



# THE UNIVERSITY OF THE WEST INDIES

ST. AUGUSTINE, TRINIDAD AND TOBAGO WEST INDIES

## *The Social Work Unit*

**Sondai**

**Social Work  
Oriented,  
Needs  
Driven  
Aids  
Interventions**

*... Pushing Forward*

**HIV- Testing and Beyond  
Exploring Experiences**

<http://sta.uwi.edu/sondai/>

Sondai is funded by UWI/Government of Trinidad and Tobago Research  
Development Fund

*Acts of Service*

## Contact Information

Sondai Project  
Social Work Unit, Department of Behavioural Sciences  
#1 Deane Street St. Augustine,  
Trinidad  
West Indies  
1-868-645-1212  
Email: [sondai@sta.uwi.edu](mailto:sondai@sta.uwi.edu)  
Website: <http://sta.uwi.edu/sondai/>

## Sondai Staff

<i>Practice Development-</i>	Mrs. Jacqueline Padmore	1-868-662 2002 ext 3046 <a href="mailto:Jacqueline.Padmore@sta.uwi.edu">Jacqueline.Padmore@sta.uwi.edu</a>
<i>Knowledge Dissemination -</i>	Mrs. Karene Nathaniel de Caires	1-868-662 2002 ext 2403 <a href="mailto:Karene.Nathaniel@sta.uwi.edu">Karene.Nathaniel@sta.uwi.edu</a>
<i>Research &amp; Publications -</i>	Professor Adele Jones	-44-148 442 2288 <a href="mailto:A.D.Jones@hud.ac.uk">A.D.Jones@hud.ac.uk</a>
<i>Research Assistant: research project –</i>	Tracie Rogers	1-868-645 1212 <a href="mailto:Tracie.Rogers@sta.uwi.edu">Tracie.Rogers@sta.uwi.edu</a>
<i>Research Assistant: publications –</i>	Priya Maharaj	1-868-645 1212
<i>Senior Practitioner –</i>	Maud Mthembu	1-868-645 1212

# **RESEARCHER'S BRIEFING PACK – PART I**

## **CONTENTS:**

- 1. Sondai Project Summary**
- 2. Research Information**
- 3. Methods**
- 4. Ethical Protocol**
- 5. Focus Group Guidance**
- 6. Research Instrument**
- 7. Data Collection 1**
- 8. Data Collection 2**
- 9. Information for Participants**
- 10. Consent Form**

## 1 SONDAI PROJECT SUMMARY

“**Sondai**” is a word from Southern Africa that means ‘keep pushing forward’ and which encapsulates the concept and aims of an initiative that is providing opportunities for research and practice for social work students at postgraduate level; developing culturally relevant psychosocial services for persons living with HIV-AIDS (PLWHA), strengthening the capacity of Social Workers and agencies involved in HIV-AIDS prevention and care and, producing and disseminating knowledge based on social work research.

**Sondai** is conceptualised as a *hub* of activity bringing together within a coherent framework the following:

- Teaching
- Research
- Practice
- Training
- International exchange
- Dissemination
- Computer technologies

### **Specific objectives include:**

1. To enhance the level of generic social work knowledge and skills in HIV-AIDS prevention, management and treatment
2. To provide specialist advanced level training to social work students and practitioners
3. HIV-AIDS agency capacity building in relation to psychosocial needs
4. To review and promote models of culturally relevant evidenced-based social work interventions for working with PLWHA
5. To identify and develop practicum opportunities in agencies working with PLWHA, thereby enhancing the provision of psychosocial services
6. To promote and facilitate international exchange in HIV-AIDS social work
7. To undertake research into the psychosocial implications of HIV-AIDS for individuals, families and communities
8. To develop and pilot the delivery of HIV sensitization training for health sector workers.
9. To ensure that the outcomes of the Sondai Project are relevant to the local context and are sustainable by linking with national policy on HIV-AIDS
10. To create accessible, user-friendly ways of sharing knowledge, practice experiences and research findings to PLWHA, agencies, practitioners and policy makers
11. To establish a database and website for the dissemination of the knowledge produced within the project

## 2. RESEARCH INFORMATION

*This section is for the researcher – please see separate information sheet for research participants*

This research project seeks to investigate perceptions and experiences of HIV in order to fully understand the range of psychosocial factors that impact upon individuals in preventing HIV transmission, in seeking treatment and in coping with the diagnosis. In particular, the study aims are to examine perceptions and experiences of test services from contemplation through to receiving test results and the psychosocial impact of diagnosis, dealing with disclosure and, accessing treatment.

The research will result in the identification of policy implications and good practice indicators for services for HIV-testing and universal treatment access with particular emphasis on the following:

- i. Addressing the psychosocial needs that may arise in scaling up HIV-testing
- ii. Facilitating increased test-seeking behaviours
- iii. Supporting HIV positive persons in dealing with diagnosis
- iv. Disclosure counselling
- v. Treatment adherence counselling.
- vi. Involvement of PLWHA in test and treatment policy and procedures
- vii. Promotion of human rights and stigma-elimination

### 2.1 RESEARCH AIMS

The overall aims of the Sondai Research Project are to:

- Identify testing models, procedures, attitudes and behaviours which *promote* or run *counter* to human rights and which *contribute to* or *confront* stigma and discrimination (first stage of the study – see below)
- Understand the links between testing and sustained health promoting behaviours (first stage – see below)
- Understand the psychosocial effects of receiving a positive diagnosis
- Understand the factors that are taken into account in the decision to disclose or not to disclose
- Examine the psychosocial factors that impact on treatment accessibility and adherence

The research project is being conducted in two stages. The first stage (completed) was based on a review of studies and sought to investigate perceptions, attitudes and experiences in relation to different HIV-testing models. This literature review is available from the Sondai office (contact Tracie Rogers). The second stage seeks to examine the psychosocial implications of post-test experiences in culture-specific contexts and

involves agency partners in Kenya and an institutional collaboration with The School of Social Work, Barry University, Florida.

**Objectives of Second Stage:**

- i. To investigate the post-test experiences of persons who are HIV positive
- ii. To explore the impact of diagnosis
- iii. To investigate the ways that people deal with disclosure and the factors that impact upon disclosure decisions
- iv. To investigate the psychosocial factors that inhibit or facilitate treatment access and adherence
- v. To undertake an international comparative analysis of these factors in order to determine country/culture-specific issues and to maximise inter-country learning and knowledge sharing

**2.2 METHODOLOGY**

The study involves three research sites classified as ‘developing’, in-transition and ‘developed’- these sites will enable an analysis of HIV within a global socio-economic context and in relation to Millennium Development Goals. The three sites are Kenya (developing), Trinidad and Tobago (in-transition) and Miami (developed). The research approach is drawn from three research traditions: social action research, participatory research and grounded theory.

Set against a global emphasis on ‘scaled up’ testing (World Health Organization (WHO) and United Nations (UNAIDS)) as the primary means of reducing the prevalence of HIV infection, a review of key literature was undertaken. This highlighted several psychosocial factors that impact upon test-seeking behaviours: perceptions and attitudes, attitudes of those conducting tests, the implications of a positive diagnosis and fears associated with disclosure. Additionally, the literature suggests that a major issue in promoting test-seeking behaviour is whether the outcome of testing will result in access to treatment, whether there is a realistic chance of prolonged life and whether these steps will improve the quality of life overall for HIV positive persons. The main findings of the literature review were discussed within the Sondai Advisory Group and the second stage of the research project was refined to focus more specifically on post-test experiences.

An initial study of post-test experiences was carried out in a rural district of Kenya. The study involved four focus groups with persons self-identifying as HIV infected or affected and semi-structured interviews with key informants. A total of 43 people participated, ranging in age from 19-55. Six of the respondents were men and 37 were women. Analysis of the data resulted in key themes being identified which in turn have been used to guide the methods and research instruments for further study in Trinidad and Miami.

## **2.2.1 Key Themes**

The key themes that emerged from the Kenya study are as follows:

### **Dealing with Diagnosis**

Sub themes: VCT experiences  
Pre-test attitudes/feelings - emotional preparedness  
Shock  
Disbelief (repeat testing)  
Denial  
Post-test adjustment  
Benefits of knowing  
Coping mechanisms

### **Disclosure**

Sub themes: Benefits/disadvantages of telling  
Disclosure - a staged process  
Indirect disclosure  
Disclosure as public service  
Disclosure for self-empowerment  
Disclosure as key to becoming healthy  
Disclosure as means of fighting stigma  
Responses to disclosure

### **Gender**

Sub themes: Male/female attitudes to testing  
Women's attitudes to husband/partner's positive status  
Men's attitudes to wife/partner's positive status  
Effect on socio-economic status: particular issues for women  
HIV-linked domestic violence  
The relationship between gender and risk  
Gender-based differences in living with HIV  
Gender-based coping mechanisms

### **Stigma and Discrimination**

Sub themes: Morality, sex and sexuality  
Multiple losses  
Breastfeeding- cultural expectations of mothers  
Self stigma  
Family stigma  
Community stigma  
Stigma & social status  
Discrimination – emotional toll of multiple rejections

### **Poverty**

Sub themes: Losing one's job  
Dependence on relatives  
Economic abandonment/destitution

Inability to contribute to the extended family  
Costs associated with HIV  
HIV-Poverty Chain: links between poverty, VCT, disclosure, living with  
HIV and increased poverty  
Wealth as protective factor

**Children, Parenting and Family Life**

Sub themes: Parenting HIV positive children  
Disclosing to children/about children  
Children's rights  
Impact of HIV on childhood experiences  
Children as sources of strength  
Parental guilt  
Impact on extended family  
Fears for the future  
Child-headed households

**Resilience, Coping, Support and Treatment**

Sub themes: Coping strategies  
Education/knowledge  
Ability to access treatment  
Traditional/alternative remedies  
Support Groups  
Family-based support strategies  
Role of religion/spirituality  
Support for women

For the purposes of further research in Trinidad and Miami the themes will be collapsed into experiences of HIV from testing through diagnosis, disclosure and accessing treatment

### **3 METHODS**

The primary method of data collection will be focus groups with purposively selected populations. However, given the sensitive nature of the topic and the concern respondents may have about confidentiality, some individual interviews may be set up. Individual interviews can be carried out face-to-face, over the telephone or by email. However in order to fully benefit from a comparative study it is important to ensure methods are similar. Focus groups form the main data collection method, semi-structured interviews can be used to supplement the focus groups. This means that interviews should explore the same themes as focus groups but with the aim of revealing a more in-depth insight into the meaning of these issues.

#### **3.1 Literature Review**

A literature review should be carried out for each research site. The primary aim of the review should be to provide the social context of HIV-AIDS in each research setting and to identify what other studies have been done that relate to this project. In particular the review should include the following:

- The current scale of the problem and predictive trends within each site
- Main drivers of the disease within culture-specific contexts
- Key demographic/socio-economic information about those most affected
- Overview of domestic policy framework and main service responses
- Specific social/cultural factors
- Other studies conducted in relation to the experiences of HIV from testing through diagnosis, disclosure and accessing treatment

(N.B the literature reviewed should relate to the particular research site)

#### **3.2 Field Work**

Focus groups will be carried out with **four** populations two of which should be gender specific and two should be mixed. Where possible, the focus groups should be set up from naturally occurring clusters of people such as existing groups of persons who are accessing antiretroviral treatment, social work services or HIV-AIDS support groups. Groups should comprise 6-10 people. The four focus groups should include:

- HIV-positive pregnant women (single gender group)
- Parents/caregivers of HIV positive children (e.g. those attending Pediatric HIV clinics) (mixed gender group)
- Men (single gender group)
- Young people 18-24 (mixed gender group)

##### **3.2.1 Inclusion Criteria**

Inclusion must be based on self-selection and informed consent. Potential participants must be given information about the project in a form that they can understand. The research information should be provided verbally as well as in written form. No

inducements should be offered (this does not include out-of-pocket expenses, travel or refreshments). Criteria for inclusion:

- Self-identifies as HIV-positive or HIV-affected (e.g. the caregiver of a child who is HIV positive, family member)
- Is accessing treatment/attending a health facility, receiving services from a social work agency, member of a support group
- Fits into one of the focus group categories

### 3.2.3 Preparing for Focus Groups

- a) Familiarise yourself with the research aims
- b) Make sure your knowledge of HIV-AIDS is current
- c) Familiarise yourself with the Focus Group Guidance included in this pack
- d) Make sure you have sufficient copies of the Participant's Information Sheet
- e) Make sure you have enough copies of the Consent Form
- f) Identify a lockable storage cabinet to keep all data
- g) Ensure all approvals/agency permissions have been obtained
- h) Prepare a list of helpful contact numbers in case any issues come up that need follow-up (e.g. specialist HIV-AIDS services, counsellors, organisations etc)
- i) If possible identify a volunteer (a Recorder) to work alongside you to document specific information – see **Data Collection 1**
- j) Obtain and test tape/electronic recording equipment
- k) Ensure venue, time & refreshments are organised and all participants notified
- l) Ensure you have a personal data sheet for each participant – see **Data Collection 2**. This information should be collected *before* or *after* the focus group – it must be collected **confidentially**.

### 3.2.3 Conducting Focus Groups

- a) Refer to the Guide in **Section 5** of this pack
- b) Each participant should be given a copy of the research information
- c) Each person should be asked to sign a consent form – they should use a false name to sign
- d) The Focus Groups should as far as possible follow the questionnaire – see **Research Instrument**.
- e) Provide 15 minutes de-briefing time at the end of the discussion – you may want to plan an exercise for participants to help them to debrief.
- f) Offer participants the information with contact numbers on should they need to follow up any issues

### 3.2.4 After the Focus Groups

- a) Arrange debriefing for yourself either with your recorder or another member of the Research Team

- b) As soon as possible make field notes – compare these with your Recorder's notes(see **Data Collection 1**) – do this for each focus group before moving on to the next
- c) Use these notes to identify preliminary themes
- d) As soon as possible arrange for tapes to be transcribed
- e) Code the data and enter in the data master sheet (see **Research Briefing Pack Part II**)

### **3.2.5 Individual interviews**

If there are difficulties in setting up the focus groups and you can identify participants who wish to take part in the study but only through an individual interview, such persons can be included in the study. You should note however, that individual interviews should be used to complement the focus group method rather than replace it. This means that respondents should be from one of the groupings listed and the interviews should be used to explore in greater depth the themes that emerged from the Kenya study. These themes form the basis of the Focus Group questionnaire – see **Research Instrument**. Interviews should therefore follow this format. Interviews can be carried out face-to-face, over the telephone or by email. Researchers must comply with the ethical protocol regardless of the form of interview. Clearly respondents being interviewed by phone will be unable to sign a consent form, however the researcher should ensure that informed consent is given verbally.

#### **4. ETHICAL PROTOCOL**

This research project explores experiences of persons affected by HIV; a group of persons who are negatively impacted by stigma and discrimination. The conduct of the research must adhere to clear ethical standards which emphasise and assure confidentiality, privacy, anonymity and informed consent.

1. The aims and objectives of the research should be clearly explained to all participants and stakeholders – see Information Sheet for Research Participants.
2. All participants will remain anonymous
3. Each participant should be allocated a code name or number, and actual names and other personal identifiers will not be used
4. Data will be kept confidential in a secured location
5. The data will only be seen by researchers
6. Due to the sensitive subject of the research, and the possibility that during interviews topics may be brought up that produce psychological stress, trauma, or fear of physical violence or detection (such as HIV+ status, undocumented status, sexual abuse, prostitution and homosexuality), the researchers should be have some social work or counselling training
7. Participants should be provided with a list of appropriate organisations/contact numbers in case further follow up support is needed
8. Supervision and guidance should be provided in each research site by an experienced researcher
9. Informed Consent will be based on the following principles:  
All participants in the project (e.g., interviewees, focus group participants will be informed of:
  - The nature of the research (goals and objectives, etc.);
  - The research methodology to be used;
  - Any risks or benefits;
  - Their right not to participate, not to answer any questions, and/or to terminate participation at anytime without prejudice;
  - Their right to anonymity and confidentiality;
9. Each person should be asked to sign a consent form – the consent form should be read out to the participant in case there are any literacy or language difficulties.

## **5. GUIDE TO CONDUCTING FOCUS GROUPS**

*(Extracted from 'Designing and Conducting Health Systems Research Projects, IDRC)*

### **5.1 Recruitment of participants**

Participants should be roughly of the same socio- economic group or have a similar background in relation to the issue under investigation. The age and sexual composition of the group should facilitate free discussion.

\* Always ensure confidentiality of opinions: Ask co-operation from the group members as well, to keep what has been discussed confidential. If group members present very personal problems and need advice or help, this should be followed up after the FG. Participants should be invited at least a day or two in advance, and the general purpose and procedures of the FG should be explained, in order to obtain their **consent to join**.

### **5.2 Selection of participants**

If you are an outsider in the research area, you may have to rely on your key informants for the first selection of participants in FGs. Your key informants to whom you have explained thoroughly the purpose and the process of the FG might each suggest some individuals who could be invited to a focus group discussion. Note that the key informants may select persons similar to themselves so that you do not get an adequate variety of views in your discussion group. So in your explanations be sure to emphasise that you want a group of people that can express a range of views, to be able to have a proper discussion. Participants in a first FG may assist to find relevant participants for other groups. Another way of getting participants is to conveniently select individuals in a systematic way, to try and ensure a range of views. You might, for example, ask every third or fourth person you find. This method might be more suitable in urban areas.

### **5.3 Physical arrangements**

Communication and interaction during the FG should be encouraged in every way possible. Arrange the chairs in a circle. Make sure that there will be no disturbances, sufficient quietness, adequate lighting, etc. Try to hold the FG in a neutral setting which encourages participants to freely express their views.

### **5.4 Preparation of a discussion guide: (see Research Instrument)**

There should be a **written** list of topics to be covered. It can be formulated as a series of open-ended questions. Guides for different groups gathered to discuss the same subject may vary slightly, depending on their knowledge or attitudes and how the subject should first be explored with them.

### **5.5 Conducting the session**

The facilitator should NOT act as an expert on the topic. His or her role is to stimulate and support discussion.

### **Introduce the session**

Introduce yourself as facilitator and introduce the recorder. Let participants introduce themselves using their code names. Put the participants at ease and explain the purpose of the FG, the kind of information needed, and how the information will be used. Ensure that all participants have signed the consent form. Ask permission to use a tape-recorder, let people hear their own voices before the session starts. You might offer drinks and allow some informal discussion before the actual session starts.

### **Encourage discussion**

Be enthusiastic and lively and show your interest in the groups' ideas. Formulate questions and encourage as many participants as possible to express their views. Use your interpersonal skills to facilitate participation. Remember there are **no** 'right' or 'wrong' answers. **React neutrally** to both verbal and non-verbal responses.

### **Encourage involvement**

Avoid a question-and-answer session. Some useful techniques include:

— Asking for clarification:

'Can you tell me more about. . . ?'

— Reorienting the discussion when it goes 'off the track':

Saying: 'Wait, how does this relate to. . . ?'

Saying: 'Interesting point, but how about. . . ?'

Using one participant's remark to direct a question to another, for example, 'Mrs. X said . . . , but how about you, Mrs. Y?'

— When dealing with a dominant participant, avoiding eye contact or turning slightly away to discourage the person from speaking, or thanking the person and changing the subject.

— When dealing with a reluctant participant, using the person's name, requesting his/her opinion, making more frequent eye contact to encourage his/her participation.

Deal correctly with **sensitive issues**. If you notice that the discussion stops when dealing with a sensitive topic, you could ask participants (if literate) to anonymously write down their responses or opinions on the topic. Alternatively, you could summarise for the group some of the opinions from previous focus group discussions, focusing on one or two major contrasting opinions. Still another strategy is to form sub-groups, and to get a member of the sub-group to summarise and present the opinions of their sub-group members after which the whole group can still discuss these opinions.

### **Build rapport, empathise**

Observe non-verbal communication. Ask yourself, 'What are they saying? What does it mean to them?' Be aware of your own tone of voice, facial expressions, body language, and those of the participants.

### **Avoid being placed in the role of expert**

When asked for **your** ideas or views by a respondent, remember that you are not there to educate or inform. Direct the questions back to the group by saying: 'What do you think', 'What would you do?' Set aside time, if necessary, after the session to give participants the information they have asked for.

Do not try to comment on everything that is being said. Don't feel you have to say something during every pause in the discussion. Wait a little and see what happens.

### **Control the rhythm of the meeting, but in an unobtrusive way**

Listen carefully, and move the discussion from topic to topic. Subtly control the time allocated to various topics so as to maintain interest. If participants spontaneously jump from one topic to another, let the discussion continue for a while since useful additional information may surface; then summarise the points brought up and reorient the discussion.

### **Take time at the end of the meeting to summarise, check for agreement and thank the participants**

Summarise the main issues brought up, check whether all agree and ask for additional comments. Thank the participants and let them know that their ideas have been a valuable contribution and will be used for planning the proposed research, intervention, or health education materials.

Listen for **additional comments** and spontaneous discussions which occur after the meeting has been closed.

## **5.6 Functions of the recorder**

The recorder should keep a record of the content of the discussion as well as emotional reactions and important aspects of group interaction. Assessment of the emotional tone of the meeting and the group process will enable you to judge the validity of the information collected during the FG. Items to be recorded include:

- Date, time, place
- Characteristics of participants
- Opinions of participants, recorded as much as possible in their own words, especially for key statements
- Emotional aspects (e.g., reluctance, strong feelings attached to certain opinions)
- Vocabulary used
- Spontaneous relevant discussions during breaks or after the meeting has been closed

It is highly recommended that a tape-recorder be used to assist in capturing information. Even if a tape-recorder is used, notes should be taken as well, in case the machine malfunctions and so that information will be available immediately after the session for discussion.

A **supplementary role** for the recorder could be to assist the facilitator (if necessary) by drawing his or her attention to missed comments from participants, missed topics (the

recorder should have a copy of the discussion guide during the FG). If necessary, the recorder could also help resolve conflict situations within the group that the facilitator finds difficult to handle on her own.

### **5.8 Duration**

You should plan for each focus group to last approximately 2 hours – this will give participants to complete the personal details sheet and also for you to debrief participants after.

## **6 RESEARCH INSTRUMENT – FOCUS GROUP QUESTIONS**

These questions are intended to guide the focus group discussion only; they should not be presented in a rigid way. There are four discussion topics- experiences of HIV from **testing** through **diagnosis**, **disclosure** and **treatment**. Each of the topics has a number of probe questions which will assist you to get started and bring discussion back to the topic. You may not be able to cover all of the areas but you should get as far as you can.

### **Focus Group with HIV-positive Pregnant Women**

#### **1. Test Experiences**

*Can you describe your experiences of being tested (e.g. why you decided to be tested, how you managed the results, what happened next and so on).*

Probe Questions

- a) *In what ways were you prepared for the results of your test*
- b) *What were the main reasons you decided to test*
- c) *What factors have helped you to accept the results*
- d) *What factors prevented you from accepting your results*
- e) *How would you describe your interactions/experiences with the clinic/health centre/doctor's office where you had your test*
- f) *Who were your main sources of support immediately after testing?*
- g) *What thoughts and feelings did you experience within the first six months after being tested?*

#### **2. Impact of Diagnosis**

*What has been the main impact of your diagnosis in terms of your own self-esteem and the effects on others around you?*

Probe Questions

- a) *How would you describe your reaction to your diagnosis*
- b) *How have these thoughts and feelings changed since you first received your results?*
- c) *How has your diagnosis affected your most personal relationships*
- d) *Has your diagnosis affected your family members, if so in what ways?*
- e) *How has your diagnosis affected your employment?*
- f) *How has your diagnosis affected your ability to work?*
- g) *Has your diagnosis affected your sexual behaviour in any way – can you say how*
- h) *Is there any other area of your life your diagnosis has affected which we have not talked about?*

#### **3. Disclosure and Factors that Impact on Disclosure**

*Can you talk about how you decided to tell others about your status (the reasons you did or didn't tell; who you told and what information you shared)?*

Probe Questions

- a) *Do you think it is important to disclose your status*

- b) *If you have not disclosed your status to anyone, can you talk about why you have not disclosed?*
- c) *What changes might influence you to disclose your status?*
- d) *If you have disclosed your status, which person did you first tell and why?*
- e) *What other persons did you disclose to? How did you decide?*
- f) *How would you describe your level of disclosure, e.g. fully disclosed, partially disclosed, only to family etc.?*
- g) *When you disclosed, what responses did you get*

#### **4. Psychosocial Factors and Treatment**

*Can you describe your experiences and views about treatment?*

Probe Questions

- a) *Are you receiving treatment*
- b) *What does treatment mean to you and does it include natural, traditional or alternative medicines*
- c) *How easy or difficult is it for you to get treatment*
- d) *Have you had any challenges in sticking to the treatment – can you say what these are*
- e) *How would describe the effects of treatment on your physical self*
- f) *How would you describe the effects on your emotional self*
- g) *Has being pregnant affected your decisions about treatment, in what ways?*
- h) *How do you think treatment will affect your child*
- i) *What are your views about breastfeeding*
- j) *How would you describe your experiences and interactions with health and social work professionals in accessing treatment and support*
- a) *What are your aspirations for the future*

## Focus Group with Parents/Caregivers of HIV-positive Children

### 1. Test Experiences

*Can you describe the experiences of your child being tested?*

Probe Questions

- a) *In what ways were you prepared for the results of the child's test*
- b) *What were the main reasons the child was tested*
- c) *What factors have helped you to accept the results*
- d) *What factors made it difficult to accept the results*
- e) *How would you describe your interactions/experiences with the clinic/health centre/doctor's office where your child was tested*
- f) *Who were your main sources of support immediately after testing?*
- g) *What thoughts and feelings did you experience within the first six months after your child was tested?*
- h) *In what ways was the testing of your child related to your own status*

### 2. Impact of Diagnosis

*What has been the main impact of the child's diagnosis in terms of the effects on the child him/herself, on you and on others around you?*

Probe Questions

- a) *Is the child aware of his/her status*
- b) *If so, who told the child and can you recall what was said*
- c) *Can you describe the child's reaction to the diagnosis*
- d) *What were your thoughts and feelings at this time*
- e) *How have these changed since you first received the results of the test?*
- f) *Can you talk about how your child's diagnosis affected other family members?*
- g) *How does your child cope with his/her diagnosis*
- h) *How has your child's diagnosis affected his/her relationships with others*

### 3. Disclosure and Factors that Impact on Disclosure

*Can you talk about how you decided to tell others about your child's status (the reasons you did or didn't tell; who you told and what information you shared)?*

Probe Questions

- a) *Can you give examples of any discussions you have had with your child about his/her status*
- b) *If you have not disclosed your child's status to anyone, can you say why not*
- c) *Can you think of circumstances in which you might want to tell others about your child's status?*
- d) *If you have disclosed the child's status, can you talk about why you decided to disclose their status and what the effect has been?*
- e) *How would you describe your child's level of knowledge about his/her status e.g. fully informed, mostly understands, knows but doesn't understand, doesn't know anything*

f) *When you disclosed, what responses did you get*

#### **4. Psychosocial Factors and Treatment**

*What have been the benefits and/or challenges in getting treatment for your child?*

Probe Questions

- a) *Is your child receiving treatment*
- b) *Has your care of your child changed since learning of his/her status – in what ways*
- c) *What are your child's views about treatment*
- d) *How easy or difficult is it for you to access treatment for him/her*
- e) *What have been the effects of treatment*
- f) *Have there been any challenges in sticking to the treatment – can you say what these are*
- g) *What things do you do to help your child to cooperate with treatment*
- h) *How would you describe your experiences and interactions with health and social work professionals in accessing treatment and support*
- i) *What are the biggest challenges that your child faces because of HIV*
- j) *What are strengths does your child possess in dealing with HIV*

## Focus Group with Men

### 1. Test Experiences

*Can you describe your experiences of being tested (e.g. why you decided to be tested, how you managed the results, what happened next and so on).*

#### Probe Questions

- a) *In what ways were you prepared for the results of your test*
- b) *What were the main reasons you decided to test*
- c) *What factors have helped you to accept the results*
- d) *What factors prevented you from accepting your results*
- e) *How would you describe your interactions/experiences with the clinic/health centre/doctor's office where you had your test*
- f) *Who were your main sources of support immediately after testing?*
- g) *What thoughts and feelings did you experience within the first six months after being tested?*

### 2. Impact of Diagnosis

*What has been the main impact of your diagnosis in terms of your own self-esteem and the effects on others around you?*

#### Probe Questions

- a) *How would you describe your reaction to your diagnosis*
- b) *How have these thoughts and feelings changed since you first received your results?*
- c) *How has your diagnosis affected your most personal relationships*
- d) *Can you talk about how your diagnosis affected your family members?*
- e) *How has your diagnosis affected your employment?*
- f) *How has your diagnosis affected your ability to work?*
- g) *Has your diagnosis affected your sexual behaviour in any way – can you say how*
- h) *Is there any other area of your life your diagnosis has affected which we have not talked about?*

### 3. Disclosure and Factors that Impact on Disclosure

*Can you talk about how you decided to tell others about your status (the reasons you did or didn't tell; who you told and what information you shared)?*

#### Probe Questions

- a) *Do you think it is important to disclose your status*
- b) *If you have not disclosed your status to anyone, can you talk about why you have not disclosed?*
- c) *What changes might influence you to disclose your status?*
- d) *If you have disclosed your status, which person did you first tell?*
- e) *Can you talk about how you decided to disclose your status to that person? What special characteristics did this person have?*
- f) *What other persons did you disclose to? How did you decide?*

- g) How will you describe your level of disclosure, e.g. fully disclosed, partially disclosed, only to family etc.?*
- h) What might influence changes in your level of disclosure?*
- i) When you disclosed, what responses did you get*

#### **4. Psychosocial Factors and Treatment**

*Can you describe your experiences and views about treatment?*

Probe Questions

- a) What does treatment mean to you and does it include natural, traditional or alternative medicines*
- b) How easy or difficult is it for you to get treatment*
- c) Do you think treatment has benefited you*
- d) Have you had any challenges in sticking to the treatment – can you say what these are*
- e) How would describe the effects of treatment on your physical self*
- f) How would you describe the effects on your emotional self*
- g) How would you describe your experiences and interactions with health and social work professionals in accessing treatment and support*
- h) What are your aspirations for the future*

## **Focus Group with Young people 18-24 (mixed gender group)**

### **1. Test Experiences**

*Can you describe your experiences of being tested (e.g. why you decided to be tested, how you managed the results, what happened next and so on).*

#### Probe Questions

- a) *In what ways were you prepared for the results of your test*
- b) *What were the main reasons you decided to test*
- c) *What factors have helped you to accept the results*
- d) *What factors prevented you from accepting your results*
- e) *How would you describe your interactions/experiences with the clinic/health centre/doctor's office where you had your test*
- f) *Who were your main sources of support immediately after testing?*
- g) *What thoughts and feelings did you experience within the first six months after being tested?*

### **2. Impact of Diagnosis**

*What has been the main impact of your diagnosis in terms of your own self-esteem and the effects on others around you?*

#### Probe Questions

- a) *How would you describe your reaction to your diagnosis*
- b) *How have these thoughts and feelings changed since you first received your results?*
- c) *Can you talk about how your diagnosis has affected your family?*
- d) *How has your diagnosis affected your school or college?*
- e) *How has your diagnosis affected your ability to work?*
- f) *Has your diagnosis affected your sexual behaviour in any way – can you say how*
- g) *Is there any other area of your life your diagnosis has affected which we have not talked about?*

### **3. Disclosure and Factors that Impact on Disclosure**

*Can you talk about how you decided to tell others about your status (the reasons you did or didn't tell; who you told and what information you shared)?*

#### Probe Questions

- a) *If you have not disclosed your status to anyone, can you talk about why you have not disclosed?*
- b) *What changes might influence you to disclose your status?*
- c) *If you have disclosed your status, which person did you first tell?*
- d) *Can you talk about how you decided to disclose your status to that person? What special characteristics did this person have?*
- e) *What other persons did you disclose to? How did you decide?*

- f) *How will you describe your level of disclosure, e.g. fully disclosed, partially disclosed, only to family etc.?*
- g) *What might influence changes in your level of disclosure?*
- h) *When you disclosed, what responses did you get*

#### **4. Psychosocial Factors and Treatment**

*Can you describe your experiences and views about treatment?*

Probe Questions

- a) *Are you receiving treatment for HIV*
- b) *What does treatment mean to you and does it include natural, traditional or alternative medicines*
- c) *How easy or difficult is it for you to get treatment*
- d) *Do you think treatment has benefited you*
- e) *Have you had any challenges in sticking to the treatment – can you say what these are*
- f) *How would describe the effects of treatment on your physical self*
- g) *How would you describe the effects on your emotional self*
- h) *How would you describe your experiences and interactions with health and social work professionals in accessing treatment and support*
- i) *What are your aspirations for the future*

## 7. DATA COLLECTION 1

### FOCUS GROUP CONTACT SUMMARY SHEET

The Recorder should complete one of these sheets for each focus group.

- Name, date, time, place of focus group
- Opinions of participants, recorded as much as possible in their own words, especially for key statements
- Emotional aspects (e.g., reluctance, strong feelings attached to certain opinions)
- Vocabulary used
- Spontaneous relevant discussions during breaks or after the meeting has been closed

Under each of the following headings summarise any key points that came up – check this with the researcher in case he/she has any other comments to add (*you will find it helpful to give yourself a separate page for each heading*):

**Dealing with Diagnosis**

**Disclosure**

**Stigma and Discrimination**

**Support and Treatment**

**Impact of Living with HIV**

**Children, Parenting and Family Life**

**Resilience and Coping Mechanisms**

Next write below any issues that struck you as salient, interesting or important not covered by the headings above

**Name of Recorder** \_\_\_\_\_



## 9. PARTICIPANT'S RESEARCH INFORMATION

*This information is for research participants*

*How to use:*

1. *Fill in the appropriate local contact details*
2. *If you would like to add anything you think is important, please do so and copy to me at: A.D.Jones@hud.ac.uk*
3. *Copy this sheet and give to everyone who takes part*
4. *Also use this when describing the research to participants*

## RESEARCH INTO PEOPLE'S EXPERIENCES OF LIVING WITH HIV-AIDS

### ***What is the study is about?***

The Social Work Unit at the University of The West Indies is working with the School of Social Work at Barry University to improve services for people affected by HIV-AIDS. This work involves research with people who are living with HIV-AIDS to understand more about how the disease has affected them and what can be done to better support them.

### ***What will the information be used for?***

The results of the study will be used to provide information that will help the appropriate authorities to put in place effective systems and better services for people affected by HIV-AIDS. The information will also help to make health and social work professionals more sensitive to people's needs and rights.

### ***How can I get involved?***

If you would like to take part you can do so either by being part of a group of other people who are affected by HIV-AIDS and have agreed to come together to discuss their experiences or through a private interview with a researcher. Please contact the number on this leaflet and a researcher will arrange to see you. If you wish you can also be interviewed by telephone or email.

### ***Who is carrying out the research?***

The research is being carried out by researchers who are also trained in social work. The research teams and contact details are:

Trinidad and Tobago: Ms Tracie Rogers	376-5081
Mrs. Jacqueline Padmore	662 2002 ext. 2403
Professor Adele Jones	0792783565 or A.D.Jones@hud.ac

Miami:

***What about confidentiality?***

We do not need to know your name at any time. When we talk about the research or write reports, we will present the results in such a way as to protect the identity of all participants. We will keep all information from the study in a locked cabinet. Please note that if you agree to take part in a group discussion, the whole group will be asked to respect the confidentiality of its members – again real names will not be used and if you feel a bit anxious about this remember that everyone in the group will be in a similar position to you.

***Do I have any rights as a research participant?***

Your participation in this study is entirely voluntary and we will respect your rights:

- To confidentiality
- To take time to decide whether to help us
- To refuse to take part
- To refuse to answer questions
- To withdraw from this project at any time
- To have a copy of the research report if you wish (you will need to provide an address for this to be sent to you)

**If you have any questions or concerns please feel free to contact any member of your local Research Team**

## 10. CONSENT FORM

**Purpose:** I have been asked to take part in a study about the psychosocial effects of living with HIV. The study will be used to help to improve services for persons affected by HIV

**Procedures:** I understand that as part of the study questions will be asked about being tested for HIV, the effects of being diagnosed HIV-positive and my views about disclosure and treatment

I will be taking part in a group discussion or an individual interview that will last approximately 1½-2 hours.

The discussion or interview will be recorded and once the research report has been written the tape will be destroyed. I understand that the information from the study will only be seen by the researchers and will be kept in a locked cabinet.

I understand that I can refuse to take part at any time or refuse to answer any questions

I understand that the information I give will only be used by the Research Team and only for the purposes of this study

I understand that the study is confidential and my real name will not be used at any stage.

If I am distressed as a result of taking part in the study, I will be given help to access counselling or support from an appropriate agency.

**I have been given a copy of this consent form**

Signature (please use an assumed name for signing)\_\_\_\_\_

Date:\_\_\_\_\_

Researcher's Signature\_\_\_\_\_Date:\_\_\_\_\_