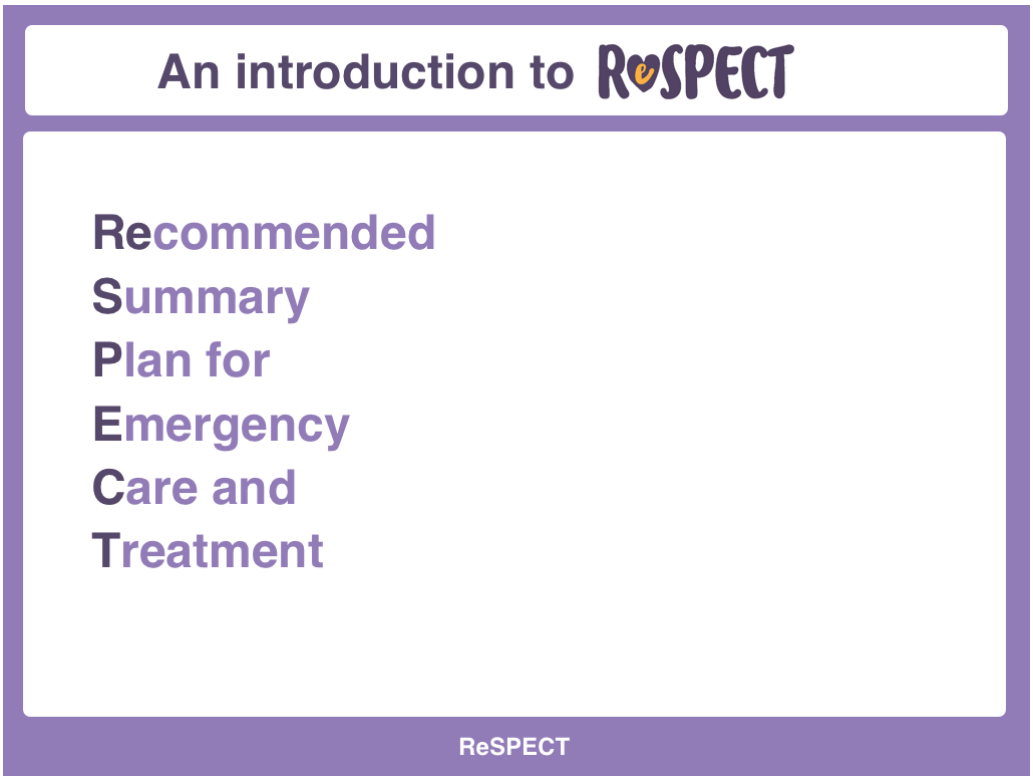
An introduction to ReSPECT

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.



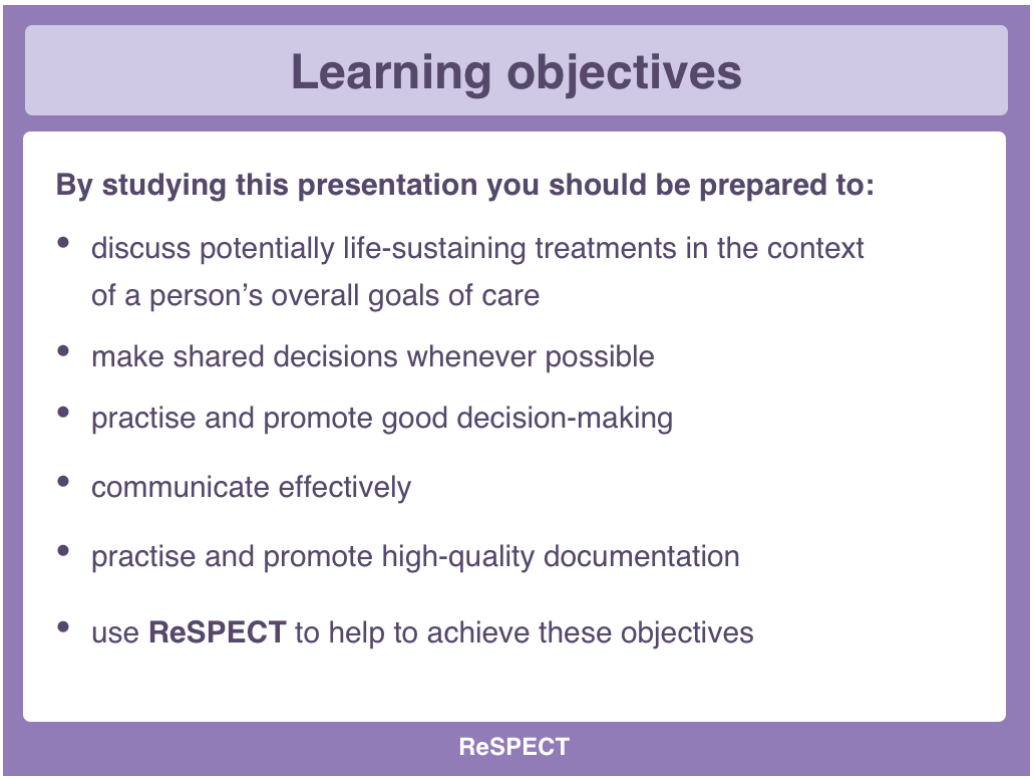
Explain the acronym ReSPECT.

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.

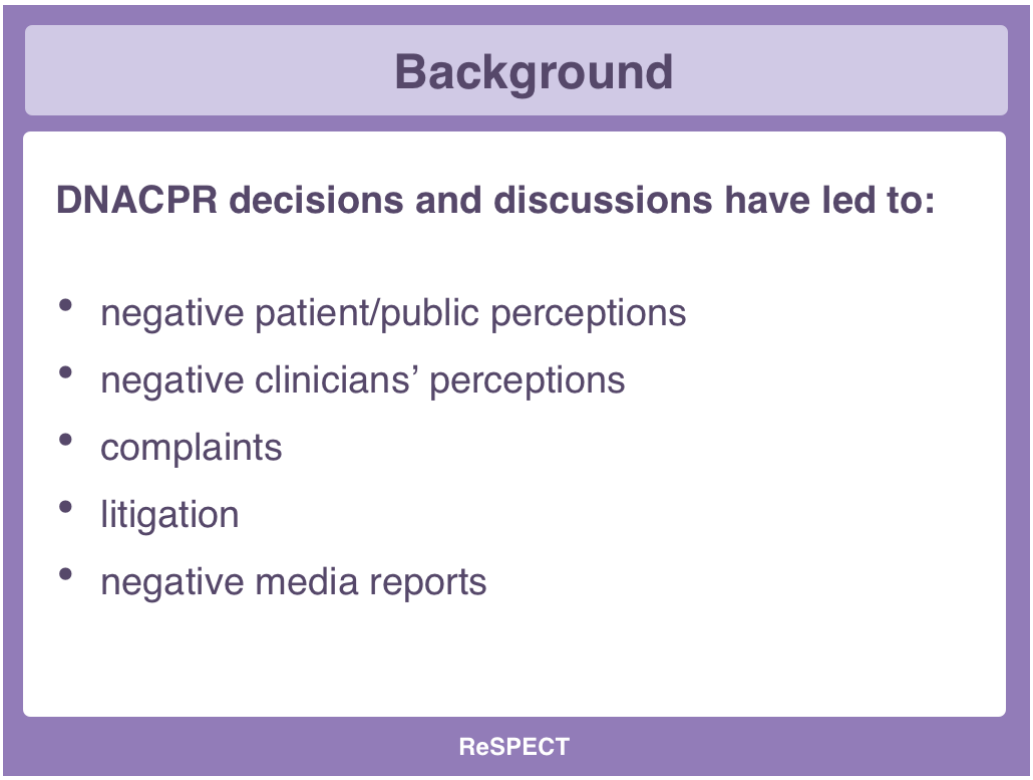
• Emergency – this summary relates only to care and treatment in a crisis; other plans may include aspects of non-urgent care and treatment.



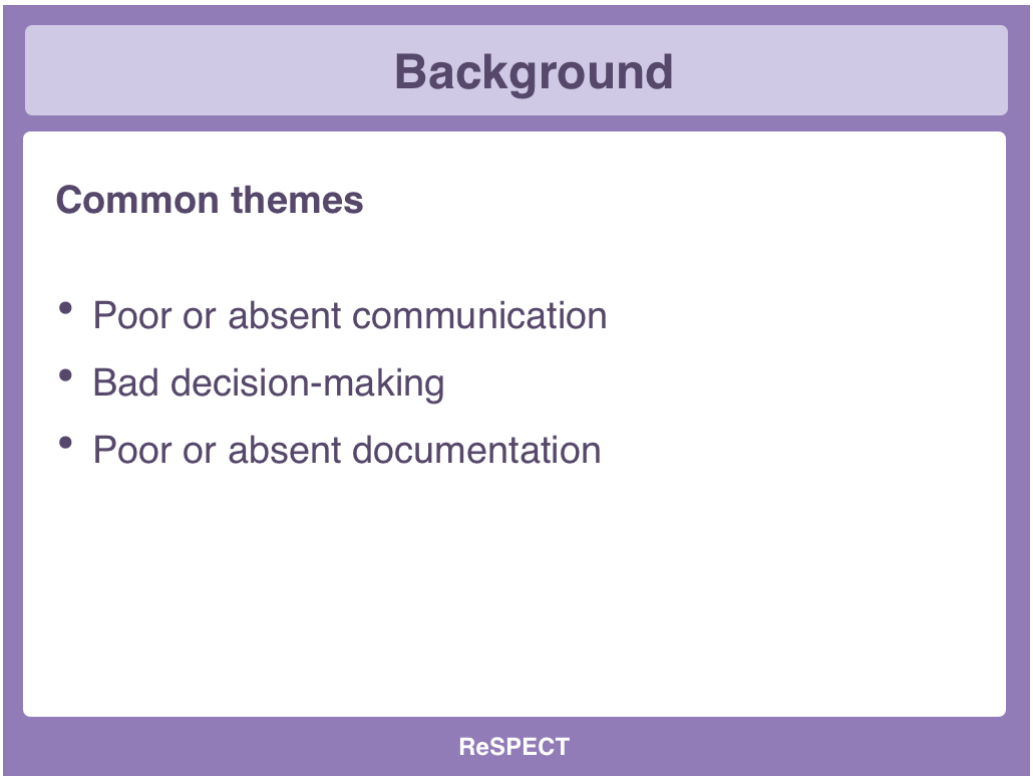
Make clear to the learners that each of these learning objectives/outcomes is important and will prepare them (and clarify the skills that they need) to use the ReSPECT process.

These are the main topics covered in this presentation.

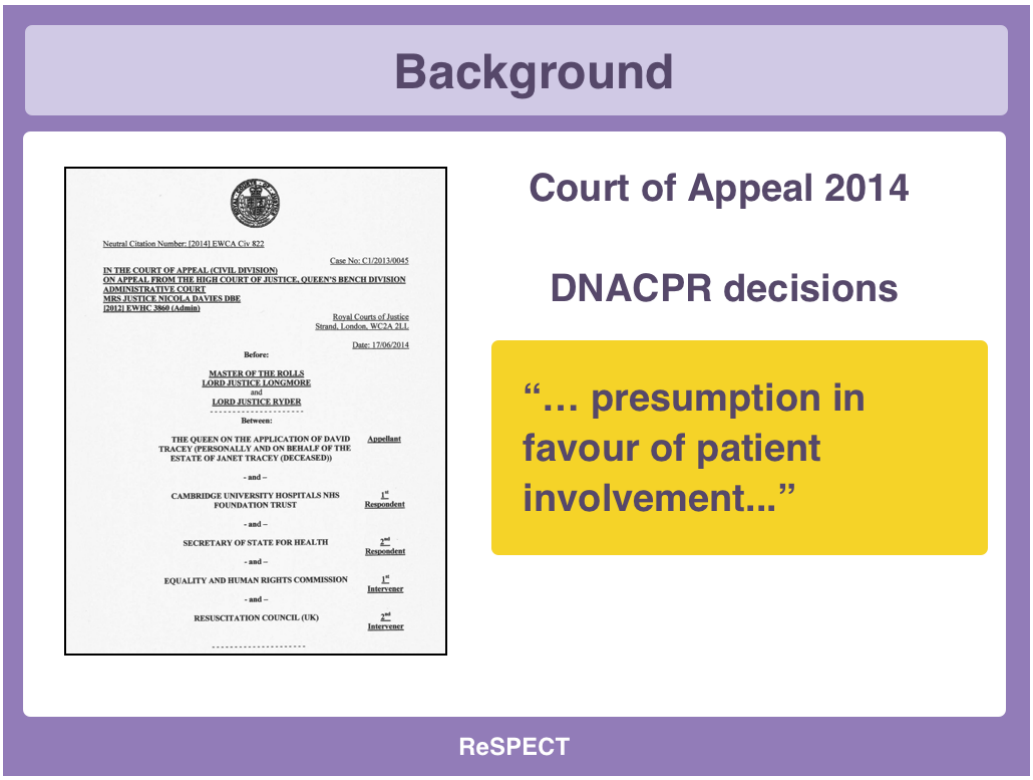
The ReSPECT project started in 2014, when the results of a systematic review of DNACPR decisions and documents were presented at a meeting at the Royal Society of Medicine, by the team from Warwick University. The full report of the study can be found at the URL shown on the slide.



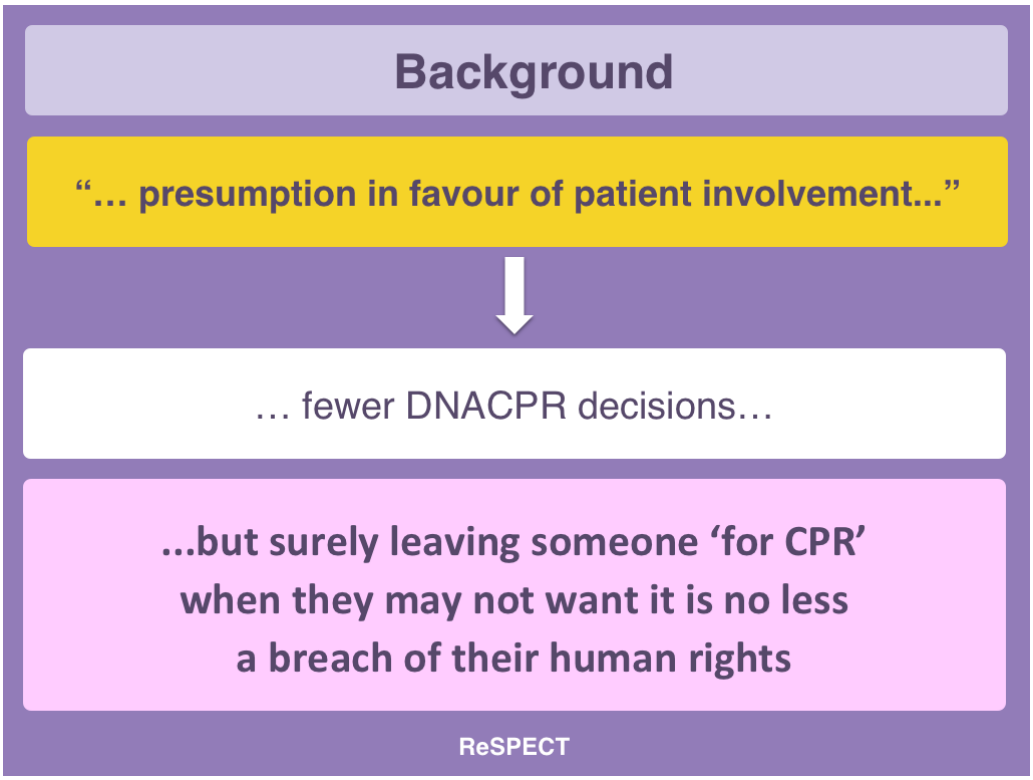
Some of the headline findings were that DNACPR decisions have been associated with negative patient and public perceptions, negative clinicians' perceptions, complaints, litigation, and negative media reports.



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

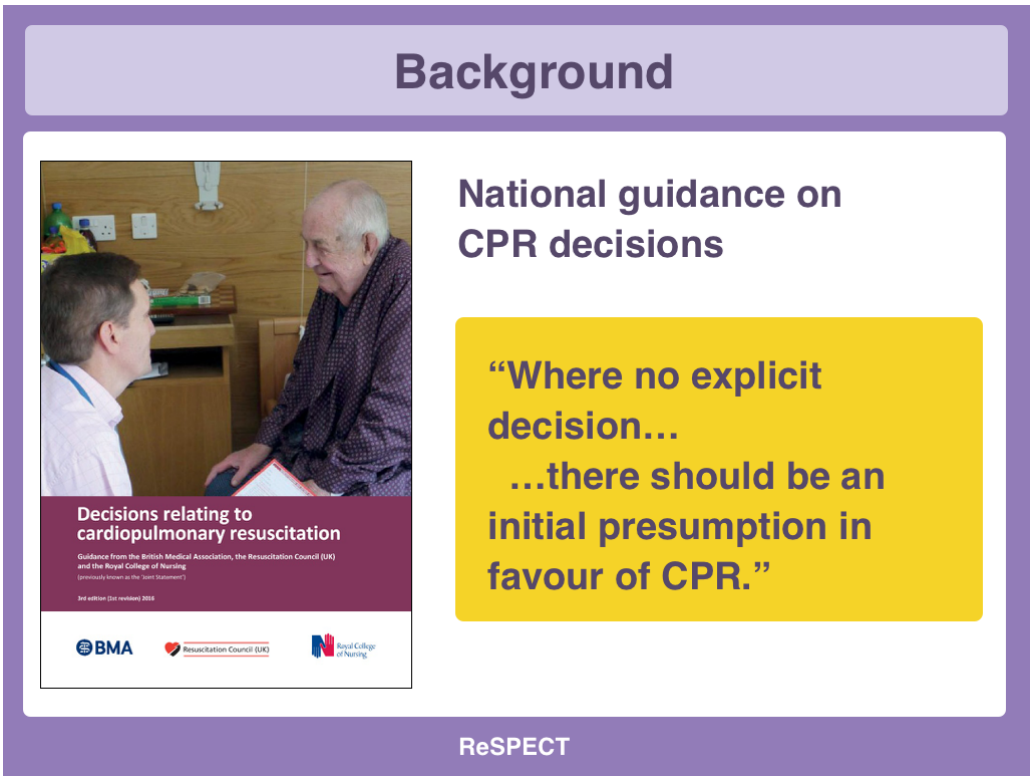


These failures were all demonstrated in the Tracey case, which came to the Court of Appeal in 2014. One of the key statements in the judgement was that, when a DNACPR decision is considered, there should be a presumption in favour of involving the patient.

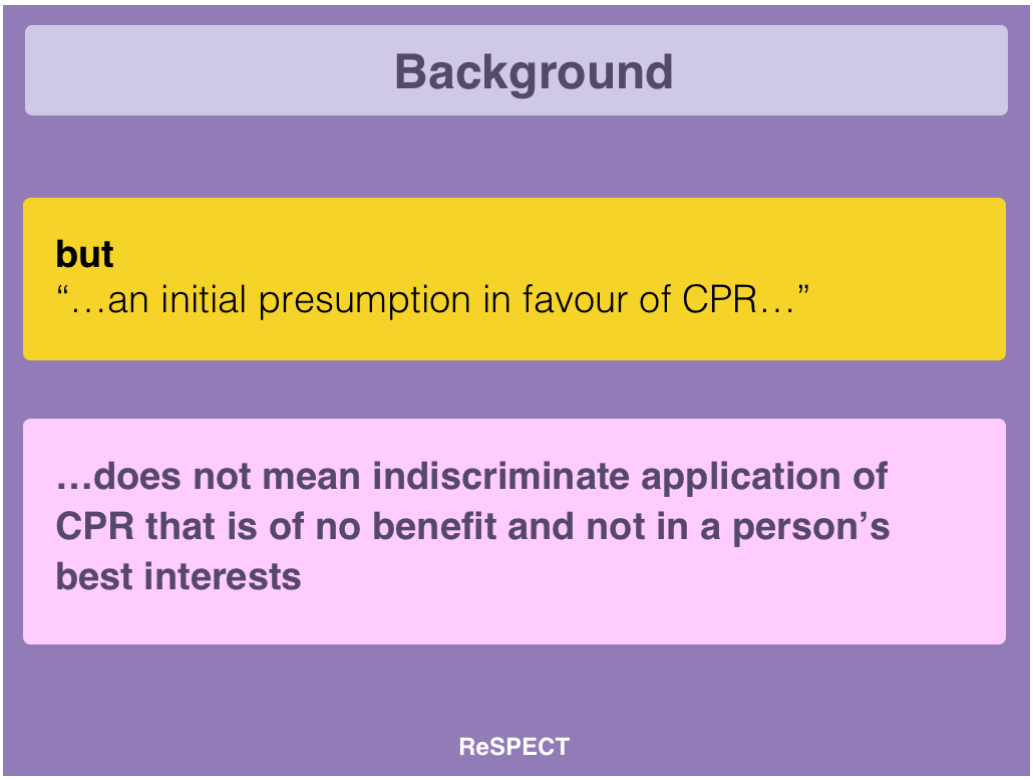


Sadly, instead of encouraging more and better communication with their patients, that 'presumption in favour of patient involvement' discouraged some clinicians from making DNACPR decisions when they were needed, and that meant that more people received CPR with no likelihood of benefit. But surely –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

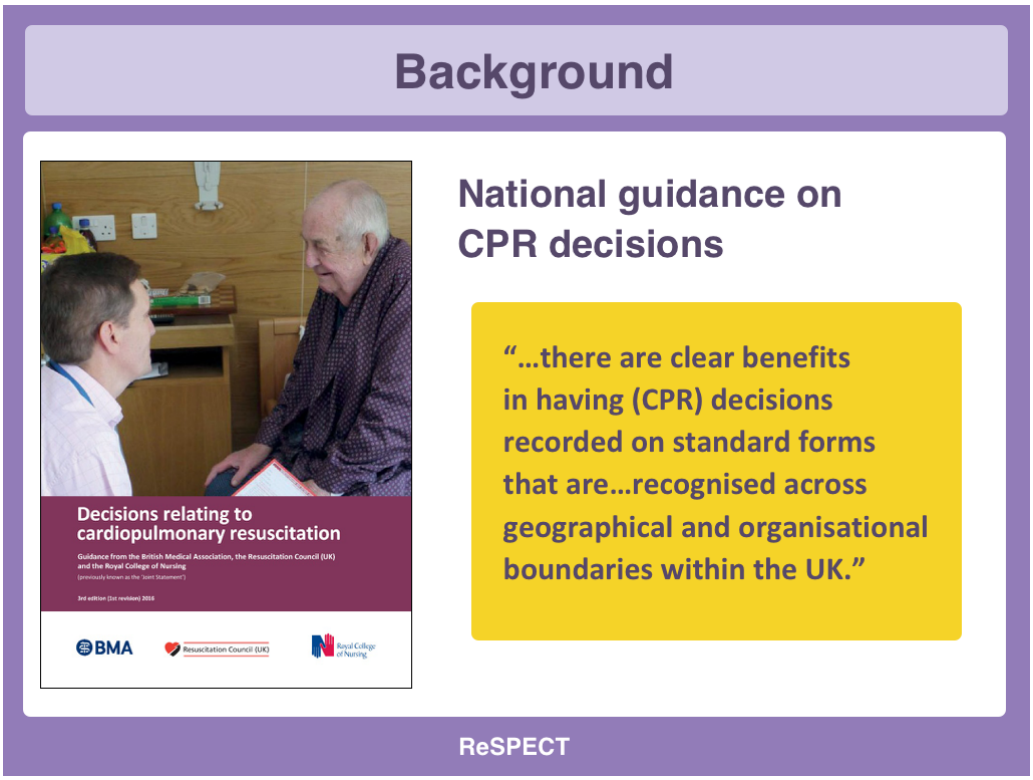
is intended to make you think carefully about the content – surely, leaving someone likely to receive CPR without giving them a chance to consider its risks and benefits, and decide whether they would want it, is no less a breach of their human rights than making a DNACPR decision without explaining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



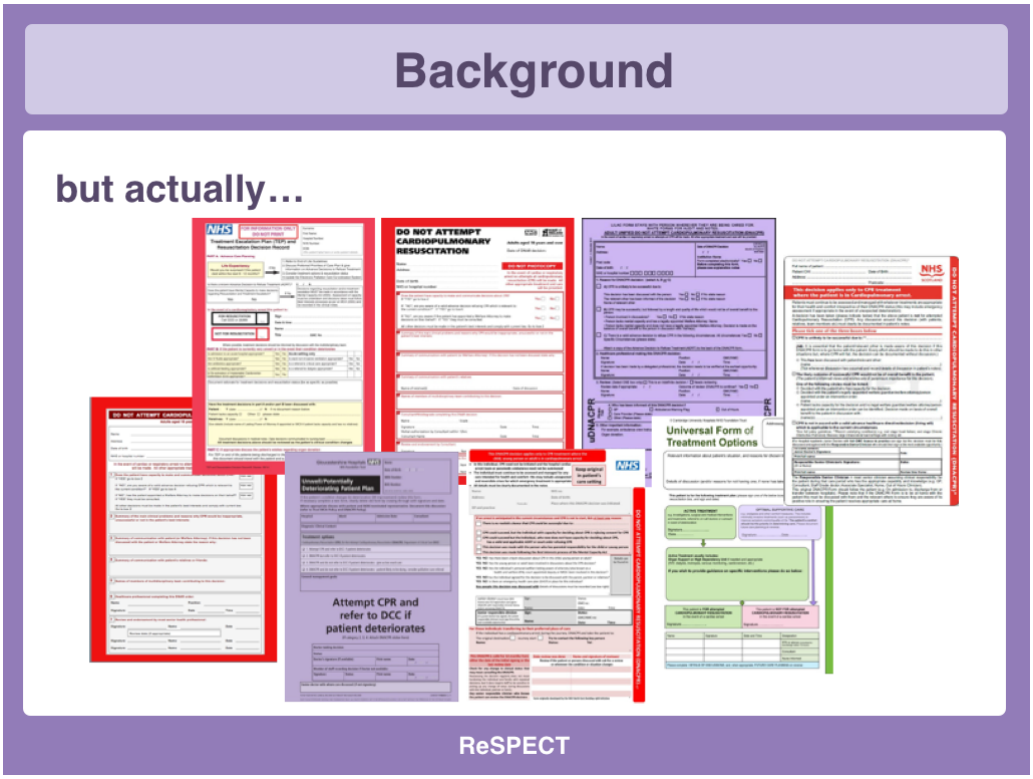
As I'm sure you all know, when CPR might work, it must be started immediately to give a person the best chance of surviving. Because of that, the national guidance from the BMA, Resuscitation Council and RCN states that where no explicit decision about CPR has been recorded, there should be an initial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



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.



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.

• 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.

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.

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:

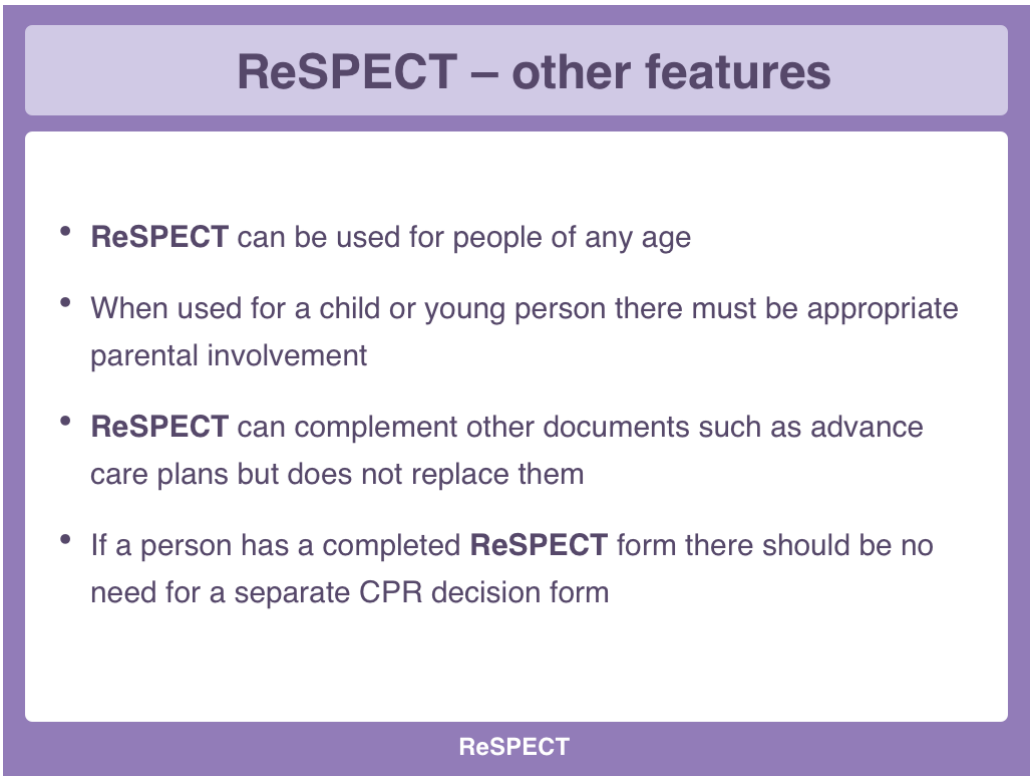
- people who have particular healthcare needs - perhaps a long-term condition or a severe disability that may deteriorate suddenly
- people who are nearing the end of

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.



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.

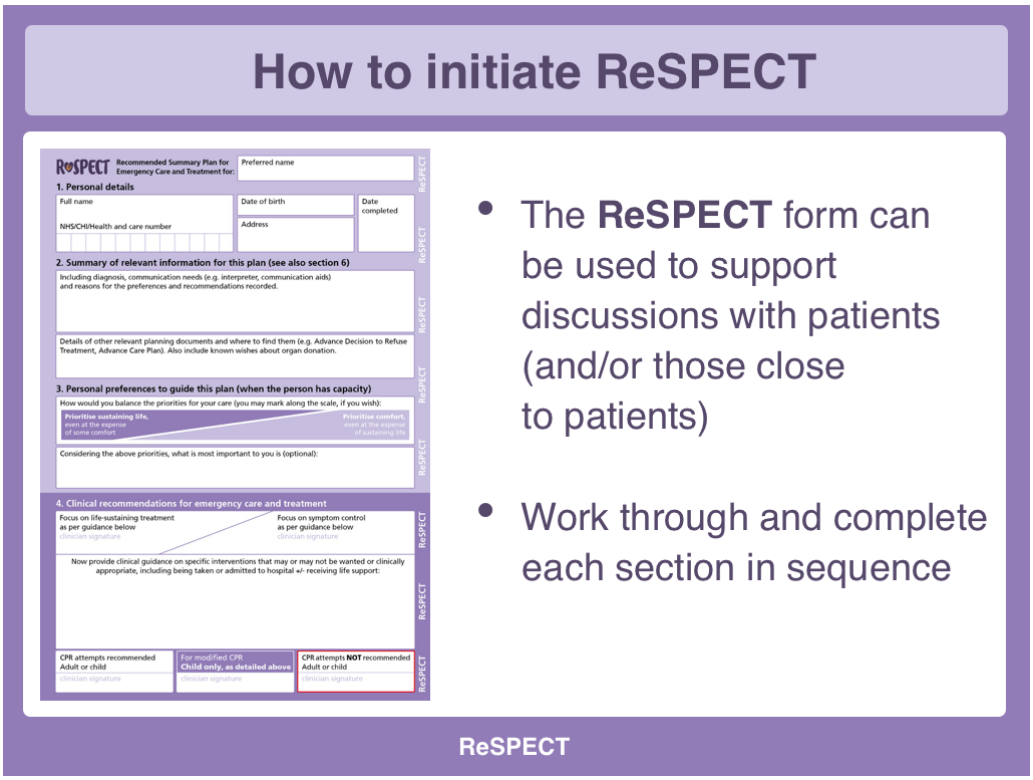
Now let's consider how we start the ReSPECT process. Having identified someone as wanting or potentially benefitting from this we MUST start with a conversation with the person or – in the case of a child – their parent(s).

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

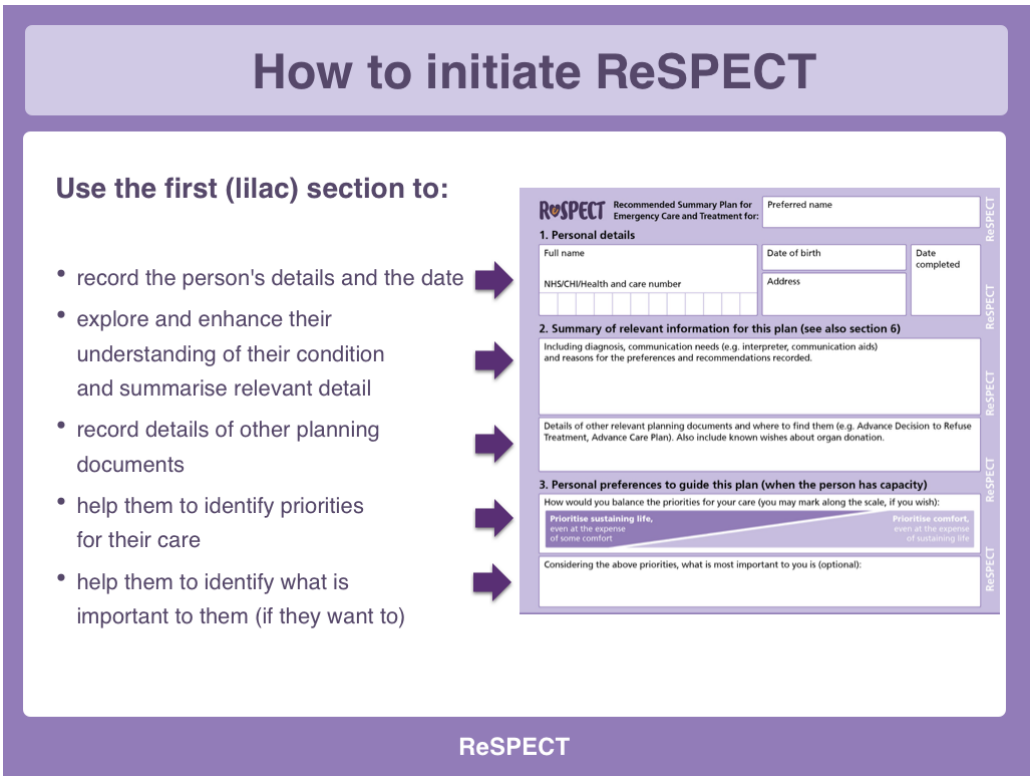
assessment is needed and should be recorded in their health record. Then we must have a conversation with family or other representatives whenever possible, to find out about the person's beliefs and previously expressed wishes.

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.



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.



In summary:

• use section 1 to record the person's full details and the date

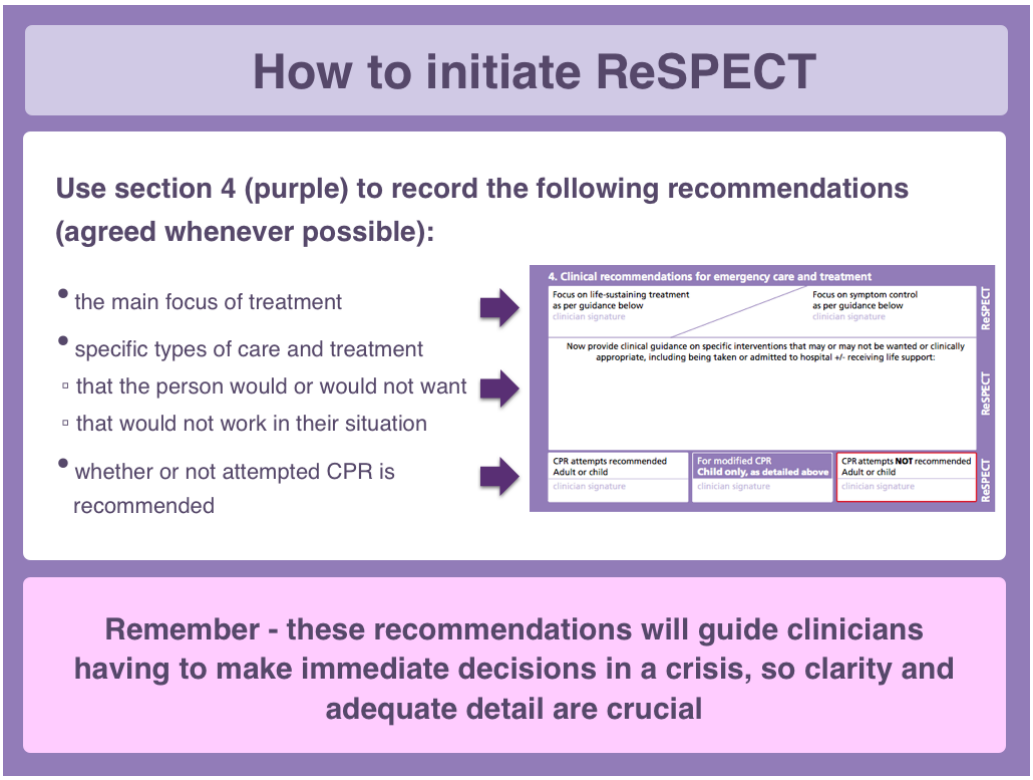
• use section 2 to explore and enhance their understanding of their condition and summarise any relevant detail,

• 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.



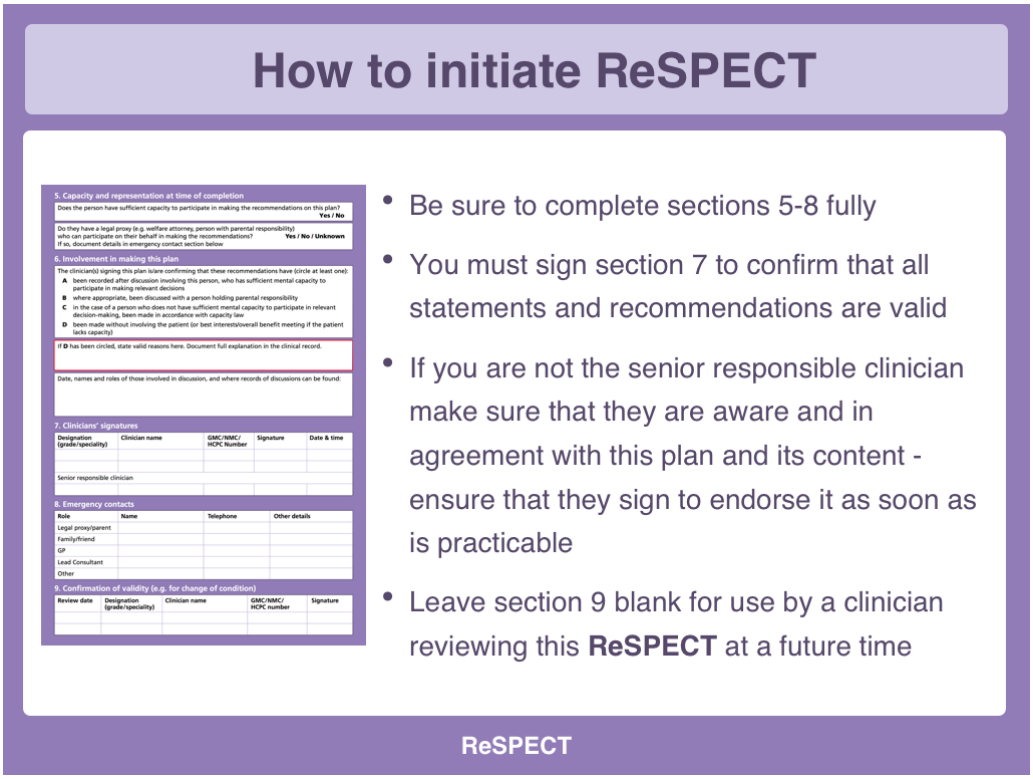
Section 4 is used to record the recommendations that arise from the person's clinical circumstances and preferences.

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.

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.



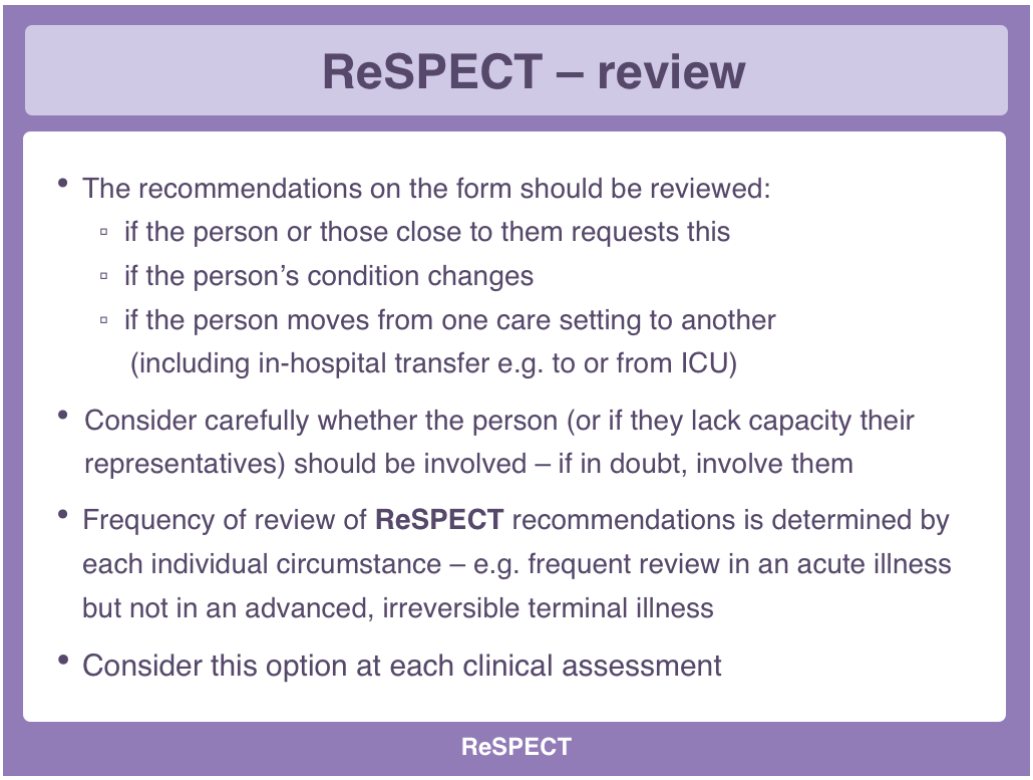
It’s important to complete sections 5-8 fully. In 5 and 6 you confirm that you have completed the process and form lawfully.

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.



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.

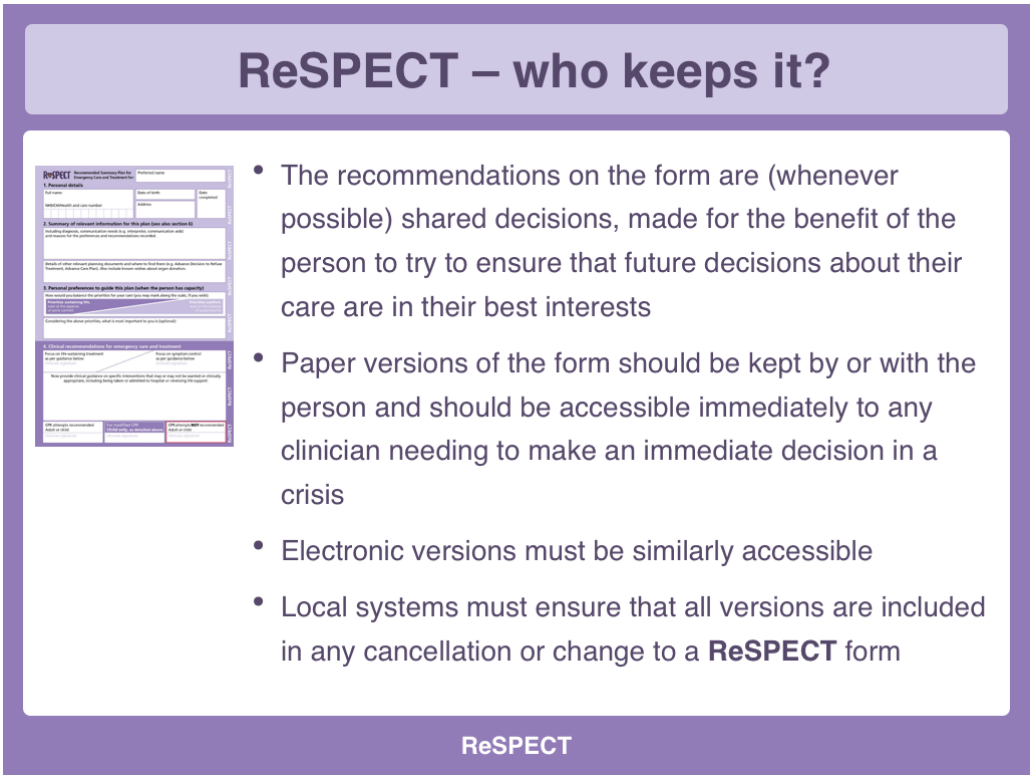
Review should be undertaken if the person or someone close to them asks for this, if the person's condition changes – for either better or worse, and when a person moves from one care setting to another. This might include a change of ward within a hospital. In some cases, review might simply involve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



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.

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 planned and carried out according to individual needs.

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).