# Making IT Meaningful: How Consumers Value and Trust Health IT

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## Acknowledgements

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# I. Executive Summary

As the nation progresses with the hard work of reforming the health care delivery system, the widespread adoption of health information technology (health IT) has become a national priority. A broad range of health care providers is working to implement and effectively use electronic health record (EHR) systems, which are essential to the success of new models of care currently being tested as a result of the Patient Protection and Affordable Care Act of 2009 (ACA).

For the promise of health IT to be realized, consumers must both trust and value it. With this in mind, the National Partnership for Women & Families and Professor Alan Westin, Ph.D., in consultation with multi-stakeholder experts in the health care, health policy and information privacy fields, designed a survey to assess patients' experiences with and trust in the use of health IT. The goals were to:

1. Explore whether trust or perceived value in health IT helps consumers benefit from the more widespread use of EHRs.
2. Measure existing levels of patient trust in how providers use paper and electronic medical record systems today and develop a demographic profile, or segmentation, of consumers most and least worried about health IT privacy. This profile can be used to identify individuals who would benefit from engagement and education to improve their comfort levels with electronic records.
3. Inform future definitions of Meaningful Use and other public policies and programs related to health IT and health reform by identifying a) what is important to patients with respect to how EHRs could improve their health and care, and b) how to improve their trust in both providers and their EHRs to protect privacy.
4. Measure experience with Meaningful Use and health IT-enabled aspects of health reform over time by establishing a baseline of consumer attitudes and opinions today, and creating a publicly-available instrument others may use as these initiatives progress.

## Who We Surveyed

Harris Interactive® conducted the study online within the United States from August 3 – 22, 2011, from a sample of respondents representative of the total U.S. population 18 years of age and older. To focus on those patients who have some experience with a medical record system (whether paper or electronic), we chose to focus on patients who met two main criteria: (1) those who have an ongoing relationship with a main care provider, and (2) those who know what kind of record system – electronic or paper – this provider uses. This yielded a total respondent pool of **1,961 adults**. This represents 56 percent of the adult population, after the data were weighted to represent the demographics of the national adult population.[1]

Among the 1,961 adults who indicated they have a primary care doctor, 58.8 percent (1,153) have medical records in electronic systems and 41.2 percent (808) said their doctor primarily relies on paper records. It is important to note that this does not represent the percentage of doctors in the U.S. who use an EHR. Rather, it represents the percentage of patients who report having a regular doctor and know what kind of record system their doctor uses (EHR or paper). For further information on how this correlates to estimated provider adoption rates nationally, see the **methodology** section of this report. In addition to the two basic samples of patients in medical

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1 For a more detailed discussion of sample weighting, please see Appendix B.

record systems, we sought to assess EHR value and trust perceptions among Hispanic adults (See sidebar: *Listening to the Hispanic Voice.*)

The purpose in constructing the sample in this way was to facilitate exploration of perceptions among patients with some experience in an EHR environment, as well as those who have not experienced health IT-enabled care.  This, we believe, is a unique attribute of this survey, in that a significant portion of our sample is responding to questions based on their own experience with EHRs, rather than in the abstract.  This distinction helps to more effectively inform public policy and programs.

The EHR and paper samples were similar in gender breakdown, age and income, but EHR respondents were more highly educated, with 55 percent having a college education, compared to 49 percent of paper-system respondents.

We found the self-reported general health status of the two sample populations (EHR and paper system) to be quite similar.  However, we identified other differences in health demographics.  More EHR respondents reported they had a sensitive health condition (57 percent compared to paper respondents at 47 percent).  EHR respondents were also somewhat higher in reporting their health care provider had told them they had a chronic condition (52 percent compared to 48 percent in paper systems).

Finally, we asked how often patients engaged in various health- promotion activities, such as taking prescription medications regularly, exercising, researching information about health conditions, etc.  We found no significant differences between EHR and paper respondents.

## Discussion/Summary of Key Findings

1.  **Patients (regardless of the type of record their physician has) see value in EHRs.**  When asked the extent to which people believe an EHR is or would be useful in accomplishing or improving upon seven key care elements,[2] between 88 and 97 percent (depending on the particular care element) of EHR respondents and between 80 and 97 percent of paper respondents say EHRs would be useful (Chart 4).  This represents a powerful seal of patient approval for EHR systems' potential impact on major aspects of the health care process.

Moreover:

▶   EHRs far outpace paper in perceived impact on quality of care.  Seventy-three percent of EHR respondents say their doctor's use of an EHR has a very or somewhat positive impact on the overall quality of health care services, compared to only 26 percent of paper system respondents who feel the same about their physician's record system (Chart 8); and

▶   Only 29 percent of paper-system respondents rated their record system positively for timely access to relevant information by the care team, compared to 80 percent of EHR respondents (Chart 6).  This is striking because timely access to relevant information by the care team is a critical component of coordinated, quality care.

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2 Care elements queried: 1) Making sure that all the different health care providers who treat a patient have timely access to all the relevant information for his or her care, like test results and diagnoses; 2) Getting tests or laboratory results to patients in a timely manner; 3) Helping patients make sure the information in their medical record is accurate; 4) Helping patients follow their health care providers' instructions for treatment or care of themselves or a family member; 5) Helping patients make or change their appointments; 6) Helping patients communicate directly with health care providers; and 7) Helping patients take and refill their medications as prescribed.

**2.   Those EHR respondents with online access to their health information see greater value in EHRs for both their providers and themselves.  Online access is correlated with enhanced trust.** Among EHR respondents, 26 percent had online access to their health information, and they were consistently more positive about perceived value of and trust in EHRs.  Overall, they were more likely to say:

▸ They are very satisfied with the EHR system (59 percent with online access; 43 percent without); and
▸ They felt their EHR had a positive effect on overall quality of health care services (82 percent with online access; 72 percent without).

Of those with online access, *80 percent use it* (Chart 12).  It is an important tool to enhance perception of record-system value: Those with online access are more likely to say EHR systems help their doctors and staff correct errors or incomplete information in the medical record (82 percent with online access; 75 percent without); and avoid medical errors (82 percent with online access; 75 percent without).

Online access to EHRs also helps them:

▸ Personally find and correct errors or incomplete information in their medical record (58 percent with online access; 46 percent without);
▸ Understand their health condition better (58 percent with online access; 46 percent without); and
▸ Keep up with their medications (54 percent with online access; 43 percent without).

*Online access also correlates with trust*: Users are more likely to say they trust their doctor and staff to protect their patient rights (78 percent with online access; 73 percent without).  Those with online access are also more likely to say they feel well informed by their doctors and staff about:

▸ How their medical information is collected and used in the EHR system (67 percent with online access; 51 percent without);
▸ Their right to be informed and exercise choice before personal medical or health information is made available to others for purposes beyond health care (62 percent with online access; 52 percent without); and
▸ Their right to see all or parts of medical record – and have a copy made (65 percent with online access; 47 percent without).

**3.   Three out of four paper-system respondents want their doctor to adopt an EHR, but more work must be done to build a *consumer* case for quality.**  When asked what impact switching from paper to an EHR would have on quality of care, 41 percent of paper-system respondents said "no impact" and 10 percent said "negative impact" (Chart 10).

These data indicate that consumers do not appear to connect EHR *adoption* to improved quality. (See sidebar at top of next page for a discussion of quality.)  In fact, almost a third of paper-system respondents are very satisfied and only 14 percent express dissatisfaction (Chart 11) with their current system, which illustrates that they don't appear to see a problem that needs fixing.

As significant investments are being made to "wire" health care, our findings indicate that it is and will continue to be important to showcase *how EHRs are being used in a way meaningful to*

*consumers*. Providing patients with online access to electronic health record data is one way to increase the perception of value and trust among patients, and other means of delivering tangible, health IT-enabled benefits to consumers should be explored as well.

**4. People are concerned about the safety of their health information.**

- ▶ Most (59 percent of EHR respondents; 66 percent of paper-system respondents) say widespread adoption of EHR systems will lead to more personal information being lost or stolen.
- ▶ Moreover, 51 percent of EHR and 53 percent of paper respondents believe the privacy of personal medical records and health information is not currently well protected by federal and state laws and organizational practices (Chart 14).

These findings suggest significant uneasiness regarding the privacy and security of electronic systems. Notably, this issue is not about trusting providers: *More than 90 percent of both paper and EHR respondents trust their doctors to protect health information* (Chart 18). Rather, this unease may point to inexperience with the capabilities of electronic systems and dissatisfaction with the legal and policy framework in place to protect health information.

When it comes to the privacy of their health information, consumers' views are complex. Although people see great value in EHRs and have high levels of trust in their doctors, our findings indicate they are also wary that more widespread use of EHRs will lead to increased data breaches. Among other findings, these should be explored more deeply and tracked over time.

> **In any discussion of quality, patients define quality differently than do "experts."**
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> Consumers do not always think of quality in terms of clinical aspects – e.g., whether care meets evidence-based guidelines. Many consumers perceive quality in terms of service quality (i.e., timeliness of appointment, friendliness of providers); people are more comfortable with, and can talk more easily about, ideas of service quality than clinical quality.[1] Online access to an EHR can affect several service dimensions if used in certain ways – e.g., filling out forms ahead of time shortens wait time, and secure messaging between provider and patient enhances ease and speed of communication. While patients may not now intuitively connect the role their record system can play in their experience or clinical quality of care, showing them how certain features of an EHR can improve both could change their perception.
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> 1 Communicating about Quality: Communications Research Conducted by the RWJF. Robert Wood Johnson Foundation. November 2007. Page 6. http://www.rwjf.org/files/research/71858.pdf

**5. Patients generally trust EHRs more than paper records.**

- ▶ Although those patients whose providers use paper systems rated their record system relatively highly on complying with patients' rights,[3] both EHR and paper respondents rated EHR systems higher than paper with respect to these capabilities (Charts 16 and 17).
- ▶ Both groups see great value in EHRs when it comes to enhancing elements of patient privacy.

**6. There is a relationship between EHR respondents' privacy/trust concerns and the value they perceive in EHRs.** In our segmentation analyses, we identified a correlation between perceptions of trust in providers to protect health information and perceptions of EHR usefulness and value: Those who are more comfortable in their privacy views are more likely to perceive and experience value of

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3 Five dimensions of privacy queried: 1) Giving patients confidence that their medical and health information is safe so unauthorized people don't see it; 2) Complying with privacy and confidentiality laws and rules; 3) Giving patients more control over how their personal medical and health information is used for purposes beyond their direct care; 4) Letting patients see a record of who has accessed their medical information; and 5) Earning the trust of patients in the way their personal medical and health information is being handled by their provider's medical record system.

their record systems, and vice versa. For example:

- ▸ EHR respondents who are more comfortable with privacy issues are 25 percentage points higher in saying the EHR has had a positive impact on the quality of their care, compared to those who are generally worried about privacy (Table 1 in Segmentation section); and

- ▸ EHR respondents who have high trust in their providers to protect health information are 49 percentage points higher than those with low trust in saying the EHR helps their doctor keep up with their health conditions and treatments (Table 7 in Segmentation section).

**7. Respondents who are worried about privacy cross demographic lines, but a few groups can be identified.** When we examined the most privacy-concerned respondents (in the Segmentation section), there were four demographic groups that were at least 4 or 5 percentage points higher than the total group of EHR respondents most worried about privacy:

- ▸ Men;
- ▸ Those earning less than $35,000 a year;
- ▸ Those age 35-46; and
- ▸ Those living in the South.

Among the paper respondents, the demographic groups 4 or 5 percentage points higher than the total "worried" group were:

- ▸ Men;
- ▸ College graduates;
- ▸ Those age 35-46; and
- ▸ Those living in the East or West.

**Listening to the Hispanic Voice**

In addition to analyzing our two basic samples (patients in EHR systems and those in paper systems), we wanted to assess record-system perceptions among Hispanic adults, including those who speak primarily Spanish. We sought to ascertain whether significant differences exist with respect to perceived value and trust in health IT systems. From a population-health perspective, one cannot talk about EHRs without mentioning this fastest-growing segment of society.[2] Accordingly, the survey was offered in both English and Spanish, and we conducted an over-sampling of Hispanic respondents. Eight percent of EHR respondents and 9 percent of those in paper systems identified themselves as Hispanic (227 respondents total).

- ▸ Hispanic adults see greater value in many aspects of the EHR system. They were more likely than the total EHR respondent pool to see EHRs as helping them maintain a healthy lifestyle (52 percent EHR Hispanics, 34 percent total EHR) and in saying the EHR helped them understand their conditions (59 percent EHR Hispanics, 46 percent total EHR).

- ▸ Hispanic respondents in EHR systems are more likely than the total EHR respondent pool to have online access to their health information (32 percent Hispanics, 26 percent total EHR) and less likely to say they never use such access (5 percent Hispanics, 20 percent total EHR).

- ▸ Those with online access to their health information are also more likely to say such access improved their desire to do something to improve their health (70 percent EHR Hispanics, 55 percent total EHR).

- ▸ However, Hispanic adults are more likely to say that widespread adoption of EHRs will lead to more data breaches (73 percent EHR Hispanics, 59 percent total EHR), and are also more likely to say existing privacy laws are not adequate (69 percent EHR Hispanics, 51 percent total EHR). Hispanic adults are more likely to report having experienced data breaches and to have withheld health information because of confidentiality concerns.

With further study and exploration, these findings could offer insight into the use of health IT as a tool to reduce health disparities and improve outcomes. It is clear that, given Hispanic adults' overall concerns about privacy and security, efforts to engage them in health IT must focus heavily on improving trust.

2 "The Hispanic Population: 2010," 2010 Census Briefs, *available at* http://www.census.gov/prod/cen2010/briefs/c2010br-04.pdf.

This finding contradicts conventional wisdom in the sense that some of the populations thought to be highly concerned about privacy – notably, persons with sensitive health conditions – did not differ significantly in the intensity of their views compared to other sub-groups.

## Beyond Technology

Consumers want, and like, EHRs – that much is clear based on our findings and analyses. In our survey results, EHRs outperform paper records in aspects of care that patients value highly. Nevertheless, many do not connect the perceived benefits with a need to switch from paper records to EHRs. Compounding this disconnect are serious privacy and security concerns about EHRs. The implications for health IT are dire: *If consumers view EHRs as a threat to privacy with little benefit to them, they may see wider adoption of EHRs as more of a hazard than an improvement.* At stake is not just EHR adoption, but also the ability to enhance patient care, improve the health of populations and control costs.

These findings underscore an ongoing challenge when it comes to consumer engagement. Many health IT thought leaders are pushing for consumers to be the "demand force for change." Our findings suggest that this is unrealistic. Consumers see potential in EHRs, but they do not yet grasp the full value, have lingering questions about privacy and security, and they don't always see a relationship between the kind of care process they desire and the role of the record system in supporting it. Given these gaps, it is unlikely they will be inspired to pressure their doctor into switching. In our findings:

### Policy Implications and Recommendations

We believe our findings have important value for health policy formulation. To make them actionable, we have developed recommendations in three main categories, discussed fully in our Policy Implications section.

### I. Consumer Education

▸ Recommendation 1: Value and privacy should be the dual focuses of education and engagement efforts.

▸ Recommendation 2: Consumers of Hispanic origin and underserved individuals should be key target audiences for education and engagement efforts.

▸ Recommendation 3: Physicians, nurses and other clinicians should play key roles in engaging consumers with information about privacy and value of health IT.

▸ Recommendation 4: ONC and OCR should track over time changes in consumer privacy views and who comprise the most comfortable and the most worried population segments.

### II. Functional and Privacy Requirements for the Meaningful Use Program

▸ Recommendation 5: Promote functionalities that support improving patients' perceptions of value and trust in Stages 2 and 3 of Meaningful Use, specifically: care coordination, online access, and those that ensure convenience and robust criteria for privacy and security education.

▸ Recommendation 6: Promote and demonstrate functionality relating to EHR "accounting of disclosures" reports, indicating when and to whom a HIPAA-covered entity has disclosed an individual's health information.

### III. Other Important Federal Programs

▸ Recommendation 7: Integrate patient-facing functionality into health information exchange initiatives such as Beacon Communities, the state Health Information Exchange (HIE) program and the Nationwide Health Information Network.

▸ Recommendation 8: Make health IT functionalities that patients value and directly benefit from key parts of new models of care under health reform.

▸ Recommendation 9: Promote further federal initiatives and regulations that provide patients with direct access to their health information.

- Almost a third of paper-system respondents are very satisfied and only 14 percent express dissatisfaction with their current record system (Chart 11);
- Most respondents (both paper-system and EHR) say they have been told little or nothing by doctors and their staffs about their patient rights (Chart 15);
- Nearly a third of EHR respondents and more than a third of paper respondents say they were not informed about how their information is collected and used (Chart 3); and
- Only about half of both groups said these issues were explained well (Chart 3).

But patients *do* want to know more. A large majority (88 percent of EHR and 82 percent of paper-system respondents) of patients want to understand how their medical information is collected and used (Chart 2). Our data show that *people care about how and when their medical information is used but do not feel that they are adequately informed.*

Our findings confirm that providers – physicians in particular – are crucial to providing such guidance and, ultimately, key to cultivating trust in EHRs. Across all respondents, individual trust in one's provider when it comes to privacy protection is tremendously high, and this trust flows to the physician's use of an EHR. EHR respondents expressing positive trust in providers to assure privacy and other patient rights are more likely to find EHR systems useful in providing or protecting patient privacy-related rights.

Physicians are the main point of contact and an obvious resource for building patient understanding about EHRs. Patients trust their doctors, despite misgivings about the trustworthiness of Accordingly, based on our analyses, physicians should play a role in engaging patients in a conversation about how EHRs work and how patient data are used and protected. Our Policy Implications section provides further recommendations on how this could be operationalized.

# II. Background and Survey Objectives

## A. Survey Context

As the nation progresses with the hard work of reforming the health care delivery system, the widespread adoption of health information technology (health IT) has become a national priority. Federal incentives for the "meaningful use" of health IT have begun to flow, and a wide range of health care providers – hospitals, physician practices, nurse practitioners, dentists and others – is working right now to implement and effectively use electronic health record (EHR) systems. In addition, EHRs are viewed by many as a key ingredient for successful performance under new models of care currently being tested as a result of the Patient Protection and Affordable Care Act of 2010 (ACA).

The first phase of the EHR incentive program known as Meaningful Use includes a range of criteria designed to spur not just adoption of these systems, but their use by providers to improve care. The measures and objectives for Stage 1 incentives include patient and family engagement dimensions, as well as privacy and security requirements.

Notably, however, there are currently few or no effective tools for measuring patient trust in and perceived benefits of EHRs based on patients' actual experiences. This survey is divided into two samples – those who have doctors that use an EHR and therefore have some experience with practical applications of health IT, and those who have doctors using paper medical records. This, we believe, is a unique attribute of this survey, in that a majority of our sample is responding to questions based on their own experience with EHRs, rather than in the abstract.

Although consumers may not understand all the precise details of the technologies, there can be no doubt that they understand the potential health IT holds to improve health care as they see and experience it. In 2009, the National Partnership commissioned public opinion research to explore the challenges patients face every day in the health care system and identify ways to talk most effectively about potential solutions. Across the entire spectrum of solutions we explored – including medical homes, health IT and payment reform – health IT was seen by these patients and caregivers as a top strategy to help address their most pressing challenges: namely, care coordination and communication with the care team. It is clear patients quickly and intuitively recognize that health IT can directly contribute to fewer medical errors, lower costs and better health outcomes. They see the benefits technology has brought to other areas of their lives and understand how private and secure health IT can improve our nation's health care system.[4]

At the same time, many consumers have privacy concerns with respect to health IT. While they see potential value, they also perceive potential risk. Without trust in how their health information is used and protected, patients may withhold sensitive health information, or otherwise reject provider use of these systems. If patients don't experience value in the way electronic records are used, it will be challenging for Meaningful Use and other programs to achieve their ambitious goals. **In other words, for the promise of health IT and health reform to be realized, consumers must both trust and value health IT.**

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4 Bechtel, Christine and Ness, Debra. "If You Build It, Will They Come?" *Health Affairs*, May 2010.

## B. Survey Objectives

This survey, developed in consultation with a Survey Advisory Committee of multi-stakeholder experts in the health care, health policy and information privacy fields,[5] was designed to understand and assess patients' expectations of and trust in the use of health IT, and, in particular, look for differences in these two areas between individuals whose doctors use EHRs and those whose providers use paper records.  Our key objectives were to:

1. Explore whether trust and/or seeing value in health IT helps consumers benefit from the more widespread use of EHRs.  In investigating this question, we also sought to ascertain whether there is a relationship between value and trust – e.g., do individuals who perceive value in health IT have more trust in the systems?  Conversely, do those who have less trust see less value?
2. Measure existing levels of patient trust in how medical record systems – both paper and electronic – are used by providers and create a segmentation that can be used to identify individuals who would benefit from engagement and education to improve their comfort levels with electronic records.
3. Inform future definitions of Meaningful Use and other public policies and programs related to health IT and health reform by identifying what is important to patients with respect to how EHRs could improve their health and care, as well as improve their trust in both providers and their EHRs to protect privacy.
4. Provide a baseline of public opinion and a survey instrument that will enable health systems, providers, policymakers or others to conduct longitudinal probes of changes in public opinion or patients' experiences in a given health environment, including tracking changes in the level of consumer trust in providers and their record systems.  This will be particularly valuable as Meaningful Use and federal privacy policies progress in the context of a nationwide health information network, and as patients are increasingly using their own health information to improve their care.

## C. How This Report Proceeds

We first describe our core methodology – the creation of our respondent samples, the development of our questionnaire, and a description of the standard and health demographics that we collected and used.  We then present findings in two main parts – those that relate to value, and those that relate to trust.  Throughout the report, we make analytical observations relevant to particular questions.  We also present an in-depth review of the views of Hispanic respondents, followed by a section describing important implications for a range of public policies based on our findings.  Our analyses related to privacy and trust segmentations are our closing sections.

The Appendices include a full list of our Survey Advisory Committee members and their affiliations, a detailed methodology discussion, and our standard and health demographic profiles.

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5 See Appendix A for a full list of committee members and their affiliations.

# III. Survey Methodology

## A. Creating the Basic Samples

Harris Interactive conducted our survey online from August 3 – 22, 2011, and developed a sample of respondents that was representative of the total U.S. population 18 years of age and older, estimated by the 2010 Census Current Population Survey at approximately 230 million adults.

### 1. Identifying Patients With A Doctor Relationship

In order to focus on patients who have some experience with a medical record system (whether paper or electronic), we chose to focus on respondents who have an ongoing relationship with a care provider. We asked respondents whether they had a "main doctor," or a doctor they see most often. Any respondents who said they did not have such a doctor were excluded from the respondent pool.

*A note about language*: We recognize that health care today is delivered by a wide range of clinicians – nurse practitioners, specialists, primary care physicians, nurses, physician assistants and others. However, for simplicity's sake we chose to ask respondents about their "doctor" and sometimes "his or her staff."

### 2. Identifying Patients in EHR or Paper-Based Record Systems

Respondents were then asked to identify the particular medical record system used by their physicians. We offered the following descriptions:

> *Some doctors and health care organizations use computers or mobile devices to record their patients' medical and health information. These electronic health records – or 'EHRs' – contain notes from your doctor or other medical personnel about your visits, diagnoses, test results, prescriptions, lifestyle and other elements of your medical history.*

> *Other doctors keep medical records primarily in paper forms, which might mean using electronic systems only for things like making appointments or handling billing.*

Respondents to this question who said they did not know the kind of record system their main doctor uses were ineligible for the survey. This gave us our total respondent pool of **1,961 adults**. This represents roughly 56 percent of the adult population, after the data were weighted to represent the demographics of the national adult population.[6]

Overall, then, our 1,961 respondents represent a current patient-with-doctors population of an estimated 129 million adults. These 1,961 respondents were divided into two groups:

▸ The 1,153 who said their doctors had EHR systems (59 percent); and
▸ The 808 who said their doctor relies primarily on paper records (41 percent).

These became our two basic respondent sets for the survey. It is important to note, however, that this does *not* represent the percentage of doctors in the U.S. who use an EHR. Rather, it represents the percentage of patients who (1) report having a regular doctor; and (2) know what kind of record

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6 For a more detailed discussion of sample weighting, please see Appendix B.

system their doctor uses (EHR or paper).  The most recent published adoption rates, as measured by the National Center for Health Statistics,[7] indicate that 57 percent of office-based physicians used an EHR.  Because our survey sample is a narrower subset of the U.S. population, and does not include, for example, those without a main doctor or those who are unsure of the type of record system used, our sample represents about 56 percent of all adults.  However, the percentage of patients who report that their regular doctor uses an EHR was not substantially different from the provider-reported 2011 adoption rates.  As noted, among our sample, about six in 10 tell us that their physician uses an EHR.

The data were weighted to be representative of the U.S. population age 18 or older on age, gender, education, geographical region and income, plus a proprietary propensity score designed to account for the bias inherent in online panel samples.

For a more complete methodology discussion, please see **Appendix B.**

## B.  Oversampling of Hispanic Respondents

In addition to our two basic samples of patients in EHR systems and those in paper systems, we sought to assess perceptions and experiences among Hispanic adults in particular to ascertain whether any significant differences exist with respect to value and trust in health IT systems.  Thus, we offered respondents the opportunity to take the survey in either English or Spanish, and we conducted an over-sampling of Hispanic respondents.  Eight percent of our EHR respondents and 9 percent of those in paper systems identified themselves as Hispanic (227 respondents total).  We discuss Hispanic responses throughout the main report, but present a full profile of Hispanic respondents in our Hispanic population analysis section.

## C.  The Questionnaire

The survey, a complete version of which can be found with the Topline Report on our website, www.NationalPartnership.org/HIT, featured 77 substantive questions or sub-questions and 33 demographics questions.  Although closed-ended questions were generally used, we used open-ended questions for six key topics, where respondents could write their own answers in free text.  This produced six sets of rich narrative comments from respondents explaining why they adopted various positions in answer to our questions.

For analytic purposes, standard demographics for cross-tabulations were collected, including region, age, gender, race/ethnicity, education, income and employment.  In addition, a set of custom health demographics was created from respondents' answers to questions about their overall health status, whether they have health insurance, whether they have a sensitive health condition (of seven listed types), and whether their health care provider told them they have or had any of 13 listed chronic conditions.  **Appendix C** shows the breakdown of our two samples by each standard demographic and health demographic.

## D.  Variations

Many surveys look for "significant" variations in the ways that standard demographic groups (by gender, age, income, race, education, etc.) or health status groups (having sensitive health

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7 Data from the annual National Ambulatory Medicare Care Survey (NCHS Data Brief, November 2011), *available at*: http://www.cdc.gov/nchs/data/databriefs/db79.htm.

conditions, in poor or fair health, etc.) score in relationship to the question results of the whole sample. In election surveys, group differences of 3 or 5 percent can flag groups to be courted or predict potential differences in election outcomes.

For our survey, in most cases we set 5 percent as the floor for noting group differences, reasoning that differences less than that would not shed much light on or serve as a likely predictor of attitudinal shifts. We looked for that 5 percent in the differences *within* sub-groups (e.g., men compared to women, high income to low income, high school to post-grads, etc.), and we identify them throughout the report.

## E. Profiles and Comparisons of Respondents

### 1. Standard Demographics

Our EHR and paper system samples proved to be quite similar in gender, age and income. However, EHR respondents were more highly educated, with 55 percent having college educations compared to 49 percent of paper-system respondents. By race and/or ethnicity, although Hispanic, Asian and mixed racial respondents were similar across the two record systems, there were higher numbers of black patients in paper systems – 15 percent, compared to only 9 percent in EHRs. With respect to white respondents, 79 percent of EHR system respondents are white, compared to 73 percent in paper systems.

In terms of standard demographics, our EHR system Hispanic adults had some significant differences with the total EHR respondent pool. Specifically, Hispanic adults were higher in male than female participants by 9 percentage points; more fell into the 35-65 age groups; higher numbers lived in the West and South; they were lighter Internet users; were more likely to have only high school or less education; and higher numbers fell into the two lower annual income levels.

### 2. Health Demographics

In terms of the self-reported general health status of the two sample populations (categorized as excellent, pretty good, fair and poor), we found them to be very similar, varying no more than 2 percentage points in each category. However, beyond general health status, there were some differences in health demographics between the two pools of respondents:

▸ EHR respondents were higher by 10 percentage points in reporting they had a sensitive health condition, (57 percent compared to 47 percent of paper system respondents). See **Appendix C** for the specific conditions presented and the incidence by type of record system.
▸ EHR respondents were somewhat higher in reporting that their health care provider told them they had a chronic condition (52 percent compared to 48 percent in paper systems).

With respect to our health demographics among Hispanic adults, they were higher in reporting themselves in excellent health, but were less likely than the total respondent pool to describe their health as "pretty good." Fewer numbers reported having used mental health services and that they have a long-term medical condition. Fewer Hispanic adults indicated that they had health insurance coverage.

Interestingly, Hispanic adults scored lower in having many adverse medical conditions than the total EHR sample reported (such as high blood pressure, high cholesterol, arthritis, asthma, heart

attack, anxiety disorder and cancer). However, the EHR Hispanic adults scored higher in having type 2 diabetes. In addition, EHR respondent Hispanics were more likely to be in solo physician practices (38 percent compared to 17 percent of the total EHR sample).

Finally, we also asked how often patients engaged in a set of health-promotion activities, such as taking prescription medications regularly, exercising, researching information about health conditions, and more (Chart 1).

**Chart 1**



How often do you do the following things as a patient?
Base = EHR group (n=1153) and paper group (n=808)
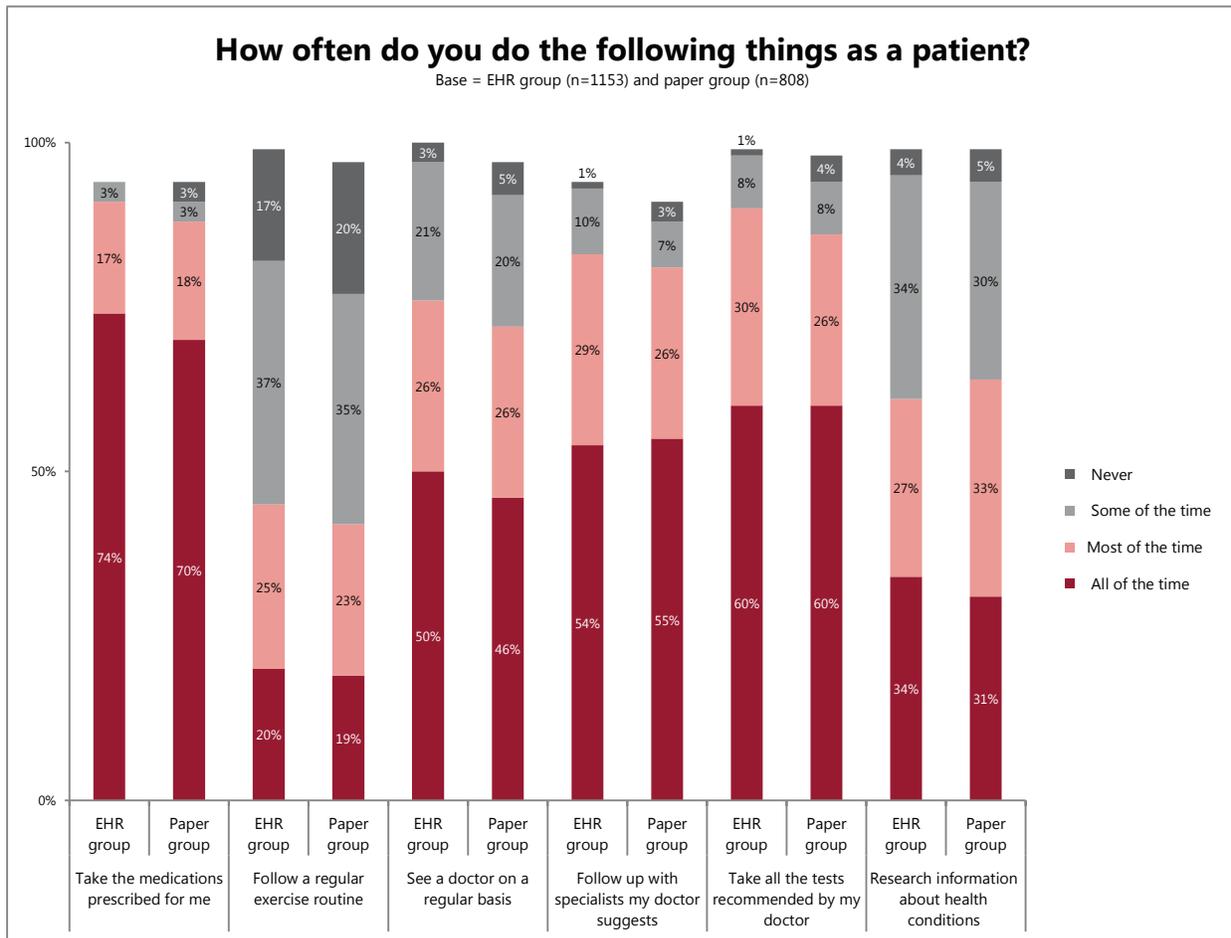
The purpose of this question was to allow us to determine in our analysis whether some patients expressing certain views were simply more "activated" than others. However, we did not find this to be the case, and instead found no significant differences in activation levels between EHR and paper respondents.

# IV. How Respondents View and Value Their Record Systems

## A.  System Operations

The "value" questions in our survey were both expansive and nuanced, designed to allow us to understand overall perceptions of EHRs, actual experienced effects of both electronic and paper systems, perceived and experienced value to providers, and perceived and experienced value to individuals themselves.

### 1. Importance of Knowing How a Record System Works

Before diving into specific, value-focused questions, we sought to establish a baseline understanding of how much our respondents generally care about understanding the collection and use of their health information.  We first asked all respondents how important it is to them as patients that they understand the collection and use of their medical and health information (Chart 2).

**Chart 2**



**How important is it to you as a patient
to understand how your medical and health information
is collected and used by the EHR / paper medical record system?**

Base = EHR group (n=1153) and paper group (n=808)

EHR group:
- Not at all important, 3%
- Not very important, 9%
- Somewhat important, 41%
- Very important, 47%

Paper group:
- Not at all important, 3%
- Not very important, 14%
- Somewhat important, 45%
- Very important, 37%

Of note, Hispanic adults in EHR systems in particular were higher in saying it is important to them to understand how their EHR works (94 percent compared to 88 percent of the total EHR sample).

Our sense is that the high level of discussions in the media about the spread of data breaches in health care systems – and about the adoption, use and implications of EHR systems – may have

sensitized patients to how their detailed medical and health information is being recorded and used. As a result, understanding this has become important to a majority of patients.

### 2. Doctor and Staff Explanation of Record System's Operations

Once we had established the extent to which respondents cared about the collection and use of their health information, we wanted to understand how well such knowledge or understanding was being conveyed to them (Chart 3).

**Chart 3**

**How well do you feel your doctor and his or her staff have informed you about how medical and health information is collected and used by the EHR / paper medical record system?**

Base = EHR group (n=1153) and paper group (n=808)

| | EHR group | Paper group |
|---|---|---|
| Did not explain it at all | 33% | 41% |
| Explained it fairly poorly | 16% | 13% |
| Explained it well | 38% | 36% |
| Explained it very well | 13% | 10% |
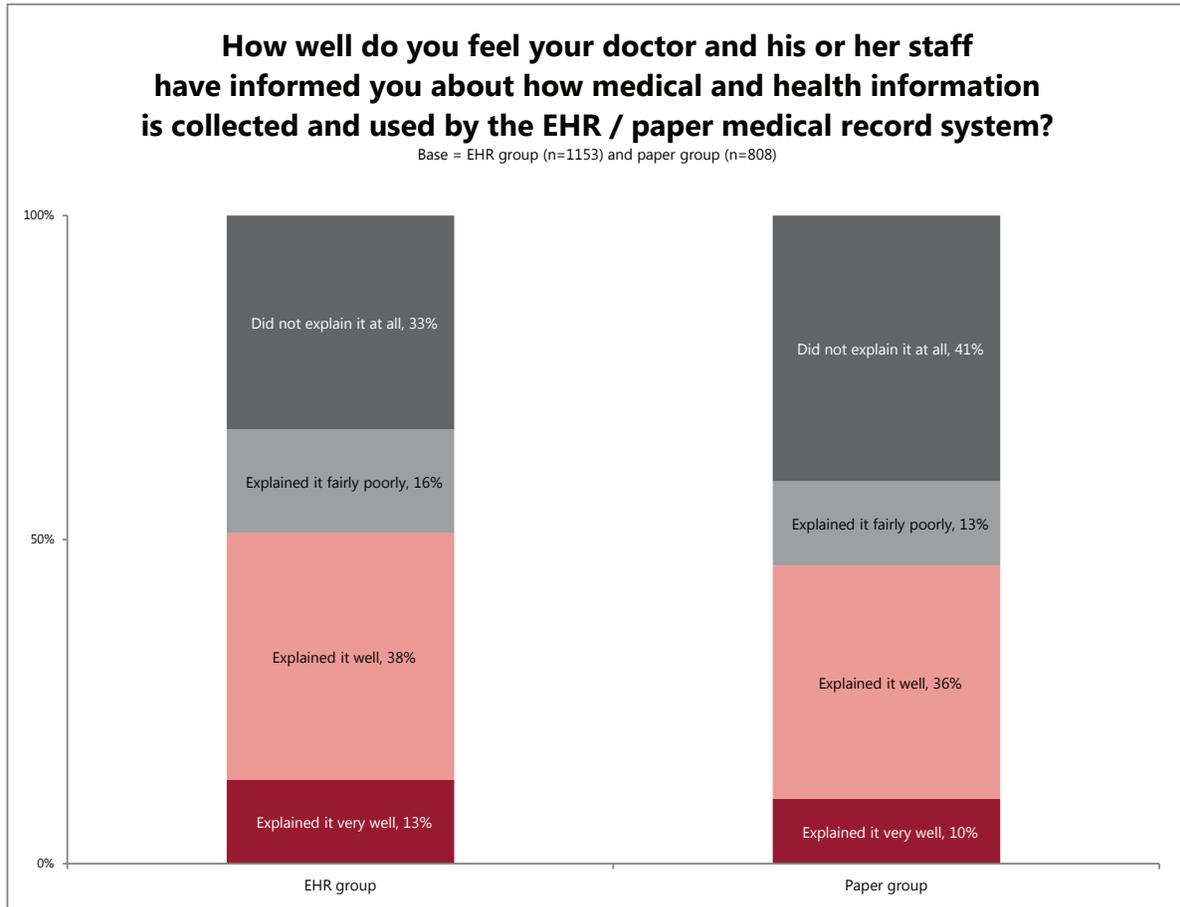
This is a very concerning picture of patient communications by health care providers and their staff. Nearly a third of EHR respondents and more than a third of paper respondents say they were not informed about how their information is collected and used, while only about half of both groups said these issues were explained well. We note that Hispanic respondents were more likely than the total sample to say that they were well informed by their doctor and staff about how their EHR system works (63 percent of Hispanic EHR respondents, compared to 51 percent of total EHR respondents).

Patients clearly care about these issues, and these data would seem to confirm a widely held belief that Health Insurance Portability and Accountability Act (HIPAA) notices are incomplete or inadequate for conveying this information, and/or that they are not accomplishing their intended purpose.

Although no one would expect to receive detailed technical specifications or complicated flow charts, effective explanations of, for example, what goes into records, who gets to see and use them,

when patients are able to decide what uses are made beyond health care, how basic data security is being applied, the patient's right to amend data, etc., would seem to be vital patient communication content if patient engagement in and comfort with EHR systems is an important goal.

## B. Usefulness of Systems in Helping with Care Delivery

### 1. Electronic Health Records

One of the important goals of this survey was to determine the extent to which people believe their medical record system accomplishes or improves upon various elements of health care.  We chose response options that studies have shown tend to be the most valuable to patients, such as care coordination or ability of patients to communicate directly with their health care providers.[8]  We asked *both* sets of respondents first about their views on electronic records (Chart 4).[9]

**Chart 4**



How useful do you think EHRs are/would be when it comes to each of the following?
Base = EHR group (n=1153) and paper group (n=808)
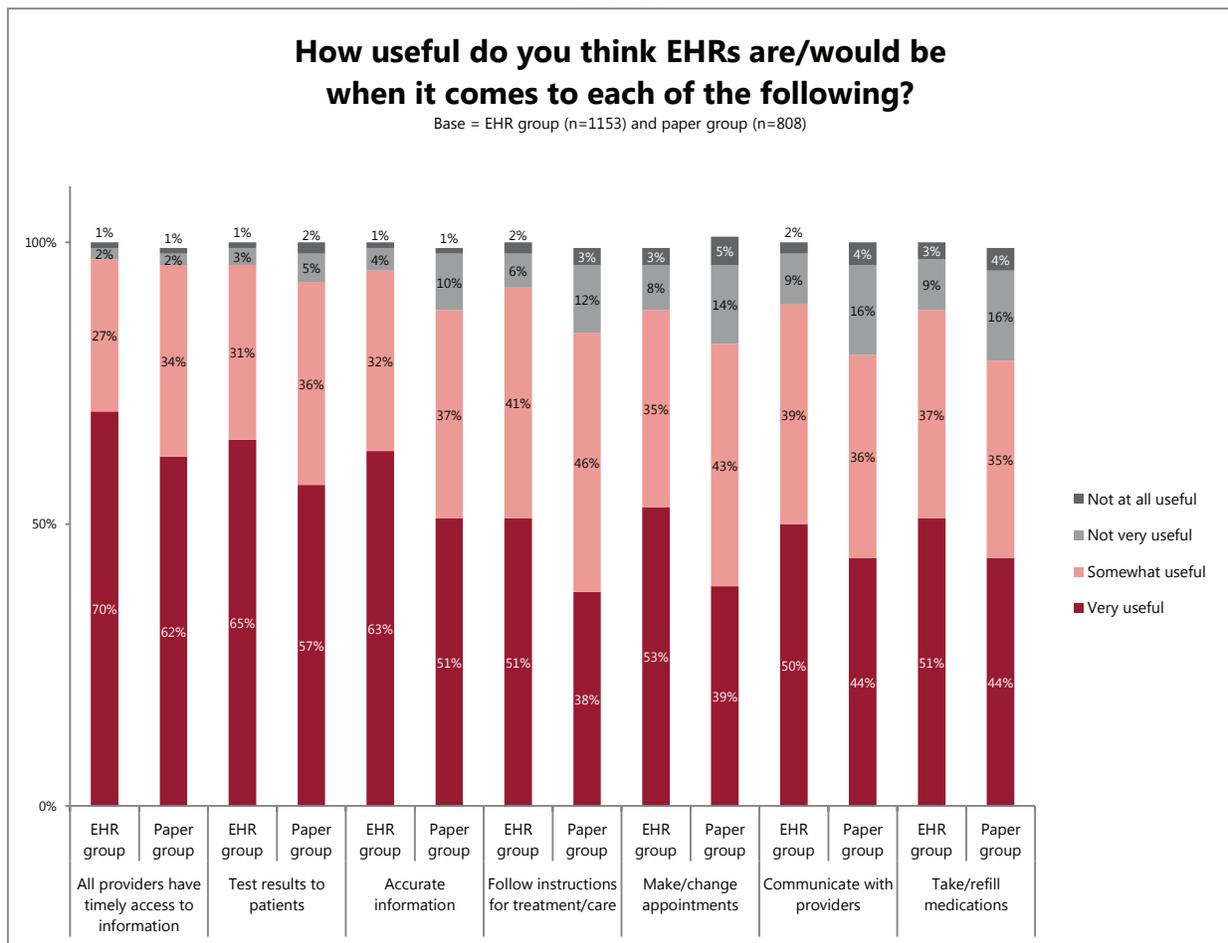
*(Note that here, as in many other places in the survey, EHR respondents are making judgments based on direct personal experience with an EHR system, while the paper-system respondents are making judgments about EHR systems based on, presumably, what they have read, heard or can imagine about EHR systems.)*

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8 *See* note 1.
9 Full text of question elements was: 1) Making sure that all the different health care providers who treat a patient have timely access to all the relevant information for his or her care, like test results and diagnoses; 2) Getting test or laboratory results to patients in a timely manner; 3) Helping patients make sure the information in their medical record is accurate; 4) Helping patients follow their health care providers' instructions for treatment or care of themselves or a family member; 5) Helping patients make or change their appointments; 6) Helping patients communicate directly with their health care providers; and 7) Helping patients take and refill their medications as prescribed.

These results – between 88 and 97 percent of EHR respondents and between 80 and 97 percent of paper system respondents saying EHRs are or (in the case of paper-system respondents) would be useful in improving various aspects of care delivery – represent a powerful seal of patient approval for EHR systems' assumed effects on major aspects of the health care process. Moreover, the higher results from EHR respondents in all but one category can be read as notably positive patient evaluations of perceived EHR system usefulness.

### 2. Paper Record Systems

The survey also asked respondents how useful they thought <u>paper</u> record systems "are/would be" in providing these same seven services (Chart 5).[10]

Two points are important to make about these ratings of paper systems. First, the ratings are fairly close between the two respondent groups, but higher numbers of paper-system respondents rated their system as useful for six of the seven patient services. This likely reflects their real-world experience limited to paper systems.

**These results represent a powerful seal of patient approval for EHR systems' assumed effects on major aspects of the health care process. Moreover, the higher results from EHR respondents in all but one category can be read as notably positive patient evaluations of perceived EHR system usefulness.**
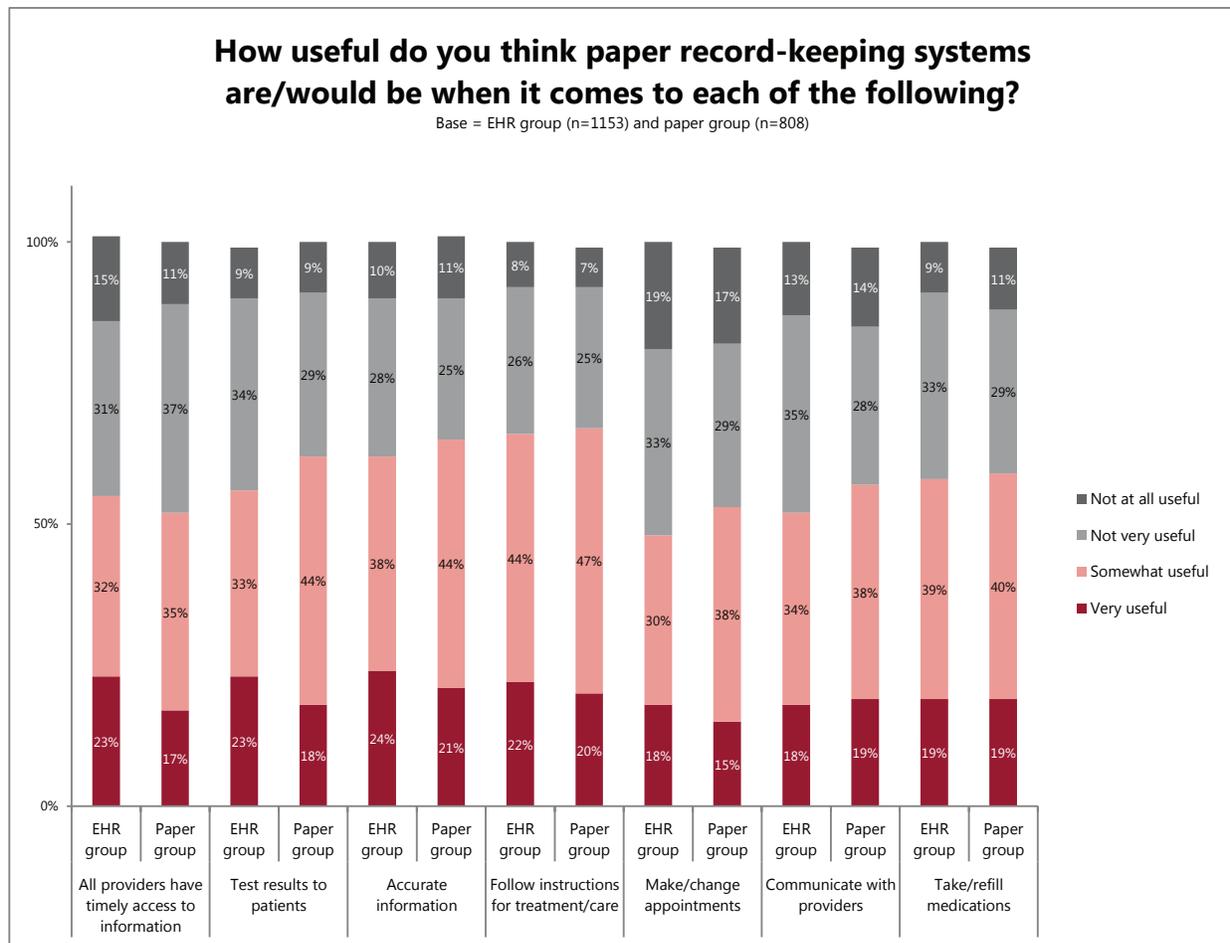
### Chart 5



How useful do you think paper record-keeping systems are/would be when it comes to each of the following?

Base = EHR group (n=1153) and paper group (n=808)

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10 For full text of question elements, see note 9.

Second, in comparing both sets of usefulness ratings – those for EHRs and paper record systems – EHRs were rated much more highly by both respondent sets.  Depending on the element, between 88 and 97 percent of EHR respondents positively rated the usefulness of these seven services in EHR systems, and between 80 and 97 percent of paper-system respondents rated the usefulness of EHR systems positively.

## C.  Usefulness of Systems to Doctors and Patients

### 1. Value of Record System to Doctors

The survey also sought to ascertain from respondents both how well they believe their provider's record system helps *their doctors and staff* to care for them (Chart 6),[11] and the extent to which the record systems helps them *personally* as patients (Chart 7).[12]

**Chart 6**



How much do you believe the
EHR / paper medical record system helps your doctor
and his or her staff with the following?

Base = EHR group (n=1153) and paper group (n=808)
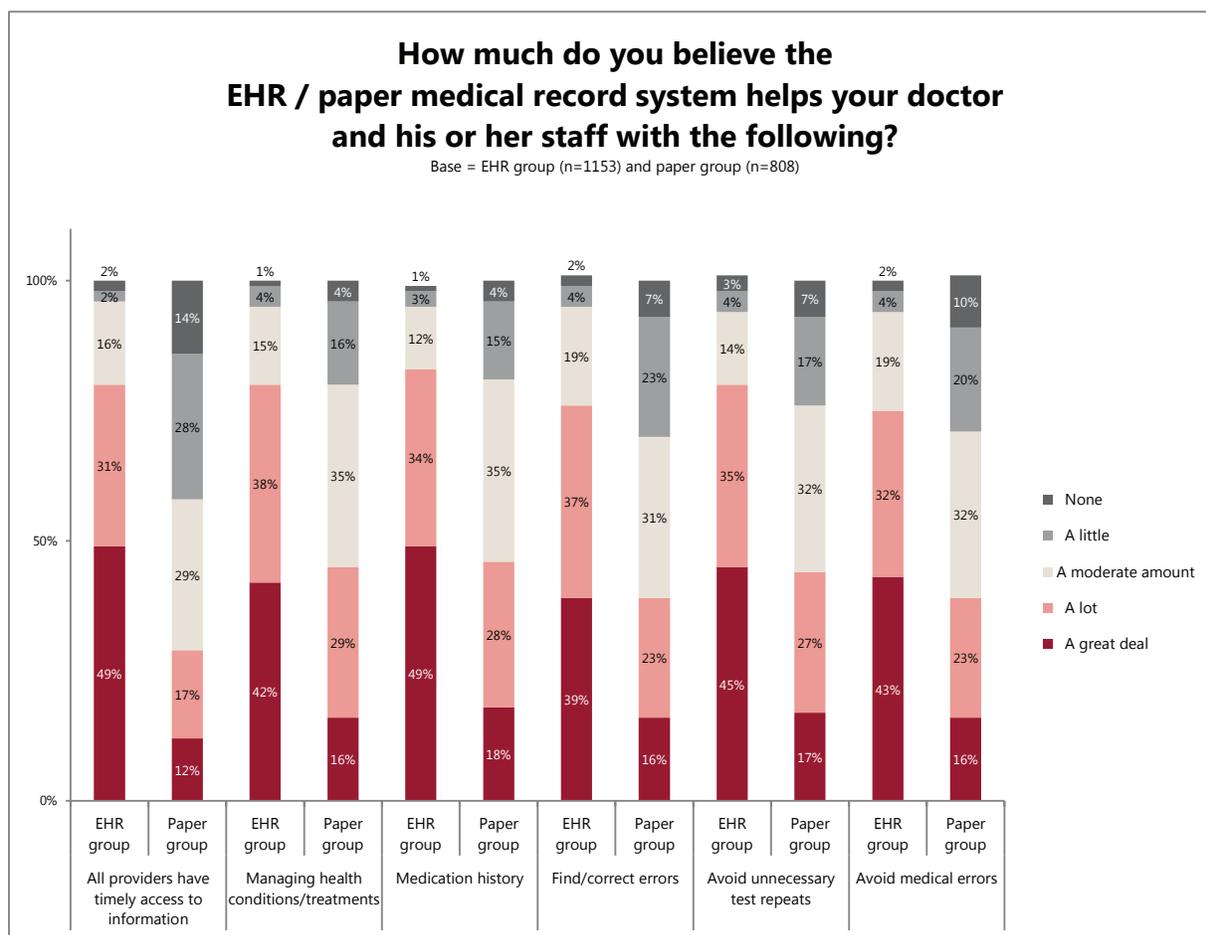
**These results are among the most dramatic in the survey.**  Seventy-five to 84 percent of respondents in EHR systems rate those systems positively as helping doctors and their staffs provide these vital services.  By contrast, only 29 to 46 percent of respondents in paper systems rated their record systems as definitely helpful to doctors and staff.  The very low 29 percent of paper-system

11 The full text of the question elements was: 1) Making sure that all the other health care providers who treat me have timely access to the relevant information for my care (i.e., test results, medications, allergies, etc.); 2) Managing and keeping up with my health conditions and treatments; 3) Keeping up with my medication history; 4) Being able to correct errors or incomplete information in my medical record; 5) Not having to repeat medical tests unnecessarily; and 6) Being able to avoid medical errors, like prescribing drugs that conflict with each other, or to which you are allergic.
12 The full text of the question elements was: 1) Avoiding having to repeatedly fill out forms regarding my medical information; 2) Understanding my health condition better; 3) Sharing information with all of my health care providers; 4) Keeping up with my medications, including remembering to take them and getting timely refills; 5) Helping maintain a healthy lifestyle, including having good nutrition, exercising regularly, not smoking, etc.; and 6) Finding and correcting errors or incomplete information in my medical record.

respondents rating their system positively for timely access to relevant information by the care team – a critical component of care coordination – is particularly striking.

If we add "a moderate amount" into the totals – since this is basically a weaker but still positive reading – EHR respondents giving positive ratings rose to between 94 and 96 percent, while paper system totals rose to between 58 and 81 percent. Very few respondents – either in EHR or paper systems – chose "a little" or "none" as their view of their own record system's value to doctors and staff. However, we note that Hispanic adults in EHR systems were somewhat *lower* than the total EHR sample in saying EHR systems were useful in helping their doctors to provide various health care services, such as keeping up with their medication history (-6 percentage points) and making sure all providers have relevant data (-5 percentage points).

**Seventy-five to 84 percent of respondents in EHR systems rate those systems positively as helping doctors and staff provide services, compared to only 29 to 46 percent of respondents in paper systems. The fact that only 29 percent of paper-system respondents rate the system positively for timely access to information by the care team is particularly striking.**

### 2. Value of Record System to Patients

The survey results show (Chart 7) that about twice as many EHR respondents rated their record system as having positive value to them ("a great deal" or "a lot") than did paper-system respondents.

### Chart 7



**How much does the EHR / paper medical record system your provider uses help you personally with the following?**

Base = EHR group (n=1153) and paper group (n=808)

| | EHR group | Paper group | EHR group | Paper group | EHR group | Paper group | EHR group | Paper group | EHR group | Paper group | EHR group | Paper group |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| None | 10% | 25% | 19% | 27% | 11% | 22% | 26% | 29% | 31% | 35% | 17% | 26% |
| A little | 9% | 15% | 14% | 17% | 9% | 21% | 12% | 17% | 12% | 16% | 13% | 24% |
| A moderate amount | 17% | 24% | 21% | 28% | 17% | 30% | 19% | 26% | 23% | 25% | 24% | 23% |
| A lot | 25% | 23% | 24% | 18% | 29% | 17% | 19% | 16% | 17% | 15% | 24% | 18% |
| A great deal | 39% | 13% | 22% | 10% | 35% | 10% | 24% | 11% | 16% | 9% | 23% | 9% |

Avoid filling out forms — Understanding my health condition better — Share info with providers — Keep up with medications — Maintain healthy lifestyle — Find/correct errors

The same ratio is present if we add "a moderate amount" into the positive group, where the EHR respondents rose to between 56 and 81 percent, while paper-system respondents increased only to between 49 and 56 percent.

Note that for four out of six of these dimensions (understanding my health condition, keeping up with my medications, helping maintain a healthy lifestyle, finding and correcting errors in my record), only a minority of respondents said the EHR helps them personally (a great deal or a lot). For these same four dimensions, between 17 and 31 percent of respondents said the system helped them "none." Given that these functionalities are technically possible with an EHR with online access for patients – with the potential exception of sharing health information with other providers outside a particular health system – it is likely that providers aren't using their systems in these ways, or are not offering these services to patients with much, if any, effect.

We found some important differences in this dimension between the general EHR sample and our Hispanic adult sample. Hispanic adults in EHR systems were much higher in rating EHRs as useful for them personally in carrying out patient health-promotion activities:

▸ Understanding their health conditions (+13 percentage points)
▸ Helping maintain a healthy lifestyle (+18 percentage points)
▸ Keeping up with medications (+11 percentage points)

**Chart 8**

## What impact do you believe your doctor's use of an EHR / paper medical record system has on the overall quality of your health care services?

Base = EHR group (n=1153) and paper group (n=808)

**EHR group**
- Very negative, 1%
- Somewhat negative, 2%
- No impact, 25%
- Somewhat positive, 42%
- Very positive, 31%

**Paper group**
- Very negative, 1%
- Somewhat negative, 15%
- No impact, 58%
- Somewhat positive, 15%
- Very positive, 11%

These data point to an important potential for EHRs – that, if used meaningfully with a focus on helping patients personally, EHRs could help facilitate activities to reduce disparities in health outcomes.

## D. Impact of Record Systems on Quality of Care

### 1. Impact of Record System on Overall Quality of Respondents' Health Care

Having asked respondents about what they saw as the effects of their record systems on specific components of their health care, and about the value both to their doctors and to them personally, the survey sought to assess the impact respondents believe the record system has had on the *overall quality* of their care (Chart 8).

Again, these results are quite dramatic. Seventy-three percent of EHR respondents see positive impacts, compared to only 26 percent of paper-system respondents. Although 25 percent of EHR respondents say they perceive no impact on the quality of their health care from their EHR system, more than twice as many paper-system respondents (58 percent) see no impact. Only 3 percent of EHR system respondents see a negative impact, compared to 16 percent of paper-system respondents.

### 2. Impact on Care of Switching to an EHR System

We explored how patients in paper systems today – 38 percent of whom have a solo practitioner as their main doctor – felt about their doctor converting to an EHR system. We asked them how valuable it would be to them that their main doctors adopt and use an electronic health record system (Chart 9).

### Chart 9



**Although you mentioned your main doctor currently uses
a paper medical record system, how valuable would it be
to you as a patient that your main doctor adopt and use
an electronic health record system?**

Base = Paper group (n=808)

Not valuable at all, 10%

Not very valuable, 18%

Somewhat valuable, 52%

Very valuable, 21%

Paper group
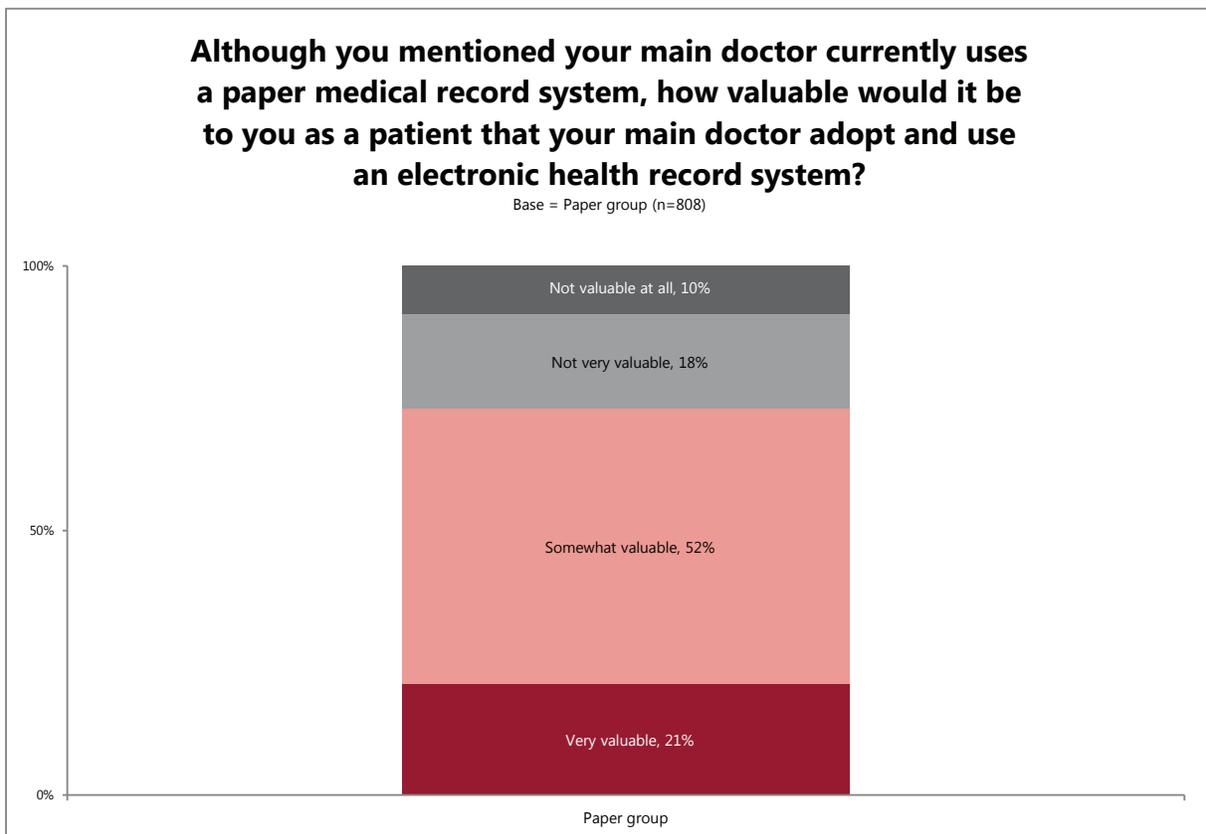
Almost three-quarters – 73 percent – of the paper system respondents said this would be either very (21 percent) or somewhat (52 percent) valuable, a striking endorsement.

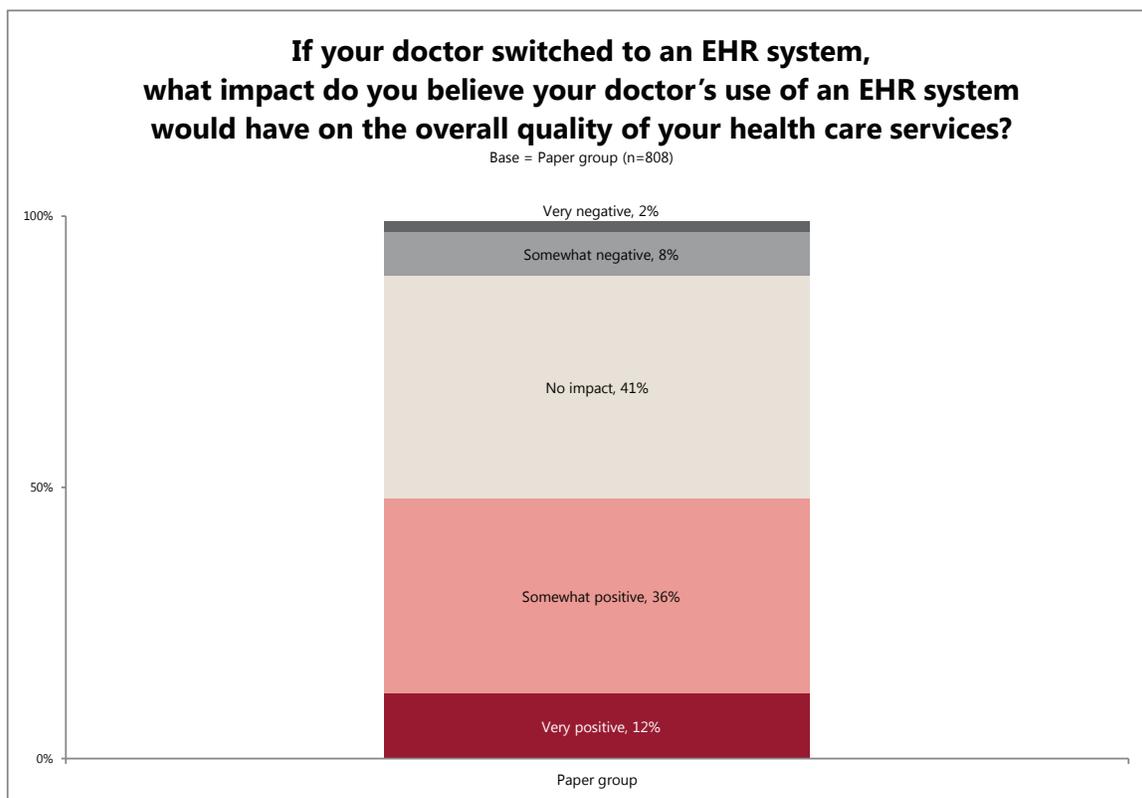We then asked the full paper-system sample about the impact they believe their doctor's use of an EHR system would have on quality of care (Chart 10). Although 48 percent of respondents said they felt there would be a positive impact of such a switch (with 12 percent answering "very positive"), a substantial 41 percent answered "no impact," and 10 percent felt there would be a negative impact. This indicates that while nearly three-quarters of paper-system respondents want their doctor to adopt an EHR, they are not connecting this adoption to improved quality.

**Chart 10**

**If your doctor switched to an EHR system,
what impact do you believe your doctor's use of an EHR system
would have on the overall quality of your health care services?**

Base = Paper group (n=808)

| | |
|---|---|
| Very negative, 2% | |
| Somewhat negative, 8% | |
| No impact, 41% | |
| Somewhat positive, 36% | |
| Very positive, 12% | |

Paper group

We note than in any discussion of quality, it is important to understand that patients often define quality differently than do "experts." Consumers do not always think of quality in terms of clinical aspects – e.g., whether care meets evidence-based guidelines. Many consumers perceive quality in terms of service quality (i.e., timeliness of appointment, friendliness of providers); people are more comfortable with, and can talk more easily about, ideas of service quality than clinical quality.[13] While patients may not now intuitively connect the role their record system can play to their experience or clinical quality of care, showing them how certain features of an EHR can improve both could change their perception.

### 3. Overall Satisfaction with Record System

Our second general assessment was designed to understand overall patient satisfaction with their current record systems. The survey asked respondents about how satisfied they are with the medical record system currently used by their doctors (Chart 11). Again, the results are compelling.

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13 Communicating about Quality: Communications Research Conducted by the RWJF. Robert Wood Johnson Foundation (November 2007. Page 6. *Available at:* http://www.rwjf.org/files/research/71858.pdf.

**A significant number of respondents in paper systems say they would see real value in their provider switching to an electronic record system, but they simultaneously do not see a problem with their current, paper system.**

**Chart 11**



**Overall, how satisfied are you as a patient with the EHR / paper medical record system your main doctor is using?**

Base = EHR group (n=1153) and paper group (n=808)
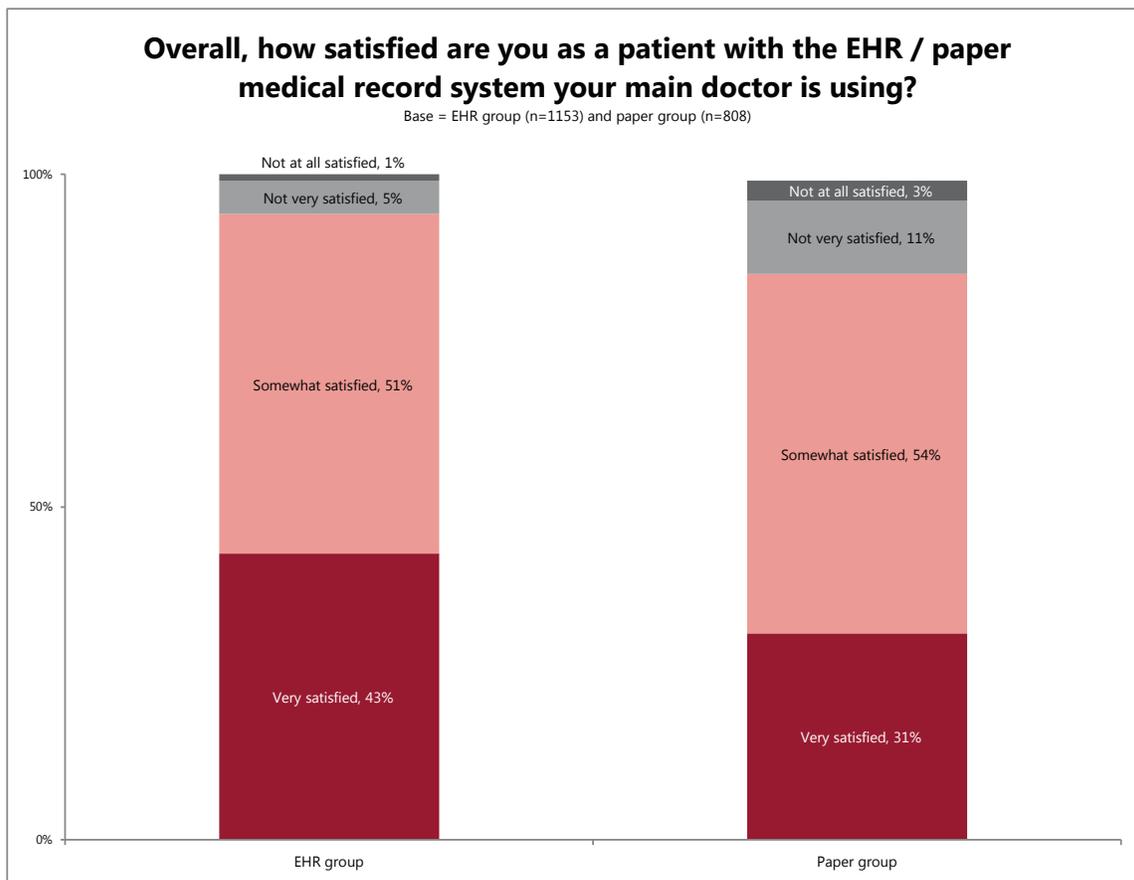
Although EHR respondents are more satisfied with their systems than paper-system respondents, almost a third of paper-system respondents are "very satisfied," and only 14 percent express dissatisfaction. Overall, then, patients are generally satisfied with their current record system, and although they see some of the potential benefits of health IT, they don't necessarily see a current problem with their record system that needs to be fixed.

## E. Online Access to Medical Records

In drafting the survey, we sought to explore whether a patient's views of an electronic health record system were affected by whether he or she had online access to his or her medical record. Our hypothesis was that people with online access to their records experience more tangible benefits of an EHR system, and therefore may express more positive opinions. We asked EHR respondents:[14]

> *Does your main doctor, the doctor you see most often, give you online access to your medical information?*

Twenty-six percent of EHR respondents said they did have such access, though EHR respondents in the West were more likely to have such access (39 percent), as were Hispanic adults (38 percent).

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14 *Note*: Patients can obtain online access to medical records in a number of ways, as products ranging from personal health records to insurance plan-provided web portals are currently available. However, we formulated our question to focus on online access provided by the patient's doctors.

When asked about the frequency of their use of online access, EHR respondents reported a wide range of usage patterns (Chart 12), but notably 48 percent are frequent or fairly frequent users (i.e., three times a year or more).  Interestingly, Hispanic adults were 15 percentage points lower in saying they never use their online access.

**Chart 12**

**How often do you log into the website offered by your doctor to see your medical information?**

Base = EHR group whose doctor provides online access (n=323)



- 3 or more times a month, 3%
- 1-2 times a month, 7%
- 7-11 times a year, 12%
- 3-6 times a year, 26%
- Once or twice a year, 32%
- Never, 20%
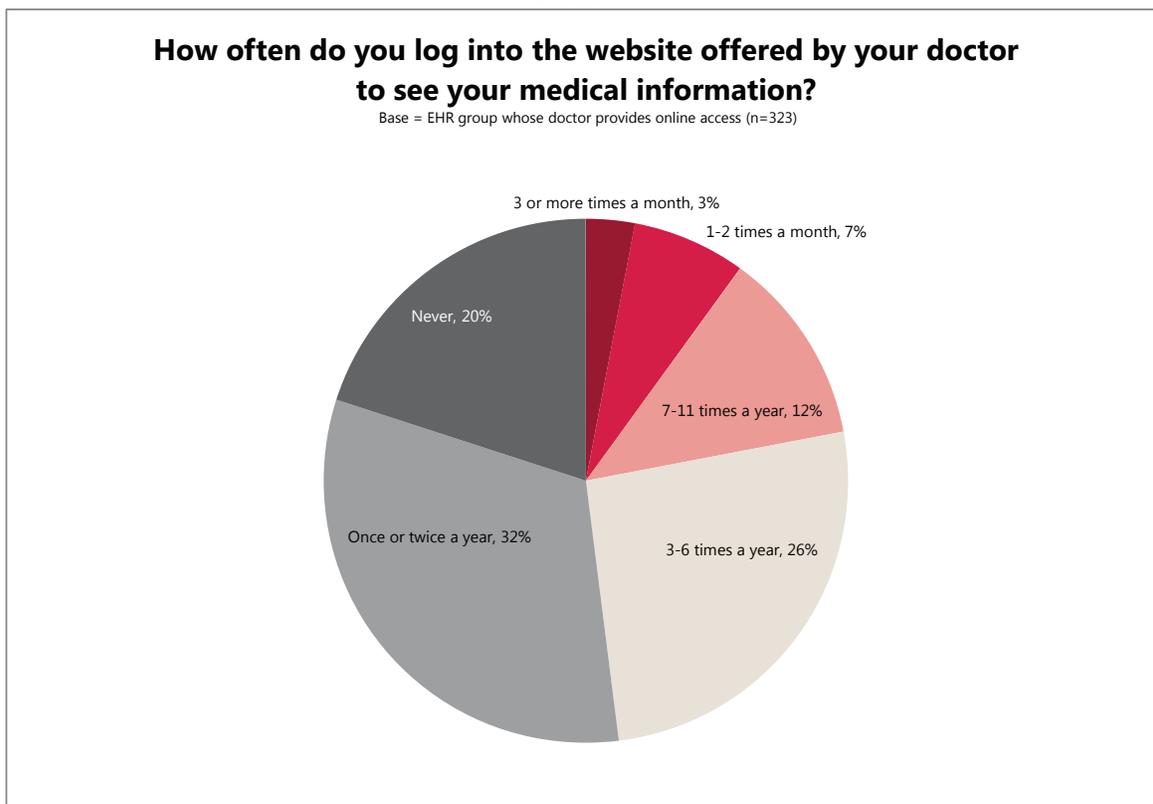
The next question explored the value of such access and asked the EHR respondents with online access how it has affected various aspects of their health and care (Chart 13).  Respondents rated the value of their online access rather highly, with strong percentages choosing "very" or "somewhat positive impact" across each listed dimension.  These positive-impact ratings portray a majority (both small and large) of online users experiencing value in their online access.  Very small numbers of EHR respondents said online access had a "somewhat negative" or "very negative" impact on the listed health or care dimension, ranging from 4 to 5 percent.

**Sixty-five percent of paper-system respondents said online access would be "very" or "somewhat important" to them.**

Finally, we asked paper-system respondents:

> *Regardless of whether you have access currently, how important is it to you that you be provided with access to your medical and health information online?*

**Nearly two-thirds – 65 percent – of these paper-system respondents said online access would be "very" or "somewhat important" to them.**  This is another important finding, as it indicates a real desire for increased access to patients' own health information, and illustrates the opportunity for improved education of providers about patients' desire for such access and its impact.  Further, as we will demonstrate below, it also presents a major opportunity to increase the trust patients have in electronic systems.

**Chart 13**

## How has having access to your medical and health information online impacted the following?

Base = EHR group who use doctor-provided online access (n=254)
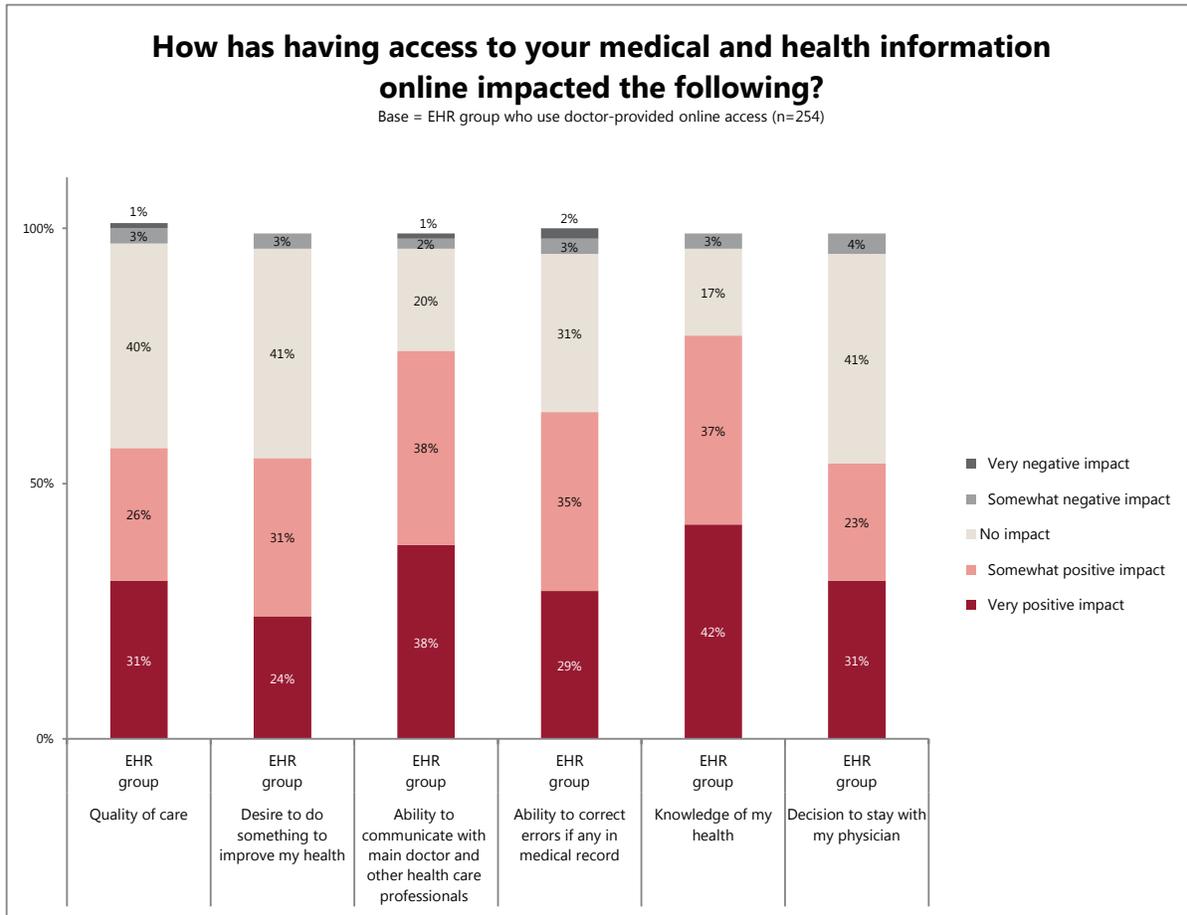


**1. Differences Between EHR Respondents with Online Access and the General EHR Sample**

There were a number of differences between respondents with online access to their medical records and the general EHR sample.  Areas where their opinions were similar included the usefulness of EHR systems for delivery of the seven health care services noted in Chart 4, as well as the usefulness of EHR systems for protecting five elements of patient privacy (described in more detail below, and illustrated in Chart 16).  Online users were also similar to all EHR respondents in how often they, as patients, said they engaged in six individual health-promotion activities, as presented in Chart 1.

However, online access respondents answered significantly differently from other EHR respondents on a number of important questions.  Online users were *more likely* than the total population of EHR respondents to:

▸ Say they were well informed by their doctors and staff on how their medical information is collected and used in the EHR system (67 percent with online access; 51 percent without);

▸ Say they were well informed by their doctors and staff about four specific patient rights and how they are protected by their EHR systems:

1. Right to be informed and exercise choice before personal medical or health information is made available to others for purposes beyond health care (62 percent with online access; 52 percent without);

2. How privacy/confidentiality of personal medical and health information is being protected (58 percent with online access; 49 percent without);
3. Right to see all or parts of medical record and have a copy made if wished (65 percent with online access; 47 percent without);
4. How security of health information is protected from accidental or malicious disclosure (58 percent with online access; 41 percent without);

▶ Rate their EHR system as very useful when it comes to:

   ▸ Helping patients take and refill their medications as prescribed (56 percent with online access; 51 percent without);
   ▸ Helping patients communicate directly with their health care providers (56 percent with online access; 50 percent without);
   ▸ Getting tests or laboratory results to patients in a timely manner (70 percent with online access; 65 percent without);

▶ Say their EHR system helps their doctors and staff when it comes to:

   ▸ Being able to correct errors or incomplete information in [their] medical record (82 percent with online access; 75 percent without);
   ▸ Being able to avoid medical errors, like prescribing drugs that conflict with each other, or to which they are allergic (82 percent with online access; 75 percent without);

▶ Say their EHR system helps them *personally* in:

   ▸ Avoiding having to repeatedly fill out forms regarding their medical information (73 percent with online access; 64 percent without);
   ▸ Sharing information with all of their health care providers (72 percent with online access; 63 percent without);
   ▸ Finding and correcting errors or incomplete information in their medical record (58 percent with online access; 46 percent without);
   ▸ Understanding their health condition better (58 percent with online access; 46 percent without);
   ▸ Keeping up with their medications, including remembering to take them and getting timely refills (54 percent with online access; 43 percent without);
   ▸ Helping maintain a healthy lifestyle, including having good nutrition, exercising regularly, not smoking, etc. (43 percent with online access; 34 percent without);

**It is likely that, as in other industries, the more personal experience patients have with their health information, and the more they can do with it, the more supportive they are of these technologies. Having online access may also help increase transparency of, and therefore trust in, record systems.**

▶ Say they felt their EHR had a positive effect ("somewhat" or "very") on their overall quality of health care services (82 percent with online access; 72 percent without);
▶ Say they are "very satisfied" with their EHR system (59 percent with online access; 43 percent without); and
▶ Say that, overall, they trust their doctor and staff to protect their patient rights (78 percent with online access; 73 percent without).

Notably, when the total EHR respondent ratings on these various questions were less positive, or mixed, **online users were consistently more positive on each of the topics cited above**. This included not only ratings of the value of EHR systems for health care services, patient rights protections and overall satisfaction with and trust in EHR system operations. It also included the belief that they had been well informed by their doctor and staff about the ways their personal health information was being collected and used, and how their patient rights were being administered.

**This points to the significant potential that online access has for improving patients' perceptions of EHRs and for helping them manage their care and their health conditions in improved ways.** It is likely that, as in other industries, the more personal experience patients have with their health information, and the more they can do with it to improve their health and care, the more supportive they are of the value of these technologies. In addition, having online access to one's own health information may also help increase transparency of, and therefore trust in, record systems.

### 2. Why Don't Some Patients Use Online Access?

To learn why a few EHR respondents (between 4 and 5 percent, depending on the particular dimension of care) with available online access saw no impact or a negative impact on their care, we collected narrative responses. We selected two of the health processes listed above – "ability to communicate with main doctor and other health care professional" and "ability to correct errors, if any in [their] medical record" – and asked those who had said there was either "no impact" or "negative impact" to explain their reason for those choices.

In terms of the ability to communicate with health professionals, the narratives presented practical and personal reasons as to why some EHR respondents felt online access was having little or no impact on their care, including:

▶ You can't communicate with the doctor through the online access;
▶ Online access doesn't contain full medical record/records are incomplete;
▶ My doctor is good and thorough on communicating with me in person at my appointments;
▶ Prefer to communicate in person/on the phone; and
▶ Healthy, no serious health issues that require further [doctor contact].

Individuals provided similarly valuable reasons for finding that online access has no impact or a negative impact in terms of correcting any errors in their medical records, including:

▶ Errors must be corrected by a physician;
▶ Do not know how to access/view medical records;
▶ Do not use online access/prefer to do it in person;
▶ Only view my annual lab reports online; and
▶ They have not corrected errors that need correcting.

These responses are important because they indicate that perceived value is driven both by patient preferences (such as for communicating in person) but also significantly by available functionality and the way online access can be used (such as for communication or correcting information). **Online access has the potential to be much more valuable to patients if the functionality can be expanded and improved, and if doctors or their staff would themselves play a role in increasing the effectiveness and use of the access they offer.**

Importantly, we can and should not place undue value on the number of times individuals log into their health record, as the number of times an account is accessed does not say anything about the value of each event, or the value to an individual of merely having the option.  The above discussion merely attempts to understand what it is about online access that patients value most, so we can work to increase this value in the future.
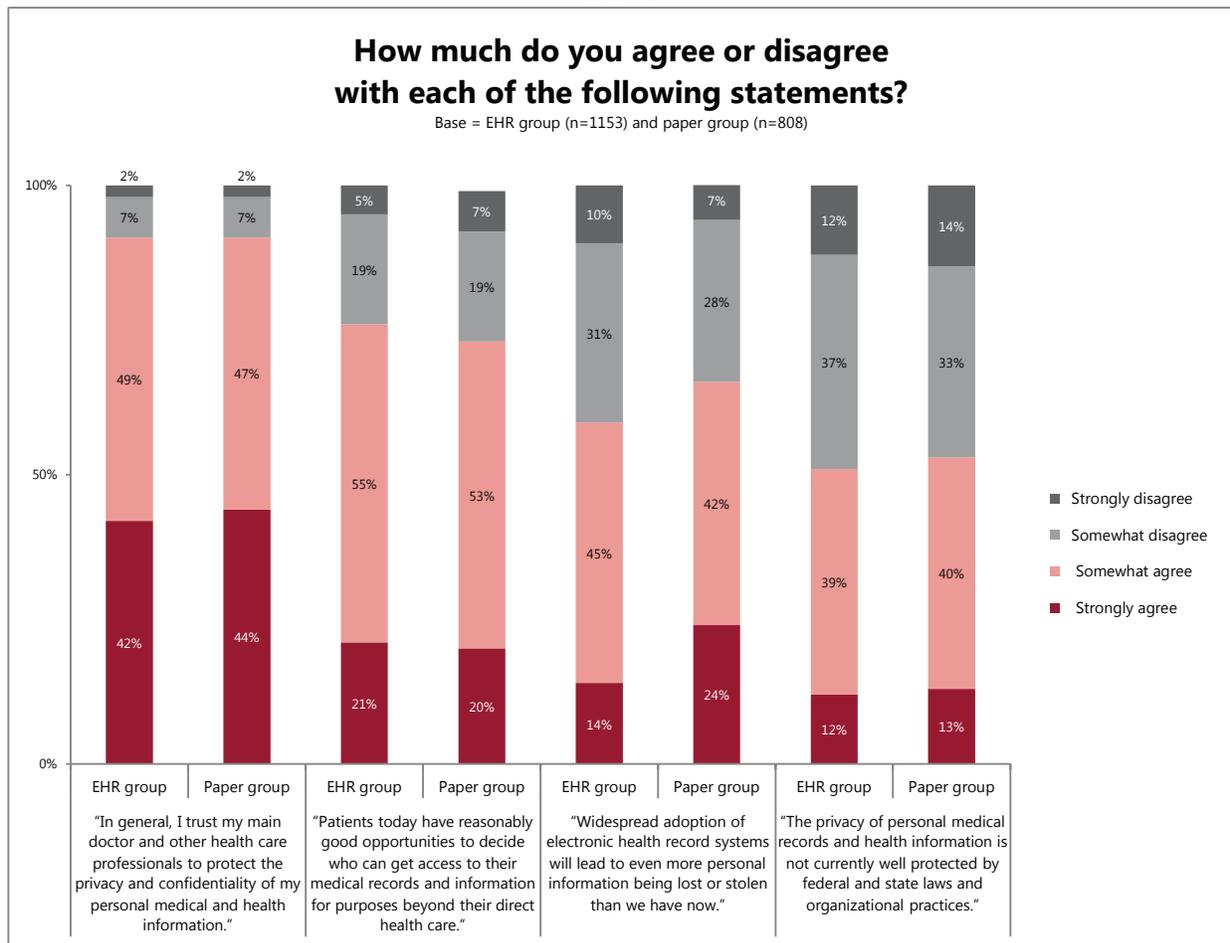
# V. Patient Trust in Record Systems

## A. Privacy Attitudes

The just-described set of questions explored the value respondents saw in both electronic and paper record systems. The second main component of our survey was designed to understand how patients view both systems' effect upon or ability to handle patient privacy rights.

First, we sought to develop a profile of each respondent's general orientation toward privacy and security issues in health care. To do this, we presented respondents with four assertive statements and asked whether they agreed (strongly or somewhat) or disagreed (strongly or somewhat) with each statement (Chart 14).[15]



**Chart 14**

**How much do you agree or disagree
with each of the following statements?**

Base = EHR group (n=1153) and paper group (n=808)

We put two of the statements into positive terms and two in negative terms, and the order of the four statements was randomized to prevent order influence:

▸ In general, I trust my main doctor and other health care professionals to protect the privacy and confidentiality of my personal medical and health information;

▸ Patients today have reasonably good opportunities to decide who can get access to their medical records and information for purposes beyond their direct health care;

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15 We used these patient privacy attitudes as a basis for our Privacy Segmentation, which was designed to stratify respondents by their general privacy orientation and then identify which groups of the population are generally high or low trusting, or somewhere in between. This segmentation is discussed in detail in our Privacy Segmentation section.

▸ Widespread adoption of electronic health record systems will lead to even more personal information being lost or stolen than we have now;

▸ The privacy of personal medical records and health information is not currently well protected by federal and state laws and organizational practices.

There are a number of things to note based on these results:

▸ Although higher in the aggregate, only 42 percent of our EHR respondents and only 44 percent of our paper-system respondents said they agreed "strongly" with general trust of their providers when it comes to protecting privacy. This suggests the respondents who chose "somewhat" – 49 percent of EHR respondents and 47 percent of paper-system respondents – still had some trust concerns with their health care providers.

▸ Regardless of the record system, neither secondary use practices in health care, nor laws and regulations, actually give patients today the sense that they have "reasonably good opportunities" to control uses beyond direct care. This fact is reflected in many health care privacy surveys that have recorded deep concerns in public opinion regarding the spread of personal health information for secondary uses such as research or marketing, unless individual patient notice and consent are provided.[16]

▸ Hispanic respondents were much more likely to agree that widespread adoption of EHRs will lead to even more personal information being lost or stolen than we have now (73 percent of those in electronic systems, compared to 59 percent of all EHR respondents; 64 percent of those in the paper group, compared to 66 percent of all paper respondents). We note that the Hispanic breakdown along system lines is the reverse of that in the general sample.

It is likely that respondents are affected by the drumbeat of recent and current media reports of large-scale data breaches from health care facilities, in both types of record systems. The lower rating of breach likelihood among EHR respondents probably reflects their greater experience with electronic records, and potentially their higher education levels.

## B. Handling of Patient Privacy Rights

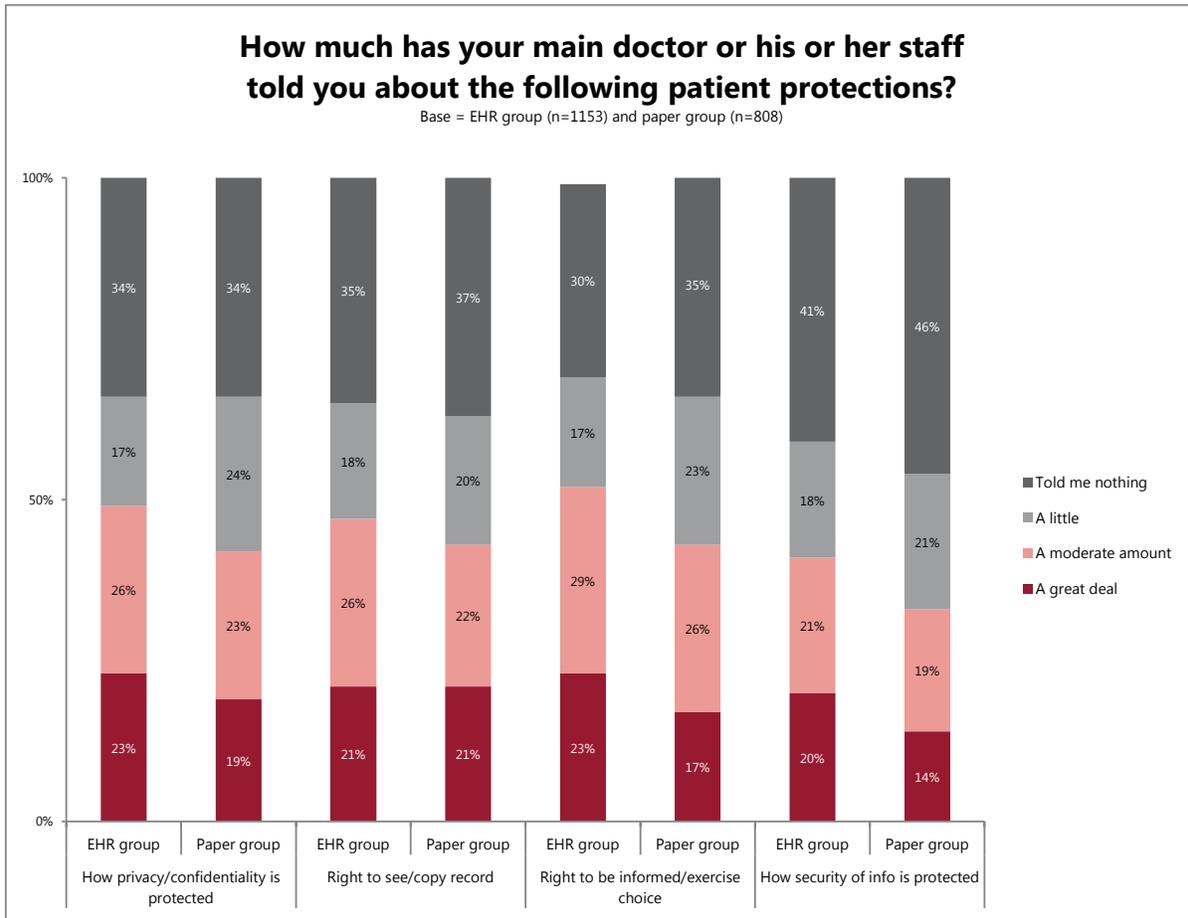### 1. Effectiveness of Provider Communications

To establish a baseline for how effective provider communications about privacy have been, we asked about the extent to which each respondent's provider has informed them of four specific legally-granted privacy rights (Chart 15):

▸ How the privacy and confidentiality of my medical and health information are being protected;

▸ My right to see all or parts of my medical record and have a copy made if I wished to;

▸ My right to be informed and exercise choice before my personal medical or health information is made available to others for purposes beyond my health care; and

▸ How the security of my health information is being protected from being disclosed accidentally or maliciously.

We note that Hispanic adult respondents in EHR systems were 10 to 21 percentage points higher than the total EHR sample in saying they felt well-informed about these privacy dimensions.

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16 *See, e.g.*, Xerox Corporation, "Security of Electronic Health Records," July 2011; Pew Internet Project, "The Social Life of Health Information," May 2011; "How Privacy Considerations Drive Patient Decisions and Impact Patient Care Outcomes," Fair Warning report, September 2011; and SailPoint Market Pulse Survey, Healthcare Results, September, 2011.

**Chart 15**

**How much has your main doctor or his or her staff
told you about the following patient protections?**

Base = EHR group (n=1153) and paper group (n=808)



Legend:
- Told me nothing
- A little
- A moderate amount
- A great deal

Categories: How privacy/confidentiality is protected | Right to see/copy record | Right to be informed/exercise choice | How security of info is protected

| | Told me nothing | A little | A moderate amount | A great deal |
|---|---|---|---|---|
| How privacy/confidentiality is protected — EHR group | 34% | 17% | 26% | 23% |
| How privacy/confidentiality is protected — Paper group | 34% | 24% | 23% | 19% |
| Right to see/copy record — EHR group | 35% | 18% | 26% | 21% |
| Right to see/copy record — Paper group | 37% | 20% | 22% | 21% |
| Right to be informed/exercise choice — EHR group | 30% | 17% | 29% | 23% |
| Right to be informed/exercise choice — Paper group | 35% | 23% | 26% | 17% |
| How security of info is protected — EHR group | 41% | 18% | 21% | 20% |
| How security of info is protected — Paper group | 46% | 21% | 19% | 14% |

Given that HIPAA and its privacy rule mandate that patients be given notice of these rights, **it is disturbing, though perhaps not surprising, to find that majorities of patients in both types of record systems feel they have not been educated adequately by doctors and their staffs in their patient rights. HIPAA privacy notices have long been understood to be an inefficient and ineffective means of patient privacy education. As we move toward more widespread adoption of EHRs, addressing this gap will be crucial.** We explore these issues further in our Policy Implications section.
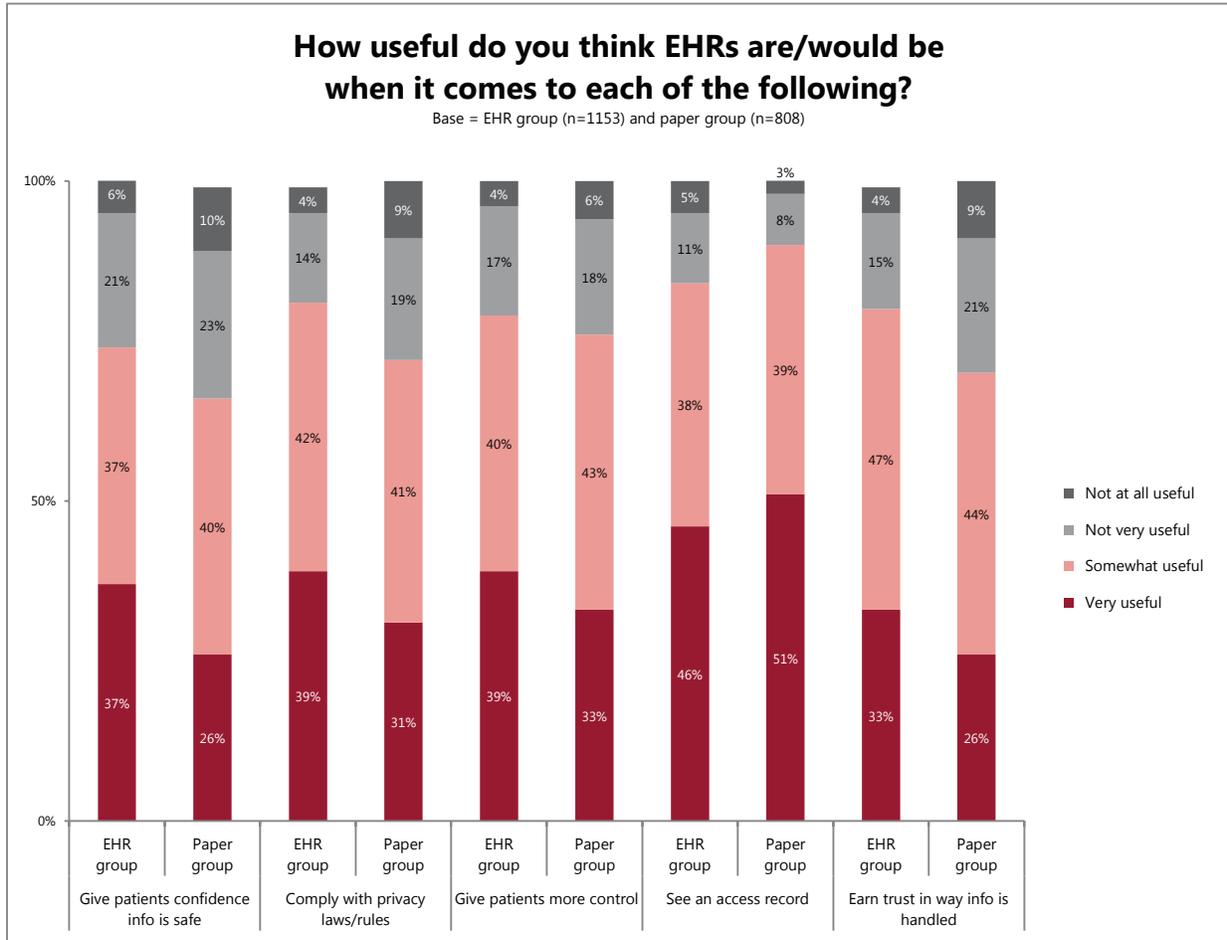
### 2. Usefulness of EHR Systems in Supporting Patient Rights

We next asked respondents how useful they found each of the two medical record systems in facilitating the delivery of five patient rights.[17] We began by asking about EHRs (Chart 16).

The results clearly show that both samples see great value in EHR systems with respect to these privacy dimensions. Hispanic respondents whose doctor has an EHR were slightly higher in believing in the usefulness of EHR systems for both giving patients more control over how their medical information is used beyond health care (83 percent, compared to 78 percent of the total EHR sample); and giving patients confidence that their health information is safe (80 percent, compared to 73 percent of the total EHR sample).

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17 Full text of rights presented for Charts 16 and 17 is as follows: 1) Giving patients confidence that their medical and health information is safe so that unauthorized people don't see it; 2) Complying with privacy and confidentiality laws and rules; 3) Giving patients more control over how their personal medical and health information is used for purposes beyond their direct care; 4) Letting patients see a record of who has accessed their medical information; 5) Earning the trust of patients in the way their personal medical and health information is being handled by their provider's medical record system.

**Chart 16**

## How useful do you think EHRs are/would be when it comes to each of the following?

Base = EHR group (n=1153) and paper group (n=808)



Legend:
- ■ Not at all useful
- ■ Not very useful
- ■ Somewhat useful
- ■ Very useful

Values by category:

**Give patients confidence info is safe**
- EHR group: Very useful 37%, Somewhat useful 37%, Not very useful 21%, Not at all useful 6%
- Paper group: Very useful 26%, Somewhat useful 40%, Not very useful 23%, Not at all useful 10%

**Comply with privacy laws/rules**
- EHR group: Very useful 39%, Somewhat useful 42%, Not very useful 14%, Not at all useful 4%
- Paper group: Very useful 31%, Somewhat useful 41%, Not very useful 19%, Not at all useful 9%

**Give patients more control**
- EHR group: Very useful 39%, Somewhat useful 40%, Not very useful 17%, Not at all useful 4%
- Paper group: Very useful 33%, Somewhat useful 43%, Not very useful 18%, Not at all useful 6%

**See an access record**
- EHR group: Very useful 46%, Somewhat useful 38%, Not very useful 11%, Not at all useful 5%
- Paper group: Very useful 51%, Somewhat useful 39%, Not very useful 8%, Not at all useful 3%

**Earn trust in way info is handled**
- EHR group: Very useful 33%, Somewhat useful 47%, Not very useful 15%, Not at all useful 4%
- Paper group: Very useful 26%, Somewhat useful 44%, Not very useful 21%, Not at all useful 9%

### 3. Usefulness of Paper Systems in Facilitating Patient Rights

We presented both sets of respondents with the same list of five patient rights and asked them how useful they thought *paper record systems* "are/would be" in supporting these rights (Chart 17).

Similar to our previous findings regarding the usefulness of EHRs in care delivery, higher percentages of paper respondents than EHR respondents rated paper systems positively on four of the five patient rights areas – between 48 and 76 percent. In addition, high numbers of paper-system respondents – between 66 and 90 percent – also rate EHR systems higher than their own system on the above privacy dimensions. However, when both sets of respondents rated *EHR systems* on these five same patient rights areas, higher percentages of EHR respondents rated their system positively – between 74 and 84 percent.

These results indicate that patients in paper systems see EHR systems as more useful both for delivering patient care and assuring patient rights.

**High numbers of paper system respondents – between 66 and 90 percent – also rate EHR systems higher than their own system on the privacy dimensions provided.**

**Chart 17**

## How useful do you think paper record-keeping systems are/would be when it comes to each of the following?

Base = EHR group (n=1153) and paper group (n=808)
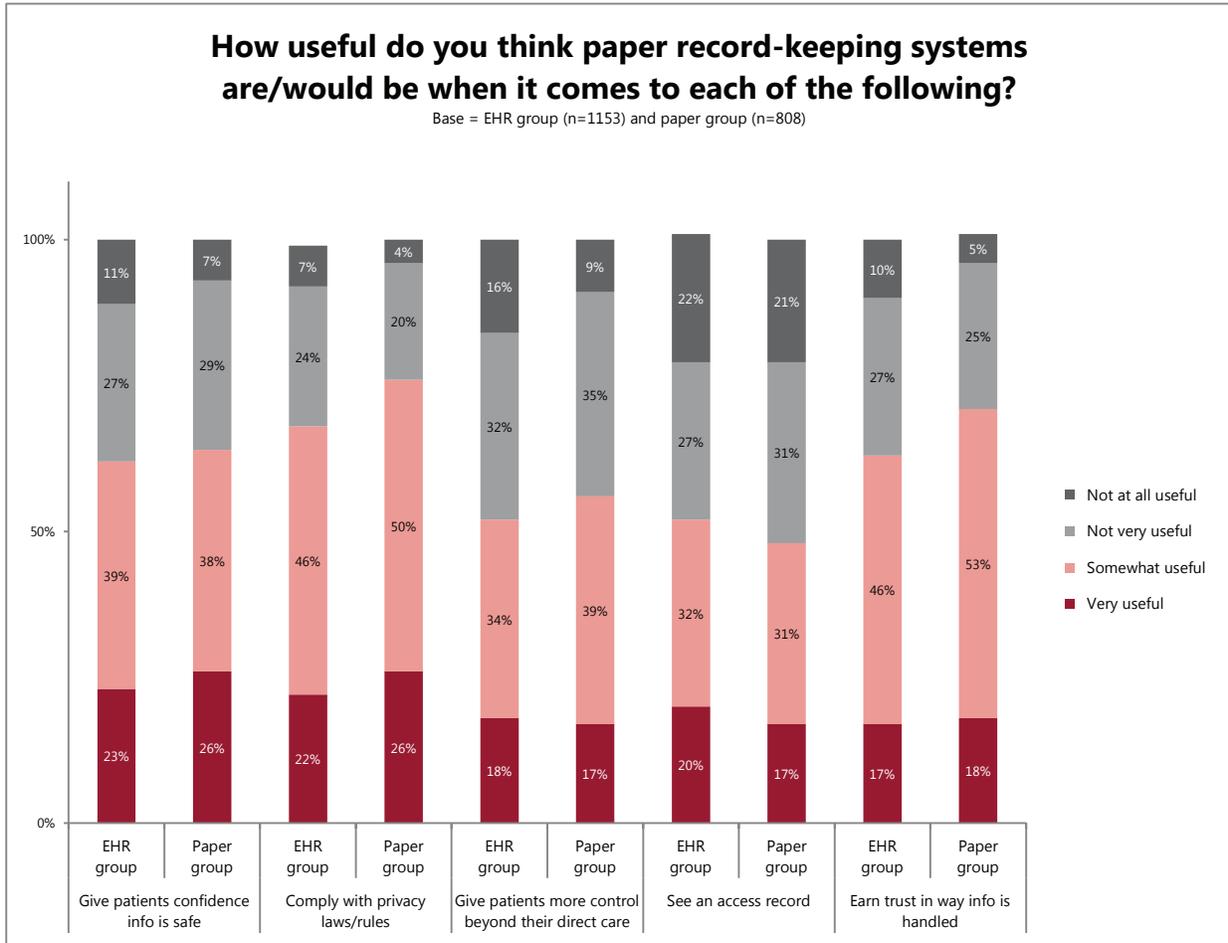


## 4. Experiences in the Handling of Personal Medical Information

The following set of three questions explored respondents' reports of concrete experiences in the handling of their personal medical and health information.  These questions were designed to understand the effect of those personal experiences on respondents' current behaviors, and how such experiences shape individuals' trust in the record system and their perception of the system's value. Because these are actual experiences reported by the adults in our sample, we also note for each how many millions of patients these percentages represent.

### a. Withholding Personal Health Information

We asked both sets of respondents:

> *Since your doctor uses [an electronic health/a paper medical record] system, have you ever decided not to provide medical or health information to a doctor or health care professional because you were worried that this would not be kept confidential?*

Five percent of EHR respondents (representing about 3.8 million adults) said they had done this, along with 8 percent of paper-system respondents (representing about 4.2 million adult patients). Combined this represents about eight million patients.  Notably, nearly a quarter (24 percent) of Hispanic paper respondents said they have withheld health information.

Respondents who said they withheld information were asked to describe the types of health information they chose not to disclose and provide some insight into why:

▸ **Sensitive lifestyle information**: *If I'm a smoker; sexual activity; recreational drug use; feminine care.*

▸ **A serious medical condition**: *Diabetes; COPD [chronic obstructive pulmonary disease]; infertility problems; acute illness; afraid insurance rates will increase.*

▸ **No confidence in the system**: *Refused to give my height and weight; refused to give Social Security number; refused to disclose prescribed medications; have chosen not to sign releases for my medical records; didn't want to share information about previous doctor care.*

▸ **Privacy and security worries**: *Could not guarantee privacy protection; feel that my private medical records should remain private; worried that the government has the right to access these records; too many people have access to private records; unsecured office/practice; doctor/staff discuss medical records with other family members.*

With respect to what happened after they chose to withhold information, some respondents said their doctor had been supportive and the problem had been resolved, while others said a diagnosis was recorded incorrectly and stayed in their record, or that their doctor had refused to treat them when they withheld information, or that test results were not issued.

What seems to be the common denominator for most of these actions is patient distrust of the health care system. This led these distrustful respondents, in both types of record systems, to withhold what was likely health care-relevant and appropriate medical information.

### b. Belief That Personal Health Information Was Released Improperly

The survey asked respondents in both record systems:

> *Since your doctor uses [an electronic health/a paper medical record system], have you ever had any of your personal medical or health information that you did not want others to know about disclosed to someone or some organization in a way that you felt was not appropriate, made you feel uncomfortable, or you felt violated your sense of confidentiality?*

Three percent of EHR respondents and 4 percent of paper-system respondents said "yes," representing about 2.3 million EHR respondents and 2.1 million paper-system respondents. Again, a much higher portion of Hispanic paper-system respondents reported inappropriate disclosures (16 percent).

Although 45 percent of EHR respondents and 49 percent of paper-system respondents answered "no," 51 percent of the EHR respondents and 47 percent of paper-system respondents chose to answer "not that I know of."

The types of health information respondents said they had had inappropriately disclosed covered a wide range of items and situations. Responses included:

- **Information breaches**: *Social Security number was stolen; records lost; computer was stolen from the office.*
- **Improper disclosures**: *My alumni college was informed without my consent; sent my medical records to another doctor without my permission; submitted information to insurance when I specifically directed them not to; medical information shared with insurance company; I received mailings (advertisements) for a specific condition I have; gossiped to other staff members and shared information with my family member; doctors/staff read my patient chart where others could hear.*
- **Administrative actions seen as improper**: *Called my listed emergency contact person with a false financial request; billing error I refused to pay and my file was turned in to a collection agency; office visit was billed under the wrong doctor and they were holding payment.*

When asked whether they had told their doctor or a member of his or her staff about the inappropriate disclosure, 74 percent of the EHR respondents and 65 percent of the paper-system respondents said "yes."  When those reporting the incident were asked how satisfied they were with the way their doctor and his or her staff "responded to the incident," 73 percent of EHR respondents and 68 percent of paper-system respondents said they were satisfied.

Those satisfied explained that, for example:

- *Issue was brought up/discussed at the hospital board meeting with the CEO; told the doctor/staff and they apologized; hospital paid for credit report tracking for one year.*

Those not satisfied also described what they were doing to address the issue:

- *Filed a complaint with the state; considering a lawsuit against the doctor; left the practice and am changing doctors; and asked me to find another primary care provider.*

### c. Data Breach Victims

We asked both samples:

*Have you ever been notified that your medical or health information or that of a close family member has been either lost or stolen?*

Four percent of EHR respondents and 4 percent of paper-system respondents said they or a close family member had experienced this personally.  To compare our survey results to the known levels of data breaches reported in the media and government data, we note that the incidence of known recent data breaches in medical record systems has been reported by HHS at 7.9 million persons, from a remarkable 30,000 medical data breaches documented since reporting of such breaches became compulsory in 2009.[18]  (According to our survey, 4 percent of EHR respondents represents about 3 million adults and 4 percent of paper-system respondents represents about 2.1 million adults, for a total of 5.1 million persons.)

As mentioned in our Methodology discussion, our 1,961 total respondents represent only about half the adult patient population of the U.S.  Thus, if we assume the same levels of data breach events would be reported by consumers without a main doctor or those not knowing what type of record system their doctor uses, then our figures could fairly be doubled, and would represent about 8.8 million adults.

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18 *See, e.g.*, "HHS Report: Nearly 7.9M Health Records Exposed," *FierceHealthcare*, September 8, 2011.  HHS reported 252 large-scale breaches (in health care organizations involving 500 or more persons' records), affecting a total of 7.8 million individuals, and "over 30,000" "small-scale breaches," affecting about 50,000 individuals' records.

## C. Documenting and Exploring Patient Trust

We have already reported the very high trust respondents said they had in their providers to protect the privacy and confidentiality of their medical and health information (91 percent of the EHR group and 92 percent of the paper group).[19]  We also reported how respondents in both systems rated the usefulness of EHR systems for "earning the trust of patients in the way their personal medical and

**Our central hypothesis, around which these questions were designed, was that respondents' views of EHRs are shaped by their general levels of trust in their provider to protect their privacy, along with the value they have experienced in their record system.**

health information is being handled by their provider's medical record system."[20]  (Eighty percent of EHR respondents said EHR systems were useful, and 70 percent of the paper group said the same.)

Our central hypothesis, around which these questions were designed, was that respondents' views of EHRs are shaped by their general levels of trust in their provider to protect their privacy, along with the value they have experienced in their record system.

### 1. Patient Trust in Doctor and Staff

Having presented questions that explored half a dozen facets of the specific handling of privacy and patient rights in the two record systems, we posed a summary question to both sets of respondents about their level of trust in their doctors and staff (Chart 18).

**Chart 18**



**Overall, how much do you trust your doctor and his or her staff to protect your privacy and other patient rights?**

Base = EHR group (n=1153) and paper group (n=808)

EHR group: Not at all, 1%; A little, 5%; A moderate amount, 21%; A lot, 42%; Completely, 31%

Paper group: Not at all, 1%; A little, 2%; A moderate amount, 20%; A lot, 44%; Completely, 32%

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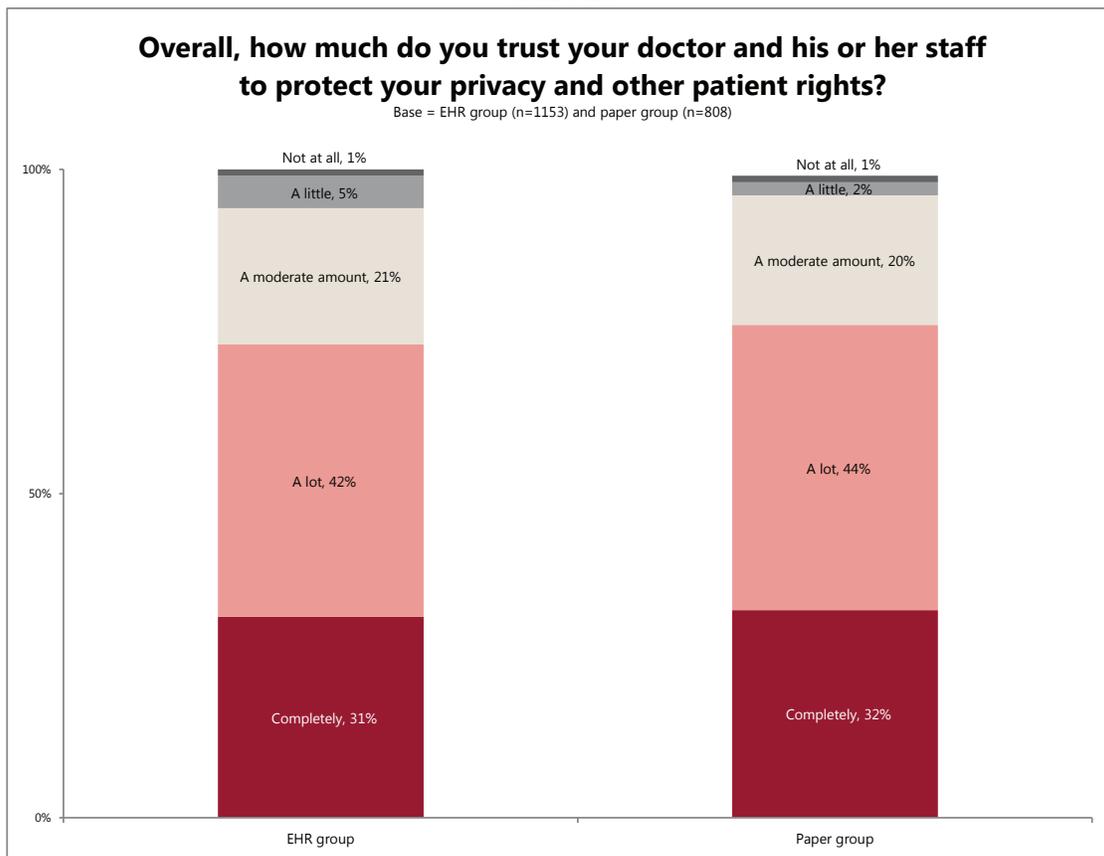
19 *See* Chart 14.
20 *See* Chart 16.

Clearly, across both systems, individual trust in one's provider when it comes to privacy protection is high. The similarity between respondent groups indicates that trust may be based more on the relationship with the provider than the system he or she uses.

### 2. Factors Driving Trust or Mistrust

In one of the most important parts of our survey, we asked both those expressing trust and those not expressing trust in their providers to explain – with narratives – why they were trustful or distrustful of their providers' ability to protect their health information.

#### a. Factors Cited as Supporting Trust

We asked the EHR and paper-system respondents who had expressed complete or a lot of trust:

> *What factors help you trust that your doctor and his/her staff will protect the privacy of your personal medical and health information?*

The factors listed as those supporting respondents' trust fall into three general categories, listed below with examples of the accompanying narratives:

▸ **Strong privacy and security policies**: *Efficient security system/protocols [doctors] have in place and follow; computer screens/personal records are in a secure, private area; records are password-protected; they are careful/follow standard protocols;* and *limited number of people [who] have access to private records.*

▸ **Relationship with doctor and staff**: *Good reputation/respectable practice; know them well, been going to this doctor a long time; they are a professional practice/staff; they look out for the best interests of the patient/good bedside manner/they care; good communications; good doctor/staff behavior and patient relationships; personal relationship/friend with the doctor/ staff; honesty and integrity; I have confidence, believe in doctor/staff;* and *ethical practice/ doctors take confidentiality oath.*

▸ **Compliance with the law and best practices**: *HIPAA laws; [doctors] discuss with me their privacy disclosure policy and confidentiality forms; require my permission/signature to release any personal information; it's the law – federal law to protect my privacy rights; efficient/competent doctor/practice/office; organized office/staff;* and *never had a problem.*

#### b. Factors Cited as Inducing Distrust

We asked EHR and paper-system respondents who expressed only "a little" trust or "not at all":

> *Why don't you have much trust in your doctor and his/her staff's ability to protect the privacy of your personal medical and health information?*

The narratives provided fall into three main categories, shown below with examples of specific respondent comments. Several parallel the categories that were cited by those who trust their doctors.

▸ **Weak or poor privacy and security**: *Don't trust using electronic health records/EHR system vulnerable to computer/Internet hacking; too many people have access to records/ know why you're visiting doctor; it's not hard to access private information; small town/*

*everyone knows each other; state/ government regulations require too much disclosure; computer screens/ personal records are left unattended/ not in a secure private area; not careful/don't see a big effort being made to keep things private; there is no permission process in place; doctor/staff doesn't follow HIPAA regulations;* and *do not have the resources to protect privacy.*
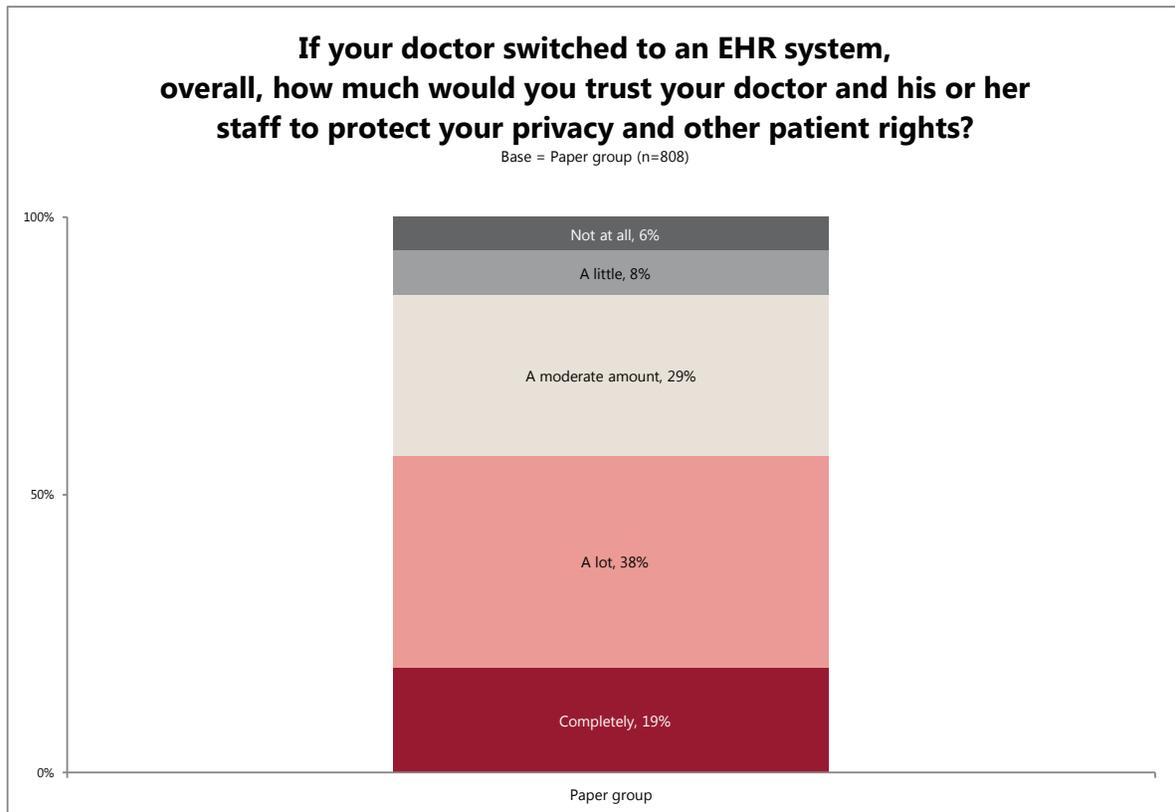
**The ultimate goal is for conversion to EHRs to be seen as highly positive** – **both because of increased value to an individual and his or her provider, and because of an EHR's ability to protect patient privacy and the security of information. Much work in making the case for EHRs remains.**

▸ **Doctor and staff not trustworthy**: *I don't have confidence in doctor/staff; have proven they can't be trusted; they are more concerned with financial matters; too young of a doctor; inappropriate behavior/patient relationship; office staff doesn't know me well or care; it's a government agency/VA/military hospital;* and *doctors work with the insurance companies.*

▸ **Poor office procedures**: *Have not been informed/[haven't] discussed with me their privacy disclosure policy/confidentiality form; office staff gossip too much/too loud; inefficient and incompetent practice; billing errors; inaccurate/incomplete documentation; too busy of an office; never received test results/follow up; have lost my medical records before; high staff turnover; office technology is not up to date; mistakes happen;* and *doesn't follow standard office protocols.*

## D. Impact on Privacy Perceptions of a Doctor Switching from Paper to Electronic Records

To understand the perceived privacy implications of a switch to EHRs, we asked respondents about their level of trust if their doctor switched to an EHR system (Chart 19).

**Chart 19**

**If your doctor switched to an EHR system, overall, how much would you trust your doctor and his or her staff to protect your privacy and other patient rights?**

Base = Paper group (n=808)

- Not at all, 6%
- A little, 8%
- A moderate amount, 29%
- A lot, 38%
- Completely, 19%

Paper group

The majority (57 percent) of paper respondents saying they would trust their doctor and staff completely or a lot is a positive finding, but still significantly lower than the levels of trust in providers to protect privacy rights displayed in Chart 18 (76 percent).

The ultimate goal is for conversion to EHRs to be seen as highly positive – both because of increased value to an individual and his or her provider, and because of an EHR's ability to protect patient privacy and the security of information.  Again, we see that much work remains in making the case for EHRs, both with respect to value and trust.

# VI. Analysis: How Hispanic Adults View Record Systems

As we noted in the Methodology section of the report, we conducted an over-sampling of Hispanic respondents, and we offered the questionnaire in both English and Spanish. Eight percent of our EHR group identified themselves as Hispanic, and 9 percent of our paper-system respondents did the same.

We noted earlier in this report that we generally would report standard or health demographic variations only when differences of 5 percent or more – higher or lower – were present between various demographic groups and the total sample of EHR or paper-system respondents. We have followed this practice in our analyses of Hispanic views below. Unless we have flagged significant differences, Hispanic adults in the two record systems took the same or close to the same positions as the totals we have described earlier in the report.

For our comparisons, we use "T" for the total-respondent positions and "H" for the position of the EHR or paper-system Hispanic adults. This section begins with an overview of findings for Hispanics in EHR systems as compared to the total sample, followed by a review of those in paper systems, and concludes with a comparison of the two Hispanic samples to each other.

The data from Hispanic respondents highlight a number of complexities in their viewpoints. For example, on the one hand Hispanic adults in both EHR and paper systems were three times more likely than the total sample to report having withheld health information from a doctor because of confidentiality concerns. On the other hand, they reported high levels of trust in their doctors. This was especially true for Hispanic adults in paper systems, 24 percent of whom reported withholding information (compared to 8 percent of the total paper sample). At the same time, they were significantly more likely to say they trust their doctor "completely or a lot" to protect their privacy (89 percent, compared to 76 percent of the total sample). *Many of these nuances and apparent conflicts are present in a number of areas, which we believe would benefit from additional research in order to understand them more fully.*

## A. Hispanic Adults in EHR Systems

### 1. Standard Demographics

Hispanic adults in EHR systems differed from the total EHR respondents as follows:

▸ More likely to be male (T 45 percent/H 54 percent);
▸ More likely to live in the West (T 22 percent/H 35 percent);
▸ More likely to have only high school or less education (T 30 percent/H 47 percent); and
▸ More likely to earn the lowest annual incomes (less than $15,000: T 6 percent/H 17 percent) and ($15,000-24,999: T 8 percent/H 20 percent).

### 2. Health Demographics

Hispanic adults in EHR systems reported health statuses that differed from the total EHR respondents as follows:

▸ More likely to say they were in "excellent" health (T 20 percent/H 26 percent);
▸ More likely to say they do not have health insurance (T 6 percent/H 14 percent);

- Less likely to use mental health services (T 28 percent/H 20 percent);
- Less likely (by 5 percent or more) to report they had been told by their provider that they had various adverse medical conditions, among them high blood pressure, high cholesterol, arthritis, asthma, heart attack, anxiety disorder and cancer;
- More likely to report they have type 1 diabetes (T 3 percent/H 9 percent) and type 2 diabetes (T 23 percent/H 34 percent); and
- EHR Hispanics were more likely to see doctors in solo practice (T 17 percent/H 38 percent) than doctors in group practices (T 83 percent/H 62 percent).

These self-reports suggest that fewer Hispanic adults in EHR systems are managing adverse health conditions than the total EHR population, but not at levels that dramatically differ from the general EHR population (such as 15 percent or more).

### 3. Substantive Differences in the EHR Hispanic Sample

Turning to how Hispanic adults in EHR systems differ from the total EHR group on our non-demographic questions, many differences are important to note.

- Online access:

  - They are more likely to have online access (T 26 percent/H 32 percent);
  - They are less likely to say they never use their online access (T 20 percent/H 5 percent); and
  - They are more likely to find that online access improves their desire to do something to improve their health (T 55 percent/H 70 percent).

- Being informed is both important to them and something they think is being handled well:

  - They were higher in saying it is important to them to understand how their EHR works (T 88 percent/H 94 percent);
  - They were more likely to say they were well informed by their doctor and staff with respect to how their EHR system works (T 51 percent/H 63 percent); and
  - They were significantly more likely to say they were well informed by their doctors and staff about all four privacy and patient rights protections presented.[21]

- Their views on EHR values varied by particular topics.

  - They were higher in believing EHR system adoptions will increase data breaches (T 59 percent/H 73 percent) and that existing privacy laws are not adequate (T 51 percent/H 69 percent);
  - They were higher in saying EHRs are useful in giving patients more control over how their medical information is used beyond health care (T 78 percent/H 83 percent); and giving patients confidence their health information is safe (T 73 percent/H 80 percent);
  - They were much higher in rating EHRs as useful for them personally in carrying out health-promotion activities. Examples: understanding their health conditions (T 46 percent/H 59 percent); helping maintain a healthy lifestyle (T 34 percent/H 52 percent); keeping up with medications (T 43 percent/H 52 percent); and

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21 *See* Chart 15.

- They were somewhat *lower* than the total EHR sample in saying that EHR systems were useful in helping their *doctors* to provide various health care services. For example: keeping up with their medical history (T 84 percent/H 78 percent) and making sure other providers have relevant data (T 80 percent/H 75 percent).

- They were much more likely to report adverse experiences with the handling of their health information:

  - They were three times more likely to say they had experienced a data breach (T 4 percent/H 12 percent) and that they had decided not to provide some health information because of confidentiality fears (T 5 percent/H 12 percent).

Taken together, these data points indicate that Hispanic adults in EHR systems have a complex and varying blend of views regarding their record systems. Although they feel generally well informed by their doctors, see great usefulness in EHRs personally when it comes to delivering health care benefits, and also see the value of EHRs for giving patients more control of their medical information, they are more skeptical about what widespread adoption of such technologies would mean from a privacy and security standpoint. Additional research into Hispanic views to explore these complexities would be valuable.

### 4. Where EHR Hispanic Respondents Did Not Differ

On some of the key questions on our survey, EHR Hispanic adults did not differ significantly in their responses from the total EHR respondents. These included:

- How often they engage in various patient health activities;
- How satisfied they were with the EHR system their doctor uses;
- What impact the EHR system has had on the overall quality of their health care; and
- Overall trust in doctor and staff to protect patient rights.

## B. Hispanic Adults in Paper Systems

### 1. Standard Demographics

Hispanic adults in paper systems paralleled the total paper system sample in almost all the standard demographics. There were only two variations of 5 percent or more, both of which were also present among EHR Hispanics:

- More likely to be aged 18-46 (T 41 percent/H 56 percent); and
- More likely to live in the West (T 17 percent/H 30 percent).

### 2. Health Demographics

The health status variations reported by Hispanic adults in paper systems closely paralleled those we noted above for Hispanic adults in EHR systems. Self-ratings of their overall health statuses were similar to those of total paper-system users, as were the numbers of those indicating they had lower health insurance coverage, lower use of mental health services and saying they have a chronic health condition.

Hispanic adults in paper systems were also significantly lower (by 5 percent or more) than the total paper-system respondents in having various adverse health conditions: high blood pressure, high cholesterol, overweight or obese, arthritis, asthma, heart disease and depression.

However, paper-system Hispanic adults did report having several conditions at rates higher than the total paper system group:

▸ They were higher in reporting they have had a sexually transmitted disease (T 7 percent/H 19 percent);
▸ They were higher in reporting having type 2 diabetes (T 22 percent/H 34 percent) and having chronic pain (T 16 percent/H 21 percent);
▸ They were higher in reporting they do not have health insurance (T 9 percent/H 14 percent); and
▸ Paper-system Hispanic adults were higher in reporting their doctor was in solo practice (T 38 percent/H 43 percent) rather than a medical group (T 62 percent/H 57 percent).

### 3. Substantive Differences in the Paper-System Hispanic Sample

With respect to how paper-system Hispanics compared to the total paper-system group on our substantive questions, many similarities and differences are useful to note.

**Paper-system Hispanic adults also appear to see the value of a switch to an electronic system more than their total paper-system counterparts do, which makes them a prime audience for additional outreach and engagement.**

▸ Being informed is important to them and something they think is handled well. Hispanic adults in paper systems were *more likely* to:

  ▸ Think it important to understand how their medical record system works (T 83 percent/H 90 percent); and
  ▸ Say their doctor and staff had informed them well about how their medical and health information was collected and used (T 46 percent/H 60 percent).

▸ They reported high levels of trust in their providers and felt well informed regarding some specific privacy rights. They were *more likely* to:

  ▸ Say that, overall, they trust their doctor and staff "completely or a lot" to protect their privacy and other patient rights (T 76 percent/H 89 percent); and
  ▸ Say that their doctor and staff had informed them well about four patient rights[22] (T 42 percent/H 53 percent).

▸ Conversely, Hispanic adults in paper systems also reported adverse experiences with respect to their health information. For example, they are *more likely* to:

  ▸ Have decided not to provide some health information to their doctor because of confidentiality concerns (T 8 percent/H 24 percent); and
  ▸ Report they have had some of their personal medical information disclosed improperly (T 4 percent/H 16 percent).

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22 *See* Chart 15.

▸ Hispanic adults in paper systems had varying views on EHRs, depending upon the particular dimension.  They were *more likely* to:

  ▸ Say their paper record system helps them *personally* carry out six health care activities;[23]
  ▸ Say, overall, they are satisfied with the paper-record system their doctor uses (T 86 percent/H 96 percent);
  ▸ Rate positively the impact of their doctor's paper-record system on the overall quality of their health care services (T 26 percent/H 39 percent);
  ▸ Say it would be important to them to get online access to their medical records (T 65 percent/H 71 percent);
  ▸ Say it would be valuable to them as a patient to have their doctor adopt and use an EHR system (T 73 percent/H 89 percent);
  ▸ Say if their doctors switched to an EHR, it would have a positive impact on the overall quality of their health care services (T 48 percent/H 58 percent); and
  ▸ Say if their doctor switched to an EHR, they would trust him or her to protect their privacy and other patient rights (T 57 percent/H 80 percent).

Much like Hispanic adults in electronic systems, paper-system Hispanics appear to more highly value knowing how their record system works, to say they feel well informed by their physicians not only about how their health information is used and collected but about their patient privacy rights, and to feel their record system helps them personally.  The similarity between respondent groups is particularly notable, as this may be a function of a factor other than a record-system indication.  Paper-system Hispanic adults also appear to see the value of a switch to an electronic system more than their total respondent pool paper-system counterparts do, which makes them a prime audience for additional outreach and engagement.  Yet, like Hispanic adults in electronic systems, those in paper systems were simultaneously more hesitant to provide health information to their doctors because of confidentiality worries and to say they have experienced some sort of improper disclosure of their medical information.  Again, these views merit further research.

Finally, Hispanic adults in paper systems were *similar* to the total paper respondent pool when it came to:

▸ Ranking the usefulness of their paper-record system to provide seven listed patient services;[24]
▸ Ranking the usefulness of their paper-record system to provide five listed patient rights;[25] and
▸ Evaluating how much their record system helps their doctor and staff to provide six patient services.[26]

## C. How EHR and Paper-System Hispanic Adults Compare

Hispanic adults in paper systems were significantly higher than those in EHR systems in saying they trusted their doctor overall to protect their privacy and patient rights (89 percent to 74 percent).  They were also significantly higher than their peers in electronic systems in reporting that they

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23 *See* Chart 7.
24 *See* Charts 4 and 5.
25 *See* Chart 16.
26 *See* Chart 6.

had three adverse experiences in the handling of their personal health information in the health care process (had some personal health information lost or stolen [21 percent paper, compared to 12 percent electronic]; had some personal health information disclosed improperly [16 percent to 5 percent]; and decided not to disclose some personal health information to providers because of confidentiality worries [24 percent to 12 percent]. In fact, both groups of Hispanic adults were also generally higher in saying these things than the total samples. Once again, this demonstrates viewpoints worth tracking over time and exploring further: Paper-system Hispanics are more likely to trust their doctors to protect their privacy, but to simultaneously feel their paper system inadequately protects their information.

Hispanic adults in EHR systems were significantly higher in saying that their record system has a positive impact on their health care services and in providing patient rights protection: 76 percent said their EHR record system has a positive impact on the overall quality of their health care (compared to 39 percent of paper-system Hispanics). In addition, many more Hispanics in EHR systems rated their systems as significantly more useful for various care delivery elements than did Hispanic paper respondents. (Examples: helping patients follow their providers' instructions with respect to treatments [95 percent of EHR Hispanics, compared to 71 percent of paper]; helping them personally not repeat tests unnecessarily [68 percent to 42 percent]; and helping patients correct any errors in their records [80 percent to 41 percent].) This is good news, illustrating that this population is experiencing the higher value of electronic systems.

**Hispanic adults should be a high-priority audience for privacy-related education, engagement and outreach.**

The same higher ratings of EHR systems registered among Hispanic adults on the ability of their record system to protect patient rights. For example, 83 percent of Hispanic EHR respondents found their system useful for giving patients more control over how their health information is used beyond direct care, compared to 60 percent of Hispanic paper-system respondents who said the same.

When the two groups of Hispanic adults are compared on the four assertive statements we used to map the overall health privacy attitudes of respondents into segments based on the degree of worry about health privacy (Chart 14), they are *similar* in trusting providers to handle their health information properly (92 percent [EHR] to 89 percent [paper]) and believing patients had reasonable control over how their health information is used beyond direct care (82 percent [EHR] to 79 percent [paper]). However, EHR system Hispanics are more likely to believe adoption of EHR systems will increase data breaches (73 percent [EHR] to 64 percent [paper]) and that health privacy is not well protected today by laws and organizational rules (69 percent [EHR] to 57 percent [paper]). This once again illustrates the worrisome finding that Hispanic adults in electronic systems have significant privacy concerns regarding their data, despite the value they see in their record systems. This segment of the population should be a high-priority audience for privacy-related education, engagement and outreach.

In our privacy and trust segmentation section, we identify where EHR and paper-system Hispanics fall on our Privacy Intensity and Provider Trust segmentations, and what seems to explain those orientations.

# VII. Policy Implications

For much of 2011, the economy, jobs, the budget deficit and attempts to repeal the Affordable Care Act (ACA) dominated political discourse, and the mood of the country seemed far from optimistic.  As we head into an election year, nine in 10 Americans don't trust the government to do the right thing,[27] and Congress's approval ratings are at record lows.[28]  The Occupy Movement and its protests across the country appear to reflect a growing discontent, and the failure of the "Super Committee" to reach agreement on ways to reduce our national debt has added to the increasing anxiety and scrutiny regarding federal spending on a wide range of programs – from defense to social programs, including health care.

Within this larger context fit the considerably high expectations for the unprecedented $44 billion federal investment in the use of health IT to help improve the quality of health care (the so-called "Meaningful Use" program), as well as the emerging requirements for health reform under the ACA, to generate meaningful changes in the way care is organized and delivered.  These expectations, combined with the broader political and policy climate, have created an even higher-stakes environment that we believe requires strong public support in order to fully succeed.  If there were to be a consumer backlash to health care delivery changes – including the use of health IT – it would likely result in mounting political pressure to defund the Meaningful Use program.

Our survey findings point to both opportunities and risks:

▸ People want EHRs – 73 percent of paper respondents want their doctors to switch from paper to electronic records.

▸ EHRs outperformed paper medical records in our survey on the aspects of care that we know patients value highly, such as care coordination, getting test results in a timely manner and helping patients follow treatment instructions.

▸ Yet, when asked what impact switching from paper to an EHR would have on quality of care, a majority of patients who currently have paper records don't readily see quality benefits: Forty-one percent of our paper sample said they would expect "no impact" and 10 percent said "a negative impact."  Further, and perhaps more alarming, one in four EHR respondents say they have seen "no impact" of their record system on the overall quality of their care thus far.

▸ Finally, there is concern among the majority of our respondents that widespread adoption of EHRs will lead to even more personal information being lost or stolen.  If people come to view EHRs predominately as something that threatens their privacy but delivers little value, they may see wider adoption of EHRs as more of a threat than an improvement in the long term.

In our view, opportunities to buttress public support for health reform and consumer participation in the "meaningful use" of EHRs fall into three main categories:

A. Consumer Education and Engagement
B. Functional and Privacy Requirements for the Meaningful Use Program
C. Other Public Programs Promoting or Relying on Health IT

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27 *New York Times* Poll on the Republican Primary and the Economy (Oct.  25), *available at*: http://www.nytimes.com/interactive/2011/10/26/us/politics/20111026_POLL.html?ref=politics.
28 Gallup, "Congress Ends 2011 With Record-Low 11 Percent Approval," *available at:* http://www.gallup.com/poll/151628/Congress-Ends-2011-Record-Low-Approval.aspx.

## A. Consumer Education and Engagement

The 2009 Health Information Technology for Economic and Climate Health (HITECH) Act mandated a consumer education campaign that is to be administered by the Office for Civil Rights (OCR), within the U.S. Department of Health and Human Services (HHS). OCR is the primary agency in HHS that oversees privacy policy in the U.S. The statutory requirements for the campaign place a heavy emphasis on privacy, but also include a focus on value. In practice, this campaign has been expanded to include consumer engagement in health IT more broadly, and it is being led in part by the Office of the National Coordinator for Health IT (ONC), in conjunction with OCR.

At the same time, state and private sector initiatives to engage and educate consumers have also taken shape. These arise in various contexts – from the Beacon Community grants to the efforts of a single health system or physician practice to ensure their patients understand the changes resulting from health IT implementation and upgrades. For all of these initiatives – whether federal, state or private sector – it will be critical to apply the findings of this survey to their strategies.

**Recommendation 1**: Value and privacy should be the dual focuses of education and engagement.

▶ Our data show a relationship between the level of concern people have regarding privacy and the value they perceive in EHRs. Similarly, there is a correlation between perceptions of trust in providers to protect health information and perceptions of the value of EHRs. The privacy and trust segmentations contained in our Segmentation Analyses report bear this out, including findings that:

  ▸ EHR respondents who are more comfortable with privacy issues are 25 percentage points higher than those who are worried about privacy in saying the EHR has had a positive impact on the quality of their care; and
  ▸ EHR respondents who have high trust in their providers to protect health information are 49 percentage points higher than those with low trust in saying the EHR helps their doctor keep up with their health conditions and treatments.

**Recommendation 2**: Consumers of Hispanic origin and underserved individuals should be key target audiences of education and engagement efforts.

**With the right engagement, this could be an opportunity to advance the use of health IT as a tool to reduce disparities in health outcomes, and to illustrate the potential of health IT to be a real equalizer.**

▶ Our data show that at the same time Hispanic consumers have clear privacy concerns, they also see greater value in many aspects of the EHR than do other populations surveyed.

  ▸ Hispanic adults in EHR systems are 14 percentage points higher in thinking widespread adoption of EHRs will lead to more data breaches, and are 18 percentage points higher in thinking existing privacy laws aren't adequate.
  ▸ However, Hispanic adults with online access to their health information are 15 percentage points higher than the total online access population in saying such access has improved their desire to do something to improve their health.
  ▸ With the right engagement, this could be an opportunity to advance the use of health IT as a tool to reduce disparities in health outcomes, and to illustrate the potential of

health IT to be a real equalizer.  Given Hispanic adults' overall concerns about privacy, efforts to engage them in health IT must be sure to address privacy and security in particular.

▸ EHR Hispanic adults were 18 percentage points higher than the total EHR sample in seeing EHRs as helping them maintain a healthy lifestyle, and they were 13 percentage points higher in saying the EHR helped them understand their conditions.

▸ Hispanic adults were the demographic sub-group most prevalent in our "low provider trust" segmentation, as discussed in our Segmentation section below.

**Recommendation 3**: Physicians, nurses and other clinical leaders should play key roles in engaging consumers with information about privacy and value of health IT.

▸ More than 90 percent of both paper and EHR respondents trust their doctors to protect health information.  These trusted messengers can best help the public understand their privacy rights and outline security practices and are in the best position to receive feedback from patients when things aren't going well.

▸ Eighty-six percent of both paper and EHR respondents who reported "high trust" felt their record system was explained well by providers and their staff.

▸ EHR respondents expressing positive trust in providers to assure privacy and other patient rights are more likely to find EHR systems useful in providing patient privacy-related rights.

▸ However, many providers are already pressed for time and are understandably likely to object to this role.  It will be important to develop, at the federal level, a consistent set of effective messages and education materials providers can easily adapt and use.

▸ It will also be critically important to determine the best media and workflow for delivering this information and engaging patients on privacy and security topics.  A revised HIPAA notice or pamphlet is likely to be insufficient.  Multi-media approaches, including mobile technologies, video and other online methods, should be explored, and measures of patient comprehension should be developed and used.

  ▸ Federally-funded health IT Regional Extension Centers and the national Health IT Resource Center could play valuable roles in testing and disseminating effective communication strategies and measures of their effectiveness.

**Recommendation 4**: ONC and OCR should track over time changes in consumer privacy views and who comprise the most comfortable and the most worried population segments when it comes to privacy, as well as the meaningful use of consumer-facing health information technologies.

▸ As illustrated in our Privacy Segmentation section below, among *EHR* respondents, men, those earning less than $35,000 a year; those aged 35-46; and those living in the South are particularly likely to be worried about health IT privacy.  Among *paper* respondents, men, college graduates; adults aged 35-46; and those living in the East or West are the most worried.  Using our survey instrument and segmentation methodology, these sub-groups and their privacy orientations could be tracked on an annual basis, in part to evaluate the impact of education and engagement initiatives.

## B. Functional and Privacy Requirements for the Meaningful Use Program

The incentive program established by HITECH that rewards hospitals and eligible professionals for adopting and using electronic health record technology in meaningful ways has been a powerful

tool for raising awareness of and commitment to health IT adoption and implementation among providers. Importantly, it has focused policy discussions upon *use* of technology rather than technology itself, emphasizing how EHRs can support both providers and patients. It will be critical to the long-term success of the program to include criteria for incentive payments that focus on value to patients as well as privacy and security.

**Recommendation 5**: Promote functionalities that support improving patients' perceptions of value and trust in Stages 2 and 3 of Meaningful Use, specifically: care coordination, online access, secure-messaging, and the ability of patients to contribute data to their record and to download their own health information. Further, functionalities must ensure convenience and enable robust privacy and security education.

> *[Patients have] a significant expectation that systems can and will talk to each other. Meaningful Use should play a far greater role than it does in Stage 1 in promoting such functionality and its effective use.*

▸ The vast majority of survey respondents – in both electronic and paper systems – think EHRs are or would be useful for care coordination (97 percent of both groups), which indicates a significant expectation that systems can and will talk to each other. Meaningful Use should play a far greater role than it does in Stage 1 in promoting such functionality and its effective use.

▸ Our data show that having online access to health information helps drive value and trust. (See discussion on p. 23 of this report.) Having a robust "View/Download" capability as a core requirement for hospitals and physician practices is a central ingredient that will improve the value consumers experience from this transformation, and help build their trust in electronic systems.

▸ Patients already see some convenience and communications benefits today: Close to two-thirds of EHR respondents believe their system helps them avoid filling out forms repeatedly and helps them communicate with their providers (compared to 36 and 27 percent of paper respondents, respectively).

> ▸ However, they are not deriving the full extent of available benefits from EHRs. Our data also found that less than half of EHR respondents believe their system helps them find/correct errors in their medical record; understand their health better; keep up with medications; or lead a healthy lifestyle (47 percent to 34 percent).[29]

▸ Patients want to understand privacy and security issues more fully (Chart 2). And those who are more comfortable with privacy issue value systems and their capabilities more highly (Tables 1 and 2). Based on our data, it follows that consumers who have greater trust in EHR systems would be more likely to seek out the benefits of health IT to engage in their health and care. Meaningful Use should include more robust criteria for patient education and engagement in this area, building on Recommendation 3 above.

**Recommendation 6**: Promote and demonstrate functionality relating to EHR "accounting of disclosures" reports, indicating when and to whom a HIPAA-covered entity has disclosed an individual's health information.

▸ Survey results indicate that 84 percent of EHR and 89 percent of paper respondents perceive EHRs as useful for letting patients see a record of who has accessed their medical records.

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29 *See* Chart 7.

- Given these high expectations, so-called "accounting of disclosures" functionality is an important area in which to enable progress from technology and implementation standpoints.
- Also of note, roughly half of paper respondents erroneously think paper record systems are useful for letting patients see a record of who has accessed their medical records. This points to a real need to *demonstrate* how EHRs, much more than paper records, can effectively facilitate this trust-building functionality.

## C. Other Important Federal Programs

In addition to the consumer engagement/education campaign and the Meaningful Use program, ONC is spearheading a number of HITECH-funded grant programs, including the Beacon Community program and the State Health Information Exchange (HIE) program, which are designed to promote the effective sharing and use of electronic health information to improve care.

At the same time, the ACA established a wide range of initiatives to test and implement changes in the way health care is organized, paid for and delivered. The Centers for Medicare & Medicaid Services (CMS) is now advancing initiatives such as Accountable Care Organizations (ACOs) and patient-centered medical homes, as well as an Independence at Home model and a Primary Care Improvement Program. These new approaches to care often include or would be enhanced by the use of health IT, and they often require meaningful patient engagement in their health and care to be successful.

**Recommendation 7**: Integrate patient-facing functionality into health information exchange initiatives such as Beacon Communities, the state HIE program and the Nationwide Health Information Network.

- The ONC-funded Beacon communities are designed to serve as the brightest guiding lights of health IT implementation in this country, and to show how health IT can be used to improve care. The state HIE program and Nationwide Health Information Network efforts are helping make progress toward nationwide connectivity, which could help facilitate care that is coordinated, efficient and safe. Yet if consumers experience more concern about privacy without experiencing much value from information exchange, these programs are likely to struggle in meeting their laudable goals.
- Our survey shows online access to health information helps drive value and trust, and that patients want EHRs to be used for more effective care coordination, convenience and care management. It is crucial that these programs, which take us beyond meaningful use of EHRs, incorporate aims to demonstrate such tangible benefits to consumers, and thus contribute to consumer perceptions of usefulness, value and increased trust.

**Recommendation 8**: Make health IT functionalities that patients value and benefit from key parts of new models of care under health reform.

- The success of federal health reform initiatives such as ACOs, patient-centered medical homes, the Primary Care Improvement Program and the Partnership for Patients will require patient and family engagement in their health and care. Focusing on the aspects of health IT that they say help improve a patient's ability to get and stay well will have the significant effect of helping to establish the foundation of patient-centered care upon

which so much of health reform is based. Our data show a number of features of EHRs are ones that patients say help them personally, such as understanding health conditions and treatments; managing medications more effectively; maintaining a healthy lifestyle; and sharing information with other providers on the care team.

▸ These EHR attributes are, in truth, desired attributes of health care itself – attributes that can be greatly enabled by technology in the context of a strong patient-provider partnership. Based on our review of recent regulations governing these new models of care, as well as our survey data, uses of health IT most important to promote include:

  ▸ Online access to downloadable health information for self-management, care coordination and avoiding repeat tests;
  ▸ Care planning and care summaries for safer transitions of care;
  ▸ Recording preferences for care;
  ▸ Providing "shared decision-making" tools and education for preference-sensitive care, where there are multiple treatment options and no single "right" answer; and
  ▸ Self-management support and health coaching.

**Recommendation 9**: Promote further federal initiatives and regulations that provide patients with direct access to their health information.

▸ Our data show that, for example, patients find EHRs very useful for receiving lab results in a timely manner (96 percent of EHR respondents) and avoiding repeat tests (79 percent of EHR respondents).

▸ Initiatives that give patients access to more information about their care and tools to make that information useful should be supported. In our view, the recent CLIA (Clinical Laboratory Improvement Amendments)/HIPAA notice of proposed rule-making (NPRM), which proposed giving patients the right to directly access their laboratory test results, is one such initiative.

> **If we have learned from past experiences, including negative consumer reactions to the early formulations of health maintenance organizations (HMOs), policy-makers and private sector thought leaders should not underestimate the need for consumer support for and involvement in these [patient-centered reform efforts].**

Given the wide array of federal, state and private sector programs now underway to improve the delivery of health care and make it more patient-centered – from Meaningful Use to ACOs and other new models of care – consumers should begin to experience health care differently in the coming years. If we have learned from past experiences, including negative consumer reactions to the early formulations of health maintenance organizations (HMOs), policy-makers and private sector thought leaders should not underestimate the need for consumer support for and involvement in these changes.

Health IT can not only serve as a foundational platform that supports health care providers by facilitating data collection, evidence-based care delivery, quality measurement and more, but can also be a central vehicle for ensuring patients tangibly benefit from changes in care delivery. Health IT can enable the most patient-centered aspects of health care reform efforts, and in so doing can help to shore up consumer support for them. In other words, if health IT functionality delivers tangible benefits patients can see and experience for themselves, consumers are more likely to support broader adoption of health technologies and to embrace new models of care as meaningfully patient-centered.

# VIII. Analysis: Health IT Privacy Segmentation and Trust Segmentation

## A. A Health IT Privacy Segmentation of Respondents

One of our key survey objectives was to ascertain whether there is a relationship between perceptions of the value of health IT and individuals' privacy beliefs or trust in their providers to protect their health information. In other words, do individuals who perceive value in health IT have more trust in the systems? Conversely, do those who have less trust see less value? And, following this, would increasing the usefulness of health IT to patients concomitantly help to increase their trust or decrease their privacy concerns?

To do so, we asked survey respondents to react to a set of four assertive statements about privacy, and we then divided the sample according to their responses into three segments – those that are *most* concerned about privacy, those who are *least* concerned and, finally, those that have *mixed* privacy views. We then tested the strength of the segmentation by looking at the substantive questions about both value and privacy in the survey, such as beliefs about whether increasing the use of EHRs will lead to more widespread privacy breaches, and individuals' views on how useful the EHR is to them personally. We then evaluated whether the segmentation produced a "scale," or spread from high to low segmentation, on a majority of these substantive questions.

The value of the privacy segmentation is that, once the three orientations are identified and verified, we can examine the demographic and health-status groups that comprise each segment. We can also then crosswalk the privacy views of each segment to their views on value and trust, and in this context ascertain whether there is a relationship between their views of privacy and their views on value or usefulness of EHRs.

Below is a description of how we developed the privacy segmentation for this survey of EHR and paper-system respondents, a discussion of what population segments make up each division, and our analysis of these results.

### 1. Creating a Health IT Privacy Segmentation

We began by taking our samples' reactions to the four assertive statements about current health IT privacy issues described earlier in this report – those about trust in providers to protect health information; patient control of secondary data uses; data breaches in EHR systems; and adequacy of current privacy laws and organizational practices.[30] Our assertive statement about trust in providers produced such extremely high trust – 91 percent of EHR respondents and 92 percent of paper-system respondents – that we discarded it from the segmentation process and used instead the other three assertive statements to create the segmentation.

We then divided respondents into three groups based on their agreements ("strongly" or "somewhat" agree) with the three assertive statements as follows:

- ▸ **WORRIED ABOUT HEALTH IT PRIVACY**: Those *disagreeing* that patients have reasonable control over secondary uses of data; *agreeing* that EHR systems will have more data breaches than paper-record systems; and *agreeing* that privacy of health records is not well protected today by existing laws and organizational practices.

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30 *See* Chart 14.

- **COMFORTABLE ABOUT HEALTH IT PRIVACY**: Those *agreeing* that patients have reasonable control over secondary uses of data; *disagreeing* that EHR systems will have more data breaches than paper-record systems; and *disagreeing* that privacy of health records is not well protected today by existing laws and organizational practices.
- **MIXED ABOUT HEALTH IT PRIVACY**: Those with responses to the three statements that indicate mixed beliefs.

Chart 20 shows how the survey respondents fall into each of the segments.

**Health IT Privacy Segmentation**
Base = EHR group (n=1153) and paper group (n=808)
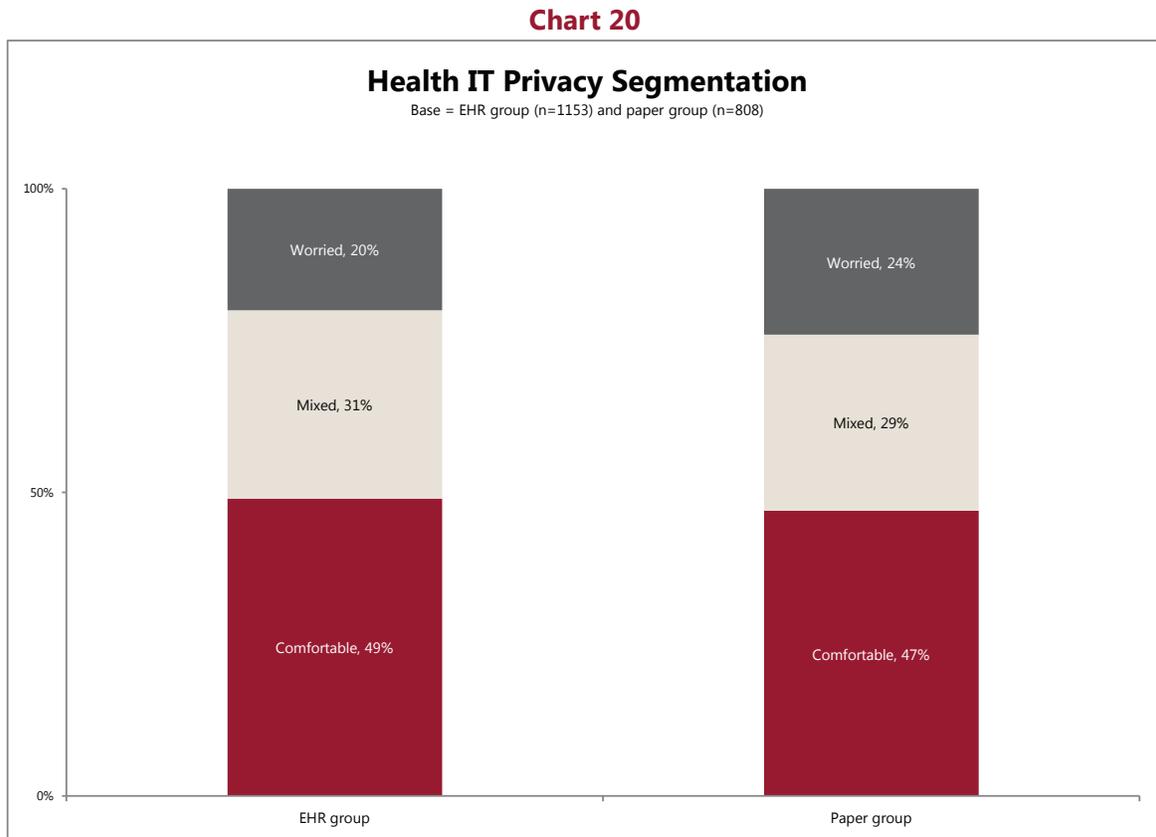
A 2007 Institute of Medicine survey on privacy and health research found virtually identical division of high, medium and low privacy intensities.[31] (With high concern translating to those worried about privacy, medium to those with mixed views, and low to those we refer to as comfortable about privacy.)

As noted, the test of any privacy segmentation is whether using it produces a scale or spread of privacy orientations from High ("worried") to Low ("comfortable") on a majority of the substantive opinion or judgment questions with privacy dimensions on a survey. **The way the segmentation operates is that, on any question, the Health IT Privacy Worried should be the *least positive* about something's usefulness or value or presence; the Health IT Privacy Comfortable will be the *most positive* about the value or presence; and the Health IT Privacy Mixed will be in the middle.**

Table 1 presents examples of the segmentation at work, first among our EHR respondents and then from the paper-system group. The same pattern of privacy segmentation effects is present for our paper respondents, as seen in Table 2.

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31 Westin, Alan, commissioned by the Institute of Medicine. "How the Public Views Privacy and Health Research: Results of a National Survey Commissioned by the Institute of Medicine," November 2007.

## Table 1
## Segmentation Examples – EHR Respondents with Affirmative or Positive Responses to Each Topic

| Topic | EHR group total (n=1153) | Privacy Segmentation | | |
|---|---|---|---|---|
| | | Worried | Mixed | Comfortable |
| Well-informed by doctor about right to control secondary uses | 52% | 29% | 55% | 61% |
| EHR system helps patients follow their providers' instructions | 92% | 86% | 91% | 95% |
| EHR system is useful in complying with privacy and confidentiality laws and regulations | 81% | 58% | 82% | 91% |
| Decided not to provide personal information to provider because of confidentiality concern | 5% | 9% | 8% | 2% |
| Overall trust in doctor to protect their privacy and other patient rights | 73% | 45% | 69% | 87% |
| Well-informed by doctor on how EHR system works | 51% | 17% | 56% | 61% |
| Overall satisfaction with doctor's EHR system | 94% | 87% | 94% | 96% |
| Positive impact of EHR system on quality of care | 72% | 58% | 65% | 83% |

## Table 2
## Segmentation Examples – Paper Respondents with Affirmative or Positive Responses to Each Topic

| Topic | Paper group total (n=808) | Privacy Segmentation | | |
|---|---|---|---|---|
| | | Worried | Mixed | Comfortable |
| Well-informed by doctor about right to control secondary uses | 43% | 29% | 44% | 51% |
| EHR system helps patients follow their providers' instructions | 84% | 75% | 83% | 89% |
| EHR system is useful in complying with privacy and confidentiality laws and regulations | 72% | 50% | 70% | 83% |
| Decided not to provide personal information to provider because of confidentiality concern | 8% | 15% | 12% | 3% |
| Overall trust in their doctor to protect their privacy and other patient rights | 76% | 66% | 70% | 85% |
| Well-informed by doctor on how paper system works | 46% | 27% | 45% | 56% |
| Paper system is useful in complying with privacy and confidentiality laws and regulations | 76% | 72% | 74% | 79% |
| If their doctor switched to an EHR system, would trust him or her to protect privacy and patient rights | 57% | 41% | 58% | 64% |

The two segmentation tables show the striking breadth of health care topics on which the privacy segmentation operates. As the examples show, the privacy segmentation is present well beyond the specific privacy- and patient rights-focused questions in our questionnaire. It operates on questions about the value of EHR and paper systems for delivering health care services, helping patients manage their care personally, explanations about how the record system operates, and even personal experiences with medical records (such as whether respondents have ever withheld

sensitive information or believe their personal health information has been disclosed improperly). It also shows an important relationship between being well-informed by doctors and their staffs about how the EHR or paper-record system works and having fewer privacy concerns.

## 2. Group Variations in the Privacy Segmentation

### a. Who Are the Most Health IT Privacy Worried?

Among EHR respondents, there are several demographic groups that were at least 4 or 5 percentage points higher (or **statistically significant**) than the total Health IT Privacy Worried (who represent 20 percent of the total EHR respondents). These groups include men; those earning less than $35,000 a year; those aged 35-46; and those living in the South.

Among paper respondents (with the total Worried at 24 percent), several groups were stronger than the total sample in their "Worried" privacy intensity. These include men; college graduates; those aged 35-46; and those living in the East or West.

### b. Who Are the Strongest Health IT Privacy Mixed?

In the EHR group, four sub-groups were higher by a statistically-significant margin than the total Health IT Privacy Mixed (31 percent of total respondents). These were Hispanic adults; those with only a high school education; those aged 35-46; and those living in the East. And, for paper respondents, three sub-groups were higher than the total Health IT Privacy Mixed (29 percent of the total group). These were Hispanic adults; those having incomes under $35,000/year; and those with only a high school education.

Hispanic respondents came out in our survey squarely as Health IT Privacy Mixed. While 31 percent of the total EHR pool falls into this Mixed category, 51 percent of Hispanic adults did – the highest demographic group by far in taking this position between the Health IT Privacy Worried and the Health IT Privacy Comfortable.

### c. Who Are the Most Health IT Privacy Comfortable?

Three sub-groups of EHR respondents were highest in their "Comfortable" privacy intensity (49 percent of total EHR participants registered as Comfortable). These higher sub-groups were those having incomes over $75,000/year; those living in the Midwest; and those in group- rather than solo-physician practices.

Among our paper system respondents (47 percent of which registered as "Comfortable"), the groups that were most prevalent in this segment were whites; those having incomes over $75,000/year; those aged 18-34; those aged 66 and over; post grads; and those living in the South.

## 3. Influence of the Health IT Privacy Intensity Segmentation on Trust Levels

The Health IT Privacy segmentation was present powerfully on most of the specific questions about trust that we asked (Tables 3 and 4).

The scope of the variation between the trust levels of the Health IT Privacy Worried and the Comfortable on the dimensions of trust demonstrates **there is a significant relationship between general views on privacy and level of trust in providers to protect health information**.

**Table 3**

## Trust Totals and Segmentation of EHR Respondents with High Levels of Agreement

| Trust Statement | EHR group total (n=1153) | Privacy Segmentation | | |
|---|---|---|---|---|
| | | Worried | Mixed | Comfortable |
| Generally trust my main doctor and other health care professionals to protect the privacy and confidentiality of my personal medical and health information | 91% | 73% | 93% | 98% |
| Usefulness of EHR systems to earn the trust of patients in the way their personal medical and health information is being handled by their providers' medical record system | 81% | 54% | 79% | 92% |
| Overall, how much you trust your doctor and his or her staff to protect your privacy and other patient rights | 73% | 45% | 69% | 87% |

**Table 4**

## Trust Total and Segmentation of Paper System Respondents with High Levels of Agreement

| Trust Statement | Paper group total (n=808) | Privacy Segmentation | | |
|---|---|---|---|---|
| | | Worried | Mixed | Comfortable |
| Generally trust my main doctor and other health care professionals to protect the privacy and confidentiality of my personal medical and health information | 92% | 78% | 92% | 98% |
| Usefulness of EHR systems to earn the trust of patients in the way their personal medical and health information is being handled by their providers' medical record system | 70% | 49% | 71% | 81% |
| Overall, how much you trust your doctor and his or her staff to protect your privacy and other patient rights | 76% | 66% | 70% | 85% |
| If their doctor switched to an EHR system, how much they would trust doctor and his or her staff to protect their privacy and other patient rights | 57% | 41% | 58% | 64% |

For example, among the EHR sample, the Health IT Privacy Worried were lower by 25 percentage points in saying they trust their doctor to protect their health information, while 98 percent of the Health IT Privacy Comfortable trusted their doctor. In other words, the more "privacy comfortable" one is, the more likely he or she is to trust his or her provider.

### 4. Analysis of the Health IT Privacy Segmentation

As we noted at the beginning of the Health IT Privacy Segmentation section, the value of this exercise is its capacity to identify the sub-groups that are the strongest Health IT Privacy Worried, Comfortable or Mixed, and to crosswalk their privacy views to the experiences and views they indicated in their answers to our survey questions regarding the usefulness and value of health IT.

As this segmentation shows, the patients we surveyed divide, on a continuing basis, into Low, Medium and High trust orientations – e.g., those that are worried, comfortable or mixed. It shows that both sets of respondents score in low to high scales on a majority of questions on the survey in a way that consistently illustrates a direct relationship between privacy intensity levels and positive or negative ratings of the usefulness of their record system for carrying out many health care activities. **Those who are more comfortable in their privacy views are more likely to perceive and experience value in their record systems** (See Tables 1 and 2). In addition, the segmentation also indicates that general comfort about privacy of health information may on its own have an impact on patients' health behaviors. Additional research is needed to more completely understand this finding.

It is the respondents in both electronic and paper systems falling into the "Worried" category who are the most appropriate target audiences for education and engagement initiatives. Again, among EHR respondents, those demographic groups include men; those earning less than $35,000 a year; those aged 35-46; and those living in the South. And, among paper respondents, they include men; college graduates; adults aged 35-46; and those living in the East or West. The overlap indicates that men between the ages of 35 and 46 might be the most obvious immediate focus of policy interventions.

> **[The survey responses] illustrate a direct relationship between privacy intensity levels and positive or negative ratings of the usefulness of their record system for carrying out many health care activities. Those who are more comfortable in their privacy views are more likely to perceive and experience value in their record systems.**

We also note that it may be the paper-record system sub-groups who are the most valuable target audiences of all. It is these individuals who are likely to experience a significant change in the way their health care is delivered in the near future, as many providers are likely to switch to

> **The overlap indicates that men between the ages of 35 and 46 might be the most obvious immediate focus of policy interventions.**

an electronic system in the coming months or years. **As such, the "Worried" paper respondents would perhaps most benefit from public programs and initiatives designed to cultivate understanding and promote the value of health IT, and ultimately to drive trust in electronic systems.** It is worth further research to understand the nuances of these populations and thus find ways to tailor public outreach programs to most effectively reach them.

## B. EHR Provider Trust Segmentation

As we have noted, one of the main objectives of our survey was to identify the extent to which patients trust their providers' use of an EHR to carry out various care delivery and rights protection activities, and then examine how these provider-focused trust levels affect EHR respondents' judgments about how well their EHR system is doing the following:

1. Helping their doctor and staff to provide good health care services;
2. Delivering good health care services to them as patients;
3. Protecting their privacy and other patient rights;
4. Helping them personally carry out patient self-help activities; and
5. Explaining to them how their EHR system works *and* how their patient rights are being protected.

We also wanted to see how provider-trust levels affected two overall judgments we asked EHR respondents to make:

1. The impact of the EHR system their doctor uses on the "overall quality" of their health care services; and
2. The general level of satisfaction EHR respondents say they have in the system their provider is using.

As discussed earlier, one of our central hypotheses was that public views on both privacy issues and value of an EHR are related to two key factors: realizing tangible benefits from the provider's use of an EHR (i.e., better care delivery and/or an improved ability to manage their own care or condition), and trust in the health care provider to protect privacy.

When we asked respondents to describe the factors that led them to high trust in their doctors and their staffs to protect their privacy, the narratives confirmed that a mixture of elements that engender trust are present: awareness of privacy protection laws and regulations; patient perceptions of good privacy and confidentiality procedures; good relationships with their doctor and a belief that their doctor cares about them; a belief that the doctor's office is ethical and well-run; and the absence of any perceived motivation by their doctors to benefit from sharing patient information improperly. When we asked respondents to describe the factors that led them to say they did not trust their doctors to protect the privacy of their personal health information, we obtained a similarly diverse set of reasons.

To further explore these views and their effect on patient perceptions of and experiences with health IT, in addition to the privacy segmentation we developed an EHR Provider Trust Segmentation, to measure levels of patients' trust in their providers with respect to handling their health information.

### 1. Developing the Provider Trust Segmentation

As described in our findings sections, we presented EHR respondents at the end of the questionnaire with a question about level of trust in privacy and patient rights (Chart 21).

For this segmentation, we combined those saying "completely" and "a lot" into what we will call a **High Provider Trust** orientation, reflecting the high trust in providers to protect privacy. Our assumption is that EHR respondents choosing "a lot" are quite trusting. We put those EHR respondents saying they had a moderate amount of trust into a **Medium Provider Trust** orientation, on the assumption that the moderate choice clearly indicated some ambivalence by respondents with respect to their levels of trust in providers. Finally, we put those EHR respondents saying they had only "a little" trust or were "not at all" trusting into a **Low** to **No Provider Trust** orientation. Our EHR respondents divided on this segmentation as seen in Chart 22.
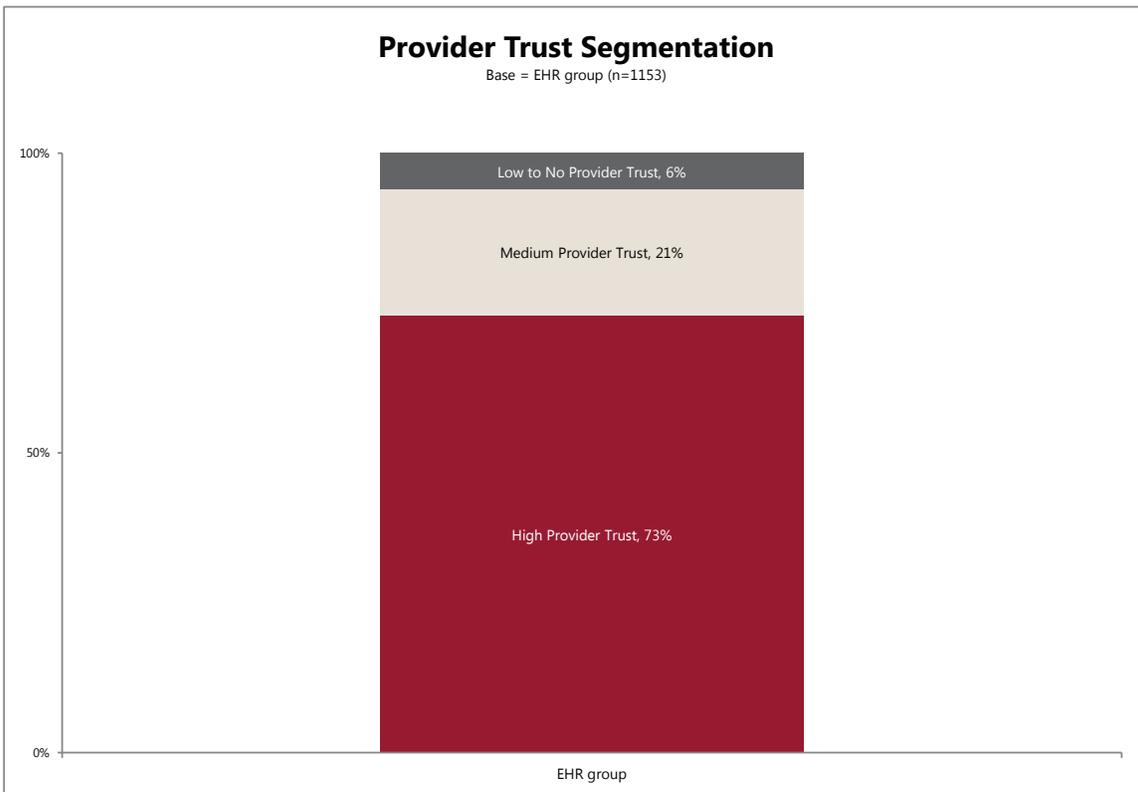
### 2. Testing the Trust Segmentation

For this segmentation to be legitimized and to work, EHR-respondent answers to the seven sets of patient judgments listed above must "scale." This means that, if our hypothesis is correct, the High Provider Trust respondents will score the most positively in seeing the value and privacy benefits of EHRs and in trusting providers; our Low to No Provider Trust respondents will choose the least positive judgments on value, privacy and trust; and responses from the Medium Provider Trust patients will be in the middle.

**Chart 21**

## Overall, how much do you trust your doctor and his or her staff to protect your privacy and other patient rights?

Base = EHR group (n=1153)

Not at all, 1%

A little, 5%

A moderate amount, 21%

A lot, 42%

Completely, 31%

EHR group

**Chart 22**

## Provider Trust Segmentation

Base = EHR group (n=1153)

Low to No Provider Trust, 6%

Medium Provider Trust, 21%

High Provider Trust, 73%

EHR group
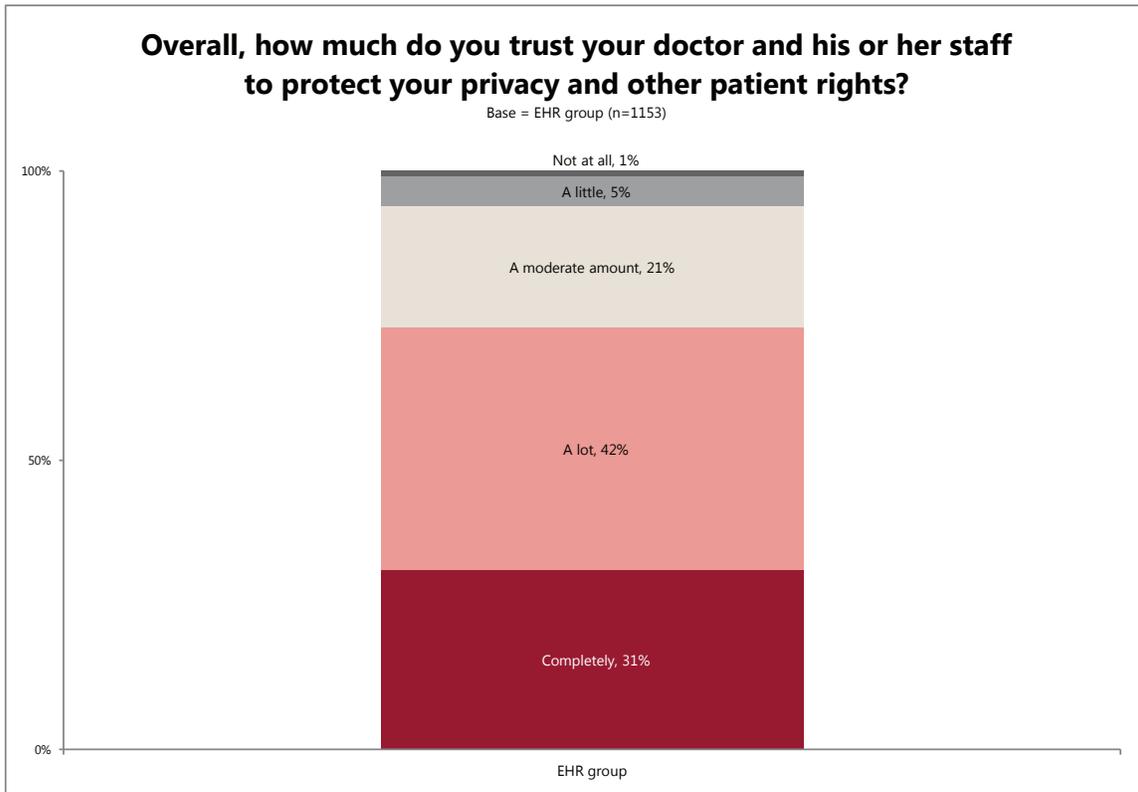
A central illustration of the effects of trust is the way EHR respondents rate the usefulness of their EHR system to deliver on five privacy benefits, which are listed in Table 5.  Table 5 shows how the total EHR respondent pool compares to our three trust segments in terms of rating EHR systems

as "very useful" or "somewhat useful" in this capacity.  If the Trust Segmentation is legitimate, we would expect to see, for example, significantly lower ratings (by 5 percent or more) among Low Trusters compared to the total EHR group in terms of the EHR's ability to deliver these benefits. Clearly, Table 5 indicates the segmentation is valid.

### Table 5
### Perceived High-Level Usefulness of EHR Systems to Deliver Privacy Benefits

| Topic | EHR group total (n=1153) | Trust Segmentation | | |
|---|---|---|---|---|
| | | High | Medium | Low |
| Giving patients confidence that their medical and health information is safe so that unauthorized people don't see it | 74% | 81% | 59% | 29% |
| Complying with privacy and confidentiality laws and rules | 81% | 87% | 73% | 42% |
| Giving patients more control over how their personal medical and health information is used for purposes beyond their direct care | 79% | 84% | 68% | 49% |
| Letting patients see a record of who has accessed their medical information | 84% | 87% | 80% | 71% |
| Earning the trust of patients in the way their personal medical and health information is being handled by their providers' medical record system | 80% | 88% | 68% | 41% |

To further test the scale, we apply it below to the survey question regarding how well EHR respondents felt their doctors or staff have informed them about how their medical and health information is collected and used by the EHR.  About 51 percent of the total EHR group said this had been explained "very well" or "well."  With respect to this question, the Provider Trust Segmentation produced statistically significant variations:

**HIGH TRUST** ............................. **59 percent said it was explained well**
**MEDIUM TRUST**....................... **31 percent said it was explained well**
**LOW TRUST**............................... **14 percent said it was explained well**

Thus, the segmentation confirms that there is a relationship between how well providers explain how information is collected and used by the EHR and trust in providers to protect privacy.

Finally, we applied the Trust Segmentation to the survey question regarding how well respondents' doctor and staff had informed them about the four patient rights (Table 6).

In this question, respondents could choose "a great deal," "a moderate amount," "a little" and "told me nothing."  Compared to the total number of EHR respondents selecting "a great deal" and "a moderate amount," the Provider Trust Segmentation worked as anticipated.

**What the Provider Trust Segmentation shows here is how painfully few of the Low Trusters feel they have been well informed, and well below half of the Medium Trusters feel the same.**  Between 49 and 60 percent of the High Trusters said that their doctor or staff had communicated well.  These findings are similar to those from our Privacy Segmentation analysis.

**Table 6**
**How Well Doctor or Staff Communicated About Patient Protects** − **Positive Responses**

| Topic | EHR group total | Trust Segmentation | | |
|---|---|---|---|---|
| | (n=1153) | High | Medium | Low |
| My right to be informed and exercise choice before my personal medical or health information is made available to others for purposes beyond my health care | 52% | 60% | 38% | 12% |
| How the privacy and confidentiality of my personal medical and health information are being protected | 49% | 56% | 33% | 12% |
| My right to see all or parts of [my] medical record and have a copy made if I wished to | 47% | 52% | 37% | 13% |
| How the security of my health information is being protected from being disclosed accidentally or maliciously | 41% | 49% | 24% | 12% |

The heavy effects of Low Trust, or what we might call distrust, appeared even in the personal experiences with the handling of respondents' personal health information.  We asked EHR respondents whether they had "ever decided not to provide medical or health-related information to a doctor or health care professional because you were worried that this would not be kept confidential."  Only 5 percent of the total EHR respondents said they had done this; in contrast, 23 percent of the Low Trusters said they had taken this action.

> **The trust segmentation is legitimate and produces wide variation (never less than 7 percentage points but often many more) in respondents' views when segmented by trust level.**

A similarly dramatic contrast was present when we asked EHR respondents: "Have you ever had any of your personal medical or health information that you did not want others to know about disclosed to someone or some organization in a way that you felt was not appropriate, made you feel uncomfortable, or you felt violated your sense of confidentiality?"  Only 3 percent of the total EHR respondents said this had happened to them, but 25 percent of the Low Trusters answered yes.

As the above analyses show, **the trust segmentation is legitimate and produces wide variation** (never less than 7 percentage points but often many more) in respondents' views when segmented by trust level.

### 3. Exploring the Relationship between Trust and Value

To test our central hypothesis that there is a relationship between trust in providers to protect privacy and the value that consumers see in EHRs, we applied the segmentation to a series of value questions.  Below we begin by applying it to the question regarding how useful the EHR is to doctors in terms of delivering health care services.  If a relationship between trust and value exists, we would expect to see differences of 5 percent or more between each high, medium or low trust segment and the overall EHR group total.  Table 7 indicates precisely these differences.

## Table 7
## Perceived Usefulness of EHR System Provider – Positive Responses

| Topic | EHR group total (n=1153) | Trust Segmentation | | |
|---|---|---|---|---|
| | | High | Medium | Low |
| Keeping up with my medication history | 84% | 90% | 71% | 47% |
| Making sure that all the other health care providers who treat me have timely access to the relevant information for my care (i.e., test results, medications, allergies, etc.) | 80% | 88% | 64% | 40% |
| Managing and keeping up with my health conditions and treatments | 80% | 89% | 59% | 40% |
| Not having to repeat medical tests unnecessarily | 79% | 87% | 65% | 39% |
| Being able to correct errors or incomplete information in my medical record | 75% | 83% | 55% | 46% |
| Being able to avoid medical errors, like prescribing drugs that conflict with each other, or to which I am allergic | 75% | 84% | 54% | 38% |

## Table 8
## Perceived Usefulness of EHR System to Respondents Personally – Positive Responses

| Topic | EHR group total (n=1153) | Trust Segmentation | | |
|---|---|---|---|---|
| | | High | Medium | Low |
| Avoiding having to repeatedly fill out forms regarding my medical information | 64% | 71% | 46% | 42% |
| Sharing information with all my health care providers | 63% | 69% | 51% | 32% |
| Finding and correcting errors or incomplete information in my medical record | 46% | 53% | 28% | 33% |
| Understanding my health condition better | 46% | 52% | 31% | 17% |
| Keeping up with my medications, including remembering to take them and getting timely refills | 43% | 48% | 32% | 23% |
| Helping maintain a healthy lifestyle, including having good nutrition | 35% | 39% | 22% | 12% |

Another area in which trust in one's provider could influence how respondents value their record system is how respondents say their provider's EHR system helps them personally. As a reminder, we asked EHR respondents: *How much does the electronic health record system your provider uses help you personally with the following?* Six types of patient activities were listed, and the responses offered were "a great deal," "a lot," "a moderate amount," "a little" and "none." The results for "helps a great deal" and "a lot" are shown in Table 8. Again, if a relationship between trust and value exists, we would expect to see differences of 5 percent or more between each high, medium or low trust segment and the overall EHR group total.

(Note that in one activity, finding and correcting errors, Low Trusters scored a little higher in rating their EHR system as useful than the Medium Trusters.)

When we asked EHR respondents: "What impact do you believe your doctor's use of an electronic health record system has on the overall quality of your health care services?," as discussed above, almost three-fourths of the total EHR sample (73 percent) chose a positive response: "very positive impact" or "somewhat positive impact." The Provider Trust results for positive impact are:

**HIGH TRUST** .......................... **80 percent said it has a positive impact on care quality**
**MEDIUM TRUST**.................... **58 percent said it has a positive impact on care quality**
**LOW TRUST**........................... **28 percent said it has a positive impact on care quality**

The segmentation results are even more striking when the comparison looks only at those choosing "very positive impact." Here the full EHR sample chose 31 percent, but the Trust Segmentation was:

**HIGH TRUST** .......................... **39 percent said it has a very positive impact on care quality**
**MEDIUM TRUST** ................... **8 percent said it has a very positive impact on care quality**
**LOW TRUST**........................... **4 percent said it has a very positive impact on care quality**

In fact, if we look at all the questions offering a "very" or "completely" answer, indicating full trust and lacking reservations, the Low Trusters drop dramatically, with even greater spreads from the EHR totals than in the "very" plus "somewhat" combinations.

The divergence between the total sample and the Low Trusters when only the "very" judgment is used was present also on the question: "Overall, how satisfied are you as a patient with the electronic heath record system your main doctor is using?" Forty-three percent of the total EHR sample said they were "very satisfied." The Provider Trust Segmentation produced:

**HIGH** .......................... **54 percent are very satisfied with the EHR their doctor is using**
**MEDIUM** ................... **14 percent are very satisfied with the EHR their doctor is using**
**LOW** .......................... **2 percent are very satisfied with the EHR their doctor is using**

**As all of the above analyses indicate, there is a relationship between trust and value.** For each of the questions to which we applied the segmentation, there were significant – and often dramatic – variations that all point to the same pattern: Those who trust their doctors to protect health information see greater value in EHRs for their doctor, as well as for themselves. They also are more satisfied with the record system and believe more strongly it has a positive impact on quality. Our "Key Take-Aways" section below offers further insight into this finding.

### a. Who They Are

EHR respondents within the High, Medium and Low Provider Trust orientations were distributed generally evenly in all but a few instances across all the demographic groups identified in our survey. In the demographic profiles of the three Trust Segments, all groups have representation in each of the three categories, though there are differences in the degree, with some being more intense than others in the segment when compared to the total, and others being less intense when compared to the total. Below we provide a profile of the most intense subgroups represented in each segment.

▸ Among the High Trusters (73 percent total), those 66 and over in age were higher in trust at 84 percent; and respondents living in the Midwest were higher at 80 percent. Groups scoring lower in their trust level were younger respondents (63 percent for 18-34 year olds, and 66 percent for those 35-46); and residents of the South (at 69 percent).

- Among the Low Trusters (6 percent total), only Hispanic adults were somewhat more intense than other groups in this segment, at 10 percent.
- Among the Medium Trusters (21 percent total), there were two groups more intense than others in this segment: those 18-34 (at 29 percent) and those 35-46 (26 percent). Three groups were lower in trust than the full sample – residents of the Midwest (15 percent); persons 66 and older (12 percent); and Hispanic adults (each at 15 percent).

### b. Summing Up the Provider Trust Segmentation Analyses

Our survey provides powerful evidence, from question responses and respondents' narrative accounts, that the patient population in our survey (those with a main doctor and knowing generally what kind of record system their doctor has) divide into three continuing orientations in terms of their trust in providers. (Again, this is trust only in doctors and staffs, not in all the other holders and users of medical records and health information.)

More importantly, our survey shows trust orientations are central determinants of patients' perceptions, evaluations, confidence in and comfort with EHR systems. What it will take to create trust among the 25 percent of patients who registered medium to no trust of providers, and also enhance the trust level of the 42 percent of EHR respondents who chose "a lot" rather than "completely" in their trust orientation, is an important area for focus of consumer engagement and education initiatives, as we discuss in our Policy Implications section.

### c. Key Take-Aways from Both the Privacy and Trust Segmentations

The privacy and trust segmentation analyses essentially demonstrated the same finding: There is a relationship between value perceptions and trust in providers, as well as value and level of concern regarding privacy. They must both be present in order for consumers to embrace health IT systems and their care process applications. Improving trust in providers and ensuring positive, valuable experiences with EHRs will likely increase public support for this ongoing health care transformation, as those who have experienced more tangible benefits from the use of EHRs tend to be more trusting of their providers and less worried about privacy.

For example, compared to those EHR system respondents scoring "Low" on our Provider Trust Segmentation:

- The EHR High Trusters were between 37 percent and 49 percentage points higher in saying EHRs were useful to providers in areas such as keeping up with medication history, making sure other providers have access to relevant patient information, avoiding repeat tests and more.
- The EHR Higher Trusters were between 17 percent and 39 percentage points higher in saying EHRs were useful to patients personally, in areas such as understanding health conditions, maintaining a healthy lifestyle, sharing information with other providers and avoiding having to repeatedly fill out forms.

**The privacy and trust segmentation analyses essentially demonstrated the same finding: There is a relationship between value perceptions and trust in providers, as well as value and level of concern regarding privacy. They must both be present in order for consumers to embrace health IT systems and their care process applications.**

The segmentations also demonstrate a relationship between trust in providers to protect health information and level of privacy concern; in other words, those with higher and medium levels of trust in their providers are generally less worried about privacy. Compared to the Privacy Comfortable respondents:

▸ The EHR Privacy Worried were lower by 42 percentage points in saying they trust their doctor to protect privacy, and the paper-system Privacy Worried were lower by 19 percentage points.

▸ The paper-system Privacy Worried were 23 percentage points lower in saying if their doctor switched to an EHR they would trust their doctor to protect privacy.

In addition, those EHR respondents who fell into the Worried category in the Privacy Segmentation were lower by 38 percentage points than the Privacy Comfortable in saying EHRs could help earn the trust of patients in the way their health information is being handled. For those in paper systems, the Privacy Worried were lower by 32 percentage points.

**Does increasing the value consumers experience increase their trust in providers or lessen their privacy concerns, or does increasing trust and comfort with privacy drive perceptions of value? Both conclusions seems plausible, although it may be that one more substantially affects the other.**

It is also clear that the more patients feel informed about how their health information is protected and what their rights are, the more value they perceive in EHRs and the more comfortable they are in their privacy views:

▸ High Trusters in electronic systems were 44 percentage points higher than Low Trusters in saying they felt well informed (56 percent compared to 12 percent, Table 6).

▸ Among EHR respondents, the Privacy Comfortable were 44 percentage points higher in saying they felt well informed by their doctor regarding how the system works (61 percent compared to 17 percent, Table 1).

▸ Among paper-system respondents, the Privacy Comfortable were 29 percentage points higher in saying they felt well informed by their doctor regarding how the system works (56 percent compared to 27 percent, Table 2).

What is not fully known to date, however, is the general direction of these relationships – in other words, does increasing the value consumers experience increase their trust in providers or lessen their privacy concerns, or does increasing trust and comfort with privacy drive perceptions of value? Both conclusions seem plausible, although it may be that one more substantially affects the other. While our survey does not permit us to definitively answer this important question, what the data do tell us is that public policies and programs, as well as providers working to implement health IT, must pay careful attention to delivering both dimensions.

Regardless, it is safe to say that if people do not experience from health IT the care benefits they value most, or if they are exposed to a drumbeat of news stories regarding violations of privacy or security, they could come to trust systems less and less, decreasing the value ascribed to them and ultimately eroding public support and willingness to participate fully in health-IT-enabled care. This could lead to a variety of negative consequences, such as withholding health information from providers, ultimately resulting in poor health outcomes.

It is critical, then, to understand what particular features and uses of health IT individuals value most – including those we explored in this survey, as well as future functions that will evolve – and subsequently build these functionalities or capabilities into the systems themselves, and more broadly into public programs such as Meaningful Use.

In addition, consistent with our Policy Recommendations, it will be crucial to further explore whether there are specific educational/communication interventions that could enhance the trust levels of the least-trusting segments and – of central importance – what kinds of legal and regulatory actions to enhance protections of patient medical records and health information might increase trust and patient participation in health IT programs.

**Finally, of equal importance will be to use this survey instrument again, to measure over time the percentages of the population and their demographics that make up these segmentations.** As Meaningful Use and other health IT and care delivery initiatives advance, it will be critical to track changes in the percent and composition of the population that make up the Health IT Privacy Worried and the Low Trusters, compared to how much of the population is increasingly Health IT Privacy Comfortable and are High Trusters. This longitudinal analysis should be used to inform future policy and communications initiatives.

# Appendix A - Survey Advisory Committee

Early in the development of this project, we assembled a top-tier group of thought leaders in the privacy and health policy fields to assist us with the development and refinement of our survey instrument, and in the interpretation of our results.  We are enormously grateful for the time each of our Survey Advisory Committee members has dedicated to this work.

Co-Director – Alan Westin, Ph.D.
　　　　　　Professor Emeritus, Columbia University

Co-Directors – Christine Bechtel & Alice Leiter
　　　　　　National Partnership for Women & Families

Advisory Committee Members:

▸ **Linda Ackerman**, Staff Counsel, Privacy Activism
▸ **Anne-Marie Audet**, Vice President, Health System Quality and Efficiency, The Commonwealth Fund
▸ **Marc Boutin**, Executive Vice President & Chief Operating Officer, National Health Council
▸ **Ted Eytan**, M.D., Director, The Permanente Federation, Kaiser Permanente
▸ **Charles Kennedy**, M.D., CEO, Aetna Affordable Care Solutions
▸ **Josh Lemieux**, Director, Healthcare Innovation Group, Intel Corp.
▸ **Deven McGraw**, Director, Health Privacy Project, Center for Democracy & Technology
▸ **Glen Moy**, Senior Program Officer, Better Chronic Disease Care program, California HealthCare Foundation
▸ **Kim Nazi**, Analyst, Veterans and Consumers Health Informatics Office, Veterans Health Administration
▸ **Joy Pritts**, Chief Privacy Officer, Office of The National Coordinator for Health IT
▸ **Lygeia Riccardi**, Senior Advisor for Consumer e-Health, Office of The National Coordinator for Health IT
▸ **Mark Rothstein**, Herbert F.  Boehl Chair of Law and Medicine; Founding Director of the Institute for Bioethics, Health Policy and Law, University of Louisville School of Medicine
▸ **Terri Shaw**, Deputy Director, the Children's Partnership
▸ **Latanya Sweeney**, Founder & Director, Data Privacy Lab; Associate Professor, Carnegie Mellon
▸ **Paul Tang**, M.D., Vice President, Chief Innovation and Technology Officer, Palo Alto Medical Foundation
▸ **Sharon Terry**, President and Chief Executive Officer, the Genetic Alliance
▸ **Eileen Twiggs**, Vice President, Health Information Technology & Business Initiatives, Planned Parenthood
▸ **Hilary Wandall**, Chief Privacy Officer and Global Privacy Leader, Merck & Co., Inc.
▸ **Adrienne White**, Healthcare Innovation Strategist, IBM

# Appendix B - Harris Interactive Methodology Explanation

***Research Methodology***: Harris Interactive® conducted the study online within the United States between August 3 and 22, 2011.  Initially, a nationally representative sample of 4,612 U.S. adults age 18 or over was contacted in order to determine who would be eligible for the full survey.

Among the 4,612 adults, 1,961 (representing 56 percent of all adults after the sample was weighted to reflect the proper demographic distribution of the adult population) of these adults indicated that they have a primary doctor and their doctor either kept medical and health information as electronic health records or paper charts.  Of these, 1,153 adults are those in EHR systems and 808 are in paper systems.

Further, in order to help ensure that we had a sufficient number of Hispanics for analytical purposes, we purposely oversampled this population.  The initial sample of 4,612 included 993 Hispanics.  These interviews we eventually weighted to properly reflect the U.S. Hispanic population.  Among these 993 interviews, 227 Hispanics were eligible to complete the full survey.  These surveys were conducted in both Spanish and English.  Approximately a quarter of the surveys were completed in Spanish.

***Weighting***: The data was weighted to be representative of the U.S. 18 or over population (estimated to be 230 million people) on age, gender, education, geographical region, income plus a proprietary propensity score designed to account for the bias inherent in online panel samples.  We separately weighted Hispanics (both from general sample and oversample), African Americans/ blacks and others for added precision within racial/ethnic groups.  The demographic targets came from the U.S. Census Bureau's March supplement of the 2010 Current Population Survey.

***Survey Error***: All sample surveys and polls, regardless of whether they use probability sampling, are subject to multiple sources of error, which are most often not possible to quantify or estimate, including sampling error, coverage error, error associated with nonresponse, error associated with question wording and response options, and post-survey weighting and adjustments.  Therefore, Harris Interactive avoids the words "margin of error," as they are misleading.  All that can be calculated is different possible sampling errors with different probabilities for pure, unweighted, random samples with 100 percent response rates.  These are only theoretical because no published polls come close to this ideal.

Respondents for this survey were selected from among those who have agreed to participate in Harris Interactive surveys.  The data have been weighted to reflect the composition of the adult population.  Because the sample is based on those who agreed to participate in the Harris Interactive panel, no estimates of theoretical sampling error can be calculated.

***About Harris Interactive***: Harris Interactive is one of the world's leading custom market research firms, leveraging research, technology and business acumen to transform relevant insight into actionable foresight.  Known widely for ***The Harris Poll*** and for pioneering innovative research methodologies, Harris offers expertise in a wide range of industries including healthcare, technology, public affairs, energy, telecommunications, financial services, insurance, media, retail, restaurant and consumer package goods.  Serving clients worldwide through our North American and European offices and a network of independent market research firms, Harris specializes in delivering research solutions that help us – and our clients – stay ahead of what's next.  For more information, please visit www.harrisinteractive.com.

# Appendix C - Demographics Information

## Summary of Survey Samples

▸ National Sample Screened by Harris Interactive: 4,612 U.S. adults (age 18 and over) online
▸ Selected for interviews: 1,961 respondents who said they had a main or primary doctor and also understood what kind of record system their doctor used:

  ▸ Respondents who said their doctor had an EHR system (as defined): 1,153
  ▸ Respondents who said their doctor had primarily a paper-based system (as defined): 808

## Standard Demographics

### Gender

|  | EHR group | Paper group |
|---|---|---|
| Male | 45% | 45% |
| Female | 55% | 55% |

### Age

|  | EHR group | Paper group |
|---|---|---|
| 18-29 | 13% | 14% |
| 30-49 | 32% | 32% |
| 50-64 | 30% | 31% |
| 65+ | 25% | 24% |

### Race or Ethnicity

|  | EHR group | Paper group |
|---|---|---|
| White | 79% | 73% |
| Black and/or African American | 9% | 14% |
| Asian or Pacific Islander | 2% | 1% |
| Mixed racial background | 1% | 1% |
| Hispanic | 8% | 9% |

### Income

|  | EHR group | Paper group |
|---|---|---|
| Less than $15,000 | 6% | 9% |
| $15,000 - $34,999 | 16% | 17% |
| $35,000 - $74,999 | 34% | 31% |
| $75,000 - $124,999 | 31% | 28% |
| $125,000 - $249,999 | 10% | 12% |
| $250,000 + | 2% | 1% |

## Education

|  | EHR group | Paper group |
| --- | --- | --- |
| High School or Less | 30% | 37% |
| College | 55% | 49% |
| Graduate School | 15% | 15% |

## Health Demographics

### Health, self-reported

|  | EHR group | Paper group |
| --- | --- | --- |
| Excellent | 20% | 22% |
| Pretty good | 57% | 55% |
| Fair | 20% | 20% |
| Poor | 3% | 4% |

### Health Insurance

|  | EHR group | Paper group |
| --- | --- | --- |
| Covered | 94% | 91% |
| Not Covered | 6% | 9% |

### Sensitive Health Condition

|  | EHR group | Paper group |
| --- | --- | --- |
| Yes | 57% | 47% |
| No | 43% | 53% |

### Types of Sensitive Health Conditions

|  | EHR group | Paper group |
| --- | --- | --- |
| Used the services of a psychologist, psychiatrist, or other mental-health professional | 28% | 24% |
| Had a long-term medical condition such as diabetes or epilepsy | 22% | 17% |
| Had a serious illness such as heart attack, stroke or cancer | 15% | 12% |
| Had any major physical or mental disabilities | 13% | 13% |
| Had a medical procedure that you did not want other people to know about | 10% | 7% |
| Had any sexually transmitted health condition | 8% | 7% |
| Had an alcohol or drug abuse problem | 5% | 6% |

### Chronic Condition

|  | EHR group | Paper group |
| --- | --- | --- |
| Yes | 52% | 48% |
| No | 48% | 52% |

## Specific Chronic Conditions, as told by health care provider

| | EHR group | Paper group |
|---|---|---|
| High blood pressure | 62% | 64% |
| High cholesterol | 49% | 49% |
| Overweight or obese | 34% | 37% |
| Arthritis | 33% | 28% |
| Type 2 Diabetes | 23% | 22% |
| Chronic pain | 21% | 16% |
| Depression | 20% | 16% |
| Heart disease or heart attack | 15% | 15% |
| Asthma or other respiratory disease | 16% | 12% |
| Anxiety disorder / PTSD | 13% | 15% |
| Cancer | 13% | 8% |
| Stroke | 3% | 1% |
| Type 1 Diabetes | 3% | 2% |
| None | 3% | 5% |
| Decline to answer | 1% | 1% |

The National Partnership for Women & Families is a nonprofit, nonpartisan organization dedicated to promoting fairness in the workplace, access to quality health care and policies that help women and men meet the dual demands of work and family. More information is available at www.NationalPartnership.org.