



State of Illinois
Department of Public Health

Annual Report Illinois Health and Hazardous Substances Registry

July 2023 through June 2024

December 2024



Annual Report
Illinois Health and Hazardous Substances Registry
July 2023 through June 2024



A Report to Gov. JB Pritzker
and the 104th General Assembly
from the
Illinois Department of Public Health
Sameer Vohra, MD, JD, MA
Director

Prepared by the
Division of Epidemiologic Studies
December 2024

Table of Contents

Acronyms.....	iii
1. Executive Summary.....	1
1.1 Illinois Health and Hazardous Substances Registry (IHHSR) Goal	1
1.2 Fiscal Year 2024 Highlights	2
1.3 Goals for Fiscal Year 2025.....	3
2. Program Data.....	4
2.1 ISCR Data Collection	4
2.2 APORS Data Collection	4
2.3 ODR Data Collection	5
2.4 Registry Data Dissemination, Reports, and Publications	6
3. Illinois State Cancer Registry	7
3.1 Review and Evaluation of Fiscal Year 2024 Goals	8
3.1.1 Maintain Completeness and Timeliness of Reporting of Cancer Incidence Cases to the Illinois State Cancer Registry	8
3.1.2 Maintain and Enhance Activities Related to Physician and Pathology Reporting	8
3.1.3 Provide Training for Reporting Facilities and for Central Registry Staff	8
3.1.4 Ensure Data Quality	9
3.1.5 Maintain Data Use Activities.....	9
3.1.6 Provide Adequate Program Management	10
3.2 Fiscal Year 2024 Major Accomplishments.....	10
3.2.1 North American Association of Central Cancer Registries Gold Certification	10
3.2.2 National Program of Cancer Registries (NPCR) Registry of Excellence	11
3.2.3 Collaboration with State and National Organizations	11
3.2.4 Quality Control Reports	12
3.3 Goals for Fiscal Year 2025.....	12
3.3.1 Maintain Completeness and Timeliness of Reporting of Cancer Incidence Cases to the Illinois State Cancer Registry	12
3.3.2 Provide Training for Reporting Facilities and for Central Registry Staff	13
3.3.3 Ensure Data Quality	13
3.3.4 Maintain Data Use Activities.....	13
3.3.5 Provide Adequate Program Management	14
4. Adverse Pregnancy Outcomes Reporting System	14
4.1 Review and Evaluation of Fiscal Year 2024 Goals	15
4.2 Fiscal Year 2024 Major Accomplishments.....	18
4.2.1 Enhancement of the APORS Database.....	18
4.2.2 Improved Birth Defects Surveillance	18
4.2.3 Evaluation of Case Management Services Provided to APORS Cases.....	19
4.2.4 Linkages with Other Programs and Activities	19
4.2.5 Quality Control Reports	21
4.3 Goals for Fiscal Year 2025.....	21
5. Occupational Disease Registry	22
5.1 Adult Blood Lead Registry (ABLR)	23
5.1.1 Fiscal Year 2024 Accomplishments	23
5.1.2 Goals for Fiscal Year 2025	24
5.2 Census of Fatal Occupational Injuries and Illnesses (CFOI)	24
5.2.1 Review and Evaluation of Fiscal Year 2024 Goals	25
5.2.2 Goals for Fiscal Year 2025	25
5.3 Survey of Occupational Injuries and Illnesses (SOII)	25
5.3.1 Review and Evaluation of Fiscal Year 2024 Goals	26
5.3.2 Survey Process and Achievements for Fiscal Year 2024	26

5.3.3	Goals for Fiscal Year 2025	26
5.4	Illinois Occupational Surveillance Program (IOSP)	26
5.4.1	Occupational Health Indicators	28
6.	Hazardous Substances Registry	31
6.1	Geocoding Process and Accomplishments	31
6.2	Goals for Fiscal Year 2025	32
7.	Cluster Inquiries and Assessments	33
7.1	Review and Evaluation of Fiscal Year 2024 Goals	33
7.2	Fiscal Year 2024 Accomplishments	33
7.3	Fiscal Year 2025 Objectives	33
8.	Research Program	33
8.1	Fiscal Year 2024 Major Accomplishments	33
8.1.1	Provision of Epidemiologic Support to IDPH Committees and Workgroups	33
8.1.2	Provision of Peer-Review Service to Scientific Publication	33
8.1.3	Provision of Epidemiologic Supervision and Tutoring.....	33
8.1.4	Publication of the IDPH Illinois Morbidity and Mortality Bulletin (IMMB)	34
8.1.5	Technical Assistance	34
8.1.6	IDPH Institutional Review Board	34
8.2	Scientific Publications in Fiscal Year 2024	34
8.3	Peer-Reviewed Articles That Used Registry Data	34
8.4	Other Recent Reports or Publications That Used Registry Data	35
8.5	Epidemiologic Report Series	35
8.6	FY 2024 Presentations by IDPH Division of Epidemiologic Studies Staff.....	36
8.7	Research Data Release and Collaborations.....	37
9.	Grants and Contracts The table below summarizes the IDPH Division of Epidemiologic Studies grant awards for FY24.....	39
9.1	Funded Grants and Contracts	40
9.1.1	National Cancer Prevention and Control Program	40
9.1.2	Surveillance, Epidemiology, and End Results.....	40
9.1.3	Perinatal Hepatitis B Program.....	40
9.1.4	Survey of Occupational Injuries and Illnesses in Illinois.....	41
9.1.5	Census of Fatal Occupational Injuries in Illinois.....	41
9.1.6	Illinois Occupational Surveillance Program.....	41

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 and Quality
APORS	Adverse Pregnancy Outcomes Reporting System
ATSDR	Agency for Toxic Substances and Disease Registry
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
FY	Fiscal Year
IBCCP	Illinois Breast and Cervical Cancer Program
ICCCP	Illinois Comprehensive Cancer Control Program
IDCFS	Illinois Department of Children and Family Services
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 Substances Registry
IMMB	IDPH's Illinois Morbidity and Mortality Bulletin
IOSP	Illinois Occupational Surveillance Program
IRB	Institutional Review Board
ISCR	Illinois State Cancer Registry
NAACCR	North American Association of Central Cancer Registries
NAD	North American Datum
NAS	Neonatal Abstinence Syndrome
NBDPN	National Birth Defects Prevention Network
NCCR	National Childhood Cancer Registry
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
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 (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)]. This is the registry's 37th annual report, describing major registry activities and accomplishments from July 2023 through June 2024 (FY24).

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 progress.
- 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.
- 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 data on public health outcomes and hazardous substances; and to use this information in decision making and public health policy development.

1.2 Fiscal Year 2024 Highlights

- Received \$3.4 million in federal funds and \$50,243 from other non-general state revenue sources, primarily through competitive processes, to support the Division of Epidemiologic Studies activities.
- Collected detailed case reports on Illinois residents with 65,397 newly diagnosed cancer cases (2020), 14,503 children with adverse pregnancy outcomes (2023), 1,992 adult lead poisoning cases (2022), 9,013 representative non-fatal occupational disease and injury sample records (2022), and 177 fatal occupational injuries (2022).
- Dr. Jane Fornoff officially accepted the position of division chief in March 2023.
- Responded to five requests for general information about the registry, 10 for epidemiologic reports and registry data, and four special data requests or collaborations from outside researchers.
- Responded to 12 inquiries about perceived cancer excesses in local communities and neighborhoods.
- Released seven reports in the Epidemiologic Report Series and prepared four written reports for registry data quality control studies.
- Authored or co-authored two scientific papers for peer-reviewed journals.
- Data released by the registry were used in at least four published studies by outside researchers.
- Data collected by the IHHSR were 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 27 employees from 27 employers with elevated blood lead levels to the U.S. Occupational Safety and Health Administration (OSHA) for onsite inspection.
- Delivered presentations at four professional meetings.
- Provided leadership and management support to the IDPH Institutional Review Board (IRB). One Division of Epidemiologic Studies staff member served as vice chair, then as chair from March 2024, and one as the IRB's standing coordinator.

- Implemented IRB management software to improve data request handling and developed manuals for IDPH staff and external researchers.

1.3 Goals for Fiscal Year 2025

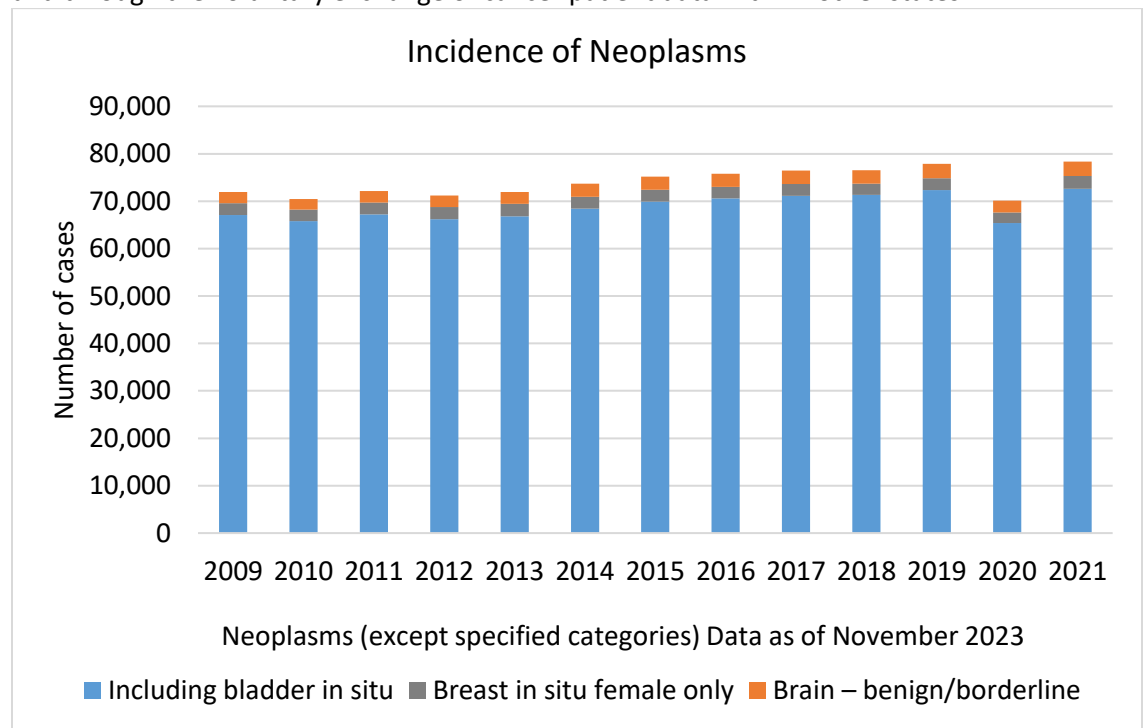
1. Continue to collect complete, timely, and high-quality data to monitor disease distributions and trends among Illinois residents.
2. Engage partners, stakeholders, and communities in data dissemination and utilization to support health research and programs.
3. Respond to public concerns about disease clusters in Illinois with registry data and information.
4. Conduct activities stipulated or required by federal cooperative or research grants and contracts.
5. Pursue grants and other funding opportunities to sustain and enhance the Division of Epidemiologic Studies' programs.
6. Conduct epidemiologic studies with registry data to inform the public health community and policymakers.
7. Provide epidemiological data and information to federal, state, and local health education and intervention programs.
8. Work through 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

Figures under section 2.1 summarize the registry’s data collection and dissemination activities for fiscal year 2024 and compare data from the previous years. To be consistent with the common reporting schedule, numbers in Table 2.1 are expressed in calendar years during which cases were diagnosed or identified. It can take two years for almost all the cases for a specific year to be reported to, or identified by, IHHSR. Due to the registry databases' dynamic nature, the table numbers may not be the same as previously reported. These numbers represent cases processed or estimated by the registry up to the time of this report, 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 are also included.

2.1 ISCR Data Collection

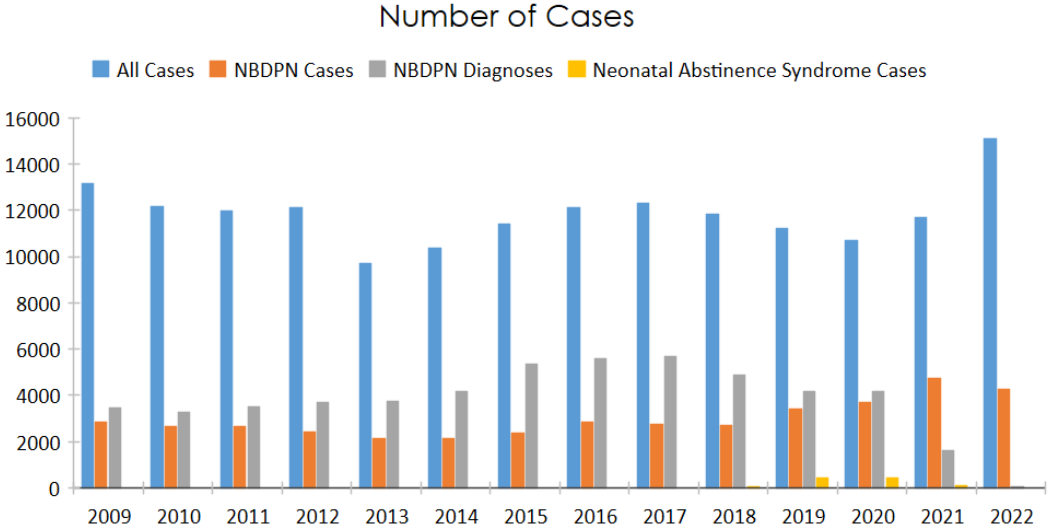
As the only population-based source for cancer incidence information in Illinois, the Illinois State Cancer Registry (ISCR) collects cancer incidence information through mandated reporting by hospitals, ambulatory surgical treatment centers, non-hospital affiliated radiation therapy treatment centers, independent pathology labs, physicians, and through the voluntary exchange of cancer patient data with 11 other states.



2.2 APORS Data Collection

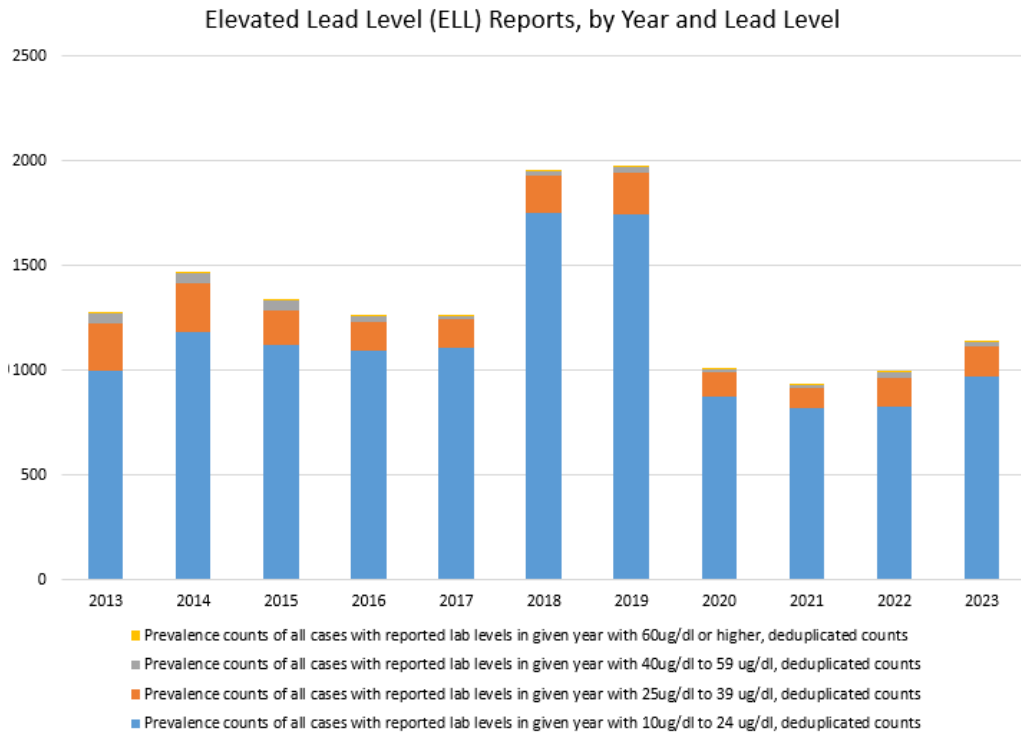
The Adverse Pregnancy Outcomes Reporting System (APORS) collects information on Illinois infants and young children born with birth defects or other abnormal conditions. APORS staff review medical records to ensure the completeness and quality of records for newborns with neonatal abstinence diagnoses (NAS) and birth defects designated by

the National Birth Defects Prevention Network (NBDPN) as core, recommended, or extended surveillance conditions. APORS started routinely reviewing medical records of infants with NAS in 2019.



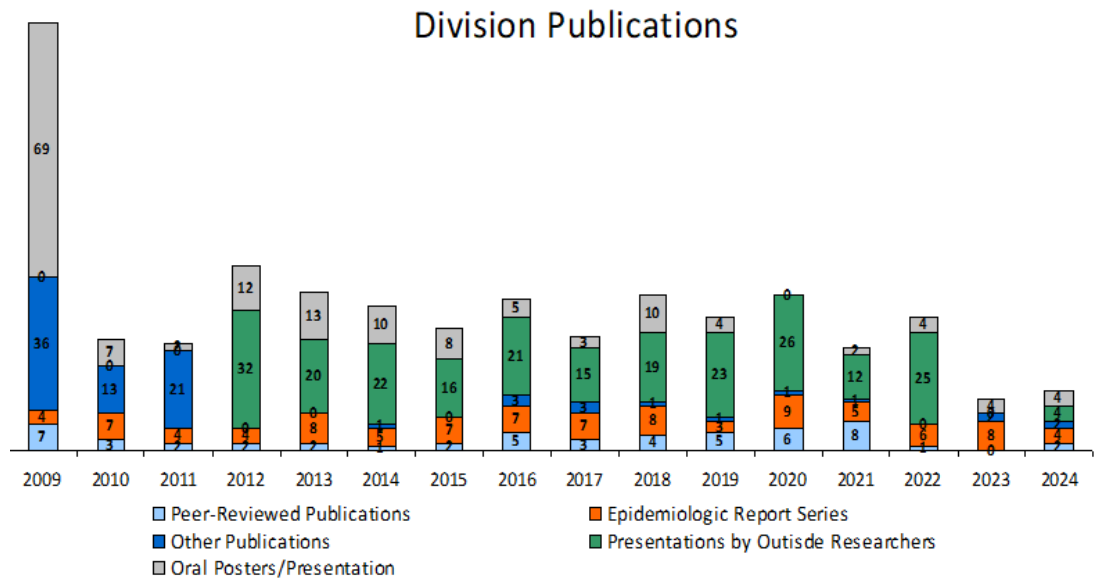
2.3 ODR Data Collection

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). ABLR is a population-based surveillance program of laboratory-reported adult blood levels. ABLR collects data on cases of elevated blood lead levels of 10 micrograms per deciliter (mcg/dL) and above for adults 16 years of age and older and notifies federal enforcement agencies to trigger inspections and/or interventions. Lastly, employees from 10 Illinois companies reported elevated blood lead levels to ABLR. CFOI documents all fatal work injuries in Illinois, collecting information on the circumstances of each fatality and the characteristics of each decedent. SOII surveys a sample of about 6,000 employers about non-fatal workplace injuries and illnesses, as well as the total number of employees and hours worked.

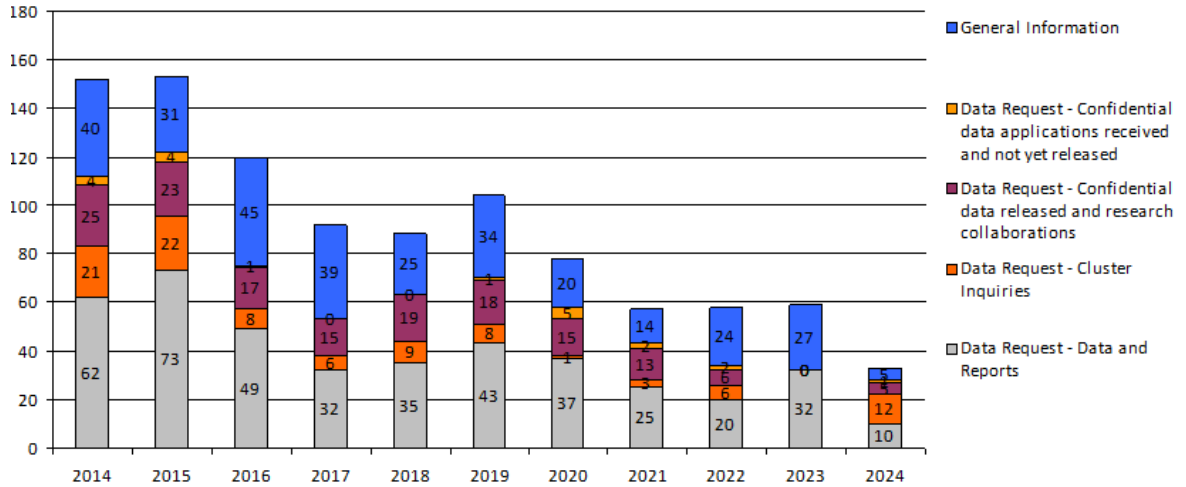


2.4 Registry Data Dissemination, Reports, and Publications

Division staff publish data in various ways, and external researchers also use IHHSR data. The Division of Epidemiologic Studies receives a variety of data requests for existing reports, and non-confidential and confidential data.



Data Requests



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 2021 diagnosis year, ISCR received reports from one Veterans Administration (VA) facility in Illinois.

ISCR continues to require reporting facilities to submit data in an electronic format. There are currently 176 reporting hospitals in Illinois, all reporting electronically. Dermatologists and pathology labs have been set up with access to a web-based reporting system. Ambulatory and radiation therapy centers use the free Abstract Plus reporting software, the Internet-based Web-Plus program, or purchase vendor software.

ISCR staff continue to work in a hybrid work status, receiving, processing, and producing cancer data. Ongoing registry tasks include quality control and assurance activities, data linkage for database enhancement, and training for both ISCR staff and cancer registrars at reporting facilities around the state. ISCR is on track for submission of 2022 diagnosis year data to the National Cancer Institute's (NCI) Surveillance, Epidemiology, and End Results Program (SEER), the U.S. Centers for Disease Control and Prevention's (CDC) National Program of Cancer Registries (NPCR), and the North American Association of Central Cancer Registries (NAACCR) in November 2024.

ISCR became part of the NCI's SEER Program in March 2021 and was awarded a contract totaling \$22,752,223 over seven years. As part of this contract, ISCR participates in bi-annual data submissions, one in October and the second in February, contributing to national cancer surveillance statistics. ISCR also provides data from the October submission to the NCI's National Childhood Cancer Registry.

3.1 Review and Evaluation of Fiscal Year 2024 Goals

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

- Case reporting was maintained via electronic audits and timeliness reviews of reporting facilities. Field staff conducted 14 in-person case finding audits for non-responsive reporting facilities, identifying 528 missed cases and reiterating reporting requirements.
- Completed interstate data exchange by transmitting 3,402 de-duplicated, edited state-specific cases to 11 states and received and processed 9,260 cases from 11 states.
- Completed death clearance for the 2021 death year and maintained a death certificate-only rate of 1.2%. In total, 4,582 cancer diagnoses were followed by 264 letters or lists mailed to hospitals, physicians, nursing homes, and hospice centers.
- Added 96.3% of cases for the 2022 diagnosis year to the ISCR database by December 2023.
- Added 100% of cases for the 2021 diagnosis year to the ISCR database by December 2023.

3.1.2 Maintain and Enhance Activities Related to Physician and Pathology Reporting

- Maintained reporting by physicians and pathology labs.
- Assisted national labs reporting to ISCR in transitioning to the Association of Public Health Laboratories Informatics Messaging Services platform (APHL-AIMS) for submission of pathology data using the NAACCR Standards for Cancer Registries, Volume 5 Laboratory Electronic Reporting for Pathology, Version 5.0 standard.

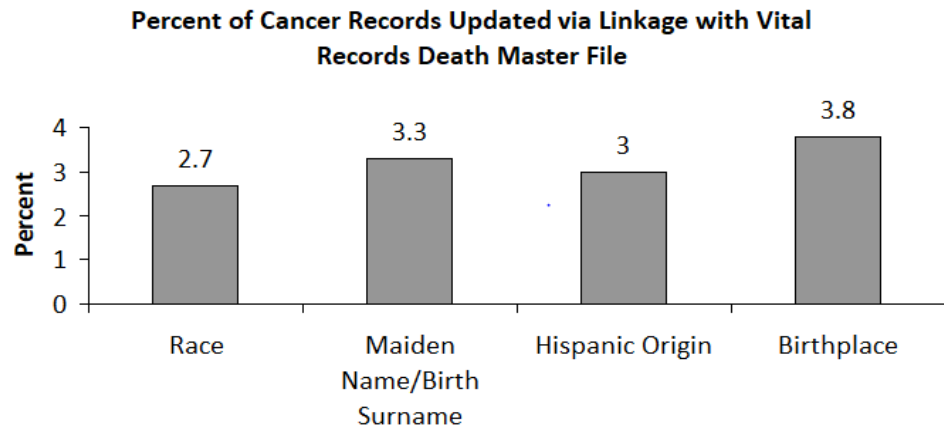
3.1.3 Provide Training for Reporting Facilities and for Central Registry Staff

- Provided on-demand access to 30 training webinars on various topics through the ISCR training website, including access to cancer site-specific coding training from NAACCR.
- Provided on-demand access to a nine-part "Introduction to Cancer Reporting" webinar training series available to cancer reporters across the state.
- Provided on-demand access to SEER*Abs Introductory Training, which covers free cancer registry reporting software available to facilities. Provided individual phone or email support for 2,102 requests related to technical support and reporting issues.

- Attended the national educational conferences of the National Cancer Registrars Association and the NAACCR, the SEER Advanced Workshops, and the SEER Principal Investigators meeting.
- Provided limited individual training conducted by the quality control field staff, as necessary.
- Provided ongoing educational opportunities for central registry staff through participation in 12 nationally broadcast education webinars.
- Held a joint in-person educational conference with the state professional association, Cancer Registrars of Illinois, which provided five continuing education credits to attendees from around the state.

3.1.4 Ensure Data Quality

- Maintained a duplicate rate of fewer than 1 per 1,000 primary cases.
- Met NPCR/NAACCR/SEER standards for data quality.
- Matched vital records death data to the ISCR database to update unknown values in the latter.



- Applied GenEDITS metafiles to the ISCR database, ran all standard setter-required edits, and performed reconciliation for identified errors.
- Added census tract information to the cancer database. All records were geocoded using the Texas A&M AGGIE geocoder interface within SEER*DMS; 94.0% 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. The percentage of override flags in the ISCR submission file was lower for all associated edits than the NPCR median.

3.1.5 Maintain Data Use Activities

- Produced annual cancer statistics, including public use data files, annual state cancer incidence and mortality reports, annual county cancer incidence reports, and updated the cancer query system.
- Provided general cancer information for cancer inquiries and conducted cancer incidence investigations when a known environmental carcinogenic exposure has been documented.
- Provided data for the Illinois Comprehensive Cancer Control Program (ICCCP).
- Provided data for the Illinois Breast and Cervical Cancer Program (IBCCP).
- Updated incidence projections.
- Submitted 1,910,684 cases to NPCR and NAACCR for the 1995-2021 diagnosis years call for data in November 2023.
- Submitted 1,690,325 cases to SEER for the 2000-2022 diagnosis years call for data in November 2023.
- Submitted 73,798 cases to NPCR and NAACCR for the 2022 diagnosis year call for data in November 2023.
- Submitted 112,589 cases to SEER for the National Childhood Cancer Registry 1995-2021 diagnosis years call for data in November 2023.
- Submitted 1,695,698 cases to SEER for the 2000-2022 diagnosis years call for data in February 2024.

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 and contract deliverables via electronic tracking and an internal database dashboard.

3.2 Fiscal Year 2024 Major Accomplishments

3.2.1 North American Association of Central Cancer Registries Gold Certification

For the 26th 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

NPCR again suspended the Registry of Excellence recognition for the 2023 NPCR data submission due to the COVID-19 pandemic. Nevertheless, ISCR met all standards associated with the Registry of Distinction quality standard, indicating complete, timely, and high-quality data for cancer control activities.

3.2.3 Collaboration with State and National Organizations

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

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

3.2.3.2 Division of Vital Records (IDPH)

Death certificate data from the Division of Vital Records (VR) is 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 is also used to populate an internet-based death query system accessible through a password and ID. Hospital-based cancer registrars use this system 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.

3.2.3.3 North American Association of Central Cancer Registries

ISCR provided comprehensive data from 1995-2021 to NAACCR in response to the call for data and the registry certification process. The data supported research and generated cancer descriptions in North America publications. Staff also participated in various NAACCR committees and workgroups, contributing knowledge and expertise to this volunteer organization.

3.2.3.4 National Program of Cancer Registries (NPCR)

ISCR submitted comprehensive data from 1995-2021 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.

3.2.3.5 NCI's Surveillance, Epidemiology, and End Results (SEER) Program

ISCR submitted comprehensive data from 2000-2021 to the SEER call for data in November 2023 and again for diagnosis years 2000-2022 in February 2024 in accordance with the NCI/SEER contract. These bi-annual data submissions contribute Illinois data to the national cancer surveillance effort and include Illinois in all SEER data products.

3.2.3.6 NCI's National Childhood Cancer Registry (NCCR)

The NCCR is a public health surveillance data resource with the primary goal to better understand the causes, outcomes, effective treatments, and the later effects of cancer among children, adolescents, and young adults in the U.S. ISCR submitted data from 1995-2021 to this effort for the November 2023 call for data.

3.2.3.7 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 breast and cervical cancer screening.

3.2.3.8 CDC Agency for Toxic Substances and Disease Registry (ATSDR)

ISCR is participating in piloting a multi-site investigation into cancer incidence in people living near ethylene oxide emitters. This is in conjunction with the CDC and ATSDR.

3.2.4 Quality Control Reports

3.2.4.1 Redeford B. *Assessment of Duplicate Records for 1995-2022 Diagnosis Years*. Quality Control Report Series 23:05. Springfield, Ill.: Illinois Department of Public Health, October 2023.

3.2.4.2 Squires, K. *Linking Illinois State Cancer Registry Records with Vital Records Death Master File to Enhance Data Completeness*. Quality Control Report Series 23:07. Springfield, Ill.: Illinois Department of Public Health, August 2023.

3.2.4.3 Redeford B. *Review of Breast Cases with Non-Specific Carcinoma and Adenocarcinoma Histologies, 2018-2022*. Quality Control Report Series 23:04. Springfield, Ill.: Illinois Department of Public Health, June 2023.

3.3 Goals for Fiscal Year 2025

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

- Perform limited facility case finding for the 2023 diagnosis year at selected reporting facilities in Illinois and track identified missed cases to ensure reporting.
- Maintain interstate data exchange and complete exchanges by October 2024.

- Continue death certificate clearance and maintain a death certificate only rate of less than 1.5%.
- Achieve 98% case reporting for the 2023 diagnosis year by February 2025
- Achieve 100% case reporting for the 2022 diagnosis year by October 2024.

3.3.2 Provide Training for Reporting Facilities and for Central Registry Staff

- Update and maintain a cancer reporting training website for Illinois cancer reporters.
- Provide 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 associations and grant meetings.
- Update membership status in national associations.

3.3.3 Ensure Data Quality

- Maintain a duplicate rate of less than 0.01% using MatchPro to review submissions for duplicate tumor reports and apply the NAACCR duplicate protocol.
- Meet SEER/NPCR/NAACCR standards for data quality and override flags.
- Perform sex verification using the established ISCR procedure.
- Apply SEER, NPCR, NAACCR, and Illinois-specific GenEDITS metafiles to the ISCR database to reconcile 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.

3.3.4 Maintain Data Use Activities

- Produce public use data set files, annual state and county incidence reports, annual state mortality report, and update the cancer query system.
- Respond to cluster inquiries.
- Provide data and support for IBCCP and ICCCP.
- Perform linkage with IBCCP and update data files.
- Produce two epidemiologic reports.
- Produce a publication for the layperson on cancer in Illinois.

- Perform linkage with Indian Health Services and update the code for Native American race.
- Process applications for confidential data.
- Update incidence and mortality projections.
- Provide data to the National Childhood Cancer Registry and participate in associated linkage and research activities.
- Submit the 1995-2022 SEER/NPCR/NAACCR/NCCR data files and the preliminary NPCR 2023 data file for the annual call for data in October/November 2024. Submit the preliminary 2022 data file for the SEER call for data in February 2025.

3.3.5 Provide Adequate Program Management

- Hold monthly staff meetings.
- Monitor grant and contract activities.
- Update advisory committee and funding agencies on grant and contract 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 to correct and to prevent developmental problems and other disabling conditions.

APORS cases meet one or more of the following criteria:

- The infant is diagnosed before 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, or cannabis use, during the pregnancy.
- The infant was born at less than 31 completed weeks of gestation.
- A neonatal or fetal death has occurred.
- The infant or young child (less 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.
- 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.

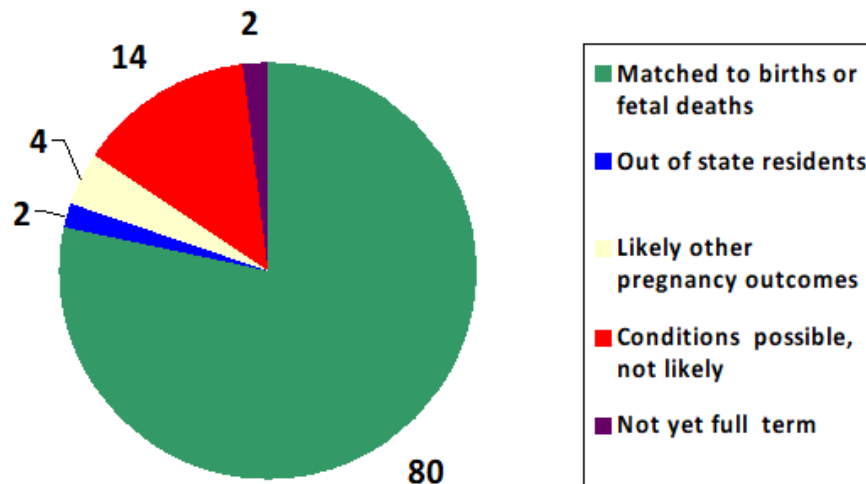
Shelly Reeter, the new APORS manager, was hired March 1, 2024.

4.1 Review and Evaluation of Fiscal Year 2024 Goals

4.1.1 Improve Casefinding

- While webinars were suspended during the COVID-19 pandemic emergency declaration, training in APORS reporting continued through formal online trainings, use of the SharePoint® site for hospital staff, computer-based trainings, conversations with hospital staff, and responses to emailed questions.
- Provided 119 training sessions by phone or WebEx call and held 1,302 consultations via telephone or email with Illinois hospitals to improve APORS reporting.
- Provided 289 consultations to local health departments via telephone or email to improve APORS follow-up.
- Updated the SharePoint® site with revised manuals and appendices and the most recent quality control reports; reminders were posted when patterns of problems were identified.
- In FY24, four genetic clinics reported 94 mothers carrying babies with prenatally suspected significant birth defects.

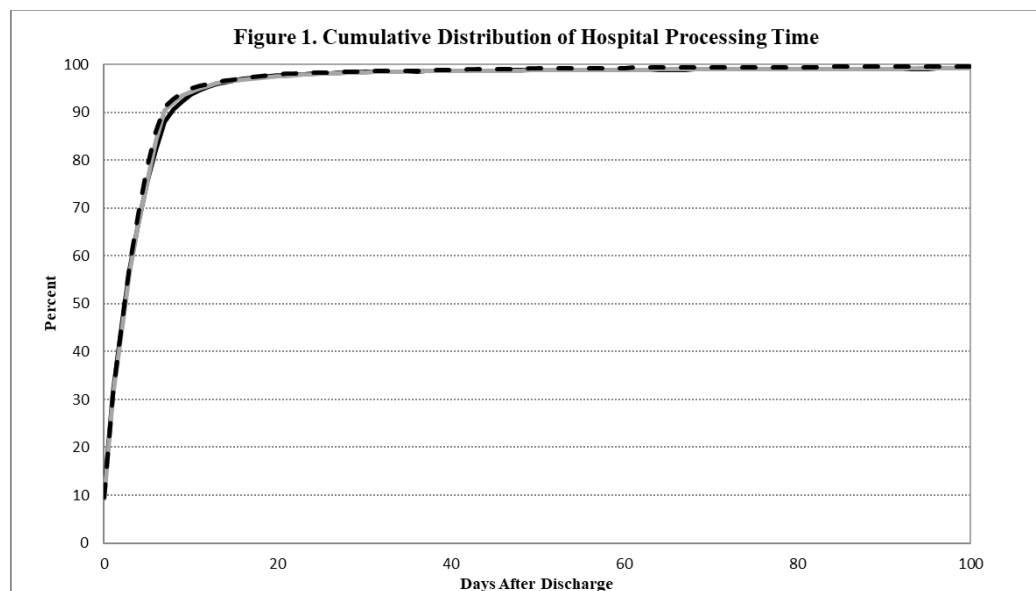
Genetic Clinic Reports of Pregnancies Affected by a Suspected Birth Defect



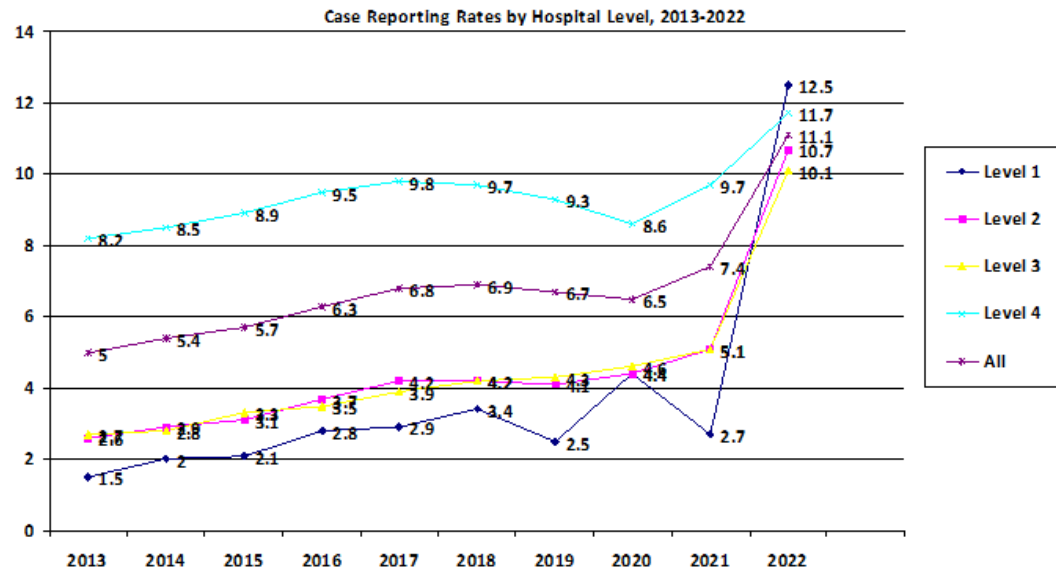
- Reviewed the medical records of 6,197 infants identified from hospital discharge data; 97.99 % of these cases had conditions that met the APORS review criteria.
- Reviewed charts of 1,410 mothers who experienced a fetal death to determine whether any birth defects were associated with the fetus. Of the reviewed charts, 4.8% were confirmed to be cases meeting the APORS criteria.

4.1.2 Improve Quality of APORS Data

- APORS aims to complete active case verification for a birth cohort during the following two years. However, case verification for the 2020 birth cohort was completed late because abstractors were asked to focus on COVID-19 in pregnancy during FY21 and FY22. Data collection for the 2021 and 2022 birth cohorts is not yet complete, but abstractors are working overtime to complete both years by March 2025.
- Evaluated the timeliness of hospital reporting for cases reported in 2022; provided hospital-specific feedback and used results to identify hospital training needs. In 2022, 91.1% 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 more intensive education to non-compliant facilities.



- Abstractors reviewed 109 charts of infants suspected to have neonatal abstinence syndrome (NAS), following the Council of State and Territorial Epidemiologists' recommendations. Of these, 99.6% were confirmed to have NAS. Another 11 cases were identified during chart review for other conditions.
- Hospitals are contacted if a report is incomplete or internally contradictory. These contacts are used as training opportunities when appropriate. If hospital staff are unaware that reports have been automatically generated by the APORS database, APORS staff notify them and ask for the reports to be completed.
- Evaluated the rates of hospital reporting in 2022. Level 1 hospitals reported the highest number of cases. The change in rates and patterns of reporting are results of collecting case data for infants prenatally exposed to cannabis. This data collection began on March 1, 2022.



Improve Program Effectiveness

- The APORS SharePoint® sites have been updated with revised manuals, appendices, and quality control reports. Hospitals and local health departments can also 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 ensure the ongoing provision of perinatal services for high-risk infants.
- A surveillance report examining the prevalence of birth defects and other adverse pregnancy outcomes was published on the Division of Epidemiologic Studies website.

4.2 Fiscal Year 2024 Major Accomplishments

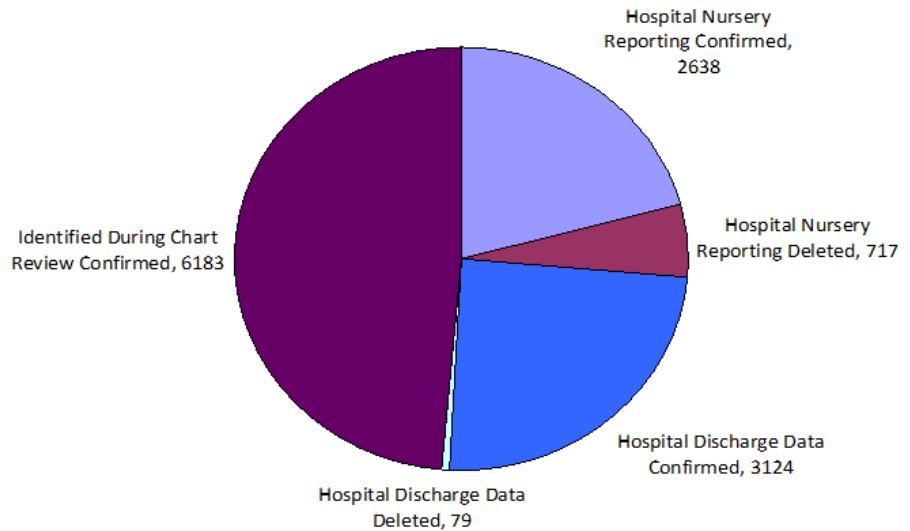
4.2.1 Enhancement of the APORS Database

APORS staff have worked with Vital Records and NetSmart to upgrade the APORS database, a Illinois Vital Records System (IVRS) module. In addition to modernizing the interface, APORS staff can now enter findings from medical records review into the same database as the reported data. This will be a much more efficient process than is currently in place. The system will also automatically generate APORS cases from fetal death certificates, reducing the need for data entry. The upgraded version of IVRS is expected to go live by July 2025.

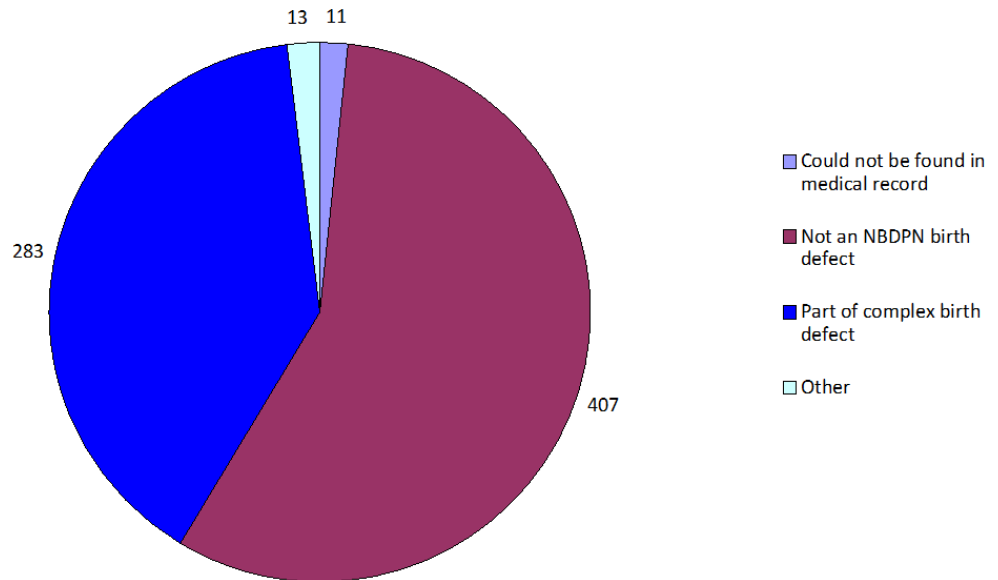
4.2.2 Improved Birth Defects Surveillance

Hospital-reported cases are a starting point for birth defect surveillance. Potential birth defect cases were provided 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 FY24, the abstractors reviewed reports of 4,333 birth defects submitted by hospitals. The charts show, for FY24, the disposition of the conditions reviewed or identified by the APORS staff, and the reasons reported defects were deleted.

Primary Sources of Diagnoses and Review Outcome



Reasons for Deleting a Reported Defect



4.2.3 Evaluation of Case Management Services Provided to APORS Cases

Home nursing visits were suspended during the COVID-19 pandemic. In-person visits slowly began again when the emergency response was lifted in FY23. A survey to evaluate case management services was not undertaken this year.

4.2.4 Linkages with Other Programs and Activities

4.2.4.1 Illinois Department of Human Services High-risk Infant Follow-up.

APORS continued identifying infants for the IDHS perinatal management and high-risk infant tracking program. Most (14,720) infants were referred for contacts by local health department nurses. Counseling for parents is provided through the nurse visits, and referrals to necessary services were offered where possible. Included are 34 children with neural tube defects, whose families were referred for prevention counseling.

4.2.4.2 IDPH Office of Disease Control. APORS identified infants for this office's sexually transmitted disease (158 newborns), HIV (73 newborns), and perinatal hepatitis B and C programs (274 newborns), which ensure infants prenatally exposed to syphilis, HIV, or hepatitis B or C infection are offered services.

4.2.4.3 IDPH Craniofacial Anomaly Program. Data on infants born with cleft lip and/or palate (158 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.

- 4.2.4.4 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 FY24, APORS referred 3,634 cases.
- 4.2.4.5 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 FY24, APORS referred 1,725 cases.
- 4.2.4.6 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 that 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 FY24, APORS referred 94 cases.
- 4.2.4.7 Illinois Department of Children and Family Services (DCFS).** Data are provided to DCFS monthly 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 ensure children receive the services they need in a timely manner.
- 4.2.4.8 Illinois Department of Healthcare and Family Services (IDHFS).** APORS data are provided monthly to IDHFS for inclusion in the Enterprise Data Warehouse. This links APORS surveillance data to case management and public aid data.
- 4.2.4.9 CDC Pregnant People-Infant Linked Longitudinal Surveillance (PILLARS).** CDC determined that IDPH would undertake longitudinal surveillance on three of the proposed outcomes: congenital cytomegalovirus (cCMV), neonatal abstinence syndrome (NAS), and stillbirths (SB). Potential cases will be ascertained from a variety of sources. APORS staff have attended meetings scheduled by the CDC; data collection is ongoing.
- 4.2.4.10 National Birth Defects Prevention Network (NBDPN.)** APORS staff contributed data to and participated in several analyses. APORS staff co-authored a journal article about national population-based estimates for major birth defects. The APORS data manager, Theresa Sandidge, served on the NBDPN Data Committee. The new APORS manager, Shelly Reeter, joined the Program and Professional Development Committee.

4.2.4.11 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 were also notified about the need to provide remote access to electronic medical records and the APORS data system.

4.2.4.12 Pregnancy Risk Assessment Monitoring System (PRAMS.) The APORS data manager served on the PRAMS Steering Committee. The committee recommended the questions that should be retained, added, or dropped from the PRAMS questionnaire.

4.2.4.13 IDPH Master Data Use Agreement. The APORS data manager served on the DUA Steering Committee. The committee provided recommendations about the different levels of data usage and mechanisms for releasing and using data by local health departments who have agreed to the DUA terms.

4.2.5 Quality Control Reports

4.2.6.1 Lingleo L, Sandidge T. *Timeliness Study – Hospital Reports of Adverse Pregnancy Outcomes Received in 2023.* Quality Control Report Series 24:01. Springfield, Ill.: Illinois Department of Public Health, January 2024

4.2.6.2 Sandidge T. *Rates of Hospital Reporting of Adverse Pregnancy Outcomes in 2022.* Quality Control Report Series 24:02. Springfield, Ill.: Illinois Department of Public Health, May 2024

4.3 Goals for Fiscal Year 2025

4.3.1 Improve Casefinding

- Train and support hospitals in the use of the APORS database to ensure cases automatically generated by the database (premature infants, triplets, or higher order births, and those with birth defects marked on the birth certificate) are completed in a timely manner.
- 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 bi-annual hospital discharge information reports to the APORS newborn cases and identify potential birth defect and NAS cases.
- Review medical reports of infants identified in hospital discharge matching to ascertain and collect new birth defect cases.
- Explore the use of hospital discharge data to ascertain infants with prenatal birth defect diagnoses, and women with early induction of labor or excessive vaginal

bleeding to ascertain new birth defect cases. Review maternal medical records where the pregnancy ended with a fetal death to find and collect new birth defect and NAS cases.

- Recruit additional genetic clinics to increase prenatal case findings.

4.3.2 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 regarding 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 regarding 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 (Postponed from FY21 due to the APORS manager and the data steward providing the hospital discharge data being extensively involved in the IDPH COVID-19 response).
- Implement an annual training plan for APORS abstractors.

4.3.3 Improve Program Effectiveness

- Work with Vital Records and Netsmart to test and roll out the new APORS module in IVRS. Train APORS staff, hospital reporters, and high-risk infant follow-up (HRIF) providers in using the new system.
- Work with Brilljent to develop IVRS computer-based training and manuals for APORS reporters and HRIF providers.
- 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 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.
- Produce statewide and county surveillance reports.

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).

The ABLR program is currently maintained by the University of Illinois at Chicago, School of Public Health, Environmental and Occupational Health Sciences. UIC began maintaining the ABLR program in November 2022.

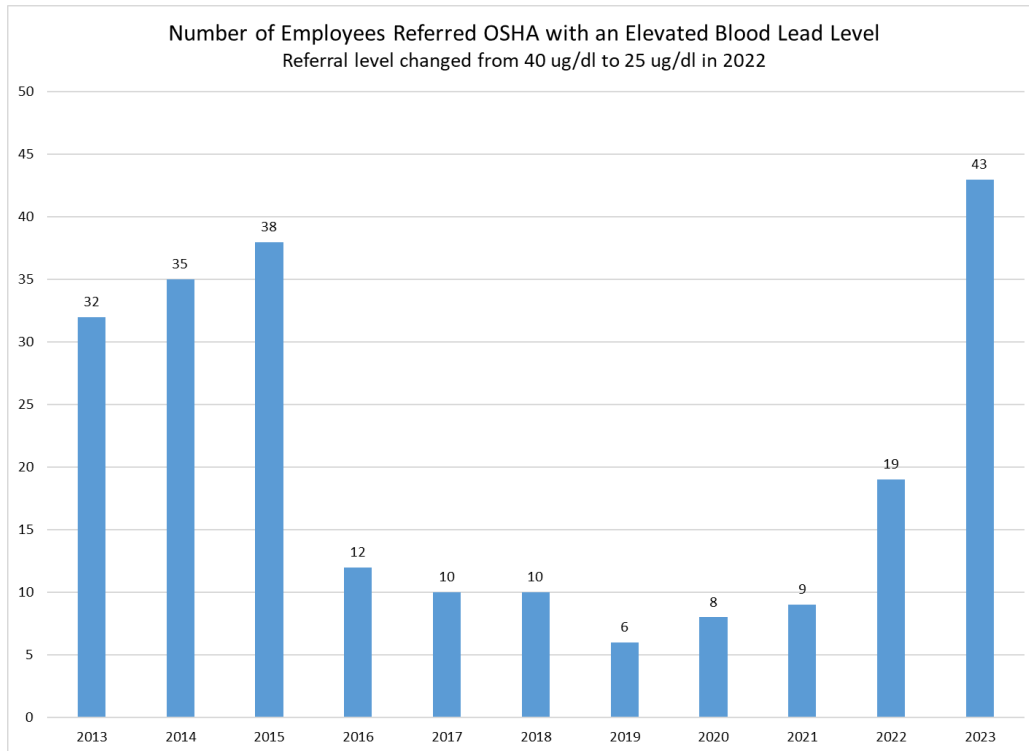
5.1 Adult Blood Lead Registry (ABLR)

ABLR collects data on 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. The Illinois Administrative Code 77 Ill Adm Code 840 defines elevated blood levels as 10 ug/dL or higher. Laboratories are mandated to report results at or above this level. ABLR staff maintain a database of blood lead levels of 10 ug/dL and higher and refer employers with an employee with blood lead levels of at least 25 µg/dL to OSHA in accordance with the memorandum of understanding. In 2023, 1,141 Illinois residents 16 years and older had blood lead levels of 10 ug/dL and higher. Among these, 971 had blood lead levels between 10 and 24.9 ug/dl, 141 had blood lead levels between 25 and 39.9 ug/dl, 24 had blood lead levels between 40 and 59.9 ug/dl, and five had blood lead levels of 60 ug/dl or higher.

In 2022, 345 facilities reported emissions of qualified lead alloys into the environment. Lead is classified as a persistent bioaccumulative toxic (PBT) chemical by the U.S. Environmental Protection Agency. The Illinois facilities reported releasing 1,090,917 total pounds of lead alloys via on-site releases and off-site releases (disposal). Emissions from 68 of the facilities accounted for 99.8% of all lead alloy environmental emissions. These facilities reportedly employed 19,415 workers (Dun and Bradstreet business analytics). Only 10 of the 68 companies participated in medical surveillance by submitting results of blood lead testing to the ABLR program.

5.1.1 Fiscal Year 2024 Accomplishments

- The ABLR program made 43 referrals to OSHA for work-related lead exposures in 2023; 27 referrals were for workers with blood lead levels between 25 and 39.9 ug/dl. The remaining 16 workers had blood lead levels exceeding 40ug/dl. No workers were identified with blood lead levels of 60 µg/dL or higher.
- Referrals made to OSHA in 2023 led to nine inspections resulting in four citations for violations of the OSH Act.



5.1.2 Goals for Fiscal Year 2025

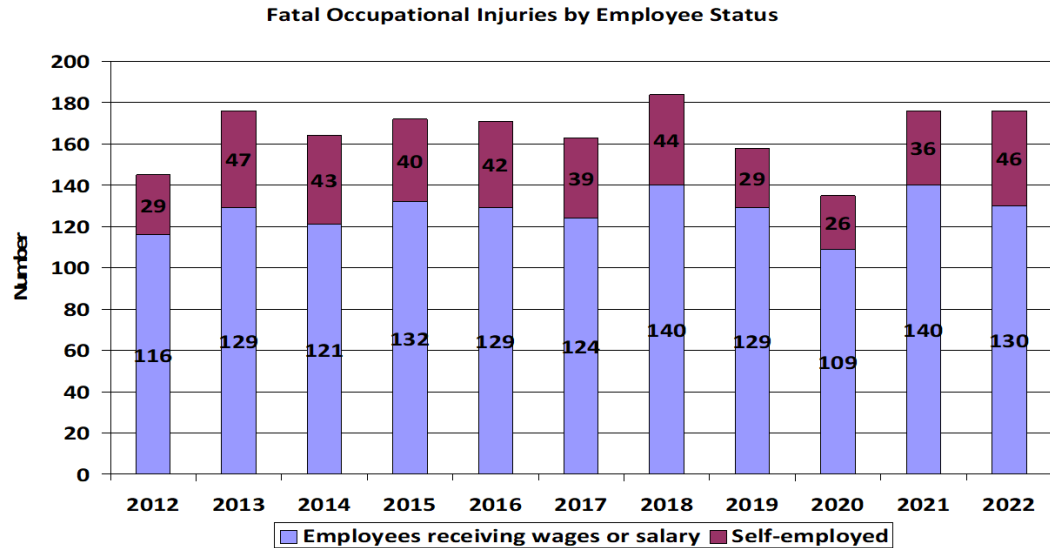
- UIC will notify OSHA quarterly of any company that has employees with elevated blood lead levels equal to or greater than 25 µg/dL.
- UIC will notify OSHA within 24 hours of any case with an elevated blood lead level equal to or greater than 60 µg/dL.
- UIC will work with the Illinois Department of Labor to proactively reach out to all 68 companies identified in the EPA Toxic Release Inventory database to recommend medical surveillance for their workforces. Medical surveillance of workers exposed to lead is proven to improve medical management to mitigate adverse health effects related to lead exposure and reduce cumulative occupational exposures to lead by identifying potential preventative controls.

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 is published each year and contains information on the workers involved and the events surrounding each fatality.

In 2022, Illinois CFOI recorded 177 work-related deaths. CFOI staff currently use several methods of capturing data for the annual reporting of injuries. They currently use a news reporting service that scours local news agencies for potential workplace deaths; the Illinois Vital Records tags and reports any death certificate that is marked workplace

injury; quarterly OSHA reports provided by BLS; the National Highway Transportation and Safety Administration annual spreadsheet; and coroner and medical examiner case fatality form.



Source: U.S. Bureau of Labor Statistics, 2021.

5.2.1 Review and Evaluation of Fiscal Year 2024 Goals

- Completed the summary report of the 2023 fatal occupational injury data. The report is currently under IDPH review.
- Provided information on fatal occupational injuries to the BLS, the funding source, in accordance with the required schedule.

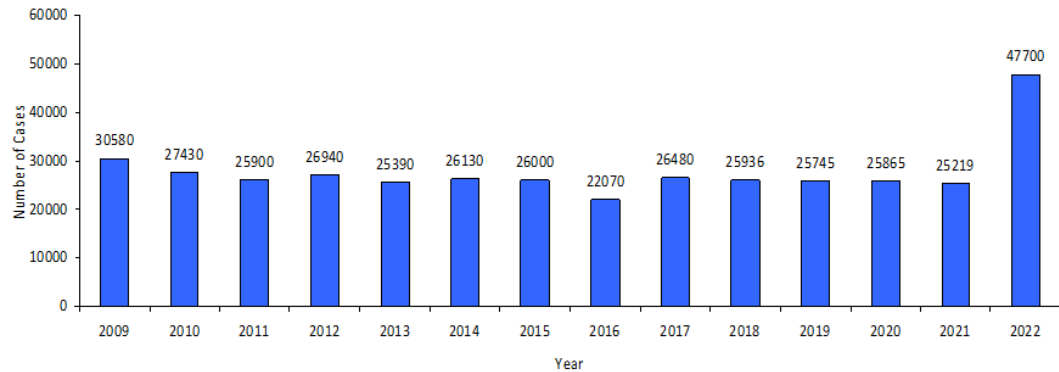
5.2.2 Goals for Fiscal Year 2025

- Publish an enhanced summary report of the 2023 fatal occupational injury data.
- Meet the deadlines for data completion required by BLS.

5.3 Survey of Occupational Injuries and Illnesses (SOII)

SOII focuses on the surveillance of non-fatal workplace injuries and illnesses. The Illinois SOII is supported through a cooperative agreement between the state and the BLS. The Illinois data are pooled with data 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 are also 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.

Survey Case Estimates based on Sampling, 2009-2022



Source: U.S. Bureau of Labor Statistics, 2021.

- Before 2022, BLS only required days away from work (DAFW) cases to be reported. In 2022, BLS started requiring, in addition to the DAFW cases, the reporting of job transfer and restriction (DJTR).

5.3.1 Review and Evaluation of Fiscal Year 2024 Goals

- Submitted data files on all reported occupational injuries and illnesses of the surveyed companies to the BLS.
- Collected, coded, and entered all 2023 data before BLS deadlines.

5.3.2 Survey Process and Achievements for Fiscal Year 2024

- In January 2024, BLS and ODR sent survey forms to a sample of 5,659 private and 369 public employers for 2023 data. A second request for data was sent in February, a third request was sent in April, a fourth request was sent in May, and a fifth request was sent in June (which is a first for Illinois). Non-responding companies were then contacted by telephone and email to solicit data. The final, overall survey response rate was 85.1%, which met the cooperative agreement minimum requirement for data publication at the time of this report.

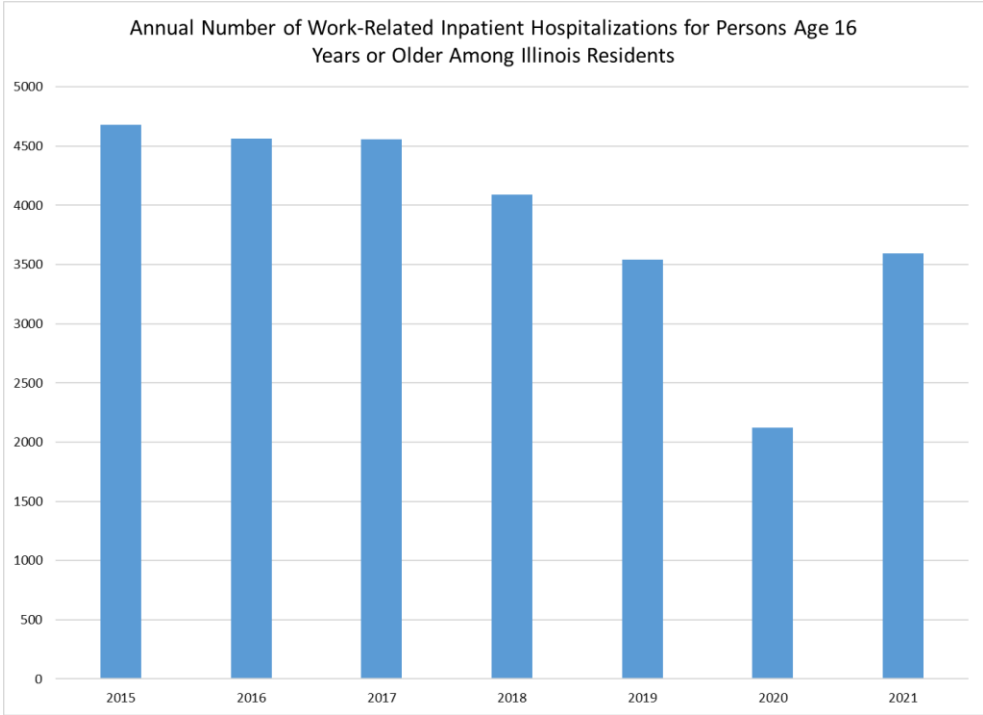
5.3.3 Goals for Fiscal Year 2025

- Continue all data collection activities in FY25 and maintain the high standards achieved by the program.
- Complete the descriptive report of the 2024 Survey of Occupational Injuries and Illnesses.
- Meet the deadlines assigned by BLS.

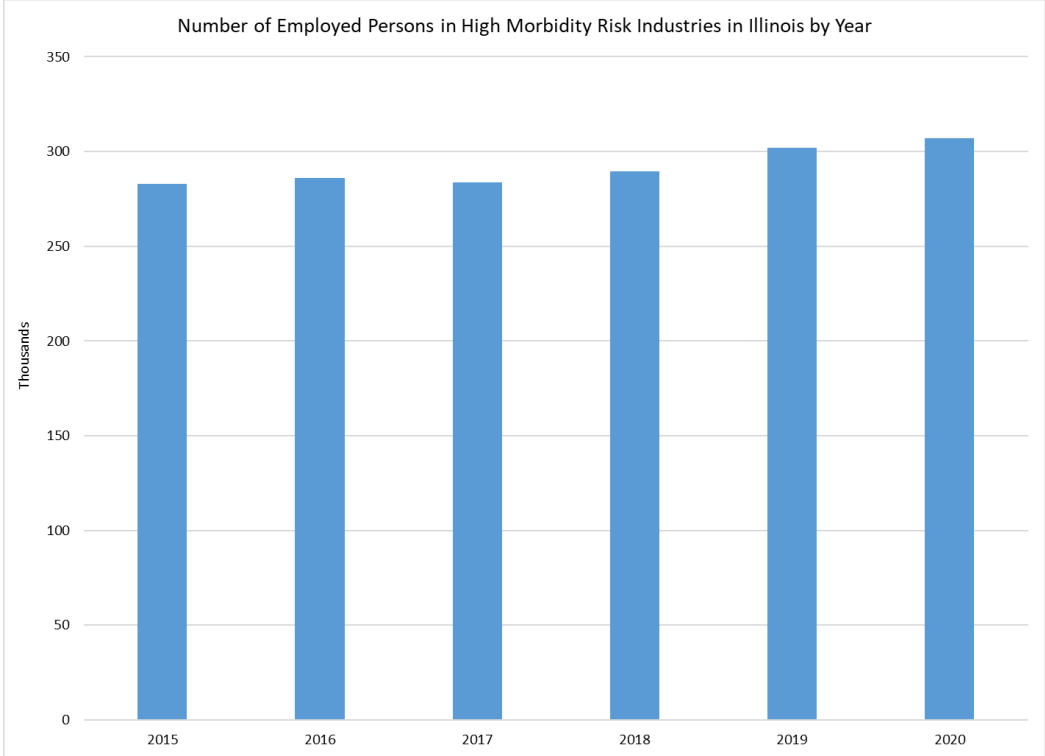
5.4 Illinois Occupational Surveillance Program (IOSP)

The Illinois Occupational Surveillance Program (IOSP; <https://illinoisinjuryprevention.uic.edu/>) is a NIOSH-funded worker surveillance program housed at UIC School of Public Health that collaborates with IDPH and other state agencies. IOSP serves as the bona fide agent of IDPH for this grant program. IOSP is

ending the first year of funding of a five-year cycle and will continue to collaborate with the Occupational Surveillance Program and the Illinois Partnership for Safety, managed by IDPH under the CDC’s Injury and Violence Prevention program. While the number of employed persons aged 16 years or older has remained relatively stable in Illinois over the past 10 years (excluding the decline during the first 12 months of the COVID-19 pandemic), there has been an increase in employment within industries associated with high morbidity risk.



The number of employees in high-morbidity employment is a general proxy measure used by NIOSH and the surveillance states to provide a gross estimate of at-risk workers. These employment numbers represent numbers within a specific NAICS industry; this does not include all workers or any workers who may have subsequent occupational morbidity. More current data is unavailable because the sampling methods for the data source have changed (US Census Bureau County Business Patterns Survey).

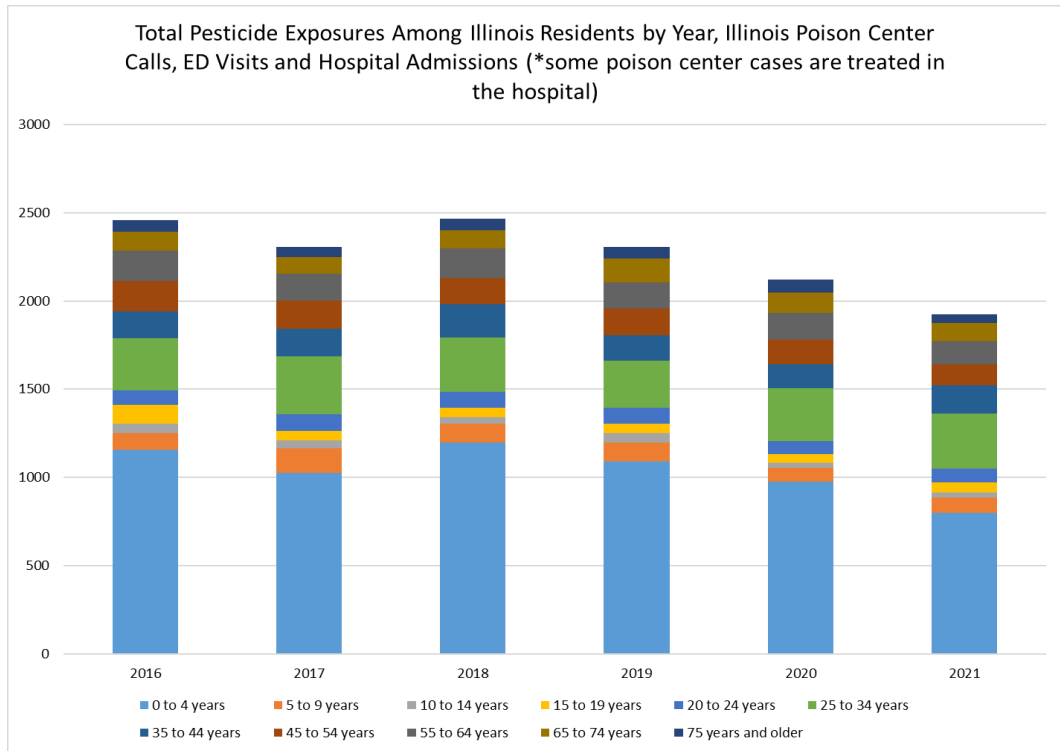


5.4.1 Occupational Health Indicators

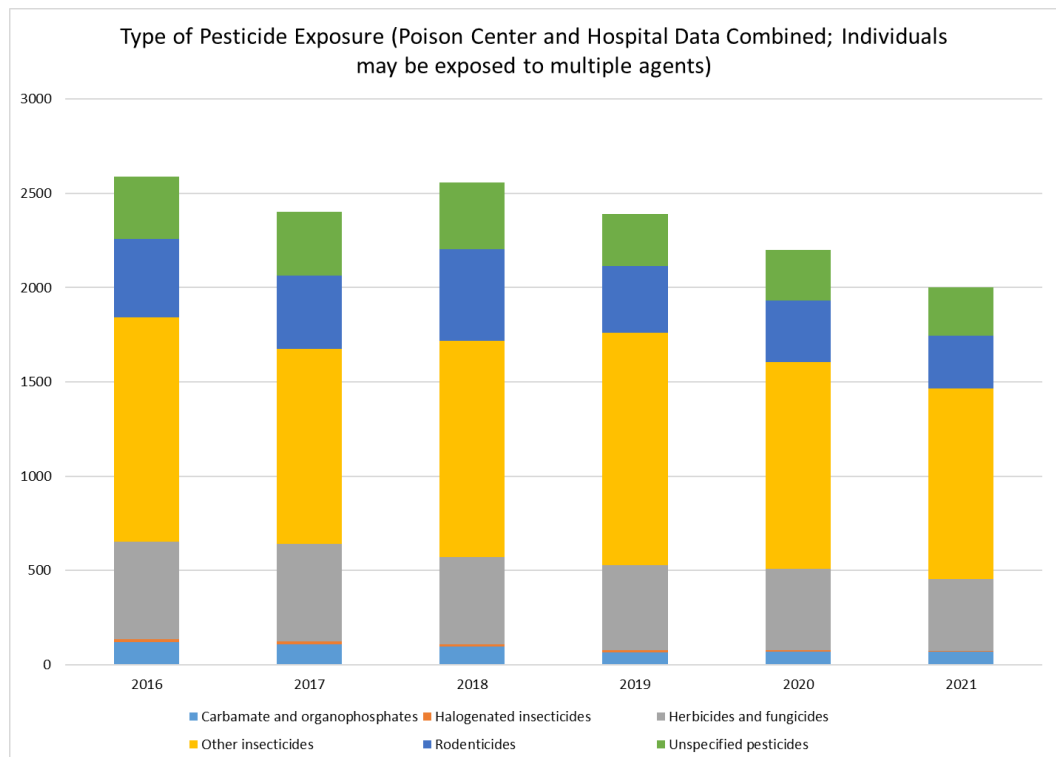
The number of employees forming the baseline for the occupational health indicators does change from year to year. The COVID-19 pandemic had a huge impact, substantially reducing the number of employees in 2020 and 2021.



Almost no pesticide poisonings are work-related (based on NIOSH's case definition of acute pesticide-related illness.) Approximately 3-4% of all pesticide exposures involving Illinois residents are identified as work-related each year. Most work-related exposures involve people between the ages of 25 and 64. Young children (<5 years) are disproportionately exposed to pesticides.



These poisonings are preventable and usually result from a failure to secure pesticides in child-proof containers and store them in child-proof cabinets above ground level. In contrast, many exposures in those 25-34 years of age involve self-harm or a suicide attempt.



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 other funded components to create value-added registry data. The geocodes assigned to cancer and birth defect incident reports form the basis for developing a comprehensive geographic information system capacity within the IHHSR system.

6.1 Geocoding Process and Accomplishments

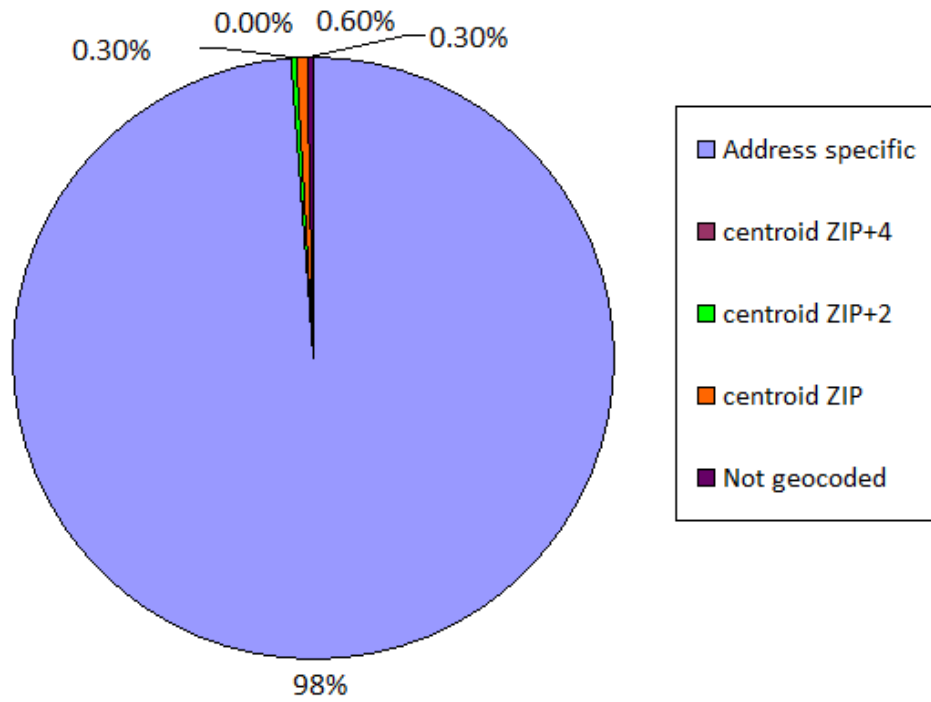
Population-based data for the Illinois State Cancer Registry were geocoded using the Texas A&M AGGIE geocoder interface within SEER*DMS, and the Adverse Pregnancy Outcomes Reporting System was geocoded in-house using the software program Map Marker USA v.31®.

The records were assigned geocodes using the North American Datum (NAD) 83 standard, the most recent available. NAD is the base set of coordinate readings that assign latitude and longitude coordinates in the United States.

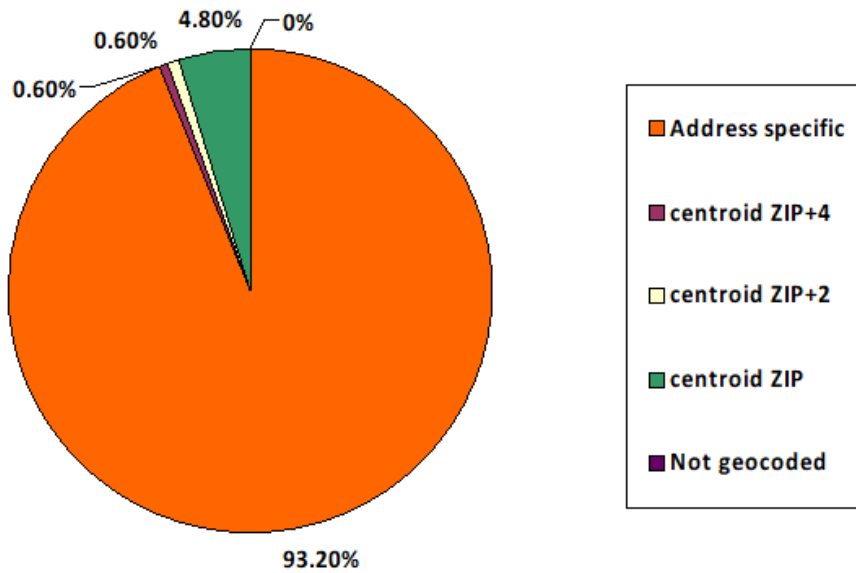
The process includes address standardization, verification of ZIP code based on city, and assignment of ZIP+4 based on address and assignment of latitude and longitude codes, including the specificity level of the code or the reason the record could not be coded.

The level of completeness for each geocode element varies little by year of diagnosis. A detailed quality assessment of the geocoding results for cancer data has been completed and serves as a reference document for researchers using geocoded registry data.

APORS Geocoding Rates 2023



ISCR Geocoding Rates 2023



6.2 Goals for Fiscal Year 2025

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

7. Cluster Inquiries and Assessments

7.1 Review and Evaluation of Fiscal Year 2024 Goals

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

7.2 Fiscal Year 2024 Accomplishments

In FY24, IDPH received 12 requests for assistance concerning perceived cancer excesses. The response protocol requires staff first to 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 its causes to help address caller concerns.

7.3 Fiscal Year 2025 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 dissemination and between raw data and information. Registry data were summarized, tabulated, analyzed, presented, and disseminated through various formats to policymakers, health professionals, and the public.

8.1 Fiscal Year 2024 Major Accomplishments

8.1.1 Provision of Epidemiologic Support to IDPH Committees and Workgroups

Division of Epidemiologic Studies staff continued to co-chair, 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 provided professional reviews to journals.

8.1.3 Provision of Epidemiologic Supervision and Tutoring

Division of Epidemiologic Studies staff provided supervisor roles and other assistance in FY24 to a graduate in the Graduate Public Service Internship Program.

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

Publication of the IMMB has been postponed indefinitely while research staff assist with the COVID-19 pandemic.

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 and de-identification of individual data records. 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 member 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.

In FY23, the IRB procured, customized, and implemented IRB software to streamline the management of IRB applications. Manuals were developed for IDPH staff responsible for data release and for researchers requesting data for human subject research.

8.2 Scientific Publications in Fiscal Year 2024

The following articles have been submitted, accepted, or published.

- 8.2.1 Estimated public health impact of concurrent mask mandate and vaccinate-or-test requirement in Illinois, October to December 2021. Castonguay FM, Barnes A, Jeon, S, Fornoff J, Adhikari BB, Fischer LS, Greening Jr. B, Hassan AO, Kahn EB, Kang GJ, Kauerauf J, Patrick S, Vohra S, Meltzer MI. BMC Public Health 24, 1013 (2024).

8.3 Peer-Reviewed Articles That Used Registry Data

- 8.3.1 Pregnancy and infant outcomes by trimester of SARS-CoV-2 infection in pregnancy—SET-NET, 22 jurisdictions, January 25, 2020–December 31, 2020.

Neelam V, Reeves EL, Woodworth KR, O'Malley Olsen E, Reynolds MR, Rende J, Wingate H, Manning SE, Romitti P, Ojo KD, Silcox K, Barton J, Mobley E, Longcore ND, Sokale A, Lush M, Delgado-Lopez C, Diedhiou A, Mbotha D, Simon W, Reynolds B, Hamdan TS, Beauregard S, Ellis EM, Seo JY, Bennett A, Ellington S, Hall AJ, Azziz-Baumgartner E, Tong VT, Gilboa SM. ; (2023). *Birth Defects Research*, 115(2), 145–159. <https://doi.org/10.1002/bdr2.2081>

8.4 Other Recent Reports or Publications That Used Registry Data

- 8.4.1 American Cancer Society. *Cancer Facts & Figures 2023*. Atlanta, GA.: American Cancer Society; 2023.July 15]. Available from: <https://nccrexplorer.ccdi.cancer.gov>.
- 8.4.2 SEER Cancer Stat Facts: Cancer of Any Site. National Cancer Institute. Bethesda, MD, <https://seer.cancer.gov/statfacts/html/all.html>
- 8.4.3 U.S. Cancer Statistics Working Group. U.S. Cancer Statistics Data Visualizations Tool, based on 2023 submission data (1999-2021): U.S. Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute; <https://www.cdc.gov/cancer/dataviz>, released June 2024.
- 8.4.4 CiNA Explorer: An interactive tool for quick access to key NAACCR cancer statistics based on the Cancer in North American (CiNA) dataset from the North American Association of Central Cancer Registries. Available from (<https://apps.naaccr.org/explorer>) 2024.
- 8.4.5 SEER*Explorer: An interactive website for SEER cancer statistics [Internet]. Surveillance Research Program, National Cancer Institute; 2024 Apr 17. [updated: 2024 Jun 27; cited 2024 Jul 15]. Available from: <https://seer.cancer.gov/statistics-network/explorer/>. Data source(s): SEER Incidence Data, November 2023 Submission (1975-2021), SEER 22 registries.
- 8.4.6 National Program of Cancer Registries and Surveillance, Epidemiology, and End Results Program SEER*Stat Database: NPCR and SEER Incidence – U.S. Cancer Statistics 2001–2021 Public Use Research Database, 2023 submission (2001–2020), United States Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute. Released June 2024. Available at www.cdc.gov/cancer/uscs/public-use.
- 8.4.7 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.

8.5 Epidemiologic Report Series

The following reports were released in IDPH's Epidemiologic Report Series. The reports are available to the public on the Division of Epidemiologic Studies' website.

- 8.5.1 Swenny M, Wamack J. Census of Fatal Occupational Injuries, Illinois 2021. Epidemiologic Report Series 23:08. Illinois Department of Public Health, May 2023

- 8.5.2 Sandidge T, Fornoff JE, Shen T. *Birth Defects and Other Adverse Pregnancy Outcomes in Illinois 2016-2020. A Report on County-Specific Prevalence* Epidemiologic Report Series 24:01, Springfield, Ill.: Illinois Department of Public Health, January 2024.
- 8.5.3 Garner K, Roy S, Koch L, Fornoff J, Kanegan M. Oral Cancer Incidence and Mortality in Illinois, 1991-2020. Epidemiologic Report Series 24:05. Springfield, Ill.: Illinois Department of Public Health, June 2024.
- 8.5.4 Roy S, Garner K, Koch L, Fornoff J. Illinois County Cancer Statistics Review Incidence, 2017-2021. Epidemiologic Report Series 24:02. Springfield, Ill.: Illinois Department of Public Health, June 2024.
- 8.5.5 Roy S, Garner K, Koch L, Fornoff J. Illinois State Cancer Incidence Review and Update, 1986-2021. Epidemiologic Report Series 24:03. Springfield, Ill.: Illinois Department of Public Health, June 2024.
- 8.5.6 Roy S, Garner K, Koch L, Fornoff J. Illinois Cancer Mortality Review and Update, 1986-2021. Epidemiologic Report Series 24:04. Springfield, Ill.: Illinois Department of Public Health, June 2024.

8.6 FY 2024 Presentations by IDPH Division of Epidemiologic Studies Staff

Title	Event	Date
APORS NAS Training and Abstraction, Data Quality Checks Webinar	PILLARS NAS Group	January 2024
Illinois Adverse Pregnancy Outcomes Reporting System APORS database	APORS Training for East Side Health District	February 2024
Illinois Adverse Pregnancy Outcomes Reporting System APORS database	CCDPH Nursing Collaborative, by WebEx	March 2024
APORS database – NAS specific training and QC	NAS PILLARS Group Call, by WebEx	March 2024
Illinois Adverse Pregnancy Outcomes Reporting System APORS database	Beloit Health Systems	April 2024
Illinois Adverse Pregnancy Outcomes Reporting System APORS database	Amita St. Joseph	April 2024
Training the Next Generation of ODS-Certified Cancer Registrars	National Cancer Registrars Association 50 th Annual Educational Conference, Indianapolis, IN	April 2024
Colorectal Cancer in Illinois	Illinois Cancer Partnership Colorectal Roundtable, by WebEx	May 2024
Illinois Adverse Pregnancy Outcomes Reporting System APORS database	Cook County Health Department	May 2024

Illinois Adverse Pregnancy Outcomes Reporting System APORS database	NWM Central DuPage Hospital	May 2024
Cancer Burden in Illinois	Illinois Cancer Partnership Annual Meeting, by WebEx	June 2024
Illinois Adverse Pregnancy Outcomes Reporting System APORS database	Cook County Health Department	July 2024
APORS database	DuPage County Health Department, Wheaton, by WebEx	February 2023
APORS refresher	MacNeal Hospital, Berwyn, by Webex	April 2023
APORS database	HRDI, Chicago, by WebEx	June 2023
Move-It Instructional Video	On-demand training for all reporting facilities	August 2023
What's New for Dermatology 2023	On-demand training for all reporting facilities	August 2023
Cancer Surveillance: Information Source for Cancer Prevention, Control, and Research	University of Illinois Chicago, School of Public Health, virtual	September 2023
ISCR Updates and Common Coding Errors Explained	Cancer Registrars of Illinois Joint Educational Meeting, Springfield	October 2023
Introduction to APORS/HRIF	University of Chicago Hospitals, Chicago, by WebEx	October 2023

8.7 Research Data Release and Collaborations

Principal Investigator (Affiliation)	Title	Date	Funding Source
Alpa V. Patel, Ph.D. American Cancer Society	Cancer Prevention Study II	1995, ongoing	ACS
Audrey French, M.D. Women's Interagency HIV Study	Women's Interagency HIV Study	2000, ongoing	NIH
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
Lynn Rosenberg, Sc.D., M.S. Sloan Epidemiology Center Boston University	Black Women's Health Study	February 2007, ongoing	NIH/NCI
Mark Canfield Texas Department of State Health Services	Study of Selected Birth Defects Among Minorities 1999-2007	July 2012, ongoing	
Gretchen Gierach Benson, Ph.D. National Cancer Institute	Infertility Follow-up Study	2012, ongoing	NCI

Garth Rauscher, Ph.D. University of Illinois at Chicago	Comparative Effectiveness of Breast Imaging Modalities: A Natural Experiment	2013, ongoing	Agency for Health Research and Quality
Herbert Chen, M.D.	Medullary Thyroid Carcinoma Surveillance Study – A Case-Series Registry	2014, ongoing	The MTC Registry Consortium
Alpa V. Patel, Ph.D.	Cancer Prevention Study III	2015, ongoing	ACS
Gary Fraser, M.D., Ph.D.	Adventist Health Study II	2015, ongoing	NCI
Eric Engels, Ph.D. National Cancer Institute	Transplant Cancer Match Study	2016, ongoing	NCI
Dr. Frank Bove, Sc.D.	Cancer Incidence Study of Marines/Navy Personnel and Civilian Employees Exposed to Contaminated Drinking Water at USMC Base Camp Lejeune	2020, ongoing	Agency for Toxic Substances and Disease Registry
Dr. Mayris Webber, Dr.PH.	Maintenance and Extension of a Cohort of Career Firefighters as a Non-WTC Exposed Comparison for the FDNY Firefighter Cohort	2020, ongoing	National Institute for Occupational Safety and Health
Humberto Parada, Jr., Ph.D., M.P.H. San Diego State University	Characterizing the Burden of Cancer among Adults from the Hispanic Community Health Study/Study of Latinos	2022, ongoing	San Diego State University HealthLINK Center for Transdisciplinary Research
Joyce Woo Ann and Robert H. Lurie Children’s Hospital of Chicago	Effects of Illinois perinatal regionalization policy for infants born with congenital heart disease	2022, ongoing	Stanley Manne Children’s Research Institute
Wendy Nembhard University of Arkansas for Medical Sciences	Mortality and Causes of Death among Children with and without Birth Defects in the United States	2022, ongoing	
Natalie Wells, M.D., M.P.H. and Shauna Stahlman, Ph.D., M.P.H.	Study on the Incidence of Cancer Diagnoses and Mortality in Military Aviators and Aviation Support Personnel	2023, ongoing	Armed Forces Health Surveillance Division, Dept. of Defense
John Kaufman, Ph.D., M.P.H.	Multi-site Cancer Incidence Assessment in Response to Community Concerns about Residential Ethylene Oxide (EtO) Exposure Associated with Medical Sterilization Facilities	2023, ongoing	Agency for Toxic Substances and Disease Registry, CDC

NOTE: Following are definitions of acronyms used in the above table: American Cancer Society (ACS), National Cancer Institute (NCI), National Institutes of Health (NIH)

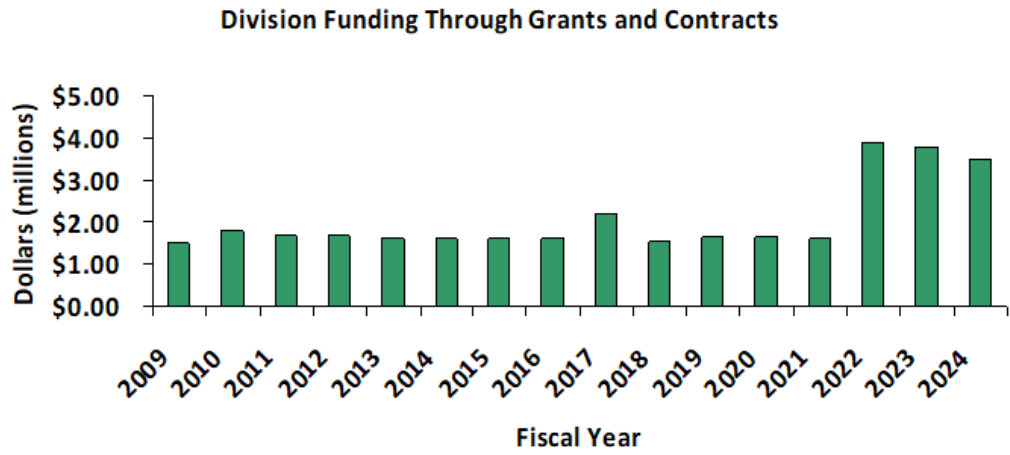
9. Grants and Contracts The table below summarizes the IDPH Division of Epidemiologic Studies grant awards for FY24.

Grant or Contract	Agency	Status	Amount	Grant Period
Occupational and Health Survey in Illinois (continuation)	BLS	Funded September 2023	\$125,600	10/1/23 – 9/30/24
Census of Fatal Occupational Injuries in Illinois (continuation)	BLS	Funded September 2023	\$106,000	10/1/23 – 9/30/24
National Cancer Prevention and Control Program-National Program of Cancer Care (continuation)	CDC	Funded June 2023	\$950,000	7/1/23 – 6/29/24
Surveillance, Epidemiology, and End Results	NCI	Funded March 2021	\$2,389,093	5/1/23 – 4/30/24
Perinatal Hepatitis B Program (submitted by IDPH Division of Infectious Diseases) (continuation)	CDC	Funded 2018	\$50,000	7/1/23 – 6/30/24
Illinois Pregnant People – Infant Linked Longitudinal Surveillance	CDC	Funded September 2023	\$800,000	9/30/23-09/29/24
Illinois Occupational Surveillance Program (IOSP)	NIOSH	Funded July 2021	\$497,218	7/1/21 – 6/30/26

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), National Institute of Occupational Safety and Health (NIOSH), and Illinois Department of Public Health (IDPH).

9.1 Funded Grants and Contracts

The Division of Epidemiologic Studies received \$3.5 million in grants for Fiscal Year 2024. IOSP received \$497,218 in grant awards for the calendar years 2021 - 2026.



9.1.1 National Cancer Prevention and Control Program

In June 2023, the CDC awarded IDPH \$7.81 million in funding for the second year of a five-year project period of the National Cancer Prevention and Control Program. This grant combined two previous grants: the National Comprehensive Cancer Control Program and the National Program of Cancer Registries (NPCR). The Division of Epidemiologic Studies received \$950,000 for the NPCR component, which is in its 30th year. The progress for this project is described in Section 3.

9.1.2 Surveillance, Epidemiology, and End Results

In March 2021, NCI announced Illinois had been chosen for the SEER program and awarded the state a contract totaling \$22,752,223, including state matching funds, over seven years. Becoming a SEER registry has been an objective of the Illinois State Cancer Registry for many years, although funding opportunities for new states to become SEER registries occur infrequently. This achievement is significant and places Illinois in the top echelon of population-based cancer registries. Illinois' participation in the SEER program will significantly expand ISCR's cancer surveillance activities in Illinois to include patient follow-up, enhanced data collection, rigorous quality control of cancer data, and increased opportunities to participate in research projects and collaborations.

9.1.3 Perinatal Hepatitis B Program

The Division of Epidemiologic Studies received \$50,000 in January 2023 to continue the expansion of APORS surveillance and data collection (26th year) to include perinatal hepatitis B and to enhance a tracking system that identifies newborn infants requiring follow-up immunization services. The progress for this project is described in Section 4.

9.1.4 Survey of Occupational Injuries and Illnesses in Illinois

IDPH received \$125,600 in September 2023 from BLS to support the 26th year of the Survey of Occupational Injuries and Illnesses (formerly the Occupational Safety and Health Survey) in Illinois. This project is described in Section 5.

9.1.5 Census of Fatal Occupational Injuries in Illinois

IDPH received \$106,000 in September 2023 from BLS to support the 32nd year of the Census of Fatal Occupational Injuries (CFOI) in Illinois. This project is described in Section 5.

9.1.6 Illinois Occupational Surveillance Program

IOSP received \$497,218 from NIOSH to submit the 25 Occupational Health Indicators for 2021-2026 by calendar year, support the Adult Blood Lead Registry, conduct active surveillance of occupational injuries and illnesses with an emphasis on underserved and precarious workers, expand occupational health informatics, translate research to practice, and train future occupational health researchers. In addition to the basic program (providing indicators, four separate programs were funded: Linking Occupational Surveillance Data, Work Practices, and OSHA Enforcement Activities; Pesticide Related Illness Surveillance Program; COVID-19 Supplemental Project to Address Vaccine Hesitancy among Essential Workers (one year only); and COVID-19 Cases in the Illinois Workers' Compensation Claims (one year only). IOSP has actively developed partnerships between the University of Illinois Chicago and the IDPH, local municipal and county health departments (e.g., Chicago, Cook County, and other agencies across the state), the Illinois Workers' Compensation Commission, the Illinois Department of Labor, the Illinois Environmental Protection Agency, the Illinois Poison Center, the regional and area OSHA offices, state and regional attorney generals, legislators, employers, worker centers, labor attorneys, community advocacy groups, and other stakeholders.