Reliable Analytics for Disease Indicators: Leveraging Smart Devices to Predict Health
(Technical Topic)

An Actor Network Theory Approach to the Improvement of Health Care in Rural America
(STS Topic)

A Thesis Prospectus Submitted to the

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On my honor as a University Student, I have neither given nor received unauthorized aid on this assignment as defined by the Honor Guidelines for Thesis-Related Assignments

Signature ____ Date __________

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Peer Review and Comments

Thank you to the people below whom have helped shape my prospectus; all of their suggestions have been noted with highlighted text.

Professor Michael Gorman provided guidance in my STS 4500 class with ways of thinking about my topic, specifically applying the Actor-Network Theory framework to my topic. He suggested that using that lens would allow me to analyze what causes instability in the system and how to fix it. I will use this guidance in analyzing "descriptive": what is, and "normative": what should be actor-networks.

My Capstone professor Laura Barnes informed me of current events (see HARPA) related to ethics and wearable technologies. This guidance allowed me to get a better picture of how these technologies are seen by the media and the general public.

My Capstone team co-authored and edited the technical portion of this prospectus. As such, that section can be credited to all nine members of my team, as well as our advisors which provided us with guidance for background on the topic.

The formatting and structure of this prospectus is loosely based on Patryck Michalik's prospectus, which was supplied by Professor Gorman as an exemplary prospectus and point of reference.

After submitting my first draft, Professor Gorman provided me with some great feedback regarding ways to think about my STS topic, as well as suggested minor changes in my logical structures. He suggested that I develop the ethical portion of my prospectus further, and mentioned utilitarianism as an ethical framework that could be applied. After looking through the different possible ethical frameworks, I decided that contractarianism (or contractualism) was the most fitting framework as I believe that building trust between businesses and users over data usage requires a consensual agreement. I do believe that utilitarianism also makes a case for the ethics of health care data usage, but I think contractarianism is more fitting. Professor Gorman also noted more practical concerns associated with my STS topic, such as hacking health care records. I discuss this topic in detail following the ethics section. I received further feedback from Professor Gorman following the submission of my final draft, primarily concerned with developing my ANT analysis in greater depth. All edits made following the final draft are highlighted blue.

I. Introduction

Thanks to the advent of digital technologies, present day Americans are the most connected they have ever been in some dimensions, yet remain fragmented across others. One particularly alarming divide in America is the difference in health care infrastructure between urban and rural communities. However, the adoption of technologies such as wearables and smartphones presents a potential remedy for the rural health predicament. Thus, the vision of both my technical and STS topics is to see how the integration of personal technology into rural communities can feasibly bridge the urban-rural health care gap.

For my technical topic, I am on a capstone team with 8 other systems engineering students working on a research initiative for the Defense Advanced Research Projects Agency Warfighter Analytics using Smartphones for Health (DARPA WASH) program. As this initiative is funded by the Department of Defense, the research is focused on being able to predict whether a soldier is fit enough to be deployed using sensors from smartphones. The research my team is doing is just one part of a very large cohort principally run by Lockheed Martin, with other firms and institutions working in tandem on specific topics. My team is focused on producing sensing algorithms that decide when to turn a sensor on or off, being sure to provide data with the greatest predictive capability at the lowest cost to battery life. As with many DARPA technologies such as ARPANET (the foundation of the Internet), this research could trickle down and provide widespread benefits to public health given enough stakeholder buy-in.

For my STS topic, I plan to apply the Actor-Network Theory framework to rural health care systems in order to examine if there are improvements to be had through the dissolution or formation of actors. Furthermore, I intend to examine if and how the technology developed in my technical portion can serve as an actant in a more productive system. I am also interested in examining the ethics of introducing such a technology into society, as wearables collect large amounts of data with little transparency to the user. I intend to incorporate ethics into my ANT analysis of rural health care systems in order to deliver a cohesive argument.

II. Technical Topic

A. Technical Problem Statement and Importance

Today, smartphones and other wearable devices are capable of collecting millions of data about each of its users daily. However, while the potential power of this data in improving society and providing other benefits is unprecedented, there is still much work to be done in creating predictive models that can efficiently extract valuable information from this data. In the Reliable Analytics for Disease Prediction capstone project, such unstructured smartphone data will be analyzed as part of an effort to create predictive health models.

B. Technical Approach

The technical project, advised by Professor Laura Barnes, Medhi Boukhechba and Lihua (Lee) Cai, specifically seeks to predict the user's health status based on smartphone-extracted contextual data. The project is a part of ongoing research conducted for the Defense Advanced Research Projects Agency (DARPA) to design and develop reliable disease detection analytics through data collected from smartphones. The ultimate goal of the research is to create " a mobile application that passively assesses a warfighter's readiness immediately and over time," (Patel, n.d., para. 5); by building predictive health analytics that utilize smartphone sensors, the onset of illnesses, concussions, or even mental health issues can be noticed in real time. In the current stage of research, the technical team will develop the tradeoff between data collection frequency and battery life. This is an important step in the feasibility of this technology and in understanding the user's environment. By gaining a better sense of these limitations, accurate predictive models can be built without the noise of dead phones or other unwarranted stimuli.

Mobile sensing data used in this research will be collected through the Sensus Application. This app, developed at the University of Virginia (UVA), uses "event-driven architecture that triggers actions in response to changes to the device or network state" (Lockheed Martin & Advanced Technology Laboratories, 2017, p.10). This data will be utilized to create context recognition models, which determine what ambulatory state the user is in, like walking, running, or sitting. Additionally, the Sensus app will push surveys as notifications to participant's mobile phones to create additional context around the data collected. These surveys will ask questions about the user's activities immediately before answering the survey, such as the user's location, length of activity, phone position, and more. This additional collected data will allow the team to build the strong foundational truth for these predictive health models.

The technical project group consists of nine undergraduate Systems Engineering students. Because of the large size, the team is divided into three subteams: the Data Modeling Team, the Data Visualization Team, and the Data Collection Team. These teams were constructed for the currents needs of the project, and are subject to change and overlap depending on the need in each area. The Data Modeling Team will work to prove the efficacy of adaptive sensing in an attempt to find a balance between data collection and battery usage. Ultimately, the team will develop an algorithm as a potential alternative to the adaptive sensing model currently being used. The Data Visualization Team will make significant improvements to the web-based visualization platform used by the researchers to increase understanding and context of the data they are collecting. Improvements to this platform will allow better insights to be easily accessible. The Data Collection Team is designated to complete the IRB so that the data collection among the student cohort can begin. Once the IRB is completed and approved, the team will be responsible for organizing the participants in the study.

At the end of the study, the team will deliver a recommendation for smartphone data collection that effectively accounts for a user's battery life and critical predictive data and a recommendation for intuitive data visualizations for the researchers' web platform.

The technical project is funded through a grant provided by DARPA. Additional resources include test phones and desktop computers to run software and view data. The technical project will produce a conference paper for the Systems Information Engineering Design Symposium (SIEDS) that will take place in May 2020.

This technical section was jointly authored by my capstone team.

III. STS Topic

A. STS Problem Statement and Importance

Many rural parts of the United States are currently underserved by their health care systems relative to urban areas, which hinders the advancement in quality of life for all Americans. For my STS topic, my research will investigate whether this problem is quantifiably important to American society, and will consider the ongoing or potential societal, structural, and ethical barriers to achieving an absolute solution.

The general health of the members in a society is of utmost importance; apart from an individual's desire to be healthy and enjoy life without medical conditions, a healthy population yields significant economic benefits. According to the US Department of Health, rising health care spending is "considered to lower the rate of growth in GDP and overall employment, while raising inflation" (Department of Health). Fueling health care spending is an increased demand for costly health care: 40% of Americans have a chronic medical condition (defined as heart disease, hypertension, diabetes, high cholesterol, COPD, stroke, cancer and obesity), which account for 75% of health care costs in the United States (National Health Council). These figures indicate that chronic illnesses, many of which are preventable, stand as roadblocks to the U.S. economy's growth in the long run, and lower Americans' standard of living. This problem is exacerbated in rural America, where populations living outside of metropolitan areas experience markedly higher rates of chronic illness; a 2017 study done by the Center for Disease Control found that nonmetropolitan populations have significantly higher rates of chronic disease compared to metropolitan populations, even when controlling for household income (CDC). As such, rural American health stands as a major concern in economics and public policy.

In order to better understand this problem, the general health care infrastructure of rural America must be examined. While I am not an expert on this topic, I am a senior firefighter in Albemarle County with a working knowledge of the infrastructure and resources available to rural areas in Albemarle County as well as experience working in surrounding counties such as

Fluvanna, Louisa, and Buckingham, which are all quite rural. I will supplement my experiences where I feel they enhance understanding of this topic.

Because rural areas are geographically isolated by widely spaced properties as well as by natural features such as mountains and forests, access to health care and emergency medical services for some can be difficult. Indeed, the average time it takes for rural Americans to drive to the nearest hospital is 17 minutes and in excess of 34 minutes in 25% of cases; compared to metropolitan populations that average around 10 minutes, the act of going to the hospital is a much larger undertaking for rural Americans (Lam et al). Due to the commitment a hospital visit necessitates on top of their already busy work schedules, many rural Americans view hospital visits differently: "...rural people may more often tend to delay treatment. Perceiving that work is more important than health care, they tend to use health care more when there are lower demands on their time from seasonal work" (Ricketts). Given that rural Americans are on average less healthy and are 3 times as likely to be injured in their occupation, their lesser propensity to utilize health care can exacerbate conditions that would normally be treated earlier on (Ricketts). Another large barrier to accessing health care in rural America is the cost of doing so. Of the Americans who are uninsured, 75% live in rural areas (Day). With health care prices increasing faster than the Consumer Price Index, affording basic treatment has gone from a necessity to a luxury for many lower income Americans (Baker). There is an unfortunate tradeoff for those that are chronically ill and unable to pay for treatment: either they get sicker or accumulate more debt.

Health care resources in rural America tend to be less advanced and generally do not attract top health care professionals. Communities can have physicians, nurse practitioners, or physician's assistants operating small clinics, however those are few and far between and do not have the technology needed for advanced diagnostics and tests: rural America houses 20% of the US population but only 11% of its doctors (Ricketts). One area where resources are seriously lacking and can lead to negative outcomes is in rural first response. With little funding for equipment, training, and even personnel, many rural areas are covered by volunteer companies that can have seriously delayed responses. In Scottsville, a town on the southern end of Albemarle county, volunteer rescue squad members were frequently unavailable and ambulances would go unstaffed, drawing resources with delayed responses from the rest of the county. In a medical emergency, a response time of 10 minutes or less is standard; in urban and suburban communities, the average EMS response time is fewer than 12 minutes, compared to 26 minutes in rural areas. In many cases, rural EMS response times can extend far beyond the average, or they never come at all. Given many rural communities already face geographic barriers in accessing consistent health care for chronic and life-threatening conditions, slow EMS response times only serve to exacerbate the health crisis.

"Wearables" are smart microprocessor devices that can be worn on the body, ranging from smart watches such as the Fitbit to smartphones such as the iPhone (Nugent et al). With the rapid development of cheap microprocessors, they have become much more affordable and are mainstream goods at this point; a recent study showed that over 70% of rural Americans own a smartphone (Pew Research). Thus, wearables can play a crucial role in bridging the health care gap in the United States. Previous attempts such as telemedicine had the aim to equalize the level of care between urban and rural areas but fell short, mostly due to the high cost of equipment and limited diagnostic power (Ricketts). From simple observation, wearables differentiate themselves from telemedicine in two major ways: they do not have the specific purpose of diagnosing disease and collect large amounts of data on the wearer using sensors. Because wearables such as smartphones and smart watches are extremely versatile devices, it can be reasoned that they are more attractive to the general consumer compared with a dedicated medical device. These devices also contain embedded sensors such as step count, accelerometer, GPS, altimeter, and occasionally heart rate, all of which collect data on the wearer at high frequency. Traditional telemedicine lacks this ability to collect and transmit large amounts of data on a patient. With advancements made by initiatives such as the research my capstone is working on, the data collected by wearables can be transformed into real predictions on health conditions using machine learning and eventually artificial intelligence. This will give those living in rural areas data-driven evidence of the need to see a health care professional, maximizing the utility of hospital visits and mitigating the risk of a medical emergency. In a normative case, this technology could even alert EMS of a medical emergency before the patient experiences any adverse effects.

As with many personalized technology products, there are certainly privacy and ethical tradeoffs associated with using wearables for predicting disease. Recent news of HARPA (the new health research wing of DARPA) planning to investigate whether violent outbreaks can be predicted using wearables has sparked controversy over government organizations and technology companies breaching civil liberties (Wan). While my research project has a potentially more ethical use case, it is similar to HARPA's proposed project when examining the risks of personal data collection. Accordingly, ethics will play a large role in designing a health care system that incorporates disease prediction technology.

Businesses are now able to use data in a way that improves their processes and user experience, which I witnessed firsthand during my internship this past summer. In using customer data on a more personal level, the transition to big data and personalization has raised many red flags centered around privacy and personal data rights. Even though we are not collecting health data presently, my capstone team's research is heavily regulated by the Institutional Review Board, or IRB. The IRB primarily serves to judge whether research methods by institutions are ethical. In the commercial space, there are very few safeguards to protect consumers against unwanted use of their data. Numerous examples of data misuse can be found in Facebook's legal history, such as the Cambridge Analytica scandal, where Facebook sold their users' data against their consent. In this case, Facebook was only able to be sued because of a breached legal contract. For the most part, companies are able to misuse user data legally due to the "terms and conditions" that every user voluntarily agrees to before using the good or service. Of course, some users are aware that their data is being sold to third parties or used for targeted advertisement, and accept it as part of a changing world where people have less privacy.

The technology that my research is developing could necessitate personal privacy tradeoffs if it is ever commercialized. Opinions on the tradeoff between the degree of personal privacy and the benefits of allowing data use vary widely from person to person. Examining the use of health care data to make predictions about a user's wellbeing using an ethical framework such as contractarianism provides insights into how this technology can be deployed in the future. Contractarianism views something as ethical provided that there is a mutual agreement between the affected parties (Cudd et al). Viewing disease prediction from a contractarian lens, the user would need to voluntarily give up personal privacy in exchange for the possibility of avoiding disease. If the contract is consensual, then the adoption of this technology would be ethical. A major roadblock that I plan to address more in my thesis is the transparency of user data usage, which at present is quite opaque; usage terms are usually a single paragraph encapsulated by a 20,000 word terms and conditions document. While these contracts can be agreed upon by both parties, the terms can mean different things to each other, opening the door for misinterpretation and abuse. This practice would need to change in order for the rural health care system to reach a normative state, as trust in technology companies is paramount to adoption. The optimal state of contractarianism and data usage is therefore one that is totally transparent and extremely explicit about the rights granted to both the user and the provider. I plan to look more at how to structure a contract such that it is both brief (for user convenience) and not open to interpretation (for user protection).

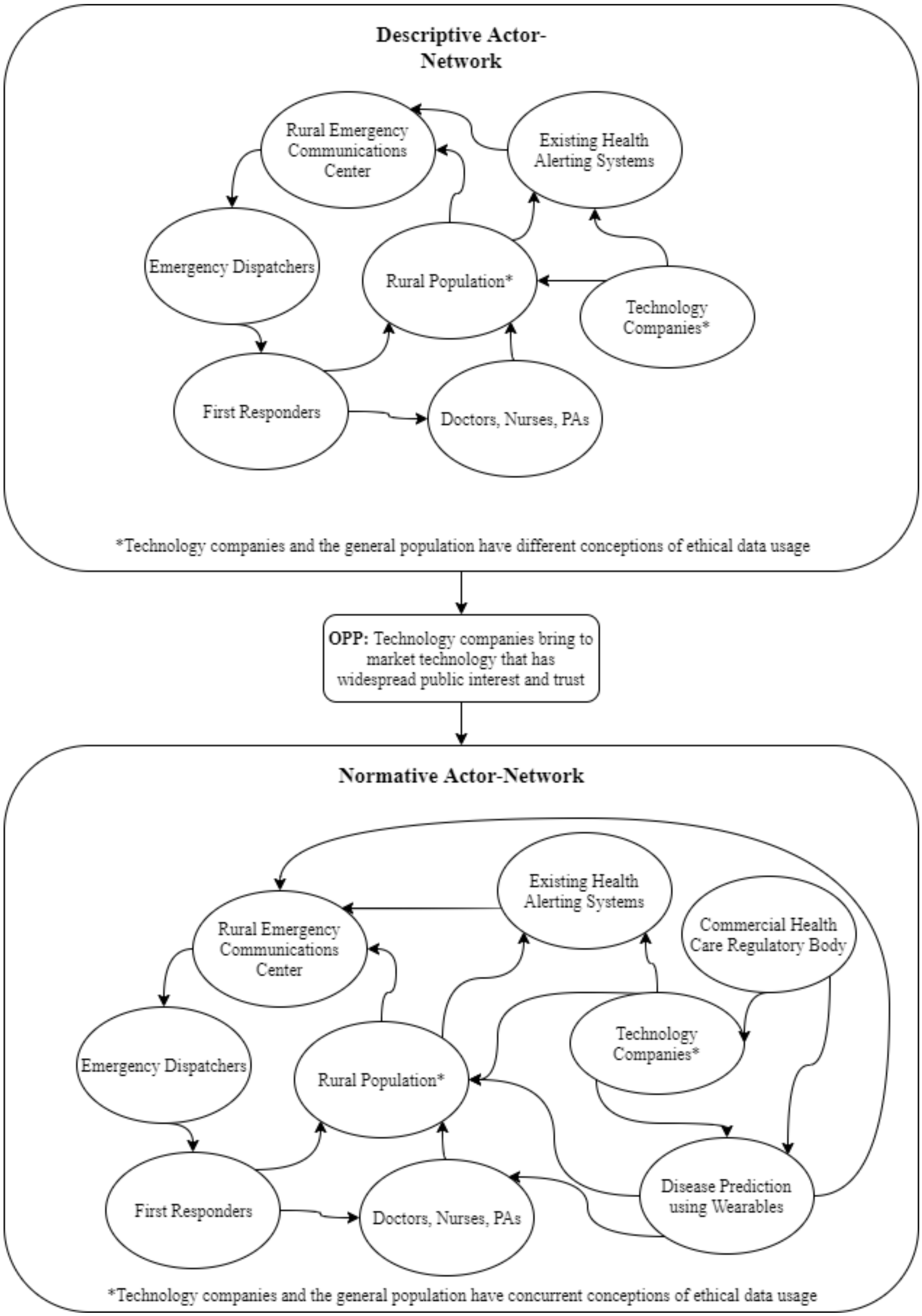
Beyond ethical issues, there are also practical considerations associated with collecting massive amounts of health data. Of utmost importance is the security of user data; security breaches leave millions of people's medical records exposed for malicious intent. In 2019 alone, over 38 million American medical records have been exposed by data breaches, roughly eleven percent of the United States population (HIPAA Journal). Any future state of health care data storage needs to have better security measures in place, such as anonymized data and better encryption. When considering the normative scenario, a rural health care system cannot function properly without adequate public trust in data security.

To frame the rural health care problem and its potential solution using wearable technology, I will employ the STS framework Actor-Network (ANT). The premise of ANT is to frame systems (networks) for analysis by examining the relationships among their encompassed entities (actors). I will be drawing analytical inspiration from an ANT paper by Kate Rodger that was assigned in my STS class, which states that ANT "examines the mechanics of power through the construction and maintenance of networks (both human and non-human)" (Rodger et al p. 647). As many of the actors in my potential network are pieces of technology, this framework will likely be a good fit for what I am trying to address. The first step of formulating actor-networks is called "problemization", which "defines the nature of the problem and identifies the involved actors, both human and non-human" (Rodger et al p. 652). Discussed thoroughly in previous sections of this paper, rural health care systems suffer from intrinsic limitations such as geographic isolation, sparse infrastructure, and long response times, as well as socioeconomic limitations such as a poor population health and low income. The geographic isolation and infrastructure issues are functions of entities that are not able to be remedied without considerable investment, which is not feasible considering the tax revenue generated by the population. General health and income are somewhat functions of the aforementioned entities, so a change from outside these problem areas would need to be used to improve overall wellbeing in rural communities.

The next step in problemization is the identification of the actors within the network. My analysis of rural health care systems will be split into both a descriptive scenario and normative scenario. The descriptive scenario is the current rural health care and telemedicine actor-network, which prior parts of this paper have addressed as a failing system. The normative network is an ideal state of rural health care—which in my opinion is one where chronic illness, acute illness, and quality of care are at parity with urban health care. The main driving force to go from the descriptive state to the normative state hinges upon the successful development of disease prediction technology, something my technical topic is working to bring to light.

The descriptive actor-network is composed of the rural population—or patients, which are the people that exchange money for care, and are free to make decisions for themselves about health and technology usage. Treating these populations are doctors, nurses, and physician's assistants that provide critical, urgent, and routine care to these rural populations, either in a rural clinic or in an urbanized hospital. Supporting the general population in times of emergency and transferring care to doctors, nurses, and PAs are first responders. They are called upon by emergency dispatchers, which are alerted by a variety of systems connected to the rural emergency communications center. These systems range from pacemakers that establish an uplink to doctors, to in-home medical alarms that can be pulled in an emergency. Designing these systems are technology companies operating with a profit and growth mindset, and not necessarily in the interest of their users. Governing the engagement between these entities are interpretations of ethical practices, some of which may not be aligned between parties.

The normative actor-network shares many of the same actors as the descriptive actor-network: the general population, the health care providers, emergency dispatchers, medical facilities, and technology companies remain unchanged, although their ways of functioning and responsibilities change with the introduction of the focal actor: disease prediction technology. Supporting and implementing this technology are the technology companies, utilizing health care-grade data handling procedures to inspire trust in their customers. As technology companies are still in competition for profit and growth, governmental regulations enter as an actor to serve as an oversight for the "ethical" handling of customer's data. In this case, "ethical" refers to the explicit and prosecutable agreement between the technology company and the user regarding how data is collected, used, and stored. Emergency dispatchers are now able to dispatch EMS resources before a person knows they are having a medical event because the technology is able to communicate seamlessly with the communications center. The doctors at the hospital are also notified of the readings produced by the technology and are prepared to admit the patient as a result. In nonemergency care, hospitals are less crowded due to the ability for doctors to diagnose patients remotely using data from their wearables. In essence, a normative network would be vigilant in sensing problematic medical conditions, and alert the necessary parties in order to increase the overall health of rural communities. Both actor networks are detailed by the figure on the following page.


Descriptive Actor-Network
Rural Emergency Communications Center
Existing Health Alerting Systems
Emergency Dispatchers
Rural Population*
Technology Companies*
First Responders
Doctors, Nurses, PAs
*Technology companies and the general population have different conceptions of ethical data usage
OPP: Technology companies bring to market technology that has widespread public interest and trust
Normative Actor-Network
Existing Health Alerting Systems
Commercial Health Care Regulatory Body
Rural Emergency Communications Center
Technology Companies*
Emergency Dispatchers
Rural Population*
Disease Prediction using Wearables
First Responders
Doctors, Nurses, PAs
*Technology companies and the general population have concurrent conceptions of ethical data usage

There are multiple obstacles preventing the transition from the descriptive to the normative scenario; the largest uncertainty is whether smartphone data can predict disease with a high enough true positive rate, and to that extent, a low enough false negative rate. However, this technology has been labeled as a priority by organizations such as DARPA whom believe in its success. For this analysis, it is assumed that disease prediction technology is available and marketable. The "obligatory passage point" or OPP is an event needed in order to align all of the actors to transition from the descriptive scenario to the normative (Rodger et al p. 652). While there are many necessary passage points needed, the largest is the adoption of this technology by the general public. Technology companies are therefore responsible for bringing this technology to the consumer markets and instilling trust in the public. Here, the notion of contractarian ethics comes into play. If the public and the technology companies agree to explicit and mono-interpretable terms upon which user data can be used, then the agreement would be both ethical and mutually beneficial. Following this OPP, the network develops further with ANT stages "interessement", "enrollment", "mobilization", and "black box" which are items I look forward to addressing in my thesis paper (Rodger et al p. 648).

IV. Conclusion

With further development of my Actor-Network Theory approach in my thesis paper, I hope to uncover the intricate relationships necessary to support and sustain the normative rural health care system. I also hope to quantify or at least qualify the degree of difficulty associated with moving from the descriptive to the normative, and investigate the stakeholder buy-in necessary to improve the quality of life for rural Americans.

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