The Recommended Summary Plan for Emergency Care and Treatment: a mixed methods evaluation

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Dr Zoe Fritz chairs the ReSPECT subcommittee for the Resuscitation Council UK, and sits on the executive committee for the Resuscitation Council UK.

Bob Ewing received funding from the study for his PPI work and was also a member of the ReSPECT national working group.

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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 where they have little to no chance of success. However, several independent reviews have identified substantial problems with the process of DNACPR decision-making and implementation. Specific concerns include a focus solely on 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, conflation of the term ‘DNACPR’, which is meant only to apply to cardiopulmonary resuscitation, to limitations on other elements of care and treatment. A stakeholder meeting in October 2014, funded as part of a previous NIHR evaluation of DNACPR decisions highlighted the need to move away from stand-alone DNACPR decisions and focus on developing patient centred, emergency care treatment plans (ECTPs). A position subsequently supported by the Health Select Committee in 2015. While 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. Shared decision making is receiving increased interest in healthcare practice and policy.

The Resuscitation Council UK and Royal College of Nursing established a national working group in 2015 to develop a national emergency care treatment planning process. This led to the development of Recommended Summary Plans for Emergency Care and Treatment (ReSPECT). 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 stand-alone do not attempt cardiopulmonary (DNACPR) decisions.

Objectives
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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 one sought to describe the clinician decision-making processes behind ReSPECT including how, when and why recommendations are made, their ethical basis and patients/family understanding and experience of the process. It also set out to explore general practitioners’ experiences of the ReSPECT process, including uptake and attitudes to ReSPECT in the community, and how ReSPECT transfers across the acute/primary care boundary.

Work package two aimed to quantify the effect of the introduction of ReSPECT 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.

Work package three set out to provide a descriptive summary of patient characteristics of adult in-patients who had a ReSPECT form in their medical records and to explore associations with different treatment recommendations. An analysis explored whether a DNACPR decision, made in the context of an overall treatment plan, is independently associated with patient harm.

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

Methods

The study used a mixed methods approach. Work package one 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 general practitioners from the surrounding areas took place between August 2017 and April 2020. Work package two used data from 189 acute hospitals who were participants in the National Cardiac Arrest Audit (NCAA) and responded to a survey and a Freedom of Information request to describe their use of DNACPR, treatment escalation plans and ReSPECT. 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 three 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 which occurred prior to the COVID-19 pandemic. Summary data are presented using descriptive statistics. Associations were explored using regression analyses. The final work package (four) aimed to draw together the key findings from the study and identify future research priorities.

Results

Six acute NHS trusts and GPs from their areas participated in work packages one and three.

Work package one used data from observations of 49 ReSPECT conversations, interviews with 47 hospital clinicians, 13 patients and 19 family members, review of 141 clinical records, and five general practitioner focus groups (27 participants). Observations and interviews were undertaken within 11 to 28 months after implementation of ReSPECT at sites.

The majority of ReSPECT conversations took place with patients identified as at risk from acute deterioration. The commonest reason for initiating discussions was the patient’s

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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, ITU admission), confirmation of previous decisions or 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 ethical principles; respect for patient autonomy and 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 wishes and preferences about CPR and / or other treatment options to some degree. However, sometimes clinicians did not seek patients’ preferences but informed them of a clinical decision, motivated by wishing to minimise futile treatments and avoid harm. Where clinicians were more certain about a patient’s trajectory and response to specific treatments, they tended to take a persuasive approach to conversations, aiming to agree the treatment recommendations deemed most appropriate medically. When clinicians were uncertain about a patient’s trajectory, the 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, their experiences 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. This was particularly prominent in Trusts where ReSPECT 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 that most forms mentioned other treatment recommendations. Forms varied substantially in the detail provided.
While specific treatment recommendations were documented in some, others included generalised statements. Many forms did not record patient wishes and preferences and it was not always clear who had been involved in the process. Because 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 ethical justifiability of many recommendations.

Community healthcare professionals (mostly General Practitioners) had varied levels of exposure to ReSPECT. They conceptualised ReSPECT as an end-of-life planning document best completed in community care settings. They reported it as an emotional process for patients and healthcare professionals. ReSPECT conversations were shaped by what a ‘good death’ is thought to be, and healthcare 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 ReSPECT forms issued in hospital are often of limited value in community settings. A digital version of ReSPECT transferable between settings might improve transferability.

Work package two 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; DNACPR + treatment escalation plans from 22% to 28%, ReSPECT from 0% to 22%. Prior to implementation of the ReSPECT process, the proportion of CPR attempts abandoned due to futility was already falling rapidly, from 9% in January 2015 to 4% in December 2016 in hospitals that went on to implement ReSPECT and from 11% in January 2015 to 6% in December 2016 in other hospitals. Post implementation, the proportion of CPR attempts abandoned due to futility fell a further 1% (to 3% in December 2019) in hospitals that implemented ReSPECT and by 2% (to 4% in December 2019) in other hospitals. Most of the reduction in proportion of CPR attempts abandoned due to futility observed during the study period (83% in ReSPECT hospitals and 73% in non-ReSPECT hospitals).
71% in other hospitals) occurred prior to ReSPECT being implemented. We found no evidence that implementation of ReSPECT had any effect on any of the secondary resuscitation outcomes (in-hospital cardiac arrest rate, patient status on team arrival, resuscitation attempts in those where resuscitation was not recommended, proportion cardiac arrests with an initially shockable rhythm, neurological outcome and survival status at hospital discharge).

Work package three evaluated 3,439 clinical records amongst whom a full ReSPECT form was completed for on average one in five (20%) in-patients (range 6% to 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, socio-economic status or the presence of learning disabilities. Patients with a ReSPECT form were less likely to survive to hospital discharge (83% versus 94%) and were more likely to be discharged to a nursing home (20% versus 8%). The majority of forms (82%) were completed following admission to hospital. Amongst these, 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 doctor (43%), nurse / allied health professional (1%).

Almost all full ReSPECT forms included recommendations relating to CPR (6% for CPR and 92% not for CPR, 2% not recorded). Broader treatment goals were present in the majority of records (focus on life-sustaining treatment (17%) or symptom control (46%). One or more specific clinical recommendation in addition to recommendations relating to CPR was 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%), renal replacement therapy (20%). Other recommendations related to the use of antibiotics (14%), palliative care (12%), hydration (12%), feeding (9%), and appropriateness of readmission to hospital (7%).
The patient's mental capacity was recorded in 86% of records of whom half were assessed as having sufficient mental capacity to be involved in making the plan and half did not. 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. This comprised either prioritise life sustaining treatment (10%), prioritise comfort (71%) or an equal balance (17%). Approximately one in five (18%) of recommendations were made without recording the involvement of the patient or families.

Analysis of data from the NHS 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 included (i) developing a programme theory to identify the hypothesised mechanisms through which the intervention is intended to work (ii) what are the advantages and disadvantages to the adoption of a single national system for emergency care treatment planning? (iii) What is the most effective approach to implementation? (iv) What are the advantages and disadvantages of digital ReSPECT forms? (v) What interventions are effective for increasing participation in emergency care treatment plans following acute hospital admission? (vi) How can the different professions (e.g., medicine, nursing, allied healthcare professional) best deliver a multi-professional approach to shared decision making for emergency care and treatment planning (vii) How, when and why are ReSPECT conversations undertaken in the community and what influence do they have on patient and health service outcomes? (viii) How effective are structured communication approaches at enhancing shared decision making related to emergency care and treatment? (ix) What decision support aids exist and how effective are they at enhancing shared decision making related to emergency care and treatment recommendations? (x) What are the training needs of those involved in making emergency care treatment plans?
(xi) What are the barriers and facilitators to improving the transparency and ethical basis for emergency care treatment recommendations?

Conclusions

NHS acute hospitals are moving away from systems which record DNACPR decisions in isolation to integrating them within broader emergency care treatment plans. At the time of the research, ReSPECT was being used in a 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 emergency care treatment plans. Clinicians’ approaches to ReSPECT were informed by the ethical 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 ReSPECT as a shared decision-making process. Involvement of patients therefore either focused on asking about their preferences for specific treatments or explaining the clinician’s recommendations. Emergency care 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 disadvantaged of the adoption of a national ECTP system, the most effective national and local implementation
approaches and whether shared decision-making approaches in the context of ECTPs could further enhance patient and family engagement.

**Study registration**

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