Illinois' Action Plan to Eliminate Vaccine-Preventable Cancers

Updated July 2022

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Introduction

The American Cancer Society estimates that in Illinois in 2021, 75,000 people will be diagnosed with cancer and 23,070 will die. More sobering: a substantial proportion of cancers are preventable. Excluding non-melanoma skin cancer, at least 42 percent of newly diagnosed cancers in the U.S. – about 797,000 cases in 2021 – are potentially avoidable.

When we avoid tobacco and second-hand smoke, exercise regularly, eat more vegetables and fruits, limit alcohol, protect our skin, get routine screenings on time, and get vaccinated as recommended, we give ourselves the best chance of living longer, healthier lives by preventing cancer and detecting it at its earliest, most treatable stages.

These statistics are sobering but they highlight the need to do more. To reduce and then eliminate vaccine-preventable cancers, we need to increase protective health behaviors and vaccinations to prevent infections from human papillomavirus and hepatitis B, two viruses that are known to cause cancer. These two viruses are driving the rising incidence rates for HPV-related head and neck cancers, also referred to as oropharyngeal cancers, and HBV-related liver cancers in Illinois.

The purpose of this plan is to find common purpose and strategy across a diverse group of stakeholders and articulate a set of objectives focused on reducing and then eliminating vaccine-preventable cancers in Illinois.

Elimination is defined as zero, or near zero, cases in a defined geographic area

While elimination is an ambitious goal, it is within reach. The World Health Organization defines elimination as a condition where there are fewer than four cases per 100,000 per year. Intermediate milestones may include micro-elimination, which is when a disease has been eliminated at a system or county-level or by specific age cohorts.

To guide the development of the plan, information was gathered from experts in public health, clinical and community-based organizations, family medicine and pediatrics, as well as parents of school age children. This work was conducted in two phases: (1) four full-day workshops held across the state that focused on strategies to increase vaccination against high-risk strains of human papillomavirus, and (2) key informant interviews, focused on strategies to increase HPV vaccination rates and close gaps on HBV vaccination rates reduce infections caused by hepatitis B virus. Key informant interviews were conducted through the state. From these phases of work, contributors developed seven objectives that stakeholders could adopt and champion within their own practice and spheres of influence.

We know prevention is about more than individual choice. We live, work, and play in environments that are shaped by policies and systems that can make access to care easier or more difficult, affordable or more expensive, welcoming or off-putting. And since early 2020, as the COVID-19 pandemic created significant personal and public health challenges, the path forward became clearer than ever: We need to be coordinated, strategic, and work together to increase vaccination rates for all recommended vaccines to safeguard the health of individuals, families, communities across the state. It is our sincere hope that this plan will spur both insights and action, help build consensus around needed policy and system improvements, and guide the many partnerships needed to advance this ambitious goal.

Viruses Associated with Cancer

An estimated 15 percent of all human cancers worldwide may be attributed to viruses.[1] Of the 219 viruses known to cause disease in humans,[2] only eight are associated with cancer (see Appendix A), including:

- Epstein-Barr virus (EBV) is associated with several malignancies including B and T cell lymphomas, some types of Hodgkin's and non-Hodgkin's lymphoma, leiomyosarcomas, and nasopharyngeal carcinomas. EBV is spread through saliva.
- Hepatitis B virus (HBV) is a leading cause of liver cancer. HBV is spread through infected body fluids.
- Hepatitis C virus (HCV) is a leading cause of liver cancer and can cause non-Hodgkin's lymphoma and some head and neck cancers. HCV is spread through infected blood.
- Human immunodeficiency virus (HIV) is thought to damage the immune system so that other oncoviruses are activated causing Kaposi sarcoma, non-Hodgkin's lymphoma, cervical cancer, and cancers of the anus, liver, mouth, throat, and lung. HIV is spread through infected body fluids.
- Human herpesvirus 8 (HHV-8) is associated with Kaposi sarcoma and primary effusion lymphoma in people who have a weakened immune system, including patients with HIV.
- Human T-lymphotropic virus type 1 (HTLV-1), rarely found in the United States, is linked with adult T-cell leukemia/lymphoma and is spread through infected body fluids.
- Merkel cell polyomavirus (MCV) is associated with an extremely aggressive and rare skin cancer. It is not fully understood how MCV is spread but it is thought that MCV is acquired through close contact, involving saliva and/or the skin early in childhood.
- Human papillomaviruses (HPV) high-risk types can cause cancer in men and women, including anal, cervical, penile, throat, vaginal and vulvar cancer. HPV is spread through skin-to-skin contact.[3]

Of these eight cancer-causing viruses, only two can be prevented through vaccination.

- The Hepatitis B (HBV) vaccine is recommended for all children and unvaccinated adults and protects against liver cancers caused by hepatitis B infections.
- The Human Papillomavirus (HPV) vaccine is recommended for children starting at age 9 and is covered as preventive care through age 26. The HPV vaccine prevents six cancers caused by nine types of human papillomavirus, including Types 6 and 11, which cause 90 percent of genital warts; Types 16 and 18, which cause about 70 percent of cervical cancers and an even higher percentage of oropharyngeal, anal, penile, vaginal, and vulvar cancers; and Types 31, 33, 45, 52, and 58, which account for an additional 10 to 20 percent of cervical cancers.[4,5,6,7]

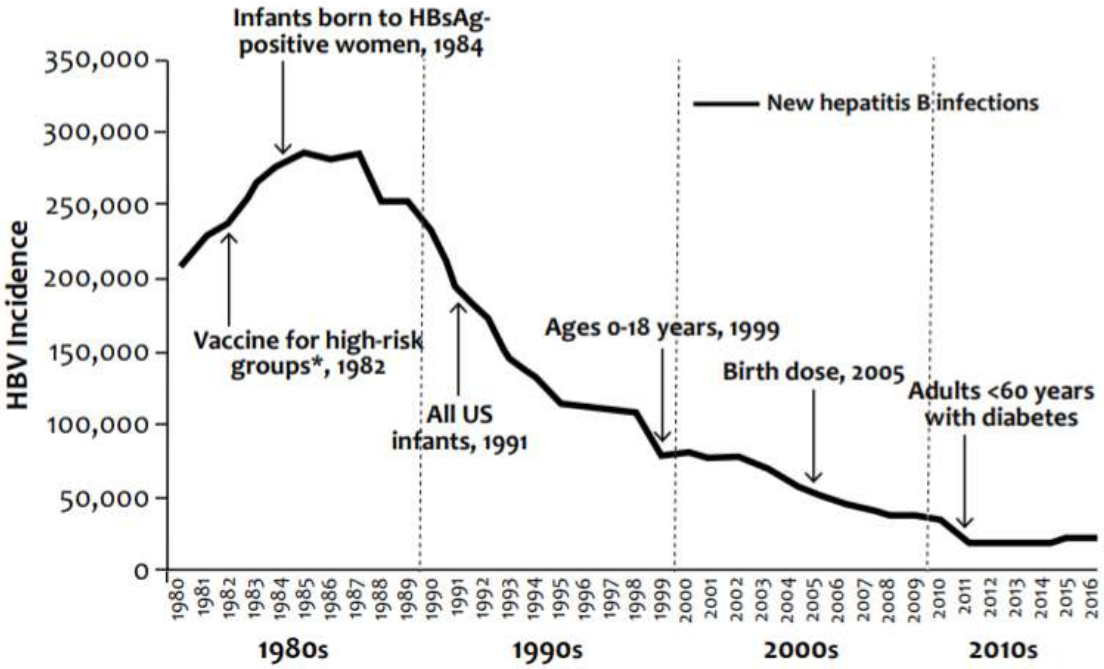
Hepatitis B (HBV) and Cancer

Hepatitis B is transmitted when blood, semen, or another bodily fluid from a person infected with the virus enters the body of someone who is uninfected. For some, hepatitis B is an acute, or short-term, illness; for others, it can become a long-term, chronic infection. Chronic hepatitis B can lead to serious health problems, including cirrhosis, liver cancer, and death. Treatments are available, but no cure exists for hepatitis B, so vaccination is essential.

Eighty percent of acute hepatitis B cases reported to CDC in 2019 were among persons 30 to 59 years of age.[8] Because a vaccine was not available when this cohort were children, they are potentially at a higher risk for hepatitis B infections and for developing and dying from related liver cancers.

The HBV vaccine prevents liver disease caused by the hepatitis B virus. The rate of reported cases of acute HBV infection in the US declined 90 percent following widespread uptake of hepatitis B vaccination in infants and children in the early-1990s, but that decline has leveled off in recent years (Figure 1). ACS estimates that about 42,230 new cases of liver cancer (including intrahepatic bile duct cancers) will be diagnosed in 2021. [9] Hepatitis B accounts for up to 50 percent of liver cancers. [10] To reduce the incidence of liver cancer associated with chronic hepatitis B infection, a concerted effort to vaccinate individuals aged 30-49 years and those at elevated risk for hepatitis B is critical. [11]

Figure 1: Hepatitis B Incidence in the United States (1980-2016)[12]



There are as many as 2.2 million individuals living with chronic hepatitis B in the United States. Two-thirds (67 percent) are not aware that they are infected, which contributes to ongoing transmission. [13, 14] Asian Americans, who make up 6 percent of the total population in the U.S., account for 58 percent of Americans living with chronic hepatitis B. [15] Many studies have shown a sharp, increased risk of liver cancer among people with chronic hepatitis B and several studies also indicate a possible association with an increased risk of pancreatic cancer. [16],[17],[18]

ACS estimates that about 42,230 new cases of liver cancer (including intrahepatic bile duct cancers) will be diagnosed in 2021. [19] Hepatitis B accounts for up to 50 percent of liver cancers. [20] To reduce the incidence of liver cancer associated with chronic hepatitis B infection, a concerted effort to vaccinate individuals aged 30-49 years and those at elevated risk for hepatitis B is critical. [21]

In Illinois, hepatitis B and hepatitis C are the two major contributing factors to the rising incidence of liver cancers (2.8 percent increase per year since 2002). The annual increase is second only to thyroid cancer. Liver cancer mortality is also increasing at a rapid rate. In Illinois, liver cancer incidence increased 40.74 percent between 2002 – 2017 (5.4 to 7.6 per 100,000) while mortality rates increased 86.11 percent.

Human Papillomavirus (HPV) and Cancer

HPV infections are quite common. Most people will get HPV at some point in their lives and are likely to remain unaware of it because it usually clears on its own. However, some HPV types are known for causing cancer. The CDC estimates that "nearly 80 million Americans are currently infected with some type of HPV."[22]

There are more than 150 types of HPV. Cutaneous types infect the skin and cause common warts, usually on hands and feet. Mucosal types cause genital warts (which rarely become cancer), low-grade and high-grade abnormalities/precancers of mucosal cells, respiratory and laryngeal papilloma, and various cancers.

According to the CDC, HPV causes 35,900 cases of cancer in the United States every year [23] (see Appendix B). High-risk sub-types of HPV (types 16, 18, 6 11, 31, 33, 45, 52 and 58) cause 90 percent cervical cancers and pre-cancers. However, HPV infections can also cause oropharyngeal cancers (cancers of the throat and tongue) and cancers of the anus, penis, vulva, and vagina. [24]

HPV is transmitted through skin-to-skin contact. Most people get infected through direct sexual contact, including vaginal, anal, and oral sex, but HPV is not exclusively a sexually transmitted disease and intercourse is not needed for transmission to occur. Initial HPV infections occur most often in people in their teens and early twenties, which is why it is recommended that children are vaccinated starting at age 9.

Cervical cancer is the only recommended screening test for HPV-related cancer. The Papanicolaou (Pap) test screens for precancers in the cervix, which may require more testing and invasive treatment.[25] There are no recommended screening tests for oropharyngeal cancers or other anogenital cancers.

The HPV test is used to detect cervical infection by high-risk types of HPV that are more likely to cause pre-cancers and cancers of the cervix. The test can be done by itself or at the same time as the Pap test, with the same swab or a second swab. There is currently no approved test for HPV in men.

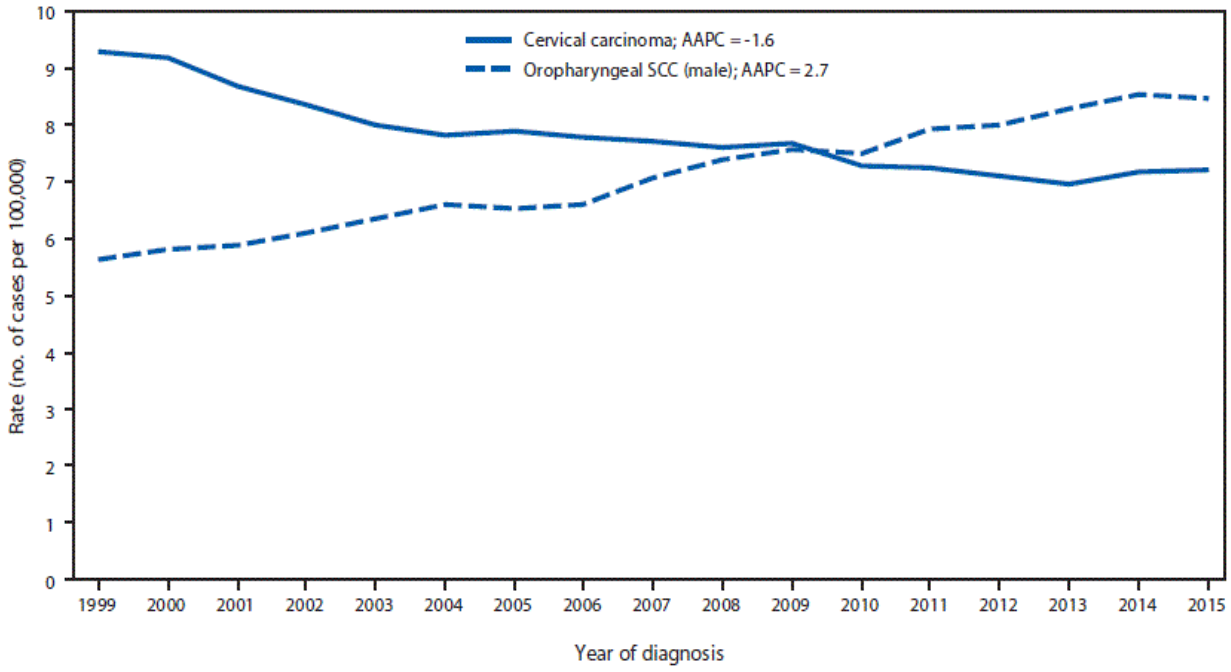
While women are more likely than men to be diagnosed with HPV-related cancers, diagnoses of HPV cancers among men are increasing. This trend is driven by increases in HPV-positive oropharyngeal cancers over the past three decades, even as incidence rates of other head and neck cancers and many other cancers are decreasing.

The number of oropharyngeal cancers attributed to HPV is now higher than the number of cervical cancers in the United States (see Figure 2). From 1984 to 2004, the CDC's National Program of Cancer Registries and the NCI Surveillance, Epidemiology, and End Results program reported a 50 percent decrease in HPV-negative oropharyngeal cancer cases and a 225 percent increase in HPV-positive cases. [26]

Figure 2: Trends in Age-Adjusted Incidence of HPV-Related Cancers (1999–2015)[27]

Cervical Cancer Among Females and Oropharyngeal Cancer Among Men in the United States

AAPC=average annual percent change; NS=not significant; and SCC = squamous cell carcinoma.



Incidence and Mortality Data for Vaccine-Preventable Cancers

Mortality rates are the best measure of progress against cancer because they are less affected by screening and detection practices than incidence rates and survival rates. The overall age-adjusted cancer death rate in the U.S. rose during most of the 20th century, peaking in 1991 at 215 cancer deaths per 100,000 people, mainly because of the smoking epidemic.

By 2018, the mortality rate had dropped to 149 per 100,000 (a decline of 31 percent) because of reductions in smoking, as well as improvements in the prevention, early detection, and treatment for some cancers. This decline translates into about 3.2 million fewer cancer deaths from 1991 to 2018 and is driven by progress against the four most common cancer types – lung, colorectal, breast, and prostate. However, while the incidence and mortality rates for most common cancers are declining, five types of cancer are increasing, two of which are vaccine-preventable---cancers caused by human papillomavirus infections and liver cancers caused by Hepatitis B infections (see Figures 3 and 4).

Figure 3: Illinois' Five-Year Mortality Rate Change for Most Common Cancers (2014-2018)
All Ages, Both Sexes, All Races including Hispanic

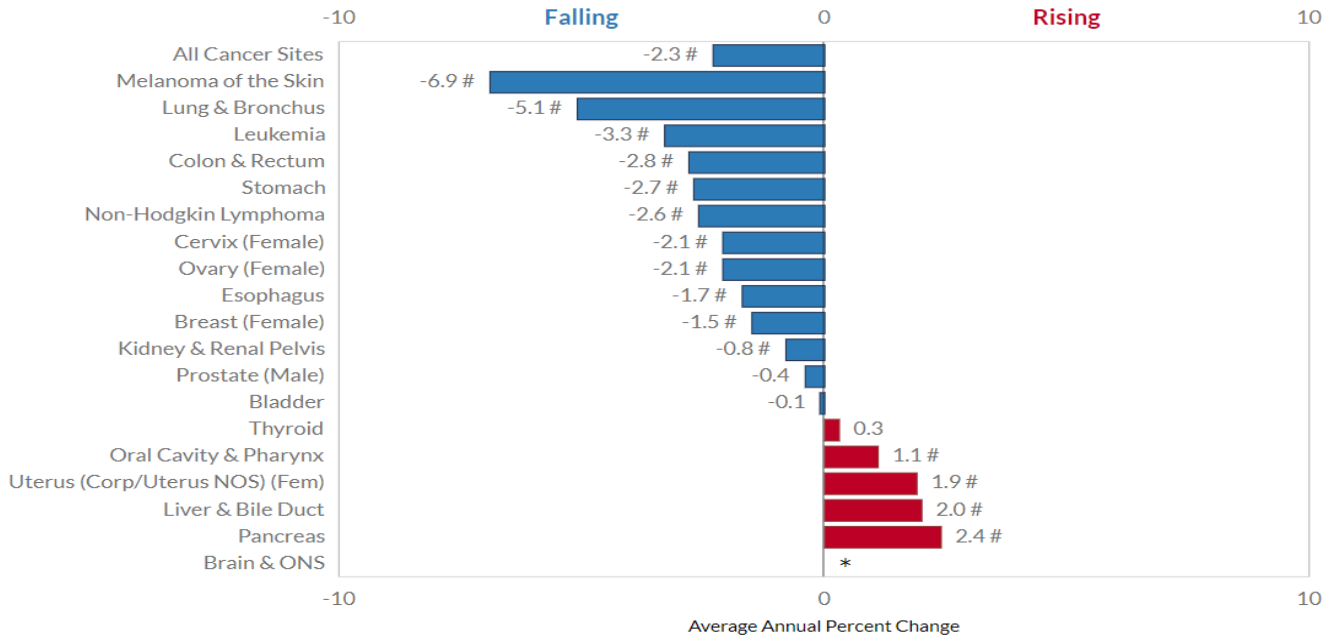


Figure 4: Illinois' Five-Year Incidence Rate Change for Most Common Cancers (2014-2018)
All Ages, Both Sexes, All Races including Hispanic

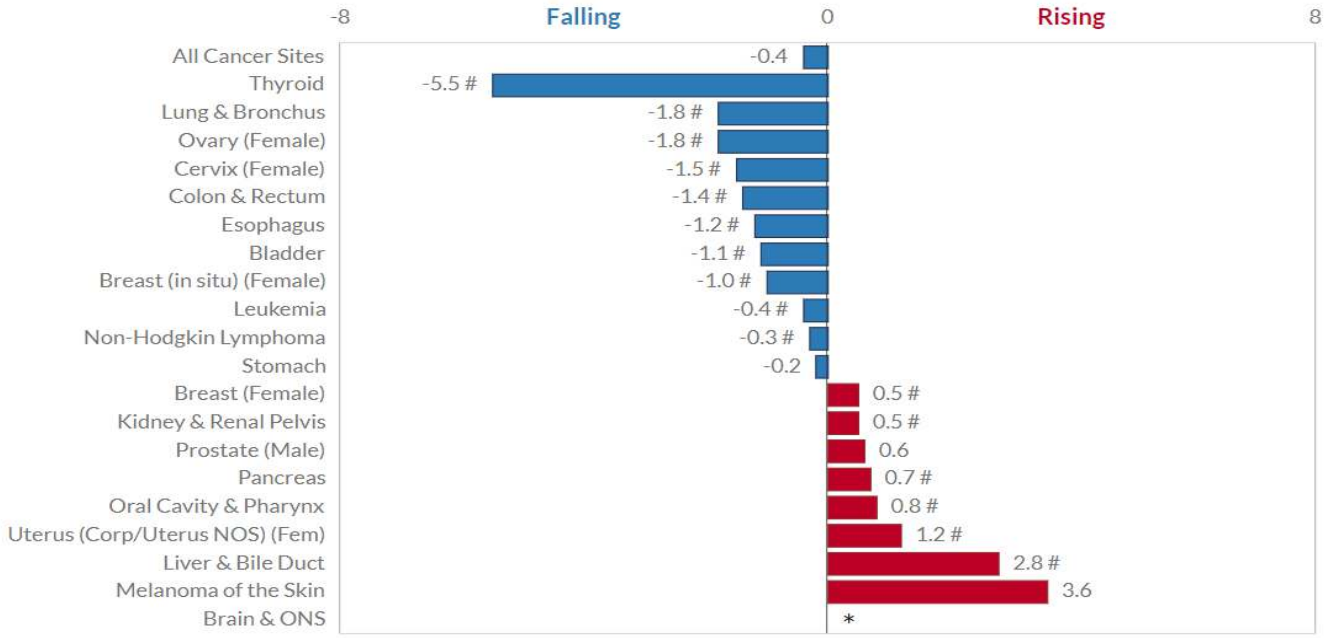
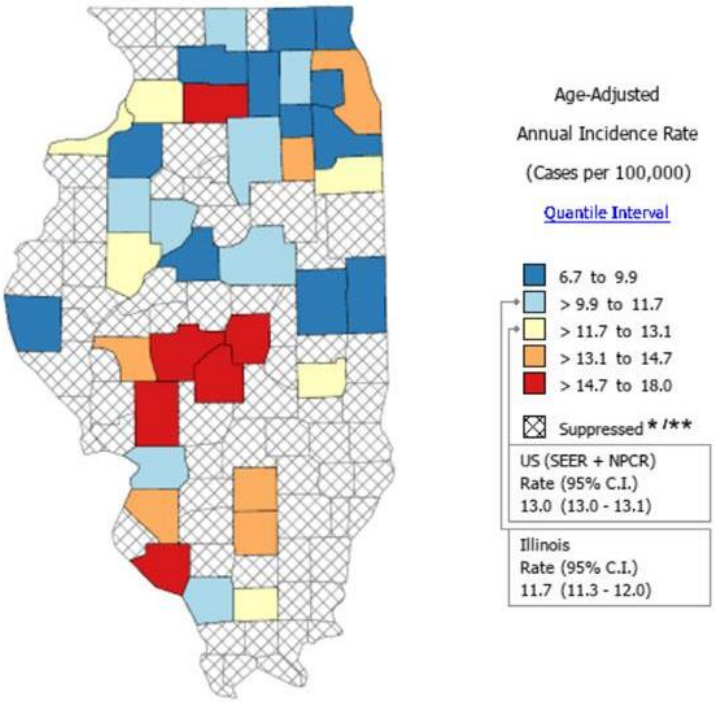


Figure 5: Illinois Incidence Liver and Bile Duct Cancers (2014-2018)
All Ages, Both Sexes, All Races including Hispanic



Liver cancer incidence has more than tripled since 1980 and continues to rise among people in Illinois. The rate continued to increase by more than 2 percent per year in women from 2013 to 2017 but has stabilized in men. Incidence varies by county, with highest rates in Lee, Sangamon, Christian, Macon, Macoupin, and Randolph counties. Liver cancer incidence is three times higher in men than in women (see Figure 5).

Cervical cancer rates for women have been declining for decades, while rates of other HPV-related cancers, specifically oropharyngeal cancers, have been increasing, especially among men, and eclipsed rates for cervical cancer in 2009. The upward trend has continued unabated. Most men diagnosed with oropharyngeal cancers are 40 years of age and older, meaning they could not receive the HPV vaccine because it was not available when they were adolescents. As vaccinated boys grow into adulthood, it is expected that the increasing trend in oropharyngeal cancers will plateau and recede (see Figure 6).

Men are more than twice as likely as women to have oral cavity cancer or oropharyngeal cancer and die from it. Risk factors for developing oral cavity cancer or oropharyngeal cancer include smoking, alcohol use, chewing tobacco and betel quid, and infection with a high-risk strain of HPV (see Figure 7).

Figure 6: Illinois Cervical Cancers (2002-2016)
All Races (including Hispanic), All Ages, Both Sexes (Source: NCI State Cancer Profiles)

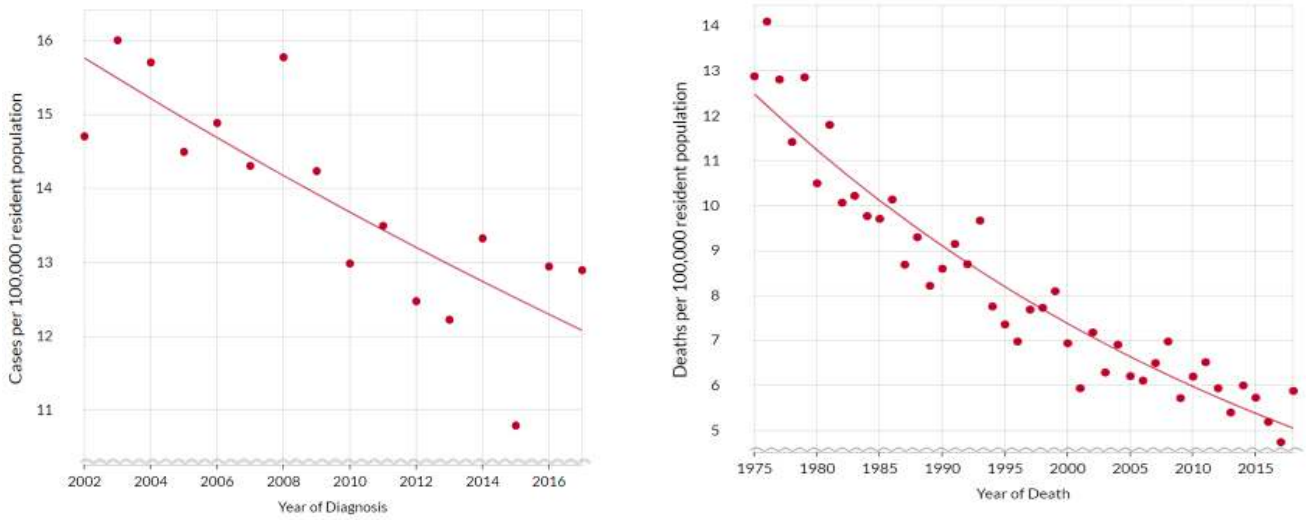
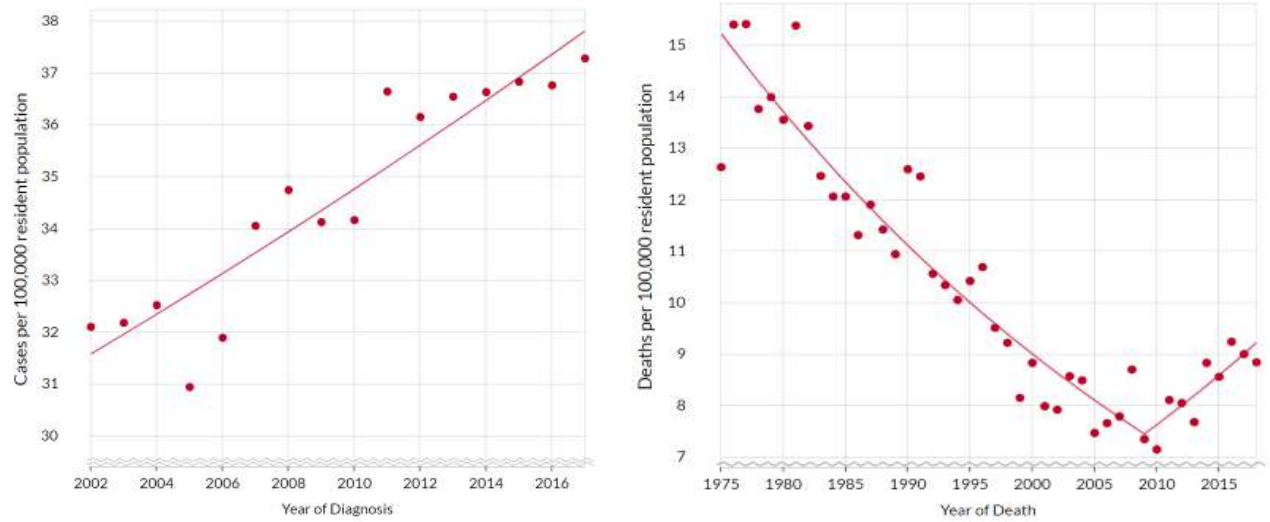
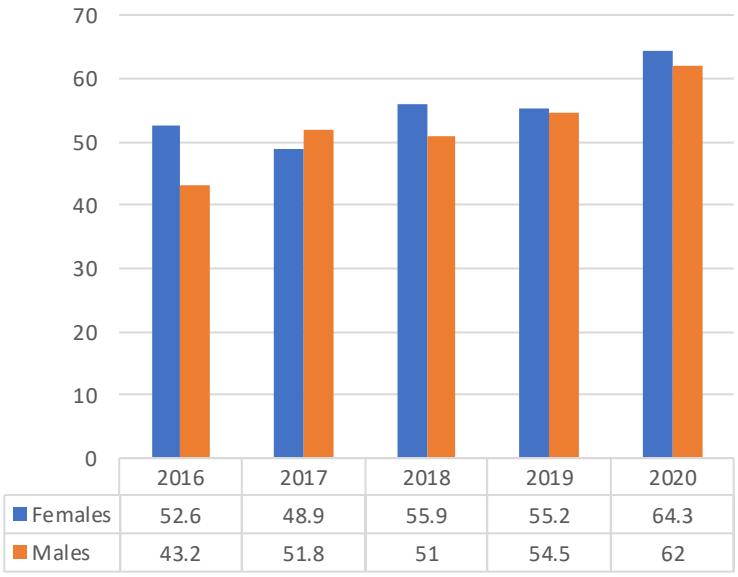


Figure 7: Illinois Oral Cavity and Pharynx Cancers (2002-2016)
All Races (including Hispanic), All Ages, Both Sexes (Source: NCI State Cancer Profiles)



Illinois Vaccination Data

Figure 8a: Up-to-Date HPV Vaccination, 13-17 years (2016-2020)[28]



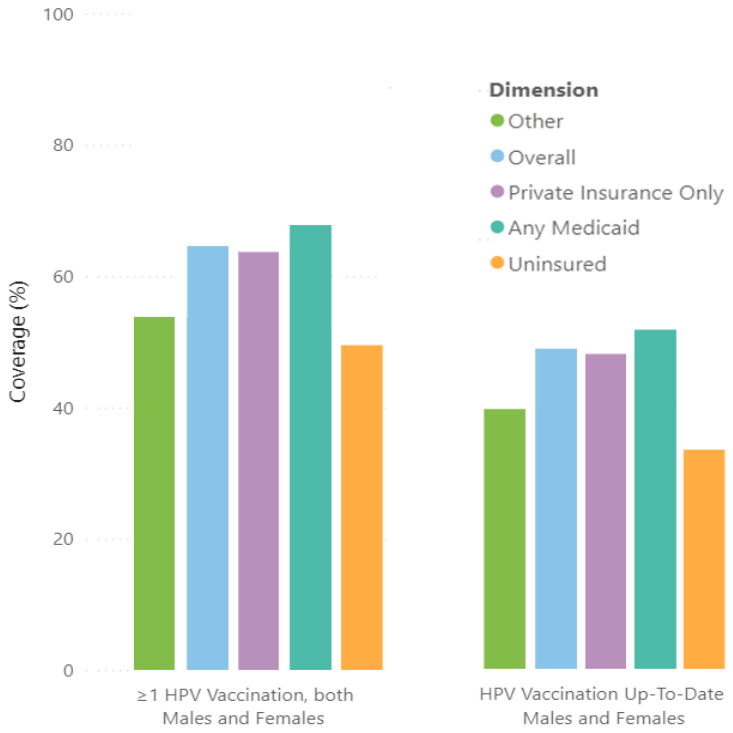
	2016	2017	2018	2019	2020
Females	52.6	48.9	55.9	55.2	64.3
Males	43.2	51.8	51	54.5	62

HPV Vaccination Data

Up-to-date HPV vaccination rates in Illinois for adolescents 13–17-year-olds is above the national average. Up-to-date HPV vaccination rates in Chicago are among the highest in the nation, while rates in Central and Southern Illinois are as much as ten percentage points lower than Chicago. In Illinois, the 2018 HPV vaccine rate was below the 70th percentile for youth between the ages of 13-17 years. Figure 8a shows up-to-date HPV vaccination rates for females and males and Figure 8b shows HPV vaccination rates by insurance type.[29]

In most states, including Illinois, the estimated percentage of Medicaid-insured teens that have started and completed the HPV vaccination series is higher than for children without health insurance and those insured by a commercial plan. Commercial plans outperform state Medicaid programs in only a handful of states, including Hawaii, Minnesota, Kentucky, and Vermont. Information sharing across all insurance providers may work to replicate successful strategies and increase HPV vaccination rates for all teens, regardless of their insurance.

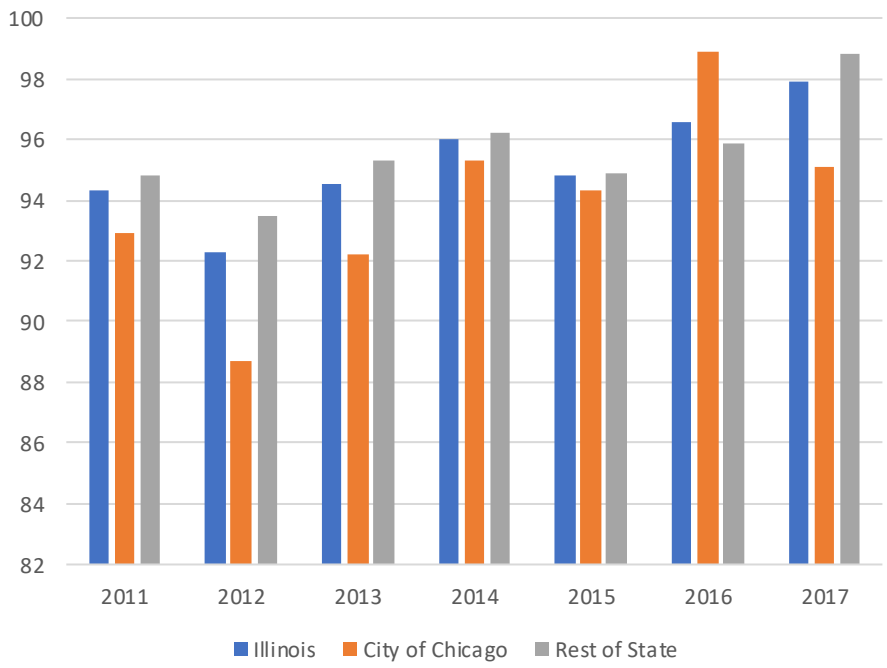
Figure 8b: HPV Vaccination Coverage by Insurance Type, 13-17 Years (2015-2019)



HBV Vaccination Data

Safe and highly effective vaccines to prevent hepatitis B were introduced in the early 1980s. By 1991, the United States adopted a public health strategy aimed at eliminating the transmission of HBV. In 1997, Illinois made HBV vaccination a requirement for childcare and school.[30] Hepatitis B vaccination rates rose quickly. Today, HBV vaccination rates in Illinois are consistently above 90 percent for infants (see Figure 9).

Figure 9: Illinois Hepatitis B Vaccination Coverage by 13 Months of Age (%)[31]



For adults born before the HBV vaccine was introduced and added to the 'Birth to 15 months immunization Schedule,' and before Illinois made it a requirement for school, the HBV vaccination rate is significantly lower. Coverage rates for hepatitis B among adults age ≥19 years in the United States averages only 30 percent.[32] Nationally, rates among adults aged 19–49 years are higher among travelers (38.9 percent) than nontravelers (24.2 percent), and higher among whites (43.6 percent) compared with Blacks (35.4 percent) and Hispanics (33.1 percent).[33] While some populations are at a higher risk for Hepatitis B infection, HBV vaccination is recommended for any adult seeking protection from HBV infection.[34]

Plan Development

The American Cancer Society facilitates an established, voluntary group of clinical and community partners partnership across the state. The Illinois HPV Advisory (aka Illinois' HPV Roundtable) initiated conversation across the state about developing a shared set of objectives to increase HPV vaccination rates and eliminate HPV-related cancers. Recognizing the Hepatitis B, like HBV, also caused liver cancers, the plan was expanded to focus on all vaccine-preventable cancers. In November 2019, ACS partner with Illinois Public Health Institute, the Illinois Department of Public Health, ninety-seven clinical and community organizations, and 261 key informants to develop a state plan for eliminating vaccine-preventable cancers. This project was developed with the intention that it would serve as a complement to the state's comprehensive cancer control program and their planning.

Action Planning Workshops

Ninety-seven participants representing more than fifty organizations contributed their expertise during four planning workshops held across the state in November 2019. These workshops were held in Chicago, Carterville, Schaumburg, and Springfield. These workshops gathered information from stakeholders about their experiences and insights around HPV vaccination.

These workshops supplied the basis upon which Illinois' Action Plan to Eliminate Vaccine-Preventable Cancers was built. Workshop participants were asked what they, their partners, and the state could to (1) increase awareness of which cancers are related to the human papillomaviruses (HPV), (2) reduce barriers to prevention and early detection for HPV-related cancers, (3) Implement innovative approaches that stakeholders can adopt to increase vaccination rates to reduce the incidence and mortality rates of HPV-related cancers, and (4) advance needed policies, data systems, and practice change.

Following the workshops, the Illinois HPV Advisory suspended its work temporarily to enable its members to take part and contribute to the development of Illinois' new Comprehensive Cancer Control Plan, which engaged stakeholders most intensely from late Fall 2020 through late Summer 2021.

Key Informant Surveys and Interviews

The American Cancer Society (ACS) surveyed and interviewed 261 adults between September 2020 and April 2021 who were either (1) parents with children under the age of eighteen, (2) subject matter experts, or (3) vaccinators. Respondents were drawn from Illinois' public health regions--specifically, at least four subject matter experts, six parents, and nine vaccinators from six of Illinois' seven public health regions, as delineated by the Illinois Department of Public Health. Because the City of Chicago already has high immunization rates, this project focused on the six regions outside of the Bellwood public health region.

Questions were based on those developed by The Strategic Advisory Group of Experts on Immunization (SAGE) Working Group on Vaccine Hesitancy, which was charged with advising WHO on overall global policies and strategies, ranging from vaccines and technology, research, and development, to delivery of immunization and its linkages with other health interventions. Additional questions were developed with the expert guidance of Dr. Manorama Mocherla Khare and Janae Danelle Lane Price at the University of Illinois.

Findings

Workshop participants were asked to individually name barriers and facilitators to preventing vaccine-preventable cancers. Barriers were defined as challenges that prevent the elimination of vaccine-preventable cancers; while facilitators were defined as strengths, assets, and reinforcing factors that support the elimination of vaccine-preventable cancers. Responses focused mostly on how to improve vaccinating teens and young adults against HPV, however participants noted vaccinating older adults against HBV was also needed to slow the rising incidence of cancers associated with hepatitis B infection.

Participants shared and discussed the barriers and facilitators with a small group. Next, participants continued working in small groups and sorted similar ideas and defined overarching barriers and facilitators. The overarching barriers and facilitators were reported out to the large group through a visual consensus building workshop. Following the identification of key barriers, participants worked together to find innovative strategies to overcome the barriers and challenges. Participants were also asked to consider how the strategy ideas could resolve underlying root causes that prevent individuals from receiving the HPV vaccine. The workshops concluded with participants prioritizing barriers and strategies based on feasibility, effectiveness, and resources, both available and needed, to execute identified strategies. (See Appendix C)

Primary Barriers

Across all locations, the most significant common barrier found was a lack of consistent data reporting from the state (and across states) and the need for a better system to evaluate population level data, both in terms of vaccination rates and incidence and mortality rates related to vaccine-preventable cancers. Additional barriers included issues affecting access (insurance coverage, transportation), issues related to providers (inconsistent or lacking recommendation), missed policy opportunities (mandated reporting, school mandates, etc.) and issues related to public awareness and health literacy (see Figure 10).

Figure 10: Primary Barriers Identified by Workshop Participants

Springfield	Chicago	Schaumberg	Carterville
Anti-vaxxer messaging	Anti-vaxxers	"Fear of vaccine" Anti-vaxxers	Anti-vaxxers
Provider bias/ hesitation/lack of information	Lack of provider education	Provider education	Physician messaging
Multiple shots needed -- Follow up requirements -- Scheduling	Lack of standardized, internal procedures, clinical processes	Logistical barriers	System/process issues (follow up)
Parent perception/fear	Stigma	Perception of risks	Stigma/culture
Lack of consistent medical home	Lack of a medical home		

Additional Barriers Identified

Springfield: Participants agreed---social media is a significant source of misinformation. They discussed the confusion about who the HPV vaccine is for since it was initially prescribed for females only. They also noted that youth were apprehensive about the pain from shots and that they lacked useful information about the purpose of vaccination and the diseases they prevented.

Chicago: Participants found barriers that fell into three categories: clinic-based barriers, data and access barriers, and relationship-based barriers. Clinic-based barriers included lack of standardized consent procedures, lack of incentives (i.e., not a clinician priority, missing policy and systems supports, not prioritized reporting measure), competing health priorities, provider burnout, and need for more effective messaging.

Data and access barriers included access to and utility of electronic health records and state IIS, the fragmentation of health records for young adults as the move from pediatric practices to adult primary care, lack of insurance coverage, and expanding strategies to target and support other clinical staff to supply vaccinations (e.g., pharmacists and dentists).

Barriers that are rooted in relationships include how well informed a parent is on vaccinations in general and adolescent vaccinations, including the scientific research on safety and efficacy. Poor communication between a parent and provider influenced parents' trust and their decision to vaccinate. Participants discussed how cultural, religious, and gender norms influenced decision-making. The persistent yet baseless fear that HPV vaccination promotes premature sexual debut was especially vexing for participants since the very first vaccine given to every infant shortly after birth is the HBV vaccine to protect against hepatitis B, which can be sexually transmitted.

Schaumburg. Participants also noted cultural and religious influences as potential barrier, as well as the lack of or infrequent adolescent well-visits, which is a factor contributing to delayed vaccination.

Carterville. Participants found that comprehensive sexual health education was outdated, and that the curriculum varied across school districts leaves adolescents and parents alike unprepared to make best choices. Also discussed were how unaddressed concerns and fears about side effects influenced parents' decision to vaccinated. Also noted was the lack of funding to support this work, from public health coalition building to proper reimbursement for administering vaccinations.

Following the conclusion of the four workshops, IPHI compiled the results and found cross-cutting themes. Common barriers, facilitators, and strategies were found across the four workshops. Workshop participants and the Illinois HPV Advisory further prioritized barriers and strategies to target in the action plan during advisory committee meetings. As a result, barriers were categorized into several themes, such as – data, policy, environment, systems, communication and trust, parents, youth, providers, and miscellaneous. The chart below supplies a detailed summary of the cross-cutting themes which informed the development of the objectives included in the proposed action plan.

Figure 11: Cross-Cutting Themes and Barriers

Data & Policy	● Data limitations. ● EHRs/I-CARE/Immunization Information Systems (IIS) ● Lack of mandate for vaccination (legislative/school) ● Not a system priority/policy ● Lack of funding to support this work ● Lack of mandate for providers to report vaccinations ● Lack of state follow up on legislation passed in 2018 that was intended to supply parents of school age children information on HPV vaccination
Systems	● Lack of standardized internal procedures and clinical processes (including follow up) ● Lack of standardized consenting procedures

Environment	• Access to vaccine (transportation, resources) • Cultural and gendered norms (gender, age, and religious beliefs) • Stigma
Patient & Parent Communications	• Parent perception / fear • Lack of public education, misinformation • Social media misinformation • Anti-vax messaging • Cost/insurance (underinsured/uninsured) • Youth – fear of shot/pain/lack of info • Lack of/outdated sexual health curriculum • Lack of consistent medical home • Lack of teen well visits/delaying vaccine
Provider Communications	• Lack of provider recommendation • Provider bias / hesitation / lack of information • Provider education and bias/hesitation • Not a clinician priority, burnout, ineffective messaging • Lack of provider incentives
Other	• Original focus on females • Expanding target clinicians

Data and Reporting

Participants reported a need for vaccination data to be accessible to the public and issued on a timely basis to be relevant to current and planned initiatives. Participants described how vaccination data can be used to engage various stakeholders and build both broad and focused understand of state and local needs so that stakeholders can target resources to increase vaccination rates, reduce disparities and infection rates, culminating in the elimination of vaccine-preventable cancers.

All workshops' participants and many key informants reported that a lack of access to up-to-date vaccination data by county and demographic factors adversely affects their ability to accurately assess local needs, disabling them and other stakeholders from focusing resources where they are most needed. State datasets published online are available only to selected users (see Figure 12).

Figure 12: State Data Sets Available Online to Specified Groups (See Restrictions)[35]

Database Title	Purpose	Restrictions	Reports Generated
Illinois Comprehensive Automated Immunization Registry Exchange (**I-CARE**)	To improve immunization coverage levels	Access is available ONLY to selected Immunization program, DPH & I-CARE development team members and enrolled providers.	Patient-specific vaccination forecasting, school physical forms, reminder/recall notification to return for overdue vaccinations, and practice and registry-based immunization coverage level assessments

Illinois National Electronic Surveillance System (**I-NEDSS**)	I-NEDSS will serve as the Department's data collection system for reportable infectious diseases. Data will be reported by local health departments, health care providers and laboratories. Data will be used for disease surveillance and control. Aggregate I-NEDSS data will be used by Infectious Disease Programs for evaluation and planning purposes.	Only registered I-NEDSS users, meeting defined criteria, will be allowed access to I-NEDSS data. Access will be further restricted by user role, jurisdiction and disease category. Data used for report purposes must be aggregate and stripped of all identifiable information.	To be determined. At a minimum, this will include number and percentage of cases by disease, subdivided by residency (statewide and county) and demographic factors (race, ethnicity, age and sex).
Contact dph.inedss@illinois.gov or dph.icare@illinois.gov for more information about either database			

Figure 13: Publicly Available Data[36]

	HEDIS	UDS	NIS
Childhood	By 2 years of age:	By 2 years of age:	By 36 months of age
	Reports a combination measure for all recommended vaccines including diphtheria, tetanus, and acellular pertussis (DTaP); polio (IPV); measles, mumps, and rubella (MMR); haemophilus influenza type B (HiB); hepatitis B (HepB or HBV), chicken pox (VZV); pneumococcal conjugate (PCV); hepatitis A (HepA); rotavirus (RV); and influenza (flu) vaccines.	Same as the HEDIS measure for childhood vaccinations.	Reports on individual rates for all recommended vaccines.
Adolescent	By 13 years of age:	Does not report adolescent immunization measures	Adults 18 years+
	Reports a combination measure that includes meningococcal meningitis, tetanus, diphtheria, pertussis (DTaP) and human papillomavirus (HPV).		Reports individual rates for influenza (flu), pneumonia, tetanus, pertussis (whooping cough), herpes zoster (shingles), and hepatitis A and B

Other public sources for vaccination data are available but have some limited usefulness for public health aims. For example, most do not supply county-level data (see Figure 13). These sources include:

- The Healthcare Effectiveness Data and Information Set (HEDIS) is published by the National Committee for Quality Assurance (NCQA). These are performance measures designed for insurers and reflect the overall status of members of specific health plans. Vaccination rates are reported as combination measures. For example, the Childhood Immunization Status (CIS) measure includes diphtheria, tetanus, and acellular pertussis (DTaP); polio (IPV); measles, mumps, and rubella (MMR); haemophilus influenza type B (HiB); hepatitis B (HepB or HBV), chicken pox (VZV); pneumococcal conjugate (PCV); hepatitis A (HepA); rotavirus (RV); and influenza (flu) vaccines. The Immunizations for Adolescents (IMA) measure includes meningococcal meningitis, tetanus, diphtheria, pertussis (DTaP) and human papillomavirus (HPV). Vaccination rates county or vaccine type are not publicly available.
- The Uniform Data System (UDS) is a set of performance measures designed for U.S. Department of Health and Human Services grantees, including health program grantees that run Federally Qualified

Health Centers (FQHCs). Like HEDIS, the UDS reports childhood immunizations as a combination measure but unlike HEDIS, does not report any measures for adolescent vaccinations. UDS reports on the overall performance of a health program grantee, not their individual service delivery sites. Vaccination rates by county, site, or vaccine type are not publicly available.

- The National Immunization Surveys (NIS) supplies state and local area estimates of vaccination coverage for children and teens using a standard survey method. The surveys collect data through telephone interviews with parents or guardians in all fifty states, the District of Columbia, and some U.S. territories, and is used to estimate vaccination coverage among children and teens as recommended by the Advisory Committee on Immunization Practices (ACIP). Estimated vaccination rates by county are not publicly available.

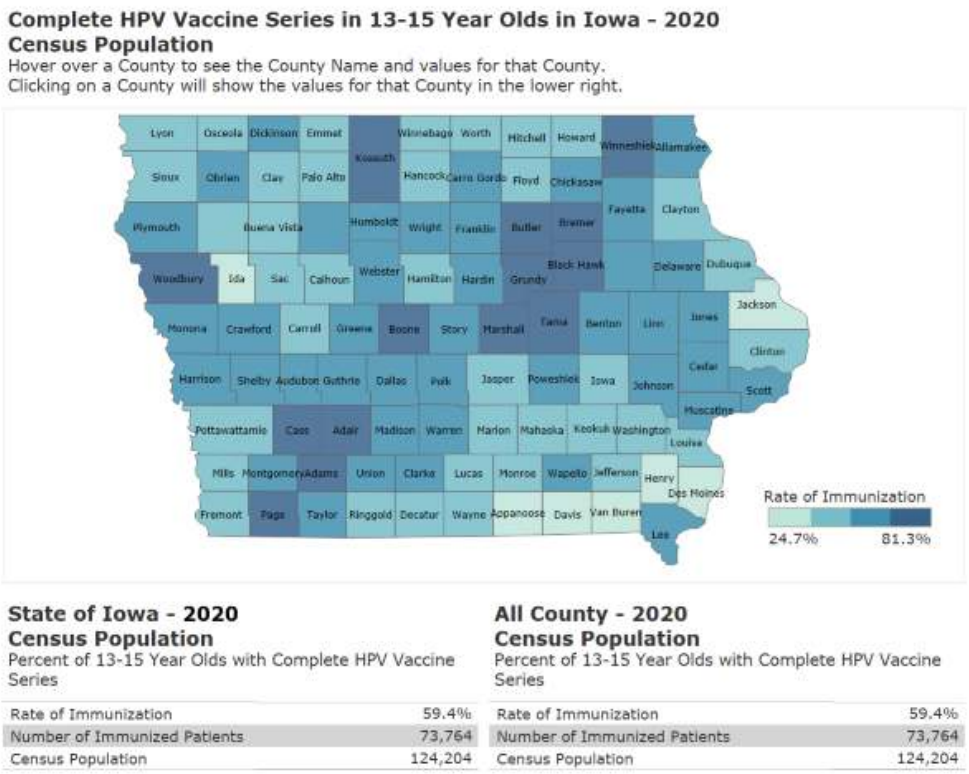
Electronic Health Records (EHR) record individual patient health information, including vaccination data including type of vaccine (childhood, adolescent, and adult) by vaccine type, date administered, provider name and are searchable by zip code, county, and state. However, EHR data are not available to the public. Personal health information (PHI) is protected under the Health Insurance Portability and Accountability Act of 1996 (HIPAA). Data can be pooled across states or regions (via Health Information Exchanges) to serve authorized public health aims and activities, such as prevention and surveillance, both of which require detailed vaccination data including and associated demographic variables.[37]

To support both state and community partner investments, participants said they wanted state vaccination data published on a regular basis, both for research purposes and to inform communications with the public. Currently, the state does not routinely publish vaccination data by county and by demographic features except for one notable and recent exception. An online search today for "Illinois vaccination data" delivers detailed data and mapping on COVID vaccination metrics but nothing comparable for routine vaccinations

In 2020, IDPH published a two-part evaluation of HPV vaccination rates including data by county and demographic factors (see Appendix D). As valuable as the 2020 report is, vaccination reporting must be routine and include county level data so the state and public health partners can focus resources on priority areas, whether in terms of absolute rate or disparities by gender or race/ethnicity.

Participants cited the reporting done by the Iowa Department of Public Health as a good example (See Figure 14) as it is done routinely and affords interactive mapping and a corresponding data file. The recent dashboard developed by IDPH to track COVID-19 transmission and vaccination rates is also a good example of the data-rich reporting that participants said that they wanted for all recommended vaccines and related preventable diseases. Given how long it can take for some HPV- and HBV-related cancers to develop, participants reported a desire for intermediate measures for tracking progress towards the elimination goal. Suggestions included trend data on HPV-related diseases such as anogenital warts and cervical precancers.

Figure 14: County-Level Vaccination Dashboard (example from the State of Iowa)



A lack of mandatory reporting was identified as a contributing barrier.

The Illinois Comprehensive Automated Immunization Registry Exchange (I-CARE) is a voluntary web-based immunization record-sharing application developed by IDPH.[38] While many providers report to I-CARE, only the subset administering publicly funded vaccinations are required to report (e.g., administered vaccines paid for using federal dollars through the Vaccines for Children (VFC) program, which immunizes children who are Medicaid-eligible, uninsured, under-insured, and American Indian or Alaska Native). The CDC estimates that approximately 50 percent of children under 19 years of age are eligible for VFC benefits.[39] This means for the other half of the population under 19 years of age, there is nothing that requires their providers to report administered vaccines to the state via I-CARE.

The Illinois State Board of Education (ISBE) reports vaccination rates for required vaccines by school and district but does not report HPV vaccination data because it is not requirement for attending a public school. Like the flu vaccine, HPV is a recommended vaccine rather than a required vaccine. The distinction is reinforced by the state's Certificate of Child Health Examination form which distinguishes between required and recommended vaccines. This distinction invites parents to think differently about the vaccines and may inadvertently invite defection from recommended but not required vaccines (see Appendix E)

Health Information Exchanges (HIEs)

While there are several HIEs operating in Illinois, most are crafted around a set of health and hospital systems in a region that all use the same EHR, making data sharing and population health reporting easier. However, these data, while useful for improving care and reducing cost for participating health and hospital systems,

are not accessible to the public. By requiring all vaccinations be reported into the state's IIS and by routinely publishing vaccination data, the state could affect a statewide health information exchange for vaccinations.

Action Plan

This plan has been developed with the input and endorsement of a wide range of organizations, individual experts, and parents who all share a common interest: Preventing cancer and saving lives. While we understand some of the recommendations and deliverables potentially require additional planning, legal, advocacy, information technology, and/or infrastructural support before becoming a reality, including them here will keep stakeholders accountable and engaged in this work. The purpose for taking this multi-disciplinary and multi-perspective approach is to explore ideas beyond the familiar canon, while giving decision-makers actionable ideas, rooted in evidence, that they can adopt and implement to increase vaccination rates, and eliminate the diseases caused by human papilloma and hepatitis B viruses. Throughout the following seven objectives, there are three recurrent themes:

- *Improve access to vaccination data*. Require that all administered vaccinations be recorded into the state's IIS. Develop two-way exchange features for payers so they can use state IIS data for HEDIS reporting. Enable online access for patients and parents to retrieve their own or their children's immunization records. A view-only format would protect the integrity of state records and allow people to print records to meet school, work, and travel requirements.
- *Build trust and influence*. There is broad consensus among contributors to this plan that providers use evidence-based strategies to increase awareness, readiness, and vaccination rates. Deliver culturally competent messaging in partnership with recognized and trusted community partners, churches, and social service allies. Address concerns and affirm that all recommended vaccines are safe. Amplify evidence-based messaging on social media in partnership with other known and trusted sources. Continue to improve the targeting of these messages to reach specific groups (i.e., assess awareness gaps and provide stronger intervention where needed).
- *Tell evidence-rich stories*. Storytelling is important not because it strays from or dilutes the science, but because it can convey facts and scientific concepts in warmer, more relatable ways, helping people get the information they need to make good, evidence-based decisions. While providers should explain the personal risks of not being vaccinated against infectious diseases caused by HPV and HBV, participants suggested that providers could also share success stories, such as how Australia is on track to eradicate cervical cancer, to help frame vaccination in terms of the welfare of one's larger groups (e.g. family, community, county, state).

Objective 1: Improve Data Collection and Reporting

To ensure a healthier population, stakeholders must have complete, dependable, and current data to inform their actions. Recommendations for improving data collection and reporting in Illinois include:

- Publish state vaccination data by vaccine type, by county, and by key demographics (age, race, gender). Include reports on the percentage of students enrolled in each county that have satisfied state immunization requirements for school entry through exemption. Publish data online and enable search, sort, and mapping features to support public health and policy making needs.
- Modify Illinois' Certificate of Child Health Examination form to remove distinction between required and recommended vaccines.

- Partner with ISBE to reinforce that additional legislative support is needed to require all administered vaccinations be recorded into the state's IIS, not just immunizations needed for school.[40]
- Explore partnering with Illinois Department of Healthcare and Family Services to require the reporting of Medicaid claims data related to all HPV-related diagnoses (anogenital warts, cervical precancers, etc.) to check progress to goal (i.e., reductions in anogenital warts and cervical precancers measure progress to goal).
- Collectively commit to continue raising awareness of the relationship between HPV and overall cancer mortality; Identify and overcome barriers which prevent awareness by including which cancers are HPV-related cancers in all incidence and mortality reporting produced by the Illinois' Cancer Registry

The state's immunization information system (IIS) is the Illinois Comprehensive Automated Immunization Registry Exchange (I-CARE). It is an immunization record-sharing application that allows providers to share the immunization records of Illinois residents with other physicians and some systems statewide, such as school systems, social service organizations (like WIC), and pharmacies. While I-CARE is, technically, bi-directional, it is not as user-friendly as other IIS and should be updated to support integration of health information and meet the needs of multiple users. Some contributors noted that IDPH recently invited a Letter of Interest from potential providers to buy and implement a new state immunization registry system. Contributors made no recommendations for a particular product. Rather, they reported what they wanted from an updated or new IIS to do.

- Update the features, interoperability, and security of Illinois' IIS to meet/exceed the policy, provider, and data standards published by American Immunization Registry Association (see Appendix F: AIRA IIS Standards) to serve population health management needs.
- Develop more robust bidirectional features, including the ability for public health practitioners and researchers to parse immunization data, analyze social determinants of health (SDOH) data, and features to help public health and immunization partners focus their staff and resource investments.
    - Providing the ability to track factors like food insecurity, access to safe green space, mode of transportation, etc. would allow for more targeted research, intervention, and eventually predictive modeling.
- With appropriate legal consultation, develop two-way exchange features for payers so they can use state IIS data for HEDIS reporting.
- Continue progress with legislative and structural support towards enabling online access for patients and parents to retrieve their own or their children's immunization records. A view-only format could protect the integrity of state records and allow people to print records to meet school, work, and travel requirements. Continue to explore options for safe and efficient use of and access to data, even for minors. Expand the function of IIS to enable users to create county-level immunization reports.
- Expand functionality to support health systems and payors scorecard their own performance and report on quality measures (e.g., UDS and HEDIS) and for public health partners and others.
- Streamline approval of new user applications and activate users' access to features based on need (e.g., public, provider, researcher, etc.).

- Train new I-CARE users quarterly. I-CARE website says it can supply an assessment of immunization coverage levels by practice but providers either do not know this or do not know how to do it. Previously, the Illinois Chapter of the Academy of Pediatrics (ICAAP) trained new users but in 2018 these responsibilities reverted to IDPH. Participants noted that the Chicago Department of Public Health Vaccines for Children program supplies robust I-CARE training program for its providers. It is recommended that the state partner with ICAAP and CDPH to restore and improve I-CARE trainings and include closed captioning for the hearing impaired and improve communication about reporting capabilities that currently exist (e.g., Coverage Level Reports).

Consider developing a quality assurance process to ensure all agency vaccination policies and measures continue to be aligned with ACIP recommendations, including Illinois Department of Children and Family Services (DCFS) and Illinois Healthcare and Family Services (HFS).

Objective 2: Improve Partner Coordination and Program Support

Continue to align partnership goals with The Illinois Cancer Partnership (ICP) around common objectives which include but are not limited to:

- Recruit more ICP members from across the state to represent more perspectives (e.g., representatives from large employer groups, health systems, and private and public insurers).
- Engage stakeholders around funding and implementing comprehensive cancer priorities year-round, not just to develop the state's comprehensive cancer plan.
- Leverage partner and state resources to implement vaccination priorities.
- Supply people living in counties with lower-than-average vaccination rates information about the benefits of vaccination (i.e., disease prevention, cancer prevention).
- Leverage and share resources across partnerships to avoid duplication of efforts.
- Engage partners in setting similar metrics and goals when working towards the same goal.

Continue to align partnership goals with The Illinois Breast and Cervical Cancer Program (IBCCP) around common objectives which include but are not limited to:

- Conduct user experience interviews to inform and update the program page on the state's website.
- Strengthen participation, partnerships and referral systems with area hospitals and physicians by Integrating digital solutions to automate eligibility checks and support online applications.
- Adopt and publish quality measures, including screening rates, completed referrals, time to payment for lead agencies and providers. Publish an annual program report online, including program outcomes, budgets, and revenue sources.
- Ensure 25 percent of general revenue funds are distributed to serve women 40+ to meet the standard established by the Centers of Disease Control.

Objective 3: Advocate for Policy Improvements

- Require all providers report the administration of any recommended vaccines to the state's IIS within a specific period, regardless of payor or provider. Ongoing legislative support may be required for improvements to these processes.
- Re-visit and update formerly proposed legislation which would require all vaccinations be reported within a specific timeframe (e.g., Michigan requires vaccination data to be uploaded within 72 hours of administration; Indiana within seven business days).
- Maintain a standing budget line to fund epidemiologists and informatic professionals; relying only on grant-funded capacity puts core public health functions at risk. As of December, 2021 a full time position has been filed in the Immunization Section.
- Explore the opportunity to extend the scope of practice for dentists, pharmacists, and pharmacy technicians to administer all recommended vaccines, not just the COVID vaccine. The Illinois Department of Financial and Professional Regulation extended the scope of practice to these licensees to allow them to administer the COVID-19 vaccine.
- Collaborate with ISBE to require reporting by school and district, religious exemptions and vaccination rates for all vaccinations reported on the Certificate of Child Health Examination form. Consider updating policy to require ISBE to report all vaccinations reported on the state form.
- Partner with stakeholder organizations such as HFS and Managed Care Organizations (MCO) to ensure that providers and hospitals are reimbursed for administration of all immunizations, not just COVID vaccinations, at a rate no lower than the Medicare reimbursement rate.
- Revisit previously proposed legislation aimed at removing religious exemptions to school vaccine mandates. In recent years, as states like Illinois ended philosophical objections, there has been a measurable rise in religious exemptions, showing that religious exemptions are not protecting religious faith as much as giving cover for secular concerns. A small number of religions are often cited to justify maintaining religious exemptions however, Christian Scientists have said that while they have "appreciated vaccination exemptions and sought to use them conscientiously and responsibly, when they have been granted" that "our practice isn't a dogmatic thing. Church members are free to make their own choices on all life decisions, in obedience to the law, including whether to vaccinate. These aren't decisions imposed by their church."[41] The Seventh Day Adventists have publicly stated that the church, "does not advocate for religious exemptions to vaccination."[42] And a survey of a wide range of religions around the world could not find any religions with anti-vaccine teachings.[43] Instead, researchers found that faith leaders around the world counsel respect for public health measures (i.e., quarantine, vaccination) and even invest in health missions that include vaccination in the interest of promoting the common good.
- Develop partnerships to collaboratively promote the use of HPV testing as a first-stage screening for women living in rural and hard-to-reach locations; include resources for follow-up cervical cancer screenings.
- Increase access to vaccination for Illinois' Medicaid insured, uninsured, under-insured, and American Indiana and Alaskan Native residents by promoting the Vaccines for Children (VFC) program and the state's online VFC provider locator: http://vfc.illinois.gov/search/.

- Expand functionality, with ongoing quality assurance, of state IIS to serve the needs of broader range of stakeholders: health and hospital systems, insurers, evaluators, insurers, researchers, parents, patients, and schools.

Objective 4: Increase HPV Vaccination Rates Among Adolescents

- Begin educating parents about vaccines earlier. Do not wait until adolescence or for a specific well-visit appointment to educate patients and their parents about adolescent vaccinations.
- Make an effective and presumptive recommendation. A presumptive recommendation from a health care provider has been shown to be the single most effective reason children get vaccinated.
- Use electronic health records and allied health staff to prompt the provider. Use systems, staff, and workflows to ensure clinicians know that a specific patient is due or overdue for a vaccination.
- Assess the need for and administer the HPV vaccine at every opportunity. Consider the following types of encounters: well child visits, sick visits, sports physicals, and nurse-only visits.
- Incorporate standing orders into clinic procedures to cut administrative burden and patient barriers. Supply walk-in or immunization-only appointments (see Appendix G).
- Explore partnerships and funding opportunities which would equip local health departments and community-based organizations with funding, supplies, and the mechanism to track HPV vaccinations.
- Track series completion and follow-up. Schedule follow-up appointments for the next dose before a patient leaves the clinic. Ask about other eligible family members in the home and schedule as needed. Remind parents when it is time for the next dose of the vaccine, or the vaccine is overdue for their child. Ensure your privacy statement includes phone, mail, email, and text messages as options for communication.
- Measure and improve performance. Purposeful quality improvement activities help increase vaccination rates by showing a starting point (a baseline screening rate), finding gaps in coverage, addressing missed opportunities, implementing policy, practice, or systems changes, and then checking changes in performance (i.e., increased rates, reduced disparities) over time.
- Encourage continuous improvement. Implement system, clinic, and provider scorecards to communicate shared purpose and goals. Solicit feedback from staff, providers, and parents to refine and improve the impact of your efforts. Conducting PDSA cycles will streamline the implementation of practice change into a strategy that meets the individual needs of a practice and providers.

Objective 5: Increase HBV Vaccination Rates Among Previously Unvaccinated Adults

Adults born after HBV became routinely recommended may not be protected against hepatitis B infection.

Hepatitis B vaccination was not available before 1981 and did not become a school-required vaccine in Illinois until 1997. This leaves most adults who are ~30 years or older unvaccinated against HBV. These adults continue to be susceptible.

- Implement systems and practice changes to avoid missed vaccination opportunities. Screening is not needed before administering hepatitis B vaccination but screening high-prevalence populations (e.g., immigrants from Southeast Asia and Sub-Saharan Africa) can help find those in need of vaccination or treatment.
- Implement standing orders which are among the most effective strategies to improve vaccination rates in adults (see Appendix G).[44] to ensure hepatitis B vaccinations become a part of their routine care. Use EHR alerts to flag relevant adults (e.g., patients with diabetes) to be sure they are vaccinated at next visit.
- Engage obstetricians to discuss prevention and treatment options with pregnant women. If a pregnant woman is unvaccinated, they can be vaccinated; pregnancy is not a contraindication to hepatitis B vaccination. Since Hepatitis B can be passed from a pregnant woman with hepatitis B to her baby at birth, health care providers can give newborns a set of shots at birth to prevent infection.
- Track vaccine administration and consider evidence-based interventions such as sending auto-reminders to ensure patients return for follow-up doses. About 75 percent of adults who start HBV vaccination do not complete the series.[45] Tactics include using IIS auto-reminders, if available, scheduling follow-up appointments during a visit, setting up transportation if needed, and mailing reminder cards.
- Evaluate caseload to order, store, administer, and bill for adult HBV vaccinations.
- Ensure that mobile clinics serving under-resourced populations have HBV vaccine on board.
- Engage local health departments to promote HBV vaccination among adults. Prepare information sheets for public health nurses, administrators, and community health workers.

Integrate hepatitis B vaccination into traditional and nontraditional settings.

- Engage primary care provider, specialty care providers, and providers serving veterans to check on adult immunization status during well visits and breast and cervical cancer screening appointments.
- To reach and vaccinate at-risk adults, partner with public health partners (e.g., local health departments, sexually transmitted infection clinics, and harm reduction programs such as needle exchanges and substance abuse treatment programs).
- Train primary care practices and providers in the state's Opioid Prescribing Registry and others who prescribe buprenorphine to treat patients for opioid disorders to simultaneously recommend HBV vaccination.
- Consider alternative locations for delivering both initial and follow-up hepatitis B vaccination doses. Some patients may find it more convenient to receive additional doses at their local pharmacy, community center, place of workshop or other nontraditional settings.

Build awareness about hepatitis B virus, infection, disease progression, and prevention strategies among adults 30 years of age and older and their providers.

- Integrate HBV vaccination into professional development curriculum for providers.
- Build awareness of hepatitis B through social media channels of associations and individual partners.
- Earn media coverage; engage experts in hepatology, oncology, infectious disease to write editorials.

Objective 6: Educate New Vaccinators

Students in training to become licensed healthcare professionals will be starting their careers in a state where the incidence rates of two vaccine-preventable cancers are rising---liver cancer and oropharyngeal cancer. They need to learn what they can do, in their future profession, to prevent these cancers. They also need to learn safety practices to protect their patients and themselves. Vaccinators are at a greater risk of sustaining a needle stick during vaccine administration.[46] Estimated risk of HBV infection after a needlestick or exposure to infected blood is up to 62 percent.[47,48]

- Invest in workforce development, both current licensees and pre-licensure students. Periodically update curriculum on needle safety practices and proper disposal.
- Partner with medical schools, community colleges, and community organizations to train clinicians and allied health before licensure and before they start to work; integrate cancer-prevention strategies into curriculum.
- Ensure ongoing professional development reflects most current recommendations.

Objective 7: Promote Digital Innovation and Cultivate Youth Leaders

Falsehoods have been shown to spread faster and further than facts, and research suggests that misinformation can have negative effects in the real world, such as amplifying controversy about vaccines and propagating unproven treatments. Health misinformation on social media, therefore, creates an urgent demand for public health researchers and practitioners to implement more influential messaging.[49]

- Understand how psychological drivers influence behavior (e.g., fear and other emotions, identity/reputation, and cognitive biases) and learn what behaviors and messaging strategies are most effective for building awareness based in facts and for developing more trusting relationships.
- Solicit, engage, and include youth leaders to develop strategies and signaling techniques such as frames and badges to promote the science and health benefits of vaccination.
- Focus social media investments on populations where vaccine uptake is lowest. Segment by zip, age, and other demographics to focus campaigns to specific populations.
- Illustrate real-world scenarios showing providers responding to mistrustful patients, building strong relationships, modeling shared decision-making.
- Learn about social media platforms and how to report posts that violate platform policies.

Conclusion

Vaccination is a safe, effective, and inexpensive disease prevention strategy that can work to eliminate certain cancers in Illinois. Public health partners across the state can help advance this goal by equipping all stakeholders with the information and resources they need to improve data collection and reporting, improve partner coordinator and program support, advocate for policy improvements, help health and hospital systems increase their vaccination rates, educate new vaccinators, promote digital innovation, and cultivate youth leadership. Together, we can make this goal a reality.

Appendices

Appendix A: Viruses Associated with Cancer

Appendix B: Supplemental Data

Appendix C: Summary of Findings

Appendix D: IDPH HPV Burden Reports, Parts I and II

Appendix E: State of Illinois Certificate of Child Health Examination Form

Appendix F: AIRA Immunization Information System (IIS) Standards

Appendix G: Sample Standing Orders

Appendix A: Viruses Associated with Cancer

Human Papillomaviruses (HPV)

Human papillomaviruses are a group of more than 150 related viruses. They are called *papillomaviruses* because some of them cause papilloma, which are more commonly known as warts. Some types of HPV only grow in skin, while others grow in mucous membranes such as the mouth, throat, or vagina.

All types of HPV spread by physical contact (touch). More than forty types of HPV can be passed on through sexual contact. Most sexually active people are infected with one or more of these HPV types at some point in their lives. At least a dozen of these types is known to cause cancer.

While HPV infections are quite common, cancers caused by HPV are not. Most people infected with HPV will not develop a cancer related to the infection. However, some people with long-lasting infections of high-risk types of HPV are at risk of developing cancer.

HPV infections of the mucous membranes can cause genital warts, but they usually have no symptoms. There are no effective medicines or other treatments for HPV, other than removing or destroying cells that are known to be infected. But in most people, the body's immune system controls the HPV infection or gets rid of it over time.

A few types of HPV are the main causes of cervical cancer, which is the second most common cancer among women worldwide. Cervical cancer has become much less common in the United States because the Pap test has been widely available for many years. This test can show pre-cancer in cells of the cervix that might be caused by HPV infection. These pre-cancer cells can then be destroyed or removed, if needed. This can keep cancer from developing.

Doctors can now also test for the presence of HPV infection as part of cervical cancer screening, which can tell them if someone might be at higher risk for cervical cancer. Nearly all individuals with cervical cancer show signs of HPV infection on lab tests. Even though doctors can test people with a cervix for HPV, there is no treatment directed at HPV itself. But there is a vaccine that can help prevent it. If HPV causes abnormal cells to start growing, these cells can be removed or destroyed.

HPV also has a role in causing cancers of the penis, anus, vagina, vulva, mouth, and throat. Smoking, which is also linked with these cancers, may work with HPV to increase cancer risk. Other genital infections may also increase the risk that HPV will cause cancer.

HPV vaccination can help prevent more than 90 percent of HPV cancers. The vaccine is approved for use in females and males starting at age 9 through age 26 and are given as a series of injections (shots). The vaccines can only be used to help prevent HPV infection – they do not stop or help treat an existing infection. To be most effective, the vaccine should be given before a person becomes sexually active (has sex with another person).

Epstein-Barr Virus (EBV)

EBV is a type of herpes virus. It is best known for causing infectious mononucleosis, often called "mono" or the "kissing disease." In addition to kissing, EBV can be passed from person to person by coughing, sneezing, or by sharing drinking or eating utensils. Most people in the United States are infected with EBV by the end of their teen years, although not everyone develops the symptoms of mono.

As with other herpes virus infections, EBV infection is life-long, even though most people have no symptoms after the first few weeks. EBV infects and stays in certain white blood cells in the body called *B lymphocytes* (also called *B cells*). There are no medicines or other treatments to get rid of EBV, nor are there vaccines to help prevent it, but EBV infection does not cause serious problems in most people.

EBV infection increases a person's risk of getting nasopharyngeal cancer (cancer of the area in the back of the nose) and certain types of fast-growing lymphomas such as Burkitt lymphoma. It may also be linked to Hodgkin lymphoma and some cases of stomach cancer. EBV-related cancers are more common in Africa and parts of Southeast Asia. Overall, very few people who have been infected with EBV will ever develop these cancers.

Hepatitis B Virus (HBV) and Hepatitis C Virus (HCV)

Both HBV and HCV cause viral hepatitis, a type of liver infection. Other viruses can also cause hepatitis (hepatitis A virus, for example), but only HBV and HCV can cause long-term (chronic) infections that increase a person's chance of liver cancer. In the United States, about half of liver cancers are linked to HBV or HCV infection. But this percentage is higher in other countries, where both viral hepatitis and liver cancer are much more common. Some research also suggests that long-term HCV infection might be linked with some other cancers, such as non-Hodgkin lymphoma.

HBV and HCV are spread from person to person in much the same way as HIV (see the section on HIV below) — through sharing needles (such as during injection drug use), unprotected sex, or childbirth. These viruses can also be transmitted through blood transfusions, but this is rare in the United States because donated blood is tested for these viruses before it can be used.

Of the two viruses, infection with HBV is more likely to cause symptoms, such as a flu-like illness and jaundice (yellowing of the eyes and skin). Most adults recover completely from HBV infection within a few months. Only a small percentage of adults go on to have chronic HBV infections, but this risk is higher in young children. People with chronic HBV infections have a higher risk of liver cancer.

HCV is less likely to cause symptoms than HBV, but it is more likely to cause chronic infection, which can lead to liver damage or even cancer. An estimated 3.2 million people in the United States have chronic HCV infection, and most of these people do not even know they have it. To help find some of these unknown infections, the US Centers for Disease Control and Prevention (CDC) recommends that all people born between 1945 and 1965 (as well as some other people at elevated risk) get blood tests to check for HCV.

Once an infection is found, treatment and preventive measures can be used to slow liver damage and reduce cancer risk. Both hepatitis B and C infections can be treated with drugs. Treating chronic hepatitis C infection with a combination of drugs for at least a few months can get rid of HCV in many people. Several drugs can also be used to help treat chronic hepatitis B. Although they do not cure the disease, they can lower the risk of liver damage and might lower the risk of liver cancer as well.

There is a vaccine to prevent HBV infection, but none for HCV. In the United States, the HBV vaccine is recommended for all children. It is also recommended for adults who are at risk of exposure. This includes people infected with HIV, men who have sex with men, injection drug users, people in certain group homes, people with certain medical conditions and occupations (such as health care workers), and others.

Human Immunodeficiency Virus (HIV)

HIV, the virus that causes acquired immune deficiency syndrome (AIDS), does not appear to cause cancers directly. But HIV infection increases a person's risk of getting several types of cancer, especially some linked to other viruses.

HIV can be spread through semen, vaginal fluids, blood, and breast milk from an HIV-infected person. Known routes of spread include: Unprotected sex (oral, vaginal, or anal) with an HIV-infected person; Injections with needles or injection equipment previously used by an HIV-infected person; Prenatal (before birth) and perinatal (during birth) exposure of infants from mothers with HIV; Breastfeeding by mothers with HIV; Transfusion of blood products containing HIV (the risk of HIV from a transfusion is less than 1 in a million in the United States due to blood testing and donor screening); Organ transplants from an HIV-infected person (donors are now tested for HIV); Penetrating injuries or accidents (usually needle sticks) in health care workers while caring for HIV-infected patients or handling their blood.

HIV infects and destroys white blood cells known as helper T-cells, which weakens the body's immune system. This might let some other viruses, such as HPV, thrive, which might lead to cancer.

Many scientists believe that the immune system is also important in attacking and destroying newly formed cancer cells. A weak immune system might let new cancer cells survive long enough to grow into a serious, life-threatening tumor.

HIV infection has been linked to a higher risk of developing Kaposi sarcoma and cervical cancer. It is also linked to certain kinds of non-Hodgkin lymphoma, especially central nervous system lymphoma.

Other types of cancer that may be more likely to develop in people with HIV infection include anal cancer, Hodgkin disease, lung cancer, cancers of the mouth and throat, some types of skin cancer, and liver cancer.

Some other, less common types of cancer may also be more likely to develop in people with HIV.

Because HIV infection often has no symptoms for years, a person can have HIV for a long time and not know it. The CDC recommends that everyone between the ages of 13 and 64 be tested for HIV at least once as part of their routine health care.

There is no vaccine to prevent HIV. But there are ways to lower your risk of getting it, such as not having unprotected sex or sharing needles with someone who has HIV. For people who are at elevated risk of HIV infection, such as injection drug users and people whose partners have HIV, taking medicine (as a pill every day) is another way to help lower your risk of infection.

For people already infected with HIV, taking anti-HIV drugs can help slow the damage to the immune system, which may help reduce the risk of getting some of the cancers above.

Human Herpes Virus 8 (HHV-8)

HHV-8, also known as *Kaposi sarcoma–associated herpes virus* (KSHV), has been found in nearly all tumors in patients with Kaposi sarcoma (KS). KS is a rare, slow-growing cancer that often appears as reddish-purple or blue-brown tumors just underneath the skin. In KS, the cells that line blood and lymph vessels are infected with HHV-8. The infection makes them divide too much and live longer than they should. These types of changes may eventually turn them into cancer cells.

HHV-8 is transmitted through sex and appears to be spread other ways, such as through blood and saliva, as well. Studies have shown that fewer than 10 percent of people in the US are infected with this virus.

HHV-8 infection is life-long (as with other herpes viruses), but it does not appear to cause disease in most healthy people. Many more people are infected with HHV-8 than ever develop KS, so it is likely that other factors are also needed for it to develop. Having a weakened immune system appears to be one such factor. In the US, nearly all people who develop KS have other conditions that have weakened their immune system, such as HIV infection or immune suppression after an organ transplant.

KS was rare in the United States until it started appearing in people with AIDS in the early 1980s. The number of people with KS has dropped in the US since peaking in the early 1990s, because of better treatment of HIV infection.

Human T-Lymphotropic Virus-1 (HTLV-1)

HTLV-1 has been linked with a type of lymphocytic leukemia and non-Hodgkin lymphoma called *adult T-cell leukemia/lymphoma* (ATL). This cancer is found mostly in southern Japan, the Caribbean, central Africa, parts of South America, and in some immigrant groups in the southeastern United States. In addition to ATL, this virus can cause other health problems, although many people with HTLV-1 do not have any of them.

HTLV-1 belongs to a class of viruses called *retroviruses*. These viruses use RNA (instead of DNA) for their genetic code. To reproduce, they must go through an extra step to change their RNA genes into DNA. Some of the new DNA genes can then become part of the chromosomes of the human cell infected by the virus. This can change how the cell grows and divides, which can sometimes lead to cancer.

HTLV-1 is spread in the same ways as HIV, such as unprotected sex with an HTLV-1-infected partner or injection with a needle after an infected person has used it. Mothers infected with HTLV-1 can also pass on the virus to their children, although this risk can be reduced if the mother does not breastfeed.

Infection with HTLV-1 is rare in the United States. Fewer than 1 percent of people in the US are infected with HTLV-1, but this rate is much higher in groups of people at elevated risk (such as injection drug users). Since 1988, all blood donated in the United States has been screened for HTLV-1. This has reduced the chance of infection through transfusion and has also helped control the potential spread of HTLV-1 infection.

Once infected with HTLV-1, a person's chance of developing ATL can be up to about 5 percent, usually after a long time with no symptoms (20 or more years).

Merkel Cell Polyomavirus (MCV)

MCV was discovered in 2008 in samples from a rare and aggressive type of skin cancer called *Merkel cell carcinoma*. Most people are infected with MCV at some point (often in childhood), and it usually causes no symptoms. But in a few people with this infection, the virus can affect the DNA inside cells, which can lead to Merkel cell cancer. Nearly all Merkel cell cancers are now thought to be linked to this infection.

It is not yet clear how people become infected with this virus, but it has been found in several places in the body, including normal skin and saliva.

Appendix B: Supplemental Data

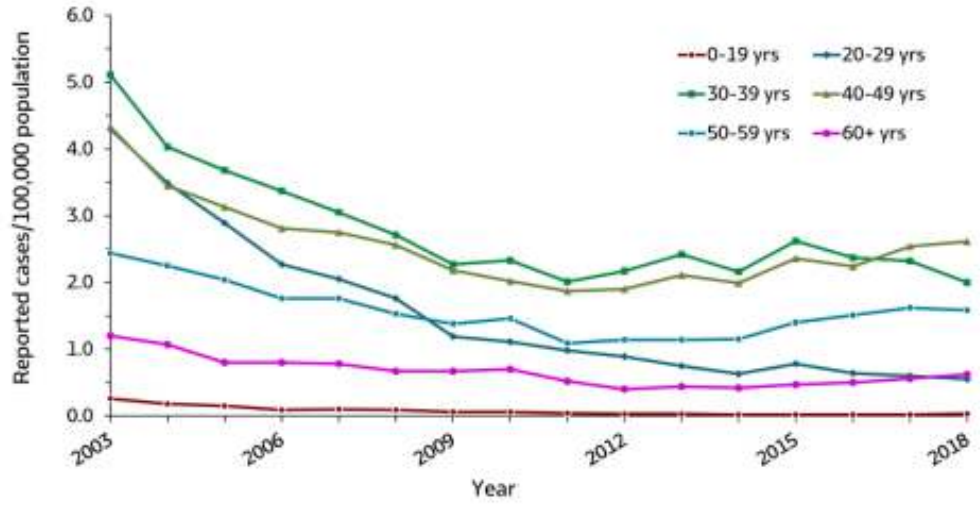
HPV-Related Cancer Cases (2013 to 2017) [50]

Cancer site	Average number of cancers per year in sites where HPV is often found (HPV-associated cancers)	Percentage probably caused by any HPV type[a]	Estimated number probably caused by any HPV type[a]
Cervix	12,143	91%	11,000
Vagina	867	75%	700
Vulva	4,114	69%	2,800
Penis	1,348	63%	900
Anus[b]	7,083	91%	6,500
Female	4,751	93%	4,400
Male	2,332	89%	2,100
Oropharynx	19,775	70%	14,000
Female	3,530	63%	2,200
Male	16,245	72%	11,800
TOTAL	**45,330**	**79%**	**35,900**
Female	**25,405**	**83%**	**21,100**
Male	**19,925**	**74%**	**14,800**

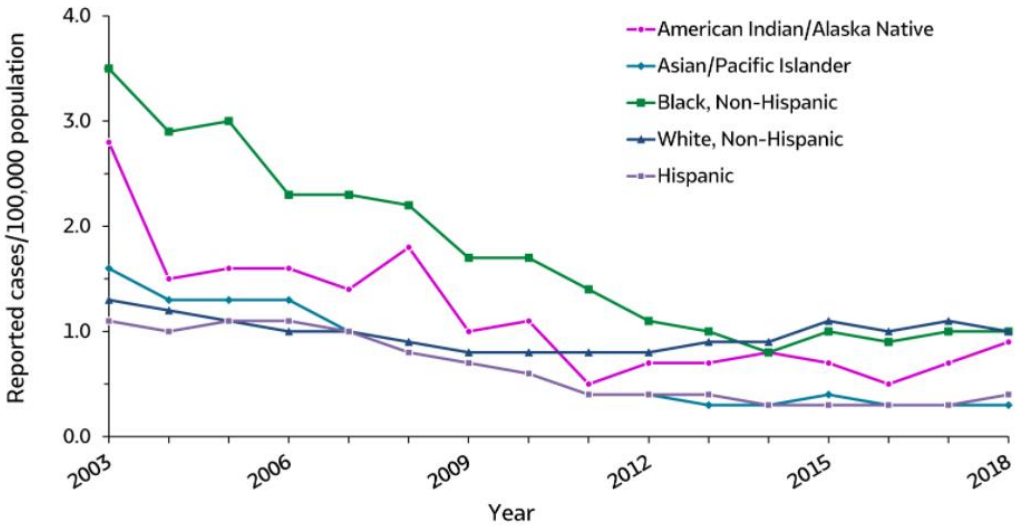
[a] HPV types detected in genotyping study; most were high-risk HPV types known to cause cancer (Saraiya M, et al. U.S. assessment of HPV types in cancers: implications for current and 9-valent HPV vaccines. Journal of the National Cancer Institute 2016;107:djv086. Estimates were rounded to the nearest 100. Estimated counts might not sum to total because of rounding.

[b] Includes anal and rectal squamous cell carcinomas.

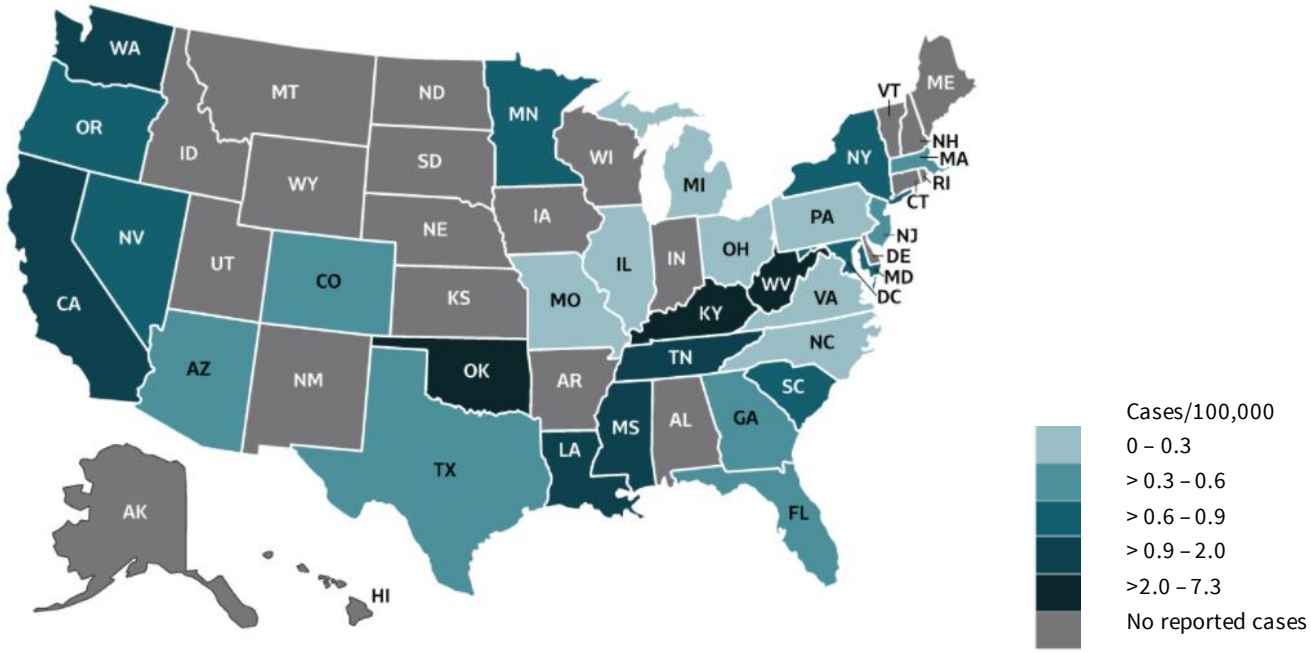
Reported Acute Hepatitis B Infections in the United States by Age Group (2018)[51]



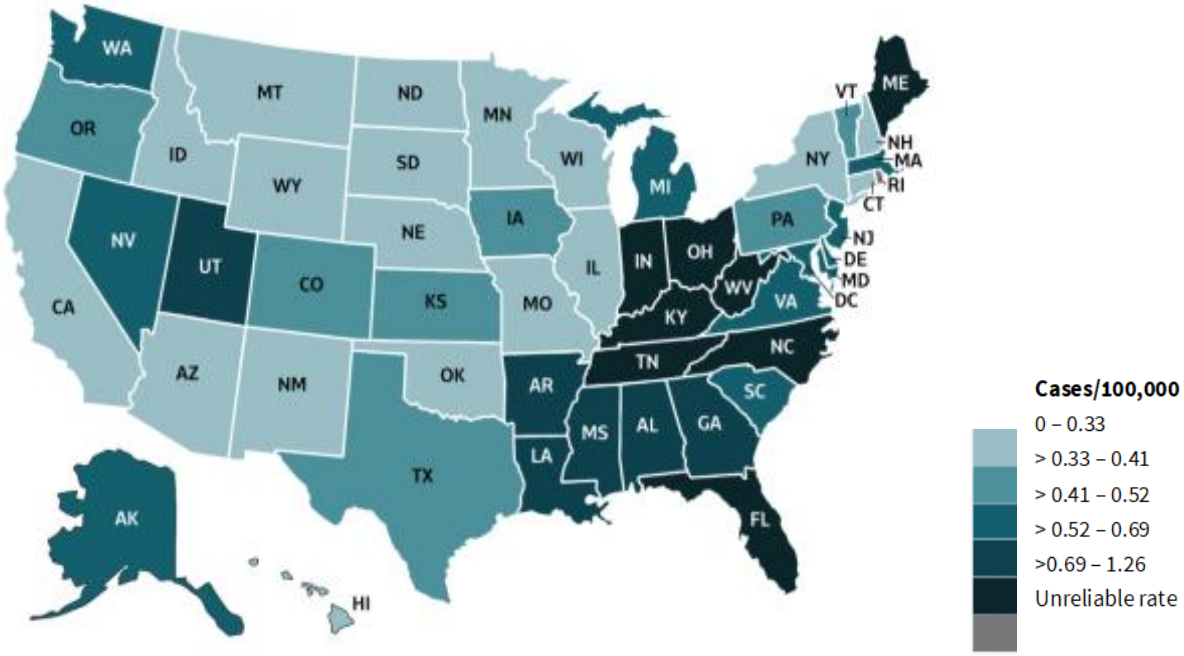
Reported Cases Acute Hepatitis B Infections by Race/ Ethnicity (2003-2018)[52]



Reported Acute Hepatitis B Infection in the United States (2018)[53]



Rate of Deaths with Hepatitis B listed as the Cause of Death Among U.S. Residents (2018)



Appendix C: Summary of Findings

Workshop Findings

Policy

Workshop participants found policy or lack thereof as a barrier to prevention and the elimination of HPV-related cancers. In Illinois, the HPV vaccine is not a mandatory vaccine on the legislative level or in public school districts. As aforementioned, the ISBE lists the HPV vaccine as a recommended vaccination rather than a required vaccination for incoming students. Currently, the distinction between required and recommended vaccinations on the State of Illinois Certificate of Child Health Examination form is a barrier to increasing vaccination rates because parents and guardians often choose to only have the required vaccines administered to their children. Introducing policy that removes that distinction or requires the HPV vaccination and/or reporting is likely to increase immunization rates.

Participants also reported that HPV has not been a system priority, resulting in a lack of funding which has been another major barrier to eliminating HPV-related cancers. Since prevention and early detection of HPV-related cancers is not a system priority, funding is still limited to support this work. To support prevention initiatives, funding is necessary for effective data reporting and compilation, messaging and education, and promotion of the HPV vaccine. Establishing this work as a priority in the system by increasing funding allocation would bring Illinois closer to eliminating HPV-related cancers.

With few exceptions, participation in I-CARE is voluntary. This means that some but not all vaccines administered in Illinois are recorded in the state's IIS. Not having a complete picture of vaccination rates across the state prevents public health partners from knowing where they should focus their staff and resources.

Participants also reported that funding for HPV vaccination and cancer prevention has not been a state priority, creating another major barrier to eliminating HPV-related cancers. To support prevention initiatives, investments must be made into a population health data management system to improve outcomes, by allowing experts to find, track, and scale high-impact interventions across the state. Supporting inputs include automated documentation and reporting, predictive modeling, multi-lingual messaging and education, and promotion vaccination as a cancer prevention strategy. Establishing this work as a priority in the system by increasing funding allocation would bring Illinois closer to eliminating HPV-related cancers.

Despite large policy gaps, stakeholders throughout the state have worked towards the vision of eliminating HPV-related cancers by supporting HPV vaccination-related legislation. In both 2007 and in 2018, legislation was introduced that requires the health department to provide information to parents and guardians of children entering the sixth grade about the linkage between HPV and related cancers as well as the availability of the HPV vaccine.[54] In 2013, as a part of the state's movement to advance comprehensive sexual health policy, Illinois passed legislation to authorize minors 12 years of age or older, who may have come into contact with any sexually transmitted infection (STI), the legal authority to consent to the treatment of or vaccination against an STI without requiring permission from a parent or guardian.[55]

Environment

Obstacles to accessing healthcare services were also identified as barriers to prevention and elimination of HPV-related cancers. Socioeconomic factors, such as – cost for uninsured or underinsured, transportation,

and rural geographic location, contribute to the lack of access to vaccination and screening for different populations. A lack of adequate and reliable transportation was cited as the most common obstacle to accessing the vaccine in both rural and urban communities. Rural communities with limited healthcare providers in their area cannot easily access screening or the vaccination. Cost of a visit, screening test, and/or HPV vaccination also serves as a socioeconomic barrier for those who are uninsured or underinsured. This is also true for adolescents who wish to receive the vaccine but are not able to afford a co-pay or who have concerns related to confidentiality and billing. The current process for vaccination requires two doses which requires two visits. This two-stage process is costly, especially for those facing socioeconomic barriers.

Participants also found cultural and gendered norms and stigma as barriers to the vision of eliminating HPV-related cancers. When the vaccine was first introduced, it was only approved for girls, which led people to believe that only girls were at risk for HPV infections. Negative gender-based biases and the stigma around sexually transmitted infections (STIs) contributed to the idea that HPV vaccination would encourage sexual intercourse. Without useful information about the virus and the vaccine, parents and guardians focused on how the virus could be transmitted. Participants said that the focus on how the virus can be transmitted, coupled with religious beliefs and cultural norms about sex led many parents to reconsider vaccination.

Historically, HPV prevention initiatives primarily focused on administering the vaccine to females. Messaging directed at females has denied the importance of administering the vaccine to males of the same age. Even though females are more likely than males to be diagnosed with HPV-related cancers, diagnoses of HPV-related oropharyngeal cancers among males have increased. Participants reported how the limitations of current public knowledge serve as a barrier to eliminating HPV-related cancers.

Systems

State Level

Participants reported that strategic coordination across the State's Comprehensive Cancer Control programs is needed to increase vaccination and screening rates and improve outcomes. These programs include the Illinois Cancer Partnership (ICP), the Illinois Breast and Cervical Cancer Program (ILBCCP) and the Illinois State Cancer Registry.

One participant shared that a workgroup in Missouri, created to reduce HPV-related cancers, pools county level vaccination data across the public health system to increase the volume of available data.

Clinic Level

Participants noted a lack of standardized procedures and processes for providers across the state in terms of administering the HPV vaccine. The current process requires two doses and two visits to the provider. Participants reported how a lack of system follow up and standing orders results in individuals not completing the vaccine series. Participants also noted that the rates of youth well visits are still low because patients do not reliably have a well visit unless needed for schools or extra-curricular activities. In addition, many youths and families lack a medical home. Standardized internal procedures for implementation and tracking follow up are necessary to improve rates of series completion.

Patient Level

Standardized consenting procedures across providers for the HPV vaccination is also necessary for prevention of HPV-related cancers. Guardians and youth are often unaware of the consenting process for vaccinations. Across the state, there is no standardized consenting procedures to inform patients of their rights to consent to the vaccine, especially for youth over the age of twelve. Youth often remain unaware of their ability to consent to the vaccine if the vaccination is not allowed by their guardian. Participants described how a standardized consenting procedure could increase rates of vaccination by informing patients of their right to consent.

Communication

Participants noted how communication and trust between providers and patients could serve as a barrier to obtaining the HPV vaccine. Individuals who have had negative experiences, heard secondhand accounts of negative experiences, might distrust the healthcare system and providers. Participants noted how the knowledge of the history of racist experimentation and mistreatment in health could lead to distrust. In addition, poor communication between the patient and provider serves as a barrier. Individuals who distrust the healthcare system or experience communication issues are potentially less likely to visit a provider, ask about the vaccine, and/or consent to receiving the vaccine. Trust and communication are vital to the patient and provider relationship and the outcome of a visit.

Parents

A lack of public awareness, social media misinformation, and parental fears were identified as barriers that prevent youth from receiving the HPV vaccination. Recent years have seen a rise in anti-vaccination sentiments supported by social media misinformation. Misconceptions on the side effects and potential harm of vaccinations have increased parental fear of vaccines. Fear of the unknown and a lack of credible and accessible public education has resulted in parents and guardians refusing to consent to the HPV vaccine. Despite extensive research being conducted, understanding of vaccinations is still limited due to a lack of consistent simplified messaging. Misinformation is easily spread through word of mouth and social media with limited efforts to counter false claims. To combat misinformation and a lack of knowledge, the public needs accurate, easily to access information and publicly available education initiatives.

Adolescents

Limited knowledge and resources to access the vaccine for youth serve as barriers to prevention and early detection. Participants noted how outdated sexual health curricula and a lack of consistent medical home prevent youth from receiving the HPV vaccine. Teen well visits are often limited to times when the visit is required by schools or extra-curricular activities, which limits the opportunities to supply HPV-related information. Additionally, a lack of teen-friendly providers does not allow for open communication to discuss HPV and the vaccination. Youth often are afraid of vaccinations due to a lack of knowledge, misinformation, and fear of pain from the vaccination. Participants reported how teen well visits with teen-friendly providers and updated sexual health curriculum could increase immunization rates by expanding knowledge of the vaccination. Participants explained how involving youth champions in prevention initiatives and campaigns would support the sustainability of these efforts.

Providers

Across all workshops, participants reported how a lack of provider recommendation prevents patients from obtaining the HPV vaccination. Time limitations, lack of a mandate (reporting or vaccine-specific), and lack of education and effective messaging remain obstacles to provider recommendation.

Participants noted that time-limited visits and the HPV vaccine being a recommended (versus a required) vaccine are barriers to discussing and administering the vaccine. Providers tend to focus on the priority issues and reasons for the visit because of time limitations. Since the HPV vaccination is not a school requirement, providers may not prioritize time to recommend or administer the HPV vaccination. This barrier can be addressed by teaching doctors, nurses, and clinicians how to make a strong recommendation for the HPV vaccine as is done with other required adolescent vaccines. The number of shots, especially when it was a three-dose series, was also reported to be a barrier.

Participants also noted that too tightly restricting the types of clinicians who can administer the vaccine is a barrier to obtaining the HPV vaccine. Limited entry points to obtaining the vaccination serve as a barrier to individuals who do not have access to a primary care physician or pediatrician. Expanding the scope of practice for licensed professionals could make it easier for people to get vaccinated during appointments made for other health care needs. Participants suggested pharmacy technicians, dental care providers such as hygienists, oncologists, urgent care providers, and school nurses as professionals whose scope of practice might be amenable for expansion. Some participants noted that providers need to know about vaccine safety, storage and handling and administrative requirements prevent some from administering vaccines.

The National Network for Oral Health Access recently published *The Role of Dental Providers in Vaccine Delivery and Policy* (August 2021) which outlines practice and policy recommendations to increase dental providers' pivotal role in the promotion and administration of HPV vaccines and eliminate this gap in potential vaccination delivery.

In addition, provider stigma of the virus and the vaccination was identified as a barrier that prevent providers from consistently administering the vaccine. HPV vaccine was originally approved for females and the public and by providers understood HPV as a sexually transmitted infection. Providers were told to administer the vaccine before sexual debut. Some providers were hesitant about discussing the vaccine with parents. Since the vaccine was introduced, approval now includes males and provider messaging has been updated to focus on cancer prevention for all youth, but participants noted that some providers are still reluctant.

Other providers need updated information and training on vaccination best practices (e.g., standing orders). Participants noted that without good data (i.e., provider scorecards) providers cannot find where the gaps are in their practice. Participants said that providers need to learn to how to effectively recommend the vaccine to patients. Clinic-based quality improvement strategies have worked to boost HPV coverage levels.

Participants also noted how low reimbursement rates for administer vaccines is a barrier, especially for immunization services reimbursed by Medicaid. In Illinois, providers are reimbursed only $6.40 for immunization administration, a rate that has remained unchanged for decades. The administration reimbursement rate should be increased to align with Medicare rate.

Participants reported that there is no pay for performance or similar incentives to prioritize HPV vaccination, a strategy that has been used successful to increase other measures. Incentive payments and increasing the reimbursement rate for administering vaccines may bring more pediatric providers back into the state's VFC program.

Facilitators

Participants also found several facilitators in the workshops. Participants were asked to find facilitators on their own, and then collaborate with small groups to categorize and align similar facilitators. These facilitators work to ensure people receive the vaccine and were identified as strengths to prevention and early detection of HPV-related cancers. Facilitators may be useful when designing and deploying strategies. Figure 6 presents the facilitators found across the four workshops.

Facilitators Across Workshops

Springfield	Chicago	Schaumburg	Carterville
Clinical best practices Standardization	Clinical best practices Standardization	Clinical best practices	Clinical best practice Standardization
Provider recommendation	Provider recommendation	Provider recommendation	Provider recommendation
Vaccine Champions	Vaccine Champions	Community and provider support and advocacy	Physician/provider support
Education for the public (specifically prevention)	Education for the public (specifically prevention)	Education for the public (specifically prevention) and literacy	Education for the public (specifically prevention)
Cost (coverage, insurance, payment)	Cost (coverage, insurance, payment)	Cost (coverage, insurance, payment)	Cost (coverage, insurance, payment)

Additional Facilitators Across Workshops

Springfield	Chicago	Schaumburg	Carterville
Excellent safety and efficacy: proven results and impact	Education system -- teaching in schools	Data	Data
Strong ACIP recommendation (start immunizing at age 9)	Expanding access to vaccinators and clinics	Community programs	Client incentives
Timing: Offer HPV with mandated vaccines (e.g., Tdap and MenACWY)	Access to youth for vaccine (including coverage)	Educated providers / Reminders available	Include dental / oral health professionals
Publication and dissemination of research	Legislative advocates	Regulations (state and school rulemaking)	Parent education available
Youth engagement and awareness	Lab science -- funding research around vaccine development	Media	Supportive policies (listed on school form)
Accurate /actionable data through QI project	Low or no cost system		Efficiency of administration

Educate school administrators, teachers, nurses, and students	Messaging		Storytelling
Culturally sensitive / resonate resources	Provider and clinical champions		
Role of quality measures (workflow pyramids, IT, BPAs/priorities as initiative			
Systems protocol for 2nd/3rd appointments			
Social media focused on benefits/cancer prevention			
Stories/testimonials			
Focus on college students; those not vaccinated during adolescence			

Facilitators found across all four workshops include clinical best practices and standardization, provider recommendation, vaccine champions, effective education and messaging to the public, and insurance coverage. Increasing payments to providers for administering vaccines and improved compliance with the VFC program can also serve as facilitators.

Clinical best practices and standardization serve as a facilitator for effectively discussing and administering the vaccine to patients. Participants noted how intentional practices for discussing and administering the vaccine integrated into office and provider workflow can increase vaccination rates. Clinical best practices such as appointment reminders and a strong provider recommendation were reported to be reliable strategies for increasing vaccination rates.

Outside of the provider and clinical field, participants noted how vaccine champions help improve awareness and uptake of recommended vaccines. Vaccine champions, such as doctors, nurses, teachers, parents, community leaders, can help build awareness, improve health literacy, and counter social media misinformation with personal testimonials and science-based narratives that focuses on cancer prevention.

Participants also noted how insurance coverage for the cost of the vaccine serves as a facilitator to the prevention of HPV-related cancers. Since recommended vaccines are covered as preventative care, the most people do no have to pay a co-pay or co-insurance to get vaccinated. This is particularly helpful for teens in Illinois who may self-consent to HPV vaccination at 12 years of age.

Barriers and Recommended Strategies

A number following a strategy shows the number of times it was suggested during the workshops

Data Limitations	
Awareness of vaccination rates at provider level	Mandatory vax reporting (policy triangle)
Add question IYS, YRBSS, and BRFSS	% pop. Screening and HPV (prox. DX genital warts) (2)
Models from other states; see what others are doing and what is working well (2)	VFC or I-CARE data - state and/or federal programs that cover vaccines
I-CARE reporting -- who reports at practice -- opportunities for auto-reporting through billing	I-CARE -- root cause provider or parents of opting out -- why are they opting out? -- how to limit opt-outs
EPIC - education of providers -- benefits of data collecting -- reimbursements and motivations	Data from Merck - # units sold
Public HIE democratizing access to data	Compare HPV data to TDAP and Meng.
Lack of a vaccine mandate (either legislation or school-based)	
If DCFS requires all ACIP rec. vaccines, why not all other agencies caring for adolescents? -- baby steps to policy	Engage organizations and groups that lobby to support mandatory HPV vacs, nursing society, ACS Cancer action network, etc. (2)
Create talking points	How did other states get the HPV vaccine mandated
Find legislative champions	Storytelling -- survivor stories
Thoughtful campaign that anticipates objections	Youth advocates
Require parents to sign refusal form (little p - policy)	Avoid stand-alone mandates
Mandating HPV vaccine (at all or just at the wrong time) might cause backlash and harm provider-patient relationships	Line up legislation to create an overall adolescent health and/or cancer prevention platform that the HPV vaccine can fit into
Target down state providers to education for pushing strong vaccine recommendation (apply similar structures for Chicago VFC provider education)	Focus on cancer prevention for adolescent population (instead of pushing for mandate), and include HPV in the cancer prevention package
Support legislation to make a sixth-grade requirement	Allow young people to universally consent to HPV at age 12+. Note: Individuals 12 years of age and older are already authorized to consent to preventive sexual health services, including HPV vaccination. [56]
Private insurance oversight of HPV immunizations rate	
Work with legislature, schools, and insurance companies to mandate vaccine use/reporting	
Access to vaccine (transportation, resources)	
Outreach clinics in schools	Immunizations available at back-to-school nights
Increase knowledge about what is available (transportation) through payor	Educate providers and public re: preventative health resources
Work with community orgs -- church vans, school buses, mass transit, local transportation companies to transport to health department/clinic (2)	Offer HPV vaccine at walk in clinics, pharmacies, schools, libraries (2)
Vaccinate at school sites, schools' physicals on site (3)	Mobile vaccine units (2)
Expand VFC access points	Expand the scope of CPN: RN to supply vaccines
Cost/insurance (underinsured/uninsured)	
Change policy to include HPV vacs in Medicaid pay for performance measures	Develop policy to vaccinate regardless of ability to pay (clinic, health dept)
Add language to say "covered by Medicaid and most private insurances"	Education from the payer to consumer re: vaccine costs, availability, etc.
Provider education on vaccine assistance programs	Update Medicaid reimbursement for vaccination.
Lack of public education -- misinformation	
Advocates	Education with good data and research (2)
Survivor/patient stories	Target parents - their "why" stories

Target youth and engage youth in message, development, and delivery	Effective media campaign with actual patients -- testimonials (i.e., smoker campaigns)
Public awareness campaigns for each HPV-related cancer; esp. oropharyngeal cancers for men	Integration into school health curriculum
School RN and health educator toolkit and curriculum	Celebrity and pop culture saturation
Clear, concise, consistent messaging from all clinicians re: cancer prevention -- "ask me about cancer prevention for your child" with supporting education and materials -- "know your status" (3)	Awareness events -- churches, health organizations/providers, schools, community centers and groups, community leaders
Video played between MA and clinician visit -- educating on all three vaccines	Downstate capacity-building in integrated health systems
Invite immunization champions to supply public education	Encourage faith-based organizations to support our initiative
Coalition building with medical homes, influential advocates, providers, insurers	Increase public awareness through community forums or more PSAs
Anti-vax messaging	
Social media campaign (share-share-share)	
Direct people to CDC/immunize.org or other evidence-based education resources	Use of motivational interviewing to uncover the true cause of the hesitation
Lack of provider recommendation -- Provider bias/hesitation/ lack of information	
Unified message from all clinic/HC providers/staff	Find a champion to advocate for HPV vacs
Add HPV vacs to EHR -- mandatory field address, best practice alert	Reminder systems -- EHR -- phone calls -- focused on medical
Offer CME for HC providers - in person/online seminar inc. data -- show rates strong effective messaging	Patient navigator or MA that can talk to parent if concerns
Supply education to up-and-coming HC providers	Optimizing EHR to ID and help vaccine admin
Clinic champion to prepare parent to accept vaccine recommendation	Understanding their immunization rate to drive change around their words
Same way/same day recommendation	MOC/CME tied to improvement
Collaborating w/ gyn, onc, head, neck surgeons, oral health -- why they need to be better vaccinations	Training in making strong recommendations
Lack of consistent medical home	
Collaboration between LHDs and healthcare systems, partner clinics, school physicians, sports physicians, vax (including HPV)	Vaccine clinics in schools -- advertise on school website -- schools distribute via email -- gas stations, laundromats
Improve communication about provider identification/linkage to care	Medical bus -- mobile clinics
Basic level -- know your assigned PCP	PCP to know clients
Original focus on females	
Targeted messaging to boys from men	HPV test/screen for men
Pro-active future Granny message "you will not make the mother of my future grandchildren sick"	HPV control cannot be exclusive to females (PAP -- cervical)
HPV self-swab testing (unpack from PAP smear)	
Parent perception/fear	
Campaign to encourage providers to start the discussion earlier -- allows parents to make informed decisions	Include HPV info with letter detailing sixth grade health requirements -- provide education for school nurses to distribute
School-age school-based (early middle school) campaigns -- incorporate with sex ed/puberty education	Establish protocol for EHR prompts to require HPV communication during patient visits (support/mandate from AAP)
Pediatricians buy in	T.V., targeted social media, billboards, pediatrician's offices/exam rooms
Effective advertising campaigns	

Create a parent ambassador program to champion HPV vax to talk to other parents (PTA meetings, libraries, churches, etc.) and partner with survivor groups (i.e., Cervivor, Spunk, etc.)	Champions -- survivors a group to support cause (i.e., parents, Drs, clergy, teachers, politicians, community leaders) (2)
HPV vaccines include adults up to age 45 -- guidelines were changed last year	Social media -- create an app for easy access information /education
Social media misinformation	
Engage teen/tween champions -- "help us create our next campaign" -- media campaign -- hashtags	Create short fact-based messaging "fact: HPV vaccine prevents cancer" (iceberg graphic)
Focus messages on cancer prevention vs. STI focus	
Youth – fear of shot/pain/lack of info	
"Cancer is more painful than a shot"	Curriculum comp. sexual health education -- Chicago has it; state has partial
Turn vaccine into an inhalable? (no fear of needles)	Youth HPV brigade shields and swords
Foster kids 12yr -- self-consent DCFS	"Talk to your parents"
IL adoption advisory/council	Statewide foster care advisory council
Lack of standardized internal procedures and clinical processes (including follow up)	
Develop standard process/policy for follow up	Insurance driven
Schedule follow up at first appt	UDS measure applies to FQHC
Flexible injection clinic hours	Standing order for second dose
Encourage use of online portal for medical records	MA order
More studies to recommend younger or single shot	Pre visit planning
Promote school-based immunizations for third series	Outreach reminder system
Make HPV vaccine a quality initiative/mandate	Refusal to vaccinate form for parents (2)
Have staff follow up and call pts. To reschedule canceled appts.	Each site can design their QI process or use existing process
Use all appts/visit types to proactively vaccinate or schedule appts.	Have "nurse champions" follow up with hesitant families to schedule appt educate staff
Provider education and bias/hesitation	
Use existing materials in novel ways	Survivor/caregiver testimony
Podcasts through professional organizations	Have a staff expert on counseling related to HPV vax
Lunch and CEs/MOC	Survivor/caregiver testimony
Surgical peer education (gyn/onc or oropharyngeal surgeons)	Encourage peds. To get certified as an adolescent-friendly practice
Encourage vax age 9	
Lack of standardized consenting procedures	
Digital/online consent processes	Careful balance – concern - regain trust
Varies widely 12+ vs. adult parents	Ok for mobile units/certain settings
Awareness of consent process	Bundle vaccines
Stigma	
Establish church-based/faith-based HPV vax promotion initiatives	Reframe language on HPV, stressing its commonality/frequency (it is a viral mediated cancer, not just an STD)
Mandated comprehensive sexual education in schools	
Cultural and gendered norms (gender/age inequality and religious beliefs)	
Find effective mechanisms to reach those populations	Consider look and feel, language, health literacy that best reflects audience
Who are the messengers (for ex, people of that community and people that have changed their minds)	Intentional inclusion of specific population engagement (i.e., partnerships/co-planners) into funding streams
Actively and thoughtfully engage focus population in outreach/education planning efforts	Consider shared language, providers that "look alike", shared culture, of community
Lack of provider incentives	HEDIS measure exists

Make it easy to know rates within clinic or practice	Work with HRSA to develop UDS
Leverage provider competitive spirit to spur behavior (unblinded physician rates)	Individual recognition for provider or champions (i.e., certificates, awards, money, recognition with peers)
Find champions/supporters within those communities	
Communication/trust	
Acknowledge history (as well as current events)	Find allies to be champions and voice around critical issues
Give language to providers around acknowledgements	Use/showcase data in plain language to show safety
Expanding target clinicians	
More venues for cross specialty education and training	PCP, IM, OB, Urgent Care, Dental, Oncology, Pharmacists (3)
Not a system priority/policy	
Work with ACS on QI projects	"we're in 2020" HPV RT pledge
HPV RT IDS influencer toolkit	
Not a clinician priority, burnout, effective messaging	
CME offerings	Sharing data, evidence-based practice
Coordinated messaging from reception (front line staff) through to providers	Engage entire clinical team to help reduce burnout (provider) (2)
Create pro-immunization clinic with posters and educated staff (reduce burden on provider to be sole champion)	Find physician champion
	HPV vacs an incentivized measure
	Include dental profession, pharmacists
	Optimize EHR
EHRs/Registries	
Integration and interoperability amongst all electronic health systems	Draft best practice tips for EHR optimization (i.e., pulling reports and turning on BPA)
Integration EHRs and I-CARE	Payer reporting of vaccines
Lack of teen well visits/delaying vaccine	
Make the "business case" for creating adolescent-friendly practices = better HEDIS measures = higher reimbursements	Slogan: "The future me is cancer free!"
	Media campaign -- community challenge
Lack of/outdated sexual health curriculum	
Widely distributing up to date small media (posters, flyers, etc.)	Coalitions that promote positive sexual health to educate school boards to change policy
Parent champions or advocates to change school policy	Find/research culturally competent sex health curriculum that is approved and up to date elsewhere
Use nontraditional and new venues to educate children, such as social media, Boys and Girls Club and other community and youth serving groups	
Lack of funding to support this work	
Accurate data to show impact	Collaboration between like-minded organizations
Find protentional funders - foundations, grants, pharma	Look for opportunities (conferences, health fairs) to share messaging
Build a business case - data, cost savings, stories	Uniform, coordinated message

Workshop Evaluation

To evaluate the effectiveness of these workshops, a Workshop Effectiveness Survey was distributed at the end of each workshop for participant's feedback. Using a range of 1 to 5, with five being "to a great extent," 97 participants were asked to score the workshop across seven areas: Workshop Objectives, Communication, Commitment to the Group, Participation, Effectiveness, Value, and Satisfaction.

Workshop Evaluation Scores (n=97)

Theme	Question	Average
Workshop Objectives	To what extent were the goals clear for this workshop?	4.67
Communication	To what extent was the discussion open, with sharing of diverse ideas and perspectives?	4.81
Commitment to the Group	To what extent was I committed to helping to achieve the group's goals for this workshop?	4.79
Participation	To what extent did I say or contribute what I thought was important to achieving our goals for this workshop?	4.72
Effectiveness	Overall, how effective was the group in meeting its goals during this workshop?	4.76
Value	How valuable was this workshop for success of creating a plan for Illinois?	4.65
Satisfaction	Overall, how satisfied were you with today's workshop?	4.72

Feedback from the participants revealed a few themes across all workshops. Several participants noted that they enjoyed the opportunity to collaborate between participants to develop barriers, facilitators, and strategies. Similarly, many participants said that the workshop was engaging, and they enjoyed that the workshops were interactive. The feedback also showed that many participants were looking forward to the next steps for this initiative. Some participants noted that the diversity of stakeholders present at the workshop served as an asset for discussion and brainstorming.

The area rated highest among participants was communication, defined by having open discussions, sharing of diverse ideas and perspectives. In future workshops, participants would like to remain in contact to hear the next steps in the process to eliminate HPV-related cancers and learn more about how to contribute to the goals of this action plan.

Key Informant Findings

The American Cancer Society (ACS) surveyed and interviewed 261 adults (93 Parents, 83 Vaccinators, and 85 Subject Matter Experts from the six public health regions outside the Bellwood region) between September 2020 and April 2021 who were either (1) parents with children under the age of 18, (2) subject matter experts, or (3) vaccinators. Respondents were drawn from Illinois' public health regions--specifically, at least four subject matter experts, six parents, and nine vaccinators from six of Illinois' seven public health regions, as delineated by the Illinois Department of Public Health. Because the City of Chicago already has high immunization rates, this project focused on the six regions outside of the Bellwood public health region.

Questions were based on those developed by The Strategic Advisory Group of Experts on Immunization (SAGE) Working Group on Vaccine Hesitancy,[57] which was charged with advising WHO on overall global

policies and strategies, ranging from vaccines and technology, research, and development, to delivery of immunization and its linkages with other health interventions. More questions were developed with the expert guidance of Dr. Manorama Mocherla Khare and Janae Danelle Lane Price at the University of Illinois.

Parent respondents (n=93) were found through ACS staff members, volunteer leadership teams, parent groups, and a targeted Facebook ad campaign, which ran in February 2021. Most parents were recruited through personal and professional networks where a personal invitation could be extended, and the purpose of the interviews and surveys could be discussed in person.

To recruit Subject Matter Experts and Vaccinators, the ACS Cancer Control staff in Illinois contacted their healthcare partners directly and engaged state health associations, local health departments, academics, and clinicians from federally qualified health centers and hospital systems to help recruit additional participants. By April 1, 2021, key informant interviews and surveys were completed with 85 Subject Matter Experts and 83 Vaccinators.

Six focus-groups met in April 2021 to explore common themes and differences. After analyzing survey and interview data, common themes and differences emerged.

Vaccinators and parents reported that reputable organizations should share social media resources. Several vaccinators reporting value in having trusted sources, such as the CDC and the World Health Organization, use social media to issue information about the safety and efficacy of recommended vaccines. Parents reported that reputable sources such as the American Cancer Society, American Academy of Pediatrics, FDA, and CDC should also share information on social media. One provider described how, during the pandemic, people were using social media frames and badges to announce their vaccine status.

Respondents did not shy away from difficult challenges around social media. One rural Vaccinator reported that one of their patients, who had a reaction to the HPV vaccine, had shared their experience throughout the

Table 1: **Communication and Media Environment**

	Parents (n=89)		**Vaccinators** (n=80)		**SMEs** (n=78)	
	#	%	#	%	#	%
Do you share information related to vaccination within your social media network?						
Yes	22	25%	46	58%	32	41%
No	65	73%	34	43%	46	59%
No reponse	2	2%	0	---	0	---
Who do you trust the most for information on immunizations?						
Your healthcare provider	59	66%	28	35%	36	46%
Scientific publications	24	27%	44	55%	38	49%
Other	3	3%	7	9%	1	1%
No reponse	3	3%	1	1%	3	4%
Who do you trust the least for information on immunizations?						
Your healthcare provider	3	3%	3	4%	2	3%
Social media	82	92%	67	84%	63	79%
Family/Friends	1	1%	10	13%	7	9%
Other	1	1%	0	---	3	4%
Scientific publications	0	---	0	---	3	4%
No reponse	2	2%	0	---	0	---

community and through social media. The effect was so amplified in their small community that it was still a struggle for the provider, even years later, to get parents to vaccinate their children. One parent reported that anti-vaccination websites look credible and authoritative, which can mislead some into believing the content. All respondents reported that social media platforms do not do enough to prevent false and conspiratorial statements from being made about vaccines, inadvertently promoting vaccine misinformation. Respondents did recognize that Facebook and other platforms were taking steps to implement new policies and systems to flag and remove false health and vaccine information. And while these changes are broadly welcomed, one vaccinator was concerned that Facebook's policy "would be seen as censorship." One SME questioned how well the new policy was working because, "Facebook was uniformly flagging vaccine information whether it's good or bad."

Table 2: **Historical Influences**

	Parents (n=89)		**Vaccinators** (n=80)		**SMEs** (n=78)	
	#	%	#	%	#	%
Can you name an event in the past that diminished your trust in vaccination?						
Yes	13	15%	3	4%	4	5%
No	74	83%	77	96%	74	95%
No reponse	2	2%	0	---	0	---
Do leaders (religious, political, teachers, healthcare workers) in your community (where you live, work, and worship) support vaccines for infants and children?						
Yes	86	97%	76	95%	77	99%
No	1	1%	1	1%	1	1%
No reponse	2	2%	3	4%	0	---

Vaccinators and SMEs agreed there is not always enough time during appointments to address the concerns of parents and patients who are hesitant about vaccination or vaccines and that parents can be overwhelmed during medical appointments, so "it would be ideal to send vaccine information, questionnaires, etc. before the appointment so that parents can come prepared with questions/paperwork with them."

Table 3: **Knowledge, Awareness & Beliefs**

	Parents (n=89)		Vaccinators (n=80)		SMEs (n=78)	
	#	%	#	%	#	%
Do you feel you get enough information about vaccines and their safety?						
Yes	73	82%	76	95%	65	83%
No	15	17%	4	5%	13	17%
No response	1	1%	0	0%	0	0%
Do you consider that some vaccines are more important than others?						
Yes	34	38%	22	28%	31	40%
No	55	62%	58	73%	47	60%
No response	0	0%	0	0%	0	0%
It is better for my child/children to develop immunity by getting sick than to get a sh						
Agree - 1	7	8%	1	1%	2	3%
2	8	9%	2	3%	3	4%
3	14	16%	8	10%	10	13%
4	14	16%	9	11%	8	10%
Disagree - 5	44	49%	57	71%	54	68%
No reponse	2	2%	3	4%	1	1%
I think it is important to get a vaccine to protect those that cannot get vaccinated.						
Agree - 1	62	70%	74	83%	64	72%
2	5	6%	3	3%	5	6%
3	12	13%	1	1%	2	2%
4	2	2%	1	1%	0	0%
Disagree - 5	6	7%	1	1%	7	8%
No reponse	2	2%	0	---	0	---

To make the most of the appointment time, vaccinators and SMEs agreed it was valuable for providers and their practices to have communications systems in place to supply information about vaccines ahead of their appointments, so parents and patients are more prepared. "Parents want information sent before their child's appointment so they can read it through and come prepared with questions."

Respondents agreed that communications are most effective when they are simple and easy to understand, tailored to match a parent or patient's preferred communication method, when they are sent ahead of the appointment, and when there are reinforced by messaging that's visible throughout the community, professional associations such as the Illinois Chapter of the Academy of Pediatrics, the American Academy of Family Physicians, from community organizations such as EverThrive, or parent-led organizations such as Boost Oregon.

SMEs and vaccinators added that visual aids can help make the decision to vaccinate easier. One vaccinator reported that they had a poster in their office that highlighted one fact about flu vaccinations and that because it was such a compelling and easy to understand fact, it helped increase rates. For example, "More than 2,000 people died in Illinois last year because of the flu. Get the flu shot and protect your child today."

One SME suggested that Vaccinators could offer educational community events, or virtual coffee hours, time outside of the office to have discussions and really listen," to further develop relationships with parents and patients, answer questions, and share resources such as "Don't Wait to Vaccinate" in different languages and at a reading level that made it easy to quickly comprehend the message.

Another common observation across all respondents was that making a distinction between recommended vaccines and vaccines needed for school may inadvertently invite parents to think differently about the

different vaccines. The State of Illinois Certificate of Child Health Examination form, for example, separates recommended vaccines into two groups: those that are required to enter school and those are not required but are nonetheless recommended. Respondents thought schools and the state immunization information system could find who complied with school entry requirements. By simply listing all recommended vaccinations on the Child Health Examination form, respondents thought it could help shift parent's feelings and increase uptake of all recommended vaccinations.

One Subject Matter Expert (SME) noted that the Certificate of Religious Exemption Form is listed on the Illinois Department of Public Health's website before the Child Health Examination Form. This seemed peculiar to this SME since every child entering public school must submit a completed and signed Examination Form and virtually no religion prohibits vaccination. "This is essentially a personal belief exemption" and "we don't need to shine a spotlight on how to refuse recommended vaccinations."

SMEs reported that providers serving diverse populations need to be culturally aware and understand why some groups distrust doctors and medicine and why other groups fear being reported and deported. One SME said that even without the luxury of time, providers need to convey that their only interest is in the health and safety of the patient.

In community clinics and FQHCs, it may be particularly valuable to implement strategies that quickly and convincingly communicate that a patient is safe seeking care and that their personal information is private. This communication can be done with trusted community partners. For example, for patients who are worried that their immigration status may disqualify them from care or result in their being reported to U.S. Immigration and Customs Enforcement, it could be reassuring to provide those patients with literature in their first language and have it co-branded with a recognized and trusted community partner, such as Illinois Coalition for Immigrant and Refugee Rights.

Table 4: **Information Confidence**

	Parents (n=89)		Vaccinators (n=80)		SMEs (n=78)	
	#	%	#	%	#	%
I trust the information I receive about shots.						
Agree - 1	43	48%	58	73%	45	58%
2	21	24%	15	19%	19	24%
3	19	21%	3	4%	8	10%
4	1	1%	0	---	5	6%
Disagree - 5	3	3%	0	---	1	1%
No reponse	2	2%	4	5%	0	---

A common theme all respondents providers, parents, and subject matter experts (SME's) was trust and influence. Seventy-three percent of Vaccinators trusted the information they receive about vaccination, compared to SMEs (58 percent) and Parents (48 percent).

Parents and SMEs alike reported that they are more likely to vaccinate when they trust their provider and their provider makes a confident, consistent recommendation. Parents wanted to know if providers vaccinated their own children and when affirmed, that information was positively influential. However, parents also expressed some skepticism, wondering if their physician might be compensated by pharmaceutical companies to recommend vaccines.

Vaccinators suggested that medical schools and continuing medical education offerings focus on training health care workers early in their career, even before they are licensed to practice, to prepare them to

respond to parents who are hesitant or who object to vaccination. One parent reported that her child, who was being seen by a general practitioner, was not getting the same kind of attention that children get when they see pediatricians, suggesting an opportunity to also offer continuing medical education opportunities to family medicine and internal medicine providers.

Vaccinators and SMEs both reported that providers who see new or expecting parents have a unique opportunity to establish themselves as a trusted authority by supplying reliable information about vaccination before their babies are born or before they enter school can equip parents to make well-informed decisions later. One Vaccinator reported that they routinely affirm a parent's decision to vaccinate while simultaneously telling the parent what they were protecting their child from: "You're such a great Mom for vaccinating Charlie against the chickenpox."

All respondents reported that it was important to build an open dialogue, to educate, and to address and not dismiss or minimize parent and patient concerns. Several types of strategies were common across all respondents. Both SME's and Parents reported that "physicians should implement shared decision-making or motivational interviewing" and that it was important for a physician to ask if a parent or patient had any questions or concerns. Parents reported that they want "physicians to listen to their concerns and be able to address them."

SMEs noted that the shift from acute care to primary and secondary prevention is possible, in part, because of the effectiveness of prevention strategies. Vaccinators agreed and reported that conversations around prevention meant helping parents and patients understand the science and evaluate risks and benefits of vaccination.

Another theme that emerged was how positive environments and experiences with a provider can help ease anxiety and hesitation around vaccines. The idea of a "vaccine-friendly" office meant more than positive, encouraging posters and literature; it included trained nurses, medical assistants, and other allied health and office staff who could confidently reinforce the provider recommendation with clear and consistent

Table 5: **Risk and Benefit Perceptions**

	Parents (n=89)		Vaccinators (n=80)		SMEs (n=78)	
	#	%	#	%	#	%
How concerned are you that your/a child might have a serious side effect from a shot?						
Unconcerned - 1	18	20%	28	35%	30	38%
2	27	30%	28	35%	20	25%
3	23	26%	13	16%	12	15%
4	11	12%	5	6%	8	10%
Concerned - 5	8	9%	3	4%	6	8%
No reponse	2	2%	3	4%	2	3%
How concerned are you that any one of the childhood shots might not be safe?						
Unconcerned - 1	32	36%	52	65%	42	53%
2	23	26%	14	18%	16	20%
3	14	16%	4	5%	7	9%
4	11	12%	4	5%	7	9%
Concerned - 5	7	8%	2	3%	4	5%
No reponse	2	2%	4	5%	2	3%
How concerned are you that a shot might not prevent the disease?						
Unconcerned - 1	33	37%	32	40%	30	38%
2	20	22%	26	33%	23	29%
3	13	15%	10	13%	11	14%
4	15	17%	6	8%	8	10%
Concerned - 5	5	6%	3	4%	5	6%
No reponse	3	3%	3	4%	1	1%
I believe that many of the illnesses that shots prevent are severe.						
Agree - 1	58	65%	63	79%	57	71%
2	12	13%	12	15%	10	13%
3	10	11%	1	1%	6	8%
4	2	2%	0	---	3	4%
Disagree - 5	5	6%	0	---	2	3%
No reponse	2	2%	4	5%	0	---

messaging as they scheduled patients, made appointment reminder calls ahead of a visit, greeted patients when they arrived for an appointment, etc.

Providers also reported that it is valuable to use all visits (including sick visits and telehealth visits) to prepare parents and patients for upcoming vaccinations. One vaccinator gives all new parents a magnet with the entire childhood immunizations schedule on it so they can see what to expect during future visits. Vaccinators said that having a "vaccine-friendly" office also meant being empathetic to parents concerns while simultaneously supplying the information parents need to feel more confident about adhering to the vaccination schedule.

One parent reported that consistent, even repetitive messaging is needed; providers should repeat their recommendation over multiple appointments to emphasize their endorsement and help busy parents remember which vaccinations are coming due when. One parent offered an example from personal experience; she said she did not vaccinate her daughter against HPV because her physician brought it up once and never again, so she did not think it was that important.

A third of parents (35 percent) reported that they knew of someone who had a bad reaction to vaccination, however, follow up questions revealed that "bad" meant emotional upset, a sore arm/injection site, and syncope. SMEs reported that parents get nervous about vaccine appointments because they are sensitive to the fact that their baby/child will become upset or cry.

Vaccinators also reported that they thought parents did not like multiple vaccines during the same visit because of concerns about causing extra pain and anxiety and wanted some control in timing the injections. Fifteen percent of Vaccinators reported knowing of children who had developed serious disease or disability because they were not vaccinated compared to only 3 percent of Parents.

Table 6: **Side Effects**

	Parents (n=89)		Vaccinators (n=80)		SMEs (n=78)	
	#	%	#	%	#	%
Do you know of anyone who has had a bad reaction to a shot?						
Yes	31	35%	20	25%	29	37%
No	58	65%	60	75%	49	63%
No reponse	0	---	0	---	0	---
Do you know of a child with a serious disease/disability because they were not vaccinated?						
Yes	3	3%	12	15%	7	9%
No	85	96%	68	85%	71	91%
No reponse	1	1%	0	---	0	---

SMEs reported that "a physician and their staff can help parents follow the recommended schedule by sharing the science but also by coaching them on strategies they can use to help soothe their baby and help their older children understand that, yes, the needle prick stings for a moment, but it's worth it because it brings years, if not a lifetime, of protection from diseases that hurt a lot more.

One Vaccinator added that direct communications with adolescents was important. In Illinois, adolescents 12 years of age and older can self-consent to HPV vaccination and other preventive services so providers have a responsibility to let them know what is going to happen during their visit, what cancers they are protecting themselves against by getting vaccinated, and what to expect at future appointments. Other respondents agreed and added that shifting the conversation to speak directly talking with adolescents was an effective strategy to help them learn how to make good healthcare decisions for themselves as they transitioned into adulthood.

Data Management

Table 7: **Performance Improvement**

	Vaccinators (n=80)	
	#	%
Does your practice routinely measure vaccination rates for the practice overall?		
Yes	49	61%
No	22	28%
No reponse	9	11%
Does your practice or health system use its reported vaccination rates to help drive quality improvement?		
Yes	53	66%
No	20	25%
No reponse	7	9%
Does your practice or health system provide vaccination rate reports to individual providers to help them see where they can improve their performance?		
Yes	24	30%
No	48	60%
No reponse	8	10%

Vaccinators were asked if their practices measured and reported their vaccination rates and if the information was used to drive quality improvement. Two-thirds of Vaccinators reported that their practices used vaccination data to drive quality improvement, however, Vaccinators also reported that about one quarter of their practices did not routinely measure and report practice-level vaccination rates (28 percent) or use data to drive quality improvement (25 percent). Most vaccinators (60 percent) reported that their practice does report vaccination rates at the provider-level.

The issue of access to vaccination records surfaced among all respondents. 72 percent of Parents reported being able to look up their child's vaccination records on the providers portal, such as MyChart, but SMEs noted that accessing one's own vaccination records through a provider portal is only one piece of a larger set of solutions and that there are still "barriers to accessing immunization and medicals

records," including system quality, language, literacy, access to a computer, and the ability of systems to consolidate records across multiple providers and geographies.

Vaccinators expressed some concern about the fidelity and reliability of data migrating from EHRs to the state's Immunization Information System (IIS) or registry. One Vaccinator mentioned "using paper immunization booklets to track vaccines" as a means of back up; and another reported that "some EHR's are antiquated and might not be able to transfer data back and forth to the state immunization registry."

Table 8a: **Systems Improvement -- Parents**

	Parents (n=89)	
	#	%
What would make it easier to access your child's immunization records?		
Access records on line	64	72%
Obtain copy during visit	9	10%
Call provider office when record is needed	9	10%
Not applicable	1	1%
No response	6	7%

Table 8b: **Systems Improvement -- SMEs**

	SMEs (n=78)	
	#	%
What would make it easier to access and use immunization data?		
Centralized Database	61	39%
Mandatory Reporting	50	32%
Vaccine reports by state / county / system / provider	42	27%
Other	2	1%
No response	5	3%
If you were in charge of designing a new IIS, what features/functions would be important to you?		
Data by age	49	63%
Data by vaccine type	54	69%
Data by county	47	60%
Trend data	40	51%
Easy access to my and my child's records	60	77%
Other	5	6%

Providers reported that it is not easy to access immunization and medical records from other states or other immunization information systems. One provider mentioned "there may be an opportunity to create policy around a national registry." As appealing as a national registry was to many respondents, Vaccinators agreed that the first step was to update Illinois' IIS and build in the functions needed to support the features needed to support providers, parents, patients, schools, and other stakeholders.

The topic of EHRs led to discussions about I-CARE, the state's Immunization Information System (IIS), with vaccinators and SMEs, who found policy and practice changes needed at both the state and national level.

Respondents reported that Illinois' IIS (I-CARE) could be improved to fulfill more functions than it does currently. According to IDPH, "I-CARE is designed to help healthcare provider's record, track, and report their patients' immunizations. The registry allows physicians to access patient records for information about immunizations administered outside their practices. Provider participation is voluntary and not all providers within the state choose to take part in the registry. Patient participation is also voluntary. Patients wishing not to have their information included in the registry may opt-out at their provider."

Vaccinators and SMEs reported that I-CARE is not as accessible or full-featured as IISs in other states. Because participation in I-CARE is voluntary (except for those administering federally funded vaccines through the Vaccines for Children program), Vaccinators and SMEs thought that I-CARE effected a sampling system, rather than an enumeration of all administered vaccinations.

In other states, patients, parents, and others can access their records directly from the IIS. For example, in Indiana, with a few clicks, patients and parents can register as an IIS user and access their records online and print a state-certified copy immunization records for work, school, sports, summer camps and other instances where a third-party verified vaccination record is needed.

In Illinois, a parent must complete this form, send it to IDPH via fax or email, and wait for a reply, which may take as long as 60 days, which is how long the request authorization is valid.

All respondents agreed it is important to promote all recommended vaccines, not just those needed for school. When a provider promotes some vaccines differently than others, it gives parents a reason to think that some vaccinations are more important than others, inadvertently creating a foothold for resistance and uncertainty.

Several Vaccinators and SMEs reported that the Illinois' Child Health Examination form may be inadvertently contributing to the drop off in rates for recommended adolescent vaccinations. The form has one section for school-required vaccinations and another for recommended vaccinations. This may inadvertently invite Parents to think school-required vaccines are more important than other recommended vaccines. One SME asked, "Why don't we change the form, so we focus on what's recommended? Schools can focus on their entry requirements."

Some respondents noted that the state could authorize access to IIS data for public health researchers, Medicaid quality review purposes (e.g., Health Services Advisory Group, currently the state's External Quality Review Organization), and to evaluate provider and payor performance (e.g., annual HEDIS reporting). A full-featured IIS can also enable providers and insurers to benchmark their performance against county and state averages.

Because laws that govern who can access state IIS data and how that data can be used are developed at the state-level, respondents agree it should be a priority of the state to improve the functionality and data quality of Illinois' IIS and reduce costs for providers, patients, and payors.

Key Informant Recommendations

Tell Evidence-Rich Stories

There is a sales adage that says, "Facts tell; stories sell." Vaccinators agreed that by supplying real-life stories, parents will understand what happens to patients that were not vaccinated. Similarly, all respondents said that in addition to explaining what diseases are prevented by which vaccines, they can fill out the picture with other "consequences for not vaccinating, such as missed school days, work, medical bills."

Vaccinators and Parents agreed with providers and said that "story telling was important to persuading parents to vaccinate their children" because storytelling could convey the science in a warmer, more relatable way.

Both Vaccinators and Parents said they wanted providers to use data and success stories, such as how Australia is on track to eradicate cervical cancer, to help frame vaccination in terms of both the individual and one's larger groups (e.g. family, community, county, state).

There was also broad agreement among all respondents that it was important to affirming that all recommended vaccines are safe to parent and patient confidence.

All respondents agreed it was important for Vaccinators to be prepared to respond to specific concerns, such as what the Vaccine Adverse Event Reporting System (VAERS) is, its purpose, and why anyone, including parents, can submit voluntary, spontaneous reports of adverse events observed after the administration of licensed vaccines. For Vaccinators who reported that parents were sometimes skeptical about the influence of pharmaceutical companies on the recommendations of providers, one Subject Matter Expert suggested

pointing parents to the Open Payments Search Tool where they can see for themselves what, if any, payments pharmaceutical companies have made to their provider.

Build Trust and Influence

- Parents agreed with Vaccinators and SMEs: It was important that providers use evidence-based strategies to increase awareness and readiness. Deliver culturally competent messaging in partnership with recognized and trusted community partners, churches, and social service allies.
- Amplify evidence-based messaging on social media, partner with reputable, accredited sources. Consider developing frames and badges to use on social media to promote the science of vaccines and vaccination.

Table 9a: **Records -- Parents**

	Parents (n=89)	
	#	%
Does your child's doctor routinely give you a copy of your child's immunization record?		
Yes	69	78%
No	18	20%
No reponse	2	2%
Are you charged a fee for a copy of your child's immunization records?		
Yes	11	12%
No	76	85%
No reponse	2	2%
If you changed providers, how did your new provide aquire your immunization records?		
Previous Practice Sent	2	2%
In Network/ Accessible	2	2%
Provided copy of files	2	2%
Not applicable	50	56%
No response	33	37%
Are you able to access your child's immunization records online?		
Yes	37	42%
No	8	9%
I don't know	42	47%
No reponse	2	2%
Not applicable	0	---
Are additional copies of immunization records required for your child to participate in sports?		
Yes	56	63%
No	31	35%
No reponse	2	2%
Not applicable	0	---

Improve Access to Vaccination Data

- Require that all administered vaccinations be recorded into the state's IIS. "State immunization registries need to be robust but that can only be done with mandated reporting by all healthcare providers for all patients."
- Develop two-way exchange features for payers so they can use state IIS data for HEDIS reporting.
- Offer patients and parents, not just providers, the option of registering online to access immunization records for school, work, and travel.

A more robust IIS could allow parents access to their child's immunization records. "Parents would love to see another way to access their kids records especially a mobile app." Yet, "vaccinators are worried about duplicate records merging into a state immunization database. If parents did have access to a state database, they would want them to have view access only and not able to add or delete records."

Table 9b: **Records -- SMEs**

	SMEs (n=78)	
	#	%
Should doctors routinely give parents a copy of a child's immunization record?		
Yes	77	99%
No	0	---
No reponse	1	1%
Should doctors be able to charge a fee for providing a copy of immunization records?		
Yes	2	3%
No	75	96%
No reponse	1	1%

Table 10: **Scheduling & Administration of Vaccinations**

	Parents (n=89)		**Vaccinators** (n=80)		**SMEs** (n=78)	
	#	%	#	%	#	%
What is the first thing you want to know when a new vaccine is introduced or announced?						
Is it safe?	62	70%	41	51%	44	56%
Is it effective?	9	10%	28	35%	24	31%
What are the side effects?	5	6%	1	1%	3	4%
Is information truthful?	1	1%	0	---	0	---
Will my child need it?	4	4%	0	---	1	1%
All of the above	5	6%	6	8%	2	3%
No response	3	3%	4	5%	0	---
It is better for children to get fewer vaccines at the same time.						
Agree - 1	17	19%	6	8%	9	11%
2	15	17%	7	9%	6	8%
3	43	48%	17	21%	33	41%
4	6	7%	12	15%	7	9%
Disagree - 5	6	7%	33	41%	23	29%
No reponse	2	2%	5	6%	0	---

Appendix D: IDPH HPV Burden Reports (parts 1 and 2)

IDPH
Illinois Department of Public Health

HPV-Associated Cancers in Illinois

Part I

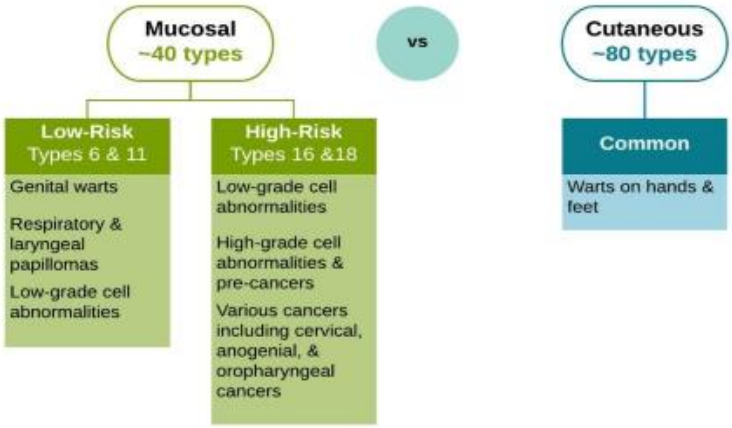
January 2021

What is Human Papillomavirus (HPV)?

Human papillomavirus (HPV) is a group of more than 200 related viruses that can enter the body through: the mucous membranes, such as the inner lining of the nose or mouth, the lining of the eyes, or the genitals; the digestive system, such as the lining of the stomach or intestines; and insect bites, needle sticks, other breaks in the skin, and unbroken skin. HPV infections are so common that nearly all men and women will get at least one type of HPV at some point in their lives.[1]

Mucosal types of HPV are commonly characterized by the type and location of infection and how likely it is for that infection to cause cancer or other cell abnormalities (Figure 1).[2] In most people, the body clears the infection on its own. But sometimes, the infection does not go away. Chronic or long-lasting HPV infections can cause pre-cancers and cancer.[2] HPV16 and HPV18 are the two subtypes that cause most HPV-associated (HPVa) cancers.[3]

Figure 1: Low- and High-Risk Mucosal and Cutaneous Types of HPV[3]



Cancer Burden Associated with HPV Infections

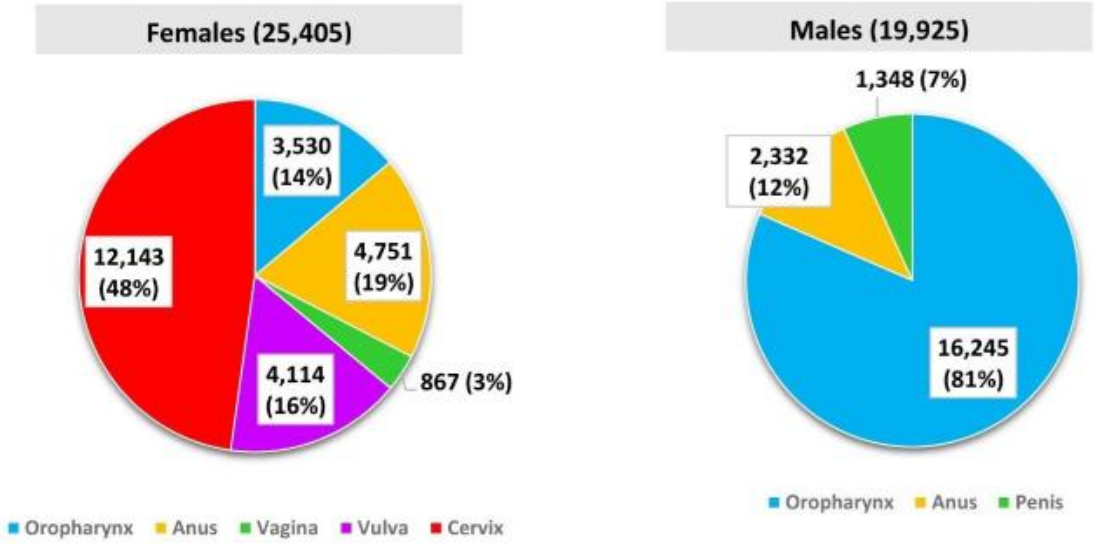
HPV has been determined to be a primary cause of six types of cancer: cervical, vulvar, and vaginal cancers in females; penile cancer in males; and oropharyngeal and anal cancers in both males and females. The term oropharyngeal cancer refers to cancers of the oropharynx (back of the throat, including the base of the tongue and tonsils)[4] and anal and rectal squamous cell carcinomas.

Evidence suggests that HPV is the cause of nearly all cervical and anal cancers, 75% of vaginal cancers, 72% of cancers of the mouth and throat (oropharyngeal), 70% of vulvar cancers, and 60% of penile cancers.[5]

Based on data from 2013 – 2017, about 43,300 new cases of HPVa cancers occurred in the United States each year, including 25,405 among females, and 19,925 among males.[6] In the U.S., almost half (48%) of HPVa cancers in women are cervical and in men more than 80% are from the oropharynx (mouth and throat) (Figure 2).

*An **HPV-associated cancer** is a specific cellular type of cancer that is diagnosed in a part of the body where HPV is often found. These parts of the body include the cervix, vagina, vulva, penis, anus, rectum, and oropharynx (back of the throat, including the base of the tongue and tonsils).[2]*

Figure 2: Number of New HPV-Associated Cancer Cases in the U.S. Per Year (2013 – 2017)



Nearly all cervical cancers (91%) are attributable to HPV16 and HPV18. Approximately 70% of oropharyngeal cancers are attributable to HPV and the other 30% are thought to be caused by behavioral risk factors like tobacco and alcohol.[7,8,9] Cancer registries do not routinely collect information about HPV status, so, in this report, HPVa cancers are defined as a specific cellular type of cancer that is diagnosed in a part of the body where HPV is often found. In Illinois, a total of 1,592 HPVa cancers, from sites where HPV is often found, were reported in 2017 (Table 1). Of these, around 80% (1,281) were attributable to (or probably caused by) HPV.

Table 1: Number of HPV-Associated and Estimated Number of HPV-Attributable Cancer Cases per Year, U.S. and Illinois (2017)

Site	Avg. # of cancers per year in sites where HPV is often found - U.S.*	% probably caused by any HPV type†	Observed Cases-Illinois‡	Estimated # probably caused by any HPV type – Illinois.&
	Number	***%***	***#***	***#***
Cervix	12,143	91%	**497**	**452**
Vulva	4,114	69%	**	**
Vagina	867	75%	**	**
Penis	1,348	63%	**47**	**30**
Oropharynx	19,775	70%	**770**	**539**
Male	16,245	72%	**653**	**470**
Female	3,530	63%	**117**	**74**
Anal	7,083	91%	**278**	**253**
Male	2,332	89%	**90**	**80**
Female	4,751	93%	**188**	**175**
Total	*43,330*	*79%*	**1,592**	**1,281**
Male	*19,925*	*74%*	**790**	**580**
Female	*25,405*	*83%*	**802**	**701**

*Centers for Disease Control and Prevention. How Many Cancers and Linked with HPV Each Year? https://www.cdc.gov/cancer/hpv/statistics/cases.htm. Accessed September 19, 2020

†HPV types detected in genotyping study; most were high-risk HPV types known to cause cancer (Saraiya M, et al. U.S. assessment of HPV types in cancers: implications for current and 9-valent HPV vaccines. *Journal of the National Cancer Institute* 2016;107:djv086.)

‡ Illinois State Cancer Registry (2017). http://www.idph.state.il.us/iscrstats/. Accessed November 2020.

& Estimated number of cancer cases in Illinois probably caused by HPV was calculated using the % of cases probably caused by HPV, multiplied by the observed number of cases reported. Estimates were rounded to the nearest 100 and might not sum to total because of rounding.

**Data has been suppressed due to confidentiality.

In 2017, females experienced a higher percentage of new HPVa cancer cases compared to males; 55% vs. 45% (Table 1). In Illinois, approximately 42% (544/1,281) of all cancer cases probably caused by HPV are of the mouth and throat (oropharynx). Cervical cancer is the most common HPVa cancer among women; 64% of all new cases among Illinois women were most likely caused by HPV. Cancer of the oropharynx (back of the throat, including the base of the tongue and tonsils) accounts for 81% of cancers probably caused by HPV in men.

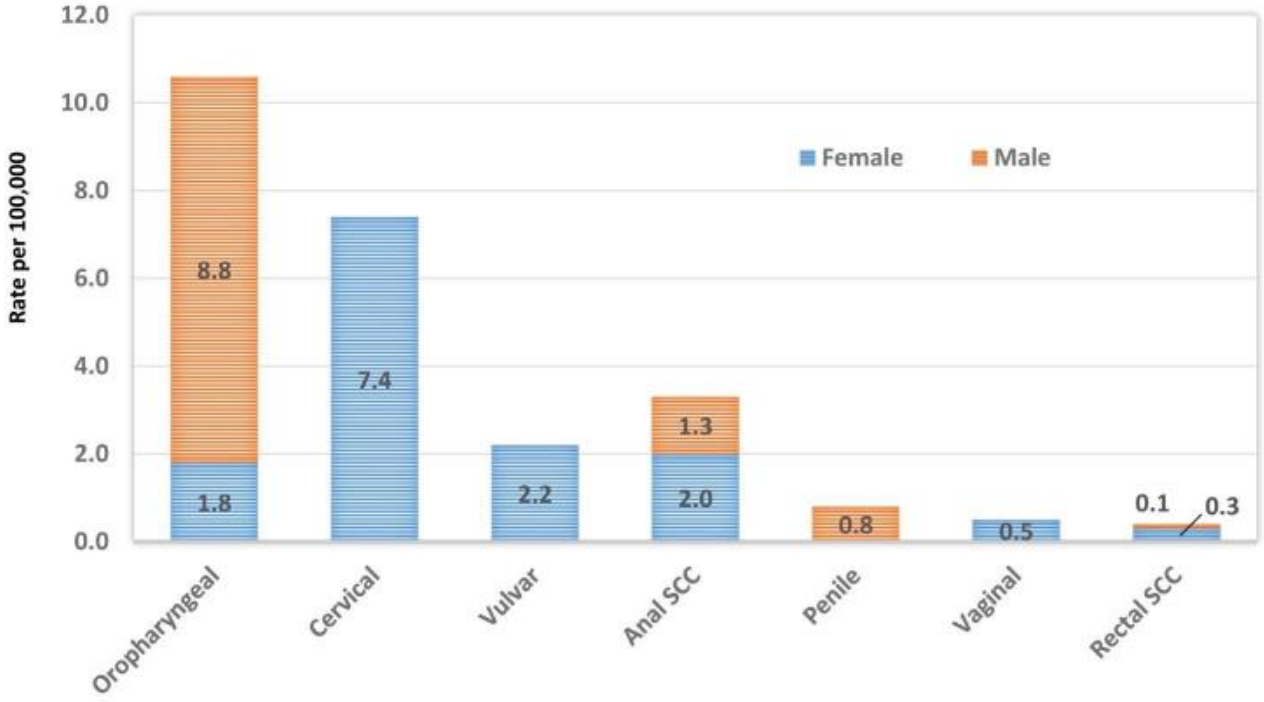
HPV-Associated Cancers Trends, by Sex (2013-2017)

Women are more likely than men to be diagnosed with HPVa cancers, as cervical cancer remains the most commonly diagnosed HPVa cancer. However, male HPV infection is also an important concern, both for the disease burden in men and for the risk of transmission to women. HPV is associated with a variety of cancers in men, including anal cancer and a subset of penile and oral

cancers. The incidence of anal and oral cancers related to HPV is increasing in the general population and is growing even faster among individuals who are immunocompromised due to HIV infection.[10] This trend is driven largely by increases in HPVa oropharyngeal cancer over the past three decades, particularly among men, even as incidence (new cancer) rates of other head and neck cancers and many other HPVa cancers are decreasing.[7]

For both males and females, incidence rates for HPVa cancers in Illinois reflect national trends. In Illinois, males are disproportionally impacted by cancers of the mouth and throat (oropharynx) as compared to females (Figure 3). Nationally, the incidence of oropharyngeal cancers among men (8.9 per 100,000) is greater than the incidence of cervical cancers among women (7.1 per 100,000).[9]

Figure 3: Age-Adjusted Rate of New HPV-Associated Cancers by Cancer Type, Female vs. Male, Illinois (2013 – 2017)



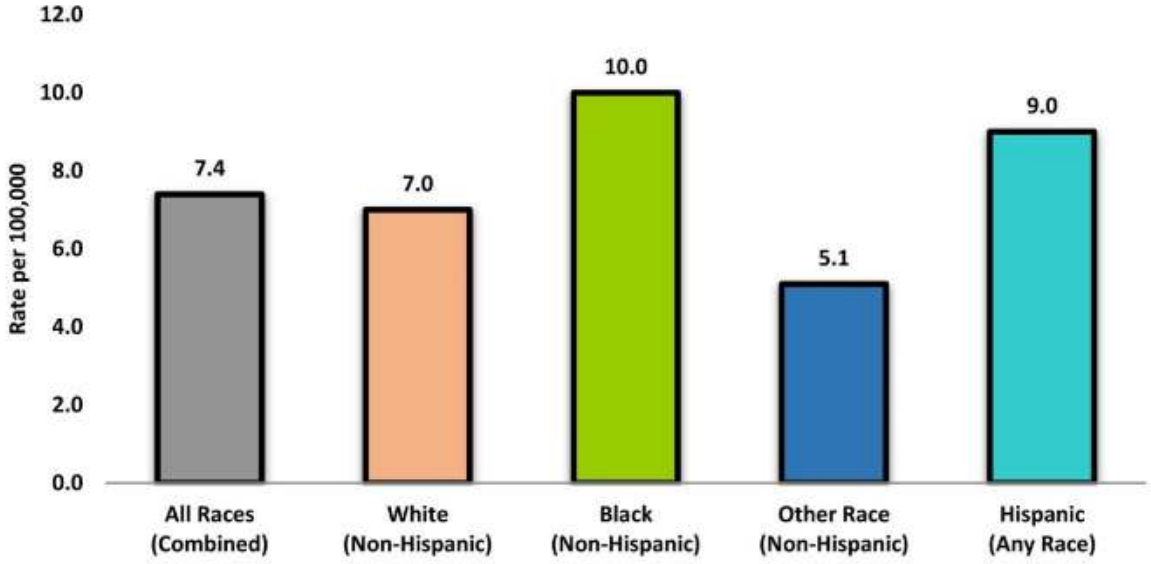
Data Source: Illinois State Cancer Registry (Accessed October 2020); rates are the number of cases per 100,000 people and are age-adjusted to the 2000 U.S. standard population.

Aside from cervical cancer screening, there are no recommended screening tests for the five other types of cancers linked to HPV, so these cancers may not be detected until they cause health problems.[11] Although the HPV vaccine was initially developed to prevent cervical cancers and other cancers of the reproductive system, the vaccine also protects against the HPV types that cause oropharyngeal cancers.[12] The rates of HPVa oropharyngeal cancers among men and cervical cancers among woman, highlight the importance of vaccinating both boys and girls.

HPV-Associated Cancers, by Race and Ethnicity

Incidence rates of HPVa cancers varies by race and ethnicity. In the U.S., Black and Hispanic women have significantly higher rates of HPVa cervical cancer when compared to non-Hispanic White women.[5] In Illinois, the highest cervical cancer incidence rates were among non-Hispanic Black women (10.0 per 100,000, [95% CI, 9.2-11.0]) and Hispanic women (9.0 per 100,000, [95% CI, 8.1-10.0]) and are significantly higher than all other race/ethnic groups (Figure 4).

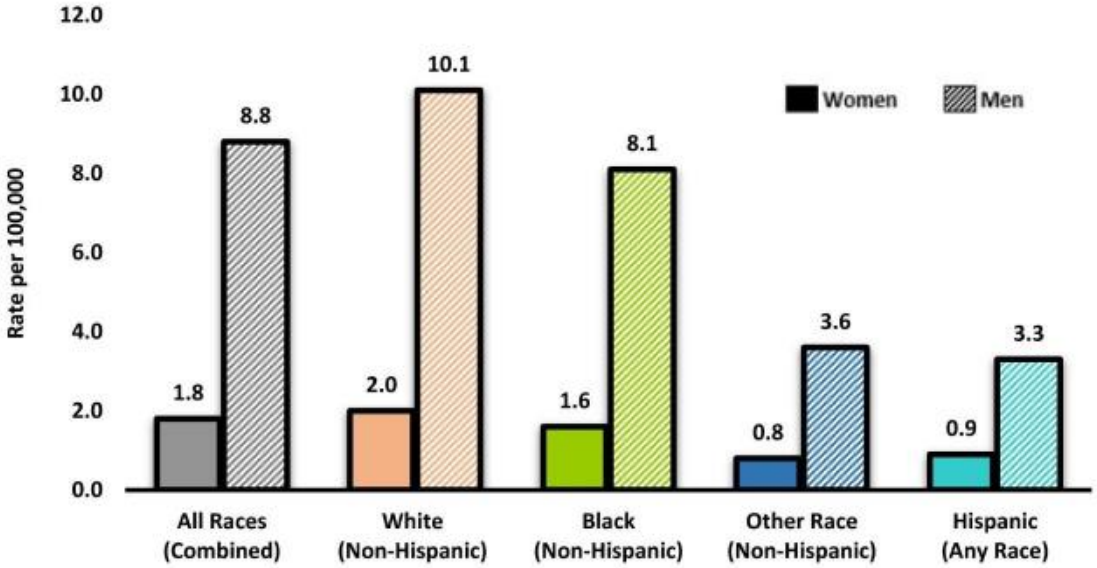
Figure 4. Rate of New HPV-Associated Cervical Cancers, by Race/Ethnicity, Illinois (2013-2017)



Data Source: Illinois State Cancer Registry (Accessed October 2020); rates are per 100,000 and age-adjusted to the 2000 US Std Population.
Other Race includes the race designations Asian/Pacific Islander and American Indian/Alaska Native.

For oropharyngeal cancer, the incidence rates were significantly greater among non-Hispanic White men (10.1 per 100,000, [95% CI, 9.7-10.5]) when compared to all other race/ethnic groups; non-Hispanic Black (8.1 per 100,000, [95% CI, 7.2-9.0]), non-Hispanic Other (3.3 per 100,000, [95% CI, 2.7-4.6]) and Hispanic (3.3 per 100,000, [95% CI, 2.7-4.1]). Among non-Hispanic White women, oropharyngeal cancer was significantly higher (2.0 per 100,000, [95% CI, 1.8-2.1]) when compared to Hispanic women (0.9 per 100,000, [95% CI, 0.6-1.3]) (Figure 5). Incidence rates for HPVa cancers were lowest among non-Hispanic (other race) populations for cervical cancer (5.1 per 100,000, [95% CI, 4.2-6.3]). Rates of new HPVa oropharyngeal cancer were lowest among non-Hispanic (other race) populations for females (0.8 per 100,000, [95% CI, 0.4-1.2]).

Figure 5. Rate of New HPV-Associated Oropharyngeal Cancers, by Sex, Race/Ethnicity, Illinois (2013-2017)



Data Source: Illinois State Cancer Registry (Accessed October 2020); rates are per 100,000 and age-adjusted to the 2000 US Std Population.
Other Race includes the race designations Asian/Pacific Islander and American Indian/Alaska Native.

HPV-Associated Cancers, Urban vs. Rural

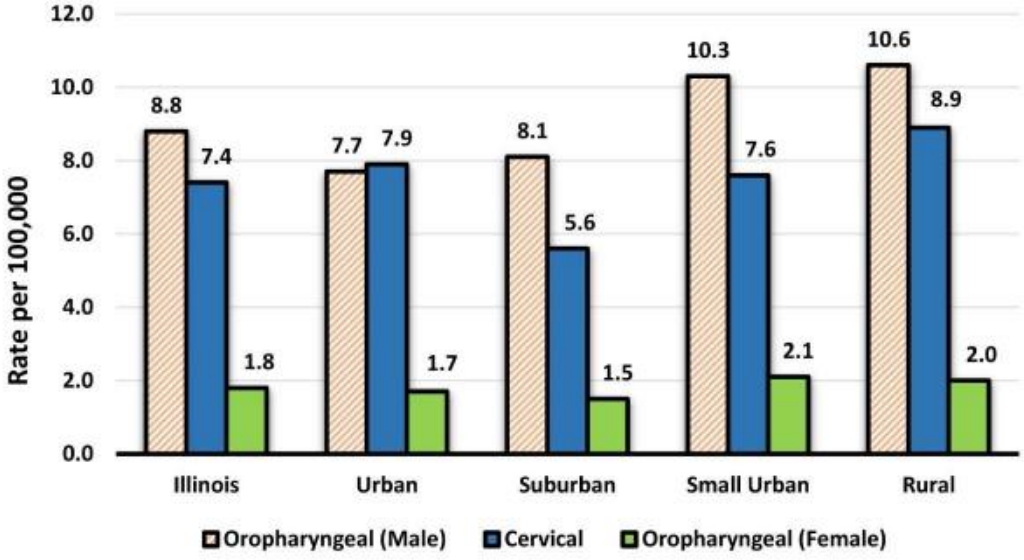
Rural populations in the U.S. and in Illinois experience consistent disparities around HPVa cancer-related disease prevention and management. Rural individuals are less likely to be aware of HPV. Among those who are aware of HPV, they are less likely to believe that HPV can cause cancer and that HPV can be transmitted through sexual contact.[13] Rural communities also experience limited access to health care and physician and mental health provider shortages that contribute to HPV health disparities. Other factors include aging populations; race/ethnicity distribution; higher rates of poor health risk behaviors, such as inadequate physical activity, unhealthy eating behaviors, smoking, and alcohol consumption, as well as lower education; and lack of safe and affordable housing. [14]

In Illinois, rural populations, when compared to populations in urban, suburban, and small urban areas*, experience some of the highest rates of HPVa cancers. Specifically, oropharyngeal cancers among males in rural Illinois (10.6 per 100,000, [95% CI, 9.9-11.4]) were significantly higher than populations in urban (7.7 per 100,000, [95% CI, 7.2-8.2]) and suburban (8.1 per 100,000, [95% CI, 7.5-8.7]) Illinois. In addition, cervical cancers were significantly higher among rural populations

Illinois State Cancer Registry county reference groups were established in 1993 and used for reference groups in investigative cancer studies. The groups are based upon population density, rate of growth, and Rural-Urban Continuum codes (https://www.ers.usda.gov/data-products/rural-urban-continuum-codes.aspx)

(8.9 per 100,000, [95% CI, 8.1-9.8]) than populations in suburban (5.6 per 100,000, [95% CI, 5.1-6.1]) Illinois (Figure 6). Populations living in small urban areas in Illinois experience the second highest rates of HPVa cancers for oropharyngeal cancer among males (10.3 per 100,000, [95% CI, 9.6-11.2]) and the third highest rates for cervical cancer (7.6 per 100,000, [95% CI, 6.9-8.4]). This data is consistent with recent studies indicating significant disparities for all HPVa cancers among rural U.S. populations compared to urban for both cancer incidence and mortality.[15]

Figure 6. Rate of New HPVa Oropharyngeal and Cervical Cancers, by Location, Illinois (2013-2017)



Data Source: Illinois State Cancer Registry (Accessed October 2020); rates are per 100,000 and age-adjusted to the 2000 US Std Population.

Conclusion

HPV is a common virus that can be spread from one person to another person through anal, vaginal, or oral sex, or through other close skin-to-skin touching during sexual activity. There is variation by cancer type, but the most common HPVa cancer is cervical cancer among women and oropharyngeal cancer among men. Non-Hispanic Black women had the highest rate of new cervical cancer cases when compared to other race/ethnic groups, while non-Hispanic White men had the highest rate of new oropharyngeal cancer. In addition, significant differences in new cancer rates for oropharyngeal and cervical cancer were observed for populations who live in rural areas, when compared to Illinois suburban areas.

Many public health strategies can be implemented to address HPVa cancers. One of the most effective evidence-based interventions is uptake of the HPV vaccine. Studies in the U.S. and other

countries have shown the HPV vaccination is preventing cancer-causing infections.[16] The highly effective 9-valent HPV vaccine, Gardasil 9, has been available for use in the United States since late 2016 and protects against nine types of HPV (types 6, 11, 16, 18, 31, 33, 45, 52 and 58).[22] The majority of HPVa cancers are caused by HPV 16 or 18. Today, Gardasil 9 is the only HPV vaccine available in the U.S. The HPV vaccine is an effective way to protect against HPV when administered at the recommended age of 11 or 12 years (or can start at age 9) for both girls and boys.

Although effective, use of the 9-valent HPV vaccine (Gardasil 9) will not eliminate the need for cancer screening in the U.S. or Illinois because not all HPV types that cause HPVa cancers are included in the vaccine. Another proven and long-standing public health measure is cervical cancer screening. Routine screening for women aged 21 to 65 years old is critical as early detection and treatment are key to positive health outcomes. Other evidence-based strategies include oral health cancer screenings as well as awareness and education strategies like those used for other sexually transmitted infections.

HPV infection remains the most common sexually transmitted infection in men and women in the United States and HPVa cancers remain a public health concern in the U.S. and Illinois. HPV infections can lead to poor health outcomes, especially for urban non-Hispanic Black women (cervical cancer) as well as rural non-Hispanic white men and women (oropharyngeal cancer). Illinois partners and stakeholder groups can work together to target disparate groups and reduce HPVa cancers.

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HPV-Associated Cancers in Illinois

Part II

June 2021

Background

The most common human papillomavirus associated (HPVa) cancers are cervical cancer among women and oropharyngeal cancer among men. In Illinois, non-Hispanic Black women have the highest rate of new cervical cancer cases among all racial/ethnic groups, while non-Hispanic White men have the highest rate of new oropharyngeal cancer cases. Further, rural populations in Illinois have significantly higher rates of oropharyngeal and cervical cancer, when compared to suburban and urban areas of Illinois. See *HPV-Associated Cancers in Illinois – Part I (December 2020)*.

One of the most effective evidence-based interventions to reduce the incidence of HPVa cancers is uptake of the HPV vaccine. Studies in the U.S. and globally have shown the HPV vaccination prevents cancer-causing infections, including the HPV types that cause most genital warts.[1,2] In fact, the HPV vaccination has the potential to prevent more than 90% of cancers caused by HPV.[3,4]

The highly effective 9-valent HPV vaccine, Gardasil® 9, has been available for use in the United States since late 2016 and protects against nine types of HPV (types 6, 11, 16, 18, 31, 33, 45, 52, and 58);[5] the majority of HPVa cancers are caused by HPV 16 or 18. Today, Gardasil® 9 is the only HPV vaccine available in the U.S. The HPV vaccine is an effective way to protect against HPV when administered at the recommended age of 11 or 12 years (or can start at age 9) for both girls and boys. In 2019, the Advisory Committee on Immunization Practices (ACIP) recommended the HPV vaccine for adults 27 – 45 years of age using a shared clinical decision-making strategy to determine if HPV vaccination for individuals within this age group is of benefit.[6]

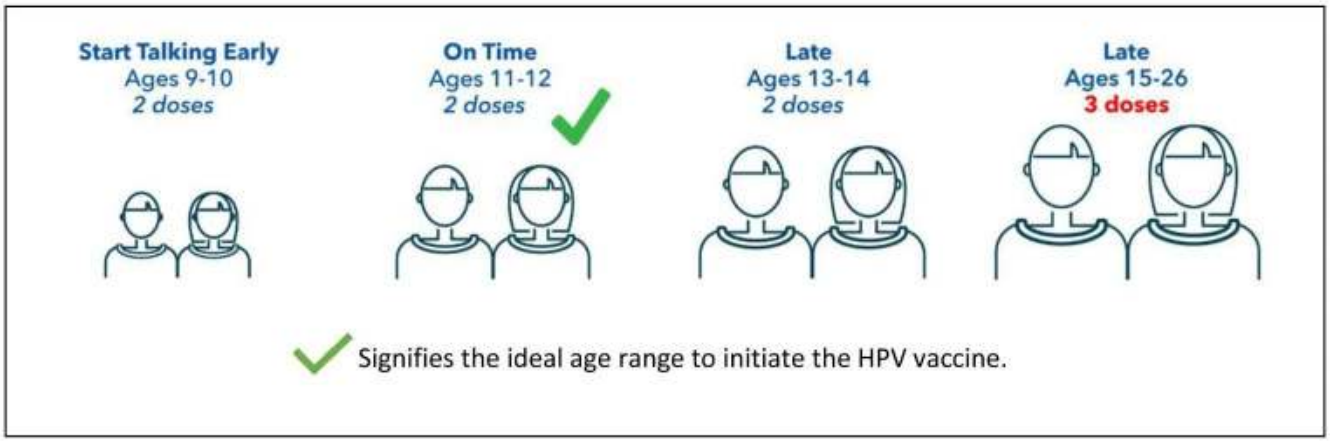
HPV Vaccines Recommended for Adolescents

Vaccines recommended for adolescents, 11 to 12 years of age, include tetanus-diphtheria-pertussis (Tdap) booster vaccination, also referred to as Tdap, and the initiation of meningococcal conjugate (MenACWY) vaccination and HPV vaccination.[7]

HPV vaccine dosage is dependent on age of initiation. Most individuals who initiate vaccination at ages 9 through 14 receive the vaccine as a two-dose series, and for those who initiate vaccination at ages 15 through 26, a three-dose series (Figure 1) is administered. For immunocompromised individuals ages 9-26 and individuals 27 years or older, a three-dose vaccination series is recommended.[8]

In Illinois, HPV vaccination is not a requirement for adolescents entering school, whereas Tdap and MenACWY are required, despite national recommendations from four leading national medical associations since 2014.[9,10]

Figure 1: Recommended Schedule for HPV Vaccination[†] (Source: CDC)

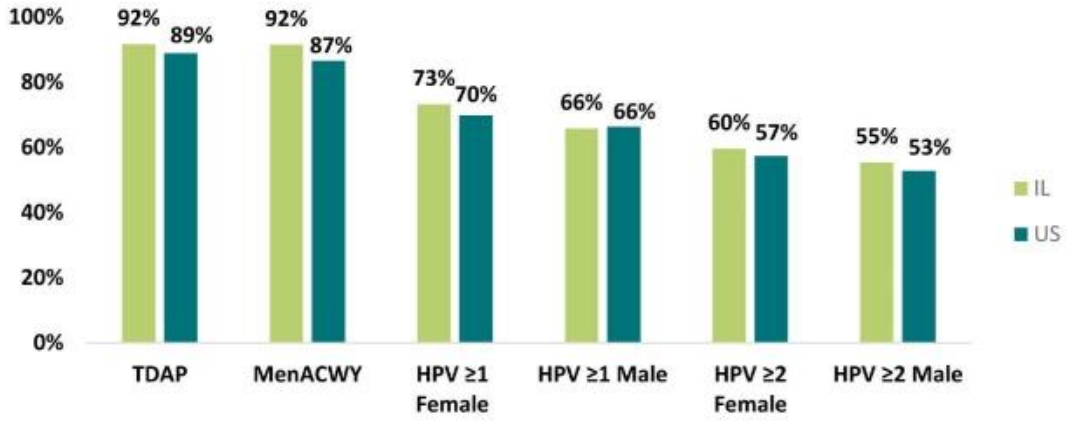


Since the HPV vaccine has been in use, rates of cancers and genital warts caused by HPV have dropped 86% among adolescent girls.[11] Although screening is available for HPV infection and for cervical cancer, no screening tests are available for the five other types of cancers caused by HPV: oropharyngeal, anal, vulvar, vaginal, and penile cancers.[12] As a result, these types of cancer are often detected at a later stage. HPV vaccination, however, can prevent these other HPV-related cancers from developing.[7]

Healthy People 2030 (HP2030) provides science-based, 10-year national objectives for improving the health of all Americans by encouraging collaborations across communities and sectors, empowering individuals toward making informed health decisions, and measuring the impact of prevention activities. The HP2030 objective for HPV is to "increase the proportion of adolescents ages 13 through 15 who receive recommended doses of the HPV vaccine."[13] Although Illinois has exceeded the HP2030 goal for Tdap (90%), the state has yet to reach the HP2030 goal of 80% for HPV vaccination (Figure 2). In Illinois, the percentage of males and females who have initiated and completed the HPV vaccination series is higher than the U.S., and females lead males in these metrics.

[†] HPV Vaccine Schedule and Dosing. Centers for Disease Control and Prevention. https://www.cdc.gov/hpv/hcp/schedules-recommendations.html. Published August 15, 2019. Accessed July 23, 2020.

Figure 2: Coverage for Recommended Adolescent Vaccines, 13-17 years (2018)[‡]



Programs and Policies to Increase HPV Vaccination

State and federally funded programs, laws, and regulations work to reduce the burden of infectious diseases, such as HPV. U.S. policies that have been effective include financing to assure access and availability of recommended vaccines[14] and ensuring a reliable and steady supply of the HPV vaccine.[15] National and state efforts are being administered to increase the proportion of adolescents receiving recommended doses of the HPV vaccine.

Specifically, the Illinois Department of Public Health's (IDPH) Illinois Comprehensive Cancer Control Program (ICCCP) works with statewide and community partners to reduce cancer incidence and mortality by addressing areas across the cancer continuum, from primary prevention to survivorship. One of the focus areas within the ICCCP includes HPV-related primary prevention strategies. One of the primary functions of the ICCCP is collaboration with the Illinois Cancer Partnership (ICP), which includes public, private, and nonprofit sectors partners that work together to establish, promote, and implement the state's cancer control plan, which is updated every five years. Increasing HPV vaccination is identified as a cancer prevention strategy in the Illinois Comprehensive Cancer Control Plan (2016-2021) and the 2022-2027 Illinois Comprehensive Cancer Control Plan with the goal of increasing the proportion of eligible adolescents who have completed the HPV vaccination series.

The IDPH ICCCP collaborates with the following internal and external programs:

- ***IDPH Vaccines for Children Program***
- ***Illinois Breast and Cervical Cancer Program***
- ***IDPH School Health Program***
- ***Illinois State Cancer Registry***
- ***IDPH Oral Health Programs***
- ***American Cancer Society***

[‡] Centers for Disease Control and Prevention TeenVax View. Data from 2018 National Immunization Survey—Teen (NIS-Teen). https://www.cdc.gov/vaccines/imz-managers/coverage/teenvaxview/data-reports/index.html. Accessed November 2020.

National HPV Vaccination Roundtable

The ICCCP actively participates in the Illinois HPV Advisory Group (National HPV Vaccination Roundtable), which is a coalition of more than 70 organizations working at the intersection of immunization and cancer prevention. Founded in 2014 by the American Cancer Society and the Centers for Disease Control and Prevention (CDC), the mission of the roundtable is to convene, communicate with, and catalyze member organizations and, by extension, the public to prevent HPV cancers and raise HPV vaccination rates.

Comprehensive Cancer Control National Partnership (CCCNP)

Since 1998, the CDC's National Comprehensive Cancer Control Program (NCCCP) has provided funding, guidance, and technical assistance that programs across the country use to develop, to implement, and to evaluate state-wide cancer control plans. NCCCP awardees advance cancer control priorities, including increasing HPV vaccination and participating in the Comprehensive Cancer Control National Partnership (CCCNP), where HPV vaccination remains a top priority.

In addition to these state and federal public health initiatives, some states have passed legislation and regulations to improve access to and uptake of the HPV vaccine as a part of their state's school attendance policies and cancer control efforts. Policy opportunities include legislative as well as system level strategies to increase HPV vaccination (see Table 1). In Illinois, all students entering sixth grade (and their parents or legal guardians) are required to be provided written information about the link between HPV and certain types of cancers.[§] In addition, individuals 18 years and younger are eligible to receive the vaccine, as medically indicated, at no cost.[**]

In 2014, four leading national medical associations — the American Academy of Family Physicians (AAFP), the American Academy of Pediatrics (AAP), the American College of Physicians (ACP), and the American College of Obstetricians and Gynecologists (ACOG) — together with the Immunization Action Coalition and the CDC, have issued a call urging physicians across the United States to educate patients about the HPV vaccine, and to strongly recommend HPV vaccination.[10]

[§] Illinois Senate Bill 2866 (2017)
[**] Illinois Senate Bill 937 (2007)

Table 1: Summary of Policy Opportunities to Increase HPV Vaccination[††]

Policy Opportunity	Description	Level
Health care provider recommendation	HPV vaccination recommendation to patients at each visit, particularly when other vaccines are being administered; decreases missed opportunities.	Provider
Reminder and recall systems*	Reminders within the electronic medical record, prompting providers to initiate HPV vaccination recommendation; patient reminders to initiate and/or complete the HPV vaccine series.	Clinic
State immunization registries*	Statewide registries in which all immunization records are entered and maintained.	State
Standing orders*	Official clinic protocols that give clinical staff authorization to complete immunizations for patients meeting recommended guidelines.	Clinic
Provider assessment and feedback evaluations*	Routine feedback to providers on patients' HPV vaccination series initiation and completion rates.	Clinic
Participation in Vaccine for Children (VFC) Program*	Clinic approval and implementation of processes that allow for participation in the VFC Program.	Clinic
Vaccination in alternative settings*	Providing HPV vaccination programs in schools, pharmacies, mobile clinics, dental practices, and other community-based, non-medical settings.	Clinic, Community
Pharmacy-related laws*	State-enacted laws allowing pharmacists to provide the HPV vaccine series to youth and young adults.	State
School-entry requirements*	State-enacted laws that require students to initiate and complete the HPV vaccine series to maintain eligibility to attend school.	State
Communication campaigns*	Leveraging rural community partnerships and voices of local residents to deliver positive HPV vaccination messaging.	Community
Rural HPV vaccination research*	Increased funding for interventional rural HPV vaccination research (e.g., randomized controlled trials, quasi-experimental studies, and pragmatic trials).	National

**"Big P" policies include legislative policies and/or other federal or state mandates*

***"Little P" policies include local written policies and system level strateiges and processes*

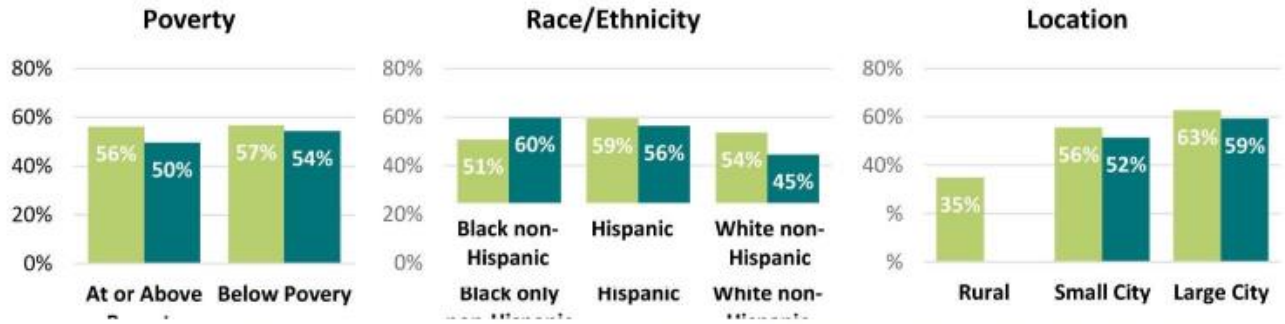
[††] St. Jude Children's Research Hospital: HPV Cancer Prevention Program (2021, April 27) *HPV Vaccination: A Look at State Policy and A Path Forward*. [Virtual Seminar].

HPV Vaccination Coverage in Illinois

HPV vaccination rates in Illinois vary by select demographic characteristics (Figure 3). Slightly more individuals living below the poverty line are up to date (UTD) on HPV vaccination compared to those living at or above poverty for both males and females. With the exception of Black non-Hispanic males, the percentage of HPV UTD is slightly higher in females than males. Hispanic females have a higher percentage of HPV UTD than Black and White non-Hispanic females. The percentage of HPV UTD in Illinois varies based on location with the highest percentage of HPV UTD for both males and females in large cities.[16] Females in rural areas of the state report the lowest HPV UTD percentage. Data on males in rural areas in the state has been suppressed due to small sample size.

The Illinois Comprehensive Automated Immunization Registry Exchange (I-CARE) is a web-based immunization record-sharing application developed by IDPH and is designed to record, to track, and to report immunizations. I-CARE 2018 data was examined to determine county-level variation in completion, also referred to as up to date (UTD), of the HPV vaccination series among 13- to 15-year-olds (Appendix A). In Illinois's 102 counties, HPV vaccination (UTD) ranged from 5% to 54%. Generally, UTD HPV vaccination percentages were higher in more urban areas, such as Cook County and Suburban Cook County, larger cities, including Chicago, Champaign, Peoria, and Springfield, and suburban areas in northeastern and central Illinois. UTD HPV vaccination percentages were lower in more rural regions in the state, particularly in northwestern and southern counties of Illinois.

Figure 3: HPV Vaccination Up to Date Percentages, Ages 13-17 by Select Demographics, Illinois (2018)



Data Source: TeenVax View, Illinois. Centers for Disease Control. Data from 2018 National Immunization Survey—Teen (NIS-Teen). https://www.cdc.gov/vaccines/imz-managers/coverage/teenvaxview/data-reports/index.html. Published July 22, 2019. Accessed June 25, 2020.

Note: UTD includes adolescents with three doses, and those with two doses (when the first HPV vaccine dose was initiated before age 15 years and time between the first and the second dose was at least five months minus four days). Data on males in rural areas in the state has been suppressed due to small sample size.

Identifying and Addressing Challenges to HPV Vaccine Uptake

One of the primary reasons behind lower rates of vaccine uptake, for both vaccine initiation and completion, ties back to parental intention to vaccinate their children. A 2020 study found the most common reason for lack of intent or vaccine hesitancy among parents to initiate the vaccine series for unvaccinated adolescents was safety concerns (23%).[17] Among parents of adolescents who received only one HPV vaccine dose, lack of a recommendation from a health care provider (22%) was the most frequently cited reason for absence of intent to complete the series

Recent studies to better understand vaccine hesitancy, related to the COVID-19 vaccine among adolescents, aligns with similar themes to include safety, trust, and perceived risk of infection.[18] Additional barriers to HPV vaccine uptake include health care access, cost, caregiver support, peer influence, school-based interventions, and provider/practice-based interventions.[19] Improving vaccine confidence remains a critical strategy to instill trust among patients, parents or families, and providers, especially among rural populations in Illinois.

Clinician recommendation remains the number one reason parents decide to vaccinate; providers can leverage their relationship with parents to provide education and to address vaccine hesitancy. Provider resources have been developed by CDC, the American Academy of Pediatrics (AAP), and the American Academy of Family Physicians (AAFP), collectively referred to as *Provider Resources for Vaccine Conversations with Parents*.

Conclusion and Next Steps

HPVa cancer cases vary by demographic and geographic factors across Illinois. Several different strategies can effectively address these variations. However, HPV vaccine uptake using evidence-based strategies is a top national objective and has been a recommendation of the Community Preventive Services Task Force since 2009. Changes in recommendations from the ACIP in 2019 include HPV vaccination catch-up among not only females, but also males, through age 26 years and a simplified immunization schedule. However, adolescents are still the main focal point to initiate the HPV vaccine to prevent HPV infection and reduce HPV-associated cancer rates.

To address disparities in vaccine uptake, the ICCCP and partners will need to focus efforts around statewide polices to support vaccination among adolescents in parallel to addressing vaccine hesitancy and other known barriers. Many statewide and community-driven strategies are being implemented and evaluated to address vaccine access as well as hesitancy among adolescents during the response to the COVID-19 pandemic. These promising practices and lessons learned

would serve well to inform future strategies to increase HPV vaccine uptake, especially among males as well as rural populations across Illinois.

Acknowledgements

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Suzanne Elder, American Cancer Society
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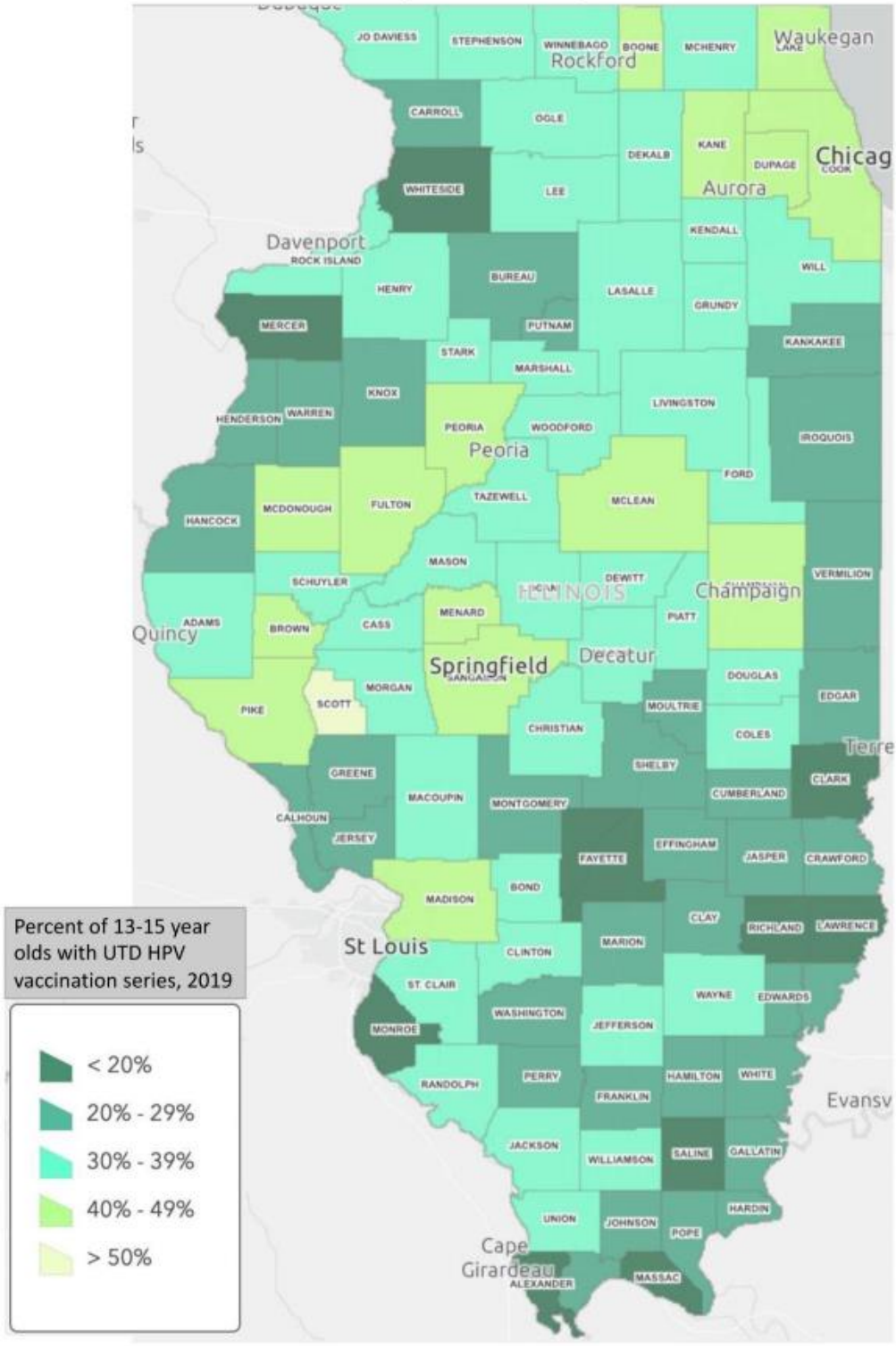
APPENDIX A: HPV Vaccination Series Up to Date Among 13 – 15 Year Olds in Illinois, By County (2019) *



Data Limitations: I-CARE data source excludes deceased patients, as well as those patients that initiated one or more doses out of state and completed their series in Illinois.

* Source: Illinois Comprehensive Automated Immunization Registry Exchange (I-CARE) data. Unpublished data from 2019
Notes: HPV Immunization rates for Illinois's 102 counties were grouped into quintiles

Appendix B: Resource Guide (HPV Associated Cancers in Illinois – Part II)

HPV-Associated Cancers in Illinois – Part I (December 2020)
https://www.dph.illinois.gov/sites/default/files/publications/hpv-associated-cancers-illinois-part-1-final-01282021.pdf

IDPH Vaccines for Children Program
http://dph.illinois.gov/topics-services/prevention-wellness/immunization/vfc-program

Illinois Breast and Cervical Cancer Program
http://dph.illinois.gov/topics-services/life-stages-populations/womens-health-services/ibccp

IDPH School Health Program
https://dph.illinois.gov/topics-services/life-stages-populations/maternal-child-family-health-services/school-health

Illinois State Cancer Registry
https://www.dph.illinois.gov/data-statistics/epidemiology/cancer-registry

IDPH Oral Health Programs
https://dph.illinois.gov/topics-services/prevention-wellness/oral-health

American Cancer Society
https://www.cancer.org/health-care-professionals/hpv-vaccination-information-for-health-professionals/our-hpv-vaccination-initatives.html

Illinois Comprehensive Cancer Control Plan (2016-2021)
https://dph.illinois.gov/sites/default/files/publications/state-cancer-plan-050818.pdf

National Vaccination HPV Roundtable
https://hpvroundtable.org/

Comprehensive Cancer Control National Partnership (CCCNP)
https://www.cccnationalpartners.org/about-us

Provider Resources for Vaccine Conversations with Parents
https://www.cdc.gov/vaccines/hcp/conversations/

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[6] Centers for Disease Control and Prevention (CDC). Grading of Recommendations Assessment, Development and Evaluation (GRADE) for use of HPV vaccine in adults ages 27 through 45 years. https://www.cdc.gov/vaccines/acip/recs/grade/HPV-adults.html. Accessed May 31, 2021.

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[8] HPV Vaccine Administration. Centers for Disease Control and Prevention. https://www.cdc.gov/vaccines/vpd/hpv/hcp/administration.html. Published March 17, 2020. Accessed June 24, 2020.

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[10] Leading Medical and Public Health Organizations Join Efforts Urging Physicians to Strongly Recommend Human Papilloma Virus (HPV) Vaccination. AAFP Home. https://www.aafp.org/media-center/releases-statements/all/2014/HPV-vaccination-dear-colleague-letter.html. Published February 12, 2014. Accessed August 4, 2020.

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[15] U.S. Department of Health and Human Services (HHS). 2010 National Vaccine Plan, Protecting the Nation's Health through Immunization. https://www.hhs.gov/sites/default/files/nvpo/vacc_plan/2010-Plan/nationalvaccineplan.pdf. Accessed May 31, 2021.

[16] MSA status was determined based on household reported city and county of residence and was grouped into three categories: MSA principal city, MSA nonprincipal city, and non-MSA. MSA and principal city were as defined by the U.S. Census Bureau (https://www.census.gov/programs-surveys/metro-micro.htmlexternal icon). Non-MSA areas include urban populations not located within an MSA as well as completely rural areas.

[17] K. Sonawane, Y. Zhu, J. Montealegre, D. Lairson, C. Bauer, L. McGee, A. Giulian, and A. Deshmukh, Parental intent to initiate and complete the human papillovavirus vaccine series in the USA; a nationwide, cross-sectional survey. Vol. 5 (pp 484-492): Sept 2020. https://doi.org/10.1016/S2468-2667(20)30139-0

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[19] Peterson CE, Silva A, Holt HK, Balanean A, Goben AH, Dykens JA. Barriers and facilitators to HPV vaccine uptake among US rural populations: a scoping review. Cancer Causes Control. 2020 Sep 31(9):801-814. doi: 10.1007/s10552-020-01323-y. Epub 2020 Jun 14. PMID: 32537702.

Appendix E: Certificate of Child Health Examinations

Student's Name Last First Middle	Birth Date Month/Day/Year	Sex	Race/Ethnicity	School /Grade Level/ID#
Address Street City Zip Code	Parent/Guardian	Telephone # Home		Work

IMMUNIZATIONS: To be completed by health care provider. The mo/da/yr for *every* dose administered is required. If a specific vaccine is medically contraindicated, a separate written statement must be attached by the health care provider responsible for completing the health examination explaining the medical reason for the contraindication.

REQUIRED Vaccine / Dose	DOSE 1 MO DA YR	DOSE 2 MO DA YR	DOSE 3 MO DA YR	DOSE 4 MO DA YR	DOSE 5 MO DA YR	DOSE 6 MO DA YR
DTP or **DTaP**						
Tdap; **Td** or Pediatric **DT** (Check specific type)	☐Tdap☐Td☐DT	☐Tdap☐Td☐DT	☐Tdap☐Td☐DT	☐Tdap☐Td☐DT	☐Tdap☐Td☐DT	☐Tdap☐Td☐DT
Polio (Check specific type)	☐ IPV ☐ OPV	☐ IPV ☐ OPV	☐ IPV ☐ OPV	☐ IPV ☐ OPV	☐ IPV ☐ OPV	☐ IPV ☐ OPV
Hib Haemophilus influenza type b						
Pneumococcal Conjugate						
Hepatitis B						
MMR Measles Mumps. Rubella						
Varicella (Chickenpox)						
Meningococcal conjugate (MCV4)						
RECOMMENDED, BUT NOT REQUIRED Vaccine / Dose						
Hepatitis A						
HPV						
Influenza						
Other: Specify Immunization Administered/Dates						

Comments: * indicates invalid dose

Health care provider (MD, DO, APN, PA, school health professional, health official) verifying above immunization history must sign below.
If adding dates to the above immunization history section, put your initials by date(s) and sign here.

Signature **Title** **Date**

Signature **Title** **Date**

ALTERNATIVE PROOF OF IMMUNITY

1. Clinical diagnosis (measles, mumps, hepatitis B) is allowed when verified by physician and supported with lab confirmation. Attach copy of lab result.
***MEASLES (Rubeola)** MO DA YR ****MUMPS** MO DA YR **HEPATITIS B** MO DA YR **VARICELLA** MO DA YR

2. History of varicella (chickenpox) disease is acceptable if verified by health care provider, school health professional or health official.
Person signing below verifies that the parent/guardian's description of varicella disease history is indicative of past infection and is accepting such history as documentation of disease.
Date of Disease **Signature** **Title**

3. Laboratory Evidence of Immunity (check one) ☐**Measles*** ☐**Mumps**** ☐**Rubella** ☐**Varicella** **Attach copy of lab result.**

*All measles cases diagnosed on or after July 1, 2002, must be confirmed by laboratory evidence.
**All mumps cases diagnosed on or after July 1, 2013, must be confirmed by laboratory evidence.

Completion of Alternatives 1 or 3 MUST be accompanied by Labs & Physician Signature: _____
Physician Statements of Immunity MUST be submitted to IDPH for review.

Certificates of Religious Exemption to Immunizations or Physician Medical Statements of Medical Contraindication Are Reviewed and *Maintained* by the School Authority.

Appendix F: AIRA Immunization Information System (IIS) Standards

Policy

- Establish interjurisdictional and bidirectional data exchange that uses data from multiple sources to validate immunization records. Data sources may include public and commercial health insurers, vital records (birth, marriage, death certificate data), pharmacies, public health departments and other state data sources (driver's license data, tax return data).
- Mandate all licensed providers are enrolled in IIS within 60 days of licensure.
- Mandate that all vaccinations are reported within 72 hours.
- Mandate that all vaccination reports are automatically uploaded to IIS by EMR by (date).
- Authorize individuals to access their own or their child's immunization record(s) from state IIS.

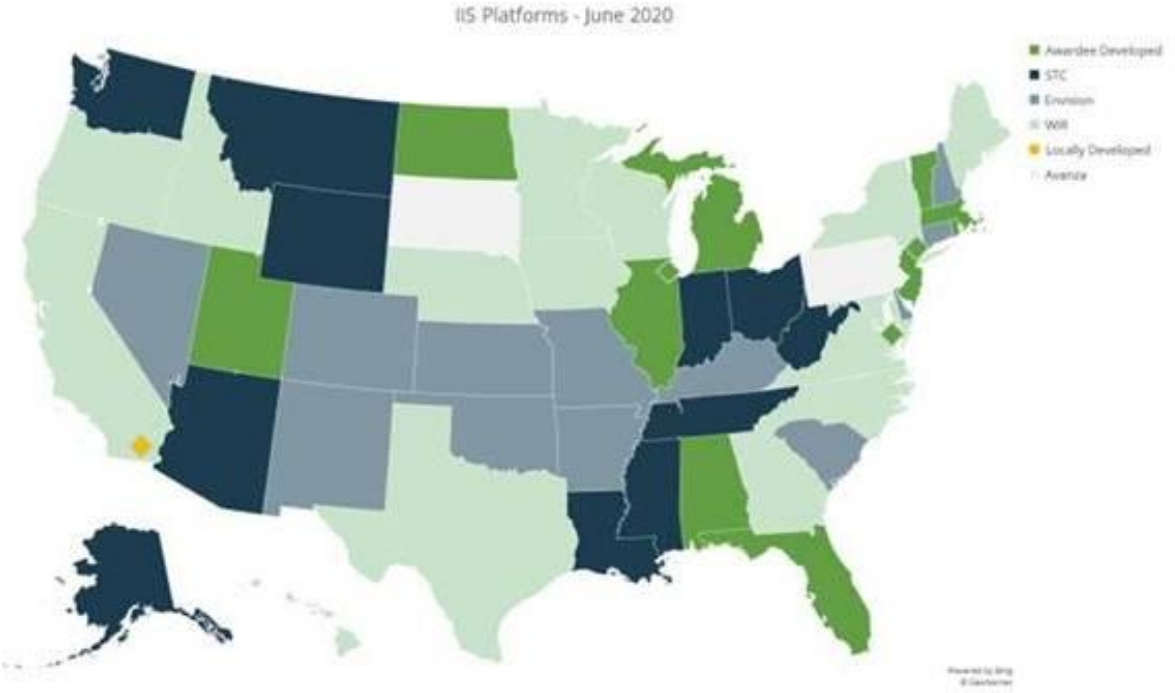
Providers

- Streamline time to onboard provider sites to the IIS; Design and test enrollment procedures.
- Establish standards and procedures for uploading vaccination data (manually and EMR-assisted)
- Create feedback loops to ensure patient demographics and vaccination status is up to date; Use bidirectional data exchange to create provider and site scorecards.

Data

- Enable all stakeholders the ability to generate state, county, and provider coverage reports.
- Use IIS data reports for payor performance reporting (UDS, HEDIS, et al) and other QI activities.
- Analyze enrollment and input data to identify providers and sites that may need support.
- Identify under-immunized populations by county, zip code, and school district.
- Publish annual immunization report, including data by county and % change over previous year.

Immunization Information Platforms (as of June 2020)[58]



Appendix G: Sample Standing Orders

Purpose

To reduce morbidity and mortality from hepatitis B virus (HBV) by vaccinating all adults who meet the criteria established by the Centers for Disease Control and Prevention's Advisory Committee on Immunization Practices.

Policy

Where allowed by state law, standing orders enable eligible nurses and other health care professionals (e.g., pharmacists) to assess the need for vaccination and to vaccinate adults who meet any of the criteria below.

Procedure

1 Assess Adults for Need of Vaccination against HBV infection according to the following criteria:

- Any person who wants to be protected from HBV infection
- Patient with diabetes mellitus (Note: for those age 60 years or older with diabetes mellitus, at the discretion of the treating clinician)
- Patient with end-stage renal disease, including patients receiving hemodialysis; HIV infection; or chronic liver disease
- Sexually active and not in a long-term, mutually monogamous relationship (e.g., more than 1 sex partner during the previous 6 months)
- Seeking evaluation or receiving treatment for a sexually transmitted infection (STI)
- A male who has sex with males
- A current or recent injection-drug user
- At occupational risk of infection through exposure to blood or blood-contaminated body fluids (e.g., healthcare worker, public safety worker, trainee in a health professional or allied health school)
- Residents or staff of an institution for persons with developmental disabilities
- Sex partner or household member of a person who is chronically infected with HBV (HBsAg-positive). (This includes an HBsAg-positive adopted child.)
- Planned travel to a country with high or intermediate prevalence of endemic HBV infection (for hepatitis B travel information from CDC, go to wwwnc.cdc.gov/travel/diseases/hepatitis-b)
- People living in correctional facilities
- All teenagers ages 18 and younger who are not fully vaccinated (see standing orders for children and teens at www.immunize.org/catg.d/p3076a.pdf)

2 Screen for Contraindications and Precautions

Contraindications

Do not give hepatitis B vaccine to a person who has experienced a serious systemic or anaphylactic reaction to a prior dose of the vaccine or to any of its components. For a list of vaccine components, refer to the manufacturer's package insert (www.immunize.org/packageinserts) or go to www.cdc.gov/vaccines/pubs/pinkbook/downloads/appendices/B/excipient-table-2.pdf.

Precautions

- Moderate or severe acute illness with or without fever

CDC recommends that until safety data are available for Heplisav-B, providers should vaccinate pregnant women needing HepB vaccination with a vaccine from a different manufacturer.

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3 Provide Vaccine Information Statements

Provide all patients with a copy of the most current federal Vaccine Information Statement (VIS). Provide non-English speaking patients with a copy of the VIS in their native language, if one is available and desired; these can be found at www.immunize.org/vis. (For information about how to document that the VIS was given, see section 6 titled "Document Vaccination.")

4 Prepare to Administer Vaccine

Choose the needle gauge, needle length, and injection site according to the following chart:

GENDER AND WEIGHT OF PATIENT	NEEDLE GAUGE	NEEDLE LENGTH	INJECTION SITE
Female or male less than 130 lbs	22–25	5/8*–1"	Deltoid muscle of arm
Female or male 130–152 lbs	22–25	1"	Deltoid muscle of arm
Female 153–200 lbs	22–25	1–1½"	Deltoid muscle of arm
Male 153–260 lbs	22–25	1–1½"	Deltoid muscle of arm
Female 200+ lbs	22–25	1½"	Deltoid muscle of arm
Male 260+ lbs	22–25	1½"	Deltoid muscle of arm

* A 5/8" needle may be used in patients weighing less than 130 lbs (<60 kg) for IM injection in the deltoid muscle only if the skin is stretched tight, the subcutaneous tissue is not bunched, and the injection is made at a 90° angle to the skin.

5 Administer Hepatitis B Vaccine according to the criteria and guidance in the tables below:

TYPE OF VACCINE	AGE GROUP	DOSE	ROUTE	INSTRUCTIONS
Heplisav-B (Dynavax)	18 yrs & older	0.5 mL	Intramuscular (IM)	Administer vaccine in deltoid muscle
Pediatric formulation of Engerix-B (GSK) or Recombivax HB (Merck)	19 yrs & younger	0.5 mL	Intramuscular (IM)	Administer vaccine in deltoid muscle.
Adult formulation of Engerix-B (GSK) or Recombivax HB (Merck)	20 yrs & older	1.0 mL	Intramuscular (IM)	Administer vaccine in deltoid muscle.

Schedules for vaccination

HISTORY OF PREVIOUS VACCINATION	FOR PATIENTS WHOSE PREVIOUS BRAND OF VACCINE IS KNOWN, CONTINUE WITH THE SAME BRAND AS SHOWN BELOW. IF BRAND IS NOT KNOWN OR IS NOT AVAILABLE, CONTINUE WITH A 3-DOSE SCHEDULE AS INDICATED IN THE RIGHT-HAND COLUMN BELOW.	
	SCHEDULE FOR ADMINISTRATION OF HEPLISAV-B	SCHEDULE FOR ADMINISTRATION OF ENGERIX-B OR RECOMBIVAX HB
None or unknown	Give a 2-dose series at 0 and 1 month.	Give a 3-dose series at 0, 1, and 6 mos.
1 dose	Give dose #2 at least 4 wks after dose #1 to complete the series.	Give dose #2 at least 4 wks after #1; then, give dose #3 at least 8 wks after dose #2 and at least 16 wks after dose #1.
2 doses		Give dose #3 at least 8 wks after dose #2 and at least 16 wks after dose #1.

NOTE 1: For people receiving hemodialysis or with other immunocompromising conditions, give either 1 dose of 40 mcg/mL (Recombivax HB) at 0, 1, and 6 mos, OR 2 doses of 20 mcg/mL (Engerix-B) administered simultaneously at 0, 1, 2, and 6 mos, OR 2 doses of 0.5 mL Heplisav-B at 0 and 1 mo.

NOTE 2: The hepatitis B vaccine series does not need to be restarted, regardless of the time that has elapsed between doses.

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Information on certain risk groups

- For persons born in Asia, the Pacific Islands, Africa, or other countries identified as having high rates of HBV infection (see *MMWR* 2005;54[RR-16]:25), ensure that they have also been tested for hepatitis B surface antigen (HBsAg) to find out if they are chronically infected. If test is performed on same visit, administer hepatitis B vaccine after the blood draw. Do not delay initiating hepatitis B vaccination while waiting for test results. If patient is found to be HBsAg-positive, appropriate medical follow-up should be provided; no further doses of hepatitis B vaccine are indicated.
- Certain people need testing for immunity (anti-HBs) 1–2 months following vaccination. Check ACIP recommendations for details (www.cdc.gov/mmwr/volumes/67/rr/pdfs/rr6701-H.pdf).

6 Document Vaccination

Document each patient's vaccine administration information and follow up in the following places:

Medical record: Document the date the vaccine was administered, the manufacturer and lot number, the vaccination site and route, and the name and title of the person administering the vaccine. You must also document, in the patient's medical record or office log, the publication date of the VIS and the date it was given to the patient. If vaccine was not administered, record the reason(s) for non-receipt of the vaccine (e.g., medical contraindication, patient refusal). Offer the vaccine to the patient at the next visit.

Personal immunization record card: Record the date of vaccination and the name/location of the administering clinic.

Immunization Information System (IIS) or "registry": Report the vaccination to the appropriate state/local IIS, if available.

7 Be Prepared to Manage Medical Emergencies

Be prepared for management of a medical emergency related to the administration of vaccine by having a written emergency medical protocol available, as well as equipment and medications. For IAC's "Medical Management of Vaccine Reactions in Adult Patients," go to www.immunize.org/catg.d/p3082.pdf. To prevent syncope, vaccinate patients while they are seated or lying down and consider observing them for 15 minutes after receipt of the vaccine.

8 Report All Adverse Events to VAERS

Report all adverse events following the administration of hepatitis B vaccine to the federal Vaccine Adverse Event Reporting System (VAERS). To submit a VAERS report online (preferred) or to download a writable PDF form, go to http://vaers.hhs.gov/reportevent.html. Further assistance is available at (800) 822-7967.

Standing Orders Authorization

This policy and procedure shall remain in effect for all patients of the _____
NAME OF PRACTICE OR CLINIC

until rescinded or until _____.
DATE

Medical Director's signature _____ Signature date _____ Effective date _____

Purpose

To reduce morbidity and mortality from human papillomavirus (HPV) infection by vaccinating all children and teens who meet the criteria established by the Centers for Disease Control and Prevention's Advisory Committee on Immunization Practices (ACIP).

Policy

Where allowed by state law, standing orders enable eligible nurses and other healthcare professionals (e.g., pharmacists) to assess the need for and vaccinate children and teens who meet any of the criteria below.

Procedure

1 Assess children and teens for need of vaccination against human papillomavirus infection based on the following criteria:

- Age 11 years and older who have not completed an HPV vaccination series
- Age 9 years and older with any history of sexual abuse or assault
- Age 9 through 10 years, without a specific risk factor, whose parent/guardian wishes to have them vaccinated

2 Screen for contraindications and precautions

Contraindication

Do not give HPV vaccine to an child or teen who has experienced a serious systemic or anaphylactic reaction to a prior dose of HPV vaccine or to any of its components (e.g., yeast). For information on vaccine components, refer to the manufacturers' package insert (www.immunize.org/fda) or go to www.cdc.gov/vaccines/pubs/pinkbook/downloads/appendices/B/excipient-table-2.pdf.

Precaution

- Moderate or severe acute illness with or without fever
- Pregnancy; delay vaccination until after completion of the pregnancy

3 Provide Vaccine Information Statements

Provide all patients (or, in the case of minors, their parent, or legal representative) with a copy of the most current federal Vaccine Information Statement (VIS). Provide non-English speaking patients with a copy of the VIS in their native language, if one is available and desired; these can be found at www.immunize.org/vis. (For information about how to document that the VIS was given, see section 6 titled "Document Vaccination.")

4 Prepare to Administer Vaccine

Choose the needle gauge, needle length, and injection site according to the following chart:

AGE OF INFANT/CHILD	NEEDLE GAUGE	NEEDLE LENGTH	INJECTION SITE
9 through 10 years	22–25	⅝**–1"	Deltoid muscle of arm*
		1–1¼"	Anterolateral thigh muscle
11 through 18 years	22–25	⅝**–1"	Deltoid muscle of arm*
		1–1½"	Anterolateral thigh muscle

* Preferred site.

** A ⅝" needle may be used for children for IM injection in the deltoid muscle only if the skin is stretched tight, the subcutaneous tissue is not bunched, and the injection is made at a 90-degree angle.

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5 Administer HPV vaccine, 0.5 mL, via the intramuscular (IM) route, according to the following tables:

Schedule for routine vaccination

TYPE OF VACCINE	AGE WHEN FIRST DOSE IS ADMINISTERED[1,2]	DOSE	SCHEDULE
HPV (Gardasil 9)	9 through 14 years	0.5 mL	Two doses, 6–12 months apart[2]
	15 years or older	0.5 mL	Three doses at 0, 1–2, and 6 months

Note: For individuals who failed to complete either the 2-dose or 3-dose schedule as stated above, do not start over. Simply follow the schedule shown below.

Schedule for catch-up vaccination

HISTORY OF PREVIOUS HPV VACCINATION	SCHEDULE FOR ADMINISTRATION OF HPV VACCINE
0 documented doses, or none known	Follow schedule as per above table.
1 previous dose when younger than age 15 years	Give dose #2 with minimum interval of 5 months[2]
2 previous doses given less than 5 months apart and dose #1 given when younger than age 15 years	Give dose #3 with minimum interval of 12 weeks after dose #2 and at least 5 months after dose #1.
1 previous dose when age 15 or older	Give dose #2 at least 4 weeks after dose #1, then give dose #3 at least 12 weeks after dose #2 and at least 5 months after dose #1.
2 previous doses when age 15 or older	Give dose #3 at least 12 weeks after dose #2 and at least 5 months after dose #1.

[1] Only two doses are recommended for anyone who begins the schedule before the 15th birthday, regardless of age at series completion.

[2] Immunocompromised persons, including those with HIV infection, should receive a 3-dose series at 0, 1–2, and 6 months, regardless of age at vaccine initiation.

6 Document Vaccination

Document each patient's vaccine administration information and follow-up in the following places:

Medical record: Record the date the vaccine was administered, the manufacturer and lot number, the vaccination site and route, and the name and title of the person administering the vaccine. You must also document, in the patient's medical record or office log, the publication date of the VIS and the date it was given to the patient. Note that medical records/charts should be documented and retained in accordance with applicable state laws and regulations. If vaccine was not administered, record the reason(s) for non-receipt of the vaccine (e.g., medical contraindication, patient refusal). Discuss the need for vaccine with the patient (or, in the case of a minor, their parent or legal representative) at the next visit.

Personal immunization record card: Record the date of vaccination and the name/location of the administering clinic.

Immunization Information System (IIS) or "registry": Report the vaccination to the appropriate state or local IIS, if available.

7 Be Prepared to Manage Medical Emergencies

Be prepared for management of a medical emergency related to the administration of vaccine by having a written emergency medical protocol available, as well as equipment and medications. For IAC's "Medical Management of Vaccine Reactions in Children and Teens," go to www.immunize.org/catg.d/p3082a.pdf. For "Medical Management of Vaccine Reactions in Adult Patients," go to www.immunize.org/catg.d/p3082.pdf. To prevent syncope, vaccinate patients while they are seated or lying down and consider observing them for 15 minutes after receipt of the vaccine.

CONTINUED ON THE NEXT PAGE ▶

8 Report Adverse Events to VAERS

Report all adverse events following the administration of HPV vaccine to the federal Vaccine Adverse Event Reporting System (VAERS). To submit a VAERS report online (preferred) or to download a writable PDF form, go to https://www.vaers.hhs.gov/reportevent.html. Further assistance is available at (800) 822-7967.

Standing Orders Authorization

This policy and procedure shall remain in effect for all patients of the _____ (NAME OF PRACTICE OR CLINIC)

effective _____ (DATE) until rescinded or until _____ (DATE).

Medical Director _____ (PRINT NAME) / _____ (SIGNATURE) _____ (DATE)

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Participating Organizations

Access Community Health Network
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American Cancer Society Cancer Action Network
American Immunization Registry Association
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