

Current smoking prevalence among American Indians and Alaska Natives (36.0 percent) is highest compared to all other racial/ethnic groups (2000 NHIS). While national and regional data exist for American Indians and Alaska Natives, tribal level data is extremely limited. Currently, there are over 500 sovereign tribal nations in the U.S. In order to better understand tobacco use among American Indians and Alaska Natives, CDC is conducting a survey project that includes:

(1) Developing a culturally appropriate Adult Tobacco Survey questionnaire for tribes.

(2) Piloting the final instrument in approximately 24 tribes represented by six Tribal Support Centers (TSCs).

In an effort to better understand the effects of smoking in American Indian and Alaska Native populations, the Support Centers for Tobacco Programs (SCTP) will utilize a culturally appropriate questionnaire for pilot implementation in six different tribal centers. The centers are located in Alaska, California, Oklahoma, Michigan, along with two tribal centers located in the upper Midwest and upper Northwest. In total, the SCTPs will collect 2,691 completed surveys (the

number varying by Center respective to the size of each tribe, 18 years of age and older), which will be representative of distinct tribal communities conducting the survey. The SCTP will be responsible for obtaining the completed surveys. Trained individuals from each of the respective communities and/or support centers will conduct interviews. Most interviews will be conducted face-to-face, with a small proportion conducted by telephone. The total annualized burden is estimated to be 1,794 hours.

Location	Number of respondents	Number of responses per respondent	Avg. burden per response (in hrs.)
Alaska .....	450	1	40/60
California .....	466	1	40/60
Michigan .....	450	1	40/60
Oklahoma .....	600	1	40/60
Upper Midwest .....	350	1	40/60
Upper Northwest .....	375	1	40/60

Dated: March 25, 2004.

**Joe E. Salter,**

*Acting Director, Management Analysis and Services Office, Centers for Disease Control and Prevention.*

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## DEPARTMENT OF HEALTH AND HUMAN SERVICES

### Centers for Disease Control and Prevention

[30Day-23-04]

#### Proposed Data Collections Submitted for Public Comment and Recommendations

The Centers for Disease Control and Prevention (CDC) publishes a list of information collection requests under review by the Office of Management and Budget (OMB) in compliance with the Paperwork Reduction Act (44 U.S.C. Chapter 35). To request a copy of these requests, call the CDC Reports Clearance Officer at (404) 498-1210. Send written comments to CDC, Desk Officer, Human Resources and Housing Branch, New Executive Office Building, Room 10235, Washington, DC 20503 or by fax to (202) 395-6974. Written comments should be received within 30 days of this notice.

*Proposed Project:* Descriptive Epidemiology of Missed or Delayed Diagnoses for Conditions Detected by Newborn Screening—New—National Center for Environmental Health

(NCEH), Centers for Disease Control and Prevention (CDC).

Every state in the United States and Washington, DC, has a public health program to test newborn babies for congenital metabolic and other disorders through laboratory testing of dried blood spots. These programs screen for between 4 and 30 different conditions including phenylketonuria (PKU) and congenital hypothyroidism, with testing performed in both state laboratories and private laboratories contracted by state health departments. The screening process or system is broader than the state public health newborn screening program, which is composed only of the laboratory and follow-up personnel. It involves the collection of blood from a newborn, analysis of the sample in a screening laboratory, follow-up of abnormal results, confirmatory testing and diagnostic work-up. Parents, hospitals, medical providers including primary care providers and specialists, state laboratory and follow-up personnel advocates, as well as other partners such as local health departments, police, child protection workers, and courts play important roles in this process.

Most children born with metabolic disease are identified in a timely manner and within the parameters defined by the newborn screening system of each state. These children are referred for diagnosis and treatment. However, some cases are not detected at all or the detection comes too late to prevent harm. These "missed cases"

often result in severe morbidity such as mental retardation or death.

In this project, we will update and expand a previous epidemiological study of missed cases of two disorders published in 1986. We will assess the number of cases of each disorder missed, and the reasons for the missed and legal outcomes, if any. The reasons for the missed will be tabulated according to which step or steps of the screening process it occurred. Data will be collected by asking state public health laboratory directors, newborn screening laboratory managers, follow-up coordinators, specialists at metabolic clinics and parent groups with an interest in newborn screening, for information regarding missed cases. An estimated 269 subjects (with an expected response rate of 80% from metabolic clinics, Lab Directors and Coordinators) will be requested to complete a short questionnaire that asks for information regarding the details of any missed cases of which they are aware.

The survey will highlight procedures and actions taken by states and other participants in newborn screening systems to identify causes of missed cases and to modify policies and procedures to prevent or minimize recurrences. The information gleaned from this study may be used to help craft changes in the screening protocols that will make the process more organized and efficient and less likely to fail an affected child. Furthermore, it is not clear that there is a systematic

assessment of missed cases on a population basis; this project will seek

to identify procedures for routine surveillance of missed cases. The

estimated annualized burden is 36 hours.

Respondents	Number of respondents	Number of responses per respondent	Average burden per response (in hours)
Lab Directors .....	42	1	10/60
Follow-up Coordinators .....	42	1	10/60
Metabolic Clinic Employee .....	120	1	10/60
Parent Advocate .....	13	1	10/60

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**Joe E. Salter,**

*Acting Director, Management Analysis and Services Office, Centers for Disease Control and Prevention.*

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## DEPARTMENT OF HEALTH AND HUMAN SERVICES

### Centers for Disease Control and Prevention

[30Day-39-04]

#### Proposed Data Collections Submitted for Public Comment and Recommendations

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*Proposed Project:* HIV/AIDS Prevention and Surveillance Project Reports, OMB No. 0920-0208—Extension—National Center for HIV, STD and TB Prevention (NCHSTP), Centers for Disease Control and Prevention (CDC).

CDC is requesting to extend the use of the currently approved form, OMB No. 0920-0208, for collecting HIV counseling, testing, and referral (CTR) program data. This current form expires March 30, 2004. This request is for an 18-month clearance past this date.

Extension of the current form will allow grantees to continue to collect CTR data as they transition to the new set of CTR variables and the new program evaluation and monitoring system (PEMS). Over the next year, grantees will either transition to the new variables once they have reprogrammed their existing computer systems, or as the CDC-provided PEMS is made available. CDC funds cooperative agreements for 65 HIV prevention projects (50 states, 6 cities, 7 territories, Washington, DC, and Puerto Rico) and approximately 50 community based organizations to support HIV counseling, testing, and referral programs.

HIV counseling, testing, and referral services in STD clinics, women's health centers, drug treatment centers, and other health facilities have been described as a primary prevention strategy of the national HIV prevention program. The funded public health departments and community based organizations have increased the provision of HIV counseling, testing, and referral activities to those at increased risk for acquiring or transmitting HIV, as well as minority communities and women of child bearing age.

CDC is responsible for monitoring and evaluating HIV prevention programs

conducted under HIV prevention cooperative agreements. HIV counseling, testing, and referral services are a vital component of HIV prevention programs. Without data to monitor and evaluate the impact of HIV counseling, testing, and referral programs, HIV prevention program priorities cannot be assessed and improved to prevent further spread of the epidemic. CDC needs minimal core data from all grantees describing CTR services provided for at-risk persons. Until grantees are prepared for collecting the new CTR variables and reporting data electronically through PEMS, it is essential that they be allowed to continue to collect the current CTR data using the existing forms.

Completing the initial data submission will take approximately 5 minutes per form. Approximately two (2) million records annually are expected from over 11,000 directly and indirectly funded grantee facilities. The total estimated burden is 167,000 hours annually. This is the estimated burden if no one transitions to the new system during the year, but it is expected that many of the grantees will transition to PEMS in phases throughout the year. Following this notice, a separate data collection for PEMS will be submitted for public comment and will include the revised CTR data variables and associated burden estimate. CDC is requesting OMB approval for 18 months, during the transition to PEMS. The estimated annualized burden is 177 hours.

Respondents	Type of form	No. of respondents	No. of responses per respondent	Average burden/response (in hrs)
Statistical Assistant .....	Locally Developed Formats .....	16	4	2
Data Entry Clerks .....	Scanned Client Record Form .....	49	4	15/60