



## 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.



# 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.)



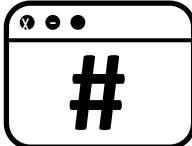
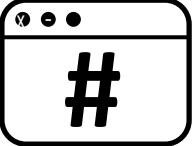
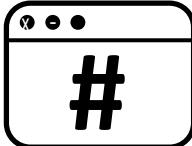
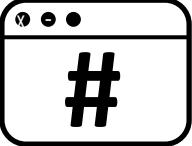
Match On Device



# Privacy Preserving Record Linkage (PPRL)

Enables linking patient records while protecting privacy

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Input	Hash Function	Output
Robby		43f5b0d6c54c5f0c4a6767c2886a762d
Robbie		e906f58a4ebf7be536bb2716b62af011
JohnSmith		4aca522ced2011e9877c3a079a7e593a
JohnQSmith		8d5deeb8679e951517588023d78498fa



# Social Determinants Data

- Granularity
- Standardization
- Linkage



# Matching Recommendations

Marital Status

Single

Divorced

Married

Widowed

the  
coordinator

etreat

## PATIENT IDENTIFICATION AND MATCHING FINAL REPORT

February 7, 2014

Prepared for the Office of the National Coordinator



# Matching Policy

BAI20740 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 of the United States of America in Congress assembled,*
- 2      **3 SECTION 1. SHORT TITLE.**
- 3      This Act may be cited as the “Patient Matching Im-
- 4      provement Act of 2020”.
- 5

HEALTH AND HUMAN

[www.nature.com/npjdigitalmed](http://www.nature.com/npjdigitalmed)

 Check for updates

## ion could help fight the coronavirus

Grannis<sup>3</sup>

29/c41746\_020\_0280\_4

### “(ii) COVID-19 LABORATORY TEST-

ING.—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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while ensuring that

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standard for a unique

ks and benefits to privacy

5HR1865SA-JES-DIVISION-A.pdf

Journal of the American Medi

## Research and Applications

### Evaluating the effect of data validation on patient match

Shaun J Grannis,<sup>1,2</sup> Huiping Xu,<sup>1,3,4</sup> Joshua Na Bo,<sup>3</sup> Ben Moscovitch,<sup>7</sup> Rita Torkzadeh

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# ONC Project US@

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

Steven Posnack | DECEMBER 1, 2020



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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**

# Future Directions

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





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