Aging, Empathy, and the Internet of Things:  
A Measure of Physician Readiness to Treat Older Adults

By

Marika A. Psyhojos

B.A. English  
Wellesley College, 2015

Submitted to the Institute for Data, Systems, and Society  
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Signature of author:  

Institute for Data, Systems, and Society  
Technology & Policy Program  
May 12, 2017

Certified by:  

Joseph F. Coughlin, Ph.D  
Director of the MIT AgeLab  
Senior Lecturer in the Department of Urban Studies & Planning  
Thesis Supervisor

Accepted by:  

Munther Dahleh, Ph.D  
Professor of Electrical Engineering & Computer Science  
Acting Director, Technology & Policy Program
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Abstract

Aging is an increasingly disruptive force in the US—nearly 1 in 5 Americans will be at least 65 years old by 2030. Largely due to the high incidence of chronic disease among older adults, health care spending is larger in magnitude for older adults than it is for any other age group. To treat older adults and reduce the prevalence of chronic disease more effectively and efficiently, health professionals may likely incorporate patient-generated health data (PGHD) from the Internet of Things (IoT). IoT devices can help providers to evaluate treatment options, compliance, and overall patient well-being. Critics of PGHD integration in the health care space cite challenges such as poor interoperability of devices and electronic health record systems, a lack of standards, a host of liability concerns, workflow interruptions, and a lack of reimbursement models. There is little research, however, that explores how the inclusion and analysis of PGHD may affect provider empathy and the physician-patient relationship.

We were interested in understanding how the integration of wearables, smart devices, and other connected health devices would affect the physician-patient (or provider-patient) relationship and how those changes might affect both providers and patient health and well-being. We conducted two surveys, one of health care providers and one of patients, to understand current and expected uses of connected health devices to examine how the collection and analysis of PGHD will affect provider empathy and the physician-patient relationship. We subsequently examine across different age groups, how the provision of health care and individual health management is projected to change as a result of PGHD analysis. Finally, we evaluate the socio-technical barriers to connected health devices and discuss the entities which could successfully mitigate these barriers, as perceived by health care providers and patients.

Thesis Supervisor: Joseph Coughlin, Ph.D.
Title: Director of the MIT AgeLab, Senior Lecturer in the Department of Urban Studies & Planning
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Chapter 1 – Introduction

1.1 Motivation

1.1.1 Aging as a Disruptive Demographic

Aging is an increasingly disruptive force in the US—nearly 1 in 5 of Americans will be at least 65 years old by 2030.¹ By 2050, the number of Americans aged 65 and older is projected to be 88.5 million, more than double the size of this population in 2010, which was 40.2 million.² There are many projections for the basic demographics that characterize these older adults; for instance, there are projections for the gender, race, and workforce participation. Over half (55%) of the individuals who are at least aged 65 in 2030 will be female, down from 57 percent in 2010.³ There will be an increase in the ethnic diversity in this population over time—the proportion of older adults in the US who are at least 65 in 2030 and who are white will decrease, while the proportion of those older adults who are non-white is projected to more than double, from 9.5 million in 2013 to 21.1 million in 2030.⁴ By 2030, approximately 20% of the workforce will be at least aged 65.⁵ These dramatic demographic changes will have wide-ranging implications across domains and for private and public interests alike. The effects of gender, race, workforce participation, and other demographic qualities are the subjects of much speculation, but there is one common denominator across all older adults which is virtually undebated—older adults are sicker than younger adults.

1.1.2 Chronic Disease in Older Adults and Health Spending

Health care spending is larger in magnitude for older adults than it is for any other age group. In 2010, older adults composed 13% of the US population but accounted for 34% of health care spending.⁶ On average, older adults account for almost five times as much health care spending as children – $18,424 per person for people aged 65 and older compared with $3,628 for children.⁷ Much of the health care spending amongst older adults is associated with chronic diseases, which are diseases that last at least three months and which increase in prevalence with age and with unhealthy lifestyle decisions.⁸ Chronic diseases are the most common and costly of all health conditions and

³ Ibid.
⁷ Ibid.
function as a major burden to the effective and efficient functioning of the US health care system.

Chronic disease accounts for 86% of US health spending and more than nine out of ten seniors have at least one chronic condition.\textsuperscript{9,10} Over three-quarters (77%) of older adults are managing at least two chronic conditions, and more than 50% of older adults are managing five or more chronic conditions.\textsuperscript{11} Among older adults, the most prevalent chronic diseases are hypertension, high cholesterol, mental illness, diabetes, and heart disease.\textsuperscript{12} Ninety percent of adults aged 55 and older have or are at risk for hypertension.\textsuperscript{13} More than 25% of older adults have high cholesterol;\textsuperscript{14} 20% of people age 55 years old struggle with at least one mental illness;\textsuperscript{15} 22% of older adults have diabetes;\textsuperscript{16} and 70% of individuals between the ages of 60 and 79 years old have heart disease.\textsuperscript{17} Obesity, a risk factor for many other chronic conditions, occurred in about 40% of individuals between 65 and 74 years old.\textsuperscript{18} Because of the massive economic and care burdens chronic diseases impose on the health care system, there are a number of agents and initiatives that are invested in integrating new ways to reduce the prevalence of chronic diseases.

1.1.3 Connected Health to Address Chronic Disease

To treat older adults and reduce the prevalence of chronic disease more effectively and efficiently, health professionals may likely incorporate patient-generated data from the Internet of Things (IoT), which is composed of all devices that are connected to the internet. IoT devices can help providers to evaluate treatment options, compliance, and overall patient well-being. Both aging and technological innovation in the IoT space are occurring at exponential rates. The use of IoT devices such as mobile phones and other connected devices is called connected health or mobile health (mHealth). In the health care space, the mHealth platforms most commonly discussed are wearable devices and smartphone apps. The US wearables market, including health and fitness devices, will generate shipments of 48 million unit sales in 2017, a 14% increase over the previous year.\textsuperscript{19} The market is likely to increasingly target the older adult

\textsuperscript{9} "Chronic Disease Prevention and Health Promotion." \textit{Chronic Disease Prevention and Health Promotion}, 14 Nov. 2016. Web.
\textsuperscript{11} Chronic Conditions Among Older Adults." \textit{Chronic Conditions Among Older Adults.} AARP. Web.
\textsuperscript{12} Ibid.
\textsuperscript{14} Chronic Conditions Among Older Adults." \textit{Chronic Conditions Among Older Adults.} AARP. Web.
\textsuperscript{17} Ibid.
population; according to one study, 53% of roughly 300 connected health device clinical trials target older adults.20

Wearable devices and other smart devices fall under the taxonomy of connected health devices in general. Connected health devices help consumers reduce the likelihood of acquiring chronic diseases by supporting them in leading more active lifestyles and in being more aware of their own health data. Apps and connected health devices are found to be helpful across all types of health interventions, such as bettering nutrition and diet, increasing exercise, and quitting smoking and alcohol.21 There are connected health devices and apps to assist in meeting or improving virtually any health goal. For example, there are devices like: step counters; smart scales which track weight and body composition over time; smart clothes which measure stress levels; smart watches which can track health measures like weight, steps taken, and blood pressure, and also can remind users to take their pills;22 and smart glucometers which track blood glucose information. Such devices have been most successful when they are de-medicalized. These devices are in addition to more than 165,000 health apps.23 The development, verification, and validation of connected health devices is an area of extremely active innovation and research, and the number and variety of apps becomes obsolete almost as one cites them.

The health data individuals collect, store, and share using connected health devices and apps are called patient-generated health data, or PGHD. PGHD are helpful for individuals to monitor their health and to keep their own health records independently, but PGHD also have the potential to be immensely helpful for health care providers. Whereas health care providers assess health metrics on a visit-to-visit basis (perhaps once a year), individuals can collect, review, and transmit PGHD second-to-second. Real-time monitoring allows health providers to develop a greater understanding of health metrics and diseases.24 Though patients have long collected their health measures, sometimes extensively, patients will be able to collect, track, and store these data much easier with the coming PGHD revolution. The frequency and granularity of health information revealed by PGHD are unprecedented. By some estimates, the US could reach a “critical mass” of physicians using PGHD by 2020.25 Patient health data stored and shared via connected health devices are “proliferating rapidly, But scientists' ability to make sense of all that information isn't keeping up.”26

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1.1.4 Technology and the Physician-Patient Relationship

Doctors’ ability to make sense of all that information “isn’t keeping up” either. Critics of PGHD integration in the health care space cite challenges such as poor interoperability of devices and electronic health record (EHR) systems, a lack of standards for the efficacy of health and fitness trackers, a host of liability concerns, workflow interruptions, too little patient visit time, and a lack of reimbursement models.

Technology reports suggest that the technology is ready for PGHD analysis to become the norm in the provision of health care, even if providers have different levels of desire to use and integrate the data into their practice. There is little information available about what health care providers think about PGHD and the integration of such data into their practice, beyond concerns for workflow, liability, and reimbursement. Furthermore, there is little research that explores how the inclusion and analysis of these data may affect provider empathy and the physician-patient relationship. How might IoT and patient-generated data transform the current model of the “physician-patient relationship” into a relationship that champions technology as an equally essential component of health care interactions? What types of data analysis demands will be placed on physicians, and what will technology-driven health care provider interactions mean for the well-being and satisfaction of patients, particularly the growing population of older adults?

Amidst the hype of mHealth technologies, a number of doctors are advocating for the important and lasting institution of the physician-patient relationship. Dr. Danielle Ofri, practicing internist and author of What Patients Say, What Doctors Hear, writes that “the single most powerful diagnostic tool is the doctor-patient conversation.”28 Strong physician-patient relationships benefit both physicians and patients; physicians who are more empathetic in their visits with patients make fewer medical errors, secure better patient outcomes, and have more satisfied patients.29 They are also happier30 and suffer fewer medical malpractice claims.31 Empathetic doctors are better diagnosticians,32 prompt better patient compliance,33 have greater levels of job satisfaction,34 and have a

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reduced risk for burnout. Patients also benefit from strong physician-patient relationships, particularly patients who are most vulnerable. Empathy relayed from provider to patient can "increase feelings of relatedness, [and] reduce patients’ experience of alienation from others." Additionally, better physician-patient communication is associated with more efficient and effective medical visits. Older adults depend on the physician-patient relationship to address not just physician and biomedical health needs, but also to address their "social, economic, cultural, and psychological vulnerabilities."  

Connected health devices could conceivably both harm and benefit the physician-patient relationship. Disparities in technological savviness and preferences could breed resentment between patients and providers, for example. On the other hand, the devices could function to alleviate many of the current strains that affect the health care system. Take, for instance, how the volume of patients seen and the associated financial structures pressure physicians into shortening visit length. The time restraint "creates resentment in the patient, who, as it turns out, is interrupted by the doctor within twelve seconds on an average visit." With such impersonal visits, patients feel unmotivated to change health behaviors. Ofri describes the effects of this lack of motivation: 50 to 75 percent of subjects do not adhere to physician advice. If PGHD collection leads to more targeted conversations and lessens resentment, compliance could improve. The analysis of PGHD could also improve the physician-patient relationship by allowing greater time for interaction when a patient requires the care of a physician. PGHD better individualizes "diagnostics and treatments, simplify real-world monitoring, and provide evidence-based guidance at the point of need," which frees up physicians’ time so that they can better serve "as a diagnostician and educator." One study found that the provider-patient relationship engendered trust when physicians were “comforting and caring, demonstrating competency, encouraging and asking questions, and explaining,” and that surprisingly, patients did not as highly value “gentleness during the examination, discussing options and asking opinions, looking in the eye, and being treated as an equal” as factors that were important in trusting physician-patient relationships. The nature of these patient preferences reveals that there is much we do not know about how patients feel understood, heard, and involved in discussions about their own health. Research is needed to understand these patient preferences better.

35 Ibid.
40 Ibid.
specifically as they evolve with the development and diffusion of technology as an increasingly prevalent component of health management.

1.1.5 Barriers to Connected Health Integration

Even under the assumption that the technologies will benefit the physician-patient relationship and translate to better health outcomes for patients, there are a significant number of barriers across legal, political, and technological domains. These barriers pose unique issues for older age groups. Most studies call on policymakers in general to address the barriers that exist in the integration of connected health devices. But as one device company spokesperson said, “This isn’t a technology or motivation problem...It’s a consumer experience problem.” From a health policy perspective, there are initiatives under way that could boost for PGHD collection and analysis. For example, the federal government's guidelines for meaningful use of EHR technology require hospital EHR systems to have the ability to collect PGHD from nonclinical sources by 2018. Significant privacy and security hurdles must be overcome, in particular the lack of rigorous and well-defined standards for patient data rights. In this research we take a different approach, asking patients and providers to rank entities which they thought would be most effective in spurring mHealth, rather than assume that the most effective entities are the ones which have traditionally set standards.

We were interested in better understanding how the integration of wearables, smart devices, and other PGHD-collcting technologies would affect the physician-patient (or provider-patient) relationship and how those changes might affect both providers and patient health and well-being. We conducted two surveys, one of health care providers and one of the general public, to understand current and expected use of smart devices for the collection of patient-generated data better, and to explore how different dimensions of the physician-patient relationship might be affected by these uses.

Scientists and physicians have spent the better part of history working to increase longevity, and this “is among humankind's greatest achievements.” The integration of mHealth devices could feasibly increase longevity further still, but it will do so only if we can better understand the use of these devices in health settings to help patients and providers “live [and practice] not just longer, but also better”.

1.2 Thesis Organization and Research Questions

This thesis is divided into six chapters and addresses the following three research questions. An overview follows.

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Research Question 1: How will the collection and analysis of PGHD affect provider empathy and the physician-patient relationship?

Research Question 2: Across different age groups, how is the provision of health care and individual health management projected to change as a result of PGHD analysis?

Research Question 3: What are the socio-technical barriers to connected health devices and which entities could successfully mitigate these barriers?

Chapter 2 presents a review of the literature, which draws on research on aging, empathy, and the Internet of Things (IoT), with a focus on devices used for mHealth and other connected health technologies.

Chapter 3 presents the description, results, and conclusions of the health care provider survey we conducted. We address Research Questions 1, 2, and 3 by explaining how health care providers perceive changes in various dimensions of the physician-patient relationship. We then discuss their patients’ supply of PGHD and providers’ respective demand for those data.

Chapter 4 presents the description, results, and conclusions of the patient survey we conducted. It is important to note that the sample of individuals discussed as “patients” are not the patients of the providers we discuss in Chapter 3. Rather, the respondents to the patient survey are individuals from a convenience sample of high income, healthy consumers who hail primarily from New England. We address Research Questions 1, 2, and 3 by explaining how patients perceive changes in various dimensions of the physician-patient relationship as a result of PGHD analysis integration or non-integration. We also discuss respondents’ collection of health data, the frequency with which certain measures are collected, and traditional versus connected methods used to collect those data.

Chapter 5 focuses primarily on addressing Research Question 3, as informed by the results from Research Questions 1 and 2.

Chapter 6 summarizes conclusions from the study and provides recommendations for future research.
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Chapter 2 - Review of the Literature

2.1 Chapter Introduction

“The single most powerful diagnostic tool is the doctor-patient conversation.” In her most recent book, What Patients Say, What Doctors Hear, Dr. Danielle Ofri asserts that the age-old relationship between physician and patient is the best way to review and assess patient health and well-being, even “despite modern medicine’s infatuation with high-tech gadgetry.” Her buckling-down on overlooked components of health care is admirable and necessary, but it would be a mistake to assume that the doctor-patient conversation will be two disparate and warring components of medical culture for long. To what extent will the doctor-patient conversation be distinct from “high-tech gadgetry”? We conducted a survey to better understand how connected health devices which collect patient-generated health data (PGHD) affect empathy and the physician-patient relationship. Age effects were constantly considered: what do these trends mean for aging physicians as well as for aging patients? We first conducted a review of the pertinent literature.

2.2 PGHD and Health Care Providers

One in six people in the US currently uses wearable technology and 77% of Americans own a smart phone. Speakers at the 2016 Connected Health Symposium held in Boston, MA took as given the fact that “by 2020, almost everyone will own at least 8 connected devices.” Even if technologists underestimate the difference between a product’s maturation and its readiness to be fully integrated into a domain such as health care, by some estimates, the U.S. could reach a critical mass of physicians using patient-generated data from connected health devices by 2020. Older adults are readily adopting these technologies too, which could hedge against the strain the demographic is predicted to impose on busy medical practices. Physicians and allied health care professionals will have to treat the growing and aging population with unprecedented clinical efficiency, all the while maintaining and enhancing the thoroughness that an increasingly technological and connected world demands. Health care providers may likely shift to incorporate PGHD from the Internet of Things (IoT) to evaluate treatment options, compliance, and overall patient healthiness.

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47 Ibid.
The story of PGHD and physicians is a giant game of *Whose Job is it, Anyways?* Patients will soon be flooding the health care system with their data; from the hours they slept each night, to the number of steps they have taken, to a macronutrient-specific analysis of the food they have consumed and logged, to their weight each morning. Physicians and allied health professionals will be the first ones to receive these data. The impending deluge of PGHD may present a massive disruption to physicians and their practices. To our knowledge, the literature considering the effect of this data disruption on older physicians is sparse, despite the fact that approximately 95,000 of the 926,000 actively practicing physicians in the US are at least 65 years old.\(^{51,52}\)

The literature about older physicians’ practice of medicine centers around diminishing competency and “when to call it quits.” Reports about the aging physician workforce discuss not if a physician will become less competent as they age, but in which ways. In his meta-analysis of articles that focus on physicians’ competence and age, Eva (2002) discusses an inverse relationship between physician age and clinical competence.\(^53\) He concludes that his findings are not intended to be ageist, but describes at length the ways in which “older doctors experience declines in working memory, the ability to store and process information, are slower in completing complex tasks, have decreased hearing, visual acuity, manual dexterity, and visuospatial ability.”\(^{54}\) Eva reviews an old publication of Day et al., who find that older physicians may be less likely than their younger colleagues to have “up-to-date knowledge bases.”\(^55\) Older physicians, Eva finds, “were more biased than young adults,” and “tend to have more difficulty comprehending messages than do younger adults.”\(^56\) A meta-analysis by Choudhry (2005) from Harvard followed Eva’s analysis and found that “Sixty-three percent of studies that reviewed the actual performance of doctors in a clinical setting found that older doctors were more likely to order unnecessary tests, fail to order necessary tests, or fail to counsel patients appropriately on preventive health strategies.”\(^{57,58}\) A professor of medicine at the University of California San Francisco wrote in the Wall Street Journal that younger physicians “are more fluent with the sciences of communication, teamwork, and improvement.”\(^59\) He adds, that “When it comes to modern technology...I never hesitate to let patients know it’s the younger doctor...that they want.”\(^60\) But if the integration of these

\(^{52}\) "Total Professionally Active Physicians.” The Henry J. Kaiser Family Foundation. Kaiser Family Foundation.
\(^{60}\) Ibid.
technological devices and the analysis of PGHD secure better health outcomes for patients, then the older physicians who integrate these technologies would be better poised than younger physicians to secure the benefits that precipitate. PGHD analysis could diminish or reverse the demographic differences in practice competencies described by Eva.

While our results indicate that older physicians had a greater interest than younger physicians did in analyzing PGHD (and expressed a sense of duty to do so), younger physicians in aggregate maintained that it “was not their job” to analyze PGHD. At the 2016 Connected Health Conference in Boston, one speaker quoted poet Samuel Taylor Coleridge. In “Rime of the Ancient Mariner,” Coleridge wrote, “Water, water, everywhere, / Nor any drop to drink.” By this, the speaker meant that the abundant data from wearables would be worthless absent a robust system or provider who could analyze and translate those data. So, whose job is it to receive, analyze, and translate all of these patient-generated data? The literature that assesses physicians’ readiness to accept PGHD and which considers whether or not a doctor should analyze these data as part of their job come primarily from technology blogs and reviews. To our knowledge, there have been no publications in a peer-reviewed journal that focuses on this question. A 2015 MIT Technology Review titled, “Your Doctor Doesn’t Want to Hear About Your Fitness-Tracker Data” discussed physicians’ collective non-interest in analyzing PGHD.61 The review involved interviews of clinicians who found PGHD analysis to be difficult or confusing. One physician explained, “They [patients] come in...with all this information—I have no idea what to do with that.”62 A research scientist at the Center for Digital Health Innovation also interviewed for the review said, “Clinicians can’t do a lot with the number of steps you’ve taken in a day.”63 The review was written in 2015 and cannot therefore account for more recent advances in technological integration. But more importantly, the review ultimately answered the question of whether physicians find PGHD all that helpful; it did not quite present whether or not physicians think it is their job to analyze the data regardless of perceived helpfulness.

Technology companies have been preparing for physicians to incorporate PGHD analysis into their job description. In 2014, GE published a report that claimed, “There has to be a marriage between data and clinical judgment.” The report adds, “Doctors of the future will act as interpreters of the data gathered from wearable devices...[and] will then be able to help guide patients through the process of making intelligent decisions based on the data gathered from their wearable devices combined with their medical history.”64

In the literature, whether or not PGHD analysis is a physician’s job is a question that goes unanswered but is one that is certainly of interest. The physicians most interested in the answer are those physicians who would be the most inundated with data. Specialists will receive only the data within their system of interest, but primary care physicians will be receiving data related to all body systems and functions. The interest

62 Ibid.
63 Ibid.
of her primary care physician constituents was echoed by Jennifer Nadelson, the Executive Director of Primary Care Progress. Primary Care Progress is a Cambridge-based, grassroots network of innovators, students, advocates, and health care providers united by a new vision for revitalizing primary care. Primary care physicians could be the first to feel the waves of PGHD entering the healthcare system, and they are at the forefront of wondering to what capacity they are responsible for analyzing the data.

While it is assumed that PGHD analysis will become invaluable, it is not understood how providers will develop the capacity to absorb and translate PGHD into modified health outcomes. One way in which connected health devices and PGHD analysis could secure better health outcomes for patients is by increasing patient health agency. There is a wealth of data to suggest that patients seek greater agency in creating and maintaining their personal health record and that patients require greater clinical empathy for better outcomes and higher satisfaction.

There is a dearth of research, however, considering how an inevitable shift towards PGHD integration will affect perceived physician empathy. This thesis adds to the literature by filling this gap. Loos (2016) is the most similar study to the analysis we conducted for this thesis. Loos called for research into how physicians incorporate PGHD into their communication with patients and their practices. Loos conducted an online survey of physicians to assess physician views on the potential integration of wearables into patient care. The survey was a mix of 23 closed-ended and open-ended questions. Physicians were asked to respond to the following six open-ended questions: 1) How useful is self-monitored information to your treatment and/or diagnosis; 2) Please explain personal use/awareness of wearable health monitors; 3) Please explain your patients’ use/awareness of wearable health monitors; 4) Please explain how useful you would find information from wearable health monitors if provided by patients; 5) How

65 "Primary Care Progress." Primary Care Progress. Web.
75 Ibid.
would you react if one of your patients asked to share data with you; 6) We welcome any comments or suggestions you have on the topic.  
Loos surveyed 39 physicians who had graduated from a medical school in Manila, Philippines. 19 of these physicians practiced in the US. The researchers concluded that physicians “think of wearables in terms of getting accurate information on patient compliance and the efficacy of treatment to inform their decision-making.” The study did not attempt to draw conclusions for physicians at large and did not use statistical tests to assess the closed-ended questions. In place of statistical tests, the authors assigned up to three codes to the responses as they touched on various constructs from the literature on the physician-patient relationship. In considering the exchange of information between physician and patient, the study found that 17.2% of respondents reported that wearables would help them assess their patients’ compliance with prescribed treatments. 11.1% of respondents mentioned a potential for more accurate communication because so much of physician-patient communication relies on a patient’s own memory of health behaviors, which are often inaccurate or even intentionally false. In considering how physicians use information from patients in making a diagnosis, 17.2% of their respondents mentioned clinical-decision making as a facet of the outcomes from wearable data. Finally, in considering how wearables affect the interpersonal relationship between physician and patient, 4.5% of their respondents mentioned honesty and 4.5% of their respondents mentioned the physician-patient relationship. The study describes potential analytic categories and lays a framework for future research, but by its own analysis, is limited by the non-use of wearable devices by the respondents or their patients, and by its small sample size. Furthermore, the frequency with which certain categories of concerns came up in the open-ended responses seemed less rigorous than closed-ended questions that could rank and compare the concerns directly. Thematically, the Loos study was quite similar to the health care provider survey we conducted, however, the scale of questions we asked and our sample size were significantly larger. This thesis has a physician sample size of 892 health care providers (75% of which are physicians), which is nearly 50 times as large as the Loos study. Our survey contained 75 questions which is more than three times the length of the Loos study. Finally, whereas the Loos study evaluated the effect of PGHD on “communication,” it did not evaluate the effect on the physician-patient relationship and empathy at large.

Because of the size of the potential wearable device market, there are significant resources invested in better understanding older adults’ use of wearable devices. Because direct-to-provider advertising is a potential means of integrating particular devices into standards of practice, device companies may look to better understand physicians’ preferences for using the devices. According to Dr. Michael Blum, a cardiologist, doctors get pitches from entrepreneurs in this space almost daily. Naturally, there is bias inherent in businesses conducting these studies and publishing reports on the results. Businesses which develop connected health devices often overstate the readiness of the devices to be integrated. While academia may be better insulated from the bias associated with driving device demand, academic labs are limited by the large cost associated with

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76 Ibid.
77 Ibid.
surveying physicians. The prohibitive cost is reflected in the dearth of academic studies which aim to understand physicians’ experiences analyzing PGHD, and subsequently, the effect these technologies have on empathy. To understand the different facets of empathy that comprise the physician-patient relationship, we conducted a literature review for the concept of empathy.

2.3 Empathy

2.3.1 The Definition of Empathy

To understand the effects of technology on empathy and of empathy on technology, it was important to first define the concept of empathy itself. There are many definitions for empathy, most of which differ based on whether or not empathy is primarily cognitive or emotional. On the one hand, a leading group from the Society for General Internal Medicine defines empathy as “the act of correctly acknowledging the emotional state of another without experiencing that state oneself.” By this definition, empathy is largely cognitive; it is the understanding of another’s condition without experiencing that condition oneself. Other definitions, by contrast, require that an individual actually experience another’s emotional state. For instance, a long-standing paper from 1981 holds that empathy is an “emotional experience between an observer and a subject in which the observer, based on visual and auditory clues, identifies and transiently experiences the subject’s emotional state.” While the confusion surrounding the cognitive and emotional components of empathy persist, there are clear and long-standing distinctions in the field of psychology. Psychology distinguishes between empathy, a cognitive process, and sympathy, an emotional process. A classic paper from 1958 defined sympathy as “the act or capacity of entering into or sharing the feelings of another,” and held that empathy by definition involved an “awareness of one's separateness from the observed.” In this thesis, we adhere to the classical psychology distinction between sympathy and empathy and hold that empathy is primarily a cognitive process. With respect to patient care, empathy is defined as “a cognitive attribute that involves an ability to understand the patient's pain, suffering, and perspective combined with a capability to communicate this understanding and an intention to help.”

A recent book published by Yale psychology professor Paul Bloom claims to advocate for the abolishment of empathy. In Against Empathy: The Case for Rational Compassion, Bloom challenges empathy as “one of our culture’s most ubiquitous sacred

cows.”83 Because the book was a topic of much recent debate, it was important to examine Bloom’s argument. Bloom claims that “...our public decisions will be fairer and more moral once we put empathy aside.”84 He argues that “Without empathy, we are better able to grasp the importance of vaccinating children and responding to climate change,” and that “our policies are improved when we appreciate that a hundred deaths are worse than one, even if we know the name of the one.”85 Bloom goes on to specifically challenge health care provider empathy: “Consider also certain special relationships, such as that between doctor and patient...it comes to these intimate relationships—the more the better. I used to believe this, but I am no longer sure.”

Bloom’s claims seem radical but become totally benign when it becomes apparent that he confuses empathy and sympathy. He writes, “A highly empathetic response would be to feel what your friend feels, to experience, as much as you can, the terrible sorrow and pain.”86 Clearly, Bloom’s definition is precisely the definition of “sympathy,” rather than empathy. Bloom’s confusion could likely result from others in the field who similarly confuse sympathy and empathy. Leslie Jamison, a medical actor and author of The Empathy Exams evaluated medical students on their ability to be empathetic. She writes, “I needed to look at him and see the opposite of my fear, not its echo.” Like Bloom, Jamison points to the negative effects associated with excessive sympathy, rather than the positive effects associated with empathy. Ironically, the solution Bloom calls for is for empathy to be “modified, shaped, and directed by rational deliberation.”87 Essentially, he calls for “empathy” to better embody its own operating definition.

This thesis will evaluate empathy in the classical psychology sense; that is, as a cognitive rather than emotional attribute.

2.3.2 Empathy in Health Systems

A shift to prioritize empathy is happening across all levels of health care. Neil Chesanow of Medscape describes the newfound prioritization of empathy as “... a part of a strategy by health systems nationwide to improve value in health care across the board. It includes investing in better information systems; introducing or expanding telemedicine services, improving customer service at every level, from admission to discharge in the case of hospitals; reducing hospital readmissions; and improving outcomes for patients with chronic conditions in outpatient settings.”88 Empathy is perhaps surprisingly considered at every level of health care, including insurance and reimbursement. The Centers for Medicare & Medicaid Services randomly surveys patients after discharge on items such as how well health care providers communicated with them, how responsive staffers were to their needs, how well the staff communicated

84 Ibid.
85 Ibid.
86 Ibid.
87 Ibid.
with them about their medications, and how well they understood their post-hospital care needs.\textsuperscript{89}

Empathy is also forging new architectural motifs and interior designs in health care spaces. A newfound emphasis on style and design nod to the importance of servicescape. Servicescape is a business term used to describe the “totality of the ambience and physical environment in which a service occurs.”\textsuperscript{90} Empathetic spaces increasingly precipitate from an industry-wide shift towards empathy, and similarly, the industry-wide shift drives the demand for more empathetic spaces. Entire journals revolve around this idea. Healthcare Design, for example, is a journal dedicated to architecture/engineering and construction (A/E/C) firms whose business it is to pursue empathy and comfort. The journal ranks the most comfortable waiting room chairs, categorizes which lighting options optimize patient moods, and details which materials most inspire healing, for example.

The intersection of health policy and empathetic health care design cannot be overlooked. A recent study tracked how the financial uncertainty that surrounded the passage and implementation of the Affordable Care Act (ACA) occluded A/E/C activity. 78 US A/E/C firms of various sizes were surveyed in January 2016 regarding their activity and demand for new projects in the recent years. 48% of the firms surveyed reported more completed healthcare projects in 2015 than in 2014, and 36% reported about the same number of completed projects.\textsuperscript{91} The single most common client goal reported for 2015 healthcare projects was future flexibility/adaptability.\textsuperscript{92} This goal is in keeping with the ACA push towards Affordable Care Organizations, which rely on reimbursement schedules that are determined by a horizontal integration of care. Flexibility and adaptability for the ACO model is a necessity. In even this small way, health policy affects considerations for empathy, and likewise, existing facility designs around empathy can influence the extent to which a national health policy initiative can be swiftly adopted or dismantled.

2.3.3 Empathy, Physicians, and the Physician-Patient Relationship

Empathy infiltrates the health care system in many interesting and understudied ways, but the focus of empathy in this thesis will be the empathy derived from the physician-patient relationship.

The benefits of empathetic physicians are rarely disputed. A recent meta-analysis of the effect of the clinician-patient relationship found that measures intended to strengthen the clinician-patient relationship were just as beneficial as taking a daily aspirin to prevent heart attack.\textsuperscript{93} Empathetic physicians make fewer medical errors, secure

\textsuperscript{89} Ibid.
\textsuperscript{92} Ibid.
better patient outcomes, and have more satisfied patients.\textsuperscript{94} They are also happier and suffer fewer medical malpractice claims.\textsuperscript{95} Empathetic doctors are better diagnosticians,\textsuperscript{96} prompt better patient compliance,\textsuperscript{97} have more job satisfaction,\textsuperscript{98} and have a reduced risk for burnout.\textsuperscript{99} Older patients in particular rely on the physician-patient relationship. Older adults depend on the physician-patient relationship to address not just physical and biomedical health needs, but also to address “social, economic, cultural, and psychological vulnerabilities.”\textsuperscript{100} When older adults are more socially supported, they may have better blood pressure regulation\textsuperscript{101} and better immune functioning.\textsuperscript{102} In a landmark study from 1927, Dr. Francis Peabody wrote, “The secret of the care of the patient is in caring for the patient.”\textsuperscript{103} Patients who have strong physician-patient relationships as a result of always seeing the same general practitioner experienced fewer re-hospitalizations.\textsuperscript{104} Ong et al. lists three reasons why communication between physicians and patients are important. These three reasons are for exchanging information, making treatment decisions, and creating an interpersonal relationship.\textsuperscript{105} Will connected health devices supplant the first two reasons, and how will the integration of these devices affect the last? Especially as the population ages, there will be more and more patients that require this care. Beyond caring for more patients and analyzing more data, physicians and allied health care professionals will have to reassess their concept of the physician-patient relationship.

There are four established models of physician-patient relationship: the paternalistic model, in which physicians have a paternal role; the informative model, in which physicians tell patients the potential treatment options and patients make their own treatment plan; the interpretive model in which physicians help patients explore their

\begin{footnotesize}
\begin{itemize}
\item \textsuperscript{95} Ibid.
\item \textsuperscript{97} Hojat, Mohammadreza, Daniel Z. Louis, Fred W. Markham, Richard Wender, Carol Rabinowitz, and Joseph Gonella. "Physicians’ Empathy and Clinical Outcomes for Diabetic Patients." \textit{Academic Medicine} 86.3 (2011): 359-64. Web.
\item \textsuperscript{99} Ibid.
\item \textsuperscript{103} Peabody, Francis W. "The Care of the Patient." \textit{JAMA} 88 (1927): 877-82. Web.
\end{itemize}
\end{footnotesize}
values and choose their own treatment based on those values; and the deliberative model in which physicians help patients develop their health-related values and choose their own treatment based on those values. The growing pervasiveness of PGHD will render these four models obsolete, however, as the focus of health care interactions shifts from the “physician-patient relationship” to the “physician-patient-technology” relationship. While a proper use of the technology may make patients feel “more understood,” facilitate otherwise unapproachable health discussions, and ultimately change health outcomes, improper use may exclude patients from being their own health advocates and may render patients less satisfied with their health care as they feel unable to express their unique health-specific values. In order for their patients to achieve the best clinical visit, physicians will have to harness the benefits of technology while also ensuring that the technology enhances—not disintegrates—clinical empathy. A “technological empathy” model must emerge that describes the new form of health care interactions to be expected by the aging population.

2.3.4 Assessing Empathy in Medicine

The assessment of empathy in medicine suffers from a giant self-reporting problem. The bulk of empathy tests rely on physicians self-reporting their interest or agreement with certain statements that have an easily-discerned correct answer. The limitation of a self-reported score is that respondents can manipulate their answers on self-reported personality tests in order to produce a more socially acceptable response. Self-reporting could muddy the observed effects of connected health devices on empathy. A descriptive matrix of common empathy scales and their respective fields, reporting styles and measures is included in Table 1.

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### Table 1. Descriptions of various empathy scales.

<table>
<thead>
<tr>
<th>Scale</th>
<th>Field</th>
<th>Reporting Method</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>JSPE (Jefferson Scale of Physician Empathy) by Center for Research in Medical Education and Health Care at Jefferson Medical College, 2001</td>
<td>Medicine</td>
<td>Self-reporting</td>
<td>20-statement questionnaire measuring empathy among physicians.</td>
</tr>
<tr>
<td>CARE (Consultation and Relational Empathy) by Glasgow University and Edinburgh University</td>
<td>Medicine (developed for primary care settings)</td>
<td>Patient-reporting</td>
<td>Patients report on how “well the doctor” was at 10 different measures including “Making you feel at ease” and “Letting you tell your story.”</td>
</tr>
<tr>
<td>TEQ (The Toronto Empathy Questionnaire) by Spreng, McKinnon, Mar &amp; Levine, 2009</td>
<td>Psychiatry Neurology</td>
<td>Self-Reporting</td>
<td>Physicians report on whether they agree with 16 items, including “When someone else is feeling excited, I tend to get excited too,” and “Other people’s misfortunes do not disturb me a great deal.”</td>
</tr>
<tr>
<td>EETS (Emotional Empathetic Tendency Scale) by Mehrabian &amp; Epstein, 1972</td>
<td>Psychology</td>
<td>Self-reporting</td>
<td>33 items using a 9-point scale measuring variables such as “Sometimes the words of a love song can move me deeply” and “I like to watch people open presents.”</td>
</tr>
<tr>
<td>Hogan Empathy Scale by Hogan, 1969</td>
<td>Clinical Psychology</td>
<td>Self-Reporting</td>
<td>64 items testing social self-confidence, even-temperedness, sensitivity, and nonconformity.</td>
</tr>
<tr>
<td>IRI (Interpersonal Reactivity Index) by Davis, 1980</td>
<td>Social Psychology</td>
<td>Self-reporting</td>
<td>28-items answered on a 5-point Likert scale. Measures include perspective taking, fantasy, empathetic concern, and personal distress.</td>
</tr>
<tr>
<td>Emotion Specific Empathy Questionnaire by Sally Olderbak</td>
<td>Psychology</td>
<td>Self-reporting</td>
<td>60-items; five items per subscale which assess both emotional and cognitive components of empathy.</td>
</tr>
<tr>
<td>BES (Basic Empathy Scale) by Jolliffe and Farrington</td>
<td>Adolescence Studies</td>
<td>Self-reporting</td>
<td>40 items measuring affective and cognitive empathy.</td>
</tr>
<tr>
<td>BEES (Balanced Emotional Empathy Scale) by Mehrabian, 2000</td>
<td>Psychology</td>
<td>Self-reporting</td>
<td>30 item questionnaire using 9-point Likert-type scale measuring emotional aspects.</td>
</tr>
</tbody>
</table>
It should be noted that to date, no clinical empathy scale exists on a broad scale that assesses empathy towards older adult patients. Such a scale should incorporate several factors that assess the physician-patient communication, with particular attention to how well a patient can hear or see their physician, how well the patient is able to understand their treatment and condition, and how well patients are able to recall the conversation and their physician’s treatment requests.

One self-reporting empathy test happens to be the most widely deployed method for assessing empathy skills in health professionals and medical students: the Jefferson Scale of Physician Empathy (JSPE). Components of the JSPE scale are included in this thesis to evaluate physician respondent empathy.

2.3.5 Selection for Empathy - Medical School Interview Process

If empathy and the physician-patient relationship are so critical to reaching correct medical diagnoses and assuring quality care, then it should follow that medical schools stop at nothing to recruit students who depict the required emotional maturity and compassion. Unfortunately, it seems as though that may be an overstatement. “It may be a long time before the personal qualities of prospective medical students will trump their scientific know-how or their desirably high scores in the MCAT,” wrote Dr. Howard Spiro, M.D. Emeritus Professor of Medicine, Yale University School of Medicine.\(^\text{108}\) He adds, “gentleness does not loom as captivating as high science grades to most deans of admission.”

New forms of interview styles for medical school applicants aim to bridge this gap by attempting to select empathetic prospective physicians.

The traditional medical school interview consists of a 45-60-minute meeting with a dean, faculty member, or panel from the medical school. Applicants are drilled on their educational background, preparedness to enter the medical profession, and self-reported character traits. Some medical schools which use the traditional interviewing method select questions more in keeping with those that select for empathy, such as questions that gage an awareness of ethics and value of diversity. The general inconsistency in this method of selecting candidates reflects a failure to prioritize the selection of character traits such as empathy and compassion. Moreover, traditional interviews are easily skewed by a single interaction.

To hone-in on evaluating empathy, many medical schools have recently moved towards innovative interview styles and other application tools. These styles include the Multiple Mini Interview (MMI), the Modified Personal Interview (MPI), and the Computer-based Assessment for Sampling Personal Characteristics Test (CASPer).

The MMI was developed as a more pleasant, predictive, and holistic interview process as compared to the traditional process.\(^\text{109}\) It was developed at McMaster University and has been implemented in medical schools since 2004. Applicants cycle through a series of approximately 8 interview rooms, each staffed by an individual.

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interviewer. At each interview station, applicants are presented with a situational, ethical, or problem-solving scenario that is printed and posted on the door. Applicants have typically two minutes to read the scenario, then have 6-8 minutes to present an answer to the interviewer. Despite the fact that the MMI might more closely assess empathetic traits, the interview method is slow to be adopted because of its substantial resource requirements and the associated modifications of campus recruitment activities, including the diminution of recruitment advantages associated with the traditional interview format.110

The MPI has been coined as an “intermediate approach” capable of balancing resource limitations with a desire for a holistic review process.111 It was developed by the University of Toronto and was first implemented in the 2013-2014 admission cycle. The MPI format was developed as a response to the poor reliability and validity of the traditional interview. Applicants are interviewed in a circuit of four brief (10-12 minutes) semi-structured interviews that are long enough to “foster a 'human touch.'” Applicants are assessed on four leadership qualities: the ability to work on teams, bandwidth and adaptability, self-reflection and personal insight, and vision and expectations.112 Because the MPI consists of only four interview stations, as opposed to eight stations, the MPI is more resource-efficient than the MMI.113

The CASPer test has been described as an at-home, computer-based MMI. All applicants to the medical schools who use the CASPer (McMaster Medical School, University of Ottawa Med School, New York Medical College, Rutgers Robert Wood Johnson Medical School, Central Michigan University College of Medicine, Quillen College of Medicine, East Tennessee State University, Tulane University College of Medicine, University of Illinois College of Medicine, Dalhousie Medical School; in addition to three nursing programs and an optometry program), and not just a fraction of competitive applicants, are required to take the test. The test is composed of a series of twelve short videos or paragraphs, each presenting an ethical dilemma, and each followed by three open-ended questions. Applicants have five minutes to answer the three scenario questions. Some weaknesses of the CASPer test have been exposed in the literature. These weaknesses include inherent cultural biases and easily distinguished correct answers.114

While the CASPer test represents breadth in this medical school interview process—thousands of prospective students can be assessed at once—patient-conducted medical school interviews, by contrast, represent depth, and are unexpectedly feasible. Likely, interactions with actual patients can most accurately assess empathy skills and most neatly align to medical schools’ collective shift towards a holistic review process. The University of Florida College of Medicine (UFCOM) in Gainesville recently published an article on their re-worked admissions process. Now in its fifth year, the process introduces patients to applicants as part of the medical school interview. Fourteen patients from a single practitioner were asked if they would like to help select the next

110 Ibid.
112 Ibid.
113 Ibid.
114 "CASPer & MMI Prep Myths Busted." BeMo Academic Consulting. Web.
generation of physicians. Each patient donated approximately 3 hours of time to the cause. Applicants were not asked to “treat” these patients and were not formally interviewed or assessed by the patients. Instead, patients and applicants met in a small group setting of 10-12 applicants in which the patients could share their story. The cited goal was to unveil the humanity of patients within a potentially machine-like, larger than life healthcare institution. Applicants are given the chance to ask questions of the patients, and then the patients are given the last word to articulate what the most important characteristics of physicians. After hearing from the patients, applicants were informally and individually asked what they thought of the experience. Their responses were surprisingly telling of their level of empathy. Some applicants considered it a “waste of time,” while others lauded the school for its focus on compassionate care and creation of “socially-conscious” people. The candid responses were used to estimate the applicants’ level of empathy.

The school found that applicants with acceptances to multiple medical schools identified the patient meetings as an important component of their decision to ultimately matriculate at UFCOM. On a five-point Likert scale with 0 being not important at all and 5 being very important, matriculating students rated the patient meetings on interview days as a 4 for their decision to come to UFCOM. The patient meetings outranked the financial support, the curriculum changes, and meeting students on interview day. Other medical schools have incorporated patients as part of their process for interviewing candidates, but the UFCOM streamlined their incorporation of patients, and can subsequently assess applicant empathy without requiring too much time or data from patients.

At first pass, a discussion of medical school interview styles may seem too far removed from the examination of physician empathy. Indeed, several studies have marked the troubling trend of medical students’ loss of empathy as they progress through their rigorous training. This trend is well-established in the literature. Locally, a 2012 study by the Boston University School of Medicine found that self-reported empathy for patients wanes as medical students advance in clinical training, especially among those entering technology-oriented specialties.\(^\text{115}\) In the BU study, 1,162 medical students took the Jefferson Scale of Physician Empathy-Student Version each year of their medical training, between the years of 2007 and 2010. There was a negative trend discovered after the longitudinal study. The authors conclude that the decline in empathy has implications for the medical school admissions process.

The empathy skills portrayed by applicants on interview day are likely not representative of their empathy skills as a sleep-deprived, thinly-spread, over-tasked intern or attending physician. But while interview day is still years removed from the students’ prolonged interactions with patients, and while empathy skills may face a toward trend over time, the interview process is still highly predictive of the baseline from which applicants begin. Furthermore, studies like the UFCOM study suggest that many applicants who put a high value on the prioritization of empathy in medicine will self-select schools that reflect that priority. The developments in medical school interview styles cannot be ignored because they present a significant bottleneck that can

reject applicants with unfavorable, apathetic personality types and accept others who exemplify empathy.

2.3.6 Empathy Training in Medical School

The initiative to select and bolster empathy skills in prospective physicians continues after applicants have matriculated. In 2012, Dr. Pauline Chen asked in the New York Times, “Can Doctors Learn Empathy?” There are many medical schools which maintain that, yes, they can.

In the fall of 2015, Harvard Medical School launched an initiative to use more drama, dance, and literature to help medical students become empathetic and reflective doctors. The empathy training includes arts-themed field trips, an artist-in-residency each spring, monthly events like open mic nights, and a collaboration with Harvard’s American Repertory Theater. In a similarly artistic vein, the Yale School of Medicine requires students to scrutinize paintings in an effort to improve their empathy by developing observation skills. Medical students at Penn State College of Medicine can take a Comics and Medicine Course to fulfill a required humanities elective. There are many examples of novel and creative empathy training modules, but there are few empathy training models which center around empathy and PGHD analysis.

2.3.7 Empathy Training for New Physicians

It has been established that there is a downward trajectory for medical students’ empathy as they progress through medical school. This trajectory continues for young physicians, as well. Dr. Helen Riess, the director of the Empathy and Relational Science Program in the department of psychiatry at the Massachusetts General Hospital in Boston, asserts that “empathy can be taught, and you can improve.” She developed empathy training modules for doctors. This training consisted of videos that teach young physicians to recognize key nonverbal cues and facial expressions in patients as well as strategies for dealing with one’s own physiologic responses to highly emotional encounters. For example, one video shows a tense exam room interaction with graphics that point to moments of physician and patient frustrations. The patients of 100 young doctors were asked to evaluate their physicians’ levels of empathy. The novelty of this study was in the metric used for empathy. In this case, the metric was not the JSPE, and was not any other self-reported measure. Instead, the metric was patient reports. Patients were asked to assess physician empathy based on their doctor’s ability to make them feel at ease, show care and compassion, and fully understand patient concerns. Half of the physicians then participated in Dr. Riess’ empathy modules. All of the doctors were evaluated again, two months later, by a second set of patients. The doctors who had participated in Dr. Riess’ empathy training modules showed statistically significant

116 Ibid.
117 Ibid.
118 Ibid.
improvements in their empathetic behavior, while those physicians who had not had the empathy training showed a decline in—and not even maintenance of—baseline empathy scores.

2.4 Implications for Connected Health Policy

If PGHD analysis benefits the physician-patient relationship and if appropriate empathy training modules could make this effect sustainable, it then becomes important to understand how and when health care professionals will have the institutional capacity to absorb and act upon IoT patient-generated data. How will these data forge and affect empathy in the physician-patient-technology relationship and how will that movement, in turn, affect patient health behaviors and outcomes? Both questions launch targets for policymakers.

The reduction of health care costs may be the least abstract contemporary goal of health policymakers (among the other chief goals of improving health care quality and access). If PGHD are found to facilitate difficult health care discussions, help physicians make more accurate diagnoses, surface patient health concerns and diseases that can subsequently be addressed earlier rather than later, reduce malpractice, educate patients on conditions and treatments, increase treatment compliance, and even discover new diseases—then health care costs can almost unequivocally be abated. If this is the case, policy initiatives should be aimed at practices and hospitals (via ranking and accreditation incentives, among others), individual patients (via subsidized technology), federal agencies (who can set standards for secure and appropriate usage, as well as set Medicare and Medicaid reimbursement rates for IoT data analysis), insurance companies (who can internalize some of the savings), and industry (which will have a greater incentive to develop more comprehensive wearables when proof of integration is established). Movement towards integration could change the system’s flat-of-the-cost-curve practice. More small-scale policies should be considered, too, such as policies that could mandate PGHD analysis training amongst health care providers and within medical school curricula. With hospitals and practices beginning to lock-in their electronic medical record platforms, it is crucial that policymakers act now to leave room for the integration of IoT data in the health care system.

Potential barriers to the effortless absorption of IoT into health settings include: work flow barriers, duration of office visits, electronic health record system compliance, lack of patient access to technology, and lack of reimbursement, as well as security and privacy concerns, provider and patient attitudes, legal questions, and lack of training. In contrast, the integration of IoT into health settings may largely benefit physicians. In this thesis, we find that across these measures, PGHD analysis is found to be significantly more helpful than harmful.

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One of the most significant concerns expressed throughout the literature regarding connected health integration, and echoed in our results, is the concern of data privacy and security. A host of reports have been published that discuss fears of data privacy breaches. These reports primarily consider federal agencies or large-scale entities as the agents who can integrate connected health devices and who could properly address privacy concerns. While studies recommend interventions across multiple stakeholders (patients, hospitals, insurance companies, Medicare, federal agencies) to better integrate connected health devices, none of the studies ask which stakeholder will be most effective at doing so. In this thesis, we examine which entities are perceived to be most effective at integrating connected health devices and setting standards in this space. The most effective entities were deemed to be technology companies and individual providers. Publications on standards setting and the address of privacy concerns should be tackled from the perspective of technology companies and providers in addition to just broad-scoped approaches through Medicare.

Older adults could be most worried about data privacy because they are likely the most vulnerable to data privacy breaches. Rarely does the literature discuss wearable device privacy concerns amongst older adults. Studies that try to illuminate older adults’ experiences with and opinions of connected health devices rarely consider privacy. Perhaps to avoid the introduction of lead bias, researchers that examine older adults’ experiences with connected health devices do not directly ask about privacy concerns, but about perceived usefulness of the connected health device, perceived ease of use of the device, attitude toward using it, behavioral intention to use, and actual device usage. Mercer et al. (2016) conducted a survey of adults over the age of 50 who were managing a chronic disease to assess these individuals’ experiences using wearable devices to manage their disease. After respondents used a particular wearable device for a period of three weeks, they were asked to fill-out a 17-item questionnaire which included items such as “The activity tracker was comfortable to wear,” and “Overall, the activity tracker was easy to use.” The researchers subsequently conducted a thematic analysis of the questionnaire. Mercer et al. concluded that there were four themes that emerged from the survey results: health technologies are likely to be outside the older user’s perceived comfort zone; after a brief trial period, users can appreciate that wearable activity trackers improve self-awareness and goal setting; wearable activity trackers are ultimately more useful as motivators than as quantifiers; and older adults are unlikely to adopt wearable activity trackers if the trackers are not sold and managed as health care devices. Not only was the concern regarding data privacy excluded from the survey variables, but it also failed to emerge as a central theme. If adults in the age group studied by Mercer et al. had less of the necessary language and rhetoric to describe privacy concerns, these types of concerns would be underrepresented in the results. In this thesis, we assumed that data

privacy could likely be a concern for older adults, even if these adults were not inclined to describe these concerns themselves. We decided to directly ask older adults and other patient respondents to rate the extent to which data privacy concerns presented as barriers to them adopting more connected health devices. One recent review of empirical studies found that privacy concerns registered in 34% of the total articles examined about older adults and wearable device integration.¹²⁶

In this thesis, we fill-in the gap of age-correlated privacy concerns. We find that not only are older adults more frequently reporting privacy concerns, but that of all individuals who were concerned about connected health device privacy and security, 63.7% hailed from the Baby Boom Generation, 19.9% hailed from the Silent Generation, and only 16.4% hailed from the Generation X respondents/Millennials. To better understand potential solutions to privacy concerns and to PGHD integration at large, it was important to first understand what the existing barriers were.

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Chapter 3 – Health Care Provider Survey

3.1 Chapter Introduction

Sir William Osler is credited with saying, “It is as important to know what kind of man has the disease, as it is to know what kind of disease has the man.” If he were alive today, Sir Osler might also wonder how technological devices will change the ways we know both man and disease. In order to understand how health care providers expect PGHD analysis to change the physician-patient relationship, we conducted a survey of health care providers. The purpose of Chapter 3 is to present the description, results, and conclusions of this survey.

Some providers resist the integration of PGHD in the health care space. These providers cite challenges such as poor interoperability of devices and electronic health record systems, a lack of standards for the efficacy of health and fitness trackers, a host of liability concerns, workflow interruptions, too little visit time, and a lack of reimbursement. Even if indicators suggest that connected health devices are sufficiently mature, much of the integration depends upon the benefit or harm physicians see as a result of including these technologies in their provision of health care.

The effects of how the analysis of these data will affect provider empathy and the physician-patient relationship amongst older patients and older providers are largely unknown. Physicians who are more empathetic in their visits with patients make fewer medical errors, secure better patient outcomes, and have more satisfied patients. They are also happier and suffer fewer medical malpractice claims and are better diagnosticians. Connected health devices could conceivably harm and benefit the physician-patient relationship. Disparities in technological savviness and preferences could breed resentment between patients and providers. On the other hand, if PGHD collection leads to more targeted conversations, treatment compliance could improve and patients would be more satisfied across multiple means. The analysis of PGHD could also improve the physician-patient relationship by allowing greater time for interaction when a patient requires the care of a physician. PGHD better individualizes “diagnostics and treatments, simplifi[es] real-world monitoring, and provide[s] evidence-based guidance at the point of need,” which frees up the time of physicians so that they can better serve “as a diagnostican and educator.”

This chapter has six further sections. In section 3.2, we describe the survey method used to evaluate health care provider perceptions of PGHD and the physician-patient relationship. We also discuss the sample, which was larger than any comparable

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an academic study of physicians, and which included a broad representation of specialists and practice locations. In section 3.3 we discuss metrics for physician empathy levels and the effects or non-effects of gender and age, respectively, on self-reported empathy levels. We also examined empathy levels across geographical regions, different medical degrees, ethnicity, and willingness to adopt technology. In section 3.4 we discuss physician demand for connected health device usage amongst their patients, as well as perceived clinic and physician readiness to receive, review, and discuss PGHD. In section 3.5 we review both qualitative, open-ended approaches as well as quantitative approaches to understanding the dimensions of the physician-patient relationship that are affected by PGHD. Section 3.6 concludes.

3.2 Methods

We conducted two surveys, one of health care providers and one of the general public, to better understand the current and expected uses of smart devices for the collection of patient-generated data.

The surveys were constructed in Qualtrics. The surveys were anonymous, confidential and in most respects identical in their questions to allow for direct comparisons of opinions between physicians and patients on some matters. The language differed in some instances to adjust for different intended audiences. The patient survey, a pilot for the health care provider survey, and the final health care provider survey were approved by the Committee on the Use of Humans as Experimental Subjects (COUHES) at MIT as protocols 1608667476, 1605571631 and 1701804837, respectively. The first page of the online survey was reserved for Informed Consent. Participants had to agree to the terms of the study in order to advance to the first set of survey questions. If individuals did not agree to the Informed Consent, they were directed to the end of the survey and did not complete it. The data were analyzed using IBM SPSS Statistics Version 24.0.0.0.

3.2.1 Survey Procedure - Health Care Provider Survey

The goal of this portion of the research was to understand how patient-generated data from smart devices affects empathy and the physician-patient relationship. To better understand physicians’ and other health providers’ use and non-use of patient-generated data from smart devices, we surveyed physicians and allied health care providers.

The target survey respondents were physicians, though other health care providers completed the survey. Health care providers were surveyed to understand what drives or discourages their use of PGHD. They answered questions regarding how the use or nonuse of patient-generated data affected their relationships with patients and subsequent patient outcomes. The survey was created in and distributed online through Qualtrics.

A pilot version of the questionnaire was fielded from July 2016 to January 2017 to determine if there were difficulties answering any of the items and to test a recruitment method of individually emailing health care providers and attempting to generate a larger snowball sample. In part, there was some concern on the part of the researcher that the questions might be considered as too abstract or futuristic. Moreover, there was some
concern that the physicians would not properly interpret the phrases “wearables,” “patient-generated data” or the “Internet-of-Things.” As a result of the pilot study, minor revisions to the survey were made, including the addition of definitions of several terms such as “patient-generated data” and “smart devices.”

The pilot study also revealed difficulties in recruitment. By January 2017, data from only 76 health care providers had been collected; at this point it was deemed unfeasible to recruit a larger pool of respondents by individually emailing providers and relying on them to refer others to the questionnaire. In place of this method, the MIT AgeLab purchased a list of physician emails from United e-Solutions, a marketing technology company that maintains email databases. The list contained a list of 205,738 emails, which is approximately a quarter of the active physicians in the United States. United e-Solutions reports that the email addresses are collected from surveys and seminars, trade shows, business directories, websites and other sources. The emails and corresponding information of the individuals in the panel were reportedly validated by United e-Solutions one day before the list purchase. United e-Solutions guaranteed a 90% accuracy on data and email delivery, but an analysis of the results revealed that individuals who were not physicians were also included on the list and completed the survey questionnaire. An email that included the survey link was sent through Qualtrics to the entirety of the list.

The questions surveyed health care providers about their principal practice setting, their relationship to patients and patients’ demographics, their use of their patients’ PGHD, and their opinions on the integration of patient-generated data from a smart device. We also collected physicians’ self-reported empathy levels using variables from the Jefferson Scale of Physician Empathy (JSPE), as well as perceptions of how empathy might change by using mHealth devices. An index of empathy was created by averaging the seven-point Likert-scale responses to the four JSPE questions that were included in the survey. Finally, we collected information about provider medical background, degree, and demographics. The demographic information collected included respondent age, ethnicity, gender, principal practice type and location, specialty, hours worked, and self-reported willingness to adopt new technologies. No financial incentive was offered for survey completion. The full surveys are provided for reference in the appendix. Alternatively, the full surveys can be acquired by emailing the authors.

The email was sent on January 20, 2017 at 3:00pm EST. Responses were collected from January 20, 2017-February 15, 2017. A second email was sent five days later, on Wednesday January 25, 2017 at 1:00pm EST, to the individuals who had not yet participated.

3.2.2 Fielding - Health Care Provider Survey

In all, 41,236 of the 205,738 emails were rejected by the destination servers, therefore only 164,502 emails were effectively sent. The total response rate was 0.43% (892 individuals completed the survey) and the partial response rate was 0.56% (1162 individuals partially completed the survey). Because no question was forced-response, the N varies from question to question. The target sample size for this study was approximately 500 physicians. This target was met, although many questions were not
answered by all 892 respondents. Response rates for physicians average at least ten percentage points lower than response rates among the general population.\textsuperscript{131}

Respondents were omitted from analysis for a number of reasons. A large proportion of respondents were omitted from analysis because they had a survey duration time of less than three minutes. The survey was estimated by Qualtrics to take approximately ten minutes; however, variability was to be expected to some degree in the survey duration for two reasons. First, there was expected variability because of the extensive display logic throughout the survey. Second, the lack of forced-response questions allowed respondents to skip through survey questions in little time while also providing valid responses to the few items they chose to answer. Respondents were also omitted from analysis if their responses to “practice specialty” indicated that they were not a health care provider or if their answers to “hours worked per typical day” indicated that they were retired. Furthermore, respondents were removed from the data set if they provided a principal practice setting zip code that was outside of the US. These exclusions reduced the effective sample size to 512.

Before sending the recruitment email, research was conducted to get a sense of the time and day of the week to send the survey that would maximize survey visibility and completion. Physicians are notoriously difficult to survey. There are a number of barriers to achieving a high response rate amongst physicians which include but are not limited to: physicians’ demanding work schedules and long hours, the large opportunity cost of completing the survey in units of both time and salary, physicians’ unwillingness to take place in a survey that generalizes their responses as profession-wide,\textsuperscript{132} physicians are surveyed frequently as professional elites,\textsuperscript{133} they are more resistant than other respondents to be restricted by closed-format questions,\textsuperscript{134} and they are difficult to reach because they have office staff who screen their inboxes for non-clinical matters.\textsuperscript{135} Thus, the web survey could have a sampling error because physician emails are not as easily accessible as physician addresses or phone numbers.\textsuperscript{136}

Physicians are also expensive respondents, traditionally at around $70-90 per complete survey, depending on the physician specialty. Nurses or other health professionals cost approximately $50 per complete survey. Qualtrics support, who provided these estimates, mentioned that large research companies such as Pfizer, with research budgets in the millions of dollars, purchase panels of 50 medical professionals at

\begin{thebibliography}{9}
\bibitem{134} Price, J. H. ""Show Me the Money:" Medical Directors' Responses to a Mail Survey." \textit{The American Journal of Managed Care}. U.S. National Library of Medicine, Nov. 2000. Web.
\end{thebibliography}
most, because of cost of physicians and the seriousness with which they take the survey. A small sample of physicians, Qualtrics offered, could provide much more thoughtful and valuable responses than a population of general respondents.

To enhance the response rate, given that the survey was long and there were no financial incentives, we offered providers the opportunity to receive a summary of the results which may be useful to their practice. Instead of shortening the survey, all questions were made as optional so that busy physicians could skip a long question rather than exit the survey altogether. As part of the informed consent, respondents were made aware of the fact that they could skip any question(s). Telephone and postal distributions, which would not have been feasible in this case given time constraints and the size of the physician email list, precipitate the highest response rate among physicians. These methods were not considered for the administration of this survey.\(^{137}\)

The significant limitation of distributing the email through Qualtrics was that MIT AgeLab sponsorship was not immediately apparent. The ‘from address’ on the email had to be noreply@qemailserver.com, which could have the tendency to be perceived not as a study from MIT but as spam. To mitigate the lack of sponsorship information, a custom ‘reply-to’ address, agelabhcicsurvey@mit.edu, was created to lend credibility to the email communication. As an additional measure to show MIT sponsorship, the subject of the email was ‘MIT AgeLab survey on Smart Devices in Health Care.’

While samples of the general population often have the highest response rates on Monday afternoons between 3-6pm or Wednesday mornings, there was no prime time to send a survey to physicians or health providers. Physicians keep schedules that are unusual, shift-based, and inconsistent with providers in other specialties. Their schedules are often inconsistent even from week-to-week. The survey was also nation-wide, so any attempts to send an email at any given time would be zero-sum among other time zones. Qualtrics also took several hours to attempt to send more than 200,000 emails, so there would be only a subset of physicians at any given time zone that would have received the email at the “target time” if such a precise approach had been possible. Physicians are more willing than other professionals to catch up on work and emails over the weekend, so it was determined that a Friday afternoon distribution beginning at 3:00pm EST would galvanize the largest response rate. The email was sent on a Friday and a follow-up email was sent on the subsequent Wednesday.

The second email was written in a more personable tone which included the researcher’s full name, role in the lab, personal email address, and which identified her as a prospective physician. Therefore, this second email used a more Dillman Tailored design, which emphasizes how the survey would be useful to the researcher and the health care community, has personalized correspondence, and has personal contact information to create trust. Among physicians who respond to surveys, there seems to be little early or late response bias.\(^{138}\)


3.2.3 Sample Description - Health Care Provider Survey

Table 2 displays descriptive information for the health care provider sample. Despite the fact that the respondents were only supposed to include physicians (the purchased list was explicitly supposed to include only physicians’ emails), only 75% of the respondents were physicians. The respondents who selected “other” for their medical degree included individuals who were health care providers but who were not doctors. Non-physician respondents included, for example, nurses, physical therapists, an alcohol and drug counselor, and wound care specialists. There were no questionnaire items in place to filter out non-physician health care providers from the sample because it was assumed that the purchased list of physician emails from United e-Solutions had been appropriately validated and would not include the emails of other such health care providers. These non-physician health care providers were not deleted from the dataset, but they were omitted from any analysis that was specifically concerned with physician responses.

To best represent the diversity of physicians who provide medical care in the United States, the goal for the composition of the sample was to include an even distribution of gender, age, ethnicity, practice type, specialty, stage of training, geographical location within the United States, and self-reported technology adoption level. We did not select for these quotas, but we presumed that the size of the United e-Solutions sample would provide variation in the sample. The sample of email addresses is skewed based on people who attend conferences and who make their email address available. See Table 2 for a detailed summary of the health care provider sample demographics.

Of note, nearly two thirds of respondents (64.6%) were male while approximately one third (35.4%) were female. This skew was unusual but welcomed, given that the majority of general survey respondents are female. The majority of respondents selected “Attending” as their stage of training (75.3%). The next most frequent stage of training was “Other.” Many of the respondents who selected “Other” for stage of training were not physicians, so attending physicians were effectively more concentrated than the data suggest. The most commonly reported practice specialties were pediatrics (12.4%), surgery (11.6%), family medicine (11.3%), and internal medicine (9.4%). While only 2.8% of respondents wrote-in geriatrics as their practice specialty, it is possible that other geriatricians selected general internal medicine, which was an existing multiple choice option. Similarly, other subspecialists could have selected more general principal practice specialties rather than writing-in their most accurate specialty.

65.9% of respondents were between the ages of 45-64 years old. This finding makes sense given the skew observed in the stage of training variable. Most physicians of this age would no longer be residents or fellows, but attending physicians. Interestingly, the next largest age group was Age 65+.

Fortunately, the sample mirrors the population of physicians actively licensed in the United States. The ethnicity of the sample was skewed at large, but quite close to the actual composition of the actively licensed physician workforce in the United States. For reference, the American Association of Medical Colleges reported in 2010 that of all MD physicians actively licensed in the United States in 2008, 75.0% were White, 6.3% were Black or African American, 0.5% were American Indian, Alaska Native, Native
Hawaiian or Pacific Islander (at the time, American Indian, Alaska Native, and Native Hawaiian or Pacific Islander was a combined category), and 12.8% were Asian. The sample was remarkably balanced by geographical region, with 28.0%, 24.5%, 29.2%, and 18.3% of respondents primarily practicing in the Northeast, Midwest, South, and West census regions, respectively.

Most respondents worked between 6-10 hours per typical day (71.6%), but more than a quarter of the sample reported working between 11-15 hours per typical day (25.2%). One provider reported working 16.5 hours per typical day. We did not collect information on the number of days per week providers worked. If respondents filled-in a range of hours worked per typical day, the average of the two hour values was taken. 5 respondents wrote-in 50 hours and 1 respondent wrote-in 80 hours, so the hours worked was divided by five in an attempt to estimate hours worked per day, rather than hours worked per week. It was noted that health care providers may work fewer or more than five days per week, but respondents were not asked how many days they work per typical week, so these six data points could be inaccurate.

Readiness of technology adoption was assessed to account for any implicit bias in the use or nonuse of patient-generated data from smart devices. Technology adoption level was normally distributed, with 25.8% of respondents as Early adopters, 54.7% as Average adopters, and 19.5% of the sample as Late adopters.

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### Table 2. Health care provider survey demographics.

<table>
<thead>
<tr>
<th>Category</th>
<th>Sample percent</th>
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<tbody>
<tr>
<td><strong>Medical degree</strong></td>
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<td>MD</td>
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<tr>
<td>DO</td>
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<td>Other</td>
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<tr>
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<tr>
<td><strong>Stage of training</strong></td>
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<tr>
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<tr>
<td>Attending</td>
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<tr>
<td>Other</td>
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<tr>
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<tr>
<td><strong>Specialty</strong></td>
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<td>Internal Medicine</td>
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<tr>
<td>Pediatrics</td>
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<td>Critical Care</td>
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<td>Emergency Medicine</td>
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<td>Endocrinology</td>
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<tr>
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<td><strong>Gender</strong></td>
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<td><strong>Age</strong></td>
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<tr>
<td>Race/ethnicity</td>
<td>Percentage</td>
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<td>----------------------------------------</td>
<td>------------</td>
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<td>1-5 hours per day</td>
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<td>11-15 hours per day</td>
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<td>16-20 hours per day</td>
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</tr>
</tbody>
</table>

Note: Table entries are sample percentages, based on the Total N number of valid cases for each descriptor variable.

### 3.3 Physician Empathy Measures

#### 3.3.1 Sample Empathy Levels

In order to understand the relationship between physician and health provider empathy and patients’ use of wearable technology in the health care space, we first established a baseline assessment of physician empathy level. To measure provider empathy, we asked providers four questions derived from the Jefferson Scale of
Physician Empathy (JSPE), a widely-used measure in the medical field. The JSPE is a 20-question measure of self-reported empathy levels. The creator of the scale, Dr. Mohammadreza Hojat, acknowledges that some of the questions seem unrelated to empathy or medicine. Regardless, he maintains that the measures, when scaled together, provide a validated measure of empathy. Although the text of the items in the JSPE is widely available, the algorithm by which the individual variables are combined to create an empathy score is undisclosed, likely related to the fee-based licensing of the test.

We selected 4 of the 20 questions from the JSPE to include in the survey. These four questions were selected for their face validity. These questions were: 1) “I try to think like my patients in order to provide better care;” 2) “I believe that empathy is an important therapeutic factor in treatment;” 3) “Emotional ties to my patients have a significant influence on patient outcomes;” and 4) “I am skilled at viewing things from my patients' perspectives.” The questions in the survey were scored on the same 7-point Likert scale as the Jefferson Scale of Physician Empathy, which ranges from “1 – Strongly disagree” to “7 – Strongly agree.” Table 3 displays the frequencies for each of the four empathy measures.

Table 3. Health care provider self-reported empathy levels. Health care providers were asked to indicate the extent to which they agreed with the empathy variables listed below. The four variables are components of the Jefferson Scale of Physician Empathy. Providers responded on a seven-point Likert scale from “1-Strongly disagree” to “7-Strongly agree.”

<table>
<thead>
<tr>
<th>Likert Score</th>
<th>“I try to think like my patients in order to provide better care”</th>
<th>“I believe that empathy is an important therapeutic factor in treatment”</th>
<th>“Emotional ties to my patients have a significant influence on patient outcomes”</th>
<th>“I am skilled at viewing things from my patients' perspectives”</th>
</tr>
</thead>
<tbody>
<tr>
<td>7 – Strongly agree</td>
<td>34.5</td>
<td>69.4</td>
<td>32.4</td>
<td>28.9</td>
</tr>
<tr>
<td>6</td>
<td>25</td>
<td>18.7</td>
<td>21.4</td>
<td>31.5</td>
</tr>
<tr>
<td>5</td>
<td>22.3</td>
<td>8.0</td>
<td>17.9</td>
<td>24.4</td>
</tr>
<tr>
<td>4</td>
<td>10.4</td>
<td>2.7</td>
<td>15.2</td>
<td>12.8</td>
</tr>
<tr>
<td>3</td>
<td>3.9</td>
<td>0.6</td>
<td>4.8</td>
<td>1.5</td>
</tr>
<tr>
<td>2</td>
<td>2.1</td>
<td>0</td>
<td>4.5</td>
<td>0.3</td>
</tr>
<tr>
<td>1 – Strongly disagree</td>
<td>1.8</td>
<td>0.6</td>
<td>3.9</td>
<td>0.6</td>
</tr>
<tr>
<td>Total N</td>
<td>336</td>
<td>337</td>
<td>336</td>
<td>336</td>
</tr>
</tbody>
</table>

Note: Table entries are sample percentages, based on the Total N number of valid cases for each descriptor variable.

Table 3 shows that across each of the four empathy questions, a majority of respondents agreed with the sentiment in the statement. Because only a small percentage of respondents disagreed with the empathy questions, the sample was deemed to be

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highly empathetic. Regardless, there was some variation across items. For example, nearly two thirds of respondents selected “Strongly Agree” to question 2 but only one third of respondents selected “Strongly Agree” to the other three questions, and nearly 15% of respondents disagreed to some extent with question 3. These responses indicate that the majority of physicians believe empathy is an important therapeutic factor, even if they vary in their confidence of being empathetic providers and to what extent their empathy may affect patient outcomes.

It is possible that there was a skew towards higher empathy in the sample for a number of reasons. The respondents who elected to take the survey did so in response to an email from the author, a prospective physician, who identified herself as such, and they were willing to participate in order to help a student researcher, even though there were no financial incentives and the survey was time-intensive. This mentorship altruism is common in the medical field. Respondents who sacrifice time and possible gain in order to help a researcher who they do not know may also be more inclined to make material sacrifices for the patients who they do know and for whom they are directly accountable. Another source of empathy skew in the sample may come from the recruitment method. The physician email addresses originated from a list that was acquired by a market research firm. The firm collects email addresses primarily by scouring the internet. Many physicians do not make their email addresses available in an effort to prevent inappropriate or excessive communication with patients. Physicians also employ other communication barriers such as having a single clinic email address or hiring an administrator whose job in part it is to screen out non-essential communications. Those physicians who post their email address online may be more willing to communicate with their patients and may thus be more empathetic.

In addition to examining each of the four individual empathy variables, we created a single overall empathy score that averaged respondent scores across these measures. The Cronbach’s alpha score for the scale was 0.620. The mean empathy score for the sample was 5.792, the median was 6.000, the standard deviation 0.950, and the range from 1.00 to 7.00, where higher scores indicated greater levels of empathy.

3.3.2 Empathy Levels by Provider Demographics

We were curious if health care provider age was a predictor of empathy level. We conducted a One-way ANOVA of age groups and empathy score. There were three age groups: Ages 18-44 (N=46), Ages 45-64 (N=203) and Ages 65+ (N=59). The empathy score tested was the score we determined by taking the mean across the four JSPE empathy variables we included on the survey. Age was not a statistically significant determinant of provider empathy level (One-way ANOVA, p=0.340). A linear regression was conducted to control for other factors that could affect empathy. Still, age was not a significant predictor of provider empathy.

There was a significant relationship between gender and overall empathy score. On average, female health care providers had higher empathy scores than male health care providers did (Equal variance assumed, N=320, t=-1.654, F(318, 298)=6.360, p=0.012) without controlling for other variables. This result is consistent with a large body of research. For example, other work has shown that female physicians use more patient-
centered communication and provide more psychosocial counseling to their patients than male physicians do. Recent research has found that physician gender may also affect patient outcomes; the researchers point to differing “practice patterns,” – which could include differences in empathy – between female and male physicians as a potential reason that elderly hospitalized patients treated by female internists have lower mortality and readmissions rates compared with those cared for by male internists. These “practice patterns,” include various empathy factors. The results of the Harvard study warrant additional empathy research to better understand how empathy and these practice patterns precipitate better outcomes for elderly patients. Alternatively, this gender-based empathy effect could be explained by the fact that women may invest more than men do in their self-image as empathetic people. Eisenberg and Lennon (1983) found that there was a significant sex difference in empathy favoring women when empathy was scored via a self-report inventory, but there was no sex difference when measures of empathy were unobtrusive observations of behavior.

To understand whether different variables were related to physicians’ empathy levels, we ran a series of ANOVAs with overall empathy score and physician demographics. Across three provider age groups (Ages 18-44, N=46; Ages 45-64, N=203; and Ages 65+, N=59), age was not statistically related to overall provider empathy level (One-way ANOVA, F(2,299)=1.084, N=302, p=0.340). A bivariate linear regression with calendar age and overall empathy score also did not reveal a statistically significant relationship between these two variables in this sample.

Ethnicity was not a statistically significant predictor of empathy levels, as determined by a univariate ANOVA. Differences in empathy levels between providers of different geographic regions were marginally significant (One-way ANOVA, F(3,313)=2.365, p=0.071). Post hoc comparisons using the Tukey HSD test indicated that the mean overall empathy score for providers in the South (M=5.5984, SD=1.03684) was significantly lower than that of providers the West (M=5.98, SD=0.954), but that

respondents from the South and West regions did not statistically significantly differ from the North and Midwest regions.

Overall mean empathy scores did not differ statistically by medical degree (MD versus DO). When practice specialties were grouped by either medical specialty or surgical specialty, however, the providers with medical specialties (M=5.86, N=232) were marginally more empathetic than the providers with surgical specialties (M=5.65, N=71), (F(1,301)=2.827, p=0.094). The frequency with which providers saw their patients was not related to overall empathy score.

We conducted an ANOVA to determine if trust in patient-generated data could predict provider empathy levels. There was a statistically significant difference between trust in PGHD and empathy levels. Providers who assigned a failing grade (D+ through F) to their trust in PGHD were significantly less empathetic than the providers who provided any C grade, any B grade, or any A grade (One-Way ANOVA, F(3,247)=5.843, N=251, p=0.001). The empathy levels in providers who assigned A grades, B grades, or C grades did not statistically differ.

3.4 Provider Demand for Data

Physicians and allied health professionals are or will soon be asked to analyze patients’ patient-generated health data from connected health devices – anything from the hours patients sleep each night, to the number of steps they have taken, to a macronutrient-specific analysis of every bit of food they have consumed and logged, to their weight each morning. The impending deluge of patient-generated data may present a massive disruption to physicians and their practices.

We wanted to understand the factors that may affect the integration of wearable and/or smart devices into the health care system. To do so, we asked a mix of closed and open-ended questions that surveyed current and projected usage of these data, as well as provider opinions about these data and their perceptions of how to integrate these technologies into their practices and professions.

3.4.1 Physician Demand for Data

“Fire me and hire a doctor that is interested in using smart devices.”

A simple linear regression was run to explore how physician age and gender were related to whether or not providers recommend connected health devices to their patients. From a regression analysis, provider gender was significant predictor of providers’ recommendations of PGHD technologies for their patients, controlling for principal practice setting type, hours worked per typical day, medical specialty, and whether or not the provider was an attending physician. Following an initial run of the data, insignificant control variables were eliminated from the analysis. The final model results are presented in Table 4.
We observed a strong gender effect; female physicians were significantly more likely than male physicians to recommend the technologies for PGHD to their patients when controlling for geographical region, willingness to adopt new technology, and ethnicity. In conducting the regression, we also observed that compared to providers who were white, providers who were other races were more likely to recommend connected health devices to their patients.

Encouraging patients to use devices to collect PGHD does not necessarily mean that health providers believe the data will be trustworthy. To assess providers’ trust levels of PGHD, we asked respondents, “How accurate do you believe patient-collected data from a smart device are? If you had to assign a grade for how accurate the data are, what would you give?” They could assign any grade from A+ to F in a dropdown menu. Translating letter grades into a numerical scale, we conducted a series of one-way ANOVAs to explore which variables affected the degree to which providers trusted PGHD. Male and female health care providers did not significantly differ in their trust levels of PGHD. Provider age was a marginally significant predictor of trust in PGHD (One-way ANOVA, F(2, 297)=2.635, N=230, p=0.074). Using a Tukey HSD test, providers between the ages of 18-44 years old assigned trust grades to PGHD that were higher on average than the grades assigned by physicians over the age of 65 years old; physicians between the ages of 45-64 years old did not statistically differ on average from physicians in older or younger age groups.

If providers trust the data and recommend the technologies for PGHD to their patients they might do so because they believe it would encourage good health behaviors from their patients. Trust in the data and recommending that patients collect them does not mean that providers necessarily consider interfacing with and reviewing these data to be part of their responsibilities. We explored responses to the following question on the survey: “I consider it my job to receive, review, and discuss patient-collected data from a smart device.” Respondents could select “Yes,” “No,” or “Maybe.” Responses were relatively evenly distributed across the three answer choices: 32.6% of respondents selected “No,” 35.8% of respondents selected “Maybe,” and 31.6% of respondents selected “Yes” (N=408).
Within the sample, we wanted to understand if there were age or gender effects on whether providers consider it their job to analyze these data. We conducted a linear regression analysis of age and gender on whether providers considered it their job to interface with PGHD, controlling for geographical region in the US, ethnicity, willingness to adopt new technologies, principal practice setting, specialty, stage of training, and hours worked per typical day. In this model, neither age nor gender were statistically significant sources of variation for whether physicians did or did not consider it their job to analyze patients’ PGHD.

We then re-ran the model, eliminating factors that were not statistically significant predictors of whether or not providers considered it their job to use their patients’ PGHD. Gender, geographical region in the US, age, typical hours worked per day, principal practice setting, specialty, and stage of training were excluded. In this model, providers who considered themselves late adopters of technology were significantly less likely than providers who considered themselves early adopters of technology to think that it was their job to interface with PGHD (p=.001). Ethnicity was not a significant source of variation in job expectations.

3.4.2 Physician and Clinic Readiness

If health care providers do not have the proper training to receive, review, assess, and discuss PGHD with their patients, then they may be of little help to patients who do collect their own data. For this reason, we asked respondents, “If you have received some sort of training or education to use patient-collected data, where did you receive this training?” By and large, health care providers have not received training to deal with these devices; 65.2% of respondents indicated that they had not have any training (N=323). 13.0% of respondents indicated they had received some sort of training at conferences. Any other training providers received from medical school, industry promotions, hospitals/clinics, literature, colleagues, and continuing medical education courses was less frequently mentioned. For the future workforce of physicians to be prepared to handle the data their patients will increasingly provide, medical school curricula need to incorporate this type of training. In order to treat the large but aging baby boomer population with the highest quality care and with the most efficiency, providers are expected to turn to wearable devices and mHealth.

3.5 Links between Empathy and Wearable Devices

The first component of Chapter 3 examined intrinsic predictors of empathy. We then reviewed providers’ perceptions of wearable devices and smart devices in the health care space. Finally, we sought to understand how providers expect these technologies to change their empathy and the physician-patient relationship, if at all.

We now turn to the question of how providers expect these technologies to change their empathy and the physician-patient relationship, if at all. One of the seven qualitative variables on the survey addressed this point directly. If providers answered that a non-zero percentage of their patients were providing them with PGHD, we asked
them, “How does your use of patient-generated data change interactions with patients?” There were 101 valid responses. Two thirds of respondents (69 of the 101) indicated that PGHD has a beneficial effect on their interactions with patients. These benefits include some of the following responses: “Demonstrates the extent of patient engagement in the solution;” “It allows me to make better guided treatment decisions. More data equals more confidence;” and “It improves the patient's participation in their own health care, and understanding of the impact of their health issues.” Of these 69 responses, 27 responses were specific to the physician-patient relationship, including comments such as, “they feel that we are spending time to get as much information as possible,” and “it creates a more trusting relationship.” Of the 27 responses that were specific to the physician-patient interaction, 100% reported that PGHD were beneficial for the interaction.

One third of respondents indicated that PGHD would either have no effect on their interactions with patients or would have a negative effect. These responses included, “could see too much time spent reviewing data and not enough time spent interacting with [patient], also concerned that data may be used by insurance companies to justify denying certain treatments;” and “It makes the patients trust the device more than the provider, they tend to push for more interventions that are not needed.”
Providers were also asked closed-ended items in the survey about the ways in which PGHD changed their interactions with their patients. All respondents were asked, “How would patient-collected data from a smart device affect the following,” and were asked to select from three answer choices—“Would be helpful,” “Would have no impact,” or “Would be harmful”—across 8 different measures of patient-related outcomes. The results are shown in Figure 1.

Across all eight measures, a higher percentage of respondents selected “Would be helpful” than selected “Would be harmful” or “Would have no impact.” The item for which there was the greatest difference between the percentage of respondents who selected “Would be helpful” and “Would be harmful” was “Assessing treatment effectiveness/tracking progress,” in which 85.2% of respondents said patient-generated data from a smart device would be helpful in this regard, and only 1.4% of respondents said patient-generated data would be harmful for this measure. Other aspects for which a high percentage of respondents reported that PGHD would be helpful were “Capturing a
more complete picture of patient health” in which 82.8% of respondents thought PGHD would be helpful, and “Assessing patient compliance with treatment” in which 80.9% of respondents thought PGHD would be helpful.

The item for which there was the smallest percentage difference between respondents who selected “would be helpful” and “would be harmful” was for “reducing unnecessary medical expenses.” This item had the fewest number of providers who indicated that PGHD might be helpful; only 47.7% of respondents reported that PGHD would be helpful for reducing unnecessary medical expenses, 46.6% of respondents reported that it would have no effect, and 6.6% of respondents reported that it would be harmful. If wearable devices or the collection of PGHD become a practice which providers demand in a vacuum and there are no external financial incentives for doing so (or there are no insurance premium reductions for doing so), then the purchase of smart devices for health purposes falls in the realm of “medical costs,” and costs would rise for both patients and insurance companies. Medical costs could also rise from PGHD if the equipment needed to receive, assess, review, and discuss these data presents a large capital cost for providers, clinics, and hospitals. Similarly, these data and devices could create large personnel costs and costs derived from investigating policy, reimbursement, and malpractice implications. PGHD might be helpful in reducing medical costs if the devices are not specifically considered medical devices, in which case medical spending would be reduced but spending overall would still increase. With more frequent health data points, outlier data points from health visits (such as white coat hypertension) are mitigated. If costly interventions are rendered unnecessary by accurate and abundant PGHD, then health costs could be saved (out of pocket for the patient, as well as for insurance companies). The variable for which PGHD integration was considered most harmful was “Making patient visits more targeted/efficient” (Figure 1). This finding could be consistent with the notion that health costs could increase if patient visits veer off into other, perhaps less relevant, aspects of patient health, and as a result additional visits must be made.

To explore if there were age or gender effects on whether respondents found PGHD helpful, harmful, or unchanging in various health care system measures we conducted a series of ANOVAs. Female health care providers were significantly more likely than male providers to find PGHD helpful in: “Assessing treatment effectiveness/tracking progress” (One-way ANOVA, F(1,315)=5.388, N=317, p=0.021); “Capturing a more complete picture of health” (One-Way ANOVA, F(1,317)=6.036, N=319, p=0.015); and “Reducing unnecessary medical expenses” (One-Way ANOVA, F=(1,313)=5.011, N=315, p=0.026). No other differences between genders regarding harmful vs. helpful effects of PGHD were statistically different. Female consumers currently use more wearable devices than men do. It may follow that female health care providers, as female consumers of wearables and smart devices, might be more inclined to see the benefits and helpfulness of PGHD in their patients if they interface more with these technologies themselves.

The only measure for which male providers were more likely than female providers to find PGHD helpful was for “communicating with other health providers about the patient’s condition.” This difference was not statistically significant (p=0.793), but it invites further research to investigate gender differences between provider-provider communications. Because such communications have significant implications for cost
and the quality of care transitions, they are particularly pertinent in providing care for older patients.

Interestingly, there were no statistical differences by age group of health care providers who find PGHD helpful or harmful for the patient-provider relationship. Anecdotal evidence suggests that older providers might be more inclined to believe that connected health devices would be harmful to visit efficiency or would be harmful to capturing a complete picture of patient health, but our data do not support these hypotheses.

### Figure 2. The effect of connected health devices on improving provider empathy.
Health care providers were asked to respond to the prompt, “Patient-collected data from a smart device would help me to…” Providers responded on a 5-point Likert scale. Note: Number of valid cases for each item ranges from 330-333.

Another way to assess providers’ perspectives on the impact of smart devices on their interactions with their patients came when we asked respondents to use a 5-point Likert
scale to respond the prompt, “Patient-collected data from a smart device would help me to…” The results from these items are presented in Figure 2. Seven of the twelve measures asked in Figure 2 were components of the CARE Patient Feedback Measure.\textsuperscript{148} We added: “have difficult discussions with my patients,” “give advice on health issues that were not the chief reason for the visit,” “make a more accurate diagnosis,” “educate the patient,” and “be honest about the patient’s health problems” (“honesty,” though not an explicit variable in the CARE measure, was part of the CARE variable of “Being Positive: having a positive approach and a positive attitude; being honest but not negative about your problems”).

The aspect in which the largest percentage of providers agreed to some extent was “educate patients,” with 25.3% of respondents selecting “Strongly agree” and 54.2% of respondents selecting “Somewhat agree,” followed by “help the patient take control (explore what they can do to improve their health),” with 33.2% of respondents selecting “Strongly agree” and 46.2% of respondents selecting “Somewhat agree.” The aspect in which there was the least tendency to agree or disagree was “make the patient feel at ease,” with 43.4% of the sample selecting “Neither agree nor disagree.” Interestingly, the item for which the highest percentage of providers disagreed to some extent was “have difficult discussions with my patients,” with 23.6% of respondents disagreeing. A “Strongly disagree” response, however, does not indicate that PGHD would harm a specific aspect of the patient-provider interaction; rather, it means that it wouldn’t necessarily help that aspect. Thus, we do not extrapolate that PGHD would make difficult discussions more difficult. Instead, we conclude from the data that providers believe that PGHD would not make difficult discussions any easier.

In order to investigate the possibility of an age effect on these empathy-tech measures, we conducted a series of ANOVAs. Physicians who were at least 65 years old were significantly more likely than physicians between the ages of 18-44 years old to agree that patient-collected data from a smart device would help them to show care and compassion (One-Way ANOVA, F(2.297)=3.296, N=300, p=0.038). This finding suggests that technological integration could render older physicians more competent than younger physicians. Amongst our physician respondents, older physicians were more willing than younger physicians to integrate connected health devices into patient care.

We also investigated the possibility of a gender effect. Female providers were more likely than male providers to agree that PGHD would assist them in “help[ing] the patient take control (explore what they can do to improve their health)” (One-Way ANOVA, F(1,315)=3.982, N=317, p=0.047). The results suggest that female physicians may be more invested than male physicians in helping patients take control of their own health, and therefore be more inclined to find ways in which PGHD might be agency-inducing for patients. Female providers may also be more inclined than male physicians to attribute an effect of patients having more control to an external device rather than to their own provision of care. That is, male providers may be more inclined than female physicians to assume a causal effect between their provision of care and a patient’s improved sense of health care agency. These findings are consistent with trends in the literature. Specifically, women are found to be more likely to attribute success to luck and

the environment whereas men are more likely to attribute success to their own ability. Thus, female providers are less likely than male providers to see a causal relationship between their own provision of care and a patient’s improved sense of agency.

Figure 3. The effects of integrating patient-generated health data on health outcomes and the physician-patient relationship. Health care providers were prompted to indicate the extent to which they agreed with the statement “If I were to use patient-collected data from smart devices when I provide healthcare...” as completed by the variables listed above. The statements were evaluated on a five-point Likert scale from “Strongly disagree” to “Strongly agree.” Note: Valid number of cases for each item ranges from 330-332.

These items asked providers to assess the effect of technology on various indicators of empathy. We then asked them to consider hypothetically what sort of effect their potential use of data from connected health devices might have on various measures of empathy and the physician-patient relationship, as well as patient satisfaction, trust, and health outcomes. All respondents were prompted with the statement, “Patient-collected data from a smart device would help me to...” and asked to indicate the degree to which they agreed using a five-point Likert scale with the different variables. The results from these items are displayed in Figure 3.

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Across all of these items, the percentage of respondents who selected “Somewhat agree” or “Strongly agree” significantly outweighed the percentage of respondents who selected “Somewhat disagree” or “Strongly disagree.” Similarly, across 11 of the 12 variables, the percentage of respondents who selected “Somewhat agree” or “Strongly agree” outweighed the percentage of respondents who selected “Neither agree nor disagree.” The only option in which the percentage of respondent who selected “Neither agree nor disagree” outweighed the percentage of respondents who agreed to some degree was the variable “have difficult discussions with my patients.”

The aspects with the greatest degree of agreement to some extent were “My patients might have better health behaviors and/or health outcomes” and “My patients would feel more involved in the decision-making process,” with 67.8% of respondents agreeing and 69.6%, respectively.

The variable with which respondents disagreed to some extent the most was “I would appear as a more committed physician,” with 22.4% of respondents disagreeing to some degree. This variable was also the one with the strongest “Strongly disagree” response, with 10.6% of respondents selecting “Strongly disagree.” The three variables with the most uncertainty, as deemed by the percentage of respondents who selected “Neither agree nor disagree,” were “My patients would have more trust in me,” “It would improve the physician-patient relationship,” and “My patients would be more satisfied with their visit,” with 49.4%, 41.2%, and 41.2% of respondents selecting “Neither agree nor disagree,” respectively.

We were interested in investigating whether age or gender was a statistically significant determinant of the degree to which providers agreed with various measures of empathy and PGHD interactions. We conducted a series of One-way ANOVAs which revealed that there were no significant differences between genders or age groups in the tech-empathy levels depicted in Figure 3.

These findings were discordant with our hypothesis. We expected that older physicians would be less likely than younger physicians to agree that PGHD would make patients more likely to disclose health patterns they are ashamed of for two reasons. First, we assumed that older providers could be aware of a “Seen-It-All Effect,” wherein their patients would be more comfortable sharing embarrassing health problems because older providers lead long careers during which it would be likely that they had treated more embarrassing health problems than any the patient presented. Second, older providers may be more adept than younger providers at putting their patients at ease, and would therefore need not rely on connected health devices for their patients to feel comfortable sharing the complete story. The current data do not support these hypotheses, but additional research is needed. We also expected that older health care providers would be less likely to believe that PGHD would improve the physician-patient relationship. The thinking was that the technology would serve as a disruption to the way these physicians have been providing health care and communicating with their patients for the better part of their careers. Our findings do not support this hypothesis; older providers in our sample did not statistically differ from younger providers in the degree to which they thought PGHD would alter the physician-patient relationship.

Male health care providers were more likely than female health care providers to agree that “If [they] used patient-collected data from smart devices [they] would appear as more committed physician[s]” (One-Way ANOVA, F(1,314)=3.861, N=316,
This finding is consistent with empathy trends in the literature. A wealth of data suggest that female physicians are more effective communicators than male physicians. Female physicians are more likely than male physicians to engage patients in positive talk, discuss psychological and social issues, engage in more verbal exchanges with patients, and spend a longer time with them.150,151,152,153,154 All of these factors support our finding that female providers might be less likely than male providers to need a tool to depict commitment to their patients. It follows that female physicians, then, would require fewer tools in the form of connected health devices to show commitment to their patients; the commitment is sufficiently displayed by deeper conversations and more profound counseling. Importantly, the finding does not suggest that female providers are not committed to the use of connected health devices; rather, they do not need the technology to enhance a demonstration of commitment.

To understand the factors that affected whether health providers think patient-collected data from smart devices would improve their patients’ trust in them, we conducted a linear regression. We analyzed the trust variable while controlling for ethnicity, gender, census region, medical degree, stage of training, average hours worked per day, principal practice setting, and self-characterization of technology adoption level. Self-characterization of technology level was the only variable that had a statistically significant effect on whether or not providers thought smart health data would improve patients’ trust in them (b=-0.203, se=0.92, p=0.028). Providers who reported themselves to be early technology adopters were those who were most likely to agree that their use of PGHD would improve patients’ trust in them.

3.5.1 PGHD and Geriatric Issues

Nearly 1 in 5 Americans will be at least 65 years old by 2030 and health care spending is larger in magnitude for older adults than it is for any other age group.155,156,157,158 Connected health devices could be integrated into the health care system

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154 Ibid.


to meet the demands of the increased number of older patients, to reduce costs, and to improve well-being overall.

To understand how patient-collected data from smart devices wearables might address problems presented by the geriatric population, we asked respondents to check all issues presented by the geriatric population that could be ameliorated with PGHD. Figure 4 presents the percentage of respondents who selected each variable.

Figure 4. The relative effects of connected health devices on achieving older adults’ health values. The collection of patient-generated health data by older adults is more frequently expected to help biometric concerns presented by aging and less frequently expected to assist in improving the physician-patient relationship. N=230. Respondents were instructed to check all that apply; percentages do not add up to 100%.

The issues that were most frequently selected were related specifically to patient outcomes while those that were less frequently selected were problems related to the physician-patient relationship. Health outcomes for older adults are dependent not only on patients’ physical health and their biomedical needs, but also on care for patients’ psychosocial needs and attention to their social, economic, cultural, and psychological vulnerabilities. Based on the providers’ responses, PGHD seems not to break down

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challenges in caring for patients’ psychosocial needs, but rather to reinforce the barriers around addressing these topics.

3.6 Chapter Summary

In this chapter, we analyzed the results from the health care provider survey we conducted. In section 3.2 we discussed the large sample size of the study which was more than 50 times the sample size of the most pertinent study on PGHD analysis and physician-patient communication. In section 3.3 we discuss metrics for physician empathy levels and found that on average female health care providers had higher empathy scores than male health care providers. This finding is supported by an abundance of associated literature. Differences in practice and outcomes between physicians of different genders was most recently and notably reported with the finding that Medicare beneficiaries who were treated by female physicians had lower hospital readmission rates and mortality rates than those treated by male physicians. Tsugawa et al. concluded that differences in practice patterns between male and female physicians may have important clinical implications for patient outcomes. The differences in practice patterns could likely be difference in styles of relaying empathy and different empathy baselines all-together. An alternative explanation for these results may be that gender-based empathy effects are due to women investing more than men do in their self-image as empathetic people. For example, Eisenberg and Lennon (1983) found that there was a significant sex difference in empathy favoring women when empathy was captured via a self-report inventory, but there was no difference when empathy was measured with unobtrusive observations of behavior.

We also found that health care providers who were more willing to adopt technology had higher empathy levels. There were no differences in mean empathy scores between age groups. There were observed differences between the empathy scores of providers of different ethnicities; providers who were non-white had higher mean empathy scores. Providers of different races may be more empathetic because they are sensitive to social disparities that exist within the health care system and amongst their patients. One study found that physician-patient communication skills presented in audiotape analysis differ by patient and physician ethnicity and that both provider attitudes towards patients as well as patient judgments of physicians have an effect.

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162 Ibid.
Future research could examine possible practice differences between providers of different ethnicities, but must be carefully conducted to present findings that acknowledge the presence of moderating factors.

In section 3.4 we found that female physicians were significantly more likely than male physicians to recommend mHealth to their patients when controlling for geographical region, willingness to adopt new technology, and ethnicity. In conducting the regression, we also observed that compared to providers who were white, providers of other races were more likely to recommend connected health devices to their patients. When providers were asked if it was their job to receive, review, and discuss PGHD, responses were relatively evenly distributed across “Yes,” “Maybe,” and “No.” By and large, health care providers have not received training to deal with these devices.

In section 3.5 we examined both qualitative and quantitative responses to how connected health affects the provider-patient relationship and health outcomes. We found that across a number of general measures, PGHD was found to be significantly more helpful than harmful. Female providers were less likely than men to find PGHD helpful for demonstrating certain empathetic behaviors. There were no significant differences between age groups in how helpful PGHD would be for demonstrating empathy.

Throughout this chapter, we have examined health care providers’ projected changes to communicating with their patients. Across all of the empathy and communication variables we analyzed, PGHD is expected to help communication between providers and patients. In the subsequent chapter, we analyze the results of the patient survey to understand how communication is affected on the other side of the provider-patient relationship. George Bernard Shaw said, “The single biggest problem in communication is the illusion that it has taken place.” In Chapter 4, we will examine the extent to which this illusion persists, according to patients.
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Chapter 4 – Patient Survey

4.1 Chapter Introduction

In Chapter 4, we examine the results of a survey we conducted to understand consumer experience with smart devices in the health care system and the effect of this use on the physician-patient relationship. The individuals who wear smart devices and wearable technologies are as much consumers as they are patients within a health care system, so we refer to respondents throughout this chapter as “patients,” though they are not the patients of the physicians we surveyed and discussed in the previous chapter. We sought to understand their interpretation of the physician-patient relationship, their reasons behind their collection (or non-collection) of PGHD, and the ways in which they perceived differences in their interactions with medical professionals because of mHealth technologies. We also examined the relative severity of various socio-technical barriers to the integration of smart devices into health settings.

Although several authors and firms have examined the impact of wearable technology and PGHD on patient health, no study focuses on physician empathy. We also add to the existing literature by specifically examining the effects of these technologies on older adults and across different age groups.

This chapter has seven further sections. Our survey methods and sample description are detailed in Section 4.2. In Section 4.3 we discuss the factors that contribute to the value patients put on the physician-patient relationship. Section 4.4 describes the health measures respondents collect on themselves and compares the methods patients use to collect those data. In Section 4.5 we examine, both quantitatively and qualitatively, the degree to which respondents of this healthy, wealthy, educated, and technologically-savvy sample believe that the doctor they see most often is ready to receive, review, analyze and discuss PGHD. Section 4.6 begins by considering the extent to which patients believe it is their doctor’s job to analyze PGHD, then finishes by comparing how PGHD will be either helpful, harmful, or will have no effect on a variety of health measures. Section 4.7 explains the ways in which PGHD have changed patients’ interactions with their doctors and also discusses how patients would interact differently with their doctor if hypothetically they were to collect PGHD. Section 4.8 concludes.

4.2 Methods

4.2.1 Survey Procedure - Patient Survey

The patient survey was composed of 55 questions which were a mixture of fixed-response and open-response questions. The survey contained questions regarding self-reported comfort with technology, health visit information, opinions on the integration of patient-generated data, participants’ use or nonuse of smart devices to collect health data, relationships with health care providers, and projected relationships with health care providers as connected health is increasingly realized. Demographic data collected
included gender, ethnicity, education level, age, zip code, and approximate household income.

The survey was created in Qualtrics and distributed through email by the MIT AgeLab volunteer database. The population of interest was 20-85 year olds living in the United States. A total of 5,015 participants from the MIT AgeLab volunteer database were invited to participate via email; 2,330 individuals opened the email and 1,110 completed the survey. Thus, the survey had a response rate of over 22%, higher than the typical AgeLab database response rate of about 18%. A second “reminder” email, in this case, was not sent, in part because the AgeLab database distribution was not able to sort the selected sample to determine which recipients had taken the survey and which had not.

Email recipients were told that the survey would ask them about their experience with technology in health care and would take 10-15 minutes. Participants could elect to be entered into a drawing to win one of ten $25 Amazon.com gift cards. Upon clicking on the survey link, participants were reminded that they would be asked a series of questions about their use (or non-use) of smart devices for health tracking and their opinions about technology in health settings. No identifying information was collected, though participants could opt to leave their email address if they were interested in receiving a summary of the survey results.

Responses were recorded from January 18 - February 16, 2017.

4.2.2 Participants - Patient Survey

Although the MIT AgeLab maintains an intentionally broad recruitment base, the database itself is composed of volunteers who are willing to sign up to be contacted about research studies, and it has a preponderance of volunteers who are older adults in the local Boston, Massachusetts, area. The final sample of participants was skewed by age, income, self-reported health, and insurance status, among other criteria. See Table 5 for a detailed demographic description of the sample. The final sample included respondents ages 18-89 years old, but consistent with the AgeLab database itself, it skewed older. The mean respondent age was 62.7 years old and the median age was 67.0 years old. This age skew was reflected in the types of health insurance respondents had, with 45.6% of respondents being covered by Medicare. The respondents also self-reported high levels health; on a five-point scale from Poor to Excellent health, none of the respondents reported being in poor health, and 62.9% of respondents reported being in “Excellent” or “Very Good” health. Also, there was a strong coastal skew in the sample, with a heavy concentration of New England residents (See Figure 5). Most respondents (93.6% of respondents) lived in either urban or suburban locations; only 6.3% of respondents lived in rural areas. Of note, however, rural areas are those in which telemedicine has had the most progress because the technologies are covered by insurance in “rural” areas which are Health Provider Shortage Areas. The effects of the urban skew on the results of this study are debatable: the urban skew could work to mitigate any potential bias towards the use of these technologies in health care, but could also more heavily reflect higher-income areas where individuals have more disposable income to purchase wearable devices as a luxury good rather than as a medical benefit or necessity.
There was a skew towards technology-savviness, with more than three quarters of respondents reporting themselves as either early or average adopters of technology. The sample was highly educated, as all participants had a high school diploma or the equivalent, and 48% of respondents listed a graduate degree as the highest level of school completed. There was also a skew towards higher-income households, with 73% of respondents reporting an annual household income of more than $50,000 and more than a third of respondents reporting a household income of at least $100,000. For reference, the median household income in the United States in 2016 was $56,516.\textsuperscript{165}

In summary, respondents represented a convenience sample of primarily older adults living in New England who self-report as healthy, wealthy, educated, and technology-savvy.

\begin{figure}
\centering
\includegraphics[width=\textwidth]{map.png}
\caption{Geographic location of patient respondents. Though respondents hailed from across the US, the map indicates a coastal skew in patient respondents, with a strong concentration in New England.}
\end{figure}

Table 5. Patient survey demographics.

| Education                                      | < High school diploma | 0  |
|                                               | High school diploma or GED | 2.3 |
|                                               | Some college             | 10.1|
|                                               | Bachelor's degree        | 23.8|
|                                               | Some graduate school, no degree | 11.5|
|                                               | Master’s degree          | 34.4|
|                                               | Advanced or professional degree | 13.8|
| Total N                                       |                          | 814 |

| Annual household income                      | Less than $25K           | 9.4 |
|                                               | $25K - $49,999           | 17.0|
|                                               | $50K - $74,999           | 22.0|
|                                               | $75K - $99,999           | 17.6|
|                                               | $100K - $149,999         | 17.6|
|                                               | > $150K                  | 16.3|
| Total N                                       |                          | 646 |

| Health insurance coverage status              | Covered                 | 98.6|
|                                               | Uncovered               | 1.4 |
| Total N                                       |                          | 881 |

| Health insurance description                  | Private                 | 45.1|
|                                               | Medicare                | 45.6|
|                                               | Medicaid                | 2.9 |
|                                               | Both Medicare and Medicaid | 2.5 |
|                                               | VA benefits              | 0.8 |
|                                               | Other                   | 3.2 |
| Total N                                       |                          | 790 |

<p>| Age                                            | Ages 72-89 years old (The Silent Generation) | 29.4 |
|                                               | Ages 53-71 years old             | 50.6 |</p>
<table>
<thead>
<tr>
<th>Category</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ages 37-52 years old (Generation X)</td>
<td>10.3</td>
</tr>
<tr>
<td>Ages 0-36 years old (Millennials)</td>
<td>9.7</td>
</tr>
<tr>
<td>Total N</td>
<td>806</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>38.8</td>
</tr>
<tr>
<td>Female</td>
<td>61.2</td>
</tr>
<tr>
<td>Total N</td>
<td>802</td>
</tr>
<tr>
<td>Ethnicity*</td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>90.73</td>
</tr>
<tr>
<td>Black or African American</td>
<td>3.71</td>
</tr>
<tr>
<td>American Indian or Alaska Native</td>
<td>0.87</td>
</tr>
<tr>
<td>Asian</td>
<td>4.20</td>
</tr>
<tr>
<td>Native Hawaiian or Pacific Islander</td>
<td>0.12</td>
</tr>
<tr>
<td>Latino or Latina</td>
<td>1.61</td>
</tr>
<tr>
<td>Other</td>
<td>2.72</td>
</tr>
<tr>
<td>Total N</td>
<td>809</td>
</tr>
<tr>
<td>Technology adoption level</td>
<td></td>
</tr>
<tr>
<td>Early adopter</td>
<td>18.3</td>
</tr>
<tr>
<td>Average adopter</td>
<td>59.3</td>
</tr>
<tr>
<td>Late adopter</td>
<td>22.3</td>
</tr>
<tr>
<td>Total N</td>
<td>878</td>
</tr>
<tr>
<td>Health</td>
<td></td>
</tr>
<tr>
<td>Excellent</td>
<td>20.5</td>
</tr>
<tr>
<td>Very good</td>
<td>42.4</td>
</tr>
<tr>
<td>Good</td>
<td>31.1</td>
</tr>
<tr>
<td>Fair</td>
<td>5.9</td>
</tr>
<tr>
<td>Poor</td>
<td>0</td>
</tr>
<tr>
<td>Total N</td>
<td>877</td>
</tr>
<tr>
<td>Location description</td>
<td></td>
</tr>
<tr>
<td>Urban</td>
<td>39.4</td>
</tr>
</tbody>
</table>

68
Table entries are percentages. *Percent of total adds up to more than 100% because respondents were instructed to check all that apply.

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Suburban</td>
<td>54.2</td>
</tr>
<tr>
<td>Rural</td>
<td>6.3</td>
</tr>
<tr>
<td>Total N</td>
<td>804</td>
</tr>
</tbody>
</table>

Notes: Table entries are percentages. *Percent of total adds up to more than 100% because respondents were instructed to check all that apply.

4.3 Patients’ Value of Physician Empathy

Before we could understand the value patients put on the physician-patient relationship, we wanted to understand patients’ likelihood of having and maintaining a relationship with a medical professional. In order to gage patients’ likelihood of having a meaningful physician-patient relationship, we asked respondents about the frequency of their health visits, whether they had a primary care physician, where they go for care, how often they exercise, and their self-reported health level. The overwhelming majority of respondents reported having a primary care physician; 96.3% of respondents had a primary care physician and only 3.7% of respondents did not. Similarly, the majority of respondents saw a health care provider of any kind—not necessarily the same provider—at least once a year. Only 5% of respondents answered “Less than once per year” when we asked respondents how often, on average, they see a health care provider of any kind (for their own health). Most respondents reported seeing a healthcare provider more than once a year; 19.4% of respondents answered that they saw a healthcare provider of any kind “Once a year,” 25.1% of respondents answered “Twice per year,” 18.4% of respondents answered “Three times per year,” and 32.2% of respondents answered “More than three times per year.” When asked “Where do you mostly go in order to receive medical care,” two thirds of respondents (67.3%) reported going to a private practice. Overall, the majority of respondents had primary care physicians and were frequently visiting private practices, which suggests that there was a non-negligible capacity for respondents to develop and maintain a strong physician-patient relationship. We gathered a rough estimate of how sick or healthy respondents may be by asking them to rate their health on a five-point scale from “Excellent” to “Poor,” and by asking them how often they exercise for at least 20 minutes. We believed that if patients were sick and not exercising, there would be evidence to suggest that they were more at risk for having one or more chronic diseases and for this reason might benefit the most from a strong physician-patient relationship. Our sample was predominantly healthy and active, but this does not undermine the importance of the relationship. Indeed, a strong physician-patient relationship could be the cause of the healthy sample. We did not ask patients to directly evaluate the relationship they had with their doctor.

There is an abundance of evidence to suggest that a strong physician-patient relationship results in better health outcomes for patients.166,167,168,169 To get a sense for

how much patients generally value the physician-patient relationship, we asked respondents to rate on a five-point scale the extent to which they agree with the following statement: “Emotional ties to physicians have a significant influence on whether I listen to their advice.” The variable served as both an indirect measure of the value patients placed on the physician-patient relationship and as an indicator for how well that relationship might translate into beneficial medical outcomes. The measure was adapted from a number of JSPE variables: “An important component of the relationship with my patients is my understanding of the emotional status of the patients and their families;” “I believe that empathy is an important therapeutic factor in medical treatment;” “I believe that emotion has no place in the treatment of medical illness;” “I do not allow myself to be touched by intense emotional relationships between my patients and their family members;” and “I consider asking patients about what is happening in their lives as an unimportant factor in understanding their physical complaints.” In total, 59.4% of respondents agreed to some extent that their emotional ties to providers have a significant effect on whether they listen to their advice. 20.3% of respondents selected “Neither agree nor disagree,” and 20.2% of respondents disagreed.

To understand if older patients were more likely to translate a strong physician-patient relationship to better health outcomes, we ran an ANOVA. There were no statistically significant differences in means in the emotional ties variable across the Silent Generation, the Baby Boom Generation, and the Generation X/Millennial age groups (One-way ANOVA, F(2,800)=0.962, p=0.383). We assumed that older patients would be more likely to value face-to-face communication with their health providers and more likely to value deep, time-tested emotional ties with their physicians, but this hypothesis was not supported by statistically significant results (although the Silent Generation did have the highest mean agreement value on this variable). Younger generations placed the lowest mean value on emotional ties to their physicians as a requisite for following their advice. We presume that younger patients may have been under the care of any one physician for less time than older generations, who may have had the same physician for decades. For this reason, younger patients may be less likely to tie following health advice to emotional connections with their physicians. Moreover, younger patients may be more data-driven in understanding and complying with advice or a prescribed treatment, and may thus be less likely to depend on the physician-patient relationship to take action on addressing health concerns. Future research should probe further for differences in how different age groups depend on the physician-patient relationship. The Jefferson Scale of Patient’s Perceptions of Physician Empathy aims to assess a patient’s experience, but is only five variables and limited in scope. A better measure of the importance of empathy in the physician-patient relationship should be developed with patient completion in mind. The differences between age groups here are small, but the overall trend is suggestive.

We then attempted to calculate a linear regression equation to predict the value placed on emotional connections to health care providers. Female respondents placed a higher value than men on emotional connections with their health care providers. This difference was marginally significant when controlling for ethnicity, income, education, type of home location (urban, suburban, rural), and age. No other factor was a significant predictor of the value placed on emotional ties with health care providers. We improved the model by removing the non-predictors, which were all other factors other than gender. We then conducted an ANOVA and found that differences between gender were non-significant (One-way ANOVA, F=(1,793)=2.447, N=795, p=0.118). This statistically non-significant regression finding after removing other variables indicates that the effect of gender on the value placed on emotional connections to health care providers is moderated by other factors which could be examined in future research.

To understand other factors besides age and gender that might make respondents, on average, more likely to translate a strong physician-patient relationship to better health outcomes, we ran a series of one-way ANOVAs on education, income, ethnicity, type of home location, whether or not a respondent had a primary care physician, whether or not a respondent had health insurance, and tech adoption readiness level. None of these factors showed a significantly difference between group means.

### 4.4 Collection of Health Data

#### 4.4.1 Technology Adoption Levels

Because we assumed that individual comfort and experience with technology were main predictors of whether or not respondents used smart devices to generate PGHD or relied on more traditional methods to collect health data, we asked respondents to rate how experienced they were with individual technologies. Only 1.0% of respondents referred to themselves as “Not experienced,” while 47.2% of the sample selected “Somewhat experienced,” and 51.8% of the sample selected “Very experienced.” We examined another technology-savviness dimension in asking respondents, “When it comes to adopting new technology, how would you characterize yourself?” There was more variation across this tech savviness measure. We calculated a linear regression of technology-savviness on other factors in our sample. We found that, compared to male respondents, female respondents were more likely than male respondents to characterize themselves as early adopters of technology. This finding was statistically significant (b=0.153, se=0.051, standardized B=0.122, p=0.003).

When eliminating other co-factors, respondents who had an annual household income of more than $150,000 were significantly more likely than respondents in any group with an annual household income of less than $75,000 to characterize themselves as early adopters of technology (One-way ANOVA, F=(5,237)=3.988, sig=0.001).

Respondents who had a primary care physician were more likely than those who did not have a primary care physician to characterize themselves as early adopters of
technology (One-way ANOVA, Tukey LSD, Bonferroni, F(1,876)=9.170, p=0.003), not controlling for other factors.

4.4.2 Collection of Various Health Measures

Once we described the inherent influences on readiness to adopt technology, we were interested in understanding if and how individuals were collecting health data on themselves. We asked respondents a number of questions regarding what kinds of health data they were collecting, the platform or device they were using to collect those data, with whom they shared those data, and subsequently, how sharing those data with a medical professional changed their interaction with that medical professional. In section 4.6 we discuss the responses regarding how sharing PGHD with a provider changed the interaction with that provider.

We calculated frequencies for the types of health data individuals collect on themselves at least once a week either by smart or traditional methods. Data on weight was most often reported as being collected by any method, but it was also the type of data that had the highest percentage of recordings via traditional (non-smart) collection methods. See Table 6 for a list of the different health measures ranked by the frequency with which respondents selected the measure as one they collect at least once a week.
Table 6. Ranked frequency of health measures collected by patients and description of devices used. Patient respondents were asked to indicate which health measures they collected at least once a week. They were subsequently asked to indicate which devices or methods they used to collect those health measures.

<table>
<thead>
<tr>
<th>Health measure</th>
<th>Percent of sample</th>
<th>Collection method used</th>
<th>Percent of measure recordings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Weight</td>
<td>63.8</td>
<td>Smart device or app</td>
<td>11.52</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Traditional scale</td>
<td>82.20</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Other</td>
<td>6.28</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Total N</td>
<td>573</td>
</tr>
<tr>
<td>Sleep</td>
<td>37.1</td>
<td>Smart device or App</td>
<td>41.54</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Clock/Count hours</td>
<td>44.92</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Other</td>
<td>13.54</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Total N</td>
<td>325</td>
</tr>
<tr>
<td>Steps taken</td>
<td>32.7</td>
<td>Smart device or App</td>
<td>82.74</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Pedometer (not connected) or notebook</td>
<td>11.61</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Other</td>
<td>5.65</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Total N</td>
<td>336</td>
</tr>
<tr>
<td>Diet/Nutrition</td>
<td>32.2</td>
<td>Smart device or App</td>
<td>40.09</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Written journal</td>
<td>34.91</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Other</td>
<td>25.00</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Total N</td>
<td>232</td>
</tr>
<tr>
<td>Heart rate</td>
<td>28.4</td>
<td>Smart device or App</td>
<td>54.97</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Take pulse with fingers</td>
<td>23.51</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Other</td>
<td>21.52</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Total N</td>
<td>302</td>
</tr>
<tr>
<td>Blood pressure</td>
<td>20.9</td>
<td>Smart device or App</td>
<td>9.04</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Traditional sphygmomanometer</td>
<td>80.40</td>
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<tr>
<td></td>
<td></td>
<td>Other</td>
<td>10.55</td>
</tr>
<tr>
<td></td>
<td>Total N</td>
<td></td>
<td></td>
</tr>
<tr>
<td>------------------------------</td>
<td>---------</td>
<td>-----</td>
<td></td>
</tr>
<tr>
<td><strong>Respiration rate</strong></td>
<td>199</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Smart wearable device or App</strong></td>
<td>36.54</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Count your own breaths</strong></td>
<td>44.23</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Other</strong></td>
<td>19.23</td>
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<td></td>
</tr>
<tr>
<td><strong>Total N</strong></td>
<td>52</td>
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</tr>
<tr>
<td><strong>Blood glucose level</strong></td>
<td>54</td>
<td></td>
<td></td>
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<tr>
<td><strong>Smart wearable device</strong></td>
<td>14.81</td>
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<tr>
<td><strong>Traditional glucometer</strong></td>
<td>75.93</td>
<td></td>
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</tr>
<tr>
<td><strong>Other</strong></td>
<td>9.26</td>
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<tr>
<td><strong>Total N</strong></td>
<td>54</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note: Collection method used “Total N” refers to the number of times any collection method was selected as a means of recording a particular health measure. Total N in the Percent of Sample column and the Percent of Measure column differ because some respondents reported collecting some health measure but did not report what kind of device they used. Total N in Percent of Sample column=823.

4.4.3 Social Barriers to PGHD Collection

To identify potential policy and industry levers that might incentivize individuals to collect more PGHD, we asked respondents to sort potential reasons that they do not collect more PGHD into three boxes: not applicable, a small reason, and a major reason. We examined the relative frequencies of the items they listed in the major reason box. The “major reason” barriers are the most salient items to consider as barriers to technology integration. The “small reason” barriers are ones that should be examined either as factors that are increasingly unproblematic or ones that could be examined as factors that will become relevant with better technology integration. Figure 6 shows the relative frequencies with which respondents selected various factors as a “major reason” for not using more smart devices to collect health data.
Some of the most frequently cited barriers to patients collecting their own health data are predictable policy levers: privacy concerns and cost concerns. The more nebulous task to address when it comes to incentivizing individuals to collect PGHD would be to convince individuals that they cannot manage without smart connected device for some aspect of their health care.

4.5 Patient Perceptions of Clinic and Physician Readiness to Incorporate PGHD

Perceived readiness of the physician to accept and analyze PGHD likely has an effect on the frequency with which patients record and share these data with medical professionals. We asked respondents, “Does the doctor you see most often seem ready to analyze data from a smart device...if you were to share that information with them? In general patients did not perceive readiness; 33.6% of respondents selected “No,” 52.5% selected “Maybe,” and 13.9% selected “Yes.” Age correlated with the degree to which individuals agreed that their doctor was ready to analyze PGHD. Individuals from the Silent Generation were the most likely to believe that their doctor was ready to analyze PGHD (19.9% of Silent Generation respondents said “Yes”) and individuals from Gen X and the Millennials were the least likely to think so (9.4% of Gen X/Millennials said “Yes”). Individuals from the Gen X/Millennial Generation were also most likely to say that they did not think their providers were ready, with 42.1% of respondents from this

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**Figure 6. Patient-reported barriers to patient-generated health data collection.**

Respondents were asked to select the variables they believed served as barriers to them using more connected health devices. Respondents were asked to sort the various barriers into three boxes labelled either “A major reason,” “A small reason,” or “Not applicable.” The data above reports the frequency of the variables being placed in the “major reason” box. Note: Number of cases=786.
generation saying “No,” and only 32.9% and 28.8% of individuals from the Baby Boom Generation and the Silent Generation saying “No,” respectively. Individuals from the Baby Boom Generation were most likely to say “Maybe” (54.3% of respondents).

Survey participants were also asked to list reasons why their doctors seemed ready to analyze PGHD. These open responses were collected. Respondents cited social and empathy factors more than technological factors as reasons why their doctor seemed ready to analyze PGHD. The most commonly cited factor for readiness was the physician’s “Openness” or “Open-mindedness;” 14.7% of respondents offered a response of this nature. If a physician seemed open-minded, the respondents explained, they would be more likely be willing to accept and analyze data. Age was also a strong factor in perceived physician readiness; 10.3% of respondents used the word “young” in some form to describe why the doctor they see most often was ready to analyze PGHD. We conclude that younger physicians—the cohort that may best be able to conceptualize a way to outsource the analysis of PGHD—are the ones who are expected to be most ready to do so. This finding underscores the importance of PGHD training within medical school curricula. Because of the rapid development of new technologies, such training should be based not around any particular technology or platform. Rather, the training should consider how to relay “Openness” to new technology so that patients feel comfortable sharing their data in ways that will ultimately benefit their health and enhance their satisfaction and utility from medical visits. The aging population will promptly sap provider resources if providers are not trained in the assessment and review of data that will make them more efficient.

Respondents perceived their doctor as unready to analyze PGHD primarily because the use of smart data had never been discussed. In some manner, 42.8% of responses (N=264) noted that their physician did not seem ready because they had never discussed smart devices or the collection of these data. Only 8.33% of responses mentioned a perceived lack of appointment time, and the older age of a provider was cited just 4.17% of the time as a factor that makes physicians seem unready to analyze PGHD. The magnitude of responses regarding social factors, such as not having discussed smart devices or a lack of appointment time, far outweighed the magnitude of responses that cited some technological component, such as a lack of technological equipment or an inability to transmit data.

It is important to consider the context of this sample in interpreting the results. This convenience sample was highly educated, wealthy, largely based in urban and suburban areas, and had an early to average adoption of new technology rate. The skepticism expressed by respondents as to their doctors’ readiness to analyze PGHD suggest that areas that are less likely to adopt technology are even less ready. Moreover, the skepticism about providers suggests that current standards of practice do not adequately incentivize technology preparation in even highly competitive, geographically desirable, and high-performing health settings. In the future, a deliberate setting of standards as well as other policy measures could be taken to appropriately incentivize physicians’ readiness for PGHD analysis.
4.6 PGHD Integration into the Health Care System

4.6.1 Patient Demand for PGHD Integration

We were interested in general demand for the integration of smart devices into the health care system. We asked respondents to rate (on a scale from 1-10 with 1=Do not want at all; 10=Very much want) how much they wanted smart devices to be integrated into the health care system. A total of 875 individuals answered the question. The mean score was 5.88 and the median value was 6, but notably, the mode of the sample was 10; 15.1% of the population said that they very much wanted smart patient-collected data to be incorporated into their health care visits. There were spikes at the values of 1, 5-8, and 10. The values of 2, 3, and 4 were low, with 6.2%, 5.8%, and 5.1% of the sample assigning those values, respectively. This dip in values could indicate a polarization of opinions surrounding these technologies or technology in general. There was not a statistically significant difference in scale value from 1-10 by age. There was, however, a statistically significant difference in mean by genders. Male respondents were more likely, on average, to assign a higher value on the 1-10 scale than female respondents were, which indicates that men in the sample reported a higher interest in having smart devices and smart data integrated into the health care system (One-way ANOVA, F(1,793)=4.958, p=0.026).

To see if this gender effect was present even controlling for other potential predictors, we regressed desired integration of connected health devices into the health care system on gender, controlling for health, education level, income, house location, ethnicity, age, health insurance coverage, and self-reported health. We then removed insignificant factors from the model (age, health, and home location). The effect of various factors on the desire to have PGHD incorporated into the health care system became more statistically significant after the model was improved (F(11,614)=3.005, p=.001). Gender did not retain its statistical significance.

4.6.2 Patients’ Expectations for Physicians’ Use of PGHD

When health care providers were asked if they considered it their job to receive, review, and discuss PGHD, responses were relatively evenly distributed across “Yes,” “Maybe,” and “No.” When patients were asked if they considered it their physicians’ job to receive, review, and discuss PGHD, the overall distribution was similar, with a slight shift towards “Yes”: 42.4% of patients said “Yes,” 22.2% of respondents said “No,” and 35.3% of respondents said “Maybe” (N=860). The slight skew towards “Yes” indicates the potential for a mismatch between the expectations of physicians and patients. Such a mismatch could create tension between patients, who want their PGHD analyzed, and physicians, who think such an analysis is outside of the scope of their job description. If their PGHD is not analyzed in the way they expect, patients may leave dissatisfied with their visits, and the physician-patient relationship may suffer, perhaps driving patients to more technologically-willing physicians (which might be beneficial for those patients, though an inconvenience). If technology-savviness correlates with care quality, then the integration of these technologies could be a source of inequality in the health care system.
Patients may start to incorporate this kind of analysis into their own health management and have increased, but unchecked, agency in their own health behaviors.

Figure 7. Helpfulness of collecting PGHD on various health-related goals. Patient respondents indicate that the integration of connected health devices is more helpful than harmful across all health outcomes measures. Note: Number of valid cases varies between 734 and 835, depending on the item.

The likelihood of individual patients to believe it is their doctor’s job to receive, review, analyze, and discuss PGHD may in large part depend on how helpful they think the collection of PGHD is in managing their own health. For example, if a patient found that collecting PGHD was helpful in detecting side effects of medications, the patient might be more likely to demand that these data be analyzed. Absent a professional (other than the physician) whose job it is to assess and review these data, the patient may come to expect the physician to do so. We asked patient respondents to indicate whether they thought collecting PGHD was helpful, had no impact, or was unhelpful to various health-related goals. While many narratives of PGHD integration indicate that smart devices serve as a burden to some health goals, we found that patients thought PGHD was significantly more helpful than unhelpful across all dimensions measured (See Figure 7).

There is consensus between the health care provider sample and the patient sample with regard to the health-related goals that respondents thought would be helped by PGHD. The top two goals both patients and providers thought would be most helped by PGHD were “...Tracking progress” and “Capturing a more complete picture of patient..."
health.” As with the health care provider sample, the item for which there was the greatest skepticism about the positive effect and the smallest discrepancy between “helpful,” “no impact,” and “unhelpful” was for reducing medical expenses. In Chapter 3, we discuss a similar result among providers, which may indicate uncertainty about how PGHD devices will be paid for and by whom. Similarly, there is uncertainty about how early PGHD integration costs. Patients, as consumers, may fear having to buy certain technologies that are not covered by health insurance. Furthermore, patients may be aware that certain costs could be passed down to them; these costs include the costs of hiring PGHD analysts or clinics and acquiring technical capital goods needed to visualize and integrate these data.

The goal for which there was the lowest percentage of patient respondents who found PGHD helpful was in “Having better access to health care services.” Various telemedicine initiatives could change the way patients access health care. Individuals who live in rural settings in particular could be the first to access both primary and specialty care via smart devices or through wearables. Companies such as Doctor on Demand and American Well offer platforms for patients to connect with medical professionals at any time, from any place via a secure audio-visual connection. If this practice becomes the standard of care for patients in rural settings, smart devices will not only be helpful for having better access to care, but will be the single critical device to do so. Thus, if telemedicine developers have an accurate vision for the future integration of telemedicine, patients could be underestimating the impact that connected health devices could have on how they receive care. Patients in this case would be under the assumption that they have to visit their doctor’s office for care, but with telemedicine integration there could be a fundamentally different care delivery model.

Unlike the findings from the health care provider sample, there were no statistically significant differences among patients by gender for whether PGHD would be helpful in tracking progress, capturing a more complete picture of health, or reducing medical expenses. There was also no significant difference by gender in finding PGHD helpful for communicating with multiple health care providers about conditions. While recent research has examined differences in empathy and communication styles of physicians based on gender, future research should consider how patients of different genders communicate with their health care providers. Findings of this nature could be used to inform medical school curricula or improve empathy training for physicians. Certainly, communication styles may vary more from person to person than they do by gender, but a foundational understanding of how different genders tend to communicate health behaviors and concerns to their physicians could serve to improve the physician-patient relationship and subsequently patient outcomes and satisfaction.

From an ANOVA analysis, respondents from Generation X and the Millennials were significantly more likely to find PGHD helpful in capturing a more complete picture of health than respondents from the Silent Generation or the Baby Boom Generation (One-Way ANOVA, F(2,759)=4.821, N=762, p=0.008). We conducted post hoc statistical analyses and found that the mean response from Generation X and the

Millennials respondents was statistically higher than that of the Silent Generation (mean difference=0.19877, SE=0.06459, p=0.005), but was only marginally different from respondents of the Baby Boomer Generation (mean difference=0.13537, SE=0.05862, p=0.055). These findings suggest that there may be generational differences in the conceptualization of a “complete picture of health.” Younger patients may believe that having a wide variety of health data, including PGHD collected and transmitted from smart devices and professionally reviewed, makes their notion of one’s health record more complete. In contrast, older patients may point to emotional factors and occurrences in interpersonal interactions as factors that complete a picture of their health.

![Geriatric Issues Addressed by Connected Health Devices](image)

**Figure 8. Geriatric Issues Addressed by Connected Health.** The collection of patient-generated health data by older adults is more frequently expected by patients of all ages to help biometric concerns presented by aging and less frequently expected to assist in improving the physician-patient relationship. Respondents were instructed to check all that apply; percentages do not add up to 100%. N=868.

To understand how PGHD could address problems more likely to be presented by the geriatric population, we asked respondents to check all issues from a list that they believed could be ameliorated with PGHD. As was the case across health care provider respondents, the measure least frequently reported was bringing up embarrassing behaviors. If older patients have relied for decades on less data-driven forms of communicating with health care providers, they may not be ashamed of revealing embarrassing health behaviors without some sort of device in hand as a distractor or “safety blanket.” The top measures across both samples addressed more medical or biological metrics, whereas the less frequently cited measures involved more psychological and social metrics. According to individuals of all ages, older patients are expected to not gain the same social and emotional benefits from PGHD collection and discussion as would younger patients. The data suggest that the technologies are perceived to be more useful for biometric factors than for supportive, empathetic factors.
4.7 PGHD and the Physician-Patient Relationship

4.7.1 Data Sharing with Physicians

Perceived helpfulness of PGHD could be dependent on patients’ experience with collecting PGHD. To see if older patients were less frequently recommended connected health devices, we asked all respondents, “How often has a doctor recommended smart technologies to you (for example, a wearable fitness tracker, a smartphone, an app, or connected health monitoring equipment)?” We found that there was a significant difference between means by generations (One-way ANOVA, F(2,797)=5.516, p=.004). Post hoc comparisons using the Bonferroni test indicated that the mean score for the Generation X/Millennials group (M=0.0625, SD=.26747) was significantly lower than the mean score for the Silent Generation group (M=0.2331, SD=.62631), but did not differ statistically from the Baby Boomer Generation (M=.1535, SD=.49435). While our previous results indicate that older patients may find PGHD less helpful in capturing a complete picture of their health than younger patients do, these findings suggest that older patients are more likely to be recommended to use technologies that they perceive to be less helpful than younger patients do. In Chapter 3, we discuss the finding that health care providers would like older patients in particular to be collecting PGHD. This result, that older patients are being recommended to use the technologies to do so more often than younger patients, is both consistent with that finding and suggests that providers are trying to meet their needs for these data.

Simply collecting PGHD through a smart device does not mean that patients necessarily share these data with providers. How often are these data shared, and if they are, what effect does this sharing have on the relationship between patient and provider? While some respondents indicated that they will be sharing these data with their doctor more after having taken the survey, we examined these dynamics for the steps taken and heart rate measures because these were the two health measures with the highest percentage of data collection via a smart device, as compared to traditional non-smart methods.

We found that 30.8% of respondents who collect heart rate data from a smart device do not share these data with a medical professional via a smart device (N=99). Only 16.2% of respondents who collect heart rate data share these data with a medical professional via a smart device and indicate that sharing changes the way the provider interacts with them (Note: the 16.2% refers to those individuals who both share the data and think it changes their physician-patient relationship). In an open response box, the respondents who indicated that sharing heart rate data changes physician-patient or provider-patient interactions listed a number of different ways the relationship had been changed. Sharing heart rate data with their health care provider via a smart device changed interactions in ways such as: “adjust meds if necessary;” “I am able to be more prepared and involved in my own care;” and “Open conversation and less hesitation on my part to ask questions.” Respondents who shared these data with a medical professional but who did not think it changed the provider-patient interaction made comments such as: “The use of my smartwatch adds data but doesn’t change the interaction;” “It has been similar to in-office measurement;” and “It goes into my medical record.”
Just 1.1% of respondents who collect steps taken data on themselves reported sharing these smart data with their doctor. Only 9.9% of the respondents who share these data with their doctor indicated that they thought sharing the data changes the interactions they have with their doctor, while 19.1% said “No” (71.0% said not applicable). Respondents who indicated a change in the physician-patient relationship offered answers which included: “Encourages me to be more active;” and “Specialist is always interested in how much I do and encouraging me to keep doing that more.” Respondents who indicated that the sharing of these data via a smart device did not change the physician-patient relationship offered reasons such as: “It just confirms a known;” and “My doctor generally approves of my exercise program but doesn’t specifically discuss number of steps.” This tendency to approve of general healthy habits but to refrain from offering specifics is intentional, according to one physician we informally interviewed. The physician discussed how he could become liable for advising a certain form of exercise or exercise regimen, for instance, so he always stayed vague when patients asked for specific advice on how to be more fit. With better standards across the health care setting and allied entities, however, physicians may be more likely to share specific recommendations which could improve overall health and patient satisfaction.

4.7.2 PGHD-Sharing Effects on the Physician-Patient Relationship

We were interested in understanding how different aspects of the physician-patient relationship would be affected by the integration of wearable and smart devices into the health care system. If some form of standards setting or regulation is to follow the wearable device boom, it should be done in a way that preserves or enhances the physician-patient relationship benefits that precipitate from analyzing and discussing PGHD. Also, understanding the various facets of the physician-patient relationship will offer clues to industry as to how to optimize their technology for user-interfaces and sharing. Finally, this analysis serves as a litmus test for future trends in patient health management—will patients be more autonomous? How will patients’ notions of trust and ease change when technology joins doctor and patient as a critical entity in the clinical exam room?

Patient perspectives on the impact of PGHD on different aspects of the physician-patient relationship are displayed in Figure 9. Many of the variables depicted in Figure 9 were derived from the CARE Measure. In Chapter 3 we examined health care providers’ responses to the same questions. While the largest percentage of providers agreed that PGHD would help education about health and conditions, in the patient sample, the largest percentage agreed that PGHD would help them to get advice on other health complaints (One-way ANOVA, F(2,793)=3.919, p=0.020). The Baby Boom Generation respondents (M=3.66, SD=1.040) were less likely than respondents from the Silent Generation (M=3.76, SD=.996) and the Generation X/Millennial Generations (M=3.92, SD=.731) to use PGHD to seek advice on multiple health issues in one visit. The difference between respondents from Generation X/Millennials respondents and Baby Boom Generation respondents was statistically
significant (Tukey HSD, p=.015). The mean values for the Generation X/Millennial group and the Silent Generation group did not differ statistically.

Figure 9. The effects of sharing patient-generated health data with providers on improving the physician-patient relationship. Patients were asked to respond to the prompt, “Patient-collected data from a smart device would help me to…” Patients responded on a five-point Likert scale from “Strongly disagree” to “Strongly agree.” Note: Number of valid cases= 818 to 826, depending on the measure.

The perceived benefits of uncovering and discussing a host of health care concerns with a doctor that were not the main reason for the visit could forecast widespread future inefficiency in health care visits. Inefficiency is already a major cause for concern for physicians, particularly among non-specialists who are financially and institutionally incentivized to spend a limited amount of time with each patient. Smart devices, absent a compelling narrative that combats efficiency concerns, could be rejected outright. On the other hand, though efficiency could seem like a poor metric for physician empathy, it could be a step towards better empathy and better quality health if wearable technology could add depth to visits in ways that make patients feel more at ease and more understood. Thus, the patient respondents’ belief that PGHD will help them to bring up associated but not principal health problems could be either beneficial or harmful, depending on the degree to which smart devices enhance or detract from provider efficiency during visits.
Figure 10. The patient-perceived effects of integrating patient-generated health data in health care visits on health outcomes and the physician-patient relationship.

Patients were asked to indicate the degree to which they agreed with the statement, “If my health care provider were to use smart patient-collected data, I would...” as completed by the variables presented above. Note: Number of cases ranges between 853 and 859, depending on the item.

Figure 10 displays patient results for their beliefs about how provider use of PGHD would affect patients and their health. We observed that more about half (50.2%) of the sample believes that PGHD analysis by their health care provider would help them to have healthier behaviors. The measure for which there was the highest percentage of a non-effect, the lowest percentage of agreement, and the highest percentage of disagreement was “have more trust in them.” Thus, patients may not directly associate having healthier behaviors and having more trust in their provider.

A series of ANOVAs revealed some significant differences in patient beliefs by age. Across age groups, the Baby Boom Generation was marginally less likely than the Silent Generation and the Gen X/Millennial generations to think that PGHD would improve the physician-patient relationship (One-way ANOVA, F(2,794)=2.341, p=.097). We conducted a Tukey HSD post hoc test to see that the mean value on a scale of 1-5 for Strongly disagree to Strongly agree of the Baby Boom Generation (M=2.96, SD=1.037) was different (with marginal significance) from the mean value of the Silent Generation...
(M=3.02, SD=1.054), but that the mean value of the Silent Generation and the Gen X/Millennial Generations (M=3.17, SD=.979) did not significantly differ.

Respondents from the Baby Boom Generation were significantly less likely to think that PGHD would make them more trusting of their physicians (One-way ANOVA, F(2,794)=5.795, p=.003). A Tukey HSD post hoc test revealed that the mean value on a scale of 1-5 for Strongly disagree to Strongly agree of the Baby Boom Generation (M=2.79, SD=1.009) was significantly less than the mean value of the Silent Generation (M=3.00, SD=1.078) and the Generation X/Millennial Generations (M=3.07, SD=0.946).

The Gen X/Millennial age group was significantly more likely than the Baby Boom Generation and the Silent Generation to think that PGHD would make them have healthier behaviors (One-way ANOVA, F(2,795)=6.729, p=.001). We conducted a Tukey HSD test which was a conservative post hoc test that does not assume equal group sizes. When comparing groups for the perceived effects of PGHD on healthiness, we found that the mean value on a scale of 1-5 for Strongly disagree to Strongly agree of the Gen X/Millennials age group (M=3.61, SD=.876) was significantly higher than the mean value of the Baby Boom Generation (M=3.28, SD=1.076) and the Silent Generation (M=3.26, SD=1.064), but the mean values of the Baby Boom Generation and the Silent Generation did not differ with statistical significance.

The Gen X/Millennial age group also reported the lowest mean value across whether PGHD would help them to express fear, understand what their provider is saying, take control of their own health, and make a plan of action with their physician. A series of Tukey HSD tests revealed that across most of these measures, the Silent Generation and The Generation X/Millennial groups did not significantly differ, but that both of these groups significantly differed from the Baby Boom Generation.

4.8 Chapter Summary

We evaluated how patients using smart devices and wearables in health care settings and their perception of how their health and the physician-patient relationship has changed as a result of these technologies. Shifting age demographics in the United States will drastically alter how patients collect and provide health data to their providers, and subsequently, the demands and expectations they place on their providers. Nevertheless, there has been little understanding of the age-related effects in valuing connected technologies in health settings, collecting various health measures via these technologies, demanding the analysis of smart health data, and how these data will affect the physician-patient relationship.

After introducing the topic and discussing survey methods in sections 4.1 and 4.2, respectively, we discussed inherent patient value of physician empathy within the sample. We found that there were no statistically significant differences in the means across age groups in the value assigned to strong physician-patient relationships, though the Silent Generation did place the highest mean value on this variable. Gender, rather than age, was associated with whether or not strong emotional ties with physicians played a role in the degree to which a patient followed their physician’s advice. Women were more likely to follow their physician’s advice if they had a strong emotional tie to their physician, while men did not rely to the same degree on the physician-patient relationship. This
finding should inform future measures which aim to assess the impact of transformative technical interventions in the health care domain. For example, if connected devices change physician empathy in the way that our results suggest, health behaviors and outcomes of female patients could be the most affected, either positively or negatively. This effect could be compounded with our finding that women were significantly more likely to characterize themselves as early adopters of technology.

In section 4.4 we examined the types of data patients collect on themselves and the methods they use to do so. We found that weight data was the type of data most reported as being collected by any method, but it was the type of data that had the highest percentage of recordings via traditional (non-smart) methods. Surprisingly, sleep data were the next most commonly collected measure, which we thought would be far less frequently recorded and certainly less frequently recorded than steps taken data. We found that among the different types of health measures collected, those which were easily integrated into the existing infrastructure of a smartphone were more likely to be recorded by a smart, non-traditional means. For example, steps taken data, diet data, and heart rate data which are all easily recorded via a smartphone were recorded via connected devices at higher percentages compared to via traditional, non-smart methods. On the other hand, blood pressure data and blood glucose level data, which require additional equipment, were not recorded via smart methods at high percentages. We conclude that these gaps should be examined by industry to understand why certain connected health technologies may not be integrating, as well as to understand where the demand exists for smart method collections. Sleep trackers could be the new Fitbit. We finished section 4.4 by examining the social barriers to technology integration. The most common reasons patients offered for not collecting PGHD was “I can manage without it,” and the second most common reason was “I have privacy concerns.” In the subsequent chapter, we examine the dimensions and effects of these privacy concerns.

In section 4.5 we discussed patient perceptions of clinic and physician readiness to incorporate PGHD into the provision of health care. We found that age factored into readiness in a variety of ways. Older adults were more likely than younger and middle-aged adults to perceive their doctor as ready to assess and analyze PGHD, while Boomers were the most uncertain. We cannot conclude that this perceived readiness across older adults is because of unfamiliarity with the necessary technologies because our sample was characterized by a high level of technology adoption. Furthermore, a physician’s youngness was cited repeatedly as a reason that that physician was ready to collect and analyze PGHD, while oldness was cited less frequently as a reason that the physician was not ready to do so. We conclude that younger physicians will be expected to analyze the technology simply because of their young age, but that older physicians are not “off-the-hook,” so to speak. Social and demographic factors were more often discussed than technological means as reasons why physicians and clinics seemed ready to receive and assess PGHD.

In section 4.6 we discussed the non-difference between age groups in the degree to which patients wanted PGHD to be integrated into the health care system, though respondents from Generation X and Millennials were more significantly likely to find connected health to be helpful in capturing a more complete picture of their health, which suggests that there are generational differences in the conceptualization of a “complete picture of health.” Future research could interview panels of older adults to get a better
understanding of what contributes to a complete picture of health. Results of this nature would inform industry partners about how best to foster the trust of older adults and would better illuminate the health values of older adults.

In section 4.7, we discussed the effects of PGHD on the physician-patient relationship. Across all measures studied, PGHD was reported to be drastically more helpful than harmful. This finding is noticeably distinct from technological reports, and is positive for device companies, which have been reported to have been less profitable in recent quarters than expected. Boomers were less likely than respondents from older and younger generations to think that connected health devices would help them to get advice on non-chief complaints. If increased efficiency in the health care system can accommodate visits in which multiple conditions are addressed at once, there could be significant reductions in medical expenses as well as significant improvements to the physician-patient relationship. Boomers were also less likely to think that PGHD would make them more trusting of their physicians. Respondents from Generation X and Millennials were more likely than respondents in other age groups to think that PGHD collection would translate to healthier behaviors. If PGHD integration means patients are more willing to take control of their own health, rather than foster a physician-patient relationship, future research should evaluate the magnitude of benefits accrued from increased patient agency against the magnitude of the loss of the physician-patient relationship “safety net.”

It is important to remember that our sample was highly healthy, wealthy, and “wise;” nearly two thirds of the sample reported being in “Excellent” or “Very good” health, more than a third of the sample reported an average annual household income of at least $100,000, and nearly half of the sample had a graduate degree. The respondents represent in many ways the prime consumers of connected health devices and of technology in general. That even these respondents thought they could “manage without” connected health technologies speaks to a potential uphill battle many device companies will face in convincing consumers in general to spend money on devices. Furthermore, the respondents thought that connected health devices would help them take control of their own health and have more agency. Because of their geography, connectedness, education-level, and wealth, these individuals are perhaps best poised to be able to assume more health agency. Individuals who are less apt to assume more health agency could be harmed if they too readily relinquish the involvement of their physician in their health care decision-making. Future research should have a more distributed sample that can better speak to the concerns less technologically-savvy individuals have on the impact of PGHD on the physician-patient relationship.

Chapter 5 will examine the policy implications of patient and provider preferences that have been expressed the preceding two chapters.
Chapter 5 – Policy Implications of Connected Health Device Integration

5.1 Chapter Introduction

A 2015 *Wired* magazine title put it simply: “The Internet of Things Is Everywhere, But It Doesn’t Rule Yet.” There are many companies, health care providers, regulators, and agencies who are trying to understand how and for whom the technologies are effective and in what scenarios and for what reasons they are not. A host of barriers exist to the integration of connected health devices, and industry and government has recently started to invest in understanding the barriers more thoroughly. These barriers include regulation uncertainty, expenses, liability concerns, lack of infrastructure, and lack of access to technological support.

While there is research that addresses general technology barriers in older adults, there is still little understanding of how the barriers to connected health technology integration exist and function amongst older adults. In this chapter, we discuss barriers specifically related to mHealth integration in the context of older adults. There are four succeeding sections in this chapter. In section 5.2, we discuss the role data privacy and security concerns have on the integration of connected health devices. Data privacy and security concerns are a top concern especially among older adults, and these concerns may be underreported as many older adults may not have the language to express their fear of data exposure, despite the fact that older adults may be the most susceptible to exposing sensitive health data. We also discuss the vagueness and inadequacy of data protection initiatives in the US, and the failure of legislative efforts to close the gaps rendered by these initiatives. In section 5.3, we discuss observed generational gaps in technological innovation and the discrepancies across age groups in current provision of PGHD to health care providers and health care providers’ perceived usefulness of PGHD for the age group. In section 5.4, we discuss standards setting goals across the entities which respondents ranked as most effective at pushing connected technologies into the health care domain. While industry at large and different levels of government may have broad means of setting standards, the entities which should perceive the highest urgency of standards setting are the ones which patients and providers will point to first as agents of effective change in this area. There was a difference between sample groups in the entities which were reported as most effective in integrating the appropriate technology into health settings. Provider respondents reported that technology companies would be the most effective agents and patients reported that individual health care providers would be the most effective agents. Subsequently, we discuss the role technology companies should have in standards setting as well as the role health care providers should play. We discuss the nascent role FDA is playing in setting digital health standards. Section 5.4 concludes.

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5.2 Privacy and Security

5.2.1 Privacy and Security Concerns in the Sample

In Chapter 4, we noted that 34.7% of patients in our sample have concerns about the privacy and security of their PGHD (Figure 6). Respondents cited this as the second most influential barrier to using a connected device to collect PGHD (Figure 6). Concerns over the privacy and security of PGHD in particular are frequently cited as barriers to technological integration for a number of reasons. Sensitive data can be mined by algorithms in a way that can lead to discriminatory pricing. According to Forrester Research and PSRA, “Polls consistently show that people are most concerned about insurers and employers accessing their health information without their permission.”\(^{172}\) This concern arises from fears about employer, insurer, and credit discrimination. Title II of the Genetic Information Nondiscrimination Act of 2009 prohibits employment discrimination based on genetic information,\(^{173}\) but the use of such information in an employment decision could be difficult to prove in a court of law. Furthermore, patients who feel that their PGHD are private and secure are more likely to support research by donating those data as long as their preferences are respected.\(^{174}\) Even short of discriminatory pricing, data that are exposed can be embarrassing or carry stigma. When adolescents perceive that health information about them are not confidential, they are less likely to seek care, particularly for reproductive health matters or substance abuse.\(^{175}\) Adults may also avoid using technology to be treated for mental health and substance abuse issues if they are concerned about data privacy.\(^{176,177,178}\)

But privacy is important even in the “absence of any embarrassment or tangible harm.”\(^{179}\) The overwhelming concern for IoT data security is represented across domains and across age levels, including older adults. Privacy of health data is a critical concern


of older adults. A recent review of empirical studies found that privacy concerns registered in 34% of the total articles examined about older adults and wearable device integration.\textsuperscript{180} Within our sample, of the respondents who cited privacy concerns as the number one reason for not using more wearable devices to collect PGHD, 63.7% hailed from the Baby Boom Generation and 19.9% hailed from the Silent Generation (16.4% hailed from the Generation X/ Millennials). Because older adults make up the majority of the body of individuals who are most concerned about privacy, any potential solution must be certain to acknowledge and protect the needs, interests, and values of older adults. Furthermore, because older adults may not have the technical language to describe their fear of data sharing, research likely under-reports the degree to which older adults are concerned about exposing sensitive data.

5.2.2 Legislative Efforts

Despite the pervasive concern for data privacy, the United States does not have any centralized, formal legislation at the federal level that deals with the privacy and protection of consumer data.\textsuperscript{181} Since the Clinton Administration, the United States has relied on a sectoral, rather than governmental, approach to protecting data.\textsuperscript{182}

This distributed approach is in contrast to the European model for protecting consumer data, which is centralized and well-defined. In the EU, the Data Protection Directive of 1995 strictly defined the purpose, transparency, and proportionality of data processing, if personal data are to be processed by companies at all.\textsuperscript{183} The EU has more recently introduced the General Data Protection Regulation, which was adopted in April of 2016 and applies from May 2018-May 2020. The General Data Protection Regulation extends the reach of the Data Protection Directive of 1995 to all foreign companies who process data on EU citizens. There is a strict fine for noncompliance: up to 100,000,000 EUR or up to 5% of the annual worldwide turnover in case of an enterprise, whichever is greater.\textsuperscript{184}

Before any meaningful solutions to and protections against security concerns can arise, there must first be efforts to describe the different dimensions of data privacy and rights that could be potential domains for solutions. There have been some federal efforts in the US to describe dimensions of privacy. The Health Insurance Portability and Accountability Act of 1996 required the Department of Health and Human Services to establish standards for privacy and security of health data. The United States Privacy Act of 2005 was not enacted by Congress, but would have required “the consent of an


\textsuperscript{182} Ibid.


individual prior to the sale and marketing of such individual's personally identifiable information, and for other purposes.\textsuperscript{185}

The most recent effort to establish standards for data privacy was the Consumer Privacy Bill of Rights (CPBR). The White House released the CPBR in 2015 at the behest of the Green Paper on Privacy and Innovation released by the Department of Commerce's Internet Policy Task Force in December 2010. The CPBR describes the common facets of data privacy values: individual control, transparency, respect for context, security, access and accuracy, focused collection, and accountability.\textsuperscript{186} The goal of describing these data privacy values was to spark future initiatives that establish a generic data-processing code of conduct for companies across all industries. The CPBR called upon the Federal Trade Commission to act as a clearinghouse for companies’ codes of conduct. It also held that violation of the established codes could warrant federal enforcement measures. Specifically regarding health care, the CPBR does not mandate that device companies obtain consent to collect health information, but it does call on companies to give individuals reasonable means to control the use of their PGHD “in proportion to the privacy risk.”

Privacy advocates argued that the bill was too vague. Some privacy law scholars said that the CPBR “failed to endow citizens with direct and clear legal rights to control who collects their information and how they use it.”\textsuperscript{187} Senator Edward J. Markey (D-MA) argued, “Instead of codes of conduct developed by industries that have historically been opposed to strong privacy measures, we need uniform and legally enforceable rules that companies must abide by and consumers can rely upon.”\textsuperscript{188} Neither the standards for companies developing their codes for consumer data privacy nor the extent of enforcement were well-defined.

5.2.3 Privacy and Security Challenges for Patients and Providers

Academia has been under pressure to develop and translate alternatives to the CPBR. Because of the ubiquity of the risk of over-exposing data, agents that control and analyze internet policy at large, for example, researchers in the MIT Internet Policy Research Initiative, have developed broad but more rigorous standards and recommendations for IoT data security and privacy. The MIT Internet Policy researchers have distributed materials that describe IoT operational domains, stakeholders, and major IoT privacy and security challenges.\textsuperscript{189} The major IoT privacy challenges and security challenges identified include information asymmetries, solution costs, standards saturation, regulation uncertainty, data aggregation, business models, economic incentives, information scope, psychological biases, accountability, device ubiquity, user knowledge, slow legislation, dynamic context, device capabilities, and negative

\textsuperscript{188} Ibid.
externalities. In Table 7, we apply these challenges to the health care setting and outline effects these barriers have on patients and health care providers.
<table>
<thead>
<tr>
<th>Privacy and Security Challenge</th>
<th>Effect on Patients</th>
<th>Effect on Providers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information Asymmetry</td>
<td>Patients have incomplete information about how their provider will use and share their PGHD. Also, patients have incomplete information about how their health data are being used and shared with device companies</td>
<td>Providers have more information than patients do about the usage and sharing of PGHD</td>
</tr>
<tr>
<td>Solution Costs</td>
<td>There are high costs associated with securing PGHD - costs could be passed down to consumers in private settings</td>
<td>Private practice providers will incur massive costs in securing the transmission and storage of patients’ data</td>
</tr>
<tr>
<td>Vague Business Models</td>
<td>Device companies can require broad and ambiguous usage rights allocations in order to secure investments; patients must comply in order to use device</td>
<td>Must operate under the vague business terms to which the patient agreed; could blindly assume undue liability and risk</td>
</tr>
<tr>
<td>Information Scope</td>
<td>Patients lack accessible guidance in constructing personal privacy and security values</td>
<td>Physicians and hospitals lack knowledge to make appropriate privacy and security decisions for PGHD</td>
</tr>
<tr>
<td>Psychological Biases</td>
<td>Patients incur risk by often preferring data functionality, usability, and convenience over PGHD security</td>
<td>Risk associated with integrating PGHD can push providers to favor less technological integration</td>
</tr>
<tr>
<td>Agency</td>
<td>PGHD collection requires that patients play an active role in securing sensitive health data; this role was historically outsourced to medical providers</td>
<td>Disinterested in assuming more responsibility in securing patient data. Also, providers may be limited in their agency by what the technology their hospital system adopts</td>
</tr>
<tr>
<td>Digitization of Information</td>
<td>Health information that becomes digitized becomes susceptible to exposure</td>
<td>Unclear liability for insecure data</td>
</tr>
<tr>
<td>Slow Legislation</td>
<td>Patients permanently expose data before protective legislation is formed and implemented</td>
<td>Slow to integrate data into practice until malpractice legislation clarifies risk to providers</td>
</tr>
<tr>
<td>Dynamic Sensitivity to Sharing</td>
<td>Privacy and security preferences can differ based on the health measure collected and over time</td>
<td>Should follow patient preferences in investing in privacy solutions for different measures, but this is subjective</td>
</tr>
<tr>
<td>Negative Externalities</td>
<td>Once privacy and security framework is established by providers, patients have few means to secure their data any more than the provider does</td>
<td>Could adopt some security and privacy framework that is less protective than what a patient prefers</td>
</tr>
</tbody>
</table>
Table 7 describes a number of PGHD security and privacy challenges that affect patients and health care providers. These challenges are dynamic and point to the many ways patients knowingly or otherwise may be vulnerable to security breaches. Across many factors, providers in private practice will bear a heavy burden in preparing security measures for PGHD. This burden is particularly challenging because of the sectoral approach taken by the United States in developing privacy standards. Although HIPAA sets forth a baseline for patient data privacy, the integration of smart devices that collect PGHD will require protections beyond this baseline. Because device developers and internet service providers are responsible for developing their own standards for data privacy, private practices must stay up-to-date on the standards of their partner clinics, specialists, and payers. If these collaborators enact lower privacy standards than the initial referring doctor, the initial doctor could be liable in the event that a patients’ data are exposed but the source of the leak is unknown. Furthermore, the investment in establishing these high standards (which is often times massive) is lost as soon as data are transferred to a second provider. On the other hand, if collaborators enact higher privacy settings than the initial referring doctor, they may seek other collaborators who adhere to stricter data policies than the initial referring doctor who has a lower standard. Thus, referral relationships may be affected by differing values for, and subsequent investment in, different policy and security measures. Moreover, physicians who go into private practice may lack frameworks for deciding between different degrees of privacy standards. Even though a high degree of security for their patients’ health data and PGHD are held paramount, the resources needed to achieve a high degree of security compete with other priorities (financial and otherwise) required to set up and maintain a private practice.

Some of the challenges described in Table 7 are simply inherent to the exercise of establishing privacy and security standards. For example, “Negative Externalities” will occur for patients and providers unless the probability of data exposure is reduced to nothing; an expensive, near-impossible, imagined point at which the data could become clinically unhelpful. If health care providers set their own baselines (beyond HIPAA) for PGHD security standards, they cannot possibly set the baseline high and low enough for all patients; privacy values differ from patient to patient. As providers adopt privacy standards, they should aim to adopt standards which are flexible to satisfy patients who have increasing high standards for privacy.

No previous research applies this framework of privacy concerns to patients and providers or specifically to older adults. Older adults may be the most susceptible to exposing their own sensitive health data. Consider, for example, the value “Information Scope,” which considers whether older adults have the range and depth of knowledge about privacy concerns to be able to construct and articulate their privacy values. They may more readily express dissatisfaction with a wearable device on grounds other than privacy, because these alternative grounds are within their vernacular. For example, older adults in one study, when asked to generally express their opinions about using wearable devices, described dissatisfaction with accuracy, size, ease of use, and the burden of ownership.\(^\text{191}\) Whereas young adults and middle aged adults may be better versed in data privacy rhetoric, older adults may not have a sufficient grasp of the language needed to advocate for their data privacy rights. For fear of ridicule or

seeming out-of-touch, older adults could subsequently become more reticent in expressing their concerns unless explicitly asked about their privacy preferences. This fear puts them at a higher risk for consenting to data sharing that is inconsistent with their health and privacy values.

5.3 Generational Gaps in Technology Integration

5.3.1 Observed Generational Gaps in Integration and Usefulness of PGHD

![Figure 11. Usefulness of patient-generated health data and the supply of those data across different patient age groups.](image)

Health care providers were asked to indicate the age groups of patients for which they would find it clinically helpful to have patient-generated health data (dark blue). Providers were also asked to indicate the age groups of patients which were currently presenting them with patient-generated health data (or whose data were being presented by a health care proxy; light blue). The largest disparities between these variables occurred at the older age groups. N=312.

We were interested in understanding the extent of PGHD collection and sharing across individuals of different ages. We aimed to uncover and compare the gaps that exist at each age group between how helpful the technology for PGHD collection would be (as deemed by a
health care provider) and how often those data are currently provided to health care providers. Understanding the gap between “usefulness” and “currently collected” illuminates the areas in which technological integration has been the poorest and where the greatest gains in treatment and health impact may be captured. Moreover, understanding these gaps point to the age groups which most urgently require measures that improve technological integration.

To understand the usage of and demand for smart patient-generated data across age groups, we asked provider respondents two similar questions. First, we asked health care providers which age groups of their patients collected data via smart devices and/or wearables. We next asked them “for which age groups would patient-generated data from a smart device be helpful for you?” It is important to consider that if a given provider did not have patients of a certain age group (for instance, if they were a pediatrician and did not have older adult patients), they would not select any of the older age groups—not because they have patients of this age who do not collect smart health data, but because they do not have patients of this age at all. Because providers were in both variables asked to consider “their patients,” there was some mitigation of this source of uncertainty.

Figure 11 describes the gap between usefulness of data (dark blue) and data which are currently collected (light blue) across age groups. There were four findings of note when comparing age groups of patients who use smart devices to collect health data against the age groups of patients for whom health care providers would find it useful to have data from such devices. The first is that across all patient age groups, health professionals would find it helpful to have more patient-generated data from smart devices than they currently have at their diagnostic disposal. The difference between the percentage of health professionals who report their patients as providing these data versus the percentage of health professionals who say it would be useful if their patients provided these data are statistically significant for those 13-18 and those over age 50: adolescents and older adults. Providers may demand more PGHD from adolescents because these data assist in uncovering and treating health conditions that may only arise or develop in adolescence; it is critical to address these conditions promptly before the patient ages and health habits become more difficult to change. Providers may have a high demand for PGHD among older adults because of the perceived benefits to this population or because these patients may be prone to forgetting or misrepresenting health habits or data. Moreover, chronic diseases are most prevalent amongst older adults. If the collection of PGHD is useful in addressing chronic diseases, providers would likely place a high value on PGHD from this population. This finding suggests that policies could incentivize the collection of PGHD from the populations for which providers most demand it.

Below the 13-18 years old age group, the two variables were not significantly different. The similarity between the two variables at the younger age groups suggests that the percentage of providers who have patients younger than 12 that collect smart health data is similar to the percentage of providers who would find smart health data helpful for that population. Roughly speaking, at these two age groups, the current collection of smart health data satisfies providers’ demand.

A second important finding involves the difference in modes between the two variables. The age group of patients who are most frequently reported as collecting health data with smart devices is the 36-50 years old age group; 58.56% of the health professionals sampled who have patients that collect smart health data reported that they treat patients in the 36-50 years old age group who collect smart data. The 22-35 years old age group was the group with the second highest percentage, with 52.25% of the sample selecting this group as one in which their patients
collect smart data. In contrast, the age group of patients for whom health professionals most frequently reported it would be helpful to have these data is the 51-62 years old age group, with 65.06% of the sample noting this age group. The next age group from whom smart patient-generated data would be most helpful to health profession is the 63-80 year old, with 63.78% of the health professional sample highlighting this age group. Thus, as a function of the percentage of health providers who selected the relevant patient age groups within each variable, health data from the 36-50 years old age bracket is most frequently reported as being currently collected, while smart health data from the 51-62 years old age bracket was the most frequently reported group for whom smart health data would be clinically helpful. Put a different way, there is a left-skewed normal distribution for each variable, but the entire distribution is shifted to the right for the “helpful” variable. In short, age groups in which smart health data collection peak are younger than age groups for whom these data would be most helpful to health care providers. This finding could suggest that although the current patient provision of PGHD may fall below providers’ demand, the demand may be better met as the next generation of people ages 22-50 ages.

A third finding of note is that the largest disparities occur within older adult age groups. In considering this finding in the context of policy decisions, it could be of use for policymakers and agencies tasked with investigating and protecting the interests of older adults to research the cause and remedy of the disparity. That is, older age groups are those age groups with the largest disparities between the percentage of providers with patients that collect smart health data and the percentage of providers who would find data for the age group useful. The largest disparity is within the 63-80-year-old age group, from which 63.78% of the health professional sample would find smart health data useful, but in which only 21.62% of the sample have patients that collect smart health data. The second largest disparity between the two variables occurs in the 81+ years old age group, in which 43.59% of respondents would find smart health data useful, but in which only 6.76% of respondents have patients that collect smart health data.

Finally, the fourth main finding is that the percentage of physicians who report that it would be helpful for any given age group to collect patient-generated data from a smart device never exceeds 65.06%. This finding may have to do with physician and clinic readiness to use these data, the time involved in analyzing it, and the lack of reimbursement, all of which are potential policy targets.

5.3.2 General Barriers to Technology Integration amongst Older Adults

We see from Figure 11 that large gaps exist between the amount of connected health devices that would be useful in the provision of health care and the amount of PGHD that is currently provided. Security and privacy concerns contribute to these gaps, but there are other factors beyond concerns for privacy and security that would prevent physicians and patients for wanting PGHD collection to be integrated into the health care system or for finding such collection “helpful.” We looked to current evaluations of technology adoption factors in the literature to explore how these barriers might explain or contribute to depressed adoption rates of such technologies. “Affordability, service trust, usability, value and system reliability [are] found to be perceived by [older adults] as the most important factors throughout the decision stages” of
technology adoption. We applied the rankings for technology adoption factors from Lee 2014 to the decision-making process of older adults in collecting PGHD to examine which of the factors were particularly relevant in health care settings. Within our sample, affordability was not a significant barrier for the adoption of PGHD by patients, nor was it a major reason physicians listed as reasons they think their patients refrain from integrating the technology; only 6.6% of health care providers believed that mHealth would hurt initiatives to reduce medical expenses (Figure 1). “Service Trust,” which is described as the “degree to which the user trusts in the brand or in features of the technology,” is in large part a barrier to PGHD integration, and in this context, fits into the discussion of privacy and security of data, because patients will refrain from collecting PGHD if they do not trust the wearable device company that is processing their data.

“Reliability of system operations” was a less relevant barrier for PGHD integration because many of the technologies are currently mature and reliable; consider, for example, the readiness of the Fitbit. Similarly, “consistency with mental models,” was less relevant because these devices often “fit the user’s expectations and conceptual ideas about how [they] should work;” no respondent in the sample cited an inconsistency with mental models as a reason why they did collect PGHD. Similarly, physicians, and older physicians in particular, reported that they were willing to adapt their mental models of practicing medicine in order to fit the needs and preferences of their patients. For example, in Chapter 3, we discuss how older health care providers offered reasons for why they consider it their job to analyze PGHD such as, “It relates to my patient so it is my job.”

“Value,” defined by Lee (2014) as the “Perceived usefulness and potential benefits of using the technology,” is a major barrier as reported by our sample to smart device integration in the health care system. In Figure 6 in Chapter 4, we see that the most frequently reported barrier to PGHD collection is “I can manage without it.” McCreadie and Tinker (2005) described how older adults adopt technology not for the sake of the gadget, but to fill a need or gap. Older adults in particular will have to be convinced of the health value in PGHD collection. Health needs are not stagnant, so patients’ perceptions of the best way to manage certain chronic conditions may change as patients develop those chronic conditions. One way to overcome the “value” barrier is for physicians and health care providers to be ready to introduce to patients the devices associated with PGHD collection as patients develop new chronic conditions. If, for example, a patient develops Type II Diabetes as an older adult, they could be taught to manage their blood glucose level through smart devices, apps, and connected glucometers rather than by traditional methods. Introducing the technologies necessary for PGHD in the management of any given disease builds-in inherent “value;” patients come to expect PGHD collection not as a means of managing their condition but as the means.

193 Ibid.
5.4 Closing the Gap - Integration Entities

Regardless of whether patients believed it was their physician’s job to receive, review, assess, and discuss PGHD, they did hold beliefs as to which entities would be most effective at convincing them to use connected health devices. Table 8 lists the potential entities ranked in order of effectiveness. It is important to note that in this comparison of provider and patient respondents draws on slightly different question wording. Physician respondents were asked to rank entities that “could effectively push patient-generated data from smart devices into the health care system,” while patient respondents were asked to rank entities that “could convince you to use, share and/or collect health data using a smart device.” The different question wordings were intended to adjust for the information asymmetry between physicians and patients; physicians have a stronger working knowledge of how the health care system changes in response to pressures by various entities than patients do. Patients can better rank the effectiveness of various entities in PGHD implementation potential by indicating which factors would effectively convince them.

Across health care provider respondents, the collective entity which was most often selected among the top three entities that could effectively push patient-generated data from smart devices into the health care system was “Technology Companies (e.g., Apple, Google);” 55.6% of the sample selected “Technology Companies” in this way. The entity which was most commonly ranked as the number one entity that could effectively push patient-generated data from smart devices into the health care system was “Insurance Companies;” 20.1% of the sample ranked “Insurance Companies” as first. It should be noted that “Technology Companies” was a close second behind for the most frequently top ranked entity, and claimed 19.1% of the sample.
Table 8. Effective integration of connected health devices by various entities. Health care provider and patient respondents were asked to rank various entities based on how effective the entities could be at integration the collection and sharing of patient-generated data into the health care system. Respondents ranked the “Top 3” most effective entities and also the single most effective entity.

<table>
<thead>
<tr>
<th>Entities</th>
<th>Health Care Provider Respondents</th>
<th>Patient Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Ranked in Top 3</td>
<td>Ranked #1</td>
</tr>
<tr>
<td>Technology companies</td>
<td>55.6</td>
<td>19.1</td>
</tr>
<tr>
<td>Insurance companies</td>
<td>47.7</td>
<td>20.1</td>
</tr>
<tr>
<td>Practices/hospitals</td>
<td>45.0</td>
<td>16.1</td>
</tr>
<tr>
<td>Federal agencies</td>
<td>37.4</td>
<td>3.6</td>
</tr>
<tr>
<td>Individual health care</td>
<td>37.3</td>
<td>12.2</td>
</tr>
<tr>
<td>providers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Individual patients or groups of patients</td>
<td>32.5</td>
<td>11.6</td>
</tr>
<tr>
<td>The federal government</td>
<td>19.4</td>
<td>6.4</td>
</tr>
<tr>
<td>Employers</td>
<td>18.2</td>
<td>5.5</td>
</tr>
<tr>
<td>Pharmacies</td>
<td>11.2</td>
<td>1.2</td>
</tr>
<tr>
<td>Local or state government</td>
<td>8.8</td>
<td>2.4</td>
</tr>
<tr>
<td>Retailers</td>
<td>6.1</td>
<td>1.8</td>
</tr>
<tr>
<td>Total N</td>
<td>329</td>
<td>329</td>
</tr>
</tbody>
</table>

Note: Table entries are percentages.

There are initiatives across many agencies and entities to integrate IoT devices such as wearables into the health care space. Usually, the standards-setting discussion revolves around local or state government actors, the federal government, employers, or insurance companies. Our surveys reveal, however, that groups of doctors and patients alike believe other entities will be more effective at integrating IoT devices into health settings (Table 8). In this section, we will analyze the types of standards setting that should be done across the two entities which doctors and patients believe will be most effective at integrating mHealth: technology companies and individual health care providers.

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5.4.1 Standards Setting for Technology Companies

A majority (55.6%) of health care providers in our sample ranked “Technology Companies” among the top three most effective entities that could push PGHD collection into the health care space (Table 8). Technology companies could include umbrella firms such as Apple, IBM, Lenovo, Microsoft, and Philips, but could also include firms that are specific to wearable devices and apps such as Fitbit, Motiv, Withings, Glooko, and SleepBot. No other entity was more frequently ranked within the top three among the health care provider sample (Table 7). Patients were less likely to consider technology companies as PGHD-integrating entities; only 4.5% of the patient sample rated the firms as the number one integrating entity, and only 14.8% of patients ranked it within the top three (Table 8).

There are almost a limitless number of standards that could be set for the health care technology industry—from device requirements such as the required image quality for devices that send dermatologists images of patients’ skin, to how accurate step data should be, to how closely devices much match FDA-clearance-level specifications. To a large extent, competition within and among connected health device markets will function as a race to the top for device quality, so these types of standards become promptly obsolete.

But the area of standards setting for technology companies that would be most effective in facilitating integration is the pursuit of stricter and clearer privacy and security policies. The CPBR articulates the goal that all firms, including technology companies, should set their own standards for privacy. Companies should create their own standards that protect individual control, mandate transparency and respect for context, define access and accuracy, and that articulate the self-enforced consequences of non-compliance. The sectoral approach to protecting consumer data adopted by the United States is fragmented; with these coverage gaps, consumers are at risk of exposing sensitive health information. HIPAA protects data within certain actors and settings, but does not necessarily cover data collected by health device companies or in health marketing like data brokers, ad agencies, data-management platforms, and marketing clouds.

A white paper asserted that, “Data can easily flow in and out of this HIPAA-free zone, and personal data that have been ‘anonymized’ can be ‘de-anonymized easily.” Unless data are directly transmitted to a doctor or hospital, wearable device PGHD are not covered by HIPAA. Therefore, “Big data can produce basically unprotected patient-level data that will serve as an effective proxy for HIPAA-protected data.”

Personal health data are subject to “condition targeting,” “look-alike modeling,” predictive analytics, “scoring,” and the real-time buying and selling of individual consumers. Even consumers who favor lower privacy standards as a means to spur innovation and support company flexibility agree that connected health devices and PGHD should be held to a higher standard than, for instance, smart phones or messaging data in general. There have been initiatives to urge device companies to prioritize, or at least consider with more rigor, measures

200 Ibid.
of securing consumer and patient data. These initiatives include urging developers to improve usability, accessibility and implement user-centered design principles into products that capture PGHD; all of these measures make it easier for patient to understand control and privacy settings and can give patients the language with which they can make suggestions if they are dissatisfied.\footnote{U.S. Department Of Health And Human Services, The Office Of The National Coordinator For Health Information Technology. "Conceptualizing a Data Infrastructure for the Capture, Use, and Sharing of Patient-Generated Health Data in Care Delivery and Research through 2024." Accenture. Accenture Federal Services, 28 Oct. 2016.} Device companies could include privacy measures within the design of a device so that data cannot be collected without a user specifically manipulating the device in a way that allows data to be collected. Moreover, privacy advocates support increased transparency with consumers about security policies; the Federal Trade Commission advocates for notice and choice methods, which are often too vague. While device companies may maintain that their devices are HIPAA compliant, Montgomery, Chester, and Kopp (2016) argue, “it is clear that the use of Big-Data technologies and operations have made it possible for health marketers to determine—with an unprecedented degree of precision—an individual’s health status, risk level, propensity to disease, and medical concerns, and to identify, locate, and target that person, without ever needing access to any medical records.”\footnote{Montgomery, Kathryn C., Jeff Chester, and Katharina Kopp. "Health Wearable Devices in the Big Data Era: Ensuring Privacy, Security, and Consumer Protection." Center for Digital Democracy (2017): School of Communication / American University.}

Older adults could be amongst the most susceptible to the risks associated with PGHD security breaches. A white paper argues, “Many of the harms associated with the collection and processing of such data, moreover, are likely to affect disproportionately the most vulnerable people in our society, including the sickest, the poorest, and those with the least education.”\footnote{Ibid.} The oldest members of our society should be included on this list. As the population of the US becomes older, markets will most aggressively target older adults to gain insights into how a large proportion of new customers function in markets. We have three recommendations in the area of standards development for older adults. First, privacy policies and notice and choice methods of mHealth should be tested to understand how well older adults comprehend them. A high degree of comprehensibility should mark companies in ways that are public and comparable as “consumer-friendly,” “honest,” or any market-tested angle that is successful amongst older adults, but not “geriatric.” Second, organizations charged with ensuring the health and wellbeing of older adults should invest resources in informing the organizations which are addressing the self-regulation security gap within technology companies. These organizations include the Digital Advertising Alliance, the Network Advertising Initiative, and the Future of Privacy Forum.\footnote{Ibid.} Third, companies should expand education initiatives so that older adults and their caregivers can learn not just how devices work, but how they function in a larger scheme of aggregating data. All around, the pace of standards development needs to improve.\footnote{Ibid.}
5.4.2 Standards Setting for Individual Health Care Providers

We have three recommendations for the development of standards setting for health care providers around wearable health technologies. First, health care providers should engage in meaningful interactions with industry promoters. Where device companies often induce demand for their devices and dictate health values to health care providers in order to secure new customers, health care providers should act as advocates for their patients and subsequently represent the interest of older adults. Health care providers could discuss the needs for clearer data usage policies for older adults, for instance. If providers can reliably and consistently advocate for their patients’ interests in this way, integration gaps can start to be addressed by device makers. Second, health care providers should establish standards of practice for data donation. Most often and for good reason, discussions about PGHD data revolve around PGHD processing that occurs without consent. While these issues should be addressed, so too should the issue of obtaining consent for PGHD aggregation amongst health care providers so that doctors can analyze their performance by looking at patient data as a whole. Carefully-constructed data aggregation done by providers, rather than by industry or government, can serve as quick, specific, and meaningful health indicators for provider standards of care and practice. Moreover, a provider’s aggregation of PGHD can be used to inform policymakers of policy approaches that need to be taken to address PGHD-specific or condition-specific issues. Finally, medical schools should set standards for PGHD analysis independently and for PGHD analysis in the context of physician empathy. Embedded within these standards should be the establishment of metrics for analyzing physician empathy amongst PGHD collection. The current measures for physician empathy do not address the large role technology will have in changing, and in some instances supplanting, the physician-patient relationship.

To assess level of training for PGHD analysis amongst currently-active health care providers, we asked respondents, “If you have received some sort of training or education to use patient-collected data, where did you receive this training?” They were asked to check all that apply from a number of different possible sources of education. These sources included: medical school, industry promotions, hospital/clinic, literature, colleagues, continuing medical education courses, conferences, other, and “I have not received any training or education regarding the use of patient-generated data.” By and large, health care providers have not received training to deal with these devices. 65.2% of health care providers in our sample indicated that they had not received any training or education regarding the use of PGHD (N=323). The answer with the next highest percentage was conferences, in which 13.0% of respondents indicated they had received some sort of training. Medical school curricula need to incorporate training around the following: 1) PGHD-collection, because the treatment of all chronic diseases and prescription practices will change drastically as data informs them; and 2) Empathy training when dealing with PGHD. Health care providers who act upon PGHD are in many instances concerned about the accuracy and precision of the health data upon which they are asked by patients to act. This type of training should be established as soon as possible in order for the future workforce of physicians to be prepared to handle larger numbers of patients and the data these patients increasingly provide. This lack of provider training is harrowing not just in terms of young physicians but also in terms of older patients. The aging population could strain health care resources if providers are not trained in the assessment and review of data that will make them more efficient.
5.4.3 Governmental Role in Standards Setting

The government will play an increasingly important role in regulating connected health devices. Moreover, the government at different levels must ensure equity and access to the necessary technologies.

By acting on data from connected health devices which are not required to meet any formal clinical standards, health care providers may expose themselves to risk of malpractice. This unwelcomed assumption of risk could prompt providers to put pressure on entities such as the FDA to set efficacy and accuracy standards for industry. The FDA is called to evaluate connected health devices and set regulatory requirements. Within the FDA, the Center for Devices and Radiological Health (CDRH, a part of the Office of Medical Products and Tobacco) is currently responsible for connected health device regulation. The CDRH has recently established the Digital Health Program, which aims to foster “collaborations and…outreach to digital health customers,” and “develops and implement[s] regulatory strategies and policies for digital health technologies.” The scope of the Digital Health Program has not yet been demonstrated, as the draft guidelines were just released in October of 2016. The device regulation by this program could include: labeling the device, defining intended uses for the device, establishing registration and device listing, setting quality standards, assigning device identifiers, and establishing methods for planned adaptation and shared learning. Sections 880.9-6992 of the U.S. FDA Code of Federal Regulations Title 21 define the standards the FDA has set for various “personal use devices,” which range from liquid bandages to lice removal kits, for example. Connected health devices could be categorized as “personal use devices,” and would drastically expand the kind and number of devices within this category. Because of the FDA’s explicit statutory capacity and obligation to regulate certain medical-purpose personal use devices, the agency is well-poised to standardize connected health device efficacy. It has made some progress over the past year in drafting device guidance for device developers. In response to privacy and security concerns on the part of device developers, the FDA published draft guidelines in 2016 entitled “Postmarket Management of Cybersecurity in Medical Devices.” The guidance discussed continuous monitoring of vulnerabilities, establishing risk mitigation programs, and proactive security troubleshooting. The draft garnered approximately 1,400 comments which will be reviewed and incorporated in 2017. Certainly, as the number of connected health devices and apps continues to grow rapidly, the pressure for regulation will become more pervasive. More rigorous and defined standards will be set by the FDA. The drive for this regulation comes from concerned patients, providers, hospitals, and even firms who aim for strategic advances based on regulatory capture.

If the government is tasked with regulating such devices, it must also regulate the way in which providers are expected to use the devices. There should be requirements set by the government that indicate the proper usage of connected health devices. These requirements would most closely mimic the requirements set for medical devices by the FDA which are well-established and incorporated into medical practice. Governmental actors that interact with medical agents who set and validate the assignment for continuing medical education credits should integrate connected health device training into continuing medical education. In playing an increasingly active role in regulating connected health devices, the FDA and other

governmental agencies signal that connected health devices are as important in health management as pharmaceuticals or other medical devices which are similarly regulated.

The federal government will play a role in ensuring equity in access to the necessary technologies. Connected health devices are inherently expensive. Data from this thesis, across industry, and from providers and patients suggest that there are benefits to collecting and sharing PGHD. As these benefits are more widely recognized as a part of “quality health care,” it will become particularly important that individuals across age groups and across social economic statuses will be able to readily access the technologies. Equal access will help to ensure continued development and investment in this space. Coughlin (1999) asserts that federal stakeholders, to provide a national vision and build a political coalition that will address the needs of older adults, should “create new or restructured institutions that will administer aging and technology policy, and implement policies that will set the agenda, stimulate the market, and ensure technological equity.” The federal government should integrate connected health devices into these initiatives. Connected health devices, as part of quality health care for older adults, will be the subject of technology policy. These devices are both a product of and a factor in a stimulated market that will work towards technological equity for older adults.

5.5 Chapter Summary

In this chapter, we addressed specific barriers to the integration of PGHD-collecting technology among patients, providers, and older adults. A primary and critical concern among older adults in the survey sample in determining whether or not to collect PGHD is privacy; this was second only to the notion that they (patient respondents) can “manage without it.” There are a dearth of substantive legislative initiatives to protect PGHD and there are large gaps in current legislative standards that expose patients, and specifically older adults, to irrevocable exposures of sensitive health data. We applied an existing and extensive framework to postulate the effects of various data privacy concerns across the domains of health care providers and patients, and we discussed the ways in which the framework illuminates the undue risk and burden assumed by private practice providers because of a lack of standards in this domain. After discussing the strong effect privacy concerns exercise as a barrier to technology integration, we described the extent of technology integration barriers (including privacy concerns) by showing across each age group the discrepancies between current collection of PGHD and the usefulness of PGHD for that age group, as determined by health care providers. We found that these discrepancies were the greatest at older age groups and for young adults and the smallest for younger age groups. Finally, we measured the frequency with which health care providers and patients reported various entities as effective agents for integrating PGHD collection into health care settings. We compared these entities and discussed privacy standards setting amongst technology companies—the entity which providers thought would be most effective at integrating technology—and health care providers—the entity which patients thought would be most effective at integrating technology. While other stakeholders such as federal agencies or the federal government at large could set more broad standards in this area, technology companies and health care providers are the agents to which consumers and patients currently expect to turn for

data protection and PGHD integration, and for this reason are the entities that in some regard have the greatest urgency in developing standards.

While we asked providers and patients to consider the role of federal agencies and insurers in integrating PGHD, we did not explicitly ask providers or patients to consider the role of Medicare. Future research should consider the role of Medicare in setting standards for PGHD, as it is the single largest payer in the US and regularly sets broad standards. As the largest payer, Medicare is responsible for a massive amount of patient data and has a repository of electronic health record information.

It is important to consider the trade-off in this context between regulation and innovation, as the “benefits of the IoT might be adversely affected should policymakers enact laws or regulations on industry.” 210 The Federal Trade Commission, in a report by experts who examined the extent of this trade-off, described arguments on either side of regulation and innovation. Experts concluded that regulation is critical to insuring future innovation, because the regulation will reassure “the public that their health data will not be used to draw unexpected inferences or incorporated into economic decision-making.” 211

In the subsequent section, we draw conclusions to this thesis and suggest areas of further research.

211 Ibid.
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Chapter 6 - Conclusions

This thesis adds to an extensive body of literature which seeks to forecast the usage and effects of connected health devices. Chapter 3 contributes to the small amount of literature which aims to understand how technology will change interpersonal relationships from a health care providers' perspective. Most connected health studies emerge from device developers whose chief interests are understanding consumers at large and driving demand. Industry competitors and venture capitalists manipulate the definitions of selected connected health terms such as “telemedicine,” “health information,” “sharing,” and “digital health tools” so that integration seems more mature and desirable. Consider, for example, the following two statements that were published by the venture capital firm Rock Health which supports a portfolio of some of the most well-known connected health firms (examples include: Honor, DrOnDemand, and Omada Health). Among the "50 things we now know about digital health consumers," which was presented to all portfolio firms, they stated:

(1) "While consumers are concerned about the privacy and security of their health data, the vast majority (77%) are interested in sharing their health information”

(2) "20% [of Americans] have asked for or downloaded a copy [of an electronic copy of their health record] in the past six months”

Would, for instance, one person telling another (even non-medical) professional about their weight qualify as "sharing their health information?" In regards to statement 2, 86.9% of office-based physicians are using an EMR/EHR system. Not all patients are seeing office-based physicians for care; many may go to emergency rooms or urgent care centers. Yet even if patients do most frequently seek care from physicians in office-based settings and even if their physician adopts some sort of EMR/EHR system, it is not guaranteed that the patient has a record that has been converted electronically. Beyond that limitation, only a percentage of the patients who seek care from an office-based physician who has adopted an EMR/EHR system and who has completed the conversion of all patient files to the electronic format know that they have a medical record and also have the capability of downloading it within the past six months. In 2015, 83.6% of adults had contact with a medical professional at all. It seems highly likely that the percentage of Americans requesting their EMR in statement 2 is drastically overstated.

There are significant financial interests vested in the success of connected health devices. Device developers and venture capitalists in the health care space are not unbiased evaluators of PGHD integration, and future academic research, which may be more insulated from financial biases depending on the funding source, should conduct these types of technology maturation studies to supplant biased data and conclusions.

The academic studies that have been conducted are limited to very small sample sizes because of the prohibitive cost associated with surveying physicians and the lack of internal

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213 Ibid.
positive or negative incentive structures that would urge physicians to respond.\textsuperscript{216} The sample size of our health care providers was 892 (75\% of which was composed of physician respondents); the survey was nearly 50 times larger than the most pertinent prior study.\textsuperscript{217} There were 23 specialties represented in our health care provider sample, whereas many studies will remain in the scope of understanding the effects of some intervention limited to one type of specialist.

There are a number of studies that deal with physician preferences and experiences with PGHD analysis and the integration of connected health devices. These studies primarily consider workflow concerns, reimbursement, and liability. Rarely do these studies consider how PGHD analysis affects the physician-patient relationship. The studies that do consider the physician-patient relationship reduce the relationship to one aspect such as “communication”, when so many other factors are at play in physician-patient interactions.\textsuperscript{218} We consider 19 empathy factors that measure levels of “trust,” “support,” “motivation,” “honesty,” and more complex indicators of empathy, such as whether or not a patient felt comfortable discussing embarrassing health behaviors. Though empathy assessments in medicine and industry suffer from a self-reporting problem, they do successfully integrate a wide range of potential factors—so too should the research that examines the effects of technology on empathy. To our further knowledge, there are few studies specifically that consider the effects of PGHD integration on older patients and there are no studies that consider the effects of PGHD integration on older providers. Thus, the comparisons we draw between age groups of providers are novel.

Although the existing literature deals extensively with patient experiences with devices and the health benefits that precipitate from the use of these devices, Chapter 4 adds to the literature in a number of ways. Because our survey was a convenience sample that skewed wealthy, healthy, educated, and more technologically savvy, we were able to draw more conservative insights when it came to setbacks and barriers to integration. In short, this sample of patient participants are best poised to integrate the technology, but they are reporting barriers in certain dimensions. Therefore, these barriers could be even more profound for patients who are less likely to have the resources to overcome them.

Table 6 presented in section 4.4.2 could be of interest to device developers because we describe the relative frequency with which patients report collecting various health measures. Technology or business indicators will report the growth of certain devices, but we do not have indicators across multiple health measures for how often patients are using connected devices versus traditional methods to collect different kinds of data. With our harmonized approach across eight health measures, we were able to uncover significant market opportunities. We discuss the opportunity for smart devices that measure weight—the most frequently reported health data that are collected, but which are measured via traditional, non-smart methods more than 80\% of the time—and for sleep—the second most frequently recorded health measure which is measured less than half the time with a smart device.

In Chapter 5, we examined the specific barriers to technology integration and conducted an analysis of how the agents who are perceived by providers and patients as those most effectively able to integrate connected health devices--technology companies and individual

\textsuperscript{217} Ibid.
\textsuperscript{218} Ibid.
health care providers--could facilitate this integration. The top barrier to PGHD collection was “I can manage without it,” which technology firms will have to address by better understanding the market. The second barrier was data privacy concerns. Samuel Greengard, business and technology writer and author of The Internet of Things (MIT Press Essential Knowledge Series) calls IoT both a “microscope and a telescope into the once invisible world between people, machines, and physical objects.”

Wearable devices in health care settings act as microscopes by allowing patients and providers to uncover health metrics and patterns that were not observable in health clinic settings. Similarly, wearable devices and the collection of PGHD act as a telescope in health settings in that the technologies allow providers and patients to observe health trends, to foresee health outcomes better, and to adjust health behaviors promptly and accordingly.

This description of the “microscope” and the “telescope” becomes uncomfortable when patients and providers become the subjects of observation, rather than the ones looking through the lens. We suggest that technology firms could better address the privacy concerns of consumers by improving notice and choice methods and then testing those methods against how well older adults understand them. Of the patients in our sample who indicated data privacy and security as their top concern for PGHD integration, 63.7% hailed from the Baby Boom Generation and 19.9% hailed from the Silent Generation. As we concluded in Chapter 5, because older adults make up the majority of individuals who are most concerned about privacy, potential privacy solutions for PGHD collection and for technology in other industries must be tailored to the needs, interests, and values of older adults. Device manufacturers should also take care to incorporate privacy by design within the devices themselves so that users must physically manipulate a device in order to collect data and are therefore aware of what data are being collected, when, and how.

Connected health integration can also be accomplished or at least facilitated by health care providers. The patient survey indicated that patients most frequently identified health care providers as the most effective integrators of these technologies, so providers should be better prepared to assume this responsibility and train to do so effectively. While individual health care providers are perhaps less effective at motivating large-scale data policy changes, they are well-suited to advocate for change within medical curricula and training. Doctors should advocate for PGHD-collection and analysis training because the treatment of all chronic diseases and prescription practices will change drastically as more data inform them.

A significant component of PGHD-collection and analysis training should also be centered on how the data affect the physician-patient relationship. Broad measures of health care provider quality, in addition to more specific medical empathy scales, should include variables that examine technology integration. Certain existing measures of health care provider quality incorporate variables regarding empathy. For example, Healthcare Compass is a website used to compare primary care doctors’ offices in Massachusetts based on how well they care for their patients. The measure has three main categories: doctors’ care for their patients, care and service from others in the doctor’s office, and willingness to recommend. The doctors’ care for their patients measure is informed by six questions about empathy, which is a positive indication that empathy measures like “how often...your provider explain[s] things in a way that is easy to understand” and “how often...your provider show respect for what you [say]” are recognized as

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important components of the modern physician-patient relationship. What is missing amongst health quality measures and which could easily be included is a consistent measure of technology adoption among providers. Once health quality measures consistently collect data about technology integration, there will be an easy way of analyzing the correlation of patient-perceived (rather than physician-reported) physician empathy levels and the integration of connected health devices.

A discussion about standards and technical barriers would be amiss if it failed to acknowledge that these questions are being considered simultaneously across industries. Health care is just one of countless and growing IoT domains. IoT devices are transforming virtually every modern industry, including: telecommunications through network management and cloud infrastructure; commerce and manufacturing through equipment monitoring and tracking; finance through remote banking; insurance through personally-tailored insurance plans; agriculture through environmental monitoring; transportation through smart transportation systems and autonomous vehicles; homes through connected appliances; the workplace through person and activity tracking; infrastructure through utility meters; public safety and defense through surveillance system and tracking; and government through compliance monitoring and auditing.

Discussions of appropriate IoT uses and standards settings are typically bounded within any single domain. But the standards setting process for any IoT domain, such as health care IoT, is exposed to the standards setting processes of other domains. Health care IoT integration and PGHD demand and supply will be influenced by the experiences of other industries as they integrate IoT data. Stakeholders and users develop opinions, preferences, and concerns within one industry, then apply those concerns knowingly or otherwise to other industries. It is important to acknowledge the broad scope of current and potential technological applications to understand how these preferences and concerns regarding the use of IoT devices in one industry intersects with those of other industries. Currently, the intersections of concerns and preferences across domains, and especially in regards to older adults within those domains, is poorly understood, and future research should seek to understand interactions in this regard.

Future Research

A number of future research initiatives have been discussed, including: the development of academic studies (or research from demand-driving firms otherwise sufficiently insulated from) studies on technology integration and maturation, the evaluation and creation of strategies for national and industry-level improvements in data privacy and security, the addition of empathy and technology integration questions in health quality surveys, and studies which aim to understand how experiences from IoT integration in one sector functions may apply to IoT integration in other sectors. Other future research could include an ethnicity-focused impact analysis of changed physician-patient relationships. In our analysis, we discovered several interesting and statistically-significant effects of race on empathy which we did not investigate further. The Tsugawa et al. study from Harvard calls for an investigation into “differences in

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practice patterns” \(^{223}\) between male and female physicians; a similar investigation could be conducted to illuminate differences in practice patterns amongst physicians of different races and ethnicities. \(^{224}\) There is some recent evidence that suggests that patient and physician races influenced empathy levels and time spent discussing mental health concerns. \(^{225}\) If physician practice patterns significantly differ, particularly for the treatment of marginalized patients, it would be beneficial to understand how these practice differences carry-into the treatment of older adults.

Along similar lines, it would be interesting to investigate the extent to which connected health devices could reinforce economic biases in the practice of medicine and in receiving quality (and equal) care. If connected health devices are not covered by insurance, as in the case of a smart phone, there could be significant financial barriers to acquiring these technologies. A Fitbit currently costs approximately $150, a smart scale costs approximately $120, and a smart mirror costs approximately $2,500. With increased integration comes increased pressure to acquire the relevant technologies. Patients who may not be able to afford the technologies would find physicians who rely on PGHD to be poor fits for providing them health care. A migration of lower-income patients to physicians who do not use the technologies (and who could be less empathetic, according to our discovered correlation between technology adoption and empathy) could follow, which would likely have negative outcomes for these lower-income patients. Just as many surgeons will refuse to perform risky surgeries that could taint their performance statistics, other specialists or general practitioners could favor the treatment of patients who are able to provide PGHD if these data render physicians better diagnosticians.

Another area of suggested research would be an examination of the medical disciplines in which collection of PGHD is already advanced or common, such as endocrinology. Patients with diabetes commonly provide their providers with PGHD from insulin pumps. Similarly, patients with congestive heart failure commonly provide their cardiologists with their weight from a smart scale so as to be monitored for water weight gain which would indicate acute failure. Case studies in either endocrinology or cardiology practices would serve to inform fields where PGHD integration might soon be headed and how integration could affect care, treatment, and the physician-patient relationship.

Finally, future research should weigh the magnitude of health benefits derived from increased patient health agency against the magnitude of the loss of the physician-patient relationship “safety net.”

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\(^{224}\) Ibid.

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Appendix A – Definitions of Terms

**Connected Health**: The integration of information technology such as mobile phones and apps, remote monitoring tools, personal health trackers, sensors, computers and networked devices, to help providers and patients manage chronic conditions, maintain health and wellness, and improve adherence, engagement and clinical outcomes.\(^{226}\)

**Empathy**: Empathy is a predominantly cognitive (rather than an emotional) attribute that involves and understanding (rather than a feeling) of experiences, concerns and perspectives of the patient, combined with a capacity to communicate this understanding.\(^{227}\)

**Health care provider**: A professional who provides preventive, curative, or rehabilitative health care services to patients. Health care providers represented in this this include but are not limited to: doctors, nurses, psychologists, and physical therapists.

**Internet of Things (IoT)**: The connection of devices to the internet.

**Mobile health (mHealth)**: “the use of mobile phones and other wireless technology in medical care.”\(^{228}\)

**Older adult**: An individual who is at least 65 years old.

**Physician-patient relationship**: A formal or inferred relationship between a physician and a patient which is established once the physician assumes the medical care or treatment of a patient.\(^{229}\)

**Patient-Generated Health Data (PGHD)**: “Health-related data created, recorded, or gathered by or from patients (or family members or other caregivers) to help address a health concern.”\(^{230}\)

In this thesis, PGHD refers to patient-generated health data that were collected using a smart device.

**Provider**: See health care provider.

**Smart devices**: “An electronic gadget that is able to connect, share and interact with its user and other smart devices.”\(^{231}\)

**Wearables**: A device that is worn to collect physiological data from the user.


Appendix B – Health Care Provider Survey

Q1.1 This survey was designed to help us better understand the use of smart devices in health care. The results may inform health policy memos and academic reports. You will be asked a series of questions about your use (or non-use) of smart devices in health care settings. The survey is anonymous and expected to take about 15 minutes. The records of the study will be kept private. In any report that might be published, we will not include any information that will make it possible to identify any participant. If you would like to receive a copy of the survey results, you can opt to leave your email address at the end of the survey. Your participation is voluntary and refusal to participate will involve no penalty. You may discontinue participation at any time and skip any question you do not wish to answer. If you have any questions, please feel free to email marikap@mit.edu. If you have any questions specifically regarding your rights as a survey participant, please email the MIT Committee on the Use of Humans as Experimental Subjects at (COUHES) at couhes@mit.edu.

By clicking START SURVEY, you are verifying that you have read this explanation of the study and you agree to participate.

- START SURVEY
- Leave survey

If Leave survey Is Selected, Then Skip To End of Survey

Q2.1 What is your principal practice specialty?
- Family practice
- Pediatrics
- Geriatrics
- General internal medicine
- General surgery
- OB/GYN
- Medical specialty:
- Surgical specialty:
- Other:

Q2.2 For the purposes of this survey, please consider patient-collected data to mean "health-related data created, recorded, or gathered by or from patients (or family members and other caregivers) to help address a health concern" (HealthIT.gov). We are interested in data that are collected, recorded, or transmitted through some sort of smart device, such as a wearable fitness tracker, a smartphone, an app, connected health monitoring equipment, etc.

Q2.3 What percentage of your patients provide you with health data from a smart device?

Display This Question:
If What percentage of your patients provide you with self-generated data? Is Greater Than 0

Q2.4 How old are your patients that collect health data (or whose data are collected) via smart devices/wearables? Check all that apply:
Q2.5 How accurate do you believe patient-collected data from a smart device are? If you had to assign a grade for how accurate the data are, what would you give?
- A+
- A
- A-
- B+
- B
- B-
- C+
- C
- C-
- D+
- D
- D-
- F
- I’m not sure

Q2.6 What best describes your principal practice setting?
- Non-federal hospital and adjacent outpatient clinics
- Federal hospital, VA or military hospital, and/or associated outpatient facilities
- Private practice
- Urgent care clinic/ambulatory surgery center
- Community health setting, including free clinics
- Nursing home or other non-hospital extended care facility
- Other:

Q2.7 Please indicate how much you agree or disagree with the following statement: My principal practice setting has adequate equipment (e.g., display screens, visualization tools) in place to receive, assess, and discuss data that patients collect with their own smart devices.
- Strongly disagree
- Disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Agree
- Strongly agree

Q2.8 What types of equipment would your principal practice setting need to be best able to receive, assess, and discuss data that patients collect with their own smart devices?
Q2.9 Please indicate how much you agree or disagree with the following statement: My principal practice setting has adequate policies and/or processes in place to receive, assess, and discuss data that patients collect with their own smart devices.

- Strongly disagree
- Disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Agree
- Strongly agree

Q2.10 What types of policies would your principal practice setting need to be best able to receive, assess, and discuss data that patients collect with their own smart devices?

Q2.11 Please indicate how much you agree or disagree with the following statement: My principal practice setting has adequate human capital/support systems in place that would assist in my ability to receive, assess, and discuss data that patients collect with their own smart devices.

- Strongly disagree
- Disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Agree
- Strongly agree

Q2.12 What types of human capital/support systems would your principal practice setting need to be best able to receive, assess, and discuss data that patients collect with their own smart devices?

Q2.13 On average, I see most of my patients...

- Less than once a year
- Once per year
- Twice per year
- Three times per year
- More than three times per year
- Other:

Q2.14 How would you describe the socioeconomic distribution of your patients?

- Mostly a mixture of socioeconomic levels
- Mostly lower income
- Mostly middle class
- Mostly higher income
- Don't know
Q2.15 How would you best describe the distribution of health insurance coverage of your patients?

- Mostly a mixture of insurance coverage
- Mostly privately insured
- Mostly covered by Medicare
- Mostly covered by Medicaid
- Mostly covered by both Medicare and Medicaid
- Mostly uncovered
- Other:
- Don't know

Q3.1 For the purposes of this survey, please consider patient-collected data to mean "health-related data created, recorded, or gathered by or from patients (or family members and other caregivers) to help address a health concern" (HealthIT.gov). We are interested in data that are collected, recorded, or transmitted through some sort of smart device, such as a wearable fitness tracker, a smartphone, an app, connected health monitoring equipment, etc.

Q3.2 Do you currently look at patient-collected data when providing healthcare to patients?

- Yes
- No

Display This Question:
If Do you currently look at patient-collected data when providing healthcare to patients? Yes Is Selected

Q3.3 In general, how often do patient-collected data influence your treatment plan?

- Never
- Rarely
- Sometimes
- Often
- Very Often
- Always

Q3.4 I consider it my job to receive, review, and discuss patient-collected data from a smart device.

- Yes
- Maybe
- No

Display This Question:
If I consider it my job to receive, review, and discuss patient-collected data from a smart device. Yes Is Selected

Q3.5 Please explain why you believe it is your job to receive, review, and discuss patient-collected data from a smart device.

Display This Question:
If I consider it my job to receive, review, and discuss patient-collected data from a smart device. Maybe Is Selected

Q3.6 Please explain why you selected "maybe," and why it might be your job to receive, review, and discuss patient-collected data from a smart device.

Display This Question:
If I consider it my job to receive, review, and discuss patient-collected data from a smart device. No Is Selected

Q3.7 Please explain why you don't believe it is your job to receive, review, and discuss patient-collected data from a smart device.
**Q3.8 How would patient-collected data from a smart device affect the following?**

<table>
<thead>
<tr>
<th>Activity</th>
<th>Would be harmful (1)</th>
<th>Would have no impact (2)</th>
<th>Would be helpful (3)</th>
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<tr>
<td>Assessing treatment effectiveness/tracking progress</td>
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<td>Detecting treatment side effects</td>
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<tr>
<td>Capturing a more complete picture of patient health</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Assessing treatment effectiveness/tracking progress</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Detecting treatment side effects</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Reducing unnecessary medical expenses</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Capturing a more complete picture of patient health</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Analyzing aggregate data from multiple patients</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Making patient visits more targeted/efficient</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Communicating with other health care providers about the patient's condition</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>

**Display This Question:**

If Do you currently use patient-collected data when providing healthcare to patients? Yes Is Selected

**Q3.9 How does your use of patient-collected data from smart devices/wearable technology change your interactions with patients?**

**Q3.10 How often do you recommend to your patients the technologies (e.g. FitBit, smart scale etc.) for patient-collected data via a smart device?**

- Never
- Rarely (less than 15% of the time)
- Sometimes (16-50% of the time)
- Often (51-75% of the time)
- Very often (76-99% of the time)
- Always

**Q3.11 I would encourage other physicians to make greater use of health data that comes from patients' smart devices/wearables/apps.**

- Strongly disagree
- Disagree
- Neither agree nor disagree
- Agree
- Strongly agree
- I'm not sure

**Q3.12 For which patient age groups would patient-collected data (specifically from a smart device) be insightful for you, if any? Check all that apply.**
Display This Question:

If For which age group would patient-generated data be insightful, if any? Check all that apply.

- 51-62 year olds
- 63-80 year olds
- 81+ year olds
- Other

Q3.13 If you believe that patient-collected data from smart devices/wearables could address problems presented by the geriatric population, which problems could be addressed? Please check all that apply.

- Medication/treatment compliance issues
- Trouble motivating patients to change health behaviors
- A feeling of being uninvolved in their own health decisions
- Difficulty recalling health habits or patterns
- A feeling of lacking support
- Reluctance to bring up embarrassing or unhealthy behaviors
- I do not believe patient-collected data could address problems presented by the geriatric population
- Other:

Q3.14 If you have received some sort of training or education to use patient-collected data, where did you receive this training? Check all that apply.

- Hospital/clinic
- Medical school
- Colleagues
- Industry promotions
- Conferences
- Continuing medical education courses
- Literature
- Other:
- I have not received any training or education regarding the use of patient-collected data from smart devices

Q4.1 On a scale of 1-10, how much would you want patient-collected data from smart technologies to be incorporated into your daily practice? (1 = Don't want at all and 10 = Very much want)

Q4.2 Please select the top 3 entities that you think could be effective in pushing patient-collected data from smart devices into the health care system. Please drag and drop the top 3 into the box.

<table>
<thead>
<tr>
<th>Top 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Insurance companies</td>
</tr>
<tr>
<td>Retailers</td>
</tr>
<tr>
<td>Practices/hospitals</td>
</tr>
<tr>
<td>Local or state governments</td>
</tr>
</tbody>
</table>
Federal agencies such as the FDA
The federal government
Individual health care providers
Individual patients or groups of patients
Employers
Technology companies (e.g. Apple, Google)
Pharmacies

Q4.3 Do the following factors prevent the integration of patient-collected data into the health care system?

<table>
<thead>
<tr>
<th>Factor</th>
<th>No opinion</th>
<th>No, this factor is not a barrier</th>
<th>Yes, this factor is somewhat of a barrier</th>
<th>Yes, this factor is an extreme barrier</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIPAA/Privacy concerns</td>
<td></td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>Provider reimbursement rates</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>Lack of incentives for patients to collect data</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>Incompatibility with EMRs</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>Lack of time</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>Insufficient technology training</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>Patients don't collect or don't share these kinds of data</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
</tbody>
</table>
Q5.1 Please respond to the following statements:

<table>
<thead>
<tr>
<th></th>
<th>1 Strongly disagree</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7 Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I try to think like my patients in order to provide better care</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I believe that empathy is an important therapeutic factor in treatment</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Emotional ties to my patients have a significant influence on patient outcomes</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I am skilled at viewing things from my patients' perspectives</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
Q5.2 Patient-collected data from a smart device (like a smartphone or a fitness wearable, for example) would help me to...

<table>
<thead>
<tr>
<th></th>
<th>Strongly disagree</th>
<th>Somewhat disagree</th>
<th>Neither agree nor disagree</th>
<th>Somewhat agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>have difficult discussions with my patients</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>give advice on health issues that were not the chief reason for the patient's visit</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>educate patients</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>make a more accurate diagnosis</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>make the patient feel at ease</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>let the patient tell their &quot;story&quot;</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>fully understand the patient's concerns</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>show care and compassion</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>explain things clearly</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>help the patient take control (explore what they can do to improve their health)</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>make a plan of action with the patient</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>be honest about the patient's health problems</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>
Q5.3 If I were to use patient-collected data from smart devices when I provide healthcare...

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly disagree</th>
<th>Somewhat disagree</th>
<th>Neither agree nor disagree</th>
<th>Somewhat agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>my patients would feel more &quot;understood&quot;</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>my patients would feel more involved in the decision-making process</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I would appear as a more committed physician</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>my patients would be more satisfied with their visit</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>my patients would have more trust in me</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>my patients would be more likely to disclose health patterns</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>they are ashamed of</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>it would improve the physician/patient relationship</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>my patients' might have better health behaviors and/or health outcomes</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

Q6.1 Which of the following types of devices do you use at least once a week to monitor your own health data (about your own body)?

- [ ] Wrist-based wearable
- [ ] Smart clothing
- [ ] A smart home appliance
- [ ] A non-wrist-based wearable
- [ ] A smartphone app
- [ ] Other:
- [ ] None of the above
Q6.2 When it comes to adopting new technology, how would you characterize yourself?
- Early adopter
- Average adopter
- Late adopter
- I don't know

Q7.1 What is your medical degree?
- MD
- DO
- Other:

Q7.2 In what stage of training are you?
- Intern
- Resident
- Fellow
- Attending
- Other

Q7.3 What is the zip code of your principal practice setting?

Q7.4 How many hours do you work per typical day (include all clinical and non-clinical duties)?

Q8.1 In what year were you born?

Q8.2 What is your gender?
- Male
- Female
- Other:

Q8.3 Please specify your ethnicity
- White
- Black or African American
- American Indian or Alaska Native
- Asian
- Native Hawaiian or Pacific Islander
- Other

Q8.4 Would you like to receive a summary of the results of this survey and remain on the MIT AgeLab's panel of physicians?
- Yes, my email is:
- No
Appendix C – Patient Survey

Q1.1 This survey was designed to help us better understand the use of smart devices in health care. You will be asked a series of questions about your use (or non-use) of these devices for health tracking and your opinions about technology in health settings. Participants who complete the survey will be entered into a drawing to win one of ten $25 Amazon.com gift cards. If you wish to be eligible for the drawing, we will ask for your e-mail address so that we can contact you if you win. Your e-mail address will not be stored with the data or retained after the drawing. The records of the study will be kept private. In any report that might be published, we will not include any information that will make it possible to identify any participant. If you would like to receive a summary of the survey results, you can opt to leave your email address at the end of the survey. Your participation is voluntary and refusal to participate will involve no penalty. You may discontinue participation at any time and skip any question you do not wish to answer. If you have any questions, please feel free to email marikap@mit.edu. If you have any questions regarding your rights as a survey participant, please email the MIT Committee on the Use of Humans as Experimental Subjects (COUHES) at couhes@mit.edu. By clicking START SURVEY, you are verifying that you have read this explanation of the study and you agree to participate.

O  START SURVEY
O  Leave survey
If Leave survey Is Selected, Then Skip To End of Survey

Q2.1 How experienced are you with various types of technology (for example, computers, smart phones, tablets)?
  O  Very experienced
  O  Somewhat experienced
  O  Not experienced
  O  Other ____________________

Q2.2 When it comes to adopting new technology, how would you characterize yourself?
  O  Early adopter
  O  Average adopter
  O  Late adopter
  O  I don't know

Q3.1 How would you describe your health?
  O  Poor
  O  Fair
  O  Good
  O  Very good
  O  Excellent

Q3.2 How often do you exercise for at least 20 minutes?
  O  Less than once a month
  O  1-3 times a month
  O  Once a week
  O  2-3 times a week
  O  4-6 times a week
  O  7+ times a week
  O  Prefer not to answer
Q3.3 On average, how often do you see a health care provider of any kind for your own health?
- Less than once a year
- Once per year
- Twice per year
- Three times per year
- More than three times per year

Q3.4 Where do you mostly go in order to receive medical care? Please check all that apply.
- Non-federal hospital and adjacent outpatient clinics
- Federal hospital, VA or military hospital, and/or associated outpatient facilities
- Private practice
- Urgent care clinic/ambulatory surgery center
- Community health setting, including free clinics
- Nursing home or other non-hospital extended care facility
- Other ____________________

Q3.5 Do you have a primary care physician?
- Yes
- No
- Other ____________________

Q3.6 Do you have health insurance for yourself?
- Yes
- No
- I don't know
- Prefer not to answer

Q4.1 Reminder: Smart patient-collected data are data that are collected, recorded, or transmitted through some sort of smart device such as a wearable fitness tracker, a smartphone, an app, or connected health monitoring equipment. On a scale of 1-10, how much would you want smart patient-collected data to be incorporated into your health care visits?
- 1 (Don't want at all)
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9
- 10 (Very much want)

Q4.2 Who are the top 3 institutions that could convince you to use, share and/or collect health data using a smart device. Please drag and drop the top 3 into the box in order.

<table>
<thead>
<tr>
<th>Top 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Insurance companies</td>
</tr>
<tr>
<td>Retailers</td>
</tr>
<tr>
<td>Practices/hospitals</td>
</tr>
<tr>
<td>Local or state governments</td>
</tr>
</tbody>
</table>
Federal agencies such as the FDA
The federal government
Individual health care providers
Individual patients or groups of patients
Employers
Companies like Apple or Google

Q4.3 Please sort the reasons why you don't use more wearables to collect health data via a smart device (like an app, fitness tracker, or connected health device, for example). You can drag and drop the items on the left into the boxes on the right.

<table>
<thead>
<tr>
<th>Not applicable</th>
<th>A small reason</th>
<th>A major reason</th>
</tr>
</thead>
<tbody>
<tr>
<td>_____ The technology is too expensive</td>
<td>_____ The technology is too expensive</td>
<td>_____ The technology is too expensive</td>
</tr>
<tr>
<td>_____ I have privacy concerns</td>
<td>_____ I have privacy concerns</td>
<td>_____ I have privacy concerns</td>
</tr>
<tr>
<td>_____ The technology isn't fun to use</td>
<td>_____ The technology isn't fun to use</td>
<td>_____ The technology isn't fun to use</td>
</tr>
<tr>
<td>_____ The technology looks &quot;uncool&quot;</td>
<td>_____ The technology looks &quot;uncool&quot;</td>
<td>_____ The technology looks &quot;uncool&quot;</td>
</tr>
<tr>
<td>_____ There aren't incentives to collect data</td>
<td>_____ There aren't incentives to collect data</td>
<td>_____ There aren't incentives to collect data</td>
</tr>
<tr>
<td>_____ It would complicate my life</td>
<td>_____ It would complicate my life</td>
<td>_____ It would complicate my life</td>
</tr>
<tr>
<td>_____ I don't know enough about these technologies</td>
<td>_____ I don't know enough about these technologies</td>
<td>_____ I don't know enough about these technologies</td>
</tr>
<tr>
<td>_____ It's too much work to learn how to use the technologies</td>
<td>_____ It's too much work to learn how to use the technologies</td>
<td>_____ It's too much work to learn how to use the technologies</td>
</tr>
<tr>
<td>_____ I can manage without it</td>
<td>_____ I can manage without it</td>
<td>_____ I can manage without it</td>
</tr>
<tr>
<td>_____ I don't think I could use it properly</td>
<td>_____ I don't think I could use it properly</td>
<td>_____ I don't think I could use it properly</td>
</tr>
</tbody>
</table>
Q5.1 How helpful for you would collecting your own data via a smart device be for each of the following? Smart devices include things like a smartphone, app, fitness tracker, or digital health monitor.

<table>
<thead>
<tr>
<th>Activity</th>
<th>1 (Would be very unhelpful)</th>
<th>2</th>
<th>3 (No impact)</th>
<th>4</th>
<th>5 (Would be very helpful)</th>
<th>I don't know</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tracking your progress towards some health goal</td>
<td>○</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Detecting side effects of medications</td>
<td>○</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reducing your medical expenses</td>
<td>○</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Capturing a more complete picture of your health</td>
<td>○</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Making your health care visits more efficient</td>
<td>○</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Communicating with multiple health care providers about your condition</td>
<td>○</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Having better access to health services</td>
<td>○</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Q5.2 How often has a doctor recommended smart technologies to you (for example, a wearable fitness tracker, a smartphone, an app, or connected health monitoring equipment)?

○ Never
○ 1 time
○ 2 times
○ More than 2 times
○ Not sure

Q5.3 To what extent do you agree or disagree with the following statement: I would specifically recommend a doctor to my friends if that doctor encouraged my use of smart devices to collect health information.

○ Strongly disagree
○ Somewhat disagree
○ Neither agree nor disagree
○ Somewhat agree
○ Strongly agree
Q5.4 Does the doctor you see most often seem ready to analyze data from a smart device (like a smartphone, a wearable fitness tracker, or connected health technology, for instance) if you were to share that information with them?
- No
- Maybe
- Yes

Display This Question:
If Does the doctor you see most often seem ready to analyze data from a smart device (like a smartphone, a wearable fitness tracker, or connected health technology, for instance) if you were to share ... Yes Is Selected
Q5.5 What makes the doctor seem ready to analyze data from a smart device?

Display This Question:
If Does the doctor you see most often seem ready to analyze data from a smart device (like a smartphone, a wearable fitness tracker, or connected health technology, for instance) if you were to share ... No Is Selected
Q5.6 What makes the doctor seem NOT ready to analyze data from a smart device?

Display This Question:
If Does the doctor you see most often seem ready to analyze data from a smart device (like a smartphone, a wearable fitness tracker, or connected health technology, for instance) if you were to share ... Maybe Is Selected
Q5.7 What would make the doctor seem more ready to analyze data from a smart device?

Q5.8 Thinking about elderly adults in particular, do you think patient-generated data from a smart device would help them to do the following? Please check all that apply.
- Follow their doctor's instructions
- Be motivated to change health behaviors
- Be involved in their own health decisions
- Remember health habits or patterns
- Feel supported
- Bring up embarrassing or unhealthy behaviors
- I do not believe patient-collected data could help elderly adults
- Other ____________________

Q6.1 Reminder: In this survey, we are interested in data that are collected, recorded, or transmitted through some sort of smart device, such as a wearable fitness tracker, a smartphone, an app, or connected health monitoring equipment. To what extent do you agree or disagree with the following statement: I consider it a physician's job to receive, review, and discuss health data collected via a smart device.
- Strongly disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Strongly agree

Q6.2 To what extent do you agree or disagree with the following statement: Emotional ties to physicians have a significant influence on whether I listen to their advice.
- Strongly disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Strongly agree
Q6.3 Reminder: Smart patient-collected data are data that are collected, recorded, or transmitted through some sort of smart device such as a wearable fitness tracker, a smartphone, an app, or connected health monitoring equipment. If my health care provider were to use smart patient-collected data, I would...

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly disagree</th>
<th>Somewhat disagree</th>
<th>Neither agree nor disagree</th>
<th>Somewhat agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>feel more &quot;understood.&quot;</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>feel more involved in the decision-making process.</td>
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<td>consider my provider as more committed.</td>
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<td>be more satisfied with my visit.</td>
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<td>have more trust in them.</td>
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<td>be more likely to talk about health patterns I am ashamed of.</td>
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<td>have a better relationship with my doctor.</td>
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<td>have healthier behaviors.</td>
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</tbody>
</table>
Q6.4 Patient-collected data is health-related data created, recorded or gathered by or from patients (or family members). Reminder: We are interested in data that are collected, recorded, or transmitted through some sort of smart device, such as a wearable fitness tracker, a smartphone, an app, or connected health monitoring equipment.

<table>
<thead>
<tr>
<th>Patient-collected data from a smart device would help me to...</th>
<th>Strongly disagree</th>
<th>Somewhat disagree</th>
<th>Neutral</th>
<th>Somewhat agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>feel at ease</td>
<td>☐</td>
<td>☐</td>
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<td>have difficult discussions with my physician</td>
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<td>learn about my conditions and treatment</td>
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<td>tell my &quot;story&quot;</td>
<td>☐</td>
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<tr>
<td>express my concerns or fears</td>
<td>☐</td>
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<tr>
<td>understand what the provider is saying</td>
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<td>take control (explore what I can do to improve my health)</td>
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<td>make a plan of action</td>
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<td>get advice on health issues that were not the main reason for my visit</td>
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<tr>
<td>receive honest feedback about my health problems</td>
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<tr>
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<td>Strongly disagree</td>
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<td>Have difficult discussions with my physician</td>
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</tbody>
</table>
Q7.1 Which of the following types of information do you collect about your own body at least once a week? For this question, consider BOTH smart data collection and more traditional collection methods. Please check all that apply.
- Heart rate
- Respiration or breathing rate
- Blood pressure
- Blood glucose or blood sugar level
- Steps taken
- Weight
- Sleep (quantity or quality of hours slept)
- Diet/Nutrition
- None of the above
- Other ____________________

Display This Question:
- If Which of the following types of your own self-generated data do you monitor and collect at least once a week? (Data that you collect about your own body) Blood glucose level Is Selected

Q7.2 What platform or device do you use to collect blood sugar or blood glucose level data? Check all that apply.
- Smart wearable device (please specify) ____________________
- Implanted medical device (please specify) ____________________
- Other medical device (please specify) ____________________
- An app (please specify) ____________________
- Traditional finger prick method (traditional glucometer)
- Other (please specify) ____________________

Display This Question:
- If Which of the following types of information or data do you collect about your own body once a week? Blood glucose or blood sugar level Is Selected

Q7.3 With whom do you share the blood sugar or blood glucose level data that you collect on yourself? Please check all that apply.
- No one
- Family members
- Friends
- Doctor(s)
- Other health professional, please specify: ____________________
- Other, please specify: ____________________

Display This Question:
- If With whom do you share the blood sugar or blood glucose level data that you collect on yourself? No one Is Not Selected

Q7.4 If you share blood sugar data from a smart device: Does the medical professional's use of your blood sugar data (from a smart device) change the way they interact with you?
- Yes, please explain: ____________________
- No, please explain: ____________________
- Not applicable - The blood sugar data is not collected or shared with a medical professional via a smart device.
Display This Question:
If Which of the following types of your own self-generated data do you monitor and collect at least once a week? (Data that you collect about your own body) Heart rate Is Selected

Q7.5 What platform or device do you use to collect heart rate data? Check all that apply.
- Smart wearable device (please specify) ____________________
- Smart clothing (please specify) ____________________
- Implanted medical device (please specify) ____________________
- Other medical device (please specify) ____________________
- An app (please specify) ____________________
- Take your pulse with your fingers
- Other (please specify) ____________________

Display This Question:
If Which of the following types of information or data do you collect about your own body once a week? Heart rate Is Selected

Q7.6 With whom do you share the heart rate data that you collect on yourself? Please check all that apply.
- No one
- Family members
- Friends
- Doctor(s)
- Other health professional, please specify: ____________________
- Other professional, please specify: ____________________

Display This Question:
If With whom do you share the heart rate data that you collect on yourself? Please check all that apply. No one Is Not Selected
And Which of the following types of information do you collect about your own body at least once a week? Heart rate Is Selected

Q7.7 If you share heart rate data from a smart device: Does the medical professional's use of these heart rate data (from a smart device) change the way they interact with you?
- Yes, please explain: ____________________
- No, please explain: ____________________
- Not applicable - The heart rate data is not collected or shared with a medical professional via a smart device.

Display This Question:
If Which of the following types of your own self-generated data do you monitor and collect at least once a week? (Data that you collect about your own body) Respiration rate Is Selected

Q7.8 What platform or device do you use to collect breathing or respiration rate data? Check all that apply.
- Smart wearable device (please specify) ____________________
- Smart clothing (please specify) ____________________
- Implanted medical device (please specify) ____________________
- Other medical device (please specify) ____________________
- An app (please specify) ____________________
- Count your own breaths
- Other (please specify) ____________________
Q7.9 With whom do you share the breathing or respiration rate data that you collect on yourself? Please check all that apply.
- No one
- Family members
- Friends
- Doctor(s)
- Other health professional, please specify: ____________________
- Other, please specify: ____________________

Q7.10 If you share breathing or respiration data from a smart device: Does the medical professional's use of these breathing or respiration rate data change the way they interact with you?
- Yes, please explain: ____________________
- No, please explain: ____________________
- Not applicable - The respiration or breathing rate data is not collected or shared with a medical professional via a smart device.
Display This Question:
If Which of the following types of your own self-generated data do you monitor and collect at least once a week? (Data that you collect about your own body) Blood pressure is selected

Q7.11 What platform or device do you use to collect blood pressure data? Check all that apply.
- Smart wearable device (please specify) ____________________
- Smart clothing (please specify) ____________________
- Implanted medical device (please specify) ____________________
- Other medical device (please specify) ____________________
- An app (please specify) ____________________
- Traditional sphygmomanometer (blood pressure cuff) either hand-operated or automated
- Other (please specify) ____________________

Display This Question:
If Which of the following types of information or data do you collect about your own body once a week... Blood pressure is selected

Q7.12 With whom do you share the blood pressure data that you collect on yourself? Please check all that apply.
- No one
- Family members
- Friends
- Doctor(s)
- Other health professional, please specify: ____________________
- Other, please specify: ____________________

Display This Question:
If With whom do you share the blood pressure data that you collect on yourself? Please check all that apply... No one is selected

And Which of the following types of information do you collect about your own body at least once a week? Blood pressure is selected

Q7.13 If you share blood pressure data from a smart device: Does the medical professional's use of your blood pressure data (from a smart device) change the way they interact with you?
- Yes, please explain: ____________________
- No, please explain: ____________________
- Not applicable - The blood pressure data is not collected or shared with a medical professional via a smart device.
Q7.14 What platform or device do you use to collect steps taken data? Check all that apply.
- Smart wearable device (please specify) ________________
- Smart clothing (please specify) ________________
- Implanted medical device (please specify) ________________
- Other medical device (please specify) ________________
- An app (please specify) ________________
- Pedometer that does not connect to the internet
- Other (please specify) ________________

Q7.15 With whom do you share the steps data that you collect on yourself? Please check all that apply.
- No one
- Family members
- Friends
- Doctor(s)
- Other health professional, please specify: ________________
- Other, please specify: ________________

Q7.16 If you share steps data from a smart device: Does the medical professional's use of your steps taken data (from a smart device) change the way they interact with you?
- Yes, please explain: ________________
- No, please explain: ________________
- Not applicable - The steps data is not collected or shared with a medical professional via a smart device.
Q7.17 What platform or device do you use to collect weight data? Check all that apply.
- Smart wearable device (please specify) ________________
- Smart clothing (please specify) ________________
- Implant medical device (please specify) ________________
- Other medical device (please specify) ________________
- An app (please specify) ________________
- Traditional scale
- Other (please specify) ________________

Q7.18 With whom do you share the weight data that you collect on yourself? Please check all that apply.
- No one
- Family members
- Friends
- Doctor(s)
- Other health professional, please specify: ________________
- Other, please specify: ________________

Q7.19 If you share weight data from a smart device: Does the medical professional's use of your weight data (from a smart device) change the way they interact with you?
- Yes, please explain: ________________
- No, please explain: ________________
- Not applicable - The weight data is not collected or shared with a medical professional via a smart device.
Display This Question:
If Which of the following types of your own self-generated data do you monitor and collect at least once a week? (Data that you collect about your own body) Sleep Is Selected

Q7.20 What platform or device do you use to collect sleep data? Check all that apply
- Smart wearable device (please specify) ____________________
- Smart clothing (please specify) ____________________
- Implanted medical device (please specify) ____________________
- Other medical device (please specify) ____________________
- An app (please specify) ____________________
- Bed-based sleep tracking device
- Sleep log/count the hours you sleep
- Other (please specify) ____________________

Display This Question:
If Which of the following types of information or data do you collect about your own body once a week? Sleep (quantity or quality of hours slept) Is Selected

Q7.21 With whom do you share the sleep data that you collect on yourself? Please check all that apply.
- No one
- Family members
- Friends
- Doctor(s)
- Other health professional, please specify: ____________________
- Other, please specify: ____________________

Display This Question:
If You share sleep data from a smart device: Does the medical professional's use of your sleep data (from a smart device) change the way they interact with you?
- Yes, please explain: ____________________
- No, please explain: ____________________
- Not applicable - The sleep data is not collected or shared with a medical professional via a smart device.
Display This Question:
If Which of the following types of your own self-generated data do you monitor and collect at least once a week? (Data that you collect about your own body) Nutrition Is Selected

Q7.23 What platform or device do you use to collect diet/nutrition data? Check all that apply.

- Smart wearable device (please specify) ______________________
- Smart clothing (please specify) ______________________
- Implanted medical device (please specify) ______________________
- Other medical device (please specify) ______________________
- An app (please specify) ______________________
- Other (please specify) ______________________

Display This Question:
If Which of the following types of information or data do you collect about your own body once a week? Nutrition Is Selected

Q7.24 With whom do you share the diet/nutrition data that you collect on yourself? Please check all that apply.

- No one
- Family members
- Friends
- Doctor(s)
- Other health professional, please specify: ______________________
- Other, please specify: ______________________

Display This Question:
If Which of the following types of information do you collect about your own body at least once a week? Nutrition Is Selected

Q7.25 If you share nutrition data from a smart device: Does the medical professional's use of your diet/nutrition data (from a smart device) change the way they interact with you?

- Yes, please explain: ______________________
- No, please explain: ______________________
- Not applicable - The diet/nutrition data is not collected or shared with a medical professional via a smart device.
**Q7.26** What platform or device do you use to collect data that you marked as "other"?

**Q7.27** With whom do you share these data? Please check all that apply.
- No one
- Family members
- Friends
- Doctor(s)
- Other health professional, please specify: ____________________
- Other, please specify: ____________________

**Q7.28** If you share data from a smart device: Does the medical professional's use of these data (from a smart device) change the way they interact with you?
- Yes, please explain: ____________________
- No, please explain: ____________________
- Not applicable - The data is not collected or shared with a medical professional via a smart device.
Q8.1 What kind of health insurance do you have?
- Please select:
  - Private
  - Medicare
  - Medicaid
  - Both Medicare and Medicaid
  - VA benefits
  - I don't know
  - Other ____________________

Q8.2 What is your gender?
- Please select
  - Male
  - Female
  - Other ____________________
  - Prefer not to answer

Q8.3 In what year were you born?

Q8.4 Please specify your ethnicity. Please check all that apply.
- White
- Black or African American
- American Indian or Alaska Native
- Asian
- Latino/Latina
- Native Hawaiian or Pacific Islander
- Other ____________________

Q8.5 What is the highest degree or level of school you have completed?
- Please select:
  - Some high school, no degree
  - High school graduate - high school diploma or the equivalent (for example: GED)
  - Some college, no degree
  - Associate degree (for example: AA, AS)
  - Bachelor's degree (for example: BA, AB, BS)
  - Some graduate school, no degree
  - Master's degree (for example: MA, MS, MEng, MEd, MSW, MBA)
  - Professional degree (for example: MD, DDS, DVM, LLB, JD)
  - Doctorate degree (for example: PhD, EdD)
  - Other ____________________

Q8.6 How would you describe the location of your home?
- Please select:
  - Urban
  - Suburban
  - Rural
  - Other ____________________
Q8.7 What is your zip code?

Q8.8 What is your approximate household income
- Please select:
  - Less than $25,000
  - $25,000-$49,999
  - $50,000-$74,999
  - $75,000 - $99,999
  - $100,000 - $149,999
  - $150,000 or more
  - Not sure
  - Prefer not to answer

Q8.9 Would you like to receive a copy of the results of this survey?
- Yes, my email is: ____________________
- No

Q8.10 If you would like to be included in the drawing for one of ten $25 Amazon gift cards, please enter your email address below.
References


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