

From the United Kingdom to Denmark: Translating and Adapting the ReSPECT Process for Emergency Care Planning

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Abstract

Within the UK, the Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) framework and its associated document facilitate collaborative decision-making and advance care planning; however, ReSPECT's implementation remains confined to the UK. This project sought to translate the original English ReSPECT document into Danish and to conduct a pilot evaluation of this adapted version across diverse clinical environments. The translation of the ReSPECT document into Danish was conducted using a forward-and-backward translation protocol, in accordance with established international translation benchmarks. Following translation, the document was pilot-tested via consultations involving patients, family members, and medical practitioners across multiple healthcare domains. Post-consultation, these individuals completed an evaluative survey regarding the document's utility. A total of 36 patients engaged in the structured consultations; evaluation surveys were completed by 15 patients, 11 family members, and 13 medical practitioners. The vast majority of patients and family members reported that the document covered all vital details and served as an effective tool for discussing future treatment preferences and care choices. Approximately two-thirds of the participating practitioners deemed the ReSPECT document highly valuable for facilitating these discussions. At the same time, one-third found it advantageous for clarifying clinical status and formulating treatment guidance. Half of the surveyed practitioners noted instances of omitted or superfluous details within the translated document. The Danish version of the ReSPECT document was identified as a constructive tool for guiding consultations on future healthcare and treatment, as well as for defining patient preferences in emergency scenarios. The study highlighted areas requiring subsequent modification to better align the document with the Danish medical system's structure. The process of translating and pilot-testing the ReSPECT framework into alternative languages is both actionable and acceptable to patients and clinical stakeholders alike.

Keywords: Advance care planning, Shared decision-making, Patient-centred care, Resuscitation, Treatment escalation plans

Introduction

Collaborative decision-making and advanced care planning involving patients represent foundational pillars of contemporary medical practice [1]. The objective of shared decision-making is to incorporate individual patient preferences directly into future healthcare and treatment paradigms [2]. Advance care planning is a mechanism that enables individuals to articulate their objectives and choices regarding prospective medical interventions and care [3] to ensure that they receive medical interventions aligned with their stated desires during severe or terminal illnesses or if they experience a loss of cognitive decision-making capacity [4]. These two practices are closely

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intertwined with patient-centered care [2], underscoring the need to comprehensively understand the experience of illness from the patient's unique perspective [1].

The Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) framework is deployed within the United Kingdom to guide prospective clinical and care planning. It was initiated in 2016 in response to data indicating that traditional Do-not-attempt-Cardiopulmonary-Resuscitation (DNACPR) directives lacked sufficient detail when addressing broader treatment plans, [5, 6] and that such orders were frequently misinterpreted as an instruction to withhold all medical care, [5-9] thereby compromising the quality of care and intervention received by individuals with active DNACPR status. The ReSPECT framework helps embed a resuscitation recommendation within the broader objectives of patient care, fostering a more ethically sound clinical approach [10, 11]. This framework encourages practitioners to establish a mutual understanding with patients spanning three distinct areas: the active diagnosis and clinical outlook; preferred medical outcomes alongside personal anxieties; and the specific interventions—including resuscitation—that are clinically indicated given the patient's precise medical status [6, 12, 13]. The final choices recorded on the ReSPECT document stem from the core values and preferences articulated during a consultative dialogue between the patient, a medical practitioner, and, if preferred, a family member [10]. The document is designed to assist the clinician in organizing this consultation while ensuring enhanced transparency regarding patient preferences and clinical guidance across diverse medical environments [14].

Several localized initiatives in Denmark [15-17] have validated the utility of advance care planning discussions, collaborative decision-making, and the formal documentation of patient choices in medical records for use during urgent scenarios when the individual can no longer articulate their preferences. Nonetheless, a uniform, nationwide advance care planning document has not yet been established or deployed, and the routine use of such documentation remains uncommon among most Danish medical practitioners [18].

Consequently, this investigation aimed to translate the standard English ReSPECT document into Danish, using established translation guidelines, followed by a pilot evaluation of the translated ReSPECT framework across a diverse range of Danish medical settings.

Materials and Methods

Translation process

To maintain cultural compatibility and conceptual equivalence with the original instrument, [5] the ReSPECT framework was translated into Danish using a forward-backward translation protocol modeled on the 10-step Principles of Good Practice for the Translation and Cultural Adaptation of Patient-Reported Outcomes [19]. The structural flow of the translation procedure is illustrated in **Figure 1**.

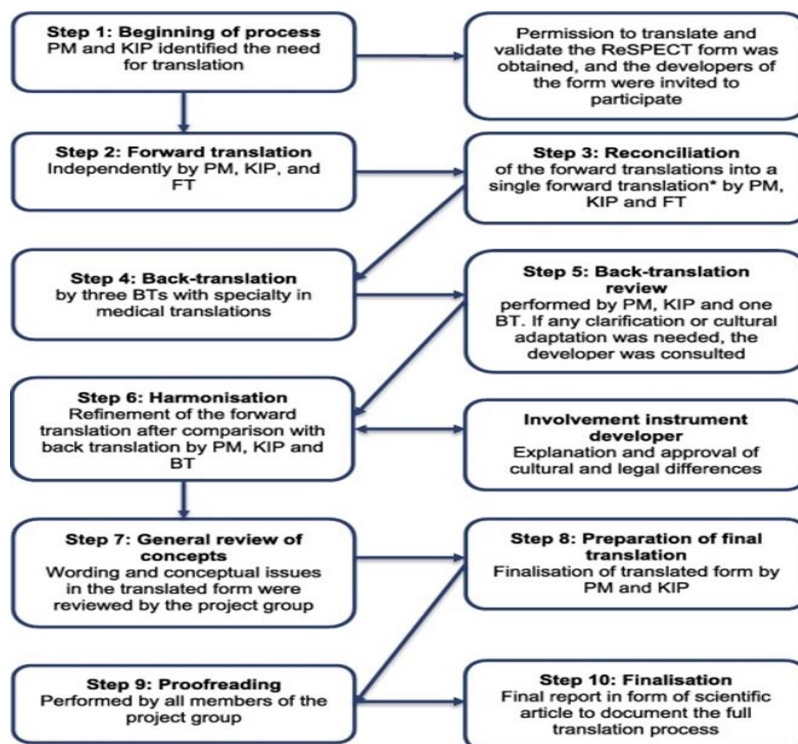


Figure 1. Flowchart of the Danish translation of the ReSPECT form following the 10-step ISPOR principles of Good Practices for the Translation and Cultural Adaptation of Patient-Reported Outcomes [19].

Abbreviations: PM = project manager, KIP = key in-country person, FT = forward translator, BT = back translator. *The three translations made separately by PM, KIP, and FT were merged into one translation after discussing the best formulations in the translated forms.

Pilot-testing of the Danish ReSPECT form

Participants and settings

The Danish iteration of the ReSPECT document was evaluated among patients, family members, and medical practitioners across a variety of clinical sectors. These included an emergency department, three intensive care environments, a cardiology department, a dedicated palliative care facility, and two general practitioners responsible for providing clinical care within local nursing home settings. This range of environments was intentionally selected to encompass a heterogeneous patient population. Before patient enrollment, the project manager conducted introductory training for participating physicians at each site on ReSPECT documentation and on delivering the corresponding advance care planning dialogues. This training was delivered either in person or via virtual presentations in Danish, lasting between 1 and 1.5 hours. Following the training, clinicians were allowed to contact the project manager to address any inquiries or uncertainties regarding the ReSPECT framework or the delivery of the discussions.

Inclusion criteria

To be eligible for inclusion, individuals had to meet the following parameters: (i) patients aged ≥ 18 years for whom a discussion regarding prospective medical care and interventions was deemed clinically beneficial, or who independently requested such a dialogue; (ii) patients possessing the cognitive capacity to comprehend the intent and implications of end-of-life care discussions; and (iii) individuals capable of understanding and communicating in Danish.

Data collection and storage

Upon providing consent for study inclusion, the patient, the participating physician, and, when available, a family member, engaged in a collaborative consultation regarding prospective clinical management and care, using the Danish ReSPECT document to guide the interaction. The ReSPECT documentation was completed dynamically during the consultation, and the clinician recorded the patient's baseline demographic and clinical data.

Approximately two weeks after the consultation, the patient and participating family member were provided with an evaluative survey designed to capture their perceptions of the dialogue and their assessment of the ReSPECT framework. These surveys were distributed via email, standard postal mail, or e-Box (the secure, state-managed digital communication network for Danish public authorities). The participating clinician received a digital questionnaire via email that focused on the execution of advanced care planning discussions and their professional evaluation of the ReSPECT document. Non-respondents were sent a follow-up reminder via email or e-Box after 2 weeks.

The survey instruments were modeled after the methodology outlined by Tuesen *et al.* [15] and adapted to align with the specific features of the Danish ReSPECT framework. The primary author executed these modifications, and the senior author formally approved the final iterations. While background demographic inquiries differed across the patient, family, and clinician surveys, the core questions evaluating the ReSPECT document remained consistent. The management and capture of research data were handled through REDCap, a secure electronic data management platform hosted by the Open Patient Data Explorative Network (OPEN) in Odense.

Statistical analysis

Qualitative free-text entries were examined using content analysis [20] to define core meaning units and thematic patterns. Direct quotations from patients and family members are presented with randomly generated, anonymous identification numbers to preserve anonymity. Quantitative survey findings were summarized and evaluated using descriptive statistical measures.

Ethical considerations

The research initiative was formally registered with the Danish Data Protection Agency (Journal No. 24/27491) and received institutional approval from the University of Southern Denmark's Research Ethics Committee (24/61675). To safeguard participant confidentiality and data integrity, a formal data processing license agreement (OP_2202) was established with OPEN.

Written informed consent was obtained from all participating subjects during the ReSPECT consultation. In the majority of clinical environments, the attending physician notified the patient and any present family members of an impending discussion regarding future care options and invited them to join the research project, allowing the patient a one- to two-day deliberation period. However, in certain clinical settings, such a deliberation timeframe was logistically unfeasible, requiring the research overview and the clinical conversation to occur concurrently. In all instances, participants were comprehensively briefed by the clinician regarding the nature of the consultation and the research framework. It was explicitly communicated that participation was entirely voluntary, that a

decision to decline would not compromise prospective medical care, that participants retained the right to withdraw from the study at any point before the conclusion of data analysis, and that all established care and treatment recommendations would be formally integrated into their permanent medical records.

Results and Discussion

The data collection window opened in March 2024 and concluded in June 2025. Linguistic adaptation of the ReSPECT framework occurred throughout the spring and summer of 2024, followed by participant recruitment from October 2024 until the close of the study in June 2025.

The translation process

The outcomes of the translation methodology illustrated in **Figure 1** are outlined below:

- Step 2–3: Initial forward translation passes demonstrated strong consensus regarding semantic intent and terminology. Minor variations were restricted to alternative synonym selections, and no critical conceptual disparities emerged. These minor differences were resolved collectively during a reconciliation workshop.
- Step 4–6: Back-translations were carried out independently by three medical translation specialists, including one native English speaker. Evaluative reviews of these back-translations led to minor stylistic improvements in the Danish text rather than structural alterations. Following cross-document harmonization, the materials were sent to the UK developer for official validation, which was granted without further revisions.
- Step 7–9: The core research team completed a final proofreading phase to eliminate awkward phrasing. No extra revisions were required.

Results from testing the Danish ReSPECT form

Thirty-six individuals across eight clinical environments were enrolled in the evaluation phase (**Table 1**). Attending clinicians noted that most participants qualified due to advanced physiological decline or old age, suggesting these patients were generally anticipated to receive invitations to discuss future clinical management. In only a single instance did a physician voice uncertainty regarding whether the advance care planning dialogue would yield practical benefits for the participant. More than 80% of these clinical consultations were completed within 30 minutes.

Table 1. Characteristics of the 36 patients who participated in a conversation with a physician about future treatment and care (from data collected by the physicians during the conversations).

Characteristic	Overall sample (n = 36)
Sex, n (%)	
Men	23 (64)
Age, mean (range)	75.6 (54–99)
Recruitment location, n (%)	
Hospital ward	7 (19)
Intensive care setting	19 (53)
Primary care practice	8 (22)
Palliative care service	2 (6)
Inclusion criterion, n (%)	
Participant's own request	2 (4)
Frailty status	8 (17)
Advanced age	12 (26)
Serious health condition ^b	23 (50)
Alternative reason	1 (2)
Unexpectedness of being invited to an ACP discussion, n (%)	
Yes	5 (14)
No	31 (86)
Perceived difficulty in determining the relevance of an ACP discussion for the patient, n (%)	
Yes	1 (3)
No	35 (97)
Length of ACP discussion, n (%)	
Less than 15 minutes	7 (19)

Between 15 and 30 minutes	23 (64)
More than 30 minutes	6 (17)
Presence of family members during the discussion, n (%)	
Yes	12 (33)
No	24 (67)
Participants who died before questionnaire completion, n (%)	
	2 (6)

^a: Different n due to multiple answers. Four patients had two or more reasons for inclusion.

^b: Cancer, cardiovascular disease, COLD, or others.

Among the 36 enrolled patients, 2 died before survey distribution, and 19 failed to return the questionnaires, yielding 15 (44%) usable patient responses (**Table 2**).

Table 2. Characteristics of the 15 patients who completed the questionnaire about the conversation with the physician and their assessment of the ReSPECT form.

Characteristic	Entire cohort (n = 15)
Sex, n (%)	
Men	11 (73)
Age, mean (range)	
	77.5 (61–93)
Had discussed personal care preferences before the ReSPECT consultation, n (%)	
Yes	9 (60)
No	6 (40)
If yes, discussion partner(s)^a, n (%)	
Family members (e.g., spouse, children)	8 (53)
Friends	0
Healthcare support staff	1 (6)
General practitioner	1 (6)
Hospital-based physician	3 (20)
Other individuals	4 (27)
Assessment of the ReSPECT document	
Readable, n (%)	
Yes	15 (100)
Understandable, n (%)	
Yes	14 (93)
No	1 (7)

^a: Different n due to multiple answers.

Over 50% of these 15 respondents had previously discussed their medical preferences with immediate family before this study. Every respondent found the ReSPECT paperwork highly legible, and only one person encountered difficulty interpreting its contents (**Table 2**).

Of the 12 family members present during the clinical sessions, 11 (92%) completed and returned their feedback forms (**Table 3**). For most relatives, this session represented the first time prospective care strategies had been openly examined with the patient. All participating relatives confirmed that the ReSPECT layout was clear and easy to follow.

Table 3. Characteristics of the 11 relatives who completed the questionnaire about the conversation with the patient and physician and their assessment of the ReSPECT form.

Characteristic	Family member participants (n = 11)
Sex, n (%)	
Men	2 (18)
Age, range (years)	
	(23–88)
Relationship to the patient, n (%)	
Spouse or partner	4 (36)
Son or daughter	5 (45)
Other family relations	2 (18)
Had previously discussed the patient's wishes before the ReSPECT consultation, n (%)	

Yes	3 (27)
No	8 (73)
Evaluation of the ReSPECT document	
Readable, n (%)	
Yes	11 (100)
Understandable, n (%)	
Yes	11 (100)

The majority of patients (73%) and relatives (82%) agreed that the document adequately captured vital clinical parameters. Furthermore, 80% of patients and 100% of relatives reported that the details shared during the dialogue were sufficient to grasp the final clinical recommendations. Patients rated the Danish ReSPECT framework as highly or exceptionally beneficial for facilitating prospective emergency care dialogues with a physician, at 13% and 40%, respectively. Among family members, these figures stood at 27% and 64%. Every participating patient and relative found the instrument useful for navigating prospective emergency care discussions.

Thirteen medical practitioners across eight distinct healthcare settings within two Danish administrative regions participated and completed the survey (**Table 4**). Every practitioner had over a decade of clinical experience, and 77% encountered clinical scenarios weekly in which an advanced care planning framework would have been advantageous. Most (69%) of these physicians observed that formalized treatment limits or care plans were missing in over half of the clinical cases where they would have been beneficial (**Table 4**).

Table 4. Characteristics of 13 physicians who participated in conversations with patients about future care and treatment and then completed a questionnaire.

Characteristic	Physician participants (n = 13)
Sex, male, n (%)	6 (46)
Age, mean (range)	49.6 (39–62)
Clinical experience as a physician, n (%)	
Less than 10 years	0
10–15 years	4 (31)
More than 15 years	9 (69)
Study site affiliation	
Two primary care practices	2
One palliative care facility	2
One cardiology department	1
One emergency medicine department	1
Three intensive care units	7
Estimated frequency of encountering acutely ill patients who would benefit from a predefined treatment plan, n (%)	
Weekly	10 (77)
Monthly	1 (8)
Several times every six months	1 (8)
A few times annually	1 (8)
Never	0
Frequency with which treatment decisions or care plans had been established before acute deterioration when considered beneficial, n (%)	
Always	0
Almost always	0
Frequently	4 (31)
About half of the time	3 (23)
Less than half of the time	3 (23)
Seldom	3 (23)
Almost never	0
Never	0

A majority of physicians (61%) classified the ReSPECT form as highly useful for framing prospective care and treatment dialogues (**Table 5**). At the same time, roughly one-third found it highly useful for defining a patient's overall health status and establishing solid clinical guidance. Most clinicians (61%) believed that utilizing the ReSPECT framework would better enable them to respect and execute patient preferences during acute medical crises. Additionally, nine (69%) clinicians reported that the tool provided valuable structural support when managing discussions with patients and family members.

Table 5. The physicians' assessment of the ReSPECT form.

Assessment item	Physicians (n = 13), n (%)
Perception of whether the ReSPECT form contained missing or unnecessary information	
Yes	6 (46)
No	7 (54)
Usefulness of the ReSPECT form during discussions about future treatment and care	
Useful to a very great extent	2 (15)
Useful to a great extent	6 (46)
Useful to a moderate extent	3 (23)
Useful to a limited extent	2 (15)
Not useful at all	0
Unsure	0
Usefulness of the form in enhancing clarity and supporting decisions beneficial to the patient	
To a very great extent	2 (15)
To a great extent	2 (15)
To a moderate extent	6 (46)
To a limited extent	0
Not at all	1 (8)
Unsure	2 (15)
Perceived value of the ReSPECT form for improving clarity and adherence to recommendations/preferences during emergencies	
To a very great extent	2 (15)
To a great extent	6 (46)
To a moderate extent	3 (23)
To a limited extent	1 (8)
Not at all	1 (8)
Unsure	0
Ways in which the form facilitated conversations regarding future treatment and care^a, n (%)	
Helped initiate the discussion	6 (46)
Improved the structure of the conversation	4 (31)
Made communication with patients (and relatives) easier	2 (15)
Assisted in explaining why particular treatments or care options were preferable	3 (23)
Did not simplify the discussion or alter the physician's usual approach	4 (31)
Other ^b	2 (15)

^a: Different n due to multiple answers.

^b: One of the physicians responding "Other" had elaborated on the answer in the corresponding free text box: "It (the ReSPECT) didn't make it any easier for me, as I had a hard time sticking to the points, as I usually start the conversation somewhere else and steer it differently. But it's probably a matter of getting used to it." (ICU physician 5).

Qualitative data (free text boxes)

Qualitative free-text entries were provided by five patients, who offered feedback regarding the positive and negative dimensions of the ReSPECT template and the clinical consultation. Four respondents expressed appreciation for the opportunity to proactively address prospective care and treatment pathways, whereas a single respondent experienced difficulty recalling the interactive session.

I think it's good to clarify what may happen [in the future, red.] together with a physician. (Pt. 7)

Similarly, final open-ended comments were submitted by six family members, all of whom underscored the fundamental value of initiating these dialogues and establishing unequivocal documentation of patient preferences.

I think it's really good that there is a focus on what patients want in terms of treatment, etc. (Rel. ICU 7)

It's a good way to have a tough conversation, especially because you have a document to work from. However, it can take away some of the natural conversation. (Rel. ICU 5)

The majority of participating medical practitioners provided free-text entries to elaborate on their appraisal of the ReSPECT layout. These responses were largely favorable regarding the implementation of structured dialogues centered on patient-led choices for prospective medical interventions.

I think the concept is really good, and we really need an overview of treatment levels – especially in the pre-hospital setting [in the pre-hospital setting]. I like that the patient gets a lot of speaking time when these decisions are being made. We sometimes think we know what patients want, but we probably don't ask enough about what is most important to them. (ICU physician 5)

First of all, the document is highly relevant! (...) The document helped initiate and maintain the conversation. Easy to use/transparent. (Physician 6)

Conversely, several clinicians offered critical appraisals regarding the design interface and specific introductory inquiries within the framework. The most prevalent critiques focused on the insufficient physical dimensions of the text boxes designated for clinical recommendations and the confusing nature of the legal-formality questions on the second page.

It's good to have on the agenda, but the document is overly formal and uses difficult language. There should be examples of what you can answer as a patient. More information about what exactly you can decide on – it's hard for patients to know. Is it admission to the intensive care unit? Intubation? Cancer treatment? Major surgery? Or what? (Physician 1)

Page 1 is good. Page 2 is an obstacle to my using the document. (Physician 3)

This project completed the linguistic translation of the ReSPECT template into Danish, followed by multi-center pilot evaluations involving medical professionals, patients, and family members across diverse healthcare environments. The compiled data indicate that a substantial majority of participants viewed the introduction of proactive care and treatment dialogues highly favorably, affirming the utility of the Danish ReSPECT framework during these clinical encounters. Additionally, participating physicians broadly agreed that the template would provide vital clarity regarding a patient's clinical baseline during acute emergencies, thereby facilitating real-time therapeutic decisions aligned with documented patient desires.

The encouraging feedback from patients, relatives, and clinicians regarding transparent communication pathways for prospective treatment plans aligns closely with outcomes documented in prior literature [21-23]. It highlights the essential need to identify and incorporate patient values directly into definitive medical recommendations [3, 16, 24]. Currently, Denmark lacks a standardized, systemic framework for executing advanced care planning initiatives [25]. In January 2025, a legislative update was enacted permitting individuals aged 60 years and older to register a binding refusal of cardiopulmonary resuscitation efforts via digital channels [26]. Notably, this web-based registration does not require a prior consultative dialogue with a healthcare professional. This hands-off mechanism for establishing DNACPR directives stands in stark contrast to observations from the present evaluation and the European Resuscitation Council's clinical guidelines on Ethics in Resuscitation [27], which position patient-centered advance care planning and explicit clinical justification as foundational components of any DNACPR order.

A robust body of research [16, 22, 24] points to an urgent need for a more structured advanced care planning methodology, alongside targeted educational training for clinical staff who direct end-of-life consultations. As observed in this pilot study, deploying a unified, nationwide advance care planning tool modeled after the ReSPECT framework could offer uniform direction for end-of-life dialogues across fragmented medical sectors, thereby streamlining the broader integration of advance care planning. Such a framework ensures an equitable care experience in which families and patients know what to expect, medical practitioners receive uniform communication training, and record-keeping is standardized to safeguard clinical decision-making during crisis scenarios.

The bulk of the critical feedback from physicians focused on omissions or areas requiring refinement within the Danish iteration, particularly the confusing legal queries on the second page. Under Danish law, clinical autonomy over life-prolonging interventions is restricted exclusively to competent patients aged 18 or older or to the responsible attending medical team [28]. This choice-making capacity may be extended to minors aged 15–17 years if the clinician determines that the adolescent fully grasps the clinical ramifications of their choices. For pediatric patients under 15 years, the authority to withhold life-prolonging measures rests solely with the treating clinician; across all age groups, no family member, legal guardian, or designated power of attorney has the legal right to veto life-prolonging treatment on behalf of the patient [28]. These statutory nuances likely explain the friction clinicians experience when confronting the page-two inquiries of the original ReSPECT template. Consequently, revisions are necessary to harmonize these parameters with Danish legal realities, thereby reducing the administrative burden on practitioners. Future research initiatives will focus on integrating these localized adjustments and evaluating the scalability of the ReSPECT document as a standardized national emergency care blueprint via expanded cohorts and real-world emergency assessments.

This investigation presents several distinctive strengths. First, the structural translation was carried out through validation protocols in direct coordination with the original UK authors. Second, cross-environment testing ensured a heterogeneous mix of patients and medical specialists. Third, the clinicians overseeing the dialogues had extensive experience in advance care planning, enabling a qualified assessment of the tool's practical relevance.

Conversely, certain limitations must be acknowledged, including the modest sample size and the high concentration of participants recruited from intensive care environments. As a result, these insights may lack broad generalizability to the wider patient populations typically eligible for such discussions. Additionally, incorporating qualitative focus groups with the participating clinicians would have yielded more precise recommendations for structural modifications, particularly regarding the layout of page two. While the data demonstrate the cross-border utility of the overarching ReSPECT framework, they also highlight that individual nations must fine-tune the document to align with local statutory requirements through iterative pilot implementations and large-scale validation studies.

Conclusion

The ReSPECT document was systematically translated into Danish and pilot-tested across multiple healthcare domains, demonstrating high readability and comprehensibility to patients, families, and practitioners alike. The framework was validated as an effective tool for guiding prospective treatment dialogues and safeguarding patient-led decisions during critical emergencies. Nonetheless, targeted structural modifications and updates to the legal formality sections are essential to properly embed the document within the administrative framework of the Danish medical system. While international frameworks for emergency care planning vary widely, the fundamental requirement for high-quality prospective care coordination remains universal. This evaluation confirms that adapting the ReSPECT framework to a novel cultural and linguistic environment is entirely viable and acceptable to both recipients and clinicians. Other nations can utilize these findings to guide their own adaptation processes, particularly regarding the critical restructuring required to align international frameworks with domestic legal requirements.

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