

Follow Up Policies And Procedures

I. Definition

- A. Follow-up of cancer patients is the systematic process of obtaining accurate information at least annually, on the patient's health, vital status, and progression of disease.

Follow-up information is extremely important for the following reasons:

1. To assist in the early identification of the recurrence of a cancer.
2. To assist the physician in getting former cancer patients to return for scheduled treatments and/or checkups.
3. To insure periodic examinations of former cancer patients since they are prone to develop other cancers.
4. To gather information so physicians can review various types of treatment in terms of survival.

- B. Follow-up information must be sought on analytic cases only (classes 0, 1, and 2), with the following exceptions:

1. Patients who are currently residing in foreign countries (New in NAACCR)
2. Patients whose only malignancy is carcinoma in situ of the cervix

These are not required to be followed, regardless of the class of the case.

- C. Follow-up is considered delinquent by the American College of Surgeons (ACoS) if the information is not successfully obtained and documented within 15 months of the patient's previous date of last contact. A successful follow-up rate of 90% of a hospital's analytic cases is considered in compliance with ACoS standards for an approved Cancer Program. It is best to maintain the highest follow-up rate possible; survival rates and other valuable statistical analyses are heavily dependent on accurate and timely follow-up information.

II. Follow-up information to be collected includes:

- A. The date of last contact. This is either the date of death or the most current date the patient was known to be alive.
- B. Survival status. This indicates whether the patient is alive (with or without disease) or dead (from causes related or unrelated to cancer).
- C. Present address of patient, if different from that originally recorded.
- D. Disease Status. This is information about whether the patient was ever disease free, and if so, the start date of the disease free interval.
- E. Date Last Cancer Status. This is the last time a physician reported on the status of the cancer in the patient.
- F. Recurrence information. This includes the date of first recurrence, the type of first recurrence, and the site(s) of first recurrence.
- G. Additional treatment received. This includes the type(s) and date(s) of therapy given after the last date of last contact.
- H. If dead, cause of death. This includes any autopsy information available on this patient.
- I. Method of obtaining follow-up information. This includes any change in the name or address of the primary or alternate contact persons or in the method for pursuing follow-up on the next attempt.

III. Procedures

- A. A list of all patients in the tumor registry for whom no contact has been recorded in the last 12 months can be generated using CPDMS.net.
- B. All cancer registries, even the smallest, need form letters, particularly to make physician contact. All form letters should be printed on hospital letterhead and should have the correct phone number, including extension, for the staff contact person. Be sure there is ample space to insert names, addresses, and any additional information about the patient on the form. The information request form for physicians requires a great deal of care in design. You must provide adequate information: the full name of the patient, the diagnosis clearly stated, and the date of your latest information. The data items you request must be arranged in a logical sequence and must be easily recorded. If you must secure physician permission to contact a patient, include that request on the form.
- C. It is customary in most registries to obtain physician permission to contact patients directly when contact through that physician is not possible. This permission may be obtained in several ways:
1. Blanket permission may be granted by action of the medical staff.
 2. In some hospitals, blanket permission to contact patients is not granted for any number of reasons. It then becomes necessary to obtain permission on a case by case basis.
- D. Follow-up information on all patients named on the follow-up control list should be pursued in an orderly and stepwise fashion:
1. Pull and review charts or any internal lists which would indicate these patients' vital status and/or disease status.
 2. Identify any patients who have returned to this hospital and record the most current date of last contact. Review these charts for any other follow-up information related to the patient's cancer progression or treatment and update the patient's record in CPDMS.net.
 3. Send letters to the primary following physician designated for the patients remaining on the list. Labels can be generated by CPDMS.net to the appropriate contact person for each patient needing follow-up.
 4. When letters are returned with current information about your cancer patients, update the patient's record in CPDMS.net.
 5. If no new information is available, or no response at all is returned, pursue alternate contacts for information about these patients. These may be other physicians, relatives or friends of the patients, or the patients themselves.
 6. If there are any patients remaining on the control list for whom no current information has been located, you may be able to confirm the patient's vital status through various public agencies: The Department of Motor Vehicles, The Department of Vital Statistics, Voters' Registration, Social Security Administration, U.S. Office of Veterans Affairs, U.S. Postal Service, newspapers, etc.

7. If all leads fail to return any current information, re-contact the patient's original or last known physician before you consider them "lost" to follow-up.
8. Record all follow-up efforts and the resulting information in the text of the patient's record.