



## CITIZEN SCIENTIST PROGRAM

### APPENDIX A: CHECKLIST OF ITEMS TO SEND BEFORE MEETING WITH THE CITIZEN SCIENTISTS

- ✓ **Biosketch:** a short biographical sketch – but not NIH-formatted. This should also be in lay language. Please see the example in this document.
- ✓ **Project Overview:** a short summary of your proposed project. Again, this should be in lay language and should include information about the research question, methods, outcomes, and what you hope to accomplish by conducting this research. Please see the examples in this document.
- ✓ **Reading materials:** Citizen scientists have expressed their need to read and comprehend as much about your project as possible in advance of meeting with you. An important piece of the citizen scientist training program includes information on the need to treat your intellectual property with strict confidentiality. Your interaction efforts will be much enhanced by providing your entire proposal or other written material for the citizen scientists' perusal.
- ✓ **Meeting Goals:** a list or description of what you hope to accomplish by meeting with the citizen scientist. This can also include a meeting agenda or list of questions.
- ✓ **Acronyms/Definitions:** send a list of acronyms or terms that need to be defined.

**1. Biosketch:** A short biographical sketch – but not in NIH format. This should also be in lay language. Please see the example below.

**2. Project Overview:** A short summary of your proposed project. Again, this should be in lay language and should include information about the research question, methods, outcomes of interest, and what you hope to accomplish by conducting this research. Please see the [rewritten lay abstract in this booklet](#) for an example of how to create a brief overview of your project.

### Short Bio example:

My name is \_\_\_\_\_,

and I am a \_\_\_\_\_

*(Doctor of Pharmacy; General Internist; etc.).*

I am currently in my \_\_\_\_\_ year of a

\_\_\_\_\_

*(post-doc; internship: etc.),*

and I am conducting this research

\_\_\_\_\_

*(as a conclusion to my formal education; as my first research project as a junior faculty, etc.).*

On this project, I will work as the

\_\_\_\_\_

*(PI or co-PI).*

# MODIFYING A SCIENTIFIC ABSTRACT

As a test, try modifying the scientific abstract below to an abstract written in lay language. When you are done, read over the two examples that illustrate effective and ineffective attempts at translating the abstract for a lay audience to familiarize yourself with best practices for preparing your documents for citizen scientist review. Pay close attention to how the reading level changes, as indicated in brackets at the end of each paragraph.

## HPV Vaccination among Medicaid Providers: Does Provider Recommendation Lead to Vaccine Administration?

Susan T. Vadaparampil, Stephanie A. Staras, Teri L. Malo, Katie Z. Eddleton, Shalanda A. Bynum, Juliette Christie, Maria Rodriguez, Anna R. Giuliano, Elizabeth A. Shenkman

**Background:** Physicians who recommend the human papillomavirus (HPV) vaccine may subsequently administer it in their office or refer patients to another facility for vaccination. The latter may lead to a delay or even failure in vaccine administration. [15.5 reading level]

**Purpose:** The primary aim of this study was to identify factors associated with differences in providers' self-report of HPV vaccine administration to 11-12 year old female Medicaid enrollees among providers who recommended the vaccine. [22.6 reading level]

**Methods:** A sample of 800 providers was randomly selected from the Florida Medicaid Master Provider File. In October 2009, primary care physicians were mailed a survey that evaluated physician demographic and practice characteristics; HPV-related information and knowledge; and HPV vaccination barriers. Physicians were asked separate questions assessing the frequency with which they recommended and administered  $\geq 1$  dose of HPV vaccine to 11-12 year old female Medicaid patients in the past 12 months. Response options were based on a 5-point Likert-type scale ranging from never to always. These responses were dichotomized into often/always vs. other responses. Among physicians who reported often/always recommending the vaccine, additional analyses were conducted to determine factors associated with vaccine administration. Provider factors (e.g., specialty) associated with vaccine administration at the

bivariate level were evaluated simultaneously in a logistic regression model with administration (often/always vs. other) as the outcome variable. [15.8 reading level]

**Results:** The response rate was 68.3% (n = 485). The current analysis included the 266 eligible respondents who reported they often/always recommended HPV vaccine. Of those physicians, 186 (69.9%) reported they often/always administered the vaccine. Administration was lower in non-Vaccines for Children (VFC) providers (odds ratio [OR], 0.162; 95% confidence interval [CI], 0.031 – 0.857) compared to Vaccines for Children (VFC) providers. Family physicians were less likely to administer, compared to Pediatricians (OR, 0.359; 95% CI, 0.132-0.977). Physicians who reported parents often/always refused HPV vaccination also were less likely to administer HPV vaccine relative to physicians who experienced less frequent refusal (OR, 0.268; 95% CI, 0.135-0.532). [16.7 reading level]

**Conclusions:** Although physician recommendation is an important first step, vaccine delivery is necessary to prevent cervical cancer and reduce subsequent cervical disparities in medically underserved populations. By identifying potential sources of discordance between vaccine recommendation and administration, health services interventions can be designed to address barriers specific to vaccine administration. [22.4 reading level]

## AN INEFFECTIVE ATTEMPT AT MODIFYING THE ORIGINAL ABSTRACT FOR A LAYPERSON READERSHIP

Here is an example of an attempt to modify the language so that the average person can easily understand the purpose of this study. The words in red indicate text that has been altered. As you can see, the reading level is still far above the recommended level of ninth grade.

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**Background:** Physicians who recommend the human papillomavirus (HPV) vaccine may later administer it in their office or send patients to another office for vaccination. The second option may lead to a delay or even failure in vaccine administration. [14.1 reading level]

**Purpose:** The primary purpose of this study was to identify things related to differences in providers' self-report of HPV vaccine administration. This study asked doctors to answer questions about 11-12 year old female Medicaid enrollees. This study included only providers who recommended the vaccine. [13.9 reading level]

**Methods:** 800 providers were randomly selected from the Florida Medicaid Master Provider File. In October 2009, primary care doctors were mailed a survey that collected information about (1) doctor and practice characteristics; (2) HPV-related knowledge; and (3) HPV vaccination barriers. Doctors were asked questions about the frequency with which they recommended and administered at least one dose of HPV vaccine to 11-12 year old female Medicaid patients in the past year. Response options were based on a 5-point scale ranging from never to always. These responses were combined to "often/always" vs. "other responses". For doctors who "often/always" recommended the vaccine, additional tests were completed to see what factors were associated with vaccine administration. We evaluated provider factors, like specialty, associated with vaccine

administration at the bivariate level. This evaluation was completed simultaneously in a logistic regression model with often/always giving the vaccine as the outcome variable. [13.2 reading level]

**Results:** The response rate for the study was 68.3% (n = 485). We included the 266 doctors who reported they often or always recommended HPV vaccine in this study. Of those doctors, 186 (69.9%) reported they often or always gave the vaccine. Non-Vaccines for Children (VFC) providers administered the HPV vaccine less often compared to Vaccines for Children (VFC) providers (odds ratio [OR], 0.162; 95% confidence interval [CI], 0.031 – 0.857). Family medicine doctors were less likely to administer the vaccine, compared to pediatricians (OR, 0.359; 95% CI, 0.132-0.977). Doctors who said parents often or always refused HPV vaccination also were less likely to give the HPV vaccine compared to doctors who experienced less frequent refusal (OR, 0.268; 95% CI, 0.135-0.532). [14.0 reading level]

**Conclusions:** Doctor recommendations are an important first step toward HPV vaccination. However, vaccine administration is needed to prevent cervical cancer and reduce the likelihood for cervical disparities in medically underserved populations. By identifying potential reasons why the vaccine is not being administered, health services interventions can be created to focus on barriers specific to vaccine administration. [17.2 reading level]

## AN EFFECTIVE ATTEMPT AT MODIFYING THE ORIGINAL ABSTRACT FOR A NON-RESEARCHER

Finally, here is an example of the abstract written in lay terms that both retains the original meaning and provides the entirety of the message without including words, phrases or concepts that would be difficult for a non-researcher to understand.

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Susan T. Vadaparampil, Stephanie A. Staras, Teri L. Malo, Katie Z. Eddleton, Shalanda A. Bynum, Juliette Christie, Maria Rodriguez, Anna R. Giuliano, Elizabeth A. Shenkman

**Background:** Some doctors recommend the human papillomavirus (HPV) vaccine. Sometimes doctors give the shot in their office but they might also send patients to another office. Sending patients to another office can mean that some patients wait to get vaccinated. Sometimes the patient doesn't get vaccinated at all. [9.4 reading level]

**Purpose:** The purpose of the study was to find differences between doctors that might be related to how they give the HPV vaccine. This study only included doctors who recommend HPV shots. This study asked doctors to answer questions about how they would talk to 11-12 year old girls who are enrolled in Medicaid about the HPV shots. [9.8 reading level]

**Methods:** We used the Florida Medicaid Master Provider File to randomly select 800 doctors. In October 2009, we mailed a survey to primary care doctors asking about (1) doctor and practice characteristics; (2) HPV-related knowledge; and (3) issues that might stop a patient from being vaccinated. We asked doctors to think about how often they recommended at least one shot of the HPV vaccine to girls. We were interested in 11-12 year old girls that have Medicaid. We gave doctors five choices ranging from never to always. We combined the responses to either "often/always" or "other responses". For doctors who "often or always" recommended the vaccine, we looked to see what factors affected how often they gave girls the vaccine. We evaluated these factors at the bivariate level. We completed these evaluations at the same time in a logistic regression

model and used "often/always giving the vaccine" as the outcome of interest. [9.7 reading level]

**Results:** 485 doctors answered our survey (68.3%). We included in our analysis the 266 doctors who reported they often or always recommended the HPV vaccine. 186 of the doctors who answered our survey said they often or always gave the vaccine to their patients. Vaccines for Children (VFC) is a federally funded program that provides vaccines to children at no cost. Doctors do not have to participate in VFC. Non-VFC doctors gave HPV shots less often compared to doctors who participated in VFC. Family medicine doctors were less likely to give the vaccine compared to pediatricians. Doctors were less likely to give HPV shots if parents often or always refused to vaccinate their child. On the other hand, doctors were more likely to give HPV vaccines when they experienced refusal less often. [9.5 reading level]

**Conclusions:** Doctor recommendation of the HPV vaccine is important. However, girls need to receive the shots to protect themselves from cervical cancer. Low-income groups, like those on Medicaid, suffer from cervical cancer more often than other groups. We need to understand why doctors recommend the vaccine but then do not administer the shots. Then we can create interventions to increase the number of girls vaccinated. [9.4]