

The Quantified Self: Utilization of a Mobile Application for the  
Self-Management of Chronic Diseases

By

Hodan A. Eyow

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Department of Health Informatics

School of Health Professions

Rutgers, the State University of New Jersey

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**Dissertation Committee:**

Fredrick Coffman, PhD - Chair

Shankar Srinivasan, PhD

Leah Varga, PhD

**Approved by the Dissertation Committee:**

_____	Date: _____
_____	Date: _____
_____	Date: _____

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## **ABSTRACT**

A contemporary trend is emerging in health informatics that literature refer to as the quantified self. Individuals engage in the self-tracking of any kind of biological, physical, behavioral, or environmental information as n=1 individual or in groups. As such, this study looks to uncover the opportunities to analyze and integrate mobile health application datasets for rendering self-tracked health data meaningful. In doing so, addressing the barriers to widespread adoption of self-tracking health and critiques regarding scientific soundness of patient generated health data. This study looks at the use of Flaredown, a mobile health application for managing any chronic condition. Data mining patient generated data is omnivorous in part because it has embarked on the project of discerning unanticipated relationships. This study examined the relationship between self-tracked symptom severity and treatment efficiency. The results found the strongest tracked symptom improvements to treatment for sharp pains followed by fatigue, brain fog, lack of motivation, fatigue and tiredness(combined) and lack of appetite. The results demonstrate that the use of mobile health application to quantifies one's health and disease state makes the individual more knowable, calculable, and administrate through continuous self-tracking symptom severity and associated treatments.

## **ACKNOWLEDGEMENT**

I start by acknowledging my Creator, Allah (SWT), for seeing me through this journey and strengthening my conviction throughout the process. This research was only possible with the guidance and support of my essential team members. I would like to acknowledge my committee chair, Dr. Fredrick Coffman and Co-Chair Dr. Shankar Srinivasan for their diligent support and guidance throughout my time in the biomedical informatics doctorate program at Rutgers. I acknowledge and deeply thank Dr. Leah Varga, my advisory committee member for her guidance and encouragement throughout this journey. I am appreciative of my professional colleagues at DC Health for providing useful feedback throughout the years. To this end, I thank you all from the core of my being for aiding in the completion of this academic goal.

## **DEDICATION**

The audacity of hope fueled my family to leave abject poverty and escalating civil conflict in Mogadishu, Somalia to provide the next generation a shot at a better life. Their conviction and hope made it possible for me to thrive as a first generation Somali American. I dedicate this dissertation to my parents Ahmed Abdulle Eyow and Qali Ahmed Ali with a special dedication to my maternal Aunts Shukri, Hodan and my late Aunt Fadumo. Their love is food to my soul and a constant motivating force in my life. I dedicate not only my dissertation but my life to them. I further dedicate this dissertation to my brothers Liban, Haroon and Loyan and younger family members. I hope this dissertation inspired each of you to see your academic goals to completion.

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# **CHAPTER I**

## **INTRODUCTION**

### **1.1 Statement of Problem**

Chronic disease has become the principal medical problem that requires patient to become partners in the process and contributing at almost every decision or action level. Patients deserve to be partners in their own health, because healthcare can be delivered more effectively and efficiently if patients are full partners in the process.<sup>1</sup> Unspecified chronic disease is a particularly difficult problem. It involves many often-frustrating non-specific symptoms that can affect all body organs and may be triggered by a vast array of biological and environmental causes. Patients diagnosed with a chronic disease often try multiple medications to manage their symptoms and can suffer from multiple episodes of acute flare-ups. Furthermore, medical specialists are generally unaware of interrelationships among the different chronic diseases or advances in treatment outside their own specialty area. As such, patients are often encouraged to journal foods, activities, stress, sleep and other environmental elements that could trigger symptoms as a traditional self-management method. However, this methodology can be inherently flawed in the back-end analysis of the data over an extended period of time. To date, existing literature on the use of smartphone applications in chronic disease management is limited in scope and often is disease specific.

### **1.2 Background**

Undistinguishable chronic illness often includes a multitude of symptoms that may be triggered by a vast array of biological and environment causes. Physicians and patient's alike are seldom to deploy data-driven interventions in the management of

chronic illnesses symptomology. As such, technological advancement ushered in the advent of mobile health that could support increased patient engagement. From fitness trackers, patient portals to smartphone applications, mobile health (mHealth) has the potential to permeate patients' everyday lives. In particular, smartphone applications hold promise for serving as a medium for chronic disease management to promote wellness and attenuate chronic condition and usher in the self-management of symptoms.

Long-term conditions and their concomitant management place considerable pressure on health care systems and patients. International clinical guidelines on the majority of long-term conditions recommend the inclusion of self-management programs in routine management.<sup>2</sup> Patients with chronic disease are inevitably personally responsible for their own day-to-day care, and are often the best placed to gauge the severity of their symptoms and the efficacy of any treatment.<sup>3</sup> Self-management by patients is not optional but inevitable because clinicians are present for only a fraction of the patient's life, and nearly all outcomes are mediated through patient behavior.<sup>4</sup>

### **1.3 Objective and Goals of the Study**

The objective of this study is to assess the use of a smartphone application for the self-management of chronic diseases particularly as it relates to identifying the relationship between tracked symptom severity and treatments in a novel dataset. The goals of the study include data mining a robust user generated dataset to generate new knowledge and insight into users' illnesses, symptoms, and treatments. In doing so, contribute new discoveries into a slowly developing body of scientific knowledge on the impact of mobile applications on self-managing and ultimately improving health outcomes.

## **1.4 Hypothesis**

This study will examine the mobile health application named Flaredown as it relates to the relationship between tracked symptom severity and treatment. What new knowledge and insight can be produced from patient generated health data? What is the relationship between tracked symptom severity in relation to treatment efficiency?

Hypothesis: The mean difference in a given tracked symptom in patients between before and after treatment is greater than 0.

$$H_1: \mu > 0$$

Null Hypothesis: The mean difference in a given tracked symptom in patients (for example, Nausea symptom) between before and after treatment is 0.

$$H_0: \mu = 0$$

## **1.5 Significance of the Study**

The use of information technology particularly mobile health solutions in the form of a smartphone application could transform the way individuals suffering with chronic illnesses monitor their symptoms and engage with their health care provider. People increasingly turn to mobile phone apps and wearable devices for health management. Nearly 70% of US adults track at least one health indicator.<sup>5</sup> This study will illustrate the further need for quantifiable and robust research into mobile health particularly patient generated health data from smartphone applications. Due to issues related to health privacy concerns and for-profit use of user generated data, many application developers do not release their aggregate data to researchers. As such, there is

little to no published data available from other mobile applications. To that end, this study is the first of its kind to closely analyze a mobile application's data for the purposes of biomedical informatics research.

## **CHAPTER II**

### **LITERATURE REVIEW**

#### **2.1 Mobile Health and Biomedical Informatics**

Given the information intensive nature of medicine, informatics has become an integral part of health care by facilitating the storage and accession of vast amounts of data. The broad scope of digital health includes categories such as mobile health (mHealth), health information technology and wearable technology which leads towards the realization of personalized medicine. The widespread adoption and use of mobile technologies steered innovative ways towards improved health. It has been showed that mHealth can address difficult problems associated with increasing number of chronic diseases related to lifestyle and the need to empower patients towards self-care and to manage their healthcare<sup>6</sup>.

Mobile health (mHealth) can be defined as the mobile computing and communication technologies in health care and public health.<sup>7</sup> A systematic literature review has found a positive trend pointed towards the development of mHealth as an autonomous field of study.<sup>8</sup> This is due to the growing interest in mHealth and the increasing complexity in research design and aim specifications as well as a diversification of impact areas. Available literature demonstrates that the use of mobile phone serves varies purposes in public health and personalized medicine. It has been used in treatment adherence, physical activity and disease management.<sup>9</sup> Compared to internet interventions through desktop and laptop computers, mobile intervention have the capacity to interact with individuals with much greater frequency. A Pew Research study

done in 2015 found that 90% of cell phone owners say they “frequently” carry their phone with them, while 6% say they “occasionally” have their phones with them. Just 3% say they only “rarely” have their cellphones with them and 1% of cellphone owners say they “never” have their phone with them.<sup>10</sup> This level of connectivity is unprecedented and serves as the one of the foundations for scaling up mHealth for disease management activities.

Additionally, mHealth and medical applications are one of the newest developments in the trajectory of digitizing health and medical information occurring the past twenty-five years.<sup>11</sup> The mass access to the World Wide Web in the mid-1990s led to the proliferations of health and medical websites with associated static discussion boards. The digital technologies of the past decade expanded the opportunities for patients to discuss their experiences in real time using a multitude of mobile application. As such, the emergence of the e-patient that are empowered to control their health via contributing to and harnessing online information and engaging in self-monitoring and self-care practices using digital technologies.<sup>12</sup>

According to the United States Food and Drug Administration (FDA), the last known industry related estimates stated that 500 million smartphone users worldwide would be using health care application by 2015, and by 2018, 50 percent of the more than 3.4 billion smartphone and tablet users will have downloaded mobile health application.<sup>13</sup> As such, the FDA continued to encourage the development of mobile medical apps that improve health care and provide consumers and health care professionals with valuable health information.



## 2.2 Characteristics of mHealth

While there is limited scientific evidence supporting the effectiveness of m-health, the ubiquity and ease of use of mobile phones in the general population provide an important opportunity for health. As such, the mHealth field has started to develop a set of terminology used in practice. Clauson et al. defined some of the common terms used in mobile health literature. Table 1 lists the commonly used terms in mobile health. <sup>14</sup>

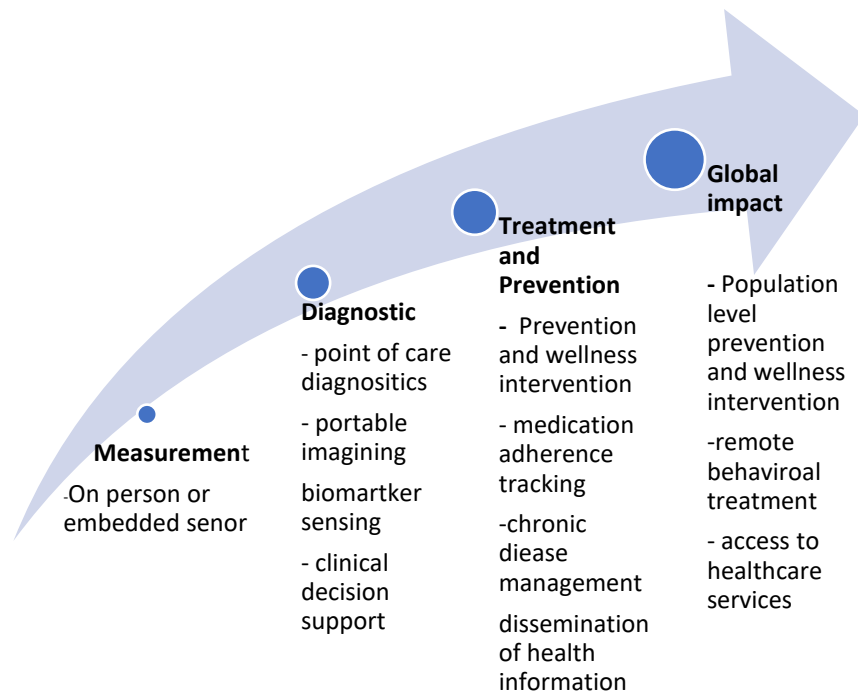
**Table 1- Commonly used Mobile Health Terminology**

<b>Term</b>	<b>Definition</b>
Mobile health (mHealth)	The use of mobile devices and global networks to deliver health services and information.
Mobile penetration	The percentage of active mobile phone numbers within a specific population calculated by the total number of phones divided by the number of users.
SMS (short message service)	enables mobile phone users to send and receive text messages; commonly referred to as text messaging or texting.
Smartphone	A mobile phone with functions of a feature phone and of a handheld computer, typically offering Internet access, data storage, e-mail capability, etc.
Application (app)	Coded software or websites designed and developed for use on a portable device. Apps enhance the features of the device by providing additional or specific functionality.

Mobile health applications are developed in a variety of domains that range from self-tracking different disease modalities to access to healthcare services. There is a gap in the literature that establishes the use of rigorous research methodology for examining the potential and challenges of utilizing mobile technologies to improve health outcomes. Currently, evidence is sparse for the efficacy of mHealth. Although these technologies may be appealing and seemingly innocuous, research is needed to assess when, where, and for whom mHealth devices, apps, and systems are efficacious.

### **2.3 Continuum of mHealth**

The use of mHealth tools has the potential to reduce the cost of health care and contribute knowledge to biomedical informatics research. Mobile health technologies can support continuous health monitoring at both the individual and population level. Kumar and colleagues created the mHealth tools continuum which highlights the various domains mHealth applications can be used by both consumers and providers for the monitoring health status to include wireless diagnostic and clinical decision support. Figure 1 shows the visualization of mHealth tools continuum.<sup>15</sup> The continuum starts with measurement tied to patient-generated biometric data such as continuous heart rate monitoring to population wide access to health care services. There is a gap in research on the characteristics of developed mobile health applications and evaluating for usability and a significant gap about the efficiency of mHealth tools across the continuum. In a health care system that is burdened with suboptimal outcomes and excessive cost, adoption of untested mHealth tools may detract from overall health improvements for patients.

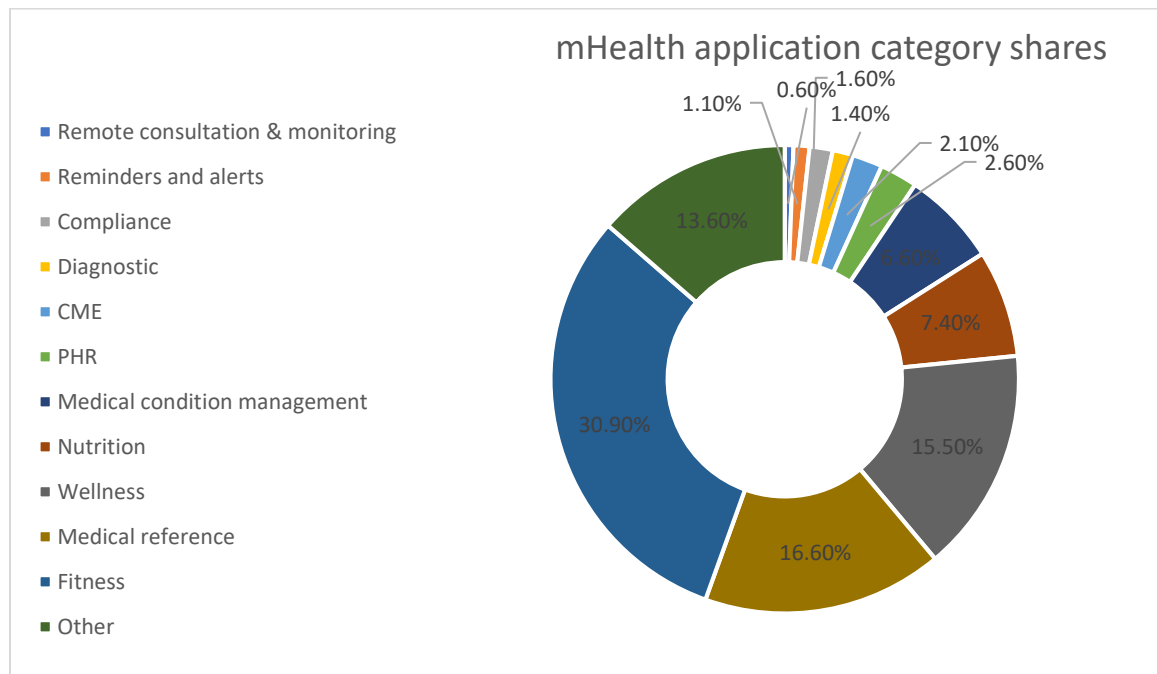


**Figure 1.** mHealth Tools Continuum

## 2.4 The mHealth app Market

Since 2000, the promise of reduced healthcare costs and improved patient outcomes associated with mHealth has inspired many to build their business models around remote patient monitoring, mobile alerts and reminders. The initial app developers entered the market too early as its conditions did not support scalability. With the launch of the Apple App Store, the mHealth market entered into the early commercialization phase. The Apple App Store has allowed mHealth solution providers to reach out to a mass market. Research2guidance, a market research firm, released whitepapers in 2014 on mHealth application publishing and discussed the size of opportunity, best practices and key trends that will shape the future of mHealth application publishing. They developed and released the mHealth application shares by

category from 808 apps from Apple store, Google Play, Blackberry App World and Windows phone store in March 2014. <sup>16</sup>



**Figure 2.** mHealth application category shares (March 2014)

Medical condition management applications represent the 5th largest group of mHealth apps (6.6%). This category consists of all apps which track, display and share user's health parameters, medicament intake, feelings, behavior or provide information on a specific health condition.

## 2.5 Barriers to adapting and utilizing mHealth

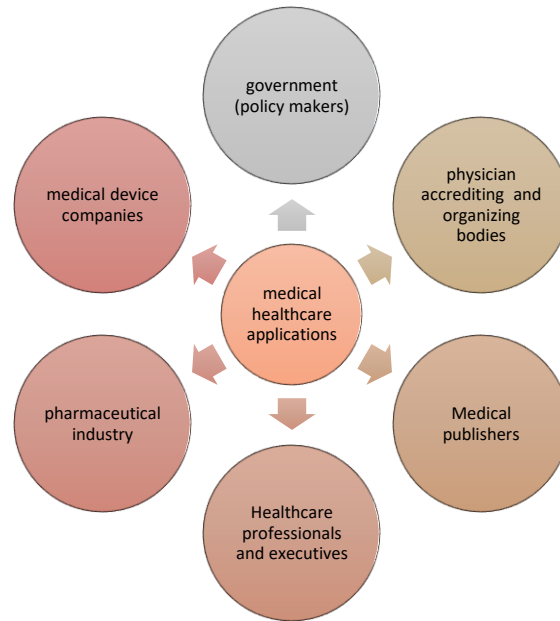
Literature discusses the quality of the mobile healthcare applications and the validity of the medical information they obtain and or collect. To date, any developer can publish a medical mobile application once conformed to the guidelines that govern the application platform such as Apple or Google. As such, health and medical applications

vary significantly in the accuracy of their content. As such, health care professionals particularly physicians can see potential benefits of mobile healthcare applications but remain wary of formally recommending applications to patients without evidence of clear professional guidelines regarding their use in practice and confidence in the security of personal health information that may be generated or transmitted.<sup>17</sup>

Mobile healthcare applications often lie outside of the regulatory protections sanctioned through the Health Insurance Portability and Accountability Act (HIPAA), which established a baseline of privacy and security protection for sensitive medical data.<sup>18</sup> This issue has been recognized in the literature with several published studies that outline the problems of the medical accuracy of mobile healthcare application. It was previously noted, “little is known about the possible dangers associated with their use. Breaches of patient confidentiality, conflicts of interests and malfunctioning clinical decision-making apps could all negatively impact on patient care.”<sup>19</sup> It has been proposed in many of the literature reviewed that medical healthcare applications should be peer-reviewed by clinical experts with the associated regulatory measures taken to safeguard the quality of care or instruction given. As such, Figure 1 demonstrates the different stakeholders that could plausibly develop the guidelines for the regulation of medical healthcare applications.

The FDA has published guidelines on ways to regulate medical healthcare applications despite the many discrepancies to the extent to which mobile application fall within their purview. As such, the FDA “intends to apply its regulatory oversight to only those mobile apps that are medical devices and whose functionality could pose a risk to a patient’s safety if the mobile app were to not function as intended”.<sup>20</sup> To that end, the

FDA has not issued an overarching software policy but has formally classified certain types of software applications that meet the definition of a medical device.



**Figure 3.** Stakeholders in the development of Mobile Healthcare Applications regulations

## 2.6 Patient Generated Health Data

Patient generated health data is defined in the literature as health-related data including “health history, symptoms, biometric data, treatment history, lifestyle choices, and other information that is created, recorded, gathered, or inferred by or from patients or their designees (i.e., care partners or those who assist them) to help address a health concern”.<sup>18</sup> Furthermore, patient generated health data is distinct from data generated in clinical settings and through encounters with providers in two significant ways. First, patients, not providers, are chiefly responsible for capturing or recording data. Second, patients direct the sharing or distributing of their health data to their providers. In these

ways, patient generated health data should match provider-directed capture of personal health data.

Dr. Gregory Abowd, PhD, distinguished professor at Georgia Tech's School of Interactive Computing, predicted in his keynote address at the American Medical Informatics Association (AMIA) 2011 Annual Symposium that "within 5 years, the majority of clinically relevant data...will be collected outside of clinical settings"<sup>21</sup>. The clinically relevant data captured outside of traditional care setting has a substantial potential to improve patient-provider communication and subsequently improve health outcomes. Shapiro et al. developed a useful framework for understanding the flow of patient generated health data. Their framework can be summed into a three-part flow: data capture, transfer and review. The data capture stage refers to the creation and storing of health data by the patient that may include written data entered via a keyboard, verbal data entered through a microphone and physiological or environmental data recorded on the monitoring device.<sup>21</sup>

Shapiro et al. discuss the barrier associated with patient generated data flow particularly as it relates to participation and consistent use among patients. "Access, usability, technology, education, health literacy, economic disparities, and so forth can be barriers to patient generated data use. Conversely, demographic factors, such as higher rates of mobile connectivity among young adults are likely to contribute to increased PGHD volume."<sup>18</sup>

Chung and Basch<sup>22</sup> discuss the potential of integrating patient generated data in cancer patients' electronic health records. There are many types of non-electronic patient generated data that is in use in clinic settings such as paper logs of blood pressures.

However, the collection and integration of the wide range of patient generated health data that can be captured during patients' everyday lives has not been typically recorded as structured or discrete data elements in electronic health records. Chung and Basch assert that “integrating patient generated health data into electronic health records could help to accelerate not only understanding a patient's cancer experience but also increasing efficiency and productivity of clinical trials, improving prediction of addressable treatment toxicities, and ultimately improving quality of care and clinical outcomes”.<sup>22</sup>

Another study accessed the growing ability to collect and transmit patient generated health data role in cancer survivorship care.<sup>23</sup> Even when survivors recover their health, cancer treatment places them at a higher risk for chronic health problems that include but are not limited fatigue and various cognitive changes both temporal and permanent.<sup>24</sup> Petersen asserts “patient generated health data makes a self-defined, rather than disease-defined, life possible. By analyzing patient generated health data, cancer survivors can identify patterns of late effect or health condition exacerbation, proactively adjust their schedule and care routines to minimize interruptions of their daily routine, and optimize their health status over extended periods of time”.<sup>23</sup> Zabora et al. further emphasis self-monitoring psychological distress through patient generated health data to manage the anxiety and depression that often accompany a diagnosis of cancer and during the period waiting for signs of cancer recurrence.<sup>25</sup>

Various literature on patient generated health data all discuss the lack of information provided in many application descriptions or on the developers' websites could means that there is often very little transparency about how users' personal information is used by the developer or other parties to which these data may be sold.



Lupton discusses the evidence of this in a self-monitoring of chronic diseases mobile healthcare application. Lobotomo Software created the popular “Diabetes Pal” mobile application. The company does not provide information on the mobile application description or its website on their privacy policy or terms and conditions of use of the app collecting and storing several aspects of personal health data.<sup>11</sup>

The ways personal health and medical data information is collected by mobile healthcare applications and used for commercial purposes and/or sold to third parties is conferred in literature.<sup>26</sup> Crawford et al. discussed the potential risk posed by data mining companies that use personal details that they can scrape from digital datasets (including their health and medical details) to construct profiles about people that may be used to limit their access to insurance, credit, employment and social security benefits.<sup>27</sup> Furthermore, digital datasets on personal health and medical details have become a target of cyber criminals.<sup>28</sup> As such, Benaloh et al. suggest a simple way to deal with the potential risks. Electronic patient health records should give patients full control over the selective sharing of their own health data. “The patient health data should be encrypted in addition to traditional access control mechanisms provided by the server.”<sup>29</sup> To that end, each patient would generate their own decryption keys and distribute them to authorized users. Putting the patient in complete control over their health data.

Very little of the literature available details the ways medical practitioners, hospital administrators, and public health professionals incorporate medical health care applications into their work practices. Furthermore, there is a gap in the literature on ways to uncover knowledge in the practices and assumptions of mobile healthcare developers and the various for-profit companies that commission mobile healthcare

application. Lastly, the literature available does not go in-depth about the way lay people and healthcare workers alike might resist the utilization of mobile healthcare applications.

## **2.7 Reliability and Validity of Patient Generated Health Data**

In 1984, Mazze et al. conducted one of the earliest studies on the reliability of patient generated health data as it relates to patients with diabetes. Mazze et al. asserted that for self-monitoring of blood glucose levels to be useful, patient-generated data must be reliable and accurate. The goal of the study was to demonstrate the high degree of correlation between patient-generated and laboratory-generated test results in the clinic or hospital. At that point, no study has directly measured the accuracy and reliability of persons with diabetes in their routine daily use of the reflectance meter and the reporting of the results of their self-monitoring.<sup>30</sup> Mazze et al. found that a “significantly lower ( $p < 0.0001$ ) mean blood glucose level was reported in the logbooks than recorded in the memory reflectance meters”. Furthermore, three fourths of the subjects had reported lower than actual mean blood glucose values. To that end, identifying a degree of unreliability and inaccuracy among the study subjects that could have a profound effect upon the usefulness of patient-generated health data.

In 2014, thirty years from the Mazze et al study, Nundy, Lu and Hogan published a study on patient generated data from mobile technologies for diabetes self-management support particularly focused on gathering provider’s perspective from academic medical center.<sup>31</sup> This study grew from the little that is known about provider’s perspectives on integrating patient generated health data into routine care. Nundy, Lu and Hogan found that providers understood the overwhelming benefits of patient-generated health data

particularly as it relates to common barriers to self-management support in clinical practice. However, expressed a number of concerns. One of the physicians in the study speaks directly to the perceived validity of patient generated health data from mobile technologies. “I think that [self-reported information] is not sensitive enough. I mean if you ask people if they take the meds as prescribed the way they are supposed to they would say yes and then you start digging in and they would say oh well but I skipped that one or I ran out of that one...”<sup>31</sup>. Another physician address concerns around the possible exclusion of patients particularly those who do not have access to more expensive technology such as smartphones. Overall, providers in the study stated “patient data collected via mobile phones may be more accurate than information collected during a clinic visit”<sup>31</sup>. This is due to data collected at more frequent intervals and not just restricted to within the clinic visits. Moreover, they could be less recall bias because the tendency to give the seemingly correct answer to the physician is minimized. However, it is important to note that most providers saw patient generated health data from mobile technologies as a complement to, not a replacement for, provider-directed history taking. As such, many of the physicians in the study saw the patient-generated health summary report as a screening tool.

Wood et al. assert that recent advancements in consumer directed personal computing technology have led to the generation of biomedically-relevant data streams with potential health applications.<sup>32</sup> They went on to emphasize that the study of patient generated data is in the infancy stage and requires significant work to be done in order to identify, acquire, validate and model relevant patient generated health data streams so that the data can be useful in the research context and ultimately in clinical care.

Additionally, monitoring devices and applications can make a real-time impact on self-management, but the validity and reliability of measurement need to be established.<sup>33</sup>

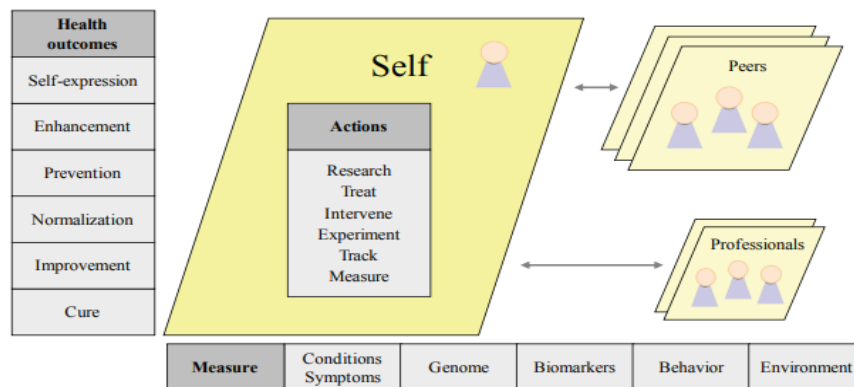
There is sparse literature and studies available that directly address the validity and reliability of patient generated health data. Moreover, there is no study found that addresses the existing validity and reliability from the angle of patient data generated from mobile health application.

## **2.8 The Quantified Self**

The emergence of this new paradigm shift in clinical research provides each individual with the ability to generate an analyzable personal data cloud of data points that will ultimately help to catalog the changes between and predictors of health and disease.<sup>34</sup> The data can be aggregated to drive insights on both a population and individual level. As such, the amount and complexity of data allows each person to serve as his or her own control over time, creating what is referred to as n of 1 studies.<sup>35</sup> N of 1 trial means that the individual through qualified self-tracking has the ability to understand his or her own patterns and baseline measures, and obtain early warnings as to when there is variance.<sup>36</sup> The ultimate goal of a n of 1 trial is to determine the optimal intervention for an individual patient using objective data-driven criteria.<sup>37</sup>

The quantified self is a movement to incorporate technology into data acquisition on aspects of a person's life in terms of inputs such as treatments taken, foods consumed and weather. States such as mood, blood oxygen level and performance on both a mental and physical level is self-monitored and often combined with wearable sensors. There are elements of a gamification approaches that allows everyday activities to be turned into games rewarding points to encourage people to complete their daily data reporting.

To that end, patients often collect data using self-quantification devices such as a mobile health application to ascertain the impact of their daily activities on illnesses and to seek subtle clues on how to improve one's functional status and quality of life. This had led to the theories around expanded the model for healthcare to incorporate data elements collected by the patient.



**Figure 4.** Expanded Model for Health and Health Care towards Personalized Medicine

Figure four demonstrate the new model described in the literature for health and health care.<sup>38</sup> The left column depicts the extended definition of health and the continuum of health outcomes. The primary focus on illness cure is expanded to include the improvement of chronic conditions moving towards the attainment of baseline health normalization and further prevention of unhealthy circumstances through the promotion of wellness. Along the bottom of the visualization are the health measures starting with the usual conditions with associated symptoms and further including genomic testing, behavioral tracking and monitoring an individual's environment. The body of Figure 3 shows the stakeholder of the multi-party health care system. Individuals are placed in the

center in regards to action-taking in areas such as “measuring, tracking, experimenting and engaging in interventions, treatments and research”<sup>38</sup>.

There is historical and clinical importance in the design and conduct of clinical trials involving the generalizability of the results especially if there is a suggested novel intervention that has population wide utility. However, Lillie et al. assert that n of 1 trial that focus exclusively on the empirically determined optimal intervention for a single patient defy generalizability but is compatible with the ultimately end point of clinical practice. Moreover, clinical studies focusing on the treatment of single patients are actually more consistent with the vision of personalized medicine than stratifying patients into groups that can plausibly benefit from a specific treatment on the basis of population-level association studies”<sup>39,40</sup>

N of 1 trials can improve care by increasing therapeutic precision and yet has not been widely adopted in part due to clinicians not valuing the reduction in uncertainty they yield weighed against the inconvenience N of 1 trials impose.<sup>41</sup> From the patient’s perspective, there is sparse literature and evidence that discusses the receptiveness, or lack thereof, to n-of-1 trials. Robust uptake of N of 1 trials would require comprehensive buy-in from health care organizations, clinicians and patients. For clinicians the barriers can be seen as conceptional, practical and structural in nature. Kravitz et al. discussed probable way to make N of 1 trials widely acceptable to clinicians. Given the existing use of science-based evidence and experience to generate a list of treatment options for the patient, it is the responsibility of the both the patients and physicians to move down the treatment lists by trial and error. For example, in a single trial for the determining the most efficient proper acid reflux medication, considerable information might be collected

by alternating two medication every fortnight for a total of eight to twelve weeks and asking patients to keep detailed symptom diaries.<sup>41</sup>

## **2.9 Self-Tracking of Health and Chronic Disease Symptomology**

Self-tracking using mobile devices has ushered in an era where individuals are more involved in the management of their health and generating data that will benefit clinical decision making and research.<sup>42</sup> The factors that lead to self-tracking and collecting data routinely and the effects of this behavior is mostly understudied. Self-tracking is defined as “the practice of repeatedly recording information such as behaviors, thoughts, and feelings about oneself. It encompasses collecting data and reflecting on it in order to acquire knowledge or achieve a goal”.<sup>43</sup> Self-tracking health and chronic disease is not a new phenomenon and was historically practiced by using methods such as using pen and paper and or storing into one’s memory.<sup>44</sup> The practice of self-tracking has gained research interest in the past decade due to the popularity of mobile technology and its ability to facilitate recording health information.<sup>45</sup> There are sparse studies on self-tracking focusing on its ability to assist in chronic disease management. This is particularly important given chronic illnesses usually require long-term treatment and management arrangements. In addition, the analysis on the collected data can benefit people suffering from these conditions by improving their knowledge about the illness, identifying triggers, and controlling health indicators.<sup>46</sup>

The Centers for Disease Control and Prevention estimates that chronic diseases account for 70% of U.S. deaths and 75% of U.S. health care spending.<sup>47</sup> Moreover, chronic diseases are prevalent affecting roughly 120 million Americans. The expansion of activity tracking and personal data collection provides the potential for patient

engagement in the management of chronic diseases.<sup>33</sup> BJ Fogg et al. discussed the importance of computers as persuasive technology with an ability to improve self-efficacy, provide personalized information, activate decision-making, and help people decrease barriers that obstruct target behaviors.<sup>48</sup> As such, pushed self-tracking using mobile technologies is one approached to supporting the self-management of chronic diseases although there is little systematic research available.<sup>49</sup> Pushed self-tracking approach is defined as when an individual is asked to self-track and it is imposed by the healthcare provider as an active part of their treatment plan.<sup>50</sup> Advocates for pushed self-tracking are particularly evident in the promotion and preventive medicine literature. The arguments for pushed self-tracking of blood glucose level and blood pressure for chronic disease patients is common in literature.<sup>51</sup> Another aspect of quantified self-tracking includes the graphical display of the patient generated health data and a feedback loop of self-experimentation and analysis. Health characteristics that are quantitative such as mood can be recorded with qualitative words that are warehoused as text or in a tag cloud, mapped to a quantitative scale, or ranked relative to other measures such as yesterday's rating.<sup>50</sup> Therefore, literature on self-tracking reveal notions of the value of patient generated health data and the importance of creating data as a means to uncover hidden patterns in individual's life that are otherwise undiscernible.

The literature review does discuss the powerlessness felt by the patient as it relates to the collection and harvesting of their health data.<sup>52</sup> The use of personal health data is often seen as a unavoidable part of accepting the terms of conditions of a self-tracking platform such a mobile health application. The developers of many mobile health applications for smartphones do not provide privacy policies and fail to inform



users the ways their personal health data might be available to third parties. Several reports have demonstrated that the security of personal data uploaded to digital platforms such as mobile applications are not always secure. As such, the vitality of personal data and the many different ways it can be repurposed cannot be accurately predicted and or controlled. As such, creating resistance to digitally self-tracking conditions, symptoms and treatments for individuals.

In particular, symptom self-tracking holds “great potential in precision medicine and can, if shared in a clinical encounter, contribute to the learning of both patient and clinician.”<sup>53</sup> Self-tracking can also significantly improve clinical measures. For example, Basch et al. did a randomized control trial of 766 patients undergoing chemotherapy. The overall survival of patients tracking 12 symptoms using a web-based platform was compared to clinical care without self-tracking involved. The results showed that patients tracking symptoms had a median overall survival of 31.2 months compared with 26.0 months for the group receiving usual care.<sup>54</sup> The main reasons for the difference included the early responsiveness of nurses on potentially adverse events and increased tolerability to chemotherapy for the patients through the process of self-tracking. To that end, real-time tracking of symptoms by patients could address problems related to managing symptoms during treatment. Patients who track their symptoms at home as they occur could share symptom severity, frequency, and duration with clinicians. Thus, clinicians could better understand and address symptom burden.<sup>55</sup>

A study conducted by Portz et al. in 2018 that examined the development and acceptability of a mobile application for tracking symptoms of health failure among older adults. The Health Failure mobile application was developed to allow patients to track

their symptoms of health failure. The users would record their weight, log their symptoms and symptom severity. As such, the areas monitored included weight, fatigue, edema, shortness of breath, cough, stomach bloat, feeling sad, and feeling anxious. Each item was dichotomous and only in cases of an affirmative response would a slider appear to indicate the symptom severity. The application was evaluated for acceptability by patients older than the age of 60. Portz et al. used a Likert scale from strongly agree to strongly disagree on questions related to their understanding of the application, ability to use the application and ability to report symptoms through the mobile application.

As such, thirty patients were recruited from HF clinics in Denver at the University of Colorado Hospital and at the University Hospital Cleveland Medical Center in Cleveland, Ohio. Participants were mostly female (60%), black (63%), and a mean of  $66 \pm 18$  years of age.<sup>56</sup> The results found that overall acceptability from users was positive with users agreeing that the mobile application was easy to use, understand, and navigate. Users also identified potential areas for improvement including tracking additional biometrics such as heart palpitations and blood pressure. Participants also recommended adding specific features such as patient-specific symptoms. In doing so, providing a more comprehensive and user driven symptom tracking mobile health application. This study further supports the need for additional research on mobile health applications that track symptoms across different demographics and age groups that is end user-driven.

## **2.10 Usability and Engagement in Self Tracking using Mobile Health Applications**

Usability of and engagement with symptom tracking apps were a recurring theme noted throughout many reviewed studies. It has been found that a high level of usability

of health tracking mobile applications is an essential component to ensuring successful engagement with these types of mobile health apps.<sup>57</sup> Anderson and colleagues explored consumers' experiences with their own personal mobile health tracking apps to manage various chronic health conditions. Participants reported that the functionality, features and usability of their own personal mobile health tracking apps were of principal importance to maintain their engagement with the health tracking applications.<sup>58</sup> Anderson and colleagues concluded that understanding the range of consumer experiences and expectations can inform design of health apps to encourage persistence in self-monitoring across chronic conditions.

The desire of participants to personalize health tracking apps to their particular needs was noted in many studies regarding usability and engagement in self-tracking using mobile applications. Goodwin and colleagues examined the viewpoints of mental health service users to inform future development of user-center mobile health tracking application. An analysis of participants interviews responses found that tracking mental health behaviors require personalizing the mobile application to meet the needs of user was of primary interest. As such, Goodwin et al. concluded that involving end users in the design of the mental health mobile health application is of critical importance for engagement and usability.<sup>59</sup>

Another study conducted by Vanderboom and colleagues looked at the feasibility of interactive technology for symptom monitoring in patients with fibromyalgia. Given the lack of literature on the appropriate methodology that systematically facilitates the integration of health information technology with clinical services between patients and providers to manage chronic diseases, Vanderboom et al. conducted quantitative and

qualitative descriptive in a sample of 20 fibromyalgia patients and found that 80% reported that monitoring symptoms using a smartphone was easy to do and 65% reported that monitoring symptoms using a smartphone helped them to promptly address their symptoms. Results from Vanderboom et al. study indicated that health IT integrated with clinical services is feasible to monitor and communicate fibromyalgia symptoms with the care team. The abovementioned studies support the existing gaps in literature and need for research into usability and feasibility of mobile health applications to track symptoms and address treatments.

### **2.11 Self-Tracking and the Effects on Health**

A national telephone survey conducted by the Pew Research Center's Internet & American Life Project found that 69% of U.S. adults keep track of at least one health indicator such as weight, diet, exercise routine, or symptom. Furthermore, people living with one or more chronic conditions are no more likely than other U.S. adults to track their weight, diet, or exercise routine. However, they are significantly more likely to track other health indicators or symptoms and this likelihood increases among those living with more than one condition. Additionally, individuals who self-track living with multiple chronic conditions are more likely to be methodical about collecting their own health data. The Pew Survey found that 45% of self-trackers with 2 or more conditions use paper such a journal compared with 37% of self-trackers with 1 condition and 28% if trackers who report no chronic condition.<sup>60</sup>

The Pew Research specified that self-tracking can affects someone's overall approach to health. In survey found that tracking has a significant impact on people living with chronic conditions. 56% of individuals surveyed with self- track living with two or

more conditions said it has affected their overall approach to maintaining their health or the health of someone they help care for, compared with 40% of individuals who self-track who report no chronic conditions. Furthermore, 53% of self-trackers living with two or more conditions say it has led them to ask a doctor new questions or to seek a second opinion, compared with 33% of trackers with no chronic conditions. 45% of trackers living with two or more conditions said it has affected a decision about how to treat an illness or condition, compared with 25% of self-trackers with no chronic conditions. The results reported came from a nationwide survey telephone interviews of 3,014 adults living in the United States. Pew Research Center's for Internet and American life Project also conducted a mobile health survey in 2012 and report that women, those under age 50, those who are better educated, and those with an annual household income over \$75,000 are more likely to have downloaded health application onto their mobile devices.

<sup>61</sup> This further illustrated the need to assess a mobile health application to validate if woman under the age of 50 are the key consumers in self-tracking and mobile health application usership.

## **2.12 Stage-Based Model of Personal Informatics**

Li and colleagues discussed the stage-based model of personal informatics which is integral to the developing body of research related to self-tracking and mobile health applications. The model is composed of five stages, preparation, collection, integration, reflection and action. Table 2 defines each stage according to Li et al. analysis of survey and interview data on personal informatics. <sup>43</sup>

Stage	Definition
Preparation	Occurs before people start collecting personal information. Rooted in people's motivation to collect personal information
Collection	Stage when people collect information about oneself through observation and reporting
Integration	Stage where the information collected are prepared, combined, and transformed for the user to reflect on.
Reflection	Stage when the user reflects on their personal information. This stage may involve looking at lists of collected personal information with visualizations.
Action	stage when people choose what they are going to do with their newfound understanding of self

**Table 2-** Stage-Based Model of Personal Informatics

An important property of personal informatics systems that the stage-based model reveals is that a barriers cascade can be defined as the problems in the earlier stages affect the later stages. That can be seen in preparation stage, when the use of the wrong tool or not collecting the right data can lead a user to change tools and subsequently ineffectively use resources and time. Furthermore, problems in the collection stage may lead to sparse datasets that are insufficient for reflection. The lacked of motivation and or time during the collection stage can lead to not having enough data to get a good time-series visualization. Additionally, problems in the integration stage such as scattered visualizations and difficult organization make reflection harder. Problems in the reflection stage such as having trouble using visualizations effectively prevent users from transitioning to the action stage.

### **2.13 Mobile Health Apps and Treatment Management**

Adherence to chronic disease management is critical to achieving improved health outcomes. The impact of treatment non-adherence to chronic disease management is significant. Hamine and colleagues assert that there is increasing use of mobile

technologies in health care and public health practice for monitoring and facilitating adherence to chronic diseases management. In their systematic review of the literature short messaging services (SMS) was the most common used treatment adherence tool in 40 percent of studies reviewed.<sup>62</sup> A more comprehensive review assessed the health impact of SMS on any type of long-term illness but found only four comparative effectiveness trials able to address the impact of mobile services on self-management.<sup>63</sup> To that end, the impact of these mobile health application on adherence to treatment regimens is understudied. There is increased need for mobile health and treatment management studies on the effects related to clinical outcomes such as morbidity, mortality, and biometric markers of clinical disease. To that end, adherence to treatment, and specifically adherence to treatment of chronic diseases, is a critical link that connects the promise of mobile health to the ultimate goal of improved clinical outcomes.

#### **2.14 Predictors of Mobile Health App Usage**

Developments in mobile health has elevated the importance of assesses the extent to which mobile technologies empowered patients and improve health across different demographics. Kontos and colleagues looked at eHealth use by sociodemographic factors, such as race/ethnicity, socioeconomic status (SES), age, and sex. Drawing data National Cancer Institute's 2012 Health Information National Trends Survey, they estimated multivariable logistic regression models to assess sociodemographic predictors of electronic health (eHealth) use among adult internet users (N=2358) across three health communication domains which were health care, health information-seeking, and user-generated content/sharing. They found that age was the sole predictor of whether adults that get online used the Internet in the past 12 months to search for health

information for themselves. Furthermore, adults aged 18-34 years were 3.5 times as likely and adults aged 35-49 years were nearly 2.5 times as likely as those 65 years and older to use the Internet to search for health information (OR 3.51, 95% CI 1.66-7.44 and OR 2.35, 95% CI 1.17-4.72, respectively).<sup>64</sup> Additionally, in direct relation to mobile application usage, Carroll et al. used the same data set and found that those who used health apps (compared with those who either did not have apps or did not have the necessary equipment) were more likely to be younger, live in metropolitan areas, have more education, have higher income, speak English well, be Asian, and report excellent health.<sup>65</sup> There is a gap in literature as it relates to the demographics of mobile application usage for those who report poor health and present with a multitude of symptoms.



## **CHAPTER III**

### **METHODOLOGY**

#### **3.1 Source of Data**

Secondary data was acquired from Flaredown LLC, a mobile health application for self-tracking and visualizing chronic diseases. The secondary data was publicly released under Creative Commons license CC BY-NC-SA 4.0 (Attribution-Noncommercial-Share Alike 4.0 International) to Kaggle.com, an online community of data scientists and machine learners owned by Google, Inc. Kaggle allows users to find and publish data sets. As such, researchers can freely share, copy and redistribute the material in any medium or format. Furthermore, researchers can adapt the data which includes remix, transform, and build upon the material under the following terms of providing attribution, non-commercial use and share any transformed material under the same license as the original.

Flaredown collects data using a different set of self-reportable questions for each illness that were established to quantify the severity of a patient's condition such as the Crohn's Disease Activity Index (CDAI). If a disease activity index doesn't exist for a given condition, Flaredown defaults to a subjective 1-10 scale in which the user indicates how severe they feel their illness is that day. Given Flaredown's use of established disease activity indicators, the patient generated health data is in a format that is accessible to research. As such, researcher can test treatments and symptoms against metrics that are already widely accepted by the medical community. Furthermore, Flaredown users are performing N of 1 trials to understand the effects of symptom

triggers and treatments. It's been demonstrated that aggregating N-of-1 trials is an effective way to study treatment efficacy at the population level.

### 3.2 Processing Data from Mobile Health App

#### 3.2.1 Data and Variable Descriptions

Flaredown mobile application requests that users create their unique set of conditions, symptoms and treatments which are referred to as “trackables”. As such, a user “check-in” each day and record the severity of symptoms and conditions, the doses of treatments, and “tag” the day with any unexpected environmental factors. Table 2 shows the data elements, associated description and type of value. The data is complex with data being represented both numerically and with text data.

**Table 3:** Data Elements from Flaredown Mobile Application

Data Element	Description	Type of Value
User_ID	Unique user identifier	Numerical and Text
Age	Users age	numerical
Sex	Male, Female, Other	Text
Country	Location of the User	Text
Checkin_date	System generated date	Numerical
Trackable_ID	System generated number that ties one day of “trackables”	Numerical
Trackable_Type	condition, treatment, symptom, food, tag, weather	Text
Trackable_Value	Name and value associated with the trackable type	Numerical and Text

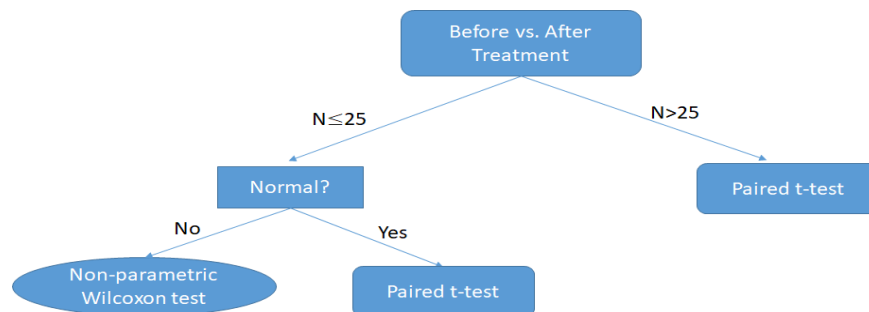
The data elements that are the most significant for this research is Trackable ID, Type and Value. Trackable ID is the primary key that ties Trackable Type and Trackable Value for any given day. The Trackable Type includes a type and an associated string of values. Treatment is a Trackable Type and categorized as anything a patient uses to improve their symptoms along with an optional dose. Condition is a Trackable Type such as Rheumatoid Arthritis rated on a scale of 0 (not active) to 4 (extremely active). A symptom is a Trackable Type and categorized as the physical or mental feature indicating a condition of disease particularly such a feature that is apparent to the user. The Trackable Value for a symptom is rated on a 0-4 scale from 0 being no symptoms and 4 equating to extreme symptoms. The Harvey Bradshaw index was incorporated as a Trackable Value for those users suffering with Chrons disease to quantify symptom severity using that metric.

A “Tag” is a Trackable Type that is a string representing an environmental factor that does not occur every day, for example “ate dairy” or “rainy day”. Food is a Trackable Type that were seeded from the publicly-available USDA food database. However, users also added many food items manually. Lastly, Weather is a Trackable Type that is pulled automatically for the user's postal code from the Dark Sky API. Weather parameters include a description, precipitation intensity, humidity, pressure, and min/max temperatures for the day. It is important to note that if users do not see a symptom, treatment, tag, or food, they have the option to name and add it to the database. This means that the data requires data cleaning before deploying inferential statistics.

### 3.3 Statistical Methodology

A series of pair-t tests or non-parametric Wilcoxon tests for within group comparison were performed for each symptom separately and subsequent p-values were obtained. If sample size is large (i.e. number of patients  $N > 25$ ), the law of large number is applied and assumption of normality is met, paired t-test is a valid test in this case to determine if there is any significant improvement after treatment. If sample is small size (i.e. number of patients  $N \leq 25$ ), normality assumption of the mean difference between before and after treatment in patients must be met for paired t-test to be a valid test. If sample size is small and normality assumption is not met, non-parametric test is carried out on the difference between and after treatment in patients. (Diagram 1).

The null hypothesis is the mean difference in a given tracked symptom in patients (for example, nausea symptom) between before and after treatment is 0. To that end, there is no improvement in a given tracked symptom after treatment. The alternative hypothesis is the mean difference in a given tracked symptom in patients between before and after treatment is greater than 0. As such, there is an improvement in a given tracked symptom after treatment. The significance threshold was set at .05



**Diagram 1:** Statistical workflow to determine if there is any improvement before and after users take medication

## CHAPTER IV

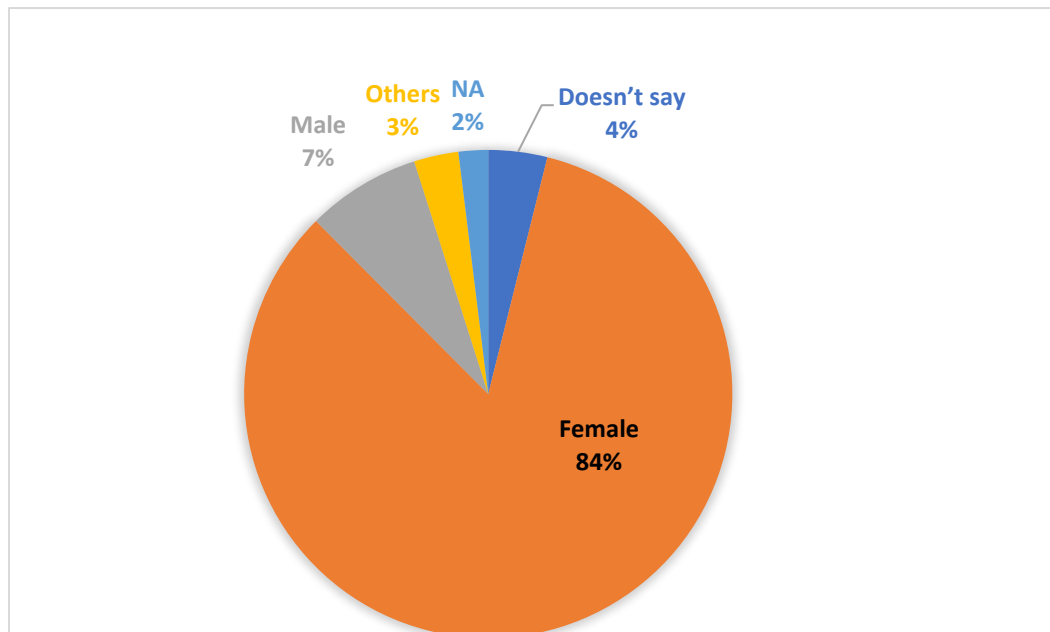
### RESULTS

#### 4.1 Summarized User Demographics and Data Statistics

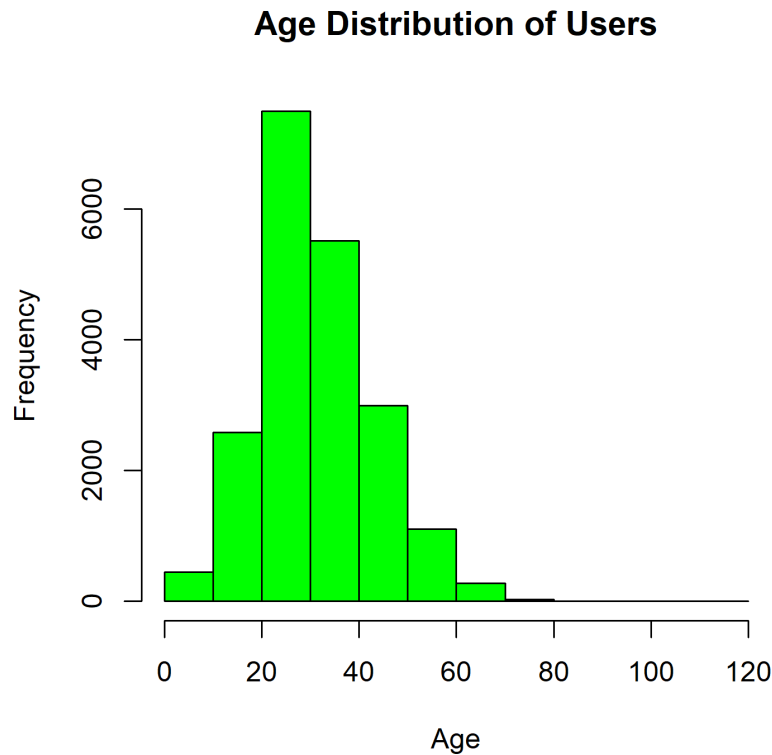
There are 22,071 unique users participating in this mobile health application study between May 12, 2017 through July 12, 2018. Majority of mobile application users are female at 84% and only 7% participants are male (Table 3 and Figure 5).

**Table 4:** Categorization on the basis sex of users

Sex of User Category	Number of users
Doesn't say	861
Female	18,459
Male	1,668
Others	652
Missing/Blank	431



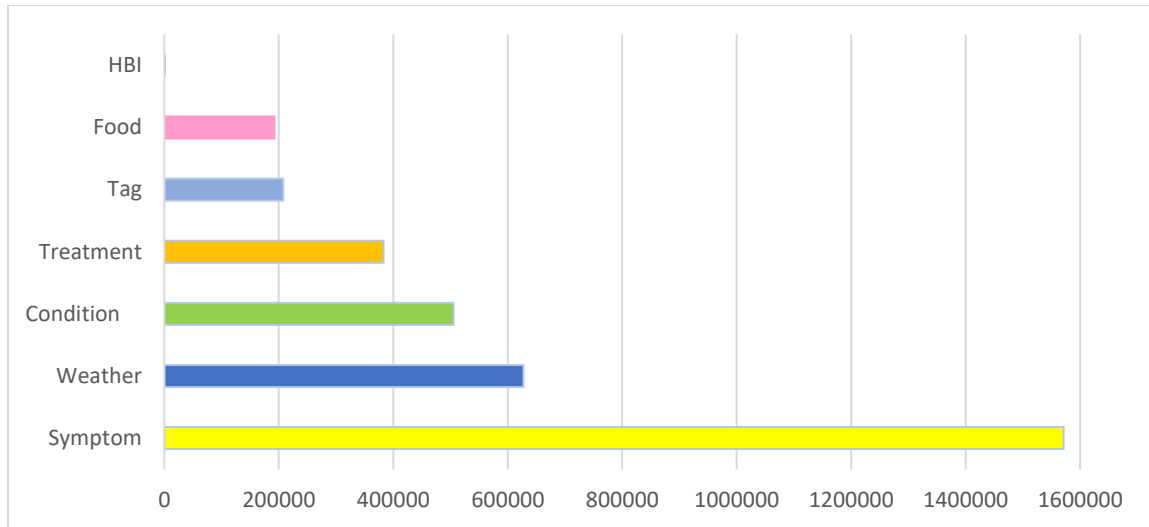
**Figure 5:** Gender Distribution for all participants in Flaredown mobile application



**Figure 6:** Age Distribution of all users

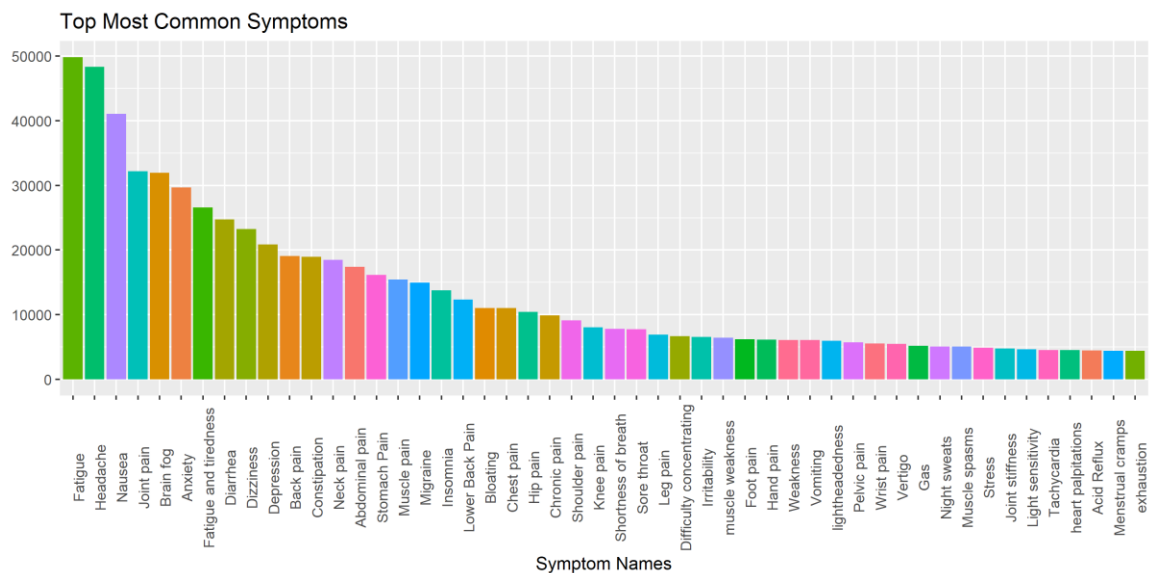
Figure 6 gives an overview of the age distribution of all users. The average age of all users is 32. The youngest user is at age 0 and the oldest user is at age 117 in this self-reported dataset. The average age of users supports existing literature on mobile health application usership.

The following is a snapshot of different types of Trackable Types in the datasets. The most collected data are symptom data, followed by weather data. Treatment data are only  $\frac{1}{4}$  or 25 percent of the symptom data. This implies that many users are tracking symptoms without tracking treatments. For the users suffering from Chrons Disease, the Harvey Bradshaw Index (HBI) was integrated as a trackable type.



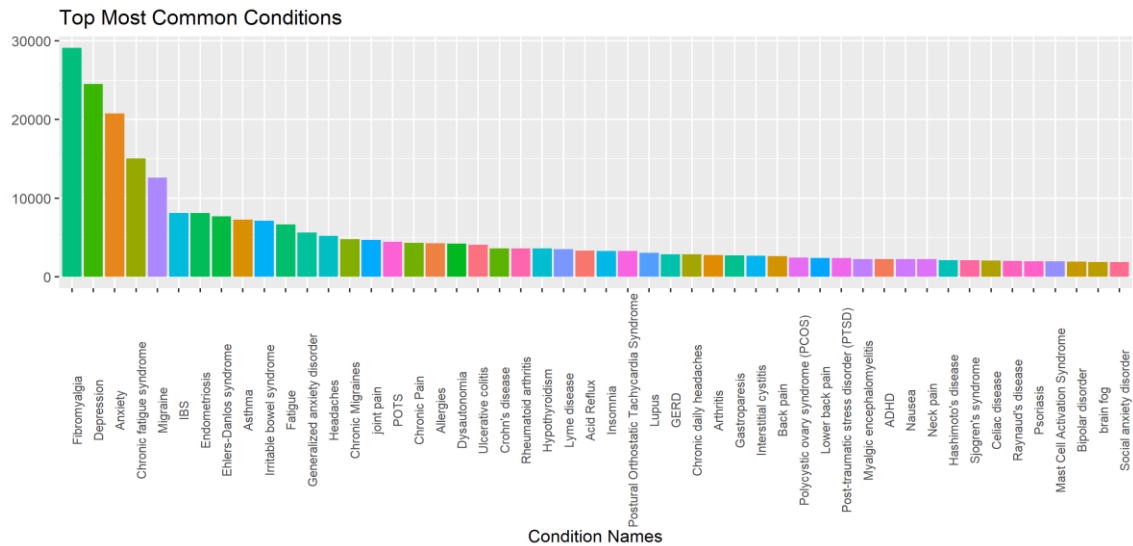
**Figure 7:** Categorization on the basis of different 'trackable\_type'

There are total of 11,547 unique symptoms. Figure 8 shows top 50 most common symptoms in the dataset. The most common symptom is Fatigue (~50,000 data points in the dataset), followed by headache (~48,000) and nausea (~41,000).



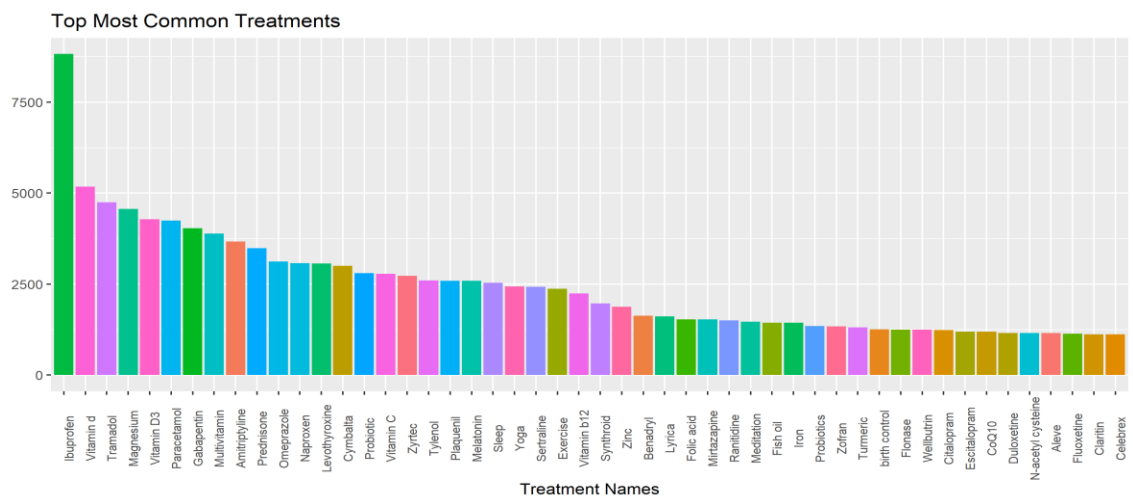
**Figure 8:** Top most common symptom names in the dataset.

There are total of 5,191 unique conditions. Figure 9 shows top 50 most common conditions in the dataset. The most common condition is fibromyalgia (~29,000 data points in the dataset), followed by depression (~25,000) and anxiety (~21,000).



**Figure 9:** Top most common condition names in the dataset.

There are total of 4,649 unique treatments. Figure 10 shows top 50 most common treatments in the dataset.



**Figure 10:** Top most common treatment names in the dataset.

The most common treatment is the over the counter drug Ibuprofen (~8,000 data points in the dataset), followed by Vitamin D (~5,000) and Tramadol (~4,700).



## 4.2 Processing of the Data and Statistical Results

Data were subset by each symptom. All different treatments that each user took are combined into one treatment group to see if taking any kind of medication can make an improvement on user's symptom. Furthermore, only treatments that are within 30 days of the onset of the first symptom for each user is used in the analysis.

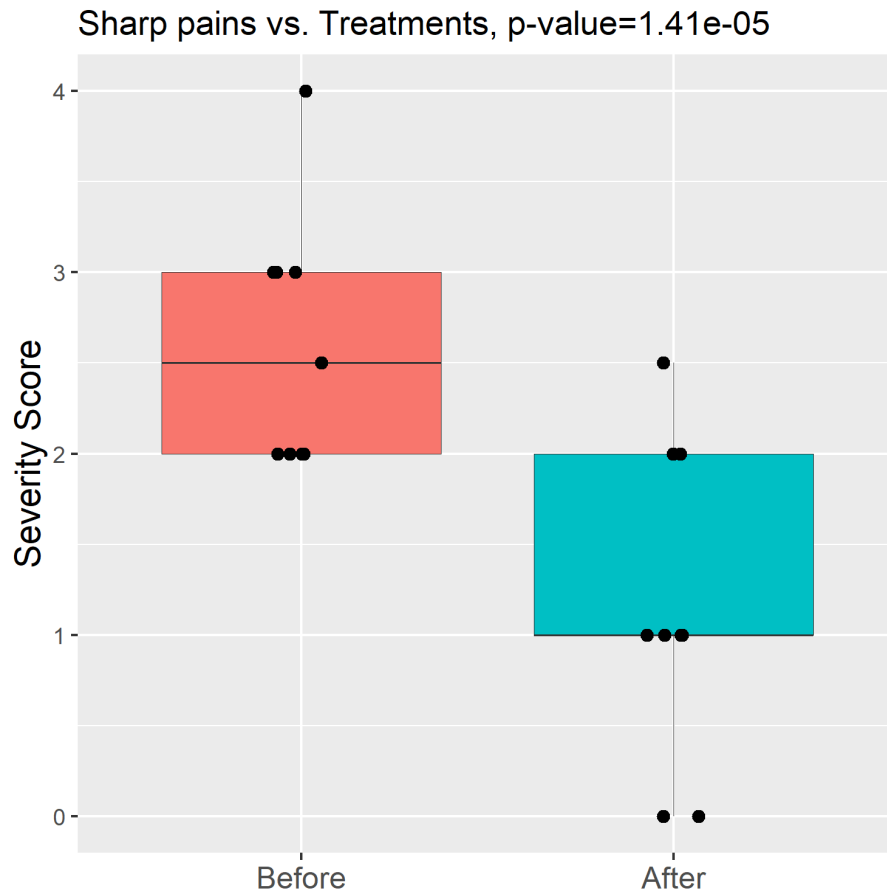
Table 5 shows aggregate statistical results for the most effective treatments to symptoms. This study found that treatment for sharp pains seem the most effective with associated p-value=1.41E-05. On average, the severity scores reduce by -1.4444 after taking the treatments to reduce sharp pains.

Interestingly, treatments to noise sensitivity and mouth sores seem to increase the severity scores, meaning that after taking the treatments, noise sensitivity and mouth sores did not reduce but increased symptom intensity after taking treatments (mean differences are 0.4596 and 0.5422 respectively). All of the results were statistically significant at an alpha level of. 05. As such, the study rejects the null hypothesis for each symptom and conclude that a significant difference does exist between tracked symptom severity and initiating treatment within 30 days of symptom onset.

**Table 5:** Top most effective treatments to symptoms, associated with the most popular treatment for each case

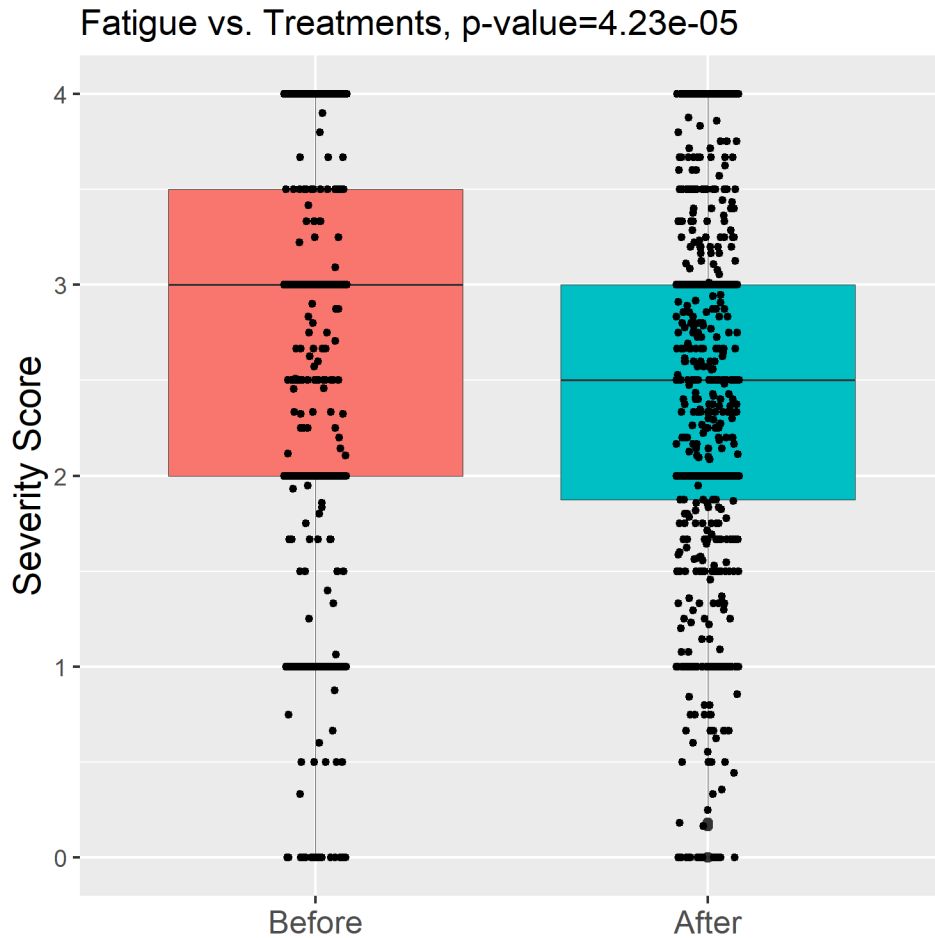
Symptom	Treatment	Sample Size	Mean Difference	P-value	Status
Sharp pains	Tramadol, Ibuprofen, Amitriptyline, paracetamol, vitamin D	9	-1.4444	1.41E-05	Reduce Severity
Fatigue	Vitamin D, Ibuprofen, gabapentin, Vitamin B, plaquenil	730	-0.1665	4.23E-05	Reduce Severity
Brain fog	Vitamin D, Vitamin B, Ibuprofen, gabapentin, magnesium	482	-0.1943	4.28E-05	Reduce Severity
Lack of Motivation	Vitamin D, Vitamin B, vyvanse, Vitamin CBD, Vitamin C	26	-1.0046	0.000278	Reduce Severity
Fatigue and tiredness	Vitamin D, Ibuprofen, Paracetamol, Gabapentin, tramadol	578	-0.1449	0.000299	Reduce Severity
Lack of Appetite	Vitamin B, Vitamin D, Gabapentin, Cymbalta	36	-0.6862	0.000461	Reduce Severity
Noise Sensitivity	Vitamin D, gabapentin, paracetamol, magnesium, omeprazole	40	0.4596	0.000584	Increase Severity
Low motivation	Tramadol, paracetamol, Vitamin D, Zyrtec, Sertraline	21	-0.6869	0.000676	Reduce Severity
Mouth sores	Plaquenil, gabapentin, Tylenol, vitamin D, trazodone	28	0.5422	0.000883	Increase Severity

#### 4.3 Boxplots for each symptom before and after treatments



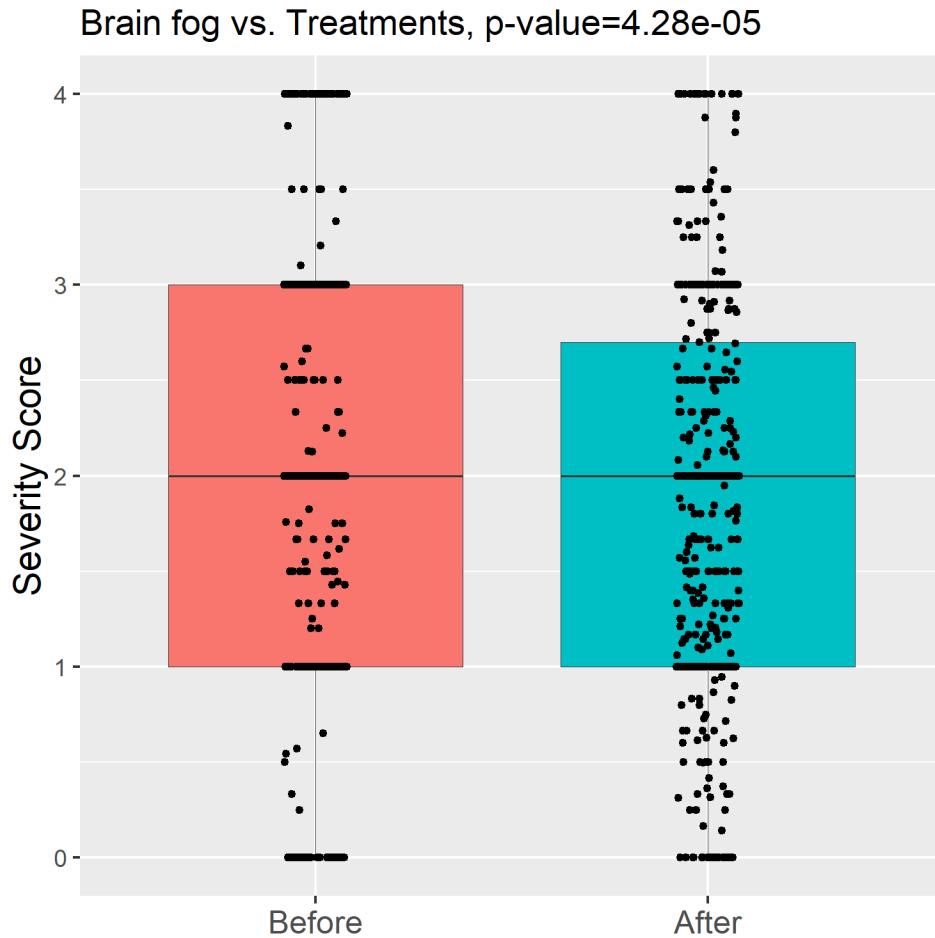
**Figure 11:** Sharp pains symptom severity before and after Treatment

The severity score for mobile application users tracking sharp pains decreased by a mean difference of -1.444 with a P-value=1.21E-05. This indicates there is a statistically significant improvement in tracked symptom severity after treatment. The most popular treatments tracked for sharp pains are Tramadol, Ibuprofen, Amitriptyline, paracetamol, vitamin D. Tramadol is a synthetic opioid analgesic medication used to treat moderate to moderately severe pain. Amitriptyline is tricyclic antidepressant used to treat symptoms of depression. Ibuprofen and paracetamol are both over the counter medications used to treatment mild to moderate pain.



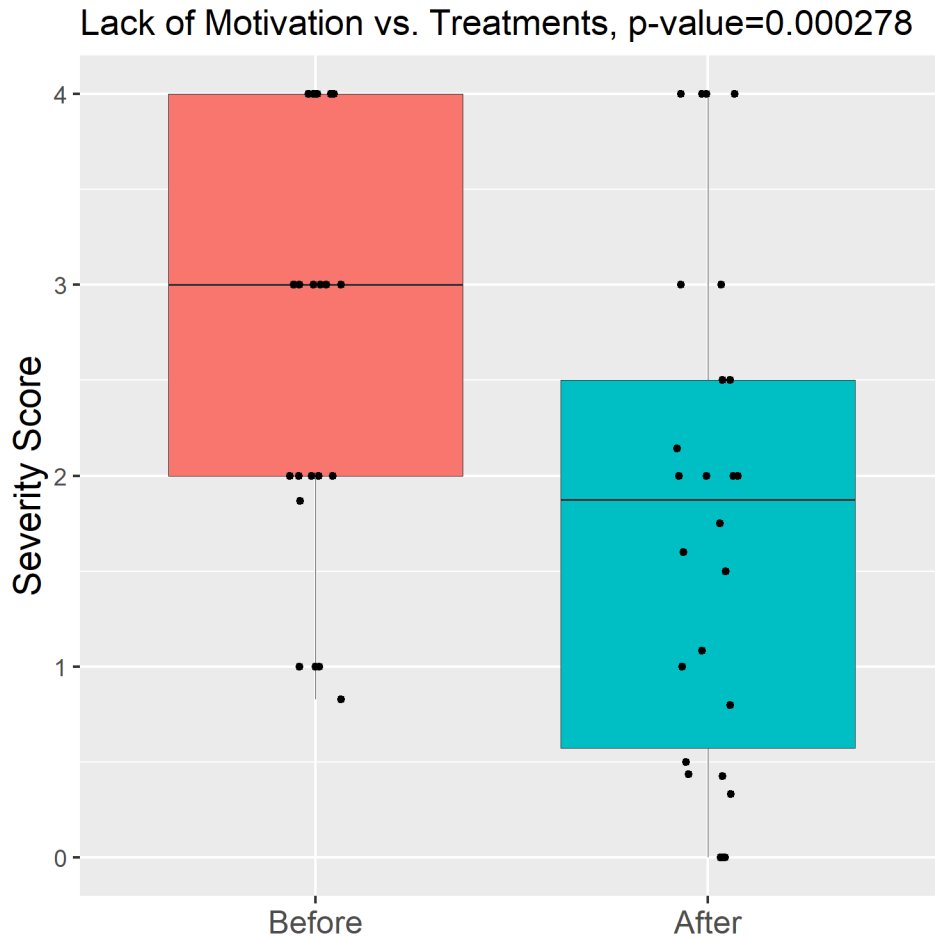
**Figure 12:** Fatigue symptom severity before and after treatment

The severity score for mobile health application users tracking fatigue decreased by a mean difference of -0.1665 with P-value= 4.23E-05. This indicates there is statistically significant improvement in tracked symptom severity after treatment. The most popular treatments tracked for fatigue are Vitamin D, Ibuprofen, gabapentin, Vitamin B, plaquenil. Gabapentin and plaquenil are both prescriptions medications that treat various conditions. In particular, Hydroxychloroquine (Plaquenil) is considered a disease-modifying anti-rheumatic drug (DMARD). It can decrease the pain and swelling of arthritis. it is used to treat rheumatoid arthritis, some symptoms of lupus, childhood arthritis (or juvenile idiopathic arthritis) and other autoimmune diseases.



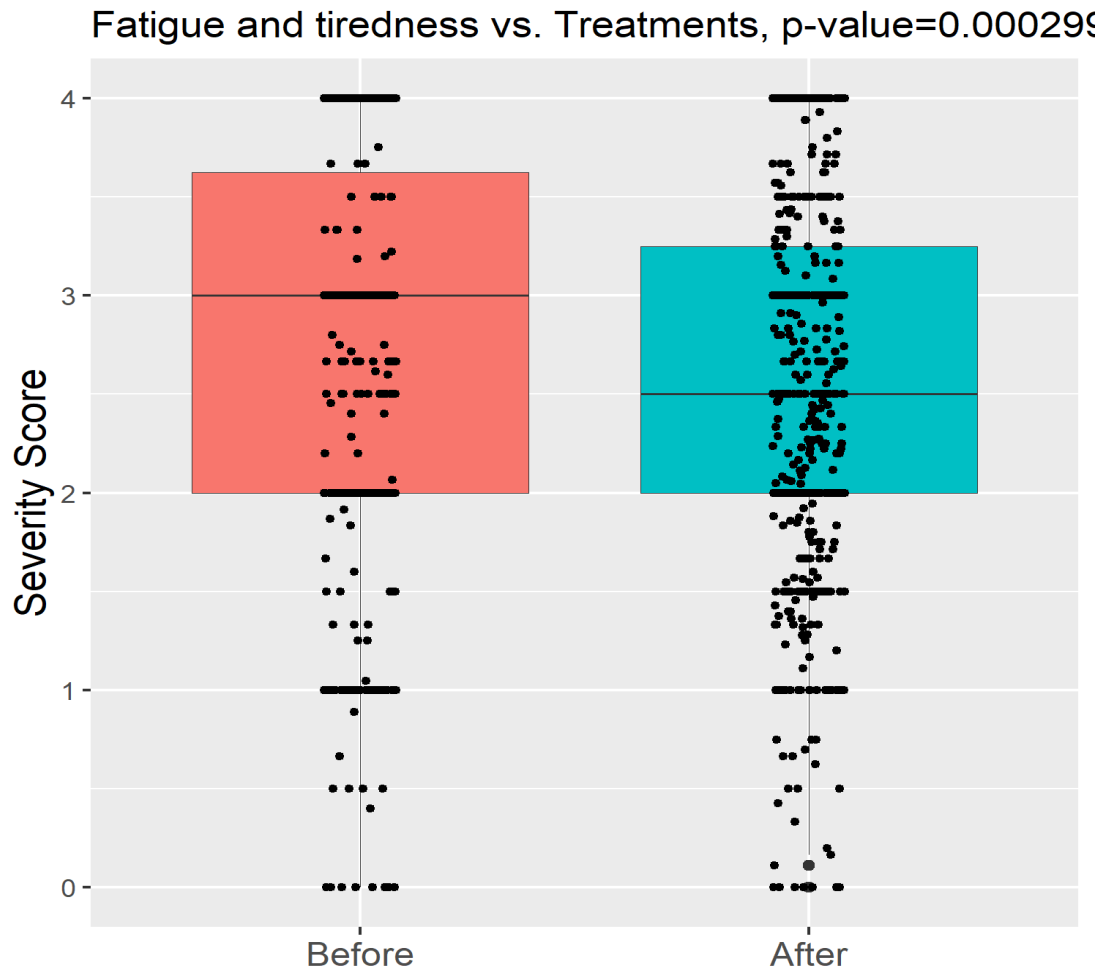
**Figure 13:** Brain fog symptom severity before and after treatment

The severity score for mobile health application users tracking brain fog decreased by a mean difference of -0.1943 with a P-value=4.28E-05. This indicates there is statistically significant improvement in tracked symptom severity after treatment. The most popular treatments tracked for brain fog include Vitamin D, Vitamin B, Ibuprofen, gabapentin, magnesium. Gabapentin is an anticonvulsant medication meant to calm hyperactivity in the brain. It's used as an adjunct treatment for partial seizures and for the management of neuropathic pain and postherpetic neuralgia.



**Figure 14:** Lack of motivation symptom severity before and after treatments

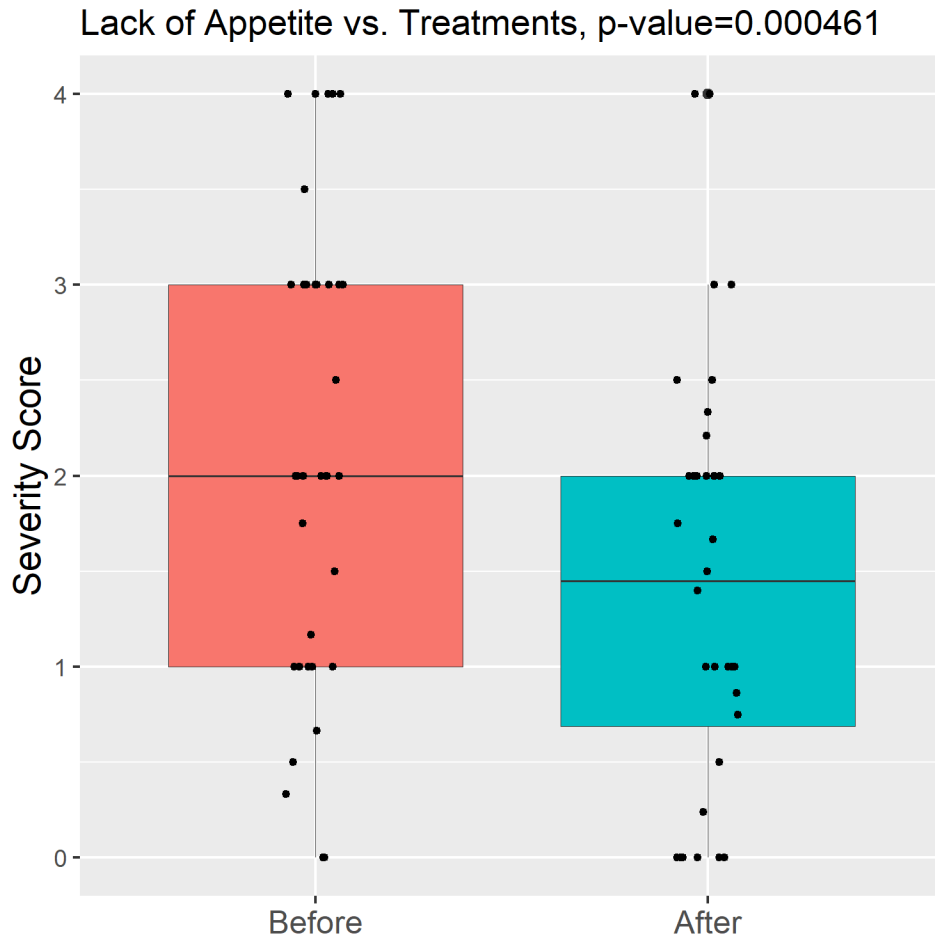
The severity score for mobile health application users tracking lack of motivation decreased by a mean difference of -1.0046 with a P-value=0.000278. This indicates there is statistically significant improvement in tracked symptom severity after treatment. The most common treatments for lack of motivation include Vitamin D, Vitamin B, Vyvanse, Vitamin CBD, Vitamin C. The only prescription medication treatment is Lisdexamfetamine (Vyvase) is a stimulant that works by restoring the balance of certain natural neurotransmitters in the brain and is used to treat attention deficit hyperactivity disorder (ADHD) as part of a total treatment plan.



**Figure 15:** Fatigue and Tiredness symptom severity before and after Treatments

The severity score for mobile health application users tracking fatigue and tiredness decreased by a mean difference of -0.1449 with a P-Value= 0.000299. This indicates there is statistically significant improvement in tracked symptom severity after treatment.

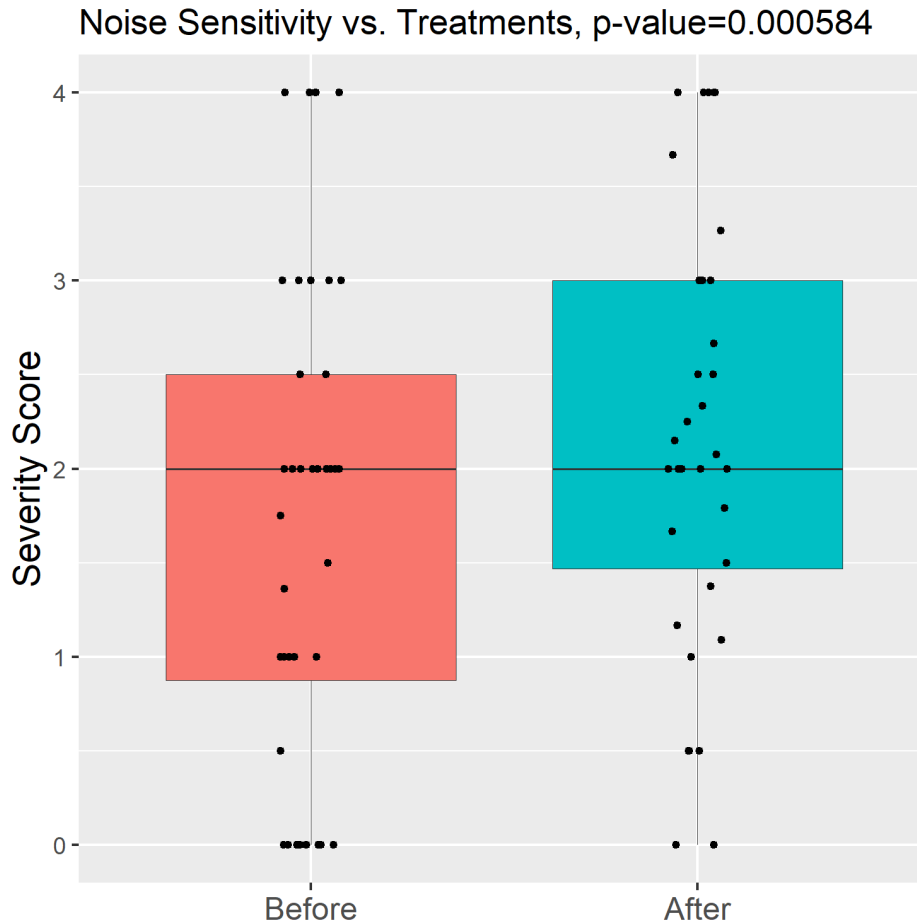
The most common treatments for fatigue and tiredness (combined) include Vitamin D, Ibuprofen, Paracetamol, Gabapentin, tramadol. Vitamin D is found to be a common efficient treatment in this study. Vitamin D is a fat-soluble vitamin that is naturally present in very few foods, added to others, and available as a dietary supplement. It is also produced endogenously when ultraviolet rays from sunlight strike the skin and trigger vitamin D synthesis.



**Figure 16:** Lack of appetite symptom severity before and after Treatments

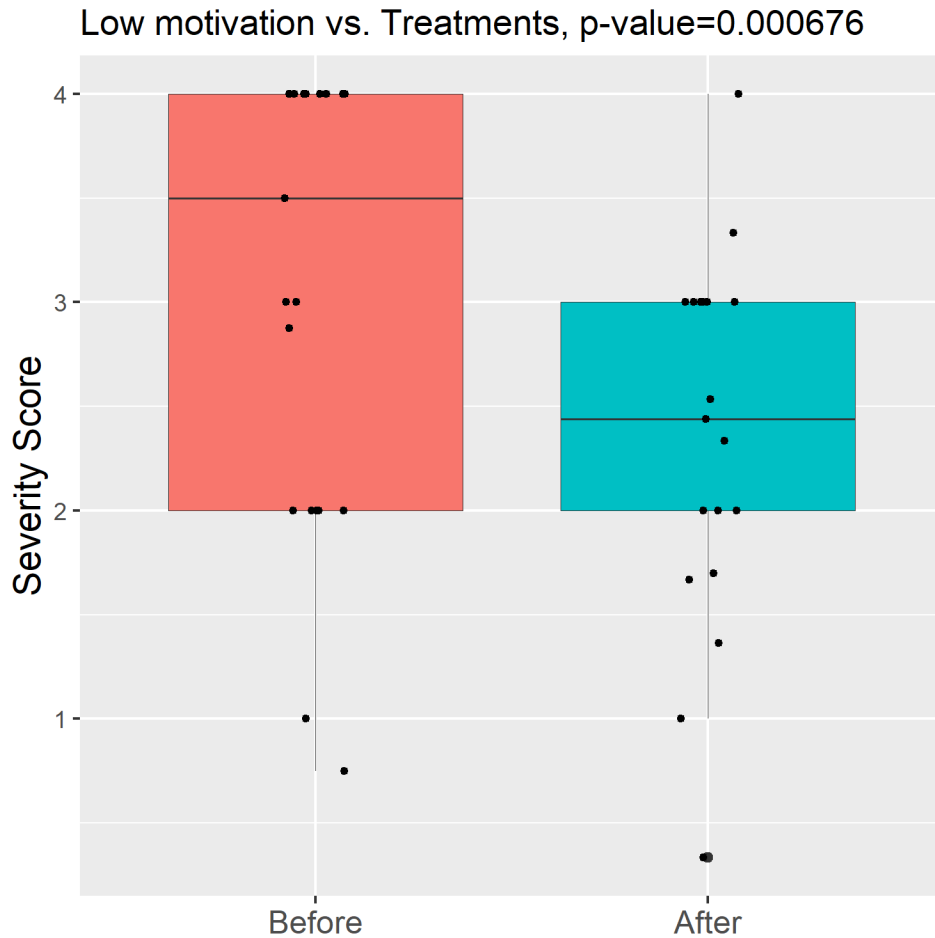
The severity score for mobile health application users tracking lack of appetite by a mean difference of -0.6862 and a P-value= 0.000461. This indicates there is statistically significant improvement in tracked symptom severity after treatment. The most common treatments for lack of appetite include Vitamin B, Vitamin D, Gabapentin, and Cymbalta. Duloxetine (Cymbalta) is in a class of medications called serotonin-norepinephrine reuptake inhibitors. Cymbalta is prescribed to treat depression and anxiety that lasts for at least six months, pain from diabetic nerve damage, fibromyalgia, and long-term muscle or bone pain.





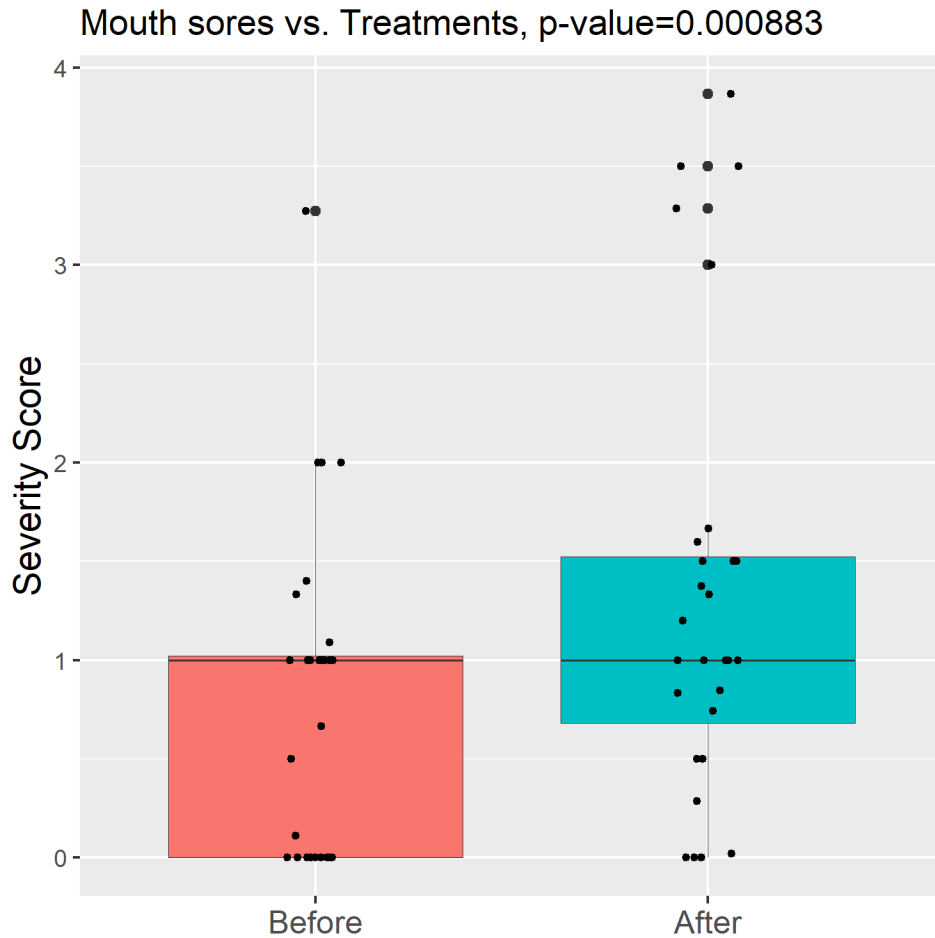
**Figure 17:** Noise Sensitivity symptom severity before and after Treatment

The severity score for mobile health application users tracking noise sensitivity increased by a mean difference of 0.4596 with a P-value=0.000584. This indicates there is a statistically significant increase in tracked symptom severity after treatment. The common treatments include Vitamin D, gabapentin, paracetamol, magnesium, omeprazole. Prilosec (omeprazole) is a proton pump inhibitor (PPI) used for the treatment of conditions such gastroesophageal reflux disease (GERD). There is existing literature that includes omeprazole as contributing to drug induced tinnitus and other hearing disorders.<sup>66</sup> This implies that taking Omeprazole for GERD could be contributing to the increased noise sensitivity in the sample.



**Figure 18:** Low Motivation symptom severity before and after Treatment

The severity score for mobile health application users tracking low motivation decreased by a mean difference of -0.6869 with a P-value=0.000676. This indicates there is statistically significant improvement in tracked symptom severity after treatment. The prevalent treatments include Tramadol, paracetamol, Vitamin D, Zyrtec, Sertraline. Zyrtec Cetirizine (Zyrtec) an over-the-counter (OTC) antihistamine used to treat cold and allergy symptoms along with swelling caused by chronic hives. There is a gap in the literature as it relates to the relationship between antihistamines and cognition.



**Figure 19:** Mouth Sores symptom severity before and after Treatment

The severity score for mobile health application users tracking mouth sores increased by a mean difference of 0.5422 and a P-value=0.000883. This indicates there is a statistically significant increase in tracked symptom severity after treatment. The common treatments include Plaquenil, gabapentin, Tylenol, vitamin D, trazodone. The findings support the sparse most qualitative research around the relationship between antidepressants and mouth ulcerations. <sup>67</sup>

## **CHAPTER V**

### **DISCUSSION**

This study demonstrated that patient generated health can provide novel insight into treatment efficiency. Of the ten most common symptoms, 80 percent of symptoms were reported as reduced upon initiating some form of treatment within 30 days. The relationship between symptom severity and treatment efficiency is an important one to explore when the cause of the symptoms is unknown or a patient has many co-morbid chronic conditions.

The data in this study is from Flaredown, a free and open source mobile health application for smartphones. Flaredown was designed with the end-user in mind and considered the unique physical manifestation of chronic illnesses. As such, patients can add any symptom, if it is not already in the database, and there are no restrictions on the data that can be inputted into the data fields. From the descriptive statistics conducted, this study found that most of the Flaredown app users are females from developed countries with notably higher user numbers in United States, United Kingdom, Canada and Australia. The element that females are the primary users of Flaredown across all regions support existing literature about mobile health application usership. All of the existing literature reviewed indicates that females experience the most common conditions in the Flaredown database at much higher rates than men in particular the autoimmune diseases.

In regards to conditions, Flaredown users tracks various conditions. This study found that the average user indicates eight conditions at any given time. It can be inferred

that chronic illness is rarely described fully by a single diagnosis. It can be further inferred that users often struggle to find a diagnosis given they can match with so many conditions. Depression and anxiety are some of the most-tracked conditions on Flaredown mobile application. There is a significant mental burden associated with living with chronic illnesses that can lead to mental distress that exhibits alongside underlying illnesses.

When analyzing symptoms, one can predict that with different conditions there would be a recognizable different set of symptoms. However, this study found that there are a few symptoms that occur in more than half of all conditions on Flaredown. That indicated that no matter what illness a user tracks, users are more likely than not to have experienced fatigue and lack of motivation. These symptoms are tied to a multitude of conditions such as depression, chronic fatigue syndrome, fibromyalgia, sleep apnea, and various autoimmune disorders such as lupus. As such, being able to track your low and/or lack of motivation along with subsequent treatments and see a quantifiable change in symptom severity is a step in a right direction towards self-management undistinguishable chronic disease.

This study establishes that users are experimenting with many non-prescription treatment options including environmental and behavioral changes, supplements and alternative therapy. For example, the study found that sleep and yoga were among the 50 most common treatments used by Flaredown users. There are a number of implications associated for both the patient and provider. From a patient perspective living with chronic illness, symptoms can change from one day to the next. In midst of a flare-up, turning to an effective complementary treatment as yoga can also serve as a coping

mechanism to treat the physical and mental strain associated with living with a chronic illness. A 2010 study in the *Journal of Consciousness and Cognition*, Zeidan et al. found that even four sessions of mindfulness meditation training can improve attention and minimize the effect of brain fog.<sup>68</sup> Another study in the *Journal of Clinical Neurology and Neurosurgery*, Velikonja and colleagues found improved selective attention and focus in people with Multiple Sclerosis after ten weeks of hatha yoga program.<sup>69</sup> From a provider perspective, being able to assess the effect of non-prescription treatments can reduce the prescription treatment burden.

In a concept analysis, Sav and colleagues did a review of literature on treatment burden associated with the management of chronic illness. The aim of the review was to describe the ways in which treatment burden has been conceptualized, define the concepts and develop a framework for understanding its attributes, antecedents and consequences. Sav et al. reviewed 1557 abstracts and the attributes of treatment burden including a dynamic process comprising of both subjective and objective elements. The antecedents include a person's age and gender, co-morbidity, high use of medication, characteristics of treatment and their relationship with health-care provider. The dominant consequence of treatment burden is non-adherence and poorer health. The findings underscore the need for researchers and health-care providers to engage in collaborative discussions and make efforts to support the alleviation of treatment burden and tailor treatment regimens to the realities of people's lives.<sup>70</sup> To this end, the literature supports the findings of this study in informing different treatments options and assessing efficiency which can reduce treatment burden and further strengthen patient-provider relationship.

In relation to assessing treatments, Gabapentin is a popular treatment for nearly all common symptoms tracked in Flaredown. Gabapentin is a nerve pain medication and anticonvulsant that also has the off-label use for people with hard to treat psychiatric disorders. In the descriptive statistics of this study on Flaredown mobile health application, depression and anxiety were the second and third respectively most common condition tracked by users. A 2015 systematic review was performed to elucidate the evidence for clinical benefit of Gabapentin in psychiatric disorders. The results found that Gabapentin has benefit for some anxiety disorders, although there are no studies for generalized anxiety disorders. There is also no clear evidence for gabapentin therapy in depression and post-traumatic stress disorder prevention.<sup>71</sup> As such, this has larger implications in terms of treatment efficiency for off-label use of Gabapentin for depression and anxiety. Through the analysis and statistical testing of patient generated health data, this study found preliminary insight on treatment efficiency of off-label treatments that requires further research.

Mobile health applications are being used with minimal knowledge of their functionality and ability to integrate data into health care systems, let alone efficacy for improving patient or clinical outcomes. The lack of efficacy testing in clinical trials is one of the biggest barriers to adoption of mobile applications. Health care providers are hesitant to prescribe mobile applications without evidence of their benefit, guidelines regarding use in clinical practice, and confidence in the privacy and security of personal health information that is both stored and transmitted.<sup>17</sup> In a study published in the Journal of Biomedical Informatics, Brown and colleagues assert that despite the growing

commercial popularity of mobile health applications, more than 95% have not been tested.<sup>7</sup>

The importance of mobile health applications and patient generated data in medical practice is understudied. One early adopter of mobile health applications is Dr. Eric Topol, a cardiologist in La Jolla, California. Dr. Topol stated that he was “...prescribing more apps than medications for the first time” and his message went viral online.<sup>72</sup> The provision of patient-centered care requires a health care environment that fosters engagement between patients and their health care providers<sup>73</sup>. One way to encourage patient-centered care is to incorporate patient-reported outcomes into clinical settings. However, this requires authentic engagement with mobile health applications from the end user. As such, end users are required to be neutral reporters of their symptoms and treatments. There is a concern that patients with difficult to metricize symptoms and undiagnosed conditions may shade their data in the direction that they think they should. The accuracy of patient-generated data is contingent upon an honest engagement with health apps. If a health app is prescribed along with a treatment and the treatment has been deemed efficient for the end-user/patient’s condition, then the patient should see a decrease in symptom severity within their logged data. The health care provider reviewing the aggregate patient generated data has more information to work from in order to guide treatment modifications along with tracked treatment adherence.

The understanding of a patient’s perspective is fundamental to delivering patient-centered care. Data from mobile health applications is considered real- world data collected outside of conventional randomized clinical trials. Currently, real world data is used to support regulatory decision-making particularly as it relates to clinical endpoints



such as safety and effectiveness outcomes. A patient-centric paradigm shift has started to occur with the integration of patient-reported outcomes (PROs) into clinical design.<sup>74</sup> It is important to consider the integration of patient-reported outcomes into the data capture process to be particularly resource intensive and maintaining patient engagement can be difficult across different groups of interest including individuals that are older, sicker or lower socioeconomic status.

Issues surrounding the representativeness of the patient population is an important area of discussion. The finding from this study has woman between the ages 20-40 as the most active users of Flaredown. Where it is possible to garner information of mHealth application user information, published data has shown active users tend to be younger, women, more highly educated and less acutely ill or functionally impaired.<sup>75</sup> It is essential to quantify demographic disparities in order to apply analytical strategies that help mitigate biases in patient representativeness. Furthermore, identifying novel proxies for gathering demographic information is one of the potential solutions. There is current research that shows the use of machine learning techniques and natural language processing that can be used to accurately infer patient demographics.<sup>76</sup> With the extract of more precise demographic data will be a more stratified sample of data that could improve external validity.

A more focused effort to address clinicians or researcher's data-related liability concerns is a continuous discussion and outcome of this study. The accuracy of data, concerns about the increase in clinician workload and responsibilities associated with acting based on patient generated data require constant development in order to bring forth robust mitigation strategies. In particular, accuracy of data and concerns about

increased clinician workload due to the volume of patient generated data from mHealth application is a vast area of discussion and contention. Inevitably, patient generated data may be inaccurate because of user error and technical difficulties with mobile devices resulting in the hesitancy to use the data for decision-making. Limiting patient generated health data source variety and recommending the use of devices that support direct or possibly automatic electronic capture is one possible mitigation strategy.

In terms of increased clinician workload given the already significant demand on clinician's time within ambulatory and outpatient health settings is a growing concern for clinicians. In particular, the volumes of patient generated health data that need to be reviewed in order to be used in the clinical decision-making process. This can be perceived as cumbersome to the clinicians or researchers when patient generated health data is unstructured and lacking the visualizations to quickly identify relevant data. As such, patient generated health data requires carefully designed workflow with accompanying responsibilities delegated within the health services setting. The workflow should consider the ways to minimize negative impacts to care team members. Furthermore, the patient generated health data need to utilize analytics tools and data dashboards to identify relevant data with ease.

The responsibility to act on the patient generated health data is one that is shared between the clinician and patient. It should not be the sole responsibility of clinicians to monitor all the data points that come in at any time and the implications associated with missing data points. The establishment of agreed upon terms and conditions that defines responsibilities and sets explicit patient-consented expectations for how the care team reviews patient generated health data is required to mitigate responsibility being placed

solely on the clinician. Furthermore, the scaled-up use of patient generated health data from mobile devices is meant to improve clinician- patient engagement and make patients a participatory partner in improving health outcomes. As such, placing all of the liability to manage and review patient generated health data undermines the goals of mobile applications for self-managing chronic ailments.

The possible integration of patient generated health data with the medical record and relevance to clinical management is a concept explored in this study. Given the lack of scientific studies on patient generated data from a mobile application, there is a lot of foundational information missing that would inform the process. Integration of patient generated health data is also deemed a liability by clinicians and researchers. Unsolicited patient generated health data without interpretation or specified use could introduce confusion to the clinical decision-making process. A possible mitigation strategy would include accepting data from patients that are formally enrolled in self-populating their medical record with their own patient generated health data. Furthermore, the mobile health application would only collect set data types or variables. As such, the medical record would only incorporate information that is relevant to the clinical-decision making process within the agreed upon tracked chronic disease. The establishment and adherence to a standard of care for the use of patient generated health data requires formalization with guidelines on the ways to address the complexities associated with the integration of specific and targeted patient generated health data into medical record.

There are five major areas of practical challenges in the implementation and utilization of mobile health applications and associated patient generated health data for

self-managing chronic disease. Table 5 identifies and summarizes the key challenges and associated components.

Challenge	Component
Interoperability	Be able to exchange information with system developed by other vendors such as electronic health records (EHR)
Network access	Be able to connect to available wireless and cellular network with speed and strength
Usability	Be able to keep a simple user interface with the right optics for user satisfaction
Data Security and Privacy	Be able to store and access the data in a secure location and through secure transmissions channels. Confidentiality of patient data to ensure HIPAA compliance
Reliability	Be able to receive FDA approval for clinical use in the United states and the results provided must be accurate enough to improve health outcomes

It is important to address the vast discrepancy in the ways organizations and individual end users address these challenges. As such, there is a need for robust technical support for both the end users and the clinicians. When challenges particularly technical are not met when they arise, clinicians and patients can experience frustration and begin to disengage from the mobile health application. A support team and troubleshooting manuals should be assembled early on and made available by the mobile health application developers. With the proper support systems established, interoperability is possible. However, interoperability with existing electronic health records platforms can only occur when significant strides are taken to limit the negative effects of health data silos. To this end, one of the ongoing priorities for the adoption of mobile health applications into clinical practice will be the rigorous assessment of mobile application quality as demonstrated in this study and effectiveness in rigorous comparative effectiveness studies.

## **CHAPTER VI**

### **STUDY LIMITATIONS AND FUTURE SCOPE OF THE STUDY**

Integral to the nature of the secondary analysis of existing data is the fact that the available data are not collected to address any particular research question or to test a specific hypothesis. It is common that important third variables were not available for the analysis. Similarly, the data was not collected for all population subgroups of interest. Another study limitation is related to the protection and confidentiality of respondents particularly as it related to patient generated health data. As such, publicly available datasets usually delete identifying variables about respondents and that can include variables that may be important in the intended analysis such as zip codes, race, and ethnicity. This can create residual confounding when the omitted variables are crucial covariates to control for in the secondary analysis.<sup>77</sup> Another major limitation of the analysis of existing data is that the researchers who are analyzing the data are not usually the same individuals as those involved in the data collection process. Therefore, they are probably unaware of study-specific nuances or glitches in the data collection process that may be important to the interpretation of specific variables in the dataset.

In this study over 80 percent of users identified as female. As such, there is a significance gender imbalance in the sample. Additionally, the aggregate raw data is strictly user-generated data. As such, data completeness across variables varies significantly. For example, a user could just track a symptom and forego tracking associated conditions and or treatments. The mobile application does not require users to input all data elements for one day's worth of trackable variables. As such, analyzing the relationship between symptom severity and treatment was contingent upon a complete

trackable id for a user on any given day in the dataset. Further studies should validate the quality of patient generated health data from mobile health applications. Additionally, this study does not address possible placebo effect associated with symptom severity and treatment tracking using a mobile health application. Future research should aim to develop a method for testing mobile health application utilization for self-managing a chronic disease symptomology and treatments compared to the efficiency of standard face-to-face clinical care for the same chronic disease using human subjects.

Commercial mobile apps for health behavior change are flourishing in the marketplace but little evidence exists to support their use. This study examines one mobile health application in terms of summarizing the content and efficacy of a commercially available mobile health application. There is a need for content analyses that can be used to compare app features with clinical guidelines, evidence-based protocols, and behavior change techniques. Furthermore, usability testing can establish how well an app functions and serves its intended purpose for a target population. Observational studies can explore the association between use and clinical and behavioral outcomes.

Finally, efficacy testing can establish whether a commercial health app impacts an outcome of interest via a variety of study designs, including randomized trials, multiphase optimization studies, and N of 1 studies. Evidence in all these forms would increase adoption of commercial mHealth apps in clinical practice, inform the development of the next generation of apps, and ultimately increase the impact of commercial health apps. In addition, there is also the need for enhanced interoperability between electronic health records and apps so that real-time data can inform clinician

decision making and clinical management. Enhanced data integration should take place within the context of robust organizational governance frameworks that take into consideration the evaluation of clinical outcomes.

The harnessing of patient generated data from mHealth apps can pose a significant risk to patients' privacy. These risks include insurance discrimination, access to health data by family members and perhaps political manipulation. Furthermore, obtaining informed consent from mobile health users can be difficult due to the arbitrary rules and definitions set forth. The reconciling of commercial terms of use with informed consent represents a challenge in the field of mHealth. The Office of the National Coordinator for Health Information Technology (ONC) released a practical guide on the capture, use and sharing of patient generated data. ONC recommends that patient generated data is stored and submitted with the same rigor as other protected health information. Due to privacy and security concerns, access to patient generated health data continued to be a limitation and challenge for comparative research.

The scope of future research should include the testing of the bidirectional flow of information between patient and clinician. In theory, a clinician can place an order for data and the patient supplies the ordered data within a specified time frame. As such, future studies should aim to establish an understanding of the generation, collection and communication of mHealth patient generated data utilizing human subjects. With increasing prevalence of chronic conditions, proactive and preventive actions is a viable outcome of increase rigorous scientific studies on patient generated health data through mobile health applications.

This study does not directly address health equity by examining the digital divide and sociodemographic characteristics of disadvantaged population groups. There is a need to acknowledge that differences in technological access, use and literacy that may replicate social inequities in the digital mHealth domain. To that end, it is essential to capture any indication related to the potential or actual equity implications of patient generated health data from mobile health applications. Future research should look at the whether the use of mobile devices for self-managing chronic diseases increases health inequalities. Mobile health applications can be effective to the extent that individuals are in a position to use them well. Yet, this is not the case for everyone and can produce a gap between users and nonusers in terms of better health outcomes through improved patient/provider engagement. A comparative study to assess the use of mobile health applications and subsequent quality of patient generated data should be done to assess the differences between users and nonuser populations.

The characteristics of people at risk of experiencing inequity as it relates to the use of mobile applications for self-managing of chronic conditions include individuals with low levels of education, low literacy, rurality, older, low income and psychological distress. Although literature has shown that older individuals are the group for whom the use mobile applications is growing most rapidly, they remain a group that requires further research to assess the feasibility and effectiveness of mobile applications on geriatric chronic disease management. Overall, there is a need for comprehensive assessment on whether mobile health applications may be contributing to a potential new digital inequality. The future scope of research should better understand the differences between people who use and people who do not use mobile health applications.



There is an intertwining of personal and collective good in the data intensive endeavors of personalized and mobile health. The development of personalized healthcare requires vast amounts of individualized health, environmental and lifestyle data. The growing use of self-tracking mobile health applications could potentially mean a significant amount of data generated beyond clinical settings. This created patients that are knowledge producers who were traditionally just knowledge recipients. In this way, patients are helping to improve population health by getting more involved in their own health. Through self-monitoring and contributing their data to the growing pool of patient generated data, mobile health app users are able to guide personalized medicine efforts.

The quantified self is aimed at using information for self-improvement with the goal to analyze and visualize one's data to look for patterns that could answer questions that individuals have been trying to understand. The quantified self is a philosophy rooted in self-discovery and self-management accompanied by increased engagement with health care providers. There are inherent technical skills needed to put complex data together and derive knowledge. However, the principles espoused by quantifying self through health and disease states using mobile health applications has been a vanguard to move towards self-empowerment and personalized healthcare.

To conclude, the goal of this study was to lay down a foundation that supports the use of mobile applications for self-management health and chronic disease. The findings suggest that mobile health applications can produce useful patient generated health data that requires further reviewed before the possible integration into medical records. The findings also suggest the need to further evaluate different populations with targeted studies on their use of mobile health apps for monitoring and tracking chronic disease.

Overall, this study contributes to a better understanding of the mobile health applications outputs in regards to tracking symptoms and treatment efficiency. As such, this study provided a baseline into the further study of mobile health application effectiveness across different variables or populations of interest. This study also highlights the need to breakdown patient generated health data silos in order to conduct comparative studies that would contribute significantly to expanding the limited body of literature available on mobile health applications effectiveness for self-management chronic disease.

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