COVER PAGE

Official Title: A Text-Based Adherence Game for Young People Living with HIV in Ghana

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EXECUTIVE SUMMARY

- This study is funded by the National Institute of Mental Health (USA). It as a K23 Patient-Oriented Career Development Award received by Rhode Island Hospital (USA) to support the research described in this protocol and the training and career development activities of Dr. Nicholas Tarantino. Grant#: K23 MH114632.

- Dr. Betty Norman will serve as PI on the project alongside Dr. Anthony Enimil (Co-PI) and Dr. Tarantino (Co-PI). Drs. Enimil and Norman are medical doctors and researchers at the HIV Clinic of the Komfo Anokye Teaching Hospital (KATH) and faculty at the Kwame Nkrumah University of Science and Technology. Dr. Tarantino is a clinical psychologist and researcher at Rhode Island Hospital and the Alpert Medical School of Brown University (USA).

- The four-year study will develop a novel text message intervention for young people living with HIV, ages 18 to 24, who receive care at the KATH HIV Clinic. The intervention will be designed to help improve their adherence to HIV care (e.g., antiretroviral adherence). More so than other age groups, young people living with HIV are at risk for adherence problems and secondary HIV transmission.

- This is a *pilot* study focused on intervention development and testing the feasibility and preliminary efficacy of the text message intervention.

- The long-term goals of the project include:
    - Improve the health and well-being of young people living with HIV in Ghana and other countries in the region.
    - Use pilot data gathered from the study to apply for additional funding which could support a larger scale randomized controlled trial of the text message intervention.
    - Strengthen existing academic collaborations between US and Ghana-based research teams.

TITLE PAGE

Title of Protocol: A Text-Based Adherence Game for Young People Living with HIV

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Prior Scientific Review: No prior review conducted.

Prior Ethical and Protocol Review: Part of the development phase of this study has been approved by the Rhode Island Hospital Institutional Review Board, Providence, Rhode Island, USA.

Collaborating Institutions: The prime institution for this project is Rhode Island Hospital (RIH), Dr. Tarantino's employer. The other institution is the Kwame Nkrumah Institute of Science and Technology (KNUST) with the research site at the Komfo Anokye Teaching Hospital (KATH).

Source of Funding: National Institute of Mental Health, USA

STRUCTURED ABSTRACT

Background: Optimal adherence to HIV treatment is a major challenge, and nonadherence is associated with heightened risks for secondary HIV transmission and poor health outcomes. In sub-Saharan Africa, an estimated one in three patients do not take antiretroviral therapy (ART) as prescribed and one in four disengage from treatment within a year of initiating ART. Adherence outcomes are even worse among older adolescents and young adults (young people) living with HIV (YPLH). General Aim: The current project aims to develop and evaluate a novel mobile health (mHealth), game-based intervention tailored for young people to promote their adherence to HIV care. Methodology: Enrolment of participants in two project phases (Development Phase and Randomized Pilot Phase) will occur at the Komfo Anokye Teaching Hospital's HIV Clinic. The Development Phase involves working with an mHealth development firm to create an initial prototype of a Text-Based Adherence Game intervention, recruiting YPLH for a youth advisory group to gain feedback on the proposed intervention, and conducting an iterative open trial of the intervention with YPLH (n = 24). The Randomized Pilot Phase will involve evaluating the intervention for feasibility and preliminary efficacy with a small randomized pilot examining biobehavioral adherence outcomes over one year in a sample of YPLH who receive the Text-Based Adherence Game versus YPLH who receive the standard of care (n = 60). Quantitative survey assessments as well as chart review of relevant health information will be conducted at three time points over the course of the year to examine differences in biobehavioral adherence outcomes between intervention and control participants. Expected Outcome: First, we expect that our mHealth intervention will be relevant, useful, and appropriately-tailored for YPLH. Second, we expect to show preliminary evidence that the intervention improves adherence outcomes among YPLH.

BACKGROUND

Older adolescents and young adults (young people) living with HIV (YPLH) account for nearly 40% of all new infections in sub-Saharan Africa (SSA) (1). Compared to *any* other age group, they are at the highest risk for antiretroviral therapy (ART) nonadherence, treatment attrition, and viral non-suppression (2, 3). Most efforts to address adherence in the SSA have targeted middle-aged adults. However, YPLH face unique developmental barriers to adherence. This includes becoming increasingly responsible for their own healthcare and being unprepared for the new social and cognitive demands of treatment self-management. Given these challenges, it is not surprising that the transition from pediatric to adult HIV services is associated with a decline in young people's engagement in HIV medical care (4).

Problem Statement: Problems with adhering to care coupled with a normative increase in sexual activity during early adulthood may be partly responsible for a rise in new HIV infections among young adults in the SSA country of Ghana (5). Unfortunately, existing interventions do not account for young people's unique barriers and facilitators associated with optimal adherence. New approaches are therefore needed to improve adherence outcomes among YPLH.

Modern mobile health (mHealth) strategies designed to improve adherence are currently not feasible for low-resource settings. This includes theory-driven mobile applications that use gamification—defined as the use of game design elements in non-game contexts (6)—where real-life adherence behaviors are combined with interesting storylines in an electronic game used to engage YPLH(7). Web and smartphone access is limited in SSA, yet traditional cellphones and text messaging are near universal. This has led to text message adherence interventions that send reminders, offer counseling support, and give greater access to HIV treatment services (8). None, however, have been enhanced with gamification or story-driven messaging.

The current study will develop a novel gamified adherence intervention for use with existing text message services in Ghana. Grounded in Social Action Theory (9) and gamification principles (10), it aims to improve adherence to care among YPLH in a way that is easily accessed, sustainable over time, and readily scaled and adapted to local contexts. Such an approach is untested but possible to implement. The intervention relies on an automated text message system (11) to deliver a Text-Based Adherence

Game. The game will consist of health promoting text message interactions and a progression of culturally informed story messages.

Hypothesis. The *central premise* guiding this work is that a Text-Based Adherence Game is a feasible and potentially effective strategy to engage YPLH in HIV care. The *overarching hypothesis* of the study is that by improving adherence to care, a gap in the HIV care cascade will be filled and rates of new infections will decline due to widespread viral suppression and an associated drop in risk for HIV transmission.

General Aim. Develop and evaluate an mHealth intervention that is youth-specific, text message-based, enhanced with gamification, and designed to promote HIV treatment adherence among YPLH in Ghana.

Specific Aims:

1. Develop a Text-Based Adherence Game to promote adherence to care by: (a) devising a game prototype which integrates culturally informed content, Social Action Theory, and gamification strategies (e.g., competition, achievements, and social interaction) via consultation with an established mHealth developer and a youth advisory group, and (b) conducting a 30-week iterative open trial of the prototype with YPLH (n = 24) to refine the intervention.

2. Evaluate the intervention for feasibility and preliminary efficacy with a randomized controlled pilot (n = 60) comparing YPLH who receive the Text-Based Adherence Game to YPLH who receive the standard of care on biobehavioral outcomes (i.e., ART adherence, HIV clinic attendance, viral load) over the course of 12-months.

Literature Review. Nonadherence to HIV treatment among people living with HIV in sub-Saharan Africa (SSA) is widespread, particularly young people. A meta-analysis found that 33% of all patients do not achieve ≥ 90% antiretroviral therapy (ART) adherence (12). Moreover, an estimated one in four are lost to follow-up within a year of initiating ART(13). Young people (aged ~18-24) living with HIV (YPLH) have the highest risk for ART nonadherence (14) and treatment attrition when compared to older adults (2, 3, 14, 15) and younger adolescents and children (2, 14, 15). Consequently, YPLH's rate of virologic failure is also higher than other age groups (14), which leads to a greater risk for HIV transmission, AIDS-defining illnesses, and death.

YPLH in SSA face a host of developmental barriers to adherence**.** Youth strive for personal agency yet are subject to conflicting societal expectations, which, in many

African settings, involves the cultural value of social interdependence (16). Problems overcoming this transition delays adult role taking (17). Some YPLH have long relied on HIV care support from others and face an even harder transition to adult roles and responsibilities including treatment self-management. The poor adherence outcomes of youth who move from pediatric to adult HIV services evidences this claim (18). Moreover, the normative process of pursuing closer peer relationships while maintaining family support presents disclosure-related challenges (19) which affects seeking support for HIV care. Cognitive development is also factor in adherence. Neurobiological research reveals that self-regulation processes linked to healthy decision-making extends well into early adulthood (20). These developmental adherence barriers co-occur with individual and sociostructural contextual factors not unique to this population. HIV stigma is a major barrier (21) as is the cost and distance of travel to HIV clinics (22). Further, individuals with mental or behavioral health concerns are at risk for nonadherence (23, 24). YPLH are consequently left without adequate support networks and personal capabilities (e.g., self-efficacy) to manage their illness themselves, two of the strongest predictors of adherence in SSA (25). This includes support to help navigate contextual barriers to adherence.

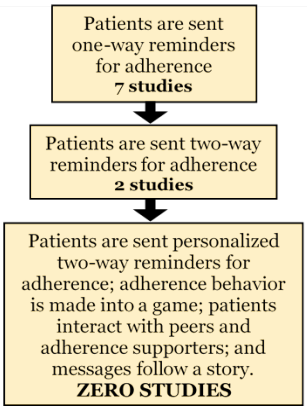
Most adherence interventions in SSA target middle-aged adults, with many studies including only small samples of YPLH (26). Current adherence interventions are a poor fit for YPLH because they do not address this group's unique adherence barriers and facilitators. Tailored programs can improve treatment outcomes (27); however, very few have been designed for youth in SSA and most have targeted youth under age 15 (28). One intervention for YPLH in SSA addressed adherence (29). Their intervention showed promise; it improved young people's retention in care using a YPLH-specific approach focused on peer support. However, it did not leverage other low-cost adherence strategies to address a broader range of adherence barriers, further engage young people in their healthcare with fun experiences, and perhaps have a broader and more meaningful influence on health behavior change. In addition, young men—a group at highest risk for poor treatment adherence (30)—were nearly absent from the trial.

Our formative work in Ghana identified two potential areas of intervention for YPLH: technology and peer support. Our team's preliminary research with an adolescent-focused ART adherence group in Ghana suggests that interventions can

conserve resources and still be effective if they build on peer support networks and fit within existing clinic services (31). We also discovered an interest among YPLH in mobile technology. We recently conducted individual interviews with 32 YPLH attending an HIV clinic in Ghana and our former research site. All owned cellphones and many were already actively engaged in a clinic-facilitated social media (WhatsApp) support group.

Text message interventions for adherence are effective but they can be enhanced. Cellphones are ubiquitous in Ghana and other areas of SSA. Approximately 85% of 18-24 year-old Ghanaians owned a text-enabled phone (32). Only a small proportion use smartphones (34%) but most send text messages (79%). Their extensive availability has led to text message adherence interventions in SSA. They work in low to middle income countries by helping clinics and patients navigate contextual barriers to adherence (e.g., problems accessing clinic services) while facilitating behavioral reminders and adherence support. For example, a study of 538 adult HIV patients in Kenya revealed that those who received a weekly text message asking "How are you?" with linkage to phone support from HIV clinic counselors had significantly greater ART adherence and viral suppression compared to patients who received the standard of care (33). No text message intervention in SSA (e.g., 8, 33) has leveraged the ability of text messages to facilitate a variety of other health promoting exchanges (see Figure 1). Text messages are a preferred way of communicating among youth in Ghana, and thus have a high potential to engage YPLH.

Figure 1. Evolution of text message approaches to adherence in SSA



Modern mobile interventions are not widely available in low resource settings**.** Electronic games have been used for 30 years to improve treatment adherence (34). They offer many advantages over other delivery methods (35)—foremost, they provide ongoing, repetitive learning opportunities with immediate feedback and monitoring outside of medical environments, while making boring, unpleasant, and routine tasks fun and engaging. They can also be more cost-effective and easier to disseminate than face-to-face approaches (36). The application of gamification principles to health promotion games is a newer and potentially more powerful intervention strategy. Gamification is defined as "the use of game design elements in non-game contexts (6)."

In a "gamified" intervention to improve adherence to HIV care, engaging in actual adherence behavior and seeking treatment support are part of the game. Interventions have begun using these strategies (7). However, the low access to affordable mobile data plans and Wi-Fi bars the use of existing gamified programs in many areas of SSA. This is unfortunate given the popularity of games in the region.

It is possible to play a Text-Based Adherence Game on low cost mobile phones without web access. Even with the advent of more technologically sophisticated games, text-based games continue to be immensely popular as smartphone apps (38). A text-based game facilitated by a fully automated computer system and played solely through text messages is a possible. This strategy has not been previously tested. Game components could consist of ART and clinic visit reminders; patient and clinic monitoring of ART adherence, clinic attendance, viral load, and CD4+ count; personalization of settings; questions, polls, and messages related to ART adherence and retention in care problems; goals, point reinforcers, achievements, and game levels; peer competition; facilitated social support interactions; linkage to HIV clinic counselors and medical staff; optional use of a progress monitoring website; and an engaging storyline. A Text-Based Adherence Game also offers an advantage over digitally complex adherence games by being easily modified. This is an important consideration as a game's relevance can diminish over time, and new barriers to adherence may emerge which need to be quickly addressed.

Modified Social Action Theory(9) (Figure 2) can guide the creation of a Text-Based Adherence Game**.** The model has rarely been applied to HIV medical adherence(39) yet experts advocate for its use in SSA settings for this purpose(40). It differs from more individualistic theories with its emphasis on contextual factors and social interdependence. The construct of social interdependence in our model is defined as the relationship and interaction between YPLH and a person in their life who provides support for adherence. Adherence behaviors will alter this relationship. For example, a friend of an HIV patient who reminds the patient to take her HIV medication could

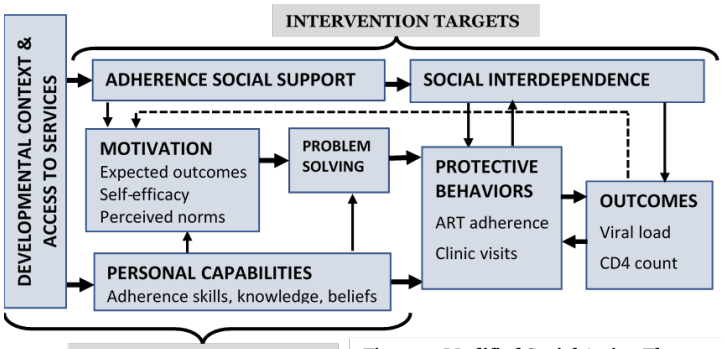


Figure 2. Modified Social Action Theory

become invested in the patient's well-being which creates a closer, more supportive relationship. Alternatively, the friend may see this task as a burden and the relationship suffers. Our modified SAT model predicts that by (a) increasing YPLH's personal capabilities related to adherence (skills, knowledge, and beliefs), (b) providing greater access to clinic and peer adherence social support, and (c) positively altering their relationship and interactions (social interdependence) with an identified supportive person, problems with developmental transitions are overcome and adherence behavior is improved. In addition, while many individual and sociostructural contextual barriers to adherence such as emotional problems and access to transportation cannot fully be addressed with a Text-Based Adherence Game, mobile access to clinic staff who can provide referrals for services can help YPLH better overcome these barriers. Finally, the model suggests that when YPLH receive feedback on their HIV-related health outcomes, their motivation to engage in protective health behaviors is enhanced.

METHODOLOGY

This research will be divided into two phases: (1) a Development Phase (Aim 1: *Develop*) in which we will conduct formative research to guide development of a Text-Based Adherence Game and gain experience with its implementation in an iterative open trial and (2) a Randomized Controlled Pilot Phase (Aim 2; *Evaluate*). See Table 1 for Study Timeline.

Table 1: Study Timeline

	Year 1				Year 2				Year 3				Year 4			
Quarters	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4
Aim 1: Develop																
Game/system creation	•	•	•													
Iterative trial					•	•	•									
Aim 2: Evaluate																
Recruitment							•	•	•							
Randomized pilot							•	•	•	•	•	•	•			
Analyses										•	•	•	•	•	•	•

Inclusion criteria. Inclusion criteria for YPLH: Males and females living with HIV, 18 to 24 years old, will be eligible for enrollment in each phase of the study according to the following criteria: (1) read English *and* speak English or a local language spoken by clinic staff (e.g., Twi), (2) in medical care for HIV and receiving ART at our clinic, (3) aware of their HIV status as per clinical record, (4) not impaired by

cognitive or medical limitations per clinician report, (5) possess a cellphone, and (6) able to give consent. *Adolescents living with HIV (ALH) between the ages 12-17 will also be eligible to participate in focus groups and cognitive interviews as part of a separate component of the Development Phase. Their eligibility criteria is as follows: (1) read English and speak English or a local language spoken by clinic staff (e.g., Twi), (2) in medical care for HIV and receiving ART at our clinic, (3) aware of their HIV status as per parent/guardian report, (4) not impaired by cognitive or medical limitations per clinician report, (6) able to give assent, and (7) their parent/guardian is able to give consent. Parents or guardians of ALH are also able to participate in focus groups and cognitive interviews as part of this separate component. Parent eligibility is as follows: (1) speak English or a local language spoken by clinic staff (e.g., Twi), (2) own a mobile phone, (3) aware of their child's HIV status, (4) not impaired by cognitive or medical limitations per clinician report, and (6) able to give consent*. Participants in the randomized pilot must have also demonstrated a recent detectable viral load. Study staff will NOT make changes to ART regimens and participants will be encouraged to speak with their doctor if they have concerns about their medications or side effects of these medications. Any unexpected ethical issues that arise with our participants will be discussed immediately with the PI. All participants will receive a resource packet including information on ART as well as references to local health and social services. We will also encourage participants to identify a treatment monitor to take part in the game. This will not be a requirement for our study, however, because those who begin playing the game without a monitor will be incentivized via game rewards to recruit one (and we will assess this occurrence). Participants without a monitor will be assigned a peer educator to fill this role. Inclusion criteria for treatment monitors includes: 1) read English and speak English or a local language spoken by clinic staff, (2) target HIV patient has agreed to their participation, (3) aware of target patient's HIV status as per patient report, (5) possess a cellphone, and (6) able to give consent.

Exclusion criteria. Individuals will be excluded if they meet any of the following criteria: (a) self-reported participation in another ART adherence-related study (YPLH only) or (b) unable to understand the consent process.

Sample, site/recruitment, and retention. We will recruit 24 YPLH and potentially 24 treatment monitors for the iterative open trial, and between 5-40 YPLH for the youth advisory group, as part of the Development Phase. The advisory board ranges from 5-40 participants because those who attend the first group meeting will be invited back to attend two to four additional meetings. However, if they are unable to attend, new participants will be added to the group. *We will also recruit 12-16 ALH and 12-16 parents/guardians of ALH for focus groups and 10 parent-ALH dyads for cognitive interviews, as part of the Development Phase*. Sixty 60 YPLH, and potentially 30 treatment monitors, will be recruited for the pilot. In the pilot, it is estimated that 70% of youth will be female given that females account for 58% of all HIV cases in Ghana and seek treatment more than males (5). About 25% of YPLH will be newly-initiated to ART. Efforts will be made to equally sample young people who acquired HIV perinatally and behaviorally. Site/recruitment: Participants will be recruited from the HIV care clinic (the Clinic) at the Komfo Anokye Teaching Hospital (KATH), a teaching hospital affiliated with the Kwame Nkrumah University of Science and Technology (KNUST) located in Kumasi. It is the second largest clinic in the country and has a patient population estimated at 4,000. Although no research activities involving human subjects will occur at Rhode Island Hospital (RIH; the co-PI's institution), RIH will support KNUST and KATH with compliance on regulatory matters, including authoring the standard operating protocol, IRB applications and approvals, quality control, and data analysis. Retention techniques: routinely updating contact information, reminder phone calls, online monitoring of game interactions, maintaining records of friend/family contacts, and obtaining an emergency contact.

Identifying eligible patients and consent procedures. Eligible patients will be identified by clinic and research staff involved with the project. All eligible YPLH will be recruited consecutively until our desired sample size is obtained. Research staff including the Research Assistant and Project Coordinator will conduct the informed consent in a private clinic room.

Development Phase (Aim 1)

The goal of the Development Phase is to create our Text-Based Adherence Game using a two-step approach: youth advisory board meetings followed by an iterative open

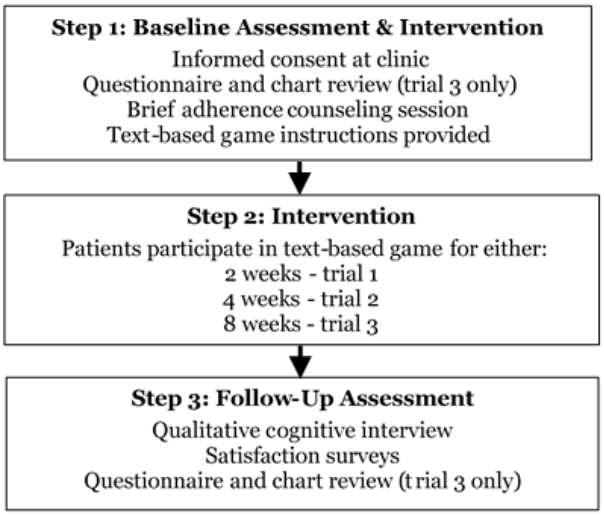
trial. The youth advisory board will be made up of five to eight YPLH. Findings from each step of this phase will be presented at board meetings held three to five times. Audio from board meetings will be digitally recorded. A working group will also be established consisting of the Project Coordinator, a clinic staff member, and the PI and Co-PI's. The working group will meet regularly for the entire project to oversee study implementation.

Adolescent and parent component. The Development Phase will also consist of a separate three-step component to explore the creation of a version of our Text-Based Adherence Game for ALH and their parents. First, 12-16 ALH will be recruited to participate in one of three focus groups. One group will include younger adolescents (12-14 years-old), one will include older adolescents (15-17 years-old), and one will have adolescents of all ages. An approximately equal number of male and female adolescents will be recruited The same number of parents (or guardians) of ALH will participate in their own focus groups. Each group will have 4-6 participants. Groups will be led in English or a local language, preference given to participants, by trained facilitators following a semi-structured focus group protocol, be conducted in private spaces at the Clinic, and last approximately two hours. ALH and parents will each be given 40 cedis for their participation. Parent and adolescent protocols will mirror each other and assess (1) barriers and facilitators to adolescent HIV treatment adherence with a focus on parenting practices and family relationships and (2) preferences for the Text-Based Adherence Game. Groups will be audio-recorded, translated (if necessary), and transcribed. Second, information gained from focus group data will be used to create a parent-based version of the Text-Based Adherence Game (see Game and system development below) to fit the needs and preferences of ALH and their parents. Third, 10 parent-adolescent dyads will participate in one of three rounds of cognitive interviews to evaluate usability of intervention prototypes. After each round of interviews, changes will be made to the intervention based on participate feedback. Cognitive interviews will be led in English or a local language, preference given to participants, by a trained facilitator in a private Clinic space and last approximately one hour. ALH and their parents will be interviewed separately and together. Interviews will be audio- recorded, translated (if necessary), and transcribed. ALH and their parents will each be given 40 cedis for their participation. Focus group and

cognitive interview parent participants will also complete a brief demographic and child health survey.

Game and system development. Game development will be a structured process of integrating gamification principles with Social Action Theory and the qualitative findings. The game will be played entirely via text messages. Messages will exclude identifying information, HIV, ART, or the Clinic name to protect privacy. Players can also text the system directly to receive progress updates, reach out for support, or send supportive messages to peers. The game will include a secure password-protected website that keeps track of each patient's individual progress. This can only be accessed by the patient. A leaderboard for all patients to see is also given with an overall game score for each patient using anonymized team names. Accessing the website will be optional and not be necessary to play the game. System development. *Dimagi* (Boston, MA, USA) has been identified as our technology provider. Dimagi provides a platform for our website and database, an application to facilitate text message exchanges, and training for research staff to learn how to manage the website, database, and application. This allows research staff to gain full control over its development and maintenance without long-term assistance. Dimagi's system will involve connecting a mobile phone with pre-paid phone credits to a computer located at the Clinic. Their web-accessed application will transmit and receive messages through this mobile phone.

Figure 3. Steps for Aim **1** Iterative Open Trial



Iterative open trial of the Text-Based Adherence Game (Aim 2). A 30-week iterative open trial of the game will be conducted with 24 YPLH starting at the end of in Year 1. About half of the YPLH recruited for the open trial will be retained in each iteration (43). The trial will help refine the protocol and Text-Based Adherence Game. YPLH will also have the option of enroling their treatment monitor. Procedures. See Figure 3. After informed consent and assessment, participants will receive standard of care (SOC) services which includes one brief adherence SOC counseling session based

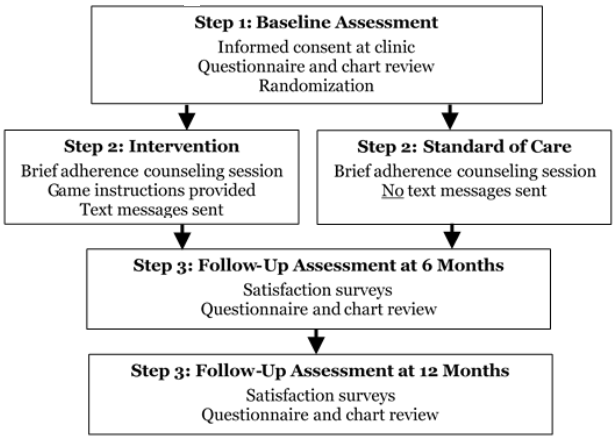
on Centers for Disease Control and Prevention guidelines (44) led by a bachelors-level clinic counselor, as needed contact with counselors, and access to a clinic social event held once per year. They will then be shown the game by a trained RA. The basic elements of the game will be demonstrated and YPLH will have an opportunity to interact with the system, with study staff, to build interest and understanding. Participants will be asked permission to enroll a treatment buddy to participate in the game as well. This person will be consented by study staff. The game also pairs participants with a peer educator who has shown good medical adherence by clinic report and is trained to provide phone peer support. Three iterations of increasing game length (two, four, and eight weeks) and number of participants (n = 6, 8, and 10) will test game prototypes. After each iteration participants will be assessed with a semi-structured cognitive interview (45) to gauge participants' opinions of the game, and its clinical utility, relevance, strengths and weaknesses, ease of use, and ability to capture their experiences (See Appendix 1 for interview guide). Audio from cognitive interviews will be digitally recorded and transcribed. They will also complete quantitative measures for similar feedback. In addition, participants will be assessed before and after the third iteration on main study variables to explore shifts in our primary and secondary outcomes. Information gained after each iteration will be used by research staff to alter the game. Study staff will also contact participants after they enroll via a phone call to trouble shoot problems playing the game. YPLH will be remunerated with an allowance of 40 Cedis for each assessment. They will also be given 40 Cedis worth of prepaid phone credits to send text messages. Treatment monitors will be compensated 40 Cedis. Measures**:** Participants' overall satisfaction with the game will be assessed using a modified version of the Client Satisfaction Questionnaire (CSQ-8) after each iteration. The CSQ is an 8-item measure with good reliability and validity and used previously with African samples (46). They will also complete a modified Session Evaluation Form (SEF), which has 13 items that reflect areas of feasibility and intervention utility. Participants will complete measures of main study outcomes using an audio-assisted computer self-interview (ACASI). Main outcome measures are listed in the next section. The last prototype will be reviewed and revised by the research team before being finalized. Training of Research Assistants (RAs), Fidelity Monitoring, and Supervision: RAs will be trained by the co-PI (Dr. Tarantino) over a period of two days to provide

game instructions. Game instructions will be audio-recorded and coded for fidelity. Problems with fidelity will trigger retraining of RAs by the PI. Peer educators will receive in-person supervision from study staff who will themselves receive Skype supervision from the Dr. Tarantino. Dr. Tarantino will also monitor participants' game activity daily via the system's website.

Randomized Controlled Pilot Phase (Aim 2)

We will evaluate the preliminary impact of the Text-Based Adherence Game run for one year compared to a control group. The pilot will include 60 YPLH on ART with the same eligibility criteria as the open trial. The same procedures will also be used pending open trial feedback. The game will be evaluated via a baseline and two follow-up assessments (6-/12-months post-baseline). Randomization will occur after enrollment using a random number generator. Participants not randomized to the Text-Based Adherence Game will receive the SOC condition as described above. See Figure 4.

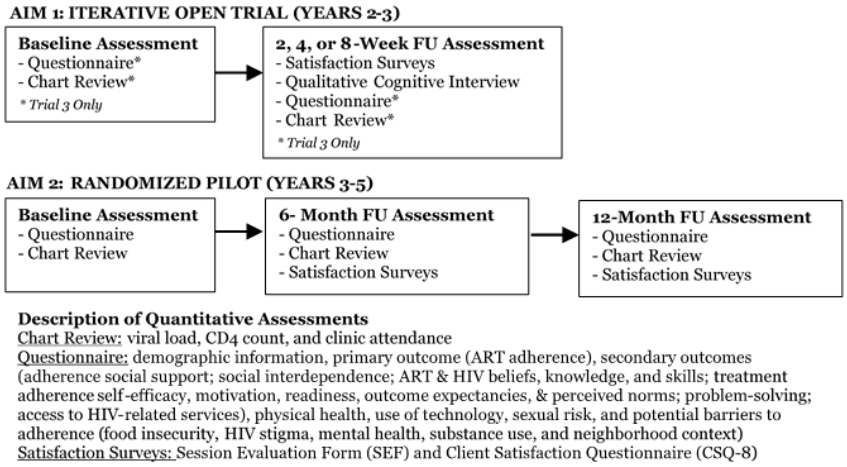
Figure 4. Steps for Aim **2** Randomized Controlled Pilot



Design Considerations. Mobile phones—access and confidentiality. Participants will need their own phones to enroll in the study. Participants are advised to password-protect their phones if possible yet many do not have this option. We will therefore (a) never send messages with identifying information or directly refer to HIV or HIV treatment, and (b) only enroll YPLH who agree to the risk of game messages being seen by others who use their phone. Phone numbers and de-identified patient information is securely stored in a HIPAA- compliant cloud database hosted by Dimagi. Only select study staff will be able to link participate names with ID numbers. Information will be stored and destroyed following HIPAA and IRB procedures (see Protection of Human Subjects). Assessments: Assessments will take 1 hour to complete and be administered in a private room in the Clinic using ACASI at baseline and 6- and 12-months post-baseline. Clinic records will also be coded for biologic outcomes and clinic visits at these

assessments. Participants will be remunerated 40 Cedis ($8) for each one. They will also be given 80 Cedis worth of prepaid phone credits to send and receive text messages at the baseline and first follow-up assessments.

Figure 5. Assessment Schedule



Measures: The measures below will evaluate HIV-related health functioning, knowledge, attitudes, and behavior. Measures previously used in Ghanaian or SSA adolescent or young adult samples were chosen when possible. If necessary, revisions to measures will be made based on formative work to ensure cultural relevancy. Primary Outcomes: Past 30-day adherence will be assessed using a 3-item measure recently developed via intensive cognitive interviewing and field tests (47) and validated against electronic drug monitoring(48) . Self report of four day ART adherence based on percent of doses taken will also be assessed using the AACTG questionnaire (49). Staff will abstract from the clinic record number of medical visits kept and missed in the past 6 months(50), and most recent HIV viral load measurement, CD4 count, and current ART schedule. See Appendix 2 for data extraction form. If viral load was not measured in the past 3 months, it will be assessed at this visit as part of routine clinical care. Secondary Outcomes: Figure 5 presents an assessment schedule for each aim and describes the secondary outcomes. Appendix 3 contains questionnaire.

Data Analytic Plan

Hypothesis One (Aim 1). The Text-Based Adherence Game will be feasible, appealing, and useful. YPLH in the third open trial iteration of the Text-Based Adherence Game will show shifts in primary and secondary outcomes in the expected directions from pre-post assessments.

Hypothesis Two (Aim 2). Compared to participants in the control group, participants in the Text-Based Adherence Game will show at 6 and 12 months post-intervention: improved ART adherence, clinic attendance, biologic functioning (lower

HIV viral load, higher CD4 count), and shifts in secondary outcomes (social support, self-efficacy, etc.) consistent with adherence promotion. Repeated measures ANCOVAs will be used to test differences over time between study conditions on each outcome variable. Missing data will be handled using multiple imputation. Potential imbalance between treatment conditions on baseline characteristics will be addressed using inverse probability of treatment weights (51). Power: As this is a pilot study and the impact of the intervention is not known, there may not be adequate power to determine its efficacy; also, pilot studies are not designed to provide accurate estimates of effect sizes upon which to base large trials(52). However, the small pilot may provide a "signal" of impact on its primary outcomes and we will examine the effects of the intervention on secondary outcomes based on Social Action Theory. We assume that retention over one year is at least 86% based on past studies conducted in Ghana (31, 53) thus 52 cases of the 60 enrolled in the pilot are available for analysis. Power analyses were run with G*Power 3(54). The model assumed 3 assessments with 52 individuals. The analyses with alpha of 0.05 and power 0.80 will be able to detect small to medium effects.

DISSEMINATION OF RESULTS

The findings from each phase of this study will be disseminated. Planned manuscripts include (1) a process analysis of our Text-Based Adherence Game using findings from the iterative open trial and youth advisory board meetings; (3) a study which presents descriptive quantitative data from our baseline sample of randomized pilot YPLH participants; and (4) the results from the randomized pilot testing the longitudinal effects of our Text-Based Adherence game on biobehavioral outcomes. Presentations will be submitted for dissemination at conferences including the meeting of the International AIDS Society. In addition, findings from our randomized pilot will be reported on https://clinicaltrials.gov/, a national (U.S.), freely-accessible registry which catalogues the results of publicly funded clinical trials. Finally, after each phase of the study, a one-page summary of the results will be written in plain language and offered to participants during their routine clinic appointments.

ETHICAL ISSUES

Participant Involvement

Participant involvement is needed to accomplish each Specific Aims 1-2: Aim 1 involves semi-structured interviews and quantitative data collection with YPLH (n = 24) following their participation in an open trial of the intervention to gauge feasibility and satisfaction. Ten of these participants will also complete quantitative self-report measures of primary and secondary study outcomes pre- and post-trial. In addition, a youth advisory board consisting of YPLH will meet with investigators three to five times to review aid in intervention development. *Finally, as part of a separate component of the Development Phase focused on adolescents living with (ALH; ages 12-17), ALH (n= 12-16) and parents of ALH (n= 12-16) will participate in focus groups, and 10 parent-ALH dyads will participate in cognitive interviews.* Aim 2 involves a randomized controlled pilot (n=60) of the intervention which includes quantitative self-report assessments and clinic chart review at baseline, 6 months, and 12 months post-baseline with YPLH.

Data Storage and Protection

All participants will be assigned a unique participant identification number (PIN). These PINs will be used to identify participants on research materials, surveys, transcripts, ACASI logs, tracking forms and all databases. Participants' names or other individually identifying information will never appear in any report resulting from this project. Separate from research records, an identifier key will be created to link the PIN to participant names and contact information in order to facilitate follow-up with participants and enter in data collected through record review (i.e., biologic functioning and clinic attendance). This identifier key will be stored separately from any research data or research-related forms (e.g. informed consent forms). All research data, research-related forms, and the identifier key will be secured in a locked cabinet or a password protected, encrypted laptop in a locked room. Electronic data will be routinely backed up onto an encrypted external hard drive. Encrypted data will be transferred via encrypted files to the co-PI (Dr. Tarantino) for quality control. Only essential project staff will have access to project data. To track participants, PI, co-PIs, and Project Coordinator will have access to a password-protected master file list linking PINs to patient records, kept in an encrypted laptop under lock and key. Electronic data will have several protections: (1) data will be securely transferred with an encrypted cloud-hosted platform (OneDrive) from Ghana to Rhode Island Hospital's data-encrypted

servers; (2) all study staff will be trained in participant data confidentiality protocols and will be consistently monitored by the co-PI on data safety and confidentiality; (3) audio files generated from the qualitative interviews will be designated with a code to ensure name confidentiality and delivered securely to a HIPAA-compliant transcription service.

Data sent and received via text messages to participants' phones for our intervention's open trial (Aim 1) and pilot (Aim 2) will be stored on a cloud-hosted server established by our technology provider (Dimagi). Text message content will not contain any identifying information or direct references to HIV, HIV treatment, or the HIV clinic. At participants' request, text messages can also be password protected. Three pieces information linked to PINs will be stored on the server for participants in these two phases of the study: (1) participants' phone numbers, (2) biologic functioning (CD4+ count, viral load), and (3) clinic appointments. For this reason, we will use Dimagi's HIPAA-compliant software to encrypt, back up, and securely store this participant data. Study staff will have full access to the server in order to upload data and monitor system use through a secure, password-protected internet portal. YPLH participants will also have partial access to the server with a password-protected user-friendly web interface which allows them to view their own personal information but not others' information. YPLH participants will also be able to view a leaderboard consisting of the anonymized names of other participants and their game point totals, as part of the Text-Based Adherence Game intervention. For example, they may see that Player X is in first place with 75 points and Player Y is in second place with 54 points. Participants will NOT be able to view each other's phones number, biologic functioning, or clinic appointments in order to protect privacy. Passwords for access will be changed periodically to ensure the security of these data.

To ensure data quality of qualitative data, digital recordings of the qualitative interviews and youth advisory board meetings will reviewed within 48 hours of the interview by the co-PI. Additionally, after the data is transcribed, transcripts will be checked for accuracy against the data files.

<u>Potential Risks</u>

There are potential risks for participants in this study: (1) potential coercion, (2) emotional discomfort from discussing sensitive topics, and (3) confidentiality breaches.

Protection Against Risk

1. Potential Coercion. The risk of potential coercion to participate will be minimized by following standard procedures for obtaining the informed consent from participants. Study personnel will fully explain the study procedures, risks, benefits, and alternatives to participants. Participants will also be reminded that study participation is voluntary and that refusing to participate or withdrawing from the study at any time will not result in any negative consequences. Recruitment for both phases of the project (Development Phase and Randomized Pilot Phase) will involve the same screening procedures.

2. Emotional discomfort. Discussing sensitive topics such as HIV infection and sexual behaviour may cause psychological distress. Study staff will continually monitor the participant for signs of distress during interviews, assessments, and introductions to the text message intervention. If signs of distress are apparent, the interviewer will offer to pause the session until the participant feels well enough to carry on and also offer more counselling and support. The participant will also be reminded that they may stop the session or un-enrol from the study at any time without penalty. In addition, the Co-PI is a US-based licensed clinical psychologist, who, while working through the PI and Project Coordinator (if not on site himself), will offer clinical advice for participants experiencing emotional distress or in need of psychological and/or psychiatric care. Participants in need of psychological or psychiatric help will be given a referral to these services.

3. Breach of confidentiality. During the consent process, risks of breaches in confidentiality will be highlighted including legal norms that would require a break in confidentiality. Research staff will receive training on the importance of keeping participant information confidential through proper record-keeping. No participant information including name, phone number, and health records will be shared with other participants in the open trial and randomized pilot through the Text-Based Adherence Game. No text messages received as part of this intervention will include this information either. Participants in the youth advisory group will also be informed

during the consent process that, while the rules of participating in the group include keeping other group member's participation in the group private, this cannot be guaranteed.

Medical or Professional Intervention in Event of Adverse Event. Although we do not anticipate any events in need of medical intervention associated with our study activities, due to our sample of YPLH we do recognize the need for some safeguards. All participants will be under the care of a physician as our study site is based in a public hospital HIV clinic and prescription of ART is an eligibility criteria of our study. All adverse events will be immediately reported to the PI. Serious adverse events will be reported to the KATH IRB, the KNUST IRB, and Rhode Island Hospital IRB as stipulated by the regulations of the IRB.

Potential Benefits of the Proposed Research to Participants and Others

There may be little or no direct benefit to participants from this study as this study is developing a novel text message program that may or may not improve adherence to HIV care for patient participants. However, reports from previous research have indicated that many participants feel that sharing information about their experiences of living with HIV or receiving HIV treatment with trained staff can be therapeutic. If requested, YPLH participants will be given information on HIV treatment, as well as referrals to local health and social services. Referrals to more intensive resources will be made as needed.

Importance of Knowledge to be Gained

This study will fill key gaps in scientific knowledge about the barriers and facilitators to HIV treatment adherence among YPLH in sub-Saharan Africa. Background literature suggests that this group has high rates of ART nonadherence, treatment attrition, and viral nonsuppression, and that these outcomes may be associated with the developmental transition from adolescence to adulthood. Additionally, the literature identifies key factors that influence ART adherence at the individual-, social-, and contextual-levels which can possibly be targeted through an engaging intervention using novel technology-based strategies. Thus, the risks of the proposed study are reasonable and balanced by the potential contribution of providing important information that can advance our knowledge of adherence to HIV care among

YPLH and whether the proposed intervention will improve adherence outcomes during this unique and vulnerable period of life.

Data and Safety Monitoring Plan

The data and safety monitoring will remain the prerogative of the project coordinator, PI and co-PIs. Data and safety monitoring will be part of the regular research meetings to be conducted.

PERSONNEL OF STUDY TEAM

Dr. Betty Norman

Role: Principal Investigator

Percent effort: 12% effort for 1.44 months, Years 1-3; 5% effort for .6 months, Year 5

Responsibilities: Dr. Norman will oversee aspects of research activities conducted in Ghana. This includes facilitating interactions with the Kwame Nkrumah University of Science & Technology IRB, protocol development, budget management, supervision of research staff, research administration, recruitment of participants, and dissemination of research results through manuscripts and conference presentations.

Dr. Anthony Enimil

Role: Co-Principal Investigator

Percent effort: 12% effort for 1.44 months, Years 1-3; 5% effort for .6 months, Year 5

*Responsibilities***:** Dr. Enimil will aid in protocol development, the recruitment and retention of adolescent and young adult patient participants and treatment monitors, supervision of research staff, manuscript authorship, and coordination of research administration, IRB involvement, and fiscal management alongside Dr. Norman.

Dr. Nicholas Tarantino

Role: Co-Principal Investigator

Percent effort: 100% effort for 12 months, Year 1; 95% effort for 11.4 months, Years 2-4

Responsibilities: Alongside the PI and Dr. Enimil, Dr. Tarantino will oversee all research activities outlined in this proposal. This includes being responsible for compiling, analyzing, and

disseminating the findings of the study, and applying for additional funding to support a large-scale trial of the intervention.

One Project Coordinator (To Be Hired)

Percent effort: 40% effort for 4.8 calendar months for Years 1-3; 10% effort for 1.2 months, Year 5

Responsibilities: One Project Coordinator will assist the PI and Co-PIs in overseeing all research activities conducted in Ghana. This includes providing supervision to a Ghana-based research assistant, facilitating interactions with the Ghana-based Institutional Review Boards, recruitment/retention of participants, administering assessments/interviews, attending meetings, producing project related reports, inventoring materials, and handling technology.

One Research Assistant (To Be Hired)

Percent effort: 40% effort for 4.8 calendar months for Years 1-3; 10% effort for 1.2 months, Year 5

Responsibilities: One Research Assistant will assist in research- related activities including obtaining consent/assent of eligible subjects (with supervision; recruitment, assessment, and retention of participants; preparing materials pertinent to the intervention; facilitating and implementing the text message-based intervention; participating in weekly research team meetings; and reporting to the Project Coordinator, PI and Co-PIs.

	Year 1	Year 2	Year 3	Year 4	**Totals**
Personnel	22800	22800	22800	7300	**75700**
Research supplies	100	126	76	130	**432**
Administration (KNUST)	916	917	915	297	**3045**
Project Site (KATH)	916	917	915	297	**3045**
Total	**24732**	**24760**	**24706**	**8024**	**82222**

SUBCONTRACT BUDGET (USD)

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Appendix 1. Draft Qualitative Interview Guides

The investigators will lead a semi-structured cognitive interview with each patient participant in the Open Trial of the Development Phase to gather information that will provide guidance in developing the Text-Based Adherence Game intervention. Following the Introduction outline below is an outline for the Verbal Interview. Each interview topic is followed by broad and generally open-ended questions. Interviewers will be instructed to ask more specific follow-up questions to probe responses to the initial open-ended questions.

Introductions

Overview: The intent of this portion of the agenda is to welcome the participant and make them as comfortable as possible by explaining the interview process and letting them know what to expect from the experience. Additionally, the investigator will explain rules concerning confidentiality, and the use of data.

- ☐ Introduce Investigator
- ☐ Explain that the overall purpose of interview is to elicit discussion about the participant's experiences with participating in the Text-Based Adherence Game.
- ☐ Sample dialogue: *"Thank you so much for agreeing to be a part of this interview today.*
  We are here today to learn about your experience with playing the Text-Based Adherence Game (referred to as TAG). As you know, our idea is to create a game that is played through text messages. The game should be fun and help young people connect with social support and focus on their HIV treatment. We want to know what people think about the game and if you have any suggestions for its improvement. You are the expert in this area. We really need to learn from you in order to make this program successful.
- ☐ Ground rules: *"You do not have to answer any questions you are uncomfortable with.*
  There is no right or wrong answers. We're interested in all opinions."
- ☐ Confidentiality: *"We work hard to make sure everything said in the interview will not be shared with anyone outside of the research team unless you tell us about a situation where you or someone else is in danger."*
- ☐ Digital Recording: *"Recordings are not shared with anyone outside of the research team, they are kept safe and private. When information is taken from the recording,*
  participants will be identified by a number only and names will not be used. Tapes will be erased once transcribed and summarized."

Verbal Interview

Feedback on the Game: The participants will be asked to talk about their impressions of the Text-Based Adherence Game (TAG).

- ☐ *"Tell me about your experience playing TAG."*
- ☐ *"What aspects of TAG did you like the most?"*
- ☐ *"How was the game helpful to your HIV treatment?"*
- ☐ *"In what ways did the game influence how you take ART?"*
- ☐ *"In what ways did the game influence your feelings towards ART?"*
- ☐ *"In what ways did the game influence your ability to attend appointments?"*
- ☐ *"What did you learn from the game?"*
- ☐ *"What aspects of TAG would you want to change?"*
- ☐ *"Tell me your thoughts about the theme of the game."*
- ☐ *"What did you think of the frequency of text messages?"*
- ☐ *"How difficult was it to read and understand the text messages?"*
- ☐ *"What did you think about competing against other young people?"*
- ☐ *"What did you think about having a treatment buddy involved?"*
- ☐ *"Tell me about getting asked to receive a phone call from the clinic?"*
- ☐ *"What would other young people living with HIV like about this game?"*
- ☐ *"Did you ever worry about privacy when playing TAG?"*
- ☐ *"If all young people at the clinic started playing this game tomorrow, what's the first thing you'd do to improve it?*

Closing

Overview: the participants will be thanked for their time and efforts

Appendix 2: Chart Review Data Abstraction Form

1) Today's date:
(MM)_____/(DD)_____/(YY)_____

2) Date of first presentation to KBTH:
(MM)_____/(DD)_____/(YY)_____

3) Age (years) _____

4) Gender
- ❑ 1 – Male
- ❑ 2 – Female

5) Marital Status
- ❑ 1 – Single
- ❑ 2 – Married
- ❑ 3 – Divorced
- ❑ 4 – Separated
- ❑ 5 – Cohabiting
- ❑ 6 – Not Available

6) Highest education level attained
- ❑ 1 – None
- ❑ 2 – Primary
- ❑ 3 – JSS
- ❑ 4 – MSLC
- ❑ 5 – Sec/Tech
- ❑ 6 – University

7) Employment/occupation at presentation

_____

8) Employment status at presentation
- ❑ 1 – Full time
- ❑ 2 – Part time
- ❑ 3 – On leave
- ❑ 4 – Unemployed
- ❑ 5 – Unknown

9) Dependent children (aged <18 years)
- ❑ 1 – Total number
  _____
- ❑ 2 – How many are HIV+
  _____

10) Funding type
- ❑ 1 – Patient out-of-pocket
- ❑ 2 – Medical insurance
- ❑ 3 – Special project
- ❑ 4 – Employer sponsored
- ❑ 5 – Unknown
- ❑ 6 – Other: _____

11) HIV status at presentation:
- ❑ Known positive
- ❑ Diagnosed at admission

12) Current WHO stage
- ❑ 1 – Stage I
- ❑ 2 – Stage II
- ❑ 3 – Stage III
- ❑ 4 – Stage IV

13) Current Drug Therapy (check all that apply):
- ❒ 1 – Stavudine)
- ❒ 2 – Zidovudine)
- ❒ 3 – Lamivudine)
- ❒ 4 – Abacavirl
- ❒ 5 – Tenofovir
- ❒ 6 – Didanosine
- ❒ 7 – Nevirapine
- ❒ 8 – Efavirenz
- ❒ 9 – Combivir (zidovudine and lamivudine)
- ❒ 10 – Kaletra (lopinavir/r)
- ❒ 11 – Nelfinavir
- ❒ 13 – Other-
  :_____

14) Most recent CD4 cell count:_____

15) Date of most recent CD4 cell count test:
_____

16) Most recent viral load:_____

17) Date of most recent viral load test:
_____

18) Detectable viral load in past six months:
- ❒ – Yes
- ❒ – No

19) Date of ART initiation:
(MM)_____/(DD)_____/(YY)_____

20) Number of clinic appointments missed in the past 6 months_____

21) Number of clinic appointments kept in the past 6 months_____

22) Number of clinic appointments missed in the past 12 months_____

23) Number of clinic appointments kept in the past 12 months_____

24) Longest period without an appointment (months):_____

25) Route of HIV infection
- ❑ 1 – Perinatal
- ❑ 2 – Behavioral
- ❑ 3 – Unknown

Appendix 3: Questionnaire and Satisfaction Surveys

ALL QUESTIONNAIRE ITEMS WILL BE READ TO PARTICIPANTS AND ADMINISTERED BY A COMPUTER PROGRAM WITH RESEARCH STAFF PRESENT FOR ASSISTANCE.

Demographic Survey

Age	_____
Gender	1- Male 2- Female 3- Other_____
Ethnicity	1- Akan 2- Ga/Dangbe 3- Ewe 4- Northern Tribes 5- Multiple 6- Other_____
What language do you speak at home?	1- Twi/Fante/Bono 2- Ga/Dangwe 3- Hausa 4- Ewe 5- English 6- Other_____
Location of home	1- Kumasi 2- Outside of Kumasi _____
Distance traveled to Fevers Unit	1- 5km or less 2- 6-10km 3- 11-15km 4- 16-20km 5- 21-25km 6- 26-30km 7- 31-35km 8- 36-40km 9- 41km or more
Time to travel to Chest Clinic	1- less than 30 minutes 2- 30 minutes to 1 hour 3- 1-2 hours 4- more than 2 hours
How do you get to Chest clinic?	1- Public transportation 2- Walk 3- Private car 4- Other_____
How much does it cost you (GHS) to get to Chest clinic?	_____
Highest Education Completed	1- None 2- Primary 3- Secondary 4- Higher education

Currently in school	1- Yes, secondary (boarding school) 2- Yes, secondary (not boarding school) 3- Yes, higher education 4- No
Live with parents or caregivers	1- Yes 2- No
Parents died as a result of AIDS	1 - Yes, one parent 2 - Yes, two parents 3 - No
Does anyone else you live with have HIV?	1- Yes 2- No
Sexual orientation	1- Straight (heterosexual) 2- Gay or lesbian (homosexual) 3- Bisexual 4- Other
Marital status	1- Single/never married 2- Married 3- Divorced/separated 4- Widowed
Relationship status	1- In a relationship, living with partner 2- In a relationship, not living with partner 3- Not in a relationship
HIV status of partner	1- HIV positive 2- HIV negative 3- Not sure
Do you have children? If yes, how many?	1- Yes 2- No _____
Religion	1- No religion 2- Catholic/Anglican 3- Protestant 4- Other Christian 5- Muslim 6- Traditionalist/spiritualist 7- Other_____
Employment	1- Unemployed 2- Self-employed 3- Private or government employment
Monthly household income (GHS)	1- No income 2- 1-99 GHS per month 3- 100-199 GHS per month 4- 200-299 GHS per month 5- 300-399 GHS per month 6- 400-499 GHS per month 7- 500 GHS or more per month

How many people are in your household?	_____
Which of the following best describes the main dwelling where you live?	1. Formal dwelling (such as a house) 2. Informal dwelling (such as shack or tent)

Subjective Social Standing

Instructions – First Ladder

Think of this ladder as showing where people stand in their communities. People define community in different ways. Please define it in whatever way is most meaningful to you. At the top of the ladder are the people who have the highest standing in their community. At the bottom are the people who have the lowest standing in their community. Where would you place yourself on this ladder? Place an X on the rung where you think you stand at this time of your life relative to other people in your community.

Instructions – Second Ladder

Think of this ladder as showing where people stand in Ghana. At the top of the ladder are the people who are the best off – those who have the most money, the best education, and the most respected jobs. At the bottom are the people who are the worst off – who have the least money, least education, and the least respected job or no job. The higher up you are on this ladder, the closer you are to the people at the top.; the lower you are, the closer you are to the people at the bottom. Where would you place yourself on this ladder? Place an X on the rung where you think you stand at this time of your life relative to other people in the Ghana.

Food Security Questions

1. "We worried whether our food would run out before we could get more."
   Was that often true, sometimes true, or never true for your household in the last month?
2. "The food that we had just didn't last, and we couldn't get more."
   Was that often, sometimes, or never true for your household in the last month?
3. "We couldn't get the kinds of foods that give us good health."
   Was that often, sometimes, or never true for your household in the last month?
4. In the last month, did (you/you or other adults in your household) ever reduce the amount of food you ate or skip meals because there wasn't enough food? Yes or No
5. In the last month, did you ever eat less because there wasn't enough food? Yes or No.
6. In the last month, were you ever hungry but didn't eat because there wasn't enough food? Y/N
7. In the last month, did you lose weight because you didn't have enough food to eat? Yes or No.
8. In the last month, did you or other adults in your household ever not eat for a whole day because there wasn't enough food? Yes or No.

Self-Efficacy for Adherence to HIV Care

In the past 6 months, how many doctor's appointments have you missed?

|_____|_____| "Appointments"

Please answer the following questions using these response options:

1 "Very Sure I Can"
2 "Pretty Sure I Can"
3 "Not Sure if I Can or Cannot"
4 "Pretty Sure I Cannot"

5 “Very Sure I Cannot”

How sure are you that you can keep doctor and other health care appointments? _____
How sure are you that you can do better with keeping doctor and other health care appointments?” _____
How sure are you that you can keep doctor and other health care appointments even if you were very tempted not to?” _____
“How sure are you that you can take the right amounts of your medicine at the right times?” _____
“How sure are you that you can do better with taking the right amounts of your medicine at the right times?” _____
“How sure are you that you can take the right amounts of your medicine at the right times even if you were very tempted not to?” _____

ART Perceived Norms

1. Based on what you personally believe, not just what your doctor tells you, what is a good rate of adherence? _____(0 to 100%)
2. How many missed doses would be of concern for you out of your next 10 doses?__
3. Based on what you personally believe, not just what your doctors tells you, what is the rate of adherence for most people your age? _____ (0 to 100%)

Problem-Solving Inventory

Instructions
How much do you agree or disagree with the following statements?

Strongly Agree					Strongly Disagree
1	2	3	4	5	6

1. I am usually able to think up creative and effective alternatives to solve a problem. ____
2. I have the ability to solve most problems even though initially no solution is immediately apparent ____
3. Many problems I face are too complex for me to solve. ____
4. I make decisions and am happy with them later. ____
5. When I make plans to solve a problem, I am almost certain that I can make them work.
6. Given enough time and effort, I believe I can solve most problems that confront me. __
7. When faced with a novel situation I have confidence that I can handle problems that may arise. __
8. I trust my ability to solve new and difficult problems ____
9. After making a decision, the outcome I expected usually matches the actual outcome. _
10. When confronted with a problem, I am unsure of whether I can handle the situation. _
11. When I become aware of a problem, one of the first things I do is to try to find out exactly what the problem is ____
12. When a solution to a problem was unsuccessful, I do not examine why it didn't work. _
13. When I am confronted with a complex problem, I do not bother to develop a strategy to collect information so I can define exactly what the problem is. ____
14. After I have solved a problem, I do not analyze what went right or what went wrong __
15. After I have tried to solve a problem with a certain course of action, I take time and compare the actual outcome to what I thought should have happened. ____
16. When I have a problem, I think up as many possible ways to handle it as I can until I can't come up with any more ideas ____
17. When confronted with a problem, I consistently examine my feelings to find out what is going on in a problem situation. ____

18. When confronted with a problem, I tend to do the first thing that I can think of to solve it. ____
19. When deciding on an idea or possible solution to a problem, I do not take time to consider the chances of each alternative being successful. ____
20. When confronted with a problem, I stop and think about it before deciding on a next step.
21. I generally go with the first good idea that comes to my mind. ____
22. When making a decision, I weigh the consequences of each alternative and compare them against each other. ____
23. I try to predict the overall result of carrying out a particular course of action, ____
24. When I try to think up possible solutions to a problem, I do not come up with very many alternatives. ____
25. I have a systematic method for comparing alternatives and making decisions. ____
26. When confronted with a problem, I do not usually examine what sort of external things my environment may be contributing to my problem. ____
27. When I am confused by a problem, one of the first things I do is survey the situation and consider all the relevant pieces of information. ____
28. When my first efforts to solve a problem fail, I become uneasy about my ability to handle the situation. ____
29. Sometimes I do not stop and take time to deal with my problems, but just kind of muddle ahead. ____
30. Even though I work on a problem, sometimes I feel like I am groping or wandering, and am not getting down to the real issue. ____
31. I make snap judgments and later regret them. ____
32. Sometimes I get so charged up emotionally that I am unable to consider many ways of dealing with my problems. ____

ART Outcome Expectancies

Instructions

We're going to ask you to think about different situations having to do with how people take their HIV medications. Use the following response options to answer the questions.

1	Not at all likely	3	Moderately likely
2	Somewhat likely	4	Very likely

Q1. If you did not take your HIV medications as they are prescribed to you, how likely is it that you would experience worsening health?_____
Q2. If you did not take your HIV medications as they are prescribed to you, how likely is it that your immune system would get weaker?_____
Q3. If you did not take your HIV medications as they are prescribed to you, how likely is it that the virus would get stronger?_____
Q4. If you did not take your HIV medications as they are prescribed to you, how likely is it that you would feel better than you do now?_____
Q5. If you did not take your HIV medications as they are prescribed to you, how likely is it that your life would be easier?_____
Q6. If you did not take your HIV medications as they are prescribed to you, how likely is it that it will not make a difference?_____
Q7. If you did not take your HIV medications as they are prescribed to you, how likely is it that your life would be shorter?_____

Motivational Readiness to Adhere to HIV Medications

Instructions

"How ready are you to take HIV medication as prescribed."

Not Ready				Unsure				Completely Ready	
1	2	3	4	5	6	7	8	9	10

"How ready are you to get to HIV medical appointments (at least 4 times a year)."

Not Ready				Unsure					Completely Ready
1	2	3	4	5	6	7	8	9	10

MOS Social Support Survey

Instructions

People sometimes look to others for companionship, assistance, or other types of support. How often is each of the following kinds of support available to you if you need it? Circle one number on each line.

	None of the time	**A little of the time**	**Some of the time**	**Most of the time**	**All of the time**
Emotional/Informational Support					
Someone you can count on to listen to you when you need to talk	1	2	3	4	5
Someone to give you information to help you understand the situation	1	2	3	4	5
Someone to give you good advice about a crisis	1	2	3	4	5
Someone to confide in or talk to about yourself or your problems	1	2	3	4	5
Someone whose advice you really want	1	2	3	4	5
Someone to share your most private worries and fears with	1	2	3	4	5
Someone to turn to for suggestions about how to deal with a personal problem	1	2	3	4	5
Someone who understands your problems	1	2	3	4	5
Tangible support					
Someone to help you if you were confined to bed	1	2	3	4	5
Someone to take you to the doctor if you needed it	1	2	3	4	5
Someone to prepare your meals if you were unable to do it yourself	1	2	3	4	5
Someone to help with daily chores if you were sick	1	2	3	4	5
Affectionate support					
Someone who shows you love and affection	1	2	3	4	5
Someone to love and make you feel wanted	1	2	3	4	5
Someone who hugs you	1	2	3	4	5

	None	**A little**	**Some**	**Most of**	**All of**

	of the time	of the time	of the time	the time	the time
Positive social interaction					
Someone to have a good time with	1	2	3	4	5
Someone to get together with for relaxation	1	2	3	4	5
Someone to do something enjoyable with	1	2	3	4	5
Additional item					
Someone to do things with to help you get your mind off things	1	2	3	4	5

HIV Care Provider Social Support

Instructions

"Care providers have different styles in dealing with patients. We would like to know more about how you feel about your care provider. Answer these questions by thinking of the main health care provider you see at your HIV clinic. Please indicate how you felt during your most recent visit to your care provider. Your responses are confidential. Please be honest and truthful. Indicate how much you agree with each of the following statements."

1 "Strongly disagree"
2 "Somewhat disagree"
3 "Neutral"
4 "Somewhat agree"
5 "Strongly agree"

1. "I feel that my care provider has provided me with choices and options."

2. "I feel understood by my care provider." _____
3. "My care provider conveys confidence in my ability to make changes." _____
4. "My care provider encourages me to ask questions." _____
5. "My care provider tries to understand how I see things before suggesting a new way to do things." _____

Adherence and Risk Reduction Social Support

Instructions

These questions are about other people in your life. Please tell me how much you agree or disagree with each sentence.

1 Strongly disagree
2 Disagree
3 Uncertain
4 Agree
5 Strongly agree

1."There are people in my life that are supportive about keeping medical appointments" _
2. "There are people in my life that are supportive about taking HIV medication"_____
3."There are people in my life that are supportive about using condoms"_____
4."There are people in my life that are supportive about telling your partner about your HIV status" ____
5. "There are people in my life that are supportive about avoiding drug use" _____
6. "There are people in my life that are supportive about avoiding alcohol use" _____

Modified Social Provisions Scale

Instructions
The next set of questions are about a particular person who you rely on the most for helping you with your HIV treatment on a daily basis. This person is typically a friend, parent or other family member, or your treatment supporter (also known as a treatment buddy) but they can also be a peer educator, clinic counselor, or someone else. He or she may remind you to take your medication, make sure you get to your HIV clinic appointments, or help you in other ways. Please identity this person:

1- Treatment supporter (treatment buddy)
2- Same-age or younger friend
3- Older adult friend
4- Parent
5- Other family member (Please describe your relationship to this person:_____)
6- Peer educator
7- Clinic counselor
8- Someone else (Please describe your relationship to this person:_____)

I'm going to ask you about your relationship with this person. Please tell me how much each statement describes your situation by using these responses. So, for example, if you feel a statement is VERY TRUE you would say Strongly Agree. If you feel a statement CLEARLY does not describe your relationship, you would answer Strongly Disagree?"

Strongly Disagree = 1
Disagree =2
Agree = 3
Strongly Agree = 4

1. This person will help me if I really need it.
2. I do not have a close relationships with my this person.
3. I can't turn to this person in times of stress.
4. This person calls on me to help him/her.
5. This person likes the same social activities I do.
6. This person does not think I am good at what I do.
7. I feel responsible for taking care of this person.
8. This person thinks the same way I do about things.
9. I do not think that this person respects what I do.
10. If something went wrong, this person would help me.
11. I have a close relationship with this person that make me feel good.
12. I can talk to this person about decisions in my life.
13. This person values my skills and abilities.
14. This person does not have the same interests and concerns as me.
15. This person does not need me to help take care of them.
16. This person is a trustworthy person I can turn to if I have problems.
17. I feel a strong emotional tie with this person.
18. I cannot count on this person for help if I really need it.
19. I do not feel comfortable talking about problems with this person.
20. This person admires my talents and abilities.
21. I do not have a feeling of closeness with my this person.
22. This person does not like to do the things I do.
23. I can count on this person in an emergency.
24. This person does not need me to take care of him/her.

Information-Motivation-Behavioral Skills ART Adherence Questionnaire

Instructions and Items
"How much do you agree with each statement?"

1. I strongly disagree
2. I somewhat disagree
3. I neither agree nor disagree
4. I somewhat agree
5. I strong agree

I1. I know how each of my current HIV medications is supposed to be taken (for example whether or not my current medications can be taken with food, herbal supplements, or other prescription medications). _____
I2. I know what to do if I miss a dose of any of my HIV medications (for example, whether or not to take the pill(s) later). _____
I3. Skipping a few of my HIV medications from time to time would not really hurt my health. _
I4 I know what the possible side effects of each of my HIV medications are. _____
I5. As long as I am feeling healthy, missing my HIV medications from time to time is OK.
I6. I understand how each of my HIV medications works in my body to fight HIV. _____
I7. If I don't take my HIV medications as prescribed, these kinds of medications may not work for me in the future. _____
I8. I believe that if I take my HIV medications as prescribed, I will live longer. _____
I9. I know how my HIV medications interact with alcohol and street drugs. _____
M1. I am worried that other people might realize that I am HIV+ if they see me taking my HIV medications. _____
M2. I get frustrated taking my HIV medications because I have to plan my life around them.
M3. I don't like taking my HIV medications because they remind me that I am HIV+._____
M4. I feel that my healthcare provider takes my needs into account when making recommendations about which HIV medications to take. _____
M5. Most people who are important to me who know I'm HIV positive support me in taking my HIV medications.
M6. My healthcare provider doesn't give me enough support when it comes to taking my medications as prescribed. _____
M7. It frustrates me to think that I will have to take these HIV medications every day for the rest of my life. _____
M8. I am worried that the HIV medications I have been prescribed will hurt my health. __
M9. It upsets me that the HIV medications I have been prescribed can affect the way I look.
M10. It upsets me that the HIV medications I have been prescribed can cause side effects.
B1. There are times when it is hard for me to take my HIV medications when I drink alcohol or use street drugs. _____

"How hard or easy would it be to do the following?"

1. Very hard
2. Hard
3. Sometimes hard, sometimes easy
4. Easy
5. Very easy

B2. How hard or easy is it for you to stay informed about HIV treatment? _____
B3. How hard or easy is it for you to get the support you need from others for taking your HIV medications (for example, from friends, family, doctor, or pharmacist)? _____
B4. How hard or easy is it for you to get your HIV medication refills on time? _____
B5. How hard or easy is it for you to take your HIV medications when you are wrapped up in what you are doing? _____
B6. How hard or easy is it for you to manage the side effects of your HIV medications?___
B7. How hard or easy is it for you to remember to take your HIV medications? _____
B8. How hard or easy is it for you to take your HIV medications because the pills are hard to swallow, taste bad, or make you sick to your stomach? _____
B9. How hard or easy is it for you to make your HIV medications part of your daily life? __
B10. How hard or easy is it for you to take your HIV medications when your usual routine changes (for example, when you travel or when you go out with your friends)? _____

B11. How hard or easy is it for you to take your HIV medications when you do not feel good emotionally (for example, when you are depressed, sad, angry, or stressed out)? ___
B12. How hard or easy is it for you to take your HIV medications when you feel good physically and don't have any symptoms of your HIV disease? _____
B13. How hard or easy is it for you to take your HIV medications when you do NOT feel good physically? _____
B14. How hard or easy is it for you to talk to your health care provider about your HIV medications? _____

HIV Treatment Readiness Measure (HTRM)

Instructions

"Please rate on a scale of 1 (strongly disagree) to 5 (strongly agree) how true each of the statements below are for you. By HIV health care provider, we mean your doctor, nurse practitioner or physician assistant."

Use the following response options:

"1=Strongly Disagree"
"2=Disagree"
"3=Neither Agree nor Disagree"
"4=Agree"
"5=Strongly Agree"

1. "I usually eat at least 3 meals each day." _____
2. "I am ready to start taking HIV medications." _____
3. "Most of the people I live with know my HIV status." _____
4. "I believe taking HIV medications can keep me healthy." _____
5. "In the past 3 months, I found myself wishing I hadn't used street drugs so often." ___
6. "Taking HIV medications would give me bad side effects." _____
7. "I would know how to contact my pharmacist or medical provider if I had problems or questions about HIV medications." _____
8. "I feel like I have a stable place to live." _____
9. "If I don't take HIV medications exactly as instructed, the HIV in my body will become resistant to the medications." _____
10. "I have a strong, trusting relationship with my medical provider." _____
11. "Even though the time may vary on the weekends, I have a regular time when I wake up and go to bed." _____
12. "I am anxious about my future because I have HIV." _____
13. "I would know who and when to call for refills for HIV medications." _____
14. "I sleep in the same bed almost every night." _____
15. "I can cope with my HIV diagnosis." _____
16. "Sometimes a homeless shelter is the only place I have to sleep." _____
17. "Most of my family and friends know my HIV status." _____
18. "My schedule is different every day." _____
19. "Taking HIV medication would not really help me." _____
20. "Even when it may be difficult, I will be able to let my medical provider know if I miss doses of HIV medications." _____
21. "I regularly go to the clinic and meet with my medical provider." _____
22. "HIV medications would be poison to my body." _____
23. "I want to start taking HIV medications." _____
24. "Despite having HIV, I can move forward with my life." _____
25. "My household members who know I have HIV would help me remember to take my medication." _____
26. "Taking HIV medications as prescribed would keep me from getting sick." _____
27. "I feel supported by my family and friends when times are tough." _____
28. "I would find it difficult to take pills at the same time every day." _____

29. "I would take HIV medications even if they made me sick at first because the side effects would go away." _____
30. "My family and friends who know I have HIV would help me remember to take my medications." _____
31. "In the past 3 months, I found myself wishing I hadn't drunk alcohol so often." _____
32. "I know that I will be able to take all of my medication correctly." _____
33. "I feel confused about what to do about my HIV." _____
34. "I always eat at least 2 meals each day." _____
35. "I do not feel respected by my medical provider." _____
36. "Taking HIV medication would be more trouble than it's worth." _____
37. "It would be important to me to take HIV medication correctly and on time every day." _____

Use the following response options:

"1=Never"
"2=Once"
"3=At least once a month"
"4=2-3 times per month"
"5=At least once a week"

1. "In the past 3 months, I have been drunk."
2. "In the past 3 months, I have used marijuana."
3. "In the past 3 months, I have used drugs such as crack, meth, or cocaine."

Use the following response options:

"1=Never"
"2=Rarely"
"3=Sometimes"
"4=Almost Always"
"5=Always"

1. "In the past month, how often have you felt lonely or sad?"
2. "In the past month, how often have you been told you seem sad or depressed?"
3. "In the past month, how often have you felt isolated or lonely, even when around other people?"
4. "In the past month, how often have you felt that things were going your way?"
5. "In the past month, how often have you felt confident in your ability to handle your personal problems?"
6. "In the past month, how often have you felt you could not cope with all the things you had to do?"

"In how many different places have you lived in the past year?" |_____|_____|

I shouldn't tell the people I live with that I have HIV."

"1=Strongly Disagree"
"2=Disagree"
"3=Neither Agree nor Disagree"
"4=Agree"
"5=Strongly Agree"

"How many people have you told your HIV status?"

"1=No one"
"2=Only one person"
"3=Some people"
"4=Most people"
"5=Everyone"

"Who have you told? Check all that apply"

"1=Partner (e.g., girlfriend, boyfriend, husband, wife)"
"2=Friend"
"3=Parent or guardian"
"4=Your Child"
"5=Healthcare provider"
"6=Teacher"
"7=Classmate"
"8=Colleague"
"9=Employer"
"10=Sibling"
"11=Other relative (not parent or guardian)"

"How many people you live with have you told your HIV status?"

"1=No one"
"2=Only one person"
"3=Some people"
"4=Most people"

HIV Knowledge

*HIV is **transmitted** by:*		
1. Living in the same house with an HIV patient	True	False
2. Sharing utensils	True	False
3. Coughing	True	False
4. Hugging someone with HIV	True	False
5. Having sex without a condom	True	False
6. Kissing	True	False
7. Having sex with multiple partners	True	False
8. Mosquito that has bitten someone with HIV	True	False
9. Through injection intravenous drug use	True	False
10. Sharing cigarettes, food, or drink	True	False
11. An HIV-infected pregnant women infecting her baby	True	False
12. You can tell someone has HIV by looking at them	True	False
13. As long as I'm tested I'm safe	True	False
14. The medication used to treat HIV	True	False
15. HIV tests	True	False
*HIV is **prevented** by:*		
1. Using condoms	True	False
*HIV is **caused** by:*		
2. A virus	True	False
3. Spiritual forces	True	False

ART Knowledge and Attitudes

Are you worried about: Responses are 1 Not at all, 2 A little, 3 Somewhat, 4 Very

1. ART side effects? _____
2. ART ineffectiveness? _____
3. Having to take ART? _____
4. Friends finding out you are on ART? _____
5. Family finding out you are on ART? _____
6. Your sexual partner finding out you are on ART? _____

Do you agree or disagree: Responses are 1 Agree, 2 Disagree

7. ART prevent mother-to-child HIV transmission_____
8. HIV can be prevented by ART after rape_____
9. HIV can be controlled by ART_____

10. HIV can be cured by ART_____
11. Taking ART prevents disease progression_____
12. Not starting ART when indicated can make you sick_____
13. Antiretroviral medicine can cause side effects_____

Importance of ART adherence: Responses are 1 Agree, 2 Disagree
14. Taking ART on schedule prevents you from being sick_____
15. Missing doses of ART leads to disease progression_____
16. Missing doses of ART increases risk of transmitting HIV_____

Adolescent Risk Behavior Assessment

In this interview, you will use the headphones to listen to questions and enter your answers into the computer. This will allow you to answer the questions in complete privacy. No one will be able to hear the questions or see the answers you put into the computer. Please be as honest as you can, and take your time to read and listen to each question before answering.		
These questions ask about your drug use, sexual behavior, and medical health. Please answer EVERY question, but only give ONE answer per question. Remember, these answers are confidential.		
1	By oral sex we mean, have you ever put your mouth on anyone else's penis/vagina or has anyone else put his/her mouth on your vagina/private parts. By vaginal sex, we mean has anyone ever put his penis into your vagina/private part. By anal sex we mean, has anyone ever put his penis in your anus/butt. Have you ever had sexual intercourse of any kind (oral, vaginal or anal)?	1= Yes 2= No [Skip]
2	The very last time you had sex, did you use a condom?	1= Yes 2= No
3	Have you ever had oral sex? (By "oral sex" we mean, have you ever put your mouth on anyone else's vagina/penis or has anyone else put his/her mouth on your vagina/private parts?)	1= Yes 2= No [Skip]
4	In the past 120 days, have you had oral sex (mouth on privates)?	1= Yes 2= No [Skip]
5	In the past 120 days, how many times have you had oral sex (mouth on privates)?	☐☐☐☐(Range 1-999)
6	In the past 120 days, when you had oral sex (mouth on privates), how many times did you use a condom (rubber) or dental dam?	☐☐☐☐(Range 0-999)
7	Have you ever had vaginal sex? (By "vaginal sex," we mean when a man puts his penis in a woman's vagina.)	1= Yes 2= No
8	In the past 120 days, have you had vaginal sex (penis in vagina)?	1= Yes 2= No [Skip]
9	In the past 120 days, how many times have you had vaginal sex (penis in vagina)?	☐☐☐☐(Range 1-999)
10	In the past 120 days, when you had vaginal sex (penis in vagina), how many times did you use a condom ?	☐☐☐☐
11	Have you ever had anal sex? (By "anal sex," we mean when a man puts his penis in someone's anus or butt.)	1= Yes 2= No
12	In the past 120 days, have you had anal sex (penis in butt)?	1= Yes 2= No [Skip]

13	In the past 120 days, how many times have you had anal sex (penis in butt)?	☐☐☐☐(Range 1-999)
14	When you had anal sex (penis in butt) during the past 120 days, how many times did you use a condom (rubber)?	☐☐☐☐(Range 0-999)
15	How many people have you had any kind of sex with (oral, vaginal, and/or anal) in your life?	☐☐☐(Range 1-99)
16	In your lifetime, have any of your sex partners been male?	1= Yes 2= No [Skip]
17	In your lifetime, how many of your sex partners have been male?	☐☐☐(Range 1-99)
18	In your lifetime, have any of your sex partners been female?	1= Yes 2= No [Skip]
19	In your lifetime, how many of your sex partners have been female?	☐☐☐(Range 1-99)
20	How many people have you had any kind of sex with (oral, vaginal and/or anal) in the past 120 days?	☐☐☐(Range 1-99)
21	During the past 120 days, have any of your sex partners been male?	1= Yes 2= No [Skip]
22	During the past 120 days, how many of your sex partners have been male?	☐☐☐(Range 1-99)
23	During the past 120 days, have any of your sex partners been female?	1= Yes 2= No [Skip]
24	During the past 120 days, how many of your sex partners have been female?	☐☐☐(Range 1-99)
25	In the past 4 months, have you been told that you have Hepatitis?	1= Yes 2= No [Skip]
26	Have you ever had or been told by a doctor or nurse that you had Gonorrhea (clap), Syphilis (syph), Chlamydia, or Trichomonas (trich)?	1= Yes 2= No [Skip]
27	How many times have you been told this?	☐☐☐(Range 1-99)
28	In the past 120 days, have you been told that you have Gonorrhea (clap), Syphilis (syph), Chlamydia, or Trichomonas (trich)?	1= Yes 2= No [Skip]
29	Have you ever had or been told by a doctor or nurse that you have genital warts?	1= Yes 2= No [Skip]
30	How many times have you been told this?	☐☐☐(Range 1-99)
31	In the past 120 days, have you been told by a doctor or nurse that you have genital warts?	1= Yes 2= No [Skip]
32	Have you ever had or been told by a doctor or nurse that you had the following medical condition? Herpes	1= Yes 2= No [Skip]
33		
34	How many times have you been told this?	☐☐☐(Range 1-99)
35	Have you ever been or gotten someone else pregnant?	1= Yes 2= No [Skip]
36	How many times have you been or gotten someone pregnant?	☐☐☐(Range 1-99)

37	With that in mind: How often do you practice safe sex?	1=Always 2=Almost always 3=Sometimes 4=Almost never 5=Never
38	During the past 120 days, how often did you use a condom when having sex?	1=Always 2=Almost always 3=Sometimes 4=Almost never 5=Never
39	In the next 120 days, how likely do you think it is that you will practice safe sex?	1=Very sure I will 2=Kind of sure I will 3=Kind of sure I won't 4=Very sure I won't
40	In the past 120 days, did you refuse or avoid having sex?	1= Yes 2= No
41	On a scale of 0-100, at this moment, how IMPORTANT is it that you use condoms when having sex? (Please enter any number 0-100) Please use the following scale to answer this question: 0=Not important at all 50=About as important as the other things I would like to achieve now 100=Most important thing in my life)	
42	On a scale of 0-100, at this moment, how CONFIDENT are you that you will use condoms while having sex? (Please enter any number 0-100) Please use the following scale to answer this question: 0=I do not think I will achieve my goal 50=I have a 50% chance of meeting my goal 100=I think I will definitely meet my goal	
43	Have you ever given sex for money, drugs, or shelter?	1= Yes 2= No
44	In the past 120 days, have you given sex for money, drugs or shelter?	1= Yes 2= No
45	Have you ever purchased or bought sex with money, drugs, or shelter?	1= Yes 2= No
46	In the past 120 days, have you purchased or bought sex with money, drugs or shelter?	1= Yes 2= No
47	In the past 120 days, when you have had vaginal or anal sex, how often were YOU using alcohol, marijuana, or other drugs?	1=Never 2=Less than half the time 3=About half the time 4=More than half the time 5=Always
48	In the past 120 days, when you have had vaginal or anal sex, how often was your PARTNER using alcohol, marijuana, or other drugs?	1=Never 2=Less than half the time 3=About half the time 4=More than half the time 5=Always

49	In the past 120 days, which of these methods have you used to prevent pregnancy? (Choose all that apply.)	1=Condoms 2=The Pill 3=A diaphragm 4=A cervical cap 5=Gels, creams, suppositories, or foams 6=Depo Provera 7=Other 8=No birth control methods in the past 90
50	Have you ever smoked cigarettes?	1=Yes 2=No
51	How old were you when you first started smoking cigarettes?	☐☐☐(Range 1-99)
66	In the last 120 days, have you smoked cigarettes?	1=Yes 2=No
67	How many days did you smoke cigarettes in the last 120 days?	☐☐☐(Range 1-99)
68	Have you ever used alcohol (beer, wine, etc.)?	1=Yes 2=No
69	How old were you when you had your first drink of alcohol, other than a few sips?	☐☐☐(Range 1-99)
70	In the past 120 days, have you ever used alcohol (beer, wine, etc.)?	1=Yes 2=No
71	How many days did you use alcohol in the last 120 days?	☐☐☐(Range 1-99)
72	How many times did you use alcohol in the last MONTH?	☐☐☐(Range 1-99)
73	For the next question, you will need to know what we mean by a "drink." For instance, a drink equals 12 ounces of beer, 1 ounce of liquor (such as whisky, gin, or vodka), or 6 ounces of wine.	none
74	Of the days when you were drinking, about how many drinks did you usually have each day?	☐☐☐(Range 1-99)
75	Of the days when you were drinking, on how many days did you get buzzed or drunk on alcohol?	☐☐☐(Range 1-99)
76	When was the last time you used any alcohol?	1=Within the past week 2=2 weeks ago 3=3-4 weeks 4=More than 4 weeks ago
77	When you drink, how often do you get drunk?	0=Don't drink 1=Stop before getting drunk 2=Almost always stop before getting drunk 3=Stop before getting drunk more than half the time 4=Get drunk more than half the time 5=Usually get drunk

78	How likely is it that you WILL drink alcohol in the future? (pick a number from 1-10)	1=Unlikely 5=Somewhat Likely 10=Very Likely
The following questions are about drugs. By "drugs" we mean street drugs or prescription medications that you took more than was prescribed, or that was not prescribed for you. Remember, do not include drugs that you took only as prescribed.		
78	Have you ever used any form of marijuana, such as pot, weed, hashish, grass or ganja?	1=Yes 2=No
79	How old were you when you tried marijuana for the first time?	☐☐☐(Range 1-99)
80	In the last 120 days, have you used any form of marijuana, such as pot, weed, hashish, grass or ganja?	1=Yes 2=No
81	In the last 120 days, how many days did you use marijuana?	☐☐☐(Range 1-99)
82	In the last MONTH, how many times did you use marijuana?	☐☐☐(Range 1-99)
83	When was the last time you used any marijuana?	1=Within the past week 2=2 weeks ago 3=3-4 weeks 4=More than 4 weeks ago
84	With whom have you smoked marijuana? Check all that apply.	1=Parent 2=Brother/Sister 3=Other Relative 4=Friend 5=Boyfriend/Girlfriend 6=Teacher/Coach 7=Therapist 8=Acquaintance 9=By myself
95	Have you ever used methamphetamines (speed)?	1=Yes 2=No
96	How old were you when you first started using methamphetamines?	☐☐☐(Range 1-99)
97	In the past 120 days, have you used methamphetamines?	1=Yes 2=No
98	How many days in the past 120 days did you use methamphetamines?	☐☐☐(Range 1-99)
99	How many days in the past 30 days have you used methamphetamines?	☐☐☐(Range 1-99)
100	Have you ever used any type of cocaine (coke, powder, crack, or freebase)?	1=Yes 2=No
101	How old were you when you first started using any type of cocaine (coke, powder, crack, or freebase)?	☐☐☐(Range 1-99)
102	In the past 120 days, have you used any type of cocaine (coke, powder, crack or freebase)?	1=Yes 2=No
103	How many days in the past 120 days did you use any type of cocaine (coke, powder, crack, or freebase)?	☐☐☐(Range 1-99)
104	How many days in the past 30 days have you used any type of cocaine (coke, powder, crack, or freebase)?	☐☐☐(Range 1-99)

105	When was the last time you used any type of cocaine (coke, powder, crack, or freebase)?	1=Within the past week 2=2 weeks ago 3=3-4 weeks 4=More than 4 weeks ago
110	Have you ever used club drugs (ecstasy "x", Special K, etc.)?	1=Yes 2=No
111	How old were you when you first started using club drugs (ecstasy "x", Special K, etc.)?	☐☐☐(Range 1-99)
112	In the past 120 days, did you use club drugs (ecstasy, "x", Special K, etc.)?	
113	How many days in the past 120 days did you use club drugs (ecstasy "x", Special K, etc.)?	☐☐☐(Range 1-99)
114	How many days in the past 30 days have you used a club drug (ecstasy "x", Special K, etc.)?	☐☐☐(Range 1-99)
115	When was the last time you used a club drug (ecstasy "x", Special K, etc.)?	1=Within the past week 2=2 weeks ago 3=3-4 weeks 4=More than 4 weeks ago
116	Have you ever used over the counter or prescription medication to get high (cough syrup, Ritalin, Oxycontin, Vicodin, etc.)?	1=Yes 2=No
117	How old were you when you first started using over the counter or prescription medication to get high (cough syrup, Ritalin, Oxycontin, Vicodin, etc.)?	☐☐☐(Range 1-99)
118	In the past 120 days, have you used over the counter or prescription medication to get high (cough syrup, Ritalin, Oxycontin, Vicodin, etc.) days?	1=Yes 2=No
119	In the past 120 days, how many times did you use over the counter or prescription medication to get high (cough syrup, Ritalin, Oxycontin, Vicodin, etc.)?	☐☐☐(Range 1-99)
120	How many days in the past 30 days have you used over the counter or prescription medication to get high (cough syrup, Ritalin, Oxycontin, Vicodin, etc.)?	☐☐☐(Range 1-99)
121	When was the last time you used any type of over the counter medication or prescription medication to get high (cough syrup, Ritalin, Oxycontin, Vicodin, etc.)?	1=Within the past week 2=2 weeks ago 3=3-4 weeks 4=More than 4 weeks ago
122	Have you ever used heroin (smack, junk, or China White)?	1=Yes 2=No
123	In the past 120 days, have you ever used heroin (smack, junk, China White)	1=Yes 2=No
124	In the past 120 days, how many times did you inject heroin?	☐☐☐(Range 1-99)
125	In the past 30 days, how many times did you inject heroin?	☐☐☐(Range 1-99)
126	How important is it for you NOT to use drugs? (pick a number from 1-10)	1=Not important 5=Somewhat important 10=Very important

127	How likely is it that you WILL use drugs in the future? (pick a number from 1-10)	1=Unlikely 5=Somewhat Likely 10=Very Likely
128	When you use drugs, how often do you get high or stoned?	1=Don't use 2=Stop before getting stoned 3=Almost always stop before getting stoned 4=Stop before getting stoned more than half the time 5=Get stoned more than half the time 6=Usually get stoned
129	Where do you usually drink/use?	0=Nowhere (don't drink/use) 1=Car/vehicle/motorcycle 2=Home 3=Friend's house 4=Party or social event 5=Park or beach 6=Shopping mall, rec center 7=School 8=Work 9=Anywhere and everywhere 10=Restaurant 11=Other
130	Please list the other place you usually drink/use.	
131	Who do you drink/use with?	0=Not applicable/don't drink or use 1=Alone 2=Casual acquaintances 3=Friends 4=Partner/boyfriend/girlfriend 5=Family members

HIV Lay Beliefs

Items

1. Witchcraft plays a role in HIV transmission. True False
2. Some traditional healers can cure AIDS. True False
3. Vitamins and fresh fruits and vegetables can cure AIDS. True False
4. HIV was created by some group, such as the CIA, to kill Africans. True False
5. There is a cure for AIDS, but it is being withheld from Africa. True False
6. Free condoms sometimes contain AIDS. True False
7. Antiretroviral treatments are poisonous and make people sicker. True False

Perceived Access to HIV Medical Care Services

Instructions

Please reflect on the degree to which you agree or disagree with the following statements related to your HIV medical care.

1 = Strongly disagree
2 = Disagree
3 = Neither agree nor disagree
4 = Agree
5 = Strongly agree

1. Sometimes I go without the HIV medical care I need because it's too expensive.
2. It is hard for me to get HIV medical care in an emergency.
3. If I have emotional problems, I have easy access to a mental health counselor.
4. If I need hospital HIV medical care, I can get admitted without any trouble.
5. I am able to get HIV medical care whenever I need it.
6. Places where I can get HIV medical care are very conveniently located.
7. I have easy access to HIV treatment counselors.

Perceived HIV-related Stigma

Use the following responses: 1 Strongly disagree 2 Disagree 3 Agree 4 Strongly agree

1. I feel I am not as good a person as others because I have HIV _____
2. Having HIV makes me feel unclean _____
3. Having HIV makes me feel I am a bad person _____
4. People's attitudes about HIV make me feel worse about myself _____
5. I feel guilty because I have HIV _____
6. Having HIV in my body is disgusting to me _____
7. People I know would treat someone with HIV as an outcast _____
8. People I know would be uncomfortable around someone with HIV _____
9. People I know believe that a person with HIV is dirty _____
10. People I know would reject someone with HIV _____
11. People I know would not want someone with HIV around their children _____
12. People I know think that a person with HIV is disgusting_____

Concerns about Disclosure Tool

Questions and Filters	Response
Indicate your agreement or disagreement with each statement: a) I am very careful who I tell that I have HIV. ____ b) I don't feel the need to hide the fact that I have HIV.____ c) I worry that people may judge me when they learn I have HIV.____ d) Telling someone I have HIV is risky____ e) Since learning I have HIV, I worry about people discriminating against me._____ f) It is easier to avoid new friendships than worry about telling someone that I have HIV _____ g) I work hard to keep my HIV a secret____	1 Strongly Disagree 2 Disagree 3 Agree 4 Strongly Agree

Past 30-Day ART Adherence

Instructions

1. In the last 30 days, on how many days did you miss at least one dose of any of your HIV medication?
Write in number of days: _____ (0–30)

2. In the last 30 days, how good a job did you do at taking your HIV medication in the way you were supposed to? □ Very poor □ Poor □ Fair □ Good □ Very good □ Excellent

3. In the last 30 days, how often did you take your HIV medication in the way you were supposed to? □ Never □ Rarely □ Sometimes □ Usually □ Almost always □ Always

Antiretroviral Adherence: ACTG

List the medications you take for HIV.

Study Drug Name/Dose	# Pills Each Time (Pills Each Dose)	# Times Per Day (Doses Per Day)

The next section of the questionnaire asks about the study medications that you may have missed taking over the last four days. Please complete the following table below.

IF YOU TOOK ONLY A PORTION OF A DOSE ON ONE OR MORE OF THESE DAYS, PLEASE REPORT THE DOSE(S) AS BEING MISSED.

Step 1 Names of your anti-HIV study drugs	HOW MANY DOSES DID YOU MISS . . . ___			
	Step 2 Yesterday	Step 3 Day before yesterday (2 days ago)	Step 4 3 days ago	Step 5 4 days ago
	• doses	• doses	• doses	• doses
	• doses	• doses	• doses	• doses

C. Most anti-HIV medications need to be taken on a schedule, such as "2 times a day" or "3 times a day" or "every 8 hours." How closely did you follow your specific schedule over the last four days?

Never	Some Of The Time	About Half Of The Time	Most Of The Time	All Of The Time
0	1	2	3	4

D. Do any of your anti-HIV medications have special instructions, such as "take with food" or "on an empty stomach" or "with plenty of fluids?" Yes____ No _____

If Yes, how often did you follow those special instructions over the last four days?

Never	Some Of The Time	About Half Of The Time	Most Of The Time	All Of The Time
0	1	2	3	4

Some people find that they forget to take their pills on the weekend days. Did you miss any of your anti-HIV medications last weekend— last Saturday or Sunday? Yes____ No ____

When was the last time you missed any of your medications? Check one.

5 Within the past week
4 1-2 weeks ago
3 2-4 weeks ago
2 1-3 months ago
1 More than 3 months ago
0 Never skip medications or not applicable

People may miss taking their medications for various reasons. Here is a list of possible reasons why you may miss taking your medications. How often have you missed taking your medications because you: (Circle one response for each question.)

	Never	Rarely	Sometimes	Often
1. Were away from home?	0	1	2	3
2. Were busy with other things?	0	1	2	3
3. Simply forgot?	0	1	2	3
4. Had too many pills to take?	0	1	2	3
5. Wanted to avoid side effects?	0	1	2	3
6. Did not want others to notice you taking medication?	0	1	2	3
7. Had a change in daily routine?	0	1	2	3
8. Felt like the drug was toxic/harmful?	0	1	2	3
9. Fell asleep/slept through dose time?	0	1	2	3
10. Felt sick or ill?	0	1	2	3
11. Felt depressed/overwhelmed?	0	1	2	3
12. Had problems taking pills at specified times (with meals, on empty stomach, etc.)?	0	1	2	3
13. Ran out of pills?	0	1	2	3
14. Felt good?	0	1	2	3

Antiretroviral Adherence: Visual Analog Scale

This measure of past 4-week antiretroviral adherence has been used in resource-limited settings in sub-Saharan Africa for patients with low literacy (Erb et al., 2017).

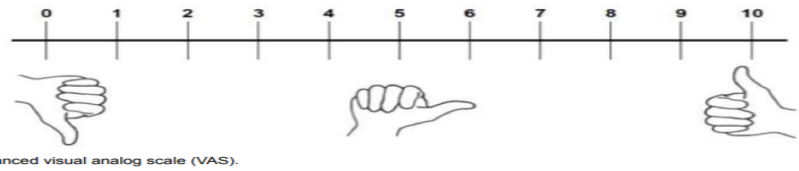

Figure 1: Pictogram-enhanced visual analog scale (VAS).
The following question was asked to the patient when showing the VAS: "How much of your HIV-medication have you taken in the last 4 weeks: Point with the finger on the line ranging from 0 to 10 to indicate where you think you are. 0 (thumb pointing downwards) means you have taken none of the pills, 5 (thumb is in a horizontal position) means you have taken half and 10 (or thumb is pointing upwards) means you have consistently taken every single pill"

Physical Health

Choose one option for each questionnaire item.

1. In general, would you say your health is:

1 - Excellent
2 - Very good
3 - Good
4 - Fair
5 – Poor

2. **Compared to one year ago**, how would you rate your health in general **now**?

1 - Much better now than one year ago
2 - Somewhat better now than one year ago
3 - About the same
4 - Somewhat worse now than one year ago
5 - Much worse now than one year ago

The following items are about activities you might do during a typical day. Does **your health now limit you** in these activities? If so, how much? Yes, limited a lot. Yes, limited a little. No, not limited at all.

3. **Vigorous activities**, such as running, lifting heavy objects, participating in strenuous sports
4. **Moderate activities**, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf
5. Lifting or carrying groceries
6. Climbing **several** flights of stairs
7. Climbing **one** flight of stairs
8. Bending, kneeling, or stooping
9. Walking **more than two kilometers**
10. Walking **one kilometer**
11. Walking **one block**
12. Bathing or dressing yourself

During the **past 4 weeks**, have you had any of the following problems with your work or other regular daily activities **as a result of your physical health**? Yes or No

13. Cut down the **amount of time** you spent on work or other activities
14. **Accomplished less** than you would like
15. Were limited in the **kind** of work or other activities
16. Had **difficulty** performing the work or other activities (for example, it took extra effort)

During the **past 4 weeks**, have you had any of the following problems with your work or other regular daily activities **as a result of any emotional problems** (such as feeling depressed or anxious)? Yes or No

17. Cut down the **amount of time** you spent on work or other activities_____
18. **Accomplished less** than you would like_____
19. Didn't do work or other activities as **carefully** as usual_____

During the **past 4 weeks**, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

1 - Not at all
2 - Slightly
3 - Moderately
4 - Quite a bit

21. How much **bodily** pain have you had during the **past 4 weeks**?
1 - None
2 - Very mild
3 - Mild
4 - Moderate
5 - Severe
6 - Very severe

1. During the **past 4 weeks**, how much did **pain** interfere with your normal work (including both work outside the home and housework)?

1 - Not at all

2 - A little bit
3 - Moderately
4 - Quite a bit
5 – Extremely

These questions are about how you feel and how things have been with you **during the past 4 weeks**. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the **past 4 weeks**…

Responses: All, most, some, a good bit, a little, or none of the time.

23. Did you feel full of energy?
24. Have you been a very nervous person?
25. Have you felt so sad that nothing could cheer you up?
26. Have you felt calm and peaceful?
27. Did you have a lot of energy?
28. Have you felt sad and depressed?
29. Did you feel worn out?
30. Have you been a happy person?
31. Did you feel tired?

C. During the **past 4 weeks**, how much of the time has **your physical health or emotional problems** interfered with your social activities (like visiting with friends, relatives, etc.)?

1 - All of the time
2 - Most of the time
3 - Some of the time
4 - A little of the time
5 - None of the time

How TRUE or FALSE is **each** of the following statements for you. Definitely true, mostly true, don't know, mostly false, definitely false.

33. I seem to get sick a little easier than other people
34. I am as healthy as anybody I know
35. I expect my health to get worse
36. My health is excellent

37a. Please tell me the year when you first tested positive for HIV. _____

37b. Please tell me the month when you first tested positive for HIV. _____

38a. Please tell me the year when you first started taking ART. _____

38b. Please tell me the month when you first started taking ART. _____

39. What was your CD4 count at your most recent laboratory test? _____

40. What was your viral load at your most recent laboratory test? _____

41. Have you ever received a diagnosis of AIDS? Yes or No.

42. In the past 6 months, how many doctor's appointments with your HIV care provider did you have scheduled? _____

43. In the past 6 months, how many doctor's appointments with your HIV care provider did you attend? _____

44. In the past 6 months, how many doctor's appointments with your HIV care provider did you miss? _____

HIV-related Health Anxiety

Instructions

To answer these questions ask yourself, "During the past week, how often has thinking about HIV infection/AIDS and my health affected this area of my life?"

Not at all 1
A little bit 2
Sometimes 3
Often 4
Always 5

1. You were thinking about HIV infection/AIDS and your health, and because of that you had trouble sleeping--either getting to sleep or sleeping through the whole night. _____
2. You were thinking about HIV infection/AIDS and your health, and because of that you had no appetite, or felt like eating very little. _____
3. You were thinking about HIV infection/AIDS and your health, and because of that you had no desire to go out and do any social activities with other people. _____
4. You were thinking about HIV infection/AIDS and your health, and because of that you had trouble concentrating at school or work because of worrying about your health _____

CES-D: Depressive Symptoms

Instructions:

I'm now going to give you a list of the ways you might have felt or behaved recently. Please tell me how often you have felt this way during the past week.

Rarely or none of the time (less than 1 day) – 1
Some or a little of the time (1-2 days) – 2
Occasionally or a moderate amount of time (3-4 days) – 3
Most or all the time (5-7 days) – 4

1. I was bothered by things that usually don't bother me.
2. I did not feel like eating; my appetite was poor.
3. I felt that I could not stop being sad even with help from family and friends.
4. I felt that I was just as good as other people.
5. I had trouble keeping my mind on what I was doing.
6. I felt depressed.
7. I felt that everything I did was an effort.
8. I felt hopeful about the future.
9. I thought my life had been a failure.
10. I felt fearful.
11. My sleep was restless.
12. I was happy.
13. I talked less than usual.
14. I felt lonely.
15. People were unfriendly.
16. I enjoyed life.
17. I had crying spells.
18. I felt sad.
19. I felt that people disliked me.
20. I could not get "going".

Mental Health Symptoms

Instructions:

Below is a list of problems people sometimes have. For each please indicate how much that problem has distressed or bothered you during the past 14 days including today. How much have you been distressed or bothered during the past 14 days, (including today) by:

	NOT AT ALL	A LITTLE BIT	MODERATELY	QUITE A BIT	EXTREMELY
1. Faintness or dizziness	0	1	2	3	4
2. Feeling no interest in things	0	1	2	3	4
3. Nervousness or shakiness inside	0	1	2	3	4
4. Pains in heart or chest	0	1	2	3	4
5. Feeling lonely	0	1	2	3	4
6. Feeling tense or keyed up	0	1	2	3	4
7. Nausea or upset stomach	0	1	2	3	4
8. Feeling blue	0	1	2	3	4
9. Suddenly scared for no reason	0	1	2	3	4
10. Trouble getting your breath	0	1	2	3	4
11. Feelings of worthlessness	0	1	2	3	4
12. Spells of terror or panic	0	1	2	3	4
13. Numbness or tingling in parts of your body	0	1	2	3	4
14. Feeling hopeless about the future	0	1	2	3	4
15. Feeling so restless you couldn't sit still	0	1	2	3	4
16. Feeling weak in parts of your body	0	1	2	3	4
17. Thoughts of ending your life	0	1	2	3	4
18. Feeling fearful	0	1	2	3	4

Perceived Neighborhood Quality

The following is measure of perceived neighborhood quality originally developed in the U.S.

Instructions: Please answer the following questions about your neighborhood.

True – 1 False - 2

01: When there is a problem around here the neighbours get together to deal with it
02: This is a close-knit neighbourhood
03: When you get right down to it no one in your neighbourhood cares much about what happens to you
04: There are adults in your neighbourhood that children can look up to
05: People around here are willing to help their neighbours
06: People in this neighbourhood generally dont get along with each other
07: You can count on adults in your neighbourhood to watch out that children are safe and dont get into trouble
08: If you had to borrow 40 cedi in an emergency you could borrow it from a neighbor.
09: When you are away from home you know that your neighbours will keep their eyes open for possible trouble at your place
10: In the neighbourhood people mostly go their own way
11: People in your neighbourhood share the same values
12: If you were sick you could count on your neighbours to go to the market for you
13: People in your neighbourhood can be trusted
14: Parents in your neighbourhood know their childrens friends
15: Children in your neighbourhood have nowhere to play but the street

16: Adults in your neighbourhood know who the local children are
17: The equipment and buildings in the park or open area that is closest to where you live are well kept
18: The open area closest to where you live is safe during the day
19: The open area closest to where you live is safe at night
20: Parents in your neighbourhood generally know each other
21: The street committee in my neighbourhood is respected
22: The street committee in my neighbourhood provides protection
23: Church groups in my neighbourhood provide food
24: There is a neighbourhood watch program in my neighbourhood
25: The neighbourhood watch program protects people in my neighbourhood
26: There are gangs in my neighbourhood
27: Gangs make my neighbourhood unsafe
28: If a group of neighbourhood children were skipping school and hanging out on a street corner how likely is it that your neighbours would do
29: If some children were damaging a local building how likely is it that your neighbours would do something about it?
30: If a child showed disrespect to an adult how likely is it that people in your neighbourhood would scold that child or tell the childs parent
31: What do people in your neighbourhood think about people your age drinking alcohol or getting drunk?
32: What do people in your neighbourhood think about people your age having sex?
33: What do people in your neighbourhood think about people your age smoking cigarettes?
34: What do people in your neighbourhood think about people your age using drugs?
35: What do people in your neighbourhood think about people your age joining gangs?
36: How easy is it for you to pick out people who are outsiders or who obviously dont live in your neighbourhood?
37: How safe do you feel your neighbourhood is?

Use of Technology

Do you own a cellphone? 1- Yes 2- No
Can you access the internet on your phone? 1- Yes 2- No
Do you own a smartphone (e.g., iPhone)? 1- Yes 2- No
Can you send text messages on your phone? 1- Yes 2- No
How often do you send text messages?

1- Every day
2- Three to four times a week
3- Once or twice a week
4- Once or twice a month
5- Less than once per month

What do you use your cellphone to do? (Click all that apply)

1- Make phone calls
2- Send text messages
3- Play games
4- Access internet
5- Other _____

Do you use pre-paid phone cards? 1- Yes 2- No
How much cedi a week do you spend on pre-paid phone cards? _____
Do you pay for a plan to make phone calls or send text messages? 1- Yes 2- No
How often do you play videogames on a console (computer, Xbox, Playstation)?

1- Every day
2- Three to four times a week
3- Once or twice a week
4- Once or twice a month
5- Less than once per month

How often do you play games on your phone?

1- Every day
2- Three to four times a week
3- Once or twice a week
4- Once or twice a month
5- Less than once per month

Do you own a computer or laptop at home? 1- Yes 2- No
How easy or hard is it for you to access a laptop or computer?
1- Very easy 3- Hard
2- Easy 4- Very Hard
How easy or hard is it for you to access the internet on your phones?
1- Very easy 3- Hard
2- Easy 4- Very Hard
How easy or hard is it for you to access the internet on a computer?
1- Very easy
2- Easy
3- Hard
4- Very Hard
How easy or hard is it for you to access wifi on your computer or phone?
1- Very easy
2- Easy
3- Hard
4- Very Hard
Can you access the internet daily or almost daily? 1- Yes 2- No

SATISFICATION SURVEYS

Client Satisfaction Questionnaire

Please help us improve our program by answering some questions about the Intervention. We are interested in your honest opinions, whether they are positive or negative. *Please answer all of the questions*. We also welcome your comments and suggestions. Thank you very much; we really appreciate your help.

Circle your answer:

1. How would you rate the quality of the game you played? Excellen, Good, Fair, or Poor.
2. Did you get information you wanted? No, definitely. No, not really. Yes, generally. Yes, definitely.
3. Would this game meet your needs?
- Almost all of my needs would be met
-Most of my needs would be met
-Only a few of my needs would be met
- None of my needs would be met
4. If a friend were interested in a similar game, would you recommend this one? No definitely not. No, I don't think so. Yes, I think so. Yes definitely.
5. How satisfied are you with the amount of activities involved with the game?
Quite satisfied, Indifferent or mildly dissatisfied, mostly satisfied, very satisfied.
6. Did the game help you to deal more effectively with issues important to you? Yes, it helped a great deal. Yes, it helped. No, it really didn't help. No, it seemed to make things worse.
7. In an overall, general sense, how satisfied are you with the game. Very satisfied. Mostly satisfied. Indifferent or mildly dissatisfied. Quite dissatisfied.
8.Would you want to use the game at home and in the future? No definitely not. No, I don't think so. Yes, I think so. Yes, definitely.

Session Evaluation Form

1 Strongly Agree 2 Agree 3 Disagree 4 Strongly Disagree

1. I learned a lot from this game
2. I will be able to apply what I learned from this game in my life.
3. I was able to do the activities.
4. The game was well organized.
5. The topics in the game were interesting
6. The presentation of the game stimulated my interest in the material.
7. The topics of the game were relevant to my life
8. The game was enjoyable.
9. I would recommend this game to others.
10. I felt comfortable during with the game.
11. What aspect of the game did you find the most useful? Why?
12. What aspect of the game did you find the least useful? Why?
13. What would you change about this game?

LOCATOR FORM

We are collecting information to help us contact you if you can't be reached on your phone. We will keep this information separate from your responses to the questionnaires or interviews you've completed. We will not give this information to anyone. We will only tell the people below that we are calling from the hospital to schedule an appointment with you.

Please fill out the following information.

1. Your full name:

   _____
   (First) (Middle) (Last)

2. Your birthday: _____

3. Your permanent address:

   _____
   (Address)

4. Home phone: (_____) _____

5. Work phone: (_____) _____

6. Cell phone: (_____) _____

7. Email address: _____

8. Social media: _____

9. Who lives at your permanent address?

   Full name: _____ _____
   (First) (Last) (Relationship)

   Full name: _____ _____
   (First) (Last) (Relationship)

   Full name: _____ _____
   (First) (Last) (Relationship)

   Full name: _____ _____
   (First) (Last) (Relationship)

10. How long have you lived at your permanent address? _____

11. Do you plan to move soon? Yes or No

    (If yes) Do you know when or where?: _____

12. When we call you at home, how would you like us to identify ourselves?

    (hospital, Korle-Bu, etc.) _____

13. What is the name, address, and phone number of any other location where you stay?

    _____
    _____

    _____
    _____

14. Please supply the names of three friends and/ or family members who generally know how to get in touch with you if you move or change phone numbers?

    Person #1

    Full name: _____

    Address: _____

    Phone number: (_____) _____ Relationship: _____

    Person #2

    Full name: _____

    Address: _____

    Phone number: (_____) _____ Relationship: _____

    Person #3

    Full name: _____

    Address: _____

    Phone number: (_____) _____ Relationship: _____

Draft of Qualitative Data Collection Guides for Adolescents and Parents

A Text-Based Adherence Game for Young People Living with HIV in Ghana

Contents

A. Focus Group Guide: Adolescent Patient

The investigators will lead a semi-structured focus group with adolescent patient participants to gather information that will provide guidance in developing a Text-Based Adherence Game intervention. Following the Introduction outline below is an outline for the Focus Group. Each focus group topic is followed by broad and generally open-ended questions. Interviewers will be instructed to ask more specific follow-up questions to probe responses to the initial open-ended questions. **While this guide provides the main topics of interest, initial questions, probes, and ordering of topic areas may be modified prior to the start of the focus group and during the focus group.**

Introductions

Overview: The intent of this portion of the agenda is to welcome the participants and make them as comfortable as possible by explaining the interview process and letting them know what to expect from the experience. Additionally, the investigator will explain rules concerning confidentiality, and the use of data.

- ☐ Introduce Investigator
- ☐ Explain that the overall purpose of focus group is to elicit discussion about the participant's experiences with HIV, HIV treatment, and technology, and their preferences for text message intervention to improve their HIV treatment adherence.
- ☐ Sample dialogue: *"Thank you so much for agreeing to be a part of this focus group. We are here today to learn about you and find out how young people feel about living with HIV and getting treatment for HIV. In addition, we're curious to find out about your experience with mobile technology including cellphones, text messages, the internet, and mobile games. Our idea is to create a game that is played through text messages. The game will be fun and help young people connect with their parents or other supportive people in their life and focus on their HIV treatment. We want to know what people think about this idea. You are the expert in this area and we are hoping that you will share your thoughts about these topics. We really need to learn from you in order to make this program successful.*
- ☐ Housekeeping: rest rooms, refreshments, breaks
- ☐ Ground rules: *"You do not have to answer any questions you are uncomfortable with. There is no right or wrong answers. We're interested in all opinions."*
- ☐ Confidentiality: *"We will work hard to make sure everything said in the interview will not be shared with anyone outside of the research team unless you tell us about a situation where you or someone else is in danger. You are also being asked to not share anything you hear about other focus group members with people outside of this focus group. What gets said in this focus group stays here. We want everyone to feel safe and comfortable to share their experiences."*
- ☐ Digital Recording: *"Recordings are not shared with anyone outside of the research team, they are kept safe and private. When information is taken from the recording, participants will be identified by a number only and names will not be used. Tapes will be erased once transcribed."*

Focus Group Outline

Demographic/Family Information: Participants will be asked general questions about their family and friends, living situation, and current schooling.

"I would like to start by getting to know all of you a little bit better."

- ☐ *"Tell me about yourselves"*
- ☐ *"Tell me about your families"*
- ☐ *"What languages do you speak at home?"*
- ☐ *"What do you like to do in your free time?"*

☐ *"Tell me about your school."*

☐ *"Tell me about your friends."*

Experience of Living with HIV: Participants will be asked preliminary questions about their experience of living with HIV.

"I would like to hear about your experiences with living with HIV."

☐ *"Tell me about the time when you found out you were HIV positive"*

☐ *"What's your understanding of how you were infected?"*

☐ *"How do you feel about it now?"*

☐ *"What's it like being a young person living with HIV?"*

☐ *"What do people in your community say about HIV?"*

☐ *"Who in your life is aware of your HIV status? Who is not aware?"*

☐ *"What's it like to tell people your status?"*

Barriers and Facilitators to HIV Treatment Adherence: Participants will be asked about the barriers and facilitators to treatment adherence.

"I would like to hear from you your experience with HIV treatment.""

☐ *"Tell me what HIV treatment has been like for you."*

☐ *"What makes it hard take antiretroviral (ART) medication?"*

☐ *"What makes it easier to take ART medication?"*

☐ *"What are the things that make it hard or easy come to medical appointments?"*

☐ *"What's it like taking your medication at boarding school?"*

☐ *"What's it like having to attend doctor's appointments while at boarding school?"*

☐ *"How much contact does your mom or dad (or other guardian) have with you while away at boarding school?"*

☐ *"What role does your family play in your HIV care?"*

☐ *"What role does your mom and dad (or other guardian) play in your HIV treatment?"*

☐ *"What things do your parents expect you to do yourself in terms of your HIV treatment (e.g., taking medication, remembering doctor's appointments)?"*

☐ *"How can your parents help you more with your HIV treatment?"*

☐ *"What it's like talking to your parents about HIV?"*

☐ *"What it's like talking to your parents about HIV medication?"*

☐ *"What's your relationship like with your parents?"*

☐ *"What role do your friends play in your HIV care?"*

☐ *"People in HIV treatment are asked to have a treatment monitor. Tell me about yours."*

☐ *"Describe your relationship with your treatment monitor."*

☐ *"Tell me about your relationship with your healthcare providers."*

☐ *"What do you providers say about doing things for yourself in terms of your HIV treatment? For example, do they say that you or your parents should remember your HIV medication?"*

Experience with Technology: Participants will be asked about their experiences with mobile phones, text messages, the internet, and mobile games.

"I would like to hear about your experience with technology."

☐ *"What's your experience been like with mobile phones?"*

☐ *"How many people your age own a mobile phone?"*

☐ *"What do you use your cellphone for (e.g., calls, text messages, games)?"*

☐ *"Have you talked to someone from the clinic on your cellphone? Tell me about that."*

☐ *"How often do you send text messages?"*

☐ *"How often do you use WhatsApp?"*

☐ *"How do you pay for phone data?"*

☐ *"Where can you access the internet? How often can you access it?"*

☐ *"How often do you play mobile games?"*

☐ *"What kinds of mobiles games do you like (e.g., sports, fighting)?"*

☐ *"Tell me about your experience with playing games with other people online."*

Suggestions for a Text-Based Adherence Game: Participants will be asked questions related to the development of our intervention.

"We have an idea to create a game using text messages. The purpose of the game is to have fun, connect with people like your parents or guardians who are supportive of your HIV treatment, and make it easier for you to take your HIV medication and show up to doctor's appointments. We want to know what you think about some of our ideas."

☐ *"We are thinking about texting you and/or your parents and guardians to remind young people to take their medication and show up at their clinic appointments. What do you think of that idea?"*

☐ *"To make this more fun, we are also thinking about texting participants bits of a story. Teens and their parents need to answer story questions in order to earn points, level up, and compete against other players, who would also be adolescents and their parents in the clinic. What do you think of that idea?"*

☐ *"Competing against other players would involve a scoreboard. This would be players with the top or lowest scores. Scoreboards would be texted to all players. What do you think of that idea?"*

☐ *"A final aspect of the game involves allowing players to reach out for support from a doctor, other healthcare provider, or peer educator at the clinic. For example, a player might be asked, 'How are you feeling today?' or "How is your child feeling today?" And if they respond 'not good,' they'll be asked if they want call from a doctor. What do you think of that idea?"*

☐ *"The game's story could be about anything. What theme would you find interesting?"*

Closing

Overview: the participants will be thanked for their time and efforts

e.g. "Thank you for participating in our interview today. You gave us lots of great information for our study. Your ideas and comments are important."

B. Focus Group Guide: Parent/Guardian of Adolescent

The investigators will lead a semi-structured focus group with the parents or guardians of adolescent HIV patients to gather information that will provide guidance in developing a Text-Based Adherence Game intervention. Following the Introduction outline below is an outline for the Focus Group. Each focus group topic is followed by broad and generally open-ended questions. Interviewers will be instructed to ask more specific follow-up questions to probe responses to the initial open-ended questions. **While this guide provides the main topics of interest, initial questions, probes, and ordering of topic areas may be modified prior to the start of the focus group and during the focus group.**

Introductions

Overview: The intent of this portion of the agenda is to welcome the participants and make them as comfortable as possible by explaining the interview process and letting them know what to expect from the experience. Additionally, the investigator will explain rules concerning confidentiality, and the use of data.

☐ Introduce Investigator
☐ Explain that the overall purpose of the focus group is to elicit discussion about the participants' experiences with caring for an adolescent child with HIV, technology, and their preferences for text message intervention to improve their child's HIV treatment adherence.
☐ Sample dialogue: *"Thank you so much for agreeing to be a part of this focus group. We are here today to learn about you and find out how parents and guardians of adolescents living with HIV feel about your child's HIV treatment. In addition, we're curious to find out about your experience with mobile*

technology including mobile phones, text messages, the internet, and mobile games. Our idea is to create a game that is played through text messages. The game will be fun and help young people connect with their parents or other supportive people in their life and focus on their HIV treatment. We want to know what people think of this idea. You are the expert in this area, and we are hoping that you will share your thoughts about these topics. We really need to learn from you to make this program successful.

- ☐ Housekeeping: rest rooms, refreshments, breaks
- ☐ Ground rules: *"You do not have to answer any questions you are uncomfortable with. There is no right or wrong answers. We're interested in all opinions."*
- ☐ Confidentiality: *"We will work hard to make sure everything said in the interview will not be shared with anyone outside of the research team unless you tell us about a situation where you or someone else is in danger. You are also being asked to not share anything you hear about other focus group members with people outside of this focus group. What gets said in this focus group stays here. We want everyone to feel safe and comfortable to share their experiences."*
- ☐ Digital Recording: *"Recordings are not shared with anyone outside of the research team, they are kept safe and private. When information is taken from the recording, participants will be identified by a number only and names will not be used. Tapes will be erased once transcribed."*

Focus Group Outline

Demographic/Family Information: Participants will be asked general questions about their children, other family members, and current living situation.

"I would like to start by getting to know all of you a little bit better."

- ☐ *"Tell me about yourselves."*
- ☐ *"Tell me about your child or children that attend this clinic."*
- ☐ *"Tell me about your other family members."*
- ☐ *"Tell me about your current living situation."*
- ☐ *"What languages do you speak at home?"*
- ☐ *"What do you like to do in your free time?"*
- ☐ *"What do you do for work?"*

Experience of Being a Parent/Guardian of an Adolescent Living with HIV: Participants will be asked preliminary questions about their experience of living with HIV.

"I would like to hear about your experiences with being a parent or guardian of an adolescent living with HIV."

- ☐ *"Tell me about the time when you found out your child was HIV positive."*
- ☐ *"What's your understanding of how he/she contracted HIV?"*
- ☐ *"Tell me about the time your child became aware they were HIV positive?"*
- ☐ *"How does your child feel about living with HIV?"*

☐ *"What does your child know about HIV? What don't they know?"*

☐ *"What's it like being a parent/guardian of an adolescent with HIV?"*

☐ *"Who in your life is aware of your child's HIV status? Who is not aware?"*

☐ *"What do people in your community say about HIV?"*

Barriers and Facilitators to Adolescent HIV Treatment Adherence: Participants will be asked about the barriers and facilitators to adolescent HIV treatment adherence.

"I would like to hear from you all about your experiences with your child's HIV treatment.""

☐ *"Tell me what your child's HIV treatment has been like for you."*

☐ *"What makes it hard for them to take their HIV medication?"*

☐ *"What makes it easier to take their HIV medication?"*

☐ *"What are the things that make it hard or easy for them to attend medical appointments?"*

☐ *"What's it like for them when to take their medication at boarding school?"*

☐ *"What's it like for them to attend doctor's appointments while at boarding school?"*

☐ *"How much contact do you have with them while away at boarding school?"*

☐ *"What role do you play in their HIV care?"*

☐ *"What things do you expect your child to do themselves in terms of their HIV treatment (e.g., taking medication, remembering doctor's appointments)?"*

☐ *"How could you better assist them with their HIV treatment?"*

☐ *"What it's like talking to your children about HIV?"*

☐ *"What it's like talking to your children about HIV medication?"*

☐ *"What's your relationship like with your children?"*

☐ *"How has helping them with their HIV treatment changed your relationship?"*

☐ *"What challenges do you have as a parent in helping them with their HIV treatment?*

☐ *"Would you be open to a counselor or someone else teaching parenting skills that could help you better assist your adolescents with their treatment?"*

☐ *"Tell me about your relationship with your child's healthcare providers."*

☐ *"What do their providers expect from your child in terms of caring for themselves? For example, do they say that they or you should remember their HIV medication?"*

Experience with Technology: Participants will be asked about their experiences with mobile phones, text messages, the internet, and mobile games.

"I would like to hear about your experiences with technology."

- ☐ *"What's your experience been like with mobile phones?"*
- ☐ *"What do you use your mobile phone for (e.g., calls, text messages, games)?"*
- ☐ *"Have you talked to someone from the clinic on your mobile phone? Tell me about that."*
- ☐ *"How often do you send text messages?"*
- ☐ *"How often do you use WhatsApp?"*
- ☐ *"How do you communicate with your adolescent child on mobile phones (e.g., text, calls, WhatsApp)?*
- ☐ *"How hard or easy is it for you to purchase phone data?"*
- ☐ *"Where can you access the internet? How often can you access it?"*
- ☐ *"How often do you play mobile games?"*
- ☐ *"What kinds of mobiles games do you like (e.g., sports, fighting)?"*
- ☐ *"Tell me about your experience with playing games with other people online."*

Suggestions for a Text-Based Adherence Game: Participants will be asked questions related to the development of our intervention.

"We have an idea to create a game using text messages. The purpose of the game is to have fun, get your child more interested in HIV treatment, and get you mobile support from providers when you need to help your child with their treatment . We want to know what you think about some of our ideas."

- ☐ *"We are thinking about texting you and/or your children to remind young people to take their medication and show up at their clinic appointments. What do you think of that idea?"*
- ☐ *"To make this more fun, we are also thinking about texting participants bits of a story. Teens and/or their parents need to answer story questions in order to earn points, level up, and compete against other players, who would also be adolescents and their parents in the clinic. What do you think of that idea?"*
- ☐ *"Competing against other players would involve a scoreboard. This would be players with the top or lowest scores. Scoreboards would be texted to all players. What do you think of that idea?"*
- ☐ *"A final aspect of the game involves allowing players to reach out for support from a doctor, other healthcare provider, or peer educator at the clinic. For example, a player might be asked, 'How are you feeling today?' or "How is your child feeling today?" And if they respond 'not good,' they'll be asked if they want call from a doctor. What do you think of that idea?"*
- ☐ *"The game's story could be about anything. What theme would you find interesting?"*

<u>Closing</u>

Overview: the participants will be thanked for their time and efforts

e.g. "Thank you for participating in our interview today. You gave us lots of great information for our study. Your ideas and comments are important."

C. Cognitive Interview Outline: Patient

The investigators will lead a semi-structured cognitive interview with parent-adolescent dyads to inform the development of a Text-Based Adherence Game intervention. Following the Introduction outline below is an outline for the Cognitive Interview. Each interview topic is followed by broad and generally open-ended questions. Interviewers will be instructed to ask more specific follow-up questions to probe responses to the initial open-ended questions. W**hile this guide provides the main topics of interest, initial questions, probes, and ordering of topic areas may be modified prior to the start of the cognitive interview and during the cognitive interview.**

Introductions

Overview: The intent of this portion of the agenda is to welcome participants and make them as comfortable as possible by explaining the interview process and letting them know what to expect from the experience. Additionally, the investigator will explain rules concerning confidentiality, and the use of data.

- ☐ Introduce Investigator
- ☐ Explain that the overall purpose of interview is to elicit discussion about the participant's experiences with participating in the Text-Based Adherence Game.
- ☐ Sample dialogue: *"Thank you so much for agreeing to be a part of this interview today. We are here today to hear what you think about this text message program called a Text-Based Adherence Game (referred to as TAG). Our idea is to create a game that is played through text messages. The game should be fun and help young people focus on their HIV treatment. We want to know what parents/guardians and young people think about the game and if you have any suggestions for its improvement. You are the expert in this area. We really need to learn from you in order to make this program successful.*
- ☐ Housekeeping: rest rooms, refreshments, breaks
- ☐ Ground rules: *"You do not have to answer any questions you are uncomfortable with. There is no right or wrong answers. We're interested in all opinions."*
- ☐ Confidentiality: *"We work hard to make sure everything said in the interview will not be shared with anyone outside of the research team unless you tell us about a situation where you or someone else is in danger."*
- ☐ Digital Recording: *"Recordings are not shared with anyone outside of the research team, they are kept safe and private. When information is taken from the recording, participants will be identified by a number only and names will not be used. Tapes will be erased once transcribed."*

Cognitive Interview

Joint Portion

Global Impressions of Game Overview: Participants will be provided with a general description of the Text-Based Adherence Game (TAG). The description will include the purpose of the game, how it will be delivered, how it will be played, and it's specific features. After this description, they will be asked the following questions:

☐ *"What is your first impression of this game?"*

☐ *"What do you like about this idea?"*

☐ *"What about our game idea don't you like?"*

☐ *"Based on this description, what questions do you have about the game?"*

☐ *"How do you think this will help you (or your child) with your (or their) HIV treatment?"*

☐ Parents only: *"How do you think this will help you better assist your child with their HIV treatment?"*

☐ Adolescent only: *"How do you think this will help your better assist you with your HIV treatment?"*

Individual Portion

Feedback on Specific Game Features: Participants will be provided with descriptions of each of the game's features followed by sample text messages. Participants may also be texted these messages during the interview. While reviewing the message interactions, they will be asked questions such as:

☐ *"What did you think of this message?"*

☐ *"What was the purpose of this message?"*

☐ *"What do you think about you think about this feature of the game (e.g., medication reminders, parenting skill messages, point system)?"*

☐ *"How could this message be improved?"*

☐ *"How often should you receive this type of message?"*

☐ *"What do you think your parent/child would think of this message?"*

☐ *"How would this message help your/your child's HIV treatment?"*

☐ *"Would you like to receive this message as part of the intervention?"*

Joint Portion

Conclusions: Participants will meet jointly again to discuss what interviewers learned during the individual portions. Summaries will be made followed by questions such as:

☐ *"Based on what you learned about the specific messages in the game, how do you feel about it now?"*

☐ *"What suggestions do you have you to improve the game?"*

☐ *"What will other young people and their parents think about the game?"*

- ☐ *"In what ways will it help with adolescent HIV treatment?"*
- ☐ *"Would you want to play this game in the future?"*

Closing

Overview: the participants will be thanked for their time and efforts

e.g. "Thank you for participating in our interview today. You gave us lots of great information for our study. Your ideas and comments are important."