Factors Of Participation In The Novel H1N1 Vaccination Campaign: A Panoramic Study Of Practitioners, Planners, Partners And Private Citizens In

Delaware

By

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Abstract

During the novel H1N1 public health event, the Delaware Division of Public Health nH1N1 working group planned dynamically to confront issues associated with logistics, operations, fiscal and administrative concerns, and also to maintain risk communications to encourage the public to receive vaccinations. Despite the successful identification and eradication of many issues and barriers, many Delawarians still did not choose to receive the vaccine, and not all providers choose to administer the vaccine, nor all to encourage their clients to receive it. This thesis is designed to identify the factors that affected the extent to which persons participated in these vaccination efforts. Feedback was gathered from healthcare providers, private citizens, and personnel who administered the programs, namely the School Vaccination Program. Feedback was gathered through interviews and attendance at meetings, and also through anonymous online surveys. Major factors of participation identified in this research were communication perceptions and realities, inclusion in planning, extra work burden associated with these vaccination efforts, the use of volunteers in operations, media propaganda, concerns regarding vaccine safety, specifically safety associated with Thimerosal, issues for those with special needs, anxiety associated with a novel public health event, persons who are categorically opposed to vaccinations as a disease control strategy, and the use of mediating structures. Among these factors, the most significant is that there were many

competing sources of information, and that the Division of Public Health was not necessarily held in superlative value by the public compared to other sources as it sought to provide information, services and guidance to the public. Future research should be conducted to identify the most efficient and trusted channels of information that can be used to communicate with the public amidst novel public health events.

Chapter One: Problem Statement and Literature Review

Problem Statement

Community participation in the novel H1N1 vaccination campaign varied, as did provider willingness to administer the vaccine. Media reporting and anecdotal discourse reflected uncertainty regarding the vaccine, concerning both the safety of the vaccine and the perceived need to receive it. This thesis is designed to explore the factors of participation in the nH1N1 vaccination efforts, depending on the role those interviewed were asked to take on. This feedback sought for this thesis includes a mix of professionals who were asked to take on an administrative or supportive role in these vaccination efforts, those who were obligated to take on an administrative or professional role in these efforts, and citizens who it was hoped would become vaccinated.

The onset of nH1N1 influenza virus in the spring of 2009 quickly became a matter of international attention and concern narrated by public health officials, government officials and media coverage alike. The virus was first seen widespread in March in Mexico, where its mortality rate was quite high and it was unknown whether it had the potential impact that some more deadly avian influenzas have. As the virus progressed through North America and overseas, the mortality rate for this strain of virus proved to be quite low, but the morbidity rate quite high, making its spread throughout the world poignantly visible. Thus, the nH1N1 influenza virus proved

concerning to health agencies, governments and private citizens alike as they followed daily updates and engineered novel responses to this novel virus. Although response to existing information was rapid, epidemiological data took time to collect and interpret. With the potential for a highly adaptable virus to be very dangerous, authorities managed this public health threat accordingly, modifying their approach as more was learned.

Initially, the medical response to suspected incidence of the virus was to test to determine if the person was actually infected with nH1N1 virus and then treat the confirmed cases with anti-virals. This same response is also used in response to seasonal influenza. However, there were a few lessons learned from this method that differed from seasonal: 1) the anti-virals were most effective when administered within the first 48 hours of the nH1N1 onset. The most reliable laboratory testing could be done by the Division of Public Health but the results took longer than 48 hours. 2) The quick laboratory tests done in doctor's offices (rapid PCR) showed many false positives, so anti-virals were used to treat people who didn't actually have nH1N1, depleting a scarce and valuable resource. (H1N1 AAR p. 24) 3) Most people did not need the anti-virals to heal from the virus. Most people had a mild case of the flu when infected. However, although they weren't common, there were deaths associated with the virus, and although many were due to underlying conditions, some deaths occurred in persons who did not have underlying chronic conditions. Pregnant women were at particularly high risk of a severe illness and even death if infected with

nH1N1. Some otherwise healthy adults and children also died from nH1N1, adding to the seeming random nature of the virus to go from mild to severe in some cases, which also increased the attention and concern of health officials and the general population. As with seasonal influenza, the ultimate best response was determined to be administering a vaccine to the public to lessen, if not prevent, their chance of catching the virus at all. However, the vaccine would need to be produced alongside seasonal influenza vaccines, and the ability to do both was unsure. The vaccines would have to be strategically dispersed. Because of the higher propensity of some groups to catch the virus, they were determined to receive priority for vaccine allocation. High risk groups for the nH1N1 influenza virus were pregnant women, children under 6 months of age (they cannot receive a vaccine), persons age 5-24, and those aged 25-64 with an underlying chronic condition. Because of this, the high priority groups for vaccinations included the above groups, except for children under 6 months of age, when the caregiver is considered the priority to vaccinate, to protect their infants who cannot receive the vaccine. In addition, healthcare workers were added as a high priority vaccination group, especially those who work with high risk groups. One unique aspect of this prioritization is that unlike seasonal influenza, this list did not include persons 65 years and older. However, although senior citizens were not at as great of risk to contact the nH1N1 virus, they were at higher risk for complications if they did contract it, making them a high priority for anti-virals administration. This caused confusion and frustration among many senior citizens, as they communicated

emphatically to Delaware Public Health's call center. A receptionist at the Call Center said some extremists told Call Center operators they believed that not being treated as a high priority group for vaccination was an attempt to "kill them off". Even if this reaction was at the extreme, it was disconcerting, particularly during a time that the Division of Public Health sought the public's trust and cooperation in order to effectively manage the situation for best health outcomes.

Senior citizens were not the only persons concerned about the vaccination. Public discourse and media coverage indicated that many were not concerned that they could not receive the vaccine, but rather suspicious that they were being encouraged to receive a vaccination that was only newly developed. This concern was not limited to private citizens unfamiliar with illness and treatment. "To me, it's just too new, there are so many risk factors that they haven't really assessed", a nursing student from Georgia said (DiSpirito, 2009). The medical community of New York conducted protests and demonstrations when the Governor of New York, David A. Paterson, made the vaccination for health care workers mandatory. He later retracted this mandate, as the vaccine production was insufficient to cover high risk groups, let alone high priority groups. (Hitt, 2009) It was unclear how so many became anxious regarding the vaccine's safety and efficacy and whether or not there was or is a general knowledge of seasonal flu vaccine production that was being used as a basis for comparison when evaluating factors such as time needed for production and safety trials.

Amidst the public concern regarding the proposed vaccine for novel H1N1, the international public health community began the process of planning and organizing vaccination efforts and the Delaware Division of Public Health was no exception. The Division of Public Health (DPH) launched a planning group and task force to determine how to distribute and administer the vaccine as quickly and comprehensively as possible. Identifying means to distribute and especially to administer the vaccine presented a challenge, as private providers were not obligated to participate in the campaign, yet DPH staff would be inadequate to vaccinate all those who were at high risk. The planning group ultimately decided on a multi-faceted approach to target vaccinating the priority groups. For adults with a condition that put them at high risk for infection and severe incidence of the virus, such as pregnant women or adults who are immune-compromised, private providers were asked to administer the vaccine. Their willingness to do so varied. To ensure that the largest high risk group, children, had no accessibility issues in receiving this vaccine, DPH used its own staff and contracted nurses to design and administer a mass vaccination campaign in schools, called the School Vaccination Program.

However, in addition to the need to engage providers to administer the vaccine, DPH needed to successfully increase public willingness and intent to receive the vaccine in order for vaccination to be an effective strategy in mitigating the spread of novel H1N1. There were public concerns about the vaccine from the start, including who would receive it, how much it would cost, and whether or not a vaccine so new

Factors of Participation In The nH1N1 Vaccination Campaign could be proven safe. A Frequently Asked Questions section was provided on the state website, a call center had a script to answer questions with the latest CDC recommendations and information was provided to persons administrating the vaccines. There was information at flu.gov and there were also many published articles detailing when a new safety study had been done for the vaccine and the results. The vaccine went through the same tests of safety and efficacy as the seasonal influenza vaccination. Information regarding these studies were published, yet the public discourse continued to reflect distrust in the vaccine and hesitation to seek it out, even from high risk groups (Survey: 46% of High Priority Adults Opt Out of H1N1 Vaccine, 2009) (Dispirito, 2009).

The school vaccination campaign was to be administered not solely by school nurses, but by Public Health nurses and also a nursing agency, Maxim, contracted by Public Health. Public Health did a lot of groundwork as they waited for the actual availability of the vaccine. They called all schools to get head counts. They predicted outcomes of how many children could be vaccinated based on how many nurses were available to vaccinate and using this matrix, they organized nursing teams. They determined the logistics and staging they would implement at various schools. The schools were notified they would be included and provided permission slips for the children to take home and sign. Because vaccine production capacity was unsure and ultimately was less than predicted, no definite schedule could be provided to the schools as they were asked to participate in the program. There were also concerns

Factors of Participation In The nH1N1 Vaccination Campaign about security at a school if it was widely known where this scarce vaccine would be present in mass quantities on a given day. This lack of a published and concrete schedule was one source of complaints that Public Health received. Ultimately, school's participation rates for the vaccine averaged between 30 and 40%, some higher than 50%, but some were lower than 10%. (Students still shun flu vaccine, 2009). One issue was that children with certain medical conditions could not receive the only type of vaccination provided at elementary schools, the FluMist, and therefore were turned away from receiving the vaccine.

Although DPH did extensive planning to conduct its administration of the School Vaccination Program, it could not conduct the program on its own. School and district personnel played a crucial role in completing the work that was needed before nursing vaccination teams would arrive at the schools. Permission slips and information needed to be distributed and returned. Individual student health histories needed review to assess possibility of counter-indications for those receiving vaccines. To further complicate matters, the uncertainty in vaccine production capabilities prevented any agency from planning a specific date and schedule, let alone coordinate this program with existing programs. Private, parochial, and public schools, including charter schools were approached to take part in this campaign. Private schools chose to participate at a rate of roughly 95%. All public schools were expected to allow the nursing teams to vaccinate their students. Depending on the school or district, persons with different job titles were chosen to act as the main point of contact for this

Factors of Participation In The nH1N1 Vaccination Campaign vaccination program. Sometimes that was the school nurse, and sometimes it was someone who played another professional role.

Another targeted group for vaccination was adults with underlying conditions that put them at high risk for contracting the virus and experiencing a severe bout of the virus. Roughly half of adults polled who fell into this category said that they did not intend to receive the vaccination if made available to them. One study produced odd results, claiming that Republicans were most likely to skip the vaccine at 74%, whereas fewer than half of Democrats were planning to opt out of being vaccinated. Southerners were also more likely to skip the vaccine, as were Born Again Christians, both at 69%. Neither the methodology used, nor reasons inferred for these findings were included in this publishing (Survey: Nearly half of adults don't plan to get H1N1 vaccine, 2009). However, it joined the large body of media surrounding the vaccination campaign. Initially, DPH relied heavily on private providers to vaccinate their own clients who had underlying conditions. Providers were instructed to register as a site to receive a delivery of vaccines and to also indicate how many vaccines they needed. DPH communicated to these providers through the Delaware Health Alert Network (DHAN) and through the Medical Society.

Because of the high risk to pregnant women demonstrated in the spring nH1N1 event, obstetricians' and gynecologists' (OB/GYN) participation in the campaign was particularly important. Like other private health care providers, they were instructed to register to receive vaccine shipments and indicate how many they would need. DPH

planners were concerned at the perceived low number of sites that were listed as registered. It seemed that OB/GYNs were not registering and that many pregnant women may not have the desired access to the vaccine through her trusted physician. Therefore, DPH conducted an informal telephone survey to the OB/GYNs registered as such practices within the state, but not listed as having registered to receive and administer vaccinations. Of over 20 called, only one provider explicitly stated that they did not wish to participate in the vaccination campaign, citing added administrative burdens and concerns about the vaccine as a reason. Others indicated an interest in providing vaccines, the only concern being why they hadn't received them yet.

Although providers still had the option of receiving vaccine shipments if requested, the Delaware Division of Public Health decided to launch mass flu vaccination clinics, one for each of the three counties, to be conducted once in November and once in December, for a total of six clinics. The hope was to provide a site to people whose private provider wasn't providing the vaccine to them and also to children who couldn't receive the vaccine in the School Vaccination Program for whatever reason. Homeschoolers reported being 'left out' of the school campaigns; this gave them a venue to become vaccinated. (Lopardi, 2009) Later, Public Health used a contracted nursing company to develop two vaccination clinics specifically for homeschoolers and private schoolers at schools without nurses. All vaccinations were provided free of charge. The goal was to vaccinate 1,000 persons a day, with a total goal of 6,000 persons being vaccinated. On the first day the clinic was conducted, over

200 people with appointments didn't show up. Some officially cancelled, but most just chose not to participate, reason unknown.

Some clinic attendees voiced concerns about the vaccines used; DPH suspected this might be a matter of contention. Due to scarce supply, some vaccines, including the vaccine provided at the clinic, contained Thimerosal, a preservative that contains mercury and is usually not recommend for children under eight or pregnant women. Delaware has a law prohibiting the administration of Thimerosal to these groups. The Director of Public Health, Dr. Rattay, declared a shortage to allow for legal use of Thimerosal-containing vaccines in children and pregnant women, and all receiving these vaccines had to sign a waiver acknowledging this. Mercury containing vaccines have been theoretically (though not empirically) linked to autism, causing much concern (Scott, 2009). The advice given at the clinic was that the amount of mercury in this vaccine is less than one would consume in a tuna sandwich, but due to public concern and public discourse, it continued to scare some away from receiving the vaccine. DPH had physicians and medical experts on site to answer questions. Anyone who requested speaking to a physician for guidance or advice was given the opportunity to do so.

Despite the initial levels of concern over nH1N1 and Public Health's tenacious efforts to safeguard the public, especially groups proven to be vulnerable to the nH1N1 virus, public discourse largely revealed anxiety and distrust regarding the vaccine and the vaccination efforts as a strategy. This seemed to be influenced by misinformation

and rumor rather than actual scientific information. Additionally, a population that was not encouraged to receive the vaccine, the geriatric population, was suspicious and anxious about being left out, rather than suspicious of the vaccine itself. Why was there such a disconnect between the public discourse and the information provided by the CDC and Public Health? How could Public Health more effectively communicate with the public to gain their buy-in? Additionally, it was not just the general population who expressed concern or reluctance to participate. Many medical professionals and persons at various schools did not seem to show a strong interest in participation, even occasionally an explicit aversion to participating. Public Health was heavily reliant on the cooperation and even endorsement from medical providers and schools, and so tried to anticipate every logistical difficulty in order to make the program easy to receive for all participating agencies. However, the logistics seemed not to be as much a concern as the receiving party's buy-in to the program. Phone surveys to smaller groups, such as the OB/GYN's registered in the state, gave some feedback, but the attitudes, beliefs, and choices of the thousands of persons involved in the school campaign and citizens in general, including those at high risk, have been a much harder to understand thus far.

Public Health tried to design a vaccination program that would provide resources and logistics to all participants as these were the anticipated roadblocks to success. However, the public had many concerns, some voiced, some not yet known or understood, that seemed to be much more influential in their decision to have

Factors of Participation In The nH1N1 Vaccination Campaign themselves or their vulnerable loved ones vaccinated. Of particular concern were the large agencies and networks whose participation was heavily relied upon in order to make the vaccination campaign a success, yet who did not seem to support the vaccination efforts or want to participate.

There have been publications and call centers set up to address concerns and provide information, but they don't seem to have gained cooperation and trust from many desired partners and citizens. Thus, the research described in this thesis was conducted to better understand the attitudes, beliefs and choices of various groups associated with the vaccination campaign.

Literature Review

This thesis seeks to identify factors influencing participation in this novel H1N1 vaccination campaign. Although this viral strain was novel, varying levels of trust in vaccines is not. There is much literature concerning fear of vaccines from various groups from countries in all regions of the world. There is also a wealth of research on willingness of health care providers to receive vaccines, let alone provide them. Although the factors described in this research are not exhaustive of all that may be found in the participation in the nH1N1 vaccination campaign, they provide insight to concerns that groups in the past have had regarding vaccines in general, regardless of the risked illness they are meant to prevent. This literature review is also highlights some factors of participation in vaccine campaigns that do not specifically reflect fear of vaccines.

A telephone poll was conducted in the United States to determine if parents had fears about vaccines for their children, and if so, what factors they identified as the cause of the doubt (Gust, 2004). The telephone poll also recorded the demographic information of respondents to analyze for significant correlations with their level of doubts, including no doubt, concerning vaccines for their children versus other factors. The study differentiated between a parent being unsure about a vaccine, delaying a vaccine because of uncertainty, and a parent ultimately refusing a vaccine because of doubts. This study also asked questions to determine if a parent changed their level of doubt concerning a vaccine, and if so, what prompted them to change their minds.

The majority of parents at all levels of doubts concerning vaccines identified concerns that a vaccine would not be safe as the main reason for doubt (Gust, 2004). For the varicella (aka chickenpox) vaccine, parents at all levels of doubt also questioned the effectiveness of the vaccine. This study was conducted before the outbreak of nH1N1 influenza, so doubts specific to that vaccine were not captured. The significant demographic factor at all levels of doubt was the age of the child being vaccinated. Parents who were unsure of vaccines and parents who ultimately refused vaccines both showed significant linkage to the maternal race/ethnicity, with white parents the most likely to refuse a vaccine and Hispanics most likely to receive recommended vaccines. Maternal age was also a significant factor correlating with a parent being unsure about a vaccine, with mothers 30 or older more concerned about vaccines. Deciding to delay a vaccine was significantly associated with the number of children in a household and maternal marital status; single mothers and mothers with more than one child were more likely to delay a vaccine (Gust, 2004).

Ultimately, if parents changed their minds to have their child vaccinated despite doubts, information or assurances from a health care provider was determined to be the most influential source of assurance or guidance .The researchers identified that they did not include questions to determine the significance of a parent's trust in the government as a factor in level of doubt in vaccines. Based on their findings, the conductors of this study demonstrated the need for a strong and trusted relationship between parents and their child's healthcare provider so that parents will be proactive

Factors of Participation In The nH1N1 Vaccination Campaign in voicing concerns, and so that providers can effectively address them. They also suggest collaboration with medical societies to encourage physicians to elicit questions from parents concerning doubt, and communications training to guide them in effectively ameliorating concerns (Gust, 2004).

Upon identifying health professionals' pivotal role in endorsing vaccine campaigns, it is also helpful to look at various health providers' attitudes towards vaccines and doubts the providers themselves might have, particularly regarding influenza vaccination (Raftopoulos, 1987). A study was conducted in Greece to determine the attitudes of nurses towards influenza vaccination. This study was conducted because the level of influenza vaccination coverage at the time of the study was 16.36% and determined low enough to prompt concern concerning the risk nonvaccinated nurses were placing on patients. The study was designed in keeping with the Health Belief Model, a model which explores the knowledge, attitudes and beliefs persons hold about a health action and which is helpful in determining perceived barriers and facilitators towards certain health decisions, in this instance, propensity to receive an influenza vaccination. This study examined potential influential factors such as perceived susceptibility to influenza, perceived benefits of taking action, perceived barriers to taking action, perceived severity (of influenza incidence), cues to action and cultural and ethnic beliefs (Raftopoulos, 1987).

Nurses were included from a diversity of settings, both public and private (Raftopoulos, 1987). It was found that most did not consider themselves at high risk

for catching influenza, attributed to good health, age, physical fitness and lack of a chronic disease. Those who did consider themselves susceptible to influenza cited direct work with patients and also job-induced fatigue that challenged their immune system. Participants were asked whether the attention to a potential avian pandemic in 2004 and 2005 influenced their decision to receive or not receive a vaccine and nearly two thirds said it did not. One participant even said she believed that the avian flu crisis was provoked by the media, indicating a perceived lack of need for the vaccine. When asked to assess other people's susceptibility to influenza, the nurses identified factors such as the state of their immune system, living conditions, age, medical history, profession and diet. The nurses agreed amongst one another that health promotion strategies should be used to encourage high risk groups to receive vaccinations (Raftopoulos, 1987).

Study participants were then asked to discuss the perceived benefits of vaccination (Raftopoulos, 1987). All participants did say that vaccination of themselves and other health care workers could protect patients at risk. However, some also believed that utilizing a hierarchy of controls (such as increased hand washing) made the spread of influenza to patients a low risk. Some even believed that nurses were exposed to illness in patients often enough to greatly increase their immunity, and were therefore not a risk for spreading influenza. Another responder believed it was the influenza vaccine that produced these antibodies to protect from infection. Although all participants agreed that certain persons were not only at high

risk for catching influenza, but also to having a more severe incidence of illness, it was determined this had little impact on their decision to receive an influenza vaccine themselves, because they did not consider themselves high risk for contacting influenza. Nurses also cited fear of vaccine-induced illness, as well as low rates of efficacy as reasons for not receiving the vaccine; one nurse thought it was as low as 40% effective. Nurses also said their busy schedules left little time to receive the vaccine. The guidelines for mandatory influenza vaccination differed for private and public nurses, possibly also affecting their decision (Raftopoulos, 1987).

Finally, participants were asked for ideas on influenza vaccine promotion to healthcare workers and also the general population (Raftopoulos, 1987). They were evenly divided on providing free vaccines to healthcare workers, some feeling they should be allocated to high risk groups first. Some endorsed national campaigns, with others advocating small, interactive group education programs. As for their role in promoting the vaccine to the general population, all participants said they would try to persuade elderly adults to receive vaccines, believing them to be at highest risk. However, some said they would also ask a physician's advice on recommending the vaccine and that they would consider the individual's medical history and whether or not they lived alone or with others. Ultimately, the participants believed they must balance the risk of influenza with an individual's risk of an adverse reaction to the vaccine. When asked to describe elderly adults' reasons to resist becoming vaccinated, the nurses described fear of counter-indication, especially influenza-like symptoms,

Factors of Participation In The nH1N1 Vaccination Campaign dislike of vaccination, low perceived susceptibility to influenza, the cost of the vaccine and lack of knowledge concerning vaccines (Raftopoulos, 1987).

Based on these findings, several recommendations were made to increase the vaccination uptake by nurses (Raftopoulos, 1987). First, that 'friendly strategies' should be used, such as support by institutional leaders, free vaccines during all shifts, clinics and mobile carts. The researcher recommended that vaccinations be promoted as part of employee health promotion programs, and to educate healthcare professionals about the risks that the health consequences they pose themselves and those in their care when they do not receive vaccinations. It was also recommended to hold education conferences and to provide and discuss educational materials that are meant for the general population. Ultimately, this study concluded that although many healthcare providers seemed willing to change their attitude towards influenza vaccination, there would need to be specific and sustained attempts to combat skepticism, mistrust and lack of knowledge concerning influenza and influenza vaccinations (Raftopoulos, 1987).

A similar study was conducted to determine the factors affecting the decision of nursing students in Taiwan to receive vaccinations, only the vaccine studied was to prevent Hepatitis B infection (Wen-Chuan, 1996). This research was designed according to the Multi-Attribute Utility theory, attempting to isolate attitudes and beliefs which accounted for decision-making and also to understand the relative contribution of each factor in the ultimate decision to receive or not to receive the

Hepatitis B vaccination. While the study of Greek nurses' attitudes to influenza vaccination promoted vaccines to lesson exposure to those in their care, the Hepatitis B vaccine was promoted to the Taiwanese nurses because they were at risk for contracting this virus because of their frequent exposure to bodily fluids. Study participants were asked whether various factors were relevant to their decision making, and if so, to rate its importance on a scale of 1 to 10. The factors that were evaluated were perceived threat of Hepatitis B infection, including perceived consequence of infection, and perceived susceptibility to infection, personal value of Hepatitis B vaccination, including concerns about the impact of vaccination and accessibility and availability, and social norms, including moral values, other people's opinions, and policy. The choice of these factors and the corresponding value was compared against whether students had completed all rounds of Hepatitis B vaccination, partially completed the four vaccinations, or were never vaccinated. Information was also gathered about the participants' years of experience in nursing and their specialization (Wen-Chuan, 1996).

The comparative findings of these many factors were as follows (Wen-Chuan, 1996). There was an inversely proportional relationship between years of experience and rate of vaccination. A strong relationship was shown between rate of vaccination and personal value of Hepatitis B vaccination, but not with perceived threat of Hepatitis B infection, nor with social norms. Specifically, concerns about the impact of the vaccine, and the accessibility and availability of the vaccine were shown to have a

Factors of Participation In The nH1N1 Vaccination Campaign significant impact on rates of vaccination. Accessibility and availability were particularly related to those who had begun, but not completed, all rounds of vaccination. Certain attitudes and beliefs concerning social norms and perceived threat of Hepatitis B infection were similar among all rates of vaccination: those fully vaccinated, partially vaccinated and those who had received no vaccination. Factors classified as social norms included social responsibility to maintain good health, responsibility to become vaccinated, family opinion, peers' opinions, and college teachers' opinion. Specific factors associated with personal value of the vaccine that accounted for compliance with Hepatitis B vaccination included time, money, and fear of pain from repeated vaccinations. Those who were vaccinated ranked the factors concerning the value of the vaccine the highest. Those who were not vaccinated placed the lowest value on a social responsibility to become vaccinated. Findings suggested to the researchers that those who were incompletely vaccinated may have ceased vaccinations because they sought out information concerning the vaccine that lowered its value to them, because they did not identify factors such as time, money, place of vaccination, nor side effects of vaccination as significant in their decision to receive the vaccine or not (Wen-Chuan, 1996).

Wen-Chuan (1996).also discussed results from related earlier studies, specifically how concern about the side effects of the vaccine showed as a significant factor in decision making in earlier studies, and yet not in this one. The possibility was suggested that side effects of the Hepatitis B vaccine were not addressed in "public

propaganda" or by the media as the government promoted the vaccine. It was also concluded that this could be why many were incompletely vaccinated; they could have received the information concerning the side effects for the first time at the vaccination and decided not to receive the subsequent vaccinations. Wen-Chuan's study also pointed out that the prior studies did not examine social norms as a factor in decision making, and that they also failed to ask research participants to assign a weight to factors they deemed relevant in decision making (Wen-Chuan, 1996).

Based on the findings of this study, the researchers made recommendations (Wen-Chuan, 1996). Firstly, it was recommended to provide information demonstrating the safety and efficacy of the vaccine during the nursing students' training course. However, it was determined that educational programs should be tailored to the factors of decision-making for the group to which they are targeted. It was also recommended to subsidize an intervention program and to create incentives, such as a regular and freely available vaccine clinics for those who deemed time and cost as factors in their decision not to be vaccinated. Finally, it was recommended to design a psychotherapeutic program to address fear of pain for vaccinations (Wen-Chuan, 1996).

General research on public perceptions and how this impacts decision making has also been done (Wilson, 2001). Public attention to vaccines, particularly vaccine safety, efficacy and counter-indications has increased as the incidence of widespread infectious disease has decreased.

Vaccines are unique among medical interventions in that they are given to healthy individuals to prevent diseases that often do not pose an immediate threat to the recipient. Many vaccine-preventable diseases are now so infrequent that the only context in which many individuals have heard of these diseases is when hypothetical adverse effects of the relevant vaccine are presented by the media as fact in an emotionally gripping story (Wilson, 2001, p. 101).

It is proposed that this may result in a greater perceived risk associated with risk of an adverse reaction to the vaccine than to the illness it is designed to prevent. Wilson asserts that "Perceptions, be they true or false, drive behavior" (Wilson, 2001, p. 101). This study of perception of risk associated with adverse effects of vaccines looks at case studies of public concern regarding the vaccines for whooping cough, poliomyelitis, and various other modern vaccines. One can find trends of not only doubt, but of widespread media coverage reporting on the doubt, and perhaps exacerbating the perception of risk of adverse effects. Theoretical concerns regarding a link between Thimerosal and autism were so strong that many states have laws restricting the use of this preservative in vaccine production (Wilson, 2001).

This study of risk perception and vaccine safety is not without recommendations, but also with modest expectations.

The debate of vaccine safety takes place in three courts: the courts of medicine and science, the court of public opinion and the legal courtroom. The rules of evidence-what constitutes proof of causation-differ in these venues, and therefore so might the judgments be rendered. (Wilson, 2001, p. 164)

Although Wilson determines that science must be the final arbiter, he also emphasizes the importance of frank information from the immunology, public health and medical communities regarding vaccines. He stresses the need for better communication to alleviate public concern, and also awareness of the likely skepticism from a public that is hearing different guidance from a plethora of information sources: media, the Internet, health officials, and scientific experts among others (Wilson, 2001).

As this literature review indicates thus far, there are many factors that go into any group's perception of the value of a vaccine, the risks it poses and their ultimate decision in whether or not to receive the vaccine. The recommendations made in the aforementioned studies generally emphasize education of and communication with the persons an administration would like to vaccinate. However, one factor of this decision making process that has historically also shown itself to be significant is the influence of trusted groups that may or may not be scientific or medical experts. This does not mean they do not have clout in advising persons within their membership about these matters.

A dramatic example of this kind of influence was seen by Nigerian leaders in response to a World Health Organization (WHO) attempt to vaccinate their children against poliomyelitis (Raufu, 2004). Dr. Datti Ahmed, speaking on behalf of The Supreme Council for Sharia, one of the most respected Muslim organizations in northern states of Nigeria, asked the government to stop the vaccination program, claiming it had uncovered US documents that promoted the depopulation of African and Muslim countries. "In the atmosphere of suspicion against the US...plus America's anti-Bin Laden rhetoric that often incorporates unflattering generalizations about Islam," Dr. Ahmed's words were taken seriously (Duodo, 2004, p.50). He also claimed that WHO had been developing anti-fertility vaccines for more than 20 years. The Supreme Council for Sharia endorsed a trip to India to test the vaccine there, as the Nigerian government endorsed another group to go to South Africa to perform a similar test. The group sent by The Supreme Council for Sharia claimed to have found strong evidence that there were anti-fertility and toxic components of the vaccine. Moreover, in an interview the lead in the India tests, Dr. Haruna Kaita, also said that it was a 'fake drug' that was not effective (Freedom of Choice in Health Care, 2003-2006). Conversely, the group that went to South Africa found no evidence of antifertility or toxic components in the vaccine and Professor Umaru Shehu, who'd been commissioned by the Nigerian government to perform the tests, called Dr. Kaita's conclusions "false and alarming" (Raufu, 2004).

The dispute between professionals who both claimed to have used the most advanced tests and found widely disparate results did not help decide the matter for Nigeria (Raufu, 2004). Traditional rulers asked for a halt to the campaign after Dr. Kaita broadcasted his findings. International attention started mounting, both in regards to the controversy, but also as stemming from the previously existing global concern; Nigeria accounted for roughly half of existing polio cases worldwide (Duodo, 2004). In addition to the endemic polio in Nigeria, incidence of polio in surrounding countries had also been traced back to Nigeria. Eradicating polio was not a matter solely for Nigerian concern; until the disease was eradicated, many remained at risk (Duodo, 2004). The international forum of discussion urged the disparate groups to come together and "'thrash out' all pending concerns...in an 'evidence-based', 'nonvituperative', and 'holistically educational' manner" (Duodo, 2004, p.51). It was also asserted that the opposition to the vaccine should not be dismissed just because the root group opposed to the vaccine was mainly composed of religious leaders (Duodo, 2004).

The case of Nigeria may be extreme, but it supports recommendations made in all cases reviewed in this literature review: communication and education are vital, as is finding the right medium to disseminate the information. Parents polled wanted assurance from a doctor (Gust, 2004). Nurses resisted vaccines largely due to mistaken perceptions about their own susceptibility to disease and risk posed to their patients and also unameliorated concerns about risk of vaccine counter-indications (Wen-

Chuan, 1996) (Raftopoulos, 1987). An analysis of risk perception emphasized that although different groups use different criteria for decision-making, this circumstance is inevitable with so many venues of information dissemination, and that effective ways of drawing out questions and answering them must be developed (Wilson, 2001). In the extreme circumstances of Nigeria, where even alleged scientific findings were in direct conflict with one another, ultimately, an honest and productive dialogue was identified as the way to work through the distrust and ultimately achieve what could be assumed to be the goal of all groups: safeguard the health of the public (Duodo, 2004).

Chapter Two: Methodology and Findings

Methodology

In an effort to gain a more panoramic understanding of the 2009 H1N1 vaccination experience from Delawareans, various groups were included in this feedback solicitation research. The groups included in research represent Division of Public Health planners, coalition groups between DPH and external healthcare practitioners, representatives of healthcare practitioners, school personnel who participated in the School Vaccination Program and private citizens, through both primary and secondary data sources. The specific groups were: the Immunization Coalition, the Center for Disability Studies and their constituents, private, public and charter school personnel, the H1N1 Planning Group, the Division of Public Health's Northern Health Services, University of Delaware's Health Services, individual workers from the Division of Public Health, and the Delaware Public Health Ethics Committee, who acted primarily in an advisory role.

All groups who were targeted for research were offered options of the means of gathering feedback, among them private interviews, focus groups, and anonymous surveys. Although the desired methodology of this author was focus groups, the ultimate goal was to include as many people who wished to provide feedback, and therefore the preference of the respondent was deferred to. Some groups contacted for feedback solicited feedback from their group prior to the meeting with the provided interview materials, enabling one person to represent the group in a private interview.

Another method of gathering feedback was attending pre-existing meetings facilitated by the group itself, while the researcher recorded. Research was gathered from the participating groups as follows:

Immunization Coalition: pre-existing meeting, follow-up with private interviews with those who indicated an interest.

Center for Disability Studies (CDS): interview with representative who conducted a telephone poll of constituents. Follow up anonymous survey provided to constituents. Private, public and charter schools: anonymous survey

Public Health's Northern Health Services: pre-existing meeting, follow-up with private interviews with those who indicated an interest

nH1N1 Planning Group: researcher acted as group organizer, gathered information at pre-existing meetings.

Delaware Public Health Ethics Committee: act as member of committee, gathered guidance and feedback in attendance of meetings.

Public Health personnel not part of nH1N1 planning group: private interviews

Limitations of Methodology.

It was hoped that this research could be done via focus groups, specifically amongst school personnel, in the goal of building rapport and potentially increasing the productivity of comments and suggestions. Conceivably, this would also have allowed further probing into certain responses in a way that a pre-written survey cannot, regardless of room for text explanation. A positive externality for participants might have been learning from one another's experiences and an increased feeling of teamwork in having worked in the same vaccination efforts, particularly for school personnel. However, although offered, this was not a method chosen by participants; those who did want to meet in person requested a private interview. This author opted for optimum inclusion over desired methodology and therefore modified the intended methodology to accommodate preference regarding focus groups.

In the research of the Center for Disability Studies (CDS) community, there was also an attempt to do both private interviews and focus groups to gain a better understanding of the concerns from this group, but there was only a response to the anonymous survey and the telephone poll that the Center for Disability Studies itself conducted. It is not known whether options were made available to accommodate all levels of ability. It is highly probable that many did not have a computer to do the online survey and also that those who might have otherwise done private interviews and/or the focus group did not have transportation or availability at the scheduled
Factors of Participation In The nH1N1 Vaccination Campaign times. It is also possible that there were special needs not known to the researcher that otherwise acted as a barrier to involvement in this feedback process.

Some groups were only offered an online survey, to preserve their anonymity. People have varying levels of comfort and interest in using online tools. It is not known if this deterred people from participating who might have participated were there another option available.

Lastly, some findings were gathered in attendance at group meetings that had well over the ten participants that focus groups are typically limited to. Chances for everyone to speak were decreased, particularly for persons not comfortable speaking in large groups.

Findings

Division of Public Health

Confidential Interviews with DPH Employees

The Division of Public Health was the primary source of planning and operations in this public health event. Therefore, DPH employees were consulted for insight. By soliciting feedback regarding internal operations, this researcher hoped to identify internally identified best practices and needs for improvement that may have affected factors of participation in these vaccination efforts. This researcher also hoped to gain contextual comparison with respondents outside of DPH to identify potential differences in perception and resulting differences in experiences during this event that may have acted as factors in participation by constituents and/or providers. Three employees of the Division of Public Health agreed to participate in private interviews. Though the interviews were conducted separately, one with two persons and one with one person, the responses were quite similar. The main points of discussion were the ways in which Public Health reallocated its services, their experience with the vaccination efforts, observations of public trends, minor concerns and overall satisfaction with the individual's experience.

All parties confirmed that priorities were realigned to service the greater priority at hand, that of a pandemic with unknown epidemiological scope. Many employees were asked to "wear different hats" from time to time, such as working in Logistics. All DPH community programs were able to continue, although the

individual disclosing this information did say that if the event were larger in scope, programs would have to be reassessed for priority. DPH employees at Public Health clinics said that some services had to be referred elsewhere. One interviewee said, "T m not sure where they went...I guess I did wonder, where did they go?" The employee said they did not know of a protocol to refer clients to outside agencies, and did not have a system for following up with clients whether they found and received the services they needed. Another employee speculated that they may have to tell the public certain services were unavailable, as other not-for-profit agencies may be limited in resources as well (personal communications, January 29, 2010) (personal communications, February 4, 2010).

All of the DPH employees felt that they were asked to play an appropriate and manageable role during the vaccination efforts. The only reservation to this statement was that certain scheduling freedoms formerly enjoyed were withdrawn during the vaccination efforts. All DPH interviewees spoke of the excellent teamwork amongst DPH employees and of their admiration for the innovation and hard work that was put forth. DPH employees voiced appreciation for the opportunity to work with DPH colleagues they hadn't previously interacted with. They spoke of gained appreciation for the work of others (personal communications, January 29, 2010) (personal communications, February 4, 2010).

When asked to discuss public participation in the vaccination efforts, one DPH interviewee expressed surprise that the participation rates in the School Vaccination

Program were so low. "It might have helped if their parents were there (at the school), so they could have asked questions." Instead, parents dealt with uncertainties of possible counter-indications to the vaccine by writing notes on the forms, which meant they couldn't be accepted. When asked where else people might go with their concerns, this health official said that people probably turned to their primary care physician, a previously trusted relationship to ameliorate their concerns. Despite some issues, this interviewee still maintained that the School Vaccination Program was a good idea as it "gets people where they're at", and was the first of its kind and scope since the polio vaccine, making it a noted accomplishment (personal communications, February 4, 2010).

In addition to observing public concern regarding the vaccine, two DPH employees interviewed reported that many clients they saw weren't interested in receiving the vaccine, as they didn't think of themselves at risk. However, these employees work in a DPH clinic and they took the opportunity to actively promote the vaccine to all who came through the doors, even if the person was there merely accompanying the person intended to be treated. In this way, they were able to vaccinate people who otherwise might not have received the vaccine. However, one issue with including people in vaccination was whether or not they had a complete vaccination record or indeed, a vaccination record at all. This was particularly an issue with immigrants, although one nurse reported that the Korean vaccination records were the best she'd seen (personal communication, January 29, 2010).

All interviewees emphasized the positive experience they had, and the pride they felt for the Division of Public Health and its efforts. There was also excitement expressed in being able to make DPH's services more well-known and appreciated by the public. "Some people think public health is just for poor people, but when people come to us, they have a good experience." The School Vaccination Program and the mass clinics were given credit for increasing the public's awareness of DPH's services and also for increasing the number of Delawareans who were able to be vaccinated (personal communications, January 29, 2010) (personal communications, February 4, 2010).

Northern Health Services.

On Thursday, January 21, 2010, the Northern Health Services (NHS) held a post-event discussion, internally referred to as a 'hotwash' of the nH1N1 mass vaccination campaign in schools, to identify best practices, areas for improvement, and protocols used. The topics of facilitated discussion were structured based on those that Public Health Preparedness must report on: staffing, communications & coordination with schools, supplies & logistics, direct operations, planning & protocols, and reporting. The NHS nurses had formed teams to service each district, so feedback often varied given the specific strategies that given teams had implemented.

The staffing issue most focused on was the use of volunteers, and how volunteer participation varied between the two visits to elementary schools. The Center for Disease Control and Prevention advised 2 doses for children under age 10. Some teams noted that there was a significant variance in the volunteer rate between the school visits for the first dose versus the second dose. The first visit saw up to 10 volunteers per day, whereas the second saw only 1 or 2, with less reliability of following through on the commitment. Although less reliability was seen in the second campaign, it was a noted issue in both campaigns. This caused a larger burden on the Delaware Public Health (DPH) staff, requiring last minute scrambling to find replacements for absent volunteers. Some teams had the same volunteer(s) continually sign up and cancel with little or no notice. This lack of consistency was seen both in the school vaccination dates and the trainings that were held beforehand, even though Factors of Participation In The nH1N1 Vaccination Campaign DPH scheduled extra trainings to try and accommodate all schedules (personal communication, January, 21, 2010).

However, other teams noted that they had very reliable volunteers. They attributed this to several factors. First of all, they facilitated open and ongoing venues of communication, contacting the volunteers on a regular basis and also encouraging them to contact them with any concerns or questions. Secondly, rather than meeting on-site, carpools were arranged so that no one had the issue of getting lost while trying to find each school; the volunteers were generally not from the district or general area in which they were volunteering. This also ensured that the entire team was present for the entire duration at each school. Lastly, certain volunteer pools were identified to consistently be the source of high levels of reliability, including those from Division of Services for Aging and Adults with Physical Disabilities (DSAAPD), Medicaid, and those from the Delaware Medical Reserve Corps. It was also identified that retired medical professionals were very reliable and seemed to enjoy participation in this campaign (personal communication, January, 21, 2010).

Another staffing issue discussed was that of the matrix used to predict need for nurses and supplies. It was identified as helpful to begin planning with, and ensured ample staffing was sought out for each school. It also ensured that both DPH nurses and Logistics had the same reference point for planning. It was mentioned that it was unfortunate Maxim did not have this same support. The only negative mentioned with the staffing matrix used by DPH was that the predictions of the need for nurses were

Factors of Participation In The nH1N1 Vaccination Campaign based on ideal preparation and readiness by schools. If schools did not have a timeefficient protocol for getting the children being vaccinated to the nurses, it often appeared that they were overstaffed due to lack of consistent flow of students. Some schools had gaps between students as long as 30 minutes, resulting in an inefficient use of DPH time. Some schools had these gaps because of their acknowledged scheduling conflicts: there was a school function, such as a puppet show, or another scheduled event, such as lunch. Other schools had gaps and it was undetermined why, but theorized by DPH that there wasn't clear communication between school nurses, teachers and school administrators, resulting in scheduling gaps. If there were significant gaps, the maximum number of students was not reached (personal communication, January, 21, 2010).

This led into a discussion of the communication successes and challenges in this campaign, notably the communication with schools. As with other aspects of this campaign, there was a range of incidence of best practices and need for improvement or redesign. The role of the school nurse was identified as the most significant factor of the experience with any school. The most favorably recalled experiences were the ones in which the nurse was willing and able to actively disseminate information, receive and answer questions and actively engage in communication with DPH to plan a successful visit. DPH acknowledged that the nurses all seemed conscientious, but did not all assume this ideal role in the campaign. DPH theorized that this was because the nurses had varying levels of support from the school administration. Some school

Factors of Participation In The nH1N1 Vaccination Campaign administrators even told DPH they were to communicate through them, not work with the nurse directly. DPH heard about many difficulties experienced by the school nurses, among them that they did not receive necessary support from school administration. Moreover, many school nurses experienced criticism, an onslaught of calls, questions and complaints from parents, and some had to work 18 hour days to play their role in this campaign (personal communication, January, 21, 2010).

As identified by DPH, one of the more challenging roles of the school nurse in this campaign, and one of the most important expected of her, was to review each student's medical history and identify those who would not be able to receive the FluMist vaccine due to potential counter-indications. This was the task largely responsible for the long days and also one that resulted in many calls from concerned parents. Parents wrote notes of their children's medical histories on the consent forms, often rendering the consent forms invalid. As with much of the general population, there was concern of the vaccine's safety and efficacy. Even when parents trusted the safety and efficacy of the vaccine, there was often the issue that their child was not able to receive FluMist due to a variety of factors, among them that the child had asthma or was under the age of 5 and was therefore not included in this vaccination outreach. Many schools had 4-year-olds as part of their student body, resulting in a high number of parents angry that their child would be left out of this opportunity for receiving the vaccine. One mistaken call-out to a school population went to all families, including those with children under the age of 5, resulting in even higher

Factors of Participation In The nH1N1 Vaccination Campaign frustration, and the school nurse was the primary recipient of these complaints (personal communication, January, 21, 2010).

Another burdensome role for school nurses identified by DPH was sending out consent forms and ensuring they were properly completed and returned in time. This was also an area in which cooperation between school personnel was understood by DPH to be an issue. Although the nurses sent the forms out, she usually did so via the teachers, so she was reliant on their commitment to remind students to return the forms. The forms that were returned were often incorrectly completed, and as aforementioned, included many notes of the child's specific medical condition. Initially, there was a broad exclusionary policy to address that; in short, when in question, don't vaccinate. DPH identified this in retrospect as too broad, particularly as some notes indicated conditions such as an allergy to strawberries as the parent's concern for counter-indication. However, some potentially serious counter-indications were not itemized as risks, such as seizures, which at least one school nurse noted with frustration. Another, somewhat anecdotal, problem was that many parents completed the forms in pencil. The trouble with the consent forms was exacerbated by the fact that a separate one was required for each dose of the vaccine given to students under age 10. So at least an equal amount of effort had to be given a second time, to get forms out and returned, but also to explain why two forms were necessary. Additionally, due to the widespread media coverage, many parents had new concerns when asked to give consent a second time. In some cases, the need for a second form

was not understood for some reason, and there were cases wherein nurses arrived, but could not vaccinate children because they only had the first form completed (personal communication, January, 21, 2010).

Logistics played a crucial role in the administration of the School Vaccination Program and Logistics staff were generally commended for their reliability, competence and professionalism. Communications between NHS and Logistics was identified as a strength, as it began early in the fall and continued throughout the campaign, with NHS always having a number to contact Logistics. There was ample storage at Emily Bissell Hospital where all vaccines and supplies were located. However, because only one storage facility was available, there was generally a morning back-up as all nurses arrived to pack their vans for the day, resulting in a time-consuming start to a fully scheduled day. The reliance on an elevator created a more intense bottleneck situation, with many people trying to use the same facilities. Parking was also identified as an issue that consumed time and added to early morning frustrations by those who needed their energy for the day of school vaccinations (personal communication, January, 21, 2010).

Direct Operations was the next area of discussion, that is, how the School Vaccination Program functioned when NHS nursing teams were in schools vaccinating. NHS determined that the role the school nurse played seemed to be a strong predictor of how smoothly the day went. NHS related tales of some schools where the nurses seemed to be a "one-man show"; one nurse ended the day in tears.

The coordination between the nurse, the administrator and the teachers also showed itself in how steady the stream of children to be vaccinated was. Ideally, students would be continually lined up so that all who had consent to be vaccinated could be. However, at some schools, NHS nurses saw gaps as long as thirty minutes (personal communication, January, 21, 2010).

Another factor in the Direct Operations was how committed and involved the school as a whole was to the vaccination program. One district's administrator accompanied the nurses to each school, which NHS thought really helped the program run smoothly. However, some schools had their own scheduled events for the day and did not want to interrupt them for the vaccination. For instance, one school was featuring a puppet show, and said they would not pull children away from it for vaccinations, even though NHS had limited time at the school. Lunch was also an activity that caused scheduling conflicts. Some logistical factors that contributed to the success of Direct Operations were keeping a television in the waiting area to help keep the kids calm who were waiting. The only logistical issue that was mentioned by NHS was the unpredictability of the room size, but that was also determined as something that could not be helped as the schools provided what they had available (personal communication, January, 21, 2010).

All in all, the nurses from Northern Health Services greatly enjoyed the School Vaccination Program. When asked if they would do it again, one responded instantly, "in a heartbeat!" Many nurses voiced their positive experiences: "It feels good to be in

the community for positive things", and "This is what Public Health is all about!" Nurses also expressed how fun it was to work with children. NHS nurses expressed few concerns about areas for change or improvement overall, but one concern was that leaving out the kids with special needs didn't feel equitable. There were many, many calls from parents with questions and concerns, particularly from those who were told their child could not be vaccinated in the School Vaccination Program, who were not given a specific alternative as to where else to receive the vaccination (personal communication, January, 21, 2010).

Outside of Division of Public Health

University of Delaware Student Health.

The University of Delaware played a vital role in the 2009 H1N1 vaccination efforts, both due to the significant incidence of the virus on campus in the spring and their ongoing responsibility for such a large population of students in a high risk age group. The Student Health Center played a strong role in not only administering the vaccine to students, but in promoting its importance and running flu clinics. For this reason, and their membership in the Immunization Coalition, this researcher was presented with and accepted the opportunity to interview a member of the Student Health Center who spoke on behalf of the Student Health Center staff. This respondent was given a copy of all interview materials a week prior to the interview, and used them to gather responses from the Student Health Center staff as a whole. The goal was to understand their experience in these efforts and how aspects facilitated or hindered their ability to vaccinate as many students as were able to receive the vaccination. Both aspects that are specific to their relationship with the Division of Public Health (DPH) and those that are not a direct result of their relationship with DPH will be discussed.

Student Health Services was confronted with many of the issues that were reflected throughout the nation in promoting and administering the 2009 H1N1 vaccine. Students had questions and concerns about the vaccine, regarding its "newness", its safety, its effectiveness, Thimerosal, and possible adverse reactions to

the vaccine. Although a small population, pregnant students were especially concerned about the Thimerosal. People also questioned the value of the vaccine; many did not see themselves at risk for catching the virus, or from having a severe incidence of the virus if they did in fact catch it. Those who did intend to receive the vaccine expressed concern of its possible interaction with the seasonal flu vaccine. And, as much of the nation experienced, the vaccine shortage made it hard to predict when vaccines would be available; by the time vaccines were available, much of the interest in receiving a vaccination had diminished (personal communication, February 5, 2010).

The University of Delaware Student Health Services worked to streamline as many processes as they had control over. To promote the vaccine, they used the popular mascot "YouDee" for a promotional poster to promote the importance of the vaccine. When students had concerns about the vaccine, they counseled them to ameliorate their concerns. They also tried to learn where concerns originated from; many students referred to their mom or their friends telling them that the novel H1N1 flu "wasn't that bad" or that the adverse effects of the vaccine were so dramatic it wasn't worth the risk. A professor, unaffiliated with Student Health Services, shared a rumor with this researcher she'd overheard in one of her classes, that a person had received the vaccine, had an adverse reaction, and now could speak only when running backwards. Much to the professor's surprise, rather than question the rumor, the other students heard the story and then declared they wouldn't receive this vaccine! Regardless of the nature of the concern, Student Health Services tried to allay the

students' fears, assuring them the vaccine went through the same safety trials as the seasonal flu vaccine and also pointing out that the nurses themselves had received the vaccine and were fine. However, it did not seem that these assurances were changing the minds of the students who had fears or concerns (personal communication, February 5, 2010).

Due to both the unlikelihood of convincing the students that the vaccine was important and safe, and also the uncertainty of when Student Health Services would receive the vaccine, they started a parallel campaign promoting a hierarchy of controls. They encouraged hand washing, staying home if you are ill, and covering your mouth if you cough or sneeze. Hand sanitizer was put in all buildings, and posters promoting these activities were disseminated throughout campus. Student Health Services also designed a new scheduling system to streamline the process; students could schedule all vaccination appointments online, 24 hours a day. This also helped to decrease call volume. However, due to the delayed receipt of the vaccine, this best practice wasn't able to be utilized in anticipation of receipt. If Student Health Services didn't know when they would receive vaccines, they couldn't post available appointments (personal communication, February 5, 2010).

There were many elements beyond the control of Student Health Services in these vaccination efforts. Most were also beyond the scope of any body, including the Division of Public Health, to completely eradicate, such as the power of rumors and credibility given to non-medical professionals. However, Student Health Services did

identify ways the Division of Public Health could seek to improve their relationship in future vaccination efforts. Along with the rest of the country, the Division did not receive as much vaccine as it expected in the schedule it had anticipated and planned for. This unmet expectation trickled down to the people who had registered to receive vaccines. Student Health Services made weekly, sometimes daily calls to check for the status of their order. The Division was unable to give them an exact date, as vaccine production continued to be less than anticipated and many healthcare providers were expecting a share of a very limited supply. This uncertainty made aspects of planning for administering the vaccine very difficult. Much to the surprise of Student Health Services, one morning 2,000 vaccines were delivered without notice. All of the vaccines they received contained Thimerosal. Fortunately, they had storage, but they did not have clinics scheduled as they were not given notice that they were receiving any vaccine. They had ordered 20,000 doses and were unsure of how to promote the clinic when they had only received a tenth of what they anticipated needing if the promotion was successful in motivating the majority of the campus community to get vaccinated. But, as the interviewee wryly pointed out, demand had decreased so much by this point that the delivery was more than sufficient, particularly given that the vaccines contained Thimerosal. However, this respondent acknowledged that DPH did not know themselves how much vaccine was coming, nor when. Student Health Services hopes that in future efforts, even if information is delayed, when a delivery is

Factors of Participation In The nH1N1 Vaccination Campaign planned they will receive as much advance notice as possible (personal communication, February 5, 2010).

When asked to reflect on the best practices that had come out of the novel H1N1 vaccination efforts, Student Health Services identified both internal and external strengths. Internally, their online scheduling system worked very well once they had the vaccine to run clinics. They intend to use this going forward. Externally, membership in the Immunization Coalition was identified as a real asset for both University of Delaware and the community as a whole, as it brought many needed insights to one table to collaborate and plan. Student Health Services also plans to remain a member of this body going forward (personal communication, February 5, 2010).

Center for Disability Studies.

The Center for Disability Studies (CDS) was a vital partner in gathering feedback for this study. They did so in two ways: they conducted their own study of their constituents by telephone poll and presented the findings to this researcher, the Section Chief of Public Health Preparedness and a County Health Administrator. The identity of those who provided findings was kept confidential by CDS. They also promoted and distributed the survey this researcher created to their client list (see Appendix 1 for the survey). Because of the design of these studies, all respondents were anonymous to this researcher.

The findings from the Center's own study were extensive and helped enlighten State Public Health planners on many opportunities for education, outreach and increased attention to accessibility issues. One issue was with transportation access, especially during the Mass Vaccination clinics held on weekends. Many of CDS's clients rely on the Delaware Authority for Regional Transit (DART) transportation services. DART services were in high demand, but of low availability, especially in the evening and on weekends (personal communication, January, 11, 2010).

A big issue was that those with special needs are heavily reliant on their physician for guidance as to how they can or cannot participate in health campaigns designed for the general public. Some persons with multiple sclerosis reported that they were advised by physicians not to receive the vaccine. Upon further probing, it was determined that the physicians were advising their clients against FluMist, a

Factors of Participation In The nH1N1 Vaccination Campaign vaccine using a live attenuated strain. The physicians and their clients were not aware that the Mass Vaccination clinics used flu shots that were medically appropriate for those with multiple sclerosis to receive. Public Health was not aware of this perception and therefore didn't address it (personal communication, January, 11, 2010).

Another group with special needs that had concerns about the vaccine being safe for them to receive was little people. They are used to assessing vaccine's appropriateness for themselves by looking at the vaccine designated for their weight group. Because of this, neither a children's nor an adult's dosage is appropriate. They were concerned that a Mass Vaccination clinic would not have the capabilities to measure a vaccine specific to their needs that would be both safe and efficacious. However, the nH1N1 vaccine was designated for groups based on age. Therefore, the adult dosage would have been appropriate for little people, but their perception resulted in their not participating in this campaign (personal communication, January, 11, 2010).

Those with cognitive disorders face their own range of barriers, real and perceived. They are more likely to have anxiety regarding medications and vaccines. They are also more likely to have anxiety about crowds and noise. Because of this, the mass vaccination clinics were not identified as an ideal place to receive vaccines for this group. Ideally, according to the Center for the Disability Studies, many prefer that health services" come to us" (those with disorders), meaning to a venue in which they already receive services (personal communication, January, 11, 2010).

Although the Center for Disability Studies polled many groups to attempt to provide representative feedback, there is not a registry of those with special needs, and therefore no practical way of ensuring comprehensiveness. However, even with the limited assurance of comprehensive feedback, enough information was gathered to feel certain that those with disabilities represent such a very broad and diverse group that it would be difficult to tailor a "one size fits all" approach to answer to their concerns and their needs (personal communication, January, 11, 2010).

The Center for Disability Studies also assisted this research by disseminating a survey and encouraging feedback. The survey was online and anonymous and contained 14 questions (see Appendix 1), meant to encourage honest feedback, be it positive, negative, or informative. Twenty-three persons responded and had much to say about the vaccine, the vaccination campaign and their concerns regarding both.

The first question asked for people to put the first word or phrase they associated with H1N1 vaccination. Responses varied, but were telling as to respondents' overall impressions. Some associated the vaccine as Public Health would intend, as a preventative measure, saying "prevention", "avoid the flu", and "needed". Some were more general: "flu", "really bad flu", "swine flu vaccine", "swine flu", and "bad flu". However, many expressed a negative association with the phrase H1N1 Vaccination, responses as follows: "too much", "no", "unnecessary", "overreaction", "confusion", "mercury and autism", (Sic) "oh gosh, another shot????", "mercury", "no way", and just "bad". One person could not pick just one word or phrase to associate,

but explained their association with H1N1 Vaccination: "Last Oct 2009 on the news of the deaths and that there was not yet a vaccination available but was being worked on ASAP. Had my doubts at first if our country could get something out 'quick' and it still be done properly after the last couple of years with the flu vaccinations being short etc." The majority of the responses, 11 out of 19, expressed doubt or explicit aversion to the phrase 'H1N1 Vaccination' when asked for their first responses.

Question two asked respondents if they thought the H1N1 vaccine was important for themselves and their family and also if they intended to receive it. Those who thought it was unimportant and didn't intend to receive the vaccination balanced those who thought that it was important and did or did intend to receive it. There was a third group of those who thought it was important, but did not intend to receive it. Most respondents clarified their response. Those who did not think it was important and did not intend to receive it had varying reasons: "I heard H1N1 is less frequent and less severe than the regular flu", "I think vaccines are pushed out way to fast and are not tested nearly as well as they should be before pumping them into the people", "I do not believe its effectiveness and safety", "I don't feel it is safe", "mercury is a neurotoxin", "has not been thoroughly tested", "side effects outweigh the vaccine". Only one of these responses indicates a lack of value for the vaccine to mitigate a disease; most indicate concerns about the safety of the vaccine. Those who said they considered the vaccine important, but did not intend to receive it gave reasons as well: "not in high risk category", "Neurologically impaired children are more susceptible to

vaccine injury", and "It's a new vaccine that was fast-tracked to market. I do not feel there was adequate research and testing done prior to it being marketed. I also feel there are too many toxins/neuro-toxins in flu vaccines". Those who valued it and did or intended to receive the vaccine didn't have many comments, but indicated they'd received it from a variety of locations, including the local farmer's market, the University of Delaware, their school, Walgreens, their work and their doctor's office.

For comparative value, question three was similar, but asked the same information about the seasonal vaccine to determine if these attitudes towards the value of a flu vaccine and the corresponding intent to receive it were specific to the H1N1 vaccine. The results were very similar; only one person changed their response, resulting in one less person who did not consider the seasonal flu vaccine important and did not intend to receive it than the H1N1 vaccine. However, the reasons given for not valuing the seasonal flu vaccine were occasionally different. While some echoed the same sort of reservations: "The same reason I stated above', "I do not believe its effectiveness and safety", "too many metals and bad substances in vaccines", "I don't feel it is safe" some had broader reasons: "more important to take Vit(amin) D3 to boost immune system", and "Side effects outweigh the vaccine. Your immune system can build on its own. Vaccines weaken them." Those who considered the seasonal flu vaccine important, but did not intend to receive it stated their reason as well: "not in high risk category", "the sickest my husband and I have ever been was after we received flu shots years ago", "My kids got it, but I don't get sick", "too many toxins

Factors of Participation In The nH1N1 Vaccination Campaign in it, as well as other personal reasons". Those who considered it important and did or intended to receive it gave no written response explaining why.

Question four asked if respondents had concerns about the H1N1 vaccine. Over half replied that they did have concerns and stated their reasons as follows: "how could a gov that can mess up so much (including the FDA with food poisons and the recalls on meds) do something like this so fast and still be right without finding out later they goofed again and so many scared people got worse or after effects as a result", "It was approved before it had enough time and studies to be proven effective and safe, and it also contain Thimerosal. It was rushed to get approval", "safety issues, I feel the vaccine has ingredients that are not safe and the fact they are injected is disturbing", "insufficient safety testing", "Thimerosal (mercury)", "not safe", "too new concerned for my daughters due that they have autism and might be vulnerable to vaccines and it might further inhibit their development", and "side effects". In general, safety of the vaccine was the biggest reason for concern, and mercury-containing Thimerosal and its link to autism, was of specific concern.

Question five asked respondents if they intended to receive a vaccine in the fall, if it would protect against both H1N1 and seasonal influenza. Although the questions regarding intent to receive and having received the H1N1 and seasonal flu vaccine both yielded nine 'yeses', only eight said they intended to receive a fall vaccine that contained both. There was not an opportunity to provide a text response in

Factors of Participation In The nH1N1 Vaccination Campaign this question, so it is unclear as to why someone who would receive both vaccines would not receive a combined vaccine.

Next, question six asked if respondents had sought out information regarding the H1N1 vaccine, and if so, through what medium. The number one answer was online, followed by a trusted person or professional, a publication such as a news journal or pamphlets, other (including AM radio, television news, pamphlets, research on vaccines, and medical doctors appearing on television), and finally the least chosen answer was 'I did not seek out additional information regarding the H1N1 vaccine'. Two respondents reported going to the Delaware Division of Public Health's website for information. Respondents were also asked to indicate which source of information they found most helpful if they used multiples sources. Only one person did and said that the most helpful source of information was his/her own doctor and their children's pediatrician.

Figure One: Table: Sources of Information

Online. Please indicate preferred website. (CDC, a news journal, Division of Public Health (DPH) website)	Publication. Please indicate publication.	A trusted person or professional. Please indicate the person's role (doctor, Public Health official, clergy, etc.)	Other. Please specify.
		doctor at CDC	
		The kids' schools sent info home.	1150 AM radio
Everyone that I could locate!	Everything the school sent home about it.	My and my children's PCP	
NVIC, ARI, mercola.com, CDC		MD's	
		pediatrician	TV news
DPH	printed media, such as newspapers	**MOST HELPFUL: doctor/pediatrician/family friend	pamphlets
flu.gov			
CDC-I found the package insert			
CDC			
DPH	read News Journal articles		Listened to MDs on TV
CDC			
			research and studies on vaccines
	PSA @ Eagle 97.7 FM radio		
	nursing literature		

Question seven sought to further qualify the sources information against one another and asked if any sources of information were confusing. The majority of responders said no. Three said yes, with the following explanations: "Media didn't tell people the downsides to the vaccine", "all information is confusing", and "leaflet that accompanied the actual vaccines stated something like 'safe for pregnant women', but NO babies had been born yet to determine the effects of the vaccine on the unborn fetuses". It is unclear if the person who stated that 'all information is confusing' was referring solely to the 2009 H1N1 vaccine.

To try and understand the evaluation of the performance of the players in the vaccination efforts, question eight asks if the respondents thought an appropriate amount of attention was given to the 2009 H1N1 vaccination efforts. The majority of respondents said yes, followed by a third of respondents who thought too much information was given to the vaccination efforts, followed by two respondents who thought that too little information was given to the H1N1 vaccination efforts.

Questions nine and ten were meant to specifically evaluate the perceived and real attention to the Center for Disability Studies population, asking if there needs were met and if sufficient accommodations were provided for their needs respectively. These were asked in two questions because the liaison from CDS advised they could pull out different responses. They did, with just over half of respondents saying that their needs were not met during this campaign (55%), yet 65% of respondents saying that they did feel there was sufficient accommodations for their needs in the

vaccination efforts. Of those who said their needs were not met, many specific reasons were given. They are as follows: "child has not gotten second dose of nasal", "My child at college was not able to get the vaccine until she returned home. This was after there were confirmed case(s) at UD", "the caution to people who are chemically sensitive was not addressed, but the caution only focused on the population with common food allergies and weakened immune system", "questions regarding ingredients and safety", "the vaccine was not widely available when it was supposed to be. Too many 'unknowns' regarding the safety of the vaccine. The CDC's 'scare tactics' did not help!", "unanswered concerns or questions regarding research and studies on this specific vaccine", "initially PSAs didn't mention where to get it and my doctor didn't have it", "although I have my family take vaccines, I think they should be made without Thimerosal", "no one has done a study on autistic children after receiving a vaccine to determine if it worsened their condition", and "not enough attention on possible side effects".

As follow up to asking for specific reasons, respondents were asked in question eleven to describe the overall quality of the H1N1 vaccination efforts a five-point scale, choosing between excellent, good, fair, poor, and very poor.





There was room for a text response next to each choice and many respondents clarified their rating. The respondent who chose 'excellent' and commented said that it was "very accessible". Those who chose 'good' gave a variety of additional comments, identifying both positive and negative aspects of the campaign; one respondent described the lack of accessibility to the vaccine while another said that they though "Health officials did the best delivery they could with the quantities available; however, US needs to upgrade our system to latest technology for faster manufacturing". Of respondents who ranked the vaccination efforts 'fair', varying reasons were given, among them the "short or late supply", and concern about the risk for individuals with autism. A third 'fair' responder went into detail over her issues with the School Vaccination Program: "The decision to only offer FluMist to the K-5 grades excluded those children with asthma and other diagnoses in which the mist was counter-indicated. Also, only offering the injection to 6-12 grades, some middle school

girls especially were too hyper to receive it (most had received the guardesil shots which can be painful). Also there was such a time delay in receiving the vaccine. Also, some children with severe learning challenges were too hyper to receive the injection at school". The one respondent who said 'poor', attributed the ranking to "too much conflicting information (doctors vs. doctors, CDC vs. news articles, etc)...The CDC scared the heck out of everybody trying to get them to get vaccinated, only to find there was (sic) NO WHERE NEAR enough of the vaccine available from the onset!". The one respondent who ranked the H1N1 vaccination efforts 'very poor' was the same respondent who said that "I think vaccines are pushed out way too fast and are not tested nearly as well as they should be before pumping them into people" in response to the question as to whether they considered the H1N1 vaccine important. The respondent referred to this answer in all questions in which they entered text following this question, including their feelings as to the importance of the seasonal flu vaccine.

Respondents were next asked what they would specifically change about future vaccination efforts. Responses ranged; some echoed previous answers, such as concerns regarding safety and effectiveness. Many responses specified different means of raising awareness and about expanding the information made available to the public: "Instead of using scare tactics to force people to get the vaccine, we should well educate people with more detailed information about vaccine studies, approval process, ingredients, side effects and options", "…wait for more information before

scaring people", "...have all your 'ducks in a row' before you put the information out to the public and be prepared for the hoards of people who will no doubt be rushing out to get the vaccine based on the information that is all over the news and in the media! I would also love to see the (sic) VACCINE INGREDIENTS published in (sic) EVERY article that is encouraging people to get vaccinated. People should know and (sic) HAVE A RIGHT TO KNOW what they are putting in their bodies and the bodies of their children!", "Let the public know what is in the vaccine, and do more research before giving the vaccine to the public", and "List the bad as well as the good. People need full education instead of always hiding in fine print." In addition to the references in the aforementioned comments, other comments focused solely on the additives in the vaccine, "the ingredients, such as mercury in the flu vaccine, aluminum, formaldehyde, etc.", and "change the preservative. Give out vitamin D3 instead". Vaccine availability was also addressed: "Ensure all physicians and schools are provided with enough doses", "US upgrade to latest technology for speedier manufacture", "Our never seems to have enough, soon enough...until after the fact. For the US and all we 'have' I need to wonder why?" and "earlier supply of vaccine". There was also a recommendation to combine the H1N1 vaccine with the seasonal flu vaccine and a recommendation to offer both (school permission) forms at the same time. Finally, one respondent said there needed to be "increased availability to the homebound".

Next, question 13 asked respondents what was done well in the vaccination efforts. 61% of the respondents chose to respond. Some responses mixed positive comments with areas for improvement: "I think word went out well, seems vaccine was available, but not enough caution/warnings for those at risk", "After the scare and long wait....at least I didn't have to pay for something I was told so many times that my family should have", "There was tons of news coverage to make people aware, however, it was (sic) OVERKILL! TOO MUCH INFORMATION, and often conflicting information", and finally that the "advertisement too well done-wasted money". Some of the aspects of the vaccination efforts that received unqualified praise were the fact that Walgreens gave free shots, that there was a "widespread effort", the triage of priority groups with limited vaccine supply, and the School Vaccination Program was mentioned positively several times in that it increased access.

Finally, respondents were asked if the 2009 H1N1 vaccination efforts affected the way they thought of the Delaware Division of Public Health (DPH). Roughly 70% of responders said that the vaccination efforts did not affect the way they thought of DPH. 20% said they now thought of DPH in a more positive way and the remaining 10% said that the vaccination efforts caused them to think of DPH is a more negative way. Some of the comments associated with thinking of DPH in a more positive way were that the vaccine was free and that it was distributed through the schools. Only one person who said the vaccination efforts did not affect their opinion of DPH commented: "I will reserve my comments on this one until I am sure of the long term

Factors of Participation In The nH1N1 Vaccination Campaign outcome." Both respondents who said that they now think of DPH in a more negative way commented, one blaming the recalled vaccines and the other saying simply "wasted money".

Division of Public Health Partnership Groups

Immunization Coalition of Delaware/Medical Alliance.

The Immunization Coalition of Delaware is a heterogeneous group joined to address the common interest of servicing immunization needs in the state, including public, private and non-profit agencies in its membership. Representatives attending the meeting attended by this researcher included pharmaceutical executives, student health nurses, members of the Medical Alliance, Division of Public Health nurses, other DPH health officials, private physicians, epidemiologists and medical contractors, among others. Representing a myriad of professional cultures and interests, the group dynamic was very much one of collaboration, mutual respect and earnestness to address the matters at hand. As this meeting took place in January 2010, the matter of focus was the novel H1N1 virus. The Coalition identified best practices, novel issues the H1N1 virus introduced for providers, and areas of concern in this campaign

A wholly positive comment made by a representative of a pharmaceutical company was that in his dealings with four states, Delaware's vaccination efforts were unique. He said he hadn't "seen anything like it", referring to the emphasis on the service to the public in this campaign, especially Delaware's initiative to remove fees associated with the vaccines for all persons who wish to receive it, so that price was not a barrier in participation. Interestingly, this led to a discussion of how that policy played out when unanticipated complications arose. There was confusion amongst

private citizens and providers alike as to the cost of the vaccine. If the vaccine was free, did that mean that administrative and office visit costs were also waived? Was it free everywhere? A press release that promoted the free vaccine at certain pharmacies to all six months and older was misleading as only persons 18 and older could be vaccinated at pharmacies. There was also mention of 'bad apples' in Maryland who were charging for the vaccine itself, contributing to public suspicion about hidden fees and possibly deterring them from taking advantage of the literally free vaccine opportunity Delaware was able to offer by reimbursing pharmacies for the administrative fees as well as offering an abundance of free mass public health clinics.

Another positive comment that was made about Delaware's vaccination efforts, specifically in juxtaposition to other states, was the Division of Public Health's willingness to form partnerships with private providers, and the wide network that existed. Delaware's School Vaccination Program utilized a private nursing agency to supplement their nursing capabilities to reach the children of Delaware. Regular updates were sent through the Delaware Health Alert Network to private healthcare providers were sent containing information concerning H1N1 and given the chance to order vaccine to administer in their practice. One means of disseminating this information was the Delaware Health Alert Network, more commonly referred to as the DHAN. Mention of the DHAN yielded mixed reactions. Some practitioners weren't familiar with the network, some thought they had signed up, but were not receiving messages and others were well aware of the network and regularly receiving

Factors of Participation In The nH1N1 Vaccination Campaign messages. Public Health employees present all reported regular receipt of these updates.

When discussing strategies for future vaccination campaigns, several issues were brought to light. One of the greatest issues was the stress and fear of the public that providers saw from the public concerning both the virus and the vaccine. "If it gets to this level again, we (providers) should reach out to priority groups, and not rely on the propaganda of the media to drive concern." This led also to a voiced need for provider education; one issue raised was providers telling clients that they needed the vaccine when they were not in the priority groups, even when the population was still being triaged because of the limited supply of the vaccine. All in all, a provider-driven campaign, rather than a media-driven campaign, was recommended as an ideal approach to conduct a campaign with consistent information backed by medical professionals. This also led to a discussion of provider willingness to vaccinate; some who eventually administered vaccinations did so because of pressure and demand from their clients. This segued to the point that many providers ordered vaccines, and wanted to participate in administering the vaccine, but did not receive their order, or did not receive the amounts they requested. For some providers this remained a "touchy subject", and a potential point of discontent with the Division of Public Health. Considering vaccine availability to providers, there was also the issue of the availability of vaccines by type; very few doctors wanted the vaccines with Thimerosal, as there was much public concern about this preservative. It was observed
Factors of Participation In The nH1N1 Vaccination Campaign that the concern was strongest amongst those who were newly aware of Thimerosal and the alleged health risks, and that this led to both delays in receiving the vaccine, and sometimes refusal altogether when providers were unable to ameliorate concerns generated by widespread media coverage of alleged health risks associated with Thimerosal.

One of the biggest successes identified in the novel H1N1 vaccination efforts was the partnerships and networks formed. The Immunization Coalition identified itself as one of these viable partnerships. The biggest areas for improvement identified were the inclusion of all providers when providing information and planning; not all providers were receiving DHAN, one of the main channels of communication from the Division of Public Health to the state's population of healthcare providers. It was suggested that working on these communication channels could help prevent mixed messages to the public and providers alike. Another area of challenge was the mediadriven public distrust of the vaccine and the corresponding anxiety regarding the vaccine. The suggested answer to this was a more 'provider-driven' awareness campaign, rather than media-driven, but it was not specifically discussed what a campaign of that nature would entail.

Delaware Public Health and Medical Ethics Advisory Group and Medical Society and Environmental Ethics Group.

In February 2010, the Delaware Public Health and Medical Ethics Advisory Group met with the Medical Society and Environmental Ethics Group. These groups are composed of private and public healthcare providers, appointed to ethics advisory committees. The DPH Ethics group was introduced with a presentation on what the group does and the population health ethics scheme that the group uses as guidance. The focus of this meeting was to initiate dialogue between the two groups, not to discuss the novel H1N1 virus and vaccination efforts. However, the conversation both discussed the pandemic directly, disasters in general, and also brought forth realizations about the groups that highlighted ways in which opportunities for collaboration and partnership between the two groups have not been fully utilized by the two groups, or does not yet exist. Although not extensive, the findings from this meeting were significant in recognizing the nature of the relationship that currently exists between private and public health care providers and directions they would like to move in.

Many questions were raised regarding the role of the Public Health Preparedness Section (PHPS), the section of the Division of Public Health that handles preparing for and mitigating public health disaster events such as the 2009 H1N1 pandemic event. "Does PHPS have a plan?" "Do they talk to hospitals?" "Where do they get their information?" "Why aren't they telling doctors?" These were some of

the questions raised by members of the Medical Society. In answer, the Section Chief stated that there were not only extensive hospital plans, but that there had been weekly conference calls with hospitals throughout the H1N1 pandemic, as well as regular communication and planning conducted when there is no public health event occurring. Further conversation revealed that it was possible there was a communication gap between the persons at the hospitals who regularly communicated with PHPS and all of the healthcare providers who could benefit and become informed by the information. It remained unclear as to whether information was provided and individuals were unaware it existed or were too busy with other responsibilities to seek it out or that individuals did not have the information for some other reason. PHPS and the Ethics Committee proposed Grand Rounds and other educational tools to build awareness of their existence and hopefully begin an open and accessible dialogue known to and referred to by the medical community.

School Vaccination Program Partners.

One of the Division's major 2009 H1N1 vaccination programs was the School Vaccination Program (SVP). This program required the coordination of the Department of Health and Social Services (DHSS) nurses, Division of Public Health (DPH) nurses and other planning personnel, nurses contracted from Maxim, and various school personnel, most notably school nurses and other administrators designated to take part in coordinating the project. The coordination and planning of this program stretched from September until the last vaccination was given in March. DPH and DHSS nurses went to the public and charter elementary schools to vaccinate grades K-5, while Maxim covered the private and parochial schools, grades K-12, as well as the public schools, grades 6-12. Participation in this campaign varied. For public schools, grades K-5 the average participation rate was 37% of students for the first dose. For the public schools, grades 6-12, the average participation rate was 34%. The average participation rate for private schools grades K-12 was slightly higher at 44%. Regardless, DPH had speculated in early planning that half of students would take advantage of this opportunity and also planned to take extra vaccinations for those who might bring in permission slips after the school reported how many parents had consented for their children to receive the vaccine. An anonymous survey written by this author was reviewed by DPH and Department of Education (DOE) personnel before being distributed to participating school communities. The survey was

answered primarily by school nurses, but also by school and district administrators.

185 persons responded. See Appendix 2 for this survey.

#	Answer	Response	%
1	New Castle County	117	66%
2	Kent County	31	18%
3	Sussex County	29	16%
	Total	177	100
			%

Figure Three: Table: Respondents by County

Note: Only 177 of 185 respondents answered this question.

As with the survey that Center for Disability Studies' clients took, the first question was to draw out word or phrase associations between "2009 H1N1 School Vaccination Program" and their general impressions. The responses were aggregated into "negative", "neutral", and "positive" categories. Some of the most common words associated with "negative" were "chaotic", "overwhelming", "paperwork", and "time consuming". Some respondents also expressed frustration concerning changing information, and lack of parental responsibility. Some "neutral" comments reflected both positive and negative impressions, such as: "organized chaos" and "difficult, but important", as well as associating the phrase in a merely literal sense: "immunization". Responses that were recorded as "positive" most often mentioned that the campaign was "organized" or "successful". Some respondents positively associated the SVP with being proud of providing this service to children and their families.

The respondents were asked whether they considered the vaccination important for their students. Most said yes, primarily citing prevention of disease, but also

prevention of school absences and also increased accessibility to include children whose families might have otherwise lacked access to the vaccine because of money or because of the general lack of accessibility of the vaccine from providers. Many also referenced that children were at high risk and thus high priority groups and referred to the SVP as a public service. Very few respondents said that they did not consider the vaccine important for their students. Those that did not gave a variety of reasons including: the vaccine is too new, "they would be better off developing natural immunity", the strain was very mild, they "did not buy into the hype of the media", and finally that the group at highest risk, asthmatics, were not able to receive the FluMist vaccine in school, which would be the group this responder felt it most important for.

Figure Four: Pie Chart: Personnel Who Considered Vaccine Important



The respondents were then asked if they had concerns about the vaccine, and also given the chance to elaborate as to why if they did have concerns. Over 40% of respondents said that they did have concerns about the vaccine. Those with concerns could be further aggregated into those who stated that their concerns were ameliorated and those who ostensibly still had concerns at the time of the survey. Respondents who said both that they had concerns, but that they no longer did, the following reasons were cited as the explanation of why they no longer had concerns: seeking out and receiving assuring information, particularly from the Centers for Disease Control and Prevention, learning that the novel H1N1 vaccine was similar in testing and design to the seasonal influenza flu vaccine, and that the respondent had concerns with all vaccines, not this vaccine in particular. Respondents who did not say that their concerns were ameliorated cited the following reasons for concern: concern about possible side effects, particularly for certain groups, the newness and ensuing

Factors of Participation In The nH1N1 Vaccination Campaign uncertainty the vaccine posed, administration of the School Vaccination Program (SVP) itself, distrust of information, especially conflicting information, and personal reasons. Certain groups that were of particular concern for side effects were children with neurological conditions, pregnant teenagers who would not disclose their pregnancy and receive a vaccine with mercury and children with allergies. Because of these concerns, one respondent said s/he thought the vaccine should be given in a doctor's office and another that s/he was worried about handling adverse reactions during the school day. The newness and ensuing uncertainty the vaccine posed was by far the most common reason given for unanswered concerns. One nurse said that although she received the vaccine herself, she did not allow her two children to receive it. The concerns that were specific to the administration of the SVP included paperwork, increased work burden (especially for the school nurse) and that this was an "unfunded request" that required funds formerly budgeted for other matters. There was distrust of information, especially conflicting information, and one respondent even said that the "media hype" was the reason the vaccine was produced so quickly at all. One respondent said that the vaccine was "essentially untested" and that the "American public was duped in being guinea pigs". Several respondents said that although they had concerns, they did not share them with anyone. "I have personal concerns about the vaccine. These concerns have nothing to do with the program or assisting with the program."

Respondents were asked what role they played in the vaccination program and whether or not it was an appropriate match for their roles and responsibilities. The most common role cited was that of school nurse, followed by school vaccination contact, local school administrator (principal, dean of students, other), other role (wellness center staff,"general assisting" (assumed to be support staff for miscellaneous tasks), lead nurse for district, clerical, coordinating role), school faculty, lead administrator (superintendent, head of district/charter, other), and district level staff. Over 90% of respondents said that their role was appropriate. However, of these responses, many qualified the appropriateness of the assignment because of the "overwhelming" amount of extra work it required. The most commonly cited source of extra work was paperwork, and one respondent said s/he felt "foolish" to have to keep sending home forms as information changed. Those who said that the role was appropriate without qualification cited two main reasons: one, that it was distinctly within their job scope to take on such a role, and two, that the pre-existing familiarity with students, staff and parents enabled their success in the role they were asked to play in this vaccination program. One respondent said that as the school psychologist, s/he initiated quelling fears and anxiety about the vaccine in students. The majority of the respondents who said that the roles and responsibilities that were asked of them were not appropriate cited the extra amount of work involved, particularly for paperwork. "I felt like the skills needed were secretarial skills". One respondent also expressed discomfort at playing a role in program though which their only in-service

was done online and that s/he was asked to take part in a program in which they had no input. Liability issues were another concern, as were parent concerns. One respondent said she/he felt an evening or weekend clinic would be more appropriate so that parents could voice their concerns and have them answered in person. Another respondent cited the large amount of paper work required as putting students at risk. Some respondents expressed frustration at taking direction from non-medical professionals to conduct the vaccination program.

#	Answer		Response	%
1	Lead Administrator:		6	3%
	Superintendent, Head of			
	District/Charter, Other			
	Administrator			
2	Local School		17	9%
	Administrator: Principal,			
	Dean of Student, Other			
3	Vaccination Contact Person		47	26
	(Designated by Lead			%
	Administrator)			
4	School Nurse		141	79
				%
5	School Faculty: Teachers,	•	7	4%
	Specialists			
6	District Level Staff	•	3	2%
7	Other role:		15	8%

Figure Five: Chart: Respondents by Role

Next, respondents were asked if they were able to make contact with the persons they needed in order to play their role in the School Vaccination Program. Nearly 90% of respondents said that they were able to make contact with who they Factors of Participation In The nH1N1 Vaccination Campaign needed during the SVP. Both respondents who said "ves" and those who replied "no" to this question mentioned some of the same characteristics. There were many comments about the Division of Public Health, most positive, but they were contradictory. Some said the DPH was "wonderful", "always available and returned phone calls quickly", and that they always adequately answered questions. However, others said that they tried to contact DPH and were "denied access". Two people who responded "yes" noted the indirect link with DPH, one saying that they found out "indirectly" that they could contact them, another saying that the channels made sense, but the answers went through many filters before they reached the asker. A "no" responded also referenced the channels of communication, saying "the lay person should have been eliminated," and another that they were told to "go through proper channels." However, the vast majority of respondents made positive comments about their communication within their school, and with Maxim, the Department of Education and DPH. The role of district coordinator was often referenced amongst "yes" respondents as valuable and helpful.

Respondents were asked if they received extra resources during the vaccination efforts. Only 9% did not receive some sort of extra resources. Resources are specified in the figure below. "Other" resources were primarily composed of volunteers, or staff who helped with the vaccination efforts, supplies for new clerical duties, compensation for extra work or time.

#	Resource	Response	%
1	Substitute nurse	130	74%
2	Substitute teacher	23	13%
3	Relocating staff resources	80	45%
4	Document printing	80	45%
5	Overtime for staff	20	11%
6	Other resources:	50	28%
7	My school or district did not provide me	16	9%
	with additional resources.		
8	I am unaware of who provided resources.	0	0%

Figure Six: Extra Resources Provided for Vaccination Efforts

Respondents were then asked if they received the information they needed, and in a timely manner. Roughly a third of respondents answered "no" to this question. They were given a chance to elaborate. The majority who answered "no" had issues with the timeliness of the information, and a few with the content of the information. The major issues identified with the timeliness of the information were the turnaround time given for consent forms (turnaround time was unanimously declared as too short by those who mentioned this), the notice given for the actual day of the clinic scheduled, particularly the second one, and the timeliness of answers given to specific questions. It was also pointed out that this affected the school's ability to answer parents' questions and receive their permission for the vaccination. The most common question that respondents noted not getting answered in a timely fashion concerned allergies and possible counter-indications. Respondents who said that they did not receive the information they needed most commonly said that it was the changes in Factors of Participation In The nH1N1 Vaccination Campaign information that proved difficult, as well as problems receiving the information the information they needed regarding allergies and possible counter-indications. One respondent expressed frustration that her/his communications were not answered regarding the need for shots instead of FluMist for their special needs students, and so a follow-up clinic had to be scheduled that came after many students had already contracted the flu or received the vaccination elsewhere. Some respondents said that they took initiative to seek information out, sometimes from other schools, especially schools that had already had a clinic. While some respondents said the clinics felt rushed, others said that there was a long delay, and with that delay, a communication gap. "It would have been nice to tell parents, "sometime in mid-January" even though we did not have a date."

Next, respondents were asked to consider the quality of the information that they received. 75% of respondents said that they did not have a problem with the quality of the information provided throughout the School Vaccination Campaign. Of the 25% that did have concerns with the quality of the information given, several consistent reasons were given for the concerns. The most common reason quality was questioned was that information was conflicting, either because it changed or because different answers were given to the same question by different parties, particularly concerning what constituted a counter-indication or a medical condition that excluded the child from receiving the vaccine. One nurse expressed frustration that certain people were left out who it was later discovered could have been vaccinated, and that

it felt like his/her hard work was wasted. Also regarding counter-indications, the consent forms and information developed for parents was the second most common reason for concern regarding the quality of the information that schools receive. One respondent reported physicians retracting diagnoses of asthma to try and enable the child to be included, as that was reported as a reason for exclusion from the FluMist vaccine. Another nurse said that the changing and conflicting information was also what they disseminated to parents and that when information changed "it made us look like we didn't know what we were talking about and angered many parents". Another respondent said that the questions on the consent forms were vague, leading parents and nurses to read much into them, ultimately resulting in a child not getting a vaccine who actually could have received it. Several respondents referred to the channels of communication that were involved in finding answers when information was unclear or didn't address concerns they or parents had. One respondent said that it appeared public health personnel were given different information, as they themselves received different answers from different people.

Next, respondents were asked if parents called them regarding the vaccine. Only 14% of respondents (including all roles, in addition to school nurses) said that they had <u>not</u> been contacted by parents with concerns. 95% of nurses said that they were contacted by parents with concerns regarding the vaccine, many referring to an "overload" of calls, and saying that concerns and questions from parents were "too numerous to mention." The most common concern was safety, and possible side

effects or long term effects of the vaccine. The next most common concern was the fact that the FluMist was a live virus, and that due to "street talk" and "media hype", there was much concern from parents and also faculty. The concern seemed to be that students receiving the vaccine would become infected, and also that the students and faculty not receiving the vaccine would also be exposed to the virus, possibly becoming infected. Some respondents reported that parents kept their children home on the day of the clinic to avoid the exposure and perceived risk. Parents also expressed concern as to who would administering the vaccine, how the clinic would be run, how their child's anxiety would be handled, and when they clinic would actually take place. Some parents sought the guidance of the respondent, and some questioned whether the vaccine was needed. When parents questioned the necessity of the vaccine they cited having already received the seasonal vaccine, using other means of lessening risk of infection, and having already had the flu as reasons they thought demonstrated their child/ren may not need the nH1N1 vaccine. Reflecting all of these concerns were the many calls asking for alternatives if their child couldn't be included in the School Vaccination Program due to pre-existing conditions, absence, the parents changed their mind, etc. Some respondents echoed the frustration of the parent in not being able to provide an alternative to them when this question was posed.

Respondents were then asked if there were problems with the consent forms used for the School Vaccination Program. A consent form was required for any child to be included in the SVP. Problems included, but were not limited to, parents

returning the forms in a timely manner, inaccuracies on the form when parents did submit it, withdrawal of permission, receiving the forms at all, collecting the forms, answering parent questions concerning the form, making copies of the forms, "other reasons" (unspecified), printing the forms, and need for translation in Creole, Spanish, Chinese, Korean, Burmese, and multiple languages needed. The most common languages needing translation were Spanish and Creole. Respondents reported that many parents circled "yes" and "no" to questions, they crossed out conditions that did apply to their child (such as asthma), wrote notes of various allergies, parents omitting health issues altogether, or parents marking "yes" to a counter-indication, but still signing that they wanted their child to receive the vaccine. Several respondents reported that parents did identify certain health issues that they knew the student had based on their own access to the child's health record, putting the nurse in a difficult situation. Parents changing their minds was a frequently identified issue, as well as parents "clearly not reading or understanding the forms". Figure presented on following page.

#	Answer		Response	%
1	Printing		28	16%
2	Copying		74	43%
3	Receiving from parents in an untimely manner		139	81%
4	Answering parent questions		86	50%
5	Translating needed in the following language:		21	12%
6	Collecting		101	59%
7	Reviewing		— 111	65%
8	Withdrawal of permission		120	70%
9	Inaccuracies of submitted form		125	73%
10	Other:		43	25%

Figure Seven: Table: Problems with Consent Forms

Next respondents were asked if they received too much, the right amount, or too little information. The majority of respondents said that they received the right amount of information, at 67%. 20% of respondents said that they received too much information, and 13% that they received too little. If they reported receiving too much or too little information, respondents were given a change to clarify the reason they expressed that. The most common reason that the information was described as too much was that it was redundant or that the pure volume took away from the many other responsibilities the person had. The next most common reason was that the information was not only large in volume, but that it was also conflicting. A couple of respondents thought the wealth of information was unneeded; one respondent stated that it was "too much in depth for a routine vaccination" and another "just provides the Factors of Participation In The nH1N1 Vaccination Campaign information needed and not all of the research behind it." Respondents who said that too little information was received stated that they didn't have the needed, accurate information, or answers to their specific questions. Respondents also said that clarification was needed concerning counter-indications.

Respondents were then asked if they sought out additional information regarding vaccines. 58% of respondents did seek out additional information, 30% of which had expressed concerns with the quality of the information that they received. Of those that did not seek out additional information, 17% had expressed concern with the quality of the information provided. Respondents were not asked specifically why they did or did not seek out additional information, although one person expressed that he/she did not "feel like it was my duty to share any other information than what was shared from DOE and DPH," in other words, that they officially disseminated solely the information that DOE and DPH distributed, not what they found on their own. In order of most commonly cited as their additional source of information, was the Centers for Disease Prevention and Control, DPH and Maxim nursing teams, other school nurses and school personnel, either the National or Delaware School Nurses Association, flu.gov, medical professionals, and general media online. Figure presented on following page.

#	Answer	Response	%
1	DPH	124	72%
2	DOE	75	43%
3	Maxim Contractor	26	15%
4	National School Nurses Association	45	26%
5	Delaware School Nurses Association	48	28%
6	flu.delaware.gov (DPH website)	69	40%
7	cdc.gov (Centers for Disease Control and Prevention website)	111	64%
8	flu.gov (U.S. Dept of Health and Human Services website)	48	28%
9	Other:	18	10%

Figure Eight: Table: Sources of Information Most Helpful/Reliable

Note: Respondents checked as many as applied

Respondents were also asked which sources of information they found the most helpful or reliable during the School Vaccination Program. The most common response was the Division of Public Health (DPH), followed closely by the Centers for Disease Control and Prevention website (CDC.gov), the Department of Education (DOE), flu.delaware.gov (DPH website), the Delaware School Nurses Association, flu.gov (U.S. Department of Health and Human Services website), National School Nurses Association, the Maxim contractor, and other sources. The most common other resource cited was other school nurses. One respondent clarified "other nurses sinking Factors of Participation In The nH1N1 Vaccination Campaign with me!" Also cited were school districts, a training program at the Center for Disability Studies, and Google. One respondent said "nobody was helpful".

Respondents were also asked whether they received an appropriate amount of attention from the Division of Public Health (DPH), the Department of Education (DOE), their own school community, or another source. Their responses broke down as follows:

#	Question	Тоо	The right	Too little	Responses	Mean
		much	amount			
1	By DPH	9, 5.29%	134, 78.82%	27,	170	2.11
				15.88%		
2	By DOE	13,	128, 77.11%	25,	166	2.07
		7.83%		15.06%		
3	By your school	11,	140, 82.84%	18,	169	2.04
	community	6.51%		10.65%		
4	Other:	16.67%	61.11%	22.22%	18	2.06

Figure Nine: Table One: Appropriate Amount of Attention by Group

Clearly, the right amount is the majority answer in all categories. Some of the other sources that were identified as providing too much, the right amount or too little attention were other school nurses, Maxim, news media, District support, Catholic school nurse lead, the wellness center and principal and secretarial staff. Many respondents did not clarify which category these other sources fell into, but of those that did, school nurses was identified as a positive form of attention, while one respondent referred to "people making decisions for other people" who this respondent

Factors of Participation In The nH1N1 Vaccination Campaign did not feel understood the role of a school nurse, which can be assumed to refer to 'too little' attention.

Respondents were asked to clarify why they expressed receiving too much or too little attention from the Department of Education (DOE), the Division of Public Health (DPH), their own school community, or any other source. The reasons varied, most commonly that the communication wasn't appropriate or sufficient, that there was a large amount of unsupported extra work, similarly that there a large amount of unsupported extra work for the school nurse, that the respondent felt that a schoolbased vaccination program wasn't appropriate, other concerns or that there were concerns about the support from Maxim. Much of the concern regarding communication was similar to what was raised in responses to previous questions, namely that it was confusing or conflicting. However, there were multiple respondents who suggested that a meeting for the school community prior to the clinic would have alleviated communication and information concerns, from school personnel as well as school communities. The burden of extra work was brought up frequently, particularly the paperwork that the SVP required. Several respondents felt that DPH only helped on the day of the clinic and that they did not receive support with the amount of work that preceded it. Several respondents expressed that other responsibilities has to be "put on the back burner" and that they had to take the work home with them to do what was expected of them. Some respondents felt that the vaccination program should not have been the responsibility of the schools in the first place. One said that

because his/her administrator did not want the vaccination for his children, that he in turn did not value the program. Some felt the responsibility of getting vaccinations for parents should fall on the parents. Of the respondents that said the SVP was not given favorable attention by school leadership, one said that it was viewed as "an intrusion to the educational process." There were several miscellaneous concerns, repeated among them the lack of DOE communication with private and parochial schools. One respondent also expressed a lack of concern from primacy care physicians who were advising parents not to participate in the SVP. There were only two concerns regarding Maxim, one that the school would have preferred to be included in the DPH outreach and the other was the delay of the actual clinic administered by Maxim.

Respondents were asked a similar follow-up question: in addition to the attention the School Vaccination Program received, did they feel it received enough support from various agencies? Again, they were asked specifically about the DOE, DPH and their own school community, as well as given a chance to describe others who did or did not give enough support during the SVP. In all categories, the majority of respondents reported receiving enough support. The majority ratio was highest in regards to the respondents own school community, with 90% of respondents reporting receiving enough support. 83% of respondents reported receiving enough support from DPH, with other sources and the DOE receiving 80% and 77% majorities,

respectively. Positive sources of "other" support were student nurse volunteers, parent

Factors of Participation In The nH1N1 Vaccination Campaign volunteers, wellness centers, Maxim and school staff. Lack of support from other sources included the principal and lack of parent volunteers.

The reasons cited for lack of support were similar to those cited for lack of attention. The most common need for more support was staffing, both specifically to supplement the nurse and also to supplement the project in general. It was also pointed out that other staff had to be pulled away from their duties to make sure everything got done for this program. One respondent cited "175+ hours of time 'donated' to the state by November". One new staffing issue that was raised was the interaction with staff on the day of the clinic; some respondents did not feel this went smoothly in regards to how many nurses they were expecting versus how many actually came, issues such as breaks, and how the on-site staff was able to work with the nursing teams.

Communication was addressed again, with respondents saying they received too little report in this regard and suggesting again that on-site visits would help from DOE and DPH representatives. One respondent also lamented "there was no support, only instruction. No empathy". It was also addressed that certain persons who were used to disseminate information didn't have all of the information, resulting in difficulty in answers during the process. A novel need for communication was identified in regards to support and that was the initiative to communicate with the population as a whole what a massive undertaking this project was, in hopes to gain their support. Budget concerns were another issue mentioned when respondents reported not receiving enough support.

Respondents were then asked whether they were able to balance their ongoing responsibilities while working to administer the School Vaccination Program. The only role within which no one replied no was the lead administrator: head of district or charter, or other administrator. Whether the respondent replied yes or no, they were given an opportunity to elaborate. The majority of respondents did reply yes; however, the elaborations largely revealed similar themes to that of those that answered no. Out of the 120 respondents who said that they were able to handle their new responsibilities and their existing responsibilities, only 20 said yes without significantly qualifying the answer, qualitatively explaining many of the same issues that those who responded no had given. Of those 20, reasons given for being able to handle the responsibilities included working in a small school, receiving support from teachers, principal and administrative staff, time management, "creative planning", that balancing "wasn't a choice", and that although they could manage their role, they thought it was most difficult for the school nurse. The qualified ves's and much of the reasons given by the no's included: the high level of stress and difficulty, not performing existing duties to meet demands of the School Vaccination Program, working significant and ongoing overtime, with and without compensation, and that extra staff was needed. When it was indicated that extra staff was needed, yes's had received supplementary staff and no's had not and stated that as a reason they could not fulfill all of their duties.

Respondents were then asked if strategies used in the 2009 H1N1 School Vaccination Program should be used in the future, and if so to specify which ones. Responses ranged from commendation of existing strategies, to suggestions for modifications. A limited number of respondents expressed an aversion from participating in this type of campaign in the future. Because so many respondents used this question to essentially answer the following question, "What would you change about vaccination efforts in the future?" similar trends are seen in both answers. However, as the respondents were intentionally making recommendations in the second answer, the response are presented below in two separate charts as not to double-count the same suggestion in two answers. Some themes overlapped, the most common being that clinics should be held with parents present to receive information and complete the consent form neatly and accurately so it is usable. However, there is also redundancy in several program aspects that some respondents said to keep and others said needed improvement for future programs, such as the division of labor or the information sharing strategies. As Northern Health Services observed when visiting multiples schools and sites, the program functioned differently at different schools and that could account for the same aspect being viewed positively by some respondents and negatively by others. The chart demonstrating answers to the question "Were there strategies used in this campaign that you think should be used in future efforts is simply divided into strategies to keep, modify and the recommendation to discard this program altogether?" For comparative value, a separate chart shows the

quantitative support for each recommendation made when respondents were

intentionally answering "What would you change about vaccination efforts in the

future?"

Figure Ten: Were there vaccination strategies used in the vaccination efforts that you think should be used in the future?

Кеер	Modify	Discard
Efficient operations	Greater involvement of parents, parents present at clinics	Intrusive
Information sharing strategies	Consent forms	Parent's responsibility
SVP as strategy for inclusion	Greater support/compensation for extra work required	No clarification
Division of work/Work of DPH and Maxim	Greater inclusion of school nurse in planning and information sharing	
Logistics/Supplies	Greater clarity in protocol, training, and information provided	
Pleasant experience with nursing teams (DPH and Maxim)	Simultaneous program for students who cannot receive FluMist/Inclusion in SVP	
Provision of extra support/staff		
Trans-agency partnership		

Note: The recommendations are presented in descending order.

Figure Eleven: Recommendations for Change

Recommendation for change	Respondent Support
	20
Parents present at clinics	30
Other/anecdotal changes	18
More efficiency with forms and protocol	16
Discard program/Do not hold at schools	13
Improved communication/more inclusion	12
of nurses in planning and information	
sharing	
Inclusion of students who cannot receive	11
FluMist	
Support for extra work	

Finally, respondents were asked to summarize their experience with the School Vaccination Program in two to three sentences. Of respondents who chose to answer this question (102 out of 183) under a fifth were singularly negative summaries. Mixed responses and positive responses were evenly split. Several respondents described this program as a great deal of work for very little benefit, many expressing frustration with parents for not taking advantage of this opportunity. Respondents who summarized the program as negative also expressed that they were unsupported by their school and that it was "way too much work for one person." One person referred to it as "an abusive thing to do for school nurses". It was also expressed that the fears of side effects and concerns regarding medical conditions made this a very difficult program to administer, particularly with the fear of the live vaccine. The last commonly cited reason given for a negative experience was the time and stress the program entailed. Those who expressed mixed feelings and positive feelings tended to

Factors of Participation In The nH1N1 Vaccination Campaign regard the program as worthwhile, cite a team effort and a shared commitment to students, refer to organization, preparation, and positive experiences with DPH and Maxim nurses. Some respondents also expressed pride in providing this service to the community, through providing accessibility to all students. This same theme of accessibility was juxtaposed among mixed and negative responses, wherein the exclusion of children who couldn't receive FluMist was brought up repeatedly. Some positive responses referred to the program as "a great learning experience," and an "unprecedented and worthwhile effort" and that the program rose from a "genuine concern in keeping children and the public healthy. We learned not only what we did know, but what we didn't that would make the process smoother next time."

Chapter Three: Discussion and Recommendations

Major Factors of Participation

Although there was quite a diverse breadth of respondents and the way in which they would have ideally participated in these vaccination efforts, there were many recurring themes as to what impacted their participation. Some apply to all groups, some to a few groups, and there are still some factors that are specific, but significant, to marginalized groups. Some factors discussed are operational, with the inference being any inefficiency in operations could be a factor in less people receiving limited vaccinations in limited time. The factors that will be discussed are:

- Communication perceptions and realities
- Inclusiveness in planning
- Extra work burden associated with these vaccination efforts
- Use of volunteers
- Media propaganda
- Vaccine safety, specifically safety associated with Thimerosal
- Persons with special needs
- Anxiety associated with a novel public health event
- Persons who are categorically opposed to vaccinations as a disease control strategy
- Use of mediating structures

Communication Perceptions and Realities.

One of the most common factors of participation in these vaccination efforts was the impact of communication strategies used and also communication perceptions and realities that were demonstrated through this research. Firstly, the Delaware Health Alert Network was something that the Division of Public Health relied on to ensure that healthcare providers throughout the state were privy to the information and guidance that they were disseminating. Information concerning the vaccine and also how to register to provide the vaccine were disseminated using this channel. However, the groups included in this research that represent healthcare providers, the Immunization Coalition, the Medical Alliance, and the Environmental Ethics committee separately expressed lack of knowledge of this network or lack of inclusion in this network, either having signed up but not receiving messaging, or not using the network. The DHAN does use mediating channels, such as the licensing agencies that providers receive information from, to help disseminate information. Providers may be receiving information that is ultimately channeled from the Delaware Health Alert Network, yet not know its origin. However, it is not known if these mediating venues maintain current contact information, or if providers regularly receive this information, specifically the information that DHAN is distributing. It is not known exactly how the gap in information sharing exists. If DPH is going to rely on this network, then there must be strategies developed to aggressively promote its existence and importance to those that DPH wishes to communicate with using this channel. That information and

promotion should go through channels of information that healthcare providers are known to refer to whenever possible. There should also be specific means of verifying membership in DHAN or its mediating venues, and a clear channel for individuals or mediating venues to express concerns, questions or doubts concerning the information disseminated, as well as any technical issues that might arise, such as having problems enrolling or receiving messaging.

Another related perception in this campaign was that the superlative value that the Division placed value on its disseminated information was similarly valued by providers and the public alike, as it was consistent with that provided nationally by the Centers for Disease Control and Prevention. However, depending on the group targeted, there were many competing sources of both information and misinformation and DPH had to compete with these sources to be sought out or referred to for information at all, for that information to be valued and trusted, and for that information or guidance to ultimately guide behavior. This competition of influences was true regarding the general public and also concerning the practitioners that DPH desired to either administer the vaccine or those they hoped would advise clients and constituents to participate in the vaccination efforts. This research demonstrated that people referred to a variety of sources, ranging from specific websites, such as the Centers for Disease Control and Prevention, to various online media, to trusted persons and professionals. It is recommended that the Division of Public Health err on the side of redundant messaging, using multiple channels of disseminating information

Factors of Participation In The nH1N1 Vaccination Campaign to try and capture people who may place higher trust or value in sources other than those explicitly known to be the Division of Public Health. This will be further discussed in the section titled "Using Mediating Structures".

Another communication perception that occurred was the perceived lack of transparency of information, when information was requested that DPH did not have, but was perceived to have, such as a set schedule of vaccine production and delivery and specific risk associated with this vaccine and the ingredients, namely Thimerosal. In reality, DPH did not have access to a set schedule of vaccine production and delivery, as vaccine production consistently fell short of projected supply on any given date. However, certain partners, such as the University of Delaware, found it very difficult to plan and promote clinics without availability information. Although respondents in this research expressed understanding that DPH may not have had the information, they wished that they would have received ongoing communications of status and certainly the earliest notice possible that a vaccine delivery would be made. which they said they did not receive. It is strongly recommended that DPH maintain status communications with partners, so that partners will feel as informed as is possible and not speculate their requests may be being overlooked. The perceived lack of transparency regarding vaccine ingredients and Thimerosal was primarily heard from Center for Disability Studies clients. It is not known whether these persons were knowledgeable regarding typical ingredients of vaccines, excepting Thimerosal. However, it is strongly recommended to seek out concerns and arenas of public

Factors of Participation In The nH1N1 Vaccination Campaign concern and distrust to answer to them. Even if these concerns are speculative, it is important to maintain rapport with citizens by answering specific concerns. It is recommended to find ways to remain more aware of public perceptions, such as town hall meetings, or strategic use of population representatives, such as the Center for Disability Studies, to be able to answer to concerns more specifically and promptly.

There was one extreme perception regarding transparency in these vaccination efforts. Workers at the Division's call center reported receiving many angry calls from the elderly population, regarding their confusion and frustration because they were not considered a priority group, especially as they are a top priority group for seasonal flu vaccinations. Further emphasizing the confusion was that elderly were a priority group for antiviral treatment should they fall ill with nH1N1. These perceived inconsistencies led to many speculations by this population, such as the accusation mentioned in this thesis' problem statement that DPH was trying to "kill them off." The extremist nature of this comment could have resulted in it not being taken seriously. However, if this perception exists, or other extremist perceptions are specifically voiced, it is strongly recommended that DPH not only answer to them, but provide a substantive explanation. In this instance, that explanation may be as follows: "Based on the information health officials were able to gather in the spring onset of nH1N1, it does not appear that persons over 65 are as likely as other groups to catch the virus. This may be because of past exposure to pandemics, and a resulting higher immunity to this influenza strain. However, because those over 65 may be less

Factors of Participation In The nH1N1 Vaccination Campaign resilient if they do fall ill, they are at priority to receive anti-virals if that should happen. The health of those over 65 is as important to DPH as all other groups. We thank you for understanding that while we are limited supply of nH1N1 vaccines, we must offer them to those who are most at risk first, such as children and pregnant women." This explanation may or may not have quelled every upset or concern. However, speaking specifically to the confusing circumstances of these vaccination efforts may engender greater trust by treating their concerns with dignity, regardless of how unsubstantiated they may seem. Perceptions function as realities to those who hold them, and remain unless meaningfully addressed.

Lack of Inclusion in Planning.

Another theme of the feedback gathered is this research was the inclusion of various agencies in planning and input in planning the vaccination efforts, most namely for school personnel and also healthcare providers. The real or perceived lack of inclusion impacted both participating in administering the vaccine (if voluntary) and promoting the vaccine to clients. The effects of not being actively included in planning had several effects. Perceptions were created regarding DPH's awareness of, consideration of and resulting efforts made regarding needs of persons or organizations. One example of this was the many perceptions among both healthcare providers and their clients in the population of persons with special needs. Because fears and concerns, such as that there was no appropriate vaccine dose for little people, were not drawn out initially and answered to, little people and their advising

Factors of Participation In The nH1N1 Vaccination Campaign physicians were under the same assumption: they did not think there was a vaccine designated for them in these vaccination efforts. Therefore, physicians advised their clients not to receive a vaccine. There was eventually a meeting held with a representative of this population from the Center for Disability Studies, and many false perceptions were drawn out in this productive dialogue. This issue is similar to the perceived lack of transparency held by this group, in that it can likely be ameliorated by more dialogue, and in this instance, that dialogue can help partnering agencies both disclose concerns, and plan with DPH how to facilitate greater inclusion by working through them, modifying existing strategies if needed. For instance, it appears specific messaging was needed to inform little people that there was a vaccine dosage appropriate for them in this campaign. This dialogue should be held early on in the vaccination efforts, and facilitated throughout so that this population is not excluded from the vaccination efforts, through perceived or real barriers.

The lack of inclusion in planning and input in planning of persons such as school nurses, also impacted their ability to stay informed through the vaccination efforts; questions took longer to ask and to answer when middlepersons in the communication process were not health practitioners. This delay in procuring information can be reasonably assumed to negatively impact participation in this campaign as over 95% of nurse respondents said that they were sought for guidance and advice from parents debating their consent to vaccinate their child. If the nurse was misinformed or not informed and not confident of when an answer to a parent's

concern would be available, the parent may decide not to vaccinate, or may not decide to vaccinate by the time the consent forms were due or the nursing team was at the school to vaccinate students with consent. Some respondents from the School Vaccination Program said that they felt foolish when they felt unanswered or when they voiced concerns from parents that they'd promised to bring forth, perceiving them to be considered, and yet didn't see a change in planning, such as disclosing the need for an alternative to FluMist for students with certain health conditions who couldn't receive it. There was also frustration expressed that a very large amount of work was being asked, but input on how to administer the program in each school was not sought from the school itself. To person who felt this way, the vaccination efforts were often described as demoralizing, frustrating, inefficient and could have impacted those persons' energy and confidence in this and future vaccination efforts. Depending on the nature of the concerns, they could have affected efficiency at specific schools and the number of children who were able to be vaccinated when the nursing teams were at the schools. It was not researched, nor is necessarily measurable, how these experiences would influence the perceptions engendered by these school personnel when administering or discussing the program, most significantly when they are being sought out for advice or answers from parents, and how that might impact a parent's willingness to give their child consent to participate in this program. Many school personnel reported working extensive overtime without compensation and this seems to be strongly associated with those who also characterize the School Vaccination
Program negatively. It is recommended to explore ways to engender a more positive last impression regarding these efforts with school personnel, especially if these personnel will be needed as partners in future efforts. Specifically, it is recommended to determine if compensation can be provided post-event. Funding for this public health event was provided prior to the vaccination efforts, unlike natural disasters, in which losses incurred or needs for compensation are funded after the event through the Stafford Act. It is not known whether an analogous strategy could be used in this regard, but it is recommended to consider the feasibility of this approach.

When considering the desire of various parties to be included in planning or at least to have input in planning, it is recommended that there is protocol designed to at least solicit input for planning. One recommended strategy is for nursing teams, or representative of them, to conduct site visits with schools, and hold a meeting to discuss how the program will work and problem-shoot school specific concerns to streamline the processes. Although all relevant persons can't fit at one table to have a meeting, taking the time to gather concerns and draw out perceptions would ostensibly function to assure parties that their concerns are known and considered by those who are ultimately planning the vaccination efforts.

To engage healthcare providers, it is recommended to use group models such as the Immunization Coalition so that a forum is provided to draw out their concerns, especially for clients with special needs. Public health planners need to be aware of all perceptions and real concerns of healthcare providers and their clients when planning

an inclusive campaign. Meetings should be held throughout the vaccination efforts, and there should be a specific channel and protocol for relaying all voiced concerns to planners, as well as a follow-up with those who raised them to inform them how they were being addressed by public health planners. It is hoped providers would then relay these strategies to their clients and either administer the vaccine themselves or inform their clients as to how and where they can receive a vaccine. As persons who receive health services from private providers seem to value their guidance over that of mass public health messaging, this is a recommended strategy to engage more people to participate in vaccination efforts by public health.

Extra Work Burden Associated with Vaccination Efforts.

Another factor impacting not only morale, but actual ability to administer this program, was the work burden it entailed, specifically for school nurses. This affected certain healthcare providers' willingness to participate in the program at all because of the extra paperwork it entailed. Public school personnel were obligated to participate in the program, so the work burden didn't preclude their participation, but it did present several issues that could be addressed. First of all, many schools provided the nurse with extra staff to assist in the management of the School Vaccination Program and this resource was mentioned many times in feedback as one that was essential for administering this program and maintaining other duties. This is strongly recommended for all school communities. It is also recommended to see how DPH could support the supplies or monies needed to provide this support, as some school

Factors of Participation In The nH1N1 Vaccination Campaign personnel respondents reported lack of funding to support these means internally and also a specific aversion to using education funds for a public health event.

In addition to the work burden that the SVP presented, the school nurse and others who participated in this program have other, pre-existing services to maintain. Personnel deviated from services that are valued could not only engender immediate resentment, but also provide just cause for resentment of the program and resistance to participation in future programs if problems occur because needed services weren't readily available. Another aspect of the work burden that was resented was that much of it was not work that needed to be done by a nurse; it could be completed by someone with clerical skills. It is strongly recommended that if support staff are available, tasks of this nature are delegated appropriately and from the beginning of the efforts to make more efficient use of the nurse for tasks that are specific to nurses. Suspension of certain services was also mentioned by personnel from the Division of Public Health as a cause of concern in these vaccination efforts. DPH personnel can't necessarily opt out of a state-administered program. However, if the suspension of certain services causes issues for their constituents and a resulting breakdown of trust, this could impact those constituents' willingness to procure services from the Division of Public Health in the future, including vaccination efforts. Even if they are not able to procure services elsewhere and therefore continue to receive them from DPH, public trust in DPH could be damaged, which could impact trust in its programs, such as vaccination efforts. In a novel public health event, DPH may have to temporarily

change priorities, but strategies should be developed to refer constituents to other healthcare service providers so that there is not an absolute deficit in needed services. Relationships for service referral should be part of preparedness planning, and those relationships are ideally developed before a novel public health event so that they are readily accessible should a novel public health event present itself, particularly when requiring a rapid response, and a corresponding efficient transfer of services and use of referral protocol.

Use of Volunteers.

When considering the work burden that these vaccination efforts created, it is not surprising that volunteers were often used in this campaign. This was both a positive factor in participating, by providing extra personnel to administer the program, and a factor that caused some issues when volunteers varied in their accountability, or weren't solicited at all. Both medical and non-medical volunteers were used in these efforts. Some best practices of volunteer usage were proactively delegating appropriate tasks to lessen work burden, proactively developing rapport through regular communication of needs and appreciation, setting up carpools for nursing teams and volunteers so that all stayed for the day and so that getting lost wasn't an issue. Specific groups associated with a good experience using volunteers were retired medical professionals and parent volunteers at schools. It is strongly recommended to maintain relations with volunteers who demonstrated accountability in this campaign, in order that the relationship remains strong for future potential

needs in a public health event. Some issues with volunteers were failure to uphold committed time, especially last-minute cancellations, or failing to show up without cancelling. It is strongly recommended to employ consistent volunteer management strategies based on best practices observed in these vaccination efforts. It is strongly recommended that tasks that can be delegated to volunteers are identified, that appropriate volunteers are actively solicited and that best practices of volunteer management are made part of protocol for volunteer usage and provided to all parties who will benefit from volunteers as a staffing resource. Increased capacity to provide services through strategic personnel expansion in a limited time is a real factor in participation in these and future vaccination efforts. Management strategies should be in place for paid and volunteer personnel alike, although it is unlikely the exact same strategies work equally for both groups. It is recommended to find innovative ways to motivate and reward volunteers, to provide incentives and means of engagement that sustain throughout vaccination efforts.

Safety of Vaccine, Particularly Concerning Thimerosal.

Another major factor of participation in these vaccination efforts was perception surrounding the safety of the vaccine, especially concerning the vaccines that contained Thimerosal. Healthcare professionals and the general public alike reflected much uncertainty that a safe and effective vaccine could be produced in such a short time. Some school personnel respondents said these concerns were ameliorated when they learned that the vaccine for nH1N1 was produced in much the same way Factors of Participation In The nH1N1 Vaccination Campaign that seasonal flu vaccines are produced and that it had undergone analogous safety trials. This kind of assurance is directly relevant to the concerns that many had regarding the vaccines safety. It is strongly recommended that vaccine promotion campaigns do not merely say that the vaccine is safe, but provide this specific, reassuring advice, especially how it corresponds to the seasonal flu vaccine in production and safety trials, as it is likely that many people with concerns about the nH1N1 vaccine may not have concerns about the seasonal flu vaccine and therefore may find this comparison reassuring.

On a related note, but distinct in nature, is the fear regarding vaccines that contain the preservative Thimerosal, which contains trace amounts of mercury. It is popularly believed that vaccines containing Thimerosal have links to autism in children, although the study that claimed this was the case has been recently retracted and largely discredited based on both lack of scientific basis and for unethical methods of research. Paul Offit, chief of infectious disease at the Children's Hospital of Philadelphia said the retraction of this study came far too late (as cited in Wang, 2010): "It's very easy to scare people; it is very hard to unscare them". That said, it is strongly recommended to increase awareness that this study has been discredited, so that one of the issues causing fear of vaccinations can begin to be ameliorated. In this outreach, strategic use of trusted persons and agencies should be used, and a "one-sizefits-all" campaign cannot be assumed to alleviate deeply engrained distrust. Particularly for persons who have a family member or other loved one who has autism

or another neurological disorder, this may be a topic that is very sensitive in nature and therefore best addressed in an intimate and trusted setting, such as a workshop by the Center for Disability Studies or their healthcare provider. It is recommended to develop educational tools that healthcare providers can provide to their clients concerning this issue. There is a law in Delaware that currently prohibits the use of Thimerosal in vaccines, and it is recommended that the State consider whether this law is necessary and appropriate. Although this law was temporarily relieved to allow the use of Thimerosal if persons signed a waiver, both the existence of the law and the consequent need to sign a waiver engendered fear of Thimerosal for those not previously familiar with it. As long as it is something that is lawfully controlled, fears that it is unsafe are substantiated to varying degrees.

Attention to Those with Special Needs.

Another factor that affected participation in this campaign in a real and perceived way was the attention that was paid to those with special needs. The School Vaccination Program for public schools grades kindergarten through fifth grade only used the FluMist vaccine, which students with various health conditions could not receive. Some of these health conditions are also conditions that predispose that child to a greater likelihood of catching the virus, suffering a more significant illness from it or both. Because this program was promoted by its proactive attempt to protect children, this was seen as inconsistent with the intent by some, as it did not include some children most in need of protection. It is strongly recommended that future

school-based campaigns maintain an adequate supply of alternate vaccinations that those with special needs can receive. Although there were other options, such as the child going to their own physician, or the child attending a mass vaccination clinic, one of the most identified strengths of this program was that it included children who would like not be able to receive the vaccine from another outside source for whatever reason. It is strongly recommended that a school-based program attempts to include all children, and does not rely on the child's ability to procure services outside of the school as this may disproportionately affect children who already lack ready access to healthcare for reasons such as lack of health insurance, lack of parent initiative, lack of transportation or other issues that aren't specifically solved if those alternatives are promoted as a means to include all students. For those with special needs of all ages, it is strongly recommended to employ rapid identification of who must avoid certain types of vaccines and to then strategize targeted, aggressive, even redundant efforts to ascertain what, if any, vaccine they may receive and the ways to provide that service for the duration of the vaccination efforts until those who would like to become vaccinated are able to do so. As the vaccination efforts progressed, the Division of Public Health did undertake this initiative in several ways: holding mass vaccination clinics, specifically reaching out to agencies that have those with special needs as their constituents, and tailoring services to reach them and also homebound persons. This was done well and seemed to be comprehensive. The same contacts and strategies should be used and employed at the beginning of future vaccination efforts.

Fear and Anxiety Associated with a Novel Public Health Event.

One of the biggest, yet least containable, factors of participation in this campaign was the categorical anxiety and uncertainty that a novel public health event can engender in populations. Some of the reasons for concern have already been discussed, such as the fear of a new vaccine, but it may be reasonably assumed that the concerns explicitly brought forth and stated aren't comprehensive in causing fear and anxiety. In a country where trust in government and government programs is not ubiquitous and most persons receive healthcare from the private sector, it is questionable whether state government, and therefore the Division of Public Health, holds enough community trust to wholly ameliorate fear and doubt of all persons, and enough clout to advise healthcare choices, especially to those who defer to their physician's advice in such matters. That said, it is unlikely that any one agency could accomplish this for the population as a whole. It is strongly recommended that agencies and persons that are already trusted by and influential in the community be identified, and pursued for relationships that can be used to disseminate information that is grounded in the scientific information that the Division of Public Health plans from, but tailored by this mediating structure to the specific needs and concerns of its constituents. Although DPH may be able to scientifically prove the validity of its strategies and information, in a time of fear, people seem to turn to venues they already trust. Emotions are not always answerable by science. Secondary data revealed sources of information that people trusted in this campaign including, but not limited to, clergy

Factors of Participation In The nH1N1 Vaccination Campaign members, celebrities, family, YouTube videos, and rumors heard from friends. Depending on the group targeted, different agencies and persons may function as valuable partners in information sharing, such as churches, community based organizations such as an Elk Lodge or YMCA, community leaders, both official leaders like fraternity and sorority leadership or neighborhood associations, and unofficial leaders, such as celebrities or persons who have become popular or trusted by specific groups. A model to develop these relationships will be discussed in the section "Use of Mediating Structures".

Another issue of trust as corresponds to fear and anxiety brought to this researcher's attention was associated with the use of outside personnel in the School Vaccination Program. This issue was raised by a kindergarten teacher whose students were scared of going with unfamiliar nurses to become vaccinated. This teacher recommended allowing the school nurse to administer the vaccines because of student familiarity with school nurses, even though this will require administering vaccinations over a longer time span. It is strongly recommended that this strategy by explored. Although it would mean vaccinating the student body would take a longer time span for any one school, it would still not run as long as the School Vaccination Program did as a whole during the nH1N1 SVP, and it would allow all schools to start at the same time. Disruption of school order and wait time for each school's vaccination day was also a contentious issue reported by school personnel. Changing the School Vaccination Program in this way would address that issue. This could lead Factors of Participation In The nH1N1 Vaccination Campaign to greater public perception of equity, and therefore greater trust, as all students in all schools would receive this public health service in the same time frame.

Media Propaganda.

The creation of a large network of trusted and influential agents would also ostensibly help address an issue with these vaccination efforts that was mentioned by every single group polled: media propaganda. It cannot be fully determined when media merely reflected rumors and public concern or when it may have functioned in engendering doubt and concern that wouldn't have otherwise existed. But it is inarguable that the media has an influence on common understanding and awareness of current events. The media reported on novel H1N1 from the onset of the pandemic, through the vaccination efforts and now as public interest is tapering off. Constitutionally, the media has a right to free speech, so preventing certain messaging, specifically sensationalist messaging, is impossible. However, there are ways in which the impact that the media has can be addressed. One is proactive campaigns to answer to rumors, even rumors assumed to be without foundation, such as one rumor propagated by a YouTube video. This video showed a person who allegedly suffered

such a severe reaction to the vaccination that she could only speak running backwards. Through secondary data, this researcher did find that some people believed this rumor and claimed it as the reason they did not receive a vaccination. Another way of mitigating the impact of sensationalist media is by working with strategic partners, such as healthcare providers, mediating structures and opinion leaders in the

community to collaborate on strategies to address media claims through venues that various groups seek out and ostensibly will place greater trust in than random media sources. Admittedly, there are some people who may not be reached through this networking. There may be people who place the most trust in media coverage, rather than sources such as DPH. Though the Division of Public Health shouldn't forgo trying to reach these groups, even at the risk of redundant measures, DPH may not ever influence the decision-making of all groups in all situations, through its own messaging or that of partners. However, remembering to consider these groups and continue to strategize ways to reach them is strongly recommended. A recent brainstorming session engendered ideas such as posting information in convenience stores, or public parks, or other places that don't have formal membership, and may be frequented by a demographic that isn't reached by other efforts. It is strongly recommended to use these strategies, and to continue to strategize campaigns that reach and meaningfully influence the most marginalized members of the population.

Persons who are Categorically Opposed to Vaccinations.

Although this thesis was researched and written with the belief that vaccinations are a positive and ideal strategy for disease control, it would be unethical to not consider the inclusion of those who are opposed to all vaccines and do not intend to receive them, regardless of the specific nature of the vaccination efforts. In these vaccination efforts, a hierarchy of controls was strongly promoted as the population waited for vaccine production and as vaccine production fell short of Factors of Participation In The nH1N1 Vaccination Campaign projections for volume and type of vaccine. Once vaccines were available, the hierarchy of controls strategy was not emphasized as strongly as becoming vaccinated. The majority of literature and health promotion associated with the novel H1N1 virus promoted receiving a vaccination, sometimes not simultaneously emphasizing the need for maintaining a hierarchy of controls. Not only does this potentially give the impression that those opposed to vaccinations are not included or considered in disease control strategies, it misses the opportunity to remind them of the social responsibility that they ideally still espouse in disease control efforts, regardless of not intending to receive a vaccination.

Use of Mediating Structures.

Multiple issues have been analyzed with the recommendation to explore the use of mediating structures. This section presents a sample outline of how to construct these relationships, using a relationship between faith-based organizations and the Public Health Preparedness Section as an example. The current status of relationships between the Division of Public Health Preparedness Section and faith-based organizations and the relevant information sharing technologies is nearly nonexistent. Therefore this is a proposal for the development of such a relationship, with an outline of how it might be constructed. This recommendation is discussed in the context of the overarching value building these relationships would have for all novel public health events, not just vaccination efforts, however, this section concludes by identifying Factors of Participation In The nH1N1 Vaccination Campaign specific ways this relationship may have functioned in and enhanced the novel H1N1 vaccination efforts.

The mission at hand is to form a structured and sustainable partnership with faith-based organizations, hereafter referred to as FBO's, when implementing Public Health Preparedness Section (PHPS) initiatives. This is a desirable partnership because it empowers trusted community leadership to be the disseminators of novel information to their members, ostensibly making it more likely to be well-received and trusted. Strategically formed, it also gives that leadership an accessible communication bridge with the government about matters of concern or conflict for their community. By more proactively addressing those issues, an ongoing dialogue and better relationship will ideally form between PHPS, the organizations it partners with and thereby its constituents.

The interest in this initiative relies heavily on trust of FBOs that the government values the beliefs and values of its people and wants to better understand those and speak to those by creating this partnership. It is hoped that valuing this makes the partnership appealing to FBOs, as they feel included and respected, and that it is desirable to PHPS, as it gains a more intimate dialogue with the public, hopefully fostering greater buy-in to its initiatives in times of public health events as well as creating a more comprehensive information sharing system. A letter will be sent to all FBO's explaining the goals of this initiative and inviting them to attend the first meeting. The first meeting will be a luncheon, to help reinforce the symbolism of a

Factors of Participation In The nH1N1 Vaccination Campaign personal partnership, not just a business arrangement. It is hoped that this kind of gesture will be a demonstration of the more personalized approach that PHPS is trying to engender with this new partnership and that this will be appreciated to the extent it will engender the commitment of the FBOs to participate in the work that building and sustaining that will entail.

Strong inter-agency relations are integral to the development of this initiative. A strong alliance needs to exist between PHPS and each agency. There also needs to be an alliance among members, at least to the extent of fostering a community of respect and dialogue. The original luncheon will begin this alliance building between members. As the network is built and the process of the partnership begins, regular meetings will be held, both on a large scale and smaller meetings to help build local networking and allow for more intimate forums, maintaining the attention to individual needs and interests in this initiative. An online forum will be made to field suggestions, questions and concerns. There will the opportunity to problem solve and strategize specific to faith and across faiths. This may help engender the idea that faiths can be unified by faith, if not by the same faith. It is also hoped that the participating members will appreciate the value of PHPS as it works to safeguard they and their members during novel public health events and further identify ways that PHPS could meet needs within their community and ways that they can support PHPS's initiatives.

Because the outreach is based on members' personal, sometimes mutually exclusive, belief systems, there will need to be proactive measures taken to make sure a community of dignity and respect is maintained for all members. This will be communicated explicitly in the materials distributed to introduce this initiative, as well as reiterated in all meetings, that this is an alliance of collaboration and acceptance. One way that a genuine alliance will be built is by guiding the group to determine common interests, to focus on the shared ideals of the group and focus less on the difference of their faiths. For instance, a shared interest might be determining how to maintain congregational communication during a disaster. Regardless of the creed followed by any one congregation, the logistics of creative communication is a subject that could have overlapping relevance between communities. Helping faith communities manage their stress and anxiety through accessible emotional support via communication during disasters is a way to help infrastructure means of fostering community morale.

The design of infrastructure in this initiative is important, in that it is usable and relevant to members, and also reliable to both members and PHPS. Hopefully, FBOs are inclined to turn to it, because it is viewed as a system of support that they are not necessarily capable of internally, such as procuring state resources and attention to specific needs or concerns within their congregation. If a point of contact (POC) is set up with communities, they will be able to quickly convey their needs to PHPS. As there are many FBOs throughout the state, working teams are also a component of a

Factors of Participation In The nH1N1 Vaccination Campaign well-structured frame and perhaps a more manageable way of maintaining communication. It should be considered whether local networks should be organized based on faith, or geography.

The teams will identify a spokesperson. Each FBO will have a spokesperson and this chain of communication will be written in black and white, with alternatives for each POC. This way, during a disaster both PHPS reaching out to the FBO teams and FBO teams reaching out to PHPS will be done by a clearly identified person, as well as when FBOs reach out to one another within and across teams. FBOs will also be asked to encourage members to become citizen emergency response training (CERT) certified, to have teams to deploy to assist members within their own FBO or to provide backup to other FBOs within their team. This trained response will build the resilience of FBOs within their own communities and for the other FBOs they support.

There is an ongoing concern of this network is keeping members' feeling a vested interest in not only membership, but working with other members and working with PHPS. The ongoing need is to maintain a balance between reasonable autonomy for FBO's self-management and the reliance and adherence to PHPS guidance. Because of that, both the development of the FBOs autonomy and the relationship with PHPS are structured into the formative action plan. The elements of this network and their corresponding frames are:

Introductory and educational materials distributed

- Introductory meeting (Webcast alternative provided)
- Establishment of POC for each FBO-Online forum and email group created
- Team formation and identification of POC for each team-online template and sample protocol
- Development of action plan by teams based on FBO specific needs; PHPS present for presentation of action plan (Webcast alternative provided)
- Identification and certification of FBO members for CERT-when appropriate, training can be done as Webcast
- Monthly team meetings with minutes report back to PHPS; PHPS representative present (Webcast alternative provided)
- Quarterly face-to-face group meetings
- Situation specific meetings time and location TBD-use of online forums and Webcasts used when appropriate
- Ongoing educational meetings: presentations on various aspects of potential public health events and their implications for FBOs-Webcasts used when appropriate or provided as alternative
- Guided planning meetings for situation-specific planning must have PHPS present, preferably a subject area expert
- Yearly reception identifying "Best Practices" and collaboratively addressing novel issues

There are some issues that might present a very tense meeting of minds in disaster planning with FBOs and it is hoped that this network will be established and a trusted forum before those develop. For instance, during a Mass Fatality Event, individuals may be asked to deviate from their typical end-of-life rituals should their loved ones pass away. This is because of the logistics of both managing a surge in bodies and also the potential that the Mass Fatality is due to an infectious disease that must be contained at the expense of a observing typical ceremonies, such as those with the body present. Asking people to give up a source of comfort and closure without any relationship would likely not be well-received. This issue is just one example of the potential need to ask people to make significant modifications to their traditions in the interest of their health and safety and that of their community. It is hoped that these issues will be addressed within the PHPS network with FBOs, and understood to introduce needs for collaborative problem-solving, rather than resented mandates from above. By unifying the health and safety of FBOs, it is hoped that PHPS will be looked to as a desirable member of the problem-solving strategy and not an impersonal government agency.

The first five years are critical in setting the stage for the organizational management of this alliance between PHPS and FBOs throughout Delaware. There is the ongoing paradox between the micro view of individual belief systems and the macro view of Public Health planning and this cannot be assumed to be quickly resolved to the buy-in of all members. However, with the ongoing commitment to

partnership, the face-to-face access of members of both FBO and PHPS, it is hoped that value will be demonstrated for all parties and finding strategies to address tough situations will be something that can be done collaboratively. It is hoped that this creation of greater information sharing and buttressing information technology will function to both create and preserve trust in the government's interest in the people and the health of the public as a whole, spiritually, physically and otherwise.

This recommendation is presented in a very broad context, but it does have specific applications for vaccination efforts, such as the way this partnership could have functioned during those with novel H1N1 influenza. Were this structure in place, FBOs could have identified fears, concerns, and special needs of their members regarding the vaccine and voiced them directly to PHPS. PHPS could have procured specific answers for the POCs, and the FBO leadership could then have communicated them to its members. FBOs could have acted as sites for vaccination, inviting nursing teams to come and vaccinate membership. This could also be opened to the surrounding community. FBO leadership could become vaccinated in front of their congregation. Seeing trusted leaders demonstrate belief in the value and safety of a health service could have functioned to encourage membership to do so as well. It is strongly recommended that the feasibility of this partnership be explored and that both the Division of Public Health as a whole and the Preparedness Section consider the value it might present in novel public health events for the Division and the community as a whole.

Concluding Thoughts

Novel H1N1 did not have the widespread mortality that it was anticipated a pandemic might have. However, in the future, a novel and more deadly disease may confront this population and the strategies to confront that may again rely on voluntary participation by the public, healthcare providers and Public Health partners. If there is not sufficient trust and communication between these groups and the Division of Public Health, the results could be catastrophic as resources and personnel are exhausted on strategies that don't successfully engage participation. It is also noteworthy that people did die from this strain, and many became ill, missing work and school. This relatively mild novel influenza strain gave the public, the healthcare community and the Division of Public Health and its partners an opportunity to employ and/or rely upon new and existing plans and partnerships. It also gave certain parties the opportunity to opt out of the vaccination efforts, which occurred for a variety of factors, many described in this thesis. This research was designed to gain and build understanding of this experience from multiple perspectives, so that future plans and strategies employ both lessons learned and best practices from this novel H1N1 public health event. It is hoped the research will be informative and useful to the groups who provided feedback and to Public Health planners. It is ultimately hoped that strategies to mitigate disease morbidity and mortality in the future will be the better for the lessons learned in this novel H1n1 public health event, including those discovered through this research.

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Appendixes

Appendix One

Questions for Center for Disability Studies Clients.

- 1. When you hear "H1N1 Vaccination", what is the first word or phrase that comes to mind?
- Do you consider the H1N1 vaccine important for yourself and/or your family? (Choose one)
 - No, I do not consider the vaccine important and I do not intend to receive it. Please indicate why you do not consider the H1N1 vaccine important (open response).
 - b. Yes, I consider the vaccine important, but I do not intend to receive it.Please indicate why you do not intend to receive it (open response).
 - c. Yes, I consider the vaccine important, and I did or I do intend to receive it. Where did you receive it? (Open response).
- Do you consider the seasonal flu vaccine important for yourself and/or your family? (Choose one)
 - a. No, I do not consider the seasonal flu vaccine important. Please indicate why you do not consider it important (open response).
 - b. Yes, I consider the seasonal flu vaccine important, but I do not intend to receive it. Please indicate why you do not intend to receive it (open response).

- c. Yes, I consider the seasonal flu vaccine important and I did or I do intend to receive it.
- 4. Did you have concerns about the H1N1 Vaccination? (Choose one)
 - a. No, I did not have concerns about the H1N1 Vaccine.
 - b. Yes, I had concerns about the vaccine. My concern was that: (open response).
- If there is a vaccine to protect against both seasonal and H1N1 in the fall, do you intend to receive it? (Choose one)
 - a. Yes
 - b. No
- 6. Did you seek out information regarding the H1N1 vaccine? Check all that apply, and please note which was most helpful and reliable.
 - a. Online. Please indicate preferred website. (CDC, a news journal, Division of Public Health (DPH), website) (Open response).
 - b. Publication. Please indicate publication (open response).
 - c. A trusted person or professional. Please indicate the person's role (doctor, Public Health official, clergy, etc) (open response)
 - d. Other. Please specify (open response).
 - e. I did not seek out information regarding the H1N1 vaccine.
- Were any sources of information confusing? If so, please indicate which. (Choose one).

- a. Yes (open response).
- b. No
- 8. Do you think an appropriate amount of attention was given to the H1N1 vaccination efforts? (Choose one)
 - a. Yes, I think the vaccination efforts were appropriate.
 - b. No, I think too much attention was given to the H1N1 vaccination efforts.
 - c. No, I think too little attention was given to the h1n1 vaccination efforts.
- Do you feel your needs were taken into account in this vaccination effort? (Choose one)
 - a. Yes, my needs were met through the H1N1 vaccination efforts.
 - b. No, my needs were not met during the H1N1 vaccination efforts. Please specify what needs were not met: accommodations, access to receive the vaccine, unanswered questions about the vaccine, etc (open response).
- 10. Do you feel there were sufficient accommodations for your needs in the vaccination efforts? (Choose one)
 - a. Yes
 - b. No
- 11. How would you describe the quality of the H1N1 vaccination efforts? Please explain. (Choose one)

- a. Excellent (open response).
- b. Good (open response).
- c. Fair (open response).
- d. Poor (open response).
- e. Very poor (open response).
- 12. What would you change about future vaccination efforts? (Open response).
- 13. What did you feel was done well in these vaccination efforts? (Open response).
- 14. Did the H1N1 vaccination efforts affect the way you view the Division of

Public Health (DPH)? Please explain. (Choose one).

- a. Yes, I now think of DPH in a more positive way (open response).
- b. The H1N1 vaccination efforts did not affect the way I think of DPH (open response).
- c. Yes, I now think of DPH in a more negative way (open response)

Appendix Two

Questions for School Personnel from School Vaccination Program.

- 1. When you think of the nH1n1 School Vaccination Program, what is the first word or phrase that comes to mind? Why? (Open response).
- 2. What student population(s) do you represent? Please check all that apply.

	K-5	6-12
School District		
Private or Parochial School		
Charter School		

- 3. In which county in your school located? (Choose one).
 - a. New Castle County
 - b. Kent County
 - c. Sussex County
- 4. Did you consider the 2009 H1n1 influenza vaccine important for your

students? Why or why not? (Choose one).

- a. Yes (open response).
- b. No (open response).
- 5. Did you have concerns about the 2009 H1N1 vaccine? Please explain (choose

one).

a. I did not have concerns about this vaccine.

- b. I did have concerns about this vaccine (open response).
- What role(s) did you play in the vaccination efforts? Please check all that apply.
 - a. Lead Administrator: Superintendent, Head of District/Charter, Other Administrator
 - b. Local School Administrator: Principal, Dean of Student, Other
 - c. Vaccination Contact Person (Designated by Lead Administrator)
 - d. School Nurse
 - e. School Faculty: Teachers, Specialists
 - f. District Level Staff
 - g. Other role (open response)
- 7. Given your knowledge and skills, were the responsibilities assigned to you in the vaccination efforts a good fit? Please explain (choose one).
 - a. Yes (open response)
 - b. No (open response)
- 8. Were you able to make contact/connections with people needed to play your role in the vaccination efforts? Please explain (choose one).
 - a. Yes (open response)
 - b. No (open response)
- 9. Did your school or district provide you with additional resources (beyond those provided by DPH) during this campaign? Please indicate all that apply.

- a. Substitute nurse
- b. Substitute teacher
- c. Relocating staff resources
- d. Document printing
- e. Overtime for staff
- f. Other resources: (open response)
- g. My school or district did not provide me with additional resources.
- h. I am unaware of who provided resources.
- 10. Who were your sources of information for in the vaccination efforts? Please check all that apply.
 - a. Division of Public Health (DPH)
 - b. Department of Education (DOE)
 - c. Maxim Contractor (open response)
 - d. Other: (open response
- 11. Did you receive the information you needed in a timely fashion to play your role in the vaccination efforts? If not, what further information did you need, and/or what were concerns about the timing of the information? Please be specific as to time frame of information needed vs. information received (choose one).
 - a. Yes, I received the information I needed in a timely manner.

- b. No, I did not receive the information I needed, or I did not receive it in a timely manner (open response).
- 12. Did you have concerns about the quality of the information provided? If so, please explain and identify the source of the information that was concerning (DPH, DOE, other).
 - a. No, I did not have concerns concerning the quality of the information provided.
 - b. Yes, I had concerns about the information provided: (open response)
- 13. Did parents contact you with concerns regarding the vaccine or vaccination efforts? If so, what were their concerns? (Choose one).
 - a. No, parents did not contact me with concerns.
 - b. Yes, parents did contact me with concerns: (open response)
- 14. Which, if any, of the following issues did you face with consent forms?
 - a. Printing
 - b. Copying
 - c. Receiving from parents in an untimely manner
 - d. Answering parent questions
 - e. Translating needed in the following language: (open response)
 - f. Collecting
 - g. Reviewing
 - h. Withdrawal of permission

- i. Inaccuracies of submitted form
- j. Other (open response)
- 15. Consider the amount of the information you received. Was it:
 - a. Too much information (open response)
 - b. The right amount of information
 - c. Too little information (open response)
- 16. Did you seek out additional information concerning the vaccine or the

vaccination efforts? If so, from what source? (Choose one)

- a. No, I did not seek out additional information.
- b. Yes, I sought out additional information from: (open response)
- 17. Which sources of information were the most helpful and reliable during the

vaccination efforts? Please check all that apply.

- a. DPH
- b. DOE
- c. Maxim Contractor
- d. National School Nurses Association
- e. Delaware School Nurses Association
- f. Flu.delaware.gov (DPH website)
- g. Cdc.gov (Centers for Disease Control and Prevention website)
- h. flu.gov (U.S. Dept of Health and Human Services website)
- i. Other: (open response)

18. Was an appropriate amount of attention given to the vaccination efforts?

(Check all that apply)

	Too much	The right amount	Too little
By DPH			
By DOE			
By your own school			
community			
Other: (open			
response)			

- 19. If you indicated that DPH, DOE, your own school community or another source should have given more or less attention to the vaccination efforts, please explain.
- 20. Did you receive sufficient support in the vaccination efforts? (Choose one per
 - row)

	Yes	No
DPH		
DOE		
Your own school		
community		
Other: (open response)		
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- 21. If you indicated that you did not receive sufficient support in the vaccination efforts, please explain (open response).
- 22. Were you able to balance the responsibilities of the 2009 H1N1 vaccination efforts with your other professional responsibilities? Please explain (choose one).
 - a. Yes (open response)
 - b. No (open response)
- 23. Were there strategies used in the vaccination efforts that you think should be used in the future? Please specify (open response).
- 24. What would you change about this type of vaccination effort in the future? (Open response).
- 25. In 2 to 3 sentences, please describe your overall experience with the 2009 H1N1 vaccination efforts (open response).

Appendix Three

Questions Used in Confidential Interviews.

- 1. When you hear "H1N1 vaccine" what is the first word or phrase that comes to mind?
- 2. Do you consider the H1N1 vaccine important and did you or do you intend to receive it? Do you consider the H1N1 vaccine important for your family?
- 3. Do you consider the seasonal flu vaccine important did you or do you intend to receive it? Do you consider the seasonal flu vaccine important for your family?
- 4. Was receiving the H1N1 vaccine more or less convenient than the seasonal flu vaccine?
- 5. Did you seek out information regarding the H1N1 vaccine? How (phone, online sources, medical providers, news journals)? What did you want to know?
- 6. Did you receive a sufficient amount of information regarding the vaccine (such as its availability, locations to receive and safety)? What, if any, information was not readily available?
- 7. What were the best sources of information for the H1N1 vaccine? Did you find any sources of information unhelpful? If so, which ones?
- 8. Did you go to the Division of Public Health for information? Did you find them a helpful source of information?
- 9. Do you think an appropriate amount of attention was given to the H1N1 vaccine by healthcare providers and Public Health?
- 10. Did you feel an appropriate amount of attention was given to your needs in this vaccination effort?
- 11. Did you attend the mass vaccination clinics? How does this compare to receiving the vaccine from a private provider?
- 12. How would you describe the quality of the H1N1 vaccine and the vaccination efforts?

- 13. What would you change?
- 14. What would you like to see done again?
- 15. Did this experience affect the way you understand the Division of Public Health and their services? If yes, positively or negatively?
- 16. What was the biggest factor in why you did or did not receive the H1N1 vaccine?
- 17. Do you plan to receive the seasonal flu vaccine (containing the novel H1N1) in the fall? Where do you expect to receive it?
- 18. What role did you play in the H1N1 vaccination campaign?
- 19. Describe your interaction with the Division of Public Health in this mass vaccination campaign.
- 20. Did you feel that you were asked to take on appropriate roles/responsibilities in this campaign?
- 21. Did you feel your needs and abilities were taken into account in this campaign?
- 22. How did the mass vaccination campaign work with your other professional responsibilities?
- 23. If you did not participate in this campaign and were asked by clients about the vaccine, what did you tell them?
- 24. How was your overall experience in the H1N1 vaccination campaign?
- 25. What would be your ideal role in future vaccination campaigns? Do you plan to be part of the seasonal flu vaccination efforts in the fall?