

Lost to Follow-Up and National Report Exclusion

"Lost To Follow-Up" Protocol:

Before declaring a patient "lost to follow-up", the following steps need to be taken:

1. Confirm the hospital contact has searched by a different combination of name(s) or date of birth. For instance, search by last name only, then cross check by date of birth. Search for similar names with different spellings, etc.
2. Check with hospital to see if there is an emergency department log book. Search by patient name, date of birth, time of arrival at ED (if this information is included in EMS record), and variations on spelling (as described above).
3. Ask EMS contact to provide any additional information (e.g. name, DOB, SSN, MRN) and confirm Destination Hospital.
4. Conduct a Google search for obituaries ("name + state name obituaries"), and check www.legacy.com or www.tributes.com. If you find a match and **can be sure** it is the correct patient (same name, DOB etc.), you can enter outcomes in CARES, make a note in the Hospital Comments box, and de-identify. Generally, if the patient died the day of arrest we enter "ER Outcome = Resuscitation terminated in the ED". If the patient died <3 days post-arrest we enter "ER Outcome = Admitted to hospital" and "Hospital Outcome = Died in the hospital." Hospital hypothermia should be left blank. *If greater than 3 days, we make a note in the "Hold Comments" section but don't enter an outcome and don't de-identify.*
5. If the Location Type was Home/Residence and the patient is a John or Jane Doe, use the Reverse Address look-up feature on www.whitepages.com to try and determine patient's last name. Provide this information to the hospital and/or conduct a Google search for obituaries.

Once the above options have been exhausted, a CARES staff member will confirm the record is "lost-to-follow up", and de-identify the record. The outstanding record will then be removed from the receiving hospital's dashboard.

Exclusion from National Report Protocol:

Context: CARES requires each site to maintain high standards in their data collection methods. This includes obtaining hospital outcomes for all records. We recognize that there are exceptional cases where despite all efforts, patient outcomes cannot be located. Our goal is to ensure that the registry is as complete as possible and the audit process is consistent across all participating CARES communities.

Threshold for National Report Exclusion: Using the protocol outlined above, our expectation is that a record should rarely be coded lost-to-follow up. In order to ensure compliance from all CARES communities and that the national dataset is as complete and thorough as possible, CARES will exclude EMS agencies from the national report that have more than 1% of all records "lost to follow-up".

It is important to note that if a site is excluded from the national report, they will still have access to all of their own data and the national data for comparative purposes. As soon as the site is able to resolve the outstanding outcomes and obtain a "lost to follow-up" average of less than 1%, they will be included in the national report.

Why 1%?: CARES began collecting data in 2006, and since then CARES has been able to achieve less than 0.4% lost to follow-up for all records. Not only do we consider this to be a strength of the registry but it is proof that this high standard is achievable for the hundreds of EMS agencies and hospitals participating in CARES.

Support: CARES staff can provide guidance and support in following the protocol above. If you have any questions, please contact your CARES Program Associate for more details.