Title: Implementation of ReSPECT in acute hospitals: a retrospective observational study

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Abstract

Aim

To evaluate, in UK acute hospitals, the implementation of Recommended Summary Plan for Emergency Care and Treatment (ReSPECT), which embeds cardiopulmonary resuscitation (CPR) recommendations within wider emergency treatment plans, through discussions between patients and clinicians. To understand for whom and how the process was being used and the quality of form completion.

Methods

A retrospective observational study evaluating emergency care and treatment planning approaches used in acute UK hospitals (2015-2019), the extent of ReSPECT use,
characteristics of patients with ReSPECT forms, and quality of completion in a sample 3000 patient case notes across six English acute hospital trusts.

Results

The use of stand-alone Do Not Attempt Cardiopulmonary Resuscitation forms fell from 133/186 hospitals in 2015 to 64/186 in 2019 (an absolute reduction of 38%). Adoption of ReSPECT accounted for 60.52% (36/60.52) of changes.

In the six sites, ReSPECT was used for approximately 20% of patients (range 6%-41%). They tended to be older, to have had an emergency admission for a medical reason, to have cognitive impairment and a lower predicted 10 year survival. Most ReSPECT forms 653/706 (92%) included a ‘not for attempted resuscitation’ recommendation. 551/706 (78%) had at least one specific treatment recommendation, other than a resuscitation status. Capacity was not recorded on 13% (95/706) of forms; 11% (79/706) did not record of patient/family involvement.

Conclusions

The use of ReSPECT has increased accounts for 60.52% of the change, observed between 2015 and 2019, from using standalone DNACPR forms to approaches which embed DNACPR decisions within in wider emergency care plans in NHS hospitals in the UK. Whilst recommendations include other emergencies most still tend to focus on recommendations relating to CPR. Completion of ReSPECT forms requires improvement.

Study registration: https://www.isrctn.com/ISRCTN11112933

Key words

Emergency care and treatment plans, DNACPR, resuscitation status, advanced care planning

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Introduction

Do not attempt cardiopulmonary resuscitation (DNACPR) orders are used to prevent attempted cardiopulmonary resuscitation when not desired by the patient or where it has little chance of success. In 2014, approximately 80% of acute NHS trusts in the UK were using standalone DNACPR forms. Concerns identified with the use of such forms include lack of communication with patients and/or their families, lack of transferability across health care settings, and DNACPR decisions being conflated with decisions about other care and treatment which may lead to avoidable patient harms. Emergency Care and Treatment Plans (ECTPs) are intended to address these concerns by creating person-centred plans that contextualise resuscitation status decisions within broader treatment escalation recommendations in advance of a medical emergency situation. The Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) is an ECTP developed in the UK (Figure 1) and is designed as a patient held document for use across healthcare settings. It supports person-centred care, a priority in UK and international health policy, through values based decision-making in individualised advance care planning.

We evaluated ReSPECT’s introduction in acute NHS hospitals in England (July 2017 to January 2020). Here we report a) how widely ReSPECT had been implemented in acute hospitals in the UK, b) for whom and how the ReSPECT process was being used and c) how well the associated ReSPECT forms were being completed.

Methods

Design

We obtained data from a) requests to NHS acute Trusts returning data to the UK’s National Cardiac Arrest Audit (NCAA) for information about ECTP approaches between 2015 and 2019; and b) a retrospective case note review at six acute trusts to explore with whom, and how, the process was being used.
Setting

We contacted all NHS acute trusts in the UK which return data to the National Cardiac Arrest Audit (NCAA)\textsuperscript{15} to find out what systems of recording DNACPR and/or emergency treatment decisions they used between 2015 and 2019. Between December 2016 and December 2018, we recruited six NHS acute trusts in England that were early adopters of ReSPECT for the case note review. We worked with the ReSPECT team at the Resuscitation Council UK to identify potential sites, taking a pragmatic approach to recruitment. Sites needed to implement within our study timeframe. To ensure an overall sample of patients similar to the adult acute patient population in England we selected sites with a variety of characteristics: serving different geographical areas and diversity of populations (e.g. urban and rural), different sizes according to inpatient bed numbers and a mixture of tertiary referral teaching hospitals and district general hospitals.

Case note review

We collected data from all adult inpatients’ records on selected wards to achieve a sample of at least 3000 (minimum 500 per site). All types of adult in-patient (except day cases, and obstetric patients) were included to minimise bias. For each ward, data were collected from entries in the notes recorded by a specific date. Wards were selected by the study research team in discussion with site research teams to ensure an appropriate range of clinical specialities that are commonly found in UK acute hospitals including medicine, older person medicine, surgery, gynaecology, trauma and orthopaedics, critical care (see Supplementary Table 1). Participants or their representatives had the opportunity to withdraw their data from the study.

Data Collection

We collected information on DNACPR and emergency treatment care planning approaches in use between 2015 and 2019 at all NHS acute trusts’ hospitals that returned data to NCAA in two stages (October 2018-April 2019 and Jan 2020).

Data collected, during case note review, included demographic information (age, sex, ethnicity, abbreviated home postcode), reason for admission, co-morbidities (cognitive
impairment, Charlson Co-morbidity index,16 GO-FAR score,17 McCabe scale18) and items from ReSPECT forms (patient preference, emergency care treatment recommendations, resuscitation status, capacity, who was involved in the discussions, when, where and by whom was the decision made). We assumed patients were for CPR and full escalation of treatment if no treatment escalation plan or resuscitation decision was recorded. Abbreviated home postcodes were collected to allow estimation of socio-economic status using the Index of Multiple Deprivation.19 Cognitive impairment included dementia, learning difficulties, cardiovascular accident/head injury, acute confusional state, or an unknown cause. The GO-FAR score is the estimated chance of surviving in-hospital cardiac arrest with good outcome.1720 The Charlson Comorbidity Index is a weighted index used to predict 10-year survival in people with multiple comorbidities.16 McCabe Scale is a single-item clinical assessment of whether the patient’s condition is likely to be fatal.

Data Management
We recorded data about hospital systems via an online electronic survey tool (Qualtrics, Provo, UT, USA; https://www.qualtrics.com). Site research staff entered data from the case-note review via a secure online platform which was stored on a secure database. We did source data verification on a random sample of patient records at each site. We planned to use and acceptance sampling approach, However, all site data quality was confirmed as acceptable after the first check

Statistical Analysis
Data are presented using standard descriptive methods. The effect of patient characteristics and involvement in making the plan on clinician recommendation (‘Focus on symptom control’, ‘Focus on life sustaining treatment’, ‘Unclear’ or ‘Not completed’) were explored with multinomial regression, using the clinician overall care recommendation of ‘focus on symptom control’ as the reference group. As an additional analysis we used logistic regression, with ReSPECT form status (yes/no) as the dependent variable, to assess the effect of patient characteristics, resuscitation status (DNACPR (yes/no)) and clinician recommendation for focus of care on whether a full ReSPECT form was completed. Risk and odds ratios (as appropriate) and 95% confidence intervals from models adjusted by 6
recruitment site only and fully adjusted (multivariable) regression models are reported; the former quantifying the effect of each characteristic on the outcome separately and the latter quantifying the independent effect (after adjusting for the other variables in the model). All analyses were undertaken using Stata 16 (StataCorp. 2019. *Stata Statistical Software: Release 16*. College Station, TX: StataCorp LLC.)

**Ethics approval**

An NHS Research Ethics Committee (REC reference: 17/WM/0134) and the Confidentiality Advisory Group (CAG reference: 17/CAG/0060) approved the study.

**Results**

We analysed data from 186 hospitals on their approaches to ECTP. Figure 2 shows the number of hospitals using each system ((i) DNACPR forms only, ii) DNACPR forms plus a treatment escalation plan (DNACPR + Treatment Escalation Plans (TEP)), iii) the ReSPECT process or iv) other emergency care plan (Other ECTP) and v) other approaches) during each quarter. Between January 2015 and December 2019 use of standalone DNACPR forms reduced from 72% (133/186) to 34% (64/186). Over the same period, use of approaches including treatment plans with CPR status decisions increased from 26% (49/186) to 59% (109/186) with uptake of ReSPECT accounting for 6952% (36/6669) of the moves away from use of standalone DNACPR. The majority of moves away from standalone DNACPR (94%, 62/66) occurred between the beginning of 2016 and end of 2018.

Five sites collected case note review data on a few of their participating wards each month over several months and one site collected data on all participating wards on one day. Two sites used electronic ReSPECT forms, rather than paper. At one of these, all patients were first screened to determine whether the clinician would be recommending them for all treatments and attempted CPR. If so, the ReSPECT discussion was curtailed, and a record was made of the decisions in the patient medical notes. These patients are denoted as having completed a screening form only. At the other site, a pre-existing electronic ECTP form was modified to include the same items as ReSPECT. Five trusts contributed data on
more than the target of 500 cases. One failed to reach its target because of the coronavirus pandemic.

We collected data on 98% of eligible patients (3,339/3,518), summarised by site, type of ward and number of participants with a ReSPECT form (Table S1). Twenty three percent (range 6%-41%) of patients had a ReSPECT form. The site that implemented screening to identify those needing a ReSPECT discussion had markedly better coverage overall than the other sites (88% compared to a maximum of 27%) and a greater proportion of participants with a full ReSPECT form (41% compared to a maximum of 27% at the other sites). Most participants (53%) were from medical wards, the mean age was 68.5 years, 50% were female, 12% from minority ethnic groups, 73% were emergency admissions, 29% were cognitively impaired. The majority (92%) survived and were discharged to their own homes (81%) (Table S2). Participant characteristics and outcomes are summarised in Table S3.

Our basic models (adjusted only by site) suggested that age at admission, sex, ethnicity, socioeconomic status, admission type (elective or emergency), patient type (medical or surgical), cognitive impairment and Charlson Index were associated with having a completed ReSPECT form but only age at admission, admission type (elective or emergency), patient type (medical or surgical), cognitive impairment and Charlson Index were significant in the multivariable model (i.e., independent effects) (Table 1). In the multivariable model, each year of age increased (relative) chance of having a full ReSPECT form by 5% (OR=1.05, 95% CI 1.04 to 1.06, p<0.001), and emergency admissions were nearly three times as likely as elective admissions to have a full ReSPECT form (OR=2.68, 95%CI 1.64 to 4.36, p<0.001). Patients on surgical wards were 43% less likely than patients on medical wards to have a ReSPECT form (OR=0.57, 95%CI 0.43 to 0.76), and those with cognitive impairment were more than twice as likely as those without cognitive impairment to have a full ReSPECT form (OR=2.17, 95%CI 1.79-2.63). There is a linear trend for those with a greater number of comorbidities to have a greater chance of having a full ReSPECT form (compared to those with 0-3 points per Charlson Index, those with 4-5 points were 38% more likely, those with 6-7 points were 49% more likely and those with 8-25 points were 46% respectively more likely to have a full ReSPECT form).
Patient’s preference and priorities for care, an optional section, were recorded on 30% of forms. Clinicians provided an overall recommendation on 71% of forms (‘Focus on symptom control’ (40%), ‘Focus on life sustaining treatment’ (17%)). In 14%, the position of the signature made it unclear which of the binary choices the clinician was recommending. This section had not been completed on 29% of forms. Only 6% of forms recorded a recommendation for attempted CPR (Table 2).

Patient’s mental capacity was recorded on 611/706 forms (87%). Patients or their families were involved in 293/706 (42%) and 220/706 (31%) of plans respectively, but 16% of forms (114/706) recorded that neither the patient or family were involved in the decision making and in 11% (79/706) this section had not been completed (Table 2).

Three quarters (551/706, 78%) of patients with a ReSPECT form had at least one intervention (other than CPR) recommended but often this would be a location of care (e.g., ‘Not for ICU’ or ‘Ward based care only’) rather than specific treatments. Further details are given (by McCabe scale group) in Table S4. When adjusted for recruitment site only, the multinomial regression models suggested that increasing age, higher Charlson index quartile, and having a condition that was thought to be ultimately or rapidly fatal (McCabe scale) were associated with greater chance of a ‘focus on symptom control’ recommendation (Table 3). However, in the fully adjusted (multivariable) model, only the Charlson index quartile was significant with those scoring 8-25 points being 79% less likely than for those scoring 0-3 points to have a ‘focus on sustaining life’ recommendation (relative risk ratio 0.21 (95% CI 0.05 to 0.80)).
Discussion

There was a reduction in the proportion of UK acute hospitals relying on standalone DNACPR orders between 2015 and 2019. This occurred in parallel with growth in emergency care treatment plans, of which ReSPECT, introduced in 2016 had seen the most growth (used in 22% of acute hospitals by 2019).

In the six case note review sites, the ReSPECT process was used for approximately one in five patients. These patients were older, were emergency or medical admissions, were more likely to have a cognitive impairment and a decreasing chance of surviving 10 years. Most plans (92%) included a ‘not for attempted resuscitation’ recommendation. The site that screened all patients to identify those likely to benefit from a ReSPECT conversation recorded ReSPECT recommendations markedly more frequently than the other sites and it also had a much higher proportion of patients with a recorded resuscitation recommendation. That ReSPECT forms were not always fully completed was of concern; in particular, the 13% that did not include a record of capacity and 11% that had no record of patient or family involvement.

For patients with ReSPECT forms there was evidence that CPR recommendations were being contextualised within other emergency care and treatment recommendations; just over 70% of patients had an overall treatment focus (life sustaining treatment or symptom control) recorded by the clinician completing the form, and 78% of patients had at least one treatment recommendation (other than for CPR status). Locations of care within acute settings (e.g., ICU and Ward) were the most common types of recommendation but such short-hand for specific interventions should be discouraged as they may be misinterpreted or understood differently in different settings. Such short-hand also limits the transferability of the form from secondary to primary care. Future training should emphasise the consistent use of more specific treatment related recommendations that are meaningful to clinicians in all settings and are clearly understood by patients and their families.
Despite the legal requirement to involve patients and/or their family members in DNACPR decisions\textsuperscript{22,23} 11\% of forms had no record of this. \textit{However, that does not necessarily mean that decisions were made without the involvement of these patients and/or families. It could simply be poor record keeping.} An audit of end of life care found similar proportions of poor record keeping.\textsuperscript{24} The imperative to include patients and families in these discussions has been highlighted during the COVID\textsubscript{19} pandemic\textsuperscript{25} resulting in an urgent UK government commissioned review.\textsuperscript{21}

Promoting use of a standardised process and plan record should improve cross organisation communication,\textsuperscript{26} however a variety of approaches remain in use for recording resuscitation and emergency care treatment recommendations across the country, with a third of acute hospitals still using standalone DNACPR forms at the end of 2019. The recommendation by the Care Quality Commission (CQC)\textsuperscript{27} for ministerial oversight is welcome and provides hope that a strategy for a national approach to DNACPR and advance care planning for emergency care and treatment might be developed to reduce the risks to care and treatment continuity when patients move across organisational boundaries.

The original conception of ReSPECT was as a plan for all patients, particularly those who could benefit from advance planning recommendations for a future emergency situation and not just those at risk of the most severe emergency, cardiac arrest.\textsuperscript{28} We found that most hospitals and clinicians chose to prioritise ReSPECT conversations, at least during this study conducted in the first two years of implementation, for patients at risk of deterioration. \textit{This may explain why those with ReSPECT forms were more likely to be medical patients and admitted in an emergency} and also suggests considerable barriers to the culture change required \textit{if} the goal of having an emergency treatment and care plan for all \textit{is to be achieved.}

Clinicians cite time constraints as a key barrier to ReSPECT conversations in acute settings.\textsuperscript{12} Aligning organisational priorities to new practices and providing active leadership support at
different organisational levels have been associated with achieving a greater culture change when implementing clinical guidelines. Active leadership includes recognition of the need for investment in training of or provision of skilled facilitators and providing them with time and authority to support staff during practice change.\textsuperscript{28,29} Organisations may wish to consider investing in structural support (time, training) to enable effective facilitation for implementing the significant culture change needed to achieve both better quality of use of and greater patient coverage with ReSPECT. Improvements in the quality of completion would include greater proportions of ReSPECT forms with more and specific treatment recommendations, more consistent completion of sections related to patient and family involvement and recording of the patient’s mental capacity as well as where a more detailed record of the process was recorded in the medical notes. Well planned public health campaigns have increased awareness of advance care planning for palliative care\textsuperscript{30,31} and could be valuable for increasing patient requests for and engagement with the ReSPECT process. Raising public awareness of the benefits of making such plans and holding conversations with general practitioners before a person becomes acutely ill could contribute more broadly to a cultural change.\textsuperscript{13} Implementing systematic screening as observed in one of our sites could trigger sufficient reflection for the doctor to a) answer the question and b) go on to complete the ReSPECT process where this was indicated. Our study does not provide insights into how much support, training and opportunity for ReSPECT conversations was also needed to achieve this change in behaviour.\textsuperscript{31}

We achieved our aim of collecting data from at least 3000 patient records from a cross-section of wards covering the typical acute hospital inpatient population in different areas of England serving a variety of populations. This sample enabled our evaluation of how and with whom the ReSPECT process was being used. The study also had several limitations. While we met our total recruitment target, one trust contributed fewer than the target of 500 cases because of the coronavirus pandemic. Additionally, although we had a roughly proportionate number of patients from minority ethnic backgrounds compared to available census data, there were insufficient numbers to allow each ethnic subgroup to be included separately in analyses. Practice might differ from what was recorded. As ReSPECT was not implemented in acute hospitals as widely or rapidly as hoped at the design stage of the
study, fewer patients than expected had a ReSPECT form, which reduced the numbers available for some analyses.

Policy guidance, intervention developments, and associated research into improving cross-organisation communication of emergency care and treatment is needed. The impact of ReSPECT on patient outcomes, including the hypothesised reduction in avoidable harm, requires further investigation. Interventions, which might include multifaceted quality improvement activities, with associated evaluation, are needed to improve patient coverage in acute hospitals with-and-to support higher quality completion of ReSPECT forms.

Conclusions

By the end of 2019, progress had been made in UK acute hospitals towards embedding CPR recommendations within broader emergency care and treatment planning approaches and ReSPECT had played a major part in this. Nevertheless, we found there was still variation in approach between different organisations.

Our evidence, from NHS trusts that were among the first to adopt ReSPECT, suggests that ReSPECT conversations were largely being undertaken with those patients who required a recommendation about CPR and that the quality of recommendations and completion of ReSPECT forms requires improvement.
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Data Statement

All data requests should be submitted to the study’s chief investigator, for consideration. Access to anonymised data may be granted following review.