Evaluating the use of the Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) in primary care

Report of the stakeholder conference for conference delegates

29/03/2023

This report is a summary of the small group discussions at the stakeholder conference on the 29th March 2023 at the Scarman centre at Warwick University. The stakeholders participating in the conference represented a wide range of perspectives and experiences of emergency care treatment planning and advance decision-making. They had a range of backgrounds including health and social care professionals, patient organisations, and researchers. This report is a summary of the notes taken in each of the small groups, which have been analysed to extract the key messages and recommendations for how emergency care treatment plans in general and the ReSPECT process specifically can be improved for the benefit of patient care. The report begins with a summary of stakeholders' reflections on the broad question of whose interests are being served during the ReSPECT process. It is then divided into the following sections:

1. Initiating the conversation
2. Having and recording the conversation
3. Articulating and interpreting the recommendations
4. Managing the plan
5. Training
6. Awareness raising and preparation

Each section ends with key messages and/or recommendations for practice, policy, or training.

FUNDED BY
NIHR | National Institute for Health and Care Research

REC reference 21/LO/0455

Whose interests are being served during the ReSPECT process?

The consensus across all groups was that the ReSPECT process should serve the interests of the person whose plan it is first and foremost. Stakeholders felt that the aim of ReSPECT should be to provide recommendations for future treatment and care that reflect the person's values and wishes and are consistent with their interests. However, the groups also reflected on the tension between a process that is person centred and a set of recommendations that are intended to guide or direct clinicians. *Are the recommendations statements of what the person wants to happen or are they clinical recommendations as indicated on the form?* This tension reflects that the process, or at least the recommendations recorded on the form, also serve the interests of healthcare professionals who will be making treatment and care decisions for the person at a time of acute deterioration or in an emergency. Several groups noted that the health care professional making these decisions is unlikely to know the person and therefore, having clear recommendations to guide them can reassure the clinician that they are acting in the person's best interests. Similarly, the form can provide clarity and reassurance for care home staff when communicating with healthcare professionals when a resident is unwell. Some groups also noted that the process, particularly the conversation, could be in the interests of the person's family, helping them to understand the person's wishes and to reduce the burden for them at the time of decision-making. Finally, groups also noted that documented emergency care treatment plans could benefit the health care system by facilitating effective decision-making at times of crises. However, there was also a concern that this could lead patients and their relatives to see emergency care treatment plans as a 'tick box exercise', causing them to mistrust the process.

In summary, the groups agreed that the process should be person centred foremost, but that health care professionals and the person's family would also benefit. The challenge is to formulate recommendations that serve the interests of both the person and those who use the form as guidance when the person is acutely unwell.

Initiating the conversation

Discussion around the conversation itself focussed firstly on initiating the conversation and then on the content and process of the conversation. In general, there appears to be a (mis)perception that ReSPECT (both the process and the form) is necessarily linked to or embedded in end-of-life discussions and end of life treatment and care decisions. This perception has implications for when a ReSPECT conversation might be initiated. For example, triggers for ReSPECT initiation might focus on patients who are receiving palliative care, or for whom a life threatening or life limiting diagnosis has been made, or whose life expectancy is thought to be short. Stakeholders reflected that this approach limits the population for whom ReSPECT becomes available and could exclude people who might want or benefit from having a ReSPECT conversation and their wishes formally recorded.

While stakeholders recognised the importance of ReSPECT conversations as part of a wider advance care planning discussion around end of life, they also suggested other potential triggers for initiating a ReSPECT conversation. These included when a person has specific risk factors for severe acute illness, or during regular reviews of someone with a chronic disease or disability. One suggestion was that for people with a learning disability, their annual health check could be an opportunity to initiate a conversation (a similar argument

FUNDED BY
NIHR | National Institute for Health and Care Research

could be used for using routine elderly health check appointments in this way). However, there was also concern that this could be misinterpreted by the person, particularly if ReSPECT is seen as associated with end-of-life care. Also, repeated reference to emergency care treatment planning could be frustrating or distressing for some people who may see it as focusing on their deteriorating health or limited life expectancy, rather than improving their current health. Some stakeholders felt that the driver for the conversation should be the person's health condition and their risk of requiring emergency treatment and care.

There was clear consensus across the groups that whatever the trigger for initiating a ReSPECT conversation, it should occur early in any disease or illness trajectory, or even before someone became unwell. This would empower people to be involved in the conversation when they had capacity and were not too sick to engage in a conversation. However, delegates also noted that a person's health changed over time, as did their wishes and preferences regarding treatment Therefore, ReSPECT was seen as a series of conversations rather than one definitive conversation. Delegates also thought that anyone should be able to initiate a ReSPECT conversation for themselves.

A further discussion point was who should be able to initiate and carry out a ReSPECT conversation. There was agreement that the conversation should ideally occur with a healthcare professional who knows the person and with whom the person has a trusted relationship. The discussions revealed that there were different levels of initiation and involvement in ReSPECT conversations: a) raising awareness of ReSPECT and preparing a person for a ReSPECT conversation; and b) the more structured ReSPECT conversation leading to the ReSPECT plan that is then recorded on the ReSPECT form. Stakeholders thought that the raising awareness and preparation conversations could be led by a wide range of different people involved with someone's care, for example care home staff or support workers but that training, and support would be needed that was tailored to specific groups. for having these conversations.

Key messages/recommendations

- ReSPECT should not only be considered in the context of end of life or palliative care.
- ReSPECT conversations should begin early and not left until emergency or end of life situations.
- There is a distinction between conversations to prepare someone for discussion of a plan and the planning conversations and these preparation conversations can be initiated by a wide range of people, with appropriate training and support.
- As people's situation and perspectives change, ReSPECT must be reviewed when this happens.
- In considering how these conversations are carried out and by whom, the current time pressures on GPs and care home staff need to be taken into account i.e., balancing the desirable with the possible).

Having and recording the conversation

Stakeholders noted that ReSPECT planning conversations were rarely single conversations but occurred over time, often with several preparatory conversations where the idea of ReSPECT was introduced. They identified several challenges that could occur in the process of the ReSPECT conversation. These included practical challenges such as having enough time to have what is a difficult and complex conversation. It was seen as especially important to ensure that enough time was given for these conversations with a person with a learning disability, in addition to ensuring they had the right support person with them. They also identified challenges in communicating the purpose of the plan, including what it can and cannot do. For example, helping the person to understand the range of situations and treatment options that might be covered in a plan and the uncertainty of predicting future situations. Stakeholders also noted that it was important to talk about what was possible and not possible in relation to recommendations, and what alternative options would be available if there was a recommendation to limit some treatments. A strong message from the meeting was that ReSPECT conversations needed to be open and honest, and that the health care professional should take time to understand what was important to the person and what their preferences were. For good conversations to occur, other communication challenges needed to be considered such as language barriers, alternative formats for the form and supporting information, and the environment in which the conversation takes place. A key issue in terms of recording the conversation and the recommendations on the form is how to ensure that these are valid and accessible when needed. There was a general consensus that a digital version of the form was the preferred option to ensure accessibility but there is a risk that this could disempower patients who would have less access to or control over their plan than with a patient held paper copy. Concerns about version control were also raised.

Key messages/recommendations

- Planning conversations need to be open and honest, person centred, and realistic.
- There needs to be sufficient time to have the conversation(s).
- Good conversations require effective communication, including appropriate language and alternative formats to written documentation. Use of videos could be considered for recording conversations for people with learning disabilities.
- Digital records of plans can increase access to the plan when needed but people may feel less in control of their plan if it is in a digital format. Problems with version control need to be addressed.

Articulating and interpreting recommendations

The main purpose of ReSPECT is to provide clear recommendations about emergency treatment and care in a situation where the person is unable to engage in the decision-making process at the time. Stakeholders agreed that it was crucially important that these recommendations were understandable to the person and their family and to the health and social care professionals who would need to interpret them in the emergency or acute situation. Commonly used phrases such as ‘for ward-based care’ or ‘not for hospital admission’ were regarded as too vague and unhelpful. However, there was general agreement that it was challenging to articulate recommendations that capture all likely scenarios. Instead, flexibility should be allowed to encompass other scenarios, include options for treatment as well as the limitations of those treatments and to make it personal to that patient but sufficiently succinct to be read and understood in an emergency. Delegates talked about the need for nuance in recommendations as it is not possible to cover every scenario. This places greater emphasis on the need to carefully and accurately document the person’s values and preferences and for healthcare professionals to take account of these when interpreting recommendations or making a decision. The groups thought that the recommendations section must include a justification or rationale for the recommendations that was linked to the person’s values and preferences. This was seen as necessary to help health care professionals interpret the recommendations in a particular situation, but also to enable a person or their family to understand and if necessary, challenge the recommendations if they disagreed with them. Stakeholders noted the difference between hospital completed recommendations, which were specific to hospital-based scenarios, and primary care-based recommendations, highlighting the need for review of recommendations as a person moves from one environment to another. They emphasised the importance of clear communication between primary and secondary care in relation to ReSPECT recommendations. The space allocated to recommendations on the form was considered too little for the level of detail that may be required, which supported stakeholders’ views on the advantage of a digital form that could allow for expansion of sections as required. While they emphasised the need for sufficient detail on the form, they also noted that these recommendations related specifically to emergency care and treatment. Broader recommendations about the person's treatment and care could be documented in an advance care plan or personal health plan where appropriate.

Linked to challenges in communicating recommendations in the ReSPECT plan is the challenge of using these recommendations in an acute or emergency situation. Stakeholders emphasised that ReSPECT recommendations are not legally binding and are there to guide healthcare professionals who make a decision in a specific situation. They emphasised that it was important that care home staff and health care professionals were made aware of this during training. However, ReSPECT recommendations appear to face two contrasting challenges in their use. In an emergency, relatives, care home staff and health care professionals may revert to the instinct to do something and make a decision that is inconsistent with a ReSPECT recommendation, for example send a person to hospital when the recommendation is to be managed at home. Alternatively, delegates described the risk of a ReSPECT recommendation being followed without considering the nuance of the situation, for example not conveying a patient to hospital because the recommendation not for admission does not specify in what circumstances admission might be appropriate. They expressed concern that having a ReSPECT plan might result in the person being seen as lower priority for a visit from a doctor or paramedic because the assumption is that they do not need an urgent decision about treatment.

Key messages/recommendations

- There is misunderstanding about the nature and authority of ReSPECT recommendations. Public and patient information and health and social care professional training need to emphasise that they are guidance for decision-makers and are not legally binding.
- Recommendations should be clear and use language that the person, their family and treating clinicians can understand.
- Recommendations should be specific to anticipated situations but allow flexibility to encompass other scenarios and include options for treatment as well as the limitations of treatment.
- Justification for the recommendations should be clearly documented in the plan to support decision-makers and enable patients and their family to understand and challenge where necessary.

Managing the plan

Delegates identified issues regarding management of the ReSPECT plan once it had been completed. A key concern was related to validity and control of the form itself. The general view was that ideally the form should be in electronic format within a digitised system where it would be accessible to anyone who needed to see it, including the patient (or the patient's NOK if the patient lacked capacity), health and social care staff involved in the person's routine care, and emergency care staff. Identified disadvantages of a paper copy were that it might not be accessible or known about in an emergency. Similarly, if the paper version was thought to be a copy and not the original form (because, for example, it had been printed in the wrong colour), it would not be considered valid. There was also a concern that if the original form was completed electronically and stored in the GP record, and a paper copy was given to the person, there was a risk of multiple versions existing which again could raise questions about a form's validity. However, some delegates questioned how people who did not have access to digital technology would be able to have control over, or knowledge of, their plan. Thus, the tension between benefit to the health system of a digitised system, and the autonomy of individuals who have a plan needs to be considered in developing such a system.

There was strong agreement among delegates that ReSPECT plans should be reviewed as a person's health status changed, noting that a person's preferences, and the treatment options available to them, may change over time, or because of a new diagnosis. Some people suggested a regular review for example at an annual health check might be helpful. Noting the difference in recommendations on a ReSPECT plan completed in hospital during an acute illness episode and one completed in primary care, it was seen as essential that plans were reviewed prior to hospital discharge.

Key messages/recommendations

- An electronic record held within a digitised system accessible by relevant health and social care professionals and the person or their next of kin should be the preferred model to ensure validity and appropriate use of the plan.
- However, it is necessary to consider how people who cannot access digital technology will have access to and control of their ReSPECT plan.
- A robust system of ReSPECtT Plan review should be in place that is responsive to changes in a person's clinical need and preferences.
- In the absence of a central digitised system for managing forms, a process for ensuring form validity (version control) needs to be put in place.

Training

Stakeholders discussed a wide range of training needs for different groups. Acknowledging that many different people could have preliminary conversations about the ReSPECT process and the idea of an emergency care treatment plan with someone, it was widely agreed that some training was required for any health and social care professional, and support workers, to give them the knowledge and confidence to initiate a discussion or respond to questions about ReSPECT. More specific training needs were identified for healthcare professionals involved in completing ReSPECT plans with people and the conversation that accompanies this process. A further area of training need related to the use of ReSPECT plans and interpretation of their recommendations. Education in the use of ReSPECT plans may be relevant for health care professionals but also for social care staff (care home and home care).

Key elements of training identified include the following (although not all will be relevant for everyone involved in the process, and the detail of the training content will vary between groups.):

- Understanding how ReSPECT fits with Advance Care Planning, Advance Decisions to Refuse Treatment, and Lasting Power of Attorney.
- Understanding the purpose of ReSPECT recommendations and their legal status.
- Assessment of capacity, how to accommodate fluctuating capacity, and how to include a person who lacks capacity in the conversation.
- Training in having these conversations, which are different from other types of conversation that a health care professional may be more familiar with. Specific focus on having conversations with people with a learning disability.
- Training in interpreting recommendations including assessment of their relevance to the situation (e.g., a plan completed in hospital when the person is acutely sick may not be relevant when they have recovered and returned home).

Delegates also discussed how training might be delivered, and again noted that a range of approaches might be required to reflect the needs of different groups. Suggestions included:

- E-Learning module for healthcare professionals with CPD accreditation.
- Integrating training on ReSPECT into Resuscitation Council UK's advanced life support training sessions.
- Identification of champions in GP practices/care homes who can support and advise other members of staff to embed the process into day-to-day practice.
- Using ECHO (Extension for Community Health Outcomes) communities of practice to share education and practice across different groups e.g. care homes and other social care organisations, learning disability liaison nurses.
- Link ReSPECT training to other training resources e.g. Daffodil Standards training for end of life care.
- Make use of available training resources such as those provided on the RCUK website. It was noted that these are infrequently used so we need to explore the barriers to their use.

It was noted that the Resuscitation Council UK has a range of information and resources to support health care professionals around ReSPECT but that these were not always known about or used.

Key messages/recommendations

- There is a need for training around the whole ReSPECT process from preparatory discussions through to use of the form in an emergency.
- Training content and format should be tailored to the needs of the different groups who may be involved in the ReSPECT process.
- Better use should be made of existing information resources.

Raising awareness and preparing for conversations

There was a general consensus that there should be initiatives to raise public awareness of ReSPECT and emergency care treatment plans more widely. Stakeholders thought this would prompt some people to initiate a conversation about their own ReSPECT plan but could also prepare people for the conversation If initiated by a healthcare professional. A range of suggestions were made on how to do this including enlisting the support of voluntary organisations to communicate to their members; including it in information about other end of life planning such as making a will, developing video narratives that include ReSPECT and including it in popular media programmes.

However, there were also several concerns raised about the potential risks of a strategy to raise public awareness. Firstly, there was a concern that increased awareness might lead to increased pressure on GPs, as people sought more information or requested a consultation to make a ReSPECT plan. Suggestions to mitigate this included directing people to an online information resource as part of the public awareness campaign. Perhaps a greater challenge that delegates identified was the risk of ReSPECT or emergency care treatment plans in general being conflated with advance care plans and therefore, associated specifically with end-of-life diagnoses and care. Stakeholders noted the opportunities for including ReSPECT awareness raising in public awareness campaigns and conversations about advance care planning. They saw these opportunities as positive, but also emphasised that it was important to raise awareness of emergency care treatment planning in situations distinct from advance care planning. Given the challenges, they suggested that any public messaging should be managed by a national ReSPECT lead while being delivered at a grass roots level.

Stakeholders also emphasised the importance of developing trust among the general population as a prerequisite to engaging people in a dialogue about ReSPECT and emergency care treatment planning. Some noted that trust in the NHS generally had been eroded in recent years, and particularly in relation to emergency care treatment decisions during COVID. This was particularly relevant for certain groups, for example people with a learning disability and other underserved populations. One way to improve trust in the process of emergency care treatment planning would be to spend time working with people to introduce them to the concept of ReSPECT, taking care to use language and resources that are tailored to their needs, experiences, and culture. Examples were suggested of using videos to explain and inform people about ReSPECT but also as an option for them to record their values and preferences prior to the ReSPECT focussed conversation with a healthcare professional. Stakeholders with experience of working with people with learning disabilities commented that this approach worked well in other situations where it was important for people to communicate their wishes, and life experiences to healthcare professionals, for example hospital passports for people with a learning disability. Engaging voluntary sector organisations in having these conversations with people in the community prior to any formal ReSPECT conversation was seen as important for facilitating trust and understanding. Stakeholders, however, also noted that these initiatives require resources (both financial and in terms of people) and we have to be realistic about what is achievable in the current resource constrained environment.

Key messages/recommendations

- People need time, information, and support to be able to think about emergency care treatment planning in advance of creating the plan.
- Public awareness campaigns can be helpful but there are risks that there may be misunderstanding particularly around how emergency care treatment plans fit with wider advance care planning conversations.
- The impact of a public awareness campaign on increased demand for GPs to have ReSPECT conversations needs to be considered.
- Supported conversations in the community can help to prepare people for emergency care treatment planning, and alternative formats for communication need to be available.
- Any initiative needs to be achievable within the available resources.

This draft report is for circulation to all stakeholders attending the meeting. Please send any comments to the study team at respectpc@warwick.ac.uk

Please note this is a draft and is confidential and should not be shared. The final version will be included in our overall project report that will be published by NIHR.