

1 **Development of the Recommended Summary Plan for Emergency Care and Treatment (ReSPECT)**

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Abstract

Introduction

Do-not-attempt-cardiopulmonary-resuscitation (DNACPR) practice has been shown to be variable and sub-optimal. This paper describes the development of the Recommended Summary Plan for Emergency Care and Treatment (ReSPECT). ReSPECT is a process which encourages shared understanding of a patient’s condition and what outcomes they value and fear, before recording clinical recommendations about cardiopulmonary-resuscitation (CPR) within a broader plan for emergency care and treatment.

Methods

ReSPECT was developed iteratively, with integral stakeholder engagement, informed by the Knowledge-to-Action cycle. Mixed methods included: synthesis of existing literature; a national online consultation exercise; cognitive interviews with users; a patient-public involvement (PPI) workshop and a usability pilot, to ensure acceptability by both patients and professionals.

Results

The majority (89%) of consultation respondents supported the concept of emergency care and treatment plans. Key features identified in the evaluation and incorporated into ReSPECT were: The importance of discussions between patient and clinician to inform realistic treatment preferences and clarity in the resulting recommendations recorded by the clinician on the form. The process is compliant with UK mental capacity laws. Documentation should be recognised across all health and care settings. There should be opportunity for timely review based on individual need.

Conclusion

ReSPECT is designed to facilitate discussions about a person’s preferences to inform emergency care and treatment plans (including CPR) for use across all health and care settings. It has been developed iteratively with a range of stakeholders. Further research will be needed to assess the influence of ReSPECT on patient-centred decisions, experience and health outcomes.

71 **Introduction**

72
73 Do-not-attempt-cardiopulmonary-resuscitation (DNACPR) decisions have been used since the
74 1970s.¹ Variations and sub-optimal practice across healthcare settings have been identified when
75 considering, discussing, and documenting anticipatory decisions about CPR.²⁻⁴ DNACPR decisions
76 were sometimes wrongly interpreted, leading to withholding of other aspects of care.^{2,5-7}
77 Documentation recording CPR decisions was often institution-specific, meaning decisions were not
78 transferrable between organisations involved in a person's care.^{8,9}

79
80 An alternative to stand-alone DNACPR decisions is the use of plans made in advance which
81 contextualise recommendations about CPR within recommendations for a person's broader
82 emergency care and treatment.^{10,11} There is evidence that clinicians welcome this approach; that it
83 promotes better recording of patient preferences,^{12,13} and can reduce patient harm when
84 compared to a simple DNACPR system.⁶ An emergency care and treatment plan can complement a
85 broader advance care plan (ACP). It provides a succinct summary of patient preferences and
86 realistic treatment recommendations to guide those needing to make immediate decisions in an
87 emergency and when loss of capacity may prevent patient involvement.

88
89 In October 2014 patients, clinicians, health service commissioners and regulators attended a
90 summit at the Royal Society of Medicine on DNACPR decisions in the UK. The meeting heard
91 findings about variation and sub-optimal practice in relation to DNACPR across healthcare settings,
92 alongside exemplars of best practice. Contextualising 'decisions' about CPR (including 'for CPR'
93 recommendations) within a nationally recognised, broader plan for emergency care and treatment
94 was identified as a key priority to improve quality of care.²

95
96 In response, the Resuscitation Council UK, in partnership with the Royal College of Nursing, clinical
97 and patient and public stakeholders including representation from all 4 nations of the UK,
98 established a Working Group, to develop a new, standardised approach to discussing and recording
99 recommendations about CPR in the context of broader emergency plans (box 1). This paper
100 describes the early development and the evaluation of **Recommended Summary Plan for**
101 **Emergency Care and Treatment (ReSPECT)** to the point where it was useable by clinicians and was
102 ready for implementation in practice with ongoing monitoring and evaluation.

103
104 *[Insert box 1]*

105
106 **Methods**

107
108 The aim was to develop an Emergency Care and Treatment Plan (ECTP) as an alternative to an
109 approach that focused solely on withholding CPR.

110 Key objectives were:

- 111
 - to bring together published evidence and clinical experience;

- 112 • to develop an approach with, and acceptable to, clinicians, patients, carers and other
- 113 members of the public;
- 114 • that the output should be used across all health and care settings;
- 115 • to contextualise a decision/recommendation about CPR within overall goals of care;
- 116 • to focus on care and treatments to be given as well as those that are not wanted or that
- 117 would not work.

118
119 An ECTP was developed and revised iteratively by integrating the Knowledge to Action (KTA) cycle¹⁴
120 with a mixed methods approach to evaluation until it was agreed to be acceptable for use in
121 clinical practice by experienced clinicians in general practice or any clinical speciality for completion
122 with patients or their representatives at any point in the patient's care. The KTA cycle is a
123 framework which conceptualises the dynamic, complex nature of translating knowledge into
124 practice, incorporating ongoing evaluation. Embedded stakeholder engagement throughout was
125 integral to the development and subsequent adoption.^{15, 16}

126

127 *Phase 1: Development of a prototype ECTP*

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129 Published literature and existing approaches to emergency care and treatment planning in the
130 National Health Service (NHS) were reviewed.^{6,11-13,17} Common and contrasting elements of
131 existing approaches were synthesised. A modified Delphi approach was used to iteratively develop
132 a prototype ECTP, integrating patients' and members of the public's perspectives with those of
133 health professionals from multiple specialities and settings. Supporting documents and resources,
134 including education materials, were developed.

135

136 *Phase 2: Consultation survey and cognitive interviews*

137

138 A survey consultation was developed to determine opinions on the generic concept of an ECTP,
139 alongside views of and comments on the prototype ECTP form, designed to "nudge" clinicians and
140 patients into a process which respected both patient preferences and clinical judgement, and
141 supporting information materials. ***As a consultation exercise we expected responses from
142 interested parties rather than a representative sample of the UK population.*** Open questions
143 inviting free-text responses, and questions requiring selection of one or more predetermined
144 responses were included. The survey was pilot tested by members of the Working Group and
145 refined to improve clarity.

146

147 The survey was administered online (SurveyMonkey, Dublin), with paper copies available on
148 request. Patients and other members of the public, health and care professionals, provider
149 organisations, regulatory bodies and any others who registered an interest were invited by email to
150 participate and cascade information to others (See supplementary table 1).

151

152 Binary and categorical response questions were analysed using descriptive statistics. One
153 researcher (CH) summarised and categorised free-text comments into themes. A second researcher
154 (GDP) tested them against the data for plausibility. Both researchers agreed the final overarching
155 themes.

156

157 A purposive sample (i.e. a non-probability sample selected to cover a variety of characteristics of
158 those who would use an ECTP) of interview participants were identified through the Working

159 Group's networks to gain a range of views and experiences. Those who agreed to take part were
160 sent the ETCP documents ahead of individual cognitive telephone interviews. A method of
161 interviewing to understand the ways respondents process and respond to what is written, to assess
162 whether their understanding was consistent with the intent of the developers. 2 members of the
163 public, 2 paramedics, 3 senior nurses (nursing home senior nurse, community matron, palliative
164 care specialist), 2 paediatricians, 2 physicians (acute and palliative care), a general practitioner (GP)
165 and a surgeon were interviewed by CH.

166
167 Clinicians were asked to 'think aloud' as they worked through how they would use the ECTP with a
168 patient.¹⁸ The sections were designed to guide or prompt the clinician about all the different
169 elements necessary to having a conversation to plan for an emergency. This approach allowed
170 identification of sections that worked well and those that were problematic. Members of the public
171 were asked to think aloud about how they would use the form to plan future care
172 recommendations with their own doctor or a relative's doctor. Paramedics, (who would rarely if
173 ever complete a plan, but would have to use the ECTP in an emergency situation), were given 2
174 emergency scenarios. They were asked to think through what they would do and asked to identify
175 potential areas of confusion and make suggestions for improvement.

176
177 Comments from participants' interviews were summarised and categorised by content and process
178 (comprehension, retrieval, decision and response processes).¹⁹ Consistency with or variation from
179 the original intent were assessed using a framework covering each section of the ECTP recorded
180 on the form.²⁰ Any consistent misunderstandings, sections that did not work as intended, or other
181 problems were identified. Views of the associated guidance documents were summarised and
182 categorised by topic according to their relevance for clarity, usefulness in relation to recording
183 discussions and the plan of care using the form or missing information that would improve the
184 guidance. Suggestions for improvements were collated and changes were made to the ECTP form
185 and supporting documents to address the identified issues.

186
187 The working title (ETCP) was replaced with "Recommended Summary Plan for Emergency Care and
188 Treatment (ReSPECT)" New documents incorporated the key changes resulting from the
189 consultation, with design by HELIX, a joint enterprise between Imperial College London and the
190 Royal College of Art.

191
192 Figure 1 shows the iterative development of the ECTP/ReSPECT form

193
194 *[Insert figure 1]*

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197 *Phase 3: Patient and public focus groups*

198
199 Patient and public feedback was sought from members of the National Institute for Health
200 Research (NIHR) Wessex Collaboration for Leadership in Applied Health Research and Care
201 (CLAHRC) patient-and-public-involvement group. The group was run as a workshop, supported by
202 trained CLAHRC facilitators. Participants worked through the ReSPECT documents (a poster and
203 flyer to raise awareness of the ReSPECT process, the form to record recommended care and
204 treatment in emergency situations, and the patient information sheet). Overall key messages to
205 feed back to the Working Group were agreed.

206

207 *Phase 4: Usability pilot*

208

209 Clinicians at four sites (Scotland, Northern England, the English Midlands and London) pilot tested
210 ReSPECT with approximately 10 patients each. Sites covered paediatric intensive care, paediatric
211 palliative care in acute and community settings, nursing home, adult hospice, community and acute
212 palliative care, and adult acute medical admissions. In larger settings the pilot was limited to
213 particular departments (e.g. acute hospital wards). A principle investigator at each site organised
214 the intervention and recruited focus group participants.

215

216 Clinician's participated in focus groups. A logic model (figure 2) of how the ReSPECT process and
217 associated materials were intended to work informed interview topics, focusing on pilot aims:

- 218 • assessment of usability in clinical practice,
- 219 • suitability and understandability of the ReSPECT process, using the form to record care and
220 treatment recommendations and associated guidance
- 221 • identification of usability improvements needed.

222 A researcher CH led five focus groups supported by JS at one site and another researcher GD at the
223 others. Interviews were audio recorded and transcribed for analysis.

224

225 *[Insert figure 2]*

226

227 Focus group transcripts were analysed using Framework analysis.²¹ A thematic framework was
228 developed, using the pilot aims and the logic model. Transcripts were inductively coded and
229 categorised independently by the 2 researchers (CH and GD). Categories were assessed for fit with
230 the framework themes, and additional themes were added where necessary. The two researchers
231 discussed and agreed the final categories and the final themes.

232

233 *Governance approvals*

234 Local approvals for service development projects were obtained at each site.

235

236 A summary of the overall development and evaluation framework is presented in figure 3.

237

238 *[Insert figure 3]*

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241 **Results**

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243 *Phase 1: Development of a prototype emergency care and treatment plan*

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245 Between 12-20% of UK acute hospitals and community services had introduced some style of ECTP
246 that had either replaced or sat alongside a DNACPR approach and form.^{6,12,24} A range of other
247 protocols and supporting documentation was examined to identify core themes from existing ECTP
248 systems to inform the prototype ECTP. These systems included: Physician Orders for Life Sustaining
249 Treatment (POLST, USA),²² Medical Orders for Scope of Treatment (MOST, Canada),²³ Universal
250 Form of Treatment Options (UFTO, Cambridge, UK),¹⁰ Treatment Escalation Plans (TEPs, Devon,
251 UK), Unwell and Potentially Deteriorating Patient Plan (UP, Gloucester, UK), Deciding Right (North
252 East England).

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Phase 2: Consultation survey and cognitive interviews

The survey was open for 6 weeks in early 2016. One thousand one hundred and twelve people and organisations participated in the survey. The majority were healthcare professionals (89%), with responses from 97 members of the public (9%). Other responses were received from professional bodies and healthcare organisations. Participant characteristics are presented in supplementary tables 2-5. Eighty nine percent of respondents liked the concept of an ECTP, and 70% (n=307) of those who expressed an opinion about it were either satisfied or very satisfied with the prototype ECTP form. The thematic analysis of the free text answers are presented in table 1 and supplementary table 8. Data saturation was reached during coding before the themes were identified.

Clinicians understood the sections of the ECTP as intended and could complete or use it in an emergency situation. The subject matter was unfamiliar and complex for the patients interviewed highlighting the need for clinicians to be skilled in involving their patients in discussions and making sure they would be able to understand what was agreed and recorded on the form. No other issues emerged that had not already been raised in the survey feedback (see table 1).

[Insert table 1]

Transition from ECTP to ReSPECT

Phase 1 and 2 findings were used to develop the next iteration of the ECTP form and supporting materials. Key changes that were introduced are summarised in Figure 3.

The resulting new iteration used the new name: Recommended Summary Plan for Emergency Care and Treatment (ReSPECT). This new acronym emphasised that patients and their clinicians should respect each other's roles and contributions to the ReSPECT process.

Patient and public workshop

Eleven participants attended the patient-and-public-involvement (PPI) workshop. Participants reported a disconnect between the poster, which they felt advertised a *patient-driven* process, and the ReSPECT form, which was to be completed by *clinicians* during or following a dialogue with a patient. They highlighted that the messaging needed to clearly convey the importance of the conversation between patient and clinician and the importance of the patient making their wishes known. Suggestions were made that resources (e.g. a ReSPECT website) should include what sort of treatments are considered emergency treatments, and more advice for patients.

Phase 3 Usability testing

Twenty-nine clinicians participated in the 5 focus groups: 14 doctors (7 consultants, 7 trainees) and 15 clinical nurse specialists (palliative care and acute medicine).

Table 2 outlines the findings. More detail is provided in supplementary table 9.

300 [insert table 2]

301
302 The recommendations based on the usability pilot findings were :

- 303 1. ReSPECT should be made available for adoption without further substantial changes
- 304 2. Educational materials should be supplemented with video simulations and examples of
305 completed forms
- 306 3. More implementation and on-going audit and quality improvement activity was needed to
307 enable the necessary culture change and change in practice. Information should be
308 provided to support sites or regions with implementation.

309
310 These were agreed by the Working Group, which also sought and followed legal advice about
311 mental capacity legislation, to ensure that the form and guidance adhered to capacity legislation in
312 the 4 UK home nations.

313 314 **Discussion**

315
316 ReSPECT, a new approach to emergency care and treatment plans was developed through a
317 combination of synthesising knowledge from existing research and national expertise, and
318 embedding evaluation with each iteration. Changes were made following a consultation, cognitive
319 interviews, workshops and usability testing. The result was an approach which could be used for all
320 age groups, in all health and care settings that was acceptable to both patients and clinicians.

321
322 Stakeholder participation was integral to this work. Its value is increasingly recognised for
323 successful implementation.²⁸ Groups which successfully produce products need to be engaged; to
324 come to wise decisions they need to have certain qualities²⁶ including diversity of opinion and
325 independence. The ReSPECT Working Group had diverse backgrounds, roles and responsibilities.
326 Members were able to draw on their specialist knowledge and from their personal experience to
327 achieve the quality of ‘decentralisation’: when individuals do not have to conform to a controlling
328 hierarchical bureaucracy. The sharing of power among members of the public, clinicians and
329 health and care organisations led to what is defined by Goodman and Thompson as engaged
330 participation;¹⁶ the willingness for prolonged collaboration with clear objectives contributed to the
331 success of the project.²⁵ Through structured processes of discussion, disagreement, and resolution
332 of disagreement the Working Group formed collective decisions from individual members’ own
333 judgements; Surowiecki²⁶ calls this quality aggregation. By creating space for opposing ideas to be
334 aired and the complexities of different health and care specialities and settings to be considered,
335 new solutions were developed.²⁷

336
337 The usability pilot demonstrated that ReSPECT was acceptable to, and usable by, frontline clinicians
338 with their patients. Developing it resulted in a sense of shared ownership, and incorporation into
339 ReSPECT of a wide range of “knowledge, knowhow and experience”. These are characteristics
340 identified by Mets and Boas as contributing to successful development of useable interventions.²⁸
341 The ReSPECT process will continue to be iteratively improved, in response to feedback from users.

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343
344 The Working Group has made ReSPECT available to adopt by health and care communities and
345 developed supporting educational and implementation materials. The Resuscitation Council UK will
346 manage a process for supporting sites to adopt the ReSPECT process and for gaining feedback to

347 monitoring its use and its impact. Communities and organisations adopting ReSPECT have been
348 asked to agree to certain ‘rights and responsibilities’, including a commitment to report adverse
349 events associated with the use of the ReSPECT process. The NIHR has funded a mixed-methods
350 evaluation of early adopting acute NHS hospitals.²⁹ An evaluation of ReSPECT’s use in community
351 settings is being planned. These national monitoring and evaluation initiatives, in addition to
352 monitoring through local audit, should provide the opportunity to understand the impact of the
353 ReSPECT process, including identification of any unintended consequences. It will also support
354 ongoing development and sustained and effective use of the ReSPECT process.

355
356 *Limitations*

357
358 The results of the consultation survey are limited to views of those who chose to take part, and
359 may have been biased towards those with strong views of support or opposition, and towards
360 health professionals. This may account for why 89% had a favourable opinion of the idea of an
361 ECTP. However, no new ideas or concerns emerged before all comments had been collated,
362 suggesting that a good variety of positive and negative views were expressed. The qualitative
363 analysis of the written survey answers and interviews meant that a breadth of views was
364 represented, rather than only majority views. The sample size for the cognitive interviews was
365 limited by resource availability, with only 2 participants from each of the different groups or
366 professions. However, when the concerns identified by participants were compared to those raised
367 by survey respondents the interviews contributed no new concerns. The small scale of the usability
368 pilot means that some difficulties with the usability of ReSPECT may not have been identified.
369 Feedback from GPs was limited. The pilot was not designed to evaluate the impact of ReSPECT on
370 patient care and outcomes and was limited to testing whether clinicians in different settings could
371 use the ReSPECT process and associated documents. The small scale of the pilot did not allow for
372 testing in organisations in all 4 UK countries. Although the NHS operates in all four countries it is
373 possible cultural differences that could influence responses to ReSPECT were not captured.
374 Ongoing monitoring and robust evaluation of its use and impacts are needed as ReSPECT is adopted
375 more widely. Finally there is a need to evaluate how ReSPECT, which provides a succinct summary
376 relating to emergency treatments integrates with more detailed advanced care plans.

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378
379 **Conclusions**

380
381 ReSPECT is designed to prompt and facilitate discussions about patient preferences to inform
382 emergency care and treatment plans (including but not restricted to a recommendation about CPR)
383 for use across all health and care settings.
384 This evaluation confirmed that ReSPECT was understood and could be used by clinicians and
385 patients in a variety of settings. Having a single form that can be used for all patients in all settings
386 means an important aim of ReSPECT has been achieved: it has the potential to improve
387 communication between organisations. Further research will be needed to assess the influence of
388 ReSPECT on person-centred discussions and decisions, care experience and on health outcomes.

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Conflicts of Interest

Gavin Perkins' and Claire Hawkes' employer, the University of Warwick, received funding from the Resuscitation Council UK to conduct the evaluation. Professors Richardson and Perkins are National Institute for Health Research (NIHR) Senior Investigators. Professor Perkins is an Editor of Resuscitation. All authors contributed to the development of ReSPECT.

The development of ReSPECT was funded by the Resuscitation Council UK, with some contribution from the Royal College of Nursing. AR's contribution to the evaluation was facilitated through funding from the National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care (NIHR CLAHRC) Wessex. Funders had no role in study design, data collection and analysis, decision to publish or preparation of the manuscript. The views expressed in this article are those of the author(s) and not necessarily those of the Resuscitation Council UK, the Royal College of Nursing, the NHS, the NIHR, or the Department of Health.

GDP, CH, ZF, AR, SA, DP, JS were members of the ReSPECT Working Group.

Data statement

All available data are presented in the article and supplementary tables.

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