Quality Counts

Patient Centered Medical Home Discussion Groups

Executive Summary

February 2009

Recruitment, analysis, and support costs for this project were made possible by grant funding from the Maine Health Access Foundation.

Background and Introduction

The Medical Home Concept

One of the leading advocates of the Patient Centered Medical Home (PCMH) concept is the Patient Centered Primary Care Collaborative (PCPCC). The PCPCC explains that although the term "Patient Centered Medical Home" was coined in 2005[1], it has its roots in other initiatives. The American Academy of Pediatrics (AAP) introduced the medical home concept in 1967, initially referring to a central location for archiving a child's medical record. In its 2002 policy statement, the AAP expanded the medical home concept to include these operational characteristics: accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective care.

The American Academy of Family Physicians (AAFP) and the American College of Physicians (ACP) have since developed their own models for improving patient care called the "medical home" (AAFP, 2004) or "advanced medical home" (ACP, 2006).

The PCPCC was created in late 2006, when the American College of Physicians, the Academy of Family Physicians, and other primary care physician groups were approached by several large national employers with the objectives of 1) facilitating improvements in patient-physician relations, and 2) creating a more effective and efficient model of health care delivery.

Maine Patient Centered Medical Home Pilot Research

Maine has been active and engaged in PCMH efforts for some time through the work of Quality Counts, the Maine Health Management Coalition, and others. In late 2008 these organizations and the Maine Health Access Foundation provided funding to further develop the concept in Maine.[2]

An important element of the PCMH effort in Maine is to engage more patients and consumers in concept development, leadership, and implementation. As part of this effort, Quality Counts asked Crescendo Consulting Group to conduct formative research about the PCMH concept in Maine through as series of four discussion groups. The Maine People's Alliance (MPA) was also engaged as a partner in the effort. The MPA provided the facilities and performed the recruiting for three of the four groups (Bangor, Lewiston, and Portland).

As part of this project, a deliberate effort was made to solicit the opinions of MaineCare clients and the uninsured. To help accomplish this, Crescendo partnered with the Offices of MaineCare Services (Maine Medicaid), who recruited and hosted the fourth group (Augusta). This group consisted of 8 MaineCare members, ranging in age from 25 to 65+. Additionally, The MPA was successful in recruiting several individuals without health insurance.

This summary includes discussion highlights from the four groups and is based upon general consensus from those groups, as well as specific comments related to individual concerns or observations. Although Crescendo's formative research for this project uses two quantitative rating

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[1] In 2005 IBM began to question the very foundation of the health care it buys, and reached a significant conclusion: when compared to other industrialized countries, U.S. health care fails to deliver comprehensive primary care because of the way primary care is financed. Primary care is the only entity charged with the longitudinal care of the whole patient, and it is the primary care relationship that has the most profound effect on health care outcomes. The idea was shaped further when the term 'patient centered medical home' was coined and took root with a number of large employers and primary care physician organizations. For more information see: http://www.pcpcc.net/content/about-collaborative

[2] For more information see: http://www.mainequalitycounts.org/library/2009-6154321840.pdf

methods, the results should not be construed as projectable to an entire population, but rather indicative of the opinions of the distinct groups. In a number of instances the qualitative comments echo those that have been voiced in other qualitative and quantitative research across the United States.

Composition of Discussion Groups

The MPA and MaineCare used a common screener guide for recruiting participants to ensure participants were Maine residents over 18 years of age who were not health care clinicians. Demographic information – while not used as screening criteria – was also collected to gain a better understanding of the groups' composition.

All but one participant stated that they currently have a primary care provider. The geographic diversity of the groups helped ensure that the opinions reflect over 20 primary care practices across the state.

Group	Participants	Male	Female	Age > 25	Age 25-44	Age 45-65	Age 65+	Caucasian	African American
Lewiston	11	7	4	1	5	5	0	8	3
Portland	10	4	6	1	3	4	2	10	0
Bangor	5	4	1	1	1	2	1	5	0
Augusta	8	2	6	0	2	5	1	8	0
Total	34	17	17	3	11	16	4	31	3

Some participants were frequent users of the health care system and others only modest or infrequent users. Everyone had enough experience in the primary care setting to be able to view the information and provide knowledgeable observations.

Health status and insurance provider are two additional characteristics that affected responses to some discussion items. Although participants were not asked to disclose information of this nature, many participants shared this information throughout the course of conversations. In the discussions, approximately ten individuals disclosed that they have a chronic health condition. It is estimated that at least nine are MaineCare members and three to four participants do not have health coverage at all.

Patient Centered Medical Home Patient Discussions

Working Hypotheses and Structure of the Discussion Guides

The working hypotheses for this research are that the PCMH is a partnership between patient and medical home providers and that a PCMH would feature some or all of the standards featured in the NCQA designation for a PCMH.

The PCMH partnership, in the words of the Center for the Advancement of Health, recognizes "that patients are not the object of care, but are rather that they are full-fledged participants in it – and that unless that participation is active and informed, the impact of health care, whether services, drugs, surgery or devices, is severely muted. People who are unable to seek care when they need it, who don't fill their prescriptions, who delay their colonoscopies indefinitely or who keep smoking – regardless of the reason – place their own health at risk, waste human and material resources and incur unnecessary expense to themselves and others." [3]

The NCQA suggests that "the Patient Centered Medical Home is a health care setting that facilitates partnerships between individual patients, and their personal physicians, and when appropriate, the patient's family." There are nine Standard areas in the NCQA PCMH[4] designation including: Access and Communication, Patient Self-management Support, Care Management, Patient Tracking and Registry Functions, Advanced Electronic Communications, Performance Reporting and Improvement, Referral Tracking, Test Tracking, and Electronic Prescribing.

To test the working hypotheses regarding partnership and standards, Crescendo developed a discussion guide that asked participants to utilize two evaluation forms, in addition to answering open-ended questions. The two rating forms were modeled after the NCQA PCMH standards; a list of ten (10) sets of patient and clinician behaviors described in the recent document from the Center for the Advancement of Health: *Supporting Patient Engagement in the Patient-Centered Medical Home*[5], and the work of the Institute for Family Centered Care[6].

The rating forms were used in the research: 1) to identify the extent to which the participants' provider offices were currently structured as a medical home, 2) to self-assess the patients' own behaviors in regard to the care partnership, and 3) to invite a discussion about where these activities overlap and where patients and providers might begin the most fruitful discussions about improvements. The discussion guide and the two questionnaires can be found in the Appendix.

To benefit the non-native speakers and those with modest reading abilities, the moderator took care to carefully read each statement on the questionnaires so as to ensure that everyone understood the intent of the questions. Each question was then discussed as a group and the relationship between the two lists were evaluated. The use of the questionnaires was not so much to develop quantitative measures amid a qualitative process - although that did occur to some degree - but to help the participants understand each other's experience in a relative way and to narrow the list of areas around which there is the most energy for change.

The four groups identified several areas in which providers and patients can begin fruitful work in developing the kind of partnership envisioned by the PCMH. There was also a great deal of energy around specific topics and consensus on many of the issues. The major themes are outlined in the following sections.

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[3] http://www.cfah.org
[4] http://www.ncqa.org/tabid/631/Default.aspx
[5] http://www.cfah.org/pdfs/PACT%20White%20Paper%20120708.pdf
[6] http://www.familycenteredcare.org/tools/downloads.html

Impressions of Provider Offices

As might be expected, there was variance both within and among the various groups regarding the experiences in the provider office. Aside from a small contingency that clearly did not have positive relationships with their primary care providers, participants generally hold their primary care provider in high regard. There was also consensus on a number of key issues. It is also worth noting that, in general, the differences in opinions within the MaineCare and uninsured populations were unremarkable. Areas of difference are noted when relevant.

Participants consistently identify three areas as needing the most improvement: being provided with treatment options[7], tracking performance between office visits[8], and receiving information about community resources.[9]

On the five-point scale used in the rating forms, more than half of the participants rated their providers' office as a one or two in providing treatment options. Supporting comments include:

- "My doctor only tells me what she thinks is best and I don't know the difference."
- "My PCP generally doesn't know; he just refers me to a specialist."
- "My doctor focuses on his own agenda. He looks at me as symptoms and not as a person. He will not listen."
- "My doctor insists that I'm diabetic and I'm not. I don't even know what the tests for diabetes are."
- "The doctor always wants me to do things his way and I would like to discuss how I think my care progresses."
- "Unless you know enough to say 'what about this?' they're not going to discuss any options with you."

Very few participants overall said that their doctor's office ever tracks their progress between visits, and those in the groups found this to be a large gap in the services they receive. Some said that if there was something particularly serious going on that they may hear from the office, but typically they do not. In many cases, participants feel this lack of communication is problematic.

- "The doctor's office should do a follow up call after a visit. When you only see someone yearly, a call in a month or so to see how everything is going would be good."
- "I can't ever get the doctor on the phone between visits, and it's hit or miss whether someone else in the office ever calls me back."

As part of this discussion, many participants expressed specific concern about not being able to get test results in a timely fashion.

- "If I have a test I just have to assume that everything's OK."
- "It's understood that no news is good news. I think that's a bad idea. Doctors' offices should make sure that everyone gets a follow up. This is a huge gap in care."
- "I think a lot of unnecessary care happens because people don't get test results."
- "My doctor sent a letter to tell me I had diabetes. I never received it and he never called to follow up." (person later found out he did not have diabetes)

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[7] Crescendo Consulting Group, Provider Office Experience Checklist, Question 8, "The doctor asks for your ideas about different choices for treatment"

[8] Ibid, Question 12, "The doctor tracks your progress between visits."

[9] Ibid, Question 5, Your doctors' office encourages you to go to programs in the community that might help you"

Those that do have contact with the doctor's office between visits say that it is usually in the form of a phone call or a letter. Only one participant currently says she has the option of e-mailing her doctor with questions between visits.

In general, participants did not understand the value of the provider recommending community resources.

Additionally, many did not understand what types of programs they might be encouraged to use. Some felt that this was not relevant to them because they do not have a chronic health condition. Other participants rated their provider's office as performing well in this area because they could find brochures and posters in waiting room areas.

Participants say they are satisfied with how quickly they are seen once they arrive for an appointment[10], the extent to which providers listen to their concerns[11], and the steps taken to ensure that next steps in the care plan are understood[12].

While many participants stated that there is often a lengthy amount of time in the examination room before they see the doctor, they at least see a nurse or other member of the health care team in a relatively short amount of time.

The primary care provider creates a "halo effect" with respect to listening to concerns and making sure that the patient understands the next steps in his or her care plan. In other words, those that were generally satisfied with their individual provider seemed to be more satisfied with their provider's office in these areas. *These responses suggest the need to better promote the team concept and the need for patients to recognize that care is also delivered by the non-physicians in the team.*

There was a small, but vocal, contingency that feel that their providers' office performed poorly in these last two areas. Again, they tended to be individuals who were not satisfied with the care they received from the office in general.[13]

Consistent with other research, participants consistently identified communication and relationship issues as being of primary importance.

Several of the items on the provider office checklist relate to how well the participant interacts with his or her provider. When asked to identify which of the items on the checklist were most important, participants most commonly stated that the provider listening to concerns and understanding treatment options were critical for them.

Several participants currently go to practices at which they do not see the same provider consistently. In all cases, participants stated that this had a negative impact on their perception of the practice, because they could not build a relationship with one provider. The groups generally feel that the lack of relationship leads to lesser quality care, a decreased likelihood to follow treatment plans, and poorer outcomes in general. *These responses suggest that building a relationship with a patient must be a team activity and that the office cannot rely on the physician alone to create a sense of rapport. This may also suggest the need for a PCMH delivery paradigm in which each participant can select a Primary Care Provider among the providers available within their PCMH practice to provide some assurance of consistency of care.*

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[10] Ibid, Question 2, "When you go to an appointment you see the doctor within 15 minutes."
[11] Ibid, Question 3, "The doctor listens to your concerns."
[12] Ibid, Question 3, "The doctor* makes sure you understand everything."
[13] There are some pilots underway nationwide designed to measure the patient experience see: http://www.cahps.ahrq.gov/content/community/Events/files/T-3-CG_Robert-Krughoff.pdf

Access and the office's ability to coordinate care were also identified as important.

Participants clearly recognized the need to have coordinated care, and cited issues in communication not only between different provider offices, but even within their own primary care practices.

- "The left hand doesn't know what the right hand is doing at my doctors' office – no one talks to each other."

This underscores the need to foster relationships between the patient and multiple members of the health care team while simultaneously emphasizing the role of the primary provider. Although the patient may be seen by and interact with a variety of providers within a PCMH office, consistently reinforcing that their primary provider is overseeing all aspects of their care will provide reassurance that the PCMH is a positive and collaborative environment in which patients can put their trust.

Both access to specialists and the coordination of care between specialists and their primary care providers were important issues to MaineCare members and the uninsured.

- "My doctor tried to send me to some big heart specialist, but I don't have insurance and I can't afford that."
- "It's really hard to find a specialist because a lot of them don't take MaineCare. My doctor doesn't seem to realize that when he refers me."
- "When I am able to find a specialist, it seems like I have a really hard time to get the specialist to send information to my regular doctor."

Opportunities exist to educate patients on the importance of other aspects of quality primary care, such as computerized medical records or recommending community resources.

While important, these components of the PCMH lagged behind patients' ratings of the other elements. *There will need to be additional emphasis on these areas in future PCMH communications.*

As mentioned above, participants generally did not see the connection between managing their health and utilizing community resources. With respect to electronic medical records, many were familiar with the term, but some were not. Among those who currently go to a practice that utilizes EMR systems, many expressed concern that it *negatively* impacted the quality of care.

- "My doctor's office seems to think that the computer system replaces the need for a physical exam."
- "I'm not sure what the benefit is…my doctor seems really frustrated with the system they use."

Self-evaluation of Patient Behaviors

In the second half of the focus group discussions, participants were given the patient self-assessment questionnaire and asked to evaluate and discuss their own behaviors in regard to their interaction with primary care. Overall, consumers understand the importance of being involved in their own care.

- "It's a necessity. I'll become invisible if I don't stand up for myself."
- "I get better healthcare now than I did a few years ago. And that's not because health care has gotten any better – it's because I'm now more assertive."

Participants generally rated themselves highly on showing up on time for appointments[14] (and bringing relevant information[15]) and asking questions until they understand[16].

Many feel that they need to be persistent to compensate for the fact that the provider is busy and may not take the time to explain things thoroughly on his/her own.

- "I go with a list and I always get answers. Sometimes when they see the list they ask me to only talk about the most important ones, but they almost always end up answering all of them."
- "Whenever I go to the doctor it seems like his hand is on the doorknob the whole time."
- "The 'doctor hand on the doorknob' scene where there is simply very little, if any, real communication realized by the patient and provider sitting together seems to be a familiar one."

Participants also feel that they do a good job of communicating with their primary care doctor when they see other providers[17].

This again underscores their perceived need to have coordinated care. Participants were most acutely aware of the necessity of coordination – and more likely to get involved – when it concerned prescription medications. For example:

- "When I see a specialist I always bring a list of the medicines I'm taking and ask them to send a fax to my regular doctor if they prescribe a new drug."
- "No one checks to make sure about the side effects, which can be significant."

The participants' self-assessment suggest that patients need to improve on: following their own care plan[18], asking for more information about treatments and tests[19], and bringing a list of questions and concerns to every visit[20].

Participants commonly said their reluctance to ask questions, specifically about treatments, were due to a perceived lack of time or a discomfort with the subject matter.

- "It's a matter of time, but also my capacity for understanding."
- "I don't know what treatment options are available so it's hard for me to question my doctor about this."

For many participants, their inability to follow their care plan has to do with their own "motivation" or

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[14] Crescendo Consulting Group Active and Engaged Patient Checklist, Question 1, "Arrive on time for appointments"
[15] Ibid Question 2, "Bring information about medications and insurance, etc. to every visit."
[16] Ibid Question 5, "Ask questions about explanations or next steps until you understand"
[17] Ibid Question 4, "Tell the doctor* when you get care elsewhere and give permission for your information to be shared"
[18] Ibid Question 9, "Follow your care plan and track progress (e.g. weight loss, blood sugar, blood pressure, etc.)
[19] Ibid Question 6, "Ask how different treatments and tests may affect you."
[20] Ibid Question 3, "Bring a list of questions and concerns to every visit

ability to change their behavior. There was, however, a contingency, particularly those who are uninsured or insured by MaineCare, who feel that they would be more successful if they were asked for their thoughts and opinions in developing the course of action.

- "There has to be a way to agree on a way to treat things. The collaboration piece is critical."

Participants also feel that their ability to follow through with a care plan would be easier if the provider's office and/or insurance plan offered more support.

- "Every patient's care plan should include a 'reality check' to identify any barriers such as access, transportation, or cost. This might help the provider and the patient develop a care plan together based on the patient's ability to follow through."

The perceived lack of support from the current health care system in following through on a care plan is most acutely experienced by MaineCare members or those who are uninsured. These participants frequently expressed that their providers "blamed" them when they did not execute on their care plans. Some feel that their doctor infers that they "don't care enough to follow through", when, in fact, these consumers feel that they do not have the ability to adhere to the provider's recommendations.

- "It would really help if MaineCare would cover gym memberships."
- "I try to eat healthy, but that food is so expensive."
- "I can't afford to do some of the things my doctor asks me to do."
- "I don't want to make excuses, but I have three kids and my husband has a health problem. I have the best intentions, but sometimes I just can't do it. I don't think my doctor understands that."

Examples of support that could be offered including having a nutritionist on site that could help develop meal plans on a budget, health plans covering gym memberships, or even simply a mechanism to facilitate communication between visits. *The comments in this regard indicated a need to address the disconnect between the participants' desire for this support and their relatively low rating of "referrals to community resources."*

Areas of Synergy and Partnership Development

At the end of the discussion, the groups reviewed the two questionnaires in tandem to identify where there were overlaps in the respective response areas.

Participants are generally able to see that a true partnership between patients and providers will require effort by both groups and that there is a need to foster further dialogue.

Interestingly enough, the areas identified as most in need of improvement for both providers and patients have to do with improving communications between patients and providers. *From the patient's perspective, successfully developing a dialogue between providers and patients would be the most critical component becoming a patient centered medical home.* The notion of fostering a dialogue creates subsequent challenges around care delivery, but it reinforces the literature in terms of the need for team-based care.

When comparing the checklists side by side, participants quickly noticed the areas in which their experience at the provider office affected their behavior as a patient and vice versa. For example, participants who feel their provider's office needs improvement in making sure next steps are understood also rated themselves highly in being persistent in asking questions.

Another area of synergy involves understanding treatments/tests and shared decision making. Participants generally feel their provider's office could improve in asking for patients' input and in explaining risks and benefits of treatments and tests. Participants also feel that they need to improve in asking about treatments and tests.

Participants have mixed opinions as to whether their provider's office supported them in completing the tasks on patient list.

Some feel that their physician's office absolutely wanted them to be involved; others experience negativity when they do.

- "I find that my doctor gets pretty indignant when I actually do any research to become educated on my condition."
- "I'm not encouraged to bring a list."

For the most part, participants also feel that their provider would evaluate their behaviors similarly using the patient assessment tool.

Participants are sympathetic to today's primary care challenges and excited by the PCMH.

Many participants are sympathetic to the challenges faced by today's primary care providers, but most feel that the system needs change. One participant said it is unrealistic for the physician to know all about the patient's life when most primary care doctors have to see 30 patients a day, at least four days a week, throughout most of the year.

When the concept of the PCMH was introduced, the participants were initially surprised that the patient could be the center of care experience. However, it did not take them long to begin to visualize the concept.

Participants identify three areas where the PCMH could make a big difference: reinventing the payment system, improving access, and changing the philosophy of health care delivery.

The consumers in these groups clearly identified a problem with the health care payment system. In general, they feel that there needs to be a shift in how services are reimbursed.

- "Physicians should be paid more for prevention."
- "Medicare should pay for more than one visit a year."
- "We need to cut out the insurance company."
- "The reimbursement system needs to be re-negotiated, or, even better, the system should be disconnected from money entirely."
- "The system seems backwards. Doctors only get paid when people get sick so they have no incentive to keep people healthy."
- "The philosophy of health care needs to change – it should not be profit driven."
- "There needs to be more of a focus on primary care in the healthcare system."

Access was also identified as an important issue in all of the groups. Many participants, regardless of insurance type, expressed frustration at how difficult it is to find a primary care doctor at all. *Limited access to providers was of particular importance to those without insurance or insured by MaineCare.*

- "It took me forever to find a doctor. It took months and I still only get to see the PA."
- "I've lived all over the United States and I was very surprised when I moved here. I couldn't believe how hard it was to find a doctor."
- I have a doctor now but he's about 30 minutes away, which is really hard with all the problems I have. I wish I could find a doctor closer, but I'm not allowed to switch because I'm already on this doctor's register and no other doctor will take me. I'm afraid to take myself off his list because then I run the risk of not finding a doctor at all."

- "I've been trying to get my daughter in a [pediatric] practice for years. Unless you know somebody or have a family member who already goes there you cannot get in."

Lastly, consumers identified a need to change the way care is delivered. *Specifically, they desire a system that puts the patient in the driver's seat and removes the barriers that restrict time with providers.*

- "I always get the feeling I'm on a schedule. I bring a list and when they see it they start to rush through it. Who's controlling the clock? It should be me."
- "How could they ever learn enough about me as an individual and manage to make a living?"
- "It seems like the clock is running the visit, not my care needs."
- "We are not embracing that patients need to be involved. We need to shift the priorities. Patients are paying the bill but they've forgotten that. The system is profit-driven and not patient-centered."
- "Patients need to know how much time they have bought. Not knowing completely dis-empowers us as patients. You should know how much time you've purchased and insist on getting that time."
- "Someone needs to look at the huge administrative burden."

Opportunities/Next Steps

The Maine PCMH discussion groups highlight several opportunities for improved engagement between providers and patients in the development of the PCMH Pilot.

- Foster a dialogue between providers and patients as the first important action in becoming a patient centered medical home. This does not need to occur within the context of the care visit.
- Help patients improve on: following their own care plan, asking for more information about treatments and tests, and bringing a list of questions and concerns to every visit.
- Determine how to build a relationship with individual patients as a team in the provider office. Recognize that the office cannot rely on the physician (or care managers) alone to create a sense of rapport.
- Promote the team concept with patients and let them know that they are the center of this team. Communicate that the team environment will lead to an increased coordination in care and help patients understand how care is being delivered by the non-physicians on the team. Focus communication efforts on assuaging the patient's biggest fear: that care is disjointed, inferior, and/or limited when more than one person (physician) is involved.
- Build communications about PCMH that reinforce that the PCMH will: reinvent the payment system in a positive way, allow for more time with their providers, improve access, and change the philosophy of health care delivery.
- Provide tools and referrals to community resources that can more fully support activated behaviors.
- Use the substantial body of knowledge about informed decision making to address both the patients' trepidation around asking questions about treatments and tests and the physicians' reluctance to allow patients to determine their own course of care.

APPENDIX

Introduction

- Hello, I'm Beth Austin from Crescendo Consulting Group, in Portland.

- You have been invited to participate in a discussion about primary care services. In the conversation today, we'll be asking for your thoughts about the experience you have at the doctor's office and the things that both you and the doctor's office can do to improve the experience.

- Just so we're all on the same page, "primary care services" refer to the experience or services you get from your primary care provider. You may also refer to this person as your "personal doctor" or "PCP". It's the place where you go for your routine healthcare needs.

- Crescendo is assisting several organizations who are working together to improve the quality of care you receive from primary care providers including the Maine Health Access Foundation and Quality Counts. As part of this work, a new primary care model called the patient-centered medical home will be piloted here in Maine early next year. Your feedback here will help us shape the new model.

- We are seeking your honest opinions. There are no right or wrong answers, nor are we seeking consensus or trying to promote a particular point of view. I'd like to hear from each of you. I'd like to hear your opinions – whether they are positive or negative - as they are all important in helping us improve the value of healthcare in Maine.

- The discussion is scheduled to go until 7:00. I will make sure that you are out on time, but to do that I will need to keep us moving so that we have time to talk about all the topics I mentioned earlier. There may be a time when I need to cut a discussion short and "parking lot" the topic for future discussion so that we can keep to the time. Don't interpret this to mean that your opinion is not important.

- I will be using a recording device for the session this evening just for future reference. Please be aware that your comments will be confidential and will not be attributed to you personally in the summary report.

- Are there any questions before we begin?

- To begin with, I'd like to go around the table and ask everyone to introduce themselves and tell us little bit about your experience with primary care. Where do you go for primary care? How many times have you been to your primary care provider in the last 12 months?

Discussion

To start, please look at the paper I'm handing out now called "Provider Office Experience" (see attached). On this piece of paper is a list of things that you happen at a typical doctor's visit. I will read through this list with you and ask you to rate your primary care office in each of the areas on a scale of 1-5, where five means that your doctor or doctor's office does an "excellent" job in this area and a one means that it needs improvement. Remember that we are talking only about your experience with your primary care provider or your personal doctor. This does not include specialists or emergency room visits, etc. As I read each item, please tell me if you don't understand or if it is not clear to you.

(Read through list and allow time for participants to record their thoughts.)

Q1-11: Now that we've all had a chance to fill this out, let's go through each of these items and discuss them a little bit. Starting with number one, could I see a show of hands – who rated this as a 5? *(count hands)* How about 3? *(count hands)* How about 1? *(count hands)* What do you think could happen to improve your experience in this area?

(Go through each item on the list and probe as necessary. On #1, ask what they consider to be a reasonable amount of time; on questions 6-12 ask whether they usually interact with the doctor or someone else on the care team.)

Q12: Thank you. Now, please go through and circle the two or three items that are most important to you.

(Allow time to do this)

What features did people circle as being most important?
PROBE: Why is this important?

Q13. Are there any features that you don't find important?

(Hand out patient check list)

Q14. Now I'm handing out another list. This one is called "Active and Engaged Patient Checklist." On this list, you will find things that patients can do to be more involved with their health and help get better care. I'd like you to think about how well you do in these areas on a scale of 1-5. For example, let's look at number 1. If you always arrive on time for an appointment, you should give yourself a 5. If you do sometimes, then you should give yourself a 3 or 4. If you rarely or never do, then you should give yourself a 2 or a 1. I'll read through the list and you can score yourself.

Q15. Please take a look at how you scored yourself. In which areas did you give yourself a 4 or 5?

Q16. In what areas do you need the most improvement?

PROBE (only if necessary): If your doctor were filling this out about you, would she or he have given you the same marks? How would it be different?

Q17. Does your doctor's office support you in doing the items on this list? What do you think your doctor's office could do to help you do better in these areas?

Q18. Which of these items do you think is most important for patients to be doing?

Q19. Now looking at the two lists together, what areas seem to have the most overlap?

Q20. If you could improve just one of these areas, what would it be?

That concludes our discussion. Thank you so much for your time and input. Before you leave, please check out the table up front. We've got some materials that you may find helpful for your doctor's visits. There's also a place where you can sign up to get more information or to get involved in other projects like these.

Provider Office Experience

Think about your experience at your primary care office and rate each of the following on a scale from 1 to 5. Remember, this is only about your experience with primary care. (1= needs improvement; 5= excellent)

	RATING				
1. You can make an appointment and be seen in a reasonable amount of time	1	2	3	4	5
2. When you go to an appointment you see the doctor within 15 minutes.	1	2	3	4	5
3. The doctor listens to your concerns	1	2	3	4	5
4. The office has electronic (computerized) medical records	1	2	3	4	5
5. Your doctors' office encourages you to go to programs in the community that might help you	1	2	3	4	5
6. The doctor (or someone else in the office)* makes sure you understand everything	1	2	3	4	5
7. The doctor* talks to you about the purpose, benefits, and risks of treatments and tests	1	2	3	4	5
8. The doctor* asks for your ideas about different choices for treatment	1	2	3	4	5
9. The doctor* recommends places to find more information on topics that are important to you	1	2	3	4	5
10. The doctor* coordinates your care with your other providers (such as specialists) in an organized way	1	2	3	4	5
11. The doctor* explains medications to you and talks about side effects	1	2	3	4	5
12. The doctor* tracks your progress between visits	1	2	3	4	5

* A nurse, a physicians' assistant, or someone else on the care team may do this instead of your doctor.

Active and Engaged Patient Checklist

The list below includes things that patients can do to be more involved in their own health and healthcare. Please rate yourself on each of the following on a scale from 1 to 5. (1= needs improvement; 5= excellent)

1.	Arrive on time for appointments	1	2	3	4	5
2.	Bring information about medications and insurance, etc. to every visit	1	2	3	4	5
3.	Bring a list of questions and concerns to every visit	1	2	3	4	5
4.	Tell the doctor* when you get care elsewhere and give permission for your information to be shared	1	2	3	4	5
5.	Ask questions about explanations or next steps until you understand	1	2	3	4	5
6.	Ask how different treatments and tests may affect you	1	2	3	4	5
7.	Tell the doctor* when you have concerns even if he or she does not ask	1	2	3	4	5
8.	Understand what your medications are for and take them exactly as the doctor prescribed	1	2	3	4	5
9.	Follow your care plan and track progress (e.g. weight loss, blood sugar, blood pressure, etc.)	1	2	3	4	5

*You might also talk to a nurse, physicians' assistant, or someone else on your care team