





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



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3-443-85-1

United States National Institutes of Health. Collaborative Perinatal Project (NCP), 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 NCP 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 NCP lasted sixteen years and included approximately 58,000 study pregnancies. Data on the women and their pregnancies and study children are included in the NCP 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 (NWSR)
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-	- " " "		
D-	- Cousin, 1st		8829
E-	- Niece/Nephew		301
F-	- Aunt/Uncle		219
G-	- Cousin, maternal		4626
H-	- Cousin, maternal in-law		1467
I-	- Cousin, maternal in-law		4250
J-	- Niece/Nephew half		343
K-	- Aunt/Uncle, half		266
L-	- Cousin, half		775
M-	- Cousin-once-removed		1405
W18-	- Cousin-2nd		1841
W18-	Visit Summary		267,128 (28,455 cases)

APPROACHES TO DOCUMENTATION

The study of the effects of Project REPP, was a longitudinal, multi-
disciplinary research program sponsored by the Developmental Neurology Branch,
Neurological Research Program, National Institute of Neurological and
Communicative Disorders and Stroke (NINDS), the National Institutes of
Health. The primary goal of REPP is the etiology of the developmental
disorders of the brain such as cerebral palsy and mental retardation,
through genetic and clinical studies which relate the events and
mechanisms of development, from the infancy to the neurological and mental
events of the first three years of the child's life as the child grows and develops.
The study is designed to identify the early appearance of cerebral palsy, mental
retardation, epilepsy, blindness, congenital malformations, minimal brain
dysplasia, language disorders, other abnormalities, or communicative
disorders in children during the perinatal period in order to develop
effective early diagnosis and intervention.

The study included approximately 50,000 women and the children
born to them during pregnancy during the study. Additional demographic
information was collected on the father and the siblings of the children and
on the parents of the women.

The data on the women's reproductive history was collected on the women within the
study during pregnancy and delivery between 1953 and 1965 and on the children
born to them during pregnancy from birth until eight years of age. The
study included data on the mother's history. The women in the study were patients
of obstetric and gynecology and related medical centers across the United States.
There are 100 hospitals in the study and 100 percent. For the most part the
children were born in hospitals.

The study is designed to represent the national population in two
major ethnic groups. They were mostly all from lower income groups and the
majority of the children are 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 refetched.

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 NINDS (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.

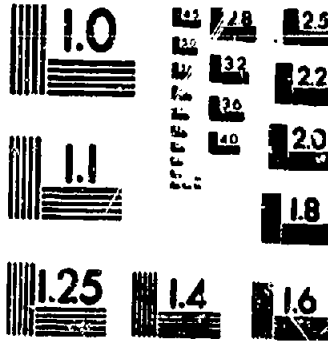
LEVEL OF VALIDATION:

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



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STANDARD REFERENCE MATERIAL 1010a
(ANSI and ISO TEST CHART No. 2)

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