<table>
<thead>
<tr>
<th>Theme</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Messaging</td>
<td>Clarification was needed regarding;</td>
</tr>
<tr>
<td></td>
<td>• the purpose of ECTP:</td>
</tr>
<tr>
<td></td>
<td>o Whose decision was being recorded (patient or clinician) and</td>
</tr>
<tr>
<td></td>
<td>o Who was responsible for it;</td>
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<tr>
<td></td>
<td>the interoperability of ECTP with other forms or systems such as advanced care plans;</td>
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<tr>
<td></td>
<td>• its use with children, including adding a recommendation for modified CPR;</td>
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<tr>
<td></td>
<td>• the accessibility of the document:</td>
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<tr>
<td></td>
<td>o How it could be accessed if a patient didn’t have it with them;</td>
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<tr>
<td></td>
<td>o Electronic versions could help;</td>
</tr>
<tr>
<td></td>
<td>o Concerns about accessibility of systems across different organisations for electronic versions.</td>
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<tr>
<td>Feedback on details of the form</td>
<td>Feedback covered:</td>
</tr>
<tr>
<td></td>
<td>• There were conflicting preferences for free text versus prespecified tick boxes for recording clinical recommendations;</td>
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<tr>
<td></td>
<td>• The requirements for signatures on the form were unclear;</td>
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<td></td>
<td>• Wording about patient identification numbers needed to allow for different systems in the 4 UK nations;</td>
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<tr>
<td></td>
<td>• Need for clarity regarding different terms used on the form;</td>
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<tr>
<td></td>
<td>• Need for clarity regarding validity of the ECTP document – to be easy for clinicians to establish in an emergency;</td>
</tr>
<tr>
<td></td>
<td>• Suggestions to improve guidance on how to complete the form;</td>
</tr>
<tr>
<td></td>
<td>• General comments on the design of the ECTP form.</td>
</tr>
<tr>
<td>Barriers to use</td>
<td>• Lack of clarity about the status of the decisions recorded on the ECTP form.</td>
</tr>
</tbody>
</table>
Table 2 Themes from the usability pilot focus groups

<table>
<thead>
<tr>
<th>Theme</th>
<th>Categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>Skilled communication by clinicians with appropriate training is required for completion of the ReSPECT process</td>
<td>Skilled communication is necessary for clinicians conducting ReSPECT process conversations. Communication skills training should be an important consideration for those using it as part of introducing the ECTP in any community or organisation.</td>
</tr>
<tr>
<td>The process would facilitate the conversation, regardless of clinicians’ experience or ability in end-of-life or life-sustaining treatment discussions</td>
<td>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.</td>
</tr>
<tr>
<td>The individualised approach to the process is essential and empowering to patients, parents of children, families and other carers</td>
<td>The individualised person-centred approach is a strength.</td>
</tr>
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<td></td>
<td>The process requires a clinician to seek the person’s views of their priorities.</td>
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<tr>
<td></td>
<td>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.</td>
</tr>
<tr>
<td>Value of the ReSPECT form in different clinical situations</td>
<td>ReSPECT would be valuable within and across different healthcare settings and for different patients.</td>
</tr>
<tr>
<td>Learning the process</td>
<td>Clinicians need to learn the process but that would come with experience.</td>
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<tr>
<td></td>
<td>Sharing experiences of using ReSPECT with colleagues was helpful.</td>
</tr>
<tr>
<td>Time to complete the process</td>
<td>Additional time is needed for completing ReSPECT.</td>
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<td></td>
<td>For some participants, it could fit it in with existing advanced care planning practice.</td>
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<tr>
<td></td>
<td>Others (e.g. in acute settings) may need to prioritise patients in most urgent need.</td>
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<tr>
<td></td>
<td>Having the conversation could be spread over more than one consultation or visit.</td>
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<tr>
<td></td>
<td>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.</td>
</tr>
<tr>
<td>Fits with current practice</td>
<td>ReSPECT fits with current practice of involving patients, parents of children and families in planning processes</td>
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<tr>
<td>---------------------------</td>
<td>----------------------------------------------------------------------------------------------------------</td>
</tr>
</tbody>
</table>
| Challenges for and advantages of communication using the ReSPECT form between settings. | Challenge: Ensuring access to ReSPECT between settings:  
  - 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).  
Advantages:  
  A means of a clinician who knows the patient well communicating recommendations to clinicians in other settings.  
  Having a document recognised as valid across different settings. |

**Participants recommendations for wider implementation**

- Support from a local champion.

- 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.

- 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.

- The development of an electronic version of the ReSPECT form.
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: ____________________________

Date: __/__/____ 2

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

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.
- The priority is to achieve a balance between getting better and ensuring good quality of life. Please consider selected treatments.
- The priority is comfort. Please consider all treatments aimed at symptom control.

Initials: ____________________________

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

- Designation: ____________________________
- Grade and specialty: ____________________________
- Print name and professional registration number: ____________________________
- Signature: ____________________________
- Date and time: ____________________________

Senior Responsible Clinician: ____________________________

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.

- Emergency contacts: ____________________________
  - Name: ____________________________
  - Telephone numbers: ____________________________
  - Other relevant details: ____________________________

- Welfare Attorney, Guardian etc.: ____________________________
- Family/friend: ____________________________
- GP: ____________________________
- Lead Consultant: ____________________________
- Specialist worker/key worker: ____________________________

Turn over to complete this ECTP.
Recommended Summary Plan for Emergency Care and Treatment for phase 3 PPI Group

1. Your details
   - Full name
   - NHS/CHI number
   - Address
   - Date completed

2. Summary of relevant information for your chosen plan
   - Including diagnosis, communication needs, (e.g. interpreter, communication aids and reason for the preferences and recommendations recorded)
   - Details of your other planning documents and where to find them (e.g. ADRT, Advance Care Plan, palliative 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:
     - Milieu for prolonging life set at the expense of comfort
     - Milieu for comfort set at the expense of prolonging life
   - 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...
   - Prioritise comfort treatments...
   - Specific preferences and clinical recommendations

5. Cardiopulmonary Resuscitation
   - For attempted CPR
     - Adult and child
     - clinician signature
   - Not for attempted CPR
     - Adult and child
     - clinician signature
   - For modified CPR
     - Child only, refer to summary in section 4
     - clinician signature

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? Yes/No/Unknown
   - If so, document details in emergency contact section below

7. Involvement in making this plan
   - The clinician signing this plan is confirming that these recommendations have... (circle one)
     - been discussed with the person who has the mental capacity to make them and that they are consistent with their wishes
     - in the case of a child, been discussed with the person holding parental responsibility
     - been made in accordance with capacity law (e.g. ADRT, or in discussion with legal proxy)
   - Discussion
     - Date, name(s) and roles of those involved, and where record 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 reason 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
   - GMR/NMC No.
   - Signature
   - Date & Time
   - Senior responsible clinician

9. Review and confirmation of validity (e.g. for change of location of care)
   - Review date
   - Designation (grade/speciality)
   - Clinician name
   - GMR/NMC No.
   - Signature

   Other recommendations (e.g. for ambulance crew)
Version of ReSPECT used for stage 4 usability pilot
Figure 3: Overview of development and evaluation process

Revisions to ECTP Document
- Consensus for ECTP prototype: phase 1
  - Contextualise resuscitation decisions among overall goals of care
  - Facilitate early discussion with patients and their families
  - Be recorded on a single piece of paper (or digital equivalent), for access in an emergency

Key revisions to ECTP prototype following phase 2
- Emphasis on recommendations made in advance.
- Clarification that clinical decision making resides with the clinician at time of emergency
- Greater emphasis on discussion between clinicians and patients/parents to complete documentation (seeking patients/preferences (section 3) clinician recommendation (section 4))
- Modified CPR option for children only
- Revision of sections on mental capacity
- Addition of section 9 to emphasise validity across settings
- Naming the process Recommended Summary Plan for Emergency Care and Treatment (ReSPECT)

Revisions to ReSPECT process following PPI group
- Messaging in guidance and posters

Key revisions to ReSPECT and recommendations following phase 4 Usability Pilot
- Section recording mental capacity legislation revised to ensure compatibility with law in all 4 home nations
- No other substantial changes made
- Recommendation to make available supporting information on implementation with associated quality improvement, including on-going audit, to support culture change for adopting organisations
- Recommendation to supplement educational information with video clips