



Recommended Summary Plan for Emergency Care and Treatment

Information for patients, families of patients
and members of the public

Version 1.0

Introduction

This leaflet is about a document called a Recommended Summary Plan for Emergency Care and Treatment (ReSPECT). It explains how recommendations about your care and treatment in a future emergency are decided and recorded on it. The leaflet may not answer all your questions, so please talk to a member of the healthcare team looking after you if there is anything you don't understand, or if you would like more information.

What is the purpose of ReSPECT?

ReSPECT is not just a form.

The purpose of the ReSPECT process is to help you and your doctors and nurses to discuss, agree and record recommendations about the types of care and treatment that you would or would not want to be considered for in an emergency. This is important, because in lots of emergencies people are not able to communicate or make decisions for themselves, so making a plan in advance helps to ensure that each person gets the care and treatment that is right for them.

Taking into account your state of health and your preferences for your future care, your ReSPECT form provides a summary of personalised recommendations for your clinical care in an emergency situation where you are not able to decide for yourself.

The health professionals looking after you in such an emergency may have to make immediate decisions about your care and treatment, but may not have met you before and may not know your wishes or your usual state of health. They may include ambulance staff, doctors and nurses. They may be looking after you at your home, in a hospital, in other places such as a nursing home or hospice, or during a journey by ambulance. When immediate decisions are needed, the recommendations on your form provide information to help them make the ones that are best for you

The ReSPECT form aims to ensure that you will receive the best possible treatment for your individual situation. It cannot be used to request or demand treatments that will not be beneficial to you.

Does it matter how old I am or that I have a disability?

No. A ReSPECT form can be used for individuals of all ages and ability, including children and young people.

What is important is:

- your views and wishes;
- your state of health;
- the likelihood of the healthcare team being able to achieve what you want.

Who decides the recommendations and completes my ReSPECT form?

Your views are crucial. The health professionals who are looking after you must give you all the information that you require about your state of health and about treatments that you may need, so that you and they can make the right decisions together.

If, after careful assessment, your healthcare team finds that you don't have the mental capacity to make the decisions that are needed for your ReSPECT form, they must make decisions that will benefit you or be in your best interests. To do this they must talk to your family or other people who are able to speak for you in order to decide on the choices that you would have made, if you had been able to.

If choices haven't been made in advance and you become critically ill, need emergency treatment and are unable to participate in making decisions about your treatment, the health professionals looking after you may complete a ReSPECT form for you. This is done in your best interests, to make sure that you receive relevant treatment and also that you are not given treatments that are of no benefit and could cause you harm. When a ReSPECT form is completed in such an emergency, the health professionals looking after you must explain and review the decisions as soon as possible with your family or other people who are important to you, and with you if you become able to participate in decisions.

Who should consider having a ReSPECT form?

Anyone may have a ReSPECT form, but it will have increasing relevance for people who have particular needs; for those who are likely to be nearing the end of their lives; or for those who want to record their care and treatment preferences for any other reason.

Where is the ReSPECT form completed?

A ReSPECT form can be completed wherever you are when the need for it is recognised. Ideally, it will be discussed with you and completed before you are critically ill, so that you have ample time to consider the decisions that are right for you and discuss these with your health professionals and, if you want to, with people who are important to you. Sometimes, that isn't possible, and a ReSPECT form is needed when someone is critically ill in hospital and there is much more urgency to record a plan for their emergency care and treatment.

What types of care and treatment will be considered and recorded?

Usually, these will depend on the choices that you want to make with your doctor or other health professional, but these individuals will guide you on the decisions that might be relevant for you. These will be about aspects of care and treatment that might be considered for you if your health deteriorates and there is a possibility that you may die.

For example, you may decide to have recorded whether or not you would want to be admitted to hospital for treatment if your health deteriorates. That could guide doctors or ambulance paramedics who are called to you in an emergency but who have not met you before. If you decide that you would want to be considered for hospital treatment, there may be some types of care or treatment that you would want and others that you would not. For example, these might include admission to an intensive care unit (ICU).

The ReSPECT form includes a specific section for recording whether or not attempting cardiopulmonary resuscitation (CPR) would be the right thing to do for you if your heart and breathing were to stop. (Please refer to CPR section below)

It is important to emphasise again that the form aims to ensure that you receive the best possible treatment for your individual situation.

Is a ReSPECT form only about withholding treatment?

No. Its purpose is to record treatments that would be wanted if needed and appropriate, as well as those that would not be wanted or would not be effective. There are many individuals whose ReSPECT forms will make clear that all possible treatment should be offered. This can be invaluable for example, to a person with a complex disability.

Can I use a ReSPECT form to insist on having treatment?

No. You can make clear what treatments you would want to be considered for and what treatments you would not want, but you may not demand or insist on receiving any particular treatment.

When should a ReSPECT form be completed?

The best time to have a ReSPECT form completed will vary in each individual.

Predicting exactly when someone will die isn't often easy, but if it is likely that a person is nearing the end of their life, consideration of a ReSPECT form is recommended. For many people this allows time and careful discussion with their health professionals and their families, enabling them to make the choices that are right for them at the time that is right for them.

Similarly, when someone has complex health needs or a condition that could lead to an emergency in which they are unable to make decisions or communicate them it is best to consider completing a ReSPECT form when they are relatively well and able to make choices.

If decisions are delayed until a person becomes critically ill or is in immediate danger of dying, they may be too unwell to make clear choices, and there is more likelihood that health professionals will have to make decisions for them.

I am currently fit and well - can I have a ReSPECT form?

Yes, you can, if you want to record your care and treatment preferences in case of an unexpected emergency. Having a ReSPECT form is of increasing relevance for anyone who is more likely to have an emergency in which they cannot make or communicate decisions. Even if they are well in between such episodes, they may want to make clear what types of care and treatment they do and do not want to be considered for.

What if I don't want a ReSPECT form?

You are entirely free to decide that. If you prefer not to discuss or consider future choices, or to make advance plans about your future care and treatment, health professionals will continue to care for you, to help you to make choices about any treatments when you need them, and to choose the treatments that are considered best for you if you are not able to make a decision at the time.

Can I change my mind?

Yes. The recommendations recorded on a ReSPECT form are the ones that are right for you when they are recorded, but if your condition or circumstances change, or if you want to change your mind for any other reason, the recommendations can be changed. Speak to a member of your healthcare team if you want to discuss this or change your mind about any of the recommendations on your ReSPECT form.

Remember also that if you decide that you don't want a ReSPECT form, you can always change your mind and consider having one at a later date, even if it doesn't feel right for you at present.

Will having a ReSPECT form affect my care?

Only in an emergency where you cannot make decisions for yourself. The ReSPECT process and form are intended to ensure that you have the care that you need and that you would want and that you don't receive treatment that you wouldn't have wanted or that will not help you but could do you harm.

Everyone has a right to be treated with dignity and respect, and to receive good care. Recommendations about your future care on your ReSPECT form will affect it only in the way that that has been discussed and recorded, and will not change any other care or treatment that you may need.

Is a ReSPECT form legally binding?

No. A ReSPECT form is to guide rapid decision-making by health professionals treating you in an emergency. How they use the information on it will depend on the exact circumstances of the emergency. However, they would have to have good reasons for ignoring the recommendations on your ReSPECT form.

In England & Wales, if an adult wants to make a legally binding refusal of one or more types of treatment they should complete an Advance Decision to Refuse Treatment (ADRT). That would not replace the ReSPECT form, which records details of care and treatments for which you would want to be considered, as well as any treatments that you wish to refuse or that would not work for you. Details of a document such as an ADRT should be recorded on your ReSPECT form.

Can my ReSPECT form be used wherever I am?

Yes. For example it can be used in your home, in hospitals, hospices, care homes, nursing homes and during ambulance journeys. For that reason it is important that you keep it with you, and that it is readily available for people who may need to see and use it. It is best to take it with you if you go out, and to make sure that your family, friends or carers know about it, and know where to find it in an emergency.

If you move from one place to another (e.g. to or from home, hospital, hospice, care home, nursing home or from one hospital ward to another) it is good practice to review the recommendations on the ReSPECT, but a new form is not needed unless the recommendations change.

Why is there a special section about CPR?

Cardiopulmonary resuscitation (CPR) is a treatment used when someone suddenly collapses due to cardiac arrest, respiratory arrest or cardiorespiratory arrest. This means that their heart and/or breathing has stopped. When this occurs, starting CPR immediately will give some individuals the chance of recovery to a length and quality of life that they value. Delay in starting CPR reduces the chance of success, so health professionals usually start CPR without delay when a person's heart and breathing stop. Making a clear recommendation in advance about CPR helps to ensure that CPR is started without hesitation in those who might benefit and would want it and that CPR is not attempted in those who would not want it or would not benefit from it.

Why shouldn't everyone be resuscitated?

CPR is by no means always successful in restarting the heart and breathing. When CPR is shown in films and TV 'soaps' they often fail to show the reality of what is involved and of the likelihood of success.

When the heart stops as part of the natural process of dying from an advanced and irreversible condition, CPR doesn't prevent death, but for some people can prolong dying or prolong suffering. CPR includes violent pressing on the chest, blowing air or oxygen into the lungs and delivering electric shocks across the chest, so when it cannot be of benefit to someone it deprives them of dignity in the last moments of their life. Because of this many people choose not to receive CPR and health professionals try to avoid attempting CPR when it will not prevent a person's death and could do them harm.

If you are someone who needs CPR to be started immediately, a complete ReSPECT form will make this decision clear, and improve your chance of survival.

If you and your health professionals decide that you won't be helped by CPR then recording this on your ReSPECT form can help to ensure that, as far as is possible, CPR is avoided.

If I don't want to have CPR, how do I make sure this is understood/known?

It's important to discuss this with the health professionals who are involved in your care, so that they can support you in making and recording the recommendation that is right for you.

Wherever you live, you can ask your health professionals to record your wishes about CPR on your ReSPECT form. If you live in England or Wales and you want to record this as a legally binding decision you can also make an Advance Decision to Refuse Treatment (ADRT) but it's best to make sure that the detail of your ADRT is recorded on your ReSPECT form so that health professionals will know about it.

The ReSPECT form must be available immediately if it is needed in an emergency. Keeping it in a prominent place in your home is important, but remember to take it with you when you go out for any reason. If you were to collapse whilst you are out, passers-by or ambulance clinicians would be unaware of a form in your pocket or handbag, so it is important that people who are with you know about your recorded wishes and where to find the form in an emergency.

What if I don't want to talk about any of this?

Some people find these kinds of discussion distressing or frightening. If you don't want to discuss these matters, for whatever reason, that's fine. Tell your healthcare team and they will support you and will act in your best interests. If necessary they will make decisions for you when they are needed.

Can my family decide for me?

If you want to, you can involve your family, friends or carers in helping you to make the decisions that are right for you. If you don't want your family or others to know about your condition or your choices, please make sure that your healthcare team knows about this so that they can respect your wishes for confidentiality.

If you are not well enough to make shared decisions with your healthcare team, they have to make decisions that are in your best interests.

Can my family decide for me? (continued)

They will usually talk to your family or other carers to help them to do this, unless you have asked them not to. However, your family and other carers will not be asked to make decisions for you unless they have been given specific legal authority to do so (for example with a Lasting Power of Attorney or as a Guardian or Welfare Attorney).

Can I see what's written about me?

Yes. You can see what's written about you.

Your ReSPECT form should stay with you wherever you are, so it's important that you know what recommendations are recorded on it and that you are comfortable with them.

In some places, documents such as ReSPECT forms are also kept electronically in your health records. Increasingly, such documents will be available to health professionals who need to see them (for example in ambulance services and hospital emergency departments) so that they have information that they need to plan your treatment in an emergency. If any changes are made to the recommendations on a paper copy of your ReSPECT form, it's important for your healthcare team to make these changes in your electronic health records as well.

You can ask the healthcare team to show you your health records and, if there is anything in them that you do not understand, they will explain it to you.

I still have some concerns or questions – who should I ask?

It's important that you raise these, in the first instance with a member of the healthcare team looking after you. It doesn't have to be a doctor or anyone in particular. Ask the person who you find it easiest to talk to, and if they can't answer your questions and concerns they will be able to find someone who can help you.

Who else can I talk to about this?

In addition to the healthcare team looking after you, there are others you may want to talk to about the recommendations in your ReSPECT form, for example:

- patient support groups
- spiritual carers or advisers
- independent advocacy services

If you need help in contacting any such people please ask a member of your healthcare team.

The following space is for you to write down any questions that you may want to ask: