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# Knowledge, Attitudes, and Behaviors of Low-Income Women considered High Priority for Receiving the Novel Influenza A (H1N1) Vaccine

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B.A. Public Health Studies Johns Hopkins University 2004

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#### Abstract

Knowledge, Attitudes, and Behaviors of Low-Income Women considered High Priority for Receiving the Novel Influenza A (H1N1) Vaccine

### By Catherine Allene Boyd

The primary purpose of this qualitative study was to explore the knowledge, attitudes, and behaviors of low-income women considered high priority for receiving the novel influenza A (H1N1) vaccine to improve communication in preparedness and response. It took advantage of existing communication frameworks through the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) to identify the factors that affect this high priority population's ability to successfully comply with vaccination recommendations and to document the systems and infrastructure needed to foster constructive responses in a sustainable manner in the future. Six focus groups with WIC clients (n=56) and 10 individual interviews with staff members were conducted at two WIC clinics in Georgia; one urban clinic in the metro-Atlanta area and one from a rural area within 90 miles of Atlanta. Data were collected after the 2009-10 influenza season and analyzed using thematic analysis. Knowledge and attitudes regarding H1N1 differed among participants with regard to perceived severity and perceived risk of influenza illness. Participants identified several barriers and motivators of receiving the vaccination, as well as information needs, sources, and information-seeking behaviors. Differences emerged between urban and rural women, as well as information between WIC clients and staff members regarding impressions of the vaccine's use or recommendation, suggesting that while the information may be provided, it is not effectively understood. The results of this study can aid in improving risk communication messages and identifying effective methods to disseminate trusted information to high priority groups. Furthermore, public health leaders can use these findings to inform comprehensive policy and planning development regarding pandemic influenza and vaccine acceptance among low-income women.

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## Chapter One

#### Introduction

#### Problem Statement

In April 2009, a novel influenza A (H1N1) virus was determined to cause influenza illness in the United States (CDC, 2009b; Garten, et al., 2009). Within weeks, this virus was transmitted in communities across North America and by June, the World Health Organization (WHO) announced uncontained community-level transmission in multiple areas throughout the world, declaring a worldwide pandemic (CDC, 2009c; WHO, 2009). Early findings suggested that global transmission of the virus was likely to persist and increase during the fall and winter in the Northern Hemisphere (Fraser, et al., 2009). Influenza vaccination is the most effective method for preventing influenza and influenza-related complications (CDC, 2010a). Therefore, the Advisory Committee on Immunization Practices (ACIP) announced a list of target groups recommended to be the first to receive influenza A (H1N1) 2009 monovalent vaccine (CDC, 2009d). Pregnant women, persons who live with or provide care for infants aged less than 6 months, and children and young adults aged 6 months to 24 years were amongst the high-priority groups identified (CDC, 2009d).

During the first six months of the pandemic, almost three-quarters of Americans responding to a survey conducted by the Harvard School of Public Health reported closely following the news regarding the novel influenza outbreaks. Yet despite this heightened awareness, less than half (46%) said the H1N1 vaccine was safe for pregnant women and only 56% reported that they felt the vaccine was safe for children aged 6 months to 2 years old. Furthermore, over half (56%) of those parents responding gave

distrust of public health officials to provide correct information about the safety of the influenza A – H1N1 vaccine as a reason for not getting children vaccinated (Blendon, Steelfisher, Benson, Weldon, & Herrmann, 2009).

Addressing effective risk communication to increase vaccine acceptance is a particularly urgent matter for pregnant women and caregivers of children. Pregnant women have an increased risk for complications from pandemic H1N1 virus infection and a high proportion (>10%) of influenza-related deaths in the United States have been in pregnant women (Jamieson, et al., 2009; Louie, Acosta, Jamieson, & Honein, 2010). Also, history has shown excess mortality amongst pregnant women in both of the previous influenza pandemics of 1918 and 1957 (Freeman & Barno, 1959; Harris, 1919). Similarly, the number of influenza-associated pediatric deaths reported to date for the 2009-2010 season is more than three times the average number reported for the past three influenza seasons (CDC, 2010b).

Breakdown in effective communication is especially true for low-income women, who have reported that their information needs for infant and self-care were not met when compared to the reports of high-income women (Sword & Watt, 2005).

Furthermore, women with lower income and education levels were less likely to seek information (Ramanadhan & Viswanath, 2006). Pregnant women with low health literacy (defined as "an individual's capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions") had more personal barriers to information seeking, such as not knowing how to use the Internet (U.S. Department of Health and Human Services, 2000; Shieh, Mays, McDaniel, & Yu, 2009).

The Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) serves low-income women who are pregnant, postpartum, and those with young children. In addition, WIC centers have a history of promoting immunization through assessment and referral in combination with other strategies that have shown to increase vaccination rates (Birkhead, Cicirello, & Talarico, 1996; Birkhead, et al., 1995; Hoekstra, et al., 1998; Hutchins, et al., 1999; Shefer, et al., 2002). Therefore, WIC provides an existing framework to create and maintain preparedness and response communication systems aimed specifically at three of the high-priority groups for H1N1 vaccination and potential future pandemics.

The primary purpose of this qualitative study was to explore the knowledge, attitudes, and behaviors of low-income women considered high priority for receiving the novel influenza A (H1N1) vaccine. Because of the nature of qualitative research, this project was not hypothesis driven; however, information from this project provided a crucial context for future planning and implementation of interventions to improve communication with identified high priority groups. It took advantage of existing communication frameworks through the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) to identify the factors that affect this high priority population's ability to successfully comply with vaccination recommendations and to document the systems and infrastructure needed to foster constructive responses in a sustainable manner in the future.

This study aimed to generate and aggregate knowledge to guide public health leadership to inform comprehensive policy and planning development regarding pandemic influenza and vaccine acceptance. The research explored the factors that

affected a community's ability to successfully respond to the H1N1 crisis. It also sought to aid in improving risk communication messages and identifying effective methods to disseminate trusted information to high priority groups. Because it leveraged an existing health system network, it allowed for the planning and implementation of these potential interventions in a sustainable manner. Furthermore, public health leaders can use information from this project to inform comprehensive policy and planning development regarding pandemic influenza and vaccine acceptance among low-income women, for which the current body of literature is scarce. The results of this study make a significant contribution to public health systems research on preparedness and emergency response capabilities, by improving communication and recommendation acceptance.

### Theoretical Framework

# The Health Belief Model

The Health Belief Model (HBM) is a value-expectancy theory developed by a group of social psychologists in the U.S. Public Health Service to explain widespread failure to people to participate in programs to prevent disease (Hochbaum 1958, Rosenstock 1974). HBM asserts that people will take action to prevent disease if they regard themselves as susceptible (perceived risk), if they believe it would have potentially serious consequences (perceived severity), if they believe that a course of action available to them would be beneficial in reducing susceptibility or severity of the condition (perceived benefits), and if they believe that the anticipated negative aspects (perceived barriers) involved in undertaking the preventative action were outweighed by its benefits. It is expected that if all of these constructs are actualized, then there will be a vastly increased likelihood that individuals will modify their behavior. Table 1 further

describes the Health Belief Model constructs and how they can be applied when endeavoring to influence behavioral change.

**Table 1: Definitions and Applications of Health Belief Model Constructs** 

Construct	Definition	Application
Perceived Susceptibility	One's opinion of chances of	Define population(s) at
	getting a condition.	risk, risk levels; personalize
		risk based on a person's
		features or behavior;
		heighten perceived
		susceptibility if too low.
Perceived Severity	One's opinion of how	Specify consequences of
	serious a condition and its	the risk and the condition.
	consequences are.	
Perceived Benefits	One's belief in the efficacy	Define action to take; how,
	of the advised action to	where, when; clarify the
	reduce risk or seriousness	positive effects to be
	of impact.	expected.
Perceived Barriers	One's opinion of the	Identify and reduce barriers
	tangible and psychological	through reassurance,
	costs of the advised action.	incentives, assistance.

(Glanz et al., 2002)

Throughout the last 50 years, summary results for HBM have provided substantial empirical support (Becker 1974, Janz and Becker 1984). Perceived barriers have shown to be the most powerful single predictors of the HBM dimensions across all studies and behaviors. Therefore, identifying these barriers can inform comprehensive policy and planning development regarding pandemic influenza and vaccine acceptance. Perceived susceptibility and perceived benefits are also important; yet perceived susceptibility was the strongest predictor of preventive health behaviors, like vaccination. For this reason, Rogers and Prentice-Dunn (1997) applied the Protection Motivation Theory which contends that the most persuasive communications are those that arouse fear while enhancing perceptions central to the HBM of the severity of an event, the likelihood of exposure to that event, and the efficacy of responses to that threat. This view of joint role

of fear and reassurance in persuasive communication is generally accepted (Glanz et al. 2002).

However, both of these models fail to adequately take into account the antecedents that affect an individual's perceptions, namely sociodemographic variables and the use of information sources. For instance, educational attainment has been identified as having an indirect effect on behavior by influencing perception (Glanz et al. 2002). Therefore, health literacy was added as an additional construct into the conceptual framework for this project as potentially moderating these dual effects. Health literacy is defined as the degree to which individuals have the capacity to obtain, process, and understand basic health information needed to make appropriate health decisions and services needed to prevent or treat illness (U.S. Department of Health and Human Services, 2000). Similarly, while Hochbaum thought readiness to take action could only be potentiated by other factors, particularly cues to instigate action, he did not study these factors empirically. Therefore, the final aim was to probe information needs, sources, communication channels, and information-seeking behavior among low-income women in order to identify the roles of media, healthcare providers, social networks, and direct experience as serving as cues to vaccination. Figure 1 is a conceptual model that shows how the Health Belief Model and additional constructs interact with one another.

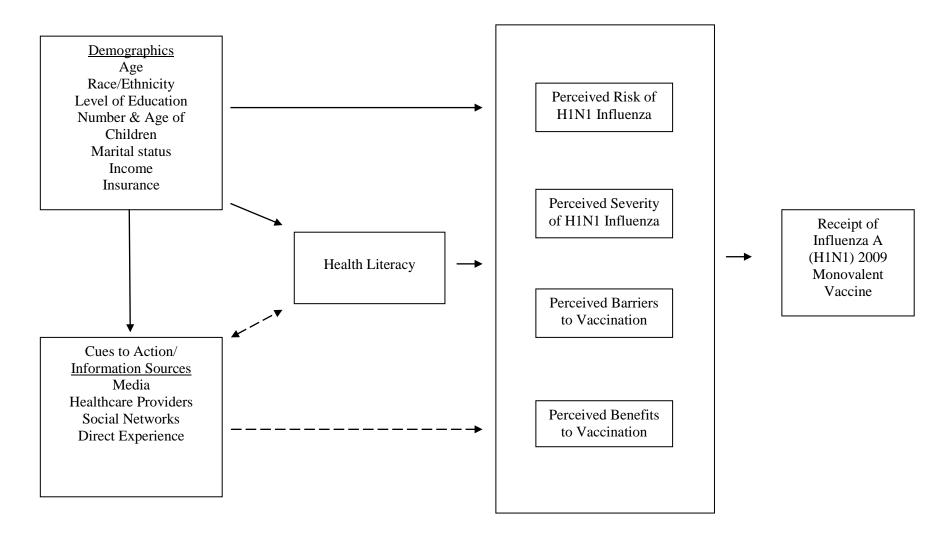


Figure 1: Proposed Conceptual Framework including Health Belief Model constructs

Purpose of the Study and Research Questions

The purpose of this study was to explore the knowledge, attitudes, and behaviors of low-income women considered high priority for receiving the novel influenza A (H1N1) vaccine. Because of the nature of qualitative research, this project was not hypothesis driven; however, information from this project provided a crucial context for future quantitative studies as well as the planning and implementation of interventions to improve communication with identified high priority groups.

The study had the following three specific aims:

- To explore knowledge and attitudes about novel influenza A (H1N1) virus in low-income women considered high priority for vaccination, particularly with regard to the perceived risk and severity of influenza, and effectiveness of the vaccine
- 2. To identify behaviors towards receipt of H1N1 vaccination, including barriers and motivators of receiving the immunization
- 3. To probe information needs, sources, communication channels, and information-seeking behavior among low-income women

### Chapter Two

#### Review of the Literature

#### Introduction

Recommendations for effective risk communication messages and dissemination methods of trusted information to high priority groups should ideally be based on a review of the published literature. Unfortunately, this was not possible. In the absence of a modern influenza pandemic, there was a dearth of information related to the systems and infrastructure needed by high priority populations to foster emergency preparedness and constructive responses in a sustainable manner. While the limited information concerning past seasonal influenza could shed some light on the response to H1N1 vaccine recommendations, data concerning the community's ability to successfully respond to the H1N1 crisis were nonexistent upon the initiation of this study. As a result, this literature review will summarize what little information is available related to seasonal influenza vaccination decision-making among women.

### Seasonal Influenza Vaccination

Several studies have shown that maternal seasonal influenza vaccination has not been associated with reports of significant adverse vaccine reactions, delivery complications, or poor fetal and infant outcomes (Black, et al., 2004; Deinard & Ogburn, 1981; Heinonen, et al., 1973; Mak, Mangtani, Leese, Watson, & Pfeifer, 2008; Munoz, et al., 2005; Yeager, Toy, & Baker, 1999). Furthermore, from an economic perspective, ongoing efforts to optimize maternal influenza immunization during pregnancy are found to be highly cost effective interventions at disease rates and severities that correspond to both seasonal influenza epidemics and occasional pandemics (Beigi, Wiringa, Bailey,

Assi, & Lee, 2009). As a result, since 2004, both the ACIP and the American College of Obstetricians and Gynecologists (ACOG) Committee on Obstetric Practice have recommended that all pregnant women during influenza season receive the inactivated vaccine, regardless of the trimester (Fiore, et al., 2008). Yet, despite acceptance within the professional health community in regards to its overall safety and public advisories, seasonal influenza vaccination remains low, with 13% of pregnant women in the United States reporting receiving the vaccination during the 2006-2007 season (Fiore, et al., 2008).

## Vaccine Decision-Making

The Pregnancy Risk Assessment Monitoring System (PRAMS) which collects data annually from approximately 30,000 women with live births in 31 states should provide more precise information regarding vaccination decision-making. Yet, it is important to note that the seven major pregnancy health topics identified as having the greatest impact on pregnancy and infant outcomes: prenatal smoking, alcohol and drug use, nutrition, vitamin supplements, prenatal weight gain, and breastfeeding, do not include vaccination as an area of population surveillance and research (Shieh, McDaniel, & Ke, 2009). Therefore, while the influenza vaccination questions were asked in 2000, only one state (Rhode Island) used questions on this topic from 2000-2003 and two states (Rhode Island and Georgia) used these questions from 2004-2008 (CDC, 2009a). Thus, currently available PRAMS data might not be generalized to all women in the United States and there is a dearth of information exploring the knowledge, attitudes, and behaviors among low-income women regarding influenza vaccination.

#### Barriers to Vaccination

The Georgia PRAMS surveys conducted between 2004 and 2007 included a follow-up question for women who reported not being vaccinated against seasonal influenza to assess their reasons. The question included was, "What were your reasons for not getting a flu vaccination during your most recent pregnancy?" Respondents were provided with a list of reasons with a choice of yes/no response and "other" with an openended response option. Previous vaccination history, provider advice, and perceptions of safety were among the reasons unvaccinated women cited for not getting the influenza vaccine. The top reasons cited were "I don't normally get the flu vaccination" (69.4%) and "my physician did not mention anything about a flu vaccine during my pregnancy" (44.5%). Twenty-eight percent were worried about the safety of the influenza vaccine for their infant and 27.1% were worried about the safety for themselves (CDC, 2009a). Misinformation regarding the severity of seasonal influenza among pregnant women and concerns about vaccine safety have been major barriers to vaccination in the past. A previous study has shown that almost 90% of pregnant women believed that they have the same risk of complications due to influenza as non-pregnant women and only half reported awareness of the national recommendations for vaccination during pregnancy (Yudin, Salaripour, & Sgro, 2009). Similarly, 80% of pregnant women incorrectly believed it could cause birth defects (Yudin, et al., 2009).

### Patient- Provider Communication

The Rhode Island PRAMS surveys included a question on provider advice, "At any time during your pregnancy, did a doctor, nurse, or other health-care worker offer you a flu vaccination or tell you to get one?" In 2007, among respondents who reported

receiving vaccination advice from a health-care provider, the prevalence of those who also were vaccinated was 65.7%. Conversely, among women who did not report receiving advice from their health-care provider about influenza vaccine, only 4.6% reported receiving the immunization (CDC, 2009a). Similarly, a study showed that although 70% of women reported wanting information about vaccines during pregnancy, only 18% reported receiving such information during prenatal care (Wu, et al., 2008). A limitation of these findings on provider recommendations was that it was assessed by maternal self-report. One study, suggested there was a significant discrepancy reported between patients' and physicians' impressions of whether the vaccine's use or recommendation was even discussed during an office visit (22% of patients vs. 74% of physicians), suggesting that while the information may be provided, it is not effectively understood by the patient (Silverman & Greif, 2001). There is some evidence that this lack of knowledge is due in part to ineffective communication.

As previously discussed, breakdown in effective communication is especially true for low-income women, who have reported that their information needs for infant and self-care were not met when compared to the reports of high-income women (Sword & Watt, 2005). Furthermore, women with lower income and education levels were less likely to seek information (Ramanadhan & Viswanath, 2006). Thus, the primary purpose of this qualitative study was to explore the knowledge, attitudes, and behaviors of low-income women considered high priority for receiving the novel influenza A (H1N1) vaccine, while probing for information needs, sources, communication channels, and information-seeking behavior to identify the roles of media, healthcare providers, social networks, and direct experience as serving as cues to vaccination.

## Chapter Three

## Methodology

#### Introduction

This research was a qualitative study using focus group discussions and one-on-one interviews. Grant funding was provided by the CDC through the Emory Preparedness and Emergency Response Research Center (Emory PERRC) and support was gained from the Georgia Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) office to conduct this pilot study. Letters of support were obtained for one clinic selected from the metro-Atlanta area (Fulton County Health Department - College Park), and another chosen from a rural area within 90 miles of Atlanta (Talbot County Health Department). Female WIC clients and staff members were recruited for this study at these two WIC clinics. Three focus groups were conducted in the participating urban clinic and three from the rural clinic with the WIC clients, while individual interviews were conducted with members of the clinic staff during normal operating hours. This study received Exempt approval from Emory University's Institutional Review Board.

### Focus Group Participants

WIC participants were recruited to participate in the six focus group discussions while they are attending the WIC clinics. Between 12-15 WIC clients were recruited for each focus group, anticipating that between 8-10 would attend the discussions with a target of 60 total participants. To be eligible to participate, the women must have been (1) 18 years or older (2) fluent in spoken English (3) enrolled in the Special Supplemental

Nutrition Program for Women, Infants, and Children (4) reside in Georgia (5) pregnant, postpartum, or caregiver of young children, and (6) provide written informed consent.

The recruitment materials specified that participants would receive reimbursement for their time in the form of \$30 as well as a healthy meal during the group discussion.

Building on approaches used successfully in the past, the WIC clinic staff aided in recruiting participants for the focus groups. Based on their advice, recruitment strategies varied greatly between the rural and urban clinic sites with different levels of success.

#### Rural Recruitment

Despite active referrals by the WIC staff in the rural clinic, it was discovered that the traditional approach to participant recruitment through flyers (Appendix A) and direct contact with WIC clients while waiting for clinic services would not be adequate due to low patient flow. Also, requiring participants to return on a different date to attend a focus group was not feasible for this population. Therefore, following the guidance of the local WIC clinic staff, all three focus groups were scheduled for the day of the annual Farmer's Market due to historically high attendance at this one day event. Following their advice, there was a tremendous amount of success recruiting eligible women to participate on the day of the focus groups through direct contact and postcard distribution (Appendix B). The women were enthusiastic about signing up to participate and recruited other women through word of mouth and telephone calls. Phone calls (Appendix C) and reminder cards and were provided to the pre-registered participants.

### Urban Recruitment

In the urban clinic, direct recruitment in the clinic waiting rooms was not permitted. However, the WIC clinic staff supported the study by allowing flyers to be

posted with a telephone contact number and permitting announcements and postcard distribution during mandatory nutrition education classes (Appendix D). Eligible women were then required to call the contact number provided on the flyer or postcard (Appendix E) or pre-register for a focus group in-person following the nutrition education class. Study participants were evenly distributed between the two methods of recruitment. Reminder cards, phone calls, and text messages were provided to the pre-registered participants. The focus groups were conducted over two days. While a Farmer's Market was occurring at the clinic during the second day that the groups were being conducted, this was not used for recruitment as women were previously registered to attend the focus group held that day.

# Focus Group Procedure

Individuals who meet the criteria for inclusion into this study were asked to participate in a focus group discussion. All focus groups were scheduled for  $1\frac{1}{2}$  to 2 hours. Originally, the intent was to stratify the focus groups by vaccination status. Stratification was possible at the urban clinic with two homogenous groups (vaccinated and unvaccinated), as well as a third heterogeneous group. However, the recruitment experience in the rural clinic site indicated that too few women received the vaccine; therefore, this type of stratification was not possible in that clinic.

Before the start of the focus group discussions, all participants provided written informed consent (Appendix F) and HIPPA authorization for the use of protected health information for the purpose of this research study (Appendix G). All participants were then asked to complete a short questionnaire (Appendix H). The semi-structured group discussions were facilitated by an Emory University faculty member using a flip chart

and supported by extensive notes taken by laptop during the discussions. The sessions were also audio-recorded.

# Focus Group Measures

The questionnaire was comprised of closed-response options to record demographic characteristics, vaccination status, as well as three questions to assess health literacy based on the work of Chew and colleagues (2009) (Appendix H). A focus group guide was developed by the research team and reviewed by the WIC collaborators (Appendix I).

### Focus Group Analysis

Data collected from the questionnaires were entered into SAS 9.2 for Windows. All electronic data was de-identified and password protected. Descriptive statistics were generated for the demographic characteristics of the participants. Recordings from each focus group were transcribed verbatim and augmented by the notes taken. Data analysis was conducted using MAXQDA software, which facilitated the processes of data retrieval and reduction necessary for the analysis of large volumes of textual data including advanced data searching and reporting functions. The data analysis proceeded in two phases. First, there was a preliminary analysis relying predominantly on a set of deductive codes representing the initial objectives of the study. This was followed by an in-depth analysis based on the emergence of key inductive themes, or concepts identified by the participants themselves as being important. Data were coded separately by two independent coders, who found consensus with the key themes to be identified, to assure 100% inter-rater reliability. If consensus was not found, a third researcher was consulted.

## Interview Participants

WIC staff members were recruited by direct contact to participate in individual interviews during their normal working hours at the two WIC clinics. Upon approach, the participants were notified that they would not receive reimbursement for their time. To be eligible to participate, the women must have been (1) 18 years or older (2) fluent in spoken English (3) employed by the Special Supplemental Nutrition Program for Women, Infants, and Children (4) reside in Georgia, and (5) provide written informed consent. All eligible staff members agreed to participate and individual interviews were conducted with the WIC staff members present on the day of the interviews including nutritionists, health associates, and one nurse director.

#### Interview Procedures

Before the start of the interview, all participants provided written informed consent (Appendix J) and HIPPA authorization for the use of protected health information for the purpose of this research study (Appendix G). All participants were then asked to complete the same short questionnaire that the focus group participants were asked to complete (Appendix H). The semi-structured interviews were conducted in a private office space. The sessions were audio recorded and supported by notes taken. *Interview Measures* 

The questionnaire was comprised of closed-response options to record demographic characteristics, vaccination status, as well as three questions to assess health literacy based on the work of Chew and colleagues (2009) (Appendix H). An interview guide was developed by the research team and reviewed by the WIC collaborators (Appendix K).

### Interview Analysis

Data collected from the questionnaires were entered into SAS 9.2 for Windows. All electronic data was de-identified and password protected. Descriptive statistics were generated for the demographic characteristics of the participants. Recordings from each interview were transcribed verbatim and augmented by the notes taken. Data analysis was conducted using MAXQDA software, which facilitated the processes of data retrieval and reduction necessary for the analysis of large volumes of textual data including advanced data searching and reporting functions. The data analysis proceeded in two phases. First, there was a preliminary analysis relying predominantly on a set of deductive codes representing the initial objectives of the study. This was followed by an in-depth analysis based on the emergence of key inductive themes, or concepts identified by the participants themselves as being important. Data were coded separately by two independent coders, who found consensus with the key themes to be identified, to assure 100% inter-rater reliability. If consensus was not found, a third researcher was consulted.

### Chapter Four

#### Results

Study Population

A total of 56 active WIC clients completed questionnaires and participated in one of six focus group discussions, ranging in size from 6-12 clients per group. A total of 30 women participated in the rural focus groups and 26 women participated in the urban focus groups. Generally, the participants in both clinics were similar in terms of key demographic variables, including age, race/ethnicity, marital status, educational attainment, employment status. Overall, the women ranged in ages from 18 to 57. On average, the participants from the urban clinic were slightly older than those in from the rural clinic (Rural Median Age=23, Urban Median Age=25). All of the participants in the rural clinic identified as being Black/African-American, while the participants at the urban clinic had a higher degree of racial/ethnic diversity, including women that identified as being White/Caucasian (4%), Hispanic/Latina (4%), and Other (4%). Most of the women had never been married, with the highest proportion (80%) in the rural clinic. A majority of the women were at least high school graduates (Rural=93%, Urban=88%). Yet, there were a greater percentage of participants in the urban clinic with higher levels of educational attainment (Rural=48%, Urban=58%). Furthermore, a higher percentage of women in the urban clinic identified as being current students (Rural=17%, Urban=27%). Finally, in both clinics large proportions of women reported not currently being employed with the highest value (47%) at the rural site. Table 2 summarizes the demographic characteristics of the focus group participants by clinic location.

**Table 2: Focus Group Participants Demographic Data** 

Table 2. Pocus Group Farticipal	Rural	Urban
	(n=30)	(n=26)
1	( /	7
Age	18-57, Median = 23	18-51, Median = 25
	,	,
Race Ethnicity		
Black/African American	100%	88%
White/Caucasian	0%	4%
Hispanic/Latina	0%	4%
Other	0%	4%
Marital Status		
Never Been Married	80%	69%
Married/Living with Partner	17%	15%
Separated	3%	4%
Divorced	0%	12%
77.		
Education	70/	120/
Less than high school	7%	12%
High School Graduates	55%	31%
Some College, Trade School	31%	46%
College Graduates	7%	8%
Post Graduate	0%	4%
Employment Status		T
Working Full-Time	17%	19%*
Working Part-Time	17%	23%*
Currently Not Working	47%	35%*
Disabled	3%	8%*
Student	17%	27%*

<sup>\*</sup>Does not total 100% because categories were not mutually exclusive

Due to low overall vaccination rates, vaccinators were considered women or their child(ren) vaccinated for H1N1, while non-vaccinators applied to women and their child(ren) not vaccinated for H1N1. Upon analysis, it was discovered that although each woman answered questions related to H1N1 vaccination status at registration to appropriately assign her to a focus group, the homogenous groups at the urban clinic did not appear to be as pure as expected, as some women responded differently to the question regarding vaccination status on the preliminary screener and the questionnaire administered the day of the focus groups. This inability to reliably determine if they or their child(ren) were vaccinated for H1N1 was the first indication to emerge from the data related to misunderstandings these women had about H1N1 and the vaccine. Table 3 below summarizes priority group membership and vaccination status of the focus group participants by clinic location, based on the results of the questionnaire.

**Table 3: Focus Group Participants Priority Group & Vaccination Status** 

Table 3: Focus Group Participants Priority Group & Vaccination Status		
	Rural	Urban
	(n=30)	(n=26)
Priority Group Membership		
Pregnant (with first child)	13% (25%)	23% (50%)
Postpartum (with first child)	20% (50%)	23% (50%)
Caregiver of Young Children	97%	96%
Number of children	1-4, Median = 2	1-4, Median = 2
Vaccination Status*		
H1N1 - Self	3%	15%
H1N1 - Child(ren)	23%	35%
Seasonal Flu - Self	13%	27%
Seasonal Flu - Child(ren)	40%	42%
No Vaccination - Self	87%	73%
No Vaccination – Child(ren)	60%	58%

<sup>\*</sup>Does not total 100% because categories were not mutually exclusive

Health literacy was assessed using a three-item subjective self report scale based on the work of Chew and colleagues (2009). In general, most of the participants rated themselves highly in their abilities to independently fill out medical forms (84-87%), read hospital materials (73-90%), and understand written information to learn about their medical conditions (80-84%). Overall, the rural WIC clinic participants tended to rate themselves higher in these areas. Table 4 summarizes the self-reported subjective measures of health literacy of the focus group participants by clinic location.

Table 4: Focus Group Participants Self-Reported Health Literacy

Table 4: Focus Group Participants Self-Reported Health Literacy		
	Rural	Urban
	(n=30)	(n=26)
How confident are you filling o	out medical forms by yourself	?
Extremely	67%	62%
Quite a bit	20%	12%
Somewhat	7%	23%
A little bit	0%	4%
Not at all	7%	0%
	•	
How often do you have someon	ne help you read hospital mat	erials?
None of the time	83%	50%
A little of the time	7%	23%
Some of the time	7%	19%
Most of the time	3%	0%
All of the time	0%	8%
How often do you have problem	ns learning about your medi	cal condition because of
difficulty understanding writte	en information?	
None of the time	70%	46%
A little of the time	10%	38%
Some of the time	13%	15%
Most of the time	7%	0%
All of the time	0%	0%

Individual interviews were conducted with 10 WIC staff members (7 urban and 3 rural) including nutritionists, health associates, and one nurse director. The staff members were similar to the WIC clients in terms of race/ethnicity, but differed in terms of age, marital status, education, and employment status. In general, staff members tended to be older, with a higher proportion married, completing higher levels of education and all employed on a full-time basis. Table 5 summarizes the demographic characteristics of the interview participants.

**Table 5: Staff Interview Participants Demographic Data** 

WIC Clinic Staff		
Age	25-56, Median = 39.5	
Race Ethnicity		
Black/African American	80%	
White/Caucasian	20%	
Marital Status		
Never Been Married	40%	
Married/Living with Partner	50%	
Divorced	10%	
Education		
Some College, Trade School	20%	
College Graduates	60%	
Post Graduate	20%	
<b>Employment Status</b>		
Health Associate	50%	
Nutritionist	40%	
Nurse Director	10%	

As healthcare professionals interacting with clients on a daily basis in a healthcare facility, the WIC clinic staff members were among those recommended to be the first to receive the H1N1 vaccine. Furthermore, 80% were caregivers of young children, identifying them as influencing the vaccination status of another high priority group; children between the ages of 6 months to 24 years of age. Preliminary analysis of the staff questionnaires revealed some differences between the urban and rural clinics related to vaccination status. While none of the WIC clinic staff at the urban clinic had been vaccinated for neither H1N1 nor the seasonal flu, all of the rural WIC clinic staff had been vaccinated for the seasonal flu with their director also receiving the H1N1 vaccination. Furthermore, of the rural WIC clinic staff with children (n=2), 50% vaccinated their children against H1N1 and 100% vaccinated their children against seasonal flu; while of the urban staff with children (n=6) only 33% vaccinated their children against H1N1 and the seasonal flu. Upon review of the interview data, these two staff members both had children with chronic health conditions and received the vaccine only following a recommendation by their primary care physician. Table 6 summarizes the vaccination status of the staff interview participants by clinic location.

**Table 6: Staff Interview Participants Vaccination Status** 

	Rural	Urban
	(n=3)	(n=7)
Vaccination Status*		
H1N1 - Self	33%	0%
H1N1 - Child(ren)	50%	33%
Seasonal Flu - Self	100%	0%
Seasonal Flu - Child(ren)	100%	33%

<sup>\*</sup>Does not total 100% because categories were not mutually exclusive

## Knowledge and Attitudes about H1N1

The first aim was to elicit the knowledge and attitudes of the WIC participants with regard to novel influenza A (H1N1), particularly perceived severity and risk of illness.

### Perceived Severity

All of the focus group and interview participants stated that H1N1 influenza was a serious illness, closely associated with death. When asked how they would feel if a member of their family was diagnosed with the illness, they agreed that they would be very concerned and one participant added that the individual was "probably going to die". There was broad consensus that the news portrayed death as a certainty. One participant reported, "the media was killing everybody off! Saying if you got it, you were going to die. Basically, dead from the get-go!"

However, participants also thought that there was a level of unnecessary panic. In the words of one focus group member:

"Like everybody thought 'Oh they coughin', they go swine flu. Oh!' You know every time somebody got sick it was like they wanted to say it was swine flu. So I think it like, created an unnecessary panic among people."

Consistent comments were that the media generally over-broadcasts warnings, proliferating unfounded fears. One participated said, "I mean because you hear every day, every time you hear something. This is coming out. This is happening. It's never as big as the media makes it." Specifically with regard to H1N1, another participant reported, "I don't think it was nearly as bad as they say it was. It may have been. I just don't think it was really, 'cause only like a handful of people died, so really." The overall sentiment of the women was that H1N1 was not as severe as initially portrayed.

### H1N1 versus Seasonal Influenza

Other consistent comments compared H1N1 to seasonal influenza in terms of severity. Yet, participants also expressed a great deal of confusion relating H1N1 to the seasonal flu. One participant stated:

"See that's the part that I did not understand. Because it was like it was the same. So how can you tell whether it was the swine or just the seasonal flu? Aren't the symptoms the same? Are the symptoms, like, are they very close by each other?"

Another participant said, "I think the flu, the seasonal flu, was actually worse than the H1N1 but they were just making a bigger deal about the H1N1."

### Perceived Risk

Most participants agreed that they did not feel personally at risk for developing H1N1 influenza. While there was broad array of ideas regarding the modes of transmission, many participants (especially in the rural clinic) expressed a failure to view H1N1 as a local threat and suggested preventative actions they took to protect themselves against infection, while others adopted a more fatalistic view.

### Transmission

All of the focus groups generated lists of the potential modes of transmission. The most common responses involved close contact/touching and inhalation. The participants seemed to recognize that H1N1 could spread throughout a family or community and suggested avoiding handshaking, as well as quarantining sick individuals and avoiding them until they were better. Three of the focus groups suggested transmission through eating and drinking, specifically mentioning that many people did not want to eat pork anymore. One participant also mentioned that she thought it could be transmitted through a swimming pool.

### **Proximity**

Many of the participants' perception of risk was influenced by the role of geography and their personal proximity to cases. Particularly in the rural clinic, all of the focus groups discussed dealing with the reports of a case in one of two nearby cities. One participant mentioned, "I work in LaGrange and allegedly there was a case in LaGrange and so everybody in LaGrange was walking around with masks." Another participant mentioned, "but like when they said it was in Columbus, everybody went to panicking." Yet, the majority felt safe, because best summarized in the words of one participant "there wasn't that many cases down this way."

Another key issue that was discussed was desire to avoid traveling and travelers. One participant suggested that individuals increased their risk of illness by "going to the different countries and stuff." One participant spoke from her personal experience that she avoided hugging a cousin, a soldier returning home from Iraq, for fear of contagion. However, this heightened sense of risk was not limited to recent travelers and extended to immigrants and those of Hispanic ethnicity. As one participated stated, "You don't think it will get here, maybe if they kept them people over there where they at." Going further, one participant asked "wasn't the high risk the Hispanic groups?" Another participant added "in school shots, the Hispanics don't have shot records, they don't have to," suggesting that they were somehow to blame. As one participant stated, the general consensus among the groups was that "there wasn't that many cases in Georgia. There wasn't that many, but it was here."

#### Prevention

In light of cases within their community, participants appeared to be divided on the issue of prevention. Many participants listed off actions taken to protect themselves and their loved ones against infection to reduce the threat of disease. These included using hand sanitizer, hand-washing, coughing into the arm of a sleeve, staying in the house, keep socks or house shoes on, taking vitamins, taking cold medication ("even when they ain't sick, just to keep from getting it"), not sharing bathrooms or phones, wearing masks, drinking fluids, wearing gloves, and scrubbing with Lysol and Clorox. Yet, not all of the participants in the groups agreed, as there were also contradicting messages as some women advocated for increasing their number of doctors' visits while others advised against this practice, instead suggesting that it was better to decrease visits to the doctor to prevent exposure. When asked about the risk of H1N1, one participant stated, "It didn't bother me. We alright. And I mean, I eat right so I guess just continue doing, you know, eat right, be fit, you know, follow your basic things, the necessities of life."

### **Fatalism**

Not all participants agreed with the prevention mentality toward mitigating risk.

Rather, one said, "I don't think you can prevent it. You're either going to get it or you're not." There were participants within each group that adopted a similar fatalistic mentality suggesting that everyone dies of something. Another participant stated, "I mean if they was gonna get it, they was gonna get it. God planned for them to go." "I mean, if it was gonna be my time. It was gonna be my time," agreed yet another. When

asked what could be done for, the general consensus among this subgroup was to hope and pray. "That's all you can do, pray," summarized one individual.

Behaviors toward Receipt of H1N1 Vaccination

The second aim was to identify factors that low-income women believe to be important when making decisions regarding vaccination, including motivators and barriers toward receiving the vaccine.

#### Motivators to Vaccination

All of the participants discussed motivating factors toward vaccination. Not all agreed that vaccination could prevent disease. However, among those that did, they sighted reasons including difficulties associated with illness including missing work, the financial costs of being sick, and the burden of taking trips to the doctor or hospital and encountering long lines and wait times. These same participants suggested that vaccination helped maintain a healthy body and most notably aided in avoiding death, as one woman asserted "you could die, anything could happen" from failing to be vaccinated.

There was also a large contingent of participants that were less optimistic about the motivation behind receiving vaccinations. Rather, they cited vaccination as compulsory. Many participants suggested that they felt coerced to vaccinate their children by simply explaining they "had to". As one participant articulated "Your kids can't go to school. You have to be vaccinated to go to public school." Other participants said that they were motivated by their supervisors to get vaccinated when clinics were offered on the job site. One participant in particular suggested an encounter with H1N1 that motivated her to become vaccinated. She said, "I worked with the school system and

there was a case. The child mother's came to school sick. They closed one room and sprayed the classroom down with Lysol. We had to take the H1N1 shot after that.

Required."

Influential people were also cited as motivators toward vaccination. Of the vaccinated, many had received recommendations from their healthcare providers. Five of the six groups generated lists of people that encouraged them to become vaccinated, including doctors, nurses, family members, and the media. One group spoke quite extensively with differing opinions about the role of celebrities. When one participant suggested that "President Barack said okay, chill out", downplaying the threat of disease, another countered that "you know he got it (the vaccination)" and followed with "I listen to Barack". This initiated a conversation within the group about the role of famous people influencing health behaviors. One participants suggested that it had been a successful tactic in regards to HIV prevention and testing saying, "you'd be surprised how many people get out to the clinics with their partners because of Puff Daddy." The participants agreed that certain people appeal to different groups, suggesting that while older people may listen to the President, it would require Lil Wayne saying "swine flu killing folks" for young people to listen. Yet, with the swine flu, most of the participants agreed that people did not care enough one way or the other. As one participant stated, "We all watch TV. They do have certain people, but I'm still on the fence."

Another source of motivation identified by the participants was the need to protect their children. Some of the participants seemed to understand that children were disproportionately affected by H1N1. One woman said, "and they was sayin' it's harder to treat in pregnant women and young children and that's why it was encouraged that the

pregnant women and young children and older people were the ones to first get the vaccination." This was echoed in consistent statements among the vaccinators. However, this motivation did not extend toward vaccinating the women themselves to prevent transmission. As one participant articulated, "I'm all for my son getting his necessary shots, but I'm not going to get it!" From these discussions a theme of maternal sacrifice also emerged that valued child welfare over the women's well-being. One woman explained, "I'd rather get him taken care of than me. Because he's younger and he gets sicker, faster than I do. So I would rather get him situated so he wouldn't have to be sick."

#### Barriers to Vaccination

All of the participants discussed barriers toward vaccination. The obstacles most frequently and extensively discussed included the side effects of injection and lack of information. Specifically non-vaccinators cited difficulties with access, including cost and transportation. Other hurdles mentioned, by some but not all of the groups, were natural immunity, religion, and conspiracy theories.

#### Side Effects

Side effects were discussed in terms of perceived barriers to vaccination among all participants. For some, it was simply the fear of needles and pain associated with an injection that prevented women from receiving the vaccine. Others cited the potential for allergic reactions and the body rejecting the vaccine. Some women suggested that children were not vaccinated because a lot of kids get sick with their other vaccinations and mothers may want to avoid the potential for fever.

All groups specifically mentioned the association between vaccination and adverse affects as portrayed in the media. The groups seemed to be aware of a popular opinion of the connection between vaccination and autism. Specifically one participant recounted:

"Usually a vaccination prevents you from getting sick, but here we go back to the media again. When they talk about you have to get your child vaccinated, but then why do they broadcast... what's her name? Is her name Holly Robinson Peete? She found out her son had autism and she was saying that she believed that if she had not had her son vaccinated that he would not have autism."

Participants in four of the groups (including all three in the rural clinic) specifically mentioned a news clip that went viral on the Internet site YouTube, showing an attractive young cheerleader presumably suffering from the affects of the H1N1 vaccination. In one woman's words:

"I seen on TV where it messed this one woman up. She got a shot. She couldn't walk straight forward, but could walk backwards. When she tried to walk forward, she started messing up."

While some participants argued that this was a hoax, others seemed less sure.

Finally, another barrier associated with side effects was the misunderstanding many of the women expressed that the vaccine could actually cause the flu. One participant shared her personal experience, relating "the one year I did get the seasonal flu vaccination, I got REAL sick, with the flu. The first and only time I took one, that's what happened, so I haven't had a vaccination since." While not all of the participants had this personal experience, most agreed with the participant that said, "I know someone that got the flu shot and got the flu. Never been sick before. Made me not want to take the shot."

#### Access

Among non-vaccinators, access was cited as a hurdle to vaccination. Despite both clinics offering the H1N1 vaccine for free, participants made comments that it did not fit into their budgets. One participant suggested "That's probably why a lot of people didn't get the vaccination because of their income." She went on to explain that "yearly vaccinations, when the kids go back to school, those are included in my insurance, but I don't have any insurance or money to pay for it (the H1N1 vaccine)."

Specific to the urban clinic were complaints about vaccine availability. One participant complained "There was a long line. I wasn't going to make an appointment." This sentiment was shared by another women who asserted:

"I was scared, but I was kinda pissed off too. They weren't making it available. They were saying 'everybody needs to run out and get it. I came here to get it. Called back week after week and they didn't have it."

She went further to argue that the lack of availability was unique to her community:

"Certain communities get certain things. You go out past 400 in Alpharetta, everybody got the shots. Anything you want. The people here with their nasty attitudes when you go in there for WIC vouchers. This community, we don't get together and speak up."

#### *Recommendations*

The participants reported that provider recommendations fell across a wide continuum. Some of the participants felt like it was the nurses' and doctors' job to suggest the vaccine despite their reservations. While recommendations served as a motivator to vaccinators, conversely, the lack of such recommendations was a barrier. A few women mentioned that their doctors encouraged them to think about it, without offering an explicit recommendation. While women in each of the focus groups stated

that they did not talk about it with their providers, because their doctors did not mention it. Others went further to suggest that their doctors warned against the vaccine "off the record."

Participants in three of the focus groups also mentioned that friends and family suggested that they not get vaccinated. One participant stated that on her way to attending that day's focus group, "my momma told me today, if they try to give you a shot, don't get it." Another woman echoed this sentiment of the desire to follow her mother's advice sharing that "my momma don't believe in getting no kind of shots. She don't take no medications. My momma told me not to get the flu shot, she don't believe in doctors." Despite these warnings, most of the women agreed that the influence of the recommendations were limited. As one women suggested, "it depends if you want to get it. They just reinforce your attitude."

#### Lack of Information

Many of the previously reported barriers were the result of a lack of information on the part of the women, which was consistently and explicitly stated by the participants. Even in the light of the knowledge that the vaccine was free, one participant countered, "even if the H1N1 shot was free, I still wouldn't have taken it, nor let my kids take it, because I didn't know anything about it. So whether it being free or not, I wouldn't take the shot." While another simply stated, "I didn't have enough facts on it. I'm sorry." The "newness" of the vaccine and the lack of research were continually referenced as impediments toward vaccination. A skeptical participant explained, "I was kinda weird with myself anyway cause they hadn't said anything about they had any test subjects or anything. They just said they had a swine flu. This is the vaccination. Go get it."

#### Information

When asked what information women needed to be better informed to overcome the barriers toward vaccination, participants summed it up with two phrases "the basics" and "the whole thing". To shed more light on this nebulous lack of information, the final aim of this study was to probe for information needs, sources, and information-seeking behavior among low-income women to help identify communication channels to disseminate trusted messages.

#### Information Needs

In each of the focus groups, women were curious to answer the same questions, including: "Where did it come from?", "How could you get it?", "How could you avoid it?", "What were the symptoms?", "How was it different from the seasonal flu?", "Who should get the vaccine?", and "How could you get rid of it?". Yet most notably was the question "What is really going on?" articulating the seemingly universal concern by the women for consistent, trusted information.

#### Information Sources/Communication Channels

All of the focus groups brainstormed a list of sources they accessed to gain information on H1N1. The findings are summarized in Table 7.

**Table 7: Identified H1N1 Information Sources** 

Categories	Source
Media	TV
	Radio
	Newspaper
	Internet
	Flyers
	Pamphlets
	Signs/Billboards
Healthcare Professionals	Primary Care Providers
	Doctors
	Nurses
	Midwives
	CDC - "Disease control 800 number"
	"That lady that came for a workshop at work"
Healthcare Facilities	Doctor's Offices/Primary Care
	Health Department
	Drug Store
	Hospitals
	Nursing Homes
	Prenatal Clinic
	Health Fairs
Other Facilities	Schools
	Workplace
	Restaurants
	Grocery Stores
	Insurance Company
	DFCS
	Identity program ("for people without insurance")
Personal Contacts	Friends
	Family
	"The community"
	"The older heads in the family"
	"Your peers"
	"Dr. Jesus"
	"Customers that got the shot"

Information Seeking-Behavior

Finally, information-seeking behavior was assessed to identify how women accessed information from these sources.

With regards to the media, the participants expressed an initial concern and fascination with the outbreak. One participant said, "people just sat there to wait on the news to come on to talk about it." Many suggested that it sparked questions and conversation. One woman said that it prompted her to call her children's doctors office and talk to the nurse, while another reported, "I know I asked, I asked, someone, I don't know who I asked. I asked, how they think they got it. How do you think the swine flu started? Somebody told me it came from a monkey and I was like 'What?'". In addition to consulting friends in person, several women went online to see what everybody else had to say about it. Yet, some women expressed frustration over their ability to find accurate information. One participant complained "I mean... they just don't get straight to the point and give it to you. They give you bits and pieces. You have to do your own research and find out on your own."

This initial curiosity eventually waned and the women shared a mutual exhaustion over what they perceived to be the oversaturation of messages inducing fear. As a result many adopted an attitude of avoidance. One participant stated, "I just turned it. Cause it was the same thing, every day." Another admitted "I listened to some of it, but when they got like 'people dying everyday... ya'll need', I be like man these folk need to go. I just changed the channel."

Going beyond the media, the women identified different behaviors associated with different information sources, as the women were generally less inclined to seek information from their providers compared to their personal contacts. While many of the women reported asking their friends and family for advice related to the vaccine, they did not report engaging in similar conversation with their healthcare providers. Rather, they deferred to their providers to initiate the conversation. For example, one participant said:

"There wasn't any research and my OB never suggested it. So I asked a couple people that were pregnant and they was like, no, no. And I asked my mom and she was like no. And he (the OB) never mentioned it, AT ALL. So I'm like, it must be something like we really don't need."

When asked to suggest ways that consistent information could be communicated, one participant in the rural clinic offered multiple suggestions specific to her community. She said:

"We got a health department, but they don't tell you enough. You gotta ask questions. Having workshops around here, places we can go to learn, people can't travel to Columbus, once a week. You got the school right there, they should come in and do seminars with the kids, teachers, and parents. Churches. People need to start coming this way, doing workshops. etc. We don't hear about it on the news, you don't hear about. If someone is in Atlanta they might bring it (the information) back. Make it more local. They always go to Columbus, LaGrange. Have focus groups. Get the community involved."

Similarly in the urban clinic it was suggested to begin having a social group, described as "You know, like, an information session, I guess, where a bunch of people gather around and talk about the issue with a professional."

Specific to the urban clinic was the suggestion that they provide vaccination messages while waiting for WIC services. Yet, a key theme that emerged specifically from the interview data was related to the disconnect within the facility infrastructure that

separates WIC from that of the general clinic services, including vaccination. As a federally funded program, with a district-level management structure, WIC operates independently of the rest of the clinic operations, despite being located with the same facility. In the staff interviews, it became evident that there are "invisible walls" barricading the WIC clinic staff from the other health promotion efforts being undertaken. Across interviews, the staff shared the same lack of information as the clients regarding H1N1 and the vaccine.

#### Chapter Five

#### Discussion

#### Knowledge and Attitudes about H1N1

Across focus groups and interviews, the participants agreed that H1N1 was a serious illness, in most cases associated with death. Yet, there was a consensus that the panic created was in large part unnecessary, as few people actually died from the disease and individuals did not feel as personal risk. In retrospect, there was a general perception that the media fueled by public health officials inherently "cried wolf", exaggerating both the severity and risk of disease. Ultimately, this created a greater barrier of distrust to overcome in mobilizing emergency response through risk communication in the future. Behaviors toward Receipt of H1N1 Vaccination

Given the extremely low vaccination rates among the WIC clients and staff alike, it seemed likely that both the quantity and quality of barriers to vaccination easily outweighed the motivators. In the absence of a perceived threat of disease and compulsory vaccination, provider recommendations continued to be the greatest predictor of vaccination. This once again, highlights the need to target healthcare providers and ensure that they support vaccination efforts. Those women that chose to vaccinate primarily did so as a way to protect their children. Thus, this could be another mechanism for motivation toward vaccinating mothers, much like the current whooping cough vaccination campaign highlighting the idea that most children acquire communicable diseases from adults. In terms of barriers, greater efforts need to be made to educate the public with regard to side effects and directly address anecdotal media

phenomenon. Public health officials should also focus efforts on making the public aware of the free or reduced cost of the vaccine and increasing availability.

Information

While women have a long list of information needs related to H1N1 and vaccination, they have an equally long list of available information sources and methods of seeking information. There are clearly multiple avenues for intervention from increasing the dissemination of governmental agencies' research findings, through engaging physicians and utilizing social networks in providing recommendations.

Similarly the feedback that emerged regarding the breakdowns in the WIC infrastructure, suggest that by facilitating coordination of services within a clinic could greatly impact vaccination by connecting women to available resources.

#### Strengths

This pilot study had several strengths. First, by selecting a sample of WIC clients it was possible to capture information from three of the high-priority groups identified by the ACIP to be the first to receive influenza A (H1N1) 2009 monovalent vaccine (CDC, 2009d). Second, the use of focus groups allowed for researchers to observe social dynamics and the ways in which participants communicate with and influence each other about the topic. The emphasis was placed on the interaction between the group members. The goal was not always to reach a consensus. Instead, the aim was for the participants to reflect on the discussion topics, present their own opinions, and to respond to comments by other group members. This information was more valuable than information about their individual views on the topic.

Another strength of this research was that it allowed for the comparison of urban and rural regions. The findings of this study indicate that future quantitative measures and interventions such as risk communication messages developed for one setting may not be appropriate for another setting in the same state. Furthermore, by including the WIC clinic staff interviews, this study was able to identify strengths and weaknesses, including existing resources and gaps in services within an existing health system network, to allow for the planning and implementation of potential interventions in a sustainable manner. The results of this study could make a significant contribution to public health systems research on preparedness and emergency response capabilities, as well as comprehensive policy and planning development regarding pandemic influenza and vaccine acceptance among low-income women, for which the current body of literature is scarce.

#### Limitations

Due to the qualitative nature of this study utilizing a small convenience sample, a central limitation is that the findings cannot be generalized to a wider population. There is the potential for selection bias because despite providing reimbursement for transportation and childcare, low income women may have limited means to travel to the WIC clinic unaccompanied. For this reason, many eligible women may have chosen not to participate in the study. Furthermore, those who did not choose to participate are likely to be fundamentally different in significant ways, as a whole, from those who chose to participate. There was also a lack of important data due to the exclusion of non-English speakers based on practical limitations of the study.

Six focus groups and ten interviews were an adequate number to collect a substantial amount of information and reach theoretical saturation. However, because of low vaccination rates it was difficult to recruit enough participants (particularly in the rural setting) to stratify groups based on immunization status. Similarly, it is possible that due to very little variability between the groups and interviews, the number could have been reduced when saturation was reached prematurely.

Focus groups and interviews were valuable methods for gathering data about the knowledge and attitudes of a community of individuals. Yet, the methodologies also had identifiable limitations. A major limitation of the focus groups was the effect of social desirability. Decisions surrounding immunization were being called into question and distrust of public health officials was growing. Vaccination has increasingly becoming a stigmatized and politicized subject. When such topics were discussed, participants may have chosen to censor their responses to avoid discomfort in front of their peers. Likewise, participants may have also changed their responses to please or to fulfill the perceived expectations of the researchers. Another challenge encountered using focus groups was confidentiality. Although it was possible to ensure confidentiality between the researchers and the participants, confidentiality among the participants could not be guaranteed. Therefore, it was important to address this in the consent forms and present guidelines prior to the start of each focus group to encourage respect and trust within the group. While focus groups have not been shown to produce significantly more information than in-depth interviews with individuals, there is research that supports the idea that participation in a group may be perceived by participants as more satisfying and stimulating and less threatening than individual face-to-face interviews (Morgan, 1998,

Wilkinson, 1998). Thus, a limitation to the one-on-on interviews with the staff members may have included the participants feeling threatened and changing their responses to fulfill the perceived expectations of the researcher regarding healthcare professionals. *Implications* 

This qualitative study generated critical information regarding the factors that affected a community's ability to successfully respond to the H1N1 crisis. Given the low vaccine uptake amongst high-priority groups of low-income women, the recent H1N1 immunization campaign could be viewed as a failure and highlights poor communication within the public health infrastructure. This research has implications for this population's ability to successfully respond to emergency preparedness recommendations during a pandemic in the future. Because the study leveraged an existing health system network, it allowed for the planning and implementation of these potential interventions in a sustainable manner. Furthermore, public health leaders could use information from this project to inform comprehensive policy and planning development regarding pandemic influenza and vaccine acceptance among low-income women, for which the current body of literature is scarce. The results of this study will make a significant contribution to public health systems research on preparedness and emergency response capabilities, by improving communication and recommendation acceptance among identified high priority groups by improving risk communication messages and identifying effective methods to disseminate trusted information to low-income women.

#### Recommendations

Table 8 summarizes the recommendations based on the findings from this study.

**Table 8: Recommendations for Public Health Officials** 

Target	Recommendations
Healthcare Providers	Partner to ensure support of vaccination efforts
	Encourage initiation of convergation recording
	Encourage initiation of conversation regarding
26.4	vaccination and vaccine recommendation
Mothers	Frame risk communication messages to motivate
	adult vaccination as a form of child protection
Low-Income Women	Educate with regards to side effects
	Directly address anecdotal media phenomenon
	Focus efforts on increasing awareness of free/reduced cost vaccine
	Employ multiple communication channels for information dissemination (i.e. media, providers, social networks)
	Send professionals into community centers to conduct face-to-face sessions regarding vaccination
WIC clinic staff	Provide workshops/trainings to address information needs of low-income women regarding vaccination
	Increase knowledge and awareness of services within local health clinics to coordinate services and connect
	women to available resources
	Incorporate vaccination messages into nutrition education classes

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#### **Appendix A: Focus Group Recruitment Flyer**

## We want to hear from you!

#### Are you...

- Female
- WIC Client
- 18 years or older
- Pregnant, Postpartum, or Caregiver of Young Children

Share your opinion!

This is a research project that wants to hear from you about what you think about the H1N1/"Swine Flu" vaccine.

#### You will...

- Complete a short questionnaire
- Participate in a 1½ 2 Hour Group Discussion

Let your voice be heard!

WIC Site Location Address City, State Zip

#### You will receive...

- A free healthy meal
- \$30 Cash

#### Contact: Cathy Boyd, Project Coordinator (786) 281-0431

WIC Focus Group Cathy Boyd (786) 281-0431	WJC Focus Group Cathy Boyd (786) 281-0431	WIC Focus Group Cathy Boyd (786) 281-0431	Cathy Boyd (786) 281-0431						
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#### **Appendix B: Rural Clinic Focus Group Recruitment Postcards**

#### Share your opinion!

## We want to hear from you!

Let your voice

be heard!

#### Are you...

- Female
- WIC Client
- 18 years or older
- Pregnant, Postpartum, or Caregiver of Young Children

Join us today at 11:30 am or 1:30 pm!

Researchers from Emory University want to know what you think about H1N1/"Swine Flu" vaccine.

#### You will...

- Complete a short questionnaire
- Participate in a 1½ 2 Hour Group Discussion at 11:30 am or 1:30 pm

#### You will receive...

- A free healthy meal
- \$30 Cash

Talbot County Health Center 1073 Woodland Highway Talbotton, Georgia Contact: Cathy Boyd (786) 281-0431

Participate today at 11:30 am or 1:30 pm!

#### **Appendix C: Focus Group Recruitment Telephone Script**

#### **Telephone Script for Invitation Call**

#### Hello, is [recipient] available?

If member is not available, ask respondent for a good time to call. Do not leave a message, your name or the reason for your call unless it is requested by the respondent.

#### When member is contacted:

#### If response is "yes":

•. Great, would you be able to join us for a 1 ½ - 2 hour discussion on: [date] at [time] p.m. at [WIC clinic site] at [address]?

Confirm time, date and location of member's focus group slot. Finally:

- To thank you, we are offering dinner to women who participate in a discussion group. We are also giving a \$30 gift card for completing the group interview to help compensate you for any costs associated with participating in the discussion.
- Because most women have busy schedules, we will do our best to start and end on time. It will really be hard for the discussions to work if you are late, so please try to arrive by [time]. We are planning to serve dinner right before our discussion, so it is even more important to arrive on time. Please don't be late!

If they have additional questions, encourage them to use (786) 281-0431 and ask to talk to Cathy Boyd or (404) 712-8539 to speak with Dr. Julie Gazmararian.

#### Appendix D: Urban Clinic Focus Group Recruitment Announcement Script

We would like to hear from you about what you think about the H1N1/"Swine Flu" vaccine. Researchers from Emory University will be visiting the clinic to listen to your opinions about H1N1 or the "Swine Flu" and are looking for WIC clients, 18 years and older to participate. You will be asked to complete a short questionnaire and participate in a 1½ - 2 hour small group discussion with other women. We do not expect any risks, but some personal questions may make some people feel uncomfortable. We do not expect any direct benefit to you for taking part. The information you give us may help health officials communicate with the public. The discussion groups will be here at [WIC site location] on [date] at [time]. Women who participate will be offered a healthy meal and \$30 for completing the group interview to help compensate for the time associated with participating in the discussion. If you would like to sign-up to participate or if you have additional questions, please contact Cathy Boyd at (786) 281-0431.

#### **Appendix E: Rural Clinic Focus Group Recruitment Postcards**

#### Share your opinion!

# We want to hear from you!

#### Are you...

Female

Let your voice be heard!

- WIC Client
  - WICChent
- 18 years or older
- Pregnant, Postpartum, or Caregiver of Young Children

Call to Enroll! Cathy Boyd (786) 281-0431

This is a research project that wants to know what you think about H1N1/"Swine Flu" vaccine.

#### You will...

- · Complete a short questionnaire
- Participate in a 1½ 2 Hour Group
   Discussion on July 6, 2010 or July 7, 2010

#### You will receive...

- A free healthy meal
- \$30 Cash

College Park Health Center 1920 John Wesley Ave College Park, GA 30337 Contact: Cathy Boyd (786) 281-0431

Call to Enroll!

**Appendix F: Focus Group Participant Informed Consent** 

Study No.: 00039925

Document Approved On: 5/28/2010 Project Approval Expires On: **5/28/2011** 

## **Emory University Rollins School of Public Health Consent to be a Research Subject**

<u>Title</u>: Knowledge, Attitudes and Behavior of H1N1 Vaccination Among Women Considered High Priority to Receive Vaccine (Pregnant or Caregiver of Young Children)

<u>Principal Investigator</u>: Julie Gazmararian, PhD, MPH, Associate Professor, Department of Epidemiology, Rollins School of Public Health, Emory University

<u>Funding Source(s)</u>: Emory Preparedness and Emergency Response Research Center (Emory PERRC), Centers for Disease Control and Prevention (CDC)

#### **Introduction**

You are being asked to be part of a research project. This form is designed to tell you everything you need to think about before you decide to consent (agree) to be in the study or not to be in the study. It is entirely your choice. If you decide to take part, you can change your mind later on and withdraw from the research study. The decision to join or not join the research study will not cause you to lose any benefits associated with the Special Supplemental Nutrition Program for Women, Infants and Children (WIC). We will enroll approximately 90 women who are clients at WIC clinics in Georgia, including those who are pregnant, postpartum, and caregivers of young children.

#### **Purpose**

The scientific purpose of this study is to look at the knowledge, attitudes, and behaviors of women considered high priority for receiving the novel influenza A (H1N1) vaccine.

#### **Procedures**

You will be asked to join a group of 9-14 women who are also WIC recipients. A trained interviewer will ask you questions about your health beliefs, knowledge, attitudes, and vaccine behaviors. Your focus group discussion will last approximately 1½ to 2 hours. It will be tape recorded and observed by members of the research team, but none of your comments will be connected to your name.

#### **Risks and Discomforts**

There are no foreseeable risks associated with this study. You may experience some emotional discomfort discussing vaccination issues with focus group members.

### Emory University IRB IRB use only

#### Document Approved On: 5/28/2010 Project Approval Expires On: **5/28/2011**

#### **Benefits**

You may have no benefit from participating in this study.

This study is designed to learn more about what people know about vaccinations, how they get the information and why they get vaccinated. The study results may be used to help other people in the future.

#### Compensation

You will be provided with a free healthy meal during the discussion. You will be given a \$30 gift card for completing the group interview.

#### **Confidentiality**

Certain offices and people other than the researchers may look at your study records. Government agencies and Emory employees overseeing proper study conduct may look at your study records. These offices include the Emory Institutional Review Board, the Emory Office of Research Compliance, and the study sponsors, Emory Preparedness and Emergency Response Research Center (Emory PERRC) and the Centers for Disease Control and Prevention (CDC). Emory will keep any research records we produce private to the extent we are required to do so by law. We will keep all research files locked in our office at Emory. Our computer files will be password protected. We may present results of this study in a medical journal or meeting. If we do, your name and other facts that might point to you will not appear when we present this study or publish its results. After the study is completed, we will destroy all information forms and the audio tapes.

#### **Costs**

There are no anticipated costs to you from being in this study.

#### Withdrawal from the Study

You have the right to leave a study at any time without penalty. This decision will not affect in any way your current or future care/services or any other benefits to which you are otherwise entitled.

#### Questions

If you have any questions about this study, contact Dr. Julie Gazmararian at (404) 712-8539 or <a href="mailto:jagazma@sph.emory.edu">jagazma@sph.emory.edu</a>. If you have questions about your rights as a research subject or if you have questions, concerns or complaints about the research, you may contact the Emory Institutional Review Board at 404-712-0720 or 877-503-9797 or <a href="mailto:irradiance-

Study No.: 00039925 **Emory U** 

Emory University IRB IRB use only

Document Approved On: 5/28/2010 Project Approval Expires On: **5/28/2011** 

#### Consent

We will give you a copy of this consent form to keep. Do not sign this consent form unless you have had a chance to ask questions and get answers that make sense to you.

Nothing in this form can make you give up any legal rights. By signing this form you will not give up any legal rights. You are free to take as much time as you need to think this over.

Please sign below if you agree to participate in this study.		
Name of Subject		
Signature of Subject Time	Date	
Signature of Person Conducting Informed Consent Discussion Time	Date	

Appendix G: HIPAA Authorization

Study No.: 00039925

Document Approved On: 5/28/2010 Project Approval Expires On: **5/28/2011** 

## **Emory University School of Medicine Research Subject HIPAA Authorization** to Use Health Information that Identifies You for a Research Study

Name of Study: Knowledge, Attitudes and Behavior of H1N1 Vaccination Among Women Considered High Priority to Receive Vaccine (Pregnant or Caregiver of Young Children)

Study Number: 00039925
Name of Principal Investigator: Julie Gazmararian, PhD, MPH, Associate Professor, Department of Epidemiology, Rollins School of Public Health, Emory University
Subject Name:

The privacy of your health information is important to us, especially if it can identify who you are. We call that your "protected health information" or "PHI." To protect it, we will follow the Health Insurance Portability and Accountability Act ("HIPAA" for short) Privacy Rule. This form explains how we will use your PHI for this study.

Please read this form carefully and if you agree with it, sign it at the end.

**Research Study:** The purpose of this study is to look at the knowledge, attitudes, and behaviors of women considered high priority for receiving the novel influenza A (H1N1) vaccine. You will be asked to join a group of women who are also WIC recipients. A trained interviewer will ask you questions and will last approximately 1½ to 2 hours. It will be tape recorded and observed by members of the research team.

#### Who will use your protected health information and for what purposes:

The following people and groups will use your protected health information for this study. Next to each group, you will see why they need to use it:

The principal investigator, the research staff, and other people and groups that help run the research study. **Purpose:** to do this study.

Emory Preparedness and Emergency Response Research Center (Emory PERRC) and Centers for Disease Control and Prevention (CDC) are the sponsors of this research. They and everyone else they need to do the research study. **Purposes:** to make sure the research is being done right, to collect information, and to think about the results.

Emory University IRB; the Emory University Office for Clinical Research; the Emory University Office of Research Compliance; research monitors and

Document Approved On: 5/28/2010 Project Approval Expires On: **5/28/2011** 

reviewers; data and safety monitoring boards; any government agencies who make the rules for the research including the Office for Human Research Protections; public health agencies. **Purposes:** to make sure this study is being run correctly and safely.

By signing this form, you would show that you agree to let any of these people and groups use your protected health information to run or monitor the research study. We will have to follow any laws that require us to pass along that information, like laws for reporting child or elder abuse. We also will follow legal requests or orders that require us to pass along your information. We may share your information with a public health group that collects information to help ensure the public's health, safety, and well-being.

#### What protected health information will be used or passed along

We may use or share the following kinds of your protected health information: whether or not you are pregnant, gave birth, are breastfeeding, and whether or not you received a vaccine.

#### **Changing your mind:**

You do not have to sign this form. Even if you do, at any time later on you may change your mind and take back your permission. If you want to do this, you must write to: Julie Gazmararian, 1518 Clifton Road, Atlanta, GA 30322.

After that point, the researchers would not collect any more of your protected health information. But they may use or pass along the information you already gave them so they can follow the law, protect your safety, or make sure the research was done properly. If you have any questions about this, please ask.

#### Other things you should know:

If we share information with people who do not have to follow the Privacy Rule, your information will no longer be protected by the Privacy Rule. Let us know if you have questions about this.

You do not have to sign this authorization form, but if you do not, you may not take part in the research study.

If the information that could identify you is removed from your health information, then the leftover information would not be covered by HIPAA, and it may be used or passed along to other persons or groups, for this study or for other purposes.

**Expiration Date:** This form will expire when the research study ends on January 31, 2011.

Study No.: 00039925

## Emory University IRB IRB use only

Document Approved On: 5/28/2010 Project Approval Expires On: **5/28/2011** 

If you have any questions regarding the study, you may call Dr. Julie Gazmararian at (404) 712-8539. If you have any questions about your rights as a study subject or anything else about the study, you may call the Emory University IRB at 404-712-0720 or 1-877-503-9797. The IRB is the office that looks out for people who take part in research studies.

A copy of this	form will be given to	you.		
Signature of S	tudy Subject			
Date	Time	_		
Printed Name	of Study Subject			
Signature of Po	erson Obtaining Autho	rization		
Date	 Time			

#### **Appendix H: Questionnaire**

Please answer each question below. The information you provide will only be used for the purposes of the study.

1.	What year were you born? 19
2.	What is your race (check one)?  White Black/African American Hispanic/Latino Asian American Indian Other: (Specify)
3.	Are you (check one):  Married/Living with partner  Divorced  Widowed  Separated  Never been married
4.	What was the last year of school you <b>completed</b> (check one)?  Less than high school  High school  Some college, trade or technical school  College graduate  Post graduate
5.	Are you (check one):  Working full-time  Working part-time  Currently not working  Disabled  Student
5.	Are you currently pregnant?  Yes No
	If yes, is this your first child?  Yes No

7. Did you give birth within the last 6 months?
Yes No
If yes, was this your first child?
Yes No
8. Do you have any children living in your household under the age of 18?
Yes If yes, how many? What age(s)?
No
9. How confident are you filling out medical forms by yourself (check one)?
Extremely Quite a bit Somewhat A little bit Not at all
10. How often do you have someone (like a family member, friend, hospital/clinic worker, or caregiver) help you read hospital materials (check one)?
All of the time  Most of the time  Some of the time A little of the time  None of the time
11. How often do you have problems learning about your medical condition because of difficulty understanding written information (check one)?
All of the time  Most of the time  Some of the time A little of the time  None of the time

12. Have you ever heard of H1N1, "Swine Flu", or Novel Influenza A?
Yes No
13. Did you receive the H1N1 ("Swine Flu", Novel Influenza A) vaccine?
Yes No
14. Did any of your children receive the H1N1 ("Swine Flu", Novel Influenza A vaccine?
Yes No I do not have any children
15. Did you receive the seasonal flu vaccine?
Yes No
16. Did any of your children receive the seasonal flu vaccine?
Yes No I do not have any children

Appendix I: Focus Group Guide

#### H1N1 Vaccination among WIC Clients Focus Group Guide

#### **Greeting & Introduction**

Good Afternoon! I am	from Emory University Rollins
School of Public Health. Thank you for con	ning to our discussion today. I appreciate
your willingness to talk openly about the H	1N1 virus, "swine flu", and your decisions
regarding vaccination. I know that some of	the things we are going to talk about are
sensitive, so I'd like encourage everyone to	respect each other. So, let's go over a few
ground rules. [Display flip chart and have ]	participants add to the list; Keep things
confidential, commit to the group, participa	te in discussion and activities, have a non-
judgmental attitude, and respect each other	(encompasses cell phone use)].
So lat's also talk about logistics. During the	a focus group discussion today I will ask the

So, let's also talk about logistics: During the focus group discussion today I will ask the group different questions. You are viewed as the experts, so I would like to hear from everyone. I will audio-tape the discussion and there is a note taker to help us remember what information was discussed. I may also write things down from time to time on a flip chart. During the discussion, feel free to help yourself to refreshments. Also, if you need to use the restroom, they are located\_\_\_\_\_\_ (point out location). At the end of our discussion today, you will receive \$30 for your time.

One last thing before we get started, I want to remind you that no one will be able to put your name with any of the comments you make. The audio-tape of our discussion will be transcribed, that is someone will use the tape to type up a document of what is said here today, but we will not use names in the transcription.

OK, before we start, there may be some confusion behind the H1N1 virus and "swine flu." Therefore to make sure that we are all talking about the same thing, I would like everyone to refer to information sheets you were given. 2009 H1N1, sometimes called "swine flu", is a new influenza virus causing illness in people. This new virus was first detected in people in the United States in April 2009. This virus is spreading from person-to-person worldwide, probably in the same way that regular seasonal influenza viruses spread. This virus was originally referred to as "swine flu" because laboratory testing showed that the virus was very similar to influenza viruses that normally occur in pigs (swine) in North America. But further study has shown that the 2009 H1N1 is very different from what normally circulates in North American pigs. From now on, I will refer to this new virus and influenza simply as H1N1, but you should understand that it means the same thing as "swine flu".

Do you have any questions?

Let's get started then, by introducing ourselves using only your first name.

#### **Focus Group Guide**

1. Let's begin by thinking back to last year, what do you remember about H1N1?

*Probe:* How could you get H1N1?

2. Think back to when you first heard about the "swine flu" and H1N1 and the feelings that came along with that. Describe how you felt about the news of the H1N1 outbreak.

Probe: How closely did you follow the news? What kinds of things did you want to know? What was confusing?

3. Describe how concerned you were that you or someone in your immediate family would get sick from H1N1.

Probe: How likely did you think that there would be a lot of people getting very sick? How could you prevent getting sick from H1N1?

4. There are many different types of illnesses, some serious and some not so serious. What would you worry about if you or someone in your family became sick from H1N1?

Probe: If you or someone you know became ill, how would they deal with it? Describe how these worries may have been different from the worries that go along with the seasonal flu.

#### **Note: Flip Chart**

5. People learn about health information in a lot of different ways. Which sources did you get the most information about the H1N1 outbreak?

Probe: Describe all the different ways you got information about the outbreak (radio, TV, online sites such as twitter, blogs, or discussion boards). Did you share the information with anyone else? Who? How?

#### **Transition:**

6. **In general**, what do people do to protect themselves from getting sick (not just from the flu, but from all diseases in general)?

*Probe:* If not mentioned – what about vaccines ("shots", "immunizations")?

7. **Generally speaking**, what do you think are the reasons why people get vaccinated ("get their shots", "get immunizations")?

*Probe:* What do you think are the main benefits of getting vaccinated?

- 8. Again, <u>in general terms</u>, what do you think are the reasons why people do <u>not</u> get vaccinated?
- 9. What do you think are the main problems with getting vaccinated?

Probe: Do you think vaccines can cause you any harm?

#### **Note: Flip Chart**

- 10. Where do you **go for advice** about vaccines?
- 11. Have you ever received advice not to get vaccinated?

Probe: Who told you? Was it a doctor? Family member? Friend? What if someone told you not to get vaccinated? Would you listen to what they tell you? Would you do something else?

12. Think about your decision to get the H1N1 vaccination, what influenced your decision to get vaccinated?

Probe: Explain how the decision was made and who helped you make them. How did you learn about the availability of the vaccine? Did you think the vaccine was safe? Were there any cases of H1N1 or swine flu among the people in your community? Were any schools closed? How easily did the virus spread throughout the community? Were there any barriers to receiving healthcare (cost, transportation, child care)?

13. Think about your decision to get the H1N1 vaccination, what influenced your decision to **not** get vaccinated?

Probe: Explain how the decision was made and who helped you make them. How did you learn about the availability of the vaccine? Did you think the vaccine was safe? Were there any cases of H1N1 or swine flu among the people in your community? Were any schools closed? How easily did the virus spread throughout the community? Were there any barriers to receiving healthcare (cost, transportation, child care)?

- 14. What other methods might you have used to help protect against H1N1?
- 15. What could public health officials have done do to improve the information they provided about the H1N1 outbreak and vaccine?

Probe: How satisfied were you with the way public health officials managed the response? What suggestions would you have for improvement in the future?

## You and the 2009 H1N1 flu vaccine

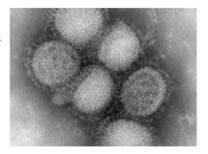


#### What is 2009 H1N1 (swine flu)?

2009 H1N1 (sometimes called "swine flu") is a new influenza virus causing illness in people. This new virus was first detected in people in the United States in April 2009. This virus is spreading from person-to-person worldwide, probably in the same way that regular seasonal influenza viruses spread. On June 11, 2009, the World Health Organization (WHO) declared that a pandemic of 2009 H1N1 flu was underway.

#### What is a pandemic?

A disease epidemic occurs when there are more cases of a disease than would normally be expected in a defined region. A pandemic is a worldwide epidemic of a disease. The H1N1 influenza pandemic has occurred because a new virus emerged that the human population does not have immunity (protection against) and it has spread all over the world. Pandemics can either be mild or serve in the illness and death they cause, and the severity of a pandemic can change over time.



#### Why is the 2009 H1N1 virus sometimes called "swine flu"?

This virus was originally referred to as "swine flu" because laboratory testing showed that many of the genes in the virus were very similar to influenza viruses that normally occur in pigs (swine) in North America. But further study has shown that the 2009 H1N1 is very different from what normally circulates in North American pigs.

For more information call **1-800-CDC-INFO** or **visit www.flu.gov** 

**Appendix J: Staff Interview Informed Consent** 

Document Approved On: 5/28/2010 Project Approval Expires On: **5/28/2011** 

## **Emory University Rollins School of Public Health Consent to be a Research Subject**

<u>Title</u>: Knowledge, Attitudes and Behavior of H1N1 Vaccination Among Low Income Women Considered High Priority to Receive Vaccine (pregnant or caregiver of young children)

<u>Principal Investigator:</u> Julie Gazmararian, PhD, MPH, Associate Professor, Department of Epidemiology, Rollins School of Public Health, Emory University

<u>Funding Source(s)</u>: Emory Preparedness and Emergency Response Research Center (Emory PERRC), Centers for Disease Control and Prevention (CDC)

#### **Introduction**

You are being asked to be in a research study. This form is designed to tell you everything you need to think about before you decide to consent (agree) to be in the study or not to be in the study. It is entirely your choice. If you decide to take part, you can change your mind later on and withdraw from the research study. The decision to join or not join the research study will not cause you to lose any benefits to which you are otherwise entitled. We will enroll approximately 10 individuals who are staff members at WIC clinics in Georgia.

#### **Purpose**

The scientific purpose of this study is to look at the knowledge, attitudes, and behaviors of WIC personnel who work with women considered high priority for receiving the novel influenza A (H1N1) vaccine.

#### **Procedures**

We are conducting a 15 minute interview with WIC clinic staff members about their health beliefs, knowledge, attitudes and vaccine behaviors. It will be tape recorded by a trained member of the research team. None of your comments will be connected to your name.

#### **Risks and Discomforts**

There are no foreseeable risk or discomforts associated with this study.

#### **Benefits**

There may be no direct benefit to you as a participant from this study. This study is designed to learn more about what people know and believe about vaccinations. The study results may be used to help other people in the future.

#### **Compensation**

You will not be offered payment for being in this study.

Study No.: 00039925

### Emory University IRB IRB use only

Document Approved On: 5/28/2010 Project Approval Expires On: 5/28/2011

#### Confidentiality

Certain offices and people other than the researchers may look at your study records. Government agencies and Emory employees overseeing proper study conduct may look at your study records. These offices include the Emory Institutional Review Board, the Emory Office of Research Compliance, and the study sponsors, Emory Preparedness and Emergency Response Research Center (Emory PERRC) and the Centers for Disease Control and Prevention (CDC). Emory will keep any research records we produce private to the extent we are required to do so by law. We will keep all research files locked in our office at Emory. Our computer files will be password protected. We may present results of this study in a medical journal or meeting. If we do, your name and other facts that might point to you will not appear when we present this study or publish its results. After the study is completed, we will destroy all information forms and the audio tapes.

#### Costs

There are no anticipated costs to you from being in this study.

#### Withdrawal from the Study

You have the right to leave a study at any time without penalty. This decision will not affect in any way your current or future care/services or any other benefits to which you are otherwise entitled.

#### **Questions**

If you have any questions about this study, contact Dr. Julie Gazmararian at (404) 712-8539 or <a href="mailto:jagazma@sph.emory.edu">jagazma@sph.emory.edu</a>. If you have questions about your rights as a research subject or if you have questions, concerns or complaints about the research, you may contact the Emory Institutional Review Board at 404-712-0720 or 877-503-9797 or <a href="mailto:irrb@emory.edu">irrb@emory.edu</a>.

#### **Consent**

We will give you a copy of this consent form to keep. Do not sign this consent form unless you have had a chance to ask questions and get answers that make sense to you.

Nothing in this form can make you give up any legal rights. By signing this form you will not give up any legal rights. You are free to take as much time as you need to think this over.

Please sign below if you agree to participate in this study.	
Name of Subject	
Signature of Subject	Date Time
Signature of Person Conducting Informed Consent Discussion	Date Time

**Appendix I: Staff Interview Guide** 

## H1N1 Vaccine Formative Research WIC Clinic Staff Interviews

Participant Name:			Position:				
	Date:	Time Start:	Time End:				
1.	(Examples: Prov	rided vaccine, referred clier	onducted related to the H1N1 vaccine.  Ints to vaccine sites, posted flyers, etc.)  It is incompared to the H1N1 vaccine.  Interest of the H1N1 vaccine.  Interest of the H1N1 vaccine.				
2.	-	atients request information tts?, Family members?	about H1N1?				
3.		•	man's decision to get the H1N1 vaccination a decision <b>not</b> to get vaccinated?	n?			
4.	Probe: How seri	•	ng H1N1 and the vaccination? Ifluenza was? Did you feel at risk? Did you	ı			
5.	Were you vaccin	nated? Why? Why not?					
6.	If you have child	lren, did any of them receiv	ve the H1N1 vaccine? Why? Why not?				