

## **An introduction to ReSPECT**

### ***Notes for presenters***

These notes are intended as a guide to presenters. Whilst many of the notes below are worded in a way that could be spoken during the presentation, they are not intended as a 'script'.

Presenters should feel free to express the learning points from each slide in their own style and using their own wording, but to use any of the offered wording that they find helpful.



Explain the acronym ReSPECT.

You may want to introduce the key elements:

- Recommended – these are recommendations not ‘orders’ or legally-binding decisions.
- Summary – this does not replace more detailed treatment plans or

advance care plans but is a summary for immediate access in a crisis.

- Emergency – this summary relates only to care and treatment in a crisis; other plans may include aspects of non-urgent care and treatment.

## Learning objectives

**By studying this presentation you should be prepared to:**

- discuss potentially life-sustaining treatments in the context of a person's overall goals of care
- make shared decisions whenever possible
- practise and promote good decision-making
- communicate effectively
- practise and promote high-quality documentation
- use **ReSPECT** to help to achieve these objectives

ReSPECT

Make clear to the learners that each of these learning objectives/outcomes is important and will prepare them (and clarify the skills that they need) to use the ReSPECT process.

## ReSPECT – presentation contents

- Background to **ReSPECT**
- What **ReSPECT** is
- Aims of **ReSPECT**
- Who **ReSPECT** is for
- How to initiate **ReSPECT**
- When to review
- **ReSPECT** – who keeps it?
- Summary

ReSPECT

These are the main topics covered in this presentation.

## Background – the evidence

**THE UNIVERSITY OF WARWICK**

**Registration**  
The standard registration fee is £120.  
• [Register online](#)

**Programme**  
09:30 Registration, coffee  
10:00 Opening and Welcome: Barry Williams and Steph Cartfield-Riskbeck  
10:10 NRIK project report: Prof. Gavin Perkins, Frances Gibbins, Anne Marie Stewther and Rob George  
11:30 Coffee  
11:50 Best practice exemplars - Li Li - doc Fitz  
12:00 Best practice exemplars - Treatment escalation pathways - David Gabbott  
12:10 Best practice exemplars - Deciding right - Claud Regnier  
12:20 Medical legal considerations - Capacity Sarah Woods (DAC Beauchcroft)  
12:40 Medical legal considerations - Tissue cases - Stephen Livers (Hampson)  
13:00 Panel discussion  
13:15 Lunch  
14:00 David Pitcher Resuscitation Council (UK) Update on the Joint Statement  
14:45 Sue West, National Clinical Director, End of Life Care Programme  
15:45 Interactive voting session - national clinical and research priorities  
16:30 Close

**Venue**  
Royal Society of Medicine

October 2014

**DNACPR**  
from  
best evidence  
to  
best policy and practice

<http://www.journalslibrary.nihr.ac.uk/hsdr/volume-4/issue-11#abstract>

ReSPECT

The ReSPECT project started in 2014, when the results of a systematic review of DNACPR decisions and documents were presented at a meeting at the Royal Society of Medicine, by the team from Warwick University. The full report of the study can be found at the URL shown on the slide.

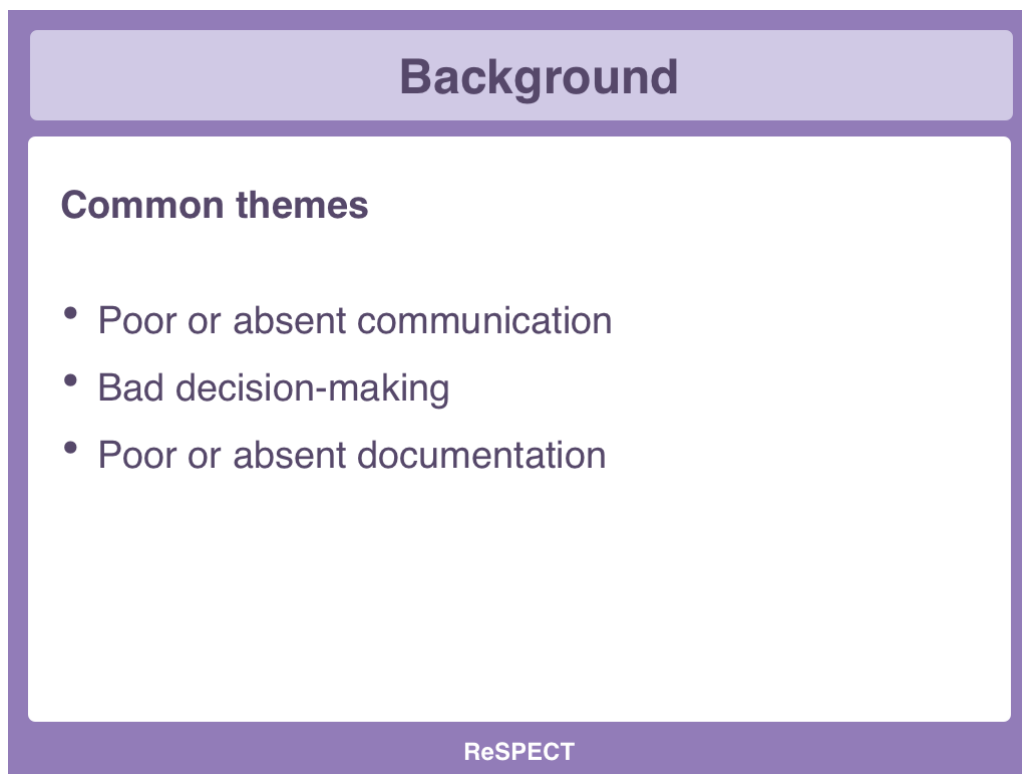
## Background

**DNACPR decisions and discussions have led to:**

- negative patient/public perceptions
- negative clinicians' perceptions
- complaints
- litigation
- negative media reports

ReSPECT

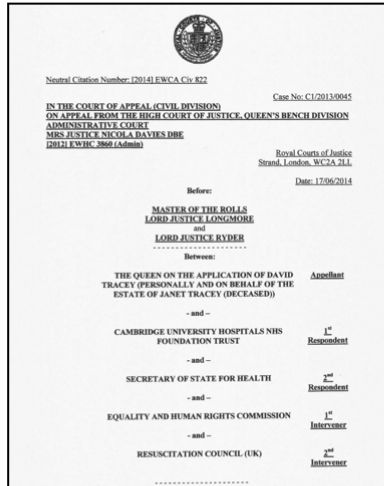
Some of the headline findings were that DNACPR decisions have been associated with negative patient and public perceptions, negative clinicians' perceptions, complaints, litigation, and negative media reports.



The common themes behind these problems were poor or absent communication, bad decision-making, and poor or absent documentation.



## Background



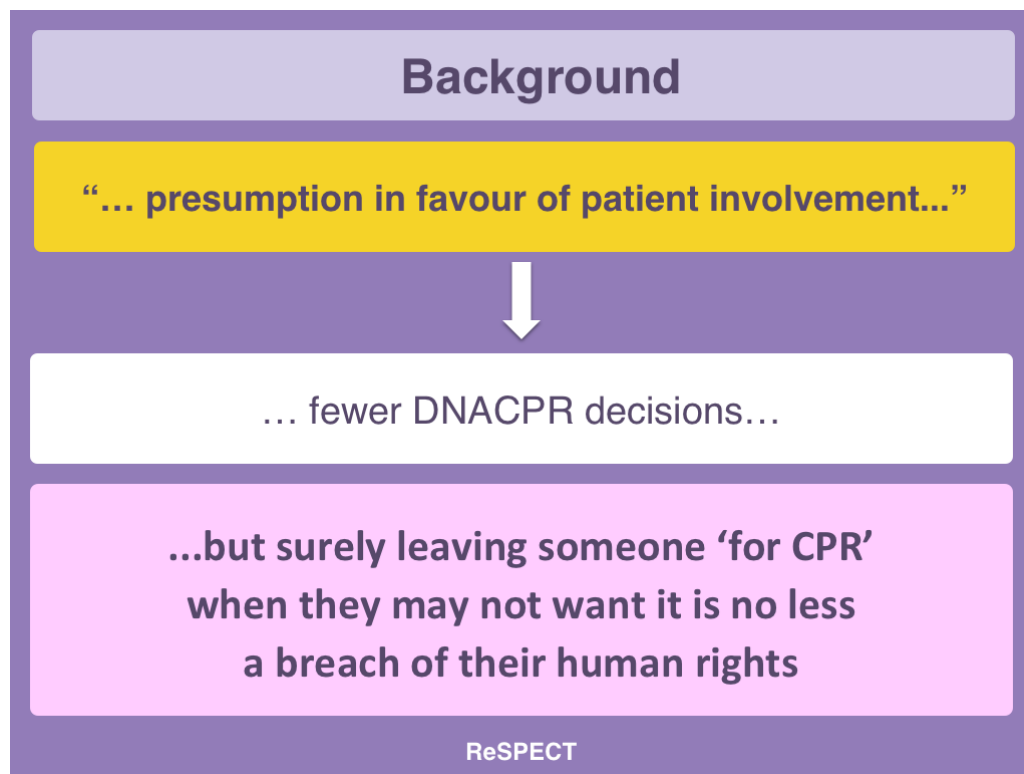
Court of Appeal 2014

DNACPR decisions

“... presumption in favour of patient involvement...”

ReSPECT

These failures were all demonstrated in the Tracey case, which came to the Court of Appeal in 2014. One of the key statements in the judgement was that, when a DNACPR decision is considered, there should be a presumption in favour of involving the patient.



Sadly, instead of encouraging more and better communication with their patients, that ‘presumption in favour of patient involvement’ discouraged some clinicians from making DNACPR decisions when they were needed, and that meant that more people received CPR with no likelihood of benefit. But surely – and where you see a box with this pink background it

is intended to make you think carefully about the content – surely, leaving someone likely to receive CPR without giving them a chance to consider its risks and benefits, and decide whether they would want it, is no less a breach of their human rights than making a DNACPR decision without explaining it to them.

## Background



### Decisions relating to cardiopulmonary resuscitation

Guidance from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing

(previously known as the Joint Statement)

3rd edition (2nd revised) 2019

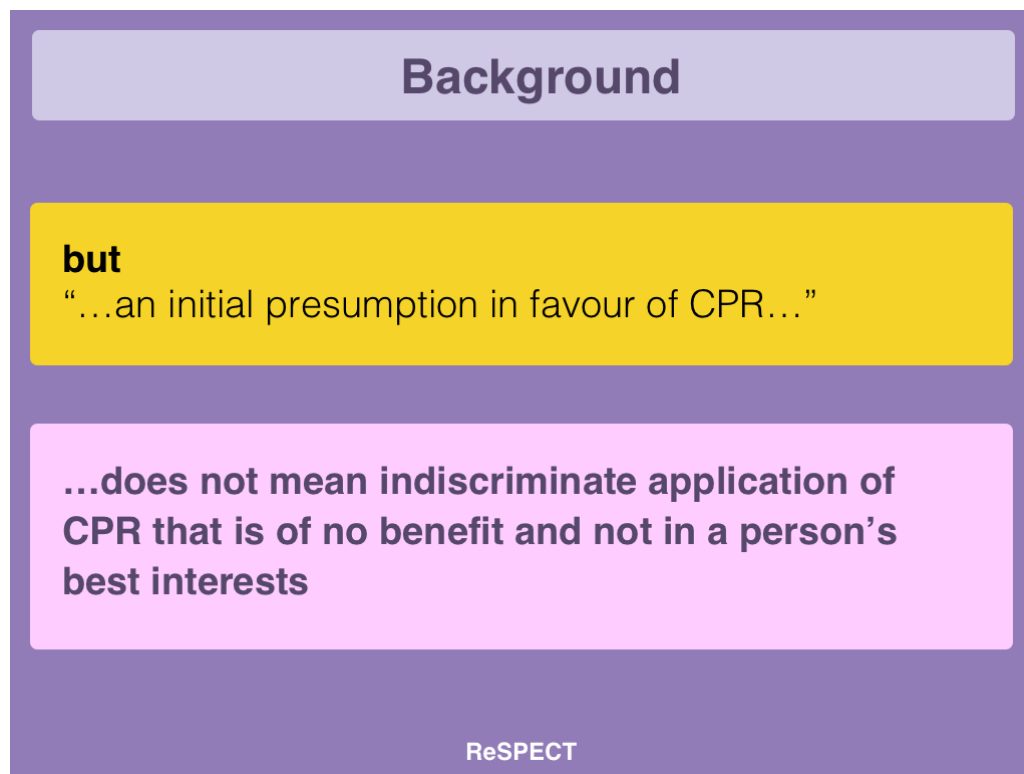


### National guidance on CPR decisions

**“Where no explicit decision...  
...there should be an initial presumption in favour of CPR.”**

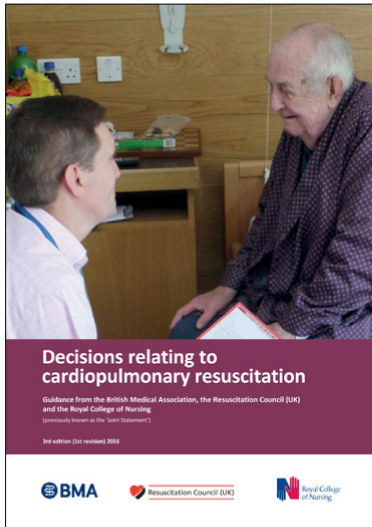
ReSPECT

As I'm sure you all know, when CPR might work, it must be started immediately to give a person the best chance of surviving. Because of that, the national guidance from the BMA, Resuscitation Council and RCN states that where no explicit decision about CPR has been recorded, there should be an initial presumption in favour of CPR.



...but an initial presumption in favour of CPR does not mean that we should attempt CPR indiscriminately when it will be of no benefit and not in a person's best interests. Again – this is a pink box – so think carefully about this point.

## Background



### National guidance on CPR decisions

**“...there are clear benefits in having (CPR) decisions recorded on standard forms that are...recognised across geographical and organisational boundaries within the UK.”**

ReSPECT

Another statement in the national guidance is that there are clear benefits in having (CPR) decisions recorded on standard forms that are recognised across geographical and organisational boundaries. This has been recommended since 2007, and was reinforced in early 2015 in a report by the Health Select Committee.

# Background

but actually...

The collage includes several documents:

- NHS Form 1000:** A form for recording patient information and clinical history.
- DO NOT ATTEMPT CARDIOPULMONARY RESUSCITATION:** A form for recording a decision not to attempt CPR.
- Universal Form of Treatment Options:** A flowchart for recording treatment options.
- Smooth Potentially Deteriorating Patient Plan:** A form for recording a plan for a patient who is potentially deteriorating.
- Attempt CPR and refer to DCC if patient deteriorates:** A form for recording a decision to attempt CPR and refer to the Deteriorating Care Coordinator (DCC) if the patient deteriorates.

ReSPECT

Unfortunately, this is still far from reality. This slide illustrates just a few of the many forms used in the UK to record recommendations about CPR. Some are DNACPR forms and on some a recommendation about CPR is recorded on a Treatment Escalation Plan style of form.

## What is ReSPECT?

- **ReSPECT** – an alternative process for discussing, making and recording recommendations about future emergency care and treatment, including CPR
- **ReSPECT** – developed by many stakeholders, including patients, doctors, nurses and ambulance clinicians, to try to achieve a process that will be adopted nationally
- **ReSPECT** focuses on treatments to be considered as well as those that are not wanted or would not work
- **ReSPECT** encourages people to plan ahead for their care and treatment in a future emergency in which they are unable to make decisions

ReSPECT

- So that – we hope – is where ReSPECT comes in. Let's consider what it is.
- ReSPECT is not just a form. It's an alternative process for discussing, making and recording recommendations about care and treatment in a future crisis, including CPR.
- ReSPECT has been developed by



many stakeholders, including patients, doctors, nurses and ambulance clinicians, to try to achieve a process that will be adopted nationally.

- It's important to remember that ReSPECT focuses on treatments that should be considered for a person, as well as those that are not wanted or that would not work in their situation.
- The aim is also for ReSPECT to encourage people to plan ahead for their care and treatment in a future crisis in which they can't make decisions for themselves.



So – what we need to make this work is **a change of culture** on the part of health and care professionals, so that they are much more willing to have conversations with their patients about these topics, and recognise their responsibility to do that and **a change of culture** on the part of members of the public, so that they come to expect these conversations as a

routine part of their care and to recognise the importance of planning ahead. It will be important that all of us look at what we need to do to embrace that change of culture, not only as professionals but maybe also as potential patients ourselves.

## ReSPECT – aims

- More conversations between people and clinicians
- More planning in advance
- Good communication
- Good decision-making
- Shared decision-making whenever possible
- Good documentation
- Better care

ReSPECT

This will inevitably take time, but if we can embrace this approach, it should lead to these conversations between people and their clinicians occurring more frequently, resulting in more advance plans for people's care. It should encourage better communication, better decision-making – with shared decision-making whenever possible, good-quality

documentation of both decisions and discussions and – if we achieve at least some of these – it should result in something that we would all aspire to – better care of our patients.

## ReSPECT – who is it for?

- Anyone, with increasing relevance for those:
  - with particular healthcare needs
  - nearing the end of their lives or at risk of cardiac arrest
  - who want to record their preferences for any reason
- A **ReSPECT** form is best completed when a person is relatively well, so that their preferences and agreed clinical recommendations are known if a crisis occurs
- If an emergency occurs in someone with no **ReSPECT** form, consider discussing and completing it as soon as possible (before or after hospital admission)

ReSPECT

Now let's consider who should be considered for ReSPECT.

Anyone who wants to can participate in the ReSPECT process, but it will be most relevant for:

- people who have particular healthcare needs - perhaps a long-term condition or a severe disability that may deteriorate suddenly
- people who are nearing the end of

their lives

- people who are at risk of cardiac arrest but are not terminally ill – this would include people with acute myocardial infarction, for example
- and others who want to record their preferences for any reason.

A ReSPECT form is best completed when a person is relatively well so that, if a crisis occurs, their preferences and agreed clinical recommendations are already known and recorded.

However, there will always be people who have a sudden, severe illness, so if an emergency occurs in someone with no ReSPECT form, consider discussing and completing one as soon as is reasonably

possible, either before or after hospital admission.



## ReSPECT – other features

- **ReSPECT** can be used for people of any age
- When used for a child or young person there must be appropriate parental involvement
- **ReSPECT** can complement other documents such as advance care plans but does not replace them
- If a person has a completed **ReSPECT** form there should be no need for a separate CPR decision form

ReSPECT

Some other features of ReSPECT are firstly that it can be used for people of any age, including children. If it is used for a child or young person, it's crucial to ensure appropriate parental involvement.

ReSPECT does not replace other documents such as adult or paediatric advance care plans but it doesn't

replace them. It simply provides a summary of those recommendations that might be needed to guide immediate decision-making in a crisis.

However, if a person has a completed ReSPECT form there should be no need for a separate CPR decision form or another treatment escalation plan.

## How to initiate ReSPECT

- This **MUST** begin with a conversation with the person or - in the case of a child - their parent(s)
- If they don't have capacity for these decisions – record the capacity assessment in their health record and have a conversation with family or other representatives whenever possible
- Make decisions when they are needed
- If no discussion is possible, record the reasons

ReSPECT

Now let's consider how we start the ReSPECT process. Having identified someone as wanting or potentially benefitting from this we **MUST** start with a conversation with the person or – in the case of a child – their parent(s).

If a person doesn't have capacity for these decisions a formal capacity

assessment is needed and should be recorded in their health record. Then we must have a conversation with family or other representatives whenever possible, to find out about the person's beliefs and previously expressed wishes.

It's crucial to make decisions when they are needed, and not delay a decision that will ensure best care because, for example, a family member isn't available to discuss it. Make the decision that's needed, record valid reasons for it, and make a clearly defined plan to discuss it as soon as the family member is available.

If no discussion is possible, be sure to record the reason why.

## How to initiate ReSPECT

The image shows a thumbnail of the ReSPECT form, titled 'Recommended Summary Plan for Emergency Care and Treatment for'. The form is divided into four main sections:

- 1. Personal details:** Includes fields for Full name, Date of birth, Date completed, NHS/CHI/Health and care number, and Address.
- 2. Summary of relevant information for this plan (see also section 6):** Includes a box for 'Including diagnosis, communication needs (e.g. interpreter, communication aids) and reasons for the preferences and recommendations recorded' and a box for 'Details of other relevant planning documents and where to find them (e.g. Advance Decision to Refuse Treatment, Advance Care Plan). Also include known wishes about organ donation.'
- 3. Personal preferences to guide this plan (when the person has capacity):** Includes a scale for 'How would you balance the priorities for your care (you may mark along the scale, if you wish):' with 'Prioritise sustaining life, even at the expense of some comfort' on the left and 'Prioritise comfort, even at the expense of sustaining life' on the right. Below this is a box for 'Considering the above priorities, what is most important to you is (optional):'.
- 4. Clinical recommendations for emergency care and treatment:** Includes two boxes: 'Focus on life-sustaining treatment as per guidance below' and 'Focus on symptom control as per guidance below'. Below these is a box for 'Now provide clinical guidance on specific interventions that may or may not be wanted or clinically appropriate, including being taken or admitted to hospital or receiving life support.'

At the bottom, there are three boxes for signatures: 'CPR attempts recommended Adult or child', 'For modified CPR child only, as detailed above', and 'CPR attempts NOT recommended Adult or child'. Each box has a line for 'clinician signature'.

- The **ReSPECT** form can be used to support discussions with patients (and/or those close to patients)
- Work through and complete each section in sequence

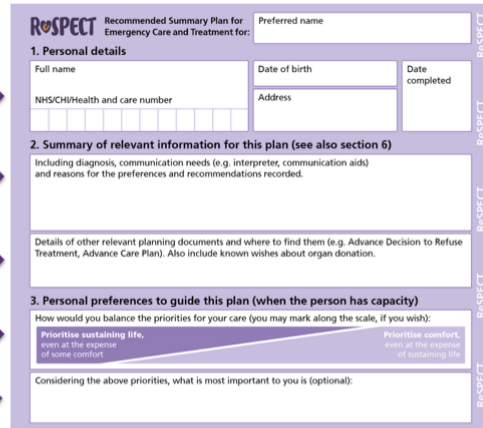
ReSPECT

If we look at the ReSPECT form itself, you will see that it can be used to support discussions with patients and people close to them. This is done by working through it in sequence, completing each section as you go. A separate presentation is available for you to work through, giving more detail on how to complete a ReSPECT form.

## How to initiate ReSPECT

### Use the first (lilac) section to:

- record the person's details and the date
- explore and enhance their understanding of their condition and summarise relevant detail
- record details of other planning documents
- help them to identify priorities for their care
- help them to identify what is important to them (if they want to)



The diagram shows the ReSPECT form with arrows pointing from the instructions to specific sections:

- Arrow 1 points to Section 1: Personal details.
- Arrow 2 points to Section 2: Summary of relevant information for this plan.
- Arrow 3 points to the sub-section for other planning documents within Section 2.
- Arrow 4 points to Section 3: Personal preferences to guide this plan.
- Arrow 5 points to the scale within Section 3.

**ReSPECT Recommended Summary Plan for Emergency Care and Treatment for:** Preferred name: \_\_\_\_\_

**1. Personal details**

Full name	Date of birth	Date completed
NHS/CHI/Health and care number	Address	

**2. Summary of relevant information for this plan (see also section 6)**

Including diagnosis, communication needs (e.g. interpreter, communication aids) and reasons for the preferences and recommendations recorded.

Details of other relevant planning documents and where to find them (e.g. Advance Decision to Refuse Treatment, Advance Care Plan). Also include known wishes about organ donation.

**3. Personal preferences to guide this plan (when the person has capacity)**

How would you balance the priorities for your care (you may mark along the scale, if you wish):

Prioritise sustaining life, even at the expense of some comfort	Prioritise comfort, even at the expense of sustaining life
---	--

Considering the above priorities, what is most important to you is (optional): \_\_\_\_\_

ReSPECT

### In summary:

- use section 1 to record the person's full details and the date
- use section 2 to explore and enhance their understanding of their condition and summarise any relevant detail,
- and also in the next box to record details of other planning documents
- if you want to, you can use the scale

to help them to understand the balance between focusing on treatment predominantly for comfort and treatment predominantly to sustain life, even if it involves some risk or discomfort; this can help them to identify and agree priorities for their care

- if they want to they can, with your help, identify and have recorded the thing or things most important to them in their life.

## How to initiate ReSPECT

Use section 4 (purple) to record the following recommendations (agreed whenever possible):

- the main focus of treatment
- specific types of care and treatment
  - that the person would or would not want
  - that would not work in their situation
- whether or not attempted CPR is recommended

4. Clinical recommendations for emergency care and treatment

Focus on life-sustaining treatment as per guidance below  
clinician signature

Focus on symptom control as per guidance below  
clinician signature

Now provide clinical guidance on specific interventions that may or may not be wanted or clinically appropriate, including being taken or admitted to hospital +/- receiving life support:

CPR attempts recommended Adult or child  
clinician signature

For modified CPR Child only, as detailed above  
clinician signature

CPR attempts NOT recommended Adult or child  
clinician signature

ReSPECT

**Remember - these recommendations will guide clinicians having to make immediate decisions in a crisis, so clarity and adequate detail are crucial**

Section 4 is used to record the recommendations that arise from the person's clinical circumstances and preferences.

The main focus on either comfort or life-sustaining care and treatment should be signed, and then there is space to record specific types of care and treatment that the person would



or would not want or that would not work in their situation. This should include basic recommendations such as whether or not the person would want to be transported to hospital. Remember to include treatments that the person would want to be considered for as well as those that aren't wanted or wouldn't work.

At the bottom there's a specific space for recording whether or not attempted CPR is recommended. There is a space to recommend modified CPR, but this is only for use in children in whom a need for specific modifications to attempted CPR has been agreed.

## How to initiate ReSPECT

Having completed discussion,  
shared decision-making and  
recording...



... turn over the form to verify  
the basis for the agreed  
recommendations

**5. Capacity and representation at time of completion**  
Does the person have sufficient capacity to participate in making the recommendations on this plan? **Yes / No**  
Do they have a legal proxy (e.g. welfare attorney, person with parental responsibility) who can participate on their behalf in making the recommendations? **Yes / No / Unknown**  
If so, document details in emergency contact section below

**6. Involvement in making the plan**  
The clinician(s) signing this plan is/are confirming that these recommendations have (circle at least one):  
**A** been recorded after discussion involving this person, who has sufficient mental capacity to participate in making relevant decisions  
**B** where appropriate, been discussed with a person holding parental responsibility  
**C** in the case of a person who does not have sufficient mental capacity to participate in relevant decision making, been made in accordance with capacity law  
**D** been made without involving the patient (or best interests/overall benefit meeting if the patient lacks capacity)  
If **D** has been circled, state valid reasons here. Document full explanation in the clinical record.

Date, names and roles of those involved in discussion, and where records of discussions can be found:

**7. Clinicians' signatures**

Designation (grade/speciality)	Clinician name	GMC/NMC/HCPC Number	Signature	Date & time
Senior responsible clinician				

**8. Emergency contacts**

Role	Name	Telephone	Other details
Legal proxy/parent			
Family/friend			
GP			
Lead Consultant			
Other			

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

Review date	Designation (grade/speciality)	Clinician name	GMC/NMC/HCPC number	Signature

ReSPECT

Having completed the process of discussion and recording of recommendations, it is essential also to complete the reverse side of the form, to confirm its validity and that it has been completed lawfully.

## How to initiate ReSPECT

**5. Capacity and representation at time of completion**  
Does the person have sufficient capacity to participate in making the recommendations on this plan? **Yes / No**  
Do they have a legal proxy (e.g. welfare attorney, person with parental responsibility) who can participate on their behalf in making the recommendations? **Yes / No / Unknown**  
If yes, document details in emergency contact section below

**6. Involvement in making this plan**  
The clinician(s) signing this plan have confirmed that these recommendations have (been at least one):  
A been recorded after discussion involving this person, who has sufficient mental capacity to participate in making relevant decisions  
B where appropriate, been discussed with a person holding parental responsibility  
C in the case of a person who does not have sufficient mental capacity to participate in relevant decision-making, been made in accordance with capacity law  
D been made without involving the patient (or best interests/benefits meeting if the patient lacks capacity)  
If B has been circled, state valid reasons here. Document full explanation in the clinical record.  
Date, names and roles of those involved in discussion, and where records of discussions can be found

**7. Clinicians' signatures**  
Designation (grade/speciality) Clinician name GMC/NMC/HCPC number Signature Date & time  
Senior responsible clinician

**8. Emergency contacts**  
Role Name Telephone Other details  
Legal proxy/parent  
Family/friend  
GP  
Lead Consultant  
Other

**9. Confirmation of validity (e.g. for change of condition)**  
Review date Designation (grade/speciality) Clinician name GMC/NMC/HCPC number Signature

- Be sure to complete sections 5-8 fully
- You must sign section 7 to confirm that all statements and recommendations are valid
- If you are not the senior responsible clinician make sure that they are aware and in agreement with this plan and its content - ensure that they sign to endorse it as soon as is practicable
- Leave section 9 blank for use by a clinician reviewing this **ReSPECT** at a future time

ReSPECT

It's important to complete sections 5-8 fully. In 5 and 6 you confirm that you have completed the process and form lawfully.

You must sign section 7 to confirm that and that all statements and recommendations are valid.

If you are not the senior responsible

clinician make sure that they are aware and in agreement with this plan and its content. You should ensure that they sign to endorse it as soon as is practicable.

Section 9 is for future use, so that a clinician can record when the recommendations have been reviewed and confirmed to be still valid. When you are completing a form initially, leave it blank.

## ReSPECT – review

- The recommendations on the form should be reviewed:
  - if the person or those close to them requests this
  - if the person's condition changes
  - if the person moves from one care setting to another (including in-hospital transfer e.g. to or from ICU)
- Consider carefully whether the person (or if they lack capacity their representatives) should be involved – if in doubt, involve them
- Frequency of review of **ReSPECT** recommendations is determined by each individual circumstance – e.g. frequent review in an acute illness but not in an advanced, irreversible terminal illness
- Consider this option at each clinical assessment

ReSPECT

People often ask how frequently the recommendations on a ReSPECT form should be reviewed or whether the form should have an expiry date. The frequency of review will vary from one person to another and should be planned for each person according to their individual situation. Imposing a random expiry date risks discouraging frequent review for those who need it,

and risks recommendations being regarded as invalid if the date for review has been overlooked.

Review should be undertaken if the person or someone close to them asks for this, if the person's condition changes – for either better or worse, and when a person moves from one care setting to another. This might include a change of ward within a hospital. In some cases, review might simply involve the transferring or receiving clinician confirming that the recommendations remain valid.

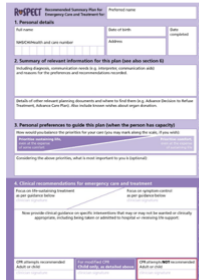
When reviewing recommendations on a person's ReSPECT form, it's important to consider carefully whether they, or if they

lack capacity their representatives, should be involved – if in doubt, involve them.

As I've already said, frequency of review of ReSPECT recommendations should be determined by each individual circumstance – frequent review will be needed in an acute illness, but not in an advanced, irreversible terminal illness.

Consider at each clinical assessment whether or not a review is needed.

## ReSPECT – who keeps it?

A thumbnail image of the ReSPECT form. The form is titled 'ReSPECT: Recommended Summary for the Emergency Care and Treatment Plan'. It includes sections for 'Personal details', 'Summary of relevant information for the plan (see also section 2)', 'Personal preferences to guide the plan (see also section 3)', and 'Clinical recommendations for emergency care and treatment'. The form is designed to be filled out by a healthcare professional in consultation with the patient or their family.

- The recommendations on the form are (whenever possible) shared decisions, made for the benefit of the person to try to ensure that future decisions about their care are in their best interests
- Paper versions of the form should be kept by or with the person and should be accessible immediately to any clinician needing to make an immediate decision in a crisis
- Electronic versions must be similarly accessible
- Local systems must ensure that all versions are included in any cancellation or change to a **ReSPECT** form

ReSPECT

Because the recommendations on the form are usually based on shared decisions for the benefit of the person, it's important that they have a sense of ownership of and responsibility for the form. Paper versions of the form should be kept by or with the person and should be accessible immediately to any clinician needing to make an immediate decision in a crisis. In their



home, the form must be kept where it will be easy to find. 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.

Whenever a ReSPECT form is cancelled or its recommendations are changed it's crucial to make sure that all versions are included in that cancellation or change.

## ReSPECT – summary

- Use **ReSPECT** to help you with good communication, decision-making and documentation
- Start with a conversation with the person or - in the case of a child - their parent(s)
- Aim to make shared decisions whenever possible
- Work through **ReSPECT** systematically to establish:
  - the background to the recommendations
  - the person's preferences for care and treatment
  - agreed (whenever possible) clinical recommendations
- Review **ReSPECT** recommendations according to individual needs

ReSPECT

In summary:

You can use ReSPECT to help you with good communication, decision-making, and documentation.

The ReSPECT process should start with a conversation with the person or - in the case of a child - their parent(s).

You should aim to make shared

decisions about the recommendations whenever possible.

You should work through ReSPECT systematically to establish:

- the background to the recommendations
- the person's preferences for care and treatment
- the clinical recommendations – whenever possible agreed with the person or their representative.

Review of ReSPECT recommendations should be planned and carried out according to individual needs.



**ReSPECT – feedback**

Your feedback is crucial

**ReSPECT** aims to be a dynamic process that responds to and develops further from feedback

The ReSPECT form and supporting materials will be available from the end of February 2017 at [www.respectprocess.org.uk](http://www.respectprocess.org.uk)

ReSPECT

Another important feature of ReSPECT is that it aims to go on developing and improving, so that it remains fit for purpose. Feedback will be crucial to this so if you encounter problems with any aspect, or if you find any aspect very helpful, please report this...

(insert on slide and describe verbally

the current/local arrangements for providing feedback and sending it to the Working Group).