

Table 1. Key themes from the consultation survey

Theme	Details
Messaging	<p>Clarification was needed regarding;</p> <ul style="list-style-type: none"> the purpose of ECTP: <ul style="list-style-type: none"> Whose decision was being recorded (patient or clinician) and Who was responsible for it; the interoperability of ECTP with other forms or systems such as advanced care plans; its use with children, including adding a recommendation for modified CPR; the accessibility of the document: <ul style="list-style-type: none"> How it could be accessed if a patient didn't have it with them; Electronic versions could help; Concerns about accessibility of systems across different organisations for electronic versions.
Feedback on details of the form	<p>Feedback covered:</p> <ul style="list-style-type: none"> There were conflicting preferences for free text versus prespecified tick boxes for recording clinical recommendations; The requirements for signatures on the form were unclear; Wording about patient identification numbers needed to allow for different systems in the 4 UK nations; Need for clarity regarding different terms used on the form; Need for clarity regarding validity of the ECTP document – to be easy for clinicians to establish in an emergency; Suggestions to improve guidance on how to complete the form; General comments on the design of the ECTP form.
Barriers to use	<ul style="list-style-type: none"> Lack of clarity about the status of the decisions recorded on the ECTP form.

Table 2 Themes from the usability pilot focus groups

Theme	Categories
Skilled communication by clinicians with appropriate training is required for completion of the ReSPECT process	<p>Skilled communication is necessary for clinicians conducting ReSPECT process conversations.</p> <p>Communication skills training should be an important consideration for those using it as part of introducing the ECTP in any community or organisation.</p>
The process would facilitate the conversation, regardless of clinicians' experience or ability in end-of-life or life-sustaining treatment discussions	<p>The process and form allow for different approaches and are mutually supportive: e.g. 1. working sequentially through the sections on the form to structure the conversation; 2. populating the form from various conversations that clinicians have already had with their patients, discussing and adding specific points as necessary.</p>
The individualised approach to the process is essential and empowering to patients, parents of children, families and other carers	<p>The individualised person-centred approach is a strength.</p> <p>The process requires a clinician to seek the person's views of their priorities.</p> <p>The conversation about a patient's priorities could help clinicians know where to start a conversation about the kind of treatments that would or would not work.</p>
Value of the ReSPECT form in different clinical situations	<p>ReSPECT would be valuable within and across different healthcare settings and for different patients.</p>
Learning the process	<p>Clinicians need to learn the process but that would come with experience.</p> <p>Sharing experiences of using ReSPECT with colleagues was helpful.</p>
Time to complete the process	<p>Additional time is needed for completing ReSPECT.</p> <p>For some participants, it could fit it in with existing advanced care planning practice.</p> <p>Others (e.g. in acute settings) may need to prioritise patients in most urgent need.</p> <p>Having the conversation could be spread over more than one consultation or visit.</p> <p>The additional time involved initially, if it could be found, would be worthwhile to try to improve quality of care and may save time later.</p>

Fits with current practice	ReSPECT fits with current practice of involving patients, parents of children and families in planning processes
Challenges for and advantages of communication using the ReSPECT form between settings.	<p>Challenge:</p> <p>Ensuring access to ReSPECT between settings:</p> <ul style="list-style-type: none"> ○ Electronic versions were seen as important but there are system challenges; ○ Important intention that it is a patient-held document but this could present challenges (e.g. patient doesn't have it with them). <p>Advantages:</p> <p>A means of a clinician who knows the patient well communicating recommendations to clinicians in other settings.</p> <p>Having a document recognised as valid across different settings.</p>
Participants recommendations for wider implementation	
<p>Support from a local champion.</p> <p>Additional educational material to supplement the presentations on the process and guide to completion used for the pilot – e.g. video clips of examples of completion and a multi-pronged approach to awareness raising.</p> <p>Other system-level implementation recommendations that could apply to all organisations were challenging to specify because of differences in local structures and processes. However, participants thought that local knowledge of systems, professional networks and previous experience of implementing care pathways would be useful.</p> <p>The development of an electronic version of the ReSPECT form.</p>	

Box 1: Aims of the ECTP/ReSPECT Working Group.

1. To establish the scope of the project and any resulting documents;
2. To identify and review examples of evidence-based best practice (national and international);
3. To involve public, patient and carer groups and other relevant stakeholders;
4. To collaborate and contribute to developing a national form that is easy to recognise and records anticipatory recommendations about CPR and about other aspects of a person's care or treatment (including but not limited to other life-sustaining treatment) if they suddenly become unwell and unable to make choices;
5. To ensure that the form is person-centred and can be used for all individuals of all ages;
6. To ensure that the process and form are developed with input from a wide range of stakeholders and is acceptable to patients, those important to them, health and care professionals, carers and other members of the public;
7. To plan implementation to try to ensure that the process is used and the form used and accepted across geographical and organisational boundaries and in a full range of health and care settings;
8. To develop plans to reduce the current negative perception of DNACPR 'decisions' and to achieve public engagement for successful implementation and acceptance of a national process and form;
9. To establish realistic timelines for development, pilot of, and implementation of the process and form across the UK.

Footnote: The Working Group included patient and public representatives alongside representatives from the Association of Ambulance Chief Executives, Association for Palliative Medicine, British Medical Association, Care Quality Commission, General Medical Council, Intensive Care Society, Joint Royal College Ambulance Liaison Committee, MenCap, National council for Palliative care, Paediatric Intensive Care Society, Professional Record Standards Body, Royal College of Anaesthetists, Royal College of Emergency Medicine, Royal College of Nursing, Royal College of Paediatrics and Child Health, Royal College of Physicians, Royal College of Surgeons, Resuscitation Council (UK), and Resuscitation Officers.

Figure 1. Iterations of the ECTP documentation from prototype to final ReSPECT version. Key changes to the overall concepts were: 1. greater focus on a clinician's role in making recommendations about what treatments would and would not be likely to work in an emergency; 2. more emphasis on discussions that lead to completion of the form, particularly the importance of seeking patient's preferences; 3. clarity that the form would record resulting agreed recommendations to guide a clinician needing to make rapid decisions in an emergency; 4. emphasis that the form should be accepted as valid across settings and should include provision for review and a signature to indicate that the form was still valid. An option for modified CPR for children only was added on advice from paediatric representatives. Revisions were made to the sections about capacity, existence of legally binding refusals of treatment, and those with legal power to make decisions on a patient's behalf.

ECTP used for phase 1 and 2.

Emergency Care & Treatment Plan

Name: _____
 Date of Birth: _____ Hospital/NHS numbers: _____
 Address: _____

1

Date: __/__/__

2

Relevant information about the individual's diagnosis, situation, ability to communicate, and reasons for the chosen plan.

3

The following treatment plan should be used as clinical guidance and is *not* a substitute for ongoing consultation and shared decision-making wherever possible. The clinician should initial ONE of the patient's priority boxes below, add relevant guidance in the large box and initial a CPR decision. The form must be signed, named and dated on the reverse.

The priority is to get better. Please consider all treatment to prolong life

Initials: 4

The priority is to achieve a balance between getting better and ensuring good quality of life. Please consider selected treatments

Initials: 4

The priority is comfort. Please consider all treatments aimed at symptom control

Initials: 4

Please provide clinical guidance on specific interventions that may or may not be wanted or clinically appropriate in community, hospital and critical care settings:

Provide details of other relevant care planning documents and/or documented wishes about organ/tissue donation (name and where held):

5

This individual is **FOR** attempted CARDIOPULMONARY RESUSCITATION

Signature..... 6

This individual is **NOT FOR** attempted CARDIOPULMONARY RESUSCITATION

Signature.....
 If the patient dies in transit please take to: 6

Turn over to complete this ECTP →

Does the (adult) individual have capacity? (see guidance notes) YES ☐ NO ☐
 Do they have a valid advance directive or ADRT? YES ☐ NO ☐
 If so, record details in box 5
 Do they have a representative with legal authority to make decisions? YES ☐ NO ☐
 (e.g. Welfare Attorney, Guardian, person with Lasting Power of Attorney for Health and Welfare)
 If so, record their contact details and document details of discussion below.

7

The clinician signing this ECTP is confirming that these decisions:

- 1. have been discussed with and agreed with the individual;
- or 2. have been made in accordance with capacity law;
- or 3. in the case of a child, the person holding parental responsibility/court order.

Date of discussion: __/__/__ Names of those present:

Full documentation of discussion can be found in:

Further conversations occurred on the following dates (state where details are recorded):

8

If there has been no shared decision-making with the individual, no shared decision-making with a representative with legal authority to make decisions or no best-interests meeting for the individual who lacks capacity, document a full explanation and a clear plan to address this in the clinical records. Summarise the reason (e.g. describe any potential to cause harm) here:

9

Designation - (Grade and specialty)	Print name & professional registration number	Signature	Date and time
Senior Responsible Clinician			

10

Plan review: If the individual's condition changes (i.e. deterioration OR improvement) review the decisions on this ECTP. Document further conversations in box 8. If necessary, complete a new form, and write "CANCELLED" clearly across both sides of this form with signature and date. The decisions on this form should be reviewed specifically before any procedure during which abrupt deterioration or cardiac arrest may occur (e.g. endoscopy, cardiac pacing, angiography, surgery or anaesthesia). Make an agreed plan on whether or not to revoke temporarily the decisions on this form and, if so, on the treatments that will be considered if abrupt deterioration or cardiac arrest occurs.

11

Emergency contacts	Name	Telephone numbers	Other relevant details
Welfare Attorney, Guardian etc.			
Family/friend			
GP			
Lead Consultant			
Specialist worker/key worker			

12

Recommended Summary Plan for Emergency Care and Treatment for phase 3 PPI Group

Recommended Summary Plan for Emergency Care and Treatment for:		Preferred name
1. Your details		
Full name	Address	Date completed
NHS/CHI number		
2. Summary of relevant information for your chosen plan		
Including diagnosis, communication needs (e.g. interpreter, communication aids and reasons for the preferences and recommendations recorded)		
Details of your other relevant planning documents and where to find them (e.g. ADRT, Advance Care Plan, paediatric care plans. Also include known wishes about organ donation)		
3. Your personal preferences to guide your care and treatment plan		
Please show your priorities for your care by marking on spectrum:		
Prioritise prolonging life, even at the expense of comfort	or	Prioritise comfort, even at the expense of prolonging life
<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>		
Considering the above priorities, what is most important to you is: (optional)		
4. In view of the above, clinical guidance for treatment options		
Prioritise life-sustaining treatments... <small>clinician signature</small>	or	Prioritise comfort treatments... <small>clinician signature</small>
Specific preferences and clinical recommendations		
5. Cardiopulmonary Resuscitation		
For attempted CPR Adult and child <small>clinician signature</small>	Not for attempted CPR Adult and child <small>clinician signature</small>	For modified CPR Child only. Refer to summary in section 4. <small>clinician signature</small>

6. Capacity and representation at time of completion				
Does the person have capacity for the decisions recommended on this plan?	Yes / No			
Do they have a legal proxy (e.g. welfare attorney, person with parental responsibility) with authority to make decisions on their behalf? <small>If so, document details in emergency contact section below</small>				
Yes / No / Unknown				
7. Involvement in making this plan				
The clinician signing this plan is confirming that these recommendations have... (circle one)				
A been discussed with this person who has the mental capacity to make them and that they are consistent with their wishes B in the case of a child, been discussed with the person holding parental responsibility C been made in accordance with capacity law (e.g. ADRT, or in discussion with legal proxy)				
Discussion				
Date, names and roles of those involved, and where records of discussions can be found				
If this plan is being completed without involving the patient (or their legal proxy or best interest meeting if they lack capacity), please document full explanation in the clinical record. State the reasons for not discussing below (i.e. explain patient refusal, describe the potential to cause significant harm, or explain need for emergency decision)				
8. Clinicians' signatures				
Designation (grade/speciality)	Clinician name	GMC/NMC No.	Signature	Date & time
<small>Senior responsible clinician</small>				
Emergency contacts				
Role	Name	Telephone	Other details	
Legal proxy				
Family/friend				
GP				
Lead Consultant				
Other				
9. Review and confirmation of validity (e.g. for change of location of care)				
Review date	Designation (grade/speciality)	Clinician name	GMC/NMC No.	Signature
Other recommendations (e.g. for ambulance crew)				

Version of ReSPECT used for stage 4 usability pilot

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

1. Your details

Full name

NHS/CHI number

Date of birth

Address

Date completed

2. Summary of relevant information for your agreed plan (see also section 6)

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

Details of your 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. Your personal preferences to guide your care and treatment plan

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):

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:

For attempted CPR
Adult or child
clinician signature

For modified CPR (Child only)
Refer to clinical guidance above
clinician signature

Not for attempted CPR
Adult or child
clinician signature

5. Capacity and representation at time of completion

Does the person have capacity for the decisions recommended on this plan? Yes / No

Do they have a legal proxy (e.g. welfare attorney, person with parental responsibility) with authority to make decisions on their behalf? Yes / No / Unknown

If so, document details in emergency contact section below

6. Involvement in making this plan

The clinician signing this plan is confirming that these recommendations have (circle one):

A been discussed with this person who has the mental capacity to make them and that they are consistent with their wishes

B in the case of a baby, child or young person, been discussed with a person holding parental responsibility

C been made in accordance with capacity law (e.g. Advance Decision to Refuse Treatment, or in discussion with legal proxy or other representatives)

Discussion (Date, names and roles of those involved, and where records of discussions can be found):

If this plan is being completed without involving the patient (or meeting to decide best interests/overall benefit with legal proxy or other representative where the patient lacks capacity), please document full explanation in the clinical record.
State the reasons for not discussing below (i.e. explain patient refusal, describe the potential to cause significant harm, or explain need for emergency decision):

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. Review and confirmation of validity (e.g. for change of location of care)

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

Figure 2

Figure 2 Logic model usability pilot

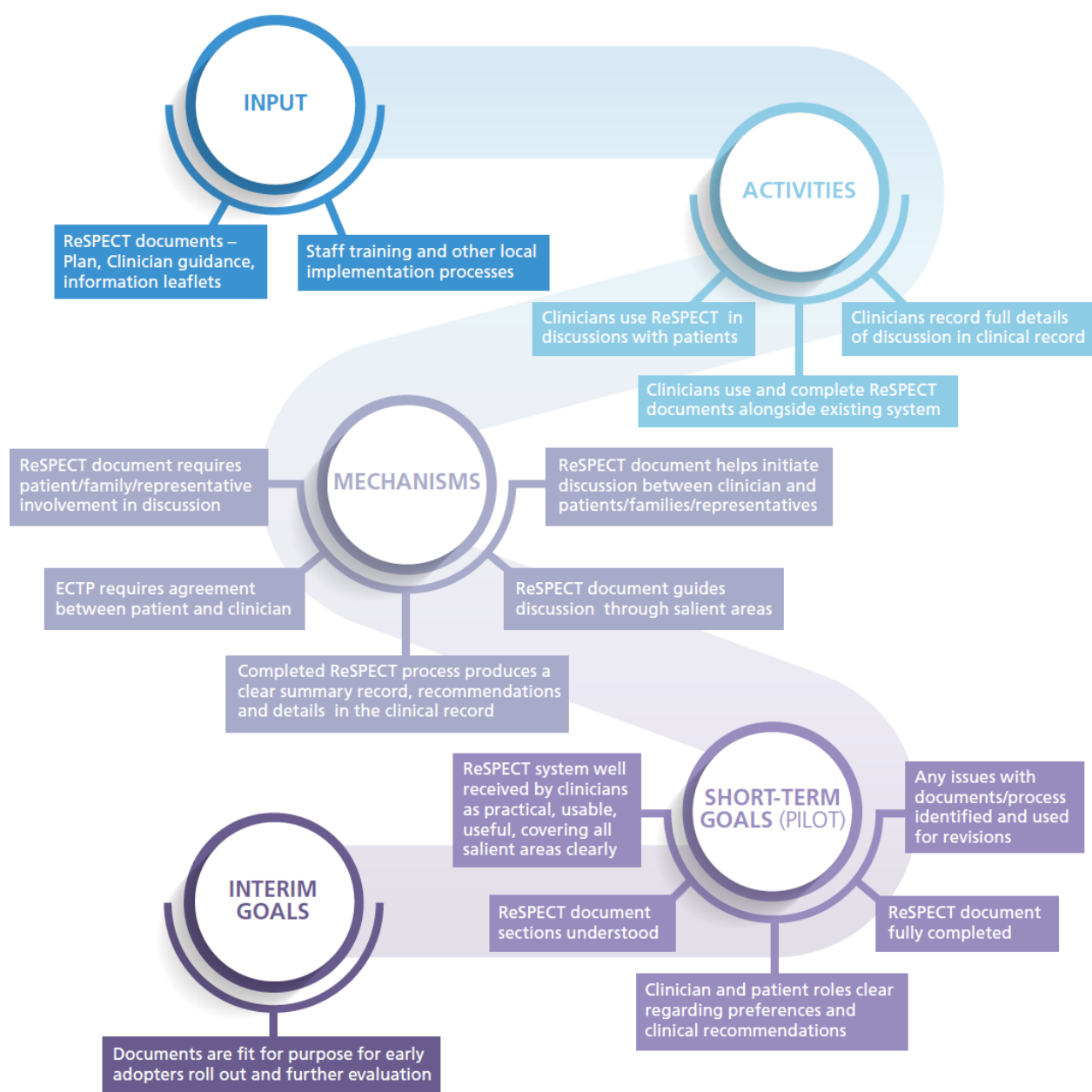


Figure 3

Figure 3: Overview of development and evaluation process

