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**PROGRAMME PAPER**

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# The Community Liaison Program: a health education pilot program to increase minority awareness of HIV and acceptance of HIV vaccine trials

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Received on March 15, 2010; accepted on January 17, 2011

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## Abstract

This paper describes a 16-month health education pilot program based on diffusion of innovation and social network theories. The program was implemented by volunteer community liaisons for the purposes of increasing awareness of and support for HIV vaccine research in minority populations. This theoretically driven pilot program allowed the liaisons to integrate delivery of the HIV vaccine research messages created for the program into their existing activities and routines. Through training in participatory engagement, volunteers were able to tailor and adapt an HIV prevention message for their communities. Process evaluation data showed that the acceptance of participatory engagement and HIV vaccine message dissemination far exceeded expectations. The anticipated number of community members to receive the message was estimated at 500 with 10 volunteer liaisons or 50 per person. However, the actual number of people reached was 644, with only 7 volunteer liaisons, or an average of 92 persons per liaison, almost double the original number. Further research is recommended to analyze the specific behavioral changes that can come from the use of social networks in HIV vaccine research awareness within minority populations.

## Introduction

Since HIV/AIDS was recognized in the United States in the early 1980s, racial and ethnic minorities and vulnerable marginalized populations have been disproportionately harmed by this epidemic. Specifically, African Americans and Latinos, who represent approximately 27% of the US population, have higher rates of HIV/AIDS—from infection with HIV to death from complications related to AIDS—as compared to other groups [1]. As of 2007, African American/Blacks had AIDS case rates 10 times that of Whites. Even though they account for approximately 12% of the total US population, they represent nearly half of all new infections and 46% of people living with HIV [2].

One response to address the disparities in AIDS rates is better communication within racial and minority ethnic groups about HIV vaccines, considered the best hope for prevention of HIV/AIDS. In light of this, program staff conceived of a culturally sensitive, innovative communication initiative that would disseminate information to minority groups about the potential benefits of vaccines that may be available in the future to prevent HIV infection. The purpose of this initiative was to have members of communities most affected by HIV/AIDS tailor the message of vaccine research with members of their social networks so that their communities could receive the information and support HIV vaccines as the best hope for HIV/AIDS prevention. They were then to disseminate this message to others in their

communities to raise awareness of HIV vaccine research. With funding from the National Institutes of Allergy and Infectious Diseases (NIAID), program staff partnered with a local university to conduct a communication and health promotion literature review to identify strategies that had proven to be effective in HIV prevention within minority populations.

Once the review was completed and armed with evidence-based effective message examples, the program staff launched a small pilot Community Liaison Program (CLP). This program attempted to recruit volunteers from all across the United States who could use their social networks to shape the most appropriate HIV vaccine research message for their networks. The liaisons were then to disseminate this tailored message to members of their larger, targeted minority communities. Process data collected at the end of this pilot program revealed positive signs of support not only for the communication techniques but also for the message.

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## Background

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Because HIV/AIDS continues to be a major public health problem with rates of infection for minorities at epidemic levels, more innovative and culturally targeted measures are needed to address the root issues associated with these infection rates. While facts, science and theory serve as the bedrock of evidenced-based initiatives, according to Bernhardt [3] in addition to science, strategies for effective communication are needed to adequately address public health problems. Given the apparent disparities in HIV prevention, treatment and care among racial/minority ethnic groups and appropriate health communication techniques are better needed to deliver information that can attempt to change HIV myths and miscommunications. In keeping with the call to use 'every effective tool possible' [4] (pg. 2053) to diminish health disparities, a variety of communication channels were attempted in this pilot project. Cultural characteristics of the liaisons factored into the selection of types of channels

given the plethora of research findings that highlighted the receptivity and acceptance of public health interventions designed for minorities and delivered by minorities [5–12, 20, 21, 22].

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## The intervention

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This 16-week pilot program was a goal focused multilevel endeavor based on diffusion of innovation theory [8, 9]. On one level, there were the innovators—program staff—and the early adopters—volunteer liaisons—who accepted the innovation—the message that HIV vaccine research was the best hope for HIV prevention. On another level, the early adopters' social networks—the focus group members—who were to help tailor this message for the early, late majority and laggards—the communities who were to be recipients. In light of this paradigm, securing early adopters, defining clear channels of communication and the timing of the strategy were key elements of the program [8, 9]. Overall, the goals of the program were (i) to have members of social networks tailor the message for their communities, (ii) to increase HIV/AIDS rate awareness among minority communities and (iii) to get other members of other social networks to share the message that HIV vaccines were the best hope for HIV prevention.

Participatory engagement proved to be a salient component of this pilot program because it served as a means of getting the buy-in and message tailoring from members of social networks. Participatory engagement—defined here as an approach where members of the community are engaged in decision making and sharing as well as ownership of the product, namely the message [20, 21]—allowed for feedback about the message and the channels of dissemination (interpersonal, print, etc.) to be selected. The channel provided the most acceptable mechanism to reach the targeted communities because consciously or unconsciously it reflected the values of the community. Whether it was interpersonal, one-on-one information sharing or reading information in a printed handout, the channel signaled the way that important news could be

disseminated within a community. To assist the early adopters, heretofore known as liaisons, in determining the best channels as well as feedback on the HIV message, the program staff provided them with training and materials.

Given that the funding for this program was only for 16 months, the liaisons were trained in the most expedient way, i.e. via conference calls and online tutorials. The liaisons were instructed to evaluate their process of data collection; however, only self-reported process data were to be collected due to constraints of time and resources. The results revealed extensive outreach by the liaisons and growing support for the innovation—the HIV vaccine—by members of the targeted communities.

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## Methodology

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The initial preparation for the pilot project required significant time commitment. An extensive literature review was conducted that provided insight into the merits of varying ways of presenting the message, i.e. shorter content or longer content and ‘gain frame’ or ‘loss frame’. Following this, identification of criteria for liaison selection occurred. This was done with staff and pilot program advisory board input. Determining the most appropriate materials and information for liaison support and education also occurred during the preparation period. However, the primary programmatic activity was the identification of potential volunteers and their recruitment.

The recruitment of volunteers, as well as education about the CLP, necessitated creative outreach initiatives and persistent follow-up by program staff. The program staff conducted a workshop at the 2008 United States Conference on AIDS (USCA) to inform attendees of the mission and goals of the NIAID HIV Vaccine Research Education Initiative and to recruit liaisons. The intentional selection of USCA as a venue for this launch offered broad exposure to the program. This conference, one of the largest AIDS-related gatherings in the United States, historically has had approximately 2000–3000 people from various parts of the

country who have an interest—often a personal passion for HIV/AIDS prevention, care and treatment work—attend its workshops, roundtables and plenaries. Following the conference, an agreement was made with the National Minority AIDS Council (NMAC) staff to distribute printed information about the CLP and volunteer liaison recruitment forms at other NMAC state and regional training events. CLP program staff also spoke to colleagues at Historically Black Colleges and Universities and encouraged them to help recruit volunteers for the program.

The specific recruitment of liaisons spanned 5 months instead of the scheduled 4-month period. While there was curiosity about the program, the ability to commit to the program’s activities and reporting requirements seemed to be barriers to many potential liaisons. At one point, the program attracted almost 20 interested liaisons but not all made the commitment. The recruitment of liaisons ended when a core group of seven persons agreed to perform all the volunteer liaison duties.

### Liaison demographic information

The seven volunteer liaisons that participated in the program were diverse, yet similar. The majority were African American females between 41 and 60 years of age who lived primarily in urban areas. However, they varied in their affiliations. Some included community- and faith-based organizations as their targeted affiliated groups, some focused on minority serving clinics, some worked with AIDS service organizations and some with colleges/universities. There was one Latina and one Caucasian male liaison, both of whom made specific outreach to Latino communities. The liaisons were located in five states—Texas, Pennsylvania, Oklahoma, North Carolina and Georgia—and seven cities: Austin, Corpus Christi, San Antonio, Philadelphia, Tulsa, Greensboro and Albany (See Table I).

### Training liaisons

Once recruited, the program staff conducted orientation, trainings and all interactions with the program remotely. Their orientation was conducted

**Table I.** *Liaison demographic information*

Group	Race	Gender	Age (years)	Location
1	African American	Female	30–45	Philadelphia, PA
2	African American	Female	46–61	Austin, TX
3	African American	Female	30–45	Greensboro, NC
4	African American	Female	46–61	Albany, GA
5	African American	Male	46–61	San Antonio, TX
6	Caucasian	Male	46–61	Corpus Christi, TX
7	Latina	Female	Missing data	Tulsa, OK

via a conference call with an in-depth explanation of the program activities visualized through a program logic model sent electronically prior to the call. Liaisons also participated in online trainings on vaccine clinical trials, including two online introductory tutorials about HIV/AIDS and HIV vaccine research found on the webpage of National Minority AIDS Council (About HIV Vaccine Awareness Vaccine Tutorial—NMAC.org-based).

Following the orientation, the liaisons received an email containing a focus group guide and instructions. (Copies of these guides and instructions can also be obtained from the first author upon request.) Focus groups served as the program's form of participant engagement. These focus group meetings were independent opportunities for each liaison to singularly convene invitees from their social networks for input into the tailoring of the HIV message for their communities-at-large. Held only once by each liaison, the focus groups served dual purposes: (i) to engage members of their networks in shaping the message for their broader targeted populace and (ii) to discuss the most appropriate channels for further dissemination of the message into their respective communities. The use of focus groups also provided the liaisons with some baseline information about the level of HIV knowledge and awareness that existed within their targeted groups.

Semi-structured focus group interviews were conducted from May to September 2009. Each liaison had autonomy in focus group participant selection and logistical arrangement. Some liaisons invited participants directly, invited participants ranged from relatives to co-workers and others made general announcements to their overall net-

works. Groups ranged in size from 5 to 11 participants. With an allotted \$200.00 for use during the focus group meeting, no individual remunerations were offered to participants; rather, the money was used to provide food for the focus groups. Specifically, there were two single-sex groups: one all female quilting group that included a relative of the female liaison convener and another all female group coordinated by a male liaison convener. There were six single race/minority ethnic groups: four African American groups and two predominately Hispanic groups: one of which was convened by the one Caucasian male liaison; this group had one female and six males (see Table II for focus group participant information).

### **Social network members involved in participatory engagement by liaison group number**

For coherence in the shaping of the message, all group participants were to respond to the same questions regarding the clarity, credibility, utility and presentation of the message. Below are the questions that guided the discussions.

- (i) What do you think is the main message of both variations?
- (ii) Do you think the message is clear?
- (iii) Do you think the message is believable?
- (iv) Do you feel that the information presented was useful?
- (v) If someone that you know and trust in your community shared this information with you how would you respond?
- (vi) What are some things you like about the way the information is being presented?

**Table II.** *Social network members involved in participatory engagement by liaison group number*

Group	Number of participants	Number by race	Number by gender	Participants connection to liaison
1	8	8 African Americans	7 Females 1 Male	Teen pregnancy center
2	6	5 African Americans 1 Latino	4 Females 2 Males	Colleagues at Student Affairs staff
3	7	7 African Americans	7 Females	Friends, family and members of social quilting group
4	5	5 African Americans	4 Females 1 Male	Church group
5	8	8 African Americans	8 Females	Friends/peers
6	7	7 Latinos	1 Female 6 Males	Colleagues
7	11	11 Latinos	11 Missing data	Missing data

- (vii) What are some of the things you do not like about the way the information is presented?
- (viii) Which variation (gain-framed or loss-framed) of the message do you think is most compelling?
- (ix) What changes if any would you suggest?

Findings received from these groups informed staff of preferences for message design and framing. Specifically, it guided staff on matter of length, e.g. if a longer version or a shorter version was preferred, as well as if a printed version or only word-of-mouth message should be used. Upon learning that both print and word-of-mouth were chosen, staff then polled advisory board members on the font type, layout and appropriate size for the print version, i.e. 3" × 5" or 5" × 7" for 'readability' by all ages.

The focus group data proved beneficial in helping to decide if the message should be 'gain' or 'loss' framed. Liaisons were to ask if the message should stress benefits of prevention (gain frame) costs associated with not using prevention (loss-frame). Research has shown that either frame could influence the persuasiveness of the HIV/AIDS messages for minority audiences [14]. Examples of these two types of messages are as follows: gain-frame, 'If you use condoms, you increase your chance of staying healthy', or loss-frame, 'If you don't use condoms, you are at greater risk of sexually transmitted diseases'. (Copies

of the final gain frame or loss frame message can be obtained from the first author upon request.)

Program staff employed a multistep approach to focus group data analysis. The data included Likert scale ratings of all aforementioned versions of the message (long, short; word-of-mouth, print and gain/loss; framed); the Likert scale spanned from 'strongly like' to 'strongly dislike'. Staff also received qualitative transcripts of each session from most of the liaisons. Based on the qualitative data, staff created a data summary sheet and numbered each group. Under each group numbered on the summary sheet was listed the question and the transcribed responses to the question. A summary tally for each question was compiled and frequencies of the positive as well as the negative responses were totaled. In addition to program staff, a university-based advisory board member and his assistant also tallied up the responses from each question and summarized the outcomes as a method of objectively confirming the results.

Based on both the Likert scale and the transcribed data, program staff tailored the message in accordance to the findings. These results revealed that most network members felt that best channel for dissemination was word-of-mouth gain-frame and, for reference, a shorter, loss-

framed, 5" × 7" printed message. Staff printed and distributed these loss-framed messages with the understanding that they would be used as

handouts to accompany the word-of-mouth statements.

Immediately after the qualitative evaluation, outcomes were revealed staff assisted each liaison in developing a 7-week dissemination plan to fit into the normal routines of each liaison.

Notwithstanding, staff guidance, each liaison was given a level of autonomy over the exact number of times to share the message, when, where and how to engage with their targeted larger communities. This level of autonomy was central to the pilot program design. Branded as easily integrated into existing service delivery processes, the HIV vaccine research message was generic but tailored by the liaisons to be specific to their communities. As a means of oversight, each plan included process outcome reporting tools. One tool was divided into sections: one section was to tally up the number of contacts made and the other section was to self-report the number who said that they would share the message with others. Another form asked the liaisons to self-report the number who said that they gained HIV awareness through interacting with them.

## Results

At the end of the 7-week message dissemination period, six of the seven liaisons submitted final process outcome reports of their activities. The following information was collected from their reports is presented in Tables III–V.

### Lessons learned

There were three lessons learned from this pilot program: (i) A diffusion strategy that allows for autonomy in its dissemination strategy, with oversight, can be an effective method for sharing factual, science-driven public health information like HIV rates. (ii) The appropriate channels for information transfer can facilitate potentially persuasive discourse about vaccine research and inspire others to share the message in a like format. (iii) The credibility of the message may be just as important as the race/ethnicity of the messenger, particularly if the message is tailored for a targeted community.

**Table III.** Total persons contacted by city

City	Austin	Corpus Christi	Philadelphia	Tulsa	Greensboro	Albany
Total contacted	122	55	161	110	119	77

**Table IV.** Total number of persons with increased awareness

City	Austin	Corpus Christi	Philadelphia	Tulsa	Greensboro	Albany
Total increased awareness	Data unusable	10	161	110	119	Data not useable; only answered 'yes'

**Table V.** Total number of persons willing to share information

City	Austin	Corpus Christi	Philadelphia	Tulsa	Greensboro	Albany
Total willing to share information	Data unusable	47	97	98	27	74



The liaisons were given a great deal of autonomy and decision-making power. They freely selected participants, venues and the time for their participatory engagement. They also developed their own dissemination plans, with approval from the program staff, which allowed them to integrate the crafted message into ongoing HIV activities in which each liaison was currently engaged. For instance, one liaison who worked at a university health department would incorporate the message of vaccine research when she gave general health and HIV/AIDS lectures to classes. Another liaison volunteered at her church and shared the information with youth there.

Those who volunteered showed commitment and cultural sensitivity regardless of race or ethnicity. The one Caucasian liaison was able to use his knowledge of Hispanic culture and fluency in Spanish to relate to the population. He was responsible for reaching out and providing HIV information on Latinos and vaccine research information to 25% of the Latinos contacted. In addition, he recruited 14% of those who were willing to share information with others.

Finally, sharing a message that was tailored for a particular community empowered that group and attracted the attention of its members. Liaisons reported that their message dissemination efforts peaked the curiosity of members of their respective targeted groups to learn more about the rates of HIV in their community. It also encouraged some members to participate in this HIV prevention communication and dissemination initiative. However, without follow-up or outcome monitoring, it is unclear if these willing members of social networks subsequently disseminated the message or what form of message was transmitted.

### **Limitations**

The lack of an outcome monitoring focused evaluation was a significant limitation in terms of assessing the effectiveness of the program. More data could have been collected from the social networks as well as from those who agreed to further disseminate the message to their own networks. The use of

more standardized program evaluations would have helped to generalize findings and to better understand issues associated with the network members' activities that lead to diffusion of the message.

Also, additional data could have been collected about dissemination activities and barriers. For example, additional qualitative data could have been collected to clarify whether the use of the printed message versus face-to-face interpersonal communication was more or less effective as a communication channel for the liaisons and why. Moreover, more than one focus group or participatory engagement event should have been conducted by each liaison in order to produce information that corroborated these findings.

Another limitation was the number of liaisons in the program. While there was interest, it was a challenge for many participants to make the commitment to volunteer for the training, the conference calls, the focus groups, the dissemination of the message and the reporting, without compensation. Although the emphasis was that this program was very easy to integrate into their work routines, it did not seem to persuade many of those initially interested. Even with the core of seven liaisons, data were only available from six liaisons, which raises questions about the overall dissemination process and commitment others less engaged may have had.

Another major limitation related to recruitment was the limited number of Latino liaisons. A better outreach and recruitment plan should have been implemented to ensure representation from this vital population group. While efforts were made to reach out to different populations, more of a concerted effort to have information in Spanish and to attend conferences and gatherings with Hispanic/Latino participants who have an interest in HIV/AIDS should have occurred. More aggressive campaigning must be done to share potentially hopeful HIV vaccine research prevention information given the rates of HIV/AIDS, specifically with Hispanic/Latino populations.

There were also constraints in time and resources. The initial NIAID funding was limited to message dissemination; therefore, little money was available for the pilot program which included

training liaisons, program reporting and data analysis. Given the focus on the message creation and the participatory engagement, only 7 weeks was allocated for the dissemination period. As referenced earlier, there was no monetary compensation available to the liaisons. This fact is highlighted in order to draw attention to the need to financially reward volunteers in exchange for their support in subsequent programs; with more attention given to monetary incentives, this could facilitate recruitment and retention efforts.

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## Conclusions

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In many ways, this pilot program exceeded expectations. Instead of having 10 liaisons reach 500 community members and recruit 250 who would be willing to share the message, we had seven liaisons reach 644 community members and 343 persons said that they would be willing to share the message with others.

As a pilot program, there were challenges that needed to be addressed, but the willingness of the liaisons to engage in this endeavor gives optimism that there will be community support for vaccine research based on information sharing about this research. This pilot program has also given us some indication of our ability to disseminate information, refined by a community, which can be quickly disseminated within that community.

Communication is vital to the overall impact of health care utilization and new initiatives. While various trials for microbicides and vaccine clinical trials have shown promise for HIV prevention, there is a disparity in the United States among those who participate in clinical trials to test the effectiveness of these innovations; there is often very low minority representation in HIV clinical trials (10, 15, 18, 19, 23–31). Sullivan *et al.* (16) found that one of the most commonly reported reasons for not participating in a clinical research study by minorities was related to a lack of information communication about the research.

Funding for HIV/AIDS communication, research, trials and prevention initiatives has been

constrained by the US 2007–2009 economic downturn, resulting in less financial resources for HIV/AIDS prevention programs than in the past. The CDC, which funds 58% or 337 million of all prevention services directly or indirectly through state and local health departments, flat-funded or reduced its HIV prevention programming (17). In addition, the federally funded AIDS Drug Assistance Program (ADAP), which provides approved AIDS medications for low-income people without insurance, served only one-third of those eligible in 2008 (17) and may serve less and less projected through proposed budget cuts. Given that minority groups, the impoverished and marginalized populations continue to bear the brunt of this pandemic, the downturn in resources has created reason for concern that rates of mortality will increase and erase limited previous gains in HIV/AIDS prevention. Thus, improved HIV/AIDS information dissemination about the hope of vaccines for prevention seems imperative to increase interest and participation in trials with persons of color.

This project shows that community-based participatory engagement regarding health education and social networks can be important components to use in increasing awareness about HIV/AIDS and HIV vaccine research. Participatory engagement brings to bear the importance of interpersonal guided, but open, communication on message construction. Social networks help to unleash the power of personal relationships in spreading health information across established communities, especially among groups, which often mistrust outsiders (13). By using the social network theory, it was revealed that through established interpersonal relationships, it could be possible to gain acceptance and dissemination of relevant health messages not only among individuals but also in hard to reach communities.

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## Funding

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National Institutes of Allergy and Infectious Disease (2145-5290-90).



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## Acknowledgements

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Our thanks to the staff of the NIAID HIV Vaccine Research Education Initiative. Note: All tools and guides are available from the author upon request.

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