



## A STUDY AND REPORT ON THE USE OF EHEALTH TOOLS FOR CHRONIC DISEASE CARE AMONG SOCIALLY DISADVANTAGED POPULATIONS An Issue Brief on eHealth Tools for Cancer Patients







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## **Executive Summary**

#### Introduction

Effectively managing and treating cancer across the care continuum requires a high degree of care coordination and patient engagement. Cancer is a complex disease with a variety of treatment options necessitating patient education and understanding to make appropriate care decisions. Patients often see multiple providers over the course of care, and may be called upon to serve as the source of information about their prior medical interactions as they progress from diagnosis to treatment to survival. During treatment, patients must adhere to complicated medication and chemotherapy regimens, all while managing debilitating physical, mental, and emotional side-effects that frequently arise as a result of treatment. In addition to these challenges, significant health disparities in the U.S. limit the ability of patients to receive and manage cancer care. Socially disadvantaged populations tend to experience poorer cancer outcomes and survival rates, and frequently participate in behaviors that can increase their risk of cancer.

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 study and review technologies that can improve cancer care and treatment management among socially disadvantaged populations. This issue brief is the final in a series of three and describes four types of eHealth tools identified for use by cancer patients: **telemedicine**, **mobile health**, **internet-based technologies**, and **social media**.

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 socially disadvantaged populations face unique challenges in establishing effective cancer care programs, including:

- Shortage of resources to effectively treat and manage care for patients
- Lack of other centers of care or specialty care providers
- Health literacy, education, and knowledge barriers
- Geographic barriers impacting patient access to medical care or terrain/climate challenges

Difficulties arising from linguistic and cultural differences

Fortunately, advances in technology have resulted in a wave of health information technology (health IT) solutions that can help providers and patients better manage cancer care. The use of health IT has been associated with improvements in patient engagement, self-management, and clinical outcomes such as psychosocial health and wellness. In fact, many of these technologies are specifically designed for use by patients to improve management, communication, and understanding. Known as "eHealth tools", these technologies can help redefine care delivery for socially disadvantaged populations and care settings with limited resources and personnel.

## Telemedicine

Telemedicine involves the use of information and communications technology to connect patients and providers who are not in close proximity. As such, telemedicine can extend access to care, communication, disease management, and support to socially disadvantaged populations. In oncology, telemedicine has been used by providers for remote consultation, to extend the reach of specialty care, and to assess and diagnose certain types of cancers. For patients, telemedicine can facilitate patient-reporting of symptoms, side-effects, and outcomes and has been used to provide information, education, and social support. Examples of case studies involving the use of telemedicine for cancer care include:

- The **Indiana Cancer Pain and Depression Trial** evaluated the use of telephonebased care management and automated symptom monitoring to reduce depression and cancer-related pain in a sample of 405 cancer patients. Patients received nurse care manager support and reported pain and depression symptoms and medication adherence, side effects, and global improvement measures via an automated telephone system or online survey. These patients experienced improvements in pain, depression, and health-related quality of life measures, as well as trends toward decreased healthcare utilization.<sup>1</sup>
- Videoconference-based support groups were established for 27 breast cancer patients within the **Northern Sierra Rural Health Network**. The support groups helped to improve nearly all psychosocial measures tested, with significant decreases in depression and posttraumatic stress disorder symptoms. Participants found the intervention valuable for helping them share information about breast cancer and emotionally connect with patients that had similar experiences.<sup>2</sup>

Such programs demonstrate the potential for telemedicine to help cancer patients manage treatment, obtain social support, and increase their understanding of cancer and prevention. Our research has found that telemedicine is well suited to expanding access to health services to populations with limited access due to distance or location.

## **Mobile Health**

Mobile health (mHealth) takes advantage of the growth in the number of patients with smartphones, as well as other technologies that support virtually instantaneous patient and provider interaction well beyond the reach of traditional healthcare. mHealth encompasses technologies such as medical devices designed for home use, smartphone and tablet applications, wireless sensors, and short message service (SMS or text-messaging) applications. mHealth empowers patients to remain active participants in their own care through tools that facilitate monitoring, communication, and self-management. Examples of mHealth use with cancer patients include:

• The **Patient Care Monitor** is a survey instrument programmed on handheld wireless tablet computers to collect patient-reported outcomes and health-related quality of life information following patient visits to Duke Breast Cancer Clinic. Sixty-six breast cancer patients used the device to complete a survey reflecting common cancer- and treatment-related symptoms, psychological concerns, functional concerns, and social concerns. Participants were satisfied with using the tablet as a means for reporting symptoms and believed that it helped them discuss medical issues with their doctor.<sup>3</sup>

Personal mobile applications are a critical component of mHealth. Over 270 applications<sup>4</sup> in the iPhone, BlackBerry, and Android marketplaces are specifically designed to support the information management, treatment planning, decision making, psychosocial, communication, and/or educational needs of cancer patients. Examples include:

- AYA (Adolescent and Young Adult) Healthy Survivorship allows users to assess their health habits and general sense of well-being, offers personalized tips for a healthier lifestyle, and features information on cancer survivorship, screening, and latent effects of treatment. Users can develop a survivorship plan and participate in an online community.
- **NCITrials@NIH** links patients to the clinical trials database hosted by the National Cancer Institute's (NCI) Center for Cancer Research (CCR) to help patients identify and share clinical trial information.
- **CaringBridge** provides a personalized online space for users to connect with others and share and receive support. CaringBridge can help a patient's family and friends coordinate care and organize helpful tasks.
- **NCI QuitPal** is designed to help users quit smoking by setting personal goals. It tracks daily smoking habits and displays information about financial and health benefits associated with progress toward the user's goals.

For socially disadvantaged populations lacking computer access, smartphones frequently serve as their only connection to the internet. In fact, racial/ethnic minorities, lower income individuals, and the elderly have rapidly begun to adopt smartphones and utilize applications. Fifty-three percent of Americans have a smartphone today.<sup>5</sup> mHealth has the potential to inexpensively help socially disadvantaged patients better understand and manage cancer.

## **Internet-based Technologies**

Patient web portals (PWPs) and comprehensive information management systems for cancer are robust internet-based tools that enable patients to learn about and manage cancer, connect with providers, and offer and receive social support. PWPs typically offer patients access to their personal medical records. Examples include:

- **MyHealth Online** is Harvard Vanguard Medical Associates' PWP. Patients can view test results, receive non-urgent medical advice, view immunization, surgical, and medical history, request and view appointments, manage prescriptions, and receive preventative care reminders. Through the portal, 522 patients overdue for colorectal cancer screening were sent automated electronic alerts with a link to a risk assessment tool. The alerts rapidly increased screening rates, and use of the tool was associated with the greatest likelihood of requesting and receiving colorectal cancer screening.<sup>6</sup>
- The **Comprehensive Health Enhancement Support System (CHESS)** includes components such as 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. Low-income women with breast cancer in rural Wisconsin and Detroit, Michigan were given access to CHESS for four months. Participants frequently accessed the system and spent more time with it than a cohort of higher-income women. As compared to

a control group of low-income women, CHESS users scored better on measures of participation in healthcare, information competence, social support, and negative emotions. $^7$ 

Unfortunately, many internet-based technologies remain proprietary tools, limiting access to disadvantaged populations. Still, these technologies have great potential to enhance education, management, communication, and psychosocial support among socially disadvantaged cancer patients.

#### Social Media

Like mHealth, social media leverages recent technological advances in communications and the internet. Social media represents the essence of the participatory nature of web 2.0, encompassing blogs, online forums, podcasts, Really Simple Syndication (RSS) feeds, social networking sites, and wikis that allow users to generate, share, and consume significant amounts of health information. Examples of social media sites for cancer patients include:

- **Circle of Sharing** is an American Cancer Society tool to that integrates with Microsoft Healthvault to help patients share information with friends and family. To assist patients with treatment decision-making, Circle of Sharing provides links and tools for patients to better understand treatments and search for clinical trials.
- Users of **I Had Cancer** can create an online profile sharing their cancer experience. Others can search by geography, age, gender, time of diagnosis, and type of cancer to identify and connect with peers.
- **MyBCTeam** aims to help patients create a supportive team to improve their experience with breast cancer. It offers a provider directory to connect patients with doctors as well as tools to identify and connect with other patients at a similar stage of care.

Other social media channels, such as YouTube, Facebook, and online support groups, have also been used to help cancer patients communicate with their providers, friends, and family, consume educational materials about cancer and prevention, and identify others with cancer to share and receive psychosocial support. Estimates of overall social media use vary from 66 percent<sup>8</sup> to nearly 80 percent<sup>9</sup> of internet users. Given the substantial number of patients using social media today - socially disadvantaged and otherwise – further research is necessary to better understand its impact on cancer care.

#### Conclusions

Rapidly increasing adoption and recent advancements in eHealth tools - particularly in the areas of telemedicine, mobile health, internet-based technologies, and social media – provide strong evidence for the potential for socially disadvantaged populations to use these tools to effectively manage their cancer.

• Cancer patients interact with eHealth tools differently than patients with heart disease and diabetes. Whereas blood glucose levels and blood pressure are effective indicators for 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 typify many eHealth tools for diabetes/heart disease are not present in cancer tools. To the extent that remotemonitoring is employed, it is used to help patients report and manage psychosocial outcomes and treatment-related side effects.

- Telehealth is an especially viable tool for reaching socially disadvantaged populations diagnosed with cancer. Feelings of isolation are common in cancer patients, and can be compounded by physical distance between the patient and their provider. Telehealth effectively overcomes geographic barriers to care and opens new lines of communication. Telemedicine can increase patient knowledge of cancer and cancer screening, improve health related quality of life and reduce depression and anxiety through side-effect and symptom management, and help provide psychosocial support to cancer patients.
- Mobile health is underutilized by oncologists. Like telehealth, mHealth can overcome geographic isolation. Given rates of smartphone adoption among all populations, mobile health may offer a cheaper alternative to telemedicine 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. We expect this to change in the future, as smartphones become more widely adopted by patients and providers alike.
- Internet-based technologies are promising tools for managing all elements of cancer care. 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 patientprovider 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.
- Social media enhances patient education and can greatly improve psychosocial aspects of cancer care. Cancer patients frequently experience feelings of confusion, fear, anxiety, isolation, loss of control, and a lack of information because of their condition and the complexities of cancer care. By connecting users with family, friends, caregivers, and others who have or have had cancer, social media can alleviate these feelings in cancer patients. Overall, eHealth tools for cancer more commonly emphasize social support than tools for diabetes and heart disease.
- More evidence is needed to confirm the overall impact of the use of eHealth tools for cancer care. Relatively few studies have evaluated the use of telemedicine, mHealth, internet-based technologies, or social media by cancer patients. Of those that have, even fewer have evaluated the impact on clinical outcomes. eHealth tools can clearly empower patients and improve psychosocial concerns, but they may not have an effect on improving the incidence or mortality of cancer.

# An Issue Brief on eHealth Tools for Cancer Patients

#### Introduction

Effectively caring for patients with complex chronic diseases like cancer, diabetes, or heart disease, is difficult without a close partnership between providers and patient. Outside of the doctor's office, patients with chronic disease are often left to manage the day-to-day needs of their condition alone. Yet, compliance with self-management regimens is notoriously low. Issues with health literacy, an understanding of chronic disease and treatment processes, and lack of access to bidirectional communication with a provider when problems arise leave many patients feeling helpless or unwilling to care for themselves. The appropriate use of health information technology (health IT) can help support patient self-management of chronic disease by both increasing their knowledge and understanding of their condition and facilitating information sharing and communication between the provider and patient.

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 study and review technologies that can improve cancer care and treatment management among socially disadvantaged populations. In follow-up to the first two briefs examining <u>diabetes</u> and heart disease, this final brief describes the four domains of technologies identified for cancer care: telemedicine, mobile health, internet-based technologies (including patient web portals), and social media. A full comprehensive report will be released in January, 2013 that will assess these technologies in the following areas:

- evidence of direct impact on cancer, diabetes, and heart disease care and control;
- availability and accessibility to socially disadvantaged communities;
- impact on risk factors that are inherent to socially disadvantaged populations;
- usability for patients and/or family, friends, and caregivers;
- cost-effectiveness for physicians, hospitals, health systems, and other healthcare providers;
- ability to exchange data within a large health information system; and
- privacy and security frameworks of each technology to protect personally identifiable health information.

#### **Overview of Cancer**

Cancer, or malignant neoplasm, is the second-leading cause of death in the United States. The term 'cancer' comprises over 100 different diseases that can affect every major organ system in the body. All cancers arise from abnormal and uncontrolled cell growth brought about by changes or damage in a cell's DNA. When mutations occur or a cell gains or loses a chromosome during mitosis, the biological pathways that normally inhibit cell division are disabled, resulting in a proliferation of damaged cells that may ultimately metastasize to other parts of the body. Mutations in oncogenes and tumor suppressor genes are the primary source of carcinogenesis, the process by which cancer arises. Oncogenes promote cell growth and division, while tumor suppressor genes inhibit division.

DNA damage or change can result from both internal factors (e.g. inherited mutations, hormones, and immune conditions) and external factors (e.g. chemicals, radiation, tobacco use, and infectious organisms). It is difficult to pinpoint the specific damage that initiates the growth of cancer cells, as these factors typically act together to promote carcinogenesis. However, it is possible to reduce one's risk of developing cancer by changing aspects of lifestyle, such as increasing physical activity, maintaining a healthy weight and diet, and limiting alcohol consumption, tobacco use and exposure to ultraviolet rays from the sun or tanning beds.<sup>10</sup>

Cancer is typically diagnosed in four stages, representing the extent and severity of the disease in the body. Stage I cancers are isolated and have better long-term prognoses, while stage IV cancers are those that have spread to other organs/systems and are usually imminently life-threatening. Cancer staging is determined by a number of factors, including the extent of the tumor, the extent of spread to lymph nodes, and the presence of metastasis.<sup>11</sup> Treatment will often vary depending on a cancer's staging. Early stage cancers, like colon cancer, my only require surgery, with more advanced therapies such as chemotherapy and radiation therapy added if the cancer has spread or has a higher likelihood of recurrence following treatment.<sup>12</sup>

Because cancer is a collection of different diseases stemming from a common cause, the effects of cancer can vary dramatically. Some cancers are more dangerous than others. Among skin cancers, for example, basal and squamous cell skin cancers are both common and relatively harmless. Melanoma, on the other hand, is much rarer and deadlier. Five-year survival rates for Stage IV Melanoma range from 15-20 percent, yet basal and squamous cell skin cancers rarely progress to the point that they can even be staged.<sup>13</sup>

Cancer treatment includes surgery, chemotherapy, radiation therapy, or some combination of the three. Less common treatments include therapies targeted to specific molecular components of a particular cancer, such as genes and proteins that contribute to cancer growth or survival, biologic/immunotherapy, and hormonal therapy. Palliative care may be provided in conjunction with cancer treatment to help patients cope with and manage side-effects.<sup>14</sup> Though more effective than in the past, cancer treatment is not foolproof. In some cases, the growth or extent of cancer is only limited by treatment (remission). In others, while all detectible traces of cancer are eliminated, cancer might eventually recur. The likelihood of cancer recurrence depends on the individual, the type of cancer, and the stage at which the cancer was treated. More than 50 percent of colon cancer patients may experience recurrence following initial treatment.<sup>15</sup> To prevent recurrence, ongoing or adjuvant therapy may be provided. Breast cancer patients undergoing five years of adjuvant therapy had recurrence rates ranging from seven (Stage I) to 13 percent (Stage III).<sup>16</sup> Treatment itself may also increase an individual's risk of developing secondary cancers.<sup>17</sup>

#### Prevalence, Incidence, and Mortality

As many as one-third of all women and half of all men will develop cancer within their lifetime.<sup>18</sup> In 2008, an estimated 11,958,000 people in the United States had cancer.<sup>19</sup> 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.<sup>20</sup> Men and women are at relatively similar risks of developing cancer (44.85% and 38.08% respectively) and of dying from the disease (23.12% and 19.50% respectively).<sup>21</sup> However, significant disparities exist across age groups. Cancer is primarily a disease that afflicts older adults; the median age of diagnosis is 66 years, and the median age of death is 72 years. Figure 1 displays the percentage of new diagnoses and deaths for different age groups for all cancer types from 2005 - 2009.<sup>22</sup> Based on data from the National Cancer Institute's Surveillance, Epidemiology and End Results (SEER) Program, overall incidence and death rates have declined each year between 2004 and 2008 (averaging -0.4% and -1.61% per year respectively).<sup>23</sup>

Age Group	Percentage of New Cancer Diagnoses	Percentage of Deaths
Under 20	1.1	.4
20 – 34	2.6	.8
35 – 44	5.5	2.4
45 – 54	14.2	8.9
55 – 64	23.4	18.3
65 - 74	24.9	24.8
75 – 84	20.6	28.9
85 +	7.7	15.5

Figure 1: Percentage of Cancer Diagnoses and Deaths by Age Group

Breast, prostate, and lung cancer are the most prevalent forms of cancer in the United States. Figure 2 displays the number of estimated new cases and deaths in 2011 from the most common forms of cancer among men and women.<sup>24</sup>

			Males	Females	-		
Prostate	240,890	29%			Breast	230,480	30%
Lung & bronchus	115,060	14%	Y		Lung & bronchus	106,070	14%
Colon & rectum	71,850	9%			Colon & rectum	69,360	9%
Urinary bladder	52,020	6%			Uterine corpus	46,470	6%
Melanoma of the skin	40,010	5%			Thyroid	36,550	5%
Kidney & renal pelvis	37,120	5%			Non-Hodgkin lymphoma	30,300	4%
Non-Hodgkin lymphoma	36,060	4%			Melanoma of the skin	30,220	4%
Oral cavity & pharynx	27,710	3%			Kidney & renal pelvis	23,800	3%
Leukemia	25,320	3%			Ovary	21,990	3%
Pancreas	22,050	3%			Pancreas	21,980	3%
All Sites	822,300	100%			All Sites	774,370	100%
All Sites nated Deaths	822,300	100%	Males	Females		774,370	100%
	<b>822,300</b> 85,600	<b>100%</b> 28%	Males	Females		<b>774,370</b> 71,340	<b>100%</b> 26%
nated Deaths			Males	Females	5		
nated Deaths	85,600	28%	Males	Females	s Lung & bronchus	71,340	26%
nated Deaths Lung & bronchus Prostate	85,600 33,720	28% 11%	Males	Females	<b>s</b> Lung & bronchus Breast	71,340 39,520	26% 15%
nated Deaths Lung & bronchus Prostate Colon & rectum	85,600 33,720 25,250	28% 11% 8%	Males	Females	s Lung & bronchus Breast Colon & rectum	71,340 39,520 24,130	26% 15% 9%
nated Deaths Lung & bronchus Prostate Colon & rectum Pancreas	85,600 33,720 25,250 19,360	28% 11% 8% 6%	Males	Females	s Lung & bronchus Breast Colon & rectum Pancreas	71,340 39,520 24,130 18,300	26% 15% 9% 7%
nated Deaths Lung & bronchus Prostate Colon & rectum Pancreas Liver & intrahepatic bile duct	85,600 33,720 25,250 19,360 13,260	28% 11% 8% 6% 4%	Males	Females	s Lung & bronchus Breast Colon & rectum Pancreas Ovary	71,340 39,520 24,130 18,300 15,460	26% 15% 9% 7% 6%
nated Deaths Lung & bronchus Prostate Colon & rectum Pancreas Liver & intrahepatic bile duct Leukemia	85,600 33,720 25,250 19,360 13,260 12,740	28% 11% 8% 6% 4%	Males	Females	s Lung & bronchus Breast Colon & rectum Pancreas Ovary Non-Hodgkin lymphoma	71,340 39,520 24,130 18,300 15,460 9,570	26% 15% 9% 7% 6% 4%
nated Deaths Lung & bronchus Prostate Colon & rectum Pancreas Liver & intrahepatic bile duct Leukemia Esophagus	85,600 33,720 25,250 19,360 13,260 12,740 11,910	28% 11% 8% 6% 4% 4%	Males	Females	s Lung & bronchus Breast Colon & rectum Pancreas Ovary Non-Hodgkin lymphoma Leukemia	71,340 39,520 24,130 18,300 15,460 9,570 9,040	26% 15% 9% 6% 4% 3%
nated Deaths Lung & bronchus Prostate Colon & rectum Pancreas Liver & intrahepatic bile duct Leukemia Esophagus Urinary bladder	85,600 33,720 25,250 19,360 13,260 12,740 11,910 10,670	28% 11% 8% 6% 4% 4% 4%	Males	Females	s Lung & bronchus Breast Colon & rectum Pancreas Ovary Non-Hodgkin lymphoma Leukemia Uterine Corpus	71,340 39,520 24,130 18,300 15,460 9,570 9,040 8,120	26% 15% 9% 7% 6% 4% 3%

Figure 2: New Cases and Deaths for Common Types of Cancer – 2011

More men and women in the United States die of lung cancer than of any other cancer. In 2011, an estimated 221,130 men and women were diagnosed and 156,940 died from lung cancer. While mortality rates among men have been declining since 1991, female mortality rates only began to decline in 2003. This disparity has been attributed to historical trends in the uptake and reduction of cigarette smoking for men and women over the past 50 years. Cigarette smoking remains the most important risk factor for lung cancer. Environmental variables such as exposure to radon gas, secondhand smoke, and asbestos can also play a critical role in increasing an individual's risk of lung cancer.<sup>25</sup>

Breast cancer is the most commonly diagnosed and second leading cause of cancer death among women. In 2011, approximately 230,480 women were diagnosed with breast cancer and 39,520 died from this disease. The incidence of female breast cancer began to decline in 2000, with a dramatic seven percent decrease between 2002 and 2003 attributed to fewer women using menopausal hormone therapy (MHT); rates have remained stable from 2004-2008. However, steady progress has been made with regards to breast cancer mortality. Earlier detection and improved treatment have contributed to a more than two percent decline annually for women 50 and older between 2004 and 2008. For women under 50, the mortality rate has declined by 3.1 percent annually during the same time period. Biological factors including age, family history, high breast tissue density, and others can increase a woman's chance of developing breast cancer. Modifiable risk factors, such as obesity, lack of physical activity, and alcohol consumption have also been linked to breast cancer.<sup>26</sup>

Among men, prostate cancer is the most commonly diagnosed and second leading cause of death from cancer. In 2011, approximately 240,890 men were diagnosed with prostate cancer and 33,720 died from this disease. Incidence and mortality rates have declined in recent years, though the impact of early screening for prostate cancer on these declines has been disputed. Risk factors that make men more susceptible to this disease include age, ethnicity, and family history of the disease. African-American men are much more likely to develop and die from prostate cancer than other ethnic/minority groups.<sup>27</sup>

## Populations at Risk of Developing Cancer

Despite decreases in the overall death and incidence rates of cancer in the United States, significant health disparities exist among subpopulations, which tend to experience cancer incidence and mortality at disproportionately higher rates. In addition to the elderly, some racial/ethnic groups experience a disproportionate cancer burden. African Americans, in particular, are the most likely to be diagnosed with and die from all cancers combined, as shown in Figure 3.<sup>28</sup>

Race/Ethnicity	Incidence Rate (per 100,000)			y Rate (per ),000)	
	Male	Female	Male	Female	
All Races	541.8	412.3	219.4	151.1	
White	542.7	423.1	216.7	150.8	
Black	627.1	398.3	288.3	174.6	
Asian/Pacific Islander	342.6	299.4	132.6	93.2	
American Indian/Alaska Native	352.7	313.8	184.9	135.9	
Hispanic	402	324.1	146.3	100.5	

Figure 3: Incidence and Mortality Rates for all Cancer Sites by Race/Ethnicity

Likewise, socially disadvantaged populations – defined for the purposes of this study as those who lack access to primary and specialty care because of low socioeconomic status or geographic barriers in rural areas – tend to experience poorer outcomes and survival rates.<sup>29</sup> 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.<sup>30</sup> 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.<sup>31</sup>

These disparities emerge from inequities in income, education, health insurance, employment, housing and standard of living as well as access barriers to high quality cancer prevention and care. Whether by choice or due to other circumstances (such as lack of access to fruits and vegetables or a safe, amenable environment to engage in physical activity), individuals with lower socioeconomic status are often more likely to take part in behaviors that increase the risk of cancer, including poor diet, alcohol and tobacco use, obesity, and lack of physical activity. All cancers that are directly caused by alcohol use and cigarette smoking could be prevented completely if people did not engage in these high-risk behaviors. As many as one-third of cancer deaths in 2011 were related to physical inactivity, overweight and obesity, and poor nutrition, and could have been reduced or prevented.<sup>32</sup>

Moreover, regular screening examinations can limit the dangers of cancer. Screenings can detect and remove precancerous growths and help providers diagnose cancer at an earlier, more treatable stage. Screenings also represent teachable moments which offer providers an opportunity to engage their patients, educate them on the dangers of high-risk behaviors, and raise awareness about cancer. However, screening rates are lowest within groups that have historically been considered among socially disadvantaged populations, such as Hispanics, persons with low-income, those with less than a high school income, and the uninsured.<sup>33</sup>

#### **Costs and Challenges Associated with Cancer**

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).<sup>34</sup> 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.<sup>35</sup> 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. Though incidence rates have been decreasing, the crude number of new cancers is expected to increase, as will the number of cancer survivors. It is estimated that there will be more than 18 million cancer survivors in 2020, a 30 percent increase from 2010.<sup>36</sup> 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.

The complex nature of cancer treatment requires an inordinate amount of coordination among numerous providers, further burdening both patients and the healthcare system. A cancer patient may see a number of specialists and other providers over the course of care.<sup>37</sup> Without a system integrating information from each clinical encounter or care coordination procedures enabling 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, who tend to have less education and lower health literacy, understanding and keeping track of this information can be overwhelming. Missing and incomplete patient information has been widely recognized as a continued source of unnecessary health care costs. Cancer and cancer treatment pose numerous challenges to the patient as well. Common therapies for treating cancer, such as radiation, chemotherapy, and surgery can 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, and depression.<sup>38</sup> Prolonged pain during and after treatment frequently disrupts a patient's sleeping and eating habits, relationships, work, hobbies, and overall sense of well-being.<sup>39</sup> It is particularly challenging to these side-effects given their pervasiveness, difficulties associated with accurately measuring them, and differences in patient and provider perceptions of the severity and extent of symptoms.

Adding to this challenge, the adverse effects of cancer and treatment persist *outside* of the provider's office, necessitating procedures for reporting and resolving issues while the patient is home. Cancer treatment also involves sensitive issues such as hospice care, end-of-life planning, grief, and bereavement that affect the psychosocial health of patients, family, and friends.<sup>40</sup> Even when cancer is in remission or cured, many patients continue to experience mental health issues such as depression, fear, and anxiety. Cancer survivors in socially disadvantaged populations have shown lower measures of psychosocial and physical quality of life, indicating that these adverse effects are exacerbated by lower socioeconomic status.<sup>41</sup>

Personal financial costs for cancer care can amount to thousands of dollars, especially for patients lacking health insurance.<sup>42</sup> While health insurance may cover the majority of treatment costs, certain treatments, medications, and therapies are often not covered or require higher out-of-pocket spending.<sup>43</sup> As a result, patients with health insurance still face significant financial burdens that can drain their savings, and patients without insurance may forgo treatment because of cost.<sup>44</sup> Clinical trials can help patients both defray medical costs for cancer, and overcome disparities in the care they receive. Though many cancer patients have taken advantage of trials, socially disadvantaged populations are less likely to enroll.<sup>45</sup> Low enrollment rates by certain racial/ethnic groups may widen disparities in cancer care, as research into treatments and therapies under development will have less data with which to understand the biological differences of cancers afflicting these populations.<sup>46</sup>

## **Health Information Technology**

Evidence-based interventions can reduce the risk of and complications from cancer through symptom and treatment side-effects management, lifestyle coaching, reduction of certain risk behaviors, self-monitoring, and appropriate use of health services. However, as detailed in the diabetes and heart disease briefs published previously in this series, these interventions often fail to reach socially disadvantaged populations for a number of reasons, including lower health literacy, geographic and financial barriers, and sociocultural and linguistic difficulties. Health information technology (health IT) has been widely recognized as having the potential to surmount common barriers to high quality cancer care by providing critical support to patients, enhancing changes within healthcare delivery, and enabling health providers with timely, secure access to real-time, actionable data to manage health at an individual and population level. Of note, the Institute of Medicine has described a rapid learning health system for cancer, powered by electronic registries, a national cancer database, and electronic health records to aggregate and analyze patient data to improve care for entire populations of cancer patients.<sup>47</sup>

On the provider side, health IT can meaningfully support cancer care for individual patients. Prior to diagnosis, administrative functions of health IT can assist providers in communicating with patients and scheduling tests, examinations, and screenings.<sup>48</sup> Clinical decision support systems can assist providers in recommending screenings, identifying appropriate treatment regimens, and managing symptoms and side-effects.<sup>49</sup> As patients undergo treatment and progress into survivorship, health IT can support care coordination and patient monitoring as they move through the care continuum and visit different providers/specialists.<sup>50</sup>

For those afflicted with cancer, the use of patient-facing technologies, also known as eHealth tools, offer similar opportunities to improve care. Telemedicine, mobile health, and internet-based technologies can all break down barriers in access to care to enable patients to monitor, track, manage, and communicate symptoms, side-effects, and quality of life. At the same time, social media can facilitate access to social support and information about cancer and treatment. However, unlike diabetes and heart disease, where self-management can effectively treat the disease, cancer treatment therapies require extensive and ongoing interaction within medical settings. As a result, many of the eHealth tools available for cancer patients have focused on helping those with cancer to manage information, alleviate the mental and physical impact of treatment, and obtain social and emotional support.

#### Telemedicine

Telemedicine is best described as the use of telecommunications and information technologies to share and maintain patient health information and to provide clinical care and health education to patients and professionals when distance separates the participants.<sup>51</sup> The principal benefit of telemedicine involves its ability to reduce or eliminate geographic and spatial barriers to care by connecting patients and providers through advanced telecommunication technologies offering bi-directional audio or video interaction. Research has found that the technology has increased access to specialty consultation, multidisciplinary care, cancer clinical trials, supportive and adjunctive care, and educational programming for patients.<sup>52</sup>

One of the most prominent applications of telemedicine is to facilitate communication and information sharing among providers. Via synchronous interactive teleconferencing, multidisciplinary care teams can meet to review and discuss a patient's medical record, including radiology and pathology reports, to suggest a diagnosis or offer a second opinion. Such meetings can enhance cancer care in rural areas by bringing the expertise of teams of specialists to bear in regions that may only otherwise be served by an individual general practitioner.<sup>53</sup> For cancers of the skin, in particular, telemedicine 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.<sup>54</sup>

Telemedicine has been directly used by cancer patients on a more limited basis. Unlike diabetes and heart disease, the use of telemedicine in oncology does not typically focus on physiologic vital sign monitoring or clinical data capture. Rather, patient-facing telemedicine applications in oncology involve patient-provider consultations, treatment, symptom, or

side-effect monitoring, and counseling. For example, veterans with abnormal thoracic radiography or other conditions in rural Wisconsin participated in pulmonary telemedicine consultations. Physicians were able to arrive at a final diagnosis during the first consultation 90 percent of the time, including 18 cases of lung cancer. Further, teleconsultations saved patients a total of nearly 300,000 miles and 748 work days in travel.<sup>55</sup> Figure 4 provides an overview of several applications of telemedicine in cancer care.

Application Studied	Effect of Intervention
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. <sup>56</sup>
Four-week telephonic intervention to educate participants 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. <sup>57</sup>
Periodic telephone intervention to provide information and guidance regarding 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 <sup>58</sup>
Home messaging device attached to patient's telephone line for daily symptom reporting	Clinically meaningful increase in health related quality of life <sup>59</sup>

Figure 4: Telemedicine Applications for Cancer Care

Teleoncology has also been used extensively outside of the United States. In Australia, oncologists have used telemedicine to provide care in rural areas that otherwise lack access to healthcare. A program in Queensland, Australia has adopted videoconferencing technology to provide teleconsultation services, treatment management, urgent care, and follow-up to cancer patients. This model demonstrates the capability of telemedicine to provide satisfactory and equitable oncology services over large distances while minimizing disturbance to family and work routines, reducing inter-hospital transfer costs, and providing immediate care when necessary.<sup>60</sup> The program was also evaluated among indigenous populations, which share experiences of poorer health outcomes, low utilization of care, delayed treatment at later stages of disease, and limited access to care with socially disadvantaged groups in the United States. The results of the evaluation demonstrated comparable levels of satisfaction among indigenous peoples and the general population.<sup>61</sup> Enabling indigenous patients to remain in their communities for care also facilitates attention to cultural norms and community involvement, as many of these patients attended

video consultations with indigenous health workers or family.<sup>62</sup> Similar results have been demonstrated by rural teleoncology programs in Canada as well.<sup>63</sup>

The following are select case studies of the use of telemedicine in cancer care:

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 5) 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).<sup>64</sup>

Outcome Measure	Usual Care	Intervention
BPI Pain Severity Score (0-10)		
Baseline	5.20	5.23
3 month follow-up	4.52	3.30
<ul> <li>6 month follow-up</li> </ul>	4.38	3.55
<ul> <li>12 month follow-up</li> </ul>	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 5: Pain and Depression-Specific Outcomes from the Indiana Cancer Pain and Depression Trial

- 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.<sup>65</sup>
- 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. Eightyfive 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 (see Figure 6). 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.<sup>66</sup>

Outcome Measure	Baseline Assessment	Post- intervention Result
Center for Epidemiological Studies Depression Scale Score (depression)	15.41	10.03 (p = 0.012)

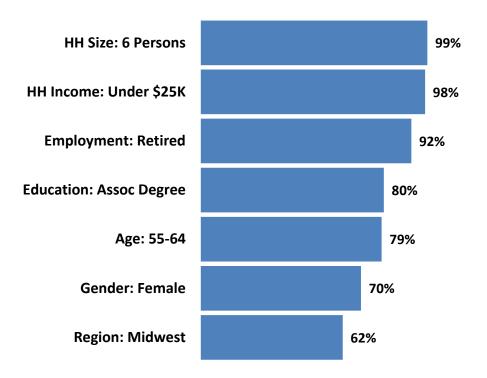
Outcome Measure	Baseline Assessment	Post- intervention Result
Posttraumatic Stress Checklist Score (posttraumatic stress)	27.24	24.73 (p = 0.027)
Cancer Behavior Inventory Score (self-efficacy for coping with breast cancer)	99.76	102.59
Courtland Emotional Control Scale Score (emotional expression)	49.57	48.48

Figure 6: Outcomes for the Northern Sierra Rural Health Network Study

As evidenced by these and other examples reviewed for this report, telemedicine represents a wide range of possible health IT solutions to improve cancer care. Research has found evidence for the effective use of telemedicine for increasing patient knowledge of cancer and cancer screening, improving health related quality of life, reducing depression and anxiety through side-effect and symptom management, and providing psychosocial support to cancer patients, among others. Because telemedicine can surmount geographic barriers to care and generally poses little or no cost to patients, it is particularly well-suited for use by socially disadvantaged populations. Though the use of teleoncology in the United States may not be as robust as in other countries, we expect increased adoption over time as providers and health systems gradually recognize the benefits of extending their services to socially disadvantaged populations.

#### **Mobile Health**

Powered largely by the rapid proliferation of cellphones and smartphones, mobile health (mHealth) is one of the fastest growing sectors of the healthcare industry. A semi-annual CTIA survey of the wireless provider industry estimated that there were 321,716,905 total wireless subscriptions in the United States in 2012.<sup>67</sup> In terms of individual ownership, the Pew Research Center has found that 85 percent of Americans own a cellular device, and 53 percent own a smartphone.<sup>68</sup> Though smartphone users tend to be younger and/or higher-income, trends in 2011 adoption rates determined by the research firm comScore indicate that the fastest growth had been among "cost-conscious" consumers, such as those in large households, with lower income, and the elderly (see Figure 7).<sup>69</sup>





Smartphones are especially popular within minority groups. Smartphone penetration among Hispanics, African-Americans and Asians/Pacific Islanders has exceeded rates for Caucasians by as much as 10 percent in the first quarter of 2012.<sup>70</sup> Additionally, lower-income smartphone owners may spend more time on their devices accessing applications and browsing the web. Their mobile web-browsing behavior serves as an extension of previously defined browsing habits.<sup>71</sup> In fact, disparities in access to household computers and the internet have prompted many lower-income, less educated, and racial/ethnic minority populations to turn to smartphones as their primary source of the internet.<sup>72</sup>

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.<sup>73</sup> Taken together, these trends indicate the extensive reach of mobile technologies in the United States and the potential for access by socially disadvantaged populations.

Mobile health itself 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.<sup>74</sup> 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.<sup>75</sup>

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.<sup>76</sup> 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.<sup>77</sup> Text-messaging has also helped promote preventative behaviors, such as using sun screen<sup>78</sup> and smoking cessation,<sup>79</sup> but not on a widespread basis in the U.S.<sup>80</sup>

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:

- 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 guality 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.<sup>81</sup>
- 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.<sup>82</sup> Further, in a separate analysis, 660 patients were divided into intervention (providers were given a summary of symptom and guality 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.<sup>83</sup>

#### **Smartphone Applications**

Although few studies have assessed the impact of mobile applications in cancer care, such applications represent a more diverse set of functionalities for the patient. One-fifth of all smartphone owners have downloaded an application to track or manage health.<sup>84</sup> Patient-centric healthcare applications cover a wide range of uses including tools for access to personal health records, medication adherence and selection, physician selection, monitoring physical well-being, health/disease monitoring and management, and healthy lifestyle suggestions.<sup>85</sup> 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, cancer-related smartphone applications designed for patient use can be categorized by four primary functions:

- 1. Resources for information and learning
- 2. Resources for decision making
- 3. Resources for social support
- 4. Resources for lifestyle management

Figure 8 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 8: 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 socially disadvantaged populations, especially, this process can be overwhelming. Many applications have been designed to help patients both learn about their cancer and manage all of their information related to care. Educational applications offer users 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 journaling 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 of treatment, 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 the disease, severity of treatment, and potential for side-effects. Multiple treatment and therapeutic options are typically available for a particular cancer, and preventative measures, such as self-examination, 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 decisionmaking applications include tools for risk assessment, breast self-examination, skin examination, identifying clinical trials, and understanding/managing information about treatment. Early Detection Plan: Breast Cancer provides educational information about breast exams, mammograms, risk factors, and signs and symptoms of cancer, and reminds users to perform routine breast self-examinations and to schedule clinical breast examinations 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, potentially increasing access to affordable, cuttingedge care among disadvantaged populations. 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. Some of the groups that have been historically socially disadvantaged, such as the elderly and certain racial/ethnic populations, often incorporate family or community members into their healthcare decision-making process or at the point of care. Social support tools can strengthen these relationships and make it simpler for non-patient caregivers to remain engaged in the patient's care. 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. **Lose It!**, for example, supports a user's weight-loss goals with tools for learning about and managing nutrition and exercise. **iFitness Pro** presents detailed information about hundreds of exercises, sortable by body region, muscle target, and the type of equipment needed. Users of **MyDrinkAware** can track their daily alcohol intake and display financial and health related costs of drinking. 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.

#### **Internet-based Technologies**

A review of the literature has identified important patient-centric, web-based technologies that can be used for cancer care. In addition to patient web portals (PWPs), the internet has enabled the development and use of comprehensive information management systems for cancer patients.

Patient web portals 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. PWPs 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.<sup>86</sup> Many PWPs offer administrative functions to help patients manage appointments, referrals, payments, insurance eligibility and claims, and medications.<sup>87</sup> Based on the information in the patient's record, PWPs can provide alerts to patients and providers reminding them to schedule or attend diagnostic tests and screenings. Results from a study of a secure-messaging system connected with a patient portal used to promote colorectal cancer screening found that e-mail reminders were as effective as reminders sent by mail at increasing the uptake of colorectal cancer screening, and that both were significantly more effective than usual care.<sup>88</sup> Unfortunately, the proprietary nature of many patient portals may limit their use by disadvantaged populations, unless those groups receive care at a medical site affiliated with a portal. Several examples of patient portals for cancer patients are presented below:

- **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.
- 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 sideeffects. 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. Seventysix 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.<sup>89</sup>
- **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.<sup>90</sup>

Like patient portals, online comprehensive information management systems can help patients learn about and manage cancer, connect with providers, and offer and receive social support. Two systems are described below:

- 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.<sup>91</sup> 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 higherincome 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 CHESS) 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, CHESS users scored better on measures of participation in healthcare, information competence, social support, and negative emotions.<sup>92</sup>
- **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 realtime, link information to calendar events, and record new information on the go. The mobile system also increased self-reported feelings of confidence and control.<sup>93</sup>

Though the use of internet-based technologies for cancer care by socially disadvantaged populations has not received much attention in the literature, we believe they hold demonstrable value for these groups.<sup>94</sup> As the CHESS study demonstrated, socially disadvantaged patients are eager for information about their condition and will proactively use online resources at their disposal. Educational materials provided through internet-based technologies can help socially disadvantaged populations learn more about cancer prevention and treatment. Where educational resources fall short, enhancing patient-provider communication through secure messaging can enable personalized coaching and support. Our search for internet-based technologies revealed that nearly every well-known cancer center in the United States has a patient portal, and we expect the adoption of patient access to their medical records to continue to increase in the future.

#### **Social Media**

In recent years, the internet has evolved from a resource for static information consumed by users to an interactive space where users contribute, edit, and share that information. In parallel, websites and applications designed to support the collaborative nature of the modern internet have experienced tremendous growth. Beginning with simple listservs in the 1990s and extending to applications today like Twitter, where users can instantaneously create and share content with millions of other people, social media is in many ways the foundation of the new online landscape. 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.<sup>95</sup> In doing so, social media supports communication on an emotional or rational level, which relates to a person's social or life contexts where it is often most effective.<sup>96</sup> By connecting individuals with shared interests, specific populations can be targeted for personalized outreach, such as racial/ethnic groups, those with family histories of cancer, or cigarette smokers.

Patients have increasingly begun to turn to the internet and social media to learn, manage, and receive support for their health. In fact, 80 percent of internet users in the United States today report having looked for health information online.<sup>97</sup> Though a "digital divide" exists between young, Caucasian, or higher-income users and the elderly, racial/ethnic minorities, and low-income groups, those with chronic conditions and internet access are as likely to access the internet for health information as the general population.<sup>98</sup> Estimates of

overall social media use vary from 66 percent<sup>99</sup> to nearly 80 percent<sup>100</sup> of internet users. Among those with internet access, there is consistent use of social networking across different socioeconomic demographics. 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 affluent peers.<sup>101</sup> Because social media is especially popular with young adults and adolescents as a whole, as well as racial/ethnic minorities, it represents a particularly salient medium through which to target socially disadvantaged members of these populations.

Patients can use social media to meet a variety of needs. Social media enables patients to share their experiences, reach out for information and opinions, and engage with peers and providers.<sup>102</sup> Blogs, online forums, podcasts, Really Simple Syndication (RSS) feeds, social networking sites, and wikis each support the health needs of patients in different ways, such as recording and sharing text, graphics, audio and video, posting and soliciting opinions, rapidly disseminating information, connecting with others in similar situations, and contributing, editing, and consuming information.<sup>103</sup> Most patients continue to rely on healthcare professionals for information, but social media works to fill in the gaps, connect patients to resources outside of the provider's office, and meet psychosocial and emotional components of care.

Studies have demonstrated that social media use is particularly common among cancer patients. For example, data from the 2007 Health Information National Trends Survey (HINTS) suggest that personal cancer experience is a predictor of participation in online support groups.<sup>104</sup> Analyses of social support groups for chronic disease on Facebook have found that cancer-related groups have attracted the most participants.<sup>105</sup> 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 increasing general cancer awareness, support groups tend to be the most active, as measured by the median number of wall posts.<sup>106</sup> A review of peer support programs 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.<sup>107</sup> Another review of online support and resources for cancer survivors reported similar outcomes and results, including 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.<sup>108</sup> One of the RCTs included in the review explored the use of online support groups among Latina immigrants with breast cancer. Though outcomes measures did not show statistical significance, the groups were both widely accepted by study participants, and statistical trends pointed to increases in feelings of hope and strength.<sup>109</sup>

YouTube is another social media resource that has been utilized by cancer patients. 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.<sup>110</sup> 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.<sup>111</sup> In addition to common social media channels like Facebook and YouTube, health-specific social networking sites have been developed for patients. PatientsLikeMe is one of the few such sites that have been evaluated in the literature. PatientsLikeMe was developed to encourage patients to share their personal healthcare data and consists of 16 disease-related communities, including cancer. Profiles on the site offer graphical displays of a user's health information, including symptoms and treatments. With access to this data, users can collaborate to evaluate the impact of interventions on health outcomes, or assist one another in making appropriate health-related decisions. Users have reported finding the site helpful for learning about symptoms they've experienced, understanding treatment side-effects, connecting with others that can provide experiential advice, and medical decision making.<sup>112</sup> Some examples of social networking sites for cancer include:

- CancerCare (<u>http://www.cancercare.org/</u>) is a national, non-profit organization that provides free, professional support to help individuals, families, caregivers, and the bereaved cope with and manage the emotional and practical challenges of cancer. CancerCare has online patient support groups led by professional oncology social workers, as well as **My Cancer Circle**, a 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.
- 2. The American Cancer Society (<u>http://www.cancer.org/index</u>) is a national, community-based health advocacy organization committed to eliminating cancer. The American Cancer Society (ACS) has three online communities for cancer patients. WhatNext is an online support network that 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 ACS resources. The site's timeline format helps to catalogue shared experiences, making them easier to find by others. The **Cancer** Survivor's Network (CSN) is an online community created by and for people affected by cancer. The network 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. ACS's **Circle of Sharing** is a tool to help patients learn more about their diagnosis and share information securely with friends and family. Patients can enter information about their cancer into Microsoft HealthVault, a free online personal health record. 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. Circle of Sharing also provides personalized medical articles for users, which can be shared with their Circle. In order to assist with treatment decision-making, Circle of Sharing provides links and tools for patients to better understand treatments and search for clinical trials. Additionally, users can access local resources such as hospitals, referrals, insurance assistance, and more.
- 3. **I Had Cancer** (<u>http://www.ihadcancer.com/</u>) is a social networking site where cancer patients, survivors, and caregivers can create an online profile 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 for sharing confidential news and messages.

- 4. MyBCTeam (<u>http://www.mybcteam.com/</u>) is the first social networking site designed specifically for cancer patients. The premise of the site involves creating a supportive team to improve the patient's experience with breast cancer. It offers a searchable provider directory to connect patients with doctors as well as functionalities for identifying other patients at a similar stage of care.
- 5. Lung Cancer Alliance (<u>http://www.donate.lungcanceralliance.org/</u>) is a national non-profit organization dedicated primarily to providing support and advocacy for those living with or at risk for lung cancer. They sponsor an online community called LungLoveLink, which has various forums, blogs, and groups to link individuals affected by lung cancer to resources and support.
- The Association of Cancer Online Resources (<u>http://www.acor.org/</u>) is an extensive collection of online cancer mailing lists, support communities, and discussion groups. ACOR offers over 130 communities on topics ranging from specific types of cancer, to treatment-related side-effects, country-specific groups, childhood cancers, and others.

Social media represents a tremendous opportunity for patients to fill gaps in their care. Social media incorporates education, information-sharing, and social support in a manner conducive to helping patients learn, understand, manage, and cope with cancer. As more of the United States becomes connected to the internet, we expect socially disadvantaged populations to continue to utilize social media resources, fostering trust, raising awareness, and reducing barriers to effective communication in cancer care.

## 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. Searches comprised of various combinations of terms, such as: -( Cancer OR neoplasm OR tumor OR oncology), -("health it" OR "health information technology" OR "health informatics" OR electronic OR mobile OR digital OR technology OR smartphone OR "mobile application" OR "mobile app" OR "social media" OR portal OR "patient portal"), -(decision support OR "medication management" OR "pain management" OR "self-management" OR "patient navigation" OR "reminder" OR "disease management"), and -(teleoncology OR telemonitoring OR telemedicine OR telehealth OR "electronic health" OR mHealth OR "mobile health"). Relevant references from extracted articles were identified to increase the literature search yield.

Only original studies published after 2005 that evaluated the use of eHealth tools (mobile health applications, telemedicine, social media and patient web portals) for cancer management were reviewed. These included studies using randomized controlled trials, observational (non-randomized controlled trials, pre-post studies, and post-intervention studies) or qualitative methods. Studies evaluating the use of health IT for other chronic diseases and opinion pieces were excluded. In addition, studies evaluating the use of electronic health records or chronic disease registries were excluded as the focus of this

project is on patient-centric tools and not on 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 414 articles were identified using the above search strategies, with 124 satisfying the inclusion/exclusion criteria. For this report, the studies identified and abstracted were classified based on methodology used, as shown in Figure 9:

Study Methodology	Number of Studies
Randomized Controlled Trial	21
Quasi-Experimental Design	21
Observational and Cross-Sectional Studies	24
Feasibility/Case Studies	43
Literature Reviews and Meta-Analyses	15
Total	124

Figure 9: 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 cancer patient outcomes, and specific characteristics of each technology that make use of the technology appropriate for socially disadvantaged populations, 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; and
- protocols developed within the technology through which personally identifiable information is protected.

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 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**

Our review of the literature generally excluded research on eHealth tools that can be used to manage non-clinical factors associated with cancer prevention. Particularly among socially disadvantaged populations, the need for comprehensive lifestyle changes associated with diet, increased physical activity, and smoking cessation are paramount to the effective management of cancer. Although technologies have been evaluated independently in such contexts, few have specifically evaluated use by a population with cancer.

Further, the limited number of studies assessing eHealth tools among socially disadvantaged populations prohibits us from drawing definitive conclusions about the overall impact of these tools. As a result, our conclusions about the potential use of these tools rely on an understanding of the general health needs of socially disadvantaged populations and the capacity for certain functionalities of the tools, such as the ability to overcome geographic barriers, to meet those needs.

Additionally, the demographic characteristics of socially disadvantaged populations indicate a wide array of cultures and ethnicities. Each group has its own distinct culture, beliefs and language when communicating with providers. A significant limitation within the studies found for this brief was the lack of a robust and comprehensive framework to assess usability. While some research described recommended functionalities for acceptance and use of patient-centered applications; very little demonstrated how various cultures could use these applications successfully. Moreover, although smartphone-based programs have generally been effective in improving patient adherence, monitoring, and disease management, the cost of regularly sending and receiving data may remain a significant financial barrier for some socially disadvantaged populations to use mobile devices, not to mention the digital divide in general which may prevent certain subpopulations from fully benefiting from advancements in internet, computer, and mobile technology.

#### Conclusions

Rapidly increasing adoption and recent advancements in eHealth tools - particularly in the areas of telemedicine, mobile health, internet-based technologies, and social media – provide strong evidence for the potential for socially disadvantaged populations to use these tools to effectively manage their cancer.

- Cancer patients interact with eHealth tools differently than patients with heart disease and diabetes. Whereas blood glucose levels and blood pressure are effective indicators for 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 typify many eHealth tools for diabetes/heart disease are not present in cancer tools. To the extent that remote-monitoring is employed, it is used to help patients report and manage psychosocial outcomes and treatment-related side effects.
- Telehealth is an especially viable tool for reaching socially disadvantaged populations diagnosed with cancer. Feelings of isolation are common in cancer patients, and can be compounded by physical distance between the patient and their provider. Telehealth effectively overcomes geographic barriers to care and opens new lines of communication. Telemedicine can increase patient knowledge of cancer

and cancer screening, improve health related quality of life and reduce depression and anxiety through side-effect and symptom management, and help provide psychosocial support to cancer patients.

- **Mobile health is underutilized by oncologists.** Like telehealth, mHealth can overcome geographic isolation. Given rates of smartphone adoption among all populations, mobile health may offer a cheaper alternative to telemedicine 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. We expect this to change in the future, as smartphones become more widely adopted by patients and providers alike.
- Internet-based technologies are promising tools for managing all elements of cancer care. 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 patientprovider 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.
- Social media enhances patient education and can greatly improve psychosocial aspects of cancer care. Cancer patients frequently experience feelings of confusion, fear, anxiety, isolation, loss of control, and a lack of information because of their condition and the complexities of cancer care. By connecting users with family, friends, caregivers, and others who have or have had cancer, social media can alleviate these feelings in cancer patients. Overall, eHealth tools for cancer more commonly emphasize social support than tools for diabetes and heart disease.
- More evidence is needed to confirm the overall impact of the use of eHealth tools for cancer care. Relatively few studies have evaluated the use of telemedicine, mHealth, internet-based technologies, or social media by cancer patients. Of those that have, even fewer have evaluated the impact on clinical outcomes. eHealth tools can clearly empower patients and improve psychosocial concerns, but they may not have an effect on improving the incidence or mortality of cancer.

As the United States healthcare system transitions to a coordinated, patient-centric model, patients will need tools to help them better manage chronic conditions themselves. Characteristics of socially disadvantaged populations, such as inadequate access to resources and lower levels of health literacy, education, and income, make it all the more imperative that these tools are designed to overcome the barriers to effective self-management. Our review of the literature and identification of commercially available tools has provided strong evidence that telehealth, mobile health, internet-based technologies, and social media can help achieve this goal by facilitating patient-provider communication, providing information and education to enhance decision-making capabilities and understanding, surmounting physical obstacles to care, and improving mental, social, and emotional well-being among cancer patients.

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