

APPENDIX B

Consent for Participation in a Research Study (Wave 2)

Study Title: Assessing HIV Education and Screening Ministries in African American Churches

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Request to Participate

You are being asked to take part in a research study that examines HIV education and screening projects in African American churches. The study is taking place at this church. The researcher in charge of this study is Jannette Berkley-Patton, PhD. While the study will be run by her, other qualified persons who work with her may act for her. This study is funded by the National Institute of Health.

The study team is asking you to take part in this research study because you are between 18 and 64 years of age. You are also either: a) a church member or b) community member using this church's outreach services (e.g., church daycare/afterschool/Summer School services for your children; food/ clothing programs, other church social services) of this predominantly African American church in the Kansas City, MO, or Kansas City, KS, metropolitan area. Church and community members from several churches will be asked to participate in this study. Research studies only include people who choose to take part. This document is called a consent form. Please read this consent form carefully and take your time making your decision. The researcher or study staff will go over this consent form with you. Ask him/her to explain anything that you do not understand. Think about it and talk it over with your family and friends before you decide if you want to take part in this research study. This consent form explains what to expect: the risks, discomforts, and benefits, if any, if you consent to be in the study.

Background

This research study is being conducted to:

- a) examine the health beliefs and behaviors related to HIV and other STDs among African American church congregants and community members;
- b) describe the capacity of Black churches to develop and implement HIV health ministries using a church-based HIV Prevention Tool Kit;
- c) improve the delivery of training and materials used to promote African American HIV and other STD ministries.

You are being asked to take part in this study because you will have an opportunity to see how this church carries out an HIV education and screening intervention named Taking It to the Pews, or TIPS. You will be one of about 110 subjects in the study at this church. About 1,540 subjects total will take part across all the churches participating in this study.

Purpose

The information from this study will be used in collaboration with Calvary Community Outreach Network, a faith-based/community-based organization serving the Greater Kansas City area, to better develop services and tools to assist African American churches in developing health ministries focused on HIV/STDs. Calvary Community Outreach Network will assist with training and providing technical assistance on HIV/STD topics with participating churches. Your church/this church will receive HIV materials/activities which will be implemented by your church leaders and members. Your church/this church will also coordinate HIV/STD

screening events run by the Kansas City Health Department, and KC CARE and JayDoc Clinics, which will take place at this church. Your participation in this research study will include you completing 4 surveys over about an 18-month period. You are not required to participate in this research study in order to receive tool kit materials/activities and partake in the trainings provided by Calvary Temple Baptist Church. Your participation in any portion of this research study is completely voluntary.

Procedures

If you choose to participate in this research study, you will be asked to complete a contact sheet with your name, phone number, address, email address, and contact information for two other people who know how to contact you. We will contact you to tell you when upcoming surveys will take place at this church. You will also complete a Church-based Health Beliefs and Behaviors Survey that will be passed out in your church/this church. The Church-based Health Beliefs and Behaviors Survey asks questions about your HIV and other health screening behaviors, HIV/STD health risk behaviors, and beliefs about HIV/STDs. The survey also asks about your religious activities, your beliefs and knowledge about HIV/STDs, whether your church should be involved in HIV/STD-related activities, and to what degree you have participated in these activities. This survey will take about 20-45 minutes to complete. You will also be given information about HIV/STDs. The survey will be administered at your church/this church, which is participating in this research study. You will put your completed survey in unmarked envelope and then place your envelope in a sealed box. Your survey responses will be completely confidential. The survey does not ask you for any personal identification.

You will need to complete this survey FOUR times. The first survey will take place today immediately after this consent process. The surveys will take place about 6 months apart over an 18-month time period. If you agree to take part in this study, you will be involved in this study for about 18 months. When you are done taking part in this study, you will still have access to the Taking It to the Pews intervention if your church/this church chooses to continue to implement it as part of their HIV ministry.

Participation in this evaluation study is voluntary at all times. You may choose to not participate or to withdraw your participation at any time. Deciding not to participate or choosing to leave the study will not result in any penalty, loss of benefits, or other privileges at your respective church, which you are entitled. If you decide to leave the study, please inform the lead researcher of this study, Jannette Berkley-Patton (berkleypattonj@umkc.edu, 816-235-6362).

Risks and Inconveniences

There are minimal risks for participating in this research study which consists of completing three surveys. The survey will ask you about your personal health status, risky health behaviors, and other sensitive personal health information. You may feel a bit uncomfortable answering some of the survey questions related to HIV/STD risk, HIV/STD testing, and other HIV/STD-related topics when completing questionnaires, particularly in the church setting. However, by creating a secret code, your responses will be totally confidential. To protect the security of responses on surveys, you will be asked to construct a unique identifier using a series of questions (e.g., "first letter of your mother's first name"). You will write your unique identifier on all survey materials. Your unique identifier number will only be on collected survey data and will serve as your study number. The survey will not ask you to write down any personal identifying information. If for whatever reasons you include personal identifying information on the survey, this information will be removed. Also, information on your contact sheet will be seen by study staff to contact you about upcoming baseline 2 (in 6-months), 12-month and 18-month surveys. Upon completion of the study, information gathered from all participants will be used in reports and/or for grant writing purposes.

Benefits

Potential benefits from participating in this evaluation study may be an increased knowledge of HIV/STDs that contributes to your prevention of HIV/STD and to your ability to share this information with friends and family. You may also choose to receive free HIV risk reduction counseling and will have access to free,

confidential HIV/STD screening at this church. Also, other African American church and community members may benefit from the information you provide through the improved development of the church-based Taking It to the Pews project, the HIV/STD Prevention, Compassion, and Action Tool Kit, church trainings on development of HIV ministries.

Fees and Expenses

There are no fees/expenses costs to you for participating in the study.

Compensation

Through Calvary Community Outreach Network, your church will receive promotional items for participating in this study, including a church-based HIV/STD Prevention, Compassion, and Action Tool Kit, a monetary stipend, promotional items, and meals/snacks during training sessions. Additionally, you will receive \$25 for completing the first baseline survey, \$25 for the second baseline survey, \$25 for completing a 12-month survey, and \$30 for completing an 18-month survey at your church. This adds up to a total of \$105 if you complete all FOUR surveys.

Alternatives to Study Participation

You can choose to not take part in this study, which means you would not complete the surveys. You may still partake in the use of the HIV/STD Prevention Tool Kit material/activities, church-based health fairs including HIV screening, and trainings offered through your church and Calvary Community Outreach Network while choosing not to participate in this evaluation research study.

Confidentiality

While we will do our best to keep the information you share with us confidential, it cannot be absolutely guaranteed. Individuals from the University of Missouri-Kansas City Institutional Review Board (a committee that reviews and approves research studies), Research Protections Program, and Federal regulatory agencies may look at records related to this study to make sure we are doing proper, safe research and protecting human subjects. The results of this research may be published or presented to others. You will not be named in any reports of the results. Also, church names will not be associated with any public use of the data.

Your name will not be collected at any time during the survey process. There will be no personal identifiers on the surveys. You will be asked to not put personal identifiers on the surveys. After completing your survey, you will immediately put it in an unmarked envelope and then put the envelope in a sealed box. Upon publication of survey data in reports, all collected survey responses will be combined as not to be able to detect any information about you or your church/this church. Survey will be maintained by the lead evaluator, Jannette Berkley-Patton, PhD in a locked filing cabinet in her secured study office and will be destroyed after 7 years. Your contact sheets will also be stored in a locked filing cabinet in her secured study office and will be destroyed after all follow-up data is collected.

Contacts for Questions about the Study

The University of Missouri-Kansas City appreciates the participation of people who help it carry out its function of developing knowledge through research. You should contact the Office of UMKC's Social Sciences Institutional Review Board at 816-235-5927 if you have any questions, concerns or complaints about your rights as a research subject. You may call the researcher Dr. Jannette Berkley-Patton at 235-6362 if you have any questions about this study. You may also call her if any problems come up. Dr. Berkley-Patton is located in the Psychology Department at the University of Missouri-Kansas City, 5030 Cherry Street, Room 308, Kansas City, MO 64110-2499.

Voluntary Participation

Taking part in this research study is voluntary. If you choose to be in the study, you are free to stop participating at any time and for any reason. If you choose not to be in the study or decide to stop participating, your decision will not affect any care or benefits you are entitled to. The researchers or sponsors may stop the study or take you out of the study at any time if they decide that it is in your best interest to do so. They may do this for medical or administrative reasons or if you no longer meet the study criteria. You will be told of any important findings developed during the course of this research.

You have read this Consent Form or it has been read to you. You have been told why this research is being done and what will happen if you take part in the study, including the risks and benefits. You have had the chance to ask questions, and you may ask questions at any time in the future by calling Dr. Jannette Berkley-Patton at 816-235-6362. By signing this consent form, you volunteer and consent to take part in this research study. Study staff will give you a copy of this consent form.

Signature (Volunteer Subject)

Date

Printed Name (Volunteer Subject)

Signature of Person Obtaining Consent

Date

Printed Name of Person Obtaining Consent