

The Role of the Cancer Registrar in the Flow of Cancer Information: A Case Study

Jane Smith learns that she likely has breast cancer.

After feeling a lump in her breast during a breast self-exam, Jane goes to her doctor who refers her for mammography. A few days later, Jane learns she likely has breast cancer and is referred to a surgeon.

Further tests are completed at the hospital and diagnosis is confirmed.

At a Detroit, Michigan hospital, further tests results determine conclusively that Jane has breast cancer.

The hospital cancer registrar creates Jane's file in the hospital's cancer registry.

Jane's reports, along with the reports of her physician's other patients, are sent to the hospital's cancer registry. The hospital's cancer registrar sorts the reports to determine which reports contain "reportable" information, such as Jane's. Non-reportable cases might include lumps deemed to be benign cysts. The cancer registrar determines if Jane is already in the hospital's registry database. Because she is not, the registrar adds a new record or patient set. The record includes Jane's:

- demographic information
- cancer diagnosis, and
- diagnostic services.

Jane begins a course of treatment.

Jane's doctor proposes a course of treatment, including a lumpectomy, radiation, and systemic therapy. It is determined that Jane has Stage I breast cancer and she begins a six-week course of radiation therapy, which takes place at a local cancer clinic. The oncologist meets with Jane to discuss systemic therapy and prescribes Tamoxifen.

The cancer registrar fully documents Jane's treatment.

The cancer registrar at the hospital examines Jane's medical file to determine where she is being treated and what treatments she is receiving. The cancer registrar will contact the oncologist or surgeon to ascertain where Jane is receiving her treatments, if the information isn't included in her chart. The cancer registrar then contacts each treatment source to gather complete information about Jane's course of treatment, which is entered into Jane's record in the cancer registry.

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Follow-up tests show Jane to be cancer free.

Her initial course of treatment now complete, Jane returns to her oncologist who orders a second mammogram and additional blood tests. She is now cancer free, but is to continue taking Tamoxifen and seeing her oncologist every six months.

Jane's data is verified and submitted to state and national cancer registries.

Jane's record is chosen for a quality assurance audit by the cancer registry supervisor. The information in the record is compared to the hospital's medical record and the additional information gathered from outside the facility. After the audit review, it is noted that the data has all been coded correctly following the correct standards. Jane's record is finalized and sent to several cancer registries.

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The data goes to the:

- **Michigan state central registry**, which is a part of the **CDC's National Program of Cancer Registries (NPCR)**; NPCR adds the information to its national data base.
- **National Cancer Institute's SEER (Surveillance Epidemiology and End Results Program) registry**, which is a representative sampling of certain geographic areas. Detroit is a SEER site.
- **American College of Surgeons (ACoS) National Cancer Data Base (NCDB)** because the hospital is an ACoS-approved cancer program.

If reports about Jane's breast cancer from other facilities are also forwarded to these central cancer registries, they will be reconciled into one case. If data inconsistencies are identified, the central registry would then return data to the hospital registry or ask for additional information. Once any outstanding issues are resolved, Jane's data will be aggregated with other data from Michigan and ultimately with national data in the NCDB and at both SEER and NPCR.

The cancer registrar will regularly follow-up for a lifetime of data.

Back in Jane's hometown, the local cancer registrar will send a letter to Jane's oncologist annually requesting information to update her disease and vital status in the cancer registry database. These follow-up letters are the basis for survival rates and disease recurrence rates and are unique to the cancer surveillance world.

Cancer registrars follow patients for the rest of their lives, thus providing accurate survival, recurrence, and outcomes information. In addition, the cancer registrar's follow-up letters often act as a prompt to the physician and the patient that it is time for a checkup.