Fostering Consumer Engagement in Practice Transformation: A Toolkit for Practices on the Journey to Patient-Centered Medical Homes
Acknowledgements:

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“A patient centered medical home (PCMH) is a model that puts the patient in the center of care, working in partnership with a primary care provider to optimize preventive health measures and care coordination. In a PCMH, the patient is an active part of the care team. As part of the team, patients within a medical home can improve the quality of care, enhance communication and smooth the way for efficient care delivery.”

Patient-Centered Primary Care Collaborative 2011
# Table of Contents

INTRODUCTION .......................................................................................................................... 1

SECTION 1 ........................................................................................................................................ 4
   APPL YING LESSONS FROM THE FIELD ................................................................. 4
   LESSONS LEARNED: TIPS FROM THE FIELD .................................................. 6

SECTION 2 ...................................................................................................................................... 8
   INCREASING CONSUMER ENGAGEMENT IN HEALTHCARE ................................. 8

SECTION 3 ..................................................................................................................................... 11
   CONSUMER PARTICIPATION IN PRACTICE TRANSFORMATION ............................. 11

SECTION 4 ..................................................................................................................................... 14
   ENGAGING CONSUMERS IN QUALITY IMPROVEMENT ......................................... 14
   ENGAGING CONSUMERS IN QUALITY IMPROVEMENT (AHRQ) ......................... 15
   THE CONSUMER ADVISORY COUNCIL .................................................................... 16
   GUIDELINES FOR ENGAGING CONSUMERS IN QUALITY IMPROVEMENT ............ 17
   QUALITY IMPROVEMENT ADVISORY COUNCIL .................................................. 19
      Consumer Application Form .................................................................................... 19
   CONSUMER ADVISORY COUNCIL MEETING ......................................................... 20
      Agenda ....................................................................................................................... 20
   DEVELOPING GOALS AND OBJECTIVES FOR MEETINGS ................................. 21
   DEVELOPING GOALS AND OBJECTIVES WORKSHEET ......................................... 22
   MEETING TIMELINE ...................................................................................................... 23
   CONSUMER ADVISORY COUNCIL ............................................................................. 24

SECTION 5 .................................................................................................................................... 25
   CONSUMER EXPERIENCE INFORMATION TO GUIDE QUALITY IMPROVEMENT ....... 25
   SURVEYING FOR QUALITY IMPROVEMENT .......................................................... 26
   CONSUMER FOCUS GROUPS ...................................................................................... 29
      Promoting Consumer Discussions that Guide Quality Improvement .................... 29
   PRINCIPLES OF CONDUCTING FOCUS GROUPS .................................................... 30
   FOCUS GROUP PREPARATION CHECKLIST ............................................................. 33
   CONSENT FORM ............................................................................................................ 34
   DEMOGRAPHICS FORM .............................................................................................. 35
   FOCUS GROUP DISCUSSION GUIDE .......................................................................... 36
   FOCUS GROUP SAMPLE QUESTIONS ......................................................................... 38

SECTION 6 .................................................................................................................................... 39
   REFERENCES ..................................................................................................................... 39
   RESOURCES ..................................................................................................................... 40
This toolkit is a source of information and guidance for practices to design accommodating and patient-centered ways to engage consumers in the quality improvement process. A firm understanding of the patient-centered medical home (PMCH) is required to describe consumer engagement in the practice transformation that is required in the patient-centered medical home model of care.

The PCMH is not a one-size-fits-all, and neither are the patients or providers who live, work and play within its walls. PCMH models are new, diverse, dynamic and evolving. We need to understand them, work with them, and design them from blueprints that meet patients’ needs. Ideally, the PCMH helps to empower patients who can participate fully in their care — and places the patient at the center as part of the care team.1

This flexibility is why a common operational definition of what the PCMH means in practice remains elusive.2

What is helpful is to examine an operational definition of consumer engagement in health care. In its 2010 release of the report Snapshot of People’s Engagement in their Health Care, the Center for Advancing Health (CFAH) provides a definition that serves well here, stating: “Engagement in health care is defined as actions that individuals must take to obtain the greatest benefit from the health care services available to them. This definition focuses on behaviors of individuals relative to their health care that are critical and proximal to health outcomes.”3 This definition suggests that there is a role that consumers must play for care to be delivered in a way that is appropriate and accessible, based on their particular needs. If practices are to design a system of care that meets the need of patient populations, improves outcomes, and ends health care disparities, consumers must have a voice and a seat at the table during the change process that the PCMH model of care requires. Consumer engagement encompasses steps that practice staff take to solicit patients’ participation and feedback about their own care.

The Massachusetts Patient Centered Medical Home Initiative (PCMHI) developed a definition of PCMH available at the end of this introduction. It is written at a sixth grade reading level, and designed to be adapted by practices to correspond to their practice’s transformation.

Patient-centered care ultimately derives from the healing relationships between providers and consumers. A patient-centered approach fosters interactions in which providers and consumers engage in two-way sharing of information and explore patients’ values and preferences. The approach is designed to help consumers make clinical decisions, to facilitate access to community resources, and to provide support to patients so that they learn self-management techniques and/or chronic disease management to maintain or improve their health.

The PCMH aims to improve clinical practice by building caring relationships that bridge demographic, social, and economic differences between providers and patients. In this context, providers provide personalized care that is in sync with the needs and preferences of patients. It is essential that all members of the care team know their patients’ social circumstances and cultural norms well enough to help with decisions about care, set action plan goals, assess patients’ capacity for self-management, promote healing, and prevent illness.  

For practices that have committed to leading the way in reinventing how primary care is delivered in the state of Massachusetts, learning how to, and increasing consumers’ engagement in their health care, is vital. To become a Patient-Centered Medical Home, practices must foster consumer participation in the transformation process. The National Committee for Quality Assurance (NCQA), in its 2011 PCMH Standards and Guidelines, has made this a “must-pass” element for certification, stating, “The practice has a process for involving patients and their families in its quality improvement efforts.” Practices that follow through on this guideline will ensure that procedural changes they adopt meet patients’ needs. Research has shown that practices that have learned the value of consumer involvement in practice transformation attest to its many benefits.

Included in this toolkit developed for the PCMH, are valuable tips and guidelines from industry leaders in providing strategies for quality improvement and patient satisfaction in health care. This toolkit provides templates, sample documents, and links to resources designed to gather vital information on consumers’ experience and satisfaction with care. Such tools will help care teams learn how best to engage consumers in quality improvement activities. The tools presented here have been tried and tested in health care organizations and have proven to be of great benefit. These are only a sample; practices have had very positive experiences with many others, and many more tools will be developed as providers partner with their patients and transform their practices.

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The Patient Centered Medical Home

You can choose to be part of a new model for getting health care. This new model is called the Patient Centered Medical Home, and it is right at [insert physician’s name/office].

WHAT TO EXPECT:

• Care from a team of health care providers.
• Care that gets you through an illness and helps to keep you well.
• Care that respects your values.
• Care that includes YOU as a member of the team, where you can talk about what you would like and how you will take charge of your own care.
• Care that is easier to schedule with flexible appointments and more ways to keep in touch with your team like phone and email.
• Care that is coordinated because your primary care providers and specialists work together.
• Care that includes what you would like, and is explained clearly in your own language. In other words, care that is designed for you.

Your health care team believes the Patient Centered Medical Home is a better way to take care of your health needs and to help you manage your own care.

You decide if you want to be part of the Patient Centered Medical Home.

Be sure to ask about the Patient Centered Medical Home at your next visit.  
[insert physician practice logo, phone number]
Applying Lessons from the Field

In 2010, the University of Massachusetts Medical School, through the MassAHEC Network of Commonwealth Medicine, engaged the Area Health Education Center of Southeastern Massachusetts (AHEC-SE) to convene focus groups with medical interpreters and community health workers. These two groups were identified as key informants, as they represent populations that are culturally and linguistically diverse and work closely with consumers who are important constituents in the PCMH Initiative. The AHEC-SE convened three focus groups, and two additional focus groups with Spanish-speaking health care consumers were conducted by the Merrimack Valley Area Health Education Center (MVAHEC).

The focus groups were held throughout the state to capture the perspectives of diverse segments of the population. As a result of these qualitative findings, AHEC-SE and MVAHEC developed a list of recommendations to inform practices of changes required during the transformation into a PCMH. Consumers engaged in the focus groups conducted by the MVAHEC went a step further, voicing how they would prefer to be engaged by practices. Although the views expressed by these consumers may be strictly representative of their own preferences, they none the less provide a snapshot of how consumers may prefer to be engaged in a PCMH. The full reports are available at [http://pcmhi.ehs.state.ma.us/](http://pcmhi.ehs.state.ma.us/).

The data led to the following findings:

1. The overwhelming majority of participants had not heard the term Patient-Centered Medical Home and felt that the term was confusing.

2. The majority of participants indicated that (a) culturally and linguistically appropriate care and (b) being viewed as a whole person, rather than a condition, were the most important components of good health care.

3. The majority of participants said that they would be willing to participate in consumer engagement activities in the development and implementation of the medical home.

A number of recommendations for practice transformation that apply to practices engaged in the transition process are offered by MVAHEC. The focus groups’ feedback, included the following:

1. Consumers reported that attending community meetings on issues relevant to their health would most likely be the activity patients would be willing to participate in.
2. Practices should ensure that the practice setting is welcoming and personnel are courteous. Whenever possible, available literature or media should reflect patients’ cultural and linguistic preference.

3. Consumers would like to participate in group activities such as exercise and support groups. Consumers reported that this would likely lead to sharing of lessons learned with relatives.

How to Use:
The following are lessons learned and tips for engaging consumers based on the feedback gathered from the focus groups.
Lessons Learned: Tips from the Field

Consider engaging consumers at the beginning:

- Discuss what a PCMH is and what the changes to the practice will mean in a way that consumers will understand, preventing patients from feeling disoriented.6

Provide customer service and cultural competency trainings to staff:

- Provide a conceptual framework that underscores best practices in working with diverse patient populations and consumer-focused care. Bring consumers into the discussion to provide valuable insights and perspectives and allow for a better understanding of how consumers want to be engaged.

Provide a variety of opportunities and venues for patients to share their opinions and to ask questions about the transformation process and the PCMH:

- Provide community meetings or town hall discussion-style forums to engage consumers in settings other than the medical practice. Assure consumers that their views are important and will contribute to improving care.

Include consumers as vital members of the health care team:

- Allow consumers, particularly those with chronic illnesses, to know that their opinions and views matter. Encourage them to voice their thoughts in managing their illness.

Facilitate a smooth process of referrals, not just for medical services but also for community-based social services:

- Engage consumers to learn what support services they need. Participate in existing networks of health and human service providers, and engage health advocacy groups that work with and represent health care consumers.7

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Assess consumers’ literacy, or determine level of education:

➢ Adapt informational material for consumers to respond to their literacy and language needs.

Continue periodic use of focus groups:

➢ Engage consumers to gather up-to-date information regarding patients’ needs, satisfaction, and suggestions for quality improvement.

Establish educational and/or support groups:

➢ Solicit from consumers what their needs and preferences are for topics of discussion. Create opportunities to provide consumers with tips for self-management of their health.

Create collaborative clinical and support teams:

➢ Inform consumers of their roles in the care team. Work collaboratively to identify the kinds of support that consumers need to stay on track with self-management techniques and to manage chronic illnesses.⁸

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⁸ Merrimack Valley Area Health Education Center. (2010). *Massachusetts Patient-Centered Medical Home Initiative: Consumer Engagement Project Focus Group Report.* Lawrence, MA
Increasing Consumer Engagement in Healthcare

The goal of increasing consumers’ engagement in care may appear daunting to a busy practice. Such an endeavor requires attention from all team members involved in providing care and spreading the PCMH model throughout the practice. The benefits derived from having consumers more involved in the care they receive and in disease prevention and management efforts are worth the investment.

To support practices committed to patient-centered care, the Center for Advancing Health (CFAH) has compiled goals and recommendations designed to help advocates and providers increase and support consumers’ engagement in the health care they receive and to engage patients in practice transformation. The recommendations offered by CFAH are the result of an extensive review of 31 national surveys of consumers’ engagement in health care. Researchers at CFAH noted that a lack of consumer involvement results in unnecessary suffering and wasted resources and contribute to disparities in health outcomes.9

How to Use:
Use the following proposed goals as guidance in why and how to develop a consumer engagement strategy. Each goal outlines specific actions that practices can take to garner consumer engagement in care. Practices are encouraged to develop a system of learning from what works or doesn’t work when reaching out to their specific patient population.

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Proposed Goals to Increase and Support Consumer Engagement
Adapted from Center for Advancing Health (2010). *A snapshot of people’s engagement in their health care.* Increasing people’s engagement in their care.

Goal 1: More effective actions by individuals
Consumers are often unaware of many of their new responsibilities, which, if not fulfilled, cause confusion and waste time and resources.

- **Make responsibilities clear:**
  - Practices should make explicit the terms of engagement.
  - Provide basic information to consumers about how to effectively interact with the care team, and discuss consumer responsibilities and those of the care team.
  - This information is necessary for consumers to work effectively and efficiently with health care providers.

- **Support the development and implementation of new strategies:**
  - Conduct research (plan, do, study, and act: PDSA cycles) to develop and test both targeted and broad strategies to support consumer performance of specific engagement behaviors in all relevant settings.
  - Consumer involvement, through feedback procedures initiated by practices such as surveys, advisory groups, and/or focus groups, is essential to ensure patient-centeredness.

Goal 2: Better tools for consumers
There is tremendous potential for web-based, device-based, and print-based tools to help consumers fulfill their responsibilities with ease and accuracy.

- **Build tools that help consumers solve problems:**
  - Ask consumers to identify specific health-related or care administration problems that they struggle with.
  - Tools designed for consumer use should be based on consumer feedback.
Provide just-in-time information and guidance:

✓ Organize self-management and chronic disease management information and support tailored to meet the needs that emerge over the course of an illness or episode.

✓ Integrate tools and information into care delivery processes.

✓ Make information available and adaptable to consumers’ diverse literacy and language needs and preferences.

Goal 3: Care that is more accountable to and with individuals

Only general and fragmented information is available about those who do not engage in care and about the barriers to engaging in care. Work to change this.

➢ Monitor engagement behaviors:

✓ Tailor and target efforts to support consumers’ capacity to engage in health care.

✓ Track the practices’ progress in effective consumer engagement.

➢ Incorporate engagement into quality performance measures:

✓ Bring to the challenge of increasing consumer engagement in care the same focus, energy, commitment, and resources as have been devoted to increasing access and improving quality.
Consumer Participation in Practice Transformation

Fostering consumer engagement in health care is an important step; however, it is only the first step in garnering consumer participation in practice transformation. It is through consumer engagement that practices realize the required adjustments that are essential to transform into patient-centered medical homes. Using patient experience information to transform care is indispensable. This requires developing processes and systems to support high levels of access for, and communication with, consumers. Capturing and using data based on consumers perceptions of care and building consumer support for evidence-based decision making is critical.10

As mentioned, patient experience surveys and focus groups provide information about patient satisfaction with and experience of care. The question is what to do with the information collected. How do practices convert the collected information to specific procedural changes that lead to successful practice transformation? The answer to questions like this can clarify changes practices can make that will have a positive effect on the quality of care experience for patients and providers.

There is no precise prescription that will meet the needs of all consumers; taking time to ask consumers for their feedback is often the only way to find answers that work. Teams that have become experts in soliciting patient input in care delivery typically use three methods to get the information they need:

1. Point-of-care data gathered at the time of the visit
2. Patient and family focus groups
3. Patient and family walkthroughs11

How to Use:
The following provides information about three different approaches to fostering active consumer participation in the practice. It also highlights some of the many benefits to applying each approach. Practices may find this useful as a quick reference guide.

Collecting Consumer Experience Feedback to Transform Care

- **Point-of-care data (e.g., surveys)**
  - Collect within or at the end of a visit, usually via very brief written or even verbal questions.
  - Use to capture patients’ experience when it is fresh.
  - Focus either on a specific area of interest to the team or on the general experience of the patient during the visit.

- **Consumer focus groups**
  - Allow patients and families to engage in a discussion about their experience with care at the practice through discussion, rather than responding to written questions.
  - Regular engagement in offering feedback, or regular participation on quality improvement teams, allows consumers’ development into a fully fledged advisory group with in-depth expertise in a specific area.

- **Patient walkthrough (Patient shadowing)**
  - Use to obtain consumer perspectives on care delivery experiences as well as the more general experience with the practice setting.
  - This can be as broad as the experience of receiving care throughout the system, or as focused as evaluating the experience of having questions answered during a visit.

Practices have used walkthroughs to explore the following:
- How patients and families are greeted
- The process of care and exchange of information
- Patient forms, educational materials, and follow-up instructions
- Characteristics of the physical environment (artwork, color, lighting, etc.)
- Public materials (posters, magazines, announcements)
Essential to remember when collecting consumer feedback

✓ Effective feedback comes from asking consumers early and often. Bring consumers in at the design level.

✓ Set realistic expectations for the amount of time and effort needed to see results.

✓ Include family members in advisory capacities when appropriate. They are an important part of the health care team, particularly with pediatric and/or dependent care patients. They offer valuable perspectives.
Engaging Consumers in Quality Improvement

The Agency for Health Research and Quality (AHRQ) has offered tips on engaging consumers in practice improvement in its 2010 report Engaging Patients and Families in the Medical Home. Researchers noted that:

“Patient and family participation in practice improvement activities has been a critical component of the medical home model. Observational studies have suggested that involving patients in practice improvement enhanced staff attitudes and increased participants’ use of services. Leaders from organizations that have involved patients and families in practice quality improvement or transformation, testify to its importance and positive impact.”

Researchers also noted that “informal methods for collecting consumer feedback are frequently used in quality improvement and are particularly useful for getting at the more specific ideas and concerns of patients and families.” Examples of informal methods include the following:

- Keeping a suggestion book or comment cards in waiting rooms
- Getting consumer input in the development of new patient materials
- Inviting patients to sit in on interviews of prospective staff

Consumer engagement activities take time and resources. Practices should consider multiple options for obtaining consumer feedback based on their particular capacity and consumer availability. Survey data may help identify problems, but finding the solutions will take additional effort. Also important to consider are consumers’ ability to work with the health care team, their breadth of experience with the health care setting, their ability and willingness to communicate concerns, and the patients’ or family members’ ability to represent patients and families broadly rather than focus narrowly on a particular issue. It is beneficial for practices to provide training and support to patients and/or family members and staff prior to having consumers regularly participating in quality improvement teams or advisory councils.12

How to Use:
Use the following as guidance to prepare the practice team to engage consumers in quality improvement activities and for sustaining consumer participation.

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Engaging Consumers in Quality Improvement (AHRQ)
Adapted from: Agency for Health Research and Quality (2010). Engaging patients and families in the medical home. AHRQ publication No.10-0083-EF. Rockville, MD.

Feasibility in routine practice

➢ Take into consideration practice size and capacity when selecting approaches to foster consumer engagement in quality improvement.

Multiple and flexible approaches to gain patient input

➢ Consider various methods for obtaining consumer feedback for practice improvement.

Identify consumers to participate in improvement activities

➢ Appoint consumers who are able to work well with the team, are comfortable sharing their views with others, and have the ability to represent patients’ views broadly.

Training

➢ Provide adequate training for staff and consumers who will be engaged in collaborative teamwork in identifying and redesigning practice procedures.

Meaningful participation

➢ Avoid using consumers as token participants. Ensure that consumers are active participants in practice transformation by setting realistic expectations of participation.

Sustaining participation

➢ Be enthusiastic and willing to embrace suggestions from consumers. Some practices offer a small reward for participation (food, gift cards, etc.) and provide meeting space and supplies. Develop a network of potential participants in the event that some consumers may not be able to continue to participate.

Motivation

➢ Provide motivation to the team and to consumers. Informing consumers of the practice’s drive to improve quality of care will help keep consumers motivated to participate in quality improvement activities.
Developing and maintaining an advisory council may not be a novel concept for many health care practices. However, convening a consumer advisory council to foster patient and family engagement in practice transformation is relatively unique. As more medical practices across the nation have set out on the journey to transform into PCMHs, they have learned that including the patient perspective in practice transformation is a must.

The 2011 National Committee for Quality Assurance (NCQA) PCMH standards have been revised. The NCQA PCMH 2011 standards stipulate that practices “involve patients/families in quality improvement teams or on the practice’s advisory council.” There are many issues to consider before setting out to engage patients and families in a new advisory council or adding consumers to an existing internal council.

**How to Use:**
The following guidelines are for practice staff to consider before approaching consumers and inviting them to participate in an advisory council. Following the guidelines are templates that can be used to start an advisory council.

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Guidelines for Engaging Consumers in Quality Improvement

Prepare staff and the practice:

- Define the advisory council’s goals and objectives, the role of the staff involved, and what you hope to gain from consumers.

- Engage major internal stakeholders in the process; their guidance and input are indispensable. Internal stakeholder involvement in the process is essential if the council is to be effective. It will also provide legitimacy and encourage participants.

- Consider which staff member/s will help. Will it be a member/s of the pilot or care team? Staff with experience coordinating a group would be beneficial to the council and can provide a measure of direction and support to potential participants.

- Provide trainings for staff on consumer relations, coordinating groups, teamwork, and redesigning practice procedures, if necessary.

- Inform practice staff and departments of the role of the consumer advisory council, and allow opportunities for all to ask questions or offer feedback.

Invite consumers to join:

- Appoint a team member or an appropriate staff person to develop a simple consumer advisory council application form, or use the Quality Improvement Advisory Council Application Form template (included at the end of this section).

- Inform potential participants of the practice’s intention to form/add consumers to the advisory council and ask if they would like to participate. Be as inclusive as possible. Participants should reflect the patient population and the community.

- Ask potential participants whether they have previously participated in an advisory board or worked collaboratively in a group. Consumers with this kind of experience may facilitate the process.

- Select consumers who are able to work well on a team, are comfortable sharing their views with others, and can offer and consider multiple perspectives.

- Be specific in stating to consumers exactly what you hope to gain from their perspectives, and allow them to openly voice their opinions on practice quality improvement.
Consider allowing consumer advisors to participate in trainings alongside staff on advisory board development and refining roles and objectives.

Encourage consumers to be active members of the board by offering opportunities to co-lead meetings or assume other active roles.

Be conscious of consumers’ time and availability. Set meeting times that will accommodate consumer participation. When possible, offer incentives.

Enthusiasm and motivation are indispensable in keeping consumers engaged in providing valuable perspectives and direction in practice transformation. Consumers must feel welcomed and at ease.

At your first meeting:

- Invite all participants to get to know one another. Run an icebreaker activity. Ask participants to suggest some ground rules.
- Invite participants to share their experiences with care received at the practice.
- Have an agenda, but be cautious not to dictate (template included at the end of this section).
- Prepare a list of questions for participants in regards to their views on quality improvement.
- Bring a list of possible topics for discussion (template included at the end of this section).
- Be conscious of how time is used. Allow plenty of opportunity for all to share their ideas and opinions.

There are many issues to consider for involving patients and families in quality improvement efforts. Advance preparation, with the aid of key internal stakeholders, is one of the most important steps in setting a solid foundation. Engaging in a novel experience such as this may be daunting, but committing to this worthwhile endeavor is important. Creativity will be an excellent tool for the staff involved to accommodate the needs of consumer advisors. Consumers undoubtedly will have much to offer to enrich the practice’s culture and procedures. Most important, as practices begin to transform and improve quality based on the needs of patients and families, this will enhance the consumer experience and lead to better health outcomes.
Quality Improvement Advisory Council
Consumer Application Form

Name: ________________________________________________________________________
Address: _____________________________________________________________________
Home phone: ______________________ Cell phone: ________________________________
E-mail address: ________________________________________________________________
Language preferred: ____________________________________________________________

Department you use most frequently:
(circle one)

Adult care

Pediatric care

Have you ever served as an advisor before? (If so, in what setting?)
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________

Would you be comfortable sharing your or your family’s experiences and opinions in health care with others?
______________________________________________________________________________
______________________________________________________________________________

Please specify what days and times would be most convenient for you to participate:
______________________________________________________________________________

List any topics you feel are important to improve the quality of the care you or your family receives at this office:
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________

Are there other patients/family members you would like to refer to the quality improvement advisory council? (If so, why do you believe they are a good candidate?)
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
Consumer Advisory Council Meeting

Agenda

Date:

1. Welcome – Introductions
   - Icebreaker activity (ex: Have patients talk about where they like to shop or a recent movie they have seen, or invite them to talk to their neighbor for three minutes and find out about their family and then introduce them.)

2. PCMH program update
   a. Consumer engagement activities
   b. Community engagement activities
   c. Experience with care
   d. Quality of care

3. New projects and opportunities

4. Discussion on the role of advisory board and role assignment

5. Recommendations from consumers and discussion

6. Announcements/Other
Developing Goals and Objectives for Meetings

Goal = WHAT you hope to accomplish. By the end of this meeting…

Example Goal
Participants will have shared their views and opinions on quality improvement activities that they feel will benefit consumer needs broadly.

Objectives = HOW you will reach this goal.

Example Objectives

Participants will:

1. Develop goals, objectives, and a realistic timeline to complete tasks, and identify who will be responsible for each task.

2. Discuss differing perspectives in regards to experience and quality of care provided at the practice.

3. Recommend strategies to enhance patients’ experience with care.

Provide continued feedback to practice staff as practice procedural changes are being applied.
Developing Goals and Objectives Worksheet

Topic: ___________________________________________________________

Time frame: ______________________________________________________

Goal:

__________________________________________________________________
__________________________________________________________________
__________________________________________________________________
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Objectives:

__________________________________________________________________
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### Meeting Timeline

<table>
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Consumer Advisory Council

Suggested Topics for Discussion:

1. **The role of consumers in quality improvement**

   **Questions for consumers:**

   - What do you envision as the role of patients and/or family members in improving the quality of care received at [insert practice name]?

   - What steps do you believe [insert practice name] should take to include patients and/or family members in quality improvement efforts?

   - In your opinion, how should [insert practice name] reach out to patients and/or family members to inform them of the opportunity to be involved in designing our quality improvement strategies?

   - In your opinion, what are some barriers that patients and/or families face that may prevent them from participating in quality improvement activities?

2. **Offering consumers opportunities to engage in quality improvement**

   - What kinds of activities, in your opinion, should [insert practice name] offer to patients and/or families to foster participation in quality improvement efforts (ex: advisory group, walkthroughs, surveys, focus groups, etc.)?

   - What is [insert practice name] doing to improve quality of care that you believe should continue?

   - What suggestions can you offer to the staff at [insert practice name] to improve the quality of care you receive here?
Consumer Experience Information to Guide Quality Improvement

When it comes to surveying your patient population, there is much to consider. One of the benefits of having an empaneled patient population is that you have a smaller group of potential participants to survey.

Before beginning a survey, preparation is essential. It is important to consider the demographics and capacity of your patient population to learn what is feasible and how a survey can be tailored to consumers’ needs and preferences. To find out what form of surveying is most appropriate to meet your consumers’ needs and preferences, the practice should involve them in the process. Whether you use a survey previously used in the office, adapt a new survey, or use one of the suggested surveys in this toolkit, consider your primary objective and what you hope to learn from the feedback.

NCQA, in their continued effort to foster a more robust patient-centered program in the PCMH 2011 standards, has called for patient survey results to help drive quality improvement. In 2012, NCQA will offer additional points based on practices’ results on the Medical Home version of the CAHPS Clinician and Group Survey. Keep in mind how the practice staff will use the information gathered from patient surveys to drive quality improvement. The American College of Physicians, through the Center for Practice Improvement and Innovation, has released the “Patient Satisfaction Tip Book: Improving Patient Perceptions.” Practices will find valuable guidance for making procedural adjustments based on consumer feedback.

How to Use:
The following is a survey guide with some important points for practice staff to consider and to help the team think about how to form and/or administer a survey. It is based on Methods in Behavioral Research (Cozby 2001).  

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Surveying for Quality Improvement

Define the research objective- The overall objective of collecting consumer experience results is to drive quality improvement. Carefully consider what questions to ask consumers, why, and how. Surveys can get out of hand when questions are asked about a topic without first thinking about how the information will be used to drive improvements.

Define your sample- In most surveys, asking some simple demographic information is necessary to adequately describe your sample. Other factual information that will be captured should be relevant to getting consumer views on practice quality improvement.

Question wording- If a practice is using an existing survey, this step does not apply unless it needs to be improved. If the practice is considering adapting an existing survey or developing a new one for the purpose of quality improvement, consider the following points:

- Questions should be simple. If the practice serves a large Limited English Proficiency (LEP) patient population, consider wording that can be easily translated so the survey can be understood.

- Avoid questions that ask multiple things at once (e.g., please tell us how difficult it is to make an appointment and get a lab result). Think about what exactly you want to know from each question and how you will use the information to tailor practice improvement.

- Phrase questions neutrally. Avoid questions that are biased toward one response over another (e.g., Isn’t it true that patients wait too long for an appointment?).

- Consider when and why to use open-ended or close-ended questions. Open-ended questions will give consumers the opportunity to respond freely based on their opinions. Close-ended questions limit the response. Close-ended questions can be true/false, yes/no, multiple choice, or answered using a scale.

Administering your survey

There are two ways to administer surveys:

1. A written questionnaire: Consumers will read the questions and write down their responses on the survey form. This can be done on paper or via the Internet.
2. An interview format: An interviewer asks the survey questions to consumers and marks the consumer responses down. This can be done either in person or by phone.

“The truth about patient satisfaction surveys is that they can help you identify ways of improving your practice. Ultimately, that translates into better care and happier patients. However, before you conduct your own patient satisfaction survey, make sure your practice is ready. First, work at cultivating an environment that embraces quality improvement.”17

A survey is a great tool to measure consumer experience with care delivery. It can guide the practice team toward finding solutions that are feasible, appropriate, and accommodating to patients’ and families’ needs.

Remember, conducting a survey only captures information at one point in time. Practices must continue to engage consumers. This will measure whether feedback-driven changes in procedures have yielded positive and sustainable results in patient experience. It is important that practices continue to compare information collected over time. This will serve to continuously drive quality improvement based on consumer feedback. Communicating to consumers about how their input will be used will validate their participation and demonstrate that the practice is following through on quality improvement based on patients’ and families’ needs and preferences. This communication can be done via a storyboard that is visible to patients, a patient newsletter sharing the results, or a thank-you note to participants.

Note:
A variety of surveys designed to measure patient satisfaction with care and quality of care are available for download on the state website under Patient-Centered Interactions Tools: http://pcmhi.ehs.state.ma.us/

The information on the following pages will also be helpful when considering which type of survey to use.

### Written questionnaire survey

<table>
<thead>
<tr>
<th>Method</th>
<th>Pros</th>
<th>Cons</th>
<th>What to Consider</th>
</tr>
</thead>
</table>
| Paper survey form | 1. Less costly  
  2. Can be anonymous  
  3. Can be administered to a captive audience, increasing likelihood of completion  
  4. Staff may be present to answer questions | 1. Consumer must be able to read and write  
  2. May be tedious  
  3. Consumers may lack motivation to complete | 1. Your sample patient populations' language and health literacy skills  
  2. Need to translate the survey  
  3. Who will administer the survey |
| Mail surveys    | 1. May be inexpensive way of contacting consumers selected for the survey  
  2. Provides opportunity for consumers to respond at their leisure | 1. High potential for low response rates  
  2. No immediate assistance if consumer has questions | Same as above, plus:  
  1. Staff time involved in mailing  
  2. Wait time for responses  
  3. Response rates |
| Internet survey | 1. Fairly easy to design/distribute using internet resources  
  2. Responses are immediately available | 1. Must decide how to sample consumers  
  2. Need to assess consumers' access and ability to use web-based surveys | Same as above, plus:  
  1. Appropriateness to patient population |

### Interview-based survey

<table>
<thead>
<tr>
<th>Method</th>
<th>Pros</th>
<th>Cons</th>
<th>What to Consider</th>
</tr>
</thead>
</table>
| Face-to-face interview | 1. Consumers are more likely to agree to participate  
  2. Response and completion rates tend to be higher  
  3. Interviewer or interpreter can clarify any misunderstandings | 1. Requires skilled interviewers  
  2. Interviewer bias  
  3. Interviewer expectations may lead to misreading of responses  
  4. Time consuming  
  5. Consumers may feel obligated to participate | 1. Which staff to assign to conduct interviews  
  2. When to conduct  
  3. How to ensure privacy and confidentiality  
  4. Who will analyze the responses  
  5. How to use the information gathered |
| Telephone interview | 1. Useful in large-scale surveying  
  2. Less expensive and time consuming  
  3. Quick to administer using computerized telephone survey | 1. Potential for low response rates  
  2. No immediate assistance if consumers require clarification | Same as above, plus:  
  1. How to include LEP consumers in your sample if appropriate |
| Focus group interview | 1. Captive participants  
  2. Many topics may be explored  
  3. Promotes in-depth discussion  
  4. Provides great deal of information | 1. May be costly  
  2. Time consuming  
  3. Requires skilled facilitators | Same as above, plus:  
  1. Who will conduct focus group  
  2. How often to conduct |
Focus groups are used in a number of settings due to their ability to generate in-depth discussion and provide access to consumer views and opinions. Consumer focus groups are useful when seeking information from low-literacy populations. They allow patients and families to engage in an open-ended discussion about their care, rather than responding to written questions. Regular consumer engagement, through regular participation in discussions that will drive quality improvement, will have a positive impact on consumer experience with care received in the PCMH.

**How to Use:**
What follows are some general principles to formulate a plan to conduct focus groups. Also included is a sample focus group kit that may be tailored to the needs of the practice.
Principles of Conducting Focus Groups

Select staff
- A focus group generally requires two facilitators. These should be staff with experience leading focus groups and who are knowledgeable about the topics that will be explored; in this case, the practice and quality improvement. With guidance, staff who have strong consumer relations skills and experience leading patient groups can be suitable facilitators.

Recruit participants
- Most focus groups have 8-10 participants. Participants should be recruited from a randomly selected list of empanelled patients. The group may consist of either a homogenous or a diverse sample group, depending on how the facilitators want to gather public opinion and how the results will be used. A homogenous group may view quality improvement issues in the same light, whereas a diverse set of participants may offer a wider range of perspectives and potential quality improvement procedural recommendations.

Set time and date
- Select a day and time that is most convenient for participants. It may be helpful to first offer some date and time options for consumers to choose from and then set a date according to their availability.

Choose a location
- Choose a location that is easily accessible to participants. The space should be comfortable and private so that discussions can be open. A conference room in the office may be a good choice. Ensure that the room is set up well in advance and enough time has been reserved for the location. Focus groups usually run from 90 minutes to two hours.

Notify participants
- Once the date, time, and location have been set, contact the consumers on your list of potential participants. A notice with all the information should be made available to participants once they agree to participate. Give yourself enough time before the actual meeting date in case some participants cancel and you need to reach out to others.

Prepare
- Although presented last, preparation is not the last step. Implementing a focus group requires substantial preparation work. Many steps are involved: questions to prepare, a script to develop, materials to gather, and consent forms to create. These steps and others that may arise require attention from facilitators and, potentially, other support staff.
Conducting focus groups requires time and attention as well as resources. When conducting focus groups with patients and/or family members whose primary language is not English interpreters may be needed. Incentives such as food/refreshments, gift cards, etc. are often used to encourage consumer participation.

Organizations may also bring in external consultants to conduct focus groups. Experienced consultants can provide the unbiased expertise required to run successful focus groups. They can also prepare the instruments and data analysis that will shine light on the next steps in quality improvement for the practice, thereby removing much of the burden from the practice staff. Depending on the size of your group and the facilitators’ own expertise conducting focus groups, the process can become costly and should be budgeted appropriately.

**How to Use:**
The following pages contain focus group preparation materials as templates that are adaptable to the needs of the practice.
YOU ARE INVITED
WE WANT TO HEAR FROM YOU!

Patients and Families Focus Group Opportunity

To reserve your space, contact:

[INSERT FACILITATORS’ CONTACT INFORMATION]

By: [INSERT DATE]

Please join us for a focus group discussion on how we can improve the quality of care you receive at [INSERT PRACTICE NAME]. Team members will facilitate a discussion to better understand your and/or your families’ needs. Together we can improve quality of care. Refreshments and a thank-you gift will be provided!
Focus Group Preparation Checklist

☐ List of participant names

☐ Gift certificates for participants

☐ Food & beverages order for delivery or pick up

☐ Paper plates, napkins, utensils, etc.

☐ Focus group script for facilitators

☐ Two notepads

☐ Name tags or table tents

☐ Pens for participant use

☐ Demographic survey

☐ Informed consent forms

☐ Markers for name tags and signs

☐ Paper to make signs for room

☐ Masking tape

☐ 2 audio recording devices, batteries, tapes (if necessary)
Consent Form

Thank you for choosing to participate in our focus group discussion.

The focus group discussion will last approximately 90 minutes and will be a discussion facilitated by the _____________________ staff. The topic is patient views and suggestions on how the practice can improve the quality of the care you and/or your family receive.

Any information obtained during the focus group discussion will remain confidential, and your name will not appear on the report or other related documents.

An audio recording of the focus group will be made and used only to document the important points mentioned during discussion. The audio recording will only be used in the development of our report; it will not be shared with other parties, and will be destroyed after the report is complete.

Your participation in this focus group discussion is completely voluntary, signing below indicates you understand this information and agree to participate.

____________________________________________________________________________
Name (Print)

____________________________________________________________________________
Signature

____________________________________________________________________________
Date

□ I am interested in learning how my feedback is being used to improve the quality of care in this office.
Private  Anonymous  Optional

Demographics Form

We are collecting information to learn more about consumers we serve. Your answers are anonymous and confidential. All categories are optional. Thank you for your participation. (Adapt as needed for practice use.)

City you live in: ______________________

How long have you or your family been patients at this office: __________

Gender:
□ Female
□ Male
□ ________________________________

Sexual Orientation:
□ Bisexual
□ Gay
□ Heterosexual
□ Lesbian
□ ________________________________

Age:
□ Under 20
□ 20 – 29
□ 30 – 39
□ 40 – 49
□ 50 – 59
□ Over 60

Country of birth: ________________

If other than US, number of years living in the US: ________

Race/Ethnicity (select all that apply):
□ American Indian or Alaskan Native
□ Asian or other Pacific Islander
□ Black or African American
□ Hispanic or Latino
□ White
□ Other: ________________________________

Language(s) spoken (select all that apply):
□ Arabic
□ Cape Verdean Creole
□ Chinese
□ English
□ Haitian Creole
□ Mon-Khmer, Cambodian
□ Portuguese
□ Russian
□ Spanish
□ Vietnamese
□ Other: ________________________________

Level of education (highest attained):
□ Certificate
Training:___________________________
□ Some high school
□ High school / GED
□ Some college
□ 2-year college degree (Associates)
□ 4-year college degree (BA, BS)
□ Master’s/Doctoral/Professional degree
□ Other: ________________________________
Focus Group Discussion Guide

Introduction:

- Thank participants for their interest and for agreeing to participate.
- Introduce yourself and other facilitator/s.
- Present rationale, goal, and objectives of the focus group meeting.
- Build rapport with participants.

Getting started:

- Review consent form, highlighting confidentiality and anonymity.
- Explain the reason for voice recorders.
- Remind participants that participation is voluntary.
- Review demographic form, explain reasoning for collecting the data.
- Clarify in detail how the group discussion is going to be conducted.
- Urge all participants to share their experiences and suggestions.

Warm-up questions (15 minutes):

- Pose opening question, allowing each participant an opportunity to respond.
- Pose introductory question that will help participants begin to think about the topic.
- Raise a transition question that will get participants to consider the topic more deeply.

Main questions (65 minutes):

- One by one, present 5-6 key questions and/or concepts regarding quality improvement that you would like to explore.
- Allow time for each participant to share their views and opinions.
- Permit participants to openly discuss; the facilitators’ role here is simply to ask the questions and moderate the discussion.
- Be sure to include some debriefing and wrap-up questions. If participants have not provided suggestions for quality improvement, wrap-up questions may generate a list of potential next steps to consider.

Closing:

- Thank participants for comments and suggestions.
- Remind participants that identifying information will not be included in report.
- Inform participants about what the practice intends to do with the information/recommendations.
- Provide facilitators’ contact information in case participants have any questions or comments subsequent to the focus group.
Things to remember:

- Promote a relaxed atmosphere.
- Be flexible when possible.
- Address those who tend to dominate discussions.
- Be attentive of conflicting views that may lead to arguments, and be proactive in steering the focus back to the topic if this occurs.
Focus Group Sample Questions

Opening Question:

1. How long have you and/or your family members been patients at this medical practice?

Introductory Questions:

2. What has been your or your family members’ experience with the quality of care you have received?

3. What would you tell a friend about the quality of care you receive at this medical office?

Transition Questions:

4. Are there any positive experiences with the quality of care you receive at this medical office?

5. Are there any negative experiences with the quality of care you receive at this medical office that you can share?

6. What would it take for this medical office to meet patients’ standards of good quality?

Key Questions:

7. What do you need to know about this medical office to be able to recommend strategies for making it better for you, your family, and/or friends?

8. If you were in charge, what kind of changes would you make in the medical office to improve things?

9. If you could change one thing to improve the quality of care you receive here, what would you change?

Closing Questions:

10. All things being considered, what is the reason for that one change?

11. What are some other ways that you think office staff should get patients’ and/or families’ opinions and recommendations to improve the quality of care?

12. What things have we missed in the discussion today that you would like to include?
References


Area Health Education Center of Southeastern Massachusetts. (2010). Massachusetts patient-centered medical home initiative: consumer engagement project focus group report. Brockton, MA


Merrimack Valley Area Health Education Center. (2010). Massachusetts patient-centered medical home initiative: Consumer engagement project focus group report. Lawrence, MA


**Resources**

**Agency for Healthcare Research and Quality:**
A branch in the U.S. Department of Health & Human Services whose mission is to advance excellence in health care delivery. [http://www.pcmh.ahrq.gov/portal/server.pt/community/pcmh__home/1483/what_is_pcmh](http://www.pcmh.ahrq.gov/portal/server.pt/community/pcmh__home/1483/what_is_pcmh)

**American Academy of Family Physicians:**
One of the largest national medical organizations, representing more than 100,300 family physicians, family medicine residents and medical students nationwide. Its mission has been to preserve and promote the science and art of family medicine and to ensure high-quality, cost-effective health care for patients of all ages. [http://www.aafp.org/online/en/home/membership/initiatives/pcmh.html](http://www.aafp.org/online/en/home/membership/initiatives/pcmh.html)

**Center for Advancing Health:**
CFAH conducts research, communicates findings and advocates for policies that support everyone’s ability to benefit from advances in health science. [www.cfaah.org](http://www.cfaah.org)

**Consumers Advancing Patient Safety:**
Consumer-led nonprofit organization formed to be a collective voice for individuals, families and healers who wish to prevent harm in healthcare encounters through partnership and collaboration. [http://patientsafety.org/](http://patientsafety.org/)

**Center for Medical Home Improvement:**
Organization dedicated to helping community-based, primary care practices and networks to transform. The mission of CMHI is to promote high quality primary care in the medical home and secure the health policy changes critical to the future of primary care. Website contains links to guides and surveys that practices may find helpful. [http://medicalhomeimprovement.org/index.html](http://medicalhomeimprovement.org/index.html)

**Center for Practice Improvement & Innovation:**

**Health Affairs:**
One of the leading journals of health policy thought and research. Publishes many valuable and insightful articles on practice transition to the PCMH. [http://www.healthaffairs.org/](http://www.healthaffairs.org/)

**Institute for Healthcare Improvement:**
Aims to improve the lives of patients, the health of communities, and the joy of the health care workforce by focusing on an ambitious set of goals adapted from the Institute of

Institute for Patient and Family-Centered Care:
Nonprofit organization that strives to provide essential leadership to advance the understanding and practice of patient and family-centered care.  http://www.ipfcc.org/

Institute of Medicine:
Independent, nonprofit organization that works outside of government to provide unbiased and authoritative advice to decision makers and the public.  http://www.iom.edu/Global/Topics/Quality-Patient-Safety.aspx

National Center for Medical Home Implementation:
This resource is for health professionals, families, and anyone interested in creating a medical home for all children and youth. Helpful guides and issues to consider in implementation are also presented.  http://www.medicalhomeinfo.org/

National Patient Safety Foundation:
Independent nonprofit whose mission is to improve the safety of care provided to patients. As a central voice for patient safety, NPSF is committed to a collaborative, inclusive, multi-stakeholder approach in all that it does.  http://npsf.org/

Patient-Centered Primary Care Collaborative (PCPCC): Center for Consumer Engagement
A branch of the PCPCC that strives to ensure the medical home model is truly patient-centered by facilitating consumer involvement and leadership in the design and evaluation of the PCMH; strengthening the consumer voice in the PCPCC; and developing a set of “best practices” for consumer engagement in PCMH.  http://www.pcpcc.net/center-consumer-engagement

Safety Net Medical Home Initiative:
A collaboration between Commonwealth Fund, Qualis Health and the MacColl Institute for Healthcare Innovation at the Group Health Research Institute, to help safety net primary care clinics become high-performing patient-centered medical homes (PCMHs) and achieve benchmark levels of quality, efficiency, and patient experience. The initiative has published many helpful guides that practices may find helpful in their transformation into a PCMH.  http://qhmedicalhome.org/safety-net/

The CAHPS Improvement Guide Practical Strategies for Improving the Patient Care Experience - Improvement Interventions:
Sponsored by (AHRQ) the Consumer Assessment of Healthcare Providers and Systems (CAHPS) program develops and supports the use of a comprehensive and evolving family of standardized surveys that ask consumers and patients to report on and evaluate their experiences with health care. These surveys cover topics that are important to consumers, such as the communication skills of providers and the accessibility of services.  http://cahps.ahrq.gov/qiguide/default.aspx