Evaluating the use of the Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) in primary care and its impact on patient treatment and care

Stakeholder meeting: pre-conference material

Introduction

Making decisions in advance about potential treatment options in future emergency situations is ethically and practically challenging. However, if done well it should lead to more person-centred care for patients at a time when they are particularly vulnerable. We are running a research project to look at one model of emergency care treatment planning and how it is used in primary care.

This document is the pre-conference material for the stakeholder conference being run as part of this project. It contains details on the background to the issue, and methods used in the different parts of the research. It is intended that this document should be read before the conference, so that at the conference we can focus on discussing the results of our research so far, and how we can improve the use of emergency care treatment plans in primary care. Delegates at the conference come from a wide range of backgrounds, including those with and without a clinical background. We have tried to ensure that this document is understandable to everyone who will be attending the conference; but please let us know if you have any questions about what is in this document.

This project is funded by the National Institute for Health Research (NIHR), and is being organised by a research group based at the University of Warwick, with collaborators from the University of Leeds and a learning disability charity (CHANGE). Members of the investigator group include lay representatives and general practitioners, as well as experts in this type of research. We also have an independent project steering committee, whose role it is to ensure the research is done well and advise on any difficulties. This committee also includes lay representatives as well as health and social care professionals. Details of the investigator group, and links to where more information on the project can be found are at the end of this document.

Background

When a person develops a life-threatening condition or has a sudden deterioration in an existing illness rapid treatment decisions are needed. Often there is limited about the patient's clinical condition or information on what the person's treatment preferences might be. To help health care professionals to make the best decisions for someone in these situations, Emergency Care Treatment plans, sometimes called Treatment Escalation Plans, can be used. These plans record which treatments health care professionals should consider for a person in a future emergency situation if the person becomes seriously unwell and is unable to communicate at the time. The plan is made with the person or if a person is not able to have a conversation about their future treatment, it is discussed with the person's family or someone close to them. However, the specific recommendations are made by the health care professional and are intended to guide future treating clinicians.

In 2016 the UK Resuscitation Council led the development of a specific model of Emergency Care Treatment Plan. This model, the Recommended Plan for Emergency Care and Treatment (ReSPECT) is now used in many NHS hospitals and primary care organisations in the UK. The ReSPECT form is a standardised document that acts as a record of the conversation between the person (or their relative) and the health care professional. The form is intended to be held by the person and transferred with them when the person moves between their home and different health care settings, for example to a hospital or hospice. A draft copy of the current version of the ReSPECT form is available on the Resuscitation Council ReSPECT website.

ReSPECT was first used in acute hospitals, mainly for people who were very sick or nearing the end of their life, but it is now being used in primary care. There may be advantages to having these conversations in primary care. For example, patients may have an established relationship with their GP, conversations can occur over an extended period, patients are less sick and more able to engage in discussion, and conversations can be placed in a wider context of advance care planning. However, there are also potential difficulties in moving ReSPECT conversations to primary care; patients and families may be less ready to think about these things until a crisis emerges, GPs may be uncertain about hospital-based treatments, and both may have concerns about the effect of a conversation on the relationship between the patient and their doctor. In our previous study evaluating ReSPECT in hospitals, we found that GPs and hospital doctors had different views about how ReSPECT was used and what should be included on the form.

The COVID 19 pandemic led to an increased focus on the use of emergency care treatment plans and doctors were encouraged to have these conversations with patients and their families. However, there was also concern that inappropriate use of plans could result in potential harm to patients. The Care Quality Commission conducted a review of Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) decisions during COVID. Their report recommendations emphasised the importance of DNACPR decisions being part of a wider conversation about future treatment planning, and that these conversations must be personalise to the individual and non-discriminatory.

The recommendations of the CQC are particularly pertinent to people with a Learning Disability (LD). There is evidence that health outcomes are often poor for people with LD because health care professionals do not understand their needs, and their needs and wishes are often not met in acute medical situations.

There is very little research on the use of emergency care treatment plans in general, and ReSPECT in particular, in the UK, and no research that has looked specifically at their use in primary care. As ReSPECT continues to be rolled out it is important to evaluate its use, to identify potential benefits, obstacles to its implementation, and its impact on patient care.

Project Aims

The aim of this project is to evaluate the use of 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.

Specifically, we aim to:

1. Understand how ReSPECT is currently used in primary care from the perspective of patients, their families, clinicians, and care providers.
2. Describe the views of the public, primary and community health care professionals, and home care workers on emergency care treatment plans in general and ReSPECT in particular.
3. Identify enablers and obstacles to embedding ReSPECT in primary care practice.
4. Explore the impact of ReSPECT on patient treatment decisions.
5. Understand how health and social care professionals can best engage people with learning disability in the ReSPECT process and coproduce relevant support materials.
6. Develop a consensus on how ReSPECT should be used in primary care.

Project methods

This research project has used different ways of finding out the answers to our main research questions. We have split the research into sections called work packages. Below we give more detail about these work packages.

Work Package one: exploring the experiences of patients, carers and clinicians.

To understand how ReSPECT is used in primary care from the perspective of GPs, patients and their relatives, and care home staff, we went to 13 GP practices and spoke to a range of practice staff about their knowledge of how the ReSPECT process worked in the practice. We also carried out in-depth interviews with patients and their relatives, GPs and members of staff in care homes associated with these GP practices.

Setting

The 13 GP practices that took part in the study were from three different NHS regions in England. For each GP practice we asked if they would introduce the study team to two care homes associated with the practice. Not all practices were able to identify two care homes.

Participants

We asked the GP practices to identify from their records all adult patients who had had a record of a ReSPECT form completed in the previous 12 months. The practice sent the study team anonymous information on the age, gender, and ethnicity of the patients identified. The practice then sent information about the study to all those patients, or to their next of kin if the patient did not have capacity to decide about taking part in research. The information included an invitation to take part in an interview about their experience of ReSPECT, and information that a researcher would be checking their medical records. Patients and relatives who agreed to take part were interviewed. In some cases, both the patient and their relative were interviewed together. We also interviewed GPs in each practice (and senior nurses in some practices) and senior staff in the care homes who agreed to participate. In addition, a researcher visited each practice to talk to clinical and administrative and staff about their knowledge and experience of the ReSPECT process. In total 61 interviews were carried out with a total of 74 individuals (21 GPs, 5 practice based nurses, 32 care home staff and 16 patients and/or their relatives). Some interviews included more than one person.

Information collected.

In the interviews GPs and senior nurses were asked about their experience of completing the ReSPECT process with their patients, including their reasons for beginning the process with a patient, where ReSPECT conversations took place and who was involved, how ReSPECT forms were completed, recorded, and stored, and what they saw as the benefits and challenges of completing the ReSPECT process for patients. Care home staff were asked about their experience of ReSPECT conversations and form completion for their residents, and how ReSPECT recommendations were or were not used when residents became unwell or deteriorated. Patients and their relatives were asked about what they remembered of the ReSPECT conversation, what they understood about the purpose of the ReSPECT form, and how they felt about the process in general. All the interviews were audio recorded and transcribed. Participants were asked if they would give consent for brief extracts of their interview to be used in the stakeholder meeting.

Analysis

The analysis process started with the research team reading transcripts of the interview recordings from each of the different groups of participants to get a broad idea of the issues that were important to the participants and to identify common themes across the different perspectives. Each record was then read closely, and parts of the record were coded so that the information from the interviews could be sorted into themes. This process of coding and sorting into themes occurred several times as our understanding of what was being said in the interviews increased. The coding was carried out by several members of the study team with one person taking responsibility for leading the coding for each set of interviews (GPs; care home staff; patients and relatives)

The interview records were analysed from three main perspectives:

1. The experiences of the different groups of people involved in the ReSPECT process of how the process worked, or didn’t work, for them.
2. The obstacles to implementing the process of ReSPECT conversations and recommendations into day-to-day GP practice.
3. The ethical issues that emerge in the process of implementing the ReSPECT process in primary care.

Work Package two: Understanding the wider context of ReSPECT implementation.

To understand how ReSPECT fits into the wider context of emergency care treatment planning we sought the views of other community health care professionals who were involved in some way in the use of ReSPECT recommendations in patient care. We also asked members of the public about their ideas on emergency care treatment planning in general and ReSPECT in particular, through focus groups and a national survey. To gain a wider GP perspective we carried out a national survey of GPs to find out about their use of emergency care treatment plans.

Focus groups.

Participants

In each of the three areas that we recruited GP practices we also carried out focus groups with members of the public who had an interest in health care and were willing to discuss emergency care treatment plans. We advertised the study through local Health Watch organisations, community groups, and GP practice patient forums. In each area we also carried out focus groups with health and social care professionals working in the community who had experience of the ReSPECT process in their work. We advertised the study through local professional organisations and groups. In addition, we recruited staff working in local hospital emergency departments to explore their experience of seeing patients with a ReSPECT form completed in primary care. People who contacted the study team to express an interest in participating were given more information and invited to a focus group. If it was not possible for someone to attend one of the planned focus groups the person was interviewed by a study researcher. A total of 39 participants took part in the focus groups or were interviewed for this work package: 20 members of the public and 17 community health and social care professionals.

Information collected.

The focus groups were facilitated by an experienced researcher. Before the focus groups with members of the public participants were sent information about ReSPECT and a copy of the ReSPECT form so that they had some familiarity with it before the meeting. Participants in the focus groups were asked their views on what they saw as the benefits of ReSPECT and/or emergency care treatment plans in general, for patients, carers, the health service, and wider society; what might get in the way of implementing ReSPECT and how these obstacles could be overcome. All the focus groups were audio recorded and transcribed for analysis.

Analysis

The analysis process began with members of the study team reading closely the transcripts of the initial focus groups in our first research area and discussing their thoughts about what they saw as the key issues that they had identified in a research meeting. These issues were documented and used to inform the development of the national survey of the public (see below). Next each focus group transcript was analysed using a similar process to that for analysis of the interview transcripts in work package one.

The focus group transcripts were analysed from two main perspectives:

1. The benefits of and obstacles to implementing ReSPECT across the wider community health care system.
2. How do members of the public understand the purpose, benefits, and difficulties of emergency care treatment planning.

<u>National surveys</u>

To gain a wider perspective on how GPs view and use emergency care treatment plans, and what members of the public think about them, we carried out two national surveys. To do this we commissioned specialist survey providers; the national centre for social research for the public survey and a commercial company MedeConnect for the GP survey.

Public survey

Using the information from our focus groups with members of the public and information from a review of the literature on emergency care treatment planning, we developed a set of questions for members of the public. We worked with the National Centre for Social Research to refine the questions to be included as a module in the 2022 British Social Attitudes survey, a UK national survey carried out by the centre each year. The set of questions was tested by researchers from the National Centre for Social Research, first in interviews with a sample of the public, and then in a pilot run of the survey with 56 participants.

Participants

The British Social Attitudes survey selects participants to include a representative sample of people from England Scotland and Wales. No more than two people per household can take part. People are sent a letter inviting them to take part. They can complete the survey online or can choose to speak to a researcher by telephone and answer the questions in this way.

Information collected.

In the survey we asked people what they thought about emergency care treatment plans, whether they would want one for themselves or a member of their family, who they would want to have the conversation with, and when they would want one. We also asked them what the benefits of such a plan might be, and what they might be concerned about if they had a plan. We received 1119 completed responses to our set of questions.

Analysis

We used simple statistics to describe the views of the participants in answer to our questions. We then analysed the data to see if any particular features were linked to particular answers, for example whether their age, or whether they had experience of chronic illness or disability, had any effect on their views about emergency care treatment plans.

GP survey

Using information from our interviews with GPs and the findings from our previous study of ReSPECT in hospitals we developed a set of questions for GPs about emergency care treatment plans in general and ReSPECT in particular. We tested these questions in interviews with a small group of GPs. We worked with a company called MedeConnect who run a monthly online survey of GPs across the UK to gather GP opinion on a range of different issues.

Participants

The MedeConnect GP survey selects participants from GPs who belong to a national online network of doctors called Doctors.net. The sample they choose is representative of GPs from across the UK and includes GPs in training. For our study questions we focussed on GPs in England.

Information collected.

In the survey we asked GPs whether they used emergency care treatment plans in their practice, and specifically whether they used ReSPECT. We asked who completed ReSPECT plans in their practice and who they thought should be able to complete these plans with patients. We also asked when they thought plans should be completed and when they should be reviewed. Finally, we asked how comfortable the GPs felt having conversations about emergency care treatment planning with patients or their families. We received 84 responses from GPs to our set of questions.

Analysis

We used simple statistics to describe the views of GPs in answer to our questions. We then analysed the data to see if any particular features were linked to particular answers, for example whether GP age, or the region in which they practised had any effect on their views about emergency care treatment plans.

Work package three: An analysis of completed ReSPECT forms in GP practices.

To understand how Respect forms were completed, and the information that was included in the recommendations for future treatment, we looked at ReSPECT forms that had been completed for patients in the 13 GP practices that took part in our study.

Participants

We asked the GP practices to identify from their records all adult patients who had had a record of a ReSPECT form completed in the previous 12 months. The practice then sent information about the study to all those patients, or to their next of kin if the patient did not have capacity to decide about taking part in research. The information explained that a researcher would be checking their medical records for a research study. The patient, or their relative if the patient lacked capacity, could opt out of the study if they wished by letting the research team know.

Information collected.

Once people had been given an opportunity to opt out, a researcher checked the records of the remaining patients to see if there was a copy of the ReSPECT form in the GP record. A copy of the ReSPECT form was made and any information that could identify the patient removed. These anonymised forms were used for our analysis. A total of 145 ReSPECT forms were collected from the 13 practices.

Analysis

Each ReSPECT form was read by a researcher and scored for how the form had been completed. Scores were given for each section of the form. Any recommendations made on the form were recorded, with the reasons for the recommendations if they were recorded. The role of the person completing the form was also noted. One researcher analysed all forms and four other researchers in the study team each analysed a quarter of the forms. We then used an ethical framework to assess the quality of the completed forms. In particular we looked for whether forms recorded the views and wishes of patients consistently and whether the recommendations were clear and the reasons for the recommendations were transparent and ethically justifiable.

Work package four

To understand the views of people with learning disability and their carers about emergency care treatment plans and to develop suggestions for how these conversations could work for the benefit of people with a learning disability we worked with CHANGE, a leading learning disability charity based in Leeds. CHANGE is co-led by people with a learning disability and their allies. Together with team members from CHANGE we invited people with a learning disability to form an Advisory Group to help us co-design a series of workshops for people with a learning disability where together we explored workshop participants' experiences and views of emergency care treatment planning in general and ReSPECT in particular. During the workshops the participants developed recommendations and suggestions for resources to support people with a learning disability and their carers and the professionals involved in their care, during the ReSPECT process. We also spoke to carers of people with a learning disability about their experiences and views of emergency care planning from the perspective of the person they care for and for themselves.

Co-production process

Participants

The CHANGE team advertised the advisory group and the workshops through their networks and other learning disability organisations. Those people who expressed an interest were sent further information about the study and a member of CHANGE contacted them to talk through the study and seek their consent to take part. We recruited five people who lived in the Leeds area to form an advisory group. We then recruited two groups of six people with a learning disability to take part in a series of online workshops. We also advertised through networks for carers of people with a learning disability to ask for volunteers to take part in a focus group or individual interview to discuss their experiences of emergency care treatment planning conversations for the person they cared for. We recruited five advisory group members, twelve people to take part in workshops, and ten carers to take part in focus groups.

Advisory group

The group met eight times during the study. Together with members of CHANGE and the study team they co-designed each workshop, taking into account what had happened at the previous workshop. They reflected on the whole process and the resources developed in the workshops. They advised the study team on how this work could be integrated into the whole study by reviewing and reflecting on emerging findings from some of the other work packages. Members of the advisory group co-developed resources to support discussions about ReSPECT with people with a learning disability in the workshops including: worksheets using the 6 part story method; an online jamboard game 'Who Said What?'; and body-mapping focusing on the person's past, present and hoped for future in relation to the ReSPECT in primary care process.

Workshops

Each group took part in five workshops during which they explored the ReSPECT process in addition to emerging findings, from previous work packages focusing on doctors, health workers, care homes and members of the public's experiences of the ReSPECT process. The outputs from each workshop were discussed with the advisory group who used this to advise on the design of the next workshop.

Analysis

The study researcher took notes at the advisory group meetings and workshops and all meetings/workshops were recorded with the consent of participants. A summary of each meeting and workshop was written by the researcher. The advisory group was analysed through a collaborative autoethnographic approach, a qualitative analysis where all those who took part in a group process, including the researcher and the facilitators, pool their experiences, finding meanings in relation to sociocultural contexts to explore the experience of co-designing the workshops.

The workshop transcripts and notes were part of a two-fold analysis. First, they were analysed as part of an ongoing process focusing, in particular, on one of the aims of this research which was to better understand how health and social care professionals can best engage people with learning disability in the ReSPECT process. This information was fed back to the advisory group where it was discussed and developed and used to form the content of the next workshop. Completed worksheets and materials co-produced by advisory group members and workers at Change were also included in the analysis process to aid in this reflective, collective autoethnographic process.

Second, workshop transcripts and notes were analysed in line with other data from the wider project, through re-reading, coding and identifying key themes.

Focus groups.

Participants

Working with CHANGE, we advertised the focus groups through networks of carers of people with learning disabilities. People who took part in the focus groups also passed the study information to other networks and groups. Carers of people with a learning disability who were interested in the study were asked to contact the study team. More information was sent to them, and a researcher spoke to them on the phone to answer questions and seek their consent to take part in a focus group or a one-to-one interview. We recruited ten participants to the focus groups.

Information collected.

The focus groups were facilitated by an experienced researcher. In the focus group we asked people what they thought might be the benefits of ReSPECT for people in general and for people with a learning disability and for their carer's. We also asked what they saw as potential, or actual, challenges to implementing ReSPECT more generally for both themselves and the person with a learning disability in their care and how these challenges could be overcome.

Analysis

The analysis process began with members of the study team transcribing the focus group recordings, making notes about what participants saw as the key issues that they had identified during the focus group meetings and individual interviews. The transcripts were then re-read and coded so that the information from the focus groups could be sorted into themes known as a thematic analysis.

Stakeholder meeting

We have invited people to our stakeholder meeting who can bring a range of different views and perspectives on emergency care treatment plans and the ReSPECT process. We have included representatives from health professional organisations, care home organisations, and patient support groups and advocacy organisations. We have also included people who have experience of implementing ReSPECT in their areas. We hope that our discussions in the meeting will help to develop recommendations and suggest resources to improve the process of emergency care treatment planning for patients, their families and the health and social care professionals involved in their care.

During the meeting we will present our initial findings from different work packages in the study. We will then ask delegates to consider a series of questions about what the findings might mean for the future development and use of emergency care treatment plans.

After the meeting

We will take note of all the feedback we have received from the stakeholder meeting and will write a report on its outcomes. We will send a copy of this report to all the people who attended the conference. You will then have an opportunity to comment on the report.

Thank You

Thank you for reading this document, and for attending the stakeholder conference. Your help in this attempt to improve the process of emergency care treatment planning for patients in the community is greatly appreciated.

Professor Anne Marie Slowther

Project information

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