

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

STANDARD OPERATING PROCEDURE (SOP) #103

SOP #103	Title: Guidelines for Maximizing Follow-up	
Approved: BMS Project Directors	Effective Date: 4/14/2014	
Attachments: Guidelines and Strategies for Maximizing Follow-up Form	Revised Date: 7/29/2024	
Forms: Guidelines and Strategies for Maximizing Follow-up Form	Review Date: 10/23/2020	
Review Committee: BMS Project Directors		

Purpose:

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

Scope:

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. Determine most recent contact information by checking medical record or other available sources.
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. Except in the case of “minimal contact participants” (see #3, below, for more detail),

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. Minimal Contact Participants: Those participants for whom a center has no current contact information on file and those who did not respond to their last two surveys can be considered “Minimal Contact Participants”. For these participants, less intensive follow-up methods can be applied and should involve:

Phone Contact (if accurate contact number is on file)

- 1 attempt during normal business hours (at different times of the day)
- 1 attempt during weekday evenings (on different days of the week)
- 1 attempt during weekends
- Contact secondary contact information on file (contacting friends or family members provided by participants during enrollment process, if IRB approved)

Send Letters or Emails to Participants and Contacts (if accurate email or physical address is on file)

- Emails to address provided by participant
- Letter to participants at last known address

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.

Location Services

- If location services are used, search once for each minimal contact participant.

Centers should track their efforts for locating participants for follow-up according to their individual needs and capacity. There is a REDCap database that can be used for documenting follow-up efforts, but its use is not required.

Required BMS National Database Follow-Up Methods

Data coordinators can use the *Guidelines and Strategies for Maximizing Follow-Up Form* (attached) to document follow-up steps taken. Prior to taking these steps, check that most recent contact information is on file by checking in the medical record or other sources available at the BMS Center.

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. *Internet Sites*

- Superpages.com, Anywho.com, theultimates.com, facebook.com
- Search engines (ex., Google and Yahoo)

3. *Send Letters or Emails to Participants and Contacts*

- Emails to address provided by participant
- Letter to participants at last known address
- Letter to contacts at last known address
- Send all physical letters via first class mail, marked 'Forwarding & Address Correction Requested', so that you can make note of any address changes.

4. *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.

5. *Death Search*

- Contact Social Security Administration at (800) 772-1213
- Local online newspaper obituary search

6. *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#

7. *Location Services*

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

Training requirements:

None

Compliance:

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

References:

None

History:

--Updated 3/10/2022 to reflect that use of REDCap database is not mandatory (to reduce burden on BMS Centers with limited staff time).
--Updated 7/19/2022 to instruct data collectors to first determine if contact information on file is most recent contact information in medical record.

Review Schedule:

At least every 5 years.

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 participant 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.

Guidelines and Strategies for Maximizing Follow-up Form

Use these methods and track using the form below or a center-specific tracking procedure.

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

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 LETTERS OR EMAILS TO Participant and CONTACTS Success?

Letter to subject at last known address _____

Letter to contacts at last known address _____

Staff initials Date completed

Send all physical 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: Use this form or similar to maintain updated contact information.

Participant 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: _____