Role of Family Medical History Information in Pediatric Primary Care and Public Health: Introduction

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ABSTRACT

In February 2006, the Centers for Disease Control and Prevention sponsored a workgroup meeting in Atlanta, Georgia, on the use of family medical history information in pediatric primary care and public health. The meeting focused on pediatric topics as part of the Centers for Disease Control and Prevention Family History Public Health Initiative. One outcome of the meeting was a series of published articles that summarized the proceedings and explored 4 topics that emerged as leading issues from the meeting: (1) optimizing use of family history in primary care; (2) linking obstetric and pediatric clinicians through preconception health care; (3) assessing potential campaigns to prevent chronic disease, starting with family history assessment in childhood; and (4) using birth defect family histories for prevention efforts. In this introduction we highlight each article and preview existing efforts in preconception health care and birth defects prevention that use family history.
Pediatric clinicians are well acquainted with many aspects of family medical histories, starting with medical conditions during pregnancy that can affect the health of infants who they might see first in the delivery room. Individuals who work in some pediatric areas of public health (such as professionals who are involved with newborn screening programs and counsel parents about carrier status for certain conditions identified at birth) are also familiar with family histories. How can these histories be better used for prevention and improving the lives of families? To address primary care and public health issues, the Centers for Disease Control and Prevention (CDC) sponsored a pediatric family history workgroup meeting in Atlanta, Georgia, in February 2006. This supplemental issue of *Pediatrics* is devoted to the proceedings of that meeting and more-in-depth articles about salient issues that were raised by the workgroup.

The roots of this project at the CDC go back to 2002, when what is now the National Office of Public Health Genomics launched the Family History Public Health Initiative. The purpose of the initiative was to evaluate the use of family history in assessing people’s risks for common diseases and developing more effective early detection and prevention strategies. The initiative has featured a new Web-based family history tool (Family Healthware) that currently focuses on 6 chronic diseases that primarily affect adults and research activities to assess the use of family medical histories as a public health strategy. The initiative also has included collaborative campaigns to increase public awareness about the importance of one’s family history and improve and facilitate the use of family history information by health professionals. One of the most visible products of these collaborations has been the development of the US Surgeon General’s online family history tool.

The primary purpose of the pediatric workgroup’s meeting in Atlanta was to discuss extending the scope of the CDC’s initiative to children and their families. Because pediatric clinicians are on the front line of gathering family history information, the opening session of the workshop focused on primary care issues. Many of the topics discussed, such as competing priorities, reimbursement issues, and other barriers to pediatric family history taking, are summarized in depth by Trotter and Martin (p S60). Their article also contains a summary of practical points for primary care clinicians and lists useful Web sites that include electronic and downloadable paper tools that can be used by families, clinicians, and public health practitioners.

The focus of the Surgeon General’s campaign, a family history tool known as My Family Health Portrait, is likely to be one of the most widely used instruments for collecting family history. Mirroring the emphasis of the CDC’s Web-based tool, My Family Health Portrait can be used to record family history and draw a family pedigree for heart disease, stroke, diabetes, colon cancer, breast cancer, and ovarian cancer. How might awareness of such conditions that primarily affect adult family members be useful for prevention and health-promotion campaigns that start in childhood? The article by Valdez et al (p S78) explores this question and will be of particular interest to public health practitioners and researchers.

Given the lack of emphasis in many existing tools on single-gene and common complex conditions that affect children in particular, the workgroup thoroughly examined the family history aspects of 5 exemplary conditions: cystic fibrosis, fragile X syndrome, autosomal-dominant polycystic kidney disease, coronary artery disease, and birth defects. Participants at the meeting agreed that family history information about these types of conditions is useful and is already gathered by pediatric clinicians to assist with diagnosis, treatment, and carrier testing. With the exception of the existing “tracking” of heart disease in electronic tools, there was less consensus about going forward with adding these disorders to tools such as Family Healthware, which uses well-established algorithms to produce individualized risk assessments based on family history. Nevertheless, steps toward making family history information more widely used in pediatric settings might easily be taken through 2 existing efforts: preconception health care and birth defects–recurrence prevention.

Dolan and Moore (p S66) discuss the use of family history information in preconception settings, which in the pediatric arena includes interconception counseling of families. Provision of preconception health care is a major multidisciplinary public health initiative that includes the development of tools with family history components for clinical use. The First Page family history tool was designed specifically for using family history information about genetic conditions and birth defects in clinical settings, and Dolan and Moore explain how algorithms for clinical decision-making are part of this paper-based tool.

The summary by Fisk Green at the end of this supplement (p S87) provides an overview for grasping the breadth of the workgroup’s discussions and the theoretical underpinnings to the meeting discussions. The criteria for selecting conditions for discussion at the meeting are outlined in the article by Fisk Green and explored in more depth with the example of birth defects in the article by Romitti (p S71). Romitti also discusses how family history information has been used for intervention to prevent birth defects in Irish families. This effort is another example of how family history information can be integrated into existing perinatal public health and family-counseling programs, such as promotion of folic acid intake to reduce the occurrence and recurrence of neural tube defects. Romitti concludes in his article that additional research is necessary before the tracking of birth defects becomes a standard component of family history tools in pediatric settings. Support for testing and
evaluation of family history–ascertainment efforts is indeed necessary, particularly for pediatric issues that have been less of a focus in early initiatives. In the meantime, the articles in this supplement provide in-depth discussion of many strategies that are available already for assisting pediatric clinicians and public health practitioners to benefit families through their histories.

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