Online Data Supplement
Palliative Care Planner (PCplanner): A Pilot Study to Evaluate Acceptability and Usability of an Electronic Health Records System-Integrated, Needs-Targeted App Platform

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Contents

1. Expanded Methods

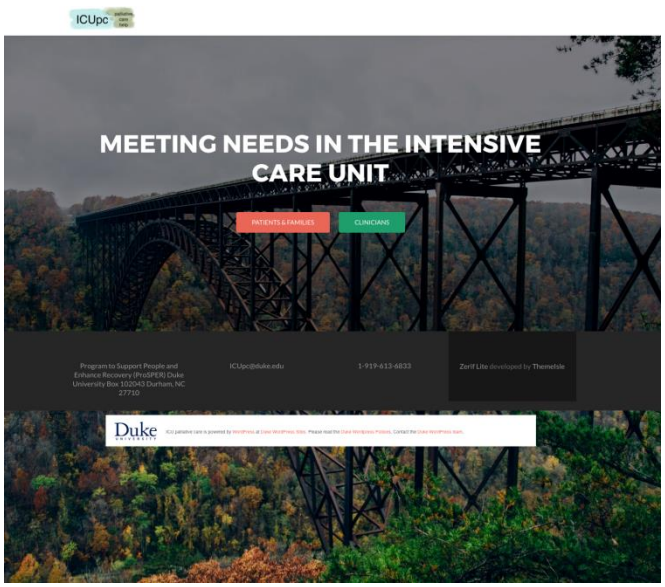
eTrigger validation process. The e-triggers shown in Table 1 were programmed in a 9-month long cycle of iterative revisions with EHR developers and clinical experts. These e-triggers were constructed from EHR vendor-agnostic Meaningful Use Common Data Set standards relevant to clinical care (e.g., SNOMED CT), pharmacy (e.g., RxNorm NLM standards), vital signs, laboratory results (LOINC), and physician billing to enable real-time use (framed with International Classification of Disease-10 codes).[10] Before live testing, we evaluated the accuracy of the e-triggers compared to manual chart review among 191 consecutive medical and surgical ICU patients over a two-week period. E-triggers were highly sensitive (>95%); specificity was 92%, with errors related primarily to intra-operative (not ICU) use of vasopressors for surgical patients and incorrect documentation of pre-admission disposition (i.e., missing data field instead of nursing home) by clinical staff. Coding was adjusted to address the vasopressor error.

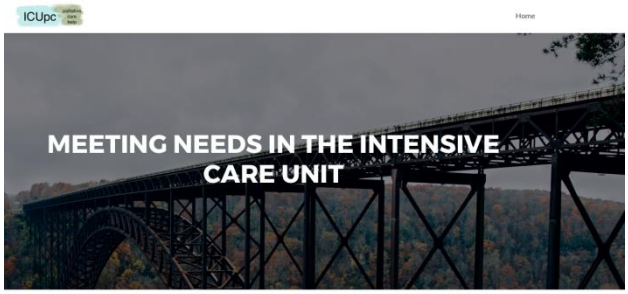
Adaptation and early validation of the NEST palliative care needs scale for ICU use. The Needs; Existential concerns; Symptoms; and Therapeutic interaction (NEST) instrument is short, applicable to inpatients and family, scored as a continuous (range 0-130) or dichotomous value, and has strong psychometric properties based on past RCTs.[1,2] We performed a series of small pilot studies to evaluate the NEST, adapt it to an ICU setting, and assess the association between NEST score and

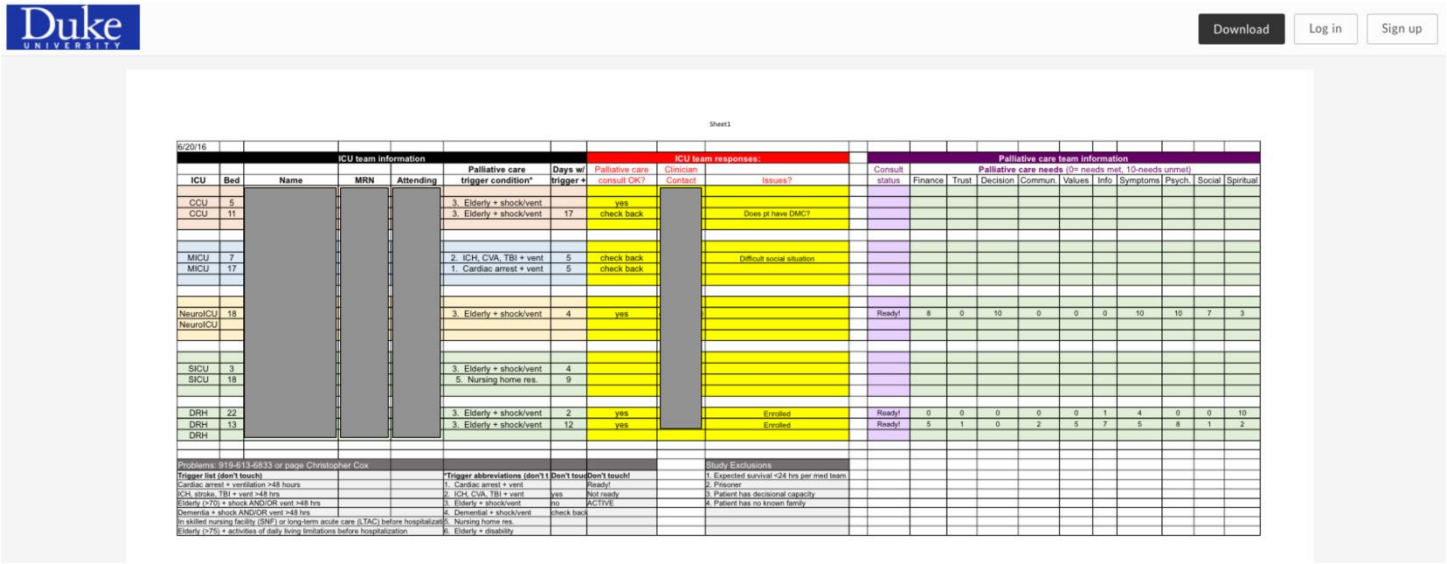
psychological distress. In Study 1, using an RCT database of 425 patients and family members provided by the instrument's developer, we found a mean=47 (SD 15) and ICC=0.52 between pre/post interviews.[1] In Study 2, we adapted a 10-item version of the NEST for the ICU setting by following a methodology similar to those who adapted the NEST for an emergency department setting,[3] and ensured that all 8 National Consensus Project Quality Domains were represented.[4,5] Formal cognitive testing with 10 ICU family members demonstrated acceptability and clarity. In Study 3, 32 ICU family members reported a median of 4 need domains with a mean total score=33 (range 3-89). Relevant domains correlated with PHQ-9 score (r=0.76), GAD-7 score (r=0.85), and satisfaction (r=0.55). Total NEST score <20 (~15% of family members) reliably identified those with very low distress (PHQ-9 or GAD-7 <5), conceivably those with needs manageable by ICU teams alone. NEST scores were responsive to change over 1 week (median 9 units, range 1-19) and the distribution was free of ceiling or floor effects (range 3-89, skewness 0.6).

3. Figures

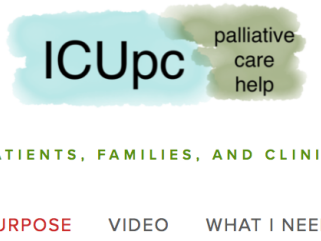
Clinician-facing PCplanner elements







Family-facing PCplanner elements



ICUpc palliative care help

The 5-minute help page

PURPOSE

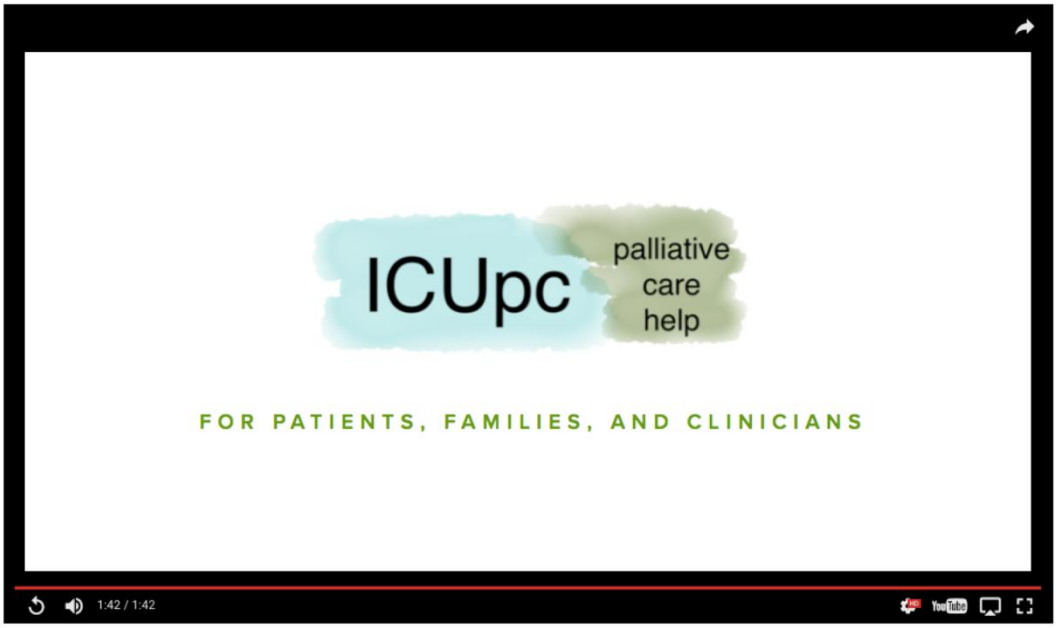
The ICU can be overwhelming. Patients are critically ill. Family members are stressed. *What can we expect? How can I make good medical decisions? Who can give me the information I need?*

ICUpc.org can help you navigate the ICU experience. ICUpc was developed by patients, family members, doctors, and nurses. Its purpose is to describe palliative care. Palliative care is provided by a team of clinicians who aim to improve quality of life. They do this by focusing on what is most important to people. Patients and families can receive palliative care regardless of age, diagnosis or disease stage, or ongoing treatments.

Using ICUpc takes less than 5 minutes:

1. Watch a **short video** to learn about the purpose of palliative care and how it could help you and your loved one in the ICU.
2. Answer a **brief survey** to let us know how you are feeling and what you need right now.

VIDEO



Thanks so much for your time!

Edit

3. Tables

eTable 1: Measures gathered from each cohort

Characteristic	Intervention patients, n=14	Intervention family members, n=18	Control A: palliative care ICU patients, n=25	Control B: medical ICU family members, n=49	Control B: medical ICU patients, n=39
Patient measures					
Patient length of stay, ventilation duration, disposition, hospice use	X	N/A	X	N/A	X
Patient-level palliative care triggers	X	N/A	X	N/A	X
Family member measures					
NEST	X	X	N/A	X	N/A
Perceived Stress Scale	X	X	N/A	X	N/A
Patient-Centeredness of Care Scale	X	X	N/A	X	N/A
Goal-concordance of care	X	X	N/A	X	N/A
Client Satisfaction Scale	N/A	X	N/A	-	N/A
Systems Usability Scale	N/A	X	N/A	-	N/A

Control A patients served as the main comparator for the intervention's general impact on patient-level clinical outcomes; **Control B patients** served as a secondary comparator. **Control B family members** served as the main comparator for the intervention's general impact on family-level clinical outcomes.

eTable 2: Study flow for intervention patients and family members

Characteristic	n
Patients screened	**423**
Patients excluded	**385**
Patient possessed decisional capacity	219
Patient <65 years old	98
Patient discharged from ICU before medical team sign-off	22
Patient died before consent	17
Family unavailable	12
Expected survival <24 hours	12
Family member needed translator	3
No known family	2
Refusals	**24**
Physician	14
Legal decision maker	10
Enrolled	**32**
Patients	14
(Family members)	(18)
(Clinicians)	(10)

eTable 3: Characteristics of clinicians involved in intervention

Characteristic	n=10
Age, no. (%)	
18 - 25	1 (10)
26 - 45	7 (70)
46 - 65	2 (20)
Female, no. (%)	9 (90)
Race, no. (%)	
White	6 (60)
Asian	3 (30)
Black	1 (10)
Hispanic ethnicity, no. (%)	0
ICU, no. (%)	
Medical	4 (40)
Palliative care	3 (30)
Cardiac	2 (20)
Neurological	2 (20)
Surgical	1 (10)
Role, no. (%)	
Nurse	5 (50)
Physician	2 (20)
Advanced practice provider	2 (20)
Social worker	1 (10)

eTable 4: Pre- and post-intervention scores for PCplanner intervention family members (n=18) and Control B medical ICU family member controls (n=49), expanded

Characteristic	Pre-intervention	Post-intervention	Change, mean (SD)	Improvement, n (%)	Control, time 1	Control, time 2	Change, mean (SD)	Improvement, n (%)	*p**
NEST total score,[1] mean (SD)	48.8 (12.38)	36.1 (13.2)	-12.7 (13.3)	12 (67)	31.1 (16.3)	35.1 (23.0)	3.4 (15.0)	8 (16)	0.0022
median (IQR)	52 (36, 58)	38 (25.5, 46.5)	-13 (5.8, 18.3)		35 (20, 45)	41 (12, 52)	2 (-7, 9)		0.005
NEST communication, mean (SD)	8.1 (2.2)	1.6 (2.2)	-7.5 (3.3)	7 (39)	1.7 (2.1)	2.0 (2.9)	-0.3 (2.9)	8 (16)	0.0000
median (IQR)	9 (8, 9.5)	1 (0, 3)	-8 (-9, -2.8)		1 (0, 3)	0 (0, 4)	0 (-1, 1)		0.0000
NEST social, mean (SD)	7.9 (2.4)	2.4 (1.8)	-5.5 (3.2)	13 (72)	1.9 (3.0)	2.3 (3.1)	0.4 (2.2)	7 (14)	0.0000
median (IQR)	9 (5, 10)	2 (1, 3.5)	-5.5 (-9, -3)		0 (0, 2)	1 (0, 4)	0 (-1, 1)		0.0000
NEST symptoms, mean (SD)	6.6 (3.6)	5.6 (2.9)	-1.6 (3.5)	7 (39)	5.7 (2.9)	5.7 (3.1)	0 (3.2)	21 (43)	0.15
median (IQR)	8 (3.5, 10)	6 (4, 8)	-0.5 (-4, 1)		6 (3, 8)	5 (3, 9)	0 (0, 1)		0.0000
NEST spiritual, mean (SD)	4.7 (3.6)	3.9 (3.1)	-0.8 (3.6)	7 (39)	4.7 (4.2)	4.3 (3.8)	0.4 (3.3)	14 (29)	0.89
median (IQR)	5 (2, 7.5)	2.5 (1, 6.5)	-0.5 (-3, 1)		4 (0, 9)	4 (0, 8.3)	0 (-1.3, 1)		0.66
NEST psychological, mean (SD)	5 (3.4)	4.4 (3.4)	-0.6 (3.4)	6 (33)	5.0 (3.7)	4.9 (4.3)	0.1 (2.1)	17 (35)	0.86
median (IQR)	5 (1.5, 8)	3 (2, 7.5)	0 (-2.3, 1)		5 (1, 9)	3 (1, 10)	0 (-1, 1)		0.56
NEST values, mean (SD)	1.9 (1.9)	1.9 (1.7)	0 (2.2)	6 (33)	1.2 (1.8)	2.3 (3.2)	-1.1 (2.9)	4 (8)	0.32
median (IQR)	2 (0, 3.5)	1.5 (0.8, 3)	0 (-2, 2)		0 (0, 2)	1 (0, 4)	0 (0, 3)		0.51
NEST information, mean (SD)	2.8 (2.6)	2.6 (2.2)	0.2 (1.5)	7 (39)	1.6 (1.6)	1.9 (2.5)	-0.3 (2.9)	7 (14)	0.62
median (IQR)	0 (2, 5)	0 (2, 5)	-0.5 (-1.3, 0.3)		1 (0, 3)	1 (0, 3)	0 (-1, 1)		0.79

NEST cultural, mean (SD)	0.5 (0.8)	0.9 (1.4)	0.4 (1.2)	1 (6)	0.4 (0.9)	2.0 (3.7)	-1.6 (2.9)	1 (2)	0.62
median (IQR)	0 (0, 1)	0 (0, 1.3)	0 (0, 0.3)		0 (0, 0)	0 (0, 4)	0 (0, 1)		0.84
NEST decisions, mean (SD)	4.6 (3.9)	5.8 (2.9)	0.6 (3.8)	5 (28)	3.3 (3.3)	3.0 (3.6)	-0.3 (2.4)	11 (22)	0.44
median (IQR)	5 (0.5, 8)	5.5 (3, 8.3)	0.5 (-2, 3)		2 (0, 7)	2 (0, 6)	0 (-1, 2)		0.59
NEST trust, mean (SD)	1.2 (0.9)	1.8 (1.5)	0.6 (1.6)	3 (17)	1.4 (1.3)	2.4 (2.8)	1.0 (2.4)	8 (16)	0.10
median (IQR)	1 (0.5, 2)	1.5 (1, 2.3)	0.5 (-0.3, 1)		1 (0, 2)	1 (0, 4)	0 (-1, 0)		0.07
NEST finances, mean (SD)	4.2 (3.1)	5.3 (3.3)	0.9 (3.3)	4 (22)	4.9 (3.6)	4.3 (3.7)	0.6 (2.3)	15 (31)	0.11
median (IQR)	5 (1.5, 5.5)	5 (2.8, 8.3)	0 (-1, 2.3)		6 (1, 8)	5 (1, 7)	0 (-1, 1)		0.21
Patient-Centeredness of Care Scale,[16] mean (SD)	37.5 (7.4)	42.1 (5.3)	6.6 (5.8)	12 (67)	-	-	-	-	-
median (IQR)	40 (29.5, 43)	43 (37.8, 47)	2.5 (-0.3, 6.3)		-	-	-	-	-
Perceived Stress Scale,[17] mean (SD)	9.7 (1.5)	8.8 (1.5)	0.8 (1.9)	12 (67)	-	-	-	-	-
median (IQR)	10 (, 10)	9 (7, 10)	1 (-0.3, 2.3)		-	-	-	-	-
Quality of Communication,[18] mean (SD)	8.2 (1.8)	9.1 (0.8)	0.9 (1.6)	11 (61)	7.8 (2.0)	7.3 (2.8)	-0.5 (1.8)	16 (33)	0.03
median (IQR)	8 (8, 9.5)	9 (8.8, 10)	1 (0, 1.3)		8 (8, 10)	8 (5.5, 9.8)	0 (-1.8, 0)		0.04
Optimism,[19] mean (SD)	3.7 (0.5)	3.4 (0.6)		1 (6)	-	-	-	-	-
agree / strongly agree, no. (%)	18 (100)	14			-	-	-	-	-

Hope, mean (SD)	3.9 (0.9)	3.6 (1.2)		1 (6)	-	-	-	-	-
usually / always, no. (%)	11	9			-	-	-	-	-
Social support, mean (SD)	4 (1.2)	4.1 (1.1)		3 (17)	-	-	-	-	-
strongly agree / agree, no. (%)	13	10			-	-	-	-	-
Self-efficacy, mean (SD)	4.3 (0.9)	4.5 (0.5)		2 (11)	-	-	-	-	-
strongly agree / agree, no. (%)	16	13			-	-	-	-	-
Understand prognosis, agree / strongly agree, no. (%)	14 (78)	17 (94)		7 (39)	-	-	-	-	-
Understand patient's life support preferences, agree / strongly agree, no. (%)	18 (100)	18 (100)		5 (28)	-	-	-	-	-
Current treatment reflects patient values, agree / strongly agree, no. (%)	16 (89)	18 (100)		7 (39)	-	-	-	-	-
Trust the clinicians,[20] agree / strongly agree, no. (%)	18 (100)	18 (100)		10 (56)	-	-	-	-	-
Conflict exists between family and clinicians, disagree / strongly disagree, no. (%)	17 (94)	18 (100)		5 (28)	-	-	-	-	-

eTable 5: Patient clinical outcomes, expanded

Variable	Intervention patients, n=14	Control A: palliative care ICU patients, n=25	Control B: medical ICU patients, n=39
Hospital length of stay, total			
mean (SD)	20.5 (9.1)	22.3 (16.0)	29.7 (16.1) *
median (IQR)	17.5 (14.8, 26.7)	18 (8.3, 35.8)	29 (17, 36) †
Hospital days before ICU admission, days			
mean (SD)	1.4 (4.4)		-
median (SD)	0 (0, 0)		-
Hospital length of stay before palliative care consultation, days			
mean (SD)	13.8 (16.1)	12.3 (13.2)	-
median (IQR)	5 (2, 29)	5.5 (1.8, 23.5)	-
Hospital length of stay after palliative care consultation, days			
mean (SD)	7.9 (6.2)	9.7 (7.9)	-
median (IQR)	6 (3, 12.5)	8 (2.5, 15.3)	-
Intensive care unit length of stay			
mean (SD)	16.1 (8.1)	11.5 (12.9)	15.1 (13.1)
median (IQR)	15.5 (9.5, 25.3)	7 (4.3, 13) †	
Intensive care unit length of stay before palliative care consultation, days			
mean (SD)	3.6 (2.7)	6.9 (7.1)	-
median (IQR)	3 (1, 5.3)	4.5 (1, 7.8)	-
Intensive care unit length of stay after palliative care consultation, days			
mean (SD)	4.4 (4.2)	5.1 (7.1)	-

median (IQR)	3 (1,7)	2 (1, 8)	-
Duration between eligibility and palliative care consultation, days			
mean (SD)	1.5 (2.4)	-	-
median (IQR)	1 (0, 1)	-	-
Mechanical ventilation			
no. (%)	9 (64)	15 (60)	27 (100%)
Mechanical ventilation duration, days, mean (SD)	15.5 (6.6)	12.2 (12.0)	17.3 (12.0)
Mechanical ventilation duration, days, median (IQR)	14.3 (11.6, 18.8)	8 (4, 15)	15.9 (7.8, 20.4)
Mechanical ventilation duration before palliative care consult, days			
mean (SD)	8.4 (4.1)	8.1 (9.7)	-
median (IQR)	6.5 (6.3, 11.9)	6 (2.5, 9.5)	-
Mechanical ventilation duration after palliative care consult, days			
mean (SD)	7.0 (6.2)	9.0 (10.4)	-
median (IQR)	5.6 (3.0, 8)	7 (1, 12.5)	-
Tracheotomy, no. (%)	4 (29)	4 (16)	3 (11)
CPR preference full care			
pre-intervention, no. (%)	13 (93)	22 (88)	-
post-intervention, no. (%)	4 (29)	8 (32)	-
CPR change after palliative care consult, days			
mean (SD)	4.6 (3.9)	5.3 (4.6)	-
median (IQR)	4.5 (1.3, 7.3)	5 (1.3, 8.8)	-
Hospital Discharge Location, no. (%)			
Home	1 (7)	2 (8)	8 (30)
Inpatient rehabilitation facility	0	0	5 (19)
Skilled nursing facility	2 (14)	1 (8)	3 (11)
Long term acute care hospital	2 (14)	2 (16)	0

Transfer to other acute care hospital	0	1 (4)	0
Hospice	5 (36)	5 (20)	2 (7)
Home hospice	2 (40)	0	0
Inpatient hospice	3 (60)	5 (100)	2 (7)
Died	4 (29)	14 (56)	9 (33)
Withdrawal of treatment	4 (100)	12 (42)	7 (78)

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