

SUMMARY

# PEPFAR Public Health Evaluation – Care and Support –



PHASE I KENYA

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# Executive Summary

## Rationale

A Public Health Evaluation (PHE) was commissioned to examine PEPFAR-funded HIV care and support. Phase 1 of this PHE aimed to describe the nature and scope of care and support provision according to the five PEPFAR care and support areas (OGAC 2006), including the types of facilities, clients seen, and availability of specific components of care. Phase 2 consisted of a longitudinal study of patients outcomes.

## Methods

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

## Main findings

### *Facility characteristics*

Nine facilities were secondary/tertiary hospitals, 15 facilities were district hospitals, 16 were health centres, 10 were dispensaries and 10 were home-based care (HBC) only facilities. The majority of the 60 facilities surveyed were government run. On the day of the survey the majority of facilities had electricity (n=46), a safe water supply (n=54) and a functioning toilet (n=52).

### *Staff characteristics*

Fewer than half of facilities had a doctor working onsite and fewer than a third had a social worker, but over two-thirds had a clinical officer, and 90% a nurse. Twelve sites (20%) had representation of at least one staff member (either full-time, part-time or voluntary) across all four clinical, spiritual, psychological and social care designations. Voluntary staff levels were high, especially in dispensaries and HBC-only facilities, and these staff members were mainly community health workers.

### *Components of care offered*

Of the 69 care components recorded in this survey a mean of 42 components were offered by facilities (including outward referrals). Referrals were generally rare, with twenty-two facilities not referring out for any care component surveyed. The components of care most frequently provided or referred for were prevention with positives, nutritional advice, pre- and post-test counselling, and multivitamins. The most rarely provided or referred for components of care were traditional healing, strong opioids, microfinance, isoniazid for TB prophylaxis and provision of household items.

- Holistic care — Some components of clinical, psychological and preventive care were each provided or referred in over 90% of facilities. Spiritual care was provided or referred at 60% and social care at 70% of facilities. Twenty-eight facilities (47%) provided or referred at least one component of care in all of clinical, psychological, spiritual, social and prevention domains.
- ART — Nearly two-thirds of facilities offered (n=35) or referred (n=4) for ARVs, which was

well supported by adherence counselling, assessment of ARV treatment failure and monitoring of ARV toxicity alongside.

- Pain management — Non-opioid analgesics were the most commonly provided or referred care component relating to pain management for palliative care. Assessment of pain, weak opioids and treatment for neuropathic pain were most commonly provided or referred by secondary/tertiary hospitals, whereas strong opioids and non-opioids were most commonly provided or referred at district hospitals. All the components of care relating to pain management examined were least commonly available at HBC-only facilities.
- Nutrition — Components of care relating to nutrition, i.e. weighing, nutritional counselling and multivitamins, were all widely available at hospitals, health centres and dispensaries. Therapeutic feeding for malnutrition was most commonly provided or referred at secondary/tertiary hospitals (75%), and more provided or referred at HBC-only facilities (50%) than at health centres (44%) or dispensaries (30%).
- Social care — The availability of the social components of care varied overall, and by facility type, with home help being most commonly provided or referred by HBC-only facilities (100%), loans/microfinance at dispensaries (20%), IGAs at district hospitals (40%) and legal services at HBC-only facilities (50%).
- Opportunistic infections and Preventive care — A preventive care package (PCP) is a small number of components of care that every person with HIV should receive as a preventative measure, to protect them from water-borne infections and malaria, and to protect them from transmitting HIV. In the survey a PCP comprising insecticide-treated bednets, safe water treatment, condoms, multivitamins and cotrimoxazole was provided in full by just 5 facilities (8%). Of the five items, multivitamins were most commonly available (90% of facilities) and bednets the least commonly available (32%). CTX was available at 49 facilities.

Few facilities provided or referred isoniazid to prevent TB. TB detection and AFB smear tests were commonly provided or referred at hospitals and health centres, but not at dispensaries or HBC-only facilities. TB treatment was widely available at all facilities except HBC-only facilities. The most common component of care relating to malaria was malaria treatment, provided or referred at nearly all facilities except HBC-only facilities. The least common component of care relating to malaria was mosquito bednets, although the availability of these was evenly distributed across the facility types.

Thirty-two facilities provided or referred all five of the components of care that reflected the description of the package of care 'Prevention with Positives' (i.e. adherence counselling, family planning counselling, patient HIV support groups, treatment of herpes and condoms).

- Diagnostic tests — The most common diagnostic test provided or referred was a rapid HIV test (82% of facilities), with pulse oximetry being the least common (18% of facilities). Other tests were most commonly provided or referred at secondary/tertiary hospitals and not provided nor referred at HBC-only facilities. Notably, the CD4 and liver function tests were provided or referred at fewer than half of facilities.
- Care provided and staff available — Few facilities provided clinical components of care without specialist trained staff, but other (non-clinical) areas of care were more commonly provided whilst employing staff without the specific training to deliver these areas of care. Twenty

facilities provided psychological care without counsellors on staff, and 16 provided social care without community health workers or social workers. The findings suggest that clinical staff at facilities may be undertaking multiple tasks alongside clinical care provision, such as undertaking laboratory tests or providing social care, counselling or other psychological care, or spiritual care.

### ***Pharmacy review***

CTX and non-opioids analgesics were the most commonly stocked drugs of those recorded, isoniazid and morphine the least common. Morphine was in stock at one site only, and this was in injectable form. Non-opioid analgesics were reported as being provided at four facilities which did not stock them in the pharmacy. The same discrepancy was observed for isoniazid at six facilities, fluconazole at 16, morphine at three and CTX at three. Stock levels for named drugs were rare, and stockouts were common, e.g. in the previous six months 27 sites had had a stockout of non-opioids, 22 of fluconazole and eleven of codeine.

### ***Document analysis***

Only 60% of facilities reported that they utilised a standardised form for first clinical assessment and 60% reported using a standardised form for assessment of patients for ongoing and repeated contact. The content of those analysed was nurse and doctor focused, i.e. did not record non-clinical problems or interventions. Forms lacked key items such as patient medical history.

### ***Staff views***

Staff felt that the strengths of their facilities included providing clinical care (especially ART, and opportunistic infection (OI) prophylaxis), having a good infrastructure (including having a range of care facilities in one place), having staff employed and trained in specialist areas, and reducing stigma. Areas for improvement desired were increasing the range of components of care available, and providing more training for staff as well as employing more specialist staff.

As well as general funding issues, staff were concerned that a lack of space, too few staff, a lack of equipment and erratic drug supplies threatened the sustainability of their services. Suggestions for reducing double counting of patients included improving the comprehensiveness of care provided on a single site, improving drug supplies, increasing patient confidentiality and increasing the number of trained staff.

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

Forty-nine FGDs took place, involving 242 patients.

Not all components care identified by staff were reported as received by patients, e.g. water treatment was reportedly offered by 37% of facilities but received by 14% of participants. Some reasons offered by patients for not having received care were lack of need, cost to patients and not meeting facility criteria.

Patients highly rated the counselling services, and felt facility services helped to reduce stigma and improve their quality of life. They requested more components of care to be available on site so that they did not have to travel (e.g. laboratory tests, microfinance and medications).

Patients requested more staff, increased hours of appointments, and transport to the facility. The problem of drug stockouts was frequently mentioned.

Patient most frequently visited additional facilities because of the availability of medications, capacity for laboratory tests and the convenience of proximity to their home.

## **Recommendations**

- Facility infrastructure requires improvement in many facilities, particularly enlarging clinic and waiting areas. Some facilities also require improved electricity and water supplies for sanitation and infection control.
- We observed a low number of care components being provided at smaller facilities, even after including availability via referral. Reliable and well-monitored referral networks for specialist HIV care and support should be established. As well as improving patient care, such networks could help to reduce the number of patients who ‘shop around’ for their health care services, and the subsequent double-counting of such patients.
- In order for reliable referrals to work, comprehensive records of patients attending facilities and the care they receive, including outward and inward referrals, are needed for good patient care and efficient use of service resources. Improvements in the detail and management of patient records need to be made.
- An increase in the numbers of specialist staff (ie staff of specific designation) is needed to ensure that staff are not reliant on operating outside their speciality. Generalist skills are important for all staff, but specialists are required for more complex cases. Increasing specialist training and employing staff to deliver non-clinical aspects of care and support, such as psychological and spiritual care, could improve care quality by freeing up more time for clinical staff to provide clinical care.
- Patient need should be assessed and documented in a multiprofessional, holistic and ongoing manner.
- The availability and accessibility of holistic care and support services should be increased.
- The provision of OI prevention should be improved. Although treatment of OIs appeared to be widespread, prevention of specific OIs and the components of the PCP were less widely offered. Specifically for CTX, although it was reported as being widely available, this was not matched by consistent pharmacy stocks or reliable sourcing by patients. Increasing the provision of reliable OI prevention and the PCP could have greater health benefits for HIV patients.
- Provision of weak and strong opioids in HIV care and support services should be urgently addressed.
- Social care should be provided, directly or by referral, at all facilities.
- Basic preventive and support services should be made available for all who need them to as many patients as possible.
- The high frequency of stock outs, and challenges in this respect described by patients, need to be addressed through improving pharmacy stock supply, control, records and storage.
- Laboratory services, particularly CD4 and liver function testing, should be made more widely available at facilities providing ART. For smaller facilities, referral networks to larger facilities for such services should be examined and strengthened.



# Summary Report

## Introduction & Purpose

This study is part of a larger, two-phase evaluation of PEPFAR-funded HIV/AIDS care and support services for in Uganda and Kenya. The aims of this evaluation were to:

- Describe the nature and scope of HIV/AIDS care and support services supported by PEPFAR, including the types of facilities available, clients seen, and availability of specific components of care.
- Evaluate how programme components and costs are related to health outcomes.

The Phase 1 objective was to undertake a cross-sectional survey of facility configuration and activity on a 10% sample of PEPFAR-funded, HIV care and support facilities in Kenya and Uganda (2007). The Phase 2 objective is to collect longitudinal prospective quantitative outcome data on 1200 new patients at 12 facilities in Kenya and Uganda, measuring both quality of life and core palliative outcomes alongside components of care received (2008). Phase 2 methodology also involves a costing analysis to determine cost of care provided. This report presents findings from Phase 1 of the Kenya study only.

## Methods

A cross-sectional survey of facility configuration and activity was conducted by collecting quantitative and qualitative data directly from facilities.

### *Sampling*

The approximately 600 PEPFAR-funded HIV care and support facilities in Kenya formed the sampling frame for this study. Exclusion criteria were: (specifically) paediatric HIV/AIDS care and support providers, and difficult to access sites (e.g. insecure, no road access). Sixty facilities (about 10%) were selected for inclusion in the study. In order to capture a range of facility sizes within the sampling frame, facilities were stratified by number of patients seen for HIV-related care in FY 06, and divided into three strata (1 to 100, 101 to 500 and >500 patients). This resulted in unequal and calculable sampling fractions. Twenty facilities were randomly sampled within each of the strata.

### *Data collection tool development*

- Senior staff interview — This tool was designed for use across a wide range of care facilities. The researchers interviewed a group of senior staff at each health facility to collect data on patient numbers, infrastructure and staffing. This tool also included a version of the Client Services Receipt Inventory (CSRI) (Beecham and Knapp 2001) adapted for the aims / context of this study. The CSRI assesses service provision / referral for various components of clinical, psychological, social and spiritual care.
- Document collection — A tool on which the existence, format, and language of various patient documents could be recorded was developed in Word. Documents surveyed included: service aims, incoming referral criteria, incoming referral forms, outgoing referral forms, patient charging forms, ART (antiretroviral therapy) protocols, care protocols, first clinical as-

assessment sheets, ongoing care assessment sheets, patient records, referral follow-up forms, stock control sheets, and patient health promotion information.

- Pharmacy review — A tool was developed on which to record the availability of specific drugs commonly used in HIV/AIDS care and support, as well as whether stocks were unexpired/expired, if there had been previous stock-outs of in-date drugs, and storage conditions.
- Patient Focus Group Discussions (FGDs) — FGDs aimed to (1) validate staff interview data relating to components of care offered; and (2) explore aspects of patient care (e.g. most valued components of care, issues in obtaining medicines). The topic guide contained question lines on the following: demographic indicators, (e.g. gender, place of residence (urban, rural or peri-urban), age household size), receipt of key components of care including daily cotrimoxazole (CTX), a mosquito bednet and nutritional counselling.
- All tools were developed by a multidisciplinary team, including medical professionals, HIV specialists and care and support researchers, in conjunction with the United States Government Care and support Technical Working Group and the country teams. All tools were piloted in one large and one small Phase 1 facility in Uganda. Following piloting, the wording and structure of the tools were modified.

### *Ethical approval*

Ethical approval was obtained from the Kenyan Medical Research Institute and the College Research Ethics Committee at King's College London. All data were anonymised and stored separately from consent forms, in a locked filing cabinet in line with ethical guidance and the Data Protection Act.

### *Data collection procedures*

Facilities were informed of the planned survey by the Ministry of Health (MOH). Pairs of Kenyan researchers attended each site to collect data on a pre-arranged day, between April and August 2007. Data were recorded on two separate sets of identical forms. One set was left with the facility; the other was taken by the researchers and used for data entry. Researchers held interviews with senior facility staff (approximately three per facility). These staff were asked to provide blank patient documents (e.g. referral forms, assessment sheets and patient information sheets), where possible. Researchers visited the pharmacy to review stocks and stock cards, with the assistance of the pharmacist or dispenser.

FGDs were held with existing patients (inclusion criteria: adults aware of their positive HIV status, and under HIV/AIDS care and support for at least six weeks, who gave informed consent to participate). Approximately five patients in each facility were invited to participate in a researcher-facilitated FGD. Patients were purposively selected by staff with the aim of obtaining a diverse group with respect to gender, age, disease stage and antiretroviral (ARV) use. Researchers took notes of the discussions; the FGD was tape-recorded as a back-up.

### *Data management and entry*

Data were transferred to the offices of the Kenyan Hospice and Palliative Care Association immediately after collection. Quantitative data were double-entered by two different researchers, and validated, using EpiData v3.1. Data from open-ended questions were entered into pre-formatted templates in MS Word 2003.

### *Data analysis*

Analysis was conducted using Stata v10 (quantitative data) and NVivo v7 (qualitative data).

- Senior staff interview — Frequency tables were generated for key responses, grouped by facility type where appropriate. A Spearman's rank test for correlation was conducted to test the reliability of routine data. The stratified random sampling technique was undertaken to ensure facilities of all sizes were surveyed; however, weighted analysis could not be undertaken due to data inconsistencies. Thematic analysis of content was conducted on responses to open-ended questions. Emerging themes were organized into data categories and then agreed between two researchers.
- Document analysis — A matrix was developed in which the number of facilities reporting having prespecified documents was recorded. In those instances where the percentage of facilities providing examples of documents as a proportion of those who reported having such documents was less than 20%, or where the absolute number of documents was five or fewer, no further analysis was undertaken. In other cases, content analysis was undertaken to determine thematic frequency of the specific nature of the information in the document fields.
- Pharmacy review: Frequency tables were generated for each drug, grouped by facility type where appropriate. Data from the pharmacy review was compared with components of care provided, as reported by senior staff.
- FGDs — Information on FGD participants' background and receipt of care items was merged with the Stata database using unique identifying variables. Care reportedly received by FGD participants was compared with the care reportedly provided by facility staff. Thematic content analysis was applied to the remaining FGD data. The principal themes were organised independently into data categories and then agreed between two researchers.

## **Findings and Discussion**

### *Response rate*

Of the sixty facilities randomly selected for Phase 1, three could not be found and were replaced. Replacement was conducted using the same method described above, i.e. each facility was replaced with another randomly selected from the same stratum. FGDs took place in 49 facilities, involving 242 patients.

### *Facility characteristics*

Facility staff were asked to indicate which facility type most closely reflected their service from a list of options. Nine facilities were secondary/tertiary hospitals, 16 facilities were district hospitals, 15 were health centres, 10 were health posts and 10 were home-based care (HBC) only facilities (Table 1).

The majority of facilities surveyed (62%) were government run. There was a wide range of authorities to which facilities must report, including the Ministry of Health, PEPFAR and non-governmental organisations (NGOs). Further research may offer insight into the convergence and divergence in data requested by these authorities and where economies of effort may be achieved.

A number of issues arose relating to facility infrastructure that may potentially impact on all aspects of care and support provision. A minority of facilities lacked some basic elements of infrastructure,

including a functioning toilet (13%), a safe water supply (20%) and electricity (23%), which have clear implications for infection control and efficiency. Staff and patients also expressed desires for improvements in patient waiting areas. Improvements to laboratory and pharmacy supplies were also requested; pharmacy stocks are discussed in more detail below.

### ***Components of care and referrals***

Of the 69 care components surveyed, a mean of 42 components were provided or referred by facilities. The availability of every component is shown in Table 2. As might be expected, the number of components provided or referred for varied greatly by facility type, with hospitals providing or referring for the most components (mean of 53 components by secondary / tertiary hospitals, and 51 by district hospitals) and dispensaries and HBC-only facilities providing or referring the fewest components (mean of 21 and 38 components respectively). Referrals were generally rare, with 22 facilities not referring out for any care component surveyed. The care components most commonly referred were psychiatric therapy, viral load testing, CD4 testing and cancer management. Most components of care were provided free of charge.

Several key components of care were not provided nor referred for in numerous facilities: spiritual visits (not provided or referred for at 41 facilities), psychiatric therapy (30 facilities), ARVs (21 facilities), physiotherapy (34 facilities), strong opioids (56 facilities), weak opioids (43 facilities), anxiety/depression treatment (18 facilities), bednets (41 facilities), or HIV testing for children (20 facilities). It is unclear why facilities would not even refer informally for many of these components, unless there were no facilities that provided such services within a reasonable distance. For the components of care rarely provided or referred, the onus is on the patient or carer to identify a provider.

### ***Provision of holistic care and support***

Facilities were analysed according to whether they provided or referred any components of care from each of the PEPFAR domains of care and support: clinical, psychological, spiritual, social or preventive care. Data indicated that true holistic care was available in fewer than half of facilities. It is noteworthy that HBC-only facilities were the facilities most often providing or referring for holistic care and support.

Considering the lack of holistic care and support provision combined with low levels of outward referral (whether formal or informal), it appears that coordinated and planned holistic care is uncommon, and so patients are having to expend time and money in having (often related) needs met. Findings indicate that patients accessed a number of services, due to the limited care range available from individual facilities (especially diagnostic testing), and frequent drug stock-outs.

The content of several key facility documents were found to be clinically focused, thus limiting the potential for non-clinical needs to be assessed, and therefore treated. Furthermore, clinical records may not reflect patient status, if services are received from non-linked facilities without referral criteria, and patients are likely to be double-counted for some related components of care. A conflicting argument against increasing the availability of care via referral is evident from the patient FGDs. Patients found time and cost significant challenges to travel. Nonetheless, reasons given by patients for choosing a facility were not exclusively related to geographical ease of accessibility.

Receiving all care components at one site, having all required medications available, and receiving private and confidential care were all important considerations. Clearly if the latter criteria were not met in one facility then further travel/time costs would be required. In rural settings the lack of alternative facilities means referral is a problem, and highlights the need to provide holistic multi-dimensional care on site. In staff interviews, the ability to offer a full range of comprehensive care was also felt to be a strength.

### ***Antiretroviral therapy (ART)***

Nearly two-thirds of facilities offered (n=35) or referred (n=4) for ARVs, which was well supported by adherence counselling, assessment of ARV treatment failure and monitoring of ARV toxicity alongside. Few facilities provided or referred for ARVs without such support services, although several other facilities provided or referred for ARV support services, but not for ARVs themselves. Facility staff interviewed identified the high degree of ARV availability at no-charge, as a service strength.

### ***Pain management***

The low availability of oral opioids found in this survey is concerning, as the most effective way to provide opioids is orally (World Health Organization 1990), especially for the high proportion of Africans living with HIV who are cared for by their families at home. Staff from three facilities reported providing morphine; however, only one of these facilities was found to have a morphine stock during the pharmacy review (injectable only). The availability of other analgesics was variable. Although 51 facilities provided or referred for non-opioid analgesics, only 23 provided or referred for a weak opioid (e.g. codeine). The high number of facilities reporting providing non-opioids to patients was found to be in line with high levels of stock during the pharmacy reviews. However, only 65% of facilities with codeine stock reported providing it to HIV patients. Codeine and non-opioid analgesic stock levels in some facilities were very low, raising questions about the sustainability of analgesia for patients.

### ***Psychological health***

Psychological care components appeared to be widely available. Pre- and post-test counselling was provided or referred for in 90% of facilities (data corroborated by patient interviews), and anxiety/depression treatment was provided or referred for in 70% of facilities. However, psychological care was provided at 20 facilities that did not employ any counsellors. Counselling services were rated highly by patients, who perceived that facilities helped to reduce stigma, and improve their quality of life.

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

The area of social care in HIV is broad. In this survey we examined the place where care was delivered (in-patient, out-patient and HBC) and availability of a number of social care components, such as home help, transport to the facility, and provision of income-generating activities (IGAs). Although nearly a third of facilities reported providing or referring for transport to their site, FGD participants commonly expressed a greater need for transport indicating that need is not being fully met with current provision. Forty-five facilities provided or referred for HBC, although the content and delivery of this care was not explored as part of this survey. Home help for the patient or family was provided by 27 facilities. When looking at the PEPFAR areas of care and support,

HBC-only facilities most commonly provided or referred for care in all five areas; one of the key reasons for this was the provision of social care that was often lacking in other facility types. Possibly the availability of social care could be increased, given that in 11 facilities community health workers were employed, but none of the PEPFAR components of social care were being provided. Nutritional counselling, multivitamins and weighing were provided or referred for in nearly all facilities, and therapeutic feeding for malnutrition was provided or referred for in over half of facilities. However, one of the most common services requested by both FGD participants and facility staff was for food for HIV patients.

### ***Opportunistic Infections and Preventive Care***

Care components that aimed to prevent patients from contracting OIs and transmitting HIV, and the treatment of OIs were explored.

The purpose of the PCP is to serve as a short list of components of care that every person with HIV should receive as a preventative measure, to protect them from water-borne infections and malaria, as well as to prevent them from transmitting HIV. It is noteworthy that only five facilities provided a package according to a simple definition of bednets, treatment to make water safe, condoms, multivitamins and CTX. In light of the low referral activity, it is likely that patients were not receiving a basic package of care, or were accessing multiple points of care (facilities) for the basic care package.

Malaria, TB and sexually transmitted infections (STIs) could be treated at the majority of hospitals and health centres. However, other OI prophylaxis components were not as widely available, although staff often suggested these were a strength of their facility. Condoms were provided or referred for at 50 facilities, although some FGD participants reported that condoms were not available to all patients. Other OI preventative efforts, such as the provision of mosquito bednets, (also part of the PCP) and isoniazid to prevent TB, were not commonly provided or referred for (17% and 32% of facilities provided or referred for these services respectively).

The availability of the components of Prevention with Positives (PWP) seemed good. All five components (adherence counselling, family planning counselling, patient HIV support groups, treatment of herpes and condoms) were offered at 32 facilities. However, there may be some differences in understanding as to what constitutes 'PWP' at both the facility and public level, as there were differences in the reported availability of the PWP constituent components and the availability of PWP itself.

### ***Laboratory services***

Laboratory services are not specified as an element of care and support but they are necessary in order to prevent and manage infections, and monitor HIV progression. Many of the laboratory services needed for HIV care were commonly provided at hospitals, but not at smaller facilities. Where laboratory services were not available, both staff and patients often expressed a desire to provide such services on site. Facilities providing laboratory services reported problems in maintaining laboratory supplies, and highlighted the need for good supply and maintenance networks.

### *Staffing and care provision*

Although most facilities had clinical staff onsite, (usually a nurse and/or clinical officers) traditional healers, social workers and spiritual care staff were rarely employed. Only 12 sites (20%) had clinical, spiritual psychological and social staff all present, of any designation.

A few facilities were providing clinical components of care without employing staff who had specialist clinical training. One might have expected more facilities to be providing some basic clinical care components without employing clinical staff, as some of these components do not require specialist staff, e.g. weighing, providing multivitamins. However, other clinical care components, such as psychological care, do require specialist staff. Psychological care was provided at 20 facilities that had no counselors present, and 16 facilities provided social care without any community workers or social workers employed. These findings suggest that staff may be undertaking tasks within multiple areas of palliative care for which they may not have specialist training. Multi-tasking could overburden staff or reduce the quality of care in specialist areas. Staff stated their desire for more specialist staff and further staff training in order to improve care. Additionally, inappropriate staffing may exacerbate patient concerns/presenting complaints, and/or lead to multiple attendances at different clinics, adding significantly to patient costs. This will be explored further in Phase 2.

Patient loads were particularly high for some types of staff calling into question quality of care. Doctors, clinical officers and counsellors had median patient loads of 559, 412, and 274, respectively. However, calculated patient loads are subject to limitations. Firstly, patient contact time was not measured. This may have resulted in over-estimated median patient load values for doctors and clinical officers, for instance, as these staff may in fact undertake only a small amount of clinical work as a proportion of their working day. Secondly, patient load was assessed against job titles, and not job functions. As above, many staff were found to be undertaking a variety of tasks that would not normally fall under their job title, e.g. nurses who primarily deliver clinical care were also undertaking counselling and dispensing. For these staff, calculated patient loads may be under-estimated.

The availability of appointments to see non-clinical staff is of potential concern. HBC-only facilities commonly offered no clinical contact time and very minimal non-clinical contact time, with around half offering only 1-15 hours per week. It is not clear what type of contact is offered at facilities where neither clinical nor non-clinical care is available.

In terms of staff retention and facility sustainability, it is notable that across the entire survey sample volunteers were providing a significant amount of care. Voluntary staff levels were 30% overall and especially high in dispensaries (50%) and HBC-only facilities (90%). Designations most commonly staffed by volunteers were spiritual staff (35% of centres), community health workers (57%), and counsellors (32%). Volunteering is a positive reflection of commitment to HIV care by a community, and enables facilities to extend their reach with limited resources. However, given the high reliance on voluntary staff found in the smaller facility types, understanding such aspects of care delivery and staff motivation are crucial to care quality and continuity of provision.

### *Pharmacy stocks*

Four key issues were identified when the pharmacies were reviewed. As above, stocks of some medications were low. CTX and non-opioid analgesics were the most commonly stocked drugs

of those recorded; isoniazid and morphine the least common. As above, morphine was in stock at one site only, and this was in injectable form. Staff reported providing non-opioid analgesics at four facilities that were found not to have any pharmacy stock; the same discrepancy was observed for isoniazid at six facilities, fluconazole at 16; morphine at three and CTX at three. Only nine facilities had stock levels to guide reordering for any medications in the pharmacy, which was corroborated by a lack of stock level records found in the pharmacy reviews.

Secondly, stock-outs were common, e.g. in previous six months 27 sites had had a stock-out of non-opioids, 22 of fluconazole and 11 of codeine. The lack of a reliable and continuous supply of drugs was noted by FGD respondents. Thirdly, expired drug stocks were found on nine occasions, and weak opioids were found to be stored in an unlocked location at three facilities. Fourth, a number of drugs were not named by staff as available for their HIV patients, even though they were in stock in the pharmacy. This finding may be due to inadequate instrument design, or clinical assessment.

However, findings imply a lack of control over drug supplies at the facility level, rather than poor inhouse stock management. Reasons behind low stock levels, common stock-outs, and presence of expired drugs, were not explored.

#### ***Validation of care components offered (FGDs)***

Some discrepancies were noted between services provided (according to providers) and services available, (according to patients) e.g. condoms and water treatment. Reasons offered by patients for lack of provision include lack of need, cost, and ineligibility. Patient eligibility for particular services was not addressed in provider interviews.

#### ***Study Strengths and Limitations***

There are a number of strengths and limitations to this survey. The facilities were selected at random from three strata based on patient numbers. However, routine patient numbers were unrelated to patient numbers reported by facilities, which meant the strata were unreliable and so the sample could not claim to represent proportionally different facility sizes. Nevertheless, the facilities surveyed were still a simple random sample and included a variety of facility sizes by patient numbers, thus allowing cautious generalisation to other PEPFAR-funded care and support services in Kenya.

The data collection tool eliciting information on care components was subject to some limitations. The PEPFAR care components used in the analysis did not contain all the components captured in the questionnaire. Also, the number of components included within each area of care varied greatly, with most areas containing about four components, and clinical care containing over 30. Therefore, the likelihood of facilities providing or referring any element of clinical care is far higher than any element of the other areas of care. This may explain the apparent lower availability of spiritual or social care, although psychological and preventative care were commonly provided/referred for even though these categories also had only small numbers of care components. Also, the non-clinical areas of care and support, defined by PEPFAR, may not include components that facilities offer and that may fall into these areas.

Furthermore, provider/patient-reported data is subject to bias. For instance, providers may have reported a component of care as “provided/referred for” that was in fact not available, or equally



providers may not have been aware of all care components available to patients. Although provider-reported information could not be accurately validated, patient FGDs allowed for some triangulation of emerging findings.

FGD participants may not have been representative of the wider HIV positive patient population. Participants were patients who were present at the facility on the day of the visit, and asked to participate by facility staff. A purposive sampling frame was developed to maximise diversity; however, it is possible that participants were, for example, more sick than average (as demonstrated by their clinic attendance). Also, some participants were “peer counsellors” or other clinic volunteers and had received training for these roles and were likely to be better informed about HIV care issues than the general lay population. Furthermore, due to the high number of FGDs undertaken over a short timescale, it was not possible to transcribe and translate the discussions. Notes were taken by the facilitator, and these were analysed for content. This method has limitations, in that notes capture less data than transcriptions; some views or opinions may not have been recorded.

With respect to the pharmacy review, it is possible that drugs with another label, or a less common formulation than the one asked about, were in use. The most commonly used drugs were reviewed — identified through wide consultation (although we chose not to include ARVs). Also, despite many documents reportedly being available, a large proportion of facilities could not supply the researchers with an example document. This limited the depth of the content analysis and raises the risk of bias.

## **Recommendations**

### ***Facility infrastructure***

Facility infrastructure requires improvement in many facilities, particularly enlarging clinic and waiting areas. Some facilities also require improved electricity and water supplies for sanitation and infection control.

### ***Health management information systems***

- We observed a low number of care components being provided at smaller facilities, even after including availability via referral. Reliable and well-monitored referral networks for specialist HIV care and support should be established. As well as improving patient care, such networks may help to reduce the number of patients who ‘shop around’ for their health care services, and the subsequent double-counting of such patients.
- In order for reliable referrals to work, comprehensive information on patients attending facilities and the care they receive, including outward and inward referrals, are needed for good patient care and efficient use of service resources. Improvements in the detail and management of patient records need to be made.

### ***Staffing***

An increase in the numbers of specialist staff (ie staff of specific designation) is needed to ensure that staff are not reliant on operating outside their speciality. Generalist skills are important for all staff, but specialists are required for more complex cases. Increasing specialist training and employing staff to deliver non-clinical aspects of care and support, such as psychological and spiritual care, could improve care quality by freeing up more time for clinical staff to provide clinical care.

***Care provision***

- Patient status should be assessed, and documented, in a multiprofessional, holistic and ongoing manner.
- The availability and accessibility of holistic care and support services should be increased within facilities.
- The provision of OI prevention should be improved. Although treatment of OIs appeared to be widespread, prevention of specific OIs and the components of the PCP were less widely offered. Specifically for CTX, although it was reported as being widely available, this was not matched by consistent pharmacy stocks or reliable sourcing by patients. Increasing the provision of reliable OI prevention and the PCP could have greater health benefits for HIV patients.
- Provision of weak and strong opioids in HIV care and support services should be urgently addressed.
- Social care should be provided, directly or by referral, at all facilities.
- Basic preventive and support services should be made available for all who need them to as many patients as possible.

***Drug supplies***

The high frequency of stock outs, and challenges in this respect described by patients, need to be addressed through improving pharmacy stock supply, control, records and storage.

***Laboratory services***

Laboratory services, particularly CD4 and liver function testing, should be made more widely available at facilities providing ART. For smaller facilities, referral networks to larger facilities for such services should be examined and strengthened.

***Further research***

In light of this survey there were a number of areas of exploration that could yield useful findings to better understand care and support provision.

- An investigation of the training available and received in the area of HIV care and support received should be undertaken. A study of the content of patient contact time would also improve understanding of how different aspects of care are delivered. Knowledge of both areas is essential to understand the extent and quality of multidisciplinary care and the confidence with which staff deliver it.
- 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.
- Further investigation of which staff members deliver which areas of care in what location (facility, home, outreach), and the content of various care components (e.g. nutritional counselling or home help) would provide a more detailed picture of how care is delivered (this will be explored in more detail in Phase 2).
- Given the high levels of stockouts found in this survey, a more detailed investigation of how drugs are supplied would be beneficial to help improve this aspect of care.
- Volunteer staff provided a significant amount of clinical and non-clinical care. Further research should investigate the motivation and needs of voluntary staff in order to sustain this cadre.

- Several potential gaps between facility provision and patient receipt of care were highlighted during this survey, such as drug availability, a requirement to meet criteria before receiving certain components of care, and accessing facilities. Further research is needed to determine the frequency, nature and effects of these gaps.
- Findings here suggest that provision of care does not necessarily equate to accessibility for patients. The extent and effects of criteria for accessing care, and other potential barriers to care, should be further investigated.
- A study of the care and support services (both specialist and alongside adult services) available to children should be undertaken.

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Table 1: Participating facilities

ID	Facility Name	Region	Self-reported Facility Type
115	Muriranjias Sub District Hospital	Central	Secondary/tertiary hospital
127	Holy Family Nagina Mission Hospital	Western	Secondary/tertiary hospital
136	Gatundu Sub District Hospital	Central	Secondary/tertiary hospital
139	St Joseph Hospital, Nyabondo	Nyanza	Secondary/tertiary hospital
154	Kakamega Provincial General Hospital	Western	Secondary/tertiary hospital
156	Nyeri Provincial General Hospital	Central	Secondary/tertiary hospital
157	Thika District Hospital	Central	Secondary/tertiary hospital
158	BOMU	Coast	Secondary/tertiary hospital
161	Jocham Hospital, Mombasa	Coast	Secondary/tertiary hospital
109	Naivasha	South Rift	District hospital
118	Marsabit District Hospital	Eastern	District hospital
124	Tana River District Hospital	Coast	District hospital
126	Lamu District Hospital	Coast	District hospital
128	St Luke's Kaloleni Hospital	Coast	District hospital
131	Keroka Sub District Hospital	Nyanza	District hospital
132	Othaya Sub District Hospital	Central	District hospital
137	Gilgil Health Centre	South Rift	District hospital
140	Kapenguria	North Rift	District hospital
144	Karatina Sub District Hospital	Central	District hospital
146	Rondo Sub District Hospital	Nyanza	District hospital
149	Teso	Western	District hospital
153	Vihiga District Hospital	Western	District hospital
155	Sindo Sub District Hospital	Nyanza	District hospital
159	Kericho District Hospital	South Rift	District hospital
102	Modogashe Sub District Hospital	North Eastern	Health centre
105	Ngorongo health centre	Central	Health centre
114	Jericho Health Centre	Nairobi	Health centre
116	Mbooni Sub District Hospital	Eastern	Health centre
120	Ugina	Nyanza	Health centre
129	Ukwala Sub District Hospital	Nyanza	Health centre
130	NEPHAK - Makadara	Nairobi	Health centre
134	Mtopanga BI	Coast	Health centre
135	Embakasi - Nairobi	Nairobi	Health centre
138	Rera Health Centre	Nyanza	Health centre

ID	Facility Name	Region	Self-reported Facility Type
141	Rwambwa Health Centre	Nyanza	Health centre
142	St Johns Ambulance	Nairobi	Health centre
143	Ogongo	Nyanza	Health centre
147	St Vincent	Nairobi	Health centre
160	Chulaimbo	Nyanza	Health centre
169	Tudor District Hospital	Coast	Health centre
101	Ndithini Mission Hospital	Eastern	Dispensary
103	Makwasinyi Dispensary	Coast	Dispensary
104	Kitobo Dispensary	Coast	Dispensary
110	Nomadic Community Trust - Charda		Dispensary
112	Nyache Health Centre	Coast	Dispensary
122	Kibos Prison Dispensary	Nyanza	Dispensary
123	Nomadic Community Trust - Lkwasi		Dispensary
133	Kapsumbeiyo Tea Estate	North Rift	Dispensary
150	NEPHAK - city centre	Nairobi	Dispensary
167	Usao Dispensary, Suba	Nyanza	Dispensary
106	NMCK/NUR - Migori	Nyanza	HBC-only
108	NEPHAK - Garissa	N Eastern	HBC-only
113	KENEPOTE – Teso	Western	HBC-only
117	NEPHAK – Karachuonyo	Nyanza	HBC-only
121	NEPHAK – Mwingi	Eastern	HBC-only
125	NEPHAK – Nyeri	Central	HBC-only
145	NEPHAK - Nakuru	South Rift	HBC-only
148	RAAG	Central	HBC-only
151	BUCOSS	Western	HBC-only
152	NEPHAK - Embakasi	Nairobi	HBC-only

Table 2: Components of care available

Type of care	Component of care	Provided here	Referred formally	Referred informally	Not provided
General clinical	Nursing care	50	0	0	10
	Adult diagnostic HIV testing	40	4	2	14
	ARVs	35	3	1	21
	Weighing	51	1	0	8
	Assess ARV treatment failure	36	1	0	23
	Monitor ARV toxicity	37	2	0	21
	Wound care	46	3	1	10
	Physiotherapy	21	4	1	34
Pain control	Assessment of pain	43	2	0	15
	Strong opioids	3	1	0	56
	Weak opioids	16	1	0	43
	Non-opioids	50	1	0	9
	Treatment for neuropathic pain	36	3	0	21
Symptom control	Anxiety/depression treatment	41	1	0	18
	Treatment for nausea/vomiting	48	1	0	11
	Treatment for skin rash/itching	49	0	0	11
	Treatment for diarrhoea	50	1	0	9
	Laxatives	35	5	0	20
	Treatment for thrush	49	0	0	11
	Treatment for oral candidiasis	49	0	0	11
	Treatment for cryptococcus	38	3	1	18
	Treatment for other fungal infections	49	0	0	11
	Treatment for herpes	45	3	0	12
	Treatment for malaria	50	0	0	10
	Tuberculosis (TB) detection	38	4	0	18
	TB treatment	43	2	0	15
	Therapeutic feeding for malnutrition	31	2	0	27
	Treatment for other opportunistic infections	50	1	0	9
Management of cancer	14	8	0	38	
Psychological	Pre- and post- test counselling	54	0	0	6
	Adherence counselling	51	1	1	7
	Family planning counselling	51	1	1	7
	Patient HIV support groups	45	1	0	14
	Family care-givers support group	20	0	0	40

Type of care	Component of care	Provided here	Referred formally	Referred informally	Not provided
Psychological con't	Family counselling	43	1	2	14
	Psychiatric therapy	15	11	4	30
Spiritual	Visit by pastor	15	0	4	41
	Prayer with patients	27	1	0	32
	Contact with traditional healer/herbalist	2	0	0	58
Social	Home help	27	0	0	33
	Transport to care centre	16	1	1	42
	Employment training/income generating activities (IGA)	16	1	1	42
	Provide household items	9	0	1	50
	Legal services	15	5	5	35
	Memory book work	14	0	1	45
	Family home help	27	0	0	33
	Loans/microfinance	5	0	2	53
	Infection control training	45	0	2	13
HIV prevention	Support for family testing	53	0	0	7
	Circumcision	28	1	1	30
	Prevention with positives	58	0	0	2
Prophylaxis & preventive care	Multivitamins	54	0	0	6
	Nutritional advice	59	0	0	1
	Access to safe drinking water at home (safe water treatment)	22	1	1	36
	Septrin/CTX	49	0	0	11
	Isoniazid	10	0	0	50
	Condoms	50	0	1	9
	Mosquito bednets	19	0	0	41
Laboratory	Liver function test	18	6	0	36
	Malaria film	40	1	0	19
	AFB smear	38	2	0	20
	CD4 count/test	20	8	0	32
	Rapid HIV test	49	0	0	11
	Pulse oximetry	10	1	0	49
	Dried blood spot for early infant diagnosis	18	7	1	34
	Viral load	6	11	0	43



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<b>Type of care</b>	<b>Component of care</b>	<b>Provided here</b>	<b>Referred formally</b>	<b>Referred informally</b>	<b>Not provided</b>
Paediatric	Paediatric ARVs	29	3	0	28
	Infant testing and counselling	31	2	0	27
	Children testing and counselling	39	0	1	20

# Powerpoint Presentation

Findings presented at HIV Implementers Meeting, Kampala, May 2008



## PEPFAR Public Health Evaluation – Palliative Care *Phase 1 Kenya*

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## Phase 1 Aim and objective

- **Aim**

- to describe the nature and scope of HIV palliative care provision supported by PEPFAR

- **Objective**

- to conduct a **cross-sectional survey** of service configuration and activity among 10% of the facilities being funded by PEPFAR HIV palliative care

### Palliative Care

*‘An approach which improves the quality of life of patients and their families facing life-threatening illness, through the prevention, assessment and treatment of pain and other physical, psychosocial and spiritual problems’*

## Methods – Site selection

- List of PEPFAR-funded PC facilities stratified by no. patients (1-100, 101-500, 501+)
- 20 facilities selected randomly from each stratum (60 in total)
- KEHPCA/APCA researchers visited each facility April-Aug 07



## Methods – Data collection tools

### Senior staff questionnaire section 1: structured interview

- Staff & patient numbers
- Facility strengths & areas for improvements
- Sustainability

### Senior staff questionnaire section 2: components of care

- Spiritual
- Psychological
- Clinical
- Social
- Prevention

### Document analysis

- Aim & criteria
- Referral & assessment forms
- Care protocols

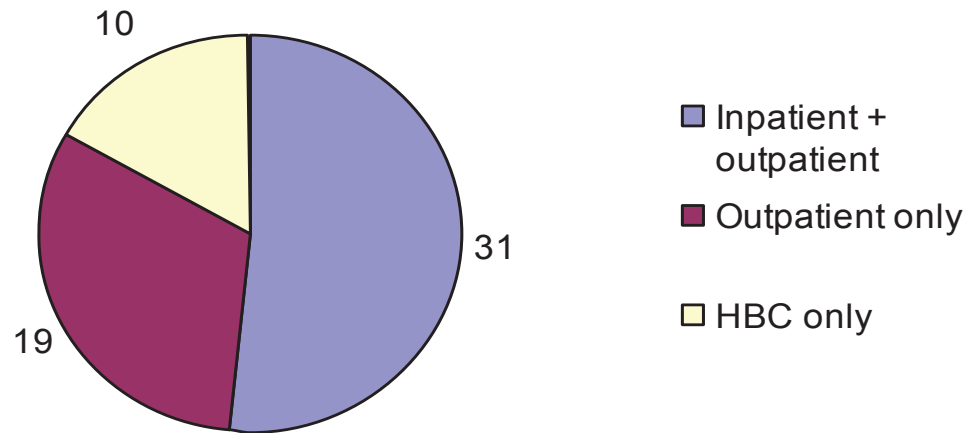
### 5 patients per site: Focus group

- Components of care received
- Problems encountered

### Pharmacy stock review

- Drugs in stock
- Supply chain
- Expiry

## Results – Types of facility



## Results – Pain management

Component of care	n (%) facilities where offered			
	Total (n=60)	Inpatient (n=31)	Outpatient (n=19)	HBC (n=10)
Assessment of pain	43 (72)	26 (84)	14 (78)	3 (30)
Non-opioids, e.g. paracetamol	50 (83)	29 (94)	18 (95)	3 (30)
Weak opioids, e.g. codeine	16 (27)	13 (42)	3 (16)	0 (0)
Strong opioids, e.g. morphine <b>1</b>	3 (5)	2 (6)	1 (6)	0 (0)

## Results – OI prevention

Component of care	n (%) facilities where offered			
	Total (n=60)	Inpatient (n=31)	Outpatient (n=19)	HBC (n=10)
CTX	49 (82)	30 (97)	17 (89)	2 (20)



## Results – Nutritional support

Component of care	n (%) facilities where offered			
	Total (n=60)	Inpatient (n=31)	Outpatient (n=19)	HBC (n=10)
Weighing	51 (85)	31 (100)	17 (89)	3 (30)
Multivitamins	54 (90)	31 (100)	19 (100)	4 (40)
Nutritional advice/counselling	59 (98)	31 (100)	19 (100)	9 (90)
Therapeutic feeding for malnutrition	31 (52)	20 (65)	7 (37)	4 (40)

## Results – Psychological health

Component of care	n (%) facilities where offered			
	Total (n=60)	Inpatient (n=31)	Outpatient (n=19)	HBC (n=10)
Pre- and post-test counselling	54 <b>(90)</b>	31 <b>(100)</b>	17 <b>(89)</b>	6 <b>(60)</b>
Treatment for anxiety/depression	41 <b>(68)</b>	28 <b>(90)</b>	12 <b>(63)</b>	1 <b>(10)</b>
Psychiatric therapy	15 <b>(25)</b>	13 <b>(42)</b>	2 <b>(11)</b>	1 <b>(10)</b>

## Results – Basic care package

Component of care	n (%) facilities where offered			
	Total (n=60)	Inpatient (n=31)	Outpatient (n=19)	HBC (n=10)
CTX	49 (82)	30 (97)	17 (89)	2 (20)
Mosquito bednets	19 (32)	8 (26)	9 (47)	2 (20)
Safe water treatment	22 (37)	13 (45)	6 (32)	3 (30)
Multivitamins	54 (90)	31 (100)	19 (100)	4 (40)
Condoms	50 (83)	28 (90)	16 (84)	6 (60)
<b>All above</b>	<b>5 (8)</b>	<b>3 (10)</b>	<b>1 (6)</b>	<b>1 (10)</b>

## Results – Patient validation

Component of care	% facilities offering component of care					
	Inpatient (n=25) (n=31)		Out-patient (n= 14)(n=19)		HBC (n=8) (n=10)	
Mosquito bednet	12%	26%	0%	47%	38%	20%
Safe water treatment	4%	45%	0%	32%	13%	30%
Nutritional advice	88%	100%	71%	100%	100%	90%
Post-test counselling	96%	100%	79%	89%	100%	60%

N patients participated in FGDs = 242 in 49 facilities

## Summary

- Facilities providing inpatient care most likely to offer most care components examined
  - Mosquito bednets most commonly offered at outpatient facilities
- Non-opioids commonly offered (83%) for pain management, but stronger analgesics rare
- CTX widely offered at inpatient (97%) and outpatient (89%) facilities
- Care to provide nutritional support widely offered
  - Nutritional advice most commonly offered component (98%)
- Most BCP components commonly offered, but only 5 facilities offer all 5 components

### Study strengths and limitations

- Every facility randomly selected and visited by trained researcher
- Self reported data, some validation
  - *Validation with some patients undertaken (e.g. have items been received)*
  - *Due to differences in data collection methods between patients and providers, comparison of findings limited.*
  - *Cannot verify if care offered by facility received by patients (Phase 2)*
- Need description of the specific nature of care components, e.g. counselling or pain management

## Recommendations and further research

### *Recommendations:*

- Increase availability of pain medication
- Increase availability of the basic care package

### *Further research:*

- Further investigate the mechanisms of prescribing/ dispensing to patients attending HBC-only facilities
- Analyse referral networks

### *Further research already underway in Phase 2:*

- Assessing the longitudinal association between care received and patient outcomes
- Exploring the content of patient/facility contact in palliative care domains



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