# CHAPTER 8

# FOLLOW-UP VISITS

**Study Documents Referred to in this Chapter:**

- 400 m walk test
- SPPB
- Disability Questionnaire
- Mobility Assessment Tool (short form): MAT-sf
- Outcome Events
- Other Health Related Events
- CHAMPS
- Accelerometry
- Blood Pressure, Radial Pulse, and Weight
- Phlebotomy
- Grip Strength
- Health Related Quality of Life
- Participant Status Change
- Process Measures
- Medication Inventory
- Quality of Well Being Scale
- Health Care Utilization Questionnaire
- Cognitive Tests
- Proxy ADL Questionnaire
- Update of Contact Information
- Cancer Follow-up Questionnaire
- Assistive Device Questionnaire
- Ankle Brachial Index
- Claudication – Follow up
- Napping, Caffeine, energy Drink Inventory
- Epworth Sleepiness Scale Questionnaire
- Insomnia Severity Index
- Pittsburgh Sleep Quality Index
- Urine Collection

# CHAPTER 8

# FOLLOW-UP ASSESSMENTS

## 8.1. OVERVIEW OF DATA COLLECTION SCHEDULE

There are two types of follow-up assessments:

1. Follow-up clinic visits, occurring every 6 months;
2. Close-out clinic visit, occurring at the end of follow-up for participants who have not received a follow-up clinic visit in the past three months.

## 8.2. MASKING OF DATA COLLECTION

Guidelines for masking the collection of data are needed to minimize the possibility that staff knowledge about a participant's group assignment will differentially affect measurements in the two groups. The study goal is to observe the basic masking principles in the collection of all study data including:

a) Study Outcomes - This is the information collected by the Outcomes Interviewer on the Study Outcomes Forms and includes major mobility disability, physical performance, ADL disability, serious fall injuries, cognition, health related quality of life, health care utilization, and cardiovascular disease and deaths as defined in the LIFE Protocol. The Study Outcomes are described in detail in Chapters 16 (Physical Measurements, 20 (Outcome Events), and 25 (Interviewing).

b) Other Data - These include all other measurements, procedures, forms, questionnaires and interviews that are designed to help assess the impact of the intervention on the Study Outcomes, e.g. process measures.

Study sites must provide clinic settings and staffing patterns that will support the masking of data collection. This ideal may be difficult to manage in practice because participants are not masked to their intervention assignment and thus may reveal this information themselves. The following principles are recommended for masking in LIFE:

1. The highest priority is given to the masking of staff that collect Study Outcomes Data, as described above. Outcomes assessment should be conducted by staff who are masked to treatment assignment.

2. Intervention tasks and measurements/interviews on a specific participant should be conducted by separate staff members.

## 8.3. SPECIAL REQUIREMENTS FOR CLINIC VISITS

Participants should be asked to report to the clinic for their follow-up visits with the following instructions:

1. Do not eat or drink anything but water for at least eight hours prior to the Month 6 clinic visit at Northwestern, Tufts, Pittsburgh, and Wake Forest and the Month 12 and 24 clinic visits at all field centers.
2. Bring all your prescription and over-the-counter medications, including vitamins and supplements, insulin, injections, and eye drops that you have taken over the past two weeks in their original containers to the visit (for recording purposes) to the Month 12 clinic visit.

*Note: Participants should take their medications as usual on the mornings of each phlebotomy visit. If a participant needs to take their medication with food, they can take the medication after the blood draw during their snack.*

3. Complete the questionnaire, which was mailed to you, about your health and use of healthcare services and bring it to the visit.
4. Wear (or bring) loose-fitting exercise clothing and sneakers.

   *Note: Clinics should have a supply of hospital-type scrubs to use if a participant is not dressed appropriately.*

5. Bring your reading glasses.
6. Bring your hearing aide.
7. Do not reveal your group assignment to your assessor.

   *Note: All participants should be reminded upon arrival at the clinic not to reveal their group assignment. Both verbal and visual aids can be used.*

### 8.3.1. Required Elements of the Follow-up Visits

The components of the follow-up visit are detailed in the LIFE Assessment Schedule, Table 8.1.

**Table 8.1. Assessments Schedule**

| Visit type | Scr | Scr | Rnd | Fu | Fu | Fu | Fu | Fu | Fu | Fu | Fu |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Visit Code | | SV1 | SV2 | F06 | F12 | F18 | F24 | F30 | F36 | F42 | Cls |
| Clinic or Home Visit number | | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| Telephone call | 1 | | | | | | | | | | |
| Activity/assessment Month | | -0.5 | 0 | 6 | 12 | 18 | 24 | 30 | 36 | 42 | |
| **Form name** | | | | | | | | | | | |
| Verbal Consent | x | | | | | | | | | | |
| Telephone screener | x | | | | | | | | | | |
| SPPB and CHAMPS Consent | | x | | | | | | | | | |
| SPPB Battery | | x | | x | x | | x | | x | | x |
| CHAMPS-18[x] | | x | | x | x | | x | | x | | x |
| Informed Consent | | x | | | | | | | | | |
| Contact Information / update | | x | | x | x | x | x | x | x | x | x |
| Demographic, social, economic | | x | | | | | | | | | |
| BP, Radial Pulse and Weight | | x | | x | | x | | x | | | |
| Waist Circumference | | x | | | | | x | | | | |
| Physical exam, Body height | | x | | | | | | | | | |
| Medication inventory | | x | | | x | | | | | | |
| Medical, hospital admission history | | x | | | | | | | | | |
| Cancer Follow-up Questionnaire[+] | | x[+] | | | | | | | | | |
| ECG | | x | | | | x | | | | | x** |
| Disability Questionnaire | | x | | x | x | | x | | x | | x |
| 400 M Walk Test * | | x* | * | x | x | x | x | x | x | x | x |
| Accelerometry[#] | | x[#] | [#] | x | x | | x | | | | |
| Process measures | | x^ | ^ | | x | | | x | | | |
| Mobility Assessment Tool, short form MATsf | | | x | | | x | | x | | | |
| 3-MS Exam and cognitive battery | | x^^ | x^^ | | | | x | | | | |
| Complete cognitive assessment[&] | | | x | | | | x | | | | |
| Quality of well being (CEA) | | | x | x | x | x | x | x | x | x | |
| Health care utilization (CEA) | | | x | x | x | x | x | x | x | x | |
| Study Eligibility Checklist | | | x | | | | | | | | |
| NEWS-A | | | x | | | | | | | | |
| Ankle Brachial Index (ABI) | | | x | | | | | x | | | x** |
| Claudication questionnaire | | | x | | | | | x | | | |
| Sleep-wake disturbances | | | x | x | | x | | x | | | |
| Pulmonary questionnaires, spirometry | | | x | x | | x | | x | | | |
| Phlebotomy/Blood Processing/Urine | | | x[@] | x[@@] | x | | x | | | | |
| Grip strength | | | x | | x | | | | | | |
| Health Related Quality of Life (HRQL) | | | x | | x | | x | | | | |
| Proxy ADL Questionnaire[%] | | | | x | x | x | x | x | x | x | x |
| Assistive Device Questionnaire[$] | | | | x | x | x | x | x | x | x | x |
| Outcome Events | | | | x | x | x | x | x | x | x | x |
| Other Health Events Questionnaire | | | | x | x | x | x | x | x | x | x |

Scr=Screening visit; V=Visit; Rnd=Randomization; F=follow-up visit; Cls=Close out visit; CEA=Cost Effectiveness Analysis; [x]CHAMPS-18 can be completed during group information/screening sessions prior to SV1; [+] Cancer Follow-up Questionnaire can also be collected a subsequent follow-up visit if not collected at Screening.*The 400 m walk test can be administered either at the end of SV1 or at SV2; ^Only 1 of the measures needs to be completed immediately after the 400 m walk: Efficacy for Walking; the others should be completed at SV2; ^^3MSE, HVLT, and DSST at SV1 and computer-based battery at SV2; [#]Accelerometry is performed in all participants at each site in conjunction with the 400 m walk; [&] A complete cognitive assessment is done in a subset of participants with high probability of MCI/dementia and in a 5% random sample (see text); [@]Includes lipid and metabolic panel, and CBC; [@@]The 6-month phlebotomy is performed only at the following sites: Northwestern University, Tufts University, University of Pittsburgh, and Wake Forest University. Urine samples are not collected at the 6-month visit. [%]The proxy ADL questionnaire is administered when a participant is not available to complete a follow-up assessment. [$]The Assistive Device Questionnaire is administered by phone when a participant cannot come to the clinic or when a home visit cannot be done. ** Measures to be obtained at closeout only if the measures were missed at the scheduled follow-up or if the scheduled follow-up visit occurred more than one year to the closeout visit.

### 8.3.2. Other Elements of the Follow-Up Visit

At each follow-up visit, the participant should update their Contact Information and Medical Records Release.

### 8.3.3. Particular Aspects of the Tasks

Blood work must be obtained in a fasting state (See Section 8.3.5.). A snack should be provided for all participants after they have completed blood draw. The suggested snack is juice and a muffin.

Blood pressure should be obtained prior to blood drawing for two reasons. First, phlebotomy can be stressful to some participants and stress can raise blood pressure, and second, the arm cuff could re-open the venipuncture site.

### 8.3.4. Suggested Order of Tasks

#### 8.3.4.1. Annual Clinic Visits

A suggested order of tasks for the Annual Clinic Visits is provided below. It is imperative that the Disability Questionnaire is administered before the 400 M Walk and the Efficacy for Walking Scale (a Process Measure) is completed immediately after the 400 M Walk. Components 2-7 must be obtained in the specified order, and Update of Contact Information should be completed prior to component 8. The remaining components can be done in any order afterwards.

1. Update of Contact Information
2. Blood drawing (12 and 24 months only)
3. Snack (12 and 24 months only)
4. Disability Questionnaire
5. Accelerometry (12 and 24 months)
6. 400 m walk (follow- up form)

7. Efficacy for Walking Scale (self administered; 12 months only)
8. Urine collection and processing (12 and 24 months only)
9. Other Process measures (12 months only)
10. Review of Quality of Well Being Scale and Health Care Utilization
11. Outcome Events
12. Other Health Related Events
13. Medication Inventory (12 months only)
14. CHAMPS
15. Health Related Quality of Life (12 and 24 months only)
16. SPPB (Short Physical Performance Battery)
17. Waist Circumference (24 months only)
18. Grip Strength (12 months only)
19. 3 MS Exam and Cognitive Battery (24 months only)
20. Complete cognitive assessment (24 months only, in subset of participants)
21. Assistive Device Questionnaire (when assessment is completed over phone)
22. Proxy ADL Questionnaire (when participant is not available)

#### 8.3.4.2. Clinic Visits at 6, 18, and 30 Months

A suggested order of tasks for these clinic visits is provided below. It is imperative that the Disability Questionnaire and the MAT-sf are administered before the 400 M Walk. Components 2-9 must be obtained in the specified order, and contact information should be updated prior to component 10. The remaining components can be done in any order afterwards.

1. Update of Contact Information
2. Blood Pressure, Radial Pulse, and Weight
3. Blood drawing (at 6 months only at Northwestern, Tufts, Pittsburgh, and Wake Forest)
4. Snack (at 6 months only at Northwestern, Tufts, Pittsburgh, and Wake Forest)
5. Disability Questionnaire (6 months only; this measure needs to be assessed before, <u>not</u> following, the 400 m walk)
6. Mobility Assessment Tool, short form (18 and 30 months; this measure needs to be assessed before, <u>not</u> following, the 400 m walk)
7. Accelerometry (6 months only)

8. 400 m walk (follow- up form)
9. Efficacy for Walking Scale (self administered; 30 months only)
10. Other Process measures (30 months only)
11. Review of Quality of Well Being Scale and Health Care Utilization
12. Outcome Events
13. Other Health Related Events
14. CHAMPS(6 months only)
15. SPPB (6 monthly only)
16. Sleep-wake disturbances
17. Pulmonary questionnaires
18. Spirometry
19. ECG (18 months only)
20. Ankle brachial index (30 months only)
21. Claudication questionnaire (30 months only)
22. Assistive Device Questionnaire (when assessment is completed over phone)
23. Proxy ADL Questionnaire (when participant is not available)

#### 8.3.4.3. Clinic Visits at 42 Months and Close-Out

The Close-Out visit is completed only if there has been no follow up visit in the past 3 months. These visits are abbreviated, as per the Assessment Schedule. The order of tasks suggested for the earlier clinic visits should otherwise be followed.

For the close-out visit, an ECG and/or ankle brachial index should be completed if the test was missed at the earlier visit or if it was not done within the past year.

### 8.3.5. Problems with Collecting Fasting Blood

Blood is required to be collected in the fasting state. Clinic staff may experience difficulty with this requirement due to two problems:

Staff may not be able to obtain blood, despite their best efforts. If there are two unsuccessful venipunctures, staff may schedule the participant to come back to the clinic on another day to draw blood if the participant is willing. Or, if the participant is unwilling to allow further attempts at another visit, the blood collection will have to be foregone.

A participant states that they have not been fasting for the required period of time for blood draw (at least eight hours). In this case, the participant could a) be

allowed to complete all other aspects of the visit and be rescheduled for a fasting blood draw at another time; or, b) the visit could be completed and the blood drawn non-fasting. The second option should be used only when clinic staff persons are reasonably sure that the participant will NOT return for fasting blood draw, since not all of the blood analyses will be affected by food intake. Always consider the participant's retention first when asking her or him to return on another day for a blood draw.

Further discussion of this issue is found in Chapter 13, Biological Specimen Collection.

### 8.3.6. Time Windows

A time window is the period of time surrounding the target date during which time the follow-up assessment should be initiated. Windows around follow-up dates are needed for the scheduling system and to minimize within person variability. All follow-up assessments (and windows) are based on the anniversary date of randomization.

The window for scheduling the follow-up clinic visits is 8 weeks total (4 weeks prior to the anniversary date and 4 weeks following). The time between follow-up clinic visits should be no shorter than 5 months and no longer than 7 months.

If the participant is in the hospital or indicates that he or she is otherwise unable to come to the clinic, LIFE attempts to complete the assessment at another time within the 8-week window; if possible, LIFE waits at least one week after hospital discharge to complete the assessment. Since participants who are acutely ill may subsequently die, LIFE attempts to determine their self-reported major mobility disability during the initial contact, to minimize potential losses to follow-up; this information is used if the participant subsequently dies or refuses to complete the follow-up assessment.

Ask the participant, "At the present time, do you need help from another person to walk across a small room? (Yes/No)".
If necessary, proxy respondents should be contacted to ascertain information regarding the participants' mobility status. Ask the proxy, "At the present time, does [participant] need help from another persons to walk across a small room?" (Yes/No).

A scheduling/tracking database has been developed as part of the study data management system to assist clinics in observing these timeframes.

#### 8.3.6.1. Missed Data Collection Windows

Considerable attempts should be made to schedule a participant for the follow-up assessments within the time windows described above. It is suggested that at least five telephone calls should be made at different dates and times.

If a data collection window is missed, the data can either be collected "out-of-window" or the data may be missed completely. In general, missed data should be avoided. Data collected out-of-window are better than no data.

#### 8.3.6.2. Missed Clinic Visits

Visits and contacts should be defined by the closest target date. For example, a Month 6 visit should not be conducted after 9 months, since after 9 months the closest target date is the Month 12 visit. Instead, the clinic should focus on scheduling the Month 12 visit in the specified window.

When all attempts to schedule a participant for a follow-up assessment within the timeframes designated above have failed, a "Missed Visit" form should be completed. Note, all attempts at phone contact should be logged in the participant's chart. Normally, five phone calls should be attempted before a Missed Visit report is completed. Proxy's and alternative contacts should also be tried.

#### 8.3.6.3. Out-of-Window Clinic Visits

On occasion, a participant may need to schedule his (her) follow-up assessment weeks or days outside of the specified window, e.g. for a vacation out of town. This is acceptable. All data should be collected at these visits even though the visit falls outside the specified window. However, the completion of the visit will not contribute to within-window follow-up rates. No special form needs to be completed to designate this visit as an "out-of-window visit". The database can determine this based on the actual visit date and the anniversary date. The Visit Code that should be recorded in the header of all the data forms is the visit code closest in time. For example, if a participant reports for their first follow-up clinic visit 8 months after randomization, the Visit Code that should be recorded is 6, indicating that the clinic conducted the Month 6 assessment.

### 8.3.7. Data Collection Priorities

The priorities for data collection should be kept in mind when establishing the order for completion of tasks during a Follow-up Clinic Visit.

### 8.3.7.1. Data Collection Priorities for Follow-up Clinic Visits

The data collection priorities for follow-up clinic visits are listed in Table 8.2. Priorities are grouped in Categories A-C, reflecting the order of their importance, with category A indicating the highest priority measures. Within each category, the specific tasks are also listed in their order of importance.

**Table 8.2. Data Collection Priorities for Follow-up Clinic Visits**

| Category A | Category B (annual) | Category C |
|---|---|---|
| 1. 400 m walk<br>2. Outcome Events<br>3. Other Health Related Events<br>4. Disability Questionnaire<br>5. SPPB<br>6. Cognitive tests<br>7. CHAMPS<br>8. Quality of well being, health care utilization<br>9. Blood Pressure, Radial Pulse, Weight<br>10. Phlebotomy<br>11. Accelerometry<br>12. Spirometry<br>13. The Mobility Assessment Tool (short form): MAT-sf<br>14. Cancer Follow-up Questionnaire (if not already collected at an earlier visit) | 1. Sleep-wake disturbances<br>2. Pulmonary questionnaire<br>3. Grip strength<br>4. Health related quality of life measures<br>5. Process measures<br>6. Medication Inventory<br>7. ECG, Ankle brachial index<br>8. Claudication questionnaire | Ancillary Studies |

### 8.3.7.2. Incomplete Data at the Annual Visit

Occasionally, a participant will be unable to complete the entire set of tasks during a follow-up clinic visit. Possible reasons for this include participant refusal and inadequate staffing. If a particular task is missed or incomplete and the participant is willing, every effort should be made to obtain these data/measurements even if they are collected outside the visit window.

If a follow-up clinic visit is completed over more than one day, all assessments that were completed for that visit should be indicated on the visit checklist. The date entered on each data form should reflect the actual date that the assessment was completed.

The most critical elements of the clinic visits are the 400 m walk test, Outcome Events, Disability Questionnaire and SPPB. If you must prioritize the tasks due to the participant's time constraints, complete these tests. See Table 8.2 for other levels of prioritization. Remember, full data are best, and partial data are

better than none at all. Whether assessments have been completed or not should be noted on each visits' visit checklist. When components are missed, the reason should be noted on the checklist.

### 8.3.7.3. Data Collection from Participants Who Have Relocated

There may be occasions when randomized participants relocate to a geographic area outside of the Study site. There are at least two approaches to collecting data from these participants.

Collection of data by telephone. The highest priority should be to complete the Disability Questionnaire, the Outcome Events form, and Assistive Device Questionnaire, followed by other instruments that can be completed over the phone. Other instruments that can be administered over the phone include the Update of Contact Information, CHAMPS, Sleep-Wake Disturbances, Pulmonary Questionnaire, Claudication Questionnaire, HRQL, and selected process measures.

Explore the possibility of scheduling the follow-up clinic visit when the participant will be returning to the area for a visit with relatives or friends.

### 8.3.7.4. Data Collection at Home Visits or via Telephone Interviews

If the participant is unable or unwilling to come to the clinic, home or institutional visits should be scheduled. Every effort should be made to personally interview and assess all participants. In the event that an in-person assessment is not possible, a telephone or proxy interview should be completed. Data collection priorities for these alternative assessments are the same as for follow-up clinic visits with the following exceptions:

Home Visit: the 400 m walk test will not be completed unless a safe and acceptable course can be set up. The highest priority should be to complete the Disability Questionnaire, Outcome Events and SPPB.

Telephone Interview: the performance-based tests and blood draw will not be completed. The highest priority should be to complete the Disability Questionnaire and Outcome Events, followed by other instruments that can be completed over the phone.

Appendix A, Home Visit Protocol, provides a complete description of the rationale, procedures and supplies that are necessary for conducting these visits.

### 8.3.7.5. Proxy Contact

If participants are not able to answer for themselves, administer the Proxy ADL Questionnaire, the Assistive Device Questionnaire, the Outcome Events

Questionnaire and associated events tracking forms (or alternative site-specific forms as discussed in MOP Chapter 20), the Quality of Well Being Scale (QWB), and the Health Care Utilization Questionnaire (HCU) to the proxy. If the site prefers, the QWB and HCU may be mailed to the proxy for completion and returned to the clinic.

## 8.4. REIMBURSEMENTS/INCENTIVES

Participants should be reimbursed for their time and travel at the completion of the follow-up clinic visits and the close-out visit. Reimbursements are not to be used as an incentive to attend intervention sessions. Instead, it should be stressed that the most critical element for attendance is the follow-up visit.

Throughout the course of the study, incentives will be provided to the clinics to use with their own discretion to motivate participation and retention (see Retention Chapter 9). These may include, but are not limited to coffee mugs, t-shirts, skin care products, etc.

## 8.5. TERMINATION

A participant will be deemed "terminated" only when all avenues of contact with the participant have been exhausted. Causes of termination may include: participant refusal, moved from area, or death. The Participant Status Change form is completed when one of these conditions has been met. Once a Participant Status Change form is completed, the database will no longer query the clinic to schedule this participant. However, if a participant is terminated due to refusal, it may still be possible to track some events using public records, e.g., obituary notices.

Important! Participants are not terminated during the study because they have experienced an outcome event (e.g., heart attack) or because they are "lost". See discussion below on "lost-to-follow-up".

## 8.6. KEEPING TRACK OF AND FINDING LOST PARTICIPANTS

It is absolutely critical to maintain contact with every participant randomized. One of the most important overall indicators of the quality of our study will be our follow-up rates. Achieving outstanding follow-up rates starts with randomization. Be careful who you randomize! Remember, all randomized participants will be followed and contribute data to analyses, even if they do not attend or adhere to interventions. Be sure to obtain good contact information on all participants at baseline and update it every six months.

Note that you should attempt to get a Social Security Number (SSN) from each participant. Make it clear to each participant that the SSN will not be shared with anyone, but that it helps us in tracking them. This is especially true when using the National Death Index (NDI). The NDI will be used to track lost participants.

A participant should not be declared as "lost-to-follow-up" until all reasonable efforts have been made to locate him (her) over a period of time. Occasionally, a participant who may be considered "lost" by a clinic, re-appears. For this reason, no participants will be terminated from LIFE for reasons of "lost-to-follow-up" during the course of the study. A Participant Status Change form should be completed during the location process to document all efforts made to contact the participant. Enter this form into the database at the end of the study.

At the end of the study, we will compute the numbers of persons for whom contact was lost during the study.

### 8.6.1. Hints for Obtaining Good Contact Information

The first step in finding lost participants is getting good contact information in the first place. Here are some hints for getting good contact information:

- Family and in-laws are better than friends, but some of both are good. We suggest that you get information on at least two relatives and two friends.
- Be sure to get middle initials and/or full names, especially if a common name.
- Get the spouse's name.
- Get the maiden name.
- If the participant doesn't have a phone and gives a friend's phone, get the friend's address.
- If the participant doesn't know an address, get a street name and a cross street nearby.
- Ask how a contact might be listed – they might be listed under a husband's name, for example.
- If the participant isn't sure of a listing, look it up yourself right away.
- Document everything that the participant says; sometimes seemingly extraneous information is useful.
- If a participant says they don't have anyone for a contact, prompt them by asking for parents, siblings, cousins, aunts, girlfriends, boyfriends, neighbors, friends at work, or just friends they "hang" with.

### 8.6.2. Suggested Steps to Locating Lost Participants

If you are attempting to find a participant and can't, don't let the trail go cold. You should start work to find the participant right away. Here are some suggested steps to find lost participants (and to trace contacts as well):

- Look in the phone book.
- Look in the city directory and criss cross or Polk directories (directories that allow you to look up an address).
- Look under name, address and phone number and look up workplace.
- Look up neighbors and call them.
- If the participant has an unusual last name, look up and call others of the same name using the phone book.
- Call the workplace and ask for the participant's department, ask for friends there.
- Look back for old contact information; this may yield persons still in touch with the participant.
- Always call a disconnected number twice over a period of several weeks to verify that it is disconnected. Some people have their number only temporarily disconnected.

**Internet resources**

There are now a variety of internet resources that may be helpful. They include resources to use to screen for death of a participant. These are listed below.

**Obituaries**

- http://www.Legacy.com - National database of recent newspaper obituaries
- http://www.obituaryregistry.com - National database of newspaper obituaries and death notices
- http://www.obitcentral.com/obitsearch - Links with different obituary search engines, including the two above. Click on "obituary search engines" to be linked to six engines that will search different regions and list all articles, birth announcements, death notices, and obituaries found in newspapers. The article will be pulled up and the name will be highlighted.
- http://www.rootsweb.com/~obituary - Daily index of obituaries from around the world. Will give citation where obituary may be found, not the obituary itself.

## Social Security Death Index (SSDI)

Most genealogy websites link to SSDI. Each has different sorting software for it and presentation. This sorts by name documented by the Social Security Administration at time of death.

- http://www.ssa.gov - Social security look-up
- http://www.ancestry.com/search/rectype/vital/ssdi/main.htm or
- http://www.ancestry.com/ssdi

## Military Locator

- http://www.militarycity.com

## Directories for Telephone and Addresses

These sites may be used for phone numbers and addresses. Many include a reverse loop by phone number, partial phone number (criss crosses), addresses, and/or email addresses, as well as international directories.

http://www.teldir.com - This site will link to other directory websites.

- http://www.anywho.com - Any who by AT&T
- http://www.infospace.com
- http://www.people.yahoo.com
- http://www.bigbook.com
- http://www.superpages.com- GTE super pages
- http://www.whowhere.com - Who, where by Lycos
- http://www.contractjobs.com/tel - Telephone directory

## State Vital Records

- http://www.vitalrec.com - This site gives the addresses and costs by state for obtaining death certificates.

## APPENDIX A: HOME VISIT PROTOCOL

**Definition**: A home visit is any visit outside the LIFE clinic.

A home visit may be done at the participant's home or other health care facility with the participant's and/or health care facility's permission. Home visits must be rare and infrequent and may not be used regularly to take place of a clinic visit.

**Purpose:** The purpose of the home visit is to collect outcome data at the semi-annual clinic visit and to retain and/or re-engage participants in the study.

The following general guidelines have been developed for out-of-clinic visits:

- Safety for the study participant as well as the staff is of utmost priority in the clinic's decision as to whether a home visit is appropriate for collection of data. **If there are questionable safety issues, DO NOT ATTEMPT A HOME VISIT.**
- Home visits may be completed for "lost-to-follow-up" participants to encourage them to return to the clinic for outcome measurements.
- Scheduled honorarium may be given to the participant at a home visit if study outcome measures are completed (except for 400 m walk test).
- All guidelines regarding collection of outcome measures must be followed (such as fasting blood draws).
- Only standardized LIFE equipment must be used for the home visit.
- Weight and blood pressure measurement "by report" is not acceptable as outcome data. Only measurements done by certified study staff will be acceptable outcome data. If unable to collect, data are considered missing and an incomplete visit form must be completed for missed outcome measures.

### Equipment & Supplies Needed for Home Visits

- Cooler with Cold packs
- Gloves
- Blue Chux
- Blood drawing supplies and vacutainers to collect samples (alcohol pads, 2 x 2 gauze, needles, tourniquet, bandaids, portable biohazard/sharps container, and 2x2 gauze). Used items will need to be returned to the clinic for proper disposal in biohazard/sharps container. Follow your local IRB regulations concerning blood collection at home.
- LIFE Scale
- Sphygmomanometer and 4 appropriately sized cuffs for measurement of blood pressure.
- Gulick II tape measure
- Jaymar grip strength dynamometer

- Premeasured 3 and 4 meter chain and masking tape to measure and mark SPPB walking course.
- Stopwatch
- Data Collection Forms
- Medical release forms, if applicable
- Pens, pencils, cosmetic marker
- Snacks (cheese or peanut butter crackers, orange juice, hard candy, etc) - in case of participant has a hypoglycemic episode or is participating in blood draw. Snacks should be stored in a separate lunch bag from the rest of the supplies
- Redi-Measure Distance Measuring Wheel and cones for 400 m walk (only if feasible)
- Laptop computer
- Accelerometer and belt
- Spirometer, spirettes, and EasyOne adapter cable
- MIP gauge and disposable mouthpieces

## DATA COLLECTION PRIORITIES FOR HOME VISITS (Table 8.3.)

| Category A | Category B | Category C |
|---|---|---|
| Disability Questionnaire<br>400 M Walk (only if feasible)<br>SPPB<br>Outcome Events<br>Other Health Related Events<br>Cognitive tests<br>CHAMPS<br>Quality of Well Being Scale, Health Care Utilization<br>Blood Pressure, Radial Pulse,Weight and Waist Circumference<br>Phlebotomy<br>Accelerometry<br>Spirometry<br>The Mobility Assessment Tool (short-form): MAT-sf<br>Cancer Follow-up Questionnaire (if not already collected at an earlier visit) | Grip Strength<br>Health Related Quality of Life<br>Process Measures<br>Medication Inventory | Ancillary Studies |