State of Illinois
Department of Public Health

Annual Report Illinois Health and Hazardous Substances Registry

July 2014 through June 2015

September 2015

IDPH
ILLINOIS DEPARTMENT OF PUBLIC HEALTH

Annual Report
Illinois Health and Hazardous Substances Registry
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A Report to Governor Bruce Rauner
and the 99th General Assembly
from the
Illinois Department of Public Health
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Prepared by the
Division of Epidemiologic Studies
September 2015

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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
IRB	Institutional Review Board
ISCR	Illinois State Cancer Registry
NAACCR	North American Association of Central Cancer Registries
NAD	North American Datum
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 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 29th annual report and it describes accomplishments and major research activities from July 2014 through June 2015 (FY15).

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 on health outcomes;
- 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 2015 Highlights

- Received $1.6 million from federal funds and nearly $31,000 from other non-general revenue sources, mostly through a competitive process, to support activities of the Illinois Department of Public Health's (IDPH) Division of Epidemiologic Studies
- Collected detailed case reports on Illinois residents with 64,402 newly diagnosed cancer cases (2012), 9,878 children with adverse pregnancy outcomes (2013), 2,347 adult lead poisoning cases (2014), 38,690 representative non-fatal occupational disease and injury sample records (2013), and 163 fatal occupational injuries (2014)
- Responded to 27 requests for general information about the registry, 77 requests for epidemiologic reports and registry data, and 23 special data requests or collaborations from outside researchers
- Responded to 22 inquiries about perceived cancer excesses in local communities and neighborhoods
- Prepared and submitted five grant proposals to support the registry's operations and research
- Released seven reports in the Epidemiologic Report Series and prepared eight written reports for quality control studies of registry data
- Authored or co-authored two scientific papers for peer-reviewed journals
- Data released by the registry were used in more than 16 published studies by outside researchers
- Actively participated in national and statewide health programs; provided data, information, and epidemiologic support as needed
- Illinois children with adverse birth outcomes were referred to programs that provide follow-up services
- Referred 38 employees from 17 employers with elevated blood lead levels to the U.S. Occupational Safety and Health Administration (OSHA)
- Delivered presentations at eight professional meetings
- Provided leadership and management support to IDPH Institutional Review Board (IRB), with two Division of Epidemiologic Studies staff serving as members, one as vice chair, and one as the IRB's standing coordinator

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), 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 2015. Instead, the council reviewed and approved the annual report via written ballot.

1.4 Goals for Fiscal Year 2016

1. Continue to collect complete, timely, and 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 compared 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 2009	Calendar 2010	Calendar 2011	Calendar 2012	Calendar 2013	Estimated 2014
ISCR Invasive Neoplasms						
(including bladder *in situ*)	66,454	64,904	65,993	64,402	67,130[1]	
Breast *in situ* female only	2,498	2,397	2,479	2,543	2,540[1]	
Brain – benign/borderline[2]	2,167	2,036	2,159	2,090	1,938[1]	
APORS Cases	13,176	12,163	12,037	12,233	9,878[3]	9,750
Occupational Disease Reports						
ABLR lead poisoning						
New reports	282	158	237	484	623[4]	1,060[5]
Total reports	684	619	506	726	2,1614	2,347[5]
Occupational Fatality Cases	186	231	235	146	176	163[5]
Injuries	159	203	177	146	176	163[5]
Illnesses[6]	27	28	54	N/A	N/A	N/A
Occupational Safety and Health Survey[8]						
Estimated Cases	42,730	39,950	38,100[7]	39,630[7]	38,690[7]	38,500
Sprains, strains	16,570	15,910	14,460[7]	14,610[7]	13,580[7]	13,600
Bruises, contusions	3,290	2,930	2,890[7]	3,350[7]	3,110[7]	3,000
Cuts, lacerations	3,750	2,560	3,750[7]	3,510[7]	3,170[7]	3,000
Fractures	3,160	3,080	2,540[7]	3,070[7]	3,340[7]	3,300
Multiple injuries	1,620	1,050	870[7]	830[7]	790[7]	800
Carpal tunnel syndrome	520	520	560[7]	590[7]	380[7]	400
Heat burns	1,020	840	280[7]	590[7]	380[7]	400
Tendonitis	110	170	130[7]	80[7]	200[7]	200
Amputations	320	290	330[7]	190[7]	260[7]	250
Chemical burns	220	80	90[7]	120[7]	180[7]	150
Occupational Illnesses[9]						
Asbestosis	491	466				
Silicosis	63	58				
Coal workers pneumoconiosis	164	149				
Hazardous Substances (GIS)[10]						
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]Collection of benign and borderline brain tumors is required as of the 2004 diagnosis year.

[3] Projected numbers are lower because of the change in the APORS case definition. The biggest impact comes from no longer collecting PDA's (patent ductus arteriosus), PFO's (patent foramen ovale) and cannabis exposure.

[4] IHHSR Rule change to lower threshold for reporting cases of elevated adult lead levels to mirror the federal requirements from ≥25µg/dL to ≥10µg/dL.

[5]Actual counts for 2014.

[6] Operation changes occurred in 2009 when paper death certificates were no longer available for review and in 2012 when BLS changed the operational process to discontinue collecting occupational illnesses. (See Section 5.2)

[7]Starting Collection Year 11, BLS conducted a pilot to collect the same information for cases with job transfer or restriction as it has for cases with days away from work in selected industries.

[8]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.

[9]Inpatient hospital discharge data for Illinois residents with either a primary or secondary diagnosis of asbestosis, silicosis or coal workers pneumoconiosis; numbers represent discharges, not patients and one patient could have been hospitalized numerous times. Data for 2011-2013 are not available due to the vacancy of hospital discharge data staff.

[10]For specific results of geocoding of APORS and cancer cases for the IHHSR, see Section 6.

Table 2.2 Registry Data Dissemination, Reports and Publications

	FY11	FY12	FY13	FY14	FY15	Estimated FY16
Data Requests						
General information	76	66	41	31	27	30
Data and reports	135	163	108	71	77	70
Cluster inquiries[1]	46	47	30	21	22	25
Confidential data released and research collaborations	14	17	24	25	23	20
Confidential data applications	6	9	6	4	4	5
Quality Assurance Studies[2]						
Casefinding visits						
APORS	397	236	225[3]	70[4]	22	15
ISCR	123	213	253	120	74	100
Cases added from casefinding visits						
APORS[5]	2,664	3,182	5,025	4,493	8,350[6]	8,000
ISCR[7]	1,204	1,129	1,689	1,089	856	500
External audits of facility data						
ISCR				179	204	100
Internal quality control reports issued						
APORS	3	3	4	3	6	6
ISCR	1	2	2	4	3	3
Public Use Microdata Files	3	3	3	3	5	5
Publications						
Epidemiologic report series	6	4	7	4	7	5
Peer-reviewed publications	2	2	2	1	2	1
Other publications	21	32	20	22	16	15
Oral/poster presentations	2	12	13	10	8	5
Grant Proposals Funded	7	6	6	5	5	5

[1] Starting in FY04, cluster evaluations were discontinued unless there is a known carcinogenic exposure. Cluster inquiries are presented to more accurately reflect the quantity of work performed.

[2] At the recommendation of the IHHSR Coordinating Council, quality assurance study counts were adjusted beginning FY05 to more accurately reflect the quantity of work performed and the outcome of that effort.

[3] Numbers are lower than FY09-11 because one abstractor resigned in FY13. In addition, more casefinding is being done remotely, reducing the need for visits.

[4] Fewer hospital casefinding visits will be conducted in FY14 onwards because field staff access medical records remotely for almost all reporting hospitals.

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

[6] Represents additional birth defects added from review of children identified from past years from a variety of data sources, and improved abstractor case finding.

[7] Represents cases missed by hospital reporting, but identified by ISCR during casefinding visits.

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 cases 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 2012 diagnosis year, ISCR received reports from five Veteran's Administration (VA) facilities in Illinois.

ISCR continues to require reporting facilities to submit cases 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.

3.1 Review and Evaluation of Fiscal Year 2015 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 17th consecutive year
- Maintained case reporting at all non-federal facilities by conducting 74 facility case finding visits for the 2013 diagnosis year. There were 856 missed cases identified.
- Completed interstate data exchange by transmitting 3,161 de-duplicated, edited state specific cases to 11 states and received and processed 9,604 cases from 10 states.
- Completed death clearance for the 2012 death year and maintained a death certificate only rate of 0.9 percent. In total, 2,327 cancer diagnoses were followed with 4,044 letters or lists mailed to hospitals, physicians, nursing homes, and hospice centers.
- Added 90 percent of cases for the 2013 diagnosis year to the ISCR database by December 2014
- Added 100 percent of cases for the 2012 diagnosis year to the ISCR database by December 2014

3.1.2 Maintain and Enhance Activities Related to Physician and Pathology Reporting

- Maintained reporting by dermatologists and pathology labs

- Expanded reporting by dermatologists in Illinois by 6 percent through focused targeting and training in the central and northern portions of the state

- Expanded electronic reporting with the addition of three new pathology laboratories

3.1.3 Provide Training for Reporting Facilities and for Central Registry Staff

- Provided basic training by entering into a limited, six-month personal services contract with the North American Association of Central Cancer Registries (NAACCR) to provide two basic training sessions, two advanced training sessions, and six staging training sessions; the onsite basic and advanced training sessions were presented in March, April, and May 2015 in south, central, and northern Illinois; the onsite staging training sessions were held in March, April, and June 2015 in south, central, and northern Illinois;. the trainer position (required by the National Program of Cancer Registries (NPCR)) has not been filled

- Provided six "Town Hall" style training webinars on SEER Summary Staging coding followed by a question and answer session for cancer reporters across the state in September, October, November, and December 2014

- Provided a SEER Summary Staging training webinar available on demand to all cancer reporters across the state

- Provided a one-day educational conference in April 2015 for cancer reporters across the state in conjunction with the Cancer Registrars of Illinois

- Provided a nine-part "Introduction to Cancer Reporting" webinar training series available on demand to all cancer reporters across the state

- Provided individual phone or e-mail support for 1,828 requests related to technical support and reporting issues

- Attended the national educational conferences of the National Cancer Registrar's Association and the North American Association of Central Cancer Registries

- Attended the annual educational conference sponsored by the Cancer Registrars of Illinois in September 2014

- Provided access to 43 advanced training workshops for 228 reporters via WebEx® utilizing nationally developed advanced training materials

- Provided limited individual training by the quality control field staff at 18 facilities

- 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 one per 1,000 primary cases
- Met NPCR/NAACCR standards for data quality
- Completed the first linkage between ISCR and the National Death Index (NDI) to identify deceased cases and update both vital status and cause of death.; a total of 21,420 cases were identified as deceased and updated accordingly in the ISCR database
- 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 15,015 cases with an unknown or missing race, 626 (4.1 percent) cases were matched and updated with a valid race; Maiden name: 18,151 cases (3.8 percent) were matched and updated with valid maiden names; Hispanic origin: 343 cases, or 6.3 percent, were matched and updated with valid data element codes for Hispanic origin.; Birthplace: of 477,494 cases with unknown or missing birthplace, 22,975 cases (4.8 percent) were matched and updated with a valid birthplace; Death variable information also was updated
- Added census tract information to the cancer database; All records were geocoded using MapMarker® Version 27 and 91.7 percent of the addresses geocoded to an address specific level
- Ensured override flags were within the NPCR average by reviewing the 2014 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 or Surveillance of Epidemiology and End Results (SEER) 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
- Provided data for the Illinois Comprehensive Cancer Control Program (ICCCP)
- Provided data for the Illinois Breast and Cervical Cancer Program (IBCCP)

- Performed data linkage with the IBCCP file and provided the required information back to the IBCCP program
- Produced one epidemiologic report
- Produced one publication for the layperson on cancer in Illinois
- Produced three quality control reports
- Responded to four applications for confidential data from outside researchers
- Updated incidence projections
- Submitted 1,193,700 cases to NPCR and NAACCR for the 1995-2012 call for data
- Submitted 67,460 cases to NPCR for the 2013 diagnosis year call for data

3.1.6 Provide Adequate Program Management

- Kept registry staff informed of grant progress, standards changes, 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 2015 Major Accomplishments

3.2.1 North American Association of Central Cancer Registries Gold Certification

For the 17th 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 percent or better completeness of case ascertainment; 98 percent validity of information recorded for selected data variables (age, sex, race and state/county); death-certificate only cases less than 3 percent; duplicate primary cases fewer than one per 1,000; 100 percent 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 Collaboration With State and National Organizations

3.2.2.1 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.

3.2.2.2 Illinois Health Data Dissemination Initiative

Staff continued to provide data to the initiative. The ISCR public data set (PDS) file, version 22 (1986-2012) was submitted in April 2015.

3.2.2.3 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 tape 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 from their facilities.

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

3.2.2.4 North American Association of Central Cancer Registries (NAACCR)

ISCR provided comprehensive data from 1995-2012 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.

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

ISCR submitted comprehensive data from 1995-2012 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. The ISCR manager attended the annual CDC-NPCR program directors meeting.

3.2.2.6 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.

3.2.2.7 American Cancer Society (ACS), Illinois Division

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.

3.2.2.8 Simmons Cancer Institute

Staff continued to participate in the establishment of Southern Illinois University School of Medicine's (SIU) Simmons Cancer Institute and its Population Science Program. In particular, registry staff continue to provide data and technical expertise to SIU Simmons Cancer Institute as SIU undertakes activities that support the competitive grant award received in February 2012 from the ACS. Registry staff co-authored a report titled "Cancer in Rural Illinois, 1990-2010 Incidence, Mortality, Staging, and Access to Care." It is anticipated staff will continue to engage in this collaboration.

3.2.3 Quality Control Reports

3.2.3.1 Parrish P. *Assessment of Duplicate Records for 1995-2012 Diagnosis Years.* Quality Control Report Series 14:07. Springfield, Ill.: Illinois Department of Public Health, November 2014.

3.2.3.2 Hebert L. *Linking Illinois State Cancer Registry Records with Vital Records Death Master File to Enhance Data Completeness.* Quality Control Report Series 14:08. Springfield, Ill.: Illinois Department of Public Health, November 2014.

3.2.3.3 Parrish P. *Quality Control on Accuracy of Coding Breslow's Thickness or Depth and Tumor Size for Melanoma Skin Cases for 2013 Diagnosis Year.* Quality Control Report Series 15:05. Springfield, Ill.: Illinois Department of Public Health, April 2015.

3.3 Goals for Fiscal Year 2016

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

- Perform facility casefinding for the 2014 diagnosis year at selected reporting facilities in Illinois and track identified missed cases to ensure reporting
- Maintain interstate data exchange and complete exchanges by November 2015
- Continue death certificate clearance and maintain death certificate only rate of less than 3 percent
- Achieve 90 percent case reporting for the 2014 diagnosis year by December 2015

- Achieve 95 percent case reporting for the 2013 diagnosis year by December 2015

3.3.2 Maintain and Enhance Activities Related to Physician and Pathology Reporting

- Maintain contact with existing dermatology offices for reporting and training (n=126)
- Maintain contact with existing pathology labs for reporting and training (n=11)
- 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 casefinding and implement any additional training needed at newly reporting dermatology offices in Illinois
- Implement Meaningful Use Stage 2 reporting with eligible providers to increase cancer reporting

3.3.3 Provide Training for Reporting Facilities and for Central Registry Staff

- Contract with NAACCR education staff to provide two basic training workshops, two advanced training workshops, and six staging training workshops
- Provide individual phone support for technical and operational issues from cancer incidence reporters and reporting facilities
- Provide access to specialized staging training from NCRA for central registry staff
- 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 percent using Link Plus to review submissions for duplicate tumor reports and apply NAACCR duplicate protocol
- Perform external quality control audits at selected reporting facilities in Illinois, provide facility-level feedback and provide a summary of findings to reporting facilities
- 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

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
- 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 code for Native American race
- Process applications for confidential data
- Update incidence and mortality projections
- Submit the 1995-2013 NPCR/NAACCR file for combined call for data and submit the 2014 data file for NPCR call for data

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 refer children who require special services 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 fewer than 30 weeks of gestation; or
- a neonatal or fetal death has occurred.

4.1 Review and Evaluation of Fiscal Year 2015 Goals

Improve Casefinding

- Seventy-six (63.3 percent) of the 120 birth hospitals that are part of the Illinois Perinatal network have been trained on and are using the APORS database introduced in FY14; More than 85 percent of cases are now being 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 use of the SharePoint® site for hospital staff, computer-based trainings, conversations with hospital staffs, and responses to questions. The more formal training process will be resumed when the training position is filled (vacant since November 2014)

- Made 23 training visits in person and 14 trainings by phone or webinar and held 1,249 consultations via telephone or e-mail with Illinois hospitals to improve APORS reporting

- Updated Sharepoint® site with revised manuals and appendices, and most recent of the quality control reports; reminders are posted when patterns of problems are identified

- Received quarterly electronic files, containing hospital discharge data for children as old as 2 years of age, from 20 of the 23 Level 3 hospitals, and an additional five Level 2 hospitals; these data have been imported into the IDPH chart review database; additional 34 cases born in 2012, 179 born in 2013, 624 born in 2014 and 236 born in 2015 were identified as possible APORS cases

- APORS abstractors have been reviewing the medical records of infants identified from hospital discharge data; on average, 44 percent of the cases were found to have conditions that meet the APORS review criteria

- Avoided the need to travel to 116 of the 122 birth hospitals, either by accessing electronic medical records remotely, or having the hospitals send charts (in electronic or paper format)

- The abstractors undertook a case-finding study at 9 hospitals with low reporting rates, compared to other hospitals providing similar levels of care. Unreported cases were identified at hospitals providing a high level of care. Most had relatively minor conditions; the unreported cases have a very limited impact on Illinois' surveillance data.

- Case-finding at sites where prenatal diagnoses are made was not implemented because of loss of staff; the program has not yet been able to fill the abstractor position vacated in April 2014, nor the one vacated in January 2015

Improve Quality of APORS Data

- Evaluated the quality of hospital reporting of adverse pregnancy outcomes in December 2014; generally, reporting quality is very good with only diagnosis reporting needing improvement; results were distributed to the hospitals

- Evaluated the timeliness of hospital reporting for cases reported in January through December 2014; provided hospital-specific feedback and used results to identify hospital training needs. In 2014, 54.6 percent of hospitals met the APORS timeliness standard of reporting cases within seven days of infants' hospital discharge. This is significantly worse than in previous years since the new database identified children that the hospitals had overlooked in 2013. APORS staff enforced the reporting of these cases in 2014, by which time reporting was late.

- Evaluated the accuracy of abstractor reviews in March 2015; results demonstrated that current APORS abstracting staff identify and abstract good quality information on chart review

- 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

- 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

- Avoided the need to travel to 116 of the 122 birth hospitals, either by accessing electronic medical records remotely, or having the hospitals send charts (in electronic or paper format)

- Distributed 400 pieces of birth defect prevention and healthy pregnancy promotional materials at the Illinois State Fair

- 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

- Surveillance reports were not produced, in part because of delays in the release of denominator (birth) data, and in part because of the loss of staff, and the need to keep the routine activities timely

- Was awarded continuation of a five-year CDC cooperative agreement

4.2 Fiscal Year 2015 Major Accomplishments

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

APORS was approved for the continuation of IDPH's five-year cooperative agreement with the CDC to enhance Illinois birth defects surveillance, prevention and service referral. Total funding for 2015 is $200,000.

4.2.2 Enhancement of the APORS Database

In August 2014, the APORS program upgraded the APORS database, developed by NetSmart® Technologies. This allowed:

- documentation that a child was transferred to another hospital;
- inclusion of time of birth (needed for babies exposed to Hepatitis B);
- collection of time and type of Hepatitis B immunization

APORS staff implemented additional reports and modifications as they were requested.

All local health departments are using the system, and 41 hospitals are registered. These hospitals report about 80 percent of the cases received by APORS.

4.2.3 Hospital Training Webinars

The APORS manager has developed and used APORS trainings that are presented interactively through Adobe® Connect™. Materials and applications are shared on participants' computer screens; polls are used to assess users' needs and documents are made available for download.

Evaluation forms are distributed after each training session, and the hospital liaison receives positive feedback from attendees.

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 regional field staff members, who then reviewed the infants' medical charts, verified the presence of birth defects, eliminated false positives, and collected additional diagnoses. In FY15, the abstractors reviewed 7,721 birth defects reported by hospitals.

Abstractors deleted 287 reported birth defects that could not be found in the charts, or that had been ruled out by the facility. Of the hospital-reported birth defects, 2,139 were not collected because the infant did not have a reportable

major birth defect or because the birth defect did not meet specific criteria (often conditions that are considered normal in a premature infant).

The abstractors verified 3,958 hospital-reported diagnoses. They clarified 413 diagnoses and added 8,350 diagnoses. In total, 12,721 birth defects were verified.

Case abstraction for 2012 birth cohort was completed in February 2015. The goal is to be complete within two years of the birth year.

4.2.5 Evaluation of Case Management Services Provided to APORS Cases

APORS collaborated with community health agencies (CHA's) in surveying APORS families offered or receiving case-management services through the High-risk Infant Follow-up Program. Families were asked whether they found the services helpful and reassuring. The response rate was 78.9 percent. The responses were overwhelmingly positive; both the program and individual nurses were acknowledged as a great benefit.

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. Approximately 9,300 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 52 children with neural tube defects, whose families were referred for prevention counseling.

APORS conducted quarterly meetings with the high-risk infant follow-up manager to improve program coordination and communication.

A new brochure was developed for hospitals to distribute to families with an APORS baby. It provides information about the High-risk Infant Follow-up program and lists contact information for organizations that may be helpful to families.

4.2.6.1.2 Illinois Department of Human Services (IDHS). Dr. Jane Fornoff serves on the steering committee of IDHS's Maternal and Child Health Advisory Board. This board advises the governor and legislature on matters affecting maternal and child health in Illinois.

4.2.6.1.3 Illinois Department of Public Health (IDPH) Division of Infectious Diseases. APORS identified infants for the IDPH Division of Infectious Diseases' sexually transmitted disease (106 newborns) and perinatal hepatitis B programs (307 newborns), which ensure infants with congenital syphilis and infants prenatally exposed to or diagnosed with a hepatitis B infection are offered services.

4.2.6.1.4 Illinois Department of Public Health Craniofacial Anomaly Program. Data on all infants born with cleft lip and/or palate (200 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.

4.2.6.1.5 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 FY14, APORS referred 4,063 cases.

4.2.6.1.6 Illinois Department of Public Health'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. Several children with hypothyroidism previously unknown to the NMS program have been identified.

4.2.6.1.7 Illinois Department of Children and Family Services (DCFS). Data is being 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 IDPH 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 submitted data for the NBDPN's annual report. The APORS manager served on the state data committee. All APORS staff attended the NBDPN's virtual annual conference.

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 Jenkins V, Fornoff J. *Quality of Hospital Reports of Adverse Pregnancy Outcomes Among 2011 Births.* Quality Control Report Series 14:05. Springfield, Ill.: Illinois Department of Public Health, December 2014.

4.2.7.2 Fornoff J. *APORS Birth Defect Case Finding Pilot Study.* Quality Control Report Series 14:06. Springfield, Ill.: Illinois Department of Public Health, December 2014.

4.2.7.3 Fornoff J. *Timeliness Study – Hospital Reports of Adverse Pregnancy Outcomes Received in 2014.* Quality Control Report Series 15:01. Springfield, Ill.: Illinois Department of Public Health, January 2015.

4.2.7.4 Fornoff J. *Family Survey of Services Provided through the High Risk Infant Follow-up (HRIF) program.* Quality Control Report Series 15:02. Springfield, Ill.: Illinois Department of Public Health, January 2015.

4.2.7.5 Fornoff J. *Rates of Hospital Reporting of Adverse Pregnancy Outcomes in 2013.* Quality Control Report Series 15:03. Springfield, Ill.: Illinois Department of Public Health, February 2015.

4.2.7.6 Snow J, Fornoff J. *Quality of Abstractor Reviews of Adverse Pregnancy Outcomes among 2010 births.* Quality Control Report Series 15:04. Springfield, Ill.: Illinois Department of Public Health, March 2015.

4.3 Goals for Fiscal Year 2016

Improve Casefinding

- Train and support hospitals in the use of the new APORS database to assure that 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
- Follow the three-year training plan to assure all hospitals receive on-going training in APORS reporting
- Provide consultation and training to supplement the three-year and self-directed training for hospital nursing staff when indicated
- Enhance the SharePoint® site for hospital staff to contain materials to 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

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

Improve Program Effectiveness

- Enhance SharePoint® sites for hospitals and community health agencies that contain relevant reference and training materials for the different groups

- Provide community health agencies and families with a birth-defect affected child with information about birth defects through publication of a series of factsheets

- Promote birth defects prevention and healthy pregnancies through publication of a series of factsheets that support healthy pregnancies

- 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 programs to assure the provision of perinatal services for high-risk infants

- 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).

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 inspections and/or interventions. 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 now mandated to report levels ≥10 µg/dL. This program was funded through a purchase order for data with the CDC's National Institute for Occupational Safety and Health (NIOSH). However, in 2013, NIOSH canceled all contracts to fund state programs that use fiscal year 2013 funds in accordance with the Budget Control Act of 2011. Starting in 2014, due to lack of funding, ABLR staff only recorded cases of ≥40µg/dL to refer employers who have employees with elevated blood lead levels ≥40µg/dL to OSHA per the memorandum of understanding. Reports for cases less than 40µg/dL were archived. In 2015, Division 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.

5.1.1 Fiscal Year 2015 Accomplishments

- Notified OSHA quarterly of any company that had employees with elevated blood lead levels ≥40 µg/dL of blood
- Notified OSHA within 24 hours of any case with an elevated blood lead level ≥60 µg/dL

5.1.2 Interventions Resulting From ABLR Notifications of Elevated Lead Results

In calendar year 2014, ABLR made 38 referrals (employees) to OSHA for 17 companies with employees who had blood lead levels greater than or equal to 40 µg/dL of blood. OSHA conducted one site safety inspection in Illinois because of the ABLR referrals. During these inspections, over exposures to lead were found, which resulted in fines totaling $10,800 in violation of OSHA rules. Three other employers referred were already under investigation by OSHA due to employee complaints.

5.1.3 Goals for Fiscal Year 2016

- Notify OSHA quarterly of any company that has employees with elevated blood lead levels equal to or greater than 40 µg/dL

- Notify OSHA within 24 hours of any case with an elevated blood lead level equal to or greater than 60 µg/dL

- Complete backlog of manual entry reports from 2014

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.

The 2014 Illinois CFOI recorded 163 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 Division of Vital Records and the manual review was no longer possible. This operational change affected the number of fatal occupational illnesses collected in Illinois. Beginning in 2012 and moving forward, the Bureau of Labor Statistics has ceased collecting work related illness fatalities (i.e. if a driver suffers a heart attack while driving, staff are directed to look at all available source documents to determine if there was an injury that preceded the heart attack. If that isn't the case, it is not entered into the system). 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 2015 Goals

- Completed the summary report of the 2012 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 2016

- Publish a summary report of the 2013 fatal occupational injury data by December 2015

- 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 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 2015 Goals

- Submitted data files on all reported occupational injuries and illnesses of the surveyed companies to the BLS
- Collected, coded, and entered all 2014 data prior to BLS deadlines

5.3.2 Survey Process and Achievements for Fiscal Year 2015

In January 2015, BLS and ODR sent survey forms to 5,686 private employers and 369 public employers for 2014 data. A second request for data was sent in February, a third request was sent in April, and a fourth request was sent in May. Non-responding companies were then contacted by telephone to solicit data. The final, overall survey response rate was 85 percent, which met the cooperative agreement minimum requirement for data publication.

5.3.3 Goals for Fiscal Year 2016

- Continue all data collection activities in FY15 and maintain the high standards achieved by the program
- Complete the descriptive report of 2013 occupational injuries and illnesses
- Meet the deadlines assigned by BLS

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 future 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.27®.

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; 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 2014

Range of Percentage Complete by Diagnosis Year			
	Average all years	**Lowest**	**Highest**
Cancer Reports (n=1,587,097 cases for diagnosis years 1986-2012)			
ZIP code	**100.0**	**100.0**	**100.0**
ZIP +4 code	95.7	91.9	98.4
Lat/Lon code [1]	100.0	100.0	100.0
address specific	91.7	86.8	94.8
centroid ZIP +4	0.7	0.4	1.2
centroid ZIP +2	0.7	0.4	1.1
centroid ZIP	7.0	3.5	11.7
APORS Reports (n= 385,596) cases for birth years 1989-2015)			
ZIP code	98.4	94.8	100.00
ZIP +4 code	92.8	87.2	99.1
Lat/Lon code [1]	96.9	91.3	100.0
address specific	91.6	86.5	98.6
centroid ZIP +4	1.1	0.7	1.8
centroid ZIP +2	1.7	0.3	3.7
centroid ZIP	2.4	0.2	5.3

[1] Latitude and longitude

6.2 Goals for Fiscal Year 2016

- Continue to geocode new records submitted to ISCR and APORS

7. Cluster Inquiries and Assessments

7.1 Review and Evaluation of Fiscal Year 2015 Goals

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

7.2 Fiscal Year 2015 Accomplishments

In FY15, the Department received 23 calls 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. For three of these calls, previous cancer cluster evaluations were already available to answer the concerns. Staff used published cancer rates by county, epidemiologic reports and data from the public data files (n=16) or general information about the frequency of cancer or causes of cancer to help address the callers' concerns. No written requests were received to conduct in-depth cluster re-evaluations when there was a known carcinogenic exposure.

7.3 Fiscal Year 2016 Objectives

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

- Complete cluster assessments within 12 months of the written request when 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.

8.1 Fiscal Year 2015 Major Accomplishments

8.1.1 Provision of Epidemiologic Support to IDPH Committees and Workgroups

IDPH Division of Epidemiologic Studies staff continued to chair and participate in IDPH's IRB, the Committee on Data Research and Release (DRRC), Illinois Health Data Dissemination Initiative (IHDDI), Illinois Health Information Exchange Committee (HIE), and Community Transformation Grant work committees. Five staff serve on different committees in various capacities.

8.1.2 Creation of New Job Titles and Descriptions for Epidemiology Research and Investigation Scientist I and II

To fill the gap for mid-level epidemiologists and increase the Department's competitiveness in recruiting and retaining research scientists, the Division has worked with the Department's Senior Medical Advisor and the state Central Management Services agency to create two new job classifications and corresponding job descriptions and grading criteria. Both job classifications are in the personnel system.

8.1.3 Participation in the Department's Successful Accreditation by the Public Health Accreditation Board (PHAB)

The Division was in charge of Domain 1 – health data collection, utilization and dissemination. All submitted evidence documents have been accepted and pass the PHAB review.

8.1.4 Publication of the Department-wide Illinois Morbidity and Mortality Bulletin (IMMB)

The Division created and published the first issue of this bulletin, targeting statewide public health professionals, researchers and policy makers. The inauguration issue contained three articles contributed by health researchers throughout the Department.

8.1.5 Technical Assistance

Technical assistance has been provided by ISCR staff in the areas of statistics/epidemiology, research methods, data confidentiality review, Freedom of Information Act (FOIA) requests, data linkage, SAS® programming, data analysis and interpretation, data de-duplication, surveillance system evaluation, quality control, and research data requests continued to be provided by

researchers to various IDPH offices and divisions. IDPH 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 and updating State Health Improvement Plan (SHIP) documents and statistics. IDPH Division of Epidemiologic Studies researchers also continued to provide guidance and technical assistance to IDHFS in its effort to establish new policy and practices for public data release. IDPH Division of Epidemiologic Studies staff also provided interviews and responses to medical requests on various disease issues.

8.2 Scientific Publications in Fiscal Year 2015

The following articles have been submitted, accepted or published.

8.2.1 Mueller G, Zahnd W, Garner K, Heitkamp R, Jenkins WD, Boehler M, Land D, Steward DE. The "Mini-Report": Use of CBPR to create a practical tool to address lung cancer disparities in rural communities submitted for publication to the *Journal of Cancer Education.* Springfield, Ill.: Center for Clinical Research, Southern Illinois University School of Medicine.

8.2.2 Canfield MA, Mai Ct, Wang Y, O'Halloran A, Fornoff J, et al. for the National Birth Defects Prevention Network. The Association Between Race/Ethnicity and Major Birth Defects in the United States, 1999-2007. *Am J Public Health*. July 2014 17:e1-e10

8.3 Other Recent Reports or Publications That Used Registry Data

8.3.1 Agency for Healthcare Research Quality (AHRQ) *2014 National Healthcare Quality and Disparities Report*. Rockville, MD.: U.S. Department of Health and Human Services, Agency for Healthcare Research and Quality. May 2015. AHRQ Pub. No. 15-0007.

8.3.2 March of Dimes. *Peristats*. Available at http://www.marchofdimes.org/Peristats/ViewSummary.aspx?reg=17&stop=60

8.3.3 National Birth Defects Prevention Network (NBDPN). August 2014. Major Birth Defects Data from Population-based Birth Defects Surveillance Programs in the United States 2007-2011: Highlighting Orofacial Clefts. National Center on Birth Defects and Developmental Disabilities, U.S. Centers for Disease Control and Prevention, Atlanta, GA (2014).

8.3.4 Ostrom QT, Gittleman H, Liao P, Rouse C, Chen Y, Dowling J, Wolinsky Y, Kruchko C, Barnholtz-Sloan J. CBTRUS Statistical Report: Primary Brain and Central Nervous System Tumors Diagnosed in the United States 2007-2011. *Neuro-Oncol* 2014 16 (suppl 4): iv1-iv63. doi:10.1093/neuonc/nou223.

8.3.5 Ostrom QT, de Blank PM, Kruchko C, Peterson CM, Liao P, Finlay JL, Stearns, DS, Wolff JE, Wolinsky Y, Letterio JJ, Barnholtz-Sloan J. CBTRUS Statistical Report: Alex's Lemonade Stand Infant and Childhood Primary Brain and Central Nervous System Tumors Diagnosed in the United States in 2007-2001. *Neuro-Oncol* 2015 16 (suppl 10): x1-x36. doi:10.1093/neuonc/nou327.

8.3.6 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.

8.3.7 U.S. Cancer Statistics Working Group. *United States Cancer Statistics: 1999-2011 Incidence and Mortality Web-based Report*. Atlanta, GA.: U.S. Department of Health and Human Services, U.S. Centers for Disease Control and Prevention and National Cancer Institute; 2014. Available at www.cdc.gov/uscs.

8.3.8 Daniels RD, Bertke S, Dahm MM, Yiin JH, Kubale TL, Hales TR, Baris D, Zahm SH, Beaumont JJ, Waters KM, Pinkerton LE. Exposure-response relationships for select cancer and non-cancer health outcomes in a cohort of US firefighters from San Francisco, Chicago and Philadelphia (1950-2009). *Occup Environ Med* February 2, 2015;0: 1-8. doi:10.1136/oemed-2014-102671.

8.3.9 Copeland G, Lake A, Firth R, Wohler B, Wu XC, Schymura M, Hofferkamp J, Sherman R, Kohler B (eds). *Cancer in North America: 2008-2012. Volume One: Combined Cancer Incidence for the United States, Canada and North America.* Springfield, Ill.: North American Association of Central Cancer Registries, Inc. June 2015.

8.3.10 Young MS. Just as there are different types of reporting facilities, there are different types of central registries. *Advance for Health Information Professionals.* King of Prussia, Pa.: January 2015. Available at http://health-information.advanceweb.com/Editorial/Content/PrintFriendly.aspx?CC=282109.

8.3.11 Copeland G, Lake A, Firth R, Wohler B, Wu XC, Schymura M, Hofferkamp J, Sherman R, Kohler B (eds). *Cancer in North America: 2008-2012. Volume Two: Registry-specific Cancer Incidence in the United States and Canada.* Springfield, Ill.: North American Association of Central Cancer Registries, Inc. June 2015.

8.3.12 Copeland G, Lake A, Firth R, Wohler B, Wu XC, Schymura M, Hofferkamp J, Sherman R, Kohler B (eds). *Cancer in North America, 2008-2012. Volume Three: Registry-specific Cancer Mortality in the United States and Canada.* Springfield, Ill.: North American Association of Central Cancer Registries, Inc. June 2015.

8.3.13 Kohler BA, Sherman RL, Howlader N, Jemal A., et al. Annual Report to the Nation on the Status of Cancer, 1975-2011, Featuring Incidence of Breast Cancer Subtypes by Race/Ethnicity, Poverty and State. *J Natl Cancer Inst* March 14, 2015 107(6):djv048. Doi:10.1093/jnci/djv048.

8.3.14 Weir HK, Johnson CJ, Mariotto AB, Turner D, Wilson RJ, Nishri D, Ward KC. Evaluation of North American Association of Central Cancer Registries' (NAACCR) data for Use in Population-Based Cancer Survival Studies. *J Natl Cancer Inst Monogr* November 2014;49:198-209. DOI:10.1093/jncimonographs/lgu018.

8.3.15 American Cancer Society. *Cancer Facts & Figures 2015*. Atlanta, GA.: American Cancer Society; 2015.

8.3.16 U.S. Department of Health and Human Services. The Surgeon General's Call to Action to Prevent Skin Cancer. Washington, DC: U.S. Department of Health and Human Services, Office of the Surgeon General, August 2014. Available at http://www.surgeongeneral.gov.

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.

8.4.1 Nguyen V, Shen T. **Illinois Occupational Injuries and Illnesses Report 2012**. Epidemiologic Report Series 15:01. Springfield, Ill.: Illinois Department of Public Health, September 2014.

8.4.2 Garner K, Shen T. **Tobacco-Related Cancer in Illinois**. Epidemiologic Report Series 15:02. Springfield, Ill.: Illinois Department of Public Health, October 2014.

8.4.3 Nguyen V, Wamack J, Bostwick J and Shen T. **Census of Fatal Occupational Injuries Illinois 2012.** Epidemiologic Report Series 15:03. Springfield, Ill.: Illinois Department of Public Health, October 2014.

8.4.4 Garner K, Shen T. **Illinois Cancer Mortality Review and Update, 1986-2011**. Epidemiologic Report Series 15:04. Springfield, Ill.: Illinois Department of Public Health, November 2014.

8.4.5 Garner K, Shen T. **Illinois State Cancer Incidence Review and Update 1986-2012.** Epidemiologic Report Series 15:05. Springfield, Ill.: Illinois Department of Public Health, May 2015.

8.4.6 Garner K, Shen T**. Illinois County Cancer Statistics Review and Incidence, 2008-2012**. Epidemiologic Report Series 15:06. Springfield, Ill.: Illinois Department of Public Health, May 2015.

8.4.7 Garner K, Shen T. **Illinois Cancer Mortality Review and Update 1986-2012**. Epidemiologic Report Series 15:07. Springfield, Ill.: Illinois Department of Public Health, June 2015.

8.5 Other Division Publications

8.5.1 Koch L, Lehnherr M, Garner K, Bostwick J. **Cancer in Illinois 2014**. Illinois Department of Public Health, Springfield, Ill.: October 2014.

8.6 Fiscal Year 2015 Presentations by IDPH Division of Epidemiologic Studies Staff

Title	Event	Date
APORS - Case Identification and Completion of Form – In-service workshop	Adventist Bolingbrook Hospital (Bolingbrook)	July 2014
APORS - Case Identification and Completion of Form – In-service workshop	Advocate Illinois Masonic Medical Center (Chicago)	July 2014
APORS Case Identification and Completion of Form – In-service training	Presence Saint Joseph Hospital (Chicago)	July 2014
APORS - Case Identification and Completion of Form – In-service training	Delnor Community Hospital (Geneva)	July 2014
APORS - Case Identification and Completion of Form – In-service training	St. John's Hospital (Springfield)	July 2014
APORS - Case Identification and Completion of Form – In-service training	Carle Foundation Hospital (Urbana)	July 2014
APORS - Case Identification and Completion of Form – In-service training	Decatur Memorial Hospital (Decatur)	July 2014
APORS - Data System Training	Barnes-Jewish Hospital (St. Louis, Missouri)	July 2014
APORS - Data System Training	SSM Cardinal Glennon Children's Medical Center (St. Louis, Missouri)	July 2014
APORS - Data System Training	St. Louis Children's Hospital (St. Louis, Missouri)	July 2014
APORS - Data System Training	Advocate BroMenn Medical Center (via teleconference)	July 2014
APORS - Data System Training	Champaign-Urbana Public Health Department (Champaign)	July 2014
APORS - Data System Training	Alexian Brothers Medical Center (via teleconference)	July 2014
APORS - Data System Training	Blessing Hospital (Quincy)	August 2014

Title	Event	Date
IRB/Research – Introduce the process and algorithm used by IDPH programs to generate and assess public use files	Chicago Department of Public Health IRB Committee	August 2014
APORS Program Overview	Pediatric Department Meeting of OSF St. Francis Medical Center (Peoria)	September 2014
APORS - Case Identification and Completion of Form – In-service training	Presence Sts. Mary and Elizabeth Medical Centers (Chicago)	September 2014
APORS - Case Identification and Completion of Form – In-service training	Adventist LaGrange Memorial Hospital (LaGrange)	September 2014
APORS - Case Identification and Completion of Form – In-service training	Elmhurst Memorial Hospital (Elmhurst)	September 2014
APORS - Case Identification and Completion of Form – In-service training	MacNeal Hospital (Berwyn)	September 2014
APORS - Case Identification and Completion of Form – In-service training	Adventist Glen Oaks Hospital (Glendale Heights)	September 2014
APORS - Case Identification and Completion of Form – In-service training	DuPage County Health Department (Wheaton)	September 2014
APORS - Data System Training	Silver Cross Hospital (New Lenox)	September 2014
Research Lecture to Graduate Students on Cancer	University of Illinois Chicago School of Public Health (Chicago)	September 2014
ISCR – "Audit Reveals…We Need More Text"	Cancer Registrars of Illinois Annual Meeting (Lombard)	September 2014
APORS - Data System Training	Franciscan St. James Health (Chicago Heights)	February 2015
Research - Lecture to Graduate Students on Cancer	University of Illinois Chicago School of Public Health (Chicago)	February 2015
APORS - "APORS: Passing the Baton"	March of Dimes 40th Annual Perinatal Nursing Conference (Lombard)	March 2015
ISCR – TNM Staging Training Workshop	Good Samaritan Regional Health Center (Mt. Vernon)	March 2015
ISCR – Multiple Primary and Histology Coding Workshop/Hematopoietic Database	DHS Computer Lab (Chicago)	March 2015
ISCR – TNM Staging Training Workshop	Swedish American Regional Cancer Center (Rockford)	March 2015

Title	Event	Date
ISCR – TNM Staging Training Workshop	Saint Joseph Medical Center (Joliet)	March 2015
ISCR – TNM Staging Training Workshop	DNR (Springfield)	March 2015
APORS – Quality Control Training	Videoconference at Perinatal Network 3 meeting	April 2015
APORS – Data System Training	Teleconference with staff from VHS Westlake Hospital (Melrose Park)	April 2015
ISCR – "How Cancer Registry Data Are Used for Research"	ISCR/CRI Spring Educational Meeting (Springfield)	April 2015
ISCR – Basic Training Workshop	Good Samaritan Regional Health Center (Mt. Vernon)	April 2015
ISCR – TNM Staging Training Workshop	Western Illinois University (Moline)	April 2015
APORS – Introduction to APORS using Adobe Connect	Barnes Jewish Hospital, Pekin Hospital and Swedish Covenant Hospital	May 2015
APORS - Introduction to APORS using Adobe Connect	Advocate Sherman Hospital	May 2015
APORS – Data System Training	Teleconference with staff from Ingalls Memorial Hospital (Harvey)	May 2015
ISCR – Basic Training Workshop	IDPH (Chicago)	May 2015
ISCR – Multiple Primary and Histology Coding Workshop/Hematopoietic Database	Good Samaritan Regional Health Center (Mt. Vernon)	May 2015
ISCR – "Is the Primary Site Really Unknown?"	National Cancer Registrars Association Annual Educational Meeting (San Antonio, TX)	May 2015
ISCR – "A Review of 2012 Diagnosis Year Cases Submitted from Seven Pathology Laboratories in Illinois	North American Association of Central Cancer Registries Annual Meeting (Charlotte, NC)	June 2015
ISCR – TNM Staging Training Workshop	Elmhurst Memorial Hospital (Elmhurst)	June 2015

8.7 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*	
Ying Wang New York State Department of Health	Survival of Infants and Children With Selected Major Birth Defects	January 2012 ongoing*	
Ying Wang New York State Department of Health	Prevalence Trends Of Selected Major Birth Defects: A Multi-State Population-based Retrospective Study, United States, 1999-2007	February 2012 ongoing*	
Illinois Department of Healthcare and Family Services	Healthcare and Family Services Data Warehouse	Ongoing monthly	
U.S. Centers for Disease Control and Prevention	Prevalence Data by Race for Selected Birth Defects for Publication in *Birth Defects Research*	May 2015	CDC
Lynn Rosenberg, Sc.D., M.S. Sloan Epidemiology Center Boston University	Black Women's Health Study	Ongoing February 2007	NIH/NCI
Rosalind Ramsey-Goldman, M.D., Dr.PH. Northwestern University	Exposure to Immunosuppressive Drugs and Cancer Risk in Systemic Lupus Erythematosus	Ongoing August 2004	NIH/NCI
Meir Stampfer, M.D. Channing Laboratory Brigham and Women's Hospital	Health Professionals Follow-up Study/Nurses' Health Study I and II	Ongoing January 2004	NIH
Eugenia Calle, Ph.D. American Cancer Society	Cancer Prevention Study II	Ongoing 1995	ACS

Louise A. Brinton, Ph.D., M.P.H. National Cancer Institute	Infertility Follow-up Study	Ongoing 2012	NCI
Alicia Gilsenan, Ph.D. RTI International	Forteo Patient Registry	Ongoing February 2010	Eli Lilly and Company
Mardge Cohen, M.D. Women's Interagency HIV Study (WIHS)	Women's Interagency HIV Study (WIHS)	Ongoing 2000	NIH
Linda Wagner-Weiner, M.D. University of Chicago	Lymphoma Risk in SLE: A Consequence of Immune Suppression?	April 2013 Ongoing	NCI Arthritis Society
Robert Daniels, Ph.D. National Institute of Occupational Safety and Health (NIOSH)	A Study of Cancer Among United States Firefighters	October 2012 Ongoing*	NIOSH
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
Charlotte Joslin, O.D., Ph.D. University of Illinois at Chicago	Local Food Environments and Disparities in Ovarian Cancer Survival	January 2013*	National Institute on Minority Health and Health Disparities
Leslie Stayner, Ph.D. University of Illinois at Chicago	A Linkage Study of Health Outcome Data in Children and Agrichemical Water Contamination Data in the Midwest	May 2013*	CDC
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
Briseis Aschebrook-Kilfoy, Ph.D., M.P.H., M.Phil.	Cancer Trends in Chicago Compared to the United States	February 2014*	
Diana Miglioretti, Ph.D.	Risk-Based Cancer Screening in Community Settings	July 2014*	NCI
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

Paulo Pinheiro, M.D., Ph.D., MSc, CTR	Cancer among Asian American Populations in the United States	March 2015*	National Institute of General Medical Sciences

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 Human Services (DHS), Geographic Information System (GIS), International Agency for Research on Cancer (IARC), National Institute of Allergy and Infectious Diseases (NIAID), National Cancer Institute (NCI), National Institutes of Health (NIH), Surveillance of Epidemiology and End Results (SEER), 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 FY2015.

Grant	Agency	Status
Occupational and Health Survey in Illinois (continuation)	BLS	Funded September 2014
Census of Fatal Occupational Injuries in Illinois (continuation)	BLS	Funded September 2014
Improvement of Birth Defects Surveillance Program	CDC	Funded January 2014
Perinatal Hepatitis B Program (submitted by IDPH, Division of Infectious Disease) (continuation)	CDC	Funded January 2015
National Cancer Prevention and Control Program-National Program of Cancer Care (new)	CDC	Funded June 2014
NOTE: Full titles of acronyms used in the above table are U.S. Centers for Disease Control and Prevention (CDC), Bureau of Labor Statistics (BLS), and Illinois Department of Public Health (IDPH).		

9.1 Funded Grants

The Division of Epidemiologic Studies received $1.6 million in grant awards in fiscal year 2015. This is a 1.8 percent increase from FY2014.

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

IDPH received $108,300 in September 2014 from the U.S. Bureau of Labor Statistics to support the 17th 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 $94,400 in September 2014 from the U.S. Bureau of Labor Statistics to support the 23rd 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 2014, IDPH received $200,000 for year five of the third round of surveillance grants. The progress for this project is described in Section 4.

9.1.4 Perinatal Hepatitis B Program

The IDPH Division of Epidemiologic Studies received $30,000 in December 2014 to continue expansion of APORS surveillance and data collection (16th year) to include perinatal hepatitis B and to enhance a tracking system to identify newborn infants requiring follow-up immunization services. The progress for this project is described in Section 4.

9.1.5 National Cancer Prevention and Control Program

In June 2014, CDC awarded IDPH $1.4 million in funding for the third year of a third five-year project period year of the National Cancer Prevention and Control Program. The awarded funds represent a 3.4 percent decrease from the previous level funding. This grant combines two previous separate grants: the National Comprehensive Cancer Control Program and the National Program of Cancer Registries (NPCR). The IDPH Division of Epidemiologic Studies received nearly $1.2 million for the NPCR component, which is in its 20th year. NPCR continues to focus on four aspects of the existing program: achieve 95 percent completeness of reporting; expand the quality control program; redesign the database in a personal computer environment; and collect, code, and computerize treatment data and occupation and industry information. The progress for this project is described in Section 3.

10. Cancer Reporting Facilities That Have Not Completed Reporting for the 2014 Diagnosis Year by July 1, 2015

Name	City
Advanced Radiation Oncology Center	Gurnee
Altman Dermatology Associates	Arlington
American Cancer Center	Elgin
Belleville Oncology Institute	Belleville
Breese Oncology	Breese
Chicago Prostate Cancer Center	Westmont
Christie Clinic Cancer Center	Champaign
Clay County Hospital	Flora
Danville Polyclinic, LTD	Danville
Franklin Hospital	Benton
Illinois Cancer Specialists	Niles
Illinois Regional Cancer Center	DeKalb
Jacksonville Oncology Institute	Jacksonville
John H. Stroger, Jr. Hospital of Cook County	Chicago
Kenneth Bielinski – Skin MD, LLC	Orland Park
Lester J. Fahrner M.D. – Christie Clinic	Champaign
Louisa Gehlmann & Marianne O'Donoghue – Illinois Dermatology Institute	Oak Brook
Marshall Browning Hospital	DuQuoin
North Suburban Dermatology Associates	Gurnee
Northwestern Medicine Proton Center	Warrenville
OSF Saint Anthony's Health Center	Alton
Peoria Day Surgery Center	Peoria
Presence Resurrection Medical Center	Chicago
Saint Anthony Hospital	Chicago
SIU School of Medicine Simmons Cancer Institute	Springfield
Southern Cook Radiation Treatment Center	Blue Island
Springfield Clinic Ambulatory Surgical Treatment Center	Springfield
Springfield Clinic Dermatology	Springfield
Strow Dermatology	Springfield
Surgical Center of the DuPage Medical Group	Lombard
Taylorville Memorial Hospital	Taylorville
Thorek Memorial Hospital	Chicago
Unitypoint Health	Trinity
Western Illinois Cancer Treatment Center	Maryville