Family History for Preventive Medicine and Public Health

Family history is known to be a risk factor for many chronic diseases—including coronary heart disease, cancer, and diabetes—but its use in preventive medicine has been de-emphasized compared with modifiable risk factors like smoking and diet. In 2002, the Centers for Disease Control and Prevention's (CDC) Office of Genomics and Disease Prevention (OGDP) organized an interdisciplinary working group with members from CDC, the National Institutes of Health (NIH), academia, state health departments, and professional organizations. The purpose of this working group is to evaluate the role of family history in risk assessment and disease prevention.

Background

Geneticists have long recognized the value of family history for diagnosing disorders due to mutations in single genes, including certain forms of common diseases. Although typically associated with a very high individual risk of disease, single-gene mutations account for a small proportion of cases. Most common diseases result from the interactions of multiple genes with multiple environmental factors in complex patterns that, despite progress in sequencing the human genome, are unlikely to be understood fully in the near future. In the meantime, family medical history represents a "genomic tool" that can capture the interactions of genetic susceptibility, shared environment, and common behaviors in relation to disease risk.

Family History Public Health Initiative

The Family History Public Health Initiative comprises an assessment of existing family history tools, the development of a family history tool for common chronic diseases, the development of a research agenda to assess the validity and utility of using family history for disease prevention, and the creation of provider education programs and public information campaigns.

This initiative includes four components:

- Assessment of existing strategies,
- Tool development,
- Research and evaluation, and
- Provider education programs and public information campaigns.

Assessment of Existing Strategies

A workshop was held in May 2002 to review what is known about family history as a risk factor for selected diseases. Ten articles based on workshop presentations were published in the February 2003 issue of the *American Journal of Preventive Medicine*. A national working group was formed to develop a long-term research agenda and to provide guidance and expertise for

the Family History Initiative. The working group includes representatives from CDC, NIH, other federal agencies, state public health programs, academia, and the health care community. After reviewing current tools developed for primary care, the working group recommended development of a prototype tool with a few selected diseases to facilitate pilot testing and evaluation in different population-based settings.

Tool Development

The prototype Web-based family history tool, Family Healthware, includes an assessment of the following:

- Personal history of heart disease, stroke, diabetes, and specific cancers (colorectal, breast, and ovarian),
- Family history of these diseases for first- and second-degree relatives, and
- Personal history of selected risk factors (e.g., smoking, exercise, etc.) and screening tests (e.g., mammography).

After an individual completes the family history assessment, a report is generated that includes the level of familial risk for each disease as well as personalized prevention messages.

A resource guide is being developed for primary care providers that includes an explanation of the risk levels, recommended interventions for each level of risk, an explanation of potential genetic conditions underlying familial risk, and additional resources for patients and providers. Diseases will be added to the tool as the risk and recommendation components are developed and validated.

Research and Evaluation

Family Healthware will be pilot-tested in a variety of public health and preventive medicine settings. CDC has awarded funding to three research centers—the University of Michigan School of Medicine, Evanston Northwestern Healthcare Research Institute, and Case Western Reserve University School of Medicine—for a collaborative study set in primary care clinics. The study will use the tool to determine whether family history risk assessment, classification, and personalized prevention messages influence health behaviors and the use of preventive medical services. Data from past and ongoing population-based studies of chronic diseases are also being analyzed as part of the initiative to help fill gaps in our understanding of the role of family history in disease prevention.

Provider Education Programs and Public Information Campaigns

CDC is working with its public health partners, including states and professional organizations, to promote the use of family history for disease prevention. Educational materials and Web resources are being developed for the public, and provider education programs are planned that will include training in the use of the new Family Healthware tool and resource guide.

For more information, please visit CDC's Office of Genomics and Disease Prevention Web site at http://www.cdc.gov/genomics.