ReSPECT study: Information for Patient Participants

You have been given this information sheet to tell you about a research study taking place in the hospital. The study is looking at how doctors and nurses use the Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) with people who are in hospital. We would like to invite you to take part in an interview with a researcher as part of this study. This information sheet explains why the study is being done and what it means for you. The researcher will go through the information sheet with you and answer any questions you have. Please ask us if there is anything that is not clear.

What is ReSPECT?
A Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) records which treatments doctors and nurses should consider in the event of an emergency if the patient is not able to communicate their wishes at the time. The plan is made with a patient when they first come into hospital. If a patient is too sick to talk to the doctor or nurse, the plan is discussed with the patient's family or someone close to the patient.

What is the purpose of the research?
We want to learn more about how doctors and nurses go about making emergency treatment plans with patients and their family. To do this we want to speak to patients and their families as well as to the doctors and nurses looking after them to find out their views about the ReSPECT plans. This will help us to work out if we need to make any changes or recommendations for improvement.

Why am I being asked to take part?
You are being asked to take part because you have had a ReSPECT plan completed. We would like to talk to you about your experience of the ReSPECT planning process.

Do I have to agree to take part?
No – it is entirely up to you. If you choose to not take part, it will not affect your treatment or care in any way. If you agree to talk to us you can change your mind at any time by telling the researcher or contacting the study co-ordinator using the information at the end of this sheet.

If you choose to withdraw from the study before we have analysed your data, we will remove the information about you that we have already obtained. If you choose to withdraw from the study after we have analysed your data we may not be able to remove the information about you. To safeguard your rights, we will use the minimum personally-identifiable information possible.

What happens if I agree to take part?
If you agree to take part, the study the researcher will arrange a time to come and talk to you about your experience. He/he will ask you some questions about what it was like to talk to your doctor or nurse about treatments and about them completing the ReSPECT form. The interview will take about 20-30 minutes. The researcher will audio record the interview if you agree. If you do not want the interview recorded then the researcher will take hand written notes.

Relevant sections of your medical notes and data collected during the study, may be looked at by individuals from the University of Warwick, from regulatory authorities or from the NHS Trust, as part of monitoring the conduct of the study.

What are the advantages of taking part?
Taking part in this study is unlikely to directly benefit you. However if you take part it will help us to understand how emergency treatment plans are made and how this process might be improved.

What are the potential disadvantages of taking part?
Talking about your experiences of discussions with your doctor about emergency treatment can be hard and may be upsetting. The researcher will check to see if you are OK and stop if the conversation is upsetting you. You will be able to take a break or stop the conversation completely at any time.

Will my involvement in this study be confidential?
All information that is collected during the study will be kept confidential at all times and held in line with the Data Protection Act 2018. Only the researcher and members of the study team will have access to information about you and it will not be shared with anyone else. The research team or a paid typist may help us to type out what you have said during the interview. We may share things you have said in your interview in presentations or written reports of the research. However, no personal information will be shared that would allow anyone else to know that they were your words. In rare situations, the research team may need to share information gained in the study if there was a worry about a major risk of serious harm to you or others. All information that we collect will be stored securely in either lockable filing cabinets or password-protected computers. The information will be kept for ten years following completion of the study.

What will happen to the results of the study?
We will summarise the findings from this research and share it with interested groups. We will do this by publishing the results in professional journals and by talking to healthcare professionals and patient group meetings. We will share any lessons learned with the national working group who developed ReSPECT. A summary of the research will be publically available on the study website.

Who is organising, funding and sponsoring the study?
The study is led by Professor Gavin Perkins who is an intensive care doctor. The National Institute for Health Research have provided funding for the study (project number 15/15/09). University Hospitals Birmingham NHS Foundation Trust and the University of Warwick are the sponsors for this study based in the United Kingdom. We will be using information provided by you in order to undertake this study. The University of Warwick will act as the data controller for this study, and are responsible for looking after your information and using it properly.

Further information on how your data will be used can be found in the ReSPECT Data Transparency Statement for Patients & Relatives which you will receive from the study researcher in addition to this information sheet. This information can also be found on the study website www.warwick.ac.uk/respectevaluation.

Who has reviewed the study?
All research in the NHS is reviewed by an independent group of people. This study has been reviewed and approved by the Coventry and Warwickshire Research Ethics Committee (REC reference: 17/WM/0134).

What if there is a problem?
If you have a question about any aspect of this study you should first speak to the study researcher who will do their best to answers your questions. You can contact the researcher on Telephone: 07384 231 325; Email: respect@warwick.ac.uk.

Any complaint about the way you have been dealt with during the study or any possible harm you might have suffered will be addressed. Please address your compliant to the following person, who is a senior University of Warwick official entirely independent of this study: Head of Research Governance, Research & Impact Services, University House, University of Warwick, Coventry, CV4 8UW. Telephone: 024 76 522746. Email: researchgovernance@warwick.ac.uk.

Your local NHS Trust Patient Advice Liaison Service (PALS) can also be contacted if you have any further concerns by telephone (insert details) or by email (insert details).

Further information and contact details

If, at any time, you would like further general information about this study, please contact the study coordinator at Warwick Clinical Trials Unit – Claire Jacques, Telephone: 02476 575923; Email: respect@warwick.ac.uk.

General study information is also available on the study website: www.warwick.ac.uk/respectevaluation

Thank you for taking the time to read this information sheet