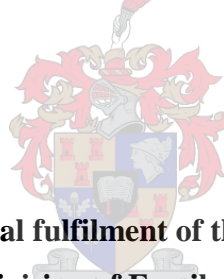


**A survey to explore factors that delay patients  
from accessing antiretroviral treatment at an  
East London Hospital Complex clinic**

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## **Declaration**

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## **ABSTRACT**

### **Introduction**

This cross-sectional study assessed factors affecting access to antiretroviral therapy (ART) among HIV patients. The aim of this study was to explore factors that delay patients from accessing antiretroviral treatment at an East London Hospital Complex clinic and to determine the pathway that people from communities in the surrounding area take in order to access antiretroviral treatment at the referral hospital ART clinic

### **Methods**

The study design was a descriptive cross-sectional survey using both open and closed questions to generate qualitative and quantitative data. The survey used a questionnaire administered via a face to face interview. 200 Adult patients (>18years old) from the local population with a CD4 count of  $\leq 100/\text{mm}^3$  referred to the ART clinic at East London Hospital Complex for the first time during May to October 2011 were interviewed.

### **Results**

With the health system, some issues were structural (staffing, availability of CD4 counts) and most were process related and reflected a poor patient experience and lack of trust in the quality of care. Contextual related issues were mainly geographic accessibility (cost and lack of transport, distance to health care facility), stigma and discrimination about HIV. Patients related factors included misperceptions and false beliefs about HIV, low level of education, socioeconomic factors, lack of family and social support such as unavailability of treatment supporter and status of patient's general health discouraged people from seeking ART. Coping strategies such as denial of results and reluctant to disclose results to other people came out as a distrust of patients in community.

### **Conclusions**

This study gives evidence that people living with HIV experience health system, patient and contextual related barriers to access HIV treatment. The majority accessed care via their local primary care clinic and traditional or alternative practitioners did not appear

to play a major role. The distance from and cost of transport to the referral hospital ART service was a major issue compounded by the difficulty of travelling when acutely sick. The expectation of long waiting times and sometimes negative staff attitudes reduced motivation. A number of other factors related to the patient, the health service and the community context were also identified. Many of these factors that reduce access to ART are amenable to change.

## **Introduction**

The introduction of antiretroviral treatment (ART) for HIV infection has made what was once a terminal illness into a treatable chronic condition. However, in low- and middle-income countries this is not yet a reality, as approximately 70% of the 9.7 million people estimated to be in need of ART do not access it.<sup>1</sup> Identifying what is keeping the ART coverage rate so low is imperative, especially when the costs of ART no longer seem to be a constraint.

In all heavily affected countries like South Africa, the AIDS epidemic is adding additional pressure on the health sector. As the epidemic matures, the demand for care for those living with HIV rises, as does the toll of AIDS on health workers. In sub-Saharan Africa, the direct medical costs of AIDS (excluding ART therapy) have been estimated at about US\$30 per year for every person infected, at a time when overall public health spending is less than US\$10 per year for most African countries.<sup>2</sup>

The number of people living with HIV worldwide continued to grow in 2008, reaching an estimated 33.4 million. The total number of people living with the virus in 2008 was more than 20% higher than the number in 2000, and the prevalence was roughly threefold higher than in 1990.<sup>3</sup> This is a strong indicator that AIDS is a major, if not the principal, factor in the overall rising number of deaths.

The impact of the AIDS epidemic is reflected in the dramatic change in South Africa's mortality rates. The overall number of annual deaths increased sharply from 1997, when 316,559 people died, to 2006 when 607,184 people died. This rise is not necessarily due solely to HIV and AIDS but it is most marked in young adults, the age group most affected by AIDS.<sup>4</sup>

Since 2000 there have been a number of steps taken by the UN and WHO to improve access to ART for people all over the world, especially in resource-poor settings. In 2000, 189 countries signed the UN Millennium Declaration and the eight Millennium Development Goals (MDG's).<sup>5</sup> Three of the eight goals are directly related to the health of women, children and people with HIV/AIDS. Since 2001 the WHO has been promoting a public health approach to ART. The WHO published their first treatment guidelines for resource-limited settings in 2002, which were revised in 2006. Guidelines for the prevention of mother to child transmission and separate guidelines for children were also developed.<sup>6</sup> These steps were supported by the increasing availability of funds through the Global Fund to Fight AIDS, Tuberculosis and Malaria.<sup>7</sup> There are however, a number of constraints in the health systems of developing countries, that will hamper the achievement of the MDG's. These include lack of human resources, financial constraints and problems with resource allocation, drug and supply systems, physical infrastructure and inadequate monitoring systems. Very little research has been done on these constraints and on strategies on how to overcome them.<sup>8</sup>

It is important to look at what factors are preventing patients from accessing ART treatment. Access to public services has been defined as the ability of Individuals to obtain the services they need and want.<sup>9</sup>

Poverty impacts on the ability to obtain care as well as experience of the care obtained. Poor and low income families often have unsatisfactory experiences at the public hospitals. One study indicates that lack of resources can severely affect the ability of the people living with HIV to obtain care, whether it is the inability to purchase transport to the health care centre or the inability to afford the fees charged at the health care centre.<sup>10</sup>

Being a developing country, South Africa faces enormous challenges with HIV treatment access on a national scale in the health system at primary and district level such as lack of well organised, coordinated structural resources. Some challenges include ensuring uninterrupted drug supplies, laboratory capacities for CD4 monitoring, accessible voluntary counselling and testing, trained healthcare workers, and effective monitoring of resistance to antiretroviral drugs.<sup>11</sup>

Stigma has been part of the HIV/AIDS epidemic since it was first identified. Stigma has impacted people with HIV throughout the world.<sup>12,13</sup> This has resulted in slow mobilization of resources and the loss of millions of lives. Unfortunately stigma is worse in societies already affected by racism, sexism and poverty.<sup>14</sup> In Nigeria 26% of HIV positive patients in one study were unwilling to seek ART at the nearest hospital because of fear of stigmatization.<sup>15</sup> Confidentiality is important in AIDS related stigma and discrimination. According to UNAIDS, AIDS related stigma is “the process of devaluation of people living with or associated with HIV/AIDS. Despite more than 20 years of awareness of AIDS, the stigmatisation of people living with HIV remains strong.”<sup>16</sup>

There are a number of problems hampering the provision of HIV counseling and testing.<sup>17</sup> As HIV testing is a key entry point to care for HIV infected individuals and ART treatment it is important that these issues be addressed. Many of these issues are worsened by the general lack of national policies and guidelines in some countries, although the South African National AIDS council has published comprehensive guidelines for the management of HIV.<sup>18</sup> Other barriers to access care that have been identified in studies in developed and developing world include denial of the disease as many don't show signs of illness, financial constraints affecting use of transport and food security, and struggles to understand the health care system.<sup>20,7</sup>

In many countries around the world women are socially vulnerable, with limited choices due to poverty, poor access to education and unequal gender relationships. These limit the choices they are able to make when trying to protect themselves from HIV and access healthcare for themselves and their children. For instance in many cultures the ability of women to discuss sex or suggest the use of condoms is decreased by balance of power in their sexual relationships, and this can increase their vulnerability to infection as well as on their access to HIV treatment.<sup>13,19</sup>

In India and Africa HIV positive women are treated differently to HIV positive men. In India, for example, the husbands who infect women may leave women living with HIV and sometimes women are rejected by the family. In some African countries, women are blamed and considered responsible for the death of their husbands when they die of HIV related infections. So it is difficult for women to disclose their

seropositive status. This can cause them to refuse to test or disclose their status and further limit their access to care.<sup>13, 20</sup>

There are gender-specific factors that influence access to ART among women in Africa for instance, not being given complete information because of being female, requiring the husband's permission to start ART, fear of divorce or rejection. In one study from Zambia 63% patients felt that health workers did not give complete information because of their sex, 45% pointed out that there were insufficient women counsellors, 57% felt difficulty to disclosing to partners, 52% thought they would need a partner's permission before starting treatment and 82% felt that cultural traditions were barriers to accessing ART.<sup>21</sup>

Attitudes and beliefs also play a major role in help seeking behaviour for HIV treatment such as feeling of hopelessness and despair, difficulties with changing of life style, fear of taking medicines for life, side effects, rejection by the family and dying from a terminal disease.<sup>22</sup>

People living with HIV disease, particularly those in small towns and rural areas, face many barriers that prevent them from receiving important life-saving services. In one study, both urban and rural respondents indicated that major barriers to services included a lack of knowledge about HIV, insufficient personal financial resources, a lack of employment opportunities and a the lack of supportive and understanding work environments.<sup>23</sup>

Another study from Tanzania showed that transportation and supplementary food costs, the referral hospital's reputation for being unfriendly and confusing, and difficulties in adhering to long-term treatment, limited accessibility. Many were reluctance to identify a "treatment buddy" as required by the programme. Simple measures to reduce perceived barriers improved initial access to treatment and help to overcome anxiety among early referrals.<sup>24</sup>

From the literature the researcher has identified factors which are important and relevant for this study.<sup>11- 25, 26,27</sup>

### **Community context factors**

- Geographic accessibility
  - Lack of public transport.
  - Cost of transport to health care facilities.
  - Distance to health facilities
  - Living in a rural area versus urban area.
- Stigma and discrimination about HIV.

### **Patient-related factors**

- Patient beliefs, ideas and coping strategies
  - Patient's traditional health beliefs.
  - Fear of terminal diagnosis/side effects of drugs/change of life style
  - Fear of isolation/rejection/divorce
  - Belief in alternative treatments e.g. vitamins sold for profit, sometimes even advised by state health workers
  - Inability to disclose positive status
  - Denial and disbelief in results.
  - Belief that they are not a candidate for ARV at present.
  - Myths and misinformation about HIV/AIDS.
  - Low level of education
- Social support from family and friends
  - Lack of family support.
  - Requiring husband's permission to access ART
  - Family responsibilities
- Illness and functioning
  - Poor physical and mental health of patients
- Socio-economic factors
  - Poverty.
  - Lack of medical insurance schemes.
  - Unemployment

### **Health system issues**

- Availability of services
  - Lack of materials or drugs needed for treatment



- Healthcare workers not available
- ARV not offered at the health facility
- Difficulties in accessing CD4 results
- Acceptability of services
  - Negative attitudes of health-care workers
  - Practitioner's health beliefs and behavior
  - Lack of language interpreters or facilities.
  - Corruption in health-care facilities
  - Poor quality of care
  - Breaches of confidentiality at clinics or hospital.
  - Lack of consistency and co-ordination across services.<sup>28,29</sup>
- Accommodation of accessibility
  - Long waiting time at clinics and hospitals
  - In-effective patient referral systems.
- Affordability of services
  - Cost of drugs.
- Utilization of services
  - Hospital congestion, sometimes because of inappropriate and unnecessary self-referrals.
- Equality in access
  - Discrimination at health facilities
  - Restrictions on providing ART e.g. withholding from clients who are thought to have an alcohol problem, or withdrawing from clients who miss an appointment or are thought to be unreliable

The researcher has been working at the East London Hospital Complex, East London, Eastern Cape, South Africa where he had a chance to work at ART clinic for some time and noticed that many patients had very low CD4 counts when referred for ART, which implied a delay in accessing treatment. This study therefore was intended to explore the factors involved in delaying the presentation of patients at the ART clinic.

## **Aims and objectives**

The aim of this study was to explore factors that delay patients from accessing antiretroviral treatment at an East London Hospital Complex clinic. Specific objectives were:

- To determine the pathway that people from communities in the surrounding area take in order to access antiretroviral treatment at the referral hospital ART clinic.
- To explore factors that delay patients from accessing ART.
- To use this information to recommend improvements to the ART programme at the East London Hospital Complex.

## **Methods**

### **Study design**

The study design was a descriptive cross-sectional survey using both open and closed questions to generate qualitative and quantitative data. The survey used a questionnaire administered via a face to face interview.

### **Setting**

Patients in Amathole district are usually diagnosed at local clinics or community health centres. Firstly counselling is done and a rapid test for HIV is carried out depending on the availability of the testing kits. The patient is then informed about the result and post-test counselling is performed at the same facility. For those testing positive some clinics also take blood for CD4 counts and send it to the East London National Health Laboratory which provides results after two days. All patients having CD4 count below  $350/\text{mm}^3$  are referred to district hospital. District hospital ARV clinics do further baseline blood tests and rule out tuberculosis before starting ARV treatment. If patients need further help they are referred to the ARV clinic at the East London Hospital Complex. The ARV clinic at the East London Hospital Complex, where this study was based, also provides district hospital level care to the immediate surrounding area.



**Figure 1: Patient referral system at Amathole district**

The researcher was working at the East London Hospital Complex. This hospital complex consists of two hospitals, namely Frere and Cecilia Makiwane. This complex receives referrals from district hospitals in its catchment area and also offers primary care as well as district hospital services to the local population. Frere Hospital (FH) is situated in the city of East London in the Amathole District of the Eastern Cape Province of South Africa and has a catchment population of 724, 312. Frere and Cecilia Makiwane hospitals are considered level 2 hospitals and therefore are a referral point for a number of districts in the province. Thus, the catchment area for these hospitals goes beyond the borders of the Amathole District.

Large numbers of patients with more complicated problems are referred from primary and district ARV clinics to the hospitals. At the same time the ARV clinic also receives uncomplicated patients from the local area who are newly diagnosed HIV positive and need ART. My study focuses on the access to care of these patients from the local

community who are newly diagnosed and accessing level 1 services at the referral hospital.

Patients present themselves at the ARV unit reception with a referral letter that contains proof of their HIV status and the results of their CD4 count. After registration a nurse takes their history and triages the patients. The patient is then seen by the adherence counsellors. The social worker also sees all the new, defaulting and virologically failing patients. The patients proceed to the doctor or a nurse depending on their triage. After the consultation with the doctor or the nurse, the patients take their prescription to the pharmacy and then return the folder to reception. The date for the next visit is given at the reception. Table I shows the current human resources available in the ART clinic of Frere Hospital.

**Table I: Human Resources at ART Clinic of Frere Hospital**

Category	Staff at the site			Required ARV Staff		Comments
	Full-time	Part-time	Total	As per approved structure	Variance	
Medical Officer	3	1	4	6	2	One part time MO
Professional Nurses	6	-	6	12	6	
Enrolled Nurses	1	-	1	2	1	On study leave. One post not filled yet
Nursing Assistants	0	-	0	2	2	Never appointed
Pharmacists	2	-	2	6	4	One is from ICAP/UFH project
Pharmacists Assistant	2	-	2	12	10	Both from ICAP
Social Worker(s)	1	-	1	2	1	One post not filled yet
Dietician/Nutritionists	0	1	1	6	6	Dietician from the main hospital
Psychologist	0	0	0	1	1	Critically needed
Professional Counsellor	0	-	0	0	0	Not on the structure
Lay Counsellors/FCG/CHW	10	-	10	30	20	4 Lay Counsellors are from ICAP
Admin Clerks/Receptionist	1	-	1	6	5	Admin officers assist clerical work

Data Capturers	2	-	2	6	4	One from ICAP.
Other (Porters)	0	-	0	1	1	Porter is needed
Phlebotomist	0	-	0	1	1	Currently using MO and Nurses

**MO:** Medical officer, **ARV:** Anti-retroviral, **ART:** Anti-retroviral treatment, **ICAP:** international centre for AIDS and treatment programs, **UFH:** university of Fort Hare, **FCG:** Field care givers, **CHW:** Community health worker.

Cecilia Makiwane Hospital has a catchment population of 800,000 with the main draining areas are of Newlands, Berlin, Mdantsane and surrounding and surroundings. Table II shows the current human resources available in the ART clinic of Cecilia Makiwane Hospital. Study was done at both ART clinics.

**Table II: Human Resources in ART Clinic of Cecilia Makiwane Hospital**

Medical Officers	1 full time medical officer. 1 community service doctor
Professional Nurse	4
Assistant Nurse	1
Pharmacist	1
Pharmacy assistant	2
Dietician	1
Social worker	1
Lay counsellor	3

### **Study population**

About 2000 new patients with a CD4 count of less than  $100/\text{mm}^3$  visit the ARV clinics at the East London Hospital in a year. Based on a confidence interval of 95%, power of 80% and precision of 7.5% a study sample size of 190 patients was considered to be a representative sample. Therefore, a sample size of 200 patients was intended.

### **Inclusion criteria**

Adult patients (>18years old) from the local population with a CD4 count of  $\leq 100/\text{mm}^3$  referred to the ART clinic at East London Hospital Complex for the first time during May to October 2011 were interviewed. A CD4 count of  $100/\text{mm}^3$  was taken as a cut off as these patients were presenting later than ideal for initiating ART, as the South Africa threshold for initiating ART was  $200/\text{mm}^3$ . They therefore represented a group of patients who had not accessed timely treatment.

### **Exclusion criteria**

Patients < 18 years of age, those already on ART and those referred from outside the local population, and who didn't give consent were not selected for study.

All consecutive patients who fulfilled eligibility criteria for selection from May, 2011 to October, 2011 were interviewed by researcher and research assistant. Research assistant was a health care worker and had two years of work experience at ART clinic.

### **Data collection**

The questionnaire was modified from tools used in previous studies<sup>21,23</sup> (see appendix 2) and had two sections. The first section explored the person's pathway to care and perception of any barriers using open ended questions and collected qualitative data. The interviews were conducted in a private, quiet and separated area to ensure confidentiality at the East London Hospital Complex ART clinics. The answers were recorded on paper verbatim or paraphrased. The second section collected quantitative data by the use of closed questions regarding factors likely to influence access to care.

The questionnaire was administered to each patient by a research assistant who also helped, when necessary with the explanation and translation of questions into Xhosa, for example if the participants were illiterate or semi-literate and had difficulty in reading or understanding. The answers were completed in English on the questionnaire by the research assistant. All participants had access to the researcher to clarify any uncertainties they faced about answering the questions.

### **Data analysis**

The quantitative data was captured using MS Excel spread sheets and analysed by a statistician from the Centre for Statistical Consultation using a statistical software

package (STATISTICA 10; Stat Soft Inc., Tulsa, OK, USA). Only descriptive statistics were required, such as frequencies and means.

Qualitative data analysis also used MS Excel spread sheets and followed the framework method. Analysis started with ‘familiarisation’ by studying the detailed notes to find out key issues in order to list key ideas and themes. A thematic index was then created that organised the themes and sub-themes. The broad framework of contextual issues, patient-related issues and health-system related issues identified in the introduction was used to help structure the index. All the data was then coded using the thematic index. Following this all the data for specific themes was brought together in one chart to enable interpretation. Interpretation looked at the range of ideas and strength of different ideas within each theme and possible explanatory connections or associations between themes.

## **Ethical considerations**

The study was approved by the Health Research Ethics Committee of Stellenbosch University (N11/04/106) as well as the ethics committee of the East London Hospital Complex.

Patient confidentiality was maintained by using codes in place of names or other identifiers in the data sheet. Informed consent was obtained from all patients by means of a written consent form in their home language with help from the research assistant. Participation was voluntary and patients were able to withdraw from the study at any time. Confidentiality of all the participants in the research was ensured, but to do this, a separate record was kept of their hospital file number name and the study code to which only the researcher had access.

## **Results**

The demographic profile of the study population is shown in Table III. The study population was almost entirely black African, mostly female and single with a mean age of 34.6 years (SD 9.33). The patients were mostly unemployed and poor with mean personal monthly income of R582 (SD 927.75) and mean household income of R1378 (SD 881.93) . Not surprisingly the majority were uninsured and largely dependent on

public health services. On average it took patients 9.0 (SD 11.50) months after diagnosis to attend the ARV clinic, although 195 (98%) had a CD4 taken at the same time. At diagnosis 109 (55%) patients were motivated to check their HIV status by nurses, 61 (31%) by family member and 22 (11%) by friends. The majority of patients were living with family (161, 80%), and only 22 (11%) lived alone or with others such as friends and colleagues (17, 9%). Twenty four (12.5%) completed primary school, while 108 (54%) finished high school and 68(34%) passed matric/grade 12.

**Table III: Demographic characteristics of study population (N=200)**

<b>Mean age</b>	34.6 ± 9.33
<b>Gender</b>	
Male	68 (34%)
Female	132 (66%)
<b>Race</b>	
Black	199 (99.5%)
Coloured	1 (0.5%)
<b>Average CD4 Count(/ mm<sup>3</sup>)</b>	39.12 ± 29.61
<b>Education</b>	
Primary school grade(1-7)	24 (12.5%)
High school (8-11)	108 (54%)
Completed grade 12	68 (34%)
<b>Medical aid</b>	
None	174 (87%)
Covered	26 (13%)
<b>Marital status</b>	
Single	148 (74%)
Married	26 (13%)
Living with partner	21 (11%)
Widow	3(2%)
Separated/divorced	2(1%)
<b>Employment</b>	
Unemployed	131 (66%)
Full-time	39 (20%)



Part-time	19 (10%)
Seasonal	11 (6%)

Table IV present the extent to which participants agreed or disagreed with various statements representing known barriers to accessing ART. More than half the respondents agreed that the cost of transport to the referral hospital and the long waiting times were issues for them. Around a third of respondents agreed that the referral hospital was too far away or that they were too sick to make the journey to the local clinic. One in five respondents were worried about discrimination, loss of confidentiality, negative reactions from health workers or struggled to accept the results. Out of 200 participants, 181(91%) visited their local clinic for HIV testing before coming to the East London ARV clinic and 16 (8%) said that they were not offered information and counselling about HIV at that time. Twenty-two (11%) reported being afraid to visit their local clinic due to stigmatization about HIV and thought that other people from their community will then know about their status.

**Table IV: Level of agreement with different statements regarding barriers to access**

Statement	Strongly agree	Agree	Disagree	Strongly disagree
	n(%)	n(%)	n(%)	n(%)
After hearing that I was HIV positive, I accepted the results	2 (1)	153 (76)	44 (22)	1 (1)
I was very sick and was unable to go to the local clinic for treatment	1 (1)	61 (30)	136 (68)	2 (1)
I did not know where to get help for HIV	1(1)	16 (8)	183 (91)	0 (0)
Other family member was sick that's why I could not go to the East London Hospital Complex ARV clinic	0 (0)	13(6)	187(93)	0 (0)
The HIV (ARV treatment) service was	2 (1)	32 (16)	166 (83)	0 (0)

not available in my area.				
I had no money for transport to visit East London Hospital Complex ARV clinic	1 (1)	105 (52)	94 (47)	0(0)
The place where the service is offered is too far.	1 (1)	76 (38)	123 (61)	0 (0)
I feared what the doctor and staff might think bad about me being HIV positive	0 (0)	43 (21)	157 (78)	0 (0)
I feared being discriminated against by the doctor and staff.	0 (0)	40 (20)	160 (80)	0 (0)
I had to wait too long for the service at East London Hospital Complex clinic.	0 (0)	164 (82)	36 (18)	0 (0)
I feared loss of confidentiality about my HIV status.	1 (1)	44 (22)	155 (77)	0 (0)
I did not feel welcome at East London Hospital ARV clinic where service was offered	0 (0)	26 (13)	174 (87)	0 (0)
Local clinic was short of staff	1(1)	29 (14)	170 (85)	0 (0)
ARV medicine was out of stock at local clinic	0 (0)	29 (14)	171 (85)	0 (0)

Table V presents factors that may impact on the ability of these patients to access ARVs at the referral hospital.

The majority (79%) were referred to the ARV clinic by a nurse from their local primary care facility. Thirteen percent were insured and 13% were also referred by a private general practitioner. More than half (134, 67%) of the studied population reported that they used a taxi service to access the ART clinic and only 36% lived within 5km. A further 31 (16%) walked to the ART clinic and 35 (18%) had access to a private car. Only 5 (3%) participants made their own decision to come directly to the East London Hospital Complex ARV Clinic bypassing their local clinic. Out of the study population

only 11 (6%) reported a visit to traditional healer, 6 (3%) had used complementary treatment in addition to ARVs and only 4 (2%) reported using alternative treatment (vitamins) for HIV instead of ARVs prior to referral to ART clinic.

**Table V: Factors likely to affect access to the ARV clinic (N=200)**

<b>Distance from ARV clinic</b>	
Very close (<1 km)	13 (7%)
Close (1-5km)	58 (29%)
Far (5-10km)	104 (52%)
Very far (>10 km)	25 (13%)
<b>Referring Clinic</b>	
Local clinic	158 (79%)
Private practice	25 (13%)
Interdepartmental (East London Hospital Complex)	7 (4%)
District hospital	4 (2%)
Other	6 (3%)

The following section presents the results of the qualitative data analysis and is organised into contextual factors, patient-related and health system-related factors.

### **Contextual factors**

A number of factors within the patients' community influenced access to the ARV clinic. The most frequently reported factors in this category were stigma and fear of discrimination because of HIV;

*"I was afraid from community because of what people would think of me having HIV positive"(study no 2)*

Lack of transport and long travelling distances to the ARV clinic also emerged as a barrier to access HIV treatment:

*"I delayed because I don't have any means of going to the clinic and I am very sick, in my area there is no public transport. We have to ask taxi from near town" (study no72)*

*"I am living far way so it was difficult for me to come because of distance as there is no clinic near to my home" (study no 184)*

### **Patient-related factor**

Patient beliefs, ideas and coping strategies

A number of patient beliefs, ideas and coping strategies influenced access to the ARV clinic. A few patients refused to believe the results and therefore did not initially act on them:

*"I thought that results are wrong and I am fine. It was a wrong report or results of some other patient and I should not worry" (study no 2)*

Some struggled with disclosure of their status to their family or parents and implications of this for their relationships. Until this was resolved they were therefore reluctant to openly attend the ARV clinic:

*"I was afraid how to tell my boyfriend and what he will think about me. He will ask me from where I got it and he will lose his trust in me" (study no 43)*

*"I was afraid of losing relationships. I thought that my partner will not allow me to sleep with her" (study no 74)*

Some patients lacked knowledge about HIV disease and treatment:

*"I wanted to know more about the virus as I was not aware what HIV is? I thought that it's like you get flu and after taking tablets become ok and didn't had any idea how I got this" (study no 69)*

Another important factor was fear of side effects from ART:

*"My delay is the result of that I am afraid of starting the ARVs they decrease appetite, give you vomiting all the time and worse rash because it's my whole life I have to eat. I have seen others who are already on treatment" (study no 41)*

Some reported fear of rejection by partners, isolation and divorce, and fear of losing one's job. A few participants consulted traditional healer or believed that by praying they could be cured from HIV:

*"After knowing that I am positive, came to home and cried a lot. I decided to take some weeks to ready myself for treatment. I was praying to God for cure because he created us and he can purify my body as well as my soul" (study no 29)*

Other minor factors identified were misunderstanding or distrusting the medicines, , fear of a terminal diagnosis, loss of hope to be cured and not believing that they were eligible for ARV treatment.

### **Social support from family and friends**

A lack of social support led to a lack of suitable treatment supporters, especially amongst those who were single. As a treatment supporter was a requirement for initiating ARVs this also delayed some people.

*"Nurse asked me to bring some body as treatment supporter and I am still finding" (study no 11)*

Family responsibilities might also delay the person seeking help for themselves:

*"I had to do many things for my family I am only bread earner for my family. My mother was sick and I was responsible to take her to hospital. I had to drop my nice daily at school; on the other hand I was also working" (study no 16)*

A lack of social support from the family might also impact on one's ability to cope and seek help:

*"To me, family is to share happiness and sadness. I wanted to cry on some one's shoulder. I was unlucky by not having any family member with me in that difficult time"(study no 14)*

### **Illness and functioning**

Participants were delayed because of physical illness or mental illness on one hand due to HIV and were not able to get help at local clinic:

*"I was very sick, bed ridden, unable to swallow food. It was difficult for me to walk because I did not had energy had severe rash on my face and red eyes. I could come here alone and I needed a helping hand to come here"* (study no 14)

*"When I knew that I am positive, I felt total black out, was unable to think and concentrate on all matters, was mentally depressed and ended up on antidepressant treatment. Sleep was away from me and did not have energy to visit clinic for HIV treatment" (study no 51)*

During interview some participants thought that they don't have any physical signs of HIV so did not bother to get treatment:

*"What I can say is that, I was never been sick except having flu. So I see no need of me to be there in that clinic, and I just decided to stay at home"* (study no 8)

On the other hand some had co-morbid illness such as heart disease or TB which acted as a delaying factor:

*"I am going always up and down to hospital because of my heart problem and TB. I want my TB to be managed by nurses first. I decided that once my TB will be cured then I will go for HIV treatment. I am human being how I can eat lot of tablets?" (Study no 94)*

### **Socio-economic factors**

These factors emerged as a major barrier. More than half of studied population were unemployed and a lack of finances lead indirectly to poor access:

*"To come here cost you a lot. I had to hire a full taxi car because I cannot sit. I was lying on back seat. So I had to bay 200 Rands. That's a lot of money and I cannot afford". (Study no 183)*

*"I did not want to delay, but I am not working at all. How you can you fight with HIV if you don't have money to buy food?"(Study no 1)*

## **Health system issues**

### **Availability of services**

A major contributing factor in this group was perceived to be a shortage of staff such as doctors and nurses:

*"I was afraid of being admitted to hospital and I wanted to stay at home. I knew that hospital is not nice place and patients are not looked after nicely, there is only one nurse in ward and lot of patients that is unfair"(study no 11)*

Other barriers were the unavailability of treatment and problems in accessing CD4 testing facilities:

*"At clinic I was told that there are no blood tubes available to do CD4 count so I had to go to hospital. When they tested me they say they are having the problem with the blood. It was clotted. I was disappointed and not happy with Lab. I was anxious to know about my results but they told me to do it again and I was feeling more mental trauma than physical trauma" (study no 103)*

### **Acceptability of services**

A large number of participants were concerned about breach of confidentiality regarding their HIV status and this delayed them seeking help at the ARV clinic:

*"I was afraid because if some knew my status he will hate me and boycott me, I am already feeling lonely" (study no 7)*

Other patients in this category delayed ARV treatment because of perceived poor delivery service particularly having to wait for a long time in queues in order to be seen:

*"I came very early here, standing 3 hours in queue but my folder was lost here .The clerk misplaced my folder and all information was inside folder. I was upset and returned back home previously" (study no 27)*

Another important factor was the unfriendly and negative attitude of the staff:

*"I am attending the clinic today, the difficulty is that they don't look after someone who is on the stretcher they are busy making gossips they help the patients who can move on their own and its painful to see how they behave" (study no 58)*

Lack of coordination and communication also came out as a hurdle to access HIV treatment:

*"I came before here and sister asked me about CD4 results. From local clinic they did not give me results. They told me verbally. So I was sent back to bring CD4 results. That is not good thing when you are sick"(study no 38)*

## **Discussion**

### **Key findings**

The average length of time from diagnosis at the local clinic to presentation at the ART clinic with a CD4 count  $<100/\text{mm}^3$  was 9 months. In terms of the pathway, majority of patients visited primary care clinics located near to their homes. Some considered alternative treatments from traditional healers, while others staying at home trying to cope through religion. However in this study it seemed that traditional or alternate healers played a smaller part than expected in the pathways. After being diagnosed as HIV positive, patients were referred for ART, but again some patients took time to accept their results and assumed that they were not a candidate for ARV,s and did not present at the referral ART clinic until they were very sick or were brought by relatives or friends. Few patients who consulted private doctor were directly referred to the ART clinic.

The factors related to delayed presentation can be related to the patient, the context and the health system as shown in Figure2.



With the health system, issues were either structural or process related. Key structural issues included poor staffing levels, a lack of availability of CD4 test results and long waiting times for consultation. Key process issues reflected a poor patient experience and lack of trust in the quality of care.

Contextual related issues were mainly geographic accessibility due to the cost of and lack of transport as well as distance to the health care facility. Cost though was the predominant issue in making use of transport. Stigma and discrimination about HIV within the community continued to play a role with concerns around disclosure and its consequences.

Patient related factors included misperceptions and false beliefs about HIV, socioeconomic factors such as poverty due to unemployment, lack of family and social support such as unavailability of treatment supporter and poor general health making the journey difficult. The majority of people had opportunities to be tested and get treatment, but it seems that they did not feel it was important to visit the clinic at an earlier stage due to their own ideas and beliefs.

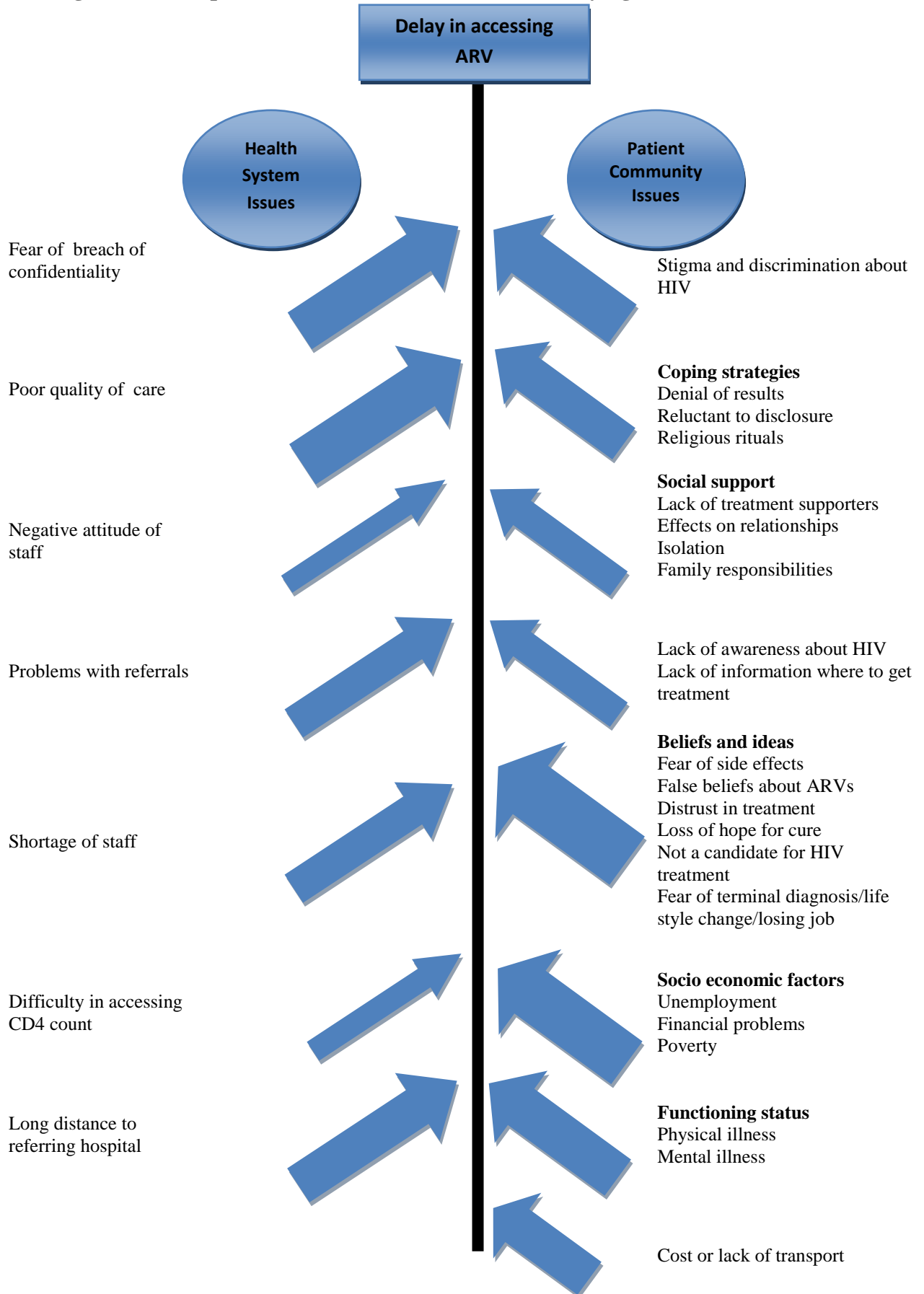
### **Comparison to the literature**

Patient and community related barriers to access were mostly similar to other studies.<sup>1, 11,12,13,14,20,21,23,24</sup> On the other hand factors such as requiring permission from one's husband to start ART, mentioned in elsewhere in the literature, was not found in this study.<sup>21</sup> Lack of suitable treatment supporters, especially amongst those who were single or living alone, came out as a factor in this study, although it is not reported elsewhere in the literature review.

Health system related barriers such as lack of health workers, as reported in this study, is a major problem in sub-Saharan Africa and has been identified as one of the most serious obstacles for implementing and planning access.<sup>30</sup> Difficulty in accessing CD4 results and laboratory, poor quality of care and breach of confidentiality, were also a contributing factor as found in other studies from developing countries.<sup>31</sup>

Health system related issues reported in the literature such as, restrictions on providing ART to certain patients who miss an appointment, cost of ART to the patient and need for interpreters were not identified as barriers to ART in this study.<sup>31</sup>

**Figure 2: Conceptual framework of all the factors delaying access to ART**



### **Limitations of the study**

The results are specific to the East London Hospital Complex and its surrounding area and should be generalised with caution to the rest of South Africa. The context however is similar to many other parts of South Africa and some of the findings may be transferable. Findings in this survey are purely descriptive of a group of people thought to be presenting late. Further research could attempt a cross-sectional analysis of people presenting on time or late and attempt to associate factors statistically with these groups. However, the mixed methods were a strength of this study

### **Implications and recommendations**

Many of the factors identified are amenable to change and there is the potential to increase accessibility to ART. The following paragraphs discuss possible interventions that could mitigate the barriers identified in this study.

Health system barriers such as organizational and structural related issues can be dealt with in part by employing more staff, especially at primary level. The staff's unfriendly and negative attitude could be changed by giving updates on HIV information, training, and group discussions to the staff. The experienced nurses could assist in counselling and giving guidance to junior staff.<sup>32</sup> Nurses should be counselled and given psychological support by seniors. Staff rotation should be implemented to decrease burnout. More staff can be appointed at primary and district centres that could help to reduce the pressure and workload in hospitals.<sup>32</sup> Access to laboratory facilities in peripheral areas should be improved so that CD4 results can be sorted out at primary level. Referral policy should be strictly followed by primary as well as district health facilities in the sense that patients referred to the ART clinic should all have base line blood tests done at the local clinic. Coordination and communication between different health facilities can be made strong by arranging monthly meetings with referral facilities to discuss problems encountered during the previous month.

Contextual barriers such as stigma and discrimination about HIV should be reduced. One study from Haiti showed that implementing daily observed treatment for HIV, similar to the TB programme, resulted in decreased stigmatization about HIV.<sup>33</sup> HIV testing can be integrated into the primary care services to increase HIV positive case finding among those presenting to primary clinic because of illness, rather than

focusing only on those who present voluntarily. Patient centred approaches decrease social barriers such as stigma and fear of discrimination.<sup>34</sup> Geographical accessibility can be improved by making ART more available in primary care clinics or providing free transport for people to attend the referral centre.

Traditional healers can be involved in community-based programmes rolling out antiretroviral therapy. They provide a substantial proportion of health care in developing countries with high burdens of HIV in sub-Saharan Africa. Some biomedical providers view them as obstacles in providing HIV treatment. However a study from Lesotho shows that traditional healers can play an important role in the successful implementation of an ART program. Traditional healers should be viewed as key collaborators and not obstacles to the rollout of comprehensive HIV services.<sup>35</sup>

Certain patient related issues, such as misinformation and false beliefs about HIV and ART can be reduced by engaging community leaders and educating people through mass media campaigns about early access to ART.

Long waiting times at this ART clinic could easily be reduced if these patients were managed at their nearest primary health care facilities. The reasons for some patients bypassing such facilities may include their perception of superior care and resources availability in level 2 hospitals; and a desire to be seen by medical doctors.<sup>36</sup> Regular visits by hospital doctors to primary health care facilities, flexible and longer operating hours of clinics, functional local clinics, and regular supplies of medication can increase access to ART.

## **Conclusions**

The average length of time from diagnosis at the local clinic to presentation at the ART clinic with a CD4 count  $<100/\text{mm}^3$  was 9 months. The majority accessed care via their local primary care clinic and traditional or alternative practitioners did not appear to play a major role. The distance from and cost of transport to the referral hospital ART service was a major issue compounded by the difficulty of travelling when acutely sick. The expectation of long waiting times and sometimes negative staff attitudes reduced motivation. A number of other factors related to the patient, the health service and the

community context were also identified. Many of these factors that reduce access to ART are amenable to change.

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## APPENDICES

### **Appendix 1: PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM**

**Title:** A survey to explore factors that prevent patients from accessing antiretroviral treatment at an East London Hospital Complex clinic.

**Principal Researcher: Dr Muhammad Sajjad Raza**

**Contact Details:** Phone 0735499984  
Hospital Address: East London Hospital Complex, East  
London  
Email [drsajjadraza@gmail.com](mailto:drsajjadraza@gmail.com)

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the study staff or doctor any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is entirely voluntary and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the Committee for Health Research Ethics Committee at Stellenbosch University and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

#### **What is this research study all about?**

This research aims to understand the difficulties that you may have in accessing treatment at this clinic. Therefore we are conducting this study to identify the obstacles in our health care system that prevents you from accessing ARV treatment for HIV.

In these interviews, we will talk about how you were referred to ARV clinic and what difficulties you faced to get treatment. Your answers will be documented but you will remain anonymous in the findings from this study.

#### **Why have you been invited to participate?**

As you are a new patient, with a low CD4 count, who needs to start treatment for HIV; we would like to know of any difficulties that you experienced in attending the clinic or any other reasons that may have delayed your attendance at the clinic.

**What will your responsibilities be?**

We would like you to complete a questionnaire, with the help of a research assistant, which asks questions about any difficulties that you experienced in attending the clinic or any other reasons that may have delayed your attendance at ARV clinic.

**Will you benefit from taking part in this research?**

You will not benefit from this, but future patients should benefit from the findings of the study.

**Are there any risks involved in your taking part in this research?**

No. The interview might bring up some issues that you find difficult to talk about or which might distress you. You are free to stop the interview at any time, and if you wish to have further counselling you can be referred to a psychologist or social worker.

**If you do not agree to take part, what alternatives do you have?**

You will continue to receive your usual care and treatment at the clinic.

**Who will have access to your medical records?**

Only the researcher and research assistant who are both health professionals.

**Will you be paid to take part in this study and are there any costs involved?**

No, you will not be paid, and there is no cost involved.

**Is there anything else that you should know or do?**

You can contact Dr Raza at phone (0735499984) if you have any concerns or complaints that have not been adequately addressed by your study doctor.

You can also contact the Committee for Human Research at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by your study doctor. You will receive a copy of this information and consent form for your records.

**Declaration by participant**

By signing below, I ..... agree to take part in a research study entitled (insert title of study).

**I declare that:**

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (place) ..... on (date) .....  
2011.

.....  
Signature of participant

.....  
Signature of witness

**Declaration by investigator**

I (name) ..... declare that:

- I explained the information in this document to .....
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use a interpreter. (If a interpreter is used then the interpreter must sign the declaration below.

Signed at (place) ..... on (date) .....  
2011.

.....  
Signature of investigator

.....  
Signature of witness

**Declaration by interpreter**

I (name) ..... declare that:

- I assisted the investigator (name) ..... to explain the information in this document to (name of participant) ..... using the language medium of Afrikaans/Xhosa.
- We encouraged him/her to ask questions and took adequate time to answer them.
- I conveyed a factually correct version of what was related to me.
- I am satisfied that the participant fully understands the content of this informed consent document and has had all his/her question satisfactorily answered.

Signed at (place) ..... On (date)  
.....

.....  
Signature of interpreter

.....  
Signature

**Appendix 2: QUESTIONNAIRE FOR INTERVIEW**

Please answer the questions that I will ask you and will write down your responses. You may ask me for an explanation of any question if you need to and you may add comment where necessary.

Date:..... Coded Serial Number:.....

**Section 1: Narrative with open questions**

Can you please explain to me what happened to you from when you were first diagnosed with HIV until coming to the clinic today?

Did you experience any difficulties in attending the clinic here today?

Can you think of any other reasons that delayed you coming to the clinic today?

Who have you consulted for help with your HIV since you were diagnosed (e.g. nurses, doctors, traditional healers, family members, friends etc.)?

## Section 2: Questionnaire with closed questions

1. Age (in years).

2. Sex

1= Male

2= Female

3. Who do you live with?

1= Alone

2= Spouse

3= Partner

4= Parents

5= Children

6= Brother or sister

7= others (please specify)

4. What is your marital status?

1=  Single

2= Married

3= Separated/Divorced

4= Widow/er

5= Living with a partner

5. Which race group do you belong to?

1= Black

2= Coloured

3= White

4= Asian

5= Other (please specify).

6. Education

What was the highest standard or grade that you passed at school?

Standard\_\_\_\_\_ OR

Grade\_\_\_\_\_

7. Employment at present.

1= Not working at all

2= Working full-time

3= Working part-time (all the time/permanently)

4= Working part-time (some of the time/seasonal)

8. What is your personal monthly income?

1=  < R1000

2= R1000-1999

3= R2000-2999

4= R3000-3999

5= R4000-5999

6= R6000-9999

7= R>10000

9. Total household income.

10. Do you have medical aid?

1= Yes.

2= No.

11. Have you visited your local clinic?

1= Yes

2= No

12. If yes did clinical staff offer you information and counselling about HIV testing?

1=  Yes

2= No

13. How far do you live from the East London Hospital Complex ARV clinic?

1=  Very close (less than 1km)



- 2=  Close (1-5km)
- 3= Far (5-10km)
- 4= Very far (more than 10km)

14. Means of transport to the East London Hospital ARV clinic.

- 1=  Walking
- 2= Taxi
- 3= Private vehicle
- 4= Other (please specify)

15. Who referred you to East London Hospital Complex ARV – what type of health worker?

- 1= Self.
- 2= Nurse.
- 3= Private General practitioner.
- 4= Public Medical officer.
- 5= Other.....

16. What level of care (facility) made the referral to East London Hospital Arv Clinic.

- 1= Local clinic
- 2= Private practice
- 3= District hospital
- 4= Interdepartmental (East London hospital complex)
- 5= Other .....

17. When you went to the clinic for the first time to check your HIV status who supported you?

- 1= Family member
- 2= Friend
- 3= Community member.
- 4= None
- 5= Other.

18. When you were diagnosed for the first time as HIV positive?

Months \_\_\_\_\_ Years \_\_\_\_\_

19. Was a CD4 count done at that time?

1= Yes

2= No

20. Have you visited a traditional healer to get a cure for HIV?

1= Yes

2= No

21. Did you use alternative treatments e.g. vitamins to treat HIV.

1= Yes

2= No

22. Did you use complementary treatment (treatment in addition to ARVs?)

1= Yes

2= No

23. Do you agree or disagree with the following statements as you were unable to get ART treatment.

Statement	Strongly agree	Agree	Disagree	Strongly Disagree
After hearing that I was HIV positive, I accepted the results				
The HIV (ARV treatment) service was not available in my area.				
I was very sick and was unable to go to the local clinic for treatment				
I did not know where to get help for HIV				
I had no money for transport to visit East				

London Hospital Complex ARV clinic				
I had to wait too long for the service at East London Hospital Complex clinic.				
The place where the service is offered is too far.				
Other family member was sick that's why I could not go to the East London Hospital Complex ARV clinic				
I feared what the doctor and staff might think bad about me being HIV positive				
I feared being discriminated against by the doctor and staff.				
I feared loss of confidentiality about my HIV status.				
I did not feel welcome at East London Hospital ARV clinic where service was offered				
Local clinic was short of staff				