



**Manual 14**  
**Community Relations**  
**August 18, 2014 - Version 2.0**

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



Tracking of Revisions to HCHS/SOL V2 MOP #14

| [Previous Manual, Date, Version] | Date(s) of Revisions;<br>source | Approved by, Date | Revisions   | Previous Page #s<br>section changed<br>etc. | Distribution<br>Date |
|----------------------------------|---------------------------------|-------------------|---|---|----------------------|
| March 28, 2008, V 1.0            | August 18, 2014                 |                   | Community Relations Manual 14-HCHS Visit 2 is significantly different than the MOP 14 designed for HCHS Baseline (Visit 1). This V2 has been adapted to fit the changes in the Community Relations concept and vision for HCHS Visit 2. | All   |                      |
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## Table of Contents

|  |          |
|--|----------|
| <b>1. INTRODUCTION.....</b>  | <b>5</b> |
| 1.1. Background.....   | 5        |
| 1.2. Community Relations Committee (CRC).....                                    | 5        |
| <b>1.2.1. Overview.....</b>  | <b>5</b> |
| <b>1.2.2. CRC Goal and Objectives.....</b>                                       | <b>5</b> |
| 1.3. Purpose.....  | 6        |
| 1.4. Structure.....  | 6        |
| <b>2. BUILDING AND SUSTAINING COMMUNITY RELATIONS .....</b>                      | <b>6</b> |
| 2.1. Name and Definition of Selected Terms.....                                  | 6        |
| 2.1.1 Hispanic/Latino.....   | 6        |
| 2.1.2 Community .....  | 7        |
| 2.2. Steps in Forming and Sustaining Local Community Advisory Groups .....       | 7        |
| 2.2.1 Identifying Intended Audiences or Stakeholders.....                        | 7        |
| 2.2.2 Developing Local Identity .....  | 8        |
| 2.2.3 Developing Principles of Cooperation.....                                  | 8        |
| 2.2.4 Facilitating the Development of Healthy Relations among Group Members..... | 8        |
| 2.3. Study Committees/Subcommittees and Community Groups Overview.....           | 8        |
| <b>2.3.1 Community Representation in HCHS/SOL Subcommittee Meetings .....</b>    | <b>8</b> |
| <b>2.4 Defining Functions/Activities of Local Community Groups.....</b>          | <b>9</b> |
| 2.4.1 Publicity/Marketing .....  | 9        |
| 2.4.2 Outreach and Visit 2 Enrollment .....                                      | 9        |
| 2.4.3 Retention Committee.....   | 10       |
| 2.4.4 Community Education.....   | 10       |
| 2.4.5 System of Referral and Follow Up.....                                      | 10       |
| 2.4.6 Information Dissemination and Evaluation .....                             | 10       |



Visit 2-Community Relations Manual 14

|              |   |           |
|--------------|---|-----------|
| 2.4.7        | Research.....   | 10        |
| <b>2.4.8</b> | <b>Training</b> .....   | <b>10</b> |
| 2.4.9        | Ancillary Studies.....  | 11        |
| 2.5.         | HCHS/SOL Primary Responsibilities.....                                  | 11        |
| 2.5.1        | Instrument Development.....   | 11        |
| 2.5.2        | Revisions of Consent Forms and Other Study Forms.....                   | 11        |
| 2.5.3        | Translation .....   | 11        |
| 2.5.4        | Fiscal, Programmatic and Administrative Management of HCHS/SOL .....    | 11        |
| 2.6.         | Liaison with HCHS/SOL Steering Committee (SC) .....                     | 11        |
| 2.7.         | Summary .....   | 12        |
| Appendix I   | Community Relations Committee 2014-2019 Work Plan .....                 | 13        |
| Appendix II  | Guidelines for Non-Federal Contributions.....                           | 14        |
| Appendix III | Suggested Form for Listing of Potential Community Partners/Stakeholders | 16        |



## **Community Relations TABLE OF CONTENTS**

### **1. INTRODUCTION**

#### **1.1. Background**

The National Institutes of Health/National Heart, Lung and Blood Institute (NIH/NHLBI) has launched the second visit for the 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), which has four (4) Field Centers located in: Miami (University of Miami), New York City (Albert Einstein College of Medicine), Chicago (University of Illinois at Chicago) and San Diego (San Diego State University). At baseline from 2008-2011, each Field Center recruited 4,000 eligible Hispanic/Latino participants representing two or more of the following groups: Mexicans/Mexican Americans, Puerto Ricans, Cubans/Cuban Americans, Dominicans/ Dominican Americans, and persons born or descended from those born in Central or South America. Each study participant will be invited to participate in the HCHS/SOL Visit 2 (2014-2019). 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 (SC) that consists of each Field Center Principal Investigator, the NHLBI Project Officer, and the Principal Investigator of the Coordinating Center (CC). This document discusses and sets policies regarding all aspects of the community relations activities.

#### **1.2. Community Relations Committee (CRC)**

##### **1.2.1. Overview**

The CRC is one of many 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 is required to participate. The CRC was established due to NHLBI's strong commitment to community input and participation in research. This was also embedded in NIH's conceptualization and vision of the study. Offers 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 will coordinate the planning and evaluation of community-based dissemination of HCHS/SOL study results, partnership activities, and other study-related activities as needed.

###### **CRC Objectives for the Visit 2 Time Period**

- 1) To utilize public relations (PR) strategies to disseminate study results in collaboration with other HCHS/SOL committees.
- 2) To conduct both process and impact evaluation of community-based Field Center dissemination activities.



### 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 efforts to standardize dissemination efforts of local Field Centers.

### 1.4. Structure

The CRC is composed of at least one member of each Field Center, Coordinating Center, Project Office and NIH.

- **Voting Members:** Each Field Center, Coordinating Center, Project Office and NIH designates one voting member of the CRC. Voting members will be asked to take the lead on action items and materials development.
- **Meeting Frequency:** The CRC will meet monthly.
- **Standing Agenda:** The monthly agenda will address updates on key CRC functions, activities and action items, and updates on FC work plans and community advisory boards.
- **Reporting:** The CRC will submit reports to the SC annually. The CRC will receive biannual reports from each FC and will include summative information.
- **Cross-Committee Collaboration:** The CRC will collaborate with other committees as requested to meet the goals of study.

## 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*<sup>1</sup>.

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<sup>1</sup> *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.

## 2.1.2 Community

Community can be defined in different ways based on: a) geographic location or b) functionality/relational/ 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.

## 2.2. Steps in Forming and Sustaining Local Community Advisory Groups

### 2.2.1 Identifying Intended Audiences or Stakeholders

All of the Field Centers already have local community groups serving in an advisory capacity to the HCHS/SOL local research teams that have been developed in the Visit 1 time period. Each team of investigators may consider identifying and establishing communication with additional *community gatekeepers* from the target communities to serve on the community advisory groups. *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 and dissemination 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 may 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
- Liaison with the HCHS/SOL Retention Committee (optional)
- Community Education
- System of Referral and Follow-up
- Study Results Dissemination and Evaluation
- 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 Visit 2 Enrollment**

This activity/working committee relates to the development and implementation of a strategic plan to engage in community outreach activities to promote Visit 2 participation 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 Visit 2 participation in the study (among those already enrolled in the study) 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 Retention 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 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 common community education plan on diverse topics that stem from HCHS/SOL baseline data 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 and Evaluation**

Once preliminary data are available, the CRC will assist study investigators to develop a plan to inform the target communities and the public at large about the study's preliminary results. In addition, evaluation of the impact of such efforts in knowledge, attitudes and behavior will be conducted on select activities. This could involve Summary Fact Sheets, organizing town hall meetings and community fora, and developing press releases for local newspapers. CRC will also explore the use of electronic communication formats and social medial tools for dissemination of study materials among community partners and to inform the general public on educational activities and study results.

### **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 Visit 2 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 raising awareness of local researchers about opportunities to apply for ancillary studies.

## **2.5. HCHS/SOL Primary Responsibilities**

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

### **2.5.1 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.

### **2.5.2 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).

### **2.5.3 Translation**

Many IRBs 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. Translation activities are organized by the HCHS/SOL Translation Committee.

### **2.5.4 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.

## **2.6. 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 subcommittees may consult community member(s) as needed and through conference calls, on issues of mutual interest and benefits. Such local community advisory 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 may also bring the issues/concerns to the SC or subcommittees as needed.



## 2.7. Summary

This document provides general guidelines for sustaining local community advisory groups and conducting common community activities across all Field Centers. It briefly describes selected steps for local Field Centers' consideration for the expansion 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 2014-2019 Community Relations Work Plan in Appendix 1 and NHLBI Guidelines for Corporate Support.



## Appendix I Community Relations Committee 2014-2019 Work Plan

What follows is a list of major CRC activities:

|   |
|---|
| <b>Activities</b>   |
| 1. <b>CR goals and Objectives, scope of work and CRC guidelines</b> for community participation   |
| 2. <b>Finalize community board/committee structure</b> (size, membership, committee structures)   |
| 3. Development <b>principles of collaboration</b>   |
| 4. <b>Discuss strategies for community entry &amp; partnerships</b> (contacting gate keepers), building cohesiveness, development of leadership and other group dynamics)             |
| <b>5. Marketing/Publicity</b>   |
| 5a Development of Project Fact Sheet, brochure, <b>newsletters</b> 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.                                  |
| <b>6. Outreach and Recruitment</b>  |
| <b>7. Retention Activities</b>  |
| <b>8. Community Education</b>   |
| 8a Identifying key local organizations/individuals to be trained to assist in community education on diverse health topics  |
| 8b Identifying bilingual educational materials /curriculum to be used   |
| 8c Evaluation of common 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)<br>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 educations 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 III 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><br>(hospital, clinics,<br>physicians,<br>nurses, etc) |      |              |         |           |       |
| Community-<br>based<br>Organizations<br>(CBOs)                           |      |              |         |           |       |
| Professional<br>Organizations  |      |              |         |           |       |
| Faith<br>Organizations   |      |              |         |           |       |
| Media  |      |              |         |           |       |
| Businesses   |      |              |         |           |       |
| Others, etc  |      |              |         |           |       |