YGetIt? Project

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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The YGetIt? Project

Intervention summary

Incidence of HIV infections is highest among young adults age 18-29yrs in the United States.[1] In New York State, young adults account for the largest number of new infections and struggle to seek and remain in HIV care.[2] This population frequently utilizes social media and digital technology to engage with peers and access information (including health information).[7] 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.
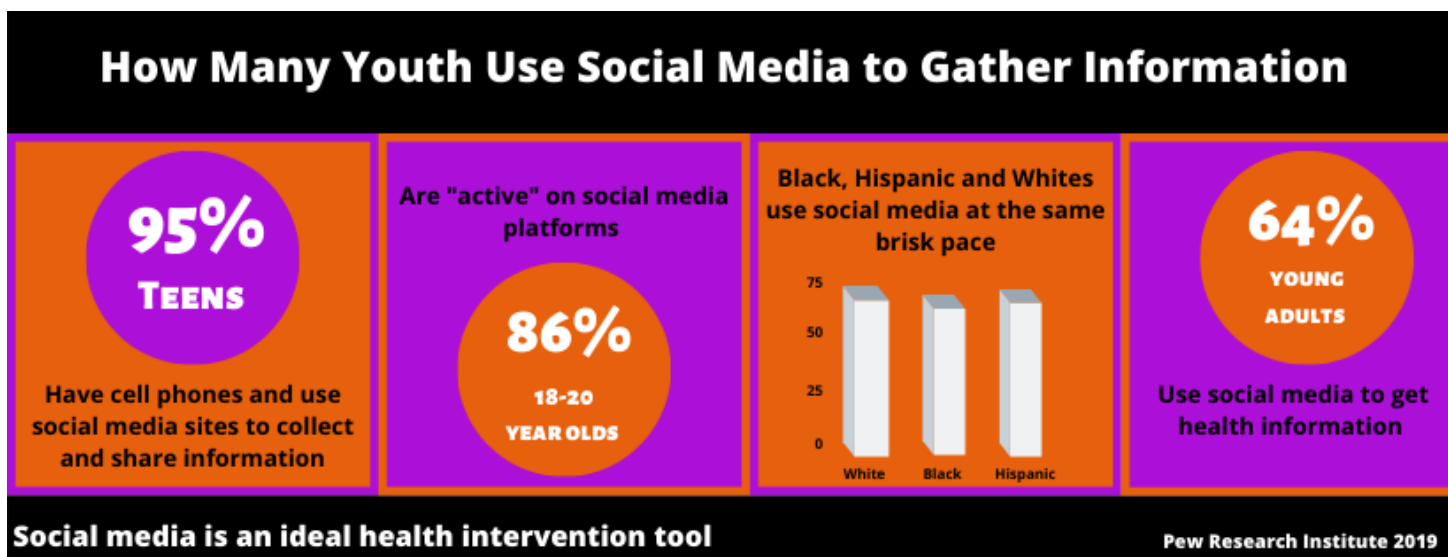
Rational and Need

Approximately 184,887 (ages 15-34) young people 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.[3,4] While 75% of people living with HIV (PLWH) are virally suppressed, 51.2% of PLWH aged 13-24 and 54.2% of PLWH aged 25-34 have achieved viral load suppression.[5] 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.[6] More than 95% of teens have cell phones and use online social media and networking sites to collect, disseminate and share information.[7] Pew Research Center reported 86% of 18-29 year old can be classified as "active" on social media.[7] Whites, Blacks, and Hispanics have broadly adopted social media at the same brisk pace.[7] 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 and have found it to be effective. A review of HIV focused social media interventions identified the following benefits to utilizing social media;
- access to information,

- enhanced ability to communicate,
- anonymous identity,
- sense of social and emotional support,
- virtual community, and
- geographical reach.[8,9]

How Many Youth Use Social Media to Gather Information

95% TEENS
Have cell phones and use social media sites to collect and share information

Are "active" on social media platforms
86%
18-20 YEAR OLDS

Black, Hispanic and Whites use social media at the same brisk pace
(bar chart: White, Black, Hispanic — axis 0, 25, 50, 75)

64% YOUNG ADULTS
Use social media to get health information

Social media is an ideal health intervention tool

Pew Research Institute 2019

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."[11] 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 for 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 finetuning 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 and retain their patients.

Theoretical Basis

Although YGI did not use a concrete theoretical construct, 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.[12] 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.
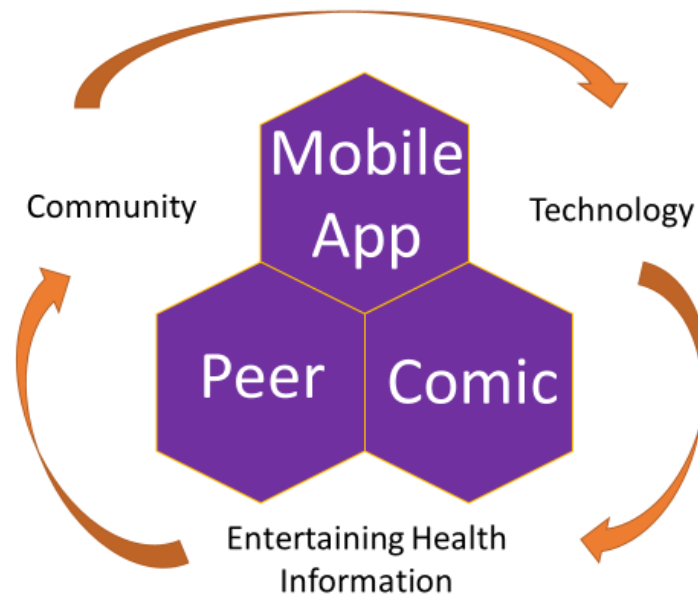
Literature illustrating the successful application of behavioral change models/theories to health focused text messaging and mobile application interventions are sparse. Irrespective of limited literature, YGI uses, 1) technology tools connect users to health information and health care team; 2) entertaining 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 Description
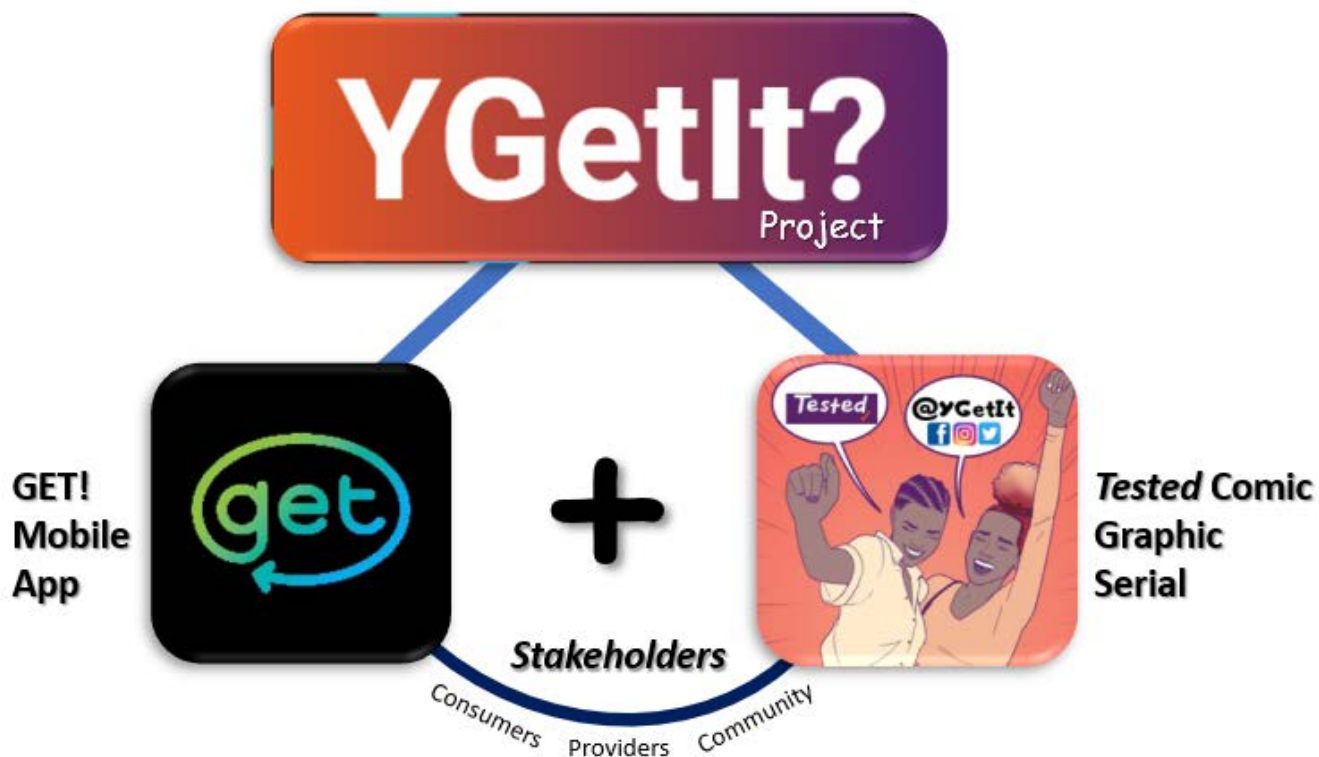
GET! provides a high level of confidentiality and security, ease of access, and discretion. It consists of an inconspicuous logo design, platform familiarity, opt in and out selection, Wi-Fi accessibility, and is transferable from one device to another. Indispensable in-app features include;


Peer Engagement Educator Professionals (PEEPs) -YGI 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.

Additional core in-app elements include:
- Medication and appointment tracking
- Easy access to care team
- Linkage to health educational resources
- Quality Assurance measures (surveys, in-person feedback, bug reporting)

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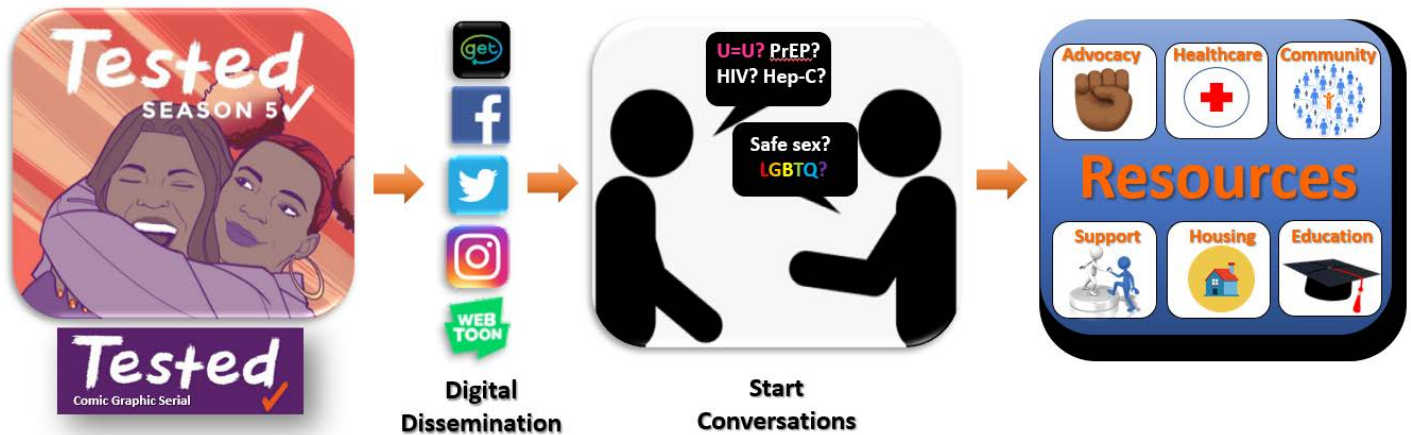
Tested, features bold images, short narratives, and draws from cultural influences to appeal to target populations. The story is kept contemporary by incorporating current events, fashion trends, and colloquial phrasing. It is made available within GET! and on public facing social media platforms Facebook,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

Critical Tested development components include;
- Comic Graphic Serial Production Team (see implementation section)
- Stakeholders input
- Tested social media strategy

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! App 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. 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.
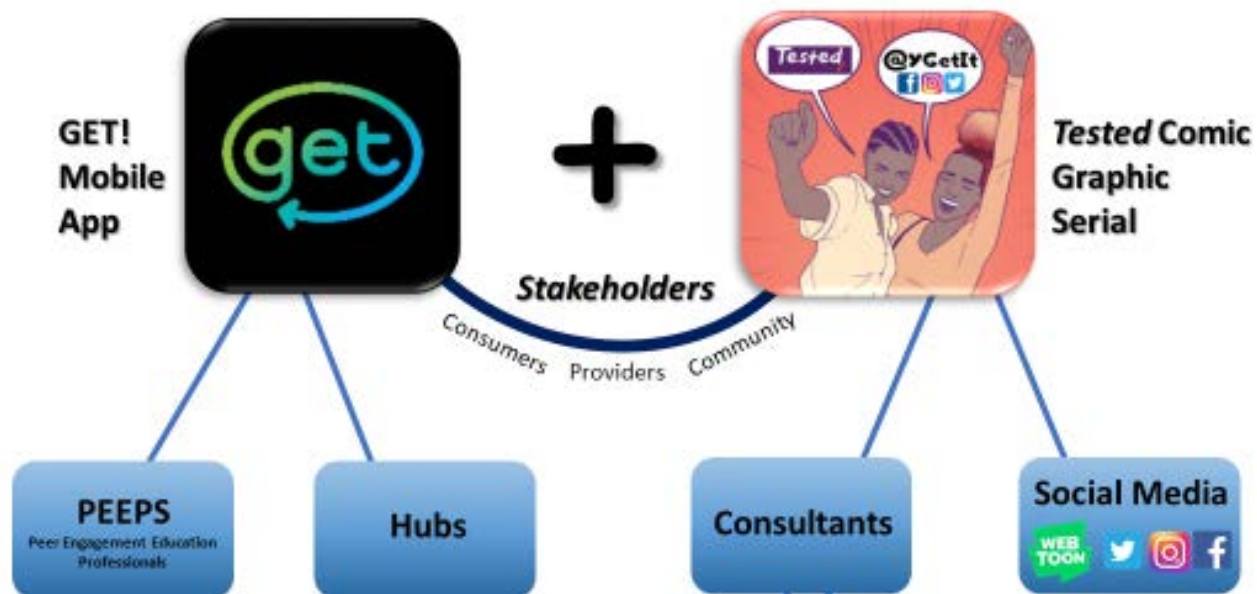
Implementation Teams
To develop and implement the YGI a variety of teams were assembled.
Project Team: Principle Investigator, Project Director, Program Coordinator

- *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%.

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 the appendices. . 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 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

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 lived experience to spread awareness of the YGI brand. This information is disseminated via Facebook, Instagram, Twitter, YouTube, and Webtoons.com.

Management of YGI social media channels is an essential part of *Tested*. YGI utilizes a social media intern with in-depth understanding of the 18-34 age demographic social media experience. The intern works closely with the project team to develop an engaging and extensive social media presence for *Tested*.

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.

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 points viewers to where it can be downloaded.

The site also features Tested content including complete seasons, linkage to resources, and character backgrounds.

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 Insights

Young adults use aspects of YGI in various ways and at different times to facilitate their healthcare needs. YGI empowers participants and adds to convenience of care.

Providers and young adult consumers may benefit from incorporating YGI into their healthcare planning to address their needs.

Resources

YGetIt? Website

YGetIt? Instagram

YGetIt? Facebook

YGetIt? Twitter

Tested on Webtoons.com

HIV.gov

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