

Completing the ReSPECT form (The practical stuff)

Section 1 - Personal details

Rationale: To ensure that someone using the form in an emergency can have absolute confidence that it belongs to the correct person.

Method: Insert clearly the person's full name, date of birth and address. Insert the date on which the form is completed. Always include the NHS or CHI number unless they do not have one. Add the name the person would like to be addressed by.

Section 2 - Summary of relevant information for this plan

Rationale: To explore and achieve a shared understanding of their present state of health and what they may expect, and to record details of other relevant documents.

Method: Before starting a ReSPECT conversation with a person (or with their family or other representatives if they lack capacity), make sure that you have the clearest possible understanding of their current state of health, based not only on reference to available records, but also discussion with other members of the health and care team. Insert here a summary of the medical background to inform recommendations that will follow (e.g. relevant diagnoses, present state of health, expected prognosis, communication difficulties and how to overcome them). Record relevant detail and the location of documents such as Advance Decisions to Refuse Treatment, advance care plans, advance statements, or organ donor cards.

Section 3 - Personal preferences to guide this plan (when the person has capacity)

Rationale: To help people understand the balance between focusing on treatment predominantly for comfort and treatment predominantly to sustain life, and to identify and agree priorities for their care, and to record the things most important to them in their life.

Method: Based on the shared understanding of their current situation and state of health that has been achieved, ask the person to consider the goals of care and treatment in their circumstances and to describe their priorities for their care. If they and you find it helpful, use the scale to help them to understand the balance between a focus on comfort and a focus on sustaining life, and how that balance may change. If they wish, they can mark the scale to indicate their current balance, but this is largely for their reference and not for use in guiding future decisions in an emergency.

Prioritise sustaining life... Prioritising life-sustaining treatments does not mean that the person would not receive treatment to control symptoms, but they may want to be considered for some life-sustaining treatments that involve a degree of discomfort or risk.

Prioritise comfort... Prioritising comfort indicates that the person wants primarily those types of care and treatment whose purpose is to control symptoms and provide comfort.

The second box is to allow people to have recorded one or two aspects of their life that are most important to them.

Section 4 - Clinical recommendations for emergency care and treatment

Rationale: To record recommendations to guide immediate decision-making in a future emergency.

Method: Based on the priorities that have just been discussed, start by signing the agreed goal of care as either focusing on life-sustaining treatment or focusing on symptom control. Record clear recommendations about the types of care or realistic treatment that the person would want to be considered for and that could help to achieve their goals of care, and those that they would not want or that would not work in their individual situation, such as admission to hospital or the intensive care unit (see 'What is ReSPECT?' if you want to know more). Recommendations can be added to clarify certain situations (such as the focus on life-sustaining treatment but does not want blood transfusion, or focus on comfort but consider non-invasive ventilation). Sign only the appropriate box.

There is then a specific space to record whether or not attempted CPR is recommended, and for children only, to recommend modified CPR. Sign one of these boxes only. Remember that there must be a presumption in favour of involvement of the person (and/or their family or other representatives) in the decision-making process unless that would cause the person harm. If CPR would not work and is not being offered, refer to the agreed goals of care and explain why CPR would not help to achieve those goals.

Section 5 - Capacity and representation at time of completion

Rationale: To record whether or not a person has capacity to participate in making the recommendations in their plan, and whether or not they have a legal proxy who must be consulted if they lack or lose capacity.

Method: Early in the process you will either have accepted that the person has or lacks capacity.

Remember that an adult must be assumed to have capacity unless it is established that they lack capacity. If you suspect that an adult person lacks capacity for the decisions needed in the ReSPECT process, perform a formal capacity assessment and document it fully in the person's health records. Answer 'yes' or 'no' in the first box. Then establish whether or not the person has a legal proxy and complete the second box, recording details of any legal proxy in section 8.

In the case of a child or young person, establish who holds parental responsibility. Insert details of any such proxy or person with parental responsibility in section 8.

Section 6 - Involvement in making this plan

Rationale: To confirm that the process and form have been completed lawfully in accordance with capacity and human rights laws, and to document who was involved in discussing and agreeing the recommendations recorded.

Method: Circle at least one of the statements A, B, C, D (more than one may apply). For example, both A and B may apply for some children and young people, and both C and D may apply for some people who lack relevant capacity.

If D is circled, indicating there has been no shared decision-making with the person themselves (or no involvement of family or other representatives of a person who does not have capacity) you must use the red-bordered box to provide reasons for this. Make sure that these reasons are detailed fully in the health record, together with a clearly defined plan to involve the person or their representatives as soon as this is possible or appropriate.

Then record the date(s) of the ReSPECT conversations, and the names and roles of those involved.

Make sure that detail of the discussions is documented in the health record. Record on the form where to find that further detail.

Section 7 - Clinicians' signatures

Rationale: To validate the entries on the form and ensure that the recommendations are endorsed by the senior responsible clinician.

Method: The professional who completes the ReSPECT form must add a legible signature and legible name and registration number, and the date and time. If they are not the senior responsible clinician (i.e. GP, consultant or a senior nurse), then the senior responsible clinician should be informed and agree to the plan's completion. They should review and endorse the recommendations by adding their signature at the earliest possible opportunity. In some circumstances, they may consider further discussion and possible revision of the plan. Refer to local policy for the timeframe in which the form needs to be countersigned by the senior responsible clinician to remain valid.

Section 8 - Emergency contacts

Rationale: To record contact details of key people to contact in the event of major deterioration, imminent death, or any change in the person's condition that may warrant reconsideration of the previously recorded recommendations.

Method: Record the contact details in the boxes provided.

Section 9 Confirmation of validity (e.g. for change of condition)

Rationale: For future use to record when the form has been reviewed and the recommendations confirmed to be still valid.

Method: This section should be left blank at the time of initial completion of the plan. Review may be triggered if the person or their representative asks for this, the person's condition has changed, or if the person is moving from one setting to another i.e. being discharged from hospital.

The recommendations on the ReSPECT form do not have a defined expiry date, as the need for review must be considered carefully for each person at each stage of their clinical progress. In an acute illness, very frequent review is likely to be needed, so you should plan for this.

Storing the form

Once a form is completed, it is important that the person keeps it with them, and that it is readily available for professionals who may need to see and use it.

At home the ReSPECT form should be kept somewhere accessible, so that their family or other representatives know exactly where to find the ReSPECT form if an emergency occurs. In a hospital, care home, hospice or other organisation the form must be stored in a clearly defined and rapidly accessible place, whether it is in paper or electronic format.

Capacity - Adults

If the person has capacity for the relevant decisions, they must be involved fully with the process of shared decision-making. Many people want to have the support of family or other representative in the discussion, and some may choose to have a family member or other representative advise them on what choices to make. If you are asked to speak to the person's family or other representative alone, and the person has capacity, then seek their permission first. If they do not want their family or other representative to know about their condition or their choices, they should make sure that the healthcare team knows about this so that their wishes for confidentiality can be respected.

If a person lacks capacity and has appointed a legal proxy (e.g. with power of attorney for health and welfare), the clinical team must involve them in making shared decisions on behalf of the person. Where there is no legal proxy, the clinical team must consult family or friends about a person's situation and previously expressed views or wishes, in order to make decisions that are in that person's best interests and for their benefit. However, the responsibility for making those decisions rests with the senior responsible clinician. The family must not be burdened with thinking that they are being asked to make these decisions.

Capacity - Children and young persons

If the young person has sufficient maturity and capacity for the relevant decisions, they should be involved in the process of shared decision-making. Some parents may advise that they wish to exclude their child from these discussions. It is important to explore and understand their reasoning for such a request and to seek an appropriate approach through which to include their child in the process.

For young people, under the age of 16, a pragmatic line must be steered regarding their involvement in order to establish a position that is ethically acceptable to all those involved. For those over 16 the Mental Capacity Act applies and their involvement in the decision making should be guided accordingly.

If a young person over 16 lacks capacity their parents will normally act as their legal proxy. As such the clinical team must involve them in making shared decisions on behalf of the person. Where this is not the case, a person will be identified by social services to fulfil the legal proxy role.

Real world tips

The 'S' in ReSPECT stands for 'summary' – in an emergency, people may not have time to read lots of text, so be clear and succinct - the information should be accessible at a glance. You can signpost to clinical records where a more detailed documentation of conversations and preferences exists. Write legibly – so there are no misinterpretations.

Think about who is going to read the form – use plain English, avoiding medical jargon and abbreviations as much as possible, as the form may be read or acted on by people with little or no medical or specialist knowledge. Think about who may need to use the form to help them make immediate decisions e.g. ambulance clinicians, out-of-hours doctors, community nurses, care home staff, hospital nurses and doctors.

Think about where the form may be used – and where the person may be when an emergency occurs, and ensure that the recommendations are relevant to all those settings.

Take time to complete the form - time spent discussing preferences and completing the form well will help ensure that the person gets their agreed treatment, and will save time during their further care, especially in a crisis, when decisions have to be made without delay.

Sign the correct boxes – take care to sign the correct boxes on the form to indicate the priorities of care and the recommendation about CPR. Signing the incorrect boxes can have serious consequences.

Sign the form – the person who has had the conversation and completed the form with the person should be the first signatory. Add a legible signature and legible name and registration number. The senior responsible clinician, such as the person's GP, consultant, or senior nurse, is responsible for the plan and if they are not the initial signatory they should sign to endorse it as soon as possible. Inform others looking after the person – if a form has been completed or updated ensure those involved in the person's care are up to date with the recommendations.