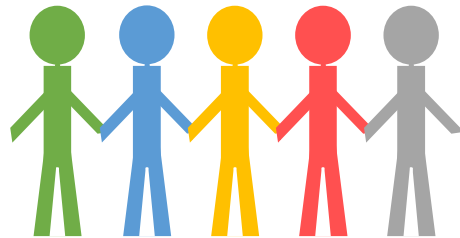


Pediatric Learning Network: Adopting PFE Strategies to Improve Pediatric Asthma Care

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

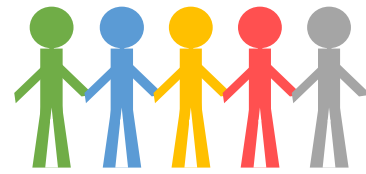
PCPCC Support and Alignment Network



Quality Improvement Leader:
Ruth S. Gubernick, PhD, MPH, PCMH CE

Practice Innovator:
Lilia Parra-Roide, MD, Dignity Health

PCPCC SAN Facilitator
Liza Greenberg, RN, MPH

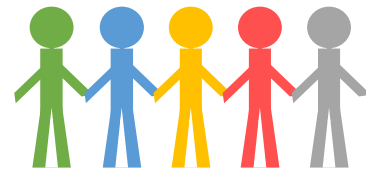


Learning Network Goal

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

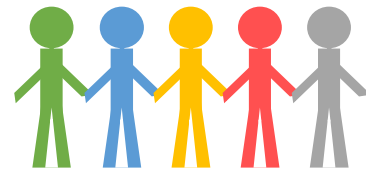
1. Today: Patient and Family Voices
2. Engaging the Patient and Family at the Point of Care (*Part 1 - shared decision-making, patient activation, health literacy, and collaborative medication management*) - June 20, 2017 3:30 ET / 12:30 PT
3. Engaging the Patient and Family at the Point of Care (*Part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



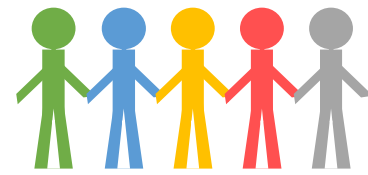
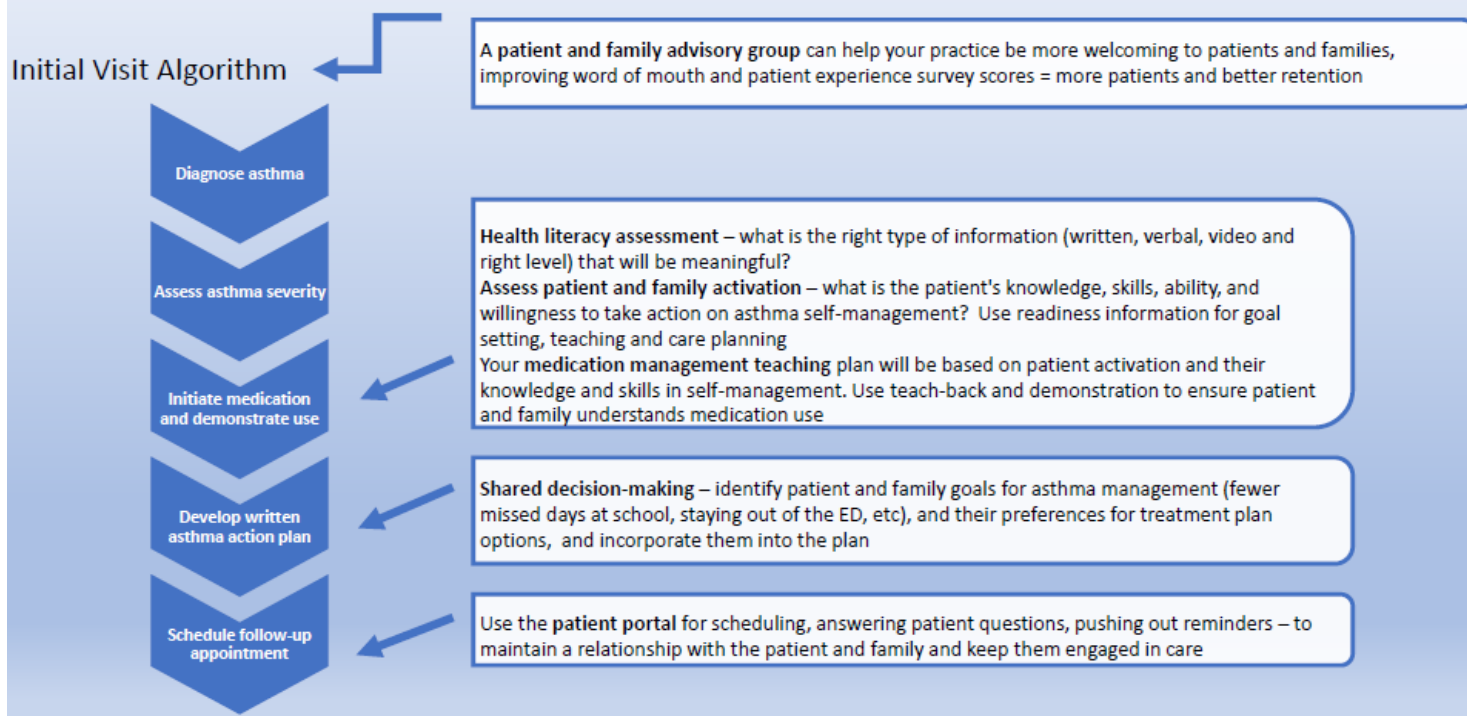
TCPI Person and Family Engagement Performance Metrics

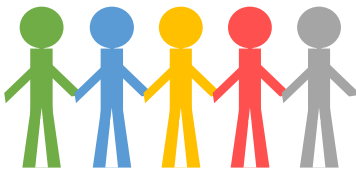
- **PFE Metric 1: Support for Patient and Family Voices:** Are there policies, procedures, and actions taken to support patient and family participation in governance or operational decision-making of the practice (Patient and Family Advisory Councils (PFAC), Practice Improvement Teams, Board Representatives,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





Defining Patient and Family Engagement

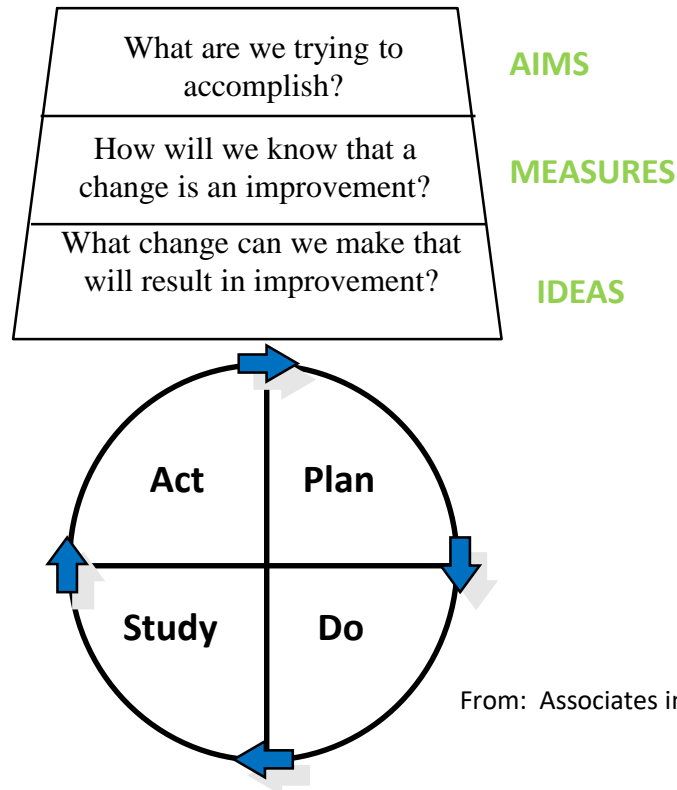
An innovative approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families

Engaging patients and families

- In their own care
- In practice improvement
- In policy (practice, hospital, community)



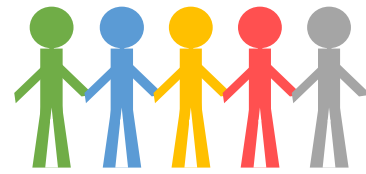
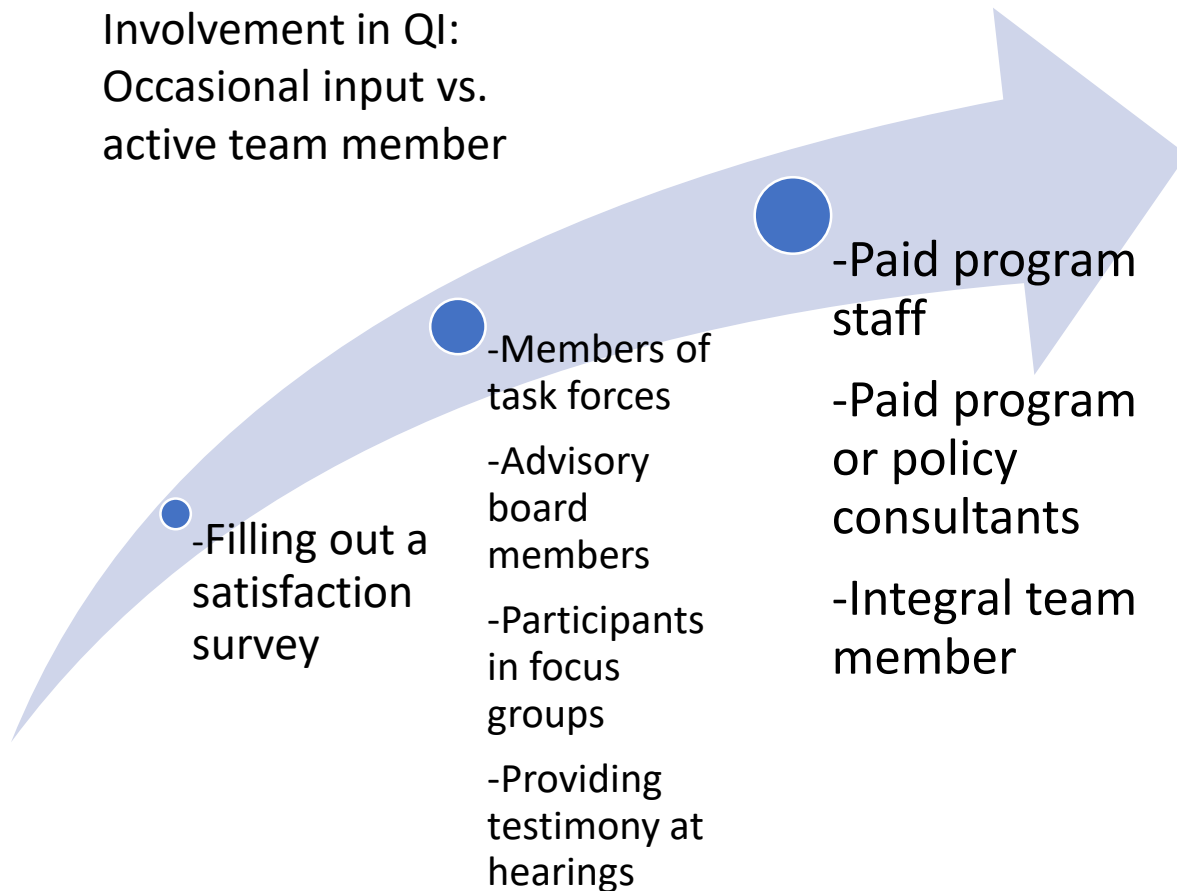
Using QI Methodology (Model for Improvement) to test changes



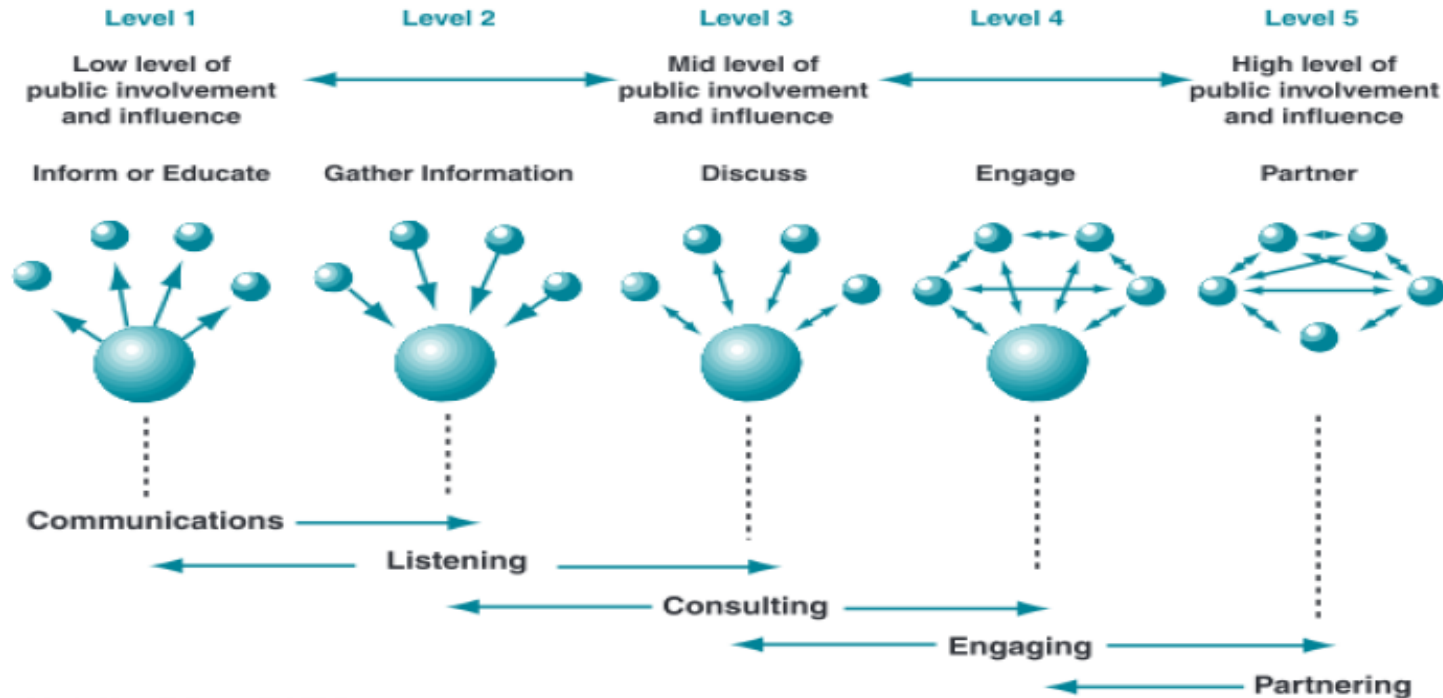
From: Associates in Process Improvement

Defining 'Involvement'

Involvement in QI:
Occasional input vs.
active team member



HEALTH CANADA'S PUBLIC INVOLVEMENT CONTINUUM



Adapted from Patterson Kirk Wallace

Health Canada. 2000. *Health Canada Policy Toolkit for Public Involvement in Decision Making*. Corporate Consultation Secretariat, Health Policy and Communications Branch, Health Canada, Retrieved May 29, 2013. < <http://www.hc-sc.gc.ca/ahc-asc/pubs/public-consult/2000decision/index-eng.php> >.

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

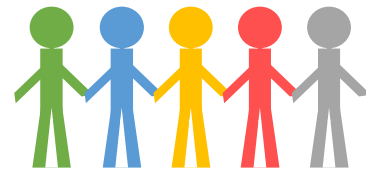
Pediatric Practice Innovator

Dr. Lilia Parra-Roide, MD

Chair, Pediatrics

Medical Director, Dignity Health Medical Group Pediatrics

Phoenix, AZ





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? ☐ 2 or fewer days per week ☐ more than 2 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? ☐ 2 or fewer times per month ☐ 3-4 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

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)

Childhood Asthma Control Test for children 4 to 11 years old. Know the score.

This test will provide a score that may help your doctor determine if your child's asthma treatment plan is working or if it might be time for a change.
How to take the Childhood Asthma Control Test
Step 1: Let your child respond to the first four questions (1 to 4). If your child needs help reading or understanding the questions, you may help, but let your child select the response. Complete the remaining three questions (5 to 7) on your own and without letting your child's response influence your answers. There are no right or wrong answers.
Step 2: Write the number of each answer in the score box provided.
Step 3: Add up each score box for the total.
Step 4: Take the test to the doctor to talk about your child's total score.

Have your child complete these questions.

1. How is your asthma today?

Very bad	Bad	Good	Very good
1	2	3	4

2. How much of a problem is your asthma when you run, exercise or play sports?

It's a big problem. I can't do what I want to do.	It's a problem and I don't like it.	It's a little problem but it's okay.	It's not a problem.
1	2	3	4

3. Do you cough because of your asthma?

Yes, all the time.	Yes, most of the time.	Yes, some of the time.	No, none of the time.
1	2	3	4

4. Do you wake up during the night because of your asthma?

Yes, all the time.	Yes, most of the time.	Yes, some of the time.	No, none of the time.
1	2	3	4

Please complete the following questions on your own.

5. During the **last 4 weeks**, how many days did your child have any daytime asthma symptoms?

Not at all	1-3 days	4-10 days	11-18 days	19-24 days	Everyday
1	2	3	4	5	6

6. During the **last 4 weeks**, how many days did your child wake up during the day because of asthma?

Not at all	1-3 days	4-10 days	11-18 days	19-24 days	Everyday
1	2	3	4	5	6

7. During the **last 4 weeks**, how many days did your child wake up during the night because of asthma?

Not at all	1-3 days	4-10 days	11-18 days	19-24 days	Everyday
1	2	3	4	5	6

19 or less

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AsthmaScore Step 2006 Revisions printed by GlaxoSmithKline (US), Inc. for use by its member healthcare providers.
AsthmaScore 10017

Take the Asthma Control Test™ (ACT) for people 12 years and older. Know your score. Share your results with your doctor.

- Step 1 Write the number of each answer in the score box provided.
- Step 2 Add up each score box for your total.
- Step 3 Take the test to the doctor to talk about your score.

1. In the past 4 weeks, how much of the time did your asthma keep you from getting as much done at work, school or home?

All of the time	Most of the time	Some of the time	A little of the time	None of the time
1	2	3	4	5

2. During the past 4 weeks, how often have you had shortness of breath?

More than once a day	Once a day	2-3 times a week	Once or twice a week	None at all
1	2	3	4	5

3. During the past 4 weeks, how often did your asthma symptoms (coughing, shortness of breath, chest tightness or pain) wake you up at night or earlier than usual in the morning?

4 or more nights a week	2-3 nights a week	Once a week	Once or twice a week	None at all
1	2	3	4	5

4. During the past 4 weeks, how often have you used your rescue inhaler or nebulizer medication (such as albuterol)?

3 or more times per day	1 or 2 times per day	2 or 3 times a week	Once a week or less	None at all
1	2	3	4	5

5. How would you rate your asthma control during the past 4 weeks?

Not controlled at all	Not well controlled	Well controlled	Completely controlled
1	2	3	4

19 or less

If your score is 19 or less, your asthma may not be controlled as well as it could be. Talk to your doctor.

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AsthmaScore 10017





Eliciting Parental Strengths and Needs

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!

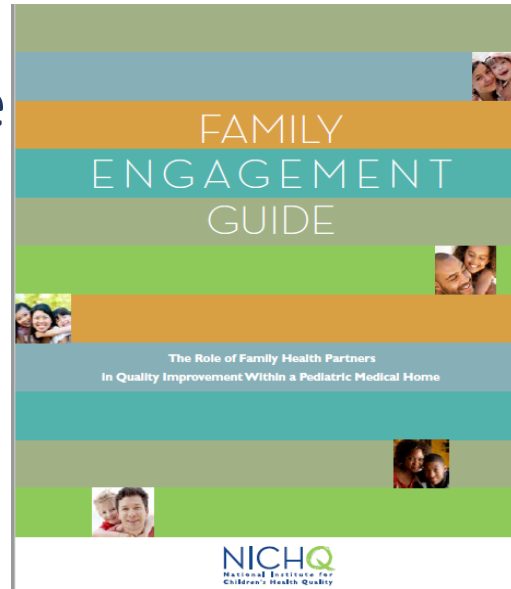
Practice Name: _____ MR Number: _____



Action Step:

Engaging and Partnering with Parents/Caregivers

- In Their Child's Care
- On Your Practice QI
- On Your PFAC



NICHQ

National Institute for Children's Health Quality

Creating a Patient and
Family Advisory Council:
A Toolkit for Pediatric Practices



30 Winter Street, 6th Floor, Boston, MA 02108
Phone 617-391-2700 Fax 617-391-2701 www.nichq.org



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

Source: Yes It Takes Time! Yes, It's Worth It! *Effectively Engaging Family Partners for Quality Improvement*. J. DesGeorges. MHCCPAAA Quality Improvement Webinar/Call, May 12, 2016.



Reality of the Challenges

- Staying connected to the project as a team member
- Volunteerism and its limitations
- Relevancy of QI work to families – it's a learning curve

Source: Yes It Takes Time! Yes, It's Worth It! *Effectively Engaging Family Partners for Quality Improvement*. J. DesGeorges. MHCCPAAA Quality Improvement Webinar/Call, May 12, 2016.



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

Source: Yes It Takes Time! Yes, It's Worth It! *Effectively Engaging Family Partners for Quality Improvement*. J. DesGeorges. MHCCPAAA Quality Improvement Webinar/Call, May 12, 2016.



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.”

Reminders

- **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**

Contact information:

Ruth Gubernick

856-477-2177

gubernrs@hln.com



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>

Contact

- Liza Greenberg, Program Director
liza@pcpcc.net

