FoNS

Person-centred and family-centred care in the intensive care unit

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Project background

The Glasgow Royal Infirmary has a large intensive care unit staffed by 100 trained nurses and supported by 10 nursing assistants. Given widespread endorsement from both healthcare providers and policymakers of patient involvement in the design of services within the NHS, staff in the ICU wanted to develop a Patient and Family Advisory Council, with the aim of creating a model of meaningful collaboration between patients, relatives and staff.

Aims and objectives

The aim of this project was to develop and implement a Patient and Family Advisory Council (PFAC) to enable patients and those close to them to share their lived experiences of care within the ICU. To achieve this aim, the objectives identified were to:

- Engage with key stakeholders in the project
- Gather information to guide the running of the PFAC
- Recruit patients and families to the council
- Understand the patient experience by actively listening to and engaging with patients and families on the council
- Use this enhanced insight into patient experience to drive improvements in the quality and safety of care
- Evaluate the PFAC

It was hoped that the PFAC would explore various topics and issues within the ICU and the information generated would feed into the staff steering group, which could then implement the changes in practice.

Implications for practice

- Meaningful collaboration is possible even in a setting like the ICU where patients are highly vulnerable
- Patients and family members have unique insights and perspectives
- Bringing patients, family members and staff to work together can offer stakeholders a fresh understanding about the journey of a patient through the ICU

This project was supported by the FoNS Patients First Programme in partnership with The Burdett Trust for Nursing

Key activities and outcomes • Staff steering group

The project team started by developing a multidisciplinary staff steering group. At the group's first meeting, a values clarification exercise was conducted to develop a shared vision. The main principle identified was that each member of the group wanted the PFAC not only to help understand the patient experience, but to also ensure that patients would have the opportunity to lead and develop the group in a way that helped future patients and groups. The staff steering group met at regular intervals.

• Other forums with patient involvement

The project team wanted to look at how patients were involved in other forums in local healthcare. Visits to other groups generated interesting information; one had a patient as co-facilitator, and another raised the question of guidelines for meetings.

• Recruitment to the PFAC

Families of patients in the ICU at the time were involved in the discussion about how to recruit patients and family members to the council. These conversations, along with the steering group meetings, raised several questions for consideration, such as: the best time to involve patients after they leave the ICU; when the patient journey starts (before the ICU); and how best to include input from all patients, with good and bad experiences of the ICU. Letters of invitation were sent out and six patients and family members agreed to take part.

• Beyond consultation to collaboration

The aim of this project was to move beyond the established model of patient consultation to one of patient collaboration. To achieve this, several strategies were implemented. The first was to have a patient or family member co-chairing/facilitating council meetings with a member of staff. It was also decided to organise meetings around a loose framework, using an adapted emotional touchpoint technique, then agree with the patient and family members on the format and content of the meeting.

• Changes in practice

The PFAC met six times and discussed various stages of the patient journey. As a result of these discussions, changes were made to information, communication, hospital signage and the family waiting room. Two examples are:

- Family members described difficulties in following signage to find the ICU when their relative was admitted. They also said they were shocked by their relative's appearance or didn't recognise them because of their condition and the amount of medical equipment in use. As a result, new signage was put up around the hospital and posters/information given to family members to prepare them for the experience of the ICU.
- The PFAC also discussed relatives' anxiety when patients are transferred to the ward from the ICU.
 Patients may still have cognitive issues and be unable to remember information such as discussions about care.
 To address this, an information leaflet is being designed for ward staff to ensure they are ready to address these difficulties with patients and their families.