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eHEALTH INITIATIVE

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A STUDY AND REPORT ON THE USE OF EHEALTH TOOLS FOR CHRONIC DISEASE CARE AMONG SOCIALLY DISADVANTAGED POPULATIONS FINAL REPORT



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Executive Summary

Introduction

Successfully managing and treating diabetes, heart disease, and cancer requires extensive coordination of care, processes, and resources between and among providers and patients. Patient self-management and education are critical to engaging individuals with these chronic conditions and encouraging them to routinely measure and monitor medications, diet, exercise, lifestyle changes, vital signs, and symptoms as they follow care plans or protocols developed with their care team. However, significant disparities in healthcare can sometimes limit the ability of patients to receive and manage their chronic conditions. The use of health information technology or “eHealth tools” has not only been associated with clinical improvements in disease prevention, management, and treatment, but also with reductions in disparities in care. eHealth Initiative, a non-profit organization whose mission is to drive improvements in the quality, safety and efficiency of healthcare through information and technology, received a grant from the California HealthCare Foundation in April 2012 to review eHealth tools that could assist socially disadvantaged patients with managing diabetes, heart disease and cancer.

For the purposes of this study, “socially disadvantaged populations” are defined as those who lack access to primary and specialty care because of low socioeconomic status or geographic barriers in rural areas. Clinical settings serving this population often face unique challenges, including:

- Shortage of resources to effectively treat and manage patient care;
- Lack of access to other centers of care or specialty care providers;
- Health literacy, education, and knowledge barriers faced by patients;
- Geographic barriers and terrain challenges that limit patient access to medical care; and
- Difficulties arising from linguistic and cultural differences.

Over a nine-month period, this study was informed by a literature review of more than 500 articles, a series of key informant interviews to fill gaps in the literature, and consultations with a Technical Advisory Group of subject matter experts. This report explores four domains of technology and eHealth tools: **telehealth, mobile health, patient web portals**, and **social media**.

Telehealth

Telehealth involves the use of information and communications technology to provide healthcare services to individuals who are not in close proximity to a provider. The use of telehealth is particularly advantageous for socially disadvantaged populations. A number of telehealth case studies utilizing diverse technical approaches, such as videoconferencing, digital retinal cameras, secure messaging, and remote monitoring are cited within this study. These studies employed different approaches to telehealth, including transmitting patient data directly to a provider in real-time, and storing the data and forwarding it to a provider upon request. Research revealed that telehealth can increase the accessibility of health services to those who are not in close proximity to a health care provider, rural populations, and those with limited ability to obtain in-person primary care services routinely or easily.

Telehealth studies discussed in the report observed improvements in care and management such as:

- **Reduction in blood glucose levels and blood pressure:** The Informatics for Diabetes Education and Telemedicine Study (IDEATel) study provided 1,600 patients with a web camera, a home glucose meter, and access to their own data and a website with educational materials on diabetes.
- **Lower cardiovascular risk factors among socially disadvantaged populations:** Insight TeleHealth system (ITSMYHealthFile) was used at Temple University and Geisinger Medical Center to examine the impact of a telehealth-supported nurse management program among rural and urban underserved populations. After one year of surveillance among a sample of 465 adults, the program reduced significant percent reduction in risk was observed among intermediate and high-risk subjects.
- **Reduced relative risk for readmission or death:** The Mobile Telemonitoring in Heart Failure Patients Study (MOBITEL) tested the impact of a home-based telemonitoring system using internet and mobile phone technology on a sample of 120 heart failure patients participating in the randomized controlled trial. Patients recorded and transmitted daily vital signs and medication dosage through patient terminals to their physicians, who were subsequently alerted by email in the event of adverse or emergency reports.
- **Decrease in diabetes-related hospitalizations as well as ED and outpatient visits:** In the Veterans Administration Care Coordination Home Telemedicine (CCHT) study, a group of over 400 diabetic veterans used a secure device to communicate information about their diabetes symptoms and health status on a daily basis over a 24 month period. Care coordinators

reviewed the data to determine if patients would receive follow-up phone calls or appointments.

- **Reduced depression and pain among cancer patients:** The Indiana Cancer Pain and Depression Trial examined the impact of a telephone-based care management and automated symptom monitoring program among 405 urban and rural patients. Nurse care managers assessed symptom response and medication adherence, provided pain and depression-specific education, and made treatment adjustments through phone calls with patients. Additionally, patients showed trends toward decreased number of hospital days and emergency department usage.

Many of the pilot programs demonstrated sustained reductions in blood glucose levels, lipid levels, blood pressure and pain, as well as reductions in emergency room visits and hospital readmissions. These studies are discussed in more detail within the report.

Mobile Health

The use of mobile health (mHealth) devices and applications for chronic disease care has been one of the most significant health IT developments of the past five years. Existing and emerging mHealth technologies, such as smartphone applications, devices with email and text messaging (SMS) functionality, pagers, and the wireless internet have helped facilitate patient self-management of chronic disease. Results from this study demonstrate that mHealth tools can be used to practically and effectively monitor a patient's status and clinical outcomes, while simultaneously increasing patient adherence to treatments.

Mobile health studies discussed in the report observed improvements in care and management such as:

- **Improved glucose levels for patients with diabetes:** The WellDoc Diabetes Manager System mobile health application provides weekly automated clinical coaching driven by real-time patient data, such as blood glucose values, carbohydrate intake, medications, and weight. Patients using this system in conjunction with a glucose monitor showed significant reductions in blood glucose levels during a 12-month randomized controlled trial.
- **Improved knowledge about condition:** DiaBetNet uses a wireless personal digital assistant (PDA) with diabetes management software and an integrated motivational game to assist youths between eight and 18 years manage their Type 2 diabetes. Seventy patients demonstrated improvements

in their overall knowledge of diabetes and continual maintenance of their blood glucose levels in a six-month pilot.

- **Decreased hospitalizations and improved physical functioning of chronic heart failure patients:** The Telemedical Interventional Monitoring in Heart Failure (TIM-HF) trial investigated the impact of remote telemedical management using portable devices among 710 patients. Over a 12 month period, patients measured ECG, blood pressure, and body weight via a personal digital assistant (PDA) that sent automated encrypted transmission telemedical centers. Hospitalization for heart failure and cardiovascular death was slightly lower among these patients, who also showed improved physical functioning.
- **Improvements in quality of life, self-care, and clinical management within heart patients:** The Mobile Phone-Based Telemonitoring for Heart Failure Management was a randomized controlled trial of 710 patients that used smartphone monitoring via text messaging to transfer real-time vital signs, symptoms, and patient-entered information. Upon transmission, intervention subjects received automated instructions and physicians were alerted in the case of an emergency. Improvements in quality of life, self-care maintenance, and clinical management were observed.
- **Improved provider communication with patients about symptoms & quality of life issues:** The Electronic Symptom Report and Assessment Cancer (ESRA-C) Study used wireless touch-screen laptop computers to assess patient-reported symptoms and quality of life measures. Patients undergoing new radiation therapy, medical oncology therapy or hematopoietic stem cell transplantation used the device twice over a period of six to seven weeks. Most patients found that using the device for symptom reporting was acceptable. Providers in the intervention arm were 29% more likely to discuss symptoms and quality of life issues that were reported at a problematic threshold level with the patient.

In addition to the published studies and trials reviewed for this report, online market research uncovered specific healthcare applications that patients can directly download onto a smartphone. Applications available to diabetes patients are particularly popular. The number of smartphone applications for diabetes has increased by almost 400% over the past three years, from 60 applications available for the iPhone, to over 260 available on various mobile platforms.

This study identified hundreds of applications available to patients. Applications cited in the report allow patients to:

- Track information about their diet, exercise regimen, and medications;

- Access interactive forums for diabetes education and support;
- Communicate information about diet, exercise and medications to providers;
- Measure and share information about an individual's heart rate;
- Predict risk of cardiovascular disease using factors such as age, gender, blood pressure, height, weight, and smoking status;
- Manage questions for and answers from providers regarding their cancer; and
- Manage treatment-related information with an emphasis on mental health and social needs.

Mobile health applications, which have significantly risen in availability over the past year, are the fastest growing sector of the patient-centered tools industry. Given the dramatic uptick in smartphone adoption in 2012, it seems likely that this area will increase exponentially over the next few years. More detail on each of the studies and applications is discussed in the full report.

Patient Web Portals

Patient web portals (PWP) are internet-based technologies that offer patients online access to their electronic health records (EHRs) and tools to help manage their chronic conditions. These systems show great promise in facilitating communication between patients and providers, as well as providing a means of accessing educational materials to assist all populations in the management and care of diabetes, heart disease and/or cancer.

PWPs discussed in the report demonstrate improvements in care, such as:

- **Positive changes in medication regimens and lower blood glucose levels:** HealthCare System's Patient Gateway allows direct patient access to an EHR through a secure Internet connection. Patients log on and review their medications and diabetes care measures and communicate with their primary care provider via secure messaging. Results from a randomized controlled trial showed changes in the medication regimens could potentially lead to better diabetes care, and a trend toward lower blood glucose levels.
- **Improved communication with providers and patients:** Kaiser Permanente HealthConnect facilitates communication between patients and providers using secure messaging through a PWP. Patients can view lab results, medications, and portions of their health record. A large percentage of the secure emails sent to providers required a clinical assessment or decision, while another significant proportion required a clinical action.
- **Providing up to date educational materials for patients:** HeartHub is a patient web portal that provides information, tools and resources on

cardiovascular disease. The online information resource repository addresses topics on multiple heart diseases and conditions, while providing patients with innovative tools like Heart360, which allows users to track health information and share results directly with their provider.

- **Improved quality of discussion between cancer patients and clinicians:** Memorial Sloan-Kettering Cancer Center (MSKCC) hosts MYMSKCC, which provides access to medical information and education resources, appointment management, secure messaging, and support for billing. Researchers at MSKCC have also used a separate online portal, the Symptom Tracking and Reporting (STAR) platform, to help patients report treatment side-effects. The STAR portal allowed patients to complete an online questionnaire about chemotherapy toxicity related symptoms and sent providers a report of symptoms that reached a threshold level. Results from a feasibility study showed an average 78 percent adherence rate for using the system at clinic visits. Patients found the system easy to use and helpful, 77 percent felt it improved the quality of discussion with clinicians, and 51 percent thought communication was improved.

PWPs are discussed in greater detail within the full report.

Social Media

Social media encompasses a wide range of online tools including discussion forums, blogs, collaborative websites (wikis), social networking sites, photo and video sharing, chat rooms, and virtual worlds. Research has found that many patients use social media to gather information about their condition to communicate more effectively with their providers, identify other individuals with similar chronic conditions with whom to share clinical information and receive support, and to identify sources of education regarding their disease.

A robust review of the literature revealed very limited research demonstrating the impact of social media on chronic disease care. Online social support programs have been shown to decrease the prevalence of adverse symptoms associated with diabetes, improve health behavior, reduce utilization of health care resources, and improve psychosocial support. Despite the wealth of social media tools available to patients, very little evidence has been documented to date on the impact of these tools and further research is needed to evaluate their effectiveness. More detail on this is discussed in the full report.

Final Thoughts

A thorough review of the literature, market, and online applications revealed that a number of studies and pilot programs have effectively documented a positive impact of eHealth tools on outcomes associated with diabetes, heart disease, and cancer. Moreover, it is clear that the use of these tools is continuing to grow. Based on results from this study, a number of overarching conclusions were reached:

- **If mHealth trends continue, there could be a significant improvement in outcomes among individuals living with diabetes and heart disease.** Mobile health applications, which have significantly risen in availability over the past year, are the fastest growing sector of the patient-centered tools industry. Given the increase in smartphone adoption within the first and second quarters of 2012, it seems likely that patient-centric technologies will utilize more mobile capabilities.
- **mHealth tools are viable eHealth tools for socially disadvantaged populations.** Increased access to mHealth among socially disadvantaged populations indicates that mHealth is an effective tool to provide outreach and access to care regardless of an individual's socioeconomic status, race, ethnicity, or geographic location. mHealth can provide vital tools to increase health care access, improve care delivery systems, and assist individuals in engaging in culturally competent outreach and education via technology that is easy to use, affordable and scalable, and has already been adopted by patients of all ages and socioeconomic status. Effective mHealth can empower patients by providing information and education about medications and risk factors, connect patients to communities and resources, and provide patient advocacy through engagement.
- **Mobile health is underutilized in the treatment and management of cancer.** Fewer studies assessed the use of mobile health by cancer patients. Like telehealth, mHealth can overcome geographic isolation. Given the rates of smartphone adoption among all populations, mobile health may offer a cheaper alternative to telehealth while simultaneously connecting more patients and providers. Though a variety of smartphone applications enable patients to learn about cancer, manage treatment, enhance decision-making, receive social support, and make important lifestyle changes, few mHealth technologies for cancer have been studied in medical settings.
- **Cancer patients interact with eHealth tools differently than patients with heart disease and diabetes.** Whereas managing indicators like blood glucose levels and blood pressure are an effective means of managing diabetes

and heart disease, physiologic measurements that patients can undertake themselves are less relevant to cancer care. As a result, the remote-monitoring capabilities that typified many eHealth tools for diabetes/heart disease were not present in cancer tools. To the extent that remote-monitoring was employed, it was used to help patients report and manage treatment related side-effects and psychosocial outcomes.

- **Patient web portals are educating patients about their chronic conditions.** Patient web portals have gained tremendous popularity over the past few years, with a number of major health organizations creating and implementing portals for their patient communities. These portals show great promise in facilitating communication between patients and providers, as well as a means of accessing educational materials to assist all populations in the management and care of their chronic conditions.
- **Patient web portals have the potential to help cancer patients manage their care across the continuum.** Patient web portals and online information management systems often blend education, treatment management, health tracking over time, and social support into a single system. Messaging features can greatly improve patient-provider communication and joint management of the information in the system fosters collaborative decision-making and patient engagement. When combined with mobile technologies, these tools are even more effective.
- **Lack of data on the effectiveness of social media has not deterred patients despite underutilization by care providers.** Despite widespread use, there is a need to study and evaluate the effectiveness of social media on the self-management of diabetes, heart disease, and cancer. Dozens of social networking communities, blogs, wikis and other platforms have demonstrated the utility of social media in helping patients form support groups, provide educational resources, share knowledge and best practices in the care and management of their condition. However, we did not identify any studies that have evaluated the effectiveness of social media on chronic care, nor its overall use among socially disadvantaged populations. Very little work has been done in this area, despite increasing trends in adoption.
- **In addition to spurring the use of electronic health records (EHRs), Meaningful Use (MU) rules may drive integration of eHealth Tools to exchange patient data and improve education, engagement, and communication efforts.** Although many of the measures and requirements of MU Stages 1 and 2 target specific objectives for eligible hospitals and physicians to record, share, and report information via EHRs, there is an underlying emphasis on improving patient access to information and education. Patient-facing technologies such as telehealth and mHealth can complement provider-centric EHR systems to improve communication, education, and exchange of

data among patient populations of all ages, genders, ethnicities, income and education levels, and geographic areas. By breaking down traditional barriers to access to care among socially disadvantaged populations, these technologies are likely to continue to grow in importance and use as EHRs are adopted by smaller clinics and hospitals serving low-income populations

- **It is not clear what patients “want” or “like”. Assumptions about patient preferences with technology have not been tested.** Very few assumptions have been tested with patient population outside of controlled experiments. While many of the studies identified in this report discuss the number and type of patients that utilized eHealth Tools, usability was not often featured by researchers in their evaluation and assessment of the tools. Despite generally accepted principles and frameworks of design for eHealth tools, it is unclear whether patients who participated in studies found the Tools usable and satisfactory for their needs. Furthermore, few eHealth Tools appear to be specifically adapted for use by those with low health literacy, those for whom English was not their primary language, or those with limited technical knowledge.

With chronic conditions disproportionately affecting socially disadvantaged populations, there is a fundamental need to provide this population with the appropriate tools to empower them to manage their health, create continuous and consistent patient-provider communication, and provide educational resources. This study documents how the use of telehealth, mobile health, patient-web portals and social media can facilitate patient self-management, improve compliance with care protocols and medication management, and reduce risk, hospital readmissions and costs of diabetes, heart disease, and cancer.

A Study and Report on the Use of eHealth Tools for Diabetes, Heart Disease, and Cancer Care

Introduction

Effectively managing chronic diseases, such as diabetes, heart disease, and cancer, requires a close partnership between patients and the providers responsible for their care. Managing these diseases extends well beyond episodic visits to a provider's office, as patients are inevitably responsible for many of the day-to-day aspects of their care. Patients with diabetes, heart disease, and cancer are frequently called upon to monitor physiological indicators, maintain a specific diet, and/or follow a complex medication regimen. Patients are also best situated to report on the severity of their symptoms and the efficacy of treatments being provided. However, compliance with self-management programs is often poor due to a number of factors, especially among socially disadvantaged populations. These groups characteristically lack the resources or know-how to facilitate self-management, and face barriers including the inability to comprehend instructions regarding vital sign tracking, medication adherence, or lifestyle management, a lack of understanding as to the severity of their condition and how to appropriately manage it, and the lack of a support infrastructure capable of prompting the patient to take appropriate action and educating them on the importance of aspects of chronic care management.

Fortunately, advances in technology are making it easier for patients to self-manage diabetes, heart disease, and cancer. Today, various components of health information technology (health IT), such as telemedicine, mobile health (mHealth), patient web portals (PWP), and social media are being effectively employed by self-management programs. These eHealth tools not only assist patients in understanding and performing self-management activities, but also improve patient-provider communication outside of the provider's office. By using these tools, patients can transmit information regarding their functional status, quality of life and physiological measures to their healthcare providers, who can then interpret the data and respond accordingly. eHealth tools often include functionalities to help patients track and understand this information, helping them be better informed about their condition. Additionally, eHealth tools open new channels of communication between patients, providers, family, friends, and community organizations to enhance education, information sharing, and

psychosocial support. eHealth tools may be particularly relevant to socially disadvantaged populations – defined as those who lack access to primary and specialty care because they are socioeconomically disadvantaged or live in rural areas – as they enable healthcare providers to reach patients in an unprecedented manner. In fact, the use of health IT has been associated with demonstrable improvements in the clinical measurement and treatment of diabetes, heart disease, and cancer among these groups.

eHealth Initiative, a non-profit organization whose mission is to research and identify the ways health information technology can be used to improve the quality, safety and efficiency of healthcare, received a grant from the California HealthCare Foundation in April 2012 to study and review technologies that can improve chronic disease care and control among socially disadvantaged populations, with a focus on diabetes, heart disease and cancer. This final report represents the culmination of over nine months of research, interviews, and case studies. Specific results for each disease were published earlier in three separate issue briefs, released in July (diabetes), November (heart disease) and December (cancer), respectively. This study focuses on specific domains of technologies identified for chronic disease care that can be used by patients, including: telehealth, mobile health, patient web portals and social media. Each identified technology was assessed for the following:

- evidence that the technology has a direct impact on chronic disease care and control;
- availability and accessibility of the technology to socially disadvantaged communities;
- impact of the technology on risk factors that are inherent to socially disadvantaged populations;
- usability of the technology for patients;
- cost-effectiveness of the technology for physicians;
- ability of the technology to exchange data within a large health information system; and
- privacy and security frameworks of each technology to protect personally identifiable health information.

A technical advisory group consisting of subject matter experts in health IT, chronic disease care, and/or healthcare among socially disadvantaged populations guided our methodological approach, which included a comprehensive literature review, key informant interviews and site visits.

The Rising Burden of Chronic Disease

Over the past several decades, the overall chronic disease burden in the United States has steadily increased. Today, chronic conditions are among the most common and expensive illnesses, despite the abundance of evidence demonstrating avoidable risk factors for these diseases. More than 133 million Americans live with at least one chronic condition,¹ and more than 25 percent of adults and 66 percent of Medicare beneficiaries are estimated to have multiple comorbid chronic conditions.² Chronic conditions increase a patient's risk of health-related complications, poor functional status, hospitalization, readmission following hospitalization, and mortality.³ Twenty-five percent of those with chronic conditions have one or more daily activity limitations. As incidence and prevalence have skyrocketed, chronic diseases have become the leading causes of death and disability nationwide. Seventy percent of deaths each year are attributable to chronic disease, with the vast majority resulting from heart disease, stroke, and cancer.⁴ Figure 1 displays the extent of reported chronic illnesses in the U.S. as of 2003 (excluding untreated or undiagnosed cases, as well as non-institutionalized populations).⁵

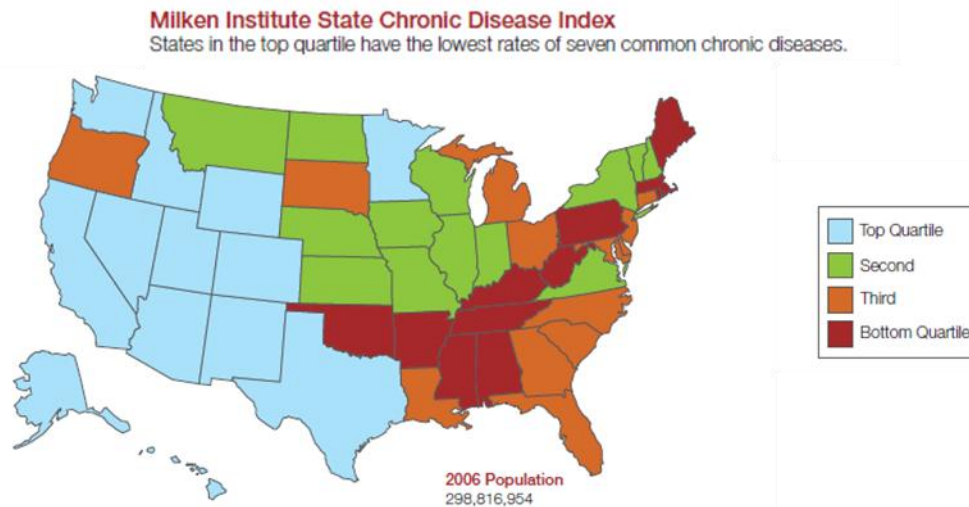


Figure 1: Chronic Disease Index (2003)

The marked increase in prevalence of chronic disease is largely attributable to the convergence of an aging population with the widespread persistence of lifestyle-related risk factors, such as obesity, sedentary behavior, environmental exposure, poor diet, and use of tobacco and alcohol.⁶ Over the past several decades,

overweight (defined as a BMI between 25 and 29) and obesity (defined as a BMI greater than 30) rates have substantially increased. Today, 35.7 percent of adults and 17 percent of youths are obese in the United States. The prevalence of obesity has tripled since 1990, when only 11.6 percent of the adult population was obese. Figure 2 displays the dramatic change in obesity rates over the past decade.⁷

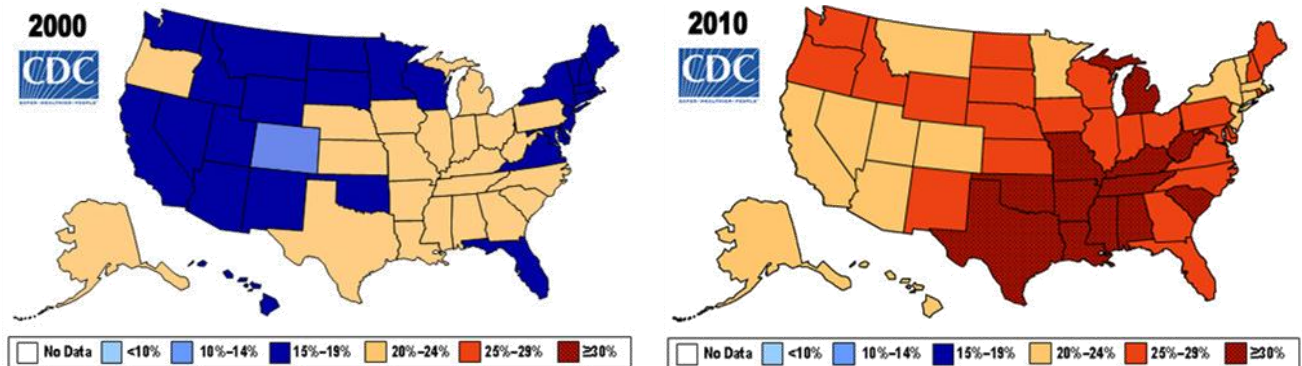


Figure 2: Prevalence of Obese Adults (BMI ≥ 30) in the U.S.

Advances in medical science and technology have also indirectly resulted in an increase in the prevalence of chronic conditions. New treatments and management procedures have enabled patients with chronic disease to live longer. Likewise, improved screening techniques have resulted in diagnoses for individuals who might otherwise have gone undiagnosed.

The Cost of Chronic Disease

Managing the effects of and treating chronic disease costs the U.S. economy more than \$1 trillion annually and accounts for 75 percent of health care spending. At current rates, these costs are projected to increase to more than \$6 trillion by 2050.⁸ Compared to other nations, the U.S. spends significantly more on health care, with an average expenditure of \$8,233 per person in 2012.⁹

Diabetes itself costs the nation almost \$100 billion annually and can cause severe complications including cardiovascular disease, neuropathy, and retinopathy that require further treatment.¹⁰ Direct expenditures for coronary heart disease (CHD) are estimated to cost \$90.9 billion per year.¹¹ The American Heart Association expects this to increase to \$218.7 billion by 2030.¹² Indirect costs account for an additional \$68.8 billion (\$58.6 billion for lost productivity from mortality and \$10.2 billion attributed to morbidity).¹³ The estimated overall cost of cancer in 2010 was \$263.8 billion: \$102.8 billion for direct medical costs (total of all health expenditures); \$20.9 billion for indirect morbidity costs (cost of lost productivity

due to illness); and \$140.1 billion for indirect mortality costs (cost of lost productivity due to premature death).¹⁴ Like healthcare costs overall, cancer costs have been increasing steadily in the U.S., especially with the development of new and more expensive treatments that target specific cancer cells and have fewer negative side effects.¹⁵ Primarily because of the growing and aging U.S. population, the annual, direct medical costs of cancer care are projected to reach \$157 billion in 2020.¹⁶

Chronic disease care is primarily financed through health insurance, including plans offered by employers, individual insurance policies, and government programs such as Medicare and Medicaid. Seventy-eight percent of private insurance spending is designated to care for chronic conditions, and the vast majority of Medicare and Medicaid funding goes to chronic disease care. More than 95 percent of Medicare spending and nearly 80 percent of Medicaid spending is for patients with chronic conditions.¹⁷

Prevalence and Mortality

Diabetes, heart disease, and cancer are consistently among the most common and deadly chronic conditions. In 2011, the U.S. Centers for Disease Control & Prevention (CDC) estimated that over 25.8 million children and adults have diabetes, representing 8.3 percent of the U.S. population. Of those, only 18.8 million people have been clinically diagnosed with the disease. Over 7 million people remain undiagnosed. Further, an estimated 79 million Americans (35% of the population) have blood glucose levels that place them at risk of developing diabetes.¹⁸ In 2007, diabetes was the seventh leading cause of death in the U.S., with 71,382 deaths attributed to disease. However, the real figure is likely much higher, as only 35 to 40 percent of diabetic patients have diabetes listed as a contributor on their death certificate.¹⁹

Heart disease is the leading cause of death among men and women in the United States and is a major cause of disability. 595,000 people die of heart disease each year, a rate equivalent to one in every four deaths.²⁰ Approximately 18.5 million Americans have coronary heart disease (CHD), with prevalence highest in the southeastern U.S. Both the prevalence and mortality of CHD have decreased over time, largely due to advances in disease prevention, treatment, and management. Prevalence rates declined from 6.7 to 6.0 percent between 2006 and 2010. Mortality rates have declined steadily since the 1960s. While the double drop in mortality and prevalence suggests that the incidence of CHD is also moribund, the crude number of individuals with CHD is expected to sharply increase to 8.6% of the population by 2020 and continue to rise unchecked in the face of an aging population, improved treatment protocols enabling patients with CHD to survive for

longer periods of time, and growing prevalence of associated risk factors.²¹ Currently, more than 37 percent of the general population has multiple modifiable risk factors for heart disease, including sedentary behavior, obesity, high blood pressure and cholesterol, cigarette smoking, diabetes, diet, and stress.²²

As many as one-third of all women and half of all men will develop cancer within their lifetime.²³ In 2008, an estimated 11,958,000 people in the United States had cancer.²⁴ In 2012, the American Cancer Society projects that 1,638,910 men and women will be diagnosed with cancer and that 577,190 will die from cancer.²⁵ Lung cancer is the deadliest form of the disease. In 2011, an estimated 221,130 men and women were diagnosed with and 156,940 died from lung cancer. Breast cancer is the most commonly diagnosed and second deadliest form of cancer in women, while prostate cancer is the most commonly diagnosed and second leading cause of death from cancer in men. In 2011, approximately 230,480 women were diagnosed with and 39,520 died from breast cancer and 240,890 men were diagnosed with and 33,720 died from prostate cancer.²⁶ Based on data from the National Cancer Institute's Surveillance, Epidemiology and End Results (SEER) Program, overall incidence and death rates for cancer have declined each year between 2004 and 2008 (averaging -0.4% and -1.61% per year respectively).²⁷ However, the crude number of new cancer diagnoses is expected to increase, as will the number of cancer survivors.²⁸

The Challenges of Treating Diabetes, Heart Disease, & Cancer

Diabetes, heart disease, and cancer are all complex diseases to treat, with many aspects of care occurring outside of the provider's office. Diabetes is typically treated through a combination of diet, physical activity, medication (insulin), and blood glucose management. Patients must also frequently monitor other health indicators such as blood pressure, cholesterol, and eye and foot health to prevent diabetes-related complications. Ideal care for diabetes involves a team of providers, including a primary care physician, an endocrinologist, a diabetes educator, dietician, podiatrist, and/or ophthalmologist.²⁹ Because much of diabetes care is performed by the patient, successfully managing diabetes relies on educating patients about their condition, particularly the importance of diet and maintaining control of blood sugar levels.³⁰ As part of the treatment process, patients and providers need to discuss the patient's status frequently, so that adjustments can be made to the patient's care plan. As such, patients should have access to tools that can help them track their treatment-related measures and quickly communicate with their care team.

Successful management of heart disease requires similar key elements, such as coordinated care, patient support and education for self-care, active communication

between patients and providers, outcome measurement, and delivery system support.³¹ Patients must measure and monitor indicators such as blood pressure and cholesterol levels at home, and undergo cardiac rehab and prevention regimens that include a combination of medication, diet, stress reduction, and physical activity. Cardiac rehab programs can improve a patient's quality of life and reduce the likelihood of another serious heart event.³² Because of the proclivity towards developing multiple diseases and complications that both cause and/or result from heart disease, patients must also be regularly screened for associated risk factors such as hypertension, diabetes, asthma, sleep apnea, and overweight.³³ As heart disease is treated across the continuum of care from prevention to treatment to wellness, patients and providers need to communicate frequently about patient health status and care planning at all stages. By maintaining open communication, providers, caregivers, friends, and family members are better able to help individuals cope with their disease and surmount symptoms such as anxiety, depression, denial, and fear.

Common cancer treatments like radiation, surgery, and some forms of chemotherapy are typically delivered in medical settings, therefore reducing the need for patients to monitor vital signs on their own. However, these treatments often cause debilitating side effects including fatigue, pain, nausea and vomiting, constipation and diarrhea, nutrition and anemia problems, fever and infection, memory and fertility issues, hair loss, lymphedema (water retention), skin changes, fever and infection, which patients must manage on an ongoing basis.³⁴ Prolonged pain during and after treatment can disrupt a patient's sleeping and eating habits, relationships, work, hobbies, and overall sense of well-being.³⁵ Many survivors require continued testing and monitoring depending on the likelihood of recurrence or the potential for other cancers to develop. Others must manage long-term side effects, resulting in additional costs to the healthcare system. Additionally, cancer treatment involves sensitive issues such as hospice care, end-of-life planning, grief, and bereavement that affect the psychosocial health of patients, family, and friends.³⁶ Like diabetes and heart disease, cancer care requires careful coordination among numerous disparate providers.³⁷

Socially disadvantaged populations – defined as those who lack access to primary and specialty care because they are socioeconomically disadvantaged or live in rural areas – disproportionately bear the burden of these chronic conditions. Socially disadvantaged populations frequently include racial and ethnic minorities, individuals of lower socioeconomic status, the elderly, and rural populations, among others. They often have less education, lack means of transportation to a primary care facility, experience difficulties with language barriers and cultural beliefs, and/or have limited financial resources or health insurance. These populations are

more likely to engage in high-risk health behaviors that can increase their chances of developing chronic conditions, such as alcohol and tobacco use, lack of physical activity, obesity, and poor diet. The adequate control of smoking, hypertension and cholesterol alone would reduce annual healthcare costs by as much as \$30 billion,³⁸ and as many as one-third of cancer deaths in 2011 were related to the inadequate control of risk factors and could have been reduced or prevented.³⁹

As a result, socially disadvantaged individuals are prone to unsuccessfully managing their chronic conditions. Low health literacy can lead to significantly less accurate perceptions of risk and knowledge of disease, making education about the prevention, treatment, management, and risks of chronic disease a vital component of care.⁴⁰ Likewise, these individuals may be less likely to discuss psychosocial issues with their providers, potentially increasing the mental and emotional strain of coping with a chronic disease.⁴¹

Clinical settings that serve socially disadvantaged populations face a number of challenges in creating effective programs to serve and assist their patients, thereby widening disparities in care. Safety-net settings typically have scarce resources with which to effectively treat patients, yet they may represent the only center for patient care in the immediate geographic area. These settings are frequently isolated from comprehensive health systems and specialty care providers that could provide clinical support. Additionally, educational, linguistic, and cultural barriers further constrain the ability of safety-net providers to offer high quality and effective care.⁴² Without a system integrating information from each clinical encounter to enable information sharing between providers, the patient must often maintain a record of their medical history and share this information with each individual provider across the care continuum. For socially disadvantaged populations, keeping track of this information can be overwhelming. Although integrated delivery systems, practices and hospitals are generally able to provide patient-centric services through extended care teams comprised of nurses, patient navigators, physician assistants, and counselors, the resource-limited nature of the safety net settings where many underserved patients seek care demands a different, innovative approach to resolve clinical, administrative, and managerial challenges.

Disparities and Socially Disadvantaged Populations

Disparities in health outcomes and prevalence and mortality rates for diabetes, heart disease, and cancer among socially disadvantaged populations indicate the extent to which these groups are challenged by chronic disease. American Indians/Alaska Natives (16.1%), African Americans (12.6%), Hispanics (11.8%),

and Asian Americans (8.4%) have higher rates of diagnosed diabetes than Caucasians (7.1%). Additionally, the rate of new cases of Type 2 diabetes among youths aged 20 years or less remains higher for African Americans and American Indians than for Caucasians. These groups are at a higher risk of Type 2 diabetes and the development of diabetes-associated complications because of later diagnosis, inadequate control of diabetes risk factors (including obesity and sedentary lifestyle), and poor self-management of the disease.⁴³ Low educational attainment has been shown to increase the risk of developing diabetes, increase the risk of having diabetes remain undiagnosed (and thus untreated), and increase the difficulty of self-management.⁴⁴

Prevalence of CHD is greatest among people above the age of 65 years (19.8%), followed by age groups 45-64 years (7.1%) and 18-44 years (1.2%).⁴⁵ American Indians/Alaska Natives (11.6%) African Americans (6.5%) and Hispanics (6.1%) are more likely to develop heart disease, as compared to Caucasians (5.8%). Rates of coronary heart disease are also twice as high among individuals with less than a high school diploma (9.2%) compared to those with a college degree (4.6%). These populations are at a higher risk of not only because of late diagnosis, inadequate control of risk factors and poor management of disease, but also interaction with determinants of health including insurance, education, employment, food deserts, and neighborhood environments that are not conducive to physical activity.⁴⁶

Cancer is another disease that primarily afflicts older adults; the median age of diagnosis is 66 years, and the median age of death is 72 years.⁴⁷ Significant health disparities also exist among racial and ethnic groups and other socially disadvantaged populations, which tend to experience poorer outcomes and survival rates.⁴⁸ African Americans, in particular, are the most likely to be diagnosed with and die from all cancers combined.⁴⁹ Family income levels have been linked to higher incidence rates for lung and cervical cancer, as well as later stage diagnosis for lung and breast cancer.⁵⁰ Socially disadvantaged populations and ethnic minorities frequently lack health insurance and are more likely to be diagnosed with cancer at a later stage when recommended treatment is intensive and costly. Further, social inequalities, such as communication barriers, provider assumptions, and discrimination can affect the relationships between patients and providers, resulting in miscommunication and substandard care.⁵¹ The psychosocial impact of cancer may be more pronounced in these populations, as socially disadvantaged cancer survivors have shown lower measures of psychosocial and physical quality of life.⁵²

eHealth Tools

The characteristics of socially disadvantaged populations, such as lower health literacy, geographic and financial barriers, and sociocultural and linguistic difficulties have stymied the adoption of evidence-based interventions that can reduce the risk of and complications from cancer, heart disease, and diabetes. However, health information technology (health IT) has been widely recognized as having the potential to surmount these common barriers to high quality care. Health IT has been used to support effective interventions for all three conditions by enhancing communication, strengthening the patient-provider relationship, facilitating the development and sharing of care plans, and improving a patient's capacity to self-monitor, track, and manage their condition. Many of these technologies are patient-centric, enabling a partnership among practitioners, patients and their families to ensure that procedures and decisions respect patient needs and preferences. Given the nature of chronic disease management, many patient-facing technologies today focus on supporting medication management to improve adherence, lifestyle modification to facilitate behavior change, and remote monitoring systems to track vital signs and provide adverse event alerts and notifications. Patient-centric health IT tools, also known as eHealth tools, include telehealth, mobile health (mHealth), patient web portals, and social media.

eHealth tools are particularly effective for their ability to overcome disparities in access to care. Socioeconomically disadvantaged populations tend to lack the resources to devote to healthy practices such as regular check-ups and screenings, obtaining proper nutrition, and exercising. Rural populations often face the additional barrier of geographic distance between themselves and local providers. eHealth tools represent a relatively low cost solution to connect patients and providers that might otherwise not be able to engage in a direct, personal clinical encounter. Through telehealth, for example, patients can receive clinical consultations at local clinics by specialists from larger, urban medical centers. mHealth can bring effective physiological monitoring and symptom reporting to patients at home. Patient web portals facilitate real-time patient-provider communication and only require basic internet access. Finally, social media can help isolated patients connect to their peers to offer and receive experiential advice and psychosocial support.

Since increasing awareness and understanding is a critical component of self-management, eHealth tools can further reduce disparities in care by helping patients overcome educational and informational barriers. Most tools incorporate educational components to help patients obtain access to information about their condition, treatments, expected side-effects, and self-management strategies. If self-guided resources fail to assist patients in understanding cancer, diabetes, and heart disease, other tools again help connect patients to their providers, community-based support resources, and others who have experienced the disease.

The following sections present an overview of each of the four types of eHealth tools we identified that have been widely applied to diabetes, heart disease, and cancer care among socially disadvantaged populations. Each section includes case studies that demonstrate the clinical outcome improvements that can be gained by the use of these tools.

Telehealth

Telehealth has revolutionized the field of medicine by removing traditional geographic barriers to care and communication by connecting patients and health providers through advanced telecommunication technologies with bi-directional audio and video interaction. The term does not refer to a single technology, but rather a group of technologies that is part of wider processes of care across diagnosis, monitoring, and therapy.⁵³ Telehealth technologies can essentially be defined as an automated support system for patients and providers to inform the decision-making process, facilitate disease management, and are used in a number of ways to collect, store, and send both objective and subjective data to providers. This can include physiological data, such as cardiac rhythm and blood pressure and glucose levels; laboratory data, such as lipid profiles, HbA1c, and non-invasive cardiac activity; behavioral information, such as dietary intake and exercise patterns; medication dosages, interactions and allergies; symptoms of related health complications and conditions; and event data, such as visits to the emergency room.

After data is collected and analyzed with clinical decision support software (CDSS) or through consultation with a physician, an appropriate response and care plan can be subsequently operationalized. Telehealth tools and systems can improve the quality of information sent to providers, improve the frequency and quality of communication between patients and providers, increase patient education and empowerment, reduce the travel time and expenses to consult a provider in-person, and create cost efficiencies due to more accurate treatments and necessary adjustments to patients' care plans. While a number of eHealth tools can be utilized in both private and public medical settings, the use of telehealth is particularly advantageous for socially disadvantaged populations by providing greater access to care, communication, disease management, and support to individuals who are not otherwise in close proximity to a healthcare provider or have limited ability to easily seek routine primary care services in person.

Home-based telehealth applications employ distinct technical approaches for use in the treatment and care of patients with chronic disease. Synchronous videoconferencing allows a patient to directly interact with a remote provider, nurse, therapist, or counselor, and discuss their health status, concerns, and

symptoms. Asynchronous, or store-and-forward systems, can transmit similar captured data onto a server for later viewing and offline display when providers are not immediately available or low bandwidth connections prevent the transmission of large datasets. Information about diet, physical activity and physiological activity can be captured through mobile applications on wireless devices and cellular phones to facilitate not only the exchange of electronic data between patients and their respective care team, but also dialogue. By enhancing the frequency, flow, and accuracy of patient-physician communication, telehealth is an effective means of improving health outcomes and engagement among underserved populations.^{54,55}

Although the technology, infrastructure, and strategy used in telehealth for diabetes, heart disease, and cancer are generally the same, the nature and severity of the disease in question holds implications for the overall approach. Generally speaking, telehealth for diabetes care focuses primarily on the surveillance and management of lifestyle, disease, and medication; teleoncology tends to focus on symptom reporting and communication; and telecardiology employs a more rigorous approach to monitor cardiac activity, structure, function, and blood flow.⁵⁶

Innovations in telecardiology have been spurred by the rise of cardiac implantable devices (apparatuses that are placed in one's chest to assist and/or monitor heart activity). Common devices such as implantable cardiac monitors, pacemakers, cardioverter defibrillators, cardiac resynchronization therapy devices, loop recorders and hemodynamic monitoring devices can facilitate the monitoring and evaluation of cardiac rhythm, blood pressure, and the presence of myocardial ischemia or reduced blood flow to the heart. The continuous stream of real-time data allows health providers to improve the monitoring, treatment, and management of heart disease, and studies have indicated that cardiac implantable devices typically receive high levels of acceptance and satisfaction among both patients and providers. Implantable devices can detect adverse events, send safety alarms, provide global positioning system information in the case of emergency, and reduce the overall volume and cost of follow-up visits.⁵⁷ More importantly, the combination of telecardiology and implantable devices is a safe alternative to conventional care that has been found to improve the provision of care and clinical outcomes while reducing the number of hospitalizations associated with heart disease.

Research has also found that teleoncology has increased access to specialty consultation, multidisciplinary care, cancer clinical trials, supportive and adjunctive care, and educational programming for patients.⁵⁸ Multi-disciplinary care teams can convene via synchronous interactive teleconferencing to review and discuss a patient's case, including radiology and pathology reports. Such meetings can enhance cancer care in rural areas by bringing the expertise of teams of specialists

to bear in regions that may only be otherwise served by an individual general practitioner. For cancers of the skin, in particular, telehealth has played an increasingly large role. Using store-and-forward technology, dermatologists can review images of suspicious marks or lesions to determine if skin cancer is a possible diagnosis. Although studies of the diagnostic accuracy of teledermatology have shown mixed results, teledermatology may actually improve the appropriate management of suspicious lesions.⁵⁹ Unlike diabetes and heart disease, the use of telehealth in oncology does not typically focus on physiologic vital sign monitoring or clinical data capture. Rather, patient-facing telehealth applications in oncology involve patient-provider consultations, treatment, symptom, or side-effect monitoring, and counseling. Telehealth consultations can accelerate the speed with which a final diagnosis is made, and save cancer patients the time and hassle of visiting multiple providers and specialists during their care.⁶⁰

A significant number of studies have examined the use of home-based telehealth in the self-management and control of chronic disease, and recent systematic reviews and meta-analyses suggest their potential to reduce mortality, hospitalization, cost of care, and adverse physical and psychosocial symptoms. Although many of these pilot studies and interventions have demonstrated significant health-related improvements after three to six months, few have investigated the long-term sustainability of clinical outcomes. The table below (figure 3) presents various applications of telehealth that have been employed by studies to support the treatment and management of heart disease, cancer, and diabetes. Following this table are a number of case studies that are described in greater detail to illustrate the impact of telehealth technology on these three interrelated chronic diseases. Given the diversity of studies with different designs, targets, patient populations and healthcare settings, the calculation of an overall effect of telehealth on chronic care was not feasible. However, it is clear that the use of telehealth has emerged as a viable option for providers to increase access to care and improve outcomes, quality of care and cost-effectiveness.

	Application Studied	Effect on Disease-Related Outcomes
Diabetes	Videoconferencing; use of a home glucose meter; access to patient’s clinical data; access to a web page for education materials	Sustained reduction in blood glucose (HgbA1C); LDL cholesterol; systolic and diastolic blood pressure ⁶¹
	Two-way educational teleconferencing; retinal imaging with a nonmydriatic retinal camera	Increase in the number of eye exams; reduced blood glucose and cholesterol level; improved self-

	Application Studied	Effect on Disease-Related Outcomes
	sent to a community health center	management behaviors ⁶¹
	Use of a digital retinal camera (EyePACS) to record and transmit retinal images to providers	Increase in the number of diabetes patients who have diabetic retinopathy; evaluation rates for diabetics rose to 20 percent, nearly double the previous rate of 10 to 12 percent
	Use of electronic secure messaging to communicate with care providers	Improved glycemic control; greater optimization of treatment regimens; increase in primary care visits ⁶²
	Wireless home blood pressure monitor and telehealth device	Sustained improvement for systolic blood pressure after 12 months
Heart Disease	Use of electronic secure messaging to monitor patient-reported symptoms and educate patients about their condition	Improved disease-specific knowledge and adherence with fluid restrictions, daily weighing, physical activity, and alcohol restriction; reduced depression. ⁶³
	Telenursing program through telephone and/or two-way videoconferencing to monitor patient behavior and adherence	Reduced hospital readmissions by 80% and overall length of visit by 300%. ⁶⁴
	Home telemonitoring program monitored reported symptoms, medication adherence, blood pressure, heart rate, urine output, weight, and a weekly ECG transmission	Increased use of beta blockers at appropriate doses and reduced rate of mortality and hospital readmission among patients; overall healthcare costs were reduced. ⁶⁵
	Telehealth kiosks installed at senior centers to monitor blood pressure	Increased patient empowerment, self-management and self-monitoring. ⁶⁶
	Web-based patient health portal to	Improved self-care, quality of life,

Application Studied		Effect on Disease-Related Outcomes
	monitor health status and telephone patients as needed	physical activity, and N-terminal prohormone brain natriuretic peptide levels (see footnote ¹). ⁶⁷
Cancer	Monthly telephone monitoring of psychological, physical, and social support distress in cancer patients aged 65 or older	Lower anxiety, depression, and overall distress. 88 percent of patients reported 'good' to 'excellent' satisfaction with the program. More referrals for patients reporting problems. ⁶⁸
	Telephonic education program about key palliative care principles and crisis prevention via practice in problem solving/decision-making skills, symptom management, communication, and advance care planning	Higher quality of life, lower depressed mood, and a trend toward reduced symptom intensity. No effect on use of hospital, emergency department, or ICU resources or survival rates. ⁶⁹
	Periodic telephonic education and guidance on prostate cancer risks and tests among African American men	Greater knowledge about prostate cancer and testing, lower level of testing decision conflict, greater proportion of men talking with a physician about prostate cancer testing for the first time ⁷⁰
	Home messaging device attached to patient's telephone line for daily symptom reporting	Clinically meaningful increase in health related quality of life ⁷¹

Figure 3: Applications of Telehealth across Disease States

¹ Brain natriuretic peptide (BNP) and N-terminal prohormone brain natriuretic peptide (NT-proBNP) levels are biochemical markers of left ventricular function and aerobic capacity in heart failure; they are often used to screen, diagnose, and establish prognosis for CHF.

Case Studies

Presented below are a series of case studies from the past five years that demonstrate the impact of telehealth and its potential clinical effectiveness in management of the selected chronic diseases among socially disadvantaged populations:

Diabetes

1. The **Informatics for Diabetes Education and Telemedicine Study (IDEATel)** used a randomized trial design to compare telehealth-based case management with usual care in older, ethnically diverse, Medicare beneficiaries with Type 2 diabetes residing in medically underserved areas of New York State. The sample consisted of 1,665 subjects who were recruited and randomized between December 2000 and October 2002. Inclusion criteria were age 55 or older, being a current Medicare beneficiary, having diabetes and being on treatment with diet, an oral hypoglycemic agent, or insulin, residence in a federally designated, medically underserved area and fluency in either English or Spanish. Participants in the intervention group were provided with a home telehealth platform that included a web camera, a home glucose meter, and access to their own data and a website with educational materials on diabetes. After five years, sustained reductions were observed in HgbA1C, LDL cholesterol, and systolic/diastolic blood pressure for patients using telemedicine compared to those receiving usual care, as shown in Figure 4.⁷²

Outcome	Usual Care	Telemedicine
HgbA1C (%)	7.38	7.09
LDL Cholesterol (mg/dl)	94.97	91.13
Systolic Blood Pressure (mm Hg)	140.15	135.83
Diastolic Blood Pressure (mm Hg)	68.29	65.66

Figure 4: Clinical Outcomes for the IDEATel Study

2. **Diabetes TeleCare** is a disease management program in rural South Carolina that provides remote education and eye screenings to socially disadvantaged individuals via telehealth technology. The goal of the program

is to help patients adhere to the American Diabetes Association guidelines related to physician assessments, medication adherence, blood glucose monitoring, and diet and exercise. Over a 12 month period, 200 patients were asked to visit their local community health center, where they interacted with a nurse/certified diabetes educator (CDE) and dietician at the University of South Carolina using two-way teleconferencing. During the first encounter, the CDE and patient established personal goals and patients were offered a 20 minute educational session and digital log to subsequently record their blood glucose levels, diet, and physical activity. Self-monitoring activities were performed daily by patients and entered into the log until they met their individual goals, at which point the intervention began to decrease. The results of the log were communicated with the CDE, dietician, and a physician. Additionally, participants were remotely screened for retinopathy using a retinal digital camera. Results were discussed with the patient using real-time videoconferencing and an appointment with an ophthalmologist was made if necessary. Although this program has yet to receive extensive evaluation, results from the first year showed that 77 percent of the patients received eye exams, as opposed to only 23 percent of patients that received usual care.⁷³ Patients for this study were recruited from three community health centers in northeast South Carolina and were located 100 miles from the self-management team and primary care physicians at the University of South Carolina. Each participant was over 35 years of age, diagnosed with high blood glucose and blood pressure, and overweight with a body mass index (BMI) of over 35. In Figure 5, the clinical outcomes of the participants as compared to their baseline data are shown.

Outcome	Baseline Data (Avg)	Results (Avg after 12 months)
HgbA1C	9.3	8.2
LDL Cholesterol (mg/dl)	108.6	89.7
BMI (kg/m)	37.1	35.8
Systolic Blood Pressure (mmHg)	135.3	127.6
Diastolic Blood Pressure (mmHg)	76.2	70.2

Figure 5: Clinical Outcomes for Diabetes Telecare Study

3. The **Veterans Administration (VA) Care Coordination Home Telemedicine (CCHT)** program was designed to reduce the use of avoidable and costly healthcare services such as hospitalizations. A pilot program was implemented at four medical centers within an integrated service network that covered most of Florida, Puerto Rico and southern Georgia. The intent was to assess healthcare services utilization by an ethnically diverse group of veterans diagnosed with Type 2 diabetes.⁷⁴ Participants used a messaging device to answer questions about their diabetes symptoms and health status on a daily basis. This data was sent to a series of care coordinators who determined whether the patient should receive a follow-up phone call or an appointment should be made with their physician. Additional tasks performed by the care coordinators included: placing new orders for medications, helping patients manage their medications, scheduling new appointments, reminding patients of their appointments, and assisting patients having difficulties with the device. The study population included 400 veterans diagnosed with Type 2 diabetes who were at high risk for multiple inpatient and outpatient visits, including those to an emergency department (ED). Veterans were eligible if they had two or more (ED) visits within a twelve month period before enrollment. They also needed access to a telephone line and had to be non-institutionalized prior to enrollment. Using a retrospective, concurrent matched cohort design, the results after 24 months showed significant decreases in diabetes-related hospitalizations as well as ED and outpatient visits, as shown in Figure 6.

Outcome	Baseline Data	Results (After 24 months)
>1 Hospitalizations	35.3	26.9
>1 ED Visits	23.7	15.8
>1 Outpatient Visits ²	8.3	4.8

Figure 6: Service-Related Outcomes for Patients in the VA CCHT Study

4. The **Addressing Diabetes in Tennessee (ADT)** project was a prospective study which examined the impact of telehealth on the quality of care among diabetic patients in five medically underserved areas of Tennessee. Diabetic patients over the age of 18 with A1C levels above eight percent were recruited and 36 patients (mean age of 55.6 years with a mean duration of

² Outpatient visits refer to a diabetes specialty clinic.

diabetes for 12 years) completed the study. Patients were delivered diabetes self-management education (DSME) by a certified educator via videoconference every 3 months to cover a variety of topics related to their condition, complications, and management and treatment of disease. Subjects showed significant improvements in A1C after three months (9.8% vs. 8.3%), as well as moderate sustained reduction in A1C over twelve months. More than forty percent of subjects achieved target A1C levels of less than seven percent, and there was a significant rise in the proportion of patients achieving target blood pressure, HDL, and triglyceride. Finally, 97% of the participants were satisfied with the program and 90% reported indirect benefits of time and money saved.⁷⁵

5. The **Telephone-Linked Care (TLC) Diabetes** program was a randomized controlled trial that evaluated the impact of an automated, interactive self-management intervention delivered by telephone in Australia. Recruited from three major diabetes clinics in Brisbane, 120 adults with type 2 diabetes were randomly allocated into an intervention or usual care group. Inclusion criteria were a type 2 diabetes diagnosis and stable pharmacotherapy of at least 3 months, age between 18-70 years, telephone access, ability to speak and understand English, and HbA1C levels higher than 7.5 percent. Exclusion criteria included psychiatric morbidity, bariatric surgery within the past 2 years, life expectancy of less than one year, and current, recent or upcoming pregnancy. The TLC system was designed to target self-management behaviors such as blood glucose testing, physical activity, nutrition, and medication by providing the intervention group with tailored information during weekly telephone calls. Trained TLC staff instructed participants on how to use the TLC Diabetes kit, which included an ACCU-CHEK Advantage glucose meter, test strips, and Bluetooth device for uploading data. Providers received an alert by email in the event of an unusual or adverse clinical event. After six months, 20% of participants in the intervention group achieved HbA1C levels of 7.0% or lower, compared with 15% in the usual care group. Significant differences in glycemic control and mental quality of life were observed between the intervention and control groups, as shown below in Figure 7.⁷⁶

Outcome	Usual Care		Telehealth		Difference between groups (ratio)
	Baseline	Post	Baseline	Post	
HbA1C (%)	8.9	8.7	8.7	7.9	0.91 ($p = 0.002$)
Health-related quality of life (mental)	49.5	48.7	49.8	51.7	3.0 ($p = 0.007$)
Health-related quality of life (physical)	45.4	45.2	45.5	45.6	0.4 ($p = 0.7$)

Figure 7: Clinical Outcomes for the TLC Diabetes Study

6. A nurse-run telehealth program was conducted by the **Denver Health Medical Center** to examine the impact on lipid control among a safety net patient population largely composed of underinsured Latinos. 762 diabetic adults at a federally funded community health center were randomly assigned to an intervention or usual-care group. Inclusion criteria were at least two clinic visits in the past year, and competency in English or Spanish. Exclusion criteria were limited to pregnancy, end-stage renal disease, and/or a comorbid condition with life expectancy of less than one year. The intervention group participated in a 20-month telephone outreach program that consisted of primary care provider-driven diabetes care with an emphasis on guideline-based lipid therapy. Trained nurses provided motivational coaching and facilitated patient self-management, managing medication, titration, and lipid levels through regular phone calls. The intervention group performed significantly better than the usual-care group by increasing the number of patients with an LDL of less than 100 mg/dL from 52% to 58.5% while the usual-care group actually decreased from 55.6% to 46.7%. The intervention group was also observed to have lower associated, average per-capita costs (\$6600 versus \$9033) and fewer hospital admissions than the control group. However, there were no significant differences in glycemic or blood pressure control.⁷⁷

Heart Disease

1. The **MOBIle TELEmonitoring in Heart Failure Patients Study (MOBITEL)** used an open-label randomized control trial design to evaluate

the impact of home-based telemonitoring using Internet and mobile phone technology on the outcome of acute worsening of heart failure (acute cardiac decompensation) between 2003 and 2008. A sample of 120 patients between the ages of 18 and 80 years (median age of 66 years) was randomly allocated into an intervention group receiving pharmacological treatment and telemedical surveillance or into a control group of pharmacological treatment only. Inclusion criteria were acute cardiac decompensation, hospital admission lasting more than 24 hours within four weeks of the intervention, and treatment according to the European Society for Cardiology guidelines. Patients in the intervention group transmitted daily vitals (blood pressure, weight, and heart rate) and medication dosage through mobile phone-based patient terminals to physicians, who were able to maintain continuous access to data via a secure Web portal. In the event that significantly adverse patient-reported vitals were submitted, physicians were automatically sent an alert by email. After six months, there was a 54% reduction of relative risk for re-admission or death among the intervention group. Intervention patients that were hospitalized for deteriorating heart failure were observed to have a significantly shorter length of stay (median of 6.5 days) compared to the control group (10.0 days).⁷⁸

2. Using **Insight TeleHealth's "ITSmyhealthfile" Telehealth System** (an interactive, internet-based disease management and integrated healthcare delivery system), researchers examined the impact of telehealth on rural and urban underserved populations at Temple University and Geisinger Medical Center. A sample of 465 subjects between the ages of 18 and 85 years were randomly allocated into a telehealth-supported nurse management program or usual care (normal nurse management program). Inclusion criteria were a 10% or greater risk of developing cardiovascular disease according to the Framingham 10-Year General Cardiovascular Risk Score formula;³ exclusion criteria included coronary artery disease, class 3 or 4 heart failure, subjects in nursing homes, and pregnancy. After one year of surveillance, a significant percent reduction in risk was observed among intermediate- and high-risk subjects in the intervention group (19.1%) compared to the usual care group (8.1%), in addition to lower blood lipid and blood pressure levels overall.^{79, 80}

³ Using data from the hallmark Framingham Heart Study, the Framingham Risk Score is used to estimate the 10-year risk of an individual for developing cardiovascular disease. The formula incorporates data such as age, gender, blood pressure, and smoking habits to assign individuals a score within the following range: low risk (0-10%), intermediate risk (10-20%), or high risk (20% or more) of developing CHD. The predicted risk score can be used to signal the need for lifestyle changes, education and/or preventive treatment.

3. The **CARME (Catalan Remote Management Evaluation)** study was a blinded randomized control trial that evaluated the impact of noninvasive real-time remote home telemonitoring program among ambulatory patients with heart failure (HF). A sample of 92 adult outpatients (mean age 66.3 and 70% of whom were male) was randomly allocated into a usual care group utilizing the Philips Motiva System (health education videos, personalized messages, alerts, and questionnaires regarding symptoms, adherence, and healthcare) or an intervention group utilizing the Motiva Plus, which used the same components in addition to self-monitoring tools (scale and sphygmomanometer). Intervention subjects monitored and recorded daily weight, blood pressure, and heart rate. Inclusion criteria were New York Heart Association functional class II-IV; in-home access to a television; and ability to conduct self-monitoring. Exclusion criteria included patients with a life expectancy of less than one year. After one year of surveillance, both groups achieved significant reductions in the number of HF-related hospitalizations, hospitalizations for other cardiac causes, and hospital days compared to baseline, as shown below in Figure 8.⁸¹

Outcome	Usual Care (Telehealth)	Telehealth and Self-monitoring
Hospitalizations related to heart failure (% reduction)	58.2%	67.8%
Hospitalizations for other cardiac causes (% reduction)	47.4%	57.6%
Length of stay for heart failure (% reduction)	64.2%	73.3%
Length of stay for other cardiac causes (% reduction)	83.9%	82.4%
Quality of life: EuroQol visual analogue scale (% improvement)	61.7%	82.3%
Quality of life: Minnesota Living with Heart Failure scale (% improvement)	64.7%	58.8%

Figure 8: Clinical Outcomes for the CARME Study

4. The **Telehealth for Heart Education Activation Rehabilitation and Treatment (tele-HEART) study** used a randomized controlled trial design to evaluate the impact of a three-month telehealth intervention on health, mental health, and service utilization outcomes of homebound older adults diagnosed with heart failure (HF). A sample of 115 participants was enrolled from St. Peters Home Health Care across the state of New York, 60% of which were female with a mean age of 79 years, 85% of which were Medicare recipients, and 25% with incomes less than \$14,000 per year. Inclusion criteria were: 65 years or older, diagnosis of HF or chronic obstructive pulmonary disease, frequent healthcare encounters reported in the past 2 months, and patient required three or more home visits per week. Exclusion criteria included physical disability, cognitive impairment or behavioral problems preventing use of a telehealth device and communication. Participants were randomly allocated into an intervention group utilizing the Honeywell “HomMed” Health Monitoring System or usual home care group. Both groups of participants received tailored education on their disease, lifestyle, and disease management techniques. In the intervention group, a care team of registered homecare nurses and a licensed practical nurse trained patients to use the HomMed System, which included a small in-home monitor whose vacuum fluorescent display and large font provided readable text and instructions written at a sixth-grade level that were supported with graphics and audio prompts. The telehealth monitoring system recorded patient data that was subsequently encoded and de-identified before transmission to the central monitoring station at the home care agency, where providers could triage patient data by color-coded levels of severity and exchange patient data via an integrated EMR with the home care team. After one year of surveillance, the intervention group reported significantly more improved quality of life, health, and social functioning symptoms, as well as reduced depression and number of emergency room visits in comparison with the usual care group. Fewer hospital days were also reported among the intervention group, although there was no significant difference in the number of episodes of home care received.⁸² Figure 9 displays the results below:

Outcome	Usual Care	Telehealth
Number of emergency room visits	1.4	0.6 (<i>p</i> =.03)
Mean days of rehospitalization	10.5	7.5

Outcome	Usual Care	Telehealth
		($p=.06$)
Number of episodes of home care	1.8	1.3 ($p=.10$)
% improvement of depression (PHQ-9 scale)	10.5%	50.3%
% improvement of depression (CES-D scale)	8.7%	47.7%
% improvement of general health (SF-36 scale)	1.2%	16.6%
% improvement of social functioning (SF-36 scale)	3.5%	21.3%

Figure 9: Clinical Outcomes for the Tele-HEART Study (after 12 months)

Telehealth has also been used to effectively prevent and/or reduce secondary risk factors such as hypertension among socially disadvantaged populations.^{83,84} Below are two examples:

1. Recognizing the proclivity of rural elderly adults dependent upon home care and facilities to age in place, researchers implemented **Technologies for Enhancing Access to Health Management (TEAhM)** to examine the feasibility of nurse-mediated telehealth technology in community-based senior centers located in a rural, underserved area of Southwestern Ohio. Over the course of 10 months, nurses monitored blood pressure data that participants were instructed to measure at least once a week. Participants were 55 years or older (median age of 74.1) and had been diagnosed with hypertension that was stabilized with oral therapy. After being trained to use the telehealth kiosk and measure their blood pressure, the intervention group was observed to have a lower mean systolic blood pressure (126mm HG) than the control group (132mm Hg).⁸⁵
2. Recent studies have also demonstrated that nurse-mediated, telephone-based disease management programs are more effective among African American patients when the program is supplanted with a home blood pressure monitoring system. For example, a prospective randomized

controlled study was conducted between 2006 and 2007 among a sample population of hypertensive members within an Aetna health maintenance organization plan. A group of 5,932 self-identified African Americans (mean age of 55.7) that had graduated high school and reported a household income under \$50,000 were randomly selected. Researchers assessed 638 individuals, 485 of whom completed follow-up assessment over the course of 12 months. In addition to providing intensive outreach, education, and training to patients, the intervention program featured a multimodal disease management program that trained nurse disease case managers in cultural competency and sent subjects culturally tailored educational materials and lifestyle counseling components. Both the intervention and control group received a wrist cuff monitor to use for home monitoring. The systolic blood pressure adjusted mean was significantly lower among the intervention group (123.6 vs. 126.7 mm HG) compared to the control. The intervention group was also 46% more likely to report weekly monitoring and 50% more likely to have blood pressure under control than the control group.⁸⁶

Cancer

1. Telephone-based care management and automated symptom monitoring was used to reduce depression and pain among cancer patients in the **Indiana Cancer Pain and Depression Trial**. 405 cancer patients with depression or cancer-related pain were recruited from 16 urban or rural community-based oncology practices, including one Veterans Affairs clinic and another clinic primarily providing care for underserved populations. Inclusion criteria were depression, persistent cancer-related pain despite medication, or both. Patients were excluded if they did not speak English, were pregnant or in hospice care, or had schizophrenia, moderately severe cognitive impairments, or a disability claim being adjudicated for pain. Nurse care managers in the intervention arm (202 patients) assessed symptom response and medication adherence, provided pain and depression-specific education, and made treatment adjustments through a series of phone calls with patients. In addition, patients reported pain and depression symptoms and medication adherence, side effects, and global improvement measures via an automated telephone system or online survey. Patients in the intervention arm had a mean age of 58.7 years, 63 percent were female, and 20 percent were African-American. Twenty-two percent had less than a high school education and 28 percent reported having an income that was “not enough to make ends meet”. Breast (27%), lung (21%), and gastrointestinal cancers (20%) were most common. At baseline, 32 percent had depression only, 24 percent had pain only, and 44 percent had both depression and pain. Patients in the control arm (203 patients) received usual care. Results

from the trial found that patients in the intervention arm experienced significantly greater improvements in both pain and depression (see Figure 10) and health related quality of life measures, including mental health, vitality, anxiety, and physical symptom burden. Additionally, intervention patients showed trends toward decreased number of hospital days (mean of 3.6 vs. 5.8) and emergency department visits (mean of 1.0 vs. 1.4).⁸⁷

Outcome Measure	Usual Care	Intervention
BPI Pain Severity Score (0-10)		
• Baseline	5.20	5.23
• 3 month follow-up	4.52	3.30
• 6 month follow-up	4.38	3.55
• 12 month follow-up	4.33	3.62
HSCL-20 Depression Severity Score (0-4)		
• Baseline	1.64	1.64
• 3 month follow-up	1.35	1.08
• 6 month follow-up	1.31	1.01
• 12 month follow-up	1.32	1.06

Figure 10: Pain and Depression-Specific Outcomes from the Indiana Cancer Pain and Depression Trial

2. The National Cancer Institute and Department of Veterans Affairs implemented the **Cancer Care Coordination/Home-Telehealth** project (Cancer CCHT) to remotely improve symptom management and reduce the use of unnecessary healthcare services (unplanned clinical visits or care). Using a matched case-control design, 43 veterans newly diagnosed with cancer, having a life-expectancy of at least six months, and receiving a treatment plan including chemotherapy at a Veterans Affairs Medical Center used a touchpad device connected to their telephone to respond to questions about chemotherapy related symptoms. Excluded were patients with severe sensory impairment, psychosis, or diagnosis of dementia or traumatic brain injury. Responses to the symptom assessment exceeding a defined threshold alerted a care coordinator who could intervene to resolve the problem through strategies such as making a timely referral to a clinic, reinforcing symptom-based education, or offering encouragement and reassurance. Patients were predominantly male (95%) with a mean age of 63.5 years. Forty-eight percent had lung cancer, 19 percent had head/neck cancer, 19

percent had colorectal cancer, and 15 percent had other cancer types. Nearly half (48%) had stage IV cancer. A control group comprised of two patients per case (82 patients total) matched by tumor type and cancer stage did not receive the symptom monitoring intervention. As predicted, compared with the control group, intervention patients had lower rates of preventable service utilization (e.g. clinic visits, hospitalizations, time spent in the hospital) and somewhat higher rates of cancer-related service utilization (planned clinical visits or care received which was within the normative bounds of the patients' cancer diagnoses, e.g. chemotherapy-related hospitalizations) after six months. Follow-up calls with care coordinators also served as access points for the patient to reach their oncologist and for pharmaceutical management.⁸⁸

3. Using the videoconferencing capabilities of the **Northern Sierra Rural Health Network**, researchers established four support groups for 27 women (mean age of 60.71 years) with breast cancer living in rural and remote areas in California. Eighty-five percent were Caucasian, and only four had less than some college education. Fourteen were treated with chemotherapy, 10 had radiation therapy, and nine had hormonal therapy. Participants visited nearby videoconferencing sites for eight weekly support group sessions. The support groups helped to improve nearly all psychosocial measures tested, with significant decreases in depression and posttraumatic stress disorder symptoms. Posttest follow-up interviews suggested that participants found the intervention valuable for (a) allowing them to share information with women with breast cancer in other rural communities; and (b) developing strong emotional bonds with other group members. Some participants believed that the 'distance' provided by using videoconferencing improved their willingness to make emotional connections with others.⁸⁹
4. The **Active After Cancer Trial (AACT)** was a multicenter randomized controlled trial that evaluated the impact of a telephone-based exercise intervention on the physical activity of cancer patients in San Diego. 121 patients were enrolled from medical oncology clinics at ten Cancer and Leukemia Group B institutions; most of the participants were Caucasian women in their 50s, with either breast cancer (83%) or colorectal cancer (17%). Eligibility criteria included stage I-III invasive breast or colorectal cancer, completion of surgery, chemotherapy and/or radiation therapy between 2-36 months prior to enrollment, and BMI of less than 47kg/m². Patients were excluded if they had recurrent cancer, uncontrolled heart disease, or were unable to perform physical activity. While the control group received usual care, the intervention group participated in a 4-month,

telephone-based exercise program which consisted of 10-11 semi-structured phone calls from behavioral counselors to set goals, assess performance, and promote self-efficacy. Participants received a workbook containing educational material, along with a New Lifestyle Digi-Walker pedometer to record at least 180 minute of moderate-intensity physical activity. The intervention group increased self-efficacy, quality of life, and physical activity, fitness, and functioning more than the control group.⁹⁰ As shown in Figure 11 below, there were significant differences in several outcomes observed in the telehealth and usual care groups.

Change in Outcomes after 4 months		
Outcome	Usual Care	Telehealth
Physical activity (min/week)	14.6	54.5
Metabolic task equivalent hours / week	1.0	3.0
6-Minute Walk Test (feet)	81.9	186.9 ($p = 0.006$)
Physical functioning (EORTC Quality of Life Questionnaire, Core 30, Version 3)	2.6	7.1 ($p = 0.04$)
Global quality of life (EORTC QLQ C-30)	-1.5	4.3 ($p = 0.10$)
Pain	-2.6	-4.9
Fatigue (FACIT scale)	2.5	4.4
Exercise self-efficacy	-0.3	0.1 ($p = 0.06$)

Figure 11: Clinical Outcomes for the Active After Cancer Trial (AACT)

5. A randomized controlled trial evaluated the impact of a telephone counseling program on psychosocial outcomes post-treatment among women with breast cancer at 21 hospitals and medical centers nationwide. Of the 304 patients enrolled, most were non-Hispanic white and about half of the sample was under the age of 50. Fifty percent were unemployed or working part-time, and there was an even distribution of women with high school, college,

and graduate education. Eligibility criteria included stage I, II, or IIIA breast cancer, and completion of treatment. Patients were excluded if they demonstrated cognitive impairments, psychosis, or suicidal behavior, received bone marrow transplants, or could not understand English. The intervention group received a 16-session telephone counseling program scheduled at regular intervals over a 12 month period, as well as a Wellness Kit. The Kit contained printed educational materials on modules covering topics related to survivorship (e.g. physical change, sexuality, relationships, economic change, etc.), relaxation tapes, and a stress management guide. In comparison with usual care, the intervention group showed significant improvement in depression ($p=0.0007$) and distress ($p = 0.007$) after 18 months, as well as significant improvement in sexual dysfunction and personal growth at both 12 and 18 months.⁹¹

6. A randomized controlled trial evaluated the impact of telephone monitoring on psychological distress symptoms among cancer patients older than 65 years. 192 cancer patients enrolled and were randomized into an intervention and usual care group. Eligibility criteria included stage III or IV breast cancer, stage C or D prostate cancer, or stage C or D colon cancer, treatment actively being received less than two months prior to recruitment, and life expectancy of more than one year. Patients in the intervention group received monthly telemonitoring (TM) in addition to educational materials (EM) on disease management, survivorship, diet, and cancer-specific information. Trained oncology nurses monitored psychological distress, physical dysfunction, and social support distress, receiving alerts in the event that adverse symptoms were reported. Patients in the usual care group received the EM without TM. After six months, the intervention group had significantly lower levels of anxiety and depression, and reported higher levels of satisfaction with the program compared to the usual care group.⁹² Figure 12 below displays several statistically significant differences that were observed.

Outcome	Usual Care		Telehealth		P (ANCOVA)
	Baseline	Post	Baseline	Post	
Psychological distress (Hospital Anxiety and Depression Scale score)	6.41	8.20	7.49	6.01	< 0.0001
Depression subscale (HADS)	2.95	4.08	3.65	3.20	0.004

Anxiety subscale (HADS)	3.46	3.25	3.84	2.81	< 0.0001
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Figure 12: Patient Outcomes of Telephone Monitoring of Psychological Distress Symptoms

Based on the studies and information gathered for this report, there is significant interest in utilizing telehealth among socially disadvantaged populations. The results from the case studies cited above indicate this approach is useful for improving clinical outcomes, reducing hospital and emergency department admissions, and lowering costs. Telehealth tools are well-suited for treating the three selected chronic diseases among socially disadvantaged populations because they enable the remote measurement, exchange and subsequent interpretation of health data, and can automatically send alerts, notifications, and more. However, telehealth was observed to be most effective when patients and/or health providers were provided with tailored training and education about how to use the technology and incorporate tools into disease management strategies. Over time, the technology for communication, data management, and decision support will improve, promising to make telehealth a useful eHealth tool to improve the quality of care and lower costs for those with diabetes, heart disease, and cancer.

Mobile Health

Mobile health (mHealth) encompasses a variety of technologies, such as medical devices designed for home use, smartphone and tablet applications, wireless sensors, and short message service (SMS or text-messaging) applications. Through these technologies, mHealth enables virtually instantaneous interaction well beyond the reach of traditional healthcare. mHealth not only has the ability to connect patients and providers over long distances in real-time, it also empowers patients to remain active participants in their own care through tools that offer tailored communication to promote self-management and patient engagement.⁹³ mHealth has been found to successfully help manage a number of aspects of chronic disease prevention and care including access to care, diet, depression, education, medication, stress, physical activity, substance abuse, and weight.⁹⁴

The recent proliferation of smartphones has reinvigorated the field of mHealth by challenging the once clear-cut definition of a medical device and offering a host of innovations that are rapidly expanding the reach of telehealth and spurring patient engagement. Of the 250 million Americans that own a mobile phone today, 114 million people are using smartphones. Not only are smartphones now the primary handset sold in stores, but the market is evolving into a more mature stage of growth after smartphone penetration grew from 38% to 50.4% between 2011 and

2012. Although smartphones were initially purchased primarily by more affluent, young, and Caucasian populations during early stages of adoption, lower income, elderly, and ethnic minority populations are using smartphones in greater numbers.⁹⁵ According to data published in a recent Nielsen Report analyzing smartphone penetration within the United States during the first quarter of 2012, each ethnic population had a larger increase in smartphone adoption as compared to non-Hispanic whites, as shown in Figure 13:⁹⁶

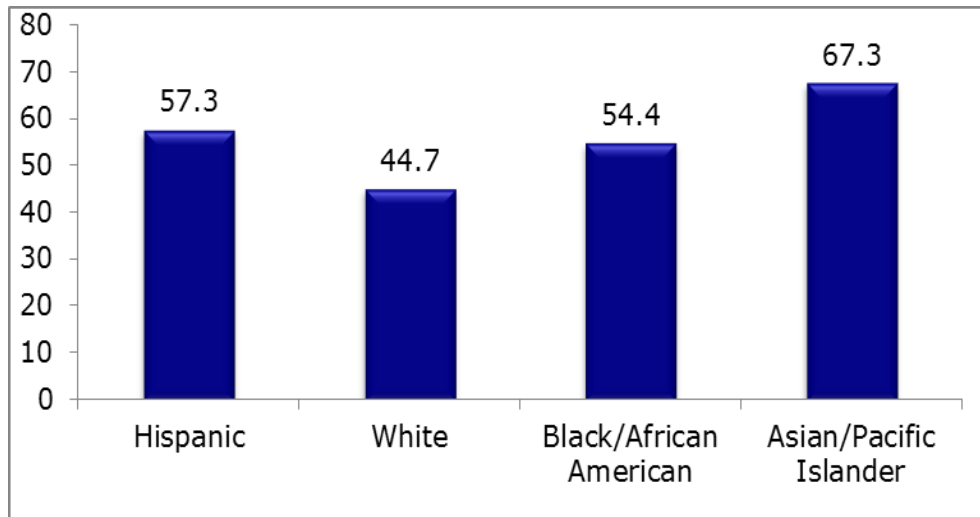


Figure 13: Percentage of Smartphone Adoption by Racial/Ethnic Group (Q1 2012)

This data suggests that smartphone adoption among Hispanic, African American, and Asian/Pacific Islander populations is growing and over the next several years, the “smartphone divide” will narrow during later stages of market maturity.

Ethnicity is not the only determinant in smartphone ownership. The Nielsen research also indicates that the adoption of smartphones is highest among individuals ages 18-45 and those with incomes higher than \$75,000. However, similar to the recent growth among minority populations, this trend is changing as smartphones are adopted by lower income and older populations. As shown in Figure 14, smartphones are beginning to be adopted by those who potentially stand to gain the most from increased access to internet connectivity, mobile device capabilities, online information, and interactive multimedia: socially disadvantaged populations.⁹⁷ Recent Pew research also suggests that smartphones are following a similar - albeit more nascent - stage of growth among populations in rural areas and/or with no college education. Currently, approximately 29% of rural populations own smartphones (compared to 50% among urban and suburban areas), while 36% of individuals with a high school diploma own smartphones (compared to 61% of those with at least a college degree).⁹⁸ Further research

indicates that the fastest growth in 2011 was among “cost-conscious” consumers, such as those in large households, with lower income, and/or elderly populations.⁹⁹

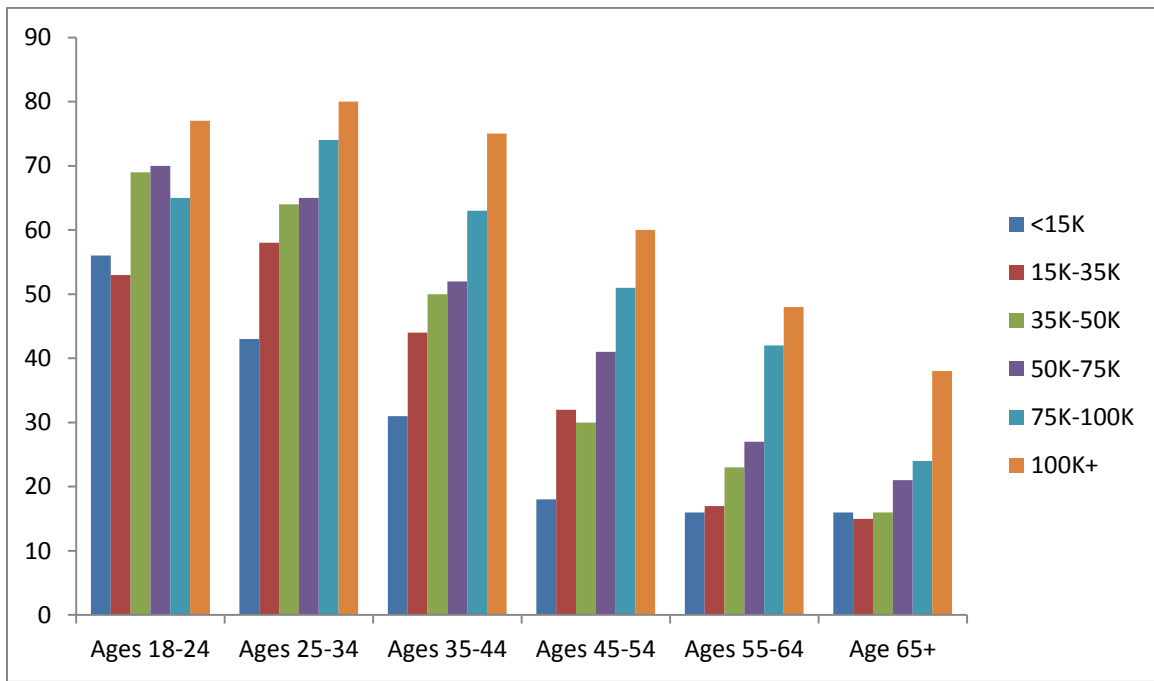


Figure 14: Smartphone Penetration by Age and Income (2012)

Disparities in access to household computers and the internet may have prompted many lower-income, less educated, and racial/ethnic minority populations to turn to smartphones as their primary internet source. Today, individuals are increasingly likely to use their mobile devices for health purposes. Nearly one third (31%) of cell phone owners have used their phone to look of health information, as compared to only 17 percent in 2010. More than half of all smartphone owners (52%) have searched for health information on their phone. Latinos and African-Americans are among the groups most likely to use their phones to find such information.¹⁰⁰ Taken together, these trends indicate the extensive reach of mobile technologies in the United States and the potential for access by socially disadvantaged populations.

Likewise, the number of mHealth applications available for smartphones is accelerating. As of 2012, there are over 40,000 health-related applications and this number is expected to double as the number of smartphone users increases and the sophistication of the technology improves.¹⁰¹ Additionally, the number of mHealth application users – defined as those who downloaded an mHealth application at least once – will reach 247 million by the end of 2012, a significant increase from the 124 million users identified in 2011. Despite potential digital literacy barriers, smartphone consumers of all ages and backgrounds have utilized medical apps to support their needs. According to a 2012 Mitchell Poll, 28% of Baby

Boomers (adults born between 1946-64) have downloaded between 1-5 apps, and almost half have downloaded six or more. As smartphones continue to become more technologically sophisticated with improved processing power and new capabilities, applications will be designed for consumers to monitor and manage their health and care as never before.

mHealth and Chronic Disease

The use of mHealth devices and applications for chronic disease care has been one of the most significant health IT developments of the past five years. Existing and emerging mHealth technologies, such as smartphone applications, devices with email and SMS functionality, pagers, and the mobile Internet can help facilitate patient self-management of diabetes, heart disease, and cancer. These eHealth tools can practically and effectively monitor a patient's status and clinical outcomes, while simultaneously increasing patient adherence to treatments.¹⁰² Some of the studies cited below indicate that the use of these technologies have contributed to significant decreases in HbA1C and LDL levels, improvements in diet and physical activity, and improved health-related outcomes for diabetic patients. The use of mHealth applications and devices may encourage these patients to adhere to their monitoring regimens by encouraging self-monitoring efforts with reminders and alerts, and serving as simple repositories for information generated by the patient, which can then be shared with the patient's care team.

The ubiquity of mobile communication devices and mobile Internet-based technology also presents a myriad of opportunities to enhance and extend heart disease prevention and management well beyond the reach of traditional care. Representing an evolution from desktop telehealth to wearable technologies, mHealth can improve the accessibility of cardiac treatment as well as the ability of patients to actively engage their providers through remote coaching, tracking, feedback, and education. Additionally, the innovations and functionality of mHealth, such as text messaging, smartphone applications and wireless sensor technology, can improve the speed, accuracy, and convenience of diagnostic tests, improve medication adherence and test result delivery, improve interactive, two-way communication, and provide simple methods for data collection, remote diagnosis, emergency tracking and access to health records.

Despite the evidence supporting the use of mHealth in caring for other chronic diseases like diabetes and heart disease, mobile health has been relatively underutilized in cancer care in the United States. While research has indicated that rural, lower-income women are more likely to express interest in receiving mammogram reminders and cancer prevention text messages than higher income women, our review of the literature did not identify any studies that used mobile

health technologies to do so.¹⁰³ SMS messaging has been used to successfully reduce the number of clinic visits for breast cancer patients texting wound drain output following breast reconstruction surgery.¹⁰⁴ Text-messaging has also helped promote preventative behaviors, such as using sun screen¹⁰⁵ and smoking cessation,¹⁰⁶ but not on a widespread basis in the U.S.¹⁰⁷

A summary of the types of mHealth applications and their associated functionality for diabetes and heart disease is shown in Figure 15 below.

Application Studied		Effect on Disease-Related Outcomes
Diabetes	Smartphone application; text (SMS) messaging; real-time transfer of information	Positive changes in HbA1C of 1.2% Positive changes in systolic blood pressure from -6 to +10 Positive changes in LDL Cholesterol of -29 to 0
	Two-way pagers	79% of the participants in this study enjoyed using the pager and felt their care was improved at the end of the study.
	Wireless, portable diabetes management system	Lower median carbohydrate intake Higher rate of transmitted HgbA1C levels Improved knowledge scores of diabetes
	Cell phones; text messaging; email	Increased intention to exercise Reduction in body mass index (BMI) Reduction in systolic/diastolic blood pressure.
Heart Disease	Smartphone monitoring via text (SMS) messaging; real-time transfer of information	Improved quality of life Improved self-care maintenance Improved clinical management ¹⁰⁸

	Application Studied	Effect on Disease-Related Outcomes
	Implantable device and wireless remote monitoring system	Reduced median time from clinical event to clinical decision from 22 to 4.6 days Reduced length of stay from 4.0 to 3.3 days ¹⁰⁹
	Cardiac rehabilitation via 3G mobile phone with built-in accelerometer sensor, camera, and video conferencing features	Improved adherence (92% compared to 70% in control) Improved physical activity and emotional state Reduction in weight and triglyceride levels ¹¹⁰

Figure 15: Overview of Mobile Health Functionalities and Results of Pilot Studies

Results from studies of the use of mobile health devices and applications in heart disease and diabetes care strongly suggest mHealth applications can help patients reduce LDL cholesterol, blood pressure, and blood glucose, monitor vital signs, and reduce sedentary behavior by encouraging a healthy, active lifestyle through diet and physical activity. Described in greater detail below are examples of mHealth devices and smartphone applications that were evaluated for the management and treatment of cancer, diabetes, and heart disease.

Smartphone Applications for Diabetes

Some examples of mHealth applications to improve diabetes care include:

1. **WellDoc DiabetesManager** is a mobile health application that provides weekly automated clinical coaching through behavioral algorithms driven by real-time patient data, such as blood glucose values, carbohydrate intake, medications, and weight. DiabetesManager also features a medication adherence program and allows for the transfer of real-time blood glucose data from patient to provider. A cluster-randomized clinical trial was conducted over one year in 2010 to evaluate the use of DiabetesManager in conjunction with a One Touch Ultra 2 blood glucose meter. Over 150 patients were divided into four clusters, with one cluster (n=23) using the DiabetesManager application with the blood glucose meter. The average

decrease in HbA1C of 1.6% for patients in this intervention group was higher than the 0.7% change observed in the control group (which used no technology).¹¹¹

2. **DiaBetNet**, developed by the MIT Media Lab, uses a wireless personal digital assistant (PDA) with diabetes management software and an integrated motivational game to assist youths between 8 and 18 years manage their Type 2 diabetes. Patients enter their vital signs for transmission to a physician, and are encouraged to play the interactive game to educate themselves about blood glucose levels, blood pressure, diet and exercise. Over 70 patients improved their overall knowledge of diabetes and maintenance of HgbA1C levels, and lowered their overall carbohydrate intake.¹¹²
3. **Diabetes QOL** allows patients to transfer their weekly self-managed blood glucose levels to their provider. The application interacts directly with a glucometer, allowing patients to seamlessly send the information via SMS on their smartphone. Every three months, the patient is asked to take the Diabetes Quality of Life Survey. Responses to the survey, along with the patient's glycemic values, are sent to health care providers. Patients receive weekly SMS treatment advice based on their glucose values and follow-up calls are made based on the results of the survey. Using a randomized controlled trial design, evaluation of the application indicated a decrease in glucose levels of 0.14% among the intervention group as opposed to an increase of 0.12% within the control group. The evaluation also demonstrated a statistically significant reduction in the number of hypoglycemic episodes and improvements in the overall quality of life of the patient.¹¹³

There are a number of other mobile health devices and applications that have been developed over the past several years, but have not been scientifically evaluated for their overall effectiveness in managing diabetes. Many of these are electronic glucometers that capture data on a patient's blood glucose level and transfer it to a provider through a centralized server or through an Internet cloud. This functionality combined with other features of the applications likely plays a key role in helping patients manage many of the risk factors associated with diabetes. Examples include:

1. **PositiveID Corporation** has created the **iglucose mobile health solution**, which collects and transmits stored data from a number of compatible electronic blood glucose meters. The data is sent to a diabetes management portal via wireless cellular technology, where glucose readings can be shared

with family members, primary care providers, or other specialists. This tool utilizes a variety of reports to inform patients about their health status, and uses a number of methods to communicate with the patient including online access, email, fax or SMS text.¹¹⁴

2. **Telcare BGM** is another wireless-capable blood glucose meter that captures patient data on HgbA1C levels and sends it directly to a centralized server. Data is then sent to a cloud-based web application where health information can be viewed by patients, family members, and health providers on a dashboard that is available through a computer, tablet, or smartphone application. The dashboard features functionality that alerts the patient when their glucose levels are trending too high or low, and suggests appropriate corrective actions.¹¹⁵
3. As part of a new initiative, the American Diabetes Association, the Centers for Disease Control and Prevention (CDC), the Health Resources and Services Administration (HRSA), two Beacon Communities, and Voxia have created the **Text4Diabetes campaign**. The campaign utilizes SMS messaging to encourage individuals to engage with and manage their health, help them assess their diabetes risk levels, and better connect them with diabetes care and wellness educational materials. The program uses text message questions to assess an individual's risk for diabetes and determine which resources are most appropriate for the user.¹¹⁶ Resources may include an online social forum, a check-up at a local pharmacy, or contact information for local health providers.

Each of the examples provided above discuss the use of mHealth as part of a larger telehealth system for diabetes. In addition to those comprehensive systems, there are also a number of specific applications that are available for direct download onto a smartphone. The number of smartphone applications for diabetes has significantly increased by almost 400% over the past three years, from 60 applications available for the iPhone, to over 260 that are available over a number of mobile platform.¹¹⁷ These applications can be divided into the following categories: insulin levels, communication, diet, physical activity, weight, and blood pressure. In Figure 16, the percentage of applications available, by category, on several popular smartphone devices is shown.

Application	Insulin	Communication	Diet	Physical Activity	Weight	Blood Pressure
Apple iPhone	35	36	26	17	19	13
Google Android	19	17	15	10	16	16
BlackBerry	5	6	3	2	5	4

Figure 16: Number and Types of Diabetes Applications Available by Smartphone Device

Three of the more popular smartphone applications based on a review by CNET Magazine include:¹¹⁸

1. **Glucose Buddy**, which was created by TuDiabetes.Com (an online community for diabetics), allows patients to enter information about their diet, exercise regimen and medications. Users can access a variety of graphs and reports to trend their diabetes and health status, and access an interactive forum for diabetes education and support
2. **Vree** is an application that enables users to self-manage their diabetes by providing an interface to enter data on blood glucose, diet, exercise and medication. The application also contains a large food database that provides nutritional information to help manage diet, access to articles and advice on diabetes management, and the ability to email a provider with the information recorded by the application.
3. **iBGStar Diabetes Manager App & Glucose Meter** includes a device that is plugged into the smartphone to view, store and track blood glucose levels. Additionally, the application matches blood sugars to a meal that an individual has just finished, stores nutritional information about the meal, and communicates that information to a provider.

mHealth for Heart Disease

Several programs have also demonstrated improvements in self-efficacy and adherence to care plans among adults at significant risk of developing or exacerbating cardiac conditions. Most mHealth interventions identified in this study

require patients to input their health information online, including blood pressure, cholesterol, current medications, weight, height and other information necessary for disease management. A provider, nurse or licensed community health worker would examine and evaluate the information, and send the patient recommendations and reminders via SMS on a regular basis. Intervention periods for these studies typically lasted from two to twelve months. Described below in greater detail are two examples:

1. The **Telemedical Interventional Monitoring in Heart Failure (TIM-HF)** trial was a randomized, controlled multicenter study that investigated the impact of remote telemedical management using portable devices among 710 patients with chronic heart failure. Inclusion criteria included stable ambulatory patients of at least 18 years of age, within the New York Heart Association class II or III, and with a left ventricular ejection fraction of less than 35 percent. Over the course of at least 12 months, 354 intervention subjects measured ECG, blood pressure, and body weight via a personal digital assistant (PDA) that sent automated encrypted transmission via cellphones to the telemedical centers. Follow-up outpatient visits were conducted at three month intervals during the first year and with less frequency the second year, during which patients complete self-administered assessments. Hospitalization for heart failure or cardiovascular death was slightly lower among the intervention group (14.7% compared to 16.5% among the usual care), which also showed improved physical functioning over the study period.¹¹⁹
2. A **home-based cardiac rehabilitation program** offered patients the ability to complete a program without traveling to a hospital or gym. Researchers developed a walking-based cardiac rehabilitation program using a smartphone to transmit ECG, heart rate, GPS-based location and speed information via Bluetooth connection to a secure server for remote monitoring. After participating in the six-week program, subjects reported improved physical performance, activity, and mental health, and rated the usability of the system favorably (4.8 on a five-point scale).¹²⁰

Smartphone Applications for Heart Disease

In the context of heart disease, applications can now monitor heart activity, improve patient-provider communication, manage heart disease, and address risk factors such as diet, physical activity, stress, and tobacco cessation. After scanning for applications specific to heart disease on the three main smartphone devices (iPhone, Android, and Blackberry), we categorized 251 applications according to five critical functions: heart activity (heart rate, cardiograph, etc.), patient-provider communication and education, risk assessment, lifestyle and disease management

(physical activity, diet, tobacco, etc.), and vitals (blood pressure, cholesterol, weight). Figure 17 displays the segmentation of application categories by percentage.

Application	Heart Activity	Communication & Education	Risk Assessment	Lifestyle & Disease Management	Vitals	Total
iPhone ¹²¹	8% (9)	22% (24)	16% (18)	28% (30)	26% (28)	109
Android ¹²²	5% (4)	29% (24)	9% (8)	40% (34)	17% (14)	84
BlackBerry ¹²³	5% (3)	31% (18)	9% (5)	24% (14)	31% (18)	58

Figure 17: Number and Types of Heart Disease Applications Available by Smartphone Device

To illustrate these functions, we have selected a number of recently developed applications that are currently being utilized to address factors expressly related to heart disease. By no means an exclusive list, these applications were selected for inclusion given their design features, rating, popularity, ease of use, function, and relevance to the study. Described below are examples of the five categories of application functions.

1. Vital Signs

In response to the growing need and desire of cardiovascular patients to measure and record vital signs such as blood pressure, cholesterol, and weight over time, applications have been designed to support disease self-management in a variety of ways. The early waves of cardiovascular applications allowed users to manually enter their blood pressure readings and view graphs illustrating their progress as well as suggestions regarding their health behavior. Today, many applications are more comprehensive in nature, permitting users to automate the recording of sophisticated health indicators. Various universal applications, such as **iBP Blood Pressure**, have been designed to record and analyze weight and blood pressure measured by an external cuff. Cuffs such as Withings' **Blood Pressure Monitor** transmit blood pressure measurements via connection to an iPhone, iPad or iPod, after which data is automatically sent to a database online which patients can access and share with their physicians.¹²⁴ Other applications, such as Taconic System's **BP Monitor**, have been designed to monitor blood pressure,

weight, medication, and meals to track the effect of changes in regimen. Similarly, **HeartWise** allows individuals to enter their blood pressure readings, pulse, and weight to calculate arterial pressure and generate graphs showing fluctuations over time.

2. Heart Activity

It is essential that cardiovascular patients are equipped with tools to accurately monitor their heart activity over time, particularly for those with conditions such as arrhythmia, atrial fibrillation, and myocardial ischemia. Unlike blood pressure or body weight measurement, heart rate can be measured directly with iPhone and Android devices by using their cameras to detect a fingertip pulse. Essentially the digital version of a pulse oximeter, applications such as Azumio's **Instant Heart Rate** measure an individual's heart rate after an index finger is placed over a camera lens for 5-10 seconds. Instant Heart Rate displays the data with a real-time photoplethysmogram (PPG),⁴ and allows for information to be shared across a variety of mediums.¹²⁵ Similarly, MacroPinch's **Cardiograph** can sync with other devices to share and print data, as well as notate location-based measurement.¹²⁶ Other applications, such as **DigiFit**, have been designed to work with a variety of external heart rate monitors and fitness sensors.

3. Risk Assessment

The calculation and assessment of risk is critical during not only teachable moments but also throughout the greater continuum of care beginning at early prevention and continuing on into wellness. The earlier that individuals are aware of the risks that behaviors or actions such as smoking or sedentary behavior pose, the more likely they will be able to control risk factors and thereby prolong their likelihood of developing serious complications or cardiovascular conditions. **Wellframe** was recently developed to increase patient engagement by providing preventive care alerts, risk assessment, educational resources and evidence-based information. It also can share information electronically with health providers through email, Direct, or printed reports. Similarly, **Heart Age** and **Heart Risk Calculator** predict risk of cardiovascular disease based on the Framingham 10-Year General Cardiovascular Risk Formula that incorporates factors like age, gender, weight, blood pressure, height, and smoking status.

⁴Photoplethysmogram is a non-invasive circulatory signal that detects variation of blood volume in tissue by illuminating the skin and measuring changes in light absorption and perfusion. Commonly displayed by pulse oximeters and bedside monitors, photoplethysmograms can monitor cardiac output and blood pressure.

4. Lifestyle and Disease Management

With each iteration and generation of smartphones that has been introduced to the market, new capabilities have enabled app developers to push the envelope with innovative features. While some of the other categories utilize advancements in wireless connectivity, incorporate external devices or include applications designed around components such as camera or dictation, lifestyle and disease management applications have generally taken an integrative approach by bundling a comprehensive package of features together for consumers' day-to-day needs. For example, applications such as **Cardiac Assist** offer patients a one-stop-shop solution by not only tracking vital signs and medication prescriptions, but also maintaining records of appointments and insurance claims as well as offering information regarding cardiovascular conditions. Others focus on more specific areas of heart disease, such as Wombat App's **Cholesterol Manager**, which allows consumers to track and manage their dietary cholesterol and fat intake. Given the wide-ranging extent of risk factors associated with cardiovascular disease, there are also a variety of applications that target healthy behavior, nutrition, physical activity, sleep, and hypertension – however only those that were expressly designed for heart disease were included in this search. For example, **Sodium One ~ Sodium Counter** and **iFood Diary** offer consumers the ability to track their food intake using an extensive database of items, and **Food Street – Heart Healthy** provides cardiovascular friendly recipes that are low in fat, salt, and cholesterol for individuals with or at risk of heart disease to use in the kitchen.

5. Patient-Provider Communication and Education

Unlike the other aforementioned categories of heart disease applications, many of those providing patient-provider communication and education solutions continue to focus on the basic integration of multimedia and information. A host of encyclopedic applications have been released for patients, medical students and/or providers to use during consultations and at home to explain, illustrate and understand the cardiovascular system through video animations and images. For example, **The Cardiovascular System Pro** offers high-definition, three dimensional images, x-rays and anatomical descriptions, and the **Cardiovascular Medicine Focus Applications** provide accurate videos and animated tours of the human

body to explain the causes, symptoms, diagnoses, treatments, procedures, and risks of heart disease. Other applications have been developed with specific functions in mind. For example, **In Case Emergency: Medi Alert** is essentially an advanced version of a medical alert bracelet that contains extensive information on an individual’s medical history, conditions, allergies, insurance, and primary care provider in the event of an emergency such as heart failure. On the other side of the spectrum, **Heart Failure Trials** empowers and informs consumers of the latest research and evidence-based medicine related to heart failure.

Although limited research exists regarding the efficacy of smartphone applications, recent studies suggest that they are living up to their promise. A case-control study was conducted among 36 volunteers from an obesity clinic to evaluate **SmartDiet**, an app that uses common gamification techniques to educate and encourage a healthy diet and physical activity.¹²⁷ Using the exercise and diet plan functions, intervention subjects could calculate the calories consumed during exercise and digested during meals. SmartDiet also featured a diet game which provided a quiz-based learning tool on lifestyle behavior and allowed users to set a target weight loss goal over the course of six months. Based on the meals and exercise reported, recommendations were regularly displayed regarding caloric intake. After a six-week study period, body composition (weight, BMI, and fat mass) decreased significantly among the intervention group, as shown in Figure 18 below.

Variable	Intervention (n = 19)			Control (n = 17)		
	Before	After	t	Before	After	t
Fat mass (kg)	17.3	16.1	2.9 (p < 0.05)	16.9	15.7	2.3
Weight (kg)	58.5	56.6	3.6 (p < 0.05)	58.3	57.8	0.8
BMI (kg/m ²)	22.2	21.4	3.6 (p < 0.05)	22.3	22.1	0.9

Figure 16: Body Composition Before/After Intervention

The majority of participants rated the accessibility and usability of the system favorably.

mHealth for Cancer

By far the most prevalent use of mHealth in cancer care is for patient outcome reporting, side-effect monitoring, and management of care and treatment. Of note, results from studies of these interventions indicate that mHealth-based patient reporting can help increase patient-provider communication. Relevant studies are described below:

1. Researchers at the Duke Breast Cancer Clinic in Duke South Hospital evaluated the **Patient Care Monitor**, a survey instrument programmed on handheld wireless tablet computers to collect patient-reported outcomes and health-related quality of life information. In a nonrandomized pilot study of 66 breast cancer patients (mean age of 54, 77% Caucasian), participants used the tablet device to complete a survey reflecting common cancer- and treatment-related symptoms, psychological concerns, functional concerns, and social concerns at four clinic visits. Participants were referred to the study by their oncologist and were eligible if they had a pathologic diagnosis of breast cancer, expected at least four visits to the Duke Breast Cancer Clinic in the ensuing six months, and were able to speak/read English. Forty-seven percent of patients had less than a college education. Following completion of the survey (77% completed the survey four times), patients could browse an educational library on the device and the software generated a summary report of the patient's responses for their provider. Results indicated a high degree of patient satisfaction with the device that increased over time as well a belief that the device was a logistically acceptable method for reporting symptoms. While the study did not assess whether using the device improved clinical outcomes or quality of life, 74 percent of users felt that the device helped them remember the symptoms they had experienced and 34 percent reported that the system encouraged them to discuss medical issues with their physician that they might otherwise have forgotten.¹²⁸
2. A similar study using wireless touch-screen laptop computers to assess patient-reported symptom and quality of life measures was performed by the Seattle Cancer Care Alliance in Seattle, Washington. During the **Electronic Symptom Report and Assessment Cancer (ESRA-C) Study**, patients undergoing new radiation therapy, medical oncology therapy or hematopoietic stem cell transplantation, at least 18 years of age, able to communicate in English, and competent to understand the study information and give informed consent used the device twice over a period of six to seven weeks (T1 = initial visit, T2 = follow-up survey approximately six weeks after beginning treatment). 342 patients were assessed at T2. Patients had a mean age of 54.28 years, 45.9 percent were female, 91.8 percent were Caucasian, 57.7 percent had a household income greater than \$55,000/year, and 68.8 percent frequently used a computer at home. Most

found that using the device for symptom reporting was acceptable. Of six acceptability questions presented at the end of the survey, five had a mean score greater than 4.0 on a five-point rating scale. Women, younger patients, and non-severely distressed participants gave higher average ratings of the system.¹²⁹ Further, in a separate analysis, 660 patients were divided into intervention (providers were given a summary of symptom and quality of life issues (SQLI) generated by the device) and control (providers did not receive the ESRA-C SQLI summary report) arms. Patient age in the intervention arm (327 total patients) ranged from 18 to 89 with a mean age of 54 years. Thirty-four were racial minorities, and 23.3 percent had an annual household income of less than \$35,000. Lymphoma (16.2%), gastrointestinal tract (12.2%) and genitourinary (11.6%) cancers were most common among the intervention patients. Results demonstrated that providers in the intervention arm were nearly 29 percent more likely to discuss SQLIs that were reported at a problematic threshold level with the patient. This effect was greatest for issues related to the impact of cancer and/or treatment on sexual activities and interest and issues relevant to social functioning.¹³⁰

Smartphone Applications for Cancer

Although few studies have assessed the impact of mobile applications in cancer care, they represent a more diverse set of functionalities for the patient. Patient-centric healthcare applications cover a wide range of uses including tools for access to personal health records, medication adherence and selection, physician selection, second opinions, the monitoring of physical well-being, health/disease monitoring and management, and healthy lifestyle suggestions.¹³¹ In cancer care, mobile applications have been designed to support information management, treatment planning, decision making, personal and social needs, patient-provider interaction, and education, among others. Based on a review of the iPhone, Blackberry, and Android application stores and other sources, smartphone applications for cancer care can be categorized into four primary functions: resources for information management and learning, resources for decision making, resources for social support, and resources for lifestyle management.

Figure 19 displays the number of applications designed for cancer patients in the application stores of the three major smartphone devices in the U.S.

Application	Information & Learning	Decision Making	Social Support	Lifestyle Management	Total
iPhone	90	61	11	52	214
Android	23	18	4	3	48
BlackBerry	2	2	0	6	10

Figure 19: Number and Types of Cancer Applications Available by Smartphone Device

Each category, along with select applications representative of the function, is presented below:

1. Resources for information and learning

The complexity of cancer care requires patients to understand, track, and manage information about their condition, treatment, and care, all while balancing the needs of daily life. For disadvantaged populations, especially, this process can be overwhelming. Many applications have been designed to help patients both learn about cancer and manage all of their information related to care. Educational applications offers user information (non-personalized or generic), glossaries, lists of common questions and answers, or links to other resources or content. Information management applications provide users with the ability to input, store, and manage personal information related to their care such as symptom information, medication information, appointments, and finances. The **Cancer.Net Application**, developed by the American Society of Clinical Oncology, offers user guides on 120 types of cancer, an interactive tool to manage questions for and answers from providers, the ability to store photographs of labels/bottles and save information about medications, a symptom tracker, and a section with news and updates from the cancer.net website. The **Cancer Guide and Tracking App** developed by LIVESTRONG offers similar functionalities for treatment management, symptom tracking, and education, while also providing multimedia journal capabilities and links to a one-on-one support service. Finally, **AYA (Adolescent and Young Adult) Healthy Survivorship** is an app for cancer survivors that allows users to assess health habits and general sense of well-being, offers personalized tips for a healthier lifestyle, and

features information on survivorship, screening, and latent effects, a survivorship plan, and an online community.

2. Resources for decision making

Decision-making can be one of the most difficult aspects of cancer care given the complexity of disease, severity of treatment, and potential for side-effects. Multiple treatment and therapeutic options are typically available for any given cancer, and preventative measures such as self-exams can raise questions about whether an individual should consult with a provider.

Applications that support decision-making help patients choose the options most relevant to their needs using patient-entered information to personalize recommendations. Common decision-making applications include tools for risk assessment, breast self-examination, skin examination, identifying clinical trials, and understanding/managing information treatment. **Early Detection Plan: Breast Cancer** provides educational information about breast exams, mammograms, risk factors, signs and symptoms, and reminds users to perform routine breast self-exams and to schedule clinical breast exams and mammograms, depending on age and health history.

UMSkinCheck allows users to create a photographic baseline of their skin and photograph suspicious moles or other skin lesions, sends automatic reminders so users can monitor changes to a skin lesion over time, and includes a risk calculator. **NCITrials@NIH** links to the National Cancer Institute's (NCI) Center for Cancer Research (CCR) clinical trial database to assist patients in identifying and sharing clinical trial information. **Breast Cancer Diagnosis Guide** walks users through their breast cancer pathology reports and tests, provides space to enter personal diagnostic information, and recommends relevant links and articles based on user inputted information.

3. Resources for social support

Cancer frequently causes damaging mental and emotional side-effects stemming from fear, worry and anxiety. Further, cancer treatment leaves many patients feeling weak or debilitated and can disrupt normal routines at home and work. Social support applications help patients overcome these difficulties by connecting users to family, friends, caregivers, other patients with cancer, and/or survivors who can lend assistance during treatment, alleviate concerns about diagnosis and treatment, or provide words of support and encouragement. **CaringBridge** is a web and mobile-accessible online space where users can set up a personal protected site for connecting

with others and sharing and receiving support. CaringBridge also offers a support planning calendar that helps family and friends coordinate care and organize helpful tasks, such as bringing a meal, taking care of pets and other needs. **My Cancer Manager** is similar to an information management application, but with an emphasis on mental health and social needs. Features of the app include monitoring common concerns and tracking potential life worries such as family, work, money and nutrition, a personal journal to record thoughts and questions, and access to educational information and a community support network.

4. Resources for lifestyle management

As described previously, lifestyle management is an essential component of preventing cancer. Numerous applications have been developed to help people live healthier lifestyles, typically focusing on physical activity or diet. Cancer-specific lifestyle applications predominately help users quit smoking or manage UV exposure. **NCI QuitPal** helps users set personal goals during their attempt to quit smoking. It can also track daily smoking habits and display information about how much money the user has saved and how their health has improved by not smoking.

At the time of this publication, a large number of smartphone applications are currently being evaluated in trials around the world and results are expected to be published beginning in early 2013. The increased availability, performance, enhanced data rates, and expected convergence of future wireless communication and network technologies around mobile health systems will accelerate the deployment of mHealth technologies and services within the next decade. As such, mHealth technologies will have a significant impact on existing health care services and will redefine the way health care is delivered for chronic disease and socially disadvantaged populations. Individuals can monitor physiological parameters associated with diabetes, heart disease or cancer, including: heart rate, blood pressure, and blood oximetry. Additionally, the wide range of applications currently available also provides interfaces to monitor physical activity, movement, diet and nutrition. The benefits of mHealth technology are extensive and will expand into ways in which socially disadvantaged populations can engage and become active participants in their health.

Patient Web Portals

Patient web portals (PWPs) pull information from a number of existing clinical systems, providing patients and providers with access to a comprehensive view of

the patient's medical history wherever they can use the internet. PWP offer the exciting possibility of truly patient-centered care through robust mechanisms for patient participation in the management of chronic disease. PWP advance the ability of patients to access and contribute pertinent information relevant to their health, such as diagnoses, immunization and insurance records, medications, allergies, and laboratory results. Health providers and patients can communicate with each other via the patient web portal, which enables meaningful participation by the patient as an equal partner in their care plan and its implementation. Depending on the exact configuration, PWP may allow for secure access to records so that appointments, health reminders and alerts, prescriptions, referrals, payments, and insurance eligibility and claims can be smoothly updated and/or adjusted by both the health provider and the patient. Recent systematic reviews of PWP-delivered disease management interventions found that PWP consistently increased satisfaction with care, improved access to health information, enhanced patient-provider communication, and resulted in better overall disease management and patient outcomes.

PWP also interface with existing clinical information systems, such as electronic health records (EHRs) or picture archiving and communication systems (PACS), to offer patients and providers a comprehensive view of the patient's medical history over the internet. PWP can help facilitate patient engagement by allowing patients to contribute information to their record, review their medical history for errors, and communicate with their provider through secure messaging.¹³² Many PWP offer administrative functions to help patients manage appointments, referrals, payments, insurance eligibility and claims, and medications.¹³³ Based on the information in the patient's record, PWP can also provide alerts to patients and providers reminding them schedule or attend diagnostic tests and screenings. All of these capabilities make portals an effective tool for encouraging engagement, by directly involving patients in their care. Unfortunately, the proprietary nature of many patient portals may limit their use for socially disadvantaged populations, unless those groups receive care from a site affiliated with a portal. Other patient portals supported by organizations like the American Heart Association are available free of charge, making them more accessible to disadvantaged populations. Provided below are descriptions of PWP used for diabetes, heart disease, and cancer.

Diabetes PWP

1. Partners HealthCare System, a multi-hospital health care network comprised of several thousand physicians caring for over one million individual patients, developed a comprehensive PWP called **Patient Gateway** that allows direct patient access to an EHR through a secure Internet connection.

Functionalities of Patient Gateway include the translation of a patient's current clinical data into an educational format, provision of patient-tailored decision support based on glucose, cholesterol, blood pressure, and weight values that are sent to the physician, and facilitation of a Diabetes Care Plan, created by the patient and sent directly to a physician. Partners HealthCare conducted an evaluation of Patient Gateway using a randomized controlled trial design involving 11 clinics and 244 patients over a period of one year. Individuals in the intervention group received an online diabetes journal two weeks prior to a physician visit and were provided access to Patient Gateway through which they could review their medications and diabetes care measures and communicate with their primary care provider via secure messaging. Individuals in the control group were provided access to Patient Gateway only. Results of this study showed changes in the medication regimens for the intervention group that could potentially lead to better diabetes care, and a trend toward lower blood glucose levels. While not conclusive, the initial results of this study indicate positive results from the use of PWP to effectively manage the risk factors and symptoms associated with Type 2 diabetes.¹³⁴

2. The Group Health Cooperative Integrated Delivery System created a PWP called **MyGroupHealth** which facilitates secure messaging between patient and provider. Messages can contain test results and other medical information related to a patient's diabetic condition. Patients who used more secure messaging had better glycemic control, though this effect could also have been partially attributable to the provider recommending medication changes, an improved overall continuity of care, or more self-care behavior by patients.¹³⁵
3. **Kaiser Permanente HealthConnect** is a large, comprehensive health information system that utilizes a PWP to facilitate communication between a patient and provider using secure messaging. In addition, patients can view their lab results and medications online, as well as portions of their health record. A large percentage of the secure emails sent to providers required a clinical assessment or decision, while another significant proportion required a clinical action.
4. **My HealthVet**, provided by the US Department of Veteran Affairs (VA), is a secure PWP that provides access to information, resources and tools to veterans for use in the management of their health. Patients can view their medical information directly through the PWP and enter data, such as blood glucose levels, blood pressure, weight and other information related to their health status. Cho et al. conducted a cross-sectional mailed survey in 2010

of 201 veterans with Type 2 diabetes to assess the use of My HealtheVet in five VA tertiary clinics. The results of the survey indicated that over half of the respondents would use the PWP to access information about their diabetes and over 41 percent of veterans would be interested in using the PWP to help monitor and track their blood glucose reading.¹³⁶

5. **HealthTrak** is The University of Pittsburg Medical Center's (UPMC) patient portal, serving as a secure online link between patients and their doctor's office. The PWP allows users to request routine appointments, renew prescriptions, access medical information including medications, immunizations, and lab results, ask billing questions and obtain quality health and disease information. HealthTrak allows diabetic patients and their physicians to spot problems early by tracking glucose levels at home.¹³⁷
6. **The MyGlucoHealth Patient Portal** is a communication and data management web site. The portal allows for automated blood glucose test results from patient meters, using Bluetooth technology or by connecting a USB cable directly to the meter. Results stored on the meter are wirelessly transmitted by mobile phone or PC to the Portal for posting, through a direct upload process. This process eliminates the need for manual logging, ensuring a higher level of accuracy for collected data. Data is then analyzed on the portal, offering patients an evaluation of blood glucose levels and allowing patients to take more ownership and control of their diabetes. The portal offers patients or caregivers the option to receive automated reminders, messages and alerts via email or text message to administer medication or check glucose levels.¹³⁸
7. **Diabit** is a PWP designed for children with diabetes and their parents, launched in Sweden in the spring of 2006. Diabit contains specific diabetes-related information and social networking functions like message boards and blogs. Text pages and interactive multimedia tools including educational videos and online simulation software are also available on the portal. In 2010, researchers from Linkoping University conducted a study on Diabit, to explore patients' and parents' attitudes towards the tailored portal. Results of the study were characterized by three main categories of portal users' attitudes: "the management tool", "the generator" and "the gatekeeper." The first category refers to the functionality of the portal, and its ability to provide patients with valuable, relevant information. The second category relates to the portal's ability to generate large amounts of peer-to-peer information through message boards and chat rooms. The third category refers to users' occasional frustration with Diabit's password requirement, which caused various access problems. Conclusions of the study suggest

PWPs like Diabit have great potential to support diabetic patients and their parents in managing their disease.¹³⁹

Heart Disease PWPs

1. **The American Heart Association's HeartHub** is a patient web portal that provides information, tools, and resources on cardiovascular disease. The online information resource repository addresses topics on multiple heart diseases and conditions, while providing patients with innovative tools like Heart360, which allows users to track health information and share results directly with their provider. The My Life Check tool encourages patient engagement through a simple lifestyle assessment.¹⁴⁰
2. **The Heart and Vascular Center of Arizona (HCVA)** implemented an interactive platform of health IT solutions developed by Kryptic, including **Patient Portal**. Patient Portal is a comprehensive PWP solution that is scalable to organizational needs, integrating document management, secure messaging, online bill pay, automated clinical reminders, and communication features that meet Meaningful Use criteria for patient engagement to facilitate care transitions. HCVA integrated Patient Portal with its EMR to streamline workflow and improve cost efficiencies associated with the entry and collection of patient health data, medication refills, and patient-physician communication.¹⁴¹
3. **CardioSmart** is the official patient portal of the American College of Cardiology (ACC). The PWP serves as an extension of the office visit and an opportunity to expand dialogue with patients. CardioSmart features information resources for multiple types of heart disease patients, in addition to educational videos and interactive tools to calculate BMI and assess risk of developing heart disease. Opportunities for patient connections are offered through peer-to-peer support for patients and caregivers.¹⁴²
4. Duke Heart Center introduced the **HealthView PWP** as part of an ongoing effort to use information technology to further improve patient care and outcomes. The portal offers patients access to tools and applications to help manage their health. Through HealthView, patients can manage prescriptions, track, copy, and print their laboratory results, review their procedure reports and enter vital signs and other data acquired through home-monitoring devices. HealthView also allows patients to view and print their cardiac images from home, making Duke Heart Center the first institution to offer access to this health information.¹⁴³

5. **The Texas Heart Institute’s Heart Information Center portal** is dedicated to providing educational information related to the prevention, diagnosis, and treatment of cardiovascular disease. The portal features online tools including risk assessments, educational guides, and an index of over 170 heart-health topics. The Heart Information Center’s “Ask a Texas Heart Institute Doctor” feature allows patients to submit questions on cardiovascular disease to professional staff members. In addition to the Heart Information Center, the Texas Heart Institute utilizes St. Luke’s Episcopal Hospital’s eCareConnection portal, which enables patients to request appointments online, send secure messages to their doctor’s office, request prescription refills and view test results.¹⁴⁴
6. **The National Health Service (NHS) Kirklees** coronary heart disease self-care portal offers patients support and information needed to manage their long term condition. The PWP gives heart disease patients access to information resources and local support and exercise groups. Kirklees self-care forum social networking functions include a forum for heart disease patients, in addition to one-to-one support from Health Trainers. The Patient Advice and Liaison Service (PALS) offers patient support access to over a million staff in thousands of locations. Kirklees’ PWP also provides patients with up to date prescription information, allowing users to discuss their prescription needs with their provider.¹⁴⁵
7. **HeartNET** is a PWP currently being trialed as part of a research project being conducted by the Heart Foundation and Edith Cowan University in Perth, Western Australia. HeartNET serves as a “heart community” for heart patients, caregivers, friends and family, designed to provide a means of communication and an opportunity to interact with other community members. Members are able to read and contribute to the discussion boards, chat with others online, send private messages, read the latest heart-health tips, and swap recipes and other information.¹⁴⁶

Cancer PWPs

1. **Navigating Cancer** is a patient portal system available for providers to implement in their practice, as well as a set of free online tools for cancer patients to use. The proprietary version offers patient access to health records, tools for patient education, an online intake process to improve administrative efficiency, and other typical features. Online tools for patients include a guide to help patients prepare for upcoming appointments, a medical records organizer to track treatment and medication information, common medical reports and forms, a daily health journal, resources from

cancer experts, and the ability to share this information with family, friends, and caregivers.

2. Memorial Sloan-Kettering Cancer Center (MSKCC) hosts **MYMSKCC**, which includes standard PWP features such as access to medical information and education resources, appointment management, secure messaging, and support for billing. Researchers at MSKCC have also used a separate online portal, the **Symptom Tracking and Reporting (STAR)** platform, to help patients report treatment side-effects. The STAR portal allowed patients to complete an online questionnaire about chemotherapy toxicity related symptoms and sent providers a report of symptoms that reached a threshold level. Researchers at MSKCC conducted a feasibility study of STAR among 107 patients (mean age of 62 years) diagnosed with thoracic malignancies and starting new chemotherapy regimens, who were not enrolled in a clinical treatment protocol and were able to read and understand English. Seventy-six percent had a computer at home, but only 47 percent reported frequent internet usage prior to the study. Thirty-eight percent had a high-school education or less. Results from the study showed an average 78 percent adherence rate for using the system at clinic visits, though the home use rate was considerably lower (only 15% of patients actively accessed the system at home). Patients found the system easy to use and helpful, 77 percent felt it improved the quality of discussion with clinicians, and 51 percent thought communication was improved.¹⁴⁷
3. **MyHealth Online** is a patient portal hosted by Harvard Vanguard Medical Associates in Massachusetts. Patients using MyHealth Online can view test results, receive non-urgent medical advice, view immunization, surgical, and medical history, request and view appointments, manage prescriptions, and receive preventive care reminders. In a randomized controlled trial, 522 of 1103 patients aged 50-75 years (mean age of 56.6 years) with an active MyHealth account and overdue for colorectal cancer screening received automated electronic alerts with a link to a risk assessment tool. Of these, 215 were male, 441 were Caucasian, and 448 had commercial health insurance. Patients who received the electronic message had higher screening rates after one month (8.3% vs. 0.2%, $p < .001$), although the effect diminished after four months (15.8% vs. 13.1%, $P = .18$). Patients who used the risk assessment tool (47 patients) were more likely to request (17% vs. 4%, $P = .04$) and receive colorectal cancer screening (30% vs 15%, $P = .06$) than nonusers.¹⁴⁸
4. **The University College Hospital London's (UCL) Macmillan Cancer Center patient portal** allows patients receiving treatment within cancer

services to access their appointment schedule and other information held about their care. Patients may send and receive non-urgent messages to and from their clinical team and much more through the PWP. The portal has three access levels: Access Level 1 allows patients to view UCHL appointments and other hospital visits, and provides access links for general and specialty specific information; Access Level 2 allows patients to send and receive non-urgent messages from their care teams, make personal notes and complete an action list set by their clinical team; Access Level 3 allows patients to view some of their UCHL documentation.¹⁴⁹

5. **Cancerview.ca** is a PWP sponsored by the Canadian Partnership Against Cancer. The portal brings together resources from partner organizations working together in cancer prevention, screening, treatment, and supportive, palliative, and end-of-life care. Online patient resources include links to chat rooms, blogs, support networks, and website building tools. CancerView users can browse the portal or use the CancerView Finder search tool to find information on a particular topic in cancer control from partner organizations.
6. The **Comprehensive Health Enhancement Support System (CHESS)** is an interactive health communication system that has been studied extensively. CHESS is comprised of disease specific modules with functions for providing information and facilitating communication and decision-making. Components of CHESS include frequently asked question and answer lists, resource guides and directories, an educational library, discussion groups, 'ask an expert' services, tools for tracking health status, decision aids, tools for developing action plans, and more. The lung cancer module added functionalities for reporting symptoms to a patient's provider and broadened to scope of available communication channels.¹⁵⁰ Of note, CHESS has been assessed among a cohort of low-income breast cancer patients as part of the Digital Divide Pilot Project (DDPP). Women living at or below 250 percent of the national poverty line in rural Wisconsin and Detroit, Michigan were loaned a computer and given internet and CHESS access for four months. Patients were eligible if they were within 1 year of diagnosis or had metastatic breast cancer and not homeless. Of 286 subjects, 229 (mean age of 51.6 years) completed a pre- and post-test assessment. 70.1 percent had Stage 0, 1, or 2 breast cancer. By comparing the usage rates of study participants with numbers from another study which included higher-income participants, the authors found that underserved women with access to CHESS will use the system as much if not more than higher-income patients (95% accessed the system at least once vs. 93%), and that access can be correlated with improvements in quality of life and greater participation in

the healthcare system. Though average use declined over time (83% logged in at week one), 30 percent of women were still logging onto the system after 16 weeks, a rate comparable to that found in the other study. Among active users of the system, lower-income women logged on more frequently than the comparable group of higher-income women. The DDPP results were also compared with results from a control group (which received an educational book about breast cancer but did not have access to CHES) of low-income patients from a different randomized controlled trial funded by the National Institute of Child Health and Development (NICHD) assessing the system. As compared to this group, CHES users scored better on measures of participation in healthcare, information competence, social support, and negative emotions.¹⁵¹

7. **HealthWeaver** is a health information management system with both web and mobile components. The HealthWeaver website enables patients to manage personal and health information for cancer treatment. It includes a calendar for managing health events and appointments, the ability to store and manage notes, lists, bookmarks, and care-related files curated by the user, a system for tracking symptoms, pain, and wellbeing with automatic graphing, and logs for medications, supplements, and the care of post-surgery wounds. The mobile phone application component provides access to the information stored in the web portion, allows users to create photo, audio, and text notes that can be linked to related appointments for easier retrieval, and synchronizes the web calendar with the native calendar application on the user's mobile device. A four week qualitative study of nine breast cancer patients ranging in age from 48 to 68 (mean=57.6, median=57) and undergoing active treatment assessed the impact of HealthWeaver. Four patients had Stage I cancer, one had Stage II, three had Stage III, and one was a metastatic patient with Stage IV illness. All but one patient had a college degree. Participants were divided into web only use or web use with mobile use, and then crossed over to the other trial arm after two weeks. Patients reported that the HealthWeaver website helped them gain better control of their information by offering a single location where cancer-related information could be organized. The use of HealthWeaver Mobile helped patients fill in the gaps when they would not have otherwise had access to the HealthWeaver system, such as at the clinic. HealthWeaver Mobile was used to access information away from the patient's computer, recall information to discuss with a provider, update calendars in real-time, link information to calendar events, and record new information on the go. The mobile system also increased self-reported feelings of confidence and control.¹⁵²

Patient web portals and online information management systems blend education, treatment management, health tracking over time, and social support into a single system. Messaging features can greatly improve patient-provider communication and joint management of the information in the system fosters collaborative decision-making and patient engagement. When combined with mobile technologies, these tools are even more effective in increasing the efficiency and productivity of care.¹⁵³ Moreover, PWPs offer unique opportunities for chronic disease patient education and engagement not only during critical teachable moments, but also across the broader continuum of care, including prevention, treatment, disease management, and wellness. Where educational resources fall short, enhancing patient-provider communication through secure messaging can enable personalized coaching and support. Though the use of internet-based technologies for chronic care by socially disadvantaged populations has not received much attention in the literature, we believe they hold demonstrable value for these groups.

Social Media

The internet has undergone a dramatic transformation in recent years, with profound effects for the healthcare system and patients. Early internet was typified by static content curated by a relatively small number of users. Individuals could access websites to consume this content, but generally lacked the ability to engage with content creators or others on the web. Today, the internet has become a far more interactive experience. Web 2.0, as it is sometimes referred to, has shifted the locus of content creation, discovery, editing, and sharing from those with the technical ability to create websites to the average internet user.

The evolution of the internet, along with technological advances that have made it faster and more accessible, has had major implications for healthcare. Patients are increasingly turning to the internet as a source of health information. In the United States, as much as 81 percent of all Internet users (59% of U.S. adults) have searched for health information online; health information seeking is the third most common use of the internet, after email and search. Unfortunately, significant disparities emerge among stratified groups. Only twenty-nine percent of adults older than 65 look online for health information, compared to 71% of adults aged between 18-29 years. Likewise, 62% of adult internet users without a high school diploma (compared to 89% with a college degree) and 41% with an income of less than \$30,000 (compared to 87% of those with an income above \$75,000) look for health information online.¹⁵⁴

Though younger, Caucasian, higher-income, and well-educated populations are more likely to have internet access and to use the internet for health information

seeking than older, minority, lower-income, and less educated groups, internet use among all groups has increased in recent years. Alternate sources of access can also alleviate the “digital divide”. Many disadvantaged populations may have access to the internet at work, school, or through public libraries.¹⁵⁵ Further, it is common for individuals to search for health information on behalf of others, such as the elderly or children.¹⁵⁶ Additionally, the presence of a chronic condition prompts even disadvantaged populations to turn to the internet at higher rates. When those with chronic disease have internet access, they are as likely to access the internet for health information as the general population.¹⁵⁷

In many ways, social media is largely responsible for enabling patients to use the internet to improve their health. Social media has developed hand-in-hand with the evolution of web 2.0. Social media integrates technology, social interaction, and content creation to collaboratively connect online information. Through social media, people or groups can create, organize, edit, comment on, combine, and share content. Social media commonly includes blogs, social networks (e.g. Facebook), microblogs (e.g. Twitter), wikis, picture/video sharing, podcasts, discussion forums, and Really Simple Syndication (RSS) feeds.¹⁵⁸ Estimates of overall social media use vary from 66 percent¹⁵⁹ to nearly 80 percent¹⁶⁰ of internet users. Social media has both democratized access to information, and fragmented its larger mass audience into closely aligned smaller groups who share common characteristics and interests.¹⁶¹ By connecting individuals with shared interests, specific populations can be targeted for personalized outreach, such as those with a family history of chronic disease. Disparities in social media use reflect the overall disparities in internet access, though when internet access is controlled for, there is consistent use of social networking across different socioeconomic demographics. Among internet users, populations with lower education and income levels, as well as racial/ethnic minorities may actually use social networking sites at a higher rate than their more advantaged peers.¹⁶² Individuals with an income less than \$49,999 engage in health-related activities using social media at higher rates than higher income populations.¹⁶³

A recent PwC survey found that more than 33% of internet users in the U.S. are using channels such as YouTube, Twitter, and Facebook to find and share medical information, research, symptoms, treatments, drugs, and health plans.¹⁶⁴ Additionally, a racially diverse group of suburban and rural diabetes patients from the southeastern U.S. reported using the internet to search for health information, frequently visiting social media sites, and expressed a willingness to discuss health information online in chat rooms, discussion groups, or online support groups independent of race.¹⁶⁵

Social media can help patients with chronic disease find information about their condition, connect with others with similar experiences, track and manage symptoms, supplement what they learn at their provider's office, receive psychosocial and emotional support, and more. Studies of an online community-based chronic disease self-management program with social media features including bulletin-board discussion groups found that the program helped patients decrease the frequency of symptoms, improve health behaviors, self-efficacy and satisfaction with care, and reduce healthcare utilization.^{166,167} Social media has even been used to identify, recruit, and evaluate patients with Spontaneous Coronary Artery Dissection (SCAD - an extremely rare type of heart disease that can often induce heart attack among predominantly young women) to a study to begin to understand SCAD etiology, prevalence, recurrence, and management, demonstrating the ability of social networking and online patient communities to foster patient enthusiasm and promote patient engagement.¹⁶⁸

YouTube has been used to push educational information to patients, and also by patients themselves to share their personal experience with chronic disease. A content analysis of 116 YouTube videos presenting information on heart attacks found videos about personal experience (19), news reports (11), videos from professional societies (15) and pharmaceutical companies (5), and lectures from medical institutes (12) presenting information about topics such as pathophysiology, signs/symptoms, tests, prevention, therapy, immediate measures to take when a heart attack is suspected, and complications. Videos describing personal experiences were "liked" most often and had the majority of comments, indicating that viewers preferred to consume content about peers' experiences rather than professional material, irrespective of authenticity or source.¹⁶⁹ Personal experience videos are also common for cancer. Narrative analysis of 35 YouTube videos created by cancer survivors found that the videos presented cancer diagnosis as unexpected, created dramatic tension and emotional engagement, and emphasized feelings of the absence of control.¹⁷⁰ Such narratives may be useful for communicating cancer-related information to others. Low-income African American women presented with personal video narratives from breast cancer survivors, as opposed to informational videos, were shown to have greater identification with the message source and more engagement with the video, leading to more discussion with family members and increased message recall.¹⁷¹

Facebook and other social networking sites have been widely used by patients with chronic disease to find information and connect with their peers. Analyses of social support groups for chronic disease on Facebook have found that cancer- and cardiovascular disease-related groups have attracted the most participants.¹⁷² In fact, over a million users have joined one or more of 620 Facebook groups

dedicated to breast cancer. While many of these groups are focused on fundraising or improving general cancer awareness, support groups tend to be the most active, as measured by the median number of wall posts.¹⁷³ An evaluation of wall posts and discussion topics within the 15 largest Facebook groups focused on diabetes management found that patients and their family members used Facebook to share personal clinical information, request disease-specific guidance and feedback and receive emotional support. Approximately two-thirds of the posts included unsolicited sharing of diabetes management strategies, and 29 percent of posts featured an effort to provide emotional support to others.¹⁷⁴ Figure 20 displays some prominent examples of social networking sites for cancer, diabetes, and heart disease patients.

Social Networking Site		Features
Diabetes	TuDiabetes (tudiabetes.org)	Members can share their experiences with diabetes through blogs, forums, events and news. The themes on the sites are centered on healthy living, best practices in self-management, nutrition and dietary advice, and emotional support
	dLife (http://www.dlife.com/)	Offers information on Type 2 diabetes symptoms, healthy diet tips and exercise suggestions, medications for diabetes control, and an online forum for individuals to share personal experiences. Uses blogs, videos and an electronic newsletter to communicate within the community
	Wellaho (https://wellaho-sanitas.applicationspot.com/)	An online treatment management system tailored to the user's condition. Helps patients learn about their condition, monitor progress, and enlist friends, family, caregivers and others into a support community
	SugarCrew (http://www.sugarcrew.com/)	Medical social network used by a clinic's doctors and staff, their referring doctors, their patients, and their corresponding family and friends. Integrates a patient's medical data and offers "gamification" tools to encourage patients to meet their health goals
	Glu (https://myglu.org/)	Social network for Type I Diabetes patients. Empowers patients through discussion, news articles, and a daily question. Glu also provides an online record of a patient's diabetes information that makes it easier to learn, understand, and

Social Networking Site		Features
		manage diabetes. Users can share their information with others and connect to research efforts
	Inspire (http://www.inspire.com/)	Social networking site for women with heart disease for sharing heart disease information, medical and community resources, and networking and support opportunities
Heart Disease	Heart Connect (www.heartconnect.com)	Provides tools and resources for members to discuss and share about relevant treatments, concerns, issues, products, and more. An app has also been developed for users to access remotely with smartphones.
	The Congenital Heart Information Network (http://www.tchin.org/)	Organization that promotes relationships among members and visitors through its website, message boards, local support groups, events and promotion of awareness of congenital heart defects.
Cancer	My Cancer Circle (https://mycancercircle.lotsahelpinghands.com/caregiving/home/)	A social networking community for caregivers. Through My Cancer Circle, caregivers can set up a support community of family members, friends and others who are close to a person diagnosed with cancer to coordinate efforts to support the patient and each other
	MyBCTeam (http://www.mybcteam.com/)	The first social networking site designed specifically for breast cancer patients. Involves creating a supportive team to improve the patient's experience with breast cancer. Offers a searchable provider directory to connect patients with doctors as well as tools for identifying other patients at a similar stage of care.
	I Had Cancer (http://www.ihadcancer.com/)	Cancer patients, survivors, and caregivers can create online profiles sharing their cancer experience. Users can search by geography, age, gender, time of diagnosis, and type of cancer to identify and connect with others with similar experiences. Peers can be invited to private circles

Social Networking Site	Features
	for sharing private news and messages.
WhatNext (http://www.whatnext.com/)	Aids cancer patients, survivors, and caregivers in gaining insight into living with cancer by connecting them to others in comparable situations. WhatNext considers factors such as cancer type, treatment experience, and diagnosis details to match users with similar peers, firsthand experiences, and resources
Cancer Survivor's Network (http://csn.cancer.org/)	Includes a member search, discussion boards, chat rooms, and a private CSN e-mail. Users can create their own personal space to share their story, photos, audio, videos, blogs, and more
Circle of Sharing (https://circleofsharing.cancer.org/)	Patients can invite friends and family into their Circle, where they will receive information on how to help the patient cope with cancer as well as health updates offered by the patient. Also provides personalized medical articles for users, which can be shared with their Circle. Assists decision-making by offering links and tools for patients to better understand treatments and search for clinical trials.

Figure 20: Social Networking Sites for Diabetes, Heart Disease, and Cancer

Online social support groups are among the most prominent uses of social media for managing cancer, diabetes, and heart disease. Qualitative reports from patients using online discussion board components of an internet-based self-management system for diabetes demonstrate that patients valued the boards for providing peer-support, tips and suggestions for managing their diabetes, and communication with others that understood what they were going through.¹⁷⁵ A review of peer support programs for cancer patients highlighted internet-based support groups as an ideal method for offering peer support. Internet-based groups provided encouragement, empowerment, information and a sense of cohesion, improved psychosocial outcomes measures, and led to confidence in involvement in self-care.¹⁷⁶ Another review of online support and resources for cancer survivors

reported similar outcomes, finding that online support can result in positive emotions, better psychosocial well-being, improved social support, more healthcare participation and health information competence, and reduced levels of depression, among others. However, of the four randomized controlled trials reviewed, none reported significant positive outcomes from the intervention group compared to the control group.¹⁷⁷ Similarly, online social support programs targeting cardiovascular disease have been shown to decrease the prevalence of associated adverse symptoms, and improve health behavior, self-efficacy, and psychosocial quality of life.¹⁷⁸

Despite the apparent potential for social media to assist patients managing chronic disease, we were unable to identify many studies that have directly evaluated the impact of social media-based interventions on patient outcomes. Several case studies involving the use of social media tools to improve cancer, diabetes, or heart disease care are presented below:

- Changrani et al. investigated the use of an online cancer support group among underserved Latina immigrants. The **Virtual Community for Immigrants with Cancer (VCIC)** web site provides informational, emotional, and social network support to Spanish-speaking women through professionally-facilitated online support group discussions. 68 immigrant women with breast cancer were allocated into a control group (20 individuals, usual care) and intervention groups (48 individuals), which participated in the online support groups. The median age of the intervention group was 46.2 years and 32 had only a high-school education or less. Participants without a computer were provided with a refurbished computer and dial-up internet connection. Depression, personal growth, and quality of life, and pain were evaluated but participation in the online support groups did not result in significant improvements on any of the measures as compared with the control group. However, statistical trends on measures of “seeing new possibilities” and feelings of strength indicated improvement in the intervention group. The authors concluded that online support groups are acceptable and feasible to immigrant communities.¹⁷⁹
- Namkoong et al. analyzed the use of social media tools within the **Comprehensive Health Enhancement Support System (CHESS)**, an interactive health communication system. CHESS is comprised of disease specific modules with functions for providing information and facilitating communication and decision-making. CHESS includes computer mediated social support (CMSS) discussion groups that allow users to anonymously share information and support. Using data from the Digital Divide Pilot Project (DDPP), which looked at the plausibility of using CHESS to improve care for low-income women with breast cancer, Namkoong et al. identified 177 women who had

written or read at least one message in the CMSS groups over the 4-month study period. Women were eligible for the DDPP study if they were at or below 250% of the federal poverty level but not homeless and within one year of diagnosis of early-stage breast cancer or metastatic breast cancer. The mean age of the participants was 51 years old and 76.3% of women were Caucasian. Participants completed a survey before the study and at 4 months to assess emotional well-being. Results did not demonstrate a significant relationship between well-being and the expression and reception of treatment information through CMSS except for those patients with higher reported health self-efficacy. Namkoong et al. did not assess whether use of the CMSS groups or CMESS overall had an impact on a patient's perceptions of their self-efficacy.¹⁸⁰

- Hess et al. conducted a qualitative survey of women with peripartum cardiomyopathy (PPCM) participating in online support groups. PPCM is an uncommon condition in which women experience symptoms of heart failure in the last month of pregnancy or in the first 5 months after delivery of a baby without any previously identified cause of heart failure. The survey consisted of 20 open-ended questions and one Likert-type question with seven statements and four answer choices sent by e-mail to women who participated in online support groups (OSGs) for PPCM patients; twelve women (aged 19 to 34 years) completed the survey. Eleven respondents were white and one was Asian. One woman had completed some graduate work, one woman had a college degree, nine had completed some college courses, and one had only completed high school. The survey results showed that OSG participants felt that the benefits of participating in the group included exchanging stories, being understood, gaining hope, and getting and sharing information. Given the rarity of PPCM, respondents highlighted the positive feelings they enjoyed as a result of finding others with the same condition.¹⁸¹

Without additional research supporting the use of social media in areas such as self-management, social media for diabetes, heart disease, and cancer care may be best suited for providing psychosocial support and basic educational information to disadvantaged populations. Online health information can be notoriously inaccurate, largely because the user-generated nature of web 2.0 supports the propagation of such information.¹⁸² For those with less education, low health literacy, and less experience navigating the internet, identifying high-quality, comprehensive information can be an overwhelming barrier. As more disadvantaged populations obtain access to the internet and grow more comfortable with finding and using content, we anticipate that this will be less of a challenge in the future. Further, the use of social media itself can help overcome issues with low quality information.¹⁸³

Providers have also begun to embrace social media, offering information that is high-quality and accurate to patient populations.

It is important to note that while there is little scientific evidence supporting the use of social media to directly improve measurable patient outcomes, social media may provide a valuable starting point for patients to begin to understand their condition. Patients often compare information they find through social media with their own experiences, thereby actively reflecting on their own condition to determine how a given piece of advice might apply.¹⁸⁴ By engaging patients in this manner and encouraging them to consider their own circumstances, social media can serve as a useful tool that can help patients devise their own strategies for coping with their illness. Rapid adoption in the use of the internet to find health-related information and participation in social media sites among all populations suggest that the use of social media for chronic disease care is still in its infancy. It is likely that new uses of social media will be developed in the future, particularly as social media represents a relatively low-cost way for providers to engage patients, and for patients to engage each other.

Assessments

Previous sections of this report explored how four categories of eHealth tools can improve the management and treatment of diabetes, heart disease, and cancer among socially disadvantaged populations. In addition to identifying evidence and case studies demonstrating the utility of eHealth tools, we also examined how four critical factors – usability, cost effectiveness, interoperability, and privacy and security – impact the design, implementation, and use of these tools.

As patients and providers alike weigh whether or not to use eHealth tools in healthcare settings and at home, these four factors are essential determinants of system efficiency, effectiveness, and user satisfaction. Evaluating eHealth tools is a fundamentally complex and difficult process because tools are created to serve a variety of functions for diverse end-users in distinct environments. The unique nature of individual users and settings raises different concerns and barriers regarding use cases for each tool, which may not necessarily be generalizable to others. Moreover, assessments are conducted in an ecosystem characterized by ongoing, continuous, and dynamic processes. As a result, disruptive innovations in technology, wireless connectivity, data management, and analytics may render assessment frameworks irrelevant or obsolete. Innovation challenges existing paradigms and offers new capabilities that were thought of as impossible only a short time prior. Consequently, eHealth Tools must be constantly reassessed to address with the changing needs of their users. Still, usability, cost effectiveness, interoperability, and privacy and security remain dominant themes over time.

Below, we address each of these themes as they relate to eHealth tools for diabetes, heart disease, and cancer care and provide a basic framework through which each can be assessed.

Usability

Usability is broadly defined by the International Organization for Standardization as “the extent to which a product can be used by specified users to achieve specified goals with effectiveness, efficiency and satisfaction in a specified context of use.”¹⁸⁵ If eHealth tools are not designed to be accessible and simple to use, potential benefits and functionalities are rendered meaningless. Just as patient-centered care models have refocused healthcare delivery on the patient’s attitudes, beliefs, and needs, usability frameworks encourage user-centered design to ensure the meaningful and quality use of technology.

Usability is often the lynchpin to foment sustainable patient engagement. Although a number of eHealth Tools are widely used by and easily accessible to socially disadvantaged populations, there is little data about their usability. Unfortunately problematic user interfaces and poor engineering design can induce unintended use, errors, and data mismanagement, all of which can ultimately compromise patient safety. Furthermore, these problems can be compounded among socially disadvantaged individuals that are not as technologically literate as the general population, or may not have the same access or ability to use Tools in practice on a regular basis.¹⁸⁶ Indeed, the greatest threats to the effective and safe use of these technologies are events that are unfamiliar to users and have not been anticipated by designers and engineers. This becomes particularly relevant when considering the unique needs and preferences of distinct user groups which may have drastically different experiences with an eHealth tool. For example, older users and diabetics suffering from retinopathy may have limited visual capability compared to younger, healthier users.¹⁸⁷

Usability studies have incorporated far-reaching disciplines such as human-computer interaction, engineering, ergonomics, design, and psychology, to offer a wide range of constructs and models

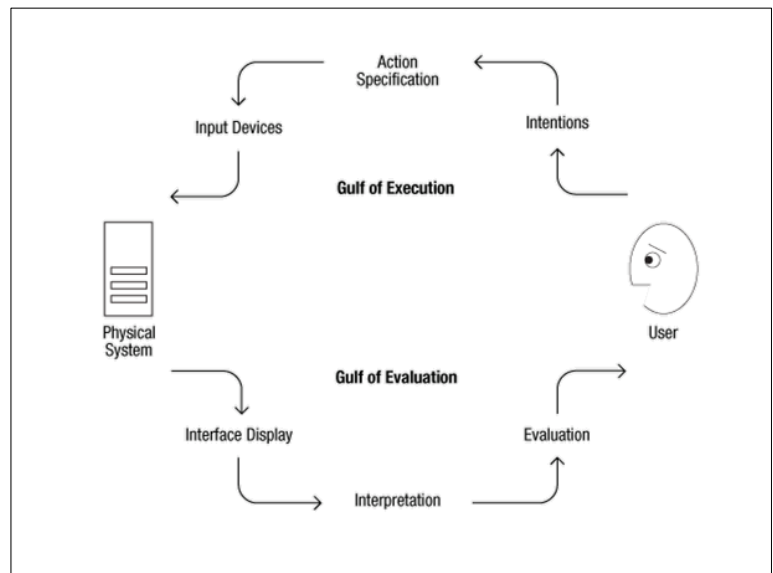


Figure 21: Theory of Action

for measuring how technology is perceived and used in different ways. However, universal to them all is recognition of the need to understand the set of core factors and knowledge that are required to properly use technology.¹⁸⁸ Usability can generally be assessed according to four major principles: user-friendliness, user design, user satisfaction and user confidence. User-friendliness and design primarily deal with the type of technology and the design of the user interface, while user satisfaction and confidence are related to a user's perceptions of the technology.

User-friendliness and user design have been analyzed through a multi-disciplinary cognitive engineering approach to human-computer interaction. Incorporating principles, methods, and tools to guide the analysis and design of computer-based systems, various conceptualizations have been developed to illustrate how humans interact with technology. Such models include Paul Norman's theory of action depicted in Figure 21.

Norman's model portrays a continuous process of user interaction with a system. Interaction begins with the user's intent (e.g. opening the application), which leads to an action (e.g. clicking on an icon) and results in a change to the state of the system, which is reflected in the user interface (e.g. the application opens a new document). Users are expected to recognize changes in the system and correctly interpret them to achieve their intended goals. Failure on the part of the system to correctly respond to a user's needs may indicate a design flaw (referred to as the "gulf of execution"), while miscomprehension of system changes by the user indicate flaws in the way the system outputs information (referred to as the "gulf of evaluation").¹⁸⁹ Such flaws can severely detract from the functioning of eHealth tools by deterring patients and providers from applying them throughout treatment.

eHealth tools with poorly executed design are especially problematic for patients trying to self-manage their chronic conditions. For example, tasks that require patients to execute lengthy sequences of actions or constantly transition between different interfaces increase the demands on the patient's working memory. Similarly, graphical representations or displays that are dense with objects and text require a high degree of cognitive processing. Systems with these design elements strain the user's attention and potentially render the tool ineffective.¹⁹⁰

Overall, assessments of usability should minimally incorporate the following elements:

1. Characterize the ease with which a user can carry out a tasks using an eHealth tool
2. Assess how users attain mastery in using eHealth tools
3. Assess the effects of tools on work practices

4. Identifying problems users have in their interaction with tools

Several examples of how usability in eHealth tools has been assessed are presented below. These examples illustrate the application of usability concepts.

Usability in Telehealth

Researchers at Temple University and Geisinger Medical Center evaluated a telehealth system for patients to report health indicators such as weight, blood pressure, physical activity, and smoking status from home. Temple University and Geisinger Medical Center both serve areas designated to be medically underserved, and 28 percent of participating patients were African-American. Patient reported blood pressure measures were compared with data captured electronically by a blood pressure device to ensure validity and accuracy of the reports. Patient data and device data showed little variance between values, ($r=0.95$ for both systolic and diastolic blood pressure), leading the researchers to conclude that the system was not difficult to use, provided a series of easy tasks for patients to follow, and did not fundamentally alter the workflow of the providers who had to view the data and respond accordingly.¹⁹¹

Overall, patient satisfaction with telehealth systems indicates a high-degree of usability. Brown-Connolly deployed a standardized patient-satisfaction questionnaire to 793 patients in 18 rural California counties. Mean satisfaction with telehealth was 4.5 out of 5. Additionally, many patients responded that they were willing to continue to use telehealth on an ongoing basis, believed the system helped them obtain correct and necessary information from their providers, and were satisfied that their questions had been adequately addressed by providers. Brown-Connolly noted that the use of telehealth reduced travel distance for patients meeting their provider by an average of 90 miles.¹⁹²

Patient Web Portals

HealthView is a web-based patient web portal that supports administrative and clinical functions including appointment scheduling, bill payment, advance registration before a clinic visit, medication list review, and lab results and vital signs viewing. Segall, et al. conducted a study in which a cohort of patients was asked to think aloud as they carried out tasks in HealthView, and then completed surveys and interviews eliciting their reactions afterwards. A large majority of the respondents indicated that the usability of the portal was enhanced by the ease of navigation, consistency of the information, clarity of the messages, organization of the information in the system, and the learnability of the system.¹⁹³

Osborn, et al. reviewed eleven usability studies of PWPs to explore whether patients were open to the idea of using technology to assist in self-managing diabetes,

salient features of PWP, and potential barriers to sustainable use. They found that a majority of patients from all age groups are not averse to using technology for diabetes management. Popular features of PWP include the ability to electronically communicate with providers and tools, schedule appointments, and receive reminders. Disease management capabilities of PWP, on the other hand, were not rated as highly by patients. Osborn, et al. concluded that such functionalities should be improved to meet patient expectations regarding the portal. The usability studies also indicated the importance of assessing usability prior to implementing a portal, as assessing the specific needs of the patient population being served by the PWP can help developers deliver tools more effectively.¹⁹⁴

mHealth

As part of the Enhanced Complete Ambient Assisted Living Experiment (eCAALYX), researchers in the European Union developed Android-enabled smartphone applications to support remote monitoring of older adults with chronic conditions and facilitate communication and follow-up with healthcare providers. Similar to other mHealth examples in this study, the design and architecture of the system enabled it to receive information from wireless health sensors and a GPS location sensor in the smartphone and transmitted information to a remote server accessible by providers. In light of potential physical and/or cognitive limitations associated with elderly populations that may impede their use of the technology, the eCAALYX mobile platform was developed with a transparent and accessible interface functionality that employed the following solutions:

- The use of a mobile phone with a large-touch screen and no buttons
- All maintenance actions performed either remotely or transparently to the user
- Navigation of the application was reduced to two accessible screens, to avoid confusion to the end-user
- The phone runs autonomously without any mandatory interaction from the user from the time it is turned on.

These design elements made it easier for older adults to record and report data directly to their provider, with little confusion regarding the functionality of the application.¹⁹⁵ Other mHealth applications and devices discussed previously in this report have also adopted a number of these principles, including abbreviated screens with easy-to-read buttons and comprehensible functions.

In a 2012 ethnographic study, researchers combined information from interviews with knowledge of user-centered design approaches employed by consumer-

oriented products to identify four common usability design themes among mHealth technologies for diabetes care that successful applications should share. These themes included fast, discrete transactions, data collection to facilitate decision making, behavior modification, and information sharing.¹⁹⁶ Each theme is described below as it applies to eHealth tools identified in this study:

Theme #1: Fast, Discrete Transactions.

Many telehealth and mobile applications assessed for this study rapidly take weight, nutrition, exercise, or health indicator measures directly from a mobile device or via user input. Data is collected and transferred wirelessly through Bluetooth technology within seconds. The information is then transferred to a central server or a cloud-based storage site, where it is kept secure and can be accessed by authorized users. Data is available for viewing moments after it is captured and transmitted.

Theme #2: Data Collection To Facilitate Decision Making

Mobile applications often utilize visual charts and graphs to illustrate a patient's health information, including daily glycemic levels, blood pressure, calorie consumption, weight, and/or physical activity. By representing data visually, users can more easily track trends and identify areas that need improvement. Further, many of these applications include decision-support prompts and alerts that notify the user or their provider when their levels fall or rise dangerously. For example, these prompts can inform the user when they have consumed more calories than recommended, when their carbohydrate intake is too high, or if they need to increase their physical activity levels.

Theme #3: Behavior Modification

Through the use of visual displays and decision support functionalities, mHealth applications seek to encourage behavioral changes in their users. Decision aids and prompts specifically remind users to complete healthy actions, while data representation and other information included in the application can educate the patient about their health and how to improve it. Our research identified a number of pilot studies that have demonstrated the utility of eHealth tools in helping patients achieve better control of their blood glucose, blood pressure, weight, symptoms, and attitude toward their disease.

Theme #4: Information Sharing

Some mobile applications integrate with other web-based applications, such as a patient web portal, or with a personal health record. Others transfer data from the patient at home to their provider. In these cases, information is being shared with

others, which facilitates patient-engagement and understanding. Effective mobile health applications may also enable patients to share their medical data with family members and informal caregivers, an important element for fomenting social support.

Each of the examples above illustrates how the tenets of usability are being implemented in practice. Of the eHealth tools described in this report, there is a notable lack of usability data related to social media given that it is still a nascent, emerging aspect of health IT. As mHealth and social media continue to change healthcare paradigms by making eHealth tools available for widespread use, new approaches, such as crowdsourcing, will likely emerge to make usability testing and evaluation a more cost-effective and time-efficient process. Moreover, development trends including rapid iteration and agile development cycles that incorporate feedback from users suggest that usability is considered central to the design and deployment of eHealth tools. Still, more research is needed to espouse best practices in developing telehealth, patient web portals, mhealth, and social media platforms, particularly among socially disadvantaged populations for which barriers to usability may be more common.

Cost-effectiveness

Given that socially disadvantaged populations often lack health insurance or the financial resources to sufficiently cover the costs of their care, the cost-effectiveness of using eHealth tools is of particular importance. Healthcare providers implementing eHealth tools for use by these individuals must understand that generating significant revenue from these tools is unlikely. However, the evidence supporting the use of these tools to provide high-quality care suggests that healthcare organizations can still realize a substantial return on investment related to cost-savings from more effective care. Successfully implementing eHealth tools for diabetes, heart disease, and cancer care requires a deep understanding of the long-term benefits of improved care, and how those benefits can ultimately decrease healthcare spending.

The costs and benefits of health IT are notoriously difficult to assess.¹⁹⁷ Often, the financial benefits associated with health IT are predicated on assumed improvements in quality of care and overall population health that are not immediately demonstrable in the short-term. Therefore, the decision to adopt health IT tools is challenging, especially as the direct costs of doing so can be quite high.¹⁹⁸ Considerations of the costs of health IT must also account for factors beyond the direct price of the tool and ongoing maintenance. Indirect costs related to staff training and workflow disruptions can pose a significant burden to healthcare organizations adopting health IT solutions.¹⁹⁹ Further, cost-savings accrued from the use of health IT may not benefit the organization implementing

the tool. For example, any tool that potentially reduces the number of hospitalizations or shifts care to physician practices could deprive a hospital of future revenue, even though the tool may represent overall cost-savings to society.²⁰⁰

The costs of telehealth, patient web portals, and to some degree, mobile health tools primarily burden healthcare providers. Patients typically only face costs for using mobile health applications, as well as social media. Though most social media tools are free to use, patients must have internet-access to take advantage of them. Likewise, data plans are necessary for smart phone owners, and many mobile applications require a fee to download. The average cost of a health-related application in the iTunes market was \$2.05 in 2012.²⁰¹ A standard smartphone data plan can cost a minimum of \$20 per month, with an additional \$40 per month for voice and messaging services.²⁰² Similarly, broadband internet access begins around \$20 per month,²⁰³ and dial-up internet costs approximately \$10 per month.²⁰⁴ Though relatively low cost, affordability remains key barrier to adoption of the internet.²⁰⁵

Unfortunately, there is no readily available framework through which to assess the cost-effectiveness of eHealth tools, and few of the studies identified in this report included information about costs. Of those that did, cost-savings were presented as outcomes of the study, but were not compared to the costs of implementing and maintaining the tool. Common models for assessing the cost-effectiveness of healthcare interventions typically rely on estimating the net cost for achieving a measurable unit of health improvement or poor outcomes averted (measures include life years gained (LYs) and quality adjusted life years gained (QALYs)).²⁰⁶ However, these models do not account for the indirect costs described above, or the indirect benefits associated with the use of the tool, such as patient empowerment or economic revenue derived from improvements in an organization's reputation for quality care. The following are examples of research related to the use of telehealth, mHealth, patient web portals, and social media for diabetes, heart disease, and cancer care that demonstrate various ways of assessing the cost-effectiveness of these technologies:

- Whitten et al. conducted a systematic review of 612 studies examining the cost-effectiveness of telehealth interventions which demonstrated the difficulties associated with assessing cost-effectiveness. Of the 612 studies, 55 articles included cost data. Of these, 24 were subjected to a full review, and only four examined costs from a societal perspective. Twenty focused on simple cost comparisons as opposed to the wider implications of the intervention for patient care. Studies used a variety of analytic methods, including cost analysis, cost minimization analysis, and

- cost effectiveness analysis, though none attempted to establish “value for money” (i.e. cost utility analysis). The benefits associated with the intervention were generally equated with cost savings and 17 studies assumed equivalence of the intervention with standard medical care without efficacy data.²⁰⁷
- Johnston, Kennedy, Murdoch, et al. described the use of teleophthalmology as a mode of technology transfer between the United Kingdom and South Africa. Technology transfer is a means of building healthcare capacity in socially disadvantaged areas by imparting specialist skills to local practitioners. Ophthalmologists at Moorfields Eye Hospital in London held videoconferencing sessions with clinicians at a hospital in South Africa to provide advice on patient diagnosis, management and treatment. Cost analysis of the program examined the costs of setting-up and running the videoconferencing equipment, as well as the changes in costs attributable to teleophthalmology in terms of clinical care (such as clinical examinations, tests, investigations and inpatient admissions). To determine effectiveness, costs were compared with disability adjusted life years (DALYs) averted (DALYs represent the sum of the value of future years of lifetime lost through premature mortality and the value of future lifetime adjusted for the average severity of disability caused by a disease). DALY measures were based on improvements in a patient’s visual acuity. 113 patients were referred to teleophthalmology in South Africa, and data from 90 patients (mean age = 26 years) was included in the analysis. The average total cost of setting up the program was £242 per patient and running costs were £91 per patient (52% was accounted for by staff costs in London and 47% was accounted for by telecommunications costs). The program did not improve costs for clinical care except for hospital admissions, resulting in an overall increase of £26 per patient. As most of the set-up and running costs were incurred by the hospital in London, the hospital in South Africa only incurred total costs of £27 per patient. Fifty-seven patients experienced improved visual acuity through the program, resulting in 6.8 DALYs averted per patient, with a cost per DALY averted of £53. The authors concluded that the program’s costs were a “modest” investment for an industrialized nation to make in a developing nation’s healthcare system. Overall, the program was deemed cost-effective for the cost of £53 per DALY averted.²⁰⁸
 - Wells, Srinath, Free, et al. evaluated a study investigating the use of an SMS-based mobile intervention to promote smoking cessation to determine the program’s cost-effectiveness. 200 smokers in the London

metropolitan area (mean age = 37 years) with an intent to quit smoking were randomized to the Text2Stop intervention or a National Health Services counseling-based behavioral modification program. Text2Stop sends motivational text-messages to users to promote adherence to cessation goals through the use of positive reinforcement to modify unwanted responses to stimuli that facilitate smoking behavior. Cessation status was assessed at 1 month and 6 months. Direct costs (£47.25 per person) of the program included monthly platform maintenance (£700), the cost of sending SMS messages to participants (£11.25 per person), and the cost of salivary cotinine testing to determine cessation status (£1980). Indirect costs (£73.09 per person) included wages of the therapists/counselors involved in constructing the text-message content, and the opportunity cost in terms of wage hours forgone by participants. The total cost of the Text2Stop program was £120.34 per person as compared to £1211.58 per person for the counseling-based program. A benchmark of £20,000 per quality adjusted life year (QALY) gained was used to assess effectiveness. The authors determined that while neither intervention achieved the effectiveness benchmark, the SMS program was more cost effective as each additional GBP spent yielded better value for the money. These results indicated that given their effectiveness at encouraging smoking cessation in the short term, SMS-based programs should be considered as part of an overall smoking cessation strategy, especially as investments in such programs may achieve economies of scale.²⁰⁹

Cost may be one of the least researched aspects of using eHealth tools to care for disadvantaged populations with diabetes, heart disease, and cancer. Cost-effectiveness studies generally lack standardized methods, and often fail to account for longer-term cost savings derived from population health improvements, enhanced quality of care, and patient empowerment. In total, the evidence supporting the positive health outcomes associated with the use of eHealth tools presented in this study suggests that the propagation of such tools represents a viable method through which to reduce healthcare spending in the U.S. As chronic disease care is among the costliest overall, significant improvements in quality can have a pronounced impact on cost.

Interoperability

Effectively using eHealth tools to help patients manage their chronic conditions often requires clinical data to be securely exchanged through multiple message formats and to and from different information systems.²¹⁰ Therefore, a semantically sound and technically feasible set of standards is needed to correctly transmit and

interpret this data. Interoperability refers to the process by which a system translates or encodes a unit of data such that another system can interpret and use that data. Although healthcare stakeholders have made tremendous strides in fostering interoperability by utilizing common standards to connect health information systems, there is no defined set of messaging or vocabulary standards universally used by existing health IT platforms. As a result, interoperability remains a significant barrier to the use of eHealth tools.

Interoperability can be understood on an internal and external level, both of which are necessary for the sustained success of eHealth tools. Internal interoperability refers to the interaction of components on an operational level, such as common physical interface standards (for example, Universal Service Bus (USB) or the American National Standards Institute (ANSI) series of standards for videoconferencing). Such standards enable devices and software from different developers to communicate and share information. Internal interoperability ensures that technology use at the point of care is successful, which often necessitates effective interfacing between systems despite differences in time, location, type of equipment and level of technical expertise. External interoperability focuses on effective networking and interaction between health information applications and health information systems. External interoperability is driven by health information standards which seek to link disparate systems, including EHRs, laboratory, pharmacy, image archival, and decision support systems. The ability to collect and exchange data across each of these systems is critical to achieving an uninterrupted and integrated continuum of care for the patient. Some of the standards used to facilitate external interoperability include those promulgated by Health Level Seven (HL7) and the Digital Imaging and Communications in Medicine (DICOM), as well as those published under the United States Health Insurance Portability and Accountability Act (HIPAA).²¹¹

Together, common standards for external and internal interoperability encompass a framework for enabling providers in distant locations or practicing in different specialties to capture, exchange, and interpret data. Telehealth and mobile health applications, in particular, have improved access to specialty care and patient education resources among socially disadvantaged populations, but many of the health IT and practice management systems used by providers in underserved areas are still incompatible with these tools or require new interfaces in order to connect. As with the rest of the health IT industry, patient-centric tools (and the systems with which they seek to connect) are plagued by proprietary specifications that inhibit data exchange.

Fortunately, standards developed for interrelated fields are being widely leveraged by eHealth tool developers. ANSI standards for videoconferencing and the use of

Coder-decoder protocols (CODECS) within the ANSI standard, for example, have led to wide-scale videoconferencing interoperability that is agnostic in terms of the hardware used individual telehealth platforms. Likewise, Hypertext Markup Language (HTML), which is commonly used by web browsers, is a widely accepted standard for telehealth, mHealth applications, and web-based technologies. HTML provides a standard for the delivery of content, as well as database and program access independent of an operating system. Finally, the use of the DICOM and Picture Archiving and Communication Systems (PACS) for digital imagery and archiving has been essential to developing store-and-forward and remote monitoring telehealth systems.

Within eHealth tools, other general approaches establishing interoperability between devices and information systems include:

- Proprietary systems, in which individual vendors ensure interoperability by constraining system integration via proprietary messaging and interfaces
- Drivers that allow for interfacing across multiple proprietary components
- Centralized translators that serve as a coordinating hub across multiple disparate platforms
- Specific system architectural requirements or constraints through architectural standards.

A number of standards, profiles, and/or collaborations have been developed to address various aspects of medical devices interoperability, including:

- ASTM F2761-09 for the integrated clinical environment
- Health level seven (HL7)
- IEEE 11073 medical device communication standards
- Medical device interoperability coordination council (MDICC)
- UL2800 for interoperable medical device interface safety

Despite extensive work to facilitate interoperability on the part of the federal government and private developers, the ability for eHealth tools to exchange data with larger healthcare information systems is all too often still a work in progress. The healthcare industry has yet to define and agree upon clinical messaging and vocabulary standards to be used across different technologies. Controlled terminologies will enhance the ability of eHealth tools to communicate effectively with EHRs and other components of a hospital information system (HIS) while

facilitating information exchange between those components, regardless of location and vendor.

Privacy and Security

As eHealth tools have become more widespread in provider settings and the patient's home, privacy and security have emerged as pressing issues. Many tools collect private medical information or clinical data from patients through a device or application, either via manual data entry or remote sensor. However, once the data is collected, stored, and/or transmitted, the patient often has little control over who is able to view it, where it is kept or sent, and how it will be used. Therefore, it is imperative that developers and healthcare providers establish clear and effective policies for maintaining the security of information and protecting the privacy of patients.

A confluence of factors, such as the growth in specialty care and emphasis on care coordination all but ensures that a patient's data will be viewed by stakeholders other than the patient and their primary care provider. In fact, the digitization of health information has created new challenges for privacy. For example, sensitive health information such as a patient's mental health status or history of substance abuse may be available to providers through an EHR without the patient's knowledge. Likewise, security breaches in EHR systems can lead to unauthorized access to patient data on an unprecedented scale. Finally, some organizations have taken advantage of the ease with which electronic data can be analyzed and have sold patient information, such as prescription histories to pharmaceutical companies.²¹² Through modifications to the Health Insurance Portability and Accountability Act (HIPAA), the federal government has attempted to remain abreast of evolving privacy concerns, but rapid advances in technology have made it difficult for bureaucratic and regulatory processes to fully adapt.

Security is another key concern for those designing eHealth Tools and the patients using them. Because providers are likely to access a patient's data from different locations or outside of an affiliate network or single health system, the data is exposed to varying levels of security risk depending on the practices of the hosting or accessing entity. Similarly, the different tools themselves pose different risks of an unauthorized breach of patient data. For example, videophone technology for real-time videoconferencing may employ a common (H.324) transmission standard. The H.324 standard enables low-quality interactive video connectivity over an analog telephone line, also known as plain old telephone service (POTS).²¹³ Because current HIPAA regulations exclude POTS-based technologies, videophone technologies pose a low security risk as to the unauthorized access or disclosure of personal health information. In such systems, the primary threat of access is if an

individual obtains a court order to wiretap the telephone line, or if the user cannot verbally verify the individual on the other end of the line.

On the other hand, store-and-forward architectures of telehealth or mobile health rely on the transmission of medical images, video clips, medical records and medical data through the use of a standard Internet Protocol (IP). Information shared over the Internet often remains accessible to individuals through the use of commercially available equipment. Therefore, to secure health information, many developers have utilized public-key encryption to safeguard the information over the Wi-Fi Protected Access (WPA) standard that is commonly used in locations where wireless internet is available.²¹⁴ Systems that use the Internet as an access point, including patient web portals, often require encrypted authentication with a user name and password. Additionally, in some cases, role-based access is created for the patient, members of the care team, and/or family members to determine who can access and use which data.

Studies we reviewed offered limited detail on privacy protocols and security measures employed by the various tools. More research is needed on the types of encryption protocols used by mHealth devices in particular, as well as the message authentication measures used to ensure data integrity when information is exchange from one entity to another. As internet- and mobile-based technologies enable new degrees of interaction, engagement, information sharing, and collaboration, they will continue to herald in new concerns and barriers related to privacy, security, convenience, anxiety, and trust among users and patients. New advanced protocols will need to be developed and promulgated that not only catch up with the speed and diffusion of technology, but also face the evolving realities of an increasingly connected and wireless society. If eHealth tools are to truly transcend existing barriers to disease management as envisioned, efforts must be designed to meet the unique needs and disparities of socially disadvantaged populations with chronic conditions such as diabetes, heart disease, and cancer.

Methodology

We began this study with a comprehensive literature review utilizing the following databases: the Medical Literature Analysis and Retrieval System Online (Medline), PubMed, and the Cumulative Index to Nursing and Allied Health Literature (CINAHL). A search was also conducted through Google Scholar. Relevant references from extracted articles were identified to increase the literature search yield. Search terms comprised of combinations such as: "diabetes & medically underserved," "heart disease & telehealth," "cancer & mobile health," "social media & diabetes," and "patient web portals & cancer."

Only original studies published after 2005 that evaluated the use of eHealth Tools (mobile health applications, telehealth, social media and patient web portals) for diabetes, heart disease and cancer management in medical practice were reviewed. These included randomized controlled trials, quasi-experimental designs (such as non-randomized controlled trials, pre-post studies, and post-intervention studies), feasibility/case studies, systematic reviews and meta-analyses, and observational and cross-sectional studies. Studies evaluating the use of health IT for other chronic diseases, theoretical articles describing the technology but not examining its application, and opinion pieces were excluded. In addition, studies evaluating the use of electronic health records, chronic disease registries, and clinical decision support were excluded as the focus of this project is on patient-centric tools and not components of health IT that are primarily used by physicians.

Titles and abstracts of selected articles were independently reviewed by two authors and, if found eligible, the full article was then obtained for additional review. When there was disagreement between the two authors about the eligibility of an article, the third author adjudicated the conflict. A total of 918 articles were identified using the above search strategies, with 427 satisfying the inclusion/exclusion criteria. For this report, the studies identified and abstracted were classified based on methodology used, as shown in Figure 22:

Study Methodology	Number of Studies
Randomized Controlled Trial	143
Quasi-Experimental Design	54
Feasibility/Case Studies	98
Systematic Reviews	83
Observational and Cross-Sectional Studies	49
Total	427

Figure 22: Number and Types of Studies Identified

Each of the articles was abstracted through a disciplined process to identify the technologies being studied, the results of the utilization of those technologies on patient outcomes, the relationship between those outcomes and risk factors

associated with socially disadvantaged populations, and specific characteristics of each technology, including:

- overall usability of the technology
- cost of the technology as well as its potential return-on-investment and cost effectiveness
- data transmission standards to determine its interoperability with larger health information systems
- protocols used by the technology to protect personally identifiable information.

Additionally, a non-traditional literature review was conducted through Google to identify specific products that employ the features and functionalities of the eHealth Tools identified in the literature review. Information about the development and proliferation of these Tools, in addition to projections about their use in the future, were abstracted from our literature review as well as online news sources, such as Healthcare Data Management, iHealthBeat, and others.

Key informant interviews were conducted to fill in the identified gaps within the literature. The informants were chosen based on the recommendation of a Technical Advisory Group formed for this project, in addition to specific individuals who were selected based on a review of their articles. A semi-structured interview protocol was designed for this purpose.

Study Limitations

This study has several limitations. The term 'socially disadvantaged' is not used ubiquitously in the literature. In many cases, characteristics such as race or geographic location serve as proxies for describing these populations. This inconsistency makes it difficult to compare findings across studies, and we were unable to undertake a comprehensive meta-analysis as a result. Further, the heterogeneity in terms of the type of study, study population, type of intervention, and measured outcomes, among others in the studies we identified, renders our findings difficult to generalize. Therefore, we are only able to present a theoretical understanding of the use of eHealth tools, and any conclusions about the effectiveness of these interventions should be interpreted with caution. Furthermore, few studies included in this report described outcomes beyond 18 months, so the long-term effectiveness of eHealth tools for socially disadvantaged populations is unknown.

This study was also limited by our search criteria. Particularly among socially disadvantaged populations, there is a need for comprehensive lifestyle changes associated with diet, physical activity, and other risk factors of chronic disease. Though many eHealth tools have been designed to address lifestyle, we did not explicitly search for such technologies, as most lifestyle interventions are broad in scope and not directed at cancer, diabetes, or heart disease patients. As a result, a potentially significant subcategory of eHealth tools may have been overlooked. Further research will be needed to identify and assess examples of the effective use of lifestyle interventions

Additionally, because of the rapidly changing nature of the healthcare industry, the introduction and adoption of novel health information technologies, and a general lack of evidence for each tool, we could not fully assess aspects such as usability, cost-effectiveness, interoperability, and privacy and security. Even when present, assessments of these factors in the studies we identified were brief or incomplete. For example, the demographic characteristics of socially disadvantaged populations encompass a wide range of cultures and ethnicities. However, usability assessments rarely captured information from each population. In the context of usability, cultural, linguistic, or physical differences can have a monumental impact, yet few studies focused on groups where these differences are common.

Overall, we believe that the evidence presented suggests some clear benefits from the use of eHealth tools by disadvantaged populations with diabetes, heart disease, and cancer, but the sheer scale of the undertaking and paucity of published evidence prohibits us from drawing definitive conclusions.

Conclusions

Recent advancements in eHealth tools, particularly in the areas of telehealth, mHealth, patient web portals and social media, show tremendous promise in helping socially disadvantaged populations manage diabetes, heart disease, and cancer.

- **If mHealth trends continue, there could be a significant improvement in outcomes among individuals living with diabetes and heart disease.**

Mobile health applications, which have significantly risen in availability over the past year, are the fastest growing sector of the patient-centered tools industry. Given the increase in smartphone adoption within the first and second quarters of 2012, it seems likely that patient-centric technologies will utilize more mobile capabilities.

- **mHealth tools are viable eHealth tools for socially disadvantaged populations.** Increased access to mHealth among socially disadvantaged populations indicates that mHealth is an effective tool to provide outreach and access to care regardless of an individual's socioeconomic status, race, ethnicity, or geographic location. mHealth can provide vital tools to increase health care access, improve care delivery systems, and assist individuals in engaging in culturally competent outreach and education via technology that is easy to use, affordable and scalable, and has already been adopted by patients of all ages and socioeconomic status. Effective mHealth can empower patients by providing information and education about medications and risk factors, connect patients to communities and resources, and provide patient advocacy through engagement.
- **Mobile health is underutilized in the treatment and management of cancer.** Fewer studies assessed the use of mobile health by cancer patients. Like telehealth, mHealth can overcome geographic isolation. Given the rates of smartphone adoption among all populations, mobile health may offer a cheaper alternative to telehealth while simultaneously connecting more patients and providers. Though a variety of smartphone applications enable patients to learn about cancer, manage treatment, enhance decision-making, receive social support, and make important lifestyle changes, few mHealth technologies for cancer have been studied in medical settings.
- **Cancer patients interact with eHealth tools differently than patients with heart disease and diabetes.** Whereas managing indicators like blood glucose levels and blood pressure are an effective means of managing diabetes and heart disease, physiologic measurements that patients can undertake themselves are less relevant to cancer care. As a result, the remote-monitoring capabilities that typified many eHealth tools for diabetes/heart disease were not present in cancer tools. To the extent that remote-monitoring was employed, it was used to help patients report and manage treatment related side-effects and psychosocial outcomes.
- **Patient web portals are educating patients about their chronic conditions.** Patient web portals have gained tremendous popularity over the past few years, with a number of major health organizations creating and implementing portals for their patient communities. These portals show great promise in facilitating communication between patients and providers, as well as a means of accessing educational materials to assist all populations in the management and care of their chronic conditions.

- **Patient web portals have the potential to help cancer patients manage their care across the continuum.** Patient web portals and online information management systems often blend education, treatment management, health tracking over time, and social support into a single system. Messaging features can greatly improve patient-provider communication and joint management of the information in the system fosters collaborative decision-making and patient engagement. When combined with mobile technologies, these tools are even more effective.
- **Lack of data on the effectiveness of social media has not deterred patients despite underutilization by care providers.** Despite widespread use, there is a need to study and evaluate the effectiveness of social media on the self-management of diabetes, heart disease, and cancer. Dozens of social networking communities, blogs, wikis and other platforms have demonstrated the utility of social media in helping patients form support groups, provide educational resources, share knowledge and best practices in the care and management of their condition. However, we did not identify any studies that have evaluated the effectiveness of social media on chronic care, nor its overall use among socially disadvantaged populations. Very little work has been done in this area, despite increasing trends in adoption.
- **In addition to spurring the use of electronic health records (EHRs), Meaningful Use (MU) rules may drive integration of eHealth Tools to exchange patient data and improve education, engagement, and communication efforts.** Although many of the measures and requirements of MU Stages 1 and 2 target specific objectives for eligible hospitals and physicians to record, share, and report information via EHRs, there is an underlying emphasis on improving patient access to information and education. Patient-facing technologies such as telehealth and mHealth can complement provider-centric EHR systems to improve communication, education, and exchange of data among patient populations of all ages, genders, ethnicities, income and education levels, and geographic areas. By breaking down traditional barriers to access to care among socially disadvantaged populations, these technologies are likely to continue to grow in importance and use as EHRs are adopted by smaller clinics and hospitals serving low-income populations
- **It is not clear what patients “want” or “like”. Assumptions about patient preferences with technology have not been tested.** Very few assumptions have been tested with patient population outside of controlled experiments. While many of the studies identified in this report discuss the number and type of patients that utilized eHealth Tools, usability was not often featured by

researchers in their evaluation and assessment of the tools. Despite generally accepted principles and frameworks of design for eHealth tools, it is unclear whether patients who participated in studies found the Tools usable and satisfactory for their needs. Furthermore, few eHealth Tools appear to be specifically adapted for use by those with low health literacy, those for whom English was not their primary language, or those with limited technical knowledge.

The transition from acute, episodic and volume-based care towards chronic, coordinated care requires changes within healthcare organizations and the delivery of care. Primary among those changes is the recognition that the patient is at the center of the care effort and is the one responsible for carrying out and monitoring the necessary actions to manage their diabetes, heart disease and/or cancer correctly and adequately. With these conditions disproportionately affecting socially disadvantaged populations, there is a fundamental need to provide these individuals with the appropriate tools to empower them to manage their health, create continuous and consistent communication with their providers, and provide resources for them to educate themselves about their condition and potential care strategies. Critical to this strategy are the use of eHealth Tools which can provide web-based health education, promotion of and support for self-management in community or home-based settings, and adherence to evidence-based clinical procedures and medications. From the information gathered for this report, it is probable that the technologies used for telehealth, mobile health, patient-web portals and social media can promote partnerships between the patient and their providers, facilitate better patient self-management, improve compliance with care protocols and medication management, and reduce the hospital readmission rate for those with any of these conditions.

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