**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 qualitative 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 qualitative component of the study**

Eligible 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. The qualitative component of the research recruited 38 participants. The sampling process aimed to recruit 42 participants (16 from Entebbe hospital; 10 from the three Health centres; and 16 from TASO) and was in two steps.

Firstly 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 lists were stratified by gender and age and a systematic random sample from each facility was taken. The sampling interval was set to select a larger random sample than actually required because of anticipated contact difficulties or refusals to participate, and the need to recruit additional participants to pre-test the qualitative instruments. Altogether, 94 possible participants were selected.

Secondly, from the list of 94, 42 participants for the study were purposively sampled, to ensure an equal gender balance, a mix of ages and a range of patient experiences, and to ensure some participants (n=3) on a second-line ART regimen were included. Four people dropped out, leaving a full set of qualitative interviews from 38 participants (18 male and 20 female. 13 were from Entebbe government hospital, 11 from the three referral health centres, and 14 from TASO Entebbe.

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**Interviews**

There were two types of qualitative interview:

1. The first type of interview was an unstructured life history interview which gave emphasis to participants’ experience of illness, treatment and recovery. For a lot of the respondents, the first interview could not be completed in one session / meeting, because of time constraints. So the fieldworker would return after a period of days or weeks to continue the life history / illness history interview. This means that for each participant there is an interview 1(a), and often an interview 1(b), and sometimes an interview 1(c) if a third visit had to be made to complete the ‘first’ interview. If more than one visit was needed to complete the first interview, the visits would usually be completed within two months. This first interview was not taped, but notes were taken and detailed life and illness history narratives were written up after the interview by the interviewers.
2. The second type of interview undertaken (Interview 2), after the first was completed, was a semi-structured interview which examined key issues around HIV self-management in more depth. This interview was taped and then transcribed and translated into English. Only one interview was undertaken in this manner.

Overall the qualitative interviews explored changes in ART patients’ lives and their self-management strategies since becoming HIV positive and starting ART, for example with respect to disclosure and management of identity, their work and daily activities, relationships, reflective and spiritual endeavours, links with civil society organisations and mobilisation of resources or support. The effects of these processes were examined in terms of how people felt about their activities and achievements (or disappointments), whether they were fulfilling important roles expected of them, their future outlook, hope and motivation.