



Making decisions about admitting people to intensive care



This is an easy to read guide to a research project which wanted to understand and improve the way doctors make decisions about people having treatment in an Intensive Care Units.*

**Intensive Care Units can also be called Critical Care Units.*

This research project started in February 2015 and finished in 2018. The research was paid for by the National Institute of Health Research, which is the research part of the UK's National Health Service (NHS).

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To read the full research report, please go to:

www.journalslibrary.nihr.ac.uk/hsdr/hsdr07390/#/abstract



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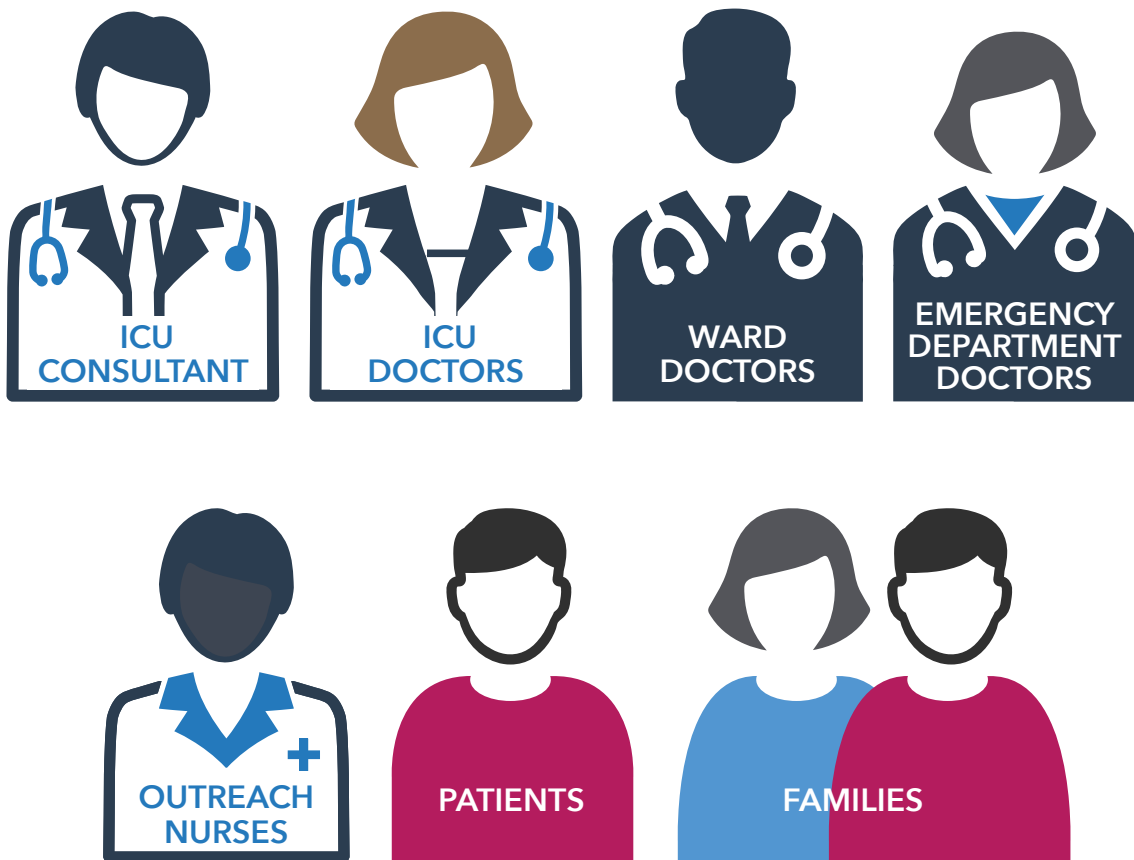


Why was this research needed?

An intensive care unit (**ICU**) is a ward in a hospital for people who need a lot of medical treatments. Often they are very ill and may die.

When a person is very ill, they may be in hospital already or they may come in by ambulance to a hospital's Accident and Emergency Department. Doctors and nurses will assess them (look at how they are) and they may think that they need treatment in an Intensive Care Unit. They let ICU doctors know about the patient. This is called a referral. A decision then needs to be made about whether the patient will benefit from treatment in an Intensive Care Unit.

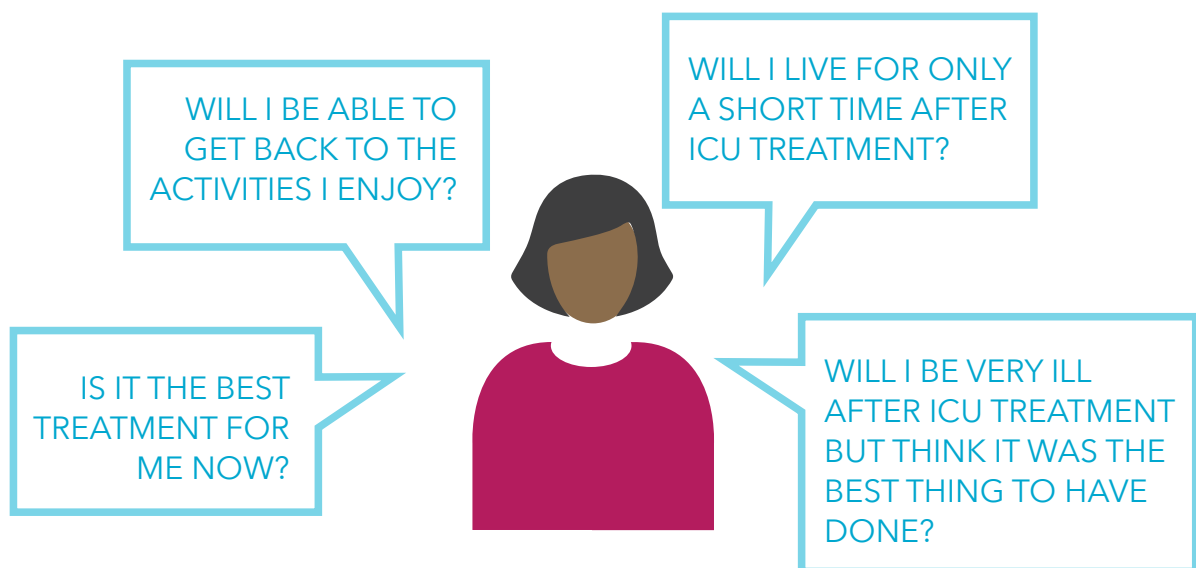
There may be many different people involved in making this decision:





A doctor from the ICU will make a final decision. He or she will ask for information about the patient, or they will come and assess the patient to see if they should come to the ICU for treatment. If they think ICU would not help that patient, the patient will have the medical care they need on the ward. For some patients, this will be making them comfortable as they come to the end of their life.

ICU treatment can save the lives of some people but it does not help everyone.



Intensive Care treatment can be very unpleasant. For example, the treatment that is needed can be distressing. Patients can become confused about where they are and what is happening. This is called delirium and can lead to people seeing and believing things that are not true. People sometimes have intensive care treatment, and find it a distressing experience, and then only live for a short time longer than if they didn't have it. Sometimes it may save their lives but they may be very ill for a long time afterwards and not able to do the things that are important to them. So they may feel that ICU treatment harmed them instead of helping them. And for people who die in ICU, they may have wanted to die at home or somewhere else in the hospital instead.



However people who are very ill and who are not given treatment in an ICU are more likely to die. And people who are very ill and quickly have treatment in an ICU are likely to do better than those waiting to have ICU treatment.

Even with ICU treatment, about 20% of patients who are admitted to ICU die before leaving hospital.

The problem is that it's not easy to say which person would be helped by intensive care treatment and which person might be harmed by it.

Also the person may be too ill to tell medical staff what they would want to happen.

This means that doctors need to decide if intensive care treatment is best for them.

At the moment there are no national training or guidelines to help doctors to make these decisions. This means that different hospitals and different doctors across the UK could make different decisions for similar patients.





What did this research want to do?

The question for this research was:



What is required for an ethically-justified patient-centred decision-making process surrounding admission to intensive care?

This means how should doctors make decisions about ICU treatment for patients that are clear and fair for everyone.

We wanted to:

Find out how these decisions are made at the moment

Put together a decision support pack to help doctors make these decisions

Find a way of checking the decisions that were made to see if they were clear and fair

Who checked that this research was ok to do?

This research was given ethical approval from the Coventry and Warwickshire Research Ethics Committee. This means that a group of people independent from the research looked at what we wanted to do and agreed that it would not harm any patients, families or healthcare professionals.



How did we do this research?

This research had five stages:

STAGE 1 Review of research

First, we did two systematic reviews. Systematic reviews means looking at other research to see what it can tell us about our research question.

Review 1 looked at research about how decisions are made about if a person should go into an ICU.

Review 2 looked at research about the experiences of the people involved in these decisions. These were healthcare professionals, patients and their families.



STAGE 2 Finding out how decisions are made

We then looked at how intensive care doctors make these decisions in six hospitals in England. For three weeks at each hospital, a researcher watched doctors and nurses to see how referrals for ICU treatment were made in that hospital and how the decision was made about if a patient was to have treatment in an ICU.

The researcher then interviewed the people involved, including:

- doctors making the referrals
- intensive care doctors
- intensive care staff who work outside the ICU (known as Critical Care Outreach)
- patients and families.



STAGE 3 Survey

We used what we had learnt from the first two stages of this research to do a survey called a 'choice experiment'. This is a way of finding out which things are most important to healthcare professionals making referrals and decisions about intensive care treatment. They were asked to read information about different imaginary (made-up) cases and see if they thought if ICU treatment would help those patients.





STAGE 4

Developing support for healthcare professionals making these decisions

We used all we had learnt from the first three stages to develop a way to help doctors to make these decisions. We called this a Decision Support Intervention. It gives suggestions about what the doctors should think about to make sure the decision is clear and fair for all patients. We showed this to people from organisations representing patients and healthcare professionals and asked what they thought about it. We used their feedback to make it better. We then asked three hospitals to use this intervention to see whether it helped better decisions to be made. We also asked intensive care doctors and ward doctors in the three hospitals if they found it helpful when they made these decisions.



STAGE 5

Finding a way of checking how well the decisions were made

To see if our decision support pack worked, we needed to know if the decisions made were clear and fair for all patients. We put together a set of questions that we used to check this in patient's notes.



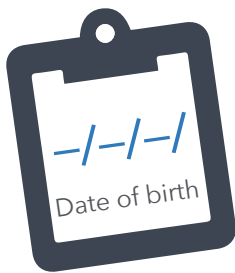


What did we find out in our research?

STAGE 1: Review of research

For review 1, we found there were 88 research studies which could give us helpful information about the things that could influence a doctor's decision about whether treatment in ICU would help a patient.

The most common things that made a difference were:



The age of the patient



What type of illness they had



If they already had a long term serious illness



What the person's life was like before they came into hospital



Which department the referring doctor had come from



If an ICU bed was available in the hospital



For review 2, there were only 12 research studies which could tell us about patients, relatives and healthcare professionals experiences of decision making.

Important areas were:



How well the clinical teams got on with each other



Good communication

(how well all the different healthcare professionals explained things to each other and to patients and relatives)



Working where resources were limited

(where there was not enough of something) such as time, staff or equipment

Healthcare professionals said they sometimes felt uncomfortable with the final decision because they didn't think it was the best decision for that patient.

A very important thing that we found out was that there has been very little research which asked patients and families about their experiences when these decisions are made.



STAGE 2: Finding out how decisions are made:

Our researchers watched 55 decisions being made for 46 people. They interviewed 101 healthcare professionals, 14 family members and 3 patients.

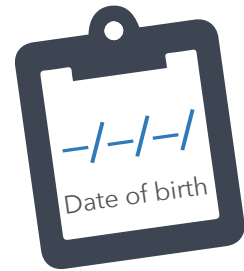
We found out that important things that were considered by doctors when making the decision to see if a patient could have ICU treatment were:



How the patient's illness might progress



If the treatment the person needed could be safely done on the ward



The age of the person



How ill they are at the time of the decision



How the person seemed



What the person's life was like before they came into hospital

By watching doctors, we found out how difficult it is to make these complicated decisions, especially as a decision may be needed quickly.



We found out that doctors didn't often ask the patient what they would want to happen (though many patients would be too ill to be able to say), and doctors didn't often ask the family what they thought the patient would want. When doctors did ask, they found it very helpful, though.

We saw times when decisions were made in a good way. This included looking at lots of different information about the patient to help make the decision and supporting the other healthcare professionals involved in making the decision. Good communication (talking to each other clearly) was very important for good decisions, particularly with other healthcare professionals and families of the patients.

We found that doctors felt the things that helped good decisions were:



When senior doctors were involved



When healthcare professionals work together to come to a decision



When doctors making the decisions see the patient

We saw that sometimes the way that decisions were made was not very good. This could happen when there was poor communication between healthcare professionals. Sometimes ICU doctors didn't understand why a patient had been referred to ICU and sometimes referring doctors were not clear what ICU treatment could and could not do for a patient. There can also be other things that can influence the decision that are not about the patient (such as if there are any ICU beds free).

We didn't often see doctors balancing how ICU treatment might harm the person with how it might help them. We also found out that junior doctors need training and support to help make these referrals and decisions.



STAGE 3: Survey

Based on what we had learnt from stage 1 and 2 in this research, we chose eight things that doctors thought were important in making these decisions.

The eight things were:



The person's age



How ill the person was

(based on examination of the patient and blood tests)



What the person's life was like before they came into hospital



If the person had other illnesses



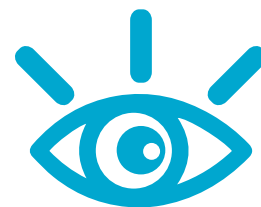
How severe any other illnesses were



Whether the family wanted the person to be treated in the ICU



If there were enough doctors and nurses on a ward where a person would have care



How the junior ICU doctor thought the patient was doing

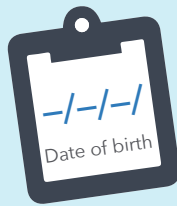


We then included these in information about imaginary patients. We asked the people filling out our survey to decide if they would admit each patient to intensive care. We could then see which of the eight things made the most difference when making this decision.



303 ICU doctors and
187 Critical Care outreach nurses
filled out our survey

We found that all eight factors were important to the final decisions, but different factors were more important for some people than others.



Overall the age of the patient was the factor that made the most difference for doctors and nurses.



STAGE 4: Developing support for healthcare professionals making these decisions

We created a support pack for doctors making these decisions.

This pack included:

- A step by step guide about the factors that need to be thought about for clear and fair decisions. For example, collecting information about the patient and their illness and then balancing all the different information collected. We included a decision support form for doctors to use based on this guide
- Information about what doctors and nurses need to include to make a good referral to ICU doctors. We included a referral form for doctors to use based on this information
- Patient and family information leaflets explaining about decision making for ICU treatment
- Information to help hospitals use this pack.



We tested this pack for **6** weeks in **3** hospitals around the UK.



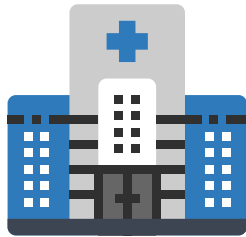
We looked at patient records of **181** people who were referred for intensive care treatment to see how the decisions were made.



We then interviewed the healthcare professionals who used it.



We interviewed:
19 referring doctors,
20 ICU doctors,
3 Critical Care Outreach nurses.



Across the **3** hospitals, the forms were used in just over a quarter of decisions about admission to intensive care.



This meant that **45** referral forms and **36** decision forms were used. The forms were more likely to be used if a patient was older.



Some doctors told us:

- they found the forms easy to use
- they were worried that they might not have time to fill them in
- they found it difficult to write down exactly how ICU treatment would be good for patient against the harm that it might do
- thinking about these points helped them talk about the issues with the other doctors and nurses
- that the decision support pack said what they usually do anyway
- that the pack reminded them to talk to patients and their families to find out what was important to them.



The patient and family information leaflets were not used at the three hospitals.

Overall referring doctors and ICU doctors felt the pack could help to make sure that the decisions made about ICU treatment are clear and fair for all people. Some hospitals asked about using our pack in the future.



STAGE 5: Finding a way of checking how well the decisions were made

We developed a way of checking patient notes to see if the decisions made were clear and fair for all patients. The tool had a list of key factors which we agreed were important for this. We gave points for each of these factors. We then used this evaluation tool to look at 40 sets of notes of people who had been referred to ICU from each of the three hospitals.



We found:

- **it wasn't always easy to find in the patient's notes what decision was made**
- **we only managed to score 54% of the decisions**
- **there was a lot of difference between how our reviewers (those looking at the notes) judged the decisions**
- **this tool was not ready to be used to judge decision-making in hospitals, but it might be useful as a way to talk about decisions and how they are made.**



How were patients and the public involved in this research?

It was very important that we heard from patients and the public about this research because decisions that are made by doctors about ICU treatment can change the lives of patients and their families. We also wanted their ideas about how we could make the patients and their families involved in the research as comfortable as possible.

We involved patients at every stage of the research:



Before we asked for funding for this research, we held a meeting for former patients and public representatives to ask them what they thought about our plans and the research question.



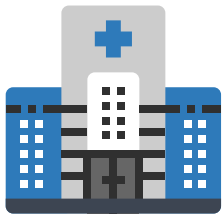
We had one patient and one public representative on our investigator team (the team that did the research). They were involved with the research for the three years.



We had a Patient and Public Involvement Advisory group. It met six times during the research.



We had an Independent Steering Group who oversaw our research and there were two patient and public members of this group. This group met six times during the research.



Three patient and public representatives spoke to us about what we found out during Stage 2 of our research (Stage 2 was when we visited hospitals to watch decisions that were made and interviewed people about them).



We held a meeting to help us with our research and we had nine people representing patients and public there.



We were not able to find people who could come to this meeting to represent patients who are older and people using mental health services, so we went to two local community groups to ask for their comments about our Decision Support pack.



We held a meeting at the end of our research to tell people about what we had found out. We included a video recording of a patient about the important points for patients and their families.

All our patient and public representatives helped make sure that this research found out things that would make a difference to patients and their families.



What could we have done better in this research?

As for all research projects, there were things that could have been better in each stage.

For example, we didn't manage to do many interviews with patients and their families in stage 2 of this research. This was because many patients and families didn't want to be interviewed at such a difficult time.

When testing our decision support pack (at stage 4) we found that:

- Eight weeks was not enough time for hospitals to be able to start using the pack, and they would have liked to have had more time
- Some hospitals used the forms but they asked for all the information to also be written in the patient notes, so this meant it took longer for the doctors to use the forms
- We also found that some doctors were confused about when the forms should be used.

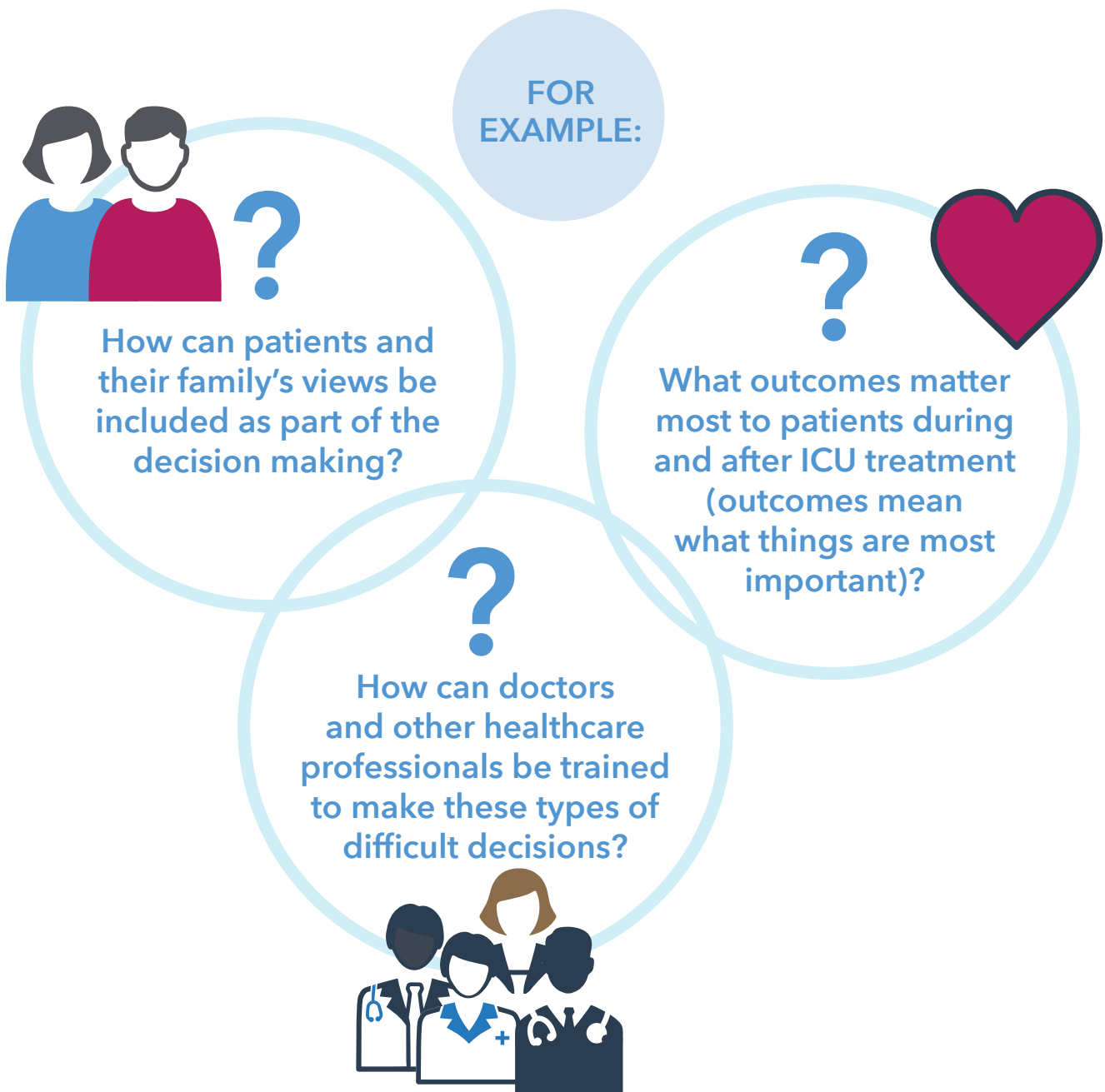


Overall, because we had lots of different ways to find out information for this research (this is known as a mixed methods research), we felt that we still found out many important things about decision making for intensive care treatment.



What research should be done next?

There are lots of areas that need to be researched about decision making around admission to intensive care.





How can I find out more about this research?

We wrote a full report about our research.

This is at www.journalslibrary.nihr.ac.uk/hsdr/hsdr07390/#/abstract

Conclusion

This research has provided information and guidance to help healthcare professionals and hospitals make better decisions for people who are very ill and their families.

This research looked at how decisions are made about people who may need ICU treatment. We found that these decisions are very complicated to make and there are lots of things that can affect the final decision. Some of these are about the patient but other things can influence the decision too (such as what else is happening at the time the decision is made and how hospitals are organised).



We found good decisions are made when healthcare professionals communicate well (talk with each other clearly) and if they trust the different medical teams involved. We found that it was hard for healthcare professionals to balance how ICU treatment might help a person and how it might harm them. Junior doctors also need more help to learn how to make these decisions. There was a general agreement from all healthcare professionals that decisions should be clear and fair for everyone.

One of the most important things that this research found out is that patients and their families are not often part of the decision making. Doctors thought that information from the patient and their family was important but they did not often ask patients and their families for it. The information leaflets we put together as part of the pack were not given to any patients and families. More work needs to be done to make involvement of patients and their families better.





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This report presents independent research funded by the National Institute for Health Research (NIHR) under the Health Services and Delivery Research Programme (Ref.13/10/14). The views expressed in this publication are those of the authors and not necessarily those of the NIHR or the Department of Health and Social Care.

