Collection of active follow-up data in a NPCR registry: A review of the Patient-Centered Outcomes project at the New Hampshire State Cancer Registry

Celaya MO1, McGinn PM1, Pollack LA2, Celaya V1, Riddle BL1, Rees JR1

1New Hampshire State Cancer Registry, Geisel School of Medicine at Dartmouth, Department of Epidemiology, Hanover, NH. 2Centers for Disease Control and Prevention, Division of Cancer Prevention and Control, Cancer Surveillance Branch, Atlanta, GA.

Background

- The New Hampshire State Cancer Registry (NHSCR) is one of five NPCR registries that participated in the CDC’s Patient Centered Outcomes (PCO) project.
- PCO entailed the collection of follow-up information for breast and colorectal cancers diagnosed in year 2011.
- We actively collected follow-up information that included vital status, disease recurrence, disease progression, and additional treatment.
- We aim to share experience and results of the PCO project in NH and consider the feasibility of obtaining current follow-up information on cancer patients in a state registry that does not usually expect these variables to be submitted by reporters.

Methods

- PCO-eligible cases were identified within the NHSCR.
- Breast (C50.0-C50.9) and colorectal (C18.0-C18.9, C19.9, C20.9) cancers diagnosed in year 2011
- Diagnosed during year 2011
- Cases reported to NHSCR through October 31, 2013, the end of the CER project
- Excluded cases with histology 9050-9055, 9140, 9590-9992
- We completed follow-up of PCO-eligible cases
  - Data collection was conducted from June 1, 2014 to July 31, 2017.
  - Active follow-up was performed for cases reported by NH sources.
  - Site visits were scheduled and medical records were reviewed by NHSCR staff at least annually.
  - Performed at 26 NH hospitals and at 2 freestanding oncology treatment facilities.
  - Remote access was provided to some facilities.
  - Passive follow-up was performed for cases reported by MA hospitals.
  - We obtained permission from MA Cancer Registry to mail follow-up forms to MA hospitals.
  - Replying to our request was completely voluntary.
  - Every year, we attended the Cancer Registry Association of New England, whose membership consists of registrars from NH and our neighboring states. This allowed us to network and promote the PCO project to MA registrars and encourage them to complete and return the follow-up forms to us. At these conferences, we also presented updates to our project and thanked every registrar present for their hard work and help with collecting follow-up data.
  - Months of follow-up were calculated by finding the time difference between Date of Diagnosis and Date of Last Contact.

Results

- There are a total of 2,102 NH breast and colorectal cancers diagnosed in year 2011.
- 548 died, and 184 were reported only by a non-NH facility.
- 20 were identified through the death clearance process.
- 60-month follow-up or greater was completed on 89.2% of cases (including those who died).
- 95% had ≥ 48 months of follow-up (including those who died).
- 96% had ≥ 36 months of follow-up (including those who died).
- 90.6% of the 1554 cases presumed alive have a Date of Last Contact in 2016 or later, at least 5 years after their diagnosis in 2011.
- 95% had ≥ 48 months of follow-up (including those who died).
- Active follow-up was performed for 88% of the cases.
- Passive follow-up performed for 9.1% of cases.
- 60-month follow-up or greater was completed on 89.2% of cases (including those who died).
- No deaths were identified through death clearance.

Discussion

- Most facilities were very receptive to working with the NHSCR on the PCO project, and those with registrars were eager to help and provided assistance in tracking down additional information.
- It was also helpful that NHSCR staff already had a good working relationship with most of the registrars in the state, and we all share a desire to provide the best possible cancer data.
- Follow-up status was easier to obtain at CoC-approved facilities as this is information that is routinely collected and available.
- Most allowed access to both the facility electronic record and the registry database so both sources could be compared.

Limitations

- Follow-up and disease status became a bit more difficult as we neared the five-year mark. Many patients had moved out of state with no additional contact information available, and as many reached five-year status, they no longer followed up with oncology or other hospital-based physicians.
- Probably the greatest challenge in completing this project was that work area/computer access needed to be scheduled around availability of same at each facility. It was helpful that we could be flexible with our schedule in order to mesh with theirs.
- One facility initially would only provide paper copies, and two others allowed very limited access. At these two facilities, IT assistance was also not available locally when needed.
- Follow-back to hospitals outside NH was challenging. Some hospitals did not respond voluntarily and we had no jurisdiction in MA.

Conclusion

Follow-up data are important to evaluate cancer survival and outcomes.

This review shows that longitudinal follow-up is feasible with a rigorous schedule of active follow-up.

We acknowledge the Centers for Disease Control (CDC) and Prevention's National Program of Cancer Registries for its support of NHSCR. Development of this project was supported in part by cooperative agreement U58/DP006298 awarded to the NH Department of Health and Human Services (NH DHHS), Division of Public Health Services, Bureau of Disease Control and Health maintenance, Health Statistics and Data Management Section. It's contents are solely the responsibility of the authors and do not necessarily represent the official views of the CDC or NH DHHS.