Development of Family Healthware™, a Web-Based Family History Screening Tool

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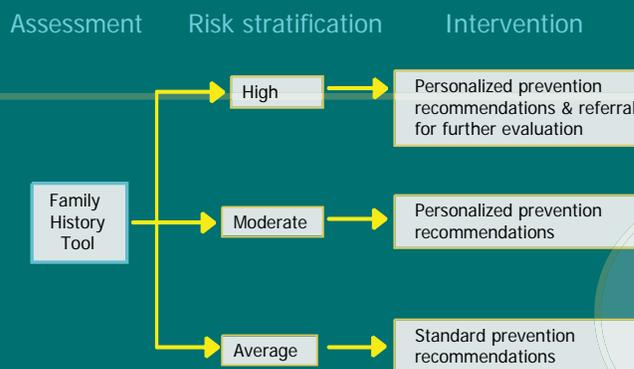
Abstract

Purpose: Family history is known to be a risk factor for many chronic diseases—including coronary heart disease, cancer, and diabetes—but it is underutilized in preventive medicine. To facilitate systematic collection, interpretation, and use of family health history, the Centers for Disease Control and Prevention has developed a new interactive, web-based family history screening tool.

Methods: Family Healthware™ was developed by a multi-disciplinary team with support from a communications firm and a software development company. The team assessed family history tools currently used or being developed, and identified key design principles for a new tool and developed criteria for selecting diseases to include in this tool. Qualitative and quantitative formative research on lay understanding of family history and genetics helped shape the tool's content, labels, and messages. Lab-based usability testing helped refine messages and tool navigation.

Results: Family Healthware™ assesses familial risk for six diseases (coronary heart disease, stroke, diabetes, and colorectal, breast, and ovarian cancer) and provides personalized "prevention plans" for lifestyle changes and screening. The tool collects data on health behaviors, screening tests, and disease history of a person's first- and second-degree relatives. Algorithms in the software analyze the family history data and assess familial risk. A second set of algorithms uses the data on familial risk level, health behaviors, and screening to generate personalized prevention messages.

Conclusion: The tool is being evaluated by three academic centers using a network of primary care practices to determine if prevention messages tailored to familial risk will motivate people to change lifestyle or screening behaviors. The study began enrolling patients in December 2005 and data collection was completed in fall of 2007. Results from this study and others will be used to modify the tool for use as a pc-based software for the general public and as a component to new or existing electronic medical records and decision support systems for preventive medicine.

Design Concept

Assessment   Risk stratification   Intervention

- Family History Tool
  - High → Personalized prevention recommendations & referral for further evaluation
  - Moderate → Personalized prevention recommendations
  - Average → Standard prevention recommendations

Key Design Principles

- Self-administered
- Easily applied and adaptable to different settings
- Simple but collects enough information to assess risk
- Tied to algorithms that interpret risk
- Useful in combination with other risk factors
- Tied to risk-appropriate and evidence-based prevention strategies

Criteria for Selecting Diseases

- Substantial public health burden
- Well defined case definition
- High awareness of disease status among relatives
- Accurately reported by relatives
- Family history is an independent risk factor
- Effective interventions for primary and secondary prevention
- Different recommendations for familial risk groups