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A Twenty-Two-Year-Old Community Advisory Board: Health Research as an Opportunity for Social Change

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Abstract

Conducting health research often requires a partnership between marginalized communities and researchers. Community organizers can broker this partnership in a way that not only produces important scientific discoveries but also brings needed resources to the communities. This article is a description of a community advisory board established in 1984 to advise researchers on a longitudinal study of the natural history of AIDS among gay men. The Board successfully guided the recruitment of more than 3,000 gay and bisexual male volunteers and, at the same time worked as a powerful change agent. An analysis of minutes from all Board meetings between 1984–2006 indicates that significant social change as well as important research findings resulted from Board actions. Community organizers who work to create a mutually beneficial partnership between communities and researchers may find new opportunities to support community growth and social justice.

Keywords

Community Advisory Board; HIV/AIDS; research; Gay men; longitudinal studies; social marketing

Introduction

The National Institutes of Health mandate in 1994 that researchers need to include women as well as racial and ethnic minorities in clinical trials and the growing interest for partnering with communities to do public health research present community organizers with opportunities for empowering marginalized communities to increase services, affect policy, and direct funds and research to areas of real community need.

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Since at least the 1970s, Community Advisory Boards (CAB) have been used to ensure that communities' mental health needs were being met, to provide citizen input to hospitals and schools and to advise researchers about subjects' rights and needs. This article describes a long-standing CAB to an HIV research study in order to show how a CAB can successfully function as a successful mechanism in carrying out research as well as in making change. It also recounts the history of this CAB, its involvement in affecting research and its major impact of the local community and beyond. Factors that seem critical to its success are described.

Background

The role and functions of community advisory boards in research are subjects of wide interest and increased study. Ethical issues concerned with obtaining free and informed consent and protecting the health and well being of subjects have been central to the field's interest in the topic. The Belmont Report clearly asserts that respect, beneficence and justice must be at the core of all human research. (National Institutes of Health, 1978). Several authors call for either the extension of Belmont principles to communities or the inclusion of a fourth principle, "respect for communities," in order to address the ways in which research affects communities, particularly those that are vulnerable in some way (Gostin, 1995; Quinn, 2004; Weijer and Emanuel, 2000). With this increase in researchers' attention to community participation in their research has come an increase in questions about developing partnerships with communities.

A number of authors have raised the thorny question of what defines community and who can speak for it (Dickert and Sugarman, 2005; Kone et al., 2000; MacQueen et al., 2001; Quinn, 2004; Weijer and Emanuel, 2000). This is an essential question that must be answered before researchers can understand with whom one needs to partner in order to understand community needs, design an effectual consent protocol, and develop a successful recruitment plan. Researchers have several avenues available as means to relate to that community. Many establish a community advisory board (CAB), which has been described by Strauss and colleagues, as consisting of community members with a common identity, history, symbolism, language and culture (2001). To establish a CAB, researchers must ask if the members of the board truly represent everyone in the community or are other methods for interaction needed (Weijer and Emanuel, 2000).

The role and functioning of such a board must be clearly defined in order to answer questions such as:

1. What are the limits of the board's authority?
2. What skills and characteristics do Board members need?
3. Is one seeking their advice or their consent?
4. Is a board necessary to provide community consent (in addition to any individual consent protocol that a researcher may have) (Quinn, 2004)?
5. What roles do community values and needs play in establishing the actual research agenda (Chene et al., 2005; Katz, 2004)?
6. To what extent should boards actually develop research protocols or participate in every day decision making such as hiring staff, choosing locations, designing materials, solving problems, and disseminating findings (Blumenthal, 2005; Dickert and Sugarman, 2005; Green and Mercer, 2001; Silvestre, 1994)?

The answers to these questions will be heavily influenced by the type of board one creates.

Quinn (2004) describes two models of CABs' - those that are study specific, which is more common and those that serve an institution or center, as opposed to one study. In a study of

CABs associated with domestic and international HIV prevention trials, Morin and colleagues (2003) identified two models of CABs based on their composition. The first is the “broad community model,” which includes wide representation, and focuses on sustainability, independent funding, accountability and helping the community to initiate research. Their second model, the “population specific” model, refers to a study-specific CAB that mirrors a particular sub-group at risk for HIV infection. Once a model is identified, questions arise about its mission and its structure including ground rules, incentives, control of their agenda, numbers of members, voting procedures, clinic staffing and their training, conflict-resolution processes and many others (Cox, Ruff, Svendsen and Abrams, 1998).

Researchers have identified a number of functions that CABs are able to perform. These include: 1) recruitment of study subjects; 2) developing a referral mechanism; 3) legitimizing the research; 4) facilitating moving into the community; 5) developing confidentiality protocols; 6) serving as a liaison between researchers and community; 7) representing community concerns and culture to researchers; 8) assisting in development of consent forms and study materials; 9) advocating for the rights of research study subjects; 10) consulting with potential study participants to provide recommendations about study enrollment and 11) disseminating results of the research (Morin, 2003; Quinn, 2004; Silvestre, 1994; Woodsong and Karim, 2005). Several authors also suggest that CABs have a role in the informed consent process (Quinn, 1994; Strauss et al., 2001; Woodsong and Karim, 2005). Board roles and functions are primarily identified by the researchers but are often revised in consultation with Board members. How Boards vary by functions and how functions change over time has not yet been fully described.

This article briefly describes the creation in 1984 of one of the earliest HIV-related community advisory boards in the country. The paper also presents data from an analysis of Board minutes between 1984 and 2006 that describes its role and changing functions over time. It becomes clear that this CAB was an important agent for social change- not a commonly identified function for such boards. Functions not usually identified with community advisory boards, such as community organizing, service development, and designing research will be described. It will describe factors that critically affected the Board’s development such as its recruitment of members, support from the researchers, trends in attendance and changing functions over time. Lastly, the paper will illustrate the benefits of partnership between a community board and research scientists.

Genesis and Establishment of the Community Advisory Board (CAB)

In 1981, the first local case of what came to be known as AIDS was diagnosed in Pittsburgh at the University of Pittsburgh Medical Center (UPMC). Dr. Charles Rinaldo, a clinical virologist and viral-immunology researcher, consulted in the diagnosis. Dr. Rinaldo and David Lyter, a gay Pitt medical student interested in gay men’s health, began a collaboration to educate the gay community about this disease and to begin research including gathering medical histories and survey data, conducting physical exams, and collecting blood and semen specimens. To do so, they worked with bar owners, community leaders, and the gay media to distribute information. Interestingly, this level of outreach was unusual in other gay communities around the country at that time (Shilts, 1987).

When the National Institutes of Health (NIH) invited proposals for epidemiological studies of AIDS among gay and bisexual men in early 1983, Drs. Rinaldo and Lyter applied. The NIH Request for Proposals directed applicants to “Develop as nearly as possible a ‘population-based’ approach to recruitment of a cohort of homosexuals into the study. The approach can employ a wide variety of techniques such as newsletter or public media announcements, organization lists, or surveys (NIH, 1983 p. 6).” They also asked for “Evidence that a chosen technique will motivate patient participation over the duration of the study and evidence that

men in sufficient numbers can be recruited in sufficient numbers within the time period allotted or patient accession (NIH, 1983 p 48.).” Drs. Rinaldo and Lyter specified in their application that the study would offer STD screening as a public health measure and an incentive. They also said that they would recruit through clinics, gay organizations, gay bars and the media. Their application was supported by letters from leaders in the lesbian and gay community.

The NIH awarded grants to the University of Pittsburgh, Johns Hopkins, Northwestern, and UCLA, in October 1983 for a collaboration that became known as the Multicenter AIDS Cohort Study (MACS). Pittsburgh was then a “low incidence” area for AIDS, which was a major basis for it being chosen by the NIH.

Recruiting a few thousand gay men in a city with a population of 424,000 thousand people (U.S. Census Bureau, 1980) was an ambitious undertaking. To do so, a community activist and organizer (the author) was hired to recruit volunteers. He created and implemented a recruitment plan based on social marketing and community organizing principles. The basic tenet of the plan was that men would volunteer for the study only if they themselves and their community leaders understood that the research was truly benefiting the community. This meant not only producing world-class research but also educating the community about prevention, protecting the community from political backlash, and organizing services for men who became infected and were dying. The establishment of a CAB was an essential tool in the process (Silvestre, 1986).

Establishing the Board

The recruiter began by identifying the characteristics of potential CAB members that would most contribute to the study including the ability to work with diverse individuals and subgroups in the gay community; available time; knowledge of and credibility among one or more subgroups; a commitment to the goals of the study; and the capacity to understand the science. Once these characteristics were identified, the recruiter asked leaders in the community to identify trusted informants with these characteristics in each of the subgroups such as men in motorcycle clubs. A number of names were suggested, often by more than one person, and the recruiter invited 30 of these people to a meeting to discuss the study in February 1984. In April 1984, the first official meeting of the PMS Community Advisory Board (hereafter the Board) took place.

The Board developed a simple statement describing its role and functions. The single goal identified by the board was to “increase the effectiveness of the Pitt Men’s Study.” In doing, the Board identified three functions that they expected to perform. They were to:

1. Serve as a communication link between study personnel and the community;
2. Help recruit volunteers into the study; and
3. Solve problems.

The original Board included 14 racially diverse male and female bar owners, active members of various organizations, and popular leaders of sub-groups of the community, including young people and people in the leather community. The Board agreed to meet regularly. In the first few years, they met nine times a year with an additional social event and a yearly commemorative service for the men who died in the study. Study staff took minutes at each meeting and those were approved by the Board at the following meeting.

Methods

This paper uses data about Board actions that were recorded in official Board minutes. The minutes were written in order to ensure the transparency of the Board’s actions to the

community and to NIH and so careful attention was paid to fully describe all Board activities. This paper used content analysis of minutes from all 225 Board meetings between 1984-2006. Each meeting constituted a sampling unit and each item in the minutes was treated as a unit of data. The data were compared by year.

To create a conceptual framework for the analysis, the first author read minutes of 10 randomly chosen set of minutes and drew up a preliminary list of numbered functions into which each discussion item recorded in the minutes could be related. Examples of functions are attending to Board morale, disseminating study results to the public, and clinic personnel. In order to increase the validity of the conceptualization, he and a second rater used the list to categorize each discussion item from another 20 randomly chosen set of minutes. The results were compared and functions that proved not to be mutually exclusive and exhaustive were redefined. A final list of numbered functions (some with sub-functions) was generated and again subjected to rating by the author and a different rater. They agreed on the categorization 92% of the time and were able to agree on the remaining 8% after a short consultation. The author then manually coded all of the individual items in the minutes and entered the results (using the number assigned to a particular function) into a database for analysis. Since each meeting included announcements about upcoming community events, those items were tabulated but not used in the analysis. The following is the coding system with examples of specific functions.

Analysis

Attendance records of all meetings were tallied and the attendance record of each member was compiled. Standard calculations were done to yield averages. In order to understand how often a function such as “recruitment” was discussed over time, the functions were tabulated on tables for each year and then compiled into a table describing all years. The summary of each year’s topics included the total number of meetings per year, the total number of functions that were discussed at all of the meetings, the identification of the issue most often discussed and the one least discussed each year. Also, a table of each year’s summary was drawn up so that each row described a month and each column a function or sub function. The number of times that a function was discussed in a particular month was recorded.

A summary table was then developed that listed each function and sub function as a row heading and each column represented a year from 1984-2006. The number of times that a function was discussed in a particular year was inserted in each box so comparisons of the frequency that the board discussed each function could be tracked over time. The distribution of functions for each year and for all the years was analyzed totaling functions in each time period, examining changes in totals per year, examining the totals of functions in the early years versus the later years, and weighing changes in occurrence for each function over the time of the study.

The first author of this paper convened and staffed all of the meetings and wrote all but one set of minutes. All minutes were distributed to all members of the Board and their input solicited to correct errors. Because the minutes do not reflect the amount of time spent on each item or the importance that Board members attributed to it, those factors cannot be reflected in the analysis. However, results of this analysis were presented to the Board and researchers associated with the Center for Research on Sexual Orientation and Health. Those forums, with investigators and Board members, provided further clarification and verification of the findings of the study.

Results

Membership

From an initial membership of fourteen people in 1984, a total of 46 people served as members between 1984 and 2006. However, four who never attended any meetings were excluded from the analysis. The remaining 42 members served a total of 262 person-years, terms ranging from 1 year to 23 years. The mean term served was 7.8 years with a mode of 2 years. Of the 42 members, 11 left the Board because they moved out of Pittsburgh. Three other members died while serving as Board members and two people returned to serve a second term on the Board. Twelve others left the Board because of other reasons. Both Board co-chairs have served throughout the history of the study. Of the members, 22% have been African American (which reflects the proportion of African Americans in our county). Twenty-two percent are women and 12% joined the Board when they were 21 years old or younger. Although a strict criterion for Board membership is individual interest and capability and not affiliation, the Board has been aware of various members' affiliations so that many sub-groups of gay and bisexual men would be represented. As a result, the Board has always included bar owners, leaders of religious, social, athletic, and leather communities, young people, and women with ties to the gay and bisexual male community, African American gay and bisexual men, and people with ties to the HIV communities.

CAB Functions

Planning Board events, such as World AIDS Day was the most frequent Board function performed (125 cites). The second most frequently reported function was community organizing (105 cites) and third was advocacy (103 cites). See Table 2 for the remaining functions in rank order.

Table 3 presents examples of activities related to each function. Activities can be characterized as those with an external focus on Board operations, those with a focus on community services, and those primarily concerned with research. Within the context of Board focused topics, examples include recruitment to the board, addressing board morale and developing a board governance system. In the area of research, the Board spent significant time discussing study protocols, recruitment and retention, considering other protocols from MACS and non-MACS investigators, considering funding cuts or opportunities, and addressing issues related to study personnel. Over the decades, Board members encountered many substantive new issues ranging from the development of new drug therapies to the impact of the Internet on sexual risk behaviors.

The four most frequently cited functions related to external community service, namely, public events, community organizing, advocacy and community education. These were cited 433 times (34% of all topics). All of the other functions involved work directly related to the success of the research. These totaled 842 citations (66%).

Trends over Time

A total of 1,275 items were discussed at meetings between 1984 and the end of 2006 averaging 55 per year. The year with the fewest different items discussed was 2004 with 33 discussed and the year with the most items was 1989 with 82.

Table 4 gives the two most frequently cited functions for each year of the study. For 18 of the 23 years of meetings, the top two included both a public health research and a community service function. During 5 of the 23 years, service functions occupied both the first and the second ranks. Of these 5 years, three of them are the last 3 years of the Board's operation when it engaged in a long and systematic effort to increase state HIV prevention funding and to

improve the state policies regarding HIV education in Pennsylvania's schools. No topic was ranked first or second every year. However, both community education and review of non-MACS initiated research ranked first or second in every year but one.

Over time some patterns are apparent. Topics during the first few years of the study (1984-1988), focused on creating and coordinating services by organizing new agencies and groups such as the Pittsburgh AIDS Task Force. Additionally, considerable time and effort focused on writing and advocating for local, state, and federal policies such as Ryan White legislation. After the development of the HIV test, efforts grew around prevention including education and the distribution of condoms. Recruitment as a focus of the Board re-emerged when NIH made money available for recruiting African American and Latino MSM in 2002. Throughout the entire study, the Board focused on volunteer satisfaction, which relates to retention. It regularly asked staff to implement focus groups to determine satisfaction and to gather ideas for new efforts. These new efforts often took the form of educational initiatives and continue to this day. The latest initiatives, based on recent focus groups, have led to a system to put out 'health alerts' via an online list serve and to an online presence in local MSM chat rooms.

While these lists represent the actual foci of the Board's attention, they do not reflect the efforts that these issues required. For example, shortly after tests to detect HIV were successfully developed, the Board and investigators were faced with testing more than a thousand frozen specimens and developing a protocol for informing men about their HIV status. At the time, the full implications of a HIV diagnosis were not clear, effective drugs to control the infection did not exist, and the drugs to treat opportunistic diseases and cancers related to infection were crude. So within a few months of the testing, PMS staff informed over a thousand men in Pittsburgh about their HIV status. For about 25% of them, the tests were positive and death was the likely outcome within a few years. Those who were involved in HIV in the mid-1980s know very well how loud the arguments about whether HIV even caused AIDS were and the amount of time and energy necessary to disseminate accurate and critical information to the at-risk community. The time and energy that the Board members expended on this issue was considerable.

Discussion

The data indicate that the Board was equally concerned with community organizing and service, and research. It should be noted that community organizing and service were not identified as a Board function when the Board was created but quickly became a major focus of Board discussion and action. While the organizing and service functions were focused in only four areas, these four were the most frequently cited board discussions in the history of the Board. At the same time, they only constituted 34% of all of the topics discussed by the Board. The remaining discussions directly related to the functioning of the Pitt Men's Study and its scientific output. This balance between service and research was maintained throughout the study with both research and service being the most or second most frequently cited activity for 18 of the 23 years of the study's existence.

It is important to note that while we can intellectually distinguish between research and service, the two are interconnected. For example, the continuing efforts by the Board to increase recruitment of men into the study (research) relied heavily on maintaining the study's high profile through community education and advocacy (service). The impact of board activism in the community on retention merits further research.

Scientific Contributions

The members of the Board directly furthered the goals of science using their own knowledge about and insights into human behavior. They did this in three ways: designing and implementing sampling frames and recruitment strategies; reviewing and revising protocols and instruments; and identifying problems that needed to be studied.

First, board members played a direct role as expert consultants in the formulation of the study's sampling frame and recruitment process, and contributed to the implementation of that plan. Because PMS staff had decided to utilize social marketing strategies for recruitment, it was critical that they identified barriers and facilitating factors related to people's willingness to join the study. Also, Board members used their insights and experience to identify all of the sub-groups within the gay community. They identified venues and gatekeepers for each group and facilitated access to the groups by study personnel. In the absence of scientifically based sampling frames of the communities of gay men or of MSM, their insights and assistance was essential. Needless to say, the quality of recruitment and, thus, of the samples provided, determined the value of the data collected. Consequently, the Board's involvement in recruitment directly affected the findings of the research.

The Board Members had direct input into the scientific process in their role as representatives of the cohort. Their task was to reduce the burdens of proposed studies and to ensure their appropriateness from the participant's point of view. As reported above, Board members reviewed study designs and instruments of PMS MACS as well as those from other researchers who proposed to gather data from the PMS cohort. Their approval was needed before the investigator's proposal could be accepted. Instruments that were developed to measure sexual orientation, relationship status of gay men, "down low" behavior and identity, adherence to medication, bare backing, drug use and other topics were reviewed with the investigator. In each case, members provided feedback and in every case, the investigators reported that their input was useful and that all of the Board's recommendations were accepted.

Finally, the Board played a role in identifying new scientific questions. It was the Board that first alerted PMS investigators to the continued practice of unsafe sex among young gay men in the late 1980s after the investigators had assumed those behaviors had declined as they had among the cohort of older men. Board members asked PMS researchers to investigate this issue. This led to an analysis of the PMS data, which indeed indicated that about 7% of young men in the late 1980s, and early 1990s were as likely to be infected as young men in 1984 (Silvestre, 1994). Their insight was confirmed on the national level when studies sponsored by the CDC found the same rate of infection and of high-risk behaviors in cities around the United States (Centers for Disease Control and Prevention, 2007). Apparently, board members can serve as expert consultants to researchers and their contributions to the scientific process should not be underestimated. This is perhaps most true in research where subjects' behaviors and culture are significant to the outcome of the study.

Contributions to Public Health Service

Board members, investigators and study staff shared a strong commitment to public health that supported prevention efforts targeting and bisexual men in the area. Since the disease was clearly related to factors such as alcohol and drug use, mental health issues, fear of discrimination and other issues, study personnel and board members saw the areas they must address in education and advocacy as quite broad. This commitment to prevention was bolstered by a number of factors. Because the study was the first source of information about this new disease, study personnel received requests for assistance from health care professionals, family members, and policy makers whose concern was stimulated as infected men moved back to the area from coastal cities. As these requests increased, the staff and board

made a conscious decision to find ways to meet these needs. Identified needs included training and consulting with policy makers, creating new community-based organizations like the Pittsburgh AIDS Task Force, networking with local and state agencies, educating policymakers, working with media, implementing risk reduction education and intervention efforts, and advocating on behalf of infected people and the communities to which they belonged. The characteristics of the HIV epidemic and or of the longitudinal study itself may have created conditions that heavily influenced the functioning of this Board and its subsequent impact on research and the research process.

Implications for Community Organizers

This paper suggests that the NIH mandate for recruiting and maintaining diverse populations of research “subjects” and the growing interest in community partnerships between communities and researchers present community organizers to a growing field of practice. Community organizing skills in creating and maintaining community mechanisms, community organizing ethics which require rigorous attention to possible threats to research subjects and their communities, and community organizers ability to understand the language and needs of health researchers make them the logical “brokers” between communities and research institutions and researchers. Community organizers can ensure that researchers do no harm and that their resources create long-term benefits to the community. They also can assist researchers successfully interact with communities so that the likelihood of successfully recruiting suitable participants, advancing knowledge, and creating beneficial interventions will be enhanced.

Research opportunities for community organizers can also increase as they see community involvement in health research as an important research arena. Few studies have been published about community advisory boards and their role in the scientific enterprise. As boards have become better appreciated for their ability to help researchers understand, recruit and retain the populations they wish to study, the need for research on the role and functions of Community Boards is becoming more apparent. Research on the needed characteristics and diversity of board members, their ability to represent their constituencies, their reasons for joining and remaining on boards, conflict resolution among board members and between boards and investigators, the staff and training resources needed by board members, differences among boards serving on cross-sectional versus longitudinal studies, differences related to the type of community they represent (geographical, racial, shared interest etc.), and board functioning and structure are issues that can benefit from the attention of community organizers.

Conclusion

Research universities and individual researchers often need the support of research volunteers from marginalized communities. This partnership can be quite productive as well as materially beneficial to the larger society, the universities, and the researchers in terms of new discoveries, university funding and enhancing careers. Research volunteers benefit by gaining access to tests and/or treatments, information, incentives and opportunities to be altruistic. As the need for research volunteers from marginalized communities grows, the need for strong partnerships with these communities will grow as well. Community Advisory Boards are a way of creating and nurturing these partnerships. The experience of our Board suggests that such a partnership can support the integrity of the scientific process, improve the research, benefit research volunteers, and strengthen communities by affecting policy, organizing to provide new services, and bringing resources into the community.

The challenges that remain are to move research universities and individual researchers to support the creation of mutually beneficial partnerships and to support communities as they

negotiate with universities and researchers. Community organizers can play a critical role in these processes.

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Table 1
Coding schema for analysis

Categories of Functions	Examples
<i>Dealing with Community Advisory Board Internal Structure</i>	
<ul style="list-style-type: none"> • Structural issues • Morale and incentives • Training • Member recruitment 	<ul style="list-style-type: none"> • Governance; rules of conduct • Board milestones, appointments, awards • Virology, epidemiology, vaccine therapy, prevention • Nomination of new board members, attendance
<i>Providing Feedback from volunteers and the community</i>	<ul style="list-style-type: none"> • Complaints, compliments and questions
<i>Taking actions in the community</i> <ul style="list-style-type: none"> • Community education • Advocacy • Community organizing 	<ul style="list-style-type: none"> • News releases, public speaking, brochures • Letters to elected officials and politicians, meetings with candidates • Founds Pittsburgh AIDS Task Force, organizes effort to legalize needleexchange in city
<i>Reviewing Study protocol</i> <ul style="list-style-type: none"> • MACS/PMH protocols • rotocols submitted by outside investigators to use PMS data • Confidentiality • Disseminating findings 	<ul style="list-style-type: none"> • Review PMS and MACS questionnaires and other instruments • Reviewing questionnaires, surveys, consent forms from non PMS researchers • Reviewing and establishing protocols • Presentations and publications
<i>Enhancing PMS Recruitment</i>	<ul style="list-style-type: none"> • Recruitment strategies and activities
<i>Planning PMS events</i>	<ul style="list-style-type: none"> • Organizing World AIDS day
<i>Reviewing PMS personnel</i>	<ul style="list-style-type: none"> • Discussions of job performance and vacancies
<i>Reacting to MACS organizational issues</i>	<ul style="list-style-type: none"> • Meetings with other MACS site, MACS policies
<i>Reacting to NIH and other funding</i>	<ul style="list-style-type: none"> • Opportunities for funding, cuts in funding
<i>Providing General health information to the community</i>	<ul style="list-style-type: none"> • General news on HIV, hepatitis and LGBT health issues

Table 2

Most frequently cited functions of the Board

Function	Number of citations
Planning board events	125
Community organizing	105
Advocacy	103
Community Education	100
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Table 3

a: Examples of externally focused activities by function	
Events	
a.	Organizing 20 annual World AIDS Day Services
b.	Healing Weekend (a community sponsored weekend for people with HIV infection to educate about health issues and to provide an opportunity for social interaction.)
Community Education	
a.	Condom use
b.	Why people should be tested for HIV
c.	Factors related to unsafe sex
d.	Diseases associated with AIDS
e.	Drug interventions
f.	Protections from discrimination related to AIDS and HIV
g.	Death and dying and the importance of autopsies
Community Organizing	
a.	The development and distribution of appropriate hospital protocols
b.	The founding of the area's oldest and largest AIDS service organization
c.	The founding of a coalition of agencies dealing with HIV
d.	Supporting domestic benefits policies at the University
Advocacy	
a.	Organizing testimony for hearings for an AIDS policy in the local school district
b.	Working to increase federal, state, and local AIDS funding
c.	Educating local candidates about the need to legalize needle exchange
Activities focused on research	
Recruitment and Retention	
a.	The development of a social marketing plan for recruitment
b.	Developing a protocol to ensure confidentiality
c.	Identifying incentives to offer participants
d.	Designing cocktail napkins with HIV Quiz questions
e.	Designing focus groups in order to understand factors central to recruiting men to sign up for autopsies at their death
Reviewing and Discussing Scientific Protocols and Proposals from MACS Scientists	
a.	Obtaining stool, urine, and semen specimens with minimum embarrassment
b.	Developing a protocol for giving HIV results to men in the study
c.	Describing the relationship of T-cell counts and morbidity and mortality in consent forms
d.	Designing studies related to hepatitis B and C prevention studies
Reviewing and Discussing New Scientific Proposals from Non-MACS Scientists	

- a. Lesbian health (Study unrelated to MACS but related to recruiting lesbians through PMS volunteers)
- b. Insurance needs of people with AIDS
- c. Employment policies and people with AIDS
- d. The use of vaccines for hepatitis B by gay and bisexual men

MACS Organizational Issues

- a. Communicating with other Community Advisory Boards of the MACS
- b. MACS policy on making data available to the general public

PMS Personnel

- a. Developing job descriptions
- b. Recruiting staff for the study

Feedback from Volunteers

- a. Complaints and compliments about staff behavior at appointments
- b. Concerns about confidentiality
- c. Concerns about some aspect of the protocol

Disseminating Research Findings from the Study

- a. Presentations at local community forums and town meetings
- b. Use of local and national media to disseminate findings
- c. Presentations at local, national, and international meetings
- d. Publication of studies in peer-reviewed journals

b. Examples of internally focused activities of the board

Board Structure

- a. The creation of its governance policy
- b. The establishment of subcommittees or task forces
- c. Scheduling meetings

Board Training

- a. Epidemiology
- b. Immunology and Virology
- c. Neuropsychology
- d. Behavioral change
- e. Medical care
- f. Discrimination law
- g. Access to services
- h. Social marketing
- i. Research
- j. IRB and research ethics

Board Morale

- a. Awards to and recognition of Board members and PMS staff

- b.** Notable achievements of Board members
- c.** Recognition of members' contributions to significant Board activities

Community Advisory Board Membership

- a.** Identifying prospective members and nomination to Board
- b.** Setting rules on minimum attendance

Table 4

Top two cited functions for each year of the CAB

Year	Top cited function	Second cited function
1984	Recruitment	Structure
1985	Feedback from men	Community organizing
1986	Community organizing	Tie between community education and recruitment
1987	Tie between community education and recruitment	
1988	Feedback from men	Advocacy
1989	Community education	MACS and non-MACS study protocols
1990	MACS study protocols	Events
1991	Community education	Tie between non MACS study protocols and events
1992	Tie between community education, non MACS study protocols and events	
1993	Tie between non MACS study protocol and general health information	
1994	General health information	NIH and other funding
1995	Non MACS protocols	General health information
1996	Community organizing	PMS personnel
1997	Non MACS protocols	Board morale
1998	Community organizing	Advocacy
1999	Events	Community organizing
2000	MACS organizational issues	Tie between event and member recruitment
2001	Tie between advocacy and general health information	
2002	Advocacy	Events
2003	Events	Tie between member recruitment and non MACS study protocols
2004	Events	Advocacy
2005	Events	Advocacy
2006	Advocacy	Events