

Family Engagement Quality Improvement Project
American Academy of Pediatrics

CONSENT TO PARTICIPATE FORM

The Family Engagement Quality Improvement Project is being conducted by the National Center for Medical Home Implementation in the American Academy of Pediatrics. The Family Engagement Quality Improvement Project is funded by a cooperative agreement from the Maternal and Child Health Bureau of the Health Resources and Services Administration.

PURPOSE OF THE PROJECT

The purpose of the Family Engagement Quality Improvement Project is to identify whether providing pediatricians and their staff with the tools and resources necessary to improve family engagement in practice, using quality improvement methods, will improve care and systems in practice. Data collection will involve patient record review, post-visit family surveys, monthly narrative surveys, monthly educational webinars, quality improvement coaching calls, and optional qualitative interviews.

HOW WE SELECTED YOU

You were selected because the application you submitted met the criteria for participation. A total of 10 pediatric primary care practices were selected from across the country.

WHAT WE WILL ASK YOU TO DO

As a participant of the Family Engagement Quality Improvement Project, you will be asked to:

- Participate in a 60-minute orientation conference call on April 27, 2016 **or** April 28, 2016, at Noon Eastern time, and complete necessary pre-work.
- Complete a pre-implementation survey in partnership with other members of your practice team.
- Review 20 patient medical records for patients age 0-18 years seen for health supervision visits as part of the baseline data collection period using the Academy's Quality Improvement Data Aggregator (QIDA). Instructions will be given to you and your team on how to utilize the QIDA).
- Collect 10 post-visit family surveys from 10 family members with patients age 0-18 years seen at the practice for health supervision visits at baseline and throughout each month of the project's 6-month action period. Enter results from post-visit family surveys into QIDA using instructions provided by project staff. All surveys will be collected in an anonymous manner so that individual families cannot be identified.
- Attend a 1.5-day Learning Session on June 3-4, 2016, at or near the AAP Headquarters in Elk Grove Village, IL (all travel expenses will be reimbursed).
- Review 10 patient medical records each month during the project's 6-month action period. Review of patient records will be conducted using the Academy's QIDA.
- Learn the *Model for Improvement* and implement Plan-Do-Study-Act (PDSA) cycles throughout the 6-month action period.
- Devote necessary resources and time to testing and implementing changes in the practice over a specified 6-month action period and work to obtain buy-in from all members of the practice.

- Work with your practice team to make appropriate changes in the structure of how care is monitored and delivered to patients and families.
- Participate in monthly 60-minute educational webinars; share lessons learned, challenges, and success with other practice teams.
- Participate in at least two 60-minute quality improvement coaching calls.
- Complete a Monthly Progress Report each month in partnership with other members of your practice team.
- Attend a 1.5-day workshop (Learning Session 2) in January 2017 (date is tentative) at or near the AAP Headquarters in Elk Grove Village, IL (all travel expenses will be reimbursed).
- Share results and progress about the project with other practice staff and physicians, including practice leadership.
- Participate as a team in a telephone evaluation interview at the end of the project, discussing your experiences with participating in, and satisfaction with, the project.
- If necessary, seek local Institutional Review Board approval for participation prior to the first in-person Learning Session.
- *Lead pediatrician only: serve as Local Leader in the attestation process required by the American Board of Pediatrics (ABP) for Part 4 Maintenance of Certification (if approved). Includes providing each pediatricians in practice interested in participating for MOC credit a document describing the requirements of their participation, monitoring pediatrician participation, and attesting that they met the project's completion criteria.*

PROJECT DURATION

The project will be implemented over the course of ten months, from May 2016 – February 2017.

RISKS OF PARTICIPATION

This project is considered to be minimal risk. This means the risks and discomfort associated with participating in this project are no greater than those ordinarily encountered in day-to-day life or during the performance of routine physical or psychological examinations or tests.

Potential loss of confidentiality

Any time information is collected, there is a potential risk of loss of confidentiality. Every effort will be made to keep your information confidential, however this cannot be guaranteed. (See confidentiality section below.)

Publications on the findings of this project will report data at the aggregate level only. No individual-level participant or parent/caregiver data will be reported.

BENEFITS OF PARTICIPATION

While there are no direct benefits to you for participating in this project, you will receive results of the patient record reviews as well as educational materials and resources related to delivering and improving family-centered care in your practice. You will also have the opportunity to learn from peers and experts in the field.

COMPENSATION

You will not be paid or compensated in any way for participating in this project.

CONFIDENTIALITY

Data collected will not include Protected Health Information. For any research publications resulting from this work, practices (or individuals) will not be linked with the data and only practice level data (aggregate) will be reported. No patients or practice staff will be identified in any report or publication about this study. Although every effort will be made to keep research records private, there may be times when federal or state law requires the disclosure of such records, including personal information. This is very unlikely, but if disclosure is ever required, the AAP will take all steps allowable by law to protect the privacy of personal information.

For quality improvement purposes, data will be aggregated by practice. In addition, practices will be identified by name in communication for quality improvement purposes with project staff working on the project. You will be able to use a secure online module to view reports of your practice's aggregate data, as well as aggregate data from other practices. Similarly, other participating practices will be able to view your practice's aggregate data via the secure online module. Data will be stored on a secure network with password protection. For research purposes, all data will be reported in aggregate, and individual practice data will not be identifiable. Potential publications may include a conceptual model of key barriers and potentially useful strategies that emerged from this project. Practice names will only be used in the acknowledgement section of any potential publications.

VOLUNTARINESS

Your participation in the project is completely voluntary. You may refuse to participate, or you may stop participating at any time and for any reason, without any penalty or impact. The investigators also have the right to stop your participation at any time. This could be because you have failed to follow the commitments described above or because the entire study has been altered or stopped.

WHOM TO CONTACT

This study was approved by the AAP Institutional Review Board. If you have any questions about the project, please contact Alex Kuznetsov, Program Manager (contact information below). If you have any questions or concerns about your rights as a research subject, please contact Erin Kelly, AAP Institutional Review Board Administrator at 847/434-4075.

CONSENT TO PARTICIPATE

I have read this statement, and I understand what it says. I agree to participate in this study under the conditions outlined above.

Please check ONE box to indicate your consent:

I will participate in the full study, including the phone interview

I will participate in the study but not the phone interview.

Signature Date _____

Printed Name _____

If you choose to participate in this project, please check the appropriate box, sign, scan and e-mail to:

Alex Kuznetsov

Program Manager

Email: akuznetsov@aap.org

Phone: 847/434-7087

You may also send a fax to:

Beth Evans

Administrative Assistant

Division of Children with Special Needs

American Academy of Pediatrics

Fax: 847/228-5034

Consent forms must be received no later than May 2, 2016.

Please keep one copy for your files.

If you would like further information about this project, contact:

Alex Kuznetsov

Program Manager

Email: akuznetsov@aap.org

Phone: 847/434-7087