AICAF Story

The American Indian Cancer Foundation (AICAF) was founded in 2009 and became operational in 2011.

A registered 501(c)(3) non-profit organization, AICAF was established to address tremendous cancer inequities faced by American Indian and Alaska Native communities.

AICAF is led by American Indians, with an array of expertise and experience serving the health needs of our people.
Our Vision

Our vision is a world where cancer is no longer a leading cause of death for American Indian and Alaska Natives.

Through hard work, culturally appropriate community-based programs, and policy change that affords Native people access to the best prevention and treatment strategies, we see a day where American Indian communities are free from the burdens of cancer.

Current Projects

- Healthy Native Foods
- Community Conversations on Tribal Health Equity
- Clinical Systems Improvement for Tobacco and Cancer Screening
- Community Health Worker & Colorectal Cancer Screening Navigator
- Evaluation Support for Tribal Cancer Projects
- Immunizations for Cancer Prevention
- Pink Shawls Breast Cancer Education
- Native Cancer Survivor Support
- Powwow for Hope
HPV background

HPV is a common infection most people come in contact with sometime in life

HPV causes many types of cancer

- Cervical
- Anal
- Penile
- Vulgar
- Vaginal
- Some throat cancers (oropharynx)

HPV and cancer

What percentage of lung cancer is caused by smoking?

80%-90%
HPV and cancer

What percentage of cervical cancer is caused by HPV?

99.9%

HPV cancer and American Indians

American Indians face significant disparities for HPV cancers

Varies by region

- Northern Plains American Indians are 4x more likely to get and die from cervical cancer
- American Indians in Minnesota 2x more likely to get throat cancers, the most common HPV cancer for men
The HPV vaccine

A vaccine is available that can protect against the types of HPV that cause 70% of these cancers.

BUT, vaccination rates are low.

Vaccination rates

General population
Girls: 53.8% first dose, 33.4% three doses
Boys: 20.8%, 6.8% respectively

American Indians
Girls: 67.7% first dose
Boys: 24.9% first dose
Research process: Planning

Prevent Cancer Foundation grant with Minnesota Cancer Alliance

Met with CDC, IHS, Fond du Lac in formative stages

Recruited a graduate student to maximize resources

Determined target audience
  - Parents or guardians of American Indian adolescents ages 7-12

Focus Groups
  - Goal: 6 focus groups with at least 36 participants
  - Locations: St. Paul and Minneapolis

Research process: Recruitment

Designed recruitment strategy

Recruited via:
  - Local organizations and community centers that serve American Indian families
    - Posted flyers
    - Utilized personal contacts
    - Organizations distributed flyers
  - Mass communications
    - Facebook (2,381 likes), Twitter (723 followers), Indian listserv (1,008 subscribers)
  - Tabled at community events (Little Earth)

Screened potential participants via phone
Participants

39 total participants
7 focus groups (range: 3-10 per group)

Participant demographics:
- Split evenly between parents of boys and girls
- Urban
- 82% were parents
- Female (95%)

Survey: Attitudes and Beliefs

I understand what HPV is.
- 61% Agree

I understand what the HPV vaccine is.
- 49% Agree

I have enough information to decide whether to vaccinate my child.
- 34% Agree
Survey: Attitudes and Beliefs

The HPV vaccine prevents cancer.
- 65% Agree
- 35% Disagree (0% Strongly disagree)

The HPV vaccine will help my child stay healthy.
- 65% Agree
- 35% Disagree (0% Strongly disagree)

The HPV vaccine could be bad for my child’s health.
- 29% Agree (0% Strongly agree)
- 71% Disagree

Survey

Where do you take this child to the doctor?
- 51% Other clinic (Not American Indian specific)
- 28% Indian Health Board
- 21% Native American Community Clinic
- 3% Emergency room

Where have you heard about the HPV vaccine?
- 18% Never heard of the HPV vaccine
- 41% Doctor
- 28% Clinic/hospital poster brochure
- 18% On the Internet
- 15% Friends
- 15% On the TV/radio/newspaper
- 10% Family
- 8% Child’s school
Research process: Focus group questions

Goals:
1. What are the knowledge gaps about the HPV vaccination, and what are the best ways to address these gaps?
2. What are attitudes and beliefs towards the HPV vaccination?
3. What other barriers are preventing parents from vaccinating their children for HPV?
4. How can educational materials be improved for American Indians?

Focus group questions

What questions would you ask?
Focus group questions

1. Tell us your first name and one thing your child does that makes you smile.
2. What is a healthy child to you?
3. Who influences parents’ decisions whether to vaccinate their children when they are in the age range of 9-12?
4. Before today’s group, what have you heard people in the Indian community say about the HPV vaccine?
5. What might stop people in your community from getting the HPV vaccine for their children?
6. Reactions to current HPV educational flyers
   - What are your reactions to this image?
   - What do you think of the message?
   - What do you think of the image itself?
   - Who would this speak to?
7. If you had to pick your favorite, which one would you choose, and why?
8. How could these messages be improved for American Indian communities?
9. What would be the best way to reach American Indian parents with these messages?
10. What would be the best way to reach your children?
11. If you were encouraging a friend or relative to get the HPV vaccination for their child, what would you say?
12. What do you still want to know about the HPV vaccine?
If there were a vaccine against cancer, wouldn't you get it for your kids?

HPV vaccine is cancer prevention. Talk to the doctor about vaccinating your 11–12 year old sons and daughters against HPV.

www.cdc.gov/vaccines/teens

You’re not opening the door to sex.

You’re closing the door to cancer.

HPV vaccine is cancer prevention. Talk to your child’s doctor about vaccinating your 11–12 year old against HPV.

www.cdc.gov/vaccines/teens
Now is the time to protect your pre-teen daughter from cervical cancer.

Cervical cancer is caused by a common virus called the human papillomavirus (HPV).

- Each year in the U.S., about 12,000 women get cervical cancer and about 4,000 women die from it.
- The HPV vaccine can prevent cervical cancer.
- The vaccine is safe and very effective.
- Doctors recommend the HPV vaccine for all 11 and 12 year old girls. Ideally, girls should get the vaccine before their first sexual contact, when they could be exposed to HPV.
- Girls and young women ages 13 through 26 should also get the vaccine if they have not done so yet.

Ask your doctor or local clinic about getting the vaccine for free through the Vaccines for Children (VFC) program.

HPV and Cancer

HPV is the number one cause of cervical cancer in the United States. In fact, about 13,000 women and 4,000 men are affected by HPV-related cancer. Many of these cancers could be prevented with vaccination. In both males and females, HPV causes cancer and serves as the first step in the development of other cancers, which cause death.

Two vaccines—Gardasil and Cervarix—are available to prevent the HPV types that cause most cervical cancers and are used. One of the HPV vaccines, Gardasil, also prevents warts and genital warts in males and females. Both vaccines are given in a series of 2 doses.

Is the HPV vaccine safe?

Yes, both HPV vaccines were studied in tens of thousands of people around the world. More than 30 million doses have been administered in the U.S. and other countries, and the vaccines have proven to be very safe. In the United States, more than 200,000 girls and young women have received the HPV vaccine in recent years.

Why does my child need this now?

HPV vaccine offers the best protection to girls and boys who receive all three vaccine doses and get the vaccine before they become sexually active with another person. It is not too late to say that your protection is needed too. In fact, it is just too early—too important to get your child vaccinated before she goes on her first sexual contact. The most effective time to receive the vaccine is before you become sexually active, and this would mean better protection for your child.
Research processes: Analysis

Extremely time consuming!
- Transcription
- Multiple rounds of coding
- Frequency charts
Research processes: Analysis

P7: Personally, I don’t understand with like flu shots, because every time I’ve gotten one I’ve gotten really sick, and my youngest son Daniel, he would get it and he would get sick. Or he didn’t get sick or something.

P6: I asked about that too, I asked why they get sick after the flu shot, and they said that it’s because they give you the flu.

P8: Yeah, but it’s like sleeping

P6: But just a small amount

P1: Yeah I got sick last time I had it, when I got pregnant with my 7-year-old, and I was sick for like 2 months, and you can’t take Nyquil or anything when you’re pregnant, so I haven’t had flu shots since.

P7: I just don’t understand why you get so terribly sick, cause I got really sick

P8: They say some people get sick, some people don’t.

P2: I’ve never gotten sick

P8: I get mine every year, and I’ve never been sick

P7: And I’m vaccinated too. So I don’t know. That’s why I wanted to come to this class to learn, because there’s so much I don’t know about vaccinations, even though I’ve always had my kids vaccinated, but there’s some things I didn’t let them get...Like the flu shots and stuff like that

Research processes: Analysis

P2: The girl’s expression. She’s kind of just like (makes face similar to the girl)...maybe? She should be smiling, happy that she got it, healthy...but she’s just like (makes face) possibly...like she’s just looking at the ceiling like “possibly…”

P7: To be honest, I don’t think a lot of 11-12 year olds would be sitting there thinking about it. It looks like a question she’s contemplating, but in all reality no kid that age is going to really contemplate about a vaccine. Unless the shot comes! Then they’re not going to want it.

P6: Really, if you think about it, it should be like a parent with maybe a boy and a girl or something, and the parent should be thinking about it (P2: yeah)

P2: That’s a good one! (all laugh)

P7: Way to go (laughs)

P7: High five! (laughs)

P6: High five

P7: Little t-rex arms (all laughing)

P2: I like her eyes though, super green. Who did her eyebrows, sorry

P7: I wasn’t going to go there...but it has to be a little Native girl, with green eyes? (laughs)
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<td>33 Cancer is a severe disease (personal and community)</td>
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<td>8/14 page 13</td>
<td>Sometimes I'm more scared of the vaccine itself than the prevention.</td>
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<td>8/21 page 2</td>
<td>You can't just trust that doctors are making the right decision for your children, because they're your children.</td>
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<td>6/26 page 8</td>
<td>Some people I know don't get vaccines for their babies, then someday like me I will come around and say &quot;you need to get vaccinated!&quot; but I won't be able to help anyone out about HPV if no one knows. If no one is aware of it.</td>
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<td>6/26 page 9</td>
<td>Get it at health fairs and just put it out there and make [HPV] more of a part of the household vaccine names, instead of making that one stand out from the rest.</td>
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| 6/26 page 9 | Don't separate it out, (The HPV vaccine) is kind of on its own when it comes to vaccines the way it sounds. I mean we all know about the other vaccines, maybe not even a bit but it's something so common in our community that it's just something that you do, and then here's this other vaccine that's kind of off to the side and everyone's kind of like "oh ok, it's not part of this group."
| 6/26 page 15 | It's opening another door, other than to talk about cancer. |
| 6/26 page 16 | If my 10-year-old saw this, he would probably just be like it, it would shut him down. Just because I know all kids are different and mature different. My son's very mature for his age, but right now sex is just not the thing for him. Maybe cancer, because his grandma has cancer. Cancer might catch his eye, but sex he might be like:"I do I don't want that!" I don't want to talk about it. I don't want to see it. Leave me alone. But now he might be like "oh, grandma has cancer so..." |
| 6/25 page 17 | I just think that for that age group it's hard, if you want to really talk to your kid about something like this, just thinking about my own son would say "I don't want to know about that, I'm not even ready. That's not for me right now." |
| 6/25 page 17 | If you want to talk to your kid about some kind of prevention, I don't think that would be the way to start it, off, with sex. |
| 6/30 page 7 | You know, if there were a vaccine against cancer, would you get it for your kids? Yeah! Just like we get for polo, or measles. |
| 6/30 page 7 | What does sex have to do with cancer? |
| 6/30 page 13 | But as far as this [the HPV vaccine], if there weren't side effects, then yeah, I would definitely recommend it. I would push it all the way, because cancer, like diabetes, is big in Native communities. |
| 7/17 page 2 | I'm leery of vaccines, you know? Just...I like to know what's in them. Where do they come from? I like to know everything about them before I give my child a vaccine, unless it's like an absolute necessary thing. |
| 7/17 page 2 | It's really hard because I do have family members who are leery about vaccination...because you're talking about the American Indian community where there has been a lot of mistrust with our government providing us with things that probably weren't ideal for our population, and so I've seen a lot of Indian people who are leery about vaccinations in general. |
| 7/17 page 3 | If there's a chance your son can get cancer and you can prevent it...that was my thought...I'm saving his life before he knows it. |
Research processes: Analysis

Important to involve American Indians at all stages of the research process, including analysis.

Example:

P2: Yeah I think the Indian communities, pretty much everybody gets vaccinated because all these other races are coming in and they're not vaccinated (P?: mmhmm) and they're spreading it around.

Research processes: Analysis

P4: I think now, with the influx of so many people coming from other countries that are not vaccinated for some of the diseases that WE have kind of not re-eradicated in the country. Like polio, there's a big influx of that, TB, that sort of thing. I think the vaccines protect us and our immune systems and help protect our kids because in schools kids are exposed to much more than we are, and they're in close quarters. And they're exposed to all kinds of other kids from other cultures and other countries, so I think it's important, for me anyways it's really important that he has the vaccines. I mean, there's pros and cons to everything, and the side effects...I think some kids, they say they've had hearing loss or whatever from the vaccines, but I think a lot of, in general that hasn't been that many...I mean, they had a polio vaccine when I was little and we got all of our shots at school. That's how far back I go.

I'm not going to tell you how old I am, but I'm up there. And at that time I had some classmates who had contracted polio so they couldn’t get the vaccine because they had already had contracted the polio virus, but when they found out there were some kids who weren’t vaccinated, they quickly rushed us in and vaccinated us. You know, and I think that that helped, it kind or eradicated a lot of it. Very seldom do you see people that have had polio at one time in their life, whereas when I was younger you used to see a lot.
Findings

Need more knowledge and awareness
- Need more info on safety, info specific to American Indians, trusted source

Influences to vaccinate
- Community, normative/required, parent’s decision, doctors
  - Peer-to-peer, policies, targeted messaging to parents

Messaging
- Needs more boys!
- Focus on cancer (and not just cervical)
- Use American Indian-specific data and images
- Outreach at community events
- Facebook and other social media
- Educational materials

Findings

Safety concerns
- Need to weigh the “pros and cons”

Mistrust
- Doctors, government, experimentation

Fear of infectious disease
- Historical context

Cancer is a severe disease
- Personal and community
Findings: Design and outreach

- People who are easily identifiable as American Indian
  - braids, long dark hair, beaded earrings, moccasins
- People in regalia, at powwows
- People from local community
- American Indian symbols and objects
  - four colors, medicine wheel, dream catcher, border, tipi, Ojibwe floral design, feathers, drums
- Words from American Indian languages (Anishinaabe, Dakota, Lakota)

Findings: Differentials

Mistrust

Sex is the wrong message

Convenience, cost not significant barriers

Need for reliable messages
AICAF team:
- Design manager
- Researchers
- Media

Resource needs:
- HPV brochure
- HPV poster/flyer
- Social media posts
- Fact sheet on HPV and HPV immunization
- Newspaper article for tribal papers announcing the need for HPV education and availability of materials

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**Resource Development**

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**HPV Cancer Prevention**

*A parent’s guide to the HPV vaccine for your 11-12 year old child*

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The American Indian Cancer Foundation asked parents what they needed to know about the HPV vaccine. We listened, and want to give parents accurate information to help them make the best choice for your child.

**Why does my child need the HPV vaccine? Is it necessary?**

Cancer is the second leading cause of death for American Indians. By getting the HPV vaccine for your child, you can protect them from many cancers, which include cervical, anal, penile, vaginal, and some throat cancers.

**What is the best age to get the vaccination?**

The vaccine is designed to be most effective for children aged 11-12. Children can start to get the vaccine at age 9, but it is not as effective. It takes a long time for cancer to develop. Getting the vaccine now, when it is most effective, will protect your children from cancers later in life.

**What is HPV, and what does it have to do with cancer?**

HPV is a common infection that can cause several types of cancer. HPV is passed from person to person, mainly through skin-to-skin contact, and people will come into contact with HPV in their lives. It is important to get the vaccination before coming into contact with HPV, which can then develop into cancer.

**Is it safe?**

Yes. There have been 17 million doses given of the HPV vaccine, with no serious safety concerns.

**Does it actually prevent cancer?**

Yes. The vaccine prevents the types of HPV that cause 99% of those cancers.

**How can I get the vaccine?**

Talk to your doctor about the HPV vaccine, even if they don’t bring it up. The vaccine is free for all American Indians through the Vaccines for Children program.
Research process: Dissemination

Dissemination
- Focus group findings
  - National conferences: NIHB, Prevent Cancer Foundation
  - Publishing a paper
- Educational materials
  - Broad dissemination
  - Tribal health systems
  - Partners across the US
  - Native Health News Alliance
  - Looking for new partners, funding for best dissemination
Thank you!

www.AmericanIndianCancer.org