Spring 5-1-2013

The U.S. Healthcare System: The Political and Personal Perspective

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The U.S. Healthcare System: The Political and Personal Perspective

A Capstone Project Submitted in Partial Fulfillment of the Requirements of the Renée Crown University Honors Program at Syracuse University

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May 2013

Honors Capstone Project in Public Health

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Date: May 1, 2013

Abstract

A large proportion of American adults lack health insurance, due to job loss and a wide variety of other issues. With the passage of the Affordable Care Act (ACA), and the Supreme Court decision affirming its constitutional legality, the availability of healthcare is set to increase in the near future. This honors thesis addresses the fit, or lack of fit, between the ACA provisions and the needs of the currently uninsured. My study involved ten interviews with patients at a free clinic for the uninsured in Syracuse, NY, and an interview with the Commissioner of Health from Onondaga County. For this study I completed an extensive literature review, wrote an IRB application, developed the interviews, administered and transcribed the recorded interviews, and analyzed the findings. Together these two perspectives help shed light on the complexities of the healthcare system and investigate whether or not the Affordable Care Act will meet the needs of those it is intentioned to reach.

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Introduction/Background

The Affordable Care Act

Over the past several years healthcare has been a politically charged topic of conversation in the United States. With the passing of the Affordable Care Act, otherwise know informally as "Obama Care," there has been even more discussion and controversy centering on the healthcare system as a whole. The question, "What does the Affordable Care Act (ACA) entail?" is one that is commonly asked by a multitude of people in all different environments. With that, this paper attempts to investigate whether or not the ACA is meeting the needs of the currently uninsured population.

Although the ACA is extremely complex and covers many different sectors of the healthcare field, below is a brief overview of the current actions, goals, and requirements that are already in progress or will be enacted by January 1st 2014. There are three main overarching goals of the ACA. The first is the expansion of affordable and higher quality care for the majority of the population. The second is an increase in accessible health insurance and care to a much larger proportion of the population than those who are currently receiving coverage. Lastly, there will be a large push for the expansion of Medicaid ("Health Insurance 101," 2010).

Since the end of September 2010 there have been several insurance reform policies that have already been initiated. For example, insurance companies are required to extend their coverage to make insurance more accessible to children, which are one of the highest risks populations. They are now required to allow the

children of the primary insurance plan holder to remain on their specific insurance plan all the way up to 26 years of age. Also, they must accept and grant coverage to any child, up until 19 years of age, despite preexisting health conditions or health standing (Cantor et al, 2012). There have also been revisions to the rules centered on premiums, in order to make stricter requirements. Insurance providers are now required to report and validate all excessive premium increases and spend at least 80% of all premiums on quality improvement and medical services ("Health Insurance 101," 2010). The new reforms also place a stronger emphasis on the importance of preventative care, and makes sure insurance companies will protect these services without cost sharing or charging deductibles ("Health Insurance 101," 2010). There are also several other reforms being enacted on a multitude of topics, these are only a few examples.

There are basic requirements that insurance providers must adhere to in order to help attain the major goals of the ACA. The ACA will also ensure that any person, who applies for health insurance, despite their health standing, will be approved. Insurance companies will no longer be permitted to deny a person based on medical, economic, social, or any other condition that previously affected insurance coverage approval. In addition, previous health problems or conditions are no longer grounds for insurance providers to charge increased premiums or exclude an individual from any benefits. There will also be a federal statute, that most insurance providers will be required to adhere to specific standards of cost sharing and benefits (Coyne et al, 2011).

There are also specific requirements that United States citizens or legal residents must abide by, as a result of ACA. If an individual does not have some form of eligible insurance coverage by January 1st 2014, they will receive a tax penalty. The thought process behind making insurance mandatory is that it will deter people from making healthcare a second priority. For example, if a person is healthy and has other financial responsibilities they might put off investing in health coverage until they became ill and need it. If only people who are sick and in need to insurance apply, there would be an elevation in insurance premiums. If all people have health insurance, regardless of their health status, the average costs for everyone will eventually be reduced. There are two different ways in which this penalty can be served, a flat rate tax penalty or a percent of taxable household income (Hall et al, 2012).

The flat rate penalty must be paid once a year starting in 2014. The flat rate penalty will increase each year that the person continues to not have coverage from a sufficient health insurance plan. Starting in 2014 the tax will be $95, and will increase to $325 in 2015 ("Health Insurance 101," 2010). If a person still has no coverage by 2016 they will be required to pay a tax penalty of $695. Beyond 2016, each year, the tax penalty will continue to increase. However, there will be a cost of living adjustment incorperated. Although the tax penalty is charged on an individual basis, there is a maximum flat rate tax per family per year. One family, regardless of how many people are in the family, cannot be penalized more than $2,085 annually ("Health Insurance 101," 2010).

The second tax penalty alternative is a percent deduction from the annual household income. Like the flat rate tax penalty each year after 2014 the penalty will increase. In 2014, 1% of taxable income will be charged, and in 2015, 2% of taxable income will be deduced. In 2016 the tax penalty will reach its maximum at, 2.5%, where, as of now, it will remain constant annually ("Health Insurance 101," 2010).

However, there are some exceptions and situations in which individuals are exempt from the tax penalty. For example, if a person would be spending more than 8% of their household income to cover their insurance premiums, they are defined as some one who cannot truly afford coverage. Also people whose income is below $9,135 annually are defined as below the tax-filing threshold, and therefore, will not to be penalized (Cantor et al, 2012). However, this creates a large area of controversy. If these people have such little financial means that they are exempt from the ACA, what implications does this make on their health status as a stressor? And, how are they supposed to afford the healthcare they need? These are, however, questions for another time. There are also several other reasons why someone would be exempt, such as, Native Americans living in the United States, people of certain religious affiliations, people who are currently incarcerated, and more. Each of these exemptions will be evaluated, thoroughly, on a case-by-case basis. Also, individuals or families who already have health insurance are not required to re-apply for insurance, as long as their insurance provider abides by the requirements of the ACA. They can remain with their

current providers, and they will be considered to be meeting the insurance requirement, and therefore, not have to pay the tax penalty.

Uninsured Populations in the United States

Although the actual percentage of people without health insurance has been gradually decreasing, there is still an enormous sector of the population that remains unable to obtain health insurance coverage, and therefore,adequate healthcare. Those living below the poverty level and racial minorities are disproportionately affected. Between 2008 and 2009 people those who possessed private health insurance, as well as insurance through an employer, decreased. Private insurance decreased from 66.7% to 63.9%, and employment based insurance decreased from 58.5% to around 55.8% (U.S. Bureau of the Census, 2012). With the decrease in private and employment-based insurance, there was naturally an influx of people applying for government based insurance. Between 2008 and 2009 the United States had the highest percent of the population receiving government health insurance since 1987, 30.6%. One of the most popular government insurance entities, Medicaid, went from covering 42.6 million people to 47.8 million people in one year alone, between 2008 and 2009 (U.S. Bureau of the Census, 2012).

As of 2011 15.7% of people living in the United States were living without health insurance. This may not seem like a very large percent of the total population, but in fact that equates to 48.6 million people. When looking at this with an even closer lens, 7.5 million are children (U.S. Bureau of the Census, 2012). Also, Blacks and Hispanics are among the highest percentage of those that

fall with in the uninsured category, with 21% and 32.4%, respectively (U.S. Bureau of the Census, 2012). .

A study conducted by, Short et al (2012) states one of the leading causes of people to be without health insurance coverage is economic instability. 23 million Americans have had one or more gaps in insurance coverage between 2004 and 2007 (Short et al, 2012). The gaps in coverage, for the most part, are attributed to loss, of employment-based coverage.

Personal Interest

My interest in the healthcare system really began when I was a freshman four years ago, and I became involved with an epidemiological chart review research project at the Amaus Clinic in downtown Syracuse. Although a small clinic, it has a huge impact on the community, providing healthcare for the homeless and the uninsured population. The project's objectives were to achieve three major goals: improve quality care, conduct Public Health research, and train students as researchers. After obtaining many institutional review board (IRB) approvals, we were able to begin our actual research. We reviewed all of the patient charts in the clinic. I spent many hours after class on Fridays and all day Saturdays reviewing charts. I carefully read through each individual chart, and then proceeded to record all patients' health history, chronic and acute problems, and medications on a separate data abstraction sheet, which were coded by numbers so that our research would remain anonymous. After every few hundred charts were completed, we compiled the data onto a Statistical Package for the

Social Sciences (SPSS) spread sheet. Through this process, the team and I were able to discover what issues were the most prevalent.

As I read through the patients' charts, they became more than two-dimensional entities. The details of their lives and health conditions made them come to life, rather then just being case studies for research. One particular example that stood out to me was a case that involved a man in his late twenties. The barriers, limitations, and struggles that this man faced were extremely enlightening. He was recovering from drug abuse, suffering from Type I diabetes and had been incarcerated. While in jail, his insulin was provided, and his diabetes was under control, but once released he had no job, no money, and no one to call on for help. He was given a 30-day supply of insulin, but after 30 days, he had to find a way to cover the costs out of his own pocket. He arrived at the Amaus Clinic with a blood pressure of 142/90, and generally in bad health. In his chart it stated that after ten visits to Amaus, his diabetes was back under control. They helped him to find work in food service, and he now lives in a local halfway house. This example resonated with me because it was my first time I was able to break out of my previously sheltered existence and acknowledge the fact that getting necessary medication was not a given for all people, and the effect being uninsured can have on the quality of a person's life.

After the chart review project came to completion, I stayed at the clinic as a volunteer. Once or twice a month I would help patients fill out necessary paperwork or help collect other initial intake information, such as vitals and height and weight measurements. When it came time to develop a concept for my

Renee Crown Honors Thesis my mind immediately went to my experiences at the clinic. My passion for the clinic coupled with the impending changes to heath care and insurance, a comparative research project focusing on health policy and uninsured patients seemed like a natural fit.

Methods

The purpose of this research project was to explore if the politically proposed Affordable Care Act corresponds with the experiences, opinions, and needs of the uninsured populations in Syracuse, NY. My hypothesis was that there is a large disconnect between the political perspective and current actions, juxtaposed to the perspective, needs, and comprehension of those who are actually are and will be affected by the Affordable Care Act.

The interviews were conducted with uninsured persons in the Syracuse, NY area. Specifically 10 patients, who attend the Amaus Clinic as their primary source of healthcare. This target population was selected based on my previous relationship with the clinic and my knowledge of the large uninsured population that frequented the clinic. I had requested and received IRB approval for a second group of interviews, which were to be conducted with Central New York policy makers and healthcare officials from a variety of different levels, areas, and parties. However, there were several roadblocks encountered with these interviews, which will be elaborated on later. All of the interviews were intended to be qualitative and in-depth. I requested that the interviewees allow me to digitally record their voices, and they the signed informed consent documents.

After the concept of this project was developed and a rough action plan was formulated, I, under the supervision of Dr. Sandra Lane, PhD, MPH, completed a Syracuse University IRB Expedited Application. The applications consisted of a rationale for my research, an extremely detailed action plan, and precautionary measures. The IRB also required several other elements that related

to the project, such as flyers, recruitment scripts, consent forms, proposed interview questions, and a comprehensive literature review. All of these documents can be found in the appendices attached at the end of this document.

This process took about three to four months, because the IRB sent the application back for revisions two or three times. Being that this was my first time independently applying for IRB approval, this was to be expected, and forced a readjustment in the timeline of the project. However, once the approval was granted, the interviews at the Amaus Clinic commenced. It took approximately three and a half months to complete the ten uninsured patient interviews.

As was stated previously, I had volunteered at this clinic during my freshman and sophomore years at Syracuse University, and Dr. Satterly, the Clinic Director, agreed to allow me to interview patients at the clinic after Syracuse University IRB approval was granted. The clinic's patients were all between the ages of 18-65. I approached them while they were in the waiting room and recited the proposed requirement script and gave them a flyer further explaining the project. All participants were notified that they would be interviewed with confidentiality, that their names were not recorded on the interview document, and were not to be associated with their answers, nor were their names to be recorded anywhere in published or publically presented materials. Also, they received a $10 reimbursement, which was generously donated by Dr. Lane, for their time and participation. If the patients agreed to participate, they were given a consent form. Once it was signed, by both the participant and myself, I proceeded with the interview.

All interviews were carried out in private medical examining rooms while the patient was waiting to be seen by a physician to ensure confidentially, but also to guarantee the comfort of the patient to answer freely and not take time away from their daily routine. These interviews addressed the patient's struggles, accomplishments, and overall experiences as a stakeholder in the healthcare system. The questions also explored their knowledge of the Affordable Care Act and their opinions about the proposed action plans. The interviews were recorded, transcribed, and stored on a secure network that could only be accessed by Dr. Lane and myself.

The second set of interviews were conducted differently then the patient interviews. There was not one uniform way of carrying out the interview process based on the variety of the policy makers and healthcare official's positions, location, availability. They were all contacted via phone or email using the proposed recruitment script. However, the original plan of conducting ten healthcare officials and policy maker interviews was unable to be completed. Only one politician, Cynthia Morrow, M.D., PhD, the Commissioner of Health for Onondaga County, agreed to participate in the project.

There were several different reasons why the healthcare officials and policy makers did not participate in this research project. Some representatives, such as Senator Schumer's Office and the Office of Onondaga County Executive Joanie Mahoney, did take the time to discuss the project with me, yet they said they would need to get back to me whether or not they would accept the invitation to participate. However, after about a month of repetitive calls and emails there

was no response or sign of participation. Others, such as Syracuse Mayor Stephanie Miner's Office, declined to participate. They stated that they did not want to share a public opinion on the issue. Others, such as New York State Assembly member Brian Kolb, did not respond at all.

Dr. Cynthia Morrow, M.D., PhD, was contacted by telephone, and I spoke to her secretary. The pre-written requirement script was utilized. We arranged a phone interview for the following week. Before the interview I sent I copy of the consent form to her office, which stated the option to have Dr. Morrow's answers be confidential or allow me to quote them for attribution. Luckily, she agreed to allow me to associate her name with her responses. Again, the interview was recorded, transcribed, and stored on a secure network that could only be accessed by Dr. Lane and myself.

After all of the interviews were complete and transcribed, I read over each interview several times in order to identify several themes that the interviews identified. I also looked at the interviews carefully, to discern issues that corresponded, or did not correspond, to elements in the ACA. Both of these types of themes—those from the interviewees and those from the ACA—were used in analyzing the interviews.

Results

After completing the interviews of the uninsured patients at the Amaus Clinic it was clear that there were several reoccurring themes. The following table lists the major themes:

Themes:		
	In Relation to the ACA	From the Interviewees
	Misinformation	Limbo or "betwixt and between"
	Confusion/Frustration	Shame

All of the patients have been without insurance for at least one year. The majority of the interviewees stated that they lost their insurance due to job instability. Due to lay-offs or decreases in hours, they could no longer afford the employee health insurance plan provided by their employer. Many of the patients discussed the concept of being in *limbo*. Victor Tuner wrote about this situation of being in limbo, as "betwixt and between." Although, Turner applied the concept to rights of passage, I think this concept can be applied to patents who do not fit into conventional economic categories, and therefore, struggle with their healthcare. They make too much money to be accepted by Medicaid. Many described drastic situations in which they had to decide between food and necessary healthcare treatments. They also stated the burden of shame and stress in their lives, which stems from their financial and healthcare volatility. Lastly, the majority of patients were uninformed and confused by the Affordable Care Act. Many did not

know what they were entitled to, or how to apply for the coverage they needed. These shared experiences seen throughout the majority of the patient interviews are very indicative of the major problems within the current healthcare system.

The qualitative results gathered from this research were harmonious with the results found in the study conduced by Short et al. (2012). The main reason patients reported for being without health insurance were lapses in employment-based coverage and the inability to qualify for Medicaid, or other government insurance plans.

One woman, who was in her mid-60s, discussed the struggles of being in-between two government systems and the effect it has had on her health status. She has been without insurance for the past 4 years. She, like the majority of the interviewees, lost her insurance when she was laid-off. She worked as an administrative assistant for a communications company in Brooklyn, NY. One day, out of the blue, she was notified that anyone who had worked less than 20 years for the company was being laid off. She had been working for them for over a decade, but it that did not matter. She was left to figure it out on her own. She applied for unemployment and continued to look for work. However, she was forced to relocate to Syracuse, NY to be with family and friends when she could no longer afford to live independently. She decided to apply for Medicaid, but was denied because she made too much from unemployment. Even though she was receiving unemployment checks, she said, she was just barely able to afford her food, rent, and other expenses. When she began to have health issues, she was advised to see a kidney specialist. The physician informed her, that she could

apply for financial aid and a payment plan. Even though she was advised to return, she could barely afford the initial visit and was left with very limited options. During the interview she sighed and stated,

> I just don't understand. I worked all my life and now I find myself in this position, with hardly anything I can do to help myself. And, the things that are supposed to help me I can't find or understand. I was an administrative assistant for 12 years…. Yet, I can't afford to go back to the doctor two or three more times at $100 a visit. I just hope it is nothing to serious, but it's stressful to worry so much.

She did not return to the doctor because she could not afford it. However, after experiencing back pain she sought the help of the Amaus Clinic, and was still awaiting a diagnosis at the time of the interview.

Another woman, who was in her mid-50's, shared that she had worked for Home Depot and Lowes for almost 10 years, however about 2 years ago they reduced her hours to 13 hours a week, compared to her average 40 hours a week previously. At first she attempted to continue to pay for the company health insurance. However, with the reduced salary and the "crappy" coverage the employment based care provided, she decided it was no longer worth her money and stress.

She no longer possessed health insurance coverage, and therefore, stopped receiving routine tests and physicals. About a year after she lost her insurance, she began to have excessive bleeding. She used all the money she had put aside for food in order to afford an appointment with a General Practitioner. After receiving an ultrasound the physician told her there was nothing unusual in the results of the tests and sent her home with a prescription for hormone therapy. Now, three years later her bleeding is worse and she has come to the clinic

because she is concerned she has some form of cancer. She expressed the frustration and embarrassment she felt after that appointment. She said she was trying to be responsible for her health, and instead she was belittled and dismissed based on her economic status. Now three years later, something she attempted to take care of might have progressed into something much more serious.

When she was employed and in a more stable financial situation she used to work at fundraisers for this exact clinic. Now, she says the shame is overwhelming. As she bows her head she said;

> I finally had to break down and apply for food stamps. I feel horrible about it. You know the cans of beans that just sit in the back of your pantry? Well, when I finally ate the last can I had, I knew I had no choice. I know there are people so much worse off then me, I don't want people to think I am abusing the system. I really hope that no one from Cazenovia recognizes me here. I used to volunteer at the fundraisers for this place, and now I am here to get help, it's mortifying.

With all of this stress and worry that occurs in her everyday life, she expressed that one of her biggest concern is being recognized at the clinic. She says the shame of living a reduced lifestyle, barely being able to take care of her everyday needs, and the stigma and treatment she has received is the worst pain of all. The loss of her job and insurance coverage has created a domino effect that not only impacts her physical health status, but all aspects of her life.

The last commonly occurring theme throughout the interviews is miscommunication and misunderstanding about the impending Affordable Care Act. A young man, probably in his late 20s to early 30s, has been without health insurance for about a year. He applied for Medicaid several months ago, but his status is still pending. Like many other patients he lost his insurance when he was

in-between job. He came to the clinic because he has asthma and the medication he needed was too expensive for him to afford. He stated, “Some people in my family have asthma too, like my little brother. So I would just take some of his puffers when I couldn't afford to get my own or was really havin’ a hard time breathin’. But. I can’t always be taking theirs, so I came here to see if I could get one of my own.” When I asked him about The Affordable Care Act, he explained that he keeps hearing people in his neighborhood and community talk about it, but he does not know much about it. He said there is more speculation and rumors than clear details and comprehension. Also, he said that he has no idea what it will offer or what it means, but he hopes it helps him better afford his asthma medication.

The next interviewee was one of the most interesting because she worked in the nursing field, yet she did not have health insurance. She would not elaborate on the details of why she was without insurance, but she did share that it was due to financial reasons, and she had been uninsured for over a year. While working in the healthcare field she is exposed to plenty of illnesses and finds herself ill very frequently, yet she cannot afford insurance for herself. She tries to stay healthy, treat herself, and use over the counter remedies. This was her first time visiting the clinic for healthcare, after she was referred here by a college.

Being that she is a nurse, she is highly involved in the healthcare system and field, and is very well informed about the Affordable Care Act. However, she still is concerned with the confusion that surrounds it. She explained, “The ACA is better than having nothing at all, but there are so many issues that need to still

be worked out." In her opinion one of those issues is helping the general public to better understand what the ACA is actually about, rather than what is digested through word of mouth or skewed media information.

There was also a man in his mid-40s who has been without insurance since him and his wife got divorced three years ago. He shared his struggles of having to provide for three children, pay his mortgage, car payments, and afford the necessary healthcare for his diabetes and other health issues, which he declined to elaborate on. He, like other patients discussed earlier, were denied Medicaid because he made too much money, even though he was working only part time when he applied.

He recently started a new job at the time of the interview, but would not be qualified for their company insurance plan until after 90 days of employment. Even when he is eligible, he will still have to pay a percentage of the coverage, which he does not think he will be able to do based on his $10 an hour salary. When asked about the ACA he said:

> I think they are trying to do something, but when its very vague and unclear its hard to have cooperation. I don't understand all the parts of it if I don't have insurance then I can get fired? But, what if I can't afford it? Then they are going to fine me? How does that make sense? Also, there are a lot of people who abuse the system. Like I could go get food stamps right now, but I don't want to because, so far, I have been able to make it work. But I can't afford insurance. Me and two other guys, we work with every day and take over time when we can and still can't make everything work, so how is it fair that there is no checks and balances for the people who coast through the system and then can get this new insurance. I just don't get it.

This man has formulated a negative opinion of the ACA based on information he has gathered through discussions with colleagues, friends, and media reports. His

perception is that it is not beneficial to the people who need it most and instead of helping it will take an even greater economic toll on him and others in a similar position. His point about the vague and unclear nature of the act as a cause for not supporting it highlights this extremely pressing issue.

This act is designed to address many aspects of the healthcare system. One of the major goals is to increase healthcare accessibility and affordability to the sectors of the population who are uninsured or underserved. However, those for whom the benefits are intended are unaware or confused about what the act entails, what they need to do to in order to gain access to the benefits, how to avoid the penalties, and the overall impact the Affordable Care Act can have on their lives.

As was previously stated, I was only able to complete one interview with the Onondaga County Commissioner of Health, Dr. Cynthia Morrow, MD, MPH. The IRB application allowed me to request public policy officals to go "on the record." In her written informed consent document for this study, Dr. Morrow allowed me to quote her personally. Dr. Morrow stated that she would only answer the questions as a Public Health Professional, not from her perspective as a healthcare deliverer, based on her current role as the Commissioner of Health.

In terms of her public health perspective she said that she is fully supportive of the ACA for numerous reasons. The most important, in her opinion, is the capacity for it to increase access to health coverage. She said:

> Whether people use it or not is another issue. The ACA has the potential to transform public health. It will provide funding for necessary community transformations. Through the grants provided by the ACA there is room for more public health initiative, and public health

> prevention. Such as, encouraging the use of population-based intervention, for example, cancer screening and immunizations.

She also mentioned the publication of the National Prevention Counsel Action Plan in June 2012, as a result of healthcare reform. She stated that this is another way in which the federal government is really making an effort to raise the bar for environmental change that could have impressive impact on the field of public health.

When asked what areas of the ACA she believes need to be changed or improved upon, she stated that her greatest concern, was not a specific change in ACA, but rather the issue of not being able to fully implement the Act without adequate funding. She fears that many proposed plans of the ACA would not end up being funded, and therefore, not enacted. In a joking tone she said:

> If I had a magic wand I would ensure they were all funded. In relation to the healthcare delivery standpoint and the insurance coverage stand point; there are a lot of things that still need to be ironed out. To get into the nitty-gritty is very challenging. My overwhelming concern is that without funding for community transformation, grants are going to be nonexistent. So the potential impact of ACA will not be realized if it is not properly funded.

When I prompted her to talk about the aspects of insurance coverage, and the effect it will have on the current uninsured population in Onondaga County she stated, “I am not comfortable getting into the details of the insurance aspect because that deals with the impact on the health delivery system, rather than the public health, which is my area.” Therefore, although she stated that she thought one of the most important outcome of the ACA was its capacity to increase access to health coverage, she was not comfortable expressing an opinion or entering

into a discussion about the plans and implication the ACA will have on the health insurance coverage process.

Discussion

The research hypothesis that there is a large disconnect between political actions and the perspective, needs, and comprehension of uninsured people who the Affordable Care Act are attempting to effect seems to be true. The conundrum stems from the lack of comprehension of patients who are currently without health insurance maintain about the details of the Affordable Care Act. Based on the information that can be deduced from the interviews conducted, it is clear that there are several reasons that contribute to this breakdown in communication and understanding.

Firstly, the people that are currently uninsured in the Syracuse, NY area are unsure where they can obtain the information they need to properly understand and formulate an opinion on the Act, as well as take the necessary measures to apply for coverage. All of the 10 people interviewed at the clinic stated that they had heard about the ACA, yet only 1 of the 10 had a clear understanding of the stipulations and potential impacts of the act. The one person who stated that she had a clear comprehension of the act was a nurse, and therefore, was heavily involved in the healthcare field and reforms surrounding it.

The majority of the patients at the Amaus Clinic, receive their information about the ACA either through word of mouth, within their communities, or through media outlets. Therefore, the information is not always completely accurate and often times biased.

Secondly, people stated when they attempted to actively seek out more information about the Act, they were unable to understand the political jargon

used in many of the publications about the ACA. Another contributing factor is, the unwillingness of politicians to speak out about the ACA, due to the controversial nature of the act. This makes it difficult for the people of Onondaga County to sort through all the information. If their political representatives are extremely elusive about the topic, it is obvious that there will be low levels of comprehension, support, and actions taken.

This project only scratches the surface on this issue. This is a relatively small-scale project, yet it highlights a real problem and need for intervention. There needs to be some sort of political action or campaign to help the uninsured populations to better understand the ACA. There needs to be a program that can help educate the general public and provide clear and detailed descriptions of the ACA's intentions, stipulations, and how to gain coverage. Without some sort of community based educational outreach the ACA will fail to meet needs of the population simply due to misinformation.

Conclusion/Limitations

Overall this study was effective in investigating the Affordable Care Act and its predicted effect on the uninsured population; however, there were several limitations that arose throughout the research process that could have had an effect on the results.

First, there were much fewer interviews conducted with healthcare officials and policy-makers than was originally proposed. This was due to difficulty contacting and receiving an answer from many of the political offices. This may further lend to the frustrating nature of the miscommunication between politicians and the general public.

Secondly, although the uninsured patient interviewee population was racially and ethnically diverse, there were more females interviewed then males. This was based on the population available to be interviewed at the clinic. This could have had a small effect on the results, although this is not projected to be a very large effect.

Lastly, I was the sole researcher, under the supervision of Dr. Lane. Due to the fact that I designed the study, the thesis, and conducted all of the interviews, there could be some unintentional bias. Although, I made a conscious effort to avoid leading questions and did not divulge my own opinions on the topic or questions, there still could have been some subconscious bias or a leading in the tone when I asked some of the questions. This could have had a potential influence on the results, but hopefully this was minimal or nonexistent.

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Turner, V. (1987). Betwixt and between: The liminal period in rites of passage. *Betwixt and Between: Patterns of Masculine and Feminine Initiation, 3-19.*

Appendices

IRB Application
Capstone Flyer
Recruitment Script
Consent Form 1- Patient Consent Form
Consent Form 2- Policy Maker/Elected Official's Consent Form
Consent Form 3- Policy Maker/Elected Official's Electronic Consent Form
Interview Questions

SYRACUSE UNIVERSITY
INSTITUTIONAL REVIEW BOARD
Full Board Review or Expedited Review Application

Check which type of review is requested:

☒ Expedited Review- One signed copy of my application for **expedited** review.
Expedited review covers research that involves only minimal risk procedures. See Standard Operating Procedure 012. http://orip.syr.edu/files/SOP%20012%20-%20Expedited.pdf for guidance.

☐ Full Board Review- One original signed hard copy plus 13 copies (14 total) of my application
Includes research that cannot be reviewed using the expedited process involving more than minimal risk to the participant and requires review by the full IRB. See Standard Operating Procedure 013. http://orip.syr.edu/files/SOP%20013%20-%20Full%20Board.pdf for guidance.

Application Checklist:

X☐ All questions on the application have been answered.

X☐ The application has been signed by the investigator/faculty advisor and when appropriate, the student.

X☐ Copies of all appropriate, consent and/or assent documents (written, electronic, or oral consent script) are included.

X☐ Copies of any research instruments (surveys, questionnaires, interview questions, etc.) are included.

X☐ Copies of all recruitment tools (flyers, emails, posters, newspaper ads, etc.) are included.

X☐ All required appendices, including a list of references are included.

X☐ Copies of other IRB approvals or letters of cooperation are included. When the investigation is to be carried out in cooperation with another institution or with an investigator at another institution, a letter indicating the willingness of the institution to cooperate in the study must be included with the proposal.

X☐ The principal investigator/faculty member and student/research staff have completed the appropriate Collaborative Institutional Training Initiative (CITI) Web-based Training Program for Human Subjects required by SU.*

X☐ All students/research staff or any other individuals listed in the application who will have direct contact with participants and/or identifiable human participant data have completed the appropriate Collaborative Institutional Training Initiative (CITI) Web-based Training Program for Human Subjects required by SU.*

* Submission of CITI Training Certificate is required **only** if CITI training was completed at another institution.

I/We assure the IRB that the following statements are true: All information provided in this form is correct. I have evaluated this protocol and determined that I have the resources necessary to protect participants, such as appropriately trained staff, necessary facilities and equipment. I will seek and obtain prior written approval from the IRB for ***any modifications*** including changes in procedures, investigators/research staff, consent forms, questionnaires, surveys, etc. I will promptly report any unanticipated problems that may occur in the course of this study. I will report any significant findings which may affect the risks and benefits to participation. I will not begin my research until I have received written notification of final IRB approval. I will comply with all IRB requests to report on the status of my study. I will maintain records of this research according to IRB standards. If any of the above conditions are not met, I understand that approval of this research may be suspended or terminated.

Faculty Member/Principal Investigator
Signed_____ Date: November 9, 2012
Name (typed): Sandra D. Lane

Student/Research Staff
Signed: _____ Date: November 9, 2012
Name (typed): Sofia Seckler

This application must be typewritten and all questions must be answered. To complete form, tab to each field. Incomplete forms will be returned to the investigator for additional information.
Outdated applications will not be accepted for review.

To edit the content of the form -unprotect the document as follows:

For Office 2003 Users (or below)

- **Browse to View->Toolbars->Forms. The Forms toolbar will pop up.**
- **Click on the padlock icon on the right side. This will unlock the form.**
- **To protect the document again when you need to click on a checkbox, click on padlock.**

For Office 2007 Users

- **On the ribbon choose Review >Protect document>Restrict Formatting and Editing>Stop Protection.**
- **To protect the document again when you need to click on a checkbox, click on>Yes, Start Enforcing Protection>OK.**

1. Protocol Information

Title of Protocol: U.S. Healthcare System: The Political and Personal Perspective

***NOTE* The Principal Investigator (PI) must be a person who holds a faculty appointment or other administrative position of Director or higher. If you have any questions regarding this IRB requirement call the IRB office at 315.443.3013 for guidance.**

Principal Investigator/Faculty Member Information

First Name: Sandra	Middle Initial: D	Last Name: Lane
Title: Professor		
Department: Public Health	College: David B. Falk College of Sport and Human Dynamics	
Campus Address: 426 Ostrom Ave Syracuse NY 13210		
Campus Phone : 315-443-2048	Fax :	
Email: sdlane@syr.edu	Cell Phone (optional):	

Student/Research Staff Information ☐**NA**

First Name: Sofia	Last Name: Seckler
☐ Graduate Student ☒ Undergraduate Student ☐ Other:	
Department: Public Health	College: David B. Falk College of Sport and Human Dynamics
Local/Campus Address: 417 Comstock Ave. Syracuse NY 13210	
Local/Campus Phone: 732-539-4985	Fax:
Email: sgseckle@syr.edu	Cell Phone (optional):

2. Funding Information

2.1. Will/has the research been submitted as a grant or contract proposal?
☒ **No** ☐ **Yes**

Will/has the research been submitted through OSP?
☒ **No** ☐ **Yes**

If yes, who is the proposed sponsor and what is the title of the proposal submitted to OSP?

Sponsor:
Title:

2.2. Is this research currently being funded in part or in whole?

☒ **No** ☐ **Yes (indicate below)**

☐ **Internal Funding (check all that apply):**

☐ **Departmental Funds**	☐ **No cost study**	☐ **Personal Funds**
☐ **Gifts**	☐ **Other, specify:**	

☐ **External Funding (list all that apply and insert additional rows if needed):**

Agency/Sponsor	**Funding Mechanisms**	
	☐ **Grant**	☐ **Contract**
	☐ **Grant**	☐ **Contract**

2.3. Has the research been reviewed before the IRB?

☒ **No** ☐ **Yes**

If yes, please give the date of the review:
and the IRB# (if known):

2.4. Is this research to be performed:

for faculty research	**X☐ No**	☐ **Yes**
for a masters thesis	**X☐ No**	☐ **Yes**
for a doctoral dissertation	**X☐ No**	☐ **Yes**
as part of a course requirement	**X☐ No**	☐ **Yes**
as an honors thesis	☐ **No**	☒ **Yes**

Other (explain):

3. Study Rationale

3.1. Using non-technical language, describe the objective of this proposed research including purpose, research question, hypothesis, etc. From your description, the IRB should be able to determine how this proposed study adds to the knowledge on the research topic in order to judge the risks and benefits to the research participants. NOTE: A reference list citing relevant background information must be provided as an appendix with this application.

This project is a comparative research project focusing on the current state of the healthcare system. The purpose is to figure out if the politically proposed healthcare plan is in line with the experiences and opinions of those people who are uninsured. The research will consist of a series of interviews. Interviews will be conducted with two groups. The first group of interviews will be conducted to gather the political perspective. We will be contacting local and state officials to gather their opinions on healthcare and what their experiences and proposed actions are in relation to healthcare. The second set of interviews will be

focused on patients at the Amaus Clinic in downtown Syracuse. This clinic provides healthcare to the under served and uninsured population in the City of Syracuse. Interviews will be conducted gathering some of the patients experience with the healthcare system, how much they are aware of the political actions in relation to the healthcare bill, and if it were up to them what would they propose (there will be no identifying information collected for this set of interviews). The hypothesis is that there is a large disconnect between the political perspective and the perspective and comprehension of those who are actually affected by the healthcare bill. A list of refrences is attatched in the appendix.

4. Methods

4.1. Provide a detailed description of what participants will be required to do; including any technical terms or procedures.

There will be two types of interviews. First a set of interviews with elected officials and Health policy makers. I will ask that those officials decide whether they would like their answers to be confidential (not associating their name with their responses and/or not mentioning there name at all as being interviewed) or if they will allow me to quote them for attribution. These elected officials/health policy maker interviews will be with up to ten individuals. Including, Senators, Congress People or their staff, Commissioner of Health and other high administrative people in state or local health departments. The interview questions are provided in the appendix. The second set of interviews will be with uninsured individuals who are patients at the Amaus free clinic in downtown Syracuse. I have previously volunteered at this clinic and Dr. Satterly, the Clinic Director, has agreed to allow me to interview patients at the clinic pending Syracuse University IRB approval. The clinic patients will all be between the ages of 18-65. They will be interviewed with confidentiality in that their names will not be recorded on the interview documents and will not be associated with their answers, nor will their names be recorded any where in published or publically presented materials. I hope to interview up to 15 patients and these interviews will address the patient's experiences in obtaining health insurance. The patient interview guide is also in the appendix. All interview of patients and policy makers will be qualitative and in depth. I will request that the interviewees allow me to digitally record their voices and they will check their agreements in the signed informed consent document.

4.2. Describe how you will have sufficient time to conduct and complete the research?

We will be devoting an entire semester and independent study class to conducting this research.

4.3. Surveys, interviews, questionnaires will be conducted:

☐ **No (Skip to 4.4)**
☒ **Yes Include all research instruments including surveys, questionnaires, sample interview questions, etc. as separate appendices. If the survey instrument is commonly used in your discipline, only provide a citation to the instrument.**

4.4. Community Based Participatory Research (CBPR) is described as research that is conducted as an equal partnership between traditionally trained "experts" and members of a community. Is this research categorized as CBPR?
☒ **No. (Skip to 4.5)**
☐ **Yes. Please explain:**

4.4.1. In CBPR research studies, the community participates fully in all aspects of the research process including conception, design, and analysis. With this in mind, describe how you plan to engage community members in your research study:

4.4.2. Describe how you plan to provide community members with appropriate training for human subjects research? Include in your description what training will be provided.

4.4.3. Describe your plan to disseminate research findings with members of the community throughout the course of your study.

4.5. Will this research be conducted by SU investigators in foreign countries?
☒ **No. (Skip to 4.6)**
☐ **Yes. An International Research Form must be completed and submitted with this application.**
http://orip.syr.edu/files/International%20Research.doc

4.6. Will this research involve genetic testing?
☒ **No. (Skip to Section 5)**
☐ **Yes. A Genetic Research Form must be completed and submitted with this application. http://orip.syr.edu/files/Genetics.doc**

5. Performance Site Information

5.1. Describe how you will have adequate facilities to conduct your study.

The interviews for the patients of (Amaus) will be conducted at the clinic. All of the elected official and policy-maker interviews will take place in their offices or over the telephone.

5.2. List all Performance Sites Other than SU *(insert additional rows if needed).*
(*This may apply when a SU investigator collaborates with a non-SU investigator or institution. Please check all that apply and add additional sites. Each will require a letter of cooperation and/or IRB approval.*)

Check all that apply	Name of Performance Site (list all participating sites below)	IRB Approval and/or Letter of Cooperation

☐	SUNY Upstate Medical University	☐ Attached ☐ Pending
☐	*Syracuse City Schools	☐ Attached ☐ Pending
☒	*Other, specify site: Amaus Clinic	☐ Attached ☒ Pending

The following additional information is required: contact information for the site, if the site has an IRB, and whether the IRB has approved the research, or plans to defer review to SU's IRB:

Amaus does not have an IRB and will defer to the SU IRB.

5.3. Will this research be conducted in a school or is it funded by the US Department of Education?

☒ **No (Skip to 5.4)**

☐ **Yes. If yes, complete the form found at:**

http://orip.syr.edu/files/Research%20Sponsored%20by%20the%20US%20Department%20of%20Education%20and-or%20Conducted%20in%20Schools.doc

5.4. Is this a multi-center research project in which Syracuse University will function as the coordinating center/lead institution? (*A multi-center study is one where different PIs at different institutions are conducting the same study.*)

☒ **No**

☐ **Yes. If yes, describe the plans to manage information obtained in multi- site research that may be relevant to the protection of research participants such as: unanticipated problems involving risks to participants or others, interim results, and protocol modifications:**

6. Research Qualifications

CITI training is required for the faculty member listed below and all researchers and research staff who have direct contact with participants and/or identifiable human participant data. NOTE: If training is not completed at the time of submission, approval of your application will be delayed.

6.1. List the names and research qualifications of the primary investigator/faculty advisor listed in Section 1 of this application.

Sandra D. Lane, Ph.D., MPH is a professor of public health and anthropology at Syracuse University and a research professor in the Department of Obstetrics and Gynecology at Upstate Medical University. Her work has been funded with 17 external grants, from the CDC, HRSA, EPA, DHHS and private foundations. Lane has published 30 peer reviewed journal articles, 19 book chapters and a 2008 book, "Why Are Our Babies Dying? Pregnancy, Birth and Death in America." She teaches a yearly course in Public Health Ethics and has completed the CITI course.

6.2. List the names and research qualifications of the student/research staff listed in Section 1 of this application.

Sofia Seckler is the student who will be conducting this research under the direction of Dr. Lane. She will be taking Public Health Ethics 415 in the Spring Semester with Dr. Lane. She has completed the CITI course and has done previous research with Dr. Lane and other professors. Therefore, she is familiar with the protection of human subject and research methods.

6.3. List the name(s) and research qualifications of all other individuals who will be involved in this research and will have direct contact with participants and/or identifiable human participant data.
None

6.4. How will you ensure that all persons listed above are adequately informed about the protocol and their research related duties and functions?
There are only two individuals Dr. Lane and Sofia Seckler who will work on this project and both of them have written the protocol together.

6.5. Explain how you will have adequate numbers of qualified staff to conduct your study.
We have addressed these issues in that in the Spring 2013 semester Ms. Seckler will be able to devoting approximately 400 hours of work to this project.

7. Characteristics of Participants

7.1. Approximate Number of Participants to be recruited:
Elected Officials/Health Policy Makers= 10 participants; Amaus Patients= 15 participants.

7.2. Sex: M ☐ F ☐ Both ☒

7.3. Age Range-Check all that apply:
- ☐ **0-6 (Include parental consent form)**
- ☐ **7-17 (Include parental consent form and child assent form)**
- ☒ **18-64**
- ☒ **65 and older**

Exact ages to be included:

7.4. When the age range indicates an upper limit, provide justification:
The Amaus Patients will have an Upper age limit of 65 because at that age people become eligible for Medicare Insurance and therefore, would not be uninsured. The Policy Makers and Elected Officials may be within the upper age limit of 65 and older

7.5. Does this study target one gender or specific social/ethnic group(s)?
- ☐ **No. (Skip to 7.6)**
- ☒ **Yes. If yes, answer 7.5.1. and 7.5.2. below.**

7.5.1. If yes, check all that are targeted/vulnerable populations (Code of Federal Regulations: http://www.access.gpo.gov/nara/cfr/waisidx_00/45cfr46_00.html).

***These additional forms can be found on the IRB Website under Special Populations:**

http://orip.syr.edu/human-research/forms-list/forms.html

- ☐ **Children/minors - *Requires additional form***
  - ☐ **Cognitively impaired - *Requires additional form***
- ☐ **Prisoners - * Requires additional form***
- ☐ **Pregnant women - *Requires additional form***
- ☐ **Legally restricted, non-prisoner**
- ☐ **Educationally disadvantaged**
- ☒ **Economically disadvantaged**
- ☐ **Elderly/aged**
- ☐ **Other, specify:**

***NOTE*: These additional forms can be found on the IRB Website (under Special Populations): http://orip.syr.edu/human-research/forms-list/forms.html**

7.5.2. Explain the rationale for using this particular group(s):

7.6. List the inclusion criteria:

Elected Officials/Policy Makers:

-An elected Official or Administrator in an agency that deals with public health who agrees to participate with written informed consent.

Amaus Patients:

-A patient at the Amaus Free Clinic who is between the ages of 18 and 85 and is uninsured.

-A patient at the Amaus Free Clinic who agrees to participate with written informed consent.

7.7. List the exclusion criteria:

Amaus patients who have health insurance.

Policy Makers and Officials have no exclusion criteria.

7.8. Does this research involve participants likely to be vulnerable to coercion or undue influence?

- ☒ **No. (Skip to 7.9)**
- ☐ **Yes. If yes, describe the additional protections included in the protocol to protect their rights and welfare.**

7.9. General state of Health: ("Unknown"- *unless you will obtain health data on participants prior to beginning the study.*)

Unkown

8. Recruitment of Participants

8.1. Describe in detail how participants will be identified and recruited. Include in your description how you will have access to a population that will allow recruitment for the number of participants required for your research. Do not merely state "Volunteers".

Recruitment of Elected Officials/Policy Makers: I will recruit the Elected Officials/Policy Makers based on their statements in the press about the Affordable Care Act. Also, other leading officials will be recruited, such as the Onondaga County Commissioner of Health and Commissioner of Mental Health.

Recruitment of Amaus Patients: Will be recruited with the following protocol. Dr. Satterly, the Clinic Director, will ask patients if they would like to speak with researcher (Sofia Seckler) and will give them an information sheet about the research. Sofia Seckler will sit in a large room near the patient care site and patients who are interested in being interviewed after speaking with Dr. Satterly can directly approach Sofia. She will explain to patients about the research and those who choose to participate at that time can sign the written informed consent. Patients may choose to participate at a later date. Sofia will be at the clinic on a regular basis when it is open and will interview patients when they choose, within the clinic hours of operation.

8.2. Describe who will recruit participants.

Sofia Seckler, the student researcher, will be primarily responsible for going to the clinic and recruiting volunteers to participate in the study as well as contacting political figures for interviews. Sandra Lane will also be assisting, in helping to contact political officials

8.3. Identify all applicable recruitment methods that apply: NOTE:Copies of all advertising materials including flyers, posters, ads, letters, scripts or detailed descriptions; including graphics MUST be provided with your application. (See SOP 036 for Recruitment/Advertising).

☒ **Flyers** ☐ **Mass E-mail Solicitation**

☐ **SU Today News Service**

☐ **Internet** ☐ **Posters**
☐ **Television**
☐ **Letter** ☐ **Newspaper**
☐ **Departmental Research Boards**
☒ **Telephone** ☐ **Radio**
☐ **Social Media**
☒ **Other (describe):** Asking patients at the clinic while they are waiting to be seen if they would be willing to be asked a few questions.
☐ **Not applicable**

8.4. Will participants be compensated?
☐ **No. (Skip to Section 9)**
☒ **Yes. If yes, answer 8.4.1. and 8.4.2. below.**
Note: All information regarding compensation must be included in consent/assent documents.

8.4.1. If Yes, specify the method of compensation (e.g. monetary, course credit, gift card, toy, etc.), the amount of compensation, and how the compensation will be awarded (per task, per session, etc.).
The Patients at the Amaus Clinic will receive ten dollars each for their participation in the interview. The policy makers and officials will not receive compensation.

8.4.2. Describe how compensation will be awarded if the participant withdraws after beginning the study. Compensation must be pro-rated in a manner that recognizes the time and effort of the participant prior to withdrawal.
The Patients will receive the ten dollars regardless of how many questions they answer. They will also receive the compensation regardless of whether or not they end the interview early.

9. <u>Informed Consent Procedures</u>

Consent is required for all human subject participants. Final copies of <u>ALL</u> consent/assent documents (including electronic or oral scripts) must be provided for IRB approval and date stamping. Informed consent/assent documents must be on *official SU departmental letterhead.* For guidance regarding informed consent, consult SOP 017-Documentation of Informed Consent
http://orip.syr.edu/files/SOP%20017%20-%20Document%20of%20Informed%20Consent.pdf **.**
For consent form instructions/sample visit:
http://orip.syr.edu/files/Consent%20Form%20Guidelines.doc
http://orip.syr.edu/files/Consent%20Form%20Sample.doc
For assent form instructions/sample visit:
http://orip.syr.edu/files/How%20to%20Prepare%20a%20Child%20Assent%20Document%20and%20Assent%20Sample.doc

9.1. How many consent documents are included with this application? 2

9.2. How many assent documents are included with this application? 0

9.3. Is more than one consent/assent document included with this application?
☐ **No. (Skip to 9.4.)**
☒ **Yes. If yes, follow instructions below (9.3.1 and 9.3.2).**
9.3.1. Assign form numbers to each individual document and add it to the footer of the document-e.g.
Consent form 1, Consent form 2, Assent form 1, etc.
9.3.2. Create a separate log as an appendices identifying each document-e.g. Consent form 1-parental consent, Consent form 2-adult participant consent; Assent form 1-child assent, etc.)

9.4. Indicate the type of consent you will obtain for your study (check all that apply).
9.4.1. Written Consent ☒ **(ATTACH COPY)**
Provide a brief statement of what will be said when the consent process is initiated:
Written consent for the patients at the clinic and written consent for the face-to-face interviews with the officials and health policy makers. For the phone interviews with officials and policy makers there will be an electronic consent.

9.4.2. Electronic Consent ☐ **(ATTACH SCRIPT)** *(This is a request to waive the required element of documentation of written consent, e.g. internet studies.)*

9.4.3. Oral Consent ☐ (ATTACH SCRIPT)
Provide the justification for the waiver of written consent:

9.4.4. N/A ☐ **Data Analysis Only, no consent form required.**

9.5. Who will conduct the consent interview?
Sofia Seckler

9.6. How will you ensure that prospective participants have sufficient opportunity to consider whether or not to participate in your study?

The nurses at the Amaus clinic will give flyers to the patients after their appointment. Those patients who are interested after reading the flyer will be directed to the researcher (Sofia Seckler) who will give them information about the research. Sofia Seckler will sit in a large room near the patient care site and patients who are interested in being interviewed can directly approach Sofia. She will explain to patients about the research and those who choose to participate at that time can sign the written informed consent. Patients may choose to participate at a later date. Sofia will be at the clinic on a regular basis when it is open and will interview patients when they choose, within the clinic hours of operation. For the elected officials and policy makers, Sofia Seckler will call them. During the phone call Sofia will read the recruitment script and briefly explain the study. If they agree she will email them the informed consent documents, If after reading the informed consent document they decide they would

like to participate, she will either set up a meeting time or schedule a phone interview. For the policy makers and elected officials who will be participating in face-to-face meetings, she will collect the signed consent form before the interview begins. For the elected officials and policy makers that have are going to participate through a phones it will be requested that they send back a confirmatory email stating that they have read the document and agree to participate.

9.7. What steps will be taken to minimize the possibility of coercion or undue influence?

The informational flyer and the written informed consent documents, and the research will also state, that participation in the study is entirely volunteer and will no way effects the patients ability to receive services at the clinic. Furthermore, the patients will be free to come to the researchers table, in the corner of the larger room, and those who choose not to will not come to the table. The policy makers and officials are unlikely to feel coursed by the researcher because they regularly interact with journalists and other news reporters from the media. Never the less, the informed consent document for the policy makers and officials will state that they can refuse the interview, stop the interview at any time, or choose not to answer any questions in the interview.

9.8. An ASSENT statement is required for participants who cannot legally give consent themselves. Assent statement:

☒ **No (Skip to 9.9)**
☐ **Yes (ATTACH COPY)**

9.8.1. From whom will consent be obtained and by what means for minors or the individuals considered to be cognitively impaired in their decision making ability? ☐ **N/A**

9.8.2. If subjects are minors, will they still be involved in the study when they reach the age of majority (18)?

☐ **No**
☐ **Yes. If yes, outline your plan to re-consent these participants when they reach the age of majority.**
☐ **N/A**

9.9. Will non-English speaking individuals be participants in the research?

☒ **No (skip to Section 10)**
☐ **Yes If yes, indicate how consent will be documented from non-English speaking participants?**

☐ **A translated written informed consent document in a language understandable to the participant. This should be an accurate translation of the full informed consent. (ATTACH COPY)**

Identify the name of the individual or translation service that provided the translation of the consent document.

List the qualifications of the individual or translation service that provided the translation of the consent document.

☐ **Orally, using a qualified translator to translate the English informed consent document to the participant, and a translated short form in a language understandable to the participant (ATTACH COPY) Identify the name of the individual or translation service that will provide translation for the consent process and during the conduct of the research.**

List the qualifications of the individual or translation service that will provide translation for the consent process and during the conduct of the research.

☐ **A confidentiality statement from**

10. Potential Financial Conflict of Interest

A conflict of interest exists when any investigator or personnel listed in this research protocol's financial interests may reasonably be affected by research, scholarship, educational or other externally funded activity. Or, when the immediate family* of anyone in such a role, have significant financial interests that may compromise, or have the appearance of compromising, an investigator's professional judgment that could directly and significantly affect the design, conduct, or reporting of the research, proposed or funded.

Federal Guidelines emphasize the importance of assuring there are no conflicts of interest in research projects that could affect the welfare of human participants. If this study involves or presents a potential conflict of interest, additional information will need to be provided to the Vice President for Research.

The following significant financial interests must be disclosed if interest is in the sponsor of the research or the product being tested:

Anything of monetary value - aggregated for the Investigator and the Investigator's spouse, domestic partner, and dependent children - including but not limited to the following:

a. Salary or other payment for services (e.g. consulting fees) of $10,000 or greater in the past year when aggregated for the immediate family;
b. Any equity interest (e.g. stocks, stock options or other ownership interests) unless it meets the following three tests:
    i. less than $10,000 in value as determined through reference to public prices or other reasonable measures of fair market value (e.g. most recent sales price recognized by the company),
    ii. constitutes less than a 5% ownership interest in any single entity, or
    iii. publicly traded on a national stock exchange,
    iv. no arrangements have been made where the value of the interest will be affected by the outcome of the research.
c. Intellectual property rights (e.g. patents, copyrights and royalties from such rights).

d. Services as an officer, director, or in any other executive position in an outside business, whether or not remuneration is received for such service.
e. Any compensation or equity interests that may be influenced by a particular outcome in sponsor-funded research, even if the identified thresholds are not met.

Syracuse University Policy on Conflict of Interest for Research Investigators: **http://orip.syr.edu/files/SOP%20032%20%20Institutional%20Conflict%20of%20Interest.pdf**

**Immediate family means a spouse, domestic partner or dependent children.*

10.1. Do any of the investigators or personnel listed in this research protocol, or members of the immediate family of the investigators or personnel, have a financial interest associated with this study that require disclosure?

☒ **No (Skip to question 10.3)**

☐ **Yes; If yes, identify the individual(s):**

10.2. Has this financial interest been disclosed and managed?

☐ **Yes. The Office of Research Integrity and Protections will verify that a management plan is in place with the Vice President for Research.**

☐ **No. If the Vice President for Research does not have an approved management plan for this research, complete Parts I and II of the Disclosure of Significant Financial Interest Form (http://osp.syr.edu/forms%20and%20pages/Forms/COI%20-%20Disclosure%20of%20Financial%20Interests%20Form.PDF) and submit it to the *Office of the Vice President for Research, 207 Bowne Hall*.**

10.3 To your knowledge, did the University, or your School/Department receive a gift or equipment donation, or promises thereof, from commercial sponsors of this research project?

☒ **No**

☐ **Yes; If yes, identify the sponsor:**

Final IRB approval cannot be granted until all potential conflict matters are settled. The IRB requires a recommendation from the Vice President for Research regarding disclosure to participants and management of the conflict.

11. <u>Data Collection, Storage of Data and/or Confidentiality</u>

Confidentiality pertains to the treatment of information that an individual has disclosed in a relationship of trust with the expectation that it will not be divulged to others in ways that are inconsistent with the understanding of the original disclosure without permission.

11.1. Specify the individually identifiable data you will obtain, use or disclose to others.

The policy makers will be requested to go on the record, in that we would like to identify their names with their responses. They will also be offered the option of having their responses be confidential. Therefore, we will not associate their names with their response. We would also not mention their names in any public document as

having being interview. For the Amaus patients we will make every effort to assure the confidentiality. Therefore all the research documents, the transcript of their interview, and the digital recording of their voice will not have their names. The only place their names will appear is on their written informed consent document. There will be no individually identifiable data obtained or disclosed for the patient interviews. There will be individual data obtained for the political interviews, yet they will have the option if they would like their name or other identifiable information to be disclosed or not

11.2.Describe how data will be maintained (e.g., paper or electronic spreadsheet, desktop computer, laptop or other portable device); how you will maintain the confidentiality and data security, (e.g., password protected computer, encrypted files, locked cabinet and office); and who will have access to the data (e.g., research team, sponsors, consultants).

We will request permission from all the interviewees (policy makers and officials and the Amaus patients) to digitally record the interviews. In the case that we do not receive permission to record the interview, but the interview still agrees to participate in the interview we will take carful hand written notes during the interview. For all Amaus patients and for the policy makers and officials who do not want their responses to be on the record none the research documents will have their names on them. The digital audio recordings will be transcribed into a word document without any names attached, except for those policy makers who have agreed to be interviewed on the record. Once the digital recordings are transcribed they will be deleted. All research material (digital recordings and word documents) will be kept on the Syracuse University secure server in a shared drive that is password protected with Dr. Lane and Sofia Seckler.

11.3 If you will be sharing data with others, describe how data will be transferred (e.g., courier, mail) or transmitted (e.g., file transfer software, file sharing, email). If transmitted via electronic networks, describe how you will secure the data while in transit.

There will be no sharing of data, only Dr. Lane and Sofia Seckler will have access to the data.

11.4 If you plan to code the data, describe the method in which it will be coded and indicate who will have access to the key to the code.

We will not Code the data in a way that I can be associated with the names of individual, with the exception of policy makers and officials who choose to go on the record. All the others will have their interview type and a number (i.e. 1-15) but their interview number will not be associated with their name.

11.5 How will you educate research staff to ensure they take appropriate measures to protect the privacy of participants and the confidentiality of data collected.

The research will only include Dr. Lane and Sofia Seckler. Sandra D. Lane, Ph.D., MPH is a professor of public health and anthropology at Syracuse University and a research professor in the Department of Obstetrics and Gynecology at Upstate Medical University. Her work has been funded with 17 external grants, from the CDC, HRSA, EPA, DHHS and private foundations. Lane has published 30 peer reviewed journal articles, 19 book chapters and a 2008 book, "Why Are Our Babies Dying? Pregnancy, Birth and Death in America." She teaches a yearly course in Public Health Ethics and has completed the CITI course. Sofia Seckler is the student who will be conducting this research under the direction of Dr. Lane. She will be taking Public Health Ethics 415 in the Spring Semester with Dr. Lane. She has completed the CITI course and has done previous research with Dr. Lane and other professors. Therefore, she is familiar with the protection of human subject and research methods.

Privacy can be defined in terms of having control over the extent, timing, and circumstances of sharing oneself (physically, behaviorally, or intellectually) with others.

11.6 Describe what provisions are in place to protect the privacy interests of participants, where "privacy interest of participants" refers to the participant's desire to limit interventions or interactions with others and to limit access of others to their private information. Examples include: location of data collection (private location vs. public location), method of data collection (focus groups vs. one-on-one interview, questionnaires vs. interviews, telephone, email and mail communications), type of information (written vs. oral), recruitment methods and cultural norms.

In reference to the Amaus patients the interview will be conducted in a corner of a large room at a private table far enough away so that conversations cannot be over heard. In the case of the policy makers and officials the interviews will be conducted in private in their offices or over the phone.

11.7 Will audio, video or film recording be used?

☐ **No. (Skip to Section 12)**

☒ **Yes. If yes, specify type of recording:** Digital Voice Recording Device

11.7.1 Describe the storage of the recordings. Include in your description who will have access to the recordings, as well as how and where they will be stored.

The stored recording will be kept on Dr. Lane's computer on a shared drive on the Syracuse University Server. It will be password protected and only accessible by Dr. Lane and Sofia Seckler. Once the interviews have been transcribed the digital recordings will be destroyed. Further, we will request that the interviewees do not mention their names or other people names during the interview therefore the interview recoding themselves will not contain any names, with the exception of any policy makers or officials who choose to have their names on the record.

11.7.2 How long will the recordings be kept and what is the disposition of the recordings once the research is complete.

Once the recordings are transcribed they will be immediately deleted.

NOTE: ***Specific permission for each type of recording must be sought in the consent form and should be indicated at the end of the document using checkboxes (_ I agree to be audio taped, _ I do not agree to be audio taped, _ I agree to be video taped, _I do not agree to be video taped, etc.)***

12. Risk to Participants

12.1. Describe in detail any possible physical, psychological, social, political, legal, economic, or other risks to the participants, either immediate or long range. Risk may be minimal but never totally absent. Do not say "No Risk".

There is minimal risk to participants. The elected officials/health policy makers will not be talking about private information they will be discussing public policy issues that their work addresses. The Amaus patients may feel some discomfort or some anxiety in discussing the issues that they have faces that have caused them to be without health insurance.

12.2. Describe what procedures will be used to minimize each risk you have stated above. Also, include in your description the availability of medical or psychological resources that participants might require as a consequence of the research, if applicable. If participants need to be debriefed at the end of the study, a copy of the debriefing statement must be attached.

For the Amaus patients if they appear to feel anxious of uncomfortable we will refer them, with their consent, to Dr. Satterly who will be present in the clinic at the time that the interviews will be conducted.

12.3. Does this research involve more than minimal risks to participants?

☒ No. (Skip to Section 13)

☐ **Yes. If yes, please provide plan for monitoring the data collected to ensure the safety of participants. (Your data safety monitoring plan must include the following: Description of who will monitor the data, what data will be monitored, how frequently will it be monitored, what analysis will be performed on the data, what decision rules (e.g. stopping rules) will be considered, if unexpected harms will be detected promptly, if an increased frequency or severity of unexpected harms will be detected promptly, if the protocol will be stopped once harms are proven to outweigh benefits.).**

13. Benefits

Note: Course credit or payment is an inducement to participate in the study and should not be described as a benefit of the research.

13.1.Describe any benefits to the participants in general.

The benefits for policy makers and officials are probably minimal for them specifically. The Benefit to the patients at the Amaus Clinic may appreciate being able to tell somebody about their struggles or experiences.

13.2.Society at large.

This study is an attempt to figure out what the opinions of the government and the opinion of people who are actually dealing with limited access to healthcare, and then compare the two.

13.3.Explain how the benefits outweigh the risks involved.

The benefits of this study out way the risks. This study is an investigative research project that can only benefit society by providing another perspective, more information, and opinions on the topic of healthcare.

A number will be assigned to your protocol. Please refer to it whenever calling or writing for information.

- **All supporting documentation including list of references, consent and/or assentform(s),surveyinstruments, interviewquestions, recruitment materials, letters of support, IRB approvals from other institutions, etc. must be included with the application.**

Return Completed Protocol To:

Office of Research Integrity and Protections

121 Bowne Hall
Syracuse University
Syracuse, NY 13244
Phone: 315-443-3013

Please send IRB notifications by:
☒ **Hard copy campus mail. All correspondence mailed to the PI/faculty member's address.**
☒ **Email notification (Only the original hard copies of date stamped consent/assent documents will be returned.)**

Capstone Flyer:

SYRACUSE UNIVERSITY AND THE AMAUS CLINIC

U.S. Health Care System: The Political and Personal

DAIVD B. FALK
SCHOOL OF SPORT AND HUMAN DYNAMIC
426 OSTROM AVE.
SYRACUSE, NY 13244

Phone: 315– 443-2048
Dr. Lane– sdlane@syr.edu
Sofia Secklcr– sgscckle@syr.edu

What to Learn More about Health Care?

This project is a comparative research project focusing on the current state of the health care system. The purpose is to compare the politically proposed health care plan to the experiences and opinions of those people who have first hand experience with the health care system.

Answer a series of interview questions and receive $10 dollars for participating.

Interviews will take place at the Amaus Clinic and will take approximately 20-30 minutes.

Recruitment Script:

Amaus Patients:

My name is Sofia Seckler, and I am an undergraduate student at Syracuse University. Dr. Sandra Lane is supervising my research. I am inviting you to participate in a research study. The purpose of the research is to figure out if there is a disconnect between the politically proposed healthcare plan and the experiences and opinions of those people who have first hand experience with being under or uninsured. In order to be eligible for this study you must be a patient at the Amaus Clinic and have no health insurance. Involvement in the study is voluntary, so you may choose to participate or not. The research will take place at the Amaus clinic. I am going to ask you 10 interview questions, which will take about 20-30 minutes. You many choose to answer all, some, or none of the questions. You will be awarded $10 for your participation. If you would like to participate you can contact Dr.Lane or myself by email. (Sofia Seckler: sgseckle@syr.edu, and Dr. Lane: sdlane@syr.edu.)

Elected Policy Makers and Officials:

My name is Sofia Seckler, and I am an undergraduate student at Syracuse University. Dr. Sandra Lane is supervising my research. I am inviting you to participate in a research study. The purpose of the research is to figure out if there is a disconnect between the politically proposed healthcare plan and the experiences and opinions of those people who have first hand experience with being under or uninsured. In order to be eligible for this research you must be a New York State elected policy maker or offical that is currently in office. Involvement in the study is voluntary, so you may choose to participate or not. The research will take place in your office or over the telephone, whichever you prefer. I am going to ask you 5 interview questions, which will take about 20-30 minutes. You many choose to answer all, some, or none of the questions. If you would like to participate you can contact Dr. Lane or myself by email. (Sofia Seckler: sgseckle@syr.edu, and Dr. Lane: sdlane@syr.edu.)

Department of Public Health, Food Studies and Nutrition
David B. Falk College of
426 Ostrom Avenue
Syracuse, NY 13244
(315) 443-2048

U.S. Healthcare System: The Political and Personal Perspective

My name is Sofia Seckler, and I am an undergraduate student at Syracuse University. Dr. Sandra Lane is supervising my research. I am inviting you to participate in a research study. Involvement in the study is voluntary, so you may choose to participate or not. This sheet will explain the study to you and please feel free to ask questions about the research if you have any. I will be happy to explain anything in detail if you wish.

I am interested in learning more about different perspectives on the access to health insurance coverage. You will be asked to answer some interview questions on your experince with the healthcare system, your knowledge of political actions in relation to the healthcare bill, and if it were up to you what would they propose. This will take approximately 30 minutes of your time. All information will be kept *anonymous.* This means that your name will not appear anywhere and your specific answers will not be linked to your name in any way.

I would like to record our interview on a digital voice recorder. The purpose of recording the interviews is so I can accurately relay your confidential statements. The recording of the interview will be transcribed then immediately deleted. All research material (digital recordings and transcriptions) will be kept on the Syracuse University secure server in a shared drive that is password protected with Dr. Lane and Sofia Seckler.

You will receive the ten dollars for your participation in this study. You will receive the ten dollars regardless of how many questions you answer, or whether or not you end the interview early.

The benefit of this research is that you will be helping us to understand your experience with the U.S. Healthcare System and helping more people to have access to health insurance. This information should help us to better understand what patients go through to receive medical care. By taking part in the research

you may benefit from being able to tell somebody about your experiences. If you feel any discomfort or anxiety in discussing the issues surrounding your experiences we will refer them, with their consent, to Dr. Satterly who will be present in the clinic at the time that the interviews will be conducted. If you do not want to take part, you have the right to refuse to take part, without penalty. If you decide to take part and later no longer wish to continue, you have the right to withdraw from the study at any time, without penalty.

If you have any questions, concerns, complaints about the research contact the Dr. Lane or Sofia Seckler at (315) 443-2048. If you have any questions about your rights as a research participant, you have questions, concerns, or complaints that you wish to address to someone other than the investigator, if you cannot reach the investigator, contact the Syracuse University Institutional Review Board at 315-443-3013.

All of my questions have been answered, I am 18 years of age or older, and I wish to participate in this research study. I have received a copy of this consent form.

___ I agree to be audio recorded.

___ I do not agree to be audio recorded.

Signature of participant Date

Printed name of participant

Signature of researcher Date

Printed name of researcher

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I am interested in learning more about different perspectives on the U.S. Healthcare System. You will be asked to answer a handful of interview questions to gather your opinions on healthcare and what your experiences and proposed actions are in relation to healthcare. This will take approximately 30 minutes of your time.

If you agree I would like to interview you "on the record." By on the record I would like to include your name and your interview responses in public documents from this research.

If you choose to have your information not on the record confidential. By this I mean I will not associate your name with your responses in any research documents or public documents. I will also not include your name as a list of interviewees in any document.

I would like to record our interview on a digital voice recorder. The purpose of recording the interviews is so I can accurately relay your statements. The recording of the interview will be transcribed then immediately deleted. All research material (digital recordings and transcriptions) will be kept on the Syracuse University secure server in a shared drive that is password protected with Dr. Lane and Sofia Seckler.

The benefit of this research is that you will be helping us to understand the U.S. Healthcare System. This information should help us to This information should

help us to better understand what political opinions and action in terms of the Healthcare System. There are no benefits to you by taking part. There is minimal risk to participating in this study. You will not be talking about any private information, but rather discussing public policy issues that your work addresses. If you do not want to take part, you have the right to refuse to take part, without penalty. If you decide to take part and later no longer wish to continue, you have the right to withdraw from the study at any time, without penalty.

If you have any questions, concerns, complaints about the research contact the Dr. Lane or Sofia Seckler at (315) 443-2048. If you have any questions about your rights as a research participant, you have questions, concerns, or complaints that you wish to address to someone other than the investigator, if you cannot reach the investigator, contact the Syracuse University Institutional Review Board at 315-443-3013.

All of my questions have been answered, I am 18 years of age or older, and I wish to participate in this research study. I have received a copy of this consent form.

___ I agree to be audio recorded.

___ I do not agree to be audio recorded.

___ I agree to have my name on the record.

___ I do not agree to have my name on the record.

Signature of participant Date

Printed name of participant

Signature of researcher Date

Printed name of researcher

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If you choose to have your information not on the record confidential. By this I mean I will not associate your name with your responses in any research documents or public documents. I will also not include your name as a list of interviewees in any document.

I would like to record our interview on a digital voice recorder. The purpose of recording the interviews is so I can accurately relay your statements. The recording of the interview will be transcribed then immediately deleted. All research material (digital recordings and transcriptions) will be kept on the Syracuse University secure server in a shared drive that is password protected with Dr. Lane and Sofia Seckler.

The benefit of this research is that you will be helping us to understand the U.S. Healthcare System. This information should help us to This information should help us to better understand what political opinions and action in terms of the Healthcare System. There are no benefits to you by taking part. There is minimal risk to participating in this study. You will not be talking about any private information, but rather discussing public policy issues that your work addresses. If you do not want to take part, you have the right to refuse to take part, without penalty. If you decide to take part and later no longer wish to continue, you have the right to withdraw from the study at any time, without penalty.

If you have any questions, concerns, complaints about the research contact the Dr. Lane or Sofia Seckler at (315) 443-2048. If you have any questions about your rights as a research participant, you have questions, concerns, or complaints that you wish to address to someone other than the investigator, if you cannot reach the investigator, contact the Syracuse University Institutional Review Board at 315-443-3013.

All of my questions have been answered, I am 18 years of age or older, and I wish to participate in this research study. I have received a copy of this consent form.

___ I agree to be audio recorded.

___ I do not agree to be audio recorded.

___ I agree to have my name on the record.

___ I do not agree to have my name on the record.

If you agree to continue with the study please send a confirmatory email stating that you have read the above document and agree to participate in the study. Emails can be sent to Dr. Lane and/or Sofia Seckler at sdlane@syr.edu or sgseckle@syr.edu.

Amaus Patient Interview Questions:

1. Do you currently have health insurance?

2. If no, how long have you been without health insurance?

3. What caused you to loose your health insurance?

4. Have you tried to apply for health insurance coverage before?

5. What is the hardest part about being uninsured? What is the easiest part?

6. What do you usually do in order to obtain medical care?

7. Have you had any positive experiences in the healthcare system?

8. Have you had any negative experiences in the healthcare system?

9. Have you been paying attention to the congressional discussions about healthcare reform?

10. What are your opinions on that?

Policy Maker/Elected Official Interview Questions:

1. What is your stance on the Affordable Care Act (ACA)?

2. How did you come to this decision?

3. In my Public Health Class we have learned that Health Policy decisions should be based on research. What research have you or your staff review to come to your decision about healthcare reform?

4. What action are you taking in respect to the healthcare?

5. Do you think the current actions/plans are beneficial? What would you improve on or change?

Capstone Project Summary

The purpose of this research project was to explore if the proposed Affordable Care Act corresponds with the experiences, opinions, and needs of the uninsured populations in Syracuse, NY. The research consisted of a series of qualitative interviews. The qualitative interviews were designed to gather information on people's experiences and opinions with healthcare and on the ACA.

There were two main focus groups. The first being uninsured persons in the Syracuse, NY area, specifically those who attended the Amaus Clinic as their primary source of healthcare. This target population was selected based on my previous relationship with the clinic and my knowledge of the large uninsured population that frequented the clinic.

The second group of interviews were supposed to be conducted with Central New York policy makers and healthcare officials from a variety of different levels, areas, and parties. However, there were several roadblocks encountered with these interviews, which will be elaborated on later.

All of the interviews were intended to be qualitative and in-depth. I requested that the interviewees allow me to digitally record their voices, and they checked their agreements in the signed informed consent documents. The informed consent documents gave an in-depth description of the project, its purpose, and what was required from the participants. It was also clearly stated in the informed consent documents that the interviewees did not have to respond to anything they did not feel comfortable discussing.

The hypothesis was that there is a large disconnect between the political perspective and current actions, in comparison to the perspective, needs, and comprehension of those who are actually effected by the Affordable Care Act.

After the concept of this project was developed and a rough action plan was formulated, I, under the supervision of Dr. Sandra Lane, PhD, MPH, completed a Syracuse University Institutional Review Board (IRB) Expedited Application. The IRB approves all research projects that have anything to do with human subjects. They check the purpose, protocols, methods, and other elements involved in the project to ensure the project is ethical and ensures the protection of all participants. Once the approval was granted, the interviews at the Amaus Clinic commenced. It took approximately three and a half months to complete the 10 uninsured patient interviews.

As was stated previously, I volunteered at this clinic and Dr. Satterly, the Clinic Director, agreed to allow me to interview patients at the clinic after the Syracuse University IRB approval was granted. The clinic patients were all between the ages of 18-65. I approached them while they were in the waiting room and recited the proposed requirement script and gave them the flyer further explaining the project. All participants were notified that they would be interviewed with confidentially, in that their names were not recorded on the interview document, and were not to be associated with their answers, nor were their names to be recorded anywhere in published or publically presented materials. Also, they would receive a $10 stipend for their time and participation.

If the patients agreed to participate they were given a consent form. Once both the participant and myself signed it,, I proceeded with the interview.

All interviews were carried out in private medical examining rooms while the patient was waiting to be seen by a physician not only to ensure confidentiality, but also to guarantee the comfort of the patient to answer freely and not take time away from their daily routine. These interviews addressed the patient's struggles, accomplishments, and overall experiences as a stakeholder in the healthcare system. The questions also explored their knowledge of the Affordable Care Act and their opinions about the proposed action plans. The interviews were recorded, transcribed, and stored on a secure network that could only be accessed by Dr. Lane and myself.

The second set of interviews were conducted differently than the patient interviews. There was not one uniform way of carrying out the interview process based on the variety of the policy makers and healthcare official's positions, locations and availability. They were all contacted via phone or email using the proposed recruitment script. However, the original plan of conducting ten heath care officials and policy maker interviews was unable to be completed. Only one politician, Cynthia Morrow, M.D., PhD, the Commissioner of Health for Onondaga County, agreed to participate in the project.

There were several different reasons why the healthcare officials and policy makers did not participate in this research project. Some representatives, such as Senator Schumer's Office and the Office of Onondaga County Executive Joanie Mahoney, did take the time to discuss the project with me, yet they said

they would need to get back to me on whether or not they would accept the invitation to formally participate. However, after about a month of repetitive calls and emails there was no response or sign of participation. Others, such as Syracuse Mayor Stephanie Miner's Office, declined to participate. They stated that they did not want to share a public opinion on the issue. Others, such as New York State Assembly member Brian Kolb, did not respond at all.

Dr. Cynthia Morrow, M.D., PhD, was contacted by telephone, and I spoke to her secretary. The pre-written requirement script was utilized. We arranged a phone interview for the following week. Before the interview, I sent I copy of the consent form to her office, which stated the option to have Dr. Morrow's answers be confidential or allow me to quote them for attribution. Luckily, she agreed to allow me to associate her name with her responses. Again, the interview was recorded, transcribed, and stored on a secure network that could only be accessed by Dr. Lane and myself.

It was concluded that the research hypothesis, that there is a large disconnect between political actions and the perspective, needs, and comprehension of uninsured people who the Affordable Care Act are attempting to help, seems to be true. The problem stems from the lack of comprehension of patients who are currently without health insurance maintain about the details of the Affordable Care Act. Based on the information that can be deduced from the interviews conducted, it is clear that there are several reasons that contribute to this break down in communication and understanding.

Firstly, people that are currently uninsured in the Syracuse, NY area are unsure where they can go get the information they need to properly understand and formulate an opinion on the Act, as well as take the necessary measures to apply for coverage. The majority of the patients at the Amaus Clinic, receive their information about the ACA either through word of mouth, within their communities, or through media outlets. Therefore, the information is not always completely accurate and often times it is biased.

Secondly, people stated when they attempted to actively seek out more information about the Act, they were unable to understand the political jargon used in many of the publications about the ACA.

Another contributing factor is the unwillingness of politicians to speak out about the ACA, due its controversial nature. This makes it difficult for the people of Onondaga County to sort through all the information. If their political representatives are extremely elusive about the topic, it is obvious that there will be low levels of comprehension, support, and actions taken.

This project is significant because it illuminates an important unmet need within the Syracuse community. This project only scratches the surface on this issue. This was a relatively small-scale project, yet it highlights a real problem and need for intervention. There needs to be some sort of political action or campaign to help the uninsured populations to better understand the ACA. There needs to be a program that can help educate the general public and provide a clear and detailed description of the ACA's intentions, stipulations, and how to gain

coverage. Without some sort of community based educational outreach the ACA will fail to meet the needs of the population simply due to misinformation.