# Demonstration Site Summary

# YGetIt? Project: Using Social Media to Do What You Need to Do

New York State Department of Health AIDS Institute

New York, New York

In the Ryan White HIV/AIDS Program (RWHAP), Part F: Special Projects of National Significance (SPNS) Program Initiative

Use of Social Media to Improve Engagement, Retention, and Health Outcomes along the HIV Care Continuum

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# **Table of Contents**

Executive Summary	2
Introduction	2
Intervention Description	4
Theoretical Basis/ Conceptual Mode	6
Intervention Typology	7
Intervention Core Elements	8
Implementation	10
Monitoring and Evaluation	18
Lessons from the Field.	26
Appendix	30

# **Executive Summary**

Incidence of HIV infections is highest among young adults age 18-29 yrs in the United States.<sup>1</sup> In New York State, young adults account for the largest number of new infections and struggle to seek and remain in HIV care.<sup>2</sup> This population frequently utilizes social media and digital technology to engage with peers and access information (including health information).<sup>3</sup> As such, digital social networks and technologies offer ideal health intervention tools.

As part of New York State's Ending the Epidemic Initiative 2020, the New York State (NYS) Department of Health AIDS Institute coordinated with various stakeholders to develop the YGetIt? Project (YGI). YGI utilizes a HIV focused health management mobile application (GET!) paired with Peer Engagement Educator Professionals (PEEPs) and a comic/graphic serial (*Tested*) which is disseminated through digital platforms.

YGI's core elements (GET! and *Tested*) facilitate timely entry of HIV positive individuals age 18-34 into HIV care. These elements encourage retention in care and achievement and/or maintenance of viral load suppression. Participants were recruited for the YGI intervention from communities disproportionately burdened by HIV/AIDS (i.e. MSM of color, transgender, people who use drugs, marginally housed) in NYS. PEEPs interact with YGI users in-person and through GET! to facilitate utilization of health care services. *Tested* uses social media channels (Facebook, Instagram and Twitter), GET! and an online comic forum (Webtoons.com) to provide education and resources regarding HIV and related health topics to youth and young adults.

## Introduction

Approximately 184,887 young people ages 15-34 in the USA are living with HIV/AIDS, and these young people are significantly less likely to be viral load suppressed despite increased access to antiretroviral therapy (ART) over the last decade. While 75% of people living with HIV (PLWH) are virally suppressed, 51.2% of PLWH aged 13-24 and 54.2% of PLWH age 25-34 have achieved viral load suppression. Innovative interventions are needed to engage and retain young people in care, and to assist them in adhering to ART to achieve viral load suppression and lead healthy lives.

Research shows that young people use their mobile devices to circulate videos and photos and to send short messages to each other as a means of communicating socially and expressing themselves. More than 95% of teens have cell phones and use online social media and networking sites to collect, disseminate and share information. Pew Research Center reported 86% of 18-29 year olds can be classified as "active" on social media. Whites, Blacks, and Hispanics have broadly adopted social media at the same brisk pace. Given social media's ability to cross socioeconomic status and racial demographic barriers, it is an ideal tool for public health intervention.

Many health organizations are using social media to reach and serve their communities. More importantly, it has been shown to be effective. A review of social media interventions pertaining to HIV/AIDS identified access to information, enhanced ability to communicate, having an anonymous identity, a sense of social and emotional support, establishing a virtual community, and geographical reach as benefits of utilizing social media to communicate about HIV.<sup>8,9</sup>

Despite perceptions of social media's impact, human engagement remains crucial. Peer navigators are pivotal and can share disease experience, culture, and socioeconomic backgrounds with the communities they serve. Mugavero et al states, "navigators may assist patients in their awareness and utilization of medical and supportive service resources available in a complex, fragmented health care system, and they often also work with patients to develop behavioral skills to improve self-care and enhance patient-provider communication." Increased access to peer support through a social media modality may facilitate further uptake of healthy behaviors among HIV positive youth.

Evidence supporting use of social media and peer-lead intervention models to improve health outcomes among HIV positive youth prompted NYS DOH AI to develop the YGI. YGI is designed to facilitate the timely entry of young people (ages 18-34) into HIV care, the prevention of vulnerable youth from dropping out of care, and achievement of sustained viral load suppression among those in care. YGI is comprised of a mobile application, GET!, developed in collaboration with Mt. Sinai AppLab, PEEPs placed at two engagement hubs; Pride for Youth Long Island Crisis Center and North Shore University Hospital. PEEPs interact with GET! users via one-to-one messaging within the app and provide in-person support as needed.

Within the app, GET! engages users with Tested. Tested features compelling stories and imagery inspired by the personal stories of young people and active peer-to-peer communication to ensure continued engagement.

YGI program analytics are collected and evaluated by CUNY School of Public Health Evaluation Center to address the effectiveness, successes, and strengths of this novel social media project. YGI helps to bolster and continue AI's work with young people living with HIV to advance health equity and reduce HIV/AIDS-related health disparities.

Stakeholders were critical to refining aspects of the intervention such as GET! features and character and story development for Tested. One such stakeholder is AI's Young Adults Consumer Advisory Committee (YACAC) group who participated in many focus groups to garner feedback. Participant feedback consistently reinforced the idea that the use of social media tools to reach this population was both apt and timely.

Outreach was conducted to gage HIV/AIDS service provider's willingness to adopt a YGI like intervention. The project was presented to NYS health and service providers during quarterly AI updates and through calls and electronic surveys. Many responses from these providers mirrored those of consumers. Many felt that the intervention provides an additional tool for clinical support staff to engage with and retain patients.

# **Intervention Description**

YGI utilizes digital tools shown to be effective at reaching young adults and improving health outcomes related to the HIV care continuum.



GET! provides a high level of confidentiality and security, ease of access, and discretion. It consists of an inconspicuous logo design, platform familiarity, opt in and out selection, Wi-Fi accessibility, and is transferable from one device to another. Comprehensive features allow users to schedule medical appointments, list and track HIV medications, track laboratory values (viral load and CD4), contact healthcare providers, and gain health knowledge. These features are housed in a secure and inconspicuous mobile app.

GET! connects users to peer support in the form of a PEEP. PEEPs are selected based on their ability to communicate with the target audience, HIV and social media knowledge and experience. PEEP training materials focused on cultural sensitivity, HIV care continuum, proficiency with GET! mobile application, and seamless integration into existing program goals.

PEEP Messaging - GET! users receive standardized messages from a PEEP via PEEP messenger. Messages are derived from the U Care 4 Life study, engagement hubs feedback, and the YGI team. Messages focus on rapport building, education, and facilitation of care. PEEPs are reflective of the intervention's target population. PEEPs learn the appropriate intervention information and are trained to deliver it in a culturally sensitive and relatable way. PEEP messenger offers users with a convenient way to answer questions and link to healthcare services.

GET! offers monthly YGI videos that address viral load suppression, medication adherence and schedules, and health and wellness. These videos feature medical professionals, HIV affected and positive individuals, community leaders, and celebrities. There are two video types which vary in length; short (15-60 seconds) and long (2-10 minutes). Users are notified through optional push notifications and secure PEEP messages when new content is available. All video content is maintained on a private YouTube channel, accessible through GET!. Content is continually updated.

GET! has a library of resources to address common barriers observed in YGI's target audience. Resources include: links to housing, insurance (ADAP), substance abuse, LGBT services, mental health, support groups, medical advances in HIV/AIDS care, women's health, youth and adolescent health, STD education and testing, partner services, and more.

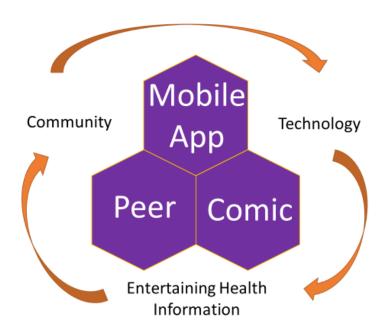


*Tested*, features bold images, short narratives, and draws from cultural influences to appeal to target populations. The story is kept contemporary by incorporating current events, fashion trends, and colloquial phrasing. It is made available within GET! and on public facing social media platforms Facebook, Instagram, Twitter, and the online comic forum Webtoons.com.

*Tested* leads viewers into the world of a diverse group of characters who are affected by HIV, Hep-C, substance use disorder (SUD) and related issues. Each *Tested* season consists of 12 episodes. Each episode is made up of five images with embedded narrative, dialogue, and links to resources.

*Tested* draws inspiration from members of the AIDS Institute's Young Adult HIV Consumer Advisory Committee (YACAC), AIDS Institute staff, focus groups conducted at HIV service organizations throughout NYS, and popular culture. Feedback is also gathered from recruitment events and comments posted on YGI social media sites (i.e. Instagram, Facebook, Twitter and Webtoons.com). The stories are relatable to a wide youth and young adult audience and motivate repeat engagement and viewership.

### Theoretical Basis / Conceptual Model



YGI did not use a concrete theoretical construct, although, it applied elements of various theories. Some of the relevant theories include Reinforcement Social Influences, Goals Skills, Emotion, Knowledge, Beliefs about Capabilities, Intentions, Optimism, and Behavioral Regulation. Manifestations of these domains appear in the form of one-to-one messaging, peer support, medication logs, appointment reminders, educational materials, general messages promoting well-being, formation of a digital community, and other self-empowerment tools.

Literature illustrating the successful application of behavioral change models/theories to health focused text messaging and mobile application interventions are sparse. Irrespective of limited literature, YGI uses, 1) technology tools connect users to health information and health care team; 2) entertaining health information educates and engages users; 3) create a space for users to communicate about their care.

These points serve as the foundation for YGI and continue to direct its development and expansion.

# **Intervention Typology**

Program Summary	Social Media Intervention Overview	Evaluation
,		Summary
New York State Department of	Technology Platforms	HIV Health Outcome
Health AIDS Institute, Health		Measures
Research Inc. (New York, NY)	Facebook: Yes	
	Social Media: Instagram, Twitter, YouTube,	Increase HIV
<b>Program Name:</b> YGetIt? Project	Webtoons.com	testing/ Positivity
	Mobile app: Yes	rate/ HIV
Target Population	Social networking sites: Yes	awareness: Yes
<b>Age:</b> 18-34	Website: Yes (mobile first)	
<b>Gender:</b> Inclusive of all gender		Improved linkage/
designations		engagement in care:
Race/Ethnicity: All	<u>Functions</u>	Yes
Sexual Orientation: All	Communication: Yes	
Sample Size: 100	<b>Education</b> : Yes – HIV, HCV, substance	Imported retention
Language: English and Spanish	abuse, health & wellness, exercise, mental	in care: Yes
Setting: Hospital and CBO	health,	
Intervention type	Gaming: Yes	Improved
Electronic, Peer-support,	<b>Information:</b> Yes	medication
Comparison group - yes	Reminders: Yes	adherence: Yes
Inclusion Criteria	Text Messaging: Yes	
<b>Unaware of HIV status:</b> No	Voice calling: Yes	Improved viral
<b>Newly diagnosed:</b> Yes	General: (General wellbeing) Yes	suppression: Yes
Not linked/engaged in care: Yes	Medical appointments: Yes	
Not retained in care/ Out of care:	<b>Medication adherence:</b> (video and text) Yes	Improved utilization
Yes	Self-monitoring: Yes	of support services:
Not adherent to HIV medication:	Skills building: Yes	Yes
Yes	Social support: Yes	
<b>Not virally suppressed:</b> Yes		Improved health
		literacy: Yes

# **Intervention Core Elements / Components**

The YGI core elements are the GET! mobile application and comic graphic serial, *Tested*.



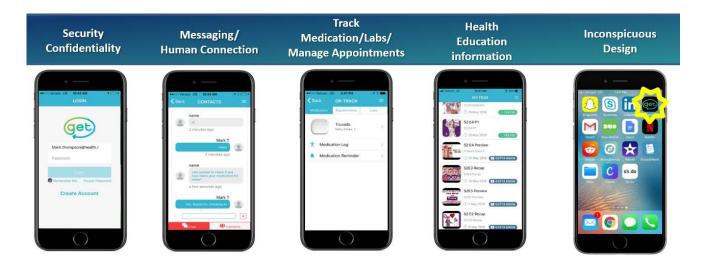
## **GET!** Mobile Application



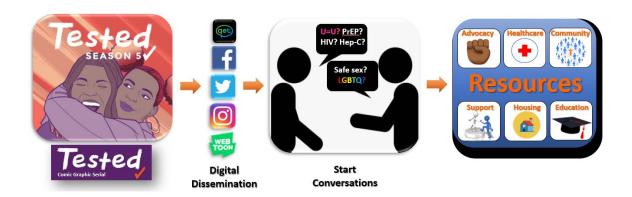
GET! creates a convenient avenue for connection to care and reinforcement of health knowledge. GET!'s confidentiality, security, ease of access and key features help to accomplish this goal to impact health outcomes.

Critical GET! development components include;

- App Developer an experienced mobile application developer with healthcare systems and HIPAA knowledge is vital for the creation of GET!.
- Stakeholders comprised of consumers, providers and members of the target community who provide input via various communications and meetings.



## **Comic Graphic Serial Tested**



*Tested* is sensitive to local influences, culture, and social media platform usage. These factors influence the look and feel of the story to reach the target audience effectively. Stories are kept contemporary by incorporating current events, fashion trends, and colloquial phrasing. Social media and online dissemination platforms are selected through input from stakeholders.

Critical comic/graphic serial development components include;

- Consultants (Illustrator and Writer) the illustrator and writer are vital for the creation of *Tested* imagery and narrative.
- Stakeholders comprised of consumers, providers and members of the target community who provide input via various communications and meetings.
- *Tested* Social Media Strategy is tailored to address the specifics of the intervention. It focuses on audience, health topics, geographical location, platform, content, etc.

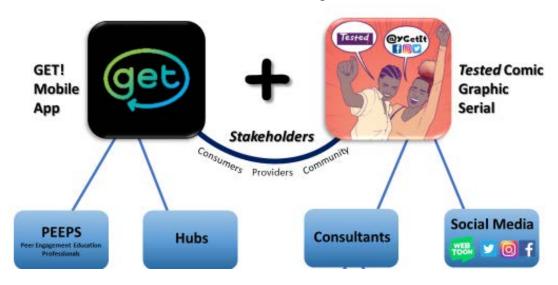
# **Adaptable Key Characteristics / Components**

YGI was designed to be adaptable to various health issues, organizational infrastructure, and geographical locations.

- Delivery platform aspects of YGI can be adapted to various digital infrastructure models including mobile first websites, progressive web applications (PWA), social media platforms and portal system. Other adaptable YGI features include content format (e.g. videos, short articles, images, etc.), dissemination strategy, text messaging content and schedule. Design of the app should be tailored to the target population for better user experience (i.e., aesthetics, form and functionality). These options should be explored for similar interventions.
- *PEEP* Various disciplines can carry out the role and responsibilities of the PEEP. (e.g. case manager, nurse, health educator, peer, etc.).
- *Comic/graphic serial comic* Adjustments to the comic may include modification of health and social topics, style format, font size, language (e.g. English, Spanish, etc.) and distribution methods (e.g. print or digital). Social media interns may not be required if project team staff have expertise in this field.

# **Implementation**

The YGI project was funded in September 2015. The project team was assembled and development of GET! and Tested started shortly thereafter. Feedback from CAC members and stakeholders were amassed to inform creation of GET! and Tested. Recruitment for GET! began in early May 2017 at North Shore University Hospital's Center for AIDS Research and Treatment (CART) Program, clinical setting, and Pride for Youth, a community-based organization. A PEEP was located at each location and was responsible for recruitment and enrollment activities. Tested was released within GET! and on public social media channels in March of 2017.



# **Implementation Teams**

To develop and implement YGI a variety of teams were assembled.

Project Team: Principle Investigator, Project Director, Program Coordinator

- *Principle Investigator:* Serves as the key individual responsible for the preparation, conduct, and administration of the grant. Estimated time and effort for this role is 75%.
- *Program Director:* Supervises program coordinator, develops timelines for the completion of program milestones, and provides contract management. Estimated time and effort for this role is 85%.
- *Program Coordinator:* Oversees and manages planning, tracking, reporting, quality management and facilitates communications with and in between project team and hubs. Estimated time and effort for this role is 100%.
- Comic Graphic Serial Production Team: consist of a writer, illustrator, and social media coordinator who collaborate with the project team, PEEPs and CAC through phone calls, emails and in-person meetings. They draw inspiration through literature, HIV support groups and AI meetings. Estimated time and effort for this team is 50%. This estimated varies based on the frequency of schedule meetings.

Engagement Hubs: are clinical and community-based organizations that provide HIV healthcare and support as well as serve a diverse racial, socioeconomic, and geographic client base. Engagement hubs serve as the recruitment, enrollment and implementation site. Engagement hub staff communicate with the project team through bi-weekly phone calls, emails and in-person meetings. Estimated time and effort for the hub is 100%.

Peer Engagement Educational Professionals (PEEPs): PEEPs are embedded in the engagement hub care team and serve as chief engager for recruitment, enrollment and continued engagement activities. PEEPs identify potential participants during scheduled HIV care appointment, support group meetings, other client engagement activities, by phone, or by email for screening and enrollment. Estimated time and effort for the hub is 45%. See Appendix 1

PEEP Expectations and Responsibilities for more details.

PEEPs encourage medication adherence and retention in care through continued communication via the GET! and in-person interactions. Within GET!, PEEPs utilize PEEP Messenger to provide basic education around HIV and sexual health, emotional support, and aid in facilitation of care logistics.

*Technology Hub:* develops and deploys GET!, communicates directly with engagement hubs and project team for maintenance, data transfer, and quality improvement through phone calls, emails and in-person meetings. A link to the mobile application description, screen shots, and a list of features can be found in appendix 2. Estimated time and effort for the hub is 20%.

*Evaluation Hub:* The evaluation hub develops outcome objectives and measures, guidance regarding IRB submissions, data collection and analysis, and creates tools for data reporting and examination. The evaluation team communicates with the project team and other hubs through phone calls, emails and in-person meetings. Estimated time and effort for the hub is 30%.

Stakeholders and Collaborative Partners: Input from stakeholders and collaborative partners was gathered through focus groups held at HIV/AIDS support organizations throughout NYC and Long Island; Safe Horizon, Community Healthcare Network, Pride for Youth Long Island Crisis Center, Housing Works, etc. Further surveys were conducted to gage HIV/AIDS service provider willingness to adopt YGI. The project was presented to NYS providers during quarterly AI updates and through calls and electronic surveys. Providers and consumers offer input for GET! design, features, user experience, *Tested* story development, study design, and direction of YGI.

YGI received in kind donations from several individuals and private companies to aid in development of the project. Donations included, logo development, video content and promotional activities.

*Trainings:* YGI trainings are designed to provide knowledge to staff who are trained to work with at-risk and young people living with HIV. Key YGI Staff (Project Coordinator, PEEP, PEEP Supervisors) completed courses and are trained to deliver the intervention. These trainings focus on use of social media tools, participant enrollment, messaging, proficiency with GET! and data collection and reporting. YGI staff must complete IRB and institutional trainings.

# Marketing/Social Marketing



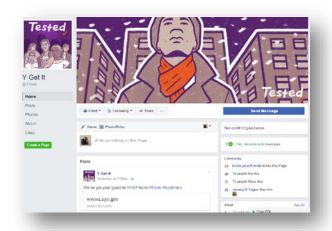
See attached YGI Social Media Marketing Manual.

Tested uses social media to reach the target audience directly and deliver thought-provoking posts about HIV healthcare. Tested provides content to its audience, utilizing images, facts and resource links, and short videos from people with live experience (Tested Talks) to spread awareness of the YGI brand. This information is disseminated via Facebook, Twitter, YouTube, Instagram and Webtoons.com. Tested social media intern has an in-depth understanding of the 18-28 age demographic social media experience. The social media consultant works closely with the project team to develop an engaging and extensive social media presence for Tested. See examples below. See Appendix 3 YGI Social Media Strategy for more detail.

*Tested on Instagram:* Instagram is the primary dissemination platforms for *Tested* episodes on social media. Serial episodes are posted at high traffic times on a weekly basis. Episodes are supplemented with additional resources and informational posts. In between seasons, a wide variety of *Tested* content is posted to retain viewer interest.



*Tested on Facebook:* Facebook serves as a hub for resources and educational information. Alongside serial postings, Facebook drives traffic to resources to impact behavioral change, promote health literacy, and improve health outcomes.



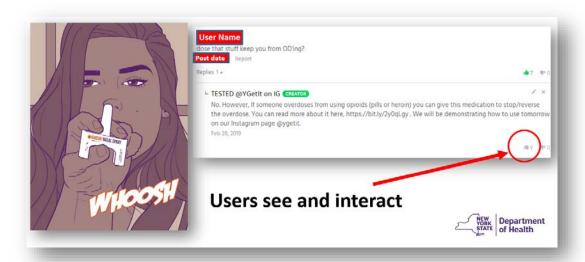


*Tested on Twitter*: The primary function of *Tested's* Twitter account is to direct traffic to *Tested's* Facebook, Instagram, Webtoons.com and YGI's website.

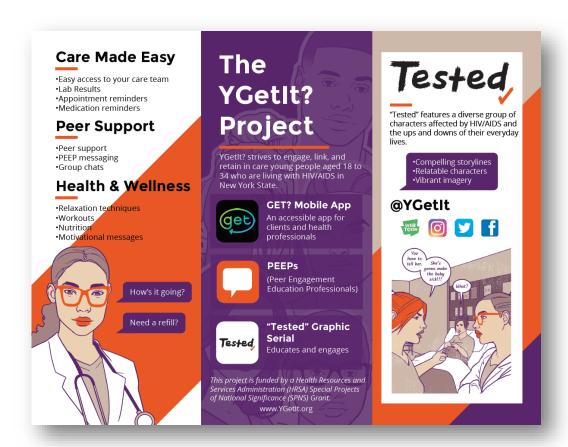


*Tested on Webtoons.com:* YGI partnered with Webtoons on World AIDS Day 2018 and was prominently featured on their homepage. Entire episodes of *Tested* are posted along with links to resources weekly. Webtoons viewers are engaged via the active comments section. Webtoons viewers are directed to other YGI platforms for further information.





*Print Marketing:* Print materials are utilized to facilitate discussion about the project and include brochures, scientific posters, promotional posters, character cards, and comic books. YGI posters and brochures are strategically placed at hubs, HIV care providers, and community-based organizations.



*YGI Website*: A public facing mobile first website, www.ygetit.org, went live in March of 2018 and provides information about the project. The site highlights GET! features and functions and directs viewers to the where

it can be downloaded. With regard to *Tested*, the site features complete seasons, linkage to resources and services pertaining to content covered in each season, and character backgrounds.



## **Outreach and Recruitment**

YGI worked with the engagement hubs and PEEPs to create a comprehensive outreach and recruitment strategy. Please see outreach and recruitment under the evaluation section as well as appendices. See Appendix 4-9 for outreach and recruitment documents.

**Procedures / Protocols for GET! portion of YGI project** - Prescreening Activities at the Engagement Hub.

Identifying individuals to participate in YGI the Engagement Hubs:

- Identified all HIV+ patients, 18-34 years of age who scheduled visits at the North Shore University Hospital clinic in the last year.
- Review missed appointments.
- Capture upcoming appointments.
- Health Education Alert (HEA) email is sent to all staff who encounter potential enrollees to refer those patients to YGI engagement hub staff.
- YGI engagement hub staff approach potential enrollee.
- If potential enrollees are unable to discuss project due to time constrains, a separate appointment is scheduled.

See flow chart for enrollment process.

# **Trainings**

YGI trainings highlight core NYS DOH AIDS Institute strategic priorities and social media strategies. Courses are designed to provide knowledge to staff who are trained to work with at-risk and young people living with HIV. Please see Appendix 10 for course list.

Key YGI Staff (Project Coordinator, PEEP, PEEP Supervisors) completed courses and are trained to deliver the intervention. These trainings focus on use of social media tools, participant enrollment, messaging, proficiency

with the GET! and Dashboards, and data collection and reporting. YGI staff must complete IRB and institutional trainings. See appendix 11-13 for training documents.

Role	Training Type
Project Team Staff	IRB, Required AIDS Institute trainings,
	ETAC data collection and reporting
	trainings
Engagement Hub Staff	Cultural sensitivity, HIPAA and confidentiality, GET App and dashboard, messaging, ACASI survey administration and data collection, IRB, YGI enrollment protocol
Technology Hub Staff	ACASI survey administration and data collection, IRB, mandatory organization trainings
Evaluation Hub Staff	ACASI survey administration and data collection, IRB, mandatory organization trainings

# **Monitoring and Evaluation**

## Primary evaluation aim:

**Aim:** Evaluate the efficacy and impact of the YGetIt? project in-person PEEPs component at improving linkage, re-engagement, retention, and other downstream outcomes for at risk youth and young adults. Our findings from the evaluation are a significant contribution to the small, yet growing literature on the use of social media to engage hard to reach patients to improve their health outcomes.

## Study population inclusion criteria

To participate in the YGetIt? evaluation, participants must meet all of the following inclusion criteria:

- HIV +, aged 18-34
- Read and speak English fluently

One of each of the following criteria is required for ETAC evaluation and **only preferred** for local evaluation.

- Diagnosed within last 12 months, or
- Never been in HIV care, or
- Received HIV care over 6 months ago, or
- Unknown or unsuppressed viral load
- Own their own personal functioning smart phone
- Live in New York and have no plans to leave for more than 6 months within the next year
- Receives or willing to receive care at the clinical engagement hub

### **Evaluation methodology and design**

**Design:** Evaluate the efficacy and impact of the GET! and in-person PEEPs component at improving health outcomes. Participants enrolled are individually randomized at a 1:1 ratio to either receive access to the GET! plus a PEEP they can communicate with outside of the app (Arm 1), or to receive access to the app alone (Arm 2). After one year, those randomized to receive the app alone were linked to a PEEP.

Our target enrollment was 100 young persons (50 in each intervention arm) from HIV care sites in NYC, Suffolk, and Nassau Counties. Primary outcomes to be examined include engagement, linkage to care and viral load suppression.

**Recruitment** was ongoing for eligible participants. Engagement hubs utilized three lists: eligibility, daily appointment and study participant follow-up. These lists were cross-referenced for recruitment and follow-up surveys. The PEEP introduces the clients to the YGetIt? study, checked eligibility, performed the study consent, ACASI survey, release of HIV confidential information form, GET! download and walk through, and provided enrollees with incentives.

Screening took place over the phone or in-person in a private location. Young people meeting the eligibility criteria were offered enrollment and consented. Those who decline to participate continued to receive the standard of care. Prior to the start of the intervention, PEEPs and health care workers at the engagement hub were oriented to the study procedures and eligibility criteria.

#### Flow of Enrollment Activities

- 1) Screen participants with screening tool.
- 2) Sign medical information release and consent form
- 3) Create GET! account in GET! dashboard which requires name, date of birth, email, phone number. App generates participant ID and designates intervention arm.
- 4) Introduce participant to ACASI survey administer on tablet.
- 5) Help participant download GET! and provide a tutorial on how to use the app.
- 6) Ensure participant ID is labeled on all signed forms
- 7) Provide participant compensation for their time and effort with gift cards and other incentives.

### Primary outcomes

Indicators measure performance at several key points along the continuum of engagement in HIV care.

The primary outcomes examined in this project include initial linkage or re-linkage (**Link/RLink**), sustained linkage or re-linkage (**Slink/SRLink**), engagement in HIV care (**EiHC**) and viral load suppression (**VLS**). Outcomes for all participants are constructed using EHR data, which includes longitudinal CD4 and VL measurements as well as medical visit dates.

**1. Linkage or re-linkage** (*Link/RLink*). Link: A person newly diagnosed with HIV with evidence of HIV care within 91 days of the date of diagnosis (we also examine 30 and

180 day intervals) are considered linked to care (i.e., Link='Yes'; otherwise Link='No'). A person previously diagnosed but out of care for 6 or more months or never engaged in care with evidence of HIV care within 91 days of enrollment is considered re-linked to care (i.e, RLink='Yes'; otherwise RLink='No').

- 2. Sustained linkage or re-linkage. (*Slink/SRLink*): A person newly diagnosed with HIV, previously dropped out of care, or was never engaged in care with evidence of HIV care within 91 days of the date of diagnosis, who is able to maintain their linkage by evidence of an additional HIV care visit between 91 and 180 days post diagnosis is considered to have sustained linkage (i.e., SLink='Yes'; otherwise SLink='No'). A person previously diagnosed but out of care for 6 or more months or never engaged in care, with evidence of HIV care within 91 days of re-engagement, who is able to maintain their re-linkage by evidence of an additional HIV care visit between 91 and 180 days post re- engagement is considered to have sustained re-linkage (i.e., SRLink='Yes'; otherwise SRLink='No').
- **3.** Engagement in HIV care (EiHC): a) EiHC1: For short-term analyses, patients with an HIV care visit in two consecutive 182-day intervals in the first 12 months of follow-up post intervention, with the first and last visit being >91 days apart, is classified as being engaged in HIV care (i.e., EiHC1='Yes'); otherwise EiHC1='No'; b) EiHC2: For long-term analyses, patients with an HIV care visit in each 182-day interval of the remaining 24 months of follow-up, with the first and last visit in each consecutive pair of 182-day intervals being >91 days apart, is classified as EiHC2='Yes'; otherwise EiHC2='No'.
- **4.** *Virologic suppression (VLS)*: a) **VLS1**: *For short-term analyses*, patients whose most recent VL test during the second half of the first 12 months of follow-up is <50 copies/mL will be classified as being virally suppressed (i.e., VLS1='Yes'); otherwise VLS1='No'. b) **VLS2**: *For long-term analyses of sustained VL suppression*, patients are classified as VLS2='Yes' if during the remaining 24 months of follow-up they have: a) at least one VL
- <50 copies/mL in each 182-day interval with the first and last test in each consecutive pair of 182-day intervals being >91 days apart; and b) no two consecutive VL >50 copies/mL in any of the 182-day intervals; otherwise VLS2='No'.

## Monitoring progress: data collection, quality review, and analysis

**Data quality checks:** Data from Engagement and Technology hubs are reviewed for completeness and accuracy upon receipt depending on the frequency of data reporting. If any potential errors are found, they are reported back to the hubs for correction or explanation. Data is summarized every 3 months and shared with the project team to monitor progress.

### **Data sources:**

The evaluation of the **YGetIt?** Project involves the use of multiple data sources that are secured, managed and cleaned by HIPAA-trained project staff. Cleaned data is merged for analysis.

**Participant and PEEP feedback:** Participant feedback mechanisms are integrated into the GET! mobile application, through a satisfaction survey and rating system. Survey data is linked and correlated with key process and outcome indicators.

**ACASI participant surveys**. Upon enrollment in the initiative and downloading of the app, participants complete a baseline questionnaire in order to collect demographic and risk data. The information collected includes intervention eligibility criteria, age, sex, gender, date of diagnosis, sexual orientation, self-reported adherence to ART if on treatment, history of drug use, diagnosed mental illness and current health status. **The survey is to be repeated every 6 months through an 18-month period.** 

**PEEPs tracking tool/intervention exposure.** A data collection tool for PEEPs to collect and record information on recruitment, screening and consent of patients, interactions with enrolled patients, and ACASI survey completion over time. The tracker also helps to monitor additional face-to-face interactions with participants that may not be captured through the GET!. This may include meeting to provide orientation to the health center and linking the patient to case management services.

**Electronic Health Records** (**medical chart data**). Electronic health record (EHR) data from North Shore University Hospital is the primary source of outcome data used in the evaluation. EHR's typically capture longitudinal, client-level data on socio-demographics, age, service need areas, medical history and comorbidities, CD4 and VL measurements, sexual risk behaviors, substance use, incarceration history, appointment dates, ART medications and treatment adherence, types of insurance, types of referrals and use of supportive services.

**GET Mobile App.** Process measure data on engagement and use of the App is routinely extracted by the data manager every two months. Data on the number of appointments tracked and attended, medication adherence, interaction with *Tested* comic serial, interaction with PEEPs and number of messages exchanged etc. is cleaned, analyzed and linked to care outcomes.

A summary of the data sources and frequency of recording and reporting are provided below.

### Data sources for local and multi-site evaluation

Data source	<u>Description</u>	Data recording frequency	Reporting
Survey on usability and acceptability of App and PEEP interactions	Surveys administered through the app on usability and acceptability of App, and PEEP interactions	Once after launch and within 3 months), every 6 months thereafter	Once after launch and within 3 months), every 6 months thereafter
ACASI participant Surveys	This survey consists of behavior and risk factor assessment and taken independently by the participant for confidentiality purposes	As participants are enrolled. Survey will be	-Daily to ETAC -ETAC will provide the local evaluation with

<u>Data source</u>	<u>Description</u>	Data recording frequency	Reporting
		conducted at Baseline, 6 months, 12 months, 18 months, 24 months	cleaned data files on a TBD basis
PEEP Tracker/Intervention Exposure (process data)	A screening contact tracker to measure recruitment success in the field by PEEPs	Daily	Forlocal evaluation only. Reported weekly to evaluation team (Mondays)
Intervention exposure is tracked from screening to longitudinal participation using 3 sheets in Excel	2. An exposure contact tracker that requires the PEEP to complete daily summaries of interaction with their participants according to the requirements of the ETAC Intervention Exposure Form	Daily	For local and multi-site evaluationProvidedto ETAC weekly (Fridays), -local eval team weekly (Mondays)
	3. A longitudinal tracking sheet that evaluates and tracks participation with the ACASI evaluation survey over the course of the intervention	Asparticipants are enrolled and upon completion of ACASI surveys	For local evaluation only. Reported weekly to evaluation team (Mondays)
Medical Chart Data/EHR data (outcome data)	Participant medical data collected from North Shore University Hospital	TBD	Bi-annually. To be used in both local and multisite evaluation.
Intervention Costing Data	Staff hours calculated for measurement of cost of intervention implementation	Monthly	Monthly (15 <sup>th</sup> of each month) to the ETAC.
GET! App Data (process and outcome data)	Data extracted from interactions with the app	Daily	-For local evaluation: Monthly. High level data including enrollment numbers will be reported weeklyFor multi-site evaluation: TBD

Confidentiality: Absolutely no data with patient identifiers should be reported by intervention sites to CUNY ISPH (local evaluator). In the case that data with identifiers are reported, CUNY ISPH and PEEPs will delete immediately wherever it has been stored or sent. Staff will be retrained on how to maintain patient privacy and confidentiality. Breach will be reported to CUNY's Human Research Protection Program office.

## Statistical analysis of YGetIt? Project

Raw data is cleaned for each of the data sources described above and analysis files are constructed combining the data for analytical purposes. Descriptive characteristics of participants including age, gender, race/ethnicity, and other demographics are summarized overall and by study arm.

Outcomes are assessed and compared for those patients in intervention arm 1 compared to intervention arm 2. Because of the small N in each arm, it is possible that randomization may not perfectly balance the study arms with regard to confounding factors. Therefore, we use logistic modeling for binary outcomes to estimate the effect of the intervention, controlling for measured factors that may be different between arms due to imbalance. Variables exhibiting a significant association in univariate analyses are included as covariates in the multivariate analyses. We conduct 'intent to treat' analyses as well as 'as treated' analyses, report 95% confidence intervals, and consider p-values equal to or less than 0.05 (two-tailed) to be significant. Statistical analyses are performed using SAS 9.4 (SAS Institute, Inc., Cary, North Carolina).

Statistical power – with an N of 60 participants in each arm, we have >80% power to detect a 50% outcome frequency verses a 75% outcome frequency in the app alone arm vs. the app plus PEEPs arm, respectively.

### **Results for Local Evaluation**

The local evaluation (our evaluation) includes 104 patients (9 of the initial 113 enrollees withdrew). The ETAC evaluation includes 47 who meet ETAC inclusion criteria.

## **Study Participant Demographics:**

Participant demographics were self-reported via ACASI survey.

AGE
Median/mean 28 years of age
Range 20 to 34 years of age,
IQR 26 to 31 years of age

Sex	Race Ethnicity
75 Male	51% Black or African-American
25 Female	31% White
2 Transgender women	30% Hispanic, Latino or Latina
1 Gender queer	4% American Indian or Alaska Native
1 Other	3% Asian
	1% Native Hawaiian or other Pacific
	Islander
	*Participants were able to select more
	than one option for race/ethnicity.

# **HIV Diagnosis (First Test Positive)**

14% Within the past 12 months (newly diagnosed)

81% More than 12 months ago

5% Don't know/ not sure

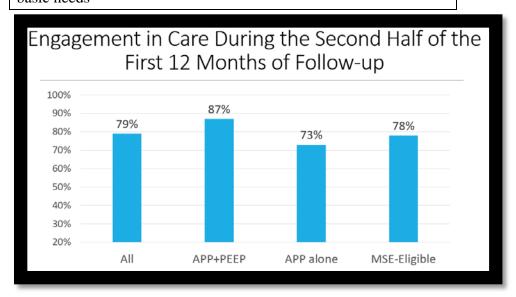
13% reported being born with HIV

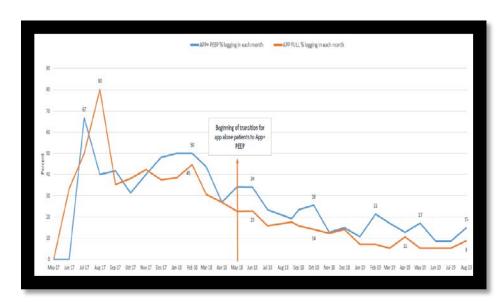
# **HIV Care Statistics**

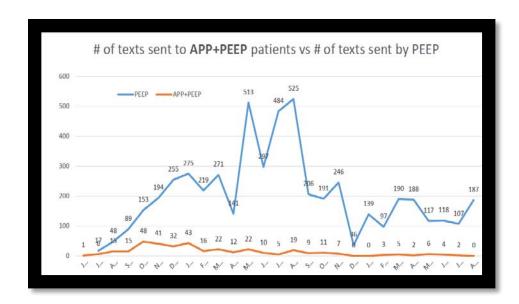
89% Reported ever taking ART or HIV medication

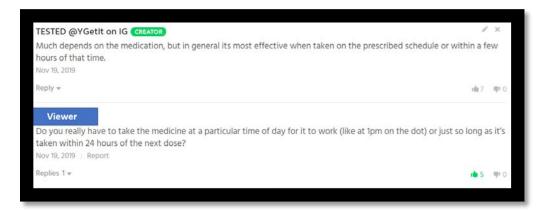
40% Reported using Medicaid Insurance, 3% unsure

12% Reported not getting medical care as money was needed for basic needs









## **Summary Points:**

- 1) GET! demonstrated potential for a positive impact on viral load suppression and retention in HIV care despite app usage decline. Average VLS among all GET! users improved from 79% to 86% with a notable increase from 64% to 74% among priority groups designated by ETAC inclusion criteria.
- 2) Tested comic graphic serial reached a young adult audience and educated, engaged and exposed this group to information about HIV and related issues in nontraditional spaces. This is evident from the approximate 280K views, 650 comments, and 30K likes across Tested dissemination platforms.
- 3) More messages by PEEPS does not mean more responses from users.
- 4) Any glitches within the application must be fixed immediately. GET! initial users who reported glitches in app performance accessed GET! with less frequency, in some cases never again, than those who began using that app after glitches were fixed.
- 5) GET! App logins declined over time.

## **Lessons from the Field**

# **Challenges:**

#### Recruitment

• Initial recruitment for the protocol at the engagement hubs was challenging for various reasons. At the community-based engagement hub, the consumers stated they attend the center to relax and socialize and not to think about health issues. Recruitment at the clinical facility was also initially challenging due to difficulties with staff buy-in and adherence to protocol and procedures.

#### GET!

- App development was an iterative process fraught with fits and starts. Software glitches slowed YGI's progress schedule and were resolved via troubleshooting with the AppLab.
- Glitches were a deterrent usage.
  - **Example:** users were unhappy with their ability to engage with "Tested" within the app as they were unable to make comments on images and they found it difficult to navigate between serial images. These factors discouraged viewership and engagement.
- Curation of content that was relevant and relatable to the audience was time consuming.
- Grasping YGI procedures and protocols was initially challenging for engagement hub staff. Numerous modes of training were devised to address this issue including in person trainings, video tutorials, flowcharts, and guidance documents.
- Messaging from PEEPs to participants was time consuming with limited participant response.

#### **Tested**

- It was challenging to identify consultants (illustrator and writer) who captures the attention of our target audience.
- Dissemination of Tested on social media and online forums was complex. This included building of an online community, coordination of influencers, content development and targeted messaging, and creation of a fluid strategy driven by frequent monitoring and analysis.
- Building and maintaining relationships with key stakeholders, consumers, providers, and CBOs was difficult. These relationships help provide the YGI team access in order to obtain feedback, tailor content, promote buy-in, and aid dissemination of the project.

#### Evaluation

- Participants expressed discontent with the length of the ACASI survey. This was a barrier to enrollment and follow up.
- Engagement hubs initially had difficulty with data collection and storage protocols.
  - **Example:** PEEPs struggled to save ACASI surveys in the proper file format for appropriate storage and transfer.

## **Successes:**

#### **Overall**

- YGI was able to coordinate a diverse and dynamic team to implement the project successfully.
- The YGI project team implemented weekly in-person training and increased communication to successfully enroll participants.
- A comprehensive HIV centered healthcare management mobile application was developed to impact each point of the HIV care continuum and beyond.
- YGI developed and disseminated an online comic/graphic serial featuring an authentic representation of life experiences to engaged and educate young adults about HIV and related issues.
- Awareness of the project was successfully achieved through partnerships with various HIV care organizations including community-based organizations, major hospital networks and state and local health departments who cater to YGI's target audience.
- The project was successfully presented at numerous scientific health conferences through poster and oral presentations. (See abstracts attached)

#### GET!

- GET! created an additional tool for patient-to-care communication. A particular user redownloaded the app across three different devices when the previous device was lost. This user was unstably housed and did not respond to their care team's traditional outreach methods; phone calls, letters, emails, and home visits. However, they did reach out to their care team exclusively via the PEEP messenger to re-engage in care. The messenger allowed this user to build rapport with a PEEP and facilitated care logistics.
- Data suggests GET! users utilized the informational section of the app, "Gotta Know," to reinforce their knowledge of medication adherence, lab results and overall health and well-being.
- Viral load suppression among the most difficult study participants increased.
- Participants with access to a PEEP were more engaged in the intervention than those who did not.

#### **Tested**

- The YGI created a relatable entertaining and engaging avenue for dissemination of health information.
- Tested was selected as an exhibitor for 2018 FlameCon, the world's largest LGBTQ focused comic convention. This opportunity garnered invaluable exposure to a wide range of young adults in this community and opened up new dissemination avenues for the comic.



• Tested was featured on the online comic forum Webtoons.com for World AIDS Day 2018. This feature put Tested in front of 5 million monthly viewers worldwide, the majority of which are under age 25. Tested was viewed upwards of 80,000 times within a week of World AIDS day and has since been viewed over 270,000 times. Webtoons viewers have engaged through the comments section on this platform to share personal stories and ask questions related to the content and subject matter of the comic. Viewers have self-identified as HIV and SUD care providers and consumers through these comments. Viewers have been provided with links to resources and services and have been educated through answers to inquires provided by the YGI team.



#### mia rania

I was so happy to read this webtoon. I'm a medical student from Asia, and this webtoon open my mind about infected patient's lifestyle. Keep moving forward

Sep 8, 2019 Report

# **Tips for Future Implementation:**

## *Identify and Train Personnel*

- Invested staff are essential.
- *Identify tech savvy and health knowledgeable staff.*
- PEEPs should be reflective of the target demographic.
- *Train staff on the intervention platform.*
- Recommend having two quality illustrators to maintain steady flow of comic graphic serial content.

#### Beta Test

• Dedicate ample time to testing the app before presenting it to users.

## Community Partnerships

• Community buy-in is essential to the success of the intervention. Spend time building relationships.

### Customization

- Tailor features, content and presentation of the app to appeal to your audience.
- Tailor message content and frequency to the target audience.

#### Contractual Process

• Contractual process can be slow. Familiarize yourself with your organizations contractual process with private, government, and other nonprofit organizations to determine realistic implementation timelines.

#### Set Realistic Goals

• Participants will utilize this type of intervention in different ways, at different rates, and for different reasons. Keep this in mind when assessing the impact of the intervention. This tool engages and empowers healthcare consumers to be advocates and active participants in their care.

#### Social Media Influencers

• Influencers can greatly increase exposure of the project. The images below show the same content posted on YGI's Instagram page (Left) verses an influencer's page (Right). There is a stark

difference in engagement, (e.g. 46 views on YGI as compared to 298 views on the influencer's channel).



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- 10) B, Genberg, Improving engagement in the HIV care cascade: A systematic review of interventions involving people living with HIV/AIDS as peers AIDS Behav. 2016 Oct; 20(10): 2452–2463.
- 11) MR, Kaufman, Health Behavior Change Models for HIV Prevention and AIDS Care: Practical Recommendations for a Multi-Level Approach J Acquir Immune Defic Syndr. 2014 Aug 15; 66(Suppl 3): S250–S258.

## APPENDIX SECTION

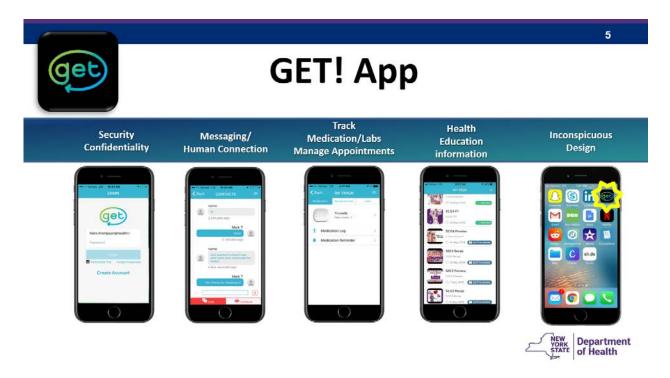
## Appendix list:

- 1. YGI Protocol documents
- 2. Implementation Flow Chart and Overview
- 3. YGI Implementation Timeline
- 4. ACASI Survey Tutorial
- 5. PEEP Messaging Guidance and Schedule
- 6. YGI Social Media Marketing Manual
- 7. Authorization for Release of Health Information and Confidential HIV Related Information Form
- 8. Consent form
- 9. Conference Abstracts
- 10. Enrollment Checklist
- 11. Links to GET! Dashboard Tutorial
- 12. Links to YGI Tracking Tutorial
- 13. "Tested" Poster
- 14. Screening documents
- 15. YGI Trainings
  - i. PEEP Training Courses
  - ii. PEEP Social Media Guide
- 16. PEEP Expectations and Responsibilities

# **Appendix 1: PEEP Responsibilities and Expectations**

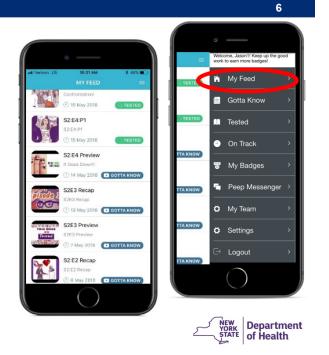
Role	Expectations	Responsibilities
Peer Engagement Educator Professional (PEEP)	Interact with patients age 18 to 34 who are living with HIV to identify those who are newly diagnosed, not actively engaged in HIV care, are not virally suppressed, or are struggling to remain adherent to HIV care.  Assist with the timely entry of young people into HIV care and the prevention of vulnerable youth from dropping out of care.  Collect data using the ACASI survey software.  Collect and report data to UCLA ETAC and YGI team members.	<ul> <li>Establish and maintain communication process (e.g. meetings, trainings, etc.) with Project Coordinator</li> <li>Complete required YGI trainings</li> <li>Recruit participants at the Engagement Hub during clinical visits, and through emails, phone calls and SMS text messages.</li> <li>Enroll patients in YGI project</li> <li>Utilize the GET! app to communicate with the participants, to engage participants in one-to-one conversation, and provide education about HIV and sexual health.</li> <li>Communicate with YGI partners as need.</li> <li>Must be a "Beacon of Knowledge"         <ul> <li>Stay abreast of what is happening in HIV/STI Care and treatment</li> <li>Be aware of specific pervasive misinformation</li> <li>Be able to deliver complicated health information in a easily understandable way</li> <li>Know the jargon</li> </ul> </li> <li>PEEPs will contribute to the GET! Development and quality improvement processes.</li> <li>Engagement hubs must advertise and promote YGI program.</li> <li>Work with Y Get It? Project Coordinator to plan for the onboarding of additional PEEPs.</li> </ul>

# **Appendix 2: GET! App Features**



# **News Feed**

- Short videos and articles
- Health and wellness
- Disease specific information
- Links to resources

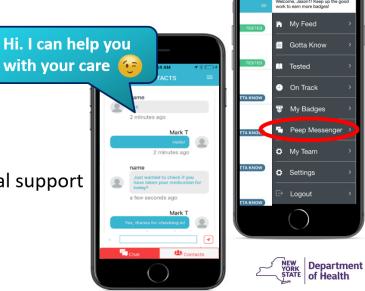


Messaging

• Build rapport

• Facilitate care logistics

• Provide social & emotional support

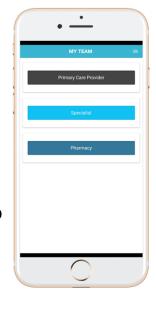


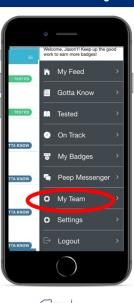
**Contacts** 

• Easily connect to care team

Customizable

• Email or call directly from the app

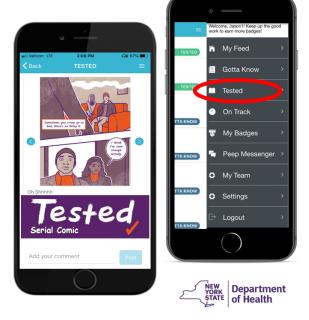




NEW YORK Department of Health

# **Tested Comic**

- Easily connect to care team
- Customizable
- Email or call directly from the app



10

# **Track Care**

# Medication

- Image of each prescribed pill
- Dose
- Medication Log
- Reminders

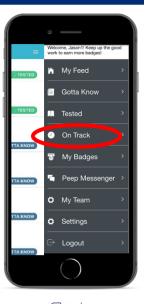
# **Appointments**

- Doctor
- Time
- Place
- Reminders

## Labs

Customizable





NEW YORK Department of Health

# **Appendix 3: YGI Social Media Training**

# **YGetIt? Project**

Social Media Marketing Training Manual

## **Table of Contents**

<b>Chapter 1: Manual Overview</b>	3			
1.1 About the Manual				
1.2 Audience				
1.3 Prerequisites				
1.4 Disclaimer				
Chapter 2: About YGetIt? So	cial Media M	arketing		4-9
2.1 Mission				
2.2 Vision				
2.3 Brand Promise				
2.4 Audience Insight				
2.5 SCOT Analysis				
2.6 Marketing Strategic	Plan			
2.7 Social Media Object	tives			
2.8 Social Media Goals				
Chapter 3: Strategies & Tacti	ics (All Platfo	rms)		10-15
Chapter 4: Facebook	16			
Chapter 5: Twitter	17			
Chapter 6: Instagram	18			
Chapter 7: Social Media Repo	ort Template.	•• •••••	•••••	19

## **Chapter 1: Manual Overview**

#### 1.1 About the Manual

Social media marketing is the activity of driving website traffic and organizational goals through social media channels. This is a brief manual that explains how to use popular social media platforms such as Facebook, Twitter, and Instagram to promote the YGetIt? (YGI) Project and create greater awareness about YGI services.

#### 1.2 Audience

This manual is designed to assist YGetIt? marketing efforts to improve the quality and performance of YGI's social media platforms.

#### 1.3 Prerequisites

Before proceeding with this manual, it is important to understand the fundamental concepts of marketing, advertising, and analyzing audience. Please review the <u>YGetIt? Social Media Strategic</u> Plan.

#### 1.4 Disclaimer

All the content and graphics published in this manual are the property of the New York State Department of Health AIDS Institute. Reuse, duplication, distribution, or republication of any contents this manual in any manner without written consent of the publisher is prohibited. This is a fluid document. Updates will occur quarterly or as needed.

## **Chapter 2: About YGetIt? Social Media Marketing**

This chapter provides a holistic understanding of the history, mission, and operation of the YGetIt? project.

#### 2.1 Mission

The mission of the YGetIt? Project is to facilitate the timely entry of young people (ages 18-34) into HIV care, the prevention of vulnerable youth from dropping out of care, and achievement of sustained viral load suppression among those in care. YGetIt? is comprised of a mobile application--developed in collaboration with Mt. Sinai App Lab—and Peer Engagement Education Professionals (PEEPs) placed at two engagement hubs: Long Island Crisis Center Pride for Youth and Northwell Health.

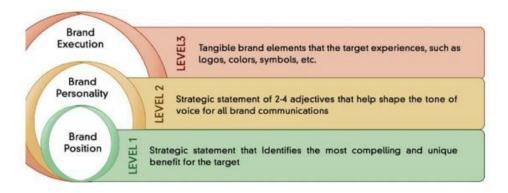
#### 2.2 Vision

The vision of the YGetIt? is to be recognized as a leading catalyst for advancing HIV/AIDS linkages, engagement, access to HIV treatment, and support resources and tools via digital and social media tools.

## 2.3 Brand Strategy and Positioning

A brand is a summation of everything a target audience knows and feels from using a product or service. Positioning is the core of brand strategy. It declares what your product/service/behavior stands for by identifying its unique benefit and conveying it to the target audience.

The brand onion consists of three levels; Brand Execution, Brand Personality, and Brand Position. Brand execution includes the tangible 'executional' elements that a brand can own in the minds and hearts of the target market. Brand personality is a strategic statement of 2-4 adjectives that helps share the tone of voice for all brand communications. It determines that packaging, advertisement, and name of the brand.



Brand positioning is a long-term proposition that can't be easily changed. It includes a positioning statement, a sentence that captures what the brand stands for from the perspective of the consumer. It defines the target audience, the frame of reference, and the core benefits that make the brand unique. A positioning statement is not a slogan, instead is an internal tool to guide the marketing strategy and execution. A The positioning statement has three parts: target audience, frame of reference (competition) and point of differentiation

A positioning statement template:

For	(target),	(brand name) is the	(frame of reference), that
is	(PoD).		

YGetIt? is a call to action dedicated to changing the circumstances of HIV-affected young adults. It transforms the way they approach their HIV management through supportive peers, evidence-based monitoring and evaluation, and digital media assistance. The brand promise of YGetIt? is to link, retain, and suppress the viral load of HIV-positive individuals take meaningful steps in their journey with HIV/AIDS for empowerment today.

#### 2.4 Audience Insight

Audience insight provides context for implementation of a project. Key factors such as age, gender, lifestyle, and behaviors must be assessed to develop goals and adopt appropriate strategies to achieve those goals.

A summary of key information gathered through baseline surveys (primary research) and experience working with the target population through focus groups, census, knowledge/behavior surveys (secondary research) is used to create an Audience Profile.

A strong audience profile includes qualitative research as a source to generate a wealth of in-depth audience insight. The profile is a living document; and thus, needs to be regularly updated as new information becomes available. Additionally, it is key to document daily routines of the target population to help inform marketing decisions from brand positioning to media placement.

When making decisions about communication materials or distribution strategies, we should continually refer to the audience profile. Use the audience profile template below as a reference.

**Audience Profile:** Josh

[a name for the profile] Josh

**Background:** a summary of all key information about the target population can capture its overarching idea

**Demographics:** age, sex, gender, hometown, marital status, education, Socioeconomic Status (SES), employment, accommodation etc.

**Psychographics:** dreams, wishes, needs, attitude, intentions, concerns and worries, values, etc

Characteristics of behavior, use of product and service: behavior, buying habits, frequency of using certain product or service

**OAM:** opportunity, capacity and motivation

Media care habits: Any information about what media is consumed and when, where or how

Perceived benefits of, barriers to the promoted, and current behaviors

The current target population for the YGI is HIV-positive young adults aged 18-34 years old. Further analysis of the social media channel insights will allow the team to identify segments of the current population. Typical segment designation for research populations are: loyals, low engagers, and non- users. Loyals are engaged individuals who are active users of the GET! App. Low engagers are a group of individuals who are followers but have not evolved to active app users. Non-users/unengaged are individuals who are neither users nor followers.

## 2.5 Situation and SCOT Analysis

The SCOT analysis is a strategic tool that is utilized to identify YGI social media strengths, challenges, opportunities, and threats. Strengths and challenges are internal factors, while opportunities and threats are external factors.

**Table 2.1 Social Media Channels** 

Social media tool	Channel URL	Purpose/description
Facebook	facebook.com/YGetIt/	Facebook is a hub for both the comic serial, Tested, and ongoing trends, news, education, and events in the HIV community
Twitter	twitter.com/ygetit	Twitter is used for quick news and support updates, driving most users to Facebook and Instagram

#### **Strengths**

- The YGI social media platforms provide objective facts and calls to action on HIV/AIDS awareness
- The serial Tested is a driving force for traffic to the platforms
- There are a designated marketing/social media staff who are dedicated to the goals of YGI
- The platforms have a culture and a voice that are positive and supportive due to the enforcement of the following core values: cooperation, courage, inspiration, integrity, perseverance, and respect
- The social media platforms have a founded persona: a cool friend, supportive peer, with cheerleader personality, upbeat, understands pop culture references, not preachy nor paternalistic

#### Challenges

- There is low market awareness of YGI since it has been recently launched
- There is no frontier between the target community and the brand
- The platforms are not receiving the support needed from media outlets
- The social media (SM) team is aware of user experience and algorithms of each platforms Platform-specific data is available; however, it requires in depth analysis to translate to meaningful reports that provide process and quality improvement recommendations

#### **Opportunities**

- YGI presents an array of upcoming high-profile special and exciting events worth capturing on social media, such as the Digital Health Technologies conference in December and the Clinical Education Initiative forum in October. Other initiatives including product app launch statewide
- The platforms can capitalize on current social media trends to increase reach and engagement including using influencer endorsement and live streaming events
- Analyze competitors continuously to keep up with market trends

#### Threats

- The social media platforms are facing mediocre engagement
- Brand impersonality is still a key issue. For this brand to come to fruition, the AIDS Institute will need to have a brand guideline booklet in place

## 2.6 Marketing Strategic Plan

The mission of the overall marketing plan is to increase the visibility and awareness of YGI, its mission and goals through educational and inspiration marketing campaigns, informative digital outreach and social media interaction and conversation in the local and national communities. The following section outlines key social and digital media outlets that are leveraged by YGetIt?, strongly

centered on social media marketing and offline audience engagement:

- Mobile Website: YGI will launch a mobile-first website where users can access basic website content and application login from other devices such as laptops, tablets, and smartphones. This mobile website will include, but not limited to, the following pages: about, use the app, events, community, tutorials, and "Tested" serial. The website will increase our Search Engine Optimization (SEO) traffic, that is our web presence; thus, increasing our user base and consumption. Additionally, it will act as a backup option, as part of our risk management plan, should the mobile application encounter operational difficulties.
- Comic Serial "Tested": The comic provides a portal to a diverse group of young characters living and managing HIV. The cast represent the daily realities of YGI target population and mirrors the vernacular, personas, and voice of the YGI Brand. Tested attracts users and potential leads and can redirect them to use the mobile app and the social media platforms.

## 2.7 Social Media Objectives

For FY 2017-2018, YGI aims to achieve the following objectives:

- 1) Develop the application as a community for support, awareness and disease management
- 2) Become a leader in the field of mobile health applications, specifically in HIV management for decreased viral load and increased HIV linkages
- 3) Establish a strong forum of community discussion and engagement
- 4) Leverage social and digital media outlets to create consumption and engagement of the GET! mobile application
- 5) Educate and empower the next generation of YGI users for HIV management

#### 2.8 Social Media Goals

Table 2.2 YGetIt? Social Media Goals

<b>Business goals</b>	Social goals	Definition	Metrics/examples of measurement
Create a community and thought leadership around brand	Consumption	How many people viewed, downloaded, or listened to the content? Do people consuming this content come back for more?	Pageviews: using web analytics like Google analytics Video views: YouTube Insights Document views: SlideShare, Scribd provide access to this data Downloads: CRM platform, Google analytics Social chatter: Mention.net, Radian6, Sysomos, Viralheat
Increase brand awareness and product traffic/engagement	Share, Likes, Retweets	How resonant is this content? How often is it shared with others?	Likes, shares, tweets, +1s, and pins: sharing tools, Google analytics Forwards: Google analytics, your email provider Inbound links: Open Site Explorer, Raven Tools, Majestic SEO are

<b>Business goals</b>	Social goals	Definition	Metrics/examples of measurement
			blogging software
Generate leads	Actions	How often does content consumption result in a lead?	For completions & downloads: your CRM and URL sharing measures how often visitors access gated content Conversion rate: How often do visitors who consume content become leads? The rate is key to viewing lead-gen from the highest level
Drive sales (i.e. new users)	Conversions	Did we actually make any behavioral impact, new clients, or because of this content?**	Manual reporting & anecdotes: qualitative reporting from surveys and questionnaires

## **Chapter 3: Strategies & Tactics (All Platforms)**

This section outlines YGI social media strategy. Market research confirms YGI must reach and engage individuals in the 18-34 age range. YGI's social media strategy will use platforms that are popular with this group and create engaging platforms specific content. The project does phenomenal work with Instagram. However, it needs to strengthen its Facebook and Twitter footprint and continue its strong presence on Instagram. This section concludes with the following recommendations:

#### 3.1 Strategies

- Establish a YGetIt? brand and social media philosophy
- Establish social media and marketing advertising budget
- Invest in monitoring and evaluation tools
- Position social media as a core component of launches and event marketing
- Implement focused tactics for each social media tool
- Employ digital/mobile health strategies for YGI website

#### YGI can implement these strategies by:

- Leveraging the expertise of social media and marketing analytics to drive decision-making
- Incorporating the social media plan with branding in marketing plans and toolkit
- Improving a weekly social media schedule with the below content, engagement, and data analysis tactics

#### 3.2 Tactics (All Platforms)

#### Content

Weekly commitment: Content generation and management requires 5 hours of work per week

• **Graphic Design:** There are free tools to create visually-appealing graphics, specifically developed for YGI target audience and business digital needs. Two of these resources are <a href="Canva">Canva</a> and <a href="Gimp">Gimp</a>. Canva is a free platform targeted for social media designs for beginners. With a quick tutorial, Canva enables you to bring designs to your target audience to increase a brand's social media presence. Gimp is an image manipulation program, which is also free of cost. Other traditional tools include, but are not limited to, Photoshop, InDesign, and Pixlr.

#### Posts

- Strategy: Adjust content curation for massive growth from the current 4-2-4-2 (4 parts original from you, 2 curated from others) to 50% curated content, 25% content from you, 20% engagement, and 5% promotional respectively
- Videos: Given our audience insight (18-34 years old), the best videos to attract the highest reach and impressions are personal stories, inspirational short videos, informational videos with meaningful resources, and "Tested" comic serial recaps. Videos also include gifs and live posts via Facebook and Instagram.
  - **Live-streaming video** is on the rise with 14% of marketers experimenting with it in 2016 and a predicted 43%. Many brands use interactive video content to engage with followers by bringing live stream events.
- Pictures: Share or create pictures related to the interests, motivations and intents of our audience. See <u>Audience Insight</u> for more information. Pictures need to follow a color scheme. YGetIt?'s color palette consist of purples, oranges, and browns. For all pictures reproduced that YGI does not own, it's common practice to state which entity owns the materials in a tag. From current data analytics, YGI audience respond best to pictures with inspirational quotes, pictures that humanize diseases.
- **Links:** Shorten website links via <u>hootsuite</u>, <u>bitly</u>, or <u>goo.gl</u> on status. It is pivotal to include shorten links to and resources and the YGI website.
- **Status:** include pop culture references, anniversaries, fan/follower shoutouts, thank yous, milestones, relevant and concise digital resources, giveaways, polls and surveys, and influencer materials.
  - **Personalizing content** by taking advantage of Facebook re-targeting that allows social media teams to craft adverts and content driven by identifying what the audience's preferences and interests
- Hashtags: Popular hashtags used in alignment with YGI brand are #Tested #YGetIt #sexeducation #sexed #HIV #STD #HIVPositive #AIDSAwareness #LGBTQ #love #staywoke #transgender #queer #queerpride #transpride #trans #WorldofTerrence #motivation #stayhealthy #hivaids #gettested #serial in addition to special occaisons or holidays such as #happyfourthjuly #merryxmas #gaynyc

## **Engagement**

**Weekly commitment:** User engagement requires 2 hours of work per week, which yields a minimum of 17 minutes daily.

- Users: There are two main methods to engage with users to create the strongest user experience. Engage daily with user comments and via private messages. Messages can be leveraged to ask for surveys. Engagement is key for both positive and negative feedback on YGI platforms. Marketers can capitalize on negative feedback and convert to leads. Examples of interacting with users via comments: "Thank you for your support @JohnDoe!" or "Happy Friday! Thank you for following us @JohnDoe! #fbf #followfriday #tgif".
- **Influencers:** Influencers help to endorse and promote our brand. Promotion of other brands allows YGI to tap into audiences of those brands and build a community.
- YGetIt? Team: YGI users appreciate moments that highlight the teams working behind the social media posts. Therefore, post behind-the-scenes such as "Working on our next comic serial featuring our awesome writer @JohnDoe! Look out for season 2 of #Tested" are encouraged to connect with users.
- **Mobile Advertising:** Leverage platform advertisement to increase user reach and consumption. This will require a social media budget with appropriate pricing strategy from every platform

## **Monitoring and Evaluation**

Weekly commitment: Data analysis requires 3 hours of work per week.

- **Monitoring:** There are a variety of tools to find relevant content that can be featured on the YGI Social media platforms, such as the following:
  - Google Alerts: Receive news alerts about HIV management resources, tools, centers, events, and mobile health apps
  - <u>SocialMention.com</u>: Similar to Google Alerts, but emphasizes search results from social media outlets.
  - Twitter Search: Check what others are saying about YGI through Twitter
- **Data Analysis:** To increase social media return on investment (ROI), YGI needs to evaluate the data garnered from analytics tools. To collect insights data, use the following:
  - HootSuite: is an online analytics tool that showcases a social media dashboard with various outlets. It allows marketing professionals to schedule updates to social networks via desktop or mobile platforms. Additionally, HootSuite tracks campaign results, industry trends, and provides analytics reports.
  - <u>Facebook Insights:</u> This is Facebook's premier analytics tool. Focus on Monthly Active Users, Lifetime Likes, Post Views, and Post Feedback. As outlined in the table below, it is important to monitor and create analytics reports on a weekly and monthly basis.
  - <u>Twitter</u>: For Twitter analytics, the following tools can be utilized: <u>Twitalyzer</u> and <u>Twitter Counter</u>. Like Facebook, it is important to monitor and create analytics reports on a weekly and monthly basis.
  - <u>Instagram</u>: The top Instagram analytics tools used by marketers are <u>Iconosquare</u>, <u>SimplyMeasured</u>, InstaFollow, <u>Union Metrics</u>, and <u>Crowdfire</u>.

• Surveys and Focus Groups: Create quarterly social media surveys in order to engage YGI audience feedback in its social media campaigns.

Data collection and reporting methodology need to be monitored daily across all social platforms. Posting schedules should be adjusted weekly to ensure YGI social strategy is aligned with user behaviors and trends. Full engagement reports will be compiled and distributed monthly.

Table 3.2 YGetIt? Social Media Analytics Report (as of June 21, 2017)

Date	Lifetime Total Likes	# change	% change	Monthly Active Users	# change	% change	Daily Likes and	% change
							Comments - Total	
	Lifetime The tot who have liked Count)			Monthly The number interacted with or viposts. This includes Fans & non-Fans. (U	ewed your l	Page or its from	Daily Likes of Page's content Count)	
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5/15/2017	13	0	0.00%					
5/31/2017	15	2	15.38%					
6/15/2017	25	10	66.67%					
Facebook Average		3	22.60%					
4/15/2017	4	n/a	n/a		n/a			n/a
4/30/2017	24	20	500%					
5/15/2017	25	1	4.17%					
5/31/2017	29	4	16%					
6/15/2017	36	5	24.14%					
Twitter Average		7.5	136.08%					
4/15/2017	46	n/a	n/a		n/a			n/a
4/30/2017	72	26	56.52%					
5/15/2017	84	12	16.67%					
5/31/2017	94	10	11.90%					
6/15/2017	113	19	20.21%					
Instagram Average		16.75	26.33%					





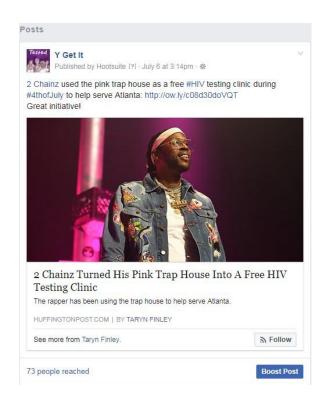
















Log in to like or comment.



## **Chapter 4: Facebook Tactics**

As of July 11, 2017, YGetIt? Has a fan base of 35 on <u>Facebook</u>. Through consistent effort with targeted paid advertisement, the project should aim to reach 1,000 fans by December 31, 2017 (at a monthly growth rate of 13.93%). The social media team is advised to implement the following strategies and tactics in order to reach its goal:

## **Audience Insight**



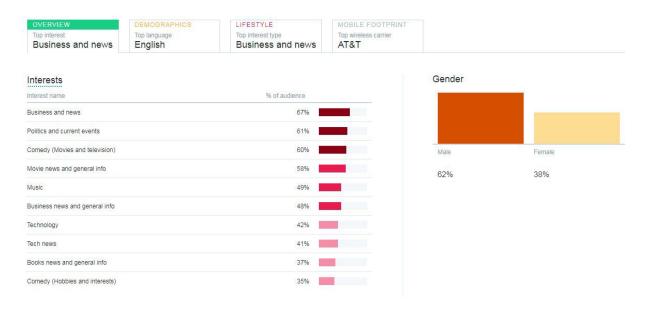
#### 4.1 Tactics

- **Posting Times/Days:** Best posting days for YGI's Facebook are Saturday, Sunday, Tuesday, Wednesday, and Friday. Best posting times are 1pm, 3pm, and 7-10pm. Posting at 3pm will get the most clicks, while 1pm will get a brand the most shares. Our audience seems to have an elevated mood on Fridays, so funny or upbeat content fits in this happiness index.
- YGetIt? Branding: Highlight YGI logo and graphics and distinguish the serial "Tested" as a core component of YGI.
- **Influencers:** Invite social celebrity and like-minded influencers to like and promote YGI page and materials. An example of a comic influencer is NYC Comic Con for the Tested serial.
- **Engagement:** Interact with the audience members, including influencers and popular brands, by asking questions and replying to inquiries in a timely manner. This means approaching users via direct messaging or within the comments section as an added engagement tool. Additionally, create new opportunities for audience engagement by implementing competitions, giveaways or polls.
- Targeted Content: include live videos, personal stories, anecdotes, inspirational pictures, relevant events, community support resources, YouTube videos, HIV management news and articles, quotes, and 'Tested' episodes.

## **Chapter 5: Twitter Tactics**

As of July 12, 2017, YGI has 47 followers on <u>Twitter</u>. The project should aim to increase the number of followers to 500 fans by December 31, 2017 (at a monthly growth rate of 13.26%).

## **5.1 Audience Insight**



#### **5.2 Tactics**

- Posting Times/Days: YGI's Twitter best posting days are Monday, Wednesday, and Friday.
  Best posting times is between 3-6:30pm. Twitter users are 181% more likely to be on Twitter
  during their commute. Wednesday around noon and 5-6pm are peak moments during
  employees' breaks
- **Data Analysis:** Monitor what individuals are saying about YGI by checking mentions and retweets daily. Use Twitter Analytics and Followerwonk to track data on your own followers to find the best times to tweet
- Engagement: Engage in meaningful chats and conversations with fellow organizations, patrons and fans. Continue to follow applicable organizations (e.g. HIV advocates, health institutions). Because of the rate of communication that occurs on Twitter, it is advisable to tweet a minimum of five times a day. Answer all inquiries and comments in a timely manner
- **Opportunities:** Create opportunities for future launches, such as "Stay tuned for our new season of Tested" and for interaction with patrons through targeted chats (e.g. #YGetItChat)

## **Chapter 6: Instagram Tactics**

As of July 2017, total followers at YGetIt?'s <u>Instagram</u> channel is 130. YGetIt? should aim to increases the number of total views 114 to 1,000 by December 31, 2017.



#### **6.1 Tactics**

- **Posting Times/Days:** YGI's Instagram best posting days are Monday and Friday. Post content more during off-work hours than during the work day, aside from peak times. Posting a video on Instagram at 9pm gets 34% more interaction. Use <u>Iconosquare</u> for Instagram analytics.
- Content: Exciting social content including ephemeral content are on the rise. To showcase a brand's personality on Instagram with authentic, unscripted, unpolished content can include how-to videos, behind-the-scenes looks, contests and giveaways, interviews, live events, daily or weekly video series, holidays, and announcements or product reveals. There is a higher focus on Instagram for stories as this platform introduced its stories feature in August 2016. Diversify posts to include pictures of inspiring quotes, real people stories, and serial segments

**Engagement:** Upload dynamic video content once to twice a month such as the future launch of GET! Mobile app, serial comic narrative storytelling,

testimonials, and app tutorials (for future use). Hire video interns to capture footage at exhibition openings and other special events related to YGI Empower staff members to utilize their smartphones and capture videos and tag YGI Create post segments such as: user stories, "ask the staff" segment, curator's corner, "a message from the AIDS Institute," and "behind the serial making." Collect app reviews and reactions on camera (for future use when launched statewide). Conduct video interviews with staff and users. Have behind the scene teaser for the project, app and events.

# **Chapter 7: Social Media Report Template**

Provided is a sample <u>excel template</u>. Below are screenshots from the template.

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## **Appendix 4: Hub Recruitment Outline**

Participants for YGI were recruited exclusively at Northwell Health's Center for AIDS Research and Treatment (CART). Hub staff employ the following tactics for recruitment, enrollment and follow-up ACASI survey administration.

#### **Phone and Email**

Patient lists are regularly reviewed to identify potential/current enrollees. Once identified PEEPs contact via email and phone calls to discuss participation in the YGI Project.

#### **Appointment Schedule**

The daily appointment schedule is reviewed the prior evening and all patients 18-34 living with HIV are flagged for YGetIt? recruitment/enrollment/ACASI survey administration.

#### **Health Education Alert**

Each morning an Email Alert is sent to the CART Team to identify patients who will meet with the YGetIt? PEEP during their appointment.

#### **Screening**

When the patient is ready to meet with the PEEP, the Medical Assistant alerts the PEEP. The PEEP then meets with the patient and screens for eligibility/ enrolls / administers ACASI survey.

#### **Consent & Enrollment**

If the patient meets eligibility and consents to participating in the YGetIt? research project, the enrollment process begins.

## **Appendix 5: YGI In-person Screening Script**

- 1.) Hi (<u>patient first name</u>), my name is (<u>PEEP name</u>), and I'm an employee here at Northwell. We are conducting a study that I wanted to tell you a little more about. I got your information through (<u>doctor/nurse/clinic recruitment</u>, <u>etc</u>). I wanted to ask you a couple of questions if that's alright.
  - *If yes:* continue below at 2.
  - If no: Is there a better time for me to reach you? I can also give you a phone number to call back if you would prefer.
    - If BETTER TIME and patient wants to be contacted later, notate in tracking sheet, then go to CLOSE.
    - o If patient REQUESTS A NUMBER, "You can reach us at xxx-xxxx between the hours of xx and xx. If no one answers, please leave a message for (PEEP name) and I will call you back personally." Go to CLOSE
  - If hard refusal: I'm sorry to have disturbed you and we will make sure to take you off our recruitment list. END

#### **SCREENING**

- 2.) To tell you a little bit more about the project: We are developing a mobile app to help people track their medication adherence and medical appointments. Would you mind if I ask you a couple of questions to determine your eligibility for the study?
  - o If yes, proceed to SCREENING TOOL
  - o **If soft refusal**, "If you change your mind you can contact me at xxx-xxx between the hours of xx and xx. If no one answers, please leave a message for (PEEP name) and I will call you back personally. **Go to CLOSE.**
  - o *If hard refusal*: I'm sorry to have disturbed you and we will make sure to take us off our recruitment list. *END*

#### **SCREENING TOOL**

Screening Questions for Y Get It?

A potential participant needs to meet all 7 of the criteria below in order to be considered eligible for the Y Get It? Study. PEEP must keep track of eligibility and consents through the PEEP Tracking Tool (Screening Tab).

#### Criteria for eligibility

	•			or spanish fluentry?
	)	/es	No	If Yes, person is eligible
2.				Are you HIV+?
	Ŋ	es	No	* Unknown*
ī	f Ves ne	rson is e	ligible *If th	ey don't know, they should be linked to testing
			_	·
		-	ening criteria.	le if they get a positive HIV diagnosis and meet
<b>3.</b> A	Are you be	etween tl	ne ages of 18	and 34?
	-		_	If Yes, person is eligible
4. <i>E</i>	TAC Crit	teria:		
				Must be eligible for at least one of the
followin	g:			and the second s
jettemi	8.			
Newly	Diagnose	d:		
a.				When were you diagnosed with HIV?
	Date: _			
				ago, person is <b>eligible</b>
Out of	care/Not <sub>s</sub>	tully reta	ined in care:	
b.				When was the last time you received HIV
	rior to to	dav?		when was the last time you received in
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	Date: _			
*If last	annointm	ent was	more than 6	months ago or patient has not been in care prior
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c.				Is your viral load
suppre	essed/und	etectabl	e?	
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*If vira	ıl load is ı	ınsuppre	ssed or perso	n does not know viral load, person is <b>eligible</b>

Must be eligible for **ALL** following:

<b>5.</b> 3	Do you hav	e your own p	ersonal function	ning smart phone?
	•	Yes	No	If Yes, person is eligible
<b>6.</b>	Do you liv	ve in New Yor	rk State?	
	•	Yes	No	If Yes, person is eligible
7.	Do you ha	ave any plans	to leave NYS fo	or more than 6 months within the next
	year?			
	•	Yes	No	If No, person is eligible
				, -

#### IF ELIGIBLE

According to these answers, you are eligible for participation in our HIV management project called Y Get It? Our app is called GET.

• CONSENTING and ENROLLMENT

To participate in any health study we are required to get your signed consent.

(Go through entire consenting and enrollment process. If patient would like to reschedule a time to finish enrollment, take down their information and date that they would like to come back. Send them a reminder call two days before that date). GO TO CLOSE

#### IF INELIGIBLE

I'm sorry, you do not meet the eligibility requirements to participate in this study because (<u>reason for ineligibility</u>). If the study is successful in helping people manage their health, the App will be made publically available.

#### **CLOSE**

3.) Thank you for taking the time to speak with me. Enjoy your day! **END** 

## **Appendix 6: YGI Phone Screening Script**

#### **OPEN**

- 1.) Hello, my name is (*PEEP name*). Can I please speak to (*patient first name*)? (*Once patient is on the line*)
  - Hi (*patient first name*), I'm an employee here at Northwell and we are conducting a study that I wanted to tell you a little more about. I got your information through (*doctor/nurse/clinic recruitment, etc*). I wanted to ask you a couple of questions; Are you in a private location and able to speak with me?
  - *If yes:* continue below at 2.
  - If no: Is there a better time for me to reach you? I can also give you a phone number to call back if you would prefer.
    - If BETTER TIME and patient wants to be called later, notate in tracking sheet, then go to CLOSE.
    - o If patient **REQUESTS A NUMBER**, "You can reach us at xxx-xxxx between the hours of xx and xx. If no one answers, please leave a message for (PEEP name) and I will call you back personally." **Go to CLOSE**
  - If hard refusal: I'm sorry to have disturbed you and we will make sure to take you off our recruitment list. END

#### **SCREENING**

- 2.) To tell you a little bit more about the project: We are developing a mobile app to help people track their medication adherence and medical appointments. Would you mind if I ask you a couple of questions to determine your eligibility for the study?
  - o If yes, proceed to SCREENING TOOL
  - o **If soft refusal**, "If you change your mind you can contact me at xxx-xxx between the hours of xx and xx. If no one answers, please leave a message for (PEEP name) and I will call you back personally. **Go to CLOSE.**
  - o If hard refusal: I'm sorry to have disturbed you and we will make sure to take you off our recruitment list. END

#### SCREENING TOOL

Screening Questions for Y Get It?

A potential participant needs to meet all 7 of the criteria below in order to be considered eligible for the Y Get It? Study. PEEP must keep track of eligibility and consents through the PEEP Tracking Tool (Screening Tab).

Criteri	<u>ia for eligibility</u>		
1.	Can you read and spe	ak English	or Spanish fluently?
	Yes	No	If Yes, person is eligible
2.			Are you HIV+?
	Yes	No	* Unknown*
		ome eligib	ney don't know, they should be linked to testing ble if they get a positive HIV diagnosis and meet.
3.	Yes	No	Are you between the ages of 18 and 34?  If Yes, person is eligible
<b>4.</b> follow	ETAC Criteria:		Must be eligible for <b>at least one</b> of the
Newl	ly Diagnosed:		
a			When were you diagnosed with HIV?
	Date:		
*If d	iagnosis was less than	12 months	ago, person is <b>eligible</b>
Out o	of care/Not fully retain	ed in care:	•
b ca	are?		When was the last time you received HIV
	Date:		
		ore than 6	months ago, person is <b>eligible</b>
Viral	l Suppression:		
c. sı	uppressed/undetectab	le?	Is your viral load
	Yes No I	Oon't Kno	w

\*If viral load is unsuppressed or person does not know viral load, person is **eligible** 

Must be eligible for **ALL** following:

5.	5. Do you have your own personal functioning smart phone?							
	Yes	No	If Yes, person is eligible					
6.	Do you live in New	York State?						
	Yes	No	If Yes, person is eligible					
7.	Do you have any pla year?	ns to leave N	YS for more than 6 months within the next					
	Yes	No	If No, the person is eligible					

#### IF ELIGIBLE

According to these answers, you are eligible for participation in our HIV management project called Y Get It? Our app is called GET.

• CONSENTING and ENROLLMENT

To participate in any health study we are required to get your signed consent.

(Ask the patient to come into the clinic so you can perform the consent and enrollment process. Note the day and time patient will come into the clinic in the PEEP Tracker). GO TO CLOSE

#### IF INELIGIBLE

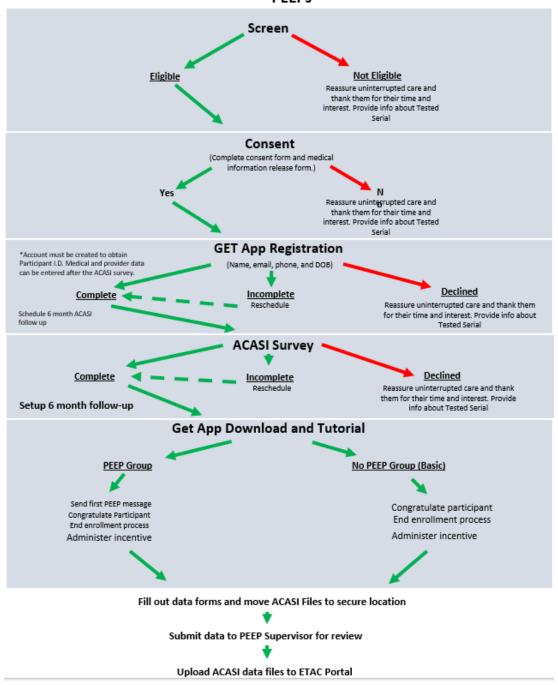
I'm sorry, you do not meet the eligibility requirements to participate in this study because (*reason* for *ineligibility*). If the study is successful in helping people manage their health, the App will be made publically available.

#### **CLOSE**

3.) Thank you for taking the time to speak with me. Enjoy your day! **END** 

## **Appendix 7 Enrollment Flow Chart**

# YGetIt? Project Enrollment Flowchart for PEEPs



# **Appendix 8: Y Get It? Project Enrollment Checklist for PEEPS**

## Total approximate time: 1h 15m

#### 1. Screening

□ Fill out screening tool

If eligible, move to step 2.

<u>If not eligible</u>, reassure uninterrupted care and thank them for their time and interest. Provide info about Tested Serial. Update *Screening Tracker*.

#### 2. Consent

- ☐ Explain and sign consent form
- □ Explain and sign medical information release form

If both signed, move to step 3.

<u>If refused</u>, reassure uninterrupted care and thank them for their time and interest. Provide info about Tested Serial. Update *Screening Tracker*.

#### 3. GET App Registration

- ☐ Create account for participant on Dashboard; requires name, date of birth, email, phone number
- □ App will generate Participant ID and Intervention Arm; notate this on consent forms: A=App, P= App + PEEP (i.e. <u>ID 7921 P</u> for Participant ID 7921 in the PEEP intervention)

If registration completed, move to step 4.

<u>If registration not completed but still interested</u>, schedule appointment for registration and ACASI for later date. Add date, time, and location of scheduled appointment to *Screening Tracker* Sheet – "Schedule First ACASI" column

<u>If refused</u>, reassure uninterrupted care and thank them for their time and interest. Provide info about Tested Serial. Update *Screening Tracker* and label them as refused consent. Bring consent forms to office and destroy in safe way (i.e. shredding with other medical info).

#### 4. ACASI

- □ Collect CD4 count, VL, medication, and provider information and add to Participant account on Get App
- ☐ Give brief introduction to ACASI survey, give participant the tablet to complete ACASI privately while you wait

<u>If ACASI completed</u>, move to step 5. Add participant to *PEEP RP* contact tracker and Longitudinal Tracking sheets in your personal tracker at the conclusion of the meeting. Schedule date for 6-month ACASI with promise to follow-up as a reminder.

<u>If ACASI not completed</u>, schedule appointment for registration and ACASI for later date. Add participant to *PEEP RP contact tracker* and *Longitudinal Tracking* sheets in your personal tracker at the conclusion of the meeting. Add scheduled appointment to *PEEP RP contact Tracker*.

<u>If refused</u>, reassure uninterrupted care and thank them for their time and interest. Add participant to *PEEP RP contact tracker* and *Longitudinal tracker*. Mark relevant ACASI session as "Hard Refusal."

- 5. Introduce Participant to Get App
  - ☐ Help Participant Download the App
  - ☐ Give Participant Brief Tutorial on App

<u>If App only group</u>, Congratulate Participant and end enrollment process.

<u>If App + PEEP group</u>, send first PEEP message to test. Congratulate participant and end enrollment process.

- 6. Immediate Post-enrollment Duties
  - $\hfill\Box$  Ensure all sheets in your personal tracking document are updated relevant to participant circumstances

If completed process, participant should be in both *PEEP RP* contact tracker and Longitudinal tracking with Baseline ACASI marked as completed and date filled in, ID added to both sheets, and intervention arm selected in Longitudinal tracking sheet. Scheduled 6-month ACASI should also be updated to reflect agreed on date.

☐ Ensure Participant ID is labeled on all signed forms

## Appendix 9: Y Get It? Daily & Weekly Checklist for PEEPS

## **Daily Duties:**

- □ Communicate with and be responsive to your assigned participants through communication on the app
- $\Box$  Log all interactions with participants in the *PEEP RP CONTACT TRACKER* sheet of your personal tracking document as soon as possible to maintain data integrity
- □ Log ACASI completion on *Longitudinal tracking*
- ☐ Fill our data forms and move ACASI files to secure location

## **Weekly Duties:**

□ Submit data to PEEP Supervisor for review by Friday Noon.

## **Appendix 10: YGI Training Course List**

## Y Get It?

## Using Social Media to Do What You Need to Do

#### Y Get It? Peer Education Training Courses

The following courses are introductory courses that are core to NYS DOH AIDS Institute strategic priorities. The *Peer Engagement and Education Professionals* (PEEPs) are required to take all these courses to become knowledgeable and trained to work with atrisk and young people living with HIV. Additionally, the listed courses should be used when onboarding of new or additional PEEPs are hired for the **Y Get It?** project. At the end of each course, PEEPs will receive a certificate of completion.

#### **Building Bridges to Cultural Competency**

This training explores the broad definition of culture and its relationship to competent and effective health care and human service delivery.

#### HIV Disclosure: Deciding Who and When to Tell\*

This training will increase health and human services providers' awareness of the multifaceted issues clients face when contemplating HIV status disclosure to family, friends and service

providers. Participants will develop the skills necessary to conduct timely ongoing assessments and discussion of HIV status disclosure as a component of effective service planning.

#### **LGBT Cultural Competency**

This training is designed to build the knowledge, attitudes and skills needed to enable non-physician health and human services providers to deliver culturally competent services to the diverse range of lesbian, gay, bi-sexual, transgender and questioning (LGBTQ) clients they serve. This interactive training will help providers identify best practices for creating a welcoming and safe environment for LGBTQ clients. It will also help participants identify communication skills needed for effective engagement of the wide range of LGBTQ clients at risk for, or living with, HIV, STIs or Hepatitis C.

#### **Motivational Interviewing**

This one-day training is designed for non-clinical providers working with clients presenting with high risk behaviors and/or those who are HIV positive. This course will provide an overview of the Motivational Interviewing approach and its value as a client-centered directive intervention. The course focuses on helping providers address client

ambivalence and the use of tools to help clients move towards less risky behaviors and change. Additional Level II and Level III training may be made available.

#### **Overview of STIs**

This two-hour webinar is designed to help non-clinical health and human service providers gain a basic understanding of common STIs to support their HIV/STI/VH prevention work. The training will review the similarities and differences in transmission, screening & testing, treatment, complications and prevention.

#### **Positive Prevention: Connecting Care and Prevention**

This one-day training will provide participants with updated information and strategies for promoting prevention among people living with HIV/AIDS. The latest research demonstrates that early initiation of treatment, retention in care and viral load suppression are critical to the health of people with HIV and also play a key role in reducing new infections. Participants will learn strategies for coupling messages about the importance of clinical care with behavioral interventions to address the risks associated with sexual and substance using behaviors.

#### Sex, Gender and HIV/STDs

This two-day training is designed to help health and human services providers promote sexual health among their clients by building their capacity to talk sensitively and non-judgmentally about sexual identity, gender identity and sexual behaviors. Topics to be covered during the training include: sexual and gender identity; strategies for talking with clients about sexual health issues; HIV/STD prevention and harm reduction strategies for sexual behaviors.

#### **Supporting Sexual Health Among Young MSM of Color**

This one-day training will explore the social factors that impact sexual and substance use behaviors among young men who have sex with men (MSM) of color. Health and human services providers will examine how these factors contribute to high rates of sexual and substance use risk behaviors among HIV positive and HIV negative MSM of color.

#### **Understanding How Antiviral Therapy Works**

This two-hour webinar is designed to provide information to support service providers on the importance of antiretroviral therapy and discuss the how the different classes of antiretroviral drugs disrupt HIV replication. Participants will also receive information on understanding and preventing drug resistance and the benefits of early initiation of antiretroviral treatment.

#### The Fundamentals of Social Media Marketing

This module covers a comprehensive introduction to the uses and impact of social media and how to effectively use the platforms for marketing and recruitment purposes.

#### **Social Media Bootcamp**

This multi-faceted portfolio provides à la carte learning modules for a number of websites and social media strategies. An account will be set up for the YGetIt? Project Team in March/April along with suggested modules for PEEP training.

## **Appendix 11: PEEP Messaging Guidance**

**Purpose:** The following document is meant to guide PEEPs regarding engagement with participants via the PEEP Messenger within the GET! mobile application.

#### **Messaging schedule:**

#### **During Enrollment**

1. PEEP sends message via GET! app to participants who are enrolled in the **PEEP+App arm** saying something along the lines of "It was great to meet you and thanks for enrolling! I'm here for you if you need anything". In your message, you could also mention something you may have bonded over during the enrollment process such as "Thanks for enrolling! Hope you enjoy that new Ramen place in Brooklyn-- So jealous! Know that I'm here for you if you need anything". The first message must be sent before the participant leaves the enrollment appointment.

#### After enrollment and going forward

Messages to participants serve a variety of functions and are based on behavioral change theories.

2. After enrollment, the schedule of messaging to all participants in the PEEP + App arm of the study is as follows:

#### Each week, messages must be sent on:

- a. Monday 9am
  - i. Messages delivered on the first Monday of each month will be reserved for personal stories. If PEEPs are HIV positive and comfortable discussing their status, they should tell a short story about their HIV journey. Stories should not be more than a paragraph or two. They can discuss challenges with medication adherence, medication side effects, dating, family life, etc. Please submit these messages to a supervisor for approval prior to sending.
- b. Tuesday 12pm
  - i. **Monday and Tuesday** (excluding the first Monday of each month) messages focus on building rapport and assessment of participant wellbeing. Phrases such as, "How's it going?", "How was your weekend?", or "Hey, how are you? Do anything fun over the weekend?", or "Hey just checking in to see how you're doing. What's new?" are ideal first messages. You can also lead with

something like, "Hey, how's it going? My Monday was terrible. How was yours?" or "I went to this amazing party over the weekend and made some bad decisions. LOL You ever have a night like that?". It is important to interject your own experiences and add authenticity to the conversation.

#### c. Friday 5pm

i. Fridays will be informational and motivational in nature. Phrases such as, "Are you running low on medication? Let us know and we can help you get a refill." and "Side effects giving you a hard time? We can help with that." Or "How's it going? Hope you're feeling healthy and strong!" should be used to prompt conversations, identify potential issues, and encourage action. You can also use emojis, see Figure 1.

#### d. Messages will also be scheduled for holidays.

i. Holidays will utilize all of these strategies. The message can change depending on the nature of the holiday for example, "Happy Thanksgiving!!! Don't forget to take your medication before you slip into a turkey coma." or "Happy New Year!!! You made it through another one virally suppressed. Congrats!! Keep up the good work."

Conversations should be dynamic/inviting and become more tailored to the individual as time goes on. PEEPs can reference the UCare4Life message list for inspiration, but messages should be modified to reflect individual PEEP voices. **Messages need to be returned promptly, within 24 hours.** 

#### **Ouestions and answers**

#### A. What if a participant doesn't respond to the message?

If there is a lapse in communication with a participant, i.e. they don't respond for a week or two, PEEP should send a re-engagement message. Something along the lines of, "hey, it's been a while---everything good?", is ideal. They should also notify that patient's case manager to avoid redundant contact.

#### B. What if PEEP will be out of town or unavailable?

PEEPs need to adhere to the messaging schedule. If a PEEP is going to be out of town or unable to send or receive messages, preparation must be made to maintain messaging. PEEPs must notify users if they are going to be absent and introduce users to the person covering for/ replacing them.

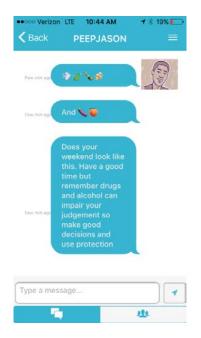
- C. What if participants ask not to be messaged again? Participants may request stoppage of these messages at any time. PEEPs will respect these requests and make note that a patient has asked that messaging be stopped in the PEEP Tracker.
- D. What if participant needs help with something related to their health that requires follow-up?

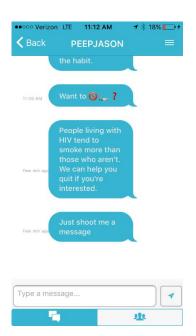
When participants ask medical question beyond the PEEP's knowledge or ability, PEEPs will consult the participants care team or refer the participant to their care team or crisis hotline. If PEEP chooses to consult care team, this must occur within 24 hours of the participant inquiry.

#### Note:

PEEP messaging will become available to all enrollees one year after their enrollment. Participants moving over from the basic account should be messaged as though they are new enrollees.

All messaging to participants should be tracked in the PEEP Tracker.





# **Appendix 12 GET! Familiarity Training**

Hub staff received multiple trainings prior to implementation of YGI. Implementation are designed to educate staff about used of GET! And GET! Dashboards and proper data collection and storage protocols. These trainings were delivered in person as well as via webinar. Find links to training webinars below.

### PEEP dashboard tutorial.

www.ygetit.org

**Data Collection Tutorial (Use of Tracking Tools)** 

www.ygetit.org

# **Appendix 13: ACASI Operation Instructions**

Use of Social Media to Improve Engagement, Retention, and Health Outcomes along the HIV

#### ACASI Breakout Session June 16, 2016 I 10:45am

#### A. ACASI Demonstration

#### 1. To review installation instructions for ACASI

- Each computer will need a separate license
- Software downloaded directly from Nova Research website after purchasing software
- Website link, serial# and password provided
- Download .EXE file that will contain modules you purchased
- Download voice module (voice option to be determined)
- See attachment for detailed instructions

#### 2. To review data file types

Files provided by ETAC (File names reflect names used for demonstration. Names will change during study. File extensions do not, e.g., **QSI** files will also have this extension):

- ETAC\_Social Media en [voice name]. QSI This is the ACASI interview file.
- ETAC.dict- Dictionary file to fix pronunciations in ACASI
- ETAC\_SocialMedia 2016-06-02.RTF -- This is the 'paper copy' of the self-administered questionnaire
- ETAC\_SocialMedia Codebook 2016-06-02.RTF-- This is the codebook that lists questions, variable names, variable labels, response codes, variable lengths, valid ranges, and allowed special codes.

# Data files create by ACASI:

- .QAD: Electronic database containing assessment data
  - o Only readable in QDS Warehouse
  - o Can contain multiple interviews
- .RTF: Text file containing responses in .QSI file o File name ends with participant ID (GUI)
  - o Separate file for each interview

# 3. To create a folder for .QSI (interview) file on laptop

• Open new folder in a location where you want your data files to be stored (will use desktop for demonstration purposes today)

Copy and save all the program files provided by the ETAC (i.e, .QSI, .DICT, .RTF) to folder you created

#### 4. To create a shortcut to folder on desktop

- Right click on .QSI file and select "Create shortcut" from dialogue box
- Use mouse to drag and drop shortcut to desktop

#### 5. To start a new interview

- Double-click on .QSI file, this will take you into the interview first screen
- To hear the audio, you need to turn on your volume control.
- For the purpose of the demo, please turn off.
- The first several screens are completed by the staff member.
  - o Participant ID number -> will have 10-character limit (will be updated to include letters, numbers, or a combination; no symbols)
  - o Interviewer initials or identification determined by demonstration sites
  - o Site ID
- Go through several screens to see how the questions appear.

### 6. To activate (make visible) the "Refuse to Answer" option button

- Click both the left and right mouse buttons simultaneously in the upper right-hand corner of the ACASI screen.
- If you are using a tablet without a mouse, "press and hold" in the upper right-hand corner. This is available for all the questions excepting ID information and Date of Birth.

# 7. To activate (make visible) the interviewer's comment box

- Click both the left and right mouse buttons simultaneously in the middle top of the ACASI screen. (Note: this currently is not working well, but we will try to get it fix.)
- If you are using a tablet without a mouse, "press and hold" in the middle top of the ACASI screen

#### 8. To save the ACASI interview

- There is a password at the very end of the survey to ensure that the respondent does not get access to the computer after completion.
- It is currently "1234".

### 9. To interrupt an interview before it is complete

• Use "Alt-F4" Or click both the left and right mouse buttons simultaneously upper left-hand corner of the ACASI screen.

- If you are using a tablet without a mouse, "press and hold" in the upper left-hand corner of the ACASI screen.
- NEVER USE "Ctrl-.Alt-Del" or Task Manager to interrupt or end an interview.

# 10. To go back or restart an incomplete interview

- CANNOT simply click on desktop shortcut, you must start new interview.
- Two step process
  - 1. Open ACASI program
  - 2. Select "Resume a prior interview" in dialogue box, then change file type to .QAD, then select incomplete interview file.

# **B.** Demonstration of Backing-Up and Renaming Files and Preparing for Weekly Uploads

# 1. Backup files <u>daily</u> from ACASI computers to local file server via encrypted USB drive

- At the end of each work day, save your .QAD and .RTF data files into at "Backup" folder.
- Rename the .QAD file using the following naming convention (e.g. Friends\_English\_m00\_060616.QAD, Friends\_Spanish\_m06\_120616.QAD)
- If you are backing up on a daily basis, you should hypothetically have 5 .QAD data files for a 5- day work week from one device.

# 2. Upload files <u>weekly</u> from local file server to the ETAC web portal-> we will provide more instructions once the data portal is set up.

#### C. Demonstration of Warehouse Manager

- 1. To create warehouse manager database file
  - Open Warehouse Manager
  - Click on "File" and then "New Warehouse" to create a warehouse database file (.QDW).
  - Select location to store **.QDW** file (we will select same folder we created for demonstration) and type file name
  - Click on "Open" and you will see a blank warehouse file

### 2. To save interview data (.QADJ file in warehouse database

- Use mouse to drag and drop .QAD file into blank warehouse file (.QDW)
- This will create a dialogue box for you to review individual interviews contained in .QAD file before they are moved to into warehouse file

- Highlight all interviews in dialogue box and use mouse to drag and drop them into blank warehouse file (if you have interviews that have been stopped and started, you will be notified by a message that the less complete interviews will not be retained in warehouse file)
- Click on red x in upper right corner of dialogue box to close it
- You will be asked if you want to save changes to .QAD file before closing it.
   Select yes as this indicates that files have been moved to warehouse in "Recorded" column.
- If you are done with warehouse file (e.g., do not have any other .QAD files to import interviews from), click on save icon and close (IMPORTANT to click on save icon to retain data from
- .QAD files, otherwise they will not be recorded in warehouse file)
- Note: This is as far as we will go with demonstration. You may need to convert interviews to a standard version or use other functions before data is ready for analysis.

### 3. To open an interview from within warehouse database to look at it

- Double click the interview, this will open a dialogue box for the interview
- Click the "Variables" tab

# 4. To edit interview from within warehouse database (3. only allows you to view data)

- Highlight interview you wish to make changes to by clicking on it
- Click on "Edit" tab
- Click on "Details" from pull-down menu (Alternatively, click on paper/pencil "Modify" icon)
- Enter your initials (any values can be entered, not a password, for tracking purposes to know who made changes)
- Dialogue box will open similar to 3., except that you can change responses to variables
- Double click variable for response you wish to change
- If you make changes, you should indicate the reason (e.g., "participant indicated different response after interview was completed")
- Once change has been made and reason for change has been entered, click on "OK" for variable dialogue box
- Click on "OK" for main dialogue box for interview unless you wish to change responses for other variables

This takes you back to main warehouse window.

# 

## To Download QDS 3.0 software:

- 1.) Go to following URL:
- 2.) QDS 3.0 Software Download
- 3.) Enter the following password along with other required information: (provided in e-mail) You will also need your serial number (provided in upper right corner of your invoice) (e.g. Q300W3062-002010-XXX)
- 4.) Click the Download button to download the software.
- 5.) Click the Save button to select a location on your machine to save the setup file.

# 

PLEASE NOTE: You must be logged on to an account with administrative privileges to install software and run the setup file below.

To unzip the QDS setup files and Install QDS, follow these steps:

- 1. Double-click on the file that you have downloaded, QDS\_30B.exe.
- 2. Click the Setup button.
- 3. Next, enter the password: (provided in e-mail)
- 4. Once you have entered the correct password, the QDS setup files will automatically be copied to your system.
- 5. The setup program will start. When prompted, enter your QDS serial number.
- 6. Follow the directions on each screen
- 7. When you reach the Setup Type screen, you will have a choice:
  - Typical: Select to install all modules purchased with this serial number on this computer.
  - Compact: Select to install with minimum required options. This setup type doesn't install the Help system or any sample files, including .bmp files.
  - Custom: Select to install a sub-set of modules purchased with this serial number on this computer. This should be used when modules from a single order need to be installed on multiple machines. This will take you to the Select Features box where you can un-check any modules that are not to be installed on this computer.
    - 1. Continue following the screens until the installation is complete.
    - 2. As a final step, check for any maintenance patches for 3.0 at URL: <a href="QDS Maintenance Updates">QDS Maintenance Updates</a>

# Getting help for QDS:

Technical support: <a href="mailto:support@novaresearch.com">support@novaresearch.com</a>

QDS Online Help QDS Video Tutorials

### \*\*\*\*\*\*\*\*\*\*\*\*ADDITIONAL ACASI INSTRUCTIONS\*\*\*\*\*\*\*\*\*\*\*

If you have purchased a license for the ACASI program and plan to use computer generated audio, you should also download one or more of the following voice font setup files:

```
att_natural_voices_v4.2_crystal16.exe (American Engish)
att_natural_voices_v4.2_mike16.exe (American Engish)
att_natural_voices_v4.2_mel16.exe (American English)
att_natural_voices_v4.2_rosa16.exe (Spanish)
```

Be sure to only install these after installing ODS, otherwise the text-to-speech feature

# **Appendix 14: YGI Consent Form**

The City University of New York School of Public Health

# CONSENT TO PARTICIPATE IN A RESEARCH STUDY

Title of Research Study: <u>Use of Social Media to Improve Engagement</u>, <u>Linkage to Care</u>, Retention, and Health Outcomes in HIV + Young Persons. *The Y Get It? Project*.

**Principal Investigator:** Denis Nash, PhD

Professor

CUNY School of Public Health 2180 Third Avenue Rm. 549

New York, NY 10035

(718) 530-0684

Denis.Nash@sph.cuny.edu

**Evaluator:** Diane Addison, MPH, MIA

**Evaluator** 

CUNY School of Public Health

2180 Third Avenue New York, NY 10035

(212) 396-7797

daddison@hunter.cuny.edu

<u>Site where study is to be conducted:</u> In a private room at participating health or community centers affiliated with Northwell Health and Pride for Youth.

Pride for Youth

2050 Bellmore Ave, Bellmore, NY 11710 (2nd floor)

Northwell Health. 300 Community Dr. Manhasset, NY 11030

You are being asked to participate in a research project because you completed the screening process and are eligible to participate in the study.

What is this study about?

The purpose of this research project is to better understand how the use of Apps, social media, and peer mentors can encourage young persons living with HIV to get health education information and increase their access to HIV care services. The results of this project may help HIV-positive young people (between the ages of 18 and 34) stay in HIV care and help them take their medication regularly to keep them healthy. For this study, we will recruit up to 170 participants that will be divided into 2 groups: Group A: Half of participants will get a peer mentor also known as a PEEP (Peer Engagement and Educator Professional) from the start, while the other half (Group B) will start with interacting with the App alone and will get a PEEP 6 months later. You will be randomized to a group.

## What is being asked of me?

If you volunteer in this research study, we will ask you to do the following:

- 1) Download the free GET App and begin interacting with it.
  - Use it to track and receive reminders about taking your medications and attending your scheduled clinical appointments.
  - You can also access health education information and interact with your peer mentor known as a PEEP through instant messaging and voice calling as assigned.
  - During this time, we will collect information typically collected from Apps like what you click on and how often, for how long you visit different information etc.
- 2) Complete a confidential evaluation survey at the beginning of the study and every six months thereafter.
  - The survey will ask questions about your gender, education, housing, how often you get HIV care, stigma etc.
- 3) Consent to allowing your clinic to share your medical record information with us.
  - O Your medical record information will be protected and remain strictly private and confidential. We would like to gather information on your CD4+ counts, viral loads, and how often you attend your clinic appointments etc.
- 4) Complete surveys administered through the App that test your HIV/health knowledge, or ask for feedback on the App (optional).
- 5) You may be invited to participate in voluntary focus groups during the length of the study (optional).
  - During the focus groups, we will discuss your experience with the APP and PEEPs.

### **Time Commitment:**

Your participation in this research study is expected to last for a total of 2 years. We expect each evaluation survey to take between 45 minutes to an hour and will take place every 6 months for the first 18 months of the study. We expect the follow-up optional focus groups to take about one hour. The location of the focus groups will be determined soon. Use the App and contact your PEEP (if assigned one) as often as you like.

## <u>Is my participation voluntary?</u>

Your participation in this research study is entirely voluntary. If you decide not to participate, there will be no penalty to you, and you will not lose any benefits to which you are otherwise entitled. If you chose not to participate, your HIV/medical care will not be affected in any way.

# Possible Discomforts and Risks:

- There are no physical risks in the project.
- However, some of the questions in the evaluation survey could make you feel embarrassed, or uncomfortable.
  - Participation in the project and response to the survey may require that you think about your housing situation, stigma, and the support system that you have around you. Answering questions about your housing stability and experience with stigma may cause some discomfort or worryespecially worry about protecting your privacy.
  - o If you are distressed or wish to talk at length about factors related to your HIV status, we can make referrals to community health, mental health, or legal organizations.
  - Although your survey answers and medical information are confidential, there is a slight chance that your information might be seen by someone who is not supposed to see it. Several steps will be taken to help prevent this. For example:
    - Your survey answers and medical information will only be labeled with a project number and never your name.
    - Your name will not be used in any reports or papers that are written about this project.
  - Our staff is also trained to protect your privacy.
  - o In the optional focus group discussion, other young persons living with HIV will be there. Although we ask everyone to keep secret what was

talked about and tell them it is important to do so, we cannot guarantee that they will.

#### **Benefits:**

- You may directly benefit by: 1) receiving up-to-date information on HIV/AIDS and STDs prevention, 2) receiving encouragement and having a way to track your medication and HIV care appointments so you stay in care and stay healthy.
- Your participation will benefit others by contributing to the understanding of how
  young people can use health Apps and work with peer mentors (PEEPs) in order
  to stay healthy. The research findings will be a valuable resource for developing
  programs to help other young people more effectively stay in care and reduce
  their HIV viral load.
- Incentives provided throughout the study may provide food stability and or entertainment value.

## What are my alternative options?

The alternative is to not participate in the study.

# Are there financial benefits or costs if you choose to participate?

#### Costs:

Participation in this project will involve no cost to you. Participation is free and voluntary.

### Will I receive any payment for participating?

For your participation in the study you will receive gift cards, travel reimbursement, one free round trip ride to a medical appointment provided by Uber for the first year of participation, entertainment opportunities, and other yet to be determined incentives. For your participation in focus groups you will receive a gift card, food, and a metro card to reimburse travel expense. For the successful completion of study you will receive gift cards.

# How will you protect my confidentiality?

### **Confidentiality:**

We will maintain our best efforts to maintain confidentiality of any information that is collected during the research study that can identify you. We will disclose this information only with your permission or as required by law. Your research records are confidential.

We will protect your confidentiality by not using your name or other personally identifying information in reports or publications resulting from the research project. Group, rather than individual results will be reported. All of your survey responses and

contributions to focus groups will be identified by code numbers or pseudonyms (a pretend name) rather than actual names and kept in locked files in the principal investigator's office. Three years after the end of the project, all surveys and data will be destroyed.

Within the mobile application, we will take a number of electronic steps to protect patient data, including use of advanced encryption, auto-logout timers, and mandate of secure passwords for providers. Message content will not be accessible without logging in to mobile application; message notifications will not display content. We will not reveal your answers to anyone. Anything with identifying information such as your name – like this consent form – will be kept separate from surveys, so that they cannot be linked, and will be in triple-locked files (locked file, in locked room, in locked office). Although data will remain confidential, I cannot guarantee what is said outside the focus group.

The research team, authorized CUNY staff, and government agencies that oversee this type of research may have access to research data and records in order to monitor the research. As this is a national project, we will share information with ETAC as required by HRSA and SPNS. Research records provided to authorized, non-CUNY individuals will not contain identifiable information about you. Publications and/or presentations that result from this study will not identify you by name.

To help us protect your privacy, we are applying for a Certificate of Confidentiality from the U.S. Health Resources and Services Administration. With this Certificate, the researchers cannot be forced to disclose information that may identify you, even by a court subpoena, in any federal, state, or local civil, criminal, administrative, legislative, or other proceedings.

Exceptions: A Certificate of Confidentiality does not prevent researchers from voluntarily disclosing information about you without your consent. For example, we will voluntarily disclose information about incidents such as child abuse or intent to hurt yourself or others. In addition, the Certificate does not prevent you or a member of your family from voluntarily releasing information about yourself or your involvement in this research. If an insurer, employer, or other person obtains your written consent to receive research information, then the researchers may not use the Certificate to withhold that information. Finally, the Certificate may not be used to withhold information from the federal government needed for auditing or evaluating federally funded projects or information needed by HRSA.

(<u>All current references to the Certificate are phrased in the future tense</u>—e.g., "we are applying for a Certificate of Confidentiality..." This language will be amended to

use the present perfect indicative tense as it is written here, "...we have obtained a Certificate of Confidentiality from..." upon official issuance of the Certificate.)

# What are your rights as a participant?

- Your participation in this research study is entirely voluntary. If you decide not to participate, there will be no penalty to you, and you will not lose any benefits to which you are otherwise entitled.
- You can decide to withdraw your consent and stop participating in the research at any time, without any penalty.

### **Questions, Comments or Concerns?**

If you have any questions, comments or concerns about the research, you can reach out to the evaluator at any time. Please contact:

> Diane Addison, Evaluator Office Number: (212) 396-7797 Email: daddison@hunter.cuny.edu.

If you have any questions concerning your rights as a participant in this study, please contact:

The Hunter College Human Research Protection (HRPP) Office Phone: (212) 650-3053 Email: hrpp@hunter.cuny.edu

\*

PARTICIPATION IN RESEARCH IS VOLUNTARY. You have the right to decline to be in this study, or to withdraw from it at any point without penalty or loss of benefits to which you are otherwise entitled.

### **Signature of Participant:**

If you agree to participate in this research study, please sign and date below. You will be given a copy of this consent form to keep.

Printed Name of Participant	Date Signed
Signature of Participant	Date Signed
Printed Name of Signature of Person Explaining Consent Form	Date Signed

Signature of Person Explaining Consent Form	Date Signed

# **Appendix 15: Authorizations**

# Authorization for Release of Health Information and Confidential HIV-Related Information\*

New York State Department of Health AIDS Institute

This form authorizes release of health information including HIV-related information. You may choose to release only your non-HIV health information, only your HIV-related information, or both. Your information may be protected from disclosure by federal privacy law and state law. Confidential HIV-related information is any information indicating that a person has had an HIV-related test, or has HIV infection, HIV-related illness or AIDS, or any information that could indicate a person has been potentially exposed to HIV.

Under New York State Law HIV-related information can only be given to people you allow to have it by signing a written release. This information may also be released to the following: health providers caring for you or your exposed child; health officials when required by law; insurers to permit payment; persons involved in foster care or adoption; official correctional, probation and parole staff; emergency or health care staff who are accidentally exposed to your blood; or by special court order. Under New York State law, anyone who illegally discloses HIV-related information may be punished by a fine of up to \$5,000 and a jail term of up to one year. However, some redisclosures of health and/or HIV-related information are not protected under federal law. For more information about HIV confidentiality, call the New York State Department of Health HIV Confidentiality Hotline at 18009625065; for more information regarding federal privacy protection, call the Office for Civil Rights at 18003681019. You may also contact the NYS Division of Human Rights at 18883923644.

By checking the boxes below and signing this form, health information and/or HIV-related information can be given to the people listed on page two (and on additional sheets if necessary) of the form, for the reason(s) listed. Upon your request, the facility or person disclosing your health information must provide you with a copy of this form.

I consent to disclosure of (please check all that apply):	
☐ My HIV-related information	
☐ My non-HIV health information	
☐ Both (non-HIV health and HIV-related information)	

Complete information for each facility/person to be given general information and/or HIVrelated information. Attach additional sheets as necessary. It is recommended that blank lines be crossed out prior to signing.

- 1) Name and address of facility/person to be given general health and/or HIVrelated information:
- 2) Reason for release, if other than stated on page 1:
- 3) If information to be disclosed to this facility/person is limited, please specify:
- 4) Name and address of facility/person to be given general health and/or HIVrelated information:
- 5) Reason for release, if other than stated on page 1:
- 6) If information to be disclosed to this facility/person is limited, please specify:
- 7) Name and address of facility/person to be given general health and/or HIVrelated information:
- 8) Reason for release, if other than stated on page 1:
- 9) If information to be disclosed to this facility/person is limited, please specify:
- 10) If any/all of this page is completed, please sign below: Signature Date
- 11) Client/Patient Number

\* This Authorization for Release of Health Information and Confidential HIVRelated Information form is HIPAA compliant. If releasing only nonHIV related health information, you may use this form or another HIPAA compliant general health release form.

DOH2557 (2/11) Page 3 of 3

# **Appendix 16: YGI RESEARCH PROTOCOL**

Protocol Title:	Y Get It? Project Using Social Media and a Peer Engagement Education
	Professional to Do What You Need to Do.
Principal Investigator:	Dr. Cheryl Smith, Dr. Charles Gonzalez
Primary Contact Name:	Dr. Beatrice Aladin/ Mark Thompson
Primary Contact Phone:	212-417-4478/ 212-417-4470
Primary Contact E-mail:	Beatrice.Aladin@health.ny.gov/
	Mark.thompson@health.ny.gov
Date Revised:	April 15, 2017
IRB Number:	17-0002

## Guidelines for Preparing a Research Protocol Plus

#### **Instructions:**

- This document should be completed if your research study has an existing protocol from a Sponsor, Lead Site, etc.
- Respond to each item, even if to indicate not applicable (N/A0.
- Do not delete any of the text contained within this document.
- Please make sure to keep an electronic copy of this document. You will need to use it, if you make modifications in the future.
- Start by entering study information into the table above, according to these rules:
  - o Protocol Title: Include the full protocol title.
  - o Investigator: include the principal investigator's name
  - o Date Revised: Indicate the date at which the protocol was last revised
  - o IRB Number: Indicate the assigned IRB number, when known. At initial submission, this row will be left blank.
- Once the table information is entered, proceed to page 2 and complete the rest of the form.

#### 1. PREVIOUS STUDY HISTORY

Has this study ever been reviewed	and rejected/disapproved by another IRB prior
to submission to this IRB?	
⊠ No	Yes – if yes, please explain:

#### 2. BRIEF SUMMARY OF RESEARCH

- The summary should be written in language intelligible to a moderately educated, non-scientific layperson.
- It should contain a clear statement of the rationale and hypothesis of your study, a concise description of the methodology, with an emphasis on what will happen to the subjects, and a discussion of the results.
- This section should be no more than ½ page

The New York State Department of Health AIDS Institute **Y Get It?** Project is designed to facilitate the timely entry of young people (ages 18-34) into HIV care, the prevention of vulnerable youth from dropping out for care, and achievement of sustained viral load suppression among those in care. The **Y Get It?** project is comprised of a mobile application developed in collaboration with Mt. Sinai App Lab—and Peer Engagement and Educator Professionals (PEEPs) placed at two engagement hubs, Northwell Health Center and Pride For Youth Long Island Crisis Center. We aim to lessen the gaps faced by youth and thus improve health outcomes for young people throughout the HIV care continuum. The **Y Get It?** mobile app component will utilize an graphic serial featuring compelling stories and imagery that will be inspired by the personal stories of young people and active peer-to-peer communication to ensure continued engagement.

In addition to the mobile app, the PEEPs will provide virtual support via the app and inperson support as needed. Application analytics will be collected and evaluated by Hunter College-School of Public Health Evaluation Center to address the effectiveness, successes, and strengths of this novel social media project, one that has the potential to generate upward trends along every stage of the HIV Care Continuum. The **Y Get It?** Project will help to bolster and continue AI's work with young people living with HIV to advance health equity and reduce HIV/AIDS-related health disparities.

In order to evaluate the efficacy of the Y Get It? Intervention, we will conduct a two arm randomized control trial to assess whether the major components of the intervention can improve health outcomes and engagement in care for young persons living with HIV. Participants enrolled will be individually randomized at a 1:1 ratio to either receive access to the Y Get It? mobile app plus a PEEP they can communicate with outside of the app (Arm 1), or to receive access to the app alone (Arm 2). After six months, those randomized to receive the app alone will also be linked to a PEEP. We aim to enroll up to 144 young persons (72 in each intervention arm) from HIV care sites in NYC. Primary outcomes to be examined include linkage to care, engagement in HIV care, and viral load suppression. At enrollment and every 6 months thereafter, each participant will complete a detailed survey and be assigned an anonymized ID to maintain confidentiality. We are required to participate in HRSA's multi-site evaluation which is being conducted by the Evaluation Technical Assistance Center (ETAC) at UCLA. The ETAC has developed the

survey and is included in this protocol. De-identified data from surveys, electronic medical records (EMRs) and the APP will be shared with the ETAC.

#### 3. RESOURCES AVAILABLE TO CONDUCT THE HUMAN RESEARCH

- Explain the feasibility of meeting recruitment goals of this project and demonstrate a potential for recruiting the required number of suitable subjects within the agreed recruitment period
  - How many potential subjects do you have access to?
- Describe your process to ensure that all persons assisting with the trial are adequately informed about the protocol and their trial related duties and functions

Recruiting young persons in research can be a challenge, however our hubs have a large and diverse HIV positive young person client population. Utilization of our 2 hubs in conjunction with social media/event outreach efforts should allow us to reach our goal of a 170 people. The North Shore University Hospital (NSUH) Center for AIDS Research & Treatment (CART) provides comprehensive HIV services to over 2100 PLWHA in the Long Island region. CART serves an ethnically and racially diverse urban and suburban population including a sizeable number of immigrant and migrant clients. The majority of CART clients are Ryan White eligible, 41% are African American and 14% are Hispanic, and 40% are women. CART is situated within the Division of Infectious Diseases of the Department of Medicine. NSUH is the flagship hospital of Northwell Health. Pride for youths serves an additional 800 to 1000 HIV persons.

Our target number of participants was selected in order to meet statistical significance with regard to power of the study data.

All participants will interact with our PEEPs for the enrollment process, survey completion, and quality control focus groups. PEEPs will be trained using the attached materials as well as fulfilling required trainings at individual sites. PEEP supervisors and all study staff will be informed about the protocol and procedures of the study at a one-day meeting.

#### 4. RECRUITMENT METHODS

- Describe the source of potential subjects
- Describe the methods that will be used to identify potential subjects
- Describe any materials that will be used to recruit subjects. A copy of any advertisements (flyers, radio scripts, etc.) should be submitted <u>along</u> with the protocol.
- If monetary compensation is to be offered, this should be indicated in the protocol

Study subjects will be recruited from Pride For Youth Long Island Crisis Center and the Northwell Health Network. PEEPs and Y Get It? project staff will interact with physicians, P.A.s, nurses, social workers, case managers, care navigators, and other staff at each hub to familiarize them with the Y Get It? project. The care staff will then inform their clients of the study participation opportunity. When an interested party has been identified, a PEEP will be altered to setup a time to meet said party.

PEEPs will maintain an active social media presence and frequent events attend by our target populations to recruit as well. With regard to events, Pride For Youth throws a POZ Night event catering to HIV positive youth monthly as well as Mpowerment events catering to at risk and HIV positive youth. Events such as this provide an ideal forum for recruitment activities.

Cash incentives will not be provided. However, incentives in the form of gift cards, transportations vouchers (free round-trip ride to medical appointment from Uber and metro cards), and entertainment opportunities will be given to participants.

#### 5. NUMBER OF SUBJECTS

• Indicate the total number of subjects to be accrued locally. If applicable, distinguish between the number of subjects who are expected to be prescreened, enrolled (consent obtained), randomized and complete the research procedures.

Intend to enroll 170 total by end of year 4 of study. We aim to enroll up to 144 young persons (72 randomized to each intervention arm) from HIV care sites in NYC.

#### 6. STUDY TIMELINES

- Describe the duration of an individuals participation in the study
- Describe the duration anticipated to enroll all study subjects
- *The estimated date of study completion*

INDIVIDUALS WILL BE ENROLLED IN THE STUDY FOR 18 MONTHS. THE DURATION ANTICIPATED TO ENROLL ALL STUDY SUBJECTS IS 2 YEARS. THE STUDY WILL BE COMPLETED WITH DATA ANALYZED BY AUGUST 31, 2019

#### 7. RESEARCH PROCEDURES

Provide a description of any procedures that differ from what is described in the main study protocol.

N/A

#### 8. STATISTICAL ANALYSIS

If the protocol you are submitting has a statistical plan within it, please confirm here, by checking the box  $\square$ 

### If the protocol does not contain a statistical plan, please address these points:

- Describe how your data will be used to test the hypotheses.
- State clearly what variables will be tested and what statistical tests will be used.
- *Include sample size calculations.*
- If this is a pilot study, state which variables will be examined for hypothesis generation in later studies.

#### 9. DATA MANAGEMENT AND CONFIDENTIALITY

- Describe the data and specimens to be sent out or received. As applicable, describe:
  - What information will be included in that data or associated with the specimens?
  - Where and how data and specimens will be stored?
  - o How long the data will be stored?
  - Who will have access to the data?
  - Who is responsible for receipt or transmission of data and specimens?
- Describe the steps that will be taken to secure the data during storage, use and transmission.

Consent forms: once patients are consented, the PEEP will hold on to the consent form and keep it in a locked drawer and designated Y Get It? staff will also have access to the forms.

ETAC surveys: This data involves a range of sociodemographic, mental health, housing, sexual history, and addiction questions. The surveys will be taken through ACASI, an automated secure survey software. The data will be stored until 2022 (3 years after the completion of the study).

### The App data:

EMR hub data: data on viral load, CD4+ counts, care retention, medication prescribed and medication adherence. The clinics will be sending the data via a secured network to our evaluation team at the CUNY School of Public Health.

#### 10. RISKS TO SUBJECTS

- Describe any potential risks which are not discussed in the protocol, their likelihood and seriousness. As a reminder, risks may be physical, psychological, social, legal or economic
- Discuss why the risks to subjects are reasonable in relation to the anticipated benefits and in relation to the importance of the knowledge that may reasonably be expected to result.
- Describe the procedures for protecting against or minimizing any potential risks, including risks to confidentiality, and assess their likely effectiveness.

There are no physical risks in the project. However, some of the questions in the evaluation survey could make participants feel embarrassed, or uncomfortable.

 Participation in the project and response to the survey may require participants to think about their housing situation, stigma, and the support system they have around them. Answering questions about housing stability and experience with stigma may cause some discomfort or worryespecially worry about protecting privacy.

Although survey answers and medical information are confidential, there is a slight chance that information might be seen by someone who is not supposed to see it. Several steps will be taken to help prevent this.

Participants may leave the study at any time without any penalty or interruption in care. Any survey questions that they find uncomfortable they are welcome to skip. Additionally, our PEEPS are trained on motivational interviewing, cultural sensitivity and HIV care etc.

#### 11. RESEARCH RELATED HARM/INJURY

- Describe the availability of medical or psychological resources that subjects might need as a result of anticipated problems that may be known to be associated with the research.
- If the research is greater than minimal risk, explain any medical treatments that are available if research-related injury occurs, who will provide it, what will be provided, and who will pay for it.

N/A

#### 12. PROVISIONS TO PROTECT PRIVACY INTERESTS OF SUBJECTS

• Describe the methods used to identify potential research subjects, obtain consent and gather information about subjects to ensure that their privacy is not invaded.

• In addition consider privacy protections that may be needed due to communications with subjects (such as phone messages or mail).

Participant survey answers and medical information will only be labeled with a project number and never a name.

Participant names will not be used in any reports or papers that are written about this project.

Staff are trained to protect participant's privacy.

Any written identifiable data will be kept in a secure locked drawer which can only be accessed by Y Get It? project staff.

A variety of electronic safeguards will be put in place to maintain privacy within the mobile application. Get App Security and Privacy

This technology platform (mobile app and web dashboard) were conceived, planned, and built with a focus on protecting patient privacy and security. Secure Microsoft cloud hosting services, governed by BAA, and industry-leading data encryption standards, protect information entered by users. Strong password requirements for dashboard users and no local data storage on smartphones are examples of measures taken to protect patient health information.

Sinai AppLab uses a combination of custom developed technologies and the best available software services and toolkits. Through our use of a hybrid development process, we ensure both iOS (Apple) and Google Play (Android) versions of patient-facing apps can be produced. This, in addition to web versions of these technologies, when appropriate, make our products available to the widest patient userbase possible. Further, years of development on custom technology platforms has produced flexible infrastructure that allows us to quickly adapt solutions for new diseases, facilities, or use cases. Use of secure, cloud-based data storage solutions allows for rapid growth and scaling across health systems. Our goal is developing digital health solutions that become essential to best practices and truly leave no patient behind.

The majority of our effort since our founding in 2013 has gone into the HealthPROMISE framework. Developed by Sinai AppLab through years of learning on patient and provider needs, HealthPROMISE has grown out of a clinical trial in one specific disease, IBD (Inflammatory Bowel Disease) to be available across sites through North America and used for a variety of chronic conditions. As a patient-reported outcomes tool, the app

lets users record symptoms, track quality of life, get educational material curated by their provider, and see the quality metrics their doctor cares most about. For providers, a web dashboard allows them or other care team members to quickly see what is happening between office visits, and act to improve patient outcomes. HealthPROMISE has also been linked with a leading Electronic Health Record (EHR) system.

Sinai AppLab technologies have gone through rigorous audit checks and, when appropriate, are compliant with HIPAA and HITECH Act standards. Security measures include, but are not limited to: industry leading encryption (of data at rest, in transit, and in use), device security measures, and use of secure protocols like HTTPS. Hypertext Transfer Protocol Secure protocol is a combination of Hypertext Transfer Protocol (HTTP) with SSL/TLS protocol, which provides encrypted communication and secure identification of a network web server. HTTPS connections are often used for payment transactions on the World Wide Web and for sensitive transactions in corporate information systems. Data is stored in Microsoft's HIPAA-compliant, secure database cloud servers, governed by Business Associate Contract (as outlined in HIPAA rules) with Mount Sinai Health System.

#### 13. COSTS TO SUBJECTS

- Describe any foreseeable costs that subjects may incur through participation in the research
- Indicate whether research procedures will be billed to insurance or paid for by the research study.

There will be no cost incurred for participation in our study.

#### 14. PAYMENT TO SUBJECTS

• Describe the amount of payment to subjects, in what form payment will be received and the timing of the payments.

Each participant will receive at minimum a 20\$ gift card when they enroll in the study and complete the baseline survey. They will receive another 20\$ gift card for each 6 month follow up survey for an 18 month period.

Other incentives will be performance based. For example if a participant who was not virally suppressed becomes virally suppressed they will receive an incentive/reward in the form of a gift card.

#### 15. CONSENT PROCESS

*If obtaining consent for this study, describe:* 

- Who will be obtaining consent
- Where consent will be obtained
- Any waiting period available between informing the prospective participant and obtaining consent
- Steps that will be taken to assure the participants' understanding
- Any tools that will be utilized during the consent process
- Information about how the consent will be documented in writing. If using a standard consent form, indicate such.
- Procedures for maintaining informed consent.

The PEEP will be consenting subjects. Consent will be obtained in a private room at each clinic/hub. For most patients recruited directly from the clinic, there will not be a waiting period, however for persons newly diagnosed and those recruited through social media, there may be a lag time between identification and obtaining consent.

There will be a detailed consent form explaining all study procedures. The consent form will be read aloud by the PEEP and the PEEP will ask the participant if they have a clear understanding of the study and if they have any questions. The consent procedure will be in standard paper form and a copy of the signed consent will be given to each participant and any study details will be available upon request. PEEP will keep the consent forms in a locked drawer and designated Y Get It? Staff will have access to them.

In the state of NY, any participants under the age of 18 are considered children. If your study involves children, additional information should be provided to describe:

- How parental permission will be obtained
- From how many parents will parental permission be obtained
- Whether permission will be obtained from individuals other than parents, and if so, who will be allowed to provide permission. The process used to determine these individual's authority to consent for the child should be provided
- Whether or not assent will be obtained from the child
- How will assent be documented
- Whether child subjects may be expected to attain legal age to consent to the procedures for research prior to the completion of their participation in the research. If so, describe the process that will be used to obtain their legal consent to continue participation in the study. Indicate what will occur if consent is not obtained from the now-adult subjects.

N/A

If the study involves cognitively impaired adults, additional information should be provided to describe:

- The process to determine whether an individual is capable of consent
- Indicate who will make this assessment
- The plan should indicate that documentation of the determination and assessment will be placed in the medical record, when applicable, in addition to the research record.
- If permission of a legally authorized representative will be obtained,
  - list the individuals from who permission will be obtained in order of priority
  - Describe the process for assent of subjects; indicate whether assent will be required of all, some or none of the subjects. If some, which subjects will be required to assent and which will not.
  - If assent will not be obtained from some or all subjects, provide an explanation as to why not
  - Describe whether assent will be documented and the process to document assent
  - Indicate if the subject could regain capacity and at what point you would obtain their consent for continued participation in the study

N/A

*If the study will enroll non-English speaking subjects:* 

- Indicate what language(s) other than English are understood by prospective subjects or representatives
- Indicate whether or not consent forms will be translated into a language other than English
- Describe the process to ensure that the oral and written information provided to those subjects will be in that language
- If non-English speaking subjects will be excluded, provide a justification for doing so

Spanish Consent forms will be translated in to Spanish by NYS DOH AI translations service.

16. WAIVER OR ALTERATION OF THE CONSENT PROCESS N/A Complete this section if you are seeking an alteration or complete waiver of the consent process.

- Describe the possible risks of harm to the subjects involved in this study and explain why the study involves no more than minimal risk to the subject:
- Explain why the waiver/alteration will not adversely affect the rights and welfare of subjects
- Explain why it is impracticable to conduct this research if informed consent is required
- If appropriate, explain how the subjects will be provided with additional pertinent information after participation. If not appropriate to do so, explain why.

Complete this section if you are obtaining informed consent but you are requesting a waiver of the documentation of consent (i.e., verbal consent will be obtained). To proceed with a waiver based on these criteria, each subject must be asked whether they wish to have documentation linking them to this study. Only complete subsection 1 OR subsection 2.

#### **SUBSECTION 1**

- Explain how the only record linking the subject to the research would be the consent document.
- Explain how the principal risk of this study would be the potential harm resulting from a breach in the confidentiality
- Indicate whether or not subjects will be provided with a written statement regarding the research.

N/A

#### **SUBSECTION 2**

- Describe the possible risks of harm to the subjects involved in this study and explain why the study involves no more than minimal risk.
- Confirm that the research only involves procedure for which consent is not normally required outside the research context.
- Indicate whether or not subjects will be provided with a written statement regarding the research.

N/A

#### 17. WAIVER OF HIPAA AUTHORIZATION

N/A

Complete this section if you seek to obtain a full waiver of HIPAA authorization to use and/or disclose protected health information.

- Describe the risks to privacy involved in this study and explain why the study involves no more than minimal risk to privacy:
- Describe your plan to protect identifiers from improper use or disclosure and to destroy them at the earliest time.
- Indicate why it is not possible to seek subjects' authorization for use or disclosure of PHI.
- Indicate why it is not possible to conduct this research without use or disclosure of the PHI.
- Indicate if PHI will be disclosed outside NSLIJ Health System, and if so, to whom.

Note: PHI disclosed outside NSLIJ Health System, without HIPAA authorization needs to be tracked. Please see guidance at <u>Northwell Health</u> for information about tracking disclosures.

N/A

Complete this section if you seek to obtain a partial waiver of the patient's authorization for screening/recruitment purposes (i.e., the researcher does not have access to patient records as s/he is not part of the covered entity)

Note: Information collected through a partial waiver for recruitment cannot be shared or disclosed to any other person or entity.

- *Describe how data will be collected and used:*
- Indicate why you need the PHI (e.g.PHI is required to determine eligibility, identifiers are necessary to contact the individual to discuss participation, other)
- Indicate why the research cannot practicably be conducted without the partial waiver (e.g. no access to medical records or contact information of the targeted population, no treating clinician to assist in recruitment of the study population, other)

N/A

#### 18. VULNERABLE POPULATIONS:

Indicate whether you will include any of these vulnerable populations. If
indicated, submit the appropriate appendix to the IRB for review:
Children or viable neonate
☐ Cognitively impaired
☐ Pregnant Women, Fetuses or neonates of uncertain viability or nonviable
☐ Prisoners

	NSLIJ Employees, residents, fellows, etc
	poor/uninsured
	Students
$\boxtimes$	Minorities
	Elderly
	Healthy Controls

If any of these populations are included in the study, describe additional safeguards that will be used to protect their rights and welfare.

All data will be de-identified. Staff will be trained in cultural and socio-economic sensitivity training, particularly between the PEEP and study subjects.

# **Appendix 17: List of YGI Abstract presentations**

# CDC Conference on Health Communication Marketing and Media -August 16<sup>th</sup> 2017 Poster

Poster title: "YGetIt?: Utilizing a Social Media Tool and Personal Health Advocate to Affect Behavioral Change Among HIV Infected Young Adults"

# **United States Conference on AIDS September 14th 2016 – Poster**

Poster title: "Using Social Media for HIV Care Engagement, Linkage, and Retention"

# Ryan White Conference December 11th 2018 - 2 Panels/1 Poster

Poster title: "Messaging Through a HIV Focused Mobile Application May Help to Facilitate Engagement in Care"

Panel title: "Special Projects of National Significance (SPNS), Social Media Initiative; Peer Supported Technology Interventions in HIV"

Panel title: "Implementation challenges encountered in the Special Projects of National Significance (SPNS) Social Media Initiatives (SMI)"

## IAPAC Adherence Conference June 9th 2018 – Poster

Poster title: "Can a Mobile App Paired With a Peer Improve Linkage and Care Among HIV Positive Young Adults?"

# Synchronicity Conference April 23rd 2019 - Panel

Panel title: "Social Media- Session: Dissemination of HIV Education Using HIV Focused Graphic Serial via Social Media and an Online Comic Forum"

# CDC Conference on Health Communication Marketing and Media - August 14<sup>th</sup> 2019 Poster

Poster Title: A HIV Centered Comic in Digital Spaces to Educate and Engage Young Adults

## American Public Health Association Annual Meeting and Expo Nov 4th 2019

Poster Title: A Multifaceted Social Media Approach to HIV care