

SUBMISSION OF INFORMATION COLLECTION
UNDER GENERIC CLEARANCES

DATE OF REQUEST: May 23, 2008

SUB AGENCY (I/C): NIH/NCI/OCE

TITLE: Web-Based Survey to Understand Public Perceptions of Genetic Testing

GENERIC CLEARANCE UNDER OMB# 0925-0046-10 **EXP. DATE:** 1/31/2010

TOTAL ANNUAL BURDEN APPROVED: 2010 hours
BURDEN USED TO DATE: 749 hours
BURDEN THIS REQUEST: 116.67 hours

ABSTRACT:

Since the recent completion of the Human Genome Project, the advent of detailed, personalized genetic knowledge has been characterized by its rapidly-accelerating pace of discovery. A newly emerging marketplace, where genetic tests are marketed directly to the consumer, often by electronic media, is providing consumers with personal genome-based information outside of the traditional medical care delivery system. These services, where consumers provide samples at home and receive the results directly, are becoming increasingly common, with multiple organizations offering numerous and sophisticated tests.

In the months since consumer genomic information services or “direct-to-consumer” genetic testing, has become widely available, there has been considerable reaction to them. These services have the potential to improve consumer engagement in medical decision-making, but consumers may not know or have access to the information necessary to evaluate the quality of the information that is provided.

To move toward understanding the consumer interest and need in the use of genetic testing, HHS’s Initiative on Personalized Health Care is sponsoring a half day workshop to look more broadly at the roles that consumer genomic information may be able to play over a longer time-frame – and in particular to examine those roles in the context of the nation’s consensus health care goals. Because little is know about this newly emerging area, HHS has teamed with NCI and proposes to conduct a web-based survey to help understand consumer knowledge and interest for genetic testing. The results of this survey will, in the short-term, be used to inform and stimulate discussion at the workshop and, in the longer-term, will inform future communications strategies, concepts, and messages of NCI and other HHS agencies. In addition, the results would provide basic understanding of the current state of the field and may be useful for evaluating future educational future initiatives.

IS RACE AND ETHNICITY DATA COLLECTED AS REQUIRED?

YES NO N/A

OBLIGATION TO RESPOND:

VOLUNTARY
 REQUIRED TO OBTAIN OR RETAIN BENEFITS
 MANDATORY

HOW WILL THIS SURVEY BE OFFERED?

WEB SITE
 TELEPHONE INTERVIEW
 MAIL RESPONSE
 IN PERSON INTERVIEW
 OTHER: _____

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