

CHIPRA Demonstration Project

Category A Family Focus Group

Summary of Qualitative Findings

November 2014

Center for Health Policy and Research

Linda Cabral

Laura Sefton

Office of Clinical Affairs

Amy Norrman-Harmon

Jillian Richard-Daniels

Table of Contents

1. Introduction	3
2. Methods.....	4
A. Participant Recruitment and Selection.....	4
B. Data Collection	5
C. Data Preparation and Analysis	6
3. Findings	6
4. Discussion	15
5. Appendices.....	17
A. Appendix 1: Recruitment Materials	Error! Bookmark not defined.
B. Appendix 2: Interview Guide	22

1. Introduction

In 2010, Massachusetts became one of ten grantees (18 states) participating in a five-year quality demonstration project established under the Children's Health Insurance Program Reauthorization Act of 2009. The Massachusetts CHIPRA project (Project) has been led by five partners – Massachusetts Medicaid (MassHealth), Boston Children's Hospital, University of Massachusetts Medical School (UMMS), Massachusetts Health Quality Partners (MHQP), and the National Institute for Children's Health Quality (NICHQ). The demonstration seeks to develop innovative approaches to improving the quality of care for children.

Massachusetts was awarded the grant to:

- Administer and evaluate the use of 24 core measures for children's healthcare quality (Core Measures) endorsed by the Centers for Medicare and Medicaid Services (CMS) (Category A);
- Support the implementation of a medical home model of care at select child-serving practices across Massachusetts (Category C); and
- Convene a Statewide Child Health Quality Coalition to lead transformational health improvements for the children of Massachusetts, and to identify gaps in pediatric quality measures (Category E).

The Massachusetts Initiative also includes an evaluation to examine each of the project categories. This report focuses on Category A.

The Category A component of the demonstration, led by MHQP, is focused on collecting data and calculating results for the CHIPRA core measures set at two points in time, Cycle 1 and Cycle 2. An additional objective of the Category A component is to explore the ways in which measures results can be shared with relevant stakeholders. As such, several reports were generated: the CHIPRA Practice Site Report, the CHIPRA Family Report, and the CHIPRA Statewide Report. The following document focuses specifically on the CHIPRA Family Report. The goal of the CHIPRA Family Report is to help families better understand healthcare quality as well as empower families to use health care quality data to make informed decisions about their family's care.

This report presents a summary of findings from a series of four family focus groups conducted in May and June 2014. Through these focus groups, the University of Massachusetts Medical School Evaluation Team (Evaluation Team) sought to answer the following questions:

1. To what extent do families find practice level reports useful?
2. What is the specific report content and format most valuable to families?
3. To what extent do families find the CHIPRA core measure set relevant?

It is important to note that the CHIPRA Family Report was generated and distributed for the purposes of this evaluation. As a result, the Evaluation Team could not assess the extent to which families were knowledgeable or aware of the CHIPRA Family Report.

2. Methods

A. Participant Recruitment and Selection

The Evaluation Team conducted four family focus groups across four different regions throughout Massachusetts: Southeast, Metro Boston, Central, and Western. Three of the four focus groups were conducted in English and one focus group was conducted in Spanish; a separate agency, the Central Massachusetts Area Health Education Center, was contracted to translate the materials and facilitate the Spanish focus group. The Evaluation Team determined that in order to obtain sufficient data and generate overarching themes, each focus group would minimally need to include 5 participants but could accommodate a maximum of 10 participants. A total of 29 parents participated in the focus groups. The sample size for each focus group was as follows:

Table 1: Practice Site Sample Characteristics

Region	Number of Participants (Total N=29)
Southeast	7
Metro Boston	8
Central	8
Western	6

The Evaluation Team collaborated with Mass Family Voices at the Federation for Children with Special Needs (Mass Family Voices), a community organization that supports families and parents of children with special healthcare needs, to conduct outreach and recruitment activities for the four focus groups. Mass Family Voices developed a flyer (Appendix 1) which was distributed to a variety of locations for each region, including health centers, hospitals, community based organizations, and provider practices. The flyer described the purpose of the focus group, emphasized the stipend for participation, and provided contact information. Potential participants who contacted the Mass Family Voices Representative were screened to ensure that they:

- Understood the purpose of the focus group;
- Had adequate literacy skills to read and answer questions about the CHIPRA Family Report;
- Was a parent or care giver to a child under the age of 18.

If a parent met these minimum screening criteria they were added to list of focus group participants. Additional information collected as part of the screening included: insurance

provider (Public/Commercial/Combination); whether or not the individual cared for a child with special health care needs; and contact information.

Participants for the Spanish Focus Group were recruited using the same protocols with the exception that materials and screenings were in Spanish. Identifying participants for the Spanish focus group proved to be more difficult. As result, the Evaluation Team enlisted additional resources from the Central Massachusetts Area Health Education Center to actively recruit potential participants via personal interactions in the community.

To maximize participation, participants were sent reminder emails a few days and the day before the focus group, as well as a reminder phone call on the day of the focus group.

B. Data Collection

Four separate focus groups were conducted at four separate locations in Massachusetts. All focus groups were held in the early evening, and on average lasted approximately 90 minutes.

The Evaluation Team used a semi-structured focus group guide (Appendix 2) to collect information specific for each evaluation aim:

1. To what extent do families find practice level data or measure results useful;
2. What is the specific report content and format most valuable to families;
3. To what extent do families find the CHIPRA core measure set relevant?

The Evaluation Team determined that the length and density of the CHIPRA Family Report (20+ pages) would impact the focus group facilitator's ability to adequately address each individual measure during a 90 minute session. As a result, the Evaluation Team developed a focus group guide in which participants were asked to review two measures in detail (a patient experience measure and a developmental screening measure) and provide feedback on the content and format for those measures only. These two measures were selected for review because they represented the two different styles in which measure result information could be presented in the CHIPRA Family Report. For this reason, the majority of parent comments about report content and format are related specifically to these two measures. After reviewing these two measures, participants were then instructed to briefly review the entire CHIPRA Family Report and provide feedback on specific sections, including the complete list of reported measures, provided below:

Patient Experience of Care

- How well doctors communicate with patients
- How well doctors coordinate care
- Getting timely appointments, care and information

Well Visits and Preventive Care

- Developmental screening, ages 0 to 3
- Well visit (check-up) at the doctor's office, ages 12 to 21

- Well visit (check-up) at the dentist office, ages 2 to 20

Acute Care (Care you get right away)

- Emergency department visits

Follow-Up Care

- Follow-up care for children prescribed ADHD medicine
- Follow-up Visit with a mental health provider after being admitted to the hospital for a mental health disorder

Care During Your Pregnancy

- Caesarean (C-section) rate for first time mothers

In addition to the questions, the focus group guide also contained an educational component about health care quality measurement which was presented by the focus group facilitator at the beginning of each focus group. The educational information was included to ensure that each focus group participant had at least a minimal understanding of healthcare quality measurement, to be able to answer questions about this complex subject.

Prior to conducting the focus groups, verbal consent from participants was obtained. To facilitate transcription, the Evaluation Team also requested permission to audio-record responses. Audio recordings were later transcribed by a contracted transcription service. At the end of each focus group, participants received a \$100 Visa gift card for their participation.

C. Data Preparation and Analysis

Audio recordings were transcribed into Microsoft Word by a contracted transcription service. Transcripts were then uploaded into Atlas.ti Version 7.1, a software program that aids in qualitative analysis.

To guide the analysis, the Evaluation Team developed a codebook and coding scheme based on the evaluation questions and themes that emerged from the data. To ensure inter-reliability, all transcripts were coded by a primary and secondary coder who reviewed each other's coded transcripts to ensure consistent code application. Coding disagreements were resolved via discussion and additional data review until consensus was achieved. The Evaluation Team then met to review each other's identification of themes in order to reach agreement on how to present them. The themes arising from this analysis are the basis of this report.

3. Findings

Across the four focus groups, there were 29 participants. Twenty eight were female, and one was male. No additional demographic data were collected at the time of the focus group. Overall, participants engaged well with the topic of health care quality. The focus groups generated a wealth of material and the results have been organized by the three evaluation

aims. A fourth section that summarizes participant suggestions for additional report content has also been included. As there were no strong differences in the data collected across the four focus groups, the data below are summarized collectively and no sub-group analyses are presented.

i. To what extent do families find practice level reports useful?

Family members generally indicated that having the CHIPRA Family Report would be useful to them. For instance, participants described the CHIPRA Family Report as a potential resource when needing to find a pediatrician and identified several situations in which they might be looking for a pediatrician, such as: dissatisfaction with current provider, being a first-time parent, and moving to a new area.

I could have saved 10 years of hell and ended up with the pediatrician I have now, if I'd had a report like this on all of my local pediatricians because I tried to find out information like this and I couldn't find anything.

Parents described the additional information included with each measure, e.g. what your doctor can do and what you (or your child) can do, as especially useful. They felt these served as “guidelines” and “reminders.”

A few parents did indicate that they envisioned using the CHIPRA Family Report to educate themselves about quality measures and become more informed about how health care quality can be measured. The report was also viewed as a vehicle to compare performance across two or more providers.

Although, some family members stated that the information available in the CHIPRA Family Report may not be something that they would use today, they liked knowing that it was available to them for future use if needed. The more customized these reports could be for families (i.e. only reporting on measures of interest; only reporting on providers within a certain mile radius), the more useful it would be to parents.

It's more relevant to me because these are the specific practices [providers] that I'm focused and interested in.

Alternatively, those participants who were generally happy with their child(ren)'s pediatrician reported that they would be less likely to use the CHIPRA Family Report. They found it to be very long and did not think they would read it in its entirety.

I just think it's too long, though, because most parents just don't have the time to [read it].

Others found limited use for the CHIPRA Family Report because the measures were too vague or difficult to understand.

Honestly, I don't even know what that title means. Public insurance score? What's the score? On the doctor's office or on the insurance? Is it a quality measure of the issues, or is it a measure of the options that they—I don't know what it is.

ii. What is the specific report content and format most valuable to families?

As described in the Methods section, two measures within the CHIPRA Family Report were explored in depth as a means to identify the report content and format most valuable to families. These measures included:

- How well doctors communicate with patients, and
- Developmental screening, ages 0 to 3

This section discusses participant feedback related to the format and utility of information presented primarily for these two measures as well as potential ways the CHIPRA Family Report could be presented and disseminated.

Results Sections:

Some family members had questions about what 'public insurance' meant and why public and commercial insurance were reported separately in the measure results sections. For some parents, this breakdown felt discriminatory, as they felt all children should receive the same care regardless of insurance status. They preferred a single score that included all patients, regardless of insurance status. Other parents liked having the public insurance reported separately and suggested that performance with the publically insured population would be a good indicator of overall performance across the practice.

If you look at how doctors treat the least among us, then that's going to give you the truest rating of how they treat their clients.

Feedback was also mixed on the value of the results tables for each measure. The tables included both the measure rate as well as circle symbols indicating statistically significant differences in performance between individual practice and statewide results. Some parents felt these tables were easy to read and enjoyed having a visual on the page.

I liked that there was numbers and like, a graph-type of piece to this paper. It's easier to read and it just explains things in a simpler way.

Other parents reported having difficulty understanding what the circle symbols meant. At least one parent indicated that that she thought the circle symbol was a visual representation of the practice's overall performance. Since information on how to interpret the circles is only

provided in the Introduction Section of the CHIPRA Family Report, a suggestion was made to have a legend at the bottom of each table. Finally, some parents preferred the tables that had both circles and rates, as opposed to just scores.

I think just the circle half-filled makes you think it's 50%.

I got lost in the table.

Some parents urged caution when interpreting the tables. They felt a provider's score could be impacted by serving a more diverse or chronically ill patient population. These parents needed more information on how each measure was calculated and the patient population served in order to assess its usefulness.

So doctor's office B does lower scores across the board, but what if doctor's office B is in the middle of the Vietnamese community, and you scored a thousand percent if you got somebody from the Vietnamese community to your office at all, and yet you're being held to a standard of maybe a more—less diverse community?

Several parents thought that including a national average for each measure (or a link to that information) would be a helpful for comparison purposes. Another suggested including the denominator of the number of patients because “you could have one in a rural area that doesn't see many kids, you could have somebody in the inner city that sees hundreds.”

Supplemental Information

In addition to being asked about how they prefer to view measure rate results, parents were also asked about their preferences for extra or supplemental information accompanying each measure. Families provided information specific to the two measures that were discussed in detail, and then about the report contents overall.

Of the two measures presented, one measure included supplemental information, such as ‘Why this Measure is Important’, ‘What You Can Do’, and ‘What Your Doctor Can Do’. The second measure did not. Parents overwhelmingly preferred having the supplemental information presented with the measure. As mentioned previously, family members particularly liked the information presented in the ‘What You Can Do’ sub-section. This sub-section provided concrete tips that parents could use to be a more active participant in their child's health care.

Respondents indicated that having information presented in this way felt “empowering” and gave them ideas for improving their interactions with the doctor's office and how they could help their child. Some parents expressed that this sub-section could be improved by making the tips shorter, with more direct phrases instead of complete sentences.

I like the 'What you can do to better communicate with your child's doctor'. It's actually something I look into all the time, to see what I can do to get better services for my daughter or if there's something that maybe I'm not seeing it the right way and maybe I need another way of looking at it to get my doctor to look into something for my daughter.

I think it's good to remind what you can do to better communicate with the doctor. It's always good to have those reminders before you go into a visit.

Similarly, some family members liked the sub-section 'What Your Doctor Can Do' which provided information on what parents can expect from their doctor.

One respondent thought that the intent of the 'What your doctor can do to better communicate with you' section was unclear and needed more explanation, while others wanted guidance on what to do as a next step if there is no success in communicating with a provider.

Ask the doctor to repeat back what you just said. I don't know. I guess that's one of those skills they—for active listening, but I'm supposed to practice that on a doctor?

For the Developmental Screening measure, parents thought that the "what you can do" and "what your doctor can do" sections, which were not included in this measure, would have been helpful to them. In addition, parents wanted information about what developmental screening would be appropriate for children age birth to age 1. Another parent thought that a description of the process that providers use to determine who gets a screening and whether providers use standardized screenings would be helpful to them.

Well, I don't like it that they're just waiting until the child is one. I mean it should be from birth. Waiting until one, you've wasted a whole year.

What you can do to also help your child. This is just like, "Okay. Your child's not reaching this milestone so here, go to early intervention.

Report Format

One suggestion was made to format the CHIPRA Family Report differently, by having the all tips in one section and all of the data tables in a separate section instead of being presented jointly by measure. Additionally some participants suggested that the 'tips' would be easier to read if they were presented in shorter, bulleted phrases with more white space.

I would make it phrases, instead of sentences, and bulleted, but then give a little more prominence to this piece of it – it looks a little squished.

Participants discussed the best vehicle for sharing the information available in the CHIPRA Family Report. Some parents felt strongly that a web-based component would be useful. Parents had more confidence that data reported in a web-based program would be more current than a paper report. Having this information available via the web would allow parents to search for and view the content that they are most interested in instead of having to read through an entire report.

Yeah, see, I don't rely on hardcopy so much. I'm much more likely to think of something that's in a file as being old and irrelevant. I'm much more likely to go online and look for what I want.

Other parents liked having a paper-based format "to reference" when they needed the information.

I always like a hardcopy to stick in my file cabinet.

Report Dissemination

In addition to discussing the best format for the CHIPRA Family Report, parents offered ideas about how primary care physicians could help disseminate the CHIPRA Family Report. These included having copies of the CHIPRA Family Report available in the doctor's waiting room; having the Medical Assistant offer the CHIPRA Family Report to patients after rooming them so that they could read it while waiting for the doctor, and having the web link to the CHIPRA Family Report printed on appointment reminder cards.

Parents also had suggestions for sharing this report outside of a primary care setting. As expectant parents are looking for pediatricians, having this report available at OB-GYN offices was seen as a good idea. Additionally, parents reported that having this information available to people registering for insurance would be helpful and could be mailed to parents along with insurance materials in a welcome packet. Another suggestion that came from the parents in the Spanish-speaking focus group was to have community-based meetings and workshops available to review the CHIPRA Family Report and explain how to use it. A final suggestion was to make these reports available to schools, particularly guidance counselors, who could then share this information with parents.

I think every community should have this, and everybody should have knowledge of this, and be made more aware. I don't know, maybe they could have like a monthly meeting, you know, in different communities, for different people...you know, get the word out.

Having the CHIPRA Family Report/information available in different languages was also important to parents, so that non-English speakers could benefit from it. One parent suggested having the CHIPRA Family Report available in audio format. Lastly, some parents liked having the website links to additional resources as part of the report.

iii. To what extent do families find the CHIPRA core measure set relevant?

Participants were asked to review the complete list of measures included in the CHIPRA Family Report and assess how meaningful and relevant the measures were to them.

Families were mixed with regard to the relevancy of the complete list of measures included in the CHIPRA Family Report. Of most importance were the patient experience measures. Some other measures (developmental screening, patient experience) were considered more relevant than others (well visits, emergency room visits, dental visits for children, C-section rates for low-risk first-time mothers). Parents found measures relevant when they had children to which the measure would apply, or if they related to the practice's capabilities.

It wouldn't be a primary reason why I chose the doctor for the dental, but I would consider [it] because what I would think to myself is, oh, he's one of those all health care doctors. He [cares] about the teeth too, and he's gonna push and ask, "Did you go to the dentist? Did you go to the dentist?" Sometimes I need that. Now, as far as the emergency department information, I don't think it's at all useful. Just like the other measures, I don't know that Dr. A's office had 58 visits to the emergency department, in some ways, it could be that's superlative because those patients are so aware of at-risk things that on the weekends, they're going to get them checked out and they're not dying at home.

I think, especially having children with a whole bunch of different issues, I think developmental screening is important.

For these health quality measures for children's life, I'm not quite sure why we care about the Caesarean.

Some parents suggested that they would need additional information to make some of the measures more meaningful to them. Suggestions included breaking down the Children's Visits to the ED measure by visit type, e.g. emergency (broken leg) versus routine care (ear infection, sore throat) as a better way to assess emergency room utilization; including score/rates for each question in the patient experience measures (so parents could focus on the elements that were important to them), and providing more information on why the measure is important to their children's care.

I wouldn't mind seeing, without it being too visually overwhelming—you know what I mean—how they scored [on the questions that make up the measure]. Because I could sit there and look at that and say, okay ... Dr. B got the lowest score. However, in question one, he got the highest score, and that's of real value to me ...

Families indicated that they would use the information in the CHIPRA Family Report when deciding on a provider, though this might not be their only source for decision-making. Others would use the information from the measures to understand what components should be a part of their child's care and as reminders before visits. One parent noted that if she had the developmental screening measure information when her son was younger, she would have addressed her child's issues differently with the pediatrician.

Because when I had my first son, he didn't talk to me. And the doctor couldn't recreate this and until my son was 3, that was when he started talking, saying words. At 3, if I had this information, I could have pushed back more on the doctor.

iv. Additional Content Recommendations

Families were asked for their feedback on other information or measures that would be useful to include in the CHIPRA Family Report. Suggested additional report content fell into the following categories: Practice and Provider related information, Access to Care measures, Care Coordination and Transitions measures and additional measures.

Practice and Provider related information

Many of the suggestions for additional report content were related to the 'operational aspects' of medical practices. These aspects included the practice hours of operation, urgent care availability, off-hours access, communication options outside of appointments (such as email), languages spoken, whether the practice was a medical home, length of patients' affiliation with the practice, and the practice's hospital affiliations.

I was just thinking average length of time that a family or child has been with the practice. If they have a high turnover rate, that might be indicative of something that's not good.

Additionally, families were interested in more information specific to the providers, such as their credentials, education, clinical areas of expertise, and length of service. However, participants did note that provider ratings were just one aspect of the care experience and suggested that information about other practice staff would be informative as well. For instance, some parents felt that knowing the extent to which practice staff were familiar with and understood the insurance environment could help to facilitate treatment process.

...you can't just get medications at your local pharmacy. Sometimes, they have to go through specialty pharmacies, and your insurance sometimes doesn't take this one or that one ... If the communication is there within the practice to know these meds and understand someone's insurance and not to put them on something that isn't gonna go through MassHealth if you have MassHealth, that you're gonna need prior

authorizations that takes two weeks, do you know what I mean? There are practicalities that no parent should have to have to figure out.”

Access to Care

Parents suggested a number of measures that centered on access to services at a practice. Families recommended several access indicators that would be helpful to them, such as time spent in the waiting room, average number of minutes per provider/patient session, number of emergency room visits for routine complaints during office hours, number of patients served by the practice, and number and type of providers (MD/NP) in the practice. Parents reported that these data would help them to make determinations about the level of availability of providers for appointments.

I'd like to know how many patients a doctor's office has. I think that would be helpful because then you kind of know if they would be able to see you on a timely basis.

Care Coordination and Transitions

Finally participants identified several additional measures pertaining to care coordination, particularly with respect to specialty care for children with special needs. These included whether the practice provides referrals to specialists and the number of successful referrals. Families were also interested in knowing how well the provider communicates and coordinates with other providers and specialists outside of their practice, as well as whether providers receive and respond to specialty care notes. Further, there was interest in knowing whether providers understand the specialists' recommendations and if those recommendations are incorporated into the care they provide to the patient.

If I had a measure of which pediatricians work with different psychiatrists in the area or could refer to psychiatrists, I'd be more likely to work with that pediatrician.

Several families wanted to know how well providers handle and prepare patients and families for the transition from pediatric to adult care. This was of particular interest to parents of children with special needs. Because these children are managing chronic illnesses, they see providers frequently and maintaining consistent care from provider to provider is a key consideration of parents as their children enter into the adult medicine world.

Weren't there a couple of issues because the one is preparing the child to transition, and then the other is who's receiving the child on the other end, and are they prepared to have a child with extra needs, and could the measure be 'in the adult provider community, this provider can meet the needs of children with complex needs.' I think that's what you need really is to integrate some of these into the adult measures ... part of the reason I choose the practice that we chose was because I have providers there too ... I'm familiar with a whole bunch of people in that practice, and I want them to be comfortable taking my child into that adult part of the practice when it's time.

Additional Measures

Respondents gave a few suggestions of additional measures related specifically to care delivery. These included appropriate vaccinations rates, developmental screening for ages 3-12, use of nutrition and holistic medicine in a practice, follow-up care for learning and developmental disabilities and mental health care, whether providers routinely perform behavioral health checks, and whether written care plans are provided to patients.

4. Discussion

Family members participating in the focus groups had varying but generally positive opinions on the value of the CHIPRA Family Report. Most could see some utility in the CHIPRA Family Report, particularly when they had children for whom the information would be relevant and for families looking for a new pediatrician. In order to be most useful, up-to-date data was desired. However, the concept of quality measures, in general, was not something that most respondents were very familiar with and, therefore, some orientation was needed in order to understand how to interpret the CHIPRA Family Report. Patient experience measures (e.g., how well doctors communicate with patients; how well doctors coordinate care; getting timely appointments, care and information) were of most interest to family members and most easily understood. In addition to information on the patient experience, family members also wanted more practical information on pediatricians, such as office hours, specialties, patient retention rate, and number of years in practice.

When disseminating a report such as this, it is important to consider user preference. There was a strong preference for having an online component to this report available. Most focus group participants were comfortable with seeking information online and would prefer to refer to a web-based report instead of a paper-based one. In order to be most useful, up-to-date data at a practice level was desired and participants believed that information online would be more current. However, there was still value seen in having hard copy reports available, particularly at doctor's offices where it could be reviewed in the waiting room.

The feedback collected from these focus groups suggest some modifications to the CHIPRA Family Report that would make it more useful to parents. These modifications include:

1. reducing the length of the report,
2. making the data tables more easily understandable (perhaps including a legend at the bottom of each table)
3. offering more information about a provider's background
4. including more than just public insurance scores
5. Having the CHIPRA Family Report available in multiple languages and formats could expand the number of parents who may benefit from the CHIPRA Family Report.

5. Appendices

A. Appendix 1: Recruitment Materials



Are you interested in Quality Health Care for Your Family?

Do you want to learn how children's health care quality is measured?

Massachusetts Family Voices at the Federation is recruiting for a 90 minute focus group FOR PARENTS and CAREGIVERS to discuss children's health care quality measures.

In this focus group we'll ask questions about quality measure reports;

- Is the information in the reports important to you?
- Would you use the information in the reports to make decisions about health care for your family?

Your feed-back during the focus groups will help improve future reports that families receive about the quality of children's health care.

Join us for these upcoming focus group:

Wednesday May 28th 7:00-8:30PM Freetown, MA

Wednesday June 4th 7:00-8:30PM Boston, MA

Monday June 9th 7:00-8:30PM Westborough, MA

Thursday June 19th 7:00-8:30PM Springfield, MA (Spanish speaking group)

Registration required, please contact Bonnie at (617) 399-8354 or email bthompson@fcsn.org **Group attendees will be PAID for their time.**

Space is limited, call early if interested. Snacks and drinks will be served.

Massachusetts Family Voices at the Federation for Children with Special Needs (<http://www.fcsn.org/mfv/>) represents families in the Massachusetts CHIPRA Demonstration Grant (Children's Health Insurance Program Reauthorization Act of 2009) a federal demonstration grant, from the Center for Medicare and Medicaid Services-(CMS), awarded to Massachusetts "to evaluate promising ideas for improving the quality of children's health care".

The Massachusetts CHIPRA Grant team is led by five partner organizations:



MassHealth, Boston Children's Hospital, Massachusetts Health Quality Partners (MHQP), National Institute for Children's Health Quality (NICHQ), and the University of Massachusetts Medical School.



¿Está usted interesado en cuidado de salud de calidad para su familia?

¿Quiere aprender cómo se mide la calidad del cuidado de la salud de los niños?

Massachusetts Family Voices está reclutando familias para formar un grupo de enfoque. En este grupo de discusión de 90 minutos de duración se hablará sobre las medidas de calidad del cuidado de la salud de los niños.

Los participantes de grupo recibirán estipendios por su tiempo

Sus sugerencias en estos grupos de discusión ayudarán a mejorar los futuros informes que los padres reciben sobre la calidad del cuidado de la salud de su niño.



Únase a nuestro próximo grupo de enfoque:

Cuándo: 19 junio 7:00-8:30 de la noche

Dónde: Springfield

Se requiere su registración; por favor llame a Marilyn al (617) 399-8354 o vía correo electrónico bthompson@fcsn.org.

El espacio es limitado, llame temprano si está interesado.

Habrá refrescos.

Massachusetts Family Voices (<http://www.fcsn.org/mfv/>) represents families in the Massachusetts CHIPRA Demonstration Grant (Children's Health Insurance Program Reauthorization Act of 2009) a federal demonstration grant, from the Center for Medicare and Medicaid Services-(CMS), awarded to Massachusetts "to evaluate promising ideas for improving the quality of children's health care".

The five Massachusetts CHIPRA Grant Partners are: MassHealth, Boston Children's Hospital, Massachusetts Health Quality Partners (MHQP), ~~National Health Care Quality Improvement Center (NHCQIC)~~, ~~Massachusetts Medical Society (MMS)~~, ~~Commonwealth Medical Center (CMC)~~, and the University of Massachusetts Medical School.

Su participación en los grupos de enfoque será privada y no est

B. Appendix 2: Interview Guide

CHIPRA Category A Family Focus Groups

INTRODUCTION

The focus group facilitator will review the following with focus group participants.

Protocol:

- Introductions: facilitator and assistant and focus group participants.
- Indicate that the anticipated length of the discussion is no more than one and ½ hour.
- Remind participants that they will receive a stipend in appreciation of their participation.

Ground rules for the discussion today:

- Everyone will have a chance to voice their experiences and opinions, although it is ok to not feel the need to answer every question if you have similar feelings and experiences as expressed by the other focus group participants.
- Respect all points of view.
- Assure confidentiality of responses.
- One at a time- please do not interrupt one another, however there is no need to raise your hand to be called on.
- There are no right or wrong answers, but rather differing points of view. We encourage you to share your point of view even if it differs from what others have to say.

Confidentiality

- Everything you share with us is considered confidential information. Only general themes will be reported across all the interviews we conduct. Quotes will only be used if they contain no identifying information and cannot be attributed to an individual.
- As a reminder, we will be recording the focus group. This is done to promote data accuracy. The recording will be used only as a back-up to our notes and will be destroyed after our notes are typed up.
- Does everyone agree to this level of confidentiality?
- Does anyone have any questions before we begin?

Part 1: Provide an overview of the purpose of the focus group.

- The state received some federal money for a project to look at how to improve the health care that children receive
- One of the goals of the project was to develop family friendly reports that could be used by parents to get information on health care scores (ratings?) on their children's doctors
- The purpose of today's focus group is to get your feedback on a sample report that was developed for parents like you. We want to hear from you what you understand/what is hard to understand; what you like/don't like, and; how you might use this information

(5 minutes)

Personal Introductions: Name, how many children and ages, and then warm up question (below).

1. Where did you get the information that helped you choose your family's doctors or clinic?

Part 2: Explanation of quality measures (*draft language*)

Before we get started with the focus group, we wanted talk to you a little bit about quality measures, what they are, why they're important and how they apply to this report and the focus group we will be having today.

We measure the quality of things every day while making decisions, like what to eat or what shoes to wear or what to watch on TV. Most decisions like these are based on personal preference and experience, but sometimes we need to make a decision about something new to us. When we can't rely on our own experiences, we look to outside information and the experience of others for guidance. Think about choosing the right doctor's office for your family. You probably consider lots of different things, like location, availability, and cost. But, you may also want to know how friendly the staff is and how well the doctor communicates or listens to you. Those kinds of questions would be hard to answer without visiting every doctor in your area. This is where quality measures come in.

A quality measure is a standard way to test, rate, or review something that can help us compare information and make decisions. Quality measures can be especially helpful when considering healthcare. For example, they can help us:

- Feel empowered. Many patients and families say they feel more in control when they have data to help them make health care decisions.
- Learn about the quality of health care you get from doctors, nurses, and other health care providers in Massachusetts.
- Learn ways to work with doctors to improve the quality of your child's health care
- Choose a doctor's office. This data might be helpful if you have a new baby or move to a new town.

There are different types of healthcare quality measures. In the report that we will be talking about today, there are two types of health quality measures:

- Patient experience data comes from parents across Massachusetts who filled out surveys about their child's health care.
- Clinical quality data looks at processes within a doctor's office. Measures look at three aspects of care: prevention (such as well visits), acute illness (such as when a child has a sore throat or a broken arm) and chronic disease (such as caring for a child with ADHD).

The type of measures that you're probably most familiar with are the patient experience measures. How many of you have ever gotten a survey asking about your doctor's office? The questions on these surveys help collect information for the patient experience measures. Some of these measures include: how well doctors talk with patients; how well doctors coordinate care; or getting timely appointments, care and information. Let's talk in a little more detail about these measures from the report.

[Hand page from report with measure]

. (10 minutes)

Part 3: Focus Group Questions/ Interaction (draft language)

2. Measure specific questions (*Highlight: PES and Developmental screening and compare differences*)

- *Why it is important*
- *Measuring xxx*
- *What you can do*
- *What your Doctor can do*
- *Learn more*
- What are your thoughts about the different sections?
 - How understandable is the information?
 - How useful is this information to you?
 - *Prompt so that all sections are discussed*

Do you prefer the measure description with more information like what can you do or what can your doctor do or the shorter measure description without it?

Transition: Now we would like to show you the full report with all ten measures.

Distribute paper copy of full report and allow time for participants to review. Direct participants attention to the list of measures on page X in the report.

This report that we will show you gives you information on how practices score on 10 different quality measures. These measures were included in this report because they cover different types of care that a child could get from birth through their teenage years.

including regular check-up visits and specialty care for conditions such as ADHD. We would like to hear what you think about these measures.

3. What are your thoughts about this list of measures?
 - How easy or hard are they to understand?
 - Are certain measures more useful to you than others? Which ones? Why?
 - Are these measures important to you? (relevance)
4. What are your thoughts on whether or not parents would read a report like this?
 - If you knew of a report like this would you recommend it to other families?
5. What is your preferred format for receiving this information? (web, paper)
 - What are your thoughts on whether or not parents would go to a website to get information like this?
6. What are your thoughts on how you would use the information in this report?
 - To make decisions about where to get your child's care?
 - Any decision about your child's care?
 - What type of care to get or ask for?
 - To help your doctor's office perform better?
7. Is there any other type of information that's not currently in the report that you would like to see?
 - Other measures?
 - More explanation on measures?
 - More supplemental materials?