Baseline (Prework) Data Results

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Genetics in Primary Care
Quality Improvement Project (QIP)
Learning Session I
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Disclosure

I have no relevant financial relationships with the manufacturers of any commercial products 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 their presentation.
Knowledge

- Understands the importance of family history in assessing predisposition to disease: 8 Strongly Agree, 6 Agree, 1 Disagree
- Understands follow-up for genetic services: 7 Strongly Agree, 5 Agree, 2 Disagree
- Understands professional role in providing genetic services: 7 Strongly Agree, 6 Agree, 1 Disagree
- Understands when and how to refer individuals with a genetic diagnosis to medical genetic specialists: 7 Strongly Agree, 5 Agree, 2 Disagree
- Can communicate genetic info in clear and non-directive manner, suitable for individuals of different backgrounds: 4 Strongly Agree, 5 Agree, 4 Disagree, 1 Strongly Disagree
- Knows how and when to refer to common community support services and agencies for genetic diseases: 4 Strongly Agree, 3 Agree, 7 Disagree
- Aware of common community support services and agencies for genetic diseases: 3 Strongly Agree, 6 Agree, 5 Disagree

Number of Practices

- Strongly Agree
- Agree
- Disagree
- Strongly Disagree

Practice Improvement Network

From the Quality Improvement Innovation Networks of the American Academy of Pediatrics

GPCI

GENETICS IN PRIMARY CARE INSTITUTE
Family History

- All practices indicate that they have EHR and that their EHR has a family history section

Use of EHR FH
- 1, Always
- 6, Usually
- 7, Sometimes

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

- Use of a standardized FH: 8 practices (6 No, 2 Yes)
- Develop follow-up plans: 11 practices (3 No, 8 Yes)
- Discuss FH with patient/family: 12 practices (2 No, 10 Yes)
## Family History

### Important to Include in Family History – Top 11

<table>
<thead>
<tr>
<th>Condition</th>
<th>Mean</th>
<th>% Include</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sensory Birth Defects</td>
<td>4.8</td>
<td>43%</td>
</tr>
<tr>
<td>Structural Birth Defects</td>
<td>4.7</td>
<td>64%</td>
</tr>
<tr>
<td>Clotting, bleeding or blood disorder</td>
<td>4.6</td>
<td>57%</td>
</tr>
<tr>
<td>Early death</td>
<td>4.6</td>
<td>79%</td>
</tr>
<tr>
<td>Known genetic condition</td>
<td>4.6</td>
<td>64%</td>
</tr>
<tr>
<td>Heart attack</td>
<td>4.5</td>
<td>79%</td>
</tr>
<tr>
<td>Patient and family concerns</td>
<td>4.5</td>
<td>50%</td>
</tr>
<tr>
<td>Knowledge/incomplete knowledge of FH if child is not biological</td>
<td>4.5</td>
<td>64%</td>
</tr>
<tr>
<td>Carrier of genetic condition</td>
<td>4.4</td>
<td>50%</td>
</tr>
<tr>
<td>Developmental delay, intellectual disability, autism spectrum disorder, learning disability</td>
<td>4.3</td>
<td>71%</td>
</tr>
<tr>
<td>Specific medical conditions that run in the family</td>
<td>4.3</td>
<td>86%</td>
</tr>
</tbody>
</table>

**Number of Practices**

- **5 - Extremely Important**
- **4 - Important**
- **3 - Important**
- **2 - Important**
- **1 - Not At All Important**
### Family History

#### Important to Include in Family History – Bottom 11

<table>
<thead>
<tr>
<th>Topic</th>
<th>5 - Extremely Important</th>
<th>4</th>
<th>3</th>
<th>2</th>
<th>1 - Not At All Important</th>
<th>Mean</th>
<th>% Include</th>
</tr>
</thead>
<tbody>
<tr>
<td>Seizures</td>
<td>5</td>
<td>8</td>
<td></td>
<td></td>
<td></td>
<td>4.2</td>
<td>71%</td>
</tr>
<tr>
<td>Consanguinity</td>
<td></td>
<td>7</td>
<td>4</td>
<td></td>
<td></td>
<td>4.1</td>
<td>14%</td>
</tr>
<tr>
<td>Multiple miscarriages or stillbirths</td>
<td>6</td>
<td>5</td>
<td></td>
<td></td>
<td></td>
<td>4.1</td>
<td>29%</td>
</tr>
<tr>
<td>Cancer &lt; 50 yrs and specify type</td>
<td>3</td>
<td>9</td>
<td></td>
<td></td>
<td></td>
<td>4.0</td>
<td>79%</td>
</tr>
<tr>
<td>Cause and age of death of family members</td>
<td>3</td>
<td>8</td>
<td></td>
<td></td>
<td></td>
<td>3.9</td>
<td>50%</td>
</tr>
<tr>
<td>Gender of family members</td>
<td></td>
<td>6</td>
<td>3</td>
<td>3</td>
<td></td>
<td>3.9</td>
<td>71%</td>
</tr>
<tr>
<td>Lineage of family member</td>
<td>4</td>
<td>6</td>
<td></td>
<td></td>
<td></td>
<td>3.9</td>
<td>86%</td>
</tr>
<tr>
<td>Received special education services</td>
<td>4</td>
<td>5</td>
<td></td>
<td>4</td>
<td></td>
<td>3.9</td>
<td>29%</td>
</tr>
<tr>
<td>Age of onset of medical condition(s) of family members</td>
<td>3</td>
<td>5</td>
<td></td>
<td>6</td>
<td></td>
<td>3.8</td>
<td>50%</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td>2</td>
<td>5</td>
<td>3</td>
<td></td>
<td>3.4</td>
<td>50%</td>
</tr>
<tr>
<td>Age of family members</td>
<td>1</td>
<td>5</td>
<td>5</td>
<td></td>
<td></td>
<td>3.2</td>
<td>36%</td>
</tr>
</tbody>
</table>
Family History

Family Member Included in Family History

- Mother: 14
- Father: 14
- Siblings: 13
- Grandparents: 11
- Aunts/Uncles: 6
- 1st Cousins: 1

No practices indicated they capture 2nd or 3rd cousins in FH
Baseline Chart Review Data
Pre-work/January 2013
Multi-Generational Family History Discussion

Practice #

A B C D E F* G H I J K L* M

Percent Achieved

Baseline
Mean - Baseline
Goal
* = NA
Baseline
Genetic Condition Registry Data
Pre-work/January 2013
Initial Size of Practice Registries for Children with Diagnosed Genetic Conditions

• < 50 patients = 4 practices
• 51-150 patients = 6 practices
• > 1000 patients = 3 practices
Age Appropriate Health Supervision Visits

Percent Achieved

Baseline
Mean - Baseline
Goal

Practice #
A B C D E F G H I J K L M
Use of Health Supervision Guidelines for Children with Genetic Conditions

Percent Achieved

Practice #

A* B C D* E F G H I J K* L* M

Baseline
Mean - Baseline
Goal

* = 0 eligible charts
Documented Next Steps/Plan of Care in Registry

- Practice #
  - A
  - B (90% Achieved)
  - C
  - D
  - E
  - F
  - G
  - H
  - I (90% Achieved)
  - J
  - K
  - L
  - M

- Percent Achieved
  - 0%
  - 10%
  - 20%
  - 30%
  - 40%
  - 50%
  - 60%
  - 70%
  - 80%
  - 90%
  - 100%

- Baseline
- Mean - Baseline
- Goal
Current Emergency Plan Available

Percent Achieved

Baseline
Mean - Baseline
Goal

* = 0 eligible charts
Genetic Services Offered
Transitions to Adult Care

Baseline
Mean - Baseline
Goal

Practice #

Percent Achieved
Palliative Care Discussion (if applicable)

Percent Achieved

Practice #

Percent Achieved

Mean - Baseline

Goal

* = 0 eligible charts
Policies and Processes - Scheduling

**Practices’ Policy and/or Processes for Scheduling**

<table>
<thead>
<tr>
<th>Number of Practices</th>
<th>Identifying genetic patients who are behind schedule for preventive services</th>
<th>Contacting genetic patients who are behind schedule for preventative services</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Policy or Process</td>
<td>11</td>
<td>9</td>
</tr>
<tr>
<td>Standard Process (not in writing)</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Written Policy</td>
<td>1</td>
<td>5</td>
</tr>
</tbody>
</table>

- **Practice asks about special needs and accommodations of genetic patients when scheduling appointments**
  - Always: 1
  - Usually: 2
  - Sometimes: 6
  - Never: 5

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*From the Quality Improvement Innovation Networks of the American Academy of Pediatrics*
Policies and Processes

Policy and/or Processes

<table>
<thead>
<tr>
<th>Developed when necessary</th>
<th>Begin transition to adult care</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Yes</strong></td>
<td><strong>No</strong></td>
</tr>
<tr>
<td>7</td>
<td>2</td>
</tr>
</tbody>
</table>

Frequency of Use

<table>
<thead>
<tr>
<th>Use health supervision guidelines for pts with known, diagnosed genetic conditions</th>
<th>Discuss palliative care with genetics patients at least annually</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Always</strong></td>
<td><strong>Usually</strong></td>
</tr>
<tr>
<td>1</td>
<td>5</td>
</tr>
</tbody>
</table>
• The vast majority of practices (12 out of 14) do not have an established process or written protocol in place to obtain emergency plans for patients with known, diagnosed genetic conditions from specialists or other providers.
Feedback from Parents and Families

Methods of feedback from parents and families

- Ask families for informal feedback at visits
  - Yes: 8
  - No: 6

- Parent/family surveys
  - Yes: 2
  - No: 12

- Parent/family advisory committee
  - Yes: 1
  - No: 13

- Parent/family focus groups
  - Yes: 1
  - No: 13

- Just over half of practices use informal feedback at visits to obtain regular feedback from genetics patients and families.
Challenges and Opportunities

• Improve communications re: genetic information
• Identification and follow up of patients with diagnosed genetic conditions
• Establish processes and develop written protocols
  – Routine use of a standardized Family History tool
  – Follow up plans and referrals, including community support services
  – Development of care plans
  – Obtaining emergency plans
  – Transitioning to adult care
  – Palliative care discussions, as appropriate
  – Ongoing feedback from patients and parents/families
Questions/Comments?