REC reference: 21/LO/0455

ReSPECT in Primary Care

Evaluating the Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) in Primary Care

Information sheet for participants (faith leaders interview study)

Thank you for considering taking part in this research study. The researcher [name] will have given you information about the study when they spoke to you on the phone. This information sheet is to help you remember what was said and to discuss the study with family and friends if you wish to. If you have any questions or concerns you can contact the study team or speak to the researcher before the interview.

This study is about how doctors and nurses have conversations with a patient or a member of their family about medical treatments that might be considered in the future if they suffer a serious deterioration in their health. We want to find out the views of faith leaders about these types of discussions, and the process of documenting them.

The study is run by The University of Warwick and is led by Professor Anne Slowther.

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

What is the study about?

ReSPECT stands for Recommended Summary Plan for Emergency Care and Treatment (ReSPECT). This records which treatments doctors and nurses should consider for a person in a future emergency situation if the person becomes seriously unwell and is unable to communicate at the time. The plan is made with the person either during a conversation with their GP or hospital doctor, or sometimes when a person is admitted to hospital. If a person isn't able to talk to their doctor or nurse about the plan, it is discussed with the person's family or someone close to them.

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. To do this we will be talking to GPs, care home staff, and most importantly patients and families who have had a ReSPECT form completed. But we also want to find out how people in the community who have not been involved in the ReSPECT process feel about it so we will be carrying out focus groups with people in the community. As part of this investigation we would like to talk to community Faith leaders to understand the different perspectives that might influence how people view the aims of ReSPECT and how it works.

Why am I being asked to take part?

This project is funded by the National Institute for Health Research (NIHR) Health Services and Delivery Research programme

You have been asked to take part because you have been identified as a Faith leader in your community.

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 you 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 manager 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.

What happens if I agree to take part?
If you agree to take part, the study researcher will arrange a mutually convenient date and time for the interview. They will also discuss with you the best way to organise the interview. This will probably be by a video link or by telephone. If COVID regulations allow, and you would prefer, we may be able to arrange an interview face to face. During the interview the researcher will provide a copy of a ReSPECT form to help the discussion. They will ask you questions about your views on the ReSPECT process and the aims behind it. They will ask you about how the values in the ReSPECT process sit with the key values of your faith, and explore challenges for people following your faith and how we might be able to mitigate them. The interview will take about 45 minutes. The recording will be typed out and any details identifying you will be removed. The information from your interview will be combined with information from all our other interviews and focus groups to give a broad picture of people's views of the ReSPECT planning process.

What are the potential advantages of taking part?
Taking part in this study is unlikely to have any direct benefit for you. However, if you take part it will help us to understand different perspectives on emergency treatment plans and how this process might be improved for people following different faiths.

What are the potential disadvantages of taking part?
Talking about the topic of emergency care planning can raise emotions, particularly if you have personal experience of these types of conversations. We won't be asking specifically about your experiences in this interview. You will be able to take a break or stop the conversation completely at any time.

Expenses and payments
In consideration for your time to take part in the interview we will send you a gift voucher worth £20.

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How will you use information about me?
We will need to use information from your interview for this research project. We will collect:

- Your name
- Your contact details so that we can contact you to arrange the focus group

People will use this information to do the research or to check your records to make sure the research is being done properly. 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 you or others. 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.

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 summarise the findings from this study and use it to help improve conversations and decisions about future treatments in emergency situations to improve patient care. The results of the study will be published in professional journals and presented at health professional and patient group meetings. A summary of the research will be publicly available on a study website.

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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 conversation 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 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 have to 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 the interview 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 typing 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 the 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 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. It is important to share research findings with other researchers so that the

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research can be used to improve patient care and treatment. 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).

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/researchprivacyn_otice

What will happen to my information if I don't want to carry on being part of the study?

If you decide that you do not want your conversation or any information collected about you to be used in the study you can inform us that you want to withdraw from the study. Any information we have about you will be destroyed. However, information cannot be withdrawn once analysis has taken place because then we will no longer be able to identify your specific information.

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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. The National Institute for Health Research have provided funding for this study (NIHR HS&DR reference number: NIHR131316). The University of Warwick are the sponsors for the study.

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 Tel: 02476 573988 or Email: respectpc@warwick.ac.uk.
If you have a problem or concern about the conduct of this study, please contact the Head of Research governance from the University of Warwick who is the study sponsor:
Email: researchgovernance@warwick.ac.uk).

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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