# Indiana State Cancer Registry

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Indiana State Department of Health

Indiana State Department of Health

# Objectives

- Learn top four cancers in Indiana
  - Incidence and mortality
- Learn about data usage in 2016
  - Your data at work
- Introduction of new programmer

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# What Does Indiana Look Like?

- Population
  - Over 6 million
- 95 counties
- 10 public health districts (PHD)

- Top four cancers
  - Lung
  - Breast
  - Colorectal
  - Prostate
- Hospitals
  - 107 Total
  - 46 Commission on Cancer

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# Indiana Incidence

**Year**: 2010-2014

**All Races**

| Site | Colon and Rectum | | Lung and Bronchus | | Breast | | Prostate | |
|---|---|---|---|---|---|---|---|---|
| **Public Health District** | *Count* | *Rate* | *Count* | *Rate* | *Count* | *Rate* | *Count* | *Rate* |
| **All Districts** | **15509** | **42.9** | **26351** | **72.2** | **23228** | **64.3** | **16523** | **94.4** |
| District 1 | 2235 | 47.9 | 3403 | 71.9 | 3218 | 68.9 | 2639 | 116.7 |
| District 2 | 1580 | 43.5 | 2540 | 69.2 | 2227 | 62.5 | 1640 | 94.4 |
| District 3 | 1653 | 40.8 | 2595 | 64.1 | 2440 | 61 | 1778 | 92.2 |
| District 4 | 806 | 42.4 | 1339 | 68.7 | 1164 | 60.7 | 842 | 90.4 |
| District 5 | 3380 | 39.3 | 5988 | 71.3 | 6219 | 70.6 | 3665 | 88.1 |
| District 6 | 1771 | 43.7 | 3199 | 77.2 | 2282 | 58.2 | 1990 | 101.8 |
| District 7 | 781 | 46.7 | 1403 | 81.6 | 1031 | 61.9 | 716 | 86.7 |
| District 8 | 924 | 46.3 | 1529 | 73.8 | 1231 | 61.5 | 835 | 84 |
| District 9 | 1118 | 42.4 | 2213 | 82.1 | 1640 | 61 | 974 | 73.2 |
| District 10 | 1261 | 42.7 | 2142 | 71.4 | 1776 | 61.5 | 1444 | 100.4 |

Rates are per 100,000 population and age-adjusted to the 2000 US Standard Population.
Source: Indiana State Cancer Registry, http://www.in.gov/isdh/24360.htm.

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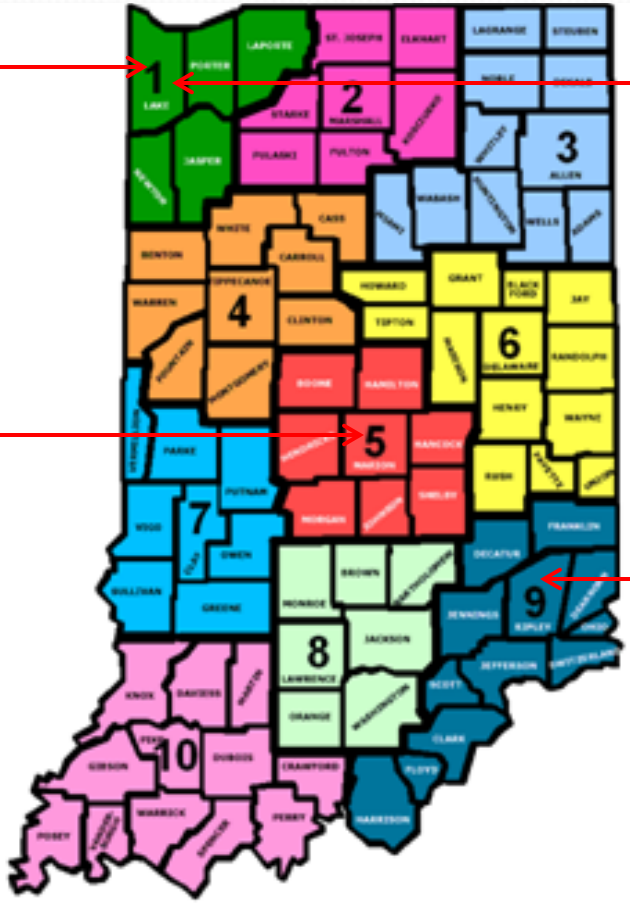
# Highest Incidence Rates
# Top Four Cancers per PHD

Colon & Rectum
47.9

Prostate
116.7




Breast
70.6

Lung & Bronchus
82.1

**Indiana Incidence Rates**
Colon & Rectum - 42.9
Lung & Bronchus - 72.2
Breast - 64.3
Prostate - 94.4

Rates are per 100,000 population and age-adjusted to the 2000 US Standard Population.
Source: Indiana State Cancer Registry, http://www.in.gov/isdh/24360.htm.

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# Indiana Mortality

**Year**: 2010-2014

**All Races**

| Site | Colon and Rectum | | Lung and Bronchus | | Breast | | Prostate | |
|---|---|---|---|---|---|---|---|---|
| **Public Health District** | *Count* | *Rate* | *Count* | *Rate* | *Count* | *Rate* | *Count* | *Rate* |
| **All Districts** | **5795** | **16** | **19942** | **54.9** | **4423** | **12.2** | **2942** | **20.9** |
| District 1 | 870 | 18.4 | 2488 | 52.8 | 642 | 13.6 | 402 | 21.9 |
| District 2 | 560 | 15.1 | 1908 | 52.1 | 416 | 11.2 | 325 | 22.2 |
| District 3 | 638 | 15.7 | 1880 | 46.6 | 534 | 13.2 | 374 | 23.5 |
| District 4 | 307 | 15.9 | 1031 | 52.9 | 240 | 12.2 | 131 | 16.7 |
| District 5 | 1262 | 15 | 4595 | 55.3 | 1045 | 12.1 | 685 | 22.2 |
| District 6 | 680 | 16.3 | 2499 | 60.3 | 487 | 12.1 | 302 | 18.1 |
| District 7 | 296 | 17.6 | 1100 | 64.4 | 216 | 12.8 | 122 | 18.2 |
| District 8 | 318 | 15.7 | 1211 | 58.7 | 256 | 12.6 | 163 | 20.6 |
| District 9 | 389 | 14.9 | 1673 | 62.7 | 259 | 9.8 | 185 | 18.6 |
| District 10 | 475 | 15.7 | 1557 | 51.7 | 328 | 11 | 253 | 21.1 |

Rates are per 100,000 population and age-adjusted to the 2000 US Standard Population.
Source: Indiana State Cancer Registry, http://www.in.gov/isdh/24360.htm.

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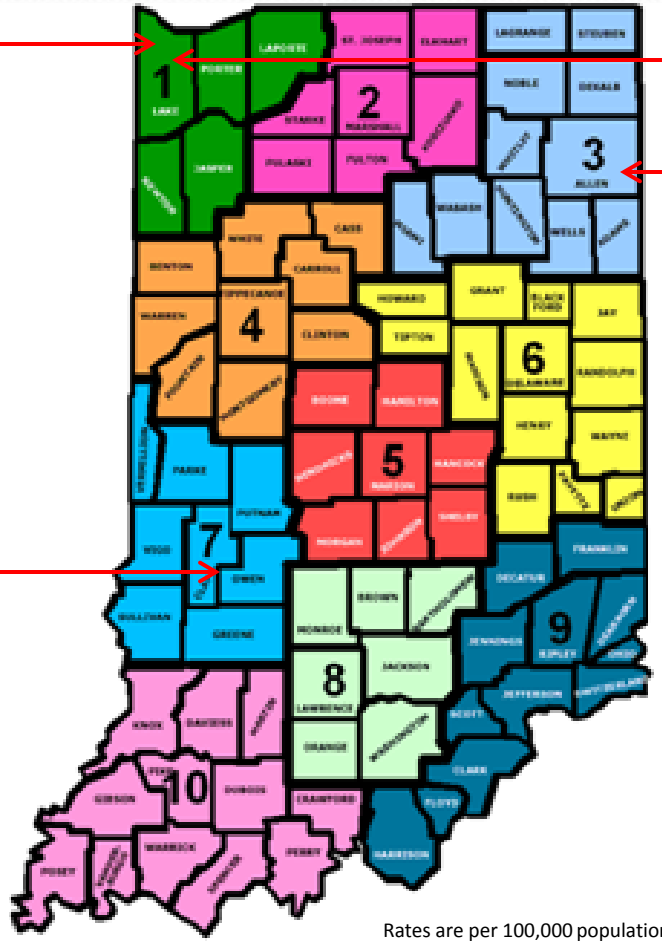
# Highest Mortality Rates
# Top Four Cancers per PHD

Colon & Rectum
18.4

Breast
13.6

Prostate
23.3

Lung & Bronchus
64.4




**Indiana Mortality Rates**

Colon & Rectum - 16
Lung & Bronchus - 54.9
Breast - 12.2
Prostate - 20.9

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Rates are per 100,000 population and age-adjusted to the 2000 US Standard Population.
Source: Indiana State Cancer Registry, http://www.in.gov/isdh/24360.htm.

# Using the Registry Data Highlights of 2016

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# National Cancer Registrars Association
## April 10-14, 2016
## Las Vegas, NV

- Cancer Surveillance Section Director, Laura Ruppert, and Health Education and Communications Director, Dawn Swindle, presented:

  - ***Using Cancer Registry Data to Enhance Comprehensive Cancer Control Communication Efforts***

  - ***Populating Hospital Cancer Registry Data into Survivorship Care Plans: A Test Run***

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# Indiana-Ohio Regional Cancer Registrars

## May 25, 2016

## Ft. Wayne, IN

- First regional meeting with Ohio
- Collaboration between Ohio Cancer Registrars Association and Indiana Cancer Registrars Association
- Focused on lung cancer

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# North American Association of Central Cancer Registries
# June 11-16, 2016
# St. Louis, MO

## *Using Geographic Information Systems to Analyze Data to Expand the Reach of the Indiana Breast and Cervical Cancer Program (IN-BCCP)*

Kate Tewanger, Cynthia Cunningham, and Laura Ruppert

- **Poster presentation**
- **Background:** The IN-BCCP provides breast and cervical cancer screening and diagnostic services to underserved women. External evaluation consultants conducted a market analysis to determine the reach and scope of the program and identify gaps or areas for improvement.
- **Purpose:** The analysis was conducted to examine where IN-BCCP provider screening sites are in relationship to potentially eligible women not participating in the program.

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# Using geographic information systems to analyze data to expand the reach of the Indiana Breast and Cervical Cancer Program (IN-BCCP)

Kate Tewanger, M.P.A., Indiana State Department of Heath (ISDH), Cynthia Cunningham, B.S., Community Solutions, Inc., Laura Ruppert, M.H.A., ISDH

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## BACKGROUND

The IN-BCCP provides breast and cervical cancer screening and diagnostic services to underserved women. The IN-BCCP has been impacted as more individuals gain access to healthcare as a result of the Affordable Care Act and the uninsured population declines. The IN-BCCP is continually assessing the evolving healthcare landscape to modify the program to meet the needs of low-income women and increase the early detection of cancer. A market analysis was conducted to determine the reach and scope of the program and identify gaps or areas for improvement.

## PURPOSE

The analysis was conducted to examine where IN-BCCP provider screening sites are in relationship to IN-BCCP participants and potentially eligible women not participating in the program.

## METHODS

An analysis was conducted using geographic information systems to analyze IN-BCCP data, Indiana State Cancer Registry (ISCR) data, and U.S. Census data from 2009 to 2013. Data was analyzed by the six IN-BCCP Regional Coordination districts and the 10 Public Health Districts (See Figures 1 and 2).

**Figure 1. IN-BCCP Screening Sites and Location of IN-BCCP Patients Between 2009 and 2013 by IN-BCCP Regional Coordination Districts**

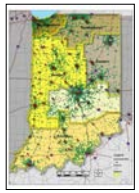
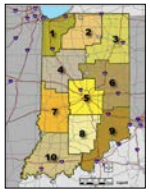


**Figure 2. Indiana Public Health Districts**



## RESULTS

The IN-BCCP has successfully maintained screening providers statewide (See Figure 1.) Figure 1 also demonstrates where IN-BCCP participants reside in relation to IN-BCCP screening sites, and the six regional coordination sites for the IN-BCCP. Regional coordination sites are staffed to coordinate the program, serve as a liaison between patient and providers, and conduct education and outreach to women.

The IN-BCCP analyzed where participants live, the screening provider locations, and how far participants travel for screening services (See Figure 3). Most IN-BCCP participants are less than 30 miles from a screening provider, although, several small pockets were identified where participants must travel 30 to 50 miles or more to reach an IN-BCCP screening site. Transportation is a common barrier to screening and follow-up for low-income IN-BCCP participants. U.S. Census data for low-income women, ages 30 to 64, who are potentially eligible for IN-BCCP in 2010 was also analyzed (See Figure 4). Examining Figures 3 and 4 together, identifies three areas that should be targeted for provider recruitment to meet the needs of IN-BCCP participants traveling more than 15 miles to a screening site as well as concentrated pockets of low-income women potentially eligible for IN-BCCP.

**Figure 3. Average Distance Traveled by IN-BCCP Participants to Screening Sites**

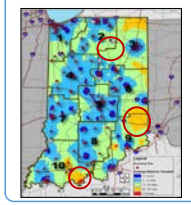
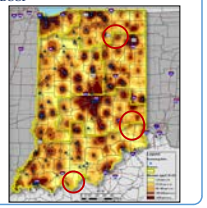


**Figure 4. 2010 U.S. Census Data for Low-Income Women Potentially Eligible for IN-BCCP**



## RESULTS

The distance traveled by IN-BCCP participants to screening sites was explored further by examining the average distance traveled by IN-BCCP participants with incomes between 150 and 200 percent of the federal poverty level (FPL), 100 and 150 percent of the FPL, and under 100 percent of the FPL. Figures 5, 6, and 7 use IN-BCCP data from 2009 to 2013 to identify areas throughout the state where women are traveling more than 30 miles to access IN-BCCP screening providers. The map of IN-BCCP participants who earn under 100 percent of the federal poverty level shows clearly that there are several areas around the state where the lowest income women are traveling more than 30 miles and, in some cases more than 50 miles, to be screened for breast and cervical cancer, specifically the eastern, northeastern and southern sections of the state. These regions tend to be rural and have a limited number of providers.

**Figure 5. IN-BCCP Participants Between 150 Percent to 200 Percent of the FPL and Average Distance Traveled to Screening Sites**

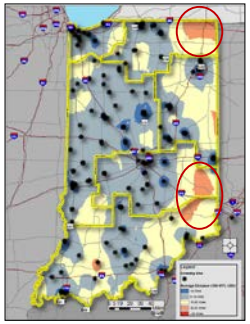


**Figure 6. IN-BCCP Participants Between 100 Percent to 150 Percent of the FPL and Average Distance Traveled to Screening Sites**

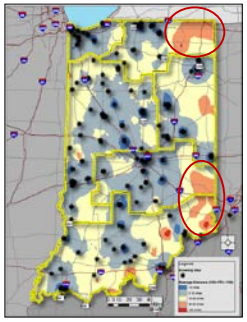
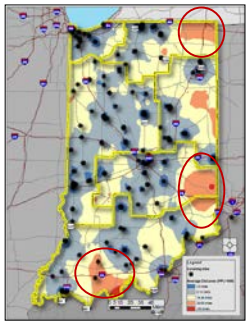


**Figure 7. IN-BCCP Participants Under 100 Percent of the FPL and Average Distance Traveled to Screening Sites**



The early detection of cancer is an important goal of the IN-BCCP because treatment is more effective when cancer is detected at an early stage. All women diagnosed with breast or cervical cancer through the IN-BCCP are enrolled in the Medicaid treatment program to ensure access to timely care. The number of cervical cancer cases was too small for analysis so only breast cancer data was analyzed. Breast cancer diagnosis data from the ISCR and the IN-BCCP during 2009 to 2013 were analyzed to assess the impact of the program throughout the state. The ISCR data was analyzed to compare the percent of breast cancers diagnosed by stage among all female breast cancer patients and compared with the percent diagnosed by stage for women diagnosed through the IN-BCCP. The data analysis identified a higher percentage of breast cancers being diagnosed at the regional stage (32.4%) for IN-BCCP participants compared to the percentage in the ISCR (23.1%), and a higher percentage of distant breast cancers (6.1%) compared to the percentage in the ISCR (5.1%) (See Figure 8). The target population for the IN-BCCP is rarely or never screened women. Many women diagnosed with breast cancer through IN-BCCP were likely to have never been screened, or were past due on screening as a result of not having access to health care or health care coverage. To further examine where the disparities in the regional stage of diagnosis exist among IN-BCCP participants, the data was analyzed by public health district, which are geographically smaller than the IN-BCCP Regional Coordination Districts (See Figure 9). The IN-BCCP is diagnosing a higher percentage of breast cancers at the regional stage in all but one of the 10 public health districts.

**Figure 8. Percent of Breast Cancers Identified by Stage in the ISCR and the IN-BCCP**

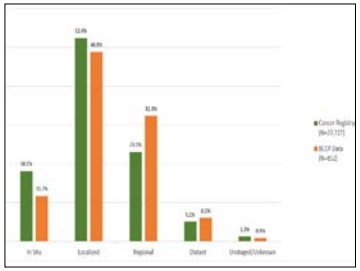
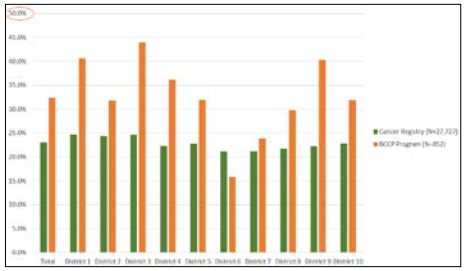



**Figure 9. Regional Stage Breast Cancers Identified by IN-BCCP as a Percent of All Breast Cancer Identified by Public Health Districts**




## RESULTS

The IN-BCCP analyzed women served between 2009 to 2013 to assess the reach of the program compared to women in Indiana who are below 200 percent of the FPL in Indiana. Income data from the U.S. Census data was used; however, the data are not available by gender, age, and income at the census tract level. As a result, tabular data from the American Community Survey Sample data from 2013 Public Use Micro Data (PUMA) files from the US Bureau of the Census were used. The IN-BCCP served 23,670 women between 2009 and 2013, which is only 1.87 percent of women potentially eligible for IN-BCCP based on age and income (See Figure 10). Although the IN-BCCP has provided access to breast and cervical cancer screening to 23,670 women, there are still many other low-income women with barriers to cancer screening.

**Figure 10. Estimated Number of Women Ages 30-69 Earning Less than 200 Percent of the Federal Poverty Level**

| | Estimated Number of Women Age 30-69 Earning < 200% FPL, 2013 | Unduplicated Count of Women in the IN-BCCP 2009-2013 | IN-BCCP Participants 2009-2013 as a percentage of Women Age 30-69 Earning < 200% FPL |
|---|---|---|---|
| State Total | 1,266,119 | 23,670 | 1.87% |
| Northwest Total | 144,895 | 3,993 | 2.76% |
| Northeast Total | 178,581 | 4,125 | 2.31% |
| Eastern Total | 233,938 | 3,785 | 1.62% |
| Western Total | 246,661 | 4,450 | 1.8% |
| Central Total | 437,176 | 3,180 | .73% |
| Southern Total | 244,166 | 4,137 | 1.69% |

## CONCLUSIONS

The analysis of IN-BCCP participants, screening sites, and average distance traveled revealed that the IN-BCCP successfully maintained providers statewide; however, several pockets were identified where provider recruitment must be directed to ensure participants have access to screening services within a reasonable driving distance, particularly where the lower income participants are located. The IN-BCCP will use these maps as tools to demonstrate the need to providers. The IN-BCCP may also use this information to encourage the nearest IN-BCCP providers with mobile units to offer services in these areas to reduce structural barriers.

Historically, the IN-BCCP has been able to provide a limited amount of services because of funding. Due to the ACA and women gaining access to healthcare coverage, the IN-BCCP has more funds available to provide services. Although the IN-BCCP is reaching rarely or never screened women that do not have access to routine medical care as evidenced by the regional and distant diagnosis data when compared with the ISCR.

In addition, the IN-BCCP began developing partnerships with health systems to implement evidence-based practices including patient reminder/recalls, providers reminders, small media, one-on-one education, and patient navigation to increase cancer screening rates within health systems. The IN-BCCP expects to reach more women and increase breast and cervical cancer screening rates in Indiana by partnering with health systems and providing patient navigation to uninsured or insured women facing barriers to screening such as transportation, fear, childcare, education, etc.

The IN-BCCP plans to further examine where women ages 30 to 69 are located using the U.S. Census Bureau and PUMA data. This analysis may also be used to partner with community health workers to recruit low-income, unscreened women, who are not connected with a health system in targeted geographic areas.

## REFERENCES


- IN-BCCP Data
- ISCR
- U.S. Census Bureau


## CONTACT INFORMATION

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# PHDs 1 & 2
# June 27, 2016
# Munster & South Bend, IN

- New regional cancer control coalitions
- Highlighting district-level data to assist in program planning
    - Incidence
    - Mortality
    - Behavioral Risk Factor Surveillance System

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# Kentucky-Indiana Regional Cancer Registrars

## September 8-9, 2016

## Louisville, KY

- First regional meeting with Kentucky
- Speakers from both sides of the river
- Well attended (170)
- Overwhelming desire to repeat the meeting in 2017

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# Indiana Public Health Conference
## September 15, 2016
## Indianapolis, IN

- Poster presentations:
  - ***Using Geographic Information Systems to Analyze Data to Expand the Reach of the Indiana Breast and Cervical Cancer Program (IN-BCCP)***
  - ***Using Cancer Data to Educate Partners about the State's Cancer Burden***

# Using Cancer Data to Educate Partners about the State's Cancer Burden

**Dawn Swindle, BS and Laura P. Ruppert, MHA**

Indiana State Department of Health

## Introduction

Cancer is a group of diseases characterized by uncontrolled growth and spread of abnormal cells. In Indiana, cancer is the second leading cause of death. Approximately 2.6 million Hoosiers, or two out of every five people now living in Indiana, will eventually be diagnosed with cancer. From 2010-2014, 166,670 Indiana residents were diagnosed with cancer, and 66,211 died as a result of the disease. In short, cancer touches us all.

Comprehensive cancer control is defined as, "a collaborative process through which a community and its partners pool resources to reduce the burden of cancer." The Indiana State Department of Health (ISDH) Cancer Control Section and the Indiana Cancer Consortium (ICC) work together with state and local partners to implement strategies from the *Indiana Cancer Control Plan* – the state's roadmap for cancer control in the areas of prevention, early detection, treatment and survivorship. This includes efforts to identify at-risk populations and educate the general public on preventive behaviors, early detection, and cancer risk. Data from the Indiana State Cancer Registry (ISCR) and the Behavioral Risk Factor Surveillance System (BRFSS) are critical to these efforts.

## How is Data Used?

ISCR data and BRFSS data are used to create cancer burden reports and conduct analysis. In addition, these data are used to develop educational materials, toolkits, fact sheets, press releases, infographics, social media campaigns, small media efforts, articles, and webcasts. The ISDH Epidemiology Resource Center assists with the development of Geographic Information Systems (GIS) maps. These maps are used to identify areas of need, areas with high cancer burdens and target populations. In addition, these data are used by regional cancer coalitions to develop action plans and focus areas.

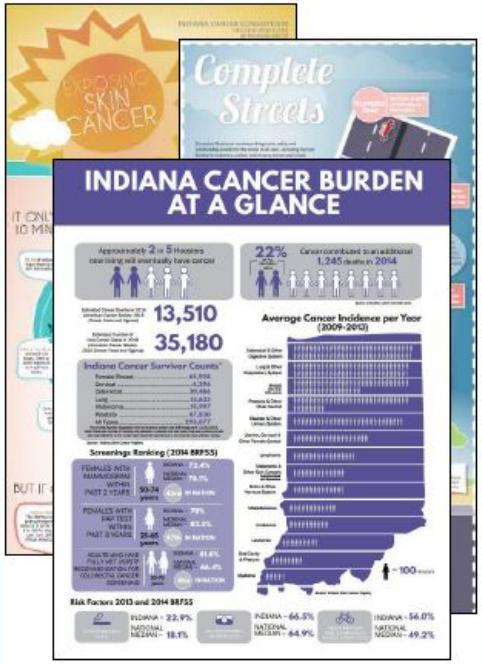
## GIS Mapping

### Acknowledgments

**A special thanks to our cancer registrars, the cancer epidemiologist, and the Indiana BRFSS coordinator. Without their hard work, none of these efforts would be possible.**

*We acknowledge the Centers for Disease Control and Prevention for its support of the Indiana Cancer Sections, under cooperative agreement 5 U58DP001884-05-00 awarded to the ISDH. The findings and conclusions listed here are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.*

## Data Communications




## Results

Integrating cancer data into education and communications materials has helped educate partners and communities about the state's cancer burden. This allows for better implementation of the *Indiana Cancer Control Plan* and more effective comprehensive cancer control efforts.

The ISDH Cancer Control Section and the ICC have developed an impressive library of materials that are updated annually.

These include:

- 15 fact sheets
- 14 toolkits
- 8 press releases (on average)
- 4 infographics
- 4 data reports (including the ICC annual report)

These materials are used by internal and external partners. According to the 2016 ICC Member Satisfaction Survey, 88% of respondents indicated an increased awareness of relevant cancer data, and 86% of respondents indicated an increase in the use of relevant cancer data.

The ISDH Cancer Control Section will continue to evaluate the use of cancer data, identify gaps and areas of need and make recommendations for additional initiatives.

# New Programmer at the Indiana State Cancer Registry



- Stephen Nygaard retired June 2016
- **Welcome to Padmini Pasam as our new programmer**

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# Results from the 2015 Call for Data

- NAACCR -**Gold Standard**
- National Program of Central Cancer Registries-**Registry of Distinction**
- Data included in the **Cancers Incidence in North America** publication
- Data included in the **United States Cancer Statistics** publication

***This reflects all of the rich data that is collected throughout Indiana!!***

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# THANK YOU FOR ALL YOU DO!

- Your data is the framework
  - Program planning
  - Research studies
  - Data presentations
  - Publications
  - Grant initiatives
  - And so much more!!

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# Any questions?

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