love this area [district] is that when I was getting treatment at Nairobi, I would be sent to almost every clinic around the city , going round the city from this hospital to another hospital, they don't have this type of medicine. They would tell me to come tomorrow. That is why I missed taking some medicines for one day. You would not get all you wanted from one facility. I would be sent to some other facilities like [name] from [name] to [name], from [name] to [name], from [name] to [name]. One day I roamed in the city for almost a whole day without getting ARVs."—P004 156

> "No I don't have any problem. When I want any medicine, I get it."—P003 158

> "Let me say that at the moment, we have not gotten any problem in relation to getting medicine but before, one would come here and get some medicines and miss others; but for now, all medicines are available here and again service is offered fast."—P003 156

Not spending too long waiting for clinical investigations and appointments was also praised:

> Interviewer: "What else is good about the services?"
> Respondent: "We don't overstay at the laboratory."—P005 158

> "I love it because they attend to me quickly and when one comes in the morning, they are able to go back home early and continue with their work."—P007 159

Negative experiences: The most common problem was waiting times for appointments and dispensing, although with the high numbers of patients and the reported staff pressures this is unsurprising and may be expected:

> "Yes, we were very many; so I spent the whole day here from 7:30 a.m. to 4:00 p.m. You see now, and it was not that I was number 50. We were so many and there were only two doctors [most patients will talk of doctor when referring to any HCWS—they do not differentiate the different cadres of HCWs]. We were in this room and the other one; you see now; patients were very many; more than the doctors."—P002 156

> "It was easy because then there were few patients, but now there are many patients; you can even come in the morning and leave at four in the evening and reach the house at seven in the evening."—P005 155

> "The service delivery here is slow. Patients are spending a lot of time on the queue. Like now we have been here since 9 a.m. and we haven't been attended to yet. She is being attended to now." (It was around 11 a.m. at this time.) —C005 158

> "Express services, please. Not spending the whole day here. We have got so many commitments outside. When you come and spend an eternity here, and in any case, a hospital is not a place you are supposed to spend a whole day [laughs]. This is because when you are here, you find other people who are in a really bad state; so the sooner you are out of the facility, the better."—C003 157

An implication of these perceived delays was patients leaving without the appropriate treatment:

> "It takes a long time such that some people leave without their medicines."—P003 157

As reported above, staff attitude commonly shaped patient experiences:

> "There are others who are cruel and others who are fine. Not everyone is the same."—P002 160

Although social problems have been earlier described as central needs to patients and families, they were sometimes ignored or clearly described as off-limits in the clinical setting:

> Interviewer: "When you meet with the HCW (health care worker), what do you discuss with them?"
> Respondent: "To tell you the truth, we don't discuss anything."—P003 158

> "They tell us that they can't discuss with us social issues, and that their work is to give us medicines. They ask us whether we want to get well or to talk about social problems. . . there are some who talk to us badly and some talk to us nicely."—P007 155

A facility not having resources to dispense for an eligible patient was also a problem :

> "Another thing is that sometimes you may come to the facility and upon weighing they find out that you have dropped in weight, and hence qualify for the supplemental flour, but you do not get the flour."—P005 155

7.5.2—Facility Strengths and Challenges

Facility strengths: When asked about the particular strengths of a facility, these mirrored the positive experiences of care, particularly staff attitudes towards patients:

> "Because when I used to go to the out patient department [i.e., the non-HIV general medical departments], and it's not that there the nurses were harsh it's just that here they have that personal touch. Here there are

> people who know me; you can see that everybody is smiling. Sometimes the support overwhelms me. That is what I mean by going an extra mile." —P002 158

Related to staff attitude, facility (and staff) responsiveness to need was also highlighted as a facility strength:

> "The services are of very high quality which I don't think can be found in other clinics. . . for one, if you are too weak and you cannot be able to fend for yourself, one is normally given some food supplements every month; if your weight is too low, you are given flour to make porridge and if you come from far and you don't have bus fare, you are reimbursed." —C003 158

> "At that time she was unable to use the stairs and when we arrived at the clinic, one health care worker would come with a wheelchair quickly to help her come upstairs to the CCC (comprehensive care clinic). I was really overjoyed by the care that we received. I would cry tears of joy. The doctor that we found would ask us questions that would encourage us." —C004 158

Rapid access to services and the availability of medicines were often cited again as strengths:

> "Again, here we receive fast service and medicines are available." —C003 159

Facility challenges: Again, the issue of patient load and waiting times was identified, and was related specifically to the problems of attending work:

> "On my part, I have not experienced anything bad about it but what I would say is that; sometimes patients are too many and I was wondering whether they could increase the number of staff to reduce the time patients have to wait for service. This is because you find that sometimes there are people who come here for services but they would like to be attended to quickly so that they can go back to their jobs." —C003 159

Both confidentiality difficulties and waiting times were linked to basic infrastructure of space and human resources:

> "There are no enough rooms. We would like to have enough rooms so that each clinician has a room to him/herself when seeing patients as opposed to two clinicians seeing two different patients in the same room . . . We need to have enough workers . . . The clinicians especially need another clinician and the data clerk is also one." —S001 156

> "I know that because of lack of space, we haven't had enough time to socially interact with the patients and even to do as much counselling as is required. So I think that is a component that is missing. We also have not been able to offer any spiritual care and not that there is lack of personnel and willingness, but it's simply because there is lack of space. Then I think the other facility we have not been able to offer is adequate support care groups. These do not exist may be because we have lacked the space; so you don't even have a room where you can meet with a support group to encourage others." —S001 159

> "Let me come straight to the CCC—we need space. Like we have only two clinical rooms yet every month we are getting an average of 100 new patients which translates to about 1,200 new patients every year. We have three clinicians and at any given time, two of them have to share one consultation room and this deprives the patient of privacy and confidentiality. Our waiting bay is becoming smaller because of the increased number of patients and sometimes some have to wait for their turn outside. If it rains, I don't know what we would do." —S002 156

While patients have highlighted the issue of staff attitudes, staff themselves noted that they were sometimes faced with communication challenges:

> "You can have a health care worker who is not from that community, and this patient does not understand Kiswahili or English. Therefore you as a health worker you cannot communicate to this patient; that communication barrier. There is a patient who is blind and you don't know the Braille method so you don't know how to communicate with them. There are also patients who are deaf and you don't know how to communicate with them. What do you call it?" —S001 157

Accessing medicines was also raised again, and as with not being able to attend work because of clinic queues, lack of medicines within a facility can also worsen poverty:

> "There are problems because at times you may be sick and you need medication but the medicines are not available and what you can only get is septrin. You have to buy the ARVs from elsewhere. The problem now is that you may not have money and therefore you can't buy the ARVs hence you are not assisted in any way." —P007 157

> "There are times you are given one medicine or two types and the other you are told there isn't; so you go to the chemist."—P002 156

Staff underlined the problems of drug availability and that patients cannot afford to buy privately:

> "Quite reliable in supplying ARVs. The problem comes in on OIs; these opportunistic infection drugs, that is where there is a big problem because the patients we have are many, and what we have is little. We hence have an inadequacy of OI drugs. Sometimes we don't give them; sometimes we can even go for three months, two months without even having amoxil (for example) to give to patients. Patients keep on coming because they can't buy; the truth is this patient cannot buy. If you give him a paper to go and buy, please be sure they will come back with that paper saying 'Has that drug come? I have not bought the drug.' "—S001 155

> "But we have problem in supplying some drugs especially the antibiotics. You find that the only drugs that are available are amoxil and septrin. You might feel the need to put someone on a stronger drug which may mean going to buy. Other drugs that are donated have a short expiry date so within two weeks they are over. So you go back to amoxil, septrin. It's the availability of the drugs. We do not have a stable supply."—S002 157

> Respondent: "I would like to have nimesulides, ibuprofen, stronger analgesics and . . . good antibiotics."
> Interviewer: "Strong analgesics like which ones?
> Respondent: Ibuprofen, diclofenac, nimesulides."—S002 157

Staff also recognised that an inability to appropriately dispense led to a greater pressure on service due to patients returning with unresolved medical problems:

> "Especially the antibiotics. Specifically for the treatment of common infections; what is for our clients. We have the antimalaria but sometimes you have a patient, who has a very bad infection; an ear infection, a throat infection, and they need a very strong antibiotic like augmentin, enthromycin, but they have to go and buy because we don't have. You find that a patient is coming with the same problem like three times. When you ask, 'you were here with the same problem' and they say yes but I couldn't afford. So they will keep coming again because of the same infections."
> —S003 157

As patients respond to therapy and live longer, clinics will increasingly be faced with the challenge of delivering second and third line therapies:

> "The main issue has been the second line drugs (ARVs) which are not readily available and currently a number of our patients on these is increasing; such that I may book a patient for these for one month but the pharmacy just has enough for two weeks. The patients then have to come back for a refill. But for first line drugs, the hospital always has enough stock."—S002 156

This supply problem also extends to lab agents and investigations:

> "When it comes to the lab investigations, we have on and off supplies of reagents that we use. Sometimes we run out of them and have to stay without doing some investigations."—S001 156

> "Another weakness would be the investigations we are not able to offer readily to patients. We sometimes have to refer patients to other laboratories outside the hospital for certain tests and these ones are expensive because they are private institutions."—S002 157

It was felt that a fully comprehensive service available on site would be most desirable:

> "We require so many things in the lab. Like doing early infant diagnosis for the children, viral loads, but you see most of our facilities in Kenya as a whole, are unable to. So you rely on other facilities like KEMRI [Kenya Medical Research Institute] where you take several weeks or months before you get the results. But if every facility in Kenya was to have comprehensive care, the facility should have almost everything. Being able to do CD4, blood count, the liver, the viral load, the PCR, so that the patient gets everything that needs to be done."—S002 158

> "Like at the pharmacy they have to send their clients all the way here coz of our weighing scale. If they could have one, we would reduce our queues. The lab, like now we don't have the reagent for CD4 counts so we have to send them somewhere else and remember they don't have transport. So for all those issues, we try where we can."—S003 157

The more comprehensive range of needs of patients and their families was recognised, and the limitations of facilities to meet these was also stated:

> "They come with those very high hopes, because may be now this one she has a family and she is not employed. We explain to them the much that we are able to offer in terms of management, treatment, sometimes if very desperate, we send the social worker to assess. Sometimes the old grand-

> mothers bringing in their orphans and all that. If they are very desperate, she links them up to the social service, even get some link to some schools for support. So, where we can, we do. But we are limited."—S003 157

Social workers were regarded as a very important resouce, but there were not enough of them:

> "The social worker is all alone; one dealing with a hundred plus everyday. Like now we have a mother who has been visited by the social worker. She is one and now she is in the field for adoption and court cases; so at least there is somebody listening to them."—S003 157

A further challenge was maintaining effective information and communication between facilities when patients have been referred outward for inpatient care:

> "Because we don't have patient in care, and the fact that we have to refer a patient, we refer the patient ourselves. We may at some point lose touch with that patient if he comes back to us especially if we don't know the facility where that patient has gone to for inpatient care. We really are out of touch. And even though our tracers try to follow up on such patients, sometimes they get overwhelmed with work and it's difficult for them to keep track of each and every patient who has been in admission and especially those patients who middle of the night and he would go to [name] or any other hospital such are the patients we would never know what is happening to them until they come back and tell us retrospectively that this is what happened to us. I see that there is a deficiency in that end. We tend to lose that little time of our care to the patients."—S001 158

The pressure on staff was understood to relate directly to the quality of care that could be offered, both in terms of time available to appropriately assess and provide care and the impact of staff burnout:

> "The numbers are increasing and for us to continue giving the patients quality care, we need quality time. I don't see the need to rush through so that I can finish with you. At the end of the day, 50% of the patients that I have seen, I haven't given them quality. . . We are four of us, so it is a thousand patients per person. A thousand patients per person per month. So it becomes quite hectic. We don't want to finish our work early or to be seen that we are seeing very many patients. Quality is the main thing."
> —S002 157

> "Weaknesses are there; like the burn outs, some times you are alone at the adherence counselling and the clients are as many as you are seeing here. Sometimes you don't get to sit and talk to clients, you shorten your discussion period instead of taking for half an hour, you discuss important issues because of the workload and there are many who are coming and they want your services. You can't stay for half an hour like it's supposed to be. Those are some of the challenges and weaknesses, that is, the workload."
> —S004 158

The need to recruit multiprofessional staff to meet patient need appropriately was also noted:

> "First of all I would start by adding nutritionists because actually the job I am doing, I sometimes go home feeling that I did not do enough. Sometimes you see a client is down but you are seeing all the files you have to tend to. I think maybe the personnel first."—S001 160

> "And currently, we do not have a nutritionist at the CCC."—S002 156

For patients with complications or disease advancement that requires an admission, limited inpatient resources hamper potential for an appropriate admission:

> "Patients, who present during the late stages of HIV, are patients who need attention to treat the opportunistic infections. If there is need to admit then you admit. Right now at [facility], admission is a problem because we have very many patients and with a very low bed capacity therefore patients are forced to sleep two in one bed. This is what discourages us from admitting patients because if we admit they may not be cared for as much as we would want to."—S002 157

Conversely, if a patient is cared for at home, there are also limited resources to provide appropriate care:

> "The challenge is in taking care of the patients at home, not medically. Taking care of them like bathing them, cooking for them, giving them basic needs; those are the main problems that we encounter because the hospital doesn't provide us with the things that we need. Like detergents; so I have to cough everything from my pocket."—S003 158

A final challenge described was the extremely complex goal of reducing stigma:

> "I think we haven't managed to reduce stigma."—S001 157

7.5.3—Suggestions for Improvement

Family carers suggested that they would like to be seen as service recipients and receive support:

> "As I carer, I would like the HIV care facility to at least know how I am living with the patient; that is, they should of course be visiting me at home and having discussions with me the way you have had discussions with me and then we can see what is happening. I need an open discussion with the health care workers and in that case I will be able to give them my open mind."—C003 155

As reflected throughout the data, the need for food and transport support was identified as a need for improvement:

> "A would also like him to get food so that the wife can cook for him to improve his health. That is what I can say are my needs."—C001 160

> "The issue of money for transport, flour for making porridge and fruits are big concerns to most people coming here because you will hear them talk about them while we are sitting at the waiting bay."—P004 156

> "When I was told that I have HIV, I was advised to be eating foods like spinach, oranges; but for people like us who are jua kali (informal artisans), whatever I get to eat is what I eat. This is what is disturbing me; nothing else. I have a bodaboda (I operate a bicycle taxi). If I get kshs 200, that is what I use to buy flour for my children and some spinach. There is nothing else."—P004 157

This view was supported by staff:

> "Nutritional supplements and providing food because some of our patients come and say they actually don't have food to eat at home and yet they have to take their drugs. Sometimes I also wish we could also be able to supplement transport for some patients because sometimes some of them come late for clinics because they had no money and they had to look for it."—S002 156

Further support for basic care provision was also recommended:

> "The assistance that we would like to get is provision of bed nets especially to those of us who cannot afford because there are a lot of mosquitoes at our place."—P005 158

> "Medicines like dettol and gloves are expensive. A pair of gloves is kshs 30 [$0.41]. At times she may vomit or start diarrhoeaing at night or get a flu and when she goes for a long call, at times she may not get to where toilet is and soils herself; and may be the gloves I had I already used them and here is a situation that has just come and I don't have an extra pair of gloves. But there was a time when we had a discussion that if you had used some gloves and then you wash them in anticipation of using them again, you will not be protecting yourself in any way. If only they could help us with such things."—C004 158

Again, basic drug supply was recommended, focused on antibiotics and analgesia:

> "Some antibiotics like Augumetine which is hardly found here and it's very costly and patients have to buy. At least if this would be found here it would be a bit better."—S001 156

> "In addition to what we have, It would be good to at times have analgesics; Strong analgesics for patients with chronic pain. We do have painkillers, I didn't mention pain killers, general basic analgesics is what we stock, but, at times its good to stock one strong analgesic not for all the patients but for those who do require . . . Oral analgesics are what we are talking about; Morphine or drugs in that category."—S001 158

> "We would really like to have Dapsone [which is a substitute for septrin] as this would be good for patients who are allergic to septrin since it's sulphur-based. Currently these patients have to buy it from town. Then we would also like to have drugs for common opportunistic infections [e.g., Herpes Zoster; i.e., acyclovir]. We would also like to have a myriad of antibiotics because patients come with infections here and there. Then also cytotoxics for patients with Kaposi Sarcoma since we get a number who cannot afford to buy them. So such drugs would be of great help if they were readily available."—S002 156

> "We don't have Morphine but I don't know whether it is possible to have it. I think it would be important to have it because of some patients."—S003 159

7.6—Multiple Identities

In this qualitative component of the study, we aimed to collect information from patients, staff, and families to triangulate data and integrate the datasets on experiences and views on care and support. The data demonstrated an interrelatedness between these roles, reflecting the fact that staff and carers may also be patients.

> "The services are really good because I am also a client here; I am HIV positive. The services are of very high quality which I don't think can be found in other clinics."—C003 158

The presence of openly HIV positive staff/carers is seen to facilitate supportive counselling:

> "You also find that when you are positive, it is easier to counsel them than when you are negative. This is because if you are not afraid about talking about your status, you are able to be more open with the patient; like most of my clients are able to accept their status quickly because I don't hide my status. I tell them, 'I was like this and this but now I am like this and that.' "—C003 158

Patients also take roles as community advocates and role models:

> "But when I joined this clinic, I found that there were many more people like me and this gave me some strength. Back in the village I still live with many more like me and I now talk to them about disclosure and how to live positively. Nowadays I don't even think about my illness."—P003 156

> "This made me resolve that even when am back in the village, I will be telling parents to take their children to be tested."—P001 156

> "Yes. And at some point, I even used to come here even though not for treatment but just to encourage others who are like me. We used to have our sessions here. . . Let me now tell you that I have become of great assistance to them; even when they need any psychosocial counselling, you find that they just call on me. . . I have now become like the family reconciliator."—P003 156

> "I come to work as a peer educator as a role model to other patients so that they can see that even if you are sick, one can still work"—P005 155

> "I share with them my status, my family background, and my work in general. I make them feel comfortable. Since I am also HIV positive, I don't let them feel like it's the end of the world for them. I give my self as an example to them and show them that they can still live. For those who want to have children, I encourage them to access treatment and they can still get children like any other person."—S003 158

7.7—Access to Care

7.7.1—Health Seeking Hehaviour

Patients described what motivated them to access HIV care, which was usually because they had unexplained symptoms and poor health that were suggestive of HIV infection and advanced disease

> "I had some complications on the body then it became a bit serious so I forwarded myself voluntarily to come and know my situation. When I came it was confirmed that I was positive."—P001 155

> "When I came here, I was feeling very bad. I did not have any appetite. I was feeling dizzy, I was experiencing diarrhoea, I developed some ulcers in the mouth, my skin changed and I developed something similar to cracks. That's when I decided to come."—P003 158

> "I learnt about it, when I suffered from small illnesses such as headaches, coughing; and then I got that disease with a burning sensation. . . Herpes Zoster. That is when I made up my mind to come to the hospital and be tested. After that, they asked me whether I would like to join a group so that I can get treatment."—P001 159

Another patient described how they were guided to access care by their spirit:

> "My spirit told me that I needed to go to the VCT centre to be tested and know my status."—P004 156

Interestingly, a patient described attending for care having previously defaulted on treatment due to their improved health status:

> "Yes, I am using but there was a time I thought I was well and I stopped about a year ago but then I fell sick again. So I have returned to the hospital so that I can continue with the ARVs."—P002 156

7.7.2—Process of Choosing a Facility

The two principle reasons for selecting a facility were proximity to home and personal recommendation:

> "When I checked, I found out that I was positive. I couldn't believe it. I later on came to this facility because it is nearer to my home."—P001 157

> "I have known about [name]. I have heard people saying that it is a good hospital, so we decided to come because of its fame." —P001 160

> "I knew about it through hearing from people from my area how good it is." —P006 156

The third reason was a direct referral from within the health system:

> "I had come for ante natal clinic. I was counselled and then sent to have my blood tested; and after that I have continued here until now. I was referred here." —P002 159

> "This facility is near. The other reason why I came is because I was pregnant and I had to come to the clinic." —P005 155

7.7.3 Eligibility Criteria

All sites said that they accept any HIV positive patient, although caution is exercised for patients wishing to access care far from their home district to reduce double counting and perceived patient stealth:

> "But other patients who have been seen in other hospitals like [name], [name] or [name], if this patient has already been started somewhere else, and he wants to come here, we advice, in fact it's a must that they should come with a referral letter. Without a referral letter we may not accept them because other patients may end up being double registered and he may use the other lot of the drugs to may be sell or something else. You never know." —S002 158

> "Maybe there are some conditions for people who have been going on care elsewhere or people who are enrolled in other centres; they have to produce a referral letter that is the condition, some previous history or some previous medical notes." —S003 155

Also, facilities expressed concern about being able to provide home follow-up:

> "It depends on the coverage area [facility name] has been given a working area currently, so if the patient that has come is within the coverage area, then we will work with them, but. . . we can not reach some areas, so we may not accept the people who come from far. . . [place names] . . . those are places that we cannot reach." —S005 160

> "Not everyone, because like now we have a boundary. We have the catchments areas. There are people who come from [place], they come from the VCT and they are referred here. They come from [places]. We refer the [area] people to [same area], [area] people to [same area], and [area] to [area]. But they prefer [this facility] because of the proper care that we have. Some of them think it is good for them to be here but now we have a catchments area because it would be hard for the outreach workers to reach some of these people because of the catchment's area boundary." —S002 160

It was also recognised that patients may struggle to afford the transport fees to travel from afar and then may default- this reflects the problems reported by patients in finding transport costs for care:

> "If they are from [district] and its environs, we readily accept them into our program. But if a client is coming from [far districts] we kindly ask them to try and access same services from [facilities] close to where they are coming from. This is because we also have to look at the issue of finances- maybe one has to come to the clinic monthly and thus we must assess whether they have money for that. These are factors that we have to look into." —S003 156

However, there were circumstances in which a patient from a further district would be accepted, and patients were permitted to enrol if they wished:

> "We always take them but since the clinic has been congested, we take those who are staying within [place]. But those coming from far, say [place] or [place], we counsel them, advice them and then refer them to their nearest clinic. But if someone has a good reason of wanting to come here we accept them. Let's say he is in [place] but he wants to move to [place] on transfer, its okay or the husband is staying in [place] and she is staying at home, so if she wants to move here she is allowed." —S003 159

> "However, this guidance on yes we accept all the HIV people who come to our clinic. Not unless somebody wants to be transferred out to the nearest CCC (comprehensive care clinic) they feel that they want to go to, may be they want to travel back home. If they want to be transferred, we do that. But we don't chase clients away." —S004 158

This awareness of the potential challenges to patients enrolled at a distance from their home were spelt out by staff:

> "There are various factors that we usually look for: First of all is they want to be enrolled on care we usually check if they are able to keep their ap-

> pointments. We can't enroll a patient who can benefit from another facility which is near his/her home. We do consider those things like cost, the distance, and then we refer them accordingly."—S004 155

> "We actually consider first of all the geographical factor. Yeah... we tend to get mostly patients who come from around for the reason that we do not want to take people from far who may be could default... you know... due to distance. Yes, at the moment actually we are operating on a kind of a divisional geographical area... Although we have people who come from far like from town which is 20 Kilometres away but we do accept because if they are able to come it is upon them."—S004 160

A response to the patient desire to enrol at a distance while meeting facility concerns about defaulting on treatment has been the decentralisation of facilities:

> "At the moment, one actually is the issue of defaulters that came in. We realized that there are a lot more than we thought. So many patients who are coming from far could actually fail to attend clinic dates... he or she fails to come to collect the drugs the following month; the issue of transport comes in; they may lack transport money to come here and the issue of transport has come in i.e. lack of transport has come in terms of fare, we realized that we were going to have a problem in terms of the regimen failure. So it was actually decided that this was a top level issue; the medical personnel thought twice that in order for this program to succeed there is need to decentralize these services; so that now at the moment am telling you we have so many ART satellites... so that [facility name] is now being made like a referral. While actually, it is not denying access to those who may be stable financially; because somebody could be in [city] and he or she doesn't want to be known that they are going for that kind of service." S005 159

Interestingly, it was acknowledged by staff that a patient's confidentiality could be threatened by accessing local care:

> "We are accepting them and we are asking them if it is possible and they are comfortable going to those nearer facilities because some people have this issue that from the nearer facilities where they come from, confidentiality is not kept."—S005 155

7.7.4 Retention and Shopping Around

The majority of respondents reported that they did not attend multiple care facilities, due to a combination of self-reported satisfaction with care and a request from their facility that they do not "shop around":

> "I don't think it is bad because if it was, I wouldn't have come back; I would just have stayed home... They tell us that we should not go looking for medical care from other sources once one has been registered at this HAART clinic."—C001 159

The primary reason for attending elsewhere was the (earlier identified) drug stockouts:

> Respondent: "Yes, septrin. I get it from the health centre; [name] health centre gives me septrin."
> Interviewer: "And why do you go there?"
> Respondent: "I go and get septrin when they get finished."—P003 159

Continuity of care was also identified as a reason for continued attendance at a single facility:

> "No, after I started coming here I have never gone to other hospitals. Even when I fall sick or have any problem, I just come here. This is because they have my file which has all my records so it is important to come here."—P007 157

The secure availability of free medications was reported as a strong motivation to remain in care:

> "The other good thing is about medicine; she always gets her medicine. She actually gets most of the medicines and she is never asked to go and buy."—C003 156

> "The one thing that has really helped us here is the availability of medicines which are also given for free. You can never come here and lack medicine; you get it instantly... We do not pay for services at all and that includes counselling. I am very very grateful to this project."—C003 159

The risks of non-availability of some components of treatment are sometimes not of patients then attending other facilities, but of patients not accessing appropriate care at all:

> "For this test here, they were saying that the machines were not operating; so we had to go to Nairobi hospital-there is a branch from Nairobi Hospital here which is up town and they were costing about Kshs 1600. So many of the patients had no money and so they would just go back home."—P002 156

This lack of access may be applicable to both investigations and medications:

> "They only pay if there is a particular drug that we don't have but the patient needs. That is when we refer them. Notably we do not have acyclovir for the management of Herpes Zoster."—S001 155

> "They have been paying for some investigations and chest X-rays. But for the time being they are just paying for chest X-ray and not the other tests." —S001 156

7.7.5—Costs to Patient

Staff generally reported that all interventions and drugs are free. For a small number of facilities specific drugs are charged but not for those who cannot afford to pay (although specific criteria were not given):

> "But these ones we don't charge them. The others are charged for septrin, but these ones we don't charge them even for the multivitamin. That is what we can call special treatment."—S001 157

A number of specific interventions were charged for in some instances:

> "For instance if we suspect a patient has TB, they have to pay for the chest X-Ray. I f a patient has another condition say like hypertension and they need an ECG; lipid profile test, they have to pay for those tests on their own."—S002 156

Facilities also try to dispense alternative drugs to those prescribed to avoid levying fees:

> "Like some antibiotics since the doctor can prescribe different antibiotics that are not available and patients have to buy. But if we have alternatives; they don't buy."—S003 159

As reported previously, even transport costs are provided in some instances, again specific criteria were not stated apart from inability to pay:

> "Transport, to and fro. And even if they come and tell us they don't have transport back, we also give them. We want to assist them as much as we can."—S004 158

7.8—Clinical Standards

7.8.1—Process of Enrollment

Patients generally reported facilities as being easy to find, and providing a welcome reception. As previously reported, long waiting was a problem.

7.8.2—Frequency of Contact

Frequency of contact was fairly routine across sites, with most seeing clinical staff fortnightly when treatment was initiated moving up to monthly for most and bi-monthly or quarterly for some who were responding well and stable on treatment or lived a long distance from the facility:

> "I come for the service once per month; the service is good, only that today it is very sluggish or rather for the past one month. Initially we used to have several doctors but they have been withdrawn. We used to have this lady who is here, we had another one in the other room, and then we have the big gentleman. But now we only have one lady. In as much as she would want to please me, she will not be able to because I am spending a lot of time here. You feel demoralised by the services."—C003 157

All offered a walk-in service for those with new emerging problems. For those with additional medical needs such as family planning, TB management as well as ART they reported frequent and repeated visits to the clinic as appointments did not coincide.

7.8.3—Monitoring and Documentation

Community workers were employed as an original mechanism to follow up patients in the community and monitor their adherence:

> "The clinic has hired these tracers [community health workers] who follow up on these patients who has delayed in collecting medicines. So for instance if there is a patient who has not been taking his or her medicines, the tracer has list of these patients and she does the follow ups. . . Some of them when you ask them why they haven't been coming to the clinic they tell you that they didn't have money, others may say that they didn't have food; so you ask them, 'aren't you giving money for transport when you come to the clinic? Why can't you borrow from someone and you will be refunded at the clinic?' At times you may be forced to bring the patient to the clinic with you."—C003 158

Monitoring is strict and patients are sometimes expected to fulfil obligations if they are to receive treatment:

> "The requirement upon joining the group was that, I must attend clinic every month until one year is over. I even signed a form indicating that I will be attending the clinic every month for them to review my status. I have to do this to keep the promise."—P001 156

Beyond adherence monitoring, a comprehensive set of monitoring forms were described:

> "Adult follow-up forms, locater form, family information table, we have unscheduled form, we have adherence form, enrolment forms, there are many forms."—S001 155

> "Yes, we have a standard form but we are not very restricted to it. We have a standard form that checks basically on their weight, height, their use of contraception, we screen for TB during every visit and then we check for any new opportunistic infection. Then we check for any side effects on ARVs and then check on their adherence on any other drug they may have been using. Check on their CD4 count then fill in and then book them for the next appointment."—S002 156

7.8.4 Referral Mechanisms

As described earlier, facilities attempted to refer patients to facilities closer to their homes which makes attendance more feasible:

> "She has told us that ARVs have been sent to [town centre near where patient/carer comes from] as well but since [patient] is just being started on them since she was initially on septrin, she was asked to come here first; then come back after two weeks for review and after that she will be referred to [town centre near where patient/carer comes from] which is closer home so that we can save on bus fare."—C003 156

Patients may be referred for convenience or for specific intervention unavailable at their main facility:

> "If they want; because somebody is willing to be referred to a nearest health centre, is going to work there. He is being transferred; he will prefer to be transferred. That is the major reason; if they will because we would not force the person to be referred is that we have almost all the drugs that are provided in Kenya!. . . The patients we refer again are the patient of KS, Kaposi's Sarcoma. Most of our patients with Kaposi's sarcoma we refer to Homa Bay for the Cytotoxic drugs treatment because we don't have Cytotoxics."—S001 155

> "We refer patients to Kenyatta National Hospital for cancer management. We also refer patients to nearer institutions; like if someone came here and we saw them and we discover that they come from [district] which is about 200 km from here; we start telling them that this is a life long treatment plan and so why would they want to spend 700 shillings every month to come and see us and there is an institution near home. And if they are willing, normally we refer them to those institutions."—S001 159

> <u>Interviewer</u>: "So sometimes a patient can ask for a transfer and for what?"
> <u>Respondent</u>: "Yes. If they feel that this place is too far an expensive to access due transport costs. Unless we have a case where a patient has cancer, we refer them to Kenyatta National Hospital for care."—S001 156

Other reasons that patients request referral are so that they can die closer to home or because they have a job of work to attend that is far away:

> "Some say that they are almost dying, and they don't want to die far away from home. The others that we refer are those that get jobs somewhere like in Nairobi and there is a health centre there, we refer them there."—S001 157

Very interestingly, one staff member highlighted a further reason for referral to closer facilities- that the patient may benefit from community-based support:

> "We do not just refer because of proximity concerns; we also refer because of social support. We realized that there are many organizations which are willing to support HIV/AIDS patients. We have for example the Constituency Aids Committees that supports patients through community-based organizations [CBOs].The fight against HIV/AIDS will only be won if all patients formed their own support networks- it's not going to be won through hospital initiatives alone. It's good to know that the social and therapy groups are the most important things and it's something that seems to be working. The future of this fight against HIV/AIDS is when all these patients will be able to form support groups and we as the HCWs be in a position to support them. These groups should then be empowered to support each other, remind each other about clinic days, consult each other when they have problems and assist each other spiritually."—S003 156

Additional stated reasons for referral were social/financial needs such as food and income generation, specific spiritual support (such as an Imam) and for an inpatient admission. If a patient is to be referred out, in order to ensure that there is continuity in adherence, one facility described a prescribing practice to ensure they have ART access whilst moving between facilities:

> "Like if you want to leave [town] tomorrow, before they go there and get stranded, maybe they don't know where to get the drugs from, and we don't write exactly which hospital, of course when somebody wants to go to Nairobi we just give the photocopy and referral letter then they can choose for themselves which hospital they want to go to. We tell them to go and find out where they can get the drugs. We give them referral letters and a supply of ARVs so that they don't go there and the following day they don't have drugs. So what we normally do is, that we give them enough supply of drugs to last them a month or two weeks to help them prepare to enrol in the other CCC (comprehensive care clinic)."—S004 158

7.8.5—Staff Education and Training

While clinical supervision was reported as routinely available for all sites if needed, in terms of advice on specific cases, there was often a lack of systematised supervision:

> Interviewer: "What supervision do you receive?"
> Respondent: "None. We only have a Medical Officer in charge but we only consult her when we have a difficult case."—S001 156
> "There is a Matron who is in charge of the place. She is our manager in this clinic. But as I do my work always, I need not be supervised. I normally do my work well but in any case, I contact her when I have something beyond my capabilities."—S003 159

> Interviewer: "Do you give some kind of supervision to workers?"
> Respondent: "Before we used to but now it's as if it has died. We used to in 2006. But in 2008, we haven't done."—S001 157

There were individuals who took responsibility for supervising the entire facility staff:

> "Everybody who works at the CCC reports to me. My work is to ensure that everything is running smoothly. I supervise for example the work of my data clerks, my data managers. At times I sit with them and see how they are collecting data and sometimes I even spend an hour or even half an hour with them when they are registering a patient and see what kind of problems they have and if they are collecting the right kind of information from the patients. Moving on to the triage nurses to see how the triaging is being done well, the vitals are being taken well. For the counsellors I have to sit with them when they are counselling a patient sometimes. Likewise I sit with the other clinicians. That's what my job is."—S001 158

Supervision for those who manage was not evident:

> Respondent: "I don't like to look at myself as a supervisor but since I am a team leader, I have no choice but sometimes just to find out how things are running on a daily basis at the clinic level and even just to find out from patients how they have been treated as they come in and out of the clinic; and to look at how many patients health workers saw in a day and see whether they have been strained and if there is a way to help them reduce their workload; so my supervision is at those levels. Then I report back to the institution and say these are the issues."
> Interviewer: "And yourself as a team leader, do you receive any form of supervision?"
> Respondent: [Laughter] "I don't know if I receive any supervision but I think the national team gets a chance once a year to walk round and see what is happening. So may be I am supervised at that level."—S001 159

In terms of supervision, a commonly used term was that of teamwork, with all of the multidisciplinary team supporting and advising each other:

> ". . . and we get to work as a team so we get to know what each one of us has been doing and really assessing if we have been doing our roles."
> —S005 157

Staff reported using mechanisms to ensure that patients do not default and attend for appointments. This is challenged by the costs of repeat attendance and by the need to attend a number of facilities when drugs stock-out. This was, interestingly, the only reason given for attending alternative clinics—that of non-availability of drugs. This was supported by staff data that also identified drug supply as a challenge.

8 Results of Costing Study

Results of the economic analysis for Kenya are presented below. Table 67 and Figure 25 show that there was wide variation in costs per patient per year, ranging from $77 at Facility 157 to $1160 at Facility 159. Facilities 156 and 158 had per patient costs of $191 and $170 respectively while the cost at Facility 155 was close to the median at $418 per patient.

There was also a wide variation in the components of the costs per patient as seen in Table 67 and Figure 25. Per patient staff costs ranged from $5 at Facility 158 to $440 at Facility 159. Similar variations existed for ARV costs per patient; Facility 156 was the lowest with $8 per patient with Facility 159 once again having the highest costs per patient at $514. In most cases other drug costs per patient were $6 or below, with the exception of Facility 156 which was $45. Laboratory costs ranged from $1 per patient at Facility 157 to $120 at Facility 159. Building and utility costs were below $100 per patient per year at all facilities. All facilities had building and utility costs of between $5 and $18, except for Facility 159 at $84.

The staffing costs are shown in more detail in Figures 26 and 27. Clinical staff dominated the costs of staffing at all facilities in Kenya. At Facility 158 and Facility 160 clinical staff salaries constituted 70% and

Figure 25: Facility Cost per Patient

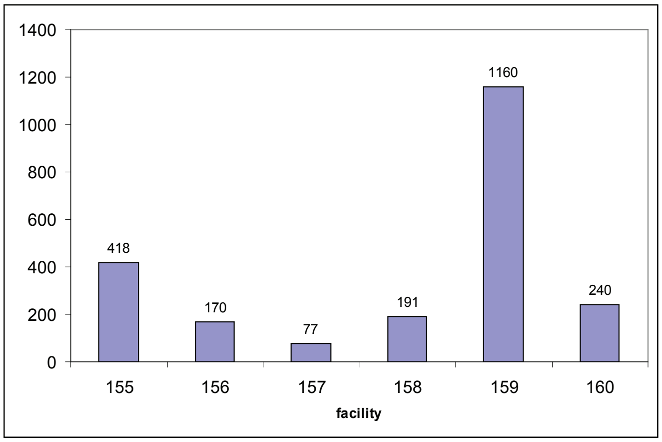


Figure 26: Cost distribution

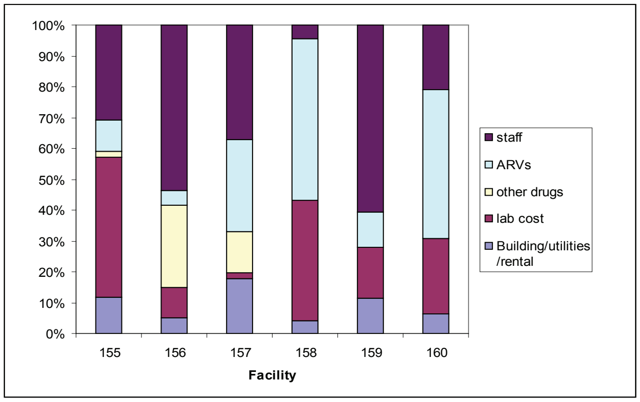


Table 67: Total and Per-patient Cost of Care (US$ per Year)

Facility	155		156		157		158		159		160	
	Total	Per Patient	Total	Per Patient	Total	Per Patient	Total	Per Patient	Total	Per Patient	Total	Per Patient
Staff	251,097	46	895,838	91	98,282	17	45,808	5	813,046	440	212,614	31
ARVs	82,838	283	77,818	8	79,075	44	567,196	138	150,535	514	485,890	163
Other Drugs	13,305	2	445,820	45	34,583	6	193	0	4814	3	4941	1
Lab Cost	370,581	69	166,147	17	5275	1	421,680	44	221,630	120	243,534	36
Building/ Utilities/Rental	94,778	18	83,713	9	47,124	8	43,721	5	154,705	84	64,719	10
Total	812,599	418	1,669,336	170	264,338	77	1,078,598	191	1,344,730	1160	1,011,697	240

60% of the total salary costs while at the other facilities the percentage was over 90% (Figure 27).

Patient loads varied widely also, for clinical and for non-clinical staff. Patient loads for clinical staff in general were lower than for non-clinical staff except in Facility 158, which also had the highest patient loads per clinical staff among the six sites in the study at 246 patients per clinical staff member. Facility 160 had the next highest patient load for clinical staff at 148 while Facility 156 and Facility 157 were at 26 and 20 respectively and Facility 159 and Facility 155 at 11 and 84 respectively. Non-clinical staff loads ranged from a low of 103 at Facility 160 to a high of 375 at Facility 157.

It was hypothesised that there would be a relationship between per patient staff costs and patient-staff ratios, i.e., facilities with high patient loads per staff should have lower staff costs. In Figure 28 a scatter plot of staff costs vs. patient-clinical staff ratios shows shows an inverse relationship, thus supporting the hypothesis.

8.1—Economies of Scale and Case Loads: Evidence from Uganda and Kenya

The relationship between size of the facilities as measured by number of patients and costs per patient per year was also examined. If there were economies of scale it would be expected that there would be a negative relationship between average costs per patient and patient numbers. This would be similar for staff costs per patient and patient loads for staff. Because there were only six facilities per country in this analysis the data for Uganda and Kenya were combined. In Figures 29 and 30 costs per patient were plotted against total number of patients registered at a facility, and again against number of HIV patients. The figures show that for both number of HIV patients and total number of patients, the cost per patient is lower in facilities with more patients.

Figure 27: Distribution of Clinical and Non-clinical Staff Costs

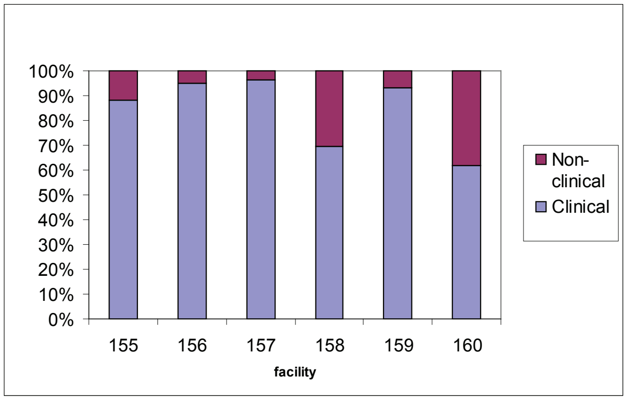


Figure 28: Patient to Staff Ratios

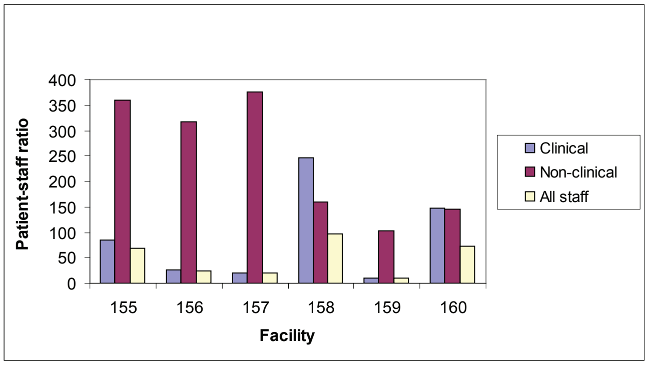


Figure 29: Staff Costs Compared to Patient-Clinical Staff Ratio

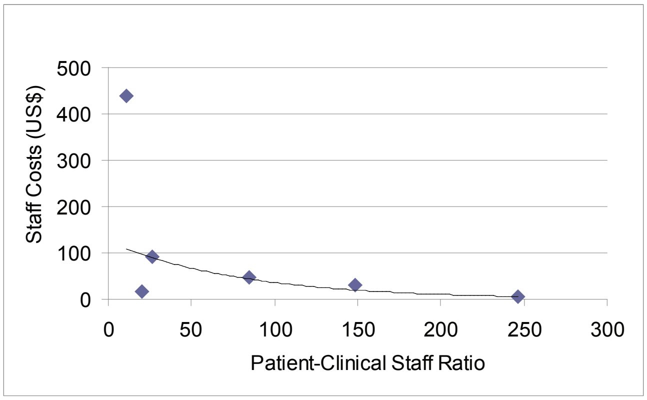


Figure 30: Relationship Between Cost Per Patient and Number of Patients

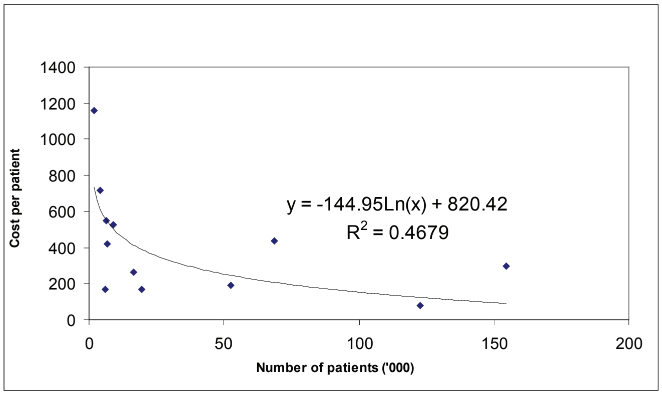
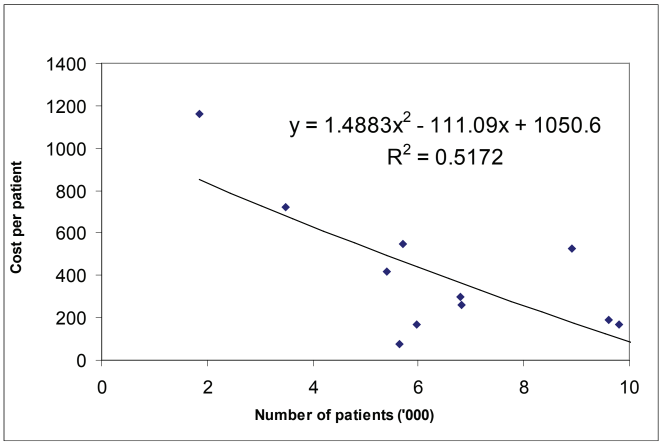


Figure 31: Relationship between Cost per Patient and Number of HIV Patients



9 Discussion of Longitudinal Quantitative Study

9.1—Facility Characteristics, Participant and Interview Numbers

Over 100 patients at each of six PEPFAR-funded facilities, 696 participants in total, were recruited to participate in a longitudinal study to examine how patient health outcomes changed under care. Patients completed questionnaires at monthly intervals, and 85.1% of participants completed all four timepoints.

Phase 1 data on staff resources and self-reported care provision clearly indicated that all six facilities were strongest in clinical care while offering very limited social and spiritual care (**1**). As an example, each facility employed up to 294 nurses but none had more than two social workers. Only three facilities had community health workers, two employed counsellors, and the survey registered only two spiritual leaders. Self-reported care also indicated that social, psychological and spiritual care elements were often not available, whereas the majority of clinical and symptom management care components were reported at all facilities. An exception was severe pain control, where opioids were rarely reported.

9.2—Participant Characteristics

9.2.1—Demography

Two-thirds of patients recruited to the study were female, and they tended to be younger than the male participants. This gender balance and age difference is similar to the findings of other studies of HIV prevalence in sub-Saharan Africa and Kenya (**34–36**). The ratio of HIV positive women to men in Kenya is approximately 1.8:1 (**37**) and among young adults aged under 25 the difference is much higher (**34**). One suggested reason for this gender discrepancy in prevalence is the frequency of relationships between older men and younger women (**38**).

There was no maximum age limit for inclusion and participants were aged up to 69. The most commonly used indicator of HIV in countries with a generalized epidemic is the prevalence in the 15–49 age group, termed "adult" (**39**). Older people form a minority of people with HIV but their health problems are likely to be more severe; in this study, older age was associated with lowered physical health at recruitment.

Almost all participants had attended primary school, and 43% had progressed to further education (high school or beyond). This level of education is better than average for Kenyan adults, particularly considering the 2:1 ratio of women to men (**36**).

9.2.2—HIV Diagnosis and Reason for Attending

The most common reason for attending at the facility was a new HIV diagnosis, and the median time from diagnosis to recruitment was 36 days. This may not be reflective of everyone cared for at the facility since the inclusion criteria stipulated that existing patients who did not have a new problem should not be approached for recruitment. Nonetheless, the implication is that services have to manage a constant intake of new people and a need for expanding services. One quarter of patients recruited were attending the facility to obtain medication or a laboratory test result, which suggests that the inclusion criteria may not have been rigorously applied.

9.2.3—Relative Wealth

Study participants were wealthier than the urban DHS sample population on indicators such as housing quality and water supply, although given that the DHS data were six years old the difference is likely to be slight (**36**).

The wealth quintiles were calculated using a published method (**14**) and aimed to give a better representation of wealth using multiple measures appropriate to the developing country setting than a single measure of wealth could achieve. People in the poorest quintile lived in a thatch or mud and pole house with an earth floor, and burned firewood for fuel. The wealthiest 20% lived in homes with cement floors where someone owned a radio, mobile phone and television.

Surprisingly, the probability of using a shared or public latrine was similar across all five quintiles, and was not associated with a general improvement in conditions as were housing material and ownership of goods. This suggests either that sanitation is not a priority or that something other than cost inhibits improvement. Having access only to a public or shared latrine, which was the situation for 42% of participants, is categorised as inadequate sanitation by the WHO (**40**) and is a major cause of ill health (**41**). Similarly, a third of participants relied on unsafe water sources with a risk of water-borne infections, which cause a high burden of morbidity and mortality in people with HIV (**42**).

9.2.4—Illness Severity

There were several problems in collecting indicators of disease severity. Disease severity was measured in three ways and for two of the measures it was not possible to use the results in further analysis. The ECOG did not discern between patients—69.3% of patients were fully active according to the ECOG at T0. WHO staging was found to be used commonly in some facilities and rarely in others. The remaining measure, patient-reported CD4 count at T1 was poorly completed and only through patient record review was the measure able to be completed satisfactorily (68 patients did not have a count at T1).

Patients were generally physically able and had a mean CD4 count of over 300 at baseline. It is important to remember that the study only recruited outpatients, the great majority of whom attended the facility without an accompanying carer. They are likely to have better physical functioning than the entire population of people with HIV (some of whom are probably unable to attend for health care) and they do not include those who arrived for care and were admitted.

Just over a third (35%) of participants had a CD4 below 200, and 37.1% had a CD4 over 350. A CD4 count over 350 cells/ml, before initiation of ART, is sometimes associated with the label 'asymptomatic', a confusion of the epidemiological disease surveillance concept of undiagnosable infection with the clinical concept of no symptoms. The information on care received and on health outcomes clearly show that even participants with a relatively high CD4 count suffered from symptoms.

CD4 count increased by 52 cells/ml over time for those with 2 counts, but these individuals may not have been representative of the entire sample as people with closely repeated CD4 tests may have been more closely monitored because they were sicker.

9.3—Care Participants Received

9.3.1—All Care Components

Participants received a mean of 11.9 components per month, showing little change over time. Altogether over three months the mean and median number of care components received per person was 20, with a maximum of 44 of a possible 52. The receipt of on average 20 care components in three months shows a high burden of care, including change in care regimes over time, and a complex set of multidimensional needs—no single care theme had as many as 20 items.

The items received by over 75% of participants were all for prevention of infections or of HIV transmission, except for ART and non-opioids. It is entirely appropriate that preventive care components should be delivered to the majority of individuals and that this should not be necessary for most curative care. Over time, prevention components such as multivitamins and CTX increased in prevalence, while pre-and post-test counselling declined and most symptom care became less common, presumably as symptoms and infections were controlled. The care component with the fastest implementation was CTX which increased rapidly in provision between T0 and T1, probably because it is proven effective, easy to deliver and supported by policy (**24**).

A third of participants received malaria treatment in the month preceding T0. Frequently, anyone with fever-like symptoms is treated for malaria until tests confirm otherwise, so the treatment does not indicate that a third of the group actually suffered from malaria during the month. A study in Kenya found that the majority of adults experiencing acute symptoms first purchased drugs over the counter (without a prescription), and then visited a health centre (**43**). It is possible that in some cases the symptoms which encouraged people to seek healthcare were first treated as malaria and later led to an HIV test. This theory is further supported by the steep decline in the proportion of patients receiving malaria treatment from T0 to T1.

Counselling/advice, nutrition, prevention and CTX were the care themes with highest provision. The nutrition care theme was high because of the single care component of nutritional counselling, which could have been categorised as counselling or as a prevention component.

9.3.2—Care Received Away from the Facility

Social and spiritual care components were most likely to be received from some other location than the study facility, in accordance with the Phase 1 results which found that these were the areas of care least commonly offered. These areas are often not seen as health issues and rather as the responsibility of others, although it is known that poverty is closely associated with negative health outcomes, and that spiritual and existential issues are common in severe disease (**44, 45**).

Clinical care components such as non-opioid analgesics which were available from facilities were also quite often received elsewhere. Phase 1 qualitative interviews showed that some patients combined HIV care from a distant ART provider with day to day healthcare from a more accessible health centre. Another possibility is that participants were buying their own medication on advice from the facility.

9.3.3—PEPFAR Care and Support Categories

Clinical and prevention care receipt were very high, as shown above by the receipt of individual components. Social care had a 60% prevalence but, as discussed above, much of this was provided from other sources, as with spiritual care. The lowest level of provision was for psychological care although the APCA African POS showed psychological problems were burdensome; for example 35% of participants had been unable to talk about how they felt in the three days prior to T0.

9.3.4—Care for the Newly Diagnosed

It is appropriate that receipt of post-test counselling should decline over time, although initial prevalence should have been higher than 83%. The care received suggests a programme of CTX, ART assessment, nutritional advice and multivitamins being implemented. There was a short delay between facility registration and ART initiation. Anecdotal evidence from facility staff indicated that the usual policy was to put the patient onto CTX for three weeks, partly as a test of adherence, before beginning ART. The fact that the delay was relatively short indicates that facilities were able to supply ART in good time, with sufficient stocks and a reliable supply chain. Twenty-nine percent of participants had received ART before recruitment to the study. Some of these could have been pregnant women taking a short course for PMTCT.

Symptom treatment was not greatly different in the newly diagnosed group from the entire sample, suggesting a similar burden of infections. Treatment for anxiety and depression were very low although HIV diagnosis is thought to be a time of great distress (**46**). The only commonly delivered components of psychological care were post-test counselling and adherence counselling, both of which are often a means of information transmission rather than a time to express feelings.

9.3.5—Preventive Care Package

Less than a quarter of participants in either group received all five elements during the study, but each component apart from an ITN was received by more than half. This pattern suggests that the elements were delivered separately rather than as a unit. It seems appropriate that the PCP elements should be provided to everyone with HIV who would benefit from them rather than all elements being delivered to all patients regardless of need.

9.4—Care Themes

9.4.1—Spiritual

Almost half of participants prayed with staff, usually, as with all spiritual care, at somewhere other than the research facility. Over two thirds met with a religious leader and the proportion remained steady over time. Given that participants obtained spiritual care for themselves at another location, increasing their time commitments and transport costs, it is clear that spiritual care was important to people in this setting.

Contact with traditional healers declined steeply after T0. Anthropological studies have shown that people combine different paradigms of health care pragmatically, incorporating theoretically irreconcilable concepts of health into a health-seeking strategy according to their perceived success(47). In this case, traditional healing and medicine appear to have been applied as sequential alternatives rather than complementary care. However, relations between traditional healing and medicine are poor in Kenya, and social desirability bias may have prevented participants telling healthcare workers that they continued to visit traditional healers.

9.4.2—Counselling and Advice

Many different forms of counselling were provided to large numbers of patients, but there is also evidence that these services may not be adequate. Psychiatric therapy was very rarely provided and was not sustained; at T3 only 0.2% of participants received it. Sixty percent of participants were in an HIV support group, and qualitative interviews at Phase 1 showed these were very highly valued. Support groups are a key element of care, yet 40% of participants did not benefit from them.

The care theme was named "counselling and advice" because many counselling care components are more focused on the delivery of information, such as nutritional counselling, which is an educational intervention to improve knowledge of food groups and vitamins. While beneficial, this kind of counselling may not address psychological issues such as anxiety, loneliness or lack of peace, which the study outcomes showed to be a burden for participants.

9.4.3—Nursing

A high proportion of participants received wound care and the proportion increased over time. Wounds could have been caused by skin breakdown related to infections, bedsores, or other conditions, as well as injuries.

9.4.4—Pain Management

Every month, each participant had a 40% probability of taking non-opioid analgesics such as paracetamol. Such common use of analgesics indicates a high prevalence of pain, but non-opioids were not followed up with other analgesics. HIV is associated with high pain prevalence and burden, particularly in the later stages (**48**), and prevalence remains high for patients on ART (**49**).

Barriers to opioid use include legal restrictions and a reluctance of health care staff to prescribe, based on fears of addiction and lethality. These opioid myths can be overcome through education and training, as advocacy can lead to policy change (**50**).

9.4.5—Symptom Management

Every month over a quarter of participants received treatment for a symptom which was not listed as a care component, indicating that the CSRI did not adequately capture all important care delivery for this population. The CSRI was composed using existing knowledge of common infections and symptoms in HIV. The specific symptom burden in Kenya was not known and it appears that there are differences between the expected symptom needs and those found in Kenya.

In the literature, receipt of ART is associated with more, not fewer, symptoms, and with greater physical and global distress (**49**). ART causes symptoms through toxicity and liver damage while reducing the risk of opportunistic infections. One possible consequence of beginning ART is immune reconstitution inflammation syndrome (IRIS), symptoms such as fever arising from the restored immune system's response to a pre-existing infection (**51**), also causing the "unmasking" of TB.

Half the study population received malaria treatment at some point during the study, although, as explained above, it is not likely that all of them had malaria infection as malaria is often diagnosed presumptively. People with HIV are at greater risk of malaria and show more severe symptoms if they get it(52), but CTX dramatically reduces the risk of malaria.

9.4.6—Nutrition

One of the main reasons for low adherence to ART is lack of food (**53**) making the drugs very difficult to take. Although multivitamins were far more commonly received than food, in a population where 9.5% required therapeutic feeding in a three month period, the prevalence of hunger and inadequate nutrition is likely to be higher than is reflected by the level of food provision in the study. Improved water source was relevant for care because water-borne infections are a common cause of morbidity and mortality for people with HIV (**42**), so the common receipt of water treatment at home was a positive finding.

9.4.7—Social

Over three months, 12% of participants obtained legal advice and 20% received home help, indicating that these services are needed in the population. Even though physical function was generally high, participants required help in social care. Memory work took place at all facilities, most commonly at Facilities 157 and 159. The original project was a scrapbook or box in which people with terminal illness would make a record to leave to their children. The term now encompasses a range of methods, often used with children but also with adults, to improve communication within families (**54**).

9.4.8—Prevention

Prevention with positives (PWP) was one of the most common components in the study. Also known as secondary prevention, it is a package of interventions aimed at preventing further transmission of HIV and protecting the HIV positive individual from coinfection with further strains of HIV (**33**). Isoniazid for TB prophylaxis was rarely used and anecdotal evidence from facility staff suggested it was not popular because it was too expensive to maintain for the large numbers of people potentially at risk of TB. Infection control training decreased over time, suggesting it was a single delivery of education rather than a sustained programme.

9.4.9—ART

Throughout the three months of follow-up the proportion of participants who received ART steadily increased. There was rapid initiation into therapy; the median time from diagnosis to study recruitment was just over a month but 75% of participants had received at least one dose of ART by T3. This speed suggests that people were diagnosed late in the disease trajectory and would have benefited from earlier diagnosis before the need for ART. Participants did not all show complete adherence to ART, which could have several possible explanations. Some participants might have received a brief course of ART for prevention of mother to child transmission. In other cases, the recording may be at fault, for example if participants received two months' supply of ART and then did not record receiving it the following month. During the civil unrest and violence in early 2008, several facilities operated this policy to reduce the number of journeys patients needed to make. Support and monitoring services were usually provided but there was still a gap between ART and support, which is worrying given the burden of symptoms experienced by people on ART.

9.4.10—CTX

As well as its use in daily prophylaxis, CTX is also prescribed as a course of antibiotics to treat infection. Participants who reported taking CTX the previous day but not having it for prophylaxis were probably in this group. Daily CTX has been shown to reduce morbidity and mortality in people with HIV in Uganda (**55**).

9.4.11—TB

The proportion of participants who received TB treatment was 12.4% at T0 and changed very little over time, although the proportion to have ever received it was higher (19.5%), showing that these were not all the same group of people receiving a course of TB treatment over the whole period of the study. TB is a very common cause of death in HIV (**56**) and HIV is the biggest risk factor for activating latent TB (**57**) which is the reason why many participants were referred to the HIV centre from chest clinics.

9.5—Health at the Beginning of the Study

The APCA African POS and MOS-HIV used to collect longitudinal data have both been validated for use with HIV positive patients in sub-Saharan Africa (**5, 58**) and have been used longitudinally (**5, 59**), demonstrating their suitability for use in this study. The MOS-HIV and APCA African POS were well completed at all time points. Missing responses for all MOS items was less than 0.5% at all timepoints. Missing responses for all APCA African POS items ranged from 0.43% of participants at T0 to 2.70% of responses at T3.

The MOS-HIV physical and mental health summary scores of the population at baseline were comparable to those found in other studies of HIV disease in the sub-Saharan African setting (**8, 11**). There is a strange pattern to the distribution of scores. They are designed to be Normally distributed around a mean of 50 with a standard deviation of ten (**12**) but in this population the upper part of the curve drops away very steeply, as though cut off. The reason for this is not known.

The APCA African POS measures multidimensional problems: pain and symptoms (physical); worry and being able to share feelings (psychological); finding life worthwhile and being at peace (spiritual); and having enough help and advice fro the family to cope (social). Each question is representative of clinical need and the items were not designed to be united into domains.

9.5.1—Problems Facing Caregivers

The findings relating to carers can only be interpreted with caution as only a small proportion of participants were accompanied by their carer to the health facility. The proportion of participants attending the facility with a carer fell from 12% at T0 to 3.4% at T3. Of those who came and completed the APCA African POS questions, carers reported receiving a lot of information, although not as much as wanted, and were not very worried but not completely confident. The low proportion of patients attending with a carer may reflect the relatively high physical wellbeing of patients, but at the same time, 35% of participants at T0 reported they had been unable to share how they felt in the previous three days. The feeling of isolation and loneliness reported by a third of participants was emphasised by the majority coming for care alone.

9.6—How Participants Differ by Facility

9.6.1—Patient Characteristics at Different Facilities

There was no marked difference between age, gender and education distributions of study participants at the different facilities, suggesting that the demographic characteristics of the sample are representative of the wider population and were not skewed by abnormal results from any facility.

9.6.2—Illness Severity at Different Facilities

Mean CD4 count varied from 266 at facility 158 to 354 at facility 159. CD4 counts in this range are well below the normal level, indicating immunosuppression and a risk of opportunistic infections. CD4 count can vary extensively within and between individuals, meaning that although CD4 count is the best way to monitor a person's disease trajectory over time it is of limited use to compare the health of large groups. Also, in interpreting the mean CD4 count change at different facilities it must be remembered that the time period over which the change was examined was different for every participant with a possible range of periods from one month to 21 months.

9.6.3—Care Received at Different Facilities

The mean number of care components received onsite varied from 7.1 at facility 157 to 13.5 at facility 155. In general the proportion of individuals receiving symptom management care components did not differ greatly over time, although the receipt of some components which were less directly relevant to clinical need did vary. For example, 91% of participants at facility 155 received condoms, but only 40% at facility 160. The proportion of participants who received malaria treatment varied from 19% at facility 156 to a very high 70% at facility 155.

Most care themes contained one component which was the most commonly received at every facility and which largely governed the prevalence of that care theme; nutritional counselling for nutrition, pain assessment for pain, visit from a faith leader for spiritual care, etc. The care theme with the widest variation in provision at T1-T3 by facility was nursing, which ranged from 5.2% at facility 157 to 79.9% at facility 158. Facility 157 employed almost ten times as many nurses as facility 158 and it is not clear why this difference in care receipt should have occurred. The result may be due to participants having different interpretations of the term 'nursing care'.

9.6.4—Health at Baseline at Different Facilities

At baseline Facility 160 had the lowest mean scores for both physical and mental health, and Facility 156 had the highest. The difference in mean scores between facilities was statistically significant for both outcomes. Facility 156 took the largest proportion of participants whose stated reason for attending at T0 was to collect medication or a lab test result. It is possible that this facility did not implement the inclusion criteria properly and recruited patients who did not have a new presenting problem. Thus their health outcomes would be higher at baseline. Meanwhile, Facility 160 recorded that the largest fraction of its participants had been referred because of an HIV test result or were newly diagnosed.

9.7—Participant Characteristics and Health

9.7.1—Gender, Age, Education

Men and women had the same health outcomes, which is in some ways surprising. Women are more vulnerable to HIV infection and might be expected to show fewer symptoms because antenatal testing is routine and both men and women are equally likely to attend for VCT (**60**). Thus, women should have a higher probability of finding out their diagnosis before sickness develops and they seek healthcare because of it, yet outcomes were the same for both genders.

Older age was associated with worsened physical health but had no association with mental health. As well as the general expectation of decreasing physical health with age, there is some evidence that HIV progresses more rapidly in older people (**61**).

9.7.2—Relative Wealth

The positive association between socioeconomic status and health outcomes is well known. In this study, participants with great relative wealth (defined using poverty quintiles after the DHS method) reported significantly higher physical and mental health at baseline. It is important to remember that though this study showed the poorest people to have worse health, there is evidence that greater proportionate wealth is a risk factor for HIV infection (**62**). The wealth quintiles used in this study were generated from the dataset and can only be used to describe individuals relative to each other, not in absolute terms, thus it is not possible to link wealth to probability of recruitment, as it is with gender.

9.7.3—Illness Severity

According to CD4 group (under 50, 50–200, 201–350 and over 350), higher physical health score was significantly associated with higher CD4 count, but the association with mental health was only weakly significant and there was no association at all between APCA African POS total score and CD4 group. The results of linear regression in Appendix I show that the apparent association between mental health and CD4 was completely confounded by physical health which was related to both. Conversely, adjusting for mental health did not eliminate the association between physical health and CD4, proving that the former result was not caused simply by overadjusting. These results show that people with HIV have similar multidimensional problems and levels of mental health at all stages of disease, after accounting for the decline in physical health.

Analysis of carer presence and outcomes in Appendix I showed that apparently carers were present to provide practical support for patients with physical needs, not psychological support for patients with mental needs. This is interesting in the light of evidence from the APCA African POS that a substantial proportion of patient need was from the psychological dimension.

9.7.4—Individual Care Components

TB is a major killer of people with HIV in sub-Saharan Africa and the combination of HIV and TB is known as a dual epidemic. In the study, people taking TB treatment before recruitment had lower physical health than those who had not. It is not known whether this difference is caused by the symptoms of TB (e.g., coughing, night sweats, weight loss, fatigue), or whether TB is a proxy for more advanced HIV disease, as results showed TB treatment was associated with lower CD4 count. However, those receiving TB treatment also had lower mental health, which is not closely associated with CD4 count, suggesting some other connection.

9.7.5—Association of Outcomes with Loss to Follow-Up

Unlike traditional techniques for analysing longitudinal data, multilevel modelling can make efficient use of data with missing timepoints. The limitation is that at least two points must be present in order to calculate change. In this study participants with fewer than four data points showed worse physical and mental health than participants who completed all four. This is unsurprising, and many studies of health over time suffer from the problem that those who are most sick are least likely to have the time and ability to complete questionnaires. Traditional techniques would have removed these non-responders from analysis and created a bias towards better health. On the other hand, there were no differences in health outcomes between those who completed only the first interview and those who completed more than one. Therefore, excluding the 60 participants who completed only T0 for longitudinal analysis did not bias the population.

9.8—Changes in Health Over Time

The use of the MOS-HIV in longitudinal studies has been demonstrated in Uganda (**11**) and internationally (**59, 63, 64**). Some studies have been analysed using traditional methods and others using longitudinal analysis similar to that presented here. Unusually, this study was multicentred and the analysis included an adjustment for clustering by facility.

The results show that study participants, who were newly diagnosed with HIV or had developed a new problem and were attending PEPFAR-funded HIV care and treatment clinics, showed statistically and clinically significant improvements in their self-reported physical and mental health during the first three months of care. It is not possible to determine within this PHE whether the improvement was caused by the care they received or whether it would have happened in any case. However, improvement in health outcomes over time is contrary to the progressive trend of HIV disease.

In the APCA African POS, any change in score is considered clinically significant, but a reduction in the proportion of people with severe or moderate problems is of more clinical interest than an overall shift from mild problems to none. The results showed that prevalence of severe problems did decline swiftly from T0 to T1 and then often plateaued, as the sustained improvement in mean scores was made up by improvements at the milder end of the spectrum. Improvement in median score was largest for the items with the lowest baseline score. This is to be expected, as the ceiling effect of the tool limited the potential for improvement of items such as symptom burden which did not begin at a particularly low level.

9.8.1—Changes in Health Over Time for Those in Most Need

Some people suffer from intractable pain or complex symptoms which are not responsive to treatment and a general increase in health outcomes may mask the small group who do not improve. In this study population, there was no evidence of such an effect, although it is important to remember that only outpatients were included and that people who left the study after T1 had lower baseline health scores than those who remained. An additional note is the phenomenon of convergence to the mean, which would give those with low scores at baseline an increased probability of showing improvement compared to the population as a whole. The association between mental health score at baseline and over time was weaker than for physical health, suggesting that outcome is more difficult to predict for those with low mental health scores.

9.8.2—Change in Health Over Time at Different Facilities

Facility 156 showed a very different mean physical health score change over time compared to the other five. Physical health score gain was not maintained after T1, with the result that Facility 156, which had the highest mean physical health at T0, had the lowest at T3. The same pattern was observed for mental health but to a lesser extent. This finding is particularly surprising given that better baseline health score was predictive of further improvement.

At Facility 156 over 60% of participants recorded their reason for attending the facility at T0 to be receiving medication or the results of a lab test. As described earlier, this reason for attending was not one of the inclusion criteria. It seems probable that participants attending for this reason were less likely to have a new problem which required particular care, which may explain why participants at Facility 156 reported better physical health at the beginning but showed less improvement in outcomes compared to other facilities.

9.9—Changes in Health Over Time in Detail

9.9.1—Participant Characteristics

Improvements in self-reported well-being were significant even after accounting for patients' background characteristics: baseline well-being, individual wealth, education, and CD4 count. The association of other potential confounders had been found to be insignificant in univariate analysis. The improvement was also not an artifact of increased loss to follow-up in those with lower health. Cross-sectional analysis showed that higher relative wealth was associated with better physical and mental health at baseline. Longitudinal analysis demonstrated that participants with greater relative wealth also showed significantly greater improvement in self-reported physical and mental health over time, even after accounting for the fact that a higher baseline score was itself a predictor of greater improvement.

Possible mechanisms for this effect include; better-off people may seek healthcare earlier in the trajectory of worsening symptoms, may be better able to afford medication, transport costs and food, may be better nourished and more likely to have health-promoting infrastructure such as a clean water source, reducing the risk of water-borne infections. Even when ART is free, there are considerable cost barriers to HIV care such as the cost of lost work time, food and transport to the care facility (**65**).

9.9.2—ART and TB Treatment

In the study, after accounting for CD4 count, knowing whether a patient was receiving ART did not help to predict physical health or the rate at which their physical health would improve. The finding was not lost in overadjustment for CD4 count, since most participants only had one CD4 count, dating from before initiation of therapy. In interpreting these results it is important to remember that the study was observational and was not designed to measure the effectiveness of ART. The participants receiving ART would have differed systematically from non-recipients, with more advanced HIV disease and in many cases a longer history of care. The results show that ART users and non-users both benefited from multidimensional care and support over a three-month period.

Change in mental health was definitely not associated with ART, TB treatment or CD4 count. The implication appears to be that mental health is complex, individual and does not rely on physical state. In the study, the majority of improvement in mental health occurred between T0 and T1.

9.9.3—Care Availability

Health outcomes were not statistically associated with the prevalence of any care themes by facility over time. This could be a true reflection of events, but there were also several factors which increased the probability of a Type II error.

The six facilities were quite similar to each other in the care they delivered. Clinical and preventive care were available to many participants, social and psychological care to fewer. Four of the six facilities were HIV clinics in public hospitals administered by the Ministry of Health. Possibly as a consequence, the variance in participant health outcome between facilities was about one twentieth the size of the variance between individuals. The models relied on variance between facilities in order to determine the association with facility-level care availability, but too little variance occurred at this level to enable useful predictions to be made (results in Appendix I). If the sample had included facilities which were very different from each other in resources and care delivery, there would have been more variance.

The analysis acknowledged that repeated measures from individuals, and measures of individuals from facilities should not be treated independently (**66**). In other words, the observations from participants from one facility were likely to be more similar than patients from different facilities, and repeated measures from one individual were likely to be more similar than measures from different individuals were accounted for by using multi-level modelling. However, the study design and analysis could not account for or detect differences in modes or frequency of care provision, staff attitude or the capability of the care providers that are likely to influence patient outcomes.

9.10—Strengths

The facilities involved in the study were selected at random (**1**), thus reducing response bias (facilities confident in the outcomes of their care being more likely to respond to an invitation to participate than others). No facilities refused to participate. The longitudinal nature of the study design enabled the change in patient outcomes to be monitored over time, thus overcoming the limitation of a before and after study design (**30**).

Eligible patients were those who were new to the facility or who were presenting with a new problem. These criteria were applied to maximise the potential of detecting any influences of care on patient outcomes in the short follow up time available for this study. Given the chronic illnesses associated with HIV infection, it seemed there was a high possibility of recruiting a great proportion of patients to the study who had had the same illness for a long time, were stable on ART, and so were unlikely to change their health outcomes in three months. There was a high response rate (95.6%) and low level of patients leaving the study over the three months (104 patients missed one or more interviews).

Subsequent patients were asked to participate if they met the inclusion criteria, until the desired number had been recruited. This minimised the possibility of healthcare workers recruiting patients who they thought likely to have favourable outcomes. There were no facilities which struggled to recruit sufficient numbers. The concise and multi-dimensional nature of the APCA African POS means this study provides valuable data on the multi-dimensional wellbeing of HIV positive patients accessing outpatient clinics in sub-Saharan Africa, and this has potential for future clinical and research uses.

9.11—Limitations

The random selection in Phase 1 was originally based on patient numbers only, and so the facilities involved in Phase 2 do not necessarily represent the diversity of geography, relative wealth of the facility catchment areas, facility funders, service provision or other aspects that may affect service provision, quality of care, facility attendance or response to treatment. Some of these factors (e.g., relative wealth of the patients, care received at the facility) were measured for individuals and so were accounted for in the analysis. Additionally, the Phase 2 facilities were selected purposively by a prreviously decided method (size).

The APCA African POS summary score has not previously been calculated and the tool was not designed to be so summarised, although the separate items have been assessed in a validation study of reliability and sensitivity (**13**).

A large number of statistical tests increases the probability of falsely identifying connections. In this study, five demographic covariates plus eight care themes were each modelled separately with two outcome variables, making 26 models. Stepwise downward regression was later used to rule out any covariates which might have been included due to Type II error.

The CSRI recorded the receipt of 52 items of care. It is possible that the tool excluded some items of care, the receipt of which could potentially have been influencing health outcomes. The act of undertaking the study may have influenced the care given, and thus affecting participant outcomes in a way that normal care would not have shown. Furthermore, even the process of asking a series of questions about how patients feel could be viewed as a form of care in itself, or it could have revealed health problems to the health provider that a normal consultation would not have detected.

The fact that almost a quarter of participants recorded their reason for coming to the facility was to obtain medication or a test result does not fit with the inclusion criteria. Possibly these participants attended to collect medication and were then discovered to have a new problem; alternatively, they may not have had a diagnosed new problem and might have been recruited anyway. The inclusion criteria were set to avoid the situation of having long-term patients with managed problems showing no change in health outcomes over three months. In the study, mean outcomes did improve over three months, and this effect could only have been weakened by the inclusion of participants who did not have new problems.

10 Discussion of Qualitative Interviews

The qualitative interviews with patients, their carers, and staff revealed greater understanding about care delivery and receipt in PEPFAR-funded HIV care and treatment facilities in Kenya. Patients and carers usually reported positive experiences of care and appreciated the receipt of symptom management, ART and counselling/information services. Patients gave each other social support and were encouraged to advocate for HIV care, and both carers and staff were likely to be HIV positive, indicating the multiple roles enacted in the health facility community. Challenges to care were long waiting times, unaffordable costs (even when treatment was free), and unreliable drug supplies. Staff reported overburden with large numbers of patients and attempts to meet costs themselves.

Anxiety was found to be a common problem amongst those living with HIV infection as well as their families. The prevalence and intensity of anxiety, it appears in the data, is compounded by poverty and stigma. It is understandable that facilities cannot always meet social needs, but these should be discussed (which they are often not) where possible to identify appropriate providers. Further, a number of patients reported that they are not asked about their emotional wellbeing during clinical encounters.

Drug availability is a systemic issue that clearly needs attention. Although ART availability did not seem to be a major problem, the provision of simple medications such as analgesics and antibiotics were problematic and led to suboptimal care as patients could not afford to purchase elsewhere. These problems were commonly reported across staff and patient/family data. Palliative care drugs were also identified as a need, with the (erroneous) expectation in one case that they would be expensive. For facilities, difficulty procuring drugs seemed to be less a problem of cost and more about unstable supply, inadequate stock and legal restrictions. Staff reported (anecdotally) that the amount of any drug that a public health facility can order per month is tightly controlled. Staff at two facilities wanted to prescribe morphine, which is difficult to access and prescribe in Kenya.

The main problem carers experienced was lack of money to pay for food, transport and school fees. Patients repeated the same three priorities for payment. For at least some patients and carers, poverty was intense. They could not afford to pay the small costs of home-based care such as disposable gloves and soap, which staff ended up providing from their own pocket. Patients in most need were refunded travel costs or given extra but there seemed to be no clear guidelines as to who was entitled, leaving the system based on charity. Staff wanted to give more than they could, and felt that they were not doing enough. Being forced to deliver inadequate care causes moral distress to staff as well as physical distress to patients (**67**). Thus the discrepancy between needs and resources, without the protection of a written policy and exacerbated by overwhelming patient numbers, puts staff at risk of burnout.

The data give useful insight into the value of community support and the role of community health workers. It should be noted that family carers are (unpaid) resources who enable patients to be cared for at home. They often reported not being asked about their own needs and experiences, and they should be given at least recognition that they may have needs to be expressed.

Patients were highly appreciative of the care and support they received, and particularly appreciated being treated courteously by staff, as was also stressed in Phase 1. The reputation of a clinic appeared to be major factor in the choice of care provider, a good reputation being highly attractive. However, while staff were caring and attentive, a few patients did note that staff attitude was occasionally not as they would hope. The expectation of confidentiality, proximity, and holistic and reliable provision of treatment and care appear to be maintained.

The staff request for paediatric counselling training which had been identified in Phase 1 was repeated.

HIV-positive children entering adolescence constitute a new, emerging group of patients who would not have lived so long before the rollout of ART, and they require specific counselling to understand and manage their condition (**68**).

Staff identified a need for more space to be able to offer counselling and confidential medical care as needed, to meet patient stated needs of guaranteed confidentiality. Patients also objected to the long waiting times, a result of overburdened staff. Time spent in the waiting bay, talking to other patients, gaining support, sometimes singing and praying together, was valuable for patients, but at the same time they did not wish to spend all day there and they felt at risk of picking up infections.

The interlinked roles of carers who were also patients, staff who were HIV positive, and patients who were community advocates illustrated the comments of some Phase 1 interviewees about the facility staff and patients as a family. Research in several countries has found that people with HIV respond best to counselling from others with HIV, and greater involvement of people with HIV/AIDS (GIPA) is a principle of HIV care and prevention. One staff member revealed their vision of HIV care:

> "The future of this fight against HIV/AIDS is when all these patients will be able to form support groups and we as the HCWs be in a position to support them. These groups should then be empowered to support each other, remind each other about clinic days, consult each other when they have problems and assist each other spiritually."

The same theme was echoed in patients' encouragement to remain active, attend weddings and celebrations, and be part of community life. By advising patients to discipline their minds not to think of themselves as isolated, staff appeared to be warding off self-imposed stigma. Having HIV seems to damage self-efficacy, and in Phase 1 the restoration of dignity and self-respect was as much an aim of microfinance programmes as was increased income. At the same time, the risk of the 'facility as family' model is that an entirely separate community of people with HIV is created, centred on their disease. This is an alternative way of life, rather than normalisation.

Staff put considerable effort into maintaining ART adherence. Techniques included referring patients to their nearest facility, deterrence of those who lived too far away, reimbursement of transport costs, asking patients to sign a pledge to attend, regular adherence counselling, and employing 'tracers' to hunt down and bring in defaulters.

The standard form for patient assessment included weight and height, TB screening, presence of OIs, ART adherence and side effects, use of other drugs and CD4 count, but no assessment of pain, symptom experience, emotional situation or psychosocial need.

10.1—Strengths and Limitations

There are several strengths and limitations to the qualitative data. Firstly, although the views of patients, carers and staff were captured in this study, which gave views from the key individuals involved in patient care, respondents were identified by the participating facilities, which may have introduced bias. Second, as the interviews were conducted in a range of languages they had to be analysed in the common language of English. Although this raised issues of translation and interpretation it allowed respondents to express themselves freely without the constraints of translating their thoughts to a less familiar language. Furthermore, the protocol ensured that interpretation of the local meaning was established. The interviews were coded twice by independent researchers in the UK and Kenya. This process gave rigour to the coding process by reducing individual bias in interpretation. In addition, the cross-country coding allowed the possibility of culturally different interpretations to arise and be discussed.

11 Discussion of Costing Study

There was considerable variation in the facility cost of providing care and support, with the main cost drivers being salaries for clinical staff, ARVs and other drugs, and lab costs. There were economies of scale, with larger facilities having lower costs per patient per year.

Providing care and support for HIV positive patients constitutes a significant part of national HIV programmes in general, and care and support is a focus of PEPFAR with its commitment to reach 12 million people with care and support services. In considering scale up and expansion of care and support services it is helpful to know the costs of such services. With almost 40 million people testing positive for HIV and nearly three million people already on ART (**39**), the financial sustainability of maintaining and expanding care and support is a challenge for the public health community.

The cost of providing comprehensive HIV care and support may vary significantly across country settings and program delivery approaches. Calculating care and support costs in a range of settings will provide estimates of annual per-patient care costs that are representative of Emergency Plan-supported programs. Understanding the contextual factors that affect the cost of providing comprehensive HIV care and support is important in interpreting comparative costs analysis across country and program settings.

The overall purpose of the costing component of this study was to estimate the average costs of providing care and support to a patient over a one year period. This could then be used to calculate life time care for patients as a function of their life expectancy, or be used to estimate scale-up requirements of program expansion. However, such modeling was not part of the present study.

11.1—Strengths and Limitations

Care and support is the aggregate of many services, (psychological support, ART, pain management, etc.) The average cost of care for patients will therefore be the aggregate of the costs of providing these individual components. Although this study examined drug, staff, laboratory and facility running costs, the costs per patient for individual components of care could not be calculated. The cost of drugs other than ARVs was a particularly difficult area. A small selection of drugs relevant to HIV care were identified, but the proportion of total drug costs spent on these would depend partly on the extent of the range of drugs offered by the facility. For other components of care where the cost drivers were higher for staff time than for drugs, such as counseling services, it was not possible to allocate proportional staff time to the specific components of care sufficiently well.

The facilities received funding from the Ministry of Health and in some cases from other donors as well as PEPFAR funding which came through partner organisations. The amount of funding received from PEPFAR and the proportion of its budget that this represented is not known, thus costs at the facility, rather than direct costs to PEPFAR, are the aim of analysis.

Care and support is provided not only at facilities but also in many cases by communities, at the family or household level or by FBOs/NGOs all of which incur costs and contribute to the overall costs of care for a patient. Individual patients may also incur costs in terms of time off of work (lost income) or the opportunity costs of their time in productive work and for transportation. Due to funding limitations, this study only looked at facility-based costs. Other areas of cost which were not represented include those incurred by program managers at the donor level, administration of donor-funded programmes, and training of specialized care and support for HIV positive patients. Lastly, the study did not take account of cost savings associated with averted illnesses or reduced in-patient costs as a result of effective care and support.

12 Integration and Conclusions

This study has shown that patients who are newly diagnosed as HIV positive or have experienced a new health problem and who are attending PEPFAR-funded HIV care and support services show statistically and clinically significant improvements in physical and mental health over the course of three months under care. Such improvements were seen even in patients with the poorest physical and mental health.

Although it was not possible to determine which care components were associated with the greatest health improvements (because the sickest patients were more likely to receive more care components and not receiving care does not mean the care was not needed), a summary of the greatest patient needs and most common care components received, as well as the notable gaps in care, can indicate the care that might be most beneficial to patient health and wellbeing. The most common care components received related to prevention of infections and maintenance of patients' physical wellbeing (e.g., CTX, nutritional advice and pre and post test counselling), ART, and pain management (assessment of pain and non-opioid analgesics). The relatively low pain, symptom and worry burden in the study population compared to other problems, as indicated by the APCA African POS, suggests that the wide provision of these care components is beneficial to patients.

The APCA African POS revealed that at the start of the study patients' lowest scores related to being unable to share their feelings with others and feeling that they and their family were not getting enough help to plan for the future. Patients reported little improvement in these concerns over the course of the study even though counselling care components were commonly received. Patient and staff interviews revealed that such care comprised mainly information transmission rather than an opportunity to discuss concerns. Furthermore, social care components were received by a minority of study participants, possibly in part because of insufficient social workers and high patient loads for non-clinical staff. These findings suggest that these important problems of patients attending care and support services are not being adequately addressed. Facilities with higher proportions of non-clinical staff did not have the highest per patient costs, suggesting that staff cost is not the reason for not providing care in this area.

The costing component of the study revealed that the major cost drivers were not consistent across the six facilities and there were large variations in the cost per patient of providing care and support. These costs were not connected to the level of health improvement experienced by patients. There are lessons to be learned from the more efficient facilities, but this must not reduce quality of care.

The longitudinal quantitative study showed that the majority of participants received some form of counselling, but qualitative evidence revealed that counselling can consist merely of information transmission from counsellor to patient, without addressing emotional issues. Anxiety and worry were shown to be severe patient problems in both qualitative and quantitative studies, and the costing study showed that the patient load for non-clinical staff (such as counsellor and social workers) is frequently unmanageable. In the qualitative interviews, staff reported insufficient social workers, and patients and carers stated that high quality care would involve being visited in their homes by someone who knew their situation.

The interviews showed that patients sometimes had to buy the drugs which were prescribed to them at a pharmacy outside the facility. Thus the distinction between "care received at the facility" and "care received elsewhere" is not as clear-cut as it appeared to be in the quantitative longitudinal study.

Facility 159 had much higher costs than any other facility. The proportion of costs to area was not greatly different from other facilities, with staff making up the largest fraction of costs. Facility 159 recruited participants with the highest health outcomes at baseline and they showed the least improvement over time. Participants at this facility made less gain because they began from a higher point.

Ceiling effects (the upper limit of outcome measures), regression to the mean (the increased probability of central values through random chance) , and the behaviour of disease and health in populations all mean that people with better health will gain less from care. In HIV the result is that a facility which receives patients whose HIV disease is more advanced could appear to gain more in health scores by offering care and support to manage symptoms, infections, psychological problems etc. Meanwhile a facility which recruited people at an early stage would not be able to do as much to help them. This effect would be more pronounced in physical than mental health because physical health is more closely linked to disease progression. Facility 159 appears to have done less for its patients in terms of health gain while costing more than twice as much per patient, but this could be the result of its offering prompt care so that patients never experience the decline and recovery of health measured at other facilities.

The main reason why qualitative interview patients attended for care was because of symptom burden. The quantitative evidence showed that participants with lower relative wealth presented with worse health outcomes, suggesting that they bore with symptoms for longer before accepting the expense of travel to the facility. The most common symptoms in qualitative interviews were pain and lack of energy, which are both invisible and often underdiagnosed or not recognised as a real problem. The multidimensional scores indicated unacceptable levels of pain, and the MOS-HIV results showed that only 23% of participants said they always had enough energy to do the things they wanted to do.

Talking about death was seen as “brave” and as something of which only a few patients (or staff) would be capable. All the facilities were predominantly for outpatients and care of the dying was not a major part, although the nine deaths during the quantitative study equate to a mortality rate of 5% per year. Care included memory work with very practical help such as taking photographs of the patient for families to keep, and legal services including will-writing. These two components of care were rarely received in the quantitative study and the interviews helped to reveal their importance in the context.

Staff reported that patients would normally have a carer with them only if they were incapable or not adhering; this was supported by evidence from the quantitative study that patients with a carer had worse physical health. Patients’ lowest scores in the multidimensional questionnaire were for lack of someone to share their feelings with and of help and advice for their family. At the same time, in qualitative interviews the staff stressed the importance of patients supporting each other and patients expressed the benefit they gained from such support. Carers were themselves often HIV positive. More patients would benefit from the emotional, social and practical support of having a carer, which should not be seen as necessary only for the physically incapable

One carer made a very good point: “the patient cannot eat alone while the child is just watching.” It is not possible to provide adequate food for a single member of a family if the others do not have enough. The carer described sharing out an orange between all members of the family, each person receiving a tiny piece. Staff reported that some patients were unable to have even one meal a day, and that the most in need were old people looking after their HIV positive orphaned grandchildren. Over 90% of quantitative study participants were given nutritional counselling. If lack of knowledge was the problem causing malnutrition, it has been adequately addressed, but the qualitative interviews show that the main reported problem was poverty.

Carers worked hard to find fruit and green vegetables for the patients. Telling patients they should eat healthily without providing them with the means to do so imposed a financial and psychological burden on families, and it is not certain that this was outweighed by any gain in health. When patients did receive a food handout (17% of the longitudinal cohort) it was usually flour for porridge delivered to those who were severely underweight. At the same time, 9.5% of participants, all outpatients, received therapeutic feeding for severe malnutrition. All the signs indicate chronic, systemic hunger as the reason for malnutrition.

Patients found benefit from time in the waiting bay, gaining social and spiritual support from other patients. However, the quantitative study showed that a lack of someone to talk to and lack of help and advice were still major problems for patients, suggesting that the communal support is not adequate to meet everyone's needs. These services need to be developed further, either by empowering patients to do more for themselves or by direct delivery of care.

The costing study showed that it was cost-effective for a facility to have a large number of patients, but staff reported that the quality of care declined in these circumstances. As the quantitative study showed that a high proportion of patients were newly diagnosed, but loss of patients was very low, the problem of patient numbers is likely to increase. The high patient-staff ratios increase waiting times, which are an impediment to satisfactory care, and raise the pressure on staff. The lack of space is also likely to become even more of a problem, which again inhibits quality care by threatening confidentiality.

Small costs to a facility, such as a shortage of lab reagents or drug stocks, impact heavily on patients as they are sometimes unable to make up these costs themselves by transport to another facility or buying the drugs at a pharmacy. Since transport cost was the largest inhibitor to attendance, the poorest patients would be most likely not to return, as was reported by staff. In the quantitative study transport costs were generously reimbursed which might have shifted the priorities, so this hypothesis could not be tested.

12.1—Strengths and Limitations

The mixed-methods design was a strength of the evaluation, allowing triangulation between the different elements. The quantitative interviews illuminated what was meant by care and support, longitudinal quantitative study showed the number of people to receive it, and the costing study showed the various ways in which it could be delivered. Far more data were collected than can be explored here and the dataset will continue to reveal insights into the experience of people receiving HIV care in Kenya.

Use of two well-validated tools, a multidimensional outcome measure as well as the more traditional quality of life questionnaire, allowed more understanding of the issues causing most concern to patients. Qualitative interviews supported this evidence that psychological problems such as loneliness and anxiety were a cause of distress in the population. The longitudinal study design was appropriate to the study, allowing observation of how quickly problems were managed over time and whether care was sporadic or maintained.

The tightly controlled methods of data collection, management and validation ensured a high quality of data in the longitudinal quantitative study. Completion was very high at all facilities and over time. Qualitative interviews were conducted by external researchers but they often took place on facility property and participants may have felt constrained in speaking negatively about the facility, even though they were assured that the recording would be confidential.

The longitudinal quantitative study was observational, not randomised. It was not a comparison between those in and out of care, nor was it designed to measure the effectiveness of ART, which as a covariate was inextricably associated with disease progression. Given the circumstances of the evaluation, a comparison group was not available and so it is not possible to determine what fraction of the findings demonstrated in this study were the result of PEPFAR funding and what would have happened without it. No data exist from before the beginning of the PEPFAR investment which could be used as a baseline.

The facilities were selected purposively from a randomly selected sample, and thus are not representative of all PEPFAR-funded programmes. An evaluation of this kind, which required resources in terms of staff time, space and basic infrastructure from its facilities could not have been carried out in a truly random sample as the majority of PEPFAR-funded Care and Support facilities are very small.

The six facilities were quite similar, which has both strengths and limitations. Equality in funding source, structure and philosophy of care prevented undue bias between the facilities as all received a similar patient population. On the other hand, the homogeneity of care delivery precluded comparison between facilities to link care to outcomes.

The study measured care received, not care needed. There is no certainty that all the care components a patient received were necessary, nor that patients received all the care they required.

13 Recommendations

13.1—For Health Professionals

- People with HIV have physical and mental health needs throughout the trajectory of illness, and mental health in particular is not related to HIV progression but can be a problem at any stage. All patients referred with HIV should be assessed for psychological need on a regular basis. Emotional wellbeing should be a core component of patient assessment in HIV monitoring upon registration and throughout patient care.
- The needs of carers should be included in the patient care encounter. Including carers early on the care trajectory would demonstrate the value of the carer role in the eyes of facilities, improve social care for patients and could help to identify patient needs that are not acknowledged by the patients themselves.
- Participants established on ART were able to further improve their physical and mental health over three months. Care and support, complementary to ART, can help to optimise health.
- All patients should be assessed for pain, which should be managed according to the WHO Pain Ladder.

13.2—For Health Facility Managers

- Health facilities should have a clear policy regarding delivery of social care, food support and financial refunds, so that the burden of decision making and payment does not fall on health delivery staff.
- Staff need to be supported and protected from risk of burnout to maintain valuable skills in health care and reduce turnover.
- There should be sufficient numbers of non-clinical staff to ensure a manageable patient load for counsellors, nutritionists, social workers and community health workers, and high quality patient care. The areas addressed by these professions are a severe cause of need for people with HIV.
- Sufficient space is essential to providing confidential counselling services and meeting patient needs.

13.3—For Policymakers

- Many participants were initiated onto ART within weeks of their HIV diagnosis, showing that they could have benefited from treatment at an earlier stage. Testing needs further encouragement so that people with HIV are identified as early as possible in the disease trajectory and gain the maximum benefit from care and support services including ART.
- No problems were reported with the supply of ARVs but supplies of other drugs were frequently unreliable, causing expense to patients and delays to care. Supply chain systems should adopt the best practices of the ART delivery system.
- Chronic hunger is not adequately managed by short-term interventions. Food shortage caused by poverty is a significant problem which inhibits delivery of HIV care. Health facilities should work towards sustainable, adequate food supply for all patients to help maintain health and adherence.
- Policymakers should advocate for increased use of appropriate analgesics, including opioids, to manage chronic pain.

13.4—For Researchers

- The evaluation model used here could be replicated in other countries.
- Facility staff who had hosted research projects for years expressed a wish to learn skills and conduct their own research. Future research programmes should include building of knowledge and capacity in host settings.
- A study of care and outcomes for children should be undertaken to explore the multidimensional problems of this important population, particularly the expanding group of HIV positive older children for whom optimal care is still being developed.
- Shortage of non-ART drugs delayed patient care and was a common complaint, but the cause of these shortages is unclear. Examination of the barriers to drug delivery and a more detailed investigation of how drugs are supplied would be beneficial in terms of care delivery and patient satisfaction.
- The APCA African POS summary score provided a useful indication of multi-dimensional problems in this study population. Further evaluation studies should measure multidimensional outcomes using mixed methods to triangulate findings.
- A study of the how different staff working in care and support of HIV patients spend their working hours would enable an examination of how care costs relate to patient outcomes.
- Further study of referral networks from individual facilities would help understand where, as well as why, patients obtain care that is not provided at the principal facility of study.

A Demography

Demography questionnaire

P1	Please indicate the patient's gender		**male=1, female=2**	☐
	I would like to ask you a few questions about your background:			
P2	How old are you (years)?			☐☐
P3	What is the highest level of education you attended?		**none=1**	
			attended primary=2	
			attended secondary=3	☐
			diploma=4	
			degree or higher=5	
P4	What is the main material used to make the floors of your house?	natural	**earth, mud, sand=1**	
		finished	**cement=2**	
			linoleum=3	☐
			parquet/polished wood=4	
			tile=5	
			carpet=6	
			stone=7	
P5	What is the main material used to make the walls of your house?	natural	**thatched/straw=1**	
		rudimentary	**mud and poles=2**	☐
			un-burnt bricks=3	
			burnt bricks with mud=4	
		finished	**cement blocks=5**	
			stone=6	
			Wood timber=7	
			burnt bricks with cement=8	
P6	What is the main material used to make the roof of your house?	natural	**thatched=1**	
		finished	**wood/planks=2**	☐
			corrugated iron sheets=3	
			asbestos=4	
			tiles=5	
			tin=6	
			cement/concrete=7	
P7	What type of toilet do you use at home?		**private flush=1**	
			private VIP latrine =2	☐
			private traditional pit (covered)=3	
			private traditional pit (uncovered)=4	
			public/shared=5	
			bush/field/other=6	
P8	How far from the facility do you live? (kilometres) If not known,		**don't know=888**	☐☐☐ km

P9	What is the main source of drinking water for your house?	safe **bottled=0** **piped inside house=1** **piped outside house (yard, public tap)=2** **protected well=3** **borehole=4** **spring/rain water=5** unsafe **unprotected well=6** **river/stream/pond=7** **tanker truck=8**	☐
P10	What type of fuel does your household mainly use for cooking?	**electricity=01, lpg/natural gas=02** **biogas=03, paraffin/kerosene=04** **coal=05, charcoal from wood=06** **firewood=07, straw/shrubs/grass=08** **dung=10, no food cooked in household=11**	☐☐
P11.1	Does anyone in the household own a …? car	**yes = 1, no = 2**	☐
P11.2	bicycle		☐
P11.3	refrigerator		☐
P11.4	television		☐
P11.5	mobile phone		☐
P11.6	radio		☐

Now I would like to ask you a few questions about your HIV diagnosis:

P12	What date did you enrol into this facility?	**dd/mm/yy** **unknown day= 15, unknown month= 06, unknown year =888888**	☐☐☐☐☐☐
P13	why did you visit this facility today?	**new illness/well-being issue = 1** **referred = 2 (from where)** **obtain medication = 3** **HIV test result = 4** **other = 5 (specify)**	☐ Place from which referred (2), or other reason for attending (5): ____________________
P14	date diagnosed HIV+	**dd/mm/yy** **unknown day= 15, unknown month= 06, unknown year =888888**	☐☐☐☐☐☐
P15	date started on ARV treatment	**dd/mm/yy** **unknown day= 15, unknown month= 06, unknown year =888888** **777777=not on ARV**	☐☐☐☐☐☐
P16	Current WHO clinical stage (1-4)	**8=don't know**	☐
P17	Most recent CD4 count	**don't know=8888**	☐☐☐☐
P18	date of most recent CD4 count	**dd/mm/yy** **unknown day= 15, unknown month= 06, unknown year =888888**	☐☐☐☐☐☐
P19	How many dependants do you have? (family members who are dependent on you including children)		☐☐

B APCA African POS and ECOG

date ☐☐☐☐☐☐

The APCA African POS & ECOG

Question number	ASK THE PATIENT Questions 1-7	POSSIBLE RESPONSES	ANSWER
Q1	Please rate your pain (from 0 = no pain to 5 = worst/overwhelming pain) during the last 3 days	**0 = No pain at all** **1 = Slight pain** **2 = Moderate pain** **3 = Severe pain (interferes with activities of daily life)** **4 = Very severe pain** **5 = Overwhelming. The worst pain you can imagine**	☝
Q2	Have any other symptoms (e.g. nausea, coughing or constipation) been affecting how you feel in the last 3 days?	**0 = no, not at all** **1 = slightly** **2 = moderately** **3 = severely** **4 = very severely** **5 = overwhelmingly**	☝
Q3	Have you been feeling worried about your illness in the past 3 days?	**0 = Not at all worried** **1 = Worried very occasionally** **2 = Worried some of time** **3 = Worried a lot of the time** **4 = Worried most of the time** **5 = Worried all of the time**	☝
Q4	Over the past 3 days, have you been able to share how you are feeling with your family or friends?	**0 = Not at all** **1 = Only once** **2 = Occasionally** **3 = Fairly frequently** **4 = Often** **5 = Yes, I've talked freely**	☝
Q5	Over the past 3 days have you felt that life was worthwhile?	**0 = Not at all** **1 = Not very often** **2 = Occasionally** **3 = Some of the time** **4 = Most of the time** **5 = Yes, all the time**	☝
Q6	Over the past 3 days, have you felt at peace?	**0 = Not at all** **1 = Not very often** **2 = Occasionally** **3 = Some of the time** **4 = Most of the time** **5 = Yes, all the time**	☝
Q7	Have you had enough help and advice for your family to plan for the future?	**0 = None** **1 = Very little** **2 = For a few things** **3 = For several things** **4 = For most things** **5 = As much as wanted**	☝
	Thank the patient		

date ☐☐☐☐☐☐

	ASK THE CARER Questions 8, 9 and 10 ONLY if consent given by patient and carer		
Q8	How much information have you and your family been given?	**0 = None** **1 = Very little** **2 = Some** **3 = Quite a lot** **4 = A great deal** **5 = As much as wanted** **7 = N/A, no carer/consent not given** **8 = carer not present at time of interview**	☝
Q9	How confident does the family feel caring for _____?	**0 = Not at all** **1 = Not confident about many things** **2 = Confident about a few things** **3 = Confident about some things** **4 = Confident about most things** **5 = Very confident** **7 = N/A, no carer/consent not given** **8 = carer not present at time of interview**	☝
Q10	Has the family been feeling worried about the patient over the last 3 days?	**0 = Not at all worried** **1 = Worried very occasionally** **2 = Worried some of time** **3 = Worried a lot of the time** **4 = Worried most of the time** **5 = Worried all of the time** **7 = N/A, no carer/consent not given** **8 = carer not present at time of interview**	☝
	ECOG (rated by the interviewer)		
Q11	Physical function of patient	**0= fully active, able to carry on all pre-disease performance without restriction** **1=Restricted in physically strenuous activity but ambulatory and able to carry out light work, e.g., light house work, office work** **2=Ambulatory and capable of all selfcare but unable to carry out any work activities. Up and about more than 50% of waking hours** **3=Capable of only limited selfcare, confined to bed or chair more than 50% of waking hours** **4=Completely disabled. Cannot carry on any selfcare. Totally confined to bed or chair**	☝

C MOS-HIV

date ☐☐☐☐☐☐

The MOS-HIV

Question number	QUESTION	POSSIBLE RESPONSES	ANSWER
I would like to ask you a few questions about your health.			
Q1	In general would you say your health is:	**Excellent=1** **Very good=2** **good=3** **fair=4** **poor=5**	☝
Q2	How much *bodily* pain have you generally had during the past thirty days?	**None=1** **Very mild=2** **Mild=3** **Moderate=4** **Severe=5** **Very severe=6**	☝
Q3	During the past thirty days, how much did pain interfere with your normal work, including both work outside the home and housework?	**Not at all=1** **A little bit=2** **Moderately=3** **Quite a bit=4** **Extremely=5**	☝
The following questions are about activities that a person might do during a typical day. Does your health now limit you in the following activities? And if so, how much?			
		Yes, limited a lot=1 **Yes, limited a little=2** **No, not limited at all=3**	
Q4.1	The kinds or amounts of vigorous activities you can do like digging, fetching water from a well, carrying a load, splitting firewood, running, lifting heavy objects or engaging in strenuous sports		☝
Q4.2	The kinds of moderate activities you can do like washing clothes, moving a jerrican of water or cleaning the house		☝
Q4.3	Walking up hill, climbing stairs		☝
Q4.4	Bending, lifting light objects or kneeling		☝
Q4.5	Walking a moderate distance, like the length of a football pitch or taking a village walk		☝
Q4.6	Feeding, dressing or bathing yourself or ability to use the latrine		☝

date ☐☐☐☐☐☐

The following questions are about work. Does your health now restrict you in doing the following kinds of work?			
Q5	Does your health keep you from working at a job, doing work around the house or attending school?	**Yes=1** **No=2**	☝
Q6	Have you been unable to do certain kinds or amounts of work, housework, schoolwork, because of your health?	**Yes=1** **No=2**	☝
For each of the following questions, please tell me the answer that comes closest to the way you have been feeling.			
	(Interviewer must begin by reading this introductory question to the patient) ***How much of the time during the past 30 days:***	**All of the time=1** **Most of the time=2** **A good bit of the time=3** **Some of the time=4** **A little of the time=5** **None of the time=6**	
Q7	Has your health limited your social activities, like visiting with friends or family?		☝
Q8.1	Have you been a very nervous person?		☝
Q8.2	Have you felt calm and peaceful?		☝
Q8.3	Have you felt depressed?		☝
Q8.4	Have you been a happy person?		☝
Q8.5	Have you felt so depressed that nothing could cheer you up?		☝
Q9.1	Did you feel full of life and energy?		☝
Q9.2	Did you feel totally without energy?		☝
Q9.3	Did you feel tired?		☝
Q9.4	Did you have enough energy to do the things you wanted to do?		☝
Q9.5	Did you feel weighed down by your health problems?		☝
Q9.6	Were you discouraged by your health problems?		☝
Q9.7	Did you feel despair over your health problems?		☝
Q9.8	Were you afraid because of your health?		☝
	(Interviewer must begin by reading this introductory question to the patient) ***How much of the time during the past 30 days:***	**All of the time=1** **Most of the time=2** **A good bit of the time=3** **Some of the time=4** **A little of the time=5** **None of the time=6**	
Q10.1	Did you have difficulty reasoning and making decisions, for example, making plans or learning new things?		☝

date ☐☐☐☐☐☐

Q10.2	Did you forget things that happened recently, for example, where you put things or when you had appointments?		☝
Q10.3	Did you have trouble keeping your attention on any activity for long?		☝
Q10.4	Did you have difficulty doing activities involving concentration and thinking?		☝
	Please tell me the answer that comes closest to describing whether the following statement is true or false for you.	**Definitely true=1 Mostly true=2 Don’t know=3 Mostly false=4 Definitely false=5**	
Q11.1	You are somewhat ill		☝
Q11.2	You are as healthy as any other person you know		☝
Q11.3	Your health is excellent		☝
Q11.4	You have been feeling bad recently		☝
Q12	How has the quality of your life been during the past thirty days? That is, how have things been going for you?	**Very well, could hardly be better=1 Pretty good=2 Good and bad parts about equal=3 Pretty bad=4 Very bad, could hardly be worse=5**	☝
Q13	How would you rate your physical health and emotional condition now compared to thirty days ago?	**Much better=1 A little better=2 About the same=3 A little worse=4 Much worse=5**	☝

D CSRI

CSRI

date ☐☐☐☐☐☐

Ask the patient if they have received the following care in the last 30 days

	Category of care	Component of care	have you received this care from any facility in the last month? **1=yes, 2=no, 8=don't know**	If yes, where? **this facility=1** **elsewhere=2** **If A=2 or 8, B=7**
Question number		**Question section:**	**A**	**B**
C1	**Spiritual**	visit by pastor etc	☐	☐
C2		prayer with staff	☐	☐
C3		contact with traditional healer	☐	☐
C4	**Psychological**	pre and post test counselling	☐	☐
C5		adherence counselling	☐	☐
C6		family planning counselling	☐	☐
C7		patient HIV support groups	☐	☐
C8		family counselling	☐	☐
C9		psychiatric therapy	☐	☐
	Clinical	**Prevention**		
C10		prevention with positives	☐	☐
		General		
C11		wound care	☐	☐
C12		other nursing care	☐	☐
C13		ART/ARV	☐	☐
C14		assess ART treatment	☐	☐
		Pain		
C15		assessment of pain	☐	☐
C16		strong opioids eg morphine	☐	☐
C17		weak opioids eg codeine	☐	☐
C18		non-opioids eg paracetemol	☐	☐
C19		treatment for neuropathic pain	☐	☐
		Symptom management		
C20		anxiety/depression treatment	☐	☐
C21		treatment for nausea/vomiting	☐	☐
C22		treatment for skin rash/itching	☐	☐
C23		treatment for diarrhoea, including ORS or drip	☐	☐
C24		treatment for constipation/laxatives	☐	☐
C25		treatment for genital thrush	☐	☐
C26		treatment for oral thrush/candidiasis	☐	☐
C27		treatment for cryptococcal meningitis	☐	☐

	Category of care	Component of care	have you received this care from any facility in the last month? **1=yes, 2=no, 8=don't know**	If yes, where? **this facility=1** **elsewhere=2** **If A=2 or 8, B=7**
Question number		**Question section:**	**A**	**B**
C28		treatment for other fungal infections	☐	☐
C29		treatment for herpes (e.g. acyclovir)	☐	☐
C30		treatment for malaria	☐	☐
C31		TB testing	☐	☐
C32		TB treatment	☐	☐
C33		therapeutic feeding for severe malnutrition, i.e. drip	☐	☐
C34		treatment for other opportunistic infections	☐	☐
C35		management of cancer	☐	☐
C36		physiotherapy i.e. excercises to help improve movement	☐	☐
		Prophylaxis		
C37		food	☐	☐
C38		multivitamins	☐	☐
C39		nutritional advice	☐	☐
C40		provided access to safe drinking water at home	☐	☐
C41		septrin/cotrimoxazole to take every day	☐	☐
C42		isoniazid (INH) to prevent TB	☐	☐
C43		condoms	☐	☐
C44		mosquito bednets	☐	☐
C45	**Social**	provide household items	☐	☐
C46		home help e.g. help with bathing, housework, cooking	☐	☐
C47		employment training/IGA	☐	☐
C48		transport/money for bus to care centre	☐	☐
C49		legal services	☐	☐
C50		memory book work	☐	☐
C51		loans/microfinance	☐	☐
C52		infection control training	☐	☐
C53	Did you sleep under a bednet last night?	**1=yes, 2=no**	☐	
C54	Did you take cotrimoxazole yesterday?	**1=yes, 2=no**	☐	

How much have you spent on your care in past month (inclu transport to facility and drugs)

C55	at this facility?	☐☐☐☐☐☐☐☐	shillings
C56	anywhere else?	☐☐☐☐☐☐☐☐	shillings

Thank patient

E Patient Qualitative Interview Schedule

- » Introduce self and background
- » Introduce project
- » Explain how patient selected
- » What we will talk about
- » How long it will last
- » Consent & confidentiality
- » Collect consent now
- » Tape recording & destruction
- » What will happen with data
- » Who to speak to if they have any questions
- » Complete basic demographic information about patient

- *Age*

- *Gender*

- *Household size*

- *Household location (urban, peri-urban, rural)*

- *Currently using ART (yes/no)*

- *History*
  - How did you come to find/access the facility?

  - Why did you come to this facility?

  - How easy/difficult was it to become a patient here?

- *Contact*
  - How often do you come to this service?

  - What do you attend the service for?

  - How satisfied are you with the service you receive?
    - * *What is good about it?*
    - * *What is not so good about it?*

  - (If the patient receives medicines) What problems, if any, have you had getting medicines?

- *Need*
  - What would you say are your biggest problems in relation to your HIV diagnosis?
    - * *(Suggestions to help patient: These could be anything, such as getting to the facility, pain or other symptoms, childcare, anxiety, etc.)*
  - Do you have any other pressing problems that may not be obviously related to HIV?
    - * *(Suggestions to help patient: Again, these could be anything such as family relationships, food, etc.)*
  - How does the facility help you with these problems, if it does?
  - What help do you currently receive (including medications) from this facility?
  - When you see the health worker, what do you talk about with them?
  - Do they ever talk with you about:
    - * *Spiritual care? – what specifically do they ask/do?*
    - * *Clinical care? – what specifically do they ask/do?*
    - * *Ways to prevent infecting others with HIV? – what specifically do they ask/do?*
    - * *Emotional/psychological wellbeing? – what specifically do they ask/do?*
    - * *Social or financial issues? – what specifically do they ask/do?*
    - * *General advice and communication skills for you? – what specifically do they ask/do?*
  - Are there ever any things you need or problems you have that you don't talk about?
  - What else does the health worker do for you?
  - Do you feel that staff ever treat you differently from other patients because you have HIV?
- What would you like an HIV care service to do for you, what things would you need?
- Which other health services do you go to?
  - Why do you go there?
  - What things do you get there?
- We are coming to the end of the interview. Is there anything we haven't asked about that is important to you? Do you have any questions?

Thank the patient.

F Carer Qualitative Interview Schedule

» Complete basic demographic information about carer:

- *Age*
- *Gender*
- *Household size*
- *Household location (urban, peri-urban, rural)*
- *Relationship to patient*
- *Contact*
    - How often does your relative see the service?
    - What do they attend the service for?
    - How satisfied are you with the service they receive?
        * *What is good about it?*
        * *What is not so good about it?*
    - Do you collect any medicines from the facility for them?
        * If so, what problems, if any, have you had getting medicines for the patient?
- *Need*
    - What would you say are your biggest problems in relation to the patient's HIV diagnosis?
        * Are there any other pressing problems you have that may not be obviously related to HIV?
    - How does the facility help you with these problems, if it does?
    - Do you ever see a health worker?
        * *If you see the health worker, what do you talk about with them?*
        * *Do they ever ask you about any problems/questions you have as a carer/relative of the patient with HIV (try to use the patient's name)?*
    - Does the health worker talk to you or your relative about:
        * *Spiritual care?*
        * *Clinical care?*
        * *How to prevent infecting others with HIV?*
        * *Emotional/psychological wellbeing?*

  - * *Social or financial issues?*
  - * General advice and communication skills?

- What else does the health worker do?

- What would you like an HIV care service to do? (i.e., what things would you, the patient, or your family need?

- We are coming to the end of the interview. Is there anything we haven't asked about that is important to you? Do you have any questions?

Thank the carer.

G Staff Qualitative Interview Schedule

- » Introduce self and background
- » Introduce project
- » Explain how staff member selected
- » What we will talk about
- » How long it will last
- » Consent and confidentiality
- » Collect written consent
- » Tape recording and destruction
- » What will happen with data
- » Who to speak to if they have any questions

- *About you*
  - What is your job title?

  - How long have you worked at this facility?

- *Access*
  - What criteria, if any, do you have for patients who want to access your service?

  - Are you able to accept all the patients that wish to access your service?
    - * *If not how do you choose them?*

  - Are there any costs to patients?

- *Contact*
  - How often/where do you see patients? (i.e. regularity of appointments)

  - Do you ever see their families?
    - * *If so are you expected to offer support to them also?*
    - * *In what ways?*
    - * *Do you?*

  - How do patients get in touch with you?

  - Can you describe the average patient encounter:
    - * *What standard forms/reporting, if any, do you have?*
    - * *What do you ask/record?*

  - What sorts of things do you to talk with the patient about? (For the following areas of care include the following areas of enquiry: do you talk about it? What do you ask? What do you do? Is it part of your job?

If not, whose? Do you refer them on in these cases? Are you confident/do you feel able to offer this care?)
Prompt:
* *Spiritual care*
* *Clinical care*
* *Ways to prevent HIV transmission*
* *Emotional/psychological wellbeing*
* *Social/economic wellbeing*
* *Bereavement*

- What do you give them?

- *Care and referrals*
  - What is the difference between caring for early and advanced disease patients with HIV?
  - What happens with dying patients?
  - Do you ever refer HIV patients on to other facilities?
    - *For what?*

- Multiprofessionalism and training
  - Do you work with other health care workers in your facility, and if so, how?
  - What sort of problems do you not ask patients about as it someone else's work?
  - What supervision do you receive/give to workers?
  - What training have you had?
  - What extra training would you like?
  - What do you consider to be your own personal skills and strengths in caring for HIV patients?
  - Where do you feel you could do better?

- Components of care
  - What problems, if any, do you find with supplying medicines to patients?
    - *Which ones do you use most/least?*
    - *What medicines don't you have that you'd like to have?*
  - If you could add extra services to your facility what would you like to provide?
  - Are there any problems relating to HIV that you can't manage in your facility (e.g. severe pain, depression, poverty)?
    - *Is there anything you do for patients in these situations?*

  - Do you refer patients to any other services?
    - * *What for?*
    - * *Please can you describe the process of referring a patient (i.e. details of any written information, patient follow-up, communication with the other facility)*

- Evaluation
  - What are the strengths of your facility?

  - What are the weaknesses of your facility?

  - What main challenges do you face in terms of sustainability for your facility?

- We are coming to the end of the interview. Is there anything else important to you that you would like to say?

H Costing Instrument

facility number **Date**

Completed by : Mackuline Atieno **Names of those interviewed**

Accountant:

Pharmacist:

Clinician (drugs, lab tests etc):

(1) Patient numbers

1 total # individuals cared for in past year (2007):

2 # individuals provided with any HIV care in past year (2007), including ART and non-ART:

3 of those, # individuals provided with ART in past year (2007):

NB: all following questions refer to **HIV care only and in the context of patients being HIV positive**

(2) staff

ask a range of staff (doctor, nurse, counsellor, CHW)

	staff type	number of HIV patients you see in a typical day	# hours spent with HIV patients per week	hours worked per week
4.1.1	doctor 1			
4.1.2	doctor 2			
4.2.1	nurse 1			
4.2.2	nurse 2			
4.3.1	counsellor 1			
4.3.2	counsellor 2			
4.4.1	community health worker 1			
4.4.2	community health worker 2			
4.5	*clinical officer*			
4.6	*pharmacist*			
4.7	*lab staff member*			
4.8	*nutritionist*			
4.9	*social worker*			
4.10	*physiotherapist*			

facility number ☐☐☐ **Date** ☐☐☐☐☐☐

(3) medicines

	medicine		**ask pharmacist Option A** **Actual** quantity dispensed in Feb-April 2008(tabs)	**OR ask clinician/pharmacist option B** **Estimated** quantity used by typical pt in 3 mths (tabs) on ART	 pre-ART
5	Abacavir (ABC)		☐☐☐☐☐☐	☐☐☐☐	▨▨▨▨
6	Didanosine (ddI)		☐☐☐☐☐☐	☐☐☐☐	▨▨▨▨
7	Efavirenz (EFV)	600mg	☐☐☐☐☐☐	☐☐☐☐	▨▨▨▨
8	Indinavir (IDV)	400mg	☐☐☐☐☐☐	☐☐☐☐	▨▨▨▨
9	Lamivudine (3TC)	150mg	☐☐☐☐☐☐	☐☐☐☐	▨▨▨▨
10	Lopinavir (LPV) + Ritonavir (RTV)	200/50mg	☐☐☐☐☐☐	☐☐☐☐	▨▨▨▨
11	Nelfinavir (NFV)		☐☐☐☐☐☐	☐☐☐☐	▨▨▨▨
12	Nevirapine (NVP)	200mg	☐☐☐☐☐☐	☐☐☐☐	▨▨▨▨
13	Stavudine (d4T)	30+40mg	☐☐☐☐☐☐	☐☐☐☐	▨▨▨▨
14	Stavudine + Lamivudine		☐☐☐☐☐☐	☐☐☐☐	▨▨▨▨
15	Stavudine + Lamivudine + Nevirapine		☐☐☐☐☐☐	☐☐☐☐	▨▨▨▨
16	Tenofovir (TDF)	300mg	☐☐☐☐☐☐	☐☐☐☐	▨▨▨▨
17	Tenofovir + Emtricitabine (FTC)		☐☐☐☐☐☐	☐☐☐☐	▨▨▨▨
18	Zidovudine (ZDV)	300mg	☐☐☐☐☐☐	☐☐☐☐	▨▨▨▨
19	Zidovudine + Lamivudine	300/150mg	☐☐☐☐☐☐	☐☐☐☐	▨▨▨▨
20	Zidovudine + Lamivudine + Nevirapine		☐☐☐☐☐☐	☐☐☐☐	▨▨▨▨
21	strong opioids eg morphine		☐☐☐☐☐☐	☐☐☐☐	☐☐☐☐
22	Septrin/cotrimoxazole		☐☐☐☐☐☐	☐☐☐☐	☐☐☐☐
23	weak opioids eg codeine		☐☐☐☐☐☐	☐☐☐☐	☐☐☐☐
non-opioid painkillers (name 3 most common)					
24.1	1 Paracetamol		☐☐☐☐☐☐	☐☐☐☐	☐☐☐☐
24.2	2 Brufen		☐☐☐☐☐☐	☐☐☐☐	☐☐☐☐
24.3	3 Aspirin		☐☐☐☐☐☐	☐☐☐☐	☐☐☐☐
25	**TB Treatment**		☐☐☐☐☐☐	☐☐☐☐	☐☐☐☐

facility number **Date**

(3) medicines continued

	medicine	**ask pharmacist Option A** **Actual** quantity dispensed in Feb-April2008 (tabs)	**OR ask clinician/pharmacist option B** **Estimated** quantity used by typical pt in 3 mths (tabs) on ART	 pre-ART
	other antibiotics for opportunistic infections (name 3 most common)			
26.1	1 Cefzil (500mg)	0		
26.2	2 Amoxil (500mg+250mg)	0		
26.3	3 Doxycycline	0		

	Name 2 most common **first** line ART regimens:		**Estimated** number of patients on this regimen
27.1	1.___ Stavudine+lamivudine+nevirapine		
27.2	2.___ Zidovudine+lamivudine+nevirapine		
	Name 2 most common **second** line ART regimens:		
28.1	1.___ Zidovudine+lamivudine+lopinavir/ritonavir		
28.2	2.___ Abacavir+didnosine+lopinavir/ritonavir		

(4) lab tests

	ask lab staff and doctor test	**Option A** **Actual** number of tests this facility conducted in Feb-April 2008	**or Option B** **Estimated** number of tests a typical patient receives in 3 months on ART	 pre-ART
29	liver function test (LFT)			
30	AFB smear (TB)			
31	CD4 count			
32	haemotology test (FHG)			
33	viral load			

facility number ☐☐☐ **Date** ☐☐☐☐☐☐

(5) building infrastructure and utilities (all, not only HIV) ask accountant/manager

34	Utility costs per month (shillings) Include water, electricity, generator fuel, communications, waste disposal etc	0
35	Transport costs, fuel, drivers, maintenance (shillings)	0
36	Clinical consumable costs per month (shillings) Include gloves, syringes, cotton wool swabs, plasters, soap, sterilising solution etc	0
37	amount spent on volunteer staff (inclu training, travel reimbursements, payment in kind) in past 3 months (shillings)	0

(6) capital costs ask accountant

38	approximate **total** facility space (sq m)	
39	approximate facility space for HIV care (sq m)	
40	rent per month, or estimated rental value	
41	number of four-wheeled vehicles	
42	number of two-wheeled vehicles	

I Further Quantitative Analysis

Loadings onto Wealth Factor

Table 68 shows the contribution of each variable to the single factor measuring socioeconomic status, with the exception of six variables which did not contribute at all. The variables loading most heavily onto the factor were a negative loading on having an earth floor, and positive loadings on using paraffin/kerosene/coal or charcoal as cooking fuel, and having piped water either inside or outside the house.

Table 68: Loadings onto Wealth Factor

Variable	Loading
Earth floor	-0.308
Paraffin/kerosene/coal cooking fuel	0.187
Piped water outside house	0.181
Charcoal for cooking fuel	0.180
Piped water inside house	0.178
Tiled/cement/asbestos/tin roof	0.168
Corrugated iron roof	0.147
Private flush toilet	0.141
Natural gas/LPG for cooking fuel	0.136
Mud and poles/unburnt brick/brick with mud walls	-0.133
Own a television	0.126
Own a refrigerator	0.105
Own a mobile phone	0.079
Own a car	0.066
Protected well/borehole/rain water	0.048
Public/shared/bush latrine	0.025
Own a radio	0.017
Polished wood/tile/carpet floor	-0.009
Own a bicycle	-0.006

Association of Mental Health Score with Physical Health Score

Linear regression was used, with CD4 count as a continuous variable, to explore the effect of CD4 on mental health score adjusting for physical health score. The hypothesis was that the observed association of mental health score and CD4 count was explained by the effect of CD4 on physical health score.

It was also hypothesised that participants with lower physical health would be more likely to be accompanied by a carer, but the same would not be true of mental health. To test this hypothesis, linear regression was used to separate the associations of carer presence with physical and mental summary scores at T0.

Table 69 shows that after adjusting for mental

Table 69: Linear Regression at T0 with Physical Health Score as an Outcome

Model	Covariate	Coefficient	Standard Error	T	P	95% CI
A	CD4 count	0.011	0.002	6.34	<0.001	0.008–0.015
B	Mental health score	0.690	0.038	18.29	<0.001	0.616–0.764
B	CD4 count	0.008	0.001	5.25	<0.001	0.005–0.010

Table 70: Linear Regression at T0 with Mental Health Score as an Outcome

Model	Covariate	Coefficient	Standard Error	T	P	95% CI
C	CD4 count	0.005	0.002	3.49	0.001	0.002 to 0.008
D	physical health score	0.507	0.028	18.29	<0.001	0.453 to 0.561
D	CD4 count	-0.001	0.001	-0.31	0.754	-0.001 to 0.002

Table 71: Linear Regression at T0 with Physical Health Score as an Outcome

Model	Covariate	Coefficient	Standard Error	T	P	95% CI
A	Carer present	-5.097	1.309	-3.89	<0.001	-7.668 to -2.527
B	Carer present	-2.724	1.054	-2.58	0.010	-4.794 to -0.655
B	mental health score	0.716	0.036	19.75	<0.001	0.644 to 0.787

Table 72: Linear Regression at T0 with Mental Health Score as an Outcome

Model	Covariate	Coefficient	Standard Error	T	P	95% CI
C	Carer present	-3.316	1.100	-3.01	0.003	-5.476 to -1.157
D	Carer present	-0.742	0.889	-0.83	0.404	-2.488 to 1.004
D	physical health score	0.505	0.026	19.75	<0.001	0455 to 0.555

health score, physical health score was still closely associated with CD4 count (p<0.001). However, when mental health score was the outcome in Table 70, there was no association between mental health and CD4 after adjusting for physical health (p=0.754). The apparent association between mental health and CD4 count in the top half of Table 70 was completely confounded by physical health score. The fact that the association did not disappear in Table 69 shows that this was not simply a product of overadjusting.

Table 71 shows that patients with a carer present at T0 had an average physical health score five points lower than those without a carer, and the difference was highly significant (p<0.001). After adjusting for mental health, the association with carer presence was reduced (because of the close correlation between physical health and mental health) but still significant (p=0.01). Conversely, Table 72 shows that although patients with carers had a mean mental health three points lower than those who came alone, this difference was completely confounded by physical health.

Details of Longitudinal Analysis Method

Multilevel modelling was carried out using the Stata xtmixed command function. Outcomes were physical health score and mental health score, measured up to three times at monthly intervals. Baseline score was incorporated as a covariate and not as an outcome. Models included levels for facility and individual. The only random effects was timepoint (interview number, rather than actual time interval), which was allowed to have a random coefficient at the individual level. Other covariates were fixed. Demographic and care theme covariates were constant over time, receipt of ART and TB treatment varied. The default independent covariance structure was used. Variance and standard error of variance were reported for random-effects parameter estimates.

Exploring the Variance at Different Levels

Multi-level modelling consists of attempting to separate the variation in scores into variance at different levels; in this case, variance within individuals over time, between individuals, and between facilities. Two techniques were used to identify the extent of the variance between facilities. Multilevel models of care relied on between-facility variances in order to function.

Table 73 shows the results of ANOVA tests comparing baseline health scores between the six facilities. The results show that facility accounted for a proportion of the variation, reducing the value of R squared. Physical health varied more between facilities than mental health did.

Additionally, a multilevel model without covariates was developed to ascertain the contribution of the facility level to change over time. In Table 74 it is clear that the great majority of variance was between individuals, rather than between facilities.

Table 73: Results of ANOVA Using Facility at T0

	n	R squared	Adjusted r squared	F	p
Physical health score	692	0.045	0.038	6.47	<0.001
Mental health score	692	0.017	0.009	2.30	0.044

Table 74: Results of Multilevel Model with Random Intercept

	Facility Level		Individual Level	
	Variance	Standard Error	Variance	Standard Error
Physical health score	3.376	2.540	53.325	4.045
Mental health score	0.476	0.547	31.871	2.455

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PEPFAR Categories of Care

Table 75: PEPFAR Categories of Care

Area of Care and Support	Care Components included from CSRI
Clinical	Pre and post test counselling Adherence counselling Nursing care Adult diagnostic HIV testing Weighing Assessment of pain Strong opioids Weak opioids Non-opioid analgesics Treatment for neuropathic pain Treatment for nausea/vomiting Treatment for skin rash/itching Treatment for diarrhoea Laxatives Treatment for thrush Treatment for oral candidiasis Treatment for cryptococcus 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 ITNs Wound care Physiotherapy
Psychological	Family counselling Psychiatric therapy Anxiety/depression treatment
Spiritual	Visit by faith leader Staff prayer with patients Contact with traditional healer/herbalist Memory book work
Social	Home help Employment training Legal services Loans/microfinance
Prevention	Family planning counselling Patient HIV support groups Support for family testing Prevention with positives Condoms

K Country-Level Coding Frames

Coding Frame Developed by APCA

- » *Components of care/care provision*
  - Curative, preventive and on going monitoring
  - VCT, RCT and Diagnostic counselling
  - Adherence counselling
  - Spiritual care
  - Bereavement care
  - Socio-economic support
  - Laboratory services
  - Psychological/emotional care
- » *Health seeking behaviour*
  - Associated with self initiation into care
    - Sickly
    - Suggestive symptoms
    - Community advice
  - Reasons for choice of facility
    - Proximity
    - Available services
    - Affordability
- » *Patient and carer needs*
  - Clinical
  - Preventive
  - Social and financial
  - Emotional/psychological
- » *Structure of HIV/AIDS care services*
  - Criteria for accessing care
  - Enrollment process
  - Frequency of care
  - Documentation in care
  - Differences in care needs for patients at different stages of disease
  - Referrals
  - Costs to patients
  - Education and training
  - Supervision
- » *Strengths, challenges, and service gaps*
  - Services facilities /patients would like to have
  - Challenges faced
  - Patients' perceptions of services received

Coding Frame Developed by KCL

- » *Carer Roles, Relationship to Patient and Facility*
  - Patient as care provider and educator
- » *Content of service receipt*
  - Advanced and bereavement care
  - Carer
  - Clinical and medicine
  - Monitoring and process
  - Preventive
  - Psychological, counselling and advice
  - Referral
  - Social
  - Spiritual
- » *Experiences of Care Provision and Receipt*
  - Negative experiences
  - Positive experiences
  - Facility self-reported strengths
  - Patient and carer self report
  - Suggested improvements
  - Clinical and facility challenges
- » *Initiating Care*
  - Criteria for service entry and care
  - Patient choice of facility
  - Process of enrollment
  - Retention and shopping around
  - Service identification of needs
- » *Needs*
  - Carers
  - Clinical
  - Preventive
  - Psychological
  - Social
  - Staff

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MOS-HIV Responses at T0

Table 76: MOS-HIV Responses at T0

Subscale	No.	Question	Responses					
			poor	**fair**	**good**	**very good**	**excellent**	
Health perception	Q1	Health is	14.4	41.7	33.3	7.5	3.2	
			true	**mostly true**	**don't know**	**mostly false**	**false**	
	Q11.1	Somewhat ill	48.0	30.3	2.0	10.1	9.7	
	Q11.4	Feeling bad recently	42.9	35.3	0.1	10.4	11.2	
			false	**mostly false**	**don't know**	**mostly true**	**true**	
	Q11.2	As healthy as anyone you know	24.1	20.3	5.6	25.4	24.6	
	Q11.3	Health is excellent	33.3	29.4	2.3	21.2	13.8	
			very severe	**severe**	**moderate**	**mild**	**very mild**	**none**
Pain	Q2	Bodily pain	5.2	14.8	29.7	22.7	11.4	16.2
			extremely	**quite a bit**	**moderately**	**a little bit**	**not at all**	
	Q3	Pain interfering with daily life	10.9	16.7	14.7	23.1	34.6	
			limited a lot	**limited a little**	**not limited at all**			
Physical function	Q4.1	Vigorous activities	26.0	37,2	36.8			
	Q4.2	Moderate activities	9.6	29.5	60.9			
	Q4.3	Walking up hill	15.4	33.1	51.6			
	Q4.4	Bending, kneeling	7.8	27.4	64.8			
	Q4.5	Walking	5.2	18.7	76.2			
	Q4.6	Self care	2.3	9.8	87.9			
			Yes		**No**			
Role function	Q5	Cannot work	23.3		76.7			
	Q6	Cannot do some work	27.2		72.8			
			Proportion of Time					
			all	**most**	**a good bit**	**some**	**a little**	**none**
Social function	Q7	Limited social activities	8.5	7.2	5.2	11.1	10.3	57.8
Mental health	Q8.1	Nervous	3.0	6.8	5.5	20.0	21.1	43.7
	Q8.3	Depressed	2.0	7.6	6.0	19.7	25.9	38.8
	Q8.5	Very depressed	1.9	4.7	4.6	13.9	22.8	52.0

Table 76: MOS-HIV Responses at T0

Subscale	No.	Question	Responses					
Vitality	Q9.2	Without energy	3.6	6.8	7.3	16.2	26.7	39.4
	Q9.3	Tired	4.6	10.2	8.6	28.4	30.1	18.1
Health distress	Q9.5	Weighed down	3.9	8.5	6.8	22.0	26.6	32.2
	Q9.6	Discouraged	3.5	7.5	5.0	16.6	26.0	41.4
	Q9.7	Despair	1.9	5.2	4.9	14.8	18.4	54.8
	Q9.8	Afraid	3.3	7.6	3.6	15.4	23.0	47.1
			none	**a little**	**some**	**a good bit**	**most**	**all**
Mental health	Q8.2	Calm and peaceful	10.1	11.8	22.4	6.3	24.4	25.0
	Q8.4	Happy	6.8	9.3	21.1	8.6	29.3	24.9
Vitality	Q9.1	Full of life	8.2	14.9	21.0	11.6	25.4	18.7
	Q9.4	Enough energy	9.2	15.5	22.2	9.8	20.7	22.6
			all	**most**	**a good bit**	**some**	**a little**	**none**
Cognitive function	Q10.1	Difficulty reasoning	3.2	6.6	5.2	15.4	17.7	51.9
	Q10.2	Forgetful	2.0	7.5	3.9	16.9	16.3	53.5
	Q10.3	Attention problem	1.7	5.5	4.2	14.7	18.9	55.0
	Q10.4	Concentration problem	2.6	5.3	4.2	13.4	16.7	57.6
			very bad	**pretty bad**	**about equal**	**pretty good**	**very good**	
QoL	Q12	Quality of life	4.3	15.1	51.3	25.2	4.0	
			much worse	**a little worse**	**the same**	**a little better**	**much better**	
Health transition	Q13	Compared to 30 days ago	4.5	17.3	27.2	35.0	16.0	

M Feedback from Dissemination

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 Nairobi in July 2009 with the research team and participating facilities. The purposes of this meeting were (a) to share the results of Phase 2 with participants; (b) to gain insight into the findings from those involved in service delivery to improve the presentation of the findings in the report; (c) to discuss the recommendations made, with the option of facilities making additional recommendations if desired.

Representatives from all six facilities, the country team and the Ministry of Health attended the workshop.

Meeting Outline

Participants were given a summary of the findings. Presentations from the research team explained (a) the parties involved and the aims, objectives and design of the evaluation; (b) methods and data collection experiences; (c) results

Participants were then divided into five groups in order to explore key themes that arose from the data in more detail. In addition to the summary report already received, each group was given relevant supplementary data (i.e., report tables and excerpts from qualitative interviews) 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 findings. In general participants found that the findings were borne out by their own experience, and agreed that there were many unmet psychosocial needs for their patients. Mental health score was consistently lower than physical health score, and it is known that mental health problems, particularly depression, are major contributors to non-adherence. The issue, participants agreed, was how to manage mental health appropriately.

There was great interest in the finding that physical and mental health scores were not significantly associated with ART use. It was emphasised that these are self-reported outcomes, and that the findings should absolutely not be interpreted to mean that ART is ineffective, rather that some problems in patient experience persist after ART. Participants would have liked to see what happened to outcomes over a longer period of time.

Some additional questions for analysis were raised in discussion. Facility staff reported they had expected that women would report better health scores than men, both because they were less likely to mention problems and because, anecdotally, men only come for testing when symptoms are severe. The results showed that in fact outcomes were not associated with gender.

Staff were interested to know whether the presence of a carer was associated with relative wealth or gender. The probability of having a carer did not differ by wealth quintile on an ANOVA test. If all observations were included, men were accompanied by a carer on 8.4% of visits and women on 5.9%, which was significant on a t-test ($p=0.02$). This contradicted the group's expectation, which was that women, believed to be more likely to disclose their status, would be accompanied more often.

Facility staff attributed the low use of morphine to regulatory restrictions but Dr Zipporah Ali, the executive director of KEHPCA, pointed out that Kenya was allowed to import 15kg of morphine per year and only made use of 5kg. She argued that use of morphine was limited by clinicians' reluctance to prescribe it, due to fears of addiction and inadequate training.

It was suggested that the civil unrest in Kenya following the 2008 presidential election, which is known to have disrupted access to care, should be considered as a contributor to mental health problems.

Meeting Feedback—Groups

ART, PCP, Pain Management, Symptom and Infection Management, Prevention

This group was surprised by the finding that self-reported outcomes were not significantly affected by ART. They suggested that pain may have been under-reported, as pain is not taken seriously as a health concern, so that patients reporting pain may be viewed as complaining.

Nutrition, Social Care, Psychological Care, Spiritual Care

This group debated whether the finding that therapeutic feeding declined over time represented a reduction in need or in provision. This is a limitation of the data which could only have been overcome through independent clinical observation of patients. It was participants' experience that over 80% of HIV patients would benefit from extra food support. Receipt of nutritional counselling was high but it was suggested that delivering this care in a group setting, alongside individual counselling, might enforce the message and take receipt to 100%.

The group reported that in their opinion pre-and post-test counselling at VCT services was not always of good quality, and therefore although over 90% of participants received it, there could still have been unmet need. Again, the evaluation was unable to determine the quality of care delivered except by change in outcomes over time.

Facility Strengths and Weaknesses

The group highlighted strengths of the six facilities including provision of counselling, ART, PWP, CTX, treatment for OIs, and streamlined referral. Adherence counselling was considered a cornerstone of patient management and the key to lifelong care. The goal was for patients to be able to attend regularly and take their medication.

Several challenges that facilities faced were identified by the group. Lack of psychosocial and spiritual care was attributed to lack of skilled staff and space. Drugs for opportunistic infections might be unavailable or too expensive. The group reported that routine medication was well supplied but second line therapies, or strong antibiotics, could be more difficult to access. Another challenge was that patients became attached to the CCC (Comprehensive Care Centre, where all HIV care is delivered) and were reluctant to transfer elsewhere. When the CCC was closed over the weekend, patients in need of care would wait rather than visit another health centre. Staff at other health centres encouraged this by refusing to treat CCC patients. The group encouraged integration of services and training so any staff could meet the needs of patients irrespective of HIV status or disease stage.

Patient Issues and Perspectives

The group reported that food was a major problem. Patients were in need but the facility did not want to encourage dependence on short-term aid by providing food in an unsustainable manner. Patients who received food became reluctant to transfer to another care centre which did not offer it. The group felt that the most effective approach would be skills training and IGA to enable families to be self-supporting.

Group participants encouraged the provision of spiritual care within facilities, in part so that patients would not visit faith healers to meet their spiritual needs. In some settings, patients would be told they had been cured and cease to take ART. Use of herbal medicines could also be a problem, as it was often not reported to health workers and could lead to side effects or reduce the effectiveness of treatment.

Carer Issues and Perspectives

The group found that there was a lack of focus on carer wellbeing, with carers complaining about long waiting times, few home visits, and severe financial restraints resulting in lack of food. The group were surprised that carers were more likely to accompany the patients in the earlier visits than later, and also that, despite the difficulties they reported, carers scored low worry on the POS.

The group endorsed the evaluation findings relating to the multiple roles of people with HIV who might be patients, carers, and peer counsellors on different occasions. They found that peer counselling was very popular and that having HIV positive staff in core areas, such as outreach, was an asset to a facility.

Each group produced recommendations, which are presented together in the table below, with the relevant data supporting them and the principle beneficiaries. Some recommendations were common to more than one group and have been merged together.

Table 77

Recommended Actions	**Data Supporting Recommendation**			**Beneficiaries**
	Longitudinal	**Qualitative**	**Cost/survey**	
Improve access to PCP components, except CTX which is well delivered.	• Low receipt of BCP components			• Patients
Improve pain assessment and management, and medical education regarding pain. Increase opioid prescription. Develop protocols and clinical training to encourage and control use	• Persistent pain over three months • Use of non-opioids very high but opioids very low	• Patient reports of pain	• Phase 1: opioids only found in injectable form	• Patients • Staff
Support and monitoring needed for ART clients, including monitoring of treatment failure and drug resistance. Conduct CD4 tests more regularly, improve use of second and third line treatments	• Patients without CD4 count • Self-reported health on ART no higher than ART-naïve patients, problems persist after treatment	• Staff report low knowledge of second line therapies		• Patients
Develop IGA, prevent dependence on food aid and make families independent. Skills training e.g. farming methods to improve yield, fishing, grants to start funds.	• High proportion receiving therapeutic feeding indicates poor nutrition. Social care is the weakest area.	• Need for food, but also dignity and sense of competence		• Patients • Families
Need more family counselling—might be related to disclosure at home, focus on this is needed	• Proportion of participants without a carer	• Anxiety related to disclosure		• Families
Incorporate psychiatric therapy fully into counselling, refer where necessary	• Low provision of psychiatric therapy	• Psychiatric problems impairing ability to work and care for family	• Phase 1: weak referral networks	• Patients
Patients should be encouraged to seek spiritual care alongside medical care, medical institutions should have spiritual leader. Staff will also benefit, and patients less likely to go to faith healers.	• Spiritual care delivery to under 80% of participants	• Patients report benefit from spiritual care, encouragement, sense of hope, community support		• Patients • Staff
Recruitment of more nutritionists, counsellors and social workers	• Low delivery of social care • Psychological and social problems more severe than physical	• Counsellors report overwork. Patient numbers, long waiting time.	• High patient:staff ratio, especially non-clinical	• Patients

Table 77				
Recommended Actions	**Data Supporting Recommendation**			**Beneficiaries**
	Longitudinal	**Qualitative**	**Cost/survey**	
Decentralise to smaller and mobile services. Equip the smaller sites to provide more care components and also do outreach.	• Loss to follow-up over time, especially for patients with poorer health scores	• Transport costs • Desire to get all care from one place		• Patients
Triage patients and reduce waiting times. Allow fast-track route to pharmacy for stable patients.	• Big range in care components received, one path not suitable for all	• Waiting times, opportunity cost	• Staff time a major expense, to be used efficiently	• Patients
Mental health worker attached to the CCC. Identify and treat anxiety and depression.	• Mental health scores lower than physical. High levels of psychological problems	• Anxiety reported		• Patients
Prioritise motivation of health workers		• High turnover, burnout. Difficulty maintaining quality care with ever increasing numbers		• Staff
Increase supply of OI drugs and make them free for those who can't pay	• High prevalence of OI treatment, including many unspecified, possibly rare conditions	• Patients unable to afford prescriptions, problems intensify due to lack of treatment		• Patients
Encourage and expand support groups	• Prevalence not 100% • Needing to share feelings a big problem	• Benefits of support groups, emotional, practical		• Patients
Involve more CHWs and encourage them to do home visits to improve psychosocial care. Work with chiefs and village elders.	• Social care and integration into daily living (e.g. home help, provision of household items) are poorly provided	• Interviews – carers lack time to see HCWs. Patients lonely, like home visits. Transport costs.		• Patients • Families
Focus on carers' wellbeing. Carers should be included in treatment plans	• Complex care regimes, difficult to manage alone	• Carers want to be included, value information to improve care		• Carers
Employ more HIV positive peer counsellors	• Lack of someone to share feelings with a major problem	• Patients appreciate peer support - social, spiritual and psychological gains		• Patients
Find more space; facility encourages multidisciplinary family meetings and psychosocial meetings but lacks space to host them		• Patients report benefits of support groups. Family care a neglected issue	• Phase 1: space a very common issue in staff interviews	• Families • Patients
Research active clinical services are essential for improving care. Facilities need resources and skills to conduct research and find answers to their questions		• Staff want to do research themselves not only host it		• Staff • Patients

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