



Angus S. King, Jr.
Governor

Kevin W. Concannon
Commissioner

STATE OF MAINE
DEPARTMENT OF HUMAN SERVICES
AUGUSTA, MAINE 04333

April 25, 1995

Hasmukh Shah, Ph.D., D.A.B.T.
Manager, Vinyl Chloride Panel
Chemical Manufacturers Association
2501 M Street NW
Washington, D.C. 20037

RS 104

Dear Dr. Shah:

We have received your request for permission to transfer to Maine death certificates related to the cohort mortality study of vinyl chloride workers from ENSR Health Sciences to Applied Epidemiology Inc. Those requesting restricted data from the Office of Data, Research, and Vital Statistics (ODRVS) are now required to complete an application form and sign a disclosure agreement prior to the release of any information.

Since I do not find an application related to this study in our files, I must ask you to complete the enclosed form and return it to us, together with a disclosure agreement signed by Dr. Kenneth Mundt at AEI. When I receive these documents, I will grant the requested permission to transfer the Maine records to AEI.

Please feel free to call me at (207) 624-5464 if you have any questions.

Sincerely,

Ellen Naor

Ellen Naor, State Registrar
of Vital Statistics

EN:sw

MAINE DEPARTMENT OF HUMAN SERVICES
OFFICE OF DATA, RESEARCH, AND VITAL STATISTICS

RS 104

Application for Release of Restricted Vital Statistics Data

Title of Study or Program: _____

1. Principal Investigator or Program Director:

Name _____

Title _____

Organization _____

Address _____

2. Contact person:

Name _____

Telephone No. _____ FAX No. _____

3. Purpose of study or program, including statutory authority, if applicable:

4. Type of records requested: _____ deaths
_____ births
_____ fetal deaths
_____ other - specify: _____

5. Form of records requested: _____ photocopies - certified
_____ photocopies - noncertified
_____ computer listing
_____ computer tape; specifications: _____
_____ other - specify: _____

Date reviewed: _____

Approved: _____ Yes _____ No

By: _____

State Registrar

\$ _____ Estimate

Continuing request? _____

Approval valid until _____

6. Will you supply identifying information to be used to select the records of interest?

☐ Yes ☐ No

If yes, what information?

If not, how is the general group of records you are requesting to be selected?

7. Approximate number of records requested: _____

8. If your request calls for the release of data on an ongoing basis, how often will you need the data supplied, and over how long a period of time?

This application is valid for up to three years for the specific uses detailed herein.

9. Is this request based on information received from the National Death Index (NDI)?

☐ Yes ☐ No

It is preferred that requests based on NDI searches be submitted using the NDI Death Certificate Request Form, accompanied by the cover page and page 3 of the NDI Application Form. A full copy of the NDI Application Form may be attached to this request in lieu of responses to questions 10 and 11 below.

10. Summary of study/program protocol. Please be as succinct as possible; your complete study protocol or program and detailed descriptions of your project and background are not necessary.
- a. Description of health or medical problem addressed or administrative purpose served by the program, demonstrating that data requested are essential, and stating primary study or program objectives and hypotheses to be tested, if applicable.
 - b. Methodology; include justification for contact with individuals named on vital records and attach copies of contact letters and consent forms if applicable.
 - c. Description of any data files that will be linked with the vital records data, demonstrating that such linkage is essential for the stated purpose.

d. Analysis plan, if applicable, indicating how data will be used and level of aggregation.

e. Description of whether, and if so, to whom restricted data will be released, demonstrating that such release is related to stated purpose.

f. Procedures for maintaining confidentiality and security of restricted data received on or through the use of vital records.

g. Procedures and timetable for disposition of any vital records received.

11. Attach copy of *Disclosure Agreement*, signed by the Principal Investigator, Program Director, or other individual responsible for conformance to standards for release of restricted data.

**MAINE DEPARTMENT OF HUMAN SERVICES
OFFICE OF DATA, RESEARCH, AND VITAL STATISTICS**

Disclosure Agreement

As the official or principal investigator of the program or research study named on this application, which involves the use of vital statistics data, I agree to abide by the provisions of M.R.S.A. Title 22, Sec. 2706 and 10-146 CMR 8. I will take all steps necessary to ensure that all those involved with the specified program or research project also abide by the provisions of this Disclosure Agreement, and that the data received are not used for any purpose other than that specified in the Application for Release of Restricted Vital Statistics Data.

I agree that the vital statistics information will not be used in a manner which will identify any individual in any results, presentations, or reports produced by the investigation, study or project, or for administrative purposes other than those specified in this application; that vital statistics data released for statistical research use will not be used for administrative, legal or other nonstatistical purposes which may directly affect particular individuals as a result of their identification in the study; that vital statistics data will be made in a manner that will protect their confidentiality; and that disposition of restricted vital statistics data will be made in a manner that will not permit unauthorized disclosure.

This agreement of non-disclosure applies to all forms of personal communication, as well as to published results, presentations and reports.

The undersigned is authorized to execute this agreement.

Principal Investigator, Program Director, or Other Responsible Individual:

Signature: _____ Date: _____

Printed Name and Title: _____

Organization: _____

Title of Program or Study: _____



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DEPARTMENT OF HUMAN SERVICES
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OFFICE OF DATA, RESEARCH, AND VITAL STATISTICS
FEES FOR RELEASE OF RESTRICTED VITAL STATISTICS DATA

VITAL RECORDS CERTIFICATES

\$10.00 - Record search and certified copy of record.

\$ 6.00 - Record search and non-certified copy of record.

The fees are for each search conducted whether or not the record is located, regardless of whether or not the presumed record number is provided by the requestor. The applicable fees must be paid in advance with a check made payable to Treasurer, State of Maine.

DATA TAPES AND DISKETTES

Requests for data will be billed according to the amount of staff time required (approximately \$30 per hour), amount of cpu time needed (\$20 per minute), number of tapes or diskettes required (\$20/\$2.50), and microcomputer use (\$5.00 per hour).

The requestor will be notified of the estimated cost of the desired product; agreement for payment must be secured prior to preparation of the information requested. A bill will be sent with the product.

If the request is from a state agency outside the Department of Human Services, the account and activity numbers must be provided so that charges can be made.

Written authorization by the requestor is required for job estimates over \$500. Any revisions to the original request which result in increasing the estimate will require another written authorization.

R 4/95

[APPLI.VS]

Office of Data, Research, and Vital Statistics, 35 Anthony Avenue
State House Station #11, Augusta, Maine 04333-0011
Tel: (207)624-5445; Vital Records (207)287-3181

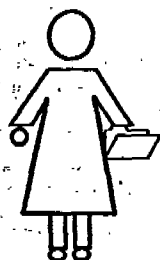
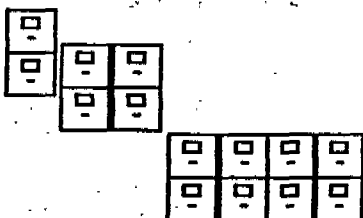
R8S151257

John R. McKernan
Governor



Jane Sheehan
Commissioner

ACCESS TO VITAL STATISTICS DATA



ADMINISTRATIVE
and
STATISTICAL RESEARCH
USES

Bill B.

636-1311

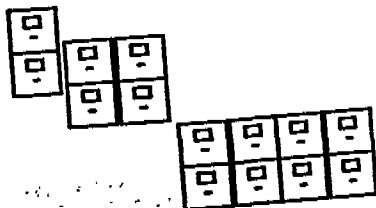
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John R. McKernan
Governor



Jane Sheehan
Commissioner

ACCESS TO VITAL STATISTICS DATA



ADMINISTRATIVE
and
STATISTICAL RESEARCH
USES



STATE OF MAINE
DEPARTMENT OF HUMAN SERVICES
100 STATE ST., MAINE 04333

Kevin W. Concannon
Commissioner

April 25, 1995

Bill B.

636-1311

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d permission to transfer the Maine records to AEI.

i have any questions.

ly,

S. Nae

Director, State Registrar
of Vital Statistics

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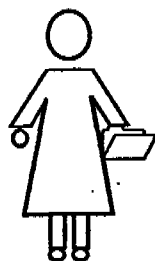
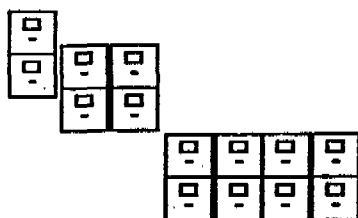
EN:sw

John R. McKernan
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Jane Sheehan
Commissioner

ACCESS TO VITAL STATISTICS DATA



ADMINISTRATIVE
and
STATISTICAL RESEARCH
USES

What:

The information contained in vital records - births, deaths, marriages and divorces - is used for historical study, genealogic research, administrative purposes and statistical research as well as for individual needs. Records that do not contain information which is confidential by law are available to the general public without restriction.

Records containing confidential information are available for general use only if they do not identify individuals. Aggregated statistical data are also available for general use.

Records which contain confidential information and identifying information, however, are restricted to those with a direct and legitimate interest in the record, such as the person named on the record and related individuals. Government agencies and those conducting statistical research also may be allowed access to restricted data for certain approved administrative or scientific purposes.

This pamphlet introduces administrative and statistical research users to the procedures for obtaining release of restricted vital statistics data. Excerpts from the rule governing such release are printed inside this folder for ready reference.

Who:

Administrative Users

Federal or State Agencies, Maine municipal governments and Maine public school districts may be allowed access to restricted data if essential to their conduct of specific official duties. The official responsible for the program must provide written assurances that the use, storage and disposition of the records will maintain their confidentiality, and that the data will not be used for any other purposes.

Statistical Research Users

Individuals and organizations may have access to restricted data if they are conducting health, medical or social research which has potential for reducing morbidity and mortality within Maine, for furthering scientific understanding of disease processes, or for improving health and social services. The person in charge of the research must provide written assurances that the use, storage and disposition of the records will maintain their confidentiality, and that the data will not be used for any other purposes.

How:

- Complete the "Application for Release of Restricted Vital Statistics Data," obtained from the Office of Data, Research, and Vital Statistics. The following information must be supplied about your program or research study, demonstrating that the restricted data you are requesting are essential for conduct of the agency's official duties or for conduct of the research:

- * Purpose for which restricted data will be used.
- * Planned contact with the person named on the record, family members, or other individuals on the basis of vital statistics data.
- * Planned linkage with other data within the requesting organization.
- * How and to whom restricted data will be released.

- Specify, as part of the application, what procedures you will use to maintain the security of the restricted data; the procedures and time table for their final disposition must also be specified.

- Include written assurances by a responsible individual in the organization that the restricted data will not be used for any purposes other than those specified in the application.

- Enclose the required fee with your application unless you have made other arrangements with the Office of Data, Research, and Vital Statistics. A set fee policy governs the provision of copies of vital records and vital statistics data in any format. In general, fees for copies of individual records are paid at the time the records are requested, unless other arrangements are made with the state registrar. If data are requested in any other format, an estimate of the cost will be provided and agreement for payment secured before the data are prepared for release, unless other arrangements are made with the state registrar.

- To request an application, please contact:

Office of Data, Research, and Vital Statistics
State House Station #11
35 Anthony Avenue
Augusta, Maine 04333-0011

Telephone: (207) 624-5445

RELEASE OF RESTRICTED VITAL STATISTICS DATA (excerpts)

1. Definitions. For purposes of this Chapter 8, the following terms shall have the meanings set forth below:

A. Administrative Purposes. "Administrative purposes" means uses of vital statistics data by federal, state or local government agencies for the conduct of their official duties, including planning, program management, eligibility determination, provision of services, quality control, and program evaluation.

C. Birth Lists. "Birth lists" means lists that shall include only the following data from birth records: child's name, date of birth, sex, city or town of birth, and mother's mailing address. In the case of adoptions and legitimations, birth lists shall contain only the name and address after adoption or legitimation, pursuant to Title 22 M.R.S.A. Sec. 2765. Birth lists shall not include parents' names or any other information from which legitimacy status can be inferred.

F. Direct and Legitimate Interest. The following individuals and entities shall be deemed to have a "direct and legitimate interest" in the data contained in a vital record.

(1) Registrant or related individuals;

(2) Federal or State agencies, Maine municipal governments and Maine public school districts, any which may require such data for administrative purposes in the conduct of their official duties; and

(3) Those individuals conducting health, medical, and social research, including those in governmental agencies, which have potential for reducing morbidity and mortality within Maine, for furthering scientific understanding of disease processes, or for improving health and social services.

(4) Others may be authorized to obtain confidential data when they demonstrate that such information is needed for the determination or protection of personal property rights.

Media representatives and commercial firms other than those conducting health, medical or social research shall not be considered to have a direct and legitimate interest.

I. Identifying Data. "Identifying data" means the names and street addresses of the registrant(s) and other individuals named on the vital record (e.g., parents, informant, physician, funeral director) and the month and day of the event. The year that an event occurred is not identifying data.

L. Nonrestricted Vital Statistics Data or Nonrestricted Data. "Nonrestricted vital statistics data" means the following information:

(1) Aggregated statistical data, including confidential data, which do not (directly or indirectly) identify any individual.

(2) Individual vital records, including confidential data, which do not (directly or indirectly) identify any individual.

(3) Information from the legal sections of individual vital records, excluding confidential data and data from which confidential information can be inferred.

(4) Birth lists.

N. Registrant. "Registrant" means the person or persons to whom the vital record pertains: the child named on a birth certificate, the decedent named on a death certificate, the bride and groom named on a marriage certificate, the husband and wife named on a divorce record, and the mother and father named on a fetal death certificate.

O. Related Individuals. "Related individuals" means a member of the immediate family of the registrant or descendants thereof, the registrant's legal custodian or guardian, or their respective authorized representatives. "Authorized representative" shall include an attorney, physician, or funeral director. Other agents authorized in writing to act in behalf of the registrant or his or her immediate family or descendants thereof are also considered to be related individuals for the purposes of this chapter. The biological parents of adopted children, when neither has custody, shall not be considered to be related individuals for the purposes of this chapter.

P. Restricted Data. "Restricted data" means confidential data presented in conjunction with identifying data or with other information which may allow indirect identification of the registrant or other individuals named on the vital record.

2. Standards for release of vital statistics data

C. Application submitted

(1) All requests for release of restricted data must be submitted to the municipal clerk or to the Office of Vital Statistics on the application form prescribed and furnished by the state registrar for the purpose of determining the requestor's eligibility to receive such data.

E. Fee

(1) All data released in response to requests (in the case of non-restricted data) or approved applications (in the case of restricted data) shall be subject to set charges in accordance with the general fee policy of the Office of Data, Research, & Vital Statistics.

(a) Fees for certified or noncertified copies of vital records are specified by regulation (10-146 CMR 8)... the applicable fees shall be paid in advance of the release of the data requested or applied for.

(b) Charges for data released in other formats (e.g., lists, labels, computer tapes, printouts, etc.) shall include, but not be limited to, computer time, programming time, materials, photocopying, and any other costs incurred in producing the requested data. An estimate of charges for such requests must be provided to the requestor and agreement for payment secured prior to preparation of the data for release.

F. Penalties

(1) Disclosure of restricted data, except as authorized in this chapter, is subject to criminal penalties as specified in Title 22, M.R.S.A. Sec. 2708(2).

(2) Any person who willfully provides false information in connection with this rule is subject to criminal penalties as specified in Title 22, M.R.S.A. Sec. 2708(2).

4. Release of restricted data for administrative and statistical research purposes.

Authorized users

The following individuals and entities shall be deemed authorized users, based upon the intended purposes or uses of such restricted data:

- (1) Administrative purposes
 - (a) Maine state government agencies and the Department.
 - (b) Federal or municipal government agencies, including public school districts.
- (2) Statistical research purposes
 - (a) Maine state government agencies conducting research related to their official duties.
 - (b) Those individuals, nonprofit organizations, public entities and businesses conducting health, medical, and social research.

Conditions for release

Restricted data may be released to an applicant only when the state registrar is satisfied that the following criteria are met:

- (1) Restricted or identifying vital statistics data are essential for the agency to conduct its official duties or for the conduct of the research.
- (2) Contact with individuals on the basis of information from vital statistics data, if intended, is required for the administrative purposes specified in the application, or in the case of a research study, meets professional standards for human subjects research.
- (3) Linkages with other data bases, if planned, are essential for the administrative purposes specified in the application or for conduct of the research and will not lead to unauthorized disclosure of restricted vital statistics data.
- (4) Restricted data will not be further disclosed or used for purposes other than those for which they were requested unless so authorized by the state registrar.
- (5) Adequate procedures are in place to secure vital statistics data from unauthorized access or use for purposes other than those for which they were requested: locked when not in use and accessed only by authorized individuals for the purposes stated in the application.
- (6) Disposition of restricted vital statistics data will be made in a manner that will not permit unauthorized disclosure.
- (7) A Disclosure Agreement has been signed by an individual authorized to execute agreements, stating that the agency or organization will meet and conform to the stated conditions under which the restricted vital statistics data will be used, as specified in the application.
- (8) Signed Disclosure Agreements have been obtained from any other organization or agency that will be receiving restricted data.

Additional conditions for statistical research use of restricted

Restricted data released for use in research shall not be used, in whole or in part, for administrative, legal or other nonstatistical purposes which may directly affect particular individuals as a result of their specific identification in the study.

F. Additional conditions for statistical research use of restricted birth certificate data.

- (1) Researchers who plan contact with the registrant, family members or other individuals, based on birth certificate data, must satisfy the state registrar that surveys and related materials (envelope, cover letter, questionnaire, other data) will not disclose legitimacy status (i.e., fact of illegitimacy).
- (2) Under no circumstances may information on father's name be released by the researcher. The presence or absence of this item on an individual record in effect may disclose legitimacy status.

G. Additional conditions for use of data from other states.

- (1) Use of vital statistics data obtained from other states in accordance with the Interstate Exchange Agreement, which do not include identifying data, may be authorized under this section for research purposes.
- (2) Research requests for release of individual names or other personal identifiers require the written permission of the state where the record is officially registered.
- (3) Administrative requests for vital statistics data obtained from other states in accordance with the Interstate Exchange Agreement require the written permission of the state where the record is officially registered.

H. Continuing use.

- (1) Restricted data may be released on an ongoing basis if needed for the requesting organization to conduct its official duties or for conduct of the research.
- (2) The state registrar may approve applications for periods of up to three years, so long as there are no significant changes, as specified in paragraph (3) below, in the uses described in the initial application.
- (3) A new or updated application must be submitted to the state registrar, together with a new Disclosure Agreement, if there are changes in any of the following areas:
 - a. Purpose of which restricted data will be used.
 - b. Contact with the registrant, family members, or other individuals on the basis of vital statistics data.
 - c. Linkage with other data within the requesting organization.
 - d. How or to whom restricted data will be released.
 - e. Procedures for securing restricted data.
 - f. Procedures and timetable for disposition of restricted data.
 - g. Individual responsible for conformance to standards for release of restricted data.
 - h. Other agencies or organizations receiving restricted data.
- (4) After three years, a new or updated application must be submitted to the state registrar, together with a new Disclosure Agreement.

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R&S151263

NON-DISCRIMINATION NOTICE

In accordance with Title VI of the Civil Rights Act of 1964, as amended by the Civil Rights Restoration Act of 1991 (42 U.S.C. Section 1981, 2000e et seq.) Section 504 of the Rehabilitation Act of 1973, as amended (29 U.S.C. Section 794, the Age Discrimination Act of 1975, as amended (42 U.S.C. Section 6101 et seq.), Title II of the Americans with Disabilities Act of 1990 (42 U.S.C. Section 12101 et seq.), and Title IX of the Education Amendments of 1972, the Maine Department of Human Services does not discriminate on the basis of sex, race, color, national origin, disability or age in admission or access to or treatment or employment in its programs and activities.

Ann Twombly, Affirmative Action Coordinator, has been designated to coordinate our efforts to comply with the U.S. Department of Health and Human Services regulation (45 C.F.R. Parts 80, 84, and 91) and the U.S. Department of Education regulations (34 C.F.R. Part 106) implementing these Federal laws. Inquiries concerning the application of these regulations and our grievance procedures for resolution of complaints alleging discrimination may be referred to Ann Twombly at 221 State Street, Augusta, Maine 04333, Telephone number: (207) 287-3488 (Voice) or 1-800-332-1003 (TTD), or the Assistant Secretary of the Office of Civil Rights, Washington, D.C.

Prepared by

State of Maine
Department of Human Services
Office of Data, Research, and Vital Statistics

Published in June, 1993
As Required by 22 MRSA Section 2701

Authorized by 22 M.R.S.A. Sec. 2706
Appropriation Number 010-10A-1116-012