

# Recommended summary plan for emergency care and treatment: ReSPECT a mixed-methods study

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## Scientific summary

### ReSPECT mixed-methods study

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# Scientific summary

## Background

Do not attempt cardiopulmonary resuscitation (DNACPR) decisions have been used across the NHS for many years. Used in the right context, DNACPR decisions have undoubtedly avoided hundreds of thousands of people receiving highly invasive, potentially painful medical interventions despite there being little to no chance of them being successful. However, several independent reviews have identified substantial problems with the process of DNACPR decision-making and implementation. Specific concerns include a focus solely on cardiopulmonary resuscitation (CPR) without considering the broader context of emergency care treatments, a lack of patient and family involvement in decision-making, unjustified DNACPR decisions being made in people with physical and mental disabilities, poor communication, inconsistent systems for recording decisions and conflation of the term 'DNACPR' (which is meant to apply only to CPR) with limitations on other elements of care and treatment. A stakeholder meeting in October 2014, funded as part of a previous National Institute for Health and Care Research (NIHR) evaluation of DNACPR decisions, highlighted the need to move away from standalone DNACPR decisions and, instead, focus on developing patient-centred emergency care and treatment plans (ECTPs), a position subsequently supported by the Health Select Committee in 2015. Although ECTPs make recommendations for future clinical decisions should an emergency arise, the process of engaging in their creation with patients and their families has similarities to involvement of patients in shared decision-making, and shared decision-making is receiving increased interest in health-care practice and policy.

In 2015, the Resuscitation Council UK (London, UK) and Royal College of Nursing (London, UK) established a National Working Group to develop a national emergency care and treatment planning process, and this led to the development of the Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) process. The ReSPECT process was developed to facilitate shared decision-making between patients and their clinical teams in the event of a future emergency when the person may lack capacity or there may be insufficient time to seek their views. By seeking patients' values and preferences and considering recommendations relating to resuscitation alongside other treatments, the ReSPECT process seeks to overcome the limitations identified with standalone DNACPR decisions.

## Objectives

The overall aim of this project was to determine, in adults admitted to acute NHS hospitals, how, when and why ReSPECT plans are made and what effects they have on patient care.

The evaluation comprised four work packages.

Work package 1 sought to describe the clinician decision-making processes behind the ReSPECT process, including how, when and why recommendations are made, their ethics basis and patients'/families' understanding and experience of the process. Work package 1 also set out to explore general practitioners' (GPs') experiences of the ReSPECT process, including uptake and attitudes to the ReSPECT process in the community and how the ReSPECT process transfers across the acute/primary care boundary.

Work package 2 aimed to quantify the effect of the introduction of the ReSPECT process in England on the frequency of, and outcomes from, in-hospital resuscitation attempts when compared with standalone DNACPR decisions, within ECTPs or treatment escalation plans (TEPs).

Work package 3 set out to provide a descriptive summary of patient characteristics of adult inpatients who had a ReSPECT form in their medical records and to explore associations with different treatment recommendations. An analysis explored whether or not a DNACPR decision, made in the context of an overall treatment plan, is independently associated with patient harm.

Work package 4 aimed to (1) synthesise the key findings from the study, (2) identify future research priorities from the patient, clinician and policy-maker perspective and (3) effectively disseminate findings, ensuring that key messages are integrated into future development work of the ReSPECT process.

## Methods

The study used a mixed-methods approach. Work package 1 used a qualitative approach to examine ReSPECT decision-making processes at six purposefully selected acute NHS hospitals. Observation of ReSPECT conversations, interviews with patients, families and hospital clinicians, review of ReSPECT forms and clinical records, and focus groups with GPs from the surrounding areas took place between August 2017 and April 2020. Work package 2 used data from 189 acute hospitals. The acute hospitals were participating in the National Cardiac Arrest Audit (NCAA) and responded to a survey and a freedom of information request to describe their use of DNACPR, TEPs and ReSPECT process. NCAA data from January 2015 to December 2019 were analysed using interrupted time series to explore changes in resuscitation process and outcomes associated with ReSPECT implementation. Work package 3 adopted a retrospective observational study design to describe the characteristics of patients who have a ReSPECT recommendation. Given previous reports of DNACPR decisions leading to harm, the study explored associations between resuscitation recommendations and harm reported via the NHS Safety Thermometer. Data were collected between October 2017 and April 2020 in relation to admissions that occurred prior to the COVID-19 pandemic. Summary data are presented using descriptive statistics. Associations were explored using regression analyses. The final work package (i.e. work package 4) aimed to draw together the key findings from the study and identify future research priorities.

## Results

Six acute NHS trusts and GPs from the areas of the trusts participated in work packages 1 and 3.

Work package 1 used data from (1) observations of 49 ReSPECT conversations, (2) interviews with 47 hospital clinicians, 13 patients and 19 family members, (3) review of 141 clinical records and (4) five GP focus groups (27 participants). Observations and interviews were undertaken within 11–28 months after implementation of the ReSPECT process at sites.

The majority of ReSPECT conversations took place with patients identified as at risk from acute deterioration. The most common reason for initiating discussions was the patient's condition. Other reasons included requests from the patient/families or hospital-based prompts. Clinicians cited time limitations as the main barrier to participating in ReSPECT conversations mostly focused on resuscitation, but also included escalation of other elements of treatment (e.g. ventilation, intensive treatment unit admission), confirmation of previous decisions and palliative/end-of-life care planning. Patients, or those close to the patient, were involved in most but not all conversations.

Clinicians' approaches to ReSPECT were informed, to varying degrees, by two key ethics principles: (1) respect for patient autonomy and (2) the duty to protect the patient from harm. How these principles influenced the process was shaped by both the clinical situation and clinicians' conceptualisation of ReSPECT as a shared decision-making process. Most conversations sought information about the patient's wishes and preferences about CPR and/or other treatment options to some degree. However, sometimes clinicians did not seek the patient's preferences but, instead, informed the patient of a clinical decision that is motivated by wishing to minimise futile treatments and avoid harm.

Where a clinician was more certain about a patient's trajectory and response to specific treatments, the clinician tended to take a persuasive approach to conversations, aiming to agree the treatment recommendations deemed most appropriate medically. When a clinician was uncertain about a patient's trajectory, then ReSPECT conversations were more exploratory, emphasising patient preferences to a greater extent. Patients and families mostly perceived ReSPECT conversations as providing information about a medical decision, rather than as a shared decision-making process. However, the experiences of patients and their families varied, with patients expressing more confusion and stress, and families expressing feelings of reassurance. The ReSPECT form was used in a small minority of conversations, limiting opportunities for patient/family engagement, and this was particularly prominent in trusts where the ReSPECT process had been digitised.

An evaluation of completed ReSPECT forms and relevant segments of patient notes showed that CPR recommendations were recorded on all forms and most forms mentioned other treatment recommendations. Forms varied substantially in the detail provided. Although specific treatment recommendations were documented in some forms, other forms included only generalised statements. Many forms did not record patient wishes and preferences and it was not always clear who had been involved in the process. As clinicians tended not to document their reasons for recommending particular treatments, and rarely the balance of burdens and benefits, it was difficult to assess the ethics justifiability of many recommendations.

Community health-care professionals (mostly GPs) had varied levels of exposure to the ReSPECT process. Community health-care professionals conceptualised ReSPECT as an end-of-life planning document that is best completed in community care settings. Community health-care professionals reported that the ReSPECT process as an emotional process for both patients and health-care professionals. ReSPECT conversations were shaped by what a 'good death' is thought to be, and health-care professionals often nudge patients in specific directions they consider best for the patient. ReSPECT recommendations were not always communicated or transferable across care settings. The focus on active treatments or use of specific phrases and jargon means that ReSPECT forms issued in hospital are often of limited value in community settings. A digital version of ReSPECT that is transferable between settings might improve transferability.

Work package 2 found that the use of DNACPR as a standalone process reduced from 72% to 34%. Over the same period, use of other advance planning increased. Use of DNACPR plus TEPs increased from 22% to 28% and use of the ReSPECT process increased from 0% to 22%. Prior to implementation of the ReSPECT process, the proportion of CPR attempts abandoned because of futility was already falling rapidly in hospitals that went on to implement the ReSPECT process (falling from 9% in January 2015 to 4% in December 2016) and in other hospitals (falling from 11% in January 2015 to 6% in December 2016). Post implementation, the proportion of CPR attempts abandoned because of futility fell a further 1% (to 3% in December 2019) in hospitals that implemented the ReSPECT process and by 2% (to 4% in December 2019) in other hospitals. During the study period, most of the reduction in proportion of CPR attempts abandoned because of futility (i.e. 83% in ReSPECT hospitals and 71% in other hospitals) occurred prior to the ReSPECT process being implemented. We found no evidence that implementation of the ReSPECT process had any effect on any of the secondary resuscitation outcomes (e.g. in-hospital cardiac arrest rate, patient status on team arrival, resuscitation attempts in patients for whom resuscitation was not recommended, proportion cardiac arrests with an initially shockable rhythm, neurological outcome and survival status at hospital discharge).

Work package 3 evaluated 3439 clinical records. Among the records, a full ReSPECT form was completed for, on average, one in five (20%) inpatients (range 6–41%). Characteristics associated with ReSPECT form completion were older age, emergency admission, admission for medical (rather than surgical) problems, increasing comorbidities and cognitive impairment. We did not find associations with ethnicity, socioeconomic status or the presence of learning disabilities. Patients with a ReSPECT form were less likely to survive to hospital discharge (83% vs. 94%) and were more likely to be

discharged to a nursing home (20% vs. 8%). The majority of forms (82%) were completed following admission to hospital and most forms were completed within the first 48 hours of admission (40%) or within the first week (60%). Consultants were involved in 84% of decisions. Other grades of clinical staff included foundation doctors (8%), middle grade doctors (43%) and nurses/allied health professionals (1%).

Almost all full ReSPECT forms included recommendations relating to CPR (6% of forms recommended CPR, 92% of forms did not recommend CPR and this was not recorded in 2% of forms). Broader treatment goals [e.g. focus on life-sustaining treatment (17%) or symptom control (46%)] were present in the majority of records. One or more specific clinical recommendations, in addition to recommendations relating to CPR, were recorded in 78% of records. The most common recommendations were about location of care (e.g. intensive care or ward-based care). Recommendations relating to specific treatments focused on critical care interventions [e.g. invasive ventilation (32%), non-invasive ventilation (26%), vasopressor support (20%) and renal replacement therapy (20%)]. Other recommendations related to the use of antibiotics (14%), palliative care (12%), hydration (12%), feeding (9%) and appropriateness of re-admission to hospital (7%).

The patient's mental capacity was recorded in 86% of records; half of these patients were assessed as having sufficient mental capacity to be involved in making the plan and the other half were assessed as not having sufficient mental capacity. One in four forms noted a legal proxy existed (e.g. lasting power of attorney). Two-thirds of patients who were recorded as having mental capacity indicated a preference in relation to their priorities for care, and this comprised prioritise life-sustaining treatment (10%), prioritise comfort (71%) or an equal balance (17%). Approximately one in five (18%) recommendations were made without recording the involvement of the patient or families.

Analysis of data from the NHS Safety Thermometer showed that most patients (81%) experienced harm-free care. Increasing age at admission, emergency admission and cognitive impairment were associated with greater risk of harm. We did not find evidence that the presence of a recommendation that CPR should not be attempted was associated with a greater risk of harm.

Identified priorities for future research include developing a programme theory to identify the hypothesised mechanisms through which the intervention is intended to work, as well as answering the following questions:

- What are the advantages and disadvantages to the adoption of a single national system for emergency care and treatment planning?
- What is the most effective approach to implementation?
- What are the advantages and disadvantages of digital ReSPECT forms?
- What interventions are effective for increasing participation in ECTPs following acute hospital admission?
- How can the different professions (e.g. medicine, nursing, allied health professional) best deliver a multiprofessional approach to shared decision-making for emergency care and treatment planning?
- How, when and why are ReSPECT conversations undertaken in the community, and what influence do these conversations have on patient and health service outcomes?
- How effective are structured communication approaches at enhancing shared decision-making relating to emergency care and treatment?
- What decision support aids exist and how effective are they at enhancing shared decision-making relating to emergency care and treatment recommendations?
- What are the training needs of those involved in making ECTPs?
- What are the barriers to and facilitators of improving the transparency and ethics basis for emergency care treatment recommendations?

## Conclusions

NHS acute hospitals are moving away from systems that record DNACPR decisions in isolation to integrating DNACPR decisions within broader ECTPs. At the time of the research, the ReSPECT process was being used in one-fifth of acute hospitals. Uptake in the community was variable and a need for greater continuity across health-care settings is needed.

Hospital clinicians prioritised ReSPECT conversations with patients whom they identified as terminally ill or anticipated were at imminent risk of deterioration. A move towards a more holistic approach in terms of treatment recommendations and conversations was observed, but there remains a focus on decisions relating to resuscitation as a central component.

Patients (and/or those close to the patient) were involved in making most but not all ECTPs. Clinicians' approaches to the ReSPECT process were informed by ethics principles, respect for patient autonomy and the duty to protect the patient from harm to varying extents, depending on the clinical situation and their conceptualisation of the ReSPECT process as a shared decision-making process. Therefore, involvement of patients focused on either asking about the patient's preferences for specific treatments or explaining the clinician's recommendations. Emergency care and treatment planning conversations are often complex and need to draw together patients' preferences and values within a framework of clinical judgement.

Further research is needed to understand the advantages and disadvantages of the adoption of a national ECTP system, the most effective national and local implementation approaches, and whether or not shared decision-making approaches in the context of ECTPs could further enhance patient and family engagement.

## Study registration

This study is registered as ISRCTN11112933.

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