A Service Evaluation of the ReSPECT Process and its Implementation in the Community Setting in Leeds

Executive Summary

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Study Summary

Item	Details
Design	Mixed-methods service evaluation
Aim	To understand how, where, when, and for whom the ReSPECT process is working in community health services in Leeds
Survey participants	113 health professionals
Health professional interviews	15 health professionals
Patient interviews	6 patients
Carer interviews	7 family carers
Settings	General practice, community services, hospices, and Yorkshire Ambulance Service

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.