Introduction:
The TBI model systems have established best practices intended to maximize follow-up and suggest additional strategies that will help with locating those participants who are difficult to find and may eventually be considered lost to follow-up.

Purpose:
By outlining consistent steps that are to be performed for each TBIMS participant, the lost to follow-up rate should be lower thus maximizing follow-up.

Scope:
All TBIMS centers including the TBIMS longitudinal follow-up centers that conduct Form II follow-ups.

Responsibilities:
The Guidelines and Strategies for Maximizing Follow-Up should be used as the best practices for follow-up for the TBIMS.

Procedural steps:
• Attempt to follow-up should begin on the follow-up window open date.

• If the data collector cannot reach a subject after 2 weeks of attempted contact, the Best Practices methods 1-8 are to be employed until the subject is reached or until the window closes.

• Best Practice #1 can be terminated or modified if no useable phone number is available or if the person indicates that he/she should only be contacted at specific times.

• If the participant requests a mailed questionnaire, Best Practice #1 can be terminated unless it becomes clear that a mail packet will not be returned. In the latter scenario, phone calls should be re-initiated to follow-up on mail packet or determine willingness to complete phone interview.
At the discretion of the data collector, a mail packet could be initiated if certain that the phone/address are correct and the participant is not responding to phone messages. Also could send mail packet to family member/support person, same reasoning.

Best Practices #2-8 should be repeated at least twice during the window if useable contact information is not obtained.

The Best Practices Methods (#1-8 listed below) are the minimum expectations for methods that are to be employed to find and interview participants.

These methods can be applied in any sequence to best fit the circumstances of each center.

Cases lost to follow-up prior to 7/1/2007 must have a completed Guidelines and Strategies for Maximizing Follow-Up Form kept on file at the center for every participant entered into the National Database as Lost. Cases entered into the database as lost to follow-up on or after 7/1/2007 are required to have the equivalent form completed in the database.

The “Additional Strategies” listed on pages 35 are recommended for each site to consider as it applies to them, but are not required.

**Best Practices Methods: (required)**

1. **Phone Contact**
   - 4 attempts during normal business hours (at different times of the day)
   - 4 attempts during weekday evenings (on different days of the week)
   - 4 attempts during weekends

2. **Directory Assistance**
   - Call directory assistance (411) in last known city of residence, and surrounding areas, to obtain updated information about subject and contacts.

3. **Internet Sites**
   - Superpages.com, Anywho.com, theultimates.com
   - Search engines (ex., Google and Yahoo)

4. **Send Letter to Subjects and Contacts**
   - Letter to subject at last known address
   - Letter to contacts at last known address
   - Send all letters via first class mail, marked ‘Forwarding & Address Correction Requested’, so that you can make note of any address changes.
5. **Hospital Information/Medical Records**
   - Check for post-discharge contact and updated information in the outpatient section of medical record.
   - Check appointment schedules, outpatient clinic lists, and/or other hospital database for new information
   - Ask social workers, clinic staff, and other hospital employees involved with the subject’s care for additional or updated information.

6. **Death Search**
   - Contact Social Security Administration at (800) 772-1213
   - Local online newspaper obituary search

7. **Inmate Search**
   - County Jail
   - State Prison – Department of Corrections (See link to Online Offender Databases in the syllabus under Residence [RES])
     - Info required: full name and **either** SS# or DOB
   - Federal Prison System
     - (202) 307-3198
     - Call 10:30am to 4:30PM EST
     - Info required: full name, DOB, and SS#

8. **Location Services**
   - Accurint, Comserv, and/or TLO (formerly Merlin) are recommended by many sites (there is a fee involved for these services).

**Additional Strategies for Maximizing Follow-Up: (Suggested)**

**Before Discharge from Rehabilitation Facility**
- Ask participant to tell his/her contacts that the study site has been given their name, the reasons why, and that they may be contacted in the future.
- Give business cards, magnet, or pens with logo/name of site to participant and/or contacts.
- Note the participant’s professional organizations (bar associations, licensures, etc.)
- Ask for a current list of healthcare providers for participant, especially primary care physician. Obtain permission/signed release forms from the subject if assistance in information gathering is needed in the future.

**Hospital Contacts**
• Contact billing office and/or hospital pharmacy for recent contact information and address changes.
• Work with doctors to schedule rehab appointments that will coincide with follow up windows.
• Regularly check clinic appointment schedules for opportunities to make contact with subject. Even if window is not open at the time of the clinic visit, this is a good time to confirm current contact information and just say hello.

Possible Contact Updates
• Contact Voter Registration/Electoral Registries
• Contact Public Health Nurses in last known county of residence.
• Contact VNA (Visiting Nurse Association) or CCS (California Children’s Services – participant must be 18 or under at time of injury) if available in your area.
• Check nursing homes in last known area of residence.
• Contact the Vital Statistics Department/Registry of Births, Deaths, and Marriages (there is a fee to obtain this information) http://www.vitalrec.com/

Phone/Mail Contact
• Mail reminder cards a few weeks before window opens, to let them know they will be hearing from you soon.
• Mail handwritten, hand-addressed note to participants who have not responded to phone calls or mail-outs.
• Send ‘attempt to contact’ letters via Certified mail.
• Ask rehab doctor for updated contact information, and/or have doctor contact via mail/phone.
• During follow up calls, ask participant if they have plans to move, or any new contact information, such as a new work, cell phone number, or email address.
• When attempting to reach participant by phone for follow up data collection, use a line with a TBI Model System Identifier, rather than using a blocked identifier (as is the case with many hospital lines).
• Have the same staff member complete all follow up calls, in the interest of building rapport and trust between the data collector and the subject. If possible, have the person who consented the subject also complete that subject’s follow up.
• Generate a monthly contact call list based on injury date. For first five years the call should be six months post injury date. So, for example, if a person was injured in January, their contact call would be in the month of July. After the fifth year of participation, change the call to the month of injury, so that in “off years” the participant is called in what would be the halfway point of their window. When the list is generated, if you’ve had recent (within 3 months) contact with a
subject, no need to call that person unless they've been difficult to track in the past.

Other methods

- Develop monthly or quarterly newsletters for distribution to all the subjects enrolled in your site. Send these via first class mail, so that they will be returned to your site with changed address information.
- Send birthday and/or holiday cards (also sent first class).
- Give gift certificates or monetary rewards for completing follow up data collection, or for notifying site of an address/phone number change.
- Discuss status of subject tracking at weekly/monthly meetings. Review call attempts, lost subjects, open and closed windows, and additional strategies for data collection.
- Call on a rainy day (especially Saturday)!

Training requirements:
Follow-up strategies will be discussed at the Data Collectors in-person conferences and is a possible topic for the quarterly data collectors teleconferences.

Compliance:

All TBIMS centers and the TBIMS longitudinal follow-up centers are required to adhere to this procedure. The Guidelines and Strategies for Maximizing Follow-up Forms on all participants submitted to the TBIMS National Database as lost to follow-up as of 1/1/07 will be reviewed during the NDSC Quality Support Visits. The electronic version of the Guidelines and Strategies for Maximizing Follow-up Forms (pop-up window) was implemented on 07/01/2007, and as of that date, the electronic version of this form will be reviewed during NDSC Quality Support Visits.

References:


History:

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<td>4/1/2006</td>
<td>Version used to create this SOP</td>
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<tr>
<td>9/16/2008</td>
<td>Transferred to SOP template and approved by SOP Review Committee</td>
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<tr>
<td>12/12/2008</td>
<td>Added that follow-up should start when window opens. Review approved by Planning Committee and Project Directors</td>
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**Traumatic Brain Injury Model Systems National Data and Statistical Center**

**STANDARDIZED OPERATING PROCEDURE 105a**

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<tr>
<th>Date</th>
<th>Description</th>
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<tbody>
<tr>
<td>10/1/2010</td>
<td>Added that cases lost to follow-up on or after 7/1/2007 are required to have Guidelines and Strategies for Maximizing Follow-Up data entered in the database</td>
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<tr>
<td>10/1/2013</td>
<td>SOP Revised to include the information from the Guidelines and Strategies for Maximizing Follow-up Form</td>
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<tr>
<td>8/21/2014</td>
<td>Clarification was made regarding how to complete procedural steps for required Best Practices. Statement added that Best Practices (steps 2-8) should be repeated at least twice during the window if useable contact information is obtained. Phone number for Federal Prison updated. Bullet added to Additional Strategies (generate a monthly contact call list to keep in touch with participants in between follow-up years).</td>
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<tr>
<td>2/19/2018</td>
<td>Added “Mail handwritten, hand-addressed note to participants who have not responded to phone calls or mail-outs.” to Phone/Mail Contact strategies.</td>
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<tr>
<td>2/11/2020</td>
<td>SOP Reviewed</td>
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**Review schedule:** At least every 5 years.