Crowdsourcing and community engagement: a qualitative analysis of the 2BeatHIV contest

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Abstract

Background: As HIV cure research advances, it is important to engage local communities. Crowdsourcing may be an effective, bottom-up approach. Crowdsourcing contests elicit public contributions to solve problems and celebrate finalists. We examine the development of a crowdsourcing contest to understand public perspectives about HIV cure research.

Methods: We examine the feasibility of using crowdsourcing contests as an effective approach to engage the public about HIV cure research. Crowdsourcing contests elicit public contributions to solve problems and celebrate finalists. We use a qualitative approach to examine the development of a crowdsourcing contest to understand public perspectives about HIV cure research.

Results: Seventy-one people participated in four focus groups. Emergent themes for HIV cure engagement included: (1) emphasizing collective approaches to HIV cure; (2) dispelling myths to spur discussion; (3) using HIV cure as motivation for participation; and (4) using creative community engagement.

Conclusion: Crowdsourcing contests may be useful for engaging local communities, developing culturally tailored awareness campaign messaging, and encouraging the public to learn more about HIV cure research.

Keywords: African Americans/blacks, community engagement, crowdsourcing, HIV/AIDS

Introduction

HIV cure research is increasingly focused on achieving sustainable, drug-free viral suppression and eliminating latent virus from the body [1]. However, many HIV cure research studies have high participant risks, such as potentially adverse side effects from experimental therapies and viral rebound from treatment interruption procedures [2]. These potential participant risks increase the importance of community engagement [3]. Community engagement involves researchers working with the public to build mutually beneficial relationships and collaborate on research design and implementation [4]. Lessons learned from HIV vaccine and antiretroviral pre-exposure prophylaxis studies suggest that failure to engage communities early in the research process may exacerbate mistrust during subsequent trials [5,6]. When HIV vaccine trials included community engagement, participants reported increased trust in scientists and trials [3,7]. Research engagement also can improve the cultural and local responsiveness of clinical studies [3,7]. However, traditional community engagement efforts are often limited in scope and designed by scientists whose perspectives, experiences, and assessment of needs do not necessarily reflect community needs. Additionally, traditional community engagement efforts may not reach potential stakeholders, like black young adults, who are typically disconnected from research [8].

New methods for community engagement relating to HIV cure research are needed for three reasons. First, myths associated with HIV cure need to be addressed. For example, there is a belief among some black people living with HIV that the government is purposefully withholding an HIV vaccine or cure from the public [9]. These myths may magnify misinformation and fuel mistrust about HIV cure research [10]. Second, a long history of power imbalances, under-representation, and exploitation of black people in clinical research have created mistrust between scientists and community members [11]. Third, current HIV cure trials are risky for patients and present limited or no direct medical benefits [12]. To address these challenges, it is imperative to involve those traditionally under-represented in HIV clinical research to provide new insights into ways to communicate the social and ethical challenges of HIV cure research.

Crowdsourcing may be useful for understanding public perspectives about HIV cure research. Crowdsourcing is a process where a group, instead of an individual, completes a task, solves a problem, or develops innovative ideas [13–15]. Some popular examples of crowdsourcing include Wikipedia and Kickstarter campaigns. Contests are a subset of crowdsourcing approaches that elicit creative contributions from the public, celebrate semi-finalists, provide prizes for the winning submissions and adopt the winning ideas [16]. Contest participants have been found to develop better or at least equivalent products to those from experts due to community-driven solutions [17–19]. Most crowdsourcing contests occur online through private sector companies who encourage participants to identify solutions to organisational problems [16,18,20] or to improve products [21,22].

Few crowdsourcing contests have been used to facilitate research engagement. Little is known about developing a crowdsourcing contest in collaboration with community. A few crowdsourcing contests have developed health interventions [13,15,21,22]. Specifically, HIV-related crowdsourcing contests have designed HIV prevention campaigns [23,24]. Previous studies show that using in-person community engagement efforts improves contestant recruitment and increases the volume of crowdsourcing contest submissions [25]. However, few crowdsourcing contests have incorporated community-based participatory research (CBPR) principles to guide their development. The purpose of this study is to examine the feasibility of using crowdsourcing contests as
a method of HIV cure research engagement and to better understand public perceptions about HIV cure research.

We used CBPR principles to guide the development of a crowdsourcing contest. CBPR research aims to equitably involve community members, organisational representatives, and/or researchers in all aspects of the research process as experts [26]. CBPR principles have been used to develop, conduct, and evaluate HIV interventions that combat HIV-related stigma [27]. Combining CBPR principles with a crowdsourcing contest may encourage a sense of community ownership and empowerment to be involved in HIV cure research [26,28,29]. This study examines the process of collaborating with community members to develop the branding and community engagement strategies for a future crowdsourcing contest where contestants would reflect on what an HIV cure would mean to their lives.

**Methods**

**Participants**

Adults who were 18 years and older and living in the Triangle region (Chapel Hill/Durham/Raleigh) of North Carolina (NC) were eligible for focus-group participation. We developed a stakeholder list that included community-based organisations, local businesses and researchers in NC who might be interested in being involved in a crowdsourcing contest. We used flyers, emails, social media advertisements and phone calls to stakeholders to recruit a convenience sample of focus-group discussion participants; we did not ask people to disclose their HIV status. Ethical approval was obtained from the Institutional Review Board at the University of North Carolina at Chapel Hill.

This study was conducted in Durham, NC, which is ranked the fifth highest county in the state for HIV infection [30]. Of all adult/adolescent HIV infections in Durham, 63.8% occur within the black community, and 40% occur among black young adults aged 20–29 years, despite the black community representing 37.2% of the city’s population [30]. At the same time, scientists in this region’s local universities lead research to develop a cure for HIV [1,31], and are likely to conduct clinical trials with human participants, including Durham residents. Given the epidemic’s impact on Durham residents and the potential for HIV cure clinical trials to be conducted in Durham’s communities, the setting was appropriate for using focus groups to develop a pilot crowdsourcing contest that would identify community perspectives about HIV cure research.

**Focus-group discussions**

From September 30, 2015 to November 5, 2015, we conducted two focus-group discussions, which lasted approximately 1.5–2 hours, and two feedback sessions, which lasted approximately 30 minutes each. The sessions conceptualised the future crowdsourcing contest’s branding (for example, contest name, logo, hashtag) and community engagement strategies. The focus-group discussions prioritised feedback on the best ways to incorporate branding and community engagement strategies to make the contest more recognisable, to increase a sense of community ownership over the contest and to reflect community preferences. At each focus group, the informed consent document was read aloud and received verbal consent from each participant. We presented brief explanations of recent HIV cure research, the importance of community engagement and the goal of the future crowdsourcing contest. The two focus-group discussions enabled participants to break into small groups to collaboratively design and pitch ideas for the contest’s branding and community engagement strategies. We asked participants to develop ideas that would attract black young adults, aged 18–35 years, to participate in a future crowdsourcing contest; however, the focus groups were open to all who were interested in participating. The focus groups were iterative, meaning that the first focus group’s participants provided feedback on small group ideas. Participants were compensated $10 gift cards for their time. The second focus group’s participants also provided verbal consent but were not compensated for participation. They reviewed ideas from the first focus-group discussion, evaluated mock-ups of those ideas and broke into small groups to provide additional contest ideas and engagement strategies.

Two feedback sessions were conducted with a convenience sample of undergraduate students to gain a sense of preferences from the target age group: undergraduate participants reviewed mock-ups from the focus-group discussions and provided feedback through open discussion and written comments. The mock-ups included images of the logo, proposed contest name and hashtag to be used on the contest and social media sites.

**Data collection and analysis**

Focus-group questions were adapted from items used in a previous HIV prevention community engagement study conducted in Durham, NC [32]. Questions asked participants to reflect on the primary messages they wished to convey to contest participants, how the contest could harness the strengths of the community and how to best encourage black young adults to participate.

Digital transcriptions of qualitative data were analysed using MAXQDA. We developed a thematic codebook through consensus among the research team by independently coding a focus-group transcript and convening to reconcile discrepancies in coding decisions. Data were coded with deductive codes based on the focus-group guide. Axial coding and memo writing were used to elucidate emergent themes [33]. We also coded the verbal and written feedback of the brand mock-ups by categorising comments as ‘negative,’ ‘neutral,’ or ‘positive.’ Negative comments indicated a clear dislike for elements of the mock-up. Neutral comments were critical and provided suggestions for change but did not indicate dislike. Positive comments indicated a clear affinity for elements of the mock-up.

**Results**

We hosted two focus-group sessions and two feedback sessions with a total of 72 participants. Table 1 shows the study participants’ demographic information. The majority of participants were between 18–23 years (n=60, 85%), ranging in age from 18 to 53 years old. The first focus group (n=7) included community members and health professionals. The second focus group (n=8) included community members with marketing and communications experience. The first undergraduate feedback session (n=39) included biology and sociology majors, and the second undergraduate feedback session (n=18) included sociology majors.

Emergent brand ideas from each focus group are included in Table 2. Later, we will examine the feedback from undergraduate students on the brand mock-ups, and outline how we incorporated focus group feedback to develop the contest’s branding and community engagement strategy.

Table 2 shows that participants preferred using messages and images that highlighted: (1) a collective approach to an HIV cure crowdsourcing contest; (2) dispelling myths to spur discussion; (3) HIV cure as motivation for participation; and (4) creative community engagement.
1. Collective approach to an HIV cure crowdsourcing contest

Many participants emphasised that the contest branding should reflect a collective effort to find a cure for HIV, for example: a black woman (early 30s) stated:

*This goes back to social responsibility. People need to be engaged to help greater society.* (Black woman, early 30s)

To the participants, a collective approach to implementing the contest meant emphasising the message that HIV/AIDS affects all people and it was everyone’s responsibility to contribute toward finding an HIV cure. Group 1 and Group 2’s branding ideas (Table 2) emphasised the importance of using a collective approach to promote the crowdsourcing contests and find a cure for HIV because they saw it as a disease that could affect anyone. No participants disagreed with the collective approach; however, some did express the importance of tailoring messaging to key populations:

*We need to make sure we are also engaging those who are poor.* (Black woman, early 50s)

Another participant in the same focus group asked:

*Who is the target demographic? Younger/older? Depending on who it is you need to tweak the message and the way you reach out to them. I don’t think a 20 year old sees it (the HIV epidemic) the same way as a 40 year old. [40 year olds] think you’re almost a leper after being diagnosed.* (Black man, early 40s)

These concerns focused on reaching those who were on a low income and young because of a perception of their higher risk for HIV/AIDS.

Conversation also focused on harnessing the momentum started by social justice movements to encourage participation in the crowdsourcing contest. Group 2 suggested the hashtag #HIVLivesMatter (Table 2). One participant stated:

*The cure is not just about meds [sic], but social justice, equity, and making sure black life is protected.* (Black man, late 30s)

Tied to empowerment, the hashtag evoked a connection to #BlackLivesMatter, a social media and social justice movement that challenges police practices and policies that result in disproportionate deaths among black men and women. The use of a personalised hashtag was explained as a good way to catch attention and increase recognition of the contest among young adults in Durham.

Many participants expressed concern that people would not see how they could be involved in HIV cure research without a scientific understanding and background. One participant asked:

*Aside from funding, how does the community impact research? I’m not a scientist and I wasn’t really sure how I personally could help find a cure.* (Black woman, early 30s)

To address this concern, focus-group participants developed empowerment messages to highlight the community’s role in finding a cure for HIV. For example, a participant suggested:

*Stay calm. Own it. Own HIV. Embrace [it].* (White man, early 30s)

This quote is representative of many participants’ discussions about the importance of designing a contest that encouraged empowerment. The discussion about empowerment focused on encouraging people to recognise their ability to get involved in finding an HIV cure through open dialogue about HIV cure myths and creative contributions.
2. Dispelling myths to spur discussion

Some participants felt it important to ensure the crowdsourcing contest addressed myths associated with HIV and HIV cure research. For example: A black man (late 30s) explained:

> We came up with the name ‘HIV Myths Exposed’ to focus the contests on dispelling rumours and myths and uncovering truths about HIV cure research. (Black man, late 30s)

Others expressed concern that people had become apathetic about HIV:

> Let’s dispel myths. Let’s re-start the conversation about AIDS. (Black woman, early 30s)

One participant specifically called out college students for not understanding the severity of the HIV epidemic:

> There is a difference between being in college and living through the Magic Johnson era. HIV used to be a death sentence, but it’s not anymore. (Black man, mid 30s)

These two participants were both over 30 years old and wanted to use messaging that invoked shock to dispel myths about HIV cure and spur discussion about HIV.

The concern about potential apathy and misinformation among young adults relates to Group 3’s logo design featuring an ‘X’ in graffiti over the words ‘HIV Myths X-posed’ (Table 2). They chose the graffiti X as a way to appeal to a younger, hip-hop influenced audience. However, after larger group discussion, a few participants who were under 30 years old expressed concern that the idea could be construed as scientists purposefully hiding facts about HIV.

One participant specifically called out college students for not understanding the severity of the HIV epidemic:

> Others expressed concern that people had become apathetic about HIV. (Black woman, early 30s)

After a search for ‘BeatHIV’ on social media sites, she discovered the name was already in use, so the focus group suggested ‘2BeatHIV’. 2BeatHIV integrated the goal for finding an HIV cure, musical references and encouraging creative contest submissions. Focus-group participants also suggested involving local organisations with the contest to co-host large community-based events. Another participant suggested involving the local gay pride parade because:

> … my partner and I would certainly become involved if we saw you at the gay pride parade. (White man, early 30s)

Others suggested similar ideas about involving people from the lesbian, gay, bi-sexual, transgender, queer (LGBTQ) community and other marginalised communities who might otherwise be harder to reach.

Table 3 shows the four major emergent themes about strategies to design and promote the crowdsourcing contest and examples of how we incorporated feedback.

A black male focus-group participant (late 30s) volunteered to design mock-ups of several potential contest names and logos based on focus-group feedback. Figure 1 provides a visual depiction of each mock-up. Because of the large numbers of feedback-session participants, not all students provided verbal or written feedback; thus, the number of comments for each mock-up differs based on the feedback provided.

The ‘2BeatHIV’ idea received the most positive feedback from participants. Out of 24 verbal comments during the feedback session, 16 were categorised as positive, three as neutral and five as negative. Figure 1 provides examples of the written feedback students provided on each mock-up.

In second place, the ‘Many Faces’ mock-up also received positive feedback. Out of 22 verbal comments from the feedback sessions, 14 were categorised as positive, four as neutral and four as negative. Both focus-group and feedback-session participants supported incorporating diverse faces into the logo to emphasise the grassroots nature of crowdsourcing.

The ‘Help Ideas Thrive’ mock-up was the least well received. Out of 25 verbal comments from the feedback sessions, four were categorised as positive, four as neutral and 17 as negative. Feedback-session participants expressed confusion about the purpose of the Venn diagram logo and criticised the name for being too long and not specific to HIV. Based on the ratio of positive to negative comments and focus-group emergent themes, the contest name officially became 2BeatHIV and the tagline became ‘Own the Cure’. Both the contest name and tagline reflect the goal of ending the HIV epidemic through a cure, community ownership over finding a cure and incorporating a music reference to encourage creativity.

Discussion

This article describes the development of a crowdsourcing contest to better understand what an HIV cure would mean in the lives of black young adults in Durham, NC. The purpose of eliciting
contest entries is to identify creative material that could be used in a future awareness campaign about HIV cure research. Some studies examining health-related crowdsourcing contests have developed public health campaigns [15,22,23,25], but private companies developed most crowdsourcing contests [16]. Few crowdsourcing studies have used CBPR principles to guide the development of the contest by soliciting community preferences [25]. This study showed that using CBPR principles could aid in developing a crowdsourcing contest that appeals to local young adults and engages them in discussions about HIV cure research.

Both black and white participants suggested using a collective approach to develop and implement the HIV cure-based crowdsourcing contest. Findings from other HIV CBPR studies show black participants prefer campaign messages that encourage community-centred approaches to HIV prevention [34,35]. The collective approach is complementary to the bottom-up approach of crowdsourcing contests used to improve HIV testing programmes [14,36]. However, a collective approach to crowdsourcing contests differs from private-sector contests that typically encourage individuals to compete against each other, rather than collaborate [13,14,20].

The crowdsourcing contest presented an opportunity to address the disproportionate impact of HIV on black people. In particular, participants suggested using hashtags that simultaneously uplifted people living with HIV and addressed the impact of HIV on black communities. The #HIVLivesMatter hashtag is modelled after #BlackLivesMatter, a social justice movement that started online and integrated grassroots organising. These findings suggest that it may be useful to develop HIV cure research messaging that is accessible to general audiences, but also connects to social issues affecting black communities. These findings reinforce the appropriateness of using CBPR principles to guide the development of a crowdsourcing contest focused on raising awareness about HIV cure research among local young adult populations.

Dispelling myths about HIV cure research was identified as important to stimulate discussion. This is consistent with other literature on community engagement with women and underrepresented minorities for clinical research [8,37]. This is particularly important because myths persist about HIV cure. These myths often prohibit people from wanting to learn more about HIV, seek conventional treatment or participate in clinical trials [38].

Lastly, participants emphasised the importance of using creative contributions to encourage broad participation. Previous CBPR HIV campaigns have incorporated creative contributions [34,39]. However, most prior studies used experts to develop the final HIV campaign and community members did not consider the format of engagement programmes. Crowdsourcing allows a broad cross-section of individuals to convey the message of HIV cure in a way that resonates with them. In particular, social media engagement was emphasised as an important avenue for reaching black young adults because it allowed for information sharing, integration of multiple media products, peer interaction and the possibility to reach out to a large number of people quickly and cheaply. Many studies have demonstrated the effectiveness of using social media to recruit potential crowdsourcing contest participants [40,41] and engage the public in HIV-related interventions [22,23,42]. Moreover, previous studies stress the importance of developing and using culturally appropriate messages tailored to the target audience [34]. Participants in this study suggested using hip-hop, spoken word poetry, paintings and other creative contributions to promote contest participation. While creative contributions may encourage participation, it is important to provide multiple ways for people to engage with the contest and contribute their ideas.

Our study has some limitations. First, the small number of participants in a single geographical region and the use of qualitative methodology limit the generalisability of the study’s findings to other demographic groups and contexts. Second, even though a little more than half of our participants were black, the majority of participants had some college education, which may skew the suggestions for contest development against low-income, key populations who are most vulnerable to the HIV/AIDS

| Theme | Examples of how we incorporated feedback |
|-------|------------------------------------------|
| (1) Collective approach to HIV cure crowdsourcing contest | • Tagline: ‘Own the Cure.’ • Use ‘We are All the Face of HIV/AIDS’ painting in promotional materials |
| • Emphasise communal nature of crowdsourcing contest | • Provided HIV/AIDS statistics about Triangle region of North Carolina • Discussed risks of HIV cure research at community events • Discussed conspiracy theories about HIV and HIV cure |
| • Provide a ‘shock and awe’ message to get people’s attention about HIV | |
| (2) Dispelling myths to spur discussion | • Host hip-hop concert and community forum about HIV cure myths and conspiracy theories • Incorporate educational statistics relevant to Durham, NC into promotional materials and community engagement activities |
| • Facilitate discussion about HIV cure myths | • Name of contest officially became 2BeatHIV • Logo was designed with red, white and black colours to resemble a record, a target, and the community having a piece of the pie |
| • Reignite interest in HIV/AIDS generally, and especially among groups often excluded from conversations about HIV | • Name of contest and promotional messages need to be specific to HIV and use the colour red |
| (3) HIV cure as motivation for participation | • Logo was designed with red, white and black colours to resemble a record, a target, and the community having a piece of the pie |
| • Name of contest and social media hashtag should be easy to remember | • Used #2BeatHIV hashtag |
| (4) Creative community engagement | |
| • Use hip hop, music, and social media to promote the contest among black young adults | • Promotional videos using hip hop music and artists • Hosted community forum about HIV conspiracy theories with hip hop concert • 2BeatHIV name references hip hop beats and music • 2BeatHIV logo resembles a music record • Encouraged submissions of music, art, video testimonials, and poetry |

Feedback on developing crowdsourcing contest and recruitment strategy

| Theme Example of how we incorporated feedback |
|-----------------------------------------------|
Third, because of the large numbers of undergraduate students in the feedback sessions, not all students provided verbal or written feedback. This limits our ability to conclusively identify preferences for the mock-ups from these groups. Future studies should examine the core themes found in this study in a more representative sample of black young adults at high risk for acquiring or living with HIV/AIDS.

Despite this study’s limitations, the findings have implications for designing future crowdsourcing contests guided by CBPR principles. This study is unique because participants represented a wide range of ages and representation from both blacks and whites who collaborated to develop an HIV-related crowdsourcing contest. Community input from multiple stakeholders for developing a crowdsourcing contest may enhance the acceptability and effectiveness of contest implementation. Qualitative findings provide more insight into black young adult’s preferences for conducting a crowdsourcing contest and HIV cure research engagement. For HIV cure research engagement with vulnerable populations, it may be useful to integrate crowdsourcing activities and current social justice issues in communities. Those conducting community engagement and crowdsourcing should look for potential synergies.

The findings from this study have implications for designing future crowdsourcing contests. Private sector professionals or researchers usually design the initial phase of crowdsourcing contests; however, these contests often seek participation from national audiences rather than specific demographic groups in a local area. Our use of CBPR principles firmly rooted the contest within the local community. Integrating CBPR principles into crowdsourcing contests may improve local participation and generate ideas that better reflect local needs. There may be challenges with scaling up CBPR to other crowdsourcing activities, especially those managed by private companies, because of potential power imbalances between companies and community groups. Future research should examine how crowdsourcing contests informed by CBPR principles may be affected by power imbalances and/or competing interests for the outcomes of the contest.

| Mock-ups | Positive | Neutral | Negative |
|----------|----------|---------|----------|
| ![Image](mock-up1.png) | (n=16/24 comments) | (n=3/24 comments) | (n=5/24 comments) |
| ![Image](mock-up2.png) | (n=14/22 comments) | (n=4/22 comments) | (n=4/22 comments) |
| ![Image](mock-up3.png) | (n=4/25 comments) | (n=4/25 comments) | (n=17/25 comments) |

Figure 1. Mock-ups and feedback on focus-group ideas for contest name, logo, and tagline.
Crowdsourcing contests may be useful for engaging local communities, developing culturally tailored campaign messaging and encouraging the public to learn more about HIV cure research. Our findings suggest that when crowdsourcing contests are developed through CBPR principles, there is even greater potential for community engagement. Future research studies are needed to evaluate the extent to which a crowdsourcing approach to community engagement could be a useful adjunct to existing CBPR practices.

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