Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

Quality Improvement Division

Guidance for Setting up and Engaging Patients and Family Members on Patient Councils

The experience of care, as perceived by the patients and service users, is a key factor in health care quality and safety. International studies show that bringing the perspectives of patients, service users and families directly into the planning, delivery and evaluation of health care and working in partnership with patients and families improves the quality and safety of health care and patient and staff experience.

Health care that is person centred has patients and their families at the centre of the design and delivery of services and empowers them to interact with the service delivery system.

At service delivery level, participation of patients and family members on patient advisory councils is one of the models of joint, collaborative working and partnership.

Collaboration between health care providers and patients and families is the foundation of person centred care. Collaboration is based on moving away from the traditional model of health care delivery based on control towards establishing:

- Mutual respect for skills and knowledge
- Honest and clear communication
- Understanding and empathy
- Mutually agreed upon goals
- Shared planning and decision making
- Open communication and sharing of information
- Accessibility and responsiveness
- Joint evaluation of progress
- Absence of labelling and blaming

What is a patient council?

A patient council partners patients and families with healthcare staff to provide guidance on how to improve the patient and family experience. Through their unique perspectives, patients and family members give input on issues that impact care, ensuring that the next patient’s or family member’s journey is easier.

How to get started?

- Designate a staff member as a liaison for collaborative working with patients and their families. This individual must be focused on person centred care and have skills or capacity to acquire skills of engaging with patients, good communication skills and experience of facilitating groups.
- Identify several staff members and clinicians to serve on an informal workgroup to support the development of collaborative working and establishment of the patient council.
- Select patients and family members to serve on the patient council.

Role of patient councils

- ⇒ Participating in service design, development and quality improvement and providing patient/family member representation to committees and working groups including, but not limited to patient safety and quality improvement, facility design, service excellence, ethics and education.
- ⇒ Representing patient and family perspectives about the healthcare experience and making recommendations for improvement.
- ⇒ Acting as a sounding board for implementation of new programs and projects.
- ⇒ Identifying existing best practices in person centred care and exploring ways to share and replicate those across the organisation.
- ⇒ Building partnerships with health care professionals based on mutual respect, open communication and information sharing.
- ⇒ Keeping patients and families as the focal point of service delivery.

Characteristics of a successful patient council member

- Have recent experience (generally within 3 years) of accessing health care as a patient, family member or carer.
- Ideally, where possible, someone who has a reference group or wider community of users to whom they can refer back on their position on any given agenda (i.e. they may come from a patient or community group.
- Respectful of others and their perspectives
- Comfortable speaking in a group and interacting with others
- Good listener
- Able to use their personal experience constructively
- Able to see beyond their own experience
- Non-judgemental
- Positive attitude
- Ability to work collaboratively with other patients and healthcare staff
- Desire to expand their knowledge and skills
- Desire to participate in bringing about meaningful change
- Able to maintain confidentiality of patient and organisational information

Tips for recruiting patient council members

- Ask healthcare staff/clinicians to identify patients or family members who they think might be interested in participating and meet the above characteristics.
- Ask patients or family members who provided feedback or made a complaint if they are interested in participating.
- Ask other patients and family members who are already involved if they know anyone who might be interested in participating.
- Post notices on information boards in reception areas, clinics and emergency departments.
- Include information about opportunities for patients and families to get involved in appointment letters, questionnaires and other patient information leaflets.
- Place posters in community locations – churches, community centres, citizens' information offices, etc.

- You may interview interested patients or family members in person or over the telephone.
- Check references.

Before patients can make a decision about whether or not they wish to participate on a patient council, they should be informed of the responsibilities associated with the role. A fact sheet, containing the following information should be prepared and offered to individuals who are being asked to participate:

- The role of the patient council
- Expectations for their participation
- Meeting times, frequency and duration
- Expectations for communication among team members between meetings
- Time commitment beyond meeting times
- What are the expected outcomes of their involvement
- Training and support to be provided
- Reimbursement of expenses

Training for patient council members

In order to facilitate effective participation by patients and family members, orientation should be provided. If the organisation has a volunteer programme, its training and orientation may be very useful for council members. Other training issues to consider include:

- Speaking the organisation's language. If there are terms that will be used frequently in meetings and documentation, make sure patients and family members understand them.
- Who is who in the organisation?
- How to prepare for a meeting?
- How meetings are conducted: format, agenda, minutes, roles, etc?
- Training for any technology that will be used, e.g. conference calls, web based tools
- Communicating collaboratively:
    - Expressing your perspective so others will listen
    - How to ask tough questions?
    - What to do when you don't agree?
    - Listening to and learning from the perspective of others
    - Thinking beyond your own experience

It is essential to have a staff member designated to coordinate the activities of the council and to act as a liaison between the council and the organisation. This person will also provide ongoing informal support to council members.

Once patient council has been set up, it will be up to the council to draw up terms of reference, elect a chairperson, secretary, etc. Some information on roles and responsibilities of the council may be presented to council members for consideration and discussion by the council.

Suggested roles and responsibilities for patient council members for consideration by the council:

- Attend each council meeting or notify a staff member in advance if unable to meet.
- Engage thoughtfully and constructively around the issues and ideas discussed during each meeting.
- Be proactive in driving improvement and bring creative ideas for change.
- Be respectful of the unique background and perspective of each member.
- Be realistic and mindful of the hospital's budgetary constraints.

Roles and responsibilities for staff members:

- Attend each council meeting.
- Prepare meeting agendas.
- Identify, invite, vet and orient potential patient council members.
- Facilitate discussions and engage all members.
- Provide a report back to the patient council on the progress on ongoing projects and any hospital changes of interest to the group.
- Assist with operations behind the scenes (e.g. book rooms).
- Minimise potential barriers to achieving established goals.
- Be an advocate for engagement with patient council

Roles and responsibilities of Chair/Co-Chair:

- Attend each council meeting
- Communicate activities of the patient council to the hospital/CHO leadership
- Co-Chair will support duties of Chair in his/her absence

Outputs of the patient council

- Patient councils will provide regular updates to the leadership team and annual progress reports.
- Patient councils may engage in a variety of information gathering activities, such as open discussions with patients and family members, including focus groups, surveys and open forums.
- Patient councils may engage in educational and policy making forums.
- Patient councils may serve as community liaisons, engaging other patients and families in various programmes as necessary.
- Members of patient councils may also serve on other committees as appropriate.

Some suggested areas/activities to consider for involving patient council members:

Patient Council should be viewed as an important resource in many ways:

- Giving advice and feedback from patient and family perspective. For successful patient engagement it is essential that feedback is sought from the patient council at the planning and design stage of programmes, projects or quality improvement initiatives.
- Membership of key service-based and corporate committees, including steering committees, taskforces and working groups
- Participating on staff job interview panels

- Welcoming new staff at induction and orientation
- Critical incident reporting, disclosure and investigations
- Participating in delivering training programme, for example bringing the patient perspective to customer service or open disclosure training

The single most important guideline for involving patients and families in patient councils is to believe that their participation is essential to the design and delivery of optimum care and services. Without ongoing and meaningful patient and family participation in all aspects of policy and service development and evaluation, the health care system will fail to respond to the real needs and concerns of its service users.

Involving patients and families will:

- Bring important perspectives about the experience of care
- Teach how systems really work
- Inspire and energise staff
- Keep staff grounded in reality
- Provide timely feedback and ideas
- Lessen the burden on staff to fix the problems – staff don't have to have all the answers
- Bring connections with the community
- Offer the opportunity for patients and families to 'give back'.

For further information, support or advice on setting up patient councils please contact Mila Whelan, Quality Improvement Division, at mila.whelan@hse.ie