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Guide for Developing a Community-Based Patient Safety Advisory Council

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Acknowledgments

We are in the midst of an exciting national movement, endorsed by health care entities and patients alike, to engage patients and families as partners with their health care providers. Including patients in the design and implementation of initiatives to improve patient safety has given new meaning to patient-centered care.

Aurora Health Care, in collaboration with Consumers Advancing Patient Safety and Midwest Airlines, implemented a patient partnership model as an intervention to improve medication safety in the outpatient setting. Bringing patients and health care providers together with a common goal offered the opportunity for collaboration and insight to the needs of our patients.

We are proud of the time, talent, and wisdom that the Walworth County, Wisconsin, Patient Safety Council invested in developing and implementing tools to improve medication safety in the outpatient setting. It was a truly phenomenal committee and provided the rewarding experience of doing something worthwhile to help patients manage their medications safely. These individuals used their personal insights, knowledge, and experience to create a safer environment for patients. They were recognized locally by the Walworth County Board of Supervisors and nationally by the Institute for Safe Medication Practices 2007 Cheers Award. As one nurse put it so succinctly, "We are finally listening to our patients." We hope this guide will help others learn to listen.

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Chapter 1. Introduction

This *Guide for Developing a Community-Based Patient Safety Advisory Council* is being made available to readers with the intent that it will provide information and guidance to empower individuals and organizations to develop community-based advisory councils. The information in this guide can help those who seek to convene advisory councils that involve patients, consumers, practitioners, and professionals from health care and community organizations for the purpose of driving change in patient safety through education, collaboration, and consumer engagement.

This guide presents a step-by-step approach and provides resources for organizational development and growth in the area of patient-centered care. In addition, it encourages a broader perspective on the definition of patient-centered care, to include community collaboration. While this guide specifically addresses patient safety advisory councils, it can also be used to set up patient councils to address other issues in which patients' voices are important, such as developing patient education materials.

The audience for this guide is primarily individuals who have a basic knowledge of patient safety and are aware of the challenges in incorporating the patient's voice in health care improvement projects. The authors assume readers have some awareness of meeting planning and logistics but that they may not have experience in crafting interactive sessions with participants who represent a variety of perspectives from the health care industry, especially those who represent the consumer experience. Readers are encouraged to refer to the references for additional resources to help fill gaps in their understanding of the concepts discussed and access additional information as needed.

Terms

The terms used in discussing patient safety work can be open to individual interpretation. To help to clarify the language used in this *Guide for Developing a Community-Based Patient Safety Advisory Council*, the following definitions are provided.

- Caregivers—Family, friends, partners, and neighbors who provide vital services to the chronically ill, elderly, and disabled.
- Patient/Consumer—Anyone who is receiving health care services. These terms are used interchangeably throughout this guide.
- **Providers**—Physicians, nurses, pharmacists, and others who provide health care services.

Guide Structure

The Guide for Developing a Community-Based Patient Safety Advisory Council consists of the following sections:

Chapter 2. Patient Safety Advisory Councils. This portion serves as an introduction to how and why patient advisory councils have become part of the patient safety movement. This portion of the guide will be most useful to individuals who are considering whether they want to develop a council. It includes a description of the benefits of creating a community-based patient advisory council for patients, health care providers, and the community. The information in this section could be used as justification and validation to gain support for developing a council from leadership and governing bodies. Particularly highlighted is the experience of the Aurora Health Care project, which led to the creation of this guide and is referred to throughout the guide as an exemplary model of a community-based advisory council.

Chapter 3. Steps to Creating a Patient Safety Advisory Council. This portion outlines 10 specific steps for those who are ready to launch a community-based advisory council. This is the "nuts and bolts" section that will be useful to project managers who are responsible for council development, implementation, and evaluation. Detailed descriptions are provided for the user to adopt or adapt to their specific community. Some of the steps include a descriptive example from the Aurora Health Care project, referencing specific tools that can be found in the appendices.

Appendixes. This section provides examples of documents and forms that were created during the Aurora Health Care project. In most cases, these documents can be adopted and adapted to meet the specific needs of the setting in which they will be used.

References. This bibliography provides resources for those who either need additional information or want to expand their project beyond the scope of this guide.

Chapter 2. Patient Safety Advisory Councils

The success of any team requires active participation from every member. The approach health care systems traditionally take neglects the most critical member of the team—the patient. Programs and policies are developed without patient input. Hospital rounds are conducted around the patients. Schedules and processes are created to meet the needs of the health care providers. This provider-centric approach does not view the patient as an engaged team member.

There is a new wave of consumers who have heard stories of or actually experienced errors, mistakes, and failures in hospitals, clinics, and pharmacies. These patients, families, community members, and employers may not understand all the complexities of the health care system, but they want to be part of the team working to correct it. And some health care providers who realize the importance of the patient perspective are inviting them into their hospitals and offices to help transform the system. Embodied by a collaborative consumer-provider relationship, these providers are transforming their culture to promote patient-centered care.¹

One formal approach to engaging patients in programs and processes is through patient advisory councils.^{2,3} Several health care organizations have been recognized for involving patients on councils, teams, and even board committees, including Dana Farber Cancer Institute, Boston, Massachusetts; Cincinnati Children's Hospital, Cincinnati, Ohio; and Children's Hospitals and Clinics, Minneapolis/St. Paul, Minnesota. However, few councils have

¹Aspden P, Wolcott JA, Bootman L, Cronenwelt LR. eds. Institute of Medicine, Preventing Medication Errors, Quality Chasm Series. Washington, DC: The National Academies Press, 2007

²Webster PD, Johnson BH. Developing and Sustaining a Patient and Family Advisory council. Bethesda, MD. Institute for Family-Centered Care. 2000.

³Ponte PR, Conlin G, Conway JB, et al. Making patient-centered care come alive: Achieving full integration of the patient's perspective. *J Nurs Admin*. 2003;33:82–90.

been created with a primary focus on patients who receive care in outpatient settings, such as clinics, retail pharmacies, or community-based health programs.

This guide describes the steps Aurora Health Care took to create a community-based patient safety council focused on improving medication safety for the outpatient population. It provides the tools needed to create a patient advisory council in your community. Using these resources, you will have all the components to build a successful team.

Background

Aurora Health Care, an integrated delivery system in Wisconsin, has 13 hospitals, more than 100 clinics, more than 120 retail pharmacies, and a home health program. For years, Aurora worked to improve safety across the continuum of care. Though Aurora staff had "talked the talk" about patient-centered care, they had not formally included patients in any team or project. As they struggled with an initiative to improve medication safety in the outpatient setting, they realized that patients' perspectives were missing. In 2005, Aurora Health Care received funding from the Agency for Healthcare Research and Quality (AHRQ) to incorporate lessons learned from inpatient examples of patient advisory councils into the implementation of an outpatient-based patient safety council.

The objective of the project was to create a place where patients and health care providers could openly discuss the barriers to and opportunities for a safe, effective medication process in the outpatient setting. The project was developed on the premise that a collaborative process, with patients and providers working together, would lead to the development of effective interventions that could be disseminated and adopted throughout the community.

Benefits of Involving Patients

Creating a patient safety advisory council benefits patients, the health care organization, and the provider.

Benefits for patients include:

- Becoming more aware and better educated on the subject.
- Gaining a better understanding of the health care system, including their organization.
- Appreciating being part of the program, listened to, and having their opinions valued.
- Becoming advocates for their organization.
- Understanding how to be an active participant in their own health care.
- Recognizing that collaboration with their providers through patientcentered care leads to better self-management of chronic conditions and improved adherence to medication regimens.
- Learning to be advocates for their family and friends.

Benefits for health care organizations include:

- Learning what the priority concerns are for patients, which may not be what the organization selects.
- Hearing directly from their customers, the patients.
- Transforming their culture toward patient-centered care.
- Developing programs and policies that are relevant to their patients' needs.
- Improving consumer satisfaction, which leads to stronger patient loyalty.
- Strengthening their community relations.

Benefits for providers include:

- Becoming more aware of the patient's perspective.
- Learning to provide care from a patient-centered approach.
- Recognizing the role of other caregivers, such as family and friends.
- Appreciating barriers—and opportunities—for patients that were previously not understood.

- Identifying system issues that need to be addressed to provide patientcentered care.
- Receiving higher satisfaction ratings by their patients as they collaborate in a patient-centered care model.¹

¹Aspden P, Wolcott JA, Bootman L, Cronenwelt LR. eds. Institute of Medicine, Preventing Medication Errors, Quality Chasm Series. Washington, DC: The National Academies Press, 2007.

Chapter 3. Steps for Creating a Patient Safety Advisory Council

Step 1 - Determine the Scope of the Council

The first steps in creating a patient advisory council are often the toughest. The concept of bringing patients to the table as part of the team can be intimidating to health care providers, and patients feel the same way. Organizing your project according to the steps identified in this guide will help the process go smoothly. However, don't let the planning prevent you from moving forward. At some point, you need to take that first step, and soon after you will see the benefits of partnering with your patients.

What: Define the Council's Goals and Objectives

Organizations that are just beginning to bring patients to the table should start with a small, narrowly focused project. This gives both providers and patients a chance to become familiar with a partnership collaboration, work out logistics, and introduce the concept to organizational leaders. A small, successful project creates the confidence to move toward a larger council with broader goals.

Even with larger councils, it is important to continually reinforce the focus on the goals and objectives established at the beginning of the project. To do that, organizations should:

- Select a specific process or aspect of care that is focused and clear.
- Conduct a patient focus group to identify the primary safety concerns of the organization's target audience.
- Conduct a staff focus group to identify the primary safety concerns of the organization's staff.
- Select a topic the organization has addressed but has not successfully resolved.

- Identify a safety concern from data and metrics available in the organization.
- Define objectives that are achievable and measurable within the project parameters.
- Focus on a particular site in which the process or aspect of care occurs, e.g., hospital-based, outpatient clinic, retail pharmacy, home, or another site.
- Select a target population to be the focus of the project goals.
- Select specific goals and objectives for the council to address.

See Appendix A for an example of project goals and objectives.

How: Define the Council's Parameters

The council's limitations and restrictions should be clearly established and defined for its members. Parameters that should be defined include:

Timeframe. A specific timeframe should be developed and followed to keep the council moving forward. For teams that are just beginning to initiate patient involvement, the project timeframe should be kept very short, e.g., less than 6 months.

Budget. Financial resources available for the council and its project should be clear. In addition to the sponsoring health care organization's providing financial support for the project, other organizations, including vendors, pharmaceutical companies, and product manufacturers, may wish to lend support as well. However, these other sources of support may have restrictions or associated requirements. For example, if a vendor or manufacturer is willing to provide financial support or contribute products, it may control the rights for advertising or insist that its logo be displayed on the final products. The project team should decide initially from what sources they are willing or legally able to accept support, either financial or otherwise.

Organizational support. In addition to financial support, the organization may provide other resources, including staff time, meeting rooms, and office supplies.

Technology. The availability and capability of technology support for the council, as well as the project, should be defined.

Meeting logistics. Time, place, frequency, and length of meetings, and total duration of the project period should be established.

Roles and responsibilities of team members.

Evaluation and outcome measurements. Data collection methods and the analysis plan should be included.

Scope of project. Clarify what the council will not be addressing.

Who: Define Council Membership

A patient advisory council should be a multidisciplinary team and include representation from the targeted patient population and the providers who care for these patients. Overall elements to keep in mind include:

Council size. Start small. If this is the first project that includes patients, consider including just a few (e.g., less than five) patients on the team. A larger council may be established after staff members are comfortable with the process of working collaboratively with patients on a project team. Patient advisory councils should be kept to 20 total members. This size allows for diverse representation but is small enough for effective communication and consensus development.

Council membership. At least half of the council's members should be patients. This allows for equal representation of patient and provider perspective. Patients feel more comfortable sharing when there are other patients present and when they are not outnumbered by providers. To create a diverse patient membership for the council, consider patients' ages, genders, medical conditions, and cultural or racial backgrounds.

Health care providers and community members comprise the remaining membership of the council. Representatives from the following groups may be considered:

• Caregivers who provide primary assistance to patients in their homes.

- Physicians, including primary care providers and consultants.
- Nurses.
- Pharmacists.
- Ancillary service staff, including insurance benefits specialists and parish nurses.

Step 2—Select the Team

The membership of the council is critical to successfully building a partnership between providers and patients. The roles of the council members in this project should be explicit. Recommended members, their key characteristics, and their specific roles and responsibilities follow.

Patients

Patient members on the council provide the consumer perspective to the project goal. They do this through sharing their own opinions and expertise as well as experiential knowledge from personal, family member, or friends' encounters with the health care issue being addressed. Key characteristics of the patient representative include:

- Good communication skills.
- The ability to collaborate with diverse individuals in a group setting.
- Representation of the consumer base in which the council exists, including cultural, racial, or ethnic communities.
- Firsthand knowledge of the topic at hand. For example, if the council represents a group of clinics, patient representatives should receive care from one of the clinics. If the focus is on a clinical condition, patient representatives should either have the condition or have family members who have it.

Roles and responsibilities of the patient representative include:

- A focus on the specific project goals and objectives.
- Commitment to improving care related to the project goals.

- The ability to maintain confidentiality.
- A willingness to communicate relevant information with family, friends, and the community to contribute to the successful achievement of the project goals and objectives.

Recruiting patients is often the most intimidating step of establishing an advisory council. Remembering that patients are friends, neighbors, community members, and sometimes family keeps this in perspective. To successfully recruit potential consumer council members:

- Obtain referrals from health care providers. The project coordinator and on-site leads, both of which are described below, should talk with staff about the council project, describe the eligibility criteria, and ask staff to make recommendations from their patient population.
- Establish initial contact with the patient through their health care provider (physician, nurse, or pharmacist). A direct request from the provider demonstrates to the patient that his or her participation and opinion is valued. The initial call is to request participation and to obtain permission to have the project coordinator contact the patient with additional details.
- Provide followup by having the project coordinator call patients who
 agree to learn more about the project. This interview should provide
 specifics on the project, including roles and responsibilities of the
 patient representatives on the council. Sufficient time, up to 1 week,
 should be allowed for patients to consider the opportunity to
 participate.

Health Care Providers

A range of providers should participate to represent the complete health care team. Depending on the scope of the council project, representatives may include doctors, nurses, pharmacists, social workers, and parish nurses. A key component of a provider representative is willingness to work collaboratively with patients and other disciplines. Health care provider representatives on

the council should be accepting of collaboration in a patient-centered care model.

Project Lead

The project lead is the coach of the team. He or she develops the project concept, acquires the necessary funding and organizational support, selects the project coordinator, and manages the entire project. Key characteristics for a project lead include:

- A leadership position in the organization.
- Expertise with the content of the project goal and objectives.
- Time available to devote to the project.
- Communication skills to work comfortably with a diverse group of organizational leaders, professionals, patients, and community members.
- Knowledge of project evaluation and data analysis.

Project lead roles and responsibilities include:

- Developing project goals and objectives.
- Defining the council's role in the organization and in relation to the project goals and objectives.
- Obtaining organizational support for the council and project.
- Acquiring financial support for the council and project.
- Recruiting, orienting, and supervising the project coordinator.
- Being a member of the council and participating in meetings.
- Participating in project activities.
- Overseeing project evaluation and data analysis.
- Ensuring the project is completed on time.
- Committing 1 to 5 hours a week, depending on the size of the project.

Project Coordinator

A critical person for successful implementation of a patient advisory council, the project coordinator is responsible for the day-to-day management of the council and its activities. The project coordinator should be the first staff member identified and engaged in the project. A project coordinator should be:

- A personable individual with excellent communication skills who is sensitive to individual council member needs; respects diversity; is able to interact with different personalities and professions; and is able to build a team based on trust, honesty, and respect.
- Connected to the community. For an outpatient-based council, the
 project coordinator must have established relations with community
 organizations. This helps build trust with council members and
 facilitates the introduction of the project into other community groups.
- A member of the project site staff. Depending on what site (hospital, clinic, pharmacy) the council represents, the project coordinator should be a staff member of that facility. The project coordinator's established relationships and trust with staff will facilitate staff engagement in and adoption of the council concept.
- Committed to the council project. The project coordinator needs to have sufficient time devoted to the project.

Project coordinator roles and responsibilities include:

- Working directly with the project lead.
- Recruiting and orienting staff members.
- Recruiting and orienting council members.
- Serving as the primary liaison to the council members; providing communication with council members via individual communications, meeting agendas and minutes; and addressing individual concerns or needs.
- Chairing all council meetings.

- Communicating with internal staff and leaders by attending department and staff meetings, individual meetings, and presentations.
- Working with external community organizations through communications, meetings, and presentations.
- Coordinating and participating in public relations and media activities, including press releases, media presentations, and public events.
- Developing and implementing project strategies and interventions in conjunction with other team members.
- Monitoring the project budget.
- Monitoring the quality of the project.
- Committing 5 to 20 hours per week, depending on the size of the project.

Physician Champion

If a council activity involves a site that includes physicians, a physician champion is an important staff member to identify. A physician champion should:

- Be a recognized leader among staff physicians, though he or she may not necessarily hold a formal title.
- Be a respected physician who works directly with the physician staff and has a vested interest in the work of the council.
- Understand and support the project.
- Be recruited at the earliest stage of the project, prior to the council being established.
- Be able to attend most council meetings. Another physician should be identified who can alternate with the physician champion at council meetings to ensure the physician perspective is represented.

Roles and responsibilities for a physician champion include:

- Encouraging other physicians to participate in the council and their activities.
- Leading other physicians to adopt patient-centered care.

- Representing the council and the physician group at professional meetings and public relations events.
- Providing the physician perspective to the council and project goals.
- Being a member of the council and participating in meetings.
- Communicating with other physicians about the council and their activities.
- Committing 1 hour per week to the project.

On-Site Staff Leads

Staff leads are the primary points of contact at the work site. If the council is representing more than multiple clinics or hospitals, each site should have an on-site lead. Staff leads may also represent a discipline or profession, e.g., nurse lead or physician lead. On-site staff leads should:

- Hold a leadership position, such as supervisor or manager, at their site.
- Have excellent communication with all staff and professions at their site.
- Be able to work and communicate effectively with the project coordinator.

Roles and responsibilities for the on-site staff lead include:

- Serving as the point of contact for project coordinator and project leader at their work site.
- Communicating with other staff at their site, providing updates on council activities and the project, collecting information from staff to share with the project coordinator, and identifying site-based barriers and opportunities for the project.
- Participating in recruiting council members.
- Serving as a member of the council by participating in meetings.
- Committing 1 to 2 hours per week, depending on the size of the project.

Other Health Care Providers

Depending on the project goals and objectives, other health care providers may need to be included on the council. For example, if the project addresses medication issues in the outpatient setting, a retail pharmacist should be included. If the project focuses on health care services provided in the home, a home health nurse should be a council member.

Community Representatives

Community members may represent a community-based organization that includes patients and providers in a separate component of care. Including community representatives broadens the scope of perspectives beyond the traditional one-on-one health care relationship between patient and doctor. The inclusion of other community members recognizes the role community organizations play in the health of an individual as well as a community. Community representatives may not be necessary for a small project or an organization's initial effort to involve patients. Examples of community organizations to consider for representation in the council include:

- Community-based organizations, such as Kiwanis, Rotary Club, Lions, Elks.
- Churches.
- Local government health and social service programs.
- Social service agencies.
- Community meal sites.
- Senior apartments.
- Women's clubs.
- Social clubs.
- Public libraries.

Community representatives should:

- Represent a community organization that is a stakeholder in the project goal or represent a community organization that has significant membership from patients and providers who are affected by the project goals and objectives.
- Be willing to exchange information between council and their community organization.
- Accept the concept of collaboration among diverse participants.

Roles and responsibilities for a community representative include:

- Focusing the work on the specific project goals and objectives.
- Committing to improving care within the community related to the specific project goals.
- Maintaining confidentiality.
- Communicating and sharing relevant information between the council and the community.
- Committing 1 to 2 hours per month, depending on the size of the project.

Step 3—Determine a Budget

Establishing a patient advisory council does not require significant funds. Many small projects can be completed with minimal staff time, voluntary patient representatives, and use of existing facilities and supplies. However, an organization that wants to establish a larger council, both in members and role, may need to commit resources to ensure its success. See Table 1 for suggested annual budgets.

Table 1: Suggested Annual Budget			
Category	Item	Est. Cost per Item	Quantity/ Frequency
Patient Representatives	Stipend per meeting	\$25-100	Team specific
Staff	Project lead	Hourly salary	1-5 hrs/week
	Project coordinator	Hourly salary	5-20 hrs/week
	Physician champion	Hourly salary	1 hr/week
	On-site lead	Hourly salary	1-2 hrs/week
	Other health care providers	Hourly salary	1 hr/week
Meetings	Room rental fee	Site specific	
	Food	Site specific	
	Supplies (binders, paper, pens)	Site specific	
Community Awareness	Printed brochures and pamphlets	\$.10	Quantity of 12,000
	Print advertisements	\$5,000	
	Press releases	Free	

Step 4—Confirm Team Members

Each person who agrees to participate on the council should complete an application form and sign a confidentiality statement. The application should provide eligibility criteria for and details on council membership. See Appendix B for a sample application form. The form should include at a minimum:

- A description of project, goals, and objectives.
- The criteria for membership.
- The responsibilities and roles of members.
- Time commitment expected for project completion.
- Supportive services.
- The specific participation requirements that vary for patients, health care providers, and community member representatives.

The confidentiality statement should comply with Health Insurance Portability and Accountability Act, or HIPAA, requirements. The form that hospital volunteers sign can serve as a template for the confidentiality statement. The organization's compliance officer should review the any confidentiality statement council members will be asked to sign. See Appendix C for a sample confidentiality statement.

Step 5—Conduct the Orientation Meeting

Because of the sensitivity of both patients and providers in participating in this new model, all council members should receive orientation. For a small project that includes a few patients on a team, the orientation can occur with one-on-one discussions at the first meeting. For larger councils with broader goals and objectives, 1 to $1\frac{1}{2}$ days should be devoted to orientation.

The focus of the orientation for small or large projects is to ensure that both patients and providers understand the process of collaboration as well as the specific project goals. Potential barriers for a successful collaboration between patients and providers should be addressed at the initial meeting. See Tables 2

and 3 for barriers that meeting planners should consider and actions that can be taken to remedy the barriers.

Holding the meeting in a special location, such as a hotel meeting room or conference center rather a hospital's meeting room, provides an atmosphere of excitement and attention to the importance of the council. A facilitator or outside speaker may help lead the council, especially if no one has previously participated in a collaboration with patients and providers. An outside speaker who has experience in consumer advocacy can relate the importance of the project.

The orientation meeting can also be a forum to build rapport and trust among council members. Sharing personal experiences related to the project goal helps create an environment of trust, and ice-breaker exercises that have patients and providers working together can initiate relationship building.

For a long-term council with a broad assignment, developing vision and mission statements as a team can be a constructive process of team building. The vision statement describes how the council views the ideal future for the health care system. The mission statement describes the primary objective of what the council is trying to achieve as an organization. See Appendix D for a sample mission and vision statement document.

Table 2 – Patient Barriers to Successful Collaborative Meetings		
Potential Patient Barriers	Recommended Actions	
Concerns about damaging their relationships with health care providers if their comments are negative.	 Select patient representatives who have trusting relationships with one or more provider representatives or the project coordinator. Use first names and no titles during council meetings. Ensure ground rules define respectful listening. Clearly identify and provide access to the project coordinator. 	

continued

Table 2 - Patient Barriers to Successful Collaborative Meetings (cont)

Table 2 – Patient Barriers to Successful Collaborative Meetings (cont)		
Potential Patient Barriers	Recommended Actions	
Concerns that their opinion may not be valued or respected.	 Project leader and coordinator should discuss goals and objectives with patient representatives individually and at council meetings. Explain that the primary goal is the inclusion of patients in the process but not all patient and provider recommendations will be incorporated. Demonstrate commitment by incorporating a patient recommendation early in the project. Hold regular, frequent meetings, especially at the beginning of the project, to build trust in the process. 	
Unfamiliarity with health care systems and the medical world; belief that they do not have enough medical knowledge to participate constructively.	 Provide educational materials, such as articles and presentations, on relevant information for the project. Conduct all council meetings using nonmedical terminology or jargon. 	
Logistical complications limiting their availability to participate in meetings.	 Select a meeting time and location to meet the needs of the patient representatives. Provide support, such as childcare and translator services, if necessary and possible. Provide a financial stipend to cover patients' costs, and reimburse them for their time commitment. 	

continued

Table 2 – Patient Barriers to Successful Collaborative Meetings (cont)			
Potential Patient Barriers	Recommended Actions		
Concerns about being active participants and contributors.	 Define initial project goals and objectives that the staff developed but allow flexibility to accommodate council input and direction. Assign council members homework and responsibilities to actively engage them 		

Table 3 – Provider Barriers to Successful Collaborative Meetings		
Potential Provider Barriers	Recommended Actions	
Concerns about revealing problems and mistakes in the system with their patients.	 Review literature and examples from other organizations that undertook similar councils. Obtain confidentiality statements from council members. Limit the scope of the project. Remind staff that patient volunteers may already be part of the organization. 	
Concerns that patients will use the council as an opportunity to vent complaints.	 Select appropriate patient representatives for council. Limit the scope, focus, and duration of project. Select a project coordinator with meeting facilitation skills to keep the council on track. 	

continued

Table 3 - Provider Barriers to Successful Collaborative Meetings (cont) Potential Provider Barriers Recommended Actions Concerns that a small number of Recognize the limitations of patients will not be representatives. representative of all patients, Highlight the current lack of any including their own. patient perspective without their involvement. Propose to expand patient number if initial project is beneficial. Cost of project. Start with a small project. Explain the limited funding needs. Explain that many patient representatives do not expect payment or costly services for participating. Provide one-on-one education and a Inexperience with patient project description by project leader collaboration models. with leadership and provider representatives. Select a project coordinator who is familiar to and trusted by provider representatives. Select a small, short-term project for initial patient involvement. Select provider representatives who are not resistant to innovative ideas. Concerns about negative Share stories from other organizations that demonstrate positive repercussions repercussions—legal or otherwise—on the staff and without negative impact. organization. Have compliance officer review forms and membership applications. Identify how the creation of the council is part of cultural transformation toward patient-centered care.

Step 6—Conduct Regular Council Meetings

Organization, planning, and preparation are key elements of an effective council meeting.

Ground Rules

- Define the ground rules, which should include respect and honesty, to set the tone for all meetings. See Appendix E for sample ground rules.
- Honor the ground rules, using the facilitator to ensure they are followed.
- Speak in nonmedical terminology.
- Agree to address all council members in the same manner (i.e., by their first names) to avoid an authority gradient between patients and providers.

Logistics

- Meeting times. Set meeting times so they are convenient for members.
 Consider any special needs council members have. For example, older patient representatives may prefer meetings to be held during daylight.
- Location. Set a meeting location that is centrally located for all council members. If there are political or community issues that could influence the council, consider a neutral location where all members are comfortable. This may be in a location that is not owned by the sponsoring health care organization. Meeting in a community-based organization's site may demonstrate community involvement in the project.
- *Project commitment.* Define the time commitment of the project, such as number, frequency, and duration of meetings, and the duration of project period. Meetings that are too long may not be productive. A specific project period keeps the council committed to completing its objectives within a defined timeframe. Meetings that are held less often than every month may lead to a loss of enthusiasm for the project. Months with multiple holidays may cause scheduling conflicts for

- council participants; consider not holding meetings during those months.
- *Stipends.* A stipend may be offered to council members for their time and effort. Patients often do not accept the stipend, but the offer of one reflects the value that an organization puts on their contributions to the project. A stipend may range from \$25 to \$100, depending on available resources, duration of meetings, and length of the project.
- *Support services.* Detail the services that will be offered for council meeting participation, such as food, childcare, transportation, and parking.
- Room setup. Arranging tables and chairs in a circle is most conducive to
 discussion and visually associated with no hierarchical relationship
 among the team members.
- *Binders.* Provide each council member a binder to maintain their materials. Include a list of members' names and contact information (after getting approval from the members to share this information); the project coordinator's contact information; a description of the project mission, including the vision, goals, and objectives; and the minutes from the last meeting.

	Aurora Health Care Project
Frequency	Monthly meetings
Duration of meetings	3 hours (includes 15-minute breaks)
Support services	Free parking; muffins, coffee, and water provided; financial stipend for patient representatives
Meeting time	9 a.m. to noon (daylight driving)
Location	Local health department meeting room (neutral location, centrally located within the community)
Project period	2 years

Standing Agenda Items

Regular agenda items that facilitate an organized project completion and build trust among the members include:

- *Check in.* At the beginning of every meeting, ask council members if they have a story to share that is related to the project goal. This may include a demonstration of the problem being addressed, a suggested intervention, or a celebration of a success that is attributed to the council's efforts.
- *Check out.* At the close of every meeting, ask each council member how he or she felt about the meeting. Did they learn something? What was most interesting? What could have been done differently? How do they feel the council is doing toward meeting its goals and objectives?
- *Meeting evaluations.* Each council member should be asked to complete an evaluation after each meeting. Share the results of these evaluations at every meeting. If evaluations address specific concerns or recommendations, take action to incorporate changes at the subsequent meetings. See Appendix F for a sample meeting evaluation.

Assignments and Homework

Council members should receive assignments when appropriate. Assignments help to get tasks done in a timely manner by spreading the work, and they also give members a sense of participation in and ownership of the project.

Use the expertise and connections of the council members. For example, if one of the council members belongs to a community organization, ask him or her to introduce the project to fellow members or to invite the project coordinator to the organization's next meeting.

Educational Presentations

Continuing education is especially important at the beginning of council development. This may include sharing written materials, articles, and professional literature. Presentations by experts from within and outside the organization provide diverse perspectives on the project goals.

Step 7—Elicit Public Relations Support and Community Engagement

Public relations and marketing may be beneficial, especially for projects that involve community members and organizations beyond the health care system. Raising awareness in the community that the council exists highlights the organization's commitment to patient-centered care and meeting the needs of consumers. Community engagement may be a powerful mechanism for promoting and achieving behavior-based healthy outcomes. By collaborating with community-based organizations, consistent education and best practices can be shared with those who provide patient care. Although the primary objective for a health care system may be to take care of their own patients, the impact from a project may reach beyond those individuals and positively affect the health of the larger community.

Recommended public relations and community engagement strategies include:

- Creating a brochure that explains the council's role and goals. A sample brochure can be found at Appendix G.
- Using advertisements to promote a project or intervention. A sample of an advertisement can be found at Appendix H.
- Media reports through newspapers, radio programs, and television spots to spread the word to and beyond the community. Holding a media event, at which reporters are invited to attend part of a council meeting and interview patient and provider representatives, can further enhance community awareness and engagement.
- Engaging a photographer to document the work—and the fun—the group had in achieving success.
- Communicating with the internal organization through newsletters, e-mail, and presentations at committee and staff meetings.
- Keeping the board of directors aware of the project by addressing some of the barriers and concerns as well as opportunities for the organization.

- Engaging local government to heighten awareness among community members. A presentation to the local board of supervisors can be made. Participating in annual Patient Safety Awareness Week activities connects the council's efforts to national programs.
- Accessing community groups and social service agencies through council members who are active in these organizations. These groups may provide perspective on the project goals and assist in dissemination of the interventions.

Step 8—Conclude With a Meeting

At the conclusion of the project time period, the council should evaluate its progress on the project and reflect on the council itself. A final meeting should be devoted to evaluation, reflection, conclusions, and recommendations for the future role of the council. Components of the final meeting may include:

- Review of the council's history from initial planning through implementation.
- Report to the council on project goals, measured outcomes, and evaluation metrics.
- Reiteration of the council's purpose: Bringing patients into the organization's infrastructure and moving toward a more patientcentered approach to health care.
- Identification of barriers and opportunities for continuation and replication of the council.
- Celebration of successes, even if project goals were not entirely met.
- Recognition of council members and their efforts from organizational and community leadership.
- Completion of the final report for organizational leadership with recommendations for continuation or replication.

Step 9-Measure Success

Several evaluation methods can be used to quantify the success of a council. Both process and outcome measures can demonstrate how the organization has met its goals for involving patients.

Suggested process measures include:

- Number of project teams that include patients as team members.
- Number of patients that have been included on project teams.
- Number of meetings in which patients participated.
- Number of patient advisory councils an organization established.
- Number of patients on the patient advisory councils.
- Number of meetings of the patient advisory council in which patients have participated.
- Number of focus groups conducted.
- Number of patient and provider interviews completed.
- Number of interventions, tools, and materials created by the council to meet the project goals and objectives.
- Number of interventions, tools, and materials disseminated to patients and the community to meet the project goals and objectives.

Suggested outcome measures include:

- Evaluation scores from each patient advisory council meeting that meet or exceed the target.
- Meeting or exceeding specific project goals and objectives.
- Impact of project on patient behaviors and practices, measured through surveys (mail, phone, or e-mail), observational studies (at clinics, pharmacies, or hospitals), and chart reviews.
- Penetration of project impact beyond targeted population (community penetration beyond the organization's patient population), measured through surveys (mail, phone, or e-mail).

- Patient satisfaction survey results meet or exceed target.
- Employee satisfaction survey results meet or exceed target.

See Appendix I for measurement examples.

Step 10—Sustain the Partnership Model

The initial excitement and passion generated by the collaboration between patients and providers can dissipate over time and with the practicality of completing a project. Although council members often feel changed by working in a partnership model, others in the organization may not experience an emotional response. Therefore, both the council members and the organization may lose the enthusiasm needed to continue and promote replication after a project has been completed.

Steps to continue cultural transformation toward patient involvement include:

- Inviting key organizational leaders to a council meeting.
- Including one or more of the patients from the council on a different project. With their experience and comfort, these patients can demonstrate to other staff how effective their involvement can be.
- Sharing the experience with other providers and staff at meetings and conferences. Council members, with a patient representative, if possible, should make the presentations.
- Obtaining funding from "nontraditional" sources, such as grants, foundations, and affiliated groups of the health care organization.
- Replicating patient involvement in small projects throughout the organization, allowing other staff to experience the benefits of working collaboratively with patients.
- Reporting on the successes of the council's efforts to organizational leadership.

Appendixes

Appendix A. Project Goals and Objectives

Before they meet regularly, patient advisory councils need to establish project goals. Examples of project goals and objectives for small and large patient advisory councils follow.

A. Scope for a small project that involves patients on the project team

Goal: Revise patient education materials that are provided to patients with congestive heart failure when they are discharged from the hospital.

Objectives:

- Obtain patient input on and recommendations for the patient education materials.
- Conduct three meetings with at least five patients participating.
- Revise current materials by incorporating the patients' recommendations.
- Prepare and print materials.

Timeframe: 4 months

Budget: \$300 to include cost of meetings, patient support, and printing costs. Funding provided by Department of Patient Education.

B. Scope for a larger project that includes the establishment of a patient advisory council

Goal: Establish a patient-provider partnership council in a community setting that will develop interventions to improve medication safety.

Objectives:

 Create a patient safety council with patient and provider representatives from hospitals, outpatient clinics, and retail pharmacies within a community.

- Develop strategies to improve medication list accuracy in outpatient medical records at the clinics.
- Implement medication safety strategies that could be used by patients in the community and by providers in the clinics.
- Measure medication list accuracy in outpatient medical records in the clinics.
- Measure the impact of the project on the satisfaction and engagement of patients, providers, council members, and the community.
- Disseminate information on the patient safety council and their activities.

Timeframe: 2 years

Budget: \$500,000. Funding provided by a grant with organizational support.

Appendix B. Council Information Sheet and Application

A sample of the member information sheet and application for patients or caregivers for the Aurora Health Care Patient Safety Partnership Council follows. With minor edits, the information and application can be adapted for use by most patient advisory councils.

Information Sheet

What is the Patient Safety Partnership Council?

The Patient Safety Partnership Council is a group of committed patients, caregivers, health care providers, and community members who work together to improve medication safety for individuals 55 years and older.

What are the criteria for being council members?

- Must be 55 years or older.
- Able to attend meetings every other month (date, time, and location to be determined).
- Must maintain appropriate and confidential handling of personal information.
- Able to listen to differing opinions and share different points of view.
- Be positive and supportive of the project's mission.
- Comfortable speaking candidly in a group.
- Able to use experience constructively.
- Able to work productively and collaboratively with council members whose background, experience, and style may be different than their own.
- Able to reflect on issues and priorities that are different than their own.

What are the responsibilities of council members?

- Be accountable to those whom they represent.
- Reach out broadly and listen to other patients, families, health care providers, and community members.

- Be committed to improve care for all patients and family members.
- Maintain confidentiality at the council meetings and outside the meetings.
- Respect the collaborative process and the council as the forum to discuss issues.
- Be willing to listen to differing views.
- Encourage all council members to share ideas and viewpoints.

What is the time commitment for council members?

Council members make a 2-year commitment. The council will meet every other month at a date, time and location to be determined by the members. Council members may be asked to participate in activities, such as educational workshops and community outreach.

What kind of support will the council members receive?

- Education and training at a $1\frac{1}{2}$ -day orientation retreat. Council members are invited to an orientation retreat. The retreat's objective is to establish a forum and a process for health care consumers and patients to partner with other health care stakeholders and, through this partnership, take on bold, creative initiatives that continuously make health care better. At the retreat, the vision, mission, and objectives of the council will be established. Patient and caregiver council members will receive one night's complimentary lodging at the conference center for the retreat. Three meals will be provided during the retreat
- Stipend for attending council meetings. Members of the patient advisory council will receive a \$100 stipend for each council meeting attended.
- Recognition. With permission, the members of the patient advisory council will be recognized through Aurora Health Care internal communications and in media and professional communications.

Application					
	Date:				
	me:				
Mai	iling Address				
Stre	et:				
City	r: State: ZIP Code:				
Hon	ne Telephone: E-mail Address:				
1.	. What is your preferred way of receiving communication about the council? E-mail Regular Mail				
2.	Is it okay to share your contact information (address, telephone number, and e-mail address) with other members of the council? Yes No				
3.	Have you received care at a clinic or hospital for which this council is being formed? Yes No				
3a.	3a. If Yes, at which clinic or hospital did you receive care?				
4.	Do you have any dietary needs we should be aware of (i.e. vegetarian)? Yes No				
	If Yes, please elaborate.				
5.	Do you have any special needs we should be aware of? Yes No				
	If Yes, please elaborate.				
6.	Why would you like to be on the council?				
7.	What issues would you like to see the council address?				
8.	What special interest or experiences would you like to offer to the council?				

Appendix C. Confidentiality Statement

Patient advisory council members must sign confidentiality statements as part of their membership processing. A sample follows.

A federal law called "HIPAA" (Health Insurance Portability and Accountability Act) defines "protected health information" and sets standards for health care providers to protect that information. The law also defines stiff penalties (fines and even imprisonment) for violating those privacy provisions. Various State laws also protect the privacy of patient information.

Protected health information includes any information regarding a patient's visit at any Aurora Health Care facility. That information includes, but is not limited to, name, address, phone number, date of birth, financial information, diagnosis, and treatment information.

In addition to defining protected health information, the law requires that we must define the minimum necessary information which employees, volunteers, contracted agencies, and other individuals can have access to. As a non-employed committee member, you may have access to protected health information. It is important that you recognize that any protected health information can only be used and disclosed as permitted by law. For example, this information cannot be shared by written, verbal, or e-mail communication at school or home; with friends or family; or outside the hospital, clinic, or other health care facility unless specifically permitted by law.

The easiest way to remember how to implement this law is the saying, "What you see or hear here, must remain here." We require your cooperation in following these rules.

Please sign below that you have reviewed this information, understand it, and agree to it.

Thank you

Thank you.
I have reviewed the information above, understand it, and agree to abide by it
Name (please print)
Signature
Date

Appendix D. Vision and Mission Statements

Sample vision and mission statements and objectives for patient advisory councils follow.

Vision

A safe, compassionate, innovative health care community that listens, learns, and responds collaboratively with patients.

Mission

The patient safety council will implement a community partnership model for the purpose of developing innovative methods to improve medication safety.

Objectives

- 1. Develop tools for identification and dispensing of medications.
- 2. Develop community awareness of the patient safety council through training and engaging the community.
- 3. Improve senior resources.
- 4. Develop a tool to help seniors understand why they take medications.
- 5. Assemble data to identify the problems.
- 6. Develop health care community awareness.
- 7. Develop a medication tracking tool.
- 8. Create a consent form identifying partners.
- 9. Identify barriers, for both consumers and providers, to the safe use of medication.
- 10. Conduct a survey of patients.
- 11. Distribute focus group findings.
- 12. Educate physicians, staff, and all health care providers.
- 13. Research what material is currently available on this topic.
- 14. Maintain credible means of measuring outcomes.

Appendix E. Meeting Ground Rules

To set the tone for the meetings and ensure all participants are comfortable, the meeting planner creates ground rules for patient advisory council meetings.

Sample ground rules for patient advisory council meetings include:

- Meetings will start and end on time.
- Everyone participates. Every member's opinion is valuable.
- Maintain confidentiality at the meeting and outside the meeting.
- Avoid sidebar conversations.
- Focus on the meeting. Avoid nonemergency interruptions.
- Voice your concerns at the meeting.
- Decisions will be criteria-based, and the council will strive for consensus.
- All members will support the decisions outside the meeting.
- All assignments will be completed on time.
- Members will think of the big picture.

Appendix F. Meeting Evaluation

Each council member should be asked to complete an evaluation after each meeting, and meeting leaders should share the results of these evaluations at every meeting. A sample evaluation form follows.

Council Meeting Evaluation					
Date:					
Scale: 1 = Strongly Disagree 3 = Agree 5 = Strongly Agree Your input about what worked for you and what didn't is truly important to us. Please give us your feedback.					
	l was comfortable 1 pngly Disagree	e expressir 2	ng my ideas and opini 3 Agree	ons. 4	5 Strongly Agree
	I feel the council of patients and heal 1 page 1 page 2 p		ective in improving cor oviders. 3 Agree	mmunicatio	on between 5 Strongly Agree
3.	I feel the council i management.	identified _I	problems and barriers	to safe me	edication 5
Stre	ongly Disagree		Agree		Strongly Agree
 I feel my participation on the council will improve my own safe medication management or the safe medication management of my patients. 					
Stre	l ongly Disagree	2	3 Agree	4	5 Strongly Agree
5. I feel the ideas generated today will develop into interventions to successfully improve medication safety.					
Str	1 ongly Disagree	2	3 Agree	4	5 Strongly Agree
		onored o	veryone's contribution	and ensura	
0.	focus.	onored ev	rei yone's continuonon	unu ensore	a we sluyed off
C.L.	l 	2	3	4	5 Strongly Access
Strongly Disagree Agree Strongly Agree					

continued

Council Meeting Evaluation (cont)					
	meeting's de 1 Disagree	esired outcomes v	were achieved 3 Agree	l. 4	5 Strongly Agree
	t my time tod 1 Disagree	ay was well spe 2	nt. 3 Agree	4	5 Strongly Agree
If Disag	ree, why? _				
9. The	following inc	lividual(s) or com	munity group(s) should be p	art of the council:
10.To i	mprove future	e meetings, we sl	hould do the f	ollowing:	
My thou	ughts or com	ments:			
•		oe contacted abo		r thoughts or a	comments, please

Appendix G. Brochure

Part of marketing the patient advisory council includes developing brochures that explain the council's roles and goals. A photo of a sample brochure follows.

A Matter of Safety

The older we get, the more medications we are likely to take. Keeping track, staying on schedule, and understanding a lot of instructions can be quite a challenge.

As patients, we may receive care in a number of places – doctors' offices, clinics, hospitals, urgent care centers – and from a number of health care providers. How can we be sure all of these places are keeping good track of the medications we take?

There's just one answer: We must work together. All of us — patients, health care providers, and the community — need to be active partners in this cause.

Walworth County Patient Safety Council

Our Vision

An innovative, compassionate, safe health care community that listens, learns and responds collaboratively with patients.

Our Mission

The Walworth County Patient Safety Council will implement a community partnership model for the purpose of developing innovative methods to improve medication safety.







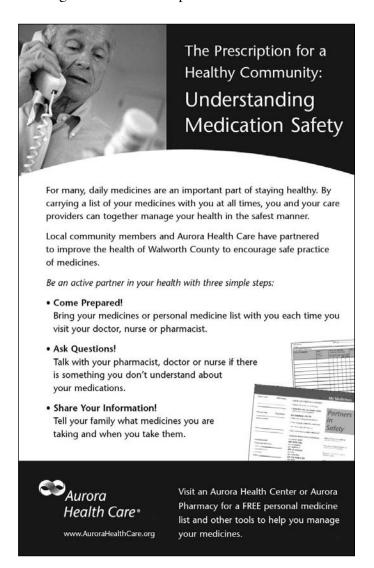
Aurora Health Care

www. Aurora Health Care.org

X25817 (02/06) ©AH

Appendix H. Advertisement

Part of spreading the word about the patient advisory council's project includes advertising in local media. A photo of an advertisement follows.



Appendix I. Process Objectives, Measurements, and Evaluation Strategies

The tables below provide examples of objectives that can be adapted for a patient advisory council and ways to measure its success.

A. Create a Patient Advisory Council

Process Objectives

- One and ½ day retreat with persons recruited from focus groups and informant interviews.
- Bi-monthly council meetings will be held during the remaining project cycle.
- Obtain evaluation from council members on group process and progress at each meeting to be used to improve council process.

Measurement and Evaluation Strategies

- Number of participants in retreat.
- Number of council meetings.
- Number of participants at bi-monthly council meetings (attendance rate = # invited/# attended).
- Evaluation forms completed by council members after each meeting.

B. Select a Project

Process Objectives

- Conduct 2 focus groups of patients, providers, and community stakeholder representatives.
- Conduct 15-20 key informant interviews with providers and clinic staff.
- 3. Conduct 10 "go-and-see" interviews of patients in their homes.
- Conduct council meetings to define the scope of the project, identify specific objectives, select intervention strategies for achieving project goals, establish evaluation measures.

- Number of focus groups.
- Number of attendees at focus groups (response rate = # invited/# attended).
- Number of key informant interviews.
- Number of "go-and-sees."
- Analysis of focus group transcripts, interview notes, and "go-and-see" records to determine most important barriers and strategies identified.
- Number of strategies and tools selected by council.

C. Implement Patient and Provider Interventions

Process Objectives

- Develop, reproduce, and distribute tools directed at patients and community members.
- Develop, reproduce, and distribute tools directed at providers.
- Provide education and training to patients and community members on the use of patient tools.
- Provide education and training to providers on the use of provider tools.
- Increase the level of awareness, availability, and acceptance of the tools through a public awareness campaign.

Measurement and Evaluation Strategies

- Number of patient and community tools distributed.
- Number of provider tools distributed.
- Number of community-based educational programs conducted.
- Number of attendees participating in community-based educational programs.
- Number of training sessions offered to providers and clinic staff.
- Number of providers attending training sessions.
- Number and type of public awareness programs.

D. Measure the Impact of Interventions

Process Objectives

- 1. Baseline and post-intervention measurements.
- Identification of correlations between intervention strategies and outcome measurements.

- Data collection:
 - a. Baseline—at project initiation.
 - b. Two post-intervention measures at 6 and 12 months following the implementation of specific strategies.
- Analysis of data to identify change between baseline to postintervention results.
- Analysis of data to identify correlation between patient and provider participation in intervention strategies to postintervention results.

E. Measure Impact of the Project on Satisfaction of Patients, Providers, and Council Members

Process Objectives

 Patients: Measure overall satisfaction of patients seen at the project sites during the course of the project.

- Data collection, patient satisfaction survey:
 - a. Baseline—at project initiation.
 - b. Post-intervention measure: At 12 months following the implementation of project interventions.
- Analysis of data to identify change between baseline to postintervention results.

- 2. Providers
 - a. Measure overall staff satisfaction at the project sites during the course of the project.
 - b. Measure perceived value of the council and project strategies.
- Data collection, employee satisfaction survey:
 - a. Baseline—at project initiation.
 - b. Post-intervention measure: At 12 months following the implementation of project interventions.
- Analysis of data to identify change between baseline to postintervention results.
- Develop and conduct survey of providers evaluating the council and specific project strategies.

- 3. Council Members
 - a. Measure council members' satisfaction with the project.
 - Measure council members' perception of effectiveness of the project to improve patient safety.
- Evaluation forms completed by council members after each meeting.
- Overall evaluation of project completed by council members.

E. Measure Impact of the Project on Satisfaction of Patients, Providers, and Council Members

Process Objectives

- Provide access to tools via Internet access.
- Replicate patient advisory councils throughout Aurora Health Care in other areas served.
- Produce publications detailing the project model, implementation strategies and tools developed.
- Present the project model, implementation strategies, and tools at conferences and meetings.

- Number of Web site hits.
- Number of patient advisory councils that are created within the Aurora Health Care system.
- Number of publications.
- Number of presentations by type of group, size of audience, and geographic location.

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