# Annual Report Illinois Health and Hazardous Substances Registry

July 2015 through June 2016

December 2016



# Annual Report Illinois Health and Hazardous Substances Registry July 2015 through June 2016



A Report to Governor Bruce Rauner and the 99th General Assembly from the Illinois Department of Public Health Nirav D. Shah, M.D., J.D. Director

Prepared by the
Division of Epidemiologic Studies
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### **Acronyms**

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

	Adult Plood Load Pogistry
ABLR	Adult Blood Lead Registry
ACS	American Cancer Society
AHRQ	Agency for Healthcare Research Quality
APORS	Adverse Pregnancy Outcomes Reporting System
BLS	Bureau of Labor Statistics (U.S. Department of Labor)
CDC	U.S. Centers for Disease Control and Prevention
CFOI	Census of Fatal Occupational Injuries
CINA	Cancer in North America
FY	Fiscal Year
GIS	Geographic Information System
IARC	International Agency for Research on Cancer
IBCCP	Illinois Breast and Cervical Cancer Program
ICCCP	Illinois Comprehensive Cancer Control Program
IDHFS	Illinois Department of Healthcare and Family Services
IDPH	Illinois Department of Public Health
IHDDI	Illinois Health Data Dissemination Initiative
IHHSR	Illinois Health and Hazardous Substance Registry
IMMB	IDPH's Illinois Morbidity and Mortality Bulletin
IRB	Institutional Review Board
ISCR	Illinois State Cancer Registry
MMWR	CDC's Morbidity and Mortality Weekly Reports
NAACCR	North American Association of Central Cancer Registries
NAD	North American Datum
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
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### 1. Executive Summary

The Illinois Department of Public Health's (IDPH) Division of Epidemiologic Studies is responsible for developing and managing the Illinois Health and Hazardous Substances Registry (IHHSR). The registry was created by the Illinois Health and Hazardous Substances Registry Act (410 ILCS 525/1 et seq.), enacted on September 10, 1984, and currently includes the following components: the Illinois State Cancer Registry (ISCR), the Adverse Pregnancy Outcomes Reporting System (APORS), the Occupational Disease Registry (ODR) [which further contains the Adult Blood Lead Registry (ABLR), Census of Fatal Occupational Injuries (CFOI) and the Survey of Occupational Injuries and Illnesses (SOII)], and a research and data dissemination section. This is the registry's 30th annual report and it describes major registry activities and accomplishments from July 2015 through June 2016 (FY16).

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 2016 Highlights

 Received \$1.6 million from federal funds and nearly \$55,000 from other non-general revenue sources, mostly through a competitive process, to support activities of the IDPH Division of Epidemiologic Studies

- Collected detailed case reports on Illinois residents with 60,891 newly diagnosed cancer cases (2014), 9,750 children with adverse pregnancy outcomes (2014), 3,056 adult lead poisoning cases (2015), 38,280 representative non-fatal occupational disease and injury sample records (2014), and 164 fatal occupational injuries (2014)
- Responded to 22 requests for general information about the registry, 59 requests for epidemiologic reports and registry data, and 27 special data requests or collaborations from outside researchers
- Responded to eight 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 one report in the CDC MMWR series, one research paper in the Illinois
  Morbidity and Mortality Bulletin, six reports in the Epidemiologic Report Series, and
  prepared seven written reports for quality control studies of registry data
- Authored or co-authored five scientific papers for peer-reviewed journals
- Data released by the registry were used in more than 21 published studies by outside researchers
- 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 followup services
- Referred 12 employees from six employers with elevated blood lead levels to the U.S.
   Occupational Safety and Health Administration (OSHA) for onsite inspection
- Delivered presentations at five 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
- On behalf of IDPH, edited and published two issues of the Illinois Morbidity and Mortality Bulletin (IMMB) with each issue containing two articles based on analyzing Illinois data

### 1.3 Illinois Health and Hazardous Substances Registry Coordinating Council

The IHHSR Act included that the Health and Hazardous Substances Coordinating Council should be comprised of the following persons, ex officio or their designees: dean of the School of Public Health of the University of Illinois at Chicago, the directors of the Illinois departments of Agriculture, Labor, Natural Resources, Nuclear Safety (now part of the Illinois Emergency Management Agency), 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 2017

- 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
- 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 2010	Calendar 2011	Calendar 2012	Calendar 2013	Calendar 2014	Estimated 2015
ISCR Invasive Neoplasms						
(including bladder in situ)	65,198	66,369	65,130	64,959	60,891 <sup>1</sup>	66,840
Breast in situ female only	2,405	2,484	2,551	2,576	2,443 <sup>1</sup>	2,400
Brain – benign/borderline <sup>2</sup>	2,078	2,217	2,169	2,144	2,036 <sup>1</sup>	2,150
APORS Cases	12,163	12,037	12,233	9,878 <sup>3</sup>	9,750	9,700
Occupational Disease Reports						
ABLR lead poisoning						
New reports	158	237	484	623 <sup>4</sup>	1,060	1,704 <sup>5</sup>
Total reports	619	506	726	2,161 <sup>4</sup>	2,347	3,056⁵
Occupational Fatality Cases	231	235	146	176	164	170
Injuries	203	177	146	176	164	170
Illnesses <sup>6</sup>	28	54	N/A	N/A	N/A	N/A
Occupational Safety and Health Survey <sup>8</sup>						
Estimated Cases based on Sample	39,950	38,100 <sup>7</sup>	39,630 <sup>7</sup>	38,690 <sup>7</sup>	38,280	38,500
Sprains, strains	15,910	14,460 <sup>7</sup>	14,610 <sup>7</sup>	13,580 <sup>7</sup>	14,320	14,000
Bruises, contusions	2,930	2,890 <sup>7</sup>	3,350 <sup>7</sup>	3,110 <sup>7</sup>	2,880	3,000
Cuts, lacerations	2,560	3,750 <sup>7</sup>	3,510 <sup>7</sup>	3,170 <sup>7</sup>	2,600	3,000
Fractures	3,080	2,540 <sup>7</sup>	3,070 <sup>7</sup>	3,340 <sup>7</sup>	4,010	4,000
Multiple injuries	1,050	870 <sup>7</sup>	830 <sup>7</sup>	790 <sup>7</sup>	1,450	1,000
Carpal tunnel syndrome	520	560 <sup>7</sup>	590 <sup>7</sup>	380 <sup>7</sup>	270	300
Heat burns	840	280 <sup>7</sup>	590 <sup>7</sup>	380 <sup>7</sup>	310	300
Tendonitis	170	130 <sup>7</sup>	80 <sup>7</sup>	200 <sup>7</sup>	70	100
Amputations	290	330 <sup>7</sup>	190 <sup>7</sup>	260 <sup>7</sup>	160	200
Chemical burns	80	90 <sup>7</sup>	120 <sup>7</sup>	180 <sup>7</sup>	60	100
Occupational Illnesses <sup>9</sup>						
Asbestosis	466					
Silicosis	58					
Coal workers pneumoconiosis	149					
Hazardous Substances (GIS)						
Geocoding registry cases	All	All	All	All	All	All

<sup>&</sup>lt;sup>1</sup>Reporting is not complete for the calendar year indicated. The numbers are estimated based on the current projected incidence.

<sup>&</sup>lt;sup>2</sup>Collection of benign and borderline brain tumors is required as of the 2004 diagnosis year.

<sup>&</sup>lt;sup>3</sup> 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.

<sup>&</sup>lt;sup>4</sup> 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.

<sup>&</sup>lt;sup>5</sup>Actual counts for 2015.

<sup>&</sup>lt;sup>6</sup> 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)

<sup>&</sup>lt;sup>7</sup>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.

<sup>&</sup>lt;sup>8</sup>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.

<sup>&</sup>lt;sup>9</sup>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.

Table 2.2 Registry Data Dissemination, Reports and Publications

	F)//1.2	EV4.2	F)/4.4	F)/4 F	EV4.C	Estimated
	FY12	FY13	FY14	FY15	FY16	FY17
Data Requests						
General information	66	41	31	27	23	20
Data and reports	163	108	71	77	59	60
Cluster inquiries <sup>1</sup>	47	30	21	22	8	6
Confidential data released and research collaborations	17	24	25	23	17	15
Confidential data applications	9	6	4	4	1	0
Quality Assurance Studies <sup>2</sup>						
Casefinding visits						
APORS	236	225	70 <sup>4</sup>	22	4	3
ISCR	213	253	120	74	31	25
Cases added from casefinding visits						
APORS <sup>5</sup>	3,182	5,025	4,493	8,350 <sup>6</sup>	7,158	7,500
ISCR <sup>7</sup>	1,129	1,689	1,089	856	683	500
External audits of facility data						
ISCR			179	204	229	0
Internal quality control reports issued						
APORS	3	4	3	6	3	3
ISCR	2	2	4	3	3	3
ABLR	0	0	0	0	1	0
Public Use Microdata Files	3	3	3	5	5	5
Publications						
Epidemiologic report series	4	7	4	7	6	4
IMMB and other publications	0	0	0	0	3	3
Peer-reviewed publications	2	2	1	2	5	3
Publications by outside researchers	32	20	22	16	21	15
Oral/poster presentations	12	13	10	8	5	3
Grant Proposals Funded	6	6	5	5	5	6

<sup>&</sup>lt;sup>1</sup> 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.

<sup>&</sup>lt;sup>2</sup> 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.

<sup>&</sup>lt;sup>4</sup> Fewer hospital casefinding visits have been conducted since FY14 because field staff access medical records remotely for almost all reporting hospitals.

<sup>&</sup>lt;sup>5</sup> Represents additional birth defects identified and confirmed through the active case verification process where the medical records or previously submitted cases are reviewed.

<sup>&</sup>lt;sup>6</sup> Represents additional birth defects added from review of children identified from past years from a variety of data sources, and improved abstractor case finding.

<sup>&</sup>lt;sup>7</sup> 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 2013 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 2016 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 18<sup>th</sup> consecutive year
- Maintained case reporting at all non-federal facilities by conducting 31 facility case finding visits for the 2014 diagnosis year. 683 missed cases were identified.
- Completed interstate data exchange by transmitting 2,535 de-duplicated, edited state specific cases to 11 states and received and processed 8,536 cases from 10 states.
- Completed death clearance for the 2013 death year and maintained a death certificate only rate of 1.1 percent. In total, 2,873 cancer diagnoses were followed with 2,847 letters or lists mailed to hospitals, physicians, nursing homes, and hospice centers.
- Added 90 percent of cases for the 2014 diagnosis year to the ISCR database by December 2015
- Added 100 percent of cases for the 2013 diagnosis year to the ISCR database by December 2015
- 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 4 percent through focused targeting and training

### 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 four basic training sessions, and six staging training sessions; the onsite basic training sessions were presented in April 2015 in south, central, and northern Illinois; the onsite staging training sessions were May 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
- Developed and presented a two day training workshop for new contractual employees on ISCR case consolidation and quality control procedures
- Provided a SEER Summary Staging training webinar available to all cancer reporters across the state
- 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 1,908 requests related to technical support and reporting issues
- Attended the national educational conferences of the National Cancer Registrar's Association and the NAACCR
- Attended the annual educational conference sponsored by the Cancer Registrars of Illinois in September 2015
- Provided access to 43 advanced training workshops for 379 reporters via WebEx® utilizing nationally developed advanced training materials
- Provided limited individual training by the quality control field staff at three 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
- Developed a database to track and assess quality of contractual staff case consolidation

 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 15,717 cases with an unknown or missing race, 680 (4.3 percent) cases were matched and updated with a valid race; Maiden name: 19,187 cases (4.9 percent) were matched and updated with valid maiden names; Hispanic origin: 415 cases, or 6.1 percent, were matched and updated with valid data element codes for Hispanic origin.; Birthplace: of 486,625 cases with unknown or missing birthplace, 30,414 cases (6.2 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 28; 92.2 percent of the addresses were geocoded to an address specific level
- Ensured override flags were within the NPCR average by reviewing the 2015
   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 one application for confidential data from outside researchers
- Updated incidence projections
- Submitted 1,268,239 cases to NPCR and NAACCR for the 1995-2013 call for data

• Submitted 67,980 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; streamlined registry operations through more efficient use of staff and resources

### 3.2 Fiscal Year 2016 Major Accomplishments

# 3.2.1 North American Association of Central Cancer Registries Gold Certification

For the 18<sup>th</sup> 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 National Program of Cancer Registries (NPCR) Registry of Excellence

For the 3<sup>rd</sup> consecutive year, ISCR has been recognized as a Registry of Excellence by the U.S. Centers for Disease Control's National Program of Cancer Registries – their highest standard for registry certification. To be awarded this honor, a registry must have met all CDC NPCR standards for data completeness and quality. ISCR is one of 22 states to receive this designation.

### 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 cancer prevention and control priorities for Illinois. Several Division of Epidemiologic Studies staff provided technical and operational support for the program through committee participation.

### 3.2.3.2 Illinois Health Data Dissemination Initiative

Staff continued to provide data to the initiative. The ISCR public data set (PDS) file, version 23 (1986-2013) was submitted in June 2016.

### 3.2.3.3 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 seen at their facilities.

The VR death tape also contributes to the data quality and itemspecific 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.

### 3.2.3.4 North American Association of Central Cancer Registries (NAACCR)

ISCR provided comprehensive data from 1995-2013 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.

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

ISCR submitted comprehensive data from 1995-2013 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.

### 3.2.3.6 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.

### 3.2.3.7 American Cancer Society (ACS)

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

### 3.2.3.8 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. It is anticipated staff will continue to engage in this collaboration.

### 3.2.4 Quality Control Reports

- **3.2.4.1** Parrish P. Assessment of Duplicate Records for 1995-2013 Diagnosis Years. Quality Control Report Series 15:08. Springfield, Ill.: Illinois Department of Public Health, November 2015.
- **3.2.4.2** Hebert L. Linking Illinois State Cancer Registry Records with Vital Records Death Master File to Enhance Data Completeness. Quality Control Report Series 15:07. Springfield, Ill.: Illinois Department of Public Health, November 2015.
- **3.2.4.3** Parrish P, Redeford B. *Quality Control Audit on Accuracy of Histology Codes in 2013 Diagnosis Year Melanoma Skin Cancer Cases.* Quality Control Report Series 16:04. Springfield, III.: Illinois Department of Public Health, May 2016.

### 3.3 Goals for Fiscal Year 2017

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

- Perform facility casefinding for the 2015 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 2016
- Continue death certificate clearance and maintain death certificate only rate of less than 3 percent
- Achieve 90 percent case reporting for the 2015 diagnosis year by December 2016
- Achieve 95 percent case reporting for the 2043 diagnosis year by December 2016

# 3.3.2 Maintain and Enhance Activities Related to Physician and Pathology Reporting

- Maintain contact with existing dermatology offices for reporting and training (n=127)
- 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 five basic training workshops, four advanced training workshops, and eight 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
- 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 one epidemiologic report
- Produce a publication for the layperson on cancer in Illinois
- Perform linkage with Indian Health Services and update code for Native American race
- Process applications for confidential data
- Update incidence and mortality projections
- Submit the 1995-2014 NPCR/NAACCR file for combined call for data and submit the 2015 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 in order to correct and prevent developmental problems and other disabling conditions.

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

APORS cases meet one or more of the following criteria:

- the infant is diagnosed prior to hospital discharge as having a positive drug toxicity for any drug; shows signs and symptoms of drug toxicity or withdrawal; or the mother admits to illegal drug use (except cannabis) during the pregnancy;
- the infant or young child (younger than 2 years of age) is diagnosed with a congenital anomaly; a congenital infection; an endocrine, metabolic, or immune disorder; a blood disorder; or another high-risk medical condition;
- the infant was born at fewer than 30 weeks of gestation; or
- a neonatal or fetal death has occurred.

### 4.1 Review and Evaluation of Fiscal Year 2016 Goals

### Improve Casefinding

- Eighty-four (69.4 percent) of the 121 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 87 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 three-year training plan will be resumed shortly now that the training position has been filled. (It was vacant from November 2014 through March 2016)

 Made nine trainings by phone or webinar and held 1,269 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 two 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 38 cases born in 2012, 104 born in 2013, 498 born in 2014 and 1,194 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, 40 percent of the cases were found to have conditions that meet the APORS review criteria
- Avoided the need to travel to 117 of the 121 birth hospitals, either by accessing electronic medical records remotely, or having the hospitals send charts (in electronic or paper format)

### Improve Quality of APORS Data

- Evaluated the timeliness of hospital reporting for cases reported in January through December 2015; provided hospital-specific feedback and used results to identify hospital training needs. In 2015, 57.7 percent of hospitals met the APORS timeliness standard of reporting cases within seven days of infants' hospital discharge. This is an improvement from the previous year, but is still showing the impact over earlier years, since the new database identifies children that the hospitals overlooked. Now that the program has a trainer again, hospitals will be notified twice yearly of their timeliness status and provide more intensive education to facilities that are non-compliant.
- Evaluated the rates of hospital reporting of adverse pregnancy outcomes in 2014. There is wide variation in the reports received as a percentage of the live births at that hospital. While there may be good reasons for this, the report gives each hospital the opportunity to compare their performance with those of facilities providing the same level of services.
- 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<sup>®</sup> site updates of revised manuals, appendices, and quality control reports, hospitals and local health departments can access the forms to request additional materials

- Two fact sheets (one on folic acid and one on microcephaly) were developed and added to the IDPH website. Another ten have been submitted to the Division of Communications for review. This project has been delayed by staff shortages.
- Avoided the need to travel to 117 of the 121 birth hospitals, either by accessing electronic medical records remotely, or having the hospitals send charts (in electronic or paper format)
- 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 the loss of staff, and the need to keep the routine activities timely
- Was awarded a new four-year CDC cooperative agreement and applied for a formulaic-funded five-year CDC cooperative agreement to perform rapid case ascertainment of birth defects associated with the Zika virus

### 4.2 Fiscal Year 2016 Major Accomplishments

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

APORS was approved for a new four-year cooperative agreement with the CDC to enhance Illinois birth defects surveillance, prevention and service referral. Total funding for 2016 is \$210,000.

### 4.2.2 Enhancement of the APORS Database

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

All local health departments are using the APORS database introduced in FY14; and 84 hospitals are registered. These hospitals report more than 85 percent of the cases received by APORS.

### 4.2.3 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 FY16, the abstractors reviewed 5,190 birth defects reported by hospitals.

Abstractors deleted 435 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, 1,476 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 2,917 hospital-reported diagnoses. They clarified 359 diagnoses and added 7,074 diagnoses. In total, 10,350 birth defects were verified.

Case abstraction for 2013 birth cohort was completed in December 2016. The goal is to be complete within two years of the birth year.

Abstractors prioritized chart review for infants reported with microcephaly in response to Zika virus concerns. They began collection of additional information, such as head circumference, length and weight measurements for infants with Zika virus-related birth defects.

### 4.2.4 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 75.8 percent. The responses were overwhelmingly positive; both the program and individual nurses were acknowledged as a great benefit.

### 4.2.5 Linkages With Other Programs and Activities

### 4.2.5.1 Perinatal Programs

### 4.2.5.1.1

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 9,700 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 59 children with neural tube defects, whose families were referred for prevention counseling.

4.2.5.1.3 IDPH Division of Infectious Diseases. APORS identified infants for the IDPH Division of Infectious Diseases' sexually transmitted disease (99 newborns) and perinatal hepatitis B programs (272 newborns), which ensure infants with congenital syphilis and infants prenatally exposed to or diagnosed with a hepatitis B infection are offered services.

APORS began working with the Division of Infectious Diseases to monitor Zika virus exposed pregnant women and their babies. APORS reports de-identified information on neonates and infants at 2, 6 and 12 months of age to the U.S. Zika Virus Pregnancy Registry. The reports are linked to the maternal reports submitted by the Division of Infectious Diseases.

The APORS Manager has been part of collaboration with staff from throughout IDPH to produce the Illinois Zika Virus Action Plan

- 4.2.5.1.4 IDPH Craniofacial Anomaly Program. Data on all infants born with cleft lip and/or palate (192 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.
- 4.2.5.1.5 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 FY16, APORS referred 3,948 cases.
- 4.2.5.1.6 IDPH's Newborn Metabolic Screening (NMS) Program.

  APORS refers newborns reported to the program with possible metabolic conditions to IDPH's NMS Program.

  This program assures children receive timely follow-up for these severe conditions. Several children with hypothyroidism previously unknown to the NMS program have been identified.
- **4.2.5.1.7** Illinois Department of Children and Family Services (DCFS). Data are 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.

### 4.2.5.1.8 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.

### 4.2.5.2 National Birth Defects Prevention Network (NBDPN)

APORS submitted data for the NBDPN's annual report. The APORS manager, Jane Fornoff, served on the state data committee. Dr. Fornoff attended the NBDPN Conference in October 2015. She served as one of the judges for the poster session. She also attended a training on Health Outcomes and Services Utilization for Children with Birth Defects offered prior to the conference. All the APORS staff attended the NBDPN's virtual annual conference held in May 2016.

### 4.2.5.3 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.

### 4.2.5.4 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.

### 4.2.6 Quality Control Reports

- **4.2.6.1** Fornoff J. *Timeliness Study Hospital Reports of Adverse Pregnancy Outcomes Received in 2015.* Quality Control Report Series 16:01. Springfield, Ill.: Illinois Department of Public Health, January 2016.
- **4.2.6.2** Fornoff J. Rates of Hospital Reporting of Adverse Pregnancy Outcomes in 2014. Quality Control Report Series 16:02. Springfield, Ill.: Illinois Department of Public Health, February 2016.

**4.2.6.3** DeSuno, N, Fornoff J. Family Survey of Services Provided Through the High Risk Infant Follow-up (HRIF) program. Quality Control Report Series 16:03. Springfield, Ill.: Illinois Department of Public Health, January 2016.

### 4.3 Goals for Fiscal Year 2017

### Improve Casefinding

- Train and support hospitals in the use of the APORS database to ensure 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 ongoing training in APORS reporting
- Provide consultation and training to supplement the three-year and selfdirected training for hospital nursing staff when indicated
- Enhance the SharePoint® site for hospital staff to include materials that supplement face-to-face and telephone consultation and training offered by APORS staff
- Match information from periodic hospital discharge information reports to the APORS newborn cases and identify potential birth defect cases
- Review medical reports of infants identified in hospital discharge matching to ascertain and collect new birth defect cases
- Begin rapid case ascertainment of birth defects associated with Zika virus
- Begin case finding at genetic clinics

### 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 CHAs 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
- Collaborate with CDC to provide data to the U.S. Zika Pregnancy Registry
- Produce statewide and county surveillance reports
- Monitor activities and accomplishments associated with meeting the goals and objectives set forth in the CDC cooperative agreement

### 5. Occupational Disease Registry

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

### 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. In 2012, the Illinois Administrative Code related to elevated blood lead definition and collection was changed to reflect the new guidelines defining elevated blood levels. Laboratories are 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. Data collection continues and in calendar year 2015 3,056 new lab reports were added to the ABLR database.

### 5.1.1 Fiscal Year 2016 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
- Completed a quality control report: Adult Blood Lead Registry Item-Specific Completeness Report 2005-2014. Bostwick J. Adult Blood Lead Registry Item-Specific Completeness Report 2005-2014. Quality Control Report Series 15:06. Springfield, Ill.: Illinois Department of Public Health, December 2015.

# 5.1.2 Interventions Resulting From ABLR Notifications of Elevated Lead Results

In calendar year 2015, ABLR made 12 referrals (employees) to OSHA for 6 companies with employees who had blood lead levels greater than or equal to  $40~\mu g/dL$  of blood. OSHA conducted two safety inspections in Illinois because of

the ABLR referrals. During these inspections, violations of OSHA rules were found and fines in the amount of \$17,960 were proposed.

### 5.1.3 Goals for Fiscal Year 2017

- 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.

Due to changes in how BLS releases data, the 2015 CFOI data will not be finalized and released until October 2016. In 2014 Illinois CFOI recorded 164 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 VR 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. 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 2016 Goals

- Completed the summary report of the 2013 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 2017

- Publish a summary report of the 2014 fatal occupational injury data by December 2016
- Meet the deadlines for data completion required by BLS

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

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

### 5.3.1 Review and Evaluation of Fiscal Year 2016 Goals

- Submitted data files on all reported occupational injuries and illnesses of the surveyed companies to the BLS
- Collected, coded, and entered all 2015 data prior to BLS deadlines

### 5.3.2 Survey Process and Achievements for Fiscal Year 2016

In January 2016, BLS and ODR sent survey forms to 5,733 private employers and 369 public employers for 2015 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 2017

- Continue all data collection activities in FY17 and maintain the high standards achieved by the program
- Complete the descriptive report of 2014 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 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.28<sup>®</sup>.

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 2015

Range of Percentage Complete by Diagnosis Year						
	Average all years	Lowest	Highest			
Cancer Reports (n=1,656,577 cases for diagnosis years 1986-2013)						
ZIP code	100.0	100.0	100.0			
ZIP +4 code	95.8	91.9	99.0			
Lat/Lon code 1	100.0	100.0	100.0			
address specific	92.2	87.1	96.2			
centroid ZIP +4	0.4	0.2	1.1			
centroid ZIP +2	0.6	0.4	1.1			
centroid ZIP	6.8	2.5	11.7			
APORS Reports (n= 39	5,921) cases for birt	h years 1989-2015	)			
ZIP code	97.9	88.9	100.00			
ZIP +4 code	92.4	87.6	99.0			
Lat/Lon code 1	96.5	91.8	100.0			
address specific	91.3	86.3	97.8			
centroid ZIP +4	1.2	0.4	1.8			
centroid ZIP +2	1.7	0.2	3.			
centroid ZIP	2.4	0.2	5.3			

### 6.2 Goals for Fiscal Year 2017

• Continue to geocode new records submitted to ISCR and APORS

### 7. Cluster Inquiries and Assessments

### 7.1 Review and Evaluation of Fiscal Year 2016 Goals

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

### 7.2 Fiscal Year 2016 Accomplishments

In FY16, IDPH received eight 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. Staff used published cancer rates by county, epidemiologic reports, and data from the public data files or general information about the frequency of cancer or causes of cancer to help address the callers' concerns.

### 7.3 Fiscal Year 2017 Objectives

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

• Complete cluster assessments within 12 months of the written request if there is a known carcinogenic exposure and a cancer assessment is launched

### 8. Research Program

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

### 8.1 Fiscal Year 2016 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 Open Data Forum. Five staff serve on different committees in various capacities.

### 8.1.2 Provision of Peer-Review Service to Scientific Publication

Division staff provided professional reviews to the Journal - Health Security on articles about climate changes and data security.

### 8.1.3 Provision of Epidemiologic Supervision and Tutoring

Division staff provided supervisor roles and other assistance to various interns, CDC assignees, CSTE fellows and CDC EIS officers during FY16.

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

The Division created and published this bulletin on behalf of IDPH. IMMB targets statewide public health professionals, researchers and policy makers. The inauguration issue contained three articles contributed by health researchers throughout IDPH. Subsequent issues contained two reports each. A total of three issues have been published as of the end of FY16.

### 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) and media 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 2016

The following articles have been submitted, accepted or published.

- **8.2.1** Yanik EL, Nogueira LM, Koch L, Copeland G, Lynch CF, Pawlish KS, Finch JL, Kahn AR, Hernandez BY, Segev DL, Pfeiffer RM, Snyder JJ, Kasiske BL, Engels EA. Comparison of cancer diagnoses between the US solid organ transplant registry and linked central cancer registries. *Am J Transplant*. 2016 May 12. doi: 10.1111/ajt.13818.
- **8.2.2** Luke B, Brown MB, Spector LG, Stern JE, Smith YR, Williams M, Koch L, Schymura MJ. Embryo banking among women diagnosed with cancer: a pilot population-based study in New York, Texas and Illinois. *J Assist Reprod Genet*. 2016 May; 33(5): 667-74. doi: 10.1007/s10815-016-0669-5.
- **8.2.3** Luke B, Brown M, Missmer S, Spector L, Leach R, Williams M, Koch L, Smith Y, Stern J, Ball G, Schymura M. Assisted Reproductive Technology Use and Outcomes Among Women With a History of Cancer. *Hum Reprod*. 2016 Jan; 31(1): 183-9. doi: 10.1093/humrep/dev288.
- **8.2.4** Luke B, Brown M, Spector L, Missmer S, Leach R, Williams M, Koch L, Smith Y, Stern J, Ball G, Schymura M. Cancer in women after assisted reproductive technology. *Fertil Steril*. 2015 Nov; 104(5): 1218-26. doi: 10.1016/h,fertbstert,2015.07.1135.
- **8.2.5** Mueller-Luckey G, Zahnd W, Garner K, Heitkamp R, Jenkins W, Boehler M, Steward D. The Mini Report: A Practical Tool to Address Lung Cancer Disparities in Rural Communities. *J Canc Educ* 2015 October 6. DOI: 10.1007/s13187-015-0921-1.

### 8.3 Other Recent Reports or Publications That Used Registry Data

- **8.3.1** Agency for Healthcare Research Quality (AHRQ) *2015 National Healthcare Quality and Disparities Report*. Rockville, MD.: U.S. Department of Health and Human Services, Agency for Healthcare Research and Quality. May 2016. AHRQ Pub. No. 16-0015. http://www.ahrq.gov/research/findings/nhqrdr/nhqdr15/index.html
- **8.3.2** March of Dimes. *Peristats*. Available at http://www.marchofdimes.org/Peristats/whatsnew.aspx?id=77

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- **8.3.9** Mai C, Kirby RS, Correa A, Rosenberg D, Petros M, Fagen MC. Public Health Practice of Population-Based Birth Defects Surveillance Programs in the United States. *J Public Health Manag Pract* 2016 May-Jun;22(3):E1-8.
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**8.3.13** Copeland G, Lake A, Firth R, Wohler B, Wu XC, Schymura M, Hofferkamp J, Sherman R, Kohler B (eds). *Cancer in North America, 2009-2013. Volume Three: Registry-specific Cancer Mortality in the United States and Canada.* Springfield, Ill.: North American Association of Central Cancer Registries, Inc. June 2016.

- **8.3.14** Kohler BA, Sherman RL, Howlader N, Jemal A., et al. Annual Report to the Nation on the Status of Cancer, 1975-2012, Featuring the Increasing Incidence of Liver Cancer. *J Natl Cancer Inst* May 1, 2016 122(9). Doi:10.1002/cncr.29936.
- **8.3.15** 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.
- **8.3.16** American Cancer Society. *Cancer Facts & Figures 2016*. Atlanta, GA.: American Cancer Society; 2016.
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- **8.3.18** Major Birth Defects Data from Population-based Birth Defect Surveillance Programs in the United States, 2008-2012: Illinois. Res A Clin Mol Teratol 2015; 103(11):S23-24.
- **8.3.19** Survival of Children with Trisomy 13 and Trisomy 18: A multi-state population-based study. Meyer Re, Liu G, Gioboa Sm, Ethen MK, Aylsworth AS, Powell CM, Flood TJ, Mai CT, Wang Y, Canfield MA, for the National Birth Defects Prevention Network. Am J Med Genet A 2016 Apr;170(4):825-37.
- **8.3.20** Jin H, Pinheiro P, Xu J, Amei A. Cancer incidence among Asian American populations in the United States, 2009-2011. *International Journal of Cancer* 00, 00-00 (2016). DOI: 10.1002/ijc.29958.
- **8.3.21** Found too late: Cancer preys on rural Americans. <a href="http://www.usatoday.com/longform/news/nation/2015/11/12/cancer-preys-upon-rural-americans/74635">http://www.usatoday.com/longform/news/nation/2015/11/12/cancer-preys-upon-rural-americans/74635</a>. November 2015.

### 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** Weems K, Bostwick J, Shen T. **Trends in Elevated Blood Lead Levels in Adults Illinois, 2005-2014**. Springfield, Ill.: Illinois Department of Public Health, September 2015.
- **8.4.2** Garner K, Shen T. Cancers Associated with Human Papillomavirus, Illinois, **2008-2012**. Epidemiologic Report Series 16:02. Springfield, Ill.: Illinois Department of Public Health, August 2015.
- **8.4.3** Weems K, Bostwick J, Shen T. **Survey of Occupational Injuries and Illnesses in Illinois, 2013**. Epidemiologic Report Series 16:03. Springfield, Ill.: Illinois Department of Public Health, December 2015.
- **8.4.4** Garner K, Shen T. **Illinois State Cancer Incidence Review and Update, 1986- 2013**. Epidemiologic Report Series 16:04. Springfield, Ill.: Illinois Department of Public Health, February 2016.
- **8.4.5** Garner K, Shen T. **Illinois County Cancer Incidence Review and Update 1986- 2013.** Epidemiologic Report Series 16:05. Springfield, Ill.: Illinois Department of Public Health, February 2016.
- **8.4.6** Garner K, Shen T. Illinois Cancer Mortality Review and Update 1986-2013. Epidemiologic Report Series 16:06. Springfield, Ill.: Illinois Department of Public Health, May 2016.
- **8.4.7** Wamack J, and Bostwick J. **Census of Fatal Occupational Injuries, 2013.** Epidemiologic Report Series 16:07. Springfield, Ill.: Illinois Department of Public Health, June 2016.

### 8.5 Other Division Publications

- **8.5.1** Koch L, Lehnherr M, Weems K, Bostwick J. **Cancer in Illinois 2015**. Illinois Department of Public Health, Springfield, Ill.: August 2015.
- **8.5.2** Alarcon WA et al. **Elevated blood lead levels among employed adults United States, 1994-2013**. CDC Morbidity and Mortality Weekly Reports (MMWR), May 2016.
- **8.5.3** Wood J, Lehnherr M, Hebert L, Garner K, Dolecek T, Shen T. **Evaluation of projection methods for cancer incidence in Illinois**. Illinois Morbidity and Mortality Bulletin (IMMB). Springfield, Ill.: Illinois Department of Public Health, IMMB 2:2-11, 2016.

# 8.6 Fiscal Year 2016 Presentations by IDPH Division of Epidemiologic Studies Staff

Title	Event	Date
APORS and Timeliness	Perinatal Network Administrators	August 2015
		August 2013
APORS-Case Identification and Completion of Form	Clinton County Health Department (webinar)	September 2015
APORS-Data System Training	Northwestern Community Hospital (Arlington Heights) webinar Carle Hospital (Champaign)	September 2015
APORS-Data System Training	teleconference	October 2015
APORS-Question and Answer Training	Northwestern Lake Forest (Lake Forest) teleconference	January 2016
APORS-Data System Training	Advocate Sherman Hospital (Elgin) teleconference	January 2016
APORS-Data System Training	Will County Health Department	April 2016
APORS-Data System Training	Roseland Hospital (Chicago) teleconference	April 2016
APORS-Data System Training	Ingalls Memorial Hospital (Peru) teleconference	May 2016
ISCR-TNM Staging Training Workshop	Good Samaritan Regional Health Center (Mt. Vernon)	May 2016
ISCR-TNM Staging Training Workshop	Swedish American Regional Cancer Center (Rockford)	May 2016
ISCR-TNM Staging Training Workshop	Department of Natural Resources (Springfield)	May 2016
ISCR-Basic Training Workshop	Good Samaritan Regional Health Center (Mt. Vernon)	April 2016
ISCR-Basic Training Workshop	Chicago Thompson Building (Chicago)	April 2016
ISCR-Basic Training Workshop	Elmhurst Memorial Hospital (Elmhurst)	April 2016
ISCR-Basic Training Workshop	Methodist Medical Center (Peoria)	April 2016
ISCR-TNM Staging Training Workshop	Michael Bilandic Bulding (Chicago)	May 2016

Title	Event	Date
	Presence St. Joseph Medical Center	
ISCR-TNM Staging Training Workshop	(Joliet)	May 2016
ISCR-TNM Staging Training Workshop	Presence St. Joseph Hospital (Elgin)	May 2016
ISCR-"ISCR Updates: TNM Staging		-
Transition and Quality Control	Cancer Registrars of Illinois Annual	
Studies"	Conference	September 2015
ISCR-"Physician Reporting Using Web Plus"	CDC/NPCR Registry Plus Users Group	October 2015
ISCR-"The Illinois State Cancer Registry"	IDPH Institutional Review Board	December 2015
ISCR-"The Illinois State Cancer		
Registry"	Illinois State Cancer Partnership	June 2016
APORS-"Illinois Zika Response and	IDPH Institutional Review Board and	
the Current Impact of Zika Infections"	IDPH Data Stewards	June 2016
	University of Illinois at Chicago,	
Shen-Guest Lecture "Cancer Cluster	School of Public Health Graduate	
Response"	Students	February 2016

### 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*	
Paul Rowan University of Texas School of Public Health	Number of VSDs and ASDs by half year	September 2015	
James Ronayne University of Illinois, Chicago	Drug Exposures in Illinois by county	January 2016	
Sonja Young Western Kentucky University	Prevalence of and Risk Factors Associated with Congenital Anomalies of the Nervous System in Kentucky and Illinois 2000-2010	April 2016	
U.S. Centers for Disease Control and Prevention	Prevalence Data by Race for Selected Birth Defects for Publication in Birth Defects Research	May 2016	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
Alicia Gilsenan, Ph.D. RTI International	Osteosarcoma Surveillance Study	September 2014 Ongoing	Eli Lilly & Company
Alpa V. Patel, Ph.D.	Cancer Prevention Study III	September 2015 Ongoing	ACS

NOTE: Following are definitions of acronyms used in the above table: American Cancer Society (ACS), U.S. Centers for Disease Control and Prevention (CDC), Cancer in North America (CINA), Illinois Department of 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)

<sup>\*</sup>Data set released; study remains open

### 9. Grants

The table below summarizes the IDPH Division of Epidemiologic Studies grant awards for FY2016.

Grant	Agency	Status
Occupational and Health Survey in Illinois (continuation)	BLS	Funded September 2015
Census of Fatal Occupational Injuries in Illinois (continuation)	BLS	Funded September 2015
Improvement of Birth Defects Surveillance Program	CDC	Funded January 2016
Perinatal Hepatitis B Program (submitted by IDPH, Division of Infectious Disease) (continuation)	CDC	Funded June 2016
National Cancer Prevention and Control Program- National Program of Cancer Care (new)	CDC	Funded June 2016

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 2016.

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

IDPH received \$107,839 in September 2015 from the U.S. Bureau of Labor Statistics to support the 18th 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 \$94,861 in September 2015 from the U.S. Bureau of Labor Statistics to support the 24<sup>rd</sup> 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 2016, IDPH received \$210,000 for year one of the fourth 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 \$50,000 in June 2016 to continue expansion of APORS surveillance and data collection (17<sup>th</sup> 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.

### 9.1.5 National Cancer Prevention and Control Program

In June 2015, CDC awarded IDPH \$9.4 million in funding for the fourth year of a third five-year project period year of the National Cancer Prevention and Control Program. This grant combines two previous separate grants: the National Comprehensive Cancer Control Program and the National Program of Cancer Registries (NPCR). The IDPH Division of Epidemiologic Studies received nearly \$1.2 million for the NPCR component, which is in its 21<sup>st</sup> year. The progress for this project is described in Section 3.

# 10. Cancer Reporting Facilities That Have Not Completed Reporting for the 2015 Diagnosis Year by July 1, 2016

Name	City		
A & G Dermatology	Chicago		
Advanced Dermatology	Moline		
Advanced Dermatology & Mohs Surgery	Batavia		
Advanced Radiation Oncology Center	Gurnee		
Alpha Med Physician Group, LLC	Tinley Park		
Altman Dermatology Associates	Arlington Heights		
American Cancer Center	Elgin		
Belleville Oncology Institute	Belleville		
Bolingbrook Dermatology - Tehming Liang, MD	Bolingbrook		
Breese Oncology	Breese		
Cancer Treatment Center	Swansea		
Centegra Hospital	McHenry		
Chicago Cosmetic Surgery and Dermatology	Chicago		
Clay County Hospital	Flora		
Cosmetic Dermatology & Surgery	Gurnee		
Dermatology Associates Of LaGrange	LaGrange		
Dundee Dermatology	West Dundee		
Elgin Gastroenterology Endoscopy Center	Elgin		
Elk Grove Dermatology - Dr. Robert Polisky	Elk Grove Village		
Fayette County Hospital	Vandalia		
Franciscan St. James Health	Olympia Fields		
Graham Hospital	Canton		
Hardin County General Hospital	Rosiclare		
Harrisburg Medical Center	Harrisburg		
Illinois Cancer Specialists	Niles		
Illinois Dermatology Institute	Park Ridge		
Illinois Regional Cancer Center LLP	DeKalb		
Jacksonville Oncology Institute	Jacksonville		
Kevin Pinski, MD	Chicago		
Kishwaukee Hospital	DeKalb		
Lawrence County Memorial Hospital	Lawrenceville		
MacNeal Hospital	Berwyn		
Macomb Oncology Institute	Macomb		
Marshall Browning Hospital	DuQuoin		
Maryville Oncology c/o Mohamed Megahy, MD	Maryville		
MCSO Affiliated Oncologists	Oak Lawn		
Medical Associates Dermatology	Chicago		
Mercy Health System (Khanna Dermatology)	Woodstock		
Mercy Regional Cancer Center (Harvard IL)	Janesville		
MetroSouth Medical Center	Blue Island		
North Suburban Dermatology Associates	Gurnee		
Northshore Dermatology Center	Lake Bluff		
Northwest Surgicare	Arlington Hts		
Northwestern Lake Forest Hospital	Lake Forest		
Northwestern Memorial HealthCare	Chicago		

Name	City	
Oak Lawn Endoscopy Center	Oak Lawn	
OSF Saint Anthony's Health Center	Alton	
Pediatrics & Dermatology	Chicago	
Presence Resurrection Medical Center	Chicago	
Provident Hospital of Cook County	Chicago	
River North Same Day Surgery Center	Chicago	
Roseland Community Hospital	Chicago	
Rush Medical Center-Department Dermatology	Chicago	
Simmons Cancer Institute, SIU School of Medicine	Springfield	
South Loop Endoscopy and Wellness Center	Chicago	
Southern Cook Radiation Treatment Center	Blue Island	
Springfield Clinic Ambulatory Surgery Treatment Center	Springfield	
Springfield Clinic Dermatology	Springfield	
Strow Dermatology, LTD	Springfield	
Surgery Center Of Centralia	Centralia	
Thorek Memorial Hospital	Chicago	
Unitypoint Health - Trinity Moline		
Valley West Hospital	Sandwich	
Wabash General Hospital Mount Carmel		

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