



Regenstrief Institute

Better Care. Better Health.



PCOR Data Standards: Linkage

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*Prepared for the May 24, 2021 NAM "Data Standards, Methods, and Policy" Workshop as part of the NAM Study
"Building Data Capacity for Patient-Centered Outcomes Research: An Agenda for 2021 to 2030" Study*



Disclosure

- Research/Academic funding
 - Patient centered outcomes research initiative (PCORI)
 - Agency for Healthcare Research and Quality (AHRQ)
 - Centers for Disease Control and Prevention (CDC)
 - The Pew Charitable Trusts
 - U.S. State Department (PEPFAR)
- Commercial activities
 - CMIO for the Indiana Health Information Exchange
 - Co-founder of Uppstroms, a social determinants data-science services company



“Five Functionalities”

- Standardized Collection of Standardized Clinical Data
- Linking Clinical and Other Data for Research
- Collecting Participant-Provided Information
- Using Clinical Data for Research
- Using Enhanced Publicly-Funded Data Systems for Research



Linking Clinical and Other Data for Research

- Evolving U.S. Patient Identity Strategy
- Digital Identity and Federation
- Privacy Preserving Record Linkage (PPRL)
- Other Data: Social Determinants



Evolving U.S. Patient Identity Strategy

DIVISION A—DEPARTMENTS OF LABOR, HEALTH AND HUMAN
SERVICES, AND EDUCATION, AND RELATED AGENCIES
APPROPRIATIONS ACT, 2020

OFFICE OF THE NATIONAL COORDINATOR FOR HEALTH INFORMATION TECHNOLOGY
(ONC)

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. The agreement encourages HHS to continue to provide technical assistance to private-sector-led initiatives to develop a coordinated national strategy that will promote patient safety by accurately identifying patients to their health information. Additionally, the agreement 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. The report shall evaluate the effectiveness of current methods and recommend actions that increase the likelihood of an accurate match of patients to their health care data. Such recommendations may or may not include a standard for a unique patient health identifier. The report shall include the risks and benefits to privacy and security of patient information.

Source: <https://docs.house.gov/billsthisweek/20191216/BILLS-116HR1865SA-JES-DIVISION-A.pdf>



Digital Identity and Federation

- Identity Frameworks
(e.g., [CARIN Alliance](#), [FHIR at Scale \(FAST\) Identity Taskforce](#))
- Identity certification
(e.g., FIDO, DirectTrust, etc.)
- Identity generation
(e.g., AllClearID, ID.me, Okta, etc.)

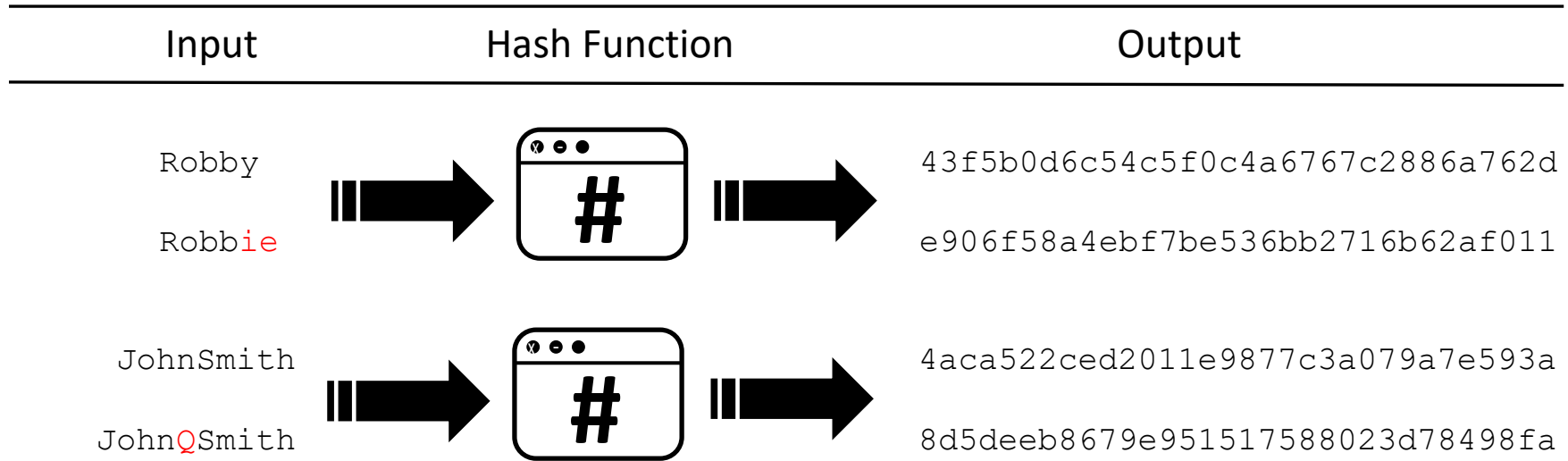


Match On Device



Privacy Preserving Record Linkage (PPRL)

Enables linking patient records while protecting privacy



Social Determinants Data

- Granularity
- Standardization
- Linkage



Matching Recommendations

PATIENT IDENTIFICATION AND MATCHING FINAL REPORT

February 7, 2014

Prepared for the Office of the National Coordinator



Matching Policy

Journal of the American Medical Association

Research and Applications

Evaluating the effect of data validation on patient matching

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Received 28 August 2018; Revised 14 December 2018; Editorial Decision 14 January 2019

BA120740 WMN

S.L.C.

116TH CONGRESS
2D SESSION

S. _____

To amend the Public Health Service Act to permit health information technology systems to use the Postal Service tool to standardize formatting in electronic health records when entering patient information to improve match rates among patient records.

IN THE SENATE OF THE UNITED STATES

Ms. HASSAN (for herself and Mr. CASSIDY) introduced the following bill; which was read twice and referred to the Committee on

A BILL

To amend the Public Health Service Act to permit health information technology systems to use the Postal Service tool to standardize formatting in electronic health records when entering patient information to improve match rates among patient records.

1 *Be it enacted by the Senate and House of Representatives*
2 *of the United States of America in Congress assembled,*

3 SECTION 1. SHORT TITLE.

4 This Act may be cited as the “Patient Matching Im-
5 provement Act of 2020”.

HEALTH AND HUMAN SERVICES

www.nature.com/npjdigitalmed

Check for updates

ion could help fight the coronavirus

Grannis³

10.1038/s41746-020-0280-4

“(ii) COVID-19 LABORATORY TESTING.—Not later than 90 days after the date of enactment of this subparagraph, the Secretary shall make available the United States Postal Service address formatting tool for use by laboratories engaged in COVID-19 testing to accompany COVID-19 laboratory results.

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standard for a unique

ks and benefits to privacy

the physician—not in authorities could contact information and unabated. on strategy will also data wherever the immunization registry systems—to check ved a dose, thus while ensuring that

SHR18655A-JES-DIVISION-A.pdf



ONC Project US@

Health IT

Say “Hey!” to Project US@ – a Unified Specification for Address in Health Care

Steven Posnack | DECEMBER 1, 2020



Standards come about for many reasons. They make things more efficient, cost effective, and safer to name a few. Often you'll hear witty banter in the standards community (I know...right!?) about whether something is “fit for purpose.” This is also accompanied by the question, “what's your use case?”

Among the outliers and edge cases there are some things on which we really do need to agree across the health care ecosystem and implement consistently. **How we represent a patient's address is one of them.** In particular, as mundane as *address* may seem it is often one of the key elements used for the purposes of patient matching and linking records, though other data like email and cell phone number are gaining in their use.

Today, as part of ONC's *API Year in Review* [virtual event](#), I announced that the Office of the National Coordinator for Health Information Technology (ONC) in collaboration with Health Level 7 (HL7), the National Council for Prescription Drug Programs (NCPDP), and X12 (along with the other standards development organizations (SDOs) and members of the [Health Standards Collaborative \(HSC\)](#) have agreed to develop a unified specification for address in health care. We call our new initiative **Project US@** and it will formally launch at the start of 2021. The project's goal is to issue a unified, cross-SDO, health care industry-wide specification for representing address within the year.


Project
US@

Unified
Specification
for Address
in health care

Categories

[Consumer Engagement](#)
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[Health Information Exchange](#)
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Future Directions

- Algorithm-based improvements
- Biometrics
- National Health ID
- Referential matching





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