Pediatric Learning Network:
Adopting PFE Strategies to Improve Pediatric Asthma Care

Lesson 1: Including the Voice of the Person and Family In Quality Improvement

PCPCC Support and Alignment Network
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Learning Network Goal

Goal: Reduce hospital admissions for asthma by improving quality of care, emphasizing person and family engagement (PFE) strategies.

Today:
• Discuss the goal of the learning network
• Describe PFE relevant to pediatric practices including American Academy of Pediatrics PFE concepts and the TCPI PFE measures as the framework
• Describe PFE measures adopted in the Transforming Clinical Practice Initiative
• Highlight innovative pediatric practice using PFE
• Offer concrete examples demonstrating adoption of the ‘patient and family voices’ metric
• Discuss reasons and ways to identify a practice’s patient population with asthma
• Share resources
Learning Network Plan

1. Today: Patient and Family Voices
2. Engaging the Patient and Family at the Point of Care (Part 1 - shared decision-making, patient activation, health literacy, and collaborative medication management) - June 20, 2017 3:30 ET / 12:30 PT
3. Engaging the Patient and Family at the Point of Care (Part 2 - shared decision-making, patient activation, health literacy, and collaborative medication management) - July 18, 2017 3:30 ET / 12:30 PT
4. Engaging the Patient and Family at the Point of Care (Part 3 – e-tools) - August 15, 2017 3:30 ET / 12:30 PT
5. Connecting patients/families with appropriate supports and services - Sept 19, 2017 3:30 ET / 12:30 PT

Plus! Action steps between each call
TCPI Person and Family Engagement Performance Metrics

➢ PFE Metric 1: Support for Patient and Family Voices: Are there policies, procedures, and actions taken to support patient and family participation in governance or operational decision-making of the practice (Patient and Family Advisory Councils (PFAC), Practice Improvement Teams, Board Representatives, etc.)?

➢ PFE Metric 2: Shared Decision-Making
➢ PFE Metric 3: Patient Activation
➢ PFE Metric 4: Active e-Tool
➢ PFE Metric 5: Health Literacy Survey
➢ PFE Metric 6: Medication Management
QI Opportunities Connected to TCPI PFE Metrics

NHLBI Asthma Care Quick Reference: Diagnosing and Managing Asthma

Initial visit algorithm showing patient and family engagement opportunities

- **Initial Visit Algorithm**
  - Diagnose asthma
  - Assess asthma severity
  - Initiate medication and demonstrate use
  - Develop written asthma action plan
  - Schedule follow-up appointment

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**A patient and family advisory group** can help your practice be more welcoming to patients and families, improving word of mouth and patient experience survey scores – more patients and better retention.

- **Health literacy assessment** – what is the right type of information (written, verbal, video and right level) that will be meaningful?
- **Assess patient and family activation** – what is the patient’s knowledge, skills, ability, and willingness to take action on asthma self-management? Use readiness information for goal setting, teaching and care planning.
- **Your medication management teaching plan** will be based on patient activation and their knowledge and skills in self-management. Use teach-back and demonstration to ensure patient and family understands medication use.

- **Shared decision-making** – identify patient and family goals for asthma management (fewer missed days at school, staying out of the ED, etc.) and their preferences for treatment plan options, and incorporate them into the plan.

- Use the patient portal for scheduling, answering patient questions, pushing out reminders – to maintain a relationship with the patient and family and keep them engaged in care.
Defining Patient and Family Engagement

An innovative approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families

Engaging patients and families

• In their own care
• In practice improvement
• In policy (practice, hospital, community)
Using QI Methodology (Model for Improvement) to test changes

- **AIMS**: What are we trying to accomplish?
- **MEASURES**: How will we know that a change is an improvement?
- **IDEAS**: What change can we make that will result in improvement?

From: Associates in Process Improvement
Defining ‘Involvement’

Involvement in QI:
Occasional input vs. active team member

- Filling out a satisfaction survey
- Members of task forces
- Advisory board members
- Participants in focus groups
- Providing testimony at hearings
- Paid program staff
- Paid program or policy consultants
- Integral team member
HEALTH CANADA’S PUBLIC INVOLVEMENT CONTINUUM

Source: Shared Plans of Care: Engaging Families in Quality Improvement. Webinar presented by Sarah Davis, JD, MPA; Center for Patient Partnerships, UW-Madison Schools of Medicine and Public Health, Law, Pharmacy, and Nursing.
Pediatric Practice Innovator

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Chair, Pediatrics
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CQN3 Asthma Data Collection Form

First Name: __________________ Last Name: __________________ Date of Birth: ______/____/____ MRN: ____________

Email address: ___________________________ Insurance Company: __________________________

Date of Visit: ______/____/____ Attending Physician: __________________________ Patient's first encounter form? □ Yes □ No

Reason for visit: □ Asthma well visit □ Asthma exacerbation □ Asthma exacerbation follow up □ Spirometry visit □Other

PARENT SECTION – Please complete questions 1-13. Thank you for helping us care for your child.

1. Has your child missed any days of school/daycare due to asthma in the past 6 months? □ Yes □ No □ Does not attend
   If yes, enter the number of days of school/daycare your child has missed in the past 6 months due to asthma _____ # of days

2. Have you or your spouse missed any work days due to your child’s asthma in the past 6 months? □ Yes □ No □ Not currently employed
   If yes, enter the number of days of work you or your spouse have missed in the past 6 months due to your child’s asthma _____ # of days

3. Has your child visited an Emergency Room or Urgent Care Center due to asthma in the past 12 months? □ Yes □ No If yes, how many visits? ___

4. Has your child been admitted to the hospital due to asthma in the past 12 months? □ Yes □ No If yes, how many admissions? ______

5. During the past week, how often did your child need a fast acting or quick relief medication, at times other than before exercise? (includes Albuterol, Ventolin®, Proventil®, Xopenex®) □ Not at all □ Less than 1 time per day □ 1-3 times per day □ 4 or more times per day □ Not sure

6. For patients who use rescue/controller inhalers, is a spacer utilized? □ Yes □ No □ Not Sure

7. How often does asthma limit your child’s activities? □ Not at all □ A little of the time □ Some of the time □ Most of the time □ All of the time

8. Over the previous 2 to 4 weeks, how frequently has your child experienced episodes of cough, shortness of breath, wheezing or reduced activity due to asthma during the DAY? □ 0 or fewer days per week □ 2 or fewer days per week □ 2 or more days per week but not daily □ Daily □ Throughout the day

9. Over the previous 2 to 4 weeks, how frequently has your child experienced episodes of cough, shortness of breath, wheezing or waking up due to asthma at NIGHT? □ 0 or fewer times per month □ 1-3 times per month □ 4 or more times per month □ More than 1 time per week but not nightly □ Often 7 times per week

10. How would you rate your child’s asthma control during the past month? □ Very poorly controlled □ Not well controlled □ Well controlled

11. How comfortable are you in your ability to manage your child’s asthma, rated on a scale of 1-10? (Please circle)
   Not Comfortable = 1 2 3 4 5 6 7 8 9 10 = Very Comfortable

12. Please mark all things (triggers) that make your child’s asthma worse:
   □ Respiratory infections □ Heat/Humidity □ Changes in weather □ Cold Air □ Air conditioning/Heating □ Strong cleaners, air fresheners, aerosols, VOC’s
   □ Exercise/increased Activity □ Irritants (select all that apply) □ Tobacco Smoke □ Wood Smoke □ Air Pollution □ Perfumes □ Incense
   □ Allergens (select all that apply) □ Carpeting □ Cockroaches □ Rodents □ Animals □ Dust □ Pollen □ Stuffed Animals □ Clutter □ Food □ Mold
   □ Other: ___________________________ □ Don’t know □ None

13. When are asthma symptoms worse? (Check all that apply) □ Winter □ Spring □ Summer □ Fall
PHYSICIAN SECTION

14. Has the patient received oral steroids for bronchospasm within the past 12 months?  □ Yes  □ No

15. Indicate the patient’s asthma severity level:  (refer to the EPR-3 Tables 4-2a, 4-2b, and 4-6)
   □ Severe Persistent  □ Moderate Persistent  □ Mild Persistent  □ Intermittent

16. Physician assessment of control: What is the patient’s current level of control during the past month?  (refer to the NHLBI EPR-3 control tables - 3-5a, 3-5b, 3-5c, 4-3a, 4-3b, 4-7)  □ Well controlled  □ Not well controlled  □ Very poorly controlled

17. Have you used the age-appropriate NHLBI EPR-3 stepwise table to identify treatment options or to adjust therapy based on asthma control?  (refer to the Stepwise Tables 4-1a, 4-1b, 4-5)  □ Yes  □ No

18a. Is the patient on a controller medication?  □ Yes  □ No  Medication name: ____________________________________

18b. If Yes, does the patient/parent report using controller medications daily?  □ Yes  □ No  □ Started this visit

19a. Does the patient have a written asthma action plan?  □ Yes  □ No

19b. If yes, was the plan updated as needed and reviewed with the patient and/or family at this visit?  □ Yes  □ No

20. For patients age 5 years and older, has the patient had spirometry in the past 1-2 years?  (Refer to Box 3-2)  □ Yes: date ___/___/____ □ No □ N/A – Younger than 5 years

21. Were asthma patient/family educational materials (other than the asthma action plan) provided and explained at this visit?  □ Yes  □ No
   □ Medication education  □ Environmental triggers  □ Smoking cessation  □ Flu shot info  □ Allergy testing  □ Use of a spacer  □ Other: ________________

22a. September-March (active flu season): Was a flu shot received?  □ Yes date ___/___/____ □ No (see below)
   If no, reason □ Patient younger than 6 months  □ Other contraindications  □ Vaccine unavailable  □ Other, please specify: ________________

22b. April-August (not flu season): Was a flu shot recommendation made for upcoming flu season?  □ Yes  □ No (see below)
   If no, reason □ Patient younger than 6 months  □ Other contraindications

23. Has the patient been seen by an allergist or pulmonologist during the last 12 months for assistance with asthma management due to severity of illness?  (refer to specialist referral criteria) Specialist: ____________________________  □ Yes  □ No  □ Referred this visit

24. Asthma Follow-up Visit: Return in: _____ weeks, or _____ months

Adapted from the Physicians Hospital Organization at Cincinnati Children’s Hospital Medical Center specifically for the AAP Chapter Quality Network Asthma Project. Copyright © 2013 American Academy of Pediatrics 3/11/2013
Action Step: Engaging Patients/Families in Conversation Related to Their/Child’s Care

- Pre-visit contact/forms (AAP Bright Futures)
- Family Strengths
- Asthma Control Test (ACT)
Understanding Your Needs for Today’s Visit

Dear Parent,

Our practice is always looking for opportunities to improve our care for your child and your family. To help us learn about your needs as a parent and those of your child, please take a moment to answer the following questions:

I. Special Health Care Needs

Does your child have any special health care needs (including chronic medical problems, such as asthma, learning or behavior problems, or other health problems, for which he or she receives special services, such as counseling, therapy, or frequent medical tests)? □ Yes □ No

II. At today’s visit, I would like to

1. Better understand my child’s development and what to expect next. □ Yes □ No
2. Discuss any concerns I have about my child. □ Yes □ No
   a. Sleep
   b. Discipline
   c. Feeding
   d. Other
3. Discuss and build on my strengths as a parent. □ Yes □ No
4. Share values or traditions that are important to my family and me. □ Yes □ No
5. Take home print resources about things with which I need help. □ Yes □ No
6. Learn about community resources that may be helpful to my family and me. □ Yes □ No

III. Please list any other specific questions or concerns you would like to discuss today.

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

Thank You!
Practice Name: ___________________ MR Number: ___________________
Action Step:
Engaging and Partnering with Parents/Caregivers

• In Their Child’s Care
• On Your Practice QI
• On Your PFAC
It Takes an Effective Team to Do QI Work!

- Members representing different kinds of expertise in the practice/organization
  - Clinical Leader
  - Technical Expertise
  - Day-to-Day Leadership
  - Administrative Staff
  - Parent/Caregiver Partner(s)
  - Practice Facilitator/QI Coach
What Good is a Parent on the Team?

- Lives it all in the ‘real world’
- Makes teams think about change/improvement outside the office doors
- Asking the politically incorrect questions
- Sense of urgency
- WWDWBW? (Translation: Who will do what by when?)
- Ideally, parent is a free agent within system

Reality of the Challenges

• Staying connected to the project as a team member

• Volunteerism and it’s limitations

• Relevancy of QI work to families – it’s a learning curve

Really, It’s Worth It to All!

- Equal Responsibility/Equal Partnership

- Scope of Work
  - “I need to feel clear about what I’m supposed to do”
  - “Our work as parents is both concrete and subjective.”

  **Action item:** make time to meet/do this together

- Ensure good communication from the team that keeps the parent plugged in
  - Assigning someone in the practice whose job it is to do ‘confirmation’ follow up with the family partner.
  - Follow up with family partners with discussions that happen during the ‘in between’ scheduled meetings.
  - Plan ahead with regularly scheduled meetings so team members have the dates in their calendars.

  **Action item:** Requires planning ahead

Bringing Parent Advisors onto your Improvement Team
-the interview which is not an interview-

Advisor name: ________________________________

Contact information: __________________________

Date: ________________________________________

Staff member name: ____________________________

Ask the parent if you can take notes (this may be helpful to your work in the future to make some documentation of the parent story).

1. Ask the parent to share their story – allow them to speak freely. What follows are some ideas to start the conversation:
   - Family structure
   - Support system at home
   - Is there one moment they will always remember (good or bad)
   - Etc.

The time spent on this is important—it not only allows you to learn about the parent and their experience, but it also serves to build your relationship with the parent on a different level (than being a member of their child’s care team). Take your time and listen to the parent.

2. Share with the parent your story – the story of the work of your practice and the collaborative to improve the outcome:
   - Describe the team
   - Describe the value of listening to parents
   - Go over some of the past agendas to describe a typical meeting
   - Suggest topics upon which they can provide insights
   - Etc.

3. Ask if they would like to be an active member of the working team and explain all that it would involve:
   - Provide calendar of meeting dates and locations
   - Provide list of others on the team and their areas of expertise
   - Provide agenda and meeting minutes from previous meetings
   - Provide contact information of group administrator
   - Provide clear expectation of what you are hoping they will provide for the group
Action Step: **Plan and Test** an Asthma Support Group

- Identify patients/families; ask them what they need/want to help them improve asthma management?
- What time works best? In conjunction with scheduling asthma follow-up visits?
- Which clinicians/staff will participate?
- Educational content (e.g., Gizmos and Gadgets, Community-based resources)
- Incentives/Needs to be able to participate
Obtaining Family Feedback

These resources provide pediatric practices with ideas for obtaining feedback from families, including patient and family advisory councils, pre-visit questionnaires, and family focus groups.

- **Family Engagement Guide: The Role of Family Health Partners in Quality Improvement Within a Pediatric Medical Home**
- **Creating a Patient and Family Advisory Council: A Toolkit for Pediatric Practices**
- **Fostering Partnership and Teamwork in the Pediatric Medical Home: A “How-To” Video Series**
- **Resources for Family Feedback**
  a. Pre-visit contact form ([English/Spanish](#))
  b. Child and Adolescent Health Assessment ([English/Spanish](#))
  c. Family/Caregiver Survey
  d. Family Focus Group Guide
  e. Post-Visit Family/Caregiver Survey ([English/Spanish](#))
- **Well-Visit Planner**
Open Discussion

Questions/Comments

- Additional PFE-related successes during the previous month(s)?
- Issues/challenges?
- Surprises or something important that you and your practice teams learned about PFE?
On the topic of PFE, from an MD in Maine participating in the Aligning Forces for Quality (RWJF) initiative...

“Learn as you go, learn from your mistakes but keep going. The fruits from this effort just increase with time.”
• **ACTION:** Plan and Test an Asthma Support Group!

• Engaging the Patient and Family at the Point of Care *(Part 1 - shared decision-making, patient activation, health literacy, and collaborative medication management)* - **June 20, 2017 3:30 ET / 12:30 PT**

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Technical Support Available from PCPPC SAN and Partners

PCPCC SAN website and PFE Resource Center
https://www.pcpcc.org/tcpi

Pediatric Asthma and PFE
https://www.pcpcc.org/tcpi/learning

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