



Manual 3

Retention

June 30, 2008 - Version 1.0

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

**Retention
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1. OBJECTIVES: RETENTION OF HCHS/SOL PARTICIPANTS

Through retention activities we aim to achieve maximum possible retention of study participants throughout the follow-up period. A separate manual outlines the follow-up process with participants and activities designed to capture annually information that will help detect outcome events (i.e. endpoints).

2. PROCEDURES FOR RETENTION OF HCHS/SOL

To best retain HCHS/SOL participants, we aim to have at least one contact with participants every quarter (i.e.3 months). Contacts with participants will include a post-visit thank-you card or call, a bi-annual newsletter, a birthday or greeting card, and a holiday or end-of-year card. We aim to design both culturally and religiously appropriate contact documents. Therefore, these contacts will be initiated by each field center and will be conducted in the language of choice (i.e. English or Spanish) of the participant. In addition, because some religions (e.g. Jehovah's Witnesses) may not celebrate birthdays or holidays, specialized cards will be designed to accommodate these participants. All newsletters and cards sent to HCHS/SOL respondents will be targeted for a 5th grade reading-level in English and Spanish.

2.1. Initial Visit Change of Address Card

To assist the field centers with obtaining change of address information, each field center should provide respondents with a self-addressed and stamped change of address card that the respondent can drop in the mail if they move. A "forever stamp" should be used to eliminate need for postage. Alternatively, some Field Centers may be able to set the cards up to be charged to the site only when returned by the respondent. *This card should be provided to the respondent at the end of the initial visit.*

2.2. Post-Visit Thank-you Card with Optional Evaluation Component

Currently, there are no requirements for a thank you call after the respondent completes the study. Respondents are called on several occasions and for the 24hr dietary recall. Therefore, an additional call is likely to be seen as a burden by respondents.

After completing their initial visit respondents will be sent a thank-you card. These cards should be mailed within 5 weeks of a respondent's initial field center visit. The 5-week time frame should allow coordination with the 24hr dietary recall, and if available, the study results report.

Study sites may, as an option, provide participants with a combined thank-you card and evaluation card at the completion of the initial visit. The thank-you/evaluation card will have an evaluation component that can be torn off and mailed back to the site. The evaluation card will be anonymous and will provide the site with information regarding the quality of the participant's visit. To monitor visit quality we encourage each site to provide these thank-you/evaluation cards to at least a small subset of participants. *This card should be provided to the respondent at the end of the initial visit.*

Although thank you calls are not being made. All sites should be aware that approximately one week after result letters are mailed, respondents who have an alert result are to receive a separate call to verify that the results have been received, answer any questions that the participant may have, and to discuss options for referrals if necessary.

2.3. Quarterly Newsletter

A newsletter will be produced and distributed to respondents quarterly (Spring, Summer, Fall, and Winter). The newsletter will be provided in English and Spanish. With careful design, it should be possible to have English on one side and Spanish on the other. The newsletter should contain at least 3 articles: (1) feature article (1-page), (2) site article (1/2 page), (3) information for all study participants (1/2 page). Therefore, each site will have responsibility to prepare one article per year. The dissemination schedule will be as follows.

- Summer – June 1 (San Diego)
- Fall – September 1 (New York)
- Winter – December 1 (Chicago)
- Spring – March 1 (Miami)

The first newsletter to HCHS/SOL participants will be planned for June 1, 2008.

The Coordinating Center will post newsletters on the HCHS/SOL website. Each site will then be responsible for downloading and distributing the newsletter to respondents. Please note that this newsletter is intended for HCHS/SOL respondents and NOT the community. The field centers may choose to send the newsletter to other interested parties and stakeholders. However, the content of the newsletter should be directed to HCHS/SOL respondents as a part of the study's retention process.

2.4. Birthday/Greeting Card

Field Centers will send a birthday card to each respondent 1-2 weeks prior to their birthday. For respondents who indicate that they do not celebrate birthdays, a greeting card will be sent in place of a birthday card. A template for these cards is provided.

The Annual Follow-Up (AFU) Participant Tracing Information Sheet (see section 5.1) will include information from the baseline survey on the religion of the respondent (Catholic, Protestant, Other Christian, Other Religion, Secular). Those respondents who indicate that they are other Christian will receive greeting cards instead of birthday cards.

2.5. Holiday/New Years Greeting Card

Field Centers will send a New Years card to each respondent in January. A template for these cards will be provided.

2.6. Primary Contact Notification Card and Letter

The respondent should be provided with a letter to give to each of his/her 3 primary contacts. These letters will indicate that the participant has provided his/her name as a contact person to

the HCHS and has given permission to the HCHS to contact him/her to obtain updated address, phone, and/or e-mail information on the participant. *This letter should be provided to the respondent at the end of the initial visit.*

At the initial visit, the HCHS/SOL participant will also be asked to sign a card addressed to his/her contact. The card will also indicate that the participant have HCHS/SOL permission to contact him/her to obtain updated address, phone, and/or e-mail information on the participant. *This card will be retained by the site and may be mailed to contacts before a site calls the contact.* This will help improve responsiveness of the contact to queries from HCHS/SOL.

2.7. USPS Address Service and Returned Mail Log

All mailings to participants should follow USPS standards for address correction/return services. Specifically, the words "ADDRESS SERVICE REQUESTED" or "RETURN SERVICE REQUESTED" should appear on the face of the card or envelope to ensure that any address changes are reported back to the Field Center (see USPS Quick Service Guide 507d, Additional Services, Ancillary Service Endorsements <http://pe.usps.com/text/qsg300/Q507d.htm> for further information).

To assist with identifying respondents who have moved and may be more difficult to follow, a returned mail log is kept by each field center for all cards and newsletters that are marked returned to sender. Each field center designs and maintains its own returned mail log. The Coordinating Center does not require a copy of these field center logs.

2.8 Retention Timeline

At the end of the initial visit, HCHS/SOL participants should be given the following: (1) a change of address card, (2) a notification letter for each of their contacts, (3) Thank-you card with evaluation tear-off card to mail back (optional). During the exit interview, HCHS/SOL participants should also be asked to sign the contact notification card in either Spanish or English. This will be kept on file by each site and sent out only as needed.

Within 5 weeks of the initial visit, HCHS/SOL participants should be mailed a thank-you card. They will receive birthday cards within 2 weeks of their birthday. They will receive New Year's cards within 2 weeks of January 1. They will receive quarterly newsletters as indicated in section 2.3.

ITEM (timing of item)	MAILINGS	CALLS	IN- PERSON	ALL SUBJECTS	SUBSET OF SUBJECTS	OPTIONAL
CY1						
Baseline Exam	X	X	X	X		
Change of Address Card (end of initial visit)	X		X	X		
Thank you card (5 weeks after initial visit)	X			X		
Thank you with evaluation card (end of initial visit)			X		X	As per site

ITEM (timing of item)	MAILINGS	CALLS	IN- PERSON	ALL SUBJECTS	SUBSET OF SUBJECTS	OPTIONAL
Contact Notification Card (signed at initial visit)	X					As per participant
Contact Notification Letter (end of initial visit)			X	X		
Alert call		X			X	
Lab results mailing	X					
Birthday/Hello card (on birthday)	X			X		As per participant
Newsletter 1 (June 1)	X		X	X		Via email
Newsletter 2 (September 1)	X		X	X		Via email
Newsletter 3 (December 1)	X		X	X		Via email
Newsletter 4 (March 1)	X		X	X		Via email
New Years Card (January 1)	X		X	X		As per participant
CY2						
AFU Pre-AFU Reminder letter	X			X		As per FC
AFU 4 components		X	X	X		
Reminder Call to AFU		X		X		
CY3						
AFU Pre-AFU Reminder letter	X			X		As per FC
AFU 4 components		X	X	X		
Reminder Call to AFU		X		X		

2.9 Translations of Newsletters, Letters, and Cards

All newsletters, thank you letters, and cards are translated by the field centers. The HCHS/SOL Translation committee will not be responsible for reviewing and/or approving these translations. The Coordinating Center and Translation Committee only have responsibility for approving the translation of data collection instruments and participants' consent forms.

To help promote standardization of the HCHS/SOL retention letters and cards, English and Spanish version of these letters and cards will be reviewed and approved by the Retention Committee. Approved English and Spanish versions will be posted on the HCHS/SOL website where they can be downloaded and tailored by each field center. To ensure that all necessary elements of the document have been included, any tailored versions of these letters and cards must be submitted to the retention committee for final approval.

2.10 Tailoring of Newsletters, Letters, and Cards

The quarterly newsletter should be downloaded from the Coordinating Center website and distributed as is. The wording of letters and cards should not be modified without prior approval from the retention committee. Letters and cards may be tailored to sites by changing or adding

(1) graphical designs or pictures to the card, (2) providing site specific address information, (3) providing site specific phone contact information, (4) changing colors of the text, and (5) changing the order of Spanish and English text where it is provided in the same card.

3. CLINIC ENVIRONMENT AND RETENTION-RELATED RESOURCES

A culturally and linguistically appropriate environment can improve retention efforts. Therefore, field centers are encouraged to use various strategies to help make the examining center waiting rooms welcoming. For example, art work by local Hispanic/Latino artists can be shown in the waiting room. Examining center clinic areas can be named after persons of interest and importance to the local community.

3.1. Educational Materials and Referral Lists

The waiting rooms for each examining center should be stocked with key educational materials and promotions relevant to the local Latino/Hispanic community. Most importantly, each field center should develop and maintain a referral list for respondents. Referral lists should include (1) information on medical providers (English and Spanish-speaking), (2) child care services, (3) educational resources, and (4) other services that respondents might need assistance with and might ask about during the course of their interviews. These referral lists should be available in the examining center waiting rooms. All study staff should be aware of these materials and be able to provide them to participants as necessary, before, during, or after the clinic visit.

3.2. Payment of Monetary Incentives

Field centers will make every effort to ensure that monetary incentives are given to respondents at the time of their initial visit. If this is not possible, field centers will ensure that monetary incentive are given to respondents within 3 weeks of their initial visit. Timely payment of incentives will help promote a positive experience and relationship between participants and field center staff.

3.3. Publicity and Coordination with Community Relations Committee

To enhance participation, the Field Centers should maintain active contact with the media in their communities. Periodic attempts will be made to provide the media with updates of the study and to enhance community support. The Community Relations committee will have primary responsibility for the development and coordination of publicity activities.

As funding permits, it is also recommended that each Field Center work with its community relations group to establish opportunities for face-to-face meetings as part of the retention strategy. These might include symposia on key issues facing the community; and these might be coordinated with or tied to other events in the community such as health forums, health fairs, community conventions, etc.

4. TRAINING AND SUPERVISION OF STAFF

Interviewers will be trained to answer basic questions about referrals and health education issues that may arise during the interview. While HCHS/SOL staff will not be able to provide a medical or social services consultation, respondents will inevitably have questions and interviewers must be trained to answer them and help refer respondents to services. Interviewers will also be trained to develop cultural competence skills that focus on strategies to connect and engage effectively with HCHS/SOL respondents as well as maintain a culturally appropriate examination environment (*calor/warmth*). Training and supervision of staff is discussed in more detail in the Recruiter's Manual.

4.1. Re-training and Information Sharing Between Interviewers and Field Center Staff

To maintain data collection quality, retraining opportunities or opportunities for refresher courses will be developed. HCHS/SOL will also create telephone and internet forums for exchange and conversation between staff across each site. This will ensure that ideas and strategies for working with our communities are shared and refined across the sites.

4.2. Supervision

Throughout the entire process from initial interview to final examination or refusal, close supervision helps maximize recruitment, retention, and the rate of response for follow-up. Supervisors will record reasons for non-response, and examine performance trends by interviewer and by area. As appropriate, supervisors will initiate re-contact with refusing participants to attempt their conversion. Detailed records of all contacts will be maintained.

To facilitate retention, staff working in every branch of a field center including both recruitment and clinic staff, must be responsive to study participants. Calls and e-mails should be returned within 72 hours. Equipment used by study participants in their home should be picked up within 72 hours after they are no longer needed and incentives should be paid within 4 weeks.