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HEALTH INFORMATION TECHNOLOGY

Approaches and Challenges to Electronically Matching Patients' Records across Providers

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Why GAO Did This Study

Health care providers are increasingly sharing patients' health records electronically. When a patient's records are shared with another provider, it is important to accurately match them to the correct patient. GAO and others have reported that accurately matching patient health records is a barrier to health information exchange and that inaccurately matched records can adversely affect patient safety or privacy. At the federal level, ONC is charged with coordinating nationwide efforts to implement and use health IT.

The 21st Century Cures Act included a provision for GAO to study patient record matching. In this report, GAO describes (1) stakeholders' patient record matching approaches and related challenges; and (2) efforts to improve patient record matching identified by stakeholders.

To do its work, GAO reviewed reports by ONC and others about patient record matching. GAO also interviewed various stakeholders that play a role in exchanging health records, including representatives from physician practices, hospitals, health systems, health information exchange organizations, and health IT vendors. GAO also interviewed other stakeholders, such as ONC officials, provider and industry associations, and researchers. GAO selected stakeholders based on background research and input from other stakeholders, and interviewed 37 stakeholders in total. The information from stakeholders is not generalizable. HHS provided technical comments on a draft of this report, which GAO incorporated as appropriate.

View GAO-19-197. For more information, contact Jessica Farb at (202) 512-7114 or farbj@gao.gov.

What GAO Found

Stakeholders GAO interviewed, including representatives from physician practices and hospitals, described their approaches for matching patients' records—that is, comparing patient information in different health records to determine if the records refer to the same patient. Stakeholders explained that when exchanging health information with other providers, they match patients' medical records using demographic information, such as the patient's name, date of birth, or sex. This record matching can be done manually or automatically. For example, several provider representatives said that they rely on software that automatically matches records based on the records' demographic information when receiving medical records electronically. Stakeholders said that software can also identify potential matches, which staff then manually review to determine whether the records correspond to the same patient. Stakeholders also said that inaccurate, incomplete, or inconsistently formatted demographic information in patients' records can pose challenges to accurate matching. They noted, for example, that records don't always contain correct information (e.g., a patient may provide a nickname rather than a legal name) and that health information technology (IT) systems and providers use different formats for key information such as names that contain hyphens.

Stakeholders GAO interviewed identified recent or ongoing efforts to improve the data and methods used in patient record matching, such as the following:

- Several stakeholders told GAO they worked to improve the consistency with which they format demographic data in their electronic health records (EHR). In 2017, 23 providers in Texas implemented standards for how staff record patients' names, addresses, and other data. Representatives from three hospitals said this increased their ability to match patients' medical records automatically. For example, one hospital's representatives said they had seen a significant decrease in the need to manually review records that do not match automatically.
- Stakeholders also described efforts to assess and improve the effectiveness of methods used to match patient records. For example, in 2017 the Office of the National Coordinator for Health Information Technology (ONC) hosted a competition for participants to create an algorithm that most accurately matched patient records. ONC selected six winning submissions and plans to report on their analysis of the competition's data.

Stakeholders said more could be done to improve patient record matching, and identified several efforts that could improve matching. For example, some said that implementing common standards for recording demographic data; sharing best practices and other resources; and developing a public-private collaboration effort could each improve matching. Stakeholders' views varied on the roles ONC and others should play in these efforts and the extent to which the efforts would improve matching. For example, some said that ONC could require demographic data standards as part of its responsibility for certifying EHR systems, while other stakeholders said that ONC could facilitate the voluntary adoption of such standards. Multiple stakeholders emphasized that no single effort would solve the challenge of patient record matching.

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Abbreviations

AHA	American Hospital Association
CHIME	College of Health Information Management Executives
DOB	date of birth
EHR	electronic health record
HHS	Department of Health and Human Services
HIE	health information exchange
IT	information technology
ONC	Office of the National Coordinator for Health Information Technology
SSN	Social Security number
QHIN	Qualified Health Information Network

January 15, 2019

The Honorable Lamar Alexander
Chairman
The Honorable Patty Murray
Ranking Member
Committee on Health, Education, Labor, and Pensions
United States Senate

The Honorable Frank Pallone Jr.
Chairman
The Honorable Greg Walden
Ranking Member
Committee on Energy and Commerce
House of Representatives

As health care providers increasingly use electronic health records (EHR), a greater share of patients' medical records are stored and exchanged electronically.[1] This exchange can occur among various types of providers—including hospitals, primary care physicians, specialty physicians, pharmacies, and laboratories—and has increased in recent years. An American Hospital Association (AHA) survey found that in 2017, 74 percent of hospitals reported sharing clinical or summary of care records electronically with other hospitals, whereas in 2012 only 30 percent of hospitals reported doing so.[2] The 2017 survey also found that 58 percent of hospitals indicated physicians at their facilities "always or sometimes" used patient health information received electronically from outside sources while treating a patient.

When a patient's medical records from one health care provider are shared with another provider, it is important that those records belonging to the same individual are accurately matched. Patient record matching is the process of comparing patient information in different health records to determine if the records refer to the same patient. Inaccurate patient record matching can adversely affect the care patients receive as well as

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[1]The Office of the National Coordinator for Health Information Technology defines an EHR as a digital version of a medical record that can include a person's medical and treatment history, such as diagnoses, medications, treatment plans, and more.

[2]AHA, *Trendwatch: Sharing Health Information for Treatment* (Washington, D.C.: March 2018).

their privacy.[3] For example, inaccurately matched records can adversely affect patients' safety if incorrect patient data are used to make medical decisions; the ECRI Institute reported the case of a patient in cardiac arrest who was mistakenly not resuscitated because the care team adhered to the wrong patient's do-not-resuscitate order.[4] We and others have reported that patient record matching has caused difficulties for providers.[5] A 2014 study found that as few as 50 percent of records are accurately matched when organizations exchange information. In AHA's 2017 survey, 45 percent of large hospitals reported that difficulties in accurately identifying patients across health information technology (IT) systems limited health information exchange.[6]

At the federal level, the Department of Health and Human Services' (HHS) Office of the National Coordinator for Health Information Technology (ONC) is responsible for coordinating nationwide efforts to implement EHRs and other health IT systems often used in patient record matching. For example, ONC sets standards for the types of information about patients that EHRs must be able to store and exchange. ONC also develops guidance and resources for the public on health IT topics, including patient record matching. The 21st Century Cures Act included a provision for us to review patient record matching efforts in the context of EHRs, including the efforts of ONC and other stakeholders.[7] We specifically focused on the patient record matching that takes place when

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[3]Ensuring appropriate matching is necessary to protect security and privacy with regard to EHRs. Inaccurate matching could lead to the inappropriate disclosure of medical information, such as if laboratory results are shared with the wrong patient.

[4]See ECRI Institute, *PSO Deep Dive: Patient Identification*, *vol. 1* (Aug. 2016). ECRI Institute is an independent nonprofit organization whose mission is to benefit patient care by promoting the highest standards of safety, quality, and cost-effectiveness in health care through research, publications, education, and consultation.

[5]See, for example, GAO, *Electronic Health Records: HHS Strategy to Address Information Exchange Challenges Lacks Specific Prioritized Actions and Milestones,* GAO-14-242 (Washington, D.C.: Mar. 24, 2014) and GAO, *Electronic Health Records: Nonfederal Efforts to Help Achieve Health Information Interoperability,* GAO-15-817 (Washington, D.C.: Sept. 16, 2015).

[6]AHA, *Trendwatch: Sharing Health Information*. A large hospital is one with greater than 300 beds.

[7]Pub. L. No. 114-255, § 4007, 130 Stat. 1033, 1184-1185 (2016).

providers and other entities exchange health information related to the provision of patient care.[8] In this report we describe

1. the patient record matching approaches used by selected stakeholders and related challenges they identified, and

2. efforts to improve patient record matching identified by ONC and selected stakeholders.

To describe the patient record matching approaches used by selected stakeholders and related challenges they identified, we reviewed published reports (including our own past reports) and other documentation about patient record matching, such as ONC's 2014 *Patient Identification and Matching Final Report*.[9] We conducted interviews with relevant stakeholders that we identified through this background research and from input from other stakeholders. Specifically, we interviewed representatives from organizations involved in exchanging health information, including providers such as physician practices and hospitals; health information exchange (HIE) organizations, which facilitate the exchange of health information among providers and other types of organizations, often at a regional level; and health IT vendors.[10] We also interviewed representatives from organizations that represent providers (AHA, the American Medical Association, and the Medical Group Management Association); health information management professionals (the American Health Information Management Association and the College of Health Information Management Executives (CHIME)); HIE organizations (the Strategic Health Information Exchange Collaboration); and health IT vendors (the Electronic Health Records Association), as well as individuals or entities with expertise or experience

[8]For this report, we focused on the accuracy of patient record matching and did not review issues associated with whether such matching—even when accurate—is appropriate or authorized. For example, we did not review how patient record matching relates to a patient's preferences regarding providers' ability to share medical records about his or her medical history and care.

[9]See Genevieve Morris et al., *Patient Identification and Matching Final Report*, a report prepared at the request of ONC (Feb. 7, 2014).

[10]We selected seven providers, based on input from stakeholders, that varied by type and size (three physician practices, two hospitals, and two health systems). We selected four regional HIE organizations, based on input from stakeholders, that varied in geographic region and patient record matching experience (in terms of years of operation, number of records exchanged, and matching approach). We also selected one national HIE organization. We selected two health IT vendors that produce EHR systems, as well as two other health IT vendors that produce other products relevant to patient record matching, based on stakeholder input.

with patient record matching issues. In addition, we interviewed officials from ONC and HHS's Agency for Healthcare Research and Quality. In total, we conducted 35 interviews with stakeholders. The information we obtained from these stakeholders is not generalizable to the experiences of other health providers, organizations, vendors, and other stakeholders regarding patient matching approaches.

To describe efforts to improve patient record matching identified by ONC and selected stakeholders, we reviewed ONC documents and reports that describe the agency's efforts related to patient record matching. For example, we reviewed ONC's 2014 *Patient Identification and Matching Final Report*, ONC's *Interoperability Roadmap*, as well as documentation of recent ONC studies related to patient record matching. In addition, we discussed patient record matching efforts with the stakeholders mentioned previously. We supplemented those discussions by conducting two additional interviews with stakeholders about their efforts to improve patient record matching; we identified these stakeholders through background research and input from other stakeholders.[11] In addition, we reviewed documentation related to those stakeholders' efforts. The information we obtained from stakeholders is not generalizable to the experiences or views of other stakeholders regarding efforts to improve patient record matching.

We conducted this performance audit from November 2017 to January 2019 in accordance with generally accepted government auditing standards. Those standards require that we plan and perform the audit to obtain sufficient, appropriate evidence to provide a reasonable basis for our findings and conclusions based on our audit objectives. We believe that the evidence obtained provides a reasonable basis for our findings and conclusions based on our audit objectives.

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[11]Specifically, during one background interview, stakeholders told us about a group of providers that collaborated to improve patient record matching. We conducted an interview with representatives from three hospitals that participated in that effort. Those representatives told us about another group of providers that collaborated to improve patient record matching; we then conducted an interview with representatives from one of the hospitals that participated in that effort.

Background

Patient Record Matching

Patient record matching is the process of comparing patient information in different health records to determine if the records refer to the same patient. This matching generally relies on the use of demographic information such as a patient's name, date of birth (DOB), sex, Social Security number (SSN), or address, among other information.[12]

Many types of stakeholders can be involved in patient record matching. Examples of stakeholders include the following:

- Health care providers, such as physicians, hospitals, and their staffs may receive records from another provider that need to be matched to existing patient records. When treating a new patient, for example, a provider might obtain records from other providers that previously cared for the patient. Similarly, a provider caring for a patient with multiple chronic conditions (e.g., heart disease, diabetes) might obtain information from other providers that are also caring for the patient. The providers must ensure that the records they obtain from other providers are matched to the correct patient and therefore properly linked with the patient's existing records.

- HIE organizations match patient records as part of their role in facilitating the electronic exchange of health information among hospitals, physicians, and other organizations. They can offer a range of services, such as allowing providers to access the medical records for a patient who has received care from other providers in the HIE organization's network. They may also obtain information from hospitals when a patient is admitted or discharged, and they then notify the patient's other providers when those events occur. In these cases, HIE organizations must accurately match records from multiple organizations to the correct patient. HIE organizations generally serve a specific state or region and match records among a network of local or state-wide providers and other entities; some, however, operate nationally.

- Health IT vendors also play a role in matching patient records. Some IT vendors, for example, provide record matching tools as part of their

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[12]In this report, the term "demographic information" refers to both the demographic and personally identifiable information used in patient record matching. Demographic information may include sex or age. Personally identifiable information may include name, date and place of birth, or SSN.

EHR systems; these tools allow providers to electronically search for patient records that are available from other providers that use the same IT vendor. Other IT vendors offer tools that allow providers or HIE organizations to leverage third-party data, such as credit-bureau data, when matching patients' medical records.

Importance of Accurate Patient Record Matching

ONC and others have reported that the ability to accurately match patient medical records across different providers is a critical part of effective health information exchange, which can benefit patient care. For example, accurate record matching can help ensure that providers have current information about patients' laboratory or other diagnostic test results; their medications; their diagnosed medical conditions, such as allergies; and their family medical histories.[13]

In contrast, when a patient's records are not accurately matched, it can adversely affect the patient's care. There are two ways in which records can fail to be accurately matched.

- **Records for different patients are mistakenly matched.** When medical records for different patients are mistakenly matched (known as a "false positive"), it can present safety and privacy concerns for patients. For example, a provider may inadvertently use information about the wrong patient, such as diagnoses or medication lists, to make clinical decisions. In addition, if the wrong patient's medical information is added to a patient's record, it could result in disclosure of that information to a provider or patient who is not authorized to view it.[14]

- **Records for the same patient are not matched.** When medical records for the same patient are not matched (known as a "false negative"), it can affect patient care. For example, providers may not have access to a relevant part of the patient's medical history—such as current allergies or prior diagnostic test results—which could help

[13]See, for example, The Pew Charitable Trusts, *Enhanced Patient Matching Is Critical to Achieving Full Promise of Digital Health Records* (Oct. 2, 2018); The Sequoia Project, *A Framework for Cross-Organizational Patient Identity Management* (May 30, 2018); and Genevieve Morris et al., *Patient Identification and Matching*.

[14]For example, a patient who requested a copy of his or her medical records or logged in to an electronic patient portal to view records could see the medical information about the other person. Similarly, a provider would be able to view medical information about a patient who is not under his or her care.

them avoid adverse events and also provide more efficient care, such as by not repeating laboratory tests already conducted.

ONC Responsibilities and Patient Record Matching

ONC leads federal efforts to promote interoperability, including setting requirements for the information that EHRs and other health IT systems should collect.[15] ONC developed certification criteria for EHRs and other health IT systems that include the ability for health IT systems to capture and exchange various types of information, including clinical data such as information on patients' allergies, as well as the patient's name, sex, and date of birth.[16] ONC also compiles an Interoperability Standards Advisory, which suggests certain standards that developers should incorporate into their products.[17]

Stakeholders Described Patient Record Matching Approaches and Associated Challenges

[15]EHR interoperability refers to the ability of EHR systems to exchange electronic health information with other systems and process the information without special effort on the part of the user, such as a health care provider. When EHR systems are interoperable, information can be exchanged—sent from one provider to another—and then seamlessly integrated into the receiving provider's EHR system, allowing the provider to use that health information to inform clinical care.

[16]For information on this voluntary ONC Health IT Certification Program, including requirements related to demographic and other data, see https://www.healthit.gov/topic/certification-ehrs/about-onc-health-it-certification-program (accessed Dec. 21, 2018).

[17]The Interoperability Standards Advisory process represents the model by which ONC will coordinate the identification, assessment, and public awareness of interoperability standards and implementation specifications that can be used by the health care industry to address specific interoperability needs including, but not limited to, interoperability for clinical, public health, and research purposes. ONC encourages all stakeholders to implement and use the standards and implementation specifications identified in the Interoperability Standards Advisory as applicable to the specific interoperability needs they seek to address.

Providers and HIE Organizations Described Using Both Manual and Automated Approaches to Patient Record Matching

All seven provider representatives we interviewed described manual matching as one of the ways that they match patient records when exchanging health information with other providers. With manual matching, an individual reviews a medical record in order to match it to the correct patient. For example, an outpatient practice representative said that to match records that the practice receives by fax, a staff member must manually review information such as name and DOB to identify the correct patient and add the new information to the correct patient's electronic record. All of the provider representatives we interviewed told us that they receive health records from other providers by fax.

Six provider representatives told us they also use health IT tools to help automatically identify and match patients' records stored in other data systems.[18] These tools generally use algorithms that compare demographic data in a patient's separate electronic records.[19] For example, representatives from four of the six providers told us they used a module offered by their EHR system vendor to match records and exchange information with other providers that use the same vendor's EHR systems.[20] The module includes an algorithm that compares patients' demographic information and, if the information in two or more records is identical or very similar, can automatically link the records. Automated matching can also involve some degree of manual review, as algorithms can identify potential matches by providing information about the likelihood that two records with similar information refer to the same individual. Afterwards, provider staff manually review the demographic information in the records and assess whether these potentially matching records should be linked as belonging to the same patient.

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[18]The remaining provider representative said that her practice rarely exchanges health information electronically and therefore relies on manual patient record matching.

[19]Algorithms that can be used to match records vary. For more information about these algorithms, see, for example, The Pew Charitable Trusts, *Enhanced Patient Matching;* The Sequoia Project, *A Framework for Cross-Organizational Patient Identity Management*; and Genevieve Morris et al., *Patient Identification and Matching.*

[20]Another provider's representative said that the provider's EHR vendor enables access to two national HIE networks, which can be used to exchange information with other participants in these networks. Also, another provider's representative told us that the provider uses a regional HIE organization, but noted that electronic exchange is limited.

Representatives from the five HIE organizations we spoke with said they use a range of automated and manual approaches to match patients' records when exchanging information.[21] Representatives from all five of the HIE organizations said that they use software with algorithms to locate and match records using demographic information provided by the providers in their networks. Though these HIE organizations' algorithms vary, they all use name, sex, DOB, and address to match patients' records. Representatives said that when the patients' records contain similar but not identical demographic information, the HIE organizations rely on staff or additional software to review potential matches and determine whether the records belong to the same patient. For example, one HIE organization representative said that his organization leverages third-party data, such as credit databases that store past names or addresses, to update demographic information for records that cannot be matched automatically.

When describing their approaches to patient record matching when exchanging information, six of the seven provider representatives said that they sometimes used HIE organizations to exchange and match records. However, none of them relied on HIE organizations as their primary way to match records and exchange health information. Five of the provider representatives we spoke with, including one provider that does not participate in an HIE organization, noted that they only exchange health information with a few providers. They explained that they were able to connect to these providers in ways other than through an HIE organization.

According to stakeholders we interviewed, it is difficult to determine the accuracy of the health IT tools used to match patients' medical records automatically. While the algorithms typically match records belonging to a patient and identify potential matches that need to be manually reviewed, users of these algorithms do not know how many matches the algorithm

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[21]The HIE organizations we spoke with served a large number of patients and exchanged large numbers of records; according to representatives, the HIE organizations served from 827,000 to 17.8 million unique patients and exchanged from 35,000 to 1.2 million records each month.

may have failed to make.[22] These stakeholders expressed concern that it is not possible to assess the accuracy of algorithms without independent testing to identify matches that the algorithm may have missed. HHS stated that the proprietary nature of many patient matching algorithms makes it difficult to assess their effectiveness.
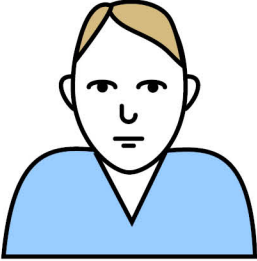
Stakeholders Said That Inaccurate, Incomplete, and Inconsistently Formatted Data Can Pose Challenges for Patient Record Matching

Representatives from providers, HIE organizations, and the other stakeholders we interviewed emphasized the importance of using quality patient demographic data when matching patients' medical records. These stakeholders noted that inaccurate, incomplete, or inconsistently formatted demographic information in patients' medical records can make it challenging to identify and match all the records belonging to a single patient. Figure 1 illustrates how the demographic information for a hypothetical patient can be recorded inaccurately, incompletely, and inconsistently across the patient's providers.

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[22]In 2018, RAND reported that few studies have measured the rates of patient record matching errors or the causes of these errors, and that health care providers do not report matching rates publicly. RAND recommended more research into the causes of record matching errors, the development of methods for health care providers to benchmark their matching rates, and requirements to publicly report matching rates. See Robert S. Rudin et al., *Defining and Evaluating Patient-Empowered Approaches to Improving Record Matching* (Santa Monica, Calif.: RAND Corporation, 2018).

Figure 1: Examples of Data Quality Issues That Can Affect Patient Record Matching

DEMOGRAPHIC INFORMATION[a]

Legal name: Johnathan Michael Smith

Nickname: Mike

Sex: Male

Date Of Birth (DOB): September 7, 1970

Current address: 174 Main Drive Springfield, NV 87064

Current phone: 500-555-5309

Old address: 145 Party Drive Springfield, NV 87064

Email address: mike_smith1@xyz.com

Social Security Number (SSN): 123-45-6789

EXAMPLES OF HOW COLLECTION OF DEMOGRAPHIC INFORMATION CAN VARY ACROSS PROVIDERS

PRIMARY CARE DOCTOR'S RECORD

Name: Johnathan M. Smith
Sex: M
DOB: 07/09/1970
Address: 145 Party Drive Springfield, NV 87064
Phone: 5005555390
Email: mike_smith1@xyz.com
SSN: XXX-XX-6789

Accuracy
• Phone number incorrect
• Address not current

Completeness
• Full middle name not included
• Does not contain full SSN

Formatting
• Sex abbreviated
• Phone number does not contain dashes
• DOB formatted as DD/MM/YYYY

CARDIOLOGIST'S RECORD

Name: Smith Mike
Sex: Male
DOB: 09/07/1970
Address: 174 Main Dr. Springfield, NV 87064
Phone: 500-555-5309
Email: mike_smith1@xyz.com
SSN: Not collected

Accuracy
• Nickname entered rather than legal name

Completeness
• SSN not collected

Formatting
• Street type abbreviated
• Phone number contains dashes
• Last name listed first

ALLERGIST'S RECORD

Name: Jonathan M. Smithe
Sex: UNK
DOB: 09071970
Address: 174 Main Drive Springfield, NV 87064
Phone: 500-555-5309
Email: Not collected
SSN: 999-99-9999

Accuracy
• First and last name spelled incorrectly

Completeness
• Sex, email address, and SSN not collected

Formatting
• Special characters removed from DOB
• SSN missing and denoted with placeholder value

LAB RESULTS RECORD

Name: Smith, Johna.
Sex: 1
DOB: 09/07/1971
Address: 17 Main Drive Springfield, NV 87046
Phone: Not collected
Email: Not collected
SSN: Not collected

Accuracy
• Address entered incorrectly

Completeness
• First name is abbreviated to fit on label
• Phone number, email address, and SSN not collected

Formatting
• Sex coded with numerical variable

Source: GAO analysis. | GAO-19-197

[a]Demographic information refers to both the demographic and personally identifiable information used in patient record matching. Demographic information may include sex or age. Personally identifiable information may include name, date and place of birth, or Social Security number.

Stakeholders described the ways in which providers or their staff can collect inaccurate demographic information from patients. According to stakeholders,

- provider staff sometimes make transcription errors when entering information into electronic records,

- patients do not always provide correct information (e.g., they register with a nickname rather than a legal name), and

- patient demographic information can change, such as when a patient moves to a new address or changes her last name, but this information is not consistently updated in all of the patient's medical records.

Provider representatives identified several reasons that patients' demographic information can be incomplete or contain different data elements across the medical records maintained by multiple providers. In particular, provider representatives explained that providers collect different information from their patients, and health IT systems can collect demographic data differently. Examples include the following:

- Two provider representatives said that their organizations do not collect patients' SSN because many patients choose not to provide that information or the information is not available. However, other provider representatives said they do collect SSNs. A health IT vendor said that the algorithms in its software do not rely on SSN as a key factor for matching records because SSN is not consistently available.

- One provider representative explained that the IT system used by the provider's laboratory does not contain fields for the same demographic information that the provider's EHR system contains. As a result, laboratory results often contain too little information to reliably match records, even if the tests were ordered using complete information.

- One provider representative explained that they do not collect patients' mothers' maiden names, though other organizations collect and use this information for patient matching.

According to stakeholders, the inconsistencies in formatting across medical records can reflect differences in health IT systems or the policies of the health care organization creating the records:

- A 2014 ONC report noted that one health IT system may list addresses in a single field, while another may separate street names from the city and state.[23]

- A 2018 report noted that providers use different standards for recording names with spaces, hyphens, or apostrophes, and that some health IT systems include special characters in phone numbers (i.e., (123) 456-7890), whereas others only allow for numbers (i.e., 1234567890).[24]

- Representatives from one HIE organization explained that providers handle missing data for fields differently; for example, one provider may enter all 9s into an SSN field when it is not available for a patient and another will enter all 0s.

Provider representatives and other stakeholders identified some patient populations for which matching is particularly challenging, due in part to data issues. Three provider representatives said that medical records for newborns often contain temporary names that are not updated with the child's legal name after it is determined, which makes it difficult to locate these records. Further, provider representatives and other stakeholders said that multiple births (e.g., twins) result in record matching challenges, as these children can have the same DOB and address, and may be named similarly. A few provider representatives said that records can be inaccurate across providers for patients from certain nationalities. For example, according to stakeholders, some east-Asian cultures use the "family name" as the first name, and some Hispanic cultures use multiple last names. Another provider representative said that a few times a month, a transgender patient's photo ID lists the wrong gender, yet the organizational policy is to record the gender exactly as it appears on a state-issued photo ID.

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[23]Genevieve Morris et al., *Patient Identification and Matching*.

[24]The Sequoia Project, *A Framework for Cross-Organizational Patient Identity Management.*

Stakeholders Identified Efforts Underway to Improve Patient Record Matching as Well as Additional Efforts ONC and Others Could Undertake

Stakeholders Have Undertaken Efforts to Improve the Demographic Data and Methods Used to Match Records

Officials from ONC, selected provider representatives, and other stakeholders we interviewed described a variety of efforts they have undertaken or are currently undertaking to improve the ability to match patients' medical records accurately. In general, these efforts focus on improving demographic data and improving the methods used for matching. These efforts are discussed in more detail below.

Efforts to Improve Demographic Data Used for Matching

ONC has reported that quality demographic data is important for effectively matching patients' medical records, and in 2017 the agency published the Patient Demographic Data Quality Framework. The Framework is a tool to help providers and other organizations assess their processes for managing data quality and improve the quality of the demographic data they use in matching. It includes, for example, questions that providers can use to identify any gaps in how they manage their demographic data.[25] In 2016, before ONC published the Framework, the agency began a pilot study to assess how the Framework could work in a clinical setting. As part of this pilot study, ONC provided training on demographic data quality to staff from two community health centers, during which it shared best practices for collecting these data.[26] After the

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[25]The questions in the Framework include whether an organization conducts periodic assessments of the selected data sets in accordance with its patient demographic data quality policies and whether it has a communications plan for informing stakeholders about policies and procedures that affect patient demographic data. See ONC, Patient Demographic Data Quality Framework, accessed October 29, 2018, https://www.healthit.gov/playbook/pddq-framework/.

[26]This ONC pilot study was implemented by the Kaiser Permanente Center for Health Research and OCHIN, a nonprofit organization that provides health IT for health care providers. Participating community health centers were recruited through OCHIN. Three centers volunteered for the pilot; one of the centers stopped participating before the study was complete.

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training, researchers who collaborated on the pilot with ONC found that there were improvements at the community health centers in indicators of how they managed data quality.[27] According to ONC officials, this pilot highlighted the effect that data quality and training have on effective patient record matching. In addition, officials said it underscored difficulties in implementing data quality improvement efforts when health care organizations have limited resources and high staff turnover. ONC officials plan to issue a final report on the pilot study; however, they said ONC is not currently planning to assess the impact of the Framework or to conduct future studies on how it works in clinical settings.

Several stakeholders told us they have worked to improve the consistency with which they record and format demographic data in their EHRs. According to ONC officials and hospital representatives, as well as other stakeholders with whom we spoke, implementing common standards for how certain demographic data should be formatted—such as names and addresses—could improve the consistency of data across providers and thus make it easier to match records. Representatives from four hospitals told us that they collaborated with other providers in their regions to implement common standards for recording patients' demographic data. They told us the following:

- In 2017, 23 providers in Texas reached agreement on, and then implemented, standards for how staff should record patients' names, addresses, and other data in order to improve record matching and facilitate health information exchange.[28] We spoke with representatives from three hospitals that were part of this effort, who all told us that the effort resulted in an increased ability to accurately match patients' medical records automatically without the need to manually review the records. (See text box.) For example, representatives from one hospital said that when patient records are not matched automatically or when there are questions about the accuracy of record matching, staff must then conduct a manual review

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[27]For example, one indicator of improvement was a decrease in how often staff created new records for patients who already had an existing EHR record at the clinic.

[28]For example, the providers agreed to enter a patient's legal name in their EHRs and only record a nickname or other form of the name as an alias or alternate name; adopt a standard for entering temporary names for newborns, based on Children's Hospital Association recommendations; and use the U.S. Postal Service's standard for recording addresses. The U.S. Postal Service has developed standards for both the content and format of addresses.

to resolve the issue. They said that they have seen a significant decrease in the need for those manual reviews since implementing the data standards. Representatives from all three hospitals estimated that the amount of manual review to resolve matching issues and match incoming records to the right patient had decreased by about 90 percent.[29] Representatives from one hospital added that they are now better able to prevent records from being matched to the wrong patient.

• One children's hospital in California worked with other local hospitals in recent years to implement a standard for how staff should record a temporary name for newborns who do not have their own name at birth.[30] According to representatives from this hospital, after implementing this standard, clinical staff are able to more easily match patients' records and therefore have access to real-time information on the care newborns received in other hospitals.

Lessons Learned from One Regional Effort to Standardize Patient Demographic Data across Multiple Providers

In 2017, 23 providers in Texas implemented agreed-upon standards for capturing patient name, address, and other data. Representatives from three participating hospitals shared with us lessons for others interested in standardizing data, such as:

• Allow sufficient time to get buy-in from staff and test for any downstream effects on other IT systems;

• Communicate the benefits of standardizing data to clinical and administrative staff; and

• Train staff on how to enter data, and then assess compliance to identify any opportunities for improvement.

Source: GAO summary of provider information. | GAO-19-197.

In a related 2017 effort, Pew Charitable Trusts sponsored a study to measure how standardizing specific types of patient demographic data could improve patient record matching. As part of this study, researchers used four data sets to test the effect that standardizing patient names, addresses, DOBs, telephone numbers, and SSNs had on record

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[29]Representatives from all three hospitals added that they have been exchanging more records electronically and that implementing the data standards was one factor that contributed to the increase in electronic records exchange.

[30]These hospitals adopted a standard that uses the mother's name and the child's sex and birth order (if applicable) to record a temporary name.

matching accuracy.[31] As of September 2018, the full findings from this study had not been published; however, according to Pew, the findings indicated that standardizing some demographic data, such as address, shows promise for increasing the likelihood that patients' records will be matched.[32]

Two stakeholders we spoke with have examined ways to boost patients' ability to electronically share data with their providers using smartphone applications or other tools. According to these stakeholders, these types of tools could improve the accuracy of the demographic data providers receive from patients, reduce manual data entry errors by providers' staff, and allow patients to update their information as changes occur, such as if they move.

- In 2015, the Workgroup for Electronic Data Interchange (WEDI) initiated a "Virtual Clipboard" project to explore the development of a mobile tool to automate the transmission of demographic, insurance, and clinical information to providers.[33] WEDI representatives told us that they had engaged with stakeholders such as providers, vendors, patient advocates, and health plans about the potential benefits of such a tool, but had not yet identified organizations prepared to move forward with developing specific applications.

- In 2017, Pew Charitable Trusts funded a RAND study on "patient-empowered" patient record matching approaches—specifically, to identify ways that patients could play an additional role in patient record matching and to select a promising solution for further

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[31]For example, researchers standardized last names by applying a rule from the Council for Affordable Quality Healthcare, a nonprofit alliance of health plans and trade associations; applying this rule led to removing special characters (such as apostrophes) and suffixes, such as "Jr." To standardize addresses, researchers applied U.S. Postal Service certified address standardization rules; in applying these rules they corrected errors that would make an address undeliverable by the U.S. Post Office, and spelled out abbreviations, such as changing "blvd" to "Boulevard." See The Pew Charitable Trusts, *Enhanced Patient Matching*.

[32]Separately, Pew found that in addition to standardizing certain commonly used demographic data elements, other data elements that appear to be increasingly collected, such as email addresses, could also be used for patient matching. See The Pew Charitable Trusts, *Enhanced Patient Matching*.

[33]WEDI is a nonprofit organization that focuses on the use of health IT to improve healthcare information exchange. Formed in 1991 by the Secretary of HHS. WEDI is a coalition comprising doctors, hospitals, and other health care providers; health plans; vendors; government officials; and other health care stakeholders.

development. In its August 2018 report, RAND proposed a solution in which patients could verify their mobile phone number and other identifying information with providers and then use a smartphone application to share this information with providers.[34]

Representatives from both WEDI and Pew told us that, when developing these types of tools, it is important to consider the practical implications for the providers that would need to be able to accept data in this way. For example, Pew representatives said that it would be important to understand whether these tools present any workflow challenges in provider settings, such as with any IT tools that providers would need to access the data stored via smartphone applications, or with the steps needed to incorporate that data into their EHR systems. Representatives from both organizations also noted that not all patients would be willing or able to use these types of tools to share data with providers. In addition, RAND reported on a range of security considerations for these types of tools. For example, RAND noted that a smartphone app that gathers health data—like its proposed patient matching solution—would introduce risk because it would contain private demographic and health information and would therefore be a target for individuals looking to steal data.[35]

Assessing and Improving Matching Methods

Officials from ONC and other stakeholders described various efforts to assess and improve the effectiveness of the methods used in matching patients' medical records. These efforts include hosting competitions, conducting studies, and issuing guidance. For example, ONC officials described the following two efforts to improve patient record matching methods:

- In 2017, ONC held a Patient Matching Algorithm Challenge in which participants competed to develop an algorithm that most accurately matched patient records in a test data set. According to ONC officials, the goals of the exercise were to bring about greater transparency on the performance of existing patient record matching algorithms, spur the adoption of performance metrics for algorithm developers, and improve other aspects of patient record matching, such as resolving

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[34]See Robert S. Rudin et al, *Defining and Evaluating Patient-Empowered Approaches*. RAND evaluated 10 patient-empowered matching approaches, such as having patients verify their identity information or their record matches; using biometric data, such as patients' fingerprints; and expanding the use of existing government-issued identifiers, such as driver's licenses. See also The Pew Charitable Trusts, *Enhanced Patient Matching*, for further discussion of patient-empowered approaches to matching.

[35]See Robert S. Rudin et al, *Defining and Evaluating Patient-Empowered Approaches*.

duplicate patient records. Over 140 teams used varying methods to match patient records using an ONC-provided test data set, and ONC selected six winning submissions based on various measures of matching accuracy. As of July 2018, ONC was analyzing data from the challenge to learn more about algorithm performance. Officials told us that the challenge highlighted limitations of commonly used matching algorithms and demonstrated that extensive manual review is often needed to accurately match patients' medical records. ONC officials told also us they plan to publish a report on their analysis of the challenge data.

- In 2017, ONC also conducted a patient record matching Gold Standard and Algorithm Testing pilot study. According to ONC officials, there is no widely used standard for assessing the accuracy of patient record matching algorithms, so the pilot was intended to create a data set with known duplicate records (that is, multiple records for the same individual) and then use it to evaluate how well a commonly-used algorithm matched those records. ONC officials told us that the pilot demonstrated how much effort is needed to evaluate the matching algorithms providers and others use, as well as the importance of using standard metrics to assess matching accuracy.[36] ONC expects to issue a final report on the results of the study.

Among the examples other stakeholders described were the following efforts to improve patient record matching methods:

- In 2018, the Sequoia Project published *A Framework for Cross-Organizational Patient Identity Management* to provide guidance to help providers and other types of health care entities improve patient record matching across organizations.[37] The report, for example, suggests ways organizations can improve their matching algorithms, and it identifies practices that organizations can use to improve how they use patient demographic data and other information when

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[36]The pilot used several metrics to gauge how well the algorithm identified all records that pertained to a patient, as well as whether algorithms incorrectly matched a patient to the wrong record.

[37]The Sequoia Project, *A Framework for Cross-Organizational Patient Identity Management* .The Sequoia Project is a nonprofit public-private collaborative chartered to advance the implementation of secure, interoperable nationwide health data sharing. This Framework was developed by a workgroup comprising industry, academic, standards development, and government experts.

matching records.[38] Representatives from the Sequoia Project told us they plan to speak with organizations that have voluntarily adopted this guidance to learn how doing so affects record matching. These representatives also said they are looking into how ONC's Patient Demographic Data Quality Framework relates to their own framework, as it may be beneficial if there were a way to link these two efforts.

- HHS's Agency for Healthcare Research and Quality funded a study that began in 2017 to evaluate patient record matching approaches, with the goal of identifying different approaches to improving the accuracy of patient record matching algorithms.[39] As part of this ongoing study, researchers are measuring how different changes to matching methods—including changes that have and have not been recommended or evaluated previously—improve matching accuracy.[40] The study is expected to run through 2022. According to researchers, their initial work tested the use of different combinations of demographic data elements, among other things. They identified a modest improvement in the accuracy of matching algorithms, and determined that further research was needed.

- In 2016, CHIME sponsored a National Patient ID Challenge that offered a monetary award for the development of a tool that matched patients' medical records with 100 percent accuracy.[41] Although the challenge was not specific to matching patient records across providers, several CHIME members who were involved with the challenge told us that they hoped to identify a patient record matching approach that could be widely adopted and easily integrated into existing EHR and HIE platforms without significant cost. They noted the challenge also was an opportunity to encourage organizations to

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[38]These practices include, for example, how to handle temporary or default values, which may be present in patient demographic data when the actual information is not readily available from the patient. The report also suggested that matching algorithms use "case insensitive matching"—that is, matching that allows data to be recorded in either upper case or lower case.

[39]See U.S. Department of Health and Human Services, Agency for Healthcare Research and Quality, Enhancing Patient Matching in Support of Operational Health Information Exchange (Indiana), accessed August 16, 2018, https://healthit.ahrq.gov/ahrq-funded-projects/enhancing-patient-matching-support-operational-health-information-exchange.

[40]Researchers plan to test a variety of methods for adjusting and using demographic data, such as standardizing and normalizing first names, last names, addresses, and SSNs; identifying nicknames; and imputing gender and ethnicity.

[41]CHIME is a professional organization for Chief Information Officers and other healthcare IT leaders.

develop effective matching methods, and to identify a matching method that did not rely solely on demographic patient information.[42] CHIME assessed submissions from a range of organizations, but suspended the challenge in November 2017, reporting that the effort did not achieve the results it had sought. CHIME members said that the challenge nonetheless helped draw attention to patient record matching issues.

In addition, several stakeholders have worked to improve the matching of medical records specifically for newborns and multiple-birth siblings such as twins, for whom matching can be particularly challenging:

- Representatives we spoke with from one children's hospital told us they have implemented indicators in their EHR to highlight when a child has a twin or other multiple-birth sibling, so that staff know that another child has similar demographic information. Representatives said that this helps prevent medical records from one child being incorrectly matched with the medical records of a sibling.[43] In 2017, this hospital began working with its health IT vendor to explore the broader use of a multiple birth indicator to improve the probability of accurate matching for the multiple birth population between different vendors' EHRs. The representatives said that while there is a standard indicator that can be used for multiple births, many organizations are not aware of it.[44]

- In addition, one researcher we spoke with is studying how using information such as physicians' names and parents' demographic data could help address record matching challenges for newborns. As noted earlier, one children's hospital worked with other local hospitals

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[42]The CHIME members noted the difficulties that stem from relying on demographic data for matching, such as data that is inaccurate or changes over time.

[43]Representatives from this hospital had previously worked with three vendors with experience matching patient records and found during the testing (pre-implementation) phase that the vendors had mistakenly determined that records for some children from multiple births were records for the same child—rather than records for siblings born at the same time.

[44]The representatives said they use a standard multiple birth indicator developed by Health Level 7 International for patient identification within their EHR. Health Level 7 International is an organization that develops standards for exchanging electronic health information. These standards define how information is packaged and communicated from one entity to another, setting the language, structure, and data types required for integration between systems.

to implement a standard for how staff record a temporary name for newborns.[45]

Stakeholders Identified Additional Efforts That ONC or Others Could Undertake to Improve Patient Record Matching

Stakeholders we spoke with said more could be done to improve the ability to accurately match patients' medical records. The stakeholders identified several efforts that could improve matching, and had varying views on the roles ONC and others should play in these efforts. Among the examples of efforts stakeholders identified that could improve matching were implementing common standards for demographic data; developing a data set to test the accuracy of matching methods; sharing best practices and other resources; implementing a national unique patient identifier; and developing a public-private collaboration effort to improve patient record matching. Multiple stakeholders noted that no single effort would be sufficient to improve matching, given the factors that contribute to matching challenges. These potential additional efforts are described below.

Implementing Common Standards for Recording Patients' Demographic Data in Health IT Systems

Several stakeholders told us that implementing common standards for recording patients' demographic data in health IT systems could improve the ability of providers to match patients' medical records. Stakeholders said that if providers implemented such standards, it could increase the extent to which they collect the same types of demographic data or use the same format for names and addresses as other providers, for example. However, stakeholders had differing views on how to reach agreement on and implement common standards among providers, as well as how feasible it would be to do so. Some said it would be helpful if ONC established requirements regarding demographic data—such as the types of data collected, and how it is formatted—potentially through the EHR certification process.[46] In contrast, other stakeholders saw an

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[45]The Joint Commission—an independent, not-for-profit organization that accredits and certifies health care organizations and programs in the United States—recently created a "distinct newborn identification requirement" for all Joint Commission-accredited hospitals and critical access hospitals that provide labor and delivery services. The requirement, effective January 1, 2019, is intended to provide more distinguishable naming methods for this population and to improve the quality and safety of care for newborns during their hospital stay following delivery. See https://www.jointcommission.org/r3_report_issue_17_distinct_newborn_identification_requirement/ (accessed Dec. 21, 2018).

[46]ONC manages the Health IT Certification Program, which certifies EHR systems that meet certain requirements. For example, certified EHR systems must have the ability to capture and exchange clinical data such as patients' allergies, as well as the patient's name, sex, and DOB.

opportunity for industry organizations to voluntarily agree to implement standards for demographic data. Some stakeholders advocated for EHR vendors to take steps to standardize the data their products allow providers to collect. A representative with one hospital said that having demographic data standards built into EHRs could minimize the amount of time needed to train staff on how to format the data they collect—and then to monitor whether they format the data correctly. A number of stakeholders said that ONC could play a role in getting industry groups to agree on and implement common data standards. ONC officials noted that as part of their role in coordinating health IT efforts, they have worked with industry groups in a number of ways and expect to continue their coordination efforts.[47]

Some stakeholders we spoke with told us that efforts to implement common demographic standards could face challenges, such as the following:

• Several said it could be difficult to reach consensus across various industry organizations on what standards to adopt and implement.

• Multiple stakeholders noted that patient preferences could affect the effectiveness of efforts to standardize data. Patients might not always be willing to provide some types of data even if providers wanted to collect it. For example, one provider noted that patients may want to use their middle name instead of their legal name.[48]

• Some stakeholders said it could be time-intensive for providers to train their staff on how to collect data in accordance with standards, or that staff might not always follow the standards. For example, a representative from one hospital that implemented demographic standards told us that they continuously train staff and perform audits to ensure that staff follow those standards.

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[47]ONC officials noted, for example, that they had worked to facilitate voluntary industry engagement through its Interoperability Standards Advisory and other public venues. They added that the agency focuses on the assessment and identification of standards for interoperability, including those that facilitate accurate patient matching, as illustrated in the Interoperability Standards Advisory. As noted earlier, ONC's Interoperability Standards Advisory suggests certain standards that developers should incorporate into their products.

[48]For example, one hospital we spoke with adopted a standard for recording newborns' names that did not incorporate the mother's maiden name, due to objections from one of their partner hospitals about doing so.

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- Some said that EHR systems differ in how they allow staff to record demographic data, which can affect providers' ability to implement standards. Some stakeholders said it can be costly for providers to update or upgrade their EHRs.

- Stakeholders cited other potential limitations of data standardization efforts. Several, for example, said that standardizing data would not prevent inaccurate or outdated data. In addition, some stakeholders did not think that data standardization would yield significant improvements.

Developing a Data Set to Test the Accuracy of Methods Used to Match Patients' Medical Records

Several stakeholders told us that developing a standard data set that organizations could use to evaluate matching methods would be helpful. Stakeholders noted that such a data set would allow health IT vendors, providers, or others to assess matching methods independently (instead of relying on vendors' reported accuracy rates, for example) and in a standardized way (by using the same data source). While stakeholders did not always specify who should develop such a data set, an official from one stakeholder involved with patient record matching and data sharing efforts said that the most useful thing ONC could do to address patient record matching would be to develop a master data set to allow testing in a uniform way. This official added that without a way to accurately and uniformly test patient record matching methods, efforts to improve patient record matching are hindered. A number of stakeholders did not specifically mention the utility of a data set, but nonetheless highlighted the importance of testing how well matching methods work.

For its part, ONC officials said that the lack of a data set for evaluating matching methods is a challenge to efforts to improve matching, and that developing such a data set would be difficult. They noted that the agency's 2017 Patient Matching Algorithm Challenge had highlighted the difficulties of creating a test data set that closely mimics real world patient data and that could be used to assess the accuracy of matching algorithms. ONC officials cited a number of challenges to developing one test data set for assessing a range of patient matching algorithms. For example, they said the data set would need to be very large; would require an extensive and expensive effort to develop; could be difficult to implement from a practical perspective; and that, because data varies widely across patient populations and organizations, might have limited application for assessing algorithms that are designed to match specific

data sets.[49] HHS also stated that the development of a data set would need to include a "key" of known duplicate patient records—that is, an indicator of which records in the data set should be matched to the same individual.

Sharing Best Practices and Other Resources Used in Matching Patients' Medical Records

According to a number of stakeholders we spoke with, more could be done to encourage the sharing of best practices and other patient record matching resources. For example, representatives from some HIEs said it would be beneficial to bring organizations together to share lessons learned and collaborate on best practices for using patient data to match records. Representatives from one industry association noted that disseminating information on patient matching errors could help organizations better understand the extent of matching errors and what causes them; for example, if information were shared about whether certain data elements are more likely to cause matching errors or problems, then organizations could work to prevent the errors or problems related to those data elements. A few stakeholders said that efforts to identify and share effective matching algorithms could expand resources to a broader range of providers. While stakeholders did not always specify who they thought should identify and share matching resources, several stakeholders saw the potential for ONC to play a role in these types of efforts. For example, representatives from one industry association said that ONC could provide information about the types of identifiers that could be used to facilitate matching, such as cell phone numbers or driver's license numbers. These representatives also said that ONC could provide information on how to address matching patient records for children and other individuals who might not have those types of identifiers. ONC officials noted that they have shared information and resources about patient matching in a number of ways, such as through the agency's Patient Demographic Data Quality Framework. They added that other organizations, such as the Sequoia Project and Pew Charitable Trusts, have worked to communicate best practices in this area.

Implementing a National Unique Patient Identifier

A number of stakeholders noted that implementing a new national, unique patient identifier specifically for use in health care settings could improve the ability to match patients' medical records. For example, having a new unique number assigned to an individual would reduce the reliance on demographic data for record matching, according to several stakeholders.

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[49]ONC officials noted that many algorithms are extensively and finely "tuned" to the population of data for which they are used, to maximize their performance.

However, stakeholders had differing views on the potential benefits and feasibility of implementing a new unique patient identifier for health care:

- Some stakeholders said that it is unlikely that any new identifier could be implemented nationwide; they cited reasons such as the prohibition on federal funds being used to develop a national unique health care identifier, as well as potential privacy concerns.[50]

- Multiple stakeholders cited potential limitations to using a national patient identifier, noting for example that—as with SSNs[51]—patients may not be willing to share their identifier, and identifiers could still be subject to manual data entry errors, data breaches, or fraud.[52]

- Some stakeholders said that a unique identifier would be the most effective way to improve matching. However, others said they did not believe a new identifier was needed, or did not think a new identifier would significantly improve matching, given the potential limitations.

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[50]HHS stated that, since fiscal year 1999, Congress has prohibited the implementation of a national patient identifier. The restriction, first enacted under the Omnibus Consolidated and Emergency Supplemental Appropriations Act of 1999, prohibits HHS from using any funds to promulgate or adopt any final standard providing for, or providing for the assignment of, a unique health identifier for an individual until legislation is enacted specifically approving the standard. See, Department of Defense and Labor, Health and Human Services, and Education Appropriations Act, 2019 and Continuing Appropriations Act, 2019, Pub. L. No. 115-245, div. B, tit. V, § 510, 132 Stat. 2981 (2018). In regard to patient matching, representatives from one HIE, for example, said that patients would likely have concerns about their privacy, such as if their identification number was compromised.

[51]The SSN is an example of a unique identifier. Identity thieves find SSNs valuable because they are the identifying link that can connect an individual's personally identifiable information across many agencies, information systems, and databases. Significant breaches have occurred within the federal government that have resulted in the unauthorized disclosure of millions of SSNs. See GAO, *Social Security Numbers: OMB Actions Needed to Strengthen Federal Efforts to Limit Identity Theft Risks by Reducing Collection, Use, and Display*, GAO-17-553 (Washington, D.C.: July 25, 2017).

[52]Pew Charitable Trusts held focus groups to gauge individuals' views of using unique identifiers to improve patient record matching. Participants were not in favor of a unique number, citing factors such as having to remember the number and the number being susceptible to theft. Participants supported using biometrics—the use of physical characteristics to identify individuals, such as fingerprint and palm vein scans. Pew reported that biometrics offer opportunities to improve matching, but their use would require significant protections for patients' biometric information; low-cost ways to adopt scanning technology in hospitals and clinics; and agreement among hospitals and technology developers on standards for how biometrics would be used. See The Pew Charitable Trusts, *Enhanced Patient Matching.*

- HHS stated that health care systems currently rely on a number of identifiers to match patient records and that a new government-generated identifier would improve matching only if other technical and non-technical challenges were solved before it was implemented. The creation, transmission, and capture of a single national patient identifier across many systems could take decades and would encounter implementation difficulties, according to HHS.

In addition, a few stakeholders said that patients might be willing to voluntarily obtain a unique identifier to use across health care settings if one were available. A representative from one provider association, for example, said that people with chronic conditions who obtain care from multiple providers might opt to obtain a unique identifier, if available, to help match their records. In its 2018 report on patient-empowered approaches to matching, RAND described various considerations for implementing a voluntary unique identifier issued by a non-federal entity. The report cited, for example, one organization's work to develop a tool to allow health care providers to offer patients a unique identifier.[53] RAND stated that although this solution would greatly improve matching if adopted, there is uncertainty that providers or patients would adopt it. Representatives from the organization that developed this tool told us that they had tested it in one location, but that it had not yet been adopted by providers.

Developing a Public-Private Collaboration Effort to Improve Patient Record Matching

Multiple stakeholders we spoke with saw a need for a collaborative public-private effort to help identify and implement efforts to improve patient record matching. For example, several stakeholders saw a specific need for a national strategy or approach for addressing patient record matching issues. Representatives from the Pew Charitable Trusts, for example, stated that a national strategy—led by the private sector, with the federal government providing support—could help reach

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[53]Specifically, RAND described an identifier-based matching approach supported by Global Patient Identifiers, Inc. Under the approach, health care providers' staff would be responsible for issuing 32-digit identifiers to patients. In a typical case, the staff would offer a new identifier to a patient who did not yet have one. If the patient wanted an identifier, the provider would first take steps to verify the patient's identify, and would then give the patient an identifier issued by a separate service. See Robert S. Rudin et al., *Defining and Evaluating Patient-Empowered Approaches*.

consensus on ways to improve matching.[54] In addition, one researcher said that ONC should help facilitate a strategy for addressing patient record matching at the provider, vendor, and national levels—and that it would be beneficial for ONC to foster collaboration among private sector organizations to address matching issues. More generally, representatives from several provider associations stated that ONC could play an important role by convening stakeholders to identify ways to improve patient record matching. As noted earlier, some stakeholders said that ONC could help industry groups agree on common data standards for EHRs. While some stakeholders we spoke with said that ONC should collaborate by supporting private-sector efforts to improve matching instead of directing those efforts, others said that ONC could potentially play more of a leadership role. Representatives from one HIE, for example, said that ONC could lead an overall effort to improve patient record matching and that private-sector organizations could lead specific actions within that larger effort.[55]

For their part, ONC officials said that public and private stakeholders should play a role in efforts to improve patient record matching. According to ONC officials, while the agency does not have sufficient resources to support broad implementation of efforts to improve patient record

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[54]In 2017, Pew Charitable Trusts convened about two dozen patient record matching experts to identify the characteristics that a national patient record matching strategy should include. Subsequently, Pew representatives and about a dozen of those experts made recommendations for such a strategy. For example, they recommended that a "neutral coordinating organization with balanced stakeholder representation" should manage the development of a national strategy and stated that ONC could provide support by updating its certification criteria to include best practices and by evaluating how to measure matching between organizations. See Torkzadeh, R. et al. "Advancing a National Patient Matching Strategy," *Journal of AHIMA*, 89, no. 7 (July-August 2018) and The Pew Charitable Trusts, *Enhanced Patient Matching.*

[55]Several stakeholders noted that ONC efforts should consider the patient record matching needs of smaller providers, as well as the role that practice management health IT systems (which can be separate from EHRs) play in collecting patient demographic data.

matching, ONC has collaborated with other stakeholders on various patient record matching issues.[56]

- ONC's August 2018 Interoperability Forum included a "patient matching track" where industry stakeholders, such as providers, health IT vendors, and researchers, discussed matching challenges and potential solutions.[57] According to ONC officials, this track covered topics such as patient-empowered solutions to matching, including smartphone applications; issues when matching patient medical records across organizations; the development of consensus on patient matching definitions and metrics; and issues when matching records for pediatric patients. The outcomes of this track, according to ONC officials, were increased awareness of a range of patient matching issues; information sharing among speakers and participants; and an opportunity to network and potentially collaborate with individuals on patient matching issues. ONC officials told us that a takeaway for them was that while various approaches to patient matching—including technical approaches such as biometrics and referential matching; efforts regarding unique identifiers; and non-technical approaches such as data quality improvement efforts—may enhance the capacity for matching, additional research is needed.[58]

- ONC participated in the Sequoia Project's development of that organization's *Framework for Cross-Organizational Patient Identity*

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[56]When discussing ONC's role in improving the ability to match patients' records, ONC officials said that the agency's current priorities are to increase interoperability as called for in the 21st Century Cures Act, and to reduce clinician burden. In addition, ONC officials noted that if resources were available, they would conduct additional research on the factors that make matching challenging—such as the quality of demographic data and the difficulties assessing the accuracy of matching algorithms—and explore additional methods for improving matching accuracy. ONC officials told us that patient matching is necessary to and supportive of the agency's priorities, and that issues associated with accurate patient matching are part of the context for issues the agency is focusing on. These officials said they view patient matching as a topic that requires ONC investment that is commensurate with the context in which it is raised and in consideration of other private sector activities, to avoid duplicating efforts.

[57]These types of ONC forums are a venue for ONC, federal partners, and industry organizations to discuss interoperability issues, according to the agency.

[58]Referential matching is the use of third-party data from non-health care sources, such as credit bureaus, to assist with matching. In its 2018 report, The Pew Charitable Trusts reported that referential matching has the potential to improve matching, but noted challenges such as patient and provider reservations about this method and limitations in its usefulness for children and other populations. See The Pew Charitable Trusts, *Enhanced Patient Matching.*

Management. During the 2018 Interoperability Forum, ONC officials and Sequoia Project representatives presented together about developing consensus on patient record matching definitions and metrics. They discussed definitions outlined in the Framework and encouraged participants to work toward consensus and transparency when measuring and reporting matching metrics, such as by forming local and national workgroups, ONC officials said.

Looking forward, ONC and some stakeholders said that the agency's current effort to establish a national framework for exchanging health information electronically is an opportunity for the agency to address patient record matching challenges. As required by the 21st Century Cures Act, ONC is taking steps to develop or support a framework for ensuring the full exchange of health information among health information networks. ONC has referred to this effort as establishing a "network of networks," and it includes the development of a common agreement among health information networks nationally, which providers and others can use to facilitate the exchange of electronic health information, including patients' health records. As part of this effort, in January 2018, ONC issued a draft Trusted Exchange Framework that included principles for the trusted exchange of information, as well as minimum required terms and conditions for the Common Agreement. ONC plans to provide funding for an industry entity to incorporate these terms and conditions into a single Common Agreement that participating Qualified Health Information Networks (QHIN) and their participants voluntarily agree to adopt.[59]

While it is too soon to tell how this ONC effort will be implemented, several stakeholders said that it could potentially improve patient record matching if, for example, it results in new guidance or standards about demographic data elements. One HIE organization, for example, said that it would be beneficial if this effort leverages non-governmental work on matching and synthesizes this work into guidance for the industry. According to ONC officials, the framework is expected to affect patient

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[59]According to ONC, QHINs would be health information networks that meet certain criteria for participating in data exchange among different networks and agree to follow the Common Agreement. The Common Agreement would include terms and conditions that apply to QHINs. ONC officials plan to award a cooperative agreement to an organization to serve as a single Recognized Coordinating Entity—a governing body expected to operationalize the Trusted Exchange Framework by incorporating the minimum required terms and conditions into the Common Agreement. ONC officials told us they plan to work with the Recognized Coordinating Entity and stakeholders to develop the Common Agreement.
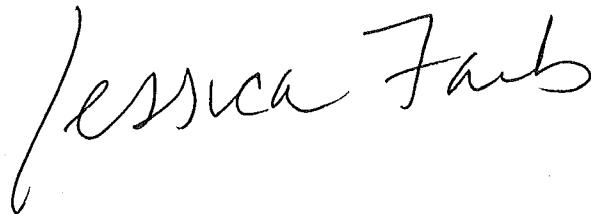
record matching by requiring participating QHINs to use ONC's Patient Demographic Data Quality Framework to evaluate their data practices.[60] The agency plans to release a second draft Trusted Exchange Framework and then release a draft Common Agreement and an updated Trusted Exchange Framework for public comment.

Agency Comments

We provided a draft of this report to HHS for review and comment. HHS provided technical comments, which we incorporated as appropriate.

We are sending copies of this report to the appropriate congressional committees, the Secretary of Health and Human Services, and other interested parties. In addition, the report is available at no charge on the GAO website at http://www.gao.gov.

If you or your staff members have any questions about this report, please contact me at (202) 512-7114 or farbj@gao.gov. Contact points for our Offices of Congressional Relations and Public Affairs may be found on the last page of this report.

Jessica Farb

Jessica Farb
Director, Health Care

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[60]ONC officials also told us that the Common Agreement will require each QHIN to (1) support the exchange of the patient record matching data included in a transition of care or referral summary, in accordance with standards outlined in regulation, and (2) provide such data when initiating or responding to queries for information. According to HHS's 2015 health IT certification criteria, for transitions of care, health IT systems must enable a user to create a transition of care or referral summary that is formatted in accordance with certain standards, using templates that include a range of data elements, at a minimum. These data elements include, for example, the Common Clinical Data Set, cognitive status, and the following "*patient matching data:*" first name, last name, previous name, middle name (including middle initial), suffix, DOB, address, phone number, and sex. See 45 C.F.R. §170.315(b)(1)(iii)(G).

Appendix I: GAO Contact and Staff Acknowledgments

GAO Contact	Jessica Farb, (202) 512-7114 or farbj@gao.gov.
Staff Acknowledgments	In addition to the contact named above, individuals making key contributions to this report include Thomas Conahan (Assistant Director), Robin Burke (Analyst-in-Charge), A. Elizabeth Dobrenz, Krister Friday, Monica Perez-Nelson, Vikki Porter, and Andrea Richardson.