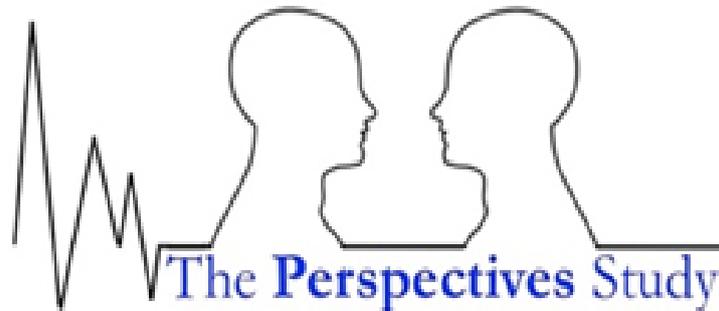


Perspectives on Enhancing Consent and Recruitment in Intensive Care Studies: Summary of the Perspectives Study



Aims of the Perspectives Study

Medical research studies in intensive care units (ICUs) are important to improve treatments for patients. Carrying out research in ICUs can be complicated. Often, patients do not have capacity to consent to take part in research.



Researchers may have to seek consent from a patient's family members instead. If family members are not available, a doctor not involved in the research, can give approval for a patient to take part in a study.

Little is known about what patients, family members, and staff think about how consent and recruitment to research is carried out in the ICU. So, we set up the Perspectives Study to explore their views.

Our overall aim was to produce good practice guidance for future medical studies that take place in the ICU. The Perspectives Study was run by a team at the University of Liverpool and supported by the Economic and Social Research Council. A small group of experienced ICU doctors, nurses, researchers, patients, and relatives have been advising us throughout the study.



What did we do?

We surveyed over 1400 ICU patients, family members, and staff across 14 hospitals in England. This included 333 patients, 488 family members, and 588 members of ICU staff.

In this survey, we asked patients and family members about their experiences of being approached about medical research while in the ICU (if applicable), and their wider views on research. We also asked staff about their experiences of approaching patients and family members about studies, and their wider views on research. We then interviewed 60 patients, family members and staff to explore their views in more depth.

What did we find?

Patients and family members were positive about research

Overall, patients and family members felt they had a positive experience:



⇒ **85%** of patients and **86%** of family members thought the information they received about the medical research study was clear.

⇒ **78%** of patients and **80%** of family members felt they had enough time to decide whether or not to take part in the study.

⇒ **87%** of patients and **94%** of family members believed the staff who talked to them about the study were approachable.

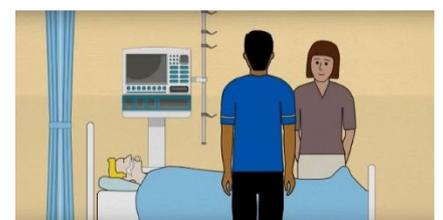
Interestingly, **84%** of patients and **83%** of family members said they felt comfortable about deciding whether or not to be involved in a research study. However, only **45%** of ICU staff believed patients and their family members felt comfortable making this decision. This suggests that ICU staff are more worried about how patients and family members feel about being approached for research studies, than the patients and family members were themselves.

Importance of clear communication

Our findings also highlighted the importance of clear communication about research. For example, some patients and family members were worried that taking part in a medical research study could slow down the patient's recovery, and this made some less willing to take part.

Although all studies carry potential risks, a patient would not be included in a study if the doctor believed that it would harm the patient. In fact, participation in research may also carry benefits and could improve a patient's condition.

Therefore, it is important for staff to explain what any potential risks and benefits might be, and to make it clear that a patient would not be included in a study if a doctor believed it would harm a patient.



Importance of explaining about the timing of medical studies

Some studies have a narrow window of time to include patients because treatment needs to be provided as soon as possible in serious illness. In these cases, a patient or family member has to be approached about the research early in their stay - in some cases just as they arrive in the ICU.

The Perspectives Study showed how important it is to explain to patients and their family members *why* they were being approached about research so early on.

What happens next?

We have used the Perspectives Study findings to produce the good practice guidance on recruitment and consent to medical studies in the ICU. We have developed this guidance as a team, working closely with former ICU patients and their relatives, researchers, ICU doctors and nurses, and people involved in approving research studies.

Want to know more?

Website

It's not possible to cover all the findings in a short booklet. More information about our findings and good practice guidance is available: <https://www.liverpool.ac.uk/population-health-sciences/departments/health-services-research/research/perspectives/about/>

Short Video

You can also learn more about research in the ICU with our short video, developed using the findings of the Perspectives Study:

<http://shorturl.at/mrk26>



If you have any questions about the Perspectives Study, please e-mail: Perspectives@liverpool.ac.uk