

**Burn Model System  
National Data and Statistical Center**

**STANDARD OPERATING PROCEDURE (SOP) #103**

<b>SOP #103</b>	<b>Title:</b> Guidelines for Maximizing Follow-up	
<b>Approved:</b> BMS Project Directors		<b>Effective Date:</b> 4/14/2014
<b>Attachments:</b> Guidelines and Strategies for Maximizing Follow-up Form		<b>Revised Date:</b>
<b>Forms:</b> Guidelines and Strategies for Maximizing Follow-up Form		<b>Review Date:</b>
<b>Review Committee:</b> BMS Project Directors		

**Purpose:**

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*SOP #103 Guidelines for Maximizing Follow-Up* implements procedural steps for contacting BMS participants and maximizing follow-up.

**Scope:**

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Applies to all BMS centers including any BMS longitudinal follow-up centers, if funded.

**Responsibilities:**

***For Implementation:***

- BMS staff responsible for locating and following up with ongoing participants in the BMS National Database (e.g., BMS researchers or clinicians, research assistants, and study coordinators).

***For Oversight:***

- Directors of BMS Centers and staff from the Burn National Data and Statistical Center (BMS NDSC).

**Procedures**

***Initiating Follow-Up***

1. Data collectors should attempt to contact the participant and collect data beginning on the follow-up window open date.
2. If the data collector cannot reach a subject after **2 weeks** of attempted contact, the *BMS National Database Follow-Up Methods 1-8* are to be employed until the subject is reached or until the window closes. Methods 1-8 are the minimum expectations to be employed to find and interview participants. These methods can be applied in any sequence to best fit the circumstances of each center. Centers who have participants located in

another country should use those strategies they have identified as best practices for locating international participants.

3. Cases entered into the database as lost to follow-up on or after 4/14/2014 are required to have the Lost to Follow-up form completed in the REDCap database.

### ***Required BMS National Database Follow-Up Methods***

Data coordinators should use the *Guidelines and Strategies for Maximizing Follow-Up Form* (attached) to document follow-up steps taken.

#### *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, facebook.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
  - Info required: full name and either SS# or DOB
- Federal Prison System
  - (202) 307-3126
  - Call 10:30am to 4:30PM EST
  - Info required: full name, DOB, and SS#

8. *Location Services*

- Accurint is recommended by some centers (there is a fee involved for these services). These require IRB approval to use.

**Training requirements:**

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None

**Compliance:**

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All BMS Centers, longitudinal follow-up centers, and the NDSC will comply with this procedure.

**References:**

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None

**History:**

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None

**Review Schedule:**

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At least every 5 years.

## Guidelines and Strategies for Maximizing Follow-up Form

As of 4/14/2014 this form must be completed and kept on file at the center for every participant that is entered into the REDCap National Database as lost to follow-up (that is they could not be located or they did not respond to contact).

### PROCEDURE for FOLLOW UP CONTACT

Window Opens: \_\_\_/\_\_\_/\_\_\_ Window Closes: \_\_\_/\_\_\_/\_\_\_ Subject ID #: \_\_\_\_\_  
 Follow-up: \_\_\_\_\_

#### 1. PHONE CONTACT Not Applicable, No Good Phone Numbers Success?

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 \_\_\_\_\_

Staff initials      Date completed

#### 2. DIRECTORY Not Applicable, International Subject Success? ASSISTANCE

Call directory assistance (411) in last known city of residence, and surrounding areas, to obtain updated information about subject and contacts. \_\_\_\_\_

Staff initials      Date completed

#### 3. INTERNET SITES Not Applicable, International Subject Success?

Superpages.com, Anywho.com, theultimates.com, facebook.com

Search engines (ex., Google and Yahoo) \_\_\_\_\_

Staff initials      Date completed

#### 4. SEND LETTER TO SUBJECT and CONTACTS Success?

Letter to subject at last known address \_\_\_\_\_

Letter to contacts at last known address \_\_\_\_\_

Staff initials      Date completed

*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** Success?

Check for post-discharge contact and update information in the outpatient section of medical record. \_\_\_\_\_

Check appointment schedules, outpatient clinic lists, and/or other hospital database for new information. \_\_\_\_\_

Staff initials      Date completed

**6. CONSULT HOSPITAL STAFF INVOLVED WITH PATIENT** Success?

Ask social workers, clinic staff, and other hospital employees involved with the subject's care for additional or updated information. \_\_\_\_\_

Staff initials      Date completed

**7. DEATH SEARCH**    Not Applicable, International Subject  Success?

Contact Social Security Administration at (800) 772-1213 or <http://ssdi.rootsweb.ancestry.com/> \_\_\_\_\_

- need SS #
- Determine subject's living status

Local online newspaper obituary search \_\_\_\_\_

Staff initials      Date completed

**8. INMATE SEARCH**    Not Applicable, International Subject  Success?

County Jail \_\_\_\_\_

State Prison – Department of Corrections \_\_\_\_\_

- Info required: full name and either SS# or DOB \_\_\_\_\_

Federal Prison System \_\_\_\_\_

- (202) 307-3126
- Call 10:30am to 4:30PM EST
- Info required: full name, DOB, and SS# \_\_\_\_\_

Staff initials      Date completed

**9. LOCATION SERVICES**    Not Applicable, International Subject  Success?

Accurant and/or Comserv are recommended by many sites (there is a fee involved for these services). \_\_\_\_\_

Staff initials      Date completed

**UPDATED CONTACT INFORMATION**

**PATIENT INFORMATION**

Street Address: \_\_\_\_\_

City, State, Zip: \_\_\_\_\_

Home #: \_\_\_\_\_ Cell #: \_\_\_\_\_ Work #: \_\_\_\_\_

Email address: \_\_\_\_\_

Additional Comments/Information: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

**CONTACT INFORMATION**

Name/Relation to subject: \_\_\_\_\_

Street Address: \_\_\_\_\_

City, State, Zip: \_\_\_\_\_

Home #: \_\_\_\_\_ Cell #: \_\_\_\_\_ Work #: \_\_\_\_\_

Email address: \_\_\_\_\_

Additional Comments/Information: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

**CONTACT INFORMATION**

Name/Relation to subject: \_\_\_\_\_

Street Address: \_\_\_\_\_

City, State, Zip: \_\_\_\_\_

Home #: \_\_\_\_\_ Cell #: \_\_\_\_\_ Work #: \_\_\_\_\_

Email address: \_\_\_\_\_

Additional Comments/Information: \_\_\_\_\_  
\_\_\_\_\_

## ADDITIONAL STRATEGIES FOR MAXIMIZING FOLLOW UP CONTACT

### **Before Discharge from BMS Facility**

- Ask participant to tell his/her contacts that the BMS clinical center has been given their name, the reasons why, and that they may be contacted in the future.
- Give brochures, business cards, magnet, or pens with logo/name of clinical center 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.
- Make sure the first interview is positive so that participants are willing to be involved in follow-up research.

### **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 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.
- Send 'attempt to contact' letters via Certified mail.
- 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.
- 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.

### **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.
  - Include summaries of BMS published studies or presented abstracts to participants can see how their data is being used. Feeling informed about the study's progress can help participants feel involved and stay interested.
- Send birthday and/or holiday cards (also send 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.

### **Potential Strategies for International Participants**

- Search engines/sites for participants from Mexico
  - <http://www.mexicoweb.com.mx/>
  - <http://www.search-engine-index.co.uk/country/mexico.asp>
  - <http://www.hi5.com>
  - <http://www.paginasblancas.com.mx/>
- Call the hospital in Mexico/other country that the patient originally came from or was transferred back to. See if they have any special connections with foundations or people there to call ask for help.