

John E. Patterson and Robert Bilgrad, National Center for Health Statistics

The National Death Index (NDI) is a central, computerized index to the death certificates filed in each State vital statistics office. This computer file contains a standard set of identifying information for each person dying in the U.S., beginning with 1979. The NDI was established to assist health and medical investigators in determining whether persons in their studies may have died, and if so, to provide the names of the States in which those deaths occurred, the dates of death, and the corresponding death certificate numbers. The NDI user can then obtain copies of death certificates from the appropriate State offices.

The NDI became operational in November 1981. As of March 31, 1985, the NDI file contained 10.3 million death records for the five-year period 1979-1983. A total of 168 NDI file searches have been performed, involving 2,352,001 records submitted by 99 NDI users. This report gives a brief overview of the NDI users and their research activities, and describes recent evaluations and planned revisions of the NDI matching criteria. Procedures for using the NDI are also presented.

1. OVERVIEW OF NDI USERS

The NDI has been used in a variety of health and medical research projects which rely on the successful ascertainment of the vital status of their study subjects. The research projects of the 99 NDI users have been grouped into five broad research categories in Table 1. These categories are (1) exposure cohorts, involving studies of the effects of being exposed to potential risk factors in the workplace, the environment, or as a result of diagnostic or therapeutic procedures; (2) disease cohorts, involving followup of persons diagnosed as having cancer or other diseases; (3) life style/risk factors, involving studies of the effects of activities such as smoking or drug abuse; (4) clinical trials, primarily involving studies of the potentially beneficial effects of various therapies for specific diseases; and (5) general population cohorts, involving followup of survey participants not selected on the basis of a specific diagnosis or exposure to risk factors.

Forty percent of the NDI users are conducting occupational studies involving followup of rosters of employees to determine whether there have been any harmful effects resulting from their exposures to potentially harmful substances. Most of these studies are being performed by the National Institute for Occupational Safety and Health as well as by oil and chemical companies. Another 28 percent of the NDI users are involved in followup activities on cohorts of persons diagnosed as having cancer or other diseases.

Table 1 also shows the types of organizations using the NDI. It should be noted that while Federal agencies account for only 18 percent of

the NDI users, the Federal government is actually providing the funding support for about three-fourths of the studies being performed by universities and consulting firms.

Many of the NDI users are either following cohorts of under 2,500 persons or use the NDI only to check on those study subjects which are considered lost to followup. Almost three-fourths of the users have submitted fewer than 10,000 names. The fewest records submitted for an NDI file search were 7. The largest volume of records was submitted by the Census Bureau for the National Longitudinal Mortality Study being supported by the National Heart, Lung and Blood Institute. Thus far, this study has involved the submission of a test file of 225,875 Census Bureau records and the main study file of 994,195 records. The study's methodology involves a search of the NDI file every two years. The second NDI search for the main study is scheduled for around July 1985 and will involve approximately 1.2 million Census Bureau records.

2. COMPLETENESS AND QUALITY OF NDI AND USER DATA

The effectiveness of the NDI matching process is dependent on the following three factors: (1) the completeness and quality of the death certificate data submitted to the National Center for Health Statistics (NCHS) by the State vital statistics offices for use in creating the NDI file, (2) the completeness and quality of the data provided by the NDI user, and (3) the effectiveness of the NDI matching criteria.

The completeness of the NDI file is probably well in excess of 99 percent. Data on virtually all deaths occurring from 1979 to 1983 have been submitted by the fifty States, the District of Columbia, New York City, Puerto Rico and the Virgin Islands. The NDI file now contains 10.3 million records. Table 2 shows that the completeness of data for most data items exceeds 97 percent except for middle initial (71.7 percent), father's surname (86.2 percent), and social security number (91.0 percent). Although 9.0 percent of the records do not contain social security numbers (as shown in Table 3), only 6.0 percent of the records for persons 22 years and older do not contain such numbers. As might be expected, death records for females have higher percentages of social security numbers not reported than records for males.

It is very difficult to assess the quality of the data on the NDI file, but we have reason to believe that it is probably quite good. The quality of the NDI data is most affected by how the death record information is reported to and recorded by funeral directors. The death certificate is a legal document which must be filed in the State where the death occurs. Most States continually encourage funeral directors to make every effort to obtain accurate information from the person making the funeral arrangements. Funeral directors have a strong incentive for

obtaining and accurately recording good identifying information on each decedent. Their clients would not be pleased if errors appeared on the certificate, since this would very likely delay settlement of claims for life insurance and other survivor benefits. All States perform 100 percent verification of the coding and keying of their records. NCHS also performs various quality control checks as the States' data are received.

The completeness and quality of data submitted by NDI users, on the other hand, vary greatly depending on how the data were collected. The complete and accurate collection of the NDI data items listed in Table 2 will, of course, enhance the effectiveness of any subsequent searches of the NDI file. This table summarizes the overall completeness of the data submitted by NDI users; however, the completeness of each data item varies greatly among the different users, especially for such items as middle initial, social security number, State of residence and State of birth.

Because of the newness of the NDI program, many users did not or could not insure the collection of all of the NDI data items. NCHS strongly encourages investigators who are or will be planning studies to make every possible effort to collect all of the NDI data items, even if the investigators do not have specific plans to conduct a followup of study subjects to ascertain their vital status. Once a study is completed, the same or other health investigators may decide that future followup of the study group may indeed be very useful. Internally, NCHS has instituted a policy requiring each new survey to collect all of the NDI data items, regardless of whether the survey staff or others in NCHS plan to use the NDI to followup on the survey participants in the future.

3. RECENT REVISIONS IN THE NDI MATCHING CRITERIA

When the NDI retrieval program was first designed and implemented, a fairly simple set of seven matching criteria was developed (1) to use most effectively the principal identifiers on the death record; (2) to satisfy the needs of the majority of potential users; (3) to make searches against the NDI very routine, eliminating the need for special programming for individual users; and (4) to take into account the policy concerns of the States. These concerns were very significant and had a major impact on the development of the initial matching criteria. Many States felt that the NDI users should be required to provide a fairly substantial body of identifying information for their subjects. They should not accept matching solely on the basis of social security numbers, for example. A number of States were also concerned about probabilistic matching. They felt that their regulations would prevent them from searching their files on a probabilistic basis, and they did not believe that they could delegate authority to NCHS to do what they would not be permitted to do themselves.

For an NDI record to qualify as a possible match with a given user record, under the initial matching criteria, at least one of the following

seven combinations of data items must agree on both records:

1. Social security number, first name.
2. Social security number, last name.
3. Social security number, father's surname.
4. If the subject is female: social security number, last name (user's record) and father's surname (NDI record).
5. Month and exact year of birth, first and last name.
6. Month and exact year of birth, first name, father's surname.
7. If the subject is female: month and exact year of birth, first name, last name (user's record) and father's surname (NDI record).

Nine evaluations of the effectiveness of the above matching criteria have been performed by NCHS and by several NDI users. The results are summarized in Table 4. Each of these evaluations involved study files of known decedents which were searched against the NDI file. In those evaluations where social security numbers were available for a large proportion of decedents, the resulting percentages of true matches (user records which were correctly identified as deceased) ranged from 92.1 percent to 98.4 percent. The differences in these percentages are attributed primarily to differences in the quality of the users' data sets. Three evaluations showed that, without the benefit of any social security numbers true matches amounted to only 79.7 percent [8], 80.0 percent [10], and 81.9 percent [9], primarily because of discrepancies in year of birth and names. However, two other users apparently had much better data on dates of birth and names because they achieved true matches of 91.1 percent [1] and 96.5 percent [3] without the benefit of social security numbers.

Most of our advisers and users have stressed that our first efforts to improve our matching criteria should be to maximize the number of true matches, even if this means a significant increase in the false matches which may be generated as a by-product. Our users have generally found that nearly all false matches can be eliminated easily by simply reviewing the output of the NDI search. This is especially true for small studies. For very large studies computerized processing of the NDI output is necessary to identify true matches and to isolate questionable matches which deserve closer inspection. Several users have developed their own computerized algorithms for this purpose.

As a result of the evaluations mentioned above, NCHS is planning to add five new matching criteria to the initial seven. The five additional matching criteria are listed below and are numbered 8 through 12 to distinguish them from the initial seven. A possible NDI record match would be generated if any of these combinations of data items agree on an NDI and a user record.

8. Month and \pm 1 year of birth, first and last name.
9. Month and \pm 1 year of birth, first and middle initials, last name.

10. Month and exact year of birth, first and middle initials, last name.
11. Month and day of birth, first and last name.
12. Month and day of birth, first and middle initials, last name.

Our evaluations have shown that by also permitting matches on month and day of birth and on month and + 1 year of birth, the percentage of true matches generated can be increased significantly. One of the NCHS evaluations mentioned previously, involving a cancer registry file containing social security numbers on 85.9 percent of its 2,598 records, showed an increase in true matches from 92.1 percent to 96.2 percent with the addition of the five new matching criteria [8]. The increase in matching effectiveness is greatest, however, for study files having very few or no social security numbers. Another NCHS evaluation involved a file without social security numbers for 607 decedents in the NCHS National Health and Nutrition Examination Study. This evaluation showed an increase in true matches from 81.9 percent to 89.5 percent [9].

The initial retrieval program permitted first names, last names and fathers' surnames to match on the basis of either their exact spelling or Soundex codes. Evaluations showed that the use of Soundex codes often generated agreements on names which were dissimilar, however, causing a number of unnecessary false positives to be generated, while adding very little to the number of true positives. With the planned implementation of the revised matching criteria, the use of Soundex codes will be eliminated. Phonetic matching will be performed only on last names and fathers' surnames and will be based on NYSIIS codes (New York State Identification and Intelligence System). The NYSIIS coding system which will be used was first modified and tested by the U.S. Department of Agriculture [11] and was subsequently adopted for use in Statistics Canada's Mortality Data Base. The computer program which assigns the modified NYSIIS codes was obtained by NCHS from Statistics Canada.

4. USING THE NDI

As mentioned above, health investigators planning to use the NDI are encouraged to collect as many of the NDI data items as possible and to insure that the data are of good quality. To become an NDI user, health investigators must first complete and submit an NDI application form. Each form is reviewed by the advisers to the NDI program to insure that (1) the proposed use of the NDI is solely for statistical purposes in medical or health research and (2) the applicant provides adequate assurances that the identifying death record information obtained from the NDI and from the State vital statistics offices will be kept confidential and will be used only for the proposed study.

Once the applicant is notified that the application is approved, the NDI user may then submit records for an NDI file search. The user must submit records on a magnetic tape which conforms with the NCHS tape specifications, file format requirements, and coding instructions.

Users planning to submit under 300 records have the option of using NCHS coding sheets. The results of an NDI file search are sent to the user (along with the user's data) within three weeks after the user's records are received by the NCHS computer facility.

The user must assess the quality of each possible NDI record match listed and determine which NDI matches are worthy of further investigation. A sample of the planned revision of the NDI Retrieval Report is presented in Table 5. The Retrieval Report lists all user records involved in a match with one or more NDI records. The State of death, death certificate number and date of death are listed for each possible match, along with an indication of which data items are in agreement. Two changes in this report should further assist NDI users in evaluating the quality of possible matches. First, the revised Retrieval Report will show which digits of the social security numbers are in agreement. The current report merely indicates whether or not there was an agreement on the entire social security number. Second, the new report will indicate the extent to which the years of birth disagree; e.g., +1 year, -1 year, -15 years, etc. The current report simply indicates whether or not there is exact agreement on the year of birth.

The user must decide which, if any, of the NDI records are true matches and then obtain copies of the death certificate from the appropriate State vital statistics offices. Most users are interested in obtaining the cause of death from the death certificate. Some users also conduct death record followback activities to the hospitals, physicians, next-of-kin, and/or other persons or establishments indicated on the death certificates. Other users simply obtain copies of certificates to assist in confirming whether a questionable match is actually the person in the study.

Once an application is approved, requests for repeat searches of the NDI file (for additional years of death or for different study subjects) do not need to go through the formal review and approval process again, as long as the information provided in the initial application remains essentially the same. Death records for a particular calendar year are added to the NDI file annually, approximately 12-14 months after the end of that calendar year. Records for deaths occurring in 1984 are scheduled to be added to the NDI file around February 1986.

5. ADDITIONAL REFERENCES CONCERNING THE NDI

In addition to the NDI users' articles and studies cited above, several other articles have been written describing the experience of NDI users [12-15]. There have also been articles written regarding the potential use of the NDI for various studies [16-18]. Finally, papers have been written in which birth certificates from the NCHS 1980 National Natality Survey were searched against the NDI to produce infant mortality rates [19-22]. Copies of these four unpublished papers can be obtained from NCHS [23].

Persons interested in receiving copies of the NDI User's Manual [24] and an NDI Application

Form should write or call:

NATIONAL DEATH INDEX
Division of Vital Statistics
National Center for Health Statistics
3700 East West Highway, Room 1-44
Hyattsville, Maryland 20782
Telephone: (301) 436-8951

NOTES AND REFERENCES

- [1] Wentworth, Deborah N., et al., "An Evaluation of the Social Security Administration Master Beneficiary Record File and the National Death Index in the Ascertainment of Vital Status," American Journal of Public Health, Vol. 73, No. 11, November 1983, pages 1270-1274.
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- [22] Placek, Paul J., "Record Linkage Methodologies in the 1980 National Natality Survey (NNS) and 1980 National Fetal Mortality Survey (NFMS)," (presented at the meetings of the International Statistical Institute, Amsterdam, The Netherlands, August 12-22, 1985).
- [23] Copies of references [19], [20], [21], and [22] can be obtained by writing to: Natality Statistics Branch, Division of Vital Statistics, National Center for Health Statistics, 3700 East-West Highway, Room 1-44, Hyattsville, Maryland 20782.
- [24] User's Manual: The National Death Index, U.S. Department of Health and Human Services, National Center for Health Statistics, DHHS publication number (PHS) 81-1148, September 1981.

Table 1

NATIONAL DEATH INDEX (NDI) USERS AND RECORD VOLUMES

NDI User Characteristics	Users		NDI Searches		User Records	
	Number	Percent	Number	Percent	Number	Percent
<u>Types of Research:</u>						
Total-----	99	100.0	168	100.0	2,352,001	100.0
Exposure cohorts						
Occupational-----	40	40.4	57	33.9	636,752	27.1
Environmental-----	5	5.1	18	10.7	78,824	3.4
Diagnostic/therapeutic---	2	2.0	3	1.8	7,566	0.3
Disease cohorts						
Cancer registries-----	13	13.1	16	9.5	38,002	1.6
Other-----	15	15.2	18	10.7	42,120	1.8
Life style/risk factors-----	9	9.1	14	8.3	116,875	5.0
Clinical trials-----	9	9.1	14	8.3	86,333	3.7
General population cohorts--	6	6.1	28	16.7	1,345,529	57.2
<u>Types of NDI Users:</u>						
Total-----	99	100.0	168	100.0	2,352,001	100.0
Federal Government-----	18	18.2	62	36.9	1,516,313	64.5
State Government-----	4	4.0	6	3.6	45,056	1.9
University-----	28	28.3	37	22.0	327,060	13.9
Private Industry-----	13	13.1	17	10.1	221,942	9.4
Hospital-----	19	19.2	22	13.1	63,120	2.7
Consulting firm-----	17	17.2	24	14.3	178,510	7.6
<u>Record Volume:</u>						
Total-----	99	100.0	168	100.0	2,352,001	100.0
Under 2,500-----	42	42.4	45	26.8	29,259	1.2
2,500 - 9,999-----	29	29.3	38	22.6	165,711	7.1
10,000 - 24,999-----	12	12.1	31	18.5	225,466	9.6
25,000 - 99,999-----	13	13.1	33	19.7	513,014	21.8
100,000 - 499,999-----	2	2.0	7	4.2	424,356	18.0
500,000+-----	1	1.0	14	8.3	994,195	42.3

Table 2

NUMBER OF RECORDS AND PERCENT COMPLETENESS
OF NATIONAL DEATH INDEX (NDI) AND USER DATA ITEMS

Data Items	NDI File	User Files
No. of Records-----	10,290,730	1,131,931*
Percent Complete:		
Last Name-----	99.9	99.9
First Name-----	99.9	99.7
Middle Initial-----	71.7	73.4
Social Security No.-	91.0	84.2
Birth Month-----	98.8	95.7
Birth Day-----	98.7	87.9
Birth Year-----	99.4	97.0
Father's Surname----	86.2	8.9
Sex-----	99.9	92.6
Race-----	97.9	53.1
Marital Status-----	99.4	17.9
State of Residence--	99.9	44.2
State of Birth-----	99.5	18.6
Age at Death-----	99.9	10.6

* The total number of user records shown excludes 1,220,070 records associated with the National Longitudinal Mortality Study, sponsored by the National Heart, Lung and Blood Institute and involving both the Census Bureau and the National Center for Health Statistics. This large volume of records was eliminated from this table to give a more realistic presentation of the completeness of the data items submitted by the other 98 NDI users.

Table 3

REPORTING OF SOCIAL SECURITY NUMBER ON NATIONAL DEATH INDEX (NDI) RECORDS;
BY SEX AND AGE AT DEATH

Age at Death	Number of NDI Records			Percent not Reported WITHIN Age/Sex Group		
	Both Sexes*	Male	Female	Both Sexes*	Male	Female
All Ages--	10,289,958	5,536,778	4,753,180	9.0	7.8	10.3
0-16-----	356,704	208,377	148,327	88.6	87.4	90.3
17-21-----	126,475	95,242	31,233	17.8	16.9	20.6
22-59-----	1,965,257	1,279,175	686,082	8.4	7.2	10.6
60+-----	7,841,522	3,953,984	3,887,538	5.3	3.6	7.2

* The record counts and percentages do not include 772 records for which sex was not reported.

Table 4

EVALUATIONS OF THE EFFECTIVENESS OF THE NATIONAL DEATH INDEX (NDI)
MATCHING CRITERIA USING RECORDS OF KNOWN DECEDENTS

NDI Users and User Studies*	Known Decedents	True Matches	Percent True Matches
University of Minnesota School of Public Health (Multiple Risk Factor Intervention Trial (MRFIT) for coronary heart disease) [1]....	191	188	98.4
Exxon Corporation Research & Environmental Health Division (Mortality study update of Exxon workers) [2]....	1,449	1,407	97.1
Harvard Medical School (Nurses health study) [3].....	346	334	96.5
Johns Hopkins School of Hygiene and Public Health (Health effects of low-level radiation in shipyard -workers) [4].....	8,947	8,485	94.8
Health Care Financing Administration (Use and costs of Medicare services by cause of death) [5].....	69,631	65,000	93.3
University of Texas at Houston School of Public Health (Hypertension Detection and Follow-up Program post trial survey) [6].....	1,154	1,074	93.1
University of Washington (Coronary Artery Surgery Study) [7].....	370	344	93.0
National Center for Health Statistics Division of Vital Statistics (Evaluation of NDI using cancer registry records) [8]			
INITIAL matching criteria:.....	2,598	2,394	92.1
Using Social Security Number (SSN).....	2,231	1,874	84.0
Using birth month/year.....	2,596	2,069	79.7
NEW matching criteria.....	2,598	2,500	96.2
Using SSN.....	2,231	1,874	84.0
Using birth month/day <u>or</u> birth month/ <u>+1</u> year.	2,596	2,351	90.6
National Center for Health Statistics Division of Analysis (First National Health and Nutrition Examination Survey epidemiologic follow-up) [9]			
INITIAL matching criteria (without SSN).....	607	497	81.9
NEW matching criteria (without SSN).....	607	543	89.5

* Numbers in brackets refer to studies cited in the NOTES and REFERENCES Section.

Table 5

RETRIEVAL REPORT -- REVISED
(All the information in this example is hypothetical.)

USER REQUEST RECORD	(POSSIBLE MATCHES = 4)	NDI APPL NO	842899	CONTROL NO	4507			
POSSIBLE DECEDENT NAME	FATHERS SURNAME	SOC SEC NO	AGE SEX RACE	MS SOR SOB	USER DATA			
REGINA HANES		000 01 9999	12 10 18 - F -	M PA LA	011580			
POSSIBLE NDI RECORD MATCHES (IN RANKED ORDER)								
STATE OF DEATH	CERT NUMBER	DATE OF DEATH	NAME F M L	FATHERS SURNAME	LN/FS	BIRTH DATE MO DY YR	AGE SEX RACE <th>MS SOR SOB</th>	MS SOR SOB
* PENNSYLVANIA	861098	02-01-81	X B X	-		X X X	- X -	X X
LOUISIANA	421304	07-07-80	X X	-		X X +01	- X -	X X
LOUISIANA	A 421304	07-07-80	I B X	-		X X +01	- X -	X X
INDIANA	698637	03-21-79	X N	-	N	X X -15	- X -	X ?

COLUMN HEADING ABBREVIATIONS:

LN/FS = Last name on user record compared to father's surname on National Death Index (NDI) record.

MS = Marital status

SOR = State of residence

SOB = State of birth

SYMBOLS USED WITHIN THE TABLE:

* = All items provided on user record matched exactly with NDI record.

Blank = User and NDI data items did not match.

X = User and NDI data items matched exactly.

- = Data item not provided by user.
For SSN: specific digits did not match.
For LN/FS: comparison was not attempted.

SYMBOLS (CONTINUED):

? = Insufficient information on NDI record.

A = Alias NDI record.

I = Only first initial of first name matched.

N = Names matched only on NYSIIS codes.

B = Middle initials not provided on either record. This occurrence is treated as a match on middle initial.

+01 = Birth year on the NDI record is one year more than the year on the user record.

-01 = Birth year on the NDI record is one year less than the year on the user record.

-15 = Difference between the two years of birth. (The two-digit birth year on the user record is subtracted from the two-digit birth year on the NDI record. Note: No distinction is made to accommodate birth years in the 1800's versus birth years in the 1900's.)