



**Portland Area Indian Health Service** 

# Evaluation of Patient and Provider Knowledge, Attitudes and Beliefs Regarding Childhood Immunizations

**Final Report** 

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#### INTRODUCTION

Childhood immunization services are one of the most fundamental preventive health services provided in medical clinics across the country and are responsible for preventing over 13 million cases of infection with vaccine-preventable diseases and 33,000 deaths annually in the U.S. The cost savings of routine childhood immunizations are likewise phenomenal. For each cohort of children vaccinated it is estimated that \$9.9 billion are saved in direct service costs and \$43.3 billion in total societal costs.<sup>1, 2</sup> Multiple factors determine whether parents utilize immunization services and the degree to which children are vaccinated according to recommended schedules. Among these factors are parents' understanding of the benefits and risks of vaccines and their perception of the risks of not being vaccinated.<sup>3, 4</sup> On the clinical side, access to immunization services and the attitudes of immunizations providers with regard to benefits and risks of vaccines and risks of vaccines and the likelihood of children being fully immunized.<sup>5-8</sup>

The Portland Area Indian Health Service (PAOIHS), in collaboration with the Northwest Portland Area Indian Health Board (NPAIHB), operates a comprehensive childhood immunization program. This program provides training opportunities for local immunizations coordinators in using the Resource and Patient Management System (RPMS) Immunizations Package, oversees quarterly web-based reporting, supports automated immunization data exchange through technical assistance to States and local sites and provides medical direction for clinical providers and immunizations coordinators with regard to outbreaks of vaccine-preventable diseases and vaccine recalls.

Aggregated, Area-wide data on vaccine coverage is obtained through the IHS National Immunization Reporting System (NIRS), a web-based reporting system that collects information from reports provided at each site from within the RPMS immunization package. Immunization coordinators at each local facility are responsible for maintaining up to date immunization data electronically in RPMS, running the reports each quarter and then inputting the information into NIRS. Recently, several sites have changed to commercially available electronic medical record systems in place of RPMS. While these sites should still track immunization data in the same way to ensure adequate immunization coverage at the community level, only one of the sites that have switched to non-RPMS systems are currently reporting data.

Immunization coverage in the Portland Area among two-year olds decreased from 2007 to 2011 (Figure 1). Two-year old immunization rates in 2007 ranged from 68% in the first quarter to 72% in the second and third quarters and remained on average 70% through the end of 2009. In 2010-2011, the rate dropped about 10% on average to 60%. Since 2008, site-specific data was available to track performance of Federal, direct service sites compared to the aggregate Portland Area. From 2010 to 2011, the average rate at Federal sites improved considerably. The disparity in two-year old immunization rates between Federal and all Portland Area has grown from an average of 5% in 2008 to 32% in 2011. The causes of this disparity are not well understood; identifying the underlying reasons for this difference in performance was one of the primary goals of this project.



#### Figure 1. Two- year old immunization rates by quarter for Portland and All IHS Areas, 2007–2011.

The figure above shows quarterly immunization coverage rates from 2007 to 2011 for Portland Area and IHS Nationally (All Areas). For 2007, the two year-old immunization bundle included 4 DTAP, 3 IPV, 1 MMR, 3 HIB, 3 HepB and 1 Varicella. In 2008, the two year-old immunization bundle included 4 DTAP, 3 IPV, 1 MMR, 3 HIB, 3 HepB , 1 Varicella and 3 Pneumococcal. From 2009 to 2011, the two-year old immunization bundle included 4 DTAP, 3 IPV, 1 MMR, 3 HIB, 3 HepB, 1 Varicella and 4 Pneumococcal. In Portland Area, immunizations rates declined deeply in 2010, with some increase seen in 2011. For Portland Area Federal Sites, immunization coverage has been at least equal to or greater than the National figures since 2009.

The Childhood Immunizations Knowledge, Beliefs and Attitudes Project had three specific aims:

- To understand attitudes and practices regarding early childhood immunizations among professional staff at Federal, direct service clinics and Tribally operated clinics in the NW; a secondary aim related to staff surveys and interviews seeks to understand more about recommended immunizations for health care personnel;
- To understand reasons for early childhood vaccine acceptance and hesitancy in three NW American Indian tribal communities;
- 3. To identify opportunities to improve the rate of early childhood immunization rates throughout the Portland Area and develop a strategic plan to make improvement.

#### **METHODS**

#### Staff Attitudes and Practices Survey

An email-based survey was sent to all sites in OR and ID for distribution to staff who have any responsibility in providing early childhood immunization services. A similar survey was distributed in WA by the American Indian Health Commission of Washington. The results of that survey can be found at: http://www.aihc-wa.com/wp-content/uploads/2011/09/Health-Care-Workers-Immunization-Project-Final-Report.pdf. The survey was sent to professional staff, nonclinical staff such as reception and patient registration and clinical staff under medical or nursing supervision- medical assistants, nursing assistants, and those working in other areas of the clinic not specifically focused on immunizations services but who could play a role in referring patients (e.g. behavioral health, dental). The survey asked about their own beliefs and practices regarding early childhood immunizations and also the provision of immunizations for health care workers. The survey link was sent to Tribal Health Directors, IHS Clinic CEOs, Medical/Clinic Directors who were in turn asked to distribute the survey widely among their staff. A response rate cannot be calculated as there is no way to know who received the link and chose not to answer. Data Collection: All data was collected using password-protected personal computers. Email/internet-based surveys were conducted using SurveyMonkey and the data were downloaded to the Project Director's computer. The full survey can be found in Appendix A-1. No personal identifying information was collected with the surveys.

#### Key Informant Interviews

We performed key informant interviews of clinical staff at Federal and Tribal clinics in ID, OR and WA. Key informant interviews were performed with professional staff (Nurses, Advanced Practice Nurses, Physicians and Physicians Assistants, Pharmacists). The interviews were conducted by phone or in person and at least two interviews were sought at each site. The initial goal was to include at least three of the six Federal sites, one in each state, and to attempt to complete interviews at all six Federal sites. Opportunities to interview were offered to all Tribal sites with a goal of reaching at least 25% of the 28 clinics providing early childhood

immunization services. The Key Informant interview guide is found in Appendix A-2; the Key Informant interview data collection guide (Appendix A-3) and a consent form for Key Informant interviews (Appendix A-4). No personal identifying information was collected with the key informant interviews.

#### Community-based Focus Groups

We conducted focus groups in 3 NW American Indian tribal communities. Focus groups were composed of parents and other care-givers of infants and children under the age of six. We sought to include a diverse cross-section of those caring for children in these communitiessingle parents, married, foster parents, grandparents and extended family members caring for young relatives. Focus groups were designed for 8-12 participants. The primary inclusion criterion was currently or recently (within the past two years) having been the primary care-giver for a child under six years old at the time that care was being provided. We worked with immunization program coordinators and community health representatives to recruit participants at the three sites that agreed to host focus groups. Recruitment methods included announcements on local radio or in tribal newspapers, invitational fliers posted in public places and word of mouth. The focus groups were  $1\frac{1}{2}$  to 2 hours in duration and were facilitated by the Project Director and a staff member from the NPAIHB NW Tribal Epidemiology Center (NWTEC). Data Collection: Focus groups were recorded if there were no objections to obtain complete transcripts. Participants were asked not to use names, in cases where this occurred, the person's name was not recorded in the transcript. Data Analysis: Information from focus groups and key informant interviews was analyzed using Atlas TI, version 7 software (Scientific Software Development GmbH, Cologne, Germany) to identify major themes and to categorize themes for understanding and future action.

The facilitator script including the questions asked is included in Appendix B-1. The consent form for participants is included in Appendix B-2 and a sample recruitment flyer is Appendix B-3.

#### Funding and Tribal Approval

This project was funded by PAOIHS with funds made available to the NPAIHB in May, 2012. The budget and timeline are in Appendix C. The Delegates of the NPAIHB approved this project at the June, 2012 Quarterly Board Meeting. Approval from the Tribes hosting focus groups was obtained prior to holding the discussions. Participants who responded to the surveys and key informant interviews were asked to obtain approval from their supervisor before participating.

#### RESULTS

#### **Focus Groups**

We conducted one focus group in each of three different tribal communities. The attendees were primarily younger parents. In each group there were also some older parents/grandparents and at least one healthcare provider (nurse, nursing assistant or medical assistant) who was also a tribal member.

The discussions revealed a number of major themes that help explain why some parents may defer vaccines or refuse them altogether. These barriers can be grouped into: 1) vaccine concerns; 2) clinic barriers- perceived low quality of care, questionable practices or mistrust of the care provided at tribal clinics; 3) mistrust of the medical establishment in general, pharmaceutical companies or government; and 4) the influence of friends, families and prominent community members who were "against" vaccines as being an important influence in their decisions not to vaccinate.

#### Vaccine Concerns

Many participants voiced concerns about the safety of vaccines in general:

"The cure is going to kill you." "[The list of] side effects is longer than [the consequences of] getting the disease."

Newer vaccines were especially mistrusted as it was felt that there was not enough data or enough time to know all the potential negative outcomes from newer vaccines. These vaccines included HPV, Tdap, varicella and the flu shot, which changes every year. Other concerns about the influenza vaccine, specifically, were:

"The [flu] shot just gives the flu on purpose." "If you're just gonna get sick, why get the shot?"

There was also still concern about mercury and thimerosol content in vaccines as well as other ingredients that could be harmful.

#### **Clinic Barriers**

One of the strongest concerns expressed was regarding the perception that care at the clinic was substandard. Participants related experiences of missed diagnoses, wrong diagnoses, inadequate or potentially harmful treatment received and inconsistent follow-up with providers. Another concern was breach of confidentiality:

"...you can't trust anybody there. You don't feel comfortable going to your own clinic."

These concerns about quality of care were not specific to immunizations, but these experiences served to undermine overall trust in the clinical services available so that some parents were reluctant to bring their children to the clinic for immunizations or to accept recommendations for immunizations when offered.

*"I think if the clinic had better services everybody would be more [apt] to get their kids immunized. I think I would."* 

#### Mistrust of Medical Establishment, Pharmaceutical Companies and Government

A small number of parents expressed concerns about general mistrust in institutions including the medical establishment, pharmaceutical companies and the government. More than once it was mentioned that physicians, hospitals and pharmaceutical companies push vaccines for the money they earn from them.

One participant questioned not only the origin of the diseases for which vaccines are offered but also the origins of the vaccines themselves and the recommendations to receive them:

"So for a government official or a social worker, any type of service from the government could mandate or strongly recommend these immunizations for these diseases that you probably never had- that raises a lot of concern for myself and for my family because we've never had any of these, why should we get these vaccines?"

Another participant expressed her fears that the government was forcing vaccines for no apparent reason:

"Sometimes I think it's a scare tactic, the government is trying to scare us into doing all this stuff when they don't even know if it works."

#### **Community Influences**

Some participants shared that their elder's views were an important influence. Many elders were described as mistrusting the advice of doctors or the government and used that as a basis for declining clinical services including immunizations. Another mentioned that elders who have survived epidemics, such as the Spanish Flu, believe that their survival indicates they no longer need to be treated for anything else. Others described elders who accepted immunizations and urged parents to immunize their children. Some elders drew from the experience of having witnessed vaccine preventable diseases. But even then, the interpretations and views were different:

"But my grandparents [saw] the mass graves where the small pox people are buried, they won't have anything to do with it."

"So I have one [elder] where she wants to get everything because she definitely doesn't want to get sick."

#### Facilitators

Focus group participants also described a number of practices and influences that facilitate or could facilitate childhood immunization. For example, within the clinic, Medical Assistants are often the first staff to ask patients about immunizations and the first to provide information or

recommendations. Others shared that their doctor is the one they trust most for information. A provider who is open and willing to answer questions can have a great influence:

*"I'd have to say my doctor's pretty good...She puts it pretty straight and easy to understand. Whenever I have a question she's more than willing to answer it."* 

This level of communication is what many participants felt would be most beneficial and, for many, it is currently lacking. Openness and flexibility are other qualities that were mentioned as important to building community trust:

" I think we really do have good healthcare providers who are open to all patients...our staff is working to kind of just be present in the community to help build the trust, not as "pushers', just to be present, just to build rapport and build a trust that has to come before we can plant the knowledge in them."

Many participants felt that more information on the benefits of vaccines would be helpful. They emphasized, however, that this information needs to be presented in a way that busy parents can readily understand. The timing of the information was also mentioned. If several pages of complicated vaccine information is given to a mother just minutes before someone comes in to vaccinate her child, there is not enough time for her to make an informed decision. Some mom's just trust, while others get scared and refuse some or all of those immunizations. One suggestion was to provide a Frequently Asked Questions type of document that might help a mom not only to find the answer to her question but to feel more comfortable asking a question that might not be included.

One participant felt that the easy to read vaccine schedule for parents was helpful and should be given to everyone to put on their refrigerator. Many others agreed that they just want information that is written in a simpler way to understand. It was clear that not one format is sufficient. Some people learn better with material they can read, others learn better when the information is explained verbally. Other formats, such as video or using social media were mentioned but drawbacks to each of these, for example, lack of cultural appropriateness, could limit the utility of these approaches.

Tribal support for delivering information was seen as important. For example, if the tribe were to put information about vaccines in the tribal newsletter or newspaper, people might be more readily accepting of the information, less skeptical.

On the question of when to provide information, it was suggested that during pregnancy would be ideal. Other ways of providing immunization information suggested were through WIC and Head Start. Providers who care for pregnant women could contribute to the helping women get information and ask questions long before the time when a child is receiving their vaccinations. There was also a strong preference for seeing a pediatrician as the doctor who was most expert at providing care for babies/children.

One healthcare worker who participated shared that patients asked if staff had received a vaccine that was being offered:

"...just saying 'Yes, we are 100% vaccinated for Tdap', I think that instilled a little bit of trust."

#### Provider surveys

#### Practice setting and roles

A total of 25 surveys were completed. About half (12/25) worked at an IHS-operated facility, 11 at a tribally-operated facility and two were from in non-clinical programs (Figure 2). The most common clinical roles of respondents were Nurse (40%), Physician (16%), and Nurse Practitioner (12%) (Figure 3). Nurses also were the most commonly identified as playing the primary role in the clinic to maintain childhood immunizations up to date. 72% of respondents indicated that it was a responsibility of all nurses, 40% said it was the responsibility of a dedicated immunizations nurse. 28% of respondents also indicated that physicians, advanced nurse practitioners and medical assistants were primarily responsible (Figure 4).





#### Figure 3. Primary clinical role of respondents







#### Figure 5. Seasonal Influenza vaccination



Figure 5 shows the majority of respondents (88%) recommend the seasonal influenza vaccine for all their patients. For the remaining respondents, 8% indicated that they offer it but not aggressively while 4% indicated that they offer it to those who need it most but not to all patients.

Regarding resources for information about influenza- the characteristics of circulating viruses, treatment recommendations and incidence of influenza, most respondents (84%) get information from the Centers for Disease Control and Prevention (CDC) (Figure 6). When responding to parents' requests for alternative immunization schedules, the majority of respondents (80%) indicated they either encourage patients/parents to follow the recommended immunization schedule or they inform the patient/parent about the risks of not following the recommended immunization schedule. About half also provide some accommodation to patient/parent's request by either providing information about alternative schedules or following the patient/parent's wishes (Figure 7).



Figure 6. Sources of Professional Information About Influenza



#### Figure 7. Responses to Parents Requesting Alternative Immunization Schedules

Figure 8. Healthcare Providers Self-Report of Annual Influenza Vaccine Receipt





Figure 9. Healthcare Providers' Self-Report of Receipt of Other Recommended Vaccines

Figure 10. Healthcare Providers' Rank Order of Factors Influencing Influenza Vaccine Receipt



Figures 8-10 reflect healthcare provider's self-reported receipt of influenza and other recommended vaccines and the most important reasons they choose to receive these vaccines. The majority of healthcare providers surveyed (80%) report that they always get their flu shot (Figure 8). Almost all (96%) also report that they have received Tdap, MMR and Hep B vaccines as well (Figure 9). Among those respondents who received a flu shot in the season just prior to the survey, the most important reason for receiving a flu shot was the belief that it would help prevent them from giving the flu to their patients. Receiving the flu shot because it was required was seen as the least important reason (Figure 10).

#### **Key Informant Interviews**

We interviewed 33 staff members from IHS, Tribal and Urban clinics throughout the Portland Area. These included medical assistants, nurses, doctors and midlevel providers. Participants provided insightful information on a broad expanse of factors that influence childhood immunization status in the Area. Major themes included facilitators of immunizations such as efforts to educate parents and community members and developing policies and procedures within the clinic regarding immunization practices. We also identified barriers within the community and within the clinic that prevented children from being immunized on time, if at all.

#### Factors that Facilitate Vaccine Awareness or Acceptance

#### Education and Health Promotion

Some providers seemed aware of the difficulty that parents have to access information that is trustworthy and understandable and for parents to have time to read the information or think about it to make an informed decision. The most common patient education methods described were face-to-face encounters between nurses, MAs and providers. Much of this education focused on trying to reassure hesitant parents of the benefits and safety of vaccines, addressing "myths" that parents may have heard or believe and helping steer them to reliable information sources. Another provider described the need to educate parents about the diseases that vaccines are designed to prevent:

# "They do think [vaccine preventable diseases are] gone and I think we need to do a lot of education with parents on the fact that if we don't keep the immunizations rates up then these diseases will return."

Typically, these education services are not provided by a certified health educator. At least one clinic identified the need to have a health educator on staff. Another respondent described how the nurse or medical assistant acts as an advocate:

"[I give them] leaflets and the handouts and if they have any questions I try to answer them and try to bring them to the provider and say, 'Hey, well this patient has a question...can you help them make an informed decision?" Community education is also important. Several respondents described outreach to community members outside of the clinic to spread awareness of the importance of childhood vaccinations, dispel myths and promote immunization according to the recommended schedules.

#### Policies and Procedures

Some clinics have adopted specific policies or developed procedures to try to ensure that children get vaccinated on time. For example, many respondents described how immunizations are reviewed from the EHR immunizations tab or the reminders tab and in the State Immunization Information System (IIS) at each visit. Part of this review includes looking at the vaccine forecast generated by the EHR or the IIS. Another part is reconciling discrepancies between the clinic's records and IIS. The third information source that is checked is other providers' offices- when patients have been seen by other providers, especially in other states, immunization records are requested and the information added into the EHR and IIS once received.

Several clinics have developed new policies that do not require a provider visit or well-child check in order to receive immunizations. Instead, immunizations are reviewed at every visit and offered at every visit. Along with this change, clinics have also developed standing orders that allow a nurse to provide any recommended immunizations for which the child is due, without needing a specific order from a provider.

Another provider described how they reach out to siblings and other family members who might be present, so they not only update the immunizations of the child being seen, but check on and offer any immunizations due for the whole family.

One provider described how alternative schedules are developed to limit the number immunizations given at one time, especially the number of live virus immunizations given simultaneously. That provider described how this was important to keeping parents who were vaccine-hesitant, but not adamantly opposed to vaccinations, engaged and willing to accept immunizations for their children. The provider also stated that these patients had 2-year old completion rates equal to or greater than the completion rates for other patients in the clinic.

"I've actually been able to immunize kids where parents came in convinced they weren't going to do certain immunizations. But you work with them, you have to be open and you have to work with them and you have to treat them like the good parents they actually are."

Several other providers stated they will try to accommodate parents' wishes for alternative schedules by allowing them to get recommended IZ's 1 or 2 weeks apart, to minimize the number pokes and keep the parent willing to get their child immunized.

#### Community Barriers

Many providers reported that a major reason for parents to refuse some or all vaccines was fear of the number of injections their child would receive. This leads to requests for alternative schedules by some parents. Most providers who commented about this agreed that it was rare and that most parents eventually do accept the recommended number of vaccines.

"Parents are mainly concerned with the number of 'pokes' their kid has to get".

Other vaccine concerns included mistrust of government or pharmaceutical companies, misinformation leading to concerns about autism or about the ingredients, including mercury and thimerosol that are used in vaccines:

*"Many believe that it's like a government conspiracy and you know the government is controlling everything we do."* 

"I think probably the biggest barrier is misinformation. A lot of parents who are scared of immunizations [have told me] that they just feel it can't be good that their child gets that many shots at one time".

"It's the autism, when they hear about the autism that's when they freak."

Another common barrier was related to parents making and keeping regular appointments such as well child visits. Providers described using any opportunity to encourage parents to get their children vaccinated, especially those who just come for episodic care. Others regularly send out reminders for appointments or letters advising that children are due for immunizations. Financial barriers and transportation difficulties were cited as common reasons why parents don't bring their children in regularly. Transportation was the most often cited barrier- parents either don't have gas money to get to the clinic, especially if they live some distance away, or they may lack reliable transportation. Even in the communities that had available public transportation, respondents still noted that patients had difficulty getting to clinic. An underlying theme, one that perhaps explains the mechanism by which these barriers tie together is that many families are living chaotic or disorganized lives- parents don't receive appointment letters or immunizations due letters sent by the clinic because of frequent changes in address. Even if they receive these letters, they still lack money or reliable transportation. Finally, struggling with other issues such as housing, employment, addiction or having children in foster care means that keeping an appointment falls lower and lower on the priority list. This is particularly true for Well Child Visits:

"Probably just being unstable and therefore healthcare is not on their priority list because they're looking for places to live and just putting off well child exams till a late date and therefore never really getting to them."

"Kids don't have a stable home life due to possibly drugs and alcohol problems, which causes children to move from parents to grandparents to foster care programs, which causes a communication breakdown. Thus these kids aren't being seen in the clinic."

"...probably just disorganized living. A lot of [children] are just living in very chaotic situations and kids are just passed around and I think there is a lack of communication and some disorganized homes and dysfunctional home situations."

One theme that was not elicited by provider interviews was the role of religious beliefs- only one provider described religious belief as a reason that children in their practice were not immunized.

#### **Clinic Barriers**

Providers also described barriers within the clinic setting that impacted childhood immunizations. One of the most common mentioned was the need for staff training. Training for all staff in the clinic to make sure that information in the medical record is updated and accurate, to reinforce the importance of the benefit of immunizations, the current vaccine schedule and best practices such as reviewing immunizations for every patient at every visit, not just for Well child visits. Other training that is needed is refresher training on immunization techniques.

Other major clinic barriers identified were staffing and time constraints. In some cases, these two constraints are related. For example, staff turnover results in delays because it takes time for a new nurse or MA to get familiar with the way immunizations are ordered and documented. When the number of providers is limited there are fewer appointments available and less ability to "squeeze" walk-ins. Or there is simply not enough time for the few staff to screen patients, get them in the room and finish with earlier patients who may need immunizations. Others noted that inadequate nursing staff can result in not having enough nurses to send out reminder letters to parents or parents may bring their kids for immunizations but leave without them if the wait is taking too long. Another clinic barrier is "missed opportunities" in which a child is seen in clinic but for various reasons, they do not receive immunizations that are due. According to one provider, this happens for walk-in appointments where there isn't enough time to do a thorough review of the immunization history, or to provide the vaccine at that visit. Several providers noted the need to hire more staff so they could devote adequate time to children's immunizations.

"The other thing we really need is more staff. There's always someone missing so we don't have someone that can really dedicate a lot of focused time just on [immunizations] because we're all wearing about four hats." "Sometimes it gets really busy and we just can't get to the shots when we need to."

One clinic had a dedicated "immunization" clinic. Once that was discontinued, the provider felt that made vaccines less available and increased the waiting time for some parents who left without getting their child vaccinated.

Finally, lack of evening or weekend clinic hours was seen as a barrier, especially for working parents.

#### Health Care Providers Vaccine Acceptance

In another section of the interview, we asked providers about their own views on immunizations for healthcare providers. These questions helped provide an understanding of the ways in which attitudes about recommended vaccines for healthcare providers contribute to the acceptance and coverage of recommended immunizations among healthcare providers.

Six respondents stated their clinics do not require any mandatory immunizations for clinic staff. The remaining 26 respondents indicated that their clinics do require some immunizations, often just for the direct patient care staff. The most common immunizations required were hepatitis B (18), MMR (14), and Tdap (11). But when asked if a mandatory immunization program for HCP in their facility could be developed, 9 respondents said "no". Three of these cited beliefs that Federal regulations might prohibit such a policy or make it difficult to enforce.

Among those who work in clinics without a mandatory immunization policy already, one felt that it could not be successfully developed in their clinic because of cultural reasons while another felt that it could be developed because of the importance of protecting staff and patients.

The most common barriers to implementing mandatory HCP immunization policies were related to personal beliefs. Multiple providers stated that employee beliefs, especially about the influenza vaccine, would make it difficult, if not impossible, to develop a mandatory policy. Common personal beliefs were that the influenza vaccine would make people sick or actually would give them the flu. Others felt that employees believed it just wouldn't work to protect them from the flu.

Education targeted to clinic employees was the activity most cited by respondents to help promote uptake of immunizations among HCPs. As one respondent put it:

"I think just education...more information about how you cannot get the flu from getting the flu shot...if you can't appeal to that then appealing to healthcare workers by saying, 'you know we are at a clinic with immune-compromised patients, with new babies, with patients with diabetes and cancer, and just like we try to make this environment safe for our patients, by not being immunized puts ourselves puts them at risk."

#### Conclusions

This project used a combination of provider surveys and interviews plus community member focus groups to explore the perceptions of providers and the beliefs and attitudes of both providers and community members regarding childhood immunizations among American Indian and Alaska Native tribal members served by the Portland Area Indian Health Service. The primary findings were:

- 1. Vaccine hesitancy is well-established in Northwest Native communities
- Reasons for vaccine hesitancy are similar to those described in non-Native communities, including concerns about autism, mercury content and belief that too many vaccines given at the same time are harmful. The exception is that AI/AN communities have beliefs grounded in their history with the US government for being skeptical or mistrustful. The historical treatment of AI/AN may make mistrust a more difficult barrier to address than others.
- Socio-economic barriers also play a large role in disrupting immunization of NW Al/AN children- lack of reliable transportation, social disruption- frequent moving, children living with extended family members and competing priorities were identified by providers as important barriers.
- 4. Within the clinic, limited staff and hours of operation and the inability to contact patients/families because of inaccurate or incomplete contact information were identified as constraints.

- 5. Patients frequently described patient education that was too difficult to understand or provided without allowing adequate time for parents to read, understand and ask questions before children received immunizations.
- 6. Healthcare providers' attitudes about immunizations were identified as an important factor for how parents and other healthcare providers accepted immunizations.
- 7. Education about immunizations was identified as an important need among both parents and healthcare providers.

#### Recommendations

#### Develop Strategic Improvement Plan

Based on the information gathered in this project, certain opportunities stand out as high priorities to improve the coverage of childhood vaccines for Portland Area AI/AN children. To address the following priorities for improvement in both early childhood immunizations and the immunization of health care personnel, the Portland Area IHS and Northwest Portland Area Indian Health Board will need to work with other partner organizations, e.g., the American Indian Health Commission of Washington (AIHC), the Washington Department of Health (WA DOH), Oregon Health Authority, Idaho Health Department, NPAIHB Tribal Health Directors and Delegates and Portland Area Immunizations Coordinators, Nurse Executives and Clinical Directors to discuss and interpret these findings to develop an Area-wide strategic plan for early childhood immunization improvement. Existing opportunities for discussion and strategic planning, such as, NPAIHB Quarterly Board Meetings and Tribal Health Director meetings, PAOIHS Clinic Director and CEO meetings, AIHC Immunizations Workgroup meetings, etc. can be used to develop and execute an Area-wide strategic plan.

These priorities can be grouped into the following categories:

- 1. Patient Education
- 2. Provider/Staff Education
- 3. Policy Development
- 4. Data Collection/Coordination
- 5. Community Engagement
- 1) Patient Education: Patient education material should be developed to meet the needs of NW AI/AN parents. Materials should be written at an appropriate reading level to be easily understood by busy parents who may have limited formal educational attainment. Educational materials should include endorsements by local Tribes or tribal organizations, with minimal reliance on US government sources to increase acceptability. The timing of providing education about immunizations should be well before the day the immunizations are to be given to allow time for the information to be absorbed and questions to be formed. Information should be repeated at each visit to increase the likelihood that it will be retained. Optimum means of delivering information need to be researched based on the latest patient education methods. For example,

motivational interviewing may be an appropriate method for engaging NW AI/AN parents regarding childhood immunizations.

- 2) Provider/Staff Education: All providers and staff should receive formal training in techniques to discuss immunizations with parents constructively to find ways to increase parents' acceptance of recommended childhood immunizations. These techniques should be evidence-based, supported by appropriate written materials and provided consistently for all staff.
- 3) Policy Development: Since this project was undertaken in 2012, the Indian Health Service has moved forward with developing a mandatory annual influenza vaccination policy for all healthcare providers. This policy was fully adopted for the 2016-17 influenza season. Tribally-operated clinics and Urban Indian Organization clinics will have the choice to adopt this policy and may wish to do so. In addition to annual influenza vaccination, there is a need to develop consistent policies for other recommended HCP vaccinations including: MMR, Tdap, hepatitis A and B and varicella. Infection control policies for PPD testing for latent tuberculosis infection should also be updated to be consistent with current CDC guidelines. Other policies such as implementing standing order protocols for immunizations, assessing all patients for needed immunizations, providing needed immunizations at all clinic visits and eliminating any barriers to receiving immunizations, e.g., providing immunizations only in well-child clinic visits should be developed and shared.
- 4) Data Collection/Coordination: Progress in establishing reliable, two-way exchange of immunization data between clinics and State-operated Immunization Information Systems must continue. Data exchange should occur regardless of the EHR in use in a given clinic, eliminating the need for double data entry and allowing for accurate information to be obtained in real-time. Immunizations reporting whether for accountability (GPRA), reimbursement (Meaningful Use/MACRA) or surveillance (IHS Quarterly Immunizations Reports) should be readily obtained from any EHR. This may need special attention for tribal sites that no longer use RPMS.
- 5) Community Engagement: Community engagement to help educate parents and caregivers about the benefits of immunization is an important strategy to help overcome vaccine hesitancy in AI/AN communities. Identifying local community immunization champions, holding community educational forums and providing outreach to other community organizations and care providers could help engage community members in support of childhood immunizations.

#### REFERENCES

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#### APPENDICES

- A-1 Immunization Provider Survey
- A-2 Key Informant Interview Guide
- A-3 Key Informant Data Collection
- A-4 Key Informant Consent
- B-1 Focus Group Script
- B-2 Focus Group Consent
- B-3 Focus Group Flyer
- C Budget/Timeline

#### **A-1 Immunization Provider Survey**

This Immunization Provider Survey has been developed by the Portland Area IHS/Northwest Portland Area Indian Health Board Immunization Program. We are hoping to learn more about the knowledge, attitudes and practices of Health Care Providers and staff in the Portland Area towards 1) early childhood immunizations; and 2) recommend immunizations for health care personnel. For this reason, we are asking all those who may be involved in providing or referring children for immunizations to complete this survey.

The survey results will be collected anonymously, we will not be able to identify who you are. The exception to this is if you choose to give us your contact information voluntarily in question 14 or 22. If you do provide contact information in response to those questions, we will still remove your contact information before analyzing the survey responses.

The survey should not take more than 20 minutes to complete. You are under no obligation to start or complete the survey. Once you start, you may stop the survey at any time. There is no benefit or compensation provided directly to you as a result of participating in this survey; we hope that the results will, however, provide a benefit to those that you serve by helping us identify opportunities to address concerns about childhood immunization services and as well as immunizations for healthcare providers.

If you have questions about the project, you may call **Thomas Weiser, Project Director** at (503) 416-3298. If you have any questions about your rights as a participant you may call the Indian Health Service Institutional Review Board (IRB) Coordinator, Clarice Charging, toll free at (877) 664-0604.

If you agree to participate, please check the "I agree" box to continue to the survey.

□ I agree

#### This first section asks about your role and work environment:

 What is your primary role in the clinic where you work? Physician

Nurse Practitioner Physician Assistant

Nurse Case Manager

Nurse (RN, LPN)

Certified Nurse Assistant (CNA)

Medical Assistant (MA)

Receptionist/Clerk

Dentist

Dental Hygienist

Dental Assistant

Social Worker

Mental Health / Substance Abuse Counselor

Psychologist

Other \_\_\_\_\_

- 2. Where do you work?
  - a. IHS facility/program
  - b. Tribal facility/program
  - c. Urban Indian facility/program
  - d. Other \_\_\_\_\_
- 3. Is your work primarily with:
  - a. Adults?
  - b. Children?
  - c. Both?
- 4. Do you manage or encounter pregnant women in your practice?
  - a. Yes
  - b. No
- 5. Who in your clinic is <u>primarily</u> responsible for maintaining up to date childhood immunizations? (Check all that apply)
  - a. Nurses
  - b. Immunization Nurse
  - c. Medical Assistants
  - d. Physicians and other licensed providers (NPs, PAs, podiatrists, dentists)
  - e. Other \_\_\_\_\_\_

#### This section will ask about your interactions with patients regarding immuinizations:

- 6. What do you tell your patients about the flu shot?
  - a. I offer it but I don't push it
  - b. I offer it to those who need it most
  - c. I recommend for all my patients
  - d. I discourage patients from getting the flu shot
- 7. Please explain why you do or do not recommend annual flu shots for all patients
- 8. Where do you turn for information about immunizations against influenza?
  - a. CDC
  - b. State Health Department
  - c. IHS (National Resources)
  - d. IHS (Area Resources)
  - e. Local Health Jurisdiction (County or City Health Department)
  - f. Other \_\_\_\_
- 9. Where do you turn for information about influenza characteristics, treatment or incidence?
  - a. CDC
  - b. State Health Department
  - c. IHS (National Resources)
  - d. IHS (Area Resources)
  - e. Local Health Jurisdiction (County or City Health Department)
  - f. Other \_\_\_\_\_\_
- 10. If your practice sees children, do you recommend immunizations according to the CDC/ACIP Immunization schedule?
  - a. No
  - b. Yes
  - c. Not Sure
- 11. When a parent requests an alternative immunization schedule for their child, which choice below best describes your response?
  - a. I always follow the patient/parent's wishes
  - b. I provide them with one or more alternative schedules that I believe are effective/safe
  - c. I try to inform the patient/parent about the risks of not following the recommended immunization schedule
  - d. I encourage patients/parents to follow the recommended immunization schedule
  - e. I encourage patients/parents who do not follow the recommended immunization schedule to find another medical provider
  - f. None of the above (Please explain)

- 12. Which of the following early childhood immunizations do you routinely advise parents to skip or <u>actively</u> discourage?
  - a. DTaP (Diphtheria, Tetanus, acellular Pertussis)
  - b. Hep A (Hepatitis A)
  - c. Hep B (Hepatitis B)
  - d. HIB (Hemophilus influenza, type B)
  - e. Influenza
  - f. MMR (Measles, Mumps and Rubella)
  - g. Rotavirus
  - h. Varicella (Chickenpox)
  - i. None, I always advise following the CDC/ACIP recommended immunization schedule (Skip to #<u>14</u>)
- 13. Why do you choose to skip or discourage the vaccine(s) you indicated in Question 12?

14.	I would be	interested ir	n learning r	nore about	improving	immunization	coverage fo	r the childr	en

- in my clinic:
  - a. Yes (optional: provide contact information\_\_\_\_\_\_ or contact Immunization Program staff at <u>tweiser@npaihb.org</u> or 503-416-3298)
  - b. No

# This next section asks about attitudes regarding recommended immunizations for healthcare personnel:

- 15. Please indicate the response that best describes your experience getting the flu shot:
  - a. I never get a flu shot (Skip to #<u>18</u>)
  - b. I sometimes get a flu shot (Skip to # <u>17</u>)
  - c. I always get the annual flu shot (Continue to #<u>16</u>)
- 16. Why do you get the flu shot every year? (Check all that apply) [or rank 1-5 in order of importance] [Then skip to Question # 19)
  - a. It is <u>required</u> for my job
  - b. It is highly recommended for my role in the clinic
  - c. I believe it helps protect <u>me</u> from getting the flu
  - d. It helps prevent me from giving the flu to patients
  - e. Other \_\_\_\_\_

- 17. Why do you get the flu shot sometimes (not always)? Check all that apply) [or rank 1-5 in order of importance] [Then skip to Question # <u>19</u>)
  - a. I am <u>not</u> required to get it for my job
  - b. I sometimes forget to get my flu shot
  - c. I don't think it works very well
  - d. I don't like the side effects
  - e. It makes me sick or gives me the flu
  - f. It is hard to get a flu shot/not always available
  - g. It is not offered at my workplace
  - h. Other \_\_\_\_\_
- 18. Why do you choose not to get a flu shot?
  - a. I am <u>not</u> required to get it for my job
  - b. I sometimes forget to get my flu shot
  - c. I don't think it works very well
  - d. I don't like the side effects
  - e. It makes me sick or gives me the flu
  - f. It is hard to get a flu shot/not always available
  - g. It is not offered at my workplace
  - h. I don't think it is safe
  - i. Other \_\_\_\_\_

19. Did you get a flu shot during this most recent flu season (September, 2011 to March, 2012)?

- a. Yes
- b. No [skip to #<u>21</u>]
- c. Don't remember [skip to #21]
- 20. Thinking about the most recent flu season, which of the following are reasons that you got a flu shot? [Rank order of importance]
  - a. It is <u>required</u> for my job
  - b. It is highly recommended for my role in the clinic
  - c. I believe it helps protect me from getting the flu
  - d. It helps prevent me from giving the flu to patients
  - e. Other \_\_\_\_\_
- 21. Other vaccines are currently recommended for health care personnel. Please indicate which of these you have had. Please indicate the reason why you did or did not receive the vaccine:

a.	Tdap	YES	NO	Reason:
b.	MMR	YES	NO	Reason:
c.	Hepatitis B	YES	NO	Reason:
d.	Hepatitis A	YES	NO	Reason:

- 22. I would be interested in learning more about improving immunization coverage for the health care personnel in my clinic:
  - a. Yes (optional: provide contact information \_\_\_\_\_\_ or contact Dr. Thomas Weiser at tweiser@npaihb.org or 503-416-3298)
  - b. No

Thank you for taking the time to complete this survey. A report of the results of this survey will be distributed by the Portland Area IHS/Northwest Portland Area Indian Health Board Immunization Program.

#### A-2 Key Informant Interview Guide

Thank you for agreeing to participate in this interview. We are hoping to collect information that will be useful in understanding the knowledge, attitudes and beliefs of health care providers and community members regarding childhood immunizations. We have developed a list of questions to help guide this discussion. Remember, you do not have to answer all questions asked and your identified answers will not be shared with your employer, employees or supervisor. In any reports that are produced from this project, quotations will not be identified. We will take care not to use any quote that could potentially identify you or cause any harm. If we decide we would like to publish something you have shared with us, we will contact you <u>first</u> to obtain your approval. We would like to keep your contact information with the notes from this interview so that we can contact you in the future if there is a need for clarification or to obtain your permission to use something that you have shared with us. Is that OK? [If yes, write down contact information in the space provided on the data collection form; If no, acknowledge that that is OK and that we can still use the information shared but we will not publish any quotes from the individual]

- a. In your opinion, what are the most significant contributors to the low rates of immunization coverage among American Indian/Alaska Native children?
- b. What barriers are present in the community that inhibit children from getting recommended immunizations on time?
- c. What barriers within the clinic setting exist that inhibit children from being vaccinated? [Are providers generally supportive of routine childhood immunizations?]
- d. When you see children needing immunizations, how do you address this?
- e. How do you address children who are missing immunizations when they have not been seen in the clinic?
- f. Have your immunization practices changed over time? What prompted you to make those changes?
- g. What do parents or community members say regarding immunizations? What comments have you heard? [Prompts: are they supportive? Are they distrusting? Do they ask for alternate vaccine schedules? Do they refuse some vaccines and accept others?]
- h. In what ways has your clinic or Tribe tried to improve immunizations coverage for children?
- i. What else could be done to improve childhood immunization coverage?
- j. What additional resources would you need to improve childhood immunization rates?
- k. Where do you generally get information about immunizations? What other reliable sources of information can you think of?
- I. What kind of information would help you in your work?
- m. What strengths do you see in the community to help address the problem of getting children immunized?

Next, I would like to ask a few questions about immunization of health care personnel in your clinic.

- a. Does your clinic require any immunizations for healthcare personnel? If so which immunizations? Are these required for all staff, or only those with direct patient contact?
- b. What percent of your clinic staff (or those required) receive the following:
  - a. Hepatitis B series
  - b. Hepatitis A series
  - c. MMR
  - d. Tdap
  - e. Annual influenza
- c. What do you think are the main barriers to health care workers getting immunized, including the annual flu shot?
- d. What more could be done to increase immunization coverage among healthcare personnel?
- e. Do you think a mandatory immunization policy could be developed at your facility? Why or why not?
- f. Would you support a mandatory immunization policy at your clinic? Why or why not?

We are finished with the questions that I have planned for today. Do you have any questions for me? Is there anything else you would like to add that might help us better understand and improve immunizations coverage?

Thank you for your time today. We greatly appreciate that you shared your knowledge and insight on this important topic with us.

#### A-3 Key Informant Data Collection

Name:	
Tribe/Clinic:	
Interview #:	
Date:	
Permission to keep contact information: D Yes	🗆 No

<u>Permission to record</u>:  $\Box$  Yes  $\Box$  No

### **Baby (Ages 0-2) Immunizations Section**

 In your opinion, what are the most significant contributors to the low rates of immunization coverage among American Indian/Alaska Native babies (children ages 0-2)?

o. What barriers are present in the community that may act to keep babies from getting recommended immunizations on time?

p. What barriers within the clinic setting exist that may act to keep babies from being vaccinated?

q. When you see babies needing immunizations, how do you address this?

r. How do you address babies who are missing immunizations when they have not been seen in the clinic?

s. Have your immunization practices changed over time? What prompted you to make those changes?

t. What do parents or community members say regarding immunizations? What comments have you heard? [Prompts: Are they supportive? Are they distrusting? Do they ask for alternate vaccine schedules? Do they refuse some vaccines and accept others?]

u. In what ways has your clinic or Tribe tried to improve immunizations coverage for babies?

v. What else could be done to improve immunization coverage for babies?

w. What additional resources would you need to improve immunization rates for babies?

x. Where do you generally get information about immunizations? What other reliable sources of information can you think of?

y. What kind of information would help you in your work?

z. What strengths do you see in the community to help address the problem of getting babies immunized?

### **Clinic Personnel Section**

g. Does your clinic require any immunizations for healthcare personnel? If so which immunizations? Are these required for all staff, or only those with direct patient contact?

h. What percent of your clinic staff (or those required) receive the following:

- a. Hepatitis B series
- b. Hepatitis A series
- c. MMR
- d. Tdap
- e. Annual influenza

i. What do you think are the main barriers to health care workers getting immunized, including the annual flu shot?

j. What more could be done to increase immunization coverage among healthcare personnel?

k. Do you think a mandatory immunization policy could be developed at your facility? Why or why not?

I. Would you support a mandatory immunization policy at your clinic? Why or why not?

Additions:

#### A-4 Key Informant Consent

Understanding Immunizations Knowledge, Attitudes and Beliefs Northwest Tribal Epidemiology Center Northwest Portland Area Indian Health Board 2100 SW Broadway, Suite 300 Portland, OR 97211 Phone: (503) 228- 4185

# **INFORMED CONSENT FORM**

#### **Investigators**

**Thomas Weiser, MD, MPH,** Project Director, Portland Area Indian Health Service and Northwest Tribal Epidemiology Center, Medical Epidemiologist

Telephone: (503) 416-3298

#### Purpose

The Northwest Portland Area Indian Health Board (NPAIHB) is conducting a public health project to understand knowledge, attitudes and beliefs about immunizations in NW Tribal communities. We wish to understand how immunizations are perceived in the community from the perspective of health care personnel serving American Indian communities in the Northwest, to understand healthcare providers' attitudes and practices regarding the administration of early childhood immunizations and healthcare providers acceptance practices regarding immunizations specifically recommended for healthcare providers. As part of this public health project, we are asking volunteers to participate in key informant interviews. The interviews will help us learn about childhood immunization knowledge, attitudes, beliefs and practices and hopefully allow us to make improvements in this important public health service for Tribes.

You were selected to participate in this interview because of your relationship to [Name of Tribe or Community] as a healthcare worker which provides you a special understanding of the health care needs of [Name of Tribe Community].

#### Procedures

If you agree to participate, you will be interviewed by a project staff member who has been trained in the interview protocol. The interview will take place in a private location at a time that is convenient for you. The interview will take about 30 minutes. All of your answers will be kept private.

#### **Risk, Stress, or Discomfort**

You can refuse to answer any question that you don't want to for any reason. You can stop the interview at any time. All project staff have been trained to keep private all the information collected during the project. If you decide not to take part, you will not be penalized in any way.

We will not tell anyone how you answer the interview questions,

#### Benefits

While you may not personally benefit from participating in this study, your experiences will help us learn more about how immunizations are viewed by the community and within in the health clinic, which might be helpful to efforts to improve immunization practices in your community.

Your participation in the interview is voluntary. The decision to participate is up to you. If you decide not to take part, or to discontinue at any point, there will be no penalty.

#### Confidentiality

The information collected during the conduct of this interview will be held in the strictest confidence at all times by project staff at the Northwest Portland Area Indian Health Board. All information will be kept in locked file cabinets and will be stored on secure, password-protected computers accessible only to authorized project staff.

If you have any questions about the project, you may call **Thomas Weiser, Project Director** at (503) 416-3298.

If you have any questions about your rights as a research participant you may call the Indian Health Service Institutional Review Board (IRB) Coordinator, Clarice Charging, toll free at (877) 664-0604.

#### **Participant Agreement**

The project described above has been explained to me. I voluntarily agree to take part in the Immunization interview I have had the chance to ask questions and receive answers. I know that I may refuse to take part or stop my participation at any time. I know that I will not lose any benefits or services that I am eligible for, even if I decide not to be interviewed or refuse to answer some questions. I understand that if I have questions about this study or what my rights are, I can call to any of the staff listed at the top of this form.

#### **B-1 Focus Group Script**

Informed Consent: Upon arrival to the site, participants will read the informed consent document and be asked to give their signed consent to take part in the discussion.

Introduction: The facilitator will welcome participants and introduce the topic of the focus group discussion, ground rules and agenda for the discussion.

Thank you for coming to participate in this focus group discussion. We will be asking questions about how you believe immunizations are accepted in the community. We are also interested in finding out about any barriers that may keep children from being immunized on time and ideas for helping improve childhood immunizations coverage in your community. By the term "childhood immunizations" we mean those immunizations given from birth through to the beginning of when a child enters school. We can talk about older children and adolescents if we have time, but our primary focus is on babies and toddlers.

[Introduce self and other staff in room]

Some of these questions may remind you of personal stories or experiences. We encourage you to share those stories if you wish. Before we begin, let us explain the ground rules.

- All members of the focus group are asked to honor the confidentiality of everyone here and to agree to not repeat anything they hear outside of this group. Also, please try not to use your own name, each others names or anything else that could identify members of the group. This will help us to safeguard your confidentiality. If at any time you feel uncomfortable remaining in the discussion group, you are permitted to leave. You do not need to explain why you wish to leave. You are welcome to keep the gift we have offered.
- Please take turns and be respectful of the person who is speaking, try to let him or her finish. Besides being courteous, we will be able to record the information and understand it better when only one person is speaking at a time.
- Remember, it's OK to disagree with what someone has said, but please remember to do it in a polite and respectful way. We really want to hear from everyone, to learn from all kinds of opinions and ideas.

Well, that's enough rules. Are there any questions about what we've said so far?

[Permission to tape record]

We would like to record this session. We want to be sure to accurately write down your discussion points, even though we won't be using names. After we transcribe or write

down everything from the recording, we will erase the tape. Do anyone of you prefer that we NOT tape the discussion?

[If YES] Okay. Thank you for letting us know. We will respect your wish and we will not record our discussion. But we will still need to take notes by hand.

a. Let's start by asking, "What do you think about childhood immunizations, in general?

Prompts: Are people supportive of getting their children immunized? Are there concerns about any specific vaccines or the number of vaccines that are recommended?

b. What do elders in the community say about immunizations and the diseases they prevent?

Prompts: Do they tell stories about family members or friends who were affected by diseases like measles, diphtheria, pertussis or polio? Do they recommend immunizations for their children/grandchildren? Do they get immunizations themselves?

- c. What do young parents say about immunizations and the diseases they prevent?
- d. Prompts: Do they feel that immunizations are less important because the diseases don't occur as often? Where do community members get information about immunizations? Is this information given in ways that people can easily understand?
- e. What problems have you heard about or experienced with immunizations?

Prompts: Have you known people in the community- family, friends or coworkers who have had a bad experience? Are there barriers to getting children immunized? What are those barriers?

- f. Do community members express doubt or distrust about the safety or efficacy of vaccines?
- g. What strengths do you see in the community that can help to address the problem of low childhood immunization rates in your community? Prompts: Are clinic providers supportive of immunization? Are there cultural or educational resources in the community that can be used?

Closing: Thank you all very much for sharing your time and your wisdom. The results of this discussion and other discussions we are hosting will be analyzed and used to help better understand how to improve immunizations coverage for American Indian/Alaska Native children. To view the final report from this project, please contact the Northwest Tribal Epicenter at: 503-228-4185 or look on our website: www.npaihb.org.

#### **B-2 Focus Group Consent**

Understanding Immunizations Knowledge, Attitudes and Beliefs Northwest Tribal Epidemiology Center Northwest Portland Area Indian Health Board 2100 SW Broadway, Suite 300 Portland, OR 97211 Phone: (503) 228- 4185

# **INFORMED CONSENT FORM**

#### **Investigators**

**Thomas Weiser, MD, MPH,** Project Director, Portland Area Indian Health Service and Northwest Tribal Epidemiology Center, Medical Epidemiologist

Telephone: (503) 416-3298

#### Purpose

The Northwest Portland Area Indian Health Board (NPAIHB) is conducting a public health research project to understand community members' knowledge, attitudes and beliefs about immunizations. We want to learn whether differences exist between elders and young parents with regard to immunizations and the diseases they prevent. We are also interested to learn whether elders and young parents influence each others' beliefs and attitudes towards childhood immunizations. We are asking volunteers to participate in focus group discussions. The focus groups will help us learn about immunization knowledge, attitudes, beliefs and practices in the community.

You were selected to participate in this focus group because you are a community member of [Name of Tribe or Community] and you have a special understanding of the health care needs of your tribe/community.

#### Procedures

If you agree to participate in this public health research project, you will participate as a member of a discussion group. The discussion group will include others besides you. The discussion group will last approximately two hours and will be led by an experienced moderator from the Northwest Tribal Epi Center along with the Project Director, Thomas Weiser.

We are unable to write fast enough to record everything said in the discussion. We would like your permission to record the focus group. You may ask for the recording to be turned off if you wish to discuss something you do not want to have recorded. Once the recordings are transcribed, the recordings will be destroyed .The typed copy of the discussion will not include your name or any other information that might let people guess who you are.

You will receive a \$20 gift card to either Safeway or Wal-Mart (participant's choice, subject to availability) for your time and participation. **Risk, Stress, or Discomfort** 

There are no physical risks associated with participation in the focus group. We will remind all participants of the importance of respecting the information shared by others and holding that information confidential. However, there is no guarantee that people will not talk about what is discussed during the focus group, and so we ask that you do not share any information you do not mind having repeated outside of the session. Every attempt will be made to ensure that you are comfortable during the focus group and that your information is kept private. Once the focus group begins, you are also free to leave at any time.

#### Benefits

While you may not personally benefit from participating in this research study, your experiences will help us learn more about how immunizations are viewed by the community which might be helpful to efforts to improve immunization practices in your community.

Your participation in the focus group is voluntary. The decision to participate is up to you. If you decide not to take part, you will not lose any benefits or services you would otherwise receive.

#### Confidentiality

The information collected during the conduct of this focus group will be held in the strictest confidence at all times by project staff at the Northwest Portland Area Indian Health Board. All information will be kept in locked file cabinets and will be stored on secure, password-protected computers accessible only to authorized project staff.

If you have any questions about the project, you may call **Thomas Weiser, Project Director** at (503) 416-3298. If you have any questions about your rights as a research participant you may call the Indian Health Service Institutional Review Board (IRB) Coordinator, Clarice Charging, toll free at (877) 664-0604.

#### **Participant Agreement**

The project described above has been explained to me. I voluntarily agree to take part in the Immunization focus group. I will receive a gift card valued at \$20 for my time and participation in the focus group. I have had the chance to ask questions and receive answers. I know that I may refuse to take part or stop my participation at any time. I know that I will not lose any benefits or services that I am eligible for, even if I decide not to be in the project or refuse to answer some questions. I understand that if I have questions about this research study or what my rights are, I can call to any of the staff listed at the top of this form.

Participant Signature

Date

#### **B-3 Focus Group Flyer**



## C Budget/Timeline

Budget: Immunizations Knowled	ge, A	Attitudes and Beliefs
Award Amount	\$	12,500.00
Category	Exp	pense
Staff		in-kind
Research Assistant	\$	6,000.00
Expenses		
- travel	\$	2,400.00
- office supplies	\$	300.00
- focus groups (advertising, incentives, supplies)	\$	2,000.00
- meeting space for Aim 3 stakeholder/ strategic planning meetings Total		1,800.00 12,500.00

		2012					2013						
	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May
Protocol	Х	Х											
Surveys /Interviews			Х	Х									
Focus Groups					Х	Х							
Data Analysis							Х	Х					
Dissemination									Х	Х			
Stakeholder/													
Strategic Planning									Х	Х	Х	Х	
Meetings													
Final Report/Plan													Х