

Memo to: Marilyn Tuttleman, Project Clearance Branch, NIH
Seleda Perryman, RCO Desk Officer, HHS
OMB Desk Officer

Through: Vivian Horovitch-Kelley, NCI OMB Liaison, NCI
From: Gregory J. Downing, D.O., Ph.D. Immediate Office of the Secretary, DHHS

Sent: Friday, June 06, 2008 4:05 PM
Subject: #0925-0046-10 generic sub-survey submitted to OMB on 6/2/08

A member of my staff, Scott Boyle, has been working with Nina Goodman (NCI) to obtain OMB-clearance of the survey OMB#0925-0046-10, "Web-Based Survey to Understand Public Perceptions of Genetic Testing." I am writing to request that you expedite the consideration of this survey and to provide some additional information for its urgency.

The Personalized Health Care Initiative, one of Secretary Leavitt's ten priority areas, has been engaged in helping to create a health care system that is consumer-centric, preventative, and personalized. An upcoming development for this personalized system is an increased understanding of the genetic basis of disease. Recently, organizations permit consumer access to their personal, genetic information. As this consumer-directed genetic test market is evolving and developing, not much is known about consumer knowledge and interest in genetic testing. These new services have occasioned considerable press and public attention. At the same time, questions have been raised quickly regarding the real value of these services to consumers, but the consumer perspective been neglected in these discussions.

The Personalized Health Care Initiative has conceptualized a workshop to explore the information needs of consumers in utilizing consumer-directed genetic testing services. This workshop is scheduled for Monday, July 7. To encourage informed discussion from the consumer perspective, we collaborated with Nina Goodman at the National Cancer Institute to develop a web-based survey to gather initial data. The primary purpose for this data is to provide context for the discussion at the workshop.

If we are unable to collect this information, we may miss an opportunity to infuse this and future discussions with informed consumer data and perspective. By expediting the review to two weeks (by June 16), the contractor can collect and analyze the data for a workshop held on July 7.

I appreciate your review of this survey and would be happy to answer any additional questions. Please let me know if you think that we should be interacting directly with OMB regarding this request.

Thanks,

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