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# COMMUNITY ADVISORY BOARDS: *Their Role in AIDS Clinical Trials*

**Lisa E. Cox, Jack R. Rouff, Kenneth H. Svendsen, Madelyne Markowitz, Donald I. Abrams, and the Terry Beirn Community Programs for Clinical Research on AIDS**

*Community-based AIDS research programs were initially federally funded in 1989. Since then, the Terry Beirn Community Programs for Clinical Research on AIDS has mandated that research units develop and maintain community advisory boards to provide advice and communicate community preferences in AIDS research. Seventeen community-based AIDS research units formed community advisory boards (CABs) based on a model developed by the Community Consortium at San Francisco General Hospital. Social workers employed by these AIDS research units surveyed 267 CAB members to ascertain board characteristics and members' perceptions of program activities. Implications for social work and future research are discussed.*

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## **Key words**

AIDS  
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community advisory boards  
HIV research  
mission statements

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**I**n the burgeoning field of HIV/AIDS research, few published articles on the history, characteristics, and functions of community advisory boards (CABs) exist. In the social work literature, no theoretical contribution or empirical research study has explored the structure, implementation, and evaluation processes of CABs in AIDS clinical trial research programs. Social workers who do not keep abreast of AIDS research trends, including the role of CABs, miss an opportunity to learn information that can help the HIV-infected clients they serve.

The purpose of this article is twofold. First, it presents introductory historical information on AIDS clinical trials and CABs. Second, it discusses descriptive findings from an exploratory mail survey and implications for future research. We reviewed literature for this article from the nonmedical press (Cohen, 1994), peer-reviewed journal articles (Allhiser, 1995; Cox, 1994; Holmberg & Baker, 1979; Spiers, 1991), the U.S. Department of Health and Human Services (DHHS) regulations (1989), Community Programs for Clinical Research on AIDS (CPCRA, 1992, 1996) handbooks, abstracts from the 7th International AIDS Conference (Cox & Markowitz, 1991), and a transcribed presentation containing the oral history of community-based AIDS research CABs (Abrams, 1995).

Despite the inattention of researchers to CABs, federal grant contractors for AIDS research programs increasingly have required input from them. For example, since 1989 the Terry Beirn Community Programs for Clinical Research on AIDS (CPCRA, 1996; DHHS, 1989) network has mandated that CABs be developed. These advisory boards were to elicit community participation, provide advice on the design of studies, and assist with recruitment and retention efforts in AIDS clinical trials research. Often, social workers were the salaried staff designated to develop and facilitate CABs.

## **COMMUNITY ADVISORY BOARDS: DEFINITION AND HISTORY**

Traditionally, CABs have been defined as active, duly organized, and representative bodies that hold regular meetings and make decisions on behalf of their membership and whose members serve without pay. Historically, advisory boards primarily have advised organizations and refrained from decision making.

Research concerning non-HIV/AIDS research CABs can be found in psychological publications (Rosnow, Rotheram-Borus, Ceci, Blanck, & Koocher, 1993), in the education literature (Dyer & Williams, 1991; Lerner, 1990; Mercurio, 1979), and in the non-HIV/AIDS medical literature (Holmberg & Baker, 1979; Mansour, 1994; Ragland & Zinn, 1979; Rosnow et al., 1993; Winn, 1994).

Dyer and Williams (1991) related that effective board operations are an art as well as a science. Lerner (1990) stated that community representatives, who can keep abreast of community needs, assist with recruitment, and help maintain good public relations, are vital members of advisory committees. Offering a less supportive view of CABs, Mercurio (1979) criticized them as still likely to be "paper" councils dominated by advantaged clientele and not representative of the community at large. Hence, this article will address how CABs connected with AIDS research programs have developed and functioned in different ways.

#### **CAB HISTORY IN AIDS RESEARCH: THE COMMUNITY CONSORTIUM EXPERIENCE**

The topic of CABs has received limited attention outside the bioethics and education literature (Dyer & Williams, 1991; Fisher, 1987; Valdiserri, Tama, & Ho, 1988). Consequently, AIDS research programs (CPCRA, 1996) have depended solely on oral history to convey the story of their CAB beginnings. Abrams (1995) has provided the best oral history of community-based AIDS CABs. This account is significant because Abrams recognized the unique contribution of advice from HIV constituents, people who are potential study participants themselves, in the design and implementation of experimental research studies. Abrams (1995), in his lecture "The Story of CABs" briefly presented some background on the development of the model:

It's an interesting story. In 1985, the mayor of San Francisco approached the chairman of the AIDS program at San Francisco General Hospital (SFGH) and said "you need to relate better to the physicians in the community who are now caring for people with AIDS." In response, a group of physicians caring for AIDS patients in the community was formed. This group was initially called the County Community Consortium (CCC) because it was a coming together of doctors at the county hospital—the AIDS center, and the community physicians. Our goals were in-

formation exchange and informing community physicians about what research we were doing. The CCC met monthly to exchange educational information and to talk about our studies. After a few months the community doctors said they could do research in their practices too.

In 1986, the Community Consortium (CC—we dropped the word "county") developed the first so called "community-based clinical trial." This trial was designed to discern if patients should be given preventive treatments after their first episode of *Pneumocystis pneumonia*—one of the first trials of PCP prophylaxis since little was known and every doctor seemed to be doing it differently.

After visiting the CC, this interesting idea intrigued New Yorkers like Mathilde Krim, PhD, President of AmFar and Joseph Sonnabend, MD, one of the major doctors in the Village, so much that they attempted to form a similar AIDS doctors' consortium in New York. Because it was difficult to engage many New York doctors who cared for AIDS patients to do clinical trials, they instead organized a new group called the Community Research Initiative (CRI) under an organization called the PWA (people living with AIDS) Coalition.

The San Francisco group was comprised of all doctors. The New York group was a mixed group with a few doctors, but mainly people living with HIV/AIDS. Historically, this was when Admiral Watkins and his AIDS Commission were touring the country to learn about the disease. While in San Francisco, I explained the concept of community-based clinical trials to the Commission. When they visited New York, the CRI put on a very well-orchestrated presentation on community-based clinical trials and suddenly, as a result of their public relations expertise, the CRI became nationally known. Meanwhile the CC (which is now 200 doctors caring for PWAs) kept meeting.

In 1987-1988, when a growing AIDS activist community in San Francisco advocated hard for more community-based clinical trials, they had become aware of the New York group and wanted to have a CRI in San Francisco. By this time, the CC had finished an aerosolized pentamidine study which was leading to a publication in the *New England Journal of Medicine* and the FDA had approved inhaled pentamidine as a prophylaxis for PCP. Activists in San Francisco, however, wanted to participate in the research process and

formed the Community Research Alliance (CRA), modeled after the CRI in New York. The CRA eventually merged with Project Inform. So, ironically, the New York CRI model which basically developed out of the San Francisco CC model, then flipped back to California as the Community Research Alliance.

Because of increasing confusion as to just who was "community" in community-based clinical trials, the CC established an organizational task force which developed a policy statement and redefined the "Community Consortium" as a group of licensed health care providers in good standing. Then an Executive Board, a Scientific Advisory Committee, and a Community Advisory Forum were all established in 1988 (the year before the CPCRA was started).

The first community advisory board of the CC was comprised of adversarial activists; however, later other more supportive members and some of my own patients were added. Finally, the San Francisco CAB became a formal established structure in 1988. Soon not only the CC, but the ACTG (AIDS Clinical Trial Group), CFAR (Center for AIDS Research), and the CPCRA (Community Programs for Clinical Research on AIDS) programs all decided to have Community Advisory Boards.

So we're sort of proud that that's how the first CAB, that we're aware of, was set up. Now, the concept of CAB is something we need to look at; because there are a limited number of people who are willing, years later, to volunteer and dedicate time and energy to participate on these boards.

#### **THE NIAID EXPERIENCE**

In 1989 a community-based clinical trials network was funded by the Division of AIDS, National Institute of Allergy and Infectious Diseases, to conduct research on treatment for HIV disease and its sequelae (CPCRA, 1996). Seventeen funded research units were located in 13 U.S. cities where the AIDS epidemic was most severe. Their mission was to conduct clinical trials.

*Clinical trials* are scientifically and methodologically sound studies on medication interventions that are in wide use or of potential use in primary care settings. Community-based clinical trial programs target members of specific populations with low rates of participation in AIDS clinical research (CPCRA, 1996).

The purpose of the CPCRA was documented in the Request for Proposal (DHHS, 1989). The

program was designed to expand clinical research on HIV disease; integrate research into the primary care of persons with HIV disease; increase accessibility to clinical trials for women, ethnic minority groups, and injecting drug users (IDUs); and conduct research that expands the clinical knowledge of the day-to-day management of HIV disease and its manifestations (DHHS, 1989).

The CPCRA initiative represented the first time in the history of the National Institutes of Health that a CAB was required to help design and implement research studies (CPCRA, 1996; DHHS, 1989). CABs function autonomously and appoint one member to serve on a national advisory board called the Community Constituency Group (CCG). CCG members conduct their work through monthly conference calls and national meetings.

The purpose of developing CABs and the CCG was to strengthen community representation within clinical trials research programs by having people infected with and affected by HIV disease participate in meetings planning and decision making. The specific role of these community advisory boards has been to provide advice and communicate community preferences in AIDS research. The purpose of community advisory boards also was stated in the federal regulations: "Demonstration of community involvement in the decision processes and governance of the offeror is desirable through relevant community membership on governing boards, Institutional Review Boards, or other advisory bodies to the offeror group" (DHHS, 1989, p.6).

CAB formation occurred differently across units. Boards like the Community Consortium were established before their grant applications were submitted. Most units, however, organized boards after receiving award notification. Unit directors, called principal investigators (PIs), generally determined how their boards would form. For CAB recruitment ideas, PIs collaborated with their staff social workers and research nurses.

#### **COMMUNITY ADVISORY BOARD SURVEY**

After gaining experience in forming and administering CABs, social workers at two AIDS research units became interested in examining CAB demographics and progress (Cox & Markowitz, 1991). As a result of this interest, we designed a survey questionnaire to explore CAB composition, size, purpose, and perceived influence. This effort represented the first time board members were asked whether they felt they were making a difference.

### Participants and Setting

Overall CAB membership consisted of 267 community AIDS activists, people with HIV, and the clinicians who treat them. Board size ranged from five to 28 members. Generally, meetings were held from two to 12 times a year (Cox, 1994). Several CABs met monthly, and such frequency appeared to enhance group formation, communication, and community involvement.

### Research Design

We gathered information with a mail survey. A cover letter, written by NIAID staff, was attached to two multiple choice questionnaires and mailed out by a University of Minnesota statistical center. Survey packets were mailed to unit staff who distributed and collected the questionnaires at CAB meetings and through subsequent follow-up mailings. Before the completion of the survey, both questionnaires were pilot tested for face validity at two CPCRA units. Members who completed the pilot test were not included in the final survey.

### Assessment Procedures: Measures

The survey determined which research units had formed CABs and what the perceptions of their members were. The survey also posed six open-ended questions. An 11-item CAB Description Questionnaire asked for information about board philosophy, existence of mission statements, goals and objectives, board size, demographics, and frequency of group meetings. This questionnaire was completed by the CAB staff liaison. A 20-item CAB Members' Questionnaire asked respondents to describe their gender, race, and role and to share their opinions on communication patterns, effectiveness of board functioning, and modes of education. Members described their board's structure, the positive and negative aspects of being a CAB member, and the degree of perceived influence over local and national protocol development activities. Essentially, this questionnaire examined members' perceptions of their influence in conducting the work of the community-based clinical trials program.

### Data Analysis Procedures

We used the Nomad statistical package (U3S International BV, 1993) to analyze data. To inspect the data and provide descriptive information concerning board member demographics, we used univariate statistics. Finally, we used chi-square

statistics to compare the overall CPCRA population with CAB membership.

### Survey Results for Description Questionnaire

All 17 units returned the CAB Description Questionnaire. Information was collected on meetings, demographics, and mission statements.

On average, slightly more than half (54 percent) of each CAB's members regularly attended meetings. Attendance was limited mainly by illness and scheduling limitations. Of 267 identified CAB members, 103 (39 percent) were people of color. Seventeen (6 percent) were injecting drug users. One hundred fifteen (43 percent) CAB members were female. Sixty-seven (25 percent) had HIV (Table 1). By comparison, 57 percent of CPCRA study patients were people of color, 39 percent were injecting drug users, 20 percent were female, and 100 percent had HIV ( $p < .01$ ). More than half of all CAB members (142 or 53 percent) were people from AIDS service organizations (Figure 1). Several units reported that a salaried AIDS research staff member (usually a social worker or research nurse) served as an ex-officio CAB facilitator rather than a full-fledged voting member.

Twelve of 17 units reported they had mission statements. These mission statements focused on advising on studies, increasing representation of targeted populations, assessing community interest in HIV and related therapies, investigating alternative therapies, and engaging in political activities to increase access to clinical trials.

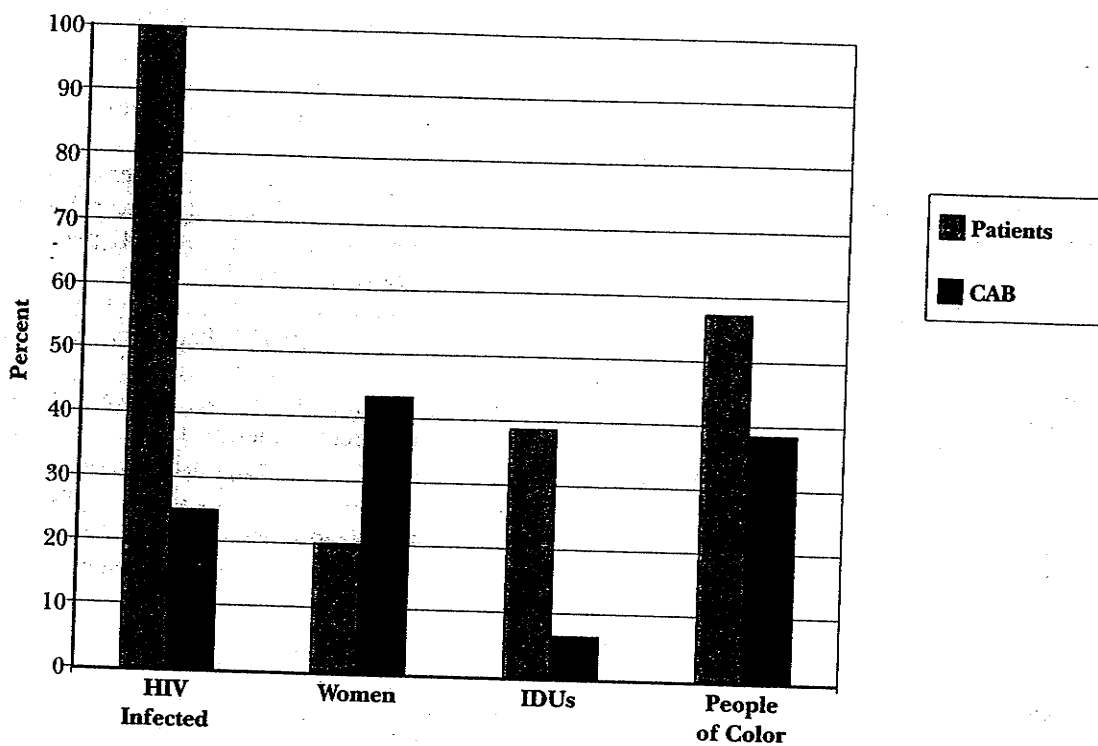
When CABs with mission statements were compared with CABs without them, several differences were noted (Table 2). CABs with mission statements tended to have better attendance and meet more frequently than those that did not have one. This appears to illustrate a trend evidenced by the subsequent findings related to meeting attendance, survey participation, and meeting frequency: Boards with mission statements encourage members to be more active and organized.

Of the 195 members of CABs with a mission statement, an average of 120 (61 percent) attended

**Table 1. Characteristics of CAB Membership**

Variables	<i>n</i>	%
People of color	103	39.0
Injecting drug users	17	6.0
Female	115	43.0
HIV positive	67	25.0

**Figure 1. Demographic Comparison between CPCRA Patients and CAB Members**



NOTES: CPCRA = Community Programs for Clinical Research on AIDS; CAB = community advisory board; IDUs = injecting drug users.

every meeting. In contrast, of the 72 members involved with CABs that did not have a mission statement, an average of 38 (53 percent) attended each meeting. CABs with mission statements also had higher rates of survey participation—46 percent of members of CABs with mission statements participated (90 of 195 members), whereas 14 percent of members of CABs without a mission statement participated (10 of 72 members). CABs with mission statements also held more meetings annually (eight versus seven).

**Table 2. Comparison of CABs by Presence of a Mission Statement**

Variables	Mission Statement (n = 12)	No Mission Statement (n = 5)	p
No. of members	16	14	.66
Attendance rate (%)	61	53	.35
No. of meetings per year	8	7	.61
Survey participation (%)	46	14	.0001

Survey respondents perceived that they were responsible for communicating community preferences concerning research; educating members about HIV disease; recruiting women, ethnic minority groups, and injecting drug users for study participation; and evaluating study-specific patient education materials. Overall, board members were minimally involved in daily unit operations.

**Survey Results for Members' Questionnaire**

Sixteen of the 17 research units completed the members' questionnaire. One hundred members' questionnaires were returned, representing 37 percent of the 17 CPCRA units' total membership.

*Respondent Characteristics.* Members who responded (respondents) and members who did not respond (nonrespondents) were similar in two areas: HIV infection (25.0 percent of respondents compared with 24.5 percent of nonrespondents had HIV,  $p = .93$ ) and gender (45.0 percent of respondents compared with 41.9 percent of nonrespondents were women,  $p = .62$ ) (Table 3).

**Table 3. Comparison of the Demographic Characteristics by Response to the CAB Members' Questionnaire**

Characteristic	% Respondents		<i>p</i>
	( <i>n</i> = 100)	( <i>n</i> = 167)	
Women	45.0	42.0	.62
People of color	31.0	43.0	.05
HIV positive	25.0	25.0	.93

Responders and nonresponders differed, however, in ethnic distribution (31.0 percent of responders compared with 43.1 percent of nonresponders were people of color,  $p = .05$ ).

At several AIDS research units, staff members served as advisory board members. Board members who were salaried staff members differed from volunteers in the perception of influence over program activities. Sixty-five percent of salaried staff members versus 43 percent of CAB volunteers felt that they had an influence on the national CPCRA ( $p = .02$ ). Of the 63 survey respondents who were CAB volunteers, 43 (73 percent) felt they were making a difference. CAB member influence was reflected in such areas as the development of bilingual brochures, changed decisions concerning protocol participation, and the creation of culturally sensitive patient education materials.

Limited knowledge about clinical trials, communication problems, and distrust of mainstream medicine were identified as possible sources of differences in perceived influence. Given these findings, future efforts at empowering local communities should explore how CAB members can see the results of their efforts.

Six open-ended questions were included in the survey. From these questions it has been inferred that most CABs emphasize and value education. The most requested topics noted by respondents were HIV disease pathogenesis, available treatments, clinical trials, research design, and pharmacology. Lecturing by principal investigators (70 percent of the CAB meetings held had PIs lecture) and by research nurses (46 percent of the CAB meetings had research nurses lecture) was the format most frequently used for education. In addition, 57 percent of respondents indicated that CAB members were educated by using literature provided by staff members. The strengths of CABs, noted in open-ended questions, included open-mindedness, genuineness, goal orientation, sensitivity to minority and gender issues, and commit-

ment to recruiting underserved populations. Most CAB members (85 percent) regarded each other as peers. Only 12 percent described relationships as hierarchical.

Additional differences among CABs were noted in leadership areas and in relations between staff and CAB members. Five of the 17 CABs (29 percent) were led either by a social worker or by an outreach worker. Four CABs (24 percent) were chaired by their PI, and eight CABs (47 percent) were chaired either by salaried staff members, such as social workers and research nurses, or by community constituents with HIV. Regarding relations between staff and CAB members, two-thirds of the respondents indicated that agendas were set by CPCRA staff, whereas one-third described CAB members as holding this responsibility. Although specific conclusions cannot be drawn from this data, we infer that CAB members enjoy less power than staff members in effecting CAB goals and objectives.

#### **DISCUSSION AND IMPLICATIONS FOR SOCIAL WORK**

In studying CABs, some authors have described the need for community consultation (Cohen, 1994; Seeley, Kengeya-Kayondo, & Mulder, 1965) or have documented the experience of a handful of groups who consult with their local community groups (Spiers, 1991). The present study differed because it focused on AIDS patients who were the objects of a consultative effort rather than on the consultants themselves.

The most notable contribution of community-based AIDS research CABs appears to be at the local level, where members reported that they influenced the direction of their programs. The findings of this article appear to indicate that CABs have more than a mere paper existence. CABs are valuable because they help design and promote AIDS research.

Historically, social workers have long been involved in coalition building, groupwork facilitation, community development, program evaluation, and practice (Fisher, 1987; Northen, 1988). Specialized medical or health social workers have served as team members in both inpatient and outpatient health settings since the early 20th century (Cabot, 1915; Carlton, 1980, 1984; Falck, 1990; Poole, 1995; Rowlands & Powderly, 1991). Health social workers are presently active in AIDS clinical trials research settings (Cox, 1994; Cox & Markowitz, 1991; Mansour, 1994). Participation

in CABs is an important and new role for social work.

Because of their training in groupwork, social workers in administrative, consultant, and coordinator roles are helping AIDS research CABs organize and work effectively. These new concepts of AIDS clinical trial social workers and community advisory boards require further research.

Given the survey results described in this article, more focus is required on how CABs can function effectively on local and national levels. In addition, community-based AIDS research boards require comparison to both non-HIV boards and boards connected with other AIDS networks. We need to know which CAB models promote the most effective communication between constituents and researchers. Such information is valuable to helping social workers and AIDS researchers better recruit and retain study participants in HIV/AIDS research.

**HSW**

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#### **ABOUT THE AUTHORS**

Lisa E. Cox, PhD, LCSW, is a research associate (with a joint faculty appointment at VCU's Division of Infectious Diseases and School of Social Work), Richmond AIDS Consortium, Medical College of Virginia, Virginia Commonwealth University, PO Box 980049, Richmond, VA 23298-0049; e-mail: lcox@hsc.vcu.edu. Jack R. Rouff, MBA, MSW, is project coordinator, Denver CPCRA, Denver. Kenneth H. Svendsen, MS, is a research fellow,

Division of Biostatistics, Coordinating Centers for Biometric Research, School of Public Health, University of Minnesota, Minneapolis. Madelyne Markowitz, MSW, ACSW, BCD, is risk coordinator, Quality Services, Clinical Resources Improvement Group, Henry Ford Hospital, Detroit. Donald I. Abrams, MD, is professor of clinical medicine, Community Consortium, University of California at San Francisco, and San Francisco General Hospital. The authors thank Dr. Thomas M. Kerkering and Dr. David Cohn for reviewing earlier drafts of this article. The authors also thank the CPCRA community advisory board members who responded to the questionnaires and the CAB members who continue to advise us on study development and implementation issues.

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