Successful QI Strategies for Integrating Genetics into a Pediatric Primary Care Practice

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Quality Improvement Advisor
June 4, 2014
Acknowledgments

• The Genetics in Primary Care Institute (GPCI) is a three-year cooperative agreement between the American Academy of Pediatrics (AAP) and the Health Resources & Services Administration (HRSA)/Maternal & Child Health Bureau (MCHB), Genetic Services Branch

• June 1, 2011—May 31, 2014
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Welcome

Genetics in Primary Care Institute
Quality Improvement Project (QIP)
• The AAP Quality Improvement Innovation Networks (QuIIN)
• QuIIN is a home to pediatric quality improvement networks at the Academy and is designed to improve care for children and their families in both the inpatient and outpatient settings.
• QuIIN members were recruited to participate in the GPCI-QIP and QuIIN staff members worked with lead GPCI staff to conduct this Quality Improvement project for 13 practice teams between November 2012 and November 2013.

For more information about QuIIN, visit: http://quiin.aap.org
Impetus for the GPCI

- Documented gaps exist in PCPs’ knowledge, attitudes, and practice
- Advances in genetics and genomics continue, prompting more demand, while workforce shortages among genetic professionals grow
- Strategies and tools are needed to improve PCPs’ role in providing genetic services
Overarching Vision

To improve PCPs’ knowledge and skills in the provision of genetic medicine
Goals of the GPCI

Quality Improvement
- Develop and test strategies to integrate genetics into the medical home

Technical Assistance Center
- Provide education and technical assistance to a wide audience of PCPs

Resident Education
- Embed genetic thinking and training into the future pediatric PCP workforce
Roles of the PCP

- **Evaluate** through screening and surveillance
- **Educate** patients and their families
- **Explain** the results
- Make **appropriate referrals**
- **Coordinate care** with a subspecialist
- **Counsel** patients and families
- Provide **long-term follow-up** and care

7 Key Roles of the Primary Care Provider

**Evaluate through Screening and Surveillance**
Use family health history for primary prevention of chronic illness and to identify a patient's need for increased surveillance.

**Educate Patients and Their Families**
Discuss the importance of screening, early diagnosis, and how genetic tendencies may be present with an acute manifestation of disease.

**Explain the Results**
Review and discuss the meaning of screening, test results, and what to expect from genetic consultation and referral.

**Make Appropriate Referrals**
Provide information based on clinical history and ensure adequate follow-up for patients.

**Coordinate Care with a Subspecialist**
Initiate a co-management plan, including treatment and diagnostic testing when appropriate.

**Counsel Patients and Families**
Help them understand and adapt to the implications of a genetic diagnosis.

**Provide Long-Term Follow-Up and Care**
Continue to support patients and families and provide primary care through an ongoing relationship within the medical home.
Baseline Needs Assessment

2012 Survey of AAP QuIN members (n=88)
• Less than half of pediatricians reported feeling competent providing services related to genetics and genomics
• 60% did not have adequate resources or information to determine which genetic tests to order
• Lack of knowledge on existing resources (eg, NBS ACT sheets)
• 100% of pediatricians agree/strongly agree that taking a FH is important for assessment of predisposition to disease
• EHRs lack functionality for recording FH information
• Less than 1/3 gather comprehensive FH from their patients

Quality Improvement Project

The GPCI Quality Improvement Project (QIP) aimed to test tools and strategies related to the integration of genetics into pediatric primary care.

Project Goals

1. Eliciting family history as part of the health supervision visit
2. Improve the delivery of care for pediatric patients with genetic conditions
3. Develop policies and improve office systems to meet the first two goals of the project
Project Oversight

EG Co-Chairpersons
• Amy Driscoll, MD, FAAP
• Beth Tarini, MD, MS, FAAP

EG Members
• Wendy Chung, MD, PhD
• Abdallah F. Elias, MD
• Ruth S. Gubernick, MPH
• Kerry Jedele, MD
• Ingrid Larson, MSN, RN, CPNP
• Beth A. Pletcher, MD, FAAP
• Michael Rinke, MD, FAAP
• Lisa M. Vasquez, MPA

Project Staff
• Michelle Esquivel, MPH
• Jill Healy, MS
• Natalie Mikat-Stevens, MPH
• Liz Rice-Conboy, MS

RC Mentors
• Sara Copeland, MD
• Kristen Cornell, MS, CGC
• Arti Pandya, MD, MBA
• Helio F. Pedro, MD
• Cecilia M. Rajakaruna, MS, CGC
• Michele Roberts, MD, PhD
• Bonnie Salbert, DO
Project Participation

• 13 teams in 11 states serving 130,000 pediatric patients annually
• Practice teams (3 people total) include a lead physician, 1-2 other clinicians, nurse or assistant staff person
• Participated in 6 months of data collection regarding project goals

Practice demographics:
• All use an EHR
• One family physician
• Diverse range of practice type, geographic setting, and patient population
Overall Patient Demographics

### Race/Ethnicity
- Black: 20.5%
- Hispanic: 21.4%
- White: 49%
- Other: 2.5%
- Asian: 5.2%
- Native Hawaiian/Other Pacific Islander: 1.0%
- American Indian/Alaska Native: 0.12%

### Insurance Status
- Uninsured: 3.4%
- Public Insurance: 48.6%
- Private Insurance: 48.1%
QIP Timeline and Overview

<table>
<thead>
<tr>
<th>Application Process:</th>
<th>Prework:</th>
<th>Action Period:</th>
<th>Evaluation:</th>
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<tbody>
<tr>
<td>• Form core improvement team and determine roles of each member</td>
<td>• Participate in Prework call on December 18 (8 am CT) or 20 (11 am CT)</td>
<td>• Participate on conference calls</td>
<td>• Conduct 6 month post-project evaluation on sustainability and continued improvement</td>
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<td>• Attend informational call on October 1 or 11</td>
<td>• Sign Consent Form</td>
<td>• Collect monthly data (chart review, registry review, and narrative report)</td>
<td>• Qualitative phone interviews</td>
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<td>• Complete project application</td>
<td>• Complete baseline data</td>
<td>• Test changes using PDSA cycles</td>
<td>• Submit final chart review and registry review data</td>
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<td></td>
<td>• Assess current practice and systems</td>
<td>• Provide feedback on tools</td>
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<td>• Create a storyboard</td>
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<td>• Make travel arrangements for Learning Session 1</td>
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<table>
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<th>Learning Session 1</th>
<th>Learning Session 2</th>
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<td>March 8-9, 2013</td>
<td>November 8-9, 2013</td>
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**Education and Mentorship Provided:**

- Change Package with resources, tools, and information
- Bi-monthly clinical team coaching calls
- Access to a multidisciplinary Expert Group and genetic professionals
- Two in-person educational sessions
- CME conference, webinars, handbook, and other ad hoc resources
Genetic Mentorship Program

Goal: To increase partnerships between PCP and genetic professionals at the local / regional level

Format:
• **Who:** A geneticist or genetic counselor paired with each practice from their region
• **What:** Meet monthly via phone, email, or in-person
• **Purpose:** Share information and resources, discuss patient cases, facilitate relationships
QI Strategies Pursued

• Storyboards

• Visual Process Mapping

• Monthly Calls and Collaborative Success & Barriers to Improvement Sharing

• Extensive Change Package

• Writing Letters home, Control Plan, Take Away Messages
Goal 1: Collect Family Histories

For all patients 0-21, collect a comprehensive FH initially as part of the health supervision visit, update annually.

- Document that multi-generational FH was created or updated/maintained using defined project components*
- Discuss current FH with patient/family
- Develop follow-up plan for positive FH or clinical concerns
- Discuss follow-up plan of care plan with family
- Document and track referrals for lab, genetics, or other
Components of Family History*

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
Goal 2: Manage care for patients with genetic conditions

Using a patient registry, track all patients 0-21 with a defined or suspected genetic disorder (using ICD-9 codes)

For all patients in the registry, ensure the following:
• Document that genetic services are offered, at least initially
• Patients are up-to-date with health supervision visits
• Follow AAP Health Supervision Guidelines (for 9 genetic conditions)
• Obtain and update emergency care plans
• Discuss transition to adult care beginning at age 12
• Offer discussions for palliative care where appropriate
Goal 3: Improve office systems

• Put a process/written protocol in place for use of a standardized family history tool
• Review examples of written protocols for implementing a family history tool in your practice
• 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
Plan your QI

What are we trying to accomplish?

Our aim is:

• By the end of the month, our practice team will meet with the genetic counselor/mentor in our Regional Genetics Collaborative, as part of a scheduled “lunch and learn” session in our office.

How will we know that a change is an improvement?

Our measures are:

• Documentation of the meeting held with our genetic counselor/mentor in our Regional Genetics Collaborative. (Including meeting agenda, meeting notes and list of attendees). Pre- and Post-tests will be conducted. Feedback will be collected from staff who attend the session.

What changes can we make that will result in an improvement?

Our Ideas for change are:

• Our physician champion will outreach a genetic counselor/mentor in our Regional Genetics Collaborative and schedule a staff education “lunch and learn” session in our office to discuss genetics in primary care and how to build a relationship with genetic professionals.
Sample PDSA Cycle

XYZ Pediatrics’ QI team decided to test the completion and review of a family health history (FH) tool with all of the project’s recommended components the one-month visit. The following is an example of their testing process, using a PDSA cycle:

**PLAN:** By the end of the next three months, our practice team will aim to complete FH tools for at least 90% of our patients seen for their one-month visit.

Copies of the Pediatric Family History tool will be made by Marie and available at the front desk. On Monday, at check-in the front desk staff will give the paper FH tool to the 3 families scheduled to come in to see Dr. Jones for their newborn’s one-month visit. The staff will ask the parent(s) to complete the form while in the waiting room.

The QI team predicted that all 3 families would complete the tool while waiting to be seen. At the end of the day they will measure the number of FH tools received and completed. They will ask the front desk staff, clinicians and families for feedback about this process and the tool.

**DO:** On Monday, the FH tools were available for families with a scheduled one-month visit. Two of the families received the FH tool at check-in but 1 was given by the MA when rooming the family because the front desk staff forgot.

**STUDY:** One family (mom and dad attended the visit) completed their FH tool (they thought it was easy to understand) but needed to ask additional family members for information. One mom only knew about her side of the family, not the dad’s. Dr. Jones did not get to review the tool with one family.

**ACT:** The team evaluated the results and decided the families need more time to complete the FH. We will try again but for the next test, Marie, our nurse, will explain the reason for collecting family histories and will plan to give the FH tool to parents at the 1-week visit, ask them to complete it at home with input from other family members and bring it back at the one-month visit.
Best Practice, Best *Process*

- **QI Anecdotes**
- **What QI Strategies and Tools worked best?**

- Obtain buy-in from all clinic staff and providers
- Conduct a needs assessment and process map to identify strategies to improve efficiency and implement strategies
- Start with small process and make adjustments, as needed
- If using an EMR – make changes to the EMR once a data collection form has been vetted and agreed upon
- Develop action plans for documenting positives on problem list and making referrals; understand red flags and know where to look for guidance
- Obtain patient/family feedback regarding the process
- Develop a written process or policy for collecting FH
GPCI QIP Results

- 13 practices completed the project
- Six month post-project follow-up data is available for 10 practices
- Thirty two physicians claimed ABP MOC Part 4
- See the evaluation feedback from the Nov 2013 Learning Session 2

### 13. Please rate the following project components in terms of their usefulness to you.

<table>
<thead>
<tr>
<th>N=30 LS2 Evaluation</th>
<th>1 Not Useful</th>
<th>2</th>
<th>3 Useful</th>
<th>4</th>
<th>5 Very Useful</th>
<th>Rating Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Face to face Learning Sessions</td>
<td>0.0% (0)</td>
<td>0.0% (0)</td>
<td>15.4% (4)</td>
<td>7.7% (2)</td>
<td><strong>76.9% (20)</strong></td>
<td>26</td>
</tr>
<tr>
<td>Monthly Conference Calls/Webinars</td>
<td>4.0% (1)</td>
<td>12.0% (3)</td>
<td><strong>48.0% (12)</strong></td>
<td>10.0% (4)</td>
<td>20.0% (5)</td>
<td>25</td>
</tr>
<tr>
<td>Regional Collaborative Mentorship Program</td>
<td>7.7% (2)</td>
<td>15.4% (4)</td>
<td>19.2% (5)</td>
<td>26.9% (7)</td>
<td><strong>30.8% (8)</strong></td>
<td>26</td>
</tr>
<tr>
<td>Project Listserv</td>
<td>4.2% (1)</td>
<td>25.0% (6)</td>
<td><strong>33.3% (8)</strong></td>
<td>8.3% (2)</td>
<td>29.2% (7)</td>
<td>24</td>
</tr>
<tr>
<td>Availability of Experts (quality improvement coach, Expert Group members)</td>
<td>0.0% (0)</td>
<td>3.8% (1)</td>
<td><strong>30.8% (8)</strong></td>
<td>15.4% (4)</td>
<td><strong>50.0% (13)</strong></td>
<td>26</td>
</tr>
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</table>
Results – Family History

Information on more family members is now being collected.

All practices, both before GPCI and at present, collected family history information on the patient’s mother and father.

The percentage of practices asking about siblings remained unchanged (92%).

No practices reported collecting information on 2nd or 3rd cousins.
Results

Improved collection of comprehensive FH over time

- Goal
- One or More Project Defined Components Included
- All Project Components Included
Results

Age Appropriate Health Supervision Visits Complete for Genetics Patients in Registry
Results, Cont.

Percent of practices that have an established process/written protocol for/to...

- Use of a standardized FH: 46% Pre, 100% Post
- Develop follow-up plans: 15% Pre, 46% Post
- Discuss FH with patient/family: 23% Pre, 62% Post

All practices now use a standardized process for FH, with roughly one-third having this process documented as a written policy.

There was an increase in the percent of practices establishing processes/written protocols for family history.
All knowledge areas assessed in the pre-survey saw at least some improvement in the post-survey, with the importance of FH, role in providing genetic services, and communicating genetic info measures seeing the highest gains.
Policies and Procedures for Patients with Genetic Conditions

<table>
<thead>
<tr>
<th>Practice has a standard process (written or not written) for...</th>
<th>Pre</th>
<th>Post</th>
<th>Δ from pre</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tracking genetic referrals made</td>
<td>38%</td>
<td>85%</td>
<td>47%</td>
</tr>
<tr>
<td>Identifying patients with a defined genetic condition</td>
<td>23%</td>
<td>77%</td>
<td>54%</td>
</tr>
<tr>
<td>Tracking children with a defined genetic condition</td>
<td>23%</td>
<td>77%</td>
<td>54%</td>
</tr>
<tr>
<td>Identifying genetic patients who are behind schedule for preventative services</td>
<td>23%</td>
<td>69%</td>
<td>46%</td>
</tr>
<tr>
<td>Contacting genetic patients who are behind schedule for preventative services</td>
<td>38%</td>
<td>69%</td>
<td>31%</td>
</tr>
<tr>
<td>Transition to adult care discussion with genetics patients by age 12</td>
<td>15%</td>
<td>62%</td>
<td>47%</td>
</tr>
<tr>
<td>Co-managing care genetics patients</td>
<td>8%</td>
<td>31%</td>
<td>23%</td>
</tr>
<tr>
<td>Obtaining emergency plans from specialists</td>
<td>15%</td>
<td>31%</td>
<td>16%</td>
</tr>
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</table>

Most practices established processes or written protocols around tracking and identification of patients with a defined genetic condition.

Fewer practices established processes or written protocols around emergency plans and co-managing care.
## Barriers to Implementation

<table>
<thead>
<tr>
<th>Barrier</th>
<th>% saying moderate or significant barrier</th>
<th>Average Rating (scale 0-4)</th>
</tr>
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<tbody>
<tr>
<td>Time it takes to develop new policies and procedures</td>
<td>69.2%</td>
<td>3.0</td>
</tr>
<tr>
<td>Time it takes to implement new policies and procedures</td>
<td>69.2%</td>
<td>2.9</td>
</tr>
<tr>
<td>Time it takes to add these components to the health supervision visit</td>
<td>46.2%</td>
<td>2.4</td>
</tr>
<tr>
<td>Limitations of the family history tools/screens in EHR</td>
<td>69.2%</td>
<td>2.7</td>
</tr>
<tr>
<td>Time required to enter the family history information into the EHR</td>
<td>46.2%</td>
<td>2.5</td>
</tr>
<tr>
<td>Difficulty in managing genetic patient registry</td>
<td>69.2%</td>
<td>2.7</td>
</tr>
<tr>
<td>Difficulty in establishing a recall system for patients</td>
<td>46.2%</td>
<td>2.2</td>
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So what?

• How can I use these lessons in my practice?
• What are some best practices identified?
Family History

Steps Towards Collecting FH
1. Obtain buy-in
2. Test FH tools, strategies to integrate into workflow
3. Discuss FH with families
4. Identify red flags
5. Follow-up with identified risk
6. Evaluate your FH tool
7. Maintain and update FH annually
Best Practices – Family History

• Obtain buy-in from all providers and clinic staff
  • Reiterate value to all, even front desk staff handing out forms
• Test various tools and approaches to collecting FH
• Begin collecting FH at new patient or 2-month visit, goal to have comprehensive FH by 2 yrs.
  • Request information from family members; others accompanying child to sick and well-check visits
• Contact genetic professionals with concerns or suspicions
• Ask family members if they have any FH concerns
• Notice red flags, even negative (everyone is “healthy”)
• Work with EHR vendor or IT dept. to model FH screen in EHR from paper form to facilitate data collection and entry
Identifying Patients with Suspected Genetic Conditions

Steps Towards Improving Patient Care
1. Recognize Clinical Red Flags
2. Identify and Follow-Up with Patients Identified at Risk
3. Talk to Parents about an At-Risk Family Health History or Genetic Referral
4. Develop Relationships with Genetic Professionals
5. Review Indications for Possible Referral for a Genetic Evaluation
6. Order Appropriate Genetic Tests
Best Practices – Identifying patients with genetic conditions

• Develop relationships with local genetics professionals, particularly genetic counselors
  • Know about your state’s Regional Genetics and Newborn Screening Collaborative ([http://www.nccrcg.org/](http://www.nccrcg.org/))
  • Become familiar with genetic red flags to increase your comfort in referring patients, ordering genetic tests
  • “Prior to this project, I didn’t consider referring for genetics without a confirmed diagnosis” – GPCI QIP participant
Providing Appropriate Care for Patients with Genetic Conditions

Steps Towards Improving Patient Care
1. Implement Systems to Improve Genetic Services
2. Create a Patient Registry
3. Follow the Health Supervision Guidelines
4. Provide Family-Centered Care
Best Practices – Providing appropriate care

- Create a Patient Registry
- Implement Systems to Improve Genetic Services
- Follow the Health Supervision Guidelines
- Provide Family-centered Care

- Check out Section 4 of the A Toolkit to Improve Care for Pediatric Patients with Genetic Conditions in Primary Care
Coordinating Care for Patients with Genetic Conditions

Steps Towards Improving Patient Care
1. Improve Processes to Co-Manage Care with Specialists
2. Obtain Current Emergency Plans (if applicable)
3. Obtain Current Emergency Letters (if applicable)
4. Plan for Transitions to Adult Care
5. Discuss Palliative Care
Best Practices – Coordinating care

- Improve Processes to Co-manage care with Specialists
- Obtain current emergency plans (if applicable)
- Obtain current emergency letters (if applicable)
- Plan for transitions to adult care
- Discuss Palliative Care (if applicable)

- Check out Section 5 of the A Toolkit to Improve Care for Pediatric Patients with Genetic Conditions in Primary Care
Project Resources

- Best Practices Toolkit – [www.geneticsinprimarycare.org](http://www.geneticsinprimarycare.org)
Additional AAP Resources

• Newborn Screening EQIPP Course
• “Dive into the Gene Pool” PediaLink Course – Coming soon!
• Medical Genetics and Pediatric Practice: A Handbook
• PediaGene: AAP Genetics Screening Guide – Mobile Device Application
Contact Us

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Questions?