**ESRC Project Title:** Life on antiretroviral therapy: People’s adaptive coping and adjustment to living with HIV as a chronic condition in Wakiso District, Uganda

**Project code:** RES-062-23-2663

**Background notes on the quantitative data / interviews**

**Study sites**

Data were collected between January 2011 and March 2012 in Wakiso District, central Uganda. Using both qualitative and quantitative methods data were gathered on PLWH’s self-management strategies on ART, the factors that enable or hinder their self-management and adjustment, and QoL and mental health outcomes indicative of successful self-management and adjustment.

Three types of ART delivery site in Wakiso District were selected to recruit participants for the study:

* the HIV clinic at the government hospital in Entebbe;
* three government health centres (level 3) that have referral links to Entebbe
* and the Entebbe branch of a well-established non-governmental organisation, The AIDS Support Organisation (TASO).

Wakiso District, which encircles the capital city Kampala, was selected as the site for ease of access to the study population (the research project and team were based at the Medical Research Council/Uganda Virus Research Institute (MRC/UVRI), Entebbe) and because of the presence of established governmental and non-governmental treatment providers.

Ethical approval for the study was obtained from the Uganda Virus Research Institute and the University of East Anglia, UK. Overall approval was granted by the Uganda National Council for Science and Technology. Pseudonyms are used in this paper to maintain confidentiality.

**Sampling for the quantitative component of the study**

The quantitative component of the study randomly recruited 423 participants: 263 people living with HIV (PLWH) taking ART, and 160 in a community control group (HIV status not known, not currently on ART).

Eligible HIV patients for the study were those who had been on ART for more than one year. A list of eligible patients was compiled for each facility.

A list of eligible patients (all those who had been on ART for at least one year) was compiled at each facility using patient files.

The 263 PLWH were recruited randomly from the ART delivery sites using patient lists (patients on ART for less than 12 months were excluded). A systematic random sample was taken using set intervals. Before the sample was taken all patients participating in the qualitative component of the study were removed from the lists.

The 160 control participants were randomly recruited from the general population in nearby villages, first stratified by gender, using resident lists from communities which had been part of an earlier MRC/UVRI study.

**Data collection measures**

The questionnaires were completed by survey enumerators, following intense training.

Two different versions of the questionnaire were used. One for the PLWH (cases) and one for the control group.

PLWH (cases) answered all sections of the survey

Controls did not need to answer questions relevant to HIV: in Section C (about HIV Treatment), Section D (about Illness perceptions) and Section E (Mental Acceptance of HIV).

Some notes on some of the sections of the instrument:

Participants provided information of their age, gender, household size, years in education, religion and marital status.

Section D of the survey assessed Illness Perceptions using a standard brief Illness Perception instrument (IPQ Brief) See this link fore details: <http://www.uib.no/ipq/>.

Section E of the survey measured mental acceptance of HIV, using a Mental Adjustment to HIV Scale (MAHIVS), an adapted version of an instrument used elsewhere to assess the mental acceptance of cancer (Mental Adjustment to Cancer Scale). The HIV version has been validated in English nad has four sub-scales: Hopelessness; Fighting Spirit/Self-Efficacy; Personal Control; and Minimisation (Ross, 1994; Ross, Hunter et al 1994). This scale has not been used in Uganda before, so after collecting the data some basic validation analysis is needed.

Section F of thequestionnaire measured quality of life, using the World Health Organisation (WHO) Quality of Life measure the WHOQOL-BREF ([Skevington et al., 2004](#_ENREF_45)). 26 items assess four domains of quality of life: 1) physical health, 2) psychological, 3) social relationships and 4) environment. Higher scores indicate better quality of life. Domain scores range from 4-20. This measure was selected as it provides an estimate of quality of life extending beyond health-related quality of life alone and has shown to be valid cross-culturally ([Skevington et al., 2004](#_ENREF_45)). The measure was translated into Luganda using the WHO guidelines and achieved adequate validity and internal consistency (Martin et al., 2013).

Section G of the questionnaire measured depression, using the Hopkins Symptom Check List (DHSCL) containing fifteen items to assess depression ([Derogatis et al., 1974](#_ENREF_10)). Scores range from 15 to 60, with higher scores indicating more symptoms of depression. This measure is commonly used as a screening tool for depression and has been validated for use in a range of cultures (for example [Cepeda-Benito & Gleaves, 2000](#_ENREF_5); [Fawzi et al., 1997](#_ENREF_14); [Lee et al., 2008](#_ENREF_26)). It is validated for use in Uganda in the Luganda language and has good predictive validity to detect depression and good internal consistency ([Bolton et al., 2004](#_ENREF_4)). Research suggests a cut-off point to indicate likely presence of depression. This point is related to context, culture and measurement version. In a recent study in Uganda, the cut-off point of total score above 30 or mean score at least 2.1 was used ([Kinyanda et al., 2011b](#_ENREF_24)).

In Section I, questions I12 (a-k) are based on a food security and coping index developed by Maxwell (1996). Participants were also asked to respond to various other questions about socio-economic status (SES)

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