A service evaluation of the ReSPECT process and its implementation in the community setting in Leeds

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STUDY SUMMARY

Study Design	Mixed method: Survey and interviews	
Research Question/Aim(s)	This is a service evaluation that seeks to understand how, where, when and for whom the ReSPECT process is working in community health services in community settings in Leeds	
Size of Sample	**Planned**	**Achieved**
Survey of health professionals (YAS, LCHT, general practice, hospices)	30-40	113 (from all services)
Interviews with health professionals (YAS, LCHT, general practice, hospices)	6-10	15 (from all services)
Interviews with patients and carers (where patient has a ReSPECT plan)	6-10 individuals	6 patients (St Gemma's) 7 carers (family members)
Study Period	1st May 2025 to 31st October 2025	11th July 2025 to 24th April 2026

EXECUTIVE SUMMARY

Background and Aim

Advance care planning (ACP) enables individuals to express preferences for future care, particularly when they may no longer be able to make or communicate decisions. The ReSPECT (Recommended Summary Plan for Emergency Care and Treatment) process supports these discussions by documenting personalised clinical recommendations for use in emergencies or clinical uncertainty. In Leeds, efforts have been made to align ReSPECT with national standards and improve digital documentation and sharing across care settings.

This service evaluation examined how the ReSPECT process is implemented across primary care and community services in Leeds. It aimed to identify what works well, for whom, and where improvements are needed, incorporating the perspectives of patients, carers, and health professionals. Community services with clinicians that can complete ReSPECT plans includes Leeds Community Healthcare NHS Trust and both Leeds hospices. The clinical system used by these services is SystmOne. Across Primary Care, SystmOne is the main clinical system used, with a minority (less than 20%) using EMIS.

ReSPECT was first implemented in community settings in 2020, with an agreement that ReSPECT plans could be completed by doctors and senior clinicians in appropriate roles to have ReSPECT discussions. Apart from doctors, senior clinicians must attend Planning Ahead training for ReSPECT Signatories and in addition should attend advanced communication skills training, both of which are delivered by the Leeds hospices. This built upon the previous, well embedded development pathway, for senior clinicians able to make DNACPR recommendations.

Methods

A mixed-methods design was used, comprising:

i. A survey of 113 health professionals across community, primary care, ambulance, and hospice services
ii. In-depth interviews with a subgroup of health professionals
iii. Interviews with six patients and their carers recruited from hospice inpatient settings

Quantitative data were analysed descriptively, while qualitative data were analysed using framework and content analysis. Findings were synthesised across all data sources.

Key Findings

1. Strong support but uneven access and use
Health professionals strongly supported ReSPECT, particularly for patients nearing the end of life, but also recognised its relevance earlier in the disease trajectory and when initiated by patients. However, some groups may be underrepresented in practice, including individuals with frailty, long-term conditions without a palliative diagnosis, and those facing inequalities (e.g. language barriers or lack of advocacy).

2. Importance of relationships and communication
ReSPECT was most effective when delivered as part of relationship-based care. Only hospice patients and their carers (family members) were interviewed, who experienced it primarily as a conversation rather than a form, with trust in clinicians - particularly community and hospice nurse specialists - being central. Health professionals similarly emphasised the importance of timing, continuity, and communication skills.
Barriers included:

- Patient and family readiness
- Misunderstanding of ReSPECT (e.g. confusion with DNACPR)
- Time pressures and workload
- Cultural and communication challenges

Patients and carers also described variable understanding of ReSPECT and how it would be used in practice. While many valued the conversations they had with clinicians, some were unclear about who could access the plan, how it would be used across services, and whether anything was expected of them following completion. Survey findings similarly showed variable awareness, availability, and use of patient information materials among health professionals. Collectively, these findings suggest a need for more consistent and accessible information for patients and families about the purpose, use, and ongoing nature of ReSPECT.

3. Documentation quality determines effectiveness

The quality of ReSPECT documentation varied widely. However, health professionals generally perceived the main sections of the form to be completed with moderate to high levels of clarity. Clinical recommendations for care and treatment escalation were viewed particularly positively, while the "what matters to the patient" section was rated somewhat less clearly documented, suggesting room for improvement but not widespread absence of information. Clinical recommendations relating to CPR were rated most clearly documented.
Positive findings included:

- CPR recommendations were usually documented clearly and consistently.
- Key clinical information, treatment escalation recommendations, and patient priorities were generally perceived to be documented with moderate to high levels of clarity.
- Well-completed ReSPECT forms were highly valued by health professionals and were seen to support decision-making, communication, and best interest discussions.
- Detailed documentation of patient wishes, treatment preferences, and escalation plans was considered particularly helpful in urgent situations.

However:

- DNACPR-only or incomplete forms were often unhelpful
- Vague or outdated documentation reduced confidence
- Plans that were not reviewed became disconnected from current care

These findings suggest that ReSPECT can be a highly effective tool when plans are completed comprehensively, kept up to date, and used to capture the broader context of patient preferences rather than CPR recommendations alone.

4. Respect used differently across settings and services

A clear distinction emerged in how ReSPECT was used across services:

- Ambulance and urgent care teams used it as a time-critical decision tool
- General practice and community teams used it for anticipatory, ongoing care planning

Hospice services used it as an embedded and iterative process, where plans were routinely reviewed, updated, and used to support ongoing conversations about individual wishes, goals of care, and appropriate interventions.While all groups valued ReSPECT, its meaning and use were shaped by clinical context, urgency, and continuity of care.

5. Major system and sharing challenges

System and sharing challenges were a major theme. Limited interoperability between IT systems and restricted access to electronic ReSPECT records for some services, particularly ambulance teams, hindered effective information sharing. Key impacts included:

- Delays in accessing patient wishes during urgent and emergency situations.
- Duplication of documentation and repeated conversations across services.
- Increased uncertainty about whether the most current ReSPECT plan was available at the point of care.

Although ReSPECT plans are completed electronically, some services rely on patient-held paper copies because they cannot access the electronic records. Ambulance clinicians therefore depend on patients, families, or care

home staff being able to locate and provide the printed paper copy during emergencies. Both professionals and patients valued wider digital access to improve continuity, accessibility, and confidence in the information available.

6. Critical role of carers

Carers played a central but often unrecognised role in making ReSPECT work in practice. They frequently:

- Located and presented their paper copy in emergencies
- Communicated patient wishes when capacity was lacking
- Supported continuity across services

While this supported continuity of care, it also placed emotional and practical burden on families, particularly when processes were rushed, poorly explained, or when carers were expected to understand and act on ReSPECT plans without receiving adequate information or support.

7. Training and confidence gaps

Among the 53 respondents for whom ReSPECT training was relevant and who had completed training, most felt at least partly prepared to discuss ReSPECT with patients, document plans, and interpret information recorded within plans. However, comments indicated variation in the quality and format of training received. Key issues included:

- Training often focused on form completion and system use rather than communication skills and complex conversations, although advanced communication skills training is also available and includes ReSPECT conversations.
- Many respondents reported that confidence was developed through clinical experience, peer support, shadowing, and multidisciplinary learning rather than training alone.
- Access to ongoing support was variable, with some respondents reporting limited opportunities for refresher training or advice in challenging situations.

Overall, respondents highlighted the value of more consistent, practical, and communication-focused training, supported by refresher sessions and opportunities for continued learning in practice.

8. ReSPECT as a "living" plan

There was broad recognition among patients, carers, and health professionals that ReSPECT should be treated as a living plan that can be revisited as health status, care needs, wishes, and preferences change.
However, there was limited clarity regarding when review should occur and who should initiate it.

- Patients and carers generally expected clinicians to initiate review
- Professionals cited time and system constraints as barriers
- Review was considered particularly important following changes in health status, transfers between care settings, hospital admissions or discharge, and changes in treatment goals

Where plans were not revisited following significant changes in circumstances, they were more likely to become outdated and less reflective of current wishes and preferences.

Conclusion

Overall, ReSPECT was viewed positively by patients, carers, and health professionals and was seen as an important tool for supporting person-centred care. When supported by strong relationships, high-quality documentation, and accessible information, it helped ensure that care reflected patient wishes and preferences. While opportunities exist to improve system interoperability, documentation, and review processes, the findings indicate that ReSPECT provides a strong foundation for advance care planning in Leeds and is well placed to support future improvements in coordinated care. Findings also highlight the importance of clear information for patients and carers and of ensuring ReSPECT plans are revisited following significant changes in circumstances so that they continue to reflect current wishes, preferences, and clinical needs.

Recommendations

Improve access to ReSPECT information across services (in progress)

- Continue citywide work to improve interoperability between systems and access to a shared ReSPECT plan to ensure clinicians can access the most current ReSPECT plan when needed.
- Strengthen ReSPECT training

Review training provision across professional groups, including GPs and medical staff.

- Increase focus on communication skills, personalised documentation, scenario-based learning and recognising when plans should be initiated, and reviewed following changes in health status, care needs, or care setting.
- Emphasise the importance of patient and carer information in communicating key messages about the purpose of ReSPECT
- Introduce refresher ReSPECT training opportunities, focussed on experiential learning.

Update patient information materials to better reflect the Leeds context and explain how ReSPECT is used in practice.

- Support clinicians to provide consistent verbal explanations and ensure information is accessible to people with different communication, language, and support needs.

Improve understanding of equity and access

- Explore which patient groups may be underrepresented in ReSPECT discussions and identify barriers to access.
- Use this information to develop targeted approaches for groups such as people with frailty, dementia, long-term conditions, care home residents, and those facing language or advocacy barriers.

BACKGROUND

Advance care planning (ACP) involves discussions between patients and care providers about future care preferences and priorities. (NHS England, 2022b) Individuals with long-term conditions or complex needs nearing the end of life should be offered the opportunity to create an ACP by their healthcare provider. (National Palliative End of Life Care Partnership, 2021) ACPs can guide care when patients are unable to make or communicate decisions.

Advance care plans can include several components under the Mental Capacity Act (MCA): (*Mental Capacity Act 2005, c. 9.*, Accessed: 20 November 2024)

- Advance Statements are non-legally binding statements about personal preferences for health or wellbeing.
- Advance Decisions to Refuse Treatment (ADRT): legally binding refusals of specific medical treatments, also known as living wills.
- Lasting Power of Attorney (LPA): legal authority granted to one or more individuals to make decisions about health, welfare, property, and finances.

The Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) process, increasingly adopted across the UK, (Resuscitation Council UK, 2023) provides personalised clinical care recommendations for emergencies or situations where the person cannot make or express decisions. These recommendations are shaped in advance through discussions between the individual, their family, and healthcare professionals to balance personal values with realistic care options. (5)

Digital approaches to documenting and sharing advance care planning information, including Electronic Palliative Care Coordination Systems (EPaCCS) and ReSPECT, can support communication and coordination across care settings. While EPaCCS is primarily focused on people with recognised palliative and end-of-life care needs, ReSPECT has a broader scope and can be used with a wider range of patients to record emergency care and treatment recommendations as well as individual wishes and preferences.(Allsop et al., 2022; Cevik et al., 2024; NHS England, 2022a; Petrova et al., 2018; Pocock et al., 2020) Digital standards for documentation of information have been developed by the Professional Records Standards Body, to ensure this information can be accessed by the right people, in the right place, at the right time. (The Professional Record Standards Body, 2022a, 2022b). EPaCCS was well embedded across community services in Leeds prior to the implementation of ReSPECT, with templates created within SystmOne and EMIS clinical systems.

Previous work by the research team found there are challenges in sharing information across settings, particularly care homes and ambulance teams.(Birtwistle et al., 2022) This information is more likely to be available for patients with cancer diagnoses than for those with other conditions.(Birtwistle et al., 2022) There is a lack of clarity on which patients should be offered opportunities to record their wishes, preferences, and care recommendations.(Bradshaw, Allsop, et al., 2024) Health professionals highlight that digital systems fail to meet the diverse needs of various care providers as well as patients.(Bradshaw, Birtwistle, et al., 2024) Ambulance teams need quick access to accurate information about patients they do not know, while palliative care teams, GPs, and care homes require systems for documenting, updating, and sharing detailed care plans.(Allsop et al., 2025) Patients and carers show varying levels of engagement with advance care planning, with some being proactive and others unaware or uninterested.(Birtwistle et al., 2024; Birtwistle et al., 2026) There is uncertainty about which professional should lead these discussions, with GPs considered less ideal by some, due to difficulties in arranging in-person consultations.(Birtwistle et al., 2024) Other concerns include

poor system interoperability, inaccuracies, unclear data storage, and restricted access.(Birtwistle et al., 2024; Birtwistle et al., 2022)

Rationale

In Leeds, recent efforts have focused on aligning clinical systems templates and tools (including EPaCCS, ReSPECT and *What Matters to Me*) in the Planning Ahead Template with the national information standard for end-of-life care set by the Professional Records Standards Body. (Leeds Palliative Care Network, 2024) Nationally the Resus Council UK oversees the implementation of ReSPECT and as an earlier adopter Leeds had representation on the city wide ReSPECT implementation Group.

A recent audit of the ReSPECT process in secondary care focused mainly on the completeness of advance care planning data in electronic records. (Anik et al., 2024) Previous audits have not covered community or primary care settings or included perspectives of patients and health professionals. This service evaluation explored the ReSPECT process comprehensively, from identification to discussion, documentation, access, review, and action, incorporating patient, caregiver, and health professional insights in Leeds. A separate project will analyse ReSPECT data recorded by primary and community services to evaluate its use.

This evaluation examined how the ReSPECT process is implemented in community and primary care services in Leeds and assessed how well it meet its aims and objectives. Although this evaluation was tailored to the local context and did not aim to produce generalisable data, it provided insights into what worked, for whom, and which areas required improvement within Leeds.

Aim

To identify and explore good practice and areas for improvement in the ReSPECT process with adults with advanced illness in Leeds.

Objectives

- To understand the patient and carer experience, priorities, and preferences regarding ReSPECT processes
- To understand the experience and needs of health professionals working in primary care and the community conducting ReSPECT processes
- To identify which aspects of the ReSPECT process are working well and what could be improved.

The aims of ReSPECT are to improve discussions and documentation of care preferences, particularly for those nearing the end of life, ensuring these preferences are shared with services involved in a patient's future care.

This evaluation aimed to identify good practices within the ReSPECT process and recommend improvements to guide future training and development in primary care and community settings in Leeds. It may strengthen the confidence of patients and health professionals in the ReSPECT process, increasing the number of patients recording their wishes. Additionally, it may help reduce inequalities, prevent inappropriate admissions, and support care aligned with individual values and preferences, enabling more people to live and die according to their wishes.

METHODS

Study design

The study comprised three studies using mixed methods to evaluate the ReSPECT process:

- Survey of health professionals in primary care and community services
- In-depth interviews with a subgroup of health professionals (online or face to face)
- Interviews with patients and carers (face to face)

Study setting

The evaluation was conducted across primary care and community services in Leeds, involving multiple organisations including hospices, GP practices, community nursing teams, ambulance services, and care homes.

Patients were identified within their usual care team at St Gemma's Hospice. Health professionals were recruited across participating organisations via established communication channels. WP3 participants were drawn from WP2 survey respondents.

Data collection

- ***Health professional survey:*** An online survey was developed using JISC Online Surveys©. It included an information sheet, consent process, mainly closed questions, and optional free-text responses. Questions were informed by a conceptual model of digital systems supporting care preferences. Participants could also express interest in follow-up interviews.
- ***Health professional interviews:*** Semi-structured interviews were conducted with a purposive subsample of survey respondents. The topic guide was informed by themes and issues emerging from the survey and focused on good practice, challenges, training needs, and the role of digital systems in supporting communication and continuity of care. Interviews were conducted by online or face to face in the workplace.
- ***Patient and carer interviews:*** Patients and carers were interviewed in the hospice setting. Interviews explored experiences of ReSPECT discussions and views on digital documentation and sharing of preferences.

Data analysis

Quantitative survey data were analysed using descriptive statistics. Qualitative data from interviews and free-text survey responses were analysed using framework analysis and content analysis. Framework analysis followed a structured approach commonly used in applied health research, including coding, charting, and interpretation of themes.

Interview data were transcribed, de-identified, and coded by the researcher. Survey data were analysed and tables and charts produced using Excel and SPSS, Sankey diagrams were created using Sankeymatic.com. Findings from all three studies were synthesised for reporting.

Data management

All data were stored securely on the University of Leeds OneDrive and were accessible only to the research team. Audio recordings were collected using encrypted devices. Interview data will be retained for ten years, while survey data will be retained for five years, before secure destruction.

Sample and Recruitment
Inclusion and exclusion criteria

Participants included patients, carers, and health professionals meeting specific criteria. Health professionals were eligible if they worked in primary care or community services in Leeds and discussed ReSPECT plans with patients as part of their role.

Exclusion criteria mirrored these requirements. Patients and carers were excluded if they were under 18, if the ReSPECT process had not been completed, or if they lacked capacity (for patients and carers themselves). Health professionals were excluded if they worked outside Leeds primary care or community services, or if discussing ReSPECT plans was not part of their role. Patients were adults with a life-limiting or terminal condition who had completed the ReSPECT process and had capacity to consent. Carers were adults supporting someone who had recently completed the ReSPECT process and had a life-limiting or terminal condition; carers themselves were required to have capacity, while the person they cared for may or may not have had capacity

Sampling approach

Sampling was appropriate for a service evaluation and aimed to include a wide range of services using ReSPECT. A purposive sampling approach was applied across the three studies. Health professionals participating in the survey were selected based on their involvement in ReSPECT discussions. Survey respondents were also invited to take part in in-depth interviews, with selection aiming to reflect a range of geographical areas and professional roles. Patients and carers were selected based on having a chronic progressive condition and recent experience of the ReSPECT process, with efforts made to achieve diversity in socioeconomic and ethnic backgrounds.

Recruitment and consent

Health professionals were recruited via email distribution lists, internal communications, newsletters, and relevant websites. Potential interview participants could also self-select through the survey. Patients and carers were identified and approached by health professionals within their usual care teams, including St Gemma's Hospice, Wheatfields Hospice, and Leeds Community Healthcare Trust teams. Informed consent was obtained from all participants prior to any study activities. Participants were provided with approved information about the evaluation and had opportunities to ask questions. For patients and carers, capacity to consent was assessed during interviews, including their ability to understand the evaluation, what participation involved, the voluntary nature of participation, and their ability to retain information, make an independent decision, and do so without coercion at the time. Capacity among health professionals was presumed on the basis of being fit for work; if concerns arose, interviews would be paused and rearranged if appropriate.

RESULTS

Health professional survey

Characteristics of respondents (Questions 1-6; 30-32)

A total of 113 health professionals submitted responses to the survey. Of these, 111 used ReSPECT plans in provision of patient care and two in the training of staff only.

Characteristics of respondents are shown in Table 1. The sample of 113 health professionals was diverse with regard to their role, with the largest groups being senior nurses (26.5%), paramedics (23.9%), and general practitioners (16.8%). Most participants were White (88.5%) and worked across a range of organisations, particularly the Yorkshire Ambulance Service (35.4%) and Leeds Community Healthcare NHS Trust (26.5%), with care commonly delivered in patients' homes as well as other settings.

Participants reported working with a wide range of populations, including people in deprived areas (66.1% frequently) and other underserved groups such as those experiencing homelessness or seeking asylum. Most respondents had substantial experience with ReSPECT, with over 90% having used it for more than two years, and reported frequent use, particularly for viewing (86.7%) and updating (72.0%) ReSPECT plans, although fewer were regularly involved in training others (33.3%).

Table 1: Characteristics of respondents to the survey

Characteristic	**N**	**%**
Role (n= 113)		
Nurse (Senior)	30	26.5
Paramedic	27	23.9
General practitioner	19	16.8
Ambulance Practitioner	13	11.5
Palliative care CNS	11	9.7
Advanced clinical practitioner	4	3.5
Palliative care consultant	3	2.7
Nurse (Band 5)	1	0.9
Other/didn't state	5	4.4
Ethnic group (n=112)		
White	100	88.5
Mixed or multiple ethnic groups	7	6.2
Asian or Asian British	3	2.7
Black, Black British, Caribbean or African	1	0.9
Other ethnic group	1	0.9
Employing organisation*		
Yorkshire Ambulance Service	40	35.4
Leeds Community Health NHS Trust	30	26.5
Hospice	17	15.0
GP Practice	14	12.4
PCN	4	3.5
Care home	3	2.7
Care settings*		
Patients home	77	68.1
Care home	48	42.5

Hospice outpatient	20	17.7
Hospice inpatient	11	9.7
Other community setting *(general practice, health centre, any emergency)*	34	30
Patients that health professionals work with**	N	%
People with a learning disability (*n=112*)		
Frequently	25	22.3
Sometimes	85	75.9
Prisoners (*n=111*)		
Frequently	17	15.3
Sometimes	40	36.0
People who are homeless (*n=111*)		
Frequently	24	21.6
Sometimes	55	49.5
Asylum seekers (*n=112*)		
Frequently	22	19.6
Sometimes	53	47.3
People living in deprived areas (*n=112*)		
Frequently	74	66.1
Sometimes	32	28.6
Length of time using ReSPECT: ***		
Recording or updating ReSPECT plans (n=75)		
More than 2 years	68	90.7
1-2 years	4	5.3
Less than 1 year	3	4.0
Viewing ReSPECT plans to inform care (n=113)		
More than 2 years	107	94.7
1-2 years	5	4.4
Less than 1 year	1	0.9
Training staff in the ReSPECT process (n=42)		
More than 2 years	33	78.6
1-2 years	6	14.3
Less than 1 year	3	7.1
How often - use of ReSPECT: ***		
Recording or updating ReSPECT plans (n=75)		
Frequently	54	72.0
Sometimes	20	26.7
Never	1	1.3
Viewing ReSPECT plans to inform care (n=113)		
Frequently	98	86.7
Sometimes	15	13.3
Training staff in the ReSPECT process (n=42)		
Frequently	14	33.3
Sometimes	28	66.7

Notes

** Respondents may be employed by more than one organisation -they may also work within more than one care setting*

*** Percentages of respondents who answered – discounting missing values*

****Percentages of respondents who to whom this applies*

Health professional views on when ReSPECT is appropriate (Questions 7-8)

Figure 1 shows that health professionals perceived the ReSPECT process as most appropriate for patients nearing the end of life, with the majority rating it as "always" appropriate in the last weeks and months of life, with 92.0% rating it as "always" appropriate in the last weeks of life and 83.2% for those in the last months. There was still strong support for its use earlier in the disease trajectory, with around half to two-thirds rating it as "always" appropriate for patients with longer prognoses, complex conditions, or those at risk of sudden deterioration.

Notably, 71.7% of respondents felt ReSPECT was always appropriate when patients expressed a wish to engage, regardless of health status, indicating broad support for patient-led initiation of conversations. Overall, responses suggest strong endorsement of ReSPECT across a range of clinical situations, although perceived appropriateness was highest in more advanced stages of illness.

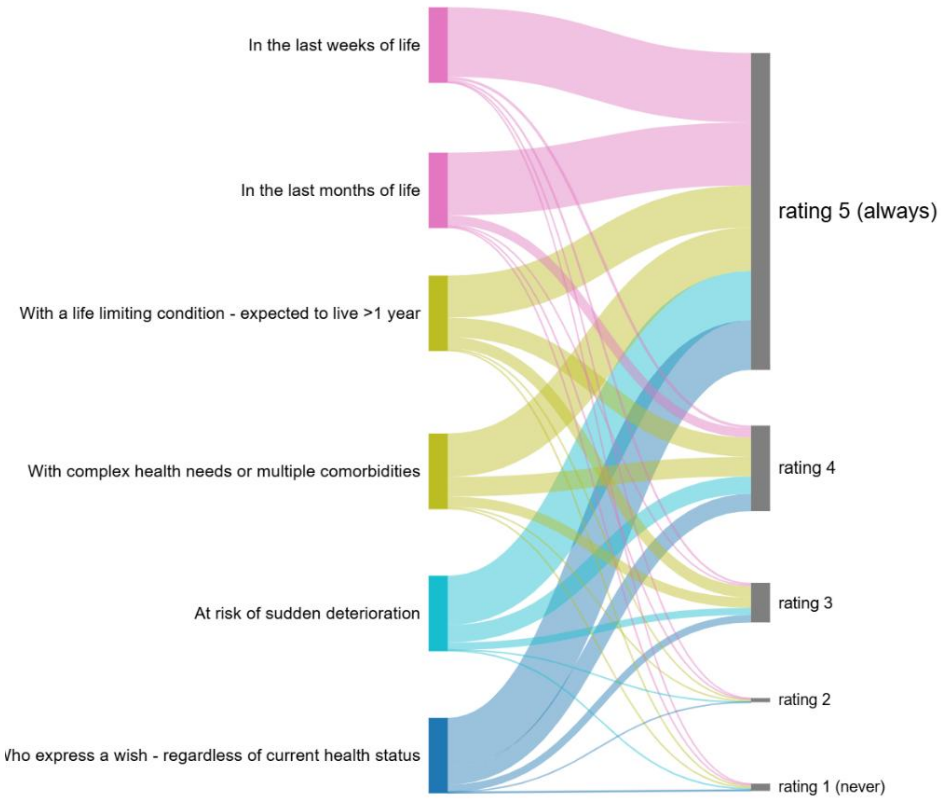

Figure 1: Which patients are appropriate for ReSPECT discussions

Rating from 1-5: where 1 = never and 5 = always

When asked if other patient groups could benefit or if any were missing out in Leeds, staff identified a broad range of individuals who may benefit from a ReSPECT plan beyond those currently targeted. These included patients following hospital admission or clinical deterioration, those living in care settings, and individuals with increasing frailty, multiple long-term conditions, or progressive illnesses such as dementia, COPD, and heart failure. Participants also highlighted patients with cognitive or communication difficulties, those who frequently use healthcare services, and individuals who express a wish to discuss their care preferences as important groups for consideration.

At the same time, respondents consistently suggested that some populations may be underrepresented in current practice. These included frail patients without a recognised palliative diagnosis, care home residents, and patients with chronic conditions such as dementia, COPD, and heart failure. Concerns were also raised

about potential inequalities, particularly for individuals with language barriers, those without an advocate, patients not well known to services, and younger people with complex conditions.

Awareness and use of ReSPECT patient information materials (Question 9)

Around two-thirds of respondents (68.1%) reported being aware of patient information materials for ReSPECT, although nearly one-third were not (Table 2). Among those who were aware, most (66.2%) indicated that information was readily available to share with patients.

Of those with access to materials, only 62.7% reported that they routinely offered this information to patients, while over one-third (37.3%) did not.

Table 2: Awareness and use of ReSPECT patient information

	Yes N (%)	No N (%)	Not applicable to my role N (%)
Are you aware of ReSPECT patient information that can be offered to patients and families? (n=113)	77 (68.1)	36 (31.9)	
Is patient information readily available for you to share with patients? (n=77)	51 (66.2)	24 (31.2)	2 (2.6)
Do you offer this information to patients? (n=51)	32 (62.7)	19 (37.3)	

Comments indicated several reasons why printed ReSPECT information was not routinely offered. Many staff felt that additional written information was unnecessary, as patients were satisfied with verbal explanations or did not require further detail. Others reported that sharing written materials was not yet embedded into routine practice or was not frequently considered, particularly when they had limited exposure to relevant patients.

Practical barriers were also highlighted, including limited availability of leaflets and difficulty accessing them in clinical settings. In some cases, the clinical context restricted opportunities to provide written information, particularly when patients were seen late in the course of illness. Overall, staff described using printed information selectively, most often when conversations were challenging or when patients or families needed additional support to understand or engage.

Barriers to ReSPECT conversations (Question 10)

Table 3 shows that respondents identified a wide range of barriers to ReSPECT discussions. These most commonly related to patient and family factors. Patients were often described as not ready to engage due to fear, distress, or discomfort discussing death, while families could also be reluctant, disagree, or override patient wishes. Misunderstanding of the ReSPECT process was frequently reported, including confusion with DNACPR recommendations and unrealistic expectations about treatment outcomes.

Practical and systemic challenges were also prominent, including time pressures, workload constraints, and difficulties related to capacity, communication, and access to information. Additional barriers included uncertainty about professional roles, lack of confidence in holding sensitive conversations, and challenges linked to timing, continuity of care, and cultural or belief-based factors.

Table 3: Barriers to ReSPECT conversations

Category	Examples
Patient readiness, fear, or reluctance	- Patients not ready to discuss - Fear, worry, or emotional distress - Death seen as taboo - Denial as coping mechanism - Patients uncomfortable discussing resuscitation or future decline
Family reluctance, disagreement, or conflict	- Families not ready even when patient is - Conflicting family opinions - Family resistance or refusal - Family overriding patient wishes - Emotional burden on relatives / LPAs
Misunderstanding or misperception of ReSPECT	- ReSPECT assumed to mean DNACPR only - Belief that it means stopping treatment or "giving up" - Confusion about ceilings of care - Unrealistic expectations of CPR outcomes - Negative perceptions linked to COVID-19 DNACPR controversies - Patients/families unaware a ReSPECT already exists
Time constraints & workload pressures	- Insufficient time overall - 10-minute consultations - Emergency or acute settings - Difficulty arranging family involvement - Need for multiple visits to complete discussions properly
Capacity, cognition, & communication barriers	- Dementia, delirium, stroke - Fluctuating or absent capacity - Patients unable to respond when seen - Hard of hearing - Language barriers - Low health literacy
Systems, documentation, & information quality	- Forms poorly or partially completed - DNACPR section only completed - Inadequate information for best-interest decisions - Forms completed without patient awareness - Poor access to records / unlinked IT systems - Variable quality of care home notes
Role boundaries, confidence, & professional uncertainty	- "Not my role" view - responsibility passed to HP familiar with the patient - Lack of confidence discussing prognosis - Discomfort with difficult conversations - Worry about damaging therapeutic relationships - Prognostic uncertainty (e.g. heart failure, ICDs)
Timing & clinical context	- Seen in emergency or end-of-life situations - Patients in last hours/days of life - Inappropriate timing during task-based care - Discharge from hospital with limited prior discussion
Cultural, religious, & belief-based factors	- Religious objections - Cultural reluctance to discuss death - Family beliefs around decision-making - Minority community distrust of healthcare services
Continuity of care & relationship limitations	- First contact with patient - Lack of established rapport - Inconsistent information between professionals - Previous poor discussions causing resistance

Key Enablers of Effective ReSPECT Discussions (Question 11)

Participants identified multiple factors that supported effective ReSPECT discussions (Table 4). Patient readiness and willingness to engage were central, particularly where individuals understood the process or wished to document their preferences. Having sufficient time and flexibility, including the opportunity for multiple conversations, was also important.

Strong relationships, continuity of care, and trust between patients, families, and clinicians facilitated more meaningful discussions, alongside appropriate timing and a supportive setting. High-quality, patient-centred communication and appropriate family involvement further enhanced engagement.

Professional confidence, knowledge, and training were key enablers, supported by clear information and preparation for both patients and clinicians. Finally, well-completed documentation and a focus on individual values helped ensure that plans accurately reflected patient preferences.

Table 4: Factors that contribute to successful ReSPECT conversations

Patient readiness, willingness & experience	-	Patient readiness to engage
	-	Patients knowing what they do or do not want
	-	Patient awareness and understanding of the ReSPECT/ACP process
	-	Patients wanting wishes documented
	-	Patients wishing to keep plans simple (e.g. DNAR only)
	-	Patients appreciating that there is a formal process to record wishes
Time, pace & flexibility	-	Adequate time for discussion
	-	Allowing patients time to think between conversations
	-	Not rushing conversations or forcing them into a single visit
	-	Understanding that readiness may develop over multiple visits
Relationship, rapport & trust	-	Prior rapport rather than first-meeting discussions
	-	Continuity with the same clinician
	-	Trusting relationship with patient
	-	Open and supportive relationships with families
Timing, setting & environment	-	Right time and right place
	-	Timing aligned with patient readiness
	-	Discussions initiated or welcomed by the patient
	-	Quiet, calm environment
	-	Presence of the right people (e.g. family, carers)
Communication quality & approach	-	Openness, honesty, and calmness
	-	High-quality communication skills
	-	Patient-focused conversations
	-	Shared understanding of the current situation
	-	Clear explanation of likely illness progression
	-	Respecting that patients may choose different options
	-	Clear discussion of best-interest planning if deterioration occurs
Family involvement & understanding	-	Family involvement when patient wishes it
	-	Educating families about illness progression
	-	Well-informed families
	-	Shared understanding between patient, family, and clinicians
	-	All are aware of patient wishes before emergencies
Professional confidence, knowledge, & training	-	Confidence in discussing sensitive topics
	-	Up-to-date understanding of illness and prognosis
	-	Knowledge of ReSPECT and ACP processes
	-	Understanding the value of the document for clinicians, patients, and relatives
	-	Advanced communication skills training (e.g. specialist training)

Information provision & preparation	-	Preparation before discussion
	-	Clear explanation of why planning is appropriate, even when patient appears well
	-	Provision of advanced care planning documents and leaflets
	-	Written information to support reflection and understanding
	-	Signposting that a ReSPECT conversation is planned
Documentation quality & process	-	Well,-written, fully completed ReSPECT forms
	-	Forms reflecting actual patient wishes
	-	Clinicians investing time to complete forms properly
	-	Patients and families aware the form exists and what it contains
	-	Previous meaningful ReSPECT discussions supporting future conversations
Understanding of Patient Values & Dignity	-	Maintaining an emphasis on dignity
	-	Respecting patient values and beliefs
	-	Documenting wishes clearly for future decision-making

Clarity of ReSPECT documentation across sections of the plan (Question 12)

Figure 2 shows that health professionals generally perceived ReSPECT documentation to be clear, particularly for sections containing clinical information and treatment recommendations. Section 2 (summary of relevant information) and Section 4 (clinical recommendations for care and treatment escalation) received predominantly positive ratings, with most respondents reporting these sections were moderately to very clear. This indicates that the core clinical elements of the ReSPECT plan are typically documented well.

Section 3 (what matters to the patient) was perceived as less clearly documented, with over one-third rating it as only moderately clear and a higher proportion of lower ratings compared to other sections.

In contrast, documentation of clinical recommendations for CPR was rated most clearly, with 71.7% describing it as “extremely clear.” This suggests that more clinically defined or standardised elements of the form are completed more consistently, while more personalised sections - particularly those capturing patient values - may be less clearly documented.

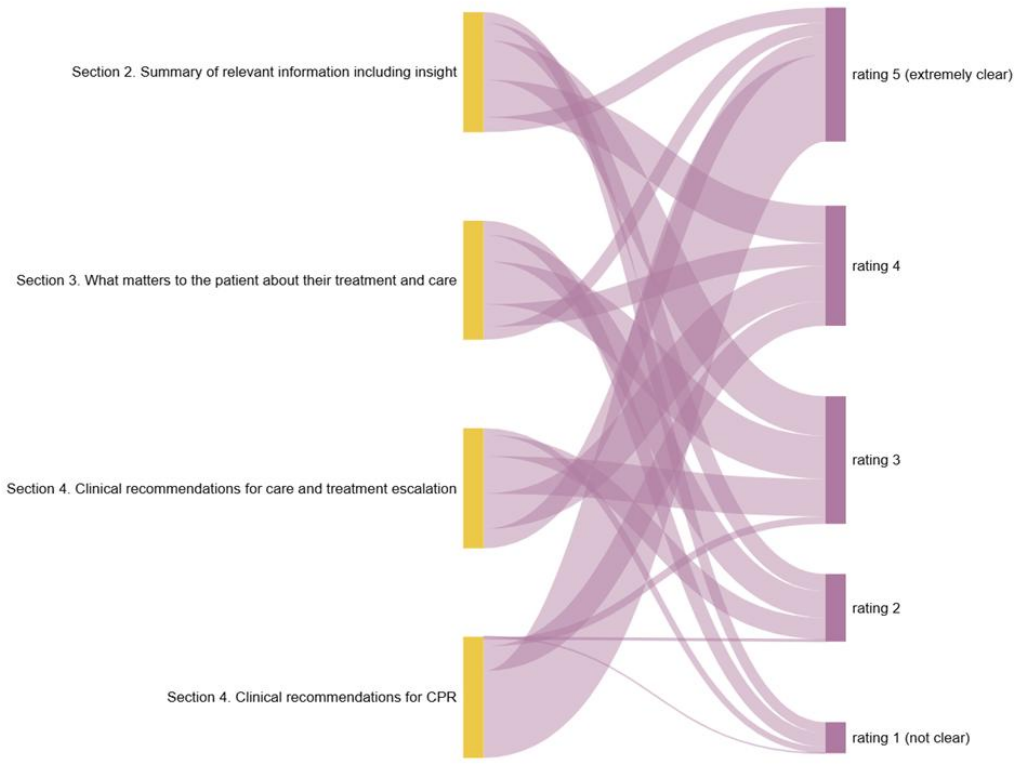

Figure 2: Health professional ratings of documentation clarity within ReSPECT sections

Rating from 1-5 where 1 = never and 5 = always

Perceived usefulness of ReSPECT in informing best interest decisions (Question 13)

Figure 3 illustrates health professionals' views on the usefulness of ReSPECT plans in informing best interest decision-making. Overall, responses indicated that ReSPECT was considered a valuable tool in supporting these decisions, particularly by providing clear documentation of patient preferences and clinical recommendations. This was seen to facilitate shared understanding among professionals and support more consistent, patient-centred decision-making when patients lack capacity or cannot communicate their wishes. There was some variation by professional group. In particular, paramedics and ambulance practitioners showed a more mixed distribution of responses regarding how useful ReSPECT was in informing best interest decisions, compared to other groups who more consistently rated it highly. This spread may reflect differences in clinical context, access to information, and the challenges of making rapid decisions in emergency settings.

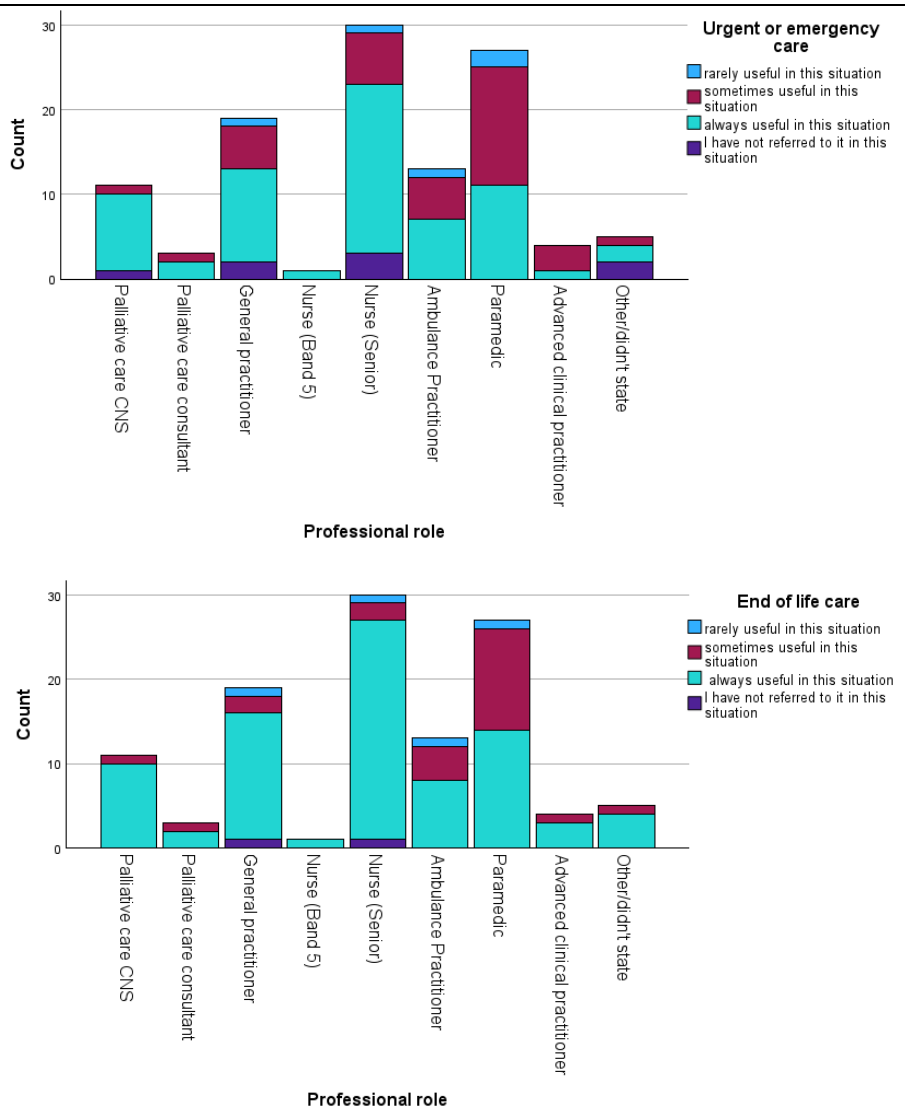

Figure 3: Usefulness in informing best interest decisions

ReSPECT Documentation and Interpretation: Facilitators and Barriers (Question 14)

Table 4 shows that the usefulness of ReSPECT documentation depended on how it was completed, interpreted, and accessed in practice. Clear, detailed, and holistic documentation - reflecting patient wishes, goals of care, and escalation plans - was seen to support effective clinical decision-making, particularly in urgent situations. Documentation was most helpful when it was specific, up to date, clearly linked to patient and family conversations, and easily accessible across care settings.

In contrast, ReSPECT became a barrier when it was treated primarily as a DNACPR tool, with minimal or vague information beyond CPR recommendations. Poorly completed, outdated, or partially filled forms, along with inconsistent documentation across services and limited accessibility, reduced its usefulness in practice. Challenges were also reported where forms did not reflect patient understanding or involve families, or where terminology was unclear or open to interpretation.

Table 4: ReSPECT documentation: factors supporting and limiting effective use

	What helps	What gets in the way
Purpose and use of the respect form	- ReSPECT used as a holistic care-planning document, not just DNACPR - Documentation reflecting broader goals of care, escalation limits, and patient priorities - Clear articulation of what the patient does and does not want	- ReSPECT used solely as a DNACPR replacement - Forms treated as a paperwork exercise - Minimal content beyond CPR status - Reversion to old DNACPR-style practice
Level of detail and specificity	- Detailed, specific free-text entries - Clear examples (e.g. when to attend hospital, what treatments are acceptable) - Explicit guidance for common scenarios (e.g. infections, fractures, trauma) - Clear documentation of preferences around comfort care, home treatment, and hospital avoidance - Clear articulation of what to do if wishes cannot be met	- Vague statements (e.g. “avoid hospital”, “if necessary”, “treat reversible causes”) - Over-use of “unknown” or “undecided” - Ambiguous escalation terminology (e.g. “Level 1/2 care” without explanation) - Abbreviations or medical jargon open to interpretation - Contradictory statements within the same form
Quality and completeness of documentation	- Forms fully completed across all relevant sections - Clear writing - Consistent completion of escalation, priorities, and patient wishes - Regular review and updating - Accurate documentation of LPoA and family involvement	- Forms partially completed (often CPR section only) - Large sections left blank or marked “unknown” - Poor-quality or rushed hospital documentation - Forms completed without patient or family awareness - Out-of-date forms not reviewed after change in condition or setting - Multiple versions with no clarity on which is current
Patient and family involvement	- Documented evidence that conversations took place - Clear reflection of patient’s expressed wishes - Family awareness and understanding of the plan - Documentation of best-interest discussions where capacity is lacking	- Patients unaware they have a ReSPECT form - Families not aware of the form or its contents - Lack of explanation about wishes, preferences, and recommendations recorded - Insight or capacity recorded inaccurately - Forms completed during acute admissions without meaningful discussion

Clinical decision-making utility	- Clear escalation plans supporting decision-making in emergencies - Documentation that prevents unnecessary hospital admissions - Clear guidance for ambulance, urgent care, and community teams - Explicit preferences supporting conveyance vs community management - Clear statement of values (quality of life vs life-prolonging treatment)	- Forms that do not guide real-world decisions - DNACPR stated without rationale or context - Conflicting or illogical plans (e.g. no hospital but for resuscitation) - Lack of guidance for common urgent scenarios - Insufficient information for paramedics or urgent care clinicians
Consistency across care settings	- Community and GP-completed forms described as more comprehensive - Alignment between hospital, GP, community, hospice, and care home documentation - Review of hospital forms before discharge	- Hospital forms containing minimal information - Disjointed systems between acute, community, hospice, and primary care - Reliance on patient-held paper copies - Duplication of conversations and documentation
Accessibility and availability	- ReSPECT forms easily visible and accessible - Forms available to ambulance and urgent care teams - Clear indication that a ReSPECT form exists and where to find it	- Forms not physically available in the home or care setting - Electronic records inaccessible or not interoperable - No single clear place to record or view the plan
Form design and structure	- Clear tick boxes for key decisions (e.g. CPR) - Structured free-text areas that prompt meaningful detail - Sections that support elaboration of "undecided" preferences	- Over-complex or overly long forms - Pictorial scales and prioritisation diagrams rarely completed - "What matters to me" sections perceived as unclear or unhelpful - Excessive written text obscuring key decisions - Lack of clarity on form review section leading to duplicate forms
Interpretation in practice	- Clear alignment between documented wishes and current clinical situation - Recognition that ReSPECT is a working document that can change - Use of ReSPECT as a starting point for further discussion	- Forms that do not match patient's current condition - Outdated documentation not reflecting change in wishes - Over-reliance on poorly completed forms - Interpretation differences between clinicians due to lack of clarity

Access to and use of systems for documentation of ReSPECT plans (Questions 15- 16)

Respondents reported variable access to systems used to create, view, and share ReSPECT plans (Figure 4). SystmOne was the most commonly used system for full access, with over half of respondents able to create, edit, and view plans, whereas access to EMIS was more limited, with most respondents reporting no access. Leeds Care Record (PPM+) and patient-held paper copies of ReSPECT plans were more commonly used for viewing information rather than editing, indicating reliance on read-only or non-digital approaches across some services. A small number of respondents also cited additional systems such as GP Connect and care home records.

Perceptions of how well electronic systems functioned were mixed (Table 5) . While just over half of respondents (54.9%) agreed or strongly agreed that electronic systems worked as intended to benefit patients,

a substantial minority (27.4%) disagreed or strongly disagreed, and 17.7% remained neutral. This suggests variability in system effectiveness, likely reflecting differences in interoperability, accessibility, and user experience across care settings.

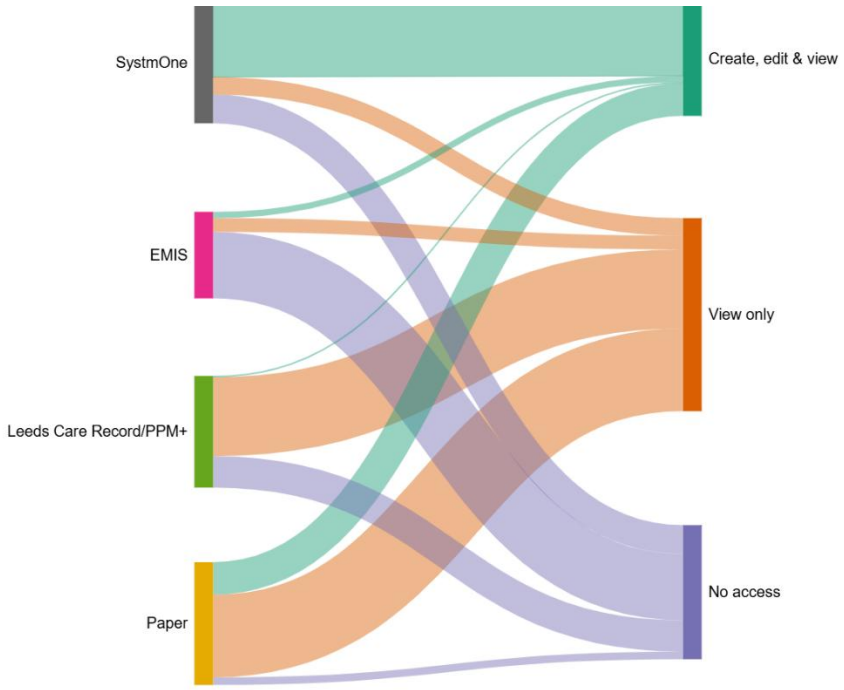

Figure 4: Access to systems for documentation of ReSPECT plans

Table 5: The use of electronic systems to record and share ReSPECT plans functions as intended to benefit patients (n=113)

	Count	%
Strongly agree	27	23.9
Agree	35	31.0
Neither agree nor disagree	20	17.7
Disagree	20	17.7
Strongly disagree	11	9.7

System and practice barriers to facilitators to sharing and using ReSPECT plans across care settings (Questions 18-19)

Responses indicated that challenges to effective sharing of ReSPECT plans occurred at both system and practice levels. At a system level, the most significant challenges related to poor interoperability between IT systems and unequal access to electronic ReSPECT records across services. While plans were completed and stored electronically, some services, particularly ambulance teams, depended on patients, families, or care home staff being able to locate and provide the printed copy of the plan during emergencies. This often resulted in fragmented information, duplication of work, delays in accessing patient wishes, and uncertainty about the most up-to-date plan. Additional challenges included system usability, lack of standardisation across organisations, and uncertainty around governance and data sharing.

At a practice level, barriers included incomplete or outdated documentation, inconsistent review and updating of plans, and communication gaps with patients, families, and between services. Sharing practices varied across

teams, and time pressures and workflow constraints further limited effective use. Family-related challenges and lack of clarity about responsibilities also contributed to inconsistencies in how ReSPECT plans were used in practice.

Use of other advance care planning and emergency care documents (Question 20)
Responses indicated that, alongside ReSPECT, a range of other advance care planning (ACP) and emergency care documents were encountered, although generally infrequently. Older DNACPR forms were still seen but were described as increasingly rare and largely replaced by ReSPECT. Advance Decision to Refuse Treatment (ADRT) documents, advance directives, and living wills were reported only occasionally, suggesting limited uptake. Some staff reported encountering condition-specific or setting-specific plans, such as emergency care plans, seizure or exacerbation plans, and hospital passports, particularly for patients with long-term conditions or in care homes. Advance care plans and documentation linked to Lasting Power of Attorney (LPA) were also noted, although these were not always accessible to healthcare professionals. Responses suggest that while a variety of ACP-related documents exist, their use is inconsistent and less prevalent than ReSPECT, with limited visibility across services and variable availability at the point of care.

Perceived preparedness and support following ReSPECT training (Question 21-22)
Excluding GPs, Yorkshire Ambulance Service staff, and one newly appointed nurse who had not yet completed formal ReSPECT training, 53 respondents were included in the training analysis. Most felt that training had prepared them to undertake key aspects of the ReSPECT process. The majority reported feeling at least partly prepared to discuss ReSPECT with patients (87%), document ReSPECT plans (87%), and interpret information recorded within plans (92%).

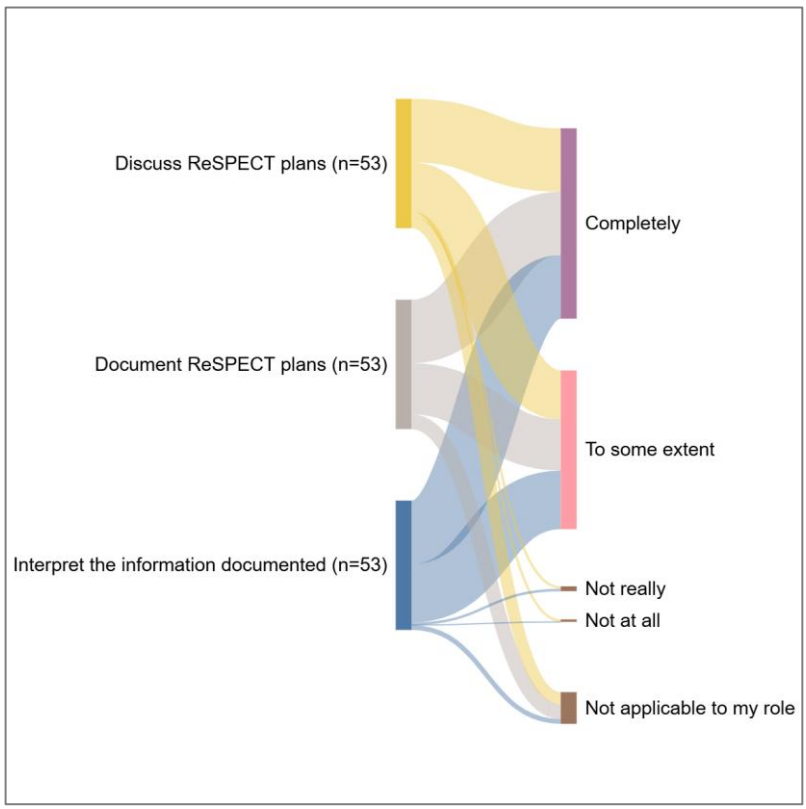

Figure 5: Perceptions of how well training prepared them to discuss, document, and interpret ReSPECT plans.

Access to ongoing support following training was more variable. While 71% reported that they could always access support when needed, a further 25% reported that support was only sometimes available, suggesting that opportunities for ongoing confidence-building and professional development were inconsistent across services.

Feedback on ReSPECT training: gaps, strengths, and ongoing needs (Question 23)
Comments highlighted variability in both the availability and quality of ReSPECT training. Many respondents reported limited or outdated training, often delivered as e-learning and focused on form completion rather than communication skills or broader clinical application. Some noted that ReSPECT was not well integrated into standard education or resuscitation training.
Where training was viewed positively, this was typically linked to interactive, face-to-face sessions, opportunities to practise difficult conversations (e.g. with role-play/actors), and learning through shadowing or multidisciplinary support. Ongoing learning and confidence-building were frequently supported through peer discussion and experience in practice rather than formal training.

Key Additional Insights (Question 24)
The final question invited respondents to provide any additional comments. Much of this feedback reflected issues already identified and reported in earlier sections. However, a number of additional insights were identified that had not been fully captured elsewhere. These included the potential to link ReSPECT information to 999 call systems to support rapid decision-making, and a perceived gap following the loss of EPaCCS as a dedicated coordination system. Respondents also highlighted the administrative burden of manual processes required to share plans across services.
Concerns were raised about the distribution of responsibility, with community clinicians often initiating complex discussions that might be better addressed earlier by specialist teams. Suggestions included the development of dedicated ACP coordination roles and ensuring ReSPECT plans are completed or reviewed prior to hospital discharge.
Finally, respondents identified issues with the design and usability of the ReSPECT form and a lack of confidence among some clinicians. Poor-quality documentation was also noted to contribute to risk-averse decision-making, such as unnecessary hospital conveyance, highlighting the wider impact of documentation quality on patient care.

Summary of survey key findings

- Health professionals expressed strong overall support for the ReSPECT process, particularly for patients approaching the end of life, while also recognising its value earlier in the disease trajectory and when initiated by patient preference. However, respondents identified gaps in access, with some patient groups - such as those with frailty, long-term conditions, or facing inequalities—potentially missing out.

- Implementation in practice was variable. While awareness of patient information materials was moderate, they were not consistently used. Barriers to effective ReSPECT discussions included patient and family readiness, misunderstandings, time pressures, and system constraints. In contrast, effective discussions were supported by patient readiness, continuity of care, strong relationships, good communication, and adequate time.

- Documentation quality was mixed. Clinical elements, particularly CPR recommendations, were generally clear, whereas more personalised sections were less consistently completed. ReSPECT was widely viewed as useful in informing best interest decisions, although perspectives were more variable among paramedics and ambulance staff, reflecting differences in clinical context.

- System and process challenges were a major theme. Limited interoperability and unequal access to electronic ReSPECT records hindered effective sharing, with some services relying on patient-held paper copies at the point of care. This contributed to duplication, delays in accessing patient wishes, and uncertainty about current plans. Effective use depended on accessible, up-to-date documentation that could be shared across care settings.

- Training was generally perceived positively by respondents for whom it was relevant, with most feeling prepared to discuss, document, and interpret ReSPECT plans. However, respondents reported variation in training quality and ongoing support, and highlighted the value of more practical, communication-focused training and refresher opportunities..

- Overall, the findings indicate strong support for ReSPECT but highlight variability in implementation, with key opportunities to improve equity of access, documentation quality, training, and system integration to ensure plans can reliably inform patient care.

Interviews

This evaluation explored experiences of the ReSPECT process across patients, carers, and health professionals working in ambulance services, general practice, community nursing teams, and specialist palliative care. The findings are presented in two main sections: professional perspectives (with sub-sections for each setting), patient and carer perspectives (case summaries) and a synthesis across all these stakeholders.

Health professional interview findings

This section presents findings from interviews with health professionals across ambulance services, general practice, community nursing, and specialist palliative care. The sample included a range of roles and settings involved in delivering and responding to the ReSPECT process, providing insight into how it is used in practice across the care pathway. Table 6 outlines the characteristics of interview participants.

Table 6: Sample of health professionals

HP01	YAS	Paramedic
HP02	YAS	Paramedic
HP03	YAS, GP Practice	Specialist Paramedic Urgent Care
HP04	Hospice	Consultant in Palliative Medicine
HP05	LCHT	Community Respiratory Nurse
HP06	LCHT	Palliative Care Lead
HP07	Hospice	Nurse Consultant
HP08	LCHT	Community Matron
HP09	LCHT	End of Life Care facilitator
HP10	LCHT	Palliative Care Lead
HP11	GP Practice	ANP
HP12	LCHT	Palliative Care Lead
HP13	GP Practice	General Practitioner
HP14	Hospice	Registered Nurse (inpatient)
HP15	GP Practice	General Practitioner

Ambulance Services: ReSPECT as a time-critical safety tool

Ambulance clinicians consistently described ReSPECT as a crucial decision-support tool used in urgent and high-risk situations. Its value lay in enabling rapid decisions about resuscitation, transfer to hospital, and best-interest care.

However, ambulance staff had no role in initiating ReSPECT and, without access to the electronic systems used to record plans, relied almost entirely on patients, families, or care home staff producing a printed copy of the ReSPECT plan at the point of care. Lack of electronic access and fragmented systems meant clinicians often worked with incomplete or absent information. Fragmented digital systems often left clinicians without access to plans patients assumed were visible across services, shifting the burden of managing unmet expectations and clinical risk onto frontline staff at moments of crisis:

> *"I think that if there was an electronic record, they [patients] would expect the NHS as a whole to be able to access that record, but of course we work on really fragmented systems and across really*

strange boundaries that that that don't communicate very effectively. So I think reality versus expectation, they're probably quite different." **HP01 (Ambulance service)**

When ReSPECT was unavailable or poorly completed, ambulance clinicians described greater uncertainty and responsibility in decision-making. As one specialist paramedic noted, forms tended to be either highly detailed or effectively empty, offering little support for nuanced judgement:

"*You very rarely see a middle ground. You either see a ReSPECT form that's very well documented and quite comprehensive, or you just see one that's empty essentially and just used as a do not resuscitate form."* **HP03 (Ambulance service)**

They described the difficulty of balancing treatment benefit against comfort without access to sufficient contextual information. In the absence of richer, shared information, ambulance teams are left to make complex judgements under pressure, reinforcing both clinical risk and moral burden at when clarity is most needed. This challenge is compounded by the fact that ReSPECT is not designed to capture detailed clinical nuance, illness trajectory, or the reasoning behind preferences, leaving frontline staff without the depth of information they would need to confidently interpret wishes in complex situations:

"You want to make the right decision, you know, and you don't, obviously when it's people say palliative care, it doesn't necessarily mean that they are end of life and that we're stopping treatment. And I think that's the problem. But whereas some are on palliative care and then might be nearing the end of life, in which case are we benefiting from aggressive treatment or are we more beneficial for comfort, but the ReSPECT forms don't really detail that, and we don't have access to anything else that does." **HP02, (Ambulance service)**

General Practice: ReSPECT as proactive, relationship-based planning

General practice professionals framed ReSPECT as part of anticipatory, longitudinal care, particularly for people with frailty, progressive illness, or living in care homes. Conversations were described as most effective when embedded within existing relationships and paced over time:

"As part of the enhanced frailty… we run them like annual reviews… and then I always offer them a ReSPECT form… some people will say 'no', some will say 'yes' and then I'll take it from there. … I try and do it as more of a conversation… if it doesn't naturally flow into those conversations, then I tend to not really push them because I sort of think, well, maybe they're not ready for it and that's fine… I'll just leave it." **HP11 (Advanced Nurse Practitioner, General Practice)**

Time constraints were acknowledged as shaping how these discussions could realistically be developed in practice:

"We're all limited by time in any given consultation… so you're building that information as you move forward in the patient journey, given the time that you might have available."
HP15 (General Practice)

Health professionals reported wide variation in ReSPECT quality, noting that forms completed in community settings were often more detailed and person-centred than those completed in hospital. A recurring frustration was that comprehensive community-generated ReSPECT forms were frequently superseded by brief hospital forms based on single encounters:

> *"You can tell the GPs that have interest in housebound, elderly care — they tend to do them properly. But a lot of the ones that come out of hospital are just treated like DNACPR… there's nothing else on there. And if they come out with one from hospital, that one tends to supersede ours because it's more recent."* **HP11 (Advanced Nurse Practitioner, General Practice)**

Some GPs described deliberately adding contextual detail such as illness trajectory and frailty status, to support interpretation by other services, particularly ambulance clinicians:

> *"I try to put as much background information on the front page so the paramedics are aware this patient is under GSF or has a life-limiting illness — that's why the decision is being made."* **HP13 (General Practice – Care Home Lead)**

Health professionals emphasised the importance of early ReSPECT completion before loss of capacity:

> *"That's why it's quite important to do it as first hand when they first come to the care home where they are still able to make their own decision. Then even two or three years later, if they lose capacity, we can still refer back and follow their wishes."* **HP13 (General Practice – Care Home Lead)**

Overall, GPs viewed ReSPECT as a valuable advance care planning tool in principle, but one whose impact is limited in practice by time pressures, variable understanding, and poor cross-sector visibility. As one GP noted, *"it's got the power to be a very good document… but a lot of these systems are working in silos, so, there isn't naturally in one place where it could fit, but that would be where it would serve best if the ReSPECT form could set as a standalone electronic document that is amendable across all of these systems."* (HP15, General Practice)

Community Nursing Teams: ReSPECT as Relationship-Based Work in Fragmented Systems

Across community nursing roles, ReSPECT was described as routine and embedded practice, closely linked to declining health, hospital discharge, and end-of-life care at home or in care homes.

ReSPECT conversations were experienced as emotionally demanding, requiring trust, sensitivity, and confidence in disease trajectories. Nurses reported particular discomfort when expected to lead discussions outside their clinical expertise:

> *"we've had somebody that's had hepatopulmonary syndrome from liver failure on oxygen and she's been really unwell and nobody had done the ReSPECT form … when her oxygen need was going upwards. I was asked to have those discussions with her, so I said to the GP, who knew her better. I don't know what the progression of the illness is going to be. I don't know those sort of things about the disease because I'm respiratory."* **HP05 (Respiratory Nurse)**

Patient-held paper ReSPECT copies were viewed as essential because emergency services could not access electronic records, yet these copies were also described as fragile, easily lost, duplicated, or outdated.

> *"I once went to visit a lady and she must have had about ten copies… one in her handbag, one on the fireplace, one in her husband's car. And you're thinking, which one is the right one?"* **HP06 (Community Nurse, Palliative Care Lead)**

Care homes emerged as a digitally excluded but operationally central setting. Although ReSPECT plans were typically created and stored electronically by healthcare professionals, care homes often relied on printed paper copies because they did not have direct access to NHS clinical systems. As one care home facilitator explained, *"most nursing homes do not have access to SystmOne… they have to have a paper copy"* (HP09).

Although care homes could make effective use of ReSPECT plans where staff continuity was high, reliance on printed copies of electronically recorded plans created vulnerabilities. This became particularly apparent during staffing changes, when agency or unfamiliar staff might have limited knowledge of residents and less confidence in interpreting available documentation. As one participant explained:

> *"When it works well and the staff know the resident, it does work well… but it falls down when the staffing changes or it's agency staff who don't know all the history."* **HP09, (End of Life Care Facilitator, Care Homes)**

Community nurses frequently acted as system navigators, duplicating documentation and revisiting conversations to compensate for fragmented digital infrastructure.

> *"Sometimes I will literally copy the information that a GP has done straight over onto our EPaCC system so that our community services can view that… we can be duplicating work that other people are doing, and that impacts on the patient and the families of having to have these conversations repeatedly."* **HP12 (Community Palliative Care Lead)**

Specialist Palliative Care (Hospice): ReSPECT as Embedded and Iterative Practice

Within hospice settings, ReSPECT was described as fully embedded and routinely considered for most patients, with forms expected at admission and checked for currency rather than treated as a one-off document. As one inpatient nurse explained, "*if they come to the hospice without it, the palliative care ambulance team won't bring somebody without it*" (HP14), while noting that details were often reviewed because "some of them could be a bit out of date" as patients' situations changed.

There was strong rejection of DNACPR-only use, with hospice clinicians valuing ReSPECT for capturing patient understanding, preferences, and the appropriateness of interventions. One palliative care community CNS described DNACPR-only forms as "*the most unhelpful document in the whole of the world*" because they revealed nothing about what patients valued or wanted (**HP07**). ReSPECT was instead used as an iterative process, where clinicians "*build a picture up over time*" of a patient's wishes, preferences, and appropriate care recommendations, rather than treating it as a one-off exercise.

Despite this, hospice staff highlighted persistent system failures, including poor cross-sector visibility and the risks of multiple versions. As community CNS, HP07 noted, "*some people have four and five ReSPECT documents because they've been done everywhere with different services*," creating uncertainty about which document should guide care.

Nevertheless, hospice professionals viewed ReSPECT as ethically aligned with palliative care values, supporting dignity, autonomy, and appropriate decision-making. As one palliative care consultant reflected, *"Despite the things we've talked about, some of the shortcomings, it's still a much better process than a DNACPR form,"* because it enables discussion of "*what they would or wouldn't want, but also what may or may not be appropriate for them*" (HP04).

Health professional perspectives

Table 7 summarises key qualitative findings on how ReSPECT is experienced and used across different clinical settings. Overall, there was a clear distinction between its use as a time-critical decision-making tool in emergency contexts and as part of ongoing, anticipatory care planning in community and primary care. The

usefulness of ReSPECT was strongly influenced by documentation quality, with detailed, patient-centred entries supporting decision-making, while limited or DNACPR-focused forms reduced its value.

Across all settings, fragmented systems and poor interoperability created barriers to accessing and sharing plans, leading to duplication, workarounds, and continued reliance on patient-held paper copies where electronic access was unavailable. Despite these challenges, ReSPECT was widely seen as aligning with person-centred care principles, with concerns focused on implementation rather than the concept itself.

Table 7: How ReSPECT is used and experienced across clinical contexts

Key finding	Summary
ReSPECT as crisis tool versus planning process	A clear distinction emerged between services encountering ReSPECT primarily at moments of crisis and those using it for anticipatory planning. Ambulance clinicians experienced ReSPECT as a time-critical safety tool, relied upon to justify rapid decisions about resuscitation, conveyance, and best-interest care. In contrast, general practice and community teams framed ReSPECT as part of longitudinal, relationship-based planning, most effective when introduced early, revisited over time, and embedded in ongoing care for people with frailty, progressive illness, or care-home residency. Specialist palliative care occupied a hybrid position, using ReSPECT both prospectively and reactively. Hospice professionals described ReSPECT as fully embedded and routinely expected, but emphasised its iterative nature rather than treating it as a one-off exercise or conversation.
Information quality and the limits of the form	Across settings, professionals highlighted wide variation in ReSPECT quality. Well-completed forms were described as highly valuable, while poorly completed forms - often limited to DNACPR recommendations - were experienced as actively unhelpful. Ambulance and hospice clinicians in particular emphasised that ReSPECT does not capture sufficient clinical nuance, illness trajectory, or reasoning, limiting its usefulness in complex situations where treatment benefit versus comfort must be weighed. General practice and community clinicians often attempted to compensate for this by adding contextual detail (e.g. frailty status, illness trajectory, escalation boundaries), explicitly writing for other services—particularly ambulance teams. This translation work underscores ReSPECT's dependence on clinician judgement and narrative quality, rather than the form alone.
Fragmented systems and workarounds	Across all professional groups, fragmented digital infrastructure emerged as a dominant constraint. Ambulance services lacked electronic access altogether; care homes were largely digitally excluded; and community, hospice, and GP systems did not reliably interoperate with hospital records. As a result, ReSPECT was frequently duplicated, superseded, or inconsistently visible. Community nurses and palliative care clinicians repeatedly described acting as system navigators, copying information between systems, re-having conversations to avoid harm, and informally breaching rules to ensure patient wishes were visible across settings. These workarounds were framed as necessary but inefficient, increasing administrative burden and reducing time available for direct patient care.
Printed copies as essential but fragile infrastructure	Despite widespread use of electronic systems to create and store ReSPECT plans, printed copies remained operationally essential in some settings, particularly for ambulance services and care homes where direct access to electronic records was limited or unavailable. However, reliance on printed copies introduced fragility: plans could be lost, duplicated, become out of date, or be unavailable at the point of care. Care homes were identified as settings where ReSPECT could work well when staff continuity and confidence were high, but where dependence on printed copies made practice more vulnerable during agency cover or out-of-hours care.
Ethical alignment and professional commitment	Despite these limitations, hospice and palliative care professionals consistently described ReSPECT as ethically aligned with palliative care values, particularly dignity, autonomy, and proportionality of treatment. There was strong rejection of DNACPR-only practice, with

Key finding	Summary
	ReSPECT valued as a means of understanding what mattered to patients and what interventions were appropriate. Across participants, frustration was directed not at the concept of ReSPECT itself, but at how systems constrained its implementation. Professionals expressed a shared view that ReSPECT's potential was undermined by poor interoperability, lack of review mechanisms, and inconsistent understanding across services.

Patient and carer interview findings

This section presents findings from interviews with patients and carers, focusing on their experiences of the ReSPECT process in the community and hospice admission. The data provide insight into how ReSPECT is understood, recalled, and used from a patient and family perspective, including how it functions in practice during changes in health status and at points of care transition.

All participants were recruited from St Gemma's Hospice as inpatients and had completed a ReSPECT plan prior to admission, as this is a requirement for hospice inpatient care. The sample included patients admitted for both symptom control and end-of-life care, with varying anticipated discharge outcomes (Table 8). Most patients were older adults with cancer diagnoses, and all had involvement from a palliative care clinical nurse specialist in completing their ReSPECT plan. Carers were present in the majority of interviews and played an important role in supporting communication, decision-making, and care.

Table 8. Patient and Carer Sample Characteristics

Patient ID	Who	Reason for hospice admission	Age group	Gender	Ethnic background	Cancer	Do you have a caregiver
PC 01	Palliative care CNS	End of life care	Over 70	Male	White British	Yes	Two daughters (one present)
PC 02	Palliative care CNS	Symptom control	Under 70	Female	White British	Yes	Nephew (not present)
PC 03	Palliative care CNS	Symptom control	Over 70	Female	White British	Yes	Husband (present)
PC 04	Palliative care CNS	End of life care	Over 70	Male	White British	Yes	Wife + daughter (present)
PC 05	Palliative care CNS	Unknown	Over 70	Female	White British	Yes	Husband (present)
PC 06	Palliative care CNS	Symptom control	Over 70	Male	Cantonese	Cancer	Wife + daughter (present)

Case 1: Patient 01 (with daughter as carer) – ReSPECT as a trusted, tool that "Worked" in crisis

Patient 01 had limited verbal capacity during the interview, with the daughter acting as interpreter and advocate. ReSPECT was introduced in the community by a St Gemma's CNS several months prior and was revisited on hospice admission. The initial conversation was described as highly sensitive, well-timed, and relational, with strong trust placed in the CNS. The patient's daughter reflected on the experience, saying:

> "*Because the conversation came as a shock to me because it's like the first time. Very sensitive, sort of, you know, [CNS]'s experience told that it was the right time to have that conversation. Quite shocked to be having that conversation for me.*"

She described the ReSPECT process as less about completing a form and more about a personal interaction:

> "*It was kept in a very personal context actually, so it was like having a conversation, with you as a friend in a way*."

The plan proved operationally effective: paramedics explicitly asked for it, it was kept visible in the home, and it directly enabled transfer to hospice when the patient could not communicate. Family members played a crucial role in locating and presenting the form, highlighting ReSPECT as a shared family resource. The patient's daughter explained:

"[Patient's partner] had to find that form for you, Dad, for the paramedics… that's one of the first things they asked for. Dad wouldn't have been aware of that because he was very poorly… I deliberately kept it on the kitchen top."

The patient expressed confidence that his wishes were accurately recorded without needing to see the document. Digital access was not viewed as important by either the patient or carer, largely because trust in the CNS removed the perceived need for oversight. When asked whether patients should be able to view this information electronically, the patient's daughter explained:

"*The [CNS] said simply, you know, 'that's what was happening and that's what's happening'. We wouldn't need to feel the need to go and look at anything*."

This case illustrates ReSPECT working effectively when relational continuity, visible and accessible patient-held documentation, and family advocacy align to support care consistent with the patient's wishes and preferences.

Case 2: Patient 02 – Strong values despite minimal recall of the form

Patient 02 did not recall completing a ReSPECT form but expressed very clear and strongly held preferences, particularly prioritising comfort over life-prolonging treatment. She framed ReSPECT primarily as a matter of rights and autonomy:

"Because you've got your, you've got your rights, haven't you … If you want, you don't want to be messed about with, we don't want to be messed about with and that's it."

Extensive personal planning (funeral arrangements, named decision-maker) was already in place, making ReSPECT feel less central to her own narrative. Trust was placed almost entirely in her nephew and hospice staff rather than documentation.

Despite limited recall, the patient was strongly supportive of ReSPECT in principle and endorsed digital recording for relevant professionals and family, with clear boundaries around privacy.

"*I don't think everybody should be able to see it. What I mean is, by the relevant people that should be able to see it. The relevant people that should be able to look at it, it should be them, and them only. And your family. Only family*."

This case shows that lack of recall does not imply lack of agency, and that ReSPECT may function as a background safeguard rather than an intervention.

Case 3: Patient 03 (with husband as carer) – ReSPECT as timely, flexible, and empowering

Patient 03 clearly recalled the ReSPECT discussion, which had taken place recently at home with a CNS. The conversation was experienced as useful and empowering, allowing wishes and preferences to be discussed and recorded while capacity was intact. The patient described declining CPR after explanation and preferring hospice care to avoid burdening family, while remaining open to hospital care for reversible conditions.

"*Whether I ever wanted to undergo CPR and I said no… I didn't want to be brought back at that stage."*

ReSPECT was understood as flexible rather than fixed. An unanticipated deterioration led to a change in preference from hospital to hospice care, which was accommodated without distress. The patient felt listened to, respected, and treated as a whole person, expressing confidence that wishes were accurately recorded:

"She was very kind, very gentle, understanding."

Although the plan had not yet been used in an emergency, it already shaped care through coordinated symptom management:

> "*CNS arranged for one of the doctors from here to come to see me to sort of set up the treatment plan for the pain control, didn't she and she came out at home again and we got that in place after that conversation and then we did have to tweak it a bit. But yes, it's it worked did the treatment plan.*"

The patient supported digital access via the NHS App for review and revision, particularly to enable future changes and family awareness:

> "*If I ever changed my mind… to see what I'd originally put on there*."

This case highlights ReSPECT as a living guide that supports autonomy, adaptability, and coordination.

Case 4: Patient 04 (with wife and daughter) – ReSPECT as pragmatic and necessary, particularly for hospice admission – but disruption for the carer

Patient 04 viewed ReSPECT as a pragmatic and necessary step, particularly to enable hospice admission. His preferences were already firmly established, including a strong wish not to die at home, reflecting both practical considerations and a wish to spare his family the burden of making decisions for him.

> *"ReSPECT for me it's something which is very relevant in the circumstances. And that there's no point in people hiding a wish or a demand when it should be known by other people who will have to deal with things when they're gone … If somebody wants to look at my wishes then fine, because eventually if they're carried out, then all it is a confirmation of what took place."*

For him, ReSPECT functioned largely as a confirmation of wishes and preferences that had already been established:

> *"I just knew that had to be done, and it was done and so we ended up here [hospice]. So it served its purpose."*

In contrast, the patient's wife experienced the process as abrupt and challenging, with limited opportunity to express her own feelings:

> "*I didn't have an opportunity to say what my feelings were… it was all about [him], as it should be, but I found it difficult."*

She also described the pace and lack of warning as unsettling:

> "*There was no warning about having to fill this in… I found it fast. Too fast."*

This highlighted a divergence between patient and carer experiences. Neither the patient nor carer retained a copy of the form, contributing to uncertainty about what had been documented. While the patient was relaxed about documentation and sharing, his wife valued the idea of electronic access to verify content over time:

> *"I would say yes [it would be useful], because we can't remember what was on the form."*

This case illustrates how ReSPECT can operate effectively at a system level while creating emotional strain for carers, especially when introduced rapidly and without shared reflection.

Case 5: Patient 05 (with husband) – ReSPECT as a one-off plan that lost salience over time

Patient 05 recalled a positive initial ReSPECT experience and felt listened to and respected at the time. However, because the plan had been completed years earlier, both patient and carer expressed uncertainty about whether it still reflected current wishes.

> *"I'm not sure because it was quite a long time ago now."* (Patient)

ReSPECT was rarely referenced in subsequent care, with later discussions focusing narrowly on DNACPR recommendations rather than the wider wishes, preferences, and treatment recommendations captured within the plan. The patient questioned whether the broader content of the ReSPECT plan continued to inform care over time:

> *"I don't think ever any clinician has ever said, 'you've signed a ReSPECT form - do you want to go ahead with this treatment?'"*

The patient had also expressed a preference to avoid hospital admission, yet this had not been revisited through the ReSPECT process:

> *"Because I've actually refused to go to hospital… and no, it was never mentioned."*

The patient's printed copy of the ReSPECT plan had been used during the ambulance transfer to the current hospice stay but was not returned afterwards, highlighting the fragility of relying on printed documentation and adding further uncertainty about access to the most current plan.

> *"The ambulance person took it with them… I don't think we've had it handed back."* (Carer)

Both patient and carer strongly supported electronic sharing and personal access, viewing this as a way of improving visibility, continuity, and ongoing engagement with the plan. This case illustrates how ReSPECT can lose salience over time when it is not revisited, readily accessible, or actively integrated into subsequent care conversations, creating a risk that documented wishes and preferences become disconnected from ongoing care.

Case 6: Patient 06 (with wife and daughter) – ReSPECT as a safeguard during incapacity

Patient 06 had little memory of the ReSPECT conversation, which had occurred recently in the community, describing it as *"nothing special."* Despite this, he clearly recalled his wish not to receive CPR, stating:

> *"When my heart stops beating, don't try to rescue. Let me go."*

His daughter confirmed that he had also clearly expressed a preference to remain at home:

> *"I think he did say he preferred to stay home. Very clearly."*

The family emphasised ReSPECT's importance when the patient became confused during acute illness, describing the form as representing his wishes when he could not communicate. Paramedics immediately asked for the patient's paper copy of the ReSPECT plan, and its availability enabled the patient's wishes and preferences to inform decision-making, even when hospital admission was temporarily required. The daughter explained:

> *"Because it's his choice… even at that moment he was confused… this form really presents what he wants."*

Carers strongly supported electronic access as an additional means when the patient's printed copy of the ReSPECT plan was unavailable. The daughter viewed electronic sharing as essential for ensuring continuity of care and timely access to the patient's wishes:

> *"If we couldn't find it, then they can find it easy to access."*

She also highlighted generational and language barriers to digital tools, noting that older family members struggled with apps and required support.

This case shows ReSPECT functioning as protective infrastructure, rather than a memorable conversation.

Patient and carer experiences

Table 9 summarises patient and carer experiences of the ReSPECT process across six cases. Overall, ReSPECT was experienced less as a standardised intervention and more as a context-dependent process, shaped by timing, illness trajectory, relationships with professionals, and the involvement of family. While all patients had completed a ReSPECT plan prior to hospice admission, the extent to which it was remembered, valued, and actively used varied considerably.

Key patterns highlight that ReSPECT could function either as a meaningful, relationship-based conversation or as a more administrative requirement, depending on how it was introduced. Recall of the process varied, but even where patients did not remember the form, they often retained clear preferences. Family members played a critical role, particularly in holding and enacting plans during crises. Experiences also differed in terms of whether ReSPECT was maintained as a living, evolving plan or became static and disconnected from ongoing care.

Across cases, patient-held paper copies of ReSPECT plans played a critical role, particularly during emergencies when clinicians needed rapid access to information about patients' wishes and preferences. However, reliance on paper copies also highlighted vulnerabilities, as they could be unavailable, misplaced, or inconsistently shared across services. Views on digital access varied, but were generally pragmatic, with patients and carers valuing accessibility and continuity while continuing to place importance on relationships and communication.

Table 9. Patient and Carer Experiences of ReSPECT

Theme	Summary
Recall and salience of ReSPECT	Patient recall ranged from highly detailed (Patient 03) to minimal or absent (Patients 02 and 06). Importantly, limited recall did not equate to lack of preferences or agency. Patients who could not remember the form often articulated clear values and preferences (e.g. prioritising comfort, refusing resuscitation), suggesting that ReSPECT functioned for some as background infrastructure rather than a memorable event. In contrast, when the discussion was recent and explicitly framed as choice-making (Patient 03), ReSPECT was experienced as empowering and meaningful.
ReSPECT as relational versus administrative	Where ReSPECT was introduced through a trusted relationship with a CNS (Patients 01 and 03), it was described as a conversation rather than a form and generated confidence without the need for oversight. In these cases, trust replaced the perceived need for patients to review documentation. Conversely, when ReSPECT was introduced rapidly or primarily to meet system requirements

	(Patient 04), it functioned administratively for the patient but created emotional difficulty for carers.
Role of family and carers	Carers played a pivotal role across cases, particularly in operationalising ReSPECT. In Patients 01 and 06, family members located and presented paper forms to paramedics when patients lacked capacity, effectively acting as custodians of patient wishes. However, carers' emotional experiences diverged from those of patients. Patient 04's case highlighted how a process that felt pragmatic to the patient could feel rushed and distressing to carers, especially when they lacked time, involvement, or access to documentation.
ReSPECT over time: Living plan or static record	Cases differed sharply in whether ReSPECT functioned as a living guide or a one-off record. Patient 03's case illustrated flexibility and review, with changing preferences accommodated without distress. By contrast, Patient 05's ReSPECT had not been revisited for years, resulting in uncertainty, DNACPR-only discussions, and a sense that the plan had become disconnected from ongoing care. This contrast underscores the importance of review and visibility over time.
Paper, digital access, and system visibility	Patient-held paper copies of ReSPECT plans were critical at points of crisis across multiple cases, particularly during ambulance attendance and transfer (Patients 01, 05, 06). These copies often provided the only readily accessible source of information about patients' wishes and preferences. However, reliance on paper also introduced fragility, as plans could be misplaced, duplicated, or inconsistently available and shared. Attitudes toward digital access varied: some patients did not see personal access as necessary where trust was strong (Patient 01), while others and most carers viewed electronic access as essential for reassurance, continuity, and the ability to check or revise plans (Patients 03, 05, 06). Support for digital access was pragmatic rather than ideological and was often linked to improved continuity, accessibility, and the ability to review or update plans, rather than a replacement for relationships and communication.

Comparison of patient, carer and health professional perspectives on ReSPECT

Table 10 compares patient and carer experiences with health professional perspectives, highlighting both alignment and differences in how ReSPECT is understood and used. Overall, patients and carers tended to experience ReSPECT as a relational, trust-based conversation, whereas professionals described it more as a clinical decision-making and planning tool shaped by role, setting, and urgency.

Key contrasts include differences in how documentation is valued (patients focusing less on the form itself, professionals prioritising clarity and accessibility), and how systems are experienced (often invisible to patients until failure points, but a major operational challenge for staff). Both groups recognised the importance of timing, relationships, and family involvement, and agreed that ReSPECT is most critical at moments of crisis or uncertainty.

The table illustrates that while there is shared commitment to person-centred care, the practical realities of delivering and using ReSPECT differ significantly across perspectives, particularly in relation to system constraints, documentation, and accountability.

Table 10: Key Points from patient, carer and health professional interviews

Theme	Patient & Carer Perspectives	Health Professional Perspectives
What ReSPECT is	Experienced primarily as a conversation grounded in trust, not a form.	Used as a decision-support and planning tool, with meaning shaped by clinical role and setting.
Timing and purpose	Most valued when introduced at the right moment and revisited as circumstances change.	Used either anticipatorily (GPs, community, hospice) or at crisis points (ambulance services).
Recall and engagement	Recall varies widely; limited recall does not mean lack of preferences or agency.	Recall assumed less important than documentation quality and visibility at point of need.
Role of relationships	Trust in clinicians (especially CNSs) often replaces the need to review documentation.	Relational continuity enables better conversations, but cannot compensate for poor system access.
Family and carers	Carers are central to finding, presenting, and enacting ReSPECT, especially in emergencies.	Carers' role is critical but often unacknowledged, with clinicians relying on them at crisis points.
Patient-held paper copies	Patient-held paper copies of ReSPECT plans were accepted and trusted, particularly when kept visible and readily available at home.	Printed copies of electronically generated ReSPECT plans were operationally essential in some settings, but vulnerable to being misplaced, duplicated, out of date, or unavailable at the point of care.
Digital access	Valued pragmatically, mainly by carers, to improve accessibility, continuity, reassurance, and opportunities for review.	Seen as necessary to reduce risk, duplication, and moral burden, but constrained by system fragmentation.
Review over time	Generally expect professionals to revisit plans when circumstances change.	Recognise the value of periodic review or 'check-ins', although time and system constraints can limit this in practice.
DNACPR vs holistic planning	Focus on dignity, comfort, place of care, and not burdening family.	Strong rejection of DNACPR-only use; value ReSPECT for capturing what matters and what is appropriate.
System failures	Often invisible until a crisis occurs; experienced as confusion or delay.	Absorbed as workarounds, duplication, and moral labour by frontline staff.
When ReSPECT matters most	At moments of crisis, transition, or reduced capacity.	At moments of risk, uncertainty, and time-pressured decision-making.

Results summary

The survey findings indicate strong overall support among health professionals for the ReSPECT process, particularly for patients approaching the end of life, while also recognising its value earlier in the disease trajectory and when initiated by patient preference. However, implementation was variable, with some patient groups potentially missing out and inconsistent provision of patient information materials. Survey findings demonstrated variable awareness, availability, and use of ReSPECT information resources, while interview participants highlighted ongoing uncertainty about how ReSPECT is shared, accessed, maintained, and reviewed across services.. Barriers to effective discussions included patient and family readiness, misunderstandings, time pressures, and system constraints, while enablers centred on strong relationships, continuity of care, good communication, and sufficient time.

Documentation quality and system functionality were key determinants of effectiveness. Clinical elements were generally well documented, but more personalised sections were less consistently completed. Although ReSPECT was widely viewed as useful for informing best interest decisions, its impact was limited by poor interoperability, and unequal access to electronic records across services. In some settings, access relied on patients, families, or care home staff being able to provide a paper copy of the plan, which hindered effective information sharing. Training was generally viewed positively by those for whom it was relevant, although respondents reported variation in training quality, access to ongoing support, and opportunities for refresher training.

Findings from interviews complemented the survey data, showing that patients and carers experienced ReSPECT primarily as a relational, trust-based conversation, while professionals viewed it as a clinical planning and decision-making tool. Despite shared commitment to person-centred care, differences emerged in how documentation, systems, and responsibilities were experienced. Overall, the findings highlight strong support for ReSPECT but emphasise the need for improved system integration, consistent implementation, and better alignment between relational and operational aspects of care.

Findings from both the survey and interviews suggested that transitions between care settings, particularly hospital discharge, could create challenges for maintaining the relevance and visibility of ReSPECT plans. Health professionals described variation in the quality and completeness of hospital-generated plans, and examples were identified where community teams revisited or updated plans following changes in health status, care setting, or patient circumstances. Patients, carers, and professionals all recognised the value of ensuring plans remained relevant over time.

DISCUSSION

This evaluation shows that ReSPECT is widely valued across patients, carers, and professionals and is seen as supporting person-centred care. Its effectiveness was greatest where strong relationships, high-quality documentation, and accessible information systems aligned, although variation in implementation remained across settings.

ReSPECT works best when seen not as a form to fill in, but as a way of coordinating care. Patients primarily experience ReSPECT as a trusted conversation, often delivered by hospice and community CNSs. In these circumstances, confidence in professional relationships replaces the need for patients to monitor documentation. This finding should be interpreted in the context of the patient sample, as all patients were recruited through hospice services and had completed ReSPECT with involvement from a palliative care CNS. As a result, experiences of ReSPECT discussions led by GPs and other professionals were less represented. In contrast, health professionals, particularly those working in ambulance services, relied on ReSPECT as a time-critical decision-support tool. This highlights an important tension within the process: patients value relational assurance and continuity, whereas services require reliable, accessible information at the point of care. The

findings also suggest that clear information provision remains an important but sometimes overlooked component of ReSPECT implementation. These findings suggest that clear and accessible information should complement ReSPECT conversations and support understanding of how plans are used in practice.

A key finding is that completion does not equal functionality. While many examples of high-quality ReSPECT documentation were described as supporting safe and proportionate care, poorly completed or DNACPR-only forms were widely reported as unhelpful and, in some circumstances, potentially risky. Current measures that focus on uptake or the presence of a ReSPECT form do not account for variation in documentation quality, relevance, or usefulness in clinical decision-making.

Carers play an essential but under-recognised role in making ReSPECT operational. Families frequently locate and present the printed ReSPECT plan, communicate wishes and preferences, and advocate during emergencies, particularly when patients lack capacity. While this supports continuity, it also transfers emotional and practical burden to carers - especially when plans are introduced rapidly or without shared reflection. This has implications for equity and sustainability of care. Where patients and carers have limited health literacy, communication difficulties, language barriers, or reduced family support, there may be additional risks that plans are less well understood or less effectively used. Ensuring patients and carers receive appropriate information and support may help reduce these inequalities.

The findings also raise questions about equity of access to ReSPECT. Health professionals identified several groups that may be underrepresented in current practice, including people with frailty, dementia, long-term conditions without a palliative diagnosis, care home residents, and those experiencing language or advocacy barriers. While the current evaluation was not designed to quantify differences in access, the findings suggest the need for further work to understand who may be missing out and how barriers can be addressed.

Fragmented digital infrastructure was the most consistent system-level failure. Ambulance services lack electronic access; care homes are largely digitally excluded; and community, hospice, and hospital systems do not reliably interoperate. As a result, community nurses and hospice clinicians routinely absorb system gaps through duplication, repeated conversations, and informal workarounds. This hidden labour is inefficient, increases moral distress, and reduces clinical capacity - yet is currently unmeasured.

Patient-held paper copies of ReSPECT plans remain essential, particularly in emergencies where some services cannot access the electronic records in which plans are created and stored. However, these copies can be lost, duplicated, or outdated, creating uncertainty about which version should guide care.

The findings also suggest that information provided to patients and carers may not currently be fulfilling its intended purpose. Although written ReSPECT materials exist, they were not consistently available or routinely provided. Patients often relied more heavily on conversations with trusted clinicians than on written information. However, both survey and interview findings suggest that clearer information could improve understanding of the purpose of ReSPECT, how plans are shared and accessed across services, the role of carers, and when plans may need to be revisited. Updating patient information resources to better reflect the Leeds context may help support more consistent understanding and engagement.

The findings highlighted the value of reviewing ReSPECT plans over time. Where ReSPECT was revisited, it functioned as a living guide that could adapt to changing wishes and circumstances. Although one of the aims of ReSPECT is to avoid unnecessary repetition of conversations, patients and professionals alike described benefits from occasional review or ‘check-in’ discussions. Patients generally expected clinicians to initiate these reviews, while professionals cited time and system constraints. These findings suggest that review is most appropriately triggered by significant changes in circumstances, such as deterioration in health, hospital admission or discharge, transfer between care settings, or changes in treatment goals and patient preferences.

Such an approach may help maintain the relevance and usefulness of ReSPECT plans while avoiding unnecessary review activity.

Transitions between care settings may represent particularly important opportunities for review. Survey respondents identified review of hospital-generated ReSPECT plans before or following discharge as an enabler of effective use, while interviews suggested that plans developed during acute admissions were sometimes perceived as less detailed than those created through ongoing community relationships. General practice, community, and hospice professionals described reviewing plans at points of transfer or admission to ensure they continued to reflect current wishes, preferences, and clinical circumstances. These findings suggest that care transitions may provide a practical trigger for proportionate review, helping to maintain the relevance, visibility, and usefulness of ReSPECT plans without requiring routine reassessment at every contact.

Finally, the findings also highlight the need to better understand variation in access to ReSPECT. Health professionals identified several groups who may be less likely to benefit from the process, including people with frailty, dementia, long-term conditions without a palliative diagnosis, care home residents, and those facing language or advocacy barriers. Further work is needed to understand whether these groups are underrepresented in current practice and to identify approaches that support more equitable access.

Taken together, the findings suggest that future improvement efforts should focus on strengthening information sharing, supporting high-quality conversations and documentation, improving patient and carer understanding, and ensuring ReSPECT remains relevant through review when significant changes in circumstances occur.

Limitations

The qualitative component of the patient interview study included only hospice in patients with advanced or terminal illness who had completed ReSPECT plan prior to admission as this was necessary to be admitted to the hospice for inpatient care. This limited transferability of findings to earlier stages of care. Patient experiences from general practice and wider community settings were not captured. In the health professional studies, perspectives from a broader range of frontline staff (e.g. routine general practice, community nursing teams, or care-home staff) may have identified further variation in ReSPECT use.

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APPENDICES

i. Health professional survey questionnaire

ii. Health professional interview schedule

iii. Patient and carer interview schedule

i. Health professional survey questionnaire

*All comments box responses are optional. Mandatory questions denoted by an asterisk**

Using the ReSPECT process in community services in Leeds

Introduction

We invite healthcare professionals working in community and primary care settings to take part in an online survey
This survey is part of a service evaluation across Leeds focusing on:

ReSPECT (Recommended Summary Plan for Emergency Care and Treatment)

Your insights will help identify what's working well and where improvements can be made for future training and development.

The survey takes approximately 10-15 minutes and is intended for healthcare staff working with patients with ReSPECT plans.

The ReSPECT process creates personalised recommendations for a person's clinical care and treatment in a future emergency in which they are unable to make or express choices. These recommendations are created through conversations between a person, their families, and their health and care professionals to understand what matters to them and what is realistic in terms of their care and treatment.
Your input is invaluable - thank you for helping to improve ReSPECT in practice! [Contact details of evaluation team]

Participant information

Click on the box to indicate agreement to participate in this study. *

☐ I have read the information sheet and agree to the conditions described. *This includes agreeing to this survey data to be stored at the University of Leeds and used in relevant future research in an anonymised form*

The survey is in 2 parts:

Part A asks some brief questions about yourself and your role.
Part B asks about your experience of the ReSPECT process.

Question 1: Are you involved in providing care for patients who have ReSPECT plans? *

- ☐ Yes, I provide patient care
- ☐ Yes, I am involved in training staff who provide patient care (but do not work with patients directly)
- ☐ No - I do not work with patients who have these plans or staff that care for them [*respondent is routed to screen 'Thank you for starting the survey. Based on your answer, you won't be able to continue, but we appreciate your interest'*]

PART A:

Your role

<u>Question 2</u>: Are you employed by*

- ☐ Leeds Community Health NHS Trust
- ☐ Yorkshire Ambulance Service
- ☐ Hospice
- ☐ Care home
- ☐ GP Practice
- ☐ Primary Care Network
- ☐ Other: **Employing organisation** [*if Other selected*] _____

<u>Question 3</u>: Please select the type of community setting you work in (tick all that apply) *

- ☐ Hospice – inpatient
- ☐ Hospice - outpatient
- ☐ Care home
- ☐ Patient home
- ☐ Community other: **Community organisation** [*if Community other selected*] _____

_

<u>Question 4</u>: Please enter your professional role or job title:*

_____

Use of ReSPECT

<u>Question 5</u>: How long have you used ReSPECT?*

	More than 2 years	1-2 years	Less than 1 year	Not applicable to my role
Recording or updating ReSPECT plans				
Viewing ReSPECT plans to inform care				
Training staff in the ReSPECT process				

<u>Question 6</u>: How often do you use ReSPECT plans?*

	Frequently	Sometimes	Never	Not applicable to my role
Recording or updating ReSPECT plans				
Viewing ReSPECT plans to inform care				
Training staff in the ReSPECT process				

Part B

Patient selection

<u>Question 7</u>: Which patients do you consider appropriate for the ReSPECT process?

Please rate each category on a scale of 1 to 5, where: 1 = Never and 5 = Always

	1	2	3	4	5
Patients in the last weeks of life					
Patients in the last months of life					
Patients with a life limiting condition and expected to live more than a year					
Patients with complex health needs or multiple comorbidities					
Patients who are at risk of sudden deterioration					
Patients who express a wish to discuss their preferences for future care - regardless of their current health status					

<u>Question 8</u>: Please add any further comments about who would benefit from a ReSPECT discussion (*e.g. are there other appropriate patients, do any patients miss out*)

_____

ReSPECT discussions with patients

<u>Question 9</u>: Are you aware of ReSPECT patient information that can be offered to patients and families?

☐ Yes
☐ No

[*If Yes*] **Is patient information readily available for you to share with patients (e.g hard copy or via website links)?**

☐ Yes
☐ No
☐ Not applicable to my role (e.g. not patient facing)

[*If Yes*] **Typically, do you offer this information to patients?**

☐ Yes
☐ No - **If not, why not?** [*if No selected*] _____

<u>Question 10</u>: What barriers do you experience with having ReSPECT conversations?

_____

<u>Question 11</u>: What factors contribute to a good ReSPECT discussion?

_____

ReSPECT - documentation and interpretation

Question 12: In your experience, how clearly documented are the following sections of the ReSPECT plan?

*Please rate each item on a scale of 1 to 5, where:1 = Not clear and 5 = Extremely clear **

	1	2	3	4	5
Section 2. Summary of relevant information including insight					
Section 3. What matters to the patient about their treatment and care					
Section 4. Clinical recommendations for care and treatment escalation					
Section 4. Clinical recommendations for CPR					

Question 13: In your experience, how useful is information in the ReSPECT plan in informing best interest decisions?

	The information is rarely useful in this situation	The information is sometimes useful in this situation	The information is always useful in this situation	I have not referred to ReSPECT plans in this situation
In urgent or emergency care?				
In end of life care?				

Question 14: Please add any comments about the documentation or interpretation of ReSPECT information here: (e.g. what is particularly helpful, what gets in the way)

_____

Sharing ReSPECT plans

We are interested in hearing about using electronic systems to record and share ReSPECT discussions.

In Leeds, we are unable to share ReSPECT plans across all clinical systems.
This means there is a need to review and record within different systems potentially creating multiple versions. A paper copy of the most up-to-date version should be with the patient. This is not ideal, and work is ongoing to find a solution.

Question 15: How do you view or complete ReSPECT plans? Select your level of access for each option/system

	Create, edit and view	View only	No access	Not applicable to my role
SystmOne				
EMIS				
Leeds Care Record/ PPM+				
Paper				

Other, please describe: _____

Question 16: To what extent do you agree with the following statement:

'***The use of electronic systems to record and share ReSPECT plans functions as intended to benefit patients***.'

☐ Strongly disagree ☐ Disagree ☐ Neither agree nor disagree ☐ Agree ☐ Strongly agree

Question 17: Please briefly describe how patients and their families have responded to, or felt about, the use of electronic systems for recording and sharing their ReSPECT plans

_____

Question 18: What barriers do you experience with sharing ReSPECT plans?

_____

Question 19: What works well with sharing ReSPECT plans?

_____

Question 20: In addition to ReSPECT, do you encounter other types of advance care plan or emergency care and treatment plan? These may either be patient or professional-initiated. *If so, please describe*:

_____

Confidence in the ReSPECT process

In Leeds, there is agreement that doctors and senior clinicians with additional training can complete ReSPECT plans with patients. *General awareness of ReSPECT is included in resuscitation training and palliative care training for services delivering end-of-life care.*

Question 21: Did the training you received prepare you to:

	Yes, completely	Yes, to some extent	No, not really	No, not at all	Have not received training	Not applicable to my role
Discuss ReSPECT information with patients?						
Document ReSPECT plans in the electronic patient record?						
Interpret the information documented in the plan?						

Question 22: Following your training, can you access support to build confidence in ReSPECT discussions in practice?

☐ Always ☐ Sometimes ☐ Rarely

Question 23: Please add any comments about the training (*e.g. what was useful, what could be improved, if you needed to supplement it*)

_____

Question 24: Any other comments

If there is anything else, you think it's important for us to know, please give brief details here:

_____

The following questions will help us understand the diversity of our respondents and the areas they work in

Question 25: Do you work with the following patient groups? *

	Frequently	Sometimes	Never
People with a learning disability			
Prisoners			
People who are homeless			
Asylum seekers			
People living in deprived areas			

Question 26: What is the first part of the postcode in the main area/s where you work? _____

Question 27: What is your ethnic group?

- ☐ White
- ☐ Mixed
- ☐ Asian
- ☐ Black
- ☐ Other, please state _____

And Finally

If you're interested in any of the following, please indicate below and provide your contact details below.

- **Invitation to participate in an interview to discuss experiences and views on using ReSPECT**. These will take place between [dates] and will last approximately 30 minutes. You can choose to participate online or via telephone. *Providing your email address does not obligate you to participate.*
- **Publication of the study findings**
- **A certificate of survey completion.** We will email a certificate to survey respondents, which may serve as evidence of service evaluation or audit participation for your annual appraisal.

I am interested in hearing about:

- ☐ an interview
- ☐ the study findings
- ☐ a certificate
- ☐ none of the above

[If any selected] **Please enter your name and email address.** *Your contact details will be stored separately and not linked to your survey responses* _____

Thank you for completing the survey

ii. Health professional interview schedule

Semi-structed interview guide

About you

- What patient groups do you work with
- How often you use the ReSPECT process as part of your role?

Prerequisites

What do you need to undertake the ReSPECT process?

- *Do you have everything you need to undertake ReSPECT discussions, documentation, review and access e.g - Training & Equipment*
- *What else would be useful to have?*

Discussion & documentation – may not be applicable to YAS

Which patients do you offer an initial ReSPECT discussion to?

How confident are you at discussing the ReSPECT information with patients?

What do you prioritise in a discussion?

- Do you think any other information would be useful to record?

Can you tell me about how patients respond to discussions

- *What parts are trickier to discuss?*
- *What issues do you experience with eliciting or documenting information?*

What happens when patients have other advance care planning or emergency care and treatment plans recorded elsewhere - in addition to ReSPECT.

What patient groups in Leeds are currently missing out on ReSPECT discussions?

Access & interpretation

When you read information documented by other health professionals, do you use this to guide the care you provide? How/why?

- *How confident are you that you are interpreting as the patient intended?*

When you document information, how do you envisage it being used by other health professionals?

- *How confident are you that they will interpret as the patient intended?*

Evaluation

How do you think ReSPECT makes a difference to patient care?

What evaluations are taking place, across the service?

- *Can you tell me about any previous evaluations across the service?*

Have any issues or complaints from patients or health professionals arisen? Describe…

Digital approach

Has the digital process functioned as intended?

How have service users felt about their experience of having information recorded and shared digitally?

What is the added value of using electronic systems to record and share information compared with other methods?

What are the problems with using electronic systems to record and share information?

Is there is anything else, you think it's important for us to know about the ReSPECT process?

iii. Patient and carer interview schedule

Semi-structed interview guide

Introductory Script:

ReSPECT stands for Recommended Summary Plan for Emergency Care and Treatment.

- *The ReSPECT process creates a personalised recommendation for your clinical care in emergency situations where you are not able to make decisions or express your wishes*
- *We are always trying to improve the experience of the patient and those closest to them.*
- *We would like to hear from you about how it felt to be part of a ReSPECT discussion so that we can understand what works well and where we can improve.*

If you are happy to take part:

- *First, I will ask you a few questions about yourself – these questions won't be audio recorded.*
- *Then I will ask you some questions about your thoughts and experience of the discussion. These questions will be recorded, and I will first check with you before starting the recorder.*

Interview procedure

PART A : Collect demographic information (not audio recorded)
PART B: Interview questions (Semi-structured questions will be phrased to reflect participants responses to preceding closed questions – prompts will be used as appropriate)

Questions

Exploring context

Clarify point in time that ReSPECT discussion took place
What do you remember about the discussion to create a plan as part of the ReSPECT conversation?

If there is no clear recollection of the discussion, ask:

- what are their thoughts about such a discussion?
- how useful would it be to them now
- what about in the future?

How did you feel when you were discussing your thoughts about future care and treatment?

Involvement in decisions about care and treatment

Were you involved as much as you wanted to be in talking about your care and treatment?
Were the people that matter to you most (e.g. family or friends), involved as much as you wanted them to be in making recommendations about your care and treatment?

Can you tell me more about how you felt about this process?

- How could this have been improved?
- How did you feel about the involvement of these friends/family?

The ReSPECT conversation, documentation and use of information

Script:

The ReSPECT process creates personalised recommendations for a person's clinical care and treatment in a future emergency in which they are unable to make or express what is important to them.

These recommendations are developed through conversations between a person, those people close to them, and their health and care professionals, to establish and agree what matters to them and what is realistic for their future care and treatment.

Listening and understanding

Do you feel the clinician listened to what you said?
Do you feel the clinician understood to what matters to you?
Do you feel the clinician took account of what matters to you?

Can you tell me more about how about how well the clinician understood you?

- Was there something in their communication or approach that stood out?

Rapport and therapeutic alliance

Do you feel you were treated with respect and dignity?
Do you feel you were treated as a whole person (e.g. by taking into account your beliefs, what's important to you)?
Do you feel confident that your ReSPECT plan reflects your wishes?
Do you feel confident that your ReSPECT plan will be accessed and used by professionals?

Can you tell me more about how well the clinician treated you?

- Were there specific actions or attitudes that were helpful?
- What wasn't so helpful?

The ReSPECT decision-making process

Were you asked to share your views about what was important in relation to health care needs and treatments
Were you given enough information to help you make informed decisions about your care and treatment?
Were care and treatment options discussed in a way you could understand?
Were you able to communicate what was important to you, openly to the healthcare professional having the ReSPECT conversation?

Can you tell me more about how well the clinician supported you in making decisions?

- What could have been better for you, what did you find useful?

Using the information recorded in ReSPECT

Did the ReSPECT conversation help you understand decisions about your care and treatment?
Have healthcare professionals worked well together in organising your care and treatment?
Do you feel the plan has recorded what is important to you (e.g. how well does it make recommendations for future emergency situations?)

Can you tell me more about how helpful you think the plan will be in supporting your care and treatment choices?

- Is there anything else you think should have been recorded?

Using a digital approach

How do you think that recording this information on your digital record will help?
How would you want your information to be used?
So far, has the digital process of recording your plan as you thought it might?

- What makes you feel this way?
- What would be more helpful to you?
- What do you think about accessing this information yourself?
- What about access for carers or family?