



September 4, 2020

Don Rucker, M.D.
National Coordinator for Health Information Technology
U.S. Department of Health and Human Services
200 Independence Avenue, SW
Washington, DC 20201

Dear Dr. Rucker:

The College of Healthcare Information Management Executives (CHIME) is pleased to offer our ongoing thought leadership as part of ONC's efforts to inform their report to Congress on technical and operational methods that improve patient identity and matching.

CHIME is a professional organization that represents more than 3,400 chief information officers (CIOs) and other senior healthcare IT leaders. CHIME enables its members and business partners to collaborate, exchange ideas, develop professionally and advocate for the effective use of information management to improve the health and care in the communities they serve. CHIME members are responsible for the selection and implementation of clinical and business systems that are facilitating healthcare transformation through technology. Our members represent some of the earliest and most prolific adopters of electronic health records (EHRs) and other health IT resources. Our mission is, "To advance and serve healthcare leaders and the industry improving health and care globally through the utilization of knowledge and technology."

CHIME has weighed in extensively with ONC on the need for accurate patient identification and the ability to correctly link patients with their medical records. We applaud ONC for hosting a second workshop on this topic to continue to explore the promising innovations in patient identity and matching. We feel this topic is pivotal to not only interoperability, but also to patient safety. Above all, CHIME continues to assert that the first policy obstacle that must be removed is Section 510 of the Labor HHS appropriations bill that has been in place for two decades. We continue to advocate strongly for Congress to remove this ban and open the pathway for a nationwide strategy to address patient identification. While our members vary in their opinions on whether a unique number should be assigned to every patient, what they can agree on is that this ban is an enormous barrier to safe and interoperable care for patients.

We also believe there is significant cost savings to be achieved if patients can be correctly identified and matched to their records, including among federal payers. **We urge ONC to work with their federal partners to study this further. In particular, we recommend ONC work collaboratively with the Centers for Medicare & Medicaid Services (CMS) to examine instances of duplicate records and overutilization as a result of identification issues with the dual eligible (Medicare and Medicaid) populations. Each state uses its own patient identification system and each Medicare beneficiary has a unique Medicare Beneficiary Identifier (MBI), potentially compounding the problem.** We believe the clinical reasons alone will deliver substantial cost savings to the healthcare system. Data definitions and data are inconsistent, requiring time consuming and costly manual intervention; we believe closer examination of this as well will uncover additional cost savings if rectified.

In light of the extraordinary year our country and the rest of the world have experienced fighting the COVID-19 pandemic, we have thoughtfully considered the implications for patient identification

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and record matching through this lens. We are deeply concerned that patients may need to have several doses of a COVID-19 vaccine and the ability for the medical system to track where patients are in their vaccine course could be hindered, given the enormous problems we have today with accurately identifying patients and correctly matching them to their medical records. This becomes even more concerning when you consider the challenges we have already outlined with Medicaid and underserved populations. We believe the current system may result in multiple record sets being sent to federal and state authorities, resulting in multiple records for the same patient. For example, a child who presents in two different emergency departments may be logged with the government as two different patients, which would be problematic when the nation is trying to track vaccine disbursement and testing results.

This will make contact tracing even harder and the long-term implications for this are troubling. As our nation races to locate a vaccine(s) for this awful disease, we worry that the number of duplicate records on patients that exist today will hinder research efforts. We know racial and ethnic minority communities already experience higher rates of mismatched records and misidentification.¹ These issues are being magnified even further throughout the COVID-19 pandemic.

For the purposes of this letter, we would like to offer our thoughts on challenges unique to children, an often-overlooked population, including issues our members have identified with Medicaid and underserved patients.

Medicaid and Other Underserved Populations

Accurate Record Matching

Providers serving patients with Medicaid, as well as others in underserved populations, have unique challenges when it comes to record matching. Medicaid patients can frequently change the providers they see. Often, Medicaid patients present at urgent care and emergency departments rather than see a primary care clinician. This results in data across multiple sites and sometimes across state lines. Some data points used to help identify patients such as addresses and phone numbers change frequently; therefore, consistently retrieving medical data on these patients is challenging. Additionally, across multiple patient groups the issue of patients with the same name being mismatched continues to exist, even after ONC highlighted the problem in its 2014 patient matching report².

Some states allow Medicaid patients to change insurers every 30 days, making it nearly impossible to track enrollment. Making matters worse, data definitions and data are inconsistent, requiring a lot of manual intervention, which is time consuming.

Data matching variables such as the Social Security numbers, as well as other variables like phone numbers, can be fluid and not easily relied upon. For instance, one day a patient could be living in a shelter and the next day living with relatives. Phone numbers may also be unreliable – they can change often, or false numbers can be given when patients worry about medical bill collection calls. In these cases, standardizing data fields will not help. Finally, patients seen in border states may have come from outside the country where there is no data exchange or insurance, making matching records extremely difficult.

In the absence of a way to easily and accurately connect Medicaid and underserved patients to their medical records, there is a need for platforms that can address the vast amounts of data and aggregate knowledge in a way that is useful for clinicians personalized to these Medicaid

¹ <https://journal.ahima.org/covid-19-magnifies-urgent-need-for-patient-identification-strategies/>

² <https://journal.ahima.org/wp-content/uploads/ONC-Patient-Identification-Matching-Final-Report-February-2014.pdf>

populations. Additionally, there needs to be a way to integrate other sources of non-health information. Data should be expanded to include social determinants of health, although tools to combine social and clinical data are not yet widely available. Aggregating this data requires engagement of community health workers, social workers, and other members of the care team. Members have also identified a need for family and household information to be linked between school and state data, as well as with data from other state agencies. Our members would also like to see more accuracy of encounter data and uniform interpretations of the data.

Accurate Patient Identification

While providers experience multiple challenges associated with patient identification across all patients, there are some situations unique to Medicaid and underserved patients such as when they are homeless or those within multi-sibling families. Our members report that it is not uncommon for a patient to be seen using another family member's insurance and some patients do not want to be properly identified for other reasons. Members in border states report many patients in these communities have the same first and last name, and even the same date of birth. Having many potential data elements that could match to multiple patients increases the likelihood for charts to be mismatched with the wrong patient. This issue does not carry across all payers as it is easier to identify patients with a Medicare beneficiary number or a private insurance ID number.

Additionally, children on Medicaid or in underserved populations may not be accompanied by a parent, yet adults provide consent for treatment. It's not uncommon for grandparents, foster parents or parents who are not married and have different names from the children to bring them into the clinic. These scenarios create a lot of ambiguity for providers when children have different names from the adults. Providers often have no idea whether the adult bringing a child in is related to them or not. It is also not uncommon for children to obtain care under a different child's name. With the increased reliance on telehealth, including audio-only phone calls, identifying a patient being seen can also be challenge.

Identification in General with Children

In addition to the specific patient identification challenges described above with children on Medicaid and those in underserved communities, other general identification issues unique to children continue to exist. Identifying children and infants can be significantly challenging for a variety of reasons. First, in the case of newborns, they are often entered into the record initially with a temporary name such as the mother's that will then be changed later. Simultaneously, the child's last name may also change from the mother's. Or a baby can be born in one hospital listed under the mother's record and name and then be treated at a different hospital after the baby has been renamed, for instance, with the father's last name. It is also very common for babies to be listed in their mother's medical record. And, in the case of multiple births these problems are magnified. Confusion for providers abounds in each of these scenarios.

Second, when it comes to identifying younger children, there are limited ways to use biometrics. Children do not have picture IDs and any photos of infants and toddlers captured in the medical record will change substantially as they grow older. One member reported to us that their duplicate rate among children is as high as 30%.

Third, children do not have any other identifiers like driver's licenses, Social Security cards and insurance ID numbers (parent's insurance or Medicaid). This creates even further challenges for identifying children than experienced with adults.

Finally, immunization data collection is state specific for children, making data sharing very challenging. One member in California reports that their state immunization registry is unable to deduplicate records. As a result, there are often multiple entries for the same child simply because they have changed addresses. This has created enormous challenges and led to a one-year delay

around care integration. Having a unique way to identify children would significantly help address this issue.

Privacy

We understand some stakeholders continue to harbor privacy concerns as they relate to unique patient identification. As noted earlier, while there are divergent views among our membership concerning whether a number is the best approach for addressing patient identification and matching issues, CHIME members are unanimous in their desire to see the appropriations ban referenced earlier removed from statute. Doing so would pave the way to explore more meaningfully a solution(s) that uniquely and accurately identify patients and correctly connect them with their records.

It is also worth noting that as discussed earlier, patients are already able to obtain care under another patient's name and insurance today, even without a patient identifier. Importantly, covered entities and their business associates under the Health Insurance Portability & Accountability Act (HIPAA) are already required to meet federal privacy requirements. When you couple these with additional state privacy requirements, healthcare entities are already compelled to meet stringent policies around protection of patient data. Furthermore, The Privacy Act of 1974 establishes a code of fair information practices among federal agencies that governs the collection, maintenance, use and dissemination of personally identifiable information about individuals.

Additionally, federal agencies that act as payers must also meet HIPAA and there is a substantial part of the U.S. population that already has a patient ID generated by the federal government. The largest federal payers – Medicare (58 million beneficiaries)³, the Department of Defense (9.6 million beneficiaries of Tricare)⁴, and the Veteran's Administration (6 million beneficiaries)⁵ – all have their own set of unique identifiers, a collective number representing 73.6 million Americans or 22% of the entire U.S. population (approximately 330 million). Each identifier system is different, creating interoperability and patient safety challenges. To date, we are unaware of any issues associated with patients having these numbers. In contrast, these numbers pale in comparison with how many Americans use the largest internet search engine, 259 million⁶, and social media platforms where geolocation data is routinely tracked with little oversight. The regulation of data under these platforms – including health data offered up freely by consumers – is lightly regulated compared with healthcare data held by HIPAA-covered entities.

We highlight below challenges related to patient record matching and accurate identification which create significant privacy issues. While we approach this from the provider perspective, we believe it is critical to note that there are real privacy concerns for patients when they cannot be correctly identified and when their records are not correctly matched to them. By our members' estimations, there are more significant upsides to removing the federal ban and significantly greater risks posed to patient privacy and safety the longer this ban remains in place.

- **Patients living but treated in border / different states:** In addition to providers struggling to correctly connect patients seen in border or multiple states, they also experience challenges determining what data can be shared when dealing with varying state policies. For example, we have a member whose organization is incorporated in Virginia who also

³ https://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/Beneficiary-Snapshot/Bene_Snapshot

⁴ <https://health.mil/I-Am-A/Media/Media-Center/Patient-Population-Statistics>

⁵ <https://www.accesscare.va.gov/Healthcare/COVID19NationalSummary#:~:text=The%20Department%20of%20Veterans%20Affairs%20%28VA%29%20is%20the,than%20350%2C000%20professionals%20within%20the%20Veterans%20Health%20Administration.>

⁶ <https://www.statista.com/topics/1001/google/#:~:text=In%20December%202018%2C%20Google%20was%20ranked%20first%20amongst,percent%20among%20the%20leading%20U.S.%20search%20engine%20providers.>

has a care setting in North Carolina. They experience difficulties attempting to meet both the Virginia and North Carolina state data sharing requirements. They must wade through a morass of data-sharing policies when a child is living in one state but was seen by a provider in a different state.

- **Children coming of age:** Disentangling children's records once they are no longer considered a minor from their guardian's records is also challenging for providers. Some get mixed together in the EHR and it's not uncommon for a child to turn 18 and for their information to continue to be sent to a guardian, a privacy violation.
- **Foster and adopted children:** Foster and adopted children routinely have portions of their names change and privacy/legal requirements can prohibit merging medical records. This makes the release of patient information complicated and there is not a standard place to document this nuance. This also causes issues for the clinicians because all the patient's medical record data is not in the same place at the point of care.
- **Ensuring data is sent to correct provider:** Patients seen by clinicians who work in more than one clinical setting can create challenges for providers when the patient presents in the emergency room. Records must be sent to the correct clinic, but without a way to accurately match a patient to their record, the records can be sent to the wrong clinic, setting providers up for a HIPAA violation.

Standards

With the federal appropriations ban remaining in place, and so many challenges related to uniquely identifying and accurately connecting patients to their records, ensuring there are standards for data variables becomes even more important. Examples of where standards are beneficial include:

- Standard naming conventions. Names that have special characters and Jr., Sr., etc. – all applications don't have the same rules depending on the EHR.
- A universal data field for multiple births. In the case of triplets, on top of the extra medical conditions that often present with multiple births, matching challenges are increased, and records can get mixed. There is an HL7 standard for multiple births, but this is not required for use among EHR vendors.
- US Postal Service standard for addresses is also not required and ONC declined to include this as a required format in the USCDI.
- A standard for handling multiple clinician addresses in the EHR:
 - Take the example of a child who presents in the emergency room and is admitted. An alert to the primary care physician needs to be sent out, however, providers often may not have an address for the physician. In fact, a hospital may have multiple addresses for a physician and the hospital may not know which one to send it to.
 - Some EHRs can't support a feature for second and third addresses. And different EHRs handle second and third addresses differently. When a provider realizes the second and third addresses are handled differently, selecting anything less than the primary address will create problems and often require providers to resort to faxing. A standard for this could help ensure information goes where it needs to go. Also, while direct interfaces can help for the first address, it will not help with the extra addresses. Issues related to lacking multiple address fields creates burdens for providers and unnecessary costs to the health system.
 - As one member of ours reflected on this, "Fine if you have simplicity of one doc one address but if you look at patient's journey they hit so many organizations and the docs work with more than 1 provider. They find data is not following. Need also standards around the address. Maybe it's the same address but they all look a bit different. Several problems aggravating each other."

- A standard data set to identify children with complex medical conditions across state lines would also be helpful.

Even with standards, some of the previously identified issues earlier in our letter cannot be resolved with more uniform data elements. For instance, with infants, using the Social Security number as a matching data point is not helpful since some infants have not yet been issued one. Although a parent's cell phone can sometimes be used for matching children, some children have their own phone, but this data is not always captured.

CHIME appreciates the opportunity to share our perspective on an issue we have long felt is the lynchpin to interoperability and a key barrier to patient safety.

Sincerely,



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CHIME



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