The Linkage of the 2021 National Ambulatory Medical Care Survey (NAMCS) Health Center (HC) Component to 2021-2022 National Death Index: Linkage Methodology and Analytic Considerations

Data Release Date: December 2, 2024

Document Version Date: February 3, 2025

Division of Analysis and Epidemiology,

National Center for Health Statistics,

Centers for Disease Control and Prevention

datalinkage@cdc.gov

Suggested Citation: National Center for Health Statistics. Division of Analysis and Epidemiology. *The Linkage of the 2021 National Ambulatory Medical Care Survey Health Center Component to 2021-2022 National Death Index: Linkage Methodology and Analytic Considerations*, FEBRUARY 2025. Hyattsville, Maryland. Available at the following address: https://www.cdc.gov/nchs/data/datalinkage/NAMCS-HC-NDI-Methodology-Analytic-Considerations.pdf

Contents

List of Acronyms

DOB, date of birth

EHR, electronic health record

E-M, expectation-maximization

ERB, Ethics Review Board

FQHC, Federally Qualified Health Centers

HC, Health Center

JW, Jaro-Winkler

NAMCS, National Ambulatory Medical Care Survey

DHCS, Division of Health Care Statistics

NCHS, National Center for Health Statistics

NDI, National Death Index

PII, personally identifiable information

PW, pair weight

RDC, Research Data Center

SSN, Social Security number

1 Introduction

As the nation's principal health statistics agency, the mission of the National Center for Health Statistics (NCHS) is to provide statistical information that can be used to guide actions and policy to improve the health of the American people. In addition to collecting and disseminating the Nation's official vital statistics, NCHS conducts several population-based surveys and healthcare establishment surveys, including the National Ambulatory Medical Care Survey (NAMCS) (accessed August 2024).In 2021 the National Ambulatory Medical Care Survey (NAMCS) began collecting electronic health records (EHRs) for ambulatory care visits that took place in health centers, known as the NAMCS Health Center (HC) Component. Even though the NAMCS HC Component is a provider survey (i.e., health centers are the sampling unit) it collects patient level personally identifiable information (PII), which enable data linkages.

Through its Data Linkage Program, NCHS has been able to expand the analytic utility of the NAMCS HC Component data by linking the patient level data with death certificate data collected from the National Death Index (NDI). This report will describe the linkage of the 2021 NAMCS HC Component to the 2021-2022 NDI. The linkage of the NAMCS HC Component patient data with mortality information creates a new data resource that can support a wide array of public health surveillance and policy evaluation studies.

This report includes a brief overview of the linked data sources, a description of the methods used for linkage, and analytic guidance to assist researchers when using the files. Detailed information on the linkage methodology is provided in Appendix I: Detailed Description of Linkage Methodology.

The linkage of the 2021 NAMCS HC Component and the 2021-2022 NDI mortality data was performed at NCHS through contract #HHS75D30123A17667 by NORC at the University of Chicago with funding from the Department of Health and Human Services' Office of the Secretary Patient-Centered Outcomes Research Trust Fund (OS-PCORTF) under a project titled "Enhancing Surveillance of Maternal Health Clinical Practices and Outcomes with Federally Qualified Health Centers' (FQHCs) Electronic Health Records Visit Data."

2 Background on Linked Files

2.1 National Ambulatory Medical Care Survey (NAMCS) Health Care (HC) Component

The National Ambulatory Medical Care Survey (NAMCS), administered by NCHS, is a national survey designed to meet the need for objective, reliable information about the provision and use of ambulatory medical care services in the United States. First fielded in 1973, NAMCS is one of the NCHS National Healthcare Surveys, a family of surveys that are provider-based, covering a broad spectrum of health care settings (https://www.cdc.gov/nchs/dhcs/index.htm) (accessed August 2024). In 2012, NCHS added a separate national sample of community health centers to NAMCS in order to produce nationally representative estimates on health center provided ambulatory care services. Beginning in 2021, NCHS developed a more targeted NAMCS Health Center (HC) Component sampling frame to focus on the collection of Electronic Health Records (EHR) for all patient visits within a sampled HC. Sampled health centers include both Federally Qualified Health Centers (FQHCs)[1] and FQHC look-alikes[2] in the 50 U.S. states and the District of Columbia, which provide ambulatory (or direct outpatient) care to the public and use an EHR system in one or more of their delivery sites.[3]

[1] Federally Qualified Health Centers (FQHCs) are health centers that receive funding from the Department of Health and Human Services' Health Resources and Services Administration (HRSA) to deliver comprehensive and affordable primary healthcare services to the nation's most vulnerable populations, including people experiencing homelessness, agricultural workers, residents of public housing, and veterans.
[2] FQHC look-alikes are health centers that meet the HRSA Health Center Program requirements but do not receive HRSA funding.
[3] More detailed information about the 2021 NAMCS sampling procedures are available at: Williams SN, Ukaigwe J, Ward BW, Okeyode T,

Participating health centers were asked to submit electronic health record (EHR) data for all patient encounters in calendar year 2021. These data included patient identifiers such as name, address, and social security number when it is available; date of visit; diagnoses and services provided or ordered during the visit; reason for visit; and clinical notes. In calendar year 2021, 29 of the 111 sampled health centers submitted data on 3,543,927 patient visits from January 1, 2021 to December 31, 2021, for an unweighted response rate of 26.1% and a weighted response rate of 26.8%. The 2021 NAMCS HC Component data are weighted and can be used to produce nationally representative estimates for visits at FQHCs.[4] However, due to the low response rate in 2021, NCHS did not release a public use file for the 2021 NAMCS HC Component, but rather made the 2021 NAMCS HC Component data available for research via the NCHS Research Data Center Network. More information about the research data files available for the 2021 NAMCS HC Component can be found here: 2021 National Ambulatory Medical Care Survey Health Center Component RDC Data Dictionary (cdc.gov) (accessed August 2024).

2.2 National Death Index (NDI)

The NDI is a centralized database of United States death record information on file in state vital statistics offices. Working with these state offices, NCHS established the NDI as a resource to aid epidemiologists and other health and medical investigators with their mortality ascertainment activities. The NDI became operational in 1981 and includes death record information for persons dying in the U.S. or a U.S. territory from 1979 onward.[5] The records, which are compiled annually, include detailed information on the underlying and multiple causes of death.

3 Linkage Methodology

3.1 Linkage Eligibility Determination

The linkage of NAMCS HC Component patient records to NDI data was approved by NCHS's Research Ethics Review Board (ERB).[6]

Linkage was attempted only for NAMCS HC Component patient records that had at least two of the following three identifiers present:

- valid SSN[7]
- valid date of birth (month, day, and year)[8]
- valid name (first, middle initial, and last)[9]

For example, if the PII on the NAMCS HC Component patient record had no SSN, a full name, and only the year of birth, the record would be considered ineligible for linkage, as only one of the criteria (i.e., that for name) was met.

himizu IM. Sampling procedures for the collection of electronic health record data from federally qualified health centers, 2021–2022 National Ambulatory Medical Care Survey. National Center for Health Statistics. Vital Health Stat Series 2(203). 2023.

[4] More detailed information on producing weighted analyses based on the 2021 NAMCS HC Component data is available at: https://www.cdc.gov/rdc/data/b1/2021-NAMCS-HCC-RDC-Data-Dictionary-508.pdf.

[5] https://www.cdc.gov/nchs/ndi/index.htm (Accessed August 2024).

[6] The NCHS ERB is an appointed ethics review committee that is established to protect the rights and welfare of human research subjects.

[7] Nine-digit SSN is considered valid if: 9-digits in length, containing only numbers, does not begin with 000, 666, or any values after 899, all 9-digits cannot be the same (i.e., 111111111, etc.), middle two and last 4-digits cannot be 0's (i.e., xxx-00-xxxx or xxx-xx-0000), and digits are not consecutive (ex. 012345678). Additionally, special SSN values (i.e., 123-123-1234, 111-22-3333, 010-010-0101, 001-01-0001, etc.) were changed to missing. Four-digit SSN is considered valid if: 4-digits in length, containing only numbers, and is between 0001 and 9999.

[8] A date of birth is considered valid if at least two of the three date parts are valid date values.

[9] A name is considered valid if: either first or last name has two or more characters, and two of the three name parts (first, middle initial, and last) are non-missing.

The variable ELIGSTAT, included on the linked NAMCS HC Component -NDI mortality variables file, provides the linkage eligibility status for each NAMCS HC Component patient record: ELIGSTAT values include 0 (ineligible) or 1 (eligible). The 2021 NAMCS HC Component included 726,384 (99.9%) patients who were determined to be eligible for linkage with NDI data.

3.2 Overview of Linkage

This section outlines steps that were used to link the 2021 NAMCS HC Component data to 2021-2022 NDI data. The linkage was conducted at a patient level using patient identifiers collected from health center submitted patient visit records. The patient identifiers collected from the visit records were used to link NDI mortality records for NAMCS HC Component patients who died any time after a 2021 health center visit through the end of the 2022 calendar year. For more detailed information on linkage methodology see Appendix I: Detailed Description of Linkage Methodology.

Prior to linkage, NCHS conducted an assessment of the 2021 NAMCS HC Component Patient PII. The results of the assessment have been provided in Appendix II: Assessment of the 2021 NAMCS HC Component Patient Identification Variables.

Linkage-eligible NAMCS HC Component patient records were linked to the NDI using the following identifiers: SSN, first name, last name, middle initial, month of birth, day of birth, year of birth, state of residence, and sex.

The NAMCS HC Component patient records and the NDI were linked using both deterministic and probabilistic approaches. For the probabilistic approach, scoring was conducted according to the Fellegi-Sunter method.[10] Following this, a selection process was implemented with the goal of selecting pairs that represented the same individual between the two data sources. It is important to note that both deterministic and probabilistic linkages were conducted separately for each sex category (males and females). That is, records on the NAMCS HC Component and NDI linkage submission files were first separated using the recorded sex value and then each set of files were separately linked.[11] The Fellegi-Sunter method assumes independence between the agreement status of variables used to score the records. Because first names are commonly associated with sex, running the linkage separately by sex ensures independence and enables more appropriate weighting of name comparisons when using the methods described by Fellegi-Sunter. [12] The following steps were implemented:

1. Separate NAMCS HC Component and NDI submission files using sex. NDI submission records were further restricted to the linkage period (i.e., 2021-2022, thus removing NDI records with missing year of death).
2. Deterministic linkage joined records on exact SSN and validated links by comparing other identifying fields (i.e., first name, last name, day of birth, etc.)
3. Probabilistic linkage identified likely matches, or links, between all records. All records were probabilistically linked and scored as follows:
    a. Formed pairs via blocking
    b. Scored pairs
    c. Modeled probability - assigned estimated probability that pairs are links
4. Pairs were selected that were believed to represent the same individual between data sources (i.e., they are a match).

[10] Fellegi, I. P., and Sunter, A B. (1969), "A Theory for Record Linkage," JASA 40 1183-1210.
[11] Before the submission records were separated, alternate submission records (see Appendix I, section 1) with an imputed sex value of male and female were created for records with missing sex.
[12] First names are often sex specific (i.e., first name Robert is usually associated with males and Mary is usually associated with females). Additionally, multiple part first and last names are more likely to be associated with females, which are handled differently when creating the linkage submission file. See Table 2 in Appendix I, Section 1 for additional information on the alternate record generation process for multiple part names.

a. Deterministic matches (from step 2) were assigned a match probability of 1
b. Record pairs selected from the probabilistic match (step 3) were assigned the model match probability. Record pairs with a match probability above the probability cut-off value were determined to be matches.

Table 1 presents the total number of 2021 NAMCS HC Component patients by age group and sex, the number who were eligible for linkage, the number who were linked to NDI data, and the percentage of all patients and those eligible for linkage who were linked to NDI data.

Table 1. Linked 2021 NAMCS HC Component and 2021-2022 NDI Mortality Records: Sample Sizes and Percent Linked, by Age and Sex

2021 NAMCS HC Component	Sample Size Total Sample	Sample Size Eligible for Linkage[2]	Sample Size Linked to 2021-2022 NDI[3]	Percent Linked Total Sample[4]	Percent Linked Eligible Sample[5]
Age[1]					
0-17	185,959	185,958	92	0.05	0.05
18-44	271,293	271,290	1,073	0.40	0.40
45-64	183,993	183,993	3,052	1.66	1.66
65 and over	85,138	85,137	5,046	5.93	5.93
Not Calculated	849	6	1	0.12	16.67
Total	727,232	726,384	9,264	1.27	1.28
Sex					
Male	309,817	309,815	4,929	1.59	1.59
Female	414,112	414,109	4,283	1.03	1.03
Missing	3,303	2,460	52	1.57	2.11
Total	727,232	726,384	9,264	1.27	1.28

[1] Age is as of date of death or final health center visit for patients not linked to the NDI. Age is calculated by subtracting patient date of birth (DOB) from either date of death or final visit date. When more than one DOB was present, the minimum of the non-missing DOB was selected.

[2] Eligibility for linkage is based upon having sufficient PII in at least two of three data element groups: SSN, name, and date of birth.

[3] This group includes linkage-eligible patients who linked to the NDI at any time during the linkage interval (2021-2022).

[4] This percentage is calculated by dividing the number of linked patients by the number of patients in the total sample.

[5] This percentage is calculated by dividing the number of linked patients by the total number of linkage-eligible patients.

4 Analytic Considerations

This section summarizes some key analytic issues for users of the linked 2021 NAMCS HC Component data and 2021-2022 NDI data. It is not an exhaustive list of the analytic issues that researchers may encounter while using the linked NAMCS HC Component-NDI data. This document will be updated as additional analytic issues are identified and brought to the attention of the NCHS Data Linkage Team (datalinkage@cdc.gov).

4.1 Analytic Considerations for NAMCS HC Component Data

4.1.1 2021 NAMCS HC Component Restricted-Use Files (RUF)

The 2021 NAMCS HC Component restricted-use survey data are made available for research use through the NCHS RDC network. For more information about obtaining access to NAMCS HC Component RUFs see Section 5.0. The NAMCS HC Component RUFs are organized as relational data tables organized by Visits, Patients, Conditions, Procedures and Weights. For more information about the specific variables and the observational unit for each data table please see the NAMCS HC Component data documentation available at: https://www.cdc.gov/rdc/data/b1/2021-NAMCS-HCC-RDC-Data-Dictionary-508.pdf.

During the 2021 NAMCS data collection period some health centers did not provide certain data elements for any of their reported visits. NCHS has provided detailed analytic guidance on how users should adjust their analysis of NAMCS HC Component data to account for complete missing data. More detailed information on methods to adjust for data missingness in the NAMCS HC Component survey data are available at: https://www.cdc.gov/rdc/data/b1/2021-NAMCS-HCC-RDC-Data-Dictionary-508.pdf.

4.1.2 Using 2021 NAMCS HC Component Visit Weights

The Division of Health Care Statistics (DHCS), NCHS, has produced visit weights that can be used to produce nationally representative estimates of ambulatory care visits occurring in Federally Qualified Health Centers.[13] For more detailed information regarding producing weighted estimates with NAMCS HC Component data please see: https://www.cdc.gov/rdc/data/b1/2021-NAMCS-HCC-RDC-Data-Dictionary-508.pdf

The linkage between the 2021 NAMCS HC Component data and NDI mortality data was conducted at a patient level using patient identifiers collected from health center submitted patient visit records. The patient identifiers collected from the visit records were used to link NDI mortality records for NAMCS HC Component patients who died any time after a 2021 health center visit through the end of the 2022 calendar year. Although DHCS has developed visit level weights for use with the NAMCS HC Component visit data, patient level weights for use with linked mortality data are not available.

4.2 Analytic Considerations for Linked NDI Data Files

4.2.1 Description of Linked NAMCS HC Component-NDI Data Files

4.2.1.1 Mortality Variables File

The linked Mortality Variables file can be used to identify which of the NAMCS HC Component patients were eligible for NDI linkage (ELIGSTAT) and those linked to an NDI record (MORTSTAT). This file contains one record for each unique NAMCS HC Component patient ID. NAMCS HC Component patient IDs with an ELIGSTAT value of

[13] Sampled NAMCS health centers include both Federally Qualified Health Centers (FQHCs) and FQHC look-alikes. FQHC look-alikes are health centers that meet the HRSA Health Center Program requirements but do not receive HRSA funding.

1 were considered eligible for NDI linkage and a MORTSTAT value 1 indicates the patient is considered deceased. The variable AGEDEATH provides the age at death for deceased NAMCS HC Component patients. For NAMCS HC Component patients who were not linked to an NDI record, variable AGEPRALV provides the age when the NAMCS HC Component patient was last presumed to be alive, which is calculated by subtracting date of birth from the end of the survey year (i.e., December 31, 2021). Underlying and multiple cause of death codes coded from the death certificate are provided for patients linked to the NDI.[14] More detailed information is available at https://www.cdc.gov/nchs/data/datalinkage/NAMCS-HC-Codebook-Mortality-Variables.pdf.

4.2.1.2 Death Certificate and NDI Match Variables File

The linked Death Certificate and NDI Match Variables file provides more detailed death certificate information including information on the county and state where the death occurred. This information can be used to link contextual information for analytic purposes.

This file also contains information on the estimated probability of match validity (PROBVALID). An estimated probability of match validity was computed for each candidate pair and compared against a probability cut-off value to determine which pairs were links (an inferred match). For additional discussion on how PROBVALID was estimated, see Appendix I – Detailed description of linkage methodology, Sections 3.3 and 3.4. NCHS used a probability cut-off value which minimized the total estimated counts of Type I error (false positive links – identified as deceased but actually alive) and Type II error (false negative links – identified as alive but actually deceased).

In the 2021 NAMCS HC Component – 2021-2022 NDI linkage, NCHS used a probability cut-off value of 0.85 to determine final match status. Candidate pairs with a PROBVALID that exceeded the probability cut-off (i.e., PROBVALID>0.85) were considered linked. For additional discussion on probability cut-off value determination and record selection, please see Appendix I, Section 4. For some analyses, it may be desirable to reduce the Type I error. To do this, researchers should increase the probability cut-off value to a value closer to 1.0. Researchers wishing to increase the probability cut-off value should request PROBVALID in their RDC proposal. Note, the probability cut-off value cannot be decreased from 0.85 as pairs estimated with lower match probability are not made available to researchers.

In addition, individual agreement weight (pair weights components) variables are available to researchers that indicate the level of agreement among the matching variables. The total pair weight, PAIRWGT, is the sum of the partial E-M adjustment factor (see Appendix I, section 3.3) and the eight pair weight components:

- First Name or First Initial (WGT_FIRST_NAME)
- Middle Initial (WGT_MIDDLE_NAME)
- Last Name or Last Initial (WGT_LAST_NAME)
- Year of Birth (WGT_DOB_YEAR)
- Month of Birth (WGT_DOB_MONTH)
- Day of Birth (WGT_DOB_DAY)
- State of Residence (WGT_STATE_RES)
- Last 4-digits of SSN (WGT_SSN4)

Each pair weight component represents a specific identifier comparison. These component values are also available to researchers upon request in their RDC proposal. For more information on how the pair weight components are calculated, refer to the methodology in Appendix I, Section 3.2. When looking at the eight component pair weights simultaneously, researchers can evaluate which identifier agreements were most indicative of being a match and which identifier non-agreements were most indicative of not being a match.

[14] Less than 0.1% of the NAMCS HC Component patients that linked were missing cause of death information on the NDI.

Mortality and death certificate variables are provided for all patients who linked to an NDI record (i.e., MORTSTAT=1). More detailed information is available at https://www.cdc.gov/nchs/data/datalinkage/NAMCS-HC-Death-Certificate-and-NDI-Match-Variables.pdf.

5 Access to Data Files

5.0 Access to the Restricted-Use Linked NAMCS HC Component – NDI Files

To ensure confidentiality, NCHS provides safeguards including the removal of all personal identifiers from analytic linked files. Additionally, the linked data files are only accessible through the NCHS Research Data Center (RDC) network for approved research projects. Researchers who wish to access the restricted-use 2021 NAMCS HC Component restricted-use survey files and the linked 2021 NAMCS HC Component-NDI data files must submit a research proposal application to the NCHS Research Data Center (RDC). The RDC staff will review all submitted proposals to determine if the proposed project is feasible and to identify any potential disclosure risks. More information regarding the NCHS RDC network and the RDC proposal application process are available from: https://www.cdc.gov/rdc/ (accessed August 2024).

5.1 Merging NAMCS HC Component Survey Data to the Linked NAMCS HC Component-NDI Files

The linkage between the 2021 NAMCS HC Component data and NDI mortality data was conducted at a patient level using patient level identifiers. The shared variable, PATIENT_ID, will be used by the RDC to merge the linked 2021 NAMCS HC Component – NDI mortality files with the restricted-use 2021 NAMCS HC Component data. Analysts should request all variables of interest from the 2021 NAMCS HC Component restricted-use data files and the linked 2021 NAMCS HC Component – NDI mortality files in their RDC proposal.

5.2 Additional Related Data Sources

The linkage of the 2021 NAMCS HC Component patient data with NDI mortality data was conducted with funding support from the Department of Health and Human Services' Office of the Secretary Patient-Centered Outcomes Research Trust Fund (OS-PCORTF). OS-PCORTF is also supporting the linkage of the 2021 NAMCS HC Component data with HUD housing assistance program data obtained through linkage with the U.S. Department of Housing and Urban Development and Medicaid and Children's Health Insurance Program Data obtained through linkage with the Transformed Medicaid Statistical Information System (T-MSIS) from the Centers for Medicare & Medicaid Services (CMS). More information about these linked data files will be published at https://www.cdc.gov/nchs/data-linkage/index.htm (accessed August 2024).

Appendix I: Detailed Description of Linkage Methodology

1 2021 NAMCS HC Component and NDI Mortality Submission Files

A linkage submission file is a dataset created for conducting linkages between two sources of data. Linkage submission files, which contained the cleaned and validated PII fields, were created separately for NAMCS HC Component patient records and for NDI administrative records. The following PII fields were individually processed and output to separate files (i.e., there were separate files for SSN, DOB, name, etc., each record showing a possible value for that field for each NAMCS HC Component patient or NDI decedent:

- SSN (validated)[15]
- DOB (month, day, and year)
- NDI DOD (month, day, and year)[16]
- Sex
- State of residence
- First, middle initial, and last name[17]

Identifier values deemed invalid by the cleaning and standardization routine were changed to a null value. A few examples where this occurred include:

- Date values: when invalid or outside of expected range
- Sex values: when multiple sex values are recorded for the same person
- Name values: multiple edits are applied:
  - Removal of special characters such as [“-.,<>/?, etc.]
  - Removal of descriptive words such as twin, brother, daughter, etc.
  - Nulling of baby names—name parts that contain specific keywords such as baby, infant, girl or boy are set to null
  - Names listed as Jane/John Doe
  - Removal of titles such as Mister, Miss, etc.
  - Removal of suffixes such as Junior, II, etc.
  - Removal of special text such as first name listed as “Void”

To increase the likelihood of finding a link, multiple or alternate submission records could be generated for each linkage eligible record in the NAMCS HC Component patient and NDI submission files based on variation of the linkage variables. Similar to the cleaning process, a more elaborate routine was used to generate alternate records involving the name fields. Alternate records were generated according to the following rules.

- Sex was missing. Two alternate records (one with male sex and the other with female) were created (note that this would result in having generated records run through both male and female specific linkage passes, and resulting duplicated links would be subsequently resolved.
- SSN with less than nine digits. A single alternate record was created where leading zeros were added to SSN values of length 7 or 8 to make a 9-digit SSN. Note, no alternate record was created if an invalid SSN

[15] Nine-digit SSN is considered valid if: 9-digits in length, containing only numbers, does not begin with 000, 666, or any values after 899, all 9-digits cannot be the same (i.e., 111111111, etc.), middle two and last 4-digits cannot be 0’s (i.e., xxx-00-xxxx or xxx-xx-0000), and digits are not consecutive (ex. 012345678). Additionally, special SSN values (i.e., 123-123-1234, 111-22-3333, 010-010-0101, 001-01-0001, etc.) were changed to missing. Four-digit SSN is considered valid if: 4-digits in length, containing only numbers, and is between 0001 and 9999.

[16] NDI administrative records with a missing year of death were removed from the submission file.

[17] The NDI administrative data included father’s surname which, when different from the recorded last name, were treated as an alternate last name that was used to create an alternate NDI submission record.

would be created by adding 0's.

- Improbable date of birth. Age at time of survey/time of death (NDI) was computed by subtracting the year of the survey/death and the year of birth. Records with age greater than 114 had a single alternate record created,
  - If month and day were suspected of being imputed (ex. Jan 1st or June 15th), entire DOB was changed to missing[18]
  - Otherwise, only year was changed to missing
- State of residence outside of U.S. and not in rest of world (RW) list. Alternate record was created with state code changed to missing
- Multiple name parts and common nicknames (see below)

NCHS created a common nickname lookup file which was used to generate a second record replacing the nickname with the associated formal name. Similarly, multiple part names (first or last) are addressed by creating alternate name records. Table 2 below provides three examples of how alternate records were generated for nick names (Patient ID 1) and multiple part names (Patient ID 2 & 3), using hypothetical patient data. For patient 2, the first name was used to generate multiple records, and for patient 3, the last name was used.

Table 2. Example of Alternate Record Generation using Name Fields

Patient ID	First Name	Middle Initial	Last Name	Alternate Record
1	Beth	A	Roberts	0
1	Elizabeth	A	Roberts	1
2	Mary Ann		Davis	0
2	Mary	Ann	Davis	1
2	Ann		Davis	1
2	Mary		Davis	1
3	Patricia	R	Drew-Hamilton	0
3	Patricia	R	Drew	1
3	Patricia	R	Hamilton	1

NOTES: The information presented in the table was fabricated to illustrate the applied approach.

Submission files, which combined the cleaned and validated PII fields, were created separately for NAMCS HC Component patient records and for NDI administrative records. During this process, multiple submission records were created for each patient/decedent to show all combinations of the recorded values for these fields. That is, if a patient/decedent had two states-of-residence recorded and three dates-of-birth recorded and each of the remaining fields had only one variant, then a total of six submission records would have been created for the patient/decedent (see Table 3 for example). Submission records that did not meet the eligibility requirements (see Section 3.1 Linkage Eligibility Determination) were removed from the submission file.

[18] Note, the date values are often recorded when the actual value is unknown.

Table 3. Example of Alternate Records Caused by Different PII Values

Patient ID	Day of Birth	Month of Birth	Year of Birth	State of Residence
1	31	12	1999	PA
1	30	12	1999	PA
1	15	12	1999	PA
1	31	12	1999	NY
1	30	12	1999	NY
1	15	12	1999	NY

NOTES: Data have been fabricated for this example. Other PII fields not shown as they are the same across all records.
PII – Personally Identifiable Information.

Additional post processing steps were taken after the initial 2021 NAMCS HC Component and NDI linkage submission files were created. First, records from both the NAMCS HC Component and NDI submission files were separated according to the sex value (male or female). As mentioned in section 3.2, the probabilistic linkage method assumes independence between the PII variables used to score the potential links. Records in the submission files were separated by sex to avoid violating this assumption, especially when first and/or last name and sex would be used as blocking and/or scoring variables. Additionally, the NDI submission file is limited to records with a date of death between January 1, 2021 and December 31, 2022. This step was taken to reduce the computational burden of linking records that will ultimately be rejected because they occur outside of the 2021-2022 linkage period.

2 Deterministic Linkage Using Unique Identifiers

The deterministic linkage, which was the next step in the linkage process, used only the NAMCS HC Component and NDI submission records that included a valid SSN. The algorithm performed two passes on the data, the first pass joining records when all 9-digits of the SSN matched and then for records where the last four digits of the SSN matched. Further, records in the 2nd pass had to have a non-missing first or last name **AND** a non-missing date of birth part (month, day, or year) to be eligible for deterministic matching using the last 4 of SSN. After records had been linked using SSN, the algorithm validated the deterministic links by comparing first name, middle initial, last name, month of birth, day of birth, year of birth, and state of residence. If the ratio of agreeing identifiers to non-missing identifiers was greater than 50% (1st pass using SSN-9) or greater than 2/3 (2nd pass using last 4 of SSN), the linked pair was retained as a deterministic match. In addition to the 2/3's agreement ratio, linked pairs in the 2nd pass were required to have at least first or last name in agreement to be deemed a deterministic match. Of note, NAMCS HC Component patients were excluded from the second pass (i.e., using the last 4-digits of SSN) if they were deterministically linked in the first pass. Additionally, deterministically linked records were excluded if the NAMCS HC Component Patient linked to more than 1 NDI death record or if the NDI date of death occurred more than three days before the last visit date on the NAMCS HC Component. The collection of records resulting from the deterministic match is referred to as the 'truth source.'

3 Probabilistic Linkage

The second step in the linkage process was to perform the probabilistic linkage for all records. To infer which pairs are links, the linkage algorithm first identified potential links and then evaluated their probable validity (i.e., that they represent the same individual). The following sections describe these steps in detail. The weighting procedure of this linkage process closely followed the Fellegi-Sunter paradigm, the foundational methodology used for record linkage. Based on Fellegi-Sunter, each pair was assigned an estimated probability representing the likelihood that it is a match – using pair weights computed (according to formula) for each identifier in the pair – before selecting the most probable match between two records.

3.1 Blocking

Blocking is a key step in the probabilistic record linkage process. It identifies a smaller set of potential candidate pairs, eliminating the need to compare every single pair in the full comparison space (i.e., the Cartesian product). According to Christen, blocking or indexing, "splits each database into smaller blocks according to some blocking criteria (generally known as a blocking key)."[19] Intuitively developed rules can be used to define the blocking criteria, however, for this linkage, variable values in the data being linked were used to inform the development of a set of blocking passes that efficiently join the datasets together (i.e., multiple, overlapping blocking passes are run, each using a different blocking key). By using these data to create an efficient blocking scheme (or set of blocking passes), a high percentage of true positive links were retained while the number of false positive links were significantly reduced. A supervised machine learning algorithm used the 'truth source' (see Appendix I section 2) as the validation dataset and the NAMCS HC Component and NDI submission records as training data. For more detailed information on the supervised machine learning algorithm used, please refer to "Learning Blocking Schemes for Record Linkage" and "Using supervised machine learning to identify efficient blocking schemes for record linkage".[20] [21]

The machine learning algorithm produced 5 blocking passes to be used in the blocking scheme. Table 4 provides the PII variables that were assigned to each of the blocking passes and the PII variables that were used to score the potential links in each of the blocking passes. Note, the variables listed in the scoring key are all PII variables not used as a blocking variable.

Table 4. Blocking and Scoring Scheme Used to Identify and Score Potential Links

Key Number	Blocking Key	Scoring Key
1	First name, month of birth, day of birth, year of birth	Middle initial, last name, state of residence
2	Month of birth, day of birth, year of birth, state of residence	First name, middle initial, last name
3	Last name, month of birth, year of birth	First name, middle initial, day of birth, state of residence
4	First name, day of birth, month of birth, state of residence	Middle initial, last name, year of birth
5	Last name, day of birth, month of birth, state of residence	First name, middle initial, year of birth

[19] Christen, Peter. Data Matching: Concepts and Techniques for Record Linkage, Entity Resolution, and Duplicate Detection. Data-Centric Systems and Applications. Berlin Heidelberg: Springer-Verlag, 2012. http://www.springer.com/us/book/9783642311635 (accessed August 2024).

[20] Michelson, Matthew, and Craig A. Knoblock. "Learning Blocking Schemes for Record Linkage." In Proceedings of the 21st National Conference on Artificial Intelligence - Volume 1, 440–445. AAAI'06. Boston, Massachusetts: AAAI Press, 2006. https://pdfs.semanticscholar.org/18ee/d721845dd876c769c1fd2d967c04f3a6eeaa.pdf (accessed August 2024).

[21] Campbell, S. R., Resnick, D. M., Cox, C. S., & Mirel, L. B. (2021). Using supervised machine learning to identify efficient blocking schemes for record linkage. Statistical Journal of the IAOS, 37(2), 673–680. https://doi.org/10.3233/SJI-200779 (accessed August 2024).

3.2 Score Pairs

Next, each pair within a given block was scored using an approach based on the Fellegi-Sunter paradigm. The Fellegi-Sunter paradigm specifies the functional relationship between agreement probabilities and agreement/non-agreement weights for each identifier used in the linkage process. The scores – pair weights – calculated in this step were used in a probability model (explained in Section 3.3), which allowed the linkage algorithm to select final links to include in the linked file. The scoring process followed the order below:

1. Calculate M- and U- probabilities (defined in Section 3.2.1)
2. Calculate agreement and non-agreement weights
3. Calculate pair weight scores

The pair scores were calculated on the agreement statuses of the following identifiers (excluding specifically the variables used to define each block—e.g., if blocking is by first name and last name, then neither were used to evaluate the pairs generated by the block):

- First Name or First Initial (when applicable)
- Middle Initial
- Last Name or Last Initial (when applicable)
- Year of Birth
- Month of Birth
- Day of Birth
- State of Residence

Except for first and last name, agreement status was set to 1 if the NAMCS and NDI values for a particular PII variable agreed exactly, 0 if they disagreed, and missing (i.e., '.') if either value was missing on the paired records. The agreement status assignment for first and last name is explained further in section 3.2.2 of this appendix.

3.2.1 M and U Probabilities

The M-probability is the probability that the identifiers on a pair of records agree, given that records represent the same person (i.e., the records are a match). M-probabilities were estimated separately within each individual blocking pass and were calculated for each of the identifiers used for scoring (Table 4). Within the blocking pass, pairs with agreeing SSN were used to calculate the M-probabilities, as these are assumed to represent the same individual. SSN agreement was defined as having 8 or more digits being the same for pairs with a full 9-digit SSN or the last 4-digits being the same for pairs with only a 4-digit SSN (ex. XXXXX9999). Further, to account for the alternate submission records generated during the creation of the submission files, the "best" agreement was taken for each of the scoring variables among the blocked records for each NAMCS HC Component patient ID and NDI ID (see Tables 5 and 6 for example of alternate record summarization). Table 5 is an example of how the agreement flags for each of the scoring variables in Blocking pass 1 are created. A value of 1 means the information in the variable is exactly matching, while a 0 means they are not. Table 6 then represents how the multiple submission records in Table 5 are summarized into one record for each NAMCS HC Component patient ID and NDI administrative ID. If any of the identifiers agree across multiple records, they are flagged as agree (i.e., set to 1). The summarized records in Table 6 are then used to estimate the M-probabilities for each of the specific scoring variables.

Table 5. Example of Agreement Flags Using Blocking Pass 1

Person Identifiers Patient ID	Person Identifiers NDI Key	PII Agreement flags[1] Middle Initial	PII Agreement flags[1] Last Name	PII Agreement flags[1] State of residence
1	1	1	0	.
1	1	.	1	0
1	1	1	0	0
2	2	1	0	0
3	789	1	1	1
3	789	0	1	1
3	789	.	1	.
3	789	0	0	1
3	322	1	0	1

NOTES: Data have been fabricated for the purposes of this example. PII – Personally Identifiable Information.
[1] Agreement status of 1 = match, 0 = non-match, and . = missing values

Table 6. Example Showing Summarization of Blocked Record Pairs for M-Probability Estimation, based on Table 5 example

Person Identifiers Patient ID	Person Identifiers NDI Key	PII Agreement flags[1] Middle Initial	PII Agreement flags[1] Last Name	PII Agreement flags[1] State of residence
1	1	1	1	0
2	2	1	0	0
3	789	1	1	1
3	322	1	0	1

NOTES: Data have been fabricated for the purposes of this example. PII – Personally Identifiable Information.
[1] Agreement status of 1 = match, 0 = non-match, and . = missing values

Several additional comparison measures were created for first and last name identifiers in the calculation of M-probabilities:

- First/last initial agreement – used in the scoring process when only an initial was present in one or more of values (i.e., one from each of the two records being compared for a specific name variable
- Jaro-Winkler Similarity Levels – this process is explained in greater detail in Section 3.2.2

The U-probability is the probability that the two values for an identifier from paired records agreed given that they were NOT a match. Similar to the M-probabilities, U-probabilities were calculated only for the PII variables not included in the blocking keys and with the exception of first and last names, were computed within the blocking pass. The U-probabilities were computed using records where non-missing SSNs were not in agreement (defined as having less than 5 matching digits when records had a full 9-digit SSN and less than 4 matching digits for records with a 4-digit SSN). In order to avoid skewing U-probabilities in blocking passes that contained a high percentage of deterministic matches, assumed matches (i.e., records where SSN was not in agreement and had majority of the non-missing PII among scoring variables in agreement) were excluded prior to calculating the U-probabilities. For example, when computing the U-probability for day of birth in blocking pass 3, record pairs that did not agree on SSN that had a majority (i.e., greater than 50%) of the PII among first name, middle initial, and state of residence in agreement were excluded from the assumed non-matches. Even though SSN did not agree, these records were assumed to be probable links given that a

majority of the PII between the NAMCS HC Component and NDI submission records agreed.

Unlike the M-probabilities, individual U-probabilities were calculated for each value of an identifier if the value was sufficiently represented in the blocking pass. Sufficient representation was defined as satisfying the following criteria:

1. Appeared in more than 2,500 record pairings (i.e., n>2,500).
2. More than 5 record pairings agreed on the value (i.e., number agree>5).
3. Agreement rate (i.e., Number of pairs that agree on value/total record pairs for that value) exceed the 5th percentile of the agreement rate across all values that met the first two conditions.

For example, if for blocking pass 1, the state of residence code for FL appeared in 30,000 record pairings, agreed on 1,560 of those pairs, and the agreement rate for state of residence exceeded the 5th percentile, then the U-probability for Florida would have been computed as 1,560/30,000=0.052 or 5.2%. A 'catch-all' category was created for all identifier values that did not meet the above criteria. The U-probability of the 'catch-all' category was computed by dividing the total number of record pairs that agreed by the total number of record pairs being used to estimate the 'catch-all' category. Further, if there was no agreement in the 'catch-all' category, the U-probability would have been set to 0. To avoid a U-probability of 0, the 'catch-all' U-probability was computed by halving the minimum (i.e., lowest) U-probability among the individual value's U-probabilities. Further, if no individual value received a U-probability (i.e., all values assigned to 'catch-all') and there was no agreement, then the U-probability was set to 0.0001. For example, if the minimum U-probability among state of residence codes was 0.052 and there was no agreement among the catch-all records, the catch-all U-probability for state of residence would be 0.026 (0.052/2). If no state of residence code received a U-probability and there was no agreement, the U-probability for state of residence code would be 0.0001. The process for calculating U-probabilities for first and last name differs from these methods and is described in Section 3.2.2.

Lastly, an adjustment was made to the final U-probabilities to account for alternate records in the submission file. With the addition of each alternate record, the chance of agreement between the NAMCS HC Component and NDI submission records increases. For example, a NAMCS HC Component patient with different months of birth reported on two different patient visit records, has twice the chance of linking to an NDI submission record. Therefore, the U-probability for that patient's month of birth should represent the combined chance of agreement across both month values. Section 3.2.3 provides a detailed description of the methods used to adjust the U-probabilities to account for the additional alternate submission records.

3.2.2 M and U Probabilities for First and Last Names

For first and last name M and U-probabilities, corresponding Jaro-Winkler levels (0.85, 0.90, 0.95, and 1.00) were calculated. Because agreement levels fall over a range, first and last name U-probabilities were computed for each Jaro-Winkler score level. The Jaro-Winkler algorithm assigns a string similarity score, between 0 and 1 (both inclusive), depending on the likeness between two strings. For example, if the first name on the NAMCS HC Component record was "Albert" and on the NDI record it was "Abert", this comparison would receive a Jaro-Winkler score of 0.96. M-probabilities are computed as the rate of agreement for all first/last names within a specific Jaro-Winkler level. For example, the M-probability for first name at the Jaro-Winkler 0.90 level is the rate of agreement for all first names with a Jaro-Winkler score of 0.90 and above.

Because of the large number of unique name values, it was impractical to compute name specific U-probabilities for each blocking pass (i.e., there would not be enough records available for it to be done accurately). Instead, U-probabilities were estimated using pairs generated by the Cartesian product of all records in the 2021 NAMCS HC Component linkage submission file and 100,000 randomly selected names from a simple random sample of 10% of records with non-missing name information from the NDI submission file (see Table 7 for the number of sampled NDI submission records).

Table 7. Count of Records from a 10% Simple Random Sample of NDI Records used to Estimate U-Probabilities for First and Last Names by Sex

Sex	Count of Sampled Records by Name First Name	Count of Sampled Records by Name Last Name
Female	1,493,427	1,497,570
Male	905,327	910,511

Complete name tallies (separately, for first and last names) were then produced for the 2021 NAMCS HC Component linkage submission file. Comparisons were made based on the Jaro-Winkler distance metric at four different levels: 1.00 (Exact Agreement), 0.95, 0.90, and 0.85. For each Jaro-Winkler level, the number of names in agreement of the 100,000 randomly selected NDI file names were then tallied.[22] [23] [24]

3.2.3 Adjustment of U-Probabilities for Alternate Submission Records

As previously mentioned in section 3.2.1, an adjustment was made to the U-probabilities to account for alternate submission records. The addition of unique values for an identifier increases the likelihood of a spurious linkage between records from the files being linked. Thus, the U-probabilities were adjusted to account for the increased probability of variable agreement (i.e., if records for the same person had multiple values for a variable, the chance of agreement with any compared record from the other file increases). Therefore, patients received an adjusted U-probability if they had identifier values that were different across their set of submission records. The adjusted U-probabilities were then applied to each record in the set of submission records that paired with an NDI administrative record. Lastly, the U-probability that is used to compute the agreement and disagreement weights (see Section 3.2.4) is the maximum between the original and adjusted U-probability (i.e., U_{Max}=Max($U_{Original}$, U_{Adjust})).

Excluding first and last name, the adjustment process began by identifying the unique set of values, and their U-probabilities, for each of the identifiers appearing in the scoring key (Table 4), for each patient. Because each value is assumed to be independent of the others, the adjusted U-probabilities were computed using the additive rule for probability as the summation of the individual value U-probabilities for each patient. That is, if a patient had three different month of birth values, the adjusted U-probability for month of birth was simply the summation of the three individual U-probabilities. Table 8 provides an example of the process used to compute the adjusted and maximum U-probabilities for month of birth.

[22] Jaro M. Advances in Record-Linkage Methodology as Applied to Matching the 1985 Census of Tampa, Florida. J Am Stat Assoc. 1987 Jan 01;406:414-420.
[23] Winkler W. String Comparator Metrics and Enhanced Decision Rules in the Fellegi-Sunter Model of Record Linkage. Proceedings of the Section on Survey Research Methods. American Statistical Association. 1990. 354-9.
[24] Resnick, D., Mirel, L., Roemer, M., & Campbell, S. (2020). Adjusting Record Linkage Match Weights to Partial Levels of String Agreement. *Everyone Counts: Data for the Public Good*. Joint Statistical Meetings (JSM). https://ww2.amstat.org/meetings/jsm/2020/onlineprogram/AbstractDetails.cfm?abstractid=312203 (accessed August 2024).

Table 8. Example Showing Computation of the Adjusted and Maximum U-probability for Month of Birth

Patient ID	Month of Birth	U-Probability	Adjusted U-Probability[1]	Maximum U-Probability[2]
1	6	0.091	0.253	0.253
1	5	0.083	0.253	0.253
1	7	0.079	0.253	0.253
2	1	0.110	0.091	0.191
2	10	0.081	0.091	0.191
3	6	0.091	0.091	0.091

NOTES: Data have been fabricated for the purposes of this example

[1] The adjusted U-probability is computed by summing the individual month of birth U-probabilities by patient ID.

[2] The maximum U-probability is the max U-probability value between the original and adjusted U-probabilities.

The first three columns of Table 8 show the unique values of month of birth and their corresponding U-probabilities (see Section 3.2.1) for patients 1, 2, and 3. The column titled "Adjusted U-Probability" is computed by totaling the individual probabilities in the third column for each patient. Finally, the maximum U-probability (last column), which was used to compute the agreement and disagreement weights (see Section 3.2.4), is the maximum value between the original and adjusted U-probability values.

For first and last names, only the 85% Jaro-Winkler level U-probability was adjusted. The higher levels (i.e., 90, 95, and 100) were not adjusted because of the hierarchical method being used to compute each of the U-probabilities at those levels (i.e., 90 is dependent on 85, 95 is dependent on 90, and 100 is dependent on 95). Before the 85% level was adjusted, names that were similar to one another were combined into a single name field. This step is necessary to avoid 'double counting' names that are highly likely to match to the same name on the NDI administrative data file. Similarity in names was defined as having a Jaro-Winkler score between 0.95 and 1 (not inclusive at the upper bound) or if one name is fully contained within another (ex. Elizabeth and Eliza). If for example, a patient had two different names, Elizabeth and Elizabith (JW_{Score}=0.967), only one would be used to adjust the 85% Jaro-Winkler U-probability. The name that is selected was determined by whichever had the highest 100% Jaro-Winkler U-probability. Using the list of 'unduplicated' names, the adjusted U-probability for the 85% Jaro-Winkler level was computed as the summation of each of the individual U-probabilities for the patient. Table 9 provides an example of the methods used to compute the adjusted U-probabilities for the 85% Jaro-Winkler level, using first name as an example.

Table 9. Example Showing Computation of the Adjusted and Maximum U-probability for First Name

Patient ID	First Name	U-Probability at 85% JW	U-Probability at 100% JW	Collapsed U-Probability[1]	Adjusted U-Probability[2]	Maximum U-Probability[3]
8	Margaret	0.008	0.99	0.008	0.009	0.009
8	Peggy	0.001	0.97	0.001	0.009	0.009
8	Marg	0.001	0.85	Collapsed	0.009	0.009
25	Elizabeth	0.09	0.99	0.09	0.09	0.09
25	Beth	0.01	0.95	Collapsed	0.09	0.09
78	Cathy	0.05	0.99	0.05	0.05	0.05

NOTES: Data have been fabricated for the purposes of this example. JW is the Jaro-Winkler string comparator function.

[1] The collapsed U-probability includes only the U-probabilities after similar names have been collapsed into a single name.

[2] The adjusted U-probability is computed by summing each of the collapsed 85% JW U-probabilities within each patient ID.

[3] The Maximum U-probability is the max U-probability value between the original and adjusted 85% U-probabilities.

The first four columns of Table 9 provide example Patient IDs, first names, and their U-Probabilities at the Jaro-Winkler 85 and 100 level for three NAMCS HC Component patients. The collapsed U-probability column (i.e., 5th column) shows that two names were collapsed into another, i.e., for patient 8, Marg was collapsed into Margaret (full-containment) and Beth was collapsed into Elizabeth (full-containment) for patient 25. Further, the collapsed U-probability is equal to the 85% JW U-probability for the name with the highest 100% JW U-probability among the names being collapsed. The adjusted U-probability (i.e., column 6) is the summation of each collapsed U-probability for each patient ID. Finally, the maximum U-probability (i.e., last column) is the max value between the adjusted U-probability and original U-probability at the 85% JW level.

3.2.4 Calculate Agreement and Non-Agreement Weights

The agreement and non-agreement weights for each record's indicators were computed using their respective M- and U-probabilities:

$$\text{Agreement Weight (Identifier)} = \log_2\left(\frac{M}{U_{Max}}\right)$$

$$\text{Non-Agreement Weight (Identifier)} = \log_2\left(\frac{(1- M)}{(1 - U_{Max})}\right)$$

Agreement weights were only assigned to identifiers that had agreeing values. Similarly, non-agreement weights were only assigned to identifiers that had non-agreeing values. A non-agreement weight was always a negative value and reduced the pair weight score. It is important to note that if the M-probability was smaller than the U-probability (i.e., M<U), the pair score (see Section 3.2.5) was not adjusted according to the agreement/non-agreement weight. Because of the logarithmic function, having a M-probability that is smaller than the U-probability would have an inverse effect on the identifier agreement weights. That is, an agreement weight computed using a M-probability that was smaller than the U-probability would produce a negative weight, while the non-agreement weight would be positive. For example, if the M-probability for month of birth was 0.989 and the U-probability was 0.9999 then the agreement and non-agreement weights would be as follows,

$$\text{Agreement Weight (Identifier)} = \log_2\left(\frac{M}{U}\right) = \log_2\left(\frac{0.989}{0.9999}\right) = -0.0158$$

$$\text{Non-Agreement Weight (Identifier)} = \log_2\left(\frac{(1- M)}{(1 - U)}\right) = \log_2\left(\frac{0.011}{0.0001}\right) = 6.781$$

3.2.5 Calculate Pair Weight Scores

In the next step, pair weights were calculated for each record in the blocking pass, which were then used in the probability model. The pair weights were calculated differently for each blocking pass (due to different PII variables contributing to the pair weight), but followed the same general process:

1. Start with a pair weight of 0.
2. Identifier agrees: add identifier-specific agreement weight into pair weight
3. Identifier disagrees: add identifier-specific non-agreement weight (which has a negative value) into pair weight
4. Identifiers cannot be compared because one or both identifiers from the respective records compared were missing, or M-probability was less than the U-probability: no adjustment made to the pair weight

First name and last name weights were assigned using Jaro-Winkler similarity scores described in Section 3.2.2. These scores ranged from 0 to 1, with 0 representing no similarity and 1 representing exact agreement. The weighting algorithm assigned all similarity scores 0.85 and below 0.85 a disagreement weight. The algorithm

assigned all similarity scores above 0.85 an agreement weight associated with the 0.85 level. If there was an agreement at the 0.85 level, the algorithm assessed the pair at the 0.90 level given that it agreed at the 0.85 level. If the names disagreed at this level, the algorithm assigned them a disagreement weight (specific to the 0.90 level given agreement at the 0.85 level). If the names agreed, the algorithm assigned them an additional agreement weight (specific to the 0.90 level). This process continued two more times: for the 0.95 and 1.00 thresholds.

3.3 Probability Modeling

A probability model, developed from a partial expectation-maximization (E-M) analysis, was applied individually to each of the blocks in the blocking scheme. Each model estimated a link probability, $P_{EM}(Match)$, for the potential matches in each blocking pass. The match probability represents the approximate likelihood that a given link is a match. These probabilities in turn allowed the linkage algorithm to:

- Combine pairs across blocking passes (Pair-weights are specific to each blocking pass and are not comparable)
- Select a "best" record among 2021 NAMCS HC Component patient IDs that have linked to multiple administrative records.
- Select final matches based on a probability cut-off value (discussed in the following Section 4)

The partial E-M model was an iterative process that can be described in 4 steps:

1. A pair-weight adjustment was computed (Adj_B) specific to blocking pass, B, by taking the log base 2 of the estimated number of matches (within blocking pass B) divided by the estimated number of non-matches in the blocking pass. For convenience, the estimated number of matches, $\widehat{N_{matches,B}}$, used in the first iteration was set to half of the pairs in the blocking pass (i.e., all pairs generated by the blocking pass specification). The number of non-matches was computed by subtracting the estimated number of matches from the number of pairs (regardless of how likely they are to be matches) in the blocking pass.

$$Adj_B = log_2\left(\frac{\widehat{N_{matches,B}}}{\widehat{N_{non-matches,B}}}\right) = log_2\left(\frac{\widehat{N_{matches,B}}}{N_{Pairs,B} - \widehat{N_{matches,B}}}\right)$$

   Note that in the first iteration, it was assumed that $\widehat{N_{matches,B}} = \widehat{N_{non-matches,B}}$, resulting in $Adj_B = 0$. If, however, in a later iteration, the number of matches was estimated to be, $\widehat{N_{matches,B}}$ = 20,000 (for example), out of the number of pairs, $N_{Pairs,B}$ = 1,000,000, then

$$Adj_B = log_2\left(\frac{20{,}000}{1{,}000{,}000 - 20{,}000}\right) \approx -5.61$$

2. The odds of a given pair, *P*, being a match were computed in blocking pass, *B*, by taking 2 to the power of the adjusted pair-weight (sum of pair-weight (*PW*) and Adj_B, the blocking pass pair weight adjustment).

$$Odds_{P,B} = 2^{PW_{P,B} + Adj,B}$$

   Continuing with the example from Step 1…

   if for Pair 1 of blocking pass B, the pair-weight is 8.4, then $Odds_{1,B} = 2^{(8.4 + -5.61)} \approx 6.9$

   if for Pair 2 of blocking pass B, the pair-weight is -2.5, then $Odds_{2,B} = 2^{(-2.5 + -5.61)} \approx 0.0036$

   …and this continues for the remaining $N_{Pairs,B}$ pairs of the blocking pass

3. Each record pair had a match probability estimated using the odds. This was accomplished by taking the odds for pair, P, in blocking pass, B, and dividing by the (Odds+1).

$$P_{EM,P,B}(Match) = \left(\frac{Odds_{P,B}}{Odds_{P,B} + 1}\right)$$

Continuing with the example…

For Pair 1 in blocking pass B, $P_{EM,P,B}(Match) = \left(\frac{6.9}{6.9 + 1}\right) \approx 0.87$

For Pair 2 in blocking pass B, $P_{EM,P,B}(Match) = (\frac{0.0036}{0.0036 + 1}) \approx 0.0036$

…and this continues for the remaining $N_{Pairs,B}$ pairs of the blocking pass.

4. The new number of matches in blocking pass were estimated. This was done by summing each of the estimated probabilities in the block.

$$\widehat{N_{matches,B}} = \sum \widehat{P_{EM,P,B}(Match)}$$

Continuing with the example, add the probabilities for every pair in the blocking pass:

$$\widehat{N_{matches,B}} = 0.87 + .0036 + \widehat{P_{EM,3,B}} + \ldots + \widehat{P_{EM,N_{Pairs,B},B}}$$

This process was repeated until convergence was reached in the number of matches being estimated. Once convergence was achieved, the final probabilities were estimated based on the last value of $\widehat{N_{matches,B}}$ to be estimated. These estimated probabilities were then used to select the final matches, as described below in Section 4.

3.4 Adjustment for SSN Agreement

Up to this point, every pair generated through the probabilistic routine was assigned a value that estimates its probability of being a match. However, this estimate did not take SSN agreement into account. This was conducted as a separate step because for the other comparison variables, M- and U- probabilities were estimated based on probable matches or non-matches that were determined based on SSN agreement, and clearly this was infeasible for SSN itself.[25]

To remedy this, before the algorithm adjudicated the matches against the probability cut-off value, one final adjustment was made to the match probabilities (for probabilistic pairs). For pairs that had an SSN on both the 2021 NAMCS HC Component and NDI submission record, the estimated probability was adjusted based on the last four digits of the SSN.

When the last four digits of SSN agreed (i.e., are exactly the same):

$$Probvalid_{SSN_{Adj}} = \frac{\left(\frac{P_{EM}(Match)}{1 - P_{EM}(Match)} \cdot \frac{M_{SSN-SSN4}}{U_{SSN-SSN4}}\right)}{\left(\left(\frac{P_{EM}(Match)}{1 - P_{EM}(Match)} \cdot \frac{M_{SSN-SSN4}}{U_{SSN-SSN4}}\right) + 1\right)}$$

[25] The M and U probabilities in the formulas refer specifically to the M and U of the last four digits of the SSN.

When the last four digits of SSN did not agree:

$$Probvalid_{SSN_{Adj}} = \frac{\left(\frac{P_{EM}(Match)}{1-P_{EM}(Match)} \cdot \frac{M_{SSN-SSN4}}{U_{SSN-SSN4}}\right)}{\left(\left(\frac{P_{EM}(Match)}{1-P_{EM}(Match)} \cdot \frac{M_{SSN-SSN4}}{U_{SSN-SSN4}}\right)+1\right)}$$

No adjustment was made for pairs that did not have an SSN on either the 2021 NAMCS HC Component patient or NDI submission record. So, for these pairs:

$$Probvalid_{SSN_{Adj}} = P_{EM}(Match)$$

4 Estimate Linkage Error, Set Probability Cut-off Value, and Select Matches

The scored (probabilistic) and deterministic linkage files for males and females were combined prior to estimating the linkage error and selecting matches. Recall the purpose for separating the records by sex was to avoid violating the independence assumption for name identifiers mentioned by Fellegi-Sunter. Now that records from each sex have been separately scored, there is no need to keep them separate.

4.1 Estimating Linkage Error to Determine Probability Cut-off Value

Subsequent to performing the record linkage analysis an error analysis was performed. There are two type of errors that were estimated:

- Type I Error: Among pairs that are linked, what percentage of them were not true matches.
- Type II Error: Among true matches, how many were not linked.

Because all records were included in the probabilistic linkage (i.e., even deterministic links), SSN agreement status (defined as seven or more matching digits for nine-digit SSN's and for SSN's that had only the last four digits, all four digits must match) was used to measure Type I error. Type I error for probabilistic links was measured as the total number of probabilistic links with non-agreeing SSN divided by the total number of probabilistic links with a valid SSN available on both the NAMCS HC Component and NDI submission record. Also, deterministically established links were considered to have 0% Type I error rates. While it was believed that the error for these links was quite small and near 0, it is expected that some error does exist even with the deterministically established links and so the estimate was likely biased low. For example, if 40% of links were derived from the deterministic method, this would reduce the estimated Type I error by the proportion of probabilistically determined linkages among all linkages. To further illustrate, if the Type I error rate for probabilistic links was estimated as 1.2%, then the estimated Type I error rate for the combined linkage process would be (0.40*0.012) = 0.0048 or 0.48%.

To measure Type II error, the truth source comprised of all matches identified in the deterministic linkage was used. Recall, the truth source contains records with full nine-digit SSN agreement (step 1) or with the last four digits of SSN in agreement (step 2). Potential deterministic matches were then validated using the available PII (see, Appendix I section 2). It was expected that this truth source had only a few exceptional pairs that were not true matches. For the probabilistic records, Type II error was estimated as the percentage of the truth source records that were not returned as links by the probabilistic method. Similarly to the computation of Type I error, an adjustment was made to the Type II error since some links having agreeing SSNs were being linked deterministically even if they were not returned by the probabilistic approach. For example, say that the probabilistic approach was able to return 97% of true matches as links. If only a probabilistic linkage was conducted, the Type II error would then be 3%. However, among the 3% not linked probabilistically, some pairs could be linked deterministically. If the deterministic linkage rate is 50% (and if we assume the

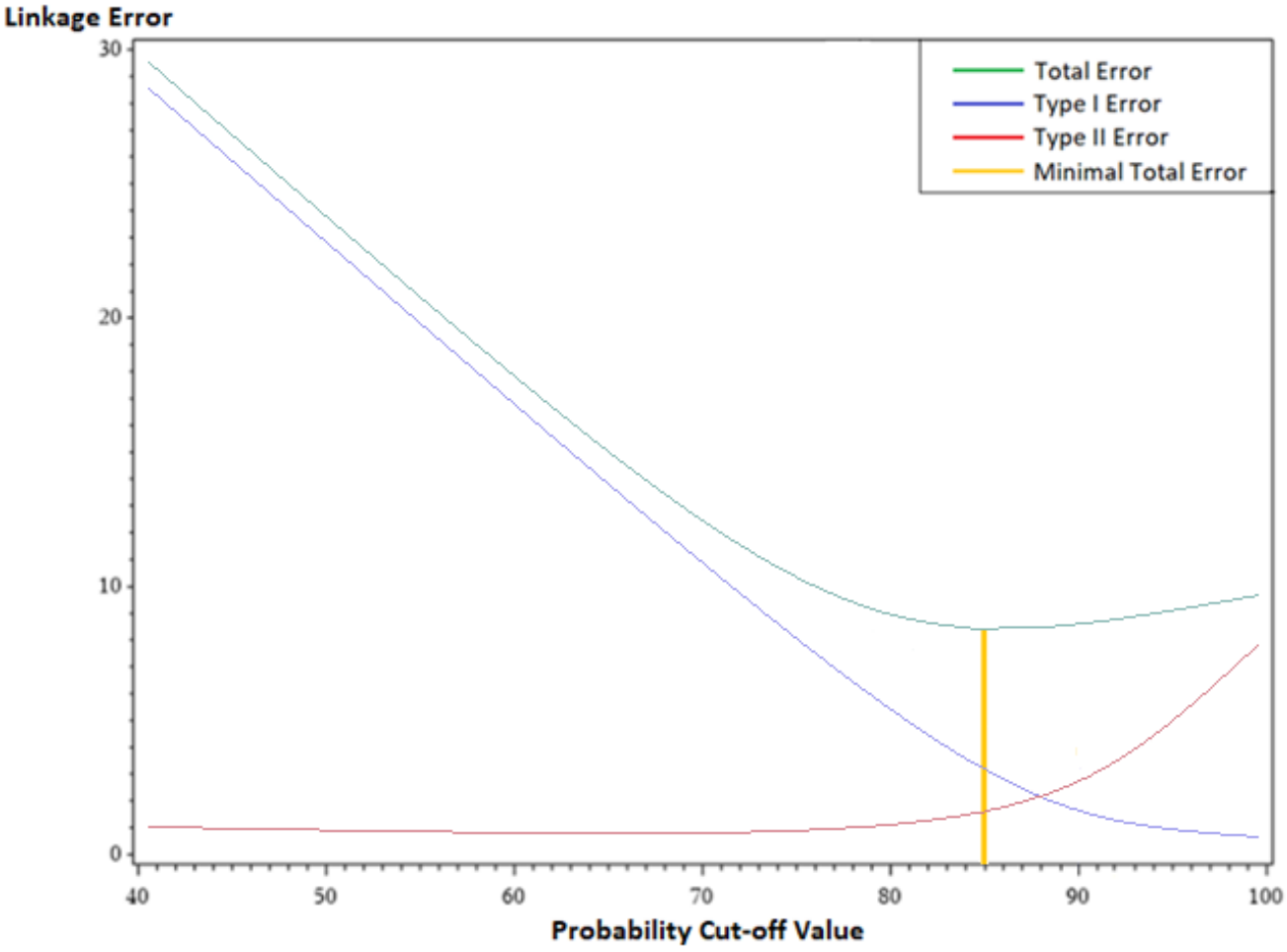
same rate among the non-linked pairs), then the Type II error rate can be estimated as 0.5*(1 – 0.97) = 0.015 or 1.5%.

4.2 Set Probability Cut-off Value

One goal of record linkage is to have the lowest errors possible. However, as more pairs are accepted, pairs that are less certain to be matches but accepted as links increase the Type I error and decrease Type II error. And as less pairs are accepted, pairs that are more certain to be matches but not accepted as links decrease the Type I error and increase Type II error. The optimal trade-off between Type I error and Type II error is not known, but it can be assumed to be optimal when the sum of Type I and Type II error is at a minimum. For this reason, Type I and Type II error are estimated at various probability cut-off values and the one that showed the lowest estimate of total error is selected (see Figure 1). For the linkage of the 2021 NAMCS and 2021-2022 NDI, the optimal probability cut-off value was set to 0.85.

Figure 1. Illustrating linkage error by probability cut-off value

(Illustrative schematic not based on actual values)



4.3 Select Links Using Probability Cut-off Value

The final step in the linkage algorithm was to determine links, which were record pairs inferred to be matches. Links were pairs where the $Probvalid_{SSN_{Adj}}$ exceeded the probability cut-off value (from Section 4.2). Further, the 'best' record pair (i.e., highest $Probvalid_{SSN_{Adj}}$) among the records that exceeded the probability cut-off value was selected for each NAMCS HC Component patient. Additionally, records were excluded from the set of selected links if one of the following two conditions was true,

(1) Full NDI date of death (i.e., non-missing day, month, and year). If the NDI date of death occurred more than 3-days prior to the last visit date on the NAMCS HC Component record.
(2) Partial NDI date of death (i.e., either day or month were missing).
   - Month of death is known, and day of death is unknown. Month and year of death must occur on or after the month and year of the last visit date on the NAMCS HC Component record.
   - Month of death is unknown. Year of death must occur on or after the year of the last visit date on the NAMCS HC Component record.

In addition, all record pairs with an adjusted probability value that fell below the cut-off (i.e., 0.85) were not linked.

4.4 Computed Error Rates of Selected Links

Final error rates were computed for selected links (described in Section 4.3). Table 10 provides the total number of selected links, the number of total links identified through deterministic and probabilistic methods, and the Type I and Type II error rates for the 2021 NAMCS HC Component NDI linkage. Because the links were selected using the SSN adjusted probability (described in Section 4.1), the overall Type I error rate was computed using the estimated match probabilities rather than using SSN agreement. For the probabilistic links, the estimated match probabilities represented the probability that the NAMCS HC Component record was a match to the NDI administrative record. In other words, if a link had an estimated probability of 0.98, then it was understood that there was a 98% chance this was a match. To estimate the Type I error rate for the probabilistic links, the chance that a link is not a match was summed (i.e., $\sum 1 - Probvalid_{SSN_{Adj}}$) and then divided by the total number of probabilistic records. The method to measure the overall Type II error remained unchanged (see Section 4.1).

Table 10. Algorithm Results for Total Selected Links

	Probability Cut-off Value	Total Selected Links	Deterministic Matches	Probabilistic Links	Est Incorrect (Type I)	Est Not Found (Type II)
2021 NAMCS HC Component	0.85	9,264	6,227	3,037	0.06%	0.87%

Appendix II: Assessment of 2021 NAMCS HC Component Patient Identification Variables

1 Background

Prior to undertaking the linkage of the 2021 NAMCS HC Component patient level data to the National Death Index, NCHS conducted an assessment of the completeness of the available patient identification variables in order to assess the feasibility of conducting linkages with NAMCS patient level data.

2 Introduction

To complete this evaluation, several assessments were performed on each of the personally identifiable information (PII) variables used to link 2021 NAMCS HC component patient records. Assessments included patient-level linkage eligibility (i.e., sufficient PII to link), variable completeness (i.e., amount of non-missingness), and an assessment of reported patient date of birth and sex.

3 Assessment of 2021 NAMCS FQHC EHR PII Variables Used for Linkage

Prior to conducting the assessments, all patient PII was first processed using a comprehensive data cleaning algorithm. The data cleaning algorithm, developed by NCHS, reviews each of the PII variables and changes any 'invalid' information to a standard variable missing value. Some examples of 'invalid' data included, but were not limited to, impossible values such as a date value of 2/31/2013, SSN value of '999999999', or a ZIP code of '00000.'

3.1 Linkage eligibility

NCHS has established standard rules for determining linkage eligibility based on a determination of whether a given patient's records have sufficient PII to conduct linkage. Section 3.1 (above) of this report provides detailed information on linkage eligibility criteria. Based on the NCHS criteria for determining linkage eligibility, 99.9% of NAMCS HC Component patient records were considered eligible for data linkage. Table 11 provides the percentage of 2021 NAMCS HC Component patients by eligibility status and available PII. Approximately half of the 2021 NAMCS HC Component patients who are linkage eligible had valid format SSN, Date of Birth, and Name information available. Further, 50.8% of 2021 NAMCS HC Component linkage eligible patients had a valid format name and date of birth available but were missing SSN. A very small number of 2021 NAMES HC Component linkage eligible patients had a valid format SSN but were missing either date of birth or name information. Additionally, a total of 848 patients or 0.1% of total patients were considered ineligible for linkage.

Table 11. Percentage of the 2021 NAMCS HC Component patients by eligibility status and PII variable status

Eligibility Status	SSN	Date of birth	Name	Percent of Patients (%)
Eligible	Available	Available	Available	49.1
Eligible	Available	Available	Missing	<0.1
Eligible	Available	Missing	Available	<0.001
Eligible	Missing	Available	Available	50.8
Ineligible	N/A	N/A	N/A	0.1

Note: Percent of patients computed as the count of patients with valid PII divided by the total count of patients (n=727,232).

3.2 Completeness of linkage variables

For the purpose of this assessment, completeness is defined as the presence of valid, non-missing information

for a specific data element. Further, for each data element, PII values are validated using predefined rules. For example, an SSN comprised of all zeros or numbers in numerical order (123-45-6789) are considered invalid and changed to missing. Table 12 shows the results of an assessment of completeness, or percent of non-missing values, for all available PII variables. Because there is an undetermined level of legitimate missingness for patient's middle initial, its completeness was not assessed. All linkage PII variables for patients who were eligible for linkage, except for SSN, had very high rates of completeness, at 99.7% or higher. SSN was only available for 49.2% of linkage eligible 2021 NAMCS HC Component patients.

Table 12. Percentage of 2021 NAMCS HC Component patients that have complete, non-missing information in each of the PII variables available for data linkage

Linkage variable name	Percent Complete (%) All patients[1]	Percent Complete (%) Linkage eligible patients[2]
Social security number (SSN)	49.1	49.2
First name	99.9	100.0*
Last name	99.9	100.0*
Day of birth	99.9	100.0*
Month of birth	99.9	100.0*
Year of birth	99.9	100.0*
Sex	99.6	99.7
ZIP code	99.7	99.8
State of residence	99.7	99.9

Note: Values have been rounded to the nearest tenth causing certain values (*) to be rounded to 100%.

[1] This percentage is calculated by dividing the number of patients with a non-missing value in each linkage variable by the number of patients in the total sample (n=727,232).

[2] This percentage is calculated by dividing the number of linkage eligible patients with a non-missing value in each linkage variable by the total number of linkage eligible patients (n=726,384).

3.3 Linkage Variable Values Assessment

Using the patient linkage eligible submission records, frequency distributions for date of birth (day/month/year of birth) were analyzed. Each distribution was assessed for the number of value levels present (ex. expecting 12 values for month) and for heaping. Heaping occurs when there is an uneven distribution of record counts that favor specific values. For example, it would be expected that the distribution of records for day of birth is close to uniform. However, if '01' was used to impute records where the day of birth is missing, the distribution of records would likely show an uneven distribution of records heavily skewed towards the first of the month (i.e., day='01'). In addition, reported values for patient sex were assessed.

3.3.1 Date of Birth

Each date part (i.e., day, month, and year) was assessed separately. The day of birth showed slight heaping on the first day of the month. However, it was not severe enough (from a record linkage perspective) to cause concern. There were no significant findings in month or year of birth. A small number of patients (<0.001%) had a visit record with a 2022 year of birth. This value was assumed to be a reporting error because the patient's visit records included 2021 visit dates. If these patient's visit records included other PII variables to be considered linkage eligible they were included in the linkage.

3.3.2 Patient sex

The 2021 NAMCS HC Component data collection processes included collecting all visit records for a given patient occurring during the 2021 data collection year. Some patient's visit records included more than one reported sex code. This occurred infrequently and only affected 0.4% of patients. Appendix I Section 1 describes how the linkage algorithm handled patients with multiple sex codes.

4 Conclusion

The overall completeness of identifier variables in the 2021 NAMCS HC Component data is high. Further, nearly all 2021 NAMCS HC Component patients (99.9%) had sufficient PII to be considered eligible for data linkage.