PATIENT ID NOW

ONC Patient Identity and Matching Working Session

August 31, 2020

Today's Topics

- The Problem: Accurately identifying patients and matching them to their data to ensure that a patient's EHR contains full, reliable information
- Background on Patient ID Now Coalition
- Issues and Challenges
  - Quality of Care and Patient Safety
  - COVID-19 Public Health Emergency
  - Privacy
  - National Patient Identification Strategy
- Patient ID Now Coalition Recommendations

Patient ID NOW Coalition

- Committed to advancing a nationwide patient identification strategy
- Seeking repeal of appropriations ban
- Formalized multi-stakeholder efforts (30+ organizations) May 2020
- Solution agnostic

https://patientidnow.org/

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Membership

The founding members of the Patient ID Coalition are the American College of Surgeons, AHIMA, CHIME, HIMSS, Intermountain Healthcare, and Premier.


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4medica®
One Patient...One Record


AMERICAN ACADEMY
OF OPHTHALMOLOGY®
Protecting Sight. Empowering Lives.


AMERICAN
COLLEGE of
CARDIOLOGY


American
Heart
Association.


AMIA
INFORMATICS PROFESSIONALS. LEADING THE WAY.


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HIMSS ELECTRONIC HEALTH RECORD ASSOCIATION


experian health


GPII
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IDENTIFIERS
INC.


Healthix


imprivata®


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ID NOW


The Joint Commission


Just Associates
MASTERING PATIENT IDENTITY


LexisNexis
RISK SOLUTIONS
Health Care


naham
National Association of
Healthcare Access Management


NASL
National Association for the
Support of Long Term Care
Insight • Advocacy • Action


Nemours.
Children's Health System


nextgen
healthcare


NEXTGATE


PacificEast


SHIEC
Strategic
Health
Information
Exchange
Collaborative


Trinity Health


verato


VITAL


Canon
CANON GROUP

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Patient Data Quality and Matching

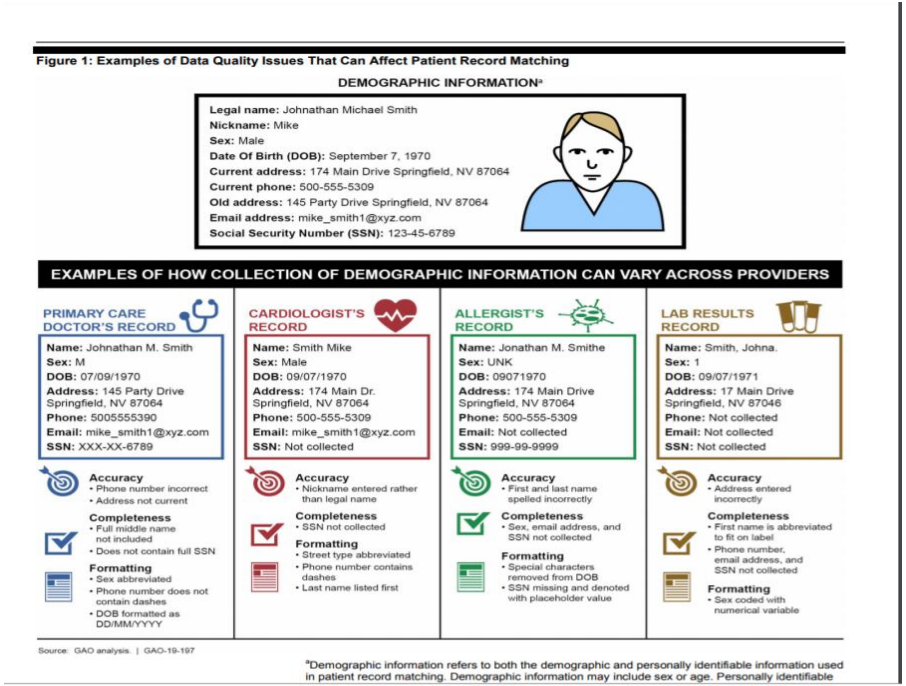

Figure 1: Examples of Data Quality Issues That Can Affect Patient Record Matching

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

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Matching Patients

(in 2011) Harris County Department of Health (Texas) 3,428,925 patients in their database:

- Number of times two or more patients shared the same first and last names: 249,213
- Number of times five or more patients shared the same last and first names: 76,354
- Number of times two or more patients shared the same last and first names, and the same date of birth: 69,807
- Number of patients named Maria Garcia: 2,488
- Number of Maria Garcia's sharing the same date of birth: 231

Harris Health System. "Harris County Hospital District Puts Patient Safety in the Palm of Your Hand." www.prlog.org/11430165-harris-county-hospital-district-puts-patient-safety-in-the-palm-of-your-hand.html.

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Summer Reading List

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Patient Identifiers are Vital

"Patient Identifiers are vital for healthcare organization's day to day operations such as the delivery of care, administrative processes, support services, record keeping, information management, and follow-up and preventive care. The revolution, currently taking place in our national healthcare delivery system and in the computer and telecommunication technologies, has expanded the scope of these functions across multiple organizations spread around the nation. In addition, patients are mobile, visit multiple providers and [are] treated by multiple organizations. Therefore, to support the continuum of care, it is necessary to uniquely identify patients across multiple providers and access their information from multiple locations."

NCVHS. ANALYSIS OF UNIQUE PATIENT IDENTIFIER OPTIONS FINAL REPORT. November 24, 1997
https://www.ncvhs.hhs.gov/wp-content/uploads/2018/03/APPAVU-508.pdf

Quality of Care and Patient Safety

- Improper,incomplete or inaccurate patient identification information
  - Jeopardizes patient care, clinical decisions, patient outcomes
    - increased chances of misdiagnosis
    - unsafe and/or unnecessary treatment
    - duplicative and/or unnecessary testing
  - Limits health information exchange and sharing
  - Raises financial and resource concerns (benefits, coverage and claims decisions)
  - Stifles and impedes interoperability, innovation, and improvements in care delivery
  - Requires work arounds, time consuming and costly processes to address data quality issues and to correct medical records
  - Effective, efficient and quality care relies on accurate patient identification

COVID-19 and Patient Identification

reports often come in duplicate, go to the wrong health department, or are missing crucial information ... a patient's phone number or address…

Staff spends hours searching databases ….. to find phone numbers and addresses that were already collected by the clinic that ordered the test in the first place.

…Nationally, about 80 percent of coronavirus test results are missing demographic information, and half do not have addresses

https://www.nytimes.com/2020/07/13/upshot/coronavirus-response-fax-machines.html

COVID-19 and Patient Identification

- Heightened awareness of patient identification and matching challenges and implications
  - data collection gaps, inconsistencies
  - poorly matched data
  - delays in sharing test results
  - inability to match results with people
  - inaccuracies in longitudinal care record
  - unknown long-term health effects
- Public health systems increasingly rely on EHR data
  - need to share and exchange information
  - incorrect or incomplete data has negative impacts
  - requires interoperability

Lippi G, Chiozza L, Mattiuzzi C, Plebani M. Patient and Sample Identification. Out of the Maze?. J Med Biochem. 2017;36(2):107-112. Published 2017 Apr 22. doi:10.1515/jomb-2017-0003 and https://www.nytimes.com/2020/07/13/upshot/coronavirus-response-fax-machines.html

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COVID-19 and Patient Identification

- **Exacerbation of health disparities in underserved communities and populations** (from: OCHIN a nonprofit health IT services provider for 500 care delivery sites):
  - Black patients make up 13% of their patient population but ***21% of duplicates***
  - Hispanic/ Latino patients make up 21% of the population that OCHIN's members serve, yet they make up ***35% of the duplications***
  - Homeless population makes up 4.3% of OCHIN patients, but 12% of its duplicates (***almost three times the expected rate)***
  - Migrant population make up 2.1% of OCHIN patients but ***3.6% of its duplicates***

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

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COVID-19 and Patient Identification

- **Preparing for a vaccine:**
  - Large-scale immunization programs will depend on accurate patient information, particularly if the vaccine requires multiple doses (Shingles, Hepatitis A, MMR, etc.)
  - We will need to identify:
    - who has had the disease
    - who has been vaccinated
    - patient outcomes
    - stockpile distribution requirements

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Persistent Perceived Privacy Issues

- **Creation of a centralized repository** with detailed information about individuals
- Potential for a **centralized database to be used for discriminatory purposes**, particularly as it relates to vulnerable populations; and
- Healthcare is only one area where data could be used
- HIPAA requirements for **privacy**
  - patient controls and consent

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The Inverse Privacy Challenge

- Current system has created an inverse privacy challenge
  - Individuals must repetitively disclose individually identifiable information to each health care provider they see
  - Inadvertent
    - disclosures of a patient's health information to the wrong persons
    - sharing information about a patient who has directed that information not be disclosed

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National Patient Identification Strategy

- Failure to accurately identify patients and match them to their data raises **patient safety and quality of care** concerns
- Narrow interpretation of Section 510 of Labor HHS Appropriations has led to the **failure to institute a nationwide patient identification strategy.**
  - **Balancing patient privacy and safety**. Countless stories of a person receiving the wrong care because they were misidentified.
  - The ban was instituted prior to **HIPAA** which **addresses** many **privacy** issues
  - HITECH established **a clear mandate** to adopt electronic health records and health information exchange capabilities
- Enactment of the 21st Century Cures Act creates a **technological approach** for the exchange of health information nationwide

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Recommendations

- Remove the ban: HHS at the table with the healthcare community
- Prioritize the accuracy of patient identification and matching
  - urgency of public health emergency
  - nationwide interoperability
- Recognize that many privacy concerns are addressed by HIPAA
- Review and consider current and emerging technology and technical approaches and solutions
- Focus on standards-based solutions
- **Develop and establish a National Patient Identification Strategy to improve patient matching** to support secure information sharing; quality, effective and efficient patient care; and patient safety

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Thank You

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Appendix

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History

- 1996 –HIPAA signed into law
  - NCVHS charged with making recommendations for Unique Patient Identifier
- 1998 – NCVHS held public hearing on patient identifier
  - Privacy advocates contacted Congress. NCVHS work halted; HHS stops work on patient ID
- 1999-2017 Labor HHS Appropriations
  - Includes provision forbidding HHS from promulgating an UPI without consulting and receiving approval from Congress
  - “HHS prohibition” continued for 3 Administrations
- 2014-2018 – HHS focused on Patient Matching
  - Algorithm challenges; algorithm attributes;
  - Innovator-in-Residence

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History

- 2016 Cures Act Enacted -- Section 4003 instructs HITAC to target its [interoperability] efforts to identifying “technology that provides accurate patient information for the correct patient, including exchanging such information, and avoids the duplication of patient records.”
- 2018 – Labor HHS Appropriations Report. Includes language for GAO study on patient matching
- 2014-2018 – HHS focused on Patient Matching
  - Algorithm challenges; algorithm attributes;
  - Innovator-in-Residence
- 2018 – Labor HHS Appropriations Report
  - Includes language for GAO study on patient matching

History

- 2019 – Labor HHS Appropriations
  - **Patient Matching** -The general provision limiting funds for actions related to promulgation or adoption of a standard providing for the assignment of a unique health identifier does not prohibit efforts to address the growing problems faced by health systems with patient matching.
  - **Directs ONC**, in coordination with other appropriate Federal agencies, to **provide a report to the Committees** one year after enactment of this Act **studying the current technological and operational methods that improve identification of patients.**

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Selected Resources

1997 NCVHS. ANALYSIS OF UNIQUE PATIENT IDENTIFIER OPTIONS FINAL REPORT. https://www.ncvhs.hhs.gov/wp-content/uploads/2018/03/APPAVU-508.pdf

2007 Privacy and Security Solutions for Interoperable Health Information Exchange Nationwide Summary https://digital.ahrq.gov/sites/default/files/docs/page/privacy-and-security-solutions-for-interoperable-hie-nationwide-summary.pdf

2008 Identity Crisis: An Examination of the Costs and Benefits of a Unique Patient Identifier for the U.S. Health Care System. Rand https://www.rand.org/pubs/monographs/MG753.html

2014 ONC Identification and Matching Final Report https://www.healthit.gov/sites/default/files/patient_identification_matching_final_report.pdf

2014 Summary of CHIME Survey https://chimecentral.org/wp-content/uploads/2014/11/Summary_of_CHIME_Survey_on_Patient_Data.pdf

2017 ONC Patient Matching Challenge https://www.patientmatchingchallenge.com/

2016 ECRI Institute Patient Safety Organization's Deep Dive: Patient Identification (Volume 1) https://www.ecri.org/components/PSOcore/Pages/DeepDive0816_Patient ID.aspx

2016 National Patient Misidentification Report, _https://pages.imprivata.com/rs/imprivata/images/Ponemon-Report_121416.pdf.

More Resources

2016 ECRI Institute's Health Technology Assessment Information Service's report Patient Identification: Literature Review (Volume 2) https://www.ecri.org/components/SpecialReports/Pages/80816.aspx

2016 Partnership for Health IT Patient Safety. Health IT Safe Practices: Toolkit for the Safe Use of Health IT for Patient Identification https://www.ecri.org/resource-center/Pages/HITPartnership.aspx

2016 ECRI Patient Identification Errors https://d84vr99712pyz.cloudfront.net/p/pdf/hit-partnership/patient-identification-evidence-based-literature-review.pdf

2016 Safe Use of Health IT https://www.jointcommission.org/-/media/tjc/documents/resources/patient-safety-topics/sentinel-event/sea_54_hit_4_26_16.pdf

2018 Legal Barriers to the Growth of Health Information Exchange—Boulders or Pebbles? https://www.milbank.org/wp-content/uploads/mq/volume-96/march-2018/MELLO_et_al-2018.pdf

2018 Enhanced Patient Matching Is Critical to Achieving Full Promise of Digital Health Records https://www.pewtrusts.org/-/media/assets/2018/09/healthit_enhancedpatientmatching_report_final.pdf

2018 Framework for Cross-Organizational Patient Identity Management Sequoia Project https://sequoiaproject.org/wp-content/uploads/2018/06/The-Sequoia-Project-Framework-for-Patient-Identity-Management-v31.pdf

2018 Roundtable on Data Sharing Policies, Data-Driven Solutions, and the Opioid Crisis.http://reports.opendataenterprise.org/HHS-Opioid-Roundtable-Report.pdf Office of the Chief Technology Officer (CTO) and Center for Open Data Enterprise (CODE)

Still More Resources

2018 Quick Safety Issue 45: People, processes, health IT and accurate patient identification https://www.jointcommission.org/-/media/tjc/newsletters/qs_hit_and_patient_id_9_25_18_finalpdf.pdf

2018 Defining and Evaluating Patient-Empowered Approaches to Improving Record Matching https://www.rand.org/content/dam/rand/pubs/research_reports/RR2200/RR2275/RAND_RR2275.pdf

2019 ONC Patient Matching, Aggregation, and Linking (PMAL) Project https://www.healthit.gov/sites/default/files/page/2019-09/PMAL%20Final%20Report-08162019v2.pdf

2019 GAO Report to Congressional Committees: Approaches and Challenges to Electronically Matching Patients' Records across Providers https://www.gao.gov/assets/700/696426.pdf

2019 Pilot of a Data Quality Frameowrk https://aspe.hhs.gov/system/files/pdf/259016/PMAL_PDDQ_Paper_08292019.pdf

2019 Issue Brief on Patient Matching https://bipartisanpolicy.org/wp-content/uploads/2019/03/BPC-HIT-Issue-Brief-on-Patient-Matching.pdf

2019 Grannis, S.J. et al, 2019, 'Evaluating the effect of data standardization and validation on patient matching accuracy', *Journal of the American Medical Informatics Association*, vol. 26, no. 5, pp. 447-456.

2020 Patient Identification Techniques – Approaches, Implications, and Findings IMIA 2020 Yearboob https://www.thieme-connect.com/products/ejournals/journal/10.1055/s-00034612