Engaging Patients and Families: How Consumers Value and Use Health IT

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About the National Partnership for Women & Families

At the National Partnership for Women & Families, we believe that actions speak louder than words, and for four decades we have fought for every major policy advance that has helped women and families.

Today, we promote fairness in the workplace, reproductive health and rights, access to quality, affordable health care, and policies that help women and men meet the dual demands of work and family. Our goal is to create a society that is free, fair and just, where nobody has to experience discrimination, all workplaces are family friendly, and no family is without quality, affordable health care and real economic security.

Founded in 1971 as the Women's Legal Defense Fund, the National Partnership for Women & Families is a nonprofit, nonpartisan 501(c)3 organization located in Washington, D.C.

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I. Executive Summary

Federal health policy is evolving rapidly, integrating a focus on improving population health outcomes and ensuring accountable care. Nearly every stakeholder recognizes that greater patientcenteredness and patient engagement are essential to the "Triple Aim" of federal health reform: improving care, improving health and reducing cost.

Anticipating the robust health information technology infrastructure that would be necessary to support health care reform, Congress enacted the Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009 to drive the adoption of health information technology (health IT). The statute leveraged the federal government's role as the largest payor for health coverage through Medicare and Medicaid in order to reach eligible hospitals and professionals across the nation with an incentive program to adopt electronic health records (EHRs) and use them meaningfully to improve patients' care.

Consumers, too, quickly and intuitively recognize that health IT can contribute directly to fewer medical errors, lower costs, and better health outcomes. They see the benefits that 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. However, questions remain about the usefulness of health IT to patients and families, as well as its impact on the U.S. health care system.

After the Medicare and Medicaid EHR "Meaningful Use" Incentive Program began, the National Partnership for Women & Families fielded a groundbreaking national survey in 2011 to assess patients' expectations and needs regarding EHRs and health IT. Much has happened in the health IT landscape since that baseline survey, so the National Partnership conducted a follow-up survey in 2014 to gauge the impact of this evolution and these initiatives from the perspective of patients and families.

In the five years since the federal program was created, the public discourse has often focused on the views of doctors, hospitals and vendors. With this survey, we hear what patients have to say. Patients have a unique vantage point: They see multiple providers and thus know whether their care is being coordinated. They know whether they have to provide the same information over and over again, or whether tests have to be repeated because the results were lost or inaccessible. Their voices offer important guidance for ensuring the overall effectiveness of health IT adoption in improving the quality and cost effectiveness of health care. Through this follow-up survey, we gauge not only consumers' perceptions of and experiences with health IT, but also continuing barriers and unmet needs.

These findings can contribute much to inform health IT policy and practice that successfully engages all consumers and provides the tools they need to promote better care and improve health outcomes. After reviewing the findings, this report distills some of the policy implications across all policies and programs, not just the Meaningful Use program. While the Meaningful Use program is a critical policy lever for improving people's electronic access and use of their health information, it is not the only lever. These survey results equally inform broader delivery system initiatives and patient engagement efforts as well.

Survey Objectives

This second national survey will help policymakers, stakeholders and the public understand and assess consumers' current expectations of electronic health records and information exchange. By repeating questions in the 2011 baseline survey and report, this second survey also provides unique data on trends in consumer attitudes from 2011 to 2014, reflecting the nation's progress from launch

of the federal Meaningful Use Incentive Program to substantial adoption and use of EHRs and initial implementation of Stage 2 and patients' online access. By adding new questions, the survey yields unique data on major new topics being discussed for subsequent stages (such as patientgenerated health data). By adding oversamples of Black/African American and Asian American respondents to that of Hispanic/Latino respondents, this survey yields critical data to assess the impact of current initiatives and ensure that health IT meets their diverse needs and helps to reduce health disparities. Collectively, the survey and report should help health care organizations, patient advocates, and policymakers understand how better to design and implement electronic health information exchange to meet the needs of patients and families.

Who We Surveyed

Harris Poll, one of the nation's leading polling organizations, conducted the survey for the National Partnership for Women & Families online between April 22 and May 7, 2014, from a sample of respondents representative of the total U.S. population of adults 18 and older. To focus on those patients who have some experience with a medical record system (whether paper or electronic), the survey identified patients who met two criteria: (1) they had an ongoing relationship with a main doctor, and (2) they knew what kind of record system — electronic or paper — the provider used. This yielded a pool of **2,045 adults** — representing 68 percent of the adult population, after the data were weighted to represent the demographics of the national adult population. The qualified pool comprised 1,192 patients whose main doctor was using an EHR and 853 patients whose main doctor was using a paper-based system.¹ We believe that this sample construction continues to be a unique attribute and contribution of this survey, by collecting a pool responding to questions based upon their own experience with EHRs rather than in the abstract. Chapter IV and Appendix A provide a useful profile of this representative sample's demographic and health characteristics.

We also conducted an oversampling of three different populations that are commonly the most underserved and suffer the greatest health disparities in the U.S. health care system today: Latino or Hispanic adults, Black or African American adults, and Asian American adults. Although we did not oversample this group, we also report in relevant areas on the views of those who identified as lesbian, gay, bisexual or transgender (LGBT), and people with disabilities, as these individuals are known to experience significant disparities in care as well.

Who Should Find the Survey Beneficial

The detailed survey findings will help providers, policymakers, technology vendors, consumer and patient advocates, payors and employers understand how best to design health IT and electronic health information exchange to meet the needs of patients and families. Chapter II summarizes some of these key uses. They underscore why policymakers must continue to encourage investment in patient-oriented features and in removing barriers to their use.

¹ Appendix B provides a more detailed discussion of the survey methodology and sample weighting. For example, while the pool of 2,045 adults comprises 1,192 EHR respondents (58.3 percent) and 853 paper-record respondents (41.7 percent), after proper weighting the EHR respondents comprise 80 percent of the total pool and paper-record respondents comprise 20 percent. This does not represent the percentage of doctors in the United States who use an EHR, nor the number of patients in the United States whose health information is in 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).

Executive Summary of Key Findings

1. Patients (regardless of the type of record system their physicians use) continue to see significant value in EHRs. Perhaps not surprisingly, there has been a considerable shift to EHRs since 2011. Patients believe that EHRs have far greater impact and usefulness for both themselves and their doctors than paper record systems.

- Eighty percent of adults in the United States with a main doctor said that their doctors use an EHR system (up from 64 percent in 2011).
- ▶ Between 85-96 percent of all patients said that the EHR was useful in various aspects of care delivery, while by comparison, only 57-68 percent saw paper records as useful.
- ▶ When asking consumers about the impact of their doctors' record systems on the doctor and on the patient personally, patients rated the helpfulness to their physicians much higher on several elements than the helpfulness to themselves.
 - Of patients with EHR systems, 70-80 percent rated those systems positively as <u>helping</u> <u>doctors and their staffs</u> provide these vital services. By contrast, only 39-55 percent of patients in paper-record systems rated those as helpful to doctors and staff.
 - ► EHR patients were more likely than paper-record patients to state that their record system <u>helped them personally</u> for various purposes (64 percent to 35 percent, compared with 43 percent to 31 percent).
- Although patients continued to find EHRs far more useful than paper-record systems in 2014, paper-record patients did view those systems somewhat more positively in 2014 than in 2011. For example, 34 percent of patients with paper-record systems said that the record system had a positive impact on their quality of care, compared with 26 percent in 2011.
- Over one-quarter (26 percent) of patients stated that it would be very valuable to them if their physicians switched from paper records to EHRs.

2. The numbers of patients with online access to the information in their providers' EHRs have nearly doubled. Half (50 percent) of patients now have online access to their health information, and those who do see even greater value in EHRs.

- Online access to EHRs has increased since 2011 from just over a quarter (26 percent) to half (50 percent) in 2014.
- ▶ Those with online access overwhelmingly make use of this capability: 86 percent use it at least once per year, and more than half (55 percent) use online access three or more times per year.
- ▶ The more frequently individuals access their health information online, the more they report that it motivates them to do something to improve their health. A dramatic 71 percent of those using online access three or more times per year report this, compared with 39 percent of those who used online access less often.
- ► Administrative or "convenience" features (such as online scheduling and medication refill requests) were rated highly by patients. EHRs were rated 31 percentage points higher than paper in scheduling or changing appointments. EHR patients were also more likely than paper-record patients to report that EHR systems help them personally a great deal or a lot in avoiding repeatedly filling out forms (64 percent, compared with 43 percent).

3. Patients and consumers want even more robust functionality and features of online access than are available today. In addition to online access to health information, many patients expressed a desire for easy, electronic methods to communicate with doctors as well as tools that help patients manage their own health, or the care of a loved one. There is work to be done to improve the experience and functionality of online access for patients and providers.

- ▶ A majority (56 percent) of patients reported that they want the ability to email their providers.
- Strong majorities also wanted the ability to review treatment plans (56 percent), doctors' notes (58 percent) and test results (75 percent), as well as to schedule appointments (64 percent) and submit medication refill requests (59 percent).
- ▶ One of the lowest-rated elements for EHR features was tracking progress toward individual health goals, a new facet we explored in 2014. Although half of patients overall (50 percent) reported that they set or track goals for their health all or most of the time, when asked about features available through online access, patients whose doctors have EHRs were least likely to have such a feature (42 percent).

4. All patients, regardless of record type, see the value of EHR systems with respect to privacy. While people continue to be concerned about the safety of their health information, those concerns are increasingly seen in the fuller context of the benefit of EHRs. We found that the more patients experience the benefits of EHRs, the more they trust providers to protect their privacy; and the more they trust that their privacy is protected, the more they use and benefit from EHRs. However, more work needs to be done to educate consumers about how their information is collected, used and protected.

- Compared with 2011, patients in 2014 are more likely to believe that EHRs are useful in giving patients more control over how personal medical information is used, earning the trust of patients in the way their medical information is being handled, complying with privacy and confidentiality laws, and giving patients confidence that their information is safe.
- ▶ Online access is a key strategy for improving patient trust in EHRs. Patients with online access to their health information trust their provider significantly more than patients with EHRs, but without online access (77 percent, compared with 67 percent).
 - High numbers of both EHR and paper-record patients stated that it was important to them to know how their information was being collected and used (88 percent of EHR patients and 82 percent of paper-record), but less than 60 percent stated that their doctors and staff did a good job of explaining how their information is used (55 percent and 51 percent, respectively, reporting "well" or "very well" explained).

5. Different populations prefer and use different health IT functionalities, and thus additional or modified strategies may be necessary to engage these patients and families. Continuing to increase the use of EHRs and providing useful online access are promising strategies to improve health outcomes and reduce health disparities for all underserved populations. However, special attention must be paid to meeting their specific health needs and promoting trust in such systems in order to maximize their value.

Non-Hispanic White patients (82 percent) were most likely to say that their main doctors use EHR systems, while Latino/Hispanic (76 percent) and Black/African American patients (76 percent) were the least likely to say so.

- Hispanic adults were significantly more likely (78 percent) than non-Hispanic Whites (55 percent) to say that having online access increases their desire to do something about their health.
- Hispanic, LGBT and Asian American individuals were among the most likely to say that they would access their personal health and medical information on a mobile device or tablet if they had the capability, including 53 percent of Hispanic adults.
 - Non-Hispanic Whites were the least likely to do so, with less than three in 10 (29 percent) saying that they would do so.
- Hispanic adults and LGBT individuals were most likely to have a physician in a solo practice (39 percent for Hispanic adults, 35 percent for LGBT individuals, compared with 25 percent of the total sample).

Chapter V presents the survey's detailed findings and strategies for patient engagement in seven key areas: adopting and using EHRs, convenience features, online access to personal health information, electronic communication and information sharing, health and care planning, privacy and trust, and designing and building for diversity.

Policy Implications and Recommendations

These and the other findings described in the full report point to some important implications for U.S. public policy that strengthen the impact of EHRs in health care transformation. They also point to several actions that providers, vendors and other stakeholders can take to ensure the full benefit of EHR and health IT investments. Chapter VII provides a full description of these implications.

Strategies for Patient Engagement

Despite its promise, we have yet to fully realize the potential of health IT to engage patients and families meaningfully and consistently. To enhance patient engagement, it is important to acknowledge that not all individuals will be engaged in the same way. In fact, the same individual might need diverse engagement strategies at different points in her life, or different, parallel strategies to address concomitant health issues.

In order to meet patients wherever they are along a continuum of engagement and health, we must leverage a variety of health IT solutions and tools capable of supporting different phases of health, consistent with shifting needs and priorities. We outline seven strategies that our survey findings suggest to engage patients and families in their health and care using health IT:

- 1) Continue to adopt and use EHRs to improve patient care, experience, access and use.
- 2) Integrate more "convenience" features as standard features of patient portals.
- Strengthen and expand electronic access to and use of clinical health information throughout new models of care delivery and payment.
- Enhance functionalities for patients to communicate with and share information with health care providers and others.
- 5) Build robust functionality to support patients and families in health and care planning.
- Foster trust with patients by showing how their health information is stored, exchanged, used and protected.
- 7) Build tools and systems that recognize and reflect demographic diversity, with particular attention to language and cultural competency issues.

All stakeholders should partner with patients and families to learn about their needs and priorities, and what health IT functionalities best serve those needs.

ADOPT AND USE EHRs

Recommendation: Federal, state and private-sector policies and programs, such as the Meaningful Use program, should continue to invest in and advance EHR functionalities that patients and families value, including health and care planning, online access, health information sharing and patient-generated health data.

Recommendation: EHR incentives — whether federal, state or private-sector — should cover a wider range of health care programs and providers than the Meaningful Use program currently covers. This will create more coordinated care and seamless information sharing across the health care continuum, including long-term care, home health and certain specialists not covered by today's incentive program.

Recommendation: A wider array of federal health programs beyond the Meaningful Use program should require the use of certified EHRs.

ONLINE ACCESS

Recommendation: Federal, state and private-sector policies and programs should advance strong online access requirements, including online access in future stages of the Meaningful Use program. More frequent online access improves health behaviors, creates value and buttresses trust among consumers.

Recommendation: Policies and programs should improve the use and experience of online access, including usability and the features offered (such as the ability to offer corrections and amendments). This should also yield workflow efficiencies for providers as more and more patients use online access.

Recommendation: Policies advancing health literacy should include an emphasis on health IT literacy.

ELECTRONIC COMMUNICATION AND INFORMATION SHARING

Recommendation: The capacities to collect patient-generated health information, share health information electronically, and set and track personal health goals are all critical components of using health IT for care planning, and all should be advanced throughout key federal health policies and programs, including the Meaningful Use program.

PRIVACY AND TRUST

Recommendation: Policies and programs can support patient trust by increasing the value of EHRs to patients, including incorporating useful features for electronic access and for sharing corrections, amendments and other patient-generated health data.

Recommendation: Policies and programs should improve the transparency of and patient education about how EHRs collect, store, use and protect personal health information. Online access features can help by offering patients a view into their medical records.

Recommendation: Policies and programs should leverage EHRs' capability to improve privacy and security, such as encrypting personal health information and prohibiting re-identification of de-identified health information. Additionally, continued development and testing of approaches that enable patients to segment their data and direct which care team members see certain pieces of information that they deem sensitive are important for enhancing consumer trust in electronic health information exchange.

DESIGNING AND BUILDING FOR DIVERSITY

Recommendation: Policies and programs should consider the different preferences, needs, experiences and barriers of diverse people and communities, and should design and build health IT to embrace that diversity and engage patients in a variety of ways.

Recommendation: Policies and programs should require collection and use of more granular demographic information in order to help providers and population-health initiatives better address the specific needs of diverse subpopulations.

Recommendation: Policies and programs should make online access even more useful for traditionally underserved populations, promoting the availability of access through mobile devices, as well as access in languages other than English.

II. How the Survey Can Be Used

The detailed survey findings reported below should help providers, policymakers, technology vendors, consumer and patient advocates, payors and employers understand how best to design electronic health information exchange to meet the needs of patients and families. They underscore why policymakers must continue to encourage investment in patient-oriented features and in additional infrastructure necessary to remove barriers to use. This table lists some of the particular uses.

USER	PURPOSE
	Understand the range of health IT functionalities that are important to patients and families and the different strategies that engage them more effectively in their care and improve health outcomes
	 Strengthen relationships with existing patients and attract new patients by offering the online services they value
Providers	 Boost the number of patients who use online access (e.g., portals) and secure messaging to meet federal requirements for Meaningful Use (and other initiatives)
	 Identify efficiencies in workflow and reduce phone call volume through effective use of secure messaging, reporting test results online and more
	 Improve patient trust through education about EHRs and privacy protections
	 Decrease health disparities and improve health status of underserved populations when using EHRs and designing online access
	 Understand and integrate the need for a multitude of health IT functionalities in order to effectively engage patients who have diverse health needs and priorities
Policymakers	 Identify future patient/family engagement requirements for the Meaningful Use and other delivery reform programs such as patient-centered medical homes (PCMHs) and accountable care organizations (ACOs)
	 Assess the effectiveness of the Meaningful Use program to date
	 Identify priority areas for future development of certified EHR functions
	 Gain market share by developing features and functions of EHRs in areas where patients and providers need them
Vendors	 Improve and diversify current EHR features in order to better meet the needs of patients and providers and improve quality, efficiency and health outcomes
vendors	 Identify areas where more education and engagement are needed to advance effective use of EHRs for both providers and patients
	 Create new health applications that advance better care for patients and families and give providers an edge in the market
	 Assess the impact of the Meaningful Use program on consumers in tangible terms
Consumer	 Inform future advocacy agendas for delivery system change, including the use of EHRs
Advocates	 Engage and educate patients and families as health care consumers in areas such as understanding the value of EHRs, bolstering consumer trust and choosing doctors

USER	PURPOSE
	 Increase the number of enrollees who use health insurance portals by improving the features offered
Health Plans	 Create new requirements for the use of EHRs under plan-created EHR incentive programs
	 Identify requirements for the use of EHRs in plan-sponsored programs like PCMHs and ACOs
	 Advance EHR-enabled patient and family engagement in health plan contracting
Employers	 Educate employees about the value of EHRs and their ability to protect privacy
	 Understand how to leverage the value of online access in employer wellness programs

III. Introduction

Many view electronic health records (EHRs) and other forms of health information technology (health IT) as essential to achieving the goals of the nation's "Triple Aim": enhancing the patient experience of care, improving the health of populations, and reducing the per capita cost of health care. Successful performance under new models of care currently being tested as a result of the Patient Protection and Affordable Care Act (ACA) will be out of reach for providers and systems that have not begun incorporating the use of modern health information technologies to improve the health of the population, as well as the quality and experience of care for individuals.

Anticipating the robust health IT infrastructure that would be necessary to support comprehensive delivery system reform, federal lawmakers first passed the Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009 to promote the adoption and use of health IT. The HITECH Act is wellknown for creating the federal program that gives incentive payments to eligible health care providers for adopting and using certified EHRs "meaningfully" to improve patient care — the "Meaningful Use" EHR Incentive Program.

Five years later, questions remain about the usefulness of health IT to patients and families, as well as its impact on U.S. health care. Measuring consumer experiences with EHRs can reveal much about whether EHRs are being used well to achieve the Triple Aim, because consumers have a unique vantage point. They see multiple providers and thus know whether their care is being coordinated. They know whether they have to provide the same information over and over again, or whether tests have to be repeated because they were lost or inaccessible. As the taxpayers who fund the program, they about the control barometer of the program.

Five Years After HITECH

To date, a wide range of health care providers — hospitals, physician practices, nurse practitioners, dentists and others — have registered for and received incentive payments under the Meaningful Use program.

- Since the first fielding of this survey in 2011, nearly all hospitals in the United States have registered for these incentives (95 percent as of June 2014), with 91 percent receiving incentive payments under the Meaningful Use program.
- As expected, adoption in physician practices is not as robust. Still, nearly 60 percent of Medicare providers and nearly 30 percent of Medicaid providers have registered for the program, with 48 percent and 22 percent, respectively, earning incentive payments.
- Sixty-eight percent of Medicare- and Medicaid-eligible providers have made financial commitments to EHR implementation as of June 2014.

should be the central barometer of the program's effectiveness.

Accordingly, we have conducted a follow-up survey to the one we fielded in 2011 to gauge the impact of this significant federal initiative from the perspective of patients and families. In the five years since the federal program was created, the public discourse has primarily focused on the views of doctors, hospitals and vendors. With this survey, we hear what patients have to say. These voices offer important guidance for ensuring the overall effectiveness of EHR adoption in improving the quality and cost effectiveness of health care, and for enhancing patient engagement.

Survey Context

Much has happened since the National Partnership for Women & Families conducted its initial survey of patients and consumers in August 2011, and there was significant need for an updated survey. Then, only small numbers of eligible professionals and hospitals had received incentive payments.

As of July 2014, 75 percent of eligible professionals and 92 percent of eligible hospitals had received incentive payments for successfully attesting to the adoption and meaningful use of EHRs. Our survey in 2014 measures this transformation from the patients' perspective, on the fifth anniversary of the HITECH Act, the very year Congress identified as the national goal for having everyone in an electronic health record.

As a result of the Meaningful Use program's requirement that providers offer patients online access to their own health information, our survey shows rapidly increasing numbers of people who have online access to their own health information. Given the heightened attention now being paid to the deployment of online access capabilities for patients, we posed survey questions designed to assess the availability of online access today, the frequency with which consumers use it, the impact it has on their health and care, and the features they can access and want.

In these final years of incentive payments for Medicare providers (penalties for non-adoption replace incentives in 2016), it is also critical to ensure that growing adoption rates are achieving the goals originally set out by the program. In other words, is care more coordinated? Is information more easily accessible to patients and families? Is it easier for them to access their care team using these technologies? How can the Meaningful Use program and other innovative models of care support additional forms of engagement by patients and their families, such as patient-contributed information that is critical to care planning and decision-making? And are the benefits of health IT adoption accruing equitably across all populations, so that disparities in health outcomes are reduced?

With this follow-up survey, we gauge not only consumers' perceptions of and experiences with health IT, but also continued barriers and unmet needs. All stakeholders can use these data to inform policies and practices that successfully engage all consumers and provide the tools they need to promote better care and improved health outcomes.

Survey Objectives

- 1. Measure consumers' experience with the Meaningful Use program and other health IT-enabled aspects of health reform, in 2014 and over time by comparing attitudes and opinions today with the baseline survey in 2011.
- 2. Explore the experiences and opinions of traditionally underserved populations, to ensure that health IT meets their needs, and make recommendations about how health IT can be used to reduce health disparities.
- 3. Identify policy recommendations for improvements to the Meaningful Use program and broader health reform initiatives, grounded in these findings, that could increase both public support and the overall effectiveness of these programs, as well as enable providers to achieve high levels of performance.

IV. Meeting Patients Where They Are: A Profile of Respondents

The National Partnership for Women & Families commissioned Harris Poll to conduct a second nationwide survey of consumers in order to assess and report their expectations and needs regarding electronic health records and information. Harris Poll fielded the survey online between April 22 and May 7, 2014, among 2,045 adults 18 and older throughout the United States who indicated that they had primary doctors and knew whether their doctors kept their medical and health information in an electronic or paper format. We focused on these individuals with knowledge of their providers' record systems in order to ensure that **the opinions expressed in the survey were based on actual experience** and that respondents served as an informed barometer of the record system's impact on their care and experience.

The final survey pool included 1,192 respondents (58 percent) whose primary doctors were using an electronic health record (EHR) system and 853 respondents (42 percent) whose primary doctors were using a paper-record system. Note that this percentage does not represent the proportion of patients nationally whose doctors have EHRs, nor the proportion of patients having their medical information in an EHR, but rather the percentage of respondents with each record type in our final sample before weighting.

The EHR and paper-record respondent groups were similar in gender, age and income. EHR respondents were most likely to be employed full time (37 percent, compared with 33 percent for paper-record respondents) or retired (28 percent, compared with 23 percent for paper-record respondents). EHR respondents also had a higher proportion of college graduates (37 percent having a college education or more, compared with 33 percent of paper-record respondents). EHR respondents had a higher proportion of non-Hispanic White respondents (70 percent, compared with 63 percent for paper-record respondents), and conversely, paper-record respondents had a higher proportion of Hispanic respondents (14 percent, compared with 11 percent of EHR respondents).

With respect to their experiences with health and health care, the EHR and paper-record respondents identified similarly in terms of health status (whether their health was excellent, pretty good, fair or poor), whether they had chronic health conditions (49 percent for EHR patients, compared with 46 percent for paper-record patients), and whether they had health insurance coverage (96 percent for EHR patients, compared with 94 percent for paper-record patients). Overall, 31 percent of respondents were covered by Medicare or Medicaid. Paper-record respondents were more likely to see doctors in solo practices (48 percent, compared with 20 percent for EHR respondents).

Since there is no firmly established demographic profile of those with physicians who use EHRs or paper-record systems, data from all respondents (qualified, non-qualified and over-quota) were weighted to the existing profile of all U.S. adults, using the 2013 Community Population Survey, thus ensuring that the survey sample is nationally representative. The qualified respondents — those having a main doctor and knowing their doctors' record systems — were then extracted for analysis. Because the entire sample of all adults was properly balanced to the U.S. census, the resulting subsamples of EHR and paper-record respondents are properly representative as well. Harris Poll used propensity score weighting to adjust for respondents' tendencies to be online.

This respondent pool represents 68 percent of the adult population of the United States, after data were weighted to represent the demographics of the national adult population. Therefore, this survey represents an estimated 160 million Americans.

Respondents for this survey were selected from those who have agreed to participate in Harris Poll's online research panel. Because the sample is based on those who were invited to participate in the online research panel, no estimates of theoretical sampling error can be calculated. For more information, see **Appendix B**.

Questions Asked

This survey follows a survey that we fielded in 2011. The original 2011 survey was intended to measure perceived benefits of and trust in EHRs based on patients' actual experiences. In this second fielding of the survey, we retained this approach in order to assess changes in attitudes in the subsequent three years and to probe experiences with systems and features emerging as a result of the national transition toward EHRs and electronic information exchange, including evolution of the Meaningful Use Incentive Program. We also added some new questions to understand patients' views and experiences regarding current topics being discussed for Stage 3 of Meaningful Use, and to understand patients' demand for more robust features, such as caregiving, care planning and goal setting, and mobile access.

First, we sought to assess consumer views of the value of EHRs and paper-record systems. We asked questions pertaining to how consumers value EHRs and paper records in areas such as the impact on the quality of health care, overall satisfaction with the record systems and the perceived usefulness of the record systems to doctors and to patients personally. We then conducted a detailed analysis of the impact of having online access to information in the EHR. We posed survey questions designed to assess the availability of online access today, the frequency with which consumers use it, the impact it has on their health and care, and the features patients can access and want.

In order to gauge trust in the record systems, we posed several survey questions designed to understand and assess the degree of trust that patients have today both in record systems and in their providers to protect the privacy of their health information. We asked respondents how useful they found each of the two medical record systems in facilitating the delivery of privacy protections.

Oversampling

In addition to our two respondent groups of patients in EHR systems and those in paperrecord systems, we sought to assess perceptions and experiences among traditionally underserved populations and to determine whether any significant differences exist with respect to the value of, use of and trust in health IT systems. Accordingly, we conducted an oversampling of three different populations who are frequently underserved in the U.S. health care system today — African American, Hispanic and Asian American adults. We also offered the questionnaire in both English and Spanish. Of the qualified survey respondents, 11 percent identified as Hispanic, 12 percent as Black/African American, and 6 percent as Asian American. Although we did not oversample this group, we also report below in relevant areas on the views of those who identified as lesbian, gay, bisexual or transgender (LGBT), and those who indicated that they have a major disability, as significant disparities in health care are well documented among these individuals.

Respondent Profile

We share below a profile of the respondent pool. For a more complete demographic breakdown of the sample, please see **Appendix A**. Some basic characteristics follow:

- ▶ All states were represented.
- ▶ Of total survey respondents, 69 percent identified as non-Hispanic White, 12 percent as African American or Black, 11 percent as Hispanic, 6 percent as Asian American or Pacific Islander, less than 1 percent of Native American or Alaskan, and 1 percent as other.
- ▶ Five percent of respondents identified as lesbian, gay, bisexual or other, and 1 percent identified as transgender.
- ▶ Respondents varied significantly in age; 12 percent of the sample was 18-29, and 24 percent was 65 or older. (See Chart 1.)
- ▶ Fourteen percent of respondents had a major physical or mental disability.
- Almost 10 percent of respondents spoke Spanish at home.
- ▶ Fifty-six percent of respondents had some college or a college degree, and one-quarter of respondents had a high school diploma or less.
- ▶ Thirty-seven percent of respondents worked full time.
- ▶ One-third of respondents (33 percent) had household income less than \$50,000 per year, and twothirds (65 percent) had household income less than \$100,000 per year. Household incomes ranged from less than \$15,000 (6 percent) to more than \$250,000 (2 percent).



Below are some of the health demographics of respondents:

- Three-fourths of respondents (75 percent) saw doctors in group practices, and one quarter (25 percent) had doctors who were in solo practices. Paper-record respondents were much more likely to have a doctor in a solo practice (48 percent, compared with 20 percent of EHR respondents). (See Chart 2.)
- Ninety-five percent of respondents were covered by some form of health insurance. Almost half (44 percent) were covered through work or a union or someone else's work or union. Fourteen percent had insurance that they or their family members purchased. Twenty-four percent were covered by Medicare and 7 percent by Medicaid the coverages relevant to the Meaningful
 Chart 2: Respondents with Main Doctors in Solo Practices and Physician Group Practices [Base = All qualified respondents (n=2045): EHR (n=1192), paper (n=853)]
- Nearly eight in 10 (78 percent) people said that their overall health was good or excellent. However, nearly half (48 percent) of the respondent pool reported that they have chronic conditions. People varied in the extent to which they engaged in certain health promotion behaviors "all of the time" or "most of the time." (See Chart 4.)

Use program. (See Chart 3.)

- Nine out of 10 were taking all medications prescribed to them, and eight out of 10 followed up with specialists recommended by their doctors.
- Seventy-eight percent were seeing a doctor on a regular basis, and 77 percent shared information with their health care providers.
- Just over half had regular exercise routines and half set or tracked goals for their health all or most of the time.
- Seven percent of respondents were providing unpaid care to a spouse, partner, family member, friend or neighbor.





Profile of Underserved Communities

Non-Hispanic White patients (82 percent) were most likely to say that their main doctors use EHR systems, while Latino/Hispanic (76 percent) and Black/African American patients (76 percent) were the least likely to say so. Overall, Hispanic adults and LGBT individuals were more likely to have a physician in a solo practice (39 percent for Hispanic individuals, 35 percent for LBGT adults, compared with 25 percent of the total sample).

There were also differences among respondents' health promotion behaviors, such as taking medications, getting regular exercise and seeing a doctor regularly. (See Chart 5.) We found:

- ▶ Asian American adults were least likely to take their medications all of the time and most likely to exercise regularly, including 33 percent who reported that they exercise regularly all of the time (compared with 24 percent of the total sample).
- ▶ African American adults were most likely to see their doctors regularly, including a significantly higher percentage (65 percent) who reported that they see their doctors regularly all of the time (compared with 53 percent of the total sample).
- ► African American adults were 10 percentage points more likely than the total sample to take all recommended tests all of the time.
- ▶ Hispanic, Black/African American and Asian American adults were 12-23 percentage points higher than non-Hispanic White adults to use a mobile or smartphone all or most of the time for electronic



access to their medical information or doctor (33 percent for Hispanic adults, 28 percent for Asian American adults and 22 percent for Black/African American adults, compared with 10 percent for non-Hispanic White adults).

▶ Asian American adults were significantly more likely than non-Hispanic Whites to set and track goals for their health "most" or "all" of the time (60 percent, compared with 47 percent), while Hispanic adults were the most likely to say they set and track goals for their health *all* of the time (30 percent, compared with 21 percent of the total sample).











Different people. Different phases of life.

Different digital tools.





MANY STRATEGIES FOR PATIENT ENGAGEMENT



V. Key Findings and the Strategies They Suggest for Effective Patient Engagement

Health IT can empower individuals with the information and electronic tools necessary to be active partners in their own health or the care of a loved one. Health IT can help patients and their caregivers make more informed decisions; be better connected; generate and share important health information; and set, track and achieve personal health and wellness goals. So far, however, we have yet to fully realize the potential of health IT to meaningfully and consistently engage patients and families in these ways.

To enhance patient engagement, it is important to acknowledge that not all individuals will be engaged in the same way. In fact, the same individual might need different engagement strategies at different points in her life, or different, parallel engagement strategies to address concomitant health issues. Fortunately, there are a variety of methods to leverage technology to enhance the quality of care, foster trust with patients, bolster engagement, and improve health outcomes.

For example, significant attention is rightly focused on the ability of technology to give individuals **electronic access to their medical records** (the premise of the View/Download/Transmit criterion in Stage 2 of Meaningful Use, for example). However, not all consumers will have the desire or need to access their clinical health information online. Health and health care may not be a high priority for every individual at any given time. Different strategies, or different combinations of strategies, may be necessary to engage these consumers in an increasingly online health environment. For example, many individuals see significant value in electronically enabled administrative or **"convenience" features** such as online appointment scheduling. Some consumers may be more likely to utilize online convenience features than to electronically access medical records or lab results. In time, those who have sampled the online health environment through online appointment scheduling, for example, may feel more comfortable utilizing more robust health IT functionality in the future.

For other patients and families, one-way access to online health information is not enough; they want easy, electronic methods to **communicate with doctors** (e.g., secure email) and **share information** pertinent to their health and care (patient-generated data). Some consumers also want health IT tools to **set and track goals** for their health and care, and the ability to connect electronically with community and support resources.

In order for EHRs to be used in meaningful ways, patients must value and trust them. Securing and **bolstering patient trust** is therefore another essential engagement strategy. Our data indicate that patient trust is associated with the individual's direct experience with the value and security of EHRs. The more patients experience the benefits of EHRs — such as online access to their own health information — the more they trust that their providers using EHRs are protecting patients' privacy. Providers can further bolster trust by explaining to patients and families how their data are being collected, exchanged, used and protected.

Finally, the value of and current barriers to electronically connected and coordinated care are not the same for everyone, including underserved communities, communities of color, people with disabilities, and people who speak languages other than English. To succeed, we must **consider all factors pertinent to individuals' health**, such as sexual orientation and gender identity, occupation, disability status, environmental factors and caregiver presence, as well as race, ethnicity and language, when designing and implementing health IT policy and practices. For example, African Americans were most likely to see their doctors regularly, while Hispanic and Asian American adults were among the most likely to say they would like access to their personal health information on a mobile device. Differences such as these will affect the ways these individuals can and will be engaged in their own health and care.

In short, with current Meaningful Use criteria requiring patients' online access to health information and with more robust criteria for patient engagement on the horizon, a variety of strategies and tools are needed to meet patients wherever they are along a continuum of engagement and health. As we build a nationwide health IT infrastructure, consumers need flexible health IT solutions and tools that are capable of supporting different phases of health and are consistent with shifting needs and priorities. In this section, we present the survey's key findings, and outline seven strategies that those findings clearly suggest to engage patients and families in their health and care using health IT. These engagement strategies reflect not only the increasing diversity of the nation, but the inevitable fluidity of consumers' health priorities and approaches to care.

Of course, different strategies will work for different patient populations. As needs and priorities change, individuals are likely to take advantage of different strategies and health IT functionalities at different times. Patients and families want to collaborate with all stakeholders to share their priorities and help to design and build health IT functionalities that best serve their needs.

1. Adopt and Use EHRs



KEY FINDING NO. 1: Patients believe that EHRs have far greater impact and usefulness for themselves and their providers than paper-record systems across a range of domains.

KEY STRATEGY NO. 1: Providers across the continuum should continue to adopt and use EHRs to improve patient care, experience, access and use.

Perhaps not surprisingly, there has been a significant shift to EHRs since 2011. We found that currently, 80 percent of adults in the United States with main doctors say their doctors use EHR systems (up from 64 percent in 2011). Overall, individuals whose doctors use EHRs were more likely to state that they were satisfied with the record system than patients with paper records (93 percent, compared with 83 percent). Patients with EHRs are also more likely to report that their doctors' use of EHRs has had a very or somewhat positive impact on the quality of health care services (70 percent, compared with 34 percent). We review these findings in detail below.

Impact on Care Delivery and Quality of Care

We asked a series of questions about the impact of both paper records and EHRs on various aspects of care delivery. We chose response options that tend to be the most valuable to patients, such as care coordination or the ability of patients to communicate directly with their health care providers.

There is a significant difference between EHRs and paper records in perceived impact on care delivery. (See Chart 6.) Between 85 and 96 percent of all patients said that EHRs were useful in various aspects of care delivery; by comparison, only 57 to 68 percent saw paper records as useful. The significantly higher ratings of EHRs across all categories serve as a powerful consumer endorsement of this record system and its uses. (See Chart 7.)

In fact, 95 percent of patients stated that they felt EHRs were useful in assuring timely access to relevant information by all of their health care providers, compared with just 60 percent who said the same about paper records. With the emphasis on provider access to information, particularly in models of care such as accountable care organizations, it is clear that consumers see significantly more value in EHRs and health IT than paper records across a range of key domains - not just timely access to relevant information by



Chart 6: Impact of Record System on



all providers, but helping patients to follow instructions for treatment or care, helping patients take and refill medications as prescribed, and others.

The survey also asked patients how useful they thought paper-record systems "are/would be" in providing these same services. Unlike ratings of EHRs, the ratings of paper-record systems are fairly close between the two respondent groups, but higher numbers of paper-system patients rated their own systems as useful for most patient services. This likely reflects the fact that their personal experience is limited only to paper systems.

Patients with EHRs rated paper records significantly lower in terms of usefulness in various aspects of care delivery (e.g., making sure all health care providers who treat a patient have timely access to all information relevant to the patient's care). Given that these individuals likely had paper records at one point in time, this suggests that patients with EHRs are directly experiencing the comparative benefits of health IT in their overall care delivery, unlike those with paper records. (See Chart 8.)

Patients are increasingly connecting the perceived benefits of EHRs with the need to switch from paper records to EHRs. In 2014, nearly half (49 percent) of patients whose doctors currently use paper-record systems believe that switching to EHR systems would have a positive impact on the overall quality of their health care services.

Impact on Providers

The survey sought to ascertain from EHR patients how well they believe their providers' EHR systems help their doctors and staff deliver care. (See Chart 9.)



These results are striking. Of patients with EHR systems, 70 percent to 80 percent rated those systems positively, helping doctors and their staffs "a great deal" or "a lot" in providing vital services. By contrast, only 39 to 55 percent of patients in paper-record systems rated them as helpful to doctors and staff. Patients with EHRs were significantly more likely than paper-record patients to say that their record systems helped their doctors and staff keep up with patients' medication history (80 percent, compared with 55 percent), manage health conditions and treatments (77 percent, compared with 49 percent), and make sure that all other health care providers have timely access to information (79 percent, compared with 39 percent), among others. The low 39 percent of paper-record patients rating their systems positively for timely access to relevant information by the care team, a critical component of care coordination, is particularly notable.

Personal Impact on Patients

The survey also sought to ascertain from patients the extent to which their providers' record systems help them personally.

Not surprisingly, patients with EHRs were more likely than those with paper records to report that their doctors' record systems helped patients personally. Specifically, they were more likely to state that their record systems helped them personally a great deal or a lot more than paper-record patients in avoiding repeatedly filling out forms (64 percent, compared with 43 percent), sharing information with health care providers (63 percent, compared with 37 percent), and finding/correcting errors in medical records (50 percent, compared with 31 percent). (See Chart 10.)



Interestingly, on three elements that were the same or very similar in both questions about the record system's impact on the doctor and also on the patient personally, the **consumers rated the helpfulness of those three elements to their physicians much higher than the helpfulness to themselves** (92 to 96 percent for doctors, and just 71 to 85 percent for patients). The elements were sharing information with providers, keeping up with medications, and finding and correcting errors.

Note that for every one of these dimensions, between 9 and 25 percent of patients said the systems helped them "none." That includes 9 percent of EHR patients who said the systems do not help them avoid repeatedly filling out forms, and 14 percent who say EHRs do not help them find or correct errors in their records at all. These results imply that consumers do not perceive EHRs to be as helpful to patients as they are to physicians. Given the development of EHRs with the physicians as clients, perhaps this is not surprising, but this paradigm must change if we would successfully engage patients and their families and improve health outcomes.



PATIENT ENGAGEMENT STRATEGY: Perhaps the evolution from paper to electronic health records seems more a core national imperative than a strategy of patient engagement, but the survey data do suggest that, for patients, it furthers engagement, too. Providers across the continuum should continue to adopt and use electronic health records to improve patient care, experience, access and use. The results indicate that adopting EHRs is a critical first step providers can take in building better relationships with patients, and enhancing patients' perception of the quality of care. Patients and families can partner with providers in implementing, promoting and evaluating EHRs. For example, providers could share their computer screen with patients during clinical encounters, allowing patients to see their medication lists or medical records. This gesture not only engages patients in the data entry, but builds a sense of partnership between providers and patients in the mutual pursuit of better health and care.

2. Convenience Features



KEY FINDING NO. 2: Patients find "convenience" features such as online scheduling, medication refill requests and avoiding repeatedly filling out forms to be very beneficial, just as they do with access to their clinical health information.

KEY STRATEGY NO. 2: Integrate "convenience" features as powerful tools that can enhance patients' comfort with and use of health IT and online access.

Efforts to engage patients in health IT often focus on access to and use of clinical health services. However, our data indicate that consumers intuitively understand how some of the more basic "convenience" features enabled by an electronic environment are valuable. These convenience features should be bolstered within patient portals and leveraged as a distinct method of engaging patients and families in the online health environment.

To boost the rates of consumers who use online access, vendors and providers should consider developing and promoting administrative or "convenience" features (such as online scheduling and medication refills). These features were rated highly by patients and are a very effective way to engage patients and families online, first in the electronic health care environment, and subsequently in their own care.

For example, appointment scheduling is popularly perceived and highly rated as a benefit of EHRs. When asked about the usefulness of both record systems in scheduling or changing appointments, EHRs were rated 33 percentage points higher than paper records by all patients as very or somewhat useful, including those whose doctors have paper records today. Patients with EHRs are also more likely than paper-record patients to say their record systems help them personally a great deal or a lot in avoiding repeatedly filling out forms than those with paper records (64 percent, compared with 43 percent). Even so, work remains to be done to enhance these convenience features since 9 percent of EHR patients said the systems do not help them avoid repeatedly filling out forms. Given that these functionalities are technically possible, providers might not be using their systems in these ways, or might not be offering these services to patients with much, if any, effect. (See Charts 11 and 12.)

PATIENT ENGAGEMENT STRATEGY: "Convenience" features are powerful tools that can enhance patients' comfort with and use of online access and should be integrated as standard, critical features of all patient portals. These features may be a natural avenue through which to seek patients' engagement. Understanding more fully how different segments of the population could benefit from using patient portals, and then building systems and provider workflows that accommodate those needs, will be important for ensuring that online access provides the maximum benefit for the broadest populations possible. Patients and families can partner with vendors and providers to identify the administrative or convenience functionalities of most value.



3. Online Access to Personal Health Data



KEY FINDING NO. 3: Easy, useful electronic access to health information is a catalyst for engaging patients and families in their care. Patients who use online access more frequently report a substantial increase in positive impact on knowledge of their health and desire to do something to improve their health.

KEY STRATEGY NO. 3: Strengthen initiatives to provide and increase the frequency of online access.

Those with online access to information in their medical records see even greater value in EHRs. Patients' top-rated features of EHRs — obtaining lab results, making sure different providers all have timely access to relevant information, and helping patients make sure that the information in their medical records is accurate — all require or can be greatly enabled by online access for patients. Even among those whose doctors use paper records, patients see the value of electronic access, with two out of three (64 percent) believing it is "very" or "somewhat important." This suggests that consumers have high expectations of what EHRs and online access will be able to do for them.

The rate of those with online access to their health information has nearly doubled since 2011. Among survey respondents whose physicians use EHRs, half (50 percent) have electronic access to their own health information. Notably, significantly more people 65 and older reported that their doctors give them online access than people in younger age categories. Those over 65 were also more likely to be satisfied with their access than were those in younger age groups. These findings question the common assumption that older patients do not have the means or the desire to make use of this important capability. In addition, these results also indicate that there is still work to be done to understand and deploy features that meet the specific needs of sub-populations, including those of younger age groups.

Overall, a majority (58 percent) of people say that having online access to their medical records has had

a positive effect on their decision to stay with their physicians, suggesting that this service will be an essential market differentiator for physicians going forward.

Frequency of Access

Patients with online access overwhelmingly use this capability. When patients have online access, 86 percent use it. Of patients whose doctors used an EHR and provided online access, 86 percent log on at least once a year, and more than half (55 percent) log on three or more times per year. (See Chart 13.)

Of the 45 percent of patients who say they hardly ever or never access their health information online, nearly seven



in 10 say it is because they do not need to. This indicates a need for deeper exploration regarding the use of online health information and the value perceived by consumers in doing so.

Impact of Online Access

The data clearly show that online access has a positive impact on a wide range of activities that are essential to better care and better health. For example, six in 10 people with online access say it improves their desire to do something about their health, which clearly has significant implications for patient engagement and improving health status. (See Chart 14.)



Even more striking, not only does online access improve patients' health behaviors across a range of domains (e.g., knowledge of health, ability to communicate with doctor), more frequent online access increases these behaviors significantly more. Notably, **the more frequently individuals access their health information online, the more they report that it motivates them to do something to improve their health,** including a dramatic 71 percent of those using online access three or more times per year who say this, compared with 39 percent who used online access less frequently.

Across every dimension we explored, those who went online three or more times per year universally reported a more positive impact. This indicates that the Meaningful Use requirement to demonstrate that patients are not just offered access, but actually use it, is an important policy to maintain and advance. (See Chart 15.)

Features of Online Access Currently Available

There is wide variation in the features of online access offered to patients today. Given this, we sought to understand the most common features available to patients currently, as well as the features they most desire. Our results show that the most commonly available features include the ability to review test results and medical records, as well as secure messaging (the ability to email the doctor's office or hospital staff), and the ability to schedule appointments and request medication refills. (See Chart 16.)

One potentially surprising finding is that nearly half (48 percent) with online access report that they have the ability to download their health information. In addition, patients who accessed their information online more frequently (three or more times per year) were significantly more likely to use downloaded information for various purposes. (See Chart 17.)





Only 15 percent of all patients who have the ability to download information, irrespective of their frequency of online access, would do nothing. Notably, patients who accessed their information online less frequently (less than three times per year), were significantly more likely to report that they "do nothing" with the downloaded information (24 percent, compared with 10 percent). These data suggest that those who use online access frequently become familiar with the capabilities and use the information more.

Desired Features of Online Access

When asked <u>what people would most like to do with online access</u>, the most desired features largely mirror the features patients are most familiar with today: the ability to review test results



and medical records, secure messaging, and the ability to schedule appointments and request medication refills. In other words, this is what patients can imagine today, but this may well change as patients have increasingly greater exposure to new features and applications, as well as the ability to register their preferences in the context of their own health needs. Additional features we explored that were desired by a majority of patients include the ability to review doctors' visit notes and treatment/care plans, as well as to access immunization records. (See Chart 18.)

The value placed on specific functionalities also varies by demographics, especially age. For example, the functionalities showing significantly higher perceived value among the Medicare (65+) population over young adults include sharing medical information and emailing physicians (30 percent compared with 20 percent, and 60 percent compared with 48 percent, respectively). For patients in the middle age categories (35-64) — those most likely to be in the position of being a caregiver — functionalities viewed as being most beneficial when compared to young adults include reviewing test results (79 percent, compared with 64 percent), viewing medical history (71 percent, compared with 61 percent), refilling medications (62 percent, compared with 49 percent), reviewing doctors' notes (63 percent, compared with 49 percent), reviewing doctors' treatment plans (64 percent, compared with 50 percent), and emailing doctors (56 percent, compared with 48 percent). The middle age ranges also were significantly more likely than those in the Medicare age range to find viewing medical history (71 percent, compared with 57 percent) and scheduling appointments (66 percent, compared with 58 percent) to be more valuable. All of these activities are key components of being in a caregiving role.

Mobile Access

We also asked respondents about whether they had accessed their medical or health information through a mobile device or whether they would like to have that capability. Few patients had accessed their information in this manner. However, patients with paper health records are more likely to want access to their personal medical and health information from a mobile device than patients with EHRs (36 percent, compared with 32 percent). These same patients previously noted that they were "satisfied" with their paper-record systems' performance. This suggests that although they are satisfied with their



current systems, they can readily see the value of having online access to health information through a mobile device, likely because they access information for other purposes in this manner.

PATIENT ENGAGEMENT STRATEGY: Electronic access to health information is a catalyst for engaging patients in their care, and initiatives to provide and increase the frequency of online access should be strengthened and expanded throughout new models of care delivery and payment. We developed a brief profile of those who use online access on a regular basis. Such a profile will help providers, payers and others boost the number of patients who go online by targeting those who are already inclined to do so.

Those who use their online access more often (defined as three times a year or more) are more likely to:

- ▶ Be in fair or poor health,
- ▶ Have one or more chronic conditions,
- > Share information with their health care providers, and
- Set or track goals for their health.

However, online access to health information is not something that only those in fair or poor health use. On the contrary, 84 percent of EHR patients in excellent or pretty good health used their online access, while 91 percent of those in fair or poor health used it.

The traits and uses above can serve as a helpful guide to effectively engage those patients and family caregivers who are likely to use online access to clinical information the most. Stakeholders should also partner with patients and families to identify and develop the online functionalities that benefit them, and to promote and implement online access.
4. Electronic Communication and Information Sharing



KEY FINDING NO. 4: Patients want to communicate with and share information with their various providers electronically, as well as with members of their family and other caregivers.

KEY STRATEGY NO. 4: Develop and integrate the various functionalities that allow patients to share their relevant health data with providers, and allow providers to incorporate and use patient data, such as family health history, medical device data, and data on social and environmental determinants of health.

Patients' access to their health information is a crucial part of engaging patients and families to achieve better care and improved health outcomes. But the survey revealed an equally compelling expectation that patients and other caregivers be able to communicate with their providers and share *patient*-generated health data. They reported expectations of a dialogue with providers — a partnership in both directions, rather than one-directional access.

As we build health IT infrastructure for the future, we must also enable bi-directional exchange of information — information sharing from providers **to** patients and families, as well as **from** patients and families to providers. This includes clinical health information that consumers share with other doctors, patients' corrections or amendments to their medical records, changes in health status, or other kinds of patient-generated health data. The information that patients and their family caregivers provide about their priorities, goals, abilities, health history, functional status and outcomes complements clinical information generated by care teams to provide a comprehensive view of an individual's health.

Sharing Relevant Health Information

Consumers are already sharing information in broad terms. Of both EHR and paper-record patients combined, 77 percent reported that they share information "all of the time" or "most of the time" with their health care providers. There are several findings that shed light on how patient-generated health information might support better care coordination, as well as work that needs to be done to ensure that this benefit is realized.

In evaluating their providers' record systems, EHR patients were much more likely than paperrecord patients to report that their record systems help patients personally a great deal or a lot in sharing information with health care providers (63 percent, compared with 37 percent).

In addition, consumers satisfied with their access to their health information (whether through an EHR or paper-record system), were significantly more likely than those less satisfied to report that they shared information with their health care provider "all of the time," which is likely an indication that the more access consumers have, the more satisfied they are, and the more they will share health information with others to improve health or care.

Thirty-eight percent of EHR and paper-record patients combined also wanted the ability to download their health information, and nearly half of those (46 percent) indicated that they would download it to share it with another doctor. This supports the important role patients can play in improving coordination of care and health information exchange if given the right information and tools.

Correcting Errors and Submitting Amendments

Correcting errors and submitting amendments are one specific type of patient-generated health information and communication. Patients with EHRs are also more likely than patients with paper records to say that their record systems help them a great deal or a lot to find and correct errors in medical records (50 percent, compared with 31 percent). Patients are often the first to identify errors in their own records. Increased access by individuals to their own health information will conceivably increase the number of errors identified by patients, thereby underscoring the need for the capability for patients to request/record a correction or amendment to their health records online. However, work remains to be done; 14 percent of EHR patients reported that their doctors' EHRs do not help patients find or correct errors in their record at all.

Secure Email

Secure messaging is a critical step toward advancing access, care coordination and information exchange between patients, caregivers and providers by enabling more efficient communication of basic information. Secure messaging is also an important means of sharing patient-generated data.

A majority of patients (56 percent), regardless of online access, wants the ability to email their providers. This indicates demand among patients and families for easy, electronic communication with health care providers to ask questions and share information, such as changes in health status. The Meaningful Use program includes a requirement for the use of such functionality by 5 percent of patients. Again, these findings suggest that this threshold is achievable when patients are effectively engaged.

Looking at communication preferences among different age ranges, the Medicare (65+) population reported significantly higher value than young adults for sharing medical information and emailing physicians (30 percent compared with 20 percent, and 60 percent compared with 48 percent, respectively). For patients in the middle age categories (35-64) — those most likely to be in the position of being a caregiver — emailing the doctor was likewise a more beneficial function than it was for young adults (56 percent, compared with 48 percent).

Some consumers have reservations about online communication. Patients with incomes less than \$35,000 per year were 10 to 11 percentage points *lower* in stating that they would use online access to email their doctors' offices if they could. Those with a high school education or less were 13 to 15 percentage points lower in stating the same compared to those with more education. The survey also showed significant differences in various subpopulations' responses regarding the likelihood that they would use key functionalities, such as emailing their doctors. We discuss these findings in more detail in strategy seven.

In addition, among those who rarely or never access EHR records, women were 7 percentage points more likely than men to say they prefer to speak with doctors in person, rather than accessing information online. This has important implications regarding what kinds of information they prefer to receive in person, as well as the necessity of physicians promoting the ways in which online access can facilitate efficient communication with the care team. The data also identify the types of functionalities to promote with women, such as highlighting the other, non-provider communication-related benefits (online scheduling, lab results, etc.). The findings also underscore the need to frame the benefits of EHRs and online access as a *supplement* to in-person communication, rather than a replacement, when educating patients and families. (See Chart 19.)





Communication Functions for Caregiving

Consumers want to leverage electronic health information access and exchange to share information not only with their health care providers, but also with family and other members of their care teams. Forty-nine percent of EHR patients with online access reported that having online access to their medical and health information very or somewhat positively impacted their ability to share information with family members or other caregivers. Moving forward, health IT should further facilitate and enhance patients' ability to share critical health information with family and other caregivers, who provide crucial support. (See Chart 20.)

PATIENT ENGAGEMENT STRATEGY: Facilitating bi-directional communication and information exchange (including acceptance of patient-generated health data) is another key strategy for patient engagement. Stakeholders should develop and integrate the various functionalities that allow patients to share their relevant health data (such as family medical history, device data, and data on social and environmental determinants of health) with providers electronically, and facilitate incorporation into medical records for subsequent use. In this way, patients and families can help to ensure the accuracy and reliability of data stored in an EHR, while simultaneously being empowered as active partners with providers in patients' health and health care.

5. Health and Care Planning



KEY FINDING NO. 5: Patients want to use health IT to help manage and plan their health and care (following treatment instructions, taking medications, tracking progress toward health goals, etc.), but they want even more advanced health IT functionality than is currently available.

KEY STRATEGY NO. 5: Develop and integrate robust functionality to support patients' efforts to manage their care and health for themselves, or for a loved one.

Offering "convenience" features such as electronic appointment scheduling or administrative forms, enabling online access to clinical information such as lab results, and facilitating patients' ability to communicate and share information with providers are effective, established strategies to engage patients in their health and care.

The ultimate question is whether and how consumers use these resources and information together to better manage their care or improve their health — arguably the holy grail of patient engagement. Approximately 85-90 percent of the determinants of health occur outside the care setting,² and this critical strategy addresses helping people manage their health and care across these other settings.

Care plans are a long-standing and effective tool in health care today, yet little progress has been made in the ability of EHR systems to effectively capture and display them for providers and patients. This is another area of significant priority for policymakers and technology developers in the future. Demand is clearly present for this feature in the market, and it is a necessary tool for providers seeking to better coordinate care, engage patients and families, and improve health outcomes under new models of care delivery. Consumers have their own vision of electronic, shared care plans that connect them to care teams and provide the information and support necessary to achieve their goals for health and wellness.³

In general, patients rate EHRs higher than paper records on functionalities critical to managing health and improving outcomes. Areas in which patients rated EHRs higher than paper records include the following:

- ▶ Helping patients follow providers' instructions for treatment (92 percent, compared with 68 percent)
- ▶ Helping patients take/refill medications (89 percent, compared with 62 percent),
- ▶ Helping patients communicate directly with their providers (90 percent, compared with 58 percent).

Survey data reveal that consumers desire a more robust care planning process than is currently enabled by EHRs. The lowest-rated element for EHR features was tracking progress toward individual health goals, a new facet we explored in 2014. Although half of patients overall (50 percent) say they set or

² Robert Wood Johnson Foundation, Frequently asked questions about the social determinants of health (2010), available at www.rwjf.org/content/ dam/files/rwjf-web-files/Research/2010/faqsocialdeterminants20101029.pdf. The Institute of Medicine recently recommended social and behavioral domains and measures for electronic health records that capture the social determinants of health. Institute of Medicine, Capturing Social and Behavioral Domains in Electronic Health Records: Phase 1 (Apr. 8, 2014), available at www.iom.edu/Reports/2014/Capturing-Social-and-Behavioral-Domains-in-Electronic-Health-Records-Phase-1.aspx.

³ See, for example, Care Plans 2.0: Consumer Principles for Health and Care Planning in an Electronic Environment (Nov. 2013), available at http://www.nationalpartnership.org/research-library/health-care/HIT/consumer-principles-for-1.pdf.

track goals for their health all or most of the time, when asked about features available through online access, patients whose doctors have EHRs are least likely to have such a feature (42 percent).

The majority of patients (56 percent), regardless of their current online access status, stated that they wanted the ability to review doctors' treatment recommendations and care plans. Half (50 percent) set or track goals for their health all or most of time, and almost one-third (31 percent) would use online access for this feature if available. Taken together, the ability to set and track health goals and the ability to review and download treatment recommendations and other key personal health information are essential elements of the kind of care plans that consumers want and deserve. Consumers want the ability to engage in a more comprehensive, longitudinal process of care planning — a proven strategy for health improvement that many new models of care incorporate, such as accountable care organizations and patient-centered medical homes.



Patients and family caregivers manage health and care in the context of a multitude of priorities and life circumstances. Caregivers also benefit from tools that help them manage the care or improve the health of a loved one. Both EHR and paper-record patients think online access is very/somewhat useful to help with caregiving responsibilities. (See Chart 21.)

PATIENT ENGAGEMENT STRATEGY: Vendors and providers should integrate robust goalsetting and tracking features into EHRs and portals to support patients' efforts to manage their care for themselves, or for a loved one. Patients and families can partner with all stakeholders to design and implement electronic tools to make health and care planning more meaningful and efficient.

6. Privacy and Trust



KEY FINDING NO. 6: The more patients experience the benefits of EHRs and online access, the more they trust that their providers using them can protect patients' privacy; and the more they trust that their privacy is protected, the more they use and benefit from EHRs.

KEY STRATEGY NO. 6: Engage and educate patients about why and how patients' health information is stored, exchanged, used and protected.

The survey explored patients' views on privacy and security of health information and patients' trust in their relationships with their doctors. We posed various survey questions designed to understand and assess the degree of trust that patients have today, both in electronic or paper-record systems generally and in their providers to protect the privacy of their health information. We found that the more patients experience the benefits of EHRs, the more they trust protection of their privacy; and the more they trust that their privacy is protected, the more they use and benefit from EHRs and electronic health information exchange. These results reflect consumers' growing awareness that while electronic health information exchange comes with inherent risks, those risks are balanced by significant benefits, such as the ability to restrict and monitor access to personal health information.

We began by exploring each respondent's general orientation toward privacy and security issues in health care. To do so, we presented patients with five statements and asked how much they agreed or disagreed with each statement. Three of the statements were in positive terms and two were in negative terms, and the order of the statements was randomized to prevent order influence. (See Chart 22.)

These results suggest several points worth noting:

- While EHR and paper-record patients had similar views for some items, EHR patients had greater trust and less reservation about privacy protections than paper-record patients for others. EHR patients were more likely to agree strongly or somewhat with the positive statement that "Electronic health record systems provide better tools to protect the privacy and security of my medical and health information." Similarly, EHR patients were less likely than paper-record patients to agree "strongly" or "somewhat" with the negative statement that "Widespread adoption of electronic health record systems will lead to even more personal information being lost or stolen than we have now."
- ▶ Although high in the aggregate, only 43 percent of EHR and paper-record patients agreed "strongly" with general trust in their providers to protect their privacy. This suggests that patients who agreed "somewhat" (48 percent of EHR patients and 46 percent of paper-record patients) still had some trust concerns.

Record Systems' Usefulness in Protecting Privacy

We also asked patients more specifically to assess the usefulness of EHRs and paper-record systems, respectively, regarding some key privacy and trust domains. (See Chart 23.)

EHR and paper-record patients alike find EHRs significantly more useful and protective of privacy across key domains, and find paper-record systems significantly less protective of privacy — especially in letting patients see who has accessed their medical information, giving patients more control over how their medical information is used beyond direct care, and earning patient trust about how their doctors'



record systems handle their medical information. Despite their usage of paper-record systems, paper-record patients are nearly identical to EHR patients in how they view the usefulness of paper records; across the board, both groups deemed EHRs very or somewhat useful at significantly greater rates.

Trust in Providers to Protect Privacy

We explored these views further and found an extremely strong relationship between people's trust in their providers and protection of privacy, and their knowledge of their providers' record systems and their personal use of online access. We asked patients how much they trust their doctors and staff to protect their privacy and other patient rights. Detailed analysis of the data shows the following points. (See Chart 24.)

- ▶ People with EHRs trust their doctors to protect privacy rights significantly more than those with paper records (72 percent trusting "completely" or "a lot," compared with 65 percent).
- ▶ Patients with online access to EHRs trust their providers significantly more than patients with EHRs but without online access (77 percent, compared with 67 percent).
- ▶ Patients who use their online access to EHRs more frequently (3-6 times per year or more) have significantly greater trust that their providers will protect their privacy and other patient rights (84 percent trusting "completely" or "a lot," compared with 69 percent).
- ▶ Patients who feel well informed about the record systems trust their doctors more than patients who do not feel well informed trust their doctors (83 percent, compared with 56 percent).
- ▶ There were no significant differences overall between EHR and paper-record patients regarding whether their providers explained the record systems well, suggesting that online access and a more transparent view into the record system are key to enhancing patient trust.



All patients were asked how well their doctors and staff informed patients about how their medical and health information is collected and used by their respective record systems. For both EHR and paper-record patients, less than 60 percent stated that their doctors and staff did a good job of explaining how patients' information is used (55 percent and 51 percent, respectively, reporting "well" or "very well" explained). Yet 88 percent of EHR patients and 82 percent of paper-record patients stated that it was important to them to know how their information is being collected and used. This highlights a continuing gap in patient education on the part of the doctor or staff.

Chart 24: How much do patients trust doctors and staff to protect their privacy and other patient rights?



PATIENT ENGAGEMENT STRATEGY: Policies should encourage providers to engage and educate patients about why and how patients' health information is stored, exchanged, used and protected. Given the exponential increase in the number of patients whose health records are now kept electronically, measuring and maintaining trust is essential to sustaining the ongoing use of EHRs and maximizing their potential to support health care transformation. Online access seems to be a catalyst for transparency and understanding that helps patients trust their records, and perhaps understand more about privacy rights. While having medical record systems explained well (whether systems are paper-based or electronic) can help people see advantages of each, having an actual view into their medical records is a major factor in increasing patient trust.

People should view the conversion to EHRs positively, both because of the potential for EHRs to support improvements in health, health care quality and patient experience, and because of EHRs' ability to protect patient privacy and the security of information. The survey suggests that future work to enhance patient trust in EHRs should focus on more effective means to inform patients about their rights with regard to data collection, use and exchange, and the features of EHRs that facilitate those rights, as well as on efforts to increase the number of patients who have and use online access, since online access is a key strategy for providing transparent and trust-enhancing views into health records.

7. Designing and Building for Diversity



KEY FINDING NO. 7: The value and uses of EHRs and electronic health information exchange are not the same for everyone, including communities of color, people with disabilities, LGBT individuals and people who speak languages other than English.

KEY STRATEGY NO. 7: Build and implement diverse functionalities to engage patients in a variety of ways.

The U.S. population is growing increasingly diverse. If health IT can be universally designed to support engagement and improvement in health status for diverse populations, it will concomitantly drive health and care improvements for everyone and thus enhance health equity.

According to the 2010 census, the Hispanic population reached 50.5 million, and more than 57 million people identified solely as Black or African American, American Indian or Native Alaskan, Asian, or Native Hawaiian and Other Pacific Islander.⁴ Approximately 60.5 million people ages 5 and older speak a language other than English at home.⁵ More than 56 million people (18.7 percent of the population) had a disability.⁶ While recent studies estimate that, overall, LGBT individuals make up 3.8 percent of the U.S. population (or roughly 9 million people), some states report significantly larger populations of people who identify as LGBT.⁷

As a nationally representative sample, our survey respondents represent the diversity of consumers across the nation, each of whom has different needs and preferences and faces unique barriers. In order to further ensure that this diversity of needs is adequately represented, we conducted an oversampling of three different populations who are traditionally underserved in the U.S. health care system today — Latino or Hispanic adults, Black or African American adults and Asian American adults. Understanding and acknowledging these differences in the design and implementation of health IT is critical for successful and widespread patient engagement.

Usefulness of Record System

Responses from all groups indicate that they find EHRs significantly more useful, and significantly more helpful to themselves personally, than paper records. (See Charts 25 and 26, reporting those who found that the record systems helped them "a great deal," "a lot" or "a moderate amount.") Asian American adults were among the most likely to report that EHRs are helpful to them in sharing information with all health care providers, and in finding and correcting errors in their medical records.

Some of the responses with the lowest percentages overall are related to personal health activities, such as keeping up with medications, helping to maintain a healthy lifestyle, tracking progress toward health goals and understanding health conditions better. These are often features that are delivered or facilitated through patient portals. Increasing the availability and the features offered by online access will be essential to delivering useful benefits to patients. (See Charts 25 and 26.)

⁴ U.S. Census Bureau, Overview of Race and Hispanic Origin: 2010 4 (2011), available at http://www.census.gov/prod/cen2010/briefs/c2010br-02.pdf.

⁵ U.S. Census Bureau, Language Use in the United States: 2011 3 (2013), available at <u>http://www.census.gov/prod/2013pubs/acs-22.pdf</u>.

⁶ U.S. Census Bureau, Americans with Disabilities: 2010 4, 8-9, 17-19 (2012), available at <u>http://www.census.gov/prod/2012pubs/p70-131.pdf%20</u>.

⁷ Gary Gates & Frank Newport, Williams Inst., Univ. of Cal. Los Angeles Sch. of Law, Gallup Special Report: New Estimates of the LGBT Population in the United States (2013), available at <u>http://williamsinstitute.law.ucla.edu/research/census-lgbt-demographics-studies/gallup-lgbt-pop-feb-2013/</u>.



* Low base size (n<100) — results should interpreted as directional in nature.



* Low base size (n<100) — results should interpreted as directional in nature.



* Low base size (n<100) — results should be interpreted as directional in nature.

Online Access

Of patients with EHRs, Asian American and Hispanic adults were most likely of any group, including the total sample, to have online access (14 and 9 percentage points higher than non-Hispanic Whites, respectively). Hispanic adults were significantly more likely (78 percent) than non-Hispanic White individuals (55 percent) to state that having online access increases their desire to do something about their health. We found similar trends among Hispanic adults in 2011, which strengthens even more the conclusion that online access continues to be essential in reducing disparities in health status. (See Chart 27.)

When asked which online features their access included, results were variable. (See Chart 28.)

- Hispanic^{*} adults were most likely to report that they could view their medical record history, email their physicians, access their immunization records, review their physicians' notes, and download their medical record history;
- ► African American^{*} adults were most likely to report that they could review test results, review their care plans and treatment recommendations, and share health information with their families; and
- ▶ Asian American^{*} adults were most likely to report that they could schedule appointments.

Having established a baseline of what features of online access are most commonly available today, we also asked what features traditionally underserved populations would most like to have. Notably, nearly every patient reported that she or he would use at least some new features. (See Chart 29.)

Strong majorities of Hispanic and Asian American adults reported that they would use online access features such as reviewing test results and medical records, scheduling appointments, submitting medication refills, reviewing treatment recommendations and emailing doctors. However,

^{*} Low base size (n<100) — results should be interpreted as directional in nature



* Low base size (n<100) — results should be interpreted as directional in nature.



Chart 29: Given the capability, which online access features would you use?

while many African American patients would use a range of new features, they generally reported less interest in the online access features surveyed. This certainly warrants further exploration.

Mobile Access

We also asked respondents about whether they had accessed their medical or health information through a mobile device and whether they would like to have that capability. Hispanic, Black/African American and Asian American patients were 12-23 percentage points more likely than non-Hispanic White patients to use a mobile or smartphone all or most of the time for electronic access to their medical information or doctor (33 percent for Hispanic patients, 28 percent for Asian American patients and 22 percent for Black/African American patients, compared with 10 percent for non-Hispanic White patients).

Among those who have not yet used mobile access, Hispanic and LGBT individuals were most likely to say they would access their personal health and medical information on a mobile device or tablet if they had the capability. Non-Hispanic White and African American individuals were least likely to say they would access their information in this manner. Given the fact that cellphone adoption rates are as high among minority populations as among non-Hispanic Whites, and smartphone adoption rates are even higher among minority populations,⁸ increasing mobile access to electronic health information and features that support health improvement and education is an essential step forward that can support patient engagement in diverse communities. (See Chart 30.)



⁸ Pew Research Center, Cell Phone and Smartphone Ownership Demographics, January 9-12, 2014, available at http://www.pewinternet.org/data-trend/ mobile/cell-phone-and-smartphone-ownership-demographics/.

Privacy and Trust

The survey explored how much the physician had told the respondent about some basic topics, such as how the privacy of one's health information is protected, the right to see all or part of one's medical record, and the right to correct or amend one's health information. Paltry numbers from all respondent groups reported that their physicians told them "a great deal" about how the privacy and confidentiality of their medical information is protected. Asian Americans reported the lowest numbers (ranging from 14 to 19 percent), followed by non-Hispanic Whites (18 to 23 percent), Hispanics (25 to 26 percent), Blacks (30 to 33 percent) and LGBT individuals (23 to 35 percent). Of particular interest is that approximately one in three of all individuals in underserved groups stated that his or her physician "told me nothing" about how privacy and confidentiality are protected — ranging from 28 percent for LGBT individuals to 33 percent for Asian Americans.

Survey data reveal that African Americans are the most skeptical about EHRs conceptually, with seven in 10 (69 percent) saying more widespread adoption will lead to more personal health information being lost or stolen. Yet more than eight in 10 African Americans (86 percent) also believe that EHRs are or would be useful in giving patients confidence that their medical information is safe (50 percent of whom say EHRs are "very useful"), as well as giving patients more control over how their information is used and complying with privacy laws (88 percent). Similar to the total sample, this could indicate that EHRs in the abstract are viewed differently compared with when individuals consider examples that directly apply to them.

PATIENT ENGAGEMENT STRATEGY: All stakeholders should build and implement diverse functionalities to engage patients in a variety of ways, with particular attention to language and cultural competency issues. Providers and vendors should partner with patients and families in underserved communities to identify additional opportunities to improve engagement (for example, offering access to critical health information in languages other than English or via mobile technologies). These strategies hold potential not only to engage patients but also to address root causes of health disparities.

VI. Trends from 2011-2014

This survey undertook to assess how consumers today experience the impact of federal initiatives designed to boost the adoption and use of EHRs. We also established a baseline of consumer views in the previous survey in 2011 and asked those questions again in 2014 to assess trends. This section outlines major trends between 2011, when we first fielded this survey, and today.

Not surprisingly, there has been a significant shift to EHRs since 2011. Currently, 80 percent of adults in the United States with a main doctor reported that their doctors use EHR systems, up from 64 percent in 2011. It is important to note that this does not represent the percentage of doctors in the United States who use EHRs. Rather, it represents the percentage of patients who report having a regular doctor and know what kind of record systems their doctors use (EHR or paper). This percentage of patients who report that their regular doctors use EHRs is nearly identical to provider-reported 2013 adoption rates; as measured by the National Center for Health Statistics,⁹ nearly eight in 10 office-based physicians use some form of an EHR.

Value

Overall, patients' views of the value of EHRs remain consistent with 2011, with more than nine out of 10 (93 percent) reporting that they were satisfied with the EHR systems their main doctors were using. Interestingly, although not outperforming EHRs overall, paper records were viewed more positively in 2014 than in 2011. For example, 34 percent of patients with paper records said that this system had a positive impact on quality of care, compared with 26 percent in 2011. This is one of several surprising findings where paper records — which do not outperform EHRs overall, as previous chapters have shown — were nonetheless viewed more positively by patients, compared with 2011. This could indicate that the various federal initiatives aimed at improving quality of care are having a positive impact on care in general, regardless of record system. (See Chart 31.)

One area of change from 2011 was in patients stating that EHRs are very useful in assuring that health care providers have timely access to relevant health information (a decrease of six percentage points from 2011 to 2014) and that EHRs help their doctors keep up with medication histories a great deal (down seven percentage points from 2011 to 2014). Since use of EHRs by doctors and access to electronic information by consumers have both increased, these decreases are concerning. Patients were also less likely to think that EHRs help doctors correct errors or incomplete information in patients' medical records. These findings are likely consistent with the continued lack of data exchange in the marketplace. A specific draft criterion in the third stage of the Meaningful Use program that would enable patients (and their authorized caregivers) to offer corrections to their medical records could help improve these numbers (and thus the quality of data in EHRs) for the future. (See Chart 32.)

Between 2011 and 2014, patients did not change significantly in their views of how EHRs help them personally, with one exception: perceptions that EHRs help patients keep up with their medications increased significantly since 2011. While Chart 32 shows some small changes, none of the other changes was statistically significant. This suggests that future increases in perceived value to patients and physicians will depend heavily upon the degree to which information is actually exchanged between physicians and between patients and their various providers.

Since 2011, consumer views of the personal helpfulness of paper-record systems have increased in all categories. Again, this is one of several findings where percentages for paper records increased since 2011. (See Chart 33.)

⁹ Hsaio, C.-J. & Hing, E., Use and Characteristics of Electronic Health Record Systems Among Office-based Physician Practices: United States, 2001–2013 (Jan. 2014) (NCHS Data Brief no. 143, reporting data from the annual National Ambulatory Medicare Care Survey).





From 2011 to 2014, the percentage of patients stating that it would be very valuable to them if their physicians switched from paper records to EHRs increased from 21 percent to 26 percent. Furthermore, in 2014, nearly half of patients whose doctors currently use paper-record systems believe that switching



to EHR systems would have a positive impact on the overall quality of their health care services, roughly the same as in 2011. (See Chart 34.)

Those who stated that switching to an EHR system would have a very positive impact significantly increased between 2011 and 2014, from 12 percent to 17 percent. Such results suggest that consumers see overall value in the use of EHRs, and the potential positive impact on the quality of their care.

Online Access

Online access has doubled since 2011, when 26 percent of EHR patients reported that their doctors gave them online access, compared with 50 percent this year. Online access to medical and health information also remains important among patients with paper records. In fact, patients in 2014 are *less likely* to say that it was not at all important, compared



with 2011 (9 percent versus 12 percent), and one-third would consider switching to doctors who offer online access. The perception of how online access affects quality of care has also increased since 2011. While our other results show that there is room for improvement, today 62 percent of patients who have online access and have used it think online access positively impacts care. (See Chart 35.)

Regardless of whether they currently have access or not, the proportion of patients who say EHRs would be useful in helping patients follow health care providers' instructions, communicating directly with health care providers, and taking or refilling medications as prescribed — all features of online access — has significantly increased since 2011. This indicates that online access



has significant potential to be a vehicle for engaging patients on the topic of quality — something that has been an elusive goal to date. Such engagement is critical for new payment models and the effectiveness of the current shift toward accountable care.

Privacy and Trust

Compared with 2011, patients in 2014 are significantly more likely to feel that EHRs are useful in giving patients more control over how personal medical information is used, earning the trust of patients in the way their medical information is being handled, complying with privacy and confidentiality laws, and giving patients confidence that their information is safe. (See Chart 36.)

The significant impact on trust that EHRs can have is critical to leverage in attempts to engage patients more actively in their health and health care. We also saw a large jump in confidence among patients with paper records that EHRs would be useful in keeping their medical and health information safe, from 67 percent in 2011 to 75 percent in 2014.

Trust levels have remained about the same since 2011, with seven in 10 patients saying that they trust their doctors and medical staffs to protect their privacy and other patient rights. To understand the perceived privacy implications of a switch to EHRs, we asked respondents how much they would trust their doctors and staffs to protect privacy and other patient rights if their doctors switched to an EHR system. (See Chart 37.)

Although nearly half of paper-record patients believe that switching to EHRs would have a positive impact on their health care services, they express somewhat less trust of their doctors and medical staffs if they did switch to EHRs. Overall, 65 percent of paper-record patients trust their doctors and staffs "completely" or "a lot" to protect their privacy and other patient rights; if their doctors switch to EHRs, 54 percent state that they would trust their doctor "completely" or "a lot." Given the contrast with the opinions of the EHR group, this suggests that patient trust is driven both by the relationship with the provider, as well as the individual's direct experience with the value and security of the record system.



Conclusion

The trends we find between 2011 and 2014 suggest that improvements can be seen. Since 2011, the availability of online access has doubled, and patients' use of that access has increased from 80 percent in 2011 to 86 percent in 2014. However, much work remains in making the case for EHRs among those with paper records today, with respect to both value and trust.

Overall, while consumer education about privacy has improved, those improvements have been mainly among those with paper records. Fortunately, our results also show that consumers see more value in EHRs than paper records for protecting privacy. But we must do better. Online access to health information provides a natural and effective context for consumers to understand and take an increased interest in the privacy and security of their health information,

Chart 37: Trust of Physician to Protect Privacy When Switching to EHR, 2011 and 2014

[Base = Paper-record respondents: 2014 (n=853); 2011 (n=808)]



as well as an effective tool to exercise their specific rights in this regard. And as our data prove, consumers with online access have higher levels of trust.

VII. Policy Implications

The survey data above disclosed seven categories of findings about patient engagement, in the areas of EHR adoption and use, convenience features, online access, electronic communication and information sharing, health and care planning, trust and privacy, and designing and building for diversity. The survey shows that consumers value certain functionalities highly, and thus these functionalities provide gateways to the kind of engagement necessary for achieving the Triple Aim. The data also show that patients perceive that EHRs are more helpful to physicians than they are to patients and their caregivers. If we are to shift from an emphasis on acute treatment toward wellness and improving the health of the population, EHRs and the information and functionality available through electronic access and patient portals must be made more valuable to consumers. Federal and state policy levers can advance and even create these needed improvements.

The survey assessed patients' views broadly, without reference to particular statutes or policies. It asked questions related to specific EHR functions and uses that might bring the most value to consumers, rather than questions about specific programs or policies, such as the Meaningful Use program. The survey results thus provide important guidance for a range of federal policies, including interoperability efforts, the federal strategic plan for health IT, payment and delivery reforms, and quality measurement, as well as the Meaningful Use program. Across them all, the findings offer insights into how policymakers should design the next phases of the Meaningful Use and other federal programs in ways that maximize the impact of health IT on patient and family engagement in health and health care — widely recognized as essential for improving care, improving health and reducing costs.

Policymakers could require or integrate incentives for use of certified EHRs beyond the Meaningful Use program and reach the broader continuum of care that the survey patients touch daily. For example, the Office of the National Coordinator announced in December 2013 that the process for creating federal EHR certification requirements would no longer be tied to the Centers for Medicare & Medicaid Services' rulemaking schedule for Meaningful Use criteria. This new approach can have potential benefits and drawbacks for consumers. This decoupling can enable accelerated innovation and advancement of new functionalities that have particular value for patients and their caregivers. However, providers might not use these innovative certified EHR features unless and until the Meaningful Use criteria are also amended to require their use. This makes it **essential that other federal health programs beyond the Meaningful Use program require and integrate incentives for use of certified EHRs.**

Federal health policy is evolving rapidly, integrating a focus on population health and accountable care that expands health care beyond the provider setting and into homes and communities. Continued momentum in engaging consumers in their health through health IT will also depend on key innovations that benefit consumers in these equally relevant settings. Federal policy must support more significant progress in the areas of communication, care planning and coordination — consistently the top consumer priorities for improving health care. National health IT and delivery system reform overall cannot be achieved otherwise.

Lastly, many of the current patient and family engagement requirements in the Meaningful Use program are **core elements that will advance interoperability efforts**. True interoperability is not just among providers; it includes interoperability with patients and their caregivers as equal partners in the continuum of care, in electronic access to and use of health information, and in building and using the learning health community.¹⁰ For example, increasing patients' access to and use of their

¹⁰ Office of the National Coordinator for Health Information Technology, Connecting Health and Care for the Nation: A 10-Year Vision to Achieve an Interoperable Health IT Infrastructure (June 5, 2014).

own health information should have a great impact on electronic health information exchange and fostering interoperability. Equipped with online access, individuals can download and share their health information with other doctors and trusted caregivers in case of emergency or when seeking second opinions. In this way, patients will play a significant, if not central, role in accelerating and intensifying efforts to realize an interoperable health care ecosystem. Federal policies that enhance individuals' access to health information and facilitate communication and information sharing with providers are critical to advancing interoperability, and should be preserved and strengthened.

Below, we distill some of the policy implications in key areas, including people's electronic access to their health information, patient-generated health data, health and care planning, privacy and trust, and designing and building for diversity.

A. Online Access, Including Mobile Access and Devices

Patients reported that online access to personal health information motivates people to want to do something about their health. This finding has significant implications for patient engagement and activation. It also holds particular promise as an effective strategy for reducing health disparities.

- Continued advancement of online access has important implications for many areas of health care and health IT. The more patients use online access, the more they are satisfied and trusting. Even more importantly, the more patients use online access, the more knowledgeable and motivated they are to improve their health. Policies should encourage providers to **partner with patients to build use of online access into their collective workflows** to create efficiencies in care and ultimately engagement in health. Scheduling appointments or checking lab results online, for example, can be used both as a gateway to engaging patients in an online health environment, as well as to improve providers' workflows.
- Patients value communication and coordination in health care, so advancing use of download and transmit features (e.g., Blue Button technology and Blue Button+) in ways that meet consumers' expectations will improve their experience and engagement, especially among those with serious health challenges. Again, technology and application developers should develop better download and transmit features and related applications, so that more applications are built that engage consumers in managing health and care.
- ► To keep people engaged, technology developers should partner with consumers to **improve the experience of online access**. Technology developers should engage providers in the design of these capabilities as well, so that technology facilitates effective workflows for patients and providers working together to meet health goals. Given many patients' preference to interact with providers in person rather than accessing information online, part of improving design in this area will be to understand more specifically what kinds of health information are most effectively shared in person, and what kinds of online information are most beneficial and valued by consumers, including those with chronic conditions, underserved individuals, women and those who are less educated.
- ▶ Prominently displaying the functionality to offer corrections and amendments to health information is essential to both patient safety and data quality efforts and to the continued engagement of patients and their families as active members of the health care team. It is telling that, despite the rapid increase in EHR adoption between 2011 and 2014, patients in 2014 did not find EHRs any more or less helpful to them personally in finding and correcting errors or incomplete information, and they perceived that EHRs helped their doctors less (dropping from 75 percent to 70 percent).

The survey showed significant differences in various subpopulations' responses on the likelihood that they would use various key functionalities, such as emailing their doctors. Exploring more deeply the particular needs and preferences of traditionally underserved populations is a critical step toward being able to leverage online access and mobile access as tools to reduce health disparities and to ensure that online access does not become yet another barrier and contributor to the perpetuation and growth of health disparities.

B. Electronic Communication and Information Sharing

We found that providing access to information naturally leads to a desire among consumers to do something with it. The survey shows that many features desired by patients involve mutual information sharing between consumers and their care teams, and this includes information they have and want to contribute to their medical records. These data, known as "patient-generated health data," are an essential component of supporting a true partnership in making and meeting health goals, and can result in more efficient, effective, safe and high-quality care.

Bi-directional exchanges of health information, including patient-generated data, are key capabilities that policy and design must advance to support the functionalities consumers want most, and they are critical for population health, care planning and care coordination across the continuum. Patients in the 2014 survey clearly indicated their desire to have the ability to share information with doctors and family members, which could be achieved by further advancement of online access features. Given the increasing use of consumer devices to manage health (from Fitbits to wireless glucometers), there is an emerging and sizable opportunity to capture these data from patients and use the data to measure and improve health status.

C. Health and Care Planning

Patients also expressed significant interest in health and care planning. **Developing and implementing better care planning features in EHRs that are connected to online access** should be a top priority for policymakers and vendors.

The ability to capture and display care plans for providers and patients is an essential component of managing health care and improving health outcomes under new payment and delivery models. Nearly six in 10 patients want EHRs to facilitate features that are integral components of care planning, including the ability to review doctors' treatment recommendations and care plans; to review test results from all their providers; to email doctors and staffs; and to manage medications.

Setting and tracking personal health goals are also foundational elements of health and care planning. While clinical treatment goals have been used widely in the past, they have most frequently been limited to a single discipline or specialty, and typically have not involved patient input. Yet the survey data show that patients often set their own health goals, and technology can create opportunities to align patients' own goals with clinical treatment goals, make those goals available to all members of the care team, and use electronic tools to record and track progress. Future health policy must advance this functionality and the information exchange infrastructure between providers and patients necessary to make it a reality.

Setting and tracking health goals using electronic tools also presents an important opportunity in reducing disparities. According to our survey, Hispanic and Asian American adults routinely set goals for their health, and all underserved populations we surveyed see the potential for EHRs to facilitate this process electronically. Setting and tracking personal health goals also provide an opportunity to advance patientgenerated health data capabilities within a clear and limited-use case. They will also encourage and support the development of a market for mobile applications and devices, and present a major opportunity for patient portals generally.

D. Privacy and Trust

Privacy and trust are vital elements of the patient-provider relationship, and health IT can be a catalyst for strengthening that relationship and empowering patients and caregivers with supportive federal policy. The survey revealed that people who have online access feel that EHRs provide better tools to protect privacy, so promoting the privacy protective aspects of health IT through federal policy is important. The survey also found that patients with EHRs are not more likely to withhold information, as some have feared.

Maintaining trust in health privacy is essential to sustaining the ongoing use of EHRs. Providers are key to this process because, according to the survey results, they are highly trusted and play a significant role in consumer understanding of privacy rights. Federal policy should encourage provider communication with patients about issues of privacy related to how their personal health information is stored, exchanged and used.

The survey also indicates that actual experience interacting with their health record systems *increases* consumers' trust and ability to see the systems' advantages. People with online access are significantly more likely to agree that EHRs provide better tools to protect privacy. To that end, **provider use of health information technology during patient encounters is a teachable moment that provides the kind of context necessary for understanding health IT's value and encouraging use of this information outside of the context of a provider encounter. For example, providers could share their computer screen with patients during clinical encounters, allowing patients to see their medication lists or medical records. This gesture not only includes patients as part of the data entry, but offers an opportunity for patients to offer corrections or new information in person. Clear communication about privacy rights and responsibilities is also necessary for both patients and providers to create the kind of trusted interactions so essential to better health. This will also provide necessary context and personal meaning for individuals to understand HIPAA privacy notices.**

Regarding EHR functionalities, federal policy should advance features to offer corrections and amendments to health information online. While some providers offer this feature online, many others do not, or the feature is not obvious. As patients and families increasingly access health information online, they will spot errors and incomplete information. They can help correct errors and enhance the quality of the data in their medical records. Offering an easy way to provide corrections, amendments or other patient-generated health data electronically will be essential to improving information accuracy and keeping patients both engaged in and trusting of EHRs.

Lastly, policies and programs should leverage EHRs' capability to improve privacy and security, such as encrypting personal health information and prohibiting re-identification of de-identified health information.

E. Designing and Building for Diversity and Diverse Communities

The survey clearly shows that different subpopulations value health IT for different reasons. Insights about the specific needs, values and barriers experienced by subpopulations provide critical guidance to policymakers on how health IT can help to reduce health disparities. If we can make health IT work for these diverse individuals, it will work for everyone. A number of critical steps toward this end can be facilitated through smart policymaking — both in the Meaningful Use program and in other federal health policy:

- ► The survey results showed distinct differences and engagement strategies across diverse demographic characteristics. Collection and use of demographic information, including race, ethnicity, preferred language, gender, LGBT status and disability status should be a requirement of all federal health policy. Where requirements do exist in some areas, the data collected are often far too general to be effective in eliminating health disparities. We must **routinely collect and use granular data on demographic variables** to measure the extent of existing disparities, understand the specific needs of subpopulations and use health IT to meet individuals' specific health and health information needs.
- ▶ Mobile technologies are increasingly essential tools for reaching diverse communities and providing them with electronic access to health information. Policymakers must facilitate the expansion of online access to health information through mobile technologies.
- Health literacy has long been a barrier to better health across many populations. Given what is now at stake, and the rising emphasis on population health and wellness, there is a growing need and incentive for concerted efforts to improve health literacy. Health IT provides a unique and effective vehicle for addressing this longstanding issue. Policies addressing health literacy should include health IT literacy, as individuals at lower levels of education and sometimes income require increased support and assistance to be able to access and understand how to use electronic health information. Incorporating these goals into a variety of federal programs could greatly improve the health literacy of our nation and help make the shift from a culture of reactive, episodic care to a culture of wellness.

In conclusion, this survey's findings can contribute much to inform health IT policies and practices that successfully engage all consumers, encourage partnership with providers, and provide the health information technology and tools the nation needs to promote better care and improve health outcomes. These policy implications can inform many policies and programs, not just the Meaningful Use program, and they suggest actions that consumers, providers, vendors and other stakeholders can take as well to advance patient engagement.

Appendix A: A Profile of Respondents' General and Health Demographics



Chart 39: Race and Ethnicity of Respondents

[Base = All qualified respondents: 2014 (n=2045), 2011 (n=1961)]













Appendix B: Harris Poll Methodology Explanation

Research Methodology: Harris Poll conducted the study online (on our behalf) within the United States from April 22 to May 2, 2014. Initially, a sample of 8,666 U.S. adults 18 or older was contacted in order to determine who would be eligible for the full survey, including oversamples. Among the 8,666 adults (including qualified, non-qualified and over-quota respondents), 2,045 indicated that they had primary doctors and that their doctors kept medical and health information either as electronic health records or as paper charts. Of these, 1,192 adults were those in EHR systems and 853 were 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 8,666 included 1,272 Hispanics. These interviews we eventually weighted to properly reflect the U.S. Hispanic population. Among these 1,272 interviews, 242 Hispanics were eligible to complete the full survey. The same process was complete for Black/African American adults (initial sample 661; final sample 221) and Asian adults (initial sample 547; final sample 218).

These surveys were conducted in both Spanish and English. Approximately a quarter of the surveys of Hispanic adults were completed in Spanish.

Weighting: The data were weighted to be representative of the U.S. population age 18 or older (estimated to be 236 million people) on age, gender, education, geographical region and 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), Blacks/African Americans, Asian Americans and others for added precision within racial/ethnic groups. The demographic targets came from the U.S. Census Bureau's March supplement of the 2013 Current Population Survey.

For example, while the pool of 2,045 adults comprises 1,192 EHR respondents (58.3 percent) and 853 paper respondents (41.7 percent), after proper weighting the EHR respondents make up 80 percent of the total pool and paper respondents make up 20 percent. This does not represent the percentage of doctors in the United States who use EHRs, nor the number of patients in the United States whose health information is in EHRs. Rather, it represents the percentage of patients who report having a regular doctor and know what kind of record system the doctor uses (EHR or paper).

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 Poll 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 Poll 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 panel, no estimates of theoretical sampling error can be calculated. **About the Harris Poll:** Over the past five decades, Harris Polls have become media staples. With comprehensive experience and precise technique in public opinion polling, along with a proven track record of uncovering consumers' motivations and behaviors, the Harris Poll has gained strong brand recognition around the world. The Harris Poll offers a diverse portfolio of proprietary client solutions to transform relevant insights into actionable foresight for a wide range of industries including health care, technology, public affairs, energy, telecommunications, financial services, insurance, media, retail, restaurant, and consumer packaged goods. Contact Harris Poll for more information.



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