Real-World Matching Performance of Deidentified Record-Linking Tokens

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Abstract

Objective Our objective was to evaluate tokens commonly used by clinical research consortia to aggregate clinical data across institutions.

Methods This study compares tokens alone and token-based matching algorithms against manual annotation for 20,002 record pairs extracted from the University of Texas Houston’s clinical data warehouse (CDW) in terms of entity resolution.

Results The highest precision achieved was 99.9% with a token derived from the first name, last name, gender, and date-of-birth. The highest recall achieved was 95.5% with an algorithm involving tokens that reflected combinations of first name, last name, gender, date-of-birth, and social security number.

Discussion To protect the privacy of patient data, information must be removed from a health care dataset to obscure the identity of individuals from which that data were derived. However, once identifying information is removed, records can no longer be linked to the same entity to enable analyses. Tokens are a mechanism to convert patient identifying information into Health Insurance Portability and Accountability Act-compliant deidentified elements that can be used to link clinical records, while preserving patient privacy.

Conclusion Depending on the availability and accuracy of the underlying data, tokens are able to resolve and link entities at a high level of precision and recall for real-world data derived from a CDW.

Keywords► patient records  ► electronic health records  ► privacy  ► research  ► dataset

Background and Significance

Health care data are fragmented across numerous collection points (electronic health records, insurance claims, pharmacy prescriptions, etc.) depending on where the patient has interacted with the health care system. Exchanging identified health care data is problematic due to ethical and regulatory requirements to protect patient privacy.

Record linkage is an entity resolution problem where information about the same individual is integrated into a single cluster, despite the individual being referenced differently by different data sources. Traditional record linkage requires personally identifying information (PII), such as name, date of birth (DOB), and address to be available in two or more datasets.1 In contrast, privacy-preserving record linkage (PPRL) allows two or more datasets to be linked (e.g.,

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to recognize the same individual within separate datasets) without sharing sensitive identifiers. Therefore, PPRL solutions are attractive, particularly for research networks involving multiple independent institutions.\(^6\)

PPRL methods can be divided into deterministic PPRL and probabilistic PPRL.\(^3\) Both approaches start with demographic data about an individual and involve one-way hashing of identifying data such that these identifying data can no longer be connected to the originating patient. Most often, the input to the one-way hash is a string (e.g., first name), and the output is a deterministically determined string that cannot be tied back to the input string on its own.

In a deterministic PPRL system, patient demographic data items are concatenated and hashed, and the resultant random string is used directly as a unique identifier for that patient. This leads to high precision but limits recall if data are inaccurate or missing. Moreover, deterministic methods cannot account for frequently changing data such as addresses, zip codes, etc., or variants such as nicknames, alternative spellings, or misspellings.

In a probabilistic PPRL system, multiple demographic identifiers are first separately encrypted, taking care to preserve enough variability in each encrypted output string to prevent dictionary attacks (i.e., brute force approach that attempts to break the encryption by matching an encrypted string against every possible encrypted string generated from some universe of inputs). The resultant collection of random strings is used as the feature set to establish a probabilistic linkage between two records. This probabilistic linkage preserves patient privacy by only admitting the minimum set of hashed elements into the feature space, but at the same time preserves as much information as possible to allow for increased recall, especially in cases of missing, changing, or inaccurate data within certain demographic elements.\(^4\)

Multiple PPRL systems exist in both academic and commercial settings. In general, these systems allow record linking while obfuscating PII. One such system was created by Datavant (Datavant, Inc., San Francisco, CA). Several hundred health care entities across the United States exchange datasets that have been deidentified by means of generating Datavant tokens from raw PII. These entities span the health care continuum, including, for example, laboratories, academic research institutions, and the U.S. National Institutes of Health. They represent a diverse set of use cases, ranging from physician National Provider Identifier numbers to laboratory test results to insurance claim charges. In addition to medical data fields, patient PII fields may vary across datasets. Moreover, the underlying populations across these sources of medical data vary considerably with respect to age, gender, and ethnicity.

### Objectives

In previous work,\(^5\) we tested a variety of record-linking algorithms and compared their performance. In this paper, we describe the results of a matching study to evaluate the matching performance of commonly-used deidentified tokens, using a large, real-world, human-annotated identi-
subjective confidence in the classification: (1) definite mismatch; (2) probable mismatch; (3) uncertain; (4) probable match; and (5) definite match. Reviewers were asked to designate a record pair as a match (4 or 5) or nonmatch (1 or 2) “only if they would have been comfortable with a computer making the same assertion automatically based on the available data.” In case of disagreement between reviewers, meaning one reviewer thought the records matched (4 or 5) while the other did not (1 or 2), or if one of the reviewers thought it was impossible to assert match status (3) with the available data, “the records were forwarded to an evaluation by four independent reviewers.” Record pairs “that were not assigned a match/nonmatch status unanimously (or by three reviewers when the fourth reviewer was uncertain [3]) went to further review by open discussion of the entire review panel (six reviewers). Only 48 record pairs could not be adjudicated by four reviewers. These were assigned by consensus (10 matched and 38 nonmatched). In all but 48 cases (0.24%) reviewers felt that the eight demographic data fields were sufficient to assign match status without requiring additional data.

Datavant software was used to create eight different encrypted tokens for each of the 40,004 records (20,002 pairs). Tokens rely on demographic factors such as first name, last name, gender, DOB, etc., to generate tokens for matching purposes. Generally, the patient’s zip code would be included in the token methodology; however, the zip code was unavailable in this dataset and was therefore excluded.

Table 1 Match algorithms used in this evaluation

| A. Token descriptions |
|------------------------|
| Name                  | Token description                                    |
| Token 1               | Last name + 1st initial of first name + gender + DOB |
| Token 2               | Last name (soundex) + first name (soundex) + gender + DOB |
| Token 3               | Last name + first name + DOB + Zip 3 (three digit zip code) |
| Token 4               | Last name + first name + gender + DOB                |
| Token 5               | SSN + gender + DOB                                   |
| Token 7               | Last name + 1st three characters of first name + gender + DOB |
| Token 9               | First name + address                                |
| Token 16              | SSN + first name                                    |
| Token 22              | Cell phone number (United States)                   |

| B. Token combinations |
|-----------------------|
| Name                  | Tokens used | Description                                      | Evaluation requirement                                      |
| Single token match    | 1 or 2, or 3 or 4, OR 5 or 16 | Two records match if they share at least a single token in common. | At least one of tokens 1,2,3,4,5, and16 is present          |
| Demographic           | 1 and 2    | Two records match on both of these tokens to indicate the records have the same name, age, and gender. | Tokens 1 and 2 are present                                  |
| Net tokens            | Any subset of 1, 2, 4, 5, 7, 9, 16 | Two records match if more tokens match than do not. Note, tokens based on email, phone, or address are excluded from this list because they are often most prone to error on input. | At least 3 of tokens 1,2,4,5,7,9, and16 are present          |
| SSN                   | 5 or 16    | Tokens 5 and 16 use SSN (United States). Two records match if either token 5 or token 16 match. | Token 5 or 16 is present                                    |

Abbreviations: DOB, date of birth; SSN, social security number.

Table 1 describes the eight tokens used in this evaluation. With single-token comparison, two records match if the relevant tokens match (i.e., Token 1 derived from record A matches Token 1 derived from record B). Table 1 describes multikoken approaches, which were selected by considering common matching strategies across sites using the Datavant token. Tokens are generated in a two-step process—one-way master token generation and then site-specific token encryption (Fig. 1).

One-Way Master Token Generation

The first step in the linkage process is to create a set of encrypted hashed tokens based on the input PII of each patient. The underlying PII is validated, concatenated, and
irreversibly hashed using the SHA-256 algorithm into a series of master tokens using a secure, fixed random string that is added to the concatenated string before creating the final token. The irreversible hashing mechanism ensures that the patient’s PII used to create the tokens cannot be recovered from the output value.

**Encrypted Site-Specific Token Generation**

The master tokens are then encrypted using a site-specific AES-128 key. The same PII will always generate the same set of master tokens, but PII is never present in any output or log stream. Only the site-specific encryption tokens are written to the output file. Since tokens are site specific, a breach at one site will not propagate across the Datavant ecosystem, which prevents the reidentification of patients across datasets at different sites and allows for a governance mechanism that prevents linking of patient records across datasets without the permission of both parties.

After tokenization, records were matched and the results were compared with manual annotation, which was considered to be the ground truth. We calculated precision, recall, and F1 using standard definitions (→ Table 2).

It is important to note that the dataset had inconsistent fill rates of PII (fill rate = 1 - missing rate) and therefore generation rates for individual tokens varied (→ Table 3). To avoid bias related to the fill rates for our dataset, we reported recall based only on record pairs in which each record contained the data required to compute the specific token or combination of tokens (see “Evaluation requirement” field in → Table 1). The “Pair fill rate” in → Tables 2A and 2B is the proportion of all record pairs for which the required data were available.

**Results**

→ Table 3 shows the demographics and rates of missing values for the study population. The data reflect inconsistent coding practices. For example, the race was sometimes listed as “Hispanic” in addition to, or instead of, ethnicity. Similarly, age was calculated based on DOB and an index date of May 05, 2011 (the date the manual review set was created) which may include errors that are reflected in the table (e.g., DOB 1/1/1900 = unknown). Since our goal was to evaluate real-world performance of PPRL, we did not harmonize the data (e.g., remove Hispanic race).

**Token Matching Evaluation**

Token 5 based on SSNs had very high precision and good recall, but relatively low fill rate (Table 2). Compared with Token 5, Token 16 had similar precision but lower recall. This may be due to the additional PII elements required by Token 5 (gender, DOB) versus Token 16 (first name); the results imply that true matches are more likely to share gender and DOB than first name.

Tokens 1, 2, and 4 use a combination of name, DOB, and gender. While each element is not uniquely identifying when used separately (e.g., there are many people named John), combinations of these elements can precisely distinguish unique individuals. Tokens 1 and 2 optimize recall, whereas Token 4 optimizes precision. Token 4 had high precision as it used exact matches of first and last name but had lower recall likely due to different spellings of those names (e.g., Stephen vs. Steven, or Nick vs. Nicholas). Tokens 1 and 2 have higher recall because they allow more flexibility with names but lower precision because, for example, they would generate
the same token value for distinct names such as "Maria" and "Marie."

**Match Approach Evaluation**

We tested four matching approaches to see how they performed relative to matching using identified data (Table 2).

**Single Token Match**

A matching strategy that leveraged multiple token types (Tokens 1, 2, 4, 5, and 16) to handle inconsistent fill rates yielded a balance of precision (97.0%) and recall (95.5%).

**Demographic**

Both Tokens 1 and 2 must match. While both Token 1 and Token 2 increase recall through fuzzy matching (just first initial is used in Token 1 and the Soundex^7 value is used for names in Token 2), when used together these tokens allow precision of 99.6% without sacrificing much recall compared with the individual tokens. A comparison of precision and recall using Token 4, which required exact match on first and last names, implies that soundex to first name was improved F1.

**Net Tokens**

The number of matching tokens must exceed the number of nonmatches when comparing the rest of the tokens available (essentially, majority rules). The advantage is that this approach considers all of the tokens available and is robust to varying fill rates. This approach performs well on precision (approaching 99.9%) though the recall was somewhat lower than other approaches at 75%.

**Social Security Number**

If the underlying SSN for each record is reliable, this algorithm yields high precision (99.5%) and good recall (90.9%).

**Hispanic Ethnicity**

Hispanic ethnicity is common in our cohort. People who identify as Hispanic are the second fastest-growing racial or ethnic group in the United States 2000 to 2019. Further, previous studies have compared algorithm performance on Hispanic versus non-Hispanic populations. Therefore, we divided the population into two distinct groups: at least one record in the pair was of Hispanic ethnicity versus neither record was of Hispanic ethnicity (or missing ethnicity data). Performance was generally similar across the two groups (Table 4), apart from lower recall for token types and algorithms that rely on first name match (exact or soundex): Token 2, demographic (which uses Token 2), and net tokens (which uses Tokens 2 and Token 4). From this, one may infer that there are more variants of the same patient’s first name in the dataset and that for this dataset, matching on Token 1, or using more permissive matching criteria such as single token match, yielded higher F1 scores. We have omitted precision and recall in cases with fewer than 50 true positive pairs as these results are not likely to be generalizable.

**Optimizing Matching using Different Tokens**

Using different tokens, either individually or in combination, changes the precision/recall tradeoff (Fig. 2).

**Discussion**

We found that a token-based matching system based on commonly available PII performed well. For use cases that require high precision, Token 5 (derived from SSN, gender, and DOB) had a precision of 99.7% and recall of 87.7%. For high recall, Token 1 (utilizing last name, first name, gender, and DOB) yielded a recall of 90.3% while maintaining

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*Table 2* Precision, recall, F1, and fill rates for the eight token types and algorithms tested in this evaluation

| Token or algorithm | True positives (TP) | False negatives (FN) | False positives (FP) | Precision | Recall | F1 | Valid pairs | Pair fill rate |
|--------------------|---------------------|----------------------|----------------------|-----------|-------|----|------------|----------------|
| Token 1            | 1,098               | 118                  | 24                   | 97.9%     | 90.3% | 94% | 20,002     | 100.00%        |
| Token 2            | 955                 | 259                  | 14                   | 98.6%     | 78.7% | 88% | 20,000     | 99.99%         |
| Token 4            | 787                 | 427                  | 1                    | 99.9%     | 64.8% | 79% | 20,000     | 99.99%         |
| Token 5            | 355                 | 50                   | 1                    | 99.7%     | 87.7% | 93% | 779        | 3.89%          |
| Token 7            | 1,076               | 138                  | 16                   | 98.5%     | 88.6% | 93% | 20,000     | 99.99%         |
| Token 9            | 271                 | 888                  | 2                    | 99.3%     | 23.4% | 38% | 18,163     | 90.81%         |
| Token 16           | 247                 | 157                  | 1                    | 99.6%     | 61.1% | 76% | 778        | 3.89%          |
| Token 22           | 476                 | 437                  | 2                    | 95.6%     | 52.1% | 67% | 13,603     | 68.01%         |
| Single Token Match | 1,161               | 55                   | 36                   | 97.0%     | 95.5% | 96% | 20,002     | 100.00%        |
| Demographic        | 925                 | 289                  | 4                    | 99.6%     | 76.2% | 86% | 20,000     | 99.99%         |
| Net Tokens         | 910                 | 304                  | 1                    | 99.9%     | 75.0% | 86% | 20,000     | 99.99%         |
| SSN                | 368                 | 37                   | 2                    | 99.5%     | 90.9% | 95% | 779        | 3.89%          |

Abbreviations: SSN, social security number.

^aRecall = TP/(TP + FN).

^bPrecision = TP/(TP + FP).

^cF1 = 2 [precision × recall] / [precision + recall].

Note: Token 3 is not listed because zip code was not included in the manual review data; therefore, the fill rate was 0%.
precision at 97.9%. Combinations of tokens can perform better than individual tokens. For example, single token match (at least one pair of Tokens 1, 2, 3, 4, 5, or 16 matches) yielded a precision of 97.0% and recall of 95.4%; performance remained high for pairs that included Hispanic ethnicity.

When missing PII fields are inconsistent across records, a multiple-token strategy is necessary. Based on matching results for individual tokens, one may also devise custom strategies, for example, in use cases where SSN is not present, one may rely on tokens derived from name, gender, and DOB.

Strengths of the study included a large, real-world, manually reviewed dataset based on 20,000 manually reviewed record pairs (i.e., 40,000 individual records). The manual review process is described in detail but includes multiple independent reviews for questionable cases, possibly decreasing errors. Previous real-world PPRL evaluations such as\textsuperscript{14,15} compared PPRL against “gold standard” matching that used unencrypted records (i.e., PPRL vs. non-PPRL). In contrast, our gold standard consisted of human-reviewed record pairs (i.e., absolute performance of PPRL). The large dataset, as well as the relatively high prevalence of Hispanic ethnicity (\textsuperscript{12,13}Table 3), allowed us to evaluate the effect of Hispanic ethnicity on match accuracy.

Our work has several limitations. First, our data were selected from a single academic health system and thus our results may not generalize to other settings. However, the Houston metropolitan area is arguably the most diverse in the country.\textsuperscript{16} Second, the manual review was limited by the available data. Thus, some errors may be undetected. As an example, infant twins are difficult to distinguish because they share many demographics including DOB, address, phone number, last name, etc., and may lack distinguishing data such as SSN. Third, we used a blocking strategy to create the dataset used for evaluation. We did this to ensure that the set contained matching records. However, it is possible that performance was altered by removing record pairs that were very unlikely to match. Since blocking eliminated “obvious” mismatches, including these cases would likely have improved performance. Finally, we did not exhaustively test all possible identifier combinations and relied upon Datavant software.

Previous studies found (or theorized) that Hispanic ethnicity was associated with lower match accuracy.\textsuperscript{12,13} In contrast, we found that Hispanic ethnicity was not consistently associated with lower recall or precision. Notably, Hispanic ethnicity is variably recorded in real-world EHR data. Ethnicity may be underreported\textsuperscript{12} and the ethnicity field is used inconsistently. We may have underrecognized Hispanic ethnicity. If so, then this would be expected to decrease the match accuracy of non-Hispanic record pairs. However, match accuracy remained high for both Hispanic and non-Hispanic record pairs.

Unlike matching systems that create a single patient ID for all datasets, the different precision and recall values of each token, or token combination, allow users to choose the best approach for their use case. Below we discuss different use cases.

**Cohort Identification (Recall > Precision)**

Examples include looking for patients with rare diseases or identifying locations with the most patients eligible for a clinical trial. In these cases, a user may decide to optimize recall to avoid missing any eligible patients, at the cost of
Table 4  Precision, recall, and fill rates for the token types and algorithms by ethnicity

| Token or algorithm | Ethnicity     | TP   | FN  | FP  | Valid pairs | Pair fill rate | Precision | Recall | F1  |
|--------------------|---------------|------|-----|-----|-------------|----------------|-----------|--------|-----|
| Token 1            | Not Hispanic  | 1,029| 110 | 23  | 13,890      | 69.44%         | 97.81%    | 90.34% | 94% |
|                    | Hispanic      | 69   | 8   | 1   | 6,112       | 30.56%         | 98.57%    | 89.61% | 94% |
| Token 2            | Not Hispanic  | 901  | 236 | 13  | 13,888      | 69.43%         | 98.58%    | 79.24% | 88% |
|                    | Hispanic      | 54   | 23  | 1   | 6,112       | 30.56%         | 98.18%    | 70.13% | 82% |
| Token 4            | Not Hispanic  | 744  | 393 | 1   | 13,888      | 69.43%         | 99.87%    | 65.44% | 79% |
|                    | Hispanic      | 34   | 0   |     | 6,112       | 30.56%         |          |        |     |
| Token 5            | Not Hispanic  | 334  | 48  | 1   | 673         | 3.36%          | 99.70%    | 87.43% | 93% |
|                    | Hispanic      | 2    | 0   |     | 106         | 0.53%          |          |        |     |
| Token 7            | Not Hispanic  | 1,007| 130 | 15  | 13,888      | 69.43%         | 98.53%    | 88.57% | 93% |
|                    | Hispanic      | 69   | 8   | 1   | 6,112       | 30.56%         | 98.57%    | 89.61% | 94% |
| Token 9            | Not Hispanic  | 259  | 827 | 0   | 12,428      | 62.13%         | 100.00%   | 23.85% | 39% |
|                    | Hispanic      | 61   | 2   |     | 5,735       | 28.67%         |          |        |     |
| Token 16           | Not Hispanic  | 233  | 148 | 1   | 672         | 3.36%          | 99.57%    | 61.15% | 94% |
|                    | Hispanic      | 9    | 0   |     | 106         | 0.53%          |          |        |     |
| Token 22           | Not Hispanic  | 449  | 411 | 18  | 9,334       | 46.67%         | 96.15%    | 52.21% | 68% |
|                    | Hispanic      | 26   | 4   |     | 4,269       | 21.34%         |          |        |     |
| Single token match | Not Hispanic  | 1,086| 53  | 34  | 13,888      | 69.43%         | 96.96%    | 95.35% | 96% |
|                    | Hispanic      | 75   | 2   | 2   | 6,112       | 30.56%         | 97.40%    | 97.40% | 97% |
| Demographic        | Not Hispanic  | 874  | 263 | 4   | 13,888      | 69.43%         | 99.54%    | 76.87% | 87% |
|                    | Hispanic      | 51   | 26  | 4   | 6,112       | 30.56%         | 100.00%   | 66.23% | 80% |
| Net tokens         | Not Hispanic  | 859  | 278 | 1   | 673         | 3.36%          | 99.88%    | 75.55% | 86% |
|                    | Hispanic      | 51   | 26  | 0   | 106         | 0.53%          | 100.00%   | 66.23% | 80% |
| SSN                | Not Hispanic  | 345  | 37  | 2   | 13,890      | 69.44%         | 99.42%    | 90.31% | 95% |

|                |                |     |     |     |             |               |           |       |     |
|                |                |     |     |     |             |               |           |       |     |

Abbreviations: FN, false negative; FP, false positive; SSN, social security number; TP, true positive.
Note: Token 3 is not listed because zip code was not included in the manual review data; therefore, the fill rate was 0%.

Fig. 2  Precision and recall of different matching strategies.
lower precision. The user might match on Token 1, or Token 5 or 16 if SSN is present.

**Cohort Analytics (Balanced Recall and Precision)**
For most analytics such as outcomes research, cost analysis, patient segmentation, drug adoption patterns, etc., it is important to have both a large sample and accurate matching. In such cases, the user might match on Token 4 alone or Token 1 and 2 together, either of the SSN-based tokens or single token match.

**Clinical Decision Support, Drug Safety, and Intervention (Recall < Precision)**
As real-world evidence is increasingly used to support drug approval decisions, risk stratification, and to recommend treatment, the underlying data must be accurate. In these cases, there is little tolerance for false-positive matches, and users may choose to optimize precision at the cost of recall. The user might match using Token 4, 5, or 16 alone, or using the net tokens match, or require all available tokens to match exactly. In contrast, drug safety monitoring may benefit from higher recall at the cost of precision to capture rare events.

**Conclusion**
Token-based matching systems can link deidentified patient records accurately. Using different token designs or combinations of tokens, users can adjust precision and recall to match their use cases.

**Clinical Relevance Statement**
Privacy-preserving record linkage (PPRL) is most commonly used in clinical research. Datavant tokens are used for National Institute of Health-sponsored multiinstitutional clinical trials and data-enabled research networks such as the Patient-Centered Outcomes Research Institute Clinical Data Research Networks. More direct clinical applications are possible such as those focusing on transitions of care across institutions and interinstitutional quality improvement projects. Health care consumers can use tokens to log into applications without revealing their identity.

**Multiple Choice Questions**
1. The token-based matching system used in this study:
   a. Requires all personally identifying information (PII) to be shared between institutions that wish to share data.
   b. Requires some PII to be shared between institutions that wish to share data.
   c. Requires PII to be shared with a trusted third party.
   d. Requires no PII to be shared and thus can be considered a form of privacy-preserving record linkage.

   **Correct Answer:** The correct answer is option d. Software used to create tokens is installed on premises; therefore, no PII needs to leave the institution.

2. The performance of token-based matching system used in this study:
   a. Is independent of the dataset.
   b. Depends on the distribution of clinical data such as vital signs, laboratory results and clinical notes.
   c. Depends on the distribution of demographic information.
   d. Depends on the speed of the processor used to calculate the token hashes.

   **Correct Answer:** The correct answer is option c. The tokens are created using one-way hash functions of demographic information. The distribution of the demographic information, therefore, determines the resulting output.

**Data Availability Statement**
The data underlying this article cannot be shared publicly due to the fact that these data are individually identifiable and represent real-world patients.

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**Conflict of Interest**
T.L., J.L., A.C., and A.Y. made contributions to this study while being employees of Datavant, Inc.

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