Making Family History Meaningful for Patients and Practices

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Quality Improvement Project
Disclosure

• I have no relevant financial relationships with the manufacturers(s) of any commercial products(s) and/or provider of commercial services discussed in this CME activity

• I do not intend to discuss an unapproved/investigative use of a commercial product/device in my presentation
Goals for Session

• Review components and utility of family history
• Discuss project aims and change package elements
• Problem-solve potential barriers/challenges
• Share practice experiences – both positive and negative
What is a Family History?

• Inexpensive, non-invasive, and informative screening procedure
• Considered the first genetic screening test
• Depicts familial patterns of disease that identify genetic and behavioral contributions
• Historically, a classic case-finding tool for single-gene disorders
Benefits and Uses

• Genetic case-finding tool for single-gene disorders
• Health promotion, risk assessment for complex disease
• Can serve as a diagnostic tool
• Existing barriers and challenges limit realization of benefits
Improved Patient Relationships

• Family history fosters provider-patient rapport:
  – Clarify misconceptions
  – Recognize inheritance patterns
  – Demonstrate variation in disease expression
  – Provide visual reminder of who is at risk
  – Emphasize need to obtain medical documentation on affected relatives
How Can Family History Be Helpful?

- Risk assessment for specific conditions
- Prevent, detect, and manage disease
- Inform a diagnostic evaluation
- Pre-conception counseling
- Foster rapport with patients
Application of Family History

- Prevention
- Screening
- Diagnosis
- Disease Management
Prevention

• Family history can prompt appropriate screening or intervention to prevent disease or delay onset

• Family history is a risk factor for common chronic diseases
  – Asthma
  – Cancer (breast, kidney, colon, etc.)
  – Cardiovascular disease
  – Diabetes
  – Osteoporosis
  – Psychiatric disorders
Examples of Screening & Family History in Pediatrics

• Sudden Cardiac Deaths in Athletes
  – Family history part of AHA screening guidelines

• Serum Lipid Screening in Athletes
  – NHLBI guidelines base screening on family history
Inform Diagnostic Evaluation

• Aid diagnosis, streamlined testing, and better long-term management

• Clinical example
  – Chronic cough with family history of asthma
QuIlIN FAMILY HISTORY PROJECT AIMS
AIM:

90% of patients have multi-generational family histories created or updated/maintained at health supervision visits, using the family history components defined by the project
Degrees of Relationship in a Family History

• First-degree relatives
  – children, siblings, parents

• Second-degree relatives
  – half-siblings, aunts, uncles, grandparents, nieces and nephews

• Third-degree relatives
  – first cousins, great-grandchild, great-grandparent
Genetics Family History Components
Disclaimer

• The evidence behind these components is sparse
• These serve as a starting point
• The goal is to test these components
YOU ARE PART OF THE PROCESS!

• We **WELCOME** feedback/discussion on components that would be helpful and/or existing components that are not
GENERAL FAMILY HISTORY ELEMENTS

- Should include following family members: parents, brothers, sisters, aunts, uncles, 1st cousins, grandparents
- Medical conditions that run in the family (2 or more family members with the condition)
- Ethnicity
- Consanguinity
- Any parent and/or patient's concern about family history
- Incomplete knowledge of family history (ie adoptions, estranged family members)
ANY FAMILY MEMBERS WHO HAVE BEEN TOLD THEY HAVE:
(ask who and what for each of the below):

- Birth Defects:
  - Structural birth defects (examples: congenital heart disease, spina bifida, extra or missing fingers, clubfeet)
  - Sensory birth defects (examples: congenital deafness, congenital blindness)
- Cancer <50 years and specify type
- Carrier of genetic condition
- Clotting, bleeding or blood disorder (examples: sickle cell, von Willebrands, hemophilia)
- Developmental delay, intellectual disability, autism spectrum disorder, learning disability
- Early Death: Sudden, unexpected, or unexplained death <50 and details of event
- Heart attack: <55 years for males and <65 years for females
- Known genetic condition
- Multiple miscarriages or stillbirths
- Received special education services
- Seizures
AIM:

Current family histories are discussed with 90% of patients/families
Points for Discussion

• Templates and scripts may be helpful resources
Points for Discussion

• Even a family history that is not concerning merits discussion

• Family history is a living, dynamic history
  – it will change over time
AIM:

90% of practices have a process/written protocol for use of a standardized family history tool
Standardizing & Documenting

• Identify WHAT works
• Make the “WHAT” systematic
• Document the “WHAT” so everyone can know about it

This is our ultimate goal for each practice!
ROLE PLAYING
# CHANGE PACKAGE ELEMENTS

## Key Change

| 1. Create and Update Family Health History Information |

**Related Project Measures**
- Family histories are created on updated/maintained at health supervision visits, using the family history components defined by the project, for all of patients.
- Current family histories are discussed with all of patients/families.
- CQI of practices have a process/written protocol for use of a standardized family history tool.

**Assess and Identify Genetic Conditions for all Patients, as part of the Health Supervision Visit**

A multi-generation family health history provides information about more than one generation of the patients’ biological relatives, age at diagnosis of disease, and age and cause of death of deceased family members.

## Ideas and Tools for Change

### COLLECT FAMILY HISTORY

- Incorporate the components of a family history defined by the project into the collection of family history information for all patients, as part of the health supervision visit.
- Select one of the 2 following family history tools to use to collect a comprehensive family health history, using the family history components defined by the project, or a combination of these (or your own tool that includes the components identified by the project) health history tools:
  - **GPCI QuIN Family History Checklist**—English and Spanish
  - **Pediatric Genetic Screening Questionnaire**—English and Spanish
  - **GPCI Family History Grid**—English and Spanish

- Develop processes/written protocols for the use of a standardized family history tool for all patients.
  - Review examples of written protocols for implementing a family history tool in your practice.
  - Develop a system for collecting and updating family health history information at each visit.
  - Create a process to make collecting/updating family histories streamlined within the practice through process mapping or other QI strategies (use ideas from the Learning Session on process mapping).
  - Develop a system for obtaining follow-up health history information from other family members (follow up with the patient to obtain additional information from the other parent, or other family member).
  - Share information about the importance of collecting family history information with other providers and clinic staff in your practice.
    - Review the "Summary of the Value Added for Family Histories" document for additional information about the value of collecting family history information from your patients.
    - Review Genetic Alliance videos about collecting family history information and GPCI video testimonials about the importance of family health histories in primary care.

### DISCUSS/REVIEW FAMILY HISTORY WITH PATIENTS

- Discuss family history information with the patient and family, regardless of the results.
  - Review templates/scripts to assist clinicians for communicating family history information to patients/families.

### UPDATE/MaintAIN FAMILY HISTORY INFORMATION

- Maintain family history information for all patients aged 0–21, and update this information annually.
  - Use the suggested follow-up questions for updating/maintaining a family history on an annual basis.
Components of Family History

• Incorporate the components of a family history defined by the project into the collection of family history information for all patients, as part of the health supervision visit
Tools

• Select one of the 3 following family history tools to use to collect a comprehensive family health history, using the family history components defined by the project,

  OR

• A combination of these

  OR

• Your own tool that includes the components identified by the project health history tools
Example Tools

- GPCI QuIN Family History Checklist—English and Spanish
- Pediatric Genetic Screening Questionnaire—English and Spanish
- GPCI Family History Grid—English and Spanish
Create Systems & Processes

• Create a system for collecting and updating family health history information at each visit
• Create a process to make collecting/updating family histories streamlined within the practice through process mapping or other QI strategies
Develop Protocols

- Develop processes/written protocols for the use of a standardized family history tool for all patients
  - Review examples of written protocols for implementing a family history tool in your practice
Summary

• Family history is an important part of the pediatric clinical encounter
• Finding ways to improve family history collection, documentation and discussion is challenging
• With your help, we can overcome the challenges and barriers
THANK YOU
FOR YOUR INTEREST AND PARTICIPATION
IN THE QuIIN GPCI PROJECT!
Questions?