QUALITATIVE PAPER

Using the recommended summary plan for emergency care and treatment (ReSPECT) in care homes: a qualitative interview study

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Abstract

Background: The Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) is an advance care planning process designed to facilitate discussion and documentation of preferences for care in a medical emergency. Advance care planning is important in residential and nursing homes.

Aim: To explore the views and experiences of GPs and care home staff of the role of ReSPECT in: (i) supporting, and documenting, conversations about care home residents’ preferences for emergency care situations, and (ii) supporting decision-making in clinical emergencies.

Setting/participants: Sixteen GPs providing clinical care for care home residents and 11 care home staff in the West of England.

Methods: A qualitative research design using semi-structured interviews.

Results: Participants’ accounts described the ReSPECT process as facilitating person-centred conversations about residents’ preferences for care in emergency situations. The creation of personalised scenarios supported residents to consider their preferences. However, using ReSPECT was complex, requiring interactional work to identify and incorporate resident or relative preferences. Subsequent translation of preferences into action during emergency situations also proved difficult in some cases. Care staff played an important role in facilitating and supporting ReSPECT conversations and in translating it into action.

Conclusions: The ReSPECT process in care homes was positive for GPs and care home staff. We highlight challenges with the process, communication of preferences in emergency situations and the importance of balancing detail with clarity. This study highlights the potential for a multi-disciplinary approach engaging care staff more in the process.

Keywords: Advance Care Planning, Recommended Summary Plan for Emergency Care and Treatment (ReSPECT), Qualitative Research, Nursing Homes, Primary Health Care, Qualitative Research, Older People
The Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) is viewed as supporting person-centred Training in completing the process and form could help ensure clear instructions are given in emergencies.

Translating preferences into action in emergency situations is a challenge of using the Recommended Summary Plan for Implementing the Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) is complex and requires a multi-disciplinary team approach, particularly involving care home staff, could support and enhance the Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) process.

Training in completing the process and form could help ensure clear instructions are given in emergencies.

**Background**

The Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) is an advance care planning (ACP) process developed by the UK Resuscitation Council [1]. It is designed to plan for patient care and decision-making during clinical emergencies when patients are unable to express their wishes. Preferences are elicited by healthcare professionals engaging in conversation(s), with patients, and sometimes their families. A written record of the conversation(s) is summarised on the ReSPECT form which should remain with the patient and be accessible to health and social care professionals [2]. ReSPECT can be used by anyone who wishes to record their preferences but is particularly relevant for people with complex health needs, people nearing the end-of-life or at risk of sudden deterioration or cardiac arrest. It is not an end-of-life planning resource although it incorporates aspects of end-of-life care; it encapsulates planning for decision-making in a clinical emergency where clinical intervention is balanced against quality of life [3].

ReSPECT was partly developed in response to the shortcomings of Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) recorded decisions, established to prevent inappropriate use of Cardio-Pulmonary Resuscitation (CPR) for patients who may not benefit from this intervention [4]. However, some patients were shown to experience unacceptable levels of care following a DNACPR notice being assigned [5–7], including access to other treatments being withheld [4, 8, 9].

Although studies have explored the use of ReSPECT in secondary and primary care [3, 10], there are limited studies examining its use in care home settings for older people (including residential homes which provide accommodation and personal care and nursing homes additionally providing nursing care). The use of ReSPECT in such settings is highly relevant due to the age, frailty and co-morbidity of the resident population. More than half of the people admitted to a nursing home will die in the following 12 months [11]. Also, care homes operate at a nexus where many healthcare professionals intersect, including care home nurses, general practitioners (GPs), community nursing teams and paramedics, and as such represents a test of how well ReSPECT supports communication between healthcare professionals and other healthcare sectors. For instance, studies suggest that ACPs decrease inappropriate hospitalisation rates [12–15].

This paper examines GPs and care home staff views and experiences of the ReSPECT process in care homes and whether it is a useful resource for: (a) GPs, residents and care home staff in facilitating and documenting resident preferences for emergency care situations and; (b) for guiding decision-making during emergency care situations.

**Methods**

**Study outline**

The study used semi-structured qualitative interviews with GPs providing clinical care for care home residents and care home staff. It was conducted in residential and nursing homes within the West of England where ReSPECT was introduced in 2019, with support and training from the West of England Academic Health Science Network (AHSN). The West of England AHSN is one of 15 AHSNs established by NHS England in 2013 to implement large scale innovation to improve health. The West of England AHSN facilitated system-wide implementation of the ReSPECT process across its region to replace the existing DNACPR form, including delivering training on completing ReSPECT forms to responsible senior clinicians in community settings.

The study was approved by the UK NHS Social Care Research Ethics Committee and the Health Research Agency (reference numbers: 268211 and 19/IEC08/0049).

The study adopted an interpretative approach seeking to understand how people make sense of their experiences of ReSPECT and explore responses to these experiences [16].

**Patient and public involvement**

The study team included a public contributor (a coordinator of a local death café and person with experience of caring for an older relative) who provided valuable input to participant-facing study materials, topic guides and data interpretation.

**Data collection**

The study team’s contacts in the region, particularly the West of England AHSN, supported recruitment of GPs and care homes. Potential participants were sent written
information describing the study and inviting them to contact the research team if they were interested in participating. Snowball sampling among GPs and care homes identified additional participants. Care home staff involved with administering ReSPECT were identified by a contact within the care home (usually managers). Care home staff facilitated recruitment of residents who had experienced the ReSPECT process by discussing the study verbally, providing written information and supporting interview participation (e.g., setting up equipment for video interviews).

Data collection occurred between July 2020 and June 2021, following the first COVID-19 lockdown in the UK and captures experiences of the ReSPECT process at a time when its use had increased. This followed guidance from NHS England recommending care home residents have ACPs in place [17].

Interviews were by phone or online. Participants provided written or audio-recorded informed consent prior to the interviews which were audio recorded, transcribed and anonymised. Interviewers (JB and JK) used topic guides based on the research questions and the existing research base around emergency care planning. The guides were used flexibly and modified following initial interviews to accommodate new topics identified by participants.

A small number of care home resident interviews were undertaken with the option of family, friends or care staff being present. However, there was a time gap between their ReSPECT conversation and the interview of over 6 months due to the COVID-19 lockdown and residents struggled to recall their conversations. A decision was made to cease resident interviews and not to include their data in the analysis.

Analysis

The transcripts were analysed thematically [18] using interpretative, inductive and deductive qualitative analysis. Analysis was an iterative process of close reading of the data, coding and elaboration of themes. In the first instance, JK and JB independently reviewed three GP interview transcripts to develop and agree a coding strategy, reflecting the research questions. The same approach was used for care staff interviews by JB and RS. JK and JB took responsibility for ongoing coding and categorisation of the data, using the QSR NVivo 12 qualitative data management software. Codes and categories were reviewed regularly by the wider multidisciplinary team, to ensure the rigour of the coding and analysis process. The project team, which included non-clinical qualitative researchers, primary and secondary care clinicians with roles at the West of England AHSN, clinical academics and a public contributor brought different perspectives and insights to the analysis. For instance, clinical team members reflected on how the findings aligned to their clinical practice and own use of ReSPECT and brought different interpretations to the non-clinical academics. Categories of data and thematic relationships were identified and written up as descriptive and interpretive accounts, supported by interview excerpts.

Results

We recruited 16 GPs (7 female, 9 male) from 13 GP practices across the West of England who were providing, or had recently been involved in providing clinical care to and nursing home residents. The length of time in their role ranged from 9 to 30 years and one participant was in the final year of GP training. This information is not available for eight participants. We recruited four care homes and interviewed 11 members of care staff (10 female, 1 male) including a care assistant, an advanced nurse practitioner, care coordinators and managers who have been in their role for 2–10 years (this information is not available for four participants). GP interviews lasted 32–75 min and care home staff interviews lasted 13–49 min.

The findings are presented under two themes:

1) The ReSPECT process: acceptability and complexity

2) ReSPECT: from conversation to clinical guidance Our data suggest that COVID-19 may have affected the preferences expressed during the ReSPECT conversations, with staff and GPs reporting residents’ reluctance to be admitted to hospital due to concern about spreading the virus to the care home when they returned and perceptions that treatment for COVID-19 would not be effective for them. GPs described having more conversations by telephone or online and some described specifically documenting what should happen in the case of a COVID diagnosis. However, the data suggest that COVID-19 did not have a substantive effect on the ReSPECT process and so the impact of the pandemic is not presented.

The ReSPECT process: Acceptability and complexity

Although ReSPECT was generally viewed favourably by GPs and care home staff, challenges created by the complexity of the process were evident. When comparing it with the processes used previously such as DNACPR, GPs and care home staff accounts suggested it went beyond dichotomous, ‘tick-box’ preferences for resuscitation which characterised DNACPR. Instead, it was seen as more person-centred and encouraged broader, more nuanced, and detailed discussions of residents’ preferences for what they wanted to happen in a clinical emergency. In contrast, DNACPR and treatment escalation plans (TEPs) were seen as being primarily about what not to do to patients, e.g., do not attempt to resuscitate or do not admit to hospital. They described the process as empowering care home residents to express their wishes and have them documented,

I think the purple ReSPECT forms are a lot kinder to the individual, if I’m honest, because it outlines their wishes. Rather than just having a plain yellow sticker that indicates they don’t want to be resuscitated, the ReSPECT form actually outlines what kind of care they wish to have. Care-Staff-30

For care home staff in particular, the changes from DNACPR to ReSPECT were not just a change in process but reflected...
a shift in the ‘values’ and underlying principles of how they engaged with people who were approaching the end-of-life,

ReSPECT, I think because it’s an important value to have. And I think it conveys that you are considering (…) the person that you’re looking after, that to me is their values, their wishes for the future are really important and that, it’s respectful to be mindful of. Care-Staff-31

Although this was the majority view among GPs and care staff, some GPs’ accounts indicated that the decision making around care planning was generally predictable for care home residents and so ReSPECT represented additional work to ensure the resident and their family members (if they lacked capacity) were involved in the process,

What you’ll get is what we saw with Liverpool pathways, what we saw with DNACPRs and we’ll see them with the ReSPECT form, it will become a piece of paper that becomes part of a process like a safeguarding referral now which you could almost pre-type it and that’s the danger. GP-7

I’m probably doing the same things and I’m just ticking the basic boxes on the form to get it done and writing a few lines. Not that different. What I do is probably similar. GP-14

The ReSPECT conversation was introduced in different ways. Summarising the resident’s medical history and current health at the start of the conversation enabled GPs to develop scenarios where care may be needed in future. These tailored, hypothetical scenarios helped residents consider their preferences for care in a range of situations in a meaningful way. This reflected the wider scope of the ReSPECT plan compared with other ACP documentation,

I find summarising that bit at the top (…) where you summarise their past medical history at the top of the ReSPECT form (…) quite useful because sometimes even the patients aren’t aware (…) and it gives them kind of an idea of like okay this is everything that’s happening to me, this is what past me at risk in this way and so and so forth and that helps us work through like, well what might the possible complications be for you? How might you end up in hospital? GP-11

However, this introduced challenges for GPs and care home staff and involved interactional work to initiate and engage residents in the conversation. The conversation took place in a social milieu in which residents brought their understanding of medical treatment from a range of sources. GPs and care home staff negotiated these understandings to create what they perceived as meaningful plans. This was not necessarily a new approach to ACP but because of the scope and level of subtlety within ReSPECT it added a level of complexity to the conversation. Residents’ and relatives’ preferences were discussed before being recorded. GPs and care home staff did not necessarily seek to change resident preferences but rather they aimed to reach a point where the resident had a clear understanding of what is involved in the different care pathways to enable an informed decision to be made. For instance, GPs emphasised the importance of being clear about the chances of successful resuscitation and the impact of invasive procedures on quality of life. They also articulated the importance of not presenting ReSPECT as overly focused on preferences for resuscitation because this could have been associated with removal of care, i.e. the ‘not for’ approach.

The ReSPECT form was recognised as valuable in facilitating the conversation, but it also brought the risk of reducing a complex and sensitive conversation to a bureaucratic process unless negotiated carefully,

The thing that I’m slightly suspicious of it is I’ve been told I need a ReSPECT form, can you fill it in for me? You know and it just gets filled in. (…) And for patients without capacity, I think in a busy general practice they just get completed like DNAs [DNACPR]. GP-7

Indeed, many GPs emphasised the value of the conversation over the form. This was achieved by not completing the form in the presence of the resident, rather it was often completed afterwards with the GP aiming to capture the key points of the conversation,

It was clear to me that the forms were much more about a conversation than they were about a defined plan. GP-2

I prefer not to have a form in front of me. I prefer to have the discussion in a bit more of a wanting to talk to a patient and their family, because I think it shows a bit more interest. GP-16

There was variation in whether residents and families viewed completed ReSPECT forms. Some GPs described summarising what they were going to document and giving the form or a copy to the resident to review, whereas others did not share the form with the residents.

Multiple contacts to complete ReSPECT, allowing residents’ time to reflect and discuss their preferences with family members impacted on time available to GPs. In a minority of cases, pressure on GP time presented an obstacle to allowing residents time to consider their preferences which risked the process losing the focus on the individual and becoming more ‘perfunctory’,

It just, I’m afraid, is another one of these things that is difficult for your average GP, who’s probably now having to deal with 40, 50 patients and enquiries a day, to be able to manage with the time, and alright to quote the word respect, that the whole process needs (…) when it gets very, very busy you end up rushing people and this is not one of the things really that should be rushed. GP-8

Although GPs described having the role of signing the ReSPECT form and taking responsibility for its contents, they valued input from care home staff. GPs and care home staff recognised that care home staff often had a personal connection with residents and a good understanding of their care needs. This was valuable when the GP did not know the resident or when residents lacked capacity and did not have family to support the process.

Some care home staff, particularly more senior staff such as care home managers, care coordinators and nurses, had conversations and wrote directly on the form which was then
completed or signed off by the GP. They also liaised with GPs to set up conversations and their presence helped support conversations. They undertook preparatory work introducing and explaining the ReSPECT process which meant the resident and relatives had thought about preferences before the conversation and were better prepared. Although care staff expressed some concerns about having responsibility for the content of the ReSPECT form, they were generally positive about being actively involved,

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If I get new residents in and we go through the conversation and I have to ask, 'Have you got a DNR and ReSPECT form in place?', if they say 'no', (…) I get the ball rolling and get to speak to the GP. I don't really have too much involvement, but I will make sure one's in place if it has to be and is wanted in place. Care-Staff-29
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The involvement of care home staff in the process was highly valued because their relationships with residents facilitate good communication between resident, relatives, clinician and care staff. Several GP and care home staff participants wanted more care home staff involvement in the ReSPECT process to reduce the risk of important information being omitted from the ReSPECT documentation and improve the translation of the written text into guidance that could be understood by a range of healthcare professionals including paramedics,

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It should be much more of a team game involving family, patient, the nursing and care team and any other healthcare provider that would come into contact. Because anyone can feed into it, they just don't and actually you're potentially missing (…) useful stuff that might not come up in a (…) five-ten minute chat about it at the end of a consultation which is essentially what you're going to be doing. GP-4
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Although many GPs emphasised to patients that ReSPECT could be changed and updated, there was some lack of consistency and no clear process for reviewing and updating the form. Some care home staff felt that a more formal mechanism for review would be appropriate,

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The ReSPECT forms do get reviewed, the only thing I would change on it is where it says, 'Date completed', I would probably implement another box saying, 'Date reviewed'. Care-Staff-30
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ReSPECT: From conversation to clinical guidance

Translating the form into action during emergencies involved communication between care home staff, relatives, healthcare providers such as paramedics and sometimes but not always the GP. Examples were given by care home staff of ReSPECT working well and being used effectively to direct emergency care decisions about hospital admission and approaches to treatment in line with resident preferences,

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I think the resident's wishes are taken into account much more (…) I think with the ReSPECT form, it clearly states whether they want hospital intervention or not and I do feel outside professionals consult that much more and take their wishes into account much more of what they want – not what we want, because it's not us – and that's the most important thing. Care-Staff-29
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I've seen it sort of in the notes from 'out of hours' that they've used it or they've read it and then it kind of impacted on what treatment they've decided with the patient or the family and the home. GP-16
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Although the overall experience was positive, care home staff recalled emergency situations where the content of the form was problematic and did not translate easily into treatment and care decisions which care home staff and paramedics could follow,

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It would be nice if whoever fills it in, (…) [does] it absolutely clearly so that we know there's not any contradiction in it because we've found ourselves in situations whereby it's kind of not clear or it's kind of contradictory. Care-Staff-26
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Similarly, GPs were not always confident that the different perspectives incorporated into the form would convert to clear guidance for other healthcare professionals,
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I find that writing that [the resident preference and differing clinical recommendation] on the form is very unclear to people reading it. It's clear what we mean but it's unclear what they'd do and that's the difficulty. GP-2
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As a result, the ReSPECT form could not always be used as an unambiguous guide for action, it often relied on some interpretation and discussion informed by the clinical situation. In some situations, it was either not sufficient on its own to inform decisions or the recommendations may not easily apply in the situation,

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Generally, the process is, somebody becomes poorly so we end up (…) calling an ambulance. In between, well I would already have got hold of the ReSPECT form, because that's my go-to, it's my Bible, so I'm already aware about whether they want to go to hospital or not. If I'm guessing that they probably do need to go to hospital then I start the conversation with them. 'Look, I understand your ReSPECT form says you really don't want to go to hospital, but I think you know, possibly for a scan or for an x-ray or (…) some new medication, it would be a really good idea if you consider it.' So, I've already started that process before the paramedics arrive, so when the paramedics arrive, they get handed the ReSPECT form straightaway and they will say straightaway, 'Oh, they don't want to go to hospital.' So, we then start the conversation with the resident again from the paramedic's point of view. Care-Staff-19
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Both GPs and care home staff highlighted that in rare cases confusion or delays occurred. This was because what was written on the form was ambiguous or inconsistent and therefore open to different interpretations. In particular, care home staff sometimes found it difficult to understand forms written in 'clinical' language in emergency situations,
and strengthen the argument for a multi-disciplinary team focusing on ReSPECT and medical treatments undertaken at higher levels of concordance between patient/family wishes. Previous studies have demonstrated the value of ACP in enhancing this role was expressed. Comparison with literature. Enhance this role was expressed. The use of tailored, hypothetical scenarios may help residents consider their preferences for care in a range of situations beyond resuscitation decision-making. Wider use of scenarios, as employed by GPs in this study, may help to optimise the ReSPECT conversation and ensure a full understanding of residents’ or patients’ preferences is elicited. In line with our findings, this research highlights the importance of balancing the plans specificity and generality to support interpretation in an emergency.

Implications for practice. The use of tailored, hypothetical scenarios may help residents consider their preferences for care in a range of situations beyond resuscitation decision-making. Wider use of scenarios, as employed by GPs in this study, may help to optimise the ReSPECT conversation and ensure a full understanding of residents’ or patients’ preferences is elicited. This study highlights the valuable role played by care home staff in facilitating and supporting ReSPECT conversations and translating them into action. A multi-disciplinary team approach, advocated for previously, involving the
person who knows the resident best (e.g. care staff and relatives), could help ensure valuable information is not missed. This could include enhancing the role of care home staff, as recommended by our participants, in undertaking these conversations and documenting preferences. Difficulties identified in interpreting the form in an emergency means the language used to document the conversation is critical for ensuring it can be interpreted and translated into action by care home staff. Training could support the development of a language for the ReSPECT form which is accessible and understandable to a wide range of health and social care professionals. This could be facilitated through multi-disciplinary workshops which incorporate the voices of patient and public contributors as well as clinicians, care staff and paramedics. The finding that ReSPECT forms were sometimes completed after the conversation points to potential ethical considerations around ensuring residents’ and relatives (as appropriate) have an opportunity to agree the contents of the form. Some care home staff in our study also felt that a more formal mechanism or guidance for review would be appropriate which is now part of the latest version of the ReSPECT form [15, 28].

Strengths and weaknesses

Most evaluations of ReSPECT have been in secondary care. This study contributes to the limited evidence on the use of the process in care homes, where it is particularly relevant. By interviewing clinicians and care home staff, we have incorporated a range of perspectives.

The COVID-19 lockdown prevented us from interviewing residents immediately following their ReSPECT conversations, which might have increased their recall. Future research could include interviews with relatives and use non-participant observation to explore how the process is experienced by residents followed immediately by interviews. Research to understand paramedics’ views on ReSPECT would add to the understanding of how ReSPECT is used in an emergency. Although we were able to get a broad sample of GPs spread across two Clinical Commissioning Group areas, we struggled to recruit care homes, which was likely due to research being seen as a low priority during the pandemic but also because the care home sector lacks a research infrastructure [29]. Social desirability bias may have influenced the findings, though challenges of using ReSPECT were reported.

Conclusion

The experience of working with the ReSPECT process in care homes was, generally, positive for GPs and care home staff. The study highlighted the challenges of moving from conversation to form completion to clinical decision-making and the importance of clear language and communication. Our data highlight the potential for engaging care staff more with this process and making ReSPECT a more multi-disciplinary process. This could reduce the demand on GP time and increase the communicability of the contents of the ReSPECT form to other healthcare professionals and care staff.

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