FORM APPROVED
OMB No. 0920-0215
Exp. Date 03/31/2023

National Death Index

NATIONAL DEATH INDEX APPLICATION

As you complete this form, please call 301–458–4444 if you have any questions

Centers for Disease Control and Prevention
National Center for Health Statistics

CDC/NCHS-6205-1
(Rev. 3/2020)

NATIONAL DEATH INDEX
National Center for Health Statistics
3311 Toledo Road, Room 5292
Hyattsville, Maryland 20782
301-458-4444
ndi@cdc.gov

Assurance of confidentiality- We take your privacy very seriously. All information that relates to or describes identifiable characteristics of individuals, a practice, or an establishment will be used only for statistical purposes. NCHS staff, contractors, and agents will not disclose or release responses in identifiable form without the consent of the individual or establishment in accordance with section 308(d) of the Public Health Service Act (42 U.S.C. 242m(d))

Note: definition of "**IDENTIFYING or IDENTIFIABLE death record information**" — Any information on death certificates, other paper documents, or in computer files which by itself, or if linked with other records, would permit the identification of one or more individuals or establishments; for example, name(s), Social Security number, exact dates, addresses, and death certificate number. Even with the removal of direct identifiers and linkable study subject identification numbers, there is still a special concern that some combinations of the remaining variables could potentially be used to identify an individual. For example, a combination of date of birth, date of death, or cause of death is considered identifiable.

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Public Health Service
Centers for Disease Control and Prevention
National Center for Health Statistics

Assigned NDI Application Number

NATIONAL DEATH INDEX APPLICATION

1. Title of study or project (must match IRB letter)

2. Individual and organization requesting use of NDI

Principal Investigator or Project Director:
Title:
Organization:
Address:

Phone no.: Ext: E-mail:

Who should be contacted if more information is needed?

Phone no.: Ext: E-mail:

3. External funding sources?

List the names of all OTHER organizations providing funding for this project and indicate the type of support provided (i.e., grant, contract, cooperative agreement, interagency agreement, or other [specify]). NOTE: Except for a FEDERAL GRANT, each sponsor must complete and sign an NDI Supplemental Confidentiality Agreement at the end of this application. If a FEDERAL GRANT, enter FEDERAL GRANT in "Name of Organization" and provide FULL Grant Number in "Type of Funding Support"

Names of Organization(s)	Type of Funding Support

4. Data sources

List all organizations (including your own) that have collected (or will be collecting) data on the study subjects. Under each organization listed, describe the types of data collected. If any of the **external** organizations listed will be receiving **IDENTIFYING or IDENTIFIABLE death record information**, they must also be listed in item 5 below.

5. Will EXTERNAL organizations (other than the NDI applicant's organization) be receiving IDENTIFYING or IDENTIFIABLE death record information?

List the names of all parties (organizations or outside consultants) that will obtain **IDENTIFYING or IDENTIFIABLE death record information** or data derivatives from NDI.
Important: *Under each organization (or consultant) listed below, specify that organization's role and what project will be performed. Also specify (1) what* ***IDENTIFYING or IDENTIFIABLE death record information*** *will be received, (2) in what form it will be received (e.g., death certificates or computer files), and (3) how the information will "flow" from one organization to another. Parties employed by your organization must complete and sign the Confidentiality Agreement. Parties in other organizations must complete and sign an NDI Supplemental Confidentiality Agreement.*

External Organization Information		
Name:		
Organization Name:		
Phone:	**Ext:**	
Email:	**Admin. Relationship:**	**Data Type:**
Organization's role and what project activities will be performed:		
Name:		
Organization Name:		
Phone:	**Ext:**	
Email:	**Admin. Relationship:**	**Data Type:**
Organization's role and what project activities will be performed:		
Name:		
Organization Name:		
Phone:	**Ext:**	
Email:	**Admin. Relationship:**	**Data Type:**
Organization's role and what project activities will be performed:		
Name:		
Organization Name:		
Phone:	**Ext:**	
Email:	**Admin. Relationship:**	**Data Type:**
Organization's role and what project activities will be performed:		

6. Summary of study protocol or project activities

In responding to the following questions, please provide sufficient detail to describe your study or project and how data obtained via NDI will be used.

6a. Will the information obtained via NDI be included in a registry or any other type of study with long-term use or an indefinite end date?

What type of study is this? (e.g., disease registry, longitudinal cohort study, cross-sectional study, case-control study)

6b. Are you getting causes of death?

All applicants must complete item 6.c. If your application involves a registry, be sure also to include the following information in item 6c. below: (1) the date the registry was founded, (2) the purpose of the registry, and (3) the eligibility criteria for including person in the registry. A registry should also refer to **Attachment B** for additional information to be included in this application.

6c. Purpose of study or project

Describe the health or medical problem(s) addressed by your study or project. Include some background information to support why the study or project is being done. What are the primary objectives? If appropriate, include a description of hypotheses to be tested.

7. Death record follow-back investigations

7a. Does this study or project plan to perform "death record follow-back" investigations? ("Follow-back investigations" means that **once NDI identifies that certain study subjects are deceased,** your staff plans to collect additional information on those subjects by going **BACK** to individuals or establishments that are mentioned in the subjects' actual death certificates.) NOTE: Follow-up refers to contacting the next-of-kin or health providers based on information already contained in researchers' file.

If **yes**, refer to **Attachment C** for additional documentation needed.

7b. If **yes**, what type of respondents will be contacted? Check all that apply.

- ☐ Decedent's next-of-kin
- ☐ Physicians
- ☐ Hospitals
- ☐ Other individuals or establishments mentioned on death record

7c. What information will be obtained from EACH type of respondent?

7d. Name the organization(s) or consultant(s) who will be contacting EACH type of respondent:

7e. Name the methods to be used in conducting follow-back investigations, including how EACH type of contact will be made:

8. Institutional Review Board (IRB) for the Protection of Human Subjects

(Defined by the U.S. Department of Health and Human Services in the Code of Federal Regulations, Title 45, Part 46)

Evidence of a current IRB review is REQUIRED for all NDI applications (please ensure that NDI applicant's name is referenced in the IRB letter). If this study or project involves death record follow-back investigations as described in item 7, a special letter from the IRB is REQUIRED (as explained in Attachment C).

8a. IRB approval status

- ☐ Full
- ☐ Expedite
- ☐ Exempt

8b. Include a copy of the IRB review and provide the following:

Name of IRB:

IRB's Multiple Project Assurance (MPA) number or Federalwide Assurance (FWA) number:

Date of most current IRB review (must be within the last 365 days)

(NOTE: If death record follow-back investigation will be performed as described in item 7, an explanation of why your organization does not require an IRB approval for such a study or project is not acceptable. If your organization does not have an IRB [that has been approved by the Office for Human Research Protections, Department of Health and Human Services], you may have the study reviewed by an approved IRB in another organization.)

9. Maintaining the Confidentiality of IDENTIFYING or IDENTIFIABLE death record information

9a. Name the organization(s), including your own, that will:

(1) Submit records of study subjects for the NDI file search(es):

Organization Name	Site Indicator

(2) Receive the results of the NDI search directly:

Organization Name	Site Indicator

Based on the results of the NDI file search(es), will copies of death certificates be requested from state vital statistics offices?

(3) Request copies of death certificates from the state vital statistics offices:

9b. Describe the following controls that would be used to store and maintain the confidentiality of the **IDENTIFYING or IDENTIFIABLE death record information** at your organization:

Physical controls – building guards, identification badges, key cards, closed circuit TV, and locked offices.

Technical controls – user identification, passwords, firewalls, encryption, virtual private network, intrusion detection system, and stand-alone desktop use only. Please be aware that the standard encryption requirement for sensitive federal information, like the NDI data, is FIPS-140-2 in accordance with NIST 800-53 (see: https://nvlpubs.nist.gov/nistpubs/FIPS/NIST.FIPS.140-2.pdf and https://nvlpubs.nist.gov/nistpubs/SpecialPublications/NIST.SP.800-53r4.pdf).

Administrative controls – frequency of backing up files, where backup files will be stored, methods to ensure least privilege access, methods for ensuring **IDENTIFYING or IDENTIFIABLE death record information** is not co-mingled with administrative records not part of this project, how use will be monitored to prevent use for purposes not approved for this project, how personnel using the system will be trained and made aware of their responsibilities for protecting the **IDENTIFYING or IDENTIFIABLE death record information**, methods for monitoring who has access to the data, and methods for ensuring return or destruction of data. Please include text indicating the number of persons who will have access to the backup files containing IDENTIFYING OR IDENTIFIABLE death record information.

NOTE: *If multiple sites are involved in the above-mentioned study project, each site must describe its own controls that would be used to maintain the confidentiality of the **IDENTIFYING or IDENTIFIABLE death record information**.*

10. Completion of study or project

10a. Is the study or project ongoing or open-ended?

If no, indicate the scheduled termination date for the study:

10b. In what form (e.g., aggregate, statistical, report, etc.) and to whom (e.g., peer-reviewed scientific journals, monographs) will the results of your study or activities be released? (NDI would appreciate a courtesy copy of any publications that may result from the use of NDI data.)

10c. Will study subjects be notified of study results?

If yes, how will the subjects be notified?

11. Data disposition plan

Some state vital statistics offices have expressed concern about indefinite retention of **IDENTIFYING or IDENTIFIABLE death record information** that could be used in the future by other persons for other purposes.

Except for data stored in registries, or other approved long-term studies, all identifying or identifiable data received from NDI must be removed from all research records at the conclusion of the study or within 5 years after receipt of the NDI data – regardless of the data set in which the data are kept. This means that all identifiers or potentially identifiable data elements associated with cause-of-death codes must be removed from all analysis files unless there is no way to identify an individual decedent. This also means that any linked files (with crosswalks) must be destroyed. **As long as there are no identifiers or linkage variables remaining in the analytic or public-use file(s), cause(s) of death codes may remain in such file(s).** (Note: Death certificates obtained directly from state offices may have to be shredded in less than 5 years depending on each state's requirements.)

1. Based on the above requirements, when do you plan to dispose of all **IDENTIFYING or IDENTIFIABLE death record information** obtained from NDI? Give the proposed month and year of destruction, or enter UNKNOWN if this is an open-ended or ongoing study that has no specific disposition plan at this time.

2. Only complete item 2a. if the above date is UNKNOWN or if the date is more than 5 years after the month and year that you submitted this NDI application.

   a. Please provide a strong justification for why the data need to be retained beyond this 5-year period.

   b. Within 5 years of submitting your NDI application, you are responsible for either (1) requesting an extension or (2) certifying the NDI data have been returned to NCHS or destroyed (see **Attachment A**). The extension request or certification of data disposal must be submitted to NDI staff within 5 years – no later than the month and year stated in the box below.