DETERMINING EFFECTIVE METHOD OF DATA SAMPLING TO DETECT USER STATUS

EFFECTS OF DATA PRIVACY REGULATIONS ON MOBILE HEALTH APPLICATIONS

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By
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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.

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Mobile smartphones have become increasingly integrated into American society over the last twenty years. A survey conducted by the Pew Research Center (2019) found that 81% of Americans own smartphones. Continued development in smartphone capabilities presents new opportunities to leverage mobile health technology. Advancements in mobile sensing technology allow sophisticated use of basic data points readily obtained through sensors in smartphone devices. Data collected through smartphones can be translated into digital biomarkers that can diagnose various medical conditions. These capabilities are available through smartphone applications (apps) called mobile health apps that users can download to their devices. Additionally, mobile health apps can act as a platform for storing personal medical data for patients to have easy access to medical records. The substantial amount of smartphone users indicates that the large market for mobile health apps. However, as the number of mobile health apps increases, users of mobile apps as well as medical professionals have rising concerns about the use of data collected through these apps. Lack of regulation and transparency of the use of personal health data in mobile health apps introduces potential risks users could face if their data was misused or exposed.

As part of developing a mobile health app, the technical project will conduct analysis to develop the most effective method of data sampling in a smartphone to collect basic data points used in predictive medical diagnosis. The analysis includes testing different sampling frequency to determine the tradeoff between data integrity and battery usage. The Science, Technology and Society (STS) research will perform a study on the implementation of data privacy laws and use Actor Network Theory (ANT) (Callon, Latour & Law, 1986) to investigate the effect new regulations will have on the development of mobile health apps. The research will investigate the current gaps in data privacy in the United States (US) and emphasize the need for nationwide

data privacy regulation. The STS research is tightly coupled with the technical topic because it will focus on the implementation of mobile health devices in society and will identify risks and potential solutions to maintaining data privacy in the app developed in the technical project.

DETERMINING EFFECTIVE METHOD OF DATA SAMPLING TO DETECT USER STATUS

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.

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 use smartphone sensors, the onset of illnesses, concussions, or even mental health issues can be noticed in real time. Figure 1 shows

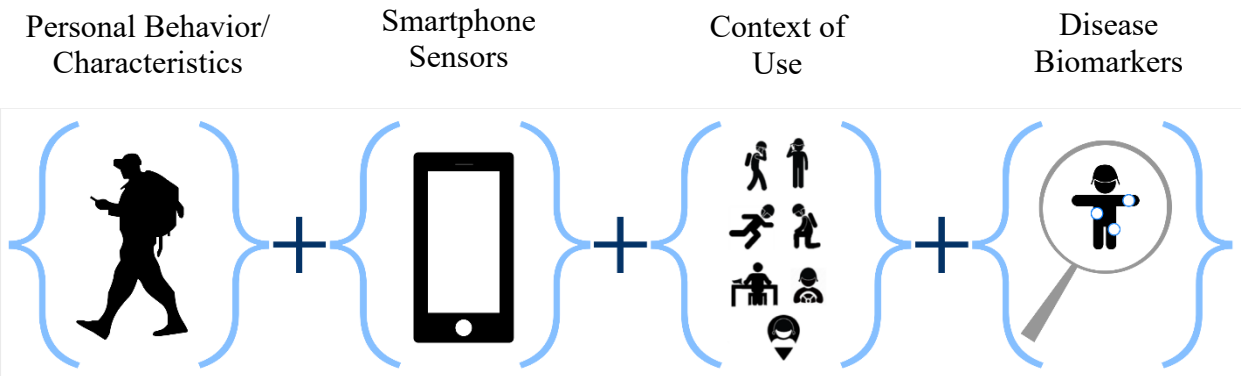

Figure 1: Warfighter Analytics Using Smartphones for Health (WASH) Program Concept. This graphic shows the grouping of the different technology contributing to the creation of the mobile health app. (Adapted by L. Perry from T. Patel, n.d.)

the combination of technology that will lead to the mobile health app created by DARPA. In the current stage of the research, the capstone team is working on the smartphone sensors to develop a 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.

RECOGNIZING A USER'S STATE FROM MOBILE SENSING DATA

Mobile sensing data used in this research will be collected through the Sensus Application. This app, developed at the University of Virginia (U.Va), 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 used 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.

TECHNICAL RESEARCH TEAM STRUCTURE

The technical project group consists of undergraduate Systems Engineering students Erin Barrett, Cameron Fard, Hannah Katinas, Charles Moens, Blake Ruddy, Shalin Shah, Ian Tucker, and Tucker Wilson. 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 current 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 in place. 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 receive approval for the study from the Institutional Review Board (IRB) so that the data collection among the student cohort can begin. Once the study is approved, the team will be responsible for organizing the participants in the study.

EXPECTED OUTCOME OF ANALYSIS

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 and Information Engineering Design Symposium (SIEDS) that will take place in May 2020.

EFFECTS OF DATA PRIVACY REGULATIONS ON MOBILE HEALTH APPLICATIONS

CURRENT STATE OF THE MOBILE HEALTH INDUSTRY

Continued advancements in mobile health apps allows users to monitor a wide variety of health conditions. The World Health Organization (2011) defines mobile health as a "medical and public health practice supported by mobile devices, such as mobile phones, patient monitoring devices, personal digital assistants (PDAs), and other wireless devices," (p. 6). These apps are becoming increasingly popular among mobile phone users; research by Krebs and Duncan (2015) determined that about 58% of smartphone users had downloaded a health-related mobile app. Additionally, the global mobile health app market was valued at $12.4 billion in 2018, with an expected annual growth rate of 44.7% (Grand View Research, 2019). These apps can be "broadly classified into fitness, lifestyle management, nutrition and diet, disease management, women's health, medication adherence, and healthcare providers," (Grand View Research, 2019, para. 6). The capabilities range from monitoring physical conditions to managing mental illnesses. However, the widespread classification indicates the lack of a proper legal definition among mobile health apps. While these apps handle sensitive health information, there is a lack of data privacy regulation controlling them, leaving users vulnerable. The STS analysis will start by organizing relevant stakeholders involved in the development and use of mobile health apps into Pacey's Triangle (Pacey, 1983). Then, the analysis will use Callon, Latour and Law's Actor Network Theory (ANT) (1986) to investigate various actors and actants influencing the creation of data privacy policy in the US to protect personal health data in mobile health apps.

HOW IS MOBILE HEALTH DATA PROTECTED?

Despite the convenience of using mobile health apps to manage illnesses, they present potentially serious risks to an individual's private health data. Research by Lang and Zawait (2018) outlines that while these devices are becoming increasingly sophisticated, they exist in a space that has not yet been clearly defined by legal regulations. While most health data is covered under the Health Insurance Portability and Accountability Act of 1996 (HIPAA), researcher Guadarrama (2018) from the Houston Law School details concerns about the gap in HIPAA coverage on mobile health devices. Natasha Singer (2019), writer for the New York Times, explains that once health data is transferred to consumer apps created by private technology companies, such as Apple's Health Records app, HIPAA no longer applies. Although users may enjoy more convenient means of accessing health records, understanding medical bills, and managing illnesses, it could come at a serious cost to their personal privacy. Users could face serious consequences if information such as prescription drug history or mental illness diagnosis is exposed through these apps. For example, insurance companies could use this information to deny coverage, or employers could use it to influence the decision to extend a job offer. Therefore, further investigation is needed to determine where the gaps in data protection lie and to emphasize the need for nationwide privacy policy in the US.

IDENTIFYING RELEVANT STAKEHOLDERS

Considering stakeholders involved in the development and use of mobile health apps is important to understand the future development and regulation of them. Figure 2 provides a breakdown of the mobile health app network in Pacey's Triangle (1983), organizing the influence of stakeholders into three aspects: cultural, technical, and organizational. Visualizing the different aspects of mobile health technology depicts the complex nature of the technology,

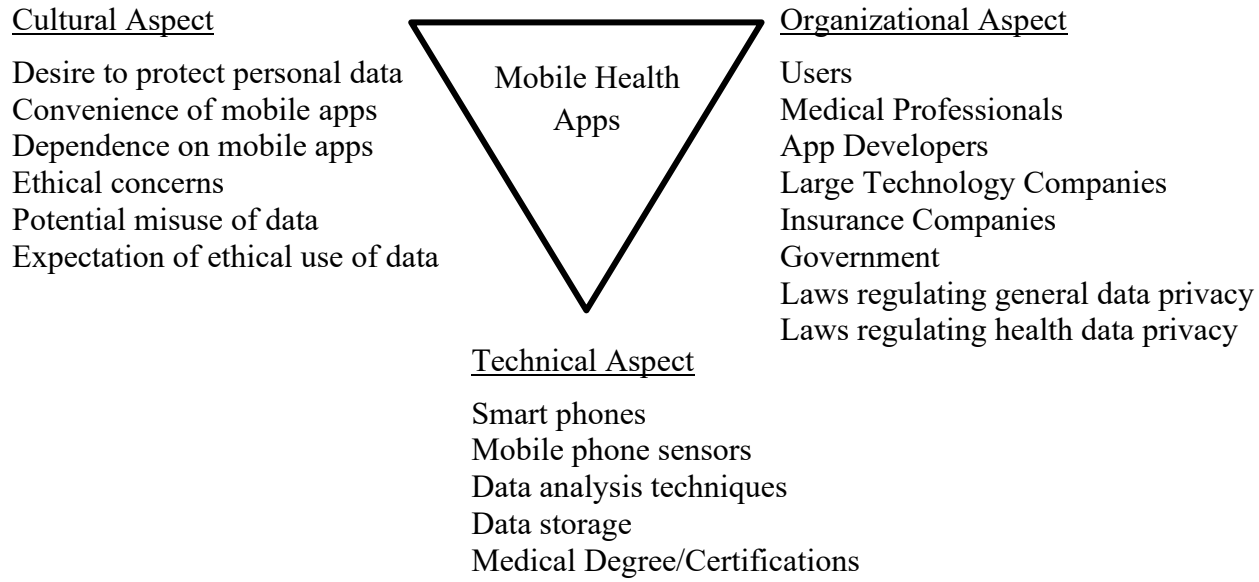

Figure 2: Using Pacey's Triangle on Mobile Health Apps: In this figure, the framework of Pacey's Triangle is adapted to mobile health apps, showing the cultural, technical and organization aspects of this technology. (Adapted by L. Perry from A. Pacey, 1983)

involving not only the influence from app developers and users, but medical professionals, government regulations, insurance companies, and cultural and ethical expectations. Currently, the issue lies in the organizational aspect because of the lack of data privacy policy in the US.

THE EFFECTS OF IMPLEMENTING DATA PRIVACY REGULATIONS

New regulations, such as the European Union's (EU) General Data Protection Regulation (GDPR), are already changing the structure of mobile health apps. Key changes set forth by GDPR include a user's right to access their data stored by a company and request for it to be deleted, as well as set standards for data storage (Key Changes with the General Data Protection Regulation, n.d.). While these regulations were only put into effect legally in the EU, the effects were felt in other countries as companies changed policies to comply. Researchers from the Center for Health Technology and Services Research at the University of Porto (2018) investigated the effects of GDPR on the development of mobile health apps. Using a use-case as

an example, they determine changes to existing mobile health apps, such as explicit user consent and proper data storage, that companies will make to comply with GDPR (Muchagata & Ferreira, 2018). Changes made in the apps forced companies to be transparent about data collection and use, giving users more protection.

GDPR sparked conversation worldwide about the need for data privacy policy. The US is starting to see the first signs of privacy policy, as California passed the California Consumer Privacy Act (CCPA) on Sept. 13, 2019, taking effect Jan. 1, 2020. Jeff Roberts (2019), writer for Fortune Magazine, outlines the CCPA and widespread effects on both consumers and large technology companies. Roberts emphasizes that the CCPA will not only affects residents of California, but almost all smartphone and social media users, as all companies that fall under the regulations must comply in order to continue to conduct business in California (para.10).

DETERMINING KEY INFLUENCES ON DEVELOPMENT

The STS research will include Actor Network Theory (ANT) (Callon, Latour & Law, 1986) to determine what mobile health data privacy regulations could look like on a national level and how it will impact the mobile health industry. Actor Network Theory analysis identifies all agents, both human and nonhuman, that influence or shape the development of the technology. Researchers at Georgetown University Medical Center (2015) used ANT to study the effects of using the Digital Pill, an advanced medical technology used to track drug adherence. Using ANT allowed the researchers to look beyond the medical and physical components of the Digital Pill, instead identifying cultural and social influences hindering the adoption of this technology among medical professionals and patients (Hurtado-de-Mendoza, Cabling, & Sheppard, 2015). The ANT analysis of the Digital Pill will be similar to the analysis of mobile health apps because it will be used to identify influences affecting the implementation

of data privacy policy on mobile health apps other than the influences from developers and medical professionals directly involved.

Figure 3 depicts a model for the relevant actors and actants involved in regulating mobile health apps. As seen in the key, mobile health apps are the central issue. Medical professionals

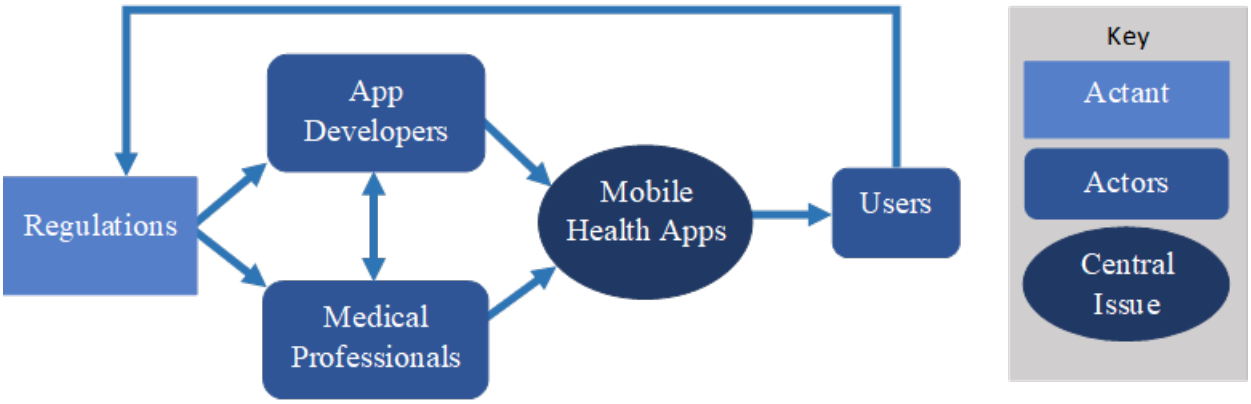

Figure 3: Network of Influential Actors and Actants. This figure depicts the relationship between agents in the development and use of mobile health technology. (L. Perry, 2019)

and app developers have the only direct influence on the creation of the app. Currently, there are no policies regulating how the apps are made and how the data is stored and shared. For example, the medical professionals involved early on in developing the technology pass the research to an app developer. However, the developer focuses on the functionality of the app itself, potentially leading to misuse of the storage, analysis and access of data collected. With data privacy regulations, both medical professionals and the app developers will have standards to follow with clearer limitations of the technology. The ANT analysis will bring insight into the effects of legal regulations as well as ethics in the development of mobile health apps. It will identify key influences involved in why these regulations are necessary as well as how they will come to be in the US.

PROPOSED RESEARCH PLAN

The STS research will perform a study on the implementation of GDPR in the EU and the effects it had on the development of mobile health apps. The research will determine mechanisms the EU has put into place to control socialized medicine and protect the users of mobile health apps. Additionally, the research will assess the effectiveness of GDPR in order to determine the viability of a similar policy in the United States surrounding mobile health apps, and more broadly data privacy. In doing so, the research will outline the current gaps in data privacy laws in the US to understand how users are at risk and why there is a need for widespread regulation. With the CCPA taking effect in the coming months, the STS research paper will provide a unique perspective on how data privacy regulations can affect both users and developers of mobile health apps in the US.

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