



State of Illinois
Department of Public Health

Annual Report Illinois Health and Hazardous Substances Registry

July 2019 through June 2020

November 2020



Annual Report
Illinois Health and Hazardous Substances Registry
July 2019 through June 2020



A Report to Governor J.B. Pritzker
and the 101st General Assembly
from the
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Acronyms

Acronyms used in the Illinois Health and Hazardous Substances Registry Annual Report

ABLR	Adult Blood Lead Registry
ACS	American Cancer Society
AHRQ	Agency for Healthcare Research Quality
APORS	Adverse Pregnancy Outcomes Reporting System
BLS	Bureau of Labor Statistics (U.S. Department of Labor)
CDC	U.S. Centers for Disease Control and Prevention
CFOI	Census of Fatal Occupational Injuries
CINA	Cancer in North America
FY	Fiscal Year
GIS	Geographic Information System
IARC	International Agency for Research on Cancer
IBCCP	Illinois Breast and Cervical Cancer Program
ICCCP	Illinois Comprehensive Cancer Control Program
IDHFS	Illinois Department of Healthcare and Family Services
IDPH	Illinois Department of Public Health
IHDDI	Illinois Health Data Dissemination Initiative
IHHSR	Illinois Health and Hazardous Substance Registry
IMMB	IDPH's Illinois Morbidity and Mortality Bulletin
IOSP	Illinois Occupational Surveillance Program
IRB	Institutional Review Board
ISCR	Illinois State Cancer Registry
MMWR	CDC's Morbidity and Mortality Weekly Reports
NAACCR	North American Association of Central Cancer Registries
NAD	North American Datum
NAS	Neonatal Abstinence Syndrome
NBDPN	National Birth Defects Prevention Network
NCI	National Cancer Institute
NIH	National Institutes of Health
NIOSH	National Institute of Occupational Safety and Health
NPCR	National Program of Cancer Registries
ODR	Occupational Disease Registry
OSH	Occupational Safety and Health Survey
OSHA	Occupational Safety and Health Administration
SEER	Surveillance of Epidemiology and End Results
SOII	Survey of Occupational Injuries and Illnesses
VA	Veteran's Administration
VR	Division of Vital Records

1. Executive Summary

The Illinois Department of Public Health's (IDPH) Division of Epidemiologic Studies is responsible for developing and managing the Illinois Health and Hazardous Substances Registry (IHHSR). The registry was created by the Illinois Health and Hazardous Substances Registry Act (410 ILCS 525/1 *et seq.*), enacted on September 10, 1984, and currently includes the following components: the Illinois State Cancer Registry (ISCR), the Adverse Pregnancy Outcomes Reporting System (APORS), the Occupational Disease Registry (ODR) [which further contains the Adult Blood Lead Registry (ABLR), Census of Fatal Occupational Injuries (CFOI) and the Survey of Occupational Injuries and Illnesses (SOII)], and a research and data dissemination section. This is the registry's 34th annual report and it describes major registry activities and accomplishments from July 2019 through June 2020 (FY20).

The mission of the IHHSR includes the following:

- collect and maintain statewide reports on the incidence of cancer, adverse pregnancy outcomes, and occupational diseases and injuries;
- conduct epidemiologic analyses and health assessments at the state and local levels;
- provide a source of information for the public;
- monitor changes in incidence to detect potential public health problems, trends, and progresses;
- use data to help target intervention resources for communities, patients, and their families;
- inform health professionals and citizens about risks, early detection, and treatment of cancers in their communities; and
- promote high-quality research to provide better information for disease prevention and control.

1.1 Illinois Health and Hazardous Substances Registry (IHHSR) Goal

The basic goal of the registry, according to the Act, is to develop and to maintain a unified system for the collection and compilation of statewide information on cancer incidence, adverse pregnancy outcomes, occupational diseases and injuries, and hazardous exposures; for correlation and analysis of information on public health outcomes and hazardous substances; and to use this information in decision making and public health policy development.

1.2 Fiscal Year 2020 Highlights

- Received \$1.66 million from federal funds and nearly \$27,500 from other non-general state revenue sources, mostly through competitive processes, to support activities of the Division of Epidemiologic Studies.
- Collected detailed case reports on Illinois residents with 63,135 newly diagnosed cancer cases (2017), 11,974 children with adverse pregnancy outcomes (2018), 2,970 adult lead poisoning cases (2019), 37,812 representative non-fatal occupational disease and injury sample records (2018), and 166 fatal occupational injuries (2018).
- Responded to 18 requests for general information about the registry, 36 requests for epidemiologic reports and registry data, and 19 special data requests or collaborations from outside researchers.
- Responded to three inquiries about perceived cancer excesses in local communities and neighborhoods.
- Prepared and submitted six grant proposals to support the registry's operations and research.
- Released one research paper in the Illinois Morbidity and Mortality Bulletin, seven reports in the Epidemiologic Report Series, and prepared six written reports for quality control studies of registry data.
- Authored or co-authored four scientific papers for peer-reviewed journals.
- Data released by the registry were used in 19 published studies by outside researchers.
- Data collected by the IHHSR registry submitted to federal and other collaborating agencies and organizations to add to various national and international health surveillance data systems.
- Actively participated in national and statewide health programs; provided data, information, and epidemiologic support as needed.
- Referred Illinois children with adverse birth outcomes to programs that provide follow-up services.
- Referred six employees from six employers with elevated blood lead levels to the U.S. Occupational Safety and Health Administration (OSHA) for onsite inspection.
- Delivered presentations at 10 professional meetings.
- Provided leadership and management support to IDPH Institutional Review Board (IRB), with three Division of Epidemiologic Studies staff serving as members -- one as vice chair, one as the IRB's standing coordinator, and one as a regular member.

- On behalf of IDPH, reviewed, edited, and published the Illinois Morbidity and Mortality Bulletin (IMMB), which features scientific articles analyzing Illinois data.

1.3 Illinois Health and Hazardous Substances Registry Coordinating Council

The IHHSR Act included that the Health and Hazardous Substances Coordinating Council should be comprised of the following persons: ex officio, or their designees: dean of the School of Public Health of the University of Illinois at Chicago, the directors of the Illinois departments of Agriculture, Labor, Natural Resources, Nuclear Safety (now part of the Illinois Emergency Management Agency), and Public Health, and of the Illinois Environmental Protection Agency. Due to time and budgetary constraints, the council did not have a face-to-face meeting in fiscal year 2020. Instead, the council reviewed and approved the annual report via written ballot.

1.4 Goals for Fiscal Year 2021

1. Continue to collect complete, timely, and high-quality data to monitor disease distributions and trends among Illinois residents.
2. Engage partners, stakeholders, and communities in data dissemination and utilization to support health research and programs.
3. Respond to public concerns about disease clusters in Illinois with registry data and information.
4. Conduct activities stipulated or required by federal cooperative or research grants.
5. Pursue grants and other funding opportunities in order to sustain and enhance the Division of Epidemiologic Studies' programs.
6. Conduct epidemiologic studies with registry data to provide information to the public health community and to policy makers.
7. Provide epidemiological data and information to federal, state, and local health education and intervention programs.
8. Work through the Division of Epidemiologic Studies Program Review and IDPH's Institutional Review Board (IRB) to provide researchers with high-quality and timely registry data to support research advancing scientific knowledge and improving public health.
9. Provide health regulatory agencies with health surveillance information to enhance their intervention and regulatory programs and to improve public health and safety.

10. Participate in national registry certification and data submission activities to maintain the registry's certification status and data utilization.

2. Program Data

Tables 2.1 and 2.2 summarize the registry's data collection and dissemination activities for last year and compare with data from the previous years. In order to be consistent with the common reporting schedule, numbers in Table 2.1 are expressed in calendar years during which cases were diagnosed or defined. There is normally a two-year time delay for cases being reported to IHHSR. Due to the dynamic nature of the registry databases, the numbers in the table may not be the same as previously reported. These numbers represent cases processed or estimated by the registry and they do not reflect rate calculations that would require population denominators, nor case completeness that would require independent evaluations. Projections or forecasts for the future year also are included.

Table 2.1 Registry Data Collection

	Calendar 2014	Calendar 2015	Calendar 2016	Calendar 2017	Calendar 2018	Estimated 2019
ISCR Invasive Neoplasms (including bladder <i>in situ</i>)	68,017	69,309	69,472	69,222	11,305 ¹	71,950
Breast <i>in situ</i> female only	2,481	2,459	2,445	2,469	2,418 ¹	2,400
Brain – benign/borderline	2,593	2,561	2,481	2,487	333 ¹	2,000
APORS Cases – All	10,361	11,382	12,309	12,388	11,974 ²	12,000
NBDPN Children	2,113	2,357	2,821	2,727	3,139 ²	3,000
# NBDPN Birth Defects	4,145	5,354	5,595	4,758	4,758	4,500
Occupational Disease Reports						
ABLR lead poisoning						
New reports	1,060	1,704	852	770	908	1,087 ³
Total reports	2,347	3,056	2,918	2,463	2,580	2,970 ³
Occupational Fatality Cases						
Injuries	164	172	171	163	166	184
Occupational Safety and Health Survey⁴						
Estimated Cases based on Sampling	38,280	39,700	33,170	37,400	37,812	27,272
Sprains, strains	14,320	15,309	11,940	12,850	13,768	13,637
Bruises, contusions	2,880	3,255	2,580	2,790	2,994	2,900
Cuts, lacerations	2,600	3,613	2,810	4,590	3,382	3,300
Fractures	4,010	4,405	3,070	4,690	3,764	3,988
Multiple injuries	1,450	715	420	300	751	727
Carpal tunnel syndrome	270	238	290	240	335	275
Heat burns	310	596	530	560	494	498
Tendonitis	70	38	70	130	98	81
Amputations	160	199	300	190	217	213
Chemical burns	60	238	60	140	133	126
Hazardous Substances (GIS)						
Geocoding registry cases	All	All	All	All	All	All

¹ Reporting is not complete for the calendar year indicated. The numbers are estimated based on the current projected incidence.

² To date 8/11/19 – data are not complete

³ Actual counts for 2019

⁴ Private industries only, cases with days away from work include those that result in days away from work with or without job transfer or restriction.

Table 2.2 Registry Data Dissemination, Reports, and Publications

	FY16	FY17	FY18	FY19	FY20	Estimated FY21
Data Requests						
General information	23	39	15	20	18	
Data and reports	59	32	33	30	36	
Cluster inquiries	8	6	9	8	1	
Confidential data released and research collaborations	17	22	19	18	15	
Confidential data applications	1	0	0	1	5	
Quality Assurance Studies						
<i>Casefinding visits</i>						
APORS	4	4	4	1	0	0
ISCR	31	51	69	42	0	0
<i>Cases added from casefinding visits</i>						
APORS ²	7,158	9,729 ³	13,573	11,080	11,637	11,500
ISCR ⁴	683	1,142	1,182	917	0	0
<i>External audits of facility data</i>						
ISCR	229	244	0	1	2	2
<i>Internal quality control reports issued</i>						
APORS	3	2	4	4	4	3
ISCR	3	3	2	2	2	2
ABLR	1	0	0	0	0	0
Public Use Microdata Files	5	5	5	5	5	5
Publications						
Epidemiologic report series	6	8	8	1	7	3
IMMB and other publications	3	2	1	1	1	1
Peer-reviewed publications	5	2	4	5	6	2
Publications by outside researchers	21	18	19	23	26	20
Oral/poster presentations	5	7	10	4	0	2
Grant Proposals Funded	5	7	5	5	5	5

¹ Fewer hospital casefinding visits have been conducted since FY14 because field staff access medical records remotely for almost all reporting hospitals.

² Represents additional birth defects identified and confirmed through the active case verification process where the medical records or previously submitted cases are reviewed.

³ The APORS program has been doing additional chart review on infants born in 2015, 2016, and 2017 with Zika-associated birth defects in collaboration with the U.S. Zika Birth Defects registry.

⁴ Represents cases missed by hospital reporting, but identified by ISCR during casefinding visits. COVID-19 required suspension of all in-person casefinding activities.

3. Illinois State Cancer Registry

As the only population-based source for cancer incidence information in Illinois, the Illinois State Cancer Registry (ISCR) collects cancer incidence information through mandated reporting by hospitals, ambulatory surgical treatment centers, non-hospital affiliated radiation therapy treatment centers, independent pathology labs, physicians, and through the voluntary exchange of cancer patient data with 11 other states. For the 2017 diagnosis year, ISCR received reports from three Veteran's Administration (VA) facilities in Illinois.

ISCR continues to require reporting facilities to submit data in an electronic format. There are currently 187 reporting hospitals in Illinois and all are reporting electronically. Dermatologists and pathology labs have been set up with access to a web-based reporting system. Ambulatory centers and radiation therapy centers use either the free Abstract Plus reporting software or the Internet-based Web-Plus program.

The COVID-19 pandemic made it necessary for all registry staff to move to a remote work setting on March 18, 2020. ISCR staff were well situated to this type of work environment as all data are received, processed, and produced electronically and have been for well over a decade. This is true of much of the cancer surveillance's work environment in the United States. Hospital cancer registrars often worked remotely prior to the pandemic and were easily adapted to continue cancer case capture and submission to ISCR. However, COVID-19 did require all in-person training workshops and casefinding audits of reporting facilities to be cancelled. ISCR was able to highlight available on-demand webinar coding training already present on the ISCR website and provide additional phone support to meet the training needs of cancer reporters. ISCR staff continue to complete all registry tasks and are on track for submission of 2018 diagnosis year data to NPCR and NAACCR in November of 2020.

3.1 Review and Evaluation of Fiscal Year 2020 Goals

3.1.1 Maintain Completeness and Timeliness of Reporting of Cancer Incidence Cases to the Illinois State Cancer Registry

- Met NAACCR gold certification standard for complete, accurate, and timely data for the 22nd consecutive year
- In-person casefinding visits for the 2018 diagnosis year were suspended due to the COVID-19 pandemic. However, case reporting was maintained as reporting facilities continued to submit cases for processing by ISCR staff.
- Completed interstate data exchange by transmitting 3,295 de-duplicated, edited state-specific cases to 11 states and received and processed 8,846 cases from 11 states.
- Completed death clearance for the 2017 death year and maintained a death certificate only rate of 2.1%. In total, 3,928 cancer diagnoses were followed with 262 letters or lists mailed to hospitals, physicians, nursing homes, and hospice centers.

- Added 17% of cases for the 2018 diagnosis year to the ISCR database by December 2019.
- Added 100% of cases for the 2017 diagnosis year to the ISCR database by December 2019.

3.1.2 Maintain and Enhance Activities Related to Physician and Pathology Reporting

- Maintained reporting by physicians and pathology labs.
- Expanded reporting by physicians in Illinois by 5% through focused targeting and training.

3.1.3 Provide Training for Reporting Facilities and for Central Registry Staff

- All in-person training was cancelled due to the COVID-19 pandemic.
- Provided on demand access to 30 training webinars on a variety of topics through the ISCR training website, including access to cancer site-specific coding training from NAACCR.
- Provided on demand access to a SEER Summary Staging training webinar available to all cancer reporters across the state.
- Provided on demand access to a nine-part "Introduction to Cancer Reporting" webinar training series available to all cancer reporters across the state.
- Provided on demand access to a melanoma coding webinar designed specifically for dermatology clinics.
- Provided individual phone or email support for 1,284 requests related to technical support and reporting issues.
- Attended the national educational conferences of the National Cancer Registrar's Association and the NAACCR, which were both held virtually due to the COVID-19 pandemic.
- Attended the annual educational conference sponsored by the Cancer Registrars of Illinois in September 2019.
- Provided access to 30 advanced training workshops for reporters via WebEx® utilizing nationally developed advanced training materials.
- Provided limited individual training conducted by the quality control field staff via phone, as necessary.
- Provided ongoing educational opportunities for central registry staff through participation in 12 nationally broadcast education webinars.

3.1.4 Ensure Data Quality

- Maintained a duplicate rate of fewer than 1 per 1,000 primary cases.
- Met NPCR/NAACCR standards for data quality.
- Applied GenEDITS metafiles to the ISCR database and ran all standard-setter required edits and performed reconciliation for identified errors.
- Matched vital records death data to the ISCR database to update unknown values in the latter; Race codes: of 20,497 cases with an unknown or missing race, 448 (2.2%) cases were matched and updated with a valid race; Maiden name: 19,584 cases (4.4%) were matched and updated with valid maiden names; Hispanic origin: 388 cases, or 4.2%, were matched and updated with valid data element codes for Hispanic origin; Birthplace: of 549,264 cases with unknown or missing birthplace, 38,195 cases (7.0%) were matched and updated with a valid birthplace; and updated Death variable information.
- Added census tract information to the cancer database; all records were geocoded using MapMarker® Version 31; 92.9% of the addresses were geocoded to an address specific level.
- Ensured override flags were within the NPCR average by reviewing the NPCR Data Evaluation Reports revealing that the percentage of override flags in the ISCR submission file were lower for all associated edits than the NPCR median.

3.1.5 Maintain Data Use Activities

- Produced annual cancer statistics, including the public use data file, annual state cancer report, annual county cancer report, and updated the cancer query system.
- Provided general cancer information for cancer inquiries and conducted cancer assessments when there is evidence of long environmental contaminations by carcinogens.
- Provided data for the Illinois Comprehensive Cancer Control Program (ICCCP).
- Provided data for the Illinois Breast and Cervical Cancer Program (IBCCP).
- Formed the Illinois Cancer Coalition in conjunction with the ICCCP and IBCCP to foster collaboration, cooperation, and data-driven practices among programs within IDPH that impact cancer prevention and control.
- Performed data linkage with the IBCCP file and provided the required information back to IBCCP.
- Produced one epidemiologic report.

- Produced two quality control reports.
- Updated incidence projections.
- Submitted 1,596,024 cases to NPCR and NAACCR for the 1995-2017 call for data.
- Submitted 12,270 cases to NPCR for the 2018 diagnosis year call for data.
- Provided IDPH with geocoding assistance for the COVID-19 data set.
- Conducted two data linkages between the ISCR cancer database and the COVID-19 database to provide sex, race, and ethnicity data for COVID-19 cases where these data had previously been coded as unknown.

3.1.6 Provide Adequate Program Management

- Kept registry staff informed of grant progress, standards change, and reporting issues through monthly staff meetings
- Monitored registry operations activities to meet grant objectives via an electronic tracker and streamlined registry operations through more efficient use of staff and resources.

3.2 Fiscal Year 2020 Major Accomplishments

3.2.1 North American Association of Central Cancer Registries Gold Certification

For the 22nd consecutive year, ISCR has been recognized as having met the **gold standard** – the highest standard for registry certification. To be awarded this honor, a registry must have 95% or better completeness of case ascertainment; 98% validity of information recorded for selected data variables (age, sex, race, and state/county); death-certificate only cases less than 3%; duplicate primary cases fewer than 1 per 1,000; 100% of the records passing the NAACCR EDITS without error; and data submissions within 24 months of the close of the accession year.

3.2.2 National Program of Cancer Registries (NPCR) Registry of Excellence

The Registry of Excellence recognition was suspended by NPCR for the 2019 NPCR data submission due to delayed national implementation of data collection requirements associated with cases diagnosed in 2018. The delayed implementation was considered beyond registry control by NPCR. Nevertheless, ISCR met all standards associated with the Registry of Distinction quality standard indicating complete, timely, and high-quality data available for cancer control activities.

3.2.3 COVID-19 Response

Beginning in May 2020, the cancer epidemiologist was mobilized and tasked with activities directly supporting IDPH's response to the COVID-19 pandemic. Activities include data analysis and interpretation of testing data, review and documentation of statistical methods provided publicly by IDPH, and daily data intelligence workgroup meetings.

3.2.4 Collaboration with State and National Organizations

3.2.4.1 Illinois Comprehensive Cancer Control Program - Illinois Department of Public Health (IDPH)

IDPH has implemented the Comprehensive Cancer Control State Plan, which identified cancer prevention and control priorities for Illinois. Several Division of Epidemiologic Studies staff provided technical and operational support for the program through committee participation.

3.2.4.2 Vital Records – Illinois Department of Public Health

Death certificate data from the IDPH Division of Vital Records (VR) are matched with the registry database on an ongoing basis. Follow-back is performed on non-matched cancer cases and death information is added to matched cases. Death information available from the VR death file also is used to populate an internet-based death query system that is accessible through password and ID. This system is used by hospital-based cancer registrars to obtain follow-up information on cancer patients seen at their facilities.

The VR death file also contributes to the data quality and item-specific completeness of the ISCR database through a matching protocol. Known information from the VR death file is imported into the ISCR database (when unknown on the ISCR database) for the following variables: race, birthplace, Hispanic origin, and maiden name.

3.2.4.3 North American Association of Central Cancer Registries (NAACCR)

ISCR provided comprehensive data from 1995-2017 to NAACCR in response to the call for data and registry certification process. The data were used to support research and generate cancer descriptions in North America publications. Staff also participated in various NAACCR committees and workgroups, contributing knowledge and expertise to this volunteer organization.

3.2.4.4 U.S. Centers for Disease Control and Prevention (CDC) National Program of Cancer Registries (NPCR)

ISCR submitted comprehensive data from 1995-2017 to the CDC NPCR call for data. All malignant tumors, whether *in situ* or invasive, were included. The annual submission satisfies the program requirements for reporting registry progress to CDC and contributes information to the national cancer surveillance effort.

3.2.4.5 Illinois Breast and Cervical Cancer Program (IBCCP)

ISCR provided data support for this state and federally-funded program, which focuses on developing comprehensive education, outreach, and screening for breast and cervical cancer.

3.2.4.6 American Cancer Society (ACS)

Illinois statewide cancer incidence and mortality data were provided to ACS for its production of Illinois Cancer Facts and Figures. Registry staff regularly attend ACS activities in the area of data and epidemiology. The collaboration is ongoing.

3.2.5 Quality Control Reports

3.2.5.1 Redeford B. *Assessment of Duplicate Records for 1995-2017 Diagnosis Years*. Quality Control Report Series 19:05. Springfield, Ill.: Illinois Department of Public Health, November 2019.

3.2.5.2 Hebert L. *Linking Illinois State Cancer Registry Records with Vital Records Death Master File to Enhance Data Completeness*. Quality Control Report Series 19:06. Springfield, Ill.: Illinois Department of Public Health, October 2019.

3.3 Goals for Fiscal Year 2021

3.3.1 Maintain Completeness and Timeliness of Reporting of Cancer Incidence Cases to the Illinois State Cancer Registry

- Perform limited facility casefinding for the 2019 diagnosis year at selected reporting facilities in Illinois and track identified missed cases to ensure reporting when circumstances permit (COVID-19).
- Maintain interstate data exchange and complete exchanges by November 2020.
- Continue death certificate clearance and maintain death certificate only rate of less than 3%.
- Achieve 90% case reporting for the 2019 diagnosis year by December 2020.
- Achieve 95% case reporting for the 2018 diagnosis year by December 2020.

3.3.2 Maintain and Enhance Activities Related to Physician and Pathology Reporting

- Maintain contact with existing physician offices for reporting and training (n=156).
- Maintain contact with existing pathology labs for reporting and training (n=12).
- Expand reporting of physician offices in Illinois by identifying offices, training personnel, and implementing reporting for those not currently submitting cases to ISCR.
- Perform facility case finding and implement any additional training needed at newly reporting physician offices in Illinois when circumstances permit (COVID-19).

3.3.3 Provide Training for Reporting Facilities and for Central Registry Staff

- Develop, update, and maintain new cancer reporting training website for all Illinois cancer reporters.
- Provide individual phone support for technical and operational issues from cancer incidence reporters and reporting facilities.
- Provide monthly advanced training workshops via the web, utilizing established seminars.
- Provide on-demand basic training webinars for cancer reporting.
- Provide on-demand staging training webinars for cancer reporting.
- Provide ongoing educational opportunities for central registry staff through webinars and attendance at relevant regional and national association and grant meetings.
- Update membership status in national associations.

3.3.4 Ensure Data Quality

- Maintain duplicate rate of less than 0.01% using Link Plus to review submissions for duplicate tumor reports and apply NAACCR duplicate protocol.
- Meet NPCR/NAACCR standards for data quality and override flags.
- Perform gender verification using established ISCR procedure.
- Apply NPCR, NAACCR and Illinois-specific GenEDITS metafiles to ISCR database for reconciliation of inter- and intra-record inconsistencies.

- Update ISCR unknown variables by linking to the IDPH's death file.
- Geocode all records on the ISCR database.
- Update case vital status via linkage with the National Death Index.

3.3.5 Maintain Data Use Activities

- Produce public use data set file, annual state and county report file, update cancer query system, and produce annual report of incidence rates by local community. Provide data visualization tools on ISCR website to facilitate understanding and access to state and local cancer data.
- Respond to cluster inquiries.
- Provide data and support for IBCCP and ICCCP.
- Perform linkage with IBCCP and update data files.
- Produce one epidemiologic report.
- Produce a publication for the layperson on cancer in Illinois.
- Perform linkage with Indian Health Services and update code for Native American race.
- Process applications for confidential data.
- Update incidence and mortality projections.
- Submit the 1995-2018 NPCR/NAACCR file for combined call for data and submit the 2019 data file for NPCR call for data.
- Provide assistance to IDPH with the COVID-19 data set as required.

3.3.6 Provide Adequate Program Management

- Hold monthly staff meetings
- Monitor grant activities
- Update advisory committee on grant progress and activities

4. Adverse Pregnancy Outcomes Reporting System

The Adverse Pregnancy Outcomes Reporting System (APORS) collects information on Illinois infants and young children born with birth defects or other abnormal conditions. The purpose of APORS is to conduct surveillance on birth defects, to guide public health policy in the reduction of adverse pregnancy outcomes, and to identify and to refer children who require special services in order to correct and prevent developmental problems and other disabling conditions.

Mandated statewide data collection began in August 1988. Licensed Illinois hospitals are required to report adverse pregnancy outcomes to APORS. In addition, APORS receives reports from four hospitals in St. Louis that are part of the southern Illinois perinatal network.

APORS cases meet one or more of the following criteria:

- the infant is diagnosed prior to hospital discharge as having a positive drug toxicity for any drug; shows signs and symptoms of drug toxicity or withdrawal; or the mother admits to illegal drug use (except cannabis) during the pregnancy;
- the infant or young child (younger than 2 years of age) is diagnosed with a congenital anomaly; a congenital infection; an endocrine, metabolic, or immune disorder; a blood disorder; or another high-risk medical condition;
- the infant was born at 31 completed weeks of gestation; or
- a neonatal or fetal death has occurred.

The COVID-19 pandemic made it necessary for all registry staff to move to a remote work setting on March 18, 2020. APORS staff were able to quickly adapt to working remotely with occasional short trips to the central office for scanning incoming paper reports and faxing chart requests to hospitals. Data collection continued as normal. Additional effort was put in by staff to assist smaller hospitals to transmit medical records to IDPH through a confidential electronic delivery system. Staff also put additional effort into helping hospital reporters submit APORS cases while they were working remotely and assist with challenges they were facing. However, COVID-19 did require all in-person training workshops and casefinding audits of reporting facilities to be cancelled. Some APORS staff were asked to contribute to the IDPH COVID-19 response by participating on the IDPH Modeling Team and providing assistance with analyses.

4.1 Review and Evaluation of Fiscal Year 2020 Goals

Improve Casefinding

- Ninety-two (81.4%) of the 113 birth facilities that are part of the Illinois Perinatal Network have been trained on and are using the APORS database introduced in FY14; more than 90% of cases are reported to APORS electronically. The database automatically generates APORS case reports for newborns who are premature (≤ 30

completed weeks); are part of triplet or higher order births; who have a serious infection, birth defect, or seizures marked on the birth certificate; or who die before the birth certificate is filed.

- Training in APORS reporting continued through formal trainings, webinars, use of the SharePoint® site for hospital staff, computer-based trainings, conversations with hospital staffs, and responses to questions.
- Provided eight trainings in person, by phone, or webinar and held 1,330 consultations via telephone or email with Illinois hospitals to improve APORS reporting.
- Updated the SharePoint® site with revised manuals and appendices, and the most recent of the quality control reports; reminders are posted when patterns of problems are identified.
- Received two hospital discharge data files covering all hospitals containing data for children as old as 2 years of age — these data have been imported into the IDPH chart review database. An additional 18 children born in 2017, 110 born in 2018, and 961 born in 2019 were identified as possible APORS birth defect cases.
- Reviewed the medical records of 1,428 infants identified from hospital discharge data; on average, 66.5% of the cases were found to have conditions that meet the APORS review criteria.
- Reviewed charts of 120 mothers who experienced a fetal death associated with a congenital anomaly noted on the fetal death certificate, to verify the information on the certificate. Of the reviewed charts, 75.0% were confirmed to be cases meeting the APORS case criteria.
- Rapid case ascertainment of birth defects associated with the Zika virus is complete.
- Four genetic clinics have reported 123 mothers carrying babies with prenatally suspected significant birth defects. Of the reports that meet the APORS criteria, most were eventually matched to an APORS report obtained from a fetal death or live delivery. Two reports (1.6%) identified APORS cases that were not reported by hospital nurseries. Neither birth nor fetal death certificates could be found for another case, indicating that the mother likely terminated the pregnancy.

Improve Quality of APORS Data

- Evaluated the timeliness of hospital reporting for cases reported in January through December 2019; provided hospital-specific feedback and used results to identify hospital training needs. In 2019, 81.6% of hospitals met the APORS timeliness standard of reporting cases within seven days of infants' hospital discharge. Hospitals are notified twice yearly of their timeliness status and provide more intensive education to facilities that are non-compliant.

- Evaluated the rates of hospital reporting in 2018. The case reporting rates ranged from 0.4% to 18.8% with the average being 6.9%. This degree of variation is not unexpected, since hospitals providing the highest level of care have the most cases to report.
- APORS aims to complete active case verification for a birth cohort during the following year. Case verification for the 2017 birth cohort was completed on time, in December 2019. A quality control report examining the quality of abstractor reviews of charts of the 2016 birth cohort was published. Frequent staff changes and increased workload due to Zika resulted in a decrease in accurate abstraction. It is anticipated that future re-abstraction studies will demonstrate an improvement in this area since every abstractor has now worked for APORS for at least three years. A training quiz was also used to monitor staff performance and individual feedback was provided.
- Abstractors began carrying out chart review for infants suspected of having NAS, following the Council of State and Territorial Epidemiologists' recommendations.
- Hospitals are contacted if a report is incomplete or is internally contradictory. These contacts are used as training opportunities when appropriate. If hospital staffs are unaware that reports have been automatically generated by the APORS database, APORS staff notifies them and asks for the reports to be completed.

Improve Program Effectiveness

- Administrative rules were drafted to add prenatal marijuana, hepatitis C, and HIV exposure to the APORS case definition. They have been submitted to the IDPH Division of Legal Services for review, but approval has been delayed because of the additional work generated by IDPH's COVID-19 response.
- In addition to the SharePoint® site updates of revised manuals, appendices, and quality control reports, hospitals and local health departments can access the forms to request additional materials.
- Maintained linkages with key organizations, such as the Illinois perinatal networks and the National Birth Defects Prevention Network, and provided data to these organizations for use in their efforts to promote birth defect prevention.
- The APORS program worked with IDPH, state, and local programs to assure the ongoing provision of perinatal services for high-risk infants.
- A surveillance report examining trends in birth defects in Illinois was prepared and is under review.
- Was awarded a renewed CDC cooperative agreement to do birth defect surveillance.
- Completed data collection of Zika-associated birth-defect data for provision to CDC.

4.2 Fiscal Year 2020 Major Accomplishments

4.2.1 Cooperative Agreement with the U.S. Centers for Disease Control and Prevention (CDC)

APORS was approved for an extension of the final year of a four-year cooperative agreement with the CDC to enhance Illinois birth defects surveillance, prevention, and service referral. Funding for 2020 is \$210,000.

4.2.2 Cooperative Agreement with the March of Dimes (MOD)

APORS has had a paper accepted for publication looking at the association of neonatal abstinence syndrome (NAS) and birth defects using data collected under this cooperative agreement.

4.2.3 Enhancement of the APORS Database

APORS staff completed modifications to the APORS database to accommodate the fields needed to document the rapid Zika ascertainment. In addition, changes were initiated to contain information collected by the abstractors during chart review. The modifications are waiting on action from IDPH's Division of Information Technology, which has been delayed by COVID-19 activities. However, the development database has been used to enter the rapid Zika ascertainment data, and it has been extracted and submitted to CDC.

All local health departments are using the APORS database introduced in FY14; and 92 hospitals are registered. These hospitals report more than 90% of the cases received by APORS.

4.2.4 Improved Birth Defects Surveillance

Hospital-reported cases are a starting point for birth defect surveillance. Potential birth defect cases were sent electronically to abstractor staff members, who then reviewed the infants' medical charts, verified the presence of birth defects, eliminated false positives, and collected additional diagnoses. In FY20, the abstractors reviewed reports of 9,124 birth defects submitted by hospitals. The table shows the disposition of the conditions reviewed by the APORS staff.

Source	Reported	Confirmed	Deleted
Hospital Nursery Reporting	7,674	4,061	2,758
Hospital Discharge Data	1,502	906	522
Chart Review	0	11,453	0
Other ¹	134	126	7
Any Source	9,310	16,546	3,288

¹Vital record certificates, genetic clinics, Newborn Hearing Screening Program

Abstractors deleted 1,379 reported birth defects that could not be found in the charts, or that had been ruled out by the facility. Another 1,730 were not collected because the infant did not have a collected birth defect or because the birth defect did not meet specific criteria (often conditions considered normal in

a premature infant). Some conditions were deleted because they were included as parts of confirmed complex conditions (1,543). The remaining 25 conditions were deleted for other reasons.

Case abstraction for 2017 birth cohort was completed in December 2019. The goal is to be complete within two years of the birth year. Abstractors continued to prioritize chart review for infants reported with microcephaly in response to Zika virus concerns. They have completed collection of additional information, such as head circumference, length, and weight measurements, for infants with Zika virus-related birth defects.

4.2.5 Evaluation of Case Management Services Provided to APORS Cases

APORS collaborated with community health agencies (CHAs) in surveying APORS families offered or receiving case-management services through the High-risk Infant Follow-up Program. CHAs have documented outcomes in 83.0% of the cases referred in FY20. Some families (24.0%) could not be contacted or live in an area where services are not available. Among the families with surviving newborns and documented outcomes who were offered services, 43.7% accepted.

A survey of the families offered services indicated that the nursing visits were helpful, and few felt they did not need them.

4.2.6 Linkages with Other Programs and Activities

4.2.6.1 Perinatal Programs

4.2.6.1.1 Illinois Department of Human Services High-risk Infant Follow-up. APORS continued to identify infants for the Illinois Department of Human Services (IDHS) perinatal management and high-risk infant tracking program. Most (8,734) infants were referred for local health department nurse visits. Physical and psychological development monitoring and counseling for parents are provided through the nurse visits. Included are 43 children with neural tube defects, whose families were referred for prevention counseling.

4.2.6.1.2 IDPH Division of Infectious Diseases. APORS identified infants for the IDPH Division of Infectious Diseases' sexually transmitted disease (88 newborns) and perinatal hepatitis B programs (244 newborns), which ensure infants with congenital syphilis and infants prenatally exposed to or diagnosed with a hepatitis B infection are offered services.

4.2.6.1.3 IDPH Craniofacial Anomaly Program. Data on infants born with cleft lip and/or palate (162 newborns) were supplied to the IDPH Division of Oral Health Craniofacial

Anomaly Program to ensure these infants receive appropriate services at multidisciplinary clinics throughout the state.

- 4.2.6.1.4 University of Illinois at Chicago Division of Specialized Care for Children (DSCC).** APORS refers newborns to the DSCC for free diagnostic services and assistance with medical treatment. The infants have, or are suspected of having, a treatable chronic medical condition. The conditions include orthopedic, visual, auditory, craniofacial, heart, and urinary defects. In FY20, APORS referred 3,912 cases.
- 4.2.6.1.5 Illinois Department of Human Services Early Intervention Program (EI).** APORS refers newborns to the EI for free developmental services. The infants have, or are suspected of having, a condition that will impact their intellectual or physical development. The conditions include brain, spinal, visual, auditory, craniofacial, and chromosomal defects. In FY20, APORS referred 1,750 cases.
- 4.2.6.1.6 IDPH's Newborn Metabolic Screening (NMS) Program.** APORS refers newborns reported to the program with possible metabolic conditions to IDPH's NMS Program. This program assures children receive timely follow-up for these severe conditions. A number of children with hypothyroidism previously unknown to the NMS program have been identified. In FY20, APORS referred 112 cases.
- 4.2.6.1.7 Illinois Department of Children and Family Services (DCFS).** Data are provided to DCFS on a monthly basis through the IHFS data warehouse. The data are pulled into individual eHealth Passports that travel with children in DCFS custody as they move between placements. This helps assure children receive the services they need in a timely manner.
- 4.2.6.1.8 Illinois Department of Healthcare and Family Services.** APORS data are provided monthly to DHFS for inclusion in the Enterprise Data Warehouse. This links APORS surveillance data to case management and public aid data. Before confidential APORS data can be accessed by anyone outside the program, requests are reviewed through the Division of Epidemiologic Studies' centralized review process. Any concerns about the application are then referred back to the researcher;

once these are addressed, the application is submitted for IRB approval.

4.2.6.2 National Birth Defects Prevention Network (NBDPN)

APORS staff contributed data to and participated in a number of analyses. The APORS manager, Jane Fornoff, and data manager, Theresa Sandidge, served on the NBDPN data committee. The abstractor liaison, Jodi Snow, served on the NBDPN data standards committee and the communications and health promotion committee.

4.2.6.3 Perinatal Networks

APORS maintained communications with the perinatal network administrators to facilitate hospital reporting of APORS cases. Timeliness for APORS reporting is used as one quality measure for hospitals' annual perinatal assessment. Administrators also were kept notified about the need to provide remote access to electronic medical records and the new APORS data system.

4.2.6.4 Pregnancy Risk Assessment Monitoring System (PRAMS)

The APORS manager served on the PRAMS Steering Committee. The committee provided recommendations about the questions that should be retained or dropped from the PRAMS questionnaire.

4.2.7 Quality Control Reports

4.2.7.1 Snow J. *Quality of Abstractor Reviews of Adverse Pregnancy Outcomes Among 2016 Reviewed Charts*. Quality Control Report Series 19:03. Springfield, Ill.: Illinois Department of Public Health, July 2019.

4.2.7.2 Sandidge T. *Family Survey of Services Provided Through the High Risk Infant Follow-up (HRIF) Program*. Quality Control Report Series 19:04. Springfield, Ill.: Illinois Department of Public Health, September 2019.

4.2.7.3 Sandidge T, Fornoff J. *Timeliness Study – Hospital Reports of Adverse Pregnancy Outcomes Received in 2019*. Quality Control Report Series 19:01. Springfield, Ill.: Illinois Department of Public Health, January 2020.

4.2.7.4 Sandidge T. *Rates of Hospital Reporting of Adverse Pregnancy Outcomes in 2018*. Quality Control Report Series 20:02. Springfield, Ill.: Illinois Department of Public Health, February 2020.

4.3 Goals for Fiscal Year 2021

Improve Casefinding

- Train and support hospitals in the use of the APORS database to ensure cases automatically generated by the database (premature infants, triplet, or higher order

births and those with birth defects marked on the birth certificate) are completed in a timely manner.

- Provide consultation and training to supplement the self-directed training for hospital nursing staff when indicated or requested.
- Enhance the SharePoint® site for hospital staff to include materials that supplement face-to-face and telephone consultation and training offered by APORS staff.
- Match information from periodic hospital discharge information reports to the APORS newborn cases and identify potential birth defect cases.
- Review medical reports of infants identified in hospital discharge matching to ascertain and collect new birth defect cases.
- Recruit additional genetic clinics to increase prenatal case findings.

Improve Quality of APORS Data

- Evaluate the accuracy of hospital reporting in terms of timeliness, completeness, and accuracy; provide hospital-specific feedback and use results to identify hospital training needs.
- Evaluate the quality of the active case verification process in terms of timeliness and accuracy, provide individual-specific feedback, and use results to identify staff training needs.
- Provide consultations and supplemental training to hospitals identified as problem reporters in terms of timeliness, accuracy, or case completeness.
- Obtain hospital discharge data for infants with NAS to identify additional cases for chart review for infants suspected of having NAS to improve surveillance.

Improve Program Effectiveness

- Work with IDPH partners to assure prenatal marijuana, hepatitis C, and HIV exposures are added to the APORS case definition through rule modification.
- Enhance SharePoint® sites for hospitals and community health agencies that contain relevant reference and training materials for the different groups.
- Maintain linkages with key organizations, such as the Illinois perinatal networks, the Greater Illinois Chapter of the March of Dimes, and the National Birth Defects Prevention Network.
- Collaborate with IDPH, state, and local health department programs to assure the provision of perinatal services for high-risk infants.

- Collaborate with CDC to provide data to the U.S. COVID-19 mother and infant registry.
- Produce statewide and county surveillance reports.
- Monitor activities and accomplishments associated with meeting the goals and objectives set forth in the CDC cooperative agreement.

5. Occupational Disease Registry

The Occupational Disease Registry (ODR) has three components: the Adult Blood Lead Registry (ABLR), the Census of Fatal Occupational Injuries (CFOI), and the Survey of Occupational Injuries and Illnesses (SOII), formerly referred to as the Occupational Safety and Health Survey (OSH).

The COVID-19 pandemic required all registry staff to move to a remote work setting on March 18, 2020. ODR staff were in the middle of the data collection period for the 2019 Survey of Occupational Injuries and Illnesses (SOII) and the 2019 Census of Fatal Occupational Injuries (CFOI) when this occurred. Because of the pandemic, many businesses were closed (temporarily or permanently) or their staff were also working remotely and did not have access to the information required to complete the survey. Although the U.S. Bureau of Labor Statistics provided a remotely accessible portal for the survey, staff were unable to make and to receive phone calls and faxes remotely. To compensate for this, ODR staff returned to the central office on a rotation that ensured recommendations for social distancing were maintained. The scheduled third and fourth mailings also were delayed due to the pandemic. ODR staff were able to meet the deadlines for the 2019 SOII and CFOI and met the required SOII response rate of 85% in spite of the challenges of COVID-19.

5.1 Adult Blood Lead Registry (ABLR)

ABLR collects data on all cases of elevated blood lead levels for adults 16 years of age and older and notifies federal enforcement agencies to trigger site inspections and/or interventions. In 2012, the Illinois Administrative Code related to elevated blood lead definition and collection was changed to reflect the new guidelines defining elevated blood levels. Laboratories are mandated to report levels ≥ 10 $\mu\text{g}/\text{dL}$. This program was funded through a purchase order for data with the CDC's National Institute for Occupational Safety and Health (NIOSH). In 2013, however, NIOSH canceled all contracts to fund state programs that use fiscal year 2013 funds in accordance with the federal Budget Control Act of 2011. Starting in 2014, due to lack of funding, ABLR staff only recorded cases of ≥ 40 $\mu\text{g}/\text{dL}$ to refer employers who have employees with elevated blood lead levels ≥ 40 $\mu\text{g}/\text{dL}$ to OSHA per the memorandum of understanding. Reports for cases less than 40 $\mu\text{g}/\text{dL}$ were archived. In 2015, Division of Epidemiologic Studies staff developed a new Access database that automated the entry of electronic reports and streamlined the manual data entry of paper reports. As a result, the backlog of 2014 electronic lab reports and all of 2015's electronic lab reports were entered in FY15. Data collection continues and in calendar year 2019, 2,970 new lab reports were added to the ABLR database.

5.1.1 Fiscal Year 2020 Accomplishments

- Notified OSHA quarterly of any company that had employees with elevated blood lead levels ≥ 40 $\mu\text{g}/\text{dL}$ of blood.

- Notified OSHA within 24 hours of any case with an elevated blood lead level ≥ 60 $\mu\text{g}/\text{dL}$.

5.1.2 Interventions Resulting from ABLR Notifications of Elevated Lead Results

In calendar year 2019, ABLR made eight referrals (employees) to OSHA for companies with employees who had blood lead levels greater than or equal to 40 $\mu\text{g}/\text{dL}$ of blood. These quarterly ABLR reports to OSHA led to no safety inspections in Illinois.

5.1.3 Goals for Fiscal Year 2021

- Notify OSHA quarterly of any company that has employees with elevated blood lead levels equal to or greater than 40 $\mu\text{g}/\text{dL}$.
- Notify OSHA within 24 hours of any case with an elevated blood lead level equal to or greater than 60 $\mu\text{g}/\text{dL}$.

5.2 Census of Fatal Occupational Injuries and Illnesses (CFOI)

The U.S. Bureau of Labor Statistics (BLS) developed CFOI as a cooperative venture between the states and the federal government to gather data about these events. IDPH has participated in CFOI since 1993. The data compiled by CFOI are published each year and contain information on the workers involved and the events surrounding each fatality.

In 2018, Illinois CFOI recorded 166 work related deaths. From January - June 2008, fatal occupational illnesses were collected by manually reviewing death certificates to collect information where the decedent's occupation, known occupational exposures, and cause of death were linked in scientific publications. In mid-2008, electronic death certificates were implemented in the IDPH Division of VR and the manual review was no longer possible. This operational change affected the number of fatal occupational illnesses collected. Beginning in 2012 and moving forward, BLS ceased collecting work-related illness fatalities. BLS has determined that because the capture of illnesses cannot be comprehensive, they would prefer staff spend time collecting and verifying injuries only.

5.2.1 Review and Evaluation of Fiscal Year 2020 Goals

- Completed the summary report of the 2018 fatal occupational injury data.
- Provided information on fatal occupational injuries to the BLS, the funding source, in accordance with the required schedule.

5.2.2 Goals for Fiscal Year 2021

- Publish a summary report of the 2019 fatal occupational injury data by January 2021.
- Meet the deadlines for data completion required by BLS.

5.3 Survey of Occupational Injuries and Illnesses (SOII) (formerly Occupational Safety and Health Survey)

SOII focuses on surveillance of non-fatal workplace injuries and illnesses. The Illinois SOII is supported through a cooperative agreement between the states and the BLS. The Illinois data are pooled with that from other states to provide the total injury and illness rate for each industrial group at the national level. Because of Illinois' participation, the data also are published annually and specifically for Illinois to give information on incidence rates for the type of injury, body part of the injury, the source of the injury, and the event causing the injury.

5.3.1 Review and Evaluation of Fiscal Year 2020 Goals

- Submitted data files on all reported occupational injuries and illnesses of the surveyed companies to the BLS.
- Collected, coded, and entered all 2018 data prior to BLS deadlines.

5.3.2 Survey Process and Achievements for Fiscal Year 2020

In January 2020, BLS and ODR sent survey forms to 5,146 private employers and 351 public employers for 2019 data. A second request for data was sent in February, a third request was sent in May due to the COVID-19 pandemic, and a fourth request was sent in June due to COVID-19. Non-responding companies were then contacted by telephone and email to solicit data. The final, overall survey response rate was 85%, which met the cooperative agreement minimum requirement for data publication.

5.3.3 Goals for Fiscal Year 2021

- Continue all data collection activities in FY21 and maintain the high standards achieved by the program.
- Complete the descriptive report of 2019 Survey of Occupational Injuries and Illnesses (SOII).
- Meet the deadlines assigned by BLS.

5.4 Illinois Occupational Surveillance Program (IOSP)

The Illinois Occupational Surveillance Program (IOSP; illinoisinjuryprevention.org) is a NIOSH funded worker surveillance program housed at UIC School of Public Health that operates in collaboration with IDPH and other state agencies.

5.4.1 Pesticide Related Illness in Illinois, 2019

Pesticide related illness (PRI) is any acute or chronic health effect that results from pesticide exposure. PRI poses a significant risk of harm to Illinois residents, both at work and at home. Every year, there are hundreds of events in which people are exposed, with dozens becoming severely ill and sometimes dying of pesticide toxicity. Pesticide exposure happens in predictable ways: workers are exposed during preparation and application of pesticides, mainly through skin

absorption; bystanders — workers and residents -- can be exposed through “drift” in agricultural applications or by residual pesticides coating surfaces in housing and office buildings, mainly through inhalation or skin transfer; and by ingestion—usually unintentional and most commonly in small children.

Pesticides are regulated on the federal level by the U.S. Environmental Protection Agency (EPA) under the Federal Insecticide, Fungicide, and Rodenticide Act (FIFRA) (7 U.S.C. secs. 136 ff, 2012).

Under FIFRA, all pesticides, which the statute defines broadly¹, must be registered prior to use. The Illinois Pesticide Act (IPA) divides the responsibilities for pesticide regulation among a number of different departments (415 ILCS 60/8/2). It places the responsibility for regulating “the purchase and use of

Illinois Facts re: pesticide use

- State population: 12.67 million
- Exposed workers: 368,984
- Agricultural land: 27 mil acres; 75% of Illinois land mass
- No. farms: 72,000
- Pesticide Applicator Licenses
 - Private: 143
 - Commercial: 44
- Percent population urban: 88.49%

pesticides pertaining to the production, protection, care, storage, or transportation of agricultural commodities and to control the use of pesticides applied by agricultural equipment” on the Illinois Department of Agriculture (IDAg). IDPH bears the responsibility for managing structural pesticides — those that are used for controlling pests that attack and destroy buildings and other structures or that attack clothing, stored food, commodities stored at food manufacturing and processing facilities, or manufactured and processed goods (415 ILCS 60/4/37). Illinois has a separate Structural Pest Control Act (SPCA) (225 ILCS 235), which prioritizes the use of less hazardous pest management methods. It is “the duty of the [Illinois] Environmental Protection Agency [IEPA] to enforce such provisions of this Act and other Acts intended to protect and preserve the quality of air, water, and guard against unreasonable contamination of land resources” (415 ILCS 60/3). IEPA is responsible for granting NPDES permits to applicators who use pesticides on or adjacent to water (“NPDES Permits,” <https://www.epa.gov/npdes> n.d.). The Illinois Emergency Management Agency (IEMA) is in charge of responding to accidental spills of certain quantities of extremely hazardous substances, a number of which, by statutory definition, are pesticides (29 ILA 430). The state may delegate certain tasks in the area of pesticide regulation to localities. However, pursuant to state law, only the largest political subdivisions (those with a

¹ From FIFRA: “The term “pesticide” means (1) any substance or mixture of substances intended for preventing, destroying, repelling, or mitigating any pest, (2) any substance or mixture of substances intended for use as a plant regulator, defoliant, or desiccant, and (3) any nitrogen stabilizer...” 7 U.S.C. 136(u). The statute goes on to articulate several relatively narrow exceptions to this broad definition.

population over 2 million) maintain any independent power to regulate pesticides (415 ILCS 60/3(4)).

Only 12 states in the U.S. conduct state-mandated public health surveillance for work-related pesticide illness, and only seven states provide resources to capture data on non-occupational cases. Illinois is not one of them.

IOSP collected data originating from the Illinois Poison Center for 2019. Data are shown in the Table 5.4.1.1, below.

Table 5.4.1.1 General Characteristics of Pesticide Related Exposure Calls to the Illinois Poison Center in 2019

General Characteristics of Pesticide Related Exposure Calls to the Illinois Poison Center in 2019					
	Herbicides and Fungicides (n=216)	Insecticides (n=1423)	Other Pesticides (n=1130)	Rodenticides (n=210)	Total (n=2979)
Gender^a					
Male	130	666	599	116	1511
Female	85	738	523	90	1436
Unknown	0	10	5	2	17
Age					
0-to-5 years	51	576	642	137	1406
6-to-9 years	6	42	45	6	99
10-to-19 years	8	73	81	6	168
20-to-29 years	19	139	78	10	246
30-to-39 years	30	116	86	8	240
40-to-49 years	14	89	53	14	170
50-to-59 years	24	109	44	3	180
60-to-69 years	21	97	29	9	156
70-to-79 years	18	62	16	2	98
80-to-100 years	4	21	11	2	38
Unknown adult (>=20 years)	17	76	28	8	129
Unknown age	4	20	15	5	44
Unknown child (<=19 years)	0	3	2	0	5
Month					
January	0	63	44	35	142
February	4	41	34	21	100
March	3	54	66	31	154
April	19	73	102	34	228
May	36	150	157	20	363
June	46	189	161	19	415
July	43	269	146	23	481
August	35	196	122	0	353
September	15	155	112	0	282

General Characteristics of Pesticide Related Exposure Calls to the Illinois Poison Center in 2019					
	Herbicides and Fungicides (n=216)	Insecticides (n=1423)	Other Pesticides (n=1130)	Rodenticides (n=210)	Total (n=2979)
October	10	123	77	0	210
November	2	60	56	0	118
December	3	50	53	27	133
Top 3 Counties^b					
Cook	43	348	360	79	830
DuPage	13	80	77	6	176
Lake	12	77	65	11	165
Level of Health Care Facility Care^c					
Treated/evaluated and released	38	200	197	50	485
Admitted to noncritical care unit	0	9	7	5	21
Admitted to critical care unit	3	6	4	2	15
Admitted to psychiatric facility	0	4	5	2	11
Patient lost to follow-up / left AMA	7	29	13	8	57
Patient refused referral to HCF	4	12	11	4	31
Management Site^d					
Managed on site (non HCF)	163	1147	875	136	2321
Patient en route to HCF	34	197	182	57	470
Patient was referred by PCC to a HCF	18	63	55	14	150
Other	0	6	14	1	21
Unknown	1	3	3	2	9
Outcome^e					
Major effect	1	2	0	0	3
Moderate effect	7	44	45	6	102
Minor effect	51	312	224	7	594
Confirmed no exposure	0	1	0	3	4
No effect	36	200	166	36	438
Unable to follow, judged as a potentially toxic exposure	12	25	18	9	64
Not followed, minimal clinical effects possible (no more than minor effect possible)	77	580	475	73	1205
Not followed, judged as nontoxic exposure (clinical effects not expected)	7	168	171	57	403
Unrelated effect, the exposure was probably not responsible for the effect(s)	25	84	30	19	158
Reason^f					
Unintentional - General	118	919	825	164	2026
Unintentional - Misuse	41	208	143	12	404

General Characteristics of Pesticide Related Exposure Calls to the Illinois Poison Center in 2019					
	Herbicides and Fungicides (n=216)	Insecticides (n=1423)	Other Pesticides (n=1130)	Rodenticides (n=210)	Total (n=2979)
Unintentional - Environmental	23	139	42	7	211
Unintentional - Occupational	23	52	51	4	130
Unintentional - Therapeutic error	0	7	2	1	10
Unintentional - Bite / sting	0	2	0	0	2
Intentional - Suspected suicide	2	13	13	11	39
Intentional - Misuse	1	21	10	0	32
Intentional - Abuse	1	1	0	1	3
Intentional - Unknown	0	0	1	0	1
Adverse reaction - Drug or other	4	40	24	6	74
Other - Contamination / tampering	2	7	9	3	21
Other - Malicious	1	4	6	0	11
Unknown reason	0	3	3	1	7
^a Missing values for Gender=15					
^b Top 3 counties with highest total values across all substances. Total missing values for Counties=139. County refers to location of caller. While not precise, most callers are located at site of exposure.					
^c Total missing values for HFC care = 2359					
^d Total missing values for Management Site = 8					
^e Total missing values for Outcome = 8					
^f Total missing values for Reason = 8					

5.4.2 Pneumoconiosis in Illinois

Pneumoconiosis is a class of lung diseases caused by the inhalation of certain dusts and the body's immune reaction; the main pathologic effect is scarring of the lungs. The principal cause of pneumoconiosis is workplace exposure, with environmental exposures rarely responsible.

Asbestos fibers, silica dust, and coal mine dust are the primary occupational hazards and lead to the diseases asbestosis, silicosis and coal workers pneumoconiosis (the latter is also called black lung disease and coal mine dust lung disease). There are other, less common dusts that can cause pneumoconiosis.

Pneumoconiosis typically takes two decades or more to develop, though short-term, intense exposure to silica dust can lead to acute and rapidly progressive forms. The severe forms of all of these diseases is manifested in lung impairment, disability, and premature death. Notably, asbestos exposure can cause bronchogenic lung cancer of all types and malignant mesothelioma, a rapidly fatal cancer of the lung's lining. Silica is also carcinogenic for the lung.

5.4.2.1 Pneumoconiosis in Illinois Protective Legislation

Table 5.4.2.1.1 Pneumoconiosis dusts, occupations at risk, protective legislation

Dust		Occupations where exposure occurred/occurs	Protective legislation
Asbestos	-Interstitial lung disease (Asbestosis) -Lung cancer -Mesothelioma of lung	Construction workers (demolition) Firefighters (exposure during fires) Auto mechanics (brake lining replacement) Manufacturing asbestos products (before 1980s) Ship building (before 1980s) Power plant workers (old boilers)	OSHA 29 CFR 1910.1001 - Asbestos.
Silica	-Interstitial lung disease (Silicosis) -Tuberculosis -Lung cancer -Chronic obstructive pulmonary disease (COPD) -Kidney disease	Sandblasting Rock drilling/roof bolting (in mines) Grinding, abrading, buffing, polishing (foundries, stone/brick masonry) Synthetic countertop installation	OSHA 29 CFR 1910.1053 1926.1153
Coal	-Interstitial lung disease (Coal mine dust disease, black lung) -Coal mining induces exposure to silica – see effects, above	Coal mining	OSHA 29 CFR 1910.1000 MSHA 30 CFR Parts 1 – 199
OSHA 29 CFR 1910 Subpart Z - Toxic and Hazardous Substances			
Other dusts, less common, that cause pneumoconiosis: aluminum, bauxite, beryllium, iron, cotton, tin, talc			

5.4.2.2 Pneumoconiosis Data Collection

From a public health perspective, pneumoconiosis is caused by human activity and can be prevented through appropriate and well characterized dust control. Because of long latency (time from first exposure to development of disease), which can be decades, the number of cases today are based on exposure some 20+ years ago.

Those who visit emergency departments or are hospitalized, appear in hospital discharge data. The Mine Safety and Health Administration keeps another dataset on black lung cases (not represented here). This likely represents a significant undercount because of the lack of recognition of these diseases by health care providers and the lack of collection of occupational history data in the medical record. These data are provided to CDC/NIOSH by the [Illinois Occupational Surveillance Program](#).

Table 5.4.2.2.1. Hospitalized cases and ED visits in Illinois, 2019 from Illinois Hospital Discharge data

	2018	2019		ICD10 codes
	Inpatient, only	E.D. visits	Inpatients	
All pneumoconioses	401	507	390	J60-J66
Coal workers pneumoconiosis	120	212	120	J60
Asbestosis	223	201	208	J61
Silicosis	35	26	26	J62
All other pneumoconioses, combined	25	71	38	J63-J66

6. Hazardous Substances Registry

The Hazardous Substances Registry component of the IHHSR is not funded. As a result, only geocoding activities are performed through support from funded components to create value-added registry data. The geocodes assigned to cancer and birth defect incident reports form the basis for development of a comprehensive geographic information system (GIS) capacity within the IHHSR system.

6.1 Geocoding Process and Accomplishments

6.1.1 Geocoding Cancer and Birth Defects Data

Population-based data for the Illinois State Cancer Registry and the Adverse Pregnancy Outcomes Reporting System were geocoded in-house using software program Map Marker USA v.30®.

The records were assigned geocodes using the North American Datum (NAD) 83 standard, which is the most recent available. NAD is the base set of coordinate readings used to assign latitude and longitude coordinates in the United States. The new standard reflects emerging knowledge about the shape of the earth and corrects for large numbers of surveying errors accumulated in the old datum (NAD27).

The process includes: address standardization; verification of ZIP code based on city; and assignment of ZIP +4 based on address and assignment of latitude and longitude codes, including specificity level of the code or reason the record could not be coded.

The level of completeness for each geocode element varied little by year of diagnosis (see range in Table 6.1.1.1). A detailed quality assessment of the geocoding results for cancer data has been completed and will serve as a reference document for researchers using geocoded registry data.

Table 6.1.1.1 Percentage of IHHSR Reports with Complete Geocoding as of November 2019

Range of Percentage Complete by Diagnosis Year			
	Average all years	Lowest	Highest
Cancer Reports (n=1,874,828 cases for diagnosis years 1986-2017)			
ZIP code	100.0	100.0	100.0
ZIP +4 code	96.3	92.0	99.4
Lat/Lon code ¹	100.0	100.0	100.0
address specific	92.8	87.1	97.2
centroid ZIP +4	0.5	0.3	0.8
centroid ZIP +2	0.6	0.4	1.2
centroid ZIP	6.0	1.8	11.7
APORS Reports (n= 439,665) cases for birth years 1989-2019)			
ZIP code	99.7	97.5	100.0
ZIP +4 code	95.8	92.5	99.4
Lat/Lon code ¹	99.7	97.5	100.0
address specific	94.6	91.6	99.0
centroid ZIP +4	1.1	0.3	1.8
centroid ZIP +2	1.6	0.1	3.7
centroid ZIP	2.3	0.2	5.3
¹ Latitude and longitude			

6.2 Goals for Fiscal Year 2021

- Continue to geocode new records submitted to ISCR and APORS.

7. Cluster Inquiries and Assessments

7.1 Review and Evaluation of Fiscal Year 2020 Goals

- Responded to all inquiries with information and educational materials regarding cancer diseases.

7.2 Fiscal Year 2020 Accomplishments

In FY20, IDPH received three requests for assistance concerning perceived cancer excesses. The response protocol requires staff to first discuss general epidemiologic information about cancer with the caller, explain the cluster protocol and expected outcomes, and send educational materials when appropriate. Staff used published cancer rates by county, epidemiologic reports, and data from the public data files or general information about the frequency of cancer or causes of cancer to help address caller concerns.

7.3 Fiscal Year 2021 Objectives

- Respond to all inquiries with information and educational materials regarding cancer diseases.
- Complete cluster assessments within 12 months of the written request if there is a known carcinogenic exposure and a cancer assessment is launched.

8. Research Program

The research section of the IHHSR provides a crucial link between data collection and data dissemination and between raw data and information. Through various formats, registry data were summarized, tabulated, analyzed, presented, and disseminated to policy makers, health professionals, and the public.

One registry staff member leads the IDPH Modeling and Data Intelligence Team contributing to the IDPH COVID-19 response. Another is part of the modeling team, and other staff members have assisted with analyses. Registry staff have examined patterns and trends in cases, testing, positivity, hospital resource use, and deaths trends. They also have forecast future trends and resource needs.

8.1 Fiscal Year 2020 Major Accomplishments

8.1.1 Provision of Epidemiologic Support to IDPH Committees and Workgroups

Division of Epidemiologic Studies staff continued to co-chair and participate in IDPH's IRB, Opioids projects/databases, IDPH Academic Partnership, IVRS Steering Committee, and Internal Data Sharing Workgroup. Six staff serve on different committees in various capacities. Division staff also supported data activities related to the response to the COVID-19 pandemic.

8.1.2 Provision of Peer-Review Service to Scientific Publication

Division of Epidemiologic Studies staff continued to provide professional reviews to the Journal of Health Security.

8.1.3 Provision of Epidemiologic Supervision and Tutoring

Division of Epidemiologic Studies staff provided supervisor roles and other assistance to various interns, CDC assignees, and CSTE fellows during FY20.

8.1.4 Publication of the IDPH Illinois Morbidity and Mortality Bulletin (IMMB)

The Division of Epidemiologic Studies continued to publish this bulletin on behalf of IDPH. IMMB targets statewide public health professionals, researchers, and policy makers. The inaugural issue contained three articles. Subsequent issues contained two reports each. A total of nine issues have been published as of the end of FY20. Only one issue was published in FY20. The second issue was postponed due to COVID-19.

8.1.5 Technical Assistance

Technical assistance has been provided by staff to various IDPH offices and divisions in the areas of statistics/epidemiology, research methods, data confidentiality review, Freedom of Information Act (FOIA) and media requests, data linkage, SAS® programming, data analysis and interpretation, data de-

duplication, surveillance system evaluation, quality control, and research data requests. Division of Epidemiologic Studies researchers were frequently called upon by the IDPH Office of the Director, the Institutional Review Board (IRB), and other IDPH programs for expertise on different technical and research issues, such as program evaluation, de-identification of individual data records, the renewal of the Public Health Department Accreditation, and updating State Health Improvement Plan (SHIP) documents and statistics. The Division researchers also continued to provide guidance and technical assistance to IDHFS in its effort to establish new policy and practices for public data release. Division staff also provided interviews and responses to medical requests on various disease issues.

8.1.6 IDPH Institutional Review Board

The Division of Epidemiologic Studies continued to staff the IDPH IRB, with one staff serving as the IRB manager, one as vice-chair, and one serving on the board. A number of data requests from outside researchers and organizations were processed and fulfilled. The IRB also serves as a link between outside researchers and IDPH Responsible Individuals (RIs) in various programs.

8.2 Scientific Publications in Fiscal Year 2020

The following articles have been submitted, accepted or published.

- 8.2.1** Population-based birth defects data in the United States, 2012 –2016: A focus on abdominal wall defects. Stallings EB, Isenburg JL, Short TD, Heinke D, Kirby RS, Romitti PA, Canfield MA, O’Leary LA, Liberman RF, Forestieri NE, Nembhard WN, Sandidge T et al. *Birth Defects Research*. 2019;111:1436–1447.
- 8.2.2** Neural tube defects in pregnancies among women living with diagnosed HIV infection, 15 Jurisdictions, 2013-2017. Reefhuis J, FitzHarris LF, Mahle Gray K, Nesheim S, Tinker SC, Isenburg J, Laffoon BT, Lowry J, Poschman K, Cragan JD, Stephens FK, Fornoff JE, Ward CA, Tran T, Hoover AE, Nestoridi E, Keranske L, Piccardi M, Boyer M, Knapp MM, Ibrahim AR, Browne ML, Anderson BJ, Shah D, Forestieri NE, Maxwell J, Hauser KW, Obiri GU, Blumenfeld R, Higgins D, Espinet CP, López B, Zielke K, Jackson LP, Shumate C, Russell K, Lampe MA. *Morbidity and Mortality Weekly Report* 2019; 69: 1-5.
- 8.2.3** Mahale P, Weisenburger DD, Kahn AR, Gonsalves L, Pawlish K, Koch L, Gomez M, Clarke C, Copeland G, Alverson G, Shiels M, Engels E. Anaplastic large cell lymphoma in human immunodeficiency virus-infected people and solid organ transplant recipients [published online ahead of print, 2020 Jun 8]. *Br J Haematol*. 2020;10.1111/bjh.16778. doi:10.1111/bjh.16778.
- 8.2.4** Spector L, Brown M, Wantman E, Letterie G, Toner J, Doody K, Ginsburg E, Williams M, Koch L, Schymura M, Luke B. Association of In Vitro Fertilization with Childhood Cancer in the United States. *JAMA Pediatrics* 2019 Apr 1:e190392. DOI: 10.1001/jamapediatrics.2019.0392.

- 8.2.5** Population-Based Surveillance for Birth Defects Potentially Related to Zika Virus Infection — 22 States and Territories, January 2016–June 2017. Smoots, AN; Olson SM; Cragan J; Delaney A; Roth NM; Godfred-Cato S; Jones AM; Nahabedian J; Fornoff J; Sandidge T *et al.* *Morbidity and Mortality Weekly Report* 2020;69:67–71. DOI: [https://dx.doi.org/10.15585/mmwr.mm6903a3external icon](https://dx.doi.org/10.15585/mmwr.mm6903a3external%20icon)
- 8.2.6** Prevalence of Birth Defects among Infants with Neonatal Abstinence Syndrome (NAS) in Illinois, 2015–2016 Fornoff, J, Sandidge T. *Birth Defects Research In press.*

8.3 Other Recent Reports or Publications That Used Registry Data

- 8.3.1** March of Dimes. *Peristats*. Available at <https://www.marchofdimes.org/Peristats/ViewSection1.aspx?reg=17&slev=4&sec=5>
- 8.3.2** Grosse S, Berry R, Tilford J, Kucik J, Waitzman N. Retrospective Assessment of Cost Savings from Prevention. *American Journal of Preventive Medicine* 2016 May volume 50, issue 5, Supplement 1, Pages S74-S80.
- 8.3.3** Birth Defects Research Part A: Clinical and Molecular Teratology Volume 111, Issue 18, November 2019, Pages: S23-S25.
- 8.3.4** Quinn T Ostrom, Gino Cioffi, Haley Gittleman, Nirav Patil, Kristin Waite, Carol Kruchko, Jill S Barnholtz-Sloan, CBTRUS Statistical Report: Primary Brain and Other Central Nervous System Tumors Diagnosed in the United States in 2012–2016, *Neuro-Oncology*, Volume 21, Issue Supplement_5, October 2019, Pages v1–v100.
- 8.3.5** U.S. Centers for Disease Control and Prevention. *State Cancer Profiles*. Interactive query available at <http://statecancerprofiles.cancer.gov/>; U.S. Department of Health and Human Services, U.S. Centers for Disease Control and Prevention.
- 8.3.6** U.S. Cancer Statistics Working Group. U.S. Cancer Statistics Data Visualizations Tool, based on 2019 submission data (1999–2017): U.S. Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute; www.cdc.gov/cancer/dataviz, June 2020.
- 8.3.7** National Program of Cancer Registries and Surveillance, Epidemiology, and End Results SEER*Stat Database: NPCR and SEER Incidence – U.S. Cancer Statistics 2001–2017 Public Use Research Database, 2019 submission (2001–2017), United States Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute. Released June 2020. Available at www.cdc.gov/cancer/uscs/public-use.

- 8.3.8** National Program of Cancer Registries and Surveillance, Epidemiology, and End Results SEER*Stat Database: NPCR and SEER Incidence – U.S. Cancer Statistics 2005–2017 Public Use Research Database, 2019 submission (2005–2017), United States Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute. Released June 2020. Available at www.cdc.gov/cancer/uscs/public-use.
- 8.3.9** Sherman R, Firth R, Charlton M, De P, Green D, Hofer B, Hofferkamp J, Hsieh M, Johnson C, Kohler B, Morawski B, Nash S, Qiao B, Wier H (eds). *Cancer in North America: 2013-2017. Volume One: Combined Cancer Incidence for the United States, Canada and North America*. Springfield, IL: North American Association of Central Cancer Registries, Inc. June 2020.
- 8.3.10** Gerlovin H, Michaud DS, Cozier YC, Palmer JR. Oral health in relation to pancreatic cancer risk in African American women. *Cancer Epidemiol Biomarkers Prev* 2019;28(4):675-9. doi: 10.1158/1055-9965.EPI-18-1053.
- 8.3.11** Sherman R, Firth R, De P, Green D, Hofferkamp J, Johnson C, Kohler B, Charlton M, Hofer B, Hsieh M, Nash S, Qiao B (eds). *Cancer in North America: 2012-2016. Volume Two: Registry-specific Cancer Incidence in the United States and Canada*. Springfield, Ill.: North American Association of Central Cancer Registries, Inc. May 2019.
- 8.3.12** Sherman R, Firth R, Charlton M, De P, Green D, Hofer B, Hofferkamp J, Hsieh M, Johnson C, Kohler B, Morawski B, Nash S, Qiao B, Wier H (eds). *Cancer in North America: 2013-2017. Volume Two: Registry-specific Cancer Incidence in the United States and Canada*. Springfield, IL: North American Association of Central Cancer Registries, Inc. June 2020.
- 8.3.13** Henley SJ, Ward EM, Scott S, et al. Annual report to the nation on the status of cancer, part I: National cancer statistics. *Cancer*. 2020;126(10):2225-2249. doi:10.1002/cncr
- 8.3.14** American Cancer Society. *Cancer Facts & Figures 2020*. Atlanta, GA.: American Cancer Society; 2020.
- 8.3.15** Noone AM, Pfeiffer RM, Dorgan JF, Magder LS, Bromber JS, Lynch CF, Morris CR, Pawlish KS, Engels EA. Cancer-attributable mortality among solid organ transplant recipients in the United States: 1987 through 2014. *Cancer*. 2019 Aug 1; 125(15):2647-2655. doi: 10.1002/cncr.32136.
- 8.3.16** Fraser GE, Cosgrove CM, Mashchak AD, Orlich MJ, Altekruise SF. Lower rates of cancer and all-cause mortality in an Adventist cohort compared with a US Census population. *Cancer* 2019 Nov 25. doi: 10.1002/cncr.32571.
- 8.3.17** Orlich MJ, Chiu THT, Dhillon PK, Key TJ, Fraser GE, Shridhjar K, Agrawal S, Kinra S. Vegetarian Epidemiology: Review and discussion of findings from

geographically diverse cohorts. *Adv Nutr* 2019 Nov 1;10(Suppl_4):S284-S295. doi: 10.1093/advances/nmy109. PMID: 31728496.

- 8.3.18** Johnson C, Wilson R, Sherman R, Firth R, Charlton M, De P, Green D, Hofer B, Hofferkamp J, Hsieh M, Kohler B, Morawski B, Nash S, Qiao B, Wier H (eds). *Cancer in North America, 2013-2017. Volume Four: Cancer Survival in the United States and Canada 2010-2016*. Springfield, Ill.: North American Association of Central Cancer Registries, Inc. June 2020.
- 8.3.19** National population-based estimates for major birth defects, 2010–2014. Mai CT, Isenburg JL, Canfield MA, et al. *Birth Defects Research*. 2019; 111:1420–1435.
- 8.3.20** Predictive value of indicators for identifying child maltreatment and intimate partner violence in coded electronic health records: a systematic review and metaanalysis. Syed S, Ashwick R, Schlosser M, Gonzalez-Izquierdo A, Li L, Gilbert R. *Archives of Disease in Childhood*. Published Online First: 11 August 2020. doi: 10.1136/archdischild-2020-319027.
- 8.3.21** Johnson CJ, Mariotto A, Qiao B, Huang B, Morawski B, Turner D, Weir H, Ellison L, Sherman R, Wilson R, Firth R (eds). *Cancer in North America: 2013-2017 Volume Five: Cancer Prevalence in the United States and Canada 2007-2016*. Springfield, IL: North American Association of Central Cancer Registries, Inc. June 2020.
- 8.3.22** Henley SJ, Thomas CC, Lewis DR, et al. Annual report to the nation on the status of cancer, part II: Progress toward Healthy People 2020 objectives for 4 common cancers. *Cancer*. 2020;126(10):2250-2266. doi:10.1002/cncr.32801.
- 8.3.23** Fortner RT, Poole EM, Wentzensen NA, Trabert B, et al. Ovarian cancer risk factors by tumor aggressiveness: An analysis from the Ovarian Cancer Cohort Consortium. *Int J Cancer*. 2019 Jul 1;145(1):58-69. doi: 10.1002/ijc.32075. Epub 2019 Jan 14. PMID 30561796.
- 8.3.24** Trabert B, Tworoger SS, O'Brien KM, Townsend MK, Fortner RT, et al; Ovarian Cancer Cohort Consortium (OC3). The Risk of Ovarian Cancer Increases with an Increase in the Lifetime Number of Ovulatory Cycles: An Analysis from the Ovarian Cancer Cohort Consortium (OC3). *Cancer Res*. 2020 Mar 1;80(5):1210-1218. doi: 10.1158/0008-5472.CAN-19-2850. Epub 2020 Jan 13. PMID: 31932455.
- 8.3.25** Fraser GE, Jacobsen BK, Knutsen SF, Mashchak A, Lloren JI. Tomato consumption and intake of lycopene as predictors of the incidence of prostate cancer: the Adventist Health Study-2. *Cancer Causes Control*. 2020 Feb 25. doi: 10.1007/s10552-020-01279-z. [Epub ahead of print]. PMID: 32100191.

- 8.3.26** Freeman VL, Naylor KB, Boylan EE, et al. Spatial access to primary care providers and colorectal cancer-specific survival in Cook County, Illinois. *Cancer Med.* 2020;9(9):3211-3223. doi:10.1002/cam4.2957.

8.4 Epidemiologic Report Series

The following reports were released in IDPH's Epidemiologic Report Series; all reports are available to the public upon request:

Swenny M, Wamack J. *Census of Fatal Occupational Injuries in Illinois, 2017.* Epidemiologic Report Series 19:01. Springfield, Ill.: Illinois Department of Public Health, July 2019.

Swenny M, Wamack J. *Survey of Occupational Injuries and Illnesses in Illinois, 2017.* Epidemiologic Report Series 19:02. Springfield, Ill.: Illinois Department of Public Health, July 2019.

Swenny M, Wamack J. *Census of Fatal Occupational Injuries in Illinois, 2018.* Epidemiologic Report Series 20:04. Springfield, Ill.: Illinois Department of Public Health, February 2020.

Swenny M, Wamack J. *Survey of Occupational Injuries and Illnesses in Illinois, 2018.* Epidemiologic Report Series 20:05. Springfield, Ill.: Illinois Department of Public Health, February 2020.

Garner K, Shen T. *Illinois State Cancer Incidence Review and Update, 1986-2017.* Epidemiologic Report Series 20:06. Springfield, Ill.: Illinois Department of Public Health, April 2020.

Garner K, Shen T. *Illinois Cancer Mortality Review and Update, 1986-2017.* Epidemiologic Report Series 20:07. Springfield, Ill.: Illinois Department of Public Health, April 2020.

Garner K, Shen T. *Illinois County Cancer Statistics Review Incidence, 2013-2017.* Epidemiologic Report Series 20:08. Springfield, Ill.: Illinois Department of Public Health, April 2020.

8.5 Fiscal Year 2020 Presentations by IDPH Division of Epidemiologic Studies Staff

Title	Event	Date
APORS Data System Training	Sarah Bush Lincoln Hospital by phone	August 2019
APORS Data System Training	SwedishAmerican Hospital (Rockford) by phone	August 2019
APORS Overview and Data System Training	Jackson County Health Department (Murphysboro) by phone	August 2019
RESEARCH-lecture on cancer surveillance to graduate students	UIC School of Public Health in Chicago	October 2019
APORS-Perinatal Hepatitis B	Various hospitals and local health departments via webinar	October 2019
APORS Data System training	Oak Park Health Department (Oak Park) by phone	November 2019
APORS Data System training	Clark County Health Department (Martinsville) by phone	November 2019
APORS Data System Training	HSHS St. Elizabeth's Hospital (O'Fallon) by phone	January 2020
APORS Data System Training	Macon County Health Department (Decatur) by phone	February 2020
APORS Database Training and Program Overview	Greene County Health Department (Carrollton) by phone	June 2020

8.6 Research Data Release and Collaborations

Principal Investigator (Affiliation)	Title	Date	Funding Source
Mark Canfield Texas Department of State Health Services	Study of Selected Birth Defects Among Minorities 1999-2007	July 2012, ongoing*	
Lynn Rosenberg, Sc.D., M.S. Sloan Epidemiology Center Boston University	Black Women's Health Study	February 2007, ongoing	NIH/NCI
Rosalind Ramsey-Goldman, M.D., Dr.PH. Northwestern University	Exposure to Immunosuppressive Drugs and Cancer Risk in Systemic Lupus Erythematosus	August 2004, ongoing	NIH/NCI
Meir Stampfer, M.D. Channing Laboratory Brigham and Women's Hospital	Health Professionals Follow- up Study/Nurses' Health Study I and II	January 2004, ongoing	NIH
Eugenia Calle, Ph.D. American Cancer Society	Cancer Prevention Study II	1995, ongoing	ACS
Brinton, Trabert, Ph.D. National Cancer Institute	Infertility Follow-up Study	2012, ongoing	NCI
Alicia Gilseman, Ph.D. RTI International	Forteo Patient Registry	February 2010, ongoing	Eli Lilly and Company
Mardge Cohen, M.D. Women's Interagency HIV Study (WIHS)	Women's Interagency HIV Study (WIHS)	2000, ongoing	NIH
Garth Rauscher, Ph.D. University of Illinois at Chicago	Comparative Effectiveness of Breast Imaging Modalities: A Natural Experiment	April 2013, ongoing	Agency for Health Research and Quality
Barbara Luke, Ph.D. Michigan State University Logan Spector, Ph.D. University of Minnesota	Assisted Reproductive Technology and Risk of Cancer in Women	January 2014*	NCI
Barbara Luke, Ph.D. Michigan State University Logan Spector, Ph.D. University of Minnesota	Assisted Reproductive Technology and Risk of Childhood Cancer	July 2016*	NCI
Diana Miglioretti, Ph.D.	Risk-Based Cancer Screening in Community Settings	July 2014*	NCI

Principal Investigator (Affiliation)	Title	Date	Funding Source
Gary Fraser, M.D., Ph.D.	Adventist Health Study II	March 2015, ongoing	NCI
Herbert Chen, M.D.	Medullary Thyroid Carcinoma Surveillance Study – A Case- Series Registry	September 2014, ongoing	The MTC Registry Consortium
Alicia Gilseman, Ph.D. RTI International	Osteosarcoma Surveillance Study	September 2014, ongoing	Eli Lilly & Company
Alpa V. Patel, Ph.D.	Cancer Prevention Study III	September 2015, ongoing	ACS
NOTE: Following are definitions of acronyms used in the above table: American Cancer Society (ACS), U.S. Centers for Disease Control and Prevention (CDC), Cancer in North America (CINA), Illinois Department of Children and Family Services (DCFS), Illinois Department of Human Services (DHS), Geographic Information System (GIS), International Agency for Research on Cancer (IARC), National Cancer Institute (NCI), National Institutes of Health (NIH), Women’s Interagency HIV Study (WIHS)			
*Data set released; study remains open			

9. Grants

The table below summarizes the IDPH Division of Epidemiologic Studies grant awards for FY20.

Grant	Agency	Status	Amount	Grant Period
Occupational and Health Survey in Illinois (continuation)	BLS	Funded September 2019	\$122,900	10/1/19 – 9/30/20
Census of Fatal Occupational Injuries in Illinois (continuation)	BLS	Funded September 2019	\$103,800	10/1/19 – 9/30/20
Improvement of Birth Defects Surveillance Program (continuation)	CDC	January 2020	\$210,000	2/1/19 – 1/31/20
National Cancer Prevention and Control Program-National Program of Cancer Care (continuation)	CDC	Funded June 2019	\$1,176,875	7/1/19 – 6/29/20
Perinatal Hepatitis B Program (submitted by IDPH Division of Infectious Disease) (continuation)	CDC	Funded 2018	\$50,000	1/1/20 – 6/30/19
NOTE: Full titles of acronyms used in the above table are U.S. Centers for Disease Control and Prevention (CDC), U.S. Bureau of Labor Statistics (BLS), and Illinois Department of Public Health (IDPH).				

9.1 Funded Grants

The IDPH Division of Epidemiologic Studies received \$1.66 million in grant awards in fiscal year 2020.

9.1.1 Survey of Occupational Injuries and Illnesses in Illinois (formerly Occupational Safety and Health Survey)

IDPH received \$122,900 in September 2019 from BLS to support the 22nd year of the Survey of Occupational Injuries and Illnesses (SOII) in Illinois. This project is described in Section 5.

9.1.2 Census of Fatal Occupational Injuries in Illinois

IDPH received \$103,800 in September 2019 from BLS to support the 28th year of the Census of Fatal Occupational Injuries (CFOI) in Illinois. This project is described in Section 5.

9.1.3 Improvement of Birth Defects Surveillance Program

In January 2020, IDPH received \$210,000 for year five of the fourth round of surveillance grants. The progress for this project is described in Section 4.

9.1.4 National Cancer Prevention and Control Program

In June 2019, CDC awarded IDPH \$8.4 million in funding for the third year of a fourth five-year project period year of the National Cancer Prevention and Control Program. This grant combines two previous separate grants: the National Comprehensive Cancer Control Program and the National Program of Cancer Registries (NPCR). The Division of Epidemiologic Studies received \$1.176 million for the NPCR component, which is in its 25th year. The progress for this project is described in Section 3.

9.1.5 Perinatal Hepatitis B Program

The Division of Epidemiologic Studies received \$50,000 in January 2020 to continue expansion of APORS surveillance and data collection (20th year) to include perinatal hepatitis B and to enhance a tracking system that identifies newborn infants requiring follow-up immunization services. This funding ended in June 2018. The progress for this project is described in Section 4.

9.2 Grant Applications Not Funded

9.2.1 Surveillance, Epidemiology and End Results

In February 2020, the Division of Epidemiologic Studies applied for funding from the National Cancer Institute (NCI) for the Surveillance, Epidemiology and End Results (SEER) program. The proposal was submitted for the eight-year project period and \$19 million in federal funding was requested. To date, NCI has not announced the awards for the SEER program. Becoming a SEER registry has been an objective of the Illinois State Cancer Registry for many years. Funding opportunities for new states to become SEER registries occur infrequently. To become a SEER registry is the epitome of cancer registration and provides additional opportunities for ISCR to participate in research, increase the data collected, and the quality of the data collected.

