Equity in the Digital Age:

How Health
Information
Technology Can
Reduce Disparities

The Asian & Pacific Islander American Health Forum (APIAHF) influences policy, mobilizes communities, and strengthens programs and organizations to improve the health of Asian Americans, Native Hawaiians, and Pacific Islanders.

The California Pan-Ethnic Health Network (CPEHN) works to ensure that all Californians have access to quality health care and can live healthy lives. We gather the strength of communities of color to build a united and powerful voice in health advocacy. You can find additional resources on advancing health equity at www.cpehn.org.

Consumers Union, the advocacy division of Consumer Reports, works for health reform, food and product safety, financial reform, and other consumer issues in Washington, D.C., the states, and in the marketplace.

The National Council of La Raza (NCLR)—the largest national Hispanic civil rights and advocacy organization in the United States—works to improve opportunities for Hispanic Americans.

Executive Summary

While enormous medical and technological advancements have been made over the last century, it is only very recently that there have been similar rates of development in the field of health information technology (HIT).[1] This report examines some of the advancements in HIT and its potential to shape the future health care experiences of consumers. Combined with better data collection, HIT offers significant opportunities to improve access to care, enhance health care quality, and create targeted strategies that help promote health equity. We must also keep in mind that technology gaps exist, particularly among communities of color, immigrants, and people who do not speak English well. HIT implementation must be done in a manner that responds to the needs of all populations to make sure that it enhances access, facilitates enrollment, and improves quality in a way that does not exacerbate existing health disparities for the most marginalized and underserved.

The following recommendations highlight what must be considered to maximize the benefit of HIT for everyone:

Expand access to health information technology in communities of color
- Increase access in underserved areas.
- Capitalize on mobile technologies to increase access for communities of color.

Minimize barriers to online eligibility and enrollment for health insurance
- Ensure that online applications only require information that is necessary to advance an application.
- Develop online applications that recognize complex mixed-status households and prevent erroneous rejections and other barriers to enrollment and eligibility.
- Strengthen existing enrollment options in addition to utilizing HIT.
- Design a web portal that takes into account differences in culture, language, and health literacy among its potential users.
- Develop an outreach and education strategy specifically for the underserved.

Improve patient care
- Enforce the required collection of demographic data.
- Hospitals, providers, and health plans should use demographic data, including race, ethnicity, and primary language to identify and address differences in utilization and health outcomes.
- Coordinate with public health departments to provide aggregate, stratified health data.
- Consider collecting and reporting data on health-related quality of life measures.
- Use patient demographic data to develop a library of materials in multiple languages for patients and care givers.

Protect the security and confidentiality of data
- Include privacy and security protections to prevent misuses of health data.

Introduction

The past two decades have seen a number of unprecedented technological advancements. In the early 1990s, the word "internet" had yet to enter the lexicon and computers were primarily used for word processing, data analysis, and the occasional game of Oregon Trail. Now, people can stream live media on handheld devices and nearly every facet of life has been adapted to include some form of digital or online technology. In the U.S., the average age at which a person obtains his or her first cell phone is just under 12 years old,[2] and eight in 10 Americans have a cell phone.[3] Out of those users, two out of every five has a phone that operates on some type of smartphone platform.[4]

These technological developments have also impacted the way Americans manage their health and interact with the health care system. A recent study found that four out of five internet users looked for health information online, making it the third most popular online activity after checking email and using a search engine.[5] The organic information collection done by patients today is evolving into a major overhaul of our health care eco-system, catalyzed by the enactment of two major health information technology (HIT) laws, the Health Information Technology for Economic and Clinical Health Act (HITECH) and the Patient Protection and Affordable Care Act (ACA). If designed appropriately, emerging technologies in this digital age can optimize the use of health information by patients and providers to improve the quality of care and help to reduce health disparities. In a recent report on technology and health, the Institute of Medicine noted:

> [Health information technology] provides an opportunity for engaging populations not historically well served by the traditional health community... The impact of facilitating patient and population contribution to, and control of, their health information has the potential to provide further insights into, and opportunities to address, disparities in underserved populations.[6]

At the same time, the development of new technologies has the potential to leave further behind those currently experiencing differences in coverage, utilization, and health outcomes. For example, the invention of central air conditioning has helped millions of people live comfortably through hot, humid summers. However, in many areas, it took several decades for central air to become prevalent and in some inner city neighborhoods, households with central air remain rare. A study of Detroit, Chicago, Minneapolis, and Pittsburgh showed a direct correlation between the rise in central air prevalence and a decline in heat-related mortality. The study also found that heat-related deaths were much more prevalent in African Americans than in Whites and attributed this disparity in part to the lack of central air in predominantly African American neighborhoods.[7] While the increase in central air facilities helped a large number of people, the communities without it were left further behind.

Similarly, as we look to harness the power of new technologies in health, we must be careful to implement policies and design the systems surrounding HIT to facilitate access for all communities. Though internet access has greatly increased nationwide over the past decade, a significant "digital divide" still exists, and many populations, most notably communities of color and people who do not speak English well, have

not achieved equitable access during this most recent technological revolution. While most communities conduct a similar amount of online activity, Latinos (55 percent) and African Americans (58 percent) are much less likely than Whites (75 percent) to have a home internet connection. Analyzed further, just one in four Latino households where Spanish is the dominant language is wired for the internet.[8] However, recent research on social media use suggests that many communities of color are finding other ways to engage online, through the use of mobile technologies and other applications and devices, which may provide alternative ways to shape HIT strategies.[9]

This report examines the recent advancement of HIT and its potential to shape the future health care experiences of consumers. There are significant opportunities to improve access to care, enhance health care quality, and create targeted strategies that help promote health equity, especially combined with improved data collection. However, implementation of these advancements must be done a manner that responds to the needs of all populations. Otherwise, the gaps in access and use that exist today could easily exacerbate disparities in health care access and outcomes for the most marginalized and underserved by our health system.

Overview

Bringing health into the information age

While enormous medical and technological advancements have been made over the last century, health information has been stuck in the equivalent of the Dark Ages. In fact, for a long time health information was confined to paper. Paper medical records, paper prescriptions, and other paper files collected in the overflowing storehouses of doctors' offices and hospitals. Unfortunately, storage rooms were often where the paper stayed. As a patient, a health file was often only as comprehensive as the records kept by the doctor you had last. This challenge was even more pronounced in medically-underserved communities. Uninsured patients who had to go from one health care provider to another often had lost or incomplete medical records. In addition, patients with health literacy and communications challenges, such as a limited understanding of English, could experience further difficulties in effectively communicating their past health issues to their providers. HIT can make health information more accessible and more functional for patients, and enable providers to avoid bureaucracy and pay attention to the practices and interventions that best help their patients.

Since 2009, two landmark pieces of legislation have created significant opportunities to reduce disparities through HIT. As part of the economic stimulus bill that year, the HITECH Act offers an estimated $27 billion for hospitals, physicians, and other eligible health care providers to implement and use electronic health records (EHRs) and build an HIT infrastructure to improve health care quality and population health. While this funding has helped hospitals and physicians improve their HIT systems, investments are also needed throughout the entire system, such as for pharmacies and labs, with a particular focus on building the infrastructure in underserved communities.

In addition, the national health care reform law enacted in 2010, the ACA, supports the standardization of demographic data collection and integrates disparities reduction in many of its provisions. The ACA also creates national requirements for internet-based enrollment procedures as states and health insurance plans offer expanded coverage to millions of Americans.

There are a number of ways we can meaningfully use[10] these new innovations to move the health care system from the Dark Ages to the 21st century.

Reaching Our Vulnerable Populations

With full implementation of health care reform and EHRs expected between 2014 and 2016, many aspects of the health care system will be shifted online. All Americans will need to be brought up to speed on these technological advancements, but there are several traditionally marginalized populations, which need particular consideration as new systems are designed. Communities of color, those who do not speak English well, and immigrants all have experienced barriers to the health care system that have led to disparate access and treatment. It will be important to understand their challenges with navigating the systems of today and tomorrow to ensure that they do not experience further disparities.

Communities of color
Racial and ethnic minorities are more likely to be uninsured than Whites. One in seven Asian Americans, Native Hawaiians and Pacific Islanders, along with one-third of Latinos and nearly one-quarter of African Americans are uninsured.[11] In addition, 30 percent of American Indians and Alaska Natives are uninsured compared to 14 percent of Whites. While Medicaid and the Children Health Insurance Program (CHIP) are major sources of coverage for communities of color, there are still large numbers of uninsured in these communities.[12]

Limited English proficient populations
In 2010, one in five Americans—representing nearly 58 million people—spoke a language other than English in the home; of those, more than two-fifths spoke English "less than very well," the threshold generally considered to be "limited English proficient" (LEP).[13] The vast majority of these Americans are people of color. For example, more than 9 million people in the United States speak Asian and Pacific Island languages at home, and more than 4 million of them are estimated to be LEP. Similarly, about 36 million speak Spanish at home; of those, about 16 million are estimated to be LEP.[14] People who are LEP represent a substantial share of Americans who experience barriers to coverage.

Immigrants and mixed-status families
Children in immigrant families represent the fastest growing segment of the nation's youth, representing more than one in five U.S. children.[15] Researchers estimate that more than half (58 percent) of the nation's 16 million Latino children are U.S.-born

citizens living with at least one immigrant parent. Further, about 3.3 million U.S.-born Latino children have at least one undocumented parent. In addition, over 60 percent of Asian Americans and 30 percent of Pacific Islanders living in the U.S. are foreign-born, representing the full spectrum of immigration status categories. Approximately 13 percent of children of Asian parents live in mixed-immigration-status (mixed-status) families.[16] These mixed-status families present enrollment challenges when members of the same household are likely to be eligible for different health coverage options.

Individuals in mixed-status families eligible to participate in public programs are often worried or fearful about exposing their undocumented family members. This is particularly the case when an undocumented parent wants to enroll his/her citizen child in public programs such as Medicaid and CHIP.[17] In addition, the automation of enrollment may exacerbate these fears and create additional barriers to enrollment by requiring unnecessary information during the application process. For example, the Henry J. Kaiser Family Foundation released a study in June 2011 and found that although most of the 32 states it studied utilized features to minimize information requested from applicants, all still asked for information that was not necessary to process an application.[18] While most allow the option to designate the person filling out the form as a "non-applicant" (e.g., they are filling it out for their child), none of the forms avoided asking for the citizenship or social security numbers of these non-applicants, which is not necessary information to enroll the applicant. These forms prevent parents who are non-citizens from completing the enrollment for their children who are citizens. To address these issues, the U.S. Department of Health and Human Services and the Department of Agriculture has developed TriAgency policy guidance to clarify when a state is and is not required to request information about citizenship, immigration status, and social security numbers.[19]

Opportunities and Barriers for Use of Technology in Communities of Color

Some populations—particularly low-income people of color, individuals living in rural areas, individuals with disabilities, and seniors—access the internet in non-traditional settings or still face barriers to accessing the internet at all.[20] These barriers can be both structural (lack of access to high speed broadband, websites that are not accessible for persons with limited English proficiency, visual impairments, or physical disabilities) and economic (cost of computers or internet service), among other challenges.

In order to reach these populations, understanding their use of online platforms and technology is essential to informing the design of future HIT. Home internet access is limited in the homes of many people of color and LEP individuals; however, there is an upward trajectory of members of these communities adopting internet use through their mobile phones.[21] Standard cell phone use has become commonplace in low-income communities and many individuals may only use a cell phone. In fact, landlines are becoming obsolete among many low-income populations, who need more flexibility

when they have multiple jobs or are away from home for long periods of time. Cell phones are also more versatile than more expensive computers because they offer additional services such as text messaging and voice mail.

While mobile internet use is increasing throughout all demographic groups, the technologies remain expensive, and are not as accessible for low-income communities. Users who access the internet via a mobile device are generally wealthier and have at least attended some college.[22] However, while it took a long-time for the internet to break through in communities of color, data indicate that there is some promise for multipurpose mobile technologies. For instance, Asians and Pacific Islanders (45 percent), Latinos (45 percent), and African Americans (33 percent) are more likely to own a smartphone than White mobile phone users (27 percent).[23] In addition, African Americans (15 percent) and Latinos (11 percent) are already using mobile health applications at a higher rate than Whites (7 percent), so this medium has the potential to engage multiple communities.[24] New technologies, such as tablet computers, are also emerging and may show promise.

If mobile strategies are developed with the mindset of increasing access, they have the potential to bridge historical gaps in outreach, education, communication, and engagement through devices that are literally in the hands of traditionally underserved populations.[25] There are already some innovative uses of mobile health technologies among low-income pregnant women,[26] Spanish-speaking migrant workers,[27] and homeless and at-risk youth,[28] communities which often experience gaps in access to home-based internet connections (see *Box 1*). By utilizing effective communications strategies and low-cost cell phone technologies, practitioners may develop ways to address online access challenges and bring low-income populations and communities of color to the edge of innovation.[29]

Though HIT has plenty of potential, there is the possibility that, if implemented improperly, the technologies could actually become barriers for some people of color

Box 1: Mobile Health Innovations

There have been a number of innovations in recent years to utilize mobile technologies to promote health.

- **Text4baby** — A fast-growing resource, over 230,000 mothers have signed up for this free service. An individual can sign up by texting her due date and zip code to a set number. She will then receive timely updates with tips on pregnancy and caring for her baby. Text4baby has partnered with 18 cell phone providers to ensure the service is free for all users.

  Text4baby is available in both English and Spanish. As of September 2011, 5 percent of all users (12,358 mothers) received the Spanish-language updates.

- Vitality GlowCaps — These devices affix to the tops of medication bottles and light up and sound when it is time to take a pill. There is also a wireless chip inside the GlowCap device that sends out a phone or text reminder if the patient forgets. The device can also notify the doctor of how well the patient is adhering to the prescription instructions, phone or contact a friend or family member, or automatically call in a refill.

- MiVIA and HealthShack — These online personal health record systems allow users to store important health information.

  Designed for migrant workers and homeless and at-risk youth who move frequently and therefore lack continuity of care, MiVIA and HealthShack are transportable Personal Health Records that can store one's health information as a person travels. Each member gets a personal identification card from community-based outreach organizations and can set up a private, secure account. The card also has detailed instructions on how to access one's records from any computer with internet connection. The ability to store and download critical health information such as diagnosis, medications, allergies, and chronic conditions supports continuity of care and decreases the chance of duplication of services.

and immigrant communities. Due to the lack of universal internet access, any HIT efforts should be implemented in tandem with existing health communication options like toll-free lines and in-person assistance. Outreach is also an important part of any new developments to the health care system, including HIT. Utilizing ethnic media like the efforts made in San Francisco's Chinatown upon the roll-out of Healthy Families (see *Box 2*)—especially newspapers and radio stations—could help increase patients' knowledge about how technological advancements are changing their health care. Partnering with community organizations and training outreach workers in underserved communities are also important for spreading word of HIT developments.

Special attention needs to be paid to HIT implementation in underserved communities. Patients might be reluctant to seek medical assistance if they encounter an automated system that is challenging to use. People who do not speak English well and people of color could become frustrated and discouraged if they feel that the technology does not support their cultural or linguistic needs. Online applications should be accessible by everyone, and should only require necessary information for enrollment (for example, a required Social Security Number field would prevent legal immigrants without a number from submitting an application).

Using HIT for Enrollment Efforts

Connecting with vulnerable populations is critical to the success of health care reform. The Affordable Care Act (ACA) includes a number of provisions that expand access to health insurance and help those that are eligible for coverage get enrolled. In California alone, about 2.13 million people who were uninsured for all or part of 2009 will be eligible for Medi-Cal, California's Medicaid program, as a result of the ACA's coverage expansion in 2014. People of color would represent roughly two thirds (67 percent) of those newly eligible in California, and 35 percent of those eligible will speak English less than very well.[31]

ACA implementation also encourages states to establish health insurance Exchanges that allow consumers to purchase affordable coverage options, with tax credits available for those earning up to 400 percent of the Federal Poverty Level. Many states have established their own Exchanges, and residents in states that choose not to implement a state Exchange will have the opportunity to participate in a federal Health Insurance Marketplace. In California, over 2.6 million nonelderly adults will be eligible to receive federal tax credits to purchase affordable health coverage in the state's health insurance Exchange, Covered California. Of these, 67 percent (approximately 1.73 million) will

be people of color, and 40 percent of the adults (or roughly 1.06 million individuals) will speak English less than very well.[32] HIT will play a pivotal role in streamlining the eligibility and enrollment systems for Medicaid and the Exchanges.

Building an enrollment portal for all

Limited English proficient individuals

It will be critical to ensure that enrollment portals and materials are translated into multiple languages. Yet even if translated websites are available, users must have access to toll-free telephone lines and in-person interpreters for assistance in their preferred language. In addition, recent data suggest that people who are proficient in languages other than English may use technology differently. One study comparing individuals speaking English to those speaking Spanish suggests that Spanish-speakers are much less likely to use online platforms, and even when they do so, they are significantly more likely to seek out in-person assistance. Thus, even those who gain access to the internet may have more success connecting to coverage and services when working with community-based organizations or other culturally competent facilitators of online technology.[33]

Immigrants and mixed-status families

An internet-based enrollment system must also recognize that many Americans live in families and households with complex structures due to different immigration statuses. These mixed-status families will encounter enrollment challenges when members of the same household are likely to be eligible for different health coverage options. Administrators developing consumer-friendly online portals must be vigilant and avoid unintentionally imposing barriers for families with complex eligibility categories. Online applications should be developed in a manner that prevents eligible members of the same family from experiencing inappropriate rejection or barriers to application and enrollment. For example, an undocumented parent must be able to use a system to enroll his/her eligible child without being prohibited from using the system because the parent's own status would fall outside the eligibility guidelines. These electronic forms should also only require information that is necessary to advance an application for the eligible family member and the system should pro-actively assure applicants that their data are protected and will not be shared with other government officials or law enforcement.

Getting everyone in

Implemented properly, HIT can also streamline the enrollment process by reducing the burden of documentation requirements. For example, applicants will be able to complete a single online form and then be enrolled in the coverage program for which they are eligible. The instantaneous nature of the internet would allow users to update their information immediately, and from any location, instead of having to submit changes via mail or at a doctor's office. A number of states have already launched online enrollment applications, including Wisconsin's ForwardHealth interChange, described in *Box 3* on Page 11.

Transparency is vital when creating these enrollment web portals. Users should have access to easy-to-read information about plan benefits, costs, complaint processes, and

services available for those not receiving coverage. This information should be prominently displayed and written so that it can be understood by all users, including people with disabilities, those with limited health literacy or computer literacy, and those who do not read or understand English well. According to an estimate of the projected 2019 Health Insurance Marketplace population, approximately one in four enrollees in the U.S. will speak a language other than English at home.[34] All information on the web portals should be written at or below a sixth-grade reading level to maximize understanding for consumers.[35] In addition, web pages should include visual and audio aids to help users navigate the website, and tag lines in multiple languages to inform limited English proficient individuals how they can access interpreter services and translated materials.

Providing additional assistance

While HIT has tremendous promise in identifying ways to increase accessibility, it is important that technological advancements do not replace other ways to receive help. Individuals and families should be able to access the system in the way they feel most comfortable, whether it be via a toll-free telephone line, by mail, or at a hospital, clinic, or doctor's office. In fact, some populations, such as immigrants and LEP individuals, prefer paper application systems. There are also some practical concerns with setting up an online system. Any web portal should be backwards-compatible to allow access for computers that might not have the most up-to-date browsers, like many public computers in low-income areas. The websites should be basic and not take too long to load, even for users on a dial-up connection, since people of color are less likely to have broadband internet access. Also, there should be secure log-ins with time-out functions, so people accessing their information via a public computer—at a library or community center—can be sure that their accounts are safe. By considering these basic requirements, online enrollment will be more accessible for people with low- and moderate-income status and people of color.

HIT can also enhance the role of facilitators in assisting people as they navigate the enrollment process. Mobile technologies may help outreach workers who are in the field meeting people where they are, such as at schools, churches, and worksites. Tablet

computers, for example, may be helpful for community outreach by providing a more interactive experience for those seeking to learn more about what services are available to them.

Improving Patient Care Through HIT

Successful implementation of electronic health records is more than shifting from paper to digital records. Electronic systems can provide clinicians with real-time information, which can lead to improved clinical decisions through reminders, alerts, and other just-in-time references.[38] Recent studies have shown quality improvement among some providers that have switched to electronic health records. A recent report in *Health Affairs* found that a secure, doctor-patient email system utilized by Kaiser Permanente produced a statistically significant improvement in quality of care over a two month span for patients with diabetes, hypertension, or both.[39] A similar study in *The New England Journal of Medicine* found that across all insurance types (including public coverage programs and private insurers), EHR sites showed significantly higher care quality and better outcomes than paper-only sites.[40]

Collecting demographic data

Having a patient's race, ethnicity, language, and other demographic data readily available is essential in identifying and reducing inequities within the health care system. Studies have shown that hospitals and health care organizations that collect race, ethnicity, and language data from their patients may be more likely to look at disparities in care, design targeted programs to improve quality of care, and provide patient-centered care. However, collection of data is often fragmented both within and across organizations due to a lack of understanding of how best to collect it from patients.[41]

HIT holds the potential to bridge some of these issues and create a more efficient means of collecting and transferring demographic and patient data. With a single online application form, demographic data can be collected at the initial point of entry into the health care system and be shared with the appropriate entities. In addition, the establishment of state health information exchanges and the eventual creation of a national network will increase clinicians' access to health information across platforms, providers, and geography.[42] Collecting patient race, ethnicity, language, and other demographic data at the onset of care, if it is not already provided by the health plan or insurer, will ensure that all providers caring for that patient both now and in the future can provide culturally and linguistically appropriate care for that patient.[43]

Transparency when collecting demographic data is necessary because many consumers may have concerns about providing information about their race or ethnicity due to experiences of data being misused, such as using the data to discriminate and red-line. When collecting the information, the application form must explain why the data are being collected and how they will be used. Studies show that the inclusion of this information on applications increases response rates.[44] In addition, how personal information will be protected should also be provided.

Using data to improve quality

Once demographic data are collected, they can be used to improve quality of care for communities of color, which could help dramatically reduce disparities. A recent study of California by the Agency for Healthcare Research and Quality found that significant disparities exist in the number of hospital admissions for certain health conditions that could have been prevented by better quality outpatient care. For example, the preventable hospital admission rate for African American children ages 2 to 17 with asthma (235.9 per 100,000 children), is roughly three and a half times that of White children (65.2 per 100,000). Significant disparities also exist in preventable admissions of African American adults (290.2 per 100,000) suffering from diabetes with long-term complications compared to White adults (77.5 per 100,000).[45] Hospitals that have race, ethnicity, and language information about their patients would be able to identify disparities within their practice setting and develop policies, as well as implement culturally appropriate programs, to address them.

Hospitals, physicians, and health plans can also use data on language needs to better provide services for patients who do not speak English well, or who are able to communicate in English but would prefer to discuss medical concerns in their native languages.[46] When health plans collect and record primary language and communication needs at the time of enrollment, they can ensure that patients can choose appropriate primary care providers. For example, health plans may identify the need for recruiting additional bilingual physicians in their network or providing interpreters for specific languages. In addition, plans need to offer websites, telephone services, and written materials that are accessible to patients who are visually or hearing impaired, and those with other physical disabilities. There are already efforts underway to develop electronic health records and other HIT that are accessible for people with disabilities. The U.S. Department of Education's National Institute on Disability and Rehabilitation Research recently awarded a grant, "Accessible Designs for Personal Health Records," to explore adaptive technology use among people with disabilities and develop guidelines and recommendations for better accessibility.[47]

Additionally, when language preference is available electronically, hospitals can have a better idea of day-to-day patient needs and can ensure the availability of interpretation and other resources, especially when a patient might require multiple services within the hospital (e.g., surgery, imaging, physical therapy).[48] For example, one area where this can be most effective is when a patient is ready to leave the hospital. Having electronic hospital discharge instructions translated in the language that a patient understands can enable patients to have easier access to important health information. These instructions can also be shared with primary care providers, pharmacists, and others for follow-up treatment. Using demographic data can also help facilitate appropriate referrals to community support services, including nutrition, exercise, peer support, adult day health, rehabilitation, child care, and transportation.

The use of HIT is also an opportunity to dramatically improve patient understanding of their medication instructions and prescriptions. A recent study found that having a limited understanding of English can increase the odds of misunderstanding English-

language prescription labels up to three times for Spanish-speaking Latinos and for those who speak Korean, and up to four times for those speaking dialects of Chinese.[49] Documenting the patient's language as part of the electronic health record and electronic prescription can help providers ensure that medication instructions and prescription drug labels will be understandable.

However, efforts are needed to ensure that these technological advancements are accessible by all populations. For example, communities of color are more reticent to participate in Kaiser Permanente's online patient portal. African American, Latino, and Filipino participants were far less likely than White participants to request a password for the internet-based patient portal, an indicator of internet access and intent to use the portal.[50] Analysis of the populations that use online health portals will help health plans and providers design interactive systems to achieve maximum participation.

Promoting public health

HIT systems could also be used more boldly to promote public health. For instance, by exchanging aggregated, stratified health data with health departments, there could be an effort to identify and monitor population-wide trends. The ACA pays significant attention to preventive approaches that promote health and wellbeing. Since the law was enacted, there have been efforts to link electronic health records and health information exchanges to public health departments and data systems.

In order for HIT to make a substantive impact on disparities reduction, secure data should be collected on community conditions and should be recorded on a wide variety of demographic characteristics (such as race, ethnicity, primary language, gender, sexual orientation and gender identity, disability, economic status, and geography). The data should then be analyzed along with local population health data collected primarily by public health departments.[51] HIT can also track health-related quality of life measures, which include a person's self-reported physical and mental health and their determinants — including health risks and conditions, functional status, social support, and socioeconomic status.[52] By recording this information and sharing the aggregate data with local public health departments and federal organizations like the Centers for Disease Control and Prevention, HIT can be used to address the root causes of disparities in health conditions such as asthma, diabetes, obesity, and many others.

An electronic link between public health departments and health records systems could provide significant opportunities to address population-wide trends. Access to aggregated health data stratified by race, ethnicity, primary language, and other demographic variables will enable public health professionals not only to identify any disparities but also the need for a focused public or community health response. For example, a sharp increase in rates of chlamydia and gonorrhea (7 percent more cases in 2010 than 2009) has prompted California schools and health departments to implement a new computer sex education program, "It's Your Game: Keep it Real," which has proven to delay sexual

activity (see *Box 4*). In addition, the San Francisco Department of Public Health has begun a text messaging service to combat sexually transmitted infections (STI), with over 3,000 subscribers. Los Angeles County has also targeted women ages 12 to 25 with an online site for ordering STI testing kits.[53] These are a few examples of how a link between health records systems and public health departments can lead to innovative strategies to improve health.

Developing culturally appropriate patient education materials

One of the great promises of electronic health record systems is the ability to share tailored reminders and other patient education materials. For example, when a patient with asthma comes to an office visit or hospital emergency room, materials on the appropriate use of asthma medications and control strategies could be easily provided. Having the ability to simply print out or share materials electronically rather than maintain an inventory will make it far more likely to have them available. The electronic health record system should be able to produce patient materials in alternate formats

and in languages other than English. Analyzing data on patients' language needs will help providers meet the needs of all of their patients.

In addition, materials related to issues like diet and nutrition could be tailored to make appropriate cultural references (e.g., rice rather than bread, or corn rather than flour tortillas), depending on the race and ethnicity of the patient. Finally, having multiple versions of health education materials with more culturally relevant visuals, pictures, and graphics can be easily achieved with an electronic archive.[55]

Recommendations

The Health Information Technology for Economic and Clinical Health (HITECH) Act and the Patient Protection and Affordable Care Act (ACA) have added legislative weight behind a tremendous cultural shift within our health care system. The implementation of HIT has the potential to improve the delivery of health care in traditionally underserved populations by expanding access and improving the quality of care. The following recommendations highlight what must be considered to maximize the benefit of HIT for everyone:

Expand access to health information technology in communities of color

- Increase access in underserved areas. Many vulnerable communities continue to lack the infrastructure to simply address the mechanics of a technology-centered health system. Pilot projects and investments through HITECH have demonstrated that supporting physicians and hospitals in the adoption of technology helps to increase integration of HIT within the health system. These investments should focus on infrastructure building in underserved communities, and include all providers who are a part of the health care delivery system, such as labs and pharmacies. Technology training also needs to be available for providers that predominantly work in underserved areas so they will be able to use new innovations to their fullest capacity.
- Capitalize on mobile technologies to increase access for communities of color. In order to reach people who do not have internet access at home, providers should utilize mobile technologies, including cell phones and smartphones, to facilitate communication between providers and patients. Providers should also develop mobile applications, websites, and forms that are compatible with mobile browsers.

Minimize barriers to online eligibility and enrollment for health insurance

- Ensure that online applications only require information that is necessary to advance an application. Do not require unnecessary information that may deter people from completing an application. These applications and the technology that support them must also include safeguards that protect the privacy, security, confidentiality, and integrity of personal health and demographic information.
- Develop online applications that recognize complex mixed-status households and prevent erroneous rejections and barriers to enrollment and eligibility, especially based on a parent or guardian's immigration status. Millions of citizen children live in mixed-

status households and will rely on a non-citizen parent or guardian to complete an application to receive health care coverage. These applications should conform to the TriAgency policy guidance regarding inquiries into citizenship, immigration status, and Social Security Numbers developed by the U.S. Department of Health and Human Services and the Department of Agriculture.[56]

- Strengthen existing enrollment options in addition to utilizing HIT. While HIT stands to improve the health experiences of millions of Americans, there will always be a certain part of the population that is left behind. In the case of health care reform, it is likely that traditionally underserved populations, such as communities of color, the limited English proficient, those with low or no health or computer literacy, among others, will continue to be underserved. Thus, HIT roll-out must be in tandem with strong third-party assistance options via toll-free lines and in-person consultation.

- Design a web portal that takes into account differences in culture, language, and health literacy among its potential users. For millions of Americans, the web portal will serve as the primary mechanism for determining their eligibility, enrolling for health coverage, and understanding their health plan. As such, the web pages, information, and materials provided through web portals must be written in plain language and at or below a sixth-grade reading level. In addition, tag lines or easily identifiable interpreter phone lines should also be provided on each web page so that limited English proficient individuals can access interpretation assistance and translated materials.

- Develop an outreach and education strategy specifically for the underserved. Traditional approaches to outreach and education do not take into account linguistic and cultural barriers, resulting in gaps in coverage for vulnerable populations. Partnering with community organizations and training outreach workers in underserved communities are critical to the successful implementation of the ACA and encouraging the use of HIT options.

Improve patient care

- Require the collection and reporting of demographic data. Using race, ethnicity, language needs, and other demographic data to understand the patient population can influence the development of patient education materials and medical staffing decisions. As such, new HIT infrastructure must support the collection of this information. The required collection of race, ethnicity, gender, disability status, and primary language data provided for in the ACA will enable providers and public health officials to better understand differences in utilization and health outcomes, particularly among communities of color. States and other data collection entities should also follow the lead of the Department of Health and Human Services, which will begin integrating questions on sexual orientation into national data collection efforts by 2013 and begin a process to collect information on gender identity.

- Hospitals, providers, and health plans should use demographic data, including race, ethnicity, and primary language to identify and address disparities in utilization and health outcome. By using this data, providers will get a better understanding of their patient population, and improve the quality and efficiency of their care delivery. For

example, if a large number of patients speak a language other than English, a hospital might hire more bilingual providers and interpreters to provide assistance and improve health communication. This information should be included in a patient's electronic health record so that every hospital or provider interaction with the patient can be delivered in a culturally and linguistically appropriate manner.

- Coordinate with public health departments to provide aggregated, stratified health data. While respecting the privacy of individuals, combining the efforts of local health departments with certain data available through providers can help track population trends and highlight and address disparities.
- Consider collecting and reporting data on health-related quality of life measures. This patient-reported physical and mental health information can be used to develop more effective public health interventions to improve health outcomes.
- Use patient demographic data to develop a library of materials for patients and care givers. Materials tailored to patients' cultural and linguistic needs—such as hospital discharge instructions and medication instructions—would help foster better understanding and increase patients' involvement in their care.

Protect the security and confidentiality of data

- Include privacy and security protections to prevent misuses of health data. The exchange of electronic health information and the technology that supports it must also promote trust and protect the privacy, security, confidentiality, and integrity of health data. The use of electronic health information should follow set rules and employ fair information practices, including:

  > *Openness and Transparency:* The shift to electronic data transfer will be a new concept for a lot of patients. In order to ease some of their concerns about the use of their personal health information, data stewards should inform them about what data exist about them, how they will be used, who can access them, and where they are kept. This information should be conveyed in an understandable manner, including translation for those who do not speak English.

  > *Collection Limitation:* Personal health information should only be collected, used, exchanged, or disclosed for the immediately specified purpose and with the knowledge and consent of the individual. Make these protections of personal information known to all consumers.

  > *Data Quality:* All data collected should be kept accurate, complete, and current. It is vital that identifying a patient and his or her health records happens quickly and efficiently.

  > *Individual Participation and Control:* A patient should be notified of the availability of his or her personal health data quickly, at no cost, and in a language that he or she can understand. If there are legal reasons why access cannot be provided, the individual has a right to know why the request was denied and to appeal the denial. Individuals should also maintain the right to challenge the collection, content, retention, use, or disclosure of their personal health

information, including the right to have certain information corrected, completed, amended, omitted, or expunged.

> *Local Control:* Personal health information should remain in the control of the patient and with permission the physicians or institutions directly involved with his or her treatment.

Along with privacy and security measures, HIT systems must be designed in a way to prevent the misuse of data, such as the 2010 incident in Utah as described in *Box 5*. These measures should pay particular attention to ways that the misuse of information can impact underserved communities and communities of color. Health data should not be used to deny or restrict insurance or health care services, to engage in deceptive marketing to patients and consumers, or to deny or restrict a patient's rights under the law, including immigration laws.

Conclusion

The recent advancement of HIT has tremendous potential to improve access to care, enhance health care quality, and create targeted strategies that promote health equity. However, implementation of these advancements must respond to the needs of all populations, particularly communities of color, immigrants, and people with limited English proficiency.

In order to maximize the effectiveness of any large-scale electronic health delivery system, its development must coincide with an effort to expand broadband coverage and an increase in the use of mobile technologies. The continued use and investment in consumer assistance tools such as toll-free phone lines and in-person consultation will also be necessary to ensure meaningful access for all.

As with the use of any technologies that are not universally accessible, the shift to a heavily HIT-based health care system can actually increase disparities without a conscious effort to include everyone. Though HIT might improve quality and efficiency for some, any gains made could exacerbate existing disparities if not implemented equitably in underserved areas. While funding has already been allocated to help major medical providers transition to electronic health information exchanges, similar efforts already underway to encourage participation by community health centers and clinics will help achieve the goal of ensuring that every American has an electronic health record by 2014.

Additionally, to achieve the ambitious goals set forth by the ACA, HIT implementation must confront the challenge of bridging the digital divide so that lack of internet access does not lead directly to poorer health.

Endnotes

1. This issue brief uses the term "health information technologies" to include electronic health records, personal health records, electronic enrollment systems, health information websites on the internet, mobile and smartphone health applications, home monitoring technologies, telehealth and telemedicine, and other health information and communications technologies that can improve access to information for both health care providers and patients/consumers, and improve communication among providers, patients/consumers, family members, and caregivers.

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Health IT facilitates coordination across public health entities and other organizations, improves identification of at-risk populations and their adherence to public health guidelines, expedites responses to threats, notifiable conditions, and adverse population events, and promotes consumer participation in public health by encouraging healthy behaviors and behaviors that screen for, detect, and effectively manage disease.

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Notes: