

Summary Participant Information Sheet (Easy Read)

What is the study about?

Sometimes when people have an emergency they are unable to tell their doctors what care and treatment they would like because they are too ill.



ReSPECT is a form that can be filled out before an emergency happens.

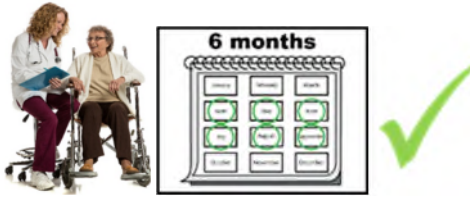
It stands for the Recommended Summary Plan for Care and Treatment.



It tells doctors what you would like to happen if you have an emergency or become very unwell.

It can be filled out by your doctor after they have talked to you about what you might want and about different treatments.

Why have I been given this leaflet?



Because your doctor has filled in a ReSPECT form for you in the last 6 months.

What are we doing?

We want to find out how people feel about ReSPECT.



We want to find out if it is the best way for people to tell their doctors about their wishes in an emergency.



We are asking people who have a ReSPECT form to tell us what they think about it.

What will happen to me if I want to take part?

A researcher would meet with you to find out what you think and feel about your ReSPECT form.



- We could meet with you by telephone, by video link, or at home.
- The meeting could last about 30 minutes.
- We will tape record what you say.
- You can have a family member or friend with you if you would like.

We would also like to look at your GP records to see whether your care and treatment matches what is said in your ReSPECT form.

A few months after the meeting, we would like to speak to you again to see if how you feel about your ReSPECT form has changed.



You can still take part in the first meeting if you do not want a second one.

Do I have to take part?

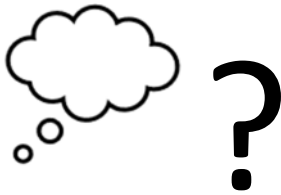
No. It is your choice.



If you decide not to take part in the study it will not affect the care or treatment that you get in any way.

Can I change my mind?

Yes. You can change your mind at any time and we will stop the meeting.



You don't have to tell us why.

After the meeting you can still change your mind but we may not be able to remove all of your information from the study.

What will I get if I take part?

You will get a £20 high street voucher



Risks of taking part?

Some people may feel sad or upset if they talk about this



Tell us if you feel sad or upset. We can stop the meeting. We can support you to get more help if you feel very sad or upset.

What information will be collected about me?

We will collect some personal information from you. This will be things like:

- Your name and how old you are.
- Your telephone number, address and email.
- Information from your GP about your ReSPECT form and any illnesses or emergencies you have.



How will you use the information about me?



In this research study we will use information from you. We will only use information that we need for the research study.

We will let very few people know your name or contact details, and only if they really need it for this study.



Everyone involved in this study will keep your data safe and secure. We will also follow all privacy rules.



At the end of the study we will save some of the data in case we need to check it or for future research.

We will make sure no-one can work out who you are from the reports we write.

If we think that you, or someone else, is not safe we will need to tell other people about this.

What will happen to the results?

We will write about the results. We will send them to journals so other people can read about them.

We will also present the results at meetings with doctors and patient groups.

Your details will be private so no one will be able to tell that they are your answers.





Who is doing the study?

The study is being done by researchers at the University of Warwick.

Professor Anne Slowther is in charge.

The study is also checked by an ethics committee, who are a group of people that will make sure the study is done well.

What if there is a problem?

If you have any questions or are worried about the study please tell us.



You can talk to the researchers at the University of Warwick.

Email: respectpc@warwick.ac.uk

Telephone: 02476 573988

If you want to complain formally you can do this too. You can speak to the Head of Research Governance at the University of Warwick.

Email: researchgovernance@warwick.ac.uk

Telephone: 02476 575733

Who do I contact if I want more information, or if I want to take part?

You can speak to the researchers:

Dr Jenny Harlock or Dr Sophie Rees



Warwick Medical School

University of Warwick

Gibbet Hill Campus

Coventry

CV4 7AL

Email: respectpc@warwick.ac.uk

Telephone: 02476 573988