



# Engaging African American teens in co-creating and disseminating social media based HIV prevention messages

Yulin Hswen<sup>1,2</sup>, David S. Bickham<sup>3,4</sup>

<sup>1</sup>Department of Social and Behavioral Sciences, Harvard T.H. Chan School of Public Health, Boston, MA, USA; <sup>2</sup>Computational Epidemiology Group, Boston Children's Hospital, Harvard Medical School, Boston, MA, USA; <sup>3</sup>Center on Media and Child Health, Department of Adolescent Medicine, Boston Children's Hospital, Boston, MA, USA; <sup>4</sup>Department of Pediatrics, Harvard Medical School, Boston, MA, USA

*Correspondence to:* Yulin Hswen, MPH. Boston Children's Hospital, BCH3393, 300 Longwood Ave, Boston MA 02215, USA.

Email: yuh958@mail.harvard.edu.

**Abstract:** Social media is a popular online activity among African American teens, and may afford opportunities for delivering HIV prevention initiatives to this at-risk group. In this case report, we describe the development and pilot testing of a program using a participatory method to engage African American teens in actively designing, co-creating, and disseminating HIV prevention messages using YouTube, a popular video sharing social media platform. We conducted two sequential formative pilot evaluations. In the first pilot study conducted in 2013 we employed a participatory research approach to develop and test a curriculum with emphasis on education, use of social media, and video production and development. During the second pilot study in 2014, we delivered the program to a group of teens and obtained feedback to further refine our curriculum. We enrolled 17 teens, ages 16–18, with 5 in the first pilot and 12 in the second pilot. Participating teens independently created and uploaded peer-generated HIV prevention videos to YouTube. Overall, teens across both pilot studies reported high satisfaction with the session content. This program was locally developed and required few resources, and emerged as feasible and something that the community center would like to continue to deliver. Employing a participatory approach for co-creating social media-based content to target HIV-related health behaviors may appeal to this generation's tech savvy youth, and can potentially inform future efforts for reaching at-risk teens.

**Keywords:** Adolescent; African American; HIV; social media; mHealth; community-based participatory research; digital health; YouTube

Received: 11 June 2018; Accepted: 25 July 2018; Published: 14 August 2018.

doi: 10.21037/jhmhp.2018.07.06

**View this article at:** <http://dx.doi.org/10.21037/jhmhp.2018.07.06>

## Introduction

African American teens experience disproportionately elevated risk for HIV compared to the general US adolescent population (1). For example, from 2005 to 2008, African American teens represented 50% of all adolescent HIV diagnoses reported across 37 states (2). This disparity highlights the need for culturally tailored prevention efforts that are relevant and meaningful to this demographic (3,4). Existing reviews have highlighted the promise of interventions aimed at reducing behaviors associated with HIV risk (5), yet there is need for novel HIV prevention

strategies that leverage digital media, popular culture, and emerging mobile technologies to appeal to this generation's tech-savvy youth (6,7).

Over 80% of adolescents, ages 12–17, use popular social media such as Facebook, Twitter, Instagram or YouTube, with African American teens among the highest users (8). Emerging evidence also shows that teens from across demographic groups are increasingly seeking health-related information online and through popular social media (9), suggesting the potential of using this medium to disseminate targeted HIV prevention messages. However, research has shown that many African Americans are

more critical of mainstream health media because of its inadequate representation of ethnic minorities (10), with African American adolescents and most often young males reporting mistrust of mainstream media (11). When HIV prevention initiatives targeting African American youth are considered irrelevant or unreliable due to lack of context or authenticity, the meaning of the initiative is obscured or negated.

These examples legitimize the need to co-develop online prevention materials with individuals from the target population. Health communication campaigns that match the cultural characteristics of minority populations can enhance receptivity, acceptance of and salience of health information and programs (12). Yet, cultural differences in how people process and use information are not always taken into account when designing health-related information (13). Active participation of the population and their communities in the co-creation of health communication messages is necessary to accurately reflect their culture (12) and generate messages that are both relevant and meaningful to this demographic (3,4). Community based participatory research (CBPR) methods, designed to engage community members from churches, schools, or community centers, has emerged as a valuable strategy for generating HIV prevention programs designed specifically for reaching at-risk African American teens (14). Interventions co-developed using participatory approaches have shown sustained outcomes and demonstrated greater program adherence, increased buy-in, and higher satisfaction among community members (14).

Few studies have explored the use of participatory approaches for co-creating online, social media-based content to target HIV-related behaviors among at-risk African American teens. In this case report, we describe the development of a community-based program for engaging African American teens in actively co-creating and disseminating social media-based HIV prevention messages using YouTube, a popular video-sharing social media platform. We outline the approach adopted for the development of this participatory method and discuss potential implications for reaching vulnerable groups.

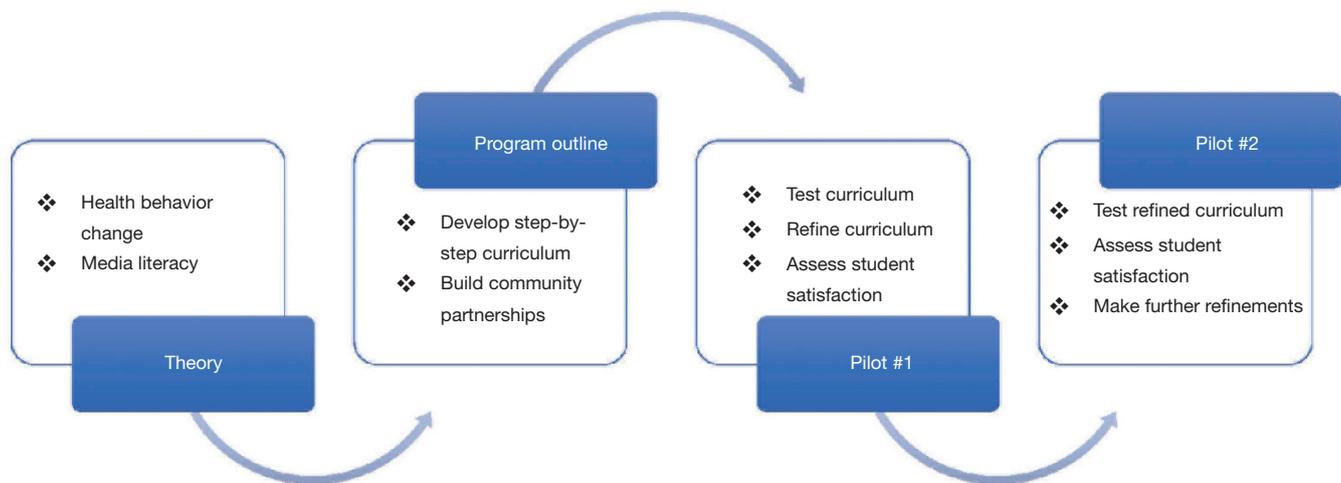
## Theory and rationale

Recognizing the high proportion of African American teens regularly using popular social media websites, there are unique opportunities to design social media-based health communication interventions for HIV prevention

among this group. Further, these individuals likely have the necessary understanding and technical skills to navigate these websites, thereby potentially overcoming technical challenges involved in content development, connecting with peers, and effectively using jargon and slang to increase content visibility and ensure rapid dissemination and uptake. These teens also have a more authentic sense of what content would be most appealing and interesting to their peers and how best to deliver it. Effective health communication strategies designed to reach African American teens using social media must be co-developed.

To refine our approach, we drew from principles of CBPR as well as applying Bandura's social cognitive theory to the design of an instructional program. CBPR directly involves participants in the conception, design and implementation of a health intervention (15). CBPR methods have been widely used in public health research as a way to involve participants in the research process and to ensure that the products of that work are more representative, culturally relevant, and meaningful for the target group (15). To encourage unhindered expression among participating teens, we adopted important aspects consistent with CBPR (16) including an emphasis on ensuring that participants felt comfortable communicating in their own language, contributing their own ideas, and being as creative as they like when developing the online HIV prevention content. An important advantage with using social media as the platform for delivering participant created HIV prevention messages is familiarity, which ensures most teens should feel at ease creating and sharing content. Studies also show that participating in the production of positive media messages can improve health-related beliefs and behaviors (17,18).

To effectively implement this participatory approach aimed at engaging teens, instructional elements were incorporated to form a 7-session curriculum informed by Bandura's social cognitive theory and designed for delivery within community-based settings. By having participants create their own media content, they model appropriate behaviors to peers, and have the opportunity to assess the social acceptability of their own behavior (19). This is consistent with Bandura's social cognitive theory, which states that behaviors are learned through modeling; therefore, narratives with personal relevance to the target audience are more likely to encourage adoption of a recommended behavior (19,20). The theory describes how social norms for behaviors can be formed through peer-to-peer interactions among small close-knit groups, where these norms get passed to other close-



**Figure 1** Iterative process to develop a program for co-creating social media-based HIV prevention messages for teens.

knit groups generating a social network dispersion effect of behaviors (21).

YouTube, a popular, wide reaching video sharing site, was selected as the target social media site because when compared to other social media platforms, such as Twitter or Facebook, content on YouTube can remain visible even after considerable time has passed. For example, a popular video posted to YouTube can still be viewed and shared among peers after several months or years; whereas, a Tweet posted to Twitter or a post on Facebook can remain visible only briefly (only a few days) and risks becoming rapidly outdated. The requirement for a video camera was not considered a limitation with using YouTube because smartphones are equipped with cameras that provide sufficient capabilities to create a film or short video. Importantly, 85% of African American teens own a smartphone, which is higher than white or Hispanic teens (both 71%) (22).

### Development process

We conducted this formative work by applying an iterative approach across two phases from April 2013 to August 2014 (Figure 1). This work was conducted through the Boston Area Health Education Center (BAHEC), a public community center in Boston, MA, serving a largely African American community. Ethical review board approval was obtained through Boston Children's Hospital (No. IRB-P00007875). Participants provided written informed consent according to procedures approved by the Boston Children's Hospital ethical review board before enrolling

in this study and for publication of the findings in this report. We enrolled 17 African American teens, ages 16–18. Five participated in the first formative pilot, and twelve participated in the second pilot. Many participants had extracurricular activities or prior school/work/family commitments, while others had to travel long distances to attend the program. Overall, most participants attended the program every week and few missed sessions during the program duration.

We initiated this project by establishing a partnership with BAHEC. Although BAHEC supported the program, limited resources and location space were barriers, and it was necessary to seek outside community facilities to host several program sessions. For example, we hosted one session at a local electronics retailer (Apple Store), as this also provided an opportunity to demo video editing methods and software and to access equipment not available at BAHEC. Additionally, through a sponsorship from one of our community contacts, we were able to secure a room at a local shared workspace.

It was very important to set strict video parameters for participants' films. Since time and resources were limited, videos had to be filmed at the program's location, using participants as actors, and keeping the final cut under 90 seconds. We posted these parameters on a white board ahead of each lesson to remind students how their ideas and storyline had to be kept within this outline. Participants' used their mobile phones for filming and for accessing social media. Each participant owned a mobile phone with a camera capable of uploading content to YouTube. Students also worked in small groups with a program facilitator to

**Table 1** Goals and activities of a program for co-creating and disseminating social media-based HIV prevention messages for teens

Session	Goals	Activities
1	(I) Identify HIV/AIDS baseline knowledge; (II) educate participants about HIV/AIDS risk related behaviors and sexually transmitted diseases	(I) HIV/AIDS icebreaker activity; (II) HIV/AIDS “couples” debate game; (III) health care worker discussion with Q/A
2	(I) Develop critical thinking skills and media literacy; (II) generate ideas and concepts for HIV/AIDS prevention messages	(I) Properties of an effective mass media campaign; (II) a focus group discussion on Internet search strategies for sexual health information; (III) analysis of 3 current YouTube HIV/AIDS video campaigns
3	(I) Set video parameters and identify limitations; (II) draft a concept and storyboard for HIV/AIDS video campaign	(I) Storyboard tutorial; (II) film techniques; (III) individual concept presentations
4	(I) Select and edit final video concept; (II) determine participant roles and responsibilities	(I) Group discussion and synthesis of ideas/concepts; (II) outline roles and responsibilities
5	(I) Film video; (II) develop participants film techniques and skills	(I) Film techniques and skills; (II) participants film video scenes
6	(I) Select final scenes; (II) edit HIV/AIDS prevention messages	(I) Digital video editing tutorial; (II) select and modify scenes individually
7	(I) Video comments and feedback; (II) approval of video release	(I) Feedback of curriculum; (II) final video presentation; (III) comments and critiques

PSA, public service announcement.

help devise their idea and refine it. To maintain the same quality of attention per student, college student mentors with background experience in film were recruited to work with each student group to help them develop their idea. A BAHEC staff member was also assigned to the program to assist us with facilitation for each class.

In designing our participatory approach, the 7-sessions were focused around three key domains: (I) education (session 1); (II) social media (session 2); and (III) video development (sessions 3–7). Prior research has shown that separating content across specified topic areas can elicit greater attention and positive perceptions (23).

### Program overview

The sessions were designed to provide participants with basic background knowledge surrounding HIV prevention behaviors, enhance their skills and techniques for creating effective health media content, and enable them to develop their own HIV prevention video using YouTube. Program sessions were each 2 hours in length and are outlined in *Table 1*. A detailed description of each session is provided below.

#### Session 1—education

A social worker and an experienced community-based

HIV/AIDS educator helped design the sexual educational curriculum focused on risk-related behaviors. The first session aimed at presenting basic topics related to HIV prevention and giving participants the opportunity to ask questions specific to their concerns or interests. Participants received an overview of the project, which emphasized its participatory approach, urging them to share perspectives and ask questions while maintaining an environment of mutual respect. The first session included icebreaker activities to allow everyone to get to know each other, and role-playing and games about safe sex to increase engagement and to focus on the causes, symptoms and treatments of sexually transmitted diseases and HIV.

#### Session 2—social media

This session explored the qualities of effective social media messages, and in particular successful YouTube videos for HIV/AIDS awareness. For example, participants were presented with a selection of popular YouTube videos focused on HIV prevention and asked to discuss their different characteristics, what they like or dislike about the videos, and what they would like to see in their own video. This session also provided the opportunity to understand how participants used social media, and also whether they used different sites for accessing sexual health information.

**Session 3—video development part I**

The first session dedicated to video development provided an introduction to basic skills and techniques for making videos, such as: using a camera or cellphone camera, taking angle or movement shots, and making a storyboard. The participants were asked to practice using a camera and creating their own storyboard to emphasize the learned material. Following this practice, participants were asked to use skills from sessions 1 and 2 to individually create storyboards focused on delivering HIV prevention messages. Participants turned in their draft storyboards at the end of the session.

**Session 4—video development part II**

In this session, participants worked on finalizing their HIV prevention storyboards. They began by working individually on their own storyboards, receiving assistance from program facilitators when necessary, before presenting their ideas to their peers. Each idea was posted on a board at the front of the room, and at the end, participants and facilitators discussed feasibility of videos given available resources, and which would be most effective for portraying the HIV prevention message. The final storyboard could consist of several of the participants' favorite ideas, as well as a combination of different concepts decided upon by the group.

**Session 5—video development part III**

This session focused on filming the video to upload onto YouTube. Participants were first provided further instruction on how to shoot the video, then in small groups of 4–5, participants were instructed to film the video according to their storyboard. Facilitators offered some supervision, mainly to ensure that participants divide filming responsibilities and answer any questions that may arise. In this session, participants were encouraged to generate whatever content they thought would most interesting and meaningful.

**Session 6—video development part IV**

This session focused on editing the video content from session 5. This session required access to computers with basic editing software, as well as instruction for the participants about how to edit, combine different scenes,

add titles, and change sound by adding narratives or music. We hosted this session at a local computer retailer to access video editing software. Participants were then free to edit their videos for the remainder of the session.

**Session 7—video development part V**

In the final session, participants had the opportunity to view each other's videos, provide helpful feedback, and finally upload the videos to YouTube.

**Practice implications**

This case report highlights the feasibility of a participatory approach involving co-creating HIV prevention messaging using social media within a community-based setting. Overall, participants reported high satisfaction with the program. While participants expressed interest in creating the YouTube videos, most believed that teenagers would not use YouTube as a resource for sexual health information. Curiously, participants overwhelmingly agreed that teenagers would use websites like Google to search for sensitive sexual health information, and would potentially search social media sites if it was something they were worried about or if there was an interesting link that they could click on to learn more (e.g., if these could be found on the right hand side of the YouTube page). Community center staff members and administrators were also enthusiastic about the sessions and the feasibility of delivering the program, prompting them to continue working with our research group to plan for the next implementation of the program.

The implementation of peer-generated HIV prevention videos, disseminated through popular social media websites, appears feasible and offers potential for engaging groups such as at-risk African American teens. A recent qualitative study highlighted that minority youth would be willing to access HIV prevention information if it is delivered through social media and if it is relevant to their interests (11). This further emphasizes the importance of engaging relevant communities in the conception, design and dissemination of HIV prevention messages to promote uptake and increase relevance. Prior research has also suggested that teens believe greater family involvement is necessary for developing and delivering effective HIV prevention messages (11), suggesting that future efforts should consider ways to engage entire families, or siblings in collaboratively generating social media content.

Growing demand for health information online, high rates of social media use, and near ubiquitous access to mobile phones among teens highlights the need for novel health communication messages that leverage the popularity of these emerging technologies (6,7). Unlike traditional health promotion efforts, social media relies on user-generated content which is often seen as authentic (24) and introduces the opportunity to develop more culturally appropriate health-related communications. Though one potential concern with free user-generated content is that it increases the possibility of wide dissemination of non-credible and ineffective health information (24). Therefore, as demonstrated in this case report, it is important to combine important principles of health communication research and theories of health behavior with novel methods of incorporating user-generated content through social media to support the design of relevant health communication messages for the target group. A participatory approach also extends beyond a one-at-a-time view of HIV prevention by considering the broader community in which individuals connect and interact with others (25), in this case the broader online network.

Several limitations with our work warrant consideration. Firstly, we described initial formative work, making it difficult to draw conclusions about the impact of our participatory approach. Importantly, it is necessary to conduct a formal evaluation of co-creating social media programs, and whether this approach is effective for influencing HIV risk behaviors among African American teens. Secondly, the small sample size in our study limits generalizability of our approach. Lastly, as reflected by participants, YouTube may have limited reach, and therefore future efforts should explore the use of other social media platforms, such as Instagram or Snapchat, for extending the reach of health promotion messaging targeting this demographic group. Despite these limitations, our approach contributes to recent calls-for-action to advance HIV prevention among adolescents (26,27) by highlighting the feasibility and appeal of a grassroots effort that leverages popular mobile and online technology.

## Conclusions

This case report can inform future efforts to bridge participatory methods by showing how popular social media can be tailored and co-developed to reach at-risk teens. There may also be opportunities to expand this approach with teens to develop HIV prevention content using other

popular social media platforms beyond YouTube. Further research needs to determine whether this approach is as effective as mainstream prevention efforts toward informing positive health behaviors and whether peer-generated messages meaningfully impact at-risk and vulnerable communities. This health communication strategy may serve as a valuable complement to existing prevention efforts.

## Acknowledgments

*Funding:* This work was supported with funding from the Boston Children's Hospital Aerosmith Endowment Fund for Prevention and Treatment of HIV and AIDS. YH reports funding from the Canadian Institutes of Health Research.

## Footnote

*Conflicts of Interest:* Both authors have completed the ICMJE uniform disclosure form (available at <http://dx.doi.org/10.21037/jhmhp.2018.07.06>). The authors have no conflicts of interest to declare.

*Ethical Statement:* The authors are accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. All procedures performed in studies involving human participants were in accordance with the Declaration of Helsinki (as revised in 2013). The Boston Children's Hospital ethical review board approved this study (No. IRB-P00007875). All participants provided written informed consent.

*Open Access Statement:* This is an Open Access article distributed in accordance with the Creative Commons Attribution-NonCommercial-NoDerivs 4.0 International License (CC BY-NC-ND 4.0), which permits the non-commercial replication and distribution of the article with the strict proviso that no changes or edits are made and the original work is properly cited (including links to both the formal publication through the relevant DOI and the license). See: <https://creativecommons.org/licenses/by-nc-nd/4.0/>.

## References

1. Jemmott JB 3rd, Jemmott LS, Fong GT. Abstinence and safer sex HIV risk-reduction interventions for African

- American adolescents: a randomized controlled trial. *JAMA* 1998;279:1529-36.
2. Centers for Disease Control Prevention (CDC). Disparities in diagnoses of HIV infection between Blacks/African Americans and other racial/ethnic populations--37 states, 2005-2008. *MMWR Morb Mortal Wkly Rep* 2011;60:93-8.
  3. Widman L, Choukas-Bradley S, Helms SW, et al. Sexual Communication Between Early Adolescents and Their Dating Partners, Parents, and Best Friends. *J Sex Res* 2014;51:731-41.
  4. DiClemente RJ, Wingood GM, Harrington KF, et al. Efficacy of an HIV prevention intervention for African American adolescent girls: a randomized controlled trial. *JAMA* 2004;292:171-9.
  5. Robin L, Dittus P, Whitaker D, et al. Behavioral interventions to reduce incidence of HIV, STD, and pregnancy among adolescents: a decade in review. *J Adolesc Health* 2004;34:3-26.
  6. Boyd D. Why youth (heart) social network sites: The role of networked publics in teenage social life. Buckingham D. editor. *The John D. and Catherine T. MacArthur Foundation Series on Digital Media and Learning*. Cambridge: The MIT Press, 2007.
  7. Centers for Disease Control and Prevention. Challenges in HIV Prevention. Centers for Disease Control and Prevention, Atlanta, Georgia. 2013. Available online: <https://www.cdc.gov/nchhstp/newsroom/docs/factsheets/challenges-508.pdf>
  8. Madden M, Lenhart A, Cortesi S, et al. Teens, social media, and privacy. Washington: Pew Research Center's Internet & American Life Project; 2013.
  9. Lenhart A, Purcell K, Smith A, et al. Social media & mobile Internet use among teens and young adults. Washington: Pew Internet & American Life Project, 2010.
  10. Brodie M, Kjellson N, Hoff T, et al. Perceptions of Latinos, African Americans, and Whites on media as a health information source. *Howard J Commun* 1999;10:147-67.
  11. Voisin D, Shiu CS, Chan Tack A, et al. In their own words: racial/ethnic and gender differences in sources and preferences for HIV prevention information among young adults. *AIDS Care* 2013;25:1407-10.
  12. Thomas SB, Fine MJ, Ibrahim SA. Health disparities: the importance of culture and health communication. *Am J Public Health* 2004;94:2050.
  13. Viswanath K, Kreuter MW. Health disparities, communication inequalities, and e-health: a commentary. *Am J Prev Med* 2007;32:S131-3.
  14. Marcus M, Walker T, Swint JM, et al. Community-based participatory research to prevent substance abuse and HIV/AIDS in African-American adolescents. *J Interprof Care* 2004;18:347-59.
  15. Bogart LM, Uyeda K. Community-based participatory research: partnering with communities for effective and sustainable behavioral health interventions. *Health Psychol* 2009;28:391-3.
  16. Wallerstein NB, Duran B. Using community-based participatory research to address health disparities. *Health Promot Pract* 2006;7:312-23.
  17. Banerjee SC, Greene K. Antismoking initiatives: Effects of analysis versus production media literacy interventions on smoking-related attitude, norm, and behavioral intention. *Health Commun* 2007;22:37-48.
  18. Rich M, Lamola S, Woods ER. Effects of creating visual illness narratives on quality of life with asthma: A pilot intervention study. *J Adolesc Health* 2006;38:748-52.
  19. Vidanapathirana J, Abramson M, Forbes A, et al. Mass media interventions for promoting HIV testing. *Cochrane Database Syst Rev* 2005;CD004775.
  20. Romer D, Sznitman S, DiClemente R, et al. Mass media as an HIV-prevention strategy: using culturally sensitive messages to reduce HIV-associated sexual behavior of at-risk African American youth. *Am J Public Health* 2009;99:2150-9.
  21. Bandura A. Social cognitive theory: An agentic perspective. *Annu Rev Clin Psychol* 2001;52:1-26.
  22. Lenhart A. Teens, social media & technology overview 2015: smartphones facilitate shifts in communication landscape for teens. Washington: Pew Research Center, 2015.
  23. Banerjee SC, Greene K. Analysis versus production: Adolescent cognitive and attitudinal responses to antismoking interventions. *J Commun* 2006;56:773-94.
  24. Chou WY, Hunt YM, Beckjord EB, et al. Social media use in the United States: implications for health communication. *J Med Internet Res* 2009;11:e48.
  25. Kippax S, Stephenson N, Parker RG, et al. Between Individual Agency and Structure in HIV Prevention: Understanding the Middle Ground of Social Practice. *Am J Public Health* 2013;103:1367-75.
  26. DiClemente RJ. Turning the Corner on the HIV

Epidemic Among Adolescents: Prioritizing Directions for Future Prevention Research. *J HIV AIDS Soc Serv* 2013;12:258-65.

27. Kasedde S, Luo C, McClure C, et al. Reducing HIV and AIDS in adolescents: opportunities and challenges. *Curr HIV/AIDS Rep* 2013;10:159-68.

doi: 10.21037/jhmhp.2018.07.06

**Cite this article as:** Hswen Y, Bickham DS. Engaging African American teens in co-creating and disseminating social media based HIV prevention messages. *J Hosp Manag Health Policy* 2018;2:41.