Improving the Patient Experience:

Developing a Patient/Family Advisory Group

A Focused Professional Paper

Submitted in partial fulfillment of the requirements of ACMPE Fellowship

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Title: Improving the Patient Experience: Developing a Patient/Family Advisory Group

I. Introduction:

As the health care environment evolves, the primary care clinic faces increased pressure from various sources such as decreased funding, more quality initiatives from government and health plans, value-based contracting and greater consumer demands. Health plans are now tying payments to providers for quality improvement measures, improved customer service and patient care. This forces the primary care clinic to look to new models for delivering medical services, improved customer service and patient care.

In 2007, all the major physician associations developed and endorsed the Joint Principles of the Patient-Centered Medical Home. The definition of a Medical Home is a patient-centered philosophy that drives primary care excellence. A true Medical Home is a model of primary care that is patient-centered, comprehensive, team-based, coordinated, and accessible and focused on quality and safety. The model was further defined by the Agency for Health Care Research and Quality (AHRQ) as a patient-centered partnership between practitioners, patients and their families that ensures decisions respect the patients wants, needs and preferences and that patients and families have the education and support they need to make decisions and participate in their plan of care.

To meet the challenges of this model, many primary care clinics have attempted to establish a partnership between the medical practice, the patients and their families through the development of a Patient/Family Advisory Group. This advisory group, consisting of patients, families, physicians and medical staff, can serve as a mechanism to review the services, programming and policies of the clinic. The ideal group would meet regularly and work collaboratively to bring about positive changes in the overall patient experience and in ways in which the primary care clinic delivers services and care.

II. Background:

This paper is a focused paper. The purpose of this paper is to identify the importance of developing and sustaining a Patient/Family Advisory Group. It will provide detailed instructions on how to establish such
a group as well as acknowledging the barriers and monitoring the relevance with ongoing quality improvement.

Data has been derived from resource review, patient survey tools and over two years of actual practical experiences.

III. Getting Started:

a. Leadership Buy-In

Probably the most critical aspect of establishing a patient/family advisory group is the strength of leadership buy-in. It is the real key to an effective program. Without the interest and support of the physicians and clinic leadership, the group cannot survive. The biggest challenge the clinic leadership faced in introducing this kind of initiative was engaging the entire leadership team. All sides were skeptical, because as health care professionals, “we know what is best for the patient”. Initial meetings were held to affirm organizational values, issues to be addressed and how clinic leadership could be involved. Each leader was given a role to assist in developing the group. They found that much of their skepticism was based on individual patient and family complaints and the fear of being told how to run their clinic. There was also a concern that as a pediatric clinic, families might try to push their own agendas such as those who do not believe in vaccinations for children. To address these issues, they set about to involve all the leadership in designing a program for the clinic’s specific needs. The leadership team established the ground rules, created roles, wrote a charter, assisted with recruitment, suggested topics for the advisory group to study and volunteered to mentor, train and participate in upcoming advisory group meetings. The leadership team met weekly for eight weeks to establish goals for the advisory group, to create a budget and discuss a timeline. By the end of the eight week period, the leadership team was engaged, enthusiastic and ready to move forward.

b. Budget
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Establishing a budget for this group was also critical. The leadership team decided that if they were going to ask patients and families to volunteer their time, they should receive both recognition and reward for their efforts. The decision was made that luncheon meetings were best for physician and staff involvement. A budget was established to include monthly luncheons, notebooks and pens for each advisory group member, clinic tee-shirts for each member, a group photograph and an annual all-clinic recognition dinner with awards. The team decided that they would base the budget on one year. The budget would be reviewed monthly and any adjustments would be discussed with the Clinic Manager and the Medical Director. It became apparent to the leadership team that a monetary investment was necessary to ensure the success of the group. The advisory group was also granted permission to decide, as a group, if additional monies were needed and to prepare a statement for the Clinic Manager and the Medical Director for review.

c. Group Charter (Appendix 1)

Another important aspect for all participants was the establishment of the “ground-rules”. A decision was made by the leadership team to develop a Group Charter. The leadership team wanted the advisory group to feel valued but they also wanted their work to be both relevant and meaningful. The charter combined the mission, principles, objectives and values of the clinic which the leadership team felt could easily be adopted by the advisory group. It was critical to the leadership team that all parties were working for the good of all the patients that were being served. They felt that by establishing these ideals in the beginning, all parties would be working together towards the same goals and objectives. By starting the advisory group on the path the clinic had established, the leadership team believed that the direction to the advisory group would be clear.

d. Recruitment (Appendix 2)

Recruitment was a challenge. It began with a survey which was mailed out to all families and patients. The survey introduced the idea of a group and solicited any interest. Those who responded with interest
were asked to provide their contact information. It was also decided at the leadership team level that the entire clinic would participate in recruitment. All clinic staff and physicians were trained on the why and how of recruiting. Staff and physicians were introduced to recruiting materials and asked to role play on how to refer the patients and families to the program. They were taught not only to explain about the advisory group but to demonstrate how the advisory group fit in the entire Medical Home philosophy. It became a very good time to refresh the entire clinic staff’s memory about what the Medical Home is and why the clinic chose to participate in a Medical Home program. It was also a good time for the Clinic Manager to review the Medical Home standards with all staff and physicians. This led to several all staff meeting discussions about Medical Home, the concept and the requirements. The staff, including the physicians, not only became recruiters but Medical Home ambassadors. Physicians especially, were asked to look for families and patients they felt would be a good fit for the advisory group. Many patients and families volunteered because their primary care physician told them they would be a wonderful candidate for the advisory group. Any patient or family member was encouraged to complete an interest card. The interest cards were routed to the Clinic Manager and the Medical Director for review.

e. Group Composition

It was decided that the initial advisory group would consist of fourteen members:

- Seven family members or patients (over the age of 16 years) from a broad spectrum of the practice.
- Seven clinic staff members including a physician liaison and the clinical psychologist.
- Voting would be a simple majority of those present.
- Each member could serve a three year term to assure continuity for a maximum for six years.
- After one year off, members would be eligible for re- membership.
- Three year terms were to be rotated to ensure overlap of members.
- Meetings would occur monthly.
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- Minutes would be taken at every meeting and a copy given to all members no less than one week before the next meeting.
- A member could resign at any time by submitting a written letter to the advisory group.
- A member may be asked to resign for failure to abide by the Group Charter or the roles and responsibilities of the group.

f. Application and Interview Process (Appendix 3)

All interest cards with an indication of interest received a phone call and an invitation to complete an application. The leadership team felt that the more seriously they took this process, the more seriously patients and families would take the process. Once an application was received, a face to face interview was scheduled with the Clinic Manager and staff volunteers. These interview meetings stressed the importance of the advisory group, the commitment of time, and the willingness to openly share while respecting the rights of others. It was important for the leadership team to know why these people wanted to volunteer. It was also important for these volunteers to understand the goals and make-up of the group. At the end of the interview process, seven candidates were selected who the interviewers felt shared the vision of a patient/family/clinic partnership. The clinic also had a waiting list of six other candidates as alternates who were also willing to serve and would have fit the criteria.

g. Roles and Responsibilities of the Advisory Group Members (Appendix 4)

Chosen advisory group members were expected to sign a letter of commitment (Roles and Responsibility Agreement) which included the expectations of each member. Members were expected to:

- Respect confidentiality at all times.
- Demonstrate a commitment to the advisory group.
- Be accountable to those they represent,
- Attend regularly scheduled meetings and annual events.
- Serve on a subcommittee, if asked.
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- Share personal stories, experiences, observations and opinions with the group.
- To reach out and listen to other patients, parents and families as well as the staff of the clinic and community members.
- Be committed to improving care for all patients and families.
- Respect the collaborative process and the forum to discuss ideas.
- Be willing to listen to and consider different points of view, share ideas for improvement and encourage others to do the same.
- To share both positive and negative experiences in a constructive way.

Clinic staff members were expected to:

- Attend the meetings and make time to implement initiatives between meetings.

Clinic leadership was expected to:

- Support and manage the group partnership
- Help ensure the group activities were relevant, meaningful and were integrated into the changes and improvements within the clinic.

Additional staff and subject matter experts would be invited to advisory group meetings to obtain feedback from the group on related issues, provide input or to educate advisory group members on specific topics as needed.

h. Commitment

It was important to the leadership team that this new group understood the importance of commitment. The team did not want patients/ families and staff to begin discussion of an issue and then have the majority of the group missing from the next discussion. Each new member and staff member was asked to sign a Roles and Responsibility Agreement form. This form represented not only a commitment to the group but a commitment to follow through on important issues with the group as a team member. This
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was considered by some to be a very formal process. The leadership team felt the more formal the process, the more importance it conveyed.

\[i. \text{ Orientation(Appendix 5)}\]

Orientation was a luncheon meeting where the candidates came together to meet the Clinic Manager and each team member for the first time. The Clinic Manager delivered a presentation which included:

- Introduction to Clinic Leadership.
- History of the Clinic.
- A Medical Home Overview.
- Expectations of Members (Roles and Responsibilities).
- Advisory Participant Questionnaire.
- What Members Can Expect From the Clinic.
- An Explanation of HIPAA.
- Confidentiality Form.
- Contact Information and Meeting Information (Times, Places, Attendees, What to Expect at the First Meeting, etc.).
- Notebooks/Pens and Tee-Shirts for each Participant.
- Menu for Luncheon for the First Meeting.

\[j. \text{ Confidentiality(Appendix 5)}\]

The importance of confidentiality was emphasized in great detail. New advisory group members were not only given a presentation regarding HIPAA in the orientation but asked to sign a confidentiality form to again reinforce the idea of being within a medical clinic where patient health information may be
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accidentally seen or heard. Staff and physicians were also re-trained on the importance of keeping patient health information in strictest confidence while advisory group members were present within the clinic. The biggest areas of vulnerability such as computer screens, tablets, facsimile and copy machines were particularly targeted.

k. Contact and Meetings

In establishing a group, it was extremely important to keep open lines of communication. Minutes needed to be sent to all group members immediately following the meetings. It was equally important to send out regular messages to the group in between meetings. Weekly reminders or current information on a topic being discussed was essential to keep everyone on track. The need for an additional meeting, a subcommittee meeting or to engage speakers or trainers were also topics for current and up-to-date communication. Answers to questions brought up during meetings or articles of relevance could also be sent before meetings.

The way in which each person needed to be communicated with had to be clearly established. Since the majority of the group used e-mail, this was chosen as the main means of communication. One family did not have a home computer, however, so correspondence sent through the United States Postal Service was the best method for them. The importance of establishing the means of communication cannot be over emphasized in keeping an advisory group cohesive.

l. The First Meeting

The first meeting began with introductions and each member telling why they wanted to be a part of this group. After lunch, the group participated in a “get-acquainted” type game facilitated by the clinical psychologist. The next discussion was a lesson on how to brainstorm ideas to identify issues and discuss them without rushing to solutions. This led to training and handouts on Plan-Do-Study-Act (PDSA) cycles and how to use this method for problem resolution. The group ended the meeting by practicing brainstorming and identifying some areas for discussion in upcoming meetings. The group was able to
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identify several areas for discussion in the coming months. These ideas were recorded on a white board along with a PDSA cycle chart example, rules for brainstorming and the general meeting rules established by the group. Most of the patients and families had never used brainstorming or PDSA cycle methods before and actually enjoyed learning how problems were solved by the group in the clinic. Several members reported later that they had applied some of the ideas from the first meeting to issues in their own personal lives.

Meetings to follow discussed the role and purpose of the group, identified more areas to study, practiced brainstorming and the use of PDSA cycles to address problem issues.

IV. Running a Successful Group

a. Establishing a Group Coordinator

It became apparent after the orientation that much of the responsibility for the group would fall on the Clinic Manager. This was clearly a problem for an already busy and involved position. It was decided by the leadership team that the responsibilities would be shared among all the leadership team. A Patient/Family Advisory Coordinator position was created with a job description that could be shared, but, depending on the future of the group, may result in a part-time position at a later date.

b. The Role of the Coordinator (Appendix 6)

The Coordinator would be the liaison between the group and the clinic leadership as well as the community both inside and outside the clinic. He or she would be responsible for overall support, management and accountability of the group. He or she would keep everyone informed, continue open lines of communication and would be in contact with patients and family members in between meetings. This person would support the members of the group and help ensure the group’s activities were
meaningfully integrated into changes and improvements within the clinic. He or she would also be the lead contact for others within the clinic or from the community seeking to be included on the agenda.

\[c. \text{ Establishing the Role and Purpose of the Group}\]

It became apparent after the first meeting, the group needed to meet again to discuss in depth the role and the purpose of the group. While the group was eager to jump into the problem solving mode, it clearly needed to review the Group Charter to look at why they were assembled and what they wanted their role and purpose to be. Were they problem identifiers, problem solvers, monitors or were they in their role as advisors? How could they work together with the staff and physicians to bring about positive change(s) for both the people who came to the clinic as well as the people who worked at the clinic? What was their role in the community both inside and outside of the clinic setting? While the group wrestled with these issues for several meetings, it also became clear that their role was all of the above. They needed to identify problems or concerns, study the problems and assist the staff in determining a solution. They did also need to develop some kind of “quality control” so that once a positive solution was found and everyone was trained, the issue would not occur again in the same way. The group also needed to be the “voice” of the patient and families. The group determined that, ultimately, they were advisors to assist the staff and physicians to understand the overall patient/family experience and to help them to improve it. The clinic clearly needed to see things from a patient/family perspective. The group also felt it was their responsibility to represent the patients and families who came to the clinic on a regular basis as well as to assist new patients and families in the transition from new patient to established patient. This ultimately helped all the staff and physicians to understand what patients and families believed was “good customer service” from the voice of the customer.

\[d. \text{ Identifying Potential Barriers}\]

Barriers to running a successful group came from several sources:
Solid leadership needed to be in place to keep the group on task and make sure that solutions do not come before all other steps. The group needed to be reminded to allow everyone to voice an opinion. Clinicians and staff needed to be reminded that they were there to collaborate and listen. As a group, they needed to look at, why the clinic does things the way they do. Is it efficient, cost effective, customer friendly? Some of the greatest ideas came from the most unlikely sources.

Time was another issue. A lively discussion could go on much longer than time permitted. The group often had to table the discussion and come back to it at the next meeting. As discussions became more meaningful, the group had a tendency to want to linger. Side conversations were not allowed. Minutes were critical in keeping the momentum going. Those taking minutes were rotated so that they were not a meeting participant during their minute-taking duties, and nothing that was discussed was lost the group.

Fear of Change was always a concern. Old habits were being replaced with listening, experimenting, studying, reviewing, retrying. The clinic was beginning to move to looking at all policies, workflows, marketing, forms, services, and changes through the eyes of the group. The clinic was a long established clinic with many physicians and staff with long tenure. Why change things that had worked for so long? What is the incentive? Was just being a good Medical Home enough? What worked for the clinic was to survey the entire group of patients and families to determine if changes were noticed and perceived as positive or negative. The changes were in fact noticed and actually making a positive difference in how the patients and families perceived the clinic. This was the turning point for the group. It was also interesting to note many more families and patients were now volunteering to be a part of the group.

e. Learning to Brainstorm

The advisory group began practicing the brainstorming techniques to find conclusions for specifically identified problems. It started with the gathering of ideas spontaneously given during a group session.
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These ideas were recorded and then ultimately the group would work to determine solution(s) to the problems. As the group progressed, this technique became too simplistic. The need for a more complex way to study the issues was needed.

\( f. \) Plan-Do-Study-Act (PDSA) Cycles

The group learned that using a Plan-Do-Study-Act (PDSA) cycle made their job easier. The work was better organized and everyone in the group, not only participated in all aspects, but participated in the success. The questions the group were asked to consider were: What are we trying to accomplish? How will we know that a change is an improvement? What change(s) can we make that will result in improvement? When the team generated a list of ideas for changes they used the PDSA cycle approach to test change. A change was then first implemented on a small scale to see if the change resulted in an improvement. The change was then gradually expanded to move to a larger sample, for example, until the change could be more widely adapted.

\( g. \) Timeline

It took the clinic approximately three months to write and develop the program. It took another two months to recruit and orient the group. At the time of this writing, the formal advisory group has been in existence for over two years. Training and learning is ongoing. Currently the ideas for topics, issues, projects, and quality measures will take the group into 2016 and beyond. More and more families and patients are asking to be a part of the group. Discussions with the advisory group and the clinic leadership team are about adding additional members in 2016.

\( h. \) Awards and Appreciation

New advisory group members were given clinic tee-shirts, notebooks and pens. Lunch was provided at every meeting. At the end of each year, an all-clinic appreciation dinner was held. Gift cards and certificates were awarded to all participants of the advisory group and clinic staff members who supported the group. The Clinic Manager and the Medical Director gave specific awards for the following:
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- Most Enthusiastic Members(s).
- Most Dedicated Member(s).
- Best Mediator.
- Best Recruiter.
- Best Team Player.
- Best Champion.

While this program does cost the clinic some additional monies, all the clinic team leadership felt that the benefits far outweighed the costs.

V. Outreach
   a. Reaching out to Other Patients and Families

As the group progressed and other staff, families and patients started to notice their progress, the group elected to look beyond the boundaries of the meetings and to work to involve the clinic community in a more tangible way. A formal photograph was taken of the advisory group and was placed on the clinic website and in the clinic lobby. Patients and families were invited to share thoughts and ideas with their advisory group. The clinic established a workflow so that patients and families could contact the advisory group members through the Acting Coordinator. The Coordinator would review the messages to make sure that they were appropriate for the group. If it was regarding a medical issue, it was routed to the Medical Director first. If it was an office issue such as a complaint about a staff member or a billing issue, it was routed to the Clinic Manager first. An example of a complaint that was routed to the advisory group first was wait times in the exam rooms. The advisory group studied the issue, looked at clinic work flows, reviewed the scheduling, talked to department heads and staff and was able to make recommendations that led to some permanent, positive solutions. As patients and families started to notice the changes and the advisory group began to gain more confidence in the work they were producing, the clinic community wanted to know more about what we were doing. The group decided to start advertising their successes.
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through social media and on the clinic website through monthly reports. The group also produced a short “who we are and what we are doing” presentation for the educational monitor in the clinic lobby.

b. Website and Social Media Presence

As the group became more active, it became important to connect to patients and families in the clinic-community. The clinic website was redesigned to house information about the group. This included individual pictures and autobiographies of group members, individual stories about why the member joined the group and what each member enjoyed about being a part of this group. It also included areas the group had identified to work on and solicited ideas from patients and families. Patients and families were encouraged to get involved by writing to the group through the website. In addition, members of the advisory group began writing about their experiences in the group and with the clinic on social media. Since everyone on the group grew to care about the clinic, their positive impressions and experiences were invaluable for new patients and families who were looking to join the clinic. It also helped existing patients and families to feel that they were represented by people just like them, who understood their issues, feelings and needs.

c. Marketing

The advisory group became by default, a wonderful marketing tool for the clinic. The members of the group were very proud of their participation and more than willing to share their experiences in clinic brochures, fliers and on the informational monitor in the lobby. The group felt it was important for everyone to know who they were, what they were doing and how important the work that they were doing was to enhance the patient experience.

d. Community Outreach

The Clinic Manager, the Clinic Medical Director and the Advisory Group members were invited to speak at a local health care conference and were also interviewed by the local newspaper as being a unique opportunity for patient/family and clinic collaboration. Advisory Group members also volunteered with
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staff and physicians to attend the local “Baby Festival” and “Children’s Health Fair” to encourage families and patients to get involved with their clinics and educate them on how primary care clinics can work as a successful Medical Home.

e. Additional Focus Groups

One of the areas of interest for the advisory group was new mothers. While there were not any new mother volunteers at that point in the group, all members in the group recognized how difficult it was for new mothers to find resources for parenting, to connect with experienced mothers and even to find a pediatrician. Often new mothers in our community were away from their families and needed support systems. The advisory group invited a group of new and expectant mothers to a defined focus group to answer questions, have open discussions and to express their opinions regarding issues facing new mothers, finding a pediatrician and gleaning support and resources. Members of the advisory group hosted a luncheon meeting, gathered resource information, invited a pediatrician to speak, developed questions to define the issues and helped moderate the group. Fifteen new and expectant mothers attended and information was gathered for use in assisting others in the community in similar situations. The information from the focus group was shared with other families in the clinic and on the website to a broader audience. More focus groups on various topics are planned for later dates such as mothers with children with autism and mothers with children who have chronic illnesses.

VI. Quality Measures

a. Characteristics of a Quality Program

Once the group became used to using brainstorming and PDSA cycles, the next step was to introduce root cause analysis and a more formal quality program. The group had come to the realization that the work they were doing was improving the quality of the services in the clinic and enhancing the patient/family experience. The issue then was how to monitor and maintain the work while continuously improving it. It
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also became apparent that the group needed to establish a quality baseline for each project and a goal for improving that baseline.

b. Root Cause Analysis

The group was trained on using root cause analysis as a method of problem solving to hone in on the root of the problem or issue. This was a more satisfactory and more organized method of coming to a solution. Once the issue was identified, the group then divided into “study groups”. Each “study group” was assigned a task. An example was the study of what it is like to be a new patient at the clinic. One group looked at scheduling, another new patient paperwork, the new patient brochure, and the new patient welcome packet. A third group posed as new patients and actually went through the process of being a new patient. Once problem areas were identified, the group then completed a root cause analysis to discover why these problems existed. It became easier for the group then to identify solutions and make creative suggestions for change.

c. Developing a Baseline for Performance Improvement

Measurement tools helped the team to determine if the changes being implemented were leading to improvement. An example of such a change was establishing a patient safety program. The first step was to appoint a clinic patient safety champion. This champion would conduct a regularly scheduled patient safety walk-around to identify potential issues. The champion also assisted the Clinic Manager in organizing and conducting safety trainings and in creating safety awareness with the staff. The advisory group assisted the champion in developing a patient safety reporting system and an adverse event response protocol. The process was then measured to see if the program did result in an improvement in patient safety. The group found that measurement was critical for implementing changes. It served as the barometer that allowed the team to know if the change was actually leading to improvement.

Another area that the team learned to focus on was basic Lean Principles:

- Specify value in the eye of the customer.
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- Identify value streams (optimum value to the customer).
- Make value flow at the pull of the customer.
- Involve and empower the employees.
- Continuously improve in the pursuit of perfection.

An example was the study by the group on wait times in the lobby. They identified the potential causes as: lack of training of the staff, poor supervisory skills (staff or physicians), ineffective scheduling, and lack of workplace organization.

The questions to study were: What is actually happening in the clinic? What does the workflow look like? Who is doing the work? Is the work necessary?

This led them to the root causes:

- Ineffective scheduling (overbooking patients for fear of patients who might not present for their appointment and not taking into account patients who arrive early and those who arrive late).
- Poor workflow (Medical Assistants not checking to see that a patient was waiting).
- Not enough help during peak times (poor staff scheduling, not staggering lunch times, break times, not staffing to the number of physicians in clinic or to the number of patients scheduled on a given day).
- Lack of follow through by staff (again, not regularly checking the schedule, not checking back with patients when the physician was running late, not reminding the physician when he or she was running behind).

The group then worked to draft a plan for improvement.

\[ d. \text{ How to Develop an Action Plan} \]

The group worked through the following process to develop a plan for improvement:

- **Identified the need for possible corrective action(s).** For example: several patient complaints regarding long wait times in the lobby.
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- **Gathered Data.** For example: information gathered from the electronic medical record practice system on the time a patient was checked into the clinic to the time he or she entered the exam room. Patients were interviewed regarding wait times.

- **Analyzed Data.** For example: root cause analysis. Why is this happening? How often? Identify possible reasons.

- **Identified the possible corrective actions.** For example: changes in staffing patterns and levels, staff re-training, improved workflow and improved scheduling patterns, better patient reminders.

- **Screened/experimented to select the best action(s).** For example: implemented one change, improved scheduling patterns.

- **Implemented action(s).** For example: implemented all corrective actions.

- **Verified action(s).** For example: checked to see if wait times had any improvement. Does the plan need re-work?

- **Sustained improvement.** For example: Review changes in 3 months with champion. Are the changes still in effect? Are the changes effective? Do they need rework?

The guiding principles were:

- Customer first.

- Go out and see the issue or problem for yourself.

- Give feedback to team members.

- Focus on true condition vs. apparent condition.

- Work towards total involvement by the clinic team rather than individual involvement.

- Management needs to: assist with problem solving, be supportive, make sure there is training in place, recognize and give rewards when appropriate and always promote teamwork.

  - **e. How to Standardize the Process to Monitor Continuous Improvement**

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The group determined that at least quarterly they needed to take the time to review the progress of every change they had implemented. The group developed a process of including the appointment of a champion whenever they implemented a change. It was then the responsibility of the champion to report back to the group on the current progress of the change. In the case of the wait times in the lobby, the action plan was working and effective and did not require re-work.

The group also developed a phrase to be attached to every written communication reviewed by the group: (“Reviewed and Approved by the Patient/Family Advisory Group”). This gave staff, patients and families the option to comment to the group on areas they felt needed to be re-addressed on any communication containing that phrase.

VII. Achievements

In the end, the advisory group was able to work collaboratively with both clinic staff and leadership. The Clinic Manager, Medical Director and the Clinic Leadership Team came to rely on this group to provide input in all areas of the clinic. The Clinic Community came to look to the advisory group as their voice. It would be hard to imagine the clinic functioning again without the benefit of this kind of group. Some of the areas that were improved with the collaboration of this group were:

- Shorter wait times in the exam rooms and the lobby.
- More efficient handling of new patients.
- More efficient patient-centered forms.
- Improved access for patients with improved workflows and scheduling.
- More welcoming clinic/lobby/cleaner better organized clinic.
- Improved patient-centered marketing.
- Improved patient-centered educational materials.
- Overall improved customer service.

VIII. Conclusion:
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In conclusion, the goal was to establish a collaborative group of patients, families, physicians and staff to bring the patient / family perspective into the design and evaluation of the primary care clinic’s processes, services, environment, equipment, and patient communication. This group was to serve to ensure that all care delivered was patient-centered and to bring patient/family concerns to staff and physician leadership. The aim was also to ensure that the clinic provided an environment that promoted trust, respect, equality and fairness while improving the patient satisfaction and experience. It also was to serve to build a strong, positive relationship between the medical practice and the community it serves.

In reviewing the progress of the group for the past two years, it would appear that the goal established was achieved. The Patient/Family Advisory Group is now an integral part of the clinic structure. Staff, physicians and management have come to rely heavily on the talent from this group to recommend and advise on all major clinic decisions and issues. The benefits from establishing a group have far outweighed anyone’s fears and reservations. The group has been beneficial in improving the patient experience as evidenced by the most recent patient/family surveys. The many complements from outside and inside the clinic as well as the many requests for information on how to establish a group, is further demonstration of how valuable a tool this group has become. A Patient/Family Advisory Group is the essence of a Patient-Centered Medical Home. It is a true example of collaboration. It gives patients and families a voice in the care being delivered, the education and support being received and ensures that decisions being made respect the wants, needs and preferences of the patient.
IX. Appendices

Appendix 1

PATIENT/ FAMILY ADVISORY GROUP CHARTER

The Patient / Family Advisory Group are an autonomous, self-governed entity with the support and guidance of __________________________.

Mission:

The Patient/ Family Advisory Group will enhance the patient and family experience in interactions with the healthcare team at __________________________. It will integrate that patient and family perspective into the planning, delivery, and assessment of healthcare at __________________________.

Guiding Principles:

Patients and families feel cared for during their entire experience at __________________________. Each patient and family is unique with diverse needs; not solely a “medical condition” to be treated.

Each healthcare staff member is a caregiver whose role and responsibility is to meet the needs of each patient and family, while maximizing patients’ opportunities for choices and respecting those choices.

Patient and families are engaged as partners and collaborators in every step of care.

The work of the Patient /Family Advisory Group will be to apply “best practices” in a way that is measurable in order to ensure that their impact on the patient and family experience is positive.

Coordinated and continuous care leads to a positive patient experience and outcomes.

Objectives:

The Patient/ Family Advisory Group:

- Ensures the healthcare team provides optimal patient experience.
- Maximizes patient opportunities and resources.
- Ensures that patients and parents are engaged in healthcare decisions.
- Assists in making the clinic welcoming and inviting to patients and families, ensuring a pleasant and comfortable experience for patients and families.
- Ensures that the clinic will be viewed in the community as demonstrating “best practices” and as a healthcare resource.
Appendix 1

PATIENT/FAMILY ADVISORY GROUP CHARTER

Values:

The Patient/Family Advisory Group support the following:

**Dignity and Respect:** The clinic listens to and honors patient and family perspectives and choices. Patient and family knowledge, values, beliefs, and cultural backgrounds are incorporated into care planning and decision-making.

**Information Sharing:** The clinic shares and communicates complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete, and accurate information in order to effectively participate in care and decision-making.

**Participation:** Patients and families are encouraged and supported in participating in care and decision-making at a level that they choose.

**Collaboration:** Parents, patients, families, and healthcare providers collaborate in policy and program development, implementation and assessment, and in facility design and education.
PATIENT AND FAMILIES WANTED!

Our goal at __________________ is to bring the patient and family perspective into everything we do!

We are currently seeking individuals who are interested in partnering with us to improve the patient experience by sharing ideas, providing feedback, and working as a team.

If you would like more information about how to become an Advisor, please visit our website at _________________.

- You may also ask one of our staff members.
- OR… Complete the back side of this card and turn it into the Front Desk, and we will contact you with more information.
Title: Improving the Patient Experience: Developing a Patient/Family Advisory Group
Appendix 2

Patient/ Family Advisory Group

INTEREST CARD

Date: ______________________________________________
Name: ______________________________________________
Email: ______________________________________________
Phone #: ____________________________________________
Best time to contact you: ______________________________

Please leave the completed card with a representative at the Front Desk.

Thank you!
Appendix 2

WANT TO BE A PIONEER? - FLYER

________________________ is seeking individuals to be a part of a Patient/Family Advisory Group.

What is a Patient/Family Advisory Group?

A group of 12-14 people, including patients, parents, caregivers, and family members, who meet every month to promote improved relationships between those receiving care and clinic staff. The group will provide a way for parents/families to review or create office policies and programs, and open the lines of communication with clinic staff to address how __________________ can better serve the needs of patients and families.

A Patient/Family Advisor Candidate would be expected to:

- Commit to a 3-year term.
- Attend 75% of all meetings.
- Be able to listen to different opinions and share different points of view.
- Respect ideas of others.
- Speak comfortably in a group.
- Get along with many different kinds of people.
- Work as part of a team.

MAKE A DIFFERENCE!

Join our team and help us improve the patient experience for patients, parents, and families.

IF YOU WOULD LIKE TO BE ON THE PATIENT/FAMILY ADVISORY GROUP, OR REQUEST MORE DETAILS, PLEASE GIVE YOUR NAME AND CONTACT INFORMATION TO THE RECEPTIONIST OR MEDICAL ASSISTANT.
Dear [Patient/Parent Name],

You have indicated that you would be interested in becoming a part of our Patient/Family Advisory Group. I’d like to take a moment to let you know a little more information about this group if you are still interested.

The purpose of the Patient/Family Advisory Group is to advise clinic administration and medical leadership on patient needs and primary care priorities from a parent/family perspective. The intent is to influence primary care strategic planning and improve office processes.

The group will consist of 14 members, 7 patients/family members and 7 diverse members from ____________________________ staff, both office and clinical.

Our next meeting is scheduled for [Day of Week], [Date] from 5:30-7:30 pm. Meetings will be held every month at an agreed upon date. Additional meetings may be required as deemed appropriate. Each meeting will be 2 hours in length and refreshments will be served during the meeting.

We would like you to become a part of this group. Is this something you would be willing to commit to? ☐ Yes ☐ No

Is there an email address we could send a confirmation to in regards to meetings, and any information that may be needed prior to the meetings?

Email: ________________________________

If no email address, can we mail information to your home? ☐ Yes ☐ No

Thank you for your time,

Name of Person_________
Title_________________
Name of Practice_______
Appendix 3

FREQUENTLY ASKED QUESTIONS

What is the purpose of Patient/Family Advisors?

- To offer a safe venue to provide input in a setting where they are receiving care.
- To promote improved relationships between parents, families, patients, and staff.
- To open lines of communication between patients, parents, families, and staff.
- To offer an opportunity for patients, parents, and families to provide input into policy and program development and actively participate in the development of new programs and services.

What is a Patient/Family Advisor?

Someone who:

- Volunteers their time to work with a healthcare organization to share their insights, thoughts, and opinions about what works and doesn’t work for people receiving services.
- Can provide fresh insights on what it's like to receive services from the healthcare system.
- Can not only bring ideas but the thoughts and ideas of others.

What do Patient/Family Advisors do?

- Bring diverse ideas and experiences to conversations about ways to improve healthcare programs, policies, services, communication, and tools.
- Talk about and help others talk about ideas so that ______________________________ can provide better healthcare.
- Work together with ______________________________ staff and physicians in planning programs.
- Think beyond what happened to them or their family members to help others have an improved experience.

What qualifications or qualities does an Advisor need?

- Share insights and experiences in ways that others can learn from.
- See beyond his or her personal experiences.
Title: Improving the Patient Experience: Developing a Patient/Family Advisory Group

- Show concern for more than one issue or agenda.
- Respect diversity and differing opinions and perspectives.
- Listen well.
- Speak comfortably in a group with candor.
- Enjoy working with others on solutions.
Appendix 3
PATIENT/ FAMILY ADVISOR APPLICATION

Date: ______________________________

Name: _____________________________ Email: _________________________________

Address: __________________________ City: __________ State: ___ Zip: _____

Home Phone: _______________________ Cell Phone: _____________________________

What is the best way to contact you? [ ] Home  [ ] Cell  [ ] Email

Please check one:

[ ] I am a parent or family member of a patient of ________________________________.

[ ] I am a patient of ________________________________.

[ ] I am involved in the care of a patient of __________________________.

Skills and Interests: If you wish to provide information, please use the space below to describe any special training, interests, hobbies, or experiences you feel could be valuable to your work as a Parent/Family Advisor with __________________________.

____________________________________________________________________________

____________________________________________________________________________

____________________________________________________________________________

____________________________________________________________________________

Please put an X in the days and times you are available for an interview:

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If you have questions, please call __________. __________. or email: ______________

Please return your completed application to:

____________________________________________
Title: Improving the Patient Experience: Developing a Patient/Family Advisory Group

ATTN: Name_________________
Address_____________________
City       ______State      Zip Code

Appendix 3

ADVISORY CANDIDATE INTERVIEW QUESTIONS

1. Why do you want to volunteer to be a patient/family partner?

2. Partners play a crucial role in the Medical Home process in that they are able to address patient/parent insights and viewpoints for the clinic team in supportive, respectful ways. Sometimes this will include gentle constructive criticism or suggestions for previously established processes. Are you comfortable respectfully sharing insights in a team of your medical providers? Can you describe some ways in which you have used constructive criticism in the past?

3. Do you have experience participating in groups? Please describe.

4. Do you have previous volunteer experience? If so, what?

5. Have you worked with a variety of people (i.e., different educational levels, cultures)? Do you feel comfortable working with a group where a variety of opinions are shared?

6. While your personal opinion is of great value, your role on the team is to represent the needs of all parents/patients. How do you feel about this?
7. Do you see any barriers or challenges in being a parent/patient partner (i.e., energy, time, transportation, availability, limitations)?
Appendix 4
ROLE & RESPONSIBILITY AGREEMENT

Patient/Family Partner Information:
Name: _____________________________ Email: _____________________________
Address: __________________________ City: _____________ State: ___ Zip: _____
Home Phone: ______________________ Cell Phone: ______________________

Commitment:

As a member of the Patient/Family Advisory Group, I commit to:

- Attending and participating in meetings.
- Maintaining confidentiality of matters discussed during meetings.
- Working collaboratively with team members, other parents, and support staff for
  _______________________.

Signatures:

Partner Name: _________________________________________________________________
Signature: _____________________________ Date: __________________

Clinic Manager: ______________________________________________________________
Signature: _____________________________ Date: __________________
Appendix 4

ROLE & RESPONSIBILITY AGREEMENT

Team Agreement

- Information that is shared in the room; stays in the room.
- Stay focused on the topic/issue at hand – keep your eyes on the purpose.
- Stay positive.
- Agree to disagree – all opinions are honored and valued.
- Do your very best to do your homework.
- Be prepared to represent the community and larger patient needs.
- Share airspace; everyone is heard.
- Review accomplishments – celebrate.
- Identify opportunities for improvement or change.
- Be on time, start and end on time.
- Let us know when you can’t be there.
- If we reach agreements as a group, we support the group decision.
- Co-chairs take action if the group will benefit.
- Coaching support is provided to the group to ensure success.
- Ask for support openly.
- Give respectful feedback if a member strays from agreement.
- All opinions are honored and valued.
YOU’RE INVITED!

Dear [Patient/Parent Name],

Thank you for expressing interest in participating in the first Patient/ Family Advisory Group at ______________. We are entering into an exciting new phase as we implement the Patient-Centered Medical Home approach to patient healthcare, and your insights, comments, and suggestions will provide us with invaluable tools as we embark on this process.

We would like to invite you to our first meeting, which will take place on Tuesday, January 14, 2014, at 5:30 pm at our ____________ Office in ______________. We hope to see you then! If you plan on attending, please confirm by calling Clinic Manager ______________________ at ______________________. Refreshments will be served for your enjoyment.

We look forward to working together with you to create a Patient-Centered Medical Home for all our children and families at ________________________!

Looking forward to getting started,

Name of Practice__________________________

Address________________________________

City__________, State__________ Zip code

Phone___________________________________
Appendix 5

WELCOME TO THE ADVISORY GROUP!

________________________

Dear [Patient/Parent Name],

On behalf of ________________________________, I would like to welcome you to the Patient / Family Advisory Group (PAG). The primary function of PAG will be to develop and improve mechanisms for patients/families to provide input to clinic administration and clinic leadership so that services are reflective of the values inherent in the core expectations of the Patient/Centered Medical Home Model. PAG will actively promote patient/family-centered care across the continuum by developing and promoting partnerships between primary care providers, patient/families, and the community.

PAG will be made up of people, like you, form the community who receive care or whose family member receives care from ____________________________. We look forward to hearing about your experiences and are excited to have you participate in the group.

The next meeting is scheduled on [Day of the Week], [Date] at [Time]. We ask that you part in front of the clinic (where you would normally park if you were coming for an office visit0 and check in at the Front Desk (as you would normally do for an appointment). Refreshments will be served during the meeting.

Attached to this letter you will find an agenda for the next meeting. If you have any questions about this group, please feel free to contact ______________________ at ______________________.

We look forward to working with you to make a difference.

Sincerely,

Name of Person

Title

Name of Practice
1. What are some specific things that you or your family would like our healthcare professionals to do differently in order to be more helpful?

2. If you had a magic wand and could change or improve healthcare for you as a patient or your child, what would you change?

3. What interests you about becoming an Advisor?

4. Would you be interested in presenting your medical experience to the staff?
   - [ ] Yes   - [ ] No

5. Tell us about your interests, skills, or talents.
Appendix 6
CONFIDENTIALITY AGREEMENT

In your role as a parent/patient partner serving on the Patient/Family Advisory Group, you will hear confidential and privileged information about your Medical Home. It is vitally important that you not share this information outside of the group meetings. All members are committed to improving the quality of care that is delivered to our patients and families. In order to improve, areas with less than ideal performance must be identified. Just like you need to feel confident that your healthcare provider will keep your personal information private, our clinic must have the same assurance from you to be willing to share areas of concern. Therefore, we ask you to sign the following agreement:

I, ____________________________, agree to keep confidential any information I obtain in the course of my participation in the ____________________________. I will not discuss any such information outside of the group meetings without the express permission of the involved parties. If I have concerns about information obtained during my participation in the process, I will bring them to the attention of the ____________________________ staff who will work with me to resolve them. This confidentiality agreement remains in place after the end of my participation in the collaborative.

Patient/Family Member:

Name: ______________________________________________________________________
Signature: ___________________________ Date: ____________

Clinic Representative:

Name: ____________________________
Signature: ___________________________ Date: ____________
Title: Patient/ Family Advisory Coordinator

Position:  

Date:  

Department:  

Reports to: Clinic Manager  

Direct Report: None  

Position Summary: Under the supervision of the Clinic Manager, the Patient/Family Advisory Coordinator coordinates the Patient/ Family Advisory Group to provide a direct channel of communication between the physicians, clinic staff, administration, visitors, parents, patients, and their families. The Patient/ Family Advisory Coordinator is responsible for promoting a safe and comfortable environment for our patients, parents, staff, and families by ensuring compliance with safety policies, training, and accountability. Behaving in a professional, customer-focused, service-oriented manner; displaying and promoting respect, care, and dignity for all internal and external customers, facilitating a team-oriented, positive attitude; striving continuously for service excellence.

Essential Functions and Primary Responsibilities:  

1. Initial and ongoing development and coordination of the Patient/Family Advisory Group and its day-to-day activities, including: recruitment and orientation of members and the Group bylaws.  
2. Promoting and strengthening both “culture” and operations around patient and family-centered care in a primary care setting. Ensures positive operational change within the operations of the clinic as recommended by the Group, and through general feedback of patient experience.
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3. Collaborating with the community to adhere to and promote the vision and goals of both the Patient-Centered Medical Home Model and Accountable Care Organization models of care delivery and coordination.

Appendix 7

ADVISORY COORDINATOR POSITION DESCRIPTION

4. Securing and training of volunteers to promote customer service on-site.

5. Serves as a resource for Supervisors and Managers to facilitate communication and resolution of potential patient/parent dissatisfaction in an early stage.

6. Completes timely and accurate documentation of all interactions with patients and parents with the Patient/Family Advisory Group, including but not limited to: patient/parent complaints, such as meeting minutes, agendas, and within the HER and other programs as required.

7. Partners with leadership to help design and implement ongoing patient satisfaction measurement tools.

8. Assists Clinic Manager and others in providing analysis and data from patient satisfaction results and general patient/family feedback.

9. Screens patient satisfaction survey results, responds and initiates follow-up with patient or parent as indicated, and uses patient experiences to facilitate improvement within the system.

10. Attends meetings and presentations as appropriate and provides assistance to departments and administration in accessing and understanding patient satisfaction survey data.

11. Assists in accomplishing practice vision and goals in relation to patient/family-centered care by fostering and maintaining a good working relationship with internal and external partners.

12. Promotes understanding and adherence by both staff and parents to patient rights and responsibility.

13. Maintains professional growth and development through participation in education programs, current literature, in-service meetings, and workshops.

14. Assists Clinic Manager in seeking financial resources for sustaining the Group and its activities.

15. Performs other related duties as assigned.
The above statements are intended to describe the general nature and level of work being performed by people assigned to this job. They do not necessarily include all the responsibilities and duties associated with this job title.

Appendix 7

ADVISORY COORDINATOR POSITION DESCRIPTION

Qualifications:

- Valid Driver’s License.
- The position strongly prefers a college degree.
- **Skills:** Good communication (both written and oral), customer service, and public relations.
Appendix 7

ADVISOR QUALITIES

- Share insights and knowledge from your own experience that others can learn from.
- Listen well.
- See beyond your own personal experiences.
- Show concern for more than one issue or agenda.
- Speak comfortably.
- Work in partnership with others.
- Represent the patient population.
X. Resources:

Books:


Jeppson, E.S. Thomas, J. 1995). Essential Allies: Families as Advisors.


Womack, J Jones, D. Lean Thinking.

Articles:

“Advancing the Practice of Patient and Family-Centered Care: How to Get Started”. Institute for Family-Centered Care.

“Advancing the Practice of Patient and Family Centered Care in Primary Care and Other Ambulatory Settings”. Institute for Patient and Family-Centered Care.

“Approaches for Patient-Centered Interactions: Creating a Truly Patient-Centered Primary Care Home”. Oregon Primary Care Association/Primary care Institute.

“Creating Patient and Family Advisory Councils”. Institute for Patient and Family-Centered Care (IPFCC).


“Eight Principles of Patient-centered Care”. Picker Institute.
Title: Improving the Patient Experience: Developing a Patient/Family Advisory Group

“Fostering Partnerships and Teamwork in the Pediatric Medical Home”. National Center for Medical Home Implementation.

X. Resources:

Articles (continued):


Improving the Patient Experience: Developing a Patient/Family/Advisory Group within the Medical Practice.

“Patient and Family Advisory Councils”. The Bristol-Myers Squibb Children’s Hospital at Robert Wood Johnson University Hospital.


Annual Reports:


Intermountain Primary Children’s Medical Center. (2010-2011).


Riley Hospital for Children. (2011).

Other Documents:

American Academy of Pediatrics. “Achieving Bright Futures”.


NCQA. “Hedis 2015 Technical Specifications for Physician Measurement”.

2
Title: Improving the Patient Experience: Developing a Patient/Family Advisory Group

Oregon Health Authority. “Patient-Centered Primary Care Home Program – 2014 Recognition Criteria”.

Oregon Health Care Quality Corporation. “Quality Corp Measures Descriptions and Methodologies”.

X. Resources:

Webinars:

American Society for Quality. “Lean Six Sigma in Health Care”.

Institute for Quality Improvement in Health Care. “Changes for Improvement in Health Care”.

Longo, Eugene. “Principles of Lean Six Sigma and CAPA.

