



Manual 14

Community Relations

March 28, 2008 - Version 1.0

Study website - <http://www.csc.unc.edu/hchs/>

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1. INTRODUCTION

1.1. Background

The National Institutes of Health-National Heart, Lung and Blood Institute (NIH-NHLBI) has launched a six and a half-year epidemiological study of health and disease among the Hispanic/Latino populations living in the United States. The Hispanic Community Health Study (HCHS) / Study of Latinos (SOL) has four (4) Field Centers located in: Miami (University of Miami), New York City (Albert Einstein College of Medicine), Chicago (Northwestern University Department of Preventive Medicine) and San Diego (San Diego State University, School of Public Health). Each Field Center is responsible for the recruitment and retention of 4,000 eligible Hispanic/Latino participants representing two or more of the following groups: Mexicans/Mexican Americans, Puerto Ricans, Cubans/Cuban Americans and persons born or descended from those born in Central or South America. Each study participant will receive, as part of the study, comprehensive health/medical assessments. The Field Centers are guided by a Coordinating Center (CC) located at the University of North Carolina (UNC) at Chapel Hill. HCHS/SOL has a Steering Committee that consists of each Field Center Principal Investigator, the NHLBI Project Officer, and the Principal Investigator of the Coordinating Center (CC). This body discusses and sets policies regarding all aspects of the research and community activities.

1.2. Community Relations Committee (CRC)

1.2.1 Overview

The CRC is one of many working committees established by HCHS/SOL Steering Committee (SC). An invitation to participate in the CRC was extended to all Field Center Principal Investigators; at least one representative from each Field Center was required to participate. The CRC was established due to NHLBI's strong commitment to community input and participation. This was also embedded in NIH's conceptualization and vision of the study. Offerors to the HCHS/SOL initiative had to demonstrate in their applications linkages and working relationships with target Hispanic/Latino communities.

1.2.2 CRC Goal and Objectives

Goal

The CRC's goal, as defined by its members, is to develop and recommend to the HCHS/SOL SC guidelines and strategies aimed at maximizing community input and participation in all phases of the study.

CRC Objectives

- To facilitate the development and sustainability of community relations between diverse sectors at the local and national levels in order to achieve research project objectives.
- To facilitate community capacity and empowerment through community health education and leadership development.

1.3. Purpose

This manual contains a series of guidelines for the HCHS/SOL SC to consider in its work to establish and sustain community relations. This manual specifically focuses on the formation of local community advisory committees/boards as a means of standardizing the efforts of local Field Centers.

2. BUILDING AND SUSTAINING COMMUNITY RELATIONS

This section describes some general guidelines in developing and sustaining community relations and in forming the local community advisory committees/boards.

2.1. Name and Definition of Selected Terms

The Hispanic/Latino multi-site study should be identified with the acronym of *HCHS/SOL*. For purposes of clarity and consistency, the following terms are defined:

2.1.1 Hispanic/Latino

For the purpose of the HCHS/SOL, the term, *Hispanic* or *Latino* refers to individuals that self-identify themselves as *Hispanic* or *Latino*. The terms *Hispanic* and *Latino* will be used interchangeably throughout this manual.

For the purpose of the local advisory committees or boards, the local Field Centers should use the term that appears to be most acceptable to the target communities; however, the term *Hispanic/Latino* follows the 1993 recommendations of the former US Surgeon General, Antonia C. Novello, MD in the report *Hispanic Agenda for Action*¹.

2.1.2 Community

Community can be defined in different ways based on: a) geographic location or b) functionality/common interest. When the term is used based on geographic location, *community* refers to individuals that live in close proximity, in a defined geographic area or location (e.g., neighborhood, city, county). When *community* is used based on functionality, it refers to groupings of individuals that have a common interest or characteristics (e.g., *the university community*, *the faith community*, *the Hispanic/Latino community*, *the Mexican community*), regardless of geographic location.

For the purpose of building community relations for the HCHS/SOL, CRC suggests the use of the word *community* to refer to both geographic and functional communities.

¹ *Hispanic Agenda For Action: One Voice, One Vision-Recommendations to the US Surgeon General to improve Hispanic/Latino health*. Washington DC: Public Health Service. Office of the U.S. Surgeon General.

2.2. Steps in forming and Sustaining Local Community Advisory Groups

2.2.1 Identifying Intended Audiences or Stakeholders

Most of the Field Centers already have local community groups serving in an advisory capacity to the HCHS/SOL local research teams. If this is not the case, the team of investigators may consider identifying and establishing communication with *community gatekeepers* from the target communities. *Gatekeepers* are individuals who know the community and its leadership and who have influence over others in regards to community issues and decisions. The individuals that serve as *gatekeepers* usually (though not necessarily) work in the community and are known and respected among community residents and/or leaders.

Even if the Field Centers already have a local community advisory group involved with the project, the Field Centers may want to expand this group to assure that there is representation of diverse sectors or *stakeholders*. This can be accomplished with the assistance of the gatekeepers.

Stakeholders are persons or organizations in the community that may benefit in some way from HCHS/SOL and from what the Field Centers are trying to do. They have a ‘stake’ in what will be or is being done and, as a result, these individuals are willing to work with the team of investigators to achieve the research objectives.

As Field Centers expand their local community advisory groups, there are several things to consider when identifying and selecting community representatives within their locality. For example, they should not only think about who is affected by the different health problems (to be assessed in the study), but those who will benefit from the local group actions. Next, they should give consideration to the involvement and resources of representatives serving in a similar capacity on other research projects. Finally, they must take into account the credibility of the individuals and organizations being considered as participants.

Potential community stakeholders comprise a diverse group of individuals, communities, political and organizational entities. Individual stakeholders can include persons and /or family members of those affected by the health problems being studied, local businesses, community residents, and concerned residents. Political and non-political organizations, such as health care providers, local professional chapters, community-based health and human services, local and state health departments, policymakers, and researchers from local institutions all have the potential to be community partners/stakeholders.

Once potential members for the local community advisory group have been identified and recruited, membership orientation sessions should be provided by the local Field Center’s leadership to assure that the membership is informed of the project’s goals and objectives and about their expected roles. Depending on the group size and changes in group composition, membership orientation updates are implemented.

Table 1 in Appendix 2 shows an example of a form that can be adapted and used in developing a list of potential community partners/stakeholders.

2.2.2 Developing Local Identity

The local Field Centers can name their local groups in any way they choose as long as the acronyms of *HCHS/SOL* are included. They can use the terms: *Advisory*, *Committee* or *Board* or any other term preferred by the local Field Center and/or its community group.

2.2.3 Developing Principles of Cooperation

The CRC suggests the following principles of cooperation to be adopted by the local community advisory groups:

- ◇ Commitment to equity;
- ◇ Commitment to high quality, ethical research;
- ◇ Commitment to community education;
- ◇ Collective interpretation, sharing of information and dissemination of results;
- ◇ Challenge social and environmental inequalities that affect health; and
- ◇ Support community changes and actions emerging from the data that ultimately will lead to positive health outcomes.

2.2.4 Facilitating the Development of Healthy Relations Among Group Members

Regardless of their purpose or composition, groups go through different stages which can vary from attraction and/or distrustfulness during the period of formation to development of strong group bonds and cohesiveness, followed by a stage of separation when the tasks have been completed. Commitments to group goals, good leadership, sound ground rules, and clear, honest and on-going communication are some key elements in building healthy relations.

Generally it is suggested that Field Centers' local community advisory committees have open meeting announcements that will allow new individuals to participate in meetings and/or to get involved during the duration of the study.

2.3. Study Committees/Subcommittees and Community Groups Overview

The Community Relations Committee (CRC) and the Local Community Advisory Groups (LCAG) are two separate entities. Members of the CRC are defined according to the description of members of subcommittees provided in the *HCHS/SOL Manual of Procedures (Manual 1)*. Community members, community leaders and members of the LCAG provide valuable insight to the CRC. However, they are not considered members of the CRC or any other subcommittee.

2.3.1 Community representation in HCHS/SOL Subcommittee Meetings

A. Members of Steering Committee subcommittees are principal investigators, co-investigators, representatives designated by the principal investigators, and representatives of the Project Office and other Institutes. Community members, community leaders and members of the LCAG can be invited to participate in conference calls held by the CRC or any other subcommittee with previous agreement from the Chair of the subcommittee.

B. During a conference call or other activities, each Field Center will select one representative to speak on behalf of that community.

C. Voting will be exercised by the members of the CRC.

D. The different subcommittees will submit recommendations to the Steering Committee. The final voting and approval will be exercised by the members of the Steering Committee.

2.4 Defining Functions/Activities of Local Community Groups

The following areas are appropriate activities for local community advisory groups:

- Publicity/Marketing
- Outreach and Liaison with the HCHS/SOL Recruitment Committee
- Liaison with the HCHS/SOL Retention Committee
- Community Education
- System of Referral and Follow-up
- Information Dissemination
- Research (optional)
- Ancillary Studies (optional)

These activities of the local community advisory groups can be conducted through the formation of working committees, if the local Field Center chooses to do so. Field Centers' local community advisory groups should have chairs and/or co-chairs, and working committees will elect or appoint conveners. Having community members in these leadership roles can facilitate the day-to-day management and activities of the advisory group in addition to facilitating leadership development.

2.4.1 Publicity/Marketing

This activity/working committee relates to the development and implementation of the study publicity campaign aimed at informing communities about the study and its benefits. Publicity can be done through:

- The use of the English and Spanish Media.
- Development of camera-ready articles in community newspapers and in Field Centers' newsletters.
- Development of project brochure.
- Development of study Fact Sheet.
- Development of posters to be placed in business establishment (e.g., beauty salon, grocery stores) and, community health centers and doctor's office.

2.4.2 Outreach and Recruitment

This activity/working committee relates to the development and implementation of a strategic plan to engage in community outreach activities to recruit eligible participants to the study in the targeted geographical areas. These activities can include making brief presentations about the project to community block clubs, local churches or places of worship, community-based organizations, consulate offices that represent diverse Latin-American countries, among other strategies.

Some other specific strategies to encourage participation in the study (among those selected to participate) include providing non-monetary incentives and retention aids in the forms of coupons/certificates to purchase food items in nearby food chain stores, and the like. These activities should be performed under the guidance of the HCHS/SOL Recruitment Committee.

2.4.3 Retention Committee

This activity/working committee relates to retention of participants in the study once they have been recruited. The work of this committee can be combined with the work of other committees and should be performed under the guidance of the HCHS/SOL Follow-up and Retention Committee.

2.4.4 Community Education

This activity/working committee relates to identification of bi-lingual educational materials and curricula, and to developing, implementing and evaluating a community education plan on diverse topics in partnerships with community organizations.

2.4.5 System of Referral and Follow Up

This activity/working committee relates to the identification of local resources and to establishing the necessary linkages and memorandum of agreement, if necessary, to refer study participants to community health and human services, particularly participants with no health insurance.

2.4.6 Information Dissemination

Once preliminary data are available, this committee or sub-committee will assist study investigators to develop a plan to inform the target communities and the public at large about the study's preliminary results. This could involve Summary Fact Sheets, organizing town hall meetings and community fora, and developing press releases for local newspapers. This committee works in partnership with the publicity/media, and community education sub-committees.

2.4.7 Research

This activity/working committee relates to assisting Field Centers in recruiting participants for focus group discussions, pilot-testing and validation of survey questionnaires; testing the clarity of the translation of diverse study forms such as Consent Forms; and assisting in the dissemination of preliminary study results. These tasks should be performed under the guidance of the SC.

2.4.8 Training

This activity/working committee relates to the development; implementation and evaluation of training programs on diverse health topics covered by the HCHS/SOL for members of the advisory committee and/or selected staff such as community health promoters. This working committee can also assist in identifying graduate, pre- and post-doctorates, and others individuals interested in research training activities.

2.4.9 Ancillary Studies

This activity/working committee relates to assisting in getting the word out to local researchers about opportunities to apply for ancillary studies.

2.4. HCHS/SOL Primary Responsibilities

Due to the complexity of HCHS/SOL, the Steering Committee (SC) has primary responsibilities for the following areas:

2.4.1 Instrument Development

This is an activity for which the SC and its sub-committees will decide specific content areas and the specific questionnaires to be used and/or medical assessments to be conducted to meet the research objectives. Community groups may participate or advise about the recruitment of focus group participants to validate and pilot-test instruments.

2.4.2 Revisions of Consent Forms and Other Study Forms

At the discretion of the SC subcommittees, community groups may advise on how to simplify forms' language or content as long as it is conducted within the study time frame. But in general, the overall structure and wording of these consents will be guided by requirements of the local Field Centers' Institution Review Boards (IRBs) and other guidelines that must be followed such as the Health Information Portability and Accountability Act (HIPAA).

2.4.3 Translation

Many Institutional Review Boards in academic institutions require professional translation services of recruitment materials, instruments, and other research tools and forms. The local Field Centers will adhere to these guidelines as well as those established by the SC. Also, focus groups, as noted above, will assure linguistic and cultural sensitivity.

2.4.4 Fiscal, Programmatic and Administrative Management of HCHS/SOL

Under the directives of the NIH-NHLBI Project Office, the Field Centers' Principal Investigators are ultimately responsible for overseeing all aspects related to the project's administrative, programmatic and fiscal activities.

2.5. Liaison with HCHS/SOL Steering Committee (SC)

1. Local community representatives can participate through telephone conference calls to address issues of concern to the Field Centers, as specified in section 2.3.1.
2. Local community representatives will be provided with an opportunity to meet with SC members when the SC meetings are conducted in their respective city (e.g., Chicago, Miami, NYC, and San Diego). Time and format will be determined by the NHLBI, the HCHS/SOL Coordinating Center, and the Field Center in question.
3. The SC and/or sub-committees should consult community member(s) as needed and through conference calls, on issues of mutual interest and benefits. These consultations must be planned and must have the approval of the Chair of the relevant Sub-Committee.)
4. In between SC meetings, representatives of the local community advisory committee/boards may provide input on HCHS/SOL matters through their local Field Center structure (e.g., advisory committee and subcommittees, local team of investigators). The local investigators would bring the issues/concerns to the SC or sub-committees as often as needed.

2.6. Summary

This document provides general guidelines for establishing and sustaining local community advisory groups. It briefly describes selected steps for local Field Centers' consideration for the formation of local advisory based on the unique characteristics and needs of their communities; describes core functions of local advisory groups in achieving HCHS/SOL research objectives; lists the SC primary responsibilities, and, suggests the different opportunities for local advisory groups to interact with members of the SC. Finally, this document provides the 2007-8 Community Relations Work Plan in Appendix 1 and NHLBI Guidelines for Corporate Support.

Appendix I Community Relations Committee 2007-08 Work Plan

What follows is a list of major CRC activities for 2007-08:

Activities
1. CR goals and Objectives, scope of work and CRC guidelines for community participation
2. Finalize community bd/committee structure (size, membership, committee structures)
3. Development principles of collaboration
4. Discuss strategies for Community entry & partnerships (contacting gate keepers), building cohesiveness, development of leadership and other group dynamics)
5. Marketing/Publicity
5a Development of Project Fact Sheet, brochure, newsletters and other project marketing materials
5b Establishment partnerships with local and national media to develop PSAs, Talk Shows, health segments during News, and/or articles in newspapers.
6. Outreach and Recruitment
7. Establishment of system of Referrals and Follow up
7. Retention Activities
8. Community Education
8a Identifying key local organizations/individuals to be trained to assist in community education on diverse health topics
Activities
8b Identifying bilingual educational materials /curriculum to be used
8c Evaluation of our educational efforts
9. Research (involvement of Adv committee in Focus groups activities, pilot testing of instruments, etc), for those sites who want community input in this process on a timing bases)
10. Research Training (optional) Assisting in identifying minority graduate students/investigators to involve in research project for sites applying for minority training grants
11. Ancillary studies (optional)—to promote research opportunities
12. Other activities

Appendix II Guidelines for Non-Federal Contributions

Final 01/29/08

Introduction

This document provides a plan for establishing guidelines for the acceptance and management of non-Federal contributions to the Hispanic Community Health Study/ Study of Latinos (HCHS/SOL) at the field center and national levels.

Goal

To establish guidelines and mechanisms for acceptance of outside contributions to HCHS/SOL.

Objective

Establish a sub-committee of the Community Relations Committee (Contributions Subcommittee) comprised of HCHS-SOL staff to identify needs, to develop criteria, and to implement a plan for accepting and utilizing outside resources.

Implementation

Identify key HCHS-SOL and NHLBI staff to focus on issues related to outside support and bring suggestions to the Steering Committee. This Contributions Subcommittee could be a subset of the Community Relations Committee.

- Develop guidelines for directing donations either toward a field center or for the NHLBI gift fund.

Develop a list of areas of need related to study activities with estimate of cost.

- Field centers will develop a list of needs appropriate for support through outside funding.

The Contributions Subcommittee will work with NHLBI project officers and others at NIH to establish the process whereby large donations will be received, monitored and disbursed.

- Large donations to the HCHS-SOL may be accepted through the NHLBI Gift Fund.*
- Decisions regarding disbursement of HCHS-SOL funds from the NHLBI Gift Fund will be made by NHLBI with recommendations from the Steering Committee.

Donation Guidelines from the NHLBI

Outside contributions may be accepted from private foundations, corporations, philanthropic organizations, or private Institutions or individuals to address emerging needs of the HCHS-SOL with particular emphasis on, but not limited to, community education, health promotion and study marketing, and public relations activities.

All field centers may establish and obtain funds for small donations by local sponsors and establish a local Circle of Friends / Círculo de Amigos del SOL to provide guidance to obtain and use of locally donated funds.

Small donations may be accepted directly by Field Centers to support breakfasts/lunches for community advisory committees/board meetings, community gatherings or retention aids.

- **Acceptable recruitment and** retention aids can be coupons, certificates, canvas bags, gift cards, and goodies e.g. stress balls, pill case dividers, cups, pens, pads.
- **Unacceptable** items are actual product samples.

Field Centers may seek support from non-Federal contributors, but this should be informal, without a structured process that would appear to make this a study that requires funding by private contributions. The recently approved increase in funds from the NIH is considered to be sufficient to complete the basic requirements of the study. However, donations for emerging needs of the HCHS/SOL with particular emphasis on, but not limited to, community education, health promotion and study marketing, and public relations activities is always helpful. Philanthropy is certainly acceptable, and there are mechanisms for larger scale public-private partnerships. Large scale donations are encouraged to be given to the NHLBI Gift Fund and the Steering Committee needs to establish a policy that this is the preferred mechanism, but not required, so as to spread the donation fairly to each Field Center. The Steering Committee will establish a policy on how to best allocate undesignated contributions and what constitutes a “small” donation that should be managed by the Field Centers.

***NHLBI Gift Fund**

Depending on the wishes of the donor, the NHLBI uses the gift funds to carry out our mission of planning, conducting, fostering, and supporting an integrated and coordinated program of basic research, clinical investigations and trials observational studies, and demonstration and education projects. NHLBI research is related to the causes, prevention, diagnosis, and treatment of heart, blood vessel, lung, and blood diseases, as well as sleep disorders. Donations to and any correspondence regarding the NHLBI Gift Fund should be sent to the Director at the following address:

Director, NHLBI
National Heart, Lung, and Blood Institute
31 Center Drive
Room 5A52, MSC 2486
Bethesda, MD 20892

Appendix II Suggested Form for Listing of Potential Community Partners/Stakeholders

Instructions: Use this form to list potential community partners/*stakeholders* to join your local group.
Under each column, please specify the information requested.

Sector	Name	Organization	Address	Telephone	Email
<i>Health care</i> (hospital, clinics, physicians, nurses, etc)					
Community-based Organizations (CBOs)					
Professional Organizations					
Faith Organizations					
Media					
Businesses					
Others, etc					