

INFORMATION SHEET and CAREGIVER CONSENT FORM

Title: VUKA Family Program: Supporting HIV-infected Youth in South Africa

Who we are

Hello, I am (field worker's name) a researcher from the Human Sciences Research Council.

What we are doing

I work with researchers from South Africa (Arvin Bhana, PhD) and the United States (Mary McKay, PhD) who are doing a research study involving families and HIV positive youth. We wish to understand the behaviour and health risks in HIV+ youth and to see if the family intervention program called VUKA will assist the family and the young person to improve their general health, their sense of themselves as healthy persons, that is, their mental health, and to help reduce the risk they may face in the future because of their HIV+ status.

Your participation

You have been chosen to participate in this study because your child is **9** to 14 years of age, was born with HIV, **knows his or her HIV status**, and receives health care at R.K. Kahn Hospital or Prince Mshiyeni Memorial Hospital.

Please understand that **your participation is voluntary** and you are not being forced to take part in this study. The choice of whether to participate or not, is yours alone. If you choose not to take part, you will not be affected in any way whatsoever. If you agree to participate, you may stop participating in the research at any time and tell me that you don't want to go continue. If you do this there will also be no penalties and you will not be prejudiced in any way.

You should also know that the family intervention program is not for medical treatment. The information is being collected for research only. You may choose not to participate. If you agree to be in this study, you will be asked to do the following:

1. You and your child will be **chosen randomly (by chance) to either participate in VUKA program activities now or in about a year. Children in both groups will continue to receive their regular medical care at the clinic they attend.**
2. **If your family is chosen to participate in VUKA now**, both you and your child will be invited to attend **10** meetings (about 2 to 3 hours each). Each session will begin with the whole group of children and caregivers sharing a meal and reading a story together. Children and caregivers will then break up into separate groups where they discuss questions related to one of the topics below. The children and caregivers will then return to a single group to share what they have discussed. The session topics will include (1) Loss and



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bereavement related to HIV/AIDS; (2) Knowledge and understanding of HIV transmission and treatment; (3) Disclosure of HIV status to others; (4) Youth identity, acceptance and coping with HIV; (5) Adherence to medical treatment; (6) Stigma and discrimination; (7) Caregiver-child communication, particularly on sensitive topics such as puberty and HIV; (8) Puberty; (9) Identifying and developing ways to keep children safe in high risk situations where sexual behaviour and drug use are possible; and (10) Social support for caregivers and youth.

3. **Whichever group you are in**, you and your child will also be asked to complete three interviews, one at the beginning of the study, one 3 months later, and then at 12 months **from the beginning of the study, using tablets or small computers**. You and your child do not have to answer any interview questions you do not want to answer. If you or your child becomes upset at any time during the intervention sessions or the interviews, someone will talk with you until you feel better.
4. **Also, for this study, if you give permission below, we will obtain your child's CD4 count and viral load from his or her medical records. This information will be kept confidential.**

How long does it take: Participation in this study will involve 2 to 3 hours each meeting for up to **10** meetings and three interviews, one at the beginning of the study, one 3 months later, and lastly 12 months later. Each interview will last for 1½ hours.

Are there any risks? There are no known risks to you or your child. However, because you will be in a group, people taking part in the program might talk about what happened in the group or outside of the group. We will remind everyone at each session that what people say in the group is private and should not be shared. Also, sometimes you and your child might feel uncomfortable with what the group is talking about. You and your child don't have to discuss any topics or take part in any activities that make you uncomfortable. The group facilitators will be available to help you if you need them.

Benefits: Each family will receive R80 per family per intervention or assessment session (R40 for participation and R40 for transportation). If you would like to receive feedback on our study, we will record your phone number on a separate sheet of paper and can send you the results of the study when it is completed.

Confidentiality: What you and your family say and do is private and confidential. We will not talk about it with anyone else in your family, your school, or your neighborhood. We will tell other group members not to talk about things that are shared in the group. But we cannot guarantee that other group members will not share information with people outside of the group. Your name or that of your child will not appear on any of the files that we use **or on the tablets where you answer questions**. All of the information that you share with us will be kept locked away. Information kept on a computer **or tablet** will only be available with a password.

When We Cannot Keep Things Private: The only time that we cannot keep things private is if we are worried that you are being harmed or that you are harming someone else. If we are





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worried that you are being abused or neglected, then we have to contact the responsible protection department in South Africa. If we are worried that you are harming yourself or someone else, then a supervisor may be told. We will tell you if someone else must be told what you have shared with us.

What If I have Any Questions?

If there is anything about the study or your participation that is unclear or that you do not understand, if you have questions or wish to report a research-related problem, you may contact Arvin Bhana at 031 242 5502, abhana@hsrc.ac.za, 750 Mary Thiphe Street, Inthuthuko Junction, Cato Manor.

Questions about Subjects Rights: For questions about your rights as a research participant, you may contact the Committee Secretary: Ms Khutso Sithole, Room 1319, 13th floor, HSRC Building, 134 Pretorius Street, Pretoria, Tel. 012-302 2012, (E-mail: ksithole@hsrc.ac.za).

Agreement to Participate

Caregiver's Consent for Self (only if 18 years and over)

I hereby agree to participate in research in the VUKA family intervention program. I understand that I am participating freely and without being forced in any way to do so. I also understand that I can stop participating at any point should I not want to continue and that this decision will not in any way affect me negatively.

I understand that this is a research project whose purpose is not necessarily to benefit me personally in the immediate or short term.

I understand that my participation will remain confidential.

Signature of participant

Date:.....I consent to participate.

Printed Name:

Caregiver’s Consent for Child (Only if 18 years and over)

I understand that the participation of my child is voluntary. My child has a right to withdraw his/her consent to participate at any time without penalty and also have a right not to answer any question that makes him/her feel uncomfortable.

I understand that confidentiality will be maintained at all times. The person asking my child questions will never tell anyone what my child has said. My child’s name will not be written down



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or recorded in any way and that no one will be able to link my child's name to the answers written down.

I understand that you will interview my child 3 times and that each interview will take approximately 1.5 hours. I understand that you will ask my child some personal questions that he/she might find difficult to answer. My child's privacy will be maintained in all published and written data resulting from this study.

I understand that you will obtain information about my child's CD4 count and viral load from his or her medical records and that this information will be kept confidential.

I understand that there might be no direct benefit to my child as an individual and that one possible limitation of participating in the interview is that my child may experience intense emotions due to recalling difficult experiences in his/her life. In the event that this should happen, you will refer my child to an organisation that can give him/her assistance and support.

In my opinion, my child understands the nature of the study and is willing to participate. I agree that my child participate in this study.

Signature of parent/ caregiver

Date:.....I consent to my child's participation

You have received a copy of this consent document to keep.

