iStockphoto

Patients Seek Better Exchange of Health Data Among Their Care Providers

Focus groups highlight issues that new federal regulations aim to address

Federal policies increasingly seek to improve and expedite patients' access to their own health data, but important questions remain as to what information patients most want, which providers they want to have access to their records, and how they regard issues of privacy and data security.

The Pew Charitable Trusts conducted focus groups centered on new federal regulations that would help providers exchange information and get patients access to their electronic health record (EHR) data more easily, including on their smartphones. These regulations from the Office of the National Coordinator of Health IT (ONC), the federal agency tasked with oversight of EHRs, have the potential to increase patient engagement in their own care as well as improve interoperability—the ability of two EHR systems to share health data effectively.

Overall, focus group participants supported efforts to improve data sharing, both among providers and with patients. While seeking patient access to data, many participants emphasized the importance of prioritizing easier data exchange among health care providers. When asked which data elements they want to access and to be exchanged among health care facilities, most participants indicated that patients should receive all information from their records, and most generally want everything exchanged between providers, although there is hesitancy around sensitive topics, particularly information on substance use history, behavioral or mental health, and social factors such as housing insecurity. Although there is overwhelming support for greater information sharing, some focus group participants raised privacy and security concerns.

These findings provide insights that can inform policymakers as they consider future rule-making to accelerate both patient access to their medical information and greater interoperability of data among health care providers.

Health data exchange can build on internet tools

Many people—particularly those with chronic health conditions—get health care services from various clinicians, resulting in records scattered across multiple facilities.[1] When patients try to share records across these sites of care, medical facilities often send information via fax machine—if at all. And, if patients want to collect all their records, they may be required to pay large fees or pick up files in person, or they may be denied access outright. [2]

Health care historically has relied on proprietary or product-specific solutions when sharing data; these have inhibited patient access to information and record exchange among providers. However, modern internet-based tools can help patients gain access to their data and aid communication among doctors, nurses, and other clinicians. These tools, called application programming interfaces (APIs), enable easy and prompt access to data much in the same way that personal finance tools and travel booking websites aggregate real-time information from multiple locations. Widespread adoption of APIs in health data exchange could transform how information is shared, freeing patients from remembering complicated medical details and hand-delivering their records to providers.

Currently, health care providers rarely employ robust APIs for data exchange. When they do, those APIs can be implemented in proprietary ways, such as not being built using common industry standards, that inhibit the use of the information by clinicians and patients. Congress addressed that challenge in the 21st Century Cures Act, which required ONC to develop new criteria for EHRs to make "all data elements" available via APIs without special effort, granting patients and providers easier access to health information and improving care.[3] In implementing this provision, ONC proposed that EHR systems would have to allow access to data using APIs built in accordance with Fast Healthcare Interoperability Resources—a common, industry-established standard—and other guidelines to ensure consistency across facilities.[4] The use of these standards-based APIs would let technology developers access individual pieces of information—such as a list of medications—instead of a broader document containing more data, some of which might be unnecessary or individual patients may not wish to share.

Focus group methodology

Given this public policy emphasis on APIs, Pew conducted focus groups across the country to explore individuals' attitudes and perceptions about sharing medical records across health care providers and patients' access to their information. Pew worked with research firms Public Opinion Strategies (POS) and Hart Research Associates to conduct nine in-person focus groups with a total of 80 participants, and one online bulletin board group with an additional 18 participants whose medical histories would have made it difficult to attend in person. A moderator used an interview guide—developed by POS, Hart, and Pew with input from external stakeholders—to help uniformly administer the focus groups across each of the patient populations.

Each focus group included a mix of gender, race, ethnicity, age, education, and income unless otherwise specified by the criteria for that group. The focus groups occurred in the summer of 2019. The in-person groups met in Morristown, New Jersey; Kansas City, Missouri; Seattle; and Nashville, Tennessee.

To capture a range of perspectives, the focus groups intentionally included different ages, health statuses, and relationships with the health care system. The African American group (which also used an African American moderator) was included to ensure this research featured input from populations with a historical mistrust of the biomedical community, to understand if that history affects current attitudes toward data sharing and access.[5]

Table 1

Location and composition of focus groups

Location	Registered voter audiences
Morristown, New Jersey	• Medicare beneficiaries age 65+ who are not eligible for Medicaid (9) • Frequent users of the health care system (9) • Caregivers of patients with chronic/serious illnesses (9)
Kansas City, Missouri	• Less frequent users of the health care system (9) • Ages 40-64 (8)
Seattle	• Ages 23-39 (9) • Frequent users of the health care system (9)
Nashville, Tennessee	• Medicare beneficiaries age 65+ who are also eligible for Medicaid (9) • African Americans (9)
Online	• Patients with serious illnesses (18)

As with all qualitative research, the format of this study emphasizes the experiences and knowledge of the participants and is not intended to be generalizable. However, the interview participants and focus group locations were chosen to obtain different perspectives.

Focus group findings reveal broad support for health data exchange

Focus group participants shared views across a range of health data topics, with perspectives generally similar across demographic groups. Participant comments addressed four key topics: interoperability and patient access to data, clinical data elements to share, exchange of social determinants data (such as information on housing or food insecurity), and concerns regarding privacy and security.

Consumers seek better access to and sharing of health data

Participants overwhelmingly supported greater access to data both for health care providers and for themselves, though they varied in their reasons for supporting provider access to their health information. Some people indicated that better communication among health care providers would improve patient care, particularly in the event of an emergency in which the patient might be unconscious or otherwise noncommunicative, while others believed that interoperability would streamline routine care. Other participants focused on safety, speculating that providers communicating effectively would eliminate potential mistakes, such as medication interactions or allergic reactions.

In addition, nearly all participants said they would like access to their medical records. Frequent health care users and patients with serious illnesses were more likely to say they want to be able to access their records electronically.

> **"I couldn't even name you all the different portals and things that I probably have. One of them I know is being canceled in November, but I couldn't even tell you really. So you get what you can and then … you call the doctor's office and they can mail it to you."**
>
> Medicare beneficiary, *Morristown, New Jersey*

Participants who wanted access to their records indicated a desire to:

- Access all of their physicians' notes and test results (including weight, blood pressure, or cholesterol levels).
- Verify the accuracy of the information included in their record.
- Compare their health data with those from previous years or visits in order to track their health.
- Refresh their memories in case they forget something the physician said during the visit, or if they have not been to the doctor recently.

The few participants who did not want to access their health records cited concerns about hacking of their personal devices and a general disinterest in medical information that they trusted their doctors to address.

Although patients overwhelmingly wanted access to their health information, when asked to select the most important use for health data exchange, they predominantly indicated that their clinicians' access to details of care should be prioritized. Patients said they preferred clinician access because it would improve the speed and efficiency with which they receive care by allowing providers to coordinate better.

> **[A]ll providers [should] have the same, most up-to-date, information about the patient. This way the patient's history is always updated and there is a lesser chance for miscommunication."**
>
> Less frequent health care user, *Kansas City, Missouri*

Given the many potential uses of APIs, participants were also asked to rank and choose the three most important benefits of these tools when offered a list of seven options. More than half of all participants selected better care coordination for all patients as the most compelling benefit. Other uses that resonated included more data sharing among providers explicitly for chronically ill patients, preventing medical errors, decreasing the number of duplicative tests, and lowering costs. The uses that resonated least related to enabling individuals to update their information, granting patients access to their medical data on a personal device, and replacing the hand delivery of records. (The appendix contains the full list of benefits given to participants.)

Specific data elements examined for access and exchange

Each patient may prioritize different information contained in an individual health record for access and exchange. Some patients may be most interested in accessing their treatment plan and medications, while they want clinicians to have their medical history and X-rays. To evaluate these preferences, focus group participants were given a list of data elements and asked which they wanted to access themselves and which they wanted providers to be able to exchange.

Most participants wanted to access everything in their health record. Nearly all patients wished to receive medication lists, treatment plans, test results, physicians' notes, and advance care plans. Some individuals did not express a desire to obtain their demographic data, substance use history, family medical history, and behavioral and mental health information, indicating that they already know this information or that it was sensitive and citing security risks once data are shared.

Patients also wanted providers to exchange most of the information in their health record, though there was some hesitation around a few data elements. Participants' top priorities for clinician access were medical history, imaging, medications, and allergies. These data elements were perceived as critical to continuity of care. And although more than half of all participants wanted insurance coverage, substance use history, behavioral health, and demographic information to be shared, these data elicited the most hesitation. Participants had concerns that this information could be used to deny or negatively affect care, or that these items were unnecessary for treatment.

Data elements for provider exchange

Participants in each group were presented with the following data elements in a randomized order and selected all they wanted providers to be able to exchange. Data elements are ordered here from most to least desired for exchange, understanding that with 98 participants, no definitive conclusions on patient priorities should be drawn from this table alone.

Patient medical history

Radiology images and reports such as X-rays, CAT scans, MRIs

Medications and prescription medicine you are currently or have taken

Allergies

Diagnosis and treatment plans

Physician notes and clinical notes on your medical care

Immunizations

Laboratory data and test results

Vital signs

Advance care plans or directives such as do-not-resuscitate orders and end-of-life care preferences

Family medical history

Demographic information about you, such as your gender, age, ethnicity

Behavioral or mental health

Substance use history

Insurance coverage, billing, and claims information

> " My concerns would be that the next doctor would be quick to take a look [at the record] without knowing the patient personally and judge them."
>
> **Medicare beneficiary,** *Morristown, New Jersey*

Focus group participants also discussed additional data elements that may be perceived as more sensitive or less directly relevant to health care, specifically related to social determinants of health (SDOH). Many medical experts have increasingly focused on integrating this information into patient care, citing the effect of social factors on health, yet little research exists on patients' attitudes about the exchange of such data among health care providers.[6]

For example, incorporating information on housing insecurity or exposure to violence into patients' records could give clinicians context when making medical decisions and could help them refer patients to outside resources. Focus group participants recognized some benefits to clinician access to these types of data for at-risk populations, such as to provide the appropriate referral services for people without stable housing or in abusive relationships.

> " If the doctor needs to know, I can tell him. I don't want to have it transferred on a profile for him that I am hungry or that I don't have a place to live at. I can tell him that if I need him to know that."
>
> **African American participant,** *Nashville, Tennessee*

As with other sensitive data elements, participants had questions and concerns, including that this information would lead to assumptions about patients and could contribute to discrimination. Some participants said that this information fell outside of a doctor's responsibility and questioned what a practitioner would be able to do to address social factors. Many participants said they would feel comfortable discussing SDOH with clinicians with whom they had an established relationship, but they had concerns about that information being shared with a different provider.

Privacy and security concerns remain

Although patients overwhelmingly supported greater access to medical records, every group raised concerns about the privacy and security of health data. Privacy refers to who is accessing and using the data, while security denotes the protection of records from unauthorized access and outside hacking.

Participants raised three main concerns around privacy. First, though they understood that an API used by hospitals would be regulated by an entity such as the federal government, participants worried that their data would not be well protected once released. For example, some participants raised questions about whether the data would be covered under the Health Insurance Portability and Accountability Act of 1996 (HIPAA), the federal law that governs data privacy in health care settings. Participants expressed serious reservations when told that the privacy of their records may not be governed by HIPAA; instead, the terms of service of the applications they use to download information would generally determine privacy. Focus group participants indicated concern that their data on a smartphone may not be adequately protected and could be sold to another commercial entity without patient consent—even if individuals technically agree to terms of service, which are

often consented to without being read in full. Second, some participants, including many people of color, worried that easier access to their data meant anyone in the hospital could see their personal information. Third, as previously mentioned, participants expressed concern that certain data elements could lead clinicians to prejudge them, which would negatively affect their treatment.

Participants also expressed apprehension about the security of their information in health care facilities and on their personal devices, citing recent data breaches at major retailers, banks, and hospitals. When asked about potential solutions, such as hospitals providing recommendations for safe apps to use or encryption, these options did not significantly alleviate concerns. Participants could not identify additional solutions that would make them feel their data were secure.

Patient perspectives should inform interoperability policy

Government agencies have taken critical steps to improve data exchange, but these focus group results point to additional actions that EHR developers, health care providers, and regulators could take to address patient priorities.

- **Support export of all data to patients.** Participants in these focus groups voiced interest in accessing all the data in their EHR, some of which are not currently available via APIs. ONC should work toward identifying data standards that can be used, and in the meantime facilitate the export of all data via other means so patients and health systems can obtain and control their information. Absent federal regulations, EHR vendors can also enable the extraction of all data from records on their own.

  Many patients will also need additional support to understand the information contained in their record. The federal government, health care facilities, and other organizations should explore and develop best practices for giving patients tools to make sense of their data.

- **Increase API use for data exchange among providers.** Given focus group patient priorities, the federal government should advance the use of APIs for data exchange among providers. Although government policies have prioritized patient access to data, participants wanted both access to their health records and provider interoperability. Second, patients have differing views on which data elements they want exchanged. Standards-based APIs, such as those built on Fast Healthcare Interoperability Resources, will allow for the exchange of only the data that patients want shared or that providers need for care rather than everything contained in records, including sensitive information. Despite increased availability of standards-based APIs, they are not yet routinely used for data exchange between providers. Participants also expressed great interest in accessing some data elements, such as clinical notes, that are currently not routinely made available to patients.

  For these reasons, ONC should continue to accelerate patient access to records while also focusing on increasing adoption of tools and policies to enable the exchange of individual data elements among providers, such as through standards-based APIs. For example, federal regulations requiring the addition of clinical notes to APIs would reflect the preferences expressed by patients in these focus groups.

  The federal government can also encourage the use of APIs for interoperability by incorporating these tools in the Trusted Exchange Framework and Common Agreement, a program created through the 21st Century Cures Act to provide the infrastructure for nationwide data exchange, and through Medicare payment policies to provide financial incentives for the use of these tools.

- **Evaluate SDOH exchange and safeguards.** Although SDOH are increasingly being used and examined in medical contexts, focus group participants expressed reluctance over the exchange of this information among providers. When assessing the increased capture and use of these sensitive data, policymakers and providers should directly address these patient concerns. For example, policymakers should evaluate how to monitor whether the exchange of SDOH information contributes to better patient outcomes, and if certain populations are adversely affected. In addition, policymakers should ensure that patients decide whether to provide this sensitive information and that protections exist for individuals who refuse. Finally, policymakers should also ensure that health care providers have the resources, tools, and training they need to act on SDOH information, such as by offering referral services.

- **Address privacy and security.** Given participant concerns about unauthorized access to their data, stakeholders should prioritize solutions for privacy and security gaps. Policymakers should evaluate the privacy and security policies of third-party applications and whether patients can readily access and understand associated disclosures on how their information will be used. Where the federal government finds deficiencies, policymakers should advance policies that protect patients' health information. Meanwhile, technology developers and health care providers should ensure that patients are fully aware of policies governing their data. Emerging industry-led codes of conduct can provide guidance on best practices, such as disclosure on whether data will be sold.[7]

Conclusion

With only a few clicks, individuals can access their banking information or assess travel options. Yet, in health care, fax machines and incomplete paper records represent the status quo. By leveraging modern internet-based tools, health care in the United States can replicate the efficiencies and benefits of data exchange realized in other industries.

Increased use of APIs—particularly those based on common standards—can help meet patients' goals on the use of their data. Clinicians could gain access to more information on patients' medical conditions from other providers to better coordinate care, while sharing only data necessary for treatment. Patients could also more easily obtain and aggregate their data, enabling them to successfully engage in their care. When implemented effectively, APIs can support patients' preferences for data access and privacy so that individuals and clinicians have the information they need to support higher-quality, more coordinated care.

Acknowledgments

Appendix

Focus group participants were asked to read through the following potential benefits of APIs and select three that they perceived to have the most important benefits. Participants were asked to rank their first, second, and third choices.

Benefits/messages

Incorporating APIs into EHRs will:

a. Allow patients to view and share with their providers their electronic health record, giving patients greater control over their health information.

b. Allow patients to download their electronic health record into health apps. Patients could use smartphone applications, for example, to hold their health data in one location. This would give patients greater access to their health information.

c. Provide physicians and health care providers with needed patient health information from many different sources seamlessly, which allows them to better coordinate patient care across multiple providers, maintain a complete and accurate medical history for patients, analyze appropriate treatment options, and inform their care decisions, which could lead to better care.

d. Address the current limitations in the design of all the different EHRs where today they are not able to communicate with each other, which could decrease the number of medical errors today based on lack of information on patients and also decrease duplicate tests, which would reduce costs.

e. Allow individuals with chronic health illnesses and all of their health care providers to have access to the patient's full health record, with a complete history of their condition and care.

f. Free up patients from having to hand-deliver their records to health care providers.

g. Allow patients to provide and update their basic health information in their health record—such as their address, contact information, and medical symptoms on file—to ensure the record is up-to-date instead of having to fill out some of the written forms in waiting rooms.

Endnotes

1   K. Chunchu et al., "A Patient Centered Care Plan in the EHR: Improving Collaboration and Engagement," *Families, Systems, and Health* 30, no. 3 (2012): 199-209.

2   L. Beard et al., "The Challenges in Making Electronic Health Records Accessible to Patients," *Journal of the American Medical Informatics Association* 19, no. 1 (2011): 116-20, https://doi.org/10.1136/amiajnl-2011-000261.

3   Congress.gov, "H.R. 34—21st Century Cures Act," accessed Jan. 29, 2020, https://www.congress.gov/bill/114th-congress/house-bill/34.

4   21st Century Cures Act: Interoperability, Information Blocking, and the ONC Health IT Certification Program, 84 Fed. Reg. 78, 16834-35 (April 23, 2019), https://www.federalregister.gov/documents/2019/04/23/2019-08178/21st-century-cures-act-interoperability-information-blocking-and-the-onc-health-it-certification.

5   V.N. Gamble, "Under the Shadow of Tuskegee: African Americans and Health Care," *American Journal of Public Health* 87, no. 11 (1997): 1773-78, https://ajph.aphapublications.org/doi/abs/10.2105/AJPH.87.11.1773.

6   M.N. Cantor and L. Thorpe, "Integrating Data on Social Determinants of Health Into Electronic Health Records," *Health Affairs* 37, no.4 (2018): 585-90, https://www.healthaffairs.org/doi/abs/10.1377/hlthaff.2017.1252; J. Benach et al., "The Challenge of MonitoringEmployment-Related Health Inequalities," *Journal of Epidemiology and Community Health* 66, no. 12 (2012): 1085-87, https://jech.bmj.com/content/jech/66/12/1085.full.pdf.

7   Scientific Committee for Animal Nutrition—European Commission, "Report of the Scientific Committee for Animal Nutrition on the Efficacy and Risk for Users of the Therapeutic Macrolides Antibiotics Tylosin and Spiramycin Used as Feed Additives" (1998), https://ec.europa.eu/food/sites/food/files/safety/docs/animal-feed_additives_rules_scan-old_report_out06.pdf; Carin Alliance, "The Carin Alliance Code of Conduct," accessed Jan. 29, 2020, https://www.carinalliance.com/our-work/trust-framework-and-code-of-conduct.

For further information, please visit:

pewtrusts.org/healthIT