

## Appendix A:

### Identified measures with published psychometric data supplemental to Toolkit

Measure name	Population Setting	Validity Testing
Domain(s)	Brief description	Reliability Data
Agitation Distress Scale <sup>1</sup> Domain(s): Emotional symptoms	Mixed cancer 6-item; clinician-rating scale	Principal components analysis reveal only 1 component; significantly correlated with agitation items on MDAS & DRS (0.61) but scale was not correlated with cognitive items  Cronbach's 0.91; inter-rater kappa 0.72-1.0
"Are you depressed?" <sup>2,3</sup> Domain(s): Emotional symptoms	Mixed diseases  Single-item screening for depression	Correctly identified diagnosis of depression in all patients  Kappa=0.76 between interviewers and observers
Bereavement Phenomenology Questionnaire (BPQ) <sup>4</sup> Domain(s): Grief and bereavement	Mixed diseases  22-items, 4 point Likert scale	Discriminant MANOVA showed decreasing scores over time; factor analysis reveals only one factor despite being designed to assess four dimensions  Cronbach's alpha 0.93
Bereavement Risk Index (BRI) <sup>5</sup> Domain(s): Grief and bereavement	Mixed diseases  Uses an adapted 8-item version	Significant differences were found between low and high-risk groups in the Brief Symptom Inventory; results persisted 25 months after death.  NR
Brief Hospice Inventory <sup>6</sup> Domain(s): Quality of life; Physical symptoms; Emotional symptoms	Mixed diseases  NR	Factor analysis reveals 2 factors  Cronbach's alpha 0.84-0.94
Brief scale <sup>7</sup> Domain(s): Quality of life	Lung cancer patients of mixed severity  (uses 2 of 5 items from Spitzer Quality of Life index); consists of 2 separate implicit scores on 3 tier scale for mood/outlook (based on 3 structured questions) and social support (based on 2 questions); clinician assessment	Reported against HADS (outlook correlation 0.61, support 0.43) and RSCL (outlook 0.64, support 0.18); correlation to corresponding Spitzer QL-Index (outlook 0.55, support 0.53)  NR
Cambridge Palliative Assessment Schedule (CAMPAS-R) <sup>8</sup> Domain(s): Physical symptoms	Mixed diseases  Patient physical and psychological symptoms, patients-rated caregiver, psychological symptoms	Correlated with EORTC & HADS items and scales for some symptoms but not others; significant differences between patients who did and who didn't survive  Cronbach's alpha 0.77-0.8

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Cancer Patient Need Survey <sup>9</sup>  Domain(s): Needs assessment (Quality of care)	Mixed cancer  51 items, 5 categories - coping needs, help needs, information needs, work needs, cancer shock needs	Discriminant validity with different scores for hospice and clinic patients - may need different instrument for hospice patients  Cronbach's alpha 0.91
Caregiving at Life's End Questionnaire <sup>10</sup>  Domain(s): Caregiver well-being	Caregivers  Seven scales; hospice caregiving experience, addressing issues such as tasks, closure, and gain; self-administered	Concurrent: scales were correlated with each other as expected (e.g., caregiver comfort and importance of caregiving tasks r=0.6)  Internal consistency: cronbach's alpha 0.67-0.90; test-retest nonsignificant differences
Comfort Assessment in Dying with Dementia (CAD-EOLD) <sup>11</sup>  Domain(s): Physical symptoms, Emotional symptoms	Single disease -advanced dementia  14 items; 4 subscales (physical distress, dying symptoms, emotional distress, well being)	Item-total correlations range 0.39 to 0.79; correlation for symptom items on SM-EOLD r = 0.475 to 0.559  Cronbach's alpha 0.85 overall; subscales (physical distress r=0.74, dying symptoms r=0.70, emotional distress r=0.82, well being r=0.80)
Communication Capacity Scale <sup>1</sup>  Domain(s): Emotional symptoms	Mixed cancer  5 item; clinician-rating scale	Principal components analysis show only 1 component; highly associated with cognitive items on MDAS and Delirium Rating Scale (0.83); not correlated with agitation items  Cronbach's 0.96; inter-rater kappa 0.78-0.95
Concept of a Good Death measure <sup>12</sup>  Domain(s): Multidimensional measure (Palliative Outcomes)	Mixed diseases; not used with patients  17 descriptive statements of components that might be related to concept of good death; 3 subscales: closure, personal control, clinical criteria	Factor analysis - 3 subscales; small-to moderate association with other measures suggesting that these are distinct but related constructs; some items with low variability  Test-retest: ICC 0.66-0.83.
Core Bereavement Items (CBI) <sup>13</sup>  Domain(s): Grief and bereavement	Mixed diseases  17 items, 3 subscales, measuring bereavement phenomena (developed from Bereavement Phenomenology Questionnaire)	Factor analysis to develop subscales; face validity examines -kept subscales that described key components of bereavement; discriminant validity to time and group effects  Cronbach's alpha 0.91

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Cornell Scale for Depression in Dementia (CSDD) <sup>14</sup>  Domain(s): Emotional symptoms	Single disease - dementia; elderly nursing home residents  19 items (16 items retained in 4 domains), 3 level scale; 2 steps - clinician interview of caregiver, brief patient interview and clinical observation	Oblique rotation 4-factor matrix with eigenvalues >1.0 account 50% variance; inter-factor correlation 0.30 for depression and disturbed sleep, others <0.181; criterion-validity done; no testing with external scales  Internal consistency 0.76 total 16 item, depression subscale 0.75, somatic 0.72; Cronbach's 0.76
Cost and Reciprocity Index (CRI) <sup>15</sup>  Domain(s): Caregiver well-being	NR  25 items(modified), 4 subscales, face-to face for hospice caregivers; concepts of social support, reciprocity, cost, and conflict	Testing was done of the original instrument in healthy populations - relations between subscales are consistent with theoretical framework.  Cronbach's alpha 0.68-0.83
Decisional Conflict Scale (DCS) <sup>16</sup>  Domain(s): Advance care planning (Treatment decisions)	Mixed diseases; applied scale to cancer patients  16 items, 5 point Likert scales; 3 subscales (uncertainty, factors contributing, and effective decision making)	Construct validity among subscales 0.58 - 0.76; criterion validity significant between certain vs. uncertain groups; 3 factor model rejected (4 factor suggested in exploratory work)  Prior testing - internal consistency 0.78-0.89; test-retest >0.80; in combined subscales in this study - uncertainty 0.75, factor contributing 0.82, and decision making 0.82
Demoralization Scale <sup>17</sup>  Domain(s): Emotional symptoms	Mixed cancer  24 items, 5 subscales, self-administered	Concurrent: correlations between different subscales and numerous other scales were significant, such as the McGill QOL, BDI, PHQ, Beck's measure of hopelessness, and desire for hastened death; Divergent: appears to be a different construct than depression, since some patients with high scores on this scale are not depressed on the BDI or PHQ  Subscale cronbach's alphas 0.71-0.89
Duke-UNC Social Support Scale <sup>18</sup>  Domain(s): Quality of life	Single disease - lung cancer  NR	NR  Cronbach's overall 0.94, subscales 0.88 to 0.92
Dyspnea Descriptor Questionnaire <sup>19</sup>  Domain(s): Physical symptoms (dyspnea)	Single disease -heart failure; study done as convenience sample at single emergency department  13 descriptors asked retrospectively (derived from literature search)	Factor analysis done - 4 factor 71%  Cronbach's 0.95; inter-item correlation 0.60

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Edmonton Functional Assessment Tool (EFAT-2) <sup>20,21</sup>  Domain(s): Functional status	Mixed diseases  10 items (revised version); professional grading and evaluation scale describing symptoms and functions, one summary functional assessment; 0-4 scale	Concurrent validity shows it to be highly correlated with KPS and ECOG; total score highly correlated with global scale. Construct validity distinguished between inpatients and home palliative care patients. EFAT -2 (revision of EFAT) <sup>22</sup> not correlated with pain; significantly different in different groups based on discharge location; factor analysis: 2 components - physical & cognitive/affective  Inter-rater, ICC 0.71; Cronbach's alpha 0.86; Interrater ICC 0.97 for self trained clinicians (n = 2) and 0.95 for formal trained (n = 2); kappa on items ranged from 0.25 to 0.96 for self trained clinician pair and 0.17 to 0.95 for formal trained
Edmonton Staging System (revised rESS) <sup>23</sup>  Domain(s): Physical symptoms	Mixed cancer  4 pain and patient features; tool for classifying cancer pain; clinician assessment	Only 3 variables were associated with time to achieve stable pain control in multivariate analysis; patients in poorest prognostic category required more time to achieve stable pain control  Inter-rater correlations range 0.68-0.95
Emanuel and Emanuel Medical Directive (revised) <sup>24</sup>  Domain(s): Advance care planning	Mixed disease  4 hypothetical scenarios, with 2 goals and 6 treatments for each	Concurrent: consistently lower preference scores across situations for those with goal "comfort care" vs "prolong life" (p<0.0001); Discriminant: hospice patients wanted fewer life-sustaining treatments than non-hospice (p<0.05 for some treatments)  71-86% endorsed "comfort care" across all hypothetical scenarios; over 21-day follow-up, test-retest kappa 0.5-0.58; Cronbach's alpha across life-sustaining treatments 0.8 within situation, and 0.66-0.86 between treatments across situations, except for pain. Article also summarized extensive psychometric evaluation of previous versions.
Family Assessment Device (FAD) <sup>25</sup>  Domain(s): Caregiver well-being, Satisfaction	Mixed disease  12 items; assess family functioning	NR  Inter-item correlations met criterion (minimum 50% with r = 0.3 to 0.7) for 18 of 20 items; item correlation to total score 0.4 to 0.75 for 12 of 12 items; Cronbach's alpha 0.88

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Family Caregiver Medication Administration Hassles Scale <sup>26</sup>  Domain(s): Caregiver well-being	Community study (details of patients not given) - looks at problems caregivers experience with assisting elderly with medications  24 items paper survey; 4 subscales (information, safety issues, scheduling, & polypharmacy); scale 0-5 for each item	Principal components and factor analysis done (66.5% cumulative variance; construct validity to Medication Complexity Index (r=0.19) & modified Caregiver Strain Index (r=0.44)  Test-Retest at 2 weeks (n=53) 0.84 (0.78-0.85 Pearson correlation across subscales); internal consistency 0.95; Cronbach's alpha (0.80-0.92 across subscales)
Family Perception of Care Scale (FPCS) <sup>27</sup>  Domain(s): Satisfaction	Mixed disease, long-term care  27 items, 4 subscales; end-of-life care in long-term care facilities; self-administered	Higher scores when death occurred in facility than in hospital (p<0.001)  Subscale cronbach's alphas 0.78-0.95
F-Care Expectations Scale <sup>25</sup>  Domain(s): Satisfaction	Mixed diseases  16 items; assess family care expectations	NR  Inter-item correlations met criterion (minimum 50% with r = 0.3 to 0.7) for 13 of 16 items; item correlation to total score 0.4 to 0.72 for 12 of 16 items; Cronbach's alpha 0.88
F-Care Perceptions Scale <sup>25</sup>  Domain(s): Satisfaction	Mixed diseases  21 items; assess family members care perceptions	NR  Inter-item correlations met criterion (minimum 50% with r = 0.3 to 0.7) for 18 of 21 items; item correlation to total score 0.4 to 0.72 for 13 of 21 items; Cronbach's alpha 0.86
Frail Elderly Functional Assessment Questionnaire (FEFA) <sup>28</sup>  Domain(s): Functional status	Mixed diseases; age > 65 years; homebound and nursing home  19 items; assess function in elderly at very low activity level; interviewer administered	Correlation to direct observation (r=0.90); also Katz's ADL index (r=0.86), Barthel index (r=0.91), Lawton's IADL index (r=0.67)  Test-retest in n = 29 at 2 week interval - kappa 0.82 overall, all items > 0.40 (0.45-0.91)
Grief Evaluation Measure <sup>29</sup>  Domain(s): Grief and bereavement	Bereaved family members  Experiences section -58 items, problems section - 33 items; self-administered	Concurrent: correlated with IES-R subscales (Impact of Event Scale - Revised) (r=0.48-0.76), TOP (Treatment Outcome Package) depression subscale 0.76-0.92 Predictive: predicted psychological adjustment (ITG - inventory of traumatic grief - r=.67)  Test-retest: r 0.88-0.97; cronbach's alpha: 0.91-0.97

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Grief Experience Inventory (GEI) <sup>24</sup>  Domain(s): Grief and bereavement	NR  102 statement self-administered inventory scaled yes/no; nine composite scales including 3 validity and 6 domains	Discriminant validity bereaved versus non-bereaved reported significant at 0.001 level on all subscales  Test-retest coefficients 0.53-0.87; Cronbach's alpha 0.52-0.84 on bereavements scales
Hebrew Rehabilitation Center for Aged index (HRCA-QL) <sup>30</sup>  Domain(s): Quality of life	Adapted for patients with advanced cancer  Version of the Spitzer Quality of Life index	Scores declined as patients became closer to death; sensitive to change in status; criterion validity correlated with KPS and IADL index  Cronbach's alpha 0.7-0.78; test-retest: 0.89; inter-rater 0.67
Hogan Grief Reaction Checklist (HGRC) <sup>31</sup>  Domain(s): Grief and bereavement	Mixed diseases  61 items; six constructs, (despair, panic behavior, blame and anger, disorganization, detachment, and personal growth)	Convergent validity to TRIG, GEI and IES ranged from $r = 0.20$ to $0.78$ with significant correlations across subscales; discriminant validity in subset of mothers who experienced death of a child by different mechanisms (illness, accident, suicide, or homicide) revealed differences in blame and anger; discriminant validity with subset of mothers with deaths <or>3 years in past revealed difference in intensity of grief and personal growth; factor analysis reported  Cronbach's alpha overall 0.90 (despair 0.89, panic behavior 0.90, blame and anger 0.79, disorganization 0.84, detachment 0.87, and personal growth 0.82); test-retest over 4 week interval significant at $p < 0.001$ (despair $r = 0.79$ , blame and anger $r = 0.56$ , disorganization $r = 0.85$ , detachment $r = 0.77$ and personal growth $r = 0.81$ )
Hospice Pressure Ulcer Risk Assessment Scale (HoRT) <sup>32</sup>  Domain(s): Clinical assessment tool	Mixed diseases  assess physical activity, age, mobility	discriminant validity with statistically significant differences between patients with and without ulcers. PPV 50%, NPV 100%.  NR
Hospital Anxiety and Depression Scale (HADS) <sup>33</sup>  Domain(s): Emotional symptoms	Breast cancer  self-report, 7-items depression, 7-items anxiety; tries to discriminate between anxiety and depression	Using cutoff value of tool, sensitivity/specificity (depression) 75%, 75%, misclassification rate 25%; (anxiety) 75%, 90%, 12%  NR
Index of support; done as part of Canadian Study of Health and Aging (CSHA) <sup>34</sup>  Domain(s): Instrumental support available to older Canadian community residents	Community study of elderly  6 items; 4 level scales; interview	4 phases: factor analysis (item correlations 0.26 to 0.83), item response theory analysis, external (construct and predictive validity on 2nd half of study population), and IRT( $r=0.53$ to network size)/classical ( $r=0.61$ ) comparison  Cronbach's alpha 0.76; IRT marginal reliability 0.85

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<p>Kansas City Cardiomyopathy Questionnaire<sup>35</sup></p> <p>Domain(s): Quality of life; Physical symptoms; Functional status</p>	<p>Single disease - CHF</p> <p>Self-administered, 23-items, HRQOL in CHF</p>	<p>Convergent validity 0.46 - 0.74 across 7 domains; physical limitation to 6-minute walk (r=0.48), SF-36 (r=0.84), LiHFe (0.65); responsiveness higher than LiHFe and SF-36 for admission with CHF exacerbation</p> <p>Cronbach's alpha 0.62-0.95 across 7 domains; test-retest at 3 months without exacerbation 0.8 to 4 point changes in 1-100 point scale</p>
<p>Life Closure Scale (LCS)<sup>36</sup></p> <p>Domain(s): Spirituality</p>	<p>Mixed cancer diagnoses</p> <p>45 items; assess psychological adaptation in dying</p>	<p>Content validity with interviews and experts evaluation</p> <p>Cronbach's alpha 0.80</p>
<p>Life Evaluation Questionnaire (LEQ)<sup>22</sup></p> <p>Domain(s): Quality of life</p>	<p>Mixed diseases</p> <p>121 items, 0-60 scale; self-administered; five subscales (freedom, appreciation of life, contentment, resentment, social integration)</p>	<p>Convergent validity to RSCL ranged from 0.01 to 0.62 (sufficient only for freedom, resentment, and social integration); convergent to MacAdam and Smith Support scale factor ranged from 0.02 to 0.62 and similarly sufficient only for freedom, resentment, and social integration; analysis with five components reported.</p> <p>Cronbach's alpha (freedom 0.70, appreciation of life 0.76, contentment 0.76, resentment 0.85, social integration 0.78); test-retest n=40, at 2-3 days (freedom r=0.80, appreciation of life r=0.91, contentment r=0.77, resentment r=0.92, social integration r=0.84)</p>
<p>Linear Analogue Scale (LAS) for quality of life in cancer patients<sup>37</sup></p> <p>Domain(s): Quality of life</p>	<p>Mixed cancer</p> <p>5 questions, linear analogue scale, self-assessment</p>	<p>Correlation between LAS and performance status (r=0.46); questionnaire and performance status (r=0.38) - overall poor performance noted</p> <p>Cronbach's alpha 0.75; subgroup LAS (alpha 0.58) compared to questionnaire (0.93); n=41 test-retest LAS (29.3% of cases judged reliable), questionnaire (82.9%)</p>

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Lung Cancer Symptom Scale (LCCS) <sup>38-41</sup>  Domain(s): Quality of life; Physical symptoms; Emotional symptoms; Functional status	Single disease - lung cancer  2 scales; patient - 9 items visual scale (100mm) and observer - 6 items (4 point or none scale)	Construct validity with KPS 0.15-0.63 across items (symptomatic distress 0.49, effect on activities 0.63, QOL 0.43); criterion validity (patient scale / observer scale respectively) - KPS (r=0.63, NA), SIP(0.40, 0.56), POMS(0.67,0.54), ATS 29 cough (0.56, 0.65) and dyspnea (0.46, 0.64), SF-MPQ (items range 0.51 - 0.67); content validity (high agreement noted without specific data); construct validity between scales: cough (r=0.74), dyspnea (r=0.66), hemoptysis (r=0.71), pain (r=0.71), wt loss (r=0.61); criterion validity to Karnofsky r=0.59  Cronbach's alpha 0.82 (patient scale) and 0.75 (observer); internal consistency to BSI (r=0.93), SIP (r=0.94), POMS (r=0.94), SF-MPQ (r=0.91, r=0.64-0.74 for 3 components); test-retest r>0.75 for all items; interobserver r>0.75 for all items except cough (r=0.65) and weakness (r=0.54); note weakness has subsequently been dropped
McMaster Quality of Life Scale <sup>42</sup>  Domain(s): Quality of life	Mixed cancer  Administered to proxies or patients; responsive to perceptions of change in clinical status (p=0.01)	Concurrent validity as correlated well with Spitzer QOL (r=0.7); those able to rate it themselves rated QOL higher than those who needed to have it read to them (p=0.04); days until death explained 7% of the variance in QOL  Interobserver r = 0.83-0.95; intrarater 1 week 0.63 (lower than on same day); Cronbach's 0.8
Measure of patients' assessment of the quality of communication about end-of-life care <sup>43</sup>  Domain(s): Advance care planning	Single disease - HIV/AIDS  4 items	Correlated with overall satisfaction with medical care (0.76); those with higher-rated communication had clinicians more likely to know if the had a durable power of attorney  Cronbach's alpha 0.81
Mental Adjustment to Cancer (MAC) scale (revised as G-MAC) <sup>44</sup>  Domains: Emotional symptoms	Mixed cancer  25 items in revised version, 5 dimensions; self-administered	Concurrent: patients with better performance status by ECOG had significantly higher mean scores on "hopeless" dimension  internal consistency: alpha 0.62-0.93; test-retest: r=0.8
Needs assessment for advanced cancer patients (NA-ACP) <sup>45</sup>  Domain(s): Needs assessment (quality of care)	Mixed cancer  7 domains; 132 items; self-administered	Construct: principal components analysis demonstrated 7 components  Internal consistency: alpha 0.79-0.98; test-retest: ICC 0.67-0.93; 103 of the items had kappa >0.4



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Pain Assessment in Advanced Dementia (PAINAD) <sup>46</sup>  Domain(s): Physical symptoms	Single disease - advanced dementia patients in nursing home  5 items with 5 subdomains of pain each with scale 3 levels (29 choices); overall additive score 0-10	Factor analysis done; convergent analysis to DS-DAT & DS-VAS (r=0.76, n=19) and PAIN-VAS (r=0.75, n=18) - note also done in different conditions (r>=0.82 in activity)  Multiple observations across 44 patients; Cronbach's alpha 0.57 - 0.83 in multiple phases
Palliative Care Outcome Scale (POS) <sup>47,48 *</sup>  Domain(s): Quality of care; Physical symptoms; Functional status; Continuity of care; Multidimensional measure	Mixed diseases  2 parts - patient & staff; each 12 items, most 0-4 scale; general audit designed as a palliative care outcome measure, eight site study	Construct validity r=0.43-0.80 against ETORTC QLC-C30 AND STAS (n=29 patients, 43 staff); change over time not statistically significant; face validity by patient survey (n=12 - qualitative)  Test-retest for seven items kappa -0.08-0.62 with % agreement 74-100%; Cronbach's alpha patient part (0.65) & staff part (0.70); Kappa > 0.3 staff compared to patient responses for 8 out of 10 items
Palliative Care Quality of Life Instrument (PQLI) <sup>49</sup>  Domain(s): Quality of life	Mixed cancer  28 items, 6 scales	Face validity: expert review, patients asked to pick most important issues, rate scales; compared patients with better & worse ECOG performance status (significant); responsiveness before and after treatment; factor analysis; construct - correlated with AQEL (correlation coefficients 0.44-0.94) and EORTC - QLQ-C30 (0.79-0.97); criterion: ability to predict independent criterion variables (p<0.001); convergent & discriminative: related to corresponding & not to non-corresponding variables on interview (p<0.001)  Cronbach's alpha 0.79; test-retest coefficients of agreement 0.82
Physical Disability Index (PDI) <sup>50</sup>  Domain(s): Functional status	NR  54 items, for use with frail individuals; requires calibrated specialized performance measuring equipment	Discriminant validity against Folstein Mini-Mental State Exam (r=0.11); convergent validity Physical Self-Maintenance Scale (r=-0.71) and Sickness Impact Profile (r=-0.59);  Test-retest in n = 36 at 2-5 days 0.97 overall, 4 subscales 0.92-0.96; interrater reliability 0.81-0.99 (mobility scale -0.02-0.70)
Postal questionnaire to examine career satisfaction with palliative care <sup>51</sup>  Domain(s): Satisfaction	Mixed diseases  89 question; after-death postal survey of caregivers	Discriminant validity tested with 36 attitudinal questions when health problems identified - only 4 were significant by Chi square; convergent testing reported in tabular form in reference  Cronbach's alpha 0.68 to 0.84 across 7 subsets
Problems and Needs in Palliative Care Questionnaire (PNPC) <sup>52</sup>  Domain(s): Needs assessment (quality of care)	Mixed cancer  13 dimensions, 138 items, self-administered	Convergent - significant correlations with related EORTC and COOP-WONCA QOL measures; needs further psychometric testing  Cronbach's alpha >0.65 for most dimensions

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<p>Quality of Dying and Death (QODD)<sup>53-56*</sup></p> <p>Domain(s): Quality of Care - multidimensional life, Functional Status, Advance Care Planning, Spirituality, Grief and Bereavement, Caregiver Well-Being</p>	<p>Mixed diseases</p> <p>31 item family after-death interview across 6 domains; separate 23-item ICU version; 2 parts assess frequency and quality ratings; also 14-item nurse caregiver measure</p>	<p>Measure development included qualitative data from multiple focus groups and interviews. QODD 31-item family after-death measure: construct validity <math>r=-0.52</math> against MSAS, <math>r=-0.47</math> MSAS psychological sub-score, <math>r=-0.42</math> MSAS physical sub-score; discriminative study with independent symptom questionnaire significant at <math>p&lt;0.01</math>, preferences at <math>p&lt;0.01</math>, and communication <math>p&lt;0.001</math>; correlation to global rating of last 7 days of life <math>r=0.55</math>, moment of death <math>r=0.51</math> (two factors explaining 38% of QODD variance)</p> <p>Overall 31-items QODD Cronbach's alpha 0.89; Cronbach's alpha 0.96 for 14 item RN version; interobserver reliability 0.44 for overall QODD (23-item ICU version) after-death survey; components ranged from 0.15 to 1.0 for frequency components (mean 0.54), 0.16 to 0.59 for quality rating component (mean 0.32)</p>
<p>Quality of End-of-Life Care and Satisfaction with Treatment (QUEST)<sup>57</sup></p> <p>Domain(s): Satisfaction</p>	<p>Mixed diseases</p> <p>4 scales (MD care, MD satisfaction, RN care, RN satisfaction); patients &amp; surrogates, rate RNs &amp; MDs</p>	<p>Reviewed by experts; construct - correlate with PSI (Patient Satisfaction Index) 0.38-0.47; subscales correlated with each other (0.47-0.69); not correlated with unrelated constructs; positive skew distribution for many items; negative correlation with symptoms; patients scores were lower for patients with DNR orders</p> <p>Test-retest: kappa 0.43-0.86 (1-2 days); Cronbach's 0.83-0.95</p>
<p>QUAL-E (Quality of Life at End of Life)<sup>58*</sup></p> <p>Domain(s): Quality of life</p>	<p>Mixed diseases</p> <p>24 items</p>	<p>Factor analysis reveals 5 domains: life completion, relationships with the health care system, preparation/anticipatory concerns, symptom impact, connectedness and affective social support.</p> <p>Cronbach's alpha 0.6-0.84</p>
<p>Relatives' patient management questionnaire<sup>59</sup></p> <p>Domain(s): Advance care planning; Satisfaction</p>	<p>Mixed cancer</p> <p>21 items, 5 scales in final version: families' attitudes, perceptions, and patterns of choice in management of terminal cancer patients</p>	<p>Construct validity inter-scale correlations 0.6-0.86; discriminant low correlation with unrelated items</p> <p>Cronbach's alpha 0.5-0.69</p>
<p>Resident Assessment Instrument for Palliative Care (RAI-PC)<sup>25</sup></p> <p>Domain(s): Physical symptoms; Emotional symptoms; Functional status; Advance care planning; Spirituality; Palliative Outcomes</p>	<p>NR</p> <p>Builds on RAI for NH resident assessment; 9 domains; for clinician assessment in NH</p>	<p>NR</p> <p>Interobserver - kappa 0.77-0.9</p>

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Rotterdam Symptom Checklist (RSCL) <sup>33</sup>  Domain(s): Physical symptoms; Emotional symptoms; Functional status	Single disease - breast cancer  Self-report; 3 subscales: physical (22 items), psychological (8 items), ADL (8 items); 4 point scale	Using cutoff value of tool, sensitivity/specificity 75%, 80%; misclassification rate 21%  NR
Santa Clara Strength of Religious Faith Questionnaire (SCSORF) <sup>60</sup>  Domain(s): Spirituality	Mixed cancer  10-items developed to evaluate links with psychological health	Convergent: strongly correlated with intrinsic religiosity, moderately correlated with religious practice, perception of self as spiritual, comfort derived from religion.  Test-retest: 0.82; Cronbach's alpha 0.95.
Satisfaction With Care at the End of Life in Dementia (SWC-EOLD) <sup>11</sup>  Domain(s): Satisfaction	Single disease - dementia  10 items; 4-point scale; one-factor	Item-total correlations range 0.33 to 0.79  Cronbach's alpha 0.90
Structured Interview for Symptoms and Concerns (SISC) <sup>61</sup>  Domain(s): Emotional symptoms; Physical symptoms	Mixed cancer  13 items; addressed broad range of symptoms briefly; interviewer-administered	Concurrent: concordance with VAS measures (correlations >0.7); sensitive to differences between subgroups with or without anxiety or depression  Interrater: intraclass correlations >0.9; test-retest 0.5-0.9
Support Team Assessment Schedule (STAS) <sup>57</sup>  Domain(s): Physical symptoms; Multidimensional measure	Mixed diseases - broadly across hospice patients; one study <sup>36</sup> applied to acute care oncology unit and a palliative care unit  17 items, scale 0-4; 7 items grouped into a) patient and family items (4) and b) service items (3); interview administered	Validity by comparison of type of rater: kappa for patient to staff (n=62-78) ranged from 0.12-0.78, total score Spearman rho 0.66; kappa for family to staff (n=58-67) ranged from -0.06-0.51, total score Spearman rho 0.44. Validity by comparison to patient rating - overall r=-0.09 palliative care and r=0.28 oncology (p>0.05); to family rating overall r=0.38 palliative care and r=0.37 oncology (p>0.05); item kappa 0.00 - 0.61.  Interobserver reliability mostly r=0.4-0.6 (range 0.27-1.0) ; intraobserver reliability (r=-0.33-0.88) for overall score and range 0.1-1.0 for items; test-retest 0.50 for palliative care team and 0.71 for oncology team
Symptom Distress Scale (SDS) <sup>62</sup>  Domain(s): Physical symptoms	Mixed diseases – applied to symptoms in females with lung cancer  10 items, self-report; modified to 13 items for lung cancer in 1980s	Factor analysis with principal components and varimax rotation - 5 factor 65% variance; also correlation of certain items to parts of Karnofsky Performance Status (r= -0.27 to -0.48) overall r=-0.58  NR

<b>Measure name</b>	<b>Population Setting</b>	<b>Validity Testing</b>
<b>Domain(s)</b>	<b>Brief description</b>	<b>Reliability Data</b>
Symptom Management at the End of Life in Dementia (SM-EOLD) <sup>11</sup>  Domain(s): Physical symptoms, Emotional symptoms	Single disease - dementia  9 items; frequency ratings of multiple symptoms	Item-total correlations range 0.18 to 0.66; correlations for symptom items on CAD-EOLD r = 0.475 to 0.559  Cronbach's alpha 0.78
Symptom Monitor <sup>63</sup>  Domain(s): Physical symptoms	Mixed diseases  10-item diary for physical symptoms	NR  Inter-rater ICCs > 0.75
Willingness to Accept Life-sustaining Treatment instrument (WALT) <sup>64</sup>  Domain(s): Advance care planning	Mixed diseases; associated with age, ethnicity, & functional impairment  No description provided	face: reviewed by patients & experts; correlated with simpler measure of preference  inter-rater 0.73-0.95; test-retest 0.49-0.93

\* Recommended Measure

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