CollaboRhythm: New Paradigms in Doctor-Patient Interaction Applied to HIV Medication Adherence

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Submitted to the Program in Media Arts and Sciences, School of Architecture and Planning, in Partial Fulfillment of the Requirements for the Degree of

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ABSTRACT

Despite astounding advances in medical knowledge and treatment in recent decades, health outcomes are disappointing and costs continue to rise. The traditional paternalistic and episodic approach to medical care is not meeting the needs of patients. CollaboRhythm is a technological platform that is being developed to enable a more modern collaborative and continuous approach to care by facilitating new paradigms in doctor-patient interaction. It asks the question: Can a system that allows patients to become active participants in their care, through data transparency, shared decision making, education, and new channels of communication, improve patient outcomes?

To begin testing the principles of CollaboRhythm, a system to support medication adherence for Human Immunodeficiency Virus (HIV) infection was created. It includes custom applications on a patient cell phone and an interactive device for the home called a Chumby as well as a collaborative workstation in the clinician's office. The applications allow the reporting of medication adherence, viewing of adherence performance including a personalized and dynamic simulation of HIV, and sending of supportive video messages. The system is novel in that it abandons the typical alarm-based method of supporting adherence and instead focuses on a multifaceted approach to generating motivation through awareness, self-reflection, education, and social support. Transparency of data and new communication channels allow efficient and socially engaging collaboration in real-time.

The HIV medication adherence system was evaluated in two stages. In the first stage, twelve patient interviews were conducted. The response to the principles of the system was positive with eleven of the twelve patients willing to share their adherence data with their clinician and all twelve agreeing that the HIV simulation and encouraging messages would motivate them to take their medications. Overall, eleven patients were interested in using the system. In the second stage, a one-month pilot deployment was conducted with four patients collaborating with an HIV medication adherence specialist. This stage also yielded encouraging results with three patients maintaining greater than 95% adherence all four patients confident that the system helped them improve their adherence. Important lessons were learned about its limitations, including ramifications of inaccurate reporting.

The results from the HIV adherence study suggest that there is merit in the new paradigms in provider-patient interaction facilitated by CollaboRhythm and that some patients are receptive to the idea of becoming more active participants in their care. Evaluations at a larger scale and for a number of clinical scenarios are warranted.

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1 INTRODUCTION

1.1 Motivation

Developed nations throughout the world are reforming their healthcare systems to contain costs and improve outcomes. Most approaches to reform focus on either modifying the behavior of clinicians or patients independently. They aim to produce incremental change through new practice policies, updated reimbursements schemes, implementation of electronic systems, or public health initiatives. But a radical rethinking of healthcare delivery, one that demands changes in the behavior of clinicians and patients as a team, may be required to significantly improve the health of the modern individual and modern society.

One way to view the problem is that patients are the most underutilized resource in healthcare. It is their health that is at stake, and they are demonstrating that they have a tremendous thirst for knowledge based on remarkable high rates of internet use for health-related information (Schwartz, et al. 2006). Unfortunately, the current model of care used by most clinicians does not embrace the contribution of the patient. This alienation not only fails to take advantage of valuable energy but likely also creates tension that may contribute to poor patient outcomes through non-adherence. After all, why would anyone want to follow instructions from a relative stranger if they had no say in the decisions that were made?

CollaboRhythm is a technological platform that has been in development for the past two years to facilitate new paradigms in provider-patient interaction. Most technology that is being developed to improve health clings to the traditional model of medical care based on paternalistic decision making and episodic encounters. The goal of the CollaboRhythm platform is to enable a more modern model of care that allows patients to become active participants. This new model is based on data transparency, shared decision making, education, and new channels of communication. The platform will allow research to be conducted for specific disease scenarios to determine if this new model of care can help to improve patient outcomes and potentially decrease healthcare costs.

1.2 Problem

Chronic disease is a significant burden to patients and to the healthcare systems of the world. It accounts for more than 75% of healthcare spending in the United States and a smaller but similarly high percentage of that in other developed nations (Centers for Disease Control and Prevention 2008). The rate of adherence to therapy for chronic disease is consistently poor with fewer than 50% of patients taking their medications correctly (World Health Organization 2003). Medication non-adherence is the cause of 10% of hospital admissions, 23% of nursing home admissions, and 125,000 deaths a year in the United States (World Health Organization 2003). In this country alone, the direct and indirect costs of non-adherence have been estimated to be greater than $177 billion a year (Ernst and Grizzle 2001). More importantly, chronic disease and poor adherence to therapy are adversely affecting the lives of billions of people.

Management of chronic disease requires patients to change their behavior, but the current healthcare systems of the world are not built to effectively assist patients in this process. The model of intermittent visits and one-sided recommendations essentially assumes that it is the responsibility of the patient to manage the necessary lifestyle changes and medication taking behavior on his or her own. In addition, barriers to patient access of data and the significant burden involved in communication with clinicians provides significant enough resistance to patients taking an active role in their care that it is easy for them to resign hope and forget about the looming threat of chronic disease.

The adherence to medications for Human Immunodeficiency Virus (HIV) is a specific example of a clinical problem that the traditional paternalistic and episodic model of care has failed to address adequately despite the availability of effective treatments. This is not to say that individual clinicians have not achieved great success with their HIV patients. Instead, the idea is that the problem has proved too big and too complicated to be handled at scale with the clinicians and resources available.

Medication adherence for HIV infection is the focus of considerable attention for a number of reasons:

- Exceptionally high adherence rates (>95%) are required for effective treatment of infection (Montaner, et al. 1998) (Paterson DL 2000).
- The current rate of adequate medication adherence is poor. It has been estimated to be between 33% and 88% depending on the patient population, definition of adherence, and method of evaluation (Friedland G 1999).
- Medication non-adherence and sub-optimal adherence in a vast majority of cases lead to AIDS, opportunistic infections, and death.
- Sub-optimal adherence has important public health implications because it leads to medication resistance and higher risk of disease transmission (Bangsberg DR 2000). Resistance rates in newly diagnosed patients to at least one medication have been reported as high as 80% (Voelker 2000).

The factors affecting HIV medication non-adherence are different for every patient case. The complexity of the medication regimen plays a role, with the number of pills, number of administrations a day, and the number of dietary and other restrictions all affecting adherence (Bartlett, et al. 2000) (D'Arminio 2000) (Stone, et al. 1988). The occurrence of side-effects has been clearly linked to medication cessation (Halkitis PN 2003). Patient factors such as level of education and literacy, alcohol and drug abuse, depression, childcare duties, economic constraints, and social support are also very important to their adherence (Halkitis PN 2003) (Chesney 1997) (Malow R 2001) (Chesney MA 2000) (Gordillo V 1999) (Murphy DA 2001). Patient education and beliefs about the effectiveness of medication are crucial (Siegel K 2000) (Ng JJ 2000).

While every patient may deal with different factors that affect adherence, it has been shown that a supportive doctor-patient relationship is capable of aiding the patient to overcome many of these factors (Stone, et al. 1988) (Morse, et al. 1991) (Sbarbaro 1990) (Stewart, McWhinney and Buck 1979). Unfortunately, most physicians do not address adherence. (Hedge and Petrak 1998) This presents a significant opportunity for improvement in HIV medication adherence, since it is likely that this important omission is due to time constraints and lack of effective tools rather than physician disregard.

1.3 Solution

The CollaboRhythm platform provides a set of technological tools that aim to facilitate new models of care that will have an impact on chronic disease management and health-related behavior change. A novel electronic record simultaneously serves the needs of the clinician and the patient. This creates total transparency and allows patients to actively engage in informed and data-driven discourse with their providers. Modern patient interfaces allow them to easily incorporate management of their health and communication with providers into their busy lives. Software agents perform robotic and routine tasks at times and at a pace convenient for patients in order to offload burden and facilitate more fruitful

communication. Finally, collaborative interfaces allow shared-decisions to be made and for patients to actively engage in education with their providers.

A system to support medication adherence for Human Immunodeficiency Virus (HIV) infection was created to begin testing the ideals of CollaboRhythm. The system aims to change the behavior of both the provider and the patient and to give them tools to work more effectively as a team. A driving hypothesis of CollaboRhythm is that patients who have more say in their health decisions and who feel more in control of their diseases may be more likely to be adherent. As a result, shared decision making, personalized visualizations, and education are core components of the HIV medication adherence system.

The HIV medication adherence system can best be described as a collaborative awareness system that allows the patient and coaching clinician to report medication adherence, track performance, and communicate efficiently. It also aims to motivate the patient and to allow the clinician to provide social support. The patient interacts with the system through either a cell phone or a Chumby (http://www.chumby.com), which is a small home electronic device with wireless internet connectivity. The clinician interacts with the system through an office workstation either alone or in collaboration with the patient. The core software interfaces are a clock visualization of the patient's medication schedule for the day, an adherence performance visualization including graphs of estimated blood concentration for each medication, a dynamic simulation of HIV infection driven by the patient's laboratory tests and adherence reports, and tools for sending and receiving asynchronous video messages.

1.4 Brief Summary of Results

The HIV medication system was evaluated in two stages in collaboration with Dr. Helene Hardy of the Center for HIV and AIDS Care and Research at Boston Medical Center under the direction of Dr. Paul Skolnik. The first stage consisted of twelve interviews in which patients had the opportunity to interact with the system and provide their feedback. Patient responses to the overall principles were positive. Eleven of the twelve patients were willing to share their adherence data with their clinician and all twelve agreed that the HIV simulation and encouraging messages would motivate them to take their medications. Overall, eleven patients agreed that they wanted to use the system to improve their medication adherence. The second stage consisted of a one-month pilot deployment of the system to four patients and an HIV medication adherence specialist. Three of the patients maintained greater than 95% adherence and all four thought that it helped to improve their adherence. One patient had a number of difficulties with both adherence and accurate reporting, which highlighted some of the limitations of the system including the potential for dishonest reporting because of reward and the potential of inappropriate sense of security due to inaccurate reporting.

1.5 Contributions

This thesis presents a technological platform that will enable research to be conducted on new paradigms in provider-patient interaction and their effects on patient outcomes. Although the evaluation that was conducted focused on HIV medication adherence, the larger contribution of this work is preliminary evidence that the more broad goals of the CollaboRhythm platform have enough merit to warrant further investigation. Patients were not only willing to be actively involved in their treatment by reporting their adherence, but they were excited about the potential that it might offer in terms of allowing improved care. This is a testament to the principle that patients really are motivated to collaborate and that this might improve their adherence and outcomes.

In the process of describing the CollaboRhythm platform and the evaluation of the HIV medication adherence system, a number of novel concepts and technical advances will also be described that are important components of the vision. These include:

- The premise of a hybrid electronic record that serves the needs of both the provider and the patient in order to maximize transparency and facilitate data-driven discussion.
- The design of a collaborative workstation for the clinician's office that allows for shared decision making and patient engagement beyond what is possible today.
- A new model for technological support of medication adherence that encourages patients to be proactive and self-reflective rather than reactive and that focuses on the importance of teamwork and social support.
- The presentation of disease state simulation as a motivational and educational tool that is both personalized and dynamic.

1.6 Organization of Thesis

Chapter 2 reviews background information relevant to the CollaboRhythm platform. Chapter 3 describes the core components of the CollaboRhythm platform. Chapter 4 reviews background relevant to the problem of HIV medication adherence. Chapter 5 presents the system that was created for supporting HIV medication adherence. Chapter 6 describes the evaluation of the system including methodology and results. Chapter 7 concludes with the contributions of the thesis and the plan for future work.

2 BACKGROUND – MEDICAL RECORDS AND PATIENT ACCESS

2.1 Electronic Medical Records

Electronic medical records are the current core effort in health information technology throughout developed countries. They are record keeping solutions that are typically managed by each individual health institution with individual patient records essentially owned by that institution. Since patients usually visit numerous health institutions in their care, this means that each institution maintains some subset of the data about that patient's health. Currently interoperability of these systems is poor. In addition, there are economic forces that encourage institutions not to share data. As a result, these separate sets of data typically remain separate, resulting in the need to repeat many medical tests or for responsibility to be placed on the patient for communicating results. This often leads to inefficiency, patient frustration, and medical errors.

Typical electronic medical record systems are designed to be used by the medical professional without viewing by or involvement from the patient. They are primarily systems for tracking patient data and managing medical billing. Most electronic medical record systems do not include interfaces for patient education, shared-decision making, or collaborative review of data.

There is little evidence that the current generation of electronic medical record systems have achieved significant improvements in efficiency or cost-effectiveness of care. There are some studies that have shown improved revenue for individual practices, but much of the increased revenue comes from more accurate and more comprehensive billing (Wang SJ 2003). This potentially increases the cost of healthcare for the nation. There is some evidence that current electronic medical records may even decrease efficiency and adversely affect patient care. A survey at a Veterans Affairs hospital showed that a significant number of patients felt that the computer adversely affected the amount of time that the physician spent talking to, looking at, and examining them (Rouf EJ 2007). A survey at Michigan State University showed that 49% of physicians felt that their EMR had decreased the ease of performing departmental work and that 61% would go back to a paper-based system if they had the chance (Whitten PL 2007). This is most likely because these systems typically take paper-based processes and simply convert them to their electronic equivalent without significant consideration of how these processes might be transformed to take advantage of technology. In addition, the electronic equivalents typically have less flexibility and may limit the ability of a clinician to express information efficiently and effectively.

Disappointment with current electronic medical record systems is reflected by the fact that the adoption of electronic medical records in the United States is currently estimated to be only 13%. More specifically, only 4% of doctors use what is considered to be a fully-functional system with electronic prescription capabilities and automatic retrieval of laboratory tests. (DesRoaches CM 2008) These low adoption rates are also affected by the high cost of implementation and maintenance of these systems.

2.2 Personal Health Records

Personal health records, also known as personally-controlled health records, are electronic records that are owned, controlled, or maintained by the patient. The premise is that, if these systems allow patients to easily aggregate data from each of the separate medical institutions, then this will allow for them to more easily track their medical care and to be more involved. They may also help to eliminate wasteful repeat testing and may help to streamline communication.

Personal health record platforms have been in development for more than a decade. Many initial implementations failed to achieve significant adoption, likely because they required patients to manually enter all of their health data and because there was little opportunity for patients to use these records in communication with clinicians.

Today there are several large personal health record efforts that are beginning to have significant traction. Most of these were inspired or built from the code base of the PING open source electronic medical record platform originally developed at the Massachusetts Institute of Technology and now known as Indivo and managed by the Children's Hospital Informatics Program (http://indivohealth.org) (Riva, et al. 2001) (Mandl, et al. 2007). The other efforts include Google Health (https://www.google.com/health) and Microsoft HealthVault (http://www.healthvault.com).

Current personal health record platforms allow data to be automatically populated from laboratories, physician offices, hospitals, and other healthcare institutions, which greatly decreases the burden of data entry for patients. Some, such as Indivo and HealthVault, also allow patients to control what permissions for manipulating data are given to each individual and medical institution. They also allow patients to view a log of data access on top of other privacy mechanisms in order to further patient control.

Unfortunately, there are still a number of barriers preventing the reality of a comprehensive personal health record. Although many standards for clinical data have been created, there are still a number of competing and incomplete representations. Because of this, reconciliation of data is poor, such that entries from multiple institutions may become duplicated and contain different subsets of information. Also, because representations have been simplified to allow for standardization, they often are not comprehensive enough to allow for optimal use of the data.

2.3 Patient Access to Medical Records

There is some evidence that facilitating patient access to their medical records can have positive effects on patient care. A comprehensive review showed that overall patients were interested in viewing their medical records, that this could have positive effects on patient education, that it allowed for correction of errors, and that it allowed patients to be more prepared for visits (Ferreira A 2007). Of particular importance was a study in England where patients were routinely given copies of their medical records prior to visits to read while waiting. This study showed that 75% of respondents stated that having access to their notes would "help break down barriers between them and the doctor" and "give information which one was not sure about". Over 70% of patients felt that it would give them more confidence in the doctor, and over 65% felt that it would help them to understand their condition and feel that their doctor understood them. Many physicians are afraid that giving patients access to records will undermine confidence, but this study showed that 67% of patients disagreed that it would give them less confidence in their doctor (Honeyman A 2005). There is often also concern from physicians that patient access to medical records will cause unnecessary and detrimental anxiety. This concern has been studied since the early 1990s, however, and has been shown to be relatively unfounded with the vast majority of patients considering the experience positive and reporting that it did not cause them to be upset or anxious (McLaren 1991) (Pyper C 2004). A study of psychiatric patients showed that 51% rated the experience as having provided helpful information and only 28% were upset with what they had read (Bernadt M 1991). It is likely that if a medical record was actually specifically designed to be used as a collaborative tool by the medical provider and the patient, that it would be received even more positively.

2.4 Physician Reactions to Informed Patients

As mentioned earlier, patient access of health information on the internet is common (Schwartz, et al. 2006). Physician reactions to this vary, but there is overall a negative opinion with belief that it contributes to misinformation, confusion, distress, and inappropriate or detrimental self-diagnosis and self-treatment (Ahmad, et al. 2006) (Kim and Kim 2009). There is also a general consensus that it leads to increased physician burden. It has been hypothesized that, in order for information retrieved by patients to be useful in care, that they will need to learn effective methods for searching for information and evaluating applicability and accuracy and that physicians need to develop new methods of communication (Murray, et al. 2003).

3 COLLABORHYTHM

CollaboRhythm is a technology platform that is being developed by the author at the MIT Media Lab to facilitate a more modern collaborative and continuous model of medical care and to allow research to be conducted on the new paradigms of interaction that it enables. The traditional paternalistic and episodic model of care that is currently employed in most medical practices is based on several archaic limitations. In the past, patients did not have access to knowledge about diseases and treatment, and they lived in a society that was accustomed to delays in communication. Doctors had to make decisions for patients, and patients had to rely on occasional visits to get the guidance that they needed. Today, in many countries and in most social circles, the internet has irrevocably changed the mindset of citizens. They are able to access an immense corpus of knowledge in an instant. They also pride themselves on being informed and empowered. In addition, text messaging, e-mail, instant messaging, and video conferencing are an important part of the way in which modern individuals connect. There is an expectation of immediacy in communication. The hypothesis of CollaboRhythm is that the traditional model of medical care cannot meet the needs of patients and produce acceptable outcomes if it does not respect the expectations of the modern individual and the changes that are taking place in society.

The CollaboRhythm platform focuses on prevention, holds shared decision-making as a vital component, transforms documentation into an educational task, and enables remote visits and collaboration that are advanced beyond simple video conferencing. The core of CollaboRhythm is a hybrid personally-controlled health record (PCHR). It is used as the data store so that patients have all of their information available wherever or whenever they may need and so that they can contribute their extremely important, yet often overlooked perspective. Novel interfaces for both patients and providers aim to allow patients to become active participants in their care beyond what is possible today. On the patient side, applications on cell phones, computers, televisions, and other interactive devices allow them to track their goals, monitor their health, and communicate more effectively with their providers. Automated artificial personalities play a critical role in this system by extending the capabilities of both individuals and their coaches. They facilitate conversation through the use of pre-visit questionnaires, follow-up evaluations, and chronic disease management tools. On the provider side, a collaborative point-of-care workstation exposes all information in patient-friendly form so that office visits are transformed into teamwork sessions. Patients are encouraged to interact in decision making processes and providers are empowered with new educational tools.

A primary goal of CollaboRhythm is to eliminate the asymmetry between doctors and patients by transforming doctors and other providers into coaches and patients into empowered individuals. The hope is that this will allow patients to become more active participants in their care. They will become more educated about their health problems, more engaged in decision making, and more likely to adhere to therapies. It aims to achieve these goals by encouraging collaboration and initiating channels of care that remain open after the patient leaves the office.

3.1 Hybrid Personally-Controlled Health Record

The core of the CollaboRhythm platform is a personally-controlled health record (PCHR) that aims to be a hybrid between an electronic medical record and a personal health record. It attempts to use the benefits of each while eliminating most of their limitations. The PCHR was implemented using Microsoft HealthVault as the data storage, encryption, and transmission backbone. The functionality of the system was modified and new data types were created to augment the capabilities of the CollaboRhythm

platform. HealthVault was chosen because it allowed this customization while Google Health did not and Indivo currently required significantly more effort to achieve the same results.

Individuals own all of their health data in CollaboRhythm's PCHR, and they can control who has access to each category of data. For example, one individual might give access to all health data to her primary care doctor but only medication adherence data to the provider who helps her manage her Coumadin regimen. Another individual may want to allow all of his de-identified data to be available for research, while another may want hers available to everyone who has the same rare disease as her. In this way, the data structure of CollaboRhythm not only addresses the future needs of individuals and their coaches, but also the health of others and the healthcare system as a whole.

An important difference in CollaboRhythm's implementation of the PCHR is that its data types are specifically designed so that they meet the needs of both providers and individuals. Providers can perform their documentation directly into the PCHR of the patient. In fact, the record at the core of CollaboRhythm has data types that are more powerful than those in current electronic medical record systems. These data types allow for providers to retrieve data in much more efficient and effective ways. For example, a provider using the system may query, "Show us the history of diabetes for the past year." Because the data structures in this record were carefully engineered, the system is actually capable of retrieving the individual's symptom diary associated with diabetes, the provider's assessment of diabetes control, all of the blood glucose measurements, all of the hemoglobin A1C measurements, the history of the dosage of metformin, and all ophthalmologic and podiatric exams, all from this single query. This type of retrieval certainly improves the efficiency of providers, but more importantly it allows the provider to remain engaged with the patient so that they can have a fruitful discussion about the data. On the other hand, with traditional data retrieval, patients are often frustrated by the perception that the providers are more concerned with interacting with the computer than with addressing their needs.

Although the literature introduced in Section 2.3 Patient Access to Medical Records suggests that physician fears about patient access to medical records are relatively unfounded, even the most progressive of record systems give physicians the opportunity to keep significant amounts of information private from patients. The hypothesis of CollaboRhythm is that even the slightest compromise in transparency of data will undermine the confidence of patients and have significant deleterious effects on successful teamwork. Clinicians using the system are not capable of hiding any data from the patient. It is likely that, with this design, clinicians will adapt to use documentation in ways that are useful to improving patient outcomes rather than making evaluative statements purely for documentation purposes. It may be considered asymmetric and potentially damaging that patients are able to control who has access to what parts of their data, but this necessary to protect patient privacy. The premise is that, typically a patient will need to agree to share all of their health data pertinent to the specialty of a given clinician in order to engage in a collaborative relationship. Summary information about what sections of data have been withheld will always be easily accessible to providers so that they do not assume that they have all data.

3.2 Ubiquitous Patient Interfaces

The CollaboRhythm platform allows for interfaces to be created on any internet-connected technology. Thus far, prototypes of interfaces for patients have been created on the computer, cell phone, television, and a novel device called a Chumby (http://www.chumby.com) that is essentially a small internet

connected device with a touch screen and other sensors. This variety of interfaces allows patients to have ubiquitous access to their health information and provides seamless connectivity with their provider coaches.

There is a long history in medicine of worship of the doctor and relegation of the patient to the role of supplicant. The goal of CollaboRhythm is to begin to eliminate this asymmetry by empowering patients to become active participants in their care. This will be done by giving them a voice to provide meaningful data, both subjective and objective, and tools to reason with and explore this data collaboratively with their provider coaches. The driving philosophy of these components is that patients are the most underutilized resource in healthcare. Instead, they should be the most revered contributors, since it is their health that is at stake.

Since CollaboRhythm is built on a personally-controlled health record (PCHR) backbone, it becomes an obvious extension that patients are free to contribute data. The challenge, however, is how to make this experience fruitful in the care of the patient and also engaging. While current personal health record systems burden patients with entering objective data including what medications they take, this is removed in CollaboRhythm because providers also use the system. Objective data including medications, lab tests, immunizations, surgical reports, etc. are already available. This allows the focus to be shifted so that patients can log the information that is important to them such as their symptoms, mood, adherence behaviors, side-effects, and alternative therapies that they are trying. The focus is also on creating new communication channels with providers, so that patients are not limited by disconnected episodic visits, but that their needs are addressed as they arise and that potential emergencies are averted. This type of interaction is necessary if primary care wishes to truly engage patients in preventative care.

3.3 Conversational Agents

There is still a considerable debate in the field of human-computer interaction about the utility of conversational agents and the settings in which they are useful (Zue and Glass 2000). The use of anthropomorphism in these interfaces is even more debatable (Dehn and van Mulken 2000) (Ferguson, et al. 2002). It has been shown, however, that relational agents can lead to improved therapeutic alliance and increased patient desire to continue using the technology in certain situations when compared to non-relational technologies (Bickmore, Gruber and Picard 2005).

The decision to develop conversational agents for the CollaboRhythm platform is based on research that has shown that computers outperform physicians in a number of tasks that are conversational in nature. A study of primary care physicians showed that they asked only 59% of essential history items (Ramsey, et al. 1998) Up to 54% of patient problems are not elicited by physicians, and physicians and patients even disagree about the reason for office visits a significant percentage of the time (Stewart, McWhinney and Buck 1979) (Boland, et al. 1998). This is not completely surprising considering that it has been found that physicians on average interrupt patients after only 24 seconds (Marvel, et al. 1999) (Rhoades, et al. 2001). Computer interfaces for medication questioning, on the other hand, do not forget to ask questions and are well received because that do not hurry patients, do not use complicated language, and do not make patients feel as if they are been evaluated (Slack and Van Cura 1979) (Mayne, Weksel and Sholtz 1968) (Bachman 2003). There is overwhelming evidence that patients report sensitive health information including alcohol use, drug use, sexual activity, suicide attempts, and domestic violence more reliably to computers than to physicians (Lucas, et al. 1977) (Paperny, et al. 1990) (Millstein and Irwin 1983)

(Greist, et al. 1973) (Lapham, Kring and Skipper 1991). Patients in these studies typically report that they want the physician to have the information elicited, but that it is difficult to present it face-to-face with a doctor.

The goal of the cited research about computer interfaces is not an attack on physicians; instead it is a suggestion that physician time is not appropriately allocated in the traditional model of medical care. The studies provide supporting evidence that computers are better at robotic and time consuming tasks and for eliciting information involving stigmata. Physicians certainly outperform computers in the majority of truly important roles including reasoning with complex diagnostic information, developing rapport with patients, and devising appropriate therapeutic interventions. The argument is that the utilization of computers for the tasks in which they excel will allow physicians to spend more time on high-level collaborative tasks such as encouraging education, facilitating shared decision making, and providing social support.

The conversational agents have been created for the CollaboRhythm platform aim to augment the capabilities of both providers and individuals. Their goal is not to replace human-to-human interactions, but instead to facilitate them in ways that are not possible because a human can only be in one place at a time and in one conversation. The programs created are advanced beyond questionnaire-based systems because they can follow complex decision trees and use commonsense artificial intelligence to allow patients to respond in natural language (Lieberman, et al. 2004). They are also capable of using human-like characters that speak in natural language and that use empathetic, affective, and other human-like relational content in their dialogue. However, because of the realization that anthropomorphism may not always be appropriate or that it may be received better by some patients than others, these components can be easily deactivated or customized.

The core agent for CollaboRhythm is one that converses with the patient at home at the point of scheduling a visit with the provider. Instead of the patient calling the office and revealing sensitive information to a human that is not directly involved in care, he or she has a conversation with Linda, a relational agent. Linda does not rush the patient or even care if the patient needs to call a family member or wait an hour to think about the answer to a question. She collects all of the necessary answers and submits them to the provider to care for the patient. Her role is not to provide diagnosis, but to prepare both the patient and the provider for the visit. In addition, the information that she elicits is critical in allowing the provider to triage care more appropriately. In most cases, the provider may be able to care for the patient remotely. In others, he or she may schedule lab tests before even seeing the patient so that care can be delivered more efficiently. The most important benefit, however, is that the provider and patient can spend their face-to-face time discussing the patient's perspective, educating, and compromising on treatment plans rather than being forced into hurried interrogation.

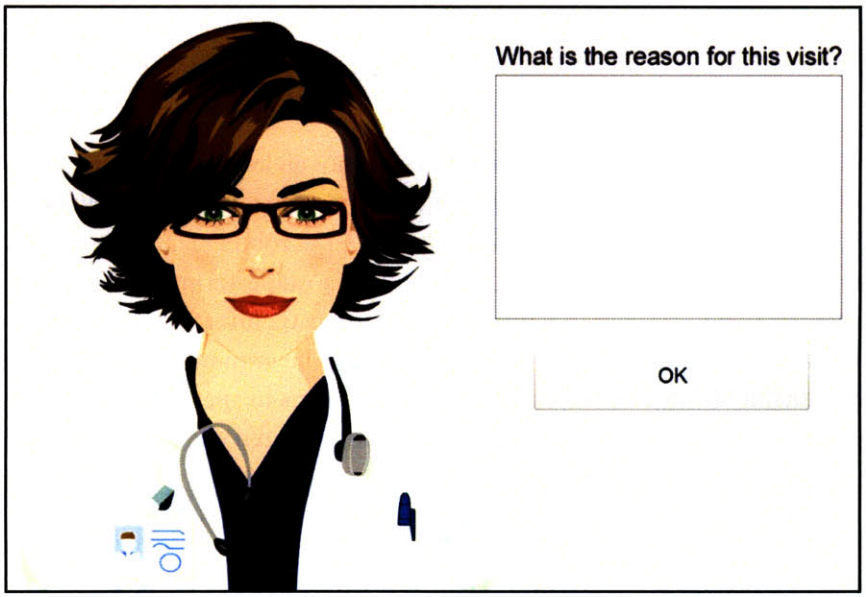

Figure 1: Anthropomorphic Conversational Agent. Linda conducts pre-visit conversations with patients in order to prepare them for visits and make sure that all of their issues are addressed.

3.4 Collaborative Point-of-Care Workstation

Typical medical record workstations are not designed to involve the patient. Their interfaces are driven by mouse and keyboard and require full clinician attention. This often causes leads to patient aggravation and ineffective communication.

The collaborative workstation for CollaboRhythm was designed to allow patients to become actively involved in their care during office visits. Data transparency, shared decision making, and engaging education are fundamental goals of the CollaboRhythm platform and are embraced by the collaborative workstation. It assumes that it is not reasonable to expect patients to contribute data about their health if they are not able to engage in discussion about this data in the office.

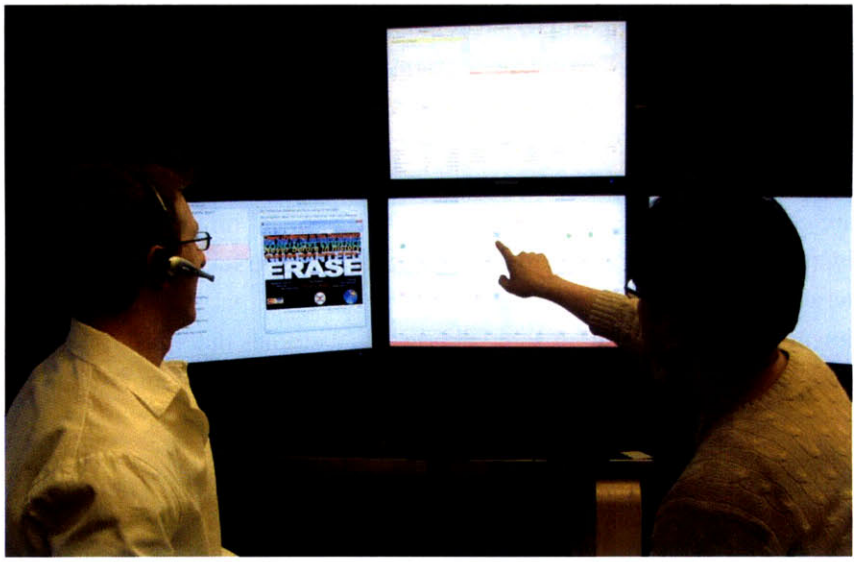

Figure 2 : Point-of-Care Collaborative Workstation. This speech and touch-controlled component of CollaboRhythm allows individuals to be involved in decisions regarding their health with their providers by exploring personal data and educational materials together. Patients are encouraged to interact with the system, to ask questions, and to provide their perspective.

The collaborative workstation is entirely voice and touch-controlled in order to eliminate the need for the provider to disengage from the individual when interacting. The goal is that the system is there to retrieve data quickly when needed, but that it does not interfere with important elements of the human-to-human interaction in medicine that are critical in developing rapport and a successful therapeutic alliance.

The system includes four large high-resolution displays in a vertical orientation (see Figure 2). There have been some preliminary investigations into collaborative medical interfaces, particularly using surface computing platforms such as Microsoft Surface (http://www.microsoft.com/surface). The disadvantage of these tabletop interfaces is that the technology becomes a divider between the provider and the individual if they are on opposite sides because one cannot view what the other is seeing without rotating the content. If they are on the same side of the table, then both people have to lean down to focus on the table rather than each other. Also, this type of interface is not appropriate for patients on the exam table, with reduced mobility, or in wheelchairs. The solution in the collaborative workstation for CollaboRhythm is to mount all four monitors on a mobile arm anchored to the ceiling so that the display can be easily accessible anywhere in the room. This also allows the system to be easily moved out of the way when not needed so that it is even less intrusive in human-to-human interactions.

Access to the collaborative workstation is controlled using radio frequency identifiers (RFIDs). These tags not only allow for secure and efficient access to data by eliminating the need for user names and passwords, but they also allow for contextually appropriate access to data. This means that the medical technician only has access to enter vital signs, while the physician has access to all of the patient's data. Of course, this is all left to the discretion of the patient, since the personally-controlled health record at the core of CollaboRhythm allows the patient to control who has access to what information.

The collaborative workstation is built using an application or widget framework. This means that individual applications can easily be added or removed in a manner similar to the iPhone or Google

Android phone. The advantage of this approach is that it will allow the system to be customizable for each individual user to an extent far beyond any current point-of-care medical information system. It will allow for the creativity of the masses to improve the overall functionality, because they will be able to create individual applications for the system based on their own expertise or experiences. For example, an innovative primary care doctor could create her own application for managing smoking cessation. The entire primary care community could then benefit from this application and other innovators could help to refine it. A motivated patient could create his own application for tracking the interventions that he is trying for his newly diagnosed psoriasis. If a significant number of patients use his application, a great deal of information could be gained about some alternative therapies that have not been formally studied. In this way, patients could help to drive new research or even to create meaningful data independent of researchers.

3.5 CollaboRhythm Does Not Assume Incremental Change

In isolation, each of the components of CollaboRhythm raises important questions about how it will be possible for clinicians to practice using such a system. The collaborative workstation, for example, will no doubt encourage patient questions and require longer office visits if introduced into the current model of care. There is an assumption in these questions; however, that the patient needs to come into the office for all care and that conversation does not happen between visits. In fact, in the modern model of care facilitated by CollaboRhythm, patients receive most of their care remotely and often asynchronously. They are only required to come to the office for critical examinations and more serious issues. As a result, a collaborative patient actively engaged in questioning is desired because the theory is that such an actively involved patient is more likely to be adherent with the shared decisions that are made and more likely to require fewer visits in the future because of effective communication. There are obviously a number of unproven assumptions in this argument, and that is why CollaboRhythm is being built, first and foremost, as a research platform.

4 BACKGROUND – HIV AND MEDICATION ADHERENCE

4.1 Human Immunodeficiency Virus (HIV) Infection

There are currently greater than 38 million people in the world living with HIV infection and more than 1 million of those are in the United States (UNAIDS and the World Health Organization 2008). Patients typically progress from HIV infection to Acquired Immune Deficiency Syndrome (AIDS) if untreated or inadequately treated. AIDS develops because HIV destroys CD4 helper t-cells, which are critical in the cell signaling pathways of the immune system. Patients die from HIV and AIDS because they develop opportunistic infections in the setting of a weakened immune system. More than 25 million people have died of AIDS since 1981 (UNAIDS and the World Health Organization 2008).

4.1.1 Treatment of HIV Infection

There are currently almost 30 different medications used to treat HIV infection. HIV kills CD4 cells by: (1) attaching to the cell surface, (2) invading the cell, (3) replicating using the cell's machinery, (4) destroying the cell during the budding of replicated viruses. Medications for treating HIV infection work by inhibiting different stages of this pathway. HIV is a highly adaptive virus, however, and is able to easily mutate to circumvent the defense provided by any one medication. As a result, the typical treatment for HIV is a cocktail of 3-4 medications. In the past, this meant 3-4 pills, 2-3 times a day. Today, however, there are one-pill, once-a-day solutions for treatment naïve patients. The majority of patients take 3-4 pills once a day.

Treatment for HIV infection has only been available for over 20 years, and patients properly maintained on treatment have lived for this entire period. It is likely that most newly diagnosed patients properly maintained on treatment will be able to live full lives without effects of HIV, since it is possible to maintain undetectable levels of HIV with proper adherence.

Patients with HIV have their HIV viral load and CD4 cell count checked regularly (typically bimonthly) in order to assess their infections status. Viral loads range from undetectable, which indicates good control of infection, to greater than a million RNA copies per milliliter of blood plasma, which indicates rampant infection. A normal CD4 count can range from approximately 400 cells per milliliter to 1500 cells per milliliter. AIDS is diagnosed when either the patient develops an opportunistic infection or the CD4 cell count drops below 200 cells per milliliter, since this typically increases the chances of developing an opportunistic infection significantly.

When progression of HIV infection is detected by rising HIV viral load and decreasing CD4 cell count, it can be difficult to determine if changes in status are due to inefficacy of the medications (because of viral resistance) or due to poor adherence. Typically patient self-reports of medication adherence are inaccurate because of recall bias and desire to appease physicians (Lu, et al. 2008) (Melbourne, et al. 1998). It is possible for pharmacists to check refill data in order to estimate adherence, but this is not easily accessible to many providers and not always accurate, especially if patient refills are automatically delivered by mail.

4.1.2 Efforts to Improve HIV Medication Adherence

As discussed in the introduction, the rate of proper adherence to HIV medications is very poor, falling somewhere between 33% and 88% depending on the patient population, definition of adherence, and

method of evaluation. (Friedland G 1999) A number of techniques have been used to attempt to improve adherence, since poor adherence is directly linked to poor patient outcomes.

4.1.2.1 Directly Observed Therapy

Directly observed therapy was developed for the treatment of tuberculosis and involves a person directly giving and observing each patient take each medication dose. It has been an effective technique for improving HIV medication adherence in some settings. (Mitty, et al. 2003) Unfortunately, with 33 million people in the world living with HIV and medications being necessary throughout life, this solution does not scale well.

4.1.2.2 Modified Directly Observed Therapy

The definition of modified directly observed therapy varies, but it typically involves and adherence support provider directly observing some percentage of medication administrations and then gradually tapering off the number of visits. The results of this type of intervention are mixed, but several studies have shown that any adherence improvements that are obtained may not be sustained after the intervention ends. (Gross, et al. 2009) (McCance-Katz, et al. 2002) (Sama, Luchters and Giebel 2008)

4.1.2.3 HIV Adherence Education and Support Programs

Adherence education programs are provided at some institutions that care for a significant number of HIV patients. Often times, patients are referred to these programs by their physicians after virologic failure, meaning that the patient's HIV viral load increased while on treatment. A number of studies have shown that these programs can be effective in increasing medication adherence and achieving virologic improvement. (Parry, et al. 2005) (Battaglioli-DeNero, et al. 2002) (Ashraf, et al. 2002) The limitation again, is the difficulty in scaling such programs, since they are not available to many doctors caring for patients with HIV and they require additional personnel. In addition, most programs have not been studied for more than a year or when patients stop attending the program, so it is not clear if the improvements are sustainable.

4.1.2.4 Electronic Reminder Devices

A number of technological solutions have been tested for improving HIV medication adherence including alarming pill boxes, text-messaging systems, two-way pager systems, and mobile phone applications. The majority of these systems have taken an alarm or alert-based approach to adherence, focusing specifically on the forgetfulness aspect of poor medication adherence. A recent review of all electronic reminder device studies concluded that there was a lack of definitive data about the effectiveness of these devices. (Wise and Operario 2008)

There are two specific studies that are most applicable to the work being presented. The first study included an automated two-way messaging system in which patients received multiple short daily messages designed to remind, educate, encourage adherence. The patients could also send responses to self-report adherence or to note side-effects. This study did not actually measure medication adherence, but did show that patients overall had a positive experience with the reminder system. The patients replied to 84% of 3 to 8 messages a day and subjectively appreciated the reminders as well as adherence support messages. (Dunbar P 2003)

The second study monitored adherence with electronic pill caps. Patients with self-reported adherence problems were randomized to an arm with a pager reminder system or one without. The arm of patients

with a pager reminder system showed an improvement from baseline 55% adherence to 70% at 2 weeks and 64% at 12 weeks. (Safren, et al. 2003) Unfortunately, these results, although statistically significant, were not enough to produce clinically significant results considering the goal of >95% adherence.

Although the results of these studies are necessary to consider, it is also important to note that adherence issues involving HIV medications have changed considerably since 2003. At that time, most medication regimens consisted for 3 or 4 pills that had to be administered 2 or 3 times a day. Many of these pills had dietary restrictions and required exact timing as well. As a result, the reminder system was of significant importance. Currently, medication regimens are possible with once a day administration, so the reminder component will likely be less important and behavioral mechanisms that focus on education and motivation will likely become more important.

4.2 Shared Decision Making to Improve Medication Adherence

Shared decision making refers to the process of a clinician and a patient collaboratively making clinical decisions. The philosophy is that actively involving patients in decisions is more likely to result in plans to which patients will adhere. Patients are also more likely to desire more education and overall take a more active role in their healthcare.

Although shared decision making is gaining more attention in the field of medicine, there is no strong evidence concerning where it is effective and where it is not. A recent meta-analysis found only eleven randomized controlled trials that compared shared decision making to traditional physician decision making in terms of patient satisfaction, treatment, and health status. The results were split with five trials showing no difference and six showing a positive effect of shared decision making. It is important to note that shared decision never showed a negative effect. (Joosten EAG 2008)

It is of note that most trials of shared decision making involved only single-visit interventions and predominantly dialogue-driven or paper-and-pencil interaction. It is possible that more continuous collaboration using dynamic and patient-friendly educational tools might provide significantly more benefit.

4.3 Performance Feedback in Supporting Medication Adherence

Performance feedback has been used extensively in fields including athletics, education, and organizational management. There is little evidence of its effectiveness, and there is even some evidence that it can impact performance negatively (Balcazar, Hopkins and Suarez 1985-1986) (Fluger and DeNisi 1996). In the field of medicine, performance feedback has not been studied significantly, but one study offers encouraging results.

A study of patients taking antipsychotic medications randomized 30 patients to either visual feedback of medication adherence or supportive counseling. Both groups attended sessions twice a month for three months. Visual feedback included reports of medication adherence that were obtained from electronic pill caps used by the patients. The supportive counseling group did not get this visual feedback. It was found that adherence rates increased slightly in the visual feedback group, but they decreased for the supportive counseling group. (Kozuki and Schepp 2006) The patient feedback in this case was only given to patients at discrete intervals rather than dynamically throughout their care. It is likely that dynamic, personalized feedback might have an even greater impact.

5 HIV MEDICATION ADHERENCE SYSTEM

A system was developed to improve HIV medication adherence by using components of the CollaboRhythm platform. Several major principles were followed in the development of the system:

- Shared decision making is a core ideal.
- Patients are encouraged to be proactive rather than reactive, meaning that easy access to information is more important than alarming functions.
- Performance feedback is used to motivate patients and encourage self-reflection.
- Disease education is central in engaging patients and maintaining adherence.
- Social support is used to encourage patients and to overcome obstacles.

The system that was developed is best described as a collaborative awareness system that allows both the patient and coaching clinician to have knowledge about when medications will be due, when they have been taken, and what the benefit is of taking these medications. In addition, the system allows the patient and coaching clinician to communicate richly and easily in order to support proper adherence.

The core components of the HIV medication adherence systems are shown in the following figure. In the development of CollaboRhythm, there was an expectation that only a subset of the components would be necessary and useful in each clinical scenario. It is of note that the HIV medication adherence system does not use any conversational agents, for example, because they were not considered critical in the success of this intervention.

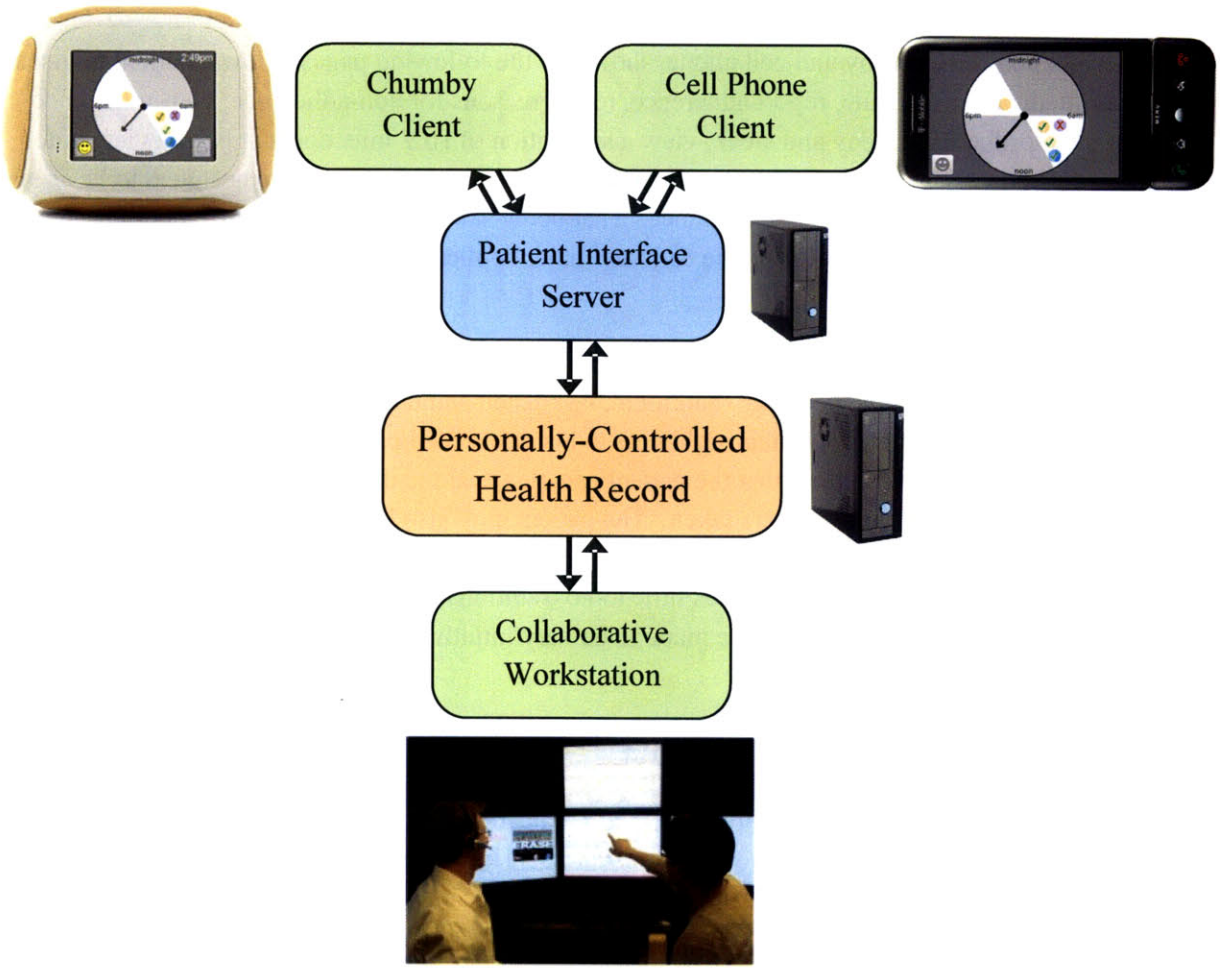

Figure 3: Core Components of the HIV Medication Adherence System. On the patient side of the system are an internet enabled device called a Chumby and an Android-based cell phone with custom software. These devices communicate with an intermediate server that in turn communicates with a personally-controlled health record server. A collaborative workstation allows the clinician working to perform shared-decision making tasks and education with the patient and also to view adherence data and to send video messages.

5.1 Personally-Controlled Health Record

The hybrid personally-controlled health record of the CollaboRhythm, described in Section 3.1 Hybrid Personally-Controlled Health Record, is used with a few minor modifications. Additional protection of patient data was provided by not using any personally identifiable information. Instead, only coded identifiers were used with all patient data. In addition, specific data types were created to enable medication scheduling and adherence tracking, which are not currently enabled in Microsoft HealthVault.

5.2 Patient Interface Server

An intermediate server written in Python is used between the personally-controlled health record and the individual patient interfaces. It processes the data from the personally-controlled health record and sends xml data to each of the clients. This processing allows each of the clients to remain as thin as possible. The intermediate server ensures that each of the interfaces is updated based on interactions that take place on any of the other interfaces. It also handles adherence reports from each of the devices and updates the underlying personally-controlled health record data model.

5.3 Patient Interfaces on Chumby and Cell Phone

The interfaces on the Chumby and cell phone, shown on the following pages, allow a patient to visualize his or her medication schedule, report adherence, report reasons for non-adherence, view adherence performance for the for the day and week, view a simulation of HIV infection status, and view video messages from the coaching clinician. The interfaces on these two devices were designed to be as similar as possible to allow for a consistent experience. That being said, there are a few differences because the cell phone is used by the patient for phone calls and other applications and the interface had to account for this.

The Chumby was chosen as a home device for the patient. The premise is that most HIV patients keep their medications either in the bedroom, bathroom, or kitchen and take them once a day. The hope is that each patient keeps the Chumby in plain sight near to his or her medications. The interface on the Chumby is always on and always visible, so that the patient can glance at the device at any time to determine when medications will be due or if they were taken. The patient may also be reminded of medications even when not actively seeking information, since the presence of the Chumby might be a reminder. Another advantage of the Chumby is that it requires little to no traditional computer skills to operate, since there is no mouse or keyboard. Interfaces can be made to be very intuitive, so that users to not even think of the Chumby as a "computer."

The cell phone was chosen as a mobile device for the patient. Although most patients have once a day regimens, some have twice a day or more frequent regimens. In addition, sometimes patients are away from home at the time that they normally take their medications. Having a mobile device for reporting and viewing adherence has value in these circumstances. The Google Android platform was chosen for the development of the cell phone interface for several reasons: (1) touch input was necessary in order to make the interface consistent with that on the Chumby, (2) the ability to have a widget that is always running and visible was considered to be necessary to support optimal awareness, (3) the ability to easily distribute and update the application to many users was necessary, (4) the potential that it would be affordable to deploy the phone to many users in the near future was a less important but significant consideration. Android was the only platform that met these criteria sufficiently.

5.3.1 Daily Medication Clock

The main screen on both the Chumby and the cell phone interfaces is a daily medication clock that displays an acceptable interval for the administration of each medication (white wedges in figure) and an icon for each medication (colored circles). Most medication reminder systems treat medication administration as an event which happens at a specific time. In fact, the lives of patients are complicated, and it is unreasonable to expect them to be interrupted at exactly the same time every day in order to take their medications. In addition, it is not medically significant if a patient takes a daily medication an hour or two before or after a regular time each day. Taking these observations into consideration, the interface was designed to give patients an awareness of the desired interval for each medication administration, allowing them to plan ahead around meetings, meals, or other significant events. The interface also shows if each medication has been taken or not for quick reference.

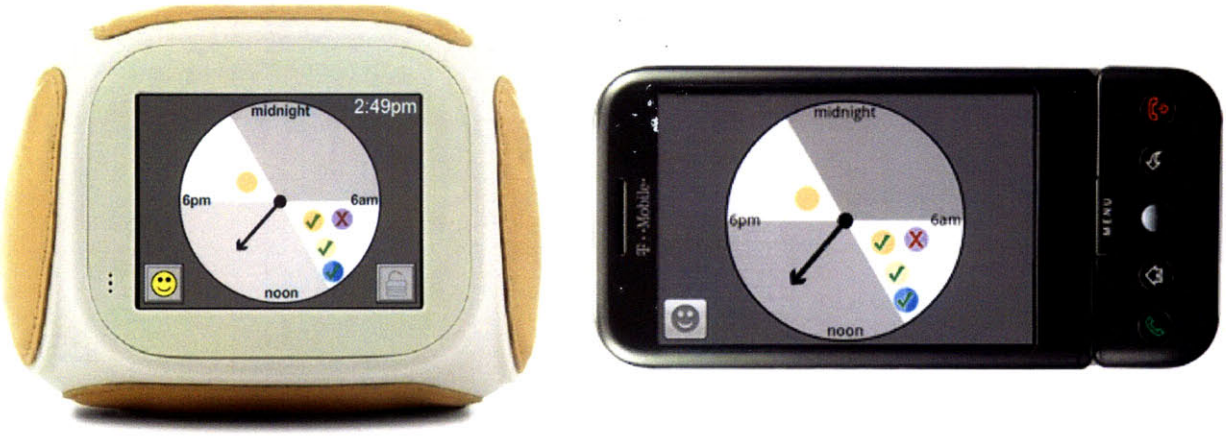

Figure 4: Daily medication clock interface on the Chumby (left) and cell phone (right). Acceptable adherence intervals are indicated in white. Each medication is indicated by a colored icon. No indicator means that administration has not been reported. A check mark indicates that a medication has been reported as administered. An x mark indicates that a medication has been reported as not administered. The button with a smiley emoticon indicates that a video message is available (discussed in a following section). The lock button on the Chumby allows the interface to be locked with a graphical password so that it is not possible to look at screens with sensitive information. The cell phone has a similar locking function built in to the main operating system.

The daily medication clock displays an entire 24 hours unlike a traditional 12 hour clock. This was considered necessary in order to allow patients to see the medications for an entire day. Patients are often confused as to whether or not they took their morning medications when the afternoon medications are due. Attempts were made to create a 12 hour clock that intuitively showed both morning and afternoon/evening medications, but no reasonable solution was determined. The main reason that a 12 hour clock was considered was to make the telling of time more simple. Instead, the purpose of the medication clock is to deemphasize the importance of exact time and to focus on the importance of relative intervals. To meet both needs, the face of the clock was reduced to only include four key time points: midnight, 6am, noon, and 6pm and a precise digital clock was added in the upper right hand corner of the Chumby interface (the phone has a digital clock already).

The daily medication clock does not show any sensitive patient information. Since it is the main screen that is visible at all times, it was considered important that it did not show information that patients were not comfortable sharing. At the same time, to the patient, the interface conveys a significant amount of information encoded by the color and time of each of the medication dots. On the Chumby, it is possible to lock the interface on the daily medication clock using the button with an image of a lock. On the cell phone, a locking mechanism is built-in.

There is also a daily medication clock widget that is displayed on the desktop of the cell phone. Since the user needs to make phone calls and perform other operations, it is not possible to have the full application running and visible at all times as on the Chumby. The widget allows the daily medication clock to be in the awareness of the user even when the application has not been deliberately launched.

Figure 5: Daily medication clock widget on cell phone. The widget allows the daily medication clock to be in the awareness of the user even when performing tasks such as making a call or sending a text message.

Although a specific effort was made to make the interfaces on the Chumby and cell phone focused on awareness rather than alarms, both devices do also use non-visual prompts to increase awareness. On the Chumby, when the hour hand enters an adherence interval, it begins playing music at a very low volume. As time progresses through the interval, the volume increases in order to gain user attention. Since the Chumby was designed to be used in the home, it was expected that the patient would be moving throughout the home during the adherence interval, so an intermittent auditory indicator would likely not be heard in many instances. On the cell phone, the system vibrates and makes a small notification tone at the beginning and every hour during the adherence interval. It is possible to choose a preference for vibration, tone, or both and to set the volume. When the user reports administration for all of the medications in an interval, the non-visual prompts are turned off on both the cell phone and the Chumby.

When the hour hand enters an adherence interval, a button also appears in the center of the clock that allows the user to quickly and easily report that all of the medications in that interval were taken. Since this is the desired behavior, it had to be made as easy as possible to achieve in order to decrease the burden of reporting. Of course there is a trade-off because this makes dishonest reporting easier.

Figure 6: Daily medication clock with quick adherence reporting button shown. When the hour hand enters an adherence interval, the quick adherence reporting button appears, allowing the user to report that all of the medications in that interval were taken. Both devices also use additional awareness prompts such as auditory and vibro-tactile.

5.3.2 Medication Instructions and Adherence Reporting

Detailed medication instructions and adherence reporting are made available by touching any of the adherence intervals on the daily medication clock. A scrollable window appears with an item for each of the medications that are scheduled to be administered during that interval. This method of adherence reporting is necessary if adherence is reported outside of the desired adherence interval or if any of the medications were not administered so that the proper time of administration or the reason for non-administration can be reported.

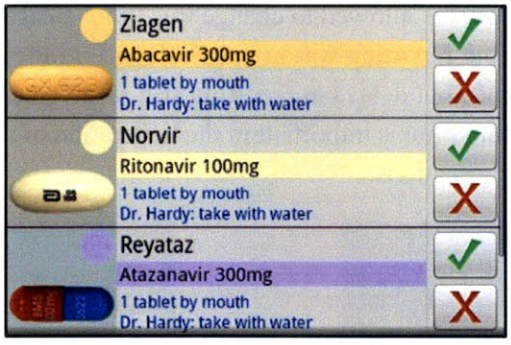

Figure 7: Medication Instructions and Adherence Reporting Screen. An image and personalized instructions are displayed for each medication in a given adherence interval. The patient can report administering or not administering each medication individually.

Each medication item shows an image of the medication, with the corresponding colored icon that appears on the daily medication clock. Currently, the color of the icon corresponds to the color of the pill with a few notable exceptions: (1) If the pill is white, a light grey color is used for the icon because white would not be visible on the white background of an adherence interval. (2) If the pill actually contains multiple active ingredients, the icon is divided into multiple shades corresponding to the number of

5.3.3 Adherence Performance Graphs

On both the Chumby and the cell phone, the patient is able to easily view his or her adherence performance for the entire week. This is viewed by using a swipe gesture to the left from the daily medication clock.

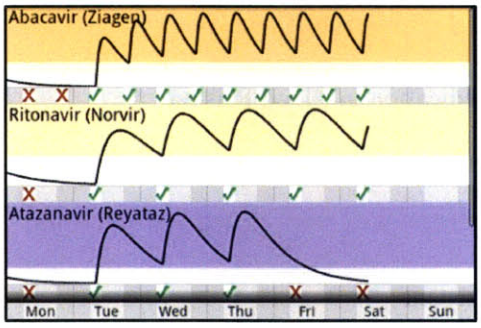

Figure 9: Adherence Performance Graphs. At the bottom of the screen, a scale is shown delineating the days of the week. Above the scale, a scrollable window is shown with an item for each pill that the patient takes. Each item shows a bar at the bottom delineating the days of the week. The white rectangles in the bars correspond to each of the scheduled medication adherence intervals. Each of these intervals shows a question mark for unreported adherence, a check mark for reported adherence, or an x for reported non-adherence. Above the adherence bar, each item shows a graph for the component medication of the pill. If the pill has more than one active ingredient, the graphs will alternate. Each graph shows a black line corresponding to the estimated plasma concentration of the medication based on the administration reports and the pharmacokinetic parameters of that medication component. The colored region of the graph represents the goal concentration. The striped region below that represents sub-optimal medication concentration. The white region below that represents minimal medication concentration, such that it can be considered ineffective.

The goal of the adherence performance graphs is to promote self-reflection and intrinsic motivation for improving performance. They are also designed to be educational about the importance of regular dosing of medications by illustrating the estimated concentration of medication in the blood plasma and the concept of maintaining a goal concentration. Typically, patients are simply told the dosing interval for a medication, but are never educated about the reason for this. As a consequence, it is very common for patients to actually take two pills once a day instead of one pill twice a day, for example. This would make the patient more likely to develop side-effects, since most medication side-effects are dose-dependent. It would also mean that the patient would have intervals of time throughout the day in which he or she was not effectively treated with the medication. Traditionally, the medication establishment has considered pharmacokinetics too complicated to be comprehended by patients. It is easy to see, however, that personalized, dynamic graphs of medication concentration that react to patient medication taking behavior could make these concepts very easy to comprehend. This may help to reduce side-effects and poor medication coverage, and, therefore, help to improve adherence.

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On both the Chumby and the cell phone, the patient is able to easily view his or her adherence performance for the entire week. This is viewed by using a swipe gesture to the left from the daily medication clock.

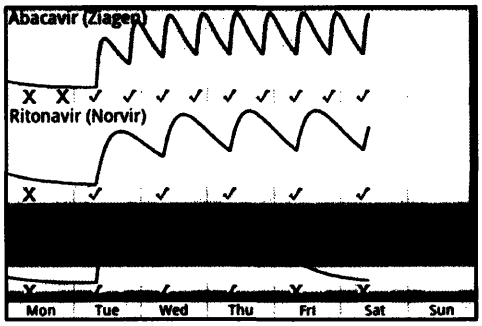

Figure 9: Adherence Performance Graphs. At the bottom of the screen, a scale is shown delineating the days of the week. Above the scale, a scrollable window is shown with an item for each pill that the patient takes. Each item shows a bar at the bottom delineating the days of the week. The white rectangles in the bars correspond to each of the scheduled medication adherence intervals. Each of these intervals shows a question mark for unreported adherence, a check mark for reported adherence, or an x for reported non-adherence. Above the adherence bar, each item shows a graph for the component medication of the pill. If the pill has more than one active ingredient, the graphs will alternate. Each graph shows a black line corresponding to the estimated plasma concentration of the medication based on the administration reports and the pharmacokinetic parameters of that medication component. The colored region of the graph represents the goal concentration. The striped region below that represents sub-optimal medication concentration. The white region below that represents minimal medication concentration, such that it can be considered ineffective.

The goal of the adherence performance graphs is to promote self-reflection and intrinsic motivation for improving performance. They are also designed to be educational about the importance of regular dosing of medications by illustrating the estimated concentration of medication in the blood plasma and the concept of maintaining a goal concentration. Typically, patients are simply told the dosing interval for a medication, but are never educated about the reason for this. As a consequence, it is very common for patients to actually take two pills once a day instead of one pill twice a day, for example. This would make the patient more likely to develop side-effects, since most medication side-effects are dose-dependent. It would also mean that the patient would have intervals of time throughout the day in which he or she was not effectively treated with the medication. Traditionally, the medication establishment has considered pharmacokinetics too complicated to be comprehended by patients. It is easy to see, however, that personalized, dynamic graphs of medication concentration that react to patient medication taking behavior could make these concepts very easy to comprehend. This may help to reduce side-effects and poor medication coverage, and, therefore, help to improve adherence.

The medication adherence graphs are computed using the following equation for each administration curve:

$$C = \frac{F \times D \times k_a}{Vd \times (k_a - k_e)} \times \left(e^{-k_e t} - e^{-k_a t}\right)$$

C = Concentration of Medication in Blood Plasma

F = Bioavailability (fraction of mediation absorbed into blood)

D = Dose of Medication

k_a = Absorption Rate Constant

k_e = Elimination Rate Constant

Vd = Volume of Distribution (the volume in the body in which the medication diffuses, weight dependent)

The actual medication adherence graphs are computed by using the superposition method. This simply requires aligning the individual curves at the appropriate times and adding them.

5.3.4 HIV Disease State Simulation

On both the Chumby and the cell phone, the patient is able to easily view a simulation of the current status of his or her HIV infection. This is viewed by using a swipe gesture to the right from the daily medication clock.

As discussed in the background section, HIV causes immunodeficiency by killing CD4 t-cells, and patients have their HIV status assessed regularly using blood tests for CD4 cell count and HIV viral load. Typically, these results are presented to patients as numbers, which can be difficult for patients to interpret. In fact, many patients cannot remember that their goal should be to achieve a low viral load and a normal or high CD4 cell count. In addition, many patients do not understand the mechanism of action of HIV medications, even the most basic notion that these medications prevent HIV replication and destruction of CD4 t-cells.

It was hypothesized that presenting information about HIV status including viral load, CD4 cell count, and the effect of HIV medication adherence to patients in a more understandable and digestible manner through dynamic, personalized simulation would help to improve patient education about HIV, stimulate active learning and questioning, and potentially improve medication adherence. The notion that this would help improve adherence is bolstered by the fact that patients with HIV who have not progressed to AIDS do not have symptoms from their disease. Given the burden of taking pills daily for the rest of one's life and the relatively high incidence of side-effects, it is reasonable that patients might opt not to take the medications if they are not convinced that the medications are providing any benefit. A simulation, however, could give a patient visual feedback about the action of the medications and a sense of control over the infection that might stimulate continued adherence. It might even be possible that a simulation showing a patient's CD4 t-cells getting attacked by HIV when he or she is not adherent with

medications could create a cognitive or visceral response from the patient, motivating improved adherence. Of course, it is important to consider that a simulation showing CD4 t-cells getting attacked by HIV continuously during prolonged periods of poor adherence might contribute to a sense of helplessness and defeat, causing a patient to give up on taking medications. This seems unlikely, but is important to consider in the evaluation of such a tool.

The simulation that was developed for the Chumby and the cell phone is programmed using a few basic rules:

1. A number of CD4 t-cells are shown proportional to the patient's most recent CD4 cell count.
2. A number of HIV viruses are shown proportional to the patient's most recent HIV viral load.
3. Each virus will randomly attack one of the CD4 t-cells in a random position, with up to 6 viruses attacking a single CD4 t-cell.
4. Each of the medication components that a patient is taking (not pills but active ingredients) contributes a component to a ring of protection around the CD4 t-cells. Each component will remove the viruses that are attacking the CD4 t-cell in its region of protection. There are three states: (1) if the current medication concentration is in the goal region, every t-cell will have that component of the ring of protection, and that component will be drawn as a solid thick line, (2) if the current medication concentration is in the sub-optimal region, it is random if each t-cell has that component of the ring of protection, and those components that are drawn as a several thin lines, (3) if the current medication concentration is in the minimal region, then none of the t-cells has that component of the ring of protection, and no components are drawn. The state of each of the medication components is also shown in a legend at the bottom of the simulation.
5. If a t-cell has no viruses attacking it, it will be in a healthy state, meaning that it is in full color and moves in a fluid manner. If a t-cell is being attacked by any viruses, it will be in a disabled state, meaning that it is grayed out and immobile. This represents the idea that t-cells are being commandeered by the virus and destroyed.
6. If a virus is attacking a t-cell, it is in an active state, meaning that it is in full color and moves in a frenetic, attacking state. This represents the idea that the virus is actively replicating. If a virus is not attacking a t-cell, it is in a subdued state, meaning that it is grayed out and immobile. This represents the ideas that the virus is not actively replication but is still a threat.

Although the simulation of HIV is a simplification of the reality of HIV infection, the overall premise is consistent with a level of comprehension of the disease beyond that that is used in typical HIV education materials.

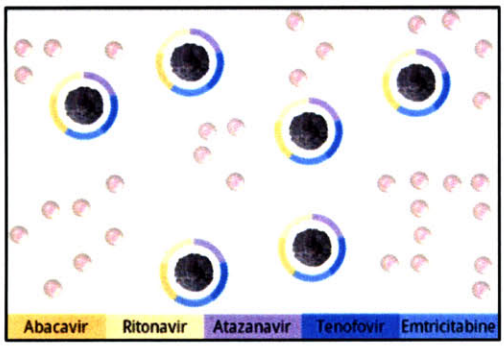

Figure 10: State of HIV Simulation with Good Adherence. This figure shows a patient with a CD4 cell count near 600, indicated by the presence of 6 CD4 cells, and an HIV viral load near 3300, indicated by the presence of 33 HIV viruses. The patient's current medication concentrations are in the goal region for all 5 medication components that the patient is currently prescribed, so all of the t-cells are fully protected and in the healthy state. (The patient actually takes 4 pills, but tenofovir and emtricitabine are both in the pill called Truvada, represented by the two shades of blue)

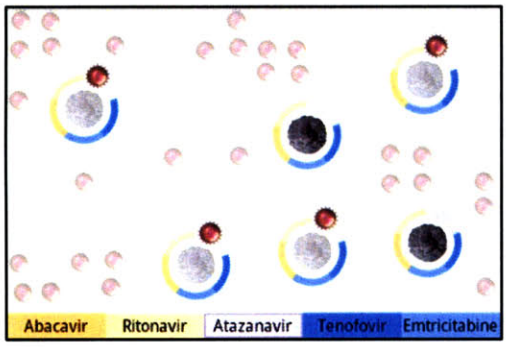

Figure 11: State of HIV Simulation with One Medication in Sub-Optimal Concentration. This figure shows the same patient (same CD4 cell count and HIV viral load) several hours later after not taking one of his medications, atazanavir. The concentration is in the sub-optimal region on the adherence graph, and this is reflected by only some of the CD4 t-cells being protected by this medication and with a weaker barrier (striped rather than solid).

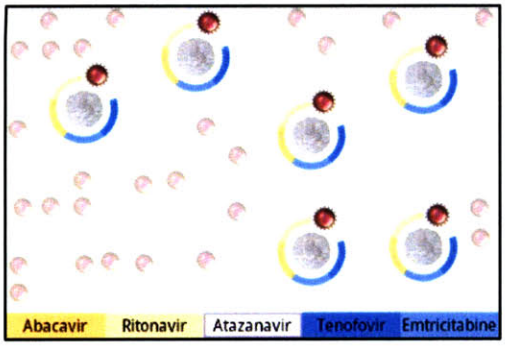

Figure 12: State of HIV Simulation with One Medication in Minimal Concentration. This figure shows the same patient after not taking his atazanavir and a few hours after the previous figure. Now the concentration is in the minimal region of the adherence graph, and this is reflected by none of the t-cells being protected by this medication. Now all of the t-cells are in the disabled state and are grayed out and immobile.

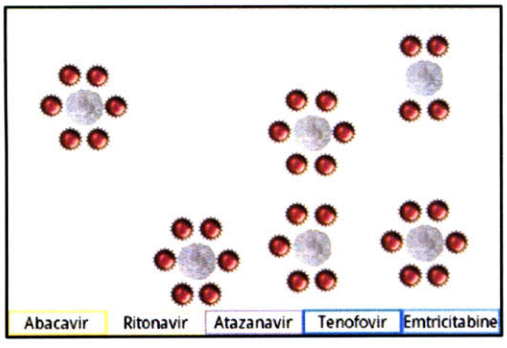

Figure 13: State of HIV Simulation with Poor Adherence. This figure shows the same patient after not taking any of his medications for a day. Now the t-cells do not have protection from any of the medications are all in the disabled state. All of the viruses are now actively attacking the t-cells.

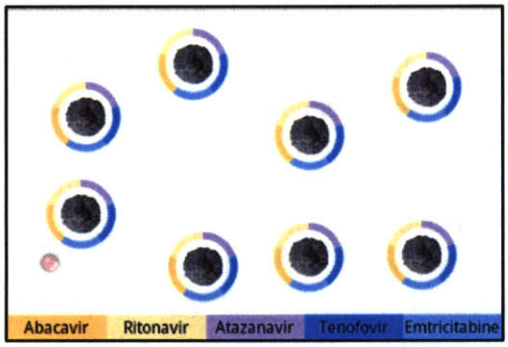

Figure 14: State of HIV Simulation after Prolonged Good Adherence. This figure shows a hypothetical situation where the same patient has had good medication adherence for an extended period of time. Prolonged good adherence typically leads to decreased viral load and increased CD4 count on subsequent lab tests. This is reflected by the decreased number of viruses in the simulation and the increased number of t-cells. It is of note that, even if the viral load is undetectable, at least one virus is shown in the simulation. This reflects the fact that HIV infection is never completely eradicated by current therapies.

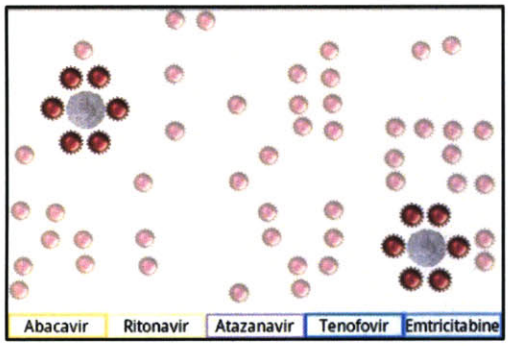

Figure 15: State of HIV Simulation after Prolonged Poor Adherence. This figure shows a hypothetical situation where the same patient has had poor medication adherence for an extended period of time. Prolonged poor adherence typically leads to increased viral load and decreased CD4 cell count on subsequent lab tests. This is reflected by the increased number of viruses in the simulation and the decreased number of t-cells.

It is of note that the HIV infection simulation does not currently have memory about previous adherence. It reflects the most recent lab tests and the current estimated concentration of each of the medications. The adherence performance graphs were designed to serve the role of giving patients an evaluation of their history of adherence, since the time maintained with good adherence obviously affects the patient's HIV status more than the adherence any one moment in time. On the other hand, the reality is that, when >95% adherence is required for viral suppression, every moment of susceptibility to viral replication is critical. For this reason, adding memory to this simulation would give patients the perception that their previous good performance might give protection from the virus, which would not be an accurate depiction of reality and would likely not be supportive of improved adherence.

In addition, the simulation does not currently account for the fact that HIV viral loads and CD4 cell counts change over time between lab tests, and the simulation is therefore most accurate immediately after lab tests and typically less reliable as time progresses. Any attempt to estimate changes in viral load and CD4 cell count based on adherence, however, would likely be inaccurate because it is highly dependent on virus subtype, individual patient, medication regimen, co-morbidities such as hepatitis C infection, and other unknown factors. This inaccuracy would likely undermine the believability of the simulation when a next lab test disagrees with the estimated change. Several other strategies for representing the progressive inaccuracy of this part of the simulation have been considered and may be implemented in the future. On the other hand, the development of new assays for viral load and CD4 cell count that do not require phlebotomy may allow these to be measured more frequently in the future, and then the simulation could be considered to be updated and accurate.

5.3.5 Viewing Video Messages from Provider

Patients can receive and view video messages from providers on both the Chumby and the cell phone. The goal of these messages is to provide social support for adherence and to build rapport through more frequent interaction than office visits, more efficient communication than telephone calls, and richer interaction than e-mail or text messages. As shown in previous images, a button with a smiley emoticon appears on the main screen when video messages are available. Upon clicking this button, a scrolled window appears with an item for each video message. Each item shows a picture of the message sender, the sender's name, a brief text subject of the message, and the date and time of the message. The patient can play any message by clicking the associated play button or delete any message by clicking the associated delete button. There is no need to listen to messages in order, such as with traditional voicemail.

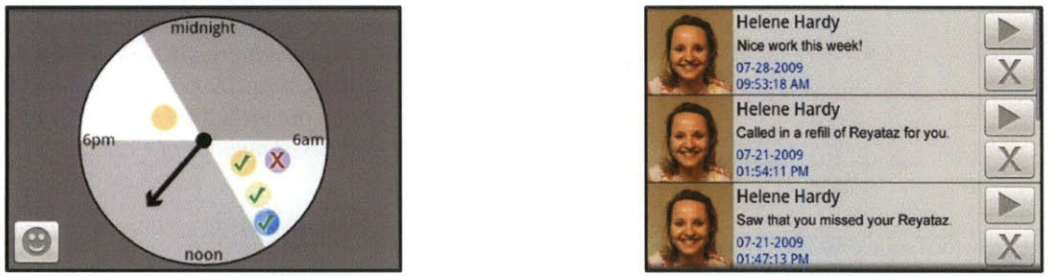

Figure 16: Viewing Video Messages. The image to the left shows the button with a smiley emoticon on the main screen indicating that a video message is available. The image to the right shows a list of video messages, which can be played in any order desired.

5.4 Collaborative Workstation

The collaborative workstation for supporting HIV medication adherence consists of a simplified version of that developed for CollaboRhythm. The software components are the same, but all of the hardware features were not used. Instead, this collaborative workstation consisted of one large display for scheduling medications, viewing adherence, and sending video messages and one small companion display for showing the HIV simulation while viewing adherence.

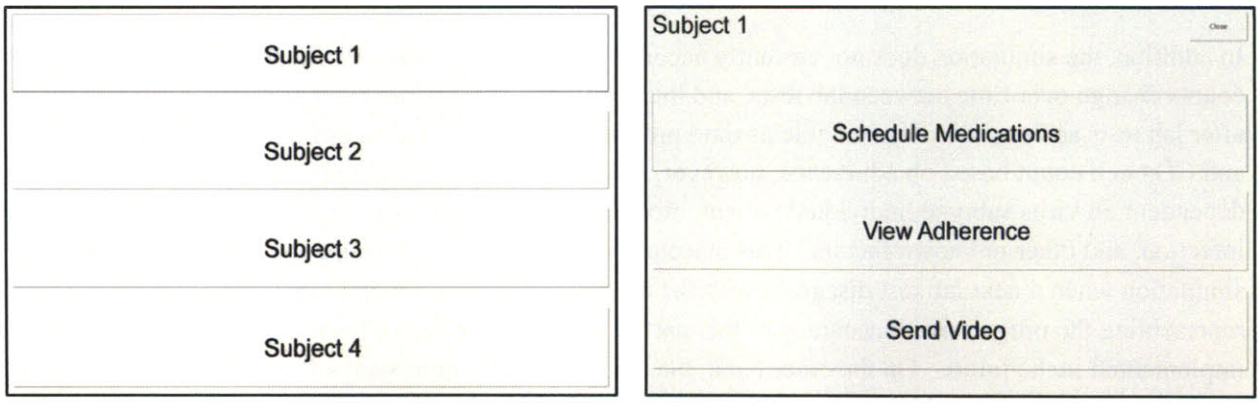

Figure 17: Navigating Patients and Performing Actions in the Simplified Collaborative Interface. Although the full collaborative interface of CollaboRhythm uses RFID to control access and provide context-awareness, only a simplified version of the system was needed for tracking adherence for a few subjects. The image to the left show a simple screen to allow the user to select the desired subject to view. The image to the right shows a simple screen that shows which subject is currently selected and allows the user to select an action to perform.

5.4.1 Collaborative Medication Scheduling

The collaborative medication scheduling interface is the first of the three interfaces of the collaborative workstation. Like the other interfaces, it was designed to allow the patient to contribute by making interactions simple and intuitive. The interface shows all of the patient's medications and allows either the patient or the clinician to schedule the medications by dragging any single medication or any group of medications along the timeline representing a day. A visualization of the daily medication clock that will be shown on the Chumby and the cell phone is displayed at the top of the screen and updated with every interaction. The adherence window scheduled for each medication is shown by a white window in the timeline as well as a white wedge on the daily medication clock. It is possible to easily adjust the window to extend +/- 1, 2, 3, or 4 hours surrounding the scheduled time.

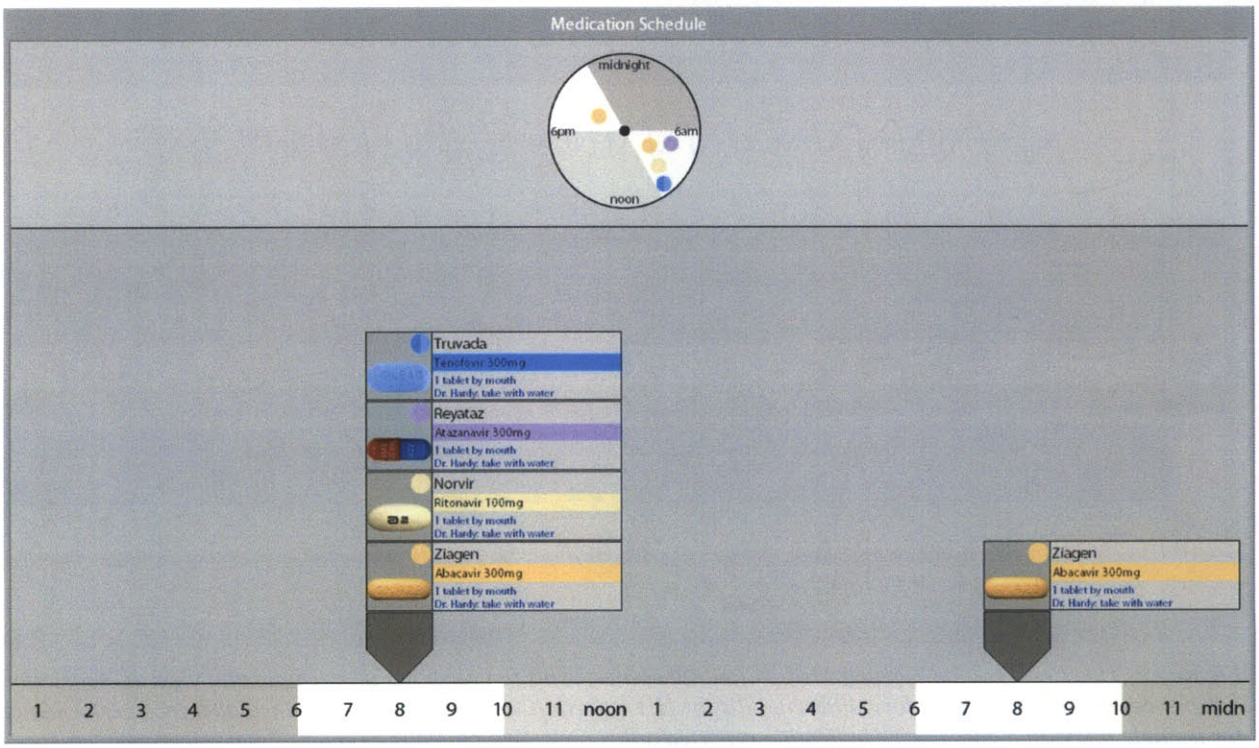

Figure 18: Collaborative Medication Scheduling Interface. This patient has four medication scheduled at 8am with a +/- 2 hour adherence window. The patient has one of these medications, Ziagen, scheduled at 8pm as well.

5.4.2 Viewing Medication Adherence

Viewing medication adherence is a critical function of the collaborative workstation. Not only does this allow the clinician to track patient adherence in order to coach and assist, but it also allows the clinician and patient to review adherence together in order to educate and motivate. CollaboRhythm includes a tool for viewing time series data of all types, and this tool is used to view mediation adherence data in a form very similar to that on the Chumby and cell phone but with more freedom to view longer periods of time and to explore the past performance.

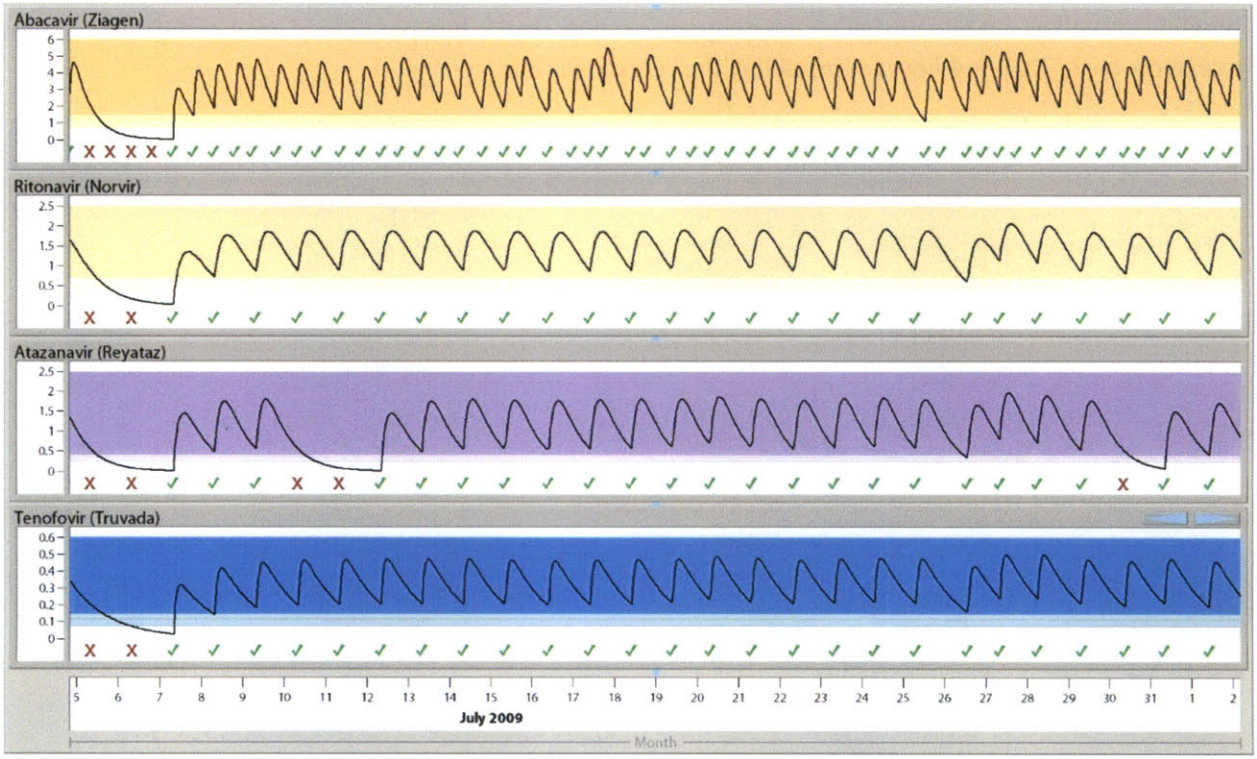

Figure 19: Timeline Tool for Viewing Medication Adherence. This figure shows an example of a view of medication adherence for a patient taking four different pills for HIV infection. Each subplot shows the adherence performance for a single pill with a check mark indicating reported adherence, an x indicating reported non-adherence, and a question mark indicating unreported adherence. Pills with multiple medication components show arrow buttons in the upper right corner for switching between views for the components, as seen for Truvada in the bottom sub-plot. Each graph shows a black line corresponding to the estimated plasma concentration of the medication based on the administration reports and the pharmacokinetic parameters of that medication component. The colored region of each graph represents the goal concentration. The striped region below that represents sub-optimal medication concentration. The white region below that represents minimal medication concentration, such that can be considered ineffective. In the current version of the timeline tool, the reasons for non-adherence are shown on separate plots synchronized with the adherence graphs, but in a new version, the non-adherence reasons will be viewed by clicking on the corresponding x marks.

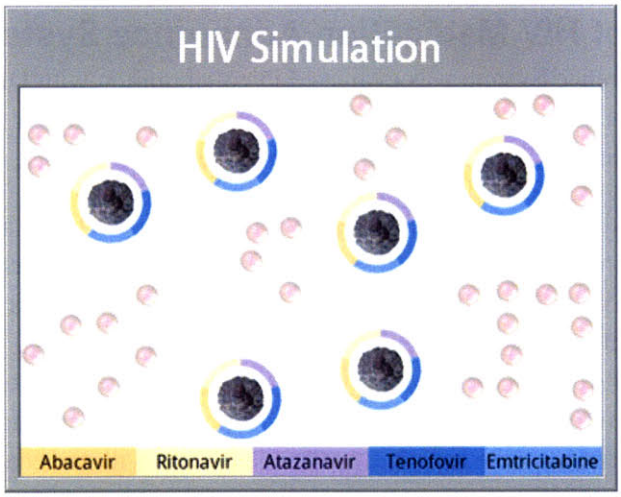

Figure 20: View of HIV Simulation in the Collaborative Interface. The timeline tool allows the user to explore time by scrubbing the scale at the bottom of the screen. When this happens, the HIV simulation shown above is updated each time the focused date is changed based on the values of HIV viral load, CD4 t-cell count, and medication concentration for that specific date and time. In this way, the interface allows the provider and patient to review a movie of the patient's simulation state and to educate and discuss issues that the patient had with adherence.

5.4.3 Sending Video Messages

A simple interface was created for sending video messages. A web cam was used with the collaborative workstation, and the user simply has to click the "Record" toggle button to begin recording and then click it again to end recording. After the video is complied, a viewing window appears below with the option to play, delete, or upload the video.

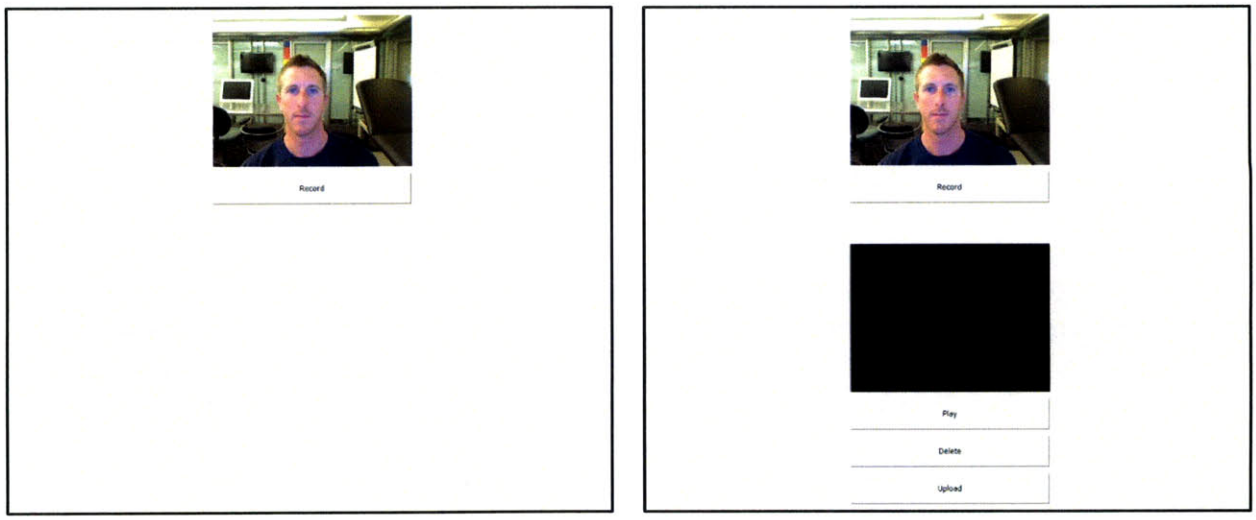

Figure 21: Interface for Recording and Uploading Video Messages. The image to the left shows the initial state of the interface. The user clicks the "Record" toggle button to start recording and clicks it again to stop recording. The image to the right show the interface after a video has been recorded. There is a viewing window and the option to play, delete, or upload the recorded video.

6 Evaluation of HIV Medication Adherence System

The HIV Mediation Adherence System was evaluated in collaboration with Dr. Helene Hardy PharmD of the Center for HIV/AIDS Care and Research at Boston Medical Center under the direction of Dr. Paul Skolnik. Dr. Hardy is a pharmacist and HIV medication adherence specialist.

Evaluation of the HIV medication adherence system was carried out in two stages. In the first stage, 12 patient interviews were conducted in order to assess patient issues with medication adherence and their feedback regarding the HIV medication adherence system. Patient interviews lasted between one and one and a half hour, and patients completed six questionnaires (See Appendix A – Stage 1, Part 1 Questionnaire Results and Appendix B – Stage 1, Part 2 Questionnaire Results). After the first stage, a few minor modifications were made to the patient interfaces. In the second stage of the evaluation, four patients from the original twelve were recruited to use the system with the coaching of Dr. Hardy and the author for four weeks. Their adherence was tracked and weekly office visits were conducted for review of adherence, pill counts, education, and feedback. Patients filled out questionnaires at the end of the first week and the end of the fourth week.

All questionnaires were coded only with unique identifiers. No identifiable patient information was recorded with the questionnaires. All questionnaires and notes were kept in a locked research filing cabinet in a locked office. Patients were instructed that the results of their questionnaires would not be available to their treating clinicians.

Patients typically had numerous questions during the completion of the questionnaires and engaged in conversation about their answers. This was encouraged because a great deal of valuable information was obtained from the qualitative observations that were made from these conversations. In addition, with only twelve subjects in stage 1 and four subjects in stage 2, these questionnaires were not designed to detect statistically significant results but to collect some descriptive statistics and to provide structure to the conversations.

6.1 Stage 1 – Patient Interviews

6.1.1 Methods

Patients for stage 1 of the evaluation were recruited from the general patient pool of the Infectious Disease Clinic at Boston Medical Center by means of flyers that were posted in the waiting room. Twelve patients were recruited who met the inclusion criteria (HIV positive, being treated with medications, older than 18 years of age, cared for at Boston Medical Center, has access to a telephone, speaks fluent English) and did not meet any of the exclusion criteria (HIV dementia or other cognitive impairments, active substance abuse, incarcerated, legally blind, or legally deaf).

Each patient was first engaged in conversation about his or her experiences with HIV infection and treatment of the disease. Notes were taken concerning overall experience, number of years living with the disease, different treatment regimens that were used, experiences with adherence with these regimens, reasons for change of regimens, and adherence aids that have been tried.

Each patient then completed three questionnaires concerning his or her understanding of HIV infection and its treatment along with his or her experiences with treatment adherence.

After the first set of questionnaires, each patient was shown the system for HIV medication adherence in an educational demonstration. Patients were allowed to ask questions, engage in conversation, and interact with the system throughout the demonstration. First, the collaborative medication scheduling interface was shown to the patient with a set of typical but not personalized HIV medications. A schedule was set according to the patient's preference for his or her medications. The daily medication clock was explained to the patient as well as the idea of adherence intervals as opposed to specific administration times. The patient tools on the Chumby and phone were then shown to the patient, which revealed the daily medication clock that was just created with the patient. Medication reporting was then explained to the patient, and he or she was allowed to report taking the medications that were scheduled for that day. Then the focus returned to the collaborative workstation, where some hypothetical adherence performance data was reviewed using the timeline tool. The premise of blood concentration was taught to each patient by reviewing the graphs and educating about the HIV simulation at the same time. Several different scenarios in the hypothetical adherence performance data were explained, highlighting all of the key states of the HIV simulation. Patient comprehension of the graphs and the simulation was then assessed by asking a series of questions about what the graph value and regions represented, what a decline in the graph meant, what an increase in the graph meant, what each of the images in the simulation represented, and what would be expected if medications were taken reliably vs. not taken reliably. Next, the ability to review the adherence performance and simulation on the Chumby and cell phone was reviewed. Finally, the idea of receiving video messages from the clinician was reviewed, and a sample video message was sent to the Chumby and cell phone for the patient to view.

After the educational demonstration, each patient was given a set of three more questionnaires assessing his or her impression of the medication adherence system, interest in using it, assessment of its potential efficacy, and concerns about privacy. At the end, each patient was given the chance to give any suggestions for improvement and was engaged in discussion about the potential of competition versus oneself, competition versus others, buddy collaboration, customizability, and possibility of earning functionality or upgrades.

6.1.2 Results

The patients included eight males and four females of ages ranging from 24 to 61with a mean age of 46. The duration of years living with HIV ranged from approximately two years to more than twenty years. The sample included nine African American and three Caucasian patients. All of the patients were of relatively low socioeconomic status and had a high school education or less. Ten of the patients had a cellular phone and two of them had a computer in the house but did not use it.

Most patients had been on more than one regimen throughout the course of treatment, with varying reasons for poor adherence leading to treatment failure including denial, not being convinced that medications were working, forgetfulness, drug abuse, alcohol abuse, homelessness, and incarceration. At the point of interview, all but one patient was actively on treatment for HIV infection. The one exception was a patient on a treatment holiday while she was dealing with changes in her housing situation. Only three of the patients currently on treatment claimed one or fewer missed medication administrations per month (~95% adherence). Only two patients were using a pill box on an ongoing basis, and only one of these patients claimed good adherence. Several patients had tried alarm devices such as watches or key chains, but none were using any of these devices on an ongoing basis, with all of them stating that they did not think that these devices helped their adherence. One patient did say that his son was very helpful

in reminding him to take his medications each day, but others claimed that they managed their medications independently.

The first three questionnaires had a total of 35 questions concerning patient's self-reported understanding of HIV infection and HIV medications, understanding of the importance of medication adherence, and issues with adherence. The results from all of these questions are shown in Appendix A – Stage 1, Part 1 Questionnaire Results, but the overall trends are summarized here.

All of the patients agreed that taking medications for HIV is important and that taking medications according to schedule is important, but only 6 agreed that they actually take their medications on schedule. The reasons for poor adherence and untimely adherence from the questionnaires and from conversation varied and included forgetfulness, side-effects, difficulty paying for medications, difficulty picking up medications, not being convinced that the medications are working, and not being convinced that missing occasional medications made a difference. The incidence and impact of side-effects were relatively low with only 3 of the 12 patients agreeing to have side-effects and most patients relating that side-effects were efficiently and effectively managed.

Only one of the patients was able to list his HIV medications and dosages without looking at a chart of pictures of the possible medications. Most patients were able to identify their HIV medications on a chart, but only about half were sure of the dose that they were taking. For this reason, several of the patients did carry a list of their medications with them.

Based on the questionnaires, most patients claimed to have a basic understanding of HIV disease and treatment. All but two, however, agreed that they would like to better understand how their medications affect their HIV infection. Subjectively, none of the patients was able to articulate the three basic points: (1) HIV destroys t-cells and weakens the immune system, (2) If untreated, the HIV viral load goes up and the t-cell count goes down, and (3) HIV medications help to stop the HIV virus from replicating and destroying t-cells, so the viral load goes down and the t-cell count goes up.

Only 7 of the 12 patients agreed that they felt like they had control over their HIV infection. 11 of the 12 patients thought that if they had some way to see how their medication were affecting their HIV infection, that they would be more motivated to take their medications and they would feel more in control of their infection.

One final notable finding was that 5 patients agreed that they could feel their medications working to fight the HIV infection. This is contrary to the notion that patients with HIV do not have symptoms from the infection. It was not clear if these patients were psychologically convinced that the medications were working or if they thought that the medications physically made them feel better. It is also possible that some patients agreed with this statement simply because they thought that they were supposed to feel their medications working.

All but one of the patients was able to answer questions assessing their comprehension of the medication concentration graphs and the HIV simulation. The one patient who failed to comprehend the concepts had received a dose of methadone (for the treatment of opioid addiction) in the morning and was falling asleep repeatedly throughout the demonstration.

Patient subjective responses to the system were highly favorable. Only one patient claimed that he thought it was too complicated, and that he would rather just use a pill box. Other patients claimed that they thought that it would help them to take their medications more reliably, and that it would help them to stay motivated. Several patients also thought that it would be very helpful for knowing if they had already taken their medications so that they would not repeat doses.

The second three questionnaires had a total of 43 questions addressing patient responses to each of the components of the HIV medication adherence system as well as their overall responses. The detailed results are shown in Appendix B – Stage 1, Part 2 Questionnaire Results, but they are summarized here.

A majority of the patients agreed that they would like to help schedule their medications and that having some ownership of the decisions made might make them more likely to respond to the Chumby and cell phone. A majority of the patients also thought that the daily medication clock was easy to understand, and all 12 patients agreed that they were able to understand that the clock showed an entire 24 hours rather than a traditional 12 hour clock. In conversation, no patients objected or claimed to have difficulty interpreting the clock in this 24 hour configuration. Most agreed that it was hard to tell time with it, but they claimed that they would just use the digital readout to tell the time and the clock face to see when medications were due. A majority agreed that they liked the idea of having freedom to take their medications during a window rather than at an exact time.

The majority of the patients were not worried about other people seeing what medications that they were taking with the Chumby and the cell phone. Those patients who had some concern were pleased with the fact that they could lock the Chumby and the cell phone.

Eleven of the twelve patients wanted their doctor to be able to track their medication adherence. The one exception was unsure if this would be an invasion of his privacy, but all of the other patients disagreed. Even this patient agreed that knowing that his doctor was tracking his adherence would motivate him to perform better. All of the patients also agreed that encouraging messages from the doctor would motivate them to achieve better adherence. Most of the patients thought that reporting medication adherence was easy and that it was worth the effort.

The majority of the patients felt that they were able to understand the graphs of concentration of medications in the blood. Most of them also agreed that this tool would help to motivate them to achieve good adherence. Most of them also disagreed with the possibility that seeing poor performance on the medication concentration graphs would be discouraging and lead to prolonged non-adherence.

All but one of the patients agreed that the HIV simulation was easy to understand, and all of the patients though that it would motivate them to take their medications better.

Most patients thought that they would like to see how they were performing compared to other patients, but few agreed that they would want to compete against other patients. Several patients agreed that they might want to be able to send and receive encouraging messages from other patients and that they would be willing to share their de-identified performance statistics. Less than half of the patients, however, were interested in sharing their medication adherence data with family or friends.

In the end, all but one patient was interested in using either the Chumby or the cell phone to improve their medication adherence. There was no strong preference for either device, except for one patient that

wanted to use the Chumby but had no interest in the cell phone. Most other patients were interested in using both devices.

6.1.3 Discussion

The results from Stage 1 of the evaluation were not only encouraging because patients were enthusiastic about the possibility of using the Chumby or cell phone to improve their adherence, but because their answers to many of the questions suggested that the core ideals of the system might be effective in achieving improved adherence where other methods had failed.

Most of the patients had tried other adherence tools, but had not found them helpful. The sense was that the reasons were similar to those hypothesized. With their stories, patients corroborated that pill boxes are difficult because they require weekly "programming" that is time consuming and prone to error. They do not really provide motivation, although they do provide indication of whether or not doses were taken. Alarm systems are often just annoying because they don't take into account the patient's schedule is different every day. It is easy to just "snooze" them and then forget about taking the medications. This information bolstered the beliefs that just-in-time information could be valuable and that adherence intervals as opposed to timed alarms are more appropriate for patients.

There was a sense that a majority of the patients missed doses because they were just not that convinced that it made difference and that they were not that motivated. They often initially claimed that simple forgetfulness was the cause, as is the typical finding in many adherence studies. Upon deeper probing, it was often discovered that there were a number of small issues that occasionally contributed. A few had occasional side-effects, but the incidence was much lower than expected, and patients seem to have little concern about this. A few had other social responsibilities that sometimes distracted their attention. None of the patients currently had unmanageable barriers (except for the one patient currently resolving her living situation). Instead, it was often just a combination of a few smaller factors that sometimes impeded their behavior along with a general "laissez faire" attitude that it didn't matter if they missed some administrations. This attitude seemed as if it might be easily overcome with a motivating tool and social support. Taking medications every day for the rest of one's life is a significant burden. Most patients only saw their providers every couple of months and did not have other social support, so if they were not motivated, then there was nothing else to keep them on track.

The idea of an awareness of disease state through simulation resonated with most patients, and they were overall very enthusiastic about how that might keep them more motivated to follow treatment rigorously. They agreed that it would help to keep them "on point" and that having a glimpse of the effect of their medications would possibly help to remind them continuously about its importance. They also felt that feedback about their performance over time would help them to be more reflective about the importance of consistent adherence. It is interesting to note that some patients already believed that they could feel the medication working to control their HIV infection. It is important to consider this type of psychological or visceral response in the setting of a disease that is not traditionally believed to cause symptoms until it has advanced to AIDS. It possibly indicates an increased likelihood that the HIV simulation might be able to bolster this response and improve adherence. As discussed previously, patients may have just agreed with this statement because they thought that they were supposed to feel the medications working.

Those patients that previously had very significant adherence barriers such as drug abuse and alcohol abuse were not sure if those tools might have helped them in the past. These situations are obviously much more complicated in terms of the behavioral psychology involved. Based on anecdotal reports from the patient interviews, cell phones are not only prevalent in the homeless and substance-abusing population of Boston but also quite important in the lives of these individuals. They thought that it would not be unreasonable to try to evaluate the tools with this population.

It is of note that several of the patients had been seen by Dr. Hardy or one of her colleagues in an HIV medication adherence clinic that she runs. Patients are referred to the clinic by their treating physicians and are seen in intermittent visits where adherence is assessed and strategies for improving adherence are discussed. Tools for supporting adherence are often provided, but the social interaction and accountability that come with regular adherence visits are just as important. These patients, on average, have significantly improved adherence over those who are not seen in the clinic.

Most patients with HIV, however, do not have access to a clinic similar to Dr. Hardy's, nor do most physicians have the time or expertise to address adherence as well as is done in this adherence clinic. The tools for social engagement and support built into the system for supporting HIV adherence allow this type of interaction to be available to a much larger number of patients and in a more continuous and efficient manner. This advance will make it possible for many more patients to have social support for adherence.

Patients were clearly interested in sharing their adherence data with their physicians or other collaborating clinicians to an extent beyond what was expected. CollaboRhythm and the system for HIV adherence were designed to allow each individual patient to control who has access to each piece of data in his or her personally-controlled health record. This was considered important not only because it would allow them to share their data with family, friends, and health applications but also because it would allow them to control what data was shared with which physicians. It was considered that many patients might not want fine grained data about all of their medication administrations to be shared with their physicians, but they would want to use it for their own self-reflection and motivation. They might see the physician receiving this data as an invasion of privacy, and this might impede good adherence by encouraging lying to the system to "look good" to the doctor. In this population of patients, however, there was a general consensus that there was no point in lying because, "the lab tests will tell the truth." They generally agreed that ongoing adherence data would help their doctors provide better care and more continuous support, which was very much in line with the hypotheses that drove the design of the system.

There was one patient that initially had an adverse reaction to the idea of the system reporting adherence to the physician. He said, "So this thing is a tattle-tale." After the rest of the system was demonstrated with supportive video messages and the ability to report reasons for non-adherence such as the need for a medication refill or the occurrence of side-effects, this patient decided that he liked the idea of sharing his adherence data. This finding is consistent with much of the research on awareness systems, and was actually a core premise in the design of the system. People in general are only willing to provide ongoing data about themselves if this generates an immediate and tangible benefit to them (Markopoulos, et al. 2004). Otherwise, even the most low-level and non-personal of data (such as motion patterns versus live video) can be seen as an invasion of privacy (Hindus, et al. 2001). The only reason that adherence data is shared in this system is because it can be used to provide significant benefit to the patient. Medications

can be refilled without requiring the patient to call into the clinic. Side-effects can be managed without requiring an office visit. Many other conveniences can also be achieved, and this was designed to make the burden of reporting adherence worth the effort and potential concerns about sharing data unimportant.

It was expected that patients with HIV would generally not be interested in sharing their adherence data with family or friends, since many of them are not open about their diagnosis. Conversations revealed that this may not be a finding unique to HIV. Six of the patients agreed that they would like to be able to share their medication adherence with family or friends, but they were less enthusiastic about it than sharing with their physician or adherence coach. The medical establishment traditionally considers that family members are key caregivers for patients and that it is critical to have them involved. Although this may be true in the current system, which is designed around episodic care, it may not be desirable to patients if a collaborative and continuous model of care is an option. Several individuals suggested that they did not wish to be treated as a patient by family and friends. They were comfortable with this type of relationship with a health professional, but they wanted to deal with their family and friends as a normal person and not as someone with a disease. This observation was enlightening, and it may be true that many other patients with mainstream diseases such as diabetes feel the same way. The model of CollaboRhythm, which enables patients to have more effective communication with providers between visits, may be welcomed because it will allow them to be less dependent on family members.

Overall, patients were more interested in cooperation with other patients than competition. They were, however, relatively interested in the idea of competing with themselves and the possibility of having gaming components incorporated into the interfaces on the Chumby and cell phone. They liked the ideas of tracking a score, opening new levels, and earning customization. These ideas were not explored very deeply, but patients were certainly familiar with customization of electronic devices from their experiences with their cell phones, and they felt that it was engaging. They were also familiar with gaming and though that the possibility of trying to outperform oneself might be fun and might improve adherence.

The tools on the Chumby and cell phone were designed to be intuitive even to those who had never used a computer. The fact that eleven of the twelve patients were able to comprehend and navigate the patient tools reasonably well on a single encounter suggests that this was achieved to a more than satisfactory level. Some concepts, such as pharmacokinetics, are traditionally considered by the medical establishment to be too complex to be comprehended by the average patient. These results have started to show that this is not true, and that patients are very capable of comprehending very advanced concepts in short periods of time if the information is presented in a personalized, dynamic, and intuitive manner. It is probably true that, if the study tried to teach patients about pharmacokinetics by studying exponential functions and absorption and elimination rate constants, that it would not have been successful. But since the concepts were taught through concrete examples with visual aids, patients understood quickly.

The majority of the patients interviewed were excited about the potential of the system for supporting HIV adherence. This is a testament to the notion that medication adherence is a complex problem and that a multifaceted approach may be most effective in engaging patients. Although some patients were positive about all of the components on the Chumby and cell phone, most were actually only enthusiastic about a few of them. Some thought that the HIV simulation would be key in motivating them while others thought that the ability to stay tightly connected with a clinician was critical. Still others were

content with having a tool that would help them keep track of their own adherence. It is possible that the overwhelmingly positive response to the technology was due to the fact that it does not attempt to treat all patients the same and does not attempt to apply one adherence method to everyone. Instead, it focuses on giving patients awareness of different information about adherence and disease state that is easily accessible but not forced. It also gives access to new forms of communication, but these are in the control of the patient as well.

6.2 Stage 2 – Deployment of HIV Adherence System

6.2.1 Methods

Stage 2 of the study was conducted with Dr. Helen Hardy and four patients who were selected from the pool of stage 1 patients.

The collaborative workstation for supporting HIV adherence was installed in Dr. Hardy's office and the Chumby and cell phone interfaces were customized to include the proper medications for each of the patients.

The stage 2 evaluation was four weeks in duration. At the beginning of the study, each of the patients came to the Infectious Disease clinic for a separate preliminary educational and instructional visit with Dr. Hardy and the author. The HIV adherence tools and interfaces were reviewed with each patient and their retention of comprehension was tested. After retention was assessed, a task was conducted in which each patient was able to collaboratively create his or her medication schedule using the interface for collaborative scheduling. Patients described their medication schedules to the author and appropriate adjustments were made, but the patients were also able to demand additional adjustments. After the schedule was created, each of the patients was given a Chumby and a cell phone with service prepaid (one patient was only given a cell phone because there was no internet connection available at his home). Each patient was instructed on adherence reporting and viewing the adherence performance, HIV simulation, and supportive videos. They were also instructed on the basic functionality of the cell phone (a T-mobile G1 with the Google Android operating system). Patients were encouraged to ask any questions that they had and to contact the study administrators with any questions or problems. Contact information for both Dr. Hardy and the author were pre-loaded onto the cell phone.

Patients returned to the clinic once a week for individualized feedback sessions. During these sessions, pill counts were conducted to allow for reconciliation of reported adherence. Reported adherence was also reviewed on the collaborative workstation, including review of the HIV simulation throughout the week with special focus on any periods of sub-optimal adherence. Patients were able to ask any questions that they desired and their feedback was elicited about their overall experience that week and any issues that arose. Between each weekly visit, adherence performance was reviewed by both Dr. Hardy and the author. Video messages of support were sent in response to these evaluations. Patients were given questionnaires about their experiences after the first and fourth weeks.

Between visits, Dr. Hardy and the author sent at least one video message of encouragement. The content varied and the messages were personalized, but they all generally suggested to "keep up the good work" and reminded patients how to avoid repeating any of their past mistakes. There were two occasions where Dr. Hardy's interface had significant problems and the messages had to be sent by the author instead.

6.2.2 Results

The recruited patients included two male and two female patients of age ranging from 43 to 61. All of the patients were of relatively low socioeconomic status, but had stable housing situations. All of the patients had a high school education or less. Two patients had sub-optimal adherence (83% and <80%) from their pharmacy refill data, and two patients had optimal adherence (>95%). Two patients had experience using cell phones and two did not. None of the patients had any significant experience using a computer.

6.2.2.1 Initial Visit

On evaluation of retention, three of the four patients were able to answer simple questions about the purpose of each of the images in the HIV simulation and the purpose and meaning of the adherence performance graphs without assistance. Patient 1 required some hints in order to recall this information.

All of the patients were able to demonstrate basic comprehension of all of the interfaces by the end of the initial visit. Patient 1 and patient 4 did not appear to be able to reason with the data as deeply as the others, but they understood the core principles.

All of the patients showed proficiency in reporting medication adherence and navigating the interfaces on the Chumby and the cell phone. Patient 4 had the most technical difficulty, as she had never had her own cell phone and also showed less manual dexterity than the others.

After the initial visit, all of the patients used the cell phone that was provided as their primary cell phone. Two of the patients did not have cell phones prior to the study. One patient discontinued the plan on his cell phone in anticipation of the study because he knew that he would receive a cell phone with paid service. The last patient had a cell phone that was paid for her by a government program, but it had limited functionality and she opted to switch to using the provided phone instead.

6.2.2.2 Patient 1 Results

Based on pharmacy refill data, patient 1 had greater than 95% HIV medication adherence prior to the study. His viral load was undetectable for at least 3 years, further indicating that his adherence was optimal. He self-reported that he took his medications reliably almost every day, but that he would occasionally miss a dose or take a dose later than he should have. The patient's main concern with his adherence was that he often second-guessed himself and that he often relied on his six year old son to remind him if he took his medications or not. He did not currently use a pill box or any alarms to help him remember to take his medications.

Patient 1 used only the cell phone as a medication adherence tool because he did not have internet connectivity at home. His routine was to report taking his medications on the cell phone immediately after he took them.

This patient did not own a cell phone prior to the study, as he claimed that he was not interested in talking on the phone much. During the study, he used the cell phone minimally other than reporting his medications. He did call the author and Dr. Hardy several times throughout the study to thank them for involving him in the study. He also claimed that he programmed in the numbers of his relatives and called them occasionally with the phone.

This patient only had difficulty reporting his medications on one occasion during the first week, and he promptly called the author. The issue was with the patient interface server, and it was fixed immediately so he could report his medication administrations.

Patient 1 had optimal adherence during the study. He only missed one pill on one occasion because he ran out of that medication on a Saturday and could not pick it up until Monday. He properly reported all of his medication administrations accurately including the one missed administration along with the reason for that non-adherence. His pill count, however, indicated that he took more pills than required of one medication in week 2 and all four medications in week 4. It is possible that he administered more medication than required or that he misplaced these pills. These additional pills were not counted in the total adherence calculations because they do not indicate superior adherence as the results would indicate if they were added.

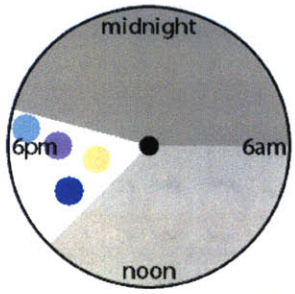

Figure 22: Patient 1 Medication Schedule. This patient reported that he typically took all four of his HIV medications at about 5:00pm or 5:30pm each day. His medications were scheduled at 5:00pm with a +/- 2 hour adherence window.

	week 1	week 2	week 3	week 4	total	adherence rate
medication 1	7/7	8/7	7/7	9/7	28/28	100%
medication 2	6/7	7/7	7/7	8/7	27/28	96.4%
medication 3	7/7	7/7	7/7	8/7	28/28	100%
medication 4	7/7	7/7	7/7	8/7	28/28	100%
		overall adherence:			**111/112**	**99.1%**

Figure 23: Patient 1 Adherence Results. This patient only missed one administration of one medication throughout the course of the study. In the first week, he ran out of one medication on Saturday and could not pick up his refill until Sunday. He pill counts indicated that he took more medication than required during the second and the fourth weeks. It is possible that he administered more medication than required or that he misplaced these pills.

	week 1	week 2	week 3	week 4	total	reporting accuracy
medication 1	7/7	7/7	7/7	7/7	28/28	100%
medication 2	7/7	7/7	7/7	7/7	28/28	100%
medication 3	7/7	7/7	7/7	7/7	28/28	100%
medication 4	7/7	7/7	7/7	7/7	28/28	100%
		overall reporting accuracy:			**112/112**	**100%**

Figure 24: Patient 1 Adherence Reporting Accuracy Results. This patient reported all of his administrations accurately. For the one medication that he missed, he accurately reported that he ran out of the medication.

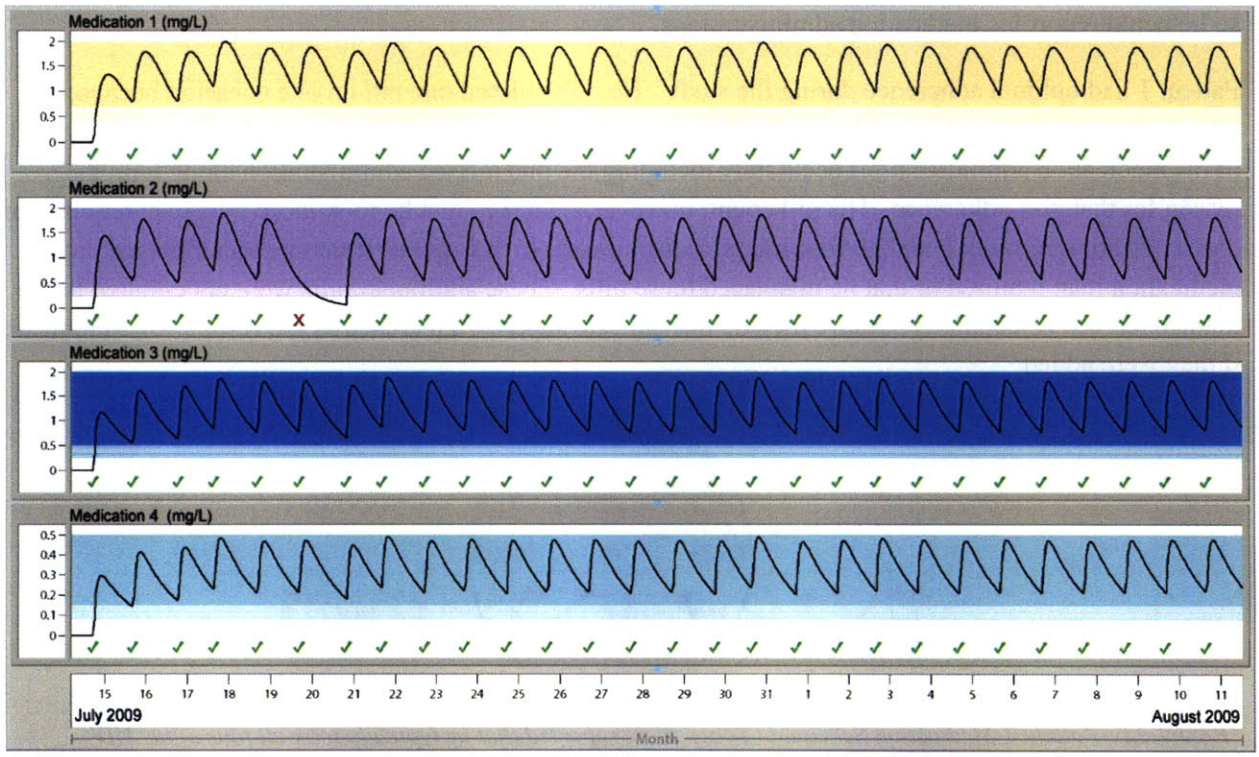

Figure 25: Patient 1 Adherence Reporting Results. This figure shows the reporting results from patient 1 that were viewed throughout the study. It can be seen that he missed one dose of medication 2 during the first week. Here his estimated medication concentration fell into the suboptimal and then the minimal regions. Otherwise his reported times of adherence were very regular as evidenced by the minimal variation in the peaks and troughs of the concentration curves.

6.2.2.3 Patient 2 Results Summary

Based on pharmacy refill data, patient 2 had an adherence rate of 83%. His viral load was currently undetectable, but he had a significant spike approximately a year and a half prior to the study. It was unclear if this spike was due to medication non-adherence within his control or other medical factors. He self-reported that he took his medications every day, although he said that he may have had some problems in the past when he was on a more complicated regimen. The patient did not currently use a pill box or any alarm system. He claimed that he would move all of his medication bottles to one drawer in the morning and then would move them to another location across the room at night after he took them. This served as an indicator of whether he had taken his medications or not.

Patient 2 used both the cell phone and the Chumby to report his medication adherence. He used the Chumby mainly as an indicator of whether he had taken his medications or not. The music that it played also served as a reminder that he claimed helped him to take his medications at regular time intervals. He used the cell phone to do most of his reporting, even if he was in the same room as the Chumby, since he took is medications at night and it meant that he didn't have to get out of bed. In general, his strategy was to report taking his medications immediately after he administrated them.

This patient had used a cell phone before but only for making phone calls. He expressed significant interest in the phone used in the study, however, and it became a very important tool in his life. He learned to text message, e-mail, search the web, and download applications and called the author regularly to learn about new functionality.

This patient had difficulty reporting his medications a few times, but this was typically due to changes that he made in the settings of the phone that had to be corrected rather than difficulty with the medication adherence tools.

Patient 2 only missed one medication administration (all four pills) based on his pill count in week three. He reported administering these medications, however, and was adamant that he did not miss them. He did claim that there was one day that week when he was intoxicated, but he claimed that he was sure that he took his medications that day.

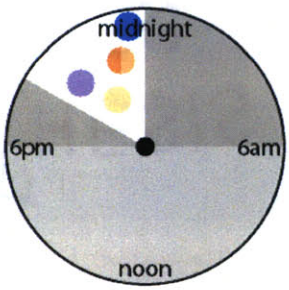

Figure 26: Patient 2 Medication Schedule. This patient reported that he typically took all four of his HIV medications at between 9:30 and 10:30pm each day. His medications were scheduled at 10:00pm with a +/- 2 hour adherence window.

	week 1	week 2	week 3	week 4	total	adherence rate
medication 1	6/6	7/7	6/7	7/7	26/27	96.3%
medication 2	6/6	7/7	6/7	7/7	26/27	96.3%
medication 3	6/6	7/7	6/7	7/7	26/27	96.3%
medication 4	6/6	7/7	6/7	7/7	26/27	96.3%
		overall adherence:			**104/108**	**96.3%**

Figure 27: Patient 2 Adherence Results. This patient only missed one administration (all four pills) throughout the course of the study. He missed the administration in the third week.

	week 1	week 2	week 3	week 4	total	reporting accuracy
medication 1	6/6	7/7	6/7	7/7	26/27	96.3%
medication 2	6/6	7/7	6/7	7/7	26/27	96.3%
medication 3	6/6	7/7	6/7	7/7	26/27	96.3%
medication 4	6/6	7/7	6/7	7/7	26/27	96.3%
		overall reporting accuracy:			**104/108**	**96.3%**

Figure 28: Patient 2 Adherence Reporting Accuracy Results. This patient inaccurately reported the one administration that he missed. On review that week, he claimed that he was sure that he took his medication that day and suggested that he thought that the pill count was likely wrong.

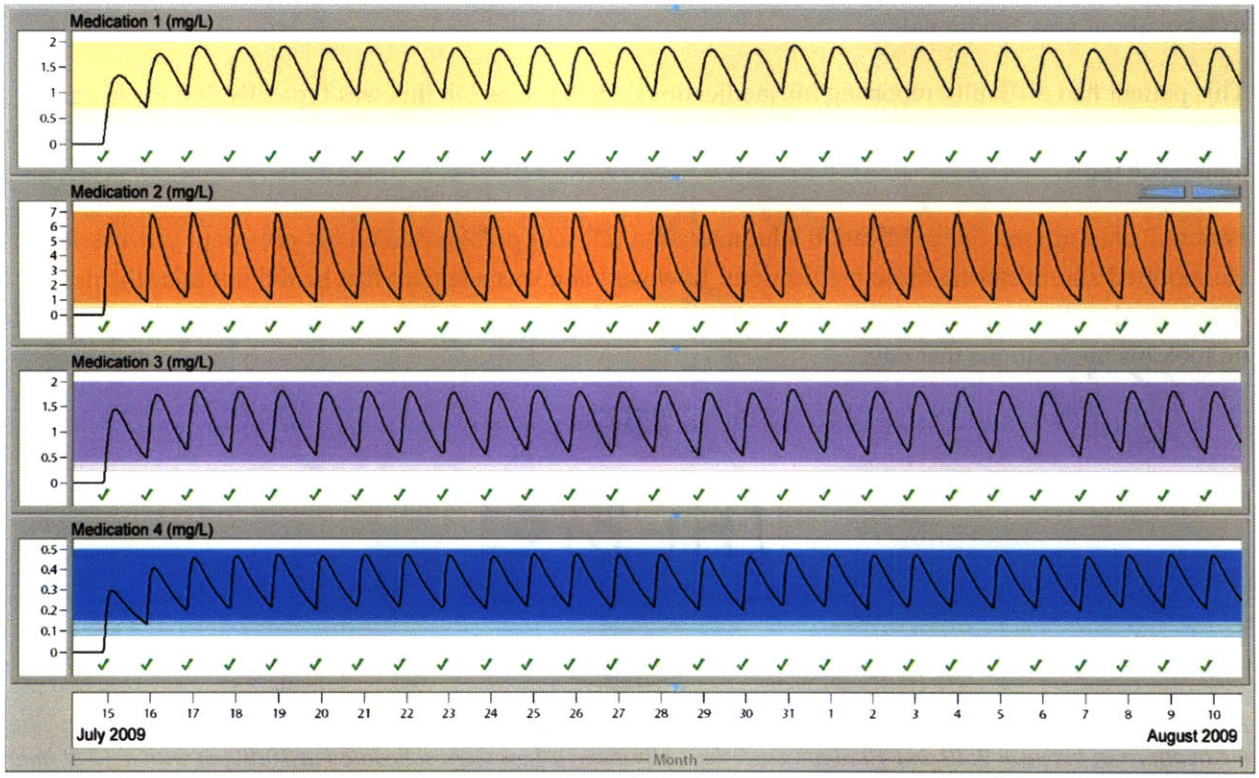

Figure 29: Patient 2 Adherence Reporting Results. It is clear that this patient's reporting was extremely regular. He claimed that he typically took his medications at the beginning of his adherence interval, especially when he was at home, because he would take them shortly after the music starting playing on the Chumby. The one administration that he missed according to his pill count is not seen in his reporting results because he reported that he administered his medications every day. During discussions, he firmly believed that he did not miss any of his medications.

6.2.2.4 Patient 3 Results Summary

Based on pharmacy refill data, patient 3 had an adherence rate of greater than 95%. Her viral load was currently undetectable, but she had mildly elevated counts for almost a year in 2008. She self reported that her adherence was good during the week but that she missed doses on the weekends occasionally. She was sure of this because she keeps her medications in a pill box in the refrigerator and sometimes sees that she missed a dose the next day. She tried a watch and a beeper as reminder alarms before but she claimed that she would usually "snooze" them, thinking that she would take her medications in a few minutes but would then forget.

Patient 3 used both the cell phone and the Chumby to report her medication adherence. She began using the Chumby as her primary reporting device but gradually adapted to use them both. Her strategy by the end was to bring her medications and the cell phone to the breakfast table with her. She would eat her breakfast, take her pills, and then report the medication administrations. Sometimes this sequence of events would be triggered by the music from the Chumby, but sometimes it was driven by routine.

This patient had used a cell phone before but only for making phone calls. She used the cell phone in the study as her primary cell phone, but she did not take a great interest in it or use it extensively.

This patient had difficulty reporting her medication adherence only on one occasion. This was due to a server outage that was promptly fixed after a phone call to the author.

Patient 3 only missed one medication administration (all four pills) based on her pill count in week three. She reported administering these medications and was relatively sure on review that she had taken them. She said that it was possible that she missed one administration, but she was relatively certain that she did not report taking her medications on any occasion that she did not actually take them. This represents the same problem that was observed with patient 2.

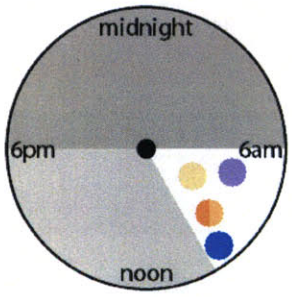

Figure 30: Patient 3 Medication Schedule. This patient reported that she typically took all four of her HIV medications at between 6:30 and 9:00am each day. His medications were scheduled at 8:00am with a +/- 2 hour adherence window.

	week 1	week 2	week 3	week 4	total	adherence rate
medication 1	7/7	7/7	7/8	7/7	28/29	96.6%
medication 2	7/7	7/7	7/8	7/7	28/29	96.6%
medication 3	7/7	7/7	7/8	7/7	28/29	96.6%
medication 4	7/7	7/7	7/8	7/7	28/29	96.6%
		overall adherence:			112/116	96.6%

Figure 31: Patient 3 Adherence Results. This patient only missed one medication administration (all four pills) throughout the course of the study. This took place during the third week of the study. She did not believe that she missed any medications on discussion of the results.

	week 1	week 2	week 3	week 4	total	reporting accuracy
medication 1	7/7	7/7	7/8	7/7	28/29	96.6%
medication 2	7/7	7/7	7/8	7/7	28/29	96.6%
medication 3	7/7	7/7	7/8	7/7	28/29	96.6%
medication 4	7/7	7/7	7/8	7/7	28/29	96.6%
		overall reporting accuracy:			112/116	96.6%

Figure 32: Patient 3 Adherence Reporting Accuracy Results. This patient inaccurately reported the one administration that she missed during the study. In discussion, she stated that she was not aware of this happening and believed that she took all of her medications.

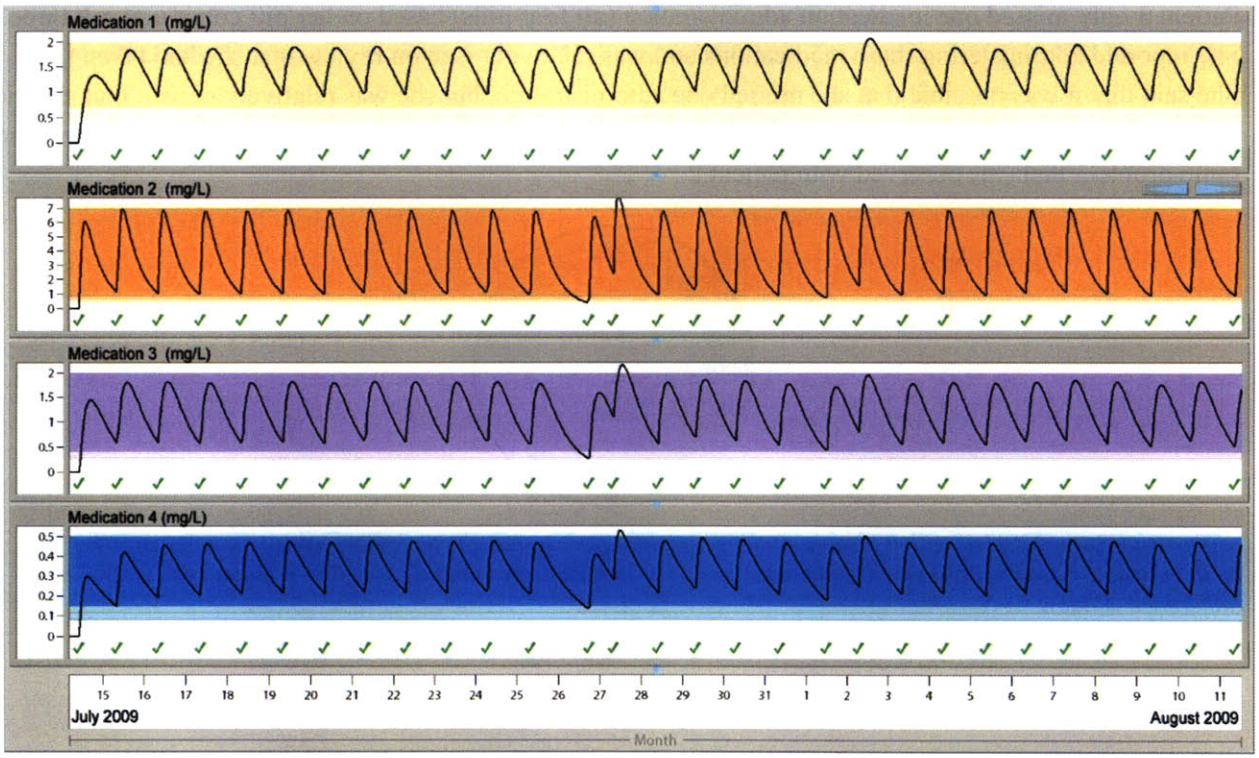

Figure 33: Patient 3 Adherence Reporting Results. This patient displayed regular reporting throughout the course of the study. There is one day where she reported taking her medications relatively late in the day, but she then resumed her normal schedule the next day. This resulted in a larger than normal trough in her blood concentration and then a larger than normal peak. The one administration that she missed according to her pill count is not seen in her reporting results because she reported that she administered her medications every day. During discussions, she was relatively sure that she did not miss any of her medications.

6.2.2.5 Patient 4 Results Summary

Based on pharmacy refill data, patient 4 had an adherence rate of less than 80%. Her viral load was currently undetectable, but she had significant elevations in 2008. She self reported that her adherence was not very good. She claimed that she had a busy schedule with events at churches and hospitals that often interfered with her taking her medications properly. She was adamant that pill boxes were too complicated for her and that she had tried several before. She had never tried any type of alarm systems. Her typical routine was to place all of her morning medications on one side of her entertainment center and all of her evening medications on the other side. She had a more complicated medication regimen than the other patients. In the afternoon, she took two pills of medication 1, two pills of medication 2, and one pill of medication three. In the late evening, she took two pills of medication 1. It is of note that she took a number of other medications in addition to her HIV medications.

Patient 4 used both the cell phone and the Chumby to report her medication adherence. She used the Chumby as her primary reporting device at home and used the phone for reporting when she was away. Her strategy was typically to report taking her medications when she was reminded by the Chumby or when she remembered on her own and to take her medications after the act of reporting. This strategy persisted despite being instructed at each visit to report after taking her medications instead of before.

This patient did not have a cell phone prior to the study. She used the cell phone in the study as her primary cell phone, but she did not take a great interest in it or use it extensively.

This patient had a number of adherence problems and a number of difficulties reporting her medication adherence throughout the study. The issues varied on a weekly basis.

In the first week, this patient had almost perfect adherence with only one missed pill, but her reporting accuracy was poor due to under-reporting. She believed that she had reported all of her administrations but later discovered that she may not have pushed the reporting button properly. This is reflected in her adherence reporting results in Figure 37. Her daughter instructed her to use her index finger rather than her thumb, and she said that after that she was able to push the button more reliably. During the visit, the feedback given by both the cell phone and the Chumby on pressing the reporting button properly was reviewed with the patient. She had not been looking to see if the quick reporting button disappeared, nor had she been looking to see if the medications were properly checked or if her adherence performance was correct. After the first visit, she did not have any problems pressing the quick reporting button properly.

During the second week, patient 4 maintained good medication adherence. She only missed two administrations of medication 1, most likely in the evening since she administered and reported all of her afternoon medications. The problem, however, was that she inaccurately reported taking all of her medications that week. On review of this data with the patient, she suggested that it was possible that she reported taking her medications late at night with the plan of going to take them but then either got distracted or fell asleep. She denied ever reporting her medications without the plan to take them.

In the third week, her adherence was worse with two missed administrations (2 pills each) of medication 1 and four missed administrations of medication 3. She again reported taking all of her medications. It appeared as if she had missed two administrations of her evening medication again, but she also missed four pills of medication 3 in the afternoon. She did not miss any of her other afternoon medications,

however. Discussion of these findings revealed that the patient may have just forgotten to grab the bottle of the one missed medication several of the days if it was accidentally moved so that it was not in close proximity to the others. She typically keeps all of her afternoon medications on one side of her entertainment center and all of her evening medications on the other side. She takes the pills directly from the bottles for each administration, so she claimed that, if one of the bottles was not in its place, she may have missed it. Again, she did not think that she missed any of her evening medications but claimed that she did fall asleep earlier than usual several days. Deeper discussion revealed that her daughter was sometimes pushing the adherence reporting button to silence the Chumby in the evening and then telling the patient to take her medications. Discussion with the daughter revealed that it was not the music from the adherence interface that was bothersome but a loud alarm tone. This alarm was not set for the study, but was potentially activated by the patient accidentally. The patient was instructed how to deactivate the alarm over the phone and claimed to have properly deactivated it. A mute button was added to the main screen on the Chumby in order to allow the music to be silenced without reporting that medications had been administered. The patient and her daughter were instructed that the mute button was for anyone in the house to use if the music was bothersome, but that the patient should be responsible for reporting.

In the fourth and final week, the patient's adherence was again relatively poor. She missed five administrations of medication 1, three administrations of medication 2, and four administrations for medication 3. These results were not consistent with any of her previous non-adherence patterns, and her reporting was again not consistent with the pill counts. The only explainable finding was that she did not report her evening medications on two occasions, which would account for two of the four missed administrations of medication 3. The odd pill counts and the inconsistent number of missed administrations did not suggest any obvious pattern of non-adherence. The patient complained of frequent headaches during the third and fourth weeks, but she did not claim that they affected her medication adherence. She thought that possibly her poor performance was because she did not hear the music on the Chumby on several occasions. This was not consistent, however, with the fact that she regularly reported that she was being adherent. She did not think that her daughter was still reporting her medication administrations for her. She claimed that this definitely did not happen during the day because he daughter was either sleeping or not in the house when she typically took her medications in the afternoon. She recounted that she still reported taking her medications before actually administering them on several occasions, and that she may have then forgotten to take them afterwards. She also thought, after it was suggested as a possibility that she may have confused some of her other medications for her HIV medications and accidentally taken the wrong pills on some of the occasions.

One other notable observation was that, on three occasions throughout the study, the patient reported taking her evening medications after midnight, and, therefore, for the following day instead of the day that she intended. This was due to the design of the system rather than misreporting by the patient, so these were promptly corrected so that the patient could properly report her medications on the evening of the appropriate day.

Prior to the final visit, patient 4 was not willing to consider a different medication schedule or using a pill box. When her adherence rates for the entire month were revealed to her at this last visit along the inaccuracy of her reporting, she decided to take several additional steps to improve her adherence. She decided to try changing her medication schedule to 8am and 8pm, to try using a pill box filled for her by

Dr. Hardy, and to move her Chumby to her bedroom with the pillbox so that it would be easier for her to report her medications immediately after taking them.

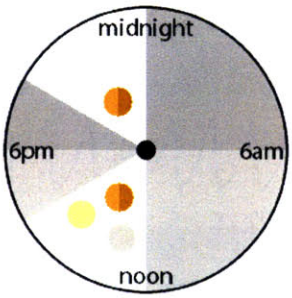

Figure 34: Patient 4 Medication Schedule. This patient reported that she typically her once a day HIV medications at 2:30pm and twice a day HIV medication at 2:30pm and 11:30pm. She claimed that this was a schedule that she developed to maximize her adherence because she would get nausea taking the medications in the morning. Also, she stayed up late, so taking her evening medications late at night was appropriate according to her. She was not interested in changing the schedule at the beginning of the study, even though the timing of doses was relatively inappropriate and her late evening dose was expected to be a problem.

	week 1	week 2	week 3	week 4	total	adherence rate
medication 1	31/32	20/24	24/28	19/28	94/112	83.9%
medication 2	16/16	12/12	14/14	9/14	51/56	91.1%
medication 3	8/8	6/6	3/7	3/7	20/28	71.4%
		overall adherence by pills:			**165/196**	**84.2%**
		by administration:			**91/112**	**81.3%**

Figure 35: Patient 4 Adherence Results. This patient only missed one pill the first week, but her adherence declined in the following weeks.

	week 1	week 2	week 3	week 4	total	reporting accuracy
medication 1	16/32	20/24	24/28	23/28	88/112	78.6%
medication 2	8/16	12/12	14/14	9/14	48/56	85.7%
medication 3	4/8	6/6	3/7	3/7	16/28	71.4%
		overall accuracy by pills:			**156/196**	**79.6%**
		by administration:			**88/112**	**78.6%**

Figure 36: Patient 3 Adherence Reporting Accuracy Results. This patient reported taking her medications inaccurately every week. In the first week, the inaccuracy was due to under-reporting, while in the following weeks it was due to over-reporting.

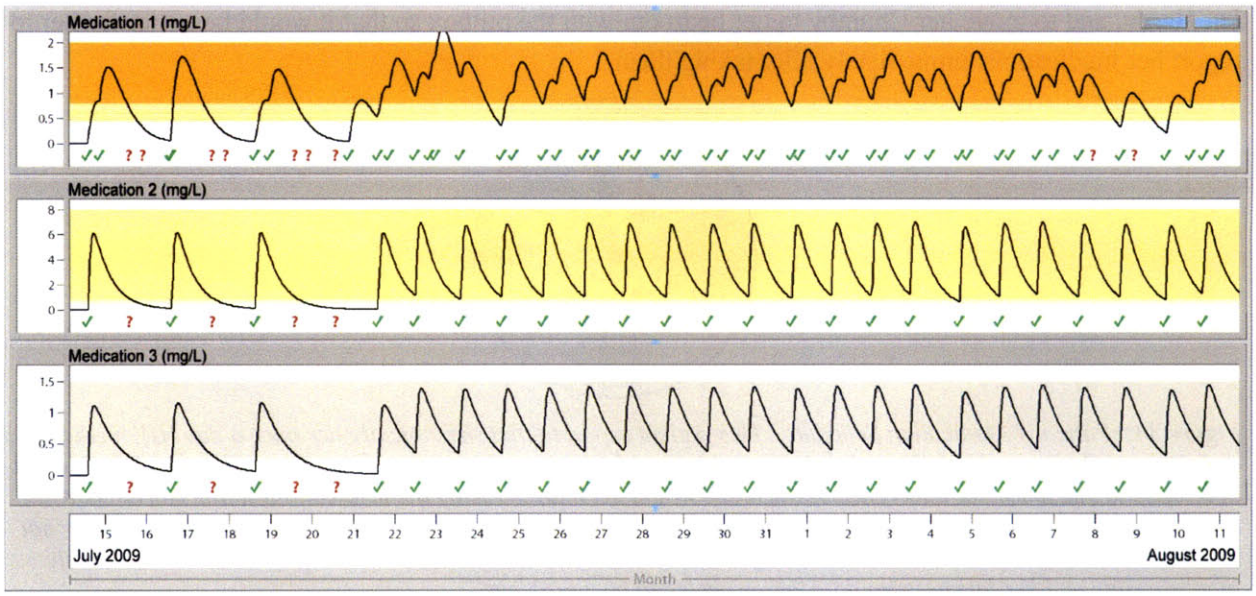

Figure 37: Patient 4 Adherence Reporting Results. During the first week, this patient displayed irregular reporting of all of her medications, caused by difficulty in accurately pushing the interface buttons. She then displayed regular reporting of her afternoon medications. Her reporting of her evening medications was relatively regular for the second half of week 2 and all of week 3 but was otherwise considerably erratic.

6.2.2.6 Patient Questionnaires

Patients completed questionnaires after the first visit and after the final visit. The goal of these questionnaires was partially to collect formal patient opinions but also to engage patients in discussion afterward.

The questionnaires given at the end of week 1 addressed patient experiences with the system that week and their initial impressions of the usefulness of the system (See Appendix C – Stage 2, Week 1 Questionnaire Results). The results revealed that the patients had a positive experience with the system. Two of the patients preferred using the Chumby and two preferred using the cell phone. They claimed that the tools were easy to use, although patient 4 claimed that they did not work as she expected, which was consistent with her reporting difficulties. There were some answers indicating that reporting was not easy on the Chumby or the cell phone, but these were by patients that were reporting on the other device. All of the patients agreed that effort involved in reporting was worth it because of the other value that they received. All of the patients felt that the medication clock was helpful in seeing if they took previous doses and that they were not confused by the fact that it showed the entire 24 hours of the day. They all strongly agreed that they liked having the freedom to take their medications during a window rather than a specified time. Patient 1 did report inconsistently that he would rather be notified exactly when he was supposed to take his medications, but in conversation he was of the opposite option, so this was likely a mistake in completing the questionnaire. All of the patients thought that the adherence performance/blood concentration graphs were helpful for education and motivation. Patient 4 did report that she was not able to understand the graphs but clarified that that was because they did not reflect her actual performance that week. All of the patients felt that it was easy to understand the HIV simulation and that it motivated them to take their medications. They also all agreed that they like sharing their adherence data with the adherence specialist and the author and that it motivated them to perform better. Video messages were also a motivating factor.

The questionnaire given to patients at the end of the study (See Appendix D – Stage 2, Week 4 Questionnaire Results) evaluated their final impressions of the usefulness of the system. All four of the patients agreed that the system helped to improve their medication adherence and that they wanted to continue using it. They all agreed that the medication clock, adherence performance graphs, HIV simulation, and supportive video messages were helpful and motivating. They all wanted to continue sharing their medication adherence data with Dr. Hardy. Everyone, with the exception of Patient 1 who only had the cell phone, thought that the combination of the cell phone and Chumby was better than just using one of the devices.

6.2.3 Discussion

There were a number of important goals for the pilot deployment of the HIV adherence system. The most global was to obtain initial patient impressions of the new types of care enabled by the CollaboRhythm platform in general. More specifically, the goal was to begin evaluating, in a subjective manner, the ability of the tools to improve patient adherence. In addition, the pilot served to test the technical aspects of the system for an extended period of time and allowed the usability of the interfaces to be evaluated by real users. The more technical issues will be addressed first followed by the more important evaluations of medication adherence and new paradigms of care.

6.2.3.1 System Performance

An initial goal of the pilot deployment was to ensure that the HIV adherence system was technically sound and would function reliably for an extended period of time. Throughout the deployment, there were relatively few technical issues. The patient interface server was down on several occasions, but the author was monitoring its status regularly and it only interfered with reporting on two occasions. The reason for the outages was not investigated thoroughly because the problem occurred only a few times and did not interfere with the study. In the future, the issue will be resolved and a back-up server strategy will be implemented to avoid any inconvenience to patients in reporting. Patients did not report having significant technical issues with their client interfaces. A few patients did report that they had to turn their Chumbies on and off on one or two occasions, but that they resumed functioning properly after that. One patient did have repeated technical difficulties with the phone, but they were due to issues independent of the HIV adherence tools, as he used the phone extensively and was exploring much of its other functionality.

6.2.3.2 Patient Interface Usability

Another goal of the deployment was to evaluate the usability of the HIV adherence interfaces on the Chumby and the cell phone. Patients 1, 2, and 3 developed mastery of the interfaces very quickly despite lacking significant experience with computers or smart phones. Patient 4 had significant issues is reporting properly during the first week, but, after only a few minutes of further instruction, she was able to report reliably and navigate the interface without help. Considering that she had no significant experience using a cell phone or computer prior to the study, her performance in interacting with the system was better than anticipated. Another notable problem was that, near the end of the study, patient 2 had forgotten that he could report taking his medications individually. He had been using the quick adherence reporting button in the middle of the clock for the entire month, and did not need to report medications individually. This suggested that it might be necessary to make it clearer that the medication adherence intervals were clickable objects. This was considered in the development of the system, but no appropriate solution was discovered at the time. It should be relatively simple to improve in the future.

6.2.3.3 Burden of Adherence Reporting

A significant concern in the development of the system was that the burden of reporting would be tiresome and considered not worth performing after an extended period of time, but the results indicated that this was not a problem. Reporting of adherence was made as simple as possible with a single button push for each group of medications, and patients agreed that this was sufficiently simple and efficient. Patient 4 actually typically reported each of her medications individually and was still not concerned about the time or effort that it required. Patients 1, 2, and 3 all developed a routine for taking their medications and reporting using the devices, and they were clear that the devices helped to make a routine that was more consistent than their previous routine. Patient 4 clearly had difficult developing an effective routine, but she still subjectively reported that the burden of reporting was insignificant.

Of course, one month is a short period of time considering that patients currently need to take their medications for the rest of their lives. Also, previous studies in electronic adherence reporting have shown poorly sustainable results. The hope is that this system will succeed where other systems have failed because (1) it gives patients more than one method for reporting with a home and mobile solution, (2) it motivates patients through the performance feedback graphs and HIV simulation (3) reporting gives significant value in terms of the need for fewer office visits and more efficient communication, and (4) reporting and achieving good adherence are fun and engaging. Patients overall agreed with these points, except that more could definitely be done to make the system fun. They did not seem that concerned that it needed to be fun, however, because of the value that it provided in terms of helping them manage their disease.

6.2.3.4 Honesty in Adherence Reporting

The honesty of adherence reporting in the HIV system was an extremely important concern. Specifically for HIV medication adherence, patients consistently commented that it would be foolish to be dishonest in adherence reporting because they knew that their laboratory reports would eventually show "the truth." The risk, however, is that the adherence performance graphs and the HIV simulation, along with a provider viewing the reports and sending encouraging videos, might provide enough immediate and tangible reward that the patient might ignore the long-term vision. In fact, the graphs and simulation were designed for the complete opposite reason. The hypothesis is that many patients fail to take their medications because the danger of HIV seems so distant and they have no immediate motivating feedback. The hope is that the personal and dynamic feedback will help patients to assign more importance to each and every medication adherence.

It was difficult to learn much from this pilot study about honesty in reporting using the HIV medication adherence tools. The problem was that each of these patients knew that pill counts would be completed at each weekly visit, so this decreased the potential benefit from dishonesty. Also, patients 2 and 3 only missed a single administration, and they were both very sincere in their beliefs that they had taken those medications. It is more likely that they simply accidentally reported taking those medications and did not complete the act. One concern is that it is possible that reporting might be too easy on the adherence tools. The problem is that increasing the effort, possibly by having patients individually report each medication or by first clicking a window saying that they are being honest, would likely increase the burden of reporting to an unacceptable level to be completed every day for an indefinite period of time. For patient 4, assessing honesty was also difficult because of the complications explained including that

her daughter sometimes reporting for her, that she often reported before actually taking her medications, and that she was taking a number of other medications and may have been confused or mistaken.

One solution to the problem of honesty in reporting that is being investigated is the design of an intelligent pill box that automatically performs the reporting for the patient. In this case, the burden of reporting becomes completely removed. Although the patient could cheat the system, this would require opening and closing each of the appropriate medication bins at the correct time each day. The effort involved in this act would be almost equivalent to the act of actually taking the medications, so there would be much less likelihood of benefit of being dishonest. If such a pillbox is built, the patient will still get all of the same feedback including the adherence performance graphs and the HIV simulation. One problem with this approach, however, is that it will be much more difficult to test with a larger population because it would require manufacturing a number of these intelligent pill boxes.

6.2.3.5 Ability to Correct Adherence Reports

It was suggested by advisors of this project that the ability to correct errors in reporting would be important in preventing user frustration from lack of credit for desired behavior. This was not built into the first generation of the patient tools because of time constraints, but the infrastructure supports it. An experience with patient 4 confirmed that this functionality will be critical to add. During the first week, she did not express any concern with her inaccurate adherence reports because she was still learning to navigate the interface and was not sure if she was reporting properly or not. After the first week, she knew how to view her adherence performance graphs, and she was concerned one day when she accidentally hit the adherence reporting button at an inappropriate time. She called the author and wanted to correct the problem so that she could properly report her adherence later. She explicitly stated that it should be possible to correct reports, and she was pleased that it could be corrected for her. She was apparently engaged by the challenge of producing excellent adherence, which was a testament to this hypothesis which was central in the design of the system. Her concern about the accuracy of her reports suggests that she might have been trying to be honest in her reporting, even though her adherence reports were inaccurate. It is also possible that she did not understand that her inaccuracy would be revealed by the pill counts, but her interviews were not suggestive of this.

The ability to correct adherence reports during the same day of the report will be an easy addition to the HIV adherence tools. The patient will be able to click on adherence intervals even after the medications in the intervals have been reported and will be able to change each of the current reported adherence states. The thread of reported states will be maintained in the data model. It will be more difficult, and likely not appropriate, to allow patients to correct adherence reports from previous days. Studies show that retrospective patient adherence reports are relatively inaccurate (Hales, et al. 1999).

6.2.3.6 Comprehension of Adherence Tools and Their Effect on Adherence

A core premise of the CollaboRhythm platform is that patients are capable of contributing to their care to an extent well beyond the opportunities that are given to them. In addition, it upholds that patients are capable of understanding concepts that the medical institution generally believes are too complicated, especially if these concepts are illustrated in a personalized and dynamic manner. This belief is highlighted by the use of adherence performance graphs and the HIV simulation in the system for HIV medication adherence. The pilot study showed some preliminary support for these assertions, but there are certainly issues that need to be discussed.

Considering the excellent adherence of patients 1, 2, and 3, it was difficult to deeply investigate their ability to reason with the medication clock, adherence performance curves, and HIV simulation. A number of their observations and comments, however, suggest that these tools were impactful. Patient 4 appeared to comprehend the tools during visits, but she failed to use them effectively to manage her medication adherence. There are a number of possible explanations for this, which teach some important lessons about how to improve these tools and apply them more effectively in the future.

Patient 1 only missed one pill during the course of the study, but this event and the data presented by the adherence tools clearly had an impact on him. When he arrived for his visit after the first week, he immediately explained the reason for his one missed pill. He explained that he also saw the decrease in that medication's curve and the break in the protective ring around his t cells. This led to questions about the significance of this missed adherence at this and a future visits. It also led to his curiosity about other aspects of HIV infection including the risk of transmission and the effect of different methods of birth control on the risk. This was very encouraging because a major goal of the CollaboRhythm platform and the HIV medication system is to encourage education and patient participation. The premise is that education that is driven by patient interest rather than clinician desire is much more likely to be effective. It was also encouraging because it meant that he comprehended the utility of the adherence performance graphs and HIV simulation and that they were motivating factors for him. He reported at each visit that he viewed the graphs and simulation daily.

Patient 2 was very clear that he did not look at the adherence performance graphs or the HIV simulation regularly. He stated, "I could just take a picture of them and put them on the wall because they aren't going to change." He appeared to comprehend the interfaces on review at each visit. He said, "That must be mine because it is perfect." He clearly had a sense of pride in the fact that his graphs and simulation showed no mistakes. He was also able to answer questions about what each of the images in the simulation represented and what would be expected if he missed one of his medications. The patient's pride in his adherence performance may have been a factor that stimulated his improvement in adherence from baseline. Pride could also be a stimulus for dishonest reporting, but this patient only had one inaccurate report, so no reasonable evaluation of this was possible.

Patient 3 only had one period of a few hours during the course of the study where her performance graphs showed sub-optimal blood concentrations of her medications. She noted, without being questioned, that she saw her t-cells being attacked during this period of time and that it let her know that she "was messing up." She took her medication immediately upon seeing this state and made it clear that it had an impact on her. She claimed that she looked at her graphs and simulation daily.

Patient 4, as explained earlier, had difficulty using the interfaces during the first week. Not only did she have difficulty reporting, but she also did not look at the graphs or simulation much that week. After the further instruction that she received at the first visit, she was definitely capable of navigating the interfaces and she was able to comprehend the basic principles of the adherence graphs and the simulation. She was even upset when it was incorrect on one occasion. She appeared to have a diminished ability, however, to use the medication adherence clock to effectively manage and properly report her medications. She was not able to use the medication adherence clock to determine if she took her medications already or not because she sometimes reported taking her medications before she actually administered them. The issue with her daughter reporting her medication administrations for her on

occasion was also a complicating factor. As a result, her graphs and simulation were not correct and they inappropriately gave the impression that she was adequately protected by her medications. It was not possible, therefore, to conjecture in any meaningful way if the graphs and simulation helped to motivate her to take her medications better even though she claimed that they did by subjective report and in questionnaires. It is necessary to consider the possibility that this patient actually did take medications at each of times that she reported but that she did not take the proper medications. She had a large number of pill bottles including her non-HIV medications and a complicated medication regimen. Even if this was the cause of her difficulties and an explanation of her good reporting but poor adherence, this still indicates a failure of the medication adherence clock, since the goal of it is to give patients access to pictures of each of their medications and detailed instructions in order to avoid this type of confusion. Patient 4 actually claimed that she did not usually use the adherence reporting button in the middle of the clock but instead reported each medication individually. This means that a picture of each medication was shown to her with instructions, but she still did not take them properly.

6.2.3.7 Overall Evaluation of the HIV Medication Adherence System

The HIV adherence tools were extremely well received by all four patients despite their different adherence histories and barriers. This suggests that there is promise in this multifaceted approach to supporting adherence. The constructive relationships developed between the patients and Dr. Hardy and the author are also a testament to the importance of social support and communication and the ability of this system to bolster those elements.

Patients 1 and 3 already had optimal adherence, but they were adamant that the adherence tools helped to make even further improvements and did not add any unacceptable burden. For patient 1, his increased independence was important because it meant that his child saw less of the struggle of his disease. The system also meant increased social support for him, as evidenced by weekly phone calls that he made just to thank the author and Dr. Hardy for their efforts. For patient 3, the improvement was just that the system helped her to be even more consistent in her adherence and gave her a greater sense of control of her disease. She liked to see that the HIV could not attack her t-cells because of her good medication adherence.

Patient 2 actually made a significant improvement in his adherence during the study compared to his baseline pharmacy refill data. This was especially interesting considering that he thought that his adherence was perfect even before the study. Although he did not look at his performance graphs and the HIV simulation regularly, it is very possible that he gained motivation from the approbation that he received from Dr. Hardy and the author.

The system failed to help patient 4 achieve optimal adherence or significant adherence improvements during the study. The main reason was that her incorrect reporting let to inaccurate adherence performance data. It is impossible for the system to serve most of its functions properly if adherence is not reported accurately. It did not appear that dishonest reporting was the cause her inaccurate data. Instead, it was more likely the consequence of confusion and improper use of the system. Improvement will have to be made to help avoid this result. This may include more in-depth patient education on the use of the system and the development of an intelligent pillbox to make the process simpler and to allow for more error checking.

Although patient 4 did not achieve optimal adherence during the study, her willingness to change her behavior (new medication schedule, using a pill box, relocating her pill box and Chumby) is definitely a success of the system. A significant aim of the system is to expose data to both the patient and the provider so that constructive conversation and education are possible. Patient 4 was initially resistant to changes in her routine even though she self-reported that her adherence was not good. The system helped to generate a more constructive conversation about adherence built on data that helped the patient to see that change could be helpful.

It is also important to note that the system was designed with the hope of producing sustainable improvements in HIV medication adherence. Although it is true that the system is not expected to work for all patients, it is likely that this will require longer than a month in some patients. More research will be required to find a good balance in the complexity of the system so that it accessible to many but also remains engaging. This may require the system to be adaptable for different patient types or to be customizable by the patients themselves.

6.2.3.8 The HIV Medication Adherence System as an Evaluation of CollaboRhythm

The HIV medication adherence system is just one illustrative example of the greater effort of CollaboRhythm. The overwhelmingly positive response of the patients in this study, independent of their personalities and adherence issues, suggests that there is significant potential for this collaborative and continuous model of care facilitated by the CollaboRhythm platform. They were very willing to engage as participants in their care to the point that they were calling the author even when necessitated by study. Their engagement also appeared to have positive effects on their adherence and sense of control of their disease. This population happened to be of considerably poor health education, but the patients proved that they were very capable of and interested in learning more about their disease.

Considering that only one provider was involved in this study, it is more difficult to draw any conclusions about how providers will react to this model of care. Their reactions will have to be evaluated in future studies. In general, Dr. Hardy was very positive about the impact of the medication adherence tools, but she still had doubts about how they could be adopted into practice on a larger scale.

7 CONCLUSION

The current model of paternalistic and episodic medical care is not compatible with the modern individual. Today's society is accustomed to instantaneous access to information and efficient communication. The internet has served to eliminate the asymmetry in knowledge that once made paternalism in care necessary. Cellular phones, text messaging, and video conferencing make episodic office visits an archaic construct.

CollaboRhythm is a technological platform that is being created to allow new paradigms of provider-patient interaction that embrace the modern individual and society. It aims to facilitate a more collaborative and continuous model of care that focuses on transparency of data, shared decision making, education, and new channels of communication. It is primarily a research tool that will allow investigations of the impact of these new paradigms on healthcare access, cost, outcomes, and experience.

A system for supporting HIV medication adherence was created to serve as an illustrative example of the capability of CollaboRhythm and to allow some of its principles to be evaluated. HIV medication adherence was chosen as a clinical problem because it is an example of the failure of the current model of care despite the availability of effective treatments. Individual clinicians have achieved commendable results, but the problem has proved too big and too complicated to be handled at scale with the clinicians and resources available.

The evaluation of the HIV medication adherence system revealed that patients were receptive to the new model of care that it allowed. All of the patients reported that the system helped them to achieve better adherence and that they wanted to continue using the tools. They became actively involved in their care and were in general more open to education and collaboration. Three of the patients maintained optimal adherence, but the system was also a success for the fourth patient because it helped to convince her that she needed to work harder and try new strategies to improve her adherence. The system did have limitations, and a number of important lessons were learned from the patient who did not achieve optimal adherence including the impact of inaccurate or dishonest reporting as well as potential solutions to these problems.

Although the evaluation that was conducted focused on HIV medication adherence, the findings suggest that there is significant merit in the principles of CollaboRhythm in general and that further investigation at a larger scale and across different disease populations is warranted.

7.1 Contributions

7.1.1 A Hybrid Electronic Record that Embraces Data Transparency

Personal health records are receiving a great deal of attention today but demonstrations of their ability to improve health outcomes have not been performed. The hybrid electronic record presented here demonstrated how it is possible for a system to serve the needs of both the clinician and the patient, and in doing so, potentially improve patient outcomes. The transparency enabled in the HIV medication adherence system allowed patients to take more control of their medication adherence and engage in more fruitful collaboration with a provider. It is possible that the combination of self-reflection and social support offered in this type of relationship could result in sustainable improvements in adherence for other patients and less likelihood of disease progression.

7.1.2 Collaborative Interfaces for Shared Decision Making

Shared decision making is receiving a lot of attention in the medical world, but there is a woeful lack of tools for truly effective and engaging investigations of its benefits. The collaborative workstation developed for CollaboRhythm will make a new set of interfaces available for anyone interested in studying the impact of patient agency on patient satisfaction, adherence to decisions, or overall outcomes. The use of a few shared decision making tools in the HIV medication adherence system also provides an illustrative example of how they can be applied. The hope is that this demonstration will inspire others to use similar collaborative interfaces in other contexts and with different patient populations.

7.1.3 A New Model for Technological Support of Medication Adherence

The typical technological approach to supporting mediation adherence is through alarm-based systems that encourage patients to be reactive. The HIV medication adherence system presented is novel in that it takes a multifaceted approach to generating motivation for patients to be proactive through awareness, self-reflection, education, and social support. It also demonstrates that technology does not need to focus only on the patient in isolation. The system allows patients to manage their adherence in collaboration with a provider. If fact, it is hypothesized that this teamwork component will be critical in its success for many patients. The transparency of data and new channels of communication will also allow for issues to be handled more efficiently and effectively.

7.1.4 Disease State Simulation as a Motivational and Educational Tool

The majority of patient education takes place through generalized examples and static materials on paper and on the internet. The provider's lessons also take place predominantly in the office during brief and often stressful visits. The problem is that patient retention of information presented in the office falls below 20%, indicating that no matter how hard a physician tries to educate within the current model of care, the results are disappointing (Roy 2003).

The simulation of HIV used in the adherence system presents an example of personalized and dynamic disease state simulation as a motivational and educational tool. This novel approach allows patients to have a glimpse of some hidden disease state that is critical in understanding the value of medication adherence or health-related behavior change. The rationale is that the immediate and tangible information will make it easier to keep on track of important health goals and more difficult to ignore issues that seem too long-term to make a difference. The disease state simulation serves as grounding for continual education. At each visit, it serves as a common model that clinician and patient can discuss together and build upon. As knowledge grows and understanding develops, the model could even adapt and represent more complex concepts. Disease state simulations may be useful in a number of chronic diseases including diabetes, asthma, hypertension, and hypercholesterolemia. They may also be useful in tools for health-related behavior change such as weight management and smoking cessation.

7.1.5 New Expectations for the Impact of Technology on Health

The most important message of this work is that, although technology can be used to make incremental improvements in the delivery of healthcare, it may be capable of facilitating a much more radical transformation – one that will dramatically improve patient outcomes, significantly decrease the cost of providing care, and overall make the experience of dealing with the healthcare establishment much more enjoyable and engaging. This is a fantastic statement, but the CollaboRhythm platform that was presented and the HIV medication adherence example provide at least some hope that such a

transformation is possible. The types of interaction that were demonstrated were dramatically different from the current approach to care, and patients with even the most difficult of social situations and barriers to health education proved to be receptive.

7.2 Future Work

Work on the HIV medication adherence system will continue over the next several years. Improvements will be made based on feedback from the pilot study including the ability to correct reporting, the addition of a weekly adherence score, customizability of the interface including music, and the ability to report subject information independent of adherence reporting. An intelligent pill box to automate reporting and minimize dishonest and inaccurate reporting will also be created. Research will then be conducted to determine if the positive results from the pilot will scale to larger numbers of patients and if the system can benefit patients with more significant adherence issues. The plan is to conduct a four month study including up to one hundred patients. During the first month, electronic pill caps and pill counts will be used to measure baseline adherence for all of the patients. Patients will then serve as their own controls for the remainder of the study, in which they will use the HIV medication adherence tools on the phone and Chumby in a manner similar to that presented in this thesis. The results will allow a determination of whether the new model of care contributes to statistically significant improvements in adherence.

The most pertinent next steps in the CollaboRhythm platform are those directly related to the management of other chronic diseases. The paradigm for supporting HIV medication adherence will also be applied to diabetes, hypertension, asthma, weight management, and smoking cessation. In order for this to be done, tools for measuring objective parameters such as blood glucose, blood pressure, peak flow, weight, etc. need to be integrated into the system.

Although the author will organize some investigations into other chronic diseases, the goal will be to make the components of the CollaboRhythm platform freely available to other researchers. The hope is that this will allow for many parallel approaches to be developed and tested in order to accelerate knowledge of the effectiveness of new models of care. A first step in evaluating the potential of this approach will be to hold a project-oriented health innovation class at the Massachusetts Institute of Technology where students will be able to build projects using the components of CollaboRhythm. This will rapidly produce a number of prototypes that may serve as additional inspiration for research.

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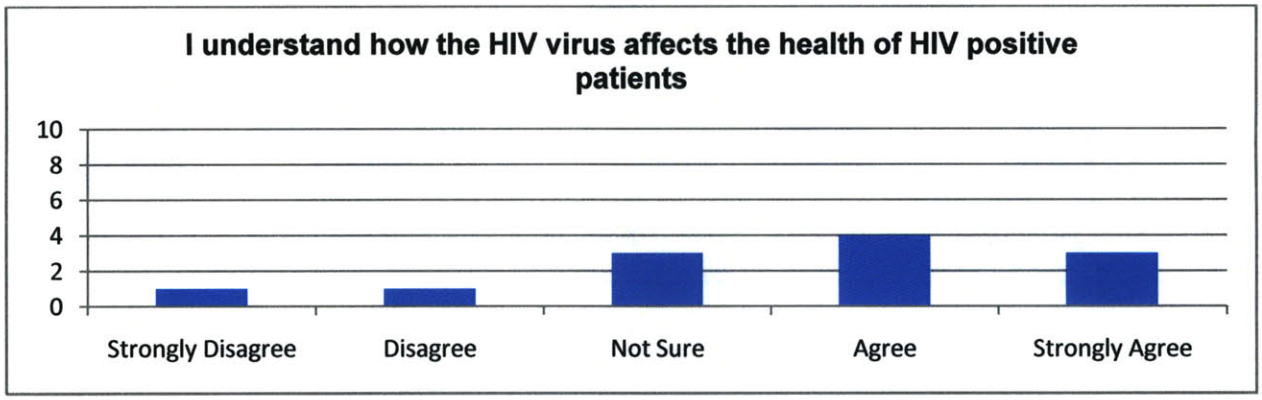
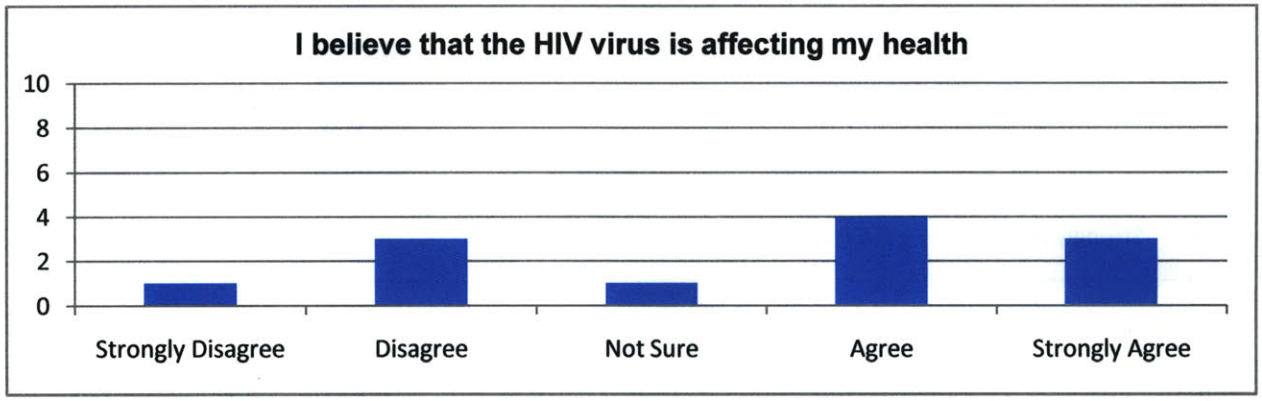
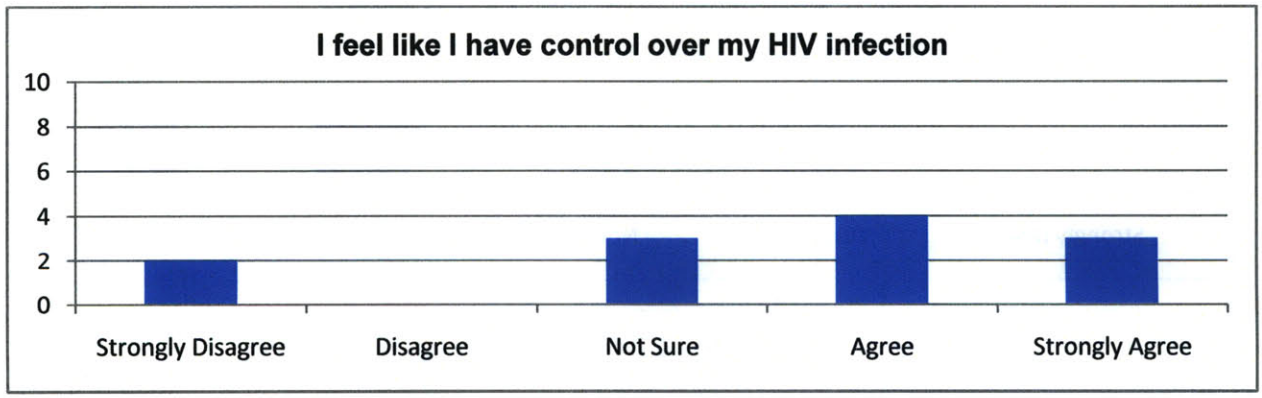
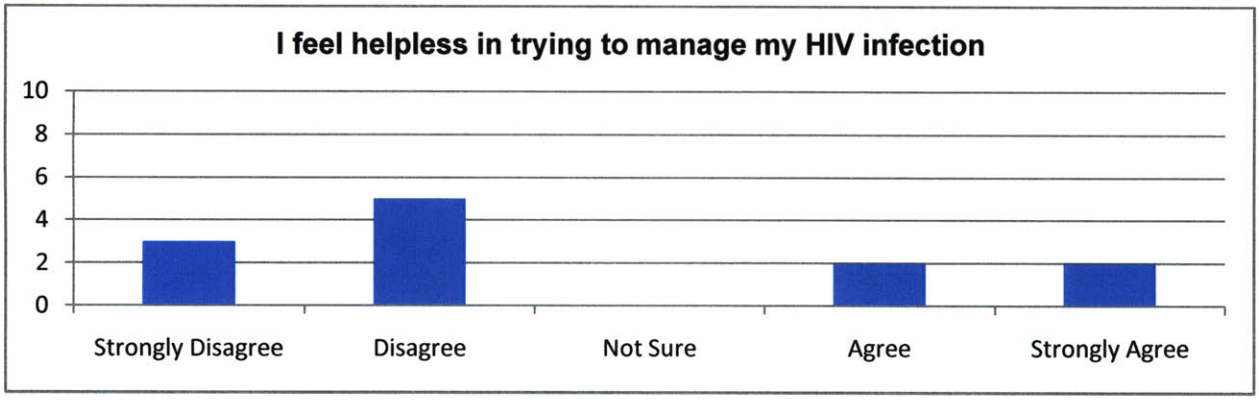
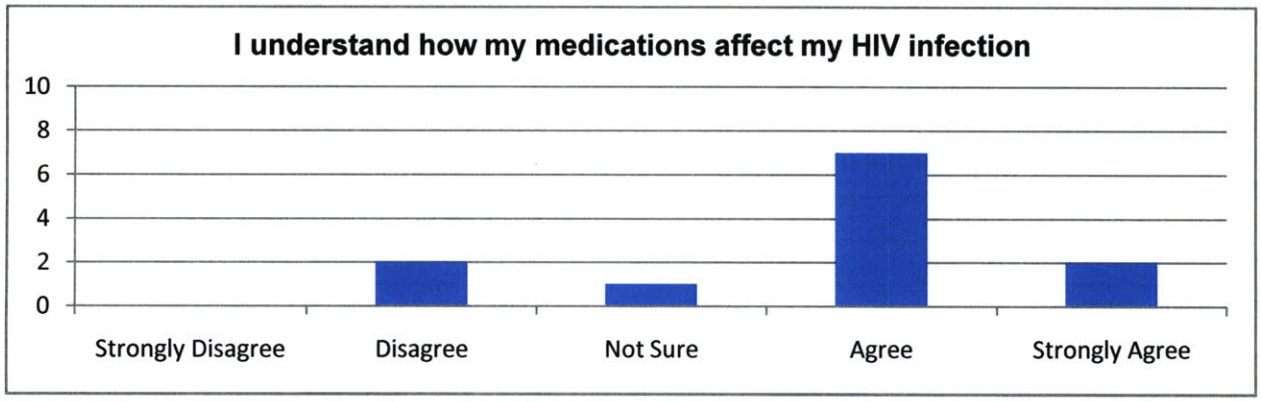
Appendix A – Stage 1, Part 1 Questionnaire Results

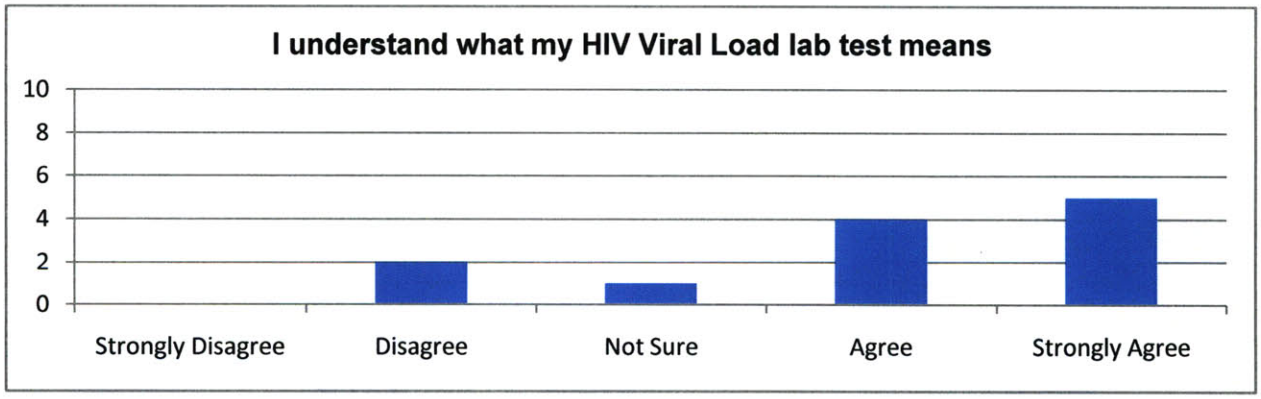


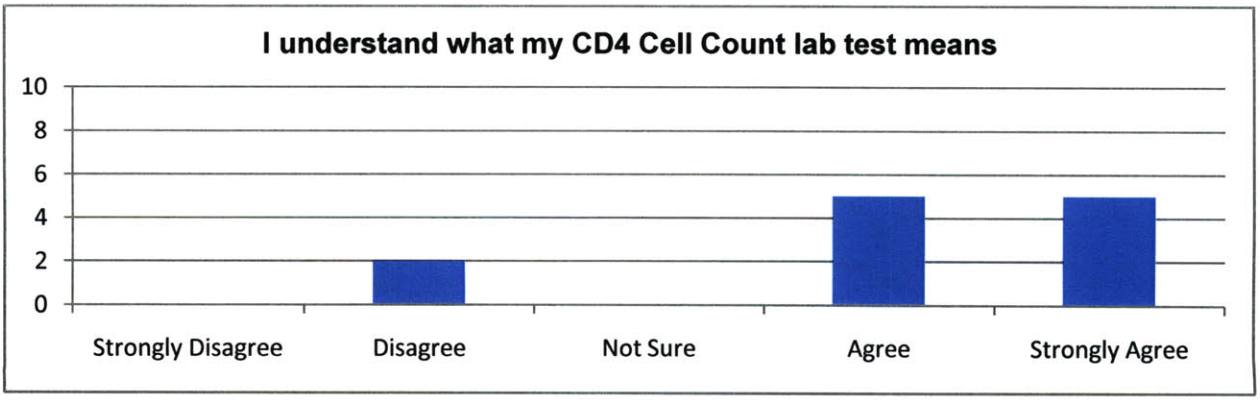


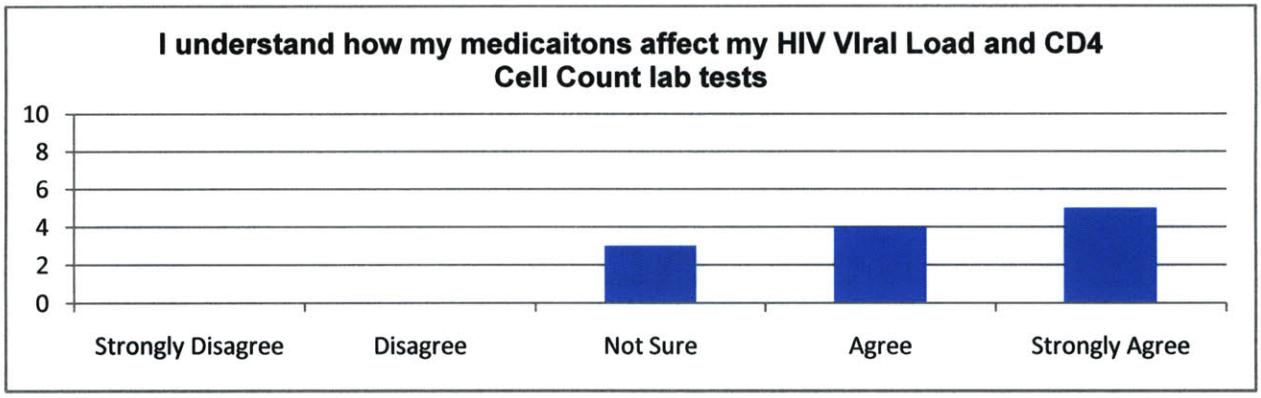


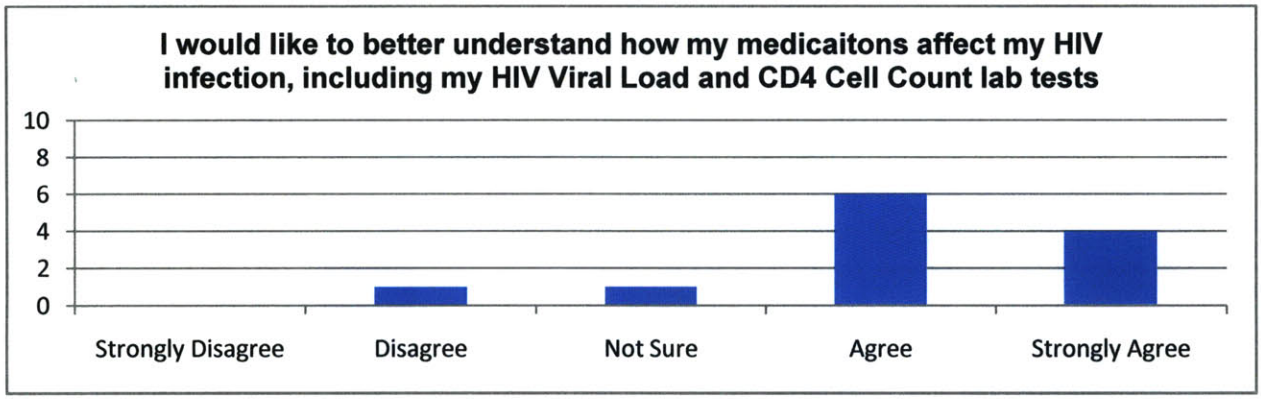

I feel helpless in trying to manage my HIV infection
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

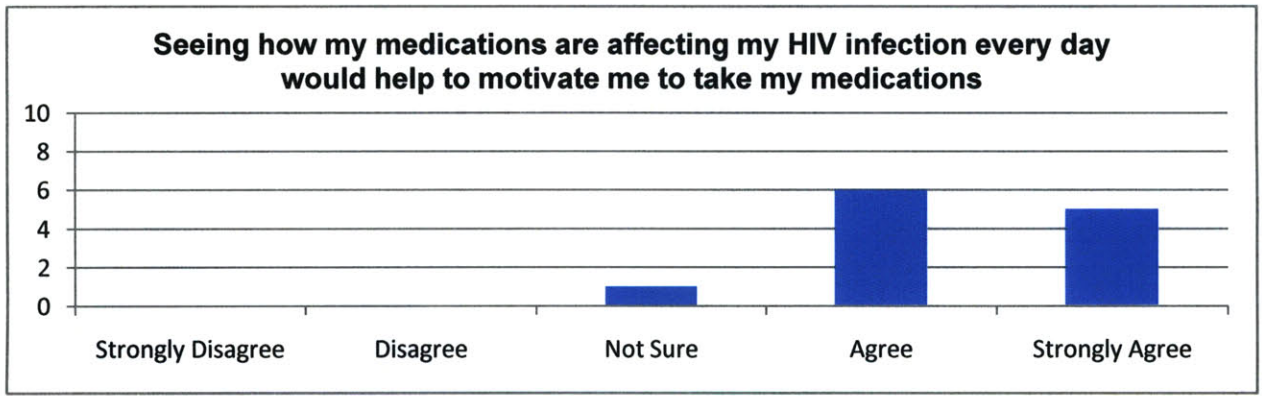

I understand how my medications affect my HIV infection
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

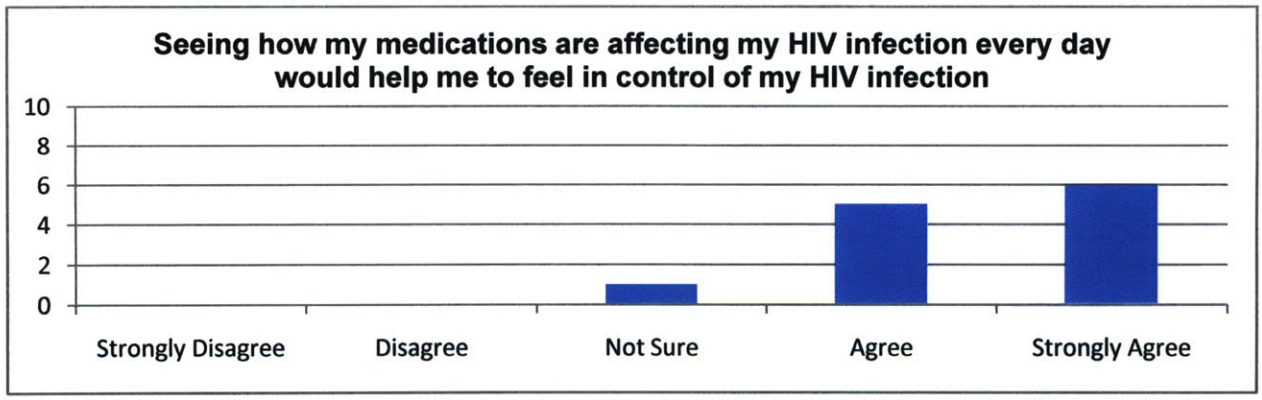

I understand what my HIV Viral Load lab test means
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

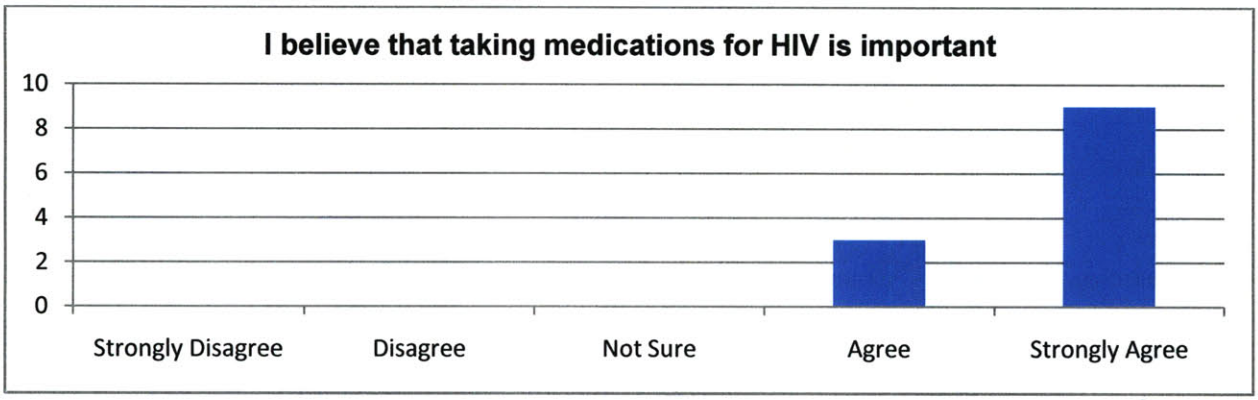

I understand what my CD4 Cell Count lab test means
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree


I understand how my medicaitons affect my HIV VIral Load and CD4 Cell Count lab tests
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree


I would like to better understand how my medicaitons affect my HIV infection, including my HIV Viral Load and CD4 Cell Count lab tests
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree


Seeing how my medications are affecting my HIV infection every day would help to motivate me to take my medications
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree


Seeing how my medications are affecting my HIV infection every day would help me to feel in control of my HIV infection
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree


I believe that taking medications for HIV is important
10
8
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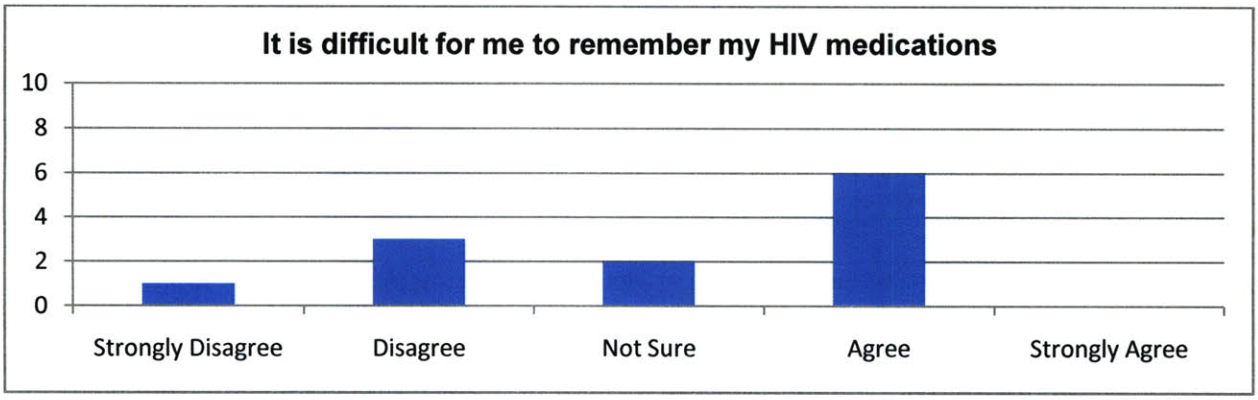
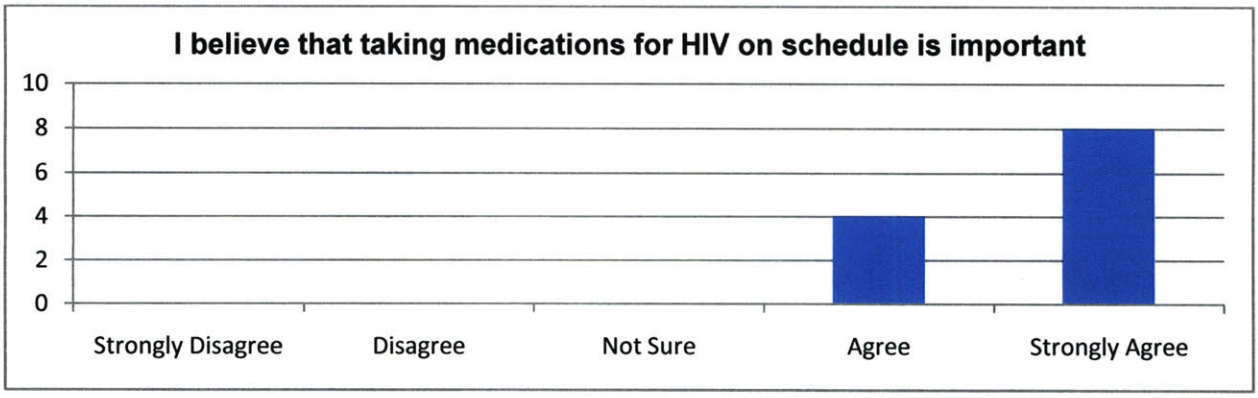
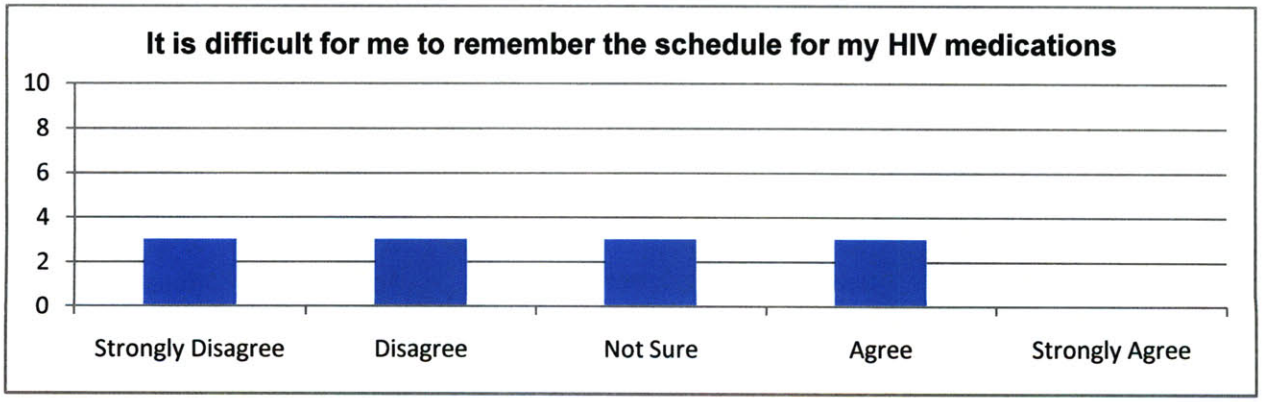
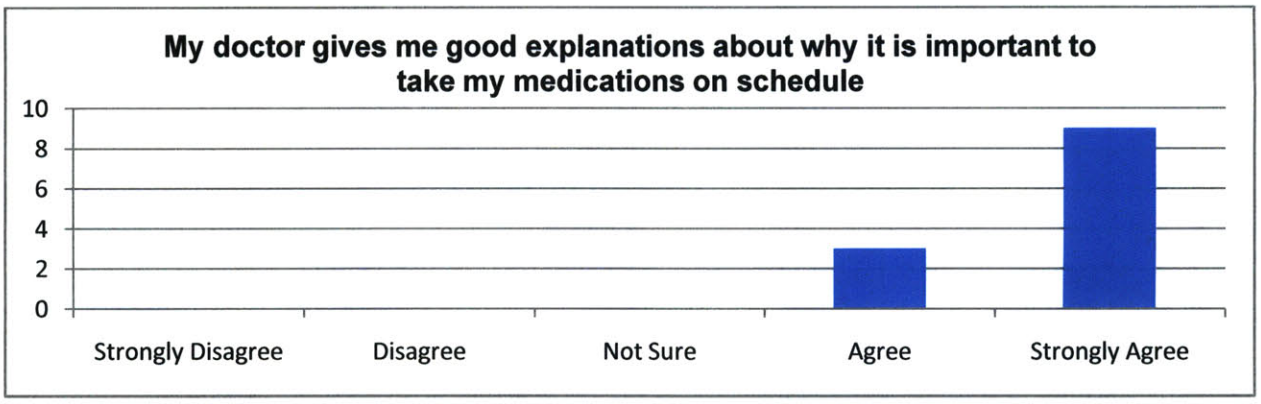
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree


It is difficult for me to remember my HIV medications
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree


I believe that taking medications for HIV on schedule is important
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree


It is difficult for me to remember the schedule for my HIV medications
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree


My doctor gives me good explanations about why it is important to take my medications on schedule
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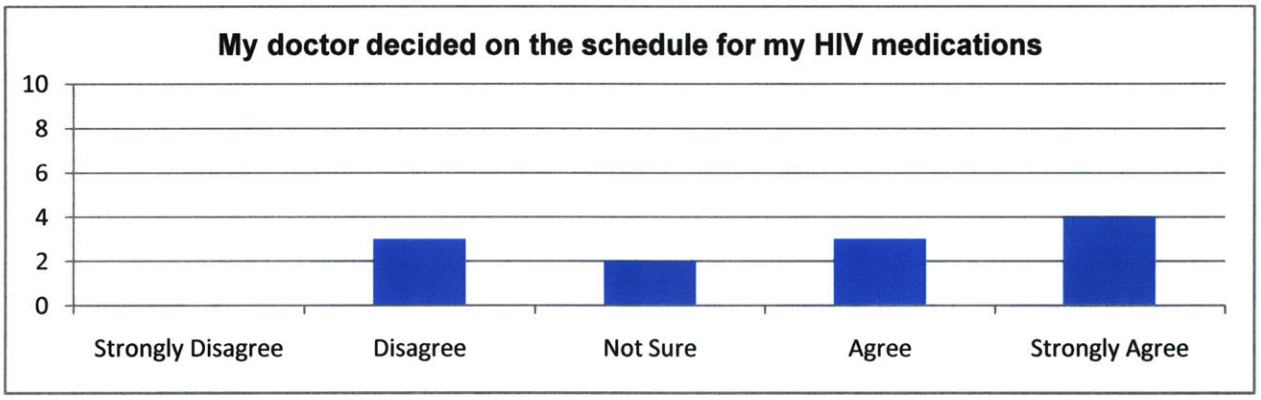
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree


My doctor decided on the schedule for my HIV medications
10
8
6
4
2
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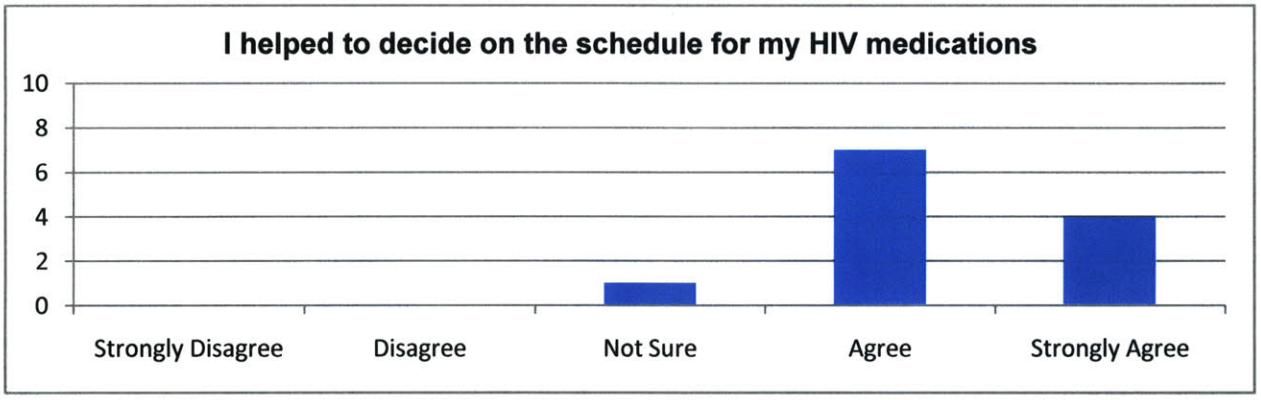
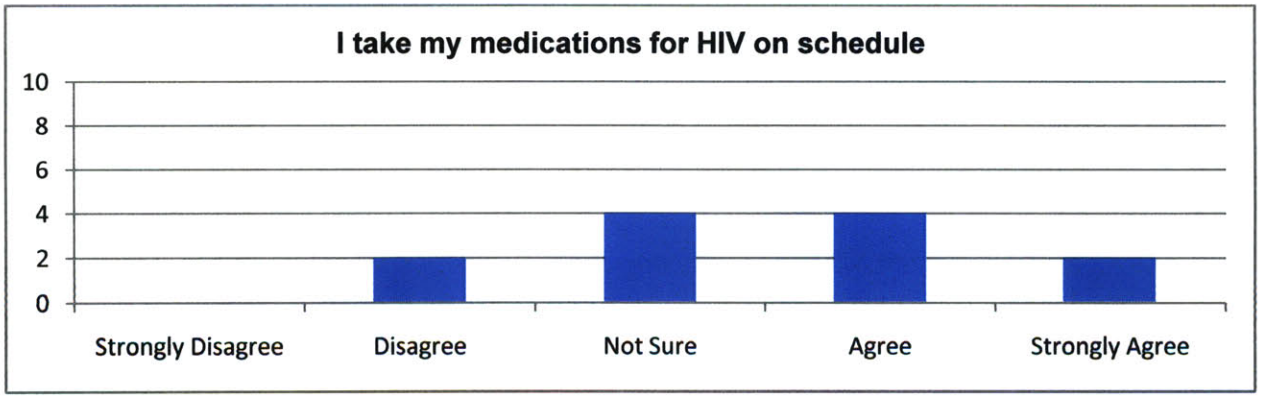
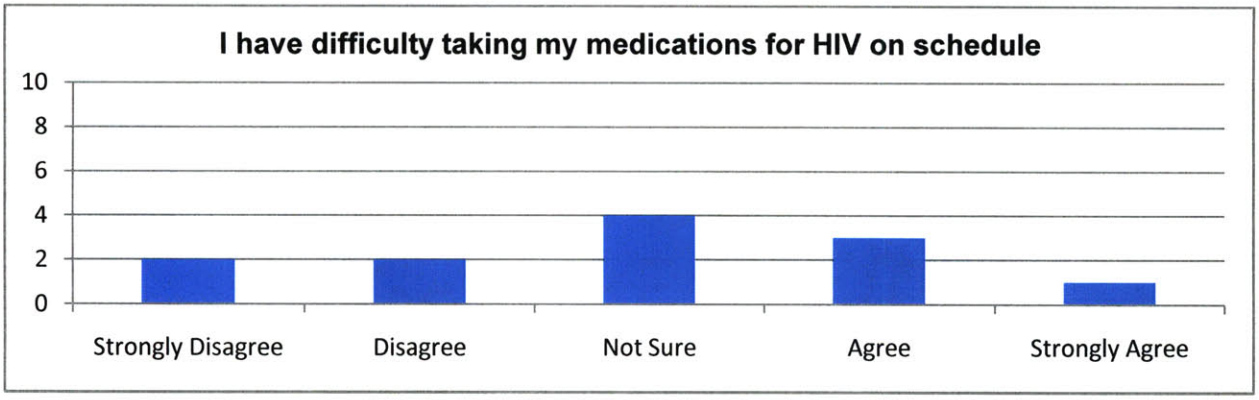
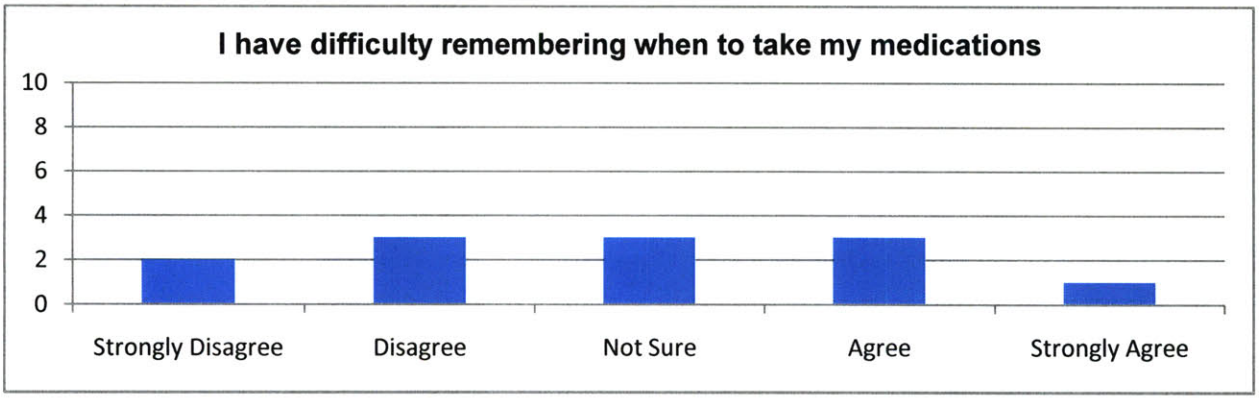
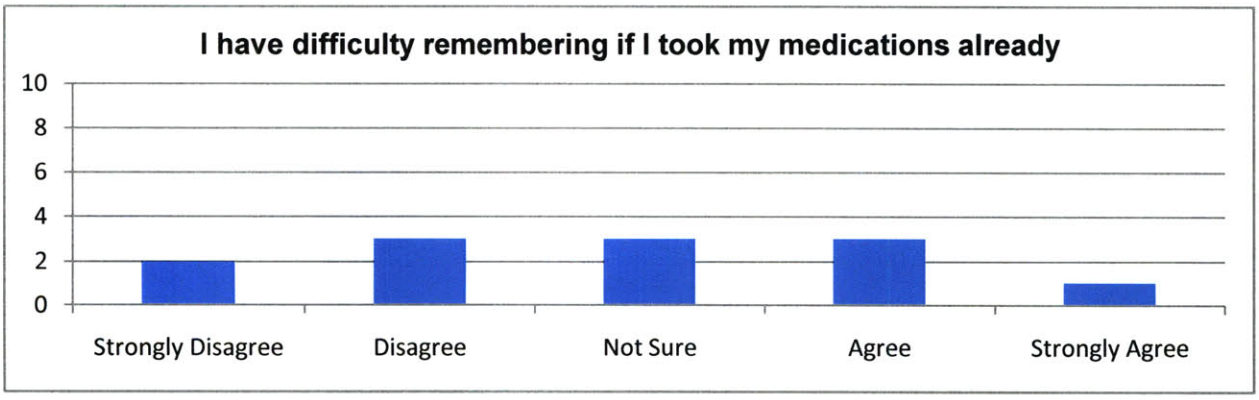
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

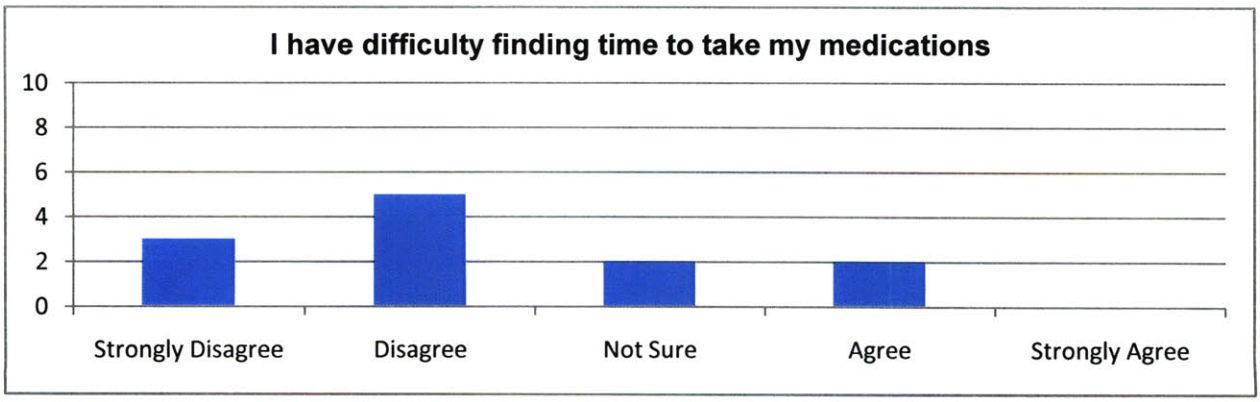

I helped to decide on the schedule for my HIV medications
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

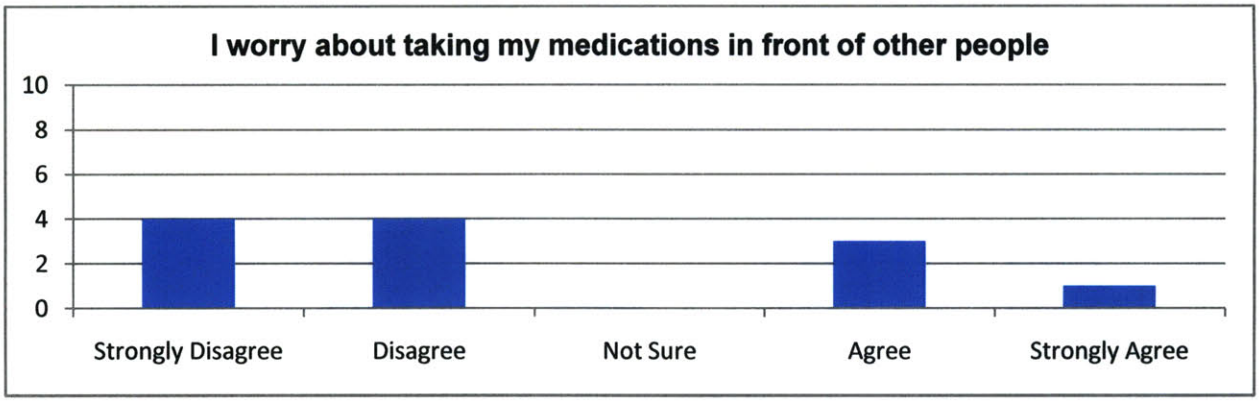

I take my medications for HIV on schedule
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

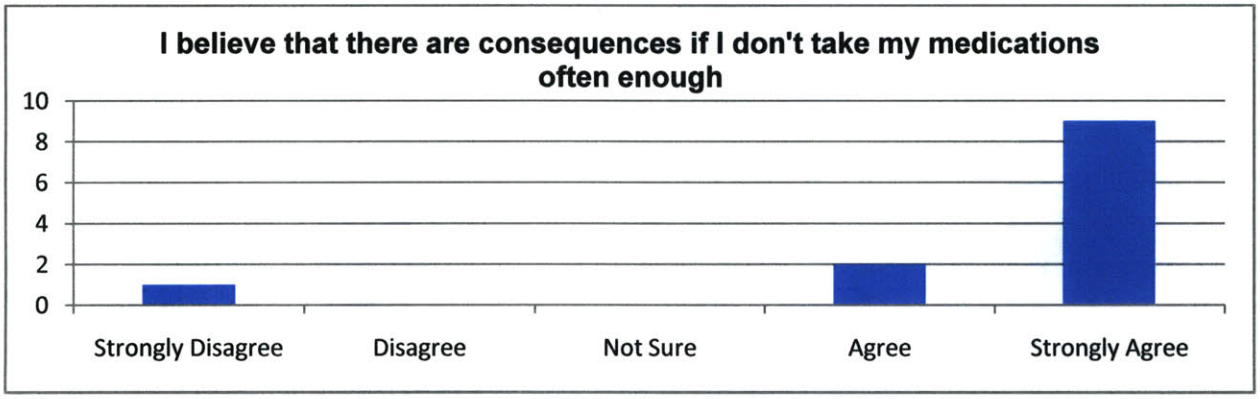

I have difficulty taking my medications for HIV on schedule
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

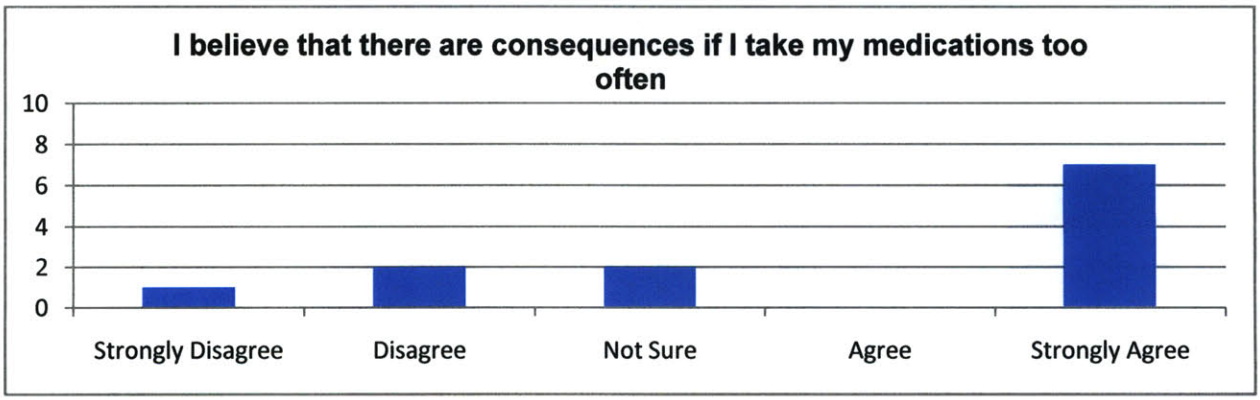

I have difficulty remembering when to take my medications
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

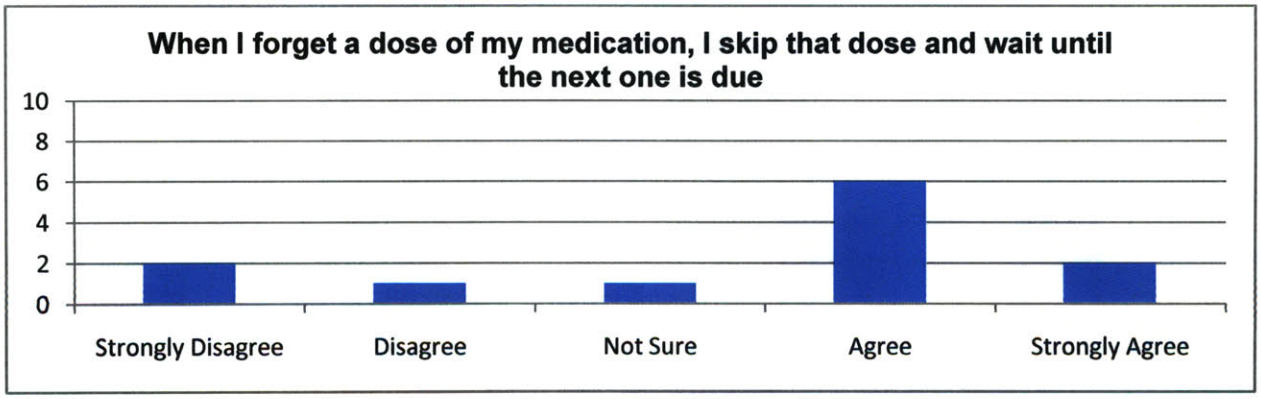

I have difficulty remembering if I took my medications already
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

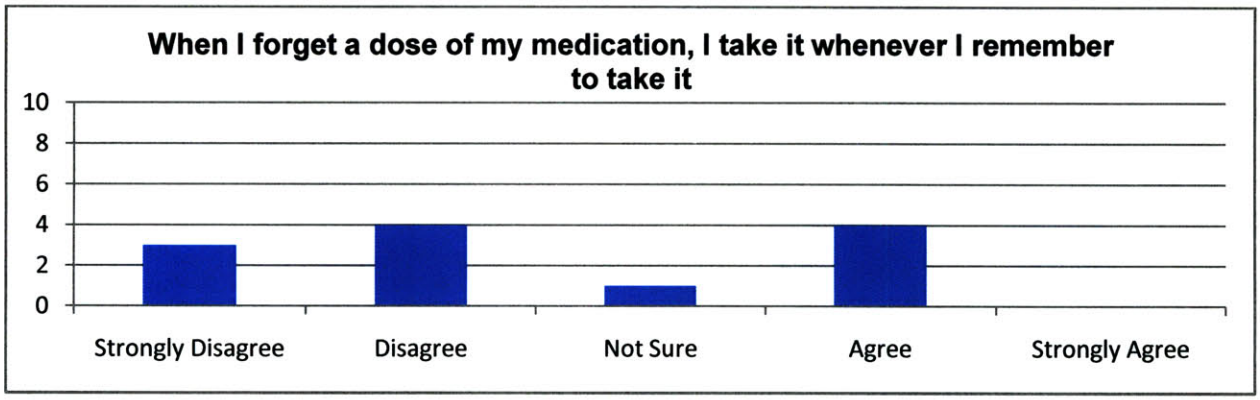

I have difficulty finding time to take my medications
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

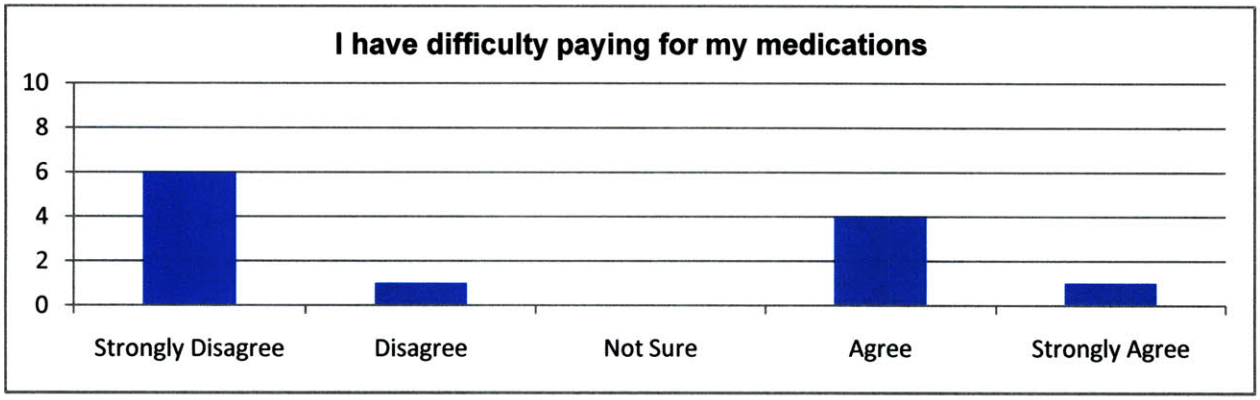

I worry about taking my medications in front of other people
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

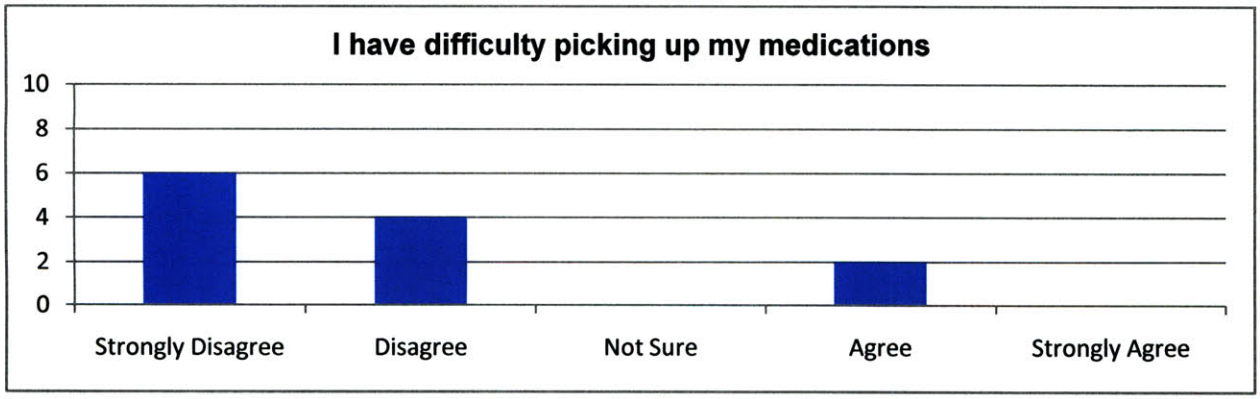

I believe that there are consequences if I don't take my medications often enough
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

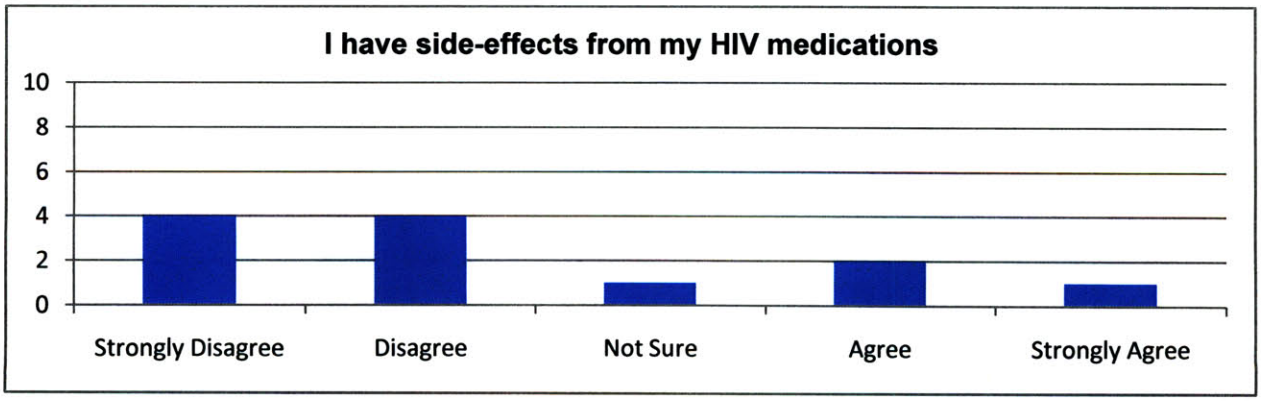

I believe that there are consequences if I take my medications too often
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

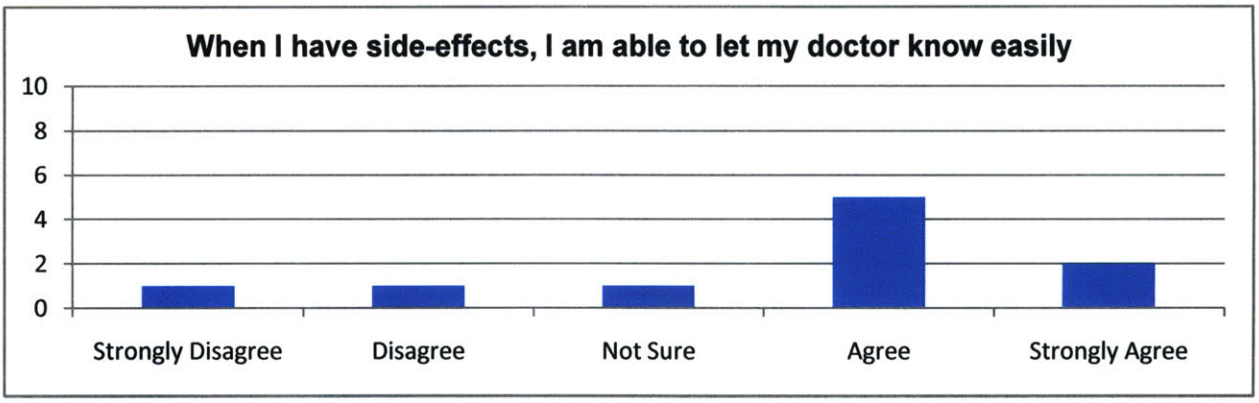

When I forget a dose of my medication, I skip that dose and wait until the next one is due
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

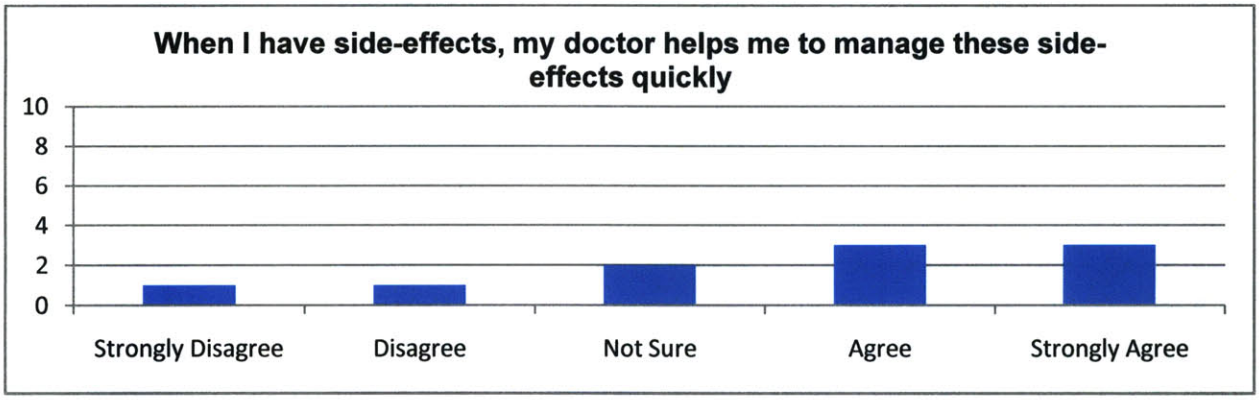

When I forget a dose of my medication, I take it whenever I remember to take it
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

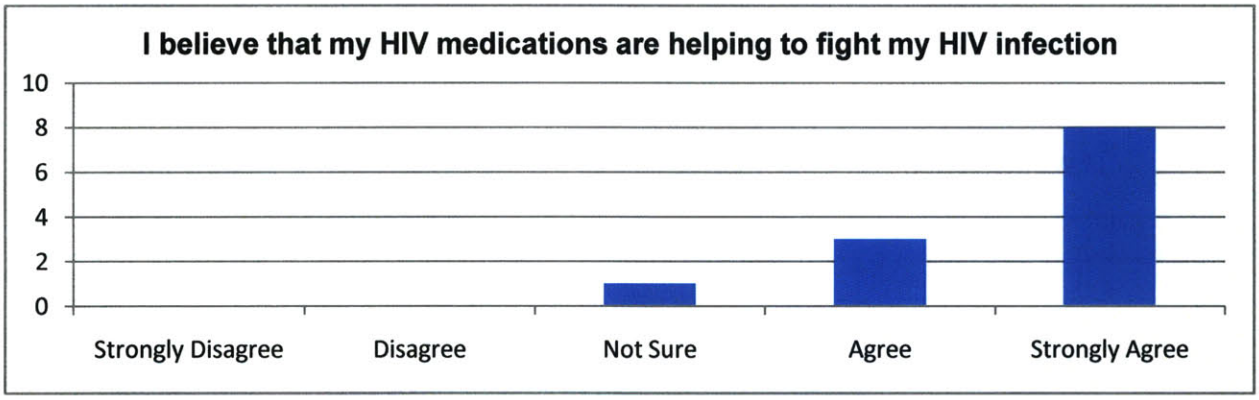

I have difficulty paying for my medications
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

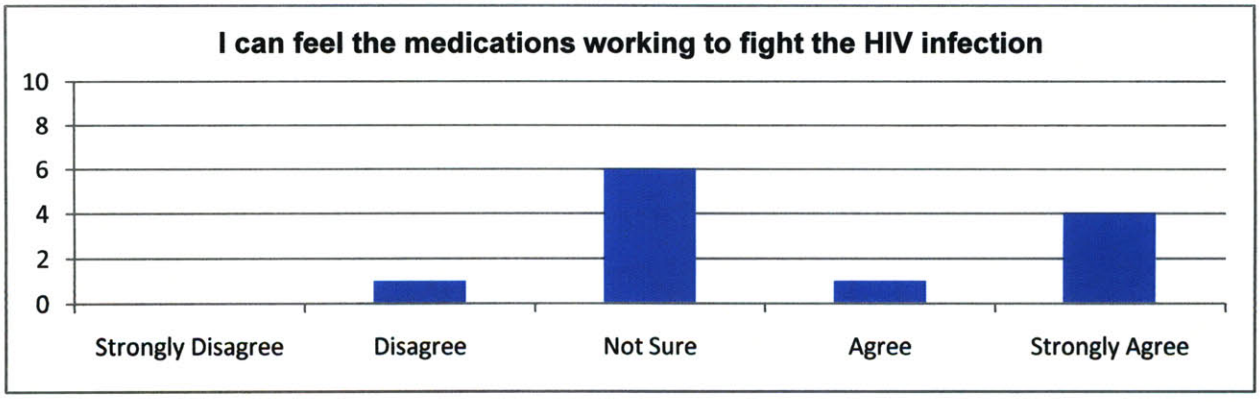

I have difficulty picking up my medications
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree


I have side-effects from my HIV medications
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

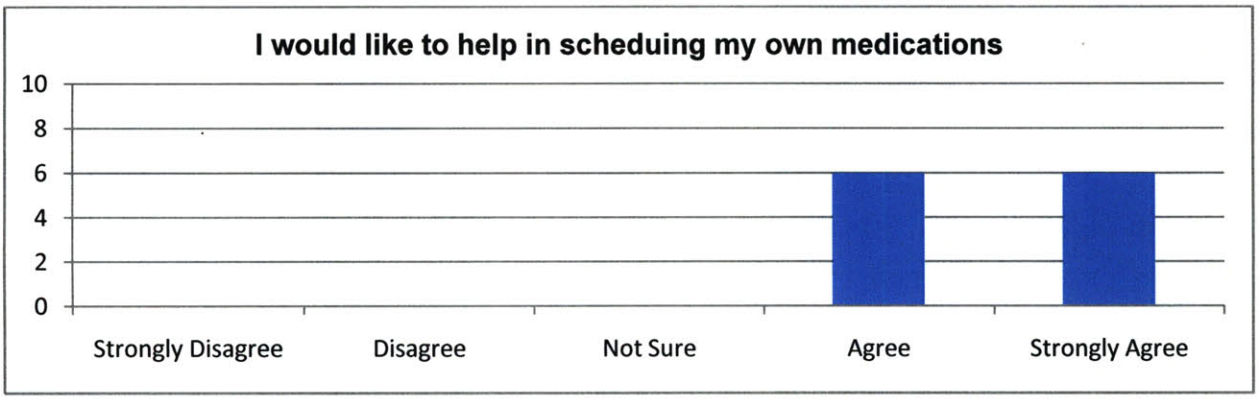

When I have side-effects, I am able to let my doctor know easily
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

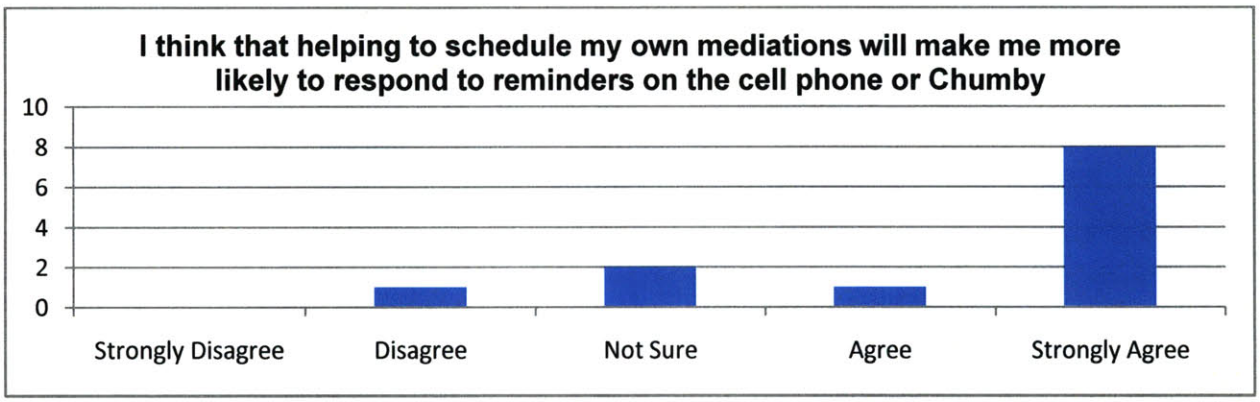

When I have side-effects, my doctor helps me to manage these side-effects quickly
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

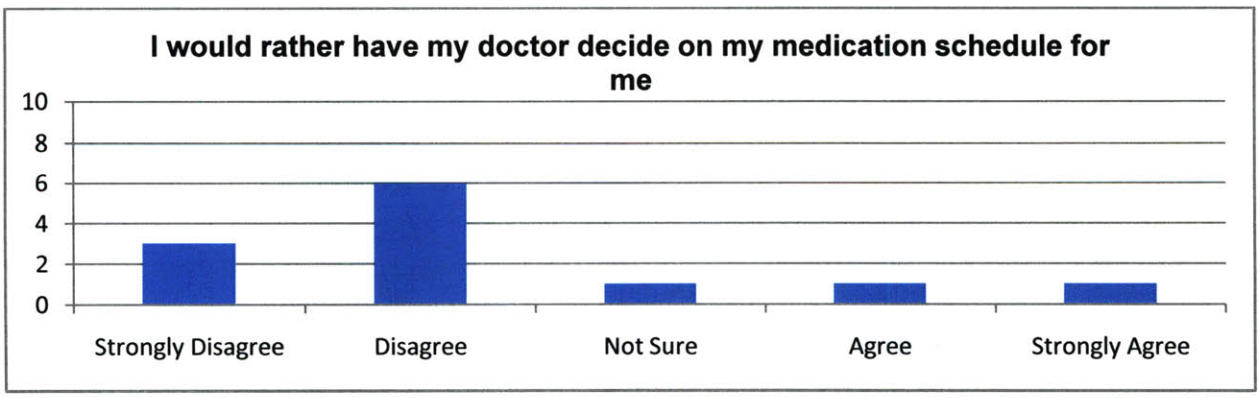

I believe that my HIV medications are helping to fight my HIV infection
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

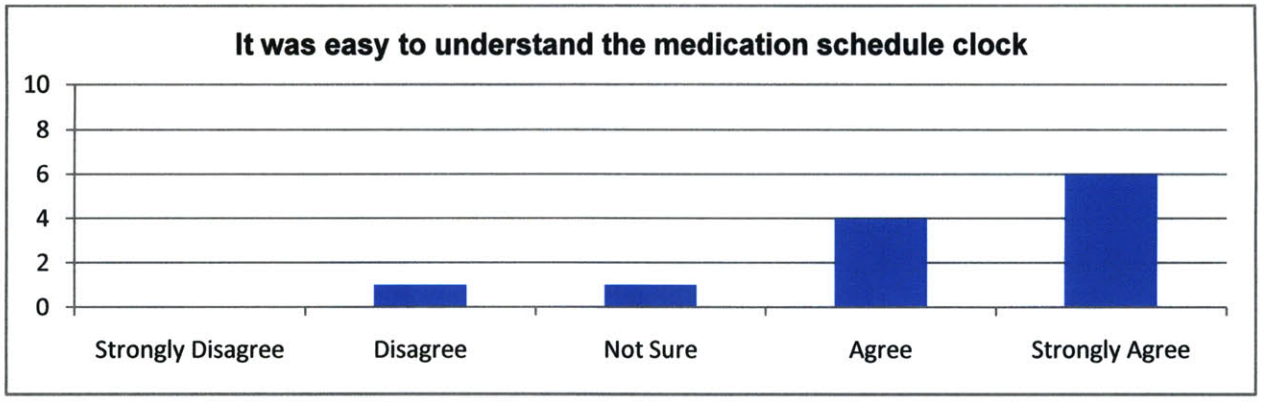

I can feel the medications working to fight the HIV infection
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

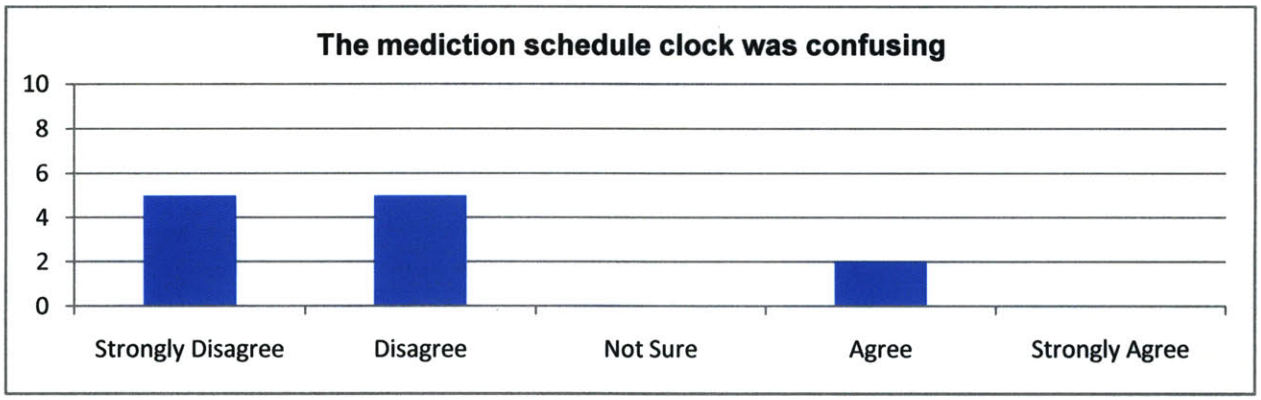
Appendix B – Stage 1, Part 2 Questionnaire Results

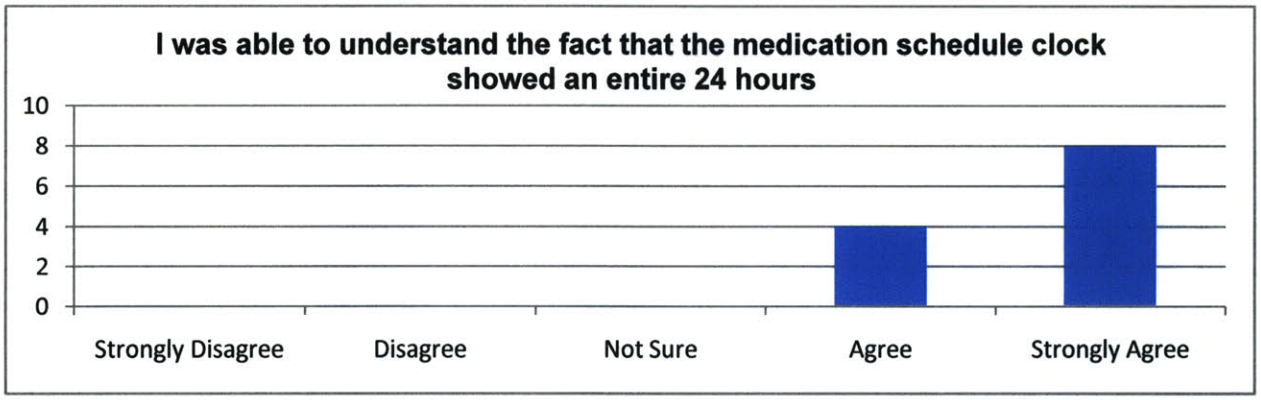


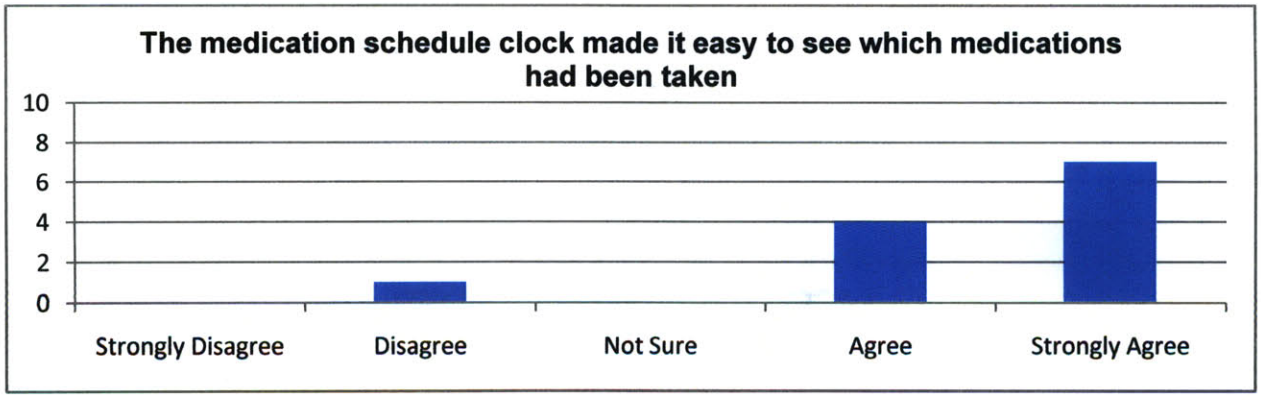


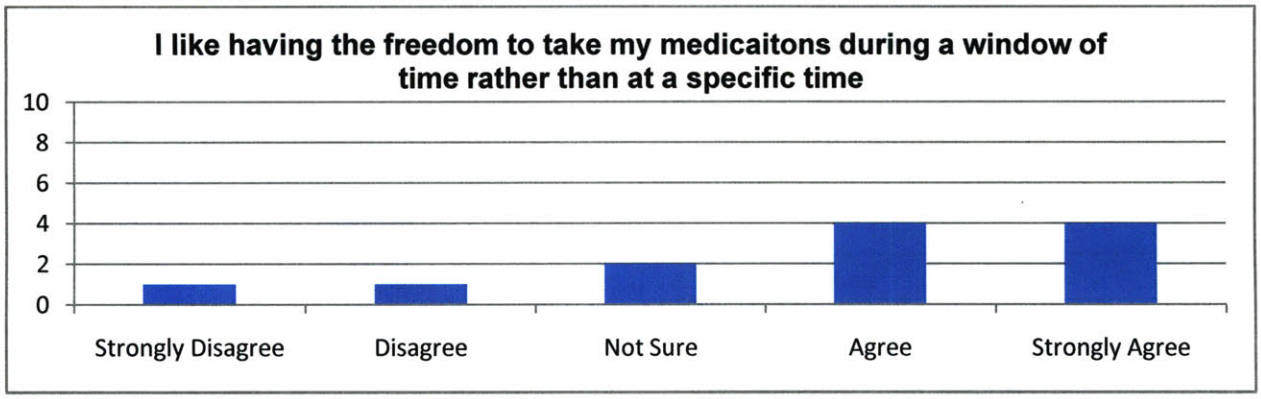


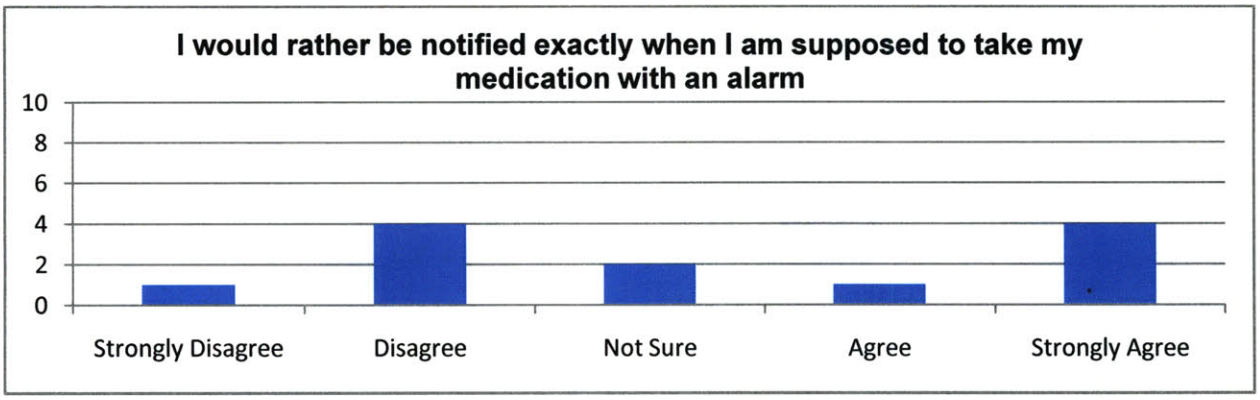

It was easy to understand the medication schedule clock
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

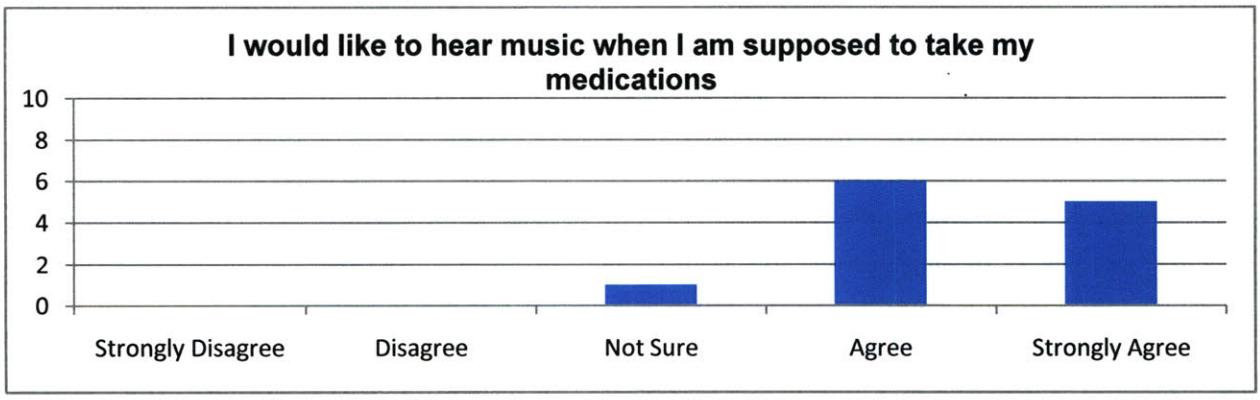

The mediction schedule clock was confusing
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

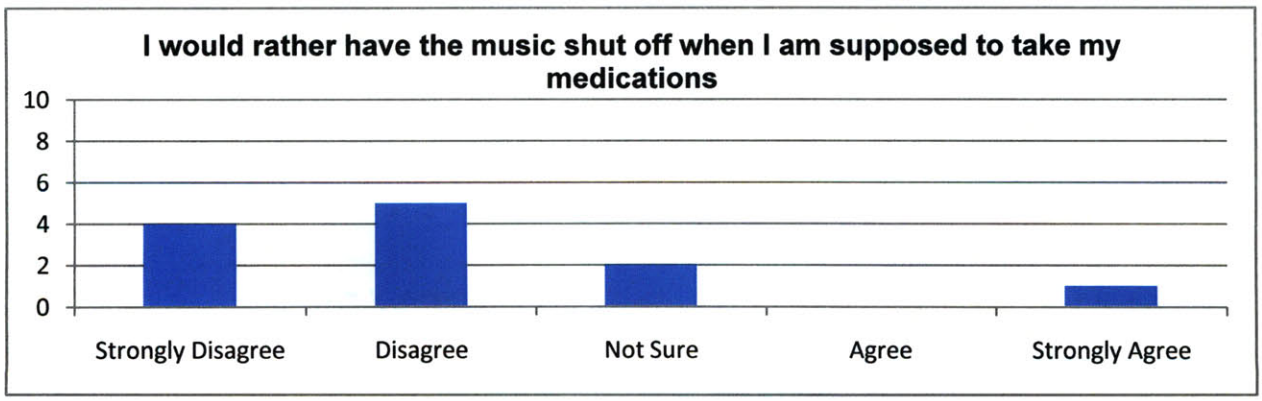

I was able to understand the fact that the medication schedule clock showed an entire 24 hours
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

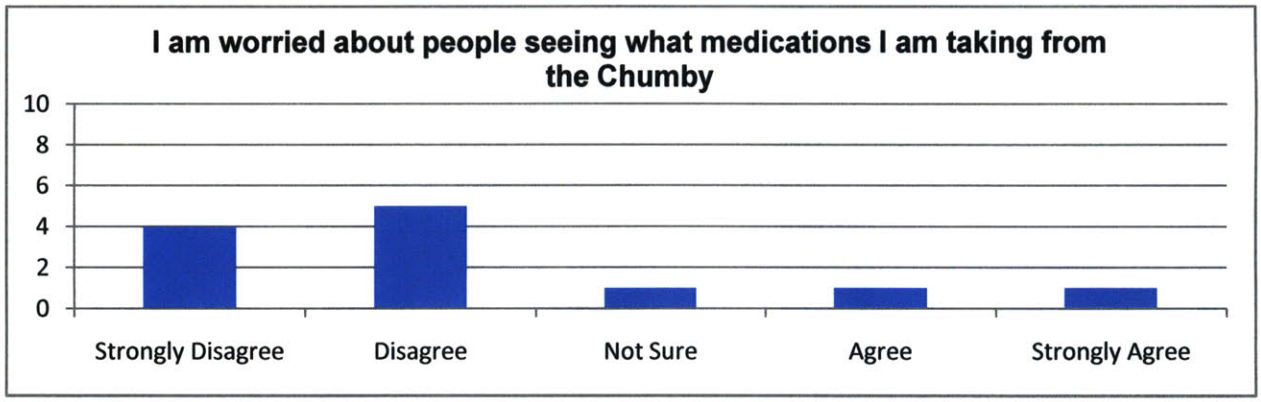

The medication schedule clock made it easy to see which medications had been taken
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

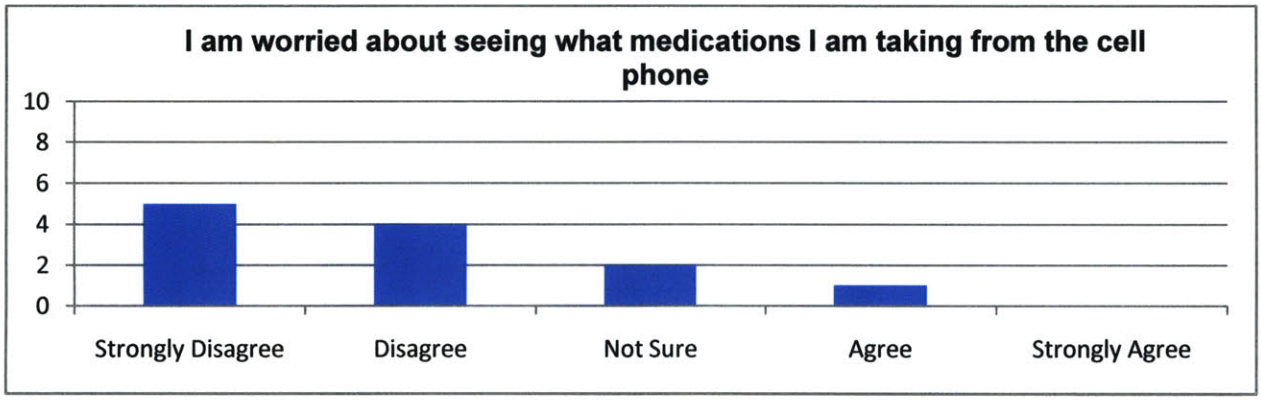

I like having the freedom to take my medicaitons during a window of time rather than at a specific time
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

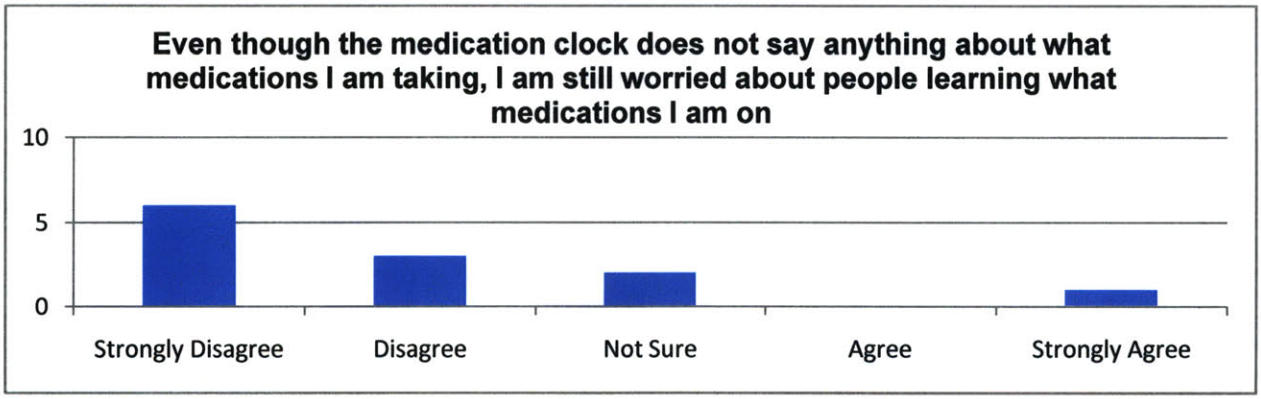

I would rather be notified exactly when I am supposed to take my medication with an alarm
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

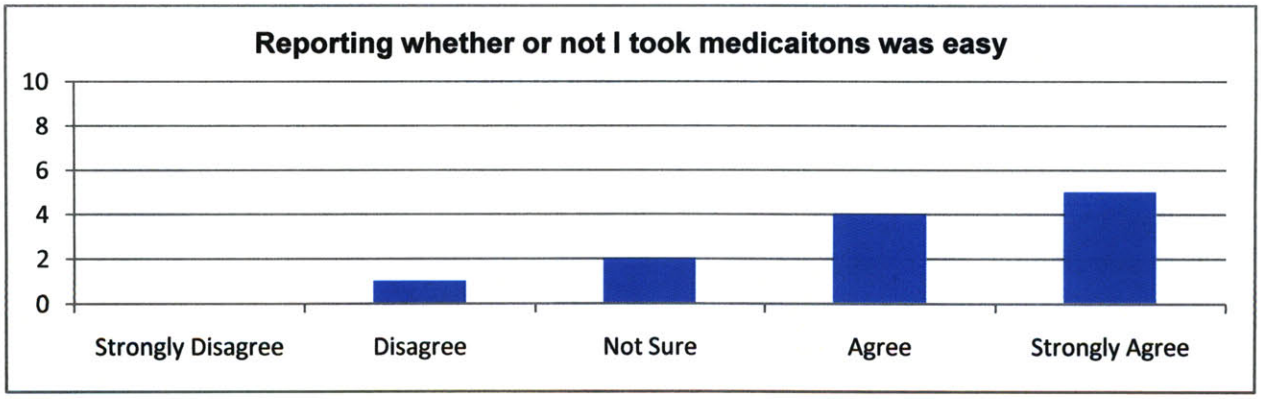

I would like to hear music when I am supposed to take my medications
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

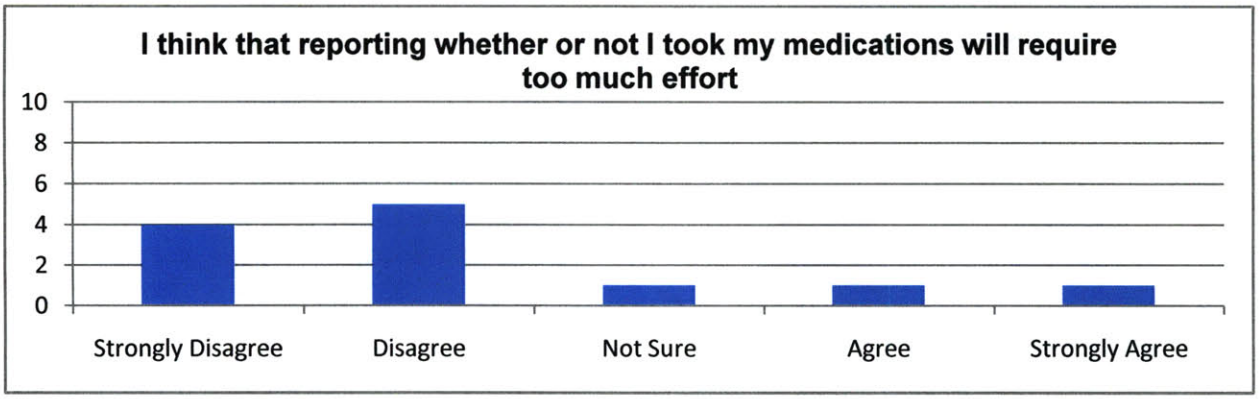

I would rather have the music shut off when I am supposed to take my medications
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

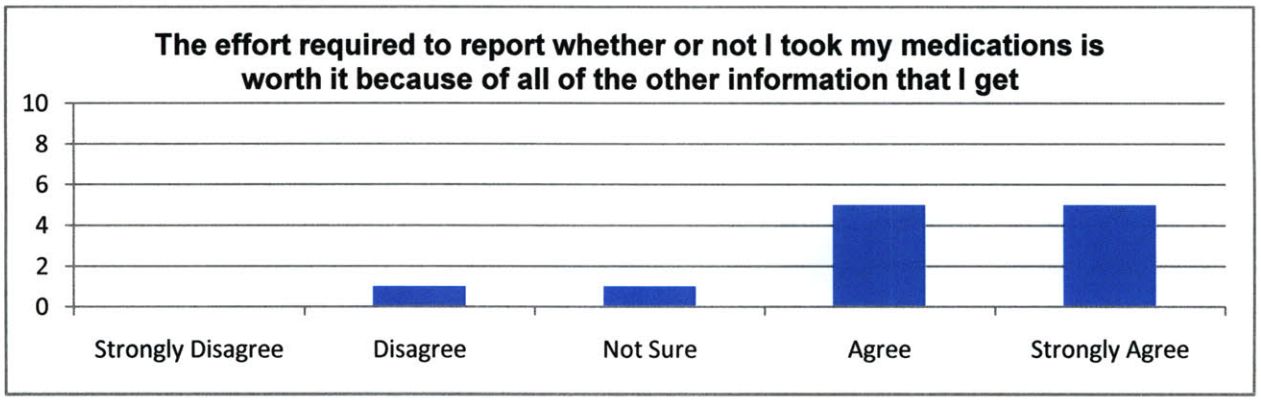

I am worried about people seeing what medications I am taking from the Chumby
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

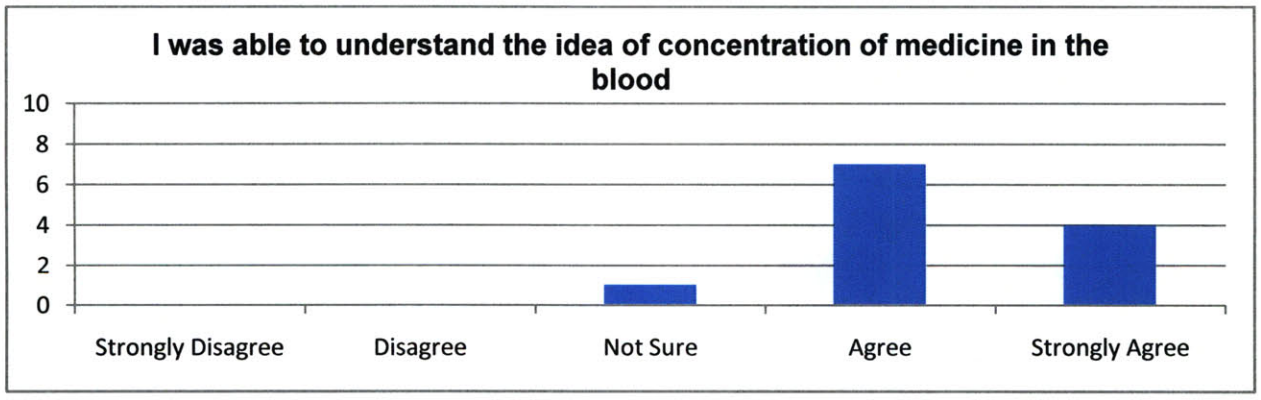

I am worried about seeing what medications I am taking from the cell phone
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

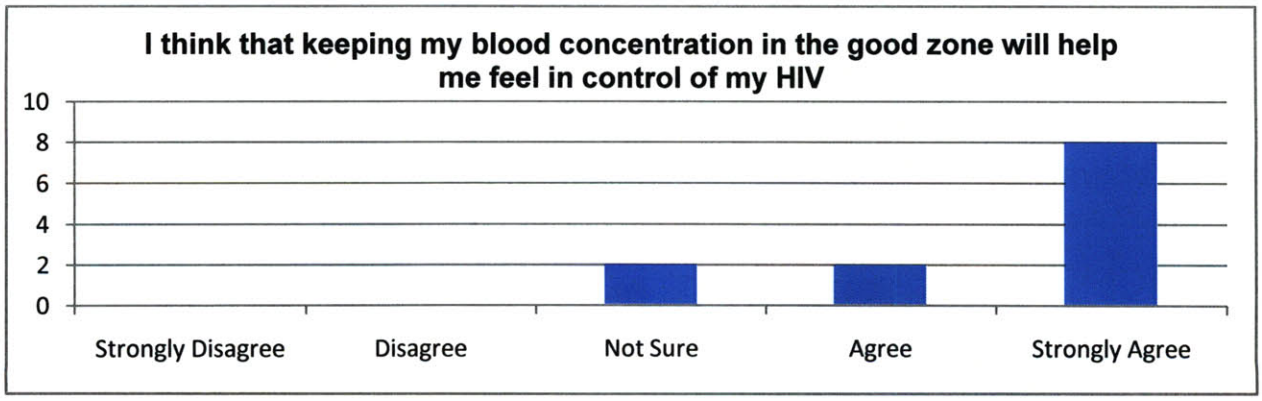

Even though the medication clock does not say anything about what medications I am taking, I am still worried about people learning what medications I am on
10
5
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

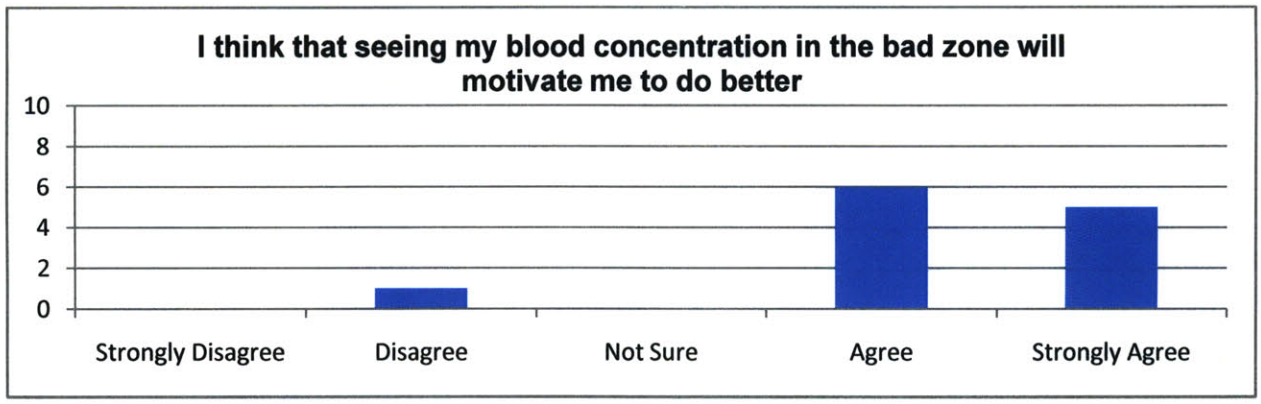

Reporting whether or not I took medicaitons was easy
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

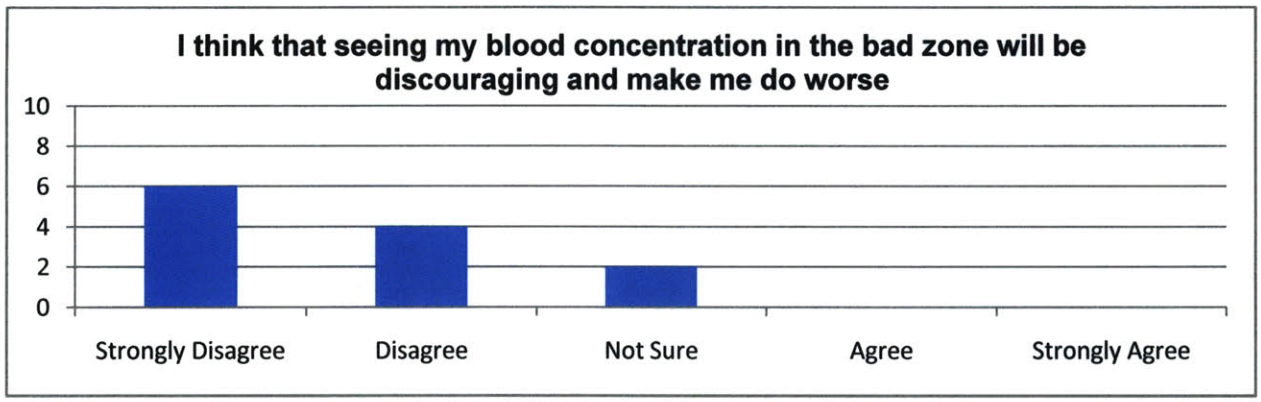

I think that reporting whether or not I took my medications will require too much effort
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

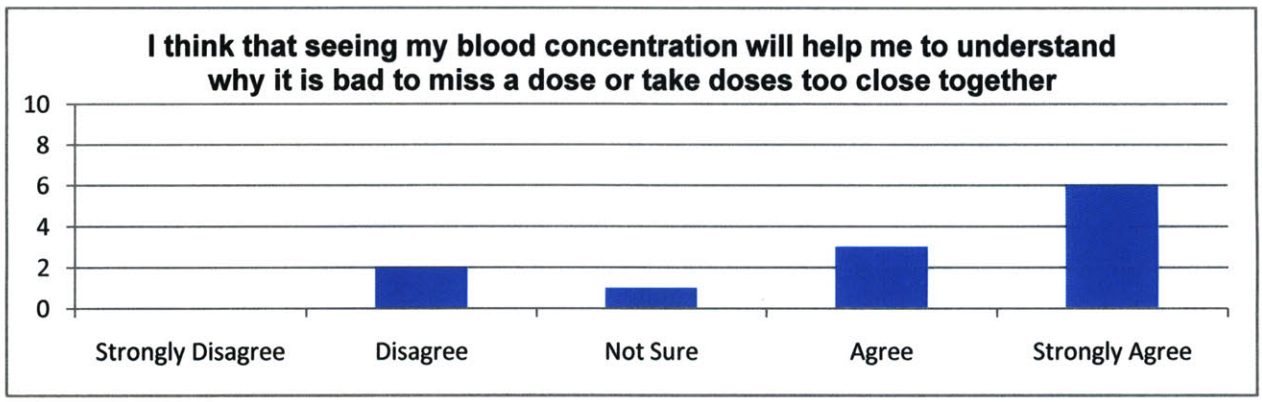

The effort required to report whether or not I took my medications is worth it because of all of the other information that I get
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

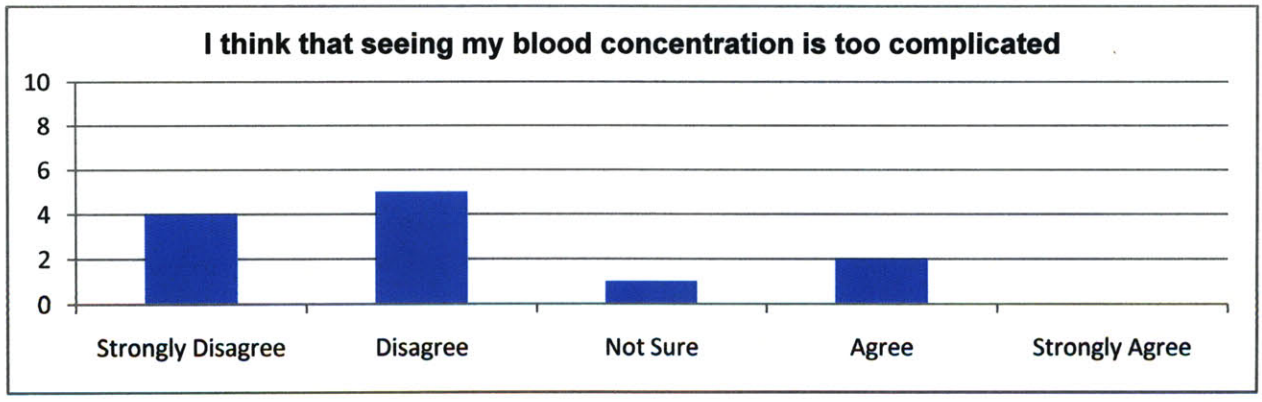

I was able to understand the idea of concentration of medicine in the blood
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

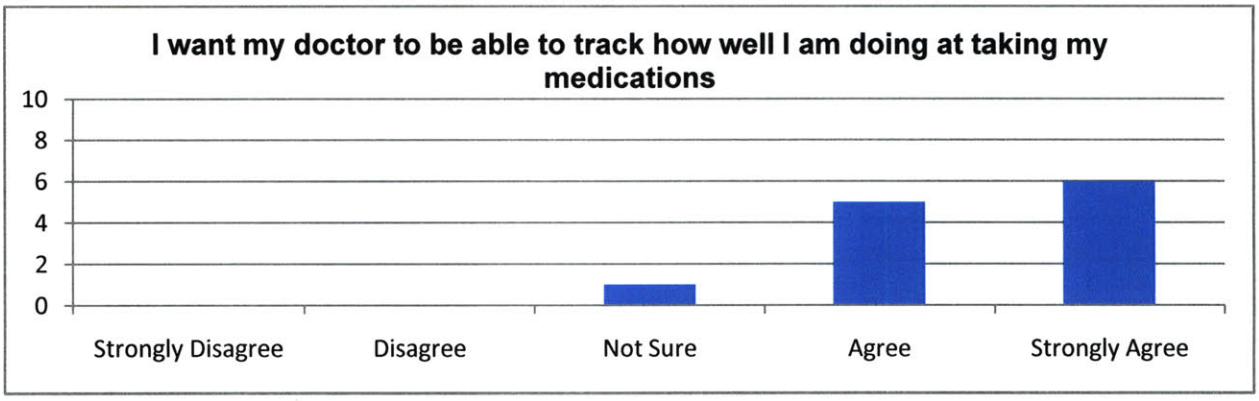

I think that keeping my blood concentration in the good zone will help me feel in control of my HIV
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

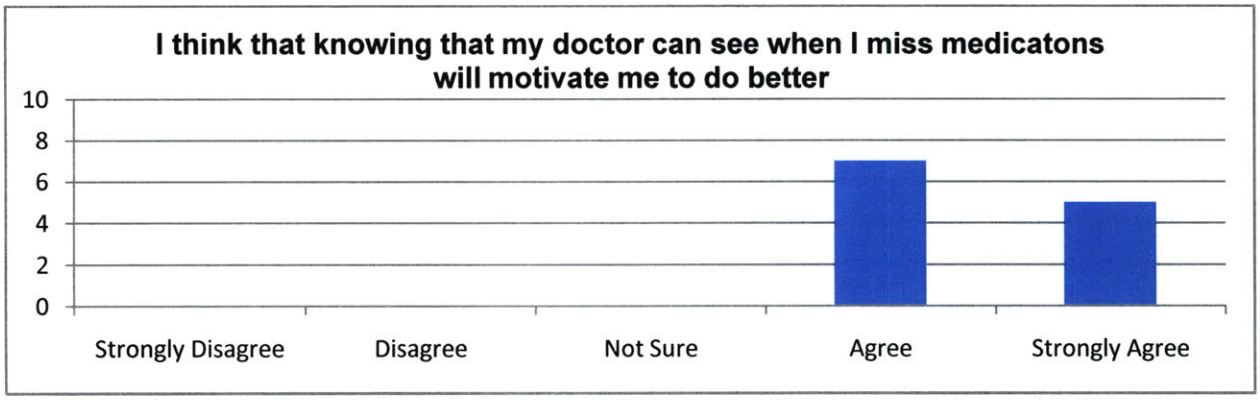

I think that seeing my blood concentration in the bad zone will motivate me to do better
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

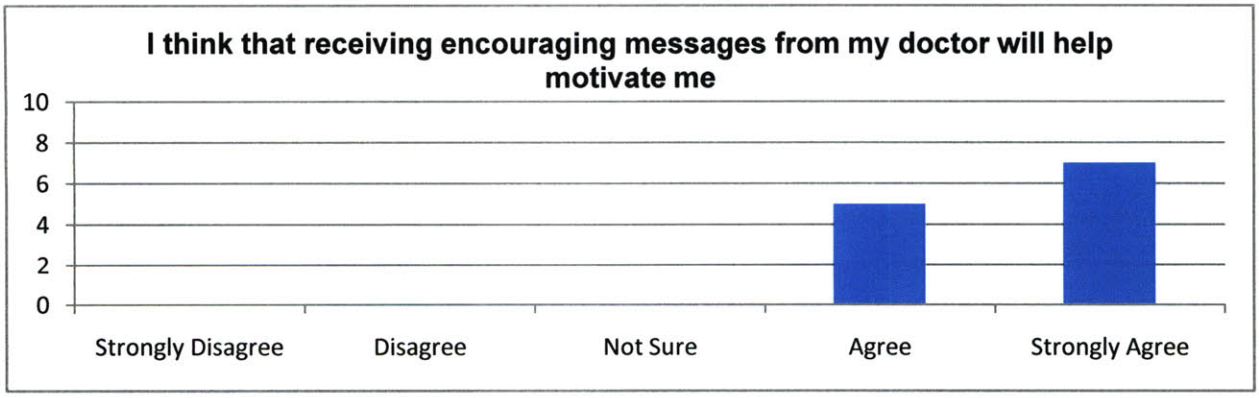

I think that seeing my blood concentration in the bad zone will be discouraging and make me do worse
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

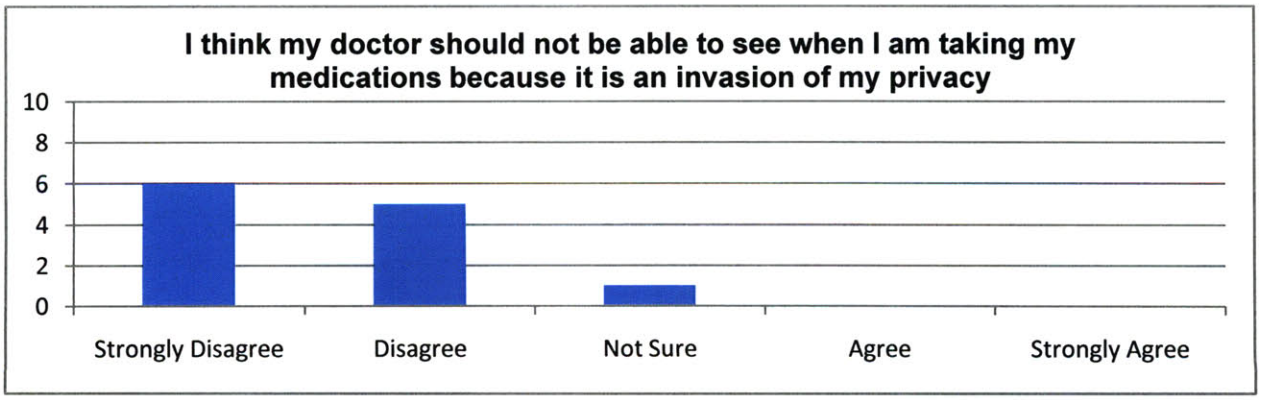

I think that seeing my blood concentration will help me to understand why it is bad to miss a dose or take doses too close together
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

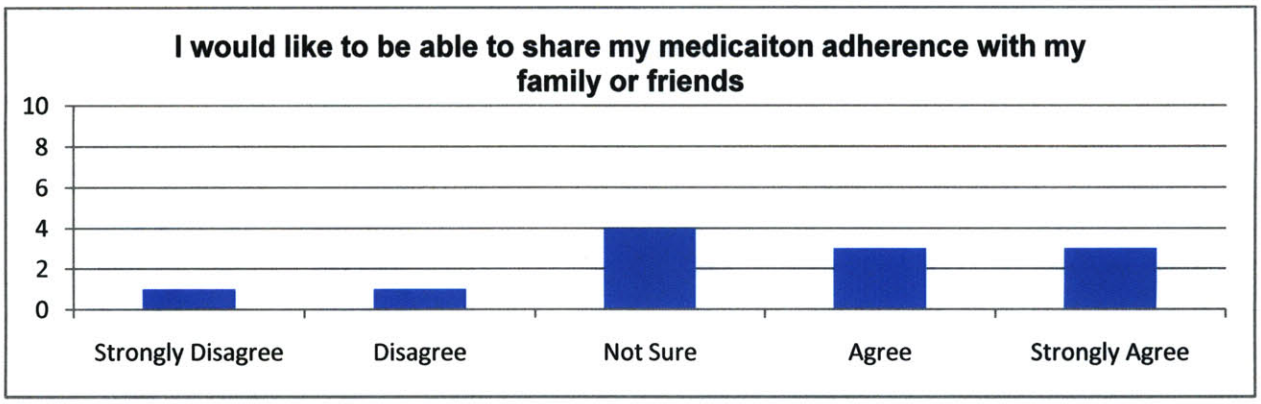

I think that seeing my blood concentration is too complicated
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

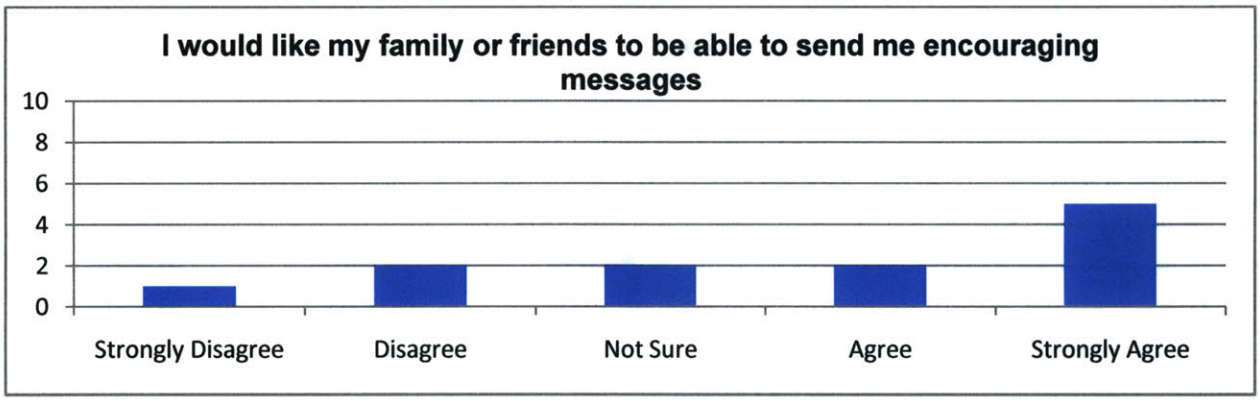

I want my doctor to be able to track how well I am doing at taking my medications
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

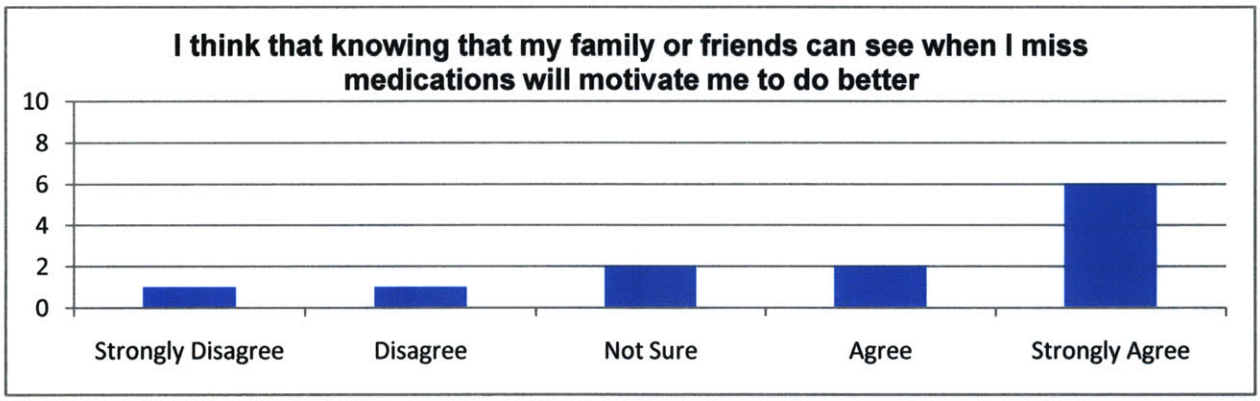

I think that knowing that my doctor can see when I miss medicatons will motivate me to do better
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

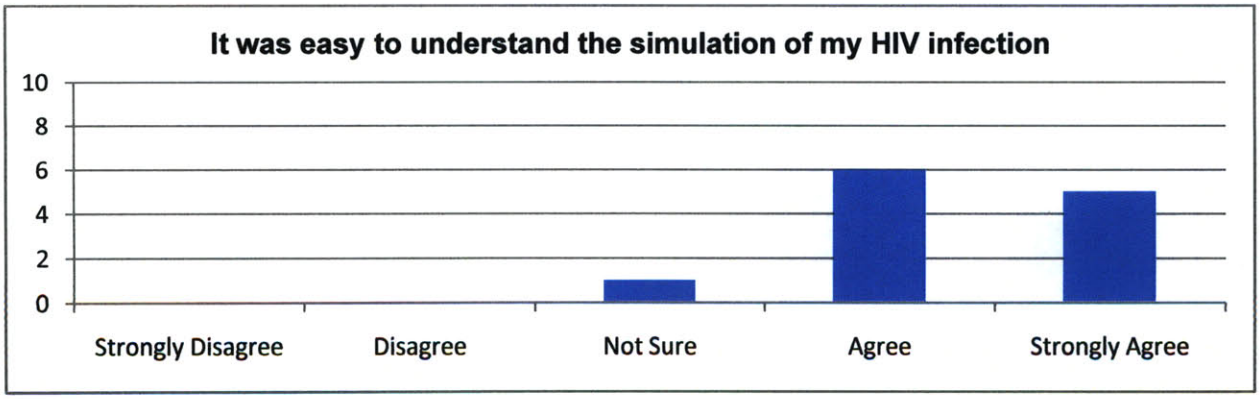

I think that receiving encouraging messages from my doctor will help motivate me
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

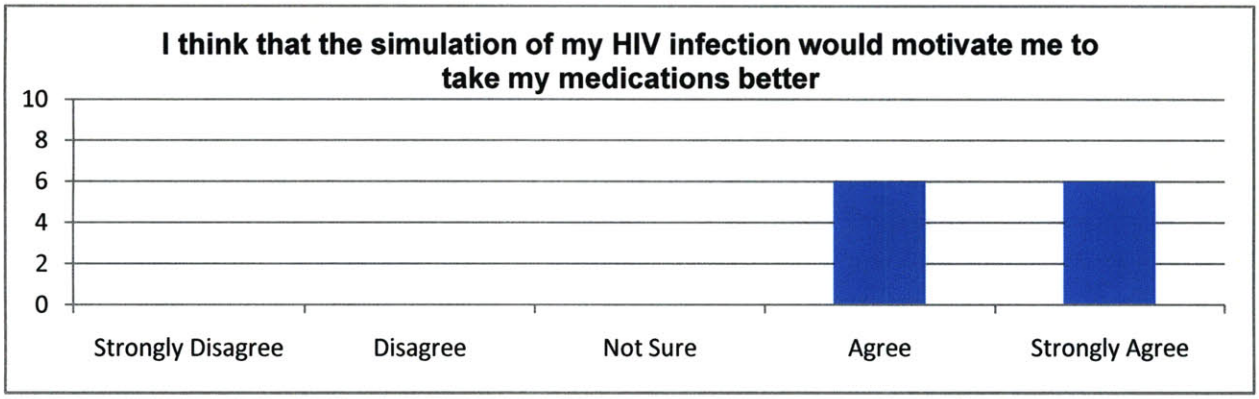

I think my doctor should not be able to see when I am taking my medications because it is an invasion of my privacy
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

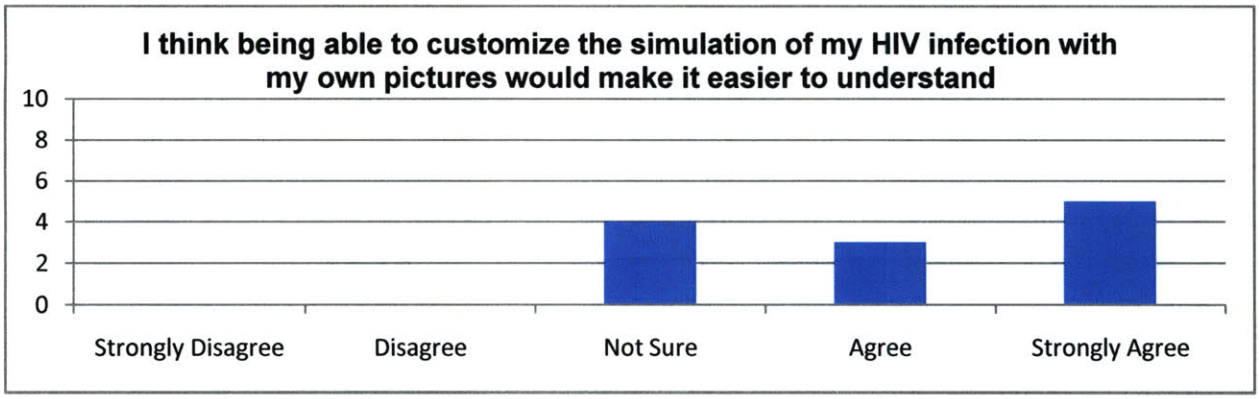

I would like to be able to share my medicaiton adherence with my family or friends
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

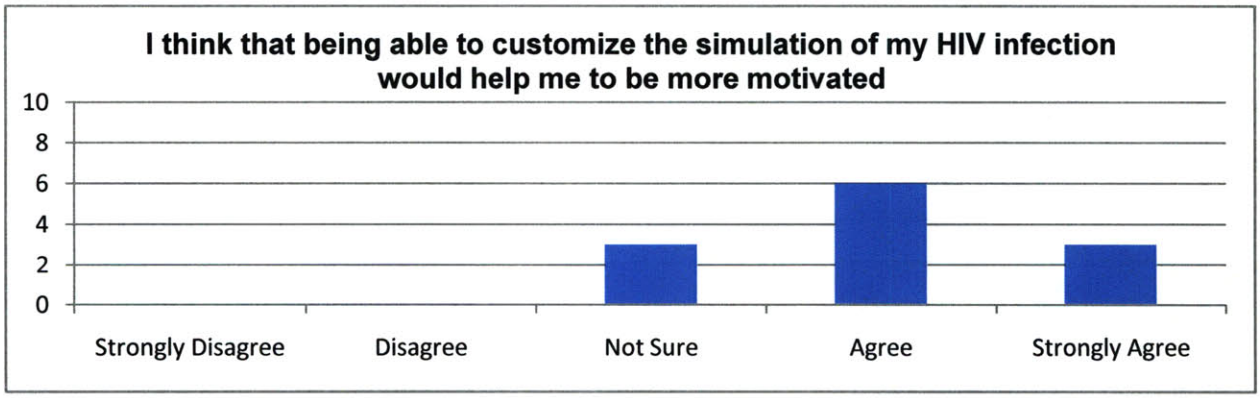

I would like my family or friends to be able to send me encouraging messages
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

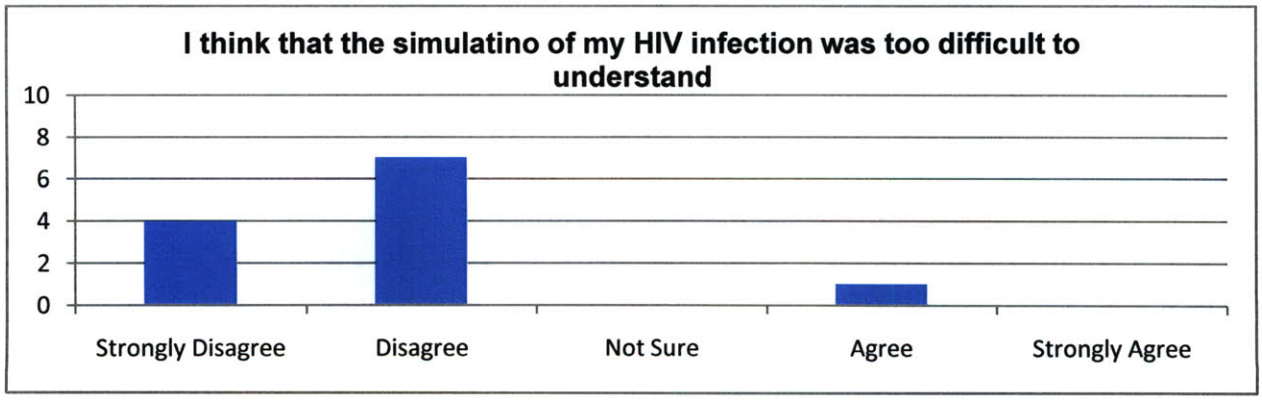

I think that knowing that my family or friends can see when I miss medications will motivate me to do better
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

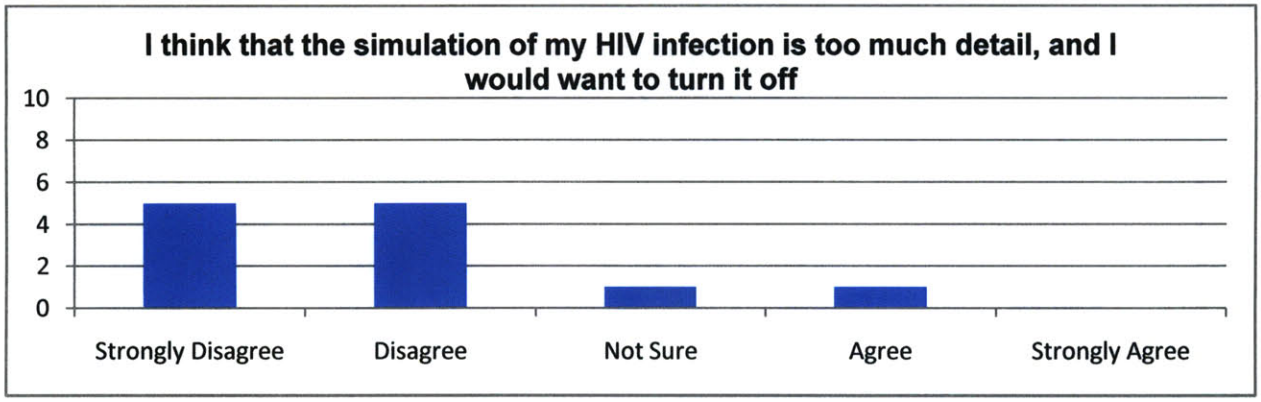

It was easy to understand the simulation of my HIV infection
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

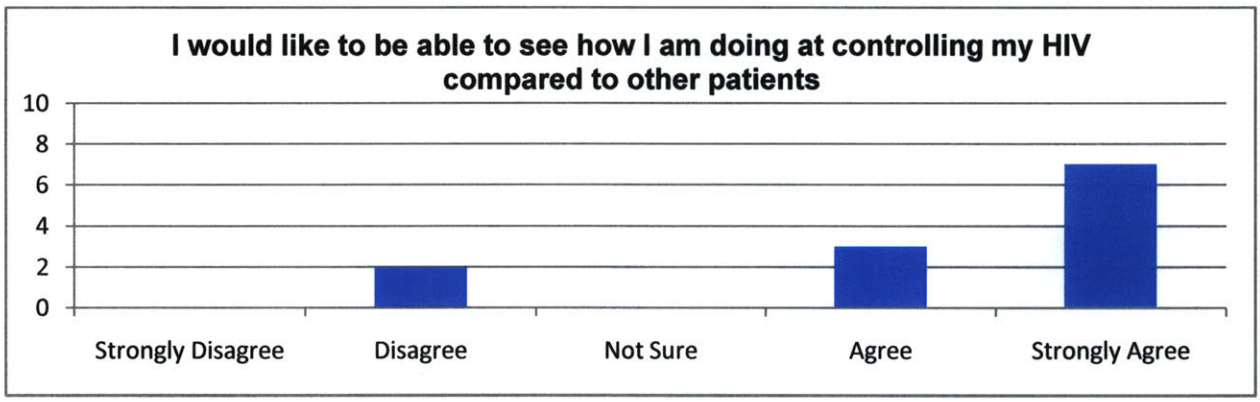

I think that the simulation of my HIV infection would motivate me to take my medications better
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

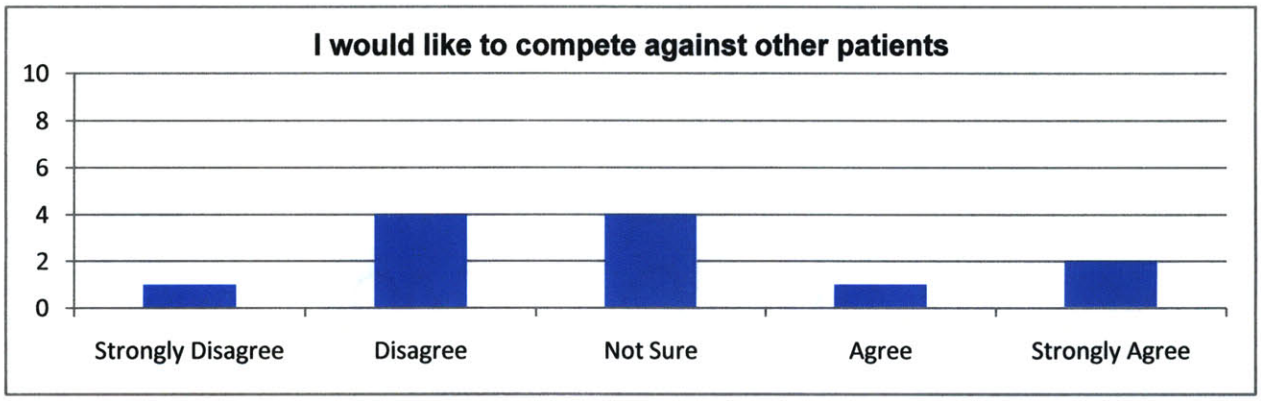

I think being able to customize the simulation of my HIV infection with my own pictures would make it easier to understand
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

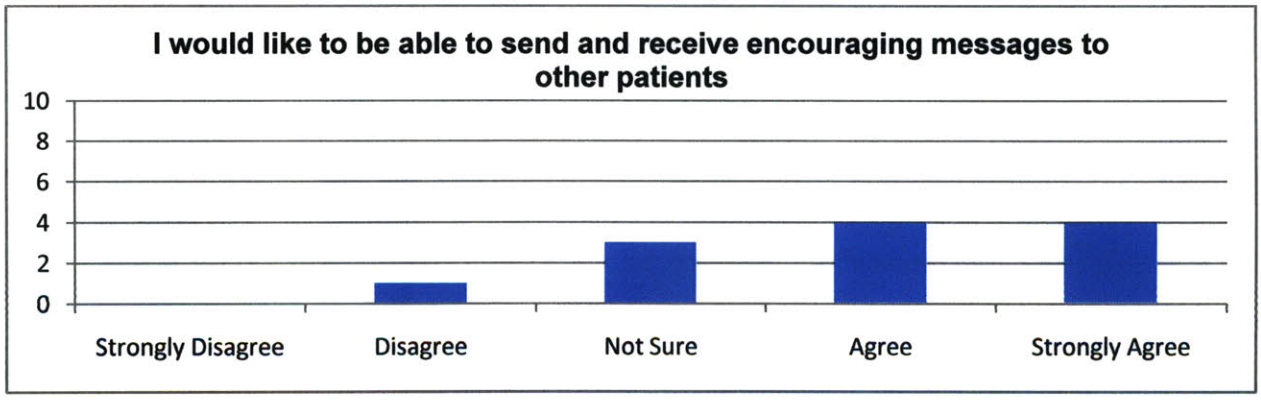

I think that being able to customize the simulation of my HIV infection would help me to be more motivated
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

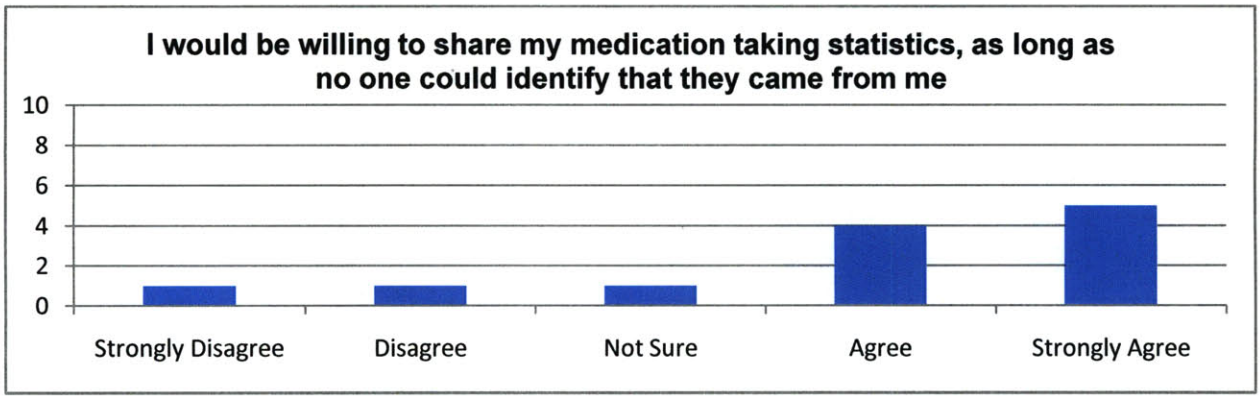

I think that the simulatino of my HIV infection was too difficult to understand
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

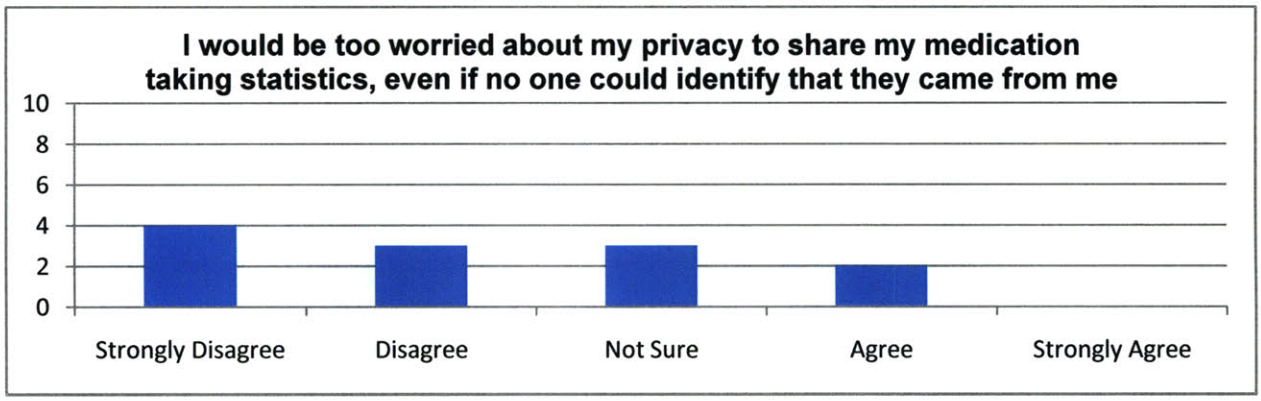

I think that the simulation of my HIV infection is too much detail, and I would want to turn it off
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

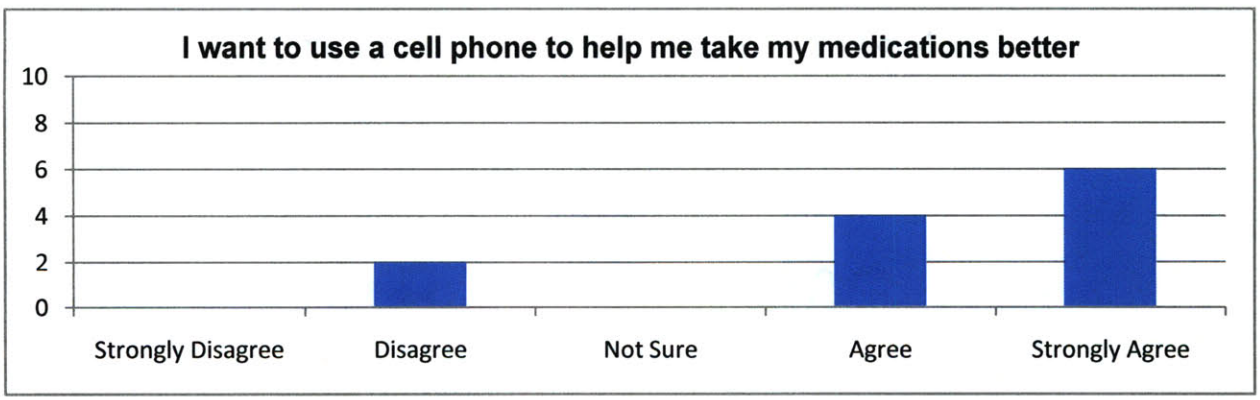

I would like to be able to see how I am doing at controlling my HIV compared to other patients
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

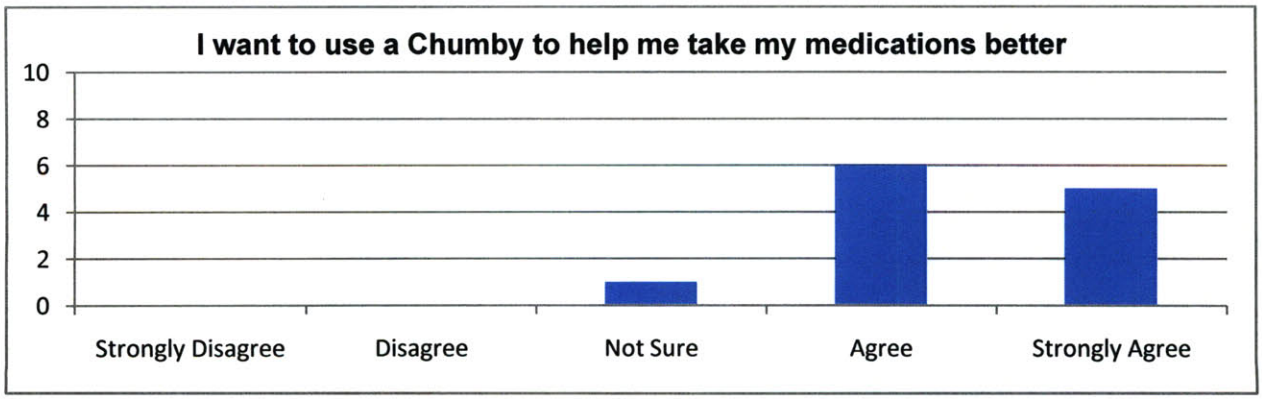

I would like to compete against other patients
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree


I would like to be able to send and receive encouraging messages to other patients
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

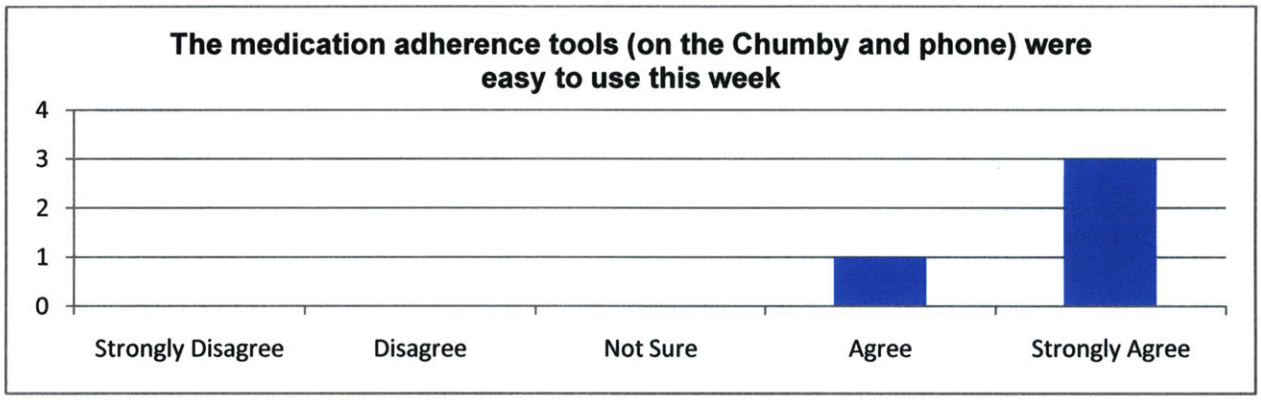

I would be willing to share my medication taking statistics, as long as no one could identify that they came from me
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

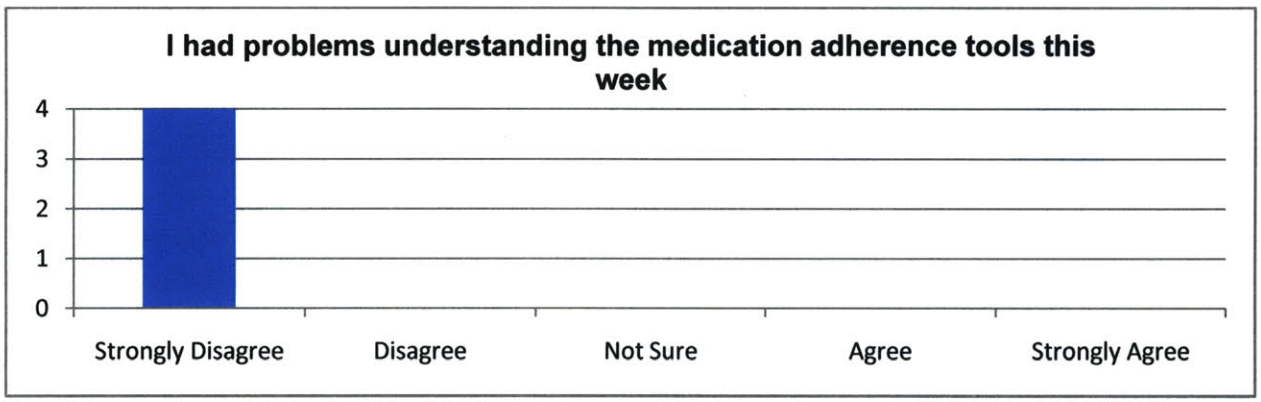

I would be too worried about my privacy to share my medication taking statistics, even if no one could identify that they came from me
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

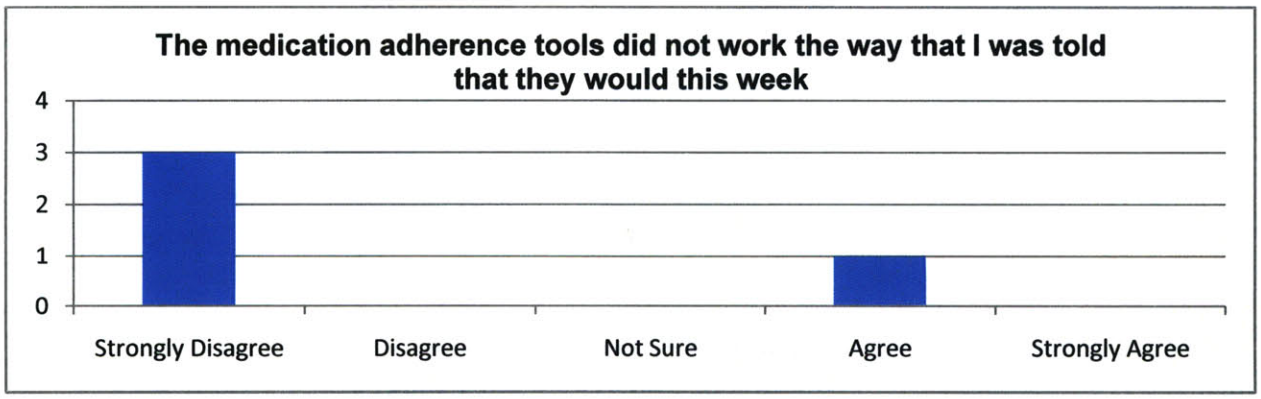

I want to use a cell phone to help me take my medications better
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

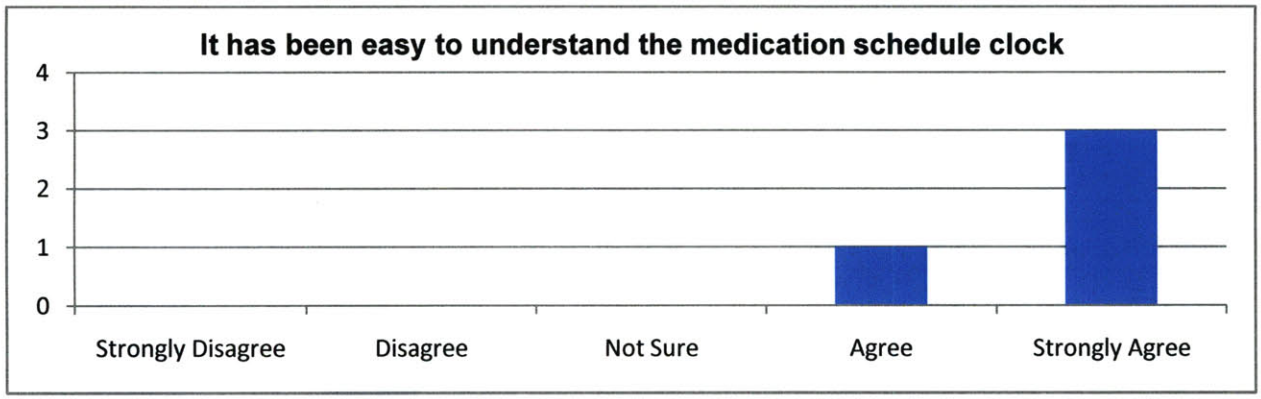

I want to use a Chumby to help me take my medications better
10
8
6
4
2
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

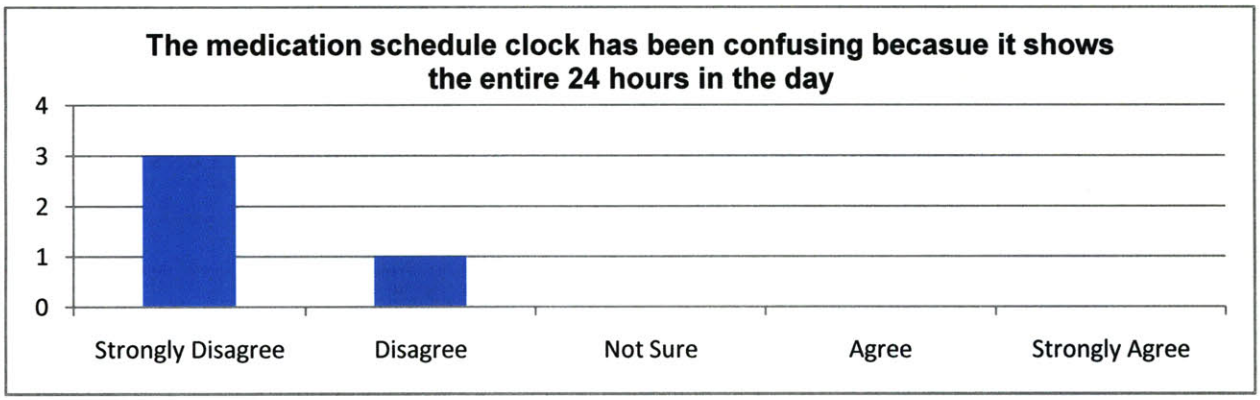
Appendix C – Stage 2, Week 1 Questionnaire Results

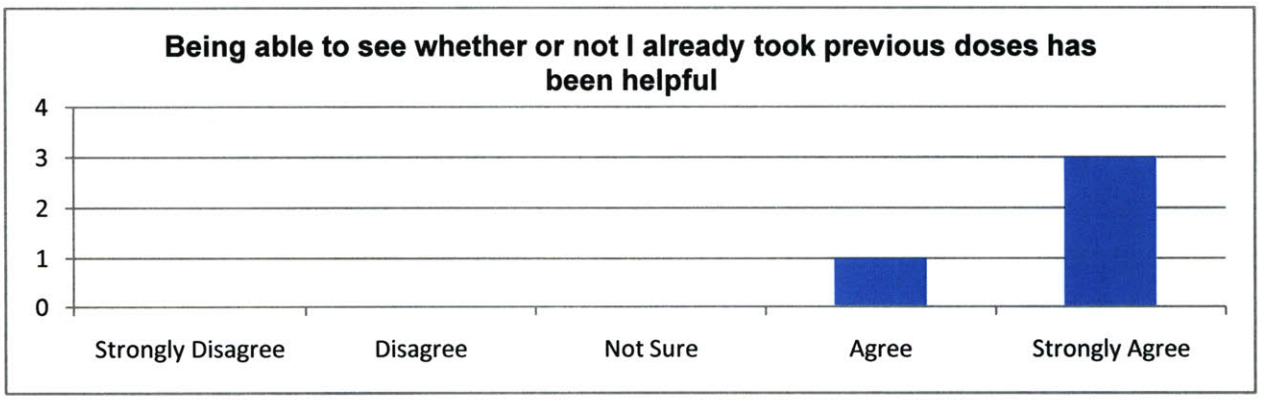


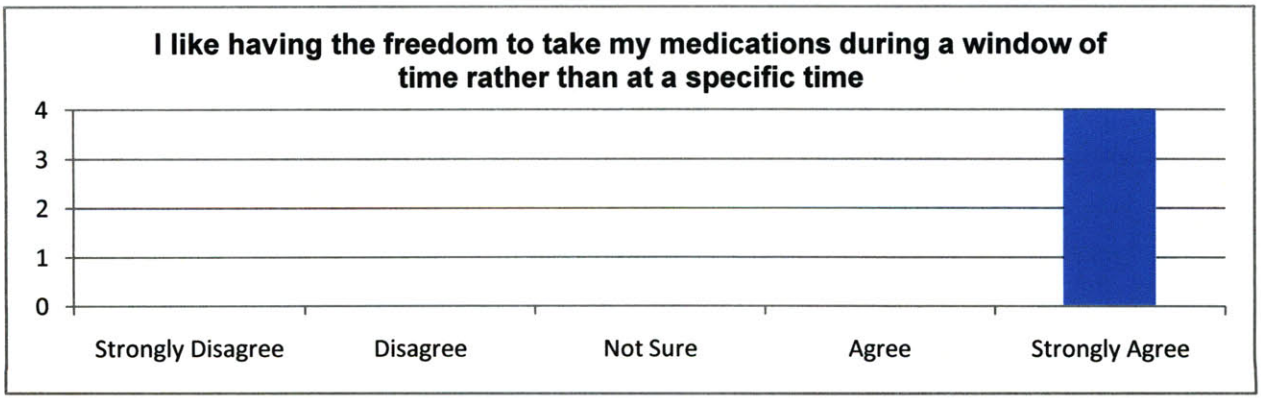


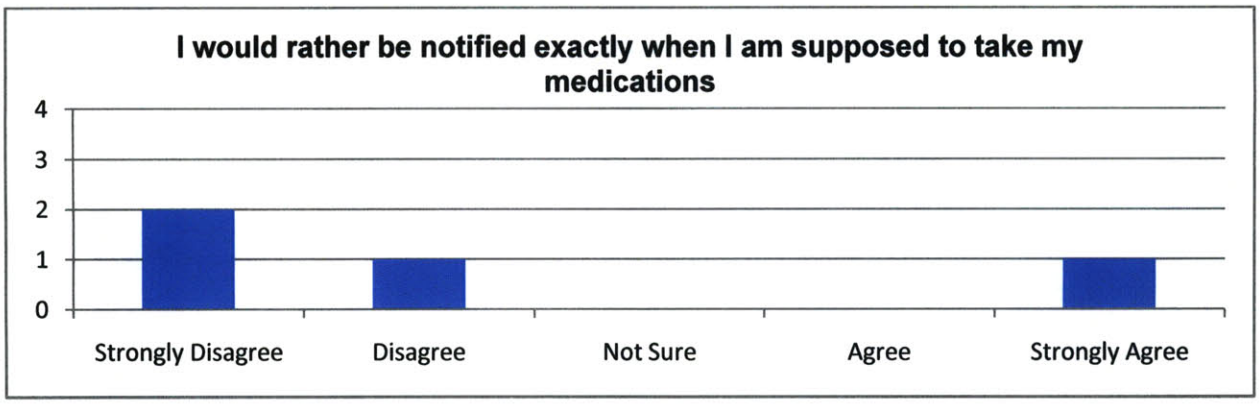


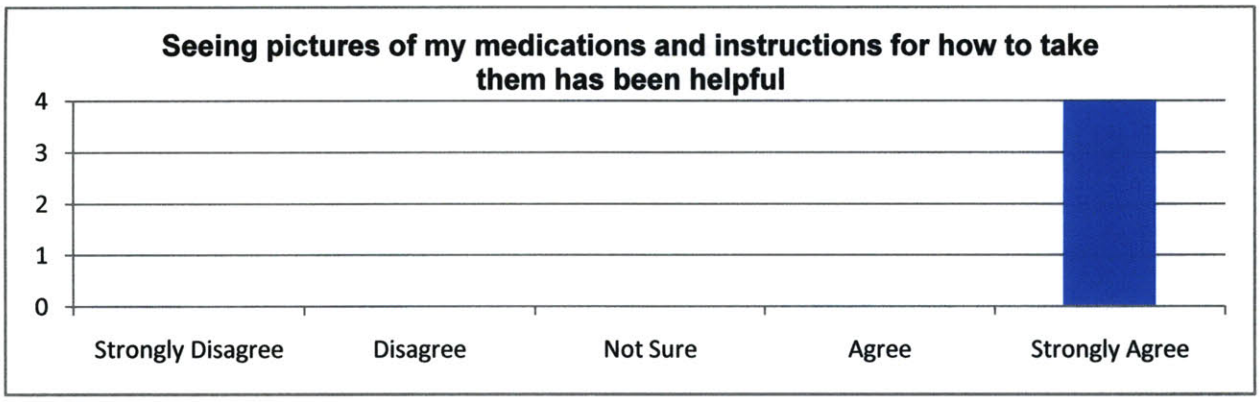

It has been easy to understand the medication schedule clock
4
3
2
1
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

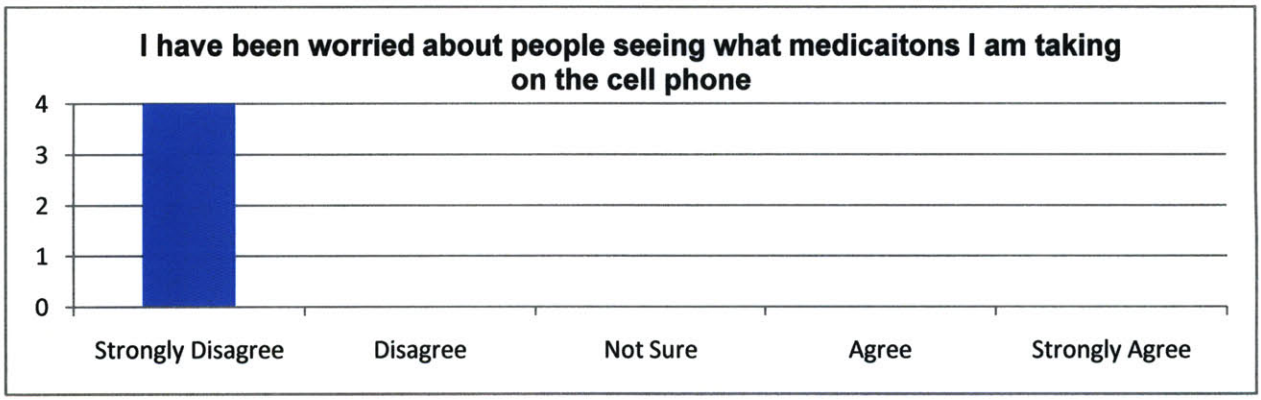

The medication schedule clock has been confusing becasue it shows the entire 24 hours in the day
4
3
2
1
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

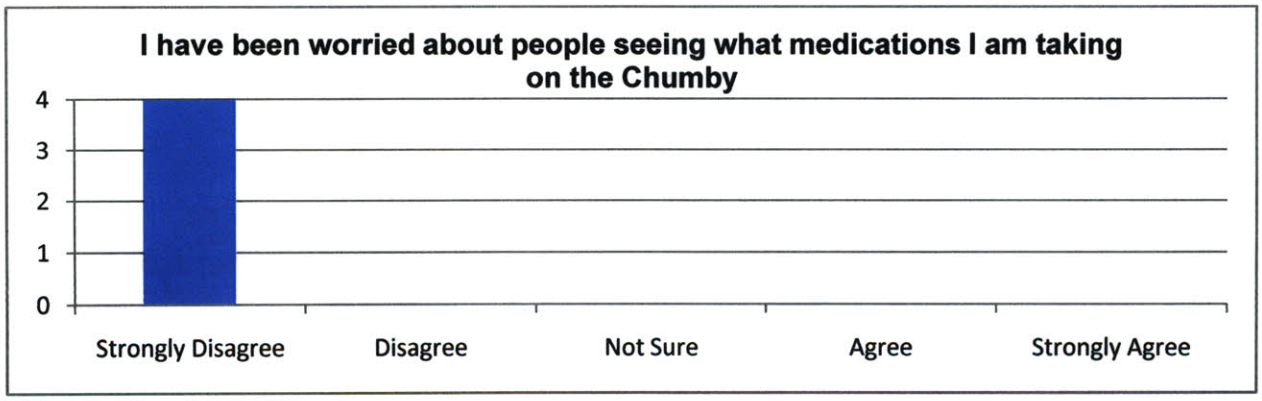

Being able to see whether or not I already took previous doses has been helpful
4
3
2
1
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

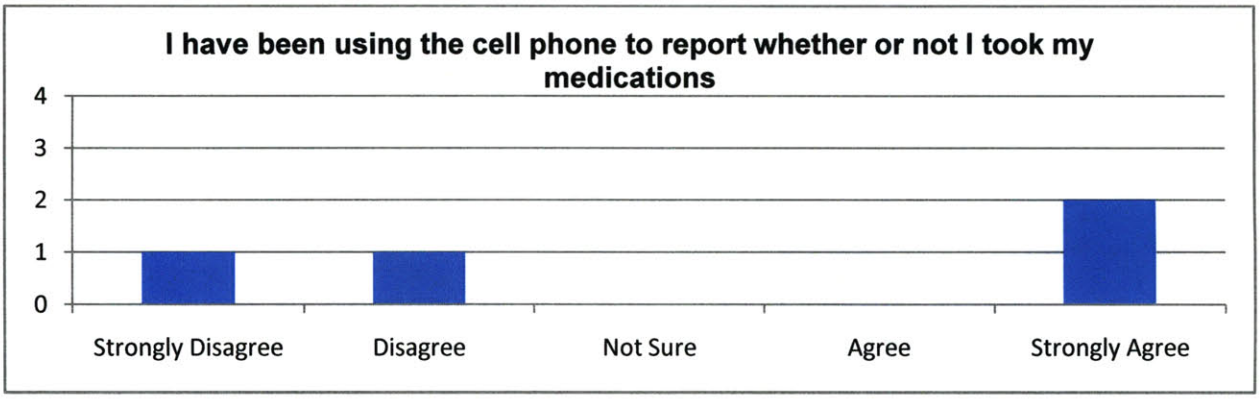

I like having the freedom to take my medications during a window of time rather than at a specific time
4
3
2
1
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

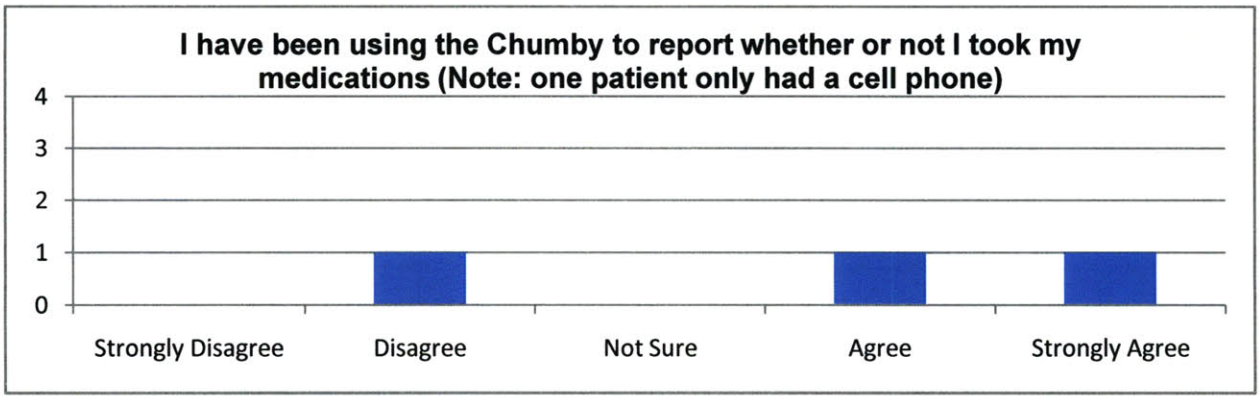

I would rather be notified exactly when I am supposed to take my medications
4
3
2
1
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

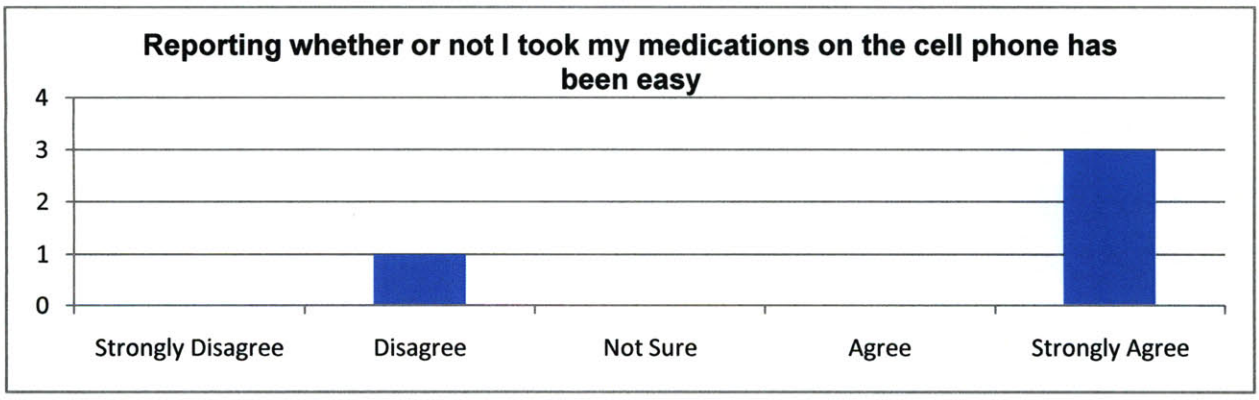

Seeing pictures of my medications and instructions for how to take them has been helpful
4
3
2
1
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

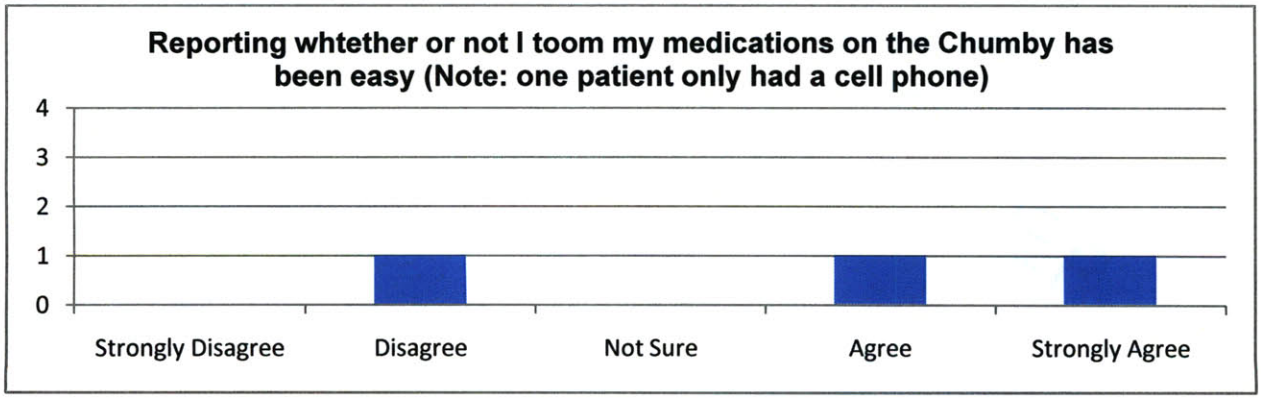

I have been worried about people seeing what medicaitons I am taking on the cell phone
4
3
2
1
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

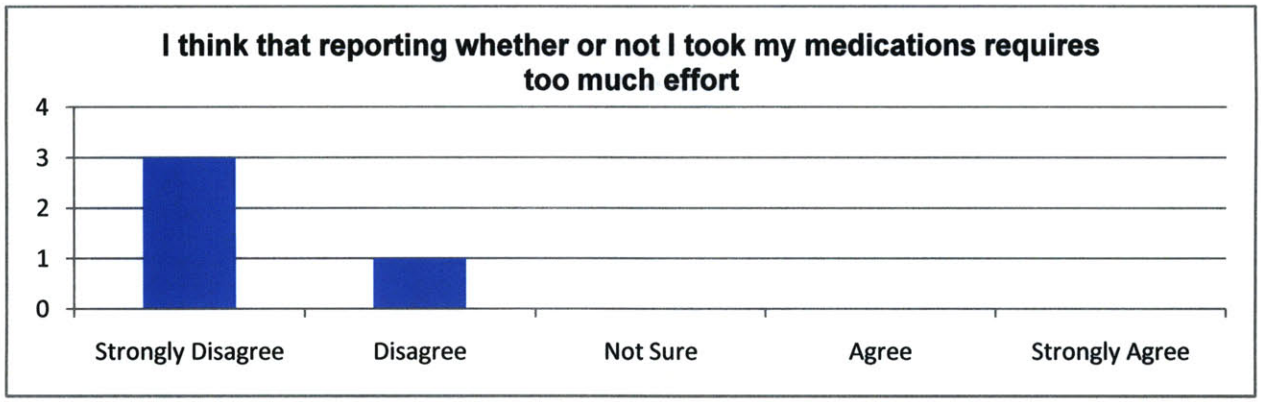

I have been worried about people seeing what medications I am taking on the Chumby
4
3
2
1
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

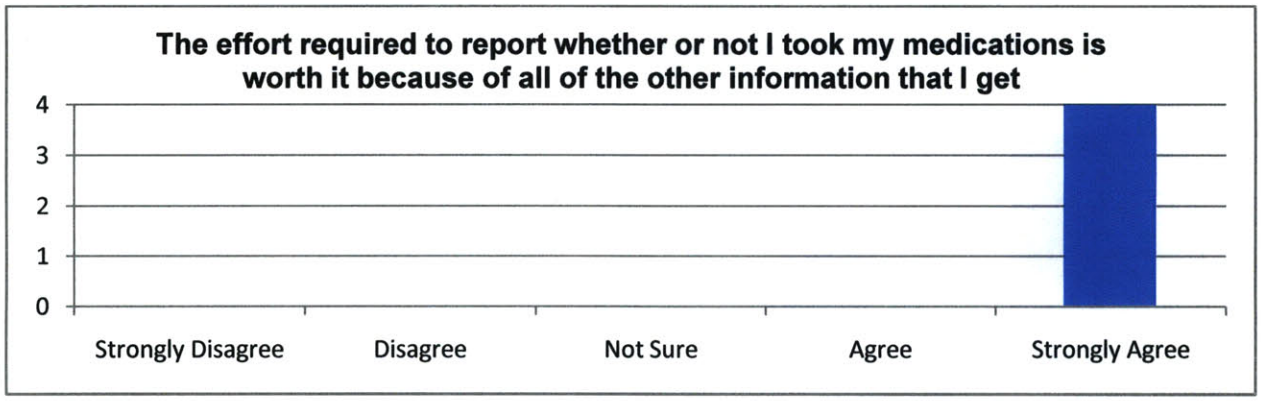

I have been using the cell phone to report whether or not I took my medications
4
3
2
1
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

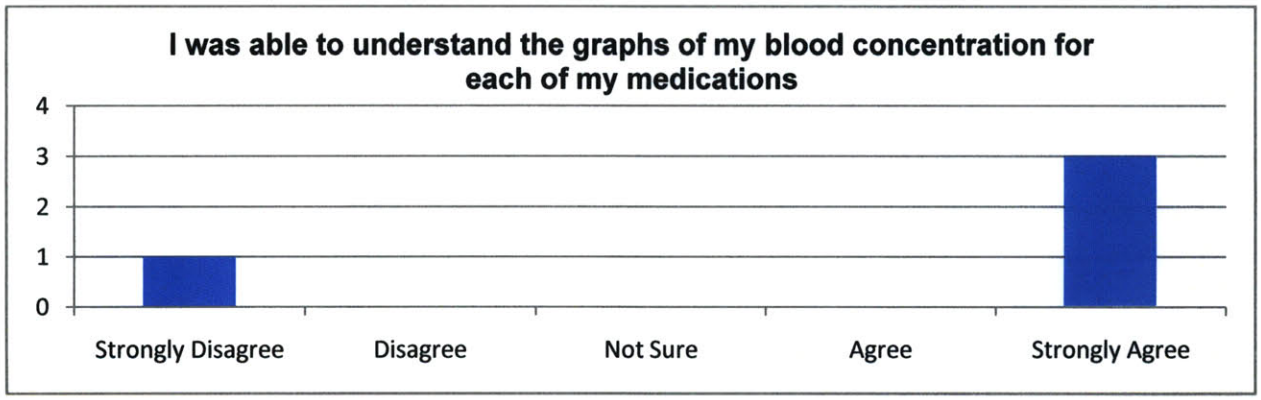

I have been using the Chumby to report whether or not I took my medications (Note: one patient only had a cell phone)
4
3
2
1
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

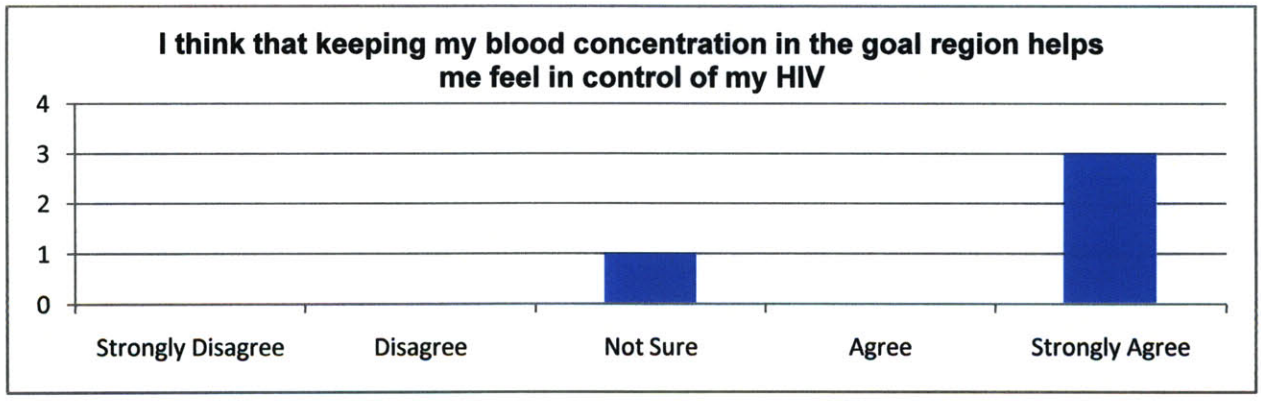

Reporting whether or not I took my medications on the cell phone has been easy
4
3
2
1
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

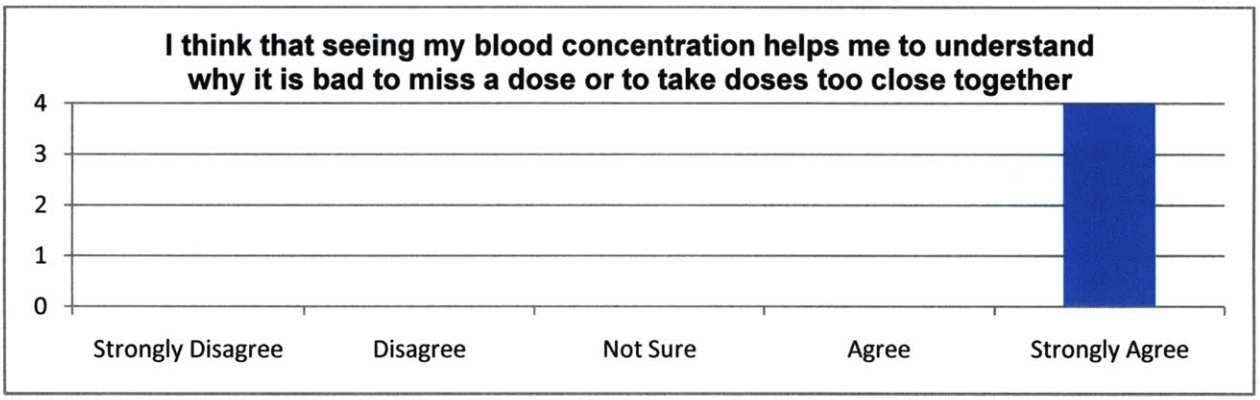

Reporting whtether or not I toom my medications on the Chumby has been easy (Note: one patient only had a cell phone)
4
3
2
1
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

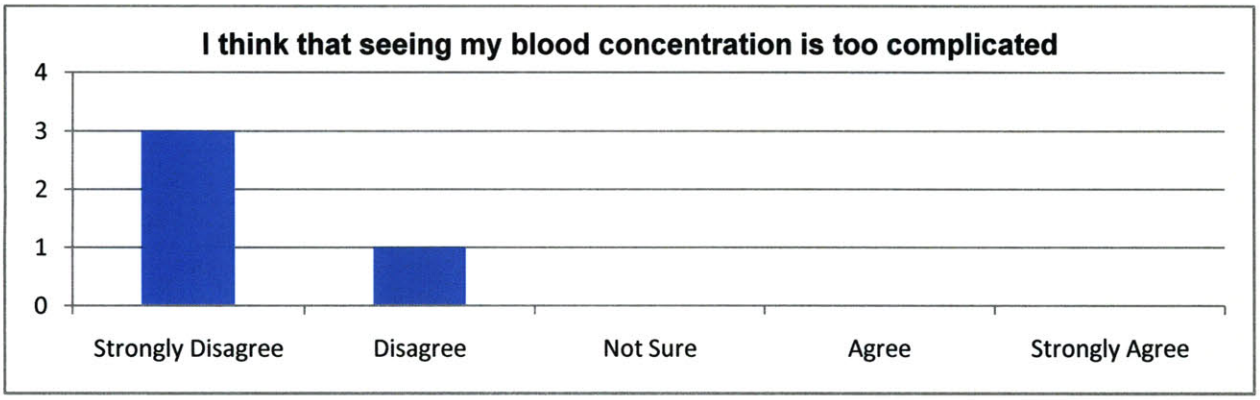

I think that reporting whether or not I took my medications requires too much effort
4
3
2
1
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

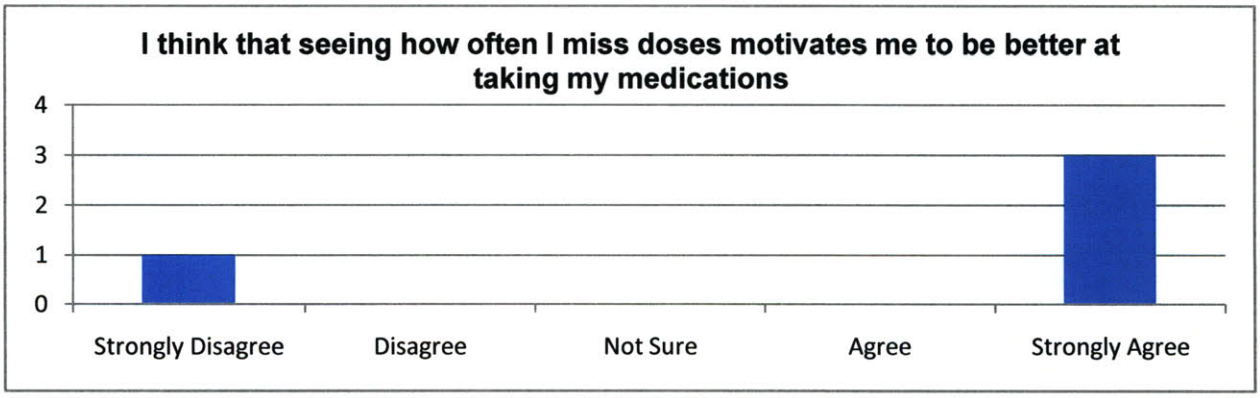

The effort required to report whether or not I took my medications is worth it because of all of the other information that I get
4
3
2
1
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

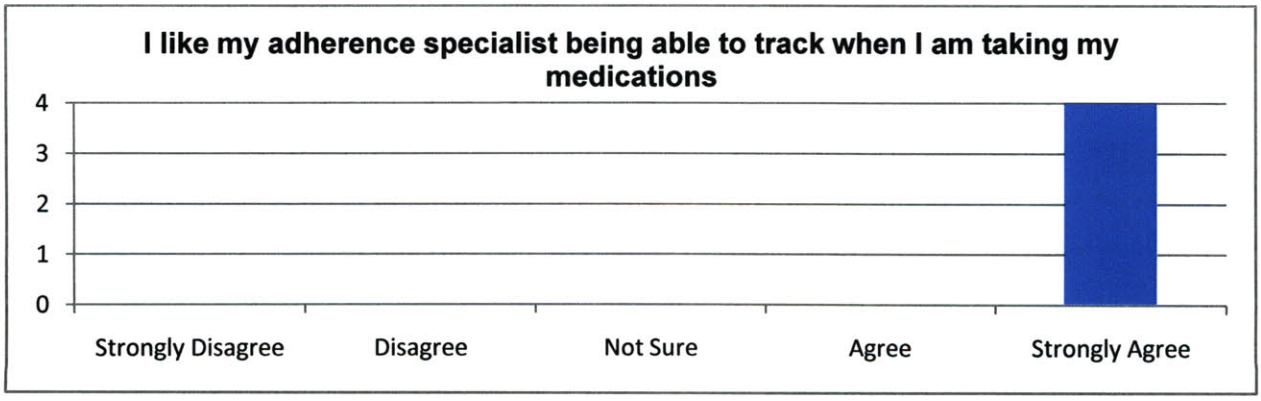

I was able to understand the graphs of my blood concentration for each of my medications
4
3
2
1
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

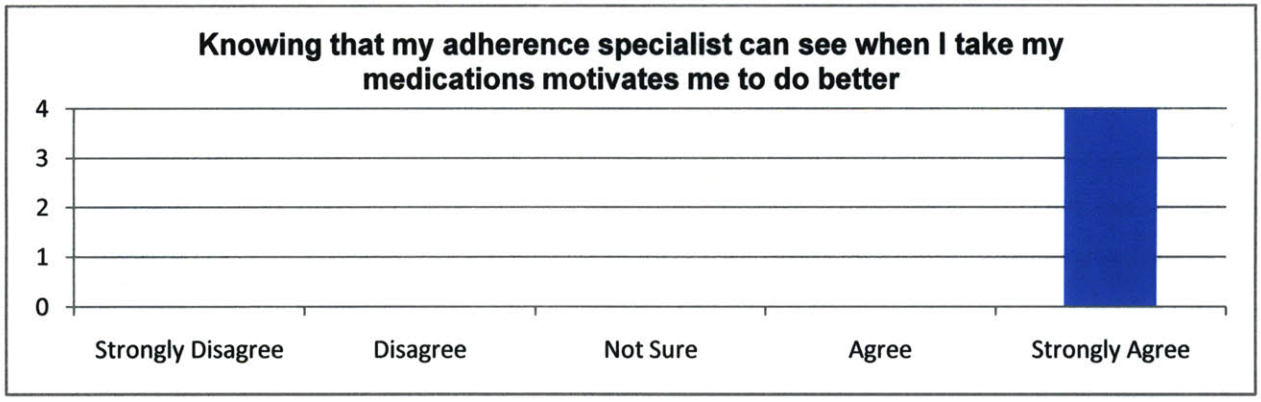

I think that keeping my blood concentration in the goal region helps me feel in control of my HIV
4
3
2
1
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

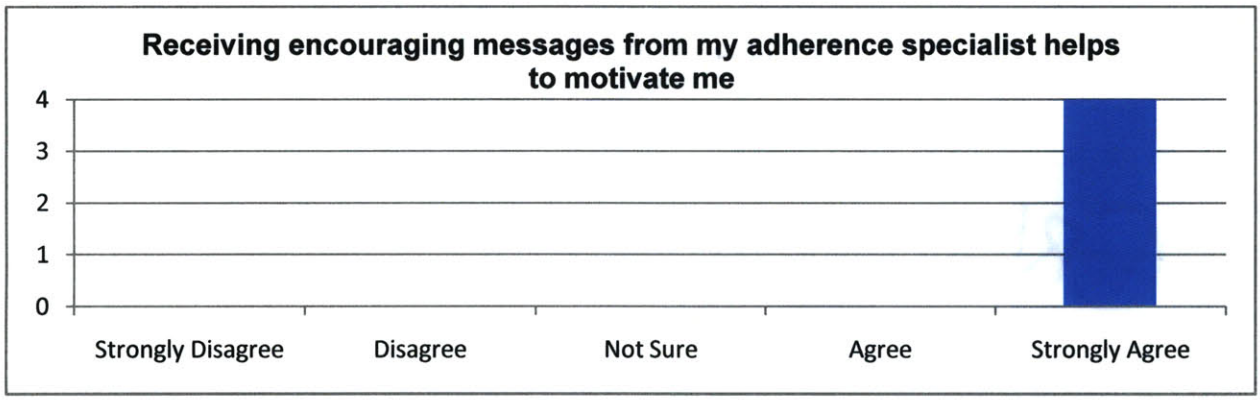

I think that seeing my blood concentration helps me to understand why it is bad to miss a dose or to take doses too close together
4
3
2
1
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

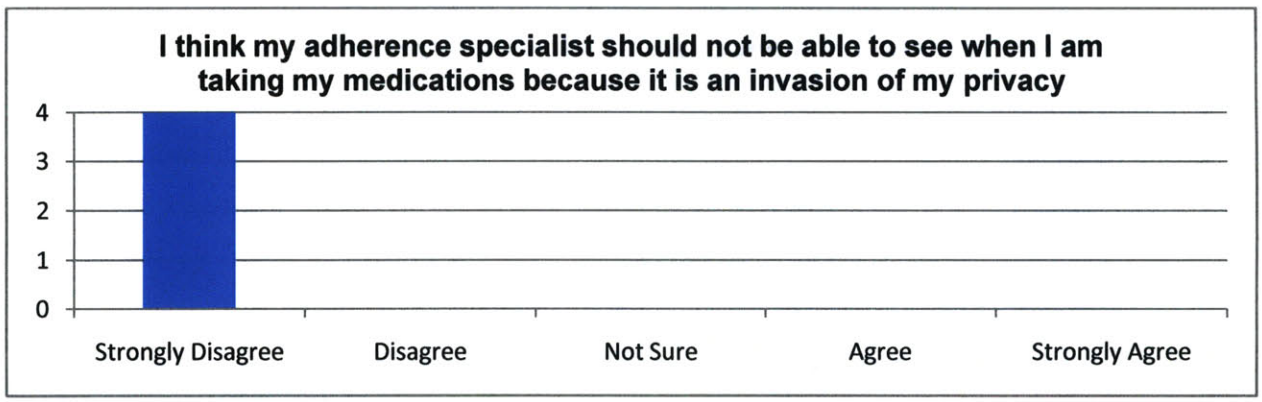

I think that seeing my blood concentration is too complicated
4
3
2
1
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

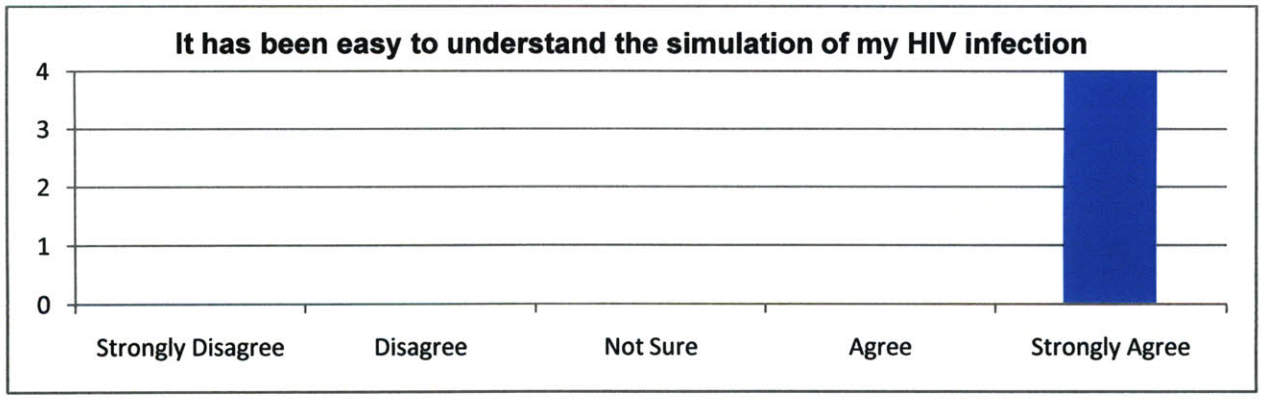

I think that seeing how often I miss doses motivates me to be better at taking my medications
4
3
2
1
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

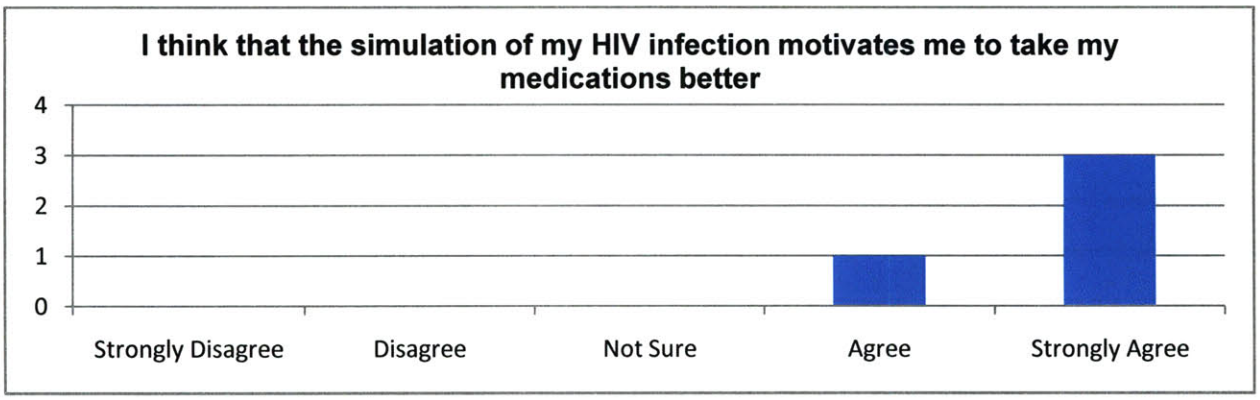

I like my adherence specialist being able to track when I am taking my medications
4
3
2
1
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

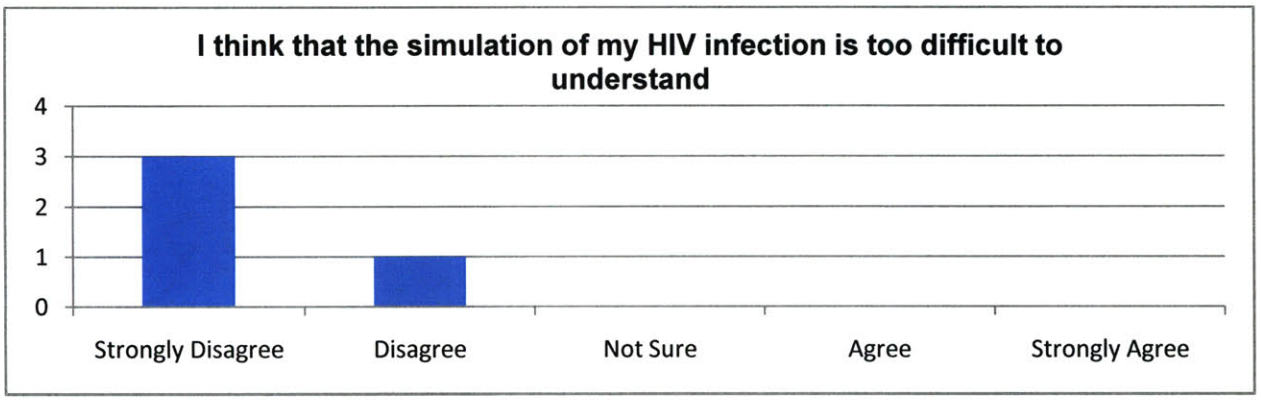

Knowing that my adherence specialist can see when I take my medications motivates me to do better
4
3
2
1
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

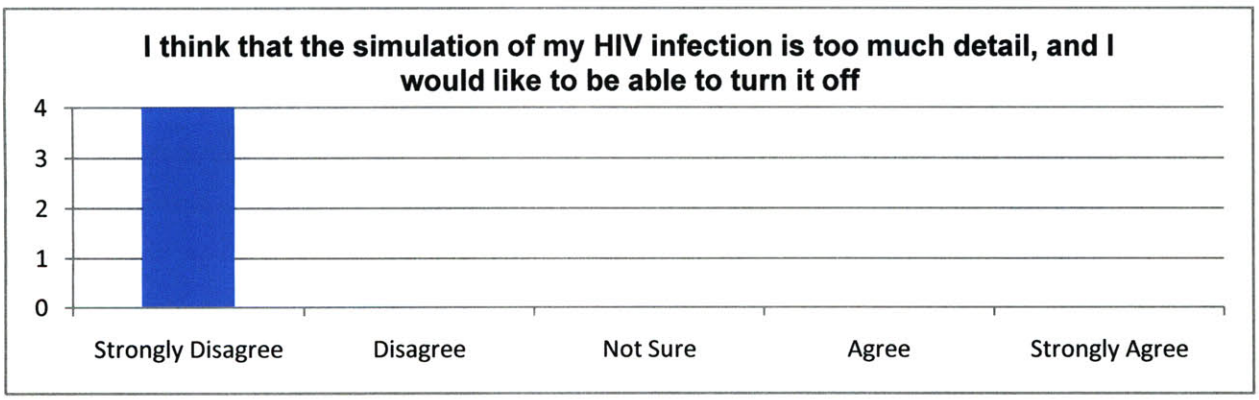

Receiving encouraging messages from my adherence specialist helps to motivate me
4
3
2
1
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree


I think my adherence specialist should not be able to see when I am taking my medications because it is an invasion of my privacy
4
3
2
1
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

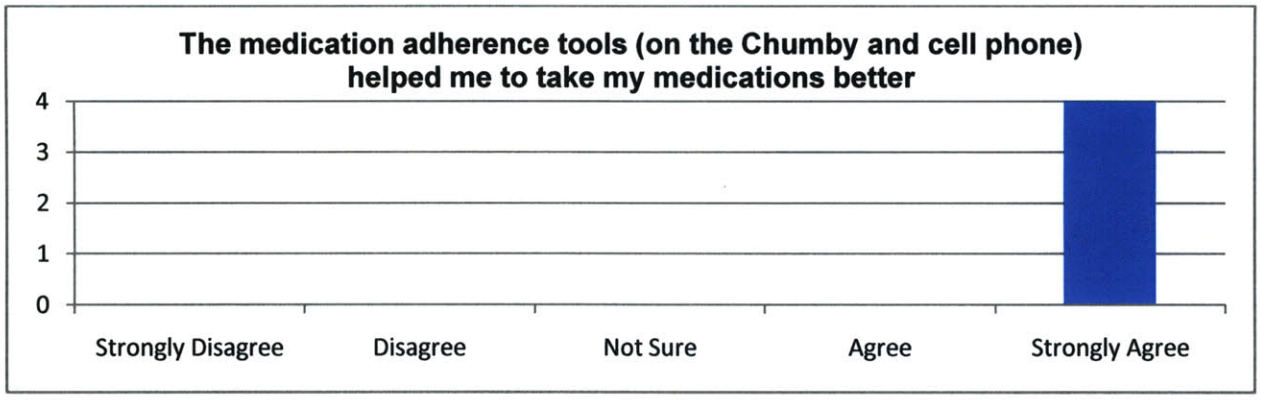

It has been easy to understand the simulation of my HIV infection
4
3
2
1
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

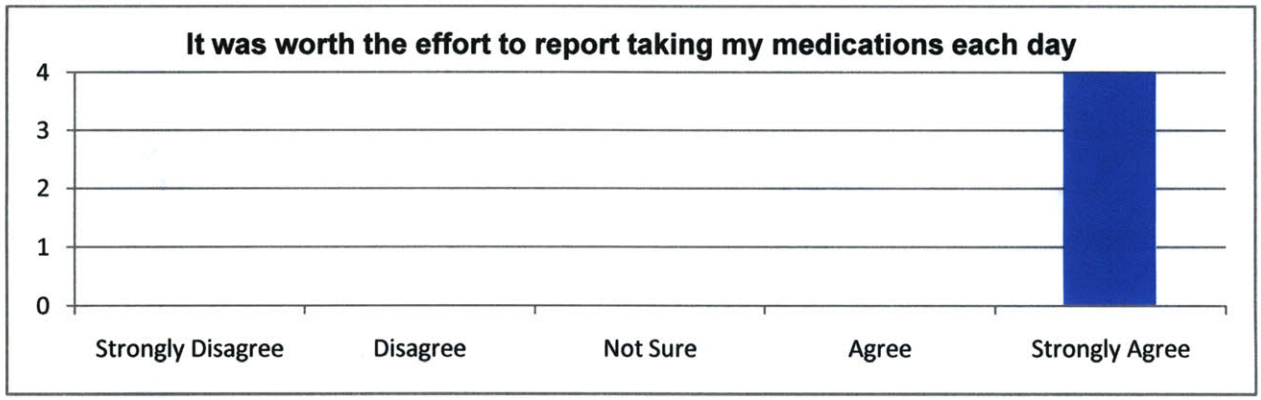

I think that the simulation of my HIV infection motivates me to take my medications better
4
3
2
1
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

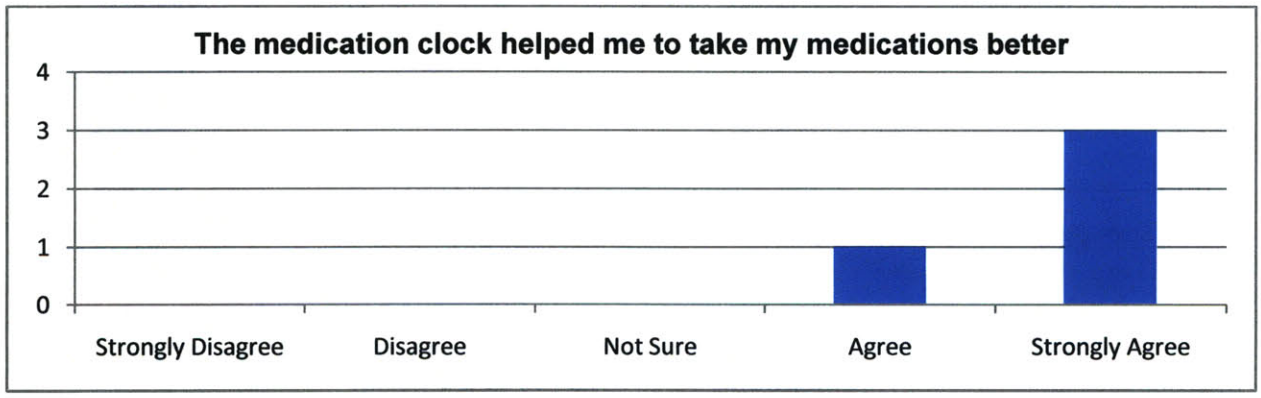

I think that the simulation of my HIV infection is too difficult to understand
4
3
2
1
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

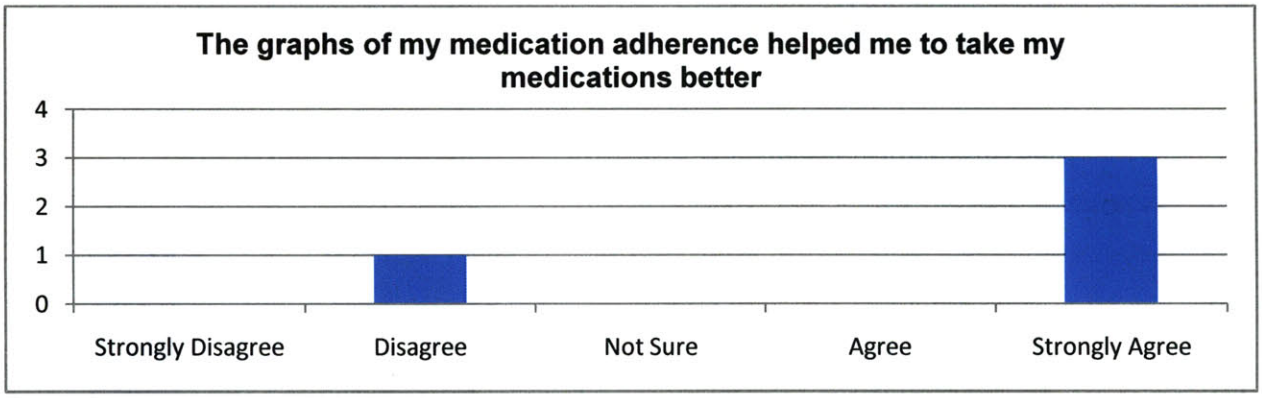

I think that the simulation of my HIV infection is too much detail, and I would like to be able to turn it off
4
3
2
1
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

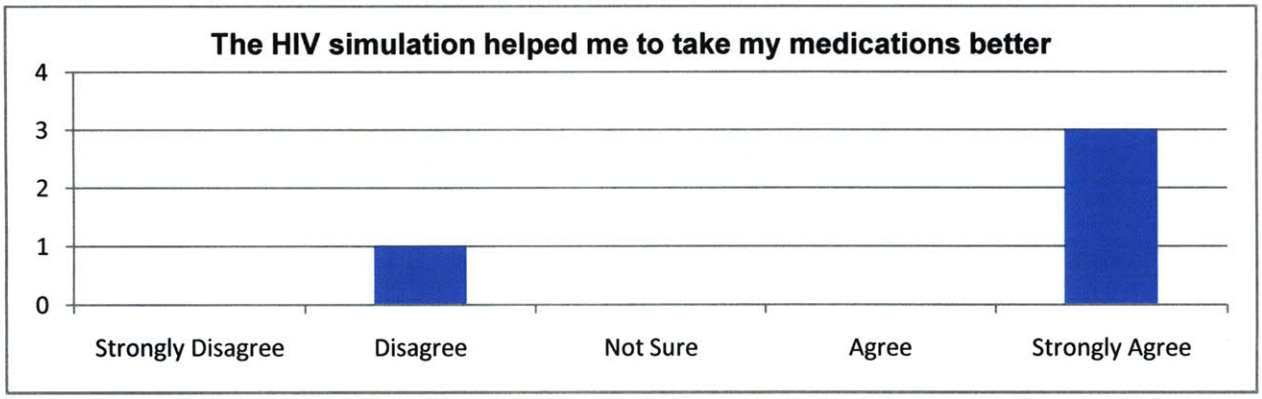
Appendix D – Stage 2, Week 4 Questionnaire Results

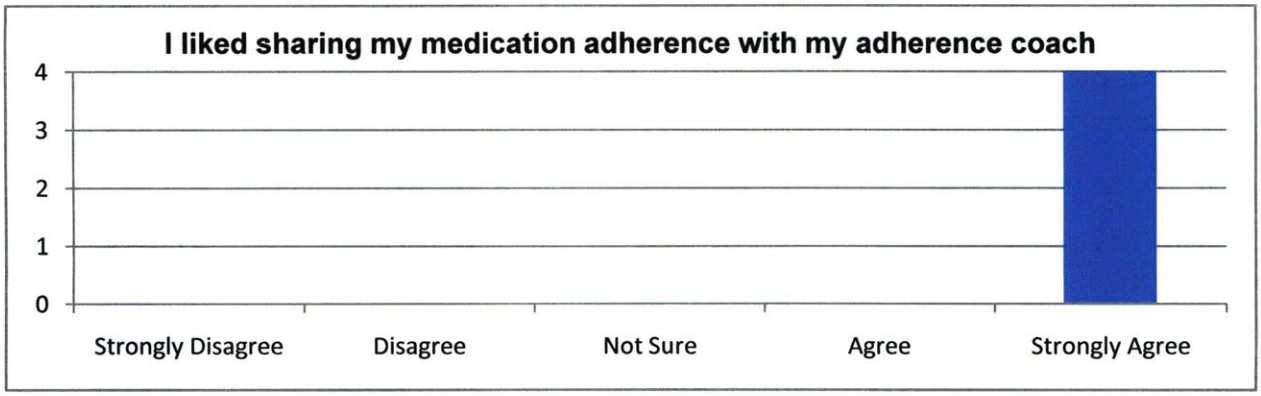


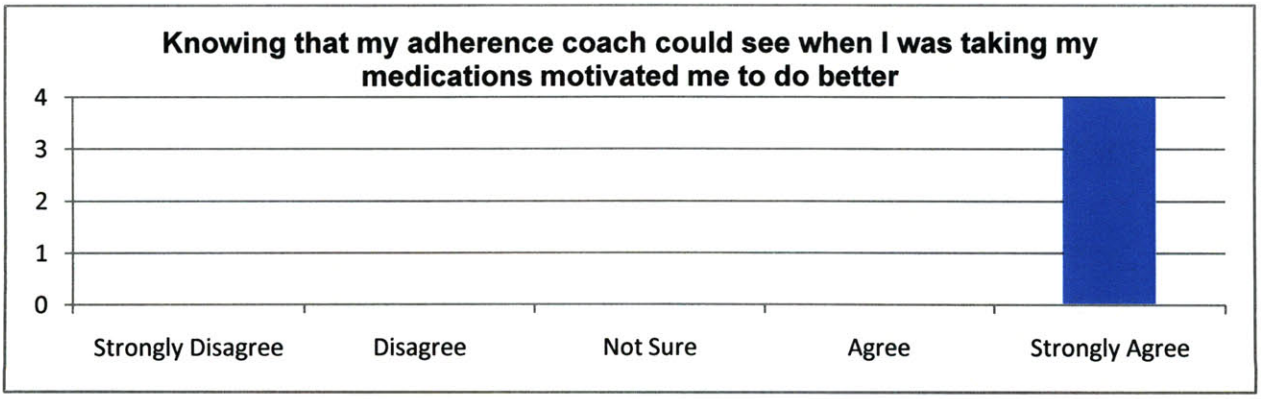


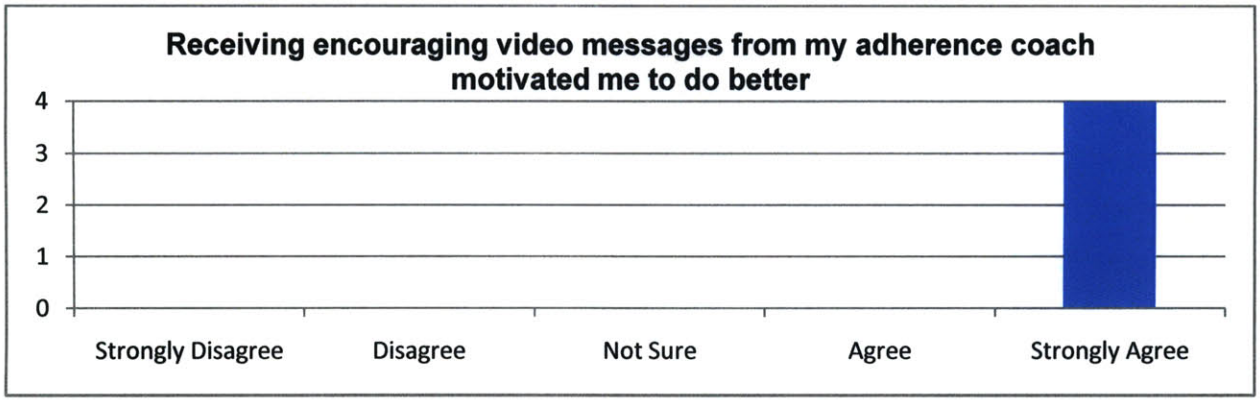


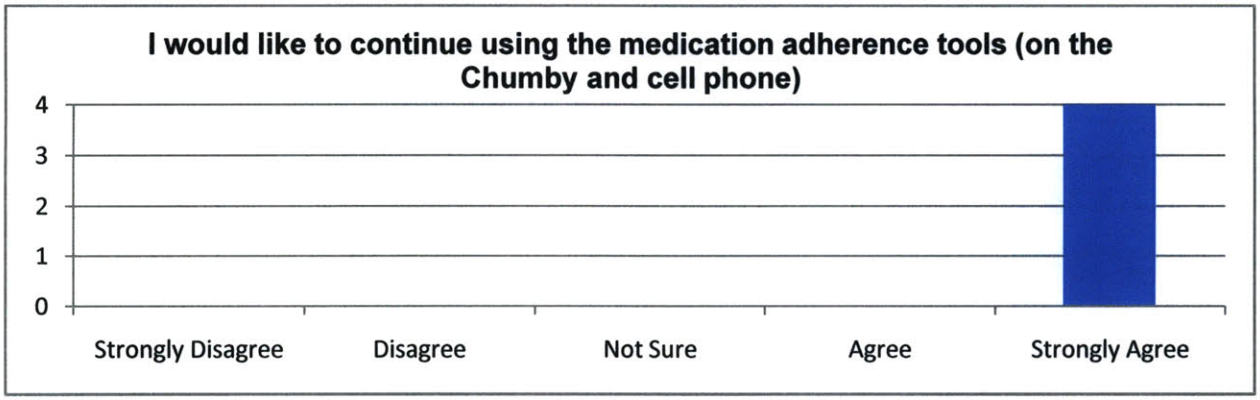

The graphs of my medication adherence helped me to take my medications better
4
3
2
1
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

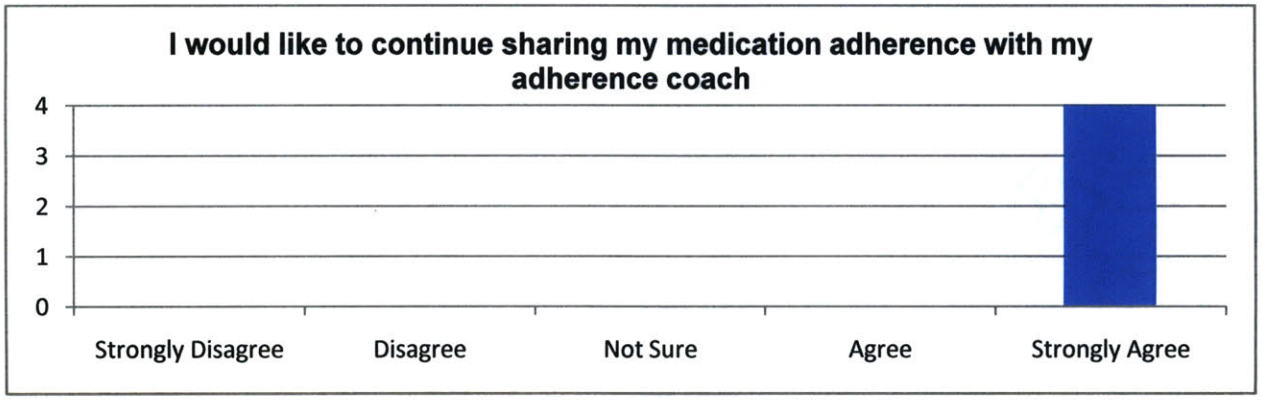

The HIV simulation helped me to take my medications better
4
3
2
1
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

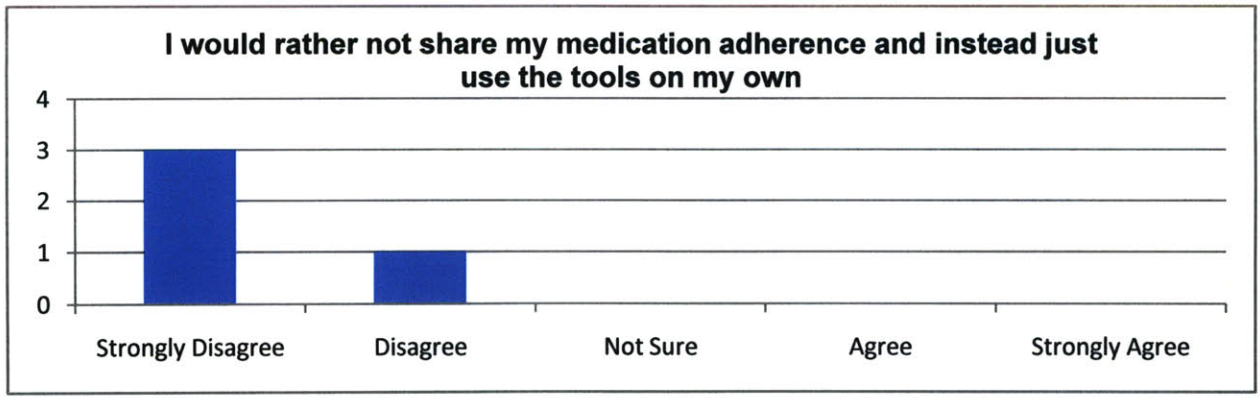

I liked sharing my medication adherence with my adherence coach
4
3
2
1
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

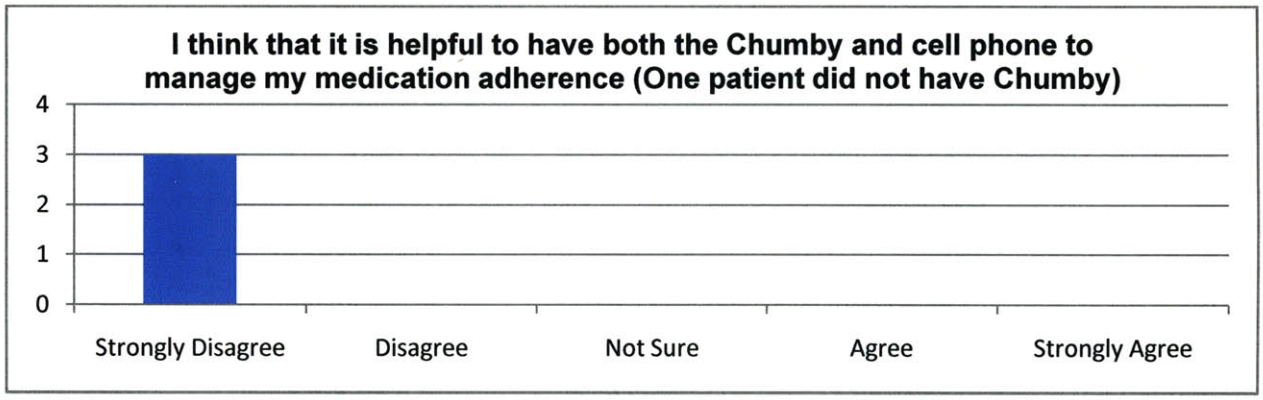

Knowing that my adherence coach could see when I was taking my medications motivated me to do better
4
3
2
1
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

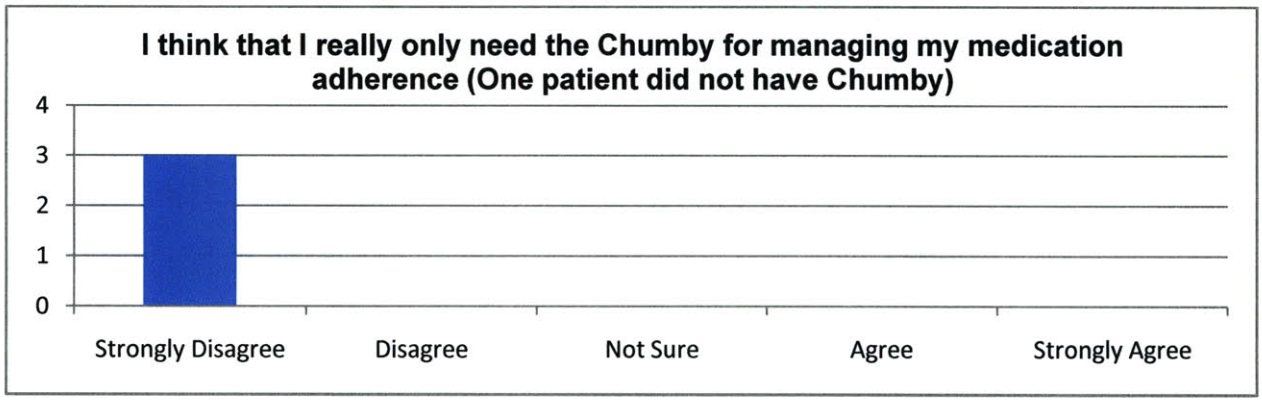

Receiving encouraging video messages from my adherence coach motivated me to do better
4
3
2
1
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree

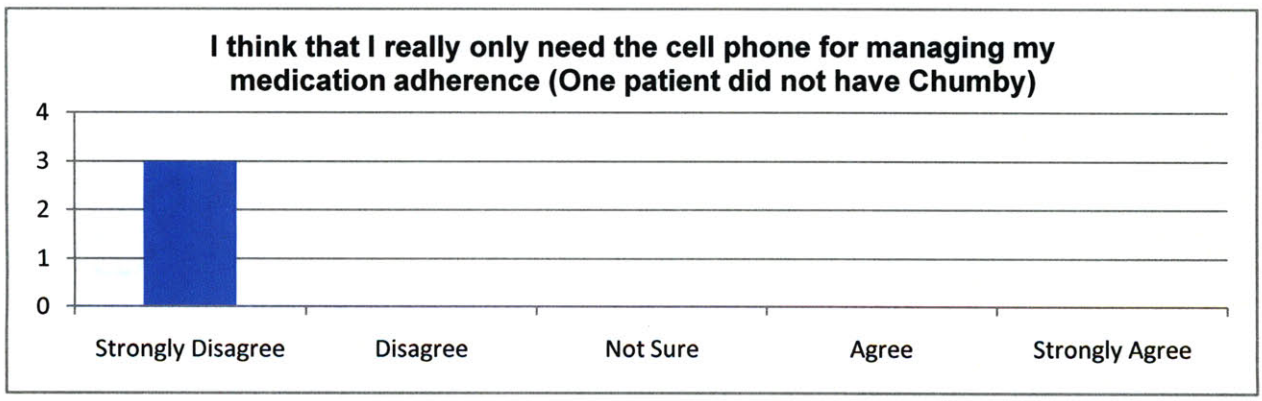

I would like to continue using the medication adherence tools (on the Chumby and cell phone)
4
3
2
1
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree


I would like to continue sharing my medication adherence with my adherence coach
4
3
2
1
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree


I would rather not share my medication adherence and instead just use the tools on my own
4
3
2
1
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree


I think that it is helpful to have both the Chumby and cell phone to manage my medication adherence (One patient did not have Chumby)
4
3
2
1
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree


I think that I really only need the Chumby for managing my medication adherence (One patient did not have Chumby)
4
3
2
1
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree


I think that I really only need the cell phone for managing my medication adherence (One patient did not have Chumby)
4
3
2
1
0
Strongly Disagree
Disagree
Not Sure
Agree
Strongly Agree