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## Implementation of HPV vaccination guidelines in a diverse population in Los Angeles: Results from an environmental scan of local HPV resources and needs

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### Abstract

Research shows that vaccination against human papillomavirus (HPV) infection is one of the most effective methods for reducing risk for cervical cancer; it also protects against other HPV-related cancers. Controversies exist regarding HPV vaccination in several communities; which may in part explain why although rates of HPV vaccination are increasing nationwide, Los Angeles County (LAC) data show that many adolescents are still not vaccinated. These adolescents remain at high-risk for infection. Using community-based participatory principles, we conducted an environmental scan that included a literature review, the development of a community advisory board, community feedback from HPV community meetings, and interviews with stakeholders to understand attitudes toward HPV vaccination and their impact in follow through with HPV

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#### Conflicts of Interest

Conflicts of interest: none.

#### Contributors

Lourdes Baezconde-Garbanati conceptualized and worked on the writing of the manuscript in addition to leading the project. Brianna A. Lienemann drafted and revised the manuscript. Marisela Robles conducted the environmental scans and literature reviews and helped to draft those sections of the manuscript. Ethel Johnson also contributed to the writing of the sections of the manuscript on environmental scans and on the literature review. Kathleen Sanchez provided feedback on different versions of the manuscript. Rita Singhal assisted in conceptualization and in writing recommendations and conclusions related to the findings. Jane Steinberg provided substantive feedback on different versions of the manuscript. Jenny M. Jaque provided ideas for the conceptualization of this manuscript and reviewed various versions providing substantive feedback. Mary Ann Pentz provided substantive feedback on different versions of the manuscript. Stephen Gruber is the main Principle Investigator in the Cancer Center, and supported the writing, providing feedback at different points throughout the life of the project and writing of the manuscript. All authors approve the final version of the article.

vaccines. Twenty-eight key stakeholders participated in our coalition comprised of community organizations and clinics with strong ties to the local community. This is the only coalition dedicated exclusively to improving HPV vaccine uptake in LAC. Of these, twenty-one participated in an environmental scan via qualitative interviews about HPV vaccination programs, service delivery priorities, and proposed steps to increase HPV vaccination uptake in LAC. The environmental scan revealed targets for future efforts, barriers to HPV uptake, and next steps for improving local HPV vaccination uptake rates. The environmental scan also identified local HPV vaccination interventions and resources. Although LAC has developed important efforts for vaccination, some interventions are no longer being implemented due to lack of funds; others have not been evaluated with sufficient outcome data. The risk for cervical and other HPV-related cancers could be greatly reduced in LAC if a multilevel, multicultural, and multilingual approach is taken to better understand rates of HPV vaccination uptake, particularly among racial/ethnic minorities and LGBTQ youth. Our environmental scan provides guidance on attitudes toward vaccination, and how best to address the needs of LAC families and providers.

### Keywords

environmental scan; HPV; vaccination; cancer; Los Angeles; adolescents

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Human papillomavirus (HPV) is a group of more than 150 related viruses that can be transmitted through intimate skin-to-skin contact [1]. Nearly 80 million people in the United States, or approximately one in four, are infected with HPV [2]. Approximately 14 million Americans, including teens, are infected each year [2]. HPV is the most common sexually transmitted infection; it is so common that nearly every sexually active adult becomes infected at some point in their lifetime [1]. HPV can be transmitted between people without any symptoms. This makes it difficult to know when you become infected with HPV or if you are transmitting it to someone else. HPV can cause genital warts and HPV-related cancers [3]. Cervical cancer is the most common type of HPV cancer with almost all cervical cancer being caused by HPV. Additional HPV-related cancers include: vulvar (69% linked to HPV), vaginal (75% linked to HPV), penile (63% linked to HPV), anal (91% linked to HPV), and oropharynx (72% linked to HPV) [3].

Although much controversy exists regarding vaccination for adolescents, and especially related to HPV, research shows that most HPV-related cancers can be prevented by HPV vaccination [3]. The Centers for Disease Control and Prevention (CDC) recommends that all children, 11 or 12 years old should receive a reduced two-dose series of HPV vaccine [2]. Individuals who begin the series at 15 years old or older and those who have a weakened immune system should receive the three-dose initially recommended series. Vaccinating preteens protects children before ever being exposed to HPV. Additionally, there is a more robust immune response to the vaccine in the preteen years [2]. While rates of HPV vaccination are increasing nationwide, particularly among ethnic minorities and those living below the poverty level, California data show that many adolescents are still not vaccinated or have not completed the three-dose series [4]. Except for the coalition formed by this project, there is no local HPV specific coalition dedicated exclusively to improving HPV vaccine uptake in LAC.

The objectives of the National Cancer Institute-funded USC Norris Comprehensive Cancer Center (hereafter, Cancer Center) HPV project at the Patient Education and Community Outreach Center were threefold. First, we identified, developed, and strengthened relationships with existing state and local coalitions, the local health department, medical providers, school-based clinics, and community agencies engaged in HPV-related cancer prevention and control efforts. Second, we conducted an environmental scan in collaboration with our partners to assess needs, resources, and understand attitudes toward HPV vaccination. Third, we are sustaining our HPV coalition activities to expand our networks and resources for the development and evaluation of interventions to continue monitoring HPV vaccination uptake in LAC.

Although environmental scans originated in the business sector, they have come to be used in public health to collect data that can be used to develop health programs and interventions tailored to the unique needs of specific communities [5]. Environmental scans can help assess strengths, weaknesses, challenges, and opportunities for improvement. They may help to refute or confirm common perceptions within the community. The methodology for environmental scans vary depending on the needs of the organization or community. However, they often include multiple sources of internal and external data (e.g., literature review, surveys, interviews with key stakeholders, internal documents, focus groups, technology), various target populations, and program planning [6]. Environmental scans can be a valuable tool to raise awareness of issues, plan for the future, develop interventions, assist in health decision-making, and provide information for the development of evidence-based policies [6]. Utilizing environmental scans most effectively requires engagement of community members in a participatory manner (CBPR). For this study, community was defined as stakeholders engaged in our coalition that represented the various sectors involved in decision-making and community members at large.

## Methods

The environmental scan was conducted between August 2014 and July 2015. It was achieved through several means: a literature review, a community advisory board (CAB), key informant interviews, and community feedback from HPV community meetings. We began by conducting a literature review. Articles published from 2013–2015 and conducted within the United States were retrieved from PUBMED. The types of study designs included were observational with or without a comparison group and intervention. The types of instrumentation within the articles were surveys, interviews, focus groups, and medical record review/chart abstraction. The focus of the articles included youth, parental and family knowledge, attitudes, and beliefs; provider knowledge, attitudes, beliefs, and practices; and HPV interventions. This literature review informed our environmental scan and is used as a backdrop for presentations and publications on the topic.

We developed a CAB in 2014 to advise the Cancer Center on issues related to HPV from the beginning of the study, in order to engage the CAB in a participatory manner. The Midwest Academy Strategy Chart helped us develop a strategy for building collaboration. The individuals who joined our CAB came from the catchment area within the Cancer Center's geographic reach in LAC. The CAB was originally comprised of approximately 8–10 key

members of the coalition and project. Its membership has now increased to approximately 30 members including representatives from local clinics, mobile health units, hospitals, local health departments, school clinics, promotores de salud/community health worker programs, community based organizations, volunteer agencies, academics, and clinicians. Key members to the advisory committee were representatives from LAC+USC Medical Center, the Norris Comprehensive Cancer Center, Patient Education and Community Outreach Center, Children's Hospital Los Angeles, The Los Angeles County Department of Public Health, the Los Angeles County Immunization Coalition, and individuals who worked in the schools on immunization and other health related matters. The CAB assisted with the environmental scan in helping to identify resources available at the community level.

We had three HPV community-input meetings, which generated discussion about the current local climate in HPV vaccination, data, resources, challenges, needs, interventions, and recommendations. Based on these discussions, we developed a list of challenges, sub-populations that we should focus on, and next steps to improve the uptake of the HPV vaccine in LAC.

Finally, we conducted interviews with stakeholders. Twenty-eight key stakeholders participated in our stakeholders' interviews. These were comprised of representatives from community organizations and clinics with strong ties to the local community. Of these, twenty-one participated in our environmental scan via qualitative telephone interviews about past and current HPV vaccination programs and procedures, service delivery priorities, and challenges and recommendations for HPV vaccination uptake in Los Angeles. Prior to the interview, they provided informed consent. The interview consisted of six open-ended questions. Examples of questions include, "Based on your experience, what do you think are some of the reasons for the low vaccine uptake," and "What do you think are some of the ways to create awareness of the vaccine and increase uptake?" Some of the items also included probes. For example, a probe for the item on reasons for low vaccine uptake was, "Are you aware of stigma associated with the vaccine (from parents, clinicians, or youth)?"

## Analysis

We reviewed responses from the interviews in a qualitative fashion, determining themes that were common among the various surveys. The thematic review was performed by selection of themes by two key members of the scientific team. Responses were then corroborated with each other and compared. Those that were similar were organized into categories (which appear below). Any additional information went into notes related to future need for studies.

## Results and Discussion

### Populations to Focus on in Future Efforts

The environmental scan revealed attitudes regarding HPV vaccination and targets for the local focus of future efforts on specific populations, the most pressing barriers to HPV uptake, and next steps for improving local HPV vaccination uptake rates. Populations with the highest priority for intervention included: 1) clinicians and other related medical

providers, 2) parents, and 3) adolescent girls and boys (ages 11–18), with a focus on LGBTQ youth.

**Clinicians and other related medical providers**—One of the most important groups to intervene with in LAC were clinicians and other related medical providers. A female, Los Angeles Unified School District (LAUSD) school representative stated, “Doctors are not recommending the vaccine. LAUSD parents are compliant if doctors were to recommend it.” In support of LAC’s need to intervene with clinicians and other related medical providers, a nationally representative survey of physicians found relatively low rates (i.e., 34.6% to 52.7%) of “always” recommending the HPV vaccine to adolescents with the lowest rates of recommendation for 11–12 year olds [7]. However, provider recommendation of the HPV vaccine can significantly improve immunization rates [8]. Further, a systematic review found that one of the most important factors in parents’ decision to vaccinate their children was health care provider recommendations [9].

**Parents**—The second population with the highest priority for intervention in LAC was parents. Considering that the CDC recommends that 11–12 year olds receive the vaccine [2], parents are largely responsible for vaccination decision-making authority. A male doctor in LAC stated, “Medical doctors are aware of parents’ stigma, but I don’t deal with that in my practice. Parents don’t see the importance of the vaccine.”

**Adolescent boys and girls**—The third population with the highest intervention needs were adolescent girls and boys, with a focus on LGBTQ youth. In reference to adolescents, a male doctor in LAC stated, “They are not coming into see their doctor, unless they are ill. They don’t see the need.” LGBTQ individuals are a population of concern as they tend to be less likely to access the medical system, and may be less likely to initiate or complete the HPV series in a timely manner for optimal vaccine effectiveness. For example, one study found that less than half of lesbian and bisexual young women had initiated HPV vaccination and 30% of those who had initiated HPV vaccination did not complete the series [10]. Further, bisexual women tend to have higher rates of HPV infection than heterosexual and lesbian women [11]. HPV vaccination rates are even lower among gay and bisexual men. A study found that only 13% had been vaccinated [12]; while a review suggests that more than 50% of HIV-negative gay and bisexual men have an HPV infection with notably higher rates among those who were HIV-positive [13].

## Challenges and Barriers

**Primary challenges**—The most pressing challenge in LAC reported was the complexity of provider communications with multicultural and multilingual parents and patients; and the lack of follow through for the 2<sup>nd</sup> and 3<sup>rd</sup> HPV vaccine dose, particularly for ethnic minority, LGBTQ youth, and low-income populations. Currently, the results suggest that there is no systematic way to screen for high-risk youth and provide follow-up in LAC. A female health care provider in LAC stated, “The clinicians are not the problem, the parents are not the problem for initial dosage. The challenge they face is the follow-up with the second and third dose.”

The second most pressing challenge identified in LAC was parental attitudes and misperceptions that the vaccine would encourage youth sexual behavior. Similarly, a systematic review found that parental concerns about the vaccine's effect of sexual behavior was a potential barrier to HPV vaccination [9]. A female community healthcare representative stated, "There are cultural barriers. Some people feel that by getting their child vaccinated they are condoning their child to be sexually active."

The third major challenge was a limited public understanding of vaccine benefits. There are public misperceptions that the vaccine protects girls against cervical cancer without health benefits for boys. Thus, the HPV vaccine was still seen as only a vaccine for girls. Similarly, a systematic review found that parents who did not vaccinate their sons reported a perceived lack of direct benefit [9].

**Additional challenges**—The environmental scan also highlighted several additional challenges. There was a general lack of knowledge about the vaccine. Supporting this finding, a systematic review found that parents tended to report needing more information before vaccinating their children [9]. A female community healthcare representative in LAC stated, "Parents are not educated about the vaccine. There is a stigma they only need the vaccine if their children are having sex. They think their child is not having sex. Therefore, they are in denial. They don't want to talk about it. Presenting it as a choice to get or not get the vaccine is the problem." There were also parental concerns in LAC about vaccine adverse effects, safety, and newness, which is also supported by a systematic review [9].

Another challenge was the complexity of minor consent and safeguard as well as maintaining privacy of youth health records. Despite minor consent laws in California established on January 1, 2012 that allow children 12 years and older to consent to confidential medical services for the prevention of sexually transmitted diseases (STD), including HPV vaccinations, without their parents' consent, HPV vaccine administration can be "tricky" because of youth access and parental intervention. Additionally, people may not be aware of the minor consent laws. As a female from a nonprofit health organization in LAC said, "HPV is tricky, you need consent from parents. The language is not clear if teens can consent for themselves or not. No massive scale campaign."

Further, it can also be difficult navigating complex health services and access. There are healthcare coverage gaps. Youth going from medically uninsured to insured or vice versa create a challenge for tracking doses and follow-up. There was a lack of regular health care visits for adolescents in LAC. Even when adolescents did attend health care visits, there was a lack of or inconsistent provider recommendation for the HPV vaccine in LAC, which is also echoed on a national level [7]. A further challenge was that the vaccines are not mandatory for school admission. Effective July 1, 2016 children in California were no longer exempt from school mandated vaccinations for personal or religious reasons; however, the HPV vaccine is only a recommended, not mandated, vaccine in California.

The cost of the vaccine may also prohibit some individuals from receiving it. It is also difficult to provide free or affordable vaccine services for undocumented young adults (18–26 years old) in LAC. A male, pharmacist in LAC stated, "It's not driving my pharmacy,

because it is a sensitive topic. Pharmacists are not recommending it. It's an expensive vaccine (\$200). It's not covered through some insurance."

From a research viewpoint, there is a lack of good data locally and nationally. There were no systematic ways of identifying LGBTQ youth in most of the surveys. As such, it was very difficult to specify HPV vaccination needs of LGBTQ youth at high risk for HPV infection in LAC. There were only a few surveys that were collecting the type of information that would allow for targeting these highly vulnerable populations. More local and national research on HPV vaccination needs to be conducted to help further understand community needs and fill in some of the gaps in knowledge.

### Recommendations to Improve Local Efforts

**Communication training for clinicians and community-based providers**—To improve vaccination rates against HPV related cancers in Los Angeles, more concerted efforts are needed in the training of clinicians and community-based providers on how to communicate more effectively with families about HPV vaccination and the importance of completing the vaccination series. A female, community healthcare representative stated in reference on how to improve vaccine uptake, "More information and resources for the community. Better communication to adolescents." While the current study found that provider communication about HPV vaccination needs to be improved in LAC, this seems to be the case nationally as well. A study found that provider recommendation of the HPV vaccine tended to be inconsistent, behind schedule, or given without urgency (i.e., did not recommend same-day vaccination) [14]. Further, HPV vaccine recommendation by physicians can significantly improve immunization rates [8]. School and clinic nurses, physicians, and staff should be trained on updated CDC HPV recommendations. Clinicians should be trained on how to explain risks and benefits of vaccination to potentially high-risk patients and their families.

**Piloting and evaluating multicultural, multilingual education-based HPV vaccination interventions**—The second highest priority was piloting and evaluating multicultural, multilingual education-based interventions (e.g., Spanish, Vietnamese, Korean, and Chinese) that would increase HPV vaccine knowledge and address parental and other attitudes, fears, and misconceptions in culturally appropriate ways regarding vaccination in general, and HPV vaccines in particular. There is some evidence to support that such an approach could be effective. For example, one multilingual, multicultural HPV vaccine education intervention to empower Latino and Korean Americans showed improvements in HPV infection and vaccine knowledge, informed decision-making, and decisional conflict [15]. Educational materials should include visual aids (e.g., pie charts, icon arrays) and be targeted at appropriate reading levels for youth and parents of varied educational levels. Such an approach has been shown to make materials more accessible for individuals with low health literacy levels due to age, language, and limited medical knowledge [16]. For example, a systematic review of interventions for individuals with low health literacy found several effective design features to mitigate the effects of low health literacy such as including icon arrays to numerical information, adding video to verbal

narrative, presenting information so that the higher number is better, and presenting important information first or by itself [17].

**Training promotores de salud and other community health workers to conduct outreach and health promotion to vulnerable groups—**

The third highest priority was training promotores de salud and other community health workers to conduct outreach and health promotion to vulnerable groups. Promoters de salud have increased cervical cancer screening in Hispanic women in the United States-Mexico border region [18], which suggests this could be an effective method to increase HPV vaccination among similar vulnerable populations. Further, there is a need to encourage outreach to the LGBTQ community to address unique issues and challenges regarding access to care and vaccinations for this population. Reiter and colleagues found that 83% of adult gay and bisexual men who had received a health care provider recommendation for HPV vaccination were vaccinated, while only 5% were vaccinated without having received a recommendation [12]. This suggests that provider outreach to this community could significantly increase vaccination uptake.

**Additional recommendations regarding HPV vaccination interventions and campaigns—**

The environmental scan also suggested additional steps to take regarding HPV vaccination interventions and campaigns. Interventions should be piloted and evaluated to increase uptake of the 2<sup>nd</sup> and 3<sup>rd</sup> dose only. Since the CDC has accepted two doses for certain age groups, more education is needed in order to promote limited doses when warranted. This may in part help alleviate concerns of parents, especially those that are already worried about vaccinations in general, but that might still see the value of protecting their children against such a pervasive type of cancer. Additionally, a non-education based intervention should be piloted and evaluated to improve vaccine uptake (i.e., an intervention focused on clinical outcomes). There should be community wide HPV awareness public health campaigns, including those that focus on youth and minority groups. These campaigns should focus on cancer in culturally and language specific ways. The campaigns should also encourage vaccination for both boys and girls. There are still parental misconceptions and limited knowledge about HPV and the vaccine in some groups.

**Additional recommendations to increase HPV vaccination uptake in LAC—**

Another recommendation is to assess LAC clinic capacity to identify high-risk youth and communication about vaccine follow-up. Additionally, LAC health care centers should create or enhance existing reminder call systems for youth and parents. Furthermore, there should be advocacy for and the development of standardized and inclusive data collection tools and methods locally and nationally. In LAC, there is a need for more information on new vaccines, Gardasil 9, other opportunities for vaccinating boys and girls against HPV, and the need to complete vaccine doses. Health care professionals and scientists who collect data and information should be encouraged to allow for a question that identifies high-risk populations, such as LGBTQ youth. LAC health care providers need to address the specific issues of ethnic minorities and LGBTQ youth. Steps should be taken to encourage legislation to help increase HPV vaccination rates not just in LAC, but also throughout California. For example, there should be greater advocacy for the vaccine to be school



required. A female school health coordinator stated in reference to how to improve vaccine uptake, “More counseling for families, making the vaccine mandatory, and Spanish materials.” As previously mentioned, a policy was enacted in 2016 that no longer allows religious or personal exemptions for school mandated vaccinations in California; however, the HPV vaccination is only a recommended, not mandated, vaccination in California. We will continue to work with our various partners and coalitions in order to encourage school-wide vaccination programs, as it has been shown to be an effective way of delivering the vaccine across multiple countries [19]. Further concerns of parents that do not wish to vaccinate need to be heard and addressed, and proper information distributed with risk and benefits so better-informed decisions can be made.

### **Local HPV Interventions and Resources**

Local HPV vaccination interventions and resources identified to improve the overall knowledge of HPV infection and vaccination as a cancer prevention strategy included: an online resource database, hotline referral services, pamphlets/booklets at proper literacy levels and in target language, online awareness campaigns, reminder calls for 2<sup>nd</sup> and 3<sup>rd</sup> doses, community based classes for parents, mobile health vaccination units, youth classes in school settings, health fairs, culturally tailored immunization programs in the target language at clinics, promotores/community health worker education, and school-based health centers that provided onsite HPV vaccinations to both male and female adolescents. In LAC, there were 73 centers and 70% of these provided onsite HPV vaccination to 13–17 year olds. Although LAC has developed important efforts, some interventions are no longer being implemented due to lack of funds; and many have not been evaluated with sufficient outcome data.

There are limited specific programs and services in LAC on HPV. County and state budget cuts have affected the provision of ongoing programs targeted to improve HPV vaccination rates. Given funding allocations, many programs have closed or are understaffed. There is a need for large HPV public health campaigns in the City and County of LA and within the catchment area of the Cancer Center, especially to increase vaccination rates among ethnic minorities and LGBTQ youth. Although some have had the first dose, there are challenges in continuing with the second and third dose (if needed).

### **Need for HPV Information**

The need for information about HPV varies. HPV vaccine information is embedded in STDs or cervical cancer prevention and control education. There is a need for HPV vaccination information to take center stage in the immunization arena to become part of a regular immunization schedule. This can take place via the schools and other community outlets. Community based education is best provided through health educators or promotores/ community health workers. These individuals have the pulse of the community. In LAC and the catchment area for the Cancer Center, we are in contact with a large group of promoters de salud, from Vision y Compromiso, a network of over 4,000 women mostly through California that can conduct door to door and small group education about HPV. Further, HPV information is provided during clinic visits using the Vaccine Information Statement

(VIS) for parents and adolescents. Materials used to promote or educate about HPV varies and many are outdated (i.e., do not include boys or the new 9 valent vaccine).

## Conclusion

Although there are many controversies and differences in attitudes regarding vaccinations overall in many communities, research indicates that vaccination against HPV is one of the most effective ways of preventing cervical cancer from occurring in sexually active individuals. Conducting an environmental scan is an essential first step in understanding HPV vaccination uptake within a community. The risk for cervical and other HPV-related cancers could be greatly reduced in LAC if a multilevel, multicultural, and multilingual approach is taken to increase rates of HPV vaccination uptake, particularly among racial/ethnic minorities and LGBTQ youth. Our environmental scan provided a guide on how best to address the needs of LAC families and providers. Clinicians and nurses should be trained on how to better communicate the importance and benefits of the HPV vaccine with parents and adolescents. Reminder call systems should be implemented for youth and parents to increase follow-up with the 2<sup>nd</sup> and 3<sup>rd</sup> dose of the HPV vaccine. Innovative and engaging educational materials need to be developed in multiple languages to inform high-risk youth and their parents. These may include videos using creative methods to reach target populations, such as narratives, Webisodes, photonovelas, and cartoons. They can be disseminated at clinic sites, community presentations, and via mobile technology, and social media outlets. Finally, public health campaigns should be developed that account for appropriate language and literacy levels. An important goal is to increase HPV vaccination knowledge and change attitudes among parents, encourage vaccination for both girls and boys, and strengthen recommendations by providers.

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### Highlights

- The highest priority is for clinicians/providers to recommend HPV vaccinations.
- The biggest challenge was provider communication with multicultural families.
- Providers need training on effective multicultural HPV vaccination communication.
- HPV vaccination uptake should be encouraged for both adolescent girls and boys.
- A multilevel, multicultural, and multilingual intervention approach is recommended.