

ENHANCING PATIENT ENGAGEMENT THROUGH PATIENT ADVISORY COUNCILS





WORLD PATIENT SAFETY DAY

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TABLE OF CONTENTS

1. Introduction	02
2. Benefits and strategies for Enhancing Patient Engagement	02
3. Patient Advisory Councils (PAC) and its objectives	03
4. Creating Patient Advisory Councils	05
5. Roles & Responsibilities	07
6. PFPSF (Patients For Patient Safety Foundation)	09
7. Initiatives by CAHO	10
8. References	11
9. Contributors	12

1. Introduction

Trust between patients and their healthcare providers is foundational to medical care. However, medical errors can result in actual harm, impacting the patient's confidence in their care and eroding their trust in the broader healthcare system. Medical mistakes often take an toll emotional OΠ healthcare providers, leading to feelings of guilt, the looming threat of physical retaliation, and potential actions. Such incidents can expedite provider burnout. Errors can also result in malpractice litigations, demanding significant time resources. These burden individual providers and can escalate insurance rates for healthcare institutions.

confirmed Research has proven benefits when patients аге recognized and taken as collaborators in their care journey: there's a marked improvement in safety, a boost in patient satisfaction, and overall better health outcomes. On World Patient Safety Day this year, on 17th September, WHO has appropriately chosen the theme, "Engaging patients for patient safety."

Through the slogan "Elevate the voice of patients!", WHO calls on all stakeholders to arrange a diverse array of activities that range from national awareness drives, policy dialogues, and advocacy events to technical workshops and capacity enhancement programs [1].

CAHO (Consortium of Accredited Healthcare Organisations) along with Patients for Patient Safety Foundation (PSPSF) are committed to engaging patients for their own safe care and reducing avoidable medical harm.

Benefits of Patient Engagement

- Unique Perspectives: Patients offer invaluable insights into healthcare from their vantage point. Their feedback can spotlight care gaps, communication breakdowns, and areas that providers might overlook.
- Building Trust: Patient empowerment can solidify the trust between them and their healthcare providers. This trust is vital for the therapeutic relationship and can significantly influence treatment success.
- Partner in Decision-Making:
 Engaged patients are more inclined to participate and partner in decision-making, working alongside healthcare professionals.
- Improved Adherence: Patients involved and knowledgeable about their healthcare journey tend to adhere more to treatment protocols and manage their conditions effectively [2].

Strategies for Enhancing Patient Engagement

- Patient Surveys & Interviews:
 Collect feedback directly from patients to understand their experiences and needs.
- Open Communication Channels: Encourage open dialogues between patients and providers.
- Patient-Family Meetings: Establish regular interactions
 with patients and their families to
 discuss care plans and address
 concerns.
- Safety & Quality Initiatives: Encourage patients to play an active role in initiatives aimed at improving care safety and quality.
- Patient Advocacy Programs:
 Create programs that champion the rights and needs of patients.
- Digital Platforms: Utilize technology to facilitate communication and engagement, such as telehealth services and patient portals.
- Educational Outreach: Empower patients through resources and support for a better understanding of their conditions and treatment choices, fostering active engagement in their care

2. THE PINNACLE OF PATIENT ENGAGEMENT: PATIENT ADVISORY COUNCILS (PAC)

What is a PAC?

The Patient Advisory Council (PAC), or the Patient and Family Advisory Council (PFAC), comprises individuals with first-hand experience as patients or caregivers. It is a platform for patients to share experiences, voice concerns, and influence decisionmaking. The Consortium of Accredited Healthcare Organizations (CAHO), along with PFPSF, strongly encourages healthcare providers to establish Patient Advisory Councils. These councils will be pivotal in ensuring patients' voices are heard, integrated, and valued in the healthcare process [3].

Objectives of PAC

- Foster Trust & Communication: By working collaboratively, healthcare providers and patients can establish strong communication channels and build mutual trust.
- Valuable Feedback: The insights of patients can be harnessed to tailor services, enhance clinical outcomes, and improve patient experience and satisfaction levels.

- Bridging the Communication Gap:
 PACs provide an avenue for open, two-way communication between patients and healthcare institutions.
- Safety Enhancements: By involving patients, adverse events, medical errors, and potential harm can be better prevented.
- Educational Initiatives: PACs can identify the most effective ways to educate and inform the patient community. It can also identify the topics that patients need to be educated about to improve safety and reduce harm.

Is PAC a new concept?

Patient Advisory Councils (PACs) are not a new concept. They have been utilized in various forms and under different names across many countries for several decades. The main goal of PACs is to involve patients and their families in decision-making processes regarding healthcare services, ensuring that healthcare providers meet patients' needs effectively.

In the U.S., the idea of patient-centred care began gaining traction in the late 20th century. PACs, often termed Patient and Family Advisory Councils (PFACs) have been implemented in many hospitals and clinics.

Organizations like the Institute for Patient- and Family-Centred Care have been advocating for their incorporation.

The Affordable Care Act (2010) also emphasized the importance of patient engagement, further propelling the adoption of PFACs.The National Health Service (NHS) in the UK has been a strong proponent of involving patients and the public in healthcare decisions.

Various mechanisms, such as Patient Participation Groups (PPGs) in primary care settings and involvement in National Institute for Health and Care Excellence (NICE) guideline development committees, have been used to ensure patient input in care delivery and policy decisions.

Canada has seen the evolution of Patient and Family Advisory Councils, especially in provinces like Alberta and British Columbia.

Their healthcare system emphasizes the importance of a patient-centred approach, and several hospitals and health systems have PACs to gain insights directly from patients and their families.

While the terminology and specifics of implementation might differ, the fundamental concept behind Patient Advisory Councils is prevalent in many countries.

The consistent lesson from international experience is that patient engagement is critical for improving the quality and safety of healthcare.

3. CREATING EFFECTIVE PATIENT ADVISORY COUNCILS (PACS)

The Patient Advisory Council (PAC), also known as the Patient and Family Advisory Council (PFAC), comprises individuals with direct experience as patients or caregivers. PACs empower patients by offering a platform to share their experience, voice concerns and actively participate in decision-making processes.

Establishing a PAC: A Step-by-Step Guide

Step 1: Initiation of the PAC

- The process should be voluntary.
- Assemble a preliminary core group, comprising proactive senior hospital members, to discuss and present the PAC's advantages to the management.
- Ideally, the CEO or COO should spearhead the initiative.
- For the success of the PAC, top management involvement is crucial.

Step 2: Mobilizing the Core Group

- This group is responsible for gathering input from crucial stakeholders during PAC formation.
- The core group assists in devising the PAC's structure, supporting member identification and selection.
- They also draft the vision, mission, goals, and bylaws of the PAC.

Step 3: Formulating the PAC Composition & Member Recruitment

- Determine the ideal PAC composition, ensuring a diverse mix of patients, family members, healthcare professionals, and hospital administrators.
- Take into account factors such as the hospital's patient demographics, offered services, and existing patient safety or quality challenges.
- Initiate the recruitment process, ensuring potential members comprehend their expected roles and responsibilities.
- Drafting a clear role description for PAC members is advisable.
- Orientation of PAC members is based on the goals, by laws and role description.

Step 4: Selection of Leadership & HCP Representatives

- Choose a healthcare leader, ideally a clinician with the CEO's trust, to chair the PAC.
- This chairperson, in conjunction with the core group, selects additional healthcare professionals as members.
- The leader serves as the vital link between the PAC and the organization's leadership.
- Assign a facilitator responsible for managing meeting logistics, from setting the agenda to tracking action items.

Step 5: Pinpointing Patient/Family Representatives (PR)

- Voluntarily select PR members from current and past long-term patients or their caregivers using the hospital database.
- Also consider candidates from local communities, civic groups, patient support groups, and NGOs.
- Representatives should come from varied backgrounds (both genders) and be equipped to bring the patient and family viewpoint to the PAC.

Step 6: Drafting the PAC Charter

 Create a comprehensive charter that delineates the PAC's purpose, goals, member roles, meeting frequency, decisionmaking procedures, and communication strategies. This charter will guide PAC operations.

Step 7: Training & Orientation

- The training should cover the significance of the PAC, its benefits, and effective management techniques
- Organize essential training for PAC members on topics like patient safety, quality improvement, communication, and group dynamics.

- Highlight the importance of commitment to attendance, participation, and involvement in patient safety projects.
- Define boundaries for what PR members should refrain from, such as influencing policy, intervening in clinical matters, seeking personal favours or financial assistance, and displaying non-congenial behaviour.

Step 8: Launching PAC

- Size: 2-20 Members
- Ratio: 1 Staff for 2-4 Patient Reps
- Meeting Frequency: Once a month or at least 1 In 2 Months
- Tenure: 2 Years;
- Renewal: 2 Terms

Step 9: Streamlining Meetings & Communication

- Organize regular PAC meetings to address concerns, strategize, and monitor progress. The frequency should align with the PAC's goals and member availability.
- Implement a robust communication strategy for both internal PAC discussions and broader communication with the hospital community.

This could encompass periodic email updates, dedicated sections in hospital newsletters, or presentations during hospital meetings.

Virtual meetings should be explored to enhance interaction among PAC members.

4. ROLES AND RESPONSIBILITIES

PATIENT REPRESENTATIVE

- Understands the Mandate: He is well-informed about the specific responsibilities and goals of the PAC, having undergone training to equip him with the necessary knowledge and skills to be an active and effective member.
- Commits Time and Attendance:
 He recognizes the importance of
 regular participation and
 dedicates the necessary time to
 attend meetings and engage fully
 in the PAC's activities.
- Engages with the Community:
 He actively engages with other
 patients, caregivers, and the
 broader community, fostering
 open communication and
 collaboration to represent diverse
 perspectives within the PAC.
- Facilitates Communication: He assists in organizing interactions that enhance communication between PAC members and the general community, ensuring that the council's work is transparent and responsive to community needs.

Collaborates with HCP
Representative: He works in
collaboration with healthcare
providers, acknowledging and
respecting the constraints and
limitations of HCPs and hospitals
while striving to align the efforts
of the PAC with the practical
realities of healthcare delivery [4].

HCP REPRESENTATIVE

- Understands the Mission and Vision: As a representative of HCP within the PAC, they are fully aware of the council's goals and have aligned themselves with the mission to ensure patientcentered care.
- Commits to Active Participation: Regular attendance at PAC meetings and dedication of time to PAC activities demonstrates a genuine commitment to enhancing collaboration between healthcare providers and patients.
- Bridges Clinical Perspectives
 with Patients: Acts as a vital link
 between the clinical staff and the
 PAC, translating medical
 information and fostering
 understanding between medical
 professionals and patients or
 caregivers.

- Facilitates Collaboration: Works diligently to create an environment of collaboration between the PAC and HCPs, •recognizing and respecting the constraints of the healthcare system while striving to foster patient-centred care.
- Engages with Providers and Community: Proactively engages with other healthcare providers and the broader community, ensuring that the diverse needs and perspectives of the healthcare system are considered within the PAC's deliberations.
- Supports Implementation of PAC Initiatives: Assists in translating the PAC's recommendations into actionable strategies within the healthcare system, playing a pivotal role in implementing changes that align with the council's goals [5].

FACILITATOR

- Ensures Inclusive Participation:
 They actively foster an environment where all members feel encouraged and empowered to speak, ensuring that diverse perspectives are heard and valued.
- Organizes and Leads Meetings:
 The facilitator plans and leads PAC meetings, setting agendas, guiding discussions, and ensuring that meetings are productive, focused, and aligned with the PAC's goals.

- Impact on Patient Care: Patient
 Satisfaction Scores: Look for
 improvements in patient
 satisfaction scores or patient
 experience surveys after the
 implementation of PAC-suggested
 initiatives.
- Rate of Reported Incidents:
 Track any reduction in reported adverse events or medical errors after implementing PAC recommendations.
- Project and Initiative Outcomes: Project Completion Rate: Evaluate the proportion of PAC-initiated successfully finished projects compared to those left unfinished. Additionally, analyze the concrete impacts of PAC recommendations, such as improvements in patient discharge processes, gauging factors like efficiency, patient comprehension, and readmission before and after rates implementation
- Feedback Mechanisms: Feedback from PAC Members: Regularly gather feedback from PAC members about their experience, including challenges faced and support needed. Ensure multiple feedback mechanisms (e.g., surveys, feedback boxes, focus groups) are available for PAC members and the broader hospital community.
- Organizational Support: Support from Top Management: Evaluate the frequency and quality of interactions between PAC and top management.

- Community Engagement: Conduct surveys or polls to gauge community awareness and perception of the PAC.
- Engagement Activities: Monitor the number and type of community outreach and engagement activities the PAC participates in or organizes. Continuous Improvement: Review and Revision: Assess how frequently the PAC reviews its charter, goals, and KPIs. Regular evaluation using these parameters will ensure that the PAC remains a dynamic and impactful entity within the healthcare institution.
- Engagement Activities: Monitor the number and type of community outreach and engagement activities the PAC participates in or organizes.
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PATIENTS FOR PATIENT SAFETY FOUNDATION (PFPSF)

ROLE OF PFPSF

 The Patients For Patient Safety Foundation (PFPSF) is a not-forprofit trust dedicated to enhancing patient safety by fostering patient involvement.

- Its primary objective is to motivate patients to actively participate in their healthcare journey, aiming to enhance outcomes and minimize avoidable harm.
- It works with a diverse group of stakeholders, including hospitals, diagnostic centres, corporate entities, insurance companies, and Third Party Administrators (TPAs).
- PFPSF is committed to educating and heightening awareness about patient safety, through its outreach program and Health education and awareness library (HEAL) on its website.
- It strives to prevent avoidable harm by empowering patients, healthcare providers, patient support groups, corporations, and caregivers to be proactive in their healthcare journey and to share their experiences, further bolstering patient safety.
- The content curated by PFPSF is specifically tailored for patients, relevant to the Indian milieu. It gathers information from esteemed global sources like the WHO and various research bodies, ensuring the content's authenticity relevance and through validation by healthcare professionals.
- Educating Patients & Caregivers about their Rights and Responsibilities
- Engaging Patients in their own care.

- Empowering community to improve communication with HCP
- Encourage patients to understand "My Health My Responsibility"

How will PFPSF support PAC?

- Collate & develop an Operating Manual for PAC with inputs from HCP & CAHO and keep it updated
- Share the list of common issues faced by Patients
- Provide content on Patient Rights
 & Responsibilities
- Educate patients on the existence of PAC and how they can involve & give suggestions
- Help to create a mechanism in the hospital for receiving & collating suggestions from patients
- Share Patient stories/ experiences to help in improving Patientcentric processes
- Provide patient relevant content e.g. Posters and write-ups from PFPSF Health Library.

How can PAC help PFPSF?

- Publicize the Rights and Responsibilities of Patients to both patients & HCP staff
- Provide us with content for advising patients on their adopting safe practices
- Encourage all your patients to refer and utilize PFPSF content
- Use PFPSF posters/ materials in hospitals & distribute them to patients.

 Support patients to subscribe to PFPSF website for useful insights on Patient Safety.

INITIATIVES BY CAHO

Awareness and Education

CAHO can raise awareness among healthcare institutions about the benefits of establishing PACs.

They can provide information and resources to hospitals, explaining the purpose and advantages of PACs in improving patient engagement, satisfaction, and outcomes. This can be done by including this topic in conferences, seminars, and policy discussions.

Guidelines and Best Practices

CAHO can help in developing guidelines and best practices for: Composition of the council, Selection process for patient representatives, Meeting frequency, Collecting patient feedback and addressing patient feedback

Training and Capacity Building

 CAHO can organize training sessions and workshops for hospital administrators and staff on how to effectively engage with PACs and utilize their insights to improve healthcare services. This can also include training for patients and their representatives on their roles and responsibilities within the council.

Facilitation and Networking

- CAHO can act as a facilitator, connecting hospitals that have successfully implemented PACs.
- This networking can encourage knowledge exchange and learn from each other's experiences.

Monitoring and Evaluation

- CAHO can assist hospitals in monitoring the performance and impact of PACs.
- They can help in designing evaluation frameworks to measure the effectiveness of PACs in bringing about positive changes in patient care and satisfaction.

Recognition

 Recognizing hospitals with successful PACs through awards can also encourage wider adoption of this patient-centric approach

Collaboration with Patient Advocacy Groups

 CAHO can collaborate with patient advocacy organizations to convey the voice of patients to the healthcare system. By working together, they can ensure that the interests and perspectives of patients are adequately represented in hospital decision-making processes.

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The success of such councils ultimately depends on the Commitment and active participation of hospitals, healthcare providers, patients, and their families.

A collaborative effort involving all stakeholders is crucial to create patient-centred healthcare environments that lead to better health outcomes and enhanced patient experiences.

We commit to join hands with PFPSF (Patients For Patient Safety Foundation) to take this initiative forward.

