



National Archives and Records Administration

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REFERENCE COPY OF TECHNICAL DOCUMENTATION FOR ACCESSIONED ELECTRONIC RECORDS (Copied: August 1, 2006)

Collaborative Perinatal Project

RG 443 United States Institutes of Health

The National Archives and Records Administration (NARA) has been accepting electronic records into its holdings since the early 1970s. Technical documentation has accompanied each transfer of electronic records. The documentation is necessary to understand the meaning of the digitized bits of information within the electronic records.

Over the decades, NARA has had different procedures for compiling technical documentation into an organized unit for researchers, and different expectations regarding the content and extent of any NARA-produced portions of the documentation. Consequently, the structure, organization and contents of the documentation reflect the procedures in place when the technical documentation was compiled and arranged and may include out of date addresses, telephone numbers, or other items of unrevised information related to the agency that created or transferred the documentation and electronic records to NARA, to the NARA unit that processed these materials, or to the physical media of the electronic records files.

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Supplemental User Note 1

Collaborative Perinatal Project (NCPP), 1958-1974
3-443-85-1

The Introduction to Documentation for the Collaborative Perinatal Project (NCPP), 1958-1974, prepared at the National Archives and Records Administration in September 1985, includes a statement concerning restrictions to access. The statement notes that the NCPP data were subject to provisions of the Privacy Act of 1974 and the Freedom of Information Act, Exemption B6, while in the custody of the creating organization, the National Institute of Neurological and Communicative Disorders and Strokes (NINCDS), the National Institutes of Health. It also notes that access to the records is restricted in keeping with National Archives General Restriction 4, and notes that records so restricted, may be released for statistical or quantitative research when the researchers have completed an "Application for Statistical Research in Records Containing Personal Information," and agreed in writing to the "Conditions of Use" of the records. Implicit is that the National Archives has approved the release of the records for the stated research.

In the summer, 1987, Trudy H. Peterson, the Assistant Archivist of the National Archives, Edie Hedlin, Director of the [National Archives] Machine-Readable Branch, and Margaret O. Adams, Archives Specialist, Machine-Readable Branch, reviewed together the restrictions on access to the electronic records of the NCPP, and the extent of the personal identifiers in these records. Dr. Peterson defined personal identifiers as variables such as Name, Address, Social Security Number (or Internal Revenue Service Taxpayer Identification). Dr. Peterson stated that if personal identifiers were removed from records restricted by National Archives General Restriction 4, the records could be released without restriction. Staff of the Machine-Readable Branch thereafter determined that only two of the NCPP files included personal identifiers, as Dr. Peterson had defined them, and these were limited to Name variables. The two files are the NCPP Master File and the NCPP Workfile 16, Serum Specimen Inventory Work File.

Subsequently, in October 1987, and with the approval of Dr. Hedlin, staff of the Machine-Readable Branch created public use extracts of these two files by blanking all data in any Name fields. Since that time, the Public Use NCPP Master File and the Public Use NCPP Workfile 16 are the source files for creating copies of the NCPP Master File and/or the NCPP Workfile 16 in filling all reproduction orders. The public use extract files will continue to be preserved until the 75-year restriction (National Archives General Restriction 4) on the release of the complete NCPP records series expires in the year 2049. Release of the Public Use NCPP Master File and/or the Public Use NCPP Workfile 16 is not contingent upon completion of the "Application for Statistical Research in Records Containing Personal Information."

None of the other files in the NCPP series transferred into the holdings of the National Archives include any personal identifiers and are therefore reproduced as transferred to the National Archives, without restriction.

Margaret O. Adams
Supervisory Archivist
March 13, 2002



National Archives and Records Administration

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Sample Dumps of Public Use Files

Collaborative Perinatal Project NN3-443-85-001

Both the Master File and Work File 16: Serum Specimen Inventory contain individuals' names and therefore are restricted for privacy reasons. NARA has created public use versions of these files wherein the names have been blanked. The sample dumps for the public use Master File and the public use Work File 16: Serum Specimen Inventory were copied from preservation job folders 95-7013 and 95-7860, respectively.

Lynn Goodsell, Archives Specialist
Electronic and Special Media Records Services Division
November 9, 2005

Public Use Master File

APS RECORD DUMP

Date: 01/29/2002 Time: 13:24

*dump
DS# 7
M06837
1st 10 records*

FILE #1 BLOCK # 0 RECORD # 0

0000 00011051000110 85446 0 01025901025909185811013721
0040 10625592115 1

FILE #1 BLOCK # 0 RECORD # 1

0050 1201305100011901999907065908882017251005899930990999205109909105
0090 65 2439

FILE #1 BLOCK # 0 RECORD # 2

00A0 220130510001199900000000000000000000000000000902100000010090000
00E0 2439

FILE #1 BLOCK # 0 RECORD # 3

00F0 030200510001190101035742121081101
0130

FILE #1 BLOCK # 0 RECORD # 4

0140 0303005100011901025910001000000000000000080000000000200000000000
0180 0

FILE #1 BLOCK # 0 RECORD # 5

0190 03041051000119010259155528302000918580821580010110999999999999
01D0

FILE #1 BLOCK # 0 RECORD # 6

01E0 130500510001199999991450110155800000000000000000000000000000000
0220 0

FILE #1 BLOCK # 0 RECORD # 7

0230 230500510001199999990000000000000000000000000000000000000999999999999
0270 91000000001000

FILE #1 BLOCK # 0 RECORD # 8

0280 1306005100011901025900
02C0

FILE #1 BLOCK # 0 RECORD # 9

02D0 230600510001190102591499990000000000000000000000000000000999999999999
0310 90

Public Use Work File 16

APS RECORD DUMP

Date: 01/29/2002 Time: 15:50

Work File
16 Public
Use

Dump
M06991
#16

PRBCCP, CARD
Ø8Ø6.P

1st 10 records

FILE #16	BLOCK # 0	RECORD # 0		
0000	08060051000119		15010259091858121	D500907055943
0040	0103010301030101			
FILE #16	BLOCK # 0	RECORD # 1		
0050	08060051000219		11010259101458115	0500807085943
0090	0103010301030101			
FILE #16	BLOCK # 0	RECORD # 2		
00A0	08060051000219		11010259101458115	D500507255943
00E0	0103010301030101			
FILE #16	BLOCK # 0	RECORD # 3		
00F0	08060051000319		19010259082458123	D501205235943
0130	0103010301030101			
FILE #16	BLOCK # 0	RECORD # 4		
0140	08060051000329		30102262032962126	R410710226243
0180	0103010301030101			
FILE #16	BLOCK # 0	RECORD # 5		
0190	08060051000329		30102262032962126	0811512266222
01D0	5101010000000000			
FILE #16	BLOCK # 0	RECORD # 6		
01E0	08060051000329		30102262032962126	D511512266243
0220	0103010301030101			
FILE #16	BLOCK # 0	RECORD # 7		
0230	08060051000339		28033064091363128	R416703306443
0270	010301030103010			
FILE #16	BLOCK # 0	RECORD # 8		
0280	08060051000339		28033064091363128	D517406046443
02C0	010301030103010			
FILE #16	BLOCK # 0	RECORD # 9		
02D0	08060051000339		28033064091363128	0817406046422
0310	0101510			



3-443-85-001

COLLABORATIVE PERINATAL PROJECT

1958 - 1974

DOCUMENTATION

Record Group 443

Records of the National Institutes of Health

01



CONTENTS

Abstract

Introduction

NCPP User's Guide

National Archives



Washington, DC 20408

August 1985
3-443-85-1

United States National Institutes of Health. Collaborative Perinatal Project (NCPP), 1958-1974 [Machine-Readable data file]. Created by the National Institute of Neurological and Communicative Disorders and Stroke (NINCDS). Washington: National Institutes of Health [producer] 1958-84; Washington: National Archives and Records Administration [distributor].

PROVENANCE: The National Institute of Neurological Diseases and Blindness (NINDB) of the National Institutes of Health instituted the Collaborative Study of Cerebral Palsy, Mental Retardation, and other Neurological and Sensory Disorders of Infancy and Childhood. From this study evolved the need for and the initiation of the NCPP and the reorganization of the NINDB into the NINCDS. Data from medical histories, examinations, and observations on the participating individuals was supplied by twelve institutions throughout the United States between 1959 and 1974.

TYPE OF FILE: Microdata. The unit of observation is the individual. There is one record for each medical examination or clinical observation.

UNIVERSE DESCRIPTION: The universe consists of samples of 300 to 2000 pregnancies per year (1959-1965) from each of twelve participating institutions: Boston Lying-In Hospital; Children's Hospital, Buffalo; Charity Hospital, New Orleans; Columbia-Presbyterian Medical Center, New York; Johns Hopkins Hospital, Baltimore; Medical College of Virginia, Richmond; University of Minnesota Hospital, Minneapolis; New York Medical Hospital; University of Oregon Medical Center, Portland; Pennsylvania Hospital/Children's Hospital, Philadelphia; Providence Lying-In Hospital; University of Tennessee College of Medicine, Memphis; The sampling frame and selection process varied from institution to institution and is fully explained in the documentation. The NCPP lasted sixteen years and included approximately 58,000 study pregnancies. Data on the women and their pregnancies and study children are included in the NCPP data base.

SUBJECT MATTER DESCRIPTION: The Collaborative Perinatal Project was a prospective study. The data constitute an important resource for biomedical and behavioral research in many areas of obstetrics, perinatology, pediatrics and developmental psychology. The data also provide a prospective base for examining neurological and neurosensory defects and the relationship of pregnancy and perinatal factors on the health of individual children. The major categories of data collected include obstetrical, pediatric, pathological, serological, socioeconomic and family, genetic history, psychological, speech, language and hearing. The mother was examined

during pregnancy, labor and delivery. The children were given neonatal examinations and follow-up examinations at four, eight, and twelve months, and three, four, seven, and eight years. Supplemental information was gathered throughout the study, including family linkages between related women participating in the NCPP. In addition to the master file there are variable files and work files arranged to facilitate researcher access of the 6700 data items.

GEOGRAPHIC COVERAGE: Geographic coding includes the city and state of the twelve participating institutions and the street address, city, and state of each patient.

TECHNICAL DESCRIPTION:

STRUCTURE: Fixed length, non-hierarchical

SIZE: Master File - 58,760 Administrative Records

SORT SEQUENCE: Records within the master file are sorted by the master file card number and a unique case number identifying the institution, mother and child. Records within the Variable file are sorted by variable and thereunder by unique case number. Records within the work files are sorted by unique case number.

REFERENCE MATERIAL:

Documentation Relating to the Collaborative Perinatal Project

Available from the Machine-Readable Branch (NNSR)

This is a guide to the machine-readable data files. It contains an introduction to the data; detailed history of data design, collection, and processing; the organization and content of the files; and codebooks.

RELATED PRINTED REPORTS:

The documentation includes an extensive bibliography of research reports based on the project data.

RELATED MACHINE-READABLE DATA FILES:

None

FILE AVAILABILITY:

The data in the NCPP contain personal identifiers and medical information protected under the Privacy Act and NARA General Restriction B4. Access to the data for statistical research may be permitted within the appropriate guidelines and restrictions.

These files are available from:

Machine-Readable Branch (NNSR)
National Archives and Records Administration
Washington, DC 20408
(202) 523-3267

DESCRIPTORS: TOXEMIA, PREGNANCY, NEUROLOGY, CEREBRAL PALSY, OBSTETRICS,
PERINATOLOGY, PEDIATRICS, DEVELOPMENTAL PSYCHOLOGY, NIH,
DRUGS, SEROLOGY, CONGENITAL MALFUNCTIONS

Work Files: W1	Socioeconomic Index at Registration	55,910	records
W2	" " " " Seven Years	40,363	"
W3	Drugs Taken During Pregnancy, Trade Names	199,088	" (49,214 cases)
W4	" " " " , Active Compounds	253,154	" (")
W5	Congenital Malformations, One & Seven Years	59,391	"
W6	Cerebral Palsy Diagnosis	53,251	
W7	Abnormalities at Seven Years	41,869	
W8	Speech, Language and Hearing at Eight Years	20,137	
W9	Toxemia Classification	58,806	
W10	Rupture of Membranes	49,188	
W11	Survey of Vital, Bacterial, Parasitic and Fungal Infections During Pregnancy	10,224	
W12	Serological Testing - Complement Fixation Tests	19,323	
W13	Serological Testing - Toxoplasmosis & Rubella	39,645	
W14	" " - Cord Blood	32,098	
W15	- Abnormalities & Controls	24,255	
W16	Serum Specimen Inventory	227,235	
W17A	Family Linkage - Mother's Relationship	8,150	
W17B	" " - Children's Relationship	12,094	
W17C-	- " " - Cousin, 1st	8829	
D-	- Niece/Nephew	301	
E-	- Aunt/Uncle	219	
F	- Cousin, maternal	4626	
G-	- Cousin, maternal in-law	1467	
H-	- Cousin, maternal in-law	4250	
I-	- Niece/Nephew half	343	
J-	- Aunt/Uncle, half	266	
K-	- Cousin, half	775	
L-	- Cousin-once-removed	1405	
M-	- Cousin-2nd	1841	
W18-	Visit Summary	267,128	(28,455 cases)



INTRODUCTION TO DOCUMENTATION

The Collaborative Perinatal Project (NCP) was a longitudinal, multi-disciplinary research effort sponsored by the Developmental Neurology Branch, Neurological Disorders Program, National Institute of Neurological and Communicative Disorders and Stroke (NINCDS), the National Institutes of Health. The project sought leads to the etiologies of the developmental disorders of childhood, such as cerebral palsy and mental retardation, through controlled medical histories and studies which relate the events and conditions of pregnancy, labor and delivery to the neurological and mental status of the children of those pregnancies as the child grows and develops. The study sought to link any later appearance of cerebral palsy, mental retardation, learning disorders, congenital malfunctions, minimal brain dysfunction, convulsive disorders, visual abnormalities, or communicative disorders to patterns during the perinatal period in order to develop strategies for prevention and intervention.

The Project consisted of approximately 58,000 women and the children resulting from their pregnancies during the study. Additional demographic information was collected on the fathers and the siblings of the children and on relatives of the women.

The medical and other information was collected on the women within the study during pregnancy and delivery between 1959 and 1965 and on the children resulting from those pregnancies from birth until eight years of age. The last information was collected in 1974. The women in the study were patients at fourteen university affiliated medical centers across the United States. Sampling rates varied from 14 percent to 100 percent. For the most part the women were clinic patients.

The sample populations do not duplicate the national population in two significant aspects: they were nearly all from lower income groups and the racial composition was approximately half-white, half-black.

The project is unique in the magnitude of the study, the comprehensiveness of the information collected, the compatibility of the information collected between cooperating institutions and across the two decades of the study, the provision for future data analysis, the prospective, longitudinal nature of the project, and the enormity of the cost (\$200 million). The medical, psychological and demographic information is not time restricted and can be linked to future medical studies. Further, since basic data collection did not involve any changes or additions in the practices or procedures at the participating institutions, the data also represent an overview of medical practices during the two decades of the project.

Medical information on the women includes history of previous pregnancies and infertility, daily cigarette consumption, drug use in pregnancy, perinatal observations, labor and delivery events, obstetrical reports, and anesthesia reports. Socioeconomic, family history and family health information also was collected.

Medical information on the children includes comprehensive examinations conducted at birth, newborn, four-months, one year and seven years; psychological testing at eight-months, four years and seven years; speech, language and hearing examinations at three years and eight years; and serological and pathological studies. Some socioeconomic and family history also is available on all siblings.

The seven volumes of documentation prepared by NINCDS to support future research in the NCPP data provide extensive detail on the background of the study, the history of the project, the sample, data collection and data processing, access to the data while in NINCDS custody and record layouts and coding for each variable within the master file, the variable file, and the work files. Appendices contain sample forms and data entry cards. The bibliography of published research based on NCPP will be updated periodically and refiched.

ACCESS TO DATA:

NCPP data was subject to the provisions of the Privacy Act of 1974 and the Freedom of Information Act, Exemption B6, while in NIH custody. No records in the physical and legal custody of the National Archives are subject to the Privacy Act. However, National Archives General Restriction 4 (105-61.5302-4 in accordance with 5 USC 552 and 44 USC 2104) restricts:

"records containing information about a living individual which reveal details of a highly personal nature that the individual could reasonably assert a claim to withhold from the public to avoid a clearly unwarranted invasion of privacy, including but not limited to information about the physical or mental health or the medical or psychiatric care or treatment of the individual, and that - (1) contain personal information not known to have been previously made public, and (2) relate to events less than 75 years old."

Such information may be released for statistical or quantitative research when the researchers have provided adequate written assurance about the protection and use of the information. Researchers seeking access to the NCPP data must complete an "Application for Statistical Research in Records Containing Personal Information" and agree in writing to the "Conditions of Use."

In keeping with the applicable statutes, the NCPP data provided for statistical or quantitative research use will not contain the name, address, or social security number of any individuals in the project. The NINDB (NINCDS) case number will be available on each data record to permit identification and linkage of all records related to a particular patient and her children. The case number includes the institution, type of patient selection, gravida identification number, order of pregnancy and child or gravida number.

LEVEL OF VALIDATION:

The elaborate data collection, input and verification procedures, as described in the User's Guide, and the extensive past use of the data both by NINCDS and by other researchers demonstrate the validity of the NCPP data. Routine preservation activities associated with accessioning the data into the National Archives also demonstrated the validity of the data. Further, due to the personal nature of the information in the data complete sample computer printouts could not be included as part of the documentation.

The documentation for the Collaborative Perinatal Project consists of the abstract, this introduction, the User's Guide, and the bibliography of published research based on NCPP data.

The documentation was prepared by Bruce Ambacher, Archivist, Machine-readable Branch.
September, 1985