

What is ReSPECT ?

ReSPECT is a process that creates personalised recommendations for a person's clinical care in a future emergency in which they are unable to make or express choices. It provides healthcare professionals responding to that emergency with a summary of recommendations to help them to make immediate decisions about that person's care and treatment.

The key stages of the ReSPECT process are:

1. Understand

To establish a shared understanding of the person's state of health and medical conditions, and what they might reasonably expect in terms of progressive deterioration, abrupt health crises and longevity.

2. Set goals

To establish what is important to the person, and what they see as the main focus for their care and treatment – balanced between sustaining life and maximising comfort – this allows people to agree their goals of care.

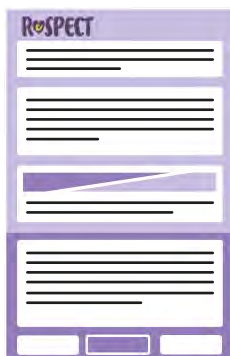
3. Plan

To discuss the treatments that should be considered for a person as well as treatments which they may not want or that may not help them. The recommendations are recorded on a ReSPECT form.

And... though ReSPECT is not legally binding, the recommendations made must be considered when making decisions about the person's care and treatment and draw attention to any other legally binding documents they may have.

A change of culture is needed to think about emergency care planning in this way, which will take time to embed among the public and among professionals.

ReSPECT stands for Recommended Summary Plan for Emergency Care and Treatment and it works like this:



- ReSPECT starts with someone who is suitable for the ReSPECT process.
- A two-way discussion then takes place between the person and the healthcare professional to enable their current and future state of health to be discussed and their priorities of care to be voiced.
- The wishes and recommendations are documented on a ReSPECT form by the healthcare professional.
- The form is kept by the person and should travel with them.
- The plan should be reviewed and can be modified whenever the person's circumstances or condition changes, or if they want to reconsider the recommendations.

In current UK practice, there are many different do not attempt cardiopulmonary resuscitation (DNACPR) and treatment escalation plan (TEP) forms – some are specific to hospital trusts and local communities and they are usually clinician-led. ReSPECT creates a unified and nationally recognised process that supports shared decision-making between a person and their healthcare professionals in making anticipatory recommendations about emergency care and potentially life-sustaining treatments, including CPR. ReSPECT is complementary to any wider process of advance or anticipatory care planning.

ReSPECT is a different kind of emergency planning process because:

- 1 ReSPECT is 'proactive' and not 'reactive'**

The recommendations are created through conversations between a person and their healthcare professional when they are well enough to make these decisions for a future emergency in which they are unable to make or express choices. The process encourages more people to make plans, even those who are currently well.
- 2 ReSPECT is personalised**

The process has been designed to be person-facing, including parts of the form which seek interaction with the person to record their priorities of care. It focuses on what is important to that person and not only on clinical recommendations.
- 3 ReSPECT involves more than just the person**

Those close to the person, such as family and/or other representatives, can be involved in the process and should be consulted if the person cannot contribute to the conversation. The multidisciplinary healthcare team can provide an agreed assessment of the person's health condition and treatment options. Involving others in the discussion enables them to hear the person's wishes first-hand and understand the basis for the recommendations recorded.
- 4 ReSPECT is about more than just a CPR decision**

The process considers broad plans for a person's emergency care and treatment, identifying care and treatments that could help them achieve their goals of care, treatments they may not want or that may not work for them. These may include being admitted to hospital in an emergency, or being admitted to intensive care. See the 'Further Information' section for examples of some other treatments that may be considered.
- 5 ReSPECT applies nationally and in all settings**

Whereas some current DNACPR and treatment escalation plan forms are only applicable within a certain organisation or community, the ReSPECT process is applicable anywhere in the UK. The form accompanies the person wherever they are and go, such as home, the Emergency Department, hospital wards, care home, hospice and when using an ambulance or other transport services. Once the recommendations are recorded they travel with the person and can be updated when necessary.
- 6 ReSPECT has been developed by national experts and members of the public**

ReSPECT has been developed by a Working Group of over 30 individuals representing the public and a number of professional organisations from a range of care settings and clinical specialties.

Professional insight

“The ReSPECT process is all about thinking ahead with patients about realistic care options in a truly person-centred way. Ultimately the process aims to help people understand the care and treatment options that may be available to them in a medical emergency and enables them to make health professionals aware of their preferences.”

Dr Juliet Spiller, Co-Chair of the ReSPECT Working Group & Consultant in Palliative Care, Edinburgh

Children and young persons

“ReSPECT works beautifully alongside the advance care planning work that’s gone on across the country - and there are a number of protocols and forms in use at the moment. The Children and Young Person's Advance Care Plan (CYPACP) is one of the most widely used forms; and the ReSPECT process and form are complementary to that. ReSPECT presents the key emergency information that may be required in an Emergency Department, or wherever the child or young person first presents, without wading through what can be a very complex document.”

Dr Peter-Marc Fortune, Co-Chair of the ReSPECT Working Group & Consultant Paediatrician

Ambulance clinicians

“Ambulance clinicians often attend emergency calls and find that a person is unable to decide or communicate their wishes. The introduction of ReSPECT means we will know what treatment they have agreed they would or wouldn’t want in an emergency, and their views about whether they want to be taken to hospital or remain in their own home environment and under what circumstances.”

Cathryn James, Association of Ambulance Chief Executives & Paramedic

FURTHER READING

What recommendations can be included on the form?

Some recommendations for care and treatment, that may be considered when having a conversation, and completing a ReSPECT form include:

- Admission to hospital from the community.
- Having intravenous antibiotics for a life-threatening infection.
- Urgent interventions, such as adrenaline for anaphylaxis, seizure control treatment and steroids in -
- Addisonian crisis.
- Receiving organ support, such as renal dialysis or ventilation.
- Having blood products.
- Having an operation.
- Admission to an intensive care unit (ICU) or high-dependency unit (HDU).

Consider listing those things that are recommended initially, followed by those that are not recommended.

Practicalities of the form

Can the form be printed in black and white?

We recommend that the ReSPECT form is printed in colour, because that makes it easy to identify and locate in an emergency. If the form is printed in black and white, there is a greater chance that it will not be found and that immediate decisions will be made that do not consider the person’s

previously expressed wishes and the agreed clinical recommendations. However, the colour of the form does not invalidate a properly followed ReSPECT process, or the preferences and clinical recommendations recorded on a form that has not been printed in the recommended colour format.

Can the form be photocopied?

We recommend that the ReSPECT form is not photocopied for clinical use, but may be photocopied for audit or administrative purposes and labelled clearly "COPY ONLY – NOT FOR CLINICAL USE".

This is to try to avoid a situation where an original ReSPECT form has been cancelled and replaced because of changed circumstances, wishes or recommendations, but a copy of a previous version has not been cancelled or destroyed, and is used to guide decision-making as if it were the current version.

Can the clinical details on the ReSPECT form be completed automatically from the electronic patient record?

No. At present the form can be printed on paper and completed by hand or used as a fillable pdf, which can then be printed so that the person can keep it with them.

Is there a plan to digitise the form?

The ReSPECT process has been designed initially as a paper-based form that remains with the person. With the development of shared record systems across local health and social care communities, the benefits of sharing a ReSPECT form electronically and being able to view and update it from different care settings should improve the ability to share current and accurate information rapidly, which is particularly important in urgent and emergency care situations.

A digital version of ReSPECT, which can be made available across care settings, including access by both 111 and the ambulance service, as well as to the person themselves, is currently being developed. Where electronic end-of-life care planning systems already exist, the ReSPECT form should run alongside these, or be integrated with them.

How ReSPECT fits in with existing documents

What happens to DNACPR forms or treatment escalation plans (TEPs) that are already in existence?

Existing DNACPR forms and TEPs will continue to be effective and do not need to be replaced immediately. When healthcare communities implement the ReSPECT process there must be a robust plan to ensure that existing DNACPR forms or TEPs remain valid for a substantial period of overlap. ReSPECT is not a replacement for a DNACPR form: the aim is to promote recording an emergency care plan by many more people, including many whose ReSPECT forms will recommend active treatment, including attempted CPR if it required.

Children and young persons

What if a child or young person already has an advance care plan (like a CYPACP that also has information about their wishes)?

Both documents work together, hand in hand. The ReSPECT form contains only a summary of recommendations to help clinicians to make an immediate decision about a child's treatment in a crisis. Their advance care plan will have more detailed information to guide their care and treatment in other circumstances. The process of advance care planning provides an opportunity to discuss also the relevant elements of a child's ReSPECT form, allowing the two documents to be completed together.

What is the difference between ReSPECT and an Advance Decision to Refuse Treatment (ADRT)?

An ADRT is a legal document that people in England & Wales can complete to refuse treatment that they do not want to receive. If it is completed according to the Mental Capacity Act 2005 it is legally binding on anyone who knows about it and who can be confident that it is valid and applicable to the situation that they are dealing with. A ReSPECT form is not legally binding and focuses only on making recommendations about care and treatment that might be considered in an emergency.

A ReSPECT form can be used to draw attention to the presence of an ADRT and should contain relevant aspects within the summary recommendations for treatment and care.

What is the difference between ReSPECT and an Advance or Anticipatory Care Plan (ACP)?

A ReSPECT form is a very specific type of ACP that summarises the emergency care aspect of a wider Advance or Anticipatory Care planning process. ReSPECT records that information so as to make it accessible rapidly to professionals who need to make immediate decisions about care and treatment in a crisis.

An ACP is made with people who are able and willing to think ahead to a time in their illness when they may be unable to express their preferences. An ACP document is usually longer and more detailed than ReSPECT. It is not restricted to planning for an emergency, and is likely to contain information about preferences such as self-management plans, place of care preferences, funeral plans, understanding of prognosis, details of financial and welfare power of attorney.

ACP and ReSPECT are entirely complementary. They may be developed together, from the same conversations, or development of one may prompt people to discuss the other.

What is the difference between ReSPECT and an end-of-life care plan?

Use of and potential benefit from the ReSPECT process is not restricted to people with life-limiting illnesses or those in need of end-of-life care. End-of-life care plans record a person's individual care and treatment needs as they approach the end of their life, and are not limited to recommendations for use in an emergency.

For people approaching the end of life, the two plans can be complementary. Care must be taken to ensure that both types of plan address the specific needs of each individual.

Why was the ReSPECT process created?

Why was the ReSPECT process created and who created it?

"The Resuscitation Council was set-up to promote CPR amongst the public and amongst health professionals. But if we are going to promote good quality resuscitation it is important that we try to resuscitate people who have some chance of benefiting, and that we don't inflict resuscitation on people that have no chance of benefiting. Because of that, DNACPR decisions were made going back to the 1970s and forwards from there. We then found that there was evidence that these decisions were being misinterpreted or misunderstood and sometimes encouraged people to maybe not focus on what people needed but more on what treatment was going to be withheld. Having seen some of that evidence emerging in 2014, a group of people from around the UK who had been involved with these sorts of projects in their own individual areas got together and realised that if we worked together we might be able to create something that could be adopted nationally and that would be of benefit to patients."

Dr Peter Davies, general practitioner, Halifax, and Care Quality Commission regional advisor in general practice, North of England, soundbite

ReSPECT has been developed by over 30 individuals representing both public and professional organisations from across the health sector, including service users and statutory organisations.

The ReSPECT process and form were developed iteratively over a period of two years. The project included public consultation, patient focus groups and usability testing, and was informed by best practice in the UK and internationally. The resulting process and form were designed to:

- be acceptable to patients, those important to patients, health professionals, carers and other members of the public.
- be underpinned by a good decision-making process.
- promote good decision-making.
- promote dialogue between individuals and clinicians.
- be used across all care settings.

- be used for individuals of all ages.
- use evidence and experience from other successful initiatives.
- consider decisions about CPR within overall goals of care.

ReSPECT was created by representatives of the public and of:

- Resuscitation Council (UK)
- Royal College of Nursing
- British Medical Association
- Care Quality Commission
- General Medical Council
- Association of Ambulance Chief Executives
- NHS Scotland
- Royal College of Anaesthetists
- Royal College of Emergency Medicine
- Royal College of Physicians
- Royal College of General Practitioners
- Royal College of Surgeons Edinburgh
- Professional Records Standards Body
- Faculty of Intensive Care Medicine
- Intensive Care Society
- Association for Palliative Medicine
- Paediatric Intensive Care Society
- Child and Young Person's Advance Care Plan Collaborative
- Joint Royal Colleges Ambulance Liaison Committee
- Marie Curie
- Macmillan Cancer Support
- Mencap
- Cambridge University Hospitals
- University of Southampton
- Warwick Clinical Trials Unit
- UCLPartners
- Wellcome Trust
- Helix Centre

Law and ethics

"As a lawyer who spends a lot of time thinking about how the mental capacity act interacts with clinical practice, ReSPECT seems to be absolutely invaluable because of what it is allowing people to do. It is moving away from thinking solely about do not resuscitate notices, into thinking about a much more holistic picture about what people want and what they don't want when it comes to treatment. The more we can make that conversation part of routine clinical practice the better."

Alex Ruck Keene, practising barrister, writer and educator specialising in mental capacity law

The ReSPECT form is not legally binding. The ReSPECT recommendations are designed to guide immediate decision-making by health and care professionals who respond to the person in a crisis, and who must have valid reasons for overriding the recommendations on a ReSPECT form.

The ethical and legal principles that underpin the guidance in 'Decisions relating to cardiopulmonary resuscitation' by the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing are valid also for the ReSPECT process.

Will the form be valid in all 4 nations as they have different capacity laws?

ReSPECT is a nationally available process and form. England and Wales have the same capacity law. When ReSPECT is adopted in Scotland some limited changes of wording may be made, but the ReSPECT process and basic structure of the form will remain the same and it is expected that a form completed in Scotland would be recognised and respected in England or

Wales, and vice versa. New capacity legislation for Northern Ireland was passed in 2016 and has many provisions in common with the law in England and Wales, but has not yet been implemented.