2019 NPCR ILLINOIS SUCCESS STORY

Illinois Cancer Registry: Kyle Garner, Lori Koch

From Registry Data, to Analysis, to Dissemination: A Population-based Cancer Incidence Investigation

NATIONAL PROGRAM OF CANCER REGISTRIES SUCCESS STORY

SUMMARY: In response to the U.S. Environmental Protection Agency's (EPA) updated cancer risk assessment for ethylene oxide (EtO), the Agency for Toxic Substances and Disease Registry (ATSDR) evaluated the implications of increased cancer risk associated with EtO emissions at an EtO emitting facility in Willowbrook, Illinois. In September of 2018, ATSDR requested that the Illinois Department of Public Health (IDPH), Illinois State Cancer Registry (ISCR) examine the residential areas surrounding the facility in Willowbrook for evidence of increased cancer incidence in that population. The cancer incidence investigation was completed, and results disseminated through a published report, webinars, and a town hall meeting.

CHALLENGE: IDPH was asked to produce an analysis to answer the following question: Is there evidence of increased cancer incidence in the area surrounding the Willowbrook, IL facility that is consistent with cancers associated with EtO exposure? Utilization of a population-based cancer incidence dataset, in addition to modeling of cancer risk, is a complementary and vital line of scientific inquiry to observe the existence of possible associations between cancer and environmental exposures. Many stakeholders were interested in the results of the forthcoming study and maintaining open communication during this process was an important goal.

SOLUTION: A population-based cancer incidence investigation was begun in September of 2018. With key data elements in place, such as modeled EtO exposure data, cancer registry incident case counts covering all Illinois residents, and detailed population figures the investigation began to take shape. Over the next several months, as IDPH staff completed a multitude of tasks such as geocoding, data analysis, and methodological discussions, stakeholders were updated on IDPH activities through a monthly letter to the mayor of Willowbrook, IL. The focus of each update was on completed activities rather than future completion dates. While communication with stakeholders was viewed as an important goal, IDPH staff understood that ISCR epidemiologists and research staff needed to maintain a balanced focus on the examination of cancer incidence in this area and should not be unduly influenced by stakeholders regarding decisions relating to analytical methods.

As completion of the investigation neared, IDPH staff recognized a need for the public to connect with IDPH regarding the report once released. A dedicated email address was created and accessed by ISCR staff to field questions from the public regarding the report, EtO, and cancer in general. In addition, ISCR staff presented study methods and results in two continuing medical education webinars, organized by ATSDR region 5 staff, to help educate family practice physicians who serve the communities of interest on the scientific and medical issues related to EtO emissions. All questions received by IDPH, no matter the conduit, were responded to in a respectful and timely fashion.

RESULTS: Once the investigation was completed and had gone through IDPH's internal communication review the report was released to the public in March of 2019 (http://www.dph.illinois.gov/sites/default/ files/publications/sterigenicswillowbrookcancer-investigationfinal_0.pdf). The following briefly summarizes the results of the investigation: "The cancer assessment examined a number of cancer sites that included cancers that have a recognized association with EtO (lymphohematopoietic and breast cancers), and other common cancer sites that have no such association with EtO, in both adult and pediatric populations surrounding the Sterigenics facility in Willowbrook, Illinois over the years 1995 through 2015. For lymphohematopoietic and breast cancers the study found increases in Hodgkin's lymphoma, and in recent years, non-Hodgkin's lymphoma. Pediatric lymphoma was also elevated during the study period. For other common cancer sites, the study found increased cancer in prostate for males, and increased cancers of the pancreas, ovary, and bladder in females. However, many apparent differences and inconsistences existed between sexes, across study areas, and among cancer sites. A number of limitations in methodology and data also exist. Future studies with larger populations and preferably involving multiple EtO emissions sites are strongly recommended to confirm this assessment's findings."

As in many scientific studies, the results of this study were not clear. Nevertheless, the observations made in this study do contribute to the body of evidence aimed at understanding the possible health effects of EtO emissions. Population-based data and methods are one important piece of evidence contributing to a host of different studies and methods that seek to understand how our environment can influence the development of cancer.

The results of the study were communicated directly to the community during a town hall meeting in May of 2019. A lengthy question and answer session followed. While the reception of the study was contentious, community member questions, no matter the subject and/or tone, were answered in a respectful fashion.

SUSTAINING SUCCESS: Completion of this investigation was made possible by the high-quality cancer surveillance data collected and maintained by ISCR staff. ISCR has been named a CDC-NPCR Registry of Excellence for the past six years and has achieved NAACCR Gold Certification for the previous 21 years. These achievements illustrate the registry's long history of excellence in the collection of complete, timely, and high-quality cancer data used to assess cancer incidence and mortality in Illinois. ISCR staff are dedicated to maintaining these high standards for all future years of data.

CONTACT INFORMATION:

Tel: 217-785-1873

http://www.dph.illinois.gov/data-statistics/epidemiology/cancer-registry

