Technology-Supported Apprenticeship in the Management of Chronic Disease

by

John Oliver Moore

B.S. Biomedical Engineering
Boston University, 2000

M.D. Allopathic Medicine
Boston University, 2005

S.M. Media Arts and Sciences
Massachusetts Institute of Technology, 2009

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

Doctor of Philosophy in Media Arts and Sciences
at the
Massachusetts Institute of Technology

September 2013

Signature redacted

Signature of Author: ______________________
Program in Media Arts and Sciences
August 7, 2013

Signature redacted

Certified by: ______________________
Franklin H. Moss
Professor of the Practice of Media Arts and Sciences
Thesis Supervisor

Signature redacted

Accepted by: ______________________
Pattie Maes
Associate Academic Head, Program in Media Arts and Sciences

Technology-Supported Apprenticeship in the Management of Chronic Disease

by

John Oliver Moore

Submitted to the Program in Media Arts and Sciences, School of Architecture and Planning on August 7, 2013 in Partial Fulfillment of the Requirements for the Degree of Doctor of Philosophy in Media Arts and Sciences

ABSTRACT

Chronic disease is the most important cause of morbidity and mortality worldwide, but the current standard of care is woefully ineffective. It is paternalistic, episodic, and perversely incentivized based on volume, resulting in poor outcomes at extraordinary cost.

Technology-supported apprenticeship is a model of chronic disease management that embraces the contribution of the patient. It is collaborative, continuous, and designed to achieve value through improvement in the experience, clinical outcomes, and cost of care. In this model, patients are the novice apprentices of master clinicians. A software platform called CollaboRhythm provides applications on mobile phones and tablets as scaffolding for collaboration. Tracking tools document progress, visualizations highlight associations between actions and outcomes, and personalized decision support encourages self-efficacy. Powerful virtual visits and instant messaging allow master clinicians to provide adaptive coaching within the context of daily life rather than in the artificial environment of the office. Apprentice patients have the potential to become master coaches themselves; thus producing an exponentially scaling health ecosystem at minimal cost.

Two randomized, controlled trials were conducted to evaluate if technology-supported apprenticeship could augment the "best of the best" in office-based care and scale it via virtual deployment. Apprentice patients for basal insulin titration at the Joslin Diabetes Center were more satisfied with their care than controls, achieved better outcomes (-3.1% vs. -2.5% HbA1C), and did so with minimal increase in cost ($206). Those for hypertension management at the Massachusetts General Hospital were also more satisfied with their care, achieved better outcomes (-26.3 vs. -15.9 mmHg SBP), and did so with negligible increase in cost ($14). Over a longer period of time, apprenticeship is projected to produce better outcomes at decreased cost.

Technology-supported apprenticeship has extraordinary potential, but the paternalistic culture of medicine and its volume-based economic model present significant impediments. Future work needs to address longer durations of coaching, greater numbers of apprentices per coach, patients as coaches, other chronic diseases, and patients with comorbidities.

Thesis Supervisor: Franklin H. Moss
Title: Professor of the Practice of Media Arts and Sciences

Technology-Supported Apprenticeship in the Management of Chronic Disease

by

John Oliver Moore

Submitted to the Program in Media Arts and Sciences, School of Architecture and Planning
on August 7, 2013 in Partial Fulfillment of the
Requirements for the Degree of Doctor of Philosophy in Media Arts and Sciences

Signature redacted

Read by: ____________________________________

Mitchel Resnick
LEGO Papert Professor of Learning Research
Massachusetts Institute of Technology
Thesis Reader

Technology-Supported Apprenticeship in the Management of Chronic Disease

by

John Oliver Moore

Submitted to the Program in Media Arts and Sciences, School of Architecture and Planning
on August 7, 2013 in Partial Fulfillment of the
Requirements for the Degree of Doctor of Philosophy in Media Arts and Sciences

Signature redacted

Read by: ____

Pattie Maes
Professor of Media Technology
Massachusetts Institute of Technology
Thesis Reader

Technology-Supported Apprenticeship in the Management of Chronic Disease

by

John Oliver Moore

Submitted to the Program in Media Arts and Sciences, School of Architecture and Planning
on August 7, 2013 in Partial Fulfillment of the
Requirements for the Degree of Doctor of Philosophy in Media Arts and Sciences

Signature redacted

Read by: ______________________________

David Judge
Medical Director, Ambulatory Practice of the Future
Massachusetts General Hospital
Thesis Reader

TABLE OF CONTENTS

1 Introduction

1.1 Problem

1.1.1 Chronic Disease is a Monumental Social and Economic Issue

Chronic disease is the most important cause of morbidity and mortality worldwide. Half of Americans have at least one chronic disease, and 70% of deaths are attributable to chronic disease. [1] In addition, the cost of healthcare associated with managing chronic disease is extraordinary. In the United States alone, the yearly cost is an estimated $1.65 trillion – more than 75% of total healthcare spending. [2] [3]

1.1.2 Today's Standard of Care for Chronic Disease Management is Ineffective

The standard of care refers to the mainstream approach to the management of a disease and often, more specifically, the minimal set of services that is acceptable. It includes the diagnostic tests and therapies as well as the care delivery model through which they are provided.

The therapies (medications, diet and exercise modification, etc.) for the chronic diseases that represent the greatest burden (hypertension, hypercholesterolemia, diabetes, etc.) are relatively well understood and effective. On the other hand, it is generally agreed that the care delivery model for making diagnoses and supporting therapy is woefully ineffective, such that the outcomes that should be achieved are not. The care delivery model predominately consists of sporadic physician office visits even though we live in an information age of hyper-connectivity. This model is the core component of the standard of care that needs to be addressed to improve outcomes and cost. [4] [5] [6] [7] [8]

In order to illustrate the inadequacy of today's standard of care, it is helpful to examine the management of specific diseases in detail. Hypertension and diabetes are excellent examples because they produce the majority of the burden on the healthcare system and because they have been studied extensively.

1.1.2.1 Hypertension Management as an Example of the Ineffective Standard of Care

Hypertension (elevated blood pressure) affects approximately 30 percent of the adult population of the United States. [9] Antihypertensive treatment has been shown to be extremely effective at preventing complications. When followed correctly, it decreases the incidence of heart attack by 20-25%, of stroke by 35-40%, and of heart failure by 50%. [10]

The standard of care for hypertension management in the United States, developed based on the benefits described, includes monthly office visits for those with elevated blood pressure. Lifestyle modification (diet and exercise) and pharmacologic therapy are to be employed in these visits along with lab testing 1-2 times a year until goal blood pressure is achieved. Once blood pressure is under control, visits can be spaced to 3- to 6-month intervals [10]

Unfortunately, estimates suggest that up to 30% of those with hypertension in the United States are undiagnosed, and the majority of those diagnosed (~52%) do not have their blood pressure controlled under the current standard of care. [9] This failure is due to both clinician and patient factors. Mean adherence of clinicians to guidelines is estimated at 53.5%. [11] An electronic monitoring study showed that half of patients who are prescribed medications stop taking them within one year. [12] Of those who take their medications, about 10% have adherence issues on any given day and about 50% have significant adherence issues in the course of their treatment. [12] Adherence to diet and exercise self-management is even more difficult than medication adherence with adherence rates below 20%. [13]

Not only is the standard of care for hypertension ineffective, it is also extremely costly with direct medical costs (treatment and complications) of approximately $100 billion a year and equally high indirect costs (lost productivity). Direct medical spending to treat hypertension was $47.5 billion in 2009, and approximately $60 billion is spent a year on complications. [14] [15] [16] The mean expenditure per person with hypertension per year is approximately $1,902, including $841 for primary treatment ($379 for prescription medications, $248 for doctor's office visits, and $214 for other expenses including ER visits, hospital stays, and home health services) and $1,061 for complications (although these costs are unevenly distributed with some patients having more complications than others). [14] [15] [16] The costs are projected to increase by 30% by 2015 and to double by 2030 based on the increased prevalence of hypertension. [16]

1.1.2.2 Diabetes Management as an Example of the Ineffective Standard of Care

It is estimated that 25.8 million people in the US (8.3% of the population) have diabetes (elevated blood sugar). 90-95% of these cases are type II diabetes (typically adult onset). [17] Blood glucose control is clearly linked to prevention of complications (death, heart attack, stroke, kidney disease, eye disease, etc.) Hemoblobin A1C (HbA1C) is a laboratory measure of the glycosylation of hemoglobin that reflects the average level of blood glucose over the last 3 months. Each 1% decrease in HbA1C is associated with a 21% reduction in risk of complications. [18]

The standard of care for management of type II diabetes involves routine office visits every 1-2 months until blood sugar is under reasonable control and then spacing to every 3 to 6 months. Patients self-monitor blood glucose (SMBG) at home with a meter and either bring in measurements to office visits or phone, fax, or e-mail them. HbA1C measurements are taken from blood draws 2-4 times a year with the goal of achieving < 7%. Clinicians advise lifestyle modification (diet and exercise) and employ oral medications and insulin as needed. Patients are often referred to nutritionists and exercise physiologists. Yearly foot and eye exams are recommended to screen for complications. Cholesterol, blood pressure, tobacco use, and aspirin use must also be addressed for all diabetics. [19]

Unfortunately, 27% of diabetics in the United States are undiagnosed and 42.9% of those diagnosed do not have HbA1C measurements below goal of 7%. [17] [19] Again this failure is due to both clinician and patient factors. Only approximately 50% of diabetic patients receive all of the recommended services from their clinicians. [20] [21] Patient medication adherence has been estimated to be between 53 and 67% using electronic monitoring. [22] [23] Adherence to diet is 37%, to exercise is 35%, to test taking is 64%, and to appointment keeping is 72% [24] The American Diabetes Association (ADA) cites that the underlying cause of this failure is a delivery system that is fragmented, lacks clinical information capabilities, often duplicates services, and is poorly designed for the coordinated delivery of chronic care. [19]

The standard of care for diabetes, like that for hypertension, is extremely expensive despite its marginal effectiveness. Direct medical costs are approximately $176 billion a year and indirect costs may be as high as $69 billion. **[25]** The cost per patient per year is approximately $7,888 ($2,394 for prescription medication and testing supplies, $909 for doctor's office visits, and $4,586 for other expenses including ER visits, hospital stays, nursing home facilities, and home health services). **[25]** A European study suggested that approximately half of the medical costs of diabetes are attributable to complications. **[26]** A recent report provided evidence that the cost of complications alone may be as high at $10,000, suggesting that the total cost per patient per year is much greater than $7,888. **[27]** The costs of managing diabetes are expected to at least double in the next 25 years with the increasing prevalence of diabetes. **[28]**

1.1.3 Today's Ineffective Standard of Care is Based on an Archaic Acute Care Model

In the beginning of the 20th century, the majority of the healthcare burden in the United States was due to acute illnesses such as bacterial pneumonia, tuberculosis, and bowel infections. **[29]** The model of care for acute illness used at the time was developed over centuries in which there was a great separation in knowledge and power between doctors and patients. This model was paternalistic, meaning that it predominantly relied on clinicians managing all of the data and making decisions for patients. It was episodic and reactive rather than proactive, meaning that it was based on sporadic interactions that were typically in response to a problem. This model was relatively effective for acute illness despite this archaic approach. The patient had a problem, the doctor prescribed a solution, and the patient hopefully recovered. **[4]**

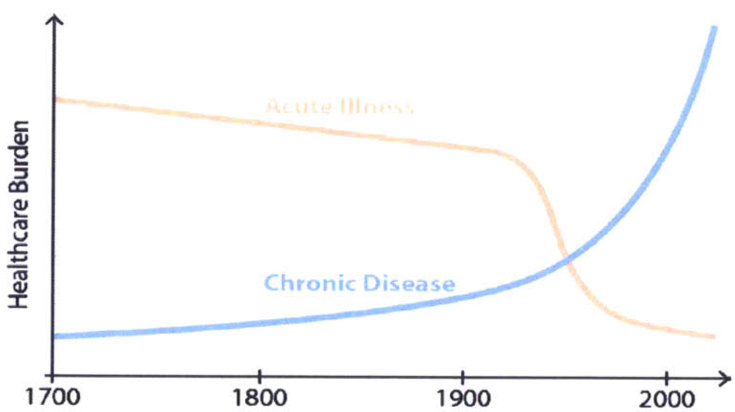


Figure 1: Shift in Healthcare Burden in the 20th Century. *The burden due to acute illness decreased gradually during the 1700s and 1800s due to public health sanitation efforts and gradual advances in medicine. The burden due to chronic disease gradually grew as a result. In the 1900s, there was a dramatic shift in burden due to the advent of antibiotics, introduction of immunizations, as well as other public health successes. Chronic disease now represents the vast majority of healthcare burden, not only in the United States, but in almost every country in the world.* ***[30]***

With the advent of antibiotics and the introduction of immunizations in the early 20th century, the institution of medicine was able to have a remarkable impact on the morbidity and mortality associated with acute illness. Life expectancy increased considerably. As a result, the prevalence of chronic diseases such as hypertension, diabetes, hypercholesterolemia, asthma, cancer, etc. began to rise dramatically. [**29**]

Now the burden of chronic disease dwarfs that of acute illness, but the standard of care has failed to adapt. The vast majority of chronic disease care is still based on an archaic acute care model of sporadic visits to the doctor's office in which paternalistic instructions and prescriptions are delivered. In addition, the model in the US is now also burdened by a volume-based (fee-for-service) payment model that prioritizes services rendered rather than positive health outcomes. This has created a significant barrier to innovation, since doctors are incentivized to not change. [**4**] [**5**] [**6**]

The evidence that this model is poorly received by patients is clear from their actions. Up to 30% of medication prescriptions are never filled, 50% of patients do not take their medications appropriately, and follow-up visit rates are dismally low. [**7**] [**8**] In addition, even when clinicians make an effort to educate patients during these brief visits, retention of information is below 20% because a hurried lecture in a stressful environment is not an effective learning tool. [**31**]

1.1.4 Today's Ineffective Standard of Care Does Not Support Patient Empowerment

Today's patients live in an information age in which they have been empowered to do things that were unimaginable in the distant past and that were only done by professionals in the recent past. They carefully monitor every transaction in their bank accounts from their mobile phones, buy and sell stocks without a broker, explore every possible flight option for vacation without a travel agent, and track packages from around the world to their doorsteps. For health, they go online to educational websites and read about the risks and benefits of different treatments, and they go on patient community websites such as PatientsLikeMe to learn from and help others. They can even go online to read any textbook or journal article that is accessible to their doctors. At the same time, the healthcare system still requires them to sit in a waiting room for an hour just to have their blood pressure checked and for the doctor to prescribe them a medication that they have to take every day, indefinitely, without an explanation of why it is necessary or how it works. Patients want to be engaged and empowered, but the system is not compatible.

A hierarchy of patient empowerment was developed to critique the ability of different models of care delivery to support patients in engaging in their care and in developing self-efficacy. The figure below illustrates the current standard of care and its place in the hierarchy of patient empowerment. Patients are striving for self-efficacy and driven to help others, but the standard of care only allows them to seek the most basic medical needs. This hierarchy will be used throughout the thesis in critiquing the standard of care, the "best of the best", and technology-supported apprenticeship.

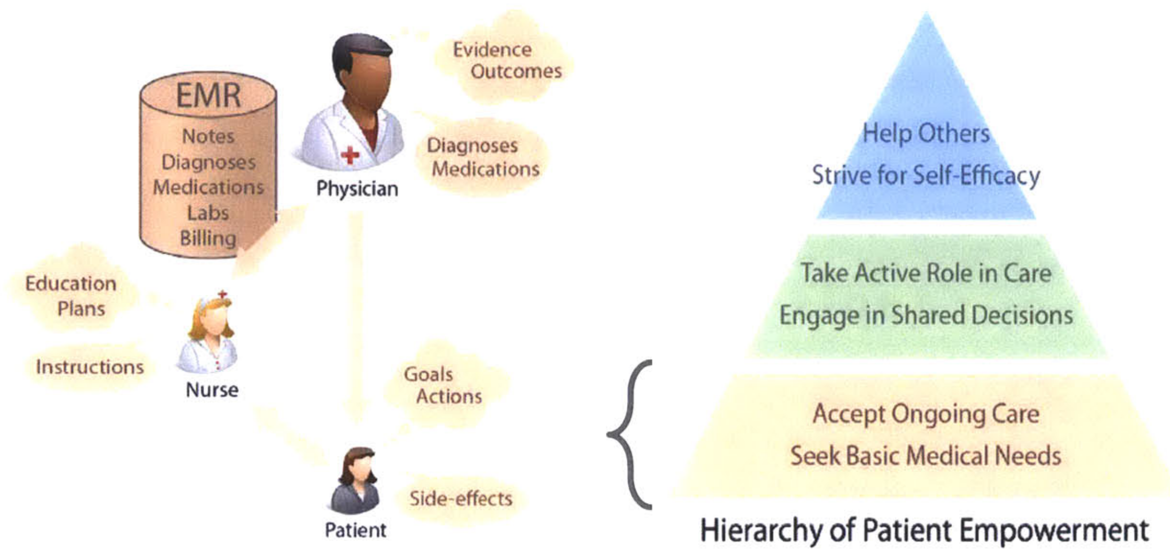


Figure 2: Standard of Care in Chronic Disease Management and Its Place in a Hierarchy of Patient Empowerment. *The image on the left represents the current standard of care based on an archaic acute care model. There is a significant power imbalance with the physician in charge and the patient as a passive recipient of prescriptive instructions. The nurse is a peripheral player focused on reacting to immediate needs of the physician and the patient. The physician and the nurse use an electronic medical record (EMR) to document and bill for their services, but this tool does not contribute significantly to patient care. In fact, it often detracts from it. The spoken communication is not captured in any formal way and many important concepts in care are never even discussed but are only fleeting thoughts of the different parties. The image on the right presents a hierarchy of patient empowerment divided into three tiers. At the lowest level, patients are supported in seeking only the most basic medical care. At the middle level, patients are engaged in shared decisions and encouraged to take an active role in their care. At the highest level, patients are empowered in developing true self-efficacy and their desire to help others to achieve self-efficacy is embraced. The current standard of care only supports patients in the lowest level of patient empowerment.*

1.1.5 Mainstream Solutions for Improving Chronic Disease Management are Inadequate

1.1.5.1 Patient-Centered Medical Home is Still Clinician-Centered, Improvements are Marginal

The most widely implemented recent solution for improving the quality and cost of care delivery, including chronic disease management, is the patient-centered medical home (PCMH). The PCMH is a team based health care delivery model that provides comprehensive and life-long patient care with the goal of optimizing patient and staff experiences, medical outcomes, safety, and system efficiency. [**32**] The core tenets are: patient-centeredness with emphasis on improved collaboration and attention to whole-person health, team-based care with coordination to meet the needs of the patient, improved access to care including prompt visits and new communication methods and information technology solutions, and a system-based approach to quality and safety. Exploration of alternative payment models is often a necessary part of achieving the goals of a PCMH. There are seven different accreditation and certification bodies, so the definition actually varies, but the core principles are relatively the same.

There are currently hundreds of PCMHs in the country, but unfortunately research suggests that improvements are marginal. As a system-based approach to quality and safety is one of the core tenets, many practices publish statistics about their improvements in medical outcomes and cost. Although many individual practices show decreases in ER visits (12% to 50%), hospital admissions (3% to 24%), and per-capita costs (1% to 25%), some showed increases. Meta-analyses and summary studies typically find that overall the benefits are small or unclear. **[33]** **[34]** **[35]** A thorough study of 36 family medicine PCMHs over 2 years revealed the following **[34]**:

1. quality scores improved by approximately 9%
2. chronic disease management scores improved by approximately 5%
3. prevention scores improved slightly
4. access scores improved slightly
5. patients did not report improvements in the quality of their care (there were even trends toward patient-perceived decreases in coordination of care, comprehensive care, and access to first-contact care)

A systematic review of 19 comparative studies of PCMHs found the following **[35]**:

1. small to moderate improvements in staff experience (low strength of evidence)
2. small improvements in patient experience (moderate strength of evidence)
3. small to moderate improvements in preventative services (moderate strength of evidence)
4. 19% reduction in ER visits
5. no significant reduction in hospital admissions
6. no evidence of overall cost savings

A major issue with the implementations of the PCMH that have been conducted thus far is that the role of the patient is relatively unchanged. Most practices have only implemented about a quarter of the components considered to be important for success. **[34]** The most commonly used approaches have been adding new staff (such as a case manager), adding home or telephone visits, and identifying high-risk patients using their electronic medical record and evidence-based clinical guidelines. **[35]** These can be considered to be relatively clinician-centric interventions since they presuppose that the solution to better patient care lies in the clinic and operational details rather than in the patients themselves. Shared-decision making, patient self-management, and other patient-centric approaches are rarely mentioned in reports. It is of note that these components are included in some recommendations for PCMHs but may be reflected in as few as 2-3 of up to 40 components. **[34]**

Another major issue with the implementations of the PCMH is that there are many definitions of what should be accomplished but very few tools available to effectively implement the components. Most implementations rely on their electronic medical record system, which was designed for a traditional medical practice, and rarely is there mention of any information technology tools to specifically address the goals of the PCMH despite the use of information technology innovation being a core tenant of the model.

1.1.5.2 Accountable Care Organizations Are Focused on Cost-Containment not Care Improvement

Accountable care organizations (ACOs) are care delivery systems composed of hospitals, physicians, and other clinician and non-clinician providers that manage the entire spectrum of healthcare services for a population of patients. They share in cost savings that they produce and are penalized for poor performance. [36] The concept of an ACO is essentially an extension of the PCMH with the addition of this financial risk and larger scope of care. As such, its tenets of safety, effectiveness, patient-centeredness, timeliness, efficiency, and equity are similar. The roll-out of ACOs has been facilitated by the Patient Protection and Affordable Care Act recently enacted under the Obama administration. [37]

Given that it has only been two years since the first ACOs began operating, there is relatively little data available about their improvements in outcome and cost. There are currently more than 300 ACOs operating in the United States. Most of them center around large hospital systems rather than primary care and most are still being paid in a fee-for-service manner rather than in bundled payments. The majority of their cost-saving measures are focused on transitioning to less costly services. For example, switching to more affordable vendors of lab services or using surgical procedures that have faster recovery times. Some are adopting techniques used in PCMHs such as identifying complicated patients who account for large cost and assigning patient navigators. Leaders of these efforts in large organizations are reporting that it takes up to a year just to implement new processes and educate their employees and patients. Given that these organizations are large, that their spending is mostly on hospital care, and that their approaches are less about adopting a more effective model of care delivery and more about identifying and cutting costs through incremental change, it is unlikely that they will significantly impact the problem of chronic disease management. This is supported by early reports from ACOs that show that they are only cutting the rate of increase in the cost of care per year as opposed to actually decreasing the cost of care. Even more telling is that this is as ambitious of a goal as they have set. The Centers for Medicare & Medicaid Services (CMS), intimately involved in the creation of the ACO model, has only projected a 0.10 percent decrease in total Medicare spending over three years. [38]

1.2 Core Tenets for Improvement

Radical new paradigms of chronic disease management paired with IT solutions need to be explored to improve chronic disease management. The lack of compelling results of PCMHs and ACOs and the tremendous scope of the problem of chronic disease management suggest that there is a need for disruptive innovation rather than incremental improvements to these models. The core values of PCMHs and ACOs (improved care coordination, increased patient centeredness, and maximized safety and outcomes) are sound, but the lack of proven examples of how to achieve significant progress leaves these models feeling more like wishes than solutions.

A set of core tenets for improvement need to be established to guide the path forward. These core tenets need to be driven by the fundamental values and goals of the key people involved, patients and clinicians, rather than based on goals of external forces such as government, insurance companies, pharmaceutical companies, etc.

1.2.1 Patients are the Most Underutilized Resource in Healthcare

Given that most chronic diseases are either directly caused by the health-related behaviors of patients (poor diet and exercise) and that the treatment of these diseases involves daily action on the part of patients (lifestyle change, measurements, and medication adherence), new paradigms of management that actually center on the patient and not the doctor's office or hospital will likely be the most effective. Patients have the potential to know more about their conditions than anyone because they live with them on a daily basis. They perform self experiments and use these experiments to guide their behavior. They also potentially have the greatest vested interest in getting them under control. The problem is that patient knowledge and motivation is not nurtured. In fact, it is typically ignored, resulting in adverse outcomes. The reality that only 2 or 3 of the nearly 40 components of the PCMH directly address patient contribution reflects that even progressive models that pride themselves in patient engagement are not really that patient-centered. These observations lead to the first core tenant in considering how to improve chronic disease management: **Patients are the most underutilized resource in healthcare**. The hierarchy of patient empowerment presented should be used in evaluating new models of care. The goal should be to support patients in reaching the pinnacle of the hierarchy through supporting development of self-efficacy and embracing the desire of patients to help others achieve self-efficacy.

1.2.2 Health takes place in the everyday lives of patients, not in a doctor's office or hospital

Given that chronic diseases require daily attention and that they present frequent challenges in the lives of patients, new paradigms of management that are constantly available to patients will likely be the most effective. The hiring of more staff and the lengthening of office hours may decrease the time to schedule a visit, but the innovation that will likely transform the management of chronic disease is the elimination of regular visits and the design of interventions that are continuously available to patients. Patients should be able to track their progress, reflect on their goals, suggest adjustments in plans, and ask for assistance whenever and wherever they desire. These observations lead to the second core tenant: **Health takes place in the everyday lives of patients, not in a doctor's office or hospital.**

1.2.3 Collaboration and information transparency, not just information access, are critical

Given the scope of the problem of chronic disease management, the large amount of data to be collected and analyzed, and the importance of communication coordination, information technology tools will need to be at the center of any successful solution. At the same time, the human component of medical practice is extremely important, and is currently being undermined by the adoption of computer systems that ignore their role in the dynamics of care delivery. Careful attention needs to be given to the unique challenges in human-computer interaction presented by this problem. These observations lead to the third core tenant: **Collaboration and information transparency, not just information access, are critical to the solution.**

1.3 Thesis Statement

The hypothesis at the core of this thesis is the following:

Technology-supported apprenticeship, as a model of care delivery and patient empowerment, can dramatically improve the experience, clinical outcomes, and cost of chronic disease management.

Apprenticeship refers to the tutelage of a community of novices in a skill or trade by one or more masters through situated learning. Situated learning refers to the process in which novices learn through participation in legitimate tasks in the same physical and social context where they will need to perform them once independent. [39] [40] It is opposed to learning through contrived exercises in an artificial environment like a classroom.

In the context of this thesis, patients are the novice apprentices of master clinician coaches. Software provides scaffolding and communication tools to allow the clinician coach to support the patient in the management of disease within the context of daily life rather than in the artificial environment of the clinician's office. These same tools allow peer apprentices to aide each other in developing self-efficacy. Apprentice patients become master patients who can serve as coaches to novices themselves, thus producing an exponentially growing health ecosystem at minimal cost.

Technology-supported apprenticeship as a paradigm of healthcare delivery fully embraces the three core tenets of improving chronic disease management. 1) Technology-supported apprenticeship harnesses the contribution of the patient and values the development of self-efficacy to the extent that apprentices can become masters. It supports patients in achieving the pinnacle of the hierarchy of patient empowerment. 2) Technology-supported apprenticeship appreciates that situated learning is the key to mastery of chronic disease management and strives to support patients continuously in the context of their lives. 3) Technology-supported apprenticeship in healthcare delivery embraces information technology to maximize collaboration among novices and masters and to provide common ground through complete transparency.

While the current model of care is paternalistic and episodic and prioritizes volume, the technology-supported apprenticeship model of care is collaborative, continuous, and prioritizes value. It engages patients, meets them in their lives, and is accountable for outcomes.

1.4 Research Questions

A number of research questions were addressed as specific goals of this thesis. They are divided into three categories based on the triple aim for improvement in healthcare:

- Experience
    - How do perceptions of quality of care compare between apprenticeship and standard of care for patients and clinicians?
    - Do patients really want to be active participants or do they just want to be told what to do by clinicians? Do patients think that they are capable of becoming masters in managing their chronic diseases? Are they interested in coaching novices once they become masters? Are clinicians willing to support patients in becoming masters? Do clinicians believe that patients are capable of becoming masters? Do they think that it is worth the effort?
    - What aspects of the technology for apprenticeship do patients and clinicians think are the most helpful?
- Clinical Outcomes
    - How do clinical outcomes compare between apprenticeship and standard of care patients?
- Cost
    - How much time and effort is required by patients in reaching these clinical outcomes? By clinicians?

- What is the estimated economic impact of apprenticeship as a paradigm of healthcare delivery based on the achieved clinical outcomes and clinician effort?

1.5 Research Approach

The development of the concept of technology-supported apprenticeship as a paradigm of healthcare delivery was informed by first-hand experience as a medical doctor, family advocate, and patient in the current healthcare system as well as deep explorations in the fields of personal health informatics, learning science, health psychology, and computer-supported cooperative work. Insights drawn from all of these sources were used in building a chronic disease management software platform for computers and mobile devices called CollaboRhythm that supports the apprenticeship paradigm. It provides tools for shared-decision making and goal setting, patient tracking of health actions, self-reflection on results, and seamless collaboration between novices and master coaches.

In the early stages of development of the platform, patient interviews, clinician interviews, and two small pilot studies for Human Immunodeficiency Virus (HIV) and hypertension medication adherence were conducted. These pilots were performed to validate the usability of the platform in those with no significant technology experience and in those perceived to have low health literacy and numeracy. Patient feedback and study observations were used to improve the platform for future studies.

The core thesis and the CollaboRhythm platform were evaluated through two randomized, controlled clinical trials in which the experience, clinical outcomes, and cost of care were analyzed. One study addressed the achievement of goal HgA1C in type II diabetic patients who were beginning insulin therapy. The second addressed the achievement of goal blood pressure in patients with hypertension. In each study, experimental subjects received the technology-supported apprenticeship model of care and the control subjects received the standard of care at the same clinic and sometimes from the same clinicians. (It is of note that these clinics were considered to be the "best of the best".) Experience was assessed using pre- and post-intervention questionnaires and interviews of patients in both experimental and control subjects. Clinical outcomes were assessed using vital signs and laboratory tests. Costs were assessed using electronic logs of communication and technology usage as well as chart review. The experience, clinical outcomes, and costs of the intervention groups were compared to:

1. The published results for the mainstream standard of care
2. The published results for novel models of care and health IT innovations, which represent the "best of the best"
3. The standard of care at the research clinics (through analysis of control subjects), which also represents the "best of the best"

1.6 Thesis Organization

Chapter 2 reviews related work including some of the most important and successful results in personal health informatics as well as insights from the fields of computer-supported cooperative work and learning science that informed this research. Chapter 3 describes the technology-supported apprenticeship model for chronic disease management in detail. Chapter 4 explains the architecture of the CollaboRhythm platform, its key features, and how it was designed to support apprenticeship. Chapter 5 details the clinical trials used to evaluate and refine the technology-supported apprenticeship model. Chapter 6 examines the strengths of technology-supported apprenticeship and challenges that need to be addressed in future work. Finally, Chapter 7 formally states the contributions of the thesis and Chapter 8 concludes the arguments for technology-supported apprenticeship as a model for improving the experience, clinical outcomes, and cost of chronic disease management.

2 Related Work

2.1 Prior Work in Improving Chronic Disease Management

There has been extensive research on the improvement of chronic disease management. Interventions have included creation of new roles, organizational restructuring, education, information technology, and various combinations of these elements. [41] Since the landscape of interventions is so large, it is helpful to focus on the problems of hypertension and diabetes management that have been discussed and to analyze the most successful approaches. These interventions can be considered to be the "best of the best" in chronic disease care delivery, and they represent a very small percentage of actual care delivery at much less than 1%.

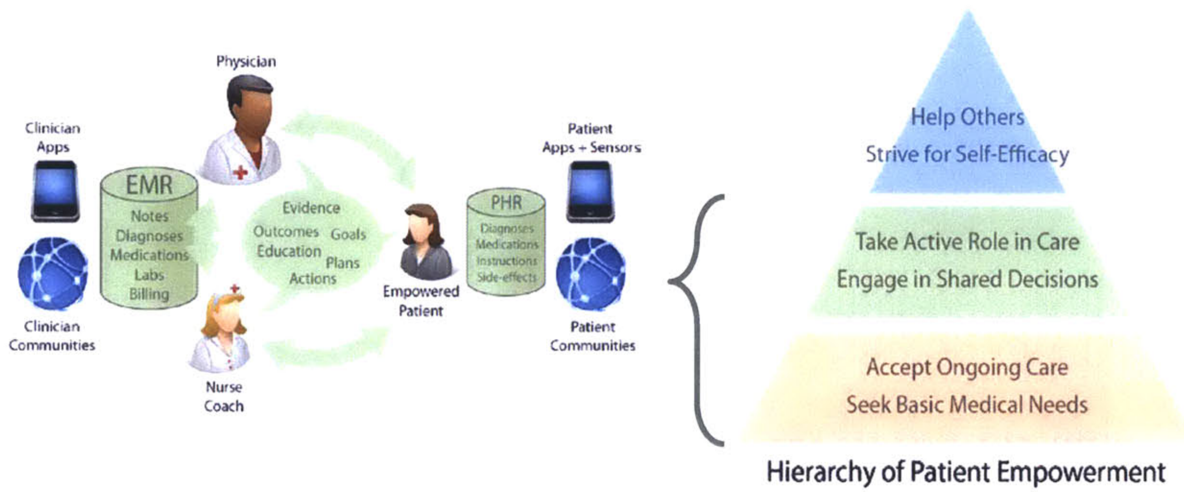


Figure 3: Best of the Best in Chronic Disease Management and Its Place in a Hierarchy of Patient Empowerment. *The image on the left represents the best of the best in chronic care delivery. It upholds the principles of patient-centered care by elevating the contribution of the patient and making him or her part of the decision-making team. It adopts new roles for clinicians, such as nurse coaches who work with patients to set goals and help them to achieve these goals. Personal health IT innovations such as Personal Health Records (PHRs) are used to help patients track their progress using applications on the web and mobile devices. This model supports the patient is progressing up the second tier in the hierarchy of patient empowerment, but is still prescriptive in how it allows patients to participate in their care. For example, patients are encouraged to do self-management of certain aspects of their care, but they are expected to follow prescriptive algorithms rather than think for themselves. A significant problem with this model is that clinicians and patients use two different sets of technology. This tends to form a rift in their efforts to work as a team.*

2.1.1 Interventions for Hypertension Management

A number of approaches have been taken to improve on the standard of care of hypertension management. These include home blood pressure monitoring, behavioral interventions / training programs, self-management, coaching, and various combinations of these components. Interventions that include combinations of the components are consistently more effective.

The minimal technology-based intervention for hypertension management is home blood pressure monitoring. In some instances, home blood pressure monitoring is simply instituted so that patients can record more data for clinicians to use in their decision making. In other situations, the theory is that providing patients with feedback about their blood pressure over time will stimulate self-reflection and lead to improved medication adherence and potentially improvements in diet and exercise. A meta-analysis of 18 randomized-controlled trials revealed improvements in blood pressure (-4.2 mmHg systolic and -2.4 mmHg diastolic) for subjects performing home blood pressure monitoring over controls. In several of the studies, subjects performing home blood pressure monitoring showed a trend toward a higher rate of attaining goal blood pressure, but this was never statistically significant. The meta-analysis suggested an improvement in the chance of attaining goal blood pressure of 1.1. [**42**]

More modern interventions including home blood pressure monitoring have also included components of web-based self-management. The aim is to further improve self-reflection and to potentially stimulate patient-initiated increased engagement with clinicians. A randomized clinical trial of web-based self-management tools for relatively technology-savvy employees of EMC Corporation was reported in 2012. There was not a statistically significant decrease in systolic blood pressure in the interventional group (-1.69 mmHg versus -0.86 mmHg in controls). When the outcome was translated into a binary outcome, then statistical significance was achieved. 21% of interventional subjects achieved a greater than 10 mmHg decrease in systolic blood pressure vs. 16% of control subjects. More interventional subjects started a new blood pressure medication during the study and more of them self-reported improved communication with their doctors, but there were not statistically significant differences in other metrics of engagement including discussions or communications with the doctor about blood pressure. [**43**]

One progressive study explored the possibility of not only giving patients the ability to self-track their blood pressures but also to self-titrate their hypertension medications. These self-managing patients actually outperformed patients who were managed in the traditional manner by doctors. Self-managing patients showed a decrease in systolic blood pressure of 17.6 mmHg while controls only showed a decrease of 12.2 mmHg over 12 months. Self-managing patients were more aggressive in adding new medications and were not found to have increased incidence of side-effects. [**44**]

Encouraging results in hypertension management have also been found in studies that have paired patient self-monitoring and self-tracking tools with personalized clinical coaching. In one study, patients with home blood pressure monitoring and a web training course achieved goal blood pressure after 1 year 36% of the time while controls who received routine care achieved goal blood pressure 31% of the time. This improvement was not statistically significant, but when web-based pharmacist coaching was added, 56% of subjects achieved goal blood pressure (<140/90 mmHg). Those who received coaching showed a 14.2 mmHg decrease in systolic blood pressure while those with only self-monitoring and web training only showed an 8.2 mmHg decrease and those with routine care showed a 5.3 mmHg decrease. [**45**]

Review articles often have difficulty drawing global conclusions about hypertension interventions because of the heterogeneity of methods and measures used in the individual studies. [**46**] There is a general consensus, however, that there is a gradual advantage in outcomes from interventions that offer only self-monitoring to those that offer self-monitoring, tools for self-management, and means for coaching from clinicians. In general, personalized coaching has outperformed curriculum-based and less personalized training programs. [46] [47]

2.1.2 Interventions for Diabetes Management

As with hypertension management, there are a tremendous number of interventions that have been studied in attempt to drive improvement in the standard of care in diabetes. Patient self-monitoring of blood glucose is part of the standard of care, but typically this data is only reviewed and acted upon at regularly scheduled office visits. Meta-analyses and review articles generally agree that interventions that aim to improve patient self-management behaviors have shown modest (~0.5% reduction in hemoglobin A1C) but consistent improvements. Those interventions that engage patients in collaborative activities are generally more effective that didactic interventions. [48] [49]

Since diabetes is a broad disease with different subtypes and stages of advancement, more specific focus is useful in investigating the effectiveness of prior interventions, the development of new solutions, and comparison between the two. Patients with type 2 diabetes (typically adult onset, due to insulin resistance) who fail to achieve control with diet, exercise, and oral medications are typically started on basal (long-acting or once-a-day) insulin. The titration of basal insulin to optimize glycemic control is a problem that on one hand is intimidating and costly. Patients need to begin injecting themselves on a daily basis and changes in dosage need to be made every few days. On the other hand, this problem lends itself well to studies of patient self-management because the protocols used for dosage titration are relatively simple. It is for these reasons that the titration of basal insulin was chosen for study in this thesis and that prior work in this area will be covered in more detail here.

There have been a number of studies to establish the effectiveness of basal insulin in decreasing hemoglobin A1C (HbA1C) in type 2 diabetic patients and in proving the non-inferiority of one type of insulin to another. Since these studies focused on proving the effectiveness of the medication, and not on the actual provision of diabetes care, they typically followed very strict titration protocols that were driven by study clinicians through regular offices visits and phone calls. They resulted in significant improvements in hemoglobin A1C but also in high rates of hypoglycemia due to the strict adherence to inflexible protocols. One study showed a 1.46% decrease in hemoglobin A1C for insulin glargine and a 1.54% decrease for insulin detemir over 24 weeks, but with 30% of subjects experiencing symptomatic hypoglycemia [50] Another study showed a 1.8% decrease in A1C for determir and a 1.9% decrease for NPH insulin over 26 weeks, but with ~50% of subjects experiencing symptomatic hypoglycemia (~10.5 events/patient/year) [51] A third study showed a 1.5% decrease in A1C for both insulin glargine and insulin detemir over 52 weeks, but with 64% of subjects experiencing symptomatic hypoglycemia (6 events/patient/year). [52]

As opposed to these efficacy studies that involved extensive clinician control, there have also been a number of studies exploring the ability of patients to self-manage their basal insulin titration. The PREDICTIVE study showed that patients self-managing their insulin titration decreased their A1C by 0.6% over 26 weeks while patients managed by the physician-driven standard of care decreased by 0.5%. The rates of symptomatic hypoglycemia were 6.44 and 4.95 events/patient/year for self-management and physician-driven care. [53] The lack of improvement associated with the physician contribution using the standard of care compared to what was achieved in the efficacy studies is remarkable.

Studies that have combined the benefits of self-management with clinical support, coaching, or education have shown that the combination results in better outcomes than self-management alone. The Goal A1C trial showed that self-titration alone resulted in a 1.3% decrease in A1C over 24 weeks while self-titration with weekly clinician-patient contact via telephone, e-mail, or fax resulted in a 1.5% decrease in A1C. [54] The INITIATE trial compared individual treatment to group treatment but included an educational program and nurse support for all subjects. Individually treated patients showed a 1.8% decrease in A1C while group treated patients showed a 2.0% decrease in A1C over 24 weeks. [55]

As with hypertension management, these studies highlight that combined interventions that include components of patient self-management and education along with longitudinal clinician support have been the most effective. Personalized interventions were again more effective than generic curriculum-based training programs.

2.2 General Trends in Care Delivery and Health Information Technology

There are a number of general trends in patient-centered care that are important to consider since they complement the hypertension and diabetes studies. These studies likely were informed by and, in turn, informed these general trends.

2.2.1 Shared Decision Making

A number of research studies have shown that including people in decisions about their health can lead to increased satisfaction with visits and adherence to regimens. [56] [57] [58] This process, called shared decision making, has not been part of the paternalistic standard of care of medicine. As patients take on larger roles in managing their diseases, they will also need to be more involved in the decisions that drive their care.

The problem with most studies of shared decision making is that they predominantly rely on in-office, on-paper, one-on-one, single-visit decisions. There is reason to believe that, if shared-decision making were to happen continuously in the real world in the context of the patient's problem, the results of these studies could be magnified. In addition, studies have not gone as far as to prove that long-term medical outcomes actually improve for patients who participate in shared decision making. The results of the hypertension and diabetes studies suggest that collaborative care that involves patients in decisions is more effective than self-management or clinician-driven care, but the actual contribution of the shared decision making in this larger setting has not been carefully measured.

2.2.2 Patient Self-Management

Numerous studies, like those for hypertension and diabetes management, have shown that patient self-management can be effective. Patients have been capable of leading the titration of their medications with even greater success than when the process is lead by a physician. [44] [53] [59] Most studies, however, conclude that the applicability is limited to patients with strong health literacy and numeracy and to situations where strict algorithms are used. [44] [53] [59] [60] [61] [62] Patients are not taught to think critically about decisions but instead are instructed to blindly follow a set of rules. This has left a large margin for improvement in clinical outcomes since the algorithms typically fail to account for all pertinent data and the nuances of successful decision making.

2.2.3 Health Psychology

Health psychology is the study of the psychological, behavioral, and social determinants of health and illness. These factors can be as important in the management of chronic disease as the biological causes. Health psychologists study such topics as how illness perceptions affect patient's actions with regard to their diseases. **[63]** **[64]** This approach allows for the design of interventions that appreciate the psychological barriers to lifestyle modification and medication adherence and that actively attempt to overcome these barriers or reorient perceptions.

2.2.4 Health Coaching

Health coaching is a field that grew out of the treatment of alcohol addiction by psychologists and is a form of positive psychology. The traditional model of care delivery is paternalistic and relies on clinicians telling patients the dangers of a disease or health-related behavior (drinking alcohol, smoking, not exercising, etc.) and then directing what the patient should take for the disease or what behavior to change. It is driven by the values, motivations, knowledge, etc. of clinician rather than those of the patient. Health coaching, on the other hand, is focused on eliciting the values of the patient and helping him or her to set their own goals for managing disease or changing health-related behavior. This internal motivation theoretically supports the effective usage of new knowledge and is a greater driver of behavior change.

The core techniques utilized by health coaches are motivational interviewing, goal setting, and appreciative inquiry. Motivational interviewing is an approach to the elicitation of patient values using open-ended questions about health behaviors, validations of those values expressed through affirmations, restatement of these values to encourage reflection, and summarization to identify commitments and establish accountability. **[65]** Goal setting intersects with motivational interviewing and highlights the focus of health coaching on the solution rather than the problem. **[66]** It is a nice example of shared decision making in that it is driven by patient values and supported by clinician knowledge. Appreciative inquiry is a questioning technique that focuses on the positive attributes or assets that a patient has for conquering a particular health goal rather than on deficiencies. The objective is to emphasize strengths to support motivation and to highlight accomplishments, even in the face of not meeting goals, in order to promote commitment. **[67]**

There is emerging evidence of the effectiveness of health coaching. Studies have shown improvements in diabetes management, cholesterol management, weight loss, and smoking cessation. Not only do these studies show improvements in the primary endpoints such as hemoglobin A1C for diabetes and LDL cholesterol, but also in driving factors such as patient knowledge, self-efficacy, quality of life, mood, etc. **[68]** **[69]** **[70]** **[71]** The quality of the evidence in these studies is not extremely strong due to lack of power and due to methods that do not always cleanly separate the health coaching from educational materials and other confounding factors, but the results are overall promising.

Although health coaching was initially a technique developed and used by psychologists, many of its basic principles are intuitive and have been used by other health care providers in some form for centuries. Today, many clinicians are receiving formal training in health coaching techniques and becoming certified health coaches. These include nurses, social workers, nurse practitioners, physician's assistants, occupational therapists, etc. The combination of clinical skills and health coaching competencies provides the opportunity for health coaching to extend into the field of disease management even more effectively.

2.2.5 Medication Adherence and Electronic Reminders

Low rates of medication adherence are a significant contributor to poor outcomes in chronic disease management, as highlighted in the cases of hypertension and diabetes. [12] [22] [23] It is a common perception that the low rates of medication adherence are due to patient forgetfulness. These electronic monitoring studies reveal that this is not likely the case because patients often maintain high rates of adherence for a period of time and then drop in adherence abruptly. This behavior suggests that medication non-adherence is potentially driven more by lack of motivation or significant barriers such as side-effects. Several studies and reviews have posited that knowledge of disease, perceptions of medication efficacy, lifestyle barriers, and lack of social support are all significant contributors to medication non-adherence. [72] [73] [74] [75] They also hypothesize that supportive physician/patient relationships can overcome these factors and improve adherence in most cases.

Given the common perception that medication non-adherence is due to forgetfulness, electronic reminder devices have been common for decades. A recent review reported that such devices produce suboptimal improvements over short periods of time, and that there is no evidence that they can produce sustainable improvements. [76]

Reflecting on these studies and the findings of self-management and health coaching literature, it is likely that interventions that focus on instilling motivation and providing ongoing support will be more effective in the management of chronic disease. This is especially true because lifestyle factors such as diet and exercise are as important or more important than medication adherence. It is abundantly clear that the factors are more affected by lack of motivation and social support than forgetfulness.

2.2.6 Personal Health Records

Personal health records, electronic records that are owned and controlled by patients as opposed to those that are owned and controlled by clinical entities (generally know as electronic medical records), are a popular topic in the field of patient-centered care. They can be seen as scaffolding for shared decision making, self-management, and health coaching because they provide a means for patients to collect data and reflect upon their performance. Unfortunately, most personal health records primarily serve as repositories of labels that have been applied to patients by clinicians. [77] [78] [79] This includes lists of problems, procedures, medications, and immunizations but rarely includes actionable information from the patient's life such as medication adherence, measurements from health sensors, and annotations of symptoms. Research has failed to address the potential of personal health records to serve as scaffolding for goal-directed communication between clinicians and patients.

2.2.7 Quantification of Health Actions Using Sensors

Patient self-tracking of important quantitative values such as temperature, blood glucose, and blood pressure have been commonplace for decades. There is a trend, however, to quantify more and more health actions in order to provide a more complete set of data for medical decision making and to motivate patient behavior change through reinforcing feedback. This includes pedometers for physical activity, electronic pill caps for medication adherence, pulse oximeters for blood oxygenation and heart rate, etc. In addition, work is being done to make all of this data automatically flow to repositories that allow it to drive applications for patients and clinicians. The benefit that these individual sensors provide is still to be proven. Based on the evidence provided in the previous sections, it is likely that having accurate and accessible data from these sensors is a necessary but not sufficient condition for improving patient care. The manner in which this data is used to improve collaboration between self-managing patients and supporting clinicians will be the critical factor.

2.3 Lessons from Computer-Supported Cooperative Work

It is clear from the scale of the problem of chronic disease management and the success of interventions that combine patient self-management with ongoing clinician support that information technology that supports collaboration will be important in achieving further improvements. The use of collaborative applications in healthcare is relatively young compared to that in business efficiency and team coordination. It is, therefore, important to look to the field of computer-supported cooperative work and specifically at groupware applications to understand key principles that affect success and technical details that inform the design of collaborative applications.

Groupware applications fail most commonly not because the desired features cannot be implemented or that performance is not sufficient but because the goals of the users are poorly captured in the high-level design of the application. [80] [81] [82] Most groupware applications are designed around the goals of the organization as a whole or the goals of the leadership. These parties want to increase overall efficiency and improve the coordination of work, but they are not the core users of the application responsible for the bulk of the work. Failure to appreciate the goals of the core users leads to poor adoption and/or improper use of the application, which typically results in the failure to achieve improvements in efficiency or effectiveness of work. Electronic medical records are a great example of the failure of groupware applications. Most electronic medical records are designed primarily to improve the efficiency of billing, the aggregation of data at the organizational level, and the documentation of services for legal protection. They fail to appreciate the goals of doctors and nurses who want to improve the experience, outcomes, and cost of patient care. [83] So doctors and nurses become frustrated by the fact that their attention is pulled from the patient and placed on the electronic medical record. [84] They take short-cuts and fail to use the electronic medical record in a way that meets it goals because those goals are not immediately consistent with their own. [85] The end result is that electronic medical records and health IT in general have not improved the effectiveness, efficiency, or safety of healthcare. [86]

Once the goals of the core users in a groupware application are deeply considered and incorporated into the design of the application, there is still tension between low-level structured workflows that help to optimize procedural tasks and higher-level unstructured communication. The advantage of structured workflows is that they lead to carefully modeled data that is amenable to machine automation, visualization, and collaborative action of other users. The disadvantage is that structured workflows sometimes prevent agility in teamwork and overly constrain solutions. [87] The optimal balance between structured workflows and unstructured communication depends not only on the overall goals of users and their relationships but also on the individual tasks that they need to perform. Designers should strive to strike a balance that maximizes outcomes and efficiency while preserving a user experience that is engaging and enjoyable. Electronic medical records represent a very poor balance between structured workflows and unstructured communication. Typically clinicians are forced to document their visits with patients using highly structured templates that require a large number of fields to be completed, even when these fields are not pertinent to the given patient issue. [85] The clinical note becomes so bloated that it no longer serves its purpose of efficient, structured documentation of information for communication between providers.

Awareness systems are a specific class of groupware applications that provide real-time, often glanceable, information (data visualizations, audio, video, etc.) between collaborators in order to optimize their interactions. The advantage is that it can take less voluntary effort on the part of collaborating individuals to stay updated on progress and to identify opportunities for requesting or providing assistance. The disadvantage of awareness systems is that they can create privacy concerns and can result in significant interruption. [88] [89] Awareness systems have been explored for health management and elderly monitoring because family members desire peace of mind that their loved ones are well. [90] [91] Interviews revealed that they wanted the information at a glance for regular reassurance as opposed requiring them to login to a system. Pilots reinforced this notion that awareness systems may provide significant value in health management applications. Attention to the value proposition to the patient being monitored is very important, however. People typically find it acceptable to share very detailed data and even streaming video and audio if they find that it improves their lives or their connectivity with loved one, but they may find the sharing of even the most innocuous data intrusive if its value is opaque, delayed, or not personal. [92] As patients begin monitoring more and more data about their health using sensors and applications in their homes, on their bodies, and on their mobile devices, the exploration of awareness systems for patients themselves as well as for caregivers will be pertinent. But it will certainly not be feasible for clinicians to monitor all of the data that comes from patients, nor will they be able to respond immediately to all patient questions and concerns, so significant attention needs to be given to effective and sustainable solutions.

2.4 Lessons from Learning Science

Education is generally considered to a very important component in improving patient outcomes, but there is a lack of deep discussion about how patients actually learn and how they might be supported in learning more effectively. It has already been highlighted that interventions for improving hypertension and diabetes management that include personalized coaching are overall more effective than didactic methods or curriculum-based courses. [46] [47] [48] [49] On the surface, it appears that this is a comparison between two different styles of education, but, as one reflects on the principles of health coaching, it is revealed that it is more focused on generating and maintaining motivation rather than on supporting patients in learning. At the same time, studies that involved educational courses typically do not focus on the longitudinal aspects of patient learning but just on providing just-in-case information at the beginning of an intervention and measuring the impact that it has on outcomes. It is clear that a great deal may be learned by exploring how learning science has been applied to other fields.

It has long been asserted that people learn most effectively through experience rather than through curriculum-based, classroom lecture. [39] [93] [40] [94] Situated learning refers to the process in which novices learn through participation in legitimate tasks in the same physical and social context where they will need to perform them once independent. [39] [40] It is opposed to learning through contrived exercises in an artificial environment like a classroom. Situated learning is just-in-time learning while curriculum-based learning is just-in-case. There is evidence from non-traditional programs, including home schooling, that students who learn through situated methods outperform students who learn through traditional methods and that they retain information and skills more effectively. [94] [95]

It seems obvious that learning through experience should be more effective than learning through curriculum-based lectures and contrived homework assignments, so why is the majority of education based on just-in-case learning? Classroom learning developed during the industrial revolution as a means to train large numbers of workers with the same basic skills to be able to work in the new ecosystem of manufacturing. [93] At the time, it was relatively effective at making sure that huge numbers of people, who did not have access to educational materials or appropriately-skilled community teachers, developed the same basic competencies. As jobs and the needs of learners have changed, the institution of education has been unable to adapt because it has created a culture based on teachers having access to knowledge and distributing it to pupils. With the advent of the internet, this division of knowledge has been eliminated, and this culture is threatened. So the institution of education has marginalized computers to separate classes to hold off change. In addition to the inability of schools to adapt, there are strong forces that prevent learners from seeking alternative education. Our system of degrees and test scores has been so engrained in the culture of employers that alternative metrics of proficiency are not accepted and alternative learners are disadvantaged. This phenomenon is interesting because it directly parallels the situation in healthcare delivery. The culture of medicine and its archaic acute care model have failed to adapt to the changing needs and aptitudes of patients. It is valuable to apply lessons learned in education reform to healthcare reform.

Outside of K-12 and college, situated learning is actually quite prevalent and effective. Apprenticeship is a concept that is familiar because it has been the means of training many types of skilled workers including tailors, carpenters, and even doctors for centuries. Apprenticeship refers to the tutelage of a community of novices in a skill or trade by one or more masters through situated learning. The apprentice strives to become a master through gradually taking on more and more significant components of the profession and requiring less and less guidance. It is a systematic process, but at the same time, a flexible path that allows the master to adapt to the aptitudes, personality, and previous experiences of the novice in order to maximize success. It is also a very social process. The cooperation of the community of apprentices as well as the competition between them are powerful factors that facilitate success and that drive motivation to succeed.

Cognitive apprenticeship, as a form of situated learning, has aimed to formalize the principles of apprenticeship and to apply them to the development of fundamental skills such as reading, writing, and arithmetic. [96] [95] The method of cognitive apprenticeship begins with the concept of scaffolding. **Scaffolding** is a set of artifacts that provide the foundation for learning. It grounds the conversation between the master and the apprentice or it serves as a tool for completing a goal or developing a skill. The pattern for making a shirt, cue cards for generating writing ideas, and a graph of a patient's blood sugars are all forms of scaffolding. **Modeling** is the process whereby the master demonstrates the way an expert achieves a goal using the scaffolding. The objective is to expose the thought process of the master and to reveal the subtleties of skill so that the novice can begin to internalize these concepts. The goal is not just to transfer domain knowledge, which is the more explicit factual and procedural knowledge, but also for the novice to learn heuristics, control strategies, and learning strategies. Heuristics are tricks of the trade or algorithms for solving specific problems. They work well for some problems but not for others. Control strategies are used to select the appropriate heuristics and to reflect on their efficacy. Finally learning strategies are used to develop heuristics and control strategies and to choose the right problems. Once the novice begins to internalize the demonstrated skills, the master begins to fade support and to encourage the novice to take on more responsibility. **Articulation** is the process in which the novice is encouraged to vocalize his or her thought process so that the domain knowledge, heuristics, and control strategies being used can be discussed and refined. **Coaching** describes the master observing the novice in this process and providing hints, suggesting scaffolding, and gently nudging the novice toward success. **Reflection** encourages the comparison of a novice's problem-solving process to that of an expert or to that of a peer. It may even involve role-playing through techniques such as reciprocal teaching where the novice pretends to be the master and to encourage articulation and to provide coaching. **Exploration**, finally, pushes the novice to tackle problems independently.

As highlighted by the importance of control strategies, cognitive apprenticeship is not just concerned with learning skills but also about developing meta-cognitive aptitude (ability to think about thinking). The theory is that this leads to true expertise. Although literature in cognitive apprenticeship does not specifically address novices becoming masters and teaching other novices, it is certainly reasonable that the development of sufficient meta-cognitive aptitude would facilitate the transition.

The development of effective technological scaffolding for chronic disease management could benefit greatly from the principles of cognitive apprenticeship. The scaffolding should support the master clinician in employing the techniques described in coaching novice patients to self-efficacy.

3 Technology-Supported Apprenticeship in the Management of Chronic Disease

Technology-supported apprenticeship is a disruptive model of chronic disease management that synthesizes the core tenets for improvement from Chapter 1 and the research insights from Chapter 2. It was developed as the underlying philosophy for this thesis.

As discussed in Chapter 1, the fundamental problem with the current model of chronic disease management is that it is paternalistic and episodic and that it prioritizes volume of services due to perverse incentives. A disruptive model of care that respects the ideals and goals of patients and clinicians needs to be collaborative and continuous and needs to prioritize value. It should strive to improve the experience, clinical outcomes, and cost of chronic disease management.

The research presented in Chapter 2 provided evidence to aid in the design of such a model of care. The medical studies explored small steps in patient-centeredness including shared decision making, self-management, and coaching and revealed that interventions that combined all of these components were typically the most effective. At the same time, these studies often failed to respect core tenets for improvement in chronic disease management by underestimating the potential of patients and by failing to foster true collaboration in the context of patients' lives. Pedagogical research showed that cognitive apprenticeship can be successfully applied as a model for teaching reading, writing, and arithmetic and that technology can play a key role in helping people to learn new concepts and skills. There is still a great deal to be understood, however, about how to most effectively apply its principles to older adults and in new domains such as health. Computer supported collaborative work research revealed that technology can be a powerful tool for improving collaboration between users and quantifying performance. But designers need to be careful that this technology respects the goals of users and does not create new burdens in their interactions, or it will not yield the desired results.

In technology-supported apprenticeship, patients are the novice apprentices of master clinician coaches. Software provides scaffolding and communication tools to allow the clinician coach to support the patient in the management of disease within the context of daily life rather than in the artificial environment of the clinician's office. These same tools theoretically allow peer apprentices to aide each other in developing self-efficacy. Apprentice patients become master patients who can serve as coaches to novices themselves; thus producing an exponentially growing health ecosystem at minimal cost.

3.1 Apprenticeship Accounts for the Goals of Patients and Clinicians

The apprenticeship model was developed based on an appreciation of the goals and values of both patients and clinicians. In general, patient goals do not focus on achieving specific medical outcomes such as a hemoglobin A1C measure or a blood pressure. Instead, patients value feeling in control of their health and receiving support when they need it. They have busy lives and do not want their health issues to be a burden to them or to their family members. Apprenticeship respects these goals and values by providing exceptional clinical support. At the same time, it appreciates that a true sense of control comes from the development of self-efficacy rather than dependence. Clinicians value feeling that they improve the lives of their patients. They want to feel good about the work that they do and do not want to be over worked or over stressed. At the same time, there is a trend toward being accountable for achieving specific outcomes, so clinicians have the goal of achieving maximum outcomes with minimum cost. Apprenticeship appreciates the fact that clinicians want to feel gratified in their work and focuses on building successful therapeutic alliances. At the same time, developing patient self-efficacy promises to contribute to superior outcomes with greater efficiency.

3.2 Technology-Supported Apprenticeship Embraces to the Core Tenets

3.2.1 Technology-Supported Apprenticeship Strives for Patient Mastery

The first tenet for improvement in chronic disease management is that **patients are the most underutilized resource in healthcare**. Technology-supported apprenticeship harnesses the contribution of the patient and values the development of self-efficacy to the extent that apprentices can become masters. It supports patients in achieving the pinnacle of the hierarchy of patient empowerment.

Most interventions and technology solutions for chronic disease management strive only for patient adherence and sufficient outcomes rather than deeper engagement. The interventions analyzed in Chapter 2 were typically designed to achieve specific outcomes for specific diseases rather than to instill self-efficacy that would lead to these outcomes. The goals of the studies typically represented the values of the researchers, not the patients. Patients were expected to follow restrictive algorithms and, at best, they would receive support from coaches in adhering to these algorithms. The limitation to sufficient outcomes without emphasis on learning actually led to suboptimal outcomes and high rates of complications such as hypoglycemia. The patients likely did not develop knowledge or skill that might translate to other health issues.

The apprenticeship model of chronic disease management strives for mastery, which implies both exceptional outcomes and self-efficacy, through profound engagement. Patients are supported by their coaches in achieving their goals but are encouraged to be more and more independent as they gain self-efficacy. The path from novice to master requires more work up front on the part of both the patient and the coach, but it eventually reaps great rewards as the novice achieves outcomes with more and more independence. The self-efficacy developed theoretically transfers to other health issues and achieves outcomes without further burden to the patient or additional clinician time or effort. Finally, as apprentice patients become masters, their altruistic desire to help others is embraced. While the current healthcare system can only scale its services linearly by training new clinicians, apprenticeship as a model for chronic disease management has the potential to scale exponentially as patients become masters capable of being coaches themselves.

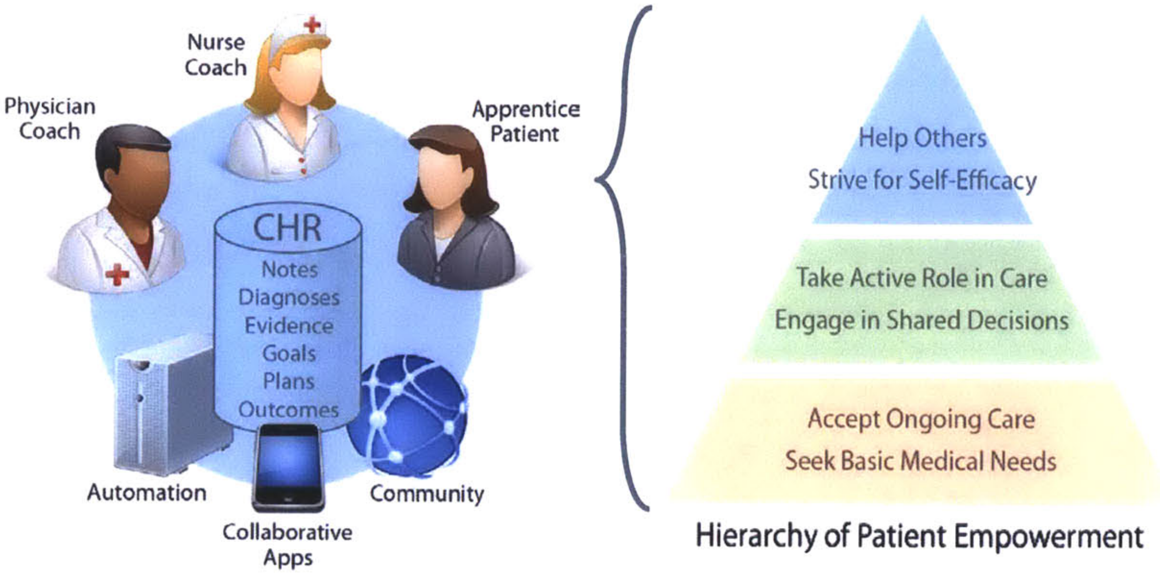


Figure 4: Technology-Supported Apprenticeship and Its Place in a Hierarchy of Patient Empowerment. *The image to the left represents the technology-supported apprenticeship model of care. The patient is elevated to an equal participant in the care team, and his or her potential to become a master in managing chronic disease is fully embraced. The team uses a collaborative health record (CHR) and collaborative applications to work together with maximal effectiveness and efficiency. The patient is supported in reaching the pinnacle in the hierarchy of patient empowerment by supporting the idea that the patient can become a master capable of coaching other patients to self-efficacy.*

3.2.2 Technology-Supported Apprenticeship Embraces Situated Learning

The second core tenet for improvement in chronic disease management is that **health takes place in the everyday lives of patients, not in a doctor's office or hospital.** Technology-supported apprenticeship appreciates that situated learning is the key to mastery of chronic disease management and strives to support patients continuously in the context of their lives.

Apprenticeship is a well developed model of situated learning. It shuns the classroom and its just-in-case model of learning in favor of learning through real world problems. Patients with chronic disease want to receive support immediately when they face obstacles and when they feel overwhelmed, not when an office appointment is available. Addressing these difficulties in such a timely manner presents spectacular opportunities for just-in-time learning. The patient is motivated and the subject matter is personal.

3.2.3 Technology-Supported Apprenticeship is Driven by Collaborative Technology

The third core tenet for improvement in chronic disease management is that **collaboration and information transparency, not just information access, are critical to the solution.** Technology-supported apprenticeship embraces information technology to maximize collaboration among novices and masters and to provide common ground through complete transparency.

Collaborative technology is at the heart of technology-supported apprenticeship. Scaffolding is critical in grounding learning in apprenticeship because it is the set of tools and artifacts that the master uses to guide the apprentice. The scaffolding of chronic disease management revolves around data. It includes patient health data, efficacy data from studies, data from others who have similar problems to the patient, etc. In order to engage meaningfully with patients around this data, it is necessary to visualize it, explore what-if scenarios, and experiment with different actions. These interactions are only feasible with the help of technology. Unlike many other apprenticeship scenarios where the novice and the master coach are typically collocated, patients and clinicians are typically remote. In order to support apprenticeship remotely, powerful communication tools are needed so that the techniques of modeling, articulation, coaching, reflection, and exploration can be leveraged. Patient and clinicians need more than the ability to videoconference, they need to have data-driven discourse leveraging the same decision making tools that they use in person. Again, this requires technology support.

3.3 Technology-Supported Apprenticeship is Extraordinarily Adaptable

Although the technology-supported apprenticeship model for chronic disease management has been presented in a rather structured manner, a key characteristic of this model is that it is actually extremely flexible. It relies on the experience of the master clinician to evaluate and adapt to the needs of each novice patient individually in order to produce the best experience and outcomes possible. The technology scaffolding is not the solution to the problem. It is simply the set of tools that makes it feasible for the humans involved to solve the problem together with maximal efficiency. This philosophy is dramatically different from many other technology-supported solutions to health management, which envision the technology as the solution and that attempt to design all of the customizability and flexibility into the software.

3.4 Walkthrough of the Technology-Supported Apprenticeship Process

3.4.1 Ownership through Shared Decision Making

The technology-supported apprenticeship process in chronic disease management begins with shared decision making that elevates the role of the patient, leverages the power of technology, and that extends outside of the clinicians office. The process includes a physician, a health coach, the patient, and key caregivers (family members and friends) having a discussion about the significance of the chronic disease in question and its associated health risks. The beginning of this discussion usually occurs co-located, but it could be remote. The goals of the clinicians are presented along with the supporting medical evidence. The perspective of the patient is elicited including his values and goals with respect to health management and the specific disease being discussed. With the group, the patient explores possible health actions that will allow him to meet his goals. This may include measurement health actions such as blood glucose or blood pressure readings; intervention health actions (therapies) such as diet, exercise, stress management, medication, etc.; and decision health actions that require adjustments to one or more health actions over time. Technology allows the team to easily weigh the risks and benefits of the possible health actions in order to make an informed decision. The patient is encouraged to create a plan to meet his goals by committing to specific health actions. The plan is only a first-pass that can be reconsidered and adapted over time, since decisions should not be made in the office in isolation of the challenges of real life.

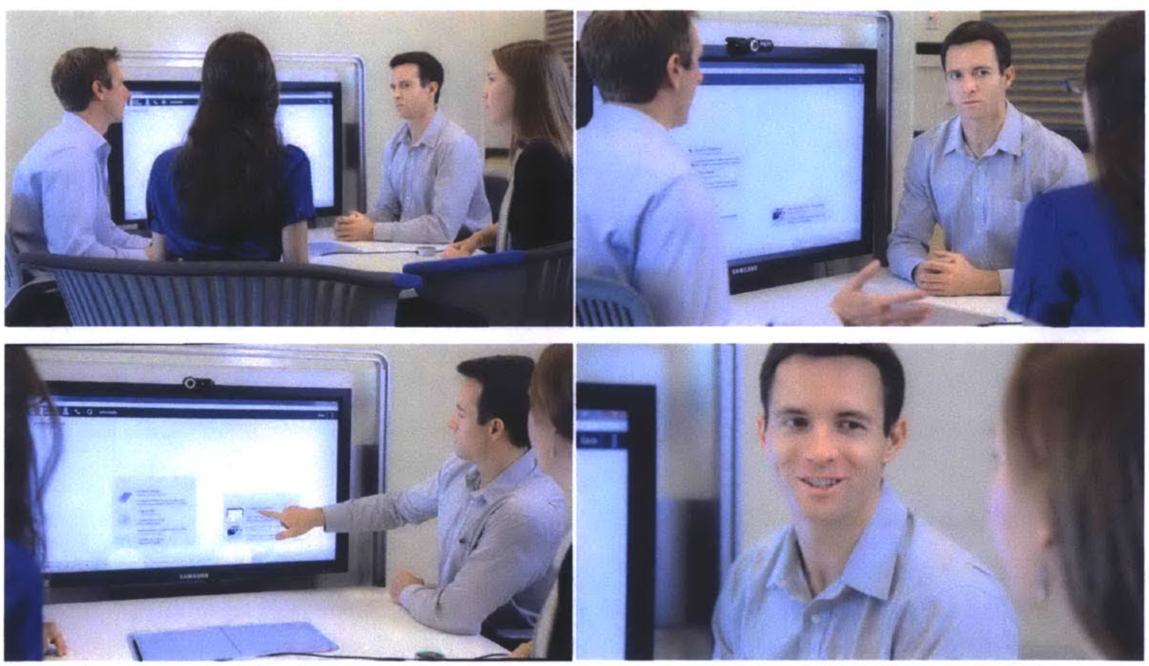


Figure 5: Shared Decision Making in the Technology-Supported Apprenticeship Model. *In this model, patients take the lead in the process but are supported by the physician, health coach, and key caregivers. Collaborative interfaces are used to explore diagnostic and treatment options and to weigh risks and benefits. It is important that the patient can interact directly with the technology, as portrayed in the bottom left image, to take ownership of decisions that are made.*

3.4.2 Awareness through Self-Tracking

The shared decisions that patients make with their team are automatically synchronized to self-tracking applications on their cell phones and tablets that they use on a daily basis. Patients track the interventions that aim to control their conditions, such as medications, and the outputs that help them assess their progress, such as blood sugar readings. They are encouraged to reflect on their progress and to make decisions on a regular basis to optimize their care. These decisions are opportunities for learning that lie at the center of the apprenticeship process. Patient self-tracking results are automatically synchronized to all of the members of the team to support this process.

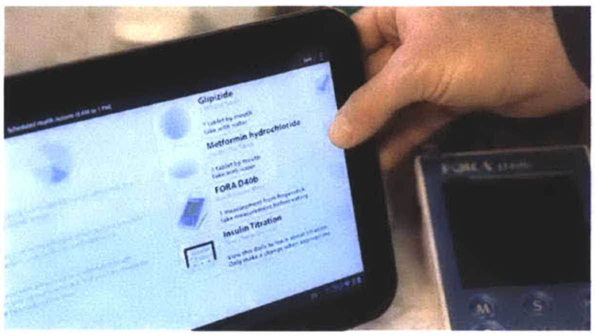
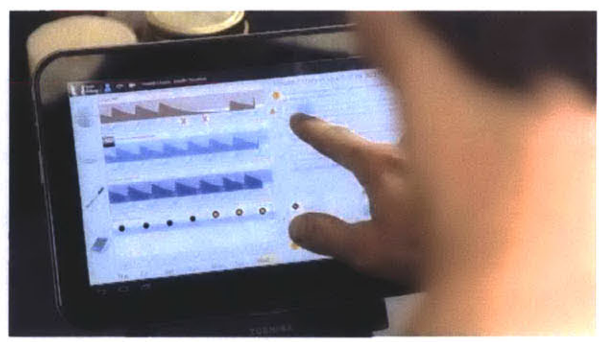


Figure 6: Patient Self-tracking Application. *The shared decisions that are made by the team are automatically synchronized to the patient's devices so that he can track adherence to his health actions.*

3.4.3 Learning through Virtual Visits

In the beginning stages of the apprenticeship process, synchronous communication tools are especially valuable because they allow the novice patient to receive engaged, real-time support from a master clinician. In many cases, it is not expected that the patient will be able to make decisions on his own in the beginning. In a virtual visit, the patient and clinician can co-navigate the same self-tracking and decision support tools that the patient has access to on a daily basis. The master clinician can model her decision making process to the novice patient to expose the types of heuristics and control strategies employed by an expert. Gradually the master clinician encourages the novice patient to articulate his decision making process and to encourage more independence. The master clinician coaches with hints, tools, and nudges to support the novice in success. The master clinician may encourage the novice patient to compare his decisions and choices to peers or to what he thinks the master would do, leveraging the technique of reflection.

Figure 7: Virtual Visit. *The virtual visit begins with a video conference so that novice patient and master clinician can see each other and frame the conversation. The real power of the virtual visit, however, lies in the ability to support data driven discourse through bilateral navigation control and screen pointing. Each user can see the other's actions without requiring additional operations to trade off control.*



3.4.4 Reinforcement through Instant Messaging

As the apprenticeship process evolves and the novice patient develops greater self-efficacy, asynchronous communication tools become more effective because, although they do not allow rich conversation, they allow for more frequent communication distributed over time with less scheduling. The same techniques of modeling, articulation, coaching, and reflection can be employed using asynchronous communication tools, although this is probably most successful when building upon previous synchronous engagement. As the novice patient becomes predominantly independent, exploration of new interventions and new ways to incorporate data into decisions is encouraged.

Figure 8: Asynchronous Video Message. *The novice patient views a recorded message from the master clinician praising him for his progress in managing his diabetes and providing him with a few tips for further improvement. The patient can view the message on his own schedule and can even view it multiple times if it provides sustainable encouragement.*

3.4.5 Social Support and Accountability Throughout

The apprenticeship model for chronic disease management, like that of apprenticeship in general, is concerned with a community of learners, not just a single novice and master. As a result, a novice patient should be able to compare his progress with other novices like him and should be able to provide and receive helpful hints to peers. This is part of the reflection process and may be employed by the master as well. Support from family members and friends is not particularly emphasized in traditional apprenticeship, but it should be addressed in chronic disease management. In this context, caregivers are an important source of logistical and emotional support. Empowering them with the same tools that master clinicians use to support patients and that patients use to support each other may provide additional resources and additional opportunity for success. At the same time, many patients do not want to be treated as such by their family and friends, so a novice patient should be able to easily decide who to engage in his apprenticeship support network. Given that all of the data sharing and communication are technology-enabled, it is easy to turn these streams on or off, but there may be important social implications and relationship consequences of such decisions that need to be appreciated.

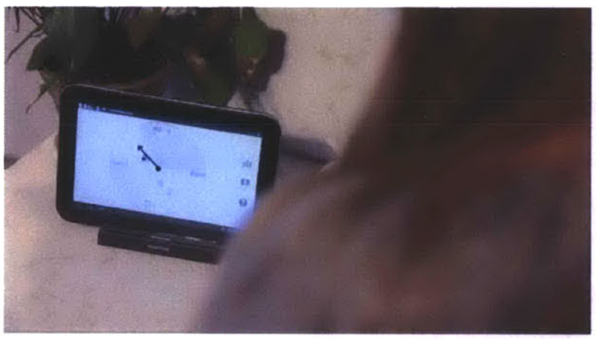


Figure 9: Support From Family Members, Friends, and Peers. *In the top images, the patient's wife sees on an awareness display that the patient has not taken his insulin and wakes him to help him stay on track. In the bottom image, the patient teaches a peer about a new recipe from a diet that has helped him to decrease his blood sugar. They are able to use the virtual visit to discuss the recipe and to explore data together that supports the diet and provides motivation.*

4 CollaboRhythm as a Platform to Support Apprenticeship in Chronic Disease Management

CollaboRhythm is a software platform that was designed to support apprenticeship in the management of chronic disease. The first goal in building the platform was to support rapid prototyping of new applications that allow apprentice patients to track health actions (taking medications, measuring blood sugar, etc.), follow their progress through visualization, and seamlessly collaborate with master clinician coaches. The second goal was to support the deployment of refined prototypes for clinical trials to validate the impact of apprenticeship on the experience, clinical outcomes, and cost of care.

In order to support rapid prototyping, the platform has an architecture that centralizes the core services for tracking of health actions, visualizing progress, creating decision support, and managing communications including virtual visits and instant messaging. Developers can quickly create custom applications by developing plug-ins that leverage these services without needing to modify them.

In order to support deployment for clinical trials, the platform was designed to perform within acceptable limits for up to 100 subjects for at least 3 months. It uses industry standard encryption to ensure patient privacy and has built-in support for remote updates to patch software bugs that arise.

The platform was steadily improved over the course of 6 years of research in the New Media Medicine group at the MIT Media Lab including many prototype projects, 2 clinical pilots, and 2 randomized, controlled clinical studies (discussed in detail in the following chapter). In 2009, it won the CIMIT Prize for Primary Healthcare, a national competition for technological innovations with great potential to support the improved delivery of care at the frontlines of medicine. In addition to our own research, every January from 2010 to 2013, a Health and Wellness Innovation event was held for two weeks at the MIT Media Lab. Engineers, clinicians, and business students from around the world worked together on teams to build applications for patient empowerment. The majority of these teams leveraged CollaboRhythm in their projects, and their needs helped to drive the further development of the platform.

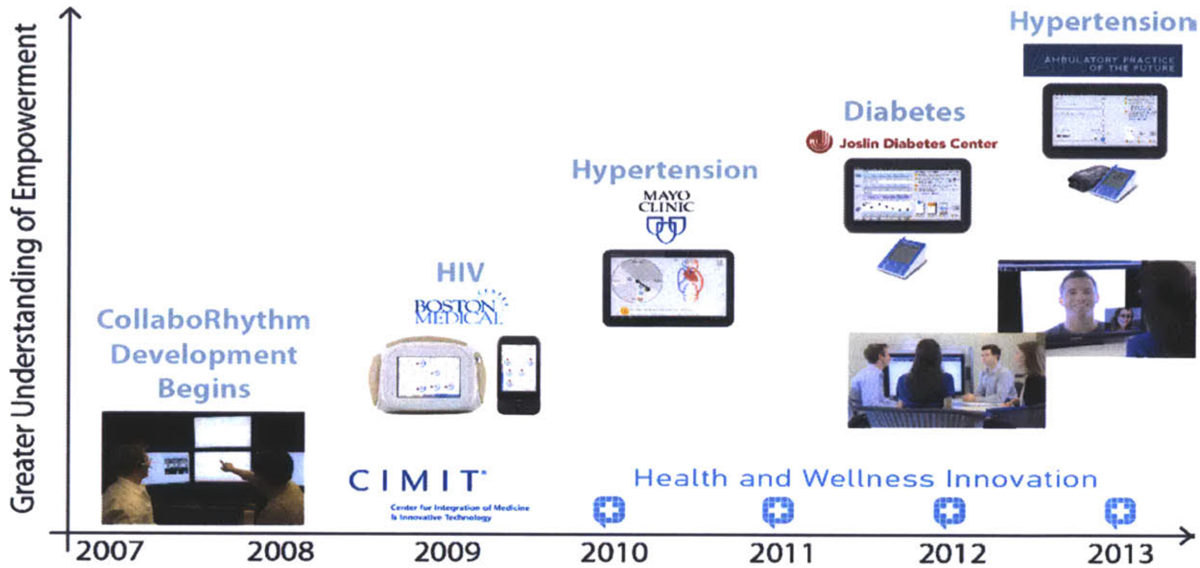


Figure 10: Timeline of CollaboRhythm Development. *Development of the platform began in the fall of 2007. With each clinical study and each Health and Wellness Innovation event, the principles behind technology-supported apprenticeship evolved and the platform progressed.*

4.1 CollaboRhythm Architecture Overview

CollaboRhythm is built as a client/server architecture. The core components, illustrated in Figure 11, are the following:

1. A client application for cell phones, tablets, and computers is configurable for patients and for care team members including clinicians, family members, and friends. The client application allows clinicians to add and schedule health actions in collaboration with patients. Patients self-track adherence to scheduled health actions (medications, measurements, decisions, etc.) using interfaces specifically designed to promote proactive decision making and self-reflection. Bluetooth devices, such as a blood glucose meter and blood pressure meter, are integrated to decrease the burden of tracking health actions. Data is synthesized into compelling visualizations and decision support tools to scaffold the apprenticeship process. Both patients and members of the care team track progress toward goals, manage care using workflows, and communicate through synchronous virtual visits and asynchronous messages.

   The client application is implemented as an Adobe Integrated Runtime (AIR) application using the Flex SDK. Adobe AIR is a cross-platform run-time system for building rich internet applications (RIA) that can be run on desktop or mobile devices. The Flex SDK is a framework for developing applications using Adobe's ActionScript programming language and can also be used to develop Flash applications that run in web browsers.

2. A collaborative health record server securely stores patient data so that it can be synchronized across client applications. Access to patient data can be granted to care team members including clinicians, family members, and friends.

   The collaborative health record server is implemented as a customized version of the Indivo X open-source personally-controlled health record. The customization predominantly includes custom xml schemas for the representation of the scheduled health actions for patients and the results of these health actions. Client applications communicate with the collaborative health record server using an XML-based REST API via SSL for encryption.

3. A set of collaboration services enable video conferencing, remote collaboration, instant messaging, and data synchronization across client applications.

   The collaboration services are implemented as a custom application on an instance of Adobe Media Server. Client applications communicate with the Adobe Media Server and with each other using the Real Time Media Flow Protocol (RTMFP), which is a proprietary protocol developed by Adobe Systems for encrypted multimedia communications through both client-server and peer-to-peer models. The remote collaboration function of the client application is achieved using remote procedure calls through the collaboration services code.

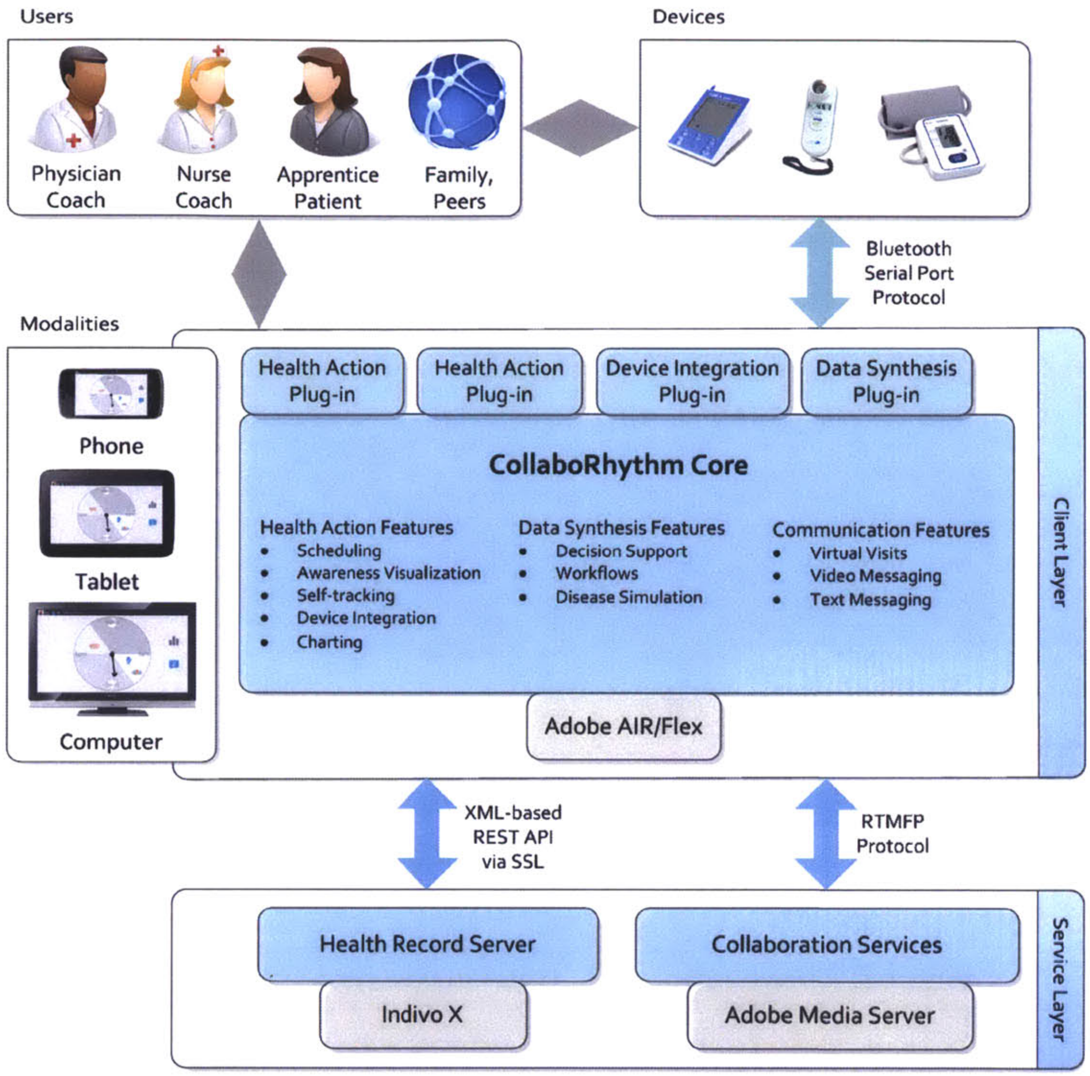


Figure 11: CollaboRhythm Architecture. *The CollaboRhythm platform consists of a client layer and a service layer. The same client application runs across phones, tablets, and computers and across users including patients, caregivers, health coaches, and physicians. It is configurable for different users and different features using a runtime-loaded settings file. The client application has a core set of features for tracking health actions, for synthesizing data to scaffold the apprenticeship process, and for supporting powerful communication. It also supports plug-ins that add new health actions, device integration, and data synthesis features. The service layer includes two components: 1) a health record server built using Indivo X that securely stores patient data so that it can be synchronized across clients 2) a set of collaboration services built on top of Adobe Media Server that enable video conferencing, remote collaboration, instant messaging, and data synchronization across clients.*

4.2 Client Application

4.2.1 Health Action Features

A fundamental function of the CollaboRhythm client application is to allow patients to self-track adherence to scheduled health actions. Core health actions include measurement health actions such as blood glucose or blood pressure readings that allow outcomes to be tracked and intervention health actions such as diet, exercise, stress management, medication, etc that allow outcomes to be optimized. The application supports the development of plug-ins, run-time loaded modules of code, which allow the customization of how health actions appear throughout the application and how patients interact with them.

The application provides a tool for scheduling health actions and for adding new health actions to the schedule. It encourages the organization of health actions into groups to minimize burden to patients. As discussed, evidence shows that reactive alarm-based systems for medication adherence are ineffective. They typically expect medication adherence at very specific times and set the patient up for failure. CollaboRhythm discourages scheduling at specific times and allows flexible adherence windows to be easily personalized. The flexible adherence windows maximize patient success and promote proactive decisions while still ensuring that health actions are performed with enough reliability that efficacy of therapies and interpretability of measurements are optimized.

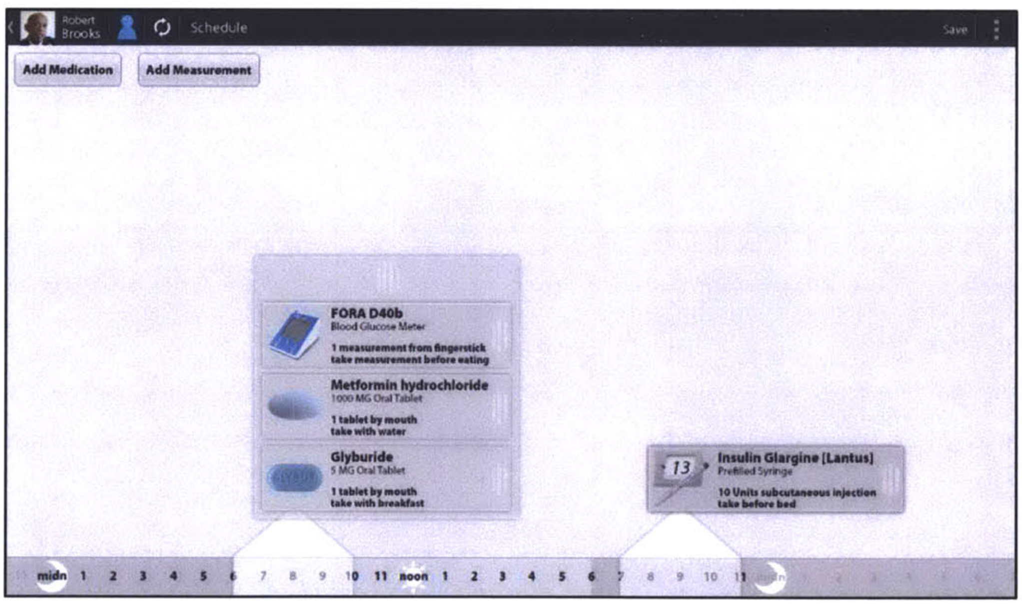


Figure 12: Schedule View. *A card is presented for each scheduled health action. In this case, Robert Brooks (a fictitious patient) has diabetes and is starting to take insulin. He has three health actions scheduled between 6am and 10am (two medications and a blood glucose measurement) and one health action scheduled between 7pm an 11pm (one medication, an injection of 13 Units of insulin). Single health actions or groups of health actions can be rescheduled by simply grabbing and dragging them across the timeline. Pinching an adherence window (white spotlight that spans a period of time on the timeline) allows it to be resized. The buttons on the top allow for the addition of new health actions. The ability to add new health actions (through buttons at the top) is supported through plug-ins.*

The home screen of the CollaboRhythm application, depicted below, shows a 24 hour clock with all of the patient's scheduled health actions visualized. The clock is designed to promote proactive decision making and to provide maximum information at a glance.

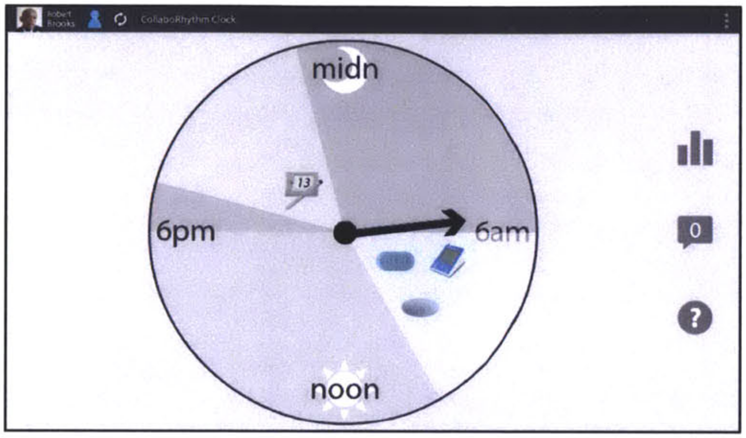


Figure 13: CollaboRhythm Clock View. *The 24 hour clock shows all of the patient's scheduled health actions. In this case, Robert Brooks has three health actions scheduled between 6am and 10am (two pills and a blood glucose measurement) and one health action scheduled between 7pm an 11pm (an injection of 16 Units of insulin). The exact spans of the adherence windows are purposefully more obscure than in the scheduling timeline in order to reinforce the notion that exact timing of adherence is not important. Patients can see and report their health actions even before they are due, which allows for proactive planning in their busy lives. The three buttons along the right side of the view are shortcuts to charts, messaging, and frequently asked questions.*

Clicking on a group of health actions on the clock takes the patient to a view that provides more detail for these scheduled health actions. For health actions that do not require additional information, such as medication adherence, clicking the check box reports adherence in one step. Optionally, clicking anywhere outside of the check box will bring up a detailed reporting view where extra information can be entered or default values can be changed.

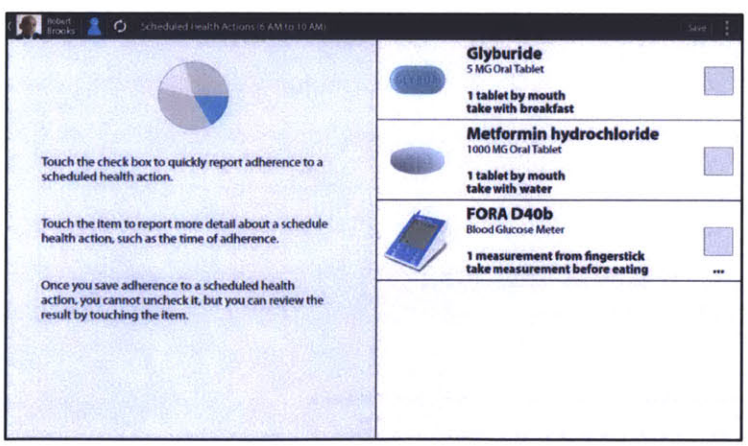


Figure 14: Scheduled Health Actions Detail View. *More detailed instructions are provided for each of Robert Brooks' health actions in the adherence window that was selected. Adherence to these health actions can be reported.*

For those health actions that require additional information, clicking the check box will always present a reporting view for input of the necessary information.

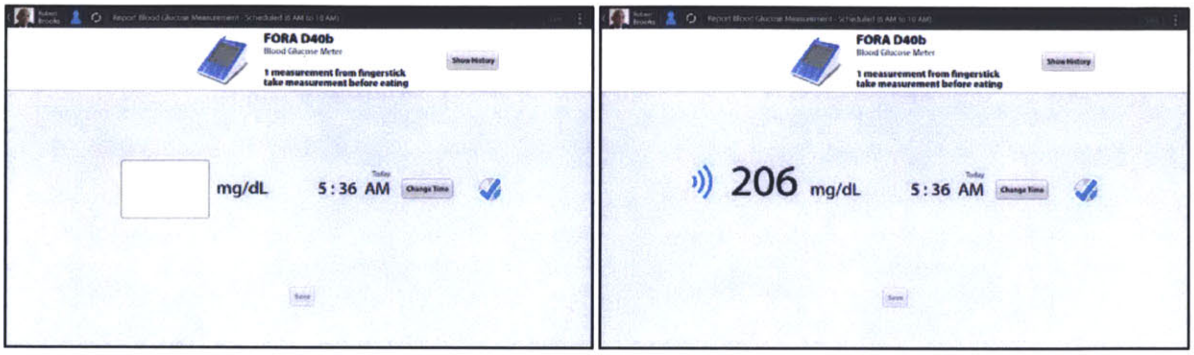


*Figure 15: **Reporting View for Blood Glucose Measurement.** Clicking on the check box for the FORA D40b blood glucose meter opens a reporting view for blood glucose values from the device as shown in the image on the left. CollaboRhythm supports communication with devices via Bluetooth serial port protocol (support for new devices can be added through plug-ins). When the patient takes a measurement from a paired device, such as this blood glucose meter, the appropriate reporting view is automatically shown, no matter where the patient is in the navigational structure of the application. The measurement is automatically entered into the reporting view, as show in the image on the right.*

Often additional action is required of the patient depending on the result of a health action. Through plug-ins, it is possible to implement any desired logic and to create any number of subsequent views from the reporting of adherence to a health action.

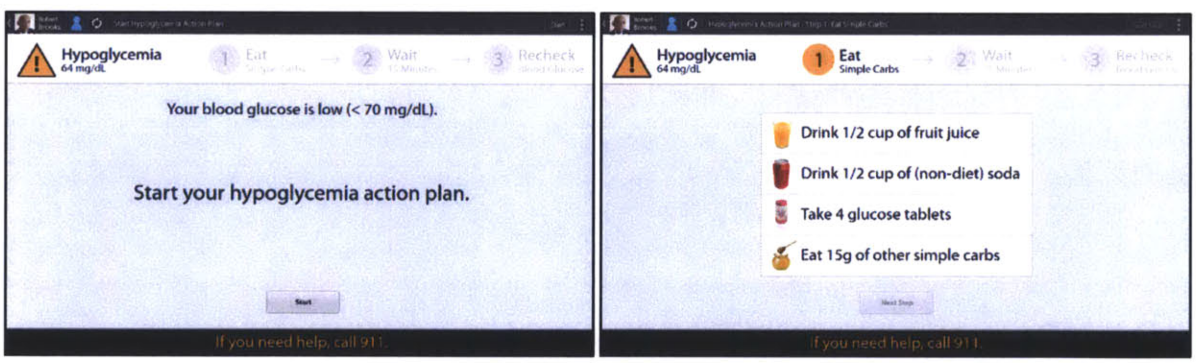


*Figure 16: **Hypoglycemia Action Plan Views.** As an example of views that are generated based on the result of a health action, this multi-step hypoglycemia action plan is initiated whenever a patient's blood glucose is less than 70 mg/dL.*

Once adherence has been reported to health actions, the results are viewable at a glance in the clock view.

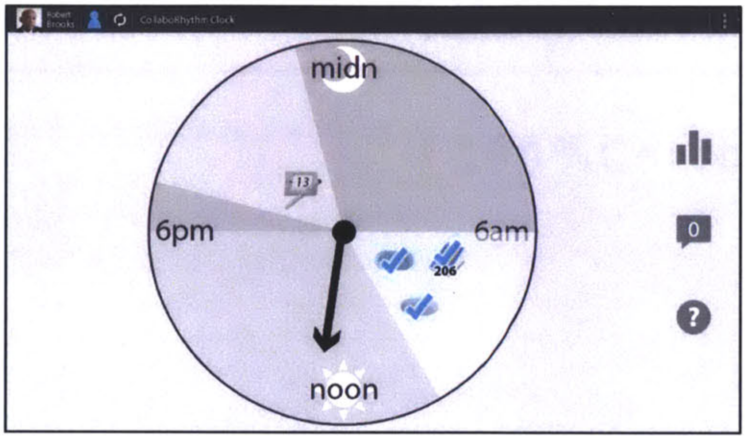


Figure 17: CollaboRhythm Clock View with Adherence Results. *A check is placed over each health action for which adherence has been reported. The result is shown for measurement health actions, such as the blood glucose of 206. The clock is not just a reminder to adhere to health actions, but it also provides this feedback to prevent accidental repeat dosing of medications and to remind patients of the values of their measurements for the day.*

Charts are accessible from the clock view by clicking on the top button on the right side of the view. The charts present the results of health actions in time series form so that the correlations between therapeutic health actions and measurement health actions can be visualized. The goal is to support self-reflection and to serve as scaffolding for decision making in the apprenticeship process. The chart for each health action is customizable through plug-ins.

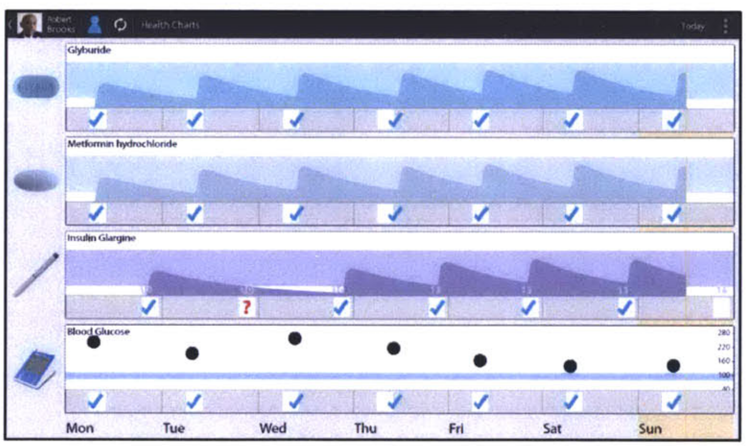


Figure 18: Health Charts View. *A chart is shown for each therapeutic and measurement health action. The strip at the bottom of each chart shows white boxes delineating the adherence windows for each scheduled occurrence of the health action. A check is shown at the time of each actual report of adherence. A question mark is plotted if adherence was not reported. The plot for the medication health actions shows an estimate of the blood (specifically plasma) concentration of the medication over time. This is only an estimate based on the patient's weight and the pharmacokinetics of the medication from studies, but the estimate provides significant value. The patient can easily see if the concentration falls in the goal range, which encourages regular dosing. If a medication is missed, the period of inefficacy is evident. If a medication is taken too frequently, the concentration will go above the goal, indicating an increased risk of dose-dependent side-effects. The plot for the blood glucose measurement health action shows the value of each measurement compared to the goal range shown in blue.*

4.2.2 Data Synthesis Features

4.2.2.1 Decision Support and Workflows

The tracking of therapeutic and measurement health actions is necessary to provide data to support the apprenticeship model of chronic disease management, but it is not sufficient to engage patients in true collaboration and to support the path to mastery. Tracking without a commensurate value proposition is burdensome and can become a mindless chore. Decision health actions are a critical concept in CollaboRhythm. They present the key data from health action tracking together with decision support tools to engage patients in small adjustments in their regimens on a regular basis. This helps patients to see for themselves the value of the data and to develop a sense of control over the disease. Clinician coaches help to guide patients through these decisions using the techniques of modeling, articulation, coaching, and reflection and gradually fade support as patients demonstrate that they are able to make the decisions independently. Decision health actions rely on the health action infrastructure of CollaboRhythm described in the previous section, but they also rely on the data synthesis functionality of the platform to create and visualize decision support.

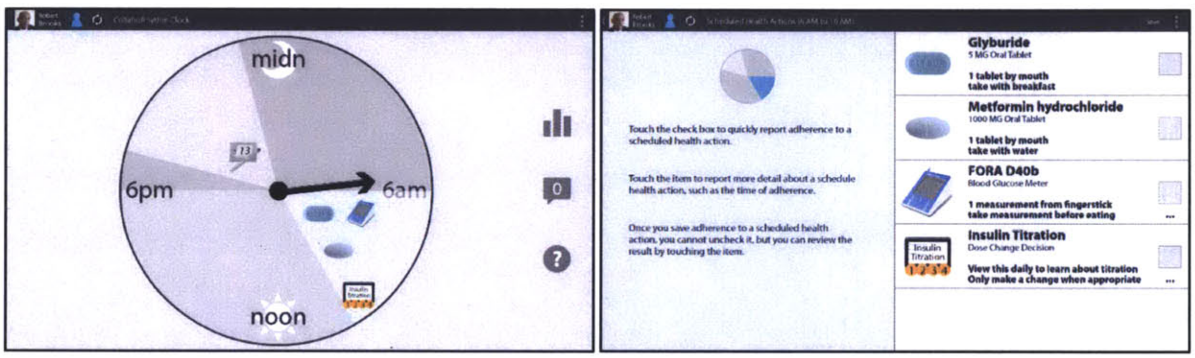


Figure 19: Clock View and Scheduled Health Actions Detail View with Decision Health Action. *This example shows the health actions for Michael Brooks with the addition of a decision health action. He is encouraged not only to track his therapeutic and measurement health actions each day but also to reflect on his progress and to consider a change in his insulin dose.*

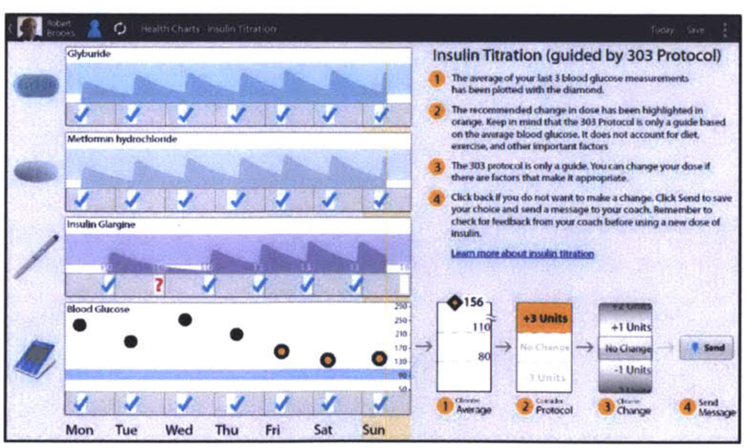


Figure 20: Insulin Titration Decision Health Action. *On the left side of the view, the charts of Robert Brooks' health actions are displayed. On the right side of the view, personalized decision support information is visualized. In this*

case, the his average blood glucose for the past three days is plotted (the three blood glucose values used are highlighted in the chart with orange dots) and the recommended change in insulin dose based on the 303 Protocol (a protocol for insulin adjustment that recommends +3 Units if the average blood glucose is > 110 mg/dL, no change if it is <= 110 and >= 80, and -3 Units if it is < 80) is highlighted. The patient can choose the desired change in insulin dose based on this decision support and send communication to the master clinician. Note that the language of the decision support appreciates the likelihood that a master considers much more information in making an informed decision than can be accounted for in such a simple algorithm.

Decision health actions also support workflows to maximize efficiency in asynchronous collaboration between novice patients and master clinicians. Instead of sending free text messages that require translation into action, workflows integrate with the clock visualization to provide glanceable feedback and allow for quick action-oriented responses.

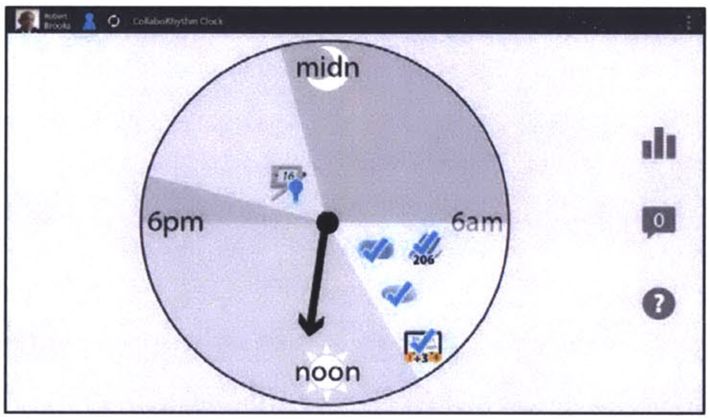


Figure 21: Layering of Insulin Titration Decision Health Action on Clock View. *If Robert Brooks decides to increase his insulin dose by 3 Units (in agreement with the 303 Protocol), the change is displayed over the insulin titration decision health action, the dose for the insulin health action is updated, and a glyph is displayed on the insulin health action to draw attention to the fact that the patient proposed a new dose. Patient glyphs are cyan and clinician glyphs are purple and have a cross on them. The light bulb glyph symbolizes a new proposal, while a thumb up glyph symbolizes agreement with a proposal.*

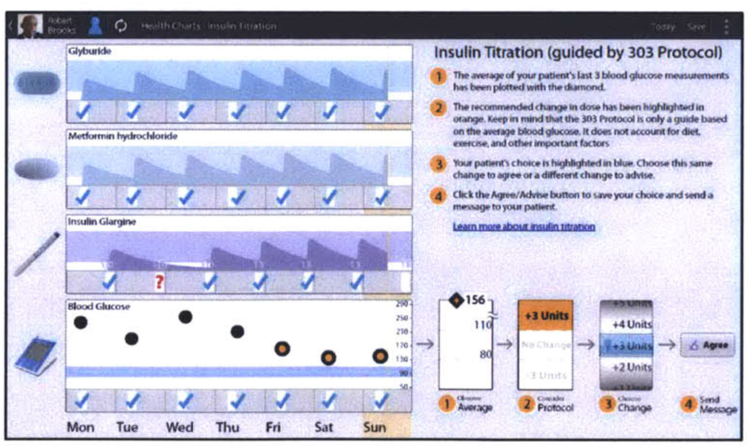


Figure 22: Master Clinician View of Insulin Titration Decision Health Action after Patient Proposal. *When the master clinician reviews Robert Brooks' insulin titration decision health action, Robert's proposed increase of 3 Units is highlighted in Step 3. The master clinician can agree with this proposal with a single click or can propose a different change if indicated.*

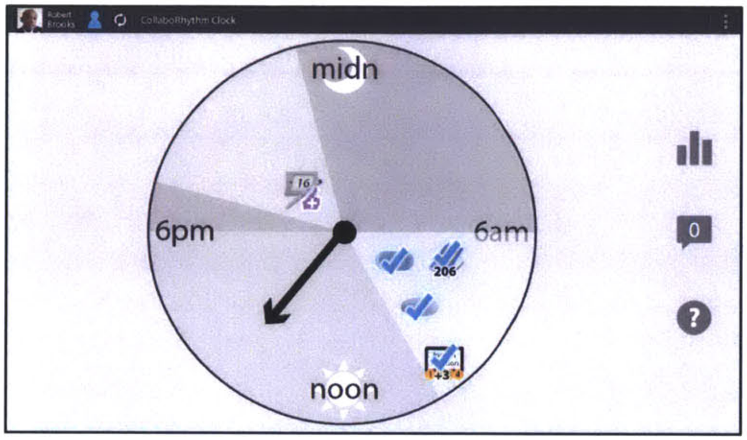


Figure 23: Clock View after Master Clinician Agreement with Proposed Insulin Dose Change. *If the clinician agrees with Robert Brooks' proposed change in insulin dose, Robert will see an updated glyph on his clock view. The purple thumb up with a cross symbolizes agreement from a master clinician.*

4.2.2.2 Disease Simulation

Much of the issue with poor control of chronic disease stems from the fact that patients typically do not experience symptoms until the disease results in secondary complications, often decades after the diagnosis of the disease. Since patients cannot see, feel, hear, or otherwise perceive the disease, it is understandable that taking action to prevent future damage is not prioritized in their otherwise busy and complicated lives. The tracking of measurement health actions such as blood glucose for diabetes and blood pressure for hypertension helps to reveal some of the hidden aspects of these diseases. Settings goals and making regular decisions to optimize therapy also helps to raise awareness, and the support of a master clinician instills a sense of social accountability and appreciation for the import of disease control. But the problem still exists that it is difficult for patients to appreciate the continual threat presented by chronic disease and to maintain motivation to perform health actions that they can only loosely link to controlling disease in their minds.

Personalized, real-time, disease-state simulations are a means to bridge the gap between health actions and disease education – between actions and consequences. They are constantly updated based on estimates of what is happening in the patient's body and the health actions performed by the patient. In this way, these simulations are a situated learning approach to health education. They serve as a powerful form of scaffolding for the apprenticeship model because they serve as artifacts that ground conversation between the novice patient and the master clinician. They also elevate the contribution of the patient in the patient-clinician dialogue because they present the opportunity for the patient, who sees them every day, to know more about the specifics of their disease than the clinician, who only sees them occasionally.

Although all of the features thus far have been illustrated for a patient with diabetes, it is helpful to explore simulations for a number of diseases to appreciate their value. Figure 24 illustrates a simulation for HIV, Figures 25 and 26 hypertension, and Figure 27 diabetes.

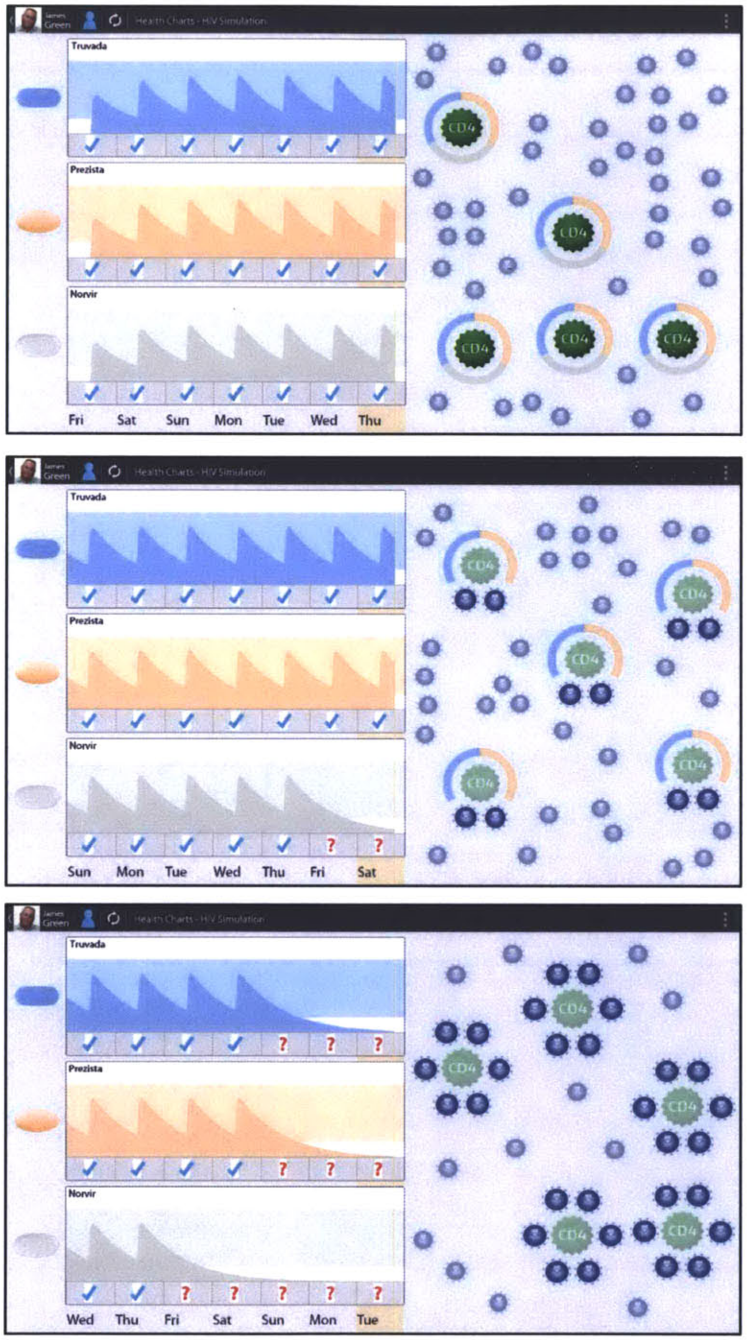


Figure 24: HIV Simulation. *HIV is a disease that is typically considered quite terrifying. The clinical scenario today is simple. If a patient does not take medication, he will typically die. If the patient does take medication, he can live a full and healthy life. Despite this seemingly compelling motivation, many patients with HIV still have poor medication adherence. Some of the factors that contribute to non-adherence include lack of understanding of the disease, lack of faith that the medication is working, and lack of social support.*

This HIV simulation aims to make the invisible virus accessible to patients and to give them a sense of control over it. It also becomes scaffolding for engaging in conversations with clinicians and receiving social support.

The number of CD4 T-cells (immune cells destroyed by HIV) in the simulation is proportional to the patient's most recent CD4 T-cell lab test. The number of viral particles is proportional to the most recent HIV viral load lab test. For each medication that is at goal concentration, a piece of a protective barrier around the T-cells is created. When the patient's adherence is optimal, as in the top image, the virus is a threat but it cannot attack the T-cells. The T-cells move around freely and impart a sense of wellness. When the patient misses a medication, as in the middle image, that part of the barrier starts to degrade, and the virus is able to attack the T-cells. When no medications are taken, as in the bottom image, then the virus is able to overwhelm the T-cells. The T-cells do not move and impart a sense of illness. The patient can improve the picture immediately by resuming adherence. Although it takes months for the number of T-cells and viral particles to change, the patient can see the medication barrier restored in hours. This short-term connection between health action adherence and improvement in disease-state simulation is critical in engaging patients effectively.

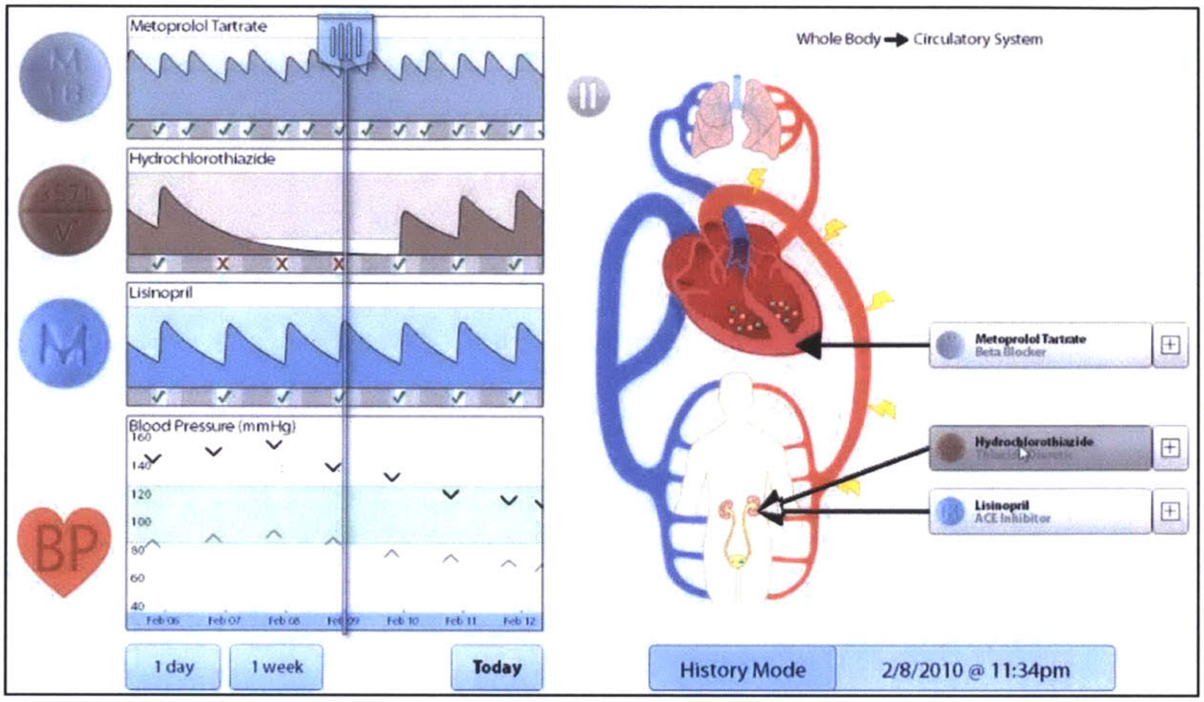


Figure 25: Hypertension Simulation. *Hypertension is a disease that causes damage over decades, leading to strokes, heart attacks, kidney disease, etc. Medications can control blood pressure and minimize the risk of these complications. At the same time, medications are burdensome to take given that the threat is so distant and vague. Many of them also have dose dependent side-effects that are related to their mechanisms of action. Not properly managing patient expectations about hypertension, the medications, and potential side-effects often leads to patients discontinuing treatment within a year.*

This hypertension simulation aims to make the invisible threat of hypertension tangible and actionable. It also aims to educate patients about how their medications work so that expectations can be managed and conversations about the trade-offs associated with medications can be effective.

An animation of the circulatory system highlights that damage is being done when hypertension medication adherence is not optimal. It is possible to click on each medication to see how it works and how it contributes to the overall simulation of the circulatory system. It is also possible to move the marker at the top of the charts to explore what the simulations look like at different times. This helps to make the link between personal data and the educational simulations more interactive and understandable.

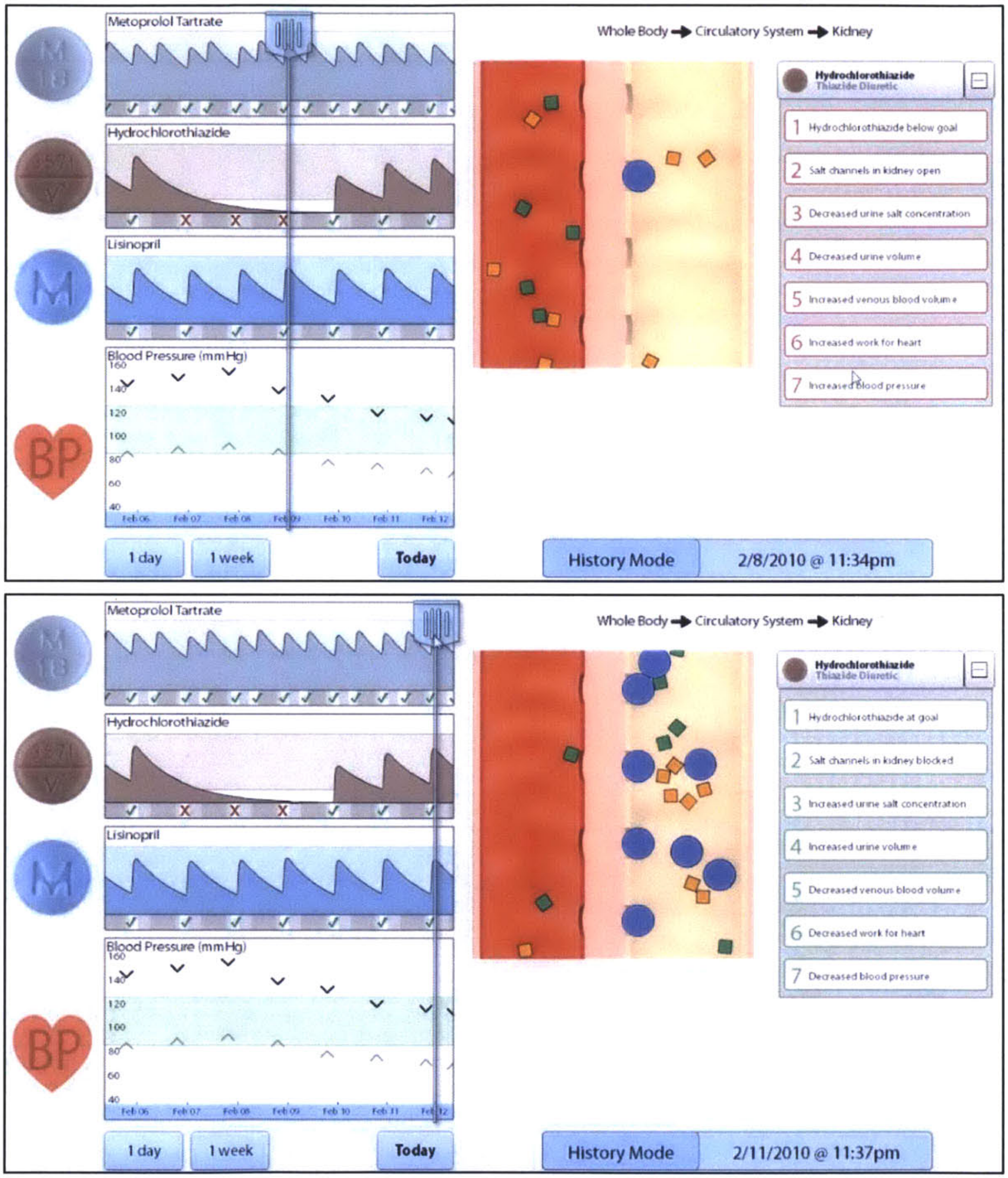


Figure 26: Hypertension Simulation for Hydrochlorothiazide. *Upon clicking on hydrochlorothiazide in Figure 25, a simulation of the mechanism of action of this drug is displayed. The medication blocks salt channels in the kidney, increases excretion of salt, increases urination, and decreases blood pressure. In the top image, the chart marker is located during a time when the patient was non-adherent to hydrochlorothiazide. The medication is not blocking the channels and salt is retained in the blood. In the bottom image, the marker is located during a period of adherence. The medication is blocking the channels and salt is wasted in the urine. In addition to motivating adherence, this simulation could be powerful in discussing the benefits of decreasing salt in diet. If less salt is in the blood, the blood pressure goes down and obviates the need to take hydrochlorothiazide.*

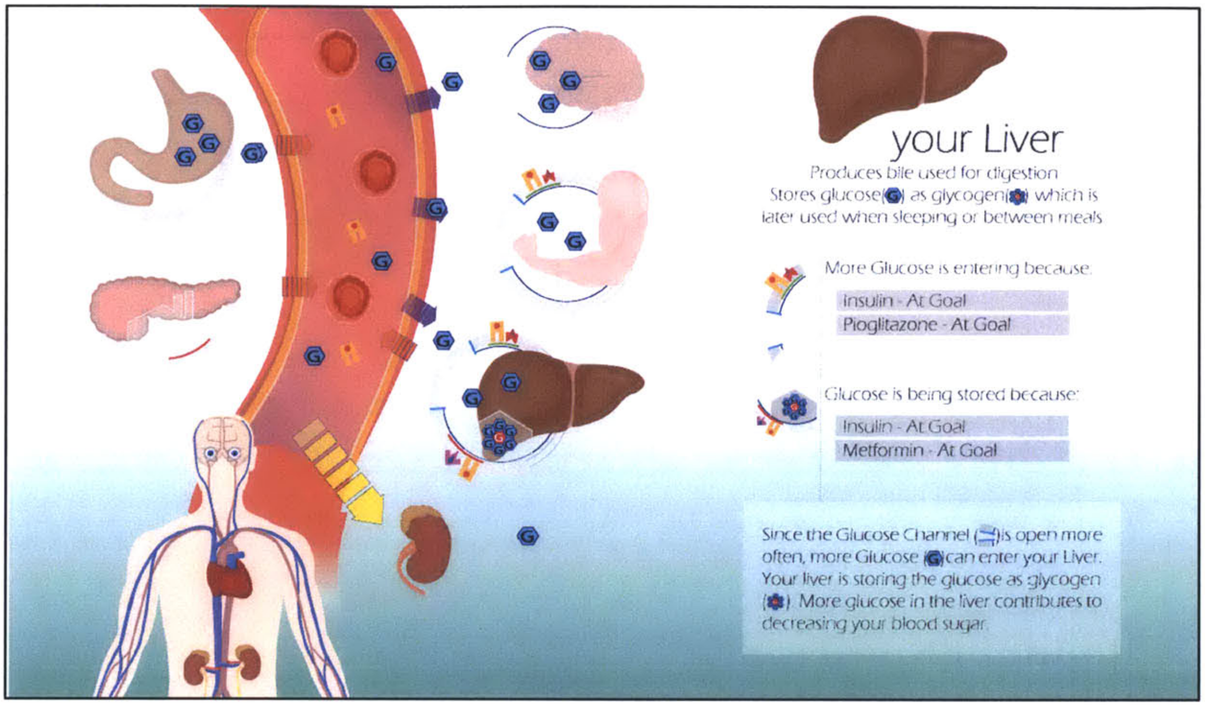


Figure 27: Diabetes Simulation. *Diabetes is very similar to hypertension in that it causes damage over decades and leads to strokes, heart attacks, kidney disease, etc. The balance of glucose in the body and the derangement of this process in diabetes is quite complicated; however, and is important for patients to understand at a reasonable level to properly manage the disease and promote healthy behavior change. This simulation (not yet implemented) demonstrates blood glucose balance in the body. It is a simplified interactive illustration of the role of each of the key organs involved in glucose balance and diabetes. The user can click on each of the organs to learn more. The state of each of the organs is affected by the presence or absence of medications and whether or not the patient is diabetic. The simulation can be put into a mode where all of the variables are driven by the patient's actual health actions or in a mode where the patient or clinician can explore "What if?" scenarios with the variables for coaching purposes.*

4.2.3 Communication Tools

Powerful communication tools are a vital part of the CollaboRhythm application. The point of tracking health actions and synthesizing the data with decision support tools and disease simulations is that they provide the grounding for reflective discussion through the apprenticeship model.

In clinician mode, the application provides a list of patients, whether or not they are currently online, and the number of unread messages from each.

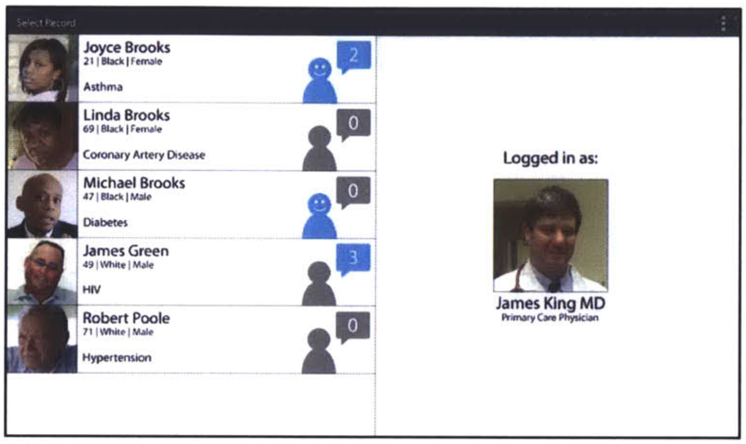


Figure 28: Select Record View for Clinician. *The grey figure means that the patient is not online while the cyan figure with the smile means that the patient is online. If there are unread messages from a patient, the message bubble is cyan and the number of unread messages is displayed.*

4.2.3.1 Virtual Visits

When the record is opened for an online patient, the clinician can initiate a virtual visit with the patient with a single click. The patient's tablet rings and an incoming call notification appears.

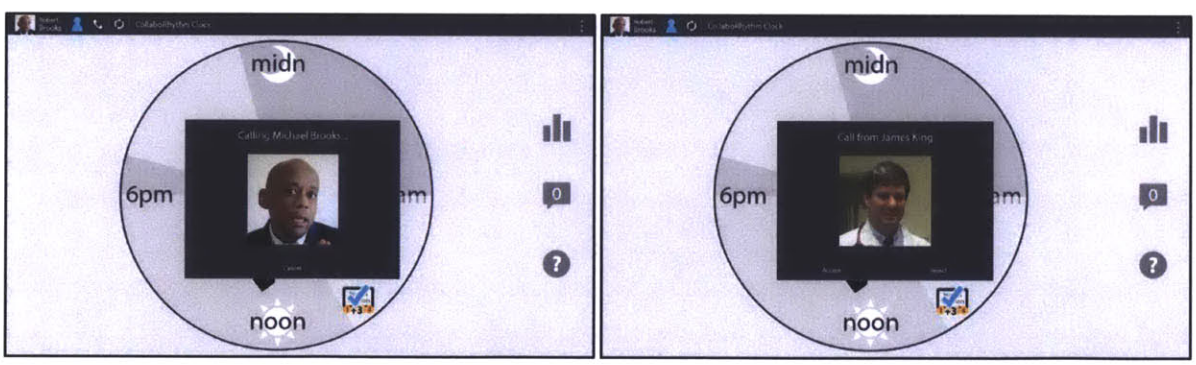


Figure 29: Initiation of Virtual Visit. *In the left image, the clinician clicks the call button that looks like a telephone, and the virtual visit is initiated. The patient's tablet rings and the virtual visit can be easily accepted or rejected.*

Once the patient accepts the incoming call, the app automatically opens a video conferencing view.

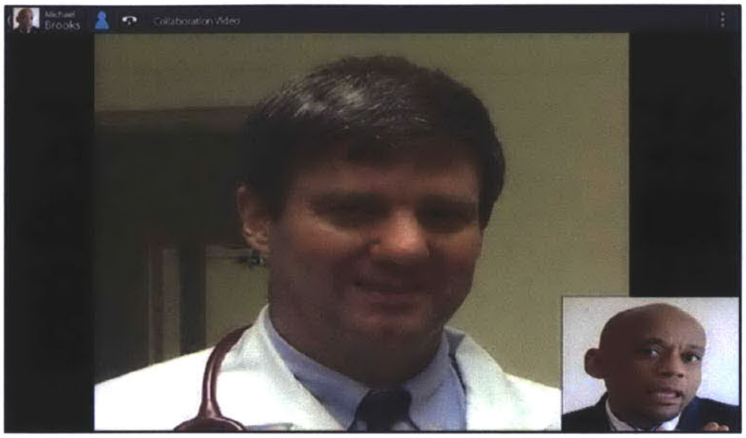


Figure 30: Collaboration Video View. *The virtual visit begins with a video conference so that the novice patient and master clinician can see each other and frame the conversation. The video view is not always visible, as in some other applications, because it can be a distraction on a small screen when the users are trying to discuss data.*

The most innovative and power feature of the virtual visit is that the clinician and the patient can co-navigate the application and can point to artifacts on the screen simultaneously. The application control is bilateral, affording each user with equal power in the collaboration, as opposed to traditional screencasting that puts one user in control. Since the collaboration is implemented using remote procedure calls rather than screencasting, it also uses less bandwidth and is often more responsive. The voice channel is open throughout the whole virtual visit, but the video is hidden until one of the users navigates back to it.

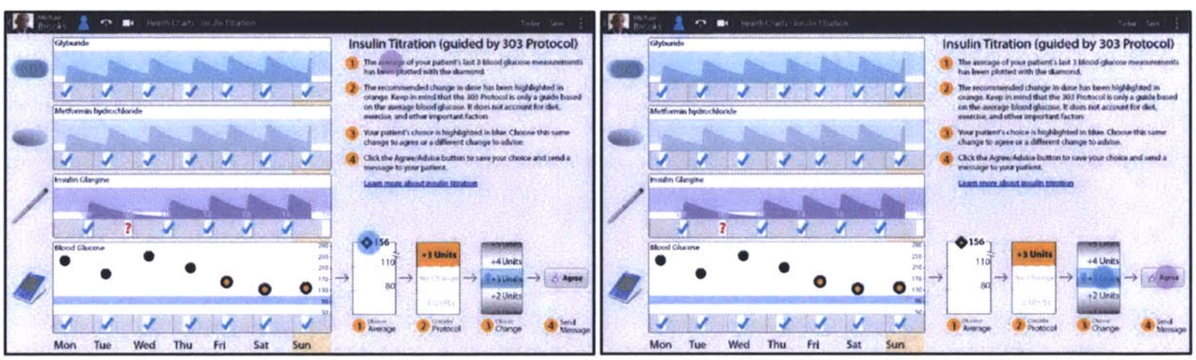


Figure 31: Bilateral Screen Pointing During a Virtual Visit. *The novice patient and the master clinician can point to information on the screen while in a virtual visit, and the other party will see a corresponding cursor in real time. The patient's cursor is cyan and the clinician's cursor is purple. The ability to refer to actual data, to point out decision support text, and to manipulate controls on the screen allows for powerful data-driven discourse and optimizes the opportunity for effective collaboration and learning. Not only can the patient and the clinician interact collaboratively on a given screen, but they can also navigate anywhere in the application collaboratively as well.*

4.2.3.2 Text and Video Messaging

Although the virtual visit features of the application are extremely powerful for collaboratively exploring data and making synchronous decisions, the major disadvantage is that virtual visits require scheduling.

This can be inconvenient when schedules do not align, and it is much more costly for the master clinician in terms of time.

Asynchronous communication tools lack some of the affordances of synchronous tools, but they allow much more frequent communication to be more evenly distributed over time. They allow the novice patients to get support that is more closely tied to the continuous way in which they experience chronic disease. When paired with asynchronously conducted workflows, they can produce outstanding efficiency and convenience while still allowing for flexibility and deeper learning.

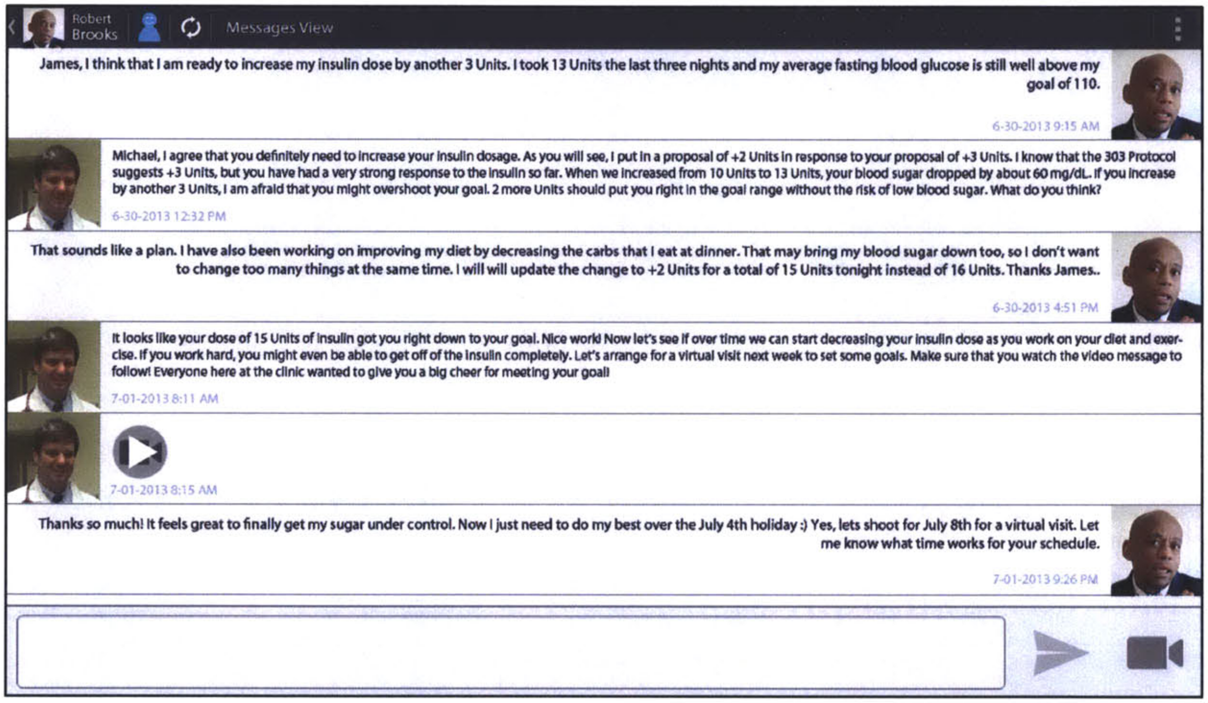


Figure 32: Messages View. *This example conversation thread highlights how the novice patient and master clinician might make shared decisions about insulin titration asynchronously and paired with the insulin titration workflow discussed earlier. The messages allow for deeper conversation and learning and present the opportunity for critical positive feedback as illustrated by the fact that the whole team sent a video message to the patient praising him for meeting his goal.*

4.3 Health Record Server

The health record server that supports the client application and allows for synchronization of data between separate client applications is a customized version of the open-source Indivo X personally controlled health record. [79] [97] [98] The core concept of Indivo X is that it provides online records for patients that they own and to which they control the access. They can grant access to their data at different levels of granularity and to different people. Indivo X consists of a back-end data store and a minimal front-end web application that allows patients to view some of their data and to share their entire record with others. The back-end has a powerful application programming interface (API), that allows third-party applications to be built on top of it. CollaboRhythm leverages only the back-end of Indivo X and its API.

The Indivo X data store is built on the concepts of accounts, records, documents, relationships, and facts. Each patient has an account including a username and password that identifies them in the system. Each patient also has a personal record, which is the collection of all of his or her health data. Health data is pushed and pulled from the record in the form of documents, which are xml documents adhering to specific schemas relevant to health data and containing a number of facts. An example of a document is a medication. It contains a number of facts including the name of the medication, the dose of the medication, and the form of the medication (tablet, capsule, suspension, etc.). Documents can be related to each other to represent meaningful connections. For example, a medication could be related to a health problem to represent that it is taken for that particular problem. Application developers that leverage Indivo X do not need to know much about the implementation of the back-end, only what type of documents they want to contribute and what they want to retrieve.

Indivo X stores facts in a Postgres database and provides a middle layer that allows facts to be added to and retrieved from the database as documents using a representational state transfer (REST) API. This middle layer also implements an access control system that only allows specific account owners to retrieve specific documents. The system has a pluggable data pipeline that allows new document types to be supported by simply providing the corresponding xml schema and a corresponding transform that represents how the composing facts should be moved in and out of the database.

CollaboRhythm leverages the pluggable data pipeline of Indivo X and relies on custom document types including health action plans, health action schedules, and health action results. Health action plans represent specific health actions that are to be performed including therapeutic health actions (medications), measurement health actions, and decision health actions. Health action schedules represent the specific schedule that is to be used for a given health action plan. Health action results represent the data that results from each occurrence of a health action plan such as a medication administration, a blood glucose measurement, etc. These documents are related to each other using Indivo relationships so that their specific associations can be tracked.

The only other customization that was made to Indivo X to support CollaboRhythm was the implementation of additional features for the messaging functionality of the system. Indivo X allows messages to be sent from one account to another, but it only provides an inbox for each account and does not track sent messages for a given account. The ability to track both inbox and sent messages was added in order to support the messaging functionality of CollaboRhythm that has been described.

An important point to make about CollaboRhythm is that it uses Indivo X more as a collaborative health record than as simply a personally controlled health record. A personally controlled health record assumes that it is predominantly a tool for patient self-tracking and management and that the clinician uses another electronic record. CollaboRhythm assumes that there is only one record for the patient and that the patient and all other parties including clinicians and caregivers use only that record. The patient can control which parties have access to what data to preserve privacy, but the advantage of using a single record is the opportunity to have a single complete and accurate record that maximizes the potential for collaboration.

4.4 Collaboration Services

Indivo X provides a way to store patient data centrally so that all client applications have access to the most up-to-date data. Since it is based on a REST API that requires the data to be pulled, it does not ensure that all of the clients are synchronized except as frequently as they pull new data. It also does not provide the services necessary for virtual visits including audio and video conferencing and remote procedure calls. A custom application on an instance of Adobe Media Server was developed to provide this functionality to the CollaboRhythm client applications.

The Adobe Media Server is a proprietary application developed by Adobe Systems for multimedia communications. It allows clients to make persistent connections to custom applications so that they can publish and subscribe to audio and video feeds and so that they can call methods on other client applications (remote procedure calls). The Real Time Media Flow Protocol (RTMFP) is a specific a proprietary protocol supported by Adobe Media Server that supports peer-to-peer audio and video communications in order to improve performance and security. It also encrypts all communications by default.

Each CollaboRhythm client connects to the custom Adobe Media Server application via the RTMFP protocol. When a clinician's client connects, it is informed of the online status of all patient clients. The clinician client initiates virtual visits by calling a remote method on the desired client through this connection. Audio and video channels for virtual visits are then handed off by the server to the individual clients so that they can handle them peer-to-peer. Any action that a user performs on a client during a virtual visit triggers the same procedure on remote clients in order to synchronize actions on the screen. Outside of virtual visits, any time that data is saved to the Indivo X server by any of the clients, all clients that have access to that data are informed so that they can immediately pull the most up-to-date data and that they are synchronized. In addition, any time that a message is sent from one account to another, all appropriate connected clients are notified of the message so that "instant" messaging is achieved as opposed to a typical batched e-mail experience.

More detail is justified for the remote collaboration capabilities during virtual visits, as there are a number of important technical issues that needed to be addressed. One important issue is that, since there is latency in the network, it is possible that one user could attempt to perform an action and that, before it is executed remotely, the other user might attempt to perform another action that would conflict. This could result in the two clients becoming out of synchronization. There are a number of possible solutions to this problem, some of which are quite complicated and attempt to never block a user action but to reconcile problems. The solution that was pursued in this implementation was to temporarily block interactions, since constraint was actually desirable in this user scenario. The goal was not primarily for the two users to work as quickly as possible at the same time but actually for them discuss options back and forth to come to a consensus. In the implementation, when one user's interaction reaches the server application, it places a block on interactions from other users until the interaction is executed on the remote clients and an execution complete message is returned to the server. The experience on the remote clients is an auditory cue that the interaction has been blocked. In reality, this scenario of collision of actions rarely occurred in our testing, since the users typically use the auditory channel to communicate as they are performing actions, and the etiquette of conversation prevented users from blocking each other. In the rare occasion of conflicting actions, it did prevent the client applications from becoming out of synchronization. The remote pointing feature of the application was implemented without the same blocking approach, since it did not present the possibility of collisions and since simultaneous cursor control was important in virtual visits.

5 Clinical Trials of Technology-Supported Apprenticeship

In order to evaluate the impact that technology-supported apprenticeship can have on the experience, clinical outcomes, and cost of chronic disease management, the model was tested with patients and clinicians with specific clinical needs. Each trial contributed new understanding to the importance of patient empowerment and how to create supportive technological scaffolding for the apprenticeship process.

In each clinical trial, the model was very similar. Each patient was engaged in a brief learning session in which a phone or tablet with a personalized CollaboRhythm application was introduced. The concept of apprenticeship (patient empowerment in the early pilots since the word apprenticeship was not yet adopted at that time) was described, and the expectations for the patient during the course of the study were outlined. The patient was sent home with the device and personalized CollaboRhythm application. Ongoing coaching support was delivered virtually by a master clinician through the CollaboRhythm application, and the patient was encouraged to gradually take more and more responsibility over time.

In the early phases of the research, two small pilot studies (HIV medication adherence and hypertension medication adherence) were conducted to ensure that patients and clinicians responded favorably to the technology-supported apprenticeship model. An additional goal of these pilots was to demonstrate that patients with low health literacy and low technology literacy were capable of engaging in their care.

In the later phases of the research, two randomized, controlled clinical trials (basal insulin titration and hypertension management) were conducted to compare the technology-supported apprenticeship model of care to the "best of the best". One goal of these studies was to demonstrate that the technology-supported apprenticeship model could allow the best example of traditional office-based model of care to be implemented virtually in a manner that it achieved equivalent results with greater potential to scale. The second goal was to demonstrate that the technology-supported apprenticeship model could actually allow these "best of the best" models of care to outperform themselves in terms of experience, clinical outcomes, and cost.

All of the tenets of the technology-supported apprenticeship model were explored in these trials except for the concept of novice patients becoming masters and coaching other patients. This concept was discussed with patients, but it could not be tested until these studies were complete and a cohort of apprentice patients had achieved mastery.

5.1 HIV Medication Adherence Pilot

Medication adherence is a significant problem in HIV, and the factors that affect non-adherence are complex. [99] [100] [101] [102] [103] As part of this study, a number of HIV patients were interviewed in attempt to understand the psychological experience of managing HIV and to develop innovative ideas about how to support improved care. It was discovered that many patients felt as if they did not have understanding of or control over the disease and that they did not feel supported socially. This was despite the fact that these patients were seen on a regular basis in the office by a PharmD HIV medication adherence specialist. Their feedback was not that these visits were poorly conducted. In fact, they were very fond of the specialist. But it was difficult to apply the information in their lives.

A CollaboRhythm application was developed that allowed patients to track their medication adherence and that translated this adherence into protection from HIV in a personalized, real-time, disease-state simulation. The goal of the simulation was to help the patients feel in control of a disease that they could not see, feel, hear, or otherwise perceive. (See Section 4.2.2.2 for more detail about the simulation.) At the same time, the application allowed a clinician coach to monitor patient progress remotely and to send messages of support.

Figure 33: HIV Medication Adherence Application. *The application was deployed on an internet media display called a Chumby, which was a predecessor of modern tablet computers, and on an early Android smartphone.*

In a one month pilot, four subjects (ages 43-61) with high school education or less and minimal to no computer experience were given a Chumby and a smart phone pre-loaded with the CollaboRhythm application and their medication regimens. The study was conducted in collaboration with the Center for HIV and AIDS Care and Research at the Boston Medical Center. It was approved by the institutional review boards at the Massachusetts Institute of Technology (MIT) and Boston Medical Center.

The three subjects who started with sub-optimal medication adherence improved (93.0% to 99.1%, 83.0% to 96.3%, and 63.9% to 81.3%). The one subject who started with optimal medication adherence (>95%) maintained this level. Given the small size of this pilot, the quantitative results were less important than the overwhelmingly positive feedback from subjects. They related that the application and the coach (the same HIV medication adherence specialist who used to see them in the office) gave them a sense of comfort and control in managing HIV that they never had before. They felt that the medication adherence tracking helped them to be more proactive about taking their medications and that the simulation helped them to better understand their disease. Most importantly, they felt more empowered to take an active role in their care and to discuss issues that were important to them.

5.2 Hypertension Medication Adherence Pilot

The encouraging results of the HIV medication adherence pilot were carried over to the problem of hypertension. As discussed previously, half of patients with hypertension do not take their medications reliably. Doubts about efficacy, side-effects, and lack of understanding of the risks of hypertension are significant factors.

A CollaboRhythm application was developed that allowed patients to track their medication adherence and that provided educational simulations about the positive effects of the medications. (See Section 4.2.2.2 for more detail about the simulations.) It also allowed a clinician coach to monitor patient progress and to send video messages of encouragement.

In a one month pilot, three elderly subjects (ages 73-89) in an assisted living/retirement facility with minimal to no computer experience were given a tablet computer pre-loaded with the CollaboRhythm application and their medication regimens. A blood pressure meter was wirelessly linked to the CollaboRhythm application to automate the process of blood pressure documentation. The study was conducted in collaboration with the Center for Innovation at the Mayo Clinic. It was approved by the institutional review boards at the Massachusetts Institute of Technology (MIT) and the Mayo Clinic.

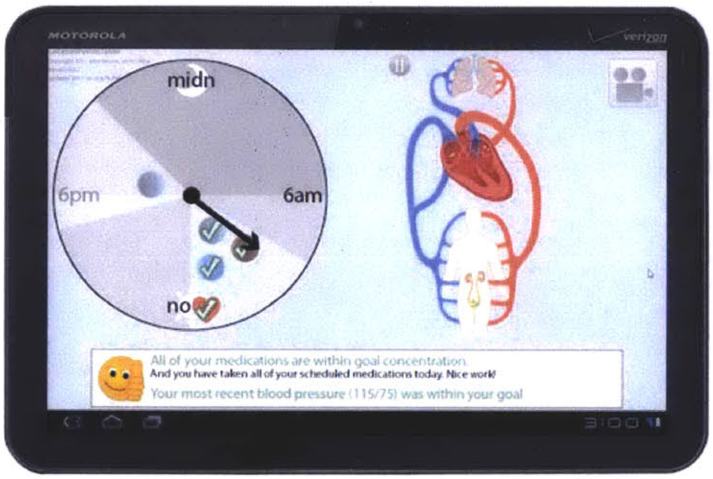


Figure 34: Hypertension Medication Adherence Application. *The application was deployed on an early Android tablet. The home screen of the application provided the clock view that has been described as well as a simplified view of the educational simulation. It also provided high-level feedback to the patient about whether or not medications were at goal concentration and whether or not the most recent blood pressure was within goal.*

Excluding the first week, during which there were some technical issues, all of the subjects had medication adherence between 96 and 100%. The subjects related that their favorite part of the intervention was having a supportive nurse coach. Surprisingly, they rarely used the educational simulations. They claimed that the simulations were not too complicated, but they were not useful because they did not change. The patients in the study had optimal medication adherence, so the simulations always looked the same. At the same time, their blood pressures were not adequately controlled. The study did not allow for changes in medication doses, so there was a poor pairing between the educational simulations and the actions that patients could take. This was not a flaw in the technology itself but a significant flaw in the model of care delivery and the extent to which it empowered patients.

5.3 Basal Insulin Titration Randomized, Controlled Trial

The flaws in the hypertension medication adherence pilot became the driving force behind the formalization of the apprenticeship model and the push for further patient involvement in frequent care decisions. Even elderly patients with no significant technology experience wanted more involvement in their care and more power to take control of their health. A clinical scenario was sought that could embody the technology-supported apprenticeship concept, and basal insulin titration in type 2 diabetes was chosen.

Patients with type 2 diabetes (typically adult onset and due to decreased insulin production or insulin resistance) who fail to achieve blood glucose control with diet, exercise, and oral medications are typically started on basal (long-acting or once-a-day) insulin. The titration of basal insulin to optimize glycemic control is intimidating to patients because they need to begin injecting themselves on a daily basis. They also need to adjust their dose every few days, presenting the risk of low blood sugar (hypoglycemia) if the dose is increased too aggressively. Since they failed diet and exercise, they are also afraid of failing at insulin management. They fear being on insulin forever and being slaves the doctor's office. It can be overwhelming. [**104**]

This clinical scenario was chosen for study because type II diabetes is one of the most significant clinical problems in this country. This specific scenario of basal insulin titration is representative of one that traditionally requires and receives significant clinical support and that is a tremendous opportunity for empowerment. It has also been studied extensively (See 2.1.2), so there are number of metrics for comparison.

This study was conducted at the Joslin Diabetes Center, the world's leading diabetes research and clinical care organization. It was approved by the institutional review boards at the Massachusetts Institute of Technology (MIT) and the Joslin Diabetes Center. The study was randomized and controlled in design in order to compare technology-supported apprenticeship in the titration of basal insulin to one of the highest standards of care. Although the Joslin model is extremely successful, it is primarily clinic-based and therefore does not scale in as cost-effective manner as an IT solution might. If the technology-supported apprenticeship model could allow Joslin personnel to outperform themselves using virtual tools, then not only could they achieve better results for their patients, but they could also provide their services to many more.

The study period for each patient was 12 weeks +/- 2 weeks with staggered recruitment. This period was chosen because it is the minimal time required to assess a change in hemoglobin A1C (HbA1C), a standard measure of blood glucose control.

The primary outcome of interest was the absolute decrease in HbA1C. The secondary outcomes were the percentage of subjects reaching glycemic control target of HbA1C <= 7.0%, the frequency of hypoglycemia, the amount of clinician time required, and subject satisfaction with diabetes care as assessed by the standard Diabetes Treatment Satisfaction Questionnaire. [**105**] The study was designed for a total sample of 40 subjects.

5.3.1 Basal Insulin Titration Randomized, Controlled Trial – Methods

5.3.1.1 Subject Recruitment

The study was advertised to all clinical staff of the Joslin Diabetes Center through word of mouth and study flyers. Those patients with type II diabetes (aged 18-75 with hemoglobin A1C 9-14%) who were being started on basal insulin therapy by their treating physicians and had internet connectivity were eligible for inclusion in the study. Patients who had significant visual or hearing impairment, who were not proficient in English, who were pregnant or lactating, who had alcohol dependency, or who required multiple daily insulin injections were excluded. Clinical staff notified the study staff as they identified potential subjects.

All patients at the Joslin Diabetes Center have a hemoglobin A1C test on the day of a physician office visit. If the treating physician makes the decision with the patient to start basal insulin, the patient receives training from a diabetes educator before actually commencing the therapy. A member of the study staff assessed patient interest in the study after this diabetes educator meeting. Interested patients went through a process of written informed consent to enroll in the study. Each patient completed a Diabetes Treatment Satisfaction Questionnaire (DTSQ) and was assigned the next sequential subject study number, which was pre-randomized to either the intervention or the control group.

5.3.1.2 Protocol for Control Subjects

Control subjects followed the typical Joslin Diabetes Center protocol for initiating and titrating basal insulin. This protocol includes a component of self-management, which is addressed during the meeting with the diabetes educator. This component typically includes oral and written instruction to increase the insulin dose by 2 Units every three days until goal blood glucose is achieved. The protocol also includes ongoing coaching in the form of face to face visits, telephone calls, fax communications, and e-mails with the educator and physician and potentially with a dietician. The timing and composition of communication typically varies considerably across patients. Control subjects were given a paper log and instructed to document their communications in an effort to quantify this component.

In the case of hypoglycemia, control subjects were encouraged to follow the hypoglycemia treatment guidelines provided by their diabetes educator and to contact their Joslin providers as part of the standard Joslin practice. They were also given a paper log to document any episodes of hypoglycemia after they had been managed.

For the purposes of this study, no changes in non-insulin diabetes medications were made for control subjects.

At the conclusion of the 12 weeks of the study, control subjects returned to the Joslin Diabetes Center. They had a repeat hemoglobin A1C test, submitted their paper logs for communication and hypoglycemia, and repeated the Diabetes Treatment Satisfaction Questionnaire (DTSQ).

5.3.1.3 Protocol for Intervention Subjects

Health actions including oral medications, insulin, blood glucose readings, and regular insulin titration decisions were loaded into each subject's personal health record after being randomized to the interventional group. Each intervention subject then had a 30 minute to 1 hour meeting with a member of the study staff, typically with John Moore. The subject was introduced to the concept of being an apprentice patient and made shared decisions about the scheduling of health actions. The subject learned to use the CollaboRhythm application (See Chapter 4 for details) on a tablet computer to self-track health actions, to review progress using the charts, to propose or agree with changes in insulin dose, and to communicate with virtual visits and messages. Each subject was assigned to a primary health coach at the Joslin Diabetes Center, either Sue Ghiloni, a certified diabetes educator or Will Hsu, an endocrinologist. Each subject was sent home with the tablet computer with the personalized CollaboRhythm application.

On the evening of recruitment, intervention subjects typically had a virtual visit with their health coach for support in administering their first insulin injection. During the course of the study, intervention subjects tracked their health actions using the CollaboRhythm tablet application. All of their data was automatically synchronized their health coaches at the Joslin Diabetes Center. Their health coaches used a combination of virtual visits and messaging to help them make decisions about their insulin titration and to manage their diabetes in general. The goal was to gradually encourage and support greater independence over time.

The insulin titration protocol that guided therapy for intervention subjects and that was implemented as decision support in the CollaboRhythm application was the 303 protocol. This protocol is described in detail and studied in previous publications. [**53**] Every three days, if the subject's average fasting blood glucose for the past three days is greater than 110 mg/dL, an increase of 3 Units is recommended. If the average fasting blood glucose is less than 110 mg/dL but greater than 80 mg/dL, then no change is recommended. If the average fasting blood glucose is less than 80 mg/dL, then a decrease of 3 Units is recommended. What are not described in detail in previous publications are all of the exceptions and edge cases evident in this algorithm. The protocol was further specified for the purposes of this study in the following way. First, a recommended change was only provided if the subject's medication adherence for the previous 4 days was 100%. Second, an average fasting blood glucose was only calculated, and a recommended change was only provided if the subject recorded a fasting blood glucose at least 3 of the past 4 days with one of those readings on the current day. Finally, the language of the decision support always reminded the subject that this protocol was only a guide and was flawed in that it didn't know about the subject's diet, exercise, and other important factors in blood glucose management.

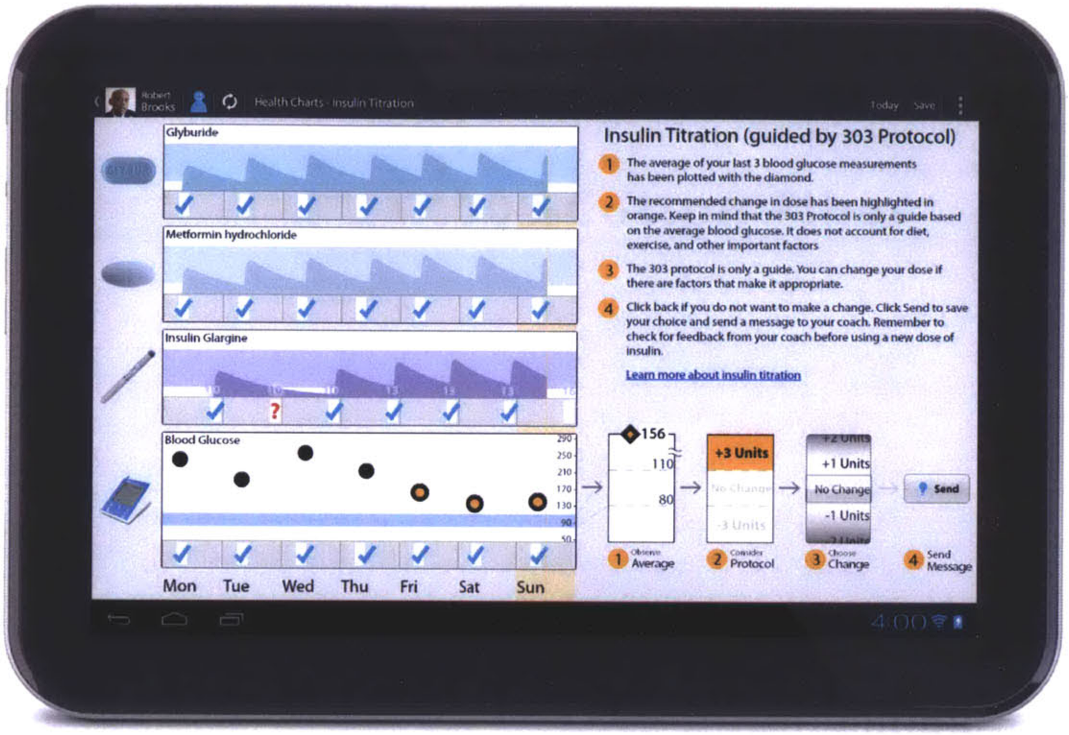


Figure 35: 303 Protocol for Insulin Titration as Decision Support in CollaboRhythm Application. *This image illustrates the implementation of decision support for the 303 protocol that was used in the insulin titration trial. The three most recent blood glucose values are indicated with an orange dot. The average is indicated in step 1, the recommended dose change in step 2, the patient's choice for dose change in step 3, and the ability to send the choice in step 4. The decision support text is updated every time the screen is viewed based on the patient's current data. It provides recommendations but emphasizes that the patient should account for other important factors such as diet and exercise.*

In the case of hypoglycemia, intervention subjects were supported with a hypoglycemia action plan executed in the CollaboRhythm tablet application. Subjects were instructed to contact their Joslin providers or to call 911 in case of emergency. All episodes of hypoglycemia were electronically logged.

For the purposes of this study, no changes in non-insulin diabetes medications were made for intervention subjects.

At the conclusion of the 12 weeks of the study, intervention subjects returned to the Joslin Diabetes Center. They had a repeat hemoglobin A1C test, returned their tablets and glucometers, repeated the Diabetes Treatment Satisfaction Questionnaire (DTSQ), and participated in an exit interview with one of the members of the study staff to assess their experience with the apprenticeship model of care and the CollaboRhythm application.

5.3.2 Basal Insulin Titration Randomized, Controlled Trial – Results

To date, 32 subjects have been recruited for the basal insulin titration study. 25 subjects have completed the study exit visit. One of these subjects was lost to follow-up while the other 6 subjects have yet to complete the duration of the study period. The study will continue to the pre-determined sample of 40 subjects. The results presented are preliminary findings for the 25 subjects who have completed the study.

A two-tailed Student's t-test for independent samples was used for all comparisons of the mean of continuous variables between the control and intervention group. A two-tailed Student's t-test for depended samples was used for all comparisons between pre- and post-study variables within the control and the intervention group. A chi-shared test was used for all comparisons of categorical variables between the control and intervention group.

The table below presents the baseline statistics for the subjects. The age, body mass index, years with diabetes, baseline HbA1C, and number of oral medications were all similar for the control and intervention groups. There were more male than female subjects in the control group, but it was not statistically significant and is not expected to be an important confounding factor.

Baseline Statistics for Subjects

	Total (n=25)	Control (n=12)	Intervention (n=13)	p-value
Age (years), mean (sd)	55.9 (12.8)	56.1 (10.1)	55.7 (15.3)	0.94
Gender, n (%)				
Female	9 (36.0)	3 (25.0)	6 (46.2)	0.07
Male	16 (64.0)	9 (75.0)	7 (53.8)	
Body mass index (kg/m^2), mean (sd) '	32.3 (6.0)	31.9 (4.7)	32.7 (7.1)	0.75
Years with diabetes, mean (sd) "	9.9 (6.1)	10.9 (6.6)	9.5 (5.9)	0.58
HbA1C (%), mean (sd)	10.8 (1.2)	10.7 (1.0)	10.9 (1.4)	0.62
# of Oral Medications, mean (sd)	1.8 (0.8)	1.9 (0.9)	1.6 (0.7)	0.40

' The body mass index was not available for one control subject.
" The years with diabetes was not available for one control subject.

5.3.2.1 Clinical Outcomes

The primary outcome of the study and the secondary clinical outcomes are presented in the table below. A trend toward a greater decrease in HbA1C for intervention subjects was observed, but it is not yet statistically significant with the current small sample size. The same number of subjects reached goal HbA1C in both groups. The frequency of hypoglycemia was not available for control subjects because only one subject completed the hypoglycemia paper log that was provided for the study and because this metric was not tracked by clinicians as part of standard care. Both control subjects and intervention subjects lost weight on average during the study, which is remarkable because basal insulin typically results in weight gain. The weight loss suggests that both groups were more vigilant about weight management than is typical. The average insulin dose was larger at the end of the study for intervention subjects but was not statistically significant.

Final Clinical Statistics for Subjects			
	Control (n=12)	Intervention (n=13)	p-value
Decrease in HbA1C (%), mean (sd)	2.5 (2.0)	3.1 (1.4)	0.40
Subjects with HbA1C <= 7%, n (%)	3 (25)	3 (23)	0.91
Frequency of Hypoglycemia (events/patient/year), mean (sd)	Not available	5.8 (14.2)	
Decrease in Weight (lbs), mean (sd) '	2.4 (7.7)	0.4 (9.5)	0.57
Insulin Dose (Units), mean (sd) "	16.1 (20.2)	30.1 (15.1)	0.07

' The final weight was not available for one control subject.

" The final insulin dose was not available for one control subject.

5.3.2.2 Cost

The amount of time that physicians and non-physicians spent interacting with both control and intervention subjects was aggregated for phone calls (assumed average time of 15 minutes) and office visits (assumed average time of 30 minutes). It was not possible to aggregate the number of e-mail communications that they had with patients due to privacy and technical limitations. The time spent sending instant messages (assumed average time of 5 minutes per message) and in virtual visits (exact time in each visit) using the CollaboRhythm tablet application was also added for intervention subjects. The cost associated with clinician time was calculated for both control and intervention subjects using the assumption of $120/hour for physicians (based on $250,000/year average salary plus benefits for endocrinologists) and $50/hour for non-physicians (based on $100,000/year average salary plus benefits for nurse certified diabetes educators). The results are summarized in the table below. There was a trend toward less physician time for intervention subjects, which was not statistically significant. Intervention subjects did receive significantly more non-physician support and overall required approximately $200 more in staff costs.

It is of note that Dr. Will Hsu played the part of coach for more than half of the intervention subjects. He also played the role of endocrinologist for some control and some intervention subjects. His time was allocated to the appropriate group based on the role that he was playing during the corresponding communication.

Final Cost Statistics for Subjects			
	Control (n=12)	Intervention (n=13)	p-value
Total Physician Time (hours), mean (sd)	1.4 (0.9)	0.8 (0.5)	0.08
Total Non-Physician Time (hours), mean (sd)	2.0 (2.2)	7.6 (2.4)	**0.000003***
Cost Estimate (dollars), mean (sd)	271.46 (167.74)	477.80 (133.51)	**0.003***

5.3.2.3 Experience

Nine control subjects and 13 intervention subjects completed both the pre-study and post-study Diabetes Treatment Satisfaction Questionnaire. Satisfaction for control subjects before and after the study did not improve by a statistically significant margin. Satisfaction for intervention subjects did, on the other hand, improve by a statistically significant margin. In addition, satisfaction for intervention subjects after the study was significantly higher than for control subjects.

Diabetes Treatment Satisfaction Questionnaire (DTSQ) Statistics for Subjects			
	Control (n=9)	Intervention (n=13)	p-value
Pre-Study Total Score (points), mean (sd)	26.8 (6.8)	25.7 (10.2)	0.77
Post-Study Total Score (points), mean (sd)	28.1 (6.4)	33.5 (2.4)	**0.04***
p-value	0.65	**0.03***	

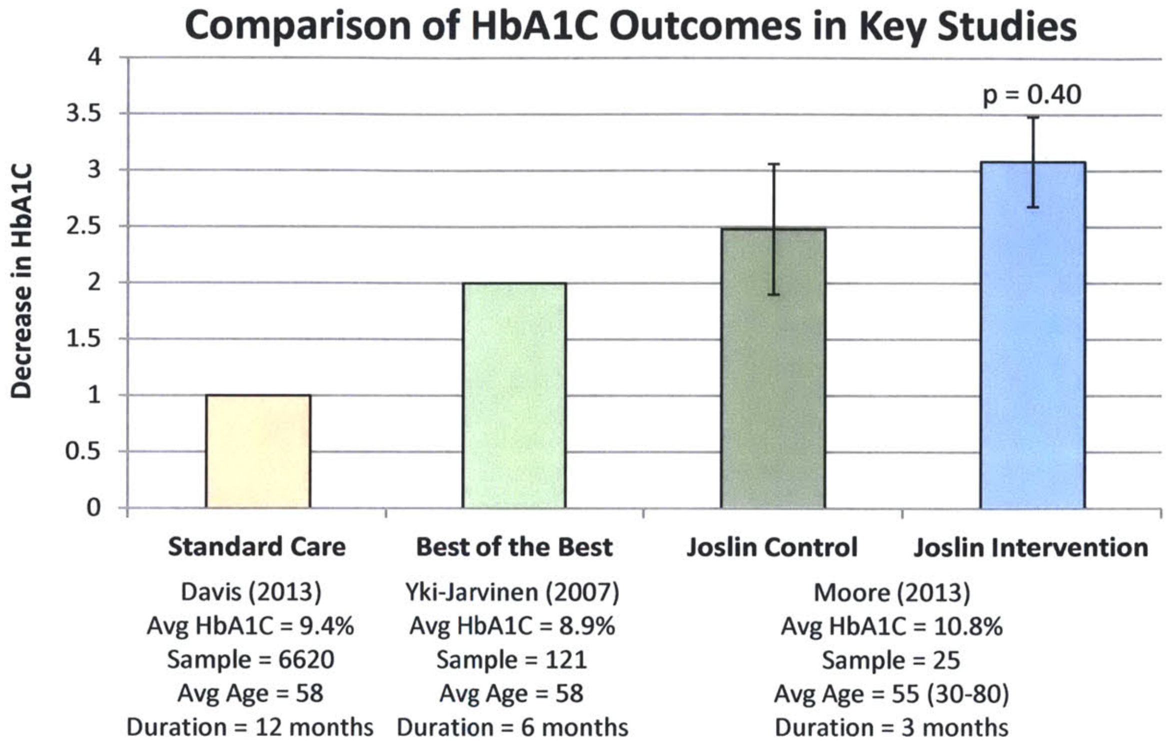
The praise that intervention subjects gave for the new model of care that they experienced was much greater than they could convey through a simple questionnaire. Only one of the 13 subjects preferred the traditional model of care, as he had significant difficulty in using the CollaboRhythm tablet application. His difficulty, however, was mainly due to inconsistent internet access. The remaining subjects found having a virtual coach comforting, convenient, and motivating. They felt that the application and coaching helped them gain insight into the relationship between their actions (diet, exercise, and medication adherence) and their blood glucose values. Many patients did not want to give up their tablets, as they related that the application gave them a sense of control and comfort.

One of the most encouraging experiences was that of a 70 year old woman with a 15 year history of diabetes and HbA1C of 12.1%. She had very little technology experience and little interest in using the tablet and CollaboRhythm application. She offered to give it a try, but she warned that people had been trying to get her to control her diabetes for years, and it didn't work. At the end of the study, she did not want to return the tablet. She explained that it gave her a sense of control over her disease, that she had fun seeing her progress each day, and that it motivated her to make significant changes in her diet. She loved having a supportive coach. Her HbA1C at the end of 10 weeks was 7.7%.

There was a great deal of constructive feedback about the application from the exit interviews as well. Subjects wanted to be able to track diet and exercise information. They also wanted the application to be faster and to work in an off-line mode. The coaches also wanted the application to be faster and have a more powerful dashboard where she could see details about each subject without opening his or her record.

5.3.3 Basal Insulin Titration Randomized, Controlled Trial – Discussion

The trend toward greater decrease in HbA1C in intervention subjects with only $200 more in cost per subject and with improvement in treatment satisfaction is extremely exciting. It suggests that technology-supported apprenticeship is likely to be effective in scaling a level of care comparable to or better than the Joslin to a much larger population in a cost-effective and well-received manner.



The chart above presents the outcomes of the control and intervention subjects in the Joslin study in the context of the results for the standard of care and the best results that have been achieved in a randomized, controlled trial. [**106**] [**55**]

First consider the difference in outcomes between the intervention group in the Joslin study and the standard of care. The intervention provides a 2% larger decrease in HbA1C. The subjects in the standard of care study started with a larger HbA1C, but the intervention group achieved their outcomes in ¼ of the time. This improvement in care has significant implications. Every 1% decrease in HbA1C results in a 21% decrease in complications of diabetes including heart attack, stroke, kidney failure, etc. A 2% decrease then equates to as much as a 40% decrease in complications. This corresponds to a dramatic improvement in quality of life. At the same time, since the cost of complications per year for patients with hypertension is approximately $10,000, it corresponds to a return of $4,000 per year and $120 K per lifetime (assuming 30 years with the disease) for a cost of only $477. [**27**] For perspective, if such an intervention were to scale to a national level, it would result in $13 B in savings per year (based on $3,500 savings/patient/year x 18.8 million patients diagnosed with diabetes x 0.20 patients on insulin). [**17**]

Next consider the difference in outcomes between the intervention group in the Joslin study and the control group. The intervention provides a 0.6% larger decrease in HbA1C. This improvement corresponds to a 12% decrease in complications and a return of $1,200 per year and $36 K per lifetime for an additional cost of only $200.

5.4 Hypertension Management Randomized, Controlled Trial

Essential hypertension refers to high blood pressure with no identifiable cause. It is the most common type of hypertension. The management of hypertension includes addressing diet, exercise, and stress along with treatment with antihypertensive medications.

This clinical scenario was chosen for study because essential hypertension is one of the most significant clinical problems in this country. It is representative of a clinical scenario that does not typically need and does not receive as intense clinical support as basal insulin titration. At the same time, outcomes are poor (see 1.1.2.1), and more intense clinical support may be warranted. It has also been studied extensively (see 2.1.1), so there are number of metrics for comparison.

This study was conducted at the Ambulatory Practice of the Future (APF) at MGH. It was approved by the institutional review boards at the Massachusetts Institute of Technology (MIT) and the Massachusetts General Hospital (MGH). This APF cares solely for employees of MGH, which allows it the freedom to explore new methods of care delivery and new payment models. The hope is that it will learn lessons that can be translated to the care of other patients. The study was randomized and controlled in design in order to compare technology-supported apprenticeship in the management of essential hypertension to one of the highest standards of care. As with diabetes care at the Joslin, the quality of hypertension care at the APF is high but does not scale in a cost-effective manner because it is predominantly clinic-based. If the technology-supported apprenticeship model could allow APF personnel to outperform themselves using virtual tools, then not only could they achieve better results for their patients, but they could also provide their services to many more.

The study period for each patient was 12 weeks +/- 2 weeks with staggered recruitment. This period was chosen because it is the minimal time required to titrate a patient up from no medication to the full medication regimen allowed in this study. The goal was to recruit as large of a sample as possible provided that all subjects could complete the study before July 31st 2013. A minimum sample of 40 subjects was desired.

The medication titration protocol in the so for this study, for both control and intervention subjects, was developed by Dr. Randall Zusman, a hypertension specialist at MGH. The protocol was as follows:

- Add lisinopril 20 mg once daily
- If blood pressure not at goal after 2 weeks, increase to lisinopril 40 mg once daily
- If patient exhibits allergy or cough with lisinopril, switch to valsartan 160 mg / 320 mg
- If blood pressure not at goal after 2 weeks, add amlodipine 5 mg once daily
- If blood pressure not at goal after 2 weeks, increase to amlodipine 10 mg once daily
- If blood pressure not at goal after 2 weeks, add hydrochlorothiazide 12.5 mg once daily
- If blood pressure not at goal after 2 weeks, increase to hydrochlorothiazide 25 mg once daily
- If blood pressure not at goal after 2 weeks, consider resistant hypertension, begin additional evaluation and remove subject from study

The primary outcomes of interest were the absolute decrease in systolic blood pressure and the number of subjects who reached the systolic blood pressure goal of less than or equal to 130 mmHg. The secondary outcomes were the absolute decrease in diastolic blood pressure, the number of subjects who reached the diastolic blood pressure goal of less than or equal to 80 mmHg, the absolute decrease in weight, the number of subjects who lost at least 5 pounds, and a hypertension knowledge score assessed by a pre- and post-study hypertension knowledge test.

5.4.1 Hypertension Management Randomized, Controlled Trial – Methods

5.4.1.1 Subject Recruitment

The study was advertised to all clinical staff of the Ambulatory Practice of the Future at MGH through word of mouth. The Ambulatory Practice of the Future was also a relatively young practice and had built a registry of patients with elevated blood pressure on recruitment that needed to be followed. Adult patients (> 18 years old) from the registry or from routine visits with essential hypertension (average blood pressure >= 140/90 and <= 180/120) who were taking 0 or 1 medications and had internet connectivity were eligible for inclusion in the study. Patients with a history of hypotension, syncope, hypertensive urgency, hypertensive emergency, labile hypertension, and proven coronary artery disease were excluded as were patients with significant visual, auditory, or cognitive impairment and patients who were not proficient in English. Clinical staff notified the nurse health coach for the study, MaryAnn Marshall on identification of any eligible subjects.

The nurse health coach for the study contacted each eligible patient to assess interest. Interested patients were scheduled for an appointment to commence the study. A process of written informed consent was carried out with each study subject. A baseline blood pressure, heart rate, and weight were measured and subject completed a hypertension knowledge assessment. Each subject was assigned the next sequential subject study number, which was pre-randomized to either the intervention or the control group.

MaryAnn Marshall was the nurse health coach for both control and intervention subjects in this study. Subjects in the both groups had an introduction visit with MaryAnn including motivational interviewing to assess their health values and to discussion hypertension management goals. MaryAnn and the patient made shared decisions about diet, exercise, stress management, and the potential of starting a hypertension medication. This visit was typically 30 minutes in duration.

5.4.1.2 Protocol for Control Subjects

Subjects in the control group received standard hypertension care from the Ambulatory Practice of the future, which includes face-to-face visits, telephone calls, and e-mails with MaryAnn to address diet, exercise, stress, and medication management. All communications with control subjects were documented electronically for the purposes of this study. The medication management of control subjects followed the same hypertension medication titration algorithm as intervention subjects for the purposes of this study.

At the conclusion of the study of the 12 weeks of the study, control subjects returned for an exit visit. Blood pressure, heart rate, and weight were measured. A hypertension knowledge assessment was completed and an exit interview was conducted.

5.4.1.3 Protocol for Intervention Subjects

Subjects in the intervention group also received instructions from MaryAnn on how to use the CollaboRhythm tablet application to self-track their medication adherence, to review progress using the charts, to propose or agree with changes in hypertension medications, and to communicate with virtual visits and messages.

Subjects in the intervention group received hypertension care primarily through the CollaboRhythm tablet application with MaryAnn to address diet, exercise, stress, and medication management. The apprenticeship model of chronic disease management was discussed with MaryAnn and with Ambulatory Practice of the Future leadership. It was also implicit in the design of the CollaboRhythm tablet application.

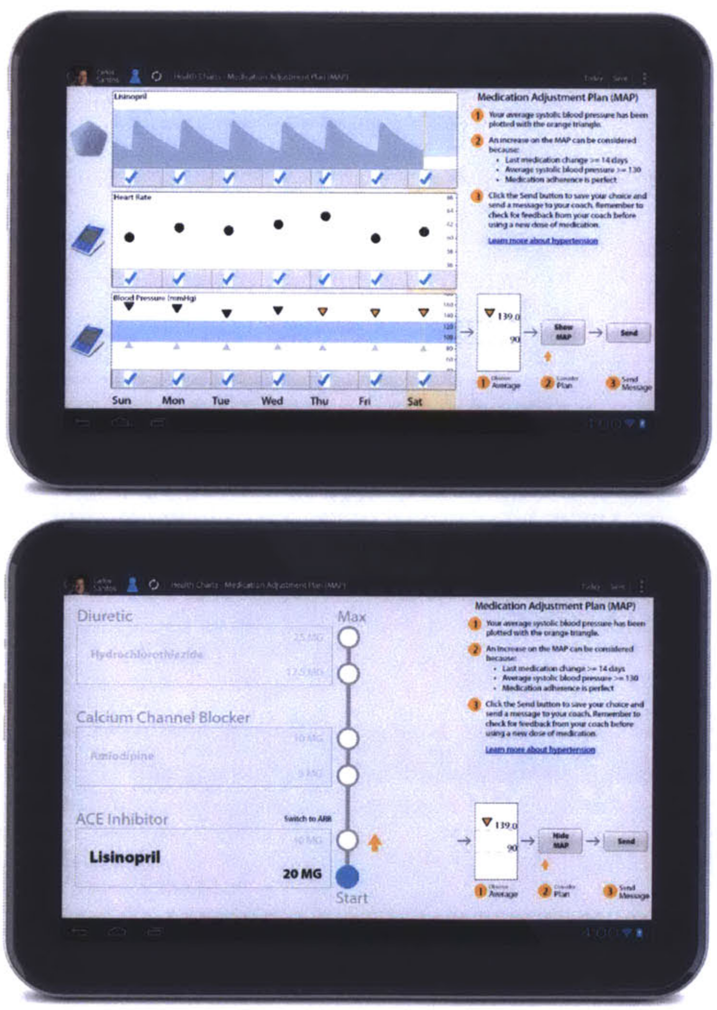


Figure 36: Hypertension Medication Adjustment Plan (MAP) in CollaboRhythm Application. *The medication titration protocol for hypertension medications was called the "Medication Adjustment Plan (MAP)" within the CollaboRhythm software. In the top image, the three most recent systolic blood pressure values are indicated with orange triangles. The average is indicated in step 1. Clicking on the "Show MAP" button in step 2 hides the graphs and shows the medication adjustment plan. Current medications are indicated with a cyan dot along the MAP and with bold black font. A recommended increase in dose is indicated by the orange up arrow beside the next dose in the MAP. The patient can click on any medication in the MAP to select it. The patient can send a message indicating the choice in step 3. The decision support text is updated every time the screen is viewed based on the patient's current data. It provides recommendations but allows for flexibility in the apprenticeship process.*

All communications with intervention subjects were automatically documented electronically. The medication management of intervention subjects followed the same hypertension medication titration algorithm (called the Medication Adjustment Plan or MAP in the software) as control subjects.

At the conclusion of the 12 weeks of the study, intervention subjects returned for an exit visit. Blood pressure, heart rate, and weight were measured. The tablet computer and blood pressure meter were returned. A hypertension knowledge assessment was completed and an exit interview was conducted.

5.4.2 Hypertension Management Randomized, Controlled Trial – Results

44 subjects were recruited for the hypertension management study. Three subjects were lost to follow-up, leaving 41 subjects who completed the study exit visit.

A two-tailed Student's t-test for independent samples was used for all comparisons of the mean of continuous variables between the control and intervention group. A chi-shared test was used for all comparisons of categorical variables between the control and intervention group.

The table below presents the baseline statistics for the subjects. The age, weight, systolic blood pressure, diastolic blood pressure, medication load, and hypertension knowledge score were similar for the control and intervention groups. There were more male than female subjects in both the control and intervention groups, but this discrepancy was not statistically significant, and the trend is not expected to be an important confounding factor.

Baseline Statistics for Subjects				
	Total (n=41)	Control (n=21)	Intervention (n=20)	p-value
Age (years), mean (sd)	50.2 (12.9)	48.7 (15.5)	51.9 (9.5)	0.42
Gender, n (%)				0.27
Female	17 (41.5)	9 (42.9)	8 (40.0)	
Male	24 (58.5)	12 (57.1)	12(60.0)	
Weight (lbs), mean (sd) '	206.6 (48.0)	202.8 (60.8)	210.9 (29.3)	0.59
Systolic BP (mmHg), mean (sd)	147.5 (9.5)	145.3 (6.3)	149.8 (11.6)	0.14
Diastolic BP (mmHg), mean (sd)	87.3 (10.0)	86.2 (11.7)	88.43 (8.1)	0.49
Medication Load, mean (sd)	0.83 (0.80)	0.76 (0.82)	0.90 (0.80)	0.59
Hypertension Knowledge Score (maximum of 11), mean (sd) "	9.2 (1.2)	9.5 (1.2)	8.9 (1.2)	0.14

' The weight was not available for one intervention subject.

" The hypertension knowledge score was not available for one intervention subject subject.

5.4.2.1 Clinical Outcomes

The primary outcome of the study and the secondary clinical outcomes are presented in the table below. Intervention subjects achieved a statistically greater decrease in systolic blood pressure than controls and a greater percentage achieved goal systolic blood pressure. There was a strong trend toward a greater decrease in diastolic blood pressure for intervention subjects, and statistically more intervention subjects achieved goal diastolic blood pressure than controls. Both control and intervention subjects lost weight on average, but there was a very large variance. The same number of subjects in each group lost greater than 5 pounds. There was not a significant difference in hypertension knowledge between the two groups, but this was not expected since both groups started the study with high scores on the assessment.

Final Clinical Statistics for Subjects			
	Control (n=21)	Intervention (n=20)	p-value
Decrease in Systolic BP (mmHg), mean (sd)	15.9 (12.4)	26.3 (11.9)	**0.009***
Subjects with Systolic BP ≤ 130, n (%)	10 (47.6)	16 (80.0)	**0.03***
Decrease in Diastolic BP (mmHg), mean (sd)	8.5 (8.7)	13.7 (9.4)	0.07
Subjects with Diastolic BP ≤ 80, n (%)	12 (57.1)	18 (90.0)	**0.02***
Decrease in Weight (lbs), mean (sd)	1.8 (9.2)	3.4 (7.4)	0.55
Subjects with Decrease in Weight ≥ 5 lbs, n (%)	8 (38.1)	8 (42.1)	0.90
Hypertension Knowledge Score, mean (sd)	10.1 (1.1)	9.9 (1.3)	0.59

5.4.2.2 Cost

The amount of time that the nurse coach spent interacting with both control and intervention subjects was aggregated for e-mails (assumed average time of 10 minutes), phone calls (assumed average time of 15 minutes) and office visits (assumed average time of 30 minutes). The time spent sending instant messages (assumed average time of 5 minutes per message) using the CollaboRhythm tablet application was also added for intervention subjects. It is of note that, although virtual visits were available as a feature, none were conducted during the course of the study. The cost associated with nurse coach time was calculated for both control and intervention subjects using the assumption of $50/hour (based on $100,000/year average salary plus benefits for nurse with health coaching certification). There was a trend toward intervention subjects receiving more support from the nurse coach that was not statistically significant. On average, intervention subjects received 0.28 hours or 16.8 minutes more time at an additional cost of $13.93.

Final Cost Statistics for Subjects			
	Control (n=21)	Intervention (n=20)	p-value
Total Nurse Coach Time (hours), mean (sd)	0.57 (0.72)	0.85 (0.54)	0.17
Cost Estimate (dollars), mean (sd)	28.57 (36.04)	42.50 (26.85)	

5.4.2.3 Experience

Twelve control subjects and 16 intervention subjects provided an experience rating during their exit interview from the study. There was a trend toward greater satisfaction for intervention subjects that was not statistically significant.

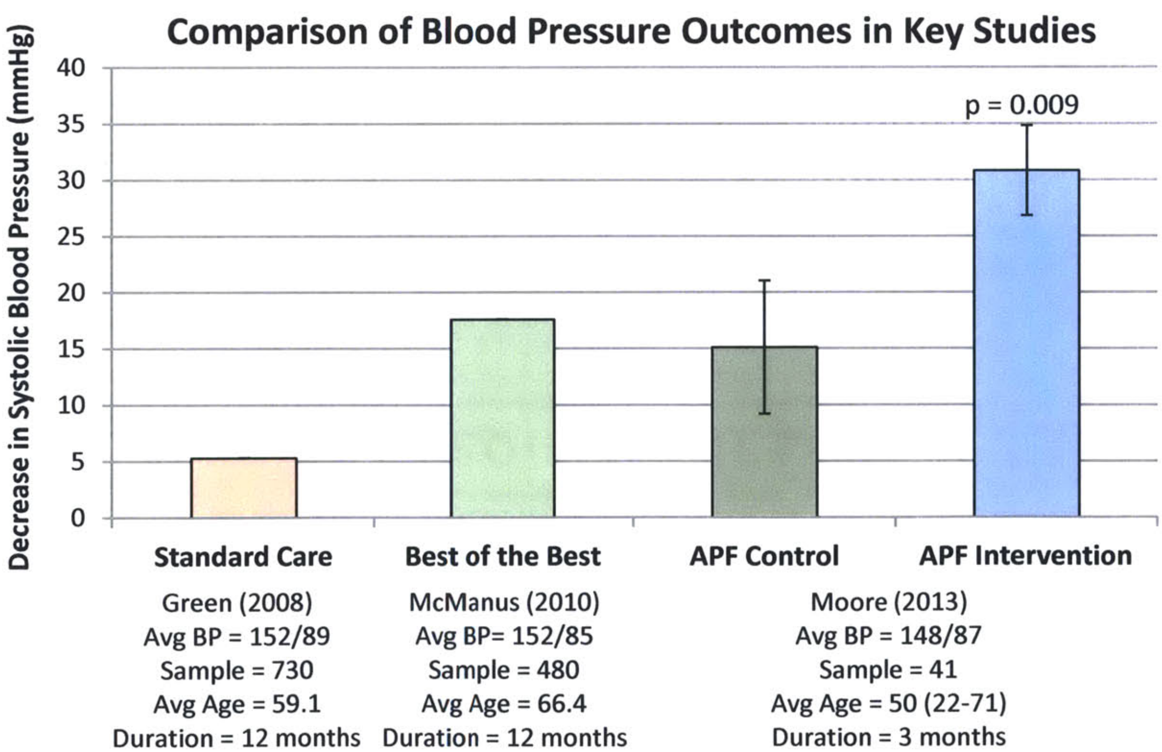
Final Experience Statistics for Subjects			
	Control (n=12)	Intervention (n=16)	p-value
Experience Rating (0-10 points), mean (sd)	7.6 (2.7)	8.9 (1.1)	0.14

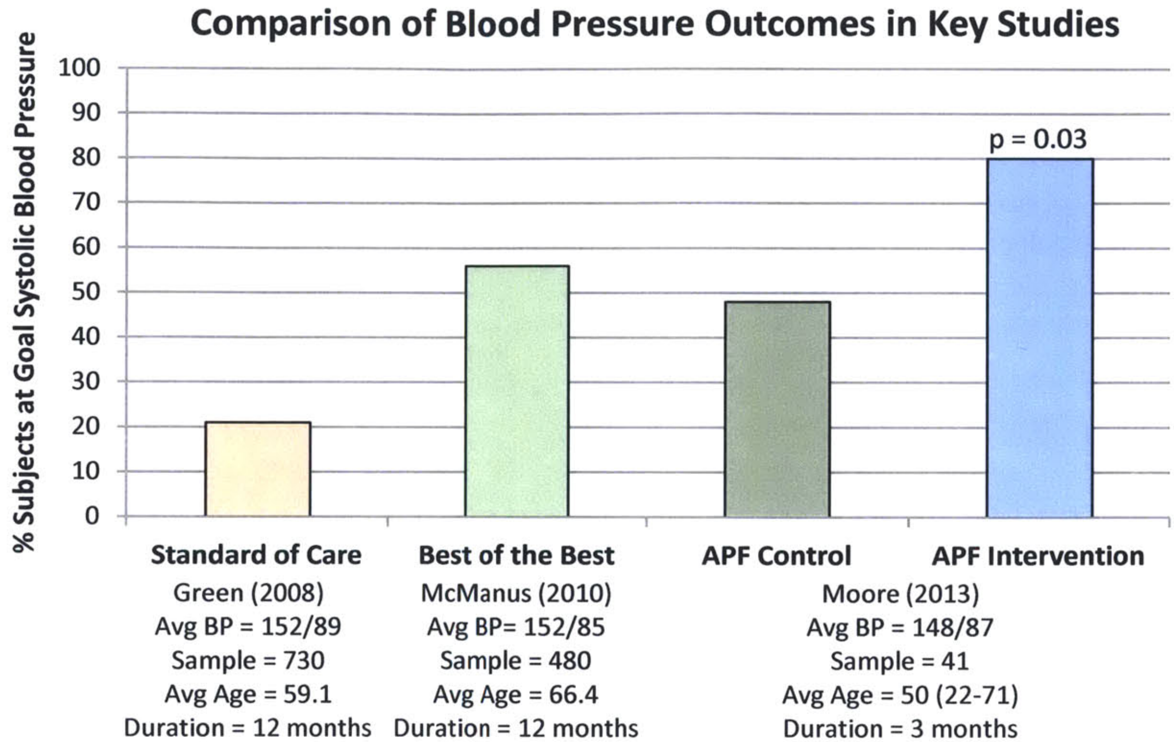
The majority of feedback from intervention subjects was obtained through the exit interview. The feedback was overwhelmingly positive. All of the subjects wanted to continue using the CollaboRhythm application after the end of the study. Some who had reached goal only wanted to use it sporadically as a "check-in", but the majority wanted to use it daily as they had for the study for an indefinite period of time. They felt that the burden of reporting was easily balanced by the value of being able to track progress and get the efficient support of a virtual health coach. They related that awareness of the associations between actions (diet, exercise, stress management, medication adherence) and blood pressure outcomes was integral to their success and their positive experience with the application. Subjects responded very favorably to the concept of patient empowerment. They said things like, "It felt good to take responsibility" and "No one has ever asked me to take responsibility for my health" and "I developed confidence that I never would have had." The nurse coach for the study exclaimed many times that she was overwhelmed with how excited her patients were in using the application with her. She also did not want to stop using the application at the end of the study.

The constructive feedback about the application was essentially the same as in the insulin titration study. The application should be faster and capable of tracking more inputs. It should have a more powerful dashboard for the coach.

5.4.3 Hypertension Management Randomized, Controlled Trial – Discussion

A 26.3 mmHg decrease in systolic blood pressure and 80% rate of goal systolic blood pressure attainment in intervention subjects is a spectacular result. This is especially true given the intervention only cost $42.50 in clinician time and that patients were excited about engaging in such a model of care and were ready to take more responsibility. The implications of scaling this intervention to a larger audience are significant.





The charts above compare the results of intervention and control subjects from the study to the standard of care and the "best of the best" in hypertension management studies. **[44]** **[45]**

First consider the difference in outcomes between the intervention group in the Ambulatory Practice of the Future (APF) study and the standard of care. The intervention provides a 59% larger rate of control in systolic blood pressure in ¼ of the time as compared to the results published by Green in the chart above. (It is of note that Green's publication also addressed a "best of the best" intervention almost as successful as that of McManus, which is discussed in Chapter 2) This improvement in care has significant implications. Control of systolic blood pressure is associated with an approximate 35% decrease in complications including heart attack, stroke, heart failure, etc. A 59% greater rate of control equates to a 21% decrease in complications. This corresponds to a dramatic improvement in quality of life. At the same time, since the cost of complications per year for patients with hypertension is approximately $1,000, it corresponds to a return of $210 per year and $6.3 K per lifetime for a cost of only $42.50. **[14]** **[15]** For perspective, if such an intervention were to scale to a national level, it would result in $11 B in savings per year (based on $168 savings/patient/year x 65 million patients with hypertension). **[9]**

Next consider the difference in outcomes between the intervention group in the APF study and the control group. The intervention provides a 32% larger rate of control in systolic blood pressure. This improvement corresponds to an 11% decrease in complications and a return of $110 per year and $3.3 K per lifetime for an additional cost of only $13.93. It is even likely that, with further improvements in the technology, such results can be achieved with less clinician work. In addition, this up-front cost is likely to reap much greater rewards in patient outcomes and decreased clinical costs over time.

6 Reflections on Technology-Supported Apprenticeship

6.1 Strengths of Technology-Supported Apprenticeship

The management of chronic diseases is difficult because every disease presents different challenges, every patient has different needs and goals, and every day offers new obstacles. The advantage of technology-supported apprenticeship is that, while the technology component provides powerful scaffolding for maximizing awareness and streamlining collaboration, the master clinical coach is able to adapt to all of these shifting variables to provide personalized support in the development of self-efficacy. This is likely a large contributing factor to the dramatic results from the clinical trials. Patients were encouraged to gain self-efficacy but felt a sense of comfort in the support that was provided.

A solution for chronic disease that relies more heavily on technology without the support of a coach falls short when compared to technology-supported apprenticeship. This claim is supported by the comparison between the intervention groups in the clinical trials and the results of published research that have consistently shown that adding coaching to chronic disease interventions improves outcomes. An argument could be made that the technology just needs to be more intelligent and to provide adaptable support in the same manner as a coach. The complexity of chronic disease management makes the successful execution of such an intervention unlikely. In addition, the value of coaching is not just in the clinical support but also in the social support accountability that patients feel.

A solution that relies more heavily on the coaching element without supportive technology scaffolding also falls short when compared to technology-supported apprenticeship. This claim is supported by the comparison between the intervention and control groups in the clinical trials. Without the ability to easily share and communicate about progress, coaches have a difficult time supporting patients in their progress. Technology scaffolding will be even more essential as the amount of data that is needed about patients in optimizing their care increases.

6.2 Challenges in Technology-Supported Apprenticeship and Future Work

There are a number of challenges in scaling the technology-supported apprenticeship model. They present many opportunities for future work.

6.2.1 Application to Other Diseases

The technology-supported apprenticeship model lends itself well to chronic diseases that require adjustments in medications or changes in lifestyle to maximize patient outcomes that can be measured either quantitatively or semi-quantitatively. For example, in the case of diabetes, the patients needed to adjust insulin doses and improve diet and exercise in order to optimize blood glucose and Hemoglobin A1C values. In the case of hypertension, the patients needed to adjust medication doses and improve diet, exercise, and stress management in order to optimize blood pressure readings. Other chronic diseases that present directly parallel scenarios include hypercholesterolemia, asthma, Parkinson's Disease, epilepsy, congestive heart failure, HIV, atrial fibrillation (anticoagulation) and many others. In fact, prototypes for many of the listed chronic diseases have been built during the annual Health and Wellness Innovation event that has been described. Chronic diseases that can be tracked in a semi-quantitative manner, such as depression, also likely lend themselves well. Patients can report the level of their symptoms each day to allow general trends to emerge. Another example is psoriasis. Patients could take pictures of their lesions on a regular basis or rate their intensity and could track correlations with medications, diet, or natural therapies.

Chronic diseases that do not have known effective treatments or that don't provide any measureable or perceivable feedback to patients are potentially not a good match for technology-supported apprenticeship, since it is difficult to engage patients and to provide useful awareness. Diseases such as amyotrophic lateral sclerosis (Lou Gehrig's Disease) fall into the category for those that do not have known effective treatments. Early-stage cancers potentially fall into the category of diseases that do not provide measureable or perceivable feedback. The interesting thing about technology-supported apprenticeship, however, is that the coaching component is so adaptable that, even if patients are not learning very specific self-efficacy skills, it may still provide significant comfort and value to patients.

Even in those chronic diseases that lend themselves well to technology-supported apprenticeship, positive results will only be achieved if patients are significantly empowered in their care. Technology-supported apprenticeship requires that patients are supported in developing self-efficacy and encouraged to take the lead in decisions. If they are just expected to adhere to prescriptions and track their progress, as in the early hypertension study at the Mayo Clinic, then they are not truly engaging in apprenticeship and their engagement and outcomes will suffer.

The above observations present the opportunity for future work. Studies could be conducted for all of these diseases listed and more to further understand the benefits and limitations of technology-supported apprenticeship. The tremendous amount of work that this presents was a driving consideration in making the CollaboRhythm platform open-source. Hopefully others with specific expertise in these areas can more easily pursue this research.

6.2.2 Patients with Comorbidities

Many patients with chronic disease suffer from more than one condition. Technology-supported apprenticeship will need to be tested in these scenarios to prove its worth at larger scale. It is expected that technology-supported apprenticeship will actually shine in these cases. Many of the subjects in the diabetes and hypertension trials actual had comorbidities. The approach of starting the process with once condition is part of the philosophy. Theoretically, the patient develops self-efficacy that then transfers over to the next condition that is addressed. In addition, since diet and exercise affect many chronic conditions, improving them for one condition benefits the others.

6.2.3 Lifestyle Tracking

Many patients in the diabetes and hypertension trial wanted the ability to track aspects of their diet and exercise so that these variables could be correlated with their disease outcomes. They were able to make changes and experience the impact without formally tracking their diet and exercise, but they thought that the addition of these features would make change even easier and more compelling. In a prototype project, FitBit data was already integrated with the CollaboRhythm platform and visualized along with blood pressure data. Given the pluggable architecture of the platform, adding support for other diet and exercise tracking is actually quite simple. Tracking diet with current approaches such as taking pictures of food, logging calories, or keeping a spoken log are quite laborious, though. Future work will need to explore the optimum balance between burden of diet and exercise tracking and value in terms of improving clinical outcomes.

6.2.4 Long-term Disease Management and Potential for Usage Fatigue

Chronic diseases typically last a lifetime. Although the results from the clinical trials presented were very encouraging, it will be necessary to prove that patients engaged in technology-supported apprenticeship will maintain these positive results. The majority of study subjects related that they wanted to continue using the technology and working with a coach indefinitely, but typically users fatigue from using the same services over long periods of time. A key benefit of technology-supported apprenticeship is that fading of support as self-efficacy is achieved is already part of the model. And if the burden of reporting can be minimized by using smart devices, it is expected that patients will want to continue with the engagement because of the significant value that it affords. They no longer need to go to office visits and they can get assistance with issues that arise almost immediately. At the same time, once the Hawthorne (observational) effect of being in the study is removed, it is likely that subjects will become more relaxed in their usage. Future research needs to be done to understand the dynamics of long term engagement and how to optimize results.

6.2.5 Scaling Coach Support to Larger Numbers of Patients

The work in this thesis focused heavily on the technology-support for apprentice patients. The technology-support for master clinician coaches was not addressed significantly, since the maximum number of subjects that any coach needed to support was 20. It is expected that, to make this model cost-effective in such a compelling way that it can make an impact on the change-resistant healthcare system, it will be meaningful for a coach to support up to 1000 patients. This will require intelligent workflow tools that help the coach to quickly identify patients who fall off track with their goals and need timely nudges as well as patients who succeed and can benefit from positive reinforcement. Each patient needs to receive an exceptional experience in order for the burden of tracking and managing chronic disease to feel justified. Patients are used to feeling like 1 in a 1000 or 1 in a million in their healthcare experiences. Even though they may be 1 in a 1000 in the technology-supported apprenticeship model, each patient needs to feel like he or she is the only patient that matters. This challenge represents a significant portion of the future work that needs to be conducted.

6.2.6 Patient Safety

Since medications and lifestyle factors are more aggressively adjusted with apprentice patients and since they take more responsibility in their care, safety is an important concern, especially as each coach assumes responsibility for more patients. This becomes an even more important concern as novice patients become masters themselves and begin helping to coach other novices. It needs to be considered, however, that the current standard of care is much more dangerous. It involves very little monitoring and poor communication. The technology-supported apprenticeship model only supports aggressive management when paired with aggressive monitoring. The tremendous amount of feedback data allows for machine and human safety checks on multiple levels. Since apprentice patients build self-efficacy through understanding rather than blindly following algorithms, they are the most important safety measure in the system. As backup, the technology-support has the potential to spot trends in data before they turn into critical values. If critical values are experienced, it can provide immediate recommendations and contact appropriate professionals. As further backup, the master coach is interacting with the apprentice patient and the technology-support at a much greater frequency than any clinician does in the standard of care.

The value of these safety checks are reflected in the results of the diabetes trial, where there were no serious episodes of hypoglycemia, and in the hypertension trial, where there were no hypotensive events. This success was achieved despite the fact that there was no significant machine-level safety support. Subjects and coaches simply kept a close eye on trends and planned accordingly. Despite this success, it will certainly be necessary to test these hypotheses in future work and to develop more sophisticated safety support at the technology level.

6.2.7 Apprentice Patients with Different Experiences and Cultures

Although the technology-supported apprenticeship model has been effective for patients with widely varying ages, widely varying educational levels, and widely varying levels of experience with technology, it has only been tested with a reasonable sample of patients in Boston, Massachusetts. Future work will need to explore the model in diverse populations from diverse cultures. Engaging master clinician coaches from similar backgrounds as the patients being supported will likely be important in achieving success.

6.2.8 Adoption Outside of Studies

The adoption of the technology-supported apprenticeship model outside of research studies is a much more complex topic. Most of care in the United States is volume-based (fee-for-service) and actually disincentivizes dedication of clinician time to support patients in achieving better outcomes. Fortunately, there are movements at the grass-roots (clinic and clinician) level all of the way up the level of the President to gradually shift toward a value-based system. The Affordable Care Act and the establishment of Accountable Care Organizations (ACOs) has been discussed, and represents the top-down approach to change. The more research is conducted that proves that progressive models of care can outperform the standard of care and the more small practices that adopt these progressive models, the greater the urgency for change will become. So an approach that takes its time to address all of the challenges that have presented will likely be more successful than one that attempts to make sweeping change in a system with significant cultural and economic inertia. At the same time, the dire economic situation within the US healthcare system and public disappointment in the poor quality of healthcare delivery in the county will likely contribute to a tipping point in the next decade. Technology to support dramatic change will be embraced, provided that it has been sufficiently validated. If new practices are maximally transparent and can actually publish their experience, clinical outcomes, and costs transparently and in real-time, these is the potential to significantly accelerate change.

In other areas of the world, where the payment model of medicine is not so complex and perversely incentivized, the culture of medicine still presents significant barrier to change. The concept of patients taking the lead in their care and clinicians becoming supportive team members is still potentially sacrilegious. It will take time and the demand of patients for the culture of medicine to adapt to the changing role of the patient and technology.

7 Contributions

7.1 Hierarchy of Patient Empowerment for Evaluating Models of Chronic Care

A three-tiered hierarchy of patient empowerment was presented and was used to reflect on the standard of care in chronic disease management, the best of the best, and the technology-supported apprenticeship model. This framework was critical in inspiring the work in this thesis and can be used by others to critique new and existing models of care.

7.2 Technology Platform (CollaboRhythm) for Prototyping and Researching New Models of Chronic Care

The CollaboRhythm platform was used to create all of the applications that were tested in this thesis, and was also used by about 200 others in building prototype projects during our Health and Wellness Innovation events. An HIV study that is currently being conducted in New Zealand using the platform, and there is another HIV study that will commence in 2014 in Boston. The pharmaceutical company Viiv is building a free commercial application to improve the care of HIV patients using the open-source code base. Hopefully many more researchers and entrepreneurs will take advantage of the open-source and pluggable platform to test their research hypotheses and prototype their innovative ideas for chronic disease care.

7.3 Technology-Supported Apprenticeship as a New Model of Chronic Care

Technology-supported apprenticeship is a rich model grounded in the principles patient-centered care, personal health informatics, health psychology, learning science, and computer-supported cooperative work. It strives to support patients in achieving the pinnacle of the hierarchy of patient empowerment and has been explored deeply using the CollaboRhythm platform. It aims to strike a balance between the scaffolding provided by the technology and the adaptability and social support/accountability provided by master clinician coaching. The hope is that patients will find delight in developing self-efficacy and helping others and that this will create dramatic change in the experience, clinical outcomes, and cost of chronic disease management.

7.4 Two Randomized, Controlled Trials Demonstrating the Potential of Technology-Supported Apprenticeship

The trials for diabetes and hypertension provided extremely encouraging support for technology-supported apprenticeship and its impact on the experience, clinical outcomes, and cost of chronic disease management. They support the patient-centered care movement and strengthen the evidence for value-based care. These clinical trials also provide guidance to others hoping to continue research in technology-supported apprenticeship through their design and through the usage of the open-source and pluggable CollaboRhythm platform.

8 Conclusion

Technology-supported apprenticeship, as a model of care delivery and patient empowerment, can dramatically improve the experience, clinical outcomes, and cost of chronic disease management. Patients respond powerfully to the associations that the technology scaffolding allows them to draw between their actions and clinical outcomes. At the same time, they embrace the opportunity to take responsibility in their care and to receive ongoing support from coaches. It feels like an opportunity to them rather than a burden. As patients delight in this new experience, they achieve dramatically improved outcomes that overshadow the standard of care and even the best of the best in research. All of this is achieved for an up-front cost to the practice that is negligible compared to the potential cost savings. With further advances in the technology and as patients gain self-efficacy over time, it is expected that patients engaging in technology-supported apprenticeship will actually cost less to support while still achieving dramatically improved outcomes. There is a significant amount of future work needs to be conducted to take this model to scale, but these early results are extremely promising.

Works Cited

[1] Centers for Disease Control and Prevention. (2012, June) Chronic Disease Prevention and Health Promotion. [Online]. http://www.cdc.gov/chronicdisease/overview/index.htm

[2] "Almanac of Chronic Disease," Partnership to Fight Chronic Disease, 2009.

[3] National Center for Chronic Disease Prevention and Health Promotion, "Chronic Diseases: The Power to Prevent, The Call to Control," Centers for Disease Control and Prevention, 2009.

[4] DS Jones, SH Podolsky, and JA Greene, "The Burden of Disease and the Changing Task of Medicine," *N Engl J Med*, June 2012.

[5] JH Thrall, "Prevalence and Costs of Chronic Disease in a Healthcare System Structured for Treatment of Acute Illness," *Radiology*, vol. 235, pp. 9-12, April 2005.

[6] "Crossing the Quality Chasm: A New Health System for the 21st Century," Insitute of Medicine, 2001.

[7] New England Healthcare Institute, "Thinking Outside the Pillbox: A System-wide Approach to Improving Patient Medication Adherence for Chronic Disease," 2009.

[8] "Adherence to Long-term Therapies: Evidence for Action," World Health Organization, 2003.

[9] "Recent Trends in the Prevalence of High Blood Pressure and its Treatment and Control," National Center for Health Statistics, Hyattsville, Maryland, 2010.

[10] AV Chobanian et al., "The seventh report of the Joint National Committee on Prevention, Detection, Evaluation, and Treatment of Hight Blood Pressure: the JNC 7 Report," *JAMA*, no. 289, pp. 2560-2572, 2003.

[11] G Ardery et al., "Explicit and Implicit Evaluation of Physician Adherence to Hypertension Guidelines," *The Journal of Clinical Hypertension*, vol. 9, no. 2, pp. 113-119, Feb 2007.

[12] B Vrijens, G Vincze, P Kristanto, J Urquhart, and M Burnier, "Adherence to prescribed antihypertensive drug treatments: longitudinal study of electronically compiled dosing histories," *BMJ*, vol. 336, p. 1114, 2008.

[13] PB Mellen, SK Gao, MZ Vitolins, and DC Goff, "Deteriorating dietary habits among adults with hypertension: DASH diatary accordance, NHANES 1988-994 and 1999-2004," *Achrives of Internal Medicine*, vol. 168, no. 3, pp. 308-314, Feb 2008.

[14] K David, "Expenditures for Hypertension among Adults Age 18 and Older, 2009: Estimates for the U.S.," Agency for Healthcare Research and Quality, Rockville, MD, Statistical Brief #371 June 2012.

[Online]. http://www.meps.ahrq.gov/mepsweb/data_files/publications/st371/stat371.pdf

[15] TA Hodgson and C Liming, "Medical Care Expenditures for Hypertension, Its Complications, and Its Comorbidities," *Medical Care*, vol. 39, no. 6, pp. 599-615, June 2001.

[16] PA Heidenreich et al., "Forecasting the Future of Cardiovascular Disease in the United States: A Policy Statement from the American Heart Association," *Circulation*, January 2011. [Online]. Medical care expenditures for hypertension, its complications

[17] "National diabetes fact sheet: national estimates and general information on diabetes and prediabetes in the United States, 2011," Centers for Disease Control and Prevention, Atlanta, GA: U.S. Departement of Health and Human Services, Centers for Disease Control and Prevention, 2011.

[18] IM Stratton et al., "Association of glycaemia with macrovascular and microvascular complications of type 2 diabetes (UKPDS 35): prospective observational study," *BMJ*, vol. 321, pp. 405-412, August 2000.

[19] American Diabetes Association, "Standards of Medical Care in Diabetes - 2013," *Diabetes Care*, vol. 36, no. Supplement 1, pp. S11-S66, January 2013.

[20] Q Mukhtar, L Pan, L Jack, and D Murphy, "Prevalence of receiving multiple preventative-care services amon adults with diabetes - United States, 2002-2004," *MMWR Morb Mortal Wkly Rep*, vol. 55, no. 44, pp. 1130-1133, 2005.

[21] (2010) Centers for Disease Control: Age-Adjusted Percentage of Adults Aged 18 Years or Older with Diagnosed Diabetes Receiving Preventative Care Practices, United States, 2010. [Online]. www.cdc.gov/diabetes/statistics/preventive/fAllPractices.htm

[22] BJ Mason, JR Matsuyama, and SG Jue, "Assessment of sulfonylurea adherence and metabolic control," *Diabetes Education*, vol. 21, pp. 52-57, 1995.

[23] AHP Paes, A Bakker, and CJ Soe-Agnie, "Impact of dosage frequency on patient compliance," *Diabetes Care*, vol. 20, pp. 1512-1517, 1997.

[24] M Peyrot et al., "Psychosocial problems and barriers to improved diabetes management: results of the Cross-National Diabetes Attitudes, Wishes, nand Needs (DAWN) Study," *Diabet Med*, vol. 22, pp. 1379-1385, 2005.

[25] American Diabetes Association, "Econonic Costs of Diabetes in the U.S. in 2012," *Diabetes Care*, pp. 1-14, March 2013.

[26] L von Ferber, I Koster, and H Hauner, "Medical costs of diabetic complications total costs and

excess costs by age and type of treatment results of the German CoDiM Study," vol. 115, no. 2, pp. 97-104, Feb 2007.

[27] "State of Diabetes Complications in America," American Association of Clinical Endocrinologists, 2006.

[28] ES Huang, A Basu, M O'Grady, and JC Capretta, "Projecting the Future Diabetes Population Size and Related Costs for the U.S.," *Diabetes Care*, vol. 32, no. 12, pp. 2225-2229, December 2009.

[29] Centers for Disease Control. Leading Causes of Death, 1900-1998. [Online]. http://www.cdc.gov/nchs/data/dvs/lead1900_98.pdf

[30] CD Mathers et al., "Global Burden of Disease in 2002: data sources, methods and results," World Health Organization, 2003.

[31] PCK Roy, "Patient's memory for medical information," *J R Soc Med*, vol. 96, no. 5, p. 219.222, May 2003.

[32] C Sia, TF Tonniges, E Osterhus, and S Taba, "History of the Medical Home Concept," *Pediatrics*, vol. 113, no. Supplement 4, pp. 1473-1478, May 2004.

[33] K Grumbach and P Grundy, "Outcomes of Implementing Patient-Centered Medical Home Interventions: A Review of the Evidence From Prospective Evaluation Studies in the United States," Center for Excellence in Primary Care and Patient-Centered Primary Care Collaborative, 2010.

[34] CR Jaen et al., "Patient Outcomes at 26 Months in the Patient-Centered Medical Home National Demonstration Project," *Annals of Family Medicine*, vol. 8, no. Supplement 1, pp. S57-S67, May 2010.

[35] GL Jackson et al., "The Patient-Centered Medical Home: A Systematic Review," *Annals of Internal Medicine*, vol. 158, no. 3, pp. 169-178, Feb 2013.

[36] ES Fisher et al., "Fostering accountable health care: moving forward in medicare," *Health Affairs*, vol. 28, no. 2, pp. 219-231, Mar-Apr 2009.

[37] DL Longworth, "Accountable care organizations, the patient-centered medical home, and health care reform: What does it all mean?," *Cleveland Clinic Journal of Medicine*, vol. 78, no. 9, pp. 571-582, September 2011.

[38] H Meyer, "Many Accountable Care Organizations Are Now Up And Running, If Not Off To The Races," *Health Affairs*, vol. 31, no. 11, pp. 2363-2367, November 2012.

[39] J Dewey, *Experience and Education.* New York: Collier Books, 1938.

[40] J Lave, *Situated Learning: Legitimate Peripheral Participation (Learning in Doing: Social, Cognitive, and Computational Perspectives).*: Cambridge University Press, 1991.

[41] EH Wagner et al., "Improving chronic illness care: translating evidence into action," *Health Affairs*, vol. 20, no. 6, pp. 64-78, Nov-Dec 2001.

[42] FP Cappuccio, SM Kerry, L Forbes, and A Donald, "Blood pressure control by home monitoring: meta-analysis of randomised trials," *BMJ*, vol. 324, p. 145, 2004.

[43] AJ Watson et al., "Evaluating a web-based self-management program for employees with hypertension and prehypertension: A randomized clinical trial," *American Heart Journal*, vol. 164, no. 4, pp. 625-631, October 2012.

[44] RJ McManus et al., "Telemonitoring and self-management in the control of hypertension (TASMINH2): a randomized controlled trial," *Lancet*, vol. 376, pp. 163-172, 2010.

[45] BB Green et al., "Effectiveness of Home Blood Pressure Monitoring, Web Communication, and Pharmacist Care on Hypertension Control: A Randomized Controlled Trial," *JAMA*, vol. 299, no. 24, pp. 2857-2867, 2008.

[46] LG Glynn, AW Murphy, SM Smith, K Schroeder, and T Fahey, "Interventions used to improve control of blood pressre in patients with hypertension," *Cochrane Database Syst Review*, vol. 17, no. 3, March 2010.

[47] LE Boulware et al., "An Evidence-Based Review of Patient-Centered Behavioral Interventions for Hypertension," *American Journal of Preventative Medicine*, vol. 21, no. 3, pp. 221-232, 2001.

[48] SL Norris, MM Engelgau, and EMV Narayan, "Effectiveness of Self-Management Training in Type 2 Diabetes: A systematic review of randomized controlled trials," *Diabetes Care*, vol. 24, no. 3, pp. 561-587, March 2001.

[49] TL Gary, JM Genkinger, E Guallar, M Peyrot, and FL Brancati, "Meta-analysis of randomized educational and behavioral interventions in type 2 diabetes," *Diabetes Education*, vol. 29, no. 3, pp. 488-501, May-June 2003.

[50] SG Swinnen et al., "A 24-Week, Randomized, Treat-to-Target Trial Comparing Initiation of Insulin Glargine Once-Daily With Insulin Detemir Twice-Daily in Patients With Type 2 Diabetes Inadequately Controlled on Oral Glucose-Lowering Drugs," *Diabetes Care*, vol. 33, no. 6, pp. 1176-1178, June 2010.

[51] K Hermansen et al., "A 26-Week, Randomized, Parallel, Treat-to-Target Trial Comparing Insulin Detemir With NHP Insulin as Add-On Therapy to Oral Glucose-Lowering Drugs in Insulin-Naive

People with Type 2 Diabetes," *Diabetes Care*, vol. 26, no. 6, pp. 1269-1274, June 2006.

[52] J Rosenstock et al., "A randomised, 52-week, treat-to-target trial comparing insulin detemir with insulin glargine when administered as add-on to glucose-lowering drugs in insulin-naive people with type 2 diabetes," *Diabetologia*, vol. 51, pp. 408-416, 2008.

[53] L Meneghini, C Koenen, W Weng, and J-L Selam, "The usage of a simplified self-titration dosing guideline (303 Algorithm) for insulin detemir in patients with type 2 diabetes – results of the randomized, controlled PREDICTIVE," *Diabetes, Obesity and Metoabolism*, vol. 9, pp. 902-913, 2007.

[54] L Kennedy, WH Herman, P Strange, and A Harris, "Impact of Active Versus Usual Algorithmic Impact of Active Versus Usual Algorithmic Versus Laboratory Measurement of HbA1c on Glycemic Control in Patients With Type 2 Diabetes: The Glycemic Optimization with Algorithms and Labs at Point of Care (GOAL A1C)," *Diabetes Care*, vol. 29, no. 1, pp. 1-8, January 2006.

[55] H Yki-Jarvinen et al., "Initiate Insulin by Aggressive Titration and Education (INITIATE): A randomized study to compare initiation of insulin combination therapy in type 2 diabetic patients individually and in groups," *Diabetes Care*, vol. 30, no. 6, pp. 1364-1369, June 2007.

[56] E A Joosten et al., "Systematic review of the effects of shared decision-making on patient satisfaction, treatment adherence and health status," *Psychother Psychosom*, vol. 77, no. 4, pp. 219-226, April 2008.

[57] A Edwards and G Elwyn, *Shared decision-making in health care: Achieving evidence-based patient choice.*: Oxford University Press, 2009.

[58] M A Stewart, I R McWhinney, and C W Buck, "The doctor/patient relationship and its effect upon outcome," *J R Coll Gen Pract*, vol. 29, no. 199, pp. 77-82, 1979.

[59] T Bodenheimer, K Lorig, H Holman, and K Grumback, "Patient Self-managment of Chronic Disease in Primary Care," *JAMA*, vol. 288, pp. 2469-2475, 2002.

[60] A Siebenhofer, K Jeitler, and I Rakovac, "Effect of patient self-testing and self-management of long-term anticoagulation on major clinical outcomes," *Ann Intern Med*, vol. 154, no. 7, pp. 472-482, 2011.

[61] A Golbeck, C Ahlers-Schmidt, and A Paschal, "A definition and operational framework for health numeracy," *Am J Preventive Med*, vol. 29, pp. 375-376, 2005.

[62] I Lipkus, G Samsa, and B Rimer, "General perfoance on a numeracy scale among highly education samples," *Medical Decision Making*, vol. 21, pp. 37-44, 2001.

[63] KJ Petrie, LA Jago, and DA Devcich, "The role of illness perceptions in patients with medical conditions," *Current Opinion in Psychiatry*, vol. 20, pp. 163-167, 2007.

[64] KJ Petrie and J Weinman, "Why Illness perceptions matter," *Clinical Medicine*, vol. 6, pp. 536-539, 2006.

[65] WR Rollnick and S Miller, *Motivational Interviewing: preparing people for change*, 2nd ed. New York: Guilford Press, 2002.

[66] T Bodenheimer and MA Handley, "Goal-setting for behavior change in primary care: and exploration and status report," *Patient education and counseling*, vol. 76, no. 2, pp. 174-180, Aug 2009.

[67] S Trajkovski, V Schmied, M Vickers, and D Jackson, "Implementing the 4D cycle of appreciative inquiry in health care: a methodological review," *Journal of Advanced Nursing*, vol. 69, no. 6, pp. 1224-1234, June 2013.

[68] RQ Wolever et al., "Integrative Health Coaching for Patients With Type 2 Diabetes: A Randomized Controlled Trial," *The Diabetes Educator*, vol. 36, no. 4, pp. 629-639, July/August 2010.

[69] MJ Vale et al., "Coaching patients On Achieving Cardiovascular Health (COACH): A Multicenter Randomized Trial in Patients With Coronary Heart Disease," *Arch Intern Med*, vol. 163, no. 22, pp. 2775-2783, 2003.

[70] RM Merrill, SG Aldana, and DE Bowden, "Employee weight management though health coaching," *Eating and weight disorders*, vol. 15, pp. e52-e59, Mar-Jun 2010.

[71] PE Terry, ELD Seaverson, MJ Staufacker, and T Akiko, "The Effectiveness of a Telephone-Based Tobacco Cessation Program Offered as Part of a Worksite Health Promotion Program," *Population Health Management*, vol. 14, no. 3, pp. 117-125, June 2011.

[72] M Banning, "A review of interventions used to improve adherence to medication in older people," *International Journal of Nursing Studies*, vol. 46, pp. 1505-1515, 2009.

[73] JA Sbarbaro, "The patient-physician relationship: compliance revisited," *Annals of Allergy*, vol. 64, pp. 321-331, 1990.

[74] J Schneider, SH Kaplan, S Greenfield, W Li, and IB Wilson, "Better physician-patient relationships are associated wit higher reported adherence to antiretroviral therapy in patients with HIV infection," *J Gen Intern Med*, vol. 19, pp. 1096-1103, 2004.

[75] MA Steward, IR McWhinney, and CW Buck, "The doctor/patient relationship and its effect upon outcome," *J R Coll Gen Pract*, vol. 29, no. 199, pp. 77-82, 1979.

[76] M Vervloet et al., "Tehe effectiveness of interventions using electronic reminders to improve adherence to chronic medication: a systematic review of the literature," *J Am Med Inform Assoc*, vol. 19, no. 5, pp. 696-704, Sept-Oct 2012.

[77] A Ferreira et al., "Why facilitate patient access to medical records," *Stud Health Technol Inform*, vol. 127, pp. 77-90, 2007.

[78] A Honeyman, B Cox, and B Fisher, "Potential impacts of patient access to their electronic care records," *Inform Prim Care*, vol. 13, no. 1, pp. 55-60, 2005.

[79] K D Mandl, W W Simons, W C Crawford, and J M Abbett, "Indivo: a personally controlled health record for health information exchange and communication," *BMC Med Inform Decis Mak*, vol. 7, p. 25, 2007.

[80] J Grudin, "Why CSCW applications fail: problems in the design and evaluation of organizational interfaces," in *CSCW '88 Proceedings of the 1988 ACM conference on Computer-supported cooperative work*, New York, NY, 1988, pp. 85-93.

[81] JA Hughes, D Randall, and D Shapiro, "Faltering from ethnography to design," in *CSCW '92 Proceedings of the 1992 ACM conference on Computer-supported cooperative work*, New York, NY, 1992, pp. 115-122.

[82] WJ Orlikowski, "Learning from Notes: organizational issues in groupware implementation," in *CSCW '92 Proceedings of the 1992 ACM conference on Computer-supported cooperative work*, New York, NY, 1992, pp. 362-369.

[83] P Whitten, L Buis, and M Mackert, "Factors impacting providers' perceptions regarding a midwestern university-based EMR," *Relemed J E Health*, vol. 13, no. 4, pp. 391-397, Aug 2007.

[84] E Rouf, J Whittle, and MD Schwartz, "Computers in the Exam Room: Differences in Physician-Patient Interaction May Be Due to Physician Experience," *J Gen Intern Med*, vol. 22, no. 1, pp. 43-48, January 2007.

[85] O Saigh, MM Triola, and RN Link, "Brief Report: Failure of an Electronic Medical Record Tool to Improve Pain Assessment Documentation," *J Gen Intern Med*, vol. 21, no. 2, pp. 185-188, Feb 2006.

[86] AL Kellermann and SS Jones, "What It Will Take to Achieve the As-Yet-Unfulfilled Promises of Health Information Technology," *Health Affairs*, vol. 32, no. 1, pp. 63-68, January 2013.

[87] KR Abbott and SK Sarin, "Experiences with workflow management: issues for the next generation," in *CSCW '94 Proceedings of the 1994 ACM conference on Computer supported cooperative work*,

New York, NY, 1994, pp. 113-120.

[88] P Markopoulos, B deRuyter, and W Mackay, *Awareness Systems: Advances in Theory, Methodology, and Design.*: Springer, 2009.

[89] SE Hudson and I Smith, "Techniques for addressing fundamental privacy and disruption tradeoffs in awareness support systems," in *CSCW '96 Proceedings of the 1996 ACM conference on Computer supported cooperative work*, New York, NY, 1996, pp. 248-257.

[90] S Consolvo, P Roessler, and B Shelton, "The CareNet Disply: Lessons Learned from an In Home Evaluation of an Ambient Display," in *Proceedings of the 6th Int'l Conference on Ubiquitous Computing: UbiComp '04*, 2004, pp. 1-17.

[91] ED Mynatt, J Rowan, S Craighill, and A Jacobs, "Digital family portraits: supporting peace of mind for extended family members.," in *CHI '01 Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, New York, NY, 2001, pp. 333-340.

[92] P Markopoulos et al., "Keeping in Touch with the Family: Home and Away with the ASTRA Awareness System," in *CHI EA '04 CHI '04 Extended Abstracts on Human Factors in Computing Systems*, New York, NY, 2004, pp. 1351-1354.

[93] I Illich, *Deschooling Society.*: Calder and Boyars Publishers, 1971.

[94] A Collins and R Halverson, *Rethinking Education in the Age of Technology.*: Teachers College Press, 2009.

[95] A Collins, J S Brown, and S E Newman, "Cognitive apprenticeship: Teaching the crafts of reading, writing, and mathematics," in *Knowing, learning, and instruction: Essays in hornor of Rober Glaser.* Hillsdale, NJ: Lawrence Erlbaum Associates, 1989, pp. 453-494.

[96] J S Brown, A Collins, and P Duguid, "Situated Cognition and the Culture of Learning," *Educational Researcher*, vol. 18, no. 1, pp. 32-42, 1989.

[97] Children's Hospital Informatics Program. (2013, July) The Indivo Personally Controlled Health Record. [Online]. http://indivohealth.org/

[98] KD Mandl and IS Kohane, "No small change for the health information economy," *New England Journal of Medicine*, vol. 360, no. 13, pp. 1278-1281, 2009.

[99] DL Paterson et al., "Adherence to protease inhibitor therapy and outcomes in patients with HIV infection," *Ann Intern Med*, vol. 133, no. 1, pp. 21-30, Jul 2000.

[100] JJ Parienti et al., "Average adherence to boosted protease inhibitor therapy, rather than the

pattern of missed doses, as a predictor of HIV RNA replication," *Clin Infect Dis*, vol. 50, no. 8, pp. 1192-1197, Apr 2010.

[101] JJ Parienti, DR Bangsberg, R Verdon, and EM Gardner, "Better adherence with once-daily antiretroviral regimens: A meta-anlysis," *Clin Infect Dis*, vol. 48, no. 4, pp. 484-488, Feb 2009.

[102] V Gordillo, J del Amo, V Soriano, and J Gonzalez-Lahoz, "Sociodemographic and psychological variables influencing adherence to antiretroviral therapy," *AIDS*, vol. 13, no. 13, pp. 1763-1769, Sept 1999.

[103] EJ Mills, JB Nachega, and C Cooper, "Adherence to HAART: A Systematic Review of Developed and Developing Nation Patient-Reported Barriers and Facilitators," *PLoS Medicine*, vol. 3, no. 11, p. e438, November 2006.

[104] WH Polonsky, L Fisher, S Guzman, L Villa-Caballero, and SV Edelman, "Psychological Insulin Resistance in Patients With Type 2 Diabetes: The scope of the problem," *Diabetes Care*, vol. 28, no. 10, pp. 2543-2545, October 2005.

[105] C Bradley, "Diabetes Treatment Satisfaction Questionniare (DTSQ)," in *Handbook of Psychology and Diabetes: A Guide to Psychological Measurement in Diabetes Research and Management*, Bradley, Ed.: Psychology Press, 1994.

[106] K Davis, M Tangirala, JL Meyers, and W Wei, "Real-world comparative outcomes of US type 2 diabetes patients initiating analog basal insulin therapy," *Current Medical Research & Opinion*, vol. 29, no. 9, pp. 1-9, 2013.

[107] Richard Kahn, Rose Marie Robertson, Robert Smith, and David Eddy, "The Impact of Prevention on Reducing the Burden of Cardiovascular Disease," *Circulation*, vol. 118, pp. 576-585, 2008.

[108] JJ Caro, AJ Ward, and JA O'Brien, "Lifetime Costs of Complications Resulting from Type 2 Diabetes in the U.S.," *Diabetes Care*, vol. 25, no. 3, pp. 476-481, March 2002.

[109] "Crossing the Quality Chasm: A New Health System for the 21st Century," Institute of Medicine, Consensus Report 2001.

Acknowledgments

Scott Gilroy was a partner is building the CollaboRhythm platform and was an important contributor to all of the work presented in this thesis.

Frank Moss contributed significantly to the underlying philosophy of patient empowerment and provided invaluable advice throughout the research process.

Mitch Resnick was a master coach in applying the principles of learning science to healthcare.

Pattie Maes provided insights from the field of computer-supported cooperative work that informed the development of the CollaboRhythm platform.

David Judge inspired many of the ideals about patient-centered care and health coaching through his work at the Ambulatory Practice of the Future.

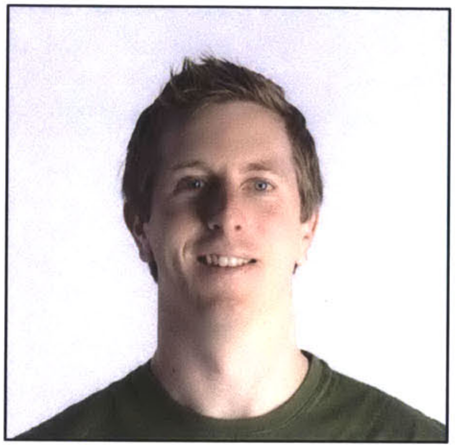
Helene Hardy PharmD and Paul Skolnik MD were collaborators at Boston Medical Center on the HIV medication adherence pilot.

Jo Augustine RN, Nathan LeBrasseur PhD, Emily Friedman, Alfred Anderson, and Nick LaRusso MD were collaborators at the Mayo Clinic Center for Innovation on the hypertension medication adherence pilot.

Will Hsu MD, Also Rossini MD, Sue Ghiloni RN CDE, Paige Ricci, and Ruyi Star MD were collaborators at the Joslin Diabetes Center on the insulin titration trial. Will was instrumental in designing and conducting the trial, and the entire team is responsible for the success that has been achieved so far.

MaryAnn Marshall RN, David Judge MD, Ben Crocker MD, Jane Maffie-Lee MSN, and Randall Zusman MD were collaborators at the Massachusetts General Hospital on the hypertension management trial. The entire team was involved in designing the trial. MaryAnn almost single-handedly conducted the entire trial and was critical in its success.

Author Biography



John Moore is a physician and technologist working to fundamentally change the role that patients can play in their care by empowering them with knowledge, understanding, confidence, and channels for communication. He studies the effect that new, technology-mediated paradigms for clinician-patient collaboration can have on the experience, clinical outcomes, and cost of healthcare.

Moore received both a BS in biomedical engineering and an MD from Boston University. Before attending medical school, he was a Fulbright Scholar in Belgium.