Using the Recommended Summary Plan for Emergency Care and Treatment in Primary Care: a mixed methods study

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Scientific summary

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Scientific summary

Background

Emergency care and treatment plans (ECTPs) focus on treatment and care in emergency or acute illness situations. Their aim is to make treatment recommendations that reflect the person's preferences and values. They are reached in discussion with the person or their family. The recommendations made are intended to guide future treating clinicians. ECTPs were developed in response to problems identified with standalone 'do not attempt cardiopulmonary resuscitation' (DNACPR) recommendations and aim to prompt wider considerations of treatment and care, including cardiopulmonary resuscitation (CPR), to provide a more holistic approach to anticipatory decision-making for emergencies.

In 2016, implementation of the 'recommended summary plan for emergency care and treatment' (ReSPECT) began in NHS acute trusts and later extended into primary care. There may be advantages to initiating the ReSPECT process in primary care. People may have an established relationship with their general practitioner (GP) and conversations can occur over an extended period. Also, they are often less sick and able to engage in discussion, with recommendations placed in a wider context of advance care planning. However, there are also potential difficulties; individuals and their families may be reluctant to think about these decisions until a crisis emerges, GPs may be uncertain about hospital-based interventions, and both may have concerns about the effect of these discussions on the patient–doctor relationship.

An evaluation of ReSPECT in early adopter NHS acute trusts sites in England found ReSPECT conversations were mainly initiated with patients nearing the end of their life or at imminent risk of deterioration. Doctors' uncertainty about a patient's prognosis, time constraints and the desire to minimise patient distress influenced both the prioritisation and content of conversations. GP focus groups suggested that hospital doctors and GPs use the process in different ways and recommendations do not always translate from one setting to another. A West of England interview study with GPs and care home staff found a generally positive attitude to ReSPECT but noted that its use was complex and there were challenges in incorporating patients' preferences into decision-making. There are no large UK studies of the use of ReSPECT or other ECTPs in the community.

Aim

To evaluate the ReSPECT process for adults in primary care to determine how, when and why it is used, and what effect it has on patient treatment and care.

Objectives

1. To understand how ReSPECT is currently used in primary care from the perspective of patients, their families, clinicians and care home staff, and to identify enablers and obstacles to the implementation of ReSPECT in primary care practice
2. To describe the views of the public and other health and social care professionals who encounter ReSPECT plans initiated in primary care, on ECTPs and ReSPECT in particular
3. To explore the impact of ReSPECT on patient treatment decisions
4. To understand how health and social care professionals can optimally engage people with learning disability in the ReSPECT process
5. To develop a consensus on how ReSPECT should be used in primary care.

Methods

We used a mixed-methods approach within an analytical framework of normalisation process theory. Qualitative data were analysed thematically. Descriptive analyses of quantitative data are presented with regression analyses for some outcomes.

Work package 1

We interviewed GPs and other practice staff, patients with a ReSPECT plan and/or their families and care home staff. We worked with 13 general practices and associated care homes across 3 areas of England.

Work package 2

We used focus groups and interviews with other health and social care professionals, members of the public and faith leaders to explore their views on ReSPECT and other forms of ECTP. We did a national survey of attitudes of the public to ECTPs using a module in the 2022 British Social Attitudes Survey administered by the National Centre for Social Research. We surveyed the experience and attitudes of GPs to ECTPs and ReSPECT using medeConnect (Abingdon, UK), a market research company focusing on healthcare professionals.

Work package 3

We used a structured evaluation tool to assess the quality of ReSPECT form completion in our 13 general practice sites.

Work package 4

We ran co-production workshops with adults with learning disability to explore their understanding of, and views on, emergency care treatment planning and to co-create resources to support engagement of people with a learning disability with ReSPECT. Using focus groups and interviews with family carers of people with a learning disability, we captured their views and experiences of emergency care treatment planning.

Work package 5

An initial synthesis of findings across the work packages informed the content of a stakeholder meeting with participants from professional and patient organisations, and implementers of ReSPECT across the UK. Key messages from small group discussions at the stakeholder meeting were integrated into the final synthesis to identify implications for practice and future research priorities.

Results

Attitudes and experiences of the public around ECTPs

Focus groups

Twenty-one members of the public participated in four groups.

Participants supported the concept of ReSPECT and thought it could be an important tool in facilitating conversations about end-of-life care. However, they thought the process and form should be more person centred. Participants thought conversations would work best when the person had an established relationship with the health professional but recognised that this was not always possible. They thought that involving the family in ReSPECT discussions was important but expressed concern about whether the plans would be available or followed in an emergency.

Public survey

The module was completed by 1135 members of the public; 17 respondents had an ECTP in place.

Respondents were supportive of anyone being able to have an ECTP if they wished 908/1135 (80%), and half of those without a plan would want one for themselves (620/1112; 56%). Most would also like to be involved in completing a plan for a close family member if the person was unable to do so themselves 930/1135 (82%). Respondents with a chronic condition that reduces daily activity were more likely to want an ECTP than those in good health [64% vs. 52%; odds ratio (OR) 1.78, 95% confidence interval (CI) 1.30 to 2.45; $p < 0.001$]. Respondents recognised benefits of ECTPs but also recognised potential risks of the ECTP recommendation becoming out of date. They would prefer to complete an ECTP with their GP or a doctor or nurse trained in ECTP conversations.

How ReSPECT is used in primary care

General practitioner survey

We received 841 valid survey responses. Half (51%) of respondents reported their practice used standalone DNACPR forms; ReSPECT forms were used by 41%. There were substantial regional differences in the forms used.

The main trigger for initiating an ECTP conversation is a diagnosis of a life-limiting or life-threatening condition (86%). While completion of an ECTP in primary care is currently carried out mainly by GPs, respondents thought that a much broader range of health and social care professionals could complete these plans, including senior community nurses (80%), senior nurses in care homes (51%) and care home managers (25%). GPs who used ReSPECT were more likely to feel comfortable having these conversations with patients and their relatives compared to GPs who reported using standalone DNACPR forms (OR 1.72, 95% CI 1.1 to 2.69 and 1.85, 95% CI 1.19 to 2.87, respectively). Nearly all (89%) respondents agreed that having a plan ensures that treating clinicians know the patient's wishes. However, 50% respondents agreed that a patient's current health condition may not be reflected in the plan and 41% that there is a serious risk that it could be out of date at the time it is needed.

Qualitative study of stakeholder experiences

A total of 13 general practices and 13 care homes participated in the qualitative study. We interviewed 21 GPs, 5 specialist nurses, 22 senior care home staff, 19 care home managers, and had clarifying conversations with 124 clinical and administrative staff across 11 practices during fieldwork visits. We conducted focus groups with 7 home care workers and 17 other healthcare professionals and interviewed 13 patients or their relatives.

All participants conceptualised ReSPECT as a person-centred process allowing patients to take some control over future medical care and treatment decisions, particularly when nearing the end of life. However, in practice, its focus was often seen as primarily about CPR. ReSPECT is usually initiated when a patient moves to a care home or starts to receive palliative care. Occasionally, a patient initiated the discussion. In timing a ReSPECT conversation, GPs try to balance minimising patient distress, uncertainty about illness trajectory and having the conversation when the patient is still able to express their wishes. GPs and care home staff emphasised the importance of time and establishing a relationship with the patient as prerequisites for a good ReSPECT conversation. However, lack of time was an obstacle for GPs. GPs, care home staff and patients felt that including families in the ReSPECT discussion was important, to ensure that families are aware of the patient's wishes and to facilitate decision-making in an emergency.

Writing the recommendations and their interpretation by clinicians and care home staff in an emergency is challenging because of uncertainty around future clinical events and treatment options. Care home staff described conflict with clinicians attending the patient in an emergency over treatment decisions, with decisions not always reflecting recommendations. Care home staff and paramedics commented on the lack of clarity of some recommendations which they described as unhelpful.

Processes for storing and sharing ReSPECT forms varied. Concerns were raised about loss of paper forms and lack of synchronisation between paper and electronic forms.

Patients' and relatives' experiences of the ReSPECT process were shaped by the ReSPECT conversations they had with healthcare professionals. Those who had a conversation where they felt listened to and received clear explanations, spoke about ReSPECT positively and showed a clearer understanding of the purpose of ReSPECT. Most participants trusted that, in an emergency, healthcare professionals would follow the recommendations recorded on the ReSPECT form.

The use of ReSPECT in primary care, both in the initial ReSPECT conversation and using the recommendations in an emergency, is informed by two key ethical principles: respect for patient autonomy and the duty to protect a patient from harm. How these principles are balanced in using ReSPECT recommendations to make a decision in the patient's best interests in an emergency is shaped by the clinical and social situation, and by decision-makers understanding of the purpose of the recommendations.

Evaluating 141 completed ReSPECT forms from 11/13 practices, 122 (87%) recorded free-text treatment recommendations other than CPR. Three-quarters 94 (76%) provided detailed recommendations on types of treatment to be considered in an emergency; 28 (23%) gave only general instructions, such as 'not for hospital admission'. The CPR recommendation was completed in just 37% of forms but this may have been related to electronic form completion. Over half (57%) of forms recorded patient preferences. However, where a patient lacked capacity the presence of a relative or lasting power of attorney was recorded in only two-thirds of forms and less than half named the person present.

What do people with a learning disability and their carers want from ReSPECT?

Twelve workshop participants and four reference group members participated in the co-production process. Twelve relative-carers of someone with a learning disability participated in focus groups or interviews.

Workshop participants wished to engage in the ReSPECT process and to be supported in that process. However, they also expressed doubt about the form being found and followed in an emergency. They made multiple suggestions to enhance the planning of ReSPECT conversations and emphasised the need for preparation before the conversation, and the presence of a trusted person to support them in the process. Family carers of people with a learning disability were cautiously supportive of ReSPECT plans and saw them in the context of their lived experience of advocating for a person with a learning disability in the healthcare system. Where ReSPECT supported this advocacy role, it was welcomed but they did not trust that it would be followed without their input. Developing a ReSPECT plan for someone with a learning disability requires time and understanding of their complex needs.

The co-production workshops informed development of an easy-read guide to ReSPECT planning and worksheets to support people with a learning disability in preparatory conversations.

Stakeholder meeting

Twenty-nine external delegates from a range of professional and patient organisations attended the meeting.

Stakeholders thought it important that ReSPECT planning should be considered more widely than in the context of end of life or palliative care. They identified a need for preparatory conversations prior to a planning conversation, suggesting that these could be initiated by a wide range of people, with

appropriate training and support. The different focus of hospital and primary care recommendations highlighted the need for review when someone moves between healthcare settings. There was consensus that an electronic system for storing and sharing ReSPECT plans was needed to ensure effective use. Shared concerns about interpretation of recommendations emphasised the importance of clear articulation of recommendations on the form, and relevant training for health and social care staff in their use.

Conclusions

The concept and aims of ECTPs including ReSPECT are widely supported by health and social care professionals, patients and the public. There is a lack of consensus on the purpose and authority of recommendations recorded in a ReSPECT plan. Patients, families and some healthcare professionals see them as determinative, while others see them as guidance. Preparatory conversations before a plan is introduced are important, particularly for people with a learning disability. The level of uncertainty around future clinical events and treatment options for someone in a community setting cannot be easily translated into specific recommendations, and recommendations recorded in hospital are often seen as unhelpful. This can create conflict when treatment decisions are made in an emergency.

There are challenges to ensuring timely access to ECTPs by the health and social care professionals who are making treatment decisions. We identified five priorities for future research:

1. Understanding the experiences and perspectives of people from minority ethnic and faith-based communities on the concept and use of emergency care treatment plans.
2. Improving integration of patient preferences into treatment decision-making in an emergency in a way that is consistent, transparent and ethically justifiable
3. Understanding the experiences and perspectives of paramedics on the use of emergency care treatment plans.
4. Identifying effective interventions for increasing awareness of and preparation for emergency care treatment planning.
5. Identifying the benefits and challenges of a shared electronic record system for emergency care treatment plans.

Study registration

This study is registered as NCT05046197.

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This article

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