Modernizing Iowa Cancer Reporting Requirements

The Iowa Cancer Registry (ICR) is a population-based cancer registry that has served the State of Iowa since 1973. Our registry is funded by the National Cancer Institute (NCI) as part of its Surveillance, Epidemiology, and End Result's (SEER) Program. The SEER Programs registries routinely collect data on patient demographics, primary tumor site, tumor morphology, stage at diagnosis, and first course of treatment. SEER is the authoritative source of information on cancer incidence and survival in the U.S.

Cancer is a reportable disease in Iowa. About 25,000 cancer abstracts per year are collected from hospitals, pathology laboratories, cancer treatment centers, and physician practices. Two-thirds of the abstracts are collected by the 14 Iowa hospitals with cancer centers that are accredited by the American College of Surgeons Commission on Cancer. The remaining abstracts are collected by ICR-employed and trained Tumor Registrars from the other 104 hospitals and non-hospital sites of diagnosis or treatment.

The overall goal of the Iowa Cancer Registry is to reduce the burden of cancer. We aim to:

- Assemble and report cancer incidence, survival and mortality among Iowans
- Provide information on changes over time in the extent of disease at diagnosis, therapy, and survival
- Promote and conduct studies to identify factors relating to cancer etiology, prevention and control
- Respond to requests from individuals and organizations in Iowa for cancer data and analyses
- Provide data and expertise for cancer research activities and educational opportunities

***According to SEER**, "The ICR provides accurate and thorough reporting of cancer disease. The ICR has been consistently recognized for its extremely high quality data. However, Iowa has some of the weakest reporting laws compared to other states. Iowa also has one of the lowest rates of e-path reporting of all SEER Registries".*

The University of Iowa
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Policy Changes Needed to Modernize Iowa Cancer Reporting Requirements

To ensure continued funding from NCI, it is necessary to address the low rate of e-path reporting and Iowa's weak cancer reporting requirements, which require a disproportionate amount of NCI funds to be spent on cancer case abstraction compared to other SEER Registries. Existing Iowa cancer reporting requirements were developed long before widespread use of electronic record systems and at a time when nearly every cancer patient received treatment in a hospital. Cancer reporting requirements must catch up with technology.

Policy Change #1: Require all reporting entities to provide data electronically whenever possible. Electronic reporting benefits reporting entities and the ICR:

Benefits of Electronic Reporting for Hospitals and Laboratories

- More timely case identification for hospital-based registries
- Improved compliance with cancer reporting requirements
- Enhanced patient privacy compared to paper reports

Benefits of Electronic Reporting for ICR

- More timely receipt of incident cases (within hours or days of diagnosis)
- More complete reporting
- Standardization of data from diverse reporting sites
- Significant labor savings

Policy Change #2: Add provisions for cost-sharing mechanisms

- **104 of 118 Iowa hospitals are not accredited by the Commission of Cancer (CoC)** and therefore do not have their own cancer registries. ICR completes ~8,000 cancer abstracts /year from these hospitals at **no cost to the hospital.**
- ICR abstracts data (~3,700 abstracts /year) for 3 CoC hospitals who have their own registries but do not collect all the elements required by SEER at **no cost to the hospital.**
- Nearly **$2 Million of ICR budget** is spent on abstracting which results in Iowa having the largest cost per case of all SEER registries.

Policy Change #3: Expand the definition of who is required to report

Currently, as the Iowa Code is written, it is often interpreted that only hospitals have to report cancer cases. This leads to underreporting of cancers that can often be treated in a clinic or outpatient setting such as with melanoma, urologic cancers (e.g., bladder and prostate) and chronic lymphocytic leukemia.

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