Recommended Summary Plans for Emergency Care and Treatment (ReSPECT) Evaluation Study

Information for primary care focus group / interview participants

We are researchers at the University of Warwick, University Hospitals Birmingham NHS Foundation Trust, Cambridge University Hospitals NHS Foundation Trust, St Christopher's Hospice, London and the Intensive Care National Audit and Research Centre. We are carrying out a study to look at how doctors and senior nurses use the ReSPECT process to make a plan with a patient and/or their family for future emergency care and treatment in case of a serious deterioration in the person's health. This part of the study is exploring primary care practitioners' experience of using the ReSPECT process and how it transfers across the primary to secondary care interface.

What is the study about?

The ReSPECT process is a discussion between a person and their doctors and nurses about the kind of treatments and care they would want in the case of an emergency. The result of this discussion is a summary of recommended treatment and care (the ReSPECT form) which can guide health care professionals looking after the person in a future emergency situation when the person cannot make decisions for themselves. The plans are made, as far as possible, ahead of any emergency situation when the person and their health care professionals are in a better position to think about what should go into the plan.

The Resuscitation Council UK and Royal College of Nursing established a working group, to develop a national form to record these plans with the aim of improving emergency care and treatment decisions for all patients. This research will look at how the ReSPECT process and the record form is working for patients, their families and their health care professionals.

What is the purpose of the study?

The objective of this part of the study is to conduct focus groups or interviews with general practitioners, district nurses and other members of community healthcare teams involved in the ReSPECT process, to explore their experiences of using the ReSPECT process, what influences its use and why, dilemmas encountered while using ReSPECT, and practitioners' understandings of what happens to the ReSPECT form when a patient is discharged from or admitted to hospital.

Why am I being asked to take part?

You have been asked to take part as your practice is located in an area served by one of the five acute NHS hospital trusts that have implemented the ReSPECT process and are participating in the evaluation study.

Do I have to agree?
You do not have to agree to take part. You are free to withdraw at any time up to the point that data analysis is commenced. If you choose to withdraw, you do not need to give a reason. If you change your mind after you have participated in a focus group or interview and do not wish for your responses to be used in the study, please contact the study co-ordinator using the contact details given at the end of the sheet.

If you withdraw from the study prior to data analysis, we will remove the information about you that we have already obtained. If you withdraw from the study after data analysis 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, a researcher from the study team will contact you to arrange a suitable date and time to invite you to attend a focus group or an individual interview conducted either in-person or over the telephone / Skype.

Focus groups will be run by trained facilitators and it is anticipated up to 8 will attend. The focus groups will approximately take between one and two hours. Discussions will be audio recorded. The audio recordings will be transcribed and anonymised for analysis.

Individual interviews will be conducted by a researcher from the ReSPECT Evaluation Study team, and will take place either in-person or over the telephone / Skype, depending on your availability and preference. The interview will take approximately one hour, and will be audio recorded. The audio recordings will be transcribed and anonymised for analysis.

What are the potential advantages and disadvantages of taking part?
There are no significant personal direct advantages or disadvantages associated with you or your practice by participating in this research. More generally, the results of this study will help to evaluate the ReSPECT process to increase our understanding of how it works.

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 compliance with the Data Protection Act 2018. Only the researcher and members of the study team will have access to the information. Any audio recordings from the interviews may be transcribed by a third party transcription service or a member of the research team contracted to work on the research project. You will be identified by a study number and no personal details will be included in the analysis of the interview transcripts. We may use written quotations from the transcripts to illustrate academic presentations or publications based on this research. However, you will not be identifiable in any published material. In exceptional circumstances the principal investigator may need to disclose information obtained in the study if there was a concern about a significant risk of

serious harm to others. Study documentation and data will be archived for at least ten years after completion of the study.

What will happen to the results of the study?

We will seek to publish the study findings in peer reviewed journals and present them to health care professionals at national and international conferences. We will make any developments to the decision support framework available to all NHS Trusts. A summary of the research findings will be provided for all participating Trusts and to patients and the public.

Who is organising, funding and sponsoring the study?

The study is led by Professor Gavin Perkins, Consultant and Professor in Critical Care Medicine at University Hospitals Birmingham NHS Foundation Trust and the University of Warwick. This project was funded by the National Institute for Health Research [Health Services and Delivery Research] (project number 15/15/09). University Hospitals of Birmingham 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 GP's 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 from Warwick Medical School who will do their best to answer your questions. You can contact the researcher via telephone: 0738 423 1325 or 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 complaint 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

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 by telephone 02476 575923 or 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.