

program access. This pilot project will be conducted during fiscal year 2005. If

successful, this surveillance system may serve as a model for surveillance in

other border communities. There will be no cost to respondents.

Respondents	Number of respondents	Number of responses per respondent	Average burden per response (in hours)	Total burden (in hours)
U.S. ....	400	1	30/60	200
Mexico ....	400	1	30/60	200
Total .....	.....	.....	.....	400

Dated: March 5, 2004.

**Alvin Hall,**

*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

[60Day-04-32]

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

In compliance with the requirement of section 3506(c)(2)(A) of the Paperwork Reduction Act of 1995 for opportunity for public comment on proposed data collection projects, the Centers for Disease Control and Prevention (CDC) will publish periodic summaries of proposed projects. To request more information on the proposed projects or to obtain a copy of the data collection plans and instruments, call the CDC Reports Clearance Officer on (404)498-1210.

Comments are invited on: (a) Whether the proposed collection of information is necessary for the proper performance of the functions of the agency, including whether the information shall have

practical utility; (b) the accuracy of the agency's estimate of the burden of the proposed collection of information; (c) ways to enhance the quality, utility, and clarity of the information to be collected; and (d) ways to minimize the burden of the collection of information on respondents, including through the use of automated collection techniques or other forms of information technology. Send comments to Seleda Perryman, CDC Assistant Reports Clearance Officer, 1600 Clifton Road, MS-E11, Atlanta, GA 30333. Written comments should be received within 60 days of this notice.

Proposed Project—Vital Statistics Training Application, OMB No. 0920-0217—Extension—National Center for Health Statistics (NCHS), Centers for Disease Control and Prevention (CDC). In the United States, legal authority for the registration of vital events, *i.e.*, births, deaths, marriages, divorces, fetal deaths, and induced terminations of pregnancy, resides individually with the States (as well as cities in the case of New York City and Washington, DC) and Puerto Rico, the Virgin Islands, Guam, American Samoa, and the Commonwealth of the Northern Mariana Islands. These governmental entities are the full legal proprietors of vital records and the information contained therein. As a result of this State authority, the collection of registration-based vital statistics at the national level, referred to as the U.S. National Vital Statistics

System (NVSS), depends on a cooperative relationship between the States and the Federal government. This data collection, authorized by 42 U.S.C. 242k, has been conducted by NCHS since it was created in 1960.

NCHS assists in achieving the comparability needed for combining data from all States into national statistics, by conducting a training program for State and local vital statistics staff to assist in developing expertise in all aspects of vital registration and vital statistics. The training offered under this program includes courses for registration staff, statisticians, and coding specialists, all designed to bring about a high degree of uniformity and quality in the data provided by the States. This training program is authorized by 42 U.S.C. 242b, section 304(a). In order to offer the types of training that would be most useful to vital registration staff members, NCHS requests information from State and local vital registration officials about their projected needs for training. NCHS also asks individual candidates for training to submit an application form containing name, address, occupation, work experience, education, and previous training. These data enable NCHS to determine those individuals whose needs can best be met through the available training resources. There is no cost to respondents in providing these data.

Respondents	Number of respondents	Number of responses/Respondents	Average burden/response (in hrs.)	Total burden hours
State, local, and Territory Registration Officials .....	57	1	20/60	19
Training applicants .....	100	1	15/60	25
Total .....	.....	.....	.....	44

Dated: March 5, 2004.

**Alvin Hall,**

*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

[60Day-04-34]

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

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Comments are invited on: (a) Whether the proposed collection of information is necessary for the proper performance of the functions of the agency, including whether the information shall have practical utility; (b) the accuracy of the agency's estimate of the burden of the proposed collection of information; (c) ways to enhance the quality, utility, and clarity of the information to be collected; and (d) ways to minimize the burden of the collection of information on respondents, including through the use of automated collection techniques or other forms of information technology. Send comments to Seleda Perryman, CDC Assistant Reports Clearance Officer, 1600 Clifton Road, MS-E11, Atlanta, GA 30333. Written comments should be received within 60 days of this notice.

Proposed Project: Understanding Family-based Detection as a Strategy for

Early Diagnosis of Hemochromatosis—New—National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP), Centers for Disease Control and Prevention (CDC).

Hemochromatosis is a disease that occurs as a result of excess iron accumulation in the tissues and organs. The majority of hemochromatosis cases are due to HFE gene mutations. Early hemochromatosis symptoms are nonspecific and are often overlooked by physicians or mistaken for other conditions. Fortunately, hemochromatosis can be detected with simple blood tests. When treatment by therapeutic phlebotomy is instituted early in the course of the disease, the many severe complications associated with hemochromatosis (e.g., cirrhosis of the liver, liver cancer, cardiomyopathy, and heart failure) can be effectively prevented.

Hemochromatosis is a genetic disease, and blood relatives of hemochromatosis patients are at increased risk. The public health strategy for early detection of hereditary hemochromatosis is making patient family members aware of their increased risk and encouraging them to seek voluntary diagnostic testing ("family-based detection"). CDC wants to evaluate family-based detection as a strategy to identify people with hemochromatosis. The proposed research project will examine the effectiveness of and barriers to the use of family-based detection as a public health strategy to reduce morbidity and mortality from genetic diseases, and in particular, hemochromatosis.

To understand the effectiveness of family-based detection for hemochromatosis the following will be evaluated:

- Barriers and motivators to family-based detection as a strategy for early diagnosis of hemochromatosis. (Early detection facilitates early treatment to slow the course of disease.)
- How physicians communicate with patients about the importance of family-based detection and the need for patients to encourage biological siblings to seek testing.

- Factors that foster good communication among biological siblings about the importance of seeking medical testing by those at increased risk of hemochromatosis.

- Factors that affect the willingness of biological siblings to take action to seek out and receive testing for hemochromatosis.

- Information and key messages that motivate patients to advise their biological siblings about their increased risk for hemochromatosis and need for diagnostic testing.

- How physicians use medical histories to identify people who should be tested because they have a relative with hemochromatosis.

The proposed research to be undertaken by CDC will incorporate several types of qualitative data collection: structured one-on-one interviews, triads (small focus groups) and traditional focus groups. Subjects will include hemochromatosis patients, biological siblings of patients, and physicians. Topics to be explored with each of the three subject groups include the knowledge, attitudes, perceptions, and behaviors related to family-based detection.

Patients will be recruited in Boston and Chicago from the following places (where hemochromatosis patients often undergo treatment by therapeutic phlebotomy):

- Blood banks
- Hospital laboratories
- Other health care provider facilities

Siblings will be recruited either through the patients or by self-referral. Health care providers will be recruited through publicly available lists of physicians, or recommendations from project staff, patients, biological siblings, blood banks, hospital laboratories, hemochromatosis organizations, and health care providers knowledgeable about hemochromatosis. Information about the study will be available on the CDC Web site. Hemochromatosis organizations will be invited to notify their members about this research. There are no costs to respondents.

Respondents	Number of respondents	Number of responses per respondent	Average response per respondent (in hours)	Total burden (in hours)
Individual Interviews with Patients and Siblings .....	15	1	2	30
Individual Interviews with Health Care Providers .....	18	1	2	36
Triads .....	30	1	2	60
Focus Groups .....	80	1	2	160
Total .....				286