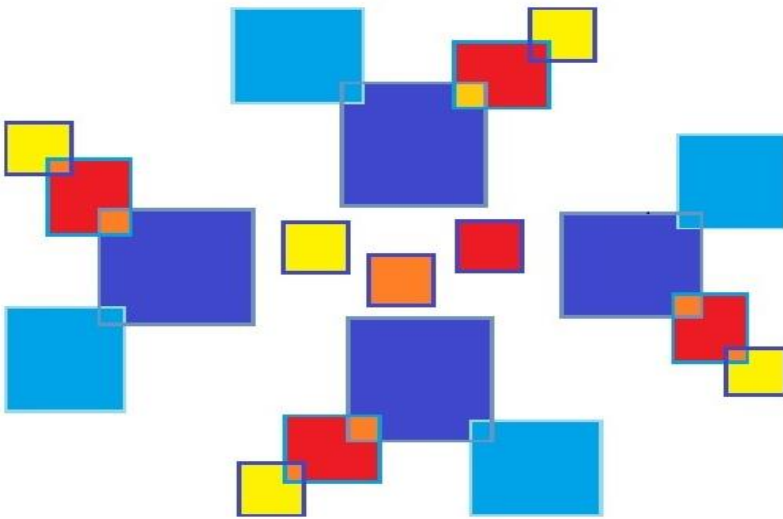


2014

Evaluating Connecticut's Health Information
Technology Exchange
Consumer Survey Report



Prepared for

Connecticut Department
of Public Health

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Contents

Executive Summary	iv
Introduction	1
Background	1
Consumers' use of technology	1
Computer and Internet use.....	1
Using the Internet to search for, track, or store health information	2
Summary	3
Consumers' knowledge and attitudes regarding HIT and HIE	3
Personal health records or patient portals.....	3
Physicians' electronic medical record systems	4
Electronically sharing health information	4
Consent model for sharing health information	5
HIT and HIE benefits and barriers	6
Summary	7
Methodology	8
Study design	8
Survey instrument.....	8
Survey administration.....	8
Analytic sample.....	9
Analytic approach.....	9
Results	10
Sample characteristics	10
Current health, health care use and satisfaction with care	11
Health literacy	12
Sources of health or medical information.....	14
Experiences with information technology.....	14
Familiarity with HIE and HIT	15
Attitudes toward health information exchange.....	16
Perceived benefits of health information technology and interest in sharing health information electronically	17
Location of consumers by Town.....	20
Discussion	22
Summary of descriptive results	22
Consumer characteristics associated with attitudes toward HIT and HIE.....	24
Limitations	25
Conclusion.....	25
Endnotes	27
Appendix A	32
Survey Instrument	32
Appendix B	44
Procurement of consumer calling lists	44
Consumer calling protocol.....	44
Disposition of consumer phone numbers.....	46
Data cleaning	46
Appendix C	47
Logistic regression analyses	47

List of Tables

Table 1. Percent of consumers agreeing that HIT and HIE may confer the following benefits.....	6
Table 2. Demographic characteristics of the survey participants.....	10
Table 3. Current health, health care use and satisfaction with care (N=629)	11
Table 4. Health literacy.....	13
Table 5. Sources of health or medical information.....	14
Table 6. Experiences with information technology (N=629).....	15
Table 7. Awareness of health information exchange and technology (N=629).....	16
Table 8. Perceptions of national health information exchange and consent model (N=629).....	17
Table 9. Benefits of health information technology adoption (N=629)	17
Table 10. Interest in accessing and sharing health information electronically (N=629)	18
Table 11. Barriers to accessing and sharing health information electronically	18
Table 12. Factors that would encourage consumers to sign up for an electronic personal health record (N=629).....	19
Table 13. Sharing health information with doctor.....	20

List of Figures

Figure 1. Consumer survey phone number list disposition.....	9
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Executive Summary

In 2010, the Connecticut Department of Public Health (DPH) entered into a Cooperative Agreement with the Office of National Coordinator for Health Information Technology (ONC), to create and implement a State Health Information Exchange (HIE). DPH received an award of \$7.3 million to initiate and sustain HIE activities in the state of Connecticut.^{1,2} The Health Information Technology Exchange of Connecticut (HITE-CT), a quasi-public agency, was created by [Public Act 10-117](#), "An Act Concerning Revisions to Public Health Related Statutes and the Establishment of the Health Information Technology Exchange of Connecticut," Sec. 82-90,96 (codified at CGS §19a-750(c)(1)), by the 2010 Connecticut General Assembly and Governor Rell. HITE-CT received \$4.3 million over the course of three years to create and implement an HIE infrastructure and facilitate exchange activities in the state. Additionally, DPH contracted with the University of Connecticut Health Center (UCHC) to evaluate the ongoing development and implementation of Connecticut's Health Information Exchange (CT-HIE).

This report summarizes the 629 responses received between 8/10/2011- 12/20/2013 in response to a telephone survey of Connecticut residents' perspectives on HIT and HIE as a way to assess their awareness of and readiness for these technologies, to learn how best to engage consumers in the state's efforts to develop an HIE, and to develop strategies to support consumers' HIT adoption.

Even though we do not have an operational statewide Health Information Exchange in the state of Connecticut (CT-HIE) as of March 14, 2014, this report provides some insights into how consumers might use EMRs, PHRs, and HIE should they become universally available. The estimates of Connecticut consumers' perspectives on HIT and HIE that we describe in this study offer meaningful information to state policy makers and stakeholders as they engage in strategic planning for these technologies, and will help to ensure that the HITECH Act's overarching goal of facilitating the availability of health information in support of a connected and seamless health care delivery system with improved treatment outcomes is achieved.

Key Findings

Descriptive Characteristics of Connecticut Residents (N=629)

- Nearly two-thirds (64%) of participants were female.
- Ages ranged from 18 to 92 and the median age was 59.
- Nearly a third (31%) of the sample was 65 or older.
- Most participants (79%) were white.
- More than half (57%) had a college degree or higher.
- The median household income was \$80,000; 20% reported a household income of \$100,000 or higher.

Current Health, Health Care, and Satisfaction with Care

- 54% of participants described their health as excellent or very good.
- 34% of participants said they had a chronic health condition.
- 24% of the participant reported 1-2 visits, 25% reported 3-4 and 36% reported more than 4 visits to a doctor or physician's assistant in the last 12 months.

- 89% of participants were satisfied with the care they received from their doctor or physician’s assistant.
- 49% of participants reported that their physician’s office had implemented an electronic medical record system and a third said they were not sure.

Health Literacy and Sources of Health or Medical Information

- 63% of participants said they read the printed health-related information they received from their physician and most participants said the material was not difficult to understand (61%) and did not contain words they were unfamiliar with (56%). However, when words in the printed materials were unfamiliar, fewer than half (42%) asked for an explanation.
- 87% of participants said they understood what their doctor said to them during their last visit and most (80%) participants who did not understand something their doctor said to them reported receiving an explanation.
- 79% of participants reported having ever looked for information on health or medical topics. The most common source of information was the Internet (87%) followed by a physician (15%).
- 48% had used the Internet to find health-related information in the past month.

Awareness of HIE and HIT

- 83% of participants had heard about electronic medical records.
- 65% of participants had heard about the electronic health information exchange.
- 50% of participants had heard of personal health records.
- 83% had never heard of the Connecticut Health Information Exchange.
- Demographic (education, gender) and individual characteristics (online experience, having a chronic health condition or a doctor with an EMR) were associated with increased awareness of HIE and HIT.

Attitudes toward HIE

- 72% supported a national HIE that was driven by patient consent.
- 57% reported that concern about privacy was the single most important barrier that was likely to get in the way of a national HIE.
- 64% expressed support for an “opt-in” and 21% supported “opt-out” consent model.

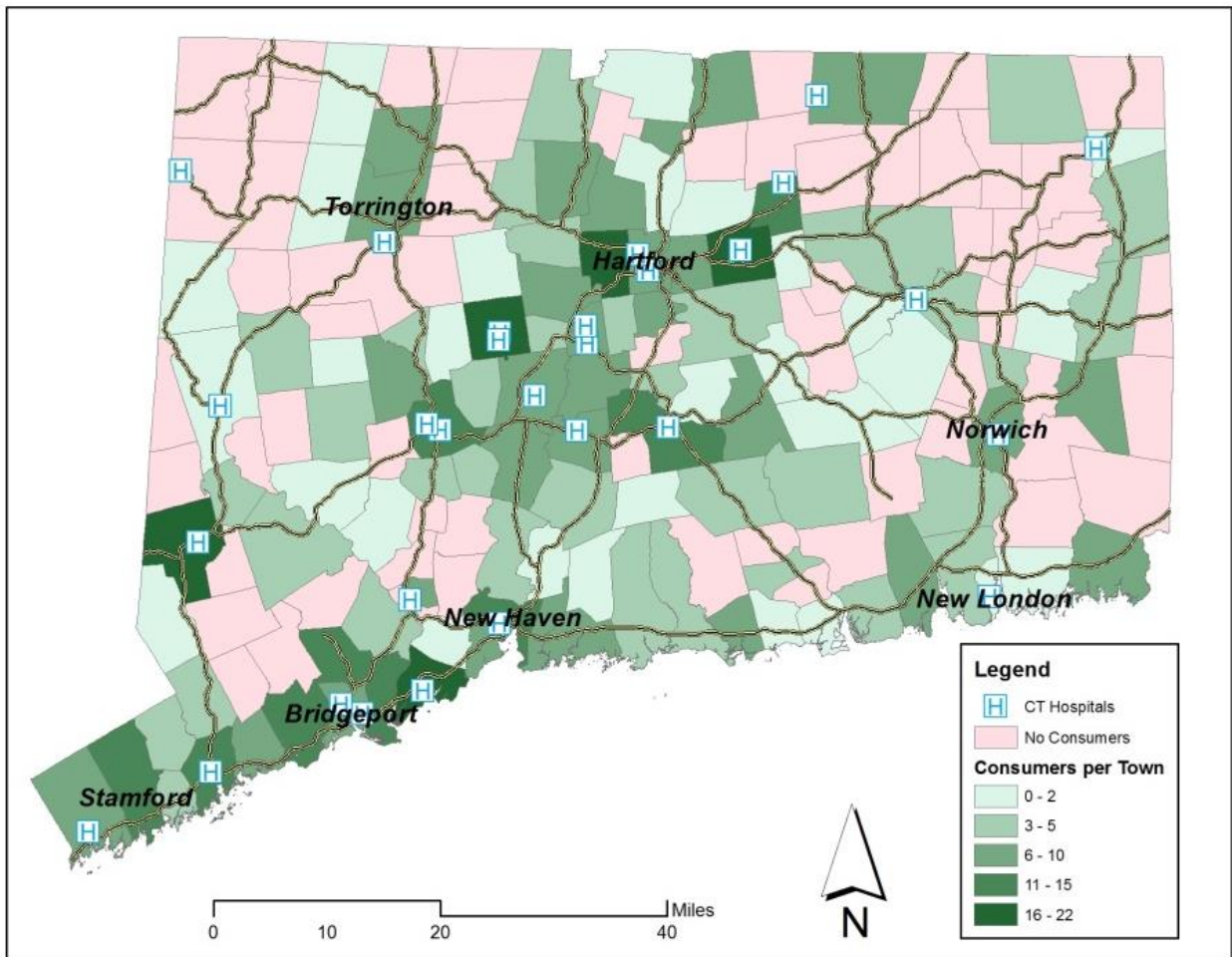
Perceived Benefits of HIT

- Most participants thought HIT adoption offered benefits in terms of:
 - better quality of care (73%),
 - better doctor-patient interaction (68%),
 - fewer medical errors (65%), and
 - reduction in duplicate tests and procedures (71%).
- 53% of participants reported an interest in having an electronic personal health record where they could manage their health information on a secure website.
- 57% of participants reported an interest in allowing their de-identified health information from their doctor’s EMRs to be shared with outside entities such as health insurance plans, researchers, and other companies.

- 47% of participants cited privacy concerns as the reason for their lack of interest in having access to an electronic personal health record and 74% cited privacy concerns as the reason for their lack of interest in allowing access to their de-identified health information.
- Participant trust in the organization in charge of collecting and maintaining their information (38%) and feeling that the organization had policies to safeguard their privacy (35%) were mentioned most frequently as factors that might persuade people to sign up for a PHR.
- 87% reported they would not intentionally withhold information from their doctor. However, if consumers thought their de-identified health information might be shared via their doctor's EMR, the proportion of consumers who said they were unsure if they would intentionally withhold information shifted from 3% to 9%, primarily due to privacy concerns.

Geographic Representation of Participants


All counties and a total of 109 towns were represented.




Introduction

Background

Substantial investments in developing and promoting health information technologies (HITs) such as physicians' electronic medical records (EMRs) and consumers' personal health records (PHRs) are being made by the U.S. government and health care industry with the expectation that HIT will improve the quality of health care and reduce medical costs.¹⁻³ A vital component of this strategy involves the electronic exchange of patients' health care information across health care providers and institutions.⁴ Health information exchange (HIE) has the potential to benefit health care providers⁵, public health departments⁶, and consumers⁷ by offering electronic access to clinical data collected and maintained in a variety of settings. Such access may improve the efficiency and quality of health care delivery⁵, reduce medical costs³ and empower patients to take a more active role in monitoring and managing their health.^{7,8}



Internet use among U.S. adults increased from 14% to 85% between 1995 and 2013.



In order for these expected gains to be realized, however, consumers need to be willing and able to participate in the system (a) by allowing their health care information to be collected and shared electronically⁹ and (b) by possessing the necessary technical skills and technology access to facilitate their use of HIT. *Consumer engagement* has been described as the “linchpin” of efforts to use HIT and HIE to address “the quality, safety, and efficiency problems that plague U.S. health care delivery.”¹⁰ A necessary first step to engaging consumers involves assessing their perspectives, knowledge, attitudes, interest in and reservations about technology in general, and HIT and HIE in particular. Understanding consumers' perspectives will help HIT and HIE supporters to identify areas for outreach and education and to highlight potential barriers to participation that should be considered when designing these systems. A 2008 report sponsored by the Robert Wood Johnson Foundation noted that, “[g]iven that the policy climate is demanding acceleration in EMR and PHR adoption and their potential impact on the delivery of health services, it is prudent to begin taking consistent and serious measure of what the public knows and does not know about these technologies.”¹¹

In the next section, we review recent literature on consumers' access to technology and the ways consumers use technology and the Internet. When available, we report national estimates for the general population of U.S. adults. When national data are not available, we turn to evidence from studies drawing on non-representative samples.

Consumers' use of technology

Computer and Internet use

Consumers' access to and comfort with using technology may promote or impede their ability to use electronic health information and influence their perceptions of the importance or benefits of health information exchange. Although a national telephone survey conducted by the Pew Research Center estimated that Internet use among U.S. adults increased from 14% to 85% between 1995 and 2013, 15% of adults still do not use the Internet.¹² Over a third of adults who reported no Internet use said the main reason was because the Internet was not relevant to

them (i.e., “just not interested,” “don’t need/don’t want it,” “too busy,” “think it is a waste of time”).¹² A starting point for engaging this group of consumers may involve learning more about how they might appreciate the utility of HIT and HIE to their personal health and well-being.

There appear to be no differences between whites, blacks, or Latinos in Internet use via mobile devices.

Previous research has suggested that, on average, computer use and online access are more common among adults who are younger, more educated, more affluent, and white.¹³⁻¹⁸ It is worth noting, however, that when it comes to mobile Internet use (e.g., via mobile phones, laptops, or tablet devices) there appear to be no differences between whites, blacks, or Latinos.^{19,20} Moreover, compared with white Americans, black and Latino Americans are more likely to access the Internet primarily via their mobile phones.²⁰ These results suggest that consumer engagement efforts must target multiple platforms (i.e., mobile and desktop) in order to include the broadest population.

There is also some evidence of variation in online access within subgroups. For example, although some surveys found that Latinos tended to report less access to the Internet than black or white Americans,²¹ Latinos who were less fluent in English, immigrants, older, had lower incomes and less education were not as likely to report Internet use when compared with Latinos who were more fluent in English, born in the U.S., younger, had higher incomes and higher levels of education.²¹⁻²³ Apart from the associations between Internet use and age, income, and education that also characterize the overall U.S. population, these findings highlight the need to consider variations in consumers’ English proficiency and literacy skills when designing HIT and HIE systems.²⁴

Using the Internet to search for, track, or store health information

In addition to assessing general use of computers and the Internet, some studies have specifically asked participants if they used the Internet to search for, track, or store health information. National estimates suggest that between a third²⁵ to more than half^{14,26} of U.S. adults turn to the Internet to find health information. Similar to the demographic characteristics associated with general use of computers and the Internet, online health information seekers tend to be female,²⁶⁻²⁸ younger,^{26,28} white,²⁶ more educated and more affluent.²⁶⁻²⁸

Although online health seeking may be gaining in popularity, managing personal health information electronically is still not commonplace. Recent national estimates for PHR use range from 2-20%, depending on when the survey was conducted and how electronic health information was defined by the researchers. A 2007 Kaiser Permanente survey reported that 12% of adults had used a health insurance company’s website to review personal medical information.²⁹ A similar estimate (14%) was obtained from the 2007 Health Information National Trend Survey (HINTS) administered by the National Cancer Institute.³⁰ Surveys commissioned by the Markle Foundation reported PHR use increased from 2% in 2003 to 3% in 2008 to 10% in 2010.³¹⁻³³ Gaylin and colleagues reported that 20% of U.S. adults in their 2009 survey said they had a PHR.³⁴ Seven percent of consumers said they had used a PHR to view,

National estimates for PHR use range from 2-20%.

store, or change their health information in a survey conducted between 12/18/09 through 1/15/10 by the California Health Foundation.¹ A Harris Poll fielded between 6/8/10 through 6/10/10 reported 7% of U.S. adults accessed their physician's EMR online and 8% had access to one, but didn't use it.³⁵ Almost 1 in 5 adults (19%) who used the Internet had gone online to track or store personal health information in the previous year, according to the 2011 HINTS.³⁶

Once again, demographic characteristics appear to differentiate consumers who used the Internet for these purposes. The 2008 Markle Foundation survey identified associations between having a PHR and being less healthy (e.g., frequent doctor visits, poor self-rated health, being disabled, or having a chronic health condition), being 33-40 years old, Hispanic, an Internet user, and earning an annual income over \$100,000.³¹ Results from the 2007 HINTS suggested consumers who were male, Hispanic, more educated, and had a regular health care provider were more likely to use the Internet to track personal health information.³⁰ A regional study found that, among patients whose physicians offered access to a PHR, blacks and Latinos, and patients with lower incomes were less likely to activate a PHR account.¹⁷

Summary

Although most Americans have access to the Internet through some form of technology (i.e., desktop or mobile devices) and many go online in search of health-related information, electronic use of PHRs or patient portals to EMRs is less prevalent.

In addition, when it comes to using the Internet for general or health-related purposes, there are clear differences in patterns of use associated with consumers' demographic characteristics. The "digital divide" in electronic access to and use of online health information has the potential to create new forms of health disparities or to worsen existing ones, as there is "growing empirical evidence linking increased access to health information via the Internet to overall improved health knowledge, better lifestyle choices, better compliance with physician recommendations and improved patient-provider communication during clinic visits."¹⁴ Conversely, leveling the playing field in terms of technology access and use may help to reduce health care inequalities.¹⁴ Engaging consumers in the use of HIT and HIE requires targeted efforts that are tailored to address the barriers to full participation that are unique to specific subgroups of consumers. Less frequent use of technology does not imply less interest, however. The next section presents results from surveys that assessed consumers' attitudes toward HIT and HIE.

Consumers' knowledge and attitudes regarding HIT and HIE

A number of national and regional surveys of consumers' knowledge, attitudes and preferences around HIT and HIE have been conducted during the past decade. Most studies have found consumers hold generally favorable attitudes toward HIT or HIE, although these favorable attitudes are tempered by concerns about the privacy and security of their health information.

Personal health records or patient portals

National estimates of consumers' awareness of or interest in PHRs have varied over time and by survey. Surveys commissioned by the Markle Foundation in 2006 and 2008 estimated that 47-65% of U.S. adults expressed interest in using a PHR.^{8,31} A 2008 Deloitte survey reported that 46% of U.S. adults would be interested in using a web site or computer software to create a PHR.³⁷ The California Health Foundation reported in 2010 that 40% of participants in their

national survey who had *not* used a PHR to view, store, or change their health information said they would be interested in doing so.¹ Gaylin and colleagues' random-digit-dial survey carried out from August to November 2009 found more than half (57%) of U.S. adults were familiar with PHRs and 68% were interested in using one.³⁴ Participants in the 2007 HINTS said it would be "very important" (47%) or "somewhat important" (33%) to access their medical information electronically.³⁰

Consumers with chronic or co-morbid health conditions^{33,38} and frequent health care users³³ were more likely to be interested in using PHRs, possibly because of the perceived value PHRs hold for sharing information and coordinating care among different medical providers. Findings relating age to PHR interest have been mixed, with some evidence suggesting that younger consumers report more interest^{8,30} while other evidence indicates middle-aged adults are more interested in using PHRs.³⁸ Similarly, evidence of gender differences has been inconsistent, with some authors reporting that females³⁸ show greater interest whereas others report males³⁹ are more likely to be interested in using PHRs. In addition, consumers who used the Internet frequently reported greater interest in PHR use.^{8,30,39} Consumers who had a regular health care provider and were Hispanic (compared with non-Hispanic white) were more likely to say it was "very important" to be able to access health information online, according to results from the 2007 HINTS.³⁰

Physicians' electronic medical record systems

Most Americans (77%) are familiar with EMRs and think they should play a role in office visits.³⁴ Although 91% of U.S. adults said consumers should have access to their physicians' EMR system⁴⁰ and more than three-quarters (78%) agreed that all their physicians should have access to their health information stored in an EMR, only 23%⁴⁰ to 28%³⁵ said their doctors had implemented such a system. An estimated 42%³⁵ to 56%¹ of consumers were not even sure if their physician used an EMR.

Electronically sharing health information

National estimates from 2012 indicate that many Americans rated electronic sharing of clinical information between their health care providers (64%) or having access to it themselves (70%) as "very important."⁴¹ Similarly, regional surveys administered in New York state reported that 67%³⁹ to 69%⁴² of participants favored allowing their medical information to be shared electronically among their doctors.

Participants in the 2007 HINTS who were older (45 years or older compared with adults ages 18-24), male, and who believed their health information was treated securely by their doctors were more likely to rate HIE among health care providers as important.³⁰

Broader information sharing was assessed by Dimitropoulos and colleagues, who reported that 90% of U.S. adults would allow at least some of their health care providers to share their health information, although 71% said they would be "somewhat" or "very" likely to request a list of recipients of that information.⁴³ The 2005 and 2010 Markle Foundation surveys estimated that 72% of U.S. adults supported the creation of a nationwide HIE for physicians and patients⁴⁴ and more than two-thirds (68%) were willing to share de-identified health information to detect disease outbreaks, bio-terror attacks, medical fraud, or for research aimed at improving health care quality.³² Consumers were less supportive when it came to sharing their health information

with commercial entities. Only 32% of participants in the 2009 California Health Foundation’s survey said they would feel comfortable allowing de-identified health information from their doctors’ EMRs to be shared with health insurance plans, researchers, or other companies.¹

These findings imply that consumers have different preferences regarding how, with whom, and for what purpose their health information might be shared.⁴⁵ It is possible that consumers’ attitudes toward HIE are more positive when they think sharing their health information will contribute to the public good. In contrast, consumers may be less willing to allow commercial or for-profit entities such as health insurance companies access to their health information due to concern about how that information may be used (e.g., to justify increases in health insurance premiums).

Consent model for sharing health information

Any framework for planning and implementing HIE must balance the clinical utility and potential benefits of data sharing against consumers’ preferences to have some control over access to their health information.¹⁰ National and regional surveys have shown clear support among consumers for a consent model in which consumers grant explicitly their permission to share their health information (known as the “opt-in” model),^{31,43,46,47} and several studies report that consumers prefer to grant access on a granular level (e.g., to specific providers or individuals) rather than across the board.^{31,43,46}

In November 2011, the Health Information Technology Exchange of Connecticut (HITE-CT) Board of Directors voted to adopt an “opt-out” consent model for HIE⁴⁸ in conjunction with the development of (a) “a robust educational plan...to ensure that all stakeholders are informed,” (b) “a strong framework for privacy, security and access that includes the workflow, audit trail, and access policies,” and (c) “a consumer’s Bill of Rights explaining what data will be in the exchange, where it will be located, and what it would be used for.”⁴⁹

Although national and regional surveys have shown clear support among consumers for an “opt-in” consent model, in November 2011, the HIT-CT BoD voted to adopt an “opt-out” consent model.

Specifically, the policy states that “PHI may flow from all participating providers for all of the providers’ patients, or for a subset of the provider patients as determined by the provider (to allow for a staged implementation) into the HITE-CT systems once notification is provided to the patient along with the option to opt out of the health information exchange.”⁵⁰

HIT and HIE benefits and barriers

As Table 1 shows, a number of surveys have queried consumers' perceptions of the benefits of PHRs, EMRs, and HIE. With the exception of a national consumer survey conducted in 2007 by Kaiser Permanente,²⁹ a plurality of U.S. adults believed that HIT and HIE offered a variety of benefits.

Table 1. Percent of consumers agreeing that HIT and HIE may confer the following benefits

	PHR	EMR	HIE
Improve quality/safety of care	71% ³⁴ ; 61% ⁵¹ ; 54% ³³	78% ³⁴ ; 66% ⁵²	79% ⁴³ ; 74% ⁴⁰ ; 68% ⁴² ; 19% ²⁹
Improve doctor-patient communication	86% ³¹ ; 66% ⁵¹		
Improve care coordination	86% ³¹		89% ⁴³
Empower patients	79% ³⁴ ; 68% ⁸ ; 68% ⁵¹	71% ³⁵	
Reduce errors	65% ³³		63% ⁴⁰ ; 15% ²⁹
Reduce costs	58% ³⁴	59% ³⁴	55% ⁴⁰ ; 24% ²⁹
Reduce redundant tests	88% ⁸ ; 86% ³¹		81% ⁴³

A small number of surveys explored consumer characteristics that were associated with perceptions of HIT or HIE benefits. Education,⁴² being under 40 years old,⁴² having a doctor who used an EMR,⁴² and greater comfort with technology³⁴ were positively associated with agreeing that EMRs or HIE would improve medical care quality.

Security and privacy concerns are the most often-mentioned barriers to consumers' acceptance of HIT and HIE. Among consumers who indicated they were not interested in using PHRs, 57% cited concerns about the privacy and confidentiality of their health information.³¹ When asked to elaborate, consumers reported they were worried about potential misuse, such as fraud or identity theft (80%), or that advertisers (77%), employers (56%), or health insurers (53%) would gain access to their personal information.⁸

- Consumers who used the health care system more often (i.e., those with chronic illnesses or frequent medical visits) were less concerned about PHR privacy and security³³ whereas consumers who were married, female, more educated, had higher incomes, with very good self-rated health or a major disability were more likely to worry about PHR privacy and security.³¹
- When it comes to EMRs, the majority of consumers report being "very" (48%³⁴ to 59%⁴³) or "somewhat" (23%⁴³) concerned about the privacy and security of their medical records. Half of U.S. adults believed that EMRs would have a detrimental effect on the privacy and security of their medical information.⁴²
- HIE elicits similar anxieties, with 75% of consumers indicating they were "very" (45%) or "somewhat" (30%) concerned about the security of HIE.⁴³ Nearly half (48%) of consumers believed that HIE would negatively affect the privacy and security of their medical information.⁴² As was the case with PHR concerns, consumers worried that HIE could result in fraud or identify theft (93%), exposure of personal information on the Internet (90%), unsolicited advertising (88%), or health-based discrimination (77%).⁴³
- Consumers who were between the ages of 40 and 64, who were employed full-time, or were members of ethnic or racial minority groups were more likely to express concern about HIE privacy and security.⁴³

Fears that their personal health information may be compromised by HIT or HIE have the potential to negatively affect the provider-patient relationship. For example, 12% of U.S. adults reported that they had withheld information from a health care provider because they were concerned about the privacy and security of their medical records.⁵³ When participants in the California Health Foundation survey were asked if they would withhold information from their doctor if he or she had an electronic medical record system that could share patients' de-identified health information with other organizations, 50% said no, 15% said yes, and 33% were not sure if they would do so.¹ Although the direct effect that withholding information from health care providers may have on an individual patient's health is clear, there is also the potential threat to the public's health and to the effectiveness of disease surveillance systems.⁵³

Given the prevalence of consumers' concerns, it is surprising and encouraging to note that between 60% to nearly 75% of consumers believe that the benefits of HIT and HIE outweigh the risks to privacy and security.^{29,40,43} This finding offers insight into the importance of winning consumers' confidence in HIT and HIE privacy and security protections as a first step toward gaining consumer confidence in these systems. In order for consumers to trust their personal health information to these systems, it is vital to create a forum in which their concerns regarding the collection, storage, and exchange of their electronic health information are given careful consideration and addressed in order to achieve widespread acceptance and participation.⁵⁴

Summary

Overall, consumers have shown enthusiasm for HIT and HIE, but remain cautious about the potential privacy and security breaches that these systems may entail. Nonetheless, when consumers balance the potential benefits of HIT and HIE against the risks of unintended or inappropriate disclosure of their personal health information, they appear to favor the possibilities that HIT and HIE offer for improving health care quality and empowering consumers to assume greater control over their own health and well-being.

In order to build upon this good will, HIT and HIE systems designers must remain aware of consumers' perspectives and keep in mind that consumers are critical to the success of efforts to use technology to improve the quality and efficiency of the U.S. health care system. The "buy-in" required from multiple competing interests - including consumers - represents a significant challenge to the adoption and implementation of statewide HIEs. Unless consumers are willing and able to participate in HIT and HIE, the expected gains to the health care system may never be realized fully despite billions of dollars in government investments.

The present study surveyed Connecticut consumers' perspectives on HIT and HIE as a way to assess their awareness of and readiness for these technologies, to learn how best to engage consumers in the state's efforts to develop an HIE, and to develop strategies to support consumers' HIT adoption.

Methodology

Study design

We conducted a cross-sectional survey of Connecticut residents' attitudes toward health information technology and exchange. English-speaking household members who were at least 18 years old were eligible to participate. The study was approved by the UCHC Institutional Review Board.

Survey instrument

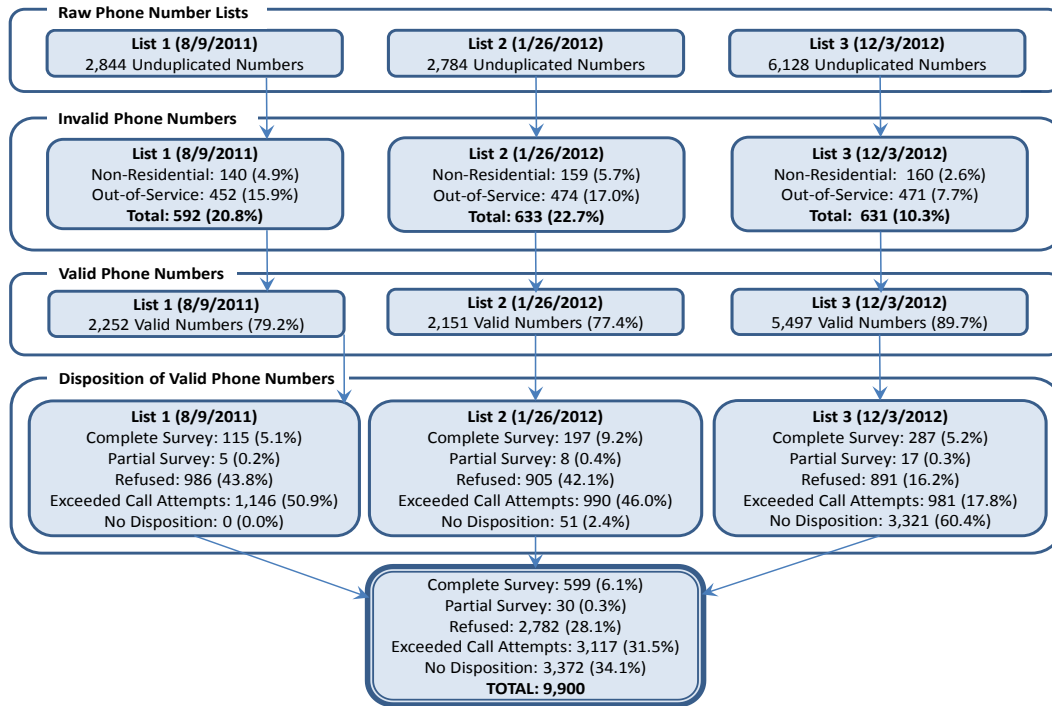
The survey was developed by the investigators and was informed by a systematic review of previous surveys on consumers and health information technology.^{1,31,32,44} Demographic and health status questions were drawn from items developed by the Centers for Disease Control and Prevention. Faculty from the Department of Community Health at St. Louis University provided guidance on measuring health literacy. The survey was pilot tested by students in a graduate class on survey research methods and was reviewed by faculty with extensive experience in conducting survey research. The University of Connecticut Health Center Institutional Review Board approved the final 32-item survey. Please see Appendix A for a copy of the survey instrument.

Survey administration

A random-digit-dial telephone survey restricted to household landline numbers was conducted by the University of Connecticut Health Center research team from August 10, 2011 through December 20, 2013. Trained interviewers contacted and screened potential participants and obtained verbal consent to conduct the survey using a standard script. In households where there was more than one adult, the protocol was designed to randomly sample household members by conducting the survey with the individual with the most recent birthday relative to the survey call date. However, due to survey staff turnover in 2012, this part of the protocol was not followed consistently. That is, some staff members would conduct the survey with the person who first answered the phone, regardless of whether or not they were the person with the most recent birthday in multi-adult households. This lapse was discovered in November 2013 and the protocol was reinstated. As a result, the sample should be considered a convenience sample rather than a random sample of Connecticut residents. Details regarding the survey protocol are found in Appendix B.

We obtained 11,756 unduplicated residential landline numbers from the Marketing Systems Group of Horsham, Pennsylvania (see Figure 1) and attempted to contact 8,384 households during the survey period. Of the 3,411 calls in which the interviewers spoke with a household member, 629 individuals completed (599) or partially completed (30) the survey and 2,782 individuals declined to participate in the survey. Using the formula developed by the American Association for Public Opinion Research,⁵⁵ the overall response rate was 6.4%.

Figure 1. Consumer survey phone number list disposition



Analytic sample

Survey data were collected using REDCap (Research Electronic Data Capture), a secure web-based application hosted at the University of Connecticut Health Center. Six hundred and eighty-three surveys were recorded in REDCap. We set aside 2 duplicate surveys, 51 surveys that were missing responses to all or most of the survey items, and 1 survey in which the interviewer discovered the participant was under age 18 when collecting demographic data at the conclusion of the survey. The analytic sample included the remaining 629 participants.

Analytic approach

Descriptive statistics were used to summarize the distributions of the survey variables. We identified factors associated with participants' attitudes toward HIT and HIE using chi-squared and Fisher's exact tests. Specifically, we investigated the following outcomes: (1) any online experience, (2) familiarity with HIE, EMRs, PHRs, or the Connecticut HIE, (3) support for a national HIE and privacy concerns (versus other concerns) as a perceived barrier to HIE, (4) preference for an "opt-in" or "opt-out" HIE consent model, (5) beliefs that HIT would improve the quality of medical care, the doctor-patient relationship, and reduce unnecessary tests or procedures or medical errors, (6) interest in using a PHR, and (7) interest in allowing de-identified health information to be shared electronically. Factors that were significantly associated ($p < .05$) with attitudes toward HIT and HIE in the bivariate analyses were then included in multivariable logistic regression models. Factors used in our models included demographic characteristics (sex, education), an indicator of any online experience, and health/health care characteristics (self-reported health, chronic health condition, health literacy, and an indicator of whether or not the participant's doctor had an EMR system). We used SAS 9.4 for all statistical analyses.

Results

Sample characteristics

Table 2 summarizes the characteristics of the 629 people who completed a survey. Nearly two-thirds (64%) of participants were female. Ages ranged from 18 to 92 and the median age was 59. Nearly a third (31%) of the sample was 65 or older. Most participants (79%) were white and more than half (57%) had a college degree or higher. The median household income was \$80,000; 20% reported a household income of \$100,000 or higher (although more than half of participants did not report their income).

Comparing the characteristics of the consumer survey sample to demographic information for Connecticut from the US Census Bureau,⁵⁶ we observed that the survey sample had a higher proportion of individuals who were women, older, better educated, and with a higher median income than the state population. Because 16% of the survey participants were missing information on race and 19% were missing information on ethnicity, we could not draw firm conclusions about whether or not the survey sample was similar to the state population in terms of its racial and ethnic composition.

Table 2. Demographic characteristics of the survey participants

	Sample (N=629)		CT Population (N=3,574,097)	
	N	%	N	%
Age				
18 - 34	28	4.4	648,275	18.1 ¹
35 - 44	66	10.5	484,438	13.5
45 - 54	125	19.9	575,597	16.1
55 - 64	134	21.3	443,452	12.4
65+	197	31.3	506,559	14.2
G	79	12.6		
Median	59		40	
Gender				
Female	404	64.2	1,834,483	51.3
Male	189	30.1	1,739,614	48.8
Missing	36	5.7		
Race				
White	497	79.0	2,772,410	77.6
Black	22	3.5	362,296	10.1
Other	12	1.9	439,391	12.3
Missing	98	15.6		
Ethnicity				
Non-Hispanic/Latino	495	78.7	3,095,010	86.6
Hispanic/Latino	12	1.9	479,087	13.4
Missing	122	19.4		
Education				

	Sample (N=629)		CT Population (N=3,574,097)	
< 9 th grade	2	0.3	109,649	4.5
Some high school	8	1.3	158,805	6.5
High school	99	15.7	677,253	27.9
Some college	100	15.9	429,013	17.6
College ²	211	33.6	671,728	27.6
Graduate school	153	24.3	384,892	15.8
Missing	56	8.9		
Income	N	%	N	%
< \$50,000	77	12.2		
\$50,000 - \$99,999	95	15.1		
>= \$100,000	125	19.9		
Missing	322	52.8		
Median	\$80,000		\$69,519	
¹ The American FactFinder table only displays age groups from 20-34.				
² Includes individuals earning Associate's and Bachelor's degrees.				

Current health, health care use and satisfaction with care

Respondents were asked several questions about their current health and physician visits to gain a sense of the extent to which they interacted with the health care system. As shown in Table 3, more than half (54%) of the participants described their health as excellent or very good. Around a third (34%) of participants said they had a chronic health condition. In terms of the frequency with which they visited a doctor or physician's assistant in the last 12 months, around a quarter of participants reported 1-2 or 3-4 visits and around a third reported more than 6 visits. Nearly 90% of participants were satisfied with the care they received from their doctor or physician's assistant.

When asked if their physician's office had implemented an electronic medical record system, nearly half (49%) of participants said yes, and a third were not sure.

Table 3. Current health, health care use and satisfaction with care (N=629)

	N	%
Health status		
Excellent	118	18.8
Very good	222	35.3
Good	166	26.4
Fair	61	9.7
Poor	12	1.9
Don't know	6	0.9
Missing	44	7.0
Diagnosed with chronic condition		
Yes	213	33.8

	N	%
No	371	59.0
Unsure	8	1.3
Missing	37	5.9
Doctor or PA visits in last year		
Did not see a doctor	25	4.0
1-2 times	148	23.5
3-4 times	157	25.0
More than 4 times	228	36.2
Missing	71	11.3
Satisfaction with health care		
Do not regularly visit a doctor	21	3.3
Very satisfied	408	64.9
Mostly satisfied	152	24.2
Neither satisfied nor dissatisfied	17	2.7
Slightly satisfied	20	3.2
Not at all satisfied	10	1.6
Missing	1	0.2
Doctor has implemented an electronic medical record		
Yes	308	49.0
No	78	12.4
Unsure	212	33.7
Missing	31	4.9

Health literacy

The Centers for Disease Control and Prevention define health literacy as “the capacity to obtain, process, and understand basic health information and services to make appropriate health decisions.”⁵⁷ A key requirement supporting health literacy is the availability of health-related information that patients can understand and use to make informed health care decisions. Table 4 shows that almost two-thirds (63%) of participants said they read the printed health-related information they received from their physician and most participants said the material was not difficult to understand (61%) and did not contain words they were unfamiliar with (56%). However, of the participants who reported some of the words in the printed materials were unfamiliar to them, fewer than half (42%) asked for an explanation. The majority (87%) of participants said they understood what their doctor said to them during their last visit. In contrast with responses to unfamiliar words in printed materials, most (80%) participants who did not understand something their doctor said to them reported receiving an explanation.

Table 4. Health literacy

The last time you received printed information from your doctor...	Sample (N=629)	
	N	%
How much of it did you read?		
A lot	273	43.4
Some	121	19.2
None	97	15.4
Don't remember; don't know	88	14.0
Missing	50	8.0
Was any of it hard to understand?		
Yes	65	10.3
No	385	61.2
Unsure	75	11.9
Missing	104	16.5
Were any words unfamiliar?		
Yes	98	15.6
No	351	55.8
Not sure	76	12.1
Missing	104	16.5
If you had trouble with some of the words, did you ask for help to understand the material?¹		
		Sample (N=98)
Yes	41	41.8
No	53	54.1
Not sure	3	3.1
Missing	1	1.0
Did your doctor use any words you did not understand during your last visit?		
		Sample (N=629)
Yes	45	7.2
No	544	86.5
Don't know	9	1.4
Missing	31	4.9
If you did not understand some words, did the doctor explain?²		
		Sample (N=45)
Yes	36	80.0
No	8	17.8
Not sure	1	2.2
¹ Only those participants who said they had trouble understanding some of the words in the printed material they received from their doctor's office answered this question.		
² Only those participants who said they had trouble understanding some of the words their doctor used during their last office visit answered this question.		

Sources of health or medical information

One way in which health care consumers take an active role in managing their health is by educating themselves with information obtained from their health care providers and other sources. The majority (79%) of participants reported having ever looked for information on health or medical topics, with the Internet being the most common source of information (Table 5).

Table 5. Sources of health or medical information

	Sample (N=629)	
	N	%
Ever looked for health or medical information		
Yes	496	78.8
No	100	15.9
Don't know	3	0.5
Missing	30	4.8
Most recent time, looked for medical information from...¹		
Sample (N=496)		
The Internet	432	87.1
Physician	74	14.9
Book	47	9.5
Magazine	36	7.3
Journal	30	6.1
Another doctor	23	4.6
Other	12	2.4
Friends or family ²	5	1.0
Pamphlets ²	5	1.0
Other health care provider ²	3	0.6
TV ²	2	0.4
¹ Only those participants who said they had ever looked for information about health or medical topics answered this question. Participants could select more than one information source.		
² These categories were derived from responses to the "Other" category.		

Experiences with information technology

Participants were asked about their use of the Internet to search for health-related information or use of online banking to assess their experience with electronic technology (Table 6). These questions provide a general sense of whether participants have the basic skills needed to use health information technology. Nearly half of participants had used the Internet to find health-related information in the past month (48%) or used online banking services (47%).

We created an indicator of "any online experience." If the participant reported ever looking for health-related information using the Internet (i.e., if they reported using the Internet the last time they looked for health-related information or had used the Internet in the past 30 days to find health related information) or had accessed banking information online in the past week, we set the indicator to "yes." Otherwise, the indicator was set to "no" or missing (if all three

questions were missing valid response values). The majority (77%) of participants reported ever having gone online.

College (OR=3.42) or graduate school education (OR=4.61) or having a doctor who used an EMR (OR=1.72) were positively associated with any online experience. Please see Appendix C, Table C 1 for detailed results from the logistic regression analysis.

Table 6. Experiences with information technology (N=629)

How often used Internet to find health-related information in past 30 days	N	%
None	287	45.6
1-5 times	233	37.0
6 or more times	68	10.8
Missing	41	6.5
How often accessed banking information online in past 7 days		
None	283	45.0
1-5 times	224	35.6
6 or more times	72	11.4
Missing	50	8.0
Any online experience		
Yes	485	77.1
No	144	22.9

Awareness of HIE and HIT

A key precursor to using health information technology or participating in health information exchange is an awareness of these concepts. Table 7 shows that most participants reported they had heard about electronic medical records (83%) and electronic health information exchange (65%). Half of participants had heard of personal health records. Most participants (83%) had never heard of the Connecticut Health Information Exchange.

Participants with college or graduate school education, who had a doctor who used an EMR, or who had online experience (i.e., Internet use or online banking use) had higher odds of being more familiar (i.e., “a lot” or “some” familiarity) with health information exchange (ORs=2.11, 5.26, 2.31, 2.50, respectively) and electronic medical records (ORs=2.54, 4.81, 3.88, 3.39, respectively). In addition, women had almost twice the odds of reporting “a lot” or “some” familiarity with electronic health records compared with men. Participants who had online experience (i.e., Internet use or online banking use) had higher odds of being more familiar with personal health records (OR=2.45). Familiarity with the Connecticut Health Information Exchange was positively associated with having a college (OR=2.85) or graduate school education (OR=3.02), having a doctor who used an EMR (OR=1.68), or having a chronic health condition (OR=1.79). Please see Appendix C, Table C 2 through Table C 5 for detailed results from the logistic regression analyses.

Table 7. Awareness of health information exchange and technology (N=629)

Have you heard about...	A lot		Some		Not at all		Unsure		Missing	
	N	%	N	%	N	%	N	%	N	%
Electronic health information exchange	173	27.5	234	37.2	203	32.3	15	2.4	4	0.6
Electronic medical records	274	43.6	250	39.8	94	14.9	7	1.1	4	0.6
Personal health records	129	20.5	188	29.9	297	47.2	10	1.6	5	0.8
The Connecticut Health Information Exchange	27	4.3	71	11.3	519	82.5	8	1.3	4	0.6

Attitudes toward health information exchange

When asked to imagine a nationwide health information exchange that was accessible to both patients and health care providers in which health information could be shared only with patients' consent, 72% of participants said they would favor such a system (Table 8). Online experience (i.e., Internet use or online banking use) (OR=1.95) and having a chronic health condition (OR=1.80) were positively associated with favoring a nationwide HIE. Please see Appendix C, Table C 6 for detailed results from the logistic regression analysis.

More than half (57%) of participants felt the most prominent barrier to achieving a nationwide HIE was privacy. Online experience (i.e., Internet use or online banking use) (OR=2.24) and not having a chronic health condition (OR=1.61) were positively associated with indicating privacy concerns (versus any other reason) represented the primary barrier to achieving a national HIE. Please see Appendix C, Table C 7 for detailed results from the logistic regression analysis.

This concern is related to the concept of "patient consent," the mechanism through which an HIE obtains permission to share patients' health information. Sixty-four percent of participants favored the "opt-in" model which requires them to explicitly grant permission to share their health information (i.e., information *is not* shared by default). Twenty-one percent of participants favored the "opt-out" model, which requires them to explicitly deny permission to share their health information (i.e., information *is* shared by default). Thirteen percent of participants did not know which HIE consent model they preferred.

Graduate school education level (OR=2.46), online experience (i.e., Internet use or online banking use) (OR=2.70) and being male (OR=1.78) were positively associated with favoring an "opt-in" consent model (compared with "opt-out" or "don't know"). Please see Appendix C, Table C 8 for detailed results from the logistic regression analysis.

Table 8. Perceptions of national health information exchange and consent model (N=629)

	N	%
Support for national HIE		
Strongly favor	99	15.7
Favor	351	55.8
Oppose	97	15.4
Strongly oppose	33	5.3
Missing	49	7.8
Barriers to achieve national HIE		
Privacy concerns	356	56.6
Cost	74	11.8
Don't know	71	11.3
Compatibility of multiple networks	34	5.4
Limited public support	29	4.6
Liability	21	3.3
None of the above	28	4.5
Missing	16	2.5
Consent model for HIE		
Opt-in	401	63.7
Opt-out	130	20.7
Don't know	80	12.7
Missing	18	2.9

Perceived benefits of health information technology and interest in sharing health information electronically

Most participants thought HIT adoption offered benefits in terms of better quality of care (73%), better doctor-patient interaction (68%), fewer medical errors (65%) and duplicate tests and procedures (71%) (Table 9).

Males (OR=1.85) and participants with chronic health conditions (OR=2.02) had higher odds of agreeing that health information technology adoption would improve quality of care. There were no characteristics associated with the odds of agreeing that health information technology adoption would improve doctor-patient interactions or help to reduce medical errors or unnecessary tests or procedures. Please see Appendix C, Table C 9 through Table C 12 for detailed results from the logistic regression analyses.

Table 9. Benefits of health information technology adoption (N=629)

	Agree		Neutral		Disagree		Missing	
	N	%	N	%	N	%	N	%
Improve quality of care	456	72.5	94	14.9	54	8.6	25	4.0
Improve doctor-patient interaction	427	67.9	95	15.1	81	12.9	26	4.1
Reduce medical errors	407	64.7	107	17.0	85	13.5	30	4.8
Reduce repeated tests and procedures	447	71.1	71	11.3	81	12.9	30	4.8

Opinions were more divided when it came to personal use of health information technology (Table 10). A little more than half of participants reported an interest in having an electronic personal health record where they could manage their health information on a secure website (53%) or in allowing their de-identified health information from their doctor’s electronic health record system to be shared with outside entities such as health insurance plans, researchers, and other companies (57%).

Online experience (i.e., Internet use or online banking use) was positively associated with interest in having a personal health record (OR=4.57) or allowing their health information to be shared (OR=2.27). Please see Appendix C, Table C 13 and Table C 14 for detailed results from the logistic regression analyses.

Table 10. Interest in accessing and sharing health information electronically (N=629)

How interested would you be in...	Having access to an electronic personal health record		Giving permission to share de-identified health related information electronically	
	N	%	N	%
Very interested	143	22.7	151	24.0
Somewhat interested	190	30.2	216	34.3
Not very interested	135	21.5	95	15.1
Not at all interested	156	24.8	150	23.9
Missing	5	0.8	17	2.7

As summarized in Table 11, participants who were not interested in having access to an electronic personal health record or allowing access to their de-identified health information most often cited privacy concerns as the reason for their lack of interest (47% and 74%, respectively). When it came to sharing their de-identified health information, 10 of the 24 participants who answered “Other” expressed concerns about how insurance companies might use their health information. The general belief was that any data sharing would be to the benefit of the insurance companies (e.g., to limit coverage, or to increase insurance premiums or corporate profits) rather than the consumers.

Table 11. Barriers to accessing and sharing health information electronically

Reasons you would not be interested in...	Having access to an electronic personal health record ¹ (N=291)		Giving permission to share de-identified health related information electronically ¹ (N=245)	
	N	% ²	N	% ²
Concerned about privacy	137	47.1	181	73.9
Don’t feel it’s necessary	77	26.5	32	13.1
Unfamiliar with technology	34	11.7	12	4.9
No Internet access	41	14.1	2	0.8
Too much responsibility	14	4.8	2	0.8
Might cost too much	4	1.4	5	2.0
Don’t know	10	3.4	9	3.7
Other	19	6.5	24	9.8

¹Only the participants who said they were “not very interested” or “not at all interested” in having access to a PHR or allowing their de-identified health information to be shared electronically answered these questions.

²Total percentage may exceed 100 because participants could select more than one reason.

Participants were asked what might persuade them to sign up for an electronic personal health record (Table 12). In line with their concerns expressed in previous questions, feeling that they could trust the organization in charge of collecting and maintaining their information (38%) and feeling that the organization had policies to safeguard their privacy (35%) emerged as the most frequently mentioned factors.

Table 12. Factors that would encourage consumers to sign up for an electronic personal health record (N=629)

	N	% ¹
Trust in organization	240	38.2
Safeguards (privacy policies)	219	34.8
Not interested ²	26	4.1
Having centralized access to health information ²	24	3.8
Popularity with family and friends	19	3.0
Improved quality of care ²	8	1.3
Already have a personal health record ²	7	1.1
Cost to the individual ²	4	0.6
Reduced medical costs ²	3	0.5
Insurance company mandate ²	2	0.3
Already interested in having a personal health record ²	1	0.2
Ease of use ²	1	0.2
Don't know	125	19.9
Other	17	2.7

¹Total percentage may exceed 100 because participants could select more than one answer.
²These categories were derived from responses to the "Other" category.

Most participants (88%) reported they would not intentionally withhold information from their doctor (Table 13). However, when asked if they would do so if there was the potential for their de-identified health information to be shared via their doctor's electronic health record system, the percentage of participants who said they were unsure shifted from 3% to 9%. Once again, privacy concerns emerged as the most prevalent reason participants chose to explain why they would withhold information from their doctor if the potential for that information being shared electronically existed (88%).

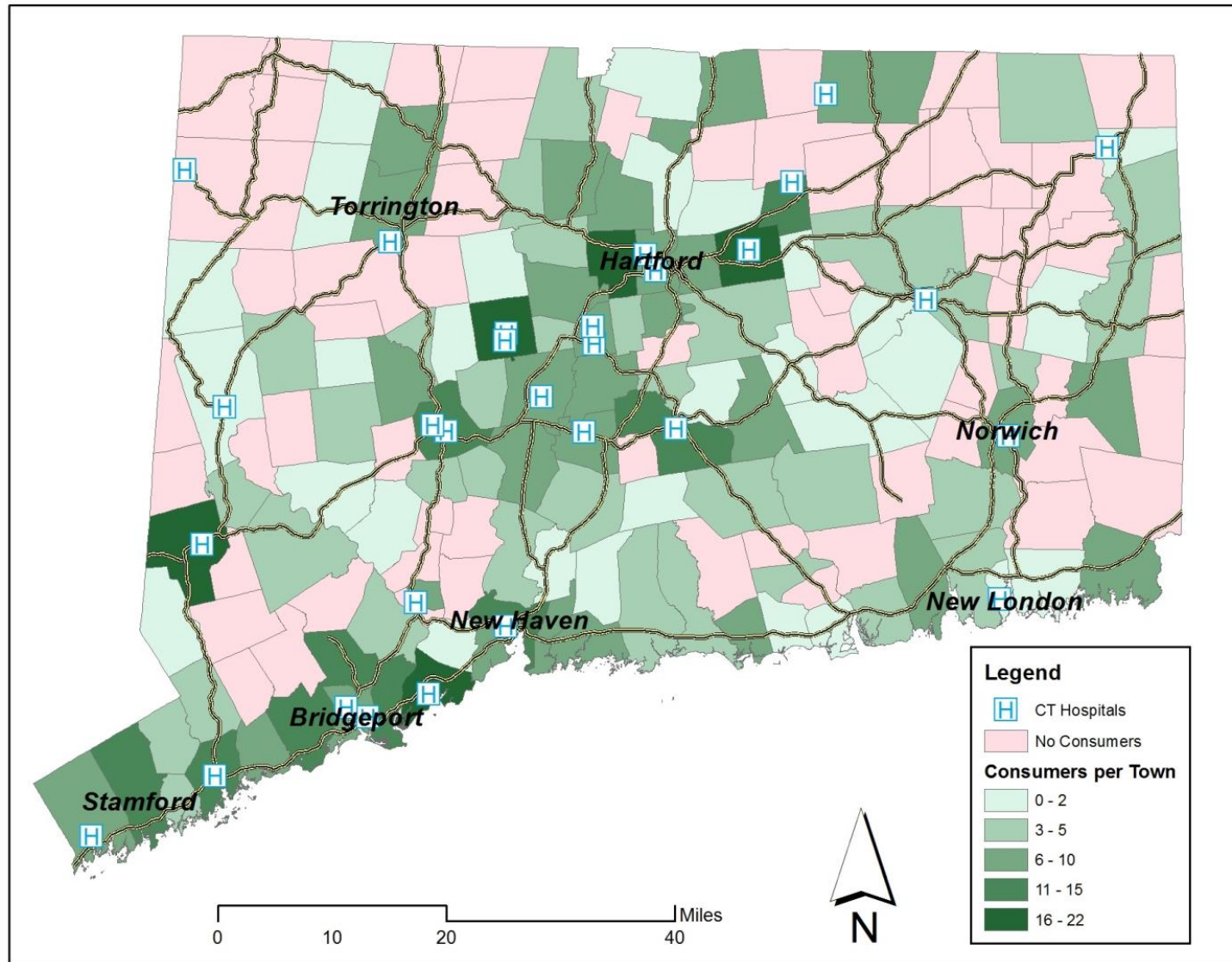
Table 13. Sharing health information with doctor

	Yes		No		Not Sure		Missing	
	N	%	N	%	N	%	N	%
Would you ever purposely withhold information from your doctor?	50	8.0	551	87.6	19	3.0	9	1.4
Would you purposely withhold information from your doctor if your doctor had an electronic health record that would allow him or her to share your de-identified health information?	56	8.9	499	79.3	55	8.7	19	3.0
Reasons to withhold information from doctor if you knew it could be shared electronically ¹					Sample (N=56)			
					N	%		
Privacy reasons					49	87.5		
Emotional reasons					5	8.9		
Other reason					5	8.9		
Concerned how insurance company will use information ²					2	3.6		
Don't know					1	1.8		
¹ Only participants who said they would withhold information from their doctor if the doctor had an EHR that would permit sharing de-identified information answered this question. More than one reason could be selected.								
² This category was derived from responses to the "Other" category.								

Location of consumers by town

We evaluated the geographic representation of the analytic sample using respondents' self-reported zip code. The respondents represented 109 of Connecticut's 169 towns. The number of respondents per town ranged from 0 to 22. Manchester and West Hartford each had 22 respondents followed by 17 in Bristol and 16 in Danbury. Sixty towns had no respondents. Towns without respondents were outside of the urban regions of Hartford, New Haven and the I-95 corridor. Map 1 on the following page shows the respondent counts by towns.

Map 1. Survey Responses by Towns in Connecticut



Discussion

Summary of descriptive results

This study documented that Connecticut consumers are well aware of HIT and HIE. Eight out of ten participants had heard about EMRs, nearly two-thirds had heard about HIE and half had heard about PHRs. In contrast, eight out of ten participants had never heard of the Connecticut HIE. Although national estimates of HIE familiarity are lacking, national estimates of familiarity with EMRs and PHRs are consistent with our results. The finding that participants were generally unaware of the Connecticut HIE points to the need for increased efforts to promote the state's activities in this domain but mostly is an accurate reflection of its non-operational status.

8 out of 10 had heard about EMRs
2 out of 3 had heard about HIE
1 in 2 had heard about PHRs
8 out of 10 had never heard of the Connecticut HIE.

Our results also described widespread support for HIE and broad recognition of the potential benefits HIT and HIE offer. Nearly three-quarters of participants favored the creation of a nationwide HIE that was accessible to both doctors and patients. Two-thirds to nearly three-quarters of participants believed that HIT could improve health care quality and doctor-patient interaction and reduce medical errors and unnecessary tests. Once again, our results are in line with estimates from national surveys and suggest that these favorable attitudes may serve as a springboard for engaging consumers in the state's HIT and HIE initiatives.

However, there appears to be a gap between support for HIT and HIE *in theory* and interest in actually *using* these technologies. A little more than half of participants were "very" or "somewhat" interested in signing up for a PHR or allowing their de-identified health information from their doctor's EMR to be shared with health insurance plans, researchers, or other companies. Comparable national estimates of interest in PHRs range from 40% to 68%. Contrasted with the results from the California Health Foundation survey (which was the source for our survey's question regarding interest in HIE), which revealed 32% of Americans indicated an interest in HIE, Connecticut's results (57%) were more favorable. It is possible that more participants might have expressed an interest in HIE if the question had not referenced health insurance companies as potential recipients of de-identified health information. A small number of participants voiced strong reservations about sharing their health information out of fear that insurance companies would use that information to limit coverage or increase health insurance premiums. These results suggest that more work needs to be done to win consumers' trust and to negotiate how and with whom consumers' health information will be shared. Previous research has found that consumers show greater willingness to share their de-identified health information for research or public health purposes and to improve health care quality and efficiency.³² Unfortunately, our survey question did not differentiate between sharing health information with public

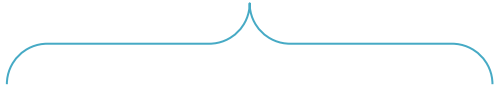
Two-thirds to nearly three-quarters of participants believed that HIT could improve health care quality and doctor-patient interaction and reduce medical errors and unnecessary tests.

versus private or commercial entities. Yet, given the national findings, Connecticut might win greater public support for HIE if consumers were given the option to specify the recipients of their health information.


Notably, a significant minority of participants in our survey simply did not feel that PHRs (27%) or HIE (13%) were necessary, despite the fact that they were just as likely as other participants to recognize the aforementioned benefits of HIT adoption. Education and outreach efforts aimed at these consumers need to address the potential benefits of HIT and HIE in ways that are meaningful to them personally. Additionally, future efforts need to better understand the needs of this group as well as gain an in-depth understanding of the context of their responses.

As was reported in several national and regional surveys, concern about the privacy and security of their health information was the most prevalent reason participants offered for their lack of interest in participating in HIT or HIE. This concern was echoed in responses to the question asking participants to identify the primary factor that would encourage them to sign up for a PHR. More than a third of participants indicated that trust in the organization or physician hosting the PHR (38%) or safeguards and privacy policies (35%) were most important.

Consent to participate in HIE is a contentious issue that requires balancing consumers' desire to exercise control over their personal health information and the (sometimes competing) interests that clinicians, public health departments, researchers, and others have in using that information for their own purposes. In line with previous studies,^{31,43,46,47} nearly two-thirds (64%) of participants in this study favored an "opt-in" consent model, which stipulates that their health information may not be shared without their permission. Yet this finding is not necessarily a reason for health care providers and other organizations eager to gain access to patients' health information to feel discouraged. As Zaghi noted, "[e]xperience in the Massachusetts pilot program and other state-level exchanges demonstrate that opt-in models can yield high consumer participation rates, but requires a lot of awareness, trust building and education for the community."⁵⁸ We did not ask participants to elaborate on their consent preferences, however, there is evidence suggesting that some consumers prefer to grant access to their health information on a granular level^{31,43,46} as opposed to providing "blanket" consent to unknown recipients. This finding may have implications for the current "opt-out" consent policy which has been adopted by HITE-CT. Given that we do not have an operational HIE, there still may be time to revise the decision on the consent model so that it reflects consumers' various preferences alongside those of other interested parties' and will no doubt require negotiation and compromise in order for HIE to succeed.



More than a third of participants indicated that trust in the organization or physician hosting the PHR (38%) or safeguards and privacy policies (35%) were primary factors that would encourage them to sign up for a PHR.



Moreover, the HIE consent model that Connecticut selects has implications that extend beyond the design of the state HIE system and efforts to promote consumers' participation. Nine percent of the participants in this survey indicated they would withhold information from their

doctor if there was a possibility that their health information might be shared with other parties, and their primary reason for doing so was out of concern for the privacy and security of their medical information. National estimates revealed that 12%⁵³ of Americans admitted to withholding information from their health care provider for that very reason and 15%¹ said they would consider doing so if they thought their doctor's EMR system might exchange their de-identified health information with other organizations. These findings need to be given careful consideration because, irrespective of the HIE consent model Connecticut implements, some consumers may decide privately to "opt-out" of information sharing by withholding information from their physicians. Such behavior may compromise individual and public health and introduce the potential for selection bias in research findings if those consumers who withhold information differ in systematic ways from those who do not.

Consumer characteristics associated with attitudes toward HIT and HIE

Online experience (i.e., Internet use or online banking activities) was the most robust predictor of familiarity with, support for, and interest in HIT and HIE. Although this is not a surprising finding and is consistent with previous research, it points to the need to engage the minority (23%) of participants in this survey who said they had not used the Internet to search for health-related information or to conduct online banking. Although our indicator of online experience may have failed to detect participants who had used the Internet for *other* purposes (i.e., we did not have a question that asked participants "Have you ever used the Internet?"), the most recent national estimates suggest that 15% of U.S. adults still do not use the Internet.¹² Because consumers' reasons for not using the Internet vary (e.g., lack of access, lack of interest), it is important to investigate consumers' barriers to Internet use and to devise strategies for overcoming them.

College or graduate school education levels and having a doctor who has implemented an EMR system were also positively associated with greater familiarity with HIE and EMRs. These results suggest the need to focus HIT and HIE education efforts on consumers with less education and also highlight the potential for physicians to participate in "HIE outreach" by implementing EMRs in their practices and discussing EMR uses and benefits with patients. Specifically, education and outreach efforts will have to use multiple approaches rather than relying on the traditional print media alone.

Participants who were male, reported graduate school education levels or who had online experience (i.e., Internet use or online banking activities) had higher odds of favoring an "opt-in" consent model for HIE compared with participants who were female, had high school or lower education levels or no online experience. We did not probe for reasons *why* participants selected a particular consent model, but it is worth noting that 13% of survey participants did not know *which* consent model they preferred. Although consumers may be familiar with the concept of "opting-out" or "opting-in" through experience with mandatory notification about information sharing from their financial institutions, it is vital that Connecticut's HIE education and outreach efforts describe clearly the implications of the model that is selected to ensure consumers are providing *informed* consent rather than consent based on insufficient or inaccurate knowledge.

Participants who had ever been diagnosed with a chronic health condition had higher odds of supporting the creation of a national HIE and of believing that HIE would improve health care quality. They were also less inclined to see privacy as a barrier to creating a nationwide HIE. It is possible that consumers with chronic health conditions are more enthusiastic about HIE because their frequent encounters with the health care system have underscored for them the importance of sharing health information between multiple providers to improve care coordination. With much to gain from HIE, consumers with chronic health conditions may agree with the national estimates that suggest the plurality of consumers believe the benefits of HIE outweigh the potential risks to privacy and security.^{29,40,43}

Limitations

There are several limitations to this study that bear mentioning. Although we used a random-digit-dial survey approach to minimize selection bias, our calling lists did not include mobile phone number and, as a result, our findings may not generalize to consumers who do not reside in households with a landline. In addition, the unintended change to the survey screening protocol that occurred in tandem with staff turnover in 2012 (and which was not discovered until the final two months of the survey) resulted in a sample that was older, more educated, wealthier, and with a higher proportion of women and white participants than is characteristic of Connecticut's general population. Because age, education, income, race-ethnicity and gender have been associated in some previous research with HIT and HIE attitudes and acceptance, the non-representative nature of our sample further limits our ability to generalize these results.

We were unable to investigate associations between the HIT and HIE outcomes and age or race-ethnicity that have been reported elsewhere due to missing data (i.e., 13% of participants were missing information on age, 16% were missing information on race, and 19% were missing information on ethnicity) and the lack of race-ethnicity variation in this sample (i.e., 79% of participants were white and non-Hispanic). One method for addressing the problem of missing data is *multiple imputation*,⁵⁹ which replaces missing data with a set of statistically-generated plausible values. We plan to investigate this option to analyze the age data in the near future.

Conclusion

This was the first survey of Connecticut consumers dedicated to examining their preferences regarding HIT and HIE. We found that many consumers were aware of and interested in HIT and HIE along with their potential for improving health care delivery, but they maintain reservations related to the privacy and security of their personal health information. We identified specific topics and target populations for education and outreach efforts aimed at motivating consumers' adoption of HIT and HIE and we discussed the limitations of our sample. Despite the limitations noted, our results were consistent with those reported by national and regional surveys, and contributed new information on consumer characteristics that were associated with HIT and HIE familiarity and support.

We noted that *consumer engagement* will play a critical role in the adoption of HIT and HIE and in their potential to generate lasting improvements the U.S. health care system.¹⁰ However, the "buy-in" required from multiple competing interests – including consumers – represents a significant challenge to the adoption and implementation of statewide HIEs. Unless consumers

are willing and able to participate in HIT and HIE, the expected gains to the health care system may never be realized fully despite billions of dollars in government investments.

Understanding consumers' viewpoints, then, is key to winning the public support that is necessary to ensure an HIE that is sustainable.

The Health Information Technology for Economic and Clinical Health (HITECH) Act aims to "improve health care and make it patient-centric through the creation of a secure, interoperable nationwide information network. A key premise is that information should follow the patient, and artificial obstacles - technical, bureaucratic, or business related - should not be a barrier to the seamless exchange of information."⁶⁰ The estimates of Connecticut consumers' perspectives on HIT and HIE that we have described in this study offer meaningful information to state policy makers and stakeholders as they engage in strategic planning for these technologies, and will help to ensure that the HITECH Act's overarching goal of facilitating the availability of health information in support of a connected and seamless health care delivery system with improved treatment outcomes is achieved.

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Appendix A

Survey Instrument

CONSUMER HEALTH INFORMATICS SURVEY

Instructions appear in [UPPERCASE LETTERS ENCLOSED IN BRACKETS].

Text to be read aloud to participants appears in **bold, lowercase letters**

Text that is underlined should be emphasized.

[THE FOLLOWING INTRODUCTORY INFORMATION WILL BE READ ALOUD TO INDIVIDUAL RESPONDENTS].

Hello, my name is _____ calling on behalf of the University of Connecticut Health Center. We are doing a survey about how health information technology such as electronic medical records affects health care consumers. Your responses will be used to better understand how individuals feel about the benefits and challenges associated with health IT. We are not trying to sell you anything. Your phone number has been chosen at random for this study.

I will not ask for your name, address, or other personal information that can identify you. I will, however, ask you for your zip code during the survey to correlate geographic information with your responses. You may refuse to give us your zip code if you so desire.

With your permission, I will record your phone number with your responses, so that we can contact you in the future for a follow-up survey. If you indicate that you would not like to participate in a follow-up survey, we will *not* record your phone number.

This survey is voluntary and will take about seven minutes to complete. You can refuse to participate or withdraw from the survey at any time. You can refuse to answer any question for any reason. The results of the survey will be publicly available when the study is complete; however, data will be reported in an aggregate form only. Your personal responses to questions will not be shared.

[IF THE RESPONDENT ASKS ANY OF THE FOLLOWING FREQUENTLY ASKED QUESTIONS, PLEASE PROVIDE THEM WITH THE APPROPRIATE RESPONSES:]

1. Why are you doing this study?

This study is part of a larger effort to assess awareness of and readiness for health information technology. Other individuals and groups that will be surveyed as part of this study include physicians, laboratories, and pharmacies. The information that is collected will give investigators a better understanding of how tools such as the electronic health record (EHR), the personal health record (PHR),

and health information exchange (HIE) can serve as both a benefit and challenge within the current health care arena.

2. Who is funding this?

This project is currently being funded by the Connecticut Department of Public Health. This particular project, though funded by the CT Department of Public Health, is being carried out by the University of Connecticut Health Center.

3. How are the results going to be used?

The results will be used in reports that are published by the University of Connecticut Health Center and given to the Connecticut Department of Public Health. Some results may be used in subsequent publications that are submitted to academic journals; however, all information provided will remain confidential. Results of the survey will be aggregated so that at no point will individual data be published or distributed.

4. How was I selected?

This study relied upon random-digit-dialing, a telephone survey strategy that gives all households with a telephone an equal chance of being selected to participate. As an individual with telephone access, you and your household became eligible to be in the sample. The selection of your phone number was completely random.

5. Where can I obtain more information?

We do have a 1-800 number that you can call to ask any additional questions you may have or to speak with someone further about the study. The 1-800 number is: 1-800-xxx-xxxx.

How many individuals in this household are 18 years or older?

[IF NONE, DISCONTINUE THE SURVEY].

[IF MORE THAN ONE INDIVIDUAL IS OLDER THAN 18 YEARS OF AGE IN THE HOUSEHOLD, ASK THE FOLLOWING QUESTION]:

Of the individuals who are 18 years or older, may we continue the survey with the person who had the most recent birthday?

[IF THAT PERSON IS UNAVAILABLE, ATTEMPT TO RESCHEDULE THE SURVEY. IF THE PERSON WITH THE MOST RECENT BIRTHDAY IS EXPECTED TO BE UNAVAILABLE FOR A LONG PERIOD OF TIME (LONGER THAN ONE MONTH), ATTEMPT TO COMPLETE THE SURVEY WITH THE INDIVIDUAL WITH THE NEXT MOST RECENT BIRTHDAY. IF THE PERSON WITH MOST RECENT BIRTHDAY IS EITHER THE CURRENT SPEAKER OR IS WILLING TO COME TO THE PHONE, CONTINUE WITH THE FOLLOWING QUESTION].

Are you willing to participate in this survey?

[IF RESPONDENT CHOOSES NOT TO PARTICIPATE, END THE SURVEY HERE].

Thank you very much for your time.

[IF RESPONDENT AGREES TO PARTICIPATE IN THE SURVEY, CONTINUE WITH THE FOLLOWING SECTIONS.]

---Pre-Survey Questions---

[EACH QUESTION SHOULD BE READ IN ITS ENTIRETY TO THE PARTICIPANT AND THE RESPONSE SHOULD BE RECORDED ACCORDING TO THE RESPONDENTS ANSWER.]

Qpre-a. What are the number of landlines which ring in your household and you might pick up? _____

Qpre-b. What are the number of cell phones used by the household? _____

Qpre-c. Is this a landline or a cell phone number? _____

[IF RESPONDENT ANSWERS CELL PHONE, PLEASE CONTINUE WITH THE FOLLOWING QUESTIONS. IF RESPONDENT ANSWERS THAT IT IS A LANDLINE, CONTINUE WITH QUESTION 1 OF THE SURVEY].

Qpre-D. Would you like to continue the survey on a cell phone or would you prefer to continue the call at a later date using a landline ? _____

[IF RESPONDENT WOULD NOT LIKE TO COMPLETE THE SURVEY USING A CELL PHONE, ATTEMPT TO RESCHEDULE THE CALL AT A LATER TIME OR USING A DIFFERENT NUMBER. IF RESPONDENT PREFERS TO USE THE CELL PHONE, PROCEED TO QUESTION 1].

---BEGIN SURVEY---

Q1. What is the ID Number?

_____ **[ENTER ID NUMBER].**

Q1a. Currently, if you regularly visit a primary care physician, how satisfied are you with the care you receive: very satisfied, mostly satisfied, neither satisfied nor unsatisfied, slightly satisfied, not at all satisfied?

1. Very satisfied
2. Mostly satisfied
3. Neither satisfied nor unsatisfied
4. Slightly satisfied
5. Not at all satisfied
6. Do not regularly visit (N/A)

Q2. Approximately how many doctors, including any individual with a medical degree, do you visit in one calendar year?

Q3. Have you heard a lot, some, or not at all about each of these new technologies in health care:

Q3a. Electronic health information exchange, where health information is shared electronically across organizations (a lot, some, not at all, or unsure)?

1. A lot
2. Some
3. Not at all
4. Unsure

Q3b. Electronic medical records, where physicians store patient health information (a lot, some, not at all, or unsure)?

1. A lot
2. Some
3. Not at all
4. Unsure

Q3c. Web sites or personal health records where people can get, keep, and update health information (a lot, some, not at all, or unsure)?

1. A lot
2. Some
3. Not at all
4. Unsure

Q3d. The Connecticut Health Information Technology and Exchange (a lot, some, not at all, or unsure)?

1. A lot
2. Some
3. Not at all
4. Unsure

Q4. Some health care institutions invite individuals to join services that provide free online electronic personal health record access. Through such a service, you could view and update your health information on a secure web site. How interested would you be in using this type of website: very interested, somewhat interested, not very interested, or not at all interested?

1. Very interested
2. Somewhat interested
3. Not very interested
4. Not at all interested

[IF RESPONDENT SELECTS NOT VERY INTERESTED OR NOT AT ALL INTERESTED, CONTINUE TO QUESTION 4A. IF RESPONDENT SELECTS VERY INTERESTED OR SOMEWHAT INTERESTED, CONTINUE TO QUESTION 5.]

Q4a. What is the main reason you are uninterested in using a personal health record?[CHECK ALL ANSWERS AS THEY APPLY TO RESPONDENT OPINIONS]. .

-
1. Concerned about privacy
 2. Unfamiliar with technology
 3. No internet access
 4. Don't feel it's necessary
 5. Too much responsibility
 6. Might cost too much
 7. Don't know
 8. Other [SEE 4B]

Q4b. [IF RESPONDENT PROVIDES RESPONSES NOT SIMILAR TO ABOVE, PLEASE DESCRIBE THEM HERE]:

Q4c. Of the answers you provided, which do you feel is most important? [THIS QUESTION SHOULD ONLY BE ASKED IF RESPONDENT PROVIDED MORE THAN ONE ANSWER TO QUESTION 4A].

Q5. If your doctor had an EHR, or an electronic health record system, your information might be shared with health insurance plans, researchers and other companies. This information would be about your health but would not contain private information like your name or date of birth. How interested would you be in allowing your health information to be shared: very interested, somewhat interested, not very interested, or not at all interested?

-
1. Very interested

2. Somewhat interested
3. Not very interested
4. Not at all interested

[IF RESPONDENT SELECTS NOT VERY INTERESTED OR NOT AT ALL INTERESTED, CONTINUE TO QUESTION 5A. IF RESPONDENT SELECTS VERY INTERESTED OR SOMEWHAT INTERESTED, CONTINUE TO QUESTION 6.]

Q5a. What is the main reason you are uninterested in sharing data in an electronic medical record? [CHECK ALL ANSWERS AS THEY APPLY TO RESPONDENT OPINIONS].

1. Concerned about privacy
2. Unfamiliar with technology
3. Don't feel it's necessary
4. Too much responsibility
5. Might cost too much
6. Don't know
7. Other [SEE 5B]

Q5b. [IF RESPONDENT PROVIDES RESPONSES NOT SIMILAR TO ABOVE, PLEASE DESCRIBE THEM HERE; OTHERWISE, LEAVE BLANK]:

Q5c. Of the answers you provided, which do you feel is most important? [THIS QUESTION SHOULD ONLY BE ASKED IF RESPONDENT PROVIDED MORE THAN ONE ANSWER TO QUESTION 5A; OTHERWISE, LEAVE BLANK].

Q6. Would you ever purposely withhold information from your doctor: yes, no, or not sure?

1. Yes
2. No
3. Not sure
4. No answer given

Q7. If your doctor had an EHR that would allow them to share your health information (but not your name, date of birth, address, or Social Security number), would there be anything that you would not tell your doctor: yes, no, or not sure?

1. Yes
2. No
3. Not sure
4. No answer given

[IF RESPONDENT SELECTS YES, CONTINUE TO QUESTION 7A. IF RESPONDENT SELECTS NO OR NOT SURE, CONTINUE TO QUESTION 8.]

Q7a. Why would you not tell your doctor information if you knew it would be shared? [CHECK ALL ANSWERS AS THEY APPLY TO RESPONDENT OPINIONS].

1. Privacy reasons
2. Emotional reasons
3. Don't know
4. Other reason [SEE 7B]

Q7b. [IF RESPONDENT PROVIDES RESPONSES NOT SIMILAR TO ABOVE, PLEASE DESCRIBE THEM HERE; OTHERWISE, LEAVE BLANK]:

Q8. Imagine a nationwide health information exchange that both doctors and patients can access. Information in the network can be controlled, and in an emergency, a patient's information could only be seen by an authorized family member or representative. Would you strongly oppose, oppose, favor, or strongly favor the creation of this type of network?

1. Strongly oppose
2. Oppose
3. Favor
4. Strongly favor

Q9. Which of the following do you consider to be the main barrier to achieving a nationwide health information exchange: privacy concerns, ensuring compatibility of multiple networks, cost, liability, limited public support, none of the above, or don't know?

1. Privacy concerns
2. Compatibility of multiple networks
3. Cost
4. Liability
5. Limited public support
6. None of the above
7. Don't know

Q10. Within a health information exchange, there are two ways that doctors could obtain your consent to participate. One way is for you to have to tell the doctor that you would allow your information to be shared before any of your information would enter the network – this is called opt-in. The other way would be that your information would enter the network unless you asked that it not be exchanged electronically – this is called opt-out. Which of these two methods would you prefer to use: opt-in, opt-out, or don't know?

1. Opt-in
2. Opt-out
3. Don't know

Q11. On a scale from 1 to 7, with 1 being the least and 7 being the greatest, please rate your level of agreement with the following:

- 1a. Health IT could improve quality of care?
- 1b. Health IT could improve doctor-patient interaction?
- 1c. Health IT could lead to a reduction in medical errors?
- 1d. Health IT could reduce the amount of unnecessary tests?

1. Improve quality of care	1	2	3	4	5	6	7
	<i>Strongly Disagree</i>		←		→		<i>Strongly Agree</i>
2. Improve doctor-patient interaction	1	2	3	4	5	6	7
	<i>Strongly Disagree</i>		←		→		<i>Strongly Agree</i>
3. Avoid medical errors	1	2	3	4	5	6	7
	<i>Strongly Disagree</i>		←		→		<i>Strongly Agree</i>
4. Reduce repeated tests and procedures	1	2	3	4	5	6	7
	<i>Strongly Disagree</i>		←		→		<i>Strongly Agree</i>

Q12. If you were offered the opportunity to sign up for a PHR, what is the primary factor that would most encourage you to join? [CHECK ALL ANSWERS AS THEY APPLY TO RESPONDENT OPINIONS].

-
1. Trust in organization or physician
 2. Safeguards (privacy policies)
 3. Popularity with friends and family
 4. Don't know
 5. Other [SEE 12A]

Q12a. [IF RESPONDENT PROVIDES RESPONSES NOT SIMILAR TO ABOVE, PLEASE DESCRIBE THEM HERE; OTHERWISE, LEAVE BLANK]:

Q13. Does your doctor currently have an electronic medical record: yes, no, or not sure?

-
1. Yes
 2. No
 3. Not sure

Q14. Have you ever been diagnosed with any type of chronic health condition (such as asthma or diabetes): yes, no, or unsure?

-
1. Yes
 2. No
 3. Unsure

Q15. Have you ever looked for information about health or medical topics: yes, no, don't know?

-
1. Yes
 2. No
 3. Don't know

[IF RESPONDENT SELECTS YES, CONTINUE TO QUESTION 15A. IF RESPONDENT SELECTS NO OR DON'T KNOW, CONTINUE TO QUESTION 16.]

Q15a. Think back to the most recent time you looked for this information. Did you look for this health information from: your physician, another doctor, the internet, a magazine, a book, a journal, or another source?

-
1. Physician
 2. Another doctor
 3. The internet
 4. Magazine

5. Book
6. Journal
7. Other [SEE 15B]

Q15b. [IF RESPONDENT PROVIDES RESPONSES NOT SIMILAR TO ABOVE, PLEASE DESCRIBE THEM HERE; OTHERWISE, LEAVE BLANK]:

Q16. For health-related concerns, how many times over the past 30 days would you say that you used the Internet to get health information?

Q17. How many times in the past 7 days did you access banking information online?

Q18. Think back to the last time you received printed information from your doctor's office. This information could be a brochure, instructions, or a pamphlet. How much of it did you read: a lot, some, none, don't know?

1. A lot
2. Some
3. None
4. Don't remember; don't know

Q19. Was any of the information in the material difficult to understand: yes, no, not sure?

1. Yes
2. No
3. Not sure

Q20. Were any of the words in the material unfamiliar to you: yes, no, not sure?

1. Yes
2. No
3. Not sure

[IF RESPONDENT SELECTS YES, CONTINUE TO QUESTION 20A. IF RESPONDENT SELECTS NO OR DON'T KNOW, CONTINUE TO QUESTION 21.]

Q20a. You answered that you had trouble with some of the words in the material. Did you ask someone such as a doctor, nurse, or family member for help understanding the material: yes, no, not sure?

-
1. Yes
 2. No
 3. Not sure

Q21. Think back to the last time you visited your doctor. During your appointment, did your doctor use any medical words that you did not understand: yes, no, don't know?

1. Yes
2. No
3. Don't know

[IF RESPONDENT SELECTS YES, CONTINUE TO QUESTION 21A. IF RESPONDENT SELECTS NO OR DON'T KNOW, CONTINUE TO QUESTION 22.]

Q21a. Did the doctor explain those words to make them easier to understand: yes, no, not sure?

1. Yes
2. No
3. Not sure

Q22. What is your zip code?

Q23. What is your gender?

1. Male
2. Female
3. Other

Q24. What was your age at your most recent birthday?

Q25. What is your total annual household income?

Q26. What is the highest level of education you have completed: less than high school, some high school, high school diploma, some college, college degree, or graduate school?

1. Less than high school
2. Some high school
3. High school diploma
4. Some college
5. College degree
6. Graduate school

Q27. What is your ethnicity? Hispanic or Latino or not Hispanic or Latino?

-
1. Hispanic or Latino
 2. Not Hispanic or Latino

Q28. Please select one of the following racial categories to describe yourself: American Indian or Alaska Native, Black or African American, Asian, Native Hawaiian or other Pacific Islander, White, or more than one of these categories? [CHECK ALL THAT APPLY].

-
1. American Indian or Alaska Native
 2. Black or African American
 3. Asian
 4. Native Hawaiian or other Pacific Islander
 5. White

Q29. Would you say your health in general is excellent, very good, good, fair, poor, or don't know?

-
1. Excellent
 2. Very good
 3. Good
 4. Fair
 5. Poor
 6. Don't know

Q30. During the past twelve months, about how many times did you see or talk to a medical doctor or assistant?

[THIS IS AN OPEN-ENDED QUESTION.]

Q31. We will be doing a follow-up to this survey in the following year. May we call you to follow-up with you at that time?

-
1. Yes
 2. No

[IF NO, REMOVE TELEPHONE NUMBER FROM MASTER LIST]

That completes our survey. Thank you very much for your time. If you have any questions or concerns, please call the following toll-free number: 1-800-xxx-xxxx.

[DISCONNECT THE CALL. THE FOLLOWING QUESTION SHOULD BE ANSWERED ONCE THE CALL HAS BEEN COMPLETED].

Q32. Please describe any thoughts or opinions regarding the survey or the respondent:

Appendix B

Procurement of consumer calling lists

The initial list of randomized Connecticut residential phone numbers was procured on August 9, 2011 from Marketing Systems Group (MSG), a company based in Horsham, Pennsylvania. UCHC ordered a batch of 6,000 phone numbers; MSG's screening processes discarded 3,156 numbers from this list as being invalid, non-residential numbers; this yielded a final list of 2,844 unduplicated telephone numbers. Calls to these numbers revealed that 140 (4.9%) were non-residential numbers (i.e. business numbers) and that 452 (15.9%) were out-of-service. MSG claimed that this was a traditional attrition rate for randomized residential calling lists following their initial screening process.

On January 6, 2012 UCHC ordered a second batch of residential phone numbers from MSG. MSG's initial screening for invalid numbers reduced this batch to 2,784 unduplicated phone numbers. Calls by UCHC survey staff determined that 159 (5.7%) of these numbers were non-residential numbers and that 474 (17.0%) were out-of-service.

On November 29, 2012, UCHC procured from MSG a final batch of 12,000 residential phone numbers. MSG's initial screening resulted in a final list of 6,128 unduplicated phone numbers. Calls to 3,157 of these numbers indicated that 160 (5.1%) were non-residential numbers and that 471 (14.9%) were out-of-service.

The three lists procured from MSG resulted in a total universe of 11,756 unduplicated numbers. No number from any of the three MSG batches duplicated a number in any other batch. 8,785 (74.7%) of the 11,756 numbers were called during the course of the survey.

Consumer calling protocol

The UCHC survey team designed a consumer calling protocol that accounted for various scenarios that could occur when an interviewer called a number. This protocol prescribed the following procedures for each potential outcome of a call:

- 1) If a call had one of the following results, the interviewer would try the number again after at least two hours had elapsed:
 - a) The interviewer got a busy signal.
 - b) The call rolled to a voice mail system that didn't allow the interviewer to leave a message.
 - c) No one answered the phone after ten rings.

If ten calls to the number yielded one of these results, then the number was classified as having exceeded its maximum number of contact attempts.

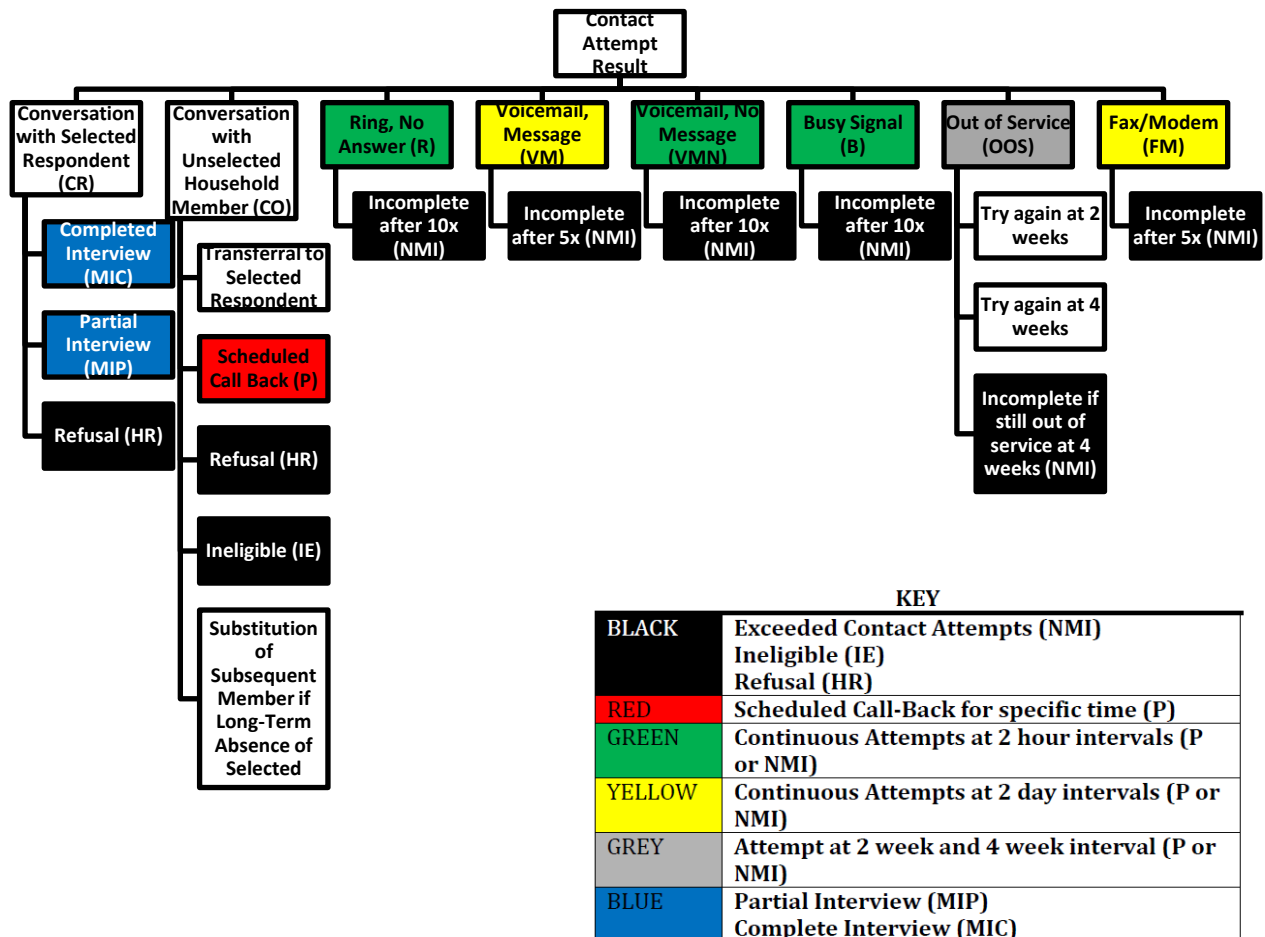
- 2) If a call had one of the following results, the interviewer would try the number again after at least two days had elapsed:
 - a) The number represented a fax or modem line.
 - b) The call rolled to a voice mail that allowed the caller to leave a message.

If five calls to this number yielded one of these results, then the number was classified as having exceeded its maximum number of contact attempts.

- 3) If the number was out-of-service, then the interviewer would try to call it again two weeks later. If it was still out-of-service, then the interviewer would try it one last time four weeks after the initial call. If the number was still out-of-service, then no further attempts were made to call it.
- 4) If the number represented a non-residential number or no one in the household spoke English, then it was immediately classified as an ineligible number and was not called again.

If the caller received a response when dialing a number, then the caller asked whether there were any individuals in the household aged 18 or older. If so, then protocol dictated that the caller ask to conduct the survey with the adult in the household having the most recent birthday. This request was intended to randomize the sample of individuals who actually took the survey. In practice, this portion of the protocol ceased to be followed after turnover of the UCHC survey staff during 2012. This portion of the protocol was re-initiated in November 2013, toward the end of survey calling activities.

Following is the flowchart given to the UCHC survey staff to guide their calling. This flowchart contains directions on how to handle each possible outcome for telephone calls.



Disposition of consumer phone numbers

The three telephone number lists procured from Marketing Systems Group (MSG) contained a total of 11,756 unduplicated telephone numbers. No numbers appeared in more than one of the three MSG batches purchased by UCHC.

Of the 11,756 unduplicated phone numbers, 8,785 (74.7%) were called by UCHC survey staff. Of these, 459 (5.2%) were non-residential numbers and 1,397 (15.9%) were out-of-service. Excluding these numbers left 6,929 valid residential numbers that survey staff called. Calls to these numbers yielded 599 complete surveys and 30 partial surveys that were retained in the final analytic data set.

Of the 6,929 residential numbers called by survey staff, respondents to 2,782 calls (40.2%) refused to take the survey. In 3,117 cases (45.0%) the caller exceeded the maximum number of contact attempts allowed by the protocol without getting any response. 2,971 (25.3%) of the 11,756 unduplicated numbers from the three MSG lists were not called by UCHC survey staff.

Using the formula developed by the American Association for Public Opinion Research,⁵⁵ the overall response rate was 6.4%. The formula is $(I+P)/(I+P) + (R+NC+O) + (UH+UO)$, where I = completed interviews, P = partial interviews, R = refusals or breakoffs, NC = non-contact numbers, UH = unknown households, and UO = unknown other. In our survey: $(599+30) / ((599+30)+(2782+3117)+(3372))$.

Data cleaning

UCHC survey staff entered a total of 683 complete and partial consumer survey records into REDCap. Of these, two (0.3%) were duplicate records created by a REDCap bug when survey staff saved completed surveys. Ten (14.6%) were excluded due to no questions being answered. In 20 cases (2.9%) the respondent indicated willingness to take the survey but answered no survey questions; these records were excluded as well. In 21 cases (3.1%) it was judged that the respondent had answered an inadequate number of questions for the survey to be analyzed usefully.

In one case (0.1%) the caller reached the end of the survey before the respondent indicated that he was only 17 years old. This survey was discarded from the analytic data set.

Appendix C

Logistic regression analyses

In the following tables, variables in bold text are significantly associated with the outcome of interest at the $p < .05$ level.

Table C 1. Characteristics associated with any online experience (“yes” vs. “no”)

N = 551	Odds Ratio	95% CI
<i>Demographic characteristics</i>		
Female vs. male	1.01	0.61-1.64
Education		
College vs. high school or less	3.42	2.02-5.80
Graduate school vs. high school or less	4.61	2.36-9.99
<i>Health and health care</i>		
Good or excellent health vs. fair or poor	1.73	0.92-3.24
Chronic health condition vs. no or unsure	0.80	0.49-1.30
Health literacy (trouble understanding words vs. no or unsure)	1.40	0.80-2.43
Doctor has an electronic medical record system	1.72	1.08-2.75

Table C 2. Characteristics associated with familiarity with health information exchange (“a lot or some” vs. “not at all or unsure”)

N = 551	Odds Ratio	95% CI
<i>Demographic characteristics</i>		
Female vs. male	0.77	0.51-1.18
Education		
College vs. high school or less	2.11	1.29-3.45
Graduate school vs. high school or less	5.26	2.87-9.64
<i>Online experience</i>		
Yes vs. no	2.50	1.54-4.06
<i>Health and health care</i>		
Good or excellent health vs. fair or poor	0.84	0.46-1.54
Chronic health condition vs. no or unsure	0.94	0.62-1.42
Health literacy (trouble understanding words vs. no or unsure)	0.81	0.52-1.27
Doctor has an electronic medical record system	2.31	1.57-3.40

Table C 3. Characteristics associated with familiarity with electronic health records (“a lot or some” vs. “not at all or unsure”)

N = 551	Odds Ratio	95% CI
<i>Demographic characteristics</i>		
Female vs. male	1.83	1.08-3.10
Education		
College vs. high school or less	2.54	1.41-4.59
Graduate school vs. high school or less	4.81	2.13-10.84
<i>Online experience</i>		
Yes vs. no	3.39	1.93-5.95
<i>Health and health care</i>		
Good or excellent health vs. fair or poor	1.46	0.71-3.01
Chronic health condition vs. no or unsure	0.96	0.56-1.69
Health literacy (trouble understanding words vs. no or unsure)	0.96	0.53-1.73
Doctor has an electronic medical record system	3.88	2.19-6.86

Table C 4. Characteristics associated with familiarity with electronic personal health records (“a lot or some” vs. “not at all or unsure”)

N = 550	Odds Ratio	95% CI
<i>Demographic characteristics</i>		
Female vs. male	1.14	0.78-1.66
Education		
College vs. high school or less	1.05	0.65-1.69
Graduate school vs. high school or less	1.63	0.95-2.80
<i>Online experience</i>		
Yes vs. no	2.45	1.51-3.98
<i>Health and health care</i>		
Good or excellent health vs. fair or poor	1.06	0.61-1.83
Chronic health condition vs. no or unsure	1.29	0.89-1.87
Health literacy (trouble understanding words vs. no or unsure)	0.73	0.48-1.10
Doctor has an electronic medical record system	1.30	0.92-1.84

Table C 5. Characteristics associated with familiarity with the Connecticut Health Information Exchange (“a lot or some” vs. “not at all or unsure”)

N = 551	Odds Ratio	95% CI
<i>Demographic characteristics</i>		
Female vs. male	0.87	0.51-1.44
Education		
College vs. high school or less	2.85	1.16-7.01
Graduate school vs. high school or less	3.02	1.17-7.77
<i>Online experience</i>		
Yes vs. no	2.08	0.90-4.77
<i>Health and health care</i>		
Good or excellent health vs. fair or poor	1.42	0.64-3.16
Chronic health condition vs. no or unsure	1.79	1.09-2.94
Health literacy (trouble understanding words vs. no or unsure)	1.10	0.62-1.93
Doctor has an electronic medical record system	1.68	1.03-2.76

Table C 6. Factors associated with support for a national health information exchange system (“strongly favor or favor” vs. “oppose or strongly oppose”)

N = 518	Odds Ratio	95% CI
<i>Demographic characteristics</i>		
Female vs. male	0.82	0.51-1.30
Education		
College vs. high school or less	0.81	0.44-1.47
Graduate school vs. high school or less	0.60	0.31-1.16
<i>Online experience</i>		
Yes vs. no	1.95	1.14-3.31
<i>Health and health care</i>		
Good or excellent health vs. fair or poor	1.13	0.58-2.23
Chronic health condition vs. no or unsure	1.80	1.11-2.91
Health literacy (trouble understanding words vs. no or unsure)	1.06	0.63-1.76
Doctor has an electronic medical record system	1.05	0.69-1.61

Table C 7. Factors associated with indicating privacy concerns are the primary barrier to achieving a national HIE (“privacy” vs. all other barriers)

N = 549	Odds Ratio	95% CI
<i>Demographic characteristics</i>		
Female vs. male	0.95	0.65-1.39
Education		
College vs. high school or less	0.94	0.58-1.52
Graduate school vs. high school or less	1.06	0.62-1.82
<i>Online experience</i>		
Yes vs. no	2.24	1.40-3.57
<i>Health and health care</i>		
Good or excellent health vs. fair or poor	1.42	0.83-2.45
Chronic health condition vs. no or unsure	0.62	0.43-0.90
Health literacy (trouble understanding words vs. no or unsure)	0.93	0.56-1.13
Doctor has an electronic medical record system	0.79	0.62-1.40

Table C 8. Factors associated with HIE consent model (“opt-in” vs. “opt-out or unsure”)

N = 549	Odds Ratio	95% CI
<i>Demographic characteristics</i>		
Female vs. male	0.56	0.37-0.86
Education		
College vs. high school or less	1.36	0.84-2.22
Graduate school vs. high school or less	2.46	1.38-4.39
<i>Online experience</i>		
Yes vs. no	2.70	1.68-4.34
<i>Health and health care</i>		
Good or excellent health vs. fair or poor	0.86	0.48-1.56
Chronic health condition vs. no or unsure	1.31	0.87-1.97
Health literacy (trouble understanding words vs. no or unsure)	0.88	0.56-1.36
Doctor has an electronic medical record system	1.10	0.75-1.60

Table C 9. Factors associated with agreement that health information technology will improve the quality of medical care (“agree” vs. “neutral or disagree”)

N = 548	Odds Ratio	95% CI
<i>Demographic characteristics</i>		
Female vs. male	0.54	0.34-0.87
<i>Education</i>		
College vs. high school or less	1.17	0.69-2.01
Graduate school vs. high school or less	1.77	0.93-3.35
<i>Online experience</i>		
Yes vs. no	1.34	0.79-2.27
<i>Health and health care</i>		
Good or excellent health vs. fair or poor	1.40	0.74-2.64
Chronic health condition vs. no or unsure	2.02	1.26-3.22
Health literacy (trouble understanding words vs. no or unsure)	1.59	0.95-2.66
Doctor has an electronic medical record system	1.44	0.95-2.17

Table C 10. Factors associated with agreement that health information technology will improve doctor-patient interactions (“agree” vs. “neutral or disagree”)

N = 548	Odds Ratio	95% CI
<i>Demographic characteristics</i>		
Female vs. male	0.72	0.47-1.09
<i>Education</i>		
College vs. high school or less	0.64	0.37-1.08
Graduate school vs. high school or less	0.88	0.48-1.60
<i>Online experience</i>		
Yes vs. no	1.41	0.86-2.31
<i>Health and health care</i>		
Good or excellent health vs. fair or poor	1.01	0.56-1.83
Chronic health condition vs. no or unsure	1.23	0.82-1.85
Health literacy (trouble understanding words vs. no or unsure)	1.11	0.71-1.74
Doctor has an electronic medical record system	1.45	1.00-2.12

Table C 11. Factors associated with agreement that health information technology will reduce unnecessary tests or procedures (“agree” vs. “neutral or disagree”)

N = 545	Odds Ratio	95% CI
<i>Demographic characteristics</i>		
Female vs. male	0.99	0.65-1.50
<i>Education</i>		
College vs. high school or less	0.78	0.46-1.33
Graduate school vs. high school or less	1.15	0.62-2.12
<i>Online experience</i>		
Yes vs. no	1.15	0.68-1.93
<i>Health and health care</i>		
Good or excellent health vs. fair or poor	1.01	0.55-1.83
Chronic health condition vs. no or unsure	1.08	0.71-1.64
Health literacy (trouble understanding words vs. no or unsure)	0.97	0.80-1.73
Doctor has an electronic medical record system	1.17	0.78-1.64

Table C 12. Factors associated with agreement that health information technology will reduce medical errors (“agree” vs. “neutral or disagree”)

N = 544	Odds Ratio	95% CI
<i>Demographic characteristics</i>		
Female vs. male	0.69	0.46-1.03
Education		
College vs. high school or less	0.70	0.42-1.17
Graduate school vs. high school or less	1.17	0.65-2.10
<i>Online experience</i>		
Yes vs. no	1.38	0.85-2.25
<i>Health and health care</i>		
Good or excellent health vs. fair or poor	1.54	0.89-2.66
Chronic health condition vs. no or unsure	0.91	0.62-1.36
Health literacy (trouble understanding words vs. no or unsure)	1.23	0.79-1.93
Doctor has an electronic medical record system	1.13	0.78-1.64

Table C 13. Factors associated with interest in having a personal health record (“very or somewhat interested” vs. “not very or not at all interested”)

N = 550	Odds Ratio	95% CI
<i>Demographic characteristics</i>		
Female vs. male	1.07	0.73-1.57
Education		
College vs. high school or less	0.93	0.57-1.53
Graduate school vs. high school or less	1.33	0.76-2.31
<i>Online experience</i>		
Yes vs. no	4.57	2.73-7.65
<i>Health and health care</i>		
Good or excellent health vs. fair or poor	1.63	0.93-2.85
Chronic health condition vs. no or unsure	1.14	0.78-1.68
Health literacy (trouble understanding words vs. no or unsure)	1.19	0.78-1.81
Doctor has an electronic medical record system	1.06	0.74-1.51

Table C 14. Factors associated with interest in allowing de-identified information from electronic health record to be shared (“very or somewhat interested” vs. “not very or not at all interested”)

N = 543	Odds Ratio	95% CI
<i>Demographic characteristics</i>		
Female vs. male	0.93	0.64-1.37
Education		
College vs. high school or less	0.83	0.51-1.34
Graduate school vs. high school or less	1.04	0.60-1.81
<i>Online experience</i>		
Yes vs. no	2.27	1.41-3.64
<i>Health and health care</i>		
Good or excellent health vs. fair or poor	1.36	0.79-2.36
Chronic health condition vs. no or unsure	1.47	1.00-2.17
Health literacy (trouble understanding words vs. no or unsure)	1.07	0.70-1.62
Doctor has an electronic medical record system	1.01	0.71-1.44