

HIV cure research community engagement in North Carolina: a mixed-methods evaluation of a crowdsourcing contest

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Abstract

Objectives: The purpose of this study was to evaluate the feasibility of using a crowdsourcing contest to promote HIV cure research community engagement.

Methods: Crowdsourcing contests are open calls for community participation to achieve a task, in this case to engage local communities about HIV cure research. Our contest solicited images and videos of what HIV cure meant to people. Contestants submitted entries to IdeaScale, an encrypted online contest platform. We used a mixed-methods study design to evaluate the contest. Engagement was assessed through attendance at promotional events and social media user analytics. Google Analytics measured contest website user-engagement statistics. Text from contest video entries was transcribed, coded and analysed using MAXQDA.

Results: There were 144 attendees at three promotional events and 32 entries from 39 contestants. Most individuals who submitted entries were black ($n=31$), had some college education ($n=18$) and were aged 18–23 years ($n=23$). Social media analytics showed 684 unique page followers, 2233 unique page visits, 585 unique video views and an overall reach of 80,624 unique users. Contest submissions covered themes related to the community's role in shaping the future of HIV cure through education, social justice, creativity and stigma reduction.

Conclusion: Crowdsourcing contests are feasible for engaging community members in HIV cure research. Community contributions to crowdsourcing contests provide useful content for culturally relevant and locally responsive research engagement.

Keywords: HIV cure research, crowdsourcing, community, social media

Introduction

As scientists examine strategies towards an HIV cure, it is imperative to identify optimal ways to engage communities most impacted by the epidemic [1]. Community engagement involves researchers working with the public to build mutually beneficial relationships and collaborate on research design and implementation [2]. Traditionally, scientists have designed community engagement activities from the top down [3,4] but these are often focused on reviewing clinical trial protocols and assisting with participant recruitment. Researchers have developed most of the existing community engagement projects, such as activities developed through community advisory boards [5,6] and an online curriculum about HIV cure research [7]. Often, these engagement efforts are focused on reaching a subgroup of community members that has previous knowledge and experience with HIV clinical research. Thus, they may not reflect the needs of the broader community and may be ineffective at involving groups that are traditionally under-represented in clinical research, such as racial/ethnic minorities, people living in rural areas and women at high risk for acquiring HIV [4,8,9]. In particular, many black young adults have not been educated about the clinical research process, are under-recruited to participate in HIV clinical trials, and are traditionally mistrustful of clinical scientists [4,8,9]. However, black young adults may be able to provide meaningful feedback that bridges the gap between HIV clinical scientists and predominantly black communities. A more bottom-up approach to HIV cure research engagement may be more effective at involving the community in the early stages of HIV cure clinical research than traditional top-down approaches.

In contrast to top-down approaches, crowdsourcing enables people with limited knowledge about HIV cure research to contribute their voice. Crowdsourcing occurs when a group of people complete a task or solve a problem through an open call, and then freely share the answer with everyone [7,10]. Crowdsourced ideas are shared with the community and the finalists are publicly celebrated [7]. A crowdsourcing approach begins with the assertion that community members working collaboratively may be better positioned to develop effective solutions compared to individual experts. Contests are a subset of crowdsourcing that elicit contributions from the public to solve a problem, entries are judged by a panel of experts and finalists are celebrated [11,12]. Most crowdsourcing contests involve diverse groups and rely on the internet to solicit entries [7,13–16]. Traditionally, many crowdsourcing projects have been driven by the private sector and have not been orientated towards solving problems embedded in local communities [7]. However, crowdsourcing is increasingly being used to address issues in public health [17], clinical trial research [18] and piloted to develop health campaign messages [15,17–19]. The purpose of this pilot study was to evaluate the feasibility of a crowdsourcing contest designed to increase HIV cure research community engagement.

Methods

We undertook formative research to inform the development of the crowdsourcing project name and contest engagement strategies [20]. We organised a series of community feedback sessions to allow the community to develop and design the community engagement strategy for the contest [20]. Project staff members developed the contest prompt and submission criteria. The goal of the contest was to develop a campaign to raise awareness about HIV cure research among black young adults. Contestants were asked to think about the possibility of an HIV cure, develop an opinion about the topic and submit a creative contribution, for

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Figure 1. Crowdsourcing contest finalist submissions

example, videos or images that reflected a thoughtful response to the prompt, ‘What does an HIV cure mean to you?’ Contestants were also asked to provide a short description to communicate their intent or additional comments about the submission. Eligible contestants included anyone aged ≥ 18 years. Contestants completed online consent and a demographic survey via the contest website. We did not ask contestants to disclose their HIV status. The members of the public could also create a profile and complete a demographic survey on the contest website to vote on entries.

Online contest submission was facilitated through a website (2BeatHIV.org) organised by IdeaScale. The site provided a platform for confidential submissions in the form of videos, images and audio. The site was open to anyone and allowed users to view contest rules and information about HIV cure research. This study was approved by the institutional review board at the University of North Carolina at Chapel Hill.

Contest recruitment and online engagement occurred for 8 weeks between 15 October and 18 December 2015. Online voting occurred for 2 weeks and another week was allotted to allow the panel of judges to review and rank the highest scored entries and select the finalists. Finalists were announced a week after the judges completed scoring the entries. Online celebration of contestants occurred for 1 month following the announcement of finalists. Finalists were celebrated online by posting their entries via the contest and social media sites with permission from contestants. We also adapted contest entries to create project-related promotional products, such as stickers, pens and posters. Lastly, we designed subsequent community engagement events that addressed insights gained from the contest submissions to facilitate dialogue about issues relevant to black young adults.

Contest promotion included multiple in-person activities, such as hosting multiple community engagement events, delivering guest lectures to undergraduate classes held during the week at a nearby historically black university, a World AIDS Day event at the local LGBTQ centre held at 18:00, and advertising with local stations that catered to predominantly black listeners. We did not ask people to disclose their HIV status; however, we recruited at HIV service organisations, HIV-related events and HIV housing communities. One in-person event was a hip-hop concert with a community forum about HIV cure conspiracy theories co-hosted by our community partners at a local black-owned restaurant at 19:00. We did not collect demographic information from in-person event attendees, but maintained detailed ethnographic notes to assess attendee demographics. We also promoted the contest online by sponsoring geo-targeted promotional flyers and videos on Facebook, Twitter and the contest website. The videos included short descriptions of the contest and voluntary interviews with community leaders and celebrities that encouraged contest

participation. To help promote the contest, we developed partnerships with over 25 organisations, businesses, artists and community leaders who work with black young adults and the larger Durham community.

Contest finalists were chosen based on a total number of votes received from other contest website members (i.e. contestants and users who registered with the contest website), and ranked evaluation from five project staff members (Figure 1). Project staff selected the entries with the highest number of online votes, ranked them based on the selection criteria and provided comments on each entry. Criteria for selecting winners included relevance to the local audience and HIV cure, originality, creativity and ability to stimulate engagement. Finalists and other submissions were celebrated online and at subsequent community events. Prize incentives included a one-night local hotel stay (first place), a \$75 local restaurant gift certificate (second place) and an honourable mention.

Crowdsourcing contest metrics

We evaluated the crowdsourcing contest by collecting online-engagement statistics, assessing the demographics of contest site users and conducting qualitative analysis of contest submissions. Online-engagement measures were extracted using Facebook and Twitter analytics for the project’s social media sites and Google Analytics for the contest website. Measures of active online engagement included page follows (unique users who subscribe to page update alerts), page visits (unique users who visited a page), video views (number of times a video was viewed online) and contest submissions. Reach was measured as the number of unique users who passively viewed any post content from the contest’s Twitter and Facebook pages [21,22]. These metrics have been used to examine the scope of community engagement for previous crowdsourcing contests [19,23–25].

Analysis

Summary statistics were used to describe contestant demographics and online engagement metrics. Digital transcriptions of audio from video submissions were analysed using axial coding in MAXQDA [26]. We used a thematic codebook previously developed by project staff members who analysed qualitative data from formative focus groups for the project [20]. Three staff members developed the codebook through consensus by independently coding a focus group transcript and convening to reconcile discrepancies in coding decisions [26]. Deductive codes identified thematic patterns in the transcripts of video contest submissions. Similar to Merchant *et al.*’s 2014 analysis of crowdsourcing contest entries, messages from contests submissions were categorised based on emergent themes. Submissions that related to multiple themes were included in multiple thematic categories [24].

Results

Online and in-person engagement metrics

Over 14 weeks, 144 people attended three in-person community engagement events, the majority (62%) of whom were black men and women aged 18–60 years. The remaining 37% of attendees were white men and women aged 18–60 years. Online engagement included a reach of 80,624 unique users. A subset of 684 unique users actively engaged with the project's social media and contest sites by making 2233 total visits. The contest website had 446 page followers and 1591 page visits. Facebook engagement had the greatest number of views, with 218 page followers, 1010 page visits, 585 video views and a reach of 48,875 unique users. Most unique users who accessed contest promotional flyers and videos on the project's Facebook page were women ($n=145$, 72%), 25–34 years ($n=77$, 29%) and resided in North Carolina ($n=170$, 78%). Twitter was the second most successful online recruitment tool, with 99 followers, 653 page visits and a reach of 31,749 unique users: women comprised 56% of unique users ($n=17,779$) and 44% were men. The majority of Twitter users were aged 25–34 years ($n=43%$) and 48% resided in North Carolina.

Contest participant demographics

There were 32 entries from 39 contestants. The majority of contestants were women ($n=23$, 59%), African American ($n=31$, 79%), had attained some college education ($n=18$, 46%) and were aged 18–23 years ($n=23$, 59%) (Table 1). Contestants submitted entries based on engagement via undergraduate class lectures ($n=23$), social media ($n=7$) and the hip-hop concert and community forum ($n=2$). An additional 407 people became members of the contest website after seeing online engagement materials and voted on contest entries, but did not participate as contestants.

Qualitative findings

The average video length was 2 minutes (0:45–5:57 minutes). Video contest entries addressed topics related to three themes: (1) the potential outcomes that an HIV cure would have for the community, (16 submissions); (2) how an HIV cure might reduce HIV-related stigma (10 submissions); and (3) necessary elements to find a cure, including access to healthcare (9 submissions).

The most popular theme that emerged from the contest submissions focused on the positive impact that a cure for HIV would have on communities, particularly African-American communities (Table 2). Specifically, contest entries highlighted the potential for an HIV cure to improve the health and happiness for those currently living with HIV. For example, a black male contestant (early 30s) said in his video submission:

You get that sense of hope and triumph of beating something that may have killed loved ones, killed friends, family, and that's plagued people for a long time

Others spoke about the specific impact a cure would have on low-income and racial/ethnic minority communities. For example, one black man's (early 40s) video submission featured a poem about an HIV cure:

With hope in the wind, tomorrow in the skies; till the cure is in our grasp, keep our eyes on the prize ...

More than 1 million in the US infected, so many more around the world.

Developing nations struggling for necessary medications.

Minority communities here juggling the rise of new cases.

I just see the faces.

Table 1. Demographic characteristics of contest submitters

Characteristics	Number (n)
Gender	
Male	16
Female	23
Total	39
Age (years)	
18–23	23
24–29	7
30–35	4
36–41	2
42–47	2
48–53	1
Total	39
Race/ethnicity	
Black/African American	31
White	2
Asian	1
Hispanic	5
Total	39
Educational attainment	
Master's degree	5
Bachelor's degree	5
Associate's degree	3
Some college, no degree	18
High-school graduate	7
Less than high school	1
Total	39
Marital status	
Single, never married	30
Legally married	3
Domestic partner relationship	5
Separated	1
Total	39
Health	
Excellent	18
Good	20
Not good	0
Poor	1
Total	39

Others focused on the potential consequences of HIV cure research. One black male contestant (late 20s) reflected:

The end of HIV could be a great future. However, it could be a double-edged sword with people not taking it as seriously as it is now.

Additionally, a white male contestant (mid 40s) created an image entitled 'What's the Goal?' featuring the words, 'AIDS: we need cure research, not hysteria. Remember HIV.'

The second most popular theme was how an HIV cure might reduce HIV-related stigma (10 submissions). Contestants touched on multiple aspects of stigma, including negative treatment from

Table 2. ‘What does HIV cure mean to you?’ contest submission themes

Themes	Total entries by theme (n)	Accompanying text
Who can find a cure for HIV?	3	‘It’s gonna take doctors who dare, scientists who care, and all the people in your neighbourhood to defeat HIV’
What is needed to find a cure?	3	‘In the black community, we really need to open up and have a serious dialogue so that people [can] feel safe and comfortable about being HIV positive’ ‘Access to the medical care, treatment, and facilities that can help them to fight HIV and stop HIV from growing and attacking CD4 cells’
How would a cure impact the community?	8	‘African Americans accounted for an estimated 44% of all new HIV infections among adults and adolescents. The estimated rate of new HIV infections for African American women was 20 times that of white women, and almost five times of Hispanics. So you ask me, a 25-year-old African American female, what an HIV cure would mean to me and my community: more than you could ever imagine’
Outcome of HIV cure		
Positive outcome, life	10	‘Not only will it give people a second chance on life, but it will be one step closer to breaking a cycle of unhealthy living’
Negative outcome, death	1	‘The end of HIV could be a great future. However, it could be a double-edged sword with people not taking it as seriously as it is now’
Social constraints/barriers/considerations	6	‘With hope in the wind, tomorrow in the skies; till the cure is in our grasp, keep our eyes on the prize. So I’m gonna speak about it. I’m gonna spit about it. More than 1 million in the US infected, so many more around the world. Developing nations struggling for necessary medications. Minority communities here juggling the rise of new cases. I just see the faces’
Stigma	6	‘People with HIV may be labelled as a skank, homosexual, or a junkie ... A cure for HIV will not only mean the elimination of the detrimental symptoms of the virus, but will also eliminate the negative labels that accompany it I think a cure would make it easier for people in China to get help and that it would be less shameful for them to have the disease. I also think that the cure would allow Chinese community to be more open and discuss about STDs and protection around STDs’ ‘First of all, it would mean that there would no longer be a negative stigmatism towards individuals that have the disease and the infection’
Economic barriers	2	‘HIV and AIDS are very, very predominant in low-class African American societies. I feel like a cure would just, it would help with the bettering of life for everyone in the community’
Lack of access to healthcare/medication	2	‘Access to the medical care, treatment, and facilities that can help them to fight HIV and stop HIV from growing and attacking CD4 cells’ ‘It also means that the \$2,000–\$5,000 that the individuals spend each month for medication could be spent toward something else. So no longer would there be a waste of \$2,000–\$5,000 a month, because now we have a cure’

others, negative labels and silence about one’s status. For example, a black woman (early 20s) stated in her video submission:

There would be no more pain and suffering. No more isolation. No more feeling like you’re less than just because you’re HIV [positive].

Similarly, a white man (early 30s) suggested:

A cure for HIV will not only mean the elimination of the detrimental symptoms of the virus, but will also eliminate the negative labels that accompany it.

A Chinese-American woman (early 20s) said in her video submission:

I think that a cure for HIV will allow the Chinese community to be more open about discussing the disease and how to protect from the disease.

Lastly, some contestants submitted entries (9 submissions) discussing the necessary elements to find a cure, including access to healthcare. In one video, a black woman (early 20s) said it was necessary to have:

... access to the medical care, treatment, and facilities that can help them to fight HIV and stop HIV from growing and attacking CD4 cells.

Another contestant (demographics unknown) said:

It’s gonna take doctors who dare, scientists who care, and all the people in your neighborhood to defeat HIV.

Similarly, six submissions emphasised that everyone has a role in finding a cure for HIV. In one video, a black woman (late 30s) suggested the black church played an important role in leading communities in ending the HIV/AIDS epidemic:

The black church [can] really help support people. That’s something that we can do to help people feel safe, to feel comfortable. We need to educate ourselves [about HIV and HIV cure research] as a community.

Contest finalists submitted entries (Figure 1) that provided potential appeal to local community members and a compelling message.

Discussion

The purpose of this pilot study was to evaluate the feasibility of a crowdsourcing contest to better understand a predominantly black community’s perspectives about the potential for an HIV cure and develop an awareness campaign about HIV cure research. We assessed the crowdsourcing contest using online engagement analytics and qualitative analysis of contest entries. Based on the quantitative and qualitative results, we found the crowdsourcing contest to be an effective mechanism to engage black young adults in North Carolina about HIV cure research. Both in-person and online engagement were useful for promoting the contest.

A combination of online and in-person engagement strategies may be useful to encourage participation for local contests. Previously published literature shows that using social media as a tool for community engagement is a useful way to disseminate information about health campaigns and promote sexual health behaviour [27,28]. This study's patterns of online engagement were similar to other health campaigns [29,30] that used social media. Based on the results, our contest website yielded the most page visits and followers; however, Facebook and Twitter were also effective. While online engagement was beneficial to promoting the contest, most contest submissions came from people who attended in-person engagement events. The in-person events and class lectures had a greater representation of black women than men, which resulted in more female contestants. As a result, some of the contest entries focused on how a cure for HIV would minimise stigmatising labels for women and reduce disparities between black women and white women; however, the majority provided messaging that was relevant to a general audience. Our findings suggest the importance of using multiple engagement strategies. It is possible that in-person engagement allowed more opportunity than social media engagement for potential contestants to ask questions and submit ideas, especially when they had limited access to the internet. Crowdsourcing contests that aim to engage local audiences should consider using a combination of strategies to promote contest submissions, including social media engagement, videos with local leaders and in-person events.

Qualitative analysis showed how messaging for HIV cure research engagement should incorporate themes related to social justice, access to healthcare and reducing HIV-related stigma. Contest entries illuminated themes that may be useful for future public health campaigns focusing on raising awareness about HIV cure research, particularly for black young adults. The majority of submissions focused on the potential for HIV cure research to increase hope among people living with HIV and reduce stigma associated with the disease. However, two submissions also reflected on the potential consequences of HIV cure research, including people not taking the disease seriously and not remembering the impact of HIV/AIDS if a cure is developed. One contestant also created a piece warning against the public resorting to hysteria about HIV without cure research. Similar to other studies that developed HIV-related campaigns with black community members, contestants' entries focused on the impact of HIV in their specific communities and demographic groups [31–33], and emphasised hopeful messaging rather than fear-induced messaging to shock the intended audience [20,34,35]. The findings from this study show that black young adults see the potential for HIV cure research to reduce stigma associated HIV, however, participants emphasised the importance of incorporating social justice components like healthcare access; the community's role in shaping the future of HIV cure through education; stigma reduction and directing attention to the disproportionate impact that the HIV epidemic has on people of colour, especially black communities. These themes may help shape future community engagement interventions among black young adults for HIV cure research engagement by focusing on the direct impact that a cure for HIV would have on stigma reduction and related social justice issues.

There were some limitations to the study. Participants in the pilot crowdsourcing contest represented demographic groups who were able to participate based on their skill set and access to resources. Low-literacy levels and limited access to computers may have prohibited potential contestants from submitting material to the contest. Additionally, we did not ask for contestants' HIV status, so we cannot assess differences in contestant perspectives based on HIV status. It may also be useful to capture potential changes

in contestants' perceptions of HIV risk as result of increased knowledge about HIV cure research. Thus, emergent themes from the contest entries may not be applicable to other black communities vulnerable to the HIV epidemic. However, we targeted recruitment efforts in diverse settings to ensure broad engagement with subgroups within the black community, including people living with HIV. The findings do provide insight into peoples' thoughts about a potential cure for HIV that can be adapted for future approaches to HIV cure research among African Americans in North Carolina. Future studies should examine how crowdsourcing contests for sexual health might best incorporate participation from people with low-literacy levels and limited access to computers, particularly because these are barriers people must also navigate when accessing resources for HIV. Finally, we are unable to apply findings from online engagement to specific demographic groups because online analytics do not collect racial/ethnic demographic data. We caution against solely relying on Facebook and Twitter analytics to assess user patterns because it is difficult to identify which unique users accessed contest material across sites. For example, the same person who visited Twitter with one username and visited Facebook with their other username would count as two unique users. Future studies should use software that can identify unique users across sites to more accurately assess online engagement. Researchers might also assess the impact of information about HIV cure research and the contest that was accessed via online engagement to other groups of people in a user's personal networks.

Conclusion

Crowdsourcing contests may be useful for HIV cure community engagement. This study's findings suggest that recruitment with in-person events, educational activities, food and online engagement may be a useful way to reach black young adults for participation in future crowdsourcing contests. Developing community partnerships with HIV community-based organisations, local businesses and key stakeholders with direct access to black young adults at high risk for acquiring HIV was vital to successful in-person engagement and contest recruitment. Crowdsourcing contests provide opportunities for community members to create campaigns and messaging around HIV cure research that reflect their lived experiences, cultural values and local context. Community contributions to crowdsourcing contests may provide useful content for culturally relevant and locally responsive campaigns. Future research should assess how crowdsourcing contests may provide an avenue for the public to address their concerns about the ethics of HIV cure research.

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