Crowdsourcing to promote HIV and sexual health services: A scoping review

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Short title: Crowdsourcing to promote HIV services

Abstract

Purpose of Review This review synthesizes evidence on the use of crowdsourcing to enhance HIV/sexual health services.

Recent Findings We identified 14 studies, including four completed randomized controlled trials (RCTs), one planned RCT, and eight completed observational studies, and one planned observational study. Three of the four RCTs indicated that crowdsourcing is an effective, low-cost approach for improving HIV testing and condom use among key populations. Results from the observational studies revealed diverse applications of crowdsourcing to inform policy, research, and intervention development related to HIV/sexual health services.

Summary Crowdsourcing can be an effective tool for informing the design and implementation of HIV/sexual health service interventions, spurring innovation in sexual health research, and increasing community engagement in sexual health campaigns. More research is needed to examine the feasibility, acceptability, and effectiveness of crowdsourcing interventions, particularly in low- and middle-income countries.

Keywords HIV • Sexual Health • Crowdsourcing • Quantitative evidence • Contests

Introduction

Despite remarkable advances in HIV prevention and treatment efforts, millions of people are infected each year. Expert-driven approaches to solving this complex public health challenge have been met with limited success. Such approaches often begin with a team of experts proposing an idea that they believe will reduce HIV transmission in a target population (see Figure 1). These ideas often come from a variety of sources, including theory, previous literature, and formative research methods. Next, the experts, who are usually not members of the communities that they seek to serve, consult with local stakeholders to solicit feedback on the ideas that have been generated in hopes of increasing the likelihood of intervention acceptability, feasibility, and efficacy. While this approach has been effective for some HIV outcomes in the short-term, it has been less effective in producing the long-term behavioral changes necessary to end the global HIV pandemic.

In recent years, researchers, practitioners, and national and global health organizations have recognized the value of participatory approaches to HIV prevention, treatment and care.[1] Crowdsourcing is such an approach and has the potential to engage difficult-to-reach populations in sexual health research. Crowdsourcing involves a group of non-experts and experts working together to solve a problem and then sharing solutions with the public.[2-4] It differs from expert-driven approaches in several ways (see Figure 1). First, crowdsourcing begins with the crowd, which represents a partnership between communities and experts. Specifically, experts pose a question to the crowd and the crowd provides solutions, guidance and suggestions. Researchers have used crowdsourcing to engage experts and non-experts in a number of fields, including data processing[5], participant surveying[6], surveillance and monitoring [7, 8], and participant engagement [9]. While there are a number of crowdsourcing models, open contests are the most common. Open contests solicit innovative contributions from the community, judge submissions, reward finalists, and implement

or share finalist ideas. The International AIDS Society, for example, has used crowdsourcing contests to solicit logo designs for their biennial conferences.[9] These contests are open to the public and enable a diverse group of individuals to play prominent roles in designing logos for the largest HIV conference in the world.

Crowdsourcing has several advantages. First, as a bottom-up approach, it provides a mechanism through which the public can contribute to the development of interventions by sharing their ideas about how to solve important problems affecting their community.[10]-[11] Second, crowdsourcing has the potential to tap into established in-person and online social networks. In doing so, crowdsourcing can solicit input from a large number of people in a relatively short time period.[12] Third, crowdsourcing methods are often less expensive than traditional social marketing approaches [13], making them particularly feasible in diverse settings, including low-resource settings.

Despite these advantages, crowdsourcing is under-utilized in HIV/sexual health research and programming.[14, 15] We conducted a scoping review to identify ways in which crowdsourcing has been used in improving HIV/sexual health services and to summarize evidence supporting crowdsourcing to improve HIV/sexual health outcomes.

Methods

We used Arksey and O'Malley's framework for conducting a scoping review, which consists of the following five stages: 1) identification of a research question; 2) identification of relevant articles; 3) article selection; 4) data charting; and 5) collating, summarizing, and reporting the results. Scoping reviews summarize the key literature on a topic to convey the breadth and depth of evidence in a particular field and seek to elucidate gaps in the literature. They are not intended as a means to systemically review studies and are often used when the literature on a particular topic is sparse.

In this review, we synthesize the evidence on the use of crowdsourcing to enhance HIV/sexual health services. Specifically, studies were included in this review if they focused on: 1) randomized controlled trials evaluating the effectiveness of crowdsourced interventions in improving HIV/sexual health outcomes; and 2) observational studies using crowdsourcing to promote sexual health, solicit ideas to improve sexual health, or describe the process involved in implementing a sexual health-based, crowdsourcing intervention.

Our search included studies that were published prior to July 16, 2018, that focused on crowdsourcing, with a particular emphasis on HIV/sexual health outcomes. We searched the following databases: PubMed, EMBASE, CINAHL and the Web of Science. We used the following search terms: HIV, sexual health, sexually transmitted disease/infection, crowdsourcing, and open/challenge contests. Detailed searching algorithms are listed in supplement A. After removing duplicate publications, the titles and abstracts of the remaining articles were evaluated for relevance by two independent reviewers (WT and TR), who also assessed each full-text article. Discrepancies were assessed by a third reviewer (CW) for discussion and resolution. We also searched the reference lists of included articles, grey literature, government reports, policy documents, NIH RePORTER, and ClinicalTrials.gov.

General results

This scoping review summarized evidence from studies about the effectiveness of crowdsourced HIV/sexual health interventions. Our initial search identified 413 citations. We included a total of 13 studies, including four completed RCTs,[13, 16-18] one planned RCT, eight completed observational studies, and one planned observational study [19-26].

Evidence from Randomized controlled trials

We included four completed RCTs [13, 16-18] and a planned RCT that assessed the effectiveness of using crowdsourced videos[18, 13, 17], messages[18, 16], and health services[16] to improve HIV/sexual health.

One study used a crowdsourcing contest to solicit videos from the public aimed at increasing HIV testing and improving sexual health.[13••] The minute-long videos were intended to promote first-time HIV testing among Chinese men who have sex with men (MSM) and transgender women[24] and an RCT was conducted to evaluate the effectiveness of the crowdsourced video intervention.[13] In the RCT, a total of 721 MSM who never tested for HIV were recruited and randomly assigned to watch either a crowdsourced video or a video developed using social marketing. The results indicated that crowdsourced video was just as effective as a social marketing video in encouraging first-time HIV testing among Chinese MSM and transgender women. Cost data showed that crowdsourcing intervention was 45% cheaper than the social marketing intervention, and those study findings were generalizable to Chinese MSM outside the study area.[27]

Additionally, the researchers evaluated the effectiveness of utilizing an open contest to improve condom use among Chinese MSM in 2015.[17 •] A total of 1173 MSM who engaged in unprotected sex in the past three months were randomly assigned to either watch a one-minute crowdsourced video or a one-minute social marketing video. The study found that the crowdsourced intervention was non-inferior to the social marketing intervention in promoting condom use among Chinese MSM. Moreover, the cost of the crowdsourced video per unit cost was less than the social marketing arm ($58 vs. $84). HIV testing rates were similar between the groups.

Another study used a crowdsourcing contest to solicit messages to promote hepatitis B and C testing among Chinese MSM.[18] A total of 556 men who had never been vaccinated for hepatitis B virus (HBV) were recruited and randomized into either the crowdsourced intervention group (received a crowdsourced intervention message on a weekly basis) or the control group (no intervention). However, due to the high rates of viewing and forwarding of the intervention messages in the control group, the confirmed HBV and hepatitis C virus (HCV) test uptake was similar between the intervention and control arms. The two groups also had similar rates of HIV testing.[18]

Next, one study used a crowdsourcing contest to implement a number of HIV health services, which included a multi-media HIV testing campaign, an online HIV self-testing model, and a local community-based testing promotion campaign.[16 ••] Specifically, the researchers initiated a: 1) national image contest, 2) regional strategy designathon, and 3) local message contest to develop the crowdsourced HIV services. After the crowdsourced HIV services were developed, a stepped wedge RCT was conducted to evaluate their efficacy in promoting HIV testing among Chinese MSM. In the stepped wedge RCT, 1381 MSM who did not get tested for HIV in the past three months from eight Chinese cities (clusters) were recruited and randomly assigned into four groups that received the same intervention in four different time periods.[16] The results of the trial suggest that the crowdsourced intervention package led to an improved uptake of HIV testing among Chinese MSM. This study also found that crowdsourcing helped to facilitate community engagement in promoting HIV testing among Chinese MSM.

Lastly, we identified one planned study aimed at evaluating the effectiveness of crowdsourcing interventions in improving HIV service. This proposed study seeks to use an open contest to develop new HIV self-testing services for Nigerian youth (UG3HD096929). The researchers will use a stepped wedge pragmatic RCT design to evaluate the

effectiveness of a participatory, crowdsourced intervention aimed at increasing HIV testing and related preventive services.

Table 1. Summary of four included randomized controlled trials that aimed to evaluate the effectiveness of crowdsourced interventions in promoting HIV/sexual health services.

Year	Location	Participants	Crowdsourced interventions	Control	Results (primary outcome)
2015	China	721 MSM who have not tested for HIV before	Crowdsourced video	Health marketing video	HIV test uptake was similar between the crowdsourced arm (37%, 114/307) and the health marketing arm (35%, 111/317). The estimated difference between the interventions was 2.1% (95% CI: -5.4% to 9.7%)
2016	China	1173 MSM who engaged in condomless sex in the past 3 months	Crowdsourced video	Social marketing video	At three months, 196/376 (52.1%) and 206/415 (49.6%) individuals reported condomless sex in the crowdsourced and social-marketing arms (estimated difference: +2.5%, 95%CI: -4.5 to 9.5%).
2016-2017	China	1381 MSM who have not tested for HIV in the past three months	A multi-media HIV testing campaign, an online HIV self-testing distribution model, and a local community-based testing promotion campaign	Standard of care	The crowdsourced intervention package improved recent HIV testing (in three months) uptake among Chinese MSM, with an increasing proportion of 8.9% (95% CI: 2.2 to 15.5). The intervention specifically increased recent HIV self-testing, with a risk ratio of 1.89 (95% CI: 1.50-2.38).
2018	China	556 MSM without HBV/HCV testing or HBV vaccination	Two images and two one-minute videos	Standard of care	The confirmed HBV and hepatitis C virus (HCV) test uptake was similar between the intervention and control arms. The two groups also had similar rates of HIV testing.

Evidence from observational studies

We identified a total of nine observational studies, including one planned study. These studies used crowdsourcing to inform policy, research, and/or intervention development. [19-26]

We found that one study used crowdsourcing in the development of sexual health policy. Specifically, this study used crowdsourcing to develop a strategy for engaging young people in decision making about HIV. [20 •] The crowdsourced project reached more than 500 young people from 79 countries. The project also led to the identification of three major priorities and six strategic actions regarding HIV related programming for youth and informed the development of UNAIDS policy priorities.

We identified five studies that used crowdsourcing in sexual health research. One research group conducted two Australia-based studies that used online contests to solicit the public's input to shape the herpes simplex virus (HSV) research. [22, 19] The first study sought ideas on strategies that the public used to destigmatize HSV as described in brief videos and to determine whether the videos successfully created destigmatized messages.[22] Participants were asked to submit 30-second videos presenting their ideas. A total of 103 entries were submitted and after the judging, six finalists were selected and awarded prizes. Thematic analysis indicated that participants used five strategies to destigmatize HSV: education, normalization, promoting disclosure, challenging negative perceptions, and articulating moral indignation.[22] Regarding the degree of success, the research team found that, despite using the same strategies, unsuccessful videos could be distinguished based upon the degree to which the participants were able to provide a balanced view of HSV and using appropriate effect (e.g., refraining from humor) in the videos. Based on their conclusions, using crowdsourced videos to reduce HSV-related stigma could be ineffective and possibly do more harm than good.[19]

The second study retrospectively analyzed 63 videos from the same contest to identify lay perspectives on HSV disclosure.[19 •] Specifically, they analyzed three components of disclosure: rationale, approach and setting, and timing based upon the type of personal relationship. They found that, among videos that included a rationale, reasons to disclose were related to disease manageability or personal values. Assessment of approach revealed both direct and indirect disclosure-related language, and settings ranged from private, semiprivate, to the public. Disclosure occurred within various types of

relationships, with the timing of disclosure varying as well. Taken together, most entries expressed expectations that those with HSV disclose their status to sexual partners.[19]

In a U.S. study, contestants submitted videos or images that embodied the significance of HIV cure research through an online platform.[25] Most participants were African American youth aged 18-23 years. Of the 144 potential contestants, 39 people submitted 32 entries. Social media analytic data showed that 684 people followed the website; there 2233 unique visits to the online platform; there were 585 unique views of the videos, and the site reached 80,624 unique users. The themes for the contest entries emphasized the importance of community engagement in promoting HIV cure research. Based on this work, the authors concluded that crowdsourcing can increase community engagement in HIV cure research.

A Chinese study described two open contests: "Testing Saves Lives" and "Sex+Health."[24] "Testing Saves Lives" solicited one-minute films from community-based organizations (CBOs) focused on promoting HIV testing in China. The video contest was publicized using the study website, direct emails to the leadership at CBOs, and through two open Skype calls. Entries were judged based upon their ability to: generate interest in HIV testing, reach untested individuals, and engage the community. The video contest was intended to: 1) empower CBOs to more effectively utilize social marketing to promote HIV testing; 2) promote multisectoral collaboration; and 3) appeal to youth from key populations. "Sex+Health" was developed to encourage Chinese youth up to age 30 to develop images aimed at sparking conversations about sexual health. Entries were judged based upon their relevance to sexual health and ability to engage Chinese youth.[24] The contest was promoted using a combination of in-person events at four high schools and universities, the US Consulate in Guangzhou and via social media. A total of 96 images were submitted for the "Sex+Health" contest over 39 days. Entries in the top five were displayed on the study team's website for six days to enable members of the public to select the winning entry. A proposed U.S. study will use an open contest to solicit messages to increase awareness and promote uptake of pre-exposure prophylaxis (PrEP). Additionally, it seeks to assess the effectiveness of the crowdsourced messages by examining neuro-imaging.

A Ugandan study used crowdsourcing in a nationwide mass media campaign aimed at promoting safe sexual practices among adolescents that included abstinence, condom use, and reducing one's number of sexual partners.[26] During "Hits for Hope," musical acts were invited to participate in a competition the required them to compose and perform an original song focused on HIV prevention. A total of 80 groups from 10 districts performed and a panel of judges comprised of Ugandan youth selected the winning song. This song was recorded and distributed to taxi drivers, youth centers, and sold commercially. Surveys of 1,681 Ugandan youth revealed that, after the campaign, condom use increased from 46%, up from 69%. Moreover, fewer youth reported that they were unsure where to retrieve condoms (from 42% to 31%).[26]

Lastly, we identified three studies that used crowdsourcing to inform HIV/ Sexual Health programs. In a multi-country open contest entitled, "Scenarios from Africa," the researchers solicited storylines from young Africans for short fiction films intended to educate their communities about HIV.[23 ••] Between 1997 and 2005, more than 100,000 young people from 37 countries participated in the contest. In 2005 alone, a total of 22,894 stories were submitted by 63,327 contest participants. After judging, 30 stories were selected as finalists. These stories were used to inform the scripts for short fiction films translated into 25 languages that were headed by renowned African directors and were further used as educational resources in sub-Saharan Africa countries.[28, 29]

Crowdsourcing methods were used to maintain an internet-based interest/advocacy sounding board that was developed to respond to parents who shared apparent instances of group B streptococcal (GBS) - linked reproductive infections, along with comments and suggestions regarding GBS disease policies and prevention.[21] Participation in the program was associated with improved knowledge of the risk of sexually-transmitted GBS and the unreliability of intrapartum antibiotic prophylaxis strategies.

We identified one planned observational study aimed to improve PrEP uptake among MSM. This study will use an open contest and a neuroimaging technique to develop and evaluate pre-exposure prophylaxis (PrEP) promotion messages for high-risk MSM in Baltimore, MD (R34MH116725).

Table 2. Summary of finished observational studies that used crowdsourcing to promote HIV/sexual health services.

Field	Year	Program name	Solicited entries	HIC or LMIC*	Outputs
Policy	2011	CrowdOutAIDS	Strategy/policy suggestion	LMIC	Suggested three major priorities and six strategic actions to engage youth in HIV-related policy
Research	1995	Hits for Hope	Songs	LMIC	Adolescents reported safer sexual practices after the mass media campaign
	2011[§]	HSV perceptions	Videos	HIC	The solicited videos discussed the motivation of HSV disclosure, the value of disclosure, and the strategies to reduce stigma, which including
	2013	Testing saves life	Videos	LMIC	One-minute videos to promote HIV testing among MSM in China
	2015-2016	2BeatHIV	Images and videos	HIC	Increased community engagement for HIV cure research
Program	1997-2005	Scenarios from Africa	Stories	LMIC	Stories were selected and transformed into short fiction films in 25 languages and were further used as an educational resource at the community level in sub-Sahara African countries
	1998-2014	GBS vaccine and patient education	Observations/comments and suggestions	HIC	The crowdsourced platform increased the knowledge of parents that GBS can be sexually transmitted

Note: * High-income countries or Low- and middle-income countries, HSV= herpes simplex virus, GBS = group B streptococcal, [§]two included studies were from the same crowdsourcing contest.

Policy and research implications

Based on the existing evidence, our scoping review identified a number of policy-related and research implications for using crowdsourcing methods to promote HIV/sexual health research and related services.

First, our scoping review suggested that most crowdsourced HIV/sexual health studies were conducted in high-income or upper-middle-income countries. As a bottom-up approach[24], with minimal costs[13] and strong community engagement[30], crowdsourcing is a promising method that could lead to improvement in current HIV/sexual health services in LMICs. However, policies and strategies for promoting this method in LMICs are lacking. People residing in LMICs are disproportionately affected by HIV and sexual health-related morbidity. As such, crowdsourcing could be used to identify and implement policies that are responsive to the community needs, while also building upon their assets.

Second, crowdsourcing can be further used to promote other HIV/sexual health services, including HIV self-testing and pre-exposure prophylaxis (PrEP). The existing crowdsourcing studies mainly focused on promoting HIV testing [13, 16], condom use [17] and other sexual health services.[19, 28] At the same time, crowdsourcing could also be used to promote HIV self-testing and PrEP. For example, crowdsourced HIV self-testing was one of three intervention components of a stepped wedge trial to improve HIV testing among MSM in China, and the study found that the intervention specifically increased recent HIV self-testing, with a risk ratio of 1.89 (95% CI 1.50-2.38).[16] In Bangkok, Thailand, a crowdsourcing contest was used to generate new and innovative messages and communication products to promote PrEP among young, high-risk MSM and transgender individuals. During the judging phase of the contest, one single crowdsourced video was viewed and judged by 22,779 people, and the majority of the surveyed MSM and transgender individuals indicated that this video was designed for them.[31] However, this remains one of the few studies in this area; therefore, additional studies aimed at promoting and evaluating the use of crowdsourcing HIVST and PrEP are needed.

Third, research aimed at promoting the dissemination and scale-up of crowdsourcing methods are needed. The majority of our knowledge regarding outcomes associated with using crowdsourcing to promote sexual health messages is based on studies that are either underpowered due to small sample sizes, focused on MSM, or mostly observational. Thus, more research is needed to examine the effectiveness of such interventions through RCTs with diverse populations. Moreover, all studies cited in this review focused on open or challenge contests to solicit ideas. Crowdsourcing could also be used to implement sexual health-based research and in research, as well as disseminate important findings. To promote the scale-up of crowdsourcing, the TDR issued a practical guide of crowdsourcing.[32]

Fourth, more effective methods for evaluating crowdsourced interventions are needed. Although several RCTs have been conducted to evaluate the effectiveness of such interventions in promoting HIV services, the development of effective measurements requires further consideration. For example, most of the existing studies relied on self-reported data collected via online surveys, asking questions about testing results, high-risk behaviors such as unprotected sex. A research checklist providing guidance on how to evaluate and standardize reporting for crowdsourced interventions could help investigators to utilize this promising approach to improving sexual health outcomes.

Conclusion

In summary, crowdsourcing can be an effective tool for informing the design and implementation of HIV and sexual health interventions. More research and community collaboration on how to use crowdsourcing to improve more types of HIV/sexual health services, including HIVST and PrEP uptake are needed.

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Compliance with Ethical Standards

Conflict of Interest The authors declare that they have no competing interests.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

Figure Legend

Figure 1 Comparison of crowdsourcing (right) and conventional (left) approaches.

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