



# Washington University in St. Louis: **WITH U**

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Implementation Toolkit



# Authors

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## Washington University in St. Louis

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## Introduction

Building off the overview provided in the Implementation Manual, this Implementation Toolkit provides additional guidance on how to adapt and implement Washington University in St. Louis' WITH U program. This Toolkit is designed to provide more detailed information to support future replicators, especially HIV service providers and on-the-ground clinic staff, who are planning for implementation or are in the process of implementing WITH U components.

The Toolkit provides tangible tools and other materials to tailor and use when replicating. Replicators are encouraged to reach out directly to the Washington University team with questions or for additional information (see the Manual for the team's contact information).



## Consent Forms

### Informed Consent for Participation in WITH U

#### INFORMED CONSENT DOCUMENT

**Project Title: WITH U: A Special Project of National Significance on Implementation of Evidence-Informed Behavioral Health Models to Improve HIV Health Outcomes for Black Men who have Sex with Men**

**Principal Investigator:** Kathryn Plax

**Research Team Contact:** Jeff Glotfelty  
(314) 273-9069  
jeffglotfelty@wustl.edu

This consent form describes the research study and helps you decide if you want to participate. It provides important information about what you will be asked to do during the study, about the risks and benefits of the study, and about your rights and responsibilities as a research participant. By signing this form you are agreeing to participate in this study.

- You should read and understand the information in this document including the procedures, risks and potential benefits.
- If you have questions about anything in this form, you should ask the research team for more information before you agree to participate.
- You may also wish to talk to your family or friends about your participation in this study.
- Do not agree to participate in this study unless the research team has answered your questions and you decide that you want to be part of this study.

This is a research study conducted by Katie Plax, MD having to do with working with a peer health navigator to determine if six months of intensive peer health navigation impacts health behaviors of young adults living with HIV. You should carefully consider the information in this consent document and discuss it with the research team. Be sure you understand why you might want to participate, or why you might not want to participate. You may choose to participate or not.

If you agree and sign this consent, you will be volunteering to participate in the research study. As a voluntary participant, you will be asked to spend 1-2 hours today to enroll in the program and take a 30 - 45 minute survey.

For the program, you will need to come to your Washington University Infectious Diseases clinic for the first, 2-month, 6-month, and 12-month sessions. Other sessions can happen at a clinic or in the community at a location of your choice. During that time:

- You will be asked to participate in a health navigation program for six months where you meet with your health navigator every week for two months followed by each month for four additional months.



- You will answer surveys throughout your participation in the program.
- Twelve months after enrollment, you will complete a follow-up evaluation session.
- You may be provided the opportunity to participate in a qualitative evaluation interview after participating in the program for six months.
- You will continue to take part in your care services as directed by your doctor or other care providers at the clinic you attend.

The main risks to you if you participate are breach of confidentiality or discomfort from the questions and topics discussed.

We don't expect this study to benefit you directly, but it will help us understand how to best use health navigators in HIV care settings. By volunteering you may help someone else in the future. There is no cost to you and you will be paid up to \$100 (in a gift cards) for being a volunteer participant. All of this information will be explained and is listed in more detail in this consent document. The research team must give you a copy of this signed consent document.

### **WHAT IS THE PURPOSE OF THIS STUDY?**

This is a research study. We invite you to participate in this research study because you are between the ages of 18-29 and have received care from a doctor, therapist, health coach, and/or case manager associated with Washington University in St. Louis' School of Medicine's Department of Infectious Diseases.

The purpose of this research study is to see if participating in intensive peer navigation within the medical care setting will improve health outcomes for young adult patients living with HIV.

### **WHAT WILL HAPPEN DURING THIS STUDY?**

During this study you will be asked to participate in a health navigation program where you will:

- Work for six months with a health navigator, which includes:
  - Two months of *weekly* sessions
  - Followed by four months of *monthly* sessions
  - Sessions can take place in person (at a Washington University Infectious Disease Clinic, in a public space in the community, or at your home), over the phone, by text message, or by video conference using the Healthie app.
- Take surveys.
  - Today you will take a 30 - 45 minute survey about you and your health-related behaviors.
  - In two months, six months, and twelve months, you will retake the survey to see if there has been any change in your answers.
  - Completing the surveys must be done in person at one of the Washington University School of Medicine Infectious Disease Clinics.
  - You are free to skip any questions that you would prefer not to answer
- You may be provided the opportunity to participate in a qualitative evaluation interview after participating in the program for six months. These interviews will take place in person or over video conference and will take approximately 30 minutes to an hour.



- Continue to take part in your care services as directed by your doctor or other care providers at the clinic that you attend.
- Every six months (2 times per year), your medical chart will be reviewed to obtain your HIV viral load, CD4 count and other medical indicators, which are taken as part of your regular medical visits.
- The questions you answer using the computer along with your medical information will be sent electronically using a code (without any information that could identify you) to the evaluation team at the University of Chicago.

A mobile and computer application (app) will be used by the health navigators to track your progress through the program. If you choose, this app can be used as an interactive participant portal to communicate with the health navigator and monitor your own progress. Downloading and using the Healthie App is optional to you for participation in this study. However, participants who chose not to use Healthie will not be able to communicate with their health navigator using video conferencing (video phone calls similar to Facetime).

The study team will work with your case manager and members of your care team to contact you if we are unable to reach you using the contact information you provide us.

**Will you collect my social security number?**

You will be asked to provide your social security number on the “Consented Participant Tracking Database” that is used track your progress through the intervention, monitor your medical outcomes, and document your information that is important to this study. The reason for collecting your social security number is to verify your identity to protect your personal information and to connect your medical records with your case management records. Collecting your social security number for this purpose is required for participation in this study.

**Will you save my research information to use in future research studies?**

We might remove identifiers from your private information and then use the information for future research studies or share them with other researchers for their future research. If this occurs, we will not ask you for additional consent for these uses of your information.

**Audio/Video Recording or Photographs**

One aspect of this study involves making audio and video recordings of you. This would happen from use of the video conferencing application used to communicate with the health navigators. The recordings will not be stored and will be destroyed within one week.

I give you permission to make audio and video recordings of me during this study.

**Yes**       **No**  
**Initials**      **Initials**

**HOW MANY PEOPLE WILL PARTICIPATE?**

Up to 200 people will take part in this study conducted by investigators at Washington University. Nationwide, up to 2,000 people may take part in this study, including at other sites.



### **HOW LONG WILL I BE IN THIS STUDY?**

If you agree to take part in this study, your involvement will last for twelve months:

- Today, you can expect to spend up to two hours to get enrolled in the study.
- Going forward, there will be at least twelve sessions (eight weekly followed by four monthly) you're your health navigator, which will last at least 15 minutes but can last longer if you want.
- You may choose to participate in a qualitative evaluation interview after participating in the program for six months, which will last between 30 minutes to an hour.
- You will also have a twelve month follow-up visit that will last from 20 minutes to an hour.

### **WHAT ARE THE RISKS OF THIS STUDY?**

You may experience one or more of the risks indicated below from being in this study. In addition to these, there may be other unknown risks, or risks that we did not anticipate, associated with being in this study.

You will be asked to provide information about your physical and mental wellbeing, housing stability, and incarceration, as well as the barriers to care that you have personally experienced. These questions may make you feel stress, embarrassment, or guilt.

Part of this study may require the use of the Healthie App on your phone. The information stored on your phone is outside the control of the research study team and there is a risk that anyone who has access to your phone may see the private information being shared by your medical team.

One risk of participating in this study is that confidential information about you may be accidentally disclosed. We will use our best efforts to keep the information about you secure. Please see the section in this consent form titled *"How will you keep my information confidential?"* for more information.

### **WHAT ARE THE BENEFITS OF THIS STUDY?**

You may or may not benefit from being in this study.

However, we hope that, in the future, other people might benefit from this study because other healthcare organizations may be able to use the program developed in this study to help people successfully manage their health.

### **WHAT OTHER OPTIONS ARE THERE?**

If you choose not to participate in this study you can still work with your care team, including a health coach, to create a strategy for achieving the best health activities for you.

### **WILL IT COST ME ANYTHING TO BE IN THIS STUDY?**

You may have costs for being in this research study. Standard texting and data rates may apply when using your mobile phone for some study activities.





### **WILL I BE PAID FOR PARTICIPATING?**

You will be paid for being in this research study. You will be asked to provide your social security number (SSN) in order for us to pay you. If your social security number is obtained for payment purposes only, it will not be retained for research purposes.

Payment for participation in the study will be provided at the enrollment session and each of the follow-up sessions, at 2-, 6-, and 12-months. The amount of compensation provided will be as follows:

1. Enrollment Session - \$25 Walmart or Target Gift Card
2. 2-month Follow up - \$25 Walmart or Target Gift Card
3. 6-month Follow up - \$25 Walmart or Target Gift Card
4. 12-month Exit - \$25 Walmart or Target Gift Card

The total compensation for participating in the study will be \$100 in Walmart or Target Gift Cards.

If needed, you can be provided with Metro (bus/train) tickets or a cab voucher for travel to and from the study site.

### **WHO IS FUNDING THIS STUDY?**

The Health Resources and Services Administration (HRSA), an agency of the U.S. Department of Health and Human Services, is funding this research study. This means that the Washington University is receiving payments from HRSA to support the activities that are required to conduct the study. No one on the research team will receive a direct payment or increase in salary from HRSA for conducting this study.

### **HOW WILL YOU KEEP MY INFORMATION CONFIDENTIAL?**

Other people such as those indicated below may become aware of your participation in this study and may inspect and copy records pertaining to this research. Some of these records could contain information that personally identifies you.

- Government representatives (including the Office for Human Research Protections) to complete federal or state responsibilities
- HRSA
- University representatives to complete University responsibilities
- Washington University's Institutional Review Board (a committee that oversees the conduct of research involving human participants) and Human Research Protection Office. The Institutional Review Board has reviewed and approved this study.
- Any report or article that we write will not include information that can directly identify you. The journals that publish these reports or articles require that we share your information that was collected for this study with others to make sure the results of this study are correct and help develop new ideas for research. Your information will be shared in a way that cannot directly identify you.



All of the information you provide will be confidential. However, we will disclose to the proper authorities information shared with us or activities we observe concerning abuse, neglect or harm to others or yourself.

To help protect your confidentiality, we will collect information from you in a private space using a computer-administrated survey that creates a private setting for sensitive information.

We will limit personal health information sent via text message to the minimum necessary. We will take measures to reduce the chance of a breach of information while text messaging. We will work with you to lower the danger of someone seeing your information from text messages on your phone. We can show you ways to protect your phone, including setting stricter security settings.

### **Are there additional protections for my health information?**

Protected Health Information (PHI) is health information that identifies you. PHI is protected by federal law under HIPAA (the Health Insurance Portability and Accountability Act). To take part in this research, you must give the research team permission to use and disclose (share) your PHI for the study as explained in this consent form. The research team will follow state and federal laws and may share your health information with the agencies and people listed under the previous section titled, "How will you keep my information confidential?"

Once your health information is shared with someone outside of the research team, it may no longer be protected by HIPAA.

The research team will only use and share your information as talked about in this form or as permitted or required by law. When possible, the research team will make sure information cannot be linked to you (de-identified). Once information is de-identified, it may be used and shared for other purposes not discussed in this consent form. If you have questions or concerns about your privacy and the use of your PHI, please contact the University's Privacy Officer at 866-747-4975.

Although you will not be allowed to see the study information, you may be given access to your health care records by contacting your health care provider.

### **If you decide not to sign this form, it will not affect**

- your treatment or the care given by your health provider.
- your insurance payment or enrollment in any health plans.
- any benefits to which you are entitled.

However, it will not be possible for you to take part in the study.

### **If you sign this form:**

- You authorize the use of your PHI for this research
- This authorization does not expire.
- You may later change your mind and not let the research team use or share your information (you may revoke your authorization).
  - To revoke your authorization, complete the withdrawal letter, found in the Participant section of the Human Research Protection Office website at



<https://hrpo.wustl.edu/participants/withdrawing-from-a-study/> or you may request that the investigator send you a copy of the letter.

○ **If you revoke your authorization:**

- The research team may only use and share information already collected for the study.
- Your information may still be used and shared as necessary to maintain the integrity of the research, for example, to account for a participant's withdrawal from the research study or for safety reasons.
- You will not be allowed to continue to participate in the study.

**Can we contact you by email, text message, or through the Healthie App?**

We would like to contact you by email, text message, or through a protected application, called Healthie, for the purposes listed below. Some of these emails may contain health information that identifies you.

- Health navigation sessions and discussions
- Prescription reminders
- Educational sessions
- Service referrals and communication
- Scheduling and appointment reminders
- General announcements

Only the research team will have access to your email, text message, or in-application communications. We will only communicate by email, text message, or through the application to send you the information listed above. If you have any questions or need to contact us for an urgent or emergent situation, please contact the research team member identified at the top of this document.

You should be aware that there are risks associated with sending your health information via email, text message, or application.

- There is always a risk that the message could be intercepted or sent to the wrong email address or phone number. To avoid sending messages to the wrong email address, the first message we send you will be a test message to ensure we have the correct email address or phone number.
- When using any computer or mobile phone you should be careful to protect your username and password. Make sure you log-out before getting up from the computer or lock your screen before leaving your phone.
- If you share a home computer with other family members, and do not want them to know you are participating in this study make sure you provide an email address that only you can access.
- Your employer will have access to any email or other electronic communications sent or received on any electronic devices used for work or through a work server.

Do you agree to allow us to send your health information via email, text message, and through the Healthie App?

**Yes**       **No**  
**Initials**      **Initials**



### **IS BEING IN THIS STUDY VOLUNTARY?**

Taking part in this research study is completely voluntary. You may choose not to take part at all. If you decide to be in this study, you may stop participating at any time. Any data that was collected as part of your participation in the study will remain as part of the study records and cannot be removed.

If you decide not to be in this study, or if you stop participating at any time, you won't be penalized or lose any benefits for which you otherwise qualify.

### **What if I decide to withdraw from the study?**

You may withdraw by telling the study team you are no longer interested in participating in the study.

### **Will I receive new information about the study while participating?**

If we obtain any new information during this study that might affect your willingness to continue participating in the study, we'll promptly provide you with that information.

### **Can someone else end my participation in this study?**

Under certain circumstances, the investigator might decide to end your participation in this research study earlier than planned. This might happen for no reason or because you changed your clinical care location or the study or clinical team judges that it would not be safe for you to continue.

Additionally, if you do not establish your first health navigation session with your health navigator within one month of consent AND do not respond to repeated attempts by the study team to contact you, you will be considered "lost to follow-up and be withdrawn from the study.

### **WHAT IF I HAVE QUESTIONS?**

We encourage you to ask questions. If you have any questions about the research study itself, please contact: Jeff Glotfelty at (314) 565-2865. If you feel that you have been harmed in any way by your participation in this study, please contact Dr. Katie Plax at (314) 454-4101 or email [plax\\_k@wustl.edu](mailto:plax_k@wustl.edu)

If you have questions, concerns, or complaints about your rights as a research participant please contact the Human Research Protection Office at 1-(800)-438-0445, or email [hrpo@wustl.edu](mailto:hrpo@wustl.edu). General information about being a research participant can be found on the Human Research Protection Office web site, <http://hrpo.wustl.edu>. To offer input about your experiences as a research participant or to speak to someone other than the research staff, call the Human Research Protection Office at the number above.

This consent form is not a contract. It is a written explanation of what will happen during the study if you decide to participate. You are not waiving any legal rights by agreeing to participate in this study.

Your signature indicates that this research study has been explained to you, that your questions have been answered, and that you agree to take part in this study. You will receive a signed copy of this form.



**Do not sign this form if today's date is after EXPIRATION DATE: N/A.**

\_\_\_\_\_  
(Signature of Participant)

\_\_\_\_\_  
(Date)

\_\_\_\_\_  
(Participant's name – printed)

**Statement of Person Who Obtained Consent**

The information in this document has been discussed with the participant or, where appropriate, with the participant's legally authorized representative. The participant has indicated that they understand the risks, benefits, and procedures involved with participation in this research study.

\_\_\_\_\_  
(Signature of Person who Obtained Consent)

\_\_\_\_\_  
(Date)

\_\_\_\_\_  
(Name of Person who Obtained Consent - printed)



## Authorization for Unencrypted Electronic Communication

The Authorization for Unencrypted Electronic Communication was required if a participant wished to text or exchange emails with a staff member. This form was used to document a participant's consent to receive emails and text messages from MCMs and HNs about health-related topics while informing them of the risks of sharing such information in an unencrypted way.



### **AUTHORIZATION TO UTILIZE UNENCRYPTED EMAIL/ TEXT MESSAGING TO COMMUNICATE PROTECTED HEALTH INFORMATION\***

Electronic mail (email) and text messaging are forms of communication that may be used between you and the providers. We want to make sure you know that unencrypted email and text communications are not secure communications. Washington University Physicians is not able to encrypt text messages. We do have the ability to encrypt email communication of protected health information. Encryption is the process of making information unreadable unless you have the password or key to decrypt the information. We will encrypt email communications unless you tell us that you prefer us to use unencrypted email. If it is your preference that we not encrypt our email communications with you, please initial here: \_\_\_\_\_

If you elect to communicate from your workplace computer, you should be aware that your employer and its agents might have access to email communications between us. Email and text communications may become a part of your patient medical record and be accessible to my clinical support staff as needed for our operations.

Incoming email communications will be reviewed and answered as soon as possible. If you have not heard from your provider's office with a response and are concerned that your message was not received, please call the office during regular business hours. EMAIL COMMUNICATION SHOULD NEVER BE USED IN THE CASE OF AN EMERGENCY OR FOR URGENT REQUESTS FOR INFORMATION.

Washington University Physicians may use text messaging to remind you of upcoming appointments and/or care coordination activities if you have elected to receive reminders in this manner. We will limit information sent via text message to the minimum necessary. Washington University Physicians does not encourage text messaging for other purposes.

This authorization may be revoked at any time and must be done in writing. It is understood that the revocation will not apply to information that has already been released based on this authorization.

Authorization is valid while in a treatment relationship with Washington University Physicians and any of its associated providers or in the event of: \_\_\_\_\_

If you agree to the foregoing terms, please indicate your acceptance by your signature that you accept the terms and conditions outlined herein.



ACCEPTED: Signature of Individual \_\_\_\_\_ Date \_\_\_\_\_

Printed Patient Name \_\_\_\_\_ DOB \_\_\_\_/\_\_\_\_/\_\_\_\_

Authorized E-mail of Individual \_\_\_\_\_

Department of origination of authorization \_\_\_\_\_

\*Please note, this form is valid for all entities and providers comprising Washington University Physicians.  
Electronic Communication Consent rev.11/2018



## Verbal Consent for Service Extension

The WITH U team provided participants with the opportunity for extended health coach services past the 6-month intervention period to provide additional support services to participants due to stressors incurred by the COVID-19 pandemic. At a participant's last appointment, the HN assessed if the participant needed additional health coaching services throughout the COVID-19 crisis and then used the following script to obtain consent.

### PHONE SCRIPT FOR CONSENT TO EXTEND SERVICE TIMELINE

**Project Title: WITH U: A Special Project of National Significance on Implementation of Evidence-Informed Behavioral Health Models to Improve HIV Health Outcomes for Black Men who have Sex with Men**

Hello,

This is **[name]** from Washington University in St. Louis-School of Medicine. Because of the COVID-19 crisis, we have learned that it may benefit some participants in the WITH U study to continue to work with their health navigator to maintain the continuity of services and support beyond the originally planned six months of the study. I am contacting you about this opportunity to see if you felt that you could benefit from keeping up your contact with your health navigator.

Please feel free to ask questions at any time.

Would you be interested in continuing? By affirming that you would like to continue in the project, you are providing verbal consent for further health navigation activities.

**[If the individual states, "no"]**

Thank you for your time and consideration. We will follow-up with you about next steps and your completion of the program as you had previously agreed. **[End the call]**

**-OR-**

**[If the individual states, "yes"]**

Thank you. Your health navigator will continue to work with you beyond the original six months of program.





# Electronic Communication and Privacy

## Standard Operating Procedure – Medical Case Management Guidelines

### WUSM Ryan White Part C/D Standard Operating Procedure

<b>Title:</b>	<b>Direct Service Staff Texting Guidelines</b>
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#### **Purpose:**

To provide guidance to direct service staff regarding utilizing SMS text messaging for client outreach and retention purposes.

#### **Background:**

Ryan White Medical Case Managers (MCM) regularly provide intensive outreach services to clients, including appointment scheduling, follow up on missed appointments, reminders of benefit enrollment deadlines, and other outreach as necessary. The goal of this outreach is to link and retain clients in medical care.

Some clients respond via text that would normally not respond to voice calls. Many clients do not retrieve their voicemail messages and would prefer an informative text message. We believe that texting is an efficient and effective way to reach many clients.

MCM will implement texting to expand their outreach capabilities. MCM will use texting to reach clients who prefer this mode of communication. Targeted groups that may benefit the most from this expanded outreach service include: hearing impaired clients, clients under 30, and clients who have insufficient voice plans, and clients who specifically enroll in text messaging projects.

#### **Procedure:**

To ensure HIPAA compliance and client data safety, the following requirements will be followed:

- An agency issued smartphone with built-in encryption must be used for texting.
- The smartphone must have the built-in encryption enabled by IT at WUSM and a passcode. Passcodes for all MCM cell phones will be the same.
- The smartphone must have Mobile Device Management (MDM) software installed by Department of Medicine IS staff. This will enforce a PIN on the phone and will enable remote wiping of the phone in case it is lost or stolen.
- Prior to using the texting function with a client, the MCM must obtain explicit, in-person, consent from the client indicating they agree to receive text messages.
  - The MCM must document client consent in SCOUT and upload the signed consent form to the documents module using the header “Email/Text Consent – 1ECONSENT.”



- If a client consents to receive automated text messages from Epharmix, the MCM must document client consent in SCOUT and upload the signed authorization to the documents module using the header “Project ARK - Automated Text Consent – PARKTEXTC.”
- Case Managers must document text message encounters with clients in SCOUT.
- If the smartphone is lost or stolen, the MCM must report the loss immediately to their supervisor and the Information Security Office.
- Leave your phone at work in a locked drawer.
  - There will be times when you are at a home visit or offsite and will not return to the office before going home. This is understandable. If you take the phone home, turn off your phone.
  - Extra keys for locked drawers will be kept in a key binder with the case management supervisor, so cell phones can be accessed if a MCM is unexpectedly out of the office and the cell phone is covered by another MCM.
- Respond to texts only during your normal work hours.
  - The maximum amount of time to respond to a text is by the end of the next business day.
  - A minimum of one text per month should be made to all active clients on the MCM caseload.
- Full client names should not be stored in the phone’s contacts/address book – use first name and last initial. If you have multiple clients with the same first name and last initial, then expand into the second letter of the last name (ex: David Bo for David Bowie).
- Coverage while out
  - The MCM that covers the caseload will also cover the cell phone. Please remember to give your cell phone to the person that is covering for you prior to leaving.
- Text messages should not include sensitive information including:
  - Client full name
  - Client date of birth
  - Client medical record number
  - Client social security number
  - Client address
  - Client diagnosis
  - Any data element that speaks to a client’s medical condition
  - The name of any medications.
  - The name of any HIV-specific location of medical clinic where client receives care (ex. cannot say Project ARK, EFA, or other agencies with specific diagnosis in name).
- Text messages should not include sensitive information, such as information that would disclose that the client is HIV positive. Use “white label” information instead (examples: medication/meds vs. complera, CD vs. CD4, VL vs. Viral Load)
- Only text your client, do not text family members or partners.



- NEVER send a group text
- Staff will not store protected client information or documents on the smartphone:
  - Text Messages must be deleted from phone after 1 week max
  - Pictures deleted from phones after 24 hours max
- Clients may NOT text documents (can email securely to wustl email account)
- To save pictures from staff phone, must be sent wustl email to wustl email [SECURE] (no texting to self)
- MCM or Washington University staff may send a client community referral information in a text message as long as the referral is not HIV-specific or may identify the health care diagnosis of a client.
- Crisis Mental Health Event
  - Follow the internal protocol for Mental Health High-Risk
    - Call the client, stop texting
    - Keep the client on the phone while alerting another staff member to call 911 and contact a staff MH Specialist.
      - The 911 call should include all pertinent information and a request to the 911 dispatcher to have the responding officer call staff back with a disposition.
      - Contact Behavioral Health Specialist at 314-747-2717; pgr 314-469-6644; or by email
      - An alphanumeric page can be sent from a computer to multiple MH Specialists at once by emailing [pager#]@myairmail.com – include the details (who/what/where) about the crisis and “911” in the page so the MH Specialist knows it is an urgent situation.
- Outgoing voicemail greeting should include the following information:
  - Staff name
  - This phone is only checked during business hours.
  - If this is a medical emergency, please contact 911.
  - If this is an urgent mental health crisis, please contact the BHR at 314-469-4908
  - If this is during business hours and you wish to speak with me please call [insert phone number for desk at MCM office location].



## Privacy Safety Assessment

As a result of discussions with Washington University's privacy office, Project ARK identified a need to educate participants who participate in programs or services that utilize text messaging on the real-life risks of text messaging. To assess a participant's understanding of the risks of receiving and sending text messages with their care providers, as part of a previous SPNS Initiative, the Project ARK team adopted a Safety Appraisal which was adapted with permission from materials out of the Center for Innovative Public Health Research and was also used during this SPNS Initiative.

### WITH U (SPNS): Privacy Safety Assessment

(Adapted from "GUY2GUY PHASE FOUR RANDOMIZED CONTROLLED TRIAL: SAFETY APPRAISAL QUESTIONS." Center for Innovative Public Health Research | [innovativepublichealth.org](http://innovativepublichealth.org))

Objective: Ensure that candidate understands and can evaluate their personal safety if someone finds messages on their phone, the computer, or overhears conversations with staff. This document is intended to serve as a guide, as the discussion will be dynamic based on candidate responses.

#### Sample Discussion:

- **[Texting]** *"We might send text messages about some sensitive stuff – like coming to clinic, reminding you to take medications, and how you are feeling. If someone saw these messages, like a partner, friend or family member, it may give them information you did not want to share. For some people, it might actually put them in danger. The person reading the text messages might ask questions, get angry or lash out physically or saying mean things."*
- **[Phone or teleconference]** *"Additionally, when you talk with your health navigator by phone or teleconference, they might discuss that same sensitive stuff. If someone overheard this conversation it may give them information you did not want to share. For some people, it might actually put them in danger. The person overhearing might ask questions, get angry or lash out physically or saying mean things."*
- *The goal of this project is to give you a tool to have the best health possible. We don't want to put anyone in danger. If you think this could be unsafe for you if someone were to read these messages, it's really important to think about it before you to agree to join the program."*
- *What do you think about the possibility of someone else (friend, partner, parent, etc) seeing messages about your healthcare? Overhearing discussions about your healthcare?*
- *What would happen if someone (friend, partner, parent, etc) saw these kinds of messages (how are you feeling today, reminders for appointments, medication reminders, discussions with your case manager)? Overheard these discussions?*



If seems **unsafe**:

- *It seems like texting with members of your healthcare team may not be a safe decision for you. If it helps, we can talk you through ways to make your phone more safe such as making sure your phone is password protected. Even with this step, someone may guess your password or demand that you give them the password. Your safety is important to me. What do you think?"*

If participant **agrees it's unsafe**:

- *"Ok. Thank you for thinking about this project. If you would like to join at a later time when it feels more safe, just let me know."*

Additional Questions for Processing:

- Who has access to your phone – who can read your messages?
- Do you have the ability to read your text messages in a private space?
- Is your phone password protected?
  - How often do you change your password?
  - Do you need help learning how to put a password protection on your phone?
- Email Apps – there are Apps that can be downloaded that can give someone else access to your text messages. Sometimes partners, parents, or friends have been known to do this.
  - Do you know what app to look for on your phone to see if this has been downloaded?
- Push Notifications – some phones have the ability to send you a preview of your email or text message without opening up your email or text message box.
  - Do you know how to turn this off? Do you need help learning how to do this?

Resource for Helpful Technical Tips:

- <http://sms.projectg2g.com/technical-guides/>

References:

- Ybarra, M. L., Prescott, T. L., Philips, G. L., 2nd, Bull, S. S., Parsons, J. T., & Mustanski, B. (2015). Iteratively Developing an mHealth HIV Prevention Program for Sexual Minority Adolescent Men. *AIDS and Behavior, In Press*. doi:10.1007/s10461-015-1146-3
- Ybarra, M. L., Prescott, T. L., Phillips, G. L., 2nd, Parsons, J. T., Bull, S. S., & Mustanski, B. (2016). Ethical Considerations in Recruiting Online and Implementing a Text Messaging-Based HIV Prevention Program With Gay, Bisexual, and Queer Adolescent Males. *Journal of Adolescent Health, 59*(1), 44-49. doi:10.1016/j.jadohealth.2016.03.020



## Health Navigator Position-Specific Documents

### Job Description: Health Navigator

WASHINGTON UNIVERSITY SCHOOL OF MEDICINE  
JOB DESCRIPTION

**JOB TITLE:** Community Outreach Rep I

**REVIEWED:** Oct 2016

**INCUMBENT:**

**POSITION REPORTS TO:** Director of Pediatric and Peer Services

**DEPARTMENT:** Pediatrics

**JOB CODE:** J1610

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**POSITION SUMMARY:** The position will serve in the role as a “Peer Advocate” which provide intensive home and community-based navigation interventions to support linkage and retention of clients in healthcare. Peer Advocates will assist in outreaching to clients lost to care and support engagement, support clients in achieving optimum health outcomes through the identification and removal of barriers, conduct orientation to medical services, accompany to appointments (as needed), provide education, offer emotional support and linkage to support services and system, address language and cultural barriers and assist the team with screening for co-morbidities which can impact access and retention in care.

This position will also function in a project coordinator role within the Peer Advocate services coordinating daily activities necessary to implement a specific prevention project. The position is responsible for identifying individuals and facilitating focus groups and individual sessions to address barriers to care. This information will be used in marketing materials aimed at engaging and re-engaging HIV positive individuals in care.

#### **PRINCIPLE DUTIES & RESPONSIBILITIES:**

##### **Essential Functions:**

Act as a member of the multidisciplinary Care Navigation Team to address the needs of clients while maintaining the confidentiality and privacy of clients by engaging in the following responsibilities:

1. Provide support to referred clients by assisting with navigation of medical appointments, orientation to care system/services, peer support and collaborating on addressing the needs identified in the joint service care plan.
2. Participate as a member of the multidisciplinary team weekly staffing to represent
3. Work with the Community Nurse to monitor kept medical appointments and CD4 counts quarterly to review each client’s adherence
4. Help remove barriers to attending medical appointments by referring to appropriate professionals as needed such as mental health services, case management, substance abuse treatment, coordination of transportation, and participation in retention activities. Conduct home visits as appropriate to execute plan of care for clients.



5. Maintain and complete required documentation for the client record for each care plan & intervention completed.
6. Complete trainings in the delivery of strength-based care and complete required orientation.

**Coordinator Functions:**

1. Facilitate focus groups and individual surveys with current and former lost to care clients to identify barriers to becoming engaged or re-engaged in care. This information will be used to develop marketing materials and opportunities to reach out to HIV positive individuals in the community.
2. Facilitate monthly regional peer meeting with peers from Washington University as well as AIDS service organization in MO and IL.
3. Coordination of the LIFE program, a six to eight week HIV 101 and HIV 102 educational session for clients. This position will help coordinate the sessions and facilitate when possible.

**MINIMUM EDUCATION & EXPERIENCE:**

Bachelor's degree or equivalent (i.e., Associate Degree plus 2 years of HIV/AIDS and/or other community outreach/education leadership experience; or HIV/AIDS and/or other community outreach/education leadership experience; 5-plus years of experience will also be considered); Master of Science degree is preferred

**PREFERRED QUALIFICATIONS:**

- Background and/or willingness to work with persons living with HIV/AIDS
- Strong verbal communication skills
- Reliable transportation
- Have knowledge and sensitivity about the needs / issues of various subpopulations such as families, young women with children, LGBT and persons living with HIV/AIDS
- Effective Organization Skills

**RELATIONSHIPS:**

Develop aligning relationships with Internal/external contacts.

***Maintain HIPAA Compliance***

**SUPERVISION:** None

**NUMERICAL DIMENSIONS:** None.

**The above statements are intended to describe the general nature and level of work performed by people assigned to this classification. They are not to be construed as an exhaustive list of all job duties performed by the personnel so classified.**

4/30/09



## Training Protocol: Health Navigator

### SPNS BMSM: Peer Health Navigator Training Protocol Washington University School of Medicine

Training	Description	Frequency	Provided by
<b>Peer Navigation Training</b>			
People to People	HIV 101 & lifecycle, medication/treatment, mental health, substance abuse and knowing the signs, resolving conflict, boundaries, role playing, self-care	Once	KC Care
Peer Navigation Training	Peer navigation, burnout, self-care, trauma-informed care	Once	Matthew Bennett, MBA, MA
Being a peer	Learning the ins and outs of being a peer	On-going	Mentoring
<b>HIV-Specific Trainings</b>			
MATEC Modules	*See below for listing of modules	On-going	MATEC on-line
<b>Human Research Trainings</b>			
CITI Training	Foundational training in human subjects research, including the historical development of human subject protections, ethical issues, and current regulatory and guidance information	Once	Internal- Wash U
HIPAA	HIPAA laws and privacy practices	Once	Internal- Wash U
Good Clinical Practice	Basic and refresher courses that provide essential good clinical practice training for research teams involved in behavioral intervention and social science research studies	Once	Internal- Wash U
<b>Position-Specific Training</b>			
Motivational Interviewing	Intro and practical applications	Two sessions	TBD
Youth Mental Health First Aid	Training teaches participants how to provide initial help to young people experiencing depression, anxiety, psychosis and substance abuse disorders	Once	NCADA
Administering and Interpreting Screening Tools	Mental Health and Substance Abuse	Once	Internal – Wash U
Programmatic Training	Program specific training about the research project procedures and practices	On-going	Health Navigation Supervisor
In it together Health Literacy Project	Helps professionals incorporate health literacy approaches into their services	One time on-line	On-line
Case Conferencing	Training on effective case conferencing	On-going	Health Navigation Supervisor
Goal Setting	Training on goal setting with clients	On-going	Health Navigation Supervisor
<b>New Hire Training</b>			
Agency Orientation	Orientation of the agency and campus	Once	Health Navigation Supervisor
Project ARK Code of Conduct	Training on the Code of Conduct	Once	Health Navigation Supervisor
Documentation	Training on Scout, EPIC, note taking	On-going	Health Navigation Supervisor
Safety on the job	How to stay safe at the job and in the field	Once	Wash U Security





Training	Description	Frequency	Provided by
Ethics	Training teaches participants about ethical decision making principles and practices.	Once	NCADA
Team Dynamics		As Needed	Health Navigation Supervisor
Cultural Competency		On-going	Internal – Wash U
<b>Optional Training</b>			
Building Blocks to Peer Success	A toolkit developed to assist trainers and program directors in planning a peer training program for HIV-positive peers.		Boston University School of Social Work

\* Midwest AIDS Training + Education Center (MATEC) Modules

<b>History of HIV in America</b>
<b>Introduction to HIV</b>
<b>HIV Viral Lifecycle</b>
<b>HIV Drug Resistance</b>
<b>HIV and Women - (optional)</b>
<b>Substance Use Disorders and HIV</b>
<b>HIV and Viral Hepatitis - (optional)</b>
<b>Community Safety for Case Managers</b>
<b>Introduction to Clinical Trials - (optional)</b>
<b>Common Opportunistic Infections and HIV</b>
<b>HIV and Inflammation - (optional)</b>
<b>Long-Term Effects of HIV Treatment</b>
<b>Introduction to HIV Testing - (optional)</b>
<b>HIV and Prevention with Positives</b>
<b>PrEP: The Changing Landscape of HIV Prevention - (optional)</b>
<b>Sexually Transmitted Infections and People Living with HIV</b>
<b>How to Take a Sexual Health History - (optional)</b>
<b>Understanding U=U</b>
<b>HIV and Cultural Diversity</b>
<b>Health Literacy in HIV Care</b>
<b>HIV and Young People</b>
<b>Cultural Health Beliefs in 3 Foreign-Borne Immigrant Populations - (optional)</b>
<b>Sexual Health and HIV - (optional)</b>
<b>Sex, Stigma and Systems: Issues in HIV Among Young MSM</b>
<b>HIV and Aging - (optional)</b>
<b>HIV and Mental Health</b>
<b>HIV and Trauma</b>
<b>Transgender Care - (optional)</b>
<b>Sex Trafficking and HIV - (optional)</b>
<b>Conflict and Crisis Management in HIV Care</b>
<b>HIV &amp; Tobacco Cessation - (optional)</b>



## Clinician Information Flyer



**WITH U**

### HEY – WHAT’S WITH U?

WITH U is a Washington University demonstration project that provides intensive peer-based health navigation to improve HIV health outcomes and link to mental wellness services.

Participants are in the program for 6 months, consisting of 12 sessions (8 weekly and 4 monthly).

Enrolled clients receive mental wellness screenings from the WITHU team at enrollment, 6-months post-enrollment and 12-month post enrollment.

**Question:** I am a provider and received a telephone encounter about a client enrolled in the WITHU program with mental wellness screening scores. What do I do?

**Answer:** Nothing immediately. The scores are provided to you as a courtesy to update providers on client’s mental wellness. Feel free to case conference with the client’s team (client, case manager, health navigator, mental wellness specialist) for more information.

### Enrollment and Positive Screening Process:

- 1) The WITHU Team will document the enrollment as a telephone encounter and route ALL members of the care team to the encounter.
- 2) The encounter will include the mental wellness screening outcomes/scores.
- 3) The WITHU team will make a referral in EPIC for Mental Wellness Services with Stacey Higgins if a client receives positive score.
- 4) Referrals are triggered beginning at the moderate/mild risk level for any one positive screen.
- 5) Thresholds for a referral are listed on the chart below:

Screening Tool	Purpose of Tool	Threshold for Referral	Risk
CRAFFT	Substance Use/Abuse	2+	Moderate/High Risk
GAD-7	Anxiety	10+	Moderate Anxiety
PHQ-9	Depression	10+	Mild Major Depression
PCL-C	Trauma	4	Trauma Identified



# Participant Session Forms

## Participant Intake Form

### Intake Form

**Preferred Name:**

Type something

**Pronoun:**

**If other**

Type something

**Contact Information**

**Phone Number:**

Type something

**Is it okay to leave a voicemail?**

Yes

No

**Email:**

Type something

**Social Media:**

Type something

**Best days and times to meet:**

Type something

**Preferred Contact Method for:**

**Scheduling and General Communication**

Phone Call

Text

Email

Healthie Message

**Meetings**

In Person

Phone Call

Text

Video/Tele-meeting

**If we can't reach you, what is an alternate contact?**

Email

Social

Other

**Please add selected contact info**

Type something

**Care Team Information**

**Case Manager:**

Type something

**Doctor:**

Type something

**Mental Wellness Counselor:**

Type something

**Other:**

Type something



What do you hope to get out of WITH U?

**B** *I* U A      

What do you want to work on together?

**B** *I* U A      

Have you worked with a health coach, peer, or mental wellness provider before?

Type something

Do you have any upcoming plans where you will not be available to meet with me? If so, when?

Type something



## End of Session Form

### Session Status (Check outcome of the session)\*

Kept

No Show

Rescheduled

Cancelled

### Modality

In-Person

Phone Call

Text Message

Telehealth

Email

Healthie Messaging

### Notes from the Session

**B** *I* U A **A**      

### Mental Wellness Check-In:

#### Mental Wellness Check-In:

Mental Wellness not discussed

Client introduced to Mental Wellness Services

Client referred to Mental Wellness Specialist

Client engaged (follow up on Appt and next visit) – kept @ least 1 Mental Wellness appt.

Checked on Mental Wellness engagement (Did client access services)?



**Goal Work this Session: (more than one goal can be worked on for each session):**

Yes

No

**Goal Identified**

Education

Support

Navigation

**Goal Attained**

Education

Support

Navigation

**Goal Check-in**

Education

Support

Navigation



**Goal Abandoned**

Education

Support

Navigation

**Topics covered in Session:**

**Education (HN driven)**

**HIV and treatment**

HIV 101

How HIV impacts the body

HIV Treatment/Role of HIV Medications

Understanding Lab Values

**Prevention**

Safer Sex

Safer Drug Use

U=U

PrEP

Provided condoms



### Adherence/Engagement

Medication

Clinical Care

Mental Wellness

WITH U Program

### Support (Client driven)

#### Support

Encouragement

Stress Management (personal crisis – getting back to baseline)

Emotional support (active listening, validation, using MI – e.g. disclosure)

Empowerment

Build Rapport/Therapeutic Alliance

Disclosure





**Navigation (HN on behalf of or with client)**

**Navigation of Clinical Care**

- Medical care
- Pharmacy
- Dental
- Specialty care
- Psychiatry
- Nutrition Consult
- Other

**If other:**

**Navigation of Behavioral Health**

- Mental Wellness
- Substance Use/Abuse
- BHR/Crisis hotline
- Support Group Linkage

**Navigation of Social Services**

- Food
- Housing
- Utilities



Transportation

Insurance

Employment Assistance

GED/Continuing Education

Toiletries, clothes or other necessities for daily living

Other

**If other:**

Type something



## Session One: End of Session Worksheet Template

<b>Session Date Range:</b>			
<b>Date of Session:</b>		<b>Time:</b>	
<b>Status:</b> <input type="checkbox"/> Kept Appt. <input type="checkbox"/> No Showed <input type="checkbox"/> Rescheduled <input type="checkbox"/> Cancelled	<b>Session Mode:</b> <input type="checkbox"/> In Person <input type="checkbox"/> Over the Phone <input type="checkbox"/> Text Message <input type="checkbox"/> Telehealth/Healthie	<b>Mental Wellness Check-In:</b> <input type="checkbox"/> Client introduced to MW services <input type="checkbox"/> Client referred -Checked on referral <input type="checkbox"/> Scheduled MW referral with client <input type="checkbox"/> Client engaged in MW services	
<b>Client SMART Goals:</b> (Specific, Measurable, Achievable, Realistic, Timely)			
Example	<b>Goal:</b> <b>S:</b> Who, what, when, where? <b>M:</b> How to track progress? <b>A:</b> How will this happen? <b>R:</b> Is this worthwhile? <b>T:</b> When is the deadline?	<b>Bucket:</b> <input type="checkbox"/> Education <input type="checkbox"/> Support <input type="checkbox"/> Navigation	<b>Status:</b> <input type="checkbox"/> Identified <input type="checkbox"/> Check-In <input type="checkbox"/> Goal Attained <input type="checkbox"/> Abandoned
Goal 1	<b>Goal:</b>  <b>S:</b> <b>M:</b> <b>A:</b> <b>R:</b> <b>T:</b>	<b>Bucket:</b> <input type="checkbox"/> Education <input type="checkbox"/> Support <input type="checkbox"/> Navigation	<b>Status:</b> <input type="checkbox"/> Identified <input type="checkbox"/> Check-In <input type="checkbox"/> Goal Attained <input type="checkbox"/> Abandoned
Goal 2	<b>Goal:</b>  <b>S:</b> <b>M:</b> <b>A:</b> <b>R:</b> <b>T:</b>	<b>Bucket:</b> <input type="checkbox"/> Education <input type="checkbox"/> Support <input type="checkbox"/> Navigation	<b>Status:</b> <input type="checkbox"/> Identified <input type="checkbox"/> Check-In <input type="checkbox"/> Goal Attained <input type="checkbox"/> Abandoned
Goal 3	<b>Goal:</b>  <b>S:</b> <b>M:</b> <b>A:</b> <b>R:</b> <b>T:</b>	<b>Bucket:</b> <input type="checkbox"/> Education <input type="checkbox"/> Support <input type="checkbox"/> Navigation	<b>Status:</b> <input type="checkbox"/> Identified <input type="checkbox"/> Check-In <input type="checkbox"/> Goal Attained <input type="checkbox"/> Abandoned



## Topics Covered in Session

### Category 1: Education

**HIV and Treatment:**

- HIV 101/Life Cycle
- How the body works
- How HIV works
- How medications work
- Understanding Lab Values

**Prevention:**

- Safer Sex
- Safer Drug Use
- U=U
- PrEP

**Adherence:**

- Medication
- Clinical Care
- Mental Wellness

### Category 2: Support

- Encouragement
- Empowerment
- Stress Management
- Emotional Support
- Disclosure

### Category 3: Navigation

**Clinical Care:**

- Medical Care
- Pharmacy
- Dental
- Specialty Care
- Other: \_\_\_\_\_

**Behavioral Health:**

- Mental Health
- Substance Use/Abuse
- BHR/Crisis Hotline

**Social Services:**

- Food
- Housing
- Utilities
- Transportation
- Insurance
- Other: \_\_\_\_\_

### Notes from Session:

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# Weekly Case Conferencing Notes Template



## WITH U Weekly Case Conferencing Meeting Health Navigator Notes

<b>Date:</b>		<b>Client:</b>		
<b>Staff Present:</b>				
<b>Health Navigators:</b> <input type="checkbox"/> <input type="checkbox"/>	<b>Mental Wellness:</b> <input type="checkbox"/> <input type="checkbox"/>	<b>Providers: (List)</b> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>		
<b>Linkage to Care Team:</b> <input type="checkbox"/>  <b>Lost to Care Team:</b> <input type="checkbox"/>  <b>Perinatal Team:</b> <input type="checkbox"/>	<b>Youth Team:</b> <input type="checkbox"/>	<b>Adult Team:</b> <input type="checkbox"/>	<b>Lead Staff:</b> <input type="checkbox"/>	<b>Outside Agency Staff (List):</b> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
<b>Presenting Issue(s):</b>  1.  2.  3.  4.				
<b>Action Steps:</b>		<b>Staff Responsible:</b>	<b>Goal Date:</b>	
1.				
2.				
3.				
4.				



# COVID-19 Modification Protocols

## Enrollment Protocol



### COVID Enrollment Process: The SPOT

The SPNS WITH U program will begin recruitment process in June 24, 2020 and will continue until December 31, 2020. Recruitment will begin at the SPOT while clinical services in other areas are still operating with limited services due to COVID.

#### **Return to Work Process:**

1. SPNS team members responsible for recruitment activities will be responsible for completing return to work duties before returning to campus.
  - Complete Learn@Work return to work module
  - Bring a clean mask each day and wear while in the building. See Kelly Righton if a new mask is needed.
  - Complete WU Screening tool and follow all instructions ([screening.wustl.edu](https://screening.wustl.edu)) for each day returning to work.
  - Staff will contact Kelly Righton via email or phone to review return to work prior to the first recruitment day at the SPOT.

#### **Mondays Prior to Weekly MAC Clinic:**

1. SPNS team will screen for eligibility before the start of each Wednesday clinic.
2. Team will discuss eligibility with Health Navigation staff during weekly Monday staff meeting.
3. Health Navigators will be on-call Wednesday afternoons if a client agrees to enrollment in WITH U program.
4. Staff to discuss eligible clients with PI before the start of clinic (either via email or by participation in staff huddle before clinic).

#### **Recruitment Process at the SPOT:**

1. Before staff attends clinic session, staff member will complete the WU Screening and send results of screening to their immediate supervisor and nurse at the SPOT.
2. Staff member will consult with team on when to approach client about WITH U program.
3. Staff member will wash hands and wear mask into the clinic room to meet with client.
4. Staff member will discuss the WITH U program and gauge client's interest. If client is interested and able to complete enrollment after scheduled clinic appointment.
5. Staff member will briefly review consent form and ask client to complete consent form. Client will read and review consent form before signing.
6. Staff member will have client sign Consent to Text/Email form at the same time client signs consent form.



### **Enrollment Process at the SPOT:**

1. If client is able to complete on-site enrollment, staff and client will complete enrollment in the drop-in space immediately following client's medical appointment. Staff will maintain a distance of six-feet during enrollment session.
2. Staff member will complete Safety Screener with client prior to enrollment.
3. Staff member will have client sign all forms prior to completion of Patient Survey:
  - Permission to Text/Email Form
  - Gift Card Receipt
4. Staff member will set up Healthie account for client and review.
5. Staff member and client will complete Patient Survey. Staff member will send link to Qualtrics survey via email to client to complete on client's personal device.
6. Staff member will assign client to work with Health Navigator and will text HN to complete Zoom call with client for introduction.
7. Staff member will introduce Mental Wellness services as part of the WITH U Program and inform client they may receive call from Mental Wellness Specialist for introduction of services. Staff will show client Digital Business Card.
8. Staff will provide client with gift card after the completion of Patient Survey.
9. Staff will document enrollment in Access Database, EPIC and Scout.
10. Signed documents will be stored in a locked file cabinet at the SPOT.
11. Staff member will wipe down surfaces in drop-in space, wash hands, and prepare for potential next enrollment.

### **Enrollment Process via Zoom:**

1. If client is unable to complete on-site enrollment, but would like to join WITH U program, staff and client will schedule a time to complete enrollment at a later date via Zoom.
2. Client must sign consent form and permission to email/text form before leaving clinic appointment before proceeding to enroll at a later date on Zoom.
3. Staff member will set-up Zoom call and invite Health Navigator and Mental Wellness Specialist to meet client virtually and introduce services. If Mental Wellness Specialist is not available to meet, staff will show Digital Business Card to introduce specialist and services.
4. Staff member will set-up a Healthie account for client, provide program overview, and complete Patient Survey with client. Patient survey can be accessed by posting Qualtrics link in "Chat" on Zoom or by directly emailing link to survey to client.
5. If client experiences challenges to accessing survey, staff member will complete survey over the phone and read survey to client.
6. Upon completion of Patient Survey, staff member will email client an electronic gift card for successful enrollment in program.
7. At the end of enrollment, HN and client may meet and complete first session together.
8. Staff will document enrollment in Access Database, EPIC and Scout.
9. Signed documents will be stored in a locked file cabinet at the SPOT.



## Evaluation Tools

Eligibility Screening Survey

# **Black Men who have Sex with Men Initiative: Eligibility Screening Questionnaire**

**Implementation of Evidence-Informed Behavioral Health Models to Improve HIV  
Health Outcomes for Black Men who have Sex with Men Initiative  
Special Projects of National Significance (SPNS)  
U.S. Health Resources & Services Administration (HRSA)**

**Multisite Evaluation Data Collection Instrument**

**August 2019**





## BMSM-ELIGIBILITY SCREENING QUESTIONNAIRE

Date: RECORDED

Time: RECORDED

Participant ID: RECORDED<sup>i</sup>

Site ID: RECORDED

### A. INTRODUCTION

- Thank you for agreeing to complete this screening tool for the WITH U research study. The questions included in this screener will be used to determine which clients are eligible to participate in the Initiative and multisite evaluation (MSE).
- Answers to screener questions will be kept strictly confidential. These data are protected by law from disclosure to outside organizations and agencies that are not involved with this study.
- This survey will take you about 10 minutes. Not all response options may apply to you, but please choose the best answer to each question. Also, if there are any questions you don't feel comfortable answering, you don't have to answer them. Your participation is voluntary.
- If you have any questions about the survey, please ask a study staff member.

### B. PATIENT DEMOGRAPHICS

We have a few questions about you that will help us determine whether you are eligible to participate in this study.

1. Have you ever been told by a doctor, nurse, or other health professional that you have HIV?<sup>ii</sup> **[HIV STATUS]**
  - a. Yes
  - b. No - **INELIGIBLE**
  - c. Don't know - **INELIGIBLE**
  - d. Decline to answer - **INELIGIBLE**
2. How old are you?<sup>iii</sup> **[AGE]**
  - a. (please specify): \_\_\_\_\_
  - b. Don't know - **INELIGIBLE**
  - c. Decline to answer - **INELIGIBLE**
3. What category best describes your race? [mark all that apply]<sup>iv</sup> **[RACE]** – **Any of these unless also marking “c” are INELIGIBLE**
  - a. American Indian/Alaska Native
  - b. Asian
  - c. Black or African American
  - d. Native Hawaiian/other Pacific Islander
  - e. White
  - f. Some other race
  - g. Don't know
  - h. Decline to answer



4. Are you of Hispanic, Latino, or Spanish origin?<sup>v</sup> **(ETHNICITY)**
- No, not of Hispanic, Latino, or Spanish origin
  - Yes, Mexican, Mexican American, Chicano
  - Yes, Puerto Rican
  - Yes, Cuban
  - Yes, another Hispanic, Latino, or Spanish origin
  - Don't know
  - Decline to answer
5. Thinking about your sexual partners in the past five years, were these partners:<sup>vi</sup> **(SEXUAL BEHAVIOR)**
- All men
  - All women - **INELIGIBLE**
  - Both men and women
  - Don't know - **INELIGIBLE**
  - Decline to answer - **INELIGIBLE**
6. Do you think of yourself as:<sup>vii</sup> **(GENDER)**
- Male
  - Female - **INELIGIBLE**
  - Transgender man/trans man/female-to-male (FTM)
  - Transgender woman/trans woman/male-to-female (MTF) - **INELIGIBLE**
  - Genderqueer/gender non-conforming/neither exclusively male or female
  - Additional gender category (please specify): \_\_\_\_\_
  - Don't know
  - Decline to answer - **INELIGIBLE**
7. What sex was originally listed on your birth certificate?<sup>viii</sup> **(SEX)**
- Male
  - Female – **INELIGIBLE unless answer to Q6 is “a” or “c”**
  - Don't know – **INELIGIBLE**
  - Decline to answer – **INELIGIBLE**

### C. ENGAGED IN CARE

8. In the past 12 months, have you had two or more HIV medical care appointments at least 90 days apart?<sup>ix</sup> **(RETAINED IN CARE)**
- Yes
  - No
  - Don't know
  - Decline to answer
9. Has your viral load been undetectable over the past 12 months?<sup>x</sup> **(VIRALLY SUPPRESSED)**
- Yes (Undetectable = < 200 copies/mL at last test)
  - No (Detectable = > 200 copies/mL at last test)
  - Don't know
  - Decline to answer

[FOR RECRUITER: A client is defined as “engaged in care” based on their responses to questions in Section C. A person would be considered engaged if he responded **Yes** to Q8 and **Yes** to Q9.]



#### D. AT RISK OF FALLING OUT OF CARE

[FOR RECRUITER: Clients who are engaged in care are not immediately ineligible. If they are **at risk of falling out of care** (based on a positive response to one or more questions in Section D), those clients would still be eligible to participate in the Initiative and study.

Please ask all of the questions below to assess if the respondent is **at risk of falling out of care** and thus **eligible** for the Initiative and study.

If a client is **engaged in care** and does not have any positive responses to the questions in Section D (meaning he is not at risk of falling out of care), he is **INELIGIBLE**.]

10a. Have you been released from jail or prison within the last 12 months?<sup>xi</sup> **RECENT INCARCERATION**

- a. Yes - **ELIGIBLE in this category**
- b. No
- c. Don't know
- d. Decline to answer

10b. Have you been unemployed for at least three months within the last 12 months?<sup>xii</sup> **EMPLOYMENT INSTABILITY**

- a. Yes - **ELIGIBLE in this category**
- b. No
- c. Don't know
- d. Decline to answer

10c. In the past 12 months, have you spent the night: [mark all that apply]<sup>xiii</sup> **HOUSING INSTABILITY**

- a. In a house/apartment that I own or rent
- b. In a hotel
- c. In a homeless shelter or transitional shelter - **ELIGIBLE in this category**
- d. On the street or other outdoor public place - **ELIGIBLE in this category**
- e. In an abandoned building - **ELIGIBLE in this category**
- f. In a car or other vehicle - **ELIGIBLE in this category**
- g. At a friend's or family member's on a temporary basis - **ELIGIBLE in this category**
- h. In a sober living or recovery program or drug treatment program - **ELIGIBLE in this category**
- i. In jail or prison - **ELIGIBLE in this category**
- j. Other (please specify): \_\_\_\_\_ - **ELIGIBLE in this category**

10d. During the past 12 months, has a doctor or nurse told you that you had a sexually transmitted infection, or STI, for example: herpes, gonorrhea, chlamydia, or genital warts?<sup>xiv</sup> **HISTORY OF STIs**

- a. Yes – **ELIGIBLE in this category**
- b. No
- c. Don't know
- d. Decline to answer

10e. In the last two weeks, how often have you been bothered by the following problems?<sup>xv</sup> **HISTORY OF ONGOING BEHAVIORAL HEALTH ISSUES**

- a. Little interest or pleasure in doing things.
  - 1. Not at all (+0)
  - 2. Several days (+1)
  - 3. More than half the days (+2)
  - 4. Nearly every day (+3)
- b. Feeling down, depressed, or hopeless.
  - 1. Not at all (+0)
  - 2. Several days (+1)



3. More than half the days (+2)
4. Nearly every day (+3)

[FOR RECRUITER: Client is **ELIGIBLE in this category** if he has a combined score of 3 or higher].

- 10f. How many times in the last year have you had five or more drinks in a day?<sup>xvi</sup> **(HISTORY OF SUBSTANCE USE)**
- a. 0 times
  - b. 1 time - **ELIGIBLE in this category**
  - c. More than once - **ELIGIBLE in this category**
  - d. Don't know
  - e. Decline to answer
- 10g. In the last 12 months, did you smoke pot (marijuana), use another street drug, or use a prescription medication "recreationally" (just for the feeling, or using more than prescribed)?<sup>xvii</sup> **(HISTORY OF SUBSTANCE USE)**
- a. Yes - **ELIGIBLE in this category**
  - b. No
  - c. Don't know
  - d. Decline to answer
- 10h. In the last 12 months, have you had a bad experience with an HIV health care provider or with clinic staff? For example, this could be insensitive or hostile questions that make you uncomfortable.<sup>xviii</sup> **(POOR HEALTHCARE EXPERIENCE)**
- a. Yes - **ELIGIBLE in this category**
  - b. No
  - c. Don't know
  - d. Decline to answer

Thank you for taking the time to complete this screener.

[end of screener]



## Quantitative Survey – Local Questions



### Introduction

Thank you for agreeing to participate in this study. We will ask you questions about your HIV, the care you receive for your HIV, and information about sexual behaviors, drugs, and alcohol use. If a question makes you feel uncomfortable or brings up feelings you want to talk about, please contact please let a study staff member know and we can refer you to someone you can talk to.

**All of the information that you provide is strictly confidential and is protected by law from disclosure to outside organizations and agencies that are not involved with this study.** Your responses will be only used for research purposes and combined with other responses. No individual names will be reported.

This survey will take you about 25-30 minutes. Not all response options may apply to you, but please choose the best answer to each question. Also, if there are any questions you don't feel comfortable answering, you don't have to answer them. Your participation is voluntary. If you have any questions about the survey, please let a study staff member know. Before starting the survey, please read and answer the statement below.

### Consent Statement:

I have read the introduction. I understand that the information I provide will be kept private and used only for evaluation purposes. My responses will be combined with the responses of others. No individual names will be reported.

- I agree with the above statement and will complete the survey.
- I do not agree with the above statement and will not complete the survey.



## Your Experiences with Your Environment

**This section will ask you about your experiences with your environment, including your experiences with food, housing, utilities, and safety.**

Within the past 3 months, did you worry that your food would run out before you got money to buy more?

- Yes
- No

Within the past 3 months, did the food you bought just not last and you didn't have money to get more?

- Yes
- No

Are you worried about losing your housing?

- Yes
- No

Within the past 3 months, have you been unable to get utilities (heat, electricity) when it was really needed?

- Yes
- No

Do you feel physically and emotionally unsafe where you currently live?

- Yes
- No

Within the past 3 months, have you been hit, slapped, kicked or otherwise physically hurt by anyone?

- Yes
- No



Within the past 3 months, have you been humiliated or emotionally abused by anyone?

- Yes
- No

## Your Feelings About Living with HIV

This section will ask you about your feelings about living with HIV.

Please note that we are asking you to indicate the degree to which each item may be bothering you in your life, *NOT* whether the item is merely true for you. If you feel that a particular item is not a bother or a problem for you, you would answer “not a problem.” If it is very bothersome to you, you might answer “A very serious problem.”

During **the past month**, how big of a problem would you say feeling overwhelmed with the demands of living with HIV has been for you?

- Not a problem
- A slight problem
- A moderate problem
- A somewhat serious problem
- A serious problem
- A very serious problem

During **the past month**, how big of a problem would you say feeling that you are often failing with your HIV routine has been for you?

- Not a problem
- A slight problem
- A moderate problem
- A somewhat serious problem
- A serious problem
- A very serious problem



During **the past month**, how big of a problem would you say not feeling motivated to keep up your HIV self-management has been for you?

- Not a problem
- A slight problem
- A moderate problem
- A somewhat serious problem
- A serious problem
- A very serious problem

During **the past month**, how big of a problem would you say feeling angry, scared, and/or depressed when you think about living with HIV has been for you?

- Not a problem
- A slight problem
- A moderate problem
- A somewhat serious problem
- A serious problem
- A very serious problem

### **One Session?**

Have you had at least one session with your Health Navigator (Josh or Torezz)?

- Yes
- No

### **Your Feelings About Your Health Navigator**

**This section will ask you about your experiences and feelings about your Health Navigator (Josh or Torezz).**

Are you able to contact your Health Navigator when you need to?

- Never
- Sometimes
- Usually
- Almost Always





Has your Health Navigator adapted his/their approach to meet with your particular HIV management needs?

- Not at all
- A little
- A moderate amount
- A great deal

Has your Health Navigator helped you set specific goals to manage your HIV?

- Not at all
- A little
- A moderate amount
- A great deal

Has your Health Navigator helped you learn new skills to achieve your goals?

- Not at all
- A little
- A moderate amount
- A great deal

Has your Health Navigator helped you solve problems that arise in managing your HIV?

- Not at all
- A little
- A moderate amount
- A great deal

Has your Health Navigator helped you become more confident to manage your HIV?

- Not at all
- A little
- A moderate amount
- A great deal



Has your Health Navigator helped you get the care you need from HIV-specific doctors and nurses?

- Not at all
- A little
- A moderate amount
- A great deal

Has your Health Navigator helped you get the behavioral health care you need from counselors or psychiatrists?

- Not at all
- A little
- A moderate amount
- A great deal

Has your Health Navigator helped you find other resources in your community to help you take care of your HIV?

- Not at all
- A little
- A moderate amount
- A great deal

Has your Health Navigator helped you to communicate effectively with your doctor or nurse about your HIV?

- Not at all
- A little
- A moderate amount
- A great deal

Has your Health Navigator helped you to communicate effectively with your medical case manager?

- Not at all
- A little
- A moderate amount
- A great deal



## Weekly Sessions

**This section will ask you about your experiences and feelings for the WITH U sessions**

I preferred to complete my weekly WITH U sessions with Josh or Torezz using (choose all that you preferred):

- Text
- Email
- Phone call
- In-person at the clinic
- In-person in the community (e.g., coffee shop or library)
- Video chat using the Healthie app
- No preference
- None of the current ways I could complete a session worked for me

Weekly WITH U sessions met my approval

- Completely disagree
- Disagree
- Neither agree nor disagree
- Agree
- Completely agree

Weekly WITH U sessions appealed to me

- Completely disagree
- Disagree
- Neither agree nor disagree
- Agree
- Completely agree



I liked the weekly WITH U sessions

- Completely disagree
- Disagree
- Neither agree nor disagree
- Agree
- Completely agree

I welcomed the weekly WITH U sessions

- Completely disagree
- Disagree
- Neither agree nor disagree
- Agree
- Completely agree

Weekly WITH U sessions seemed fitting

- Completely disagree
- Disagree
- Neither agree nor disagree
- Agree
- Completely agree

Weekly WITH U sessions seemed applicable

- Completely disagree
- Disagree
- Neither agree nor disagree
- Agree
- Completely agree



Weekly WITH U sessions seemed like a good match

- Completely disagree
- Disagree
- Neither agree nor disagree
- Agree
- Completely agree

Weekly WITH U sessions helped me meet my goals

- Completely disagree
- Disagree
- Neither agree nor disagree
- Agree
- Completely agree

Weekly WITH U sessions were doable

- Completely disagree
- Disagree
- Neither agree nor disagree
- Agree
- Completely agree

## Conclusion

What can we do to improve HIV care services for Black men living with HIV?

Please do not include any personal information that could make it possible for us to identify you (things like your name or age).



Is there anything else you want to add?

Please do not include any personal information that could make it possible for us to identify you (things like your name or age).



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<sup>i</sup> A participant ID number is used to link participants' eligibility data (e.g., demographics and care status), the BMSM-PS data, and any other participant-level data (e.g., viral load) obtained for the NORC ETAP's multisite evaluation of the Initiative.

<sup>ii</sup> Modified from BRFSS.

<sup>iii</sup> From the EPPEC Cross-Site Evaluation Patient Assessment (retrieved from the UCSF CAPS site):

<https://prevention.ucsf.edu/sites/prevention.ucsf.edu/files/uploads/tools/surveys/pdf/EPPEC-PatientAssessment.pdf>.

<sup>iv</sup> Split to race/ethnicity based on OMB 2020 Census Program Memorandum Series: 2018.02: [https://www2.census.gov/programs-surveys/decennial/2020/program-management/memo-series/2020-memo-2018\\_02.pdf](https://www2.census.gov/programs-surveys/decennial/2020/program-management/memo-series/2020-memo-2018_02.pdf).

<sup>v</sup> Split to race/ethnicity based on OMB 2020 Census Program Memorandum Series: 2018.02: [https://www2.census.gov/programs-surveys/decennial/2020/program-management/memo-series/2020-memo-2018\\_02.pdf](https://www2.census.gov/programs-surveys/decennial/2020/program-management/memo-series/2020-memo-2018_02.pdf).

<sup>vi</sup> Adapted from the National Sexual Health Survey and CDC Sexual Behavior Questions (CSBQ):

<https://prevention.ucsf.edu/research-project/national-sexual-health-survey-nshs>; [http://chipts.ucla.edu/wp-content/uploads/downloads/2012/01/CDC-Sexual-Behavior-Questions-CSBQ\\_.pdf](http://chipts.ucla.edu/wp-content/uploads/downloads/2012/01/CDC-Sexual-Behavior-Questions-CSBQ_.pdf).

<sup>vii</sup> Question language recommended by CDC and leading experts in LGBT health, such as NAM and the Joint Commission.

<sup>viii</sup> Question language recommended by CDC and leading experts in LGBT health, such as NAM and the Joint Commission.

<sup>ix</sup> Uses the HAB-preferred RWHAP "retention in care" indicator.

<sup>x</sup> Indicator recommended by NORC ETAP subject matter experts (SMEs).

<sup>xi</sup> Indicator recommended by NORC ETAP SMEs.

<sup>xii</sup> Indicator recommended by NORC HIV SMEs.

<sup>xiii</sup> This question was recommended by Friends Research Institute, Inc., one of the SPNS BMSM Initiative recipients. The ETAP added the recall period (12 months) to align with other items in this questionnaire.

<sup>xiv</sup> From CDC Sexual Behavior Questions (CSBQ): [http://chipts.ucla.edu/wp-content/uploads/downloads/2012/01/CDC-Sexual-Behavior-Questions-CSBQ\\_.pdf](http://chipts.ucla.edu/wp-content/uploads/downloads/2012/01/CDC-Sexual-Behavior-Questions-CSBQ_.pdf).

<sup>xv</sup> This is the PHQ-2 tool, which was recommended by an NORC behavioral health expert. <https://www.hiv.uw.edu/page/mental-health-screening/phq-2>.

<sup>xvi</sup> Single item screener recommended by NORC behavioral health expert. This tool was validated with an adult population (as described here): <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2695521/>.

<sup>xvii</sup> Single item screener recommended by NORC behavioral health expert. This tool was validated with an adult population (as described here): <https://www.ncbi.nlm.nih.gov/pubmed/30352333>.

<sup>xviii</sup> Recommended by Jessica Xavier and HAB staff.



## Local Evaluation



### Introduction

Thank you for agreeing to participate in this study. We will ask you questions about your HIV, the care you receive for your HIV, and information about sexual behaviors, drugs, and alcohol use. If a question makes you feel uncomfortable or brings up feelings you want to talk about, please contact please let a study staff member know and we can refer you to someone you can talk to.

All of the information that you provide is strictly confidential and is protected by law from disclosure to outside organizations and agencies that are not involved with this study. Your responses will be only used for research purposes and combined with other responses. No individual names will be reported.

This survey will take you about 25-30 minutes. Not all response options may apply to you, but please choose the best answer to each question. Also, if there are any questions you don't feel comfortable answering, you don't have to answer them. Your participation is voluntary.

If you have any questions about the survey, please let a study staff member know.

Before starting the survey, please read and answer the statement below.

### Consent Statement:

**I have read the introduction. I understand that the information I provide will be kept private and used only for evaluation purposes. My responses will be combined with the responses of others. No individual names will be reported.**

- I agree with the above statement and will complete the survey.
- I do not agree with the above statement and will not complete the survey.

### Your Experiences with Your Environment

**This section will ask you about your experiences with your environment, including your experiences with food, housing, utilities, and safety.**

**Within the past 3 months, did you worry that your food would run out before you got money to buy more?**

- Yes
- No





**Within the past 3 months, did the food you bought just not last and you didn't have money to get more?**

- Yes
- No

**Are you worried about losing your housing?**

- Yes
- No

**Within the past 3 months, have you been unable to get utilities (heat, electricity) when it was really needed?**

- Yes
- No

**Do you feel physically and emotionally unsafe where you currently live?**

- Yes
- No

**Within the past 3 months, have you been hit, slapped, kicked or otherwise physically hurt by anyone?**

- Yes
- No

**Within the past 3 months, have you been humiliated or emotionally abused by anyone?**

- Yes
- No

## **Your Feelings About Living with HIV**

**This section will ask you about your feelings about living with HIV.**

**Please note that we are asking you to indicate the degree to which each item may be bothering you in your life, *NOT* whether the item is merely true for you. If you feel that a particular item is not a bother or a problem for you, you would answer "not a problem." If it is very bothersome to you, you might answer "A very serious problem."**

**During the past month, how big of a problem would you say feeling overwhelmed with the demands of living with HIV has been for you?**

- Not a problem
- A slight problem
- A moderate problem
- A somewhat serious problem
- A serious problem
- A very serious problem



**During the past month, how big of a problem would you say feeling that you are often failing with your HIV routine has been for you?**

- Not a problem
- A slight problem
- A moderate problem
- A somewhat serious problem
- A serious problem
- A very serious problem

**During the past month, how big of a problem would you say not feeling motivated to keep up your HIV self-management has been for you?**

- Not a problem
- A slight problem
- A moderate problem
- A somewhat serious problem
- A serious problem
- A very serious problem

**During the past month, how big of a problem would you say feeling angry, scared, and/or depressed when you think about living with HIV has been for you?**

- Not a problem
- A slight problem
- A moderate problem
- A somewhat serious problem
- A serious problem
- A very serious problem

## **One Session?**

**Have you had at least one session with your Health Navigator (Josh or Torezz)?**

- Yes
- No

## **Your Feelings About Your Health Navigator**

**This section will ask you about your experiences and feelings about your Health Navigator (Josh or Torezz).**

**Are you able to contact your Health Navigator when you need to?**

- Never
- Sometimes
- Usually
- Almost Always



**Has your Health Navigator adapted his/their approach to meet with your particular HIV management needs?**

- Not at all
- A little
- A moderate amount
- A great deal

**Has your Health Navigator helped you set specific goals to manage your HIV?**

- Not at all
- A little
- A moderate amount
- A great deal

**Has your Health Navigator helped you learn new skills to achieve your goals?**

- Not at all
- A little
- A moderate amount
- A great deal

**Has your Health Navigator helped you solve problems that arise in managing your HIV?**

- Not at all
- A little
- A moderate amount
- A great deal

**Has your Health Navigator helped you become more confident to manage your HIV?**

- Not at all
- A little
- A moderate amount
- A great deal

**Has your Health Navigator helped you get the care you need from HIV-specific doctors and nurses?**

- Not at all
- A little
- A moderate amount
- A great deal

**Has your Health Navigator helped you get the behavioral health care you need from counselors or psychiatrists?**

- Not at all
- A little
- A moderate amount
- A great deal



**Has your Health Navigator helped you find other resources in your community to help you take care of your HIV?**

- Not at all
- A little
- A moderate amount
- A great deal

**Has your Health Navigator helped you to communicate effectively with your doctor or nurse about your HIV?**

- Not at all
- A little
- A moderate amount
- A great deal

**Has your Health Navigator helped you to communicate effectively with your medical case manager?**

- Not at all
- A little
- A moderate amount
- A great deal

## **Your Feelings About WITH U Sessions**

**This section will ask you about your experiences and feelings about WITH U sessions**

**I preferred to complete my weekly WITH U sessions with Josh or Torezz using (choose all that you preferred):**

- Text
- Email
- Phone call
- In-person at the clinic
- In-person in the community (e.g., library or coffee shop)
- Video chat using the Healthie app
- No preference
- None of the current ways I could complete a session worked for me

### **Weekly WITH U sessions met my approval**

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



**Weekly WITH U sessions appealed to me**

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

**I liked the weekly WITH U sessions**

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

**I welcomed the weekly WITH U sessions**

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

**Weekly WITH U sessions seemed fitting**

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

**Weekly WITH U sessions seemed applicable**

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

**Weekly WITH U sessions seemed like a good match**

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



### **Weekly WITH U sessions helped make my goals seem possible**

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

### **Weekly WITH U sessions seemed doable**

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

### **Conclusion**

- **What can we do to improve HIV care services for Black men living with HIV?**
- **Please do not include any personal information that could make it possible for us to identify you (things like your name or age).**
- **Is there anything else you want to add?**
- **Please do not include any personal information that could make it possible for us to identify you (things like your name or age).**



## Qualitative Interviews

# **SPNS BSM Interview Guides**

## **Youth Interview Questions**

Thank you so much for meeting with me today. I really appreciate the opportunity to ask you questions about WITH U.

I'm a researcher at Washington University and we're trying to understand how WITH U is working. We know that the best way to do that is to ask the experts – and that's you!

I want to remind you that your participation in this interview is completely voluntary and that you're free to skip any questions you'd prefer not to answer or to stop the interview at any time.

Do you have any questions for me at this point?

### **1. Icebreaker**

- a) To start with, I just want to say that I wish I could be sitting with you in person! These are strange, tough times and that makes me really appreciate that you're willing to have this conversation to help make this program better and help others.

How are you doing?

- b) And can you tell me a little about how you became involved with the WITH U program?
  - a. Can you tell me a bit more about when you started the program? Were you able to have any in-person sessions?
    - i. How did you feel about that? We've talked to some people who really prefer in-person sessions, some who really prefer virtual, and some who don't care either way. How about for you?
  - b. From what we've heard, it sounds like you had weekly check-ins at the beginning and then switched to monthly check-ins. Is that right? How many of those monthly check-ins have you had?
  - c. How did that switch from weekly to monthly go?
  - d. [If they started more than 6 months ago] and have you continued with the check-ins after the first 6 months? How did you decide on that?

### **2. General reactions**

- a) Great, thanks. And how do you think things have gone with the program?



a. Can you tell me a little more about that?

b) We're asking people if the program was **useful** to them, which is a little different from whether or not they liked it. So, what do you think? How useful was it to you?

a. Can you tell me a little more about that? What was/wasn't useful about it to you?

### 3. Components

Thank you. Now I want to ask you about some of the different ways you've worked with your Health Navigator and see if you feel like some were more helpful than others and why. I'm going to run through them kind of like a survey first and then we'll go back and talk more about them.

This is with two scales of 1-5, the first one is how much you liked something and the second one is how useful you thought it was. 1 means you didn't like it at all or it wasn't useful at all and 5 means you loved it or it was really useful to you.

	<b>How much you liked it</b> 1 = didn't like it at all 5 = loved it	<b>How useful it was</b> 1 = wasn't useful at all 5 = really useful
First, can you tell me how much you <b>liked</b> the ways you worked together to understand your medical care? And how <b>useful</b> was that to you?		
How much you <b>liked</b> the ways you worked towards completing goals? And how <b>useful</b> was that to you?		
How much you <b>liked</b> the ways the Navigator tried to help support you emotionally? And how <b>useful</b> was that to you?		
How much you <b>liked</b> ways the Navigator tried to help you build other supports (stress management, disclosure, encouragement, and being able to talk with people experiencing negative emotions)? And how <b>useful</b> was that to you?		
How much you <b>liked</b> ways you worked together to problem solve or support attending clinic appointments, etc.? And how <b>useful</b> was that to you?		





	<b>How much you liked it</b> 1 = didn't like it at all 5 = loved it	<b>How useful it was</b> 1 = wasn't useful at all 5 = really useful
How much you <b>liked</b> how your Navigator worked to find new resources and help link you to those services (utility support, housing support, etc).? And how <b>useful</b> was that to you?		

Great, thank you. Let's go back for a minute and maybe you can tell me a little more about your answers. [PROMPT FOR REACTIONS TO EACH ITEM]

#### 4. Outcomes

Wonderful, thanks. We're almost done.

- a. Next, we want to ask what you've gotten out of being in WITH U.

If you were talking to someone who was thinking about joining the program, how would you describe what you got out of being in it?

- a. Can you tell me more about that?

- b. Do you think other people in the program got that out of the program too?

- a. Why do you think that is?

- b. Were there any things you were hoping to get out of it but didn't or any things you were disappointed with or did not work well for you?

#### 5. Suggestions

Ok, we just have two more questions for you.

First, COVID-19 is only one pandemic in this country – the other racism and violence against Black Americans. We wanted to ask you how the attention to racism and violence and the national response to it has played out for you while you've been part of the program?

Thank you, this is the last question. We really want to make this program the best it can be and, as I said before, we know that you guys who were in it are the experts.

So, if you were in charge of the program and had a magic wand, what would you change to make it better and help people more?



## 6. Wrap-up

That's it, thank you so much!

I really appreciate your honesty, it's so important during times like this that programs that are meant to help people actually do help – and if they don't, it's so important that people who are running the program hear that, even if it's disappointing, because you can never make things better if you don't know what's wrong.

So, before we hang up, is there anything else you think would be helpful for me to know?

Great, thank you again! We will let Jeff or Stacey know that you have completed this interview and they will send a \$25 Walmart e-gift card to the email on file. Do you need to update your email address with us?

Thank you so much!



## Navigator Interview Questions

Thank you so much for meeting with me today. I really appreciate the opportunity to ask you questions about what it's been like working as a navigator in the WITH U program.

I'm a researcher at Wash U and we're trying to understand how WITH U is working and I want to remind you that your participation in this interview is completely voluntary and that you're free to skip any questions you'd prefer not to answer or to stop the interview at any time.

Do you have any questions for me at this point?

### 1. Icebreaker

- a) To start with, I just want to say that I wish I could be sitting with you in person! These are strange, tough times and that makes me all the more appreciative that you're willing to have this conversation to help make this program better and help others.

How are you doing?

- b) Can you tell me a little about how you became involved with being a navigator in the WITH U program?

### 2. COVID changes

- a) So the program started before the pandemic and then what happened? How did things change?
- b) What were the sessions like after the pandemic started vs. before?
- c) Are there any aspects of how the program has been working during the pandemic that you think should be kept after we're able to return to regular life?

### 3. General reactions

- a) So stepping back, how do you think things have gone *overall* with the program?
  - a. Can you tell me a little more about that?
- b) And what do you think about how **useful** the program has been to the people you've worked with?
  - a. Can you tell me a little more about that? What was/wasn't useful about it to them?
  - b. Is there anything you can think of that was more useful about the program to some groups of people vs. others?



- c) And do you think people liked being in the program? You know, sometimes something helps us a lot but it's no fun doing it.
- a. Can you tell me a little more about that? What specifically do you think people liked/didn't like about it?

#### 4. Components

Now I want to ask you about some of the different parts of the program and see if you feel like some were more helpful than others to the people you worked with and why. I'm going to run through them kind of like a survey first and then we'll go back and talk more about them.

This is with two scales of 1-5, the first one is how much you think they liked something and the second one is how useful you thought it was for them. 1 means they didn't like it at all or it wasn't useful at all to them and 5 means they loved it or it was really useful to them.

	<b>How much you think they liked it</b> 1 = didn't like it at all 5 = loved it	<b>How useful you think it was to them</b> 1 = wasn't useful at all 5 = really useful
First, can you tell me how much you think they <b>liked</b> the ways you worked together to understand their medical care? And how <b>useful</b> do you think that was to them?		
How much you think they <b>liked</b> the ways you worked towards completing goals? And how <b>useful</b> do you think that was to them?		
How much you think they <b>liked</b> the ways you tried to help support them emotionally? And how <b>useful</b> do you think that was to them?		
How much you think they <b>liked</b> ways you tried to help them build other supports (stress management, disclosure, encouragement, and being able to talk with people experiencing negative emotions)? And how <b>useful</b> do you think that was to them?		



	<b>How much you think they liked it</b> 1 = didn't like it at all 5 = loved it	<b>How useful you think it was to them</b> 1 = wasn't useful at all 5 = really useful
How much you think they <b>liked</b> ways you worked together to problem solve or support attending clinic appointments, etc.? And how <b>useful</b> do you think that was to them?		
How much you think they <b>liked</b> how you worked to find new resources and help link them to those services (utility support, housing support, etc).? And how <b>useful</b> do you think that was to them?		

Great, thank you. Let's go back for a minute and maybe you can tell me a little more about [PROMPT FOR REACTIONS TO EACH ITEM].

### 5. Outcomes

Wonderful, thanks. We're almost done.

- a. Next we want to ask what you think the people you worked with have gotten out of being in WITH U.

If you were talking to someone you haven't worked with and who was thinking about joining the program, how would you describe what the people you've been working with got out of being in it?

- a. Can you tell me more about that?
- b. Were there any things you think they were hoping to get out of it but didn't or anything you think they were disappointed with?

### 6. Suggestions

Ok, we just have two more questions for you.

First, COVID-19 is only one pandemic in this country – the other that has finally gotten attention again is racism and violence against Black Americans. We wanted to ask you how the attention to racism and violence and the national response to it has played out for you while you've been part of the program?



Thank you, this is the last question. We really want to make this program the best it can be and we know that as navigators you guys are the experts.


So, if you were in charge of the program and had a magic wand, what would you change to make it better and help people more?

## **7. Wrap-up**

That's it, thank you so much! I really appreciate your honesty, it's so important during times like this that programs that are meant to help people actually do help – and if they don't, it's so important that people who are running the program hear that, even if it's disappointing because you can never make things better if you don't know what's wrong.

So, before we hang up, is there anything else you think would be helpful for me to know?

Thank you so much!



## Qualitative Evaluation Report

### Program Impact & Helpfulness

#### Emotional Support

##### Not Alone

Nearly half of participants interviewed specifically said the WITH U program gave them a sense that they were “not alone.” Part of feeling not alone was having a peer to connect with who shared life experiences and elements of their identity with participants. A larger part of not feeling alone was the knowledge that participants had someone they could rely on for anything that came up in life, someone who was “in my corner.”

“Sometimes we need that support to know that somebody’s still rooting for you.”

“It’s a beautiful thing to know that you’re not alone in this.”

“He was there to walk my through it. Held my hand, held my hand.” (in context of coming to terms with diagnosis/understanding medical care)

“When I told him about my car accident and I sent him a picture, he was like – he really felt it. He was really sorry about it and he was like, ‘You gonna get a new car. I have faith in you.’ It was good to hear that from somebody.”

Of note, more than one-quarter of participants specifically mentioned being “checked on” as a way in which their health navigators helped them feel they were not alone. In some cases, respondents admitted that they might not even respond to check-in texts from their health navigators and valued them all the same.

“[My health navigator] was always checking on me...he was just always popping up, like, ‘Hey, are you okay? What’s going on?’ So he was always in communication, always just checking up on me in general.”

“When I got [my health navigator], I was doing bad. So I needed some real support – he called me three times a day. He stuck his neck out on the line. I don’t even think he was supposed to do the things that he did, you know, with doing as much as he did...it was like he was with me the whole time.”

“Like sometimes he just shoot out a text to see how I’m doing and sometimes it be at the perfect time.”

##### Reassurance

Participants valued the reassurance they received from their health navigators regarding accessing support when they had instrumental or mental health needs. Even when participants did not actually end up asking for or receiving assistance, they indicated that they placed a high value on being reminded that help was available to them.

##### *Instrumental Needs*

Nearly a third of participants expressed appreciation for their health navigators’ frequent reassurance that resources are available to them should they need assistance with housing, utilities, transportation, or food.

“Even just knowing that you still have that ability to have that support if you fall down to hard times is one of the biggest helps because, again, it’s a lot on your mind.”

“[My health navigator] always asked if I needed food in the house, if I’m struggling with food. [He said] if that was the case he’ll be able to get me connected with Food Outreach or something like that.”



### *Mental Health Needs*

About one-fifth of participants noted that they appreciated that their health navigators reminded them of the availability of mental health resources.

“[My health navigator] definitely always made sure to let me know, ‘If you do randomly get maybe depressed, we do have services. We can talk to [therapist name]. We can get those referrals.’ So they were always making sure that I knew that there were resources available, even though at the moment I didn’t need anything.”

“[My health navigator] always encouraged me to let him know if I needed a therapist...making sure I get counseling and stuff like that [if I needed it].”

### *Self-Efficacy & Sense of Wellbeing*

More than a third of participants described the program as bringing them a heightened sense of self-efficacy and well-being. One participant described the program as helping him maintain “that mission to keep going, out of anything,” and others echoed the sentiment that the program helped them be ready to weather future times of difficulty. As one participant said,

“You’re going to have moments where you’re down, but [participating in the program is] going to help you get through those very small moments where you still do get down.”

Another explained,

“One thing I really learned from [my health navigator] is to really just speak things into existence. He also told me, when you’re in that moment, not to dwell in it or not to let it eat at you. That’s one of the biggest takeaways that I learned from [my health navigator].”

Other participants noted that knowing their health navigator was available contributed to their sense of self-confidence, explaining,

“[My health navigator] helped me with self-esteem, like confidence, attitude – having a different outlook on life and approach. Just having a good sense of well-being because I knew that I have people that will help...someone that understands what you need to be human.”

“I was always self-conscious, even though nobody knows what’s going on with me...[my health navigator] pretty much helped me understand it – like I’m still normal, you know? That’s honestly the best feeling out of all of it.”

Another participant described getting that motivation to keep going directly from his health navigator.

“[My health navigator] is going to help put it in perspective, saying, ‘Of course you’re going to have your down times where things may not be going the way you want.’ But in all of it, it was just a blessing, just being patient.”

As another participant put it, “it could be a reminder for you to...just to stay on top of your game, like, for real, like your life, your health.”

Having confidence that when hard time came up in the future, they would be able to overcome them gave participants peace of mind and better day-to-day well-being. One participant explained that by helping him with the “problems that [he had] within” himself, participating in the program helped him with “living





everyday life normally,” and that the program was “bringing me back to me.” He elaborating that by participating in the WITH U program, “you’ll get peace of mind. You will get a sense of security within yourself.” Another participant closely echoed this sentiment: “It’s helped me find myself again.”

## Goal Setting Framework

### Short- and Long-Term Goal Setting

Most participants described engaging in a goal-setting process with their health navigator in which they set short and long-term goals. As a part of this process, participants reported that their health navigators would help them identify tangible steps towards their goals, and resources needed to reach their goals. One participant explained,

“The goal thing...they help you set goals and try to obtain them. Help you find different resources. Help you get to your doctor’s appointment. Will be at your doctor’s appointments, so you can have someone there to lean on if you feel the need to.”

### Goal Topics

The goals that participants set with their health navigators can be classified in two main categories: 1) addressing social determinants of health, and 2) health goals.

#### *Social Determinants of Health*

Goals that were focused on addressing social determinants of health included finding stable housing, getting access to reliable transportations (e.g., purchasing a car), completing their college degree, finding a job, or advancing their career. Below is an example of short-term goals set by a participant:

“as far as short-term goals...as far as me getting back to permanent work and getting... like getting my financial life stable and getting my life back on track in general, like as far as working, housing, getting my own vehicle again, and stuff like that.”

Participants described receiving instrumental support from their health navigators and case managers to achieve these goals.

“they hooked me up with a program and they provided temporary housing for me. I was there for 3 months and like they helped me. They helped me get a place and they helped me get some stability in my life, like for real.”

#### *Health Goals*

Health goals set by participants in the WITH U program primarily focused on weight loss and management and HIV care, including decreasing viral load and increasing medication adherence. One participant shared his progress towards accomplishing his goals of healthy eating and weight loss,

“I wanted to get my health better, as far as like, eating better...doing things like that...losing a couple pounds. And it actually really worked. He was like, “It can just be something small.” And I set that goal and it actually worked. I’m down about 15-20 pounds.”

A different participant reported that he and his health navigator discussed a goal of improving CD4 cell counts and HIV viral load through medical adherence.



“We set goals to where we want to get to, as far as the [CD4] number rising or the [viral load] number dropping. And we just go from there. Pretty much he just keeping check to make sure I’m taking my medicine.”

### Progress Towards Goals

Many participants reported that they achieved their goals while working with their health navigator in the WITH U program. One participant described his progress towards goals focused on transportation and education,

“So I got most of the goals right...like, at least most of them. Like, I got a new car, which, it’s still a put-put, but it’s a car. It’s a running car. Another goal was to go back to school. I’m paying off those student loans, so I can go back this year, which is good, because that was one of my goals, too...”

Some participants have not yet accomplished their stated goals. For some of those participants, continued work towards goals after completing the WITH U program depended somewhat on whether they stayed in regular contact with their health navigator. One participant who was no longer in contact with his health navigator explained,

“Yeah, just because now he’s not there to motivate me as much as he was when he was frequently reaching out to me. I mean, do still have my goals, but I kind of get offset with other stuff that I have to do.”

Conversely, a participant who was still in contact with his health navigator reported a continued focus on goals,

“So it’s good and it’s comforting to know that he’s still being consistent. I still talk to him about the goals that we established in our in-person meetings. And so I keep him up to date with those things...”

### Gained Knowledge and Life Skills

More than one-fifth of participants explained that by participating in WITH U they were able to gain knowledge and life skills that they would not have gotten otherwise. Some of this knowledge was about medical care that participants would not have gained simply by talking with their medical providers. One explained,

“I honestly believe that I would have got a *sense* of understanding [listening to my doctor alone], but I wouldn’t have *understood*. It would have been everybody trying to explain, but I don’t think that nobody could have explained it or broke it down or gave as much knowledge to it as [my health navigator] could.”

This participant attributed that additional knowledge as stemming from his health navigator’s follow-ups with him after doctors’ appointments as well as his health navigator’s unique perspective as someone who personally understands the medical needs of someone living with HIV.

Participants added that being in the WITH U program helped them gain knowledge outside of medical advice.

“Outside of what’s going on health-wise, you also get good advice and stuff and good resources about things that aren’t even related to it...I’ve learned a lot of different things just by being in the program and having [program staff] to talk to.”

As another participant put it, “they give you that *extra* knowledge.”

Another participant appreciated his health navigator’s coaching about expressing difficult emotions. He explained,

Participant: He did tell me I needed to speak to more people I’m closer to just because I bottle everything up. So he did encourage me to speak to friends or family.



Interviewer: Has that been a good experience thus far?

Participant: Family, not so much. Friends, yes.

## Instrumental Support

### Social Determinants of Health

#### *Referrals & Resources*

Participants valued their health navigators' efforts to connect them with resources and referrals when they needed assistance with things like transportation, housing, or food access.

"Both [my case manager and health navigator helped] with the car situation with me being immobile – that might impact me on getting to work, which might impact me on being able to pay rent. So they pretty much help me out with some resources, just in case I need rental assistance."

"[My health navigator] helped me with bus tickets and stuff, to get to work. I remember I didn't have a way to work and I ended up asking him. Well, he let me know that he had a bus pass for me."

"[My health navigator] even helped me with problem solving for my rent assistance when I needed it and my utilities. He was able to get in contact with [my case manager] the same day."

While health navigators connected participants to housing referrals via their case managers in some situations, in other cases they helped participants find rental options.

"[My case manager] was more of, 'Let me know what you find, and I can help you get the paperwork started.' And then [my health navigator] was more like, 'Hey, they got a place here. They got a place there.' He was giving me a lot of options."

In one case, a participant noted that his health navigator helped him comply with court-ordered community service,

"It was a law situation that I was in and I needed to do community service and I was kind of like looking around already but nothing was really like, 'I feel like I should do that.' So, I was having him reach out and find resources that I could go to voluntary work. I didn't finish, but it most definitely got me started because by myself, it was not happening (laughs)."

#### *Reminders*

Participants in the program experience a great deal of complexity in their lives and valued their health navigators' reminders regarding medical appointments and staying on top of their medications.

"[My health navigator] was very consistent with helping remind me, just saying, 'Hey, you have an appointment in a few days. Are you able to make it?' Or the day of, he'll say, 'Hey, are you still able to meet or do you need to reschedule?' So he was A-1 with helping me stay on top of my appointments and my prescriptions."

"One thing about [my health navigator], he don't play that! You better make sure you take your damn medication! [laughs]"

"[My health navigator] made sure that I was on my appointments. He was big on that. 'You know you got an appointment Tuesday, right? You gonna be there?'"



### *Health Literacy*

Upon diagnosis, some participants noted that they had to ascend a steep learning curve with how to take care of their health. They appreciated their health navigators for being a resource for questions that had in the moment.

“I was struggling taking my medication. I didn’t know if these side effects was wrong, were they right? What should I do when the side effects occur as well as what happens if I do this wrong? What about my CD4 count? Like all that. It was nothing but questions as well as to try to understand the lifestyle that I’m going to have to live for the rest of my life – and he was there to walk me through it.”

## Relationship with Health Navigator

### *Always There*

When describing the WITH U program in general terms, most interviewees emphasized their health navigators’ availability and personalities as being vital to their positive experiences. The majority of participants explained that working with a health navigator ensured they had someone “that’s always there.” Health navigators achieved this feeling for their participants through open-door policies, acting as listening ears whenever needed, and regularly checking in with participants even when the participants did not respond. Some participants mentioned that while they do not check-in with their navigators regularly or may not have seen the value of having a navigator before starting the program, knowing that there is a person there for them to rely on when they need support in any kind of way makes a big difference for their sense of wellbeing.

“Your navigator is that person that you can always count on that will be there for you. It’s like a breath of fresh air when you know that you have somebody that you can call and count on the help you when you need it.”

“He’s just been there, always.”

“He’s just very good with just being there...to reach out to if I needed an extra ear to vent to.”

“There’s always someone there for you to talk to you.”

“Anytime I needed to talk, he was there to listen.”

### *Regular Check-Ins*

Regular check-ins via text message or call made a big difference to participants, even when they did not respond.

“We still send each other inspirational quotes or just checking with each other just to make sure that we’re both okay.”

One participant noted that while he “always shut [his health navigator] down,” when the health navigator tried to talk to him about his emotions, there was value in knowing “you can have someone there to lean on if you feel the need to.”

Forming that regular check-in habit at the beginning of the relationship helped some participants feel confident that even when they were not in as frequent contact with their health navigator, the navigator was always there if needed.



“Participant: When [my health navigator] got me, I was doing bad. So I needed some real support. So [he] called me three times a day...it was like [he] was with me the whole time.

Interviewer: And even when it went less frequent, did you feel like you had the amount of support that you needed still?

Participant: Nah, cause I know how to pick that phone up and call...I will call him. I’m calling [my health navigator, my health navigator] know to answer my calls...we got that understanding.”

### *Being Explicit*

Health navigators demonstrated their support to participants not only by regularly contacting them via text or call to check in, but also by directly telling participants that they as health navigators are always available. Many participants specifically mentioned an “open-door policy” that their health navigator had.

“He always tells me every conversation, ‘If you need anything, I’m here.’”

### *Accountability*

Knowing that their health navigators would check in on them regularly helped some participants feel accountable for maintaining their health and progressing on their goals. One participant described his health navigator’s consistency with check-ins as motivating because he would want to have positive updates to share when check-ins occurred. As one participant put it, “It was kind of like an older sibling, in a sense, kind of thing. Just checking in and then you’re like, ‘damn, I gotta do it.’”

### *Someone Who Understands*

Over half of the participants interviewed noted that having a health navigator with similar life experiences and identities greatly enhanced their relationships. Many participants mentioned the importance of having a health navigator who is HIV positive and can share their experiences of being diagnosed while also highlighting the added value of having Black, male, and gay health navigator. Participants explained that their health navigators could really understand where they were coming from because “this is someone in the same shoes as you.” These commonalities helped “really broke down your guard.” As another participant explained, “he understands me all the way.”

Having someone with similar experiences also helped participants build rapport quickly, enabling them to get more out of their health navigator relationship.

“Most of the times where I am trying to get someone to understand the situation for what it is, it take me longer to like explain it. But I feel like when a person actually understand what I’m saying to them, it makes it easier for me to like, just go on more than just one topic.”

Participants also valued the ability to learn from their health navigators’ personal experiences. While it was important that health navigators were peers, participants also benefited from having navigators who had more experience living with HIV than themselves. As one participant explained, “he would know how to deal with that, because he had more experience and more time within the community.” Another participant explained that having a health navigator who had years of prior experience with HIV helped him feel at ease.

“He said ‘I’ve had it for over 10 years. And I’m still okay, just taking meds. And everything will be alright.’ It kind of made me comfortable.”



Having had HIV for a long period of time prior to being a health navigator also helped navigators provide advice based on personal experiences that participants greatly valued. For example, one participant was having physical difficulty taking his pills. He spoke about it to his case manager, but got the most valuable advice from his health navigator.

“So [my case manager] was the one that was trying to see if I could get a smaller pill instead of taking two big pills every day. I’m not a pill person, so taking two, I’m not going to want to take it. And then [my health navigator] was like, ‘You can eat pudding. You can have like, pudding or something that you wash it down.’ And it helps a lot.”

### Health Navigator Traits

Participants explained that their health navigators’ personalities were integral to their experiences of the WITH U program. Participants valued the health navigators’ ability to be genuine and patient.

#### *Genuine*

Over a quarter of participants valued the “genuine” concern their health navigators exhibited for them. Part of this feeling of being genuine entailed participants feeling that when they had positive achievements, their health navigators were truly happy for them.

“When I got my results back when I first found out I was undetected, before I could reach out to him, he text me like, with such excitement. It was just so beautiful.”

As another participant put it, “you can tell that someone actually has the same excitement for you.”

Another part of feeling that their health navigators were “genuine” entailed participants feeling that when they were struggling, their health navigators deeply cared about helping them surpass challenges. For one participant, that genuine concern was demonstrated through repeated outreach when they were struggling.

It was “a genuine concern type of thing...a genuine, ‘I want to make sure you’re okay. I want to make sure you’re good.’ It wasn’t again, just an isolated incident. I think, honestly, that made a difference to me.”

#### *Patient*

A quarter of participants said that their health navigators’ willingness to explain things thoroughly and patiently to them made a big impact on both their relationship with the navigator and their ability to better understand their medical needs.

“He takes the time to explain...I think it’s his level of...his personality, per say, is what makes it a total difference for me... [he’s] always willing to go the extra mile if he can...he’ll ensure he explains it to me in a way that I understand.”



## COVID-19 Impact

The onset COVID-19 pandemic occurred during WITH U program implementation. As expected, many participants were interviewed reported being impacted by the pandemic. Participants reported that the pandemic affected their employment as well as their personal lives.

### Employment Impact

#### Physical and Emotional Stress

Participants who were employed during the pandemic described high levels of physical and emotional stress related to COVID-19 restrictions and precautions. One participant explained the toll working during the pandemic had on him,

“You wearing a mask, mind you, for 10 hours straight. And so you have to learn how to breathe for those 10 hours while moving exact... Like I wish I could be lying to you right now, but I can’t make this up. So even on my off... I say that to say, even on my off days, my body is such like achy or tired mindset, and on top, you also fighting against that you work overnight. So of course, all you want to do is sleep. So just imagine you sleeping, you achy... Yeah, it’s starting to wear on me a little bit now.”

#### Under-employment and Financial Strain

Several participants also reported under-employment and financial strain due to COVID-19. One participant described losing multiple jobs as a result of the pandemic.

“I had 3 jobs during covid, but I got laid to all 3. But after that...so I would say it was about a good 4 to 5 months before I was actually stable.”

Another participant described needing help with housing after losing his job due to the pandemic economy. He also expressed appreciation for the steps his health navigator took to ensure his safety and health during that difficult time.

“I have definitely been referred to [the housing program] a couple of times. When I was going through a couple financial crises and especially when COVID started...I lost my job and things like that, just due to the pandemic. So they were very present throughout the whole COVID process or the whole COVID pandemic or whatever they want to call it now. They have really been present, just want to ensure that I’m okay. Like, “Hey, are you eating? Do you have a place that’s warm? Are you safe?” And things like that.”

### Personal-Emotional Impact

#### Managing Difficult Life Circumstance and Emotions

Participants reported managing difficult emotions and life circumstances related to the pandemic. Some reported feeling isolated due to social distancing measures and limits on in-person contact with friends, family, and services providers. One participant described the loneliness he felt as a result of virtual interactions,

“It takes away like, the humane feeling of like, being around another person. It feels very constricted, in a sense. Like, “Oh, my gosh. I have to live my life through a screen,” type of feeling. And it doesn’t feel all that good to not have so much human interaction sometimes, because you do get lonely. But more importantly, it’s very easy to be one of those people that become really withdrawn...like withdrawn from the world.”



Participants also reported dealing with death in their communities. One participant explained that their health navigator continued to check in with him despite his inability to respond frequently during this difficult time.

“I’ve had, I think, at this point I’m up to 12 deaths. So they’ve been kind of like, “Hey, I know it’s been a little hard for you to communicate with everybody,” and just checking up on me from there. I’ve just had a string of deaths going on.”

### Resilience

Several participants described their process of successfully adapting to new circumstances and means of communication that were necessitated by the COVID-19 pandemic. One participant explained that, given the pandemic context, “I think we’re kind of managing it pretty okay...People still gotta get up, try to be nice, do the best thing they can, and still live.” Another participant reported finding purpose in his job changes due to COVID-19,

“So I went from cooking and being a freelance artist, to being a traveling bank teller. So it’s kind of different, but I’m here for a reason. And I believe that.”

## Engagement

### Satisfaction with Engagement

#### Preference for More Frequency

Many participants expressed a desire for frequent contact with their health navigator. According to participants, frequent contact helped them progress towards their goals and reflected the important relationship they had build with their health navigator. One participant described talking with his health navigator three times each day when he began the program.

“I wasn’t really on my meds like I was supposed to had. And I was kinda feeling a little down. When I got him...when [my health navigator] got me, I was doing bad. So I needed some real support. So [my health navigator] called me 3 times a day. He stuck his neck out on the line. [He] talked to me every day, 3 times a day. It was like, I was...it was like [he] was with me the whole time.”

Several participants who had decreased the frequency with which they communicated with their health navigator stated a preference for more frequent contact. As one participant explained,

“[Our conversations] was weekly and now I really don’t hear from him as much now. But yeah, it’s been like that. But I want it to go back where it started...which I think I’ll tell him. I’ll talk to him about that, because it was better when he was contacting me frequently.”

A second participant expressed frustration about the number of days it took for his health navigator to respond to a text message. He felt the slow response time impeded the usefulness of the WITH U program.

“There were times that...like I said, I would message him back from what he said, and then he wouldn’t message me back for 4 days. And then I would be like, “Well, this conversation is kind of dead. I don’t know what you really want from me.”

#### Already in Regular Contact

Although several participants preferred more frequent contact with their health navigator, others described satisfaction with the frequency with which they communicated. Many of these participants reported that they remained in regular contact with their health navigator after officially completing the WITH U intervention. One





participant said that his health navigator “try to send me stuff that will inspire me. I don’t have a conversation with him like I used to. He just tries to send me stuff that will uplift me and send me offers of like, programs that I can be interested in doing.” Another participant explained,

“I still keep in touch with my navigator...like I have an appointment coming up and like we still talk and text. So, and then, do video chats like this as well. So it’s been good, cause we still keep in contact.”

### Reduced Contact Meets Needs

A smaller number of participants reported that the reduced frequency with which they communicated with their health navigator after the initial two months of the intervention was acceptable. Some of these participants explained that pursuing and accomplishing their employment and education goals resulted in having less available time to meet with a health navigator. One participant said,

“See, like right after we started going from the weekly to monthly, it was when I had actually started working. So in a way, it kind of worked out a little bit, so that way I wouldn’t feel like I’m ignoring or neglecting the text messages or the phone calls. (laugh) And [my health navigator] was very understandable and also happy for me to be back working as well.”

A second participant described the transition from weekly to monthly contact with his health navigator as appropriate and helpful given his changing life circumstances.

“I mean, it worked out perfectly, because now that I’m a teacher now, it works better. Because I feel like, yeah, it was better, cause I just got a lot going on. I’m in school. It’s crazy. I’m just trying to get my education so I can become a teacher and everything. It’s been a lot going on. So, I really like it so far.”

### COVID-19 Implications

The onset and rapid spread of the COVID-19 epidemic in the United States necessitated a move from in-person to virtual delivery of the WITH U program. This meant that participants engaged with their health navigators primarily through Zoom and FaceTime chats, phone calls, and text messaging.

#### Convenience

Several participants explained that virtual meetings with case managers were preferable to in-person meetings because they were more convenient. Other participants said they were able to easily adapt to the virtual sessions and did not find them inferior to in-person sessions.

“Honestly, I guess recently it’s been a lot easier and convenient to do Zoom, because I do it from the comfort of my own home, versus getting up and fighting through traffic and everything else.”

“[Meeting virtually has] been cool. It hasn’t’ been difficult at all. It’s just something else we gotta do. The world is always changing...like for real...carousel never stops turning. So we gotta evolve, I guess, and figure out new ways to do stuff.”

“So with me, I kind of like the FaceTime and Zoom meetings, because I can see the person face to face. But even though I can’t actually see them in person, I’m still able to see them face to face or whatever. So I’m actually cool with it.”



### Need for Human Connection

Although many participants were satisfied with virtual delivery of the WITH U intervention, some reported a strong desire for in-person sessions. Participants explained that in-person sessions led to improved relationship-building, reduced isolation, and avoided technological difficulties.

“I think COVID played a lot into all of this, because I do believe that if we were able to sit face-to-face, [my health navigator and I] could build a better connection with each other. But because of the COVID restrictions, we don’t...”

“But in general, like, if I were to do this in person, again, like, I would be at Starbucks. I would rather do it at a public setting where it’s comfortable, versus Zoom, who keeps freezing and we have to start over and, “Oh, my gosh. Can you hear me?” “I can hear you, but you can’t hear me.”

### Preferences for Communication Medium

Approximately seven participants reported a preference for in-person communication with their health navigator, four preferred Zoom or FaceTime calls, four preferred phone calls or texting, and six reported being adaptive to whatever communication medium was needed. Examples of preferences for in-person and virtual communication are provided in the above section on COVID-19 implications. Participants who reported being adaptive to different communication mediums explained that their relationship with their health navigator was more important than how they communicated with each other.

### Barriers to Engagement

A small number of participants reported barriers to engagement with the WITH U program.

#### Work Schedules

Two participants described their erratic work schedules impeding their ability to engage with their health navigator.

“At first my schedule was up in the air with my other job, so I didn’t really have set off days. So we have to schedule and kind of scramble around that.”

“...because I’ve been going in between jobs, and so I’ve been doing a lot of production jobs, so it’ll be hard for me to actually answer my phone while being at work. During the times that we’ll schedule to talk or if he’ll just shoot me a text during the day and just to see how I’m doing...sometimes I be at work and so sometimes I’ll have to wait until I go on break or something, to be able to reply back to him.”

#### Refusing Help

Two other participants described not engaging with the program due to mental health problems or a desire for self-sufficiency. These circumstances led these participants to refuse help during WITH U sessions or to not respond when their health navigator reached out.

“At the time I told him no when I actually did need help...And the only reason I say, “No, I didn’t need help,” is because I knew I was going to get...I always make a way for myself.”

“[My health navigator] will probably say, “Well, I reached out to [him] a few times and I never got a response.” He won’t be lying. He wouldn’t be lying. I’m going to sit here and tell you that. He wouldn’t be lying. So he might have reached out to me and wanted to have a conversation with me. But depending on what I was going through or what was going on, he didn’t get a response.”



## Health Navigators

### Distinct Roles (Health Navigators vs. Case Managers)

Most participants drew clear distinctions between the roles of their health navigator and case manager, explaining that they would go to each one for different needs.

#### Depends on Content

Over half of the participants interviewed explained that they made a clear distinction between what to discuss with their health navigator and what to go to their case manager for. The clearest distinction is that participants would go to their case managers for assistance with instrumental needs such as referrals for housing or keeping their paperwork up to date. Participants were less precise in describing what they would go to the health navigators for because they would more or less go to them for anything except for referrals and paperwork. As one participant succinctly put it, “the case manager is going to handle all the paperwork and the [health navigator] is just your life coach.”

#### Emotional Connection

Part of why participants turned to their health navigators for almost all concerns besides referrals and paperwork is that participants developed close emotional connections with their health navigators. As one participant described, “I have more of a bond with [my health navigator] than my case manager.” Some participants indicated they would go to their health navigators if they were feeling down or wanted to update someone on their day-to-day life.

“My health navigator, he’s like, more so in that I can talk to about what I am doing on a regular basis, every here and there.”

Four participants explained that their health navigator helped them work on their goals, so even while they might get referrals to meet certain goals from their case manager, they would go to their health navigator to work on the process of goal setting. One participant detailed that his health navigator “was more of like my guy to, again, the step-by-step process without using the resources in that time...even with the resources.”

Three participants attributed their closer connection with their health navigators to gender.

“That’s basically it, just because he’s a guy.”

“To be honest, the more male perspective of things. That was one thing that I really, I did enjoy, was being able to work with a male.”

#### Similar to a Therapist (Emotional Support)

Of participants who worked with a therapist, half reported that they did not see a difference in working with a therapist compared to the support they got from their health navigators.

“[My therapist and my health navigator] they’re not really different to me because I’m comfortable talking to both of them about everything that’s going on within my life.”

“When it’s like a really, really bad day, I will call [my therapist] first and then [my health navigator]...or, no...I don’t know! At that point, when it’s like a bad day and my mind is crazy, I’m going to call whoever, whenever!”



“[My therapist] is just like [my health navigator]. They’re both very helpful....Like, they’re neck and neck when it comes to their jobs.”

Two participants specifically called out gender as an important difference between their therapists and health navigators, noting that it was more helpful to interact with another man on particular topics.

“I think honestly, I feel like it was easier with [my health navigator] because communicating with someone who I consider a male peer, as opposed to a female who is a little bit older than me, there’s a different dynamic there. There was still like a little comfortability with [my health navigator] that wasn’t there [with my therapist].”

“By me being a gay man, it tends to come off that you are more comfortable with another male. He can understand things a little bit better than talking to a woman can. So, that’s one thing that I absolutely loved. I would never want to change that (laughs).”

## Recommendations

When asked about possible improvements to the program, approximately one-fifth of participants said the program was perfect the way it is. Those who had suggestions for improvement suggested either more contact with their health navigators or creating structures that would offer a sense of community with other program participants.

### Increased Contact with Health Navigator

More than one-quarter of participants wanted more contact or connection with their health navigators. These remarks were often made in reference to the program model where contact decreased from weekly to monthly.

“[My health navigator] hasn’t told me why it went down to one month...Don’t take away my guidance (laughs)! I wouldn’t say every week, maybe two weeks, so that way I can hear from him twice in a month.”

“What do I wish? Probably just more time with [my health navigator]. Like, if I needed to talk to someone on an every day basis versus like a once-a-week kind of thing.”

### Sense of Community

Some participants expressed a desire for the program to incorporate the opportunity to be in community with others who have similar experiences. Some suggestions were creative idea like creating a drop-in center or 24-hour hotline. Others expressed a desire for informal in-person events while at the same time acknowledging that others might not be comfortable due to confidentiality/anonymity concerns.

“Like extend me an invitation to do like a brunch or lunch with everyone to kind of get to meet people that’s in the same situation.”

“I would say there should be more of a group thing. If we were always talking to each other...you would probably have way more faith and want to do better, like want to take your medication – you’ll want to live – just because you seek like, your friends living.”