



Most Americans Want to Share and Access More Digital Health Data

Survey can inform federal policies to expand use of electronic health records, protect patient privacy

Overview

Americans' medical histories have largely been digitized over the past two decades as hospitals and physician's offices moved from paper-based to electronic health record (EHR) systems.¹ Congress has invested billions of taxpayer dollars to accelerate this transition, authorizing federal rules to expand individuals' access to their health records and to help clinicians share data and coordinate care for patients they have in common.²

To build on this progress, policymakers need to know how Americans perceive these issues and the extent to which they will embrace wider adoption of data exchange and access. Do patients want their personal health information made more accessible for themselves, and across multiple providers and even via third-party apps? What kind of information are they comfortable sharing? How confident are they that their data will be protected? What role do they want the federal government to play?

This brief presents the results of a nationally representative survey conducted in June and July 2020 for The Pew Charitable Trusts that was designed to inform lawmakers and regulators as they work to further modernize the U.S. health care system by enhancing patient and clinician access to data held in thousands of EHR systems across the nation. (See the methodology for more information about the survey.)

Among the survey's major findings:

- Eighty-one percent of adults support increased access to health information for patients and providers.
- More than two-thirds of adults want their clinicians to exchange some health information that federal data-sharing polices don't currently require, such as advanced care plans or end-of-life preferences, images (such as X-rays), and family medical histories.
- Most Americans want their data to be both more accessible and better protected. For example, although most respondents want to use apps on smartphones, tablets, and computers to access their health information, those who expressed serious privacy concerns nearly doubled—from 35% to 62%—when they were told that federal privacy protections do not cover data stored on apps. Many said that extending these laws could help alleviate their apprehension.
- Across political party lines, most adults—82% of Democrats, 66% of independents, and 51% of Republicans—support additional federal measures to improve the accurate exchange of records between health care providers.
- About 4 in 10 survey respondents said the coronavirus pandemic made them more likely to support efforts that enable data-sharing among a patient's providers and let people download their personal data from EHRs to apps on smartphones and other devices.
- By a roughly 2-to-1 margin, respondents were comfortable with their health providers scanning patient fingerprints or assigning individuals a unique number or code to ensure that different EHR systems correctly match records for the same person, a long-standing challenge of data exchange.

Taken together, the survey responses highlight several gaps in federal health IT policy that are preventing EHRs from reaching their full potential. The federal government should consider the following steps:

- Federal agencies should incentivize prompt adoption of national data standards so that EHRs can easily share data with both patients and providers.
- The national set of data that all EHRs must be able to share with one another should include all of the elements that patients want their providers to document and share.
- Congress and federal agencies should examine how privacy laws could be updated to account for new developments, such as the increased use of health-related apps.
- Federal agencies should research using biometrics (such as fingerprints) to potentially improve the accuracy of patient matching.

Federal policy sets the stage for improved data exchange

Federal policymakers have taken several important steps to make EHR data more accessible to patients and easily shared by clinicians.

To fully realize the benefits of the easier data-sharing and better health management that EHR systems can provide, Congress in 2009 spurred their adoption by hospitals and doctor's offices with the Health Information Technology for Economic and Clinical Health Act, which offered financial incentives for providers to implement these systems.³ Since then, data exchange among health care providers has increased; in 2017, 90% of acute care hospitals (excluding those affiliated with the Veterans Administration or Department of Defense) electronically exchanged patient health information with external providers.⁴

Even so, some barriers to data-sharing among providers and with patients persisted. In 2016, Congress passed the 21st Century Cures Act and included a mandate that EHRs use tools such as application programming interfaces (APIs) to gather information into one place and allow for easier data-sharing.⁵ APIs serve as digital translators, allowing different software systems to gather information from one another. Although commonly used in many industries and services—such as websites that let consumers compare and buy airline flights, hotel rooms, and financial products—APIs have not been widely adopted by health care organizations.

To implement the lawmakers' mandate, the Office of the National Coordinator for Health Information Technology (ONC) identified a set of information that EHRs must be able to share with one another called the U.S. Core Data for Interoperability (USCDI), which includes demographics, medications, clinical notes, allergy information, and other key elements.⁶ In 2020, the agency finalized a rule requiring that EHRs make that data available to patients and health care organizations using APIs; the rule will take effect in December 2022.⁷ However, the USCDI doesn't cover all parts of the medical record—for example, images such as X-rays are omitted. (ONC plans to expand the data elements within USCDI on an annual basis to ensure that the data set includes all the clinical information that patients and providers need.)

Other congressional efforts to advance data-sharing among health care providers have encountered resistance. In the Health Insurance Portability and Accountability Act (HIPAA) of 1996, Congress directed federal agencies to establish unique identifiers for patients that could help EHRs correctly match records for the same individual. But for the past 25 years, lawmakers have attached language to annual appropriations bills that blocks spending to create patient identifiers, citing concerns about patient privacy.⁸

Key findings

Respondents' thoughts on health IT in general

Eighty-five percent of respondents said at least some of their health care providers used electronic record systems, and 67% said all their clinicians did. But only 36% reported that all of their providers' EHRs let them access their own records electronically, through a smartphone app or an online patient portal, for example.

Personal access to EHRs fell unequally across racial and socioeconomic groups. While 64% of White respondents said they had access to at least some of their electronic records, 58% of African Americans and 47% of Hispanics said they did. Likewise, less than half of respondents with a high school education or less, or an income below \$40,000, reported being able to access their records electronically.

Provider access is important, but with caveats for some information

A clear majority of respondents—81%—said different providers should be able to share health data about patients they have in common. More than 2 in 3 want their various clinicians to exchange specific information in health records—such as advanced care plans or end-of-life preferences, images, and family medical histories—that federal data-sharing polices don't currently require.

Some respondents expressed concerns about providers sharing certain types of information. Seventy-five percent of respondents were comfortable discussing social determinants of health—such as homelessness, hunger, or exposure to violence—with clinicians.⁹ However, only 48% said they wanted information on social determinants of health shared among providers. Even smaller shares of African American (47%) and Hispanic (33%) respondents were comfortable with providers sharing this data with other providers.

More information helped assuage some people's concerns. In a follow-up question, respondents read that studies have shown that exposure to violence and lack of access to healthy food or housing can influence a person's health. After seeing this information, 62% of those surveyed, including 58% of African American respondents and 46% of Hispanics, said they would support the sharing of such data among providers.

Even so, the responses to that question echo the results of previous Pew-led focus groups in which participants expressed concerns about sharing data on social determinants because they felt they could be prejudged by their health care provider.¹⁰

Table 1

Most Survey Respondents Want Their Clinicians to Share Data in EHRs Among Themselves

Types of medical information, ranked by support for provider-to-provider exchange

	Yes, would want to share	No, would not want to share	Don't care either way	Don't know/refused/skipped
Allergies	80%	8%	12%	<0.5%
Immunizations	78%	9%	13%	<0.5%
Medications and prescription medicines	78%	12%	9%	1%
Vital signs	76%	10%	14%	<0.5%
Radiology images and reports	76%	12%	11%	1%
Advanced care plans or directives	76%	13%	11%	<0.5%
Laboratory test results	74%	13%	12%	<1.5%
History of medical conditions	71%	15%	13%	1%
Treatment plans	70%	15%	14%	<1.5%
Family medical history	69%	18%	13%	<0.5%
Physician and clinical notes	67%	21%	11%	<1.5%
Demographic information	63%	14%	23%	<0.5%
Behavioral or mental health history	52%	28%	20%	<0.5%
Substance use history	51%	26%	23%	<0.5%
Social determinants of health	48%	31%	20%	<1.5%
Insurance claims and billing	48%	33%	19%	<0.5%

Notes: The boxes in gray represent data elements that are not required to be shared under USCDI version 1.

The question stated: "Listed below are some of the different types of information in a patient's electronic medical or health records. For each, please select if you would or would not want your different doctors, hospitals and other health care providers to be able to electronically share this kind of information between their electronic health records systems when they are caring for you, or if you do not care either way."

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Patients want greater access to their records

A majority of respondents (61%) said they want to be able to access their medical records from providers' EHRs on mobile device apps or through an online patient portal. Interest varied between generations, with 53% of Baby Boomers (ages 56-74) desiring the ability to download data, compared with 67% of Millennials (ages 24-39).

Large majorities said they wanted access to specific data, including laboratory test results (89%), their history of medical conditions and past diagnoses (88%), treatment plans (87%), and radiology images and reports such as X-rays, CAT scans, or MRIs (87%). The COVID-19 pandemic has also highlighted the importance of patient access to some of this information; for example, 87% of respondents wanted access to data on immunizations.

Table 2

Patients Want Access to Data

Types of medical information, ranked by support for personal access

	Yes, would want access	No, would not want access	Don't care if I have access	Don't know/refused/skipped
Laboratory test results	89%	6%	5%	<0.5%
History of medical conditions	88%	6%	5%	<1.5%
List of medications and prescription medicines	87%	5%	7%	1%
Vital signs	87%	5%	8%	<0.5%
Immunizations	87%	5%	8%	<0.5%
Treatment plans	87%	6%	6%	1%
Radiology images and reports	87%	6%	6%	1%
Physician and clinical notes	84%	6%	9%	1%
Insurance billing and claims	84%	7%	9%	<0.5%
Allergies	83%	6%	10%	1%
Advanced care plans or directives	82%	8%	9%	1%
Family medical history	80%	7%	12%	<1.5%
Behavioral or mental health history	74%	11%	14%	1%
Substance use history	61%	13%	25%	<1.5%
Demographic information	58%	11%	30%	1%
Social determinants of health	57%	16%	26%	1%

Notes: The boxes in gray represent data elements that are not required to be shared under USCDI version 1.

The question stated: "Listed below are some of the different types of information in a patient's electronic medical or health records. For each, please select if you personally would or would not want to be able to electronically access, view and download this kind of information from your electronic health records or if you do not care either way."

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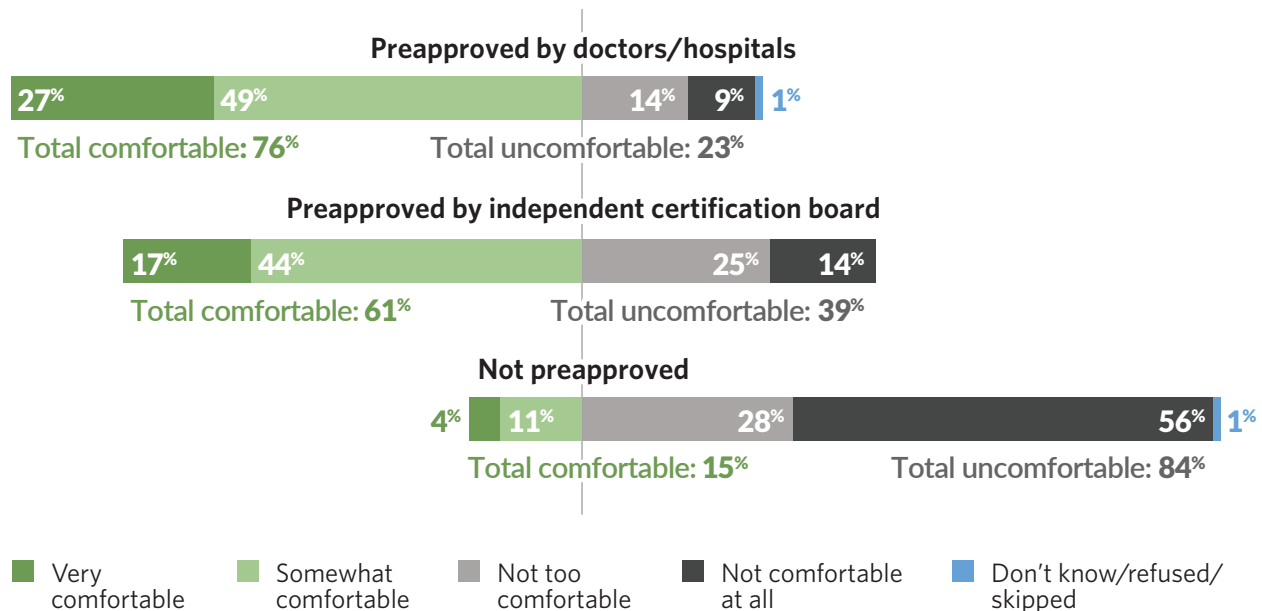
Apps are also popular, but patients want expert recommendations

As health information has gone digital, the use of health apps—generally available via smartphones—has also grown. These apps can help patients access their health records with the touch of a finger, and to aggregate data from multiple health care providers in one place. However, as a relatively new development in health care, these apps can also raise concerns about the suitability of current federal privacy regulations.

Most respondents wanted the ability to download their records to various health apps, although some types of apps were viewed with skepticism. In particular, respondents expressed more comfort with apps that had been preapproved by health care providers or independent agencies such as the Joint Commission, an organization that accredits health care programs in the United States.

Figure 1

Apps Without Provider or Independent Approval Viewed Skeptically Respondents' level of comfort downloading health data to apps



Note: The question stated: "Please indicate how comfortable you would feel downloading and storing your medical information and data on the different types of health apps that you select to use on your smart phone, computer or tablet with the specifications below."

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At the same time, these apps could introduce privacy issues that federal laws do not yet address. Asked about the privacy of their health data when it is downloaded to apps, 35% of respondents said they were extremely or very concerned; that number rose to 62% when they were told that federal privacy laws, such as HIPAA, do not cover data downloaded to apps, and that the apps' terms of service would protect the data instead. When respondents were given the opportunity to elaborate on their concerns in free text, they expressed particular worries about identity theft and blackmail; discrimination; the absence of federal data protections; and a desire to protect their information from access by large technology companies. Respondents commented that changes to federal law, such as a requirement that applications follow HIPAA's requirements, could help assuage those concerns.

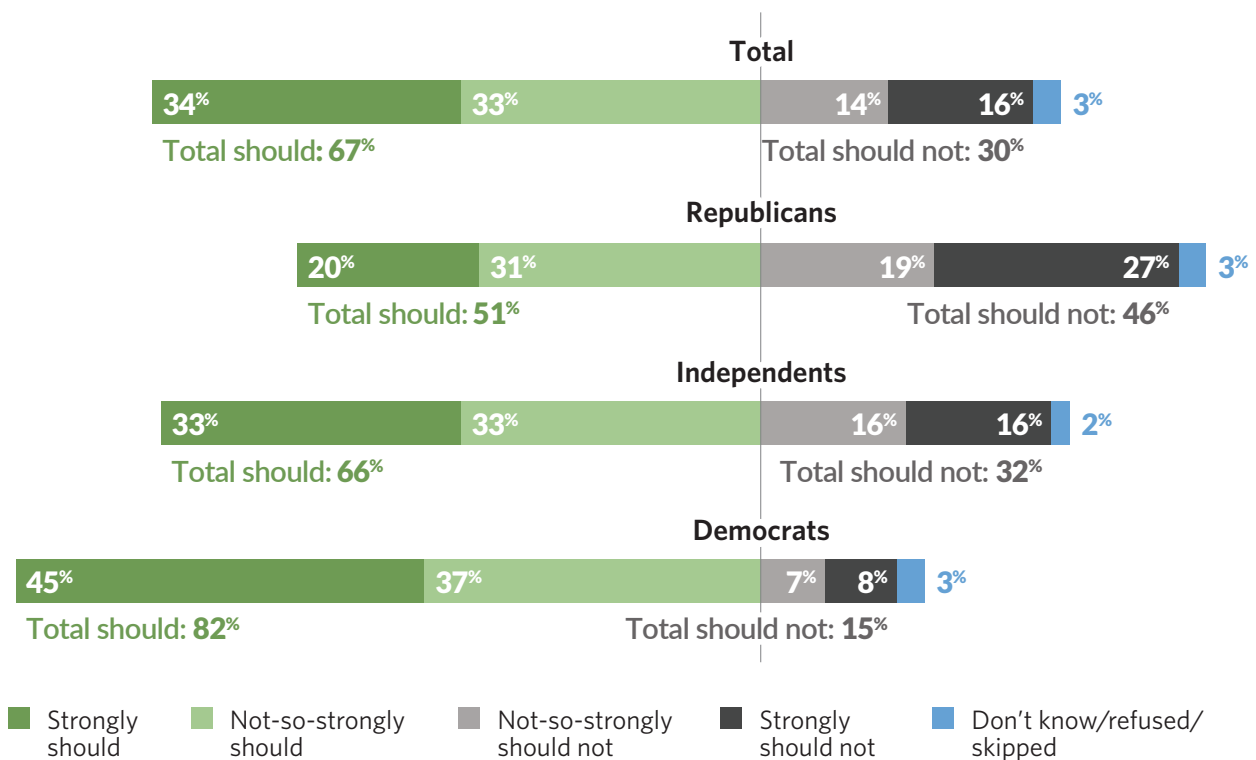
Respondents want government to act on patient matching

Respondents strongly backed efforts to improve patient matching, with 74% supporting federal policy changes to set national standards that could improve matching rates. In addition, 67% supported the federal government spending money to make improvements; this included majorities of Democratic respondents as well as just over half of Republicans, a notable finding given that much of the congressional opposition to a unique patient identifier has come from Republicans.

Figure 2

Majorities Support Federal Spending to Improve Patient Matching, Regardless of Party

Support for additional spending, by party affiliation



Note: The question stated: "Do you think that the federal government should or should not be allowed to spend money on the development of new ways for health care providers to more accurately match up a patient's electronic health records across multiple health care providers? (Do you feel that way strongly or not-so-strongly?)"

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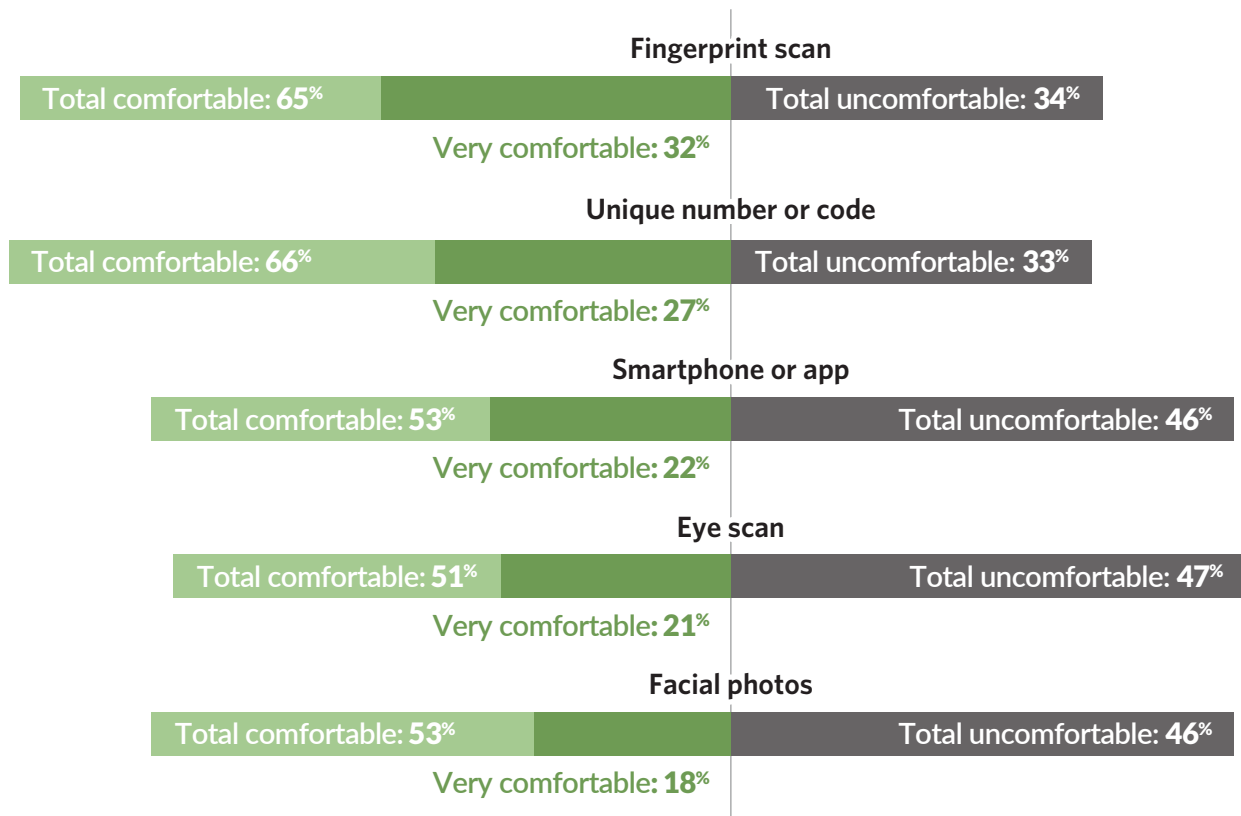
Respondents were given five options for how to improve matching and asked which ones they would support. Biometric options—matching patients’ records based on a personally identifiable physical characteristic such as fingerprints—were especially popular. Sixty-five percent said they would be at least somewhat comfortable with using their fingerprints to help link their records, while smaller majorities were comfortable using eye scans or facial photos. In total, 77% of patients said they were somewhat or very comfortable with at least one biometric option.

In addition, 66% were at least somewhat comfortable with the option of assigning each patient a unique identifier—a number or code—that would be entered whenever a patient checked in.

Figure 3

Broad Comfort With Different Types of Patient Matching Solutions

Matching options ranked by “very comfortable” responses



Note: The question stated: “Listed below are some of the different ways being considered that would more accurately match up a patient’s electronic health records across multiple health care providers. For each one, please indicate how comfortable you would be with your health care provider using it to match up your electronic health records across multiple health care providers.”

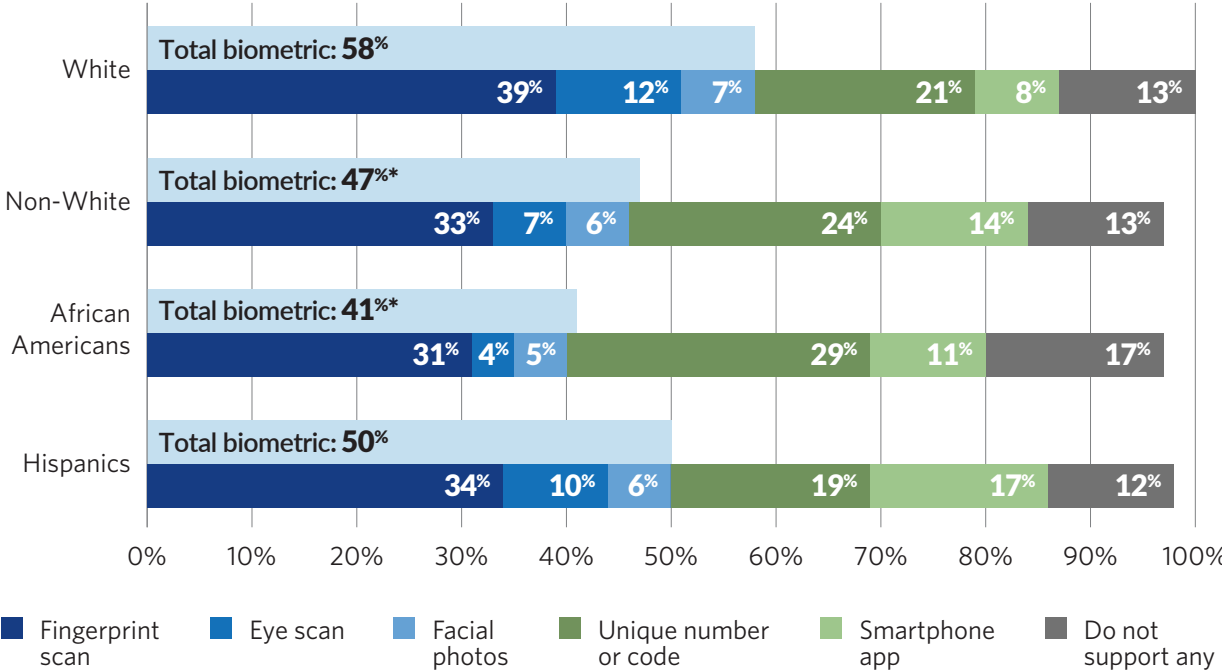
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Overall, when asked which option they would most support being implemented, 54% of respondents selected a biometric option as their first choice; 37% selected a fingerprint scan as the top option. However, this support was not equal across racial groups. Although 58% of White respondents chose one of the listed biometric options as their first choice, only 50% of Hispanics and 41% of African Americans did so. In addition, although at least a plurality of Hispanic and African American respondents selected fingerprints as their first choice, they were less likely to support each biometric matching option than were White respondents.

Figure 4

Biometric Identifiers Are Popular Options to Enhance Patient Record-Matching

Respondents' first-choice identifier among five tested, by race and ethnicity



*Total may not match exactly due to rounding.

Note: "Refused/skipped" data not shown. The net non-White category consists of those who identify as African American or Hispanic. The combined category is used in this brief so that broad comparisons can be made to highlight differences between groups. When possible, Pew prefers to break out subgroups to show the differences that may exist between groups of people. The use of a net non-White category is not intended to obscure the fact that the experiences and behaviors of Black Americans, Hispanic Americans, and Americans of other races and ethnicities may be quite different.

COVID-19 has made all of these policies slightly more popular

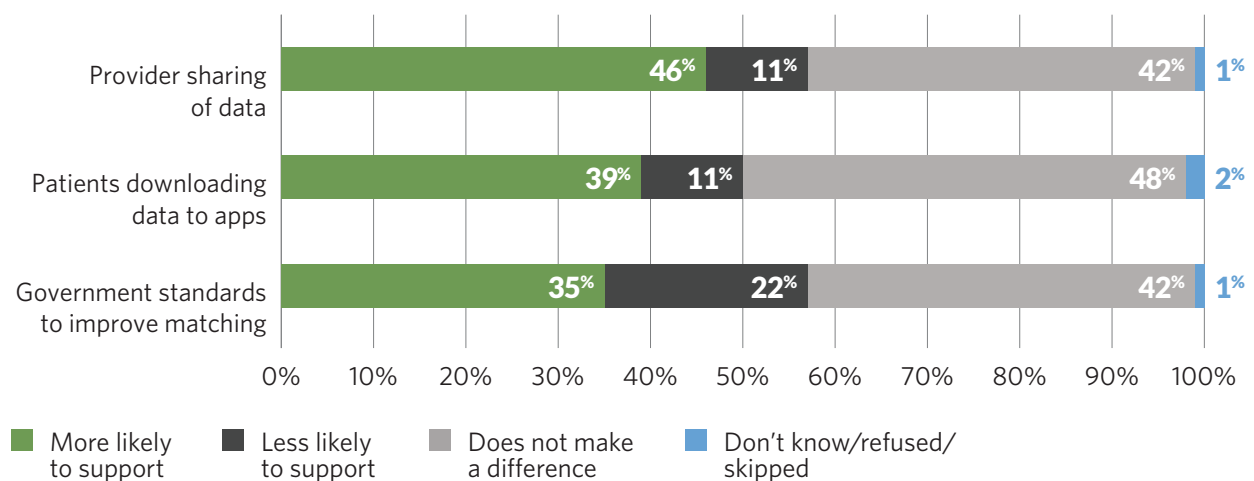
The COVID-19 pandemic has highlighted the role that technology can play in providing care. In particular, correct identification of patients across the health care spectrum can ensure that patients, providers, and public health officials receive accurate COVID-19 test results and is a vital component in vaccine distribution.

Because the survey was conducted during the pandemic, it included questions about how respondents' views on health IT had changed; respondents were generally more supportive of various government actions. When asked whether the outbreak made them more or less likely to support efforts to improve data-sharing, 46% indicated that it increased their support, while 42% said it made no difference. Similarly, more than a third of respondents said it had made them more likely to support efforts to allow patients to download their health data to apps and to support the setting of federal standards to improve matching rates. However, in both of those cases, pluralities said it had made no difference in their opinions.

Figure 5

Pandemic Made Some Adults More Supportive of Data-Sharing

Description of main questions, broken out by changes in support because of pandemic



Note: The question stated: "Please select whether the coronavirus situation makes you more likely or less likely to support each of the following or if the coronavirus situation does not make a difference in your opinion of these things one way or the other."

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Policy recommendations

Americans broadly support federal action to improve health data-sharing, such as the ability to access health data through apps and the creation of national standards to more accurately link patients' records held at different facilities. The COVID-19 pandemic has made a significant number of Americans more likely to support these policies. Although any changes may come too late to help address that crisis, they could easily help in a future emergency.

Fully realizing those goals, however, will require the government, EHR vendors, hospitals, and providers to act. In particular, federal policymakers should consider the following actions:

- ONC should include more data—such as images and social determinants of health—in the USCDI so that patients and providers could access them using APIs, and should encourage providers to discuss the importance of this data with their patients to assuage any concerns.
- ONC and the Centers for Medicare & Medicaid Services should incentivize early adoption of APIs, given the fact that rules from the 21st Century Cures Act that would expand their use have been delayed until December 2022. ONC should also make it clear that the implementation will not be further delayed.
- Congress, with support from the Department of Health and Human Services (HHS), should ensure that patient privacy is protected, including updating HIPAA as necessary.
- Congress and HHS should investigate opportunities to improve patient matching, including examining whether the long-standing ban on a unique patient identifier should be removed, and have government take the lead on a national approach to link records.
- ONC should consider how biometrics could help address patient matching deficiencies.
- Because personal access to electronic health records may vary among different racial or socioeconomic groups, policymakers should consider existing disparities when developing policies or regulations meant to increase access to health information.

Conclusion

EHRs have already transformed how providers approach caring for their patients; they could offer an opportunity for individuals to take a more active role in improving their health. The COVID-19 pandemic, with an increased use of telehealth services, has made the potential benefits of this technology more apparent.

As these systems continue to evolve, this survey shows that most Americans clearly recognize the potential benefits that improved health IT can offer, and they want this transformation of the health care system to continue—in ways that may conflict with long-standing government policy, such as the congressional funding ban on developing a unique patient identifier, or in ways that could expand current policies, such as requiring more data to be shared through APIs.

The federal government, EHR and app developers, and health care providers have an opportunity to address some long-standing concerns with America's health IT systems. As this survey shows, patients are ready for them to take advantage of it.

Survey methodology

The survey included a nationally representative sample of 1,213 adults (ages 18+), with a margin of error of +/-3.49 percentage points.¹¹ Interviews were conducted between June 1 and July 3, 2020; 90% of respondents answered online, and the remainder did so by phone. The survey was offered in English and Spanish.

Public Opinion Strategies and Hart Research Associates designed and administered the survey in conjunction with Pew. The survey was conducted using NORC at the University of Chicago's AmeriSpeak panel, a nationally representative, probability-based panel of the U.S. household population.¹²

In addition to the survey questions, researchers asked respondents several demographic questions to help provide additional insights into how different groups viewed these issues. These questions included political party affiliation; income; education; races and ethnicities; and which type of health insurance respondents had, if any.

For questions on sharing health information, respondents were split into two groups. Researchers asked one group whether they wanted access to their health information, while the other group was asked whether they wanted various health care providers they visited—such as a primary care physician or a specialist—to be able to share the information with one another. The survey asked both groups about 16 categories of health information that providers could share via tools such as APIs that can communicate between different systems. The categories of data to be shared included allergies, vital signs, laboratory test results, behavioral health history, and other aspects of a participant's medical history.

EHR data categories included in the survey (and descriptions shown to respondents)

- Advanced care plans or directives (such as do-not-resuscitate orders or end-of-life care preferences).
- Allergies.
- Clinical notes (physician and clinical notes on a patient's medical care).
- Current and past medications.
- Demographic data (such as gender, age, or ethnicity).
- Family medical history.
- Immunizations.
- Insurance billing and claims information.
- Laboratory test results.
- Mental or behavioral health history .
- Personal medical history (medical conditions and past diagnoses).
- Radiology images and reports such as X-rays, CAT scans, and MRIs.
- Social determinants of health (information such as exposure to violence or history of physical abuse, hunger or lack of access to healthy food, or homelessness or lack of access to housing).
- Substance use history.
- Treatment plans.
- Vital signs (such as blood pressure).

Endnotes

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- 11 B. Moscovitch, "Americans Want Federal Government to Make Sharing Electronic Health Data Easier," The Pew Charitable Trusts, Sept. 16, 2020, <https://www.pewtrusts.org/en/research-and-analysis/articles/2020/09/16/americans-want-federal-government-to-make-sharing-electronic-health-data-easier>.
- 12 Randomly selected U.S. households are sampled using area probability and address-based sampling, with a known, nonzero probability of selection from the NORC National Sample Frame. These sampled households are then contacted by U.S. mail, telephone, and field interviewers (face to face). The panel provides sample coverage of approximately 97% of the U.S. household population. Those excluded from the sample include people with P.O. box-only addresses, some addresses not listed in the U.S. Postal Service Delivery Sequence File, and some newly constructed dwellings. While most AmeriSpeak households participate in surveys by web, non-internet households can participate in AmeriSpeak surveys by telephone. Households without conventional internet access but having web access via smartphones are allowed to participate in AmeriSpeak surveys by web.

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