MPA

Master of Public Administration
Capstone Applied Research Project

Understanding Childhood Immunization Religious Exemption Rates in Lane County

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Executive Summary

This report explores potential reasons behind high childhood immunization exemption rates for non-medical reasons in Lane County, Oregon. Methods of analysis include Qualtrics software tracking for survey data, comparisons with results from similar surveys taken in Ashland and Lane County, and thematic analyses of focus group sessions and clinician interviews. Results show that parents who exempt, or consider exempting, do so for a wide variety of reasons, and the majority chooses on a vaccine-by-vaccine basis. A clinician who develops trusting relationships with parents best assuages their concerns. The quality of information exchanged during conversations with clinicians significantly impacts how much parents trust clinicians with immunization-related decisions.

However, this analysis drew from a small sample of clinicians and parents, and does not necessarily reflect the breadth of views of Lane County vaccine hesitant parents. Recommendations for Lane County Public Health include providing resources to clinicians about improving relationships with patients, actively supplying the public with information about vaccines and their ingredients, and exploring vaccine-related legislation that relies less on coercion.

Introduction

Family immunization exemption rates in Oregon far exceed the national average, with Lane County being one of the highest exempted counties in the state. This exemption rate at the kindergarten level, which stood at 7.4 percent during the 2012- 2013 school year, poses a potential public health threat, particularly for those children whose health conditions preclude them from receiving immunizations (Lane County Public Health, 2013). Reasons for exempting children in areas outside of Lane County range from government mistrust to the perceived link between autism and vaccinations, though exact reasons for claiming religious exemptions in Lane County remain unclear (Omer et al, 2009).

In light of the county's relatively high exemption rate, and the recent pertussis outbreaks in Washington and California, Lane County Public Health wants to examine the reasons behind families choosing to exempt their children. Our team of University of Oregon Master of Public Administration students is pleased to work with them on this issue for our Capstone Applied Research Project. Our research will be used to develop strategies for encouraging immunizations, which will inform future public outreach strategies.

Background

Vaccinations are widely regarded as a top success of modern day medicine, with 98 percent of vaccine preventable diseases eradicated in the US today (Salmon et al, 2006). Nevertheless, a debate around compulsory vaccination policy continues in many states. While the CDC recommends which vaccines to mandate and the optimal immunization schedule, compulsory vaccination is legislated by the states. This results in wide variance of policy throughout the nation. All states accept medical immunization exemptions. In addition, 48 states, including

Oregon, allow religious exemptions and 21 also allow philosophical (Omer et al, 2009).

Studies on vaccination risks and benefits, parental decisions to exempt their children for non-medical reasons, and policy trends behind mandatory immunization have received national attention in recent years. Increasing trends in non-medical exemptions have been directly related to outbreaks of vaccine-preventable diseases, most notably pertussis occurrences in Washington (Spadafora, 2012) and California (Winter et al, 2010). Oregon's geographic location between these two outbreak areas, combined with high exemption rates, makes the state extremely susceptible to its own large-scale outbreak.

Though some studies have identified general parental concerns about immunizations by region or state, a more effective public health outreach program in Lane County needs specific data about what concerns Lane County-area parents. Further, the parental motivations behind seeking exemptions are under-researched. This research will help inform more tailored public health outreach in Lane County, as well as deepening knowledge about the increasing non-medical exemption trend.

Literature Review

Question 1: What are the risks and benefits of vaccines?

Oregon law requires kindergarten-aged children to be immunized for ten vaccine-preventable diseases. Vaccinations for pneumococcus, rotavirus, and haemophilus influenza b are also recommended (Oregon Health Authority, 2010). Comprehensive data about Oregon and Lane County compliance rates does not exist at the kindergarten level. However, preschool and day care level data is available, although these requirements differ slightly (Oregon Health Authority, 2011). The following table summarizes vaccination requirements for kindergarten and preschool or day care level children, and compliance rates by vaccine for both Oregon and Lane County.

Table 1: Vaccination Requirements and Compliance Rates

Vaccination	Number Required for Kindergarten or Grade 1-4 Admission (Oregon Health Authority, 2011)	Number Required for Preschool or Child Care Admission, Aged 18 Months or Older (Oregon Health Authority, 2011)	Compliance Rate in Oregon for Children Aged 19-35 Months (CDC, 2011)	Compliance Rate in Lane County, Aged 2 Years (CDC, 2010)
Diptheria-Tetanus/Pertussis (DTaP)	5	4	76.6%	80.7%
Polio	4	3	90.2%	90.5%

(Table 1, Continued)

Vaccination	Number Required for Kindergarten or Grade 1-4 Admission (Oregon Health Authority, 2011)	Number Required for Preschool or Child Care Admission, Aged 18 Months or Older (Oregon Health Authority, 2011)	Compliance Rate in Oregon for Children Aged 19-35 Months (CDC, 2011)	Compliance Rate in Lane County, Aged 2 Years (CDC, 2010)
Varicella (Chicken Pox)	1	1	89.3%	89.9%
Measles-Mumps-Rubella (MMR)	1	1	90.6%	91.9%
Measles	1	N/A	N/A	N/A
Haemophilus Influenza B (Hib)	N/A	3 or 4	90.2%	93.3%
Hepatitis B	3	3	85.3%	89.7%
Hepatitis A	2	2	56.6%	89.0%
Pneumococcal Conjugate Vaccine (PCV)	N/A	4 (Recommended)	79.9%	85.1%
Rotavirus	N/A	3 (Recommended)		60.9%

Variability in vaccine compliance rates can occasionally be traced to the increased complexity of the vaccine schedule, as studies have identified a link between combination vaccines (such as MMR and DTaP) and higher compliance rates (Dodd, 2003). However, parental fear of vaccine-related risks, which can occasionally overwhelm data on their benefits, is of equal concern.

- **Risks Directly Associated with Vaccines**

Thimerosal, a preservative in more than thirty multi-dose vaccines, has drawn negative attention for its mercury content despite requirements to limit this substance to below toxic levels for infant's doses. While this preservative itself has been credited with reactions in patients with thimerosal allergies, metabolites of thimerosal has been linked to renal damage and neurologic abnormalities in children. These symptoms can be exacerbated in low birth weight infants (Ball et al, 2001). However, studies have shown those adults who were immunized as a child with a vaccine containing thimerosal are at no more risk for neurodevelopmental problems than those who were not vaccinated with thimerosal (Offit, 2012). Nevertheless, the Food and Drug Administration recommended the removal of thimerosal from childhood vaccines in 1999 (FDA, 2012).

Anaphylaxis, a severe and potentially life-threatening allergic reaction, has also been causally associated with a variety of vaccines, particularly MMR, hepatitis B, diphtheria-tetanus-whole cell pertussis (DTP), Hib, and oral polio vaccine (OPV). In particular, DTP and MMR have been

associated with seizures, while DTP's potential link to encephalopathy has been tested with inconsistent results. Such cases are often presented as case studies through the media, with little attention to their prevalence. However, several large population studies found 0.65 cases of anaphylaxis per million doses, none of which were fatal (Bohlke et al, 2005), a borderline link between DTP and MMR vaccines and febrile seizures after receiving the vaccination (Barlow et al, 2001), and extremely rare instances of encephalopathy related to DTP (Walker et al, 1988). Though MMR and OPV are the most common vaccines associated with anaphylaxis cases, the condition is generally associated with patients who receive a combination of vaccines at one time (Bohlke et al, 2005).

- **Risks of Comorbid Diseases**

The potential link to autism rates is one of the most prevalent concerns regarding vaccines. Of particular concern is the role of the combined MMR vaccine, or the frequency in which it is administered. However, a longitudinal study comparing trends in both autism rates and increases in MMR vaccines from 1980 to 1994 indicates increasing autism rates are independent of the number of MMR vaccinations given – a result which repudiates the controversial Great Britain study that sparked concern in the first place (Dales et al, 2001).

Concern for other associations between vaccines and various diseases have sparked numerous studies, many with divergent results. For example, some studies link DTP vaccinations to sudden infant death syndrome (SIDS), but they overlook that the critical time frame for SIDS naturally overlaps the recommended schedule for a child's first two DTP vaccinations (Walker et al, 1987). Other studies have found that infants who did not receive either an on-schedule DTP or OPV were more likely to die of SIDS (Hoffman et al, 1987). Still other studies have examined links between vaccines and leukemia (Dockerty et al, 1999) or type 1 diabetes mellitus (DeStefano et al, 2001), finding borderline relationships that were dwarfed by other confounding factors, such as socioeconomic status, family history, and preexisting conditions.

- **Benefits Directly Associated with Vaccines**

Overall, vaccines are praised as one of the greatest tools in preventive medicine. The individual benefits of immunization expand beyond basic protection from preventable diseases to include reduced health care costs, mitigated loss of wages and productivity due to unexpected illness, and reduced costs associated with common complications of these diseases (Zhou et al, 2005). Vaccination program benefits are still overwhelmingly high even when costs for immunization-related adverse events are taken into consideration. However, the ratio of benefits to adverse event costs varies significantly by the disease in question and its associated immunization schedule (White et al, 1985).

- **Benefits Indirectly Associated with Vaccines**

The indirect effects of a well-vaccinated community, mainly reduced overall disease-related risk, are another strong benefit. Areas with larger anti-vaccine movements have far higher rates of vaccine-preventable diseases than highly vaccinated areas, with one study finding that 11 percent of children vaccinated for measles will contract the disease from a child who has been exempted for non-medical reasons (Felkin et al, 2000). Children who require a medical exemption from immunizations – either due to immune deficiencies, allergies, or preexisting conditions – are put

in greater risk as compliance rates around them decrease. Delaying vaccinations can have similar effects, but the strength of these effects is inconsistent depending upon the disease and the length of delay (Omer at al, 2009). Finally, just as decreased immunization rates exacerbate outbreaks, increased immunization rates can mitigate them just as strongly. A simulation model based on United States influenza trends, determined that an increase of vaccination rates to 20 percent in children aged 6 months to 18 years would decrease influenza cases in that age group by 49percent, and by 43 percent in adults. An increased program that reached 80 percent of children would reduce influenza cases by 95 percent in that age group, and by 86 percent in adults (Weycker et al, 2005).

Question 2: What is the existing evidence of the reasons families' opt-out of vaccines?

Even with vaccines available and with strong evidence showing their benefits in preventing diseases, some parents still continue to opt out of vaccinating their children. The justification for this may come from many different sources.

- **Fear of Vaccine Side Effects**

The single most damaging piece of work for vaccines is an article written in 1998 for the medical journal Lancet, by Dr. Andrew Wakefield. In his study he argues a causal link exists between MMR vaccines and autism (Roope, 2013). In 2004, the Lancet retracted his article and Wakefield lost his medical license. Many doctors feel this article and similar nonscientific information fuel parents' fear of vaccines (Roope, 2013). A case-study showed that 69 percent of parents who had chosen not to vaccinate their children cited fear that the vaccine may cause harm to their child as the number one reason to not vaccinate (Omer et al, 2009).

- **Misinformation**

Another reason parents opt-out of vaccinating their children is misinformation gained from parent groups. Often times these parent groups create websites that are critical of vaccinations. Many parents rely on the Internet as their source of information for vaccinations (Diekema 2005). Since there is no check on the validity of information on websites and the ease with which people can access the Internet these websites that are critical of vaccination further spread misinformation. Actress Jenny McCarthy fronts one of these parent organizations and claims autism is partly caused by "the tripling of vaccines given to children in the past 15 years with unstudied ingredients like, mercury, aluminum, and liver viruses" (Coombes, 2009). These parent groups, especially those fronted by celebrities, feed on fear and spread false or poor information on to parents who have done little to none of their own research.

Julie Leask, an expert on the anti-vaccination movement in Australia, has identified themes in the rhetoric used by anti-vaccination groups. The subtext to the message is the same, "there are universal themes of cover up; vaccines as poisonous chemical cocktails, an unholy alliance for profit, the threat of excessive government control; and the back to nature ideal" (Coombes, 2009). Pru Hobson-West, a senior research fellow at the Centre for Applied Bioethics, University of Nottingham, studied groups in the UK that were critical of vaccinations. She found that the more radical groups didn't necessarily have personal experience with vaccine damage but were often seasoned campaigners for other causes like alternative medicine and against the use of

animals for testing. She also found that these groups did not make their case against vaccines by weighing potential risk with benefits but rather discussed risks as unknowns (Coombes 2009).

- **Victims of Their Own Success**

Thanks to the success of vaccines and high immunization coverage throughout the United States, cases of vaccine preventable diseases such as polio, measles, mumps, rubella, and pertussis have dropped to extremely low numbers, and in some case nearly eradicated (Salmon et al, 2005). Due to these low frequencies, parents feel that the severity of, and the susceptibility to, these diseases have decreased (Omer et al, 2009). Much of this success comes from herd immunity, the concept that because a large portion of the population has been immunized they provide a level of protection from those who have not. However, increasing rates of under immunized children put herd immunity at risk. Also with the relative ease of travel, a disease that is all but eradicated in the United States may be contracted by a traveler in Europe or Asia and brought back to the United States.

- **Costs**

The cost of vaccines can also be a barrier to immunization. The cost of fully vaccinating a child has increased from $155 in 1995 to $1,170 in 2007 (Lee et al, 2007). However, the Centers for Disease Control (CDC) program, Vaccines for Children (VFC) offers vaccines at no cost for eligible children. Any child under the age of 19 and is either Medicaid-eligible, uninsured, underinsured, or is American Indian or Alaska Native is eligible for the VFC program (CDC). Most doctors are VFC members and thus can give free vaccinations if needed.

Question 3: What is the effectiveness of policy interventions that encourage vaccines?

With varying compulsory vaccination policies across the US, comes a range of effectiveness in assuring that children receive immunizations.

- **Policies Affecting the Ease of Exemption**

Just as the legislation differs between states, so does the administrative complexity for obtaining a non-medical exemption. In some states, like Washington, parents seeking non-medical exemptions must present an exemption certificate signed by their pediatrician when entering school (Tavernise, 2012). This contrasts with Oregon, which requires a religious exemption form signed by a parent and turned over to the public health department (Oregon Health Authority). Oregon law defines “religion” for the purpose of immunization requirements to be “any system of beliefs, practices or ethical values” (National Vaccination Information Center, 2012). Other states allow a social worker, nurse, or school official to sign an exemption certificate. Five states require exemption certificates to be renewed annually (Rota et al, 2001).

The rigor for obtaining a non-medical exemption is associated with the level of vaccination in that state (Salmon, 2005; Omer et al, 2006; Omer et. al, 2009; Rota et al, 2001; Diekema, 2012). In states like Oregon and Arizona where it is relatively simple to obtain an exemption, the rates rose by an average of 13 percent a year from 2006-2011 as opposed to states with a more stringent policy where the rates increased an average of 8 percent (Tavernise, 2012). Between 1991 and 2004, the mean annual incidence of pertussis in states with administratively simple

exemptions was nearly double that in states with complicated administrative procedures (Omer et al, 2006; Omer et al, 2009).

Arkansas serves as a good example of a strict administrative exemption protocol that allows religious exemptions to those who adamantly seek them. Arkansas children are granted an exemption if they "(1) provide a notarized statement requesting an exemption, (2) complete an educational component on the risks and benefits of vaccination sponsored by the Department of Health, (3) sign a statement of informed consent, including a 'statement of refusal to vaccinate' and acknowledgement that their children may be removed from schools during an outbreak" (Salmon, 2005, p. 781). The Arkansas law does not allow the Health Department to reject an exemption application if these criteria are met (Salmon, 2005).

- **Information For Parents**

Studies show many parents with under-vaccinated children lack information about the dangers of immunization exemptions, while fully unvaccinated children mostly come from families consciously choosing not to vaccinate (Omer et al, 2009). Although several reasons can account for under-vaccination, this lack of information is cited as a key component (Salmon, 2005). Sometimes under-vaccinated children have missed an appointment due to scheduling, lack of knowledge, or the expense of the care. Salmon et al (2005) found that mailing parents information about immunization requirements, the justifications for immunization, and how to get children immunized, helps reduce under-vaccination. Other researchers in St. Louis conducted a study on the effectiveness of providing parents with individualized calendars on immunization rates. Each month of the calendar consisted of a picture of the baby, vaccination reminders, and other information such as birthdays of parents and siblings and general parenting tips. Acting as an incentive, study participants were only given the next set of calendar months when they returned to the health center for a scheduled immunization. The study followed clients of two inner-city public health centers in St. Louis. At the end of the study, 82 percent of children whose parents had received the calendars were up to date on their vaccinations, compared with 65 percent in the control group. An individualized reminder about vaccination, with pictures that hold parents' attention, seems to be an effective strategy to raise rates (Kreuter et al, 2004; National Vaccine Advisory Committee, 1999; Dietz et al, 2000; Rota, 2001).

- **Community Innovation**

Some communities are using innovative coalitions to reach out to parents with vaccination information. All state immunization programs depend on schools and other community resources to promote and enforce vaccinations (Morrow, 2007). A low income, Latino neighborhood in New York was the site for a study to measure the success of building a coalition to increase vaccination rates. Researchers brought together 23 community organizations to envelop families with culturally appropriate outreach and education. Information on vaccines was included with five other community programs, such as housing assistance, parenting classes, and Women, Infants and Children (WIC) enrollment. Coalition members received training on the issue, and parents received immunization calendars and phone calls or cards if a vaccine became overdue. Compared to a control cohort from within the same community, the study found that children with the coalition support had 11 percent higher immunization rates (Findley et al, 2008). Additionally, the Advisory Committee on Immunization Practices and the National Vaccine

Advisory Committee recommends linking immunization information, assessment and tracking to WIC recipients (ACIP, 1996; National Vaccine Advisory Committee, 1999).

- **Healthcare Professionals**

While innovative ideas like coalitions help promote vaccinations, parents continuously cite healthcare providers as the top source of immunization information (Omer, et al 2009; Salmon et al, 2005). Pediatricians, physicians, nurses—and in particular school nurses—are critical access points to information. In a 2004 study, researchers found that schools without a nurse on staff were likely to have higher exemption rates (Salmon et al, 2004). This same study found that many school personnel were unaware or misinformed about the susceptibility of under-vaccinated children to serious illness (Salmon et al, 2004).

In Szilagyi's 1994 study, physicians cited missed preventive care appointments as a top barrier to immunization because they were less likely to vaccinate when a child was ill. This same study found that pediatricians were more likely to track immunization records than physicians (Szilagyi, 1994). Better immunization schedule education for all physicians and healthcare providers could be a way to curb this leniency (Szilagyi, 1994). Taking this a step further, some researchers claim that physicians have the duty to inform themselves about the history of the anti-vaccine movement, its concerns, fears, sources of information, and its continued evolution. Only then can physicians adequately respond to the questions and calm the fears of their patients (Poland and Jacobson, 2012). Diekema believes the most important factor in persuading hesitant parents is the family physician. Ideally this person has earned the trust of the family, listens carefully to their concerns, and responds appropriately and persuasively to those concerns (2012).

- **Social Marketing**

The use of marketing techniques to bring about a behavioral change has been used to reduce tobacco use, drinking and driving, and to promote seat-belt use – similar techniques could prove beneficial to increasing vaccination rates. "A communications strategy that goes beyond the pediatrician's office requires that the messengers (whether groups or individuals) be likable, trustworthy, and seen as working toward the same goal as parents" (Opel et al, 2009). Furthermore, the message itself must engage people on an emotional level and drive them to action. Stories about families and individuals are more likely to do this than data and statistics. Research also suggests that when people are doubtful about the veracity of a particular argument and are well educated, they respond well to two-sided messages such as: "While 20 percent of parents don't follow the recommended vaccine schedule for their children, most parents do" (Opel et al, 2009).

Washington aimed its social marketing campaign at 'hesitant' parents of children less than 2 years of age or those expecting a child. Hesitant parents were defined as those who had not yet decided whether or not to vaccinate their children, or who were not following the recommended time schedule. Rather than focusing on parents who had strong, fixed opinions, hesitant parents were targeted because they made up a larger group of people, who were "more likely to be open to considering vaccination, and likely to proceed with vaccination if perceived barriers are addressed" (Opel et al, 2009).

Research Questions

- Among parents choosing not to immunize their children in Lane County, what are their stated reasons and concerns?
  - Do parents perceive some vaccines to be riskier than others?
  - What do some parents find alarming about the structure of immunization schedules?
  - Where do parents get their information about immunization safety, risks, and benefits?
  - Approximately how many of the religious exemptions are actually religious?
  - What are the demographics of those families who choose not to immunize their children?

Research Design, Methodology and Data Collections

To gather parental concerns on a quantitative and qualitative level, as well as to assess the level and quality of communication with clinicians, we chose a mixed-methods research approach. These research methods included a parent survey, parent focus groups, clinician interviews, and comparison with existing surveys.

1.) Parent Survey

We targeted parents who chose to seek a non-medical immunization exemption for at least one child, or considered seeking this type of exemption, to participate in the survey. To best reach this population, we contacted the eleven Lane County schools with the highest exemption rates to determine their willingness to assist in outreach to parents (Appendix A). We requested that the schools either announce our study in their newsletters, which included links to the online version of the survey, or distribute paper copies of the survey with a pre-stamped return envelope included. Additionally, we distributed half-sheets of paper to several schools with descriptions of the research project, and directions on how participate in the online survey. To increase the response rate, we also conducted outreach to family organizations, parent groups, and daycares that are legally obligated to require immunizations (Appendix B). To ensure we reached the broadest audience, we conducted grassroots outreach by asking personal contacts familiar with Lane County parent social circles to circulate the link to the survey.

The thirty-five question survey covered five topics: the parent's personal experience with immunization exemption, concerns that fueled pursuit of the exemption, the quality and level of communication with healthcare providers about childhood immunizations, the parent's sources of information regarding vaccinations, and basic demographics. All questions were based on information that was either requested by Lane County Public Health, or was included in previous successful parental outreach surveys based on our secondary research. Questions ranged from simple yes-no inquiries to multiple choice and Likert scale responses (Appendix C).

The survey was offered in both paper and electronic formats to encourage a high response rate, and was available in both English and Spanish. Contact information was only taken if the parent was interested in participating in a focus group for this study, or if the parent wanted to participate in a drawing for one of five $20 gift cards to Market of Choice; otherwise, survey respondents and responses remained anonymous.

Outreach to high-exemption schools began in the last two weeks of February, with outreach to daycares and other child-related organizations in the area beginning in the first week of April. The final survey was released to parents in both paper and online formats on March 11th, and the survey formally closed on April 30th. A total of 85 participated in the survey.

Limitations:

While surveys are an effective scientific research instrument, the use of this method in our research faced some limitations. First, because we focused our research in the Eugene/Springfield area, rural parents were less likely to receive the survey. Second, surveying only schools with high exemption rates may impact results due to sampling error; a high exemption rate for a single school does not guarantee that the exempting parents are the best representatives of this population. Finally, even with a considerable amount of outreach, we ultimately had no control over whether or not a parent chooses to take the survey.

We chose not to ask parents to associate their survey with a particular school or organization because they may be associated with more than one. However, not collecting this data became a concern because it is possible that a single school or organization, or a small group of them, were overrepresented in the results.

2.) Survey Comparison

Using secondary source information saves time that would be otherwise spent gathering the research first hand. Looking at secondary sources also allowed us to interpret past research that we would not have been able to collect at present due to changes in the sample group, as well as time and cost constraints. We used secondary sources as the basis for our background information. Secondary data also informed our survey, interview, and focus group questions. Furthermore, secondary sources served as a comparison between the findings from our research and the information previously collected on this topic.

Cindy Morgan, the communicable disease Nursing Supervisor at Lane County Public Health, provided us with a wide range of information sources. These included the immunization exemption rates by school and grade for Lane County, both in the 2011-2012 and the 2012-2013 school years, results from similar immunization exemption surveys conducted in Josephine County and the state of Oregon, and a breakdown of the recommended vaccination schedule by age or grade. Much of this information served as the basis for our survey questions and outreach methods.

Limitations:

One major limitation of secondary information is that methods used by the researcher may be unknown. The research questions may have been leading or poorly worded—all of which could skew the data. Even though we may be unaware of the research collection methods, we still feel secondary research can provide a useful comparison.

3.) Parent Focus Groups

We held two focus groups in order to gain an in-depth understanding of the perspectives of Lane County residents who exempt their children from vaccinations or deviate from the recommended schedule. A focus group is a qualitative research method where a facilitator leads a panel of stakeholders in a discussion about their personal experiences or perceptions regarding a specified topic (Morgan, 1988). This research method is particularly helpful when trying to obtain the reason why stakeholders have certain opinions. The group discussion environment allows participants to speak freely with one another about the topic within their own context, which can yield a rich and unique body of qualitative data (Stewart and Shamdasani, 1990). Furthermore, a focus group can allow participants to elaborate on positions they may not have been able to fully explain in survey answers.

We identified focus group participants from survey respondents who indicated their willingness to partake in further study. Thirty-five survey respondents expressed interest in participating in a focus group, with a total of thirteen ultimately participating amongst the two focus group sessions. We developed a detailed interview protocol, which included a description of the research, review of informed consent, ground rules for the discussion, and interview questions (Appendix D). The questions were constructed based on survey question themes, and asked in an open-ended manner to encourage discussion. The focus groups were held over the course of the last two weeks of April at times convenient to the parents. Each parent was given a $20 gift card to Market of Choice for participation.

During each focus group, one researcher took notes while another facilitated the discussion. Due to their semi-structured nature, the discussions varied slightly between the two sessions as participants responded to one another's comments and the facilitator asked follow up questions as appropriate. Digital audio recordings were transcribed and the transcripts analyzed to identify common themes.

Limitations:

Focus groups are most valuable when participants feel safe enough to express their full thoughts about a subject. Because of the close-knit nature of the parent community in Eugene, several of the focus group participants were familiar with each other prior to the session. Although this did not appear to create a conflict during the groups, the participants could have altered their responses based on any personal relationships.

A general limitation of the focus group method is that the views of the participants may not be representative of the diversity of thought surrounding vaccines among Lane County residents. To avoid this barrier as much as possible, the analysis of the focus group data centered on common themes amongst the sessions and participants, rather than unique personal experiences.

4.) Clinician Interviews

To better understand the conversations about immunizations between parents and healthcare providers, we held semi-structured interviews with both traditional and alternative clinicians. The interviews set out to gather information about how clinicians approach the topic of

immunization with parents, and what type of responses they receive. To get a diversity of perspectives, we targeted a range of clinicians from the following professional categories in the greater Eugene and Springfield area: doctors (MD), osteopaths (DO), nurse practitioners (NP), physician's assistants (PA), and naturopaths (ND). Oregon does not have a homeopathic licensing board, so homeopaths were excluded from clinician interviews. Chiropractors were also excluded from the survey, as they do not provide primary medical care. Hospital staff records and professional licensing boards and associations helped us locate eligible participants, and news sources and advocacy groups helped us identify clinicians with varying opinions about childhood immunizations. Only clinicians who treated children, specifically in a pediatric or family medicine setting, were considered eligible for an interview. We began identifying potential interviewees at the beginning of March, and our target clinician list was completed by March 22nd.

As semi-structured interviews allow for variation of questions depending on the tone of the interview, they often elicit unique and valid responses. The themes of the interview questions included how much time clinicians spend discussing immunizations with parents, how they position immunizations in these discussions (and who typically initiates the conversations), and what kind of information they get from parents during these conversations. We also asked about any conflicts that have ever arisen from a disagreement between the clinician and the patients regarding a child's immunizations, as well as what types of strategies (if any) clinicians use to increase vaccination rates. (Appendix E).

Interview scheduling took place during the first two weeks of April, either by contacting the clinicians by email or phone. After outreach to 76 clinicians, 8 doctors, 1 osteopath, 1 joint doctor/osteopath, 1 naturopath, and 1 school nurse responded for interviews. These were conducted either in person or by phone or email. Participants were told that their responses would remain completely anonymous, even if quoted in this study, and overall responses would only be presented in summary form. This confidentiality statement encouraged several of the practitioners to open up and answer the questions honestly. Though clinicians were aware that they would be quoted in the report, all personal identifiers, such as gender and professional category or specialty, were removed.

Limitations:

Our access to clinicians depended solely on their willingness and availability to be interviewed for our study. Because the clinicians self-selected to participate, we were unable to engage with a wide range of opinions and experiences. Also, a sample of 13 clinicians is not adequately representative of the clinician population in Lane County. However, by speaking with clinicians with shared convictions about immunizations, we developed a robust body of strategies for engaging with vaccine-resistant parents, which might prove useful to Lane County Public Health.

Findings

1.) Parent Survey

Between March 11th and April 30th, 2013, a total of 85 Lane County parents participated in the survey; any paper surveys were entered into the online Qualtrics system.

What follows is a brief discussion of selected results from the 5 sections of the survey.

- **Immunization Exemptions**

Slightly under half of the respondents (45 percent) have obtained an immunization exemption for one or more of their children. Of those who have obtained an exemption, 82 percent were religious exemptions (Table 2).

Table 2: Exemption Types

Answer	Response	%
Medical	6	18%
Religious	27	82%
Total	33	100%

However, our focus was not only aimed at the attitudes of parents who have already exempted their children from vaccinations, but also those who have ever considered exempting. To capture this population, we asked the question "Have you ever *considered* obtaining an immunization exemption for any of your children?" (italics added), to which 75 percent of respondents answered "yes" (Table 3).

Table 3: Ever Considered Obtaining and Exemption

Answer	Response	%
Yes	54	75%
No	18	25%
Total	72	100%

- **Immunization Concerns**

The top two stated reasons parents pursued or considered an exemption were "Ingredients in vaccines" and "I am uncomfortable about the vaccine schedule" (Table 4).

Q: For which reasons did you pursue or consider a medical or religious exemption? Please select all that apply.

Table 4: Reasons for Pursuing or Obtaining an Exemption

Answer	Response	%
Illnesses caused by vaccines are worse than the disease the vaccine prevents	23	30%
I do not think my child will contract the disease that a vaccine prevents	25	33%

(Table 4, Continued)

Answer	Response	%
I want my children to get sick naturally	28	37%
I can't afford the cost of vaccinating my child	1	1%
I am uncomfortable about the vaccine schedule	33	43%
Ingredients in vaccine	48	63%
My religion is against vaccinations	4	5%
My child has a medical condition	6	8%
Neurological or developmental complications	18	24%
Other	26	34%

Nearly half of respondents stated either agreement or strong agreement with the statement, "vaccines can lead to neurological and developmental complications" (Table 5).

Table 5: Level of Agreement that Vaccines can Lead to Neurological and Development Complications

Answer	Response	%
Strongly Disagree	9	13%
Disagree	10	14%
Neither Agree nor Disagree	16	23%
Agree	22	32%
Strongly Agree	12	17%
Total	69	100%

Regarding vaccination concerns, the highest level of agreement (63 percent) was reported with the statement: "A baby's immune system is not strong enough to handle all of the recommended vaccines" (Table 6).

Table 6: Level of Agreement that a Baby's Immune System is not Strong Enough for all Immunizations on the Recommended Schedule

Answer	Response	%
Strongly Disagree	6	9%
Disagree	7	10%
Neither Agree nor Disagree	12	17%
Agree	23	33%
Strongly Agree	21	30%
Total	69	100%

Neither the cost of vaccinations, nor religion, were major factors in the decision-making of the respondents, as only 6 percent and 8 percent (respectively) described them as such. Furthermore, 76 percent of respondents would pursue philosophical exemptions instead of religious ones if given the option.

Although a majority of respondents have concerns about vaccines, many still see value in them; well over half (59 percent) believe in the concept of herd immunity, and 73 percent have at least partially immunized children.

Respondents were given the opportunity to expand on their concerns about vaccinations. Several of these responses are included in the table below (some spelling and grammar has been changed for clarity) (Table 7).

Table 7: Free Responses About Vaccination Concerns

I am grateful for vaccines, they serve an amazing purpose and do a lot of good. However I worry our schedule is too intense for children so small, and because some vaccines do cause reactions in some children, I believe a balanced approach is best. My son is almost 2 and now caught up, but we did a delayed schedule and spaced out our visits to the doctor. I am very grateful that was an option.
I am concerned about the current legislation that attempts to make exemptions more difficult to obtain.
We made our decisions vaccine-by-vaccine, looking at the incidence and seriousness and curability of the disease and also the risks of that particular vaccine. It was not an all or nothing philosophy. I used a religious exemption because that was the easiest one but my refusals were not based on religion but on informed choice and health philosophy. My 3 children eventually got all the main vaccinations, but not when they were so young. I gave their immune systems more time to strengthen before giving them the shots and only gave them before an overseas trip in which we might be exposed to lots more disease.
My main concern about the vaccine schedule is aluminum toxicity in infants, and the potential long-term effects on the immune system (as of yet unknown).

(Table 7, Continued)

My concerns were: so many at once for a little baby, and the possibility of autism. Also ingredients in vaccines. I spaced them out more than recommended, waited until he was 11 or 12 to do varicella & Hep B. Now I have a 1 year old and am getting her vaccines closer to recommended schedule, although I will wait on Hep B w/ her as well. I'd say trust in the Dr. is my reason for being more traditional this time around. Same pediatrician for 14 yrs now!
I have concerns about single dose multiple immunization vaccines for example MMR or DTaP. Options should be available to get separate vaccines.
I find the ever-growing vaccination schedule to be a huge issue, particularly since the effects of new vaccines are not studied over a significantly long period of time. Basically the first generations receiving a vaccine are the ones doing the testing. Also, where is the discussion around long-term issues? Where is the discussion around whether a vaccine is really necessary? Every time a new vaccine comes out the medical establishment's line is that OF COURSE IT'S NECESSARY.
It concerns me deeply when I see vaccines marketed and advertised (eg. gardisil). I believe pharmaceutical companies value profits much more than human health, and I do not trust them to do sufficient clinical testing. The chance of a severe injury is very rare, around 1 in a million for most vaccines, but the cumulative effects of injecting heavy metals into an infant is not well studied and I believe the risk is significant. The majority of vaccines are important and necessary but I prefer to spread them out as much as possible to minimize the effects of the heavy metals in my child's body.

- **Communication with Healthcare Providers**

A majority of parents reported discussing the risks and benefits of vaccines with their child's healthcare provider (Table 8).

Table 8: Respondents who Discussed Risks and Benefits of Vaccines with their child's clinician

Answer	Response	%
Yes	57	83%
No	12	17%
Total	69	100%

Furthermore, 76 percent reported being either "somewhat" or "very comfortable" having immunization related conversations with health care providers. An overwhelming number (82 percent) of these providers were noted to be MD's.

- **Information Sources**

Parents receive vaccine-related information from a variety of sources, and place varying amounts of trust in each of them. The information source with the highest mean Likert score (2.89) was scholarly journals, followed closely by the children's health care provider (2.84), and friends and fellow parents (2.70).

As shown by the following table, the amount of trust parents put in various sources follows a similar pattern (Table 9).

Table 9: Level of Trust in Immunization Sources

How trustworthy are the following:	Not at All	A Little	Somewhat	Very Much	Completely	Mean
Your own healthcare provider	7	8	21	29	2	3.16
Your child(ren)'s health care provider	8	6	20	31	2	3.19
Family members	13	9	26	18	1	2.78
Friends and fellow parents	8	8	28	21	2	3.01
Church groups	50	10	3	4	0	1.42
Government agencies	30	12	18	7	0	2.03
Newspapers/radio/ television	26	24	15	2	0	1.9
Magazines	30	21	14	2	0	1.82
Scholarly journals	4	6	22	32	3	3.36
Internet sources	11	24	20	10	2	2.52
Celebrities/athletes	59	6	1	1	0	1.16

- **Demographics**

The last section of the survey asked parents various demographic questions. The following is a brief summary of their answers:

- 82 percent of respondents are either married or in a domestic partnership.
- 70 percent reported having either a bachelor's degree or higher.
- Mean age of survey respondent: 36.7
- Mean number of children living in the household: 1.7
- 94 percent reported their race as 'White or Caucasian.'
- 17 percent reported household income under $25,000/year; 29 percent between $25,001 and $50,000/year; 26 percent between $50,001 and $75,000/year; and 21 percent between $75,001 and $100,000/year.
- 85 percent reported having health insurance for their children. Of those, 21 percent have public health insurance.
- The vast majority of respondents live in the Eugene/Springfield area; the two most common zip codes reported were 97405 (32 percent), and 97402 (19 percent).

- **Differences Between Parents Who Have Exempted Their Children from Vaccines and Those Who Have Merely Considered Exemption**

Although these two groups shared similar concerns regarding vaccinations, some interesting differences were found. Select differences are listed below:

  - Parents who have exempted their children were more likely to "agree" or "strongly agree" with the statements "Vaccines can cause Autism" and "Vaccines can lead to neurological and developmental complications" (38 percent to 20 percent; 67 percent to 45 percent, respectively).
  - Parents who have exempted their children expressed more concern with the possible negative side effects of the MMR vaccine than parents who have merely considered exemptions (42 percent to 25 percent) who rated the DTaP as the vaccine that concerned them most (30 percent).
  - Parents who have exempted their children were less likely to report being "somewhat comfortable" or "very comfortable" discussing vaccines with their children's healthcare provider (72 percent to 90 percent).
  - On average, parents who have exempted their children reported slightly higher education levels as well as total household income than parents who have merely considered exemptions
  - The top 5 sources for vaccine related information for parents who have obtained exemptions were: 1.) Scholarly journals; 2.) Friends and fellow parents; 3.) Internet sources; 4.) Their child's healthcare provider; 5.) Family members. For parents who have merely considered obtaining an exemption, the top 5 sources are slightly different: 1.) Their child's healthcare provider; 2.) Scholarly journals; 3.) Friends and fellow parents; 4.) Internet sources; 5.) Their own healthcare provider.

2.) Survey Comparison

Secondary research can provide valuable benchmarks and comparison points for primary research analysis. We used two other surveys that were similar to our own to compare the findings. The first was conducted in Ashland, Oregon in 2003; the second was a 2010 survey used to identify the populations in Lane County that had the highest levels of immunization exemptions. These two surveys help us analyze our own research results to identify any trends, notable changes, or drastically differing results.

One key feature of our survey was not just the total number of immunization exemptions, but how many people actually consider exemption as an option. We found that 75 percent of respondents considered obtaining an exemption for their children. This is a higher rate than the Ashland survey, which found a rate of 48 percent (Robinson et al, 2003). Because the 2010 Lane County survey was specifically targeting those who actually exempted, it did not gather any data on those who had merely considered exemptions.

- **Average Number of Children per House**

Our survey examined if the number of children in a household played a role in increasing exemption rates. Large families could make it difficult for a parent to get all of their children immunized, so the parent may choose to immunize some and not others or maybe none at all. We found that the average number of children under the age of 18 in the households of survey respondents was 1.7, which is slightly less than the Ashland survey's average of 1.9 children (Robinson et al, 2003). In our survey 18 percent of respondents had three children or more. Of this population, nearly half of them had received immunization exemptions. Of the half that did

not receive exemptions, four considered obtaining one and two did not. The Ashland survey found no significant link between the number of children in a household and the number of exemptions (Robinson et al, 2003). Due to a nonrandom, small sample, our survey cannot reasonably link family size to immunizations exemption rates.

- **Health Insurance**

The literature review indicated health insurance can be a strong influence on immunization rates. Factors such as high co-pays and deductibles can pose a significant barrier to getting children adequately vaccinated. Our survey found that 85 percent of respondents had health insurance for their children; this is slightly less than the 92 percent of respondents in the Ashland survey. Whereas the Ashland survey found that children without health insurance were 1.8 times more likely to get an exemption, uninsured children in our survey were more than twice as likely to have an exemption in our survey (Robinson et al, 2003).

- **Sources of Information**

One of our key research objectives was to determine the types of sources parents turn to for immunization information. Both the Ashland survey and the 2010 Lane County survey asked the same type of question, though the data collection methods differed. The Ashland and Lane County surveys asked respondents to select all applicable sources of immunization-related information, while we gathered the same type of data on a Likert scale. This approach allowed us to see to what extent each source influenced the decision making process, not just which sources were consulted.

For both the Ashland survey and the Lane County surveys, health care providers were listed as the primary source of immunization information, with 89 percent and 84 percent of respondents using them as a source, respectively (Robinson et al, 2003; deBroekert, 2010). Our research found that children's health care providers came in second (with a mean Likert score of 2.84) to scholarly journals (2.89). It is important to note that scholarly journals were not an option on either of the other surveys.

In both of the other surveys, family and friends were the second most trusted source of information regarding immunizations; family and friends also ranked highly on our survey. Two of the three least used sources for the Ashland survey were radio and television, with 15 percent and 19 percent of parents using these sources to gather information (Robinson et. Al 2003); the Lane County survey found only 14 percent of parents used television as a source of information (deBroekert, 2010). Our survey category included radio, television, and newspapers, which could have increased the number of people relying on these sources for information. However, even with the addition of newspapers, this option was still our fourth lowest response at a mean Likert score of 1.69, meaning that the respondents rely on these sources between 'not at all' and 'a little.'

- **Reasons for Exempting**

This topic is one of the core driving forces for most immunization exemption research, including ours. Respondent reasons for not vaccinating their children often follow common themes, which helps explain the high immunization exemption rates in Lane County. The survey conducted in

Lane County in 2010 found that 69 percent of the respondents were comfortable taking the risk of their child contracting a vaccine preventable disease (deBroekert, 2010). Our survey found similar concerns, specifically that the risks posed by vaccines are perceived as worse than the disease the vaccine prevents. This was our fourth most cited reason for seeking exemptions. The 2010 survey also found that that the second most cited reason for exempting was the conviction that children should get sick naturally, with 55 percent of respondents choosing this option (deBroekert, 2010). In our survey, this was our third most popular reason for exemption. Our second least cited reason was for religious objections, which was the least frequent reason for the 2010 Lane County survey.

- **Personal Experience with Vaccine Risks**

The Ashland survey asked respondents about their experience with a child harmed by vaccines, as well as the level of personal connection between the respondent and the harmed child. The questions asked whether the parent heard about the harmed child from the media, a friend or associate, or even their own children. However, our survey focused strictly on whether the respondent had firsthand knowledge of a child who was harmed by a vaccine. The Ashland survey found that 30 percent of parents who personally knew someone who has been harmed by vaccinations had obtained an exemption, our survey found 62 percent for the same population (Robinson et al, 2003).

3.) Focus Groups

- **Participant Immunization Choices**

A total of thirteen Lane County parents participated in the two focus group sessions, which were held on April 17th and April 26th. The participants represented a broad spectrum of immunization practices, with one parent choosing to fully immunize her child on an alternative schedule, one parent choosing to fully exempt her only child, and eleven parents choosing varying degrees of immunization exemption for their children. This variance consisted of three main choices: 1.) partially immunizing the oldest child, and fully exempting the younger children in the family; 2.) selectively exempting children from particular vaccinations, such as Varicella, Gardasil, Hepatitis B or Hepatitis A, or 3.) opting to only give their child a vaccine they perceived as particularly important, such as DTaP or MMR.

First, participants who partially immunized the oldest child, and fully exempted the younger children in the family noted that they felt pressured into vaccinating their oldest child. As they learned more about immunizations and gained confidence in parenting decisions, they felt better able to stand up to pediatricians or family members who pressured them to vaccinate. Several of the participants stated that they switched healthcare providers due to feeling pressured during medical appointments. One participant described:

> My son got one series of shots because they were very pushy. I gave in, and I regret that, and then we switched pediatricians. I went to a naturopath when my daughter was born. My kids don't see a doctor regularly because they don't need to (Participant 12, Focus Group, April 26, 2013).

Another participant stated:

> I now feel comfortable, but with my first pediatrician it was tense. I got a recommendation from a friend. For us, it was really uncomfortable. Stayed with her for about a year, probably a little longer than I should have. You get this idea that she's the doctor, she knows best, but I had to remind myself that I am in charge of my child's care (Participant 4, Focus Group, April 17, 2013).

Of the parents who exempted children from specific vaccinations or, opted to only give their child a vaccine they perceived as particularly important, most agreed that it was important to weigh the risks of the disease with the likelihood that their child would actually come in contact with it. Others noted that they perceived a vaccine's potential side effects as riskier than the disease itself. One participant stated that she would have given her child the pertussis vaccine if she could have vaccinated for only that illness, rather than the combined DTaP shot (Participant 1, Focus Group, April 17, 2013). Other participants agreed that they would be more likely to give their children immunizations if they were available separately, rather than as a compound shot.

All of the participants who decided to at least partially immunize one of their children chose an alternative vaccination schedule. Many of the participants felt their child was too young to withstand the recommended amount of shots at one time. Several noted that they could not justify giving their infant shots when the baby was still developing. Others felt the schedule was not designed for medical reasons, but for convenience reasons.
A participant stated:

> From what I've heard, it's really more just about parent compliance why they give all those doses at once—there is no other reason to give all at one time. Parents are more likely to get vaccinated when they don't have to make multiple trips. (Participant 4, Focus Group, April 17, 2013).

This perception of vaccinating based on convenience was particularly prominent when discussing chicken pox. Four participants noted that they felt vaccinating for chicken pox was more about keeping parents at work, instead of at home with a sick child (Participants 2, 3, Focus Group, April 17, 2013; and Participants 10, 12, Focus Group, April 26, 2013). One of these participants stated she vaccinated her child for chicken pox because she or her husband could not take two weeks off of work if their child were to contract the illness (Participant 10, Focus Group, April 26, 2013).

- **Participant Information Sources and Attitudes**

As a whole, participants felt reasonably well informed about immunizations. They agreed that their knowledge was primarily based on their own research, conversations with friends and personal experiences. While not all participants could recall their exact information sources when choosing immunization practices, four participants noted Dr. Robert Sears's book, "The Vaccine Book: Making the Right Decision for Your Child," as the largest influence on their vaccination choices (Participants 1, 4, 5, Focus Group, April 17; Participant 6, Focus Group, April 26, 2013). These participants felt Dr. Sears outlined immunization options by vaccine, based on the needs of a specific child, rather than a one size fits all approach.

Several participants said they researched most of their immunization decisions online. One said she compared the World Health Organization recommended schedule and the Centers for Disease Control schedule with the one recommended by Dr. Sears (Participant 4, Focus Group, April 17, 2013). Another stated that she consulted Wikipedia (Participant 2, Focus Group, April 17, 2013), and others could not recall the specific web sites they visited.

Participants felt that for informed consent to occur, clinicians needed to share more information about vaccines (Participants 1, 2, 4, Focus Group, April 17, 2013; Participants 9, 10, Focus Group, April 26, 2013). One in particular noted that she takes offense when the medical community assumes she cannot decipher pros and cons of vaccines for herself (Participant 9, Focus Group, April 26, 2013). While not all participants cited their child's healthcare provider as a reliable source for immunization information, those that did indicated that their relationship was respectful and based on a history of trust.

A participant stated:

> I didn't have much time to read at the time, with a small baby in my arms. But, I really trust my nurse practitioner, who has seen my husband since he was an infant, and now sees everyone in my family. She parents pretty much exactly the way we do as well (Participant 3, Focus Group, April 17, 2013).

Lastly, multiple participants voiced concern about the reliability of new vaccines. In particular, they questioned the amount of testing new vaccines, like Gardasil, had undergone before coming to market. Four participants emphasized that science is not perfect, and recommendations of what is beneficial or harmful can change as research improves (Participants 2, 3, 4, 5, Focus Group, April 17, 2013; Participants 9, 10, 13, Focus Group, April 26, 2013).

A participant stated:

> Public opinion isn't a good enough argument. In popular culture there is a lot of information that changes, like you shouldn't eat eggs, but now you can eat eggs. Or don't eat red meat, well now you can eat red meat. That whole public opinion thing, it's not a good enough argument (Participant 2, Focus Group April 17, 2013).

Participants in both focus groups seem to lack trust in publicly provided health information, particularly in regard to recent scientific studies.

- **Clinician Interactions**

All participants agreed that medical providers should be well informed about vaccinations and their potential side effects. Of those who felt negatively about interactions with their child's healthcare provider, three participants had exchanges that led them to believe the clinician was under-informed about vaccinations (Participant 1, Focus Group, April 17, 2013; Participants 10, 13, Focus Group, April 26, 2013). One said the clinician did not provide her with enough vaccination information (Participant 10, Focus Group, April 26, 2013), another said the clinician gave wrong information about necessary immunizations for travel (Participant 13, Focus Group, April 26, 2013), and a third said the clinician was unaware of preventative immune system boosting methods like breast feeding during vaccination (Participant 1, Focus Group, April 17,

2013). All described an erosion of trust in the clinician following these interactions. One participant stated:

> Most doctors don't even know that you need a booster. There just is no informed consent about vaccinations (Participant 1, Focus Group, April 17, 2013).

Another participant stated:

> Wouldn't getting all the information [referring to vaccine ingredients, potential side effects, consequence of not getting the vaccine, alternate schedules] really be informed consent (Participant 10, Focus Group, April 26, 2013)?

However, not all of the participants felt negatively about their clinician interactions. Those who felt positive noted their child's healthcare provider was non-judgmental and welcomed immunization discussions. One participant said that her child's healthcare provider encourages her to email relevant academic articles circulating amongst the parent community (Participant 5, Focus Group, April 17, 2013). The clinician does this to stay abreast of the topics of greatest concern to her patients. Another participant noted that open communication was critical to effective healthcare stating:

> Our doctor said 'I would like to talk to you about vaccines, and I am okay with however you decide.' She didn't do fear mongering, she listened and was open to questions. I felt good about it (Participant 6, Focus Group, April 26, 2013).

A separate participant agreed, stating:

> That has been a saving grace for us as well [referring to her accepting doctor]. He embraces a great conversation and doesn't push me to get vaccinations. That makes a big difference and can make you okay with getting more, when we really listen to each other (Participant 11, Focus Group, April 26, 2013).

These experiences illustrate the importance of participatory parent-clinician relationships based on transparency and respectful discussion.

- **Alternative Prevention Strategies**

Regardless of their children's immunization status, all participants agreed that good nutrition was important to boost a child's immune system. Several of the participants stated that they took particular care to ensure their child's immune system was as strong as possible in the weeks before and after a vaccination. They cited breastfeeding during vaccinations and the use of probiotics as effective strategies. Three participants said they use a product called Vaccishield, which is designed to boost immunity before a vaccination (Participant 1, 3, 5, Focus Group, April 17, 2013).

3.) Clinician Interviews

- **Clinician Opinions About Immunizations**

Every participating clinician reported being in support of immunizations, regardless of their professional category, and most praised immunizations as one of the greatest preventive medical achievements to date. One clinician said that not immunizing children is "one hundred percent wrong on a moral and public health basis" (Clinician 8, personal interview; April 16, 2013).

Three clinicians referenced not only the public health benefits of immunizations, but also the decreased rates of secondary infections that often accompany certain vaccine-preventable diseases. Specifically, the first clinician expressed great relief when treating immunized children who are sick, as they can rule out a variety of infections based on the child's immunization record:

> I trained in the last decade, and older partners used to see some really severe forms of infection along with the diseases themselves... One in particular is haemophilus influenza type b, which causes bad meningitis and epiglottitis. Another is measles. Even the pneumococcus vaccine has resulted in less severe disease (like meningitis, pneumonia, bacteremia) (Clinician 7, personal interview; April 16, 2013).

The second clinician actively educates patients about secondary infections, hoping that parents will realize that immunizations prevent far more than just the vaccine-preventable diseases themselves (Clinician 9, personal interview; April 16, 2013). Another clinician mentioned that treating one disease is far simpler than treating a disease with a secondary infection (Clinician 7, personal interview; April 16, 2013).

However, some clinicians expressed resistance to certain immunizations, particularly some of the more recently developed vaccines. This resistance stems from a variety of concerns; one clinician worries that the medical community is "overdoing it" with vaccines for less serious diseases, as well as the expense of new vaccines due to the heavy research and development that preceded it. This clinician is also concerned about the "overall burden to a child," noting that "every shot is a traumatic moment" (Clinician 5, personal interview; April 12, 2013). Another clinician's concerns had more to do with the unknown effects of the vaccines than the cost. This clinician waits several years before recommending a new vaccine to ensure that "any kinks have been worked out" (Clinician 6, personal interview; April 15, 2013).

Overall, the clinicians were eager to support immunization programs, especially of the serious or life-threatening diseases that are now extremely rare in the United States. Consequently, several felt that the rarity of these diseases is a key cause behind increasing vaccine resistance in the community. In fact, one clinician is concerned that "some people will have to get polio to encourage parents to vaccinate at the proper level" (Clinician 3, personal interview; April 9, 2013). However, awareness of vaccine hesitancy in Lane County varies by clinician.

- **Understanding of the Vaccine Hesitancy in Lane County**

Ten out of the twelve clinicians have heard that Lane County is less likely to vaccinate than other parts of the state. One clinician pointed out "specific pockets of high immunization rates," such as St. Thomas Aquinas and the Waldorf schools (Clinician 4, personal interview; April 9 2013).

Perspectives about why parents choose to exempt varies. One clinician believes that parents underestimate the severity of these now rare diseases, such as polio (Clinician 6, personal interview; April 15, 2013). Others describe parents who show concerns after their child developed mild to moderate symptoms upon receiving a vaccine (Clinician 6, personal interview; April 15, 2013), or are concerned about their child developing one or more of the "hypothetical and largely discredited" risks associated with vaccines (Clinician 10, personal interview; April 17, 2013). Still others have "extremely paranoid" patients (Clinician 3, personal interview; April 9, 2013) or those who are suspicious of the corporate vaccine manufacturers (Clinician 11, personal interview; April 19, 2013). One clinician's anti-immunization families actively try to educate them about their reasons for refusing vaccines (Clinician 8, personal interview; April 16, 2013), while another clinician's patients trust every medical decision, save immunizations, to the clinician (Clinician 11, personal interview; April 19, 2013).

Six clinicians expressed frustration about vaccine resistance among their patients, and the difficulty in having immunization-related conversations with them. Three of the clinicians speculated about deeper motives behind parents refusing vaccinations, and all three mentioned a "strong culture of individualism and mistrust of others" that leads to parents seeking immunization advice outside of the physicians themselves (Clinician 6, personal interview; April 15, 2013). One clinician suspects that independently researched "self-care" relates back to "Protestantism and self-interpretation of the Bible" (Clinician 6, personal interview; April 15, 2013), while another hears many parents defend their positions with a terse "I have done a lot of reading on this topic" (Clinician 8, personal interview; April 16, 2013). Another clinician perceives the entire movement as "dominated by fear" (Clinician 11, personal interview; April 19, 2013).

Three clinicians made observations about the types of parents that typically refuse vaccines. One observed a cultural trend in immunization-resistant parents, saying that the two groups most likely to exempt are "the highly educated professor type and the more stereotypical hippie type of person" (Clinician 1, personal interview; April 5, 2013). Another clinician saw an ethnic trend within their patient population, and provided some theories as to why this trend exists:

> I treat a lot of Latino families, and I have never, EVER, had a Latino family decline a vaccine. People in this country have a basic sense that children just don't get sick and die. My Latino patients, many of whom come from small towns, have a very different perspective first-hand. The diseases that go unseen by American parents are still a very real presence [for them]. Some of my Latino families are disappointed if their child doesn't need a vaccine at a well-child visit! It is my Caucasian parents, or at least my American-born parents, that show any resistance (Clinician 11, personal interview; April 19, 2013).

Meanwhile, another clinician observed that "there is no way to tell" which parents are going to seek exemptions; a "'vanilla' looking family" may be wildly suspicious of vaccines, while a "'hippie' looking family" may have no concerns about the recommended vaccines or schedule

(Clinician 4, personal interview; April 9, 2013). This clinician also reported that many of their patients are on Medicare and Medicaid, and are under-immunized because of "spotty medical care" (ibid).

- **Information Exchange with Parents**

The clinicians' personal perspectives about immunizations, and their opinions about why certain parents resist vaccinations, provide the basis for a good portion of their strategy for talking to parents about recommended vaccines. The conversations between clinicians and patients varied between interviewees on several levels, including whether the clinician or the parents initiate the conversation, the time when the conversation is initiated, and the type of information that is exchanged.

Only one clinician reported initiating the conversation with parents, though nearly every clinician interviewed implied that they take a proactive approach to the conversation. Two reported talking about vaccination preferences at pre-natal visits. One of these was the only one who reported seeing newborns in the hospital, during which they immediately recommend the hepatitis B vaccination (Clinician 8, personal interview; April 16, 2013). Another clinician always starts the conversation at a child's two-month well-child checkup, the visit that corresponds with the first major recommended round of immunizations (Clinician 1, personal interview; April 5, 2013), and another uses any well-child visit preceding a scheduled vaccination to talk about the next round of vaccines (Clinician 11, personal interview; April 19, 2013). Three clinicians reported talking about vaccinations at any visit that requires them, while five reported at least asking about immunization history at every physical. Another explores the immunization history of any patient who has an open wound (Clinician 3, personal interview; April 9, 2013).

All but one clinician talked about the information that they give to "concerned" or "resistant" parents, though every clinician mentioned giving some form of "routine allopathic advice" to parents about vaccinations (Clinician 2, personal interview; April 5, 2013). Three clinicians offer patients the standard CDC vaccine information packet, but only one clinician reported offering the packet to "parents who don't want to talk" (Clinician 4, personal interview; April 9, 2013).

Many of the parental concerns mentioned follow the same pattern we discovered in our literature review, survey, and focus groups, including: vaccine-related risks and side effects, vaccine ingredients, the number of vaccines given, government conspiracies, and other associated safety risks versus benefits. Of the eight clinicians that mentioned discussing these concerns with parents, four mention offering scientific sources and other "studies that debunk many concerns" (Clinician 3, personal interview; April 9, 2013). One clinician reviews with patients that:

> …babies get exposed to more antigens in a day than they do in a [compound] vaccine… The complications are also minimal, especially compared to the diseases themselves, and vaccines are much purer than they used to be (Clinician 1, personal interview; April 5, 2013).

Including this clinician, six others also discuss the vaccine-preventable diseases themselves. The conversations typically address weighing the symptoms and risks of the diseases against the "mostly hypothetical" risks of vaccines, emphasizing that "the actual diseases are worse"

(Clinician 10, personal interview; April 17, 2013). One clinician has found this type of discussion effective, noting that "most people have never seen the illnesses that the vaccine is preventing, and sometimes just explaining about the severity of the disease that is being prevented will convince a patient to immunize their children" (Clinician 6, personal interview; April 15, 2013). Another clinician talked about their own experiences as a parent, and how their children are fully immunized (Clinician 11, personal interview; April 19, 2013).

Five clinicians mentioned actively asking the parents about their motivations and concerns. Four talked about asking only resistant parents about their concerns, while one clinician encourages every parent to voice concerns and ask questions (Clinician 11, personal interview; April 19, 2013). Another tries to "ask as non-judgmentally as possible why parents don't want to vaccinate" (Clinician 1, personal interview; April 5, 2013), and a third also asks about a parent's future plans, such as daycare, to best balance parental concerns with future health risks to the child (Clinician 5, personal interview; April 12, 2013). The fourth clinician gives parents who refuse vaccines a survey about their decision along with the standard vaccine refusal form (Clinician 4, personal interview; April 9, 2013).

- **Strategies to Encourage Vaccination**

Despite the information that clinicians provide for their patients, parental reactions range from receptive to completely resistant. One clinician noted, "[The topic of childhood vaccines] is a delicate conversation, and families don't often want to admit the real reasons why they exempt until they are sure that the physician won't judge them" (Clinician 4, personal interview; April 9, 2013). Many clinicians have developed personal strategies to help patients feel safe, to gain patient trust, and to encourage childhood vaccinations.

Though nine clinicians talked about their individual strategies to increase vaccination among their patients, the vast majority of these strategies are unique to each. While four are against alternative immunization schedules due to "too much room for error" (Clinician 7, personal interview; April 16, 2013) and the difficulty in catching up once patients "get behind on the immunization schedule" (Clinician 12, personal interview; April 23, 2013), three will "concede to… selective vaccinations" (Clinician 4, personal interview; April 9, 2013) or a personalized immunization schedule if patients wish (Clinician 2, personal interview; April 19, 2013). Three clinicians prioritize certain "fatal" vaccines over the non-fatal "recommended" vaccines (Clinician 1, personal interview; April 5, 2013), or vaccinating for the riskiest diseases earlier on in their alternative schedule (Clinician 7, personal interview; April 16, 2013).

One clinician prefers a more straightforward approach with their patients, and is "very proud" of what has been a "very effective" method:

> If you don't want to vaccinate, you either believe that we were better off in the pre-vaccine era, or you feel your child is protected by herd immunity. You're not going to be better off, ever, in a pre-vaccine era, or you're being selfish by relying on other parents who vaccinate. What would the world look like if the rest of parents went about vaccines the same way that you did (Clinician 8, personal interview; April 16, 2013)?

Four clinicians preferred a non-confrontational approach, including building a trusting relationship with parents. One participant said that parents are receptive to vaccinating when clinicians "show support and make the process as easy as possible" (Clinician 12, personal interview; April 23, 2013). Another said that by "foster[ing] trust, and over time, a patient may be more receptive to behavioral change" (Clinician 6, personal interview; April 15, 2013). A third clinician said that by actively building trusting relationships, they have "very few fully unimmunized patients" (Clinician 7, personal interview; April 16, 2013).

- **Conflicts with Parents**

Unfortunately, a variety of conflicts can arise between particularly resistant patients and the most effective clinicians. One clinician reported never having a conflict with a patient (Clinician 12, personal interview; April 23, 2013), three reported "disagreements, but not to the point of big, ugly confrontations" (Clinician 8, personal interview; April 16, 2013), and six reported an outright conflict regarding vaccinations.

Of these conflicts, three resulted in the patient being immunized for at least one vaccine-preventable disease. One was the case of a completely unimmunized child who had stepped on a rusty nail, and was at high risk for tetanus; the child received the tetanus vaccine and its series of boosters after a disagreement with the child's parent (Clinician 3, personal interview; April 9, 2013). Another instance was a patient who was convinced that the flu vaccine gave him a cold, rather than the vaccine causing short-term low-grade symptoms or the patient contracting a cold elsewhere (Clinician 6, personal interview; April 15, 2013). The third involved a child's mother bringing the child in for vaccines when the father, who was adamantly against vaccines, was out of town (Clinician 9, personal interview; April 16, 2013).

One clinician experienced a conflict early on in their career that was severe enough to influence their approach to vaccinations to the present day:

> The worst case I have ever seen was when I started practicing medicine. A few babies died of SIDS after getting immunized, and I was crushed. I wondered if vaccines were behind their deaths. Because of that, I never make vaccines a big enough deal with parents to be annoying. I also give parents as much information as possible, because parents should know what to expect when kids get vaccinated, and what kids are getting. They should know why their kid's arm hurts, or why he has a fever after a shot; those are common side effects (Clinician 5, personal interview; April 12, 2013).

None of the participating clinicians ever admitted to refusing care over an immunization-related disagreement, and six flatly refuse to discontinue care. As one clinician mentioned, "adversarial relationships don't benefit the child in question at all" (Clinician 11, personal interview; April 19, 2013). Three other clinicians echo similar sentiments, stressing that "parents are just generally trying to do right by their kids," and "even if [clinicians] don't agree with them, I do not see the point in taking that hard of a line" (Clinician 8, personal interview; April 16, 2013). None of the clinicians were aware of a parent discontinuing care due to an immunization-related disagreement.

Discussion

While the mixed method research approach yielded a variety of results, three key themes appeared prominently in our findings.

First, parents who seek non-medical immunizations exemptions for their children cannot be generalized into one demographic or "type." As our literature review indicated, parents have a multitude of reasons for opting not to immunize their children, and those in Lane County proved to be no different. While some parents believe that a young child's immune system is not strong enough to handle all the recommended vaccines, others feel that some vaccines are under-tested, and still others feel their child does not need every recommended immunization, given age and lifestyle considerations. Certainly some of the exempting population could be classified as completely opposed to compulsory vaccination. However, the majority of our research indicates that many Lane County parents who opt out of childhood immunizations do so on a vaccine-by-vaccine basis. They are not particularly against immunizations as a whole, but rather see themselves as active participants in their child's healthcare.

These attitudes lead directly into our second key theme: the critical importance of open and constructive dialogue between parents and their child's healthcare provider. This concept was particularly apparent in the focus group and clinician interview research. Parents who felt pressured or uncomfortable with their clinicians felt less at ease with discussing the topic of childhood immunizations. While the majority of survey respondents felt comfortable interacting with their doctors, 17 percent reported that they have never discussed vaccines with their child's healthcare provider. Furthermore, any real, or perceived, condescension can damage clinician credibility in the eyes of the parents, which undermines the effectiveness of a health care provider discussing the medical care of a child with a parent. Further, clinicians reported successful attempts to encourage vaccinations when they actively engaged their patients, building trust over time. While a clinician may feel frustrated or shocked by a parent's vaccine hesitancy, the parent may feel equally affronted by the clinician's dismissal of their concerns.

Regarding immunizations, research indicates that the most effective clinician-parent relationships occur when both parties participate in a two-way dialogue about medical treatment. Several of the research-participating parents and clinicians cited positive experiences when discussing immunizations, and credited them to relationships built on mutual respect and active, open information exchange.

Perceptions about how well informed parents and clinicians were in immunization-related discussions varied significantly between interview and focus group responses. While several parents perceived their child's clinician as hasty and unknowledgeable about short and long-term vaccine side effects, several clinicians felt parents with immunization concerns were not acting in the best or most informed interest of their children. Interestingly, Lane County Public Health was never mentioned as an information source or regulating agency when discussing immunizations. This third theme illustrates the parental desire for more immunization-related transparency, citing mistrust about the quantity and quality of information that government agencies give to the public. Many parents who participated in our research work hard to inform

themselves about current immunization issues, and find it suspicious when they feel that vital information is withheld.

Recommendations

Our research indicates that to reduce non-medical immunization exemptions in Lane County, Public Health departments should consider the following recommendations:

1. Parents desire a respectful, two-way information exchange between themselves and clinicians. This reflects the importance of a trusting and open relationship between these two parties. Lane County Public Health should explore additional training programs and/or develop new materials to aid clinicians in having constructive, respectful conversations with parents. This may involve supporting clinicians to conduct peer-to-peer or clinic-level training programs. Whether it is wise or feasible for LCPH to maintain an active role in these trainings and discussions is an open question, however the department should consider initiating and facilitating the process in the early stages.

2. Parents would benefit from more transparency about all aspects of immunizations. This includes: providing more information about vaccine ingredients, potential short and long-term side effects from each vaccine, potential secondary infections that can accompany a vaccine preventable disease, potential consequences of not vaccinating, and vaccination schedules, including why some vaccines are bundled together. The outreach materials should be easily readable, as accurate as possible, readily available in several forms (such as in handouts and online), and should be actively distributed so parents do not feel that they have to "hunt down" the information. Most importantly, the language of the handouts must be informative, but not patronizing or condescending.

3. The Oregon Department of Health should pursue further research into effective state-level policies to reduce de facto philosophical exemptions, such as increasing the levels of approval or types of justification necessary to acquire one. However, public health departments should be aware that these types of restrictive actions may erode the chances of developing trusting relationships between the public and government agencies. Oregon Senate Bill 132, which will require exempting parents to receive additional information about vaccine-preventable diseases, either through an online video or their health care practitioner, emphasizes the one-way conversation that typically alienates parents from trusting the information given. Oregon SB 132 should be considered only after public outreach efforts and clinician engagement have failed. Alternative legislation that explores increased pharmaceutical industry vaccine transparency, particularly in regard to ingredients, risks, and efforts for healthier or "greener" immunizations, may strengthen some of that already tenuous trust. Finally, legislation should take into consideration that the majority of "religious" exemptions included in this study were grounded in philosophical rather than religious concerns, and that a "philosophical" choice may need to be added to reflect true parental reasons for exempting.

Works Cited

1. Advisory Committee on Immunization Practices (n.d.). Recommendations of the advisory committee on immunization practices: programmatic strategies to increase vaccination coverage by age 2 years – linkage of vaccination and WIC services. Retrieved from: http://www.cdc.gov/mmwr/preview/mmwrhtml/00040658.htm.

2. Ball, L., Ball, R., Pratt, D., (2001). An assessment of thimerosol use in childhood vaccines. *Pediatrics, 107*(5), 1147-1154.

3. Barlow, W., Davies, R., Glasser, J., Rhodes, P., Thompson, R., Mullooly, J., Black, S., Shinefield, H., Ward, J., Marcy, M., DeStefano, F., Chen, R., (2001). The risk of seizures after receipt of whole-cell pertussis or measles, mumps, and rubella vaccine. *The New England Journal of Medicine, 345*(9), 656-661.

4. Bohlke, K., Davis, R., Marcy, M., Braun, M., DeStefano, F., Black, S., Mullooly, S., Thompson, R., (2005). Risk of anaphylaxis after vaccination of children and adolescents. *Pediatrics, 112*(4), 815-820.

5. CDC - VFC Current vaccine price list - vaccines for children program. (n.d.).*Centers for Disease Control and Prevention*. Retrieved from: http://www.cdc.gov/vaccines/programs/vfc/awardees/vaccine-management/price-list/index.html.

6. CDC Features - VFC Program: vaccines for uninsured children. (n.d.). *Centers for Disease Control and Prevention*. Retrieved from: http://www.cdc.gov/features/vfcprogram/.

7. Coombes, R., (2009). Vaccine Disputes. *British Medical Journal*, *338*(7710), 1529.

8. Dales, L., Hammer, S.J., Smith, N.J., (2001). Time trends in autism and in MMR immunization coverage in California. *Journal of the American Medical Association, 285*(9), 1183-1185.

9. deBroekert, M., (2010). Summary of Survey of Parents of Under Immunized Children in Facilities with High Religious Exemption Rates and of Healthcare Providers Who Give Immunizations to Children.

10. DeStefano, F., Mullooly, J., Okoro, C., Chen, R., Marcy, M., Ward, J., Vadheim, C., Black, S., Shinefield, C., Davis, R., Bohlke, K., (2001). Childhood vaccinations, vaccination timing, and risk of Type 1 diabetes mellitus. *Pediatrics, 108*(6), 108-112.

11. Diekema, D., (2005). Responding to parental refusal to immunization of children. *Pediatrics: The Official Journal Of The American Acadamey Of Pediatrics*,*115*(5), 1429.

12. Diekema, D., (2012). Improving childhood vaccination rates. *The New England Journal of Medicine*. 366(5), 391-393.

13. Dietz, V., Baughman, A., Dini, E., Stevenson, J., Pierce, B., Hersey, J., (2000). Vaccination practices, policies and management factors associated with high vaccination coverage levels in Georgia public clinics. *Arch Pediatr Adolesc Med*. 154, 184-189.

14. Dockerty, J., Skegg, D., Elwood, J., Herbison, G., Becroft, D., Lewis, M., (1999). Infections, vaccinations, and the risk of childhood leukaemia. *British Journal of Cancer, 80*(9), 1483-1489.

15. Dodd, D., (2003). Benefits of combination vaccines: effective vaccination on a simplified schedule. *The American Journal of Managed Care, 9*(1), 6-12.

16. Feikin, D., Lezotte, D., Hamman, R., Salmon, D., Chen, R. Hoffman, R., (2000). Individual and community risks of measles and pertussis associated with personal exemptions to immunization. *Journal of the American Medical Association, 284*(24), 3145-3150.

17. Feudtner, C., Marcuse, E., (2001) Ethics and immunization policy: promoting dialogue to sustain consensus. *Pediatrics,* 107(5).

18. Findley, S., Irigoyen, M., Sanchez, M., Stockwell, M., Mejia, M., Guzman, L., Andres-Martinez, R., (2008). Effectiveness of a community coalition for improving child vaccination rates in New York City. *American Journal of Public Health*, 98(11), 1959-1961.

19. Hoffman, H., Hunter, J., Damus,K., Pakter, J., Peterson, D., van Belle, G. Hasselmeyer, E., (1987). Diphtheria-tetanus-pertussis immunization and sudden infant death: results of the national institute of child health and human development cooperative epidemiological study of sudden infant death syndrome risk factors. *Pediatrics, 79*(4), 598-611.

20. Kennedy, A., Brown, C., Gust, D., (2005) Vaccine beliefs of parents who oppose compulsory vaccination. *Public Health Reports,* (120).

21. Kreuter, M., Caburnay, C., Chen, J., Donlin, M., (2004). Effectiveness of individually tailored calendars in promoting childhood immunization in urban public health centers. *American Journal of Public Health*, 94(1), 122-127.

22. Lane County Public Health (2012). Lane County Public Health Authority comprehensive plan submitted December 2012 for fiscal year 2013/14. Retrieved from: http://public.health.oregon.gov/providerpartnerresources/localhealthdepartmentresources/documents/annual plans/annualplan2013-2014/lane_county_annual_plan_2013.pdf.

23. Lane County Public Health (2013). Lane County immunization status report for the 2012/2013 school year. Information provided by Cindy Morgan April 3, 2013.

24. Lee., G. Sntoli, J., Hannan, C., Messonnier, M., Sabin, J., Rusinak, D., Gay, C., Lett, S., Lieu, T., (2007) Gaps in vaccine financing for underinsured children in the United States. *Journal of the American Medical Association,* 298(6).

25. Montgomery, D. (2012, December 28). Lawmakers: let parents opt out vaccines for their kids. *Argus Leader*, p. 1. Retrieved from: http://www.argusleader.com/article/20121228/NEWS/312280007/Lawmaker-Let-parents-opt-out-vaccines-their-kids.

26. Morgan, David L. Focus groups as qualitative research. Newbury Park, Calif.: Sage Publications, 1988. Print.

27. Morrow, H., Collins, B., Smith, D., (2007) Public health coalitions: patterns and perceptions in state immunization programs. *Journal of Health and Human Services Administration,* 30(2)156-157.

28. Offit, P. (n.d.). Medscape: Medscape Access. *Medscape: Medscape News Today*. February 11, 2013, Retrieved from: http://www.medscape.com/viewarticle/776.

29. Omer, S., Pan, W., Halsey, N., Stokley, S., Moulton, L., Navar, A., Pierce, M., Salmon, D., (2006) Nonmedical exemptions to school immunization requirements: secular trends and association of state policies with pertussis incidence. *Journal of the American Medical Association*, 296(14).

30. Omer, S., Salmon, D., Orenstein, W., deHart, M., & Halsey, N. (2009). Vaccine refusal, mandatory immunization, and the risks of vaccine-preventable diseases. *The New England Journal of Medicine*, *360*(19), 1981-1988.

31. Omer, S., Salmon, D., Orenstein, W., deHart, P., Halsey, N., (2009). Vaccine refusal, mandatory immunization, and the risks of vaccine preventable diseases. *The New England Journal of Medicine, 360*(19), 1981-1988.

32. Opel, D., Diekema, D., Lee, N., Marcuse, E., (2009). Social marketing as a strategy to increase immunization rates. *Arch Pediatr Adolesc Med*. 163(5), 432-437.

33. Oregon Health Authority (2010). Lane County immunization rates, 2005-2010. Retrieved from: https://public.health.oregon.gov/PreventionWellness/VaccinesImmunization/Documents/county/Lane.pdf.

34. Oregon Health Authority (2011). Immunization requirements, 2012-2013 school year. Retrieved from: http://public.health.oregon.gov/PreventionWellness/VaccinesImmunization/GettingImmunized/Documents/SchBusEng12.pdf.

35. Oregon State Vaccine Requirements – National Vaccine Information Center. (n.d.). *National Vaccine Information Center – Vaccine Watch Dog*. Retrieved from: http://www.nvic.org/Vaccine-Laws/state-vaccine-requirements/oregon.aspx.

36. Peterson, R., Cook, C., Yerxa, M., Marshall, J., Pulos, E., Rollosson, M., (2012). Improving immunization coverage in a rural school district in Pierce County, Washington. *The Journal of School Nursing*. 28(5), 352-357.

37. Poland, G., Jacobson, R., (2012). The clinician's guide to the anti-vaccinationists' galaxy. *Human Immunology*. 73, 859-866.

38. Robinson, S., Timmons, A., Duncan, L., Guadino, J., Priedeman, M., Colling, H., (2003) *What Ashland Parents Told Us About Religious Exemptions.* State of Oregon, Department of Human Services, Immunization Program. Retrieved from: http://dhs.state.or.us/publichealth/imm/law/ashlandfinalreport.pdf.

39. Roope, J. (n.d.). Opting out of vaccinations could get tougher in California - CNN.com. *CNN.com - Breaking News, U.S., World, Weather, Entertainment & Video News*. Retrieved from: http://www.cnn.com/2012/06/04/health/california-vaccination-opt-out.

40. Salmon, D., Moulton, L., Omer, S., Chace, L., Klassen, A., Talebian, P., Halsey, N., (2004) Knowledge, attitudes, and beliefs of school nurses and personnel and associations with nonmedical immunization exemptions. *Pediatrics*.113(6).

41. Salmon, D., Moulton, L., Omer, S., deHart, P., Stockley, S., Halsey, N., (2005) Factors associated with refusal of childhood vaccines among parents of school-aged children. *Journal of the American Medical Association*.159.

42. Salmon, D., Omer, S., Moulton, L., Stokley, S., deHart, P., Lett, S., Norman, B., Teret, S., Halsey, N., (2005) Exemptions to school immunization requirements: the role of school-level requirements, policies, and procedures. *American Journal of Public Health*, 95(3).

43. Spadafora, M. J. (2012, April 3). Whooping cough spreading fast in state; vaccinations urged. *The Seattle Times*.

44. Stewart, David W., and Prem N. Shamdasani. Focus groups: theory and practice. Newbury Park, Calif.: Sage Publications, 1990. Print.

45. Szilagyi, P., Doane, C., Roghmann, K., Rodewald, L., Humiston, S., Raubertas, R., Cove, L., Lind, P., Tobin, M., Hall, C., (1993) Missed opportunities for childhood vaccinations in office practices and the effect on vaccination status. *Pediatrics.* 91(1).

46. Szilagyi, P., Hager, J., Roghmann, K., Doane, C., Cove, L., Rodewald, L., Humiston, S., Fleming, G., Hall, C., (1994) Immunization practices of pediatricians and family physicians in the United States. *Pediatrics*, 94(4).

47. Tavernise, S. (2012, September 19). Washington state makes it harder to opt out of immunizations. *The New York Times,* 1. Retrieved from: http://www.nytimes.com/2012/09/20/health/washington-state-makes-it-harder-to-forgo-immunizations.html?_r=0 .

48. The National Vaccine Advisory Committee. (1999) *The Journal of the American Medical Association*. 281(4), 363-370.

49. The National Vaccine Information Center. (2012) Oregon state vaccine requirements. Retrieved from: http://www.nvic.org/Vaccine-Laws/state-vaccine-requirements/oregon.aspx.

50. Walker, A., Jick, H., Perera, D., Knauss, T., Thompson, R., (1988). Neurologic events following diptheria-tetanus-pertussis immunization. *Pediatrics, 81*(3). 345-349.

51. Walker, A., Jick, H., Perera, D., Thompson, R., Knauss, T., (1987). Diptheria-tetanus-pertussis immunization and sudden infant death syndrome. *American Journal of Public Health, 77*(8), 945-951.

52. Weycker, D., Edelsberg, J., Halloran, M., Longini Jr., I., Nizam, A., Ciuryla, V., Oster, G., (2005). Population-wide benefits of routine vaccination of children against influenza. *Vaccine, 23*(10), 1284-1293.

53. White, C., Koplan, J., Orenstein, W., (1985). Benefits, risks and costs of immunization for measles, mumps and rubella. *American Journal of Public Health, 75*(7), 739-744.

54. Winter, K., Harriman, K., Schechter, R., Yamada, E., Talarico, J., & Chavez, G. (2010). Notes from the field: Pertussis – California, January-June 2010. *Morbidity and Mortality Weekly Report, 59*(26), 817.

55. Zhou, F., Santoli, J., Messonnier, M., Yusuf, H., Shefer, A., Chu, S., Rodewald, L., Harpaz, R., (2005). Economic evaluation of the 7-vaccine routine childhood immunization schedule in the United States. *Archives of Pediatric and Adolescent Medicine, 150*, 1136-1144.

Appendix A:

Lane County School Outreach

School	2010 Enrollment	2010 Exemption Rate (%)	Web site
Eugene Waldorf	153	73	http://www.eugenewaldorf.org/contact/
Homesource Charter	199	28	http://www.homesourcefamily.us/contactus.html
Network Charter	98	28	http://networkcharterschool.org/content/about-ncs
Arts and Tech Academy	400	20	http://ata.4j.lane.edu/staff/
Spencer Butte Middle	426	15	http://schools.4j.lane.edu/spencerbutte/staff/
Roosevelt Middle	522	11	http://schools.4j.lane.edu/roosevelt/
Far Horizons Montessori	64	17	http://farhorizonsmontessori.com/wp/
Ridgeline Montessori	193	30	www.ridgeline.org
Village School	206	58	http://happyvillage.org/
Family Elementary	144	64	http://www.family.4j.lane.edu/FamilySchool/Splash.html
St. Thomas Beckett Academy	99	72	http://sttbchurch.org/

Lane County Parent Organization Outreach

Organization	Web site
Eugene Rec	http://www.eugene-or.gov/index.aspx?NID=139
Eugene Library	http://www.eugene-or.gov/index.aspx?NID=130
Springfield Library	http://wheremindsgrow.org/
Willamalane	http://www.willamalane.org/
The Network of Family Resource Centers	http://preventionlane.org/parents-frcs.htm
Relief Nursery	http://www.reliefnursery.org/
Family Relief Nursery	http://www.familyreliefnursery.org/
Pearl Buck Center	http://www.pearlbuckcenter.com/
Parenting Now!	www.parentingnow.org
Head Start	http://www.hsolc.org/
Peace Health Birth Center	http://bit.ly/14XGkkr
Attachment Parents of Lane County	https://www.facebook.com/APLaneCounty
Family Programs at the UO	https://www.facebook.com/uofamilyprograms
Go Mom Go	http://gomomgoeugene.weebly.com/
Moss Street	http://moss.uoregon.edu/
Vivian Olum	http://olum.uoregon.edu/
Spenser View	http://pages.uoregon.edu/nsu/?p=76

Appendix C

Survey

This survey is designed for parents who have at least one child between kindergarten and middle school ages, and who have concerns or objections to immunizations or the recommended immunization schedule. All responses are COMPLETELY CONFIDENTIAL, and will only be presented in summary form with all other compiled surveys.

The survey only requires contact information for the respondent if the respondent is interested in participating in a focus group on this topic, or would like to be entered in a drawing for a $20 gift card to Market of Choice (five respondents will receive a gift card). Otherwise, respondents will not be contacted beyond this survey. Respondents who participate in the focus groups will only be contacted to schedule a convenient date and time for the focus group, and will otherwise not be contacted.

SECTION I: IMMUNIZATION EXEMPTIONS

Please answer each question to the best of your ability.

1. **Have you ever obtained an immunization exemption for any of your children?**

   Yes No

   a. **If yes, was it a medical or religious exemption?**

      Medical Religious

   b. **If no, have you ever considered obtaining an immunization exemption for any of your children?**

      Yes No

2. **For which reasons did you pursue or consider a medical or religious exemption? Please circle all that apply.**

   - Illnesses caused by vaccines are worse than the disease the vaccine prevents
   - I do not think my child will contract the disease that a vaccine prevents
   - I am uncomfortable about the vaccine schedule
   - Neurological or developmental complications
   - Ingredients in vaccines
   - I want my children to get sick naturally
   - My religion is against vaccinations
   - I couldn't afford the cost of vaccinating my child
   - My child has a medical condition
   - Other (please specify): _____

3. **If given the option, would you pursue an exemption for philosophical reasons rather than religious reasons?**

Yes No

4. **If they are exempt, do/does your child(ren) have any of their required vaccines?**

Yes No

5. **If they are exempt, from which vaccines are they exempt? Please circle all that apply.**

- Diptheria/Tetanus/Pertussis (DTaP)
- Polio
- Varicella (chicken pox)
- Measles/Mumps/Rubells (MMR)
- Hepatitis B
- Hepatitis A
- Hib flu
- Other (please specify): _____

SECTION II: IMMUNIZATION CONCERNS

Please circle the answer that reflects your level of agreement with the following statements.

6. **Overall, the risks of vaccines outweigh the benefits.**

Strongly disagree Somewhat disagree Somewhat agree Strongly agree Don't know

7. **Vaccines often lead to neurological and developmental complications.**

Strongly disagree Somewhat disagree Somewhat agree Strongly agree Don't know

8. **Vaccines can cause autism.**

Strongly disagree Somewhat disagree Somewhat agree Strongly agree Don't know

9. **A baby's immune system is not strong enough to handle all of the recommended vaccines.**

Strongly disagree Somewhat disagree Somewhat agree Strongly agree Don't know

10. **Vaccines protect the community as well as the person being vaccinated.**

Strongly disagree Somewhat disagree Somewhat agree Strongly agree Don't know

11. If vaccines were more affordable, I would be more likely to immunize my children.

Strongly disagree Somewhat disagree Somewhat agree Strongly agree Don't know

12. If the vaccination schedule was spread out over a longer period of time, I would be more likely to immunize my children.

Strongly disagree Somewhat disagree Somewhat agree Strongly agree Don't know

13. My religion is a major factor affecting my decision to obtain an exemption.

Strongly disagree Somewhat disagree Somewhat agree Strongly agree Don't know

14. Have any of your children's healthcare providers ever discussed the pros and cons of vaccinations with you?

Yes No

15. Have any of your family or friends (or their children) been harmed by vaccines?

Yes No

16. If you are concerned with any negative side effects related to vaccines, which vaccines concern you the most? Please circle all that apply.

- Diptheria/Tetanus/Pertussis (DTaP)
- Polio
- Varicella (chicken pox)
- Measles/Mumps/Rubells (MMR)
- Hepatitis B
- Hepatitis A
- Hib flu
- None/not applicable
- Other (please specify): _____

17. Do you have any additional comments regarding your concerns about vaccinations? Please describe them here. Please indicate if you would like a response to your comments.

SECTION III: COMMUNICATION WITH HEALTHCARE PROVIDERS

1. **How comfortable do you feel discussing vaccinations with your child(ren)'s healthcare provider?**

Not at all comfortable	A little comfortable	Somewhat comfortable	Very comfortable	Completely comfortable

2. **What kind of healthcare provider do/does your school-age child(ren) usually go to for healthcare needs? Please circle all that apply.**

Doctor (MD)	Nurse practitioner (NP)	Naturopath (ND)	
Osteopath (DO)	Physician's Assistant (PA)	School nurse	Other

3. **How many times in the past year has your youngest child visited any health care provider other than a dentist?**

0	1 - 2	3 - 4	5 - 6	7 - 8	9 - 10	More than 10

4. **Which healthcare provider generally has the most influence on the immunization-related healthcare decisions you make for your children?**

Doctor (MD)	Nurse practitioner (NP)	Naturopath (ND)	Not Applicable
Osteopath (DO)	Physician's Assistant (PA)	School nurse	Other

SECTION IV: INFORMATION SOURCES

5. **To what extent do you rely on the following sources for immunization-related information?**

Your own healthcare provider	Not at all	A little	Somewhat	Very much	Completely
Your child(ren)'s healthcare provider	Not at all	A little	Somewhat	Very much	Completely
Family members	Not at all	A little	Somewhat	Very much	Completely
Friends and fellow parents	Not at all	A little	Somewhat	Very much	Completely

Church groups	Not at all	A little	Somewhat	Very much	Completely
Government agencies	Not at all	A little	Somewhat	Very much	Completely
Newspapers/radio/television	Not at all	A little	Somewhat	Very much	Completely
Magazines	Not at all	A little	Somewhat	Very much	Completely
Scholarly journals	Not at all	A little	Somewhat	Very much	Completely
Internet sources	Not at all	A little	Somewhat	Very much	Completely
Celebrities/athletes	Not at all	A little	Somewhat	Very much	Completely

6. How much do you trust certain sources?

Your own healthcare provider	Not at all	A little	Somewhat	Very much	Completely
Your child(ren)'s healthcare provider	Not at all	A little	Somewhat	Very much	Completely
Family members	Not at all	A little	Somewhat	Very much	Completely
Friends and fellow parents	Not at all	A little	Somewhat	Very much	Completely
Church groups	Not at all	A little	Somewhat	Very much	Completely
Government agencies	Not at all	A little	Somewhat	Very much	Completely
Newspapers/radio/television	Not at all	A little	Somewhat	Very much	Completely
Magazines	Not at all	A little	Somewhat	Very much	Completely
Scholarly journals	Not at all	A little	Somewhat	Very much	Completely
Internet sources	Not at all	A little	Somewhat	Very much	Completely
Celebrities/athletes	Not at all	A little	Somewhat	Very much	Completely

SECTION V: DEMOGRAPHICS

7. What is your zip code?

_____

8. How many children under the age of 18 live in your house at least part of the time?

_____

9. What are their ages?

_____

10. What is your marital status?

- Married
- Domestic Partnership
- Single Parent
- Divorced
- Other _____

11. What is your highest level of completed education?

- Middle School
- High School Diploma / GED
- Trade School
- Associate Degree
- College Degree
- Post Collegiate Degree

12. What is your race? (Please select all that apply)

- Hispanic or Latino
- American Indian or Alaska Native
- Asian
- Black or African American
- Native Hawaiian or Other Pacific Islander
- White or Caucasian
- Middle Eastern
- Other: _____

13. What is your age?

_____

14. What is your approximate collective household income?

- $0 - $25,000
- $25,001 - $50,000
- $50,001- $75,000
- $75,001 - $100,000
- $100,001 - $150,000
- $150,001 or more

15. Are your children covered by health insurance?

Yes No

16. If yes, is it public (Medicaid, CHIP, OHP) or private insurance?

Public Private

SECTION VI: FOCUS GROUP AND RAFFLE

17. Would you be interested in participating in a focus group on this topic?

Yes No

18. If yes, please list a phone number or email address where we may reach you. Your contact information will not be shared with anyone, and will only be used for the purposes of scheduling you in a focus group.

If you want to be entered in the raffle for a $20 gift to Market of Choice, but do not want to participate in a focus group, please select "No" for the previous question, but leave contact information so we may notify you if you win.

Phone: _____ Email: _____

Group Interview Instrument

Introduction (10 minutes):

Good evening and thank you all for attending. My name is Eric Doyle and I'm a graduate student in the Public Administration program at the University of Oregon. This is my colleague Kate March, who will be taking notes tonight.

As mentioned in the introductory email to you, we are conducting research about childhood immunization decisions in Lane County. The purpose of this group interview is to discuss your concerns or issues with required immunizations, alternative approaches to immunizations, and the decisions behind exempting your children from immunizations for religious and other non-medical reasons.

Just as a reminder, I'd like to go over the consent process for this interview. You all received a consent letter attached to the confirmation email - please sign the copy at your seat if you haven't done so already. Access to the interview records will be limited to the four of us graduate students conducting this group project, and our faculty advisor Colleen Chrisinger.

This discussion will be recorded on Kate's laptop. She will also take notes on her ipad. Any paper notes will be transcribed digitally and the paper copies destroyed along with the recording file. In the final report, comments from interview participants will be generalized, and anonymous. While we will provide a general overview of this interview to Lane County Public Health, we will not give them a copy of the recording or transcript and will not provide them with a list of participants.

Furthermore, participants will not be identified in the final report. Your participation is voluntary. You are free to withdraw from the interview at any time for any reason. Do you have any questions about your rights during the interview process or how your responses will be presented in the report?

Some helpful **Groundrules** to make this effort as successful as possible include:

1. CONFIDENTIALITY: It is important that all of you agree to keep confidential the identities of your fellow participants.

2. PARTICIPATE: Please participate freely in the discussion. We need to hear each of your opinions and experiences.

3. RESPECT: Please respect the opinions of others and also speak one at a time.

4. STICK-TO-TOPIC: Let's try to stay on topic, we don't want to run out of time – and be mindful about leaving opportunities for others to respond as well.

5. QUESTION: We encourage questions if you are uncertain about the process or topics- just ask!

6. REMEMBER: there are no "right" or "wrong" answers- just tell us your experience!

Ok, we'll go ahead and get started. Feel free to stop me and ask questions at any time.

Questions:

1. To begin, can we go around the room and introduce yourselves and the age of your children, and their current immunization status?

2. Please tell the story of how you came to your current stance on vaccinations. Include any significant books, articles, people, and/or experiences that have shaped your beliefs over time, and where you stand today.

3. For those of you who have at least partially immunized your children, what were your initial reactions when your children received their vaccinations?

    Looking back, how do you feel about those vaccinations now?

4. I'd like to discuss your interaction with healthcare providers about immunizations. How comfortable do you feel discussing vaccinations with your child(ren)'s healthcare provider?

    If you do not feel comfortable, why?

5. Have any of your children's healthcare providers ever discussed the pros and cons of vaccinations with you?

    If yes, how did your feelings about vaccinations change after the conversation?

6. Have you or your children, or any of your family or friends (or their children) been harmed by vaccines?

    If yes, please describe the situation.

7. Please describe any alternative treatments or prevention strategies you have used instead of vaccinations.

8. Statistics show that parents who exempt their children from some or all vaccinations are in the minority. How does this minority status affect your behavior? Do you hesitate before telling others about your beliefs? Do you ever feel discriminated against?

9. Are there any other experiences or opinions you'd like to share before we wrap this up?

Conclusion:

Thanks so much for volunteering your time to participate in this study. Your input has been very valuable. Do you have any questions about the research? Feel free to contact me if any questions come up after we leave – you all have my email.

Clinician Interview Instrument

Hi, my name is _____. I am a student at the University of Oregon and I am doing a research study about the reasons that parents exempt their children from immunization requirements in Lane County.

Would it be okay with you if I used the information we talk about in my study? This is completely voluntary and you may say no if you do not want this information used in the study. If you agree and we start talking and you decide you no longer want to do this, we can stop at any time. I will not identify you or use any information that would make it possible for anyone to identify you in any presentation or written reports about this study.
If it is okay with you, I might want to use direct quotes from you, but these would only be cited as from a person. There is no expected risk to you for helping me with this study. There are no expected benefits to you either. Do you still want to talk with me?

1. What are your personal opinions about immunizations?

2. What kind of information do you tell your patients about immunizations?

3. How much do you talk to your patients about immunization-related issues?

4. Have you ever had a conflict with a patient regarding immunizations?

5. How aware are you about the anti-immunization movement in the community?

6. Has a disagreement with a patient regarding immunizations ever led to you refusing care or the patient changing medical providers?

7. What strategies for increasing vaccination rates have you found to be successful?

8. Is there any final statement you would like to make about childhood immunizations in Lane County?