

Terms of Reference

Service Users & Carers Group**Study title:**

The effectiveness of interventions to promote patients' and families' involvement in adult intensive care unit (ICU) settings: a systematic review.

Project summary:

Politicians, doctors, nurses and other health professionals have long called for greater patient and family member involvement in adult intensive care units (ICU) to contribute, in partnership with health professionals, to the delivery of quality care; this is a priority area for the National Health Service, identified through a priority-setting partnership involving patients and carers. This is in response to a shared understanding that such involvement improves the quality and safety of care through better communication between patients, families and health professionals. Effort has been dedicated to activities designed to improve the participation of patients and their family members; however, there continues to be uncertainty about how well these activities work, and which are most likely to be successful. In this project we will work closely with patients, carers and health professionals – following a comprehensive and detailed approach known as ‘systematic review’ – to understand the effectiveness and quality of evidence of such activities. Specifically, we will search a range of research databases and journals to identify reports of activities to improve the participation of patients and family members in adult intensive care. Information on available involvement activities, evaluation methods and outcomes will be examined and considered together. The quality of included research will be assessed in a detailed way following standard guidance. Results from this work will generate a comprehensive picture about what activities are available, which have been shown to work so far and under what circumstances. This will be shared with different hospitals and patient groups across England, to help them make informed decisions about which activities might suit them best. Our results will also identify any gaps in existing research, which will help plan future work to address such gaps and support greater patient and family member involvement in ICU.

Aim of the research

Using a systematic review approach, the project seeks to answer the following question: *What are the available interventions, and which are most effective, for including patients and family members in the care processes and decisions made in adult intensive care unit (ICU) settings?*

Role of the Service Users & Carers Group

The Service Users & Carers Group (SUCG) will act as a consultation committee and sounding board to the research team. The SUCG will consider and provide recommendations on the review approach, dissemination of information and actions based on the review findings.

1. Accountability

The SUCG will be Chaired by Ms Sally Brearley. The members of the SUCG are accountable to the communities, organisations or service users they represent. The review team is accountable for the execution and delivery of the project. The chief investigator, Andreas Xyrichis, is responsible to the project funder (National Institute for Health Research).

2. Responsibilities

- To consider and give feedback on the review protocol (e.g. choice of keywords, inclusion/exclusion criteria of studies) to ensure the search approach is comprehensive and captures as much relevant literature as possible;
- To assist the review team with suggesting possible strategies for dissemination and application of the review findings/conclusions, to ensure these reach to and are meaningful for ICU patients and family members, for example through helping design social media activities and user-friendly publications;
- To advise on the development of a follow-up study and funding application, designed to empirically validate the review findings in the NHS, to ensure future work is again grounded in patient and public involvement.

3. Training

Introductory training in the project research approach, known as systematic review, will be provided by the review team. This may include short presentations, video clips as well as accessible reading material. Support to members of the SUCG will be provided throughout by the chief investigator and the Chair, Sally Brearley.

4. Reimbursement

Travel costs for participation in face-to-face meetings can be reimbursed on provision of full receipt. An honorarium equal to £20/hour is offered in recognition of SUCG members' time and expert input. The project can contribute to potential childcare, carer or personal assistant costs equal to £50/day on provision of relevant receipt. Depending on the timing of meetings, refreshments as well as light breakfast/ lunch /afternoon tea will be provided.

5. Meetings

The SUCG will meet either physically or virtually between two and four times in the duration of the project. Dates of meetings are to be arranged with input from the SUCG members, but are anticipated to be in February 2018, September 2018, and January 2019. The duration of meetings will be agreed with the SUCG members and is likely to be between one and three hours. Agenda and documents for the meetings will be distributed at least 1 week in advance.

Person Specification

We invite individuals with recent and direct experience of intensive care services in the National Health Service in England. Individuals may have experience through being cared for in an intensive care unit (ICU) themselves or may have had a close family member for whom they cared for during their stay in ICU. Individuals with previous experience of being involved in research are especially welcomed. Our SUCG is open to all individuals who meet the person specification, but we will seek to establish a group that has representation from a mix of individuals of different age, gender, ethnicity and experience.

For further information please contact:

Chair, Service Users & Carers Group

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