ReSPECT in Primary Care

Evaluating the Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) in Primary Care
Information sheet for GP/senior nurse interview

The practice (NAME) is taking part in a research study led by Professor Anne Slowther at the University of Warwick which is looking at how the ReSPECT process is used in Primary Care. As part of this study we would like to interview General Practitioners and senior practice nurses about their experience of using the ReSPECT process. We are inviting you to take part in an interview with a study researcher to explore your experience of using ReSPECT.

Section 1: what is the study about and what does it mean for me if I take part?

What is the study about?

The Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) is a process that records a summary of the discussion between a health care professional and a patient, or their family (if the patient lacks capacity) about treatments that may or may not be considered in a future emergency situation. This includes relevant health information, information about the patient's wishes and values, and the agreed recommendations about treatment. It is used to guide clinicians and other healthcare professionals looking after a patient in a future emergency situation when the person cannot make decisions for themselves. It sets Do Not Attempt Cardiopulmonary Resuscitation Decisions in the context of overall care and treatment plans. ReSPECT is now being used in primary care settings in many areas across the UK.

What is the purpose of the study?

The study will investigate how, when, and why ReSPECT is used in Primary Care and what effect it has on patient treatment and care. We will look at this from the point of view of GPs, practice staff, managers of care homes, and importantly from the point of view of patients and their families. This study is part of a wider project evaluating ReSPECT in Primary Care.

Why am I being asked to take part?

You have been asked to take part because you are a GP or senior practice nurse working in a practice that has implemented the ReSPECT process. Your practice has agreed to be one of the study sites and we are now seeking consent from individual GPs and senior nurses in the practice to participate.

What will happen if I agree to take part?

If you agree to take part in the research the researcher will contact you to arrange a convenient time for the interview to take place. We plan for interviews to be carried out either by video link using a University approved secure system or by telephone if you prefer. It may be possible to carry out an interview face to face, depending on national and local guidance relating to COVID-19. If this is the case, you will be offered that option in addition to the video or telephone option. Before the interview takes place, you will be asked to give written consent. If

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the interview takes place by videoconferencing or telephone, we will send you a consent form prior to the interview. Before the researcher begins the interview, they will read out the statements on the consent form and ask if you agree. The researcher will then, with your agreement sign the consent form on your behalf. A copy of this will then be sent to you electronically or by post. The interview will last approximately 30 minutes and with your permission will be audio or video recorded. The researcher will ask you about your experience of having ReSPECT discussions with patients or their family, how the process works in your practice, and any challenges you have experienced.

Do I have to take part?

No you do not have to take part in the study, and if you agree to be interviewed you can change your mind at any time prior to data being analysed. We will wait two weeks before we analyse any data from your interview. If you change your mind after you have done the interview with the researcher, please contact the study manager using the contact details given at the end of the sheet.

What are the potential advantages of taking part?

Taking part in this study is unlikely to have any direct benefit for you or your practice. However, taking part will help increase our understanding of how ReSPECT is used in Primary Care and how anticipatory decisions are made and acted upon when patients become acutely ill.

What are the potential disadvantages of taking part?

The interview will require some of your time which may place an extra burden on your already very busy clinical schedule. We will organise the timing to fit with your schedule and the practice will be paid for your time during the interview. There are a range of support services for professionals provided including the BMA support for doctors and the RCN Foundation has a repository of resources for nurses and allied health professionals which you may find helpful.

How will you use information about me?

We will need to use information from your interview for this research project. We will also need to use your name and your contact details so that we can contact you to arrange an interview

People will use this information to do the research. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

We will keep all information about you safe and secure. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

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 patients. Should this occur we will discuss it with you.

What are my choices about how my information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have unless you ask us not to. We need to manage your study records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

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Where can I find out more about how my information is used?
You can find out more about how we use your information:

- at www.hra.nhs.uk/information-about-patients/
- the leaflet available from www.hra.nhs.uk/patientdataandresearch
- by asking one of the research team
- by sending an email to respectpc@warwick.ac.uk, or
- by ringing us on 02476 573988.

Further information about how we process your information can be found in section two of this information sheet.

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. The findings will also be made available to the national working group who developed ReSPECT and to the GP practices and care homes taking part so they can make any necessary improvements. We will make any developments to the ReSPECT process available to all health and social care commissioning organisations. A summary of the research findings will be provided for health care professionals and to patients and the public.

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Section 2: How will information about me be kept safe?

What information will be collected for the study?

We will ask for your contact details for the study. We will store them on a secure university server in a password-protected file for the duration of the data collection period. This will be kept separate from any other information collected for the study. Access to your information will be restricted to staff working on the study who have a justifiable need to access it.

The interview with the researcher will be recorded on an encrypted audio recorder or computer and securely transferred to the University of Warwick computer servers for secure and protected storage. Any notes made by the researcher will also be stored securely in the University. Access to this information will be restricted to authorised members of the study team who have a justifiable need to access the data. You will have 14 days following the recording to reconsider if you are happy for us to use this information, after which we will analyse the interview. Once the interview is analysed it will not be possible to remove your interview data from the study.

What will happen to the information collected?

The University of Warwick will act as the data controller for this study. As a publicly funded organisation, the University of Warwick must ensure that it is in the public interest when we store personally identifiable information from people who have agreed to take part in research. This means that we will only use your data in the ways needed to conduct and analyse the research study, and we will hold your data securely in line with current general data protection regulations (Data Protection Act, 2018).

We may contract a university-approved external company to write up the recording of your conversation with the researcher. This is called transcribing. If we do, the recording file will be labelled with an identification number only. We recognise that during your conversation the researcher may refer to you by name so to ensure any identifiable information is protected, the person writing up the interview will be required to sign a confidentiality agreement with the University of Warwick.

The transcription notes will be labelled with an identification number and will not contain any personal information about you. The notes will be securely transferred from the external company back to the University of Warwick. The external company will destroy all information once it has completed this work. Once the notes have been verified by the study team, we will permanently delete the recording of your interview. At the end of the study we will delete your personal contact information so you will not be able to be identified from any of the research data (the data will be anonymised).

The University of Warwick has in place policies and procedures to keep your data safe. Further information on how your data will be used can be found on the University of Warwick webpage: https://warwick.ac.uk/services/idc/dataprotection/privacynotices/researchprivacynotice

The members of the study team who analyse the information will not be able to identify you. It is possible that the anonymised (not identifiable to you) data may be shared in the future with other Higher Education Institutions, organisations or companies that work within health research. Direct quotes may be used when we present the results in the study report and future publications but these will be anonymised (you will not be able to be identified from these quotes).

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Section 3: Study oversight and contact details for queries or concerns

Who is organising, funding, and sponsoring the study?

The study is led by Professor Anne Slowther, Professor of Clinical Ethics at Warwick Medical School who has a clinical background in general practice. This project was funded by the National Institute for Health Research [Health Services and Delivery Research] ref: NIHR131316).

The University of Warwick is the sponsor for this study based in the United Kingdom. We will be using information provided by you and your practice in order to undertake this study. The University of Warwick will act as the data controller for this study, and is responsible for looking after your information and using it properly.

Further information on how participant data will be used can be found in the ReSPECTPC Data Transparency Statement for GP practices and care homes which you will receive from the study researcher in addition to this information sheet. This information can also be found on the study website …..

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 NHS London South East Research Ethics Committee).

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 answers your questions. You can contact the researcher on 02476 573988, Email: respectpc@warwick.ac.uk)

Who should I contact if I wish to make a complaint?

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 person below, 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
Email: researchgovernance@warwick.ac.uk
Tel: 02476 575733

If you wish to raise a complaint about how we have handled your personal data, you can contact our Data Protection Officer who will investigate the matter: DPO@warwick.ac.uk. If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO).

Further information and contact details

If, at any time, you would like further general information about this study, please contact the study manager Katie Bruce, tel: 02476 573988

General study information is also available on the study website: tinyurl.com/k87v5fda

Thank you for taking the time to read this information sheet

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